

Understanding Body-Based Communication of Physical Discomfort in Non-Verbal Children with Cri-du-Chat Syndrome

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ABSTRACT:

Background: Communicating physical discomfort is especially important for children with communication disorders, particularly those who are non-verbal. Parents, teachers, and therapists play a key role in recognizing behaviors that signal illness and pain.

Objective: This study aimed to identify and characterize body-based behaviors used by children with Cri-du-Chat syndrome to communicate illness and pain, as reported by their parents.

Methods: A quantitative, survey-based study was conducted with 44 parents of children with Cri-du-Chat syndrome in the United States. Data were collected using an author-designed questionnaire and the Functional Communication Parent Questionnaire (FCPQ). Two physical states were analyzed: feeling sick and pain.

Results: Children most frequently used vocalizations, gestures, and body postures to communicate illness and pain. Illness was mainly expressed through body postures, vocalizations, and sound signals, whereas pain was more often communicated through vocalizations, sound signals, gestures, and pointing. Some children did not intentionally communicate these conditions.

Conclusions: Recognizing behaviors that signal illness and pain may support the rapid identification of poor well-being and help explain a child's unwillingness to participate in daily, educational, or therapeutic activities. This is important for the child's safety, autonomy, and more appropriate support in home, educational, and therapeutic settings.

Keywords: body-based communication, Cri-du-Chat syndrome, non-verbal communication, physical discomfort

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1. Introduction

Communication difficulties are common in children with significant cognitive and developmental impairments, including those associated with rare genetic syndromes (Dhondt et al., 2021). One such condition is Cri-du-Chat syndrome (CdCs), also known as 5p deletion syndrome, a rare disorder characterized by delayed motor and communication development, intellectual disability, and a range of behavioral and physical features (Jones et al., 2013; Corrêa et al., 2019). Many children with CdCs remain non-verbal and rely on non-symbolic forms of communication (Kamyk-Wawryszuk, 2018).

For these children, communicating physical discomfort is especially important. Parents, teachers, and therapists often need to interpret body-based behaviors, such as vocalizations, gestures, and body postures, to recognize whether a child feels ill or is in pain. Such behaviors may function as meaningful pre-symbolic forms of communication and may also support the planning of augmentative and alternative communication (AAC) interventions.

Previous research on Cri-du-Chat syndrome has focused mainly on language development and general communication skills, with less attention paid to the communication of physical discomfort (Cornish & Munir, 1998; Kamyk-Wawryszuk, 2018). Studies in other populations with communication disabilities suggest that illness and pain are often expressed through non-verbal behaviors (Solodiuk, 2013). Therefore, the present study aimed to identify and characterize body-based behaviors used by children with Cri-

du-Chat syndrome to communicate illness and pain, as reported by their parents.

2. Methodology

- **Design:** The study employed a quantitative research design using a diagnostic survey approach. It aimed to identify and characterize body-based behaviors used by children with Cri-du-Chat syndrome to communicate illness and pain, as reported by their parents.

Main research question: How do children with Cri-du-Chat syndrome communicate illness and pain through body-based behaviors, as reported by their parents?

Detailed questions: 1) What behaviors are used to communicate illness? 2) What behaviors are used to communicate pain?

- **Participants/Sample:**

Forty-four parents from the United States participated in the study. Participants were recruited through a parent association supporting families of children with Cri-du-Chat syndrome, using a non-probability sampling approach with voluntary participation. The use of an international sample, primarily from the United States, allowed access to a larger and more active network of families affected by Cri-du-Chat syndrome.

Inclusion criteria were as follows: being a parent or primary caregiver of a child with a confirmed diagnosis of Cri-du-Chat syndrome, the presence of communication difficulties and special educational needs, the presence of at least 15 out of 27 characteristic symptoms of the syndrome, and the child being under 18 years of age.

The questionnaire was completed by one parent of each child. Although the final sample size was lower than the estimated requirement, this reflects the limited accessibility of the target population and is consistent with research involving rare genetic syndromes.

Communication abilities

The majority of children were non-verbal. Four children used single spoken words (e.g., “mama,” “give,” “yes,” “bye-bye”) to communicate, and two children used augmentative and alternative communication, primarily pictographic systems.

Age and diagnostic characteristics

The children with Cri-du-Chat syndrome whose communication was described by their parents had a mean age of 8.41 years ($SD = 3.18$; range: 2–13 years). The mean age at diagnosis was 1.78 years ($SD = 1.52$; range: 0–6 years). Most of the children were female ($N = 26$, 59.09%). The children presented an average of 7 somatic symptoms ($M = 7.25$, $SD = 2.78$, $min = 2$, $max = 15$) and 5 psychomotor deficits ($M = 5.34$, $SD = 1.86$, $min = 2$, $max = 10$).

Ethical Considerations

The study procedures involving human participants were reviewed and approved by the Kazimierz Wielki University Research Ethics Committee in Bydgoszcz. Participation was voluntary and anonymous, and informed consent was obtained from all respondents prior to participation. Participants were informed that they could withdraw from the study at any stage without providing any reason and without any consequences. All data were anonymized and

were accessible only to authorized members of the research team.

Instruments:

Two research instruments were used in the study: an author-designed questionnaire concerning Cri-du-Chat syndrome and the Functional Communication Parent Questionnaire (FCPQ; Wilson & Girdersleeve-Neumann, 2014). The author-designed questionnaire was used to collect parent-reported information on the child's demographic, clinical, psychomotor, and behavioral characteristics relevant to communication functioning. The FCPQ is a caregiver-report tool designed to identify functional communication targets in children with speech and communication disorders. For the purposes of this study, only the “Requests and Needs” section was analyzed. The questionnaire was used to identify body-based behaviors through which children communicated illness and pain. In this study, body-based communication was operationalized as observable, non-verbal, or minimally verbal behaviors through which a child expressed physical discomfort. The analysis focused on two categories of physical condition: illness and pain. Prior to its use, the author-designed questionnaire underwent content validation through expert review by specialists in developmental disorders and augmentative and alternative communication (AAC). A pilot study with a small group of parents of children with Cri-du-Chat syndrome from Poland was conducted to assess comprehensibility and feasibility. Minor revisions were introduced based on the feedback obtained.

• Procedure

Data were collected through an online survey administered via a secure Google Forms platform. Parents received a link to the questionnaire through a parent association supporting families of children with Cri-du-Chat syndrome. The questionnaire was completed remotely at a time and place chosen by the participants. Responses were recorded electronically, exported to Microsoft Excel for data cleaning and organization, and then prepared for statistical analysis. No identifying personal data were collected, and access to the dataset was restricted to the research team.

• Data Analysis

Descriptive statistics were used to summarize the frequency and distribution of body-based communication behaviors related to illness and pain. Data were analyzed using Statistica 13.3 (TIBCO Software Inc.).

A total of 100 individuals responded to the survey. Of these, 44 responses were complete, met the inclusion criteria, and were included in the final dataset. Although the final sample size was lower than the estimated requirement, this reflects the limited accessibility of the target population and is consistent with research involving rare genetic syndromes.

3. Results

Illness

Children diagnosed with Cri-du-Chat syndrome communicate feeling ill mainly through postures, vocalization, and sound signals. Gestures and engagement behaviors were used least frequently. Some children reported no feeling of illness.

The most frequently reported communication behaviors by parents are body postures. Parents know that their child feels illness when they lie down on the floor next to them, look tired, and refuse to eat or want to be hugged. Sometimes, children fidget on the chair, curl up under a blanket, or manifest behaviors that could be classified as self-harm (hitting their head or pulling their ear). In contrast, the purpose of the new external stimulus is to “divert attention” from illness. Most children use vocalizations and other sound signals to communicate illness. They say words like: “It hurts,” “I feel bad,” or “Oh, mum.” Some children cry or stop communicating by making sounds. Some articulate the syllables “so” and “av” or make individual sound signals or groan. Fewer communication behaviors were associated with gestures and finger pointing to indicate where a child experiences pain. The least frequent were activities intended to engage others, such as mimicking the doctor. Some children do not intentionally disclose this condition (Table 1).

Table 1 Body-based behavior communication reported by parents indicates illness in children with Cri-du-Chat syndrome.

Physical Condition: Illness		
Communication Behavior	Description of the Child's Behavior	N (%)
Body posture	Lies on the floor close to the parent	6 (13.64)
	Looks “tired,” refuses to eat, is moody and fussy	5 (11.36)
	Wants to be hugged	3 (6.82)

	Hugs up under a blanket	1 (2.27)
	Hits their head	1 (2.27)
	Pulls their ear	1 (2.27)
	It looks like they are about to throw up	1 (2.27)
	Fidgets on the chair	1 (2.27)
Facial mimicry		0 (0)
Gestures and pointing their finger	Touches the hurting spot	5 (11.36)
Eye contact		0 (0)
Vocalization and sound signals	Says, "It hurts," "I feel bad," "Oh, mum"	11 (25.00)
	Cries	6 (13.64)
	Is quiet	5 (11.36)
	Vocalizes the sounds "so" and "av."	2 (4.55)
	Makes short sound signals	1 (2.27)
	Groans	2 (4.55)
Activities intended to engage other persons	Pretends to be a doctor	3 (6.82)
Does not communicate the condition		5 (11.36)
No answer		2 (4.55)

Feeling Pain

Feeling pain is a challenging experience for a child. The child's behavior often changes, primarily if the child cannot communicate pain verbally. Children with CdCs communicate pain through behaviors such as vocalizations, sound signals, gestures, finger-pointing, and body postures, or they do not intentionally communicate pain. The parents reported vocalizations and other sound signals as the most typical behaviors for pain communication. Most children cried, said, "It hurts," or vocalized the sounds "so," "bu-bu," and "au." Screaming was the least frequent reaction. Children also communicated pain through gestures and pointing. They showed the hurt spot, made the

"pain" gesture, or used another gesture, such as "boo-boo," which their parents understood as an expression of pain. The third way to communicate pain was by body postures. Parents reported that their son/daughter would hide or hit their head. Some parents reported that their children did not communicate pain through body gestures and had high pain thresholds. In terms of activities intended to engage other persons, children ask their parents to kiss the hurting spot, or they show that someone hit them. The child's behavior also changes, and parents report efforts to attract others' attention. Some respondents said that they found it difficult to associate any specific behaviors their children used to communicate pain (Table 2).

Table 2 Body-based behavior communication reported by parents indicating pain in children with Cri-du-Chat syndrome

Physical condition: feeling pain		
Communication behavior	Description of the Child's Behavior	N (%)

Body posture	The body posture does not suggest that a child is in pain; the child has a low pain threshold	6 (13.64)
	Hides	1 (2.27)
	Hits their head	1 (2.27)
Facial mimicry		0 (0)
Gestures and pointing their finger	Points to the hurting spot	8 (18.18)
	Makes the “pain” gesture	5 (11.36)
	Makes the “boo-boo” and “ouch” gesture	2 (4.55)
Eye contact		0 (0)
Vocalization and sound signals	Cries	14 (31.82)
	Vocalizes sounds “so”, “bu-bu,” “au”	6 (13.64)
	Says “It hurts”	6 (13.64)
	Screams	1 (2.27)
Activities intended to engage other persons	A child’s behavior changes to attract the attention of others	2 (4.55)
	Wants to be kissed on the painful spot	1 (2.27)
	Shows someone, e.g., a brother, hitting them	1 (2.27)
Does not communicate		8 (18.18)
I do not know/do not recognize any specific behavior		5 (11.36)
No answer		1 (2.27)

Discussion

The present study aimed to identify and characterize body-based behaviors used by children with Cri-du-Chat syndrome to communicate illness and pain, as reported by their parents. The findings indicate that children with CdCs use a range of body-based behaviors, particularly vocalizations, sound signals, gestures, and body postures, to express physical discomfort. Illness was mainly communicated through body postures, vocalizations, and sound

signals, whereas pain was most often expressed through vocalizations, sound signals, gestures, and pointing. These results suggest that even in the absence of verbal language, children with CdCs use meaningful and observable behaviors to communicate important physical states.

These findings are consistent with previous research showing that children with communication and intellectual disabilities often express pain through non-verbal behaviors, especially vocalization and crying (Solodiuk,

2013). They also support earlier observations that non-speaking children may rely on body-based behaviors as functional forms of communication in everyday contexts (Dhondt et al., 2021). In this sense, the results extend previous research on Cri-du-Chat syndrome, which has focused primarily on delayed language development and general communication skills (Cornish & Munir, 1998; Kamyk-Wawryszuk, 2018), by showing how children communicate physical discomfort through pre-symbolic behavior. The findings have practical implications for parents, teachers, and therapists. Better recognition of body-based signals related to illness and pain may support earlier response, more accurate interpretation of the child's needs, and more individualized intervention planning. These behaviors may also serve as a foundation for augmentative and alternative communication (AAC) assessment and intervention.

A limitation of the study is that the data were based exclusively on parent reports, which may be affected by individual differences in perception and interpretation. The study was also based on a relatively small, non-random sample, reflecting the difficulty of recruiting participants from a rare clinical population. In addition, the voluntary nature of participation may have

introduced self-selection bias, as more engaged parents may have been more likely to participate. Despite these limitations, the study provides valuable insight into an underexplored aspect of communication in children with Cri-du-Chat syndrome.

5. Conclusion

This study showed that children with Cri-du-Chat syndrome use a range of body-based behaviors, including vocalizations, gestures, and body postures, to communicate illness and pain. The findings indicate that even non-verbal children can express physical discomfort through meaningful and observable behaviors that may be recognized by parents and other caregivers.

These results highlight the importance of improving awareness of body-based communication in everyday care and educational practice. Better recognition of such behaviors may support earlier and more appropriate responses to children's needs and may also inform AAC assessment and intervention planning. Future research should include larger samples and observational methods to further examine how children with rare genetic syndromes communicate physical discomfort in different contexts.

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