



## **Touch as part of parent-child communication with a child mechanically ventilated at home – Introduction to the issue**

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A mechanically ventilated child, due to frequent hospitalizations and associated participation in sometimes painful medical procedures, may associate touch negatively. The article's purpose is to show the place of touch in communication between a parent and a child who is mechanically ventilated at home. It indicates the importance of touch and its role when a child requires medical equipment for everyday functioning and does not use verbal language to communicate with others. Such an experience – a negative touch associated with an adult – can also be transferred to relationships with other people and be used in communication. It can contain elements of aggression and resistance based on the child's fear of contact. The child's stay at home will be associated with learning to communicate based on positive touch. It is possible that signals can be introduced to anticipate the activity in which the child will participate. This process will build a sense of security in them, reduce their fear of contact with an adult, and give them a sense of agency.

*Keywords:* touch, parent, mechanically ventilated child (LTV)

### **Introduction**

Following the most straightforward definition, communication conveys thoughts and emotional content in a sender-receiver relationship. It can proceed on two levels: 1) non-verbal, i.e., body posture, gestures, facial expressions, the intonation of speech, and 2) verbal, i.e., the spoken word. Touch plays a significant role in non-verbal communication, as it allows for the assessment of a child's health condition and emotional state during contact and the nursing process. Following Supreet et al. (2024), it was assumed that touch is

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“any percept arising from contact with and to the body surface” (Saluja et al., 2024, p. 2). Touch is symbolic and associated with care and support (Bargiel-Matusiewicz & Hofman, 2005). Thus, it can be assumed that “the primary sense for understanding surrounding events is touch, and the most prominent recipient of this sense is the hand. Through the touch of the hand, the child learns the face of their mother, receives stimuli of heat and cold, and the normal function of the upper limb allows them to play, perform self-care, later write initially, and finally work professionally. All the abovementioned is especially true for people whose functioning in professional life depends on the precision of this complex mechanism” (Chochowska & Marcinkowski, 2013, p. 270). A multitude of experiences, including tactile experiences related to a medical procedure, the process of caring for a sick child, are not always associated with feeling positive emotions. First, they need to be more conducive to developing communication (Sandnes & Uhrenfeldt, 2024), as they can hinder it. Additionally, researchers, including Stamatis (2011), emphasize that “The hunger for safe and affectionate human contact comfort may be more intense than our hunger for food and almost as necessary to our survival as to other species” (Stamatis, 2011, p. 1430). These are the main reasons why a parent should pay attention to the touch they use when caring for a mechanically ventilated (LTV) child at home.

The article’s purpose is to show the place of touch in communication between a parent and a child who is mechanically ventilated at home. It indicates the importance of touch and its role when a child requires medical equipment for everyday functioning and does not use verbal language to communicate with others.

### **The importance of touch in child development**

Touch accompanies a person throughout life, regardless of age, property, or social status. It can perform various functions and enable many tasks. According to researchers, including Barnett (1972), Field (2001), and Geldard (1960), touch is the primary means by which humans interact with the world around them. It is also essential to the child’s cognitive, social, and physical development (Hertenstein et al., 2009). However, the most crucial stages are infancy and early childhood. At this stage of human development, contact through touch is more potent. As Zagórska (2013) points out, the need for touch and closeness to the parent does not diminish as the child grows. Touch is often seen as a natural form of expressing emotions (Zagórska, 2013). It allows family members to show affection and causes a person to gain confidence in the world. Hertenstein and his team (2009) emphasize, “Based on the limited research conducted on touch and emotion, two general claims have been made regarding the role of touch in emotional communication. First, touch has been claimed to communicate the hedonic value of emotions. Second, touch was thought to merely amplify the intensity of displays from the face and emotional voice”

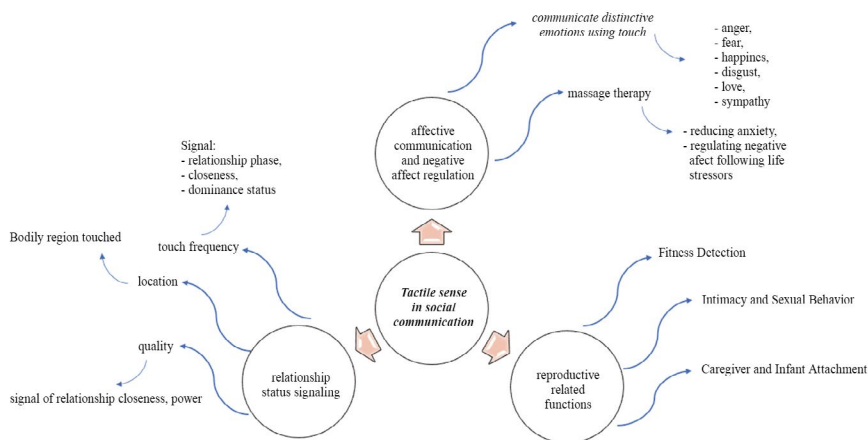
(Hertenstein et al., 2009, p. 566). It is essential when illness occurs, as “illness is a situation in which the tender touch of a loved one is irreplaceable. The child should then be provided with conditions that provide plenty of positive tactile sensations so that he or she is not afraid of medical procedures or injections” (Zagórska, 2013, p. 180). Touch can also be therapeutic and is used in many methods, such as Marianna and Christopher Knill’s activity programs (Kamyk-Wawryszak, 2017).

### **Touch in communication, care, and nurturing of the chronically ill child**

Touch is perceived as the sense that plays the most significant social role because it is based on interaction with another person (Stamatis, 2011). It will also play a role in social communication. Saluja and his team (2024) detailed three sub-functions of the tactile sense in social communication: (1) effective communication and negative affect regulation, (2) relationship status signaling, and (3) reproductive-related functions (Figure 1).

**Figure 1**

*Three sub-functions of the tactile sense in social communication*



Source: Based on: Saluja S., Croy I., Stevenson R.J. (2024). The Functions of Human Touch: An Integrative Review. *Journal of Nonverbal Behavior* <https://doi.org/10.1007/s10919-024-00464-x>.

Humans can use touch to communicate emotions. Hertenstein et al. (2009) indicated that touch can convey emotions such as anger, fear, happiness, sadness, disgust, love, gratitude, and compassion (Hertenstein et al., 2009). It may also reduce anxiety. Additionally, physical contact and related closeness will regulate and even have a repair function in friendly relationships. Touch will also indicate a close relationship between people or a power status. If

we consider it from this perspective, we must take into account its frequency (amount used), location (bodily area touched), and quality (type of touch used). The frequency will indicate the dynamics of the relationship. Body areas and the quality of touch may refer to both the cultural patterns of a given country and the closeness of relationships with others, e.g., with a parent (hugging, touching body parts such as the chest) (Saluja et al., 2024). Field (1999) believes that children with less physical contact with their parents are touched and hugged less often but often receive physical punishment, and may show more negative interactions than their peers (Field, 1999). Touch as an element of communication may be used more often when a family member is sick as a comfort and support.

**Table 1**

*Body-based communication behaviors and their interpretability, according to Jerzyk (2019)*

<b>Behavior</b>	<b>Interpretation</b>
<i>Nodding head + eyeballs stable + body relaxed</i>	I still want; sometimes approval; I choose it; I accept what you say
<i>Not nodding + body relaxed</i>	I want to finish
<i>Not nodding + tense body + cringing from the tracheostomy tube</i>	definitely and immediately want to end it
<i>Tensed whole body + head tilt</i>	I don't like it; it's uncomfortable; I have a wet diaper
<i>Tense whole body + head tilting + legs tilted to the left + "upturned" eyeballs</i>	I don't like it very much; I'm angry; something hurts me; leave me; I don't want it
<i>A gurgling sound from the tracheostomy tube during activity, combined with more secretions</i>	I don't like it
<i>Tight skin on the forehead, veins visible on temples</i>	It is awful; I am extraordinarily dissatisfied
<i>Warping the mouth into a so-called horseshoe shape</i>	I am going to cry
<i>Sight focused on the person</i>	It is good; I like it; I accept it
<i>Looking at the object</i>	I am interested in this; I like it
<i>Tensed legs bent to the left side</i>	Always indicate that something is wrong
<i>Nostrils dilating rhythmically</i>	I get nervous; I want to poop (from the parent interview)

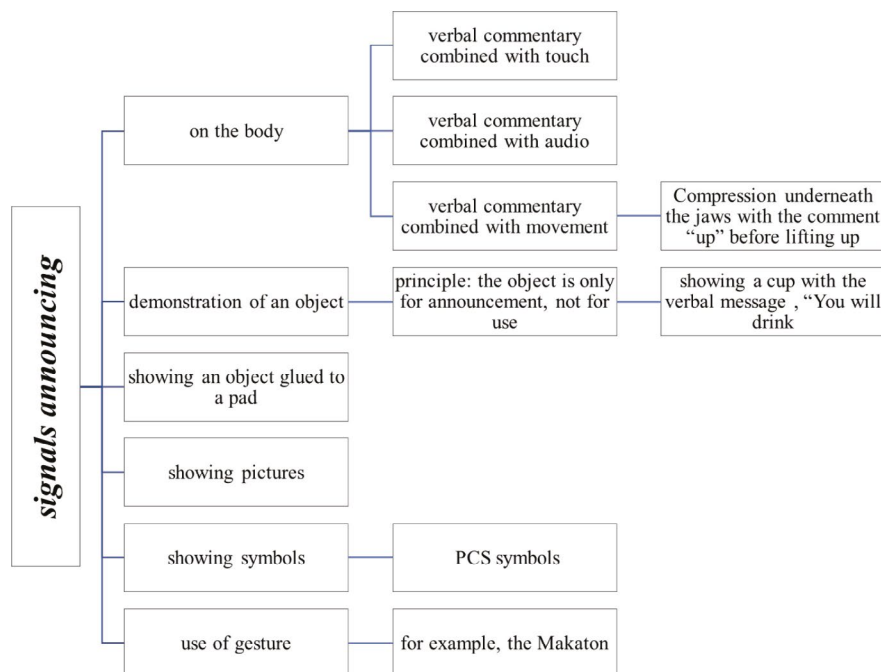
Source: M. Jerzyk (2019). Oddziaływania wspierające rozwój komunikacji osób z głęboką, wieloraką niepełnosprawnością, „Terapia specjalna dla dzieci i dorosłych,” p. 21, permission of the author has been obtained.

Children with a diagnosed chronic illness, the consequences of which often include various disabilities, including complex disabilities, perceive others

using their bodies and body contact. Andreas Fröhlich (2016) stresses that such children can collect and value experiences with their bodies. Most notably, in their functioning, they use their bodies to convey their messages. Using it, they can signal their needs and emotions (Fröhlich, 2016). Jerzyk (2019) offered an interpretation of selected communication behaviors based on the child's body and its signals using the example of a boy diagnosed with cerebral palsy and a tracheostomy (Table 1).

## Figure 2

### *Announcement signals on the body*



Source: Based on: A. J. Kopeć. (n.d.). Sygnały uprzedzające. Stowarzyszenie Tęcza, [https://teczka.org/wp-content/uploads/2020/05/Aygna%C5%82y-uprzedzaja%CC%A8ce\\_Strategia-AAC.pdf](https://teczka.org/wp-content/uploads/2020/05/Aygna%C5%82y-uprzedzaja%CC%A8ce_Strategia-AAC.pdf), access date: 01.02.2024.

Using his body and the opportunities it gives him, a child can signal various sensations and states through facial expressions, eye contact, vocalizations, or body tension. For example, by making a sound of cringing, he can let the parent know that he dislikes something, or by looking at the caregiver, he signals that his current activity pleases him and does not cause any discomfort. In communication with a non-speaking child, so-called anticipatory signals are also used, understood as “actions we perform towards children to warn them about something. We warn the child about what will

happen in a moment. Anticipatory signals must be adequate about the sensory and cognitive capacities of the child” (Kopeć, n.d.). These include but are not limited to announcing signals on the body, showing the child objects that he or she will associate with performing the activity, showing objects taped to a pad, showing pictures of objects or symbols representing the activity, and using a gesture (Figure 2) (Kopeć, n.d.).

### **Touch as one of the communication elements for a non-speaking child mechanically ventilated at home**

A child who experiences a chronic disease and its consequences in daily functioning (e.g., mechanical ventilation) due to participation in many different medical procedures may associate adult touch positively or negatively. From a medical perspective, one can observe that touch can be instrumental (based on physical contact with the patient to facilitate specific medical actions), expressive (spontaneous and sometimes referred to as “comforting touch” or “caring touch”), or indefinite. There is also a division into procedural touch (the implementation of a given action related to a medical procedure, such as measuring the patient’s pulse) and non-procedural touch (such as holding the patient’s hand in the context of showing support). Also, the term ‘therapeutic touch’ can be found in the literature. It means “the intentional touching of a person to benefit him physically or psychologically, as in the case of massage” (Gale & Hegarty, 2000, p. 98).

Researchers – including Sandnes and Uherenfeldt (2024) – pointed out that in the past, stroking a patient’s cheek, hugging him, and holding his hand were sometimes referred to in medical literature as “non-necessary touch” (Sandnes & Uherenfeldt, 2024, p. 2). This situation could result from a lack of understanding of the role this form of care may play in the patient’s treatment process. Currently, the concept of caring touch is perceived as “a common ICN (in intensive care units) measure linked to ethical practice” (Sandnes & Uherenfeldt, 2024, p. 3).

On the other hand, adopting the perspective of a parent, caregiver, or therapist, it can be pointed out that “the chief place in non-verbal communication is occupied by touch because, during examinations and nursing procedures, it makes it possible to learn about the patient’s health condition. According to Sandnes and Uherenfeldt (2024), “caring touch emerges as an important aspect of everyday ICNs, providing a silent language for communicating with critically ill patients. No words are necessary in this form of communication, although a caring touch can also be used to reinforce words being said. With their caring touch, ICNs aim to convey support, care, and hope, while also fostering and maintaining a trusting relationship with their patients. This is important as it helps humanize patient care” (Sandnes & Uherenfeldt, 2024, p. 8). Touch also has “symbolic value, signifies care, support” (Bargiel-Matusiewicz & Hofman,

2005, p. 49). Both rocking and various forms of tactile stimulation of the body of a child who is ill or has a disability can be used to soothe or relax him. The mere contact through touch during classes or joint activities provides an opportunity to experience kinesthetic sensations and allows the child to learn about their body. It also provides an opportunity to perceive positive emotions expressed by adults, and most importantly, in the case of a child with a medical condition, it provides a sense of security. In the parent-child relationship, the frequency and variety of touch contact will promote the child's development of a communicative attitude (Kamyk-Wawryszuk, 2017; Piszczek, 1997). As previously mentioned, the announcing signals that a parent will use in communicating with a child during nursing activities should consider the child's sensory and cognitive capabilities.

Thus, in the case of a mechanically ventilated child, it must be taken into account that he or she may perform some range of motion, as in the case of neuromuscular diseases (depending on the severity of the disease), or be entirely dependent on the parent for daily functioning, as in the case of Odin's Curse disease. Kopeć (n.d.) offered examples of activities and signals that can be used in communicating with a child, such as announcements, which are based on touch. They can also communicate with a mechanically ventilated child (Table 2).

**Table 2**

*Proposal of sample activities and the signals that announce them*

Activity	Signal
Saying hello	A handshake
Ending	Signal on the body: Compress the child's chest with the whole hand
More	Signal on the body – double slap of the therapist's hand on the client's left shoulder
Lifting/moving	Signal on the body – pressure under the armpits
Diaper changing	Signal on the body – hip compression
Meal	Signal on the body – touching the mouth with a spoon
Take a walk	Touching the sole of the shoe to the child's foot
Drinking	Signal on the body – touching the mouth with a clean spoon
Stimulation	Scented signal on the body – touching the nose

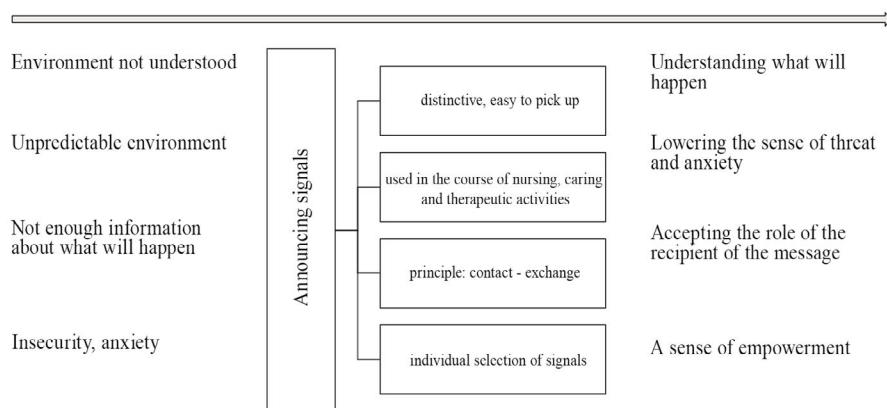
Source: A. J. Kopeć. (n.d.). Sygnały uprzedzające. Stowarzyszenie Tęcza, dostęp: [https://tecza.org/wp-content/uploads/2020/05/Aygna%C5%82y-uprzedzaja%CC%A8ce\\_Strategia-AAC.pdf](https://tecza.org/wp-content/uploads/2020/05/Aygna%C5%82y-uprzedzaja%CC%A8ce_Strategia-AAC.pdf), access date: 01.02.2024.

As the table above shows, the announcing or preceding sign is a simple movement, often intuitive. It should be associated with an activity, such as saying hello, shaking (or touching) the hand, or walking, touching the sole of the shoe of the child's foot. Some of these may be modified due not only to the individual predisposition of the child but also to the fact that the child may not take products by mouth, but may have a nasogastric probe in place or a

percutaneous endoscopic gastrostomy in place. In that case, the parent, together with the child, can choose another anticipatory sign to indicate eating (such as touching the wing of the nose on the side where the probe is placed or touching the side of the child where he or she has a PEG in place). For a mechanically ventilated child, returning home from the intensive care unit can be a stressful situation. The home environment may be incomprehensible and somehow unpredictable to him, and can cause insecurity and anxiety. Because the child has limited or no ability to communicate verbally with others, there may also be a situation in which he or she does not receive enough information about what is about to happen (Figure 3).

**Figure 3**

*Anticipatory signals and their meaning can be used in communicating with a mechanically ventilated child at home*



Source: Based on:

Jerzyk M. (2020). Sygnały na ciele- geneza, teoria, praktyka [Signals on the body – origins, theory, practice], „Terapia specjalna dla dzieci i dorosłych”, pp. 14-19.

Introducing anticipatory signals that are individually tailored to the child, easy to pick up, and based on the contact-exchange principle will allow them, among other things, to assume the role of receiver. Their use is intended to forewarn a mechanically ventilated child about an activity that will take place, which will allow them to prepare for a new activity/situation, reduce stress, and give them a sense of agency (Fig. 2) (Kopeć, n.d.). There are specific stages of applying anticipatory signal strategies to the child's body. The first refers to making contact with the child. The second is when an adult performs a signal on the child's body. In the third stage, the parent waits for a reaction from the child; this is the fourth stage. The fifth and sixth stages involve the parents' acceptance of the reaction and their re-execution of the signal on the body. The seventh stage is waiting, and the eighth is the reaction. The last two, the ninth



and tenth, are the acceptance of the reaction and the parent's execution of the action announced by the anticipatory signal. The fourth, fifth, seventh, and eighth stages can be skipped (Jerzyk, 2020). Gale and Hegarty (2000) believe that using touch with people who require support in their daily functioning brings them both physical and emotional benefits. The abovementioned is why touch should become part of the support offered to the child by the caregiver.

A child with a chronic disease who is hospitalized frequently or for long periods experiences various types of touch in connection with their treatment process. As Betts points out, not all touch used by medical personnel (here, he gives the example of nurses) can be interpreted positively. Thus, healthcare professionals who use touch when performing various activities around a patient must understand the therapeutic possibilities of this approach. In medical terms, touch "can be instrumental (this includes all the functional touching necessary to perform physical procedures, such as dressing wounds or measuring pulses) or expressive (used to convey feelings)" (Betts, 2002, p. 259).

Given this situation, a child in an intensive care unit may experience both the positive and negative aspects of touch. They will transfer these experiences to their relationships with those who will care for them at home. Hence, it is essential to understand the role that touch plays in the daily functioning of a mechanically ventilated child at home and its importance when they have no verbal speech and use touch for communication. Karlsen and her team (2023) analyzed the literature on the communication of mechanically ventilated people. She pointed out that this area has yet to be thoroughly researched. Some publications primarily address the experiences of patients, medical personnel (such as nurses), or family members regarding communication, how to resolve communication problems, and the introduction of alternative and augmentative communication (AAC) (Karlsen et al., 2023). However, there needs to be more publications addressing the issue of communication with mechanically ventilated children and the importance of touch in it. At the same time, it is worth noting that the type of communicative behavior manifested by mechanically ventilated children will depend on the background of the mechanical ventilation (what disease, its course, and impact on the child's cognitive functions), as well as the extent of motor skills, both in the area of fine and gross motor skills. The greater the child's motor capabilities, the more touch will be one of the communication elements rather than the leading channel. When using touch to communicate with a mechanically ventilated child, it is worthwhile to introduce signs that announce the activity about to be performed. Those signs are simple to perform with a simple movement and do not require the support of equipment or other tools. However, it must be established individually with the child and constantly repeated. Maintaining the pattern or movement of the given announcing sign is necessary. Applying it will allow one to actively participate in the child's life and maintain autonomy and a sense of agency.

### Implications for practice

Teaching parents of a mechanically ventilated child at home how to use positive touch will create an opportunity to introduce communication through body signals (touch signals) and learn to utilize alternative communication methods that incorporate touch. This will increase the child's independence, despite the limitations they experience, which will translate into greater autonomy and a sense of agency necessary during therapy and rehabilitation. Positive touch will help build the basic skills that require establishing a relationship with an adult and a sense of security. It is essential to remember that the skin is one of the earliest developed senses, and touch stimulates brain function, playing a significant role in learning about one's own body, including its schema, among other things. As a result, the child will be able to identify and indicate the parts of the body that hurt or the areas where they feel discomfort during therapeutic exercises, which will improve their quality of life.

### Recommendation for further research

- Research on touch communication of mechanically ventilated children needs to be deepened and expanded to include such aspects as, but not limited to:
- Ways of obtaining consent from the child to participate in activities of daily living, therapy using touch as a communication tool;
- Teaching positive touch to a child requiring medical equipment in daily functioning, after a stay in the intensive care unit, and the principles of its introduction during pedagogical and speech therapy;
- Developing a scheme for implementing the stages of familiarization with the touch of an adult (therapist), during therapeutic activities.

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## Dodir kao deo komunikacije roditelja sa detetom sa mehaničkom ventilacijom u kući – Uvod u problem

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Dete sa mehaničkom ventilacijom, zbog čestih hospitalizacija i pridruženog učešća u ponekad bolnim medicinskim procedurama, može negativno da reaguje na dodir. Svrha ovog stručnog rada je da pokaže mesto dodira u komunikaciji između roditelja i deteta koje je mehanički ventilirano kod kuće. Ukazuje na važnost dodira i njegovu ulogu kada je detetu potrebna medicinska oprema za svakodnevno funkcionisanje i kada ne koristi verbalni jezik za komunikaciju sa drugima. Takvo iskustvo – negativan dodir povezan sa odraslom osobom takođe se može preneti na odnose sa drugim ljudima i koristiti u komunikaciji. Može da sadrži elemente agresije i otpora usled straha deteta od kontakta. Boravak deteta kod kuće biće povezan sa učenjem komunikacije na osnovu pozitivnog dodira, što je moguće kada se uvedu signali koji predviđaju aktivnost u kojoj će dete učestvovati. Ovaj proces kod njega će izgraditi osećaj sigurnosti, minimizirati osećaj straha od kontakta sa odraslom osobom i dati mu osećaj kontrole.

*Ključne reči:* dodir, roditelj, dete sa mehaničkom ventilacijom (LTV)

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