



## Pre-verbal communication behaviours in children with Cri du chat syndrome in the opinion of parents

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Cri du chat syndrome (CdC) is a rare disease characterized, among others, by the presence of decreased muscle tone, microcephaly and high palate. We also observe hypoplasia of the mandible, abnormal structure and function of the larynx (somatic symptoms) as well as psychomotor development disorders and intellectual disability (psychomotor symptoms). The children display a varied level of functioning; most of them do not use verbal speech. Describing the problem of pre-verbal communication behaviours we took into account the following elements: the level of primary, sensory and auditory communication behaviours, as well as the organization of behaviours and signalling needs.

The objective of the paper is to describe the pre-verbal behaviours in children with Cri du chat syndrome. The following questions were formulated: What is the level of pre-verbal communication (primary, sensory and auditory) in the child with CdC syndrome? What communication behaviours can be distinguished in the child with CdC syndrome and what is their level of organization? What is the level of signalling needs in the child with CdC?

The pre-verbal communication behaviours in children with Cri du chat syndrome presented in the article are diverse, ranging from the ability to use gestures to signal needs, to vocalizing in order to provoke the contact with another person. Behav-

iours displayed by the daughter/son and indicated by parents may be the basis for the process of teaching pre-verbal communication.

**KEY WORDS:** communication, communication disorders, child with Cri du chat syndrome

## Introduction

Given the fact that a disease was diagnosed in no more than 5 in 10,000 people, the state of knowledge about the functioning of these patients and the possibilities of treatment is insufficient. Moreover, because the development of children with a rare genetic syndrome and intellectual disability differ from person to person it is often difficult to outline the common features. Children with rare genetic syndromes are more and more often diagnosed with verbal speech difficulties, hence there is a need to deepen the knowledge about pre-verbal communication behaviours in order to support them – often with alternative forms of communication. Most children with Cri du chat syndrome (CdC) do not use verbal speech. Few publications dedicated to this subject do not exhaust the issue<sup>1</sup>. The lack of systematized scientific knowledge and scarce reports on the communication of children with CdC prompted us to explore the topic. The following questions were formulated in the study: What is the level of pre-verbal communication (primary, sensory and auditory) in the child with CdC syndrome? What communication behaviours can be distinguished in the child with CdC syndrome and what is their level of organization? What is the level of signalling needs in the child with CdC?

The objective of the paper is to describe pre-verbal behaviours in children with Cri du chat syndrome. The answers to the questions

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<sup>1</sup> One of them is an article by Marzena Buchnat, Aneta Wojciechowska and Michał Rzepka (father of a girl with CdC) entitled “Supporting the development of speech and communication in children with the Cri du Chat syndrome”, which was published on the Speech Therapy Forum.

formulated in the study fill the gap in the theory of special education and allow therapists to plan effective supportive activities to be used at an early stage of the development of children with CdC syndrome and other congenital development disorders.

## Communication behaviours

The communication skills developed and acquired as the child grows up cause that it becomes more and more involved in the world around by making contact first with people from the nearest, then from further surroundings. In this way the child gains new experiences and skills. It is worth mentioning that verbal speech is not/does not have to be the main carrier of information in the child with a rare genetic syndrome or congenital malformations which may restrict the above process.

As Mieczysław Plopa emphasizes, every behaviour is a form of communication in the communication system, because *„people who interact with each other convey information by everything they do and say (or do not do and say), and thus they influence the course of interaction”*<sup>2</sup>. Although the researcher points to communication behaviours in the marital relationship, the issue can be transferred to a parent-child relationship. Given that a girl/boy with developmental disorders not using verbal speech establishes contact with an adult to communicate and makes attempts to convey the information in a non-verbal way by using the available means, we can assume that every child's activity which is aimed at establishing contact with parents in order to signal needs, well-being or transfer other important message through the repertoire of childlike behaviours, such as gestures, meanings, symbols, items, etc. will be a communication behaviour. The perception of each behaviour as a (potential) form of communication allows for better understand of the meaning of non-verbal signals that appear in the interaction between two

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<sup>2</sup> Plopa M., *Bonds in marriage and family. Test methods*. Wyd. „Impuls”, Kraków 2005, p. 110.

people. These signals have an impact on communication because they have a symbolic meaning<sup>3</sup>. Communication behaviours are a consequence of the development and integration of the child's cognitive, social and motor sphere. As they are often disturbed in children with intellectual or coupled disability, teaching patients how to communicate effectively is a long-lasting process with variable dynamics (there are periods of rapid mastery of skills and stagnation; regresses can not be excluded). Communication behaviours have both non-verbal and verbal dimensions. In the 1970s, in order to assess children's communication capabilities, researchers dealing with mute children began to use research findings on the development of pre-verbal communication between infants and their carers. The basic assumption was made that in order to evaluate the child's readiness for communication, we should first pay attention to the pragmatic function of communication between the boy/girl and his/her caregiver<sup>4</sup>. According to Maria Piszczek, this type of communication „develops in the context of social relations and involves predictable connections between an adult and the child”<sup>5</sup>. Thus, such an approach to the communication behaviours of children with disorders requires the assessment in the social context which is the background for the exchange of information between the child and the adult. It is also important to observe whether and to what extent these behaviours are intentional<sup>6</sup>. Considering intentionality, we should bear in mind the ability to distinguish between action and intention. A child who behaves intentionally has a specific purpose of taking an action. In the event of obstacles on the way to achieve a goal, the child takes indirect steps to eliminate them. When the child reaches the stage of development at which means are distinguished from purposes, intentional communication begins to develop, which is manifested by showing parents needs and

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<sup>3</sup> Ibid., pp. 110-112

<sup>4</sup> Piszczek M., *Diagnosis and support for child development. Selected issues*, Methodological Center for Psychological and Pedagogical Assistance, Warsaw 2007, pp. 42-43.

<sup>5</sup> Ibid., p. 42.

<sup>6</sup> Ibid., pp. 42-43.

wishes through various behaviours with the simultaneous directing parents' attention to a given object or a need<sup>7</sup>. In this way the child learns how to summon an adult, ask and set requirements<sup>8</sup>. According to Lidia Grzesiuk, four categories can be used to describe communication behaviours. The first of them are intentional and unintentional messages which have been distinguished based on the relationship between the behaviour of a given person and the intention to convey a specific content. An intentional message transmits the information whose content is intended to be consciously revealed. Unintentional messages do not carry intentional meaning, but provide information about the performer of the action. The second category involves a division into verbal and non-verbal behaviours which have been distinguished based on the means of communication used by the child<sup>9</sup>. The third category includes „*messages directly/indirectly expressing the internal states of the performer of the action, determined on the basis of the overtness of the information conveyed*”<sup>10</sup>. The last category are relational and neutral messages, which in the aspect of communication behaviours, are analyzed in terms of whether their contents relates to the emotions of a communicating person or to the external environment/partners<sup>11</sup>.

Analyzing the aforementioned categories Magdalena Grochowalska indicated their possible importance to understanding non-

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<sup>7</sup> Ibid., pp. 43–45; Piszczek M., *Alternative and assistive communication methods in the education of children with deep mental impairment and autism*. Part I, Revalidation, No. 2(8), 2000, pp. 13–21; Idem, Piszczek M., *Alternative and assistive communication methods in the education of children with deep mental impairment and autism*. Part II, Revalidation, No. 1(9), 2001, pp. 3–21.

<sup>8</sup> Idem, *Diagnosis and support for child development. Selected issues*, Methodological Center for Psychological and Pedagogical Assistance, Warsaw 2007, pp. 43–44.

<sup>9</sup> L. Grzesiuk, *Studies on interpersonal communication*, Laboratory of Psychological Tests PTS, Warsaw 1994, pp. 12–21.

<sup>10</sup> M. Grochowalska, *Gesticulation and speech. Non-verbal communication in pre-school children*. Wyd. Naukowe Akademii Pedagogicznej, Kraków 2002, p. 11.

<sup>11</sup> L. Grzesiuk, *Studies on interpersonal communication*, Laboratory of Psychological Tests PTS, Warsaw 1994, pp. 12–21.

verbal forms of communication in children<sup>12</sup>. For the need of the research, the author adopted the category of pre-verbal communication behaviours specifying that her analysis of pre-verbal communication behaviours in the child with multiple development disorders, congenital malformations – here Cri du chat syndrome – included the following elements: the level of primary, sensory and auditory communication behaviours, as well as the organization of behaviours and signalling needs.

### **Child with Cri du chat syndrome – clinical picture and development opportunities in a psycho-pedagogical perspective**

In 1963 the French geneticist Jerome Léjeune noted that on the first days after birth some children manifest high and silent crying. Because this symptom is typical of this disorder the condition was named Cri du chat syndrome (from the French cri du chat – ‘*cat-cry*’). It is a rare genetic disease diagnosed in about 1 in 15–20 thousand up to 1 in 50 thousand live births<sup>13</sup>. Cri du chat syndrome is also often referred to as the 5p monosomy syndrome, chromosome 5p deletion syndrome, Lejeune’s syndrome and *cat cry syndrome*<sup>14</sup>. The last name is less frequently used because it has a stigmatizing dimension. CdC most often arises *de novo*, sometimes as a result of translocation or mosaicism inherited from one of parents. According to the literature, the causes of the disorder include partial chromosomal aberration and less often total deletion of the short arms of chromosome 5.

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<sup>12</sup> Ibid., p. 11

<sup>13</sup> P.C. Mainardi, M.L. Albani, M. Pedrinazzi, *ABC – Cri du Chat Syndrome (Cat cry syndrome)*, information materials published by A.B.C. Associazione Bambini Cri du chat (Association for Children with Cri du Chat syndrome), Italy 2014, p. 1.

<sup>14</sup> ICD-10 classification: Q93.4 – Deletion of the short arm of chromosome 5. “Q93.4 is a billable ICD code used to specify a diagnosis of deletion of short arm of chromosome 5. A ‘billable code’ is detailed enough to be used to specify a medical diagnosis”, Source: <https://icd.codes/icd10cm/Q934>.

The condition leads to a delay in development or intellectual disability<sup>15</sup>. The clinical symptoms of CdC are divided into two main groups. The first group are somatic symptoms, the second group – psychomotor symptoms. It is also possible to describe characteristic mental traits (see Table 2).

**Table 1.** The clinical symptoms of Cri du chat syndrome.

Somatic symptoms	Psychomotor symptoms
<ul style="list-style-type: none"> <li>– low birth weight of the child,</li> <li>– decreased muscle tone,</li> <li>– microcephaly,</li> <li>– facial changes: oval face, low set ears, hypertelorism, epicanthic fold,</li> <li>– high palate; hypoplasia of the mandible, cleft lip and palate (rarely),</li> <li>– abnormal structure and function of the larynx,</li> <li>– transverse furrow of the hand; <b>syndactyly</b> (rare),</li> <li>– scoliosis,</li> <li>– epilepsy,</li> <li>– heart defects.</li> </ul>	<ul style="list-style-type: none"> <li>– psychomotor development disorders,</li> <li>– motor coordination disorders,</li> <li>– intellectual disability of various degrees (about 70% – significant and deep, 20% moderate, 10% mild).</li> </ul>
<b>Characteristic mental features</b>	
<ul style="list-style-type: none"> <li>– friendly temperament,</li> <li>– hyperexcitability,</li> <li>– nervous tics,</li> <li>– self-harm,</li> <li>– autostimulation,</li> <li>– autistic behaviours,</li> <li>– withdrawal.</li> </ul>	

Source: Czapiga A. Child with *Cri du Chat syndrome*, [in:] *Ill children, disabled and with developmental difficulties*, B. Cytowska, B. Winczura, A. Stawarski (ed.), Wyd. „Impuls”, Kraków 2013, pp. 121-129, Mainardi P.C., *Cri du Chat syndrome*. Orphanet Journal of Rare Diseases, [ojrd.biomedcentral.com](http://ojrd.biomedcentral.com), 9 September 2017, Mainardi P. C., Albani M.L., Pedrinazzi M., *ABC – Cri du Chat Syndrome (Cat cry syndrome)*, information materials published by A.B.C. Associazione Bambini Cri du chat (Association for Children with Cri du Chat syndrome).

<sup>15</sup> A. Czapiga, *Child with Cri du Chat syndrome*, [in:] *Ill children, disabled and with developmental difficulties*, B. Cytowska, B. Winczura, A. Stawarski (ed.), Wyd. „Impuls”, Kraków 2013, p. 125.

Apart from the aforementioned symptoms, speech, concentration and motor activity disorders can also be noticed<sup>16</sup>. The research conducted in 2002 in the United States by Denis J. Campbell revealed the specificity of communication development in children with CdC (Table 3) with a significant delay compared to healthy peers.

**Table 2.** The development of communication in children with Cri du chat syndrome in the light of literature reports

Skill	Developmental standard	Age range	Age of child with CdC
Cooing	about 7 months	4-48 months	about 14 months
Saying first words	about 10 months	7-72 months	about 23 months
Understanding commands	about 10 months	6-120 months	about 23 months
Communication using other signs	about 12 months	1-11 years	about 2 years
Using words	about 20 months	1-12 years	about 4 years

Source: Buchnat M., Wojciechowska A., Rzepka M., *Supporting the development of speech and communication in children with Cri du Chat Syndrome*, Speech therapy forum 2014, No. 22, p. 114; Campbell D.J., *Early Development of Individuals with Cri du Chat Syndrome* (unpublished doctoral dissertation, Auburn University), Auburn 2002.

The spread between the developmental standard and the moment when the abovementioned skills are achieved by the child with CdC counted in months indicates the individualized character of the development of these children. Somatic and psychomotor symptoms as well as mental traits are formed individually. An early support of the child with CdC and the involvement of various specialists gives an opportunity to initiate the phase of functional diagnosis and therapy involving sensitive development stages. The work will include polysensory stimulation, shaping perceptual-

<sup>16</sup> M. Buchnat, *Cri du Chat Syndrome*, [in:] *Unknown? Understood. Developmental disorders in children with rare genetic syndromes and congenital malformations*, M. Buchnat, K. Pawelczak (ed.), Wyd. Naukowe UAM, Poznań 2013, p. 180.



motor integration, and awareness of one's own body<sup>17</sup>. Alina Czapiga described a plan of revalidation work and psychological therapy for a girl/boy with CdC indicating the spheres that should be stimulated. These included the orientation-cognitive, intellectual (mental operations), emotional, motivational processes and control mechanisms<sup>18</sup>.

## Research methodology

The research was carried out using the diagnostic survey method and the following tools:

- original questionnaire to assess the functioning of the child with CdC,
- original questionnaire to evaluate the communication behaviours of the child with CdC,
- questionnaire to examine communication skills in children with deeper intellectual disabilities (with significant and deep intellectual disability) by Elżbieta M. Minczakiewicz,
- individual communication competence sheet – the area of pre-verbal communication by Aleksandra Nowak, Katarzyna Kobylacka-Sikora.

The main research problem was as follows: what are pre-verbal communication behaviours in the child with Cri du chat syndrome in the opinion of parents?

The following specific questions were also formulated:

- What is the level of pre-verbal communication (primary, sensory and auditory) in the child with Cri du chat syndrome?
- What communication behaviours can be distinguished in the child with CdC syndrome and what is their level of organization?
- What is the level of signalling needs by the child with CdC?

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<sup>17</sup> A. Czapiga, *Child with Cri du Chat syndrome*, [in:] *Ill children, disabled and with developmental difficulties*, B. Cytowska, B. Winczura, A. Stawarski (ed.), Wyd. „Impuls”, Kraków 2013, p. 128.

<sup>18</sup> *Ibid.*, pp. 127–128.

**Table 3.** The number of children with CdC syndrome living in Poland

Source	Year	Number of children	Notes
<a href="http://www.genetyczne.pl">www.genetyczne.pl</a>	2009	from 50 to 60	none
<a href="http://www.gazetakrakowska.pl">www.gazetakrakowska.pl</a>	2012	about 50	none
<a href="http://www.poradnikzdrowia.pl">www.poradnikzdrowia.pl</a>	2016	about 50	none
<a href="https://parenting.pl">https://parenting.pl</a>	2017	30	none
<a href="http://www.stefanek-lubin.pl/">www.stefanek-lubin.pl/</a>	2017	about 45	Data from the Association for Children with Genetic Disorders „GEN” (currently according to the data available on <a href="http://bazy.ngo.pl">http://bazy.ngo.pl</a> in the state of liquidation, therefore it is not possible to confirm this information with the members of the association board)

Source: own study based on <https://www.genetyczne.pl/choroby-genetyczne/zespol-cridu-chat-objawy-diagnostyka-leczenie/> dated 1 August 2017; Zuzia Trojan fights with „cat cry syndrome”. We can help her, <http://www.gazetakrakowska.pl/artykul/585287,zuzia-trojan-walczy-z-kocim-krzykiem-mozemy-jej-pomoc,id,t.html>, dated 29 May 2012; [http://www.poradnikzdrowie.pl/zdrowie/choroby-genetyczne/zespol-kociego-krzyku-przyczyny-objawy-leczenie\\_42069.html](http://www.poradnikzdrowie.pl/zdrowie/choroby-genetyczne/zespol-kociego-krzyku-przyczyny-objawy-leczenie_42069.html), dated 10 October 2017; E. Rycerz, *Cat cry syndrome-symptoms, treatment*, <https://parenting.pl/zespol-kociego-krzyku-objawy-leczenie>, dated 8 May 2017; [http://www.stefanek-lubin.pl/o\\_chorobie.html](http://www.stefanek-lubin.pl/o_chorobie.html), dated 10 October 2017.

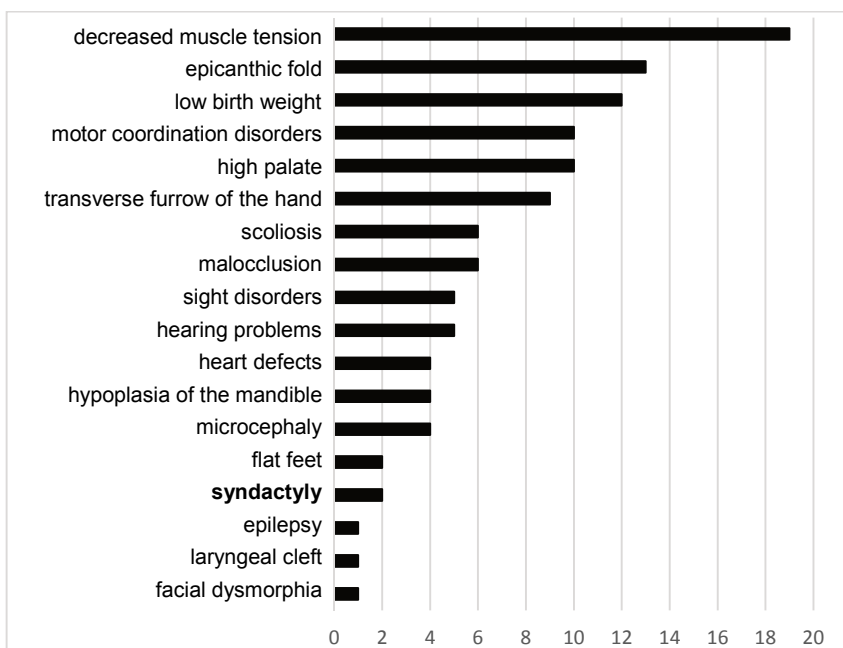
The study lasted from August to December 2017 and consisted of three stages. The first (initial) stage included the collection and analysis of literature on the development and functioning of people with CdC and search for associations/foundations looking after children with CdC. In Poland, there are no organizations exclusively for parents of these children. The only dynamic form of support is the *Cri du chat Polska* group created within the Facebook social network. It has a closed character and gathers parents, also those living abroad. Various sources give a different number of people with CdC living in Poland: the values vary from 30 to 60 (Table 3), including children and adolescents. Hence the limited number of

parents who took part in the research. The second stage included the selection of people for the research. The selection criteria were as follows: having a child with CdC and being a resident of Poland. The questionnaire could be completed by only one parent. It was available on the forum for four months; the information about the research was posted on the forum for parents of children with CdC and in the group on the web portal. The third stage of the study involved the analysis of the material collected.

The study involved 20 parents at the age of 27-45 years (19 mothers and one father – only one parent of a given child, the decision which parent will complete the questionnaire was made by the respondents). Almost half of the respondents had secondary education (9). The second largest group were people with higher education (8), followed by occupational (2) and primary (1) education. Most parents (7) lived in the city of 50,000 up to 100,000 residents. The remaining respondents lived in the city of up to 50,000 inhabitants (5), in the countryside (4) and in the city above 200,000 inhabitants (4). Cri du chat was usually diagnosed in the first (5), second (4) or third (5) child. The age range of children was from 2 to 13 years. The mean age was 10 years.

The parents participating in the study completed questionnaires dedicated to the assessment of pre-verbal communication behaviours in their children constituting the group:

- in terms of sex: 13 girls and 7 boys;
- currently attending: special education school (6), therapeutic kindergarten (3), rehabilitation-educational centre (2), special education school (1), integration facility (1), special education secondary school (1), public school (1), having individual teaching program (1), staying at home and not attending any educational institution (3) and those covered by early development support (1);
- with the following CdC clinical symptoms: most children had decreased muscle tone (19), low birth weight (12), high palate and impaired motor coordination (10). Other clinical symptoms are presented in Figure 1;



**Fig. 1.** The clinical symptoms in children with CdC syndrome

Source: own study.

- with the following psychiatric features: attention disorders (16), hyperexcitability (13), friendly disposition (12), aggressive behaviours (11), intense autostimulation (9), nervous tics (6), autistic behaviours (4);
- with diagnosed intellectual disability at the following degree: mild (1), moderate or significant (18), deep (1);
- in which less than half of children used alternative communication in everyday life (8). The parents indicated the following methods: Makaton, PCS and gestures, sounds or own method;
- with the medical statement or opinion on the need for early development support (16), special education (15), individual tuition (2);

- attending classes in speech therapy (15), revalidation (12), early development support and sensory integration (11), behavioural therapy (3).

### Pre-verbal communication behaviours in the child with Cri du chat syndrome – study results

As for the area of primary communication, half (10) of children with CdC always express their feelings in a specific way and react specifically to single stimuli from the closest environment.

Most of the children from time to time (9) or sometimes (6) react to the surrounding signals in a non-specific manner with a body movement, e.g. by tension of the whole body. As for specific reactions to single selected stimuli from the environment, such as turning the head in the direction of the mother's voice or relaxing when touched by the mother, half of the children always (10) reacted, the others often (9) responded. Only eight children had awareness of their own body (8) (Table 4).

**Table 4.** Primary communication in children with CdC syndrome

Primary communication	Frequency (number of responses)				
	never	with help	sometimes	often	always
Non-specific way of expressing own feelings	4	0	9	5	2
Specific way of expressing own feelings	1	0	3	6	10
Non-specific way of reacting to external signals by body movement	2	0	9	6	3
Specific way of reacting to single selected external stimuli	1	0	0	9	10
Awareness of one's own body	1	1	5	5	8

Source: own study.

As for the area of pre-verbal communication at the sensory level, almost half of the children often (9) or always (8) react with a movement to the environment signal. These reactions include, for example, the extension of the arms as a response to the noise or smile at the sight of the mother (Table 5).

**Table 5.** Sensory communication in children with CdC syndrome.

Sensory communication	Frequency (number of responses)				
	never	with help	sometimes	often	always
Differentiated motor reaction depending on the external signal	1	0	2	9	8
Reacting to the voice – active search for the voice source, temporary establishing and maintaining visual contact	0	0	1	4	15

Source: own study.

Most of the children (15) respond to selected stimuli from the environment, such as the voice of a parent always actively seeking the source of the sound. After localizing the direction from which the voice of the mother or father was heard, the children made a brief eye contact with an adult. The majority of caregivers believe that their children (13) always respond to their name and often initiate contact with another person using a gesture or touch. On the other hand, half of the children (10) always in a specific way signal their needs related to everyday rituals. Fewer children always (8) or often (7) respond to simple verbal messages from the environment. Only a few children sometimes (7) or often (5) signal their needs by a certain gesture or movement. Other communication situations at the level of the organization of one's own behaviour appeared in individual cases – the results are shown in Table 6.

The analysis of the children's contact with the environment at the specific-visual level using the elements of speech sounds showed that the vast majority of children (17) often use gestures in

the situational context and vocalize (14) in order to provoke contact with another person. However, over half (11) always express their emotional states with their facial expression. The evaluation of vocalization in the child with CdC syndrome includes the use of voice to make an attempt to imitate phonemes, syllables, to the extent determined by the readiness of articulation organs.

**Table 6.** Contact with the environment at the level of organization of one's own behaviour in children with CdC syndrome

Communication at the level of organization of behaviours	Frequency (number of responses)				
	never	with help	sometimes	often	always
Reacting to the sound of one's name	0	0	0	7	13
Reacting to simple verbal messages from the environment	1	1	3	7	8
Specific way of signalling needs related to daily rituals	2	2	3	3	10
Initiating contact with another person by gestures, touch	0	1	1	13	5
Signalling needs with a specific gesture, movement	6	1	7	5	1

Source: own study.

The second most numerous group of behaviours, which were manifested by the children at the level described as „frequent“, is the use of a gesture to show understanding of words (10); signalling one's own needs using a specific sound (9); understanding the meaning of some words and entering into a dialogue through the use of sounds and/or gestures (9), and facial expression to show emotional states (45%); participation in the word-picture dialogue and temporary reaction to the ban by discontinuing the performance of a given activity (8). Other communication situations at the level of contact with the environment were less frequently reported in children – the results are shown in Table 7.

**Table 7.** Contact of children with CdC syndrome with the environment at the specific-visual level using speech sounds elements

Contact with the environment at the specific-visual level with the use of speech sounds elements	Frequency (number of responses)				
	never	with help	sometimes	often	always
Imitating vocalization of the other person	0	2	7	7	4
Vocalizing to provoke contact with another person	1	1	3	14	1
Signalling needs with a specific sound	3	2	2	9	4
Understanding the meaning of some words	0	0	3	9	8
Auditory tracing of the content of the ambient speech	0	1	6	7	6
Participating in the word-and-picture dialogue	2	2	6	8	2
Using a gesture to show that they understand words	4	1	3	10	2
Making attempts to use the voice to imitate phonemes, syllables	2	2	4	7	5
Using facial expression to show emotional states	0	0	0	9	11
Understanding simple commands	1	3	0	7	9
Using gestures in the situational context	0	1	2	17	0
Entering dialogue through the sound and/or gesture	1	2	6	9	2
Pointing with the hand towards an item desired	2	1	2	6	9
Temporary reaction to the ban by discontinuation an activity	1	0	10	8	1

Source: own study.

More than half of the children with CdC covered by the study (12) demonstrate reactions that are understandable to the people around. A significantly smaller group (5) were behaviours that were aimed at making a caregiver aware of the child’s needs in a given



situation. The remaining children sporadically made attempts to establish contact (3) (see Table 8).

Most of the children (11) can use gestures and facial expression to demonstrate their needs or well-being. Fewer than half (6) call their mother in a difficult situation requiring support of an adult and signal anxiety to their mother (3) (Table 9).

The vast majority of the children (16) with CdC syndrome seek contact with their mother, and are happy to find her (Table 10).

**Table 8.** Communication of needs in children with CdC syndrome

Communication of needs and interests	Frequency (number of responses)
Showing needs in an understandable manner	5
Sometimes reacting in an understandable manner	12
Occasional attempts of understandable reactions	3

Source: own study.

**Table 9.** Establishing contact between children with CdC syndrome and the parent

Communication of needs by establishing contact with the mother	Frequency (number of responses)
Using gestures and eyes (facial expression) to manifest needs or mental states	11
Calling for the mother in a difficult situation	6
Signalling anxiety to the mother	3

Source: own study.

**Table 10.** The reaction to the mother in children with CdC syndrome

Reaction to the mother	Frequency (number of responses)
Show happiness in an understandable manner when find the mother	16
Look for the mother who hid	3
Do not show any reaction, for example, looking for the mother	1

Source: own study.

In the opinion of the parents, all children in the aspect of:

- auditory reactions: smile in response to talking, touching or stroking; they recognize the father's voice and show it;
- interactions: they produce intentional sounds, cheer up in the contact with relatives; change facial expression depending on the circumstances, explore unknown surroundings, observe strangers;
- communication of needs and interests: they express anger when they are dissatisfied, get close to relatives or acquaintances and reach out their hands to be picked up or hugged (to arose an interest in oneself).

In the opinion of caregivers, most children (16-19) with CdC in the aspect of:

- auditory interactions: stand still when hearing their mother's voice, listen intently to the sounds in the room, cheer up to the voice of siblings, actively react when hear a stranger talking and getting close, search and touch mother's lips when they make sounds, imitate and make intentional sounds directed towards their relatives, distinguish strange, unknown voices signalling their needs to household members;
- interaction: touch the mother's body; distinguish strange, unknown voices, laugh when somebody talks to them, make sounds of the human speech (usually single) in contact with relatives, actively search and examine the faces of household members, reach out their hands to be noticed or hugged, hug in the arms of the mother or relatives in the face of fear of the unknown, wave their hand for goodbye to relatives;
- communication of needs and interests: look for the father at the order of the mother or siblings, stroke, embrace and kiss their parents when asked to do so, bring an item (toy) indicated, look for a person in the household for help (for example, in passing a drink, putting on a potty, doing up clothes, tying shoelaces, etc.) or playing, express an interest in an item by examining it with their hands and mouth (touch, tap, throw, raise, etc.).

## Discussion and summary

K. Cornish and J. Pigram examined 27 children with CdC from the United States. The analysis of the level of communication showed that most of the children acquired the ability to communicate without using the verbal sphere. According to the researchers the lack of speech did not hinder communication because the children were able to signal their needs in a non-verbal way<sup>19</sup>. A few years later, a study conducted by Á. Rodríguez-Caballero, D. Torres-Lagares et al. also demonstrated that children can express their needs by establishing an appropriate relationship with adults, even though some of them lacked the ability to develop the verbal speech<sup>20</sup>. The researchers believe that the differences in the level of communication in people with CdC can be attributed to both phenotypic traits and the influence of external environment factors<sup>21</sup>. However, the authors did not specify the type of these behaviours. The above conclusion has also been confirmed by the research presented by the author of this article. The lack of verbal speech in children with CdC does not deprive them of the ability to communicate with relatives. Pre-verbal communication behaviours in children with Cri du Chat shown in this paper are diverse and range from using a gesture to indicate needs at a given moment, to vocalizing in order to provoke contact with another person. Behaviours displayed by the daughter/son and indicated by parents may be the basis for the process of teaching pre-verbal communication. According to M. Buchant, A. Wojciechowska and M. Rzepka this process should include:

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<sup>19</sup> K.M. Cornish, J. Pigram, *Developmental and behavioural characteristics of Cri du Chat Syndrome*. Archives of Disease in Childhood, No. 75, 1996, pp. 448–450.

<sup>20</sup> Research on verbal speech in children with CdC was carried out in 2007 by KM Kristoffersen, the results are presented in the article “*Speech and language development in cri du chat syndrome: A critical review*”, “*Clinical Linguistics & Phonetics*” June 2008, vol. 22(6), pp. 443–457.

<sup>21</sup> Á. Rodríguez-Caballero, D. Torres-Lagares, A. Rodríguez-Pérez, M. Serrera Figallo, J-M. Hernández-Guisado, G. Machuca-Portillo, *Cri du chat syndrome: A critical review*, Med Oral Patol Oral Cir Bucal. 2010 May 1, 15(3), p. 477.

- motivating the child to make contact with an adult person,
- giving communication intentions to both sounds and movements made by the child,
- organizing a common field of attention,
- learning to use objects in a functional way,
- initiating simple movement games with a parent and alternating games,
- introducing into the process of therapy/learning objects known by the child with indicating their application<sup>22</sup>.

Thus, pre-verbal communication behaviours of the child noticed by parents become relevant. The analysis of the empirical material shows that children with CdC aged 2-13 years (D=6) exhibit behaviours at the level of:

- primary communication:
  - o expressing own feelings in a specific way (frequency: always, 10 in total),
  - o responding in a specific way to individual selected stimuli from the environment (frequency: always, 10 in total),
- sensory communication:
  - o responding to the voice, active search for the sound source, establishing a temporary eye contact (frequency: always, 15 in total),
- auditory communication:
  - o vocalizing in order to establish contact (frequency: often, 15 in total),
  - o using gestures to show that they understand words (frequency: often, 10 in total),
  - o using gestures in the situational context (frequency: often, 17 in total),
  - o using facial expression to show emotional states (frequency: always, 11 in total),

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<sup>22</sup> M. Buchnat, *Cri du Chat Syndrome*, [in:] *Unknown? Understood. Developmental disorders in children with rare genetic syndromes and congenital malformations*, M. Buchnat, K. Pawelczak (ed.), Wyd. Naukowe UAM, Poznań 2013, p. 117.

- organization:
  - o responding to one's name (frequency: always, 13 in total),
  - o signalling needs related to everyday rituals in a specific way (frequency: always, 13 in total),
  - o using gestures to initiate contact with another person (frequency: often, 11 in total),
- signalling needs:
  - o child's reactions are understandable (frequency: sometimes, 12 in total),
  - o using gestures and sight to manifest needs and well-being (frequency: always, 11 in total)
  - o finding the mother and a joy of seeing her (frequency: always, 16 in total).

The level of the skills is varied, just like the group of respondents (it is worth reminding that 11 children covered by the study were intellectually disabled).

Parental responses regarding children's communication behaviours prove their high awareness that every action – gesture, sound – is a message that needs to be strengthened and expanded whenever possible. At the same time, parents are aware that the transfer and reception of information by a daughter or son is limited as a consequence of the specificity of both somatic and psychological symptoms in Cri du chat syndrome.

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