

Evaluation

For the **Provincial Stroke Rounds Planning Committee:**

- To plan future programs
- For quality assurance and improvement
- For **You**: Reflecting on what you've learned and how you plan to apply it can help you enact change as you return to your professional duties
- For **Speakers**: The responses help understand participant learning needs, teaching outcomes and opportunities for improvement.

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Please take 2 minutes to fill the evaluation form out. Thank you!

Mitigating Potential Bias

The Provincial Stroke Rounds Committee mitigated bias by ensuring there was no industry involvement in planning or in the education content.

The Ontario Regional Education Group (OREG) host member, on behalf of the Provincial Stroke Rounds Committee, reviewed the initial presentation supplied by the speaker to ensure no evidence of bias.



BUILDING AWARENESS: HELPING KIDS UNDERSTAND STROKE AND APHASIA

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Disclosure

- **Affiliations:** Lisa works at Lear Communication as well as March of Dimes Canada, Alessandra works at Critical Trauma Therapy
- **Financial Support:** *This session/program has not received financial or in-kind support*
- **Mitigating Potential Bias:** *Lisa is the author of Listen With Your Heart: Helping Kids Understand Stroke and Aphasia and receives financial compensation for sales of the book*
- Some slides have been adapted with permission from a presentation by Brooke Ryan

Learning Objectives

Upon completion, participants will be able to:

- Explore the unique challenges faced by individuals with acquired communication disorders and their families.
- Assess the role of provincial stroke services and networks in supporting families, particularly children, affected by stroke and aphasia.
- Identify effective resources and strategies to support children and families navigating communication disorders.
- Understand the importance of a multidisciplinary approach when working with families

*June is Stroke and Aphasia
Awareness Month!*



BACKGROUND AND RESEARCH



Stroke Statistics in Canada

- 1 Stroke every five minutes
- Stroke in young adults (under 50 years) is estimated to represent 10-15% of all strokes.
- Many of these stroke survivors have young children and face unique challenges around parenting and family functioning.

What is the Impact on Families?

- Stress is highest for families who have multiple young children, and where the parent with stroke was the main income earner.
- When stroke also results in aphasia, unique challenges are created as communication is fundamental to family functioning.



Consider how many times you communicated with family members just this morning...

Challenges Faced by Children

Research suggests that children with parents who have an acquired brain injury, like stroke, face difficulties in the areas of participation and functioning.

- **Parents' reported changes:**

- *increased anger, anxiety and children took on more of a caregiver role after parental injury (Walker et al. 2021) leading to parentification and potential resentment or stress.*

- **Child's self-reported changes:**

- *feeling fear, isolation, and general confusion. Kieffer-Kristensen & Johansen (2013), particularly when a parent's communication style changes suddenly.*

Challenges Faced by Children

Dawes et al. (2020) also found that a lack of information leads children to have misguided hopes for their parents' recovery outcomes.

But...

- Children of parents with ABI who were given age appropriate information and invited into decision making meetings found this to be a positive experience, expressing that it allowed them to gain insight on their parents' goals and progress.
- Research in other fields such as children of parents with cancer or mental health challenges points to benefits, including reduction in misconceptions about the parental illness and a general sense of “relief” (Oja et al., 2020).

Shrubsole et al., 2021; Walker et al., 2021; Kieffer-Kristensen & Johansen, 2013; Dawes et al., 2024; Dawes et al., 2020)

Family-Centered Care in Stroke Rehabilitation

Engaging family caregivers in the planning and delivery of care was associated with improved patient outcomes and better preparedness for post-discharge life.

Family-centred care increased patients' satisfaction by 30% and reduced hospital readmission rates by 15% compared to traditional care models (Creasy et al., 2015).

Family-Centered Care in Stroke Rehabilitation: The Gap

Despite the known benefits of family-centered approaches to care, there is little existing evidence regarding whether providers are currently including the children of their clients with acquired communication disorders in their services.

One study in Australia reported that **over 80% of SLPs** surveyed had **seen parents with an acquired communication disability** who had children under the age of **18 years in the past 12 months**.

More than 75% reported ***rarely*** provided ***information, education, or counselling*** services to the ***children*** of parents with an ***acquired communication disability***.

Why might children be excluded from the rehabilitation process?

Lack of:

- Clinician skills, knowledge and training
- knowledge on providing education and counselling to children
- Access to the children, and lack of confidence to even attempt to provide such services (Shrubsole et al., 2021).
- Clinical guidelines regarding the proper approach to including children in the therapeutic process (Dawes et al., 2024).
- Age appropriate resources that healthcare professionals could use to engage children (Shrubsole et al., 2021; Walker et al., 2021; Dawes et al., 2024, Dawes et al., 2020).
- Interprofessional collaboration and knowledge of community resources/funding

Additionally, clinicians might view this as out of their scope of practice (Webster & Daisley 2007).



WAYS TO OVERCOME BARRIERS

Addressing Systemic Gaps Through Interdisciplinary Family-Centered Care

- Collaborating with the SLP to address emotional and relational challenges linked to aphasia
- Emphasizing the importance of interdisciplinary care to treat the *whole person*—not just the speech disorder
- Counselling supports clients in processing frustration, grief, and identity shifts
- Helps children and loved ones understand and adapt to communication changes
- *Family Systems Theory* guides us in addressing the needs of the entire family unit
- Fosters empathy, resilience, and stronger connections through open dialogue and emotional support
- Encourages holistic, sustainable outcomes by supporting every member of the family

Challenges Faced by Parents with Aphasia

Identity Shift:

- Loss of the parental role, including challenges in guiding, disciplining, and mentoring children.
- Feelings of inadequacy, frustration, or grief related to changes in communication ability and self-expression.

Parenting and Communication Difficulties:

- Struggles to communicate effectively with children, leading to potential misunderstandings or emotional disconnect.
- Navigating moments of frustration or anger when unable to express oneself or understand others fully.

Complicated Grief:

- Both the parent and family may experience grief over the loss of previous communication dynamics and shared activities.
- Navigating grief while maintaining resilience and connection is critical to family well-being.

Counselling Strategies: *Family Systems Theory*

Key tenets of Family Systems Theory include:

- ***Interconnectedness:*** Family members are interdependent, and changes or challenges affecting one member impact the entire family system.
- ***Homeostasis:*** Families strive to maintain balance and stability, adapting to disruptions while trying to preserve functionality.
- ***Triangles:*** Triangular relationships, often involving three individuals, arise as a way to manage stress or conflict.

Counselling Strategies: *Family Systems Theory*

Key tenets of Family Systems Theory include:

- ***Differentiation of Self:*** Individuals within the family vary in their ability to maintain their identity while being connected to the family.
- ***Family Roles and Patterns:*** Repeated behaviors and interactions create roles and patterns that guide family functioning.

Family Systems Theory: in Application

Understanding Family Dynamics:

- Assess how aphasia affects the family system as a whole. For example, they might explore shifts in roles (e.g., children taking on more responsibilities) and stress dynamics.
- This helps families recognize the broader impact and work collectively toward solutions.

Family Systems Theory: in Application

Fostering Open Communication:

- Therapists/counsellors can teach children developmentally appropriate ways to communicate with a parent who has aphasia, emphasizing alternative communication methods such as gestures, visual aids, or technology.
- Interventions may involve creating family agreements on using inclusive communication strategies.

Family Systems Theory: in Application

Promoting Adaptation and Resilience:

- Families are encouraged to adapt to their new reality while maintaining a sense of cohesion. For instance, family therapy sessions might focus on identifying and celebrating small successes in communication.
- Counselling helps normalize feelings of frustration or grief while encouraging a shift toward problem-solving and mutual support.

Family Systems Theory: in Application

- **Empowering Children Through Education:** Children need to understand what aphasia is in simple, clear terms. Addressing misconceptions and teaching empathy are key components of this education.
- **Balancing Individual and Family Needs:** FST highlights the importance of differentiation of self. For children, this might involve encouraging hobbies, friendships, and academic pursuits.
- **Utilizing Triangular Relationships:** Triangles often form in families dealing with aphasia. Counsellors can help families recognize and manage these dynamics, ensuring they remain healthy and functional.

Family Systems Theory: in Application

- **Family Meetings:** Facilitate structured discussions to share feelings, strategies, and successes.
- **Workshops for Children:** Organize group sessions where children of parents with aphasia learn from peers and engage in supportive activities.
- **Creative Expression:** Use art, play therapy, or storytelling to help children process their experiences and communicate their emotions.
- **Skill-building Sessions:** Teach the entire family techniques for active listening, patience, and effective non-verbal communication.

Outcomes of *FST*-Based Interventions

1. Improved Familial Cohesion

▪ ***Enhanced Communication:***

- Families adopt inclusive communication strategies (e.g., gestures, visual aids, technology).
- Greater understanding of each member's needs and feelings reduces conflict.

▪ ***Strengthened Emotional Bonds:***

- Shared problem-solving fosters unity and trust.
- Families celebrate small successes, reinforcing positive interactions.

▪ ***Increased Resilience:***

- Families develop coping mechanisms to navigate ongoing challenges.
- The system becomes more adaptable to future stressors.

Outcomes of *FST*-Based Interventions

2. Positive Impact on Child Development

- ***Emotional Well-being:***

- Children feel supported, less confused, and more secure.
- Reduced anxiety as they learn to understand the condition and its implications.

- ***Social Skills:***

- Education about aphasia fosters empathy and emotional intelligence.
- Opportunities for peer support enhance confidence and connection.

- ***Cognitive Growth:***

- Problem-solving and creative communication activities stimulates cognitive flexibility and adaptability.

- ***Role Modelling:***

- Observing parents adapt and persevere teaches resilience.

Outcomes of *FST*-Based Interventions

3. **Rehabilitation of the Affected Parent**

- ***Increased Engagement:***

- Consistent family involvement motivates the parent to participate in therapeutic exercises.
- Regular practice of communication skills in a supportive environment enhances recovery.

- ***Emotional Support:***

- Feeling understood and included reduces isolation and depression.
- Improved self-esteem.

- ***Functional Benefits:***

- A collaborative home environment reinforces the work done in therapy.
- Progress in daily communication builds independence and confidence

Outcomes of *FST*-Based Interventions

4. Broader Family Functioning

- **Role Adjustment:**
 - Families successfully navigate changes in roles (e.g., caregiving, household management).
 - Clear boundaries and expectations reduce stress and prevent burnout.
- **Problem-solving Skills:**
 - Families gain tools for resolving future challenges collaboratively.
 - A proactive approach to managing stress creates long-term stability.
- **Quality of Life:**
 - Improved emotional climate fosters overall well-being.
 - Families experience a greater sense of purpose and fulfillment as they work toward shared goals.

5. Community and Societal Impact

- **Advocacy Skills:**
 - Families become better advocates for the affected parent in healthcare, education, and community settings.
- **Awareness and Empathy:**
 - Educated children and families contribute to societal understanding of aphasia.
 - Participation in support groups or public forums fosters broader acceptance and inclusion.

Other Notable Counselling Techniques

- **Mindfulness-Based Techniques:**

- *Meditation, breathing exercises, body (PMR)*

- **Validation Techniques:**

- *Reflective listening, empathy statements, and normalizing experiences*

- **Solution-Focused Technique:**

- *Miracle question, scaling progress, and identifying strengths.*

- **Cognitive-Behavioural Techniques:**

- *Cognitive restructuring, thought records, and behavioral activation*

- **Emotion-Focused Techniques:**

- *Emotion regulation, empathic attunement, and the two-chair technique*

Positive Parenting in the Context of Aphasia

For Parents with Aphasia:

- Focusing on strengths rather than limitations, such as finding new ways to connect with children.
- Practicing patience with oneself and seeking professional support when needed to adapt parenting strategies.
- Setting realistic expectations for daily parenting tasks.

For Partners/Co-Parents:

- Offering emotional and practical support to the parent with aphasia while maintaining a united front in parenting.
- Encouraging shared family activities.

Positive Parenting in the Context of Aphasia

For Children (Age-Appropriate Approaches):

- **Early-aged Adolescents:** Explaining aphasia in simple, relatable terms to foster understanding and reduce fear or confusion. Using storytelling, play therapy, or visual aids to help them express emotions.
- **Middle-aged Adolescents/Teens:** Encouraging open dialogue about their experiences and emotions. Offering strategies to help them support their parent, while addressing feelings of frustration or sadness.

Positive Parenting in the Context of Aphasia: Storybooks

- **The use of storybooks to discuss the challenging topic of aphasia has not been well researched, however:**
 - *found to be effective in allowing children who have a sibling with a disability to better identify, express, and cope with potentially challenging and confusing feelings (DeVries & Sudan, 2019).*
 - *effective method to aid children who have a parent with a mental illness, promoting resilience and serving as a “jumping off point” for “discussion of sensitive topics” with the child (Vetri et al., 2022).*

Positive Parenting in the Context of Aphasia: Storybooks

Rudine Sims Bishop a professor of education: For a child, every book serves one of three possible functions: as a mirror, window or a sliding door







"Let's go home, Daddy," said Sam.

"Okay, home, Sarah," said Daddy.

Sam looked at Daddy and giggled, "Daddy, I'm not Sarah, that's Mom's name." Sam thought Daddy was making a joke, but realized Daddy wasn't laughing.

Daddy had a new look on his face. He seemed... embarrassed.

Sam didn't know what to do. She didn't mean to make Daddy feel bad. She smiled and said, "Let's go."

Daddy nodded and they walked home.

Ask the child: Has ____ ever called you the wrong name? If so, how did it make you feel? Has ____ ever used a wrong word when talking to you (e.g. mixing up yes and no)? How did that feel?

Remember What Sam Learned

- The brain controls the body
- When the communication part of the brain gets hurt, that's called aphasia
- Communication is when we share our thoughts with each other
- Aphasia makes it hard to get thoughts in and out
- People with aphasia are still smart
- **You can find new ways to communicate!**



Some Final Questions to Discuss

What did you learn about stroke and aphasia?

Who should we share this new information with?

What questions do you still have?

Thank you!

- **McMaster S-LP students:** Elena Gamm & Daniela Pantusa
- **Dr. Brooke Ryan:** Some content and slides were adapted with permission from Dr. Ryan

Reflexive Question: Your Experience...

- What are you currently doing to serve this population?
- Is there anything you could do differently?
- What role could Stroke Networks play in filling knowledge gaps?
- What opportunities do you have to work collaboratively?
- Have you ever worked with kids re: parental stroke/ aphasia?
- If yes:
 - *What resources did you use?*
 - *What challenges did you encounter?*

If No:

- *What barriers do you anticipate?*
- *Do you feel equipped to provide support/ education?*
- How could you use ***Listen With Your Heart*** in your practice?

Question & Answer Period



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