

On the Banks of the River Styx

New Perspectives on Terminal Lucidity
and other Near-Death Phenomena



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The Puzzle of Terminal Lucidity in Dying Children and Adults: Exploring Permissive vs. Productive Hypotheses for Brain Function

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Bial Foundation Symposium
2026
Porto, Portugal

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Exploring *End of Life Experiences*: Medical vs. 1st Person Experiences

How do we deal with the dissonance?

Scientific American, 2014:

- *I'm as sworn to radical rationalism as the next neo-Darwinian materialist. That said, over the years I've had to "quarantine," for lack of a better word, a few anomalous personal experiences that have stubbornly defied my own logical understanding of them.*

--Jesse Bering, Prof., U. of Otago



Overview: What is Terminal Lucidity?

- Definition: The unexpected surge of mental clarity and memory shortly before death in a dying person
- History of the phenomenon
- Current research on TL in children and adults
- Exploration of Productive vs. Permissive hypothesis of brain fn.
- Unexpected effects of episodes on caregivers
- Why is this important to modern medical care and our understanding of the nature of consciousness?



Background:

What do we know about Terminal Lucidity?

- Until recently, only case reports, published in the medical literature.
- Sometimes referred to as lightening up before death, because it directly preceded the last clinical decline and death of a patient.
- Shift in awareness in 2009: Michael Nahm, from Freiburg, & Bruce Greyson from the U. Virginia named the phenomenon Terminal Lucidity.
- Also Peter Fenwick and his colleagues found that 70% of caregivers in nursing homes had witnessed TL in dying patients with dementia.
- Triggers for TL and underpinnings have remained unknown.



One previous case example: Terminal Lucidity in a 91-yr-old woman w/ Stroke

- She had suffered 2 strokes:
- The 1st: paralyzed her L side and affected her speech
- With the 2nd: now completely paralyzed and had no speech
- Her daughter was with her just before death:
- She heard her mother exclaim something,
 - -smile brightly, turn her head and sit up in bed,
 - -raise her arms and joyously say her husband's name
- Then her arms dropped, she sank back and died.
(Noyes, 1952)



Basel Eldadah, Supervisory medical officer at National Inst on Aging, has become interested in the phenomenon.

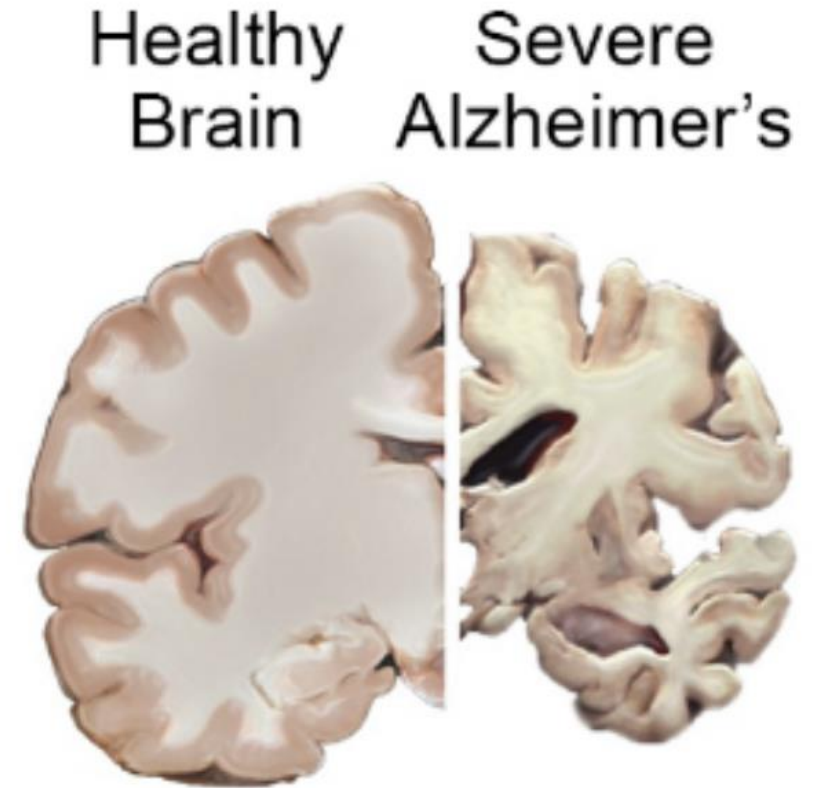
- He says in a blog from NIA:
- There is a phenomenon that does not fit our conceptions that is generating new interest. A number of case reports refer to an unexpected return of mental clarity in individuals with longstanding dementia or other neuropsychiatric conditions.
- It's been called "paradoxical lucidity" due to its puzzling nature, or "terminal lucidity" because it seems to occur at the end of life.
-
- in 2019 NIA sponsored a "Paradoxical Lucidity in Late-Stage Dementia" workshop.
- They convened experts in neuroscience, geriatrics, and other fields to discuss the available scientific evidence and identify research questions to advance the study of lucidity in people with dementia.
- NIA released two "Lucidity in Dementia" funding opportunity announcements in 2020 and funded 6 projects.



The nature and contributing factors to TL are poorly understood, as it often occurs in children or adults whose neurological decline is believed to be irreversible.

To clarify, we ask:

- Are there potential triggers that contribute to eliciting episodes of TL (e.g., medication, treatment, disease progression and other confounding variables)?
- Do unexpected surges of mental clarity correlate with unexpected physical strength or body movements that were previously deemed impossible?
- Are near-death visions reported in the context of TL related to the degree of increased mental clarity and connectedness before death?



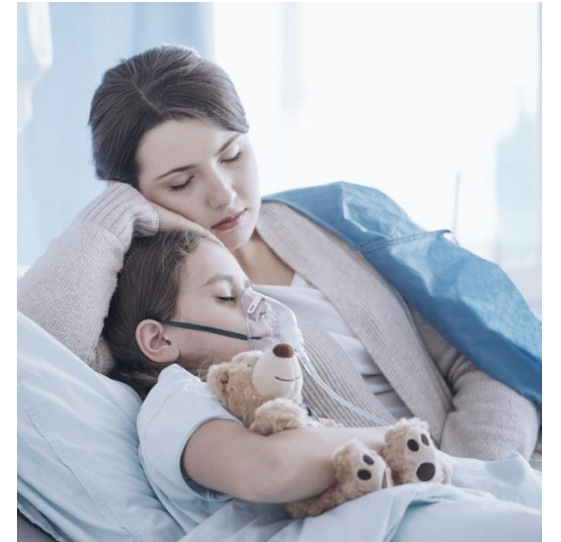
Methods/Study Population



- We created an online questionnaire, that captured significant information about subjects who had experienced a TL episode including:
 - underlying medical condition,
 - treatment regimen (and recent changes),
 - physical and mental capacities just before the TL episode,
 - and behaviors that occurred during the episode itself.
- We conducted 2 studies: on TL in children and on adults
- Adult study: 36 cases met our inclusion criteria
- Child study: 11 cases met our inclusion criteria
- Respondents: nurses, physicians, hospice workers, chaplains, relatives
- Medical condition
 - Adults: dementia/ Alzheimer's, various cancer diagnoses, stroke, often w/ coma
 - Children: leukemia, immune disease, kidney disease, brain tumor, coma

3-year-old girl's final days with her family:

She was no longer speaking, eating, or responding to parents/providers... After nearly 2 weeks of intense conversations [by the doctor] with parents and a Catholic priest and more rapid deterioration in their daughter, the parents were able to agree to a ...modified Do Not Resuscitate status change. That evening, the patient “miraculously” awoke and asked for her usual “comfort” items i.e., the Lion King movie, parents, toys, and food. She had multiple conversations with her parents that evening, which they and the bedside nurse stated were “like a miracle.” During the conversations with her parents, she “reviewed” all the important people in her life and “prayed” for them. After several hours, she asked to “go to bed.” Over the next 24-48 hours, she never “awoke” again, and she ultimately died peacefully of cardiac arrest in her parents' arms.



Duration of TL Episode & Time before Death in Children

- The most frequent duration of TL was a few minutes to an hour (64%)
- And 28% were in the last minutes, 25% in the last hours, and 45% in the last 2 days.

Duration of TL - Child	% of Sample
Minutes, to an hour	64%
More than 1 hour, but less than a day	27%
More than a day	09%

Time Before death-Child	% of Sample
Minutes before death	28%
1-24 hours before death	25%
2-5 days before death	45%

Duration of TL Episode & Time before Death in Adults

- The most frequent duration of TL was 10 minutes or less (57%)
- And roughly 2/3 of the patients died within 24 hours after TL (62%)

Duration of TL - Adult	Count	% of Sample
Less than 10 minutes	20	57
More than 10 minutes, but less than 1 hour	5	14
More than 1 hour, but less than a day	9	26
More than a day	1	3

Proximity to death- Adult	Count	% of Sample
Few minutes before death	4	11
1-12 hours before death	11	31
13-24 hours before death	7	20
2-5 days before death	11	31
6-10 days before death	2	6

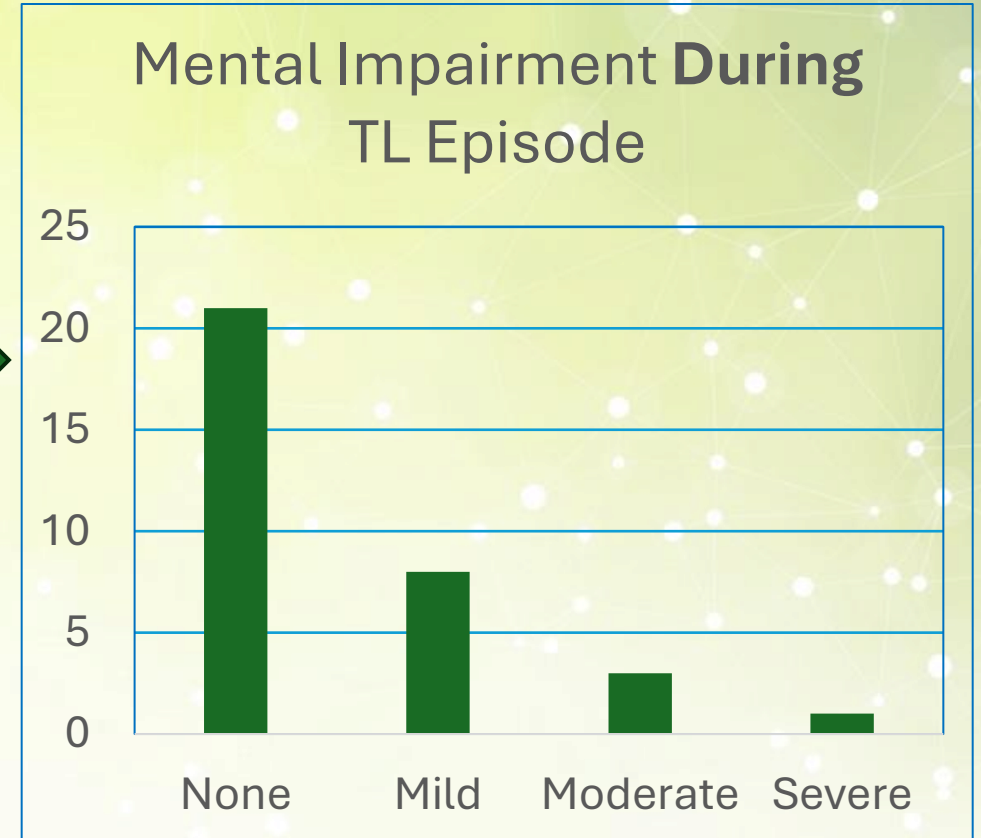
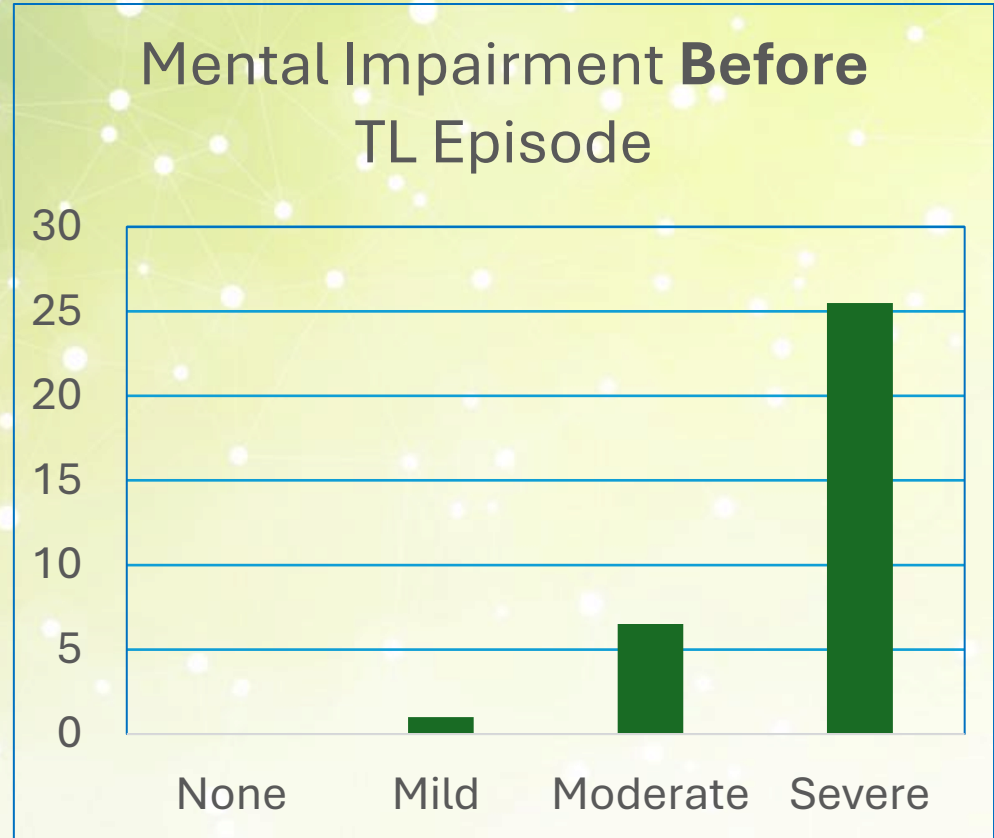
62%

Momentary Lucidity Before Passing in a 63-year-old witnessed by a nurse

- A 63-year-old patient with an advanced brain tumor was unable to communicate for 2 weeks and wasn't oriented in time, place or person. His condition deteriorated visibly and death seemed to be near. At night he was restless, his breathing was irregular. I sat down at his bedside and held his hand, which he refused to let go of.
- His breathing became shallower and he seemed more relaxed. Unexpectedly, he opened his eyes, looked at me and maintained eye contact. Then he addressed me by my name and said "I thank you for being here. I thank you in general for everything you have done for me and especially thank you for your accompanying in dying. I was completely surprised by his sudden clarity, I was amazed that he knew my name and even more surprised by his choice of words." I never used this term as it did not seem possible for us to accompany patients in dying. So not only the patient's sudden clarity, but also his choice of words was remarkable. About 2 hours later, the patient passed away very quietly.



Shift from Severe Cognitive Impairment to Little or No Impairment During TL: Adults



Lucidity, singing & conversation in a dying woman witnessed by her daughter

- It was a day before my mother's birthday. She was going to be 94, and she had Alzheimer's, and she had been mainly out of the normal state.
- **She didn't recognize anyone for at least a year.** She lived in a nursing home and we went to visit her, and my friend Angie, Liz and I **went to visit her the day before her birthday for her pre birthday.** She did not recognize us. And Liz said, Louise, tomorrow is your birthday! And mom just looked at her with empty eyes.
- **We began to sing the Birthday song in Dutch, "Long shall she live in the glory." Her eyes brightened, she clapped her hands and sang along with us, and she sang "Long shall I live in God's glory."**
- She then kissed us and said how happy she was to see us.
- And then, we turned around, and as soon as we turned around the awareness had gone out of her eyes.
- And **she died within the next 6 hours.**



Shift from Moderate-Severe Cognitive Impairment to Little-No Impairment During TL in Children

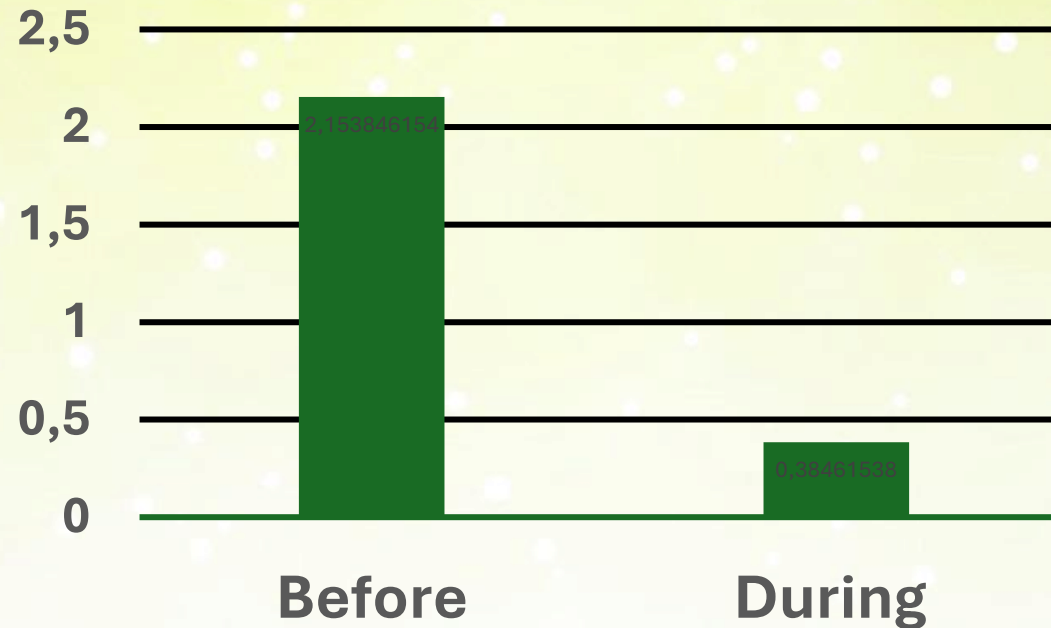
Severe mental impairment

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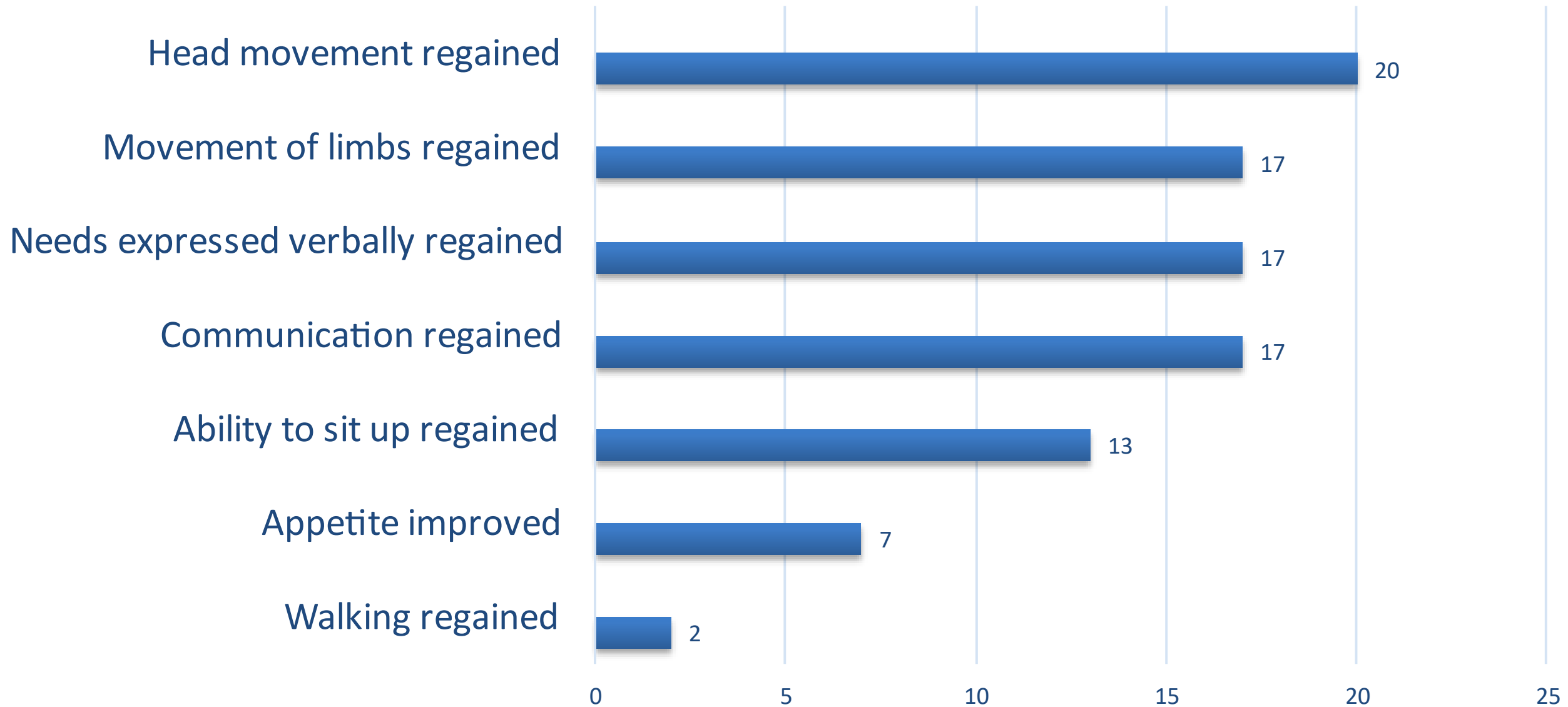


No mental impairment
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Mental State



Frequency of Regained Abilities or Behaviors During Terminal Lucidity



Were Physical Abilities Regained During TL Episode? (Adults)

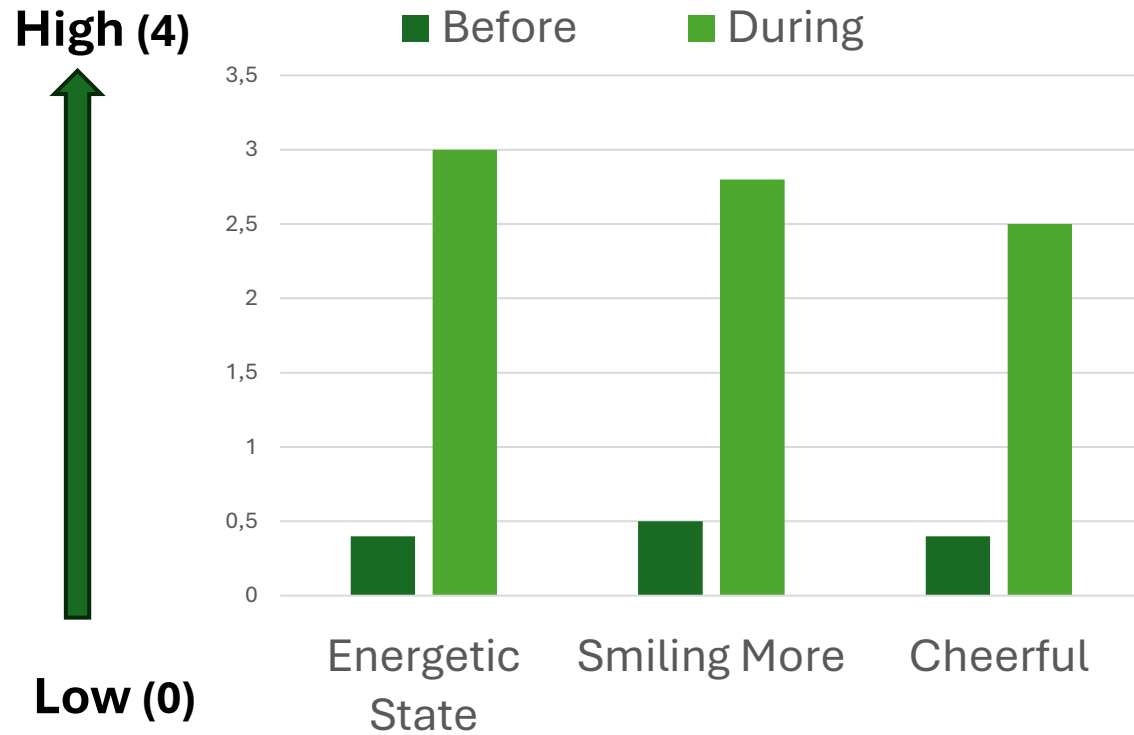


- Example from a nurse: The lady I remember most vividly had been unresponsive for days and was considered to be in the terminal phase of life. I came in one morning expecting that she had died overnight and found her sitting up eating breakfast-she was happily chatting with her family who were a bit stunned to say the least. As I was aware that this might be a case of TL, I explained to the family that her bright condition may not last - and she died that night.

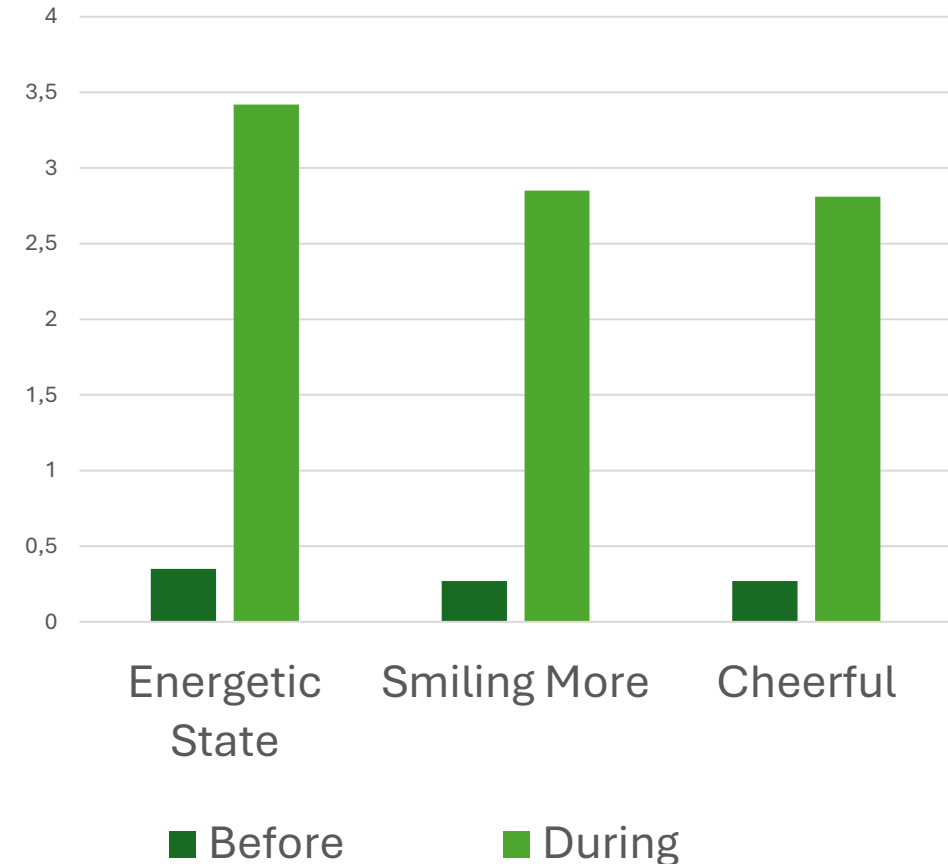
Improvements in Emotional State During TL Episode



CHILDREN



ADULTS



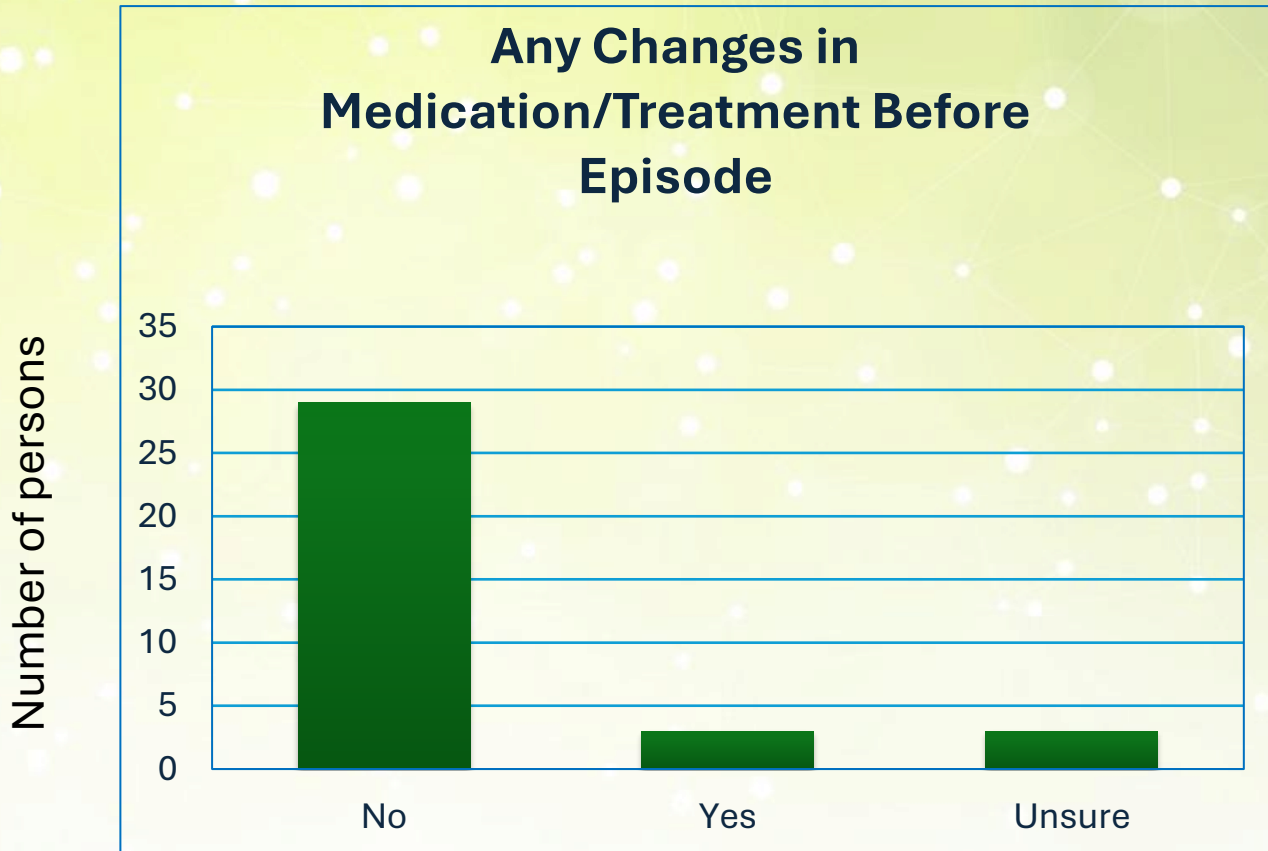
Children Reassured Parents That they would be taken care of

- *One child told her parents not to worry about her as she had seen another child who had died a short time before and the child would be with her....*
- *Another communicated to the nurses to tell his parents not to worry about him as Grandma was going to be with him.*
- *A boy who was just 19 months old at the time of death, “communicated with his parents that he ‘was ready to go home’ and that ‘he and parents would be OK’ using sign language and verbal language.”*



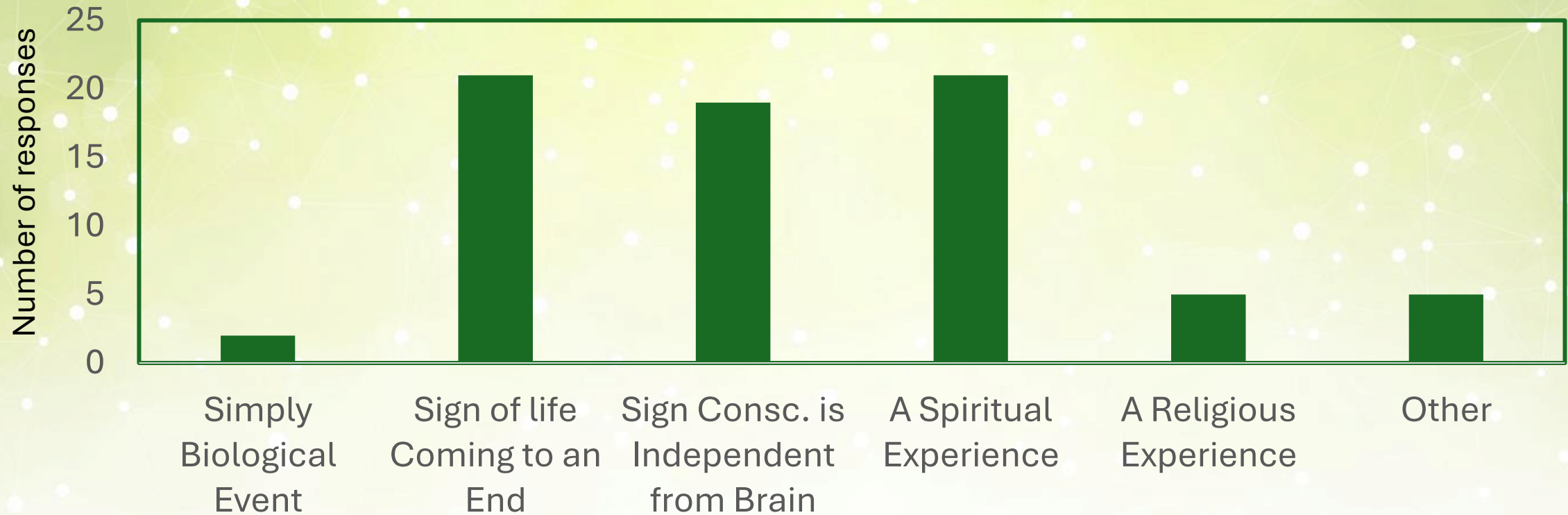
Was Medication/Treatment or Physical Condition Responsible for Episode?

When clinical staff or caregivers were asked if changes in the patient's condition or medication/treatment prior to their terminal lucidity episode could have been responsible for the TL experience, 29 of 35 said this was not the case (3 yes, 3 unsure).

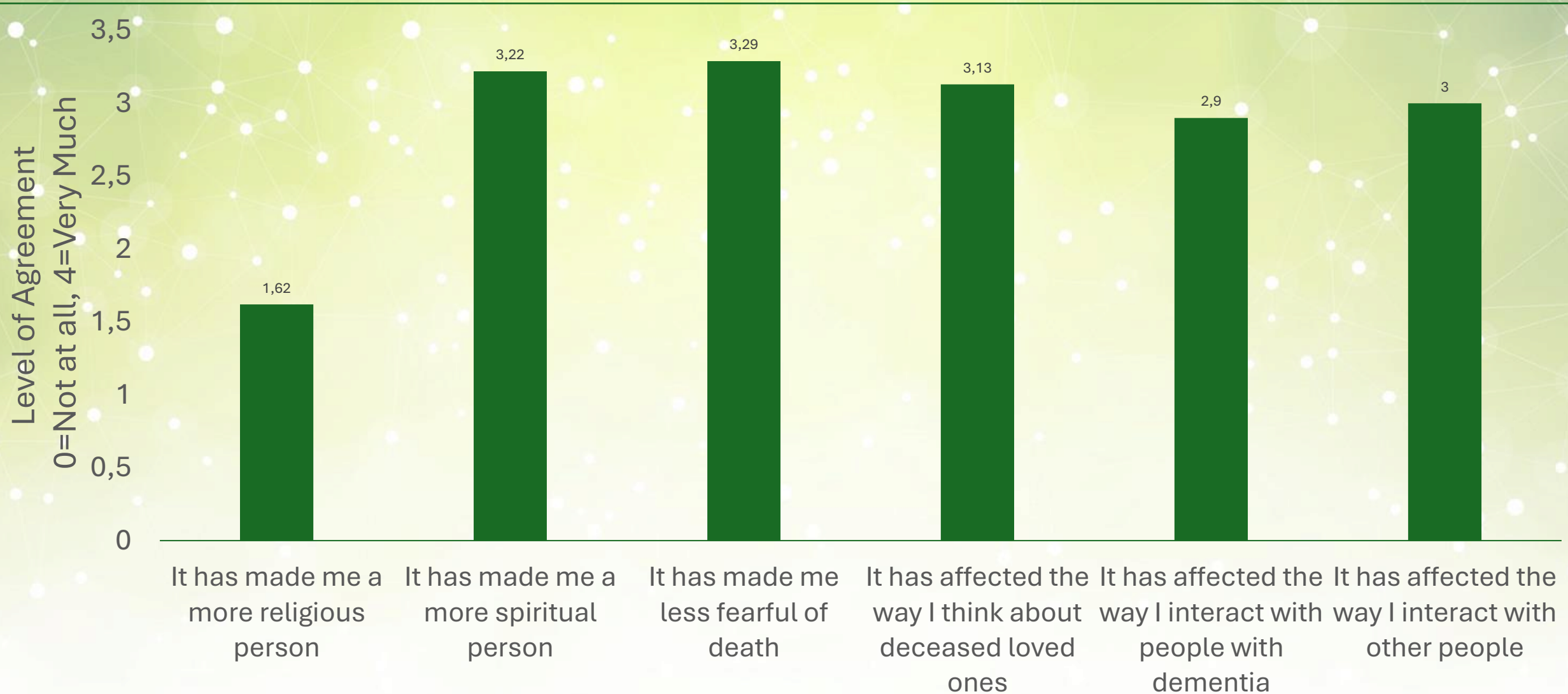


Did Witnesses Feel Transformed by the TL Event? We asked them:

How Would You Explain the Lucidity Events?



Question to Witness: What Impact Did the Event Have on You?



Transformation in a Young Woman Whose Fiancé Was Dying of a Brain Tumor



She had been very distressed by the progression of the disease, but just before he died, she said, "when I entered the familiar room, I was surprised at the brightness there. It was like summer sunshine. It came from his face which was glowing and his eyes were very bright and sparkling. They spoke to me of joy and hope and wonder. His soul had returned to give me a message of life eternal and oneness.

I was 36 at the time and my life totally changed. I had to find out. I had been like most of my generation, not open to anything beyond the material. I was with a political group and it was all about changing the outer world. But then I was so thrown by it that I spent several years learning meditation and at the same time I learned astrology, because I had to find some answers. So that is how I found my life path, that lasted to the age I am now. My main purpose is to experience, rather than think. And to become more aware through meditation, which I have been doing since then, to have deeper experiences while I am living, and not on the level of words.

Why do we believe the study of TL is important?

Implications for Medical Care

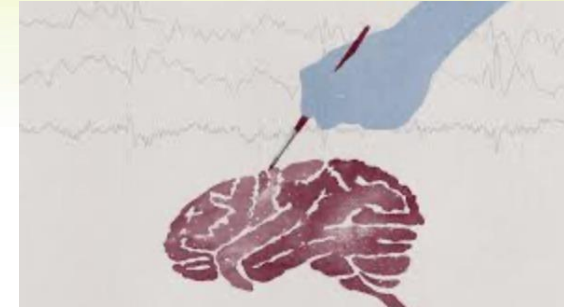
- Changing medical care can facilitate the emergence of TL:
 - A high percentage of persons die in intensive care units.
 - Both relatives and the dying individual may feel distress in this situation.
 - A need for more palliative care for patients and their families when death is imminent.



Why do we believe the study of TL important?

Implications for Our View of Consciousness

- ▶ TL research does not support the theory that consciousness is solely the product of activity of the brain.
 - ▶ **Was not correlated** with changes in **medication, treatment, or other variables** that would physically promote mental clarity.
 - ▶ **Was correlated with unexpected physical strength** or body movements that were **previously deemed impossible**.
 - ▶ **Near-death visions were** associated with **increased mental clarity** and **connectedness with family**, rather than mental confusion.
- ▶ Thus, it can contribute to a new understanding of the nature of consciousness as fundamental, with the brain being permissive, rather than productive of consciousness.



**If you have witnessed such an experience or know someone:
Here is the Link to our adult TL Survey:**

<https://app.onlinesurveys.jisc.ac.uk/s/northampton/terminal-lucidity-adult-survey>

Link to Children's TL Survey:

<https://app.onlinesurveys.jisc.ac.uk/s/northampton/tl-survey-children>

www.terminallucidityresearch.ac.nz/

Thank you! The Team



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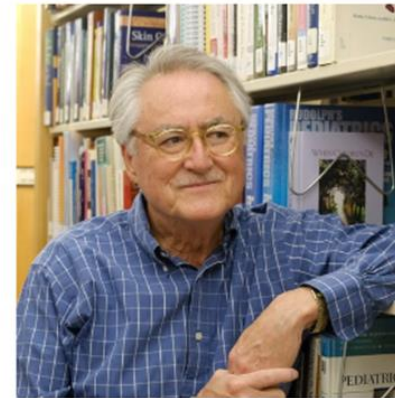
Karalee Kothe



Renaud Evrard



Maryne Mutis



Allan Kellehear



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Thank you!

And now we have time for Questions