

Dying without a voice:

Improving communication when a child can no longer speak

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Background

The majority of children with brain tumors that are resistant to treatment rapidly lose their ability to speak and write due to progressive neurological impairment and/or fatigue. Often, it becomes increasingly difficult for caregivers to decipher the child's wants and needs or to effectively determine whether their child is in pain. Compromised communication can be emotionally devastating, increasing the child's and family's distress and diminishing their ability to cope. The child's inability to communicate their needs, hopes, fears and feelings, may result in a loss of independence, withdrawal and isolation. While communication skills are impaired, the child's intellect is often intact, further contributing to frustration and despair. The goal of this project is to collect and disseminate information about creative communication strategies, important issues to discuss and opportunities for family members and professionals to enhance communication when a dying child has trouble speaking.

Methods

We interviewed 14 families who had a child between the ages of 4 and 16 years old, whose ability to communicate was compromised while in the palliative care of the Brain Tumor Program at SickKids hospital, and had died 6 months to 3 years prior to being involved in research. Interviews lasted between 25 minutes and 2 hours, were digitally recorded, transcribed and coded using NVIVO software to facilitate thematic analysis.

Interview Themes	Common Issues Described
Child's changing function	Speech, sensory perception, motor skills, strength, energy, coordination, attention,
Psychosocial issues – Child & Family	Relative awareness of potential change/loss of function and independence, frustration, worry, hope, maintaining connections with loved ones
Communication Strategies	Range of techniques, how to know what to try, when to start, how to teach/learn/adapt
Discussing complex issues – What? How?	Physical, medical, emotional, spiritual issues, preparation for end of life, death, unspoken questions, fears,
Family needs	Information, advice and support from staff, devices to assist communication

“What techniques did you use to communicate?”

Families have described a variety of creative communication strategies, each with their individual pros and cons.

- **Writing** – This may include use of paper, dry-erase board, or Magna-Doodle
Pros: familiarity of these tools, portability and range of messages that can be expressed. Magna-Doodles were also felt to be more like games than assistive devices.
Cons: required reading and writing abilities, fine motor control and co-ordination.
- **Charts, picture boards or books** – Tools are often home-made and designed by caregivers. Children point to a message, or caregivers point and the child indicates “yes” or “no.”
Pros: personalized, familiar, portable, modifiable. Charts often used to guide questions to identify needs, wishes.
Cons: risk of becoming reliant on the tool. Some families got “stuck” trying to express a message that was not included.
- **Alphabet board** – This board allows the child to spell words by pointing to letters or to nod when caregivers point to the correct letters or message.
Pros: range of messages, portable.
Cons: time- and energy-consuming, requires patience, attention span, clear vision and spelling ability.
- **Computer keyboard** – Tool involves typing / pointing to letters.
Pros: range of messages.
Cons: not portable, requires fine-motor control, co-ordination, spelling & familiarity with QWERTY keyboard.
- **Assistive devices** – These devices are individualized and often include buttons with single or multiple messages; accessed via a laptop or a tablet for typing or a touch-screen.
Pros: range of messages, portable.
Cons: risk of becoming reliant on the tool and losing ability to use it effectively; potential technical problems, difficulty learning and using a device; lack of access to assistive technology.
- **Non-verbal communication** – This may include sign language or codes developed by families; gestures, hand signals, pointing, facial expressions and lip reading.
Pros: can create gestures or signals for any message; supports intimate communication through eye contact, touch, etc.; a list of gestures and their meanings can enhance effectiveness.

Cons: requires practice and familiarity.

- **Yes/No questions** – Eventually this method was used by all families, often supported by lists to guide questions. The child’s signals for “yes” included thumbs up; nodding head, raising eyes or eyebrows; moving a finger or toes, etc. This communication method required caregivers to learn their child’s cues, facial expressions, preferences, to be patient, rely on their intuition, and to frame everything as a “yes” or “no” question (i.e. rather than asking “How are you feeling?” which could refer to loneliness, pain, boredom, etc., ask “How is your stomach feeling?” or “Are you lonely?”).

Pros: no equipment or supplies needed to ask questions about needs, emotions, activities, etc. Intimate connection and relationship aspects of communication are maintained.

Cons: requires patience and familiarity.

“What was most important to talk about?”

“Everything was important.” Parents described struggling with the child’s loss of ability to “be her (or him) self” or to use the familiar phrases that reflected their character. They explained that continuing to acknowledge the child, including them in interactions even when they were unable to speak, paying attention to facial expressions and body language helped to maintain familiar communication with family members, visitors and health care professionals. Important topics to discuss included:

- **Physical comfort** - ability to express hunger, thirst, needs to reposition, use the bathroom or indicate pain.
- **Emotional needs** - some used charts showing a range of facial expressions for the child to point to, others asked questions based on non-verbal cues, ie “You look like you’re feeling ____, are you?” Physical closeness and affection were also very meaningful ways of offering support.
- **Spirituality and end of life issues** - for some families, caring for emotional needs - meant discussing death and the child’s continuing presence in the family. Many parents struggled with, but treasured the opportunity to tell their child, “We’ll miss you so much, but we’ll be okay and so will you. You will always be part of our family.”

Family, friends and familiar activities were topics that helped maintain “normal” communication and meaningful connections.

Family Communication Handbook

Throughout the interviews, families highlighted the urgent need to create a resource for other families, offering strategies and advice around the communicative and psychosocial needs associated with their child’s changing function. To meet this need our team is developing a “Family Communication Handbook” based on the insights and experiences shared in these interviews. The Table of Contents will include:

- Quick Tips – Things to keep in mind when communicating with a child who has trouble speaking
- A New Approach to Communication
 - Preparing for the unexpected
 - Different ways to ask questions
 - *How* to communicate
- Communication Strategies
 - Tools, Techniques, Challenges
 - Deciding what to try, When and how to change strategies
- Communication Topics
 - Physical; Medical; Emotions; Activities; People & pets; Future, spirituality & death.
- Supporting children, supporting yourselves
 - Common struggles; Supporting siblings; Challenges parents faced; Support from others
- Tools – Alphabet board, pain scale, body outline & feeling faces

How we can help families

Due to the high degree of difficulty associated with learning to use a new device or skill as the children lost physical and/or neurological function, it was crucial to introduce and to rehearse communication strategies as early as possible in order for families to communicate comfortably and efficiently.

To acknowledge and prepare for this, families require health care professionals to:

- explain that their child could eventually lose the ability to speak, as soon as this is recognized as a possibility;
- tell them what to look for as indications that the child’s abilities are changing;
- show them when we recognize these signs and help them find tools and strategies they can practice as early as possible, even before these strategies are needed, and;
- help them adapt strategies to meet the child’s and family’s changing needs.

Developing a rapport with families early on is critical to establish a context in which to explore and support families through these challenges. Creating an ongoing dialogue with families that includes communication with their child can focus initially on the diagnosis and treatment and evolve into discussions about life, death, and their own care and wishes at the end of life.

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