

Priorities of Patients, Caregivers and Physicians On Favorable Stroke Outcomes in People Living with Dementia – The SEED Qualitative Study



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Take-home message: Stroke care for people living with pre-existing dementia should measure success through both functional recovery and preservation of personal identity and quality of life.

INTRODUCTION

- **People living with pre-existing dementia (PLWD)** who have experienced a stroke are known to have poorer post-stroke outcomes than people without pre-existing dementia. Yet, their perspectives are missing in stroke literature¹.
- We sought to understand the **priorities and experiences of PLWD, caregivers, and physicians** with stroke care experience, **regarding favorable post-stroke outcomes in PLWD**.

METHODS

- Patients were identified by reviewing clinical notes from stroke cases admitted or consulted by the Calgary Stroke Program at the Foothills Medical Centre in Calgary, Alberta, Canada.
- Eligibility criteria included : ≥65 years old, with a diagnosis of acute stroke in addition to pre-existing dementia, and a family-caregiver willing to participate. Physicians from various medical specialties with experience in stroke care were invited by email to participate.
- Participants completed in-depth, semi-structured interviews, which were audio-recorded, transcribed, and analyzed using interpretive grounded theory².

References

1. Kassir, S., & Béjot, Y. (2025). Preexisting cognitive impairment in patients with acute stroke. *Frontiers in neurology*, 16, 1629461. <https://doi.org/10.3389/fneur.2025.1629461>
2. Sebastian, K. (2019). Distinguishing Between the Types of Grounded Theory: Classical, Interpretive and Constructivist. *Journal for Social Thought*.

Ethics approval: This study was approved by the University of Calgary Conjoint Health Research Ethics Board (REB23-0176 and REB23-1712). All participants provided informed consent.

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RESULTS

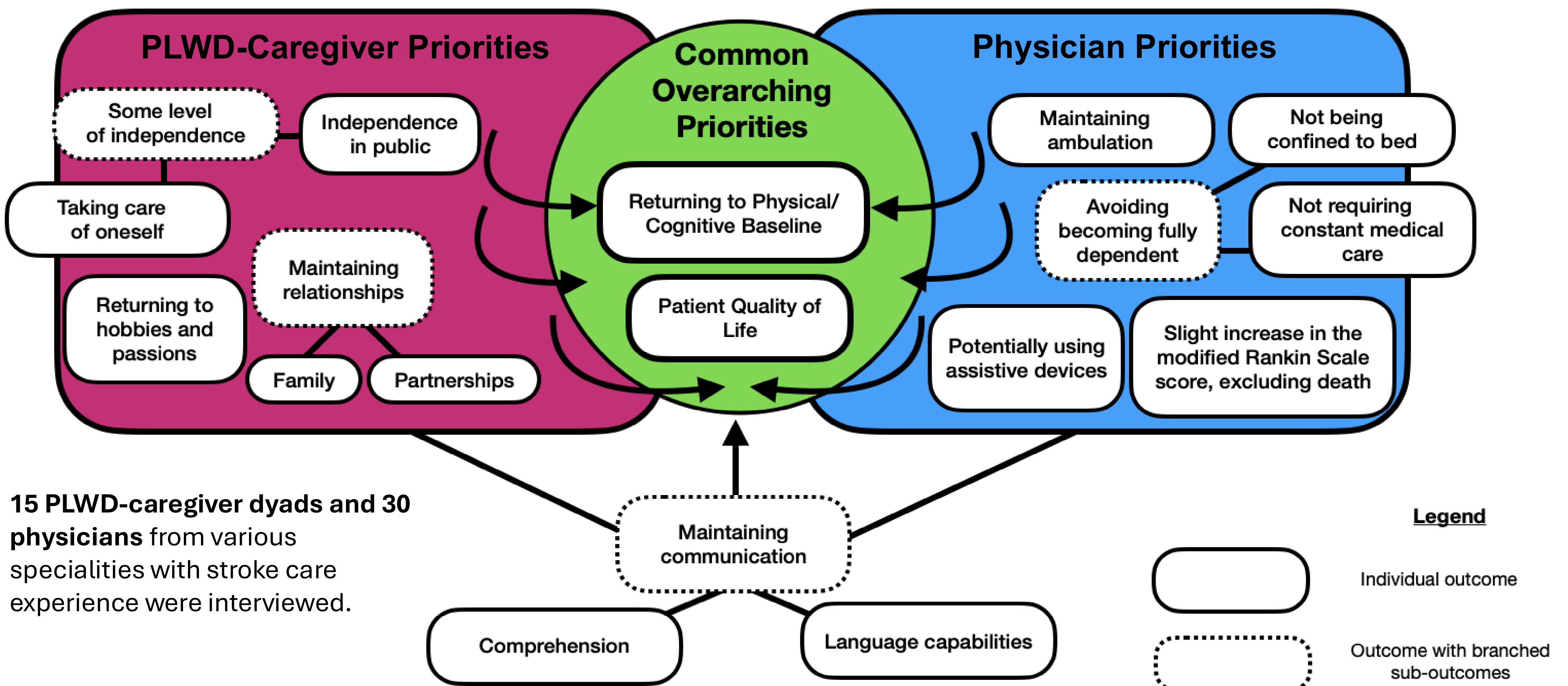


Figure 1. Concept summary of PLWD-caregiver dyads (pink box) and physician (blue box) perspectives regarding favorable stroke outcomes. Both groups prioritize preserving the quality of life of PLWD and returning to baseline (green circle).

- **In PLWD-caregiver interviews: Maintaining aspects of personal identity** were deemed as favorable outcomes. This included maintaining some level of **independence**, continuing to enjoy hobbies and activities, and safeguarding **roles and relationships in family and society**.
- **In physician interviews: returning to baseline function in PLWD was agreed as the most favorable outcome, but physicians also agreed on uncertainties given the nature of the stroke, warranted interventions, and limitations in pre-stroke status.**

"Before when she just had dementia, she could maintain her routine with some assistance, like namely from like a caregiver. But now, her routine is determined by others. Like by her facility. So that is the primary change after the stroke...dementia patients can exist for a length of time. They can live a life that they're familiar with. But after a major stroke, at least from my mother's case, now it's just, there's no agency left." – Caregiver 12

"I always tell families we can never get patients better than the baseline that they entered this illness with, and the best-case scenario is if we can get them back to their baseline...the most realistic scenario is that they will come out of this event with increased cognitive deficit. And so, then it becomes a question of what functions can we preserve to maintain that quality of life." – ER Physician 2

Caregivers and physicians commonly prioritized preserving quality of life and returning to baseline as favorable outcomes (Figure 1).

CONCLUSIONS

- PLWD-family caregiver dyads and physicians prioritize preserving the quality of life of PLWD and returning to baseline as favorable outcomes. Physicians primarily perceive a return to baseline in terms of physical and cognitive functionality, and PLWD-family caregivers additionally emphasize preserving a sense of independence and personal identity.
- Future studies of PLWD should foster collaborative decision-making roadmaps that build on these shared priorities that ensure patient-centric care practices.