2025 North Carolina Brain Injury Conference

Supporting the Supporters: Addressing the Needs of Brain Injury Caregivers

Dr. Kayli Reyna, EdD, Clinical Assistant Professor
Dr. Patricia Kay Reyna, EdD, Research Associate

Brain Injury Conference
April 14-15th, 2025
Lumina on
Wrightsville Beach

Brain Injury Association of North Carolina

Brain Injury Association of North Carolina

Foundational Knowledge

- In 2017, over 1.1 million U.S. emergency visits and hospitalizations involved traumatic brain injury (TBI) - not including other types of brain injury (e.g., stroke, hypoxia, disease process; exposure to toxins; Reid & Finger, 2017).
- The number of brain injury caregivers in the U.S. is unknown.
- Families of brain injury survivors are often overlooked victims of trauma, needing intensive support and intervention (Florian & Katz, 1991).

By the end of this session, attendees will better understand brain injury family caregivers (e.g., adult, children), the research on their challenges and needs, and potential support strategies.

Objectives

- **Objective 1:** Identify Caregiver Roles: Define the roles of caregivers for brain injury survivors, highlighting the challenges they face.
- **Objective 2:** Review and Discuss Research Findings: Review recent research data on the health and well-being of caregivers, emphasizing their unique struggles.
- **Objective 3:** Review Emotional Impact: Identify the emotional and psychological effects of caregiving, including stress, anxiety, and burnout.
- **Objective 4:** Identify Caregiver Needs: Highlight specific needs for support, including emotional resources, respite care, and community assistance.
- **Objective 5:** Discuss Support Strategies/Explore Community Engagement: Share potential strategies and resources, such as support groups and counseling, to empower caregivers in their roles. Discuss how public libraries serve as safe spaces for connection and support, fostering community engagement among survivors and their families.

Brain Injury Family Caregivers

Family Caregiver Defined:

Family caregivers may include spouses, parents, children, extended family members, partners, friends, and peers who provide any care including emotional and social supports.

(Reyna et al., in submission)

Overview of Potential Family Caregiver Roles

- Medical – Communicates with doctors, tracks medications, and manages medical appointments.
- Physical – Assists with mobility, personal hygiene, and daily activities.
- Cognitive – Helps with memory, organization, and problem-solving.
- Emotional – Provides reassurance, encouragement, and mental health support.
- Behavioral – Helps manage mood swings, impulsivity, and frustration.
- Rehabilitation – Supports physical, occupational, and speech therapy exercises.
- Financial – Oversees bills, insurance claims, and budgeting.
- Legal – Assists with disability claims, legal rights, and workplace accommodations.
- Social – Encourages social interactions and community engagement.
- Respite – Arranges self-care breaks for themselves and other family members.
- Mediator – Mediates relationship interactions within family/others

Research Insights

Research shows that caregivers are at risk of caregiver burden

Research also shows caregivers may lose hope over time

INCREASE KNOWLEDGE TO PROBLEM SOLVE!

INCREASE SELF-EFFICACY!

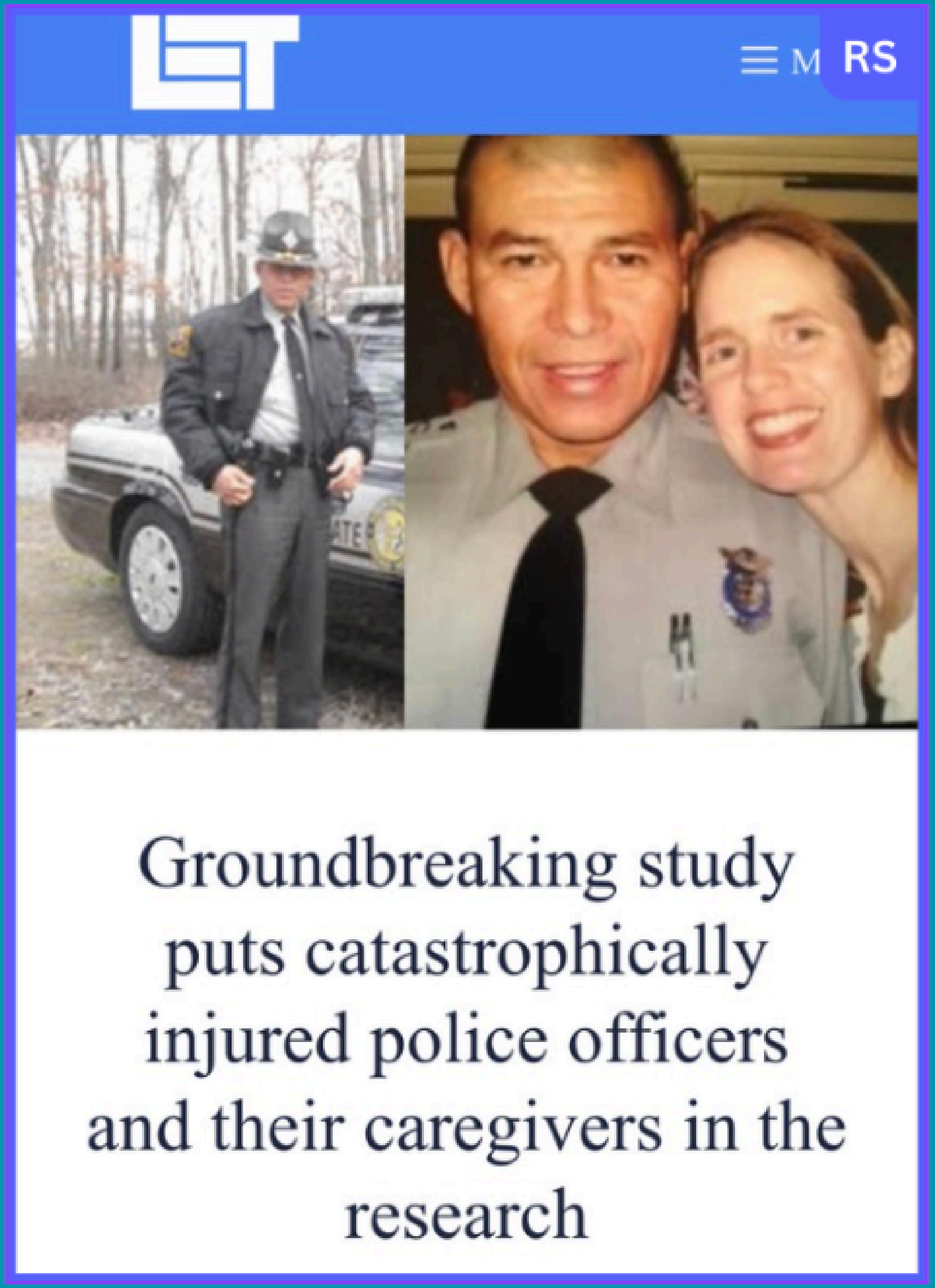
(Reyna, 2024)

INCREASE HOPE!

Why Hope is Important

- **Hope** increases capacity to thrive within stressful and difficult environments (Hellman et al., 2018; Moore et al., 2017).
- **Hope** mitigates caregiver burden (García-Castro et al., 2020).
- **Hope** thwarts suicidal ideation (Umphrey , et al. 2020)
- **Hope** enables persons to be more resilient (Hartmann et al., 2018).
- **Hope** correlates with a higher quality of life (Duggleby et al., 2014).
- **Hope** is an effective coping strategy (García-Castro et al., 2020).

Research on TBI Knowledge, Self-Efficacy, Hope



Groundbreaking study puts catastrophically injured police officers and their caregivers in the research

Research Article

Traumatic Brain Injury Training Program Value to Caregivers of Law Enforcement Officers, Fire Fighters and Veterans

Patricia Kay Reyna, Melissa McCart, Laurie Ehlhardt Powell, Kayli Sol Reyna, Rollen Fowler, Kaye Herth &

...show all

Received 22 Jun 2023, Accepted 22 Jan 2024, Published online: 09 Feb 2024

https://doi.org/10.1080/15325024.2024.2314299

Current Research/Participant Groups

- Investigating the lived experiences of first responders with traumatic brain injury (TBI) and/or catastrophic injury (CI) in the US, their caregivers, and children in the home *through the lens of family caregivers (n = 27;* Reyna et al., 2023-2024). Study Complete. Manuscript in submission.

- Investigating the lived experiences of law enforcement officers in the US, their caregivers, children in the home after TBI and/or invisible injury (II) *through the lens of law enforcement officers with lived TBI/II experience (n = 3) and their caregivers n = 3;* Reyna et al., 2024). Study complete. Data analysis phase.

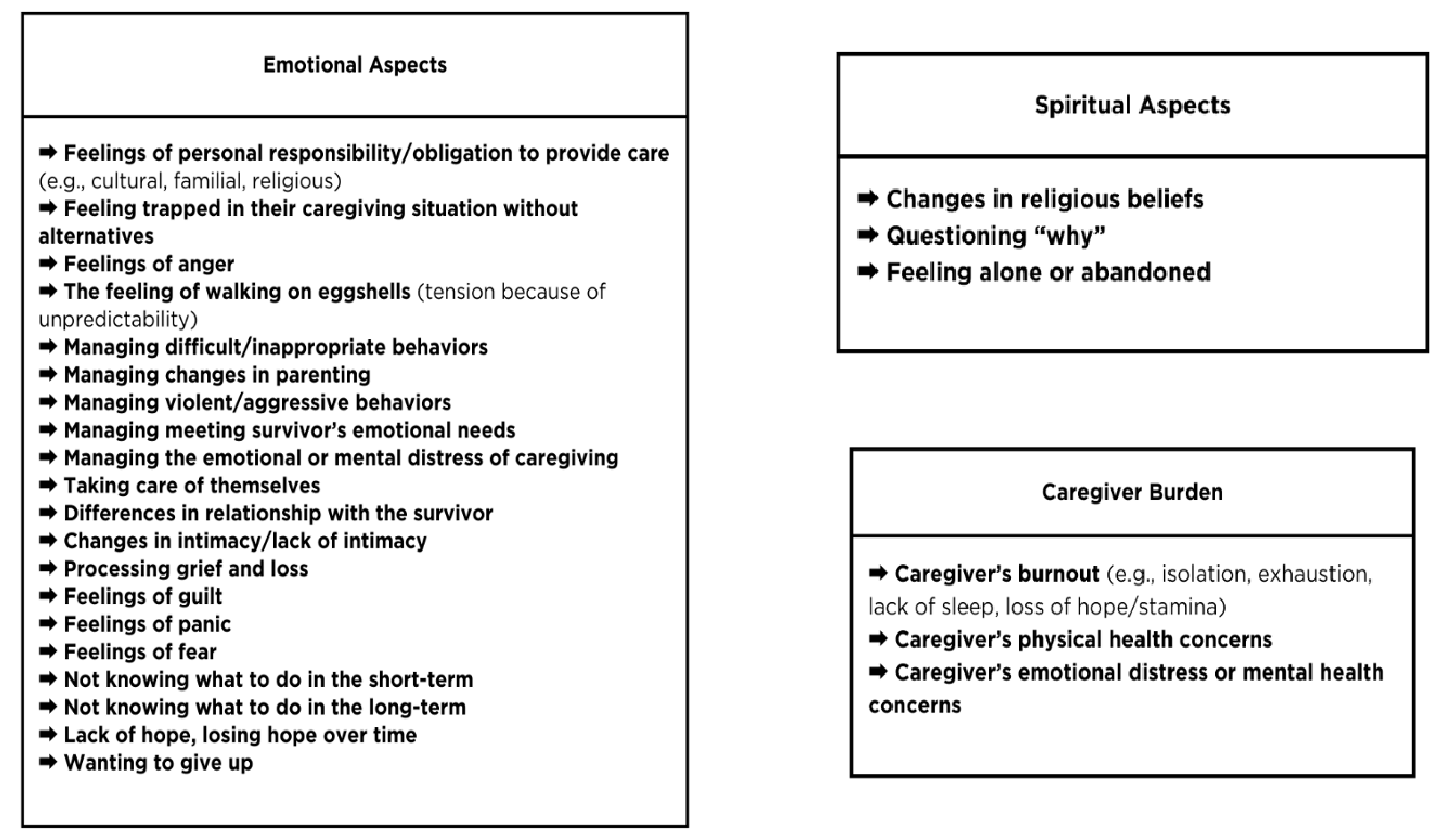
- Investigating the prevalance of brain injury among first responders who died by suicide *through the lens of family survivors* (Reyna et al., 2025). Study in progress.

- Investigating lived experiences of persons with brain injury in the US, their caregivers, and children in the home *through the lens of family caregivers* (Reyna et al., 2025). Study in progress.

cbirt The Center on Brain Injury Research and Training

Adult Family Caregivers

Understanding the Challenges/Impacts



Emotional Aspects

- **Feelings of personal responsibility/obligation to provide care** (e.g., cultural, familial, religious)
- **Feeling trapped in their caregiving situation without alternatives**
- **Feelings of anger**
- **The feeling of walking on eggshells** (tension because of unpredictability)
- **Managing difficult/inappropriate behaviors**
- **Managing changes in parenting**
- **Managing violent/aggressive behaviors**
- **Managing meeting survivor's emotional needs**
- **Managing the emotional or mental distress of caregiving**
- **Taking care of themselves**
- **Differences in relationship with the survivor**
- **Changes in intimacy/lack of intimacy**
- **Processing grief and loss**
- **Feelings of guilt**
- **Feelings of panic**
- **Feelings of fear**
- **Not knowing what to do in the short-term**
- **Not knowing what to do in the long-term**
- **Lack of hope, losing hope over time**
- **Wanting to give up**

Spiritual Aspects

- **Changes in religious beliefs**
- **Questioning "why"**
- **Feeling alone or abandoned**

Caregiver Burden

- **Caregiver's burnout** (e.g., isolation, exhaustion, lack of sleep, loss of hope/stamina)
- **Caregiver's physical health concerns**
- **Caregiver's emotional distress or mental health concerns**

Daily Living Aspects

- ➡ Assisting with personal care such as eating, bathing, toileting, and dressing
- ➡ Providing physical assistance, including lifting and carrying
- ➡ Finding activities that the survivor can participate in and are eligible to receive
- ➡ Providing daily emotional support/encouragement

Respite Care

- ➡ Getting a short break from caregiving
- ➡ Finding paid help such as personal care attendants or respite workers
- ➡ Finding temporary substitute to provide occasional care

Medical/Rehabilitation Aspects

- ➡ Coordinating or providing transportation
- ➡ Meeting the financial burden of caregiving
- ➡ Coordinating and managing medications, medical equipment, and other medical care, including care coordination
- ➡ Understanding and managing legal, financial, and/or other insurance issues or benefits
- ➡ Feeling the need to “fight” for care
- ➡ Discrimination/fear of discrimination by service providers

Social Aspects

- ➡ Helping the survivor to communicate with others
- ➡ Educating others, including health care personnel, about the injury
- ➡ Managing and meeting social needs
- ➡ Getting time with other family members, or meeting other family members’ needs
- ➡ Loss of community

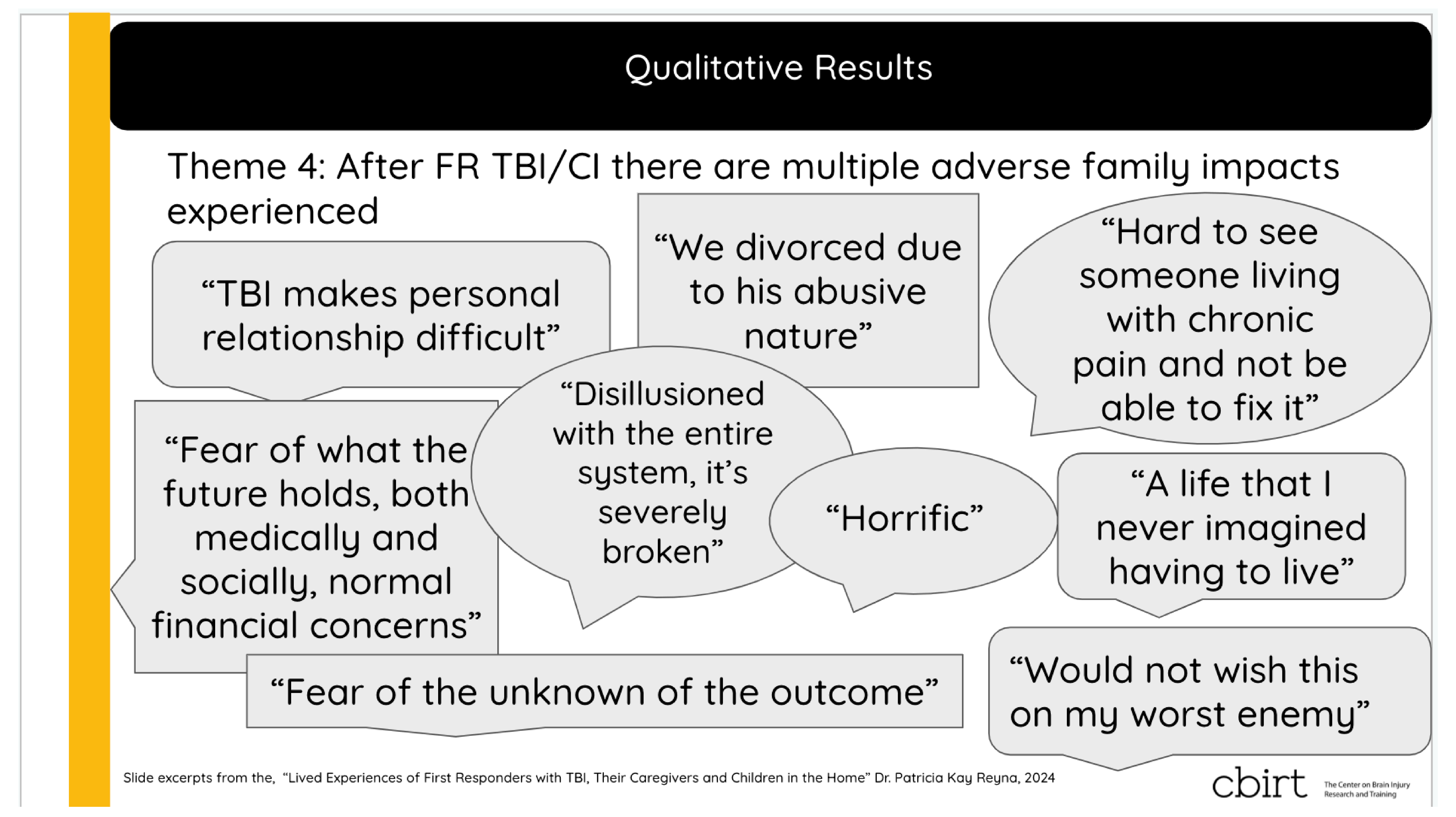
What aspects of caregiving have been challenging to you personally?

Aspects of Caregiving Personally Challenging to the Caregiver

Slide excerpts from the, "Lived Experiences of First Responders with TBI, Their Caregivers and Children in the Home" Dr. Patricia Kay Reyna, 2024

cbirt The Center on Brain Injury Research and Training

- Top 4 challenging aspects of caregiving:
  - Providing daily emotional support and encouragement
  - Changes in relationships with family and friends
  - The feeling of walking on eggshells (tension because of unpredictability)
  - Changes in intimacy/lack of intimacy with first responder



Qualitative Results

Theme 4: After FR TBI/CI there are multiple adverse family impacts experienced

"TBI makes personal relationship difficult"

"We divorced due to his abusive nature"

"Hard to see someone living with chronic pain and not be able to fix it"

"Fear of what the future holds, both medically and socially, normal financial concerns"

"Disillusioned with the entire system, it's severely broken"

"Horrific"

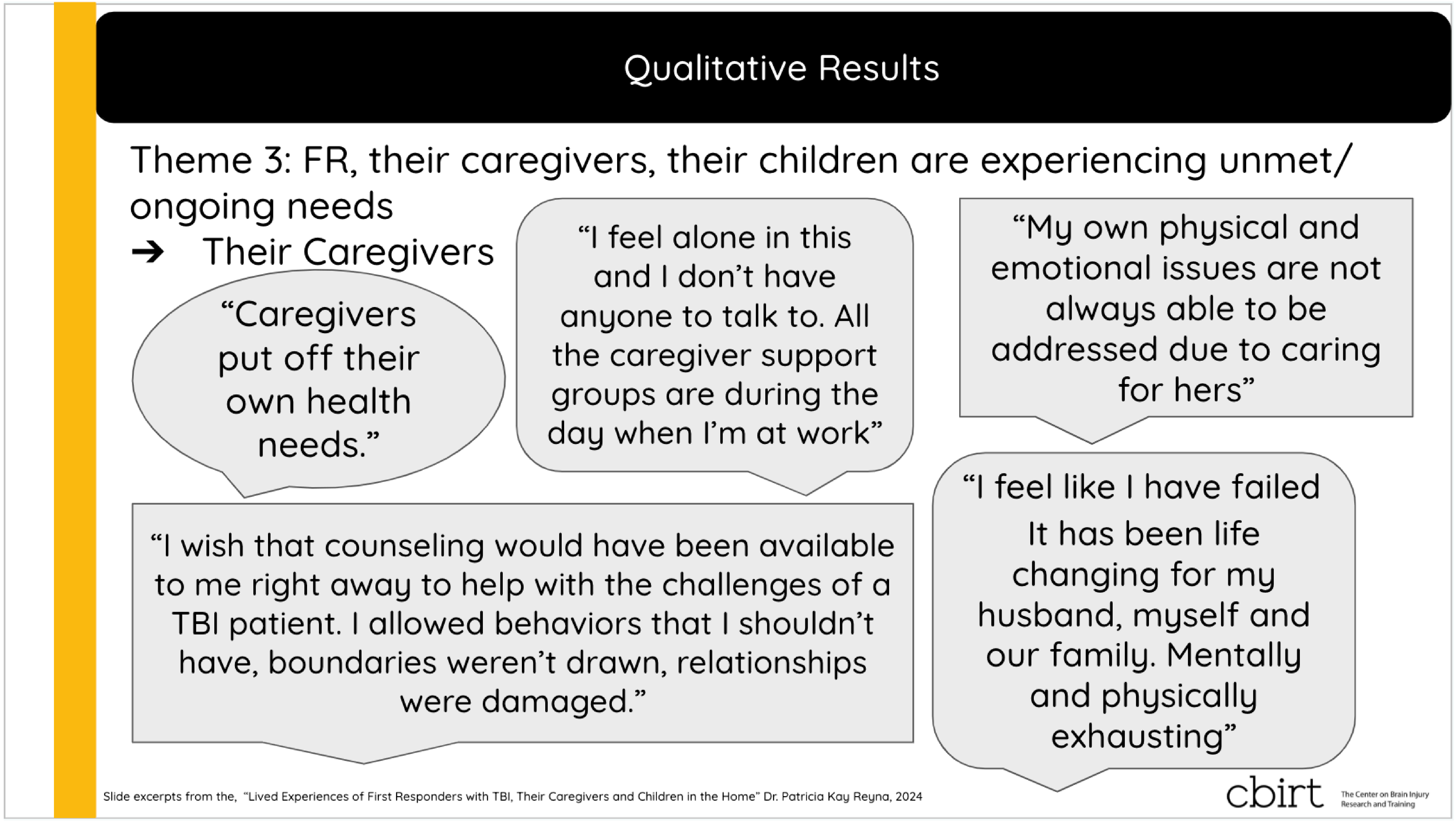
"A life that I never imagined having to live"

"Fear of the unknown of the outcome"

"Would not wish this on my worst enemy"

Slide excerpts from the, "Lived Experiences of First Responders with TBI, Their Caregivers and Children in the Home" Dr. Patricia Kay Reyna, 2024

cbirt The Center on Brain Injury Research and Training



Qualitative Results

Theme 3: FR, their caregivers, their children are experiencing unmet/ ongoing needs

➔ Their Caregivers

“Caregivers put off their own health needs.”

“I feel alone in this and I don’t have anyone to talk to. All the caregiver support groups are during the day when I’m at work”

“My own physical and emotional issues are not always able to be addressed due to caring for hers”

“I wish that counseling would have been available to me right away to help with the challenges of a TBI patient. I allowed behaviors that I shouldn’t have, boundaries weren’t drawn, relationships were damaged.”

“I feel like I have failed

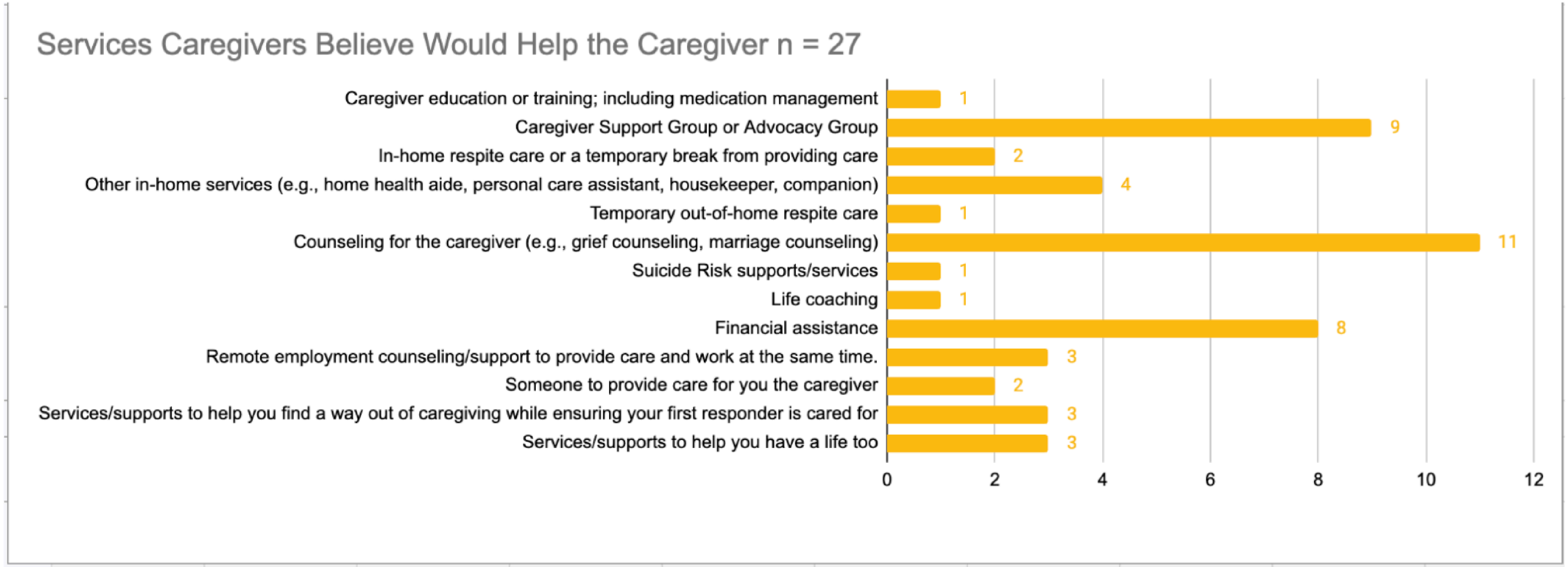
It has been life changing for my husband, myself and our family. Mentally and physically exhausting”

Slide excerpts from the, “Lived Experiences of First Responders with TBI, Their Caregivers and Children in the Home” Dr. Patricia Kay Reyna, 2024

cbirt The Center on Brain Injury Research and Training

Supports
Needed

What caregiving-related services would help you as a caregiver?



Slide excerpts from the, "Lived Experiences of First Responders with TBI, Their Caregivers and Children in the Home" Dr. Patricia Kay Reyna, 2024

cbirt The Center on Brain Injury Research and Training

- Top 4 caregiver service needs:
    - Counseling for the caregiver (e.g., grief counseling, marriage counseling)
    - Caregiver support group of advocacy group
    - Financial assistance
    - In-home health services (e.g., home health aide, personal care assistant, housekeeper, companion)

Children as Caregivers

Who Are These Children?

- Any child living in a home with a brain injury survivor. Children can become caregivers.
- Limited current research.
- Often excluded from recovery processes (Dawes et al., 2022).
- Limited supports/interventions (Dawes et al., 2022).

Children as Caregivers-From Lived Experience

Emotional and Psychological Impact

- Increased anxiety and stress due to family instability.
- Feelings of isolation and difficulty expressing emotions.
- Fear and uncertainty about the injured parent’s condition.
- Role confusion and emotional burden from added responsibilities.
- Difficulty forming and maintaining social relationships.
- Behavioral changes, including withdrawal or aggression.
- Impact on self-esteem and overall emotional well-being.

Educational Challenges

- Difficulty concentrating and processing information.
- Emotional stress affecting academic performance.
- Lack of awareness among educators about their unique needs.
- Struggles with completing homework and maintaining routines.

Family and Social Dynamics

- Shifts in parent-child roles due to caregiving responsibilities.
- Strained relationships with the brain-injured parent.
- Increased tension or conflict among family members.
- Feelings of neglect or resentment from siblings.
- Difficulty maintaining friendships and social connections.
- Lack of understanding from extended family and community.

Impacts on
Daily Life of
Children in the Home

Disruptions to Routine

- Unpredictable daily schedules due to medical needs.
- Financial instability affecting basic needs and lifestyle.
- Reduced participation in social and recreational activities.
- Lack of stability leading to increased stress and anxiety.

Role Reversals and Responsibilities

- Children taking on caregiving duties for the injured parent.
- Increased household responsibilities for children.
- Acting as an emotional support system for family members.
- Feeling pressure to mature faster than peers.
- Struggling with personal identity and independence.

Access to Support Networks

- Limited awareness of available community resources.
- Lack of peer groups for children in similar situations.
- Geographic or financial barriers to accessing programs.
- Emotional hesitation in sharing struggles with others.

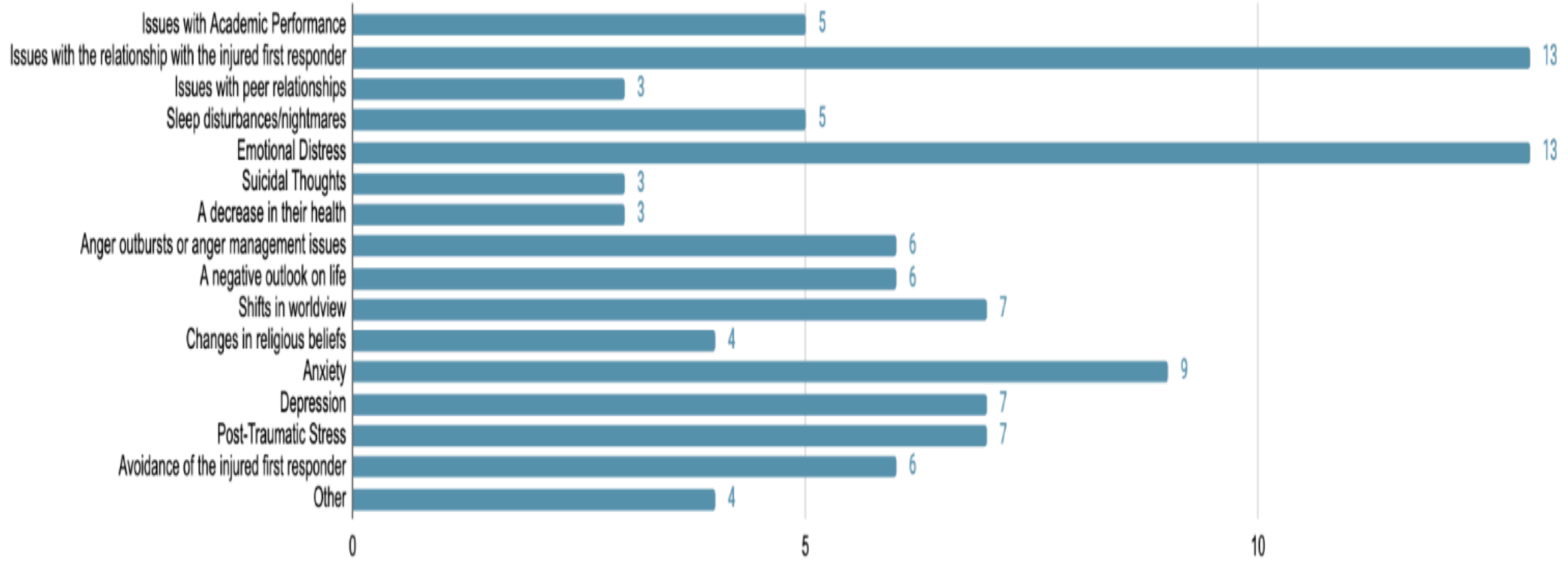
Research Insights Children in the Home

Challenges Children in the Home: One Study

Caregiver Reported Challenges: Children in the Home

- Issues with academic performance
- Issues with the relationship with the survivor
- Issues with peer relationships
- Sleep disturbances/nightmares
- Emotional distress
- Suicidal thoughts
- A decrease in their health
- Anger outbursts or anger management issues
- A negative outlook on life
- Shifts in worldview
- Changes in religious beliefs
- Anxiety
- Depression
- Post-traumatic stress
- Avoidance of the survivor

If there are/were children in the home affected by the first responder's injury, have you noticed if the children have/had any of the following challenges after the first responder's injury? (*n* = 19)



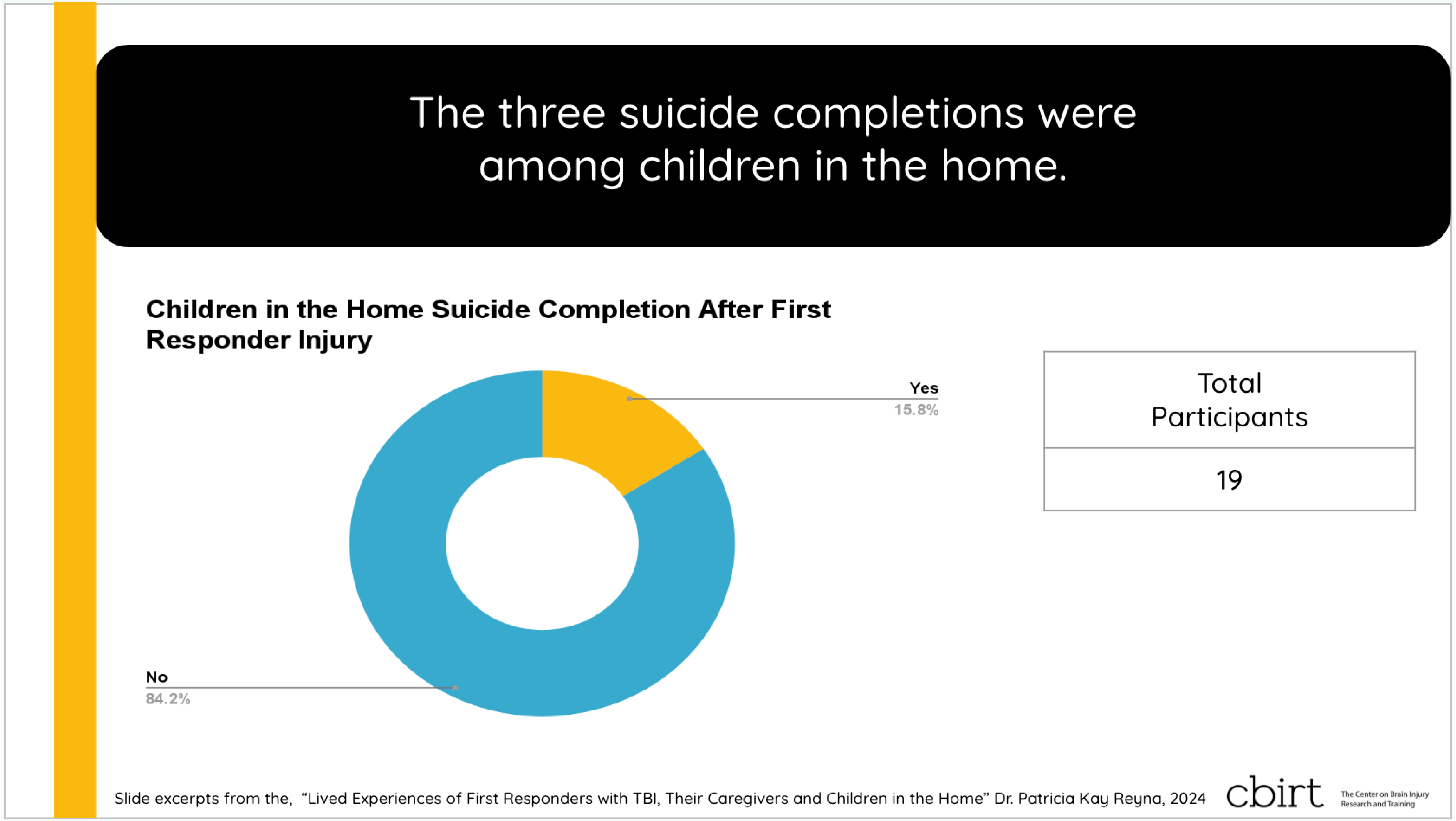
Slide excerpts from the, "Lived Experiences of First Responders with TBI, Their Caregivers and Children in the Home" Dr. Patricia Kay Reyna, 2024

cbirt The Center on Brain Injury Research and Training

[redacted]

- Top 4 ways children were affected:
  - Issues with the relationship with the injured first responder
  - Emotional distress
  - Anxiety
  - Shifts in worldview, depression, post-traumatic stress

Slide excerpts from the, “Lived Experiences of First Responders with TBI, Their Caregivers and Children in the Home” Dr. Patricia Kay Reyna, 2024



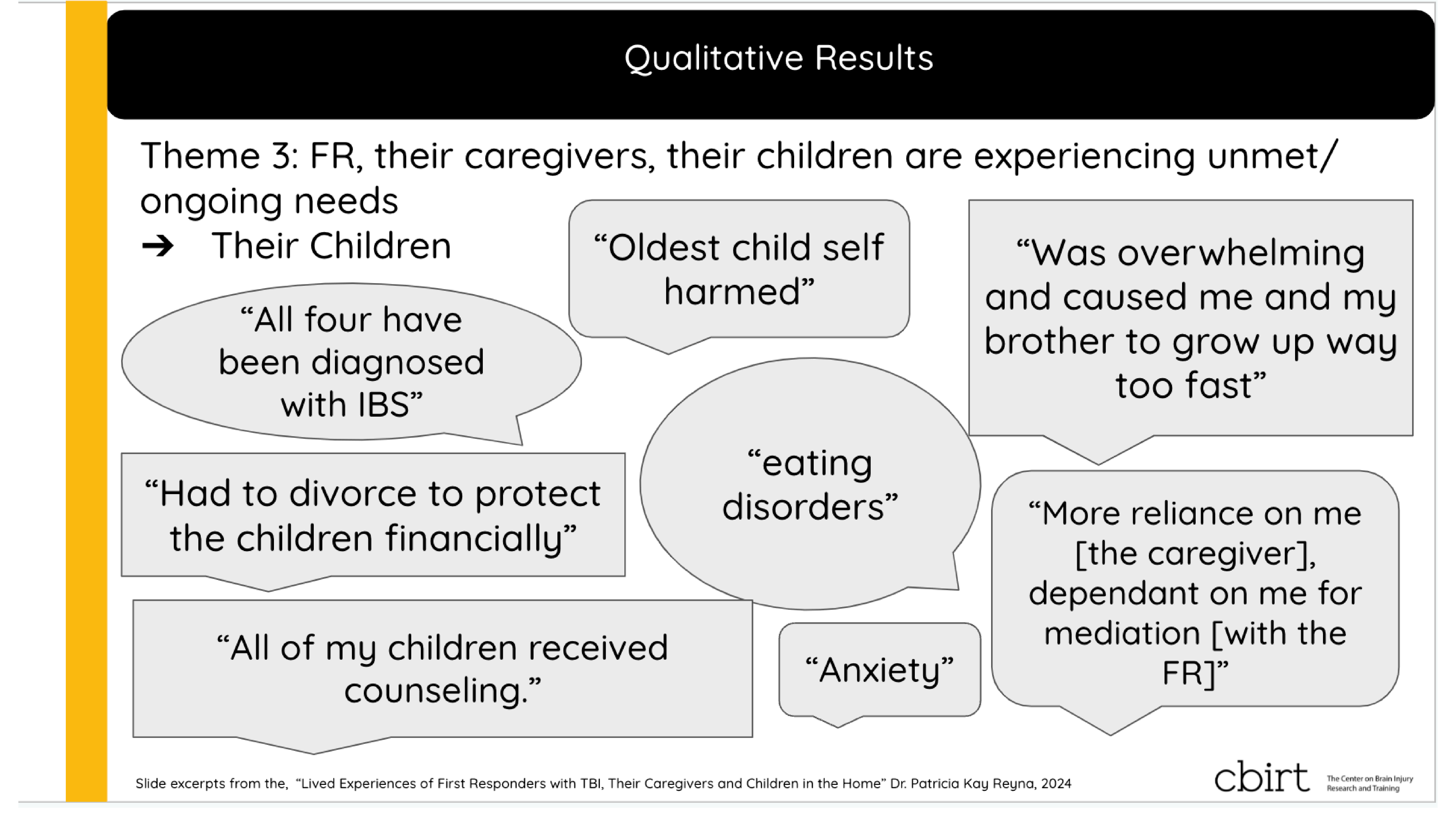
The three suicide completions were among children in the home.

Children in the Home Suicide Completion After First Responder Injury

Total Participants
19

Slide excerpts from the, "Lived Experiences of First Responders with TBI, Their Caregivers and Children in the Home" Dr. Patricia Kay Reyna, 2024

cbirt The Center on Brain Injury Research and Training



Qualitative Results

Theme 3: FR, their caregivers, their children are experiencing unmet/ ongoing needs

➔ Their Children

“Oldest child self harmed”

“Was overwhelming and caused me and my brother to grow up way too fast”

“All four have been diagnosed with IBS”

“eating disorders”

“Had to divorce to protect the children financially”

“More reliance on me [the caregiver], dependant on me for mediation [with the FR]”

“All of my children received counseling.”

“Anxiety”

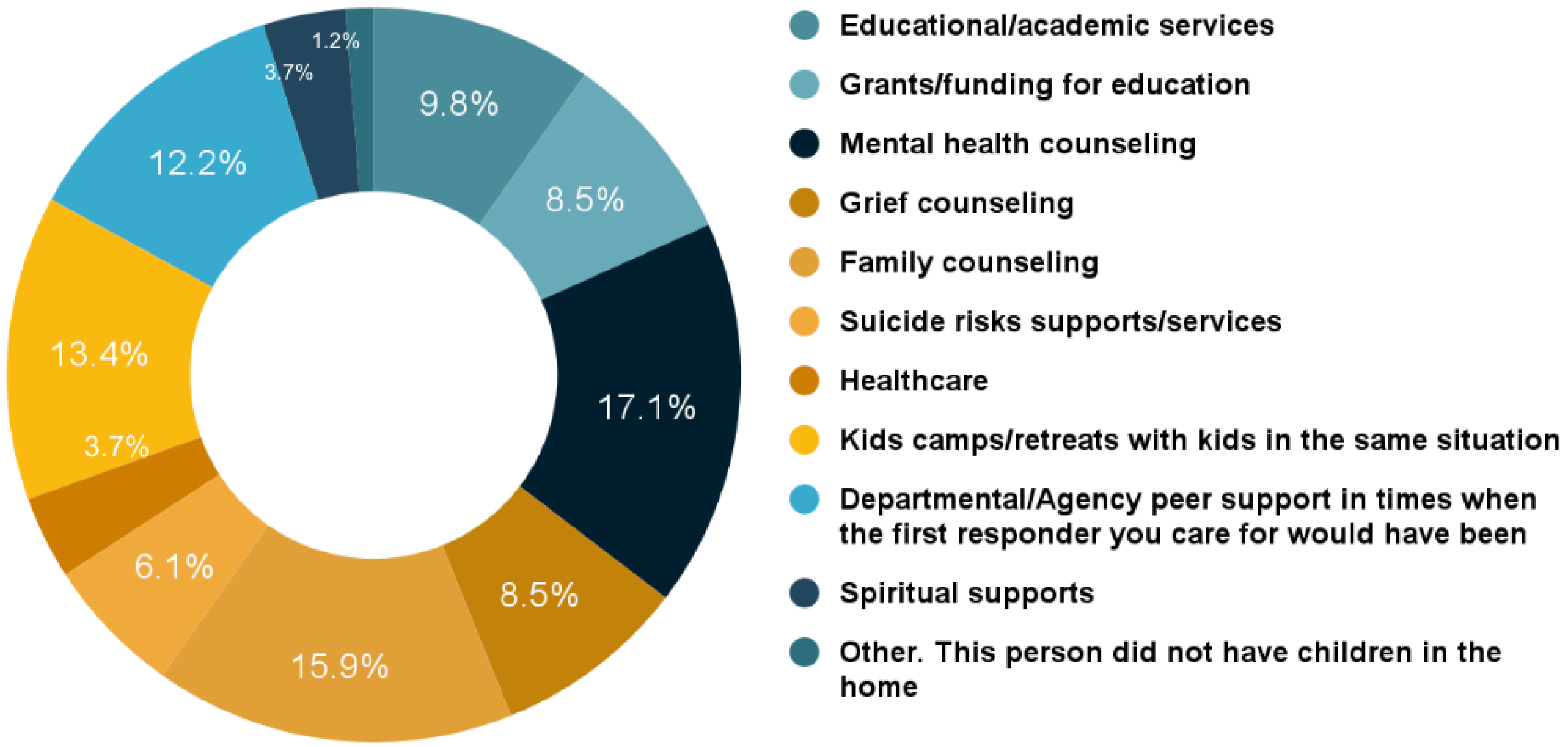
Slide excerpts from the, “Lived Experiences of First Responders with TBI, Their Caregivers and Children in the Home” Dr. Patricia Kay Reyna, 2024

cbirt The Center on Brain Injury Research and Training

Supports Needed Children in the Home

Quantitative Results:

If there are/were children in the home affected by the first responder’s injury, what services do you think would be helpful/would have been helpful to the children?



Services that would have been helpful to children in the home

Total Participants
20

Slide excerpts from the, “Lived Experiences of First Responders with TBI, Their Caregivers and Children in the Home” Dr. Patricia Kay Reyna, 2024

cbirt The Center on Brain Injury Research and Training

Family Caregiver Support Strategies

Suggested Strategies

- Provide appropriate medical care and support to the person who is injured throughout their lifetime.
- Create/provide interventions/supports to increase knowledge, self-efficacy, hope.
- Provide supports to the family.
- Provide supports to children in the home.

Potential Community Resources

- **Public Libraries**
- **Community centers offering family assistance programs**
- **Faith-based groups providing emotional and spiritual guidance**
- **Youth mentoring and peer support programs**
- **Healthcare providers specializing in rehabilitation and family care**
- **Online forums and virtual support networks for caregivers and children**

Final Thoughts

- **More than 30 years ago**, Florian and Katz (1991) reported that “families of persons with TBI can be viewed as the other and often neglected victims of trauma and as a potentially high-risk group that requires intensive intervention services and support” (Florian & Katz, 1991, p. 268).
- **We must do more to support these families.**

References

Dawes, K., Carlino, A., van den berg, M. & Killington, M. (2022). Life altering effects on children when a family member has an acquired brain injury; a qualitative exploration of child and family perceptions. Disability and Rehabilitation, 44(2), 282-290. https://doi.org/10.1080/09638288.2020.1766582

Duggleby W, Doell H, Cooper D, Thomas R, Ghosh S. The quality of life of male spouses of women with breast cancer: Hope, self-efficacy, and perceptions of guilt. Cancer Nursing. 2014;37(1). doi: 10.1097/NCC.0b013e31827ca807.

Florian, V., & Katz, S. (1991). The other victims of traumatic brain injury: Consequences for family members. Neuropsychology, 5(4), 267-279.

García-Castro FJ, Alba A, Blanca MJ. Association between character strengths and caregiver burden: Hope as a mediator. Journal of Happiness Studies. 2020;21(4):1445-62. doi: 10.1007/s10902-019-00138-2.

Hartmann JASJ, Fernandes A, Medeiros A, Vasconcelos CAC, Pinheiro K, Amorim LLL, et al. Hope as a behavior and cognitive process: A new clinical strategy about mental health's prevention. Medicine (Baltimore). 2018;97(36):e12130. doi: 10.1097/md.0000000000012130. PubMed PMID: 30200101; PubMed Central PMCID: PMC6133436.

Hellman CM, Worley JA, Munoz RT. Hope as a coping resource for caregiver resilience and well-being. In: W. Bailey, Harrist A, editors. Family caregiving: Fostering resilience across the life course: Springer; 2018. p. 81-98.

Moore M, Kiatchai T, Ayyagari RC, Vavilala MS. Targeted areas for improving health literacy after traumatic brain injury. Brain Inj. 2017;31(13-14):1876-81. doi: https://doi.org/10.1080/02699052.2017.1346291.

Reid L. D., Finger, K.R. (2017). Inpatient stays and emergency department visits involving traumatic brain injury, 2017: Statistical Brief #255. https://hcup-us.ahrq.gov/reports/statbriefs/sb255-Traumatic-Brain-Injury-Hospitalizations-ED-Visits-2017.jsp

References Continued

Reyna, P. K., McCart, M., Ehlhart Powell, L., Reyna, K. S., Fowler, R., Herth, K. & Glang, A. (2024). Traumatic brain injury training program value to caregivers of law enforcement officers, fire fighters and veterans. Journal of Loss and Trauma, 1-23. https://doi.org/10.1080/15325024.2024.2314299

Reyna, P. K., Powell, L., Reyna, S., Gomez, D., McCart, M., Glang, A. (2025). Experiences/needs of US first responders, family caregivers, and children after TBI/catastrophic injury. [In Submission]. University of Oregon.

Umphrey, L. R., Sherblom, J. C., & Swaitkowski, P. (2020). Relationship of self-compassion, hope, and emotional control to perceived burdensomeness, thwarted belonginess, and suicidal ideation. The Journal of Crisis Intervention and Suicide Prevention. Advance online publication. https://doi.org/10.1027/0227-5910/a00097

Thank you

Dr. Patricia K. Reyna

- kayreyna@cbirt.org

Dr. Kayli Reyna

- ksreyna@uncg.edu