

Respite for All Faith-Based Model Decreases Stigma and Improves Care Partners' Relationships with Loved Ones Living with Dementia

Steven R. Sabat

Professor Emeritus of Psychology
Georgetown University

Abigail C. Howell

Department of Psychology
Georgetown University

Daphne M. Johnston

First United Methodist Church
Montgomery, Alabama

Stigma Surrounding Dementia is Associated with

Feelings of Burden

Social Isolation

Fear of being judged by public due to behavioral manifestations of dementia,

All of which are considered a public health concern

And affect negatively the lives of care partners and people living with dementia.

RFA Ministry

- Emphasizes friendships and relationships with spiritual foundations. “We work to mirror the relationship we as Christians are called to enter into and see Christ’s example of friendship as the ultimate goal” (Johnston,2020 p. 72) .
- God’s presence can be known in those living with dementia. Bishop Lawson Bryan of the Methodist Church notes that “Respite is redemptive in that it brings together people of differing faith traditions. Those with dementia are Christian, Jewish, Buddhist and of other faith groups or belong to no particular faith background at all...Through Respite, those with dementia become our teachers and they help us to learn that our worth is not limited to our cognitive abilities”

Respite for All Model (RFA)

- Integrated, volunteer driven, faith-based program for people living with dementia and care partners concurrently
- Volunteers (retired adults) are trained re cognitive and social strengths of people living with dementia
- Ratio of 25 participants and 20 volunteers plus one paid Director and P/T Co-Director; Meets in space donated by house of worship. Present study was of RFA at First United Methodist Church, Montgomery, Alabama
- Meets for 4 hours/day, 4 days/week emphasis placed on creating warm, social relationships; lines between volunteers and participants are often blurred while working side by side to achieve common goals
- No identification re diagnosis; only first names on badges
- Volunteers not paired with particular participants
- Activities: OMA arts projects, story-telling (TimeSlips based), lunch, physical fitness, music, community service projects
- Participants can opt out of activities if they wish
- Support groups and educational workshops for care partners

Training of Volunteers

- Strength-based, person-centered approach
- Elements of Kitwood's Positive Person Work
- Using Indirect Repair to facilitate conversation
- Validation of speaker's perspective/feelings
- Attending to participants' nonverbal communication: what people say and do are attempts to communicate
- Allowing for extended periods of silence if word-finding problems arise
- Use of gestures to accompany spoken words
- Engage participants to help with setting up activities, serving food, welcoming new people, etc.
- Learn about possible variability in performance and mood

Study of Care Partners' Experience as a Result of RFA

24 Care Partners (12 Men, 12 Women)

Attended at least 2-4 years of monthly support/educational groups of RFA before pandemic began

Their loved ones attended RFA multiple times per week and had been diagnosed with dementia as many as 11 years earlier and as few as 2 years earlier.

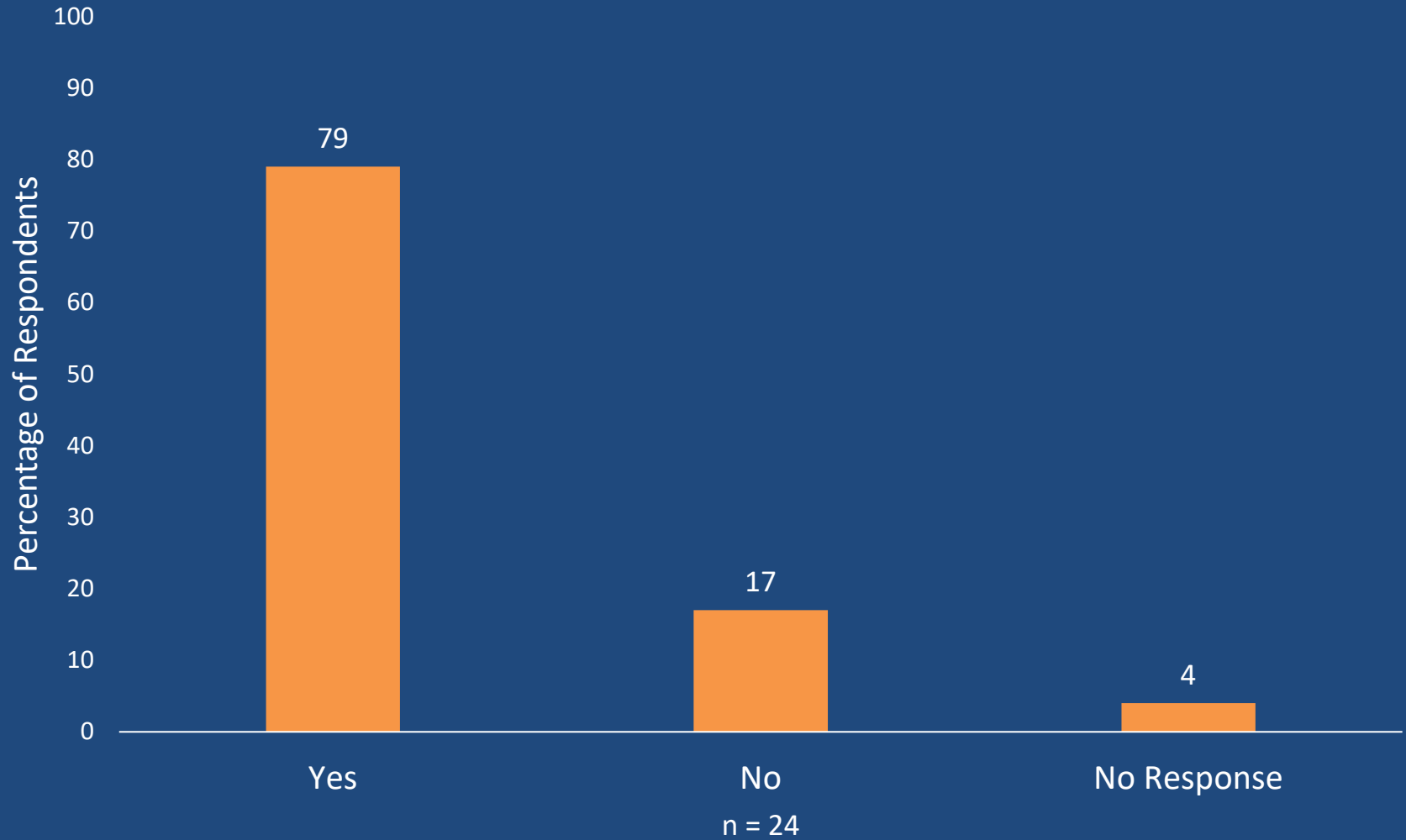
Mean years since diagnosis = 5.57 Median = 5 Mode = 6

Distributed survey by mail during 2021 pandemic

Mixed methods: “Yes-No”; “Never-Sometimes-Always”; “Very-Somewhat-Not At All” questions

Open-ended questions provided qualitative aspects of CPs' subjective experience.

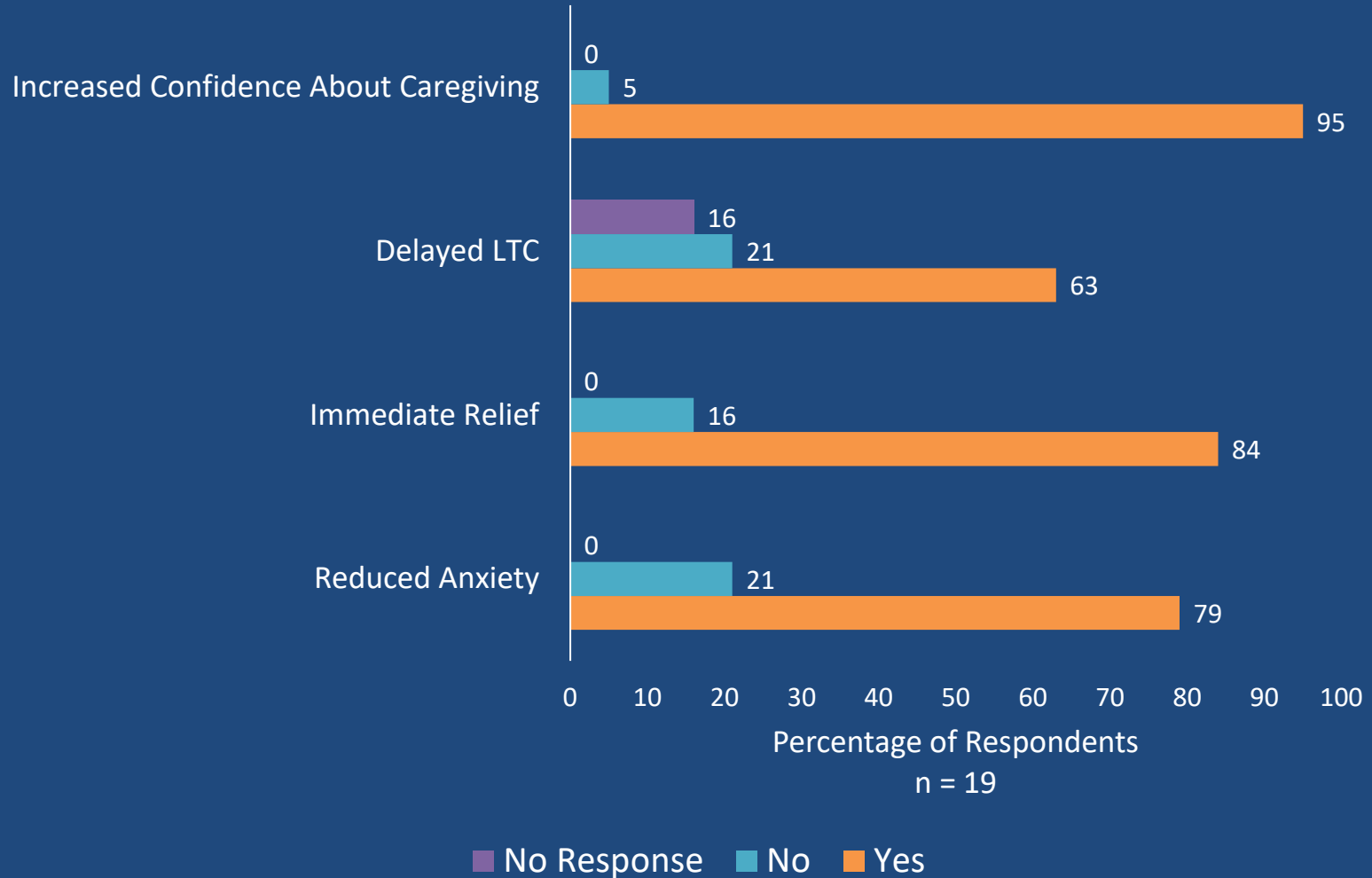
CPs' Stigma Reduction Post-RFA



Care Partners' Reflections

- CP 3: “No one in the Respite program backed away. Rather, they embraced us with the dementia diagnosis. We were all people enjoying the togetherness.”
- CP 17: “The support group showed me that so many other caregivers were suffering the same issues I had. Example: out in public when mother would act ‘inappropriately’, usually hugging strangers too much, etc., I learned to relax and help mother. It was OK.”
- CP 19: “I realized my husband was one of many, and people who have no clue about the disease can just get over themselves if they have a problem with his lack of ‘normalcy’.”

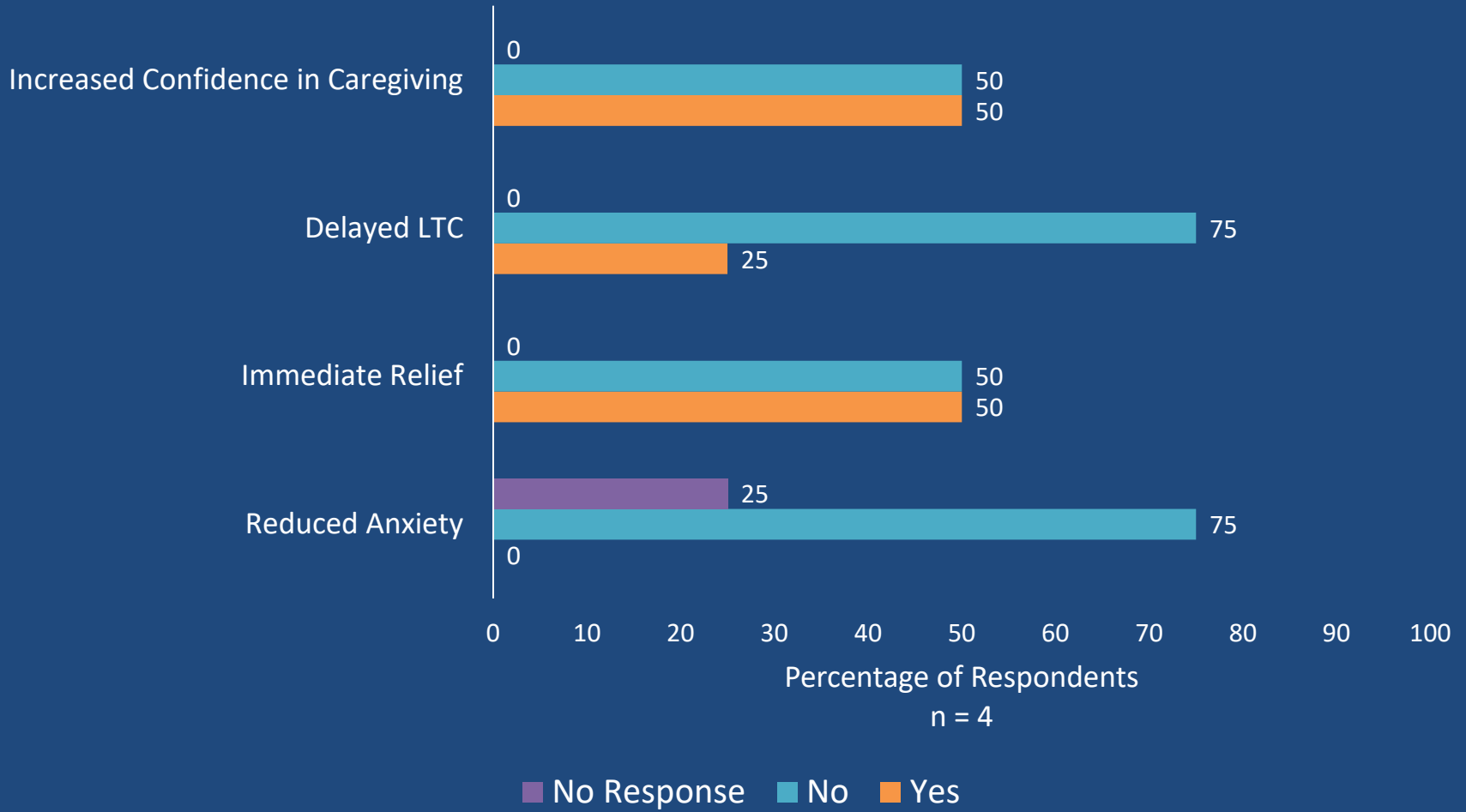
Care Partner Outcomes Of Those Who Noted Decreased Stigma About Dementia Following Respite



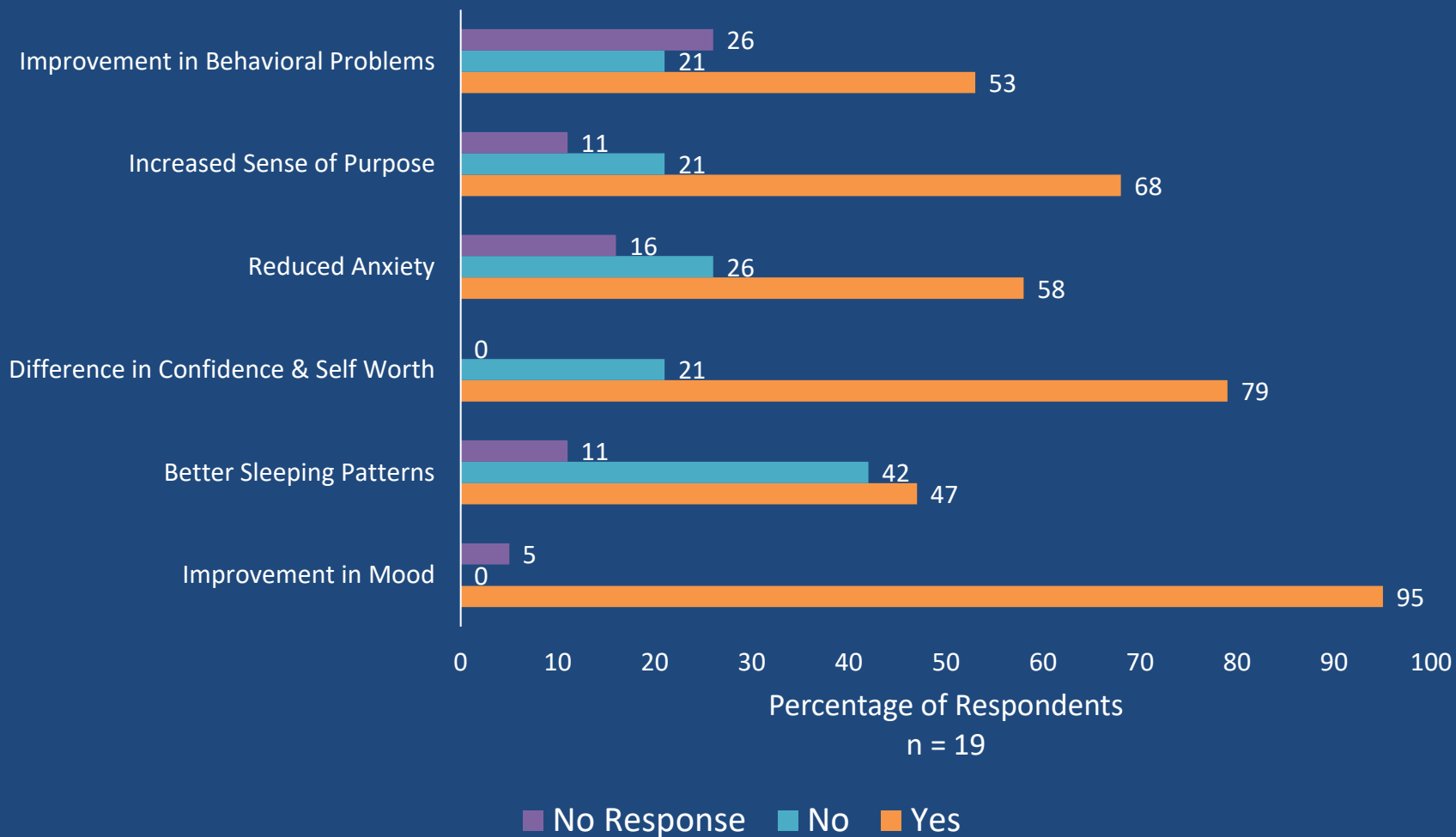
Care Partners' Reflections

- CP 18: “Respite has encouraged me to learn more and be more sensitive and patient.”
- CP 19: “Understanding certain behaviors and how to handle them—or not to be perplexed by them. Because I changed. Also, when he was happy, I was happy...”
- CP 13: “Support for caregivers has helped me acknowledge and deal with my emotions and be more constructive.”
- CP 17: “Being amongst others, others who were also like my mother, I knew she was loved and understood in the best environment possible. This made me much less anxious about our journey with dementia.

Care Partner Outcomes of Those Who Did Not Note Decreased Stigma About Dementia Following Respite



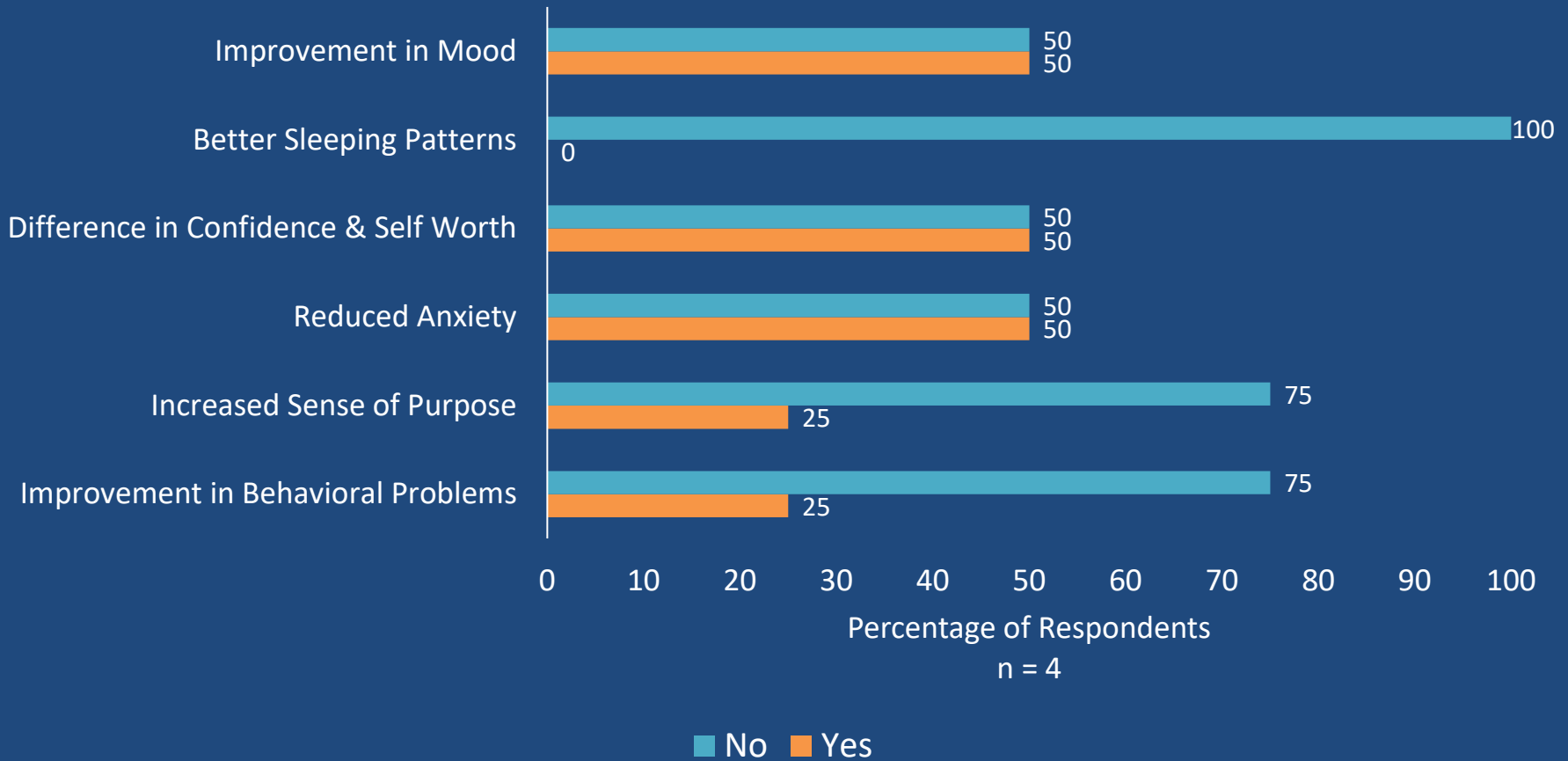
Care Partner Assessments of Changes In Loved One With Dementia Post-Respite: CPs Who Experienced a Decrease in Stigma



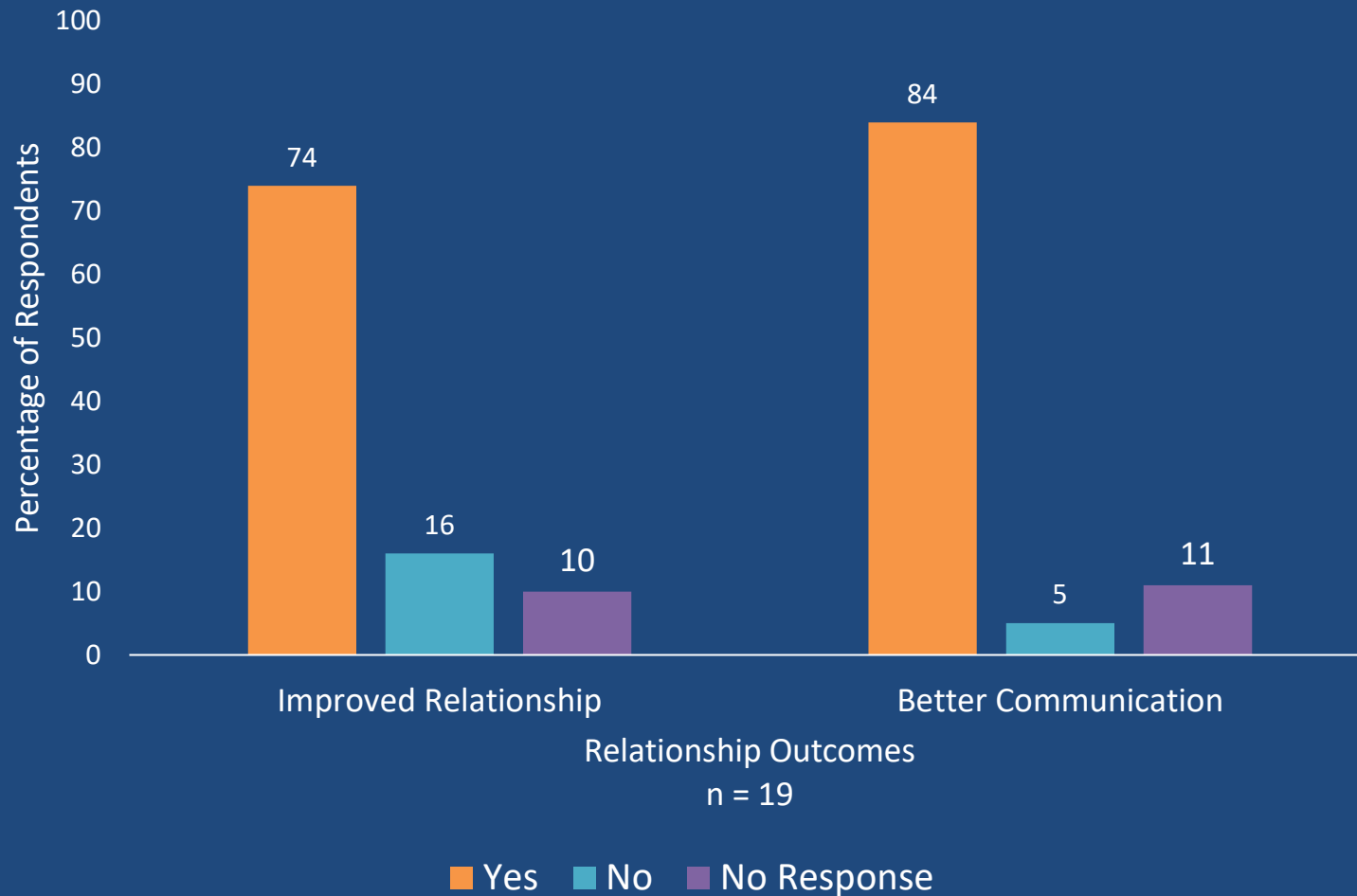
Care Partners' Reflections

- CP 21: “Many more smiles and actions indicating she is not as agitated. The happiness she experiences at Respite is brought home to make her act better and respond to us more positively. She is less combative.”
- CP 1: “Offered to help more when I’m cleaning the house or carrying groceries. That was something she stopped before—seemed more ready to get involved.”
- CP 24: “He would always be relaxed, ready for a nap, and awaken rejuvenated to go work outside. There was nothing in the respite world to create anxiety, only anticipation for what was next.”
- CP 16: “She had avoided social situations and she willingly went into Respite without me”
- CP 3: “He was happy again. He loved the new friends he had made and was excited to go to Respite and live again!”

Care Partner Assessments of Changes in Loved One Post-Respite Of Those Who Did Not Note Decreased Stigma



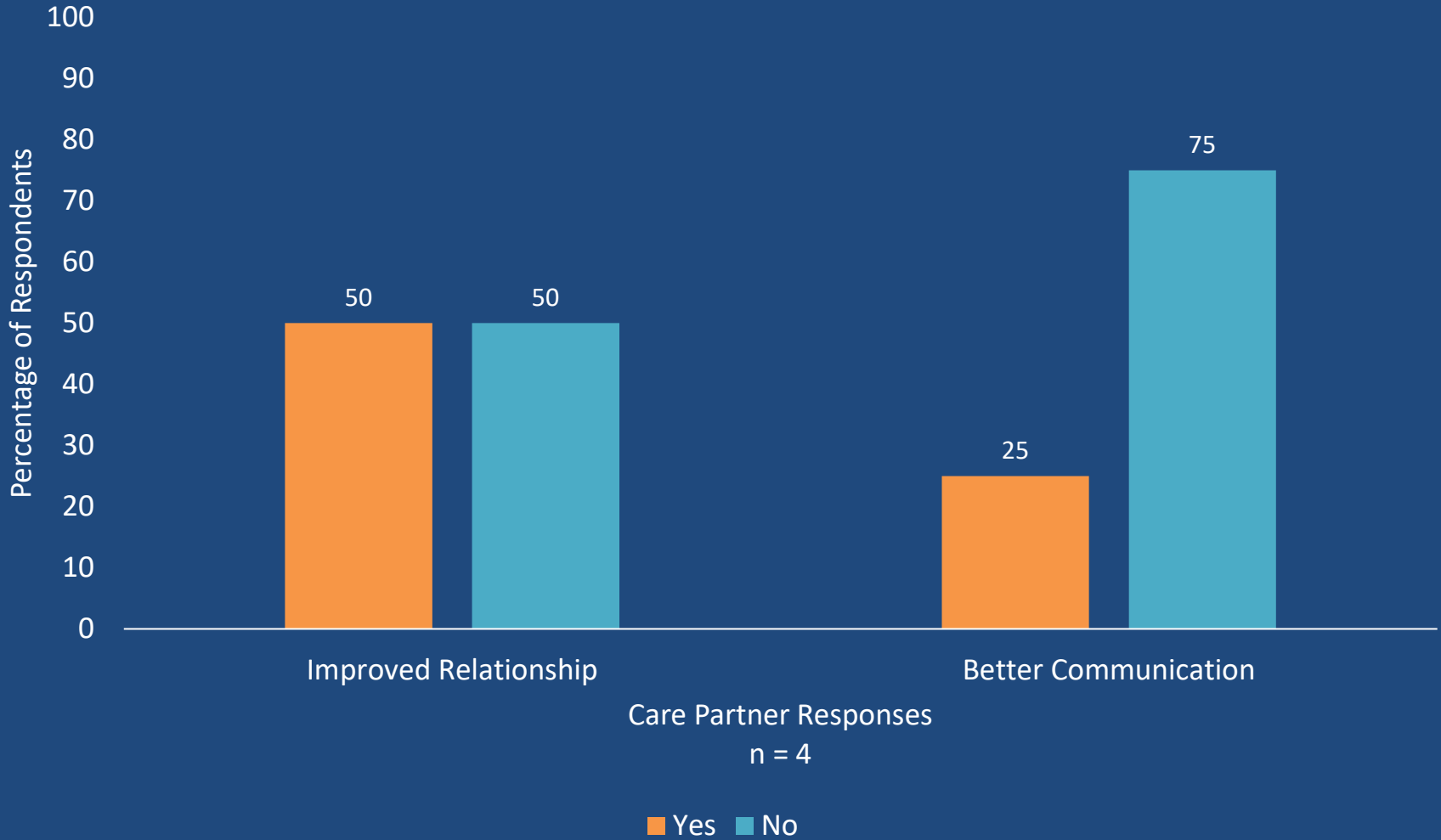
Relationship Outcomes Of Care Partners Who Noted a Decreased Sense of Stigma About Dementia



Care Partners' Reflections

- CP 17: “I learned so much! I learned better ways to communicate. I learned that I could say nothing and it might be the best thing! I was able to understand WHY she was doing and acting differently and how much she was experiencing that was so, so, tough. It helped me see things from her perspective.”
- CP 19: “I used shorter, more specific words, breaking down a ‘task’ into (smaller individual) steps.”
- CP 24: “We did Respite mostly together as a couple. His favorite days were when I went with him. He loved seeing me laugh and mix. We were always proud of each other. Respite was our date day.”

Relationship Outcomes of Those Who Did Not Note Decreased Stigma



Summary: Respite for All Model

- Provides enlivening, relationship encouraging, person-centered experiences for people living with dementia and concurrent educational workshops and support groups for care partners
- Reduces stigma around dementia in large majority of care partners while improving communication and relationships in dyads
- *Reductions in stigma are connected with and/or affected by:*
- Reported improvements in care partners' confidence re caregiving, reductions in their reported anxiety, able to delay long-term care for loved one
- Improved mood, sense of purpose, and self-confidence in people living with dementia, and decreases in their anxiety

Thank You

- First United Methodist Church, Montgomery, Alabama
- Respite for All Foundation
- Participating care partners
- Participants living with dementia