

# NAVIGATING THE UNSEEN: UNVEILING THE TRUE IMPACT OF CAREGIVING IN STROKE RECOVERY

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# PRESENTER DISCLOSURE

- **Presenter:** Jill Cameron
- **Relationships with commercial interests:**
  - **Grants/Research Support:** Grant support from the Heart and Stroke Foundation of Canada
  - **Speakers Bureau/Honoraria:** none
  - **Consulting Fees:** none
  - **Other:** none

# MITIGATING POTENTIAL BIAS

- **Presenter:** Jill Cameron
- **Mitigation of conflict:** I will not be presenting any results from my projects funded by the Heart and Stroke Foundation.

# LEARNING OBJECTIVES

- 1. Recognize the crucial role of caregivers in stroke recovery and understand the diverse challenges they encounter throughout the caregiving journey.**
- 2. Explore the hidden costs of caregiving in stroke recovery, including physical, emotional, and financial burdens on caregivers and their families.**
- 3. Identify practical strategies and resources to support caregivers in managing the demands of caregiving while maintaining their well-being.**

# Why Care for Caregivers?

- 1 in 4 Canadians are caregivers (~8.2 Million, 20+ years, [2024 Statscan](#))
- Saving health care system \$60 billion/year (Fast, 2019)
- US over \$450 billion/year (Feinberg, 2011)
- Support stroke survivor recovery, rehabilitation, community re-integration, nursing home and end-of-life care
- Many caregivers experience stress, burden, poor mental health, quality of life, disrupted life, work, etc...
  - ~ can ultimately impact patient outcomes
- Not standard clinical practice to support caregivers

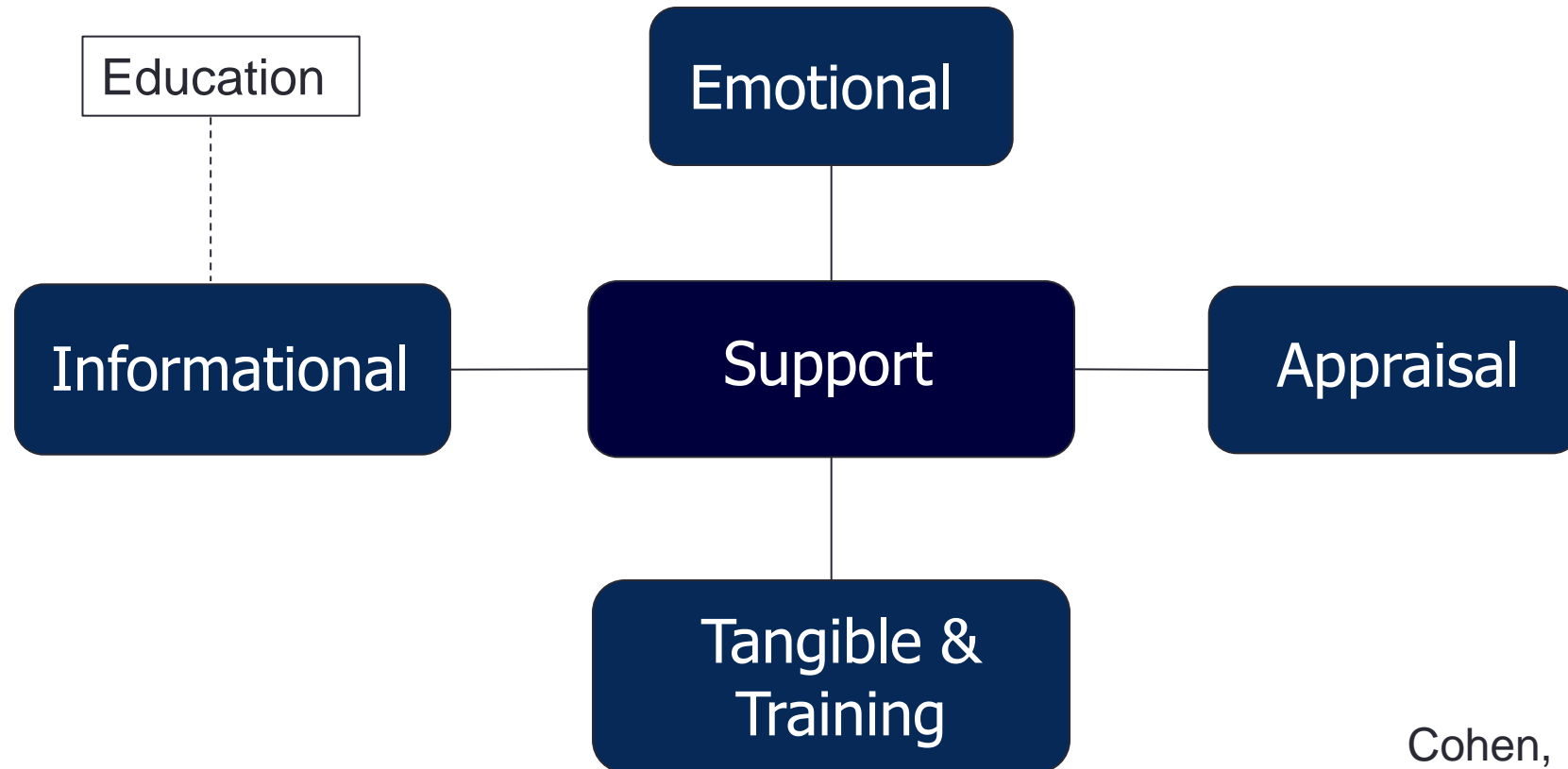
# Caregiving Journey Crosses Many Care Environments



Long-term Care  
Palliative Care



# Caregivers Need Support



Cohen, 1992

# Caregivers Need the Right Support at the Right Time: “Timing It Right” Framework

- Comprehensive five-phased approach to support families from the hospital to the home
- Emphasizes the timing of support needs across the care continuum
- *Premise*: addressing phase-specific needs will enhance family preparedness, ease transitions across care environments, and minimize negative outcomes (e.g., burden)

Cameron & Gignac. Patient Educ Couns, 2008;70:305-314  
Cameron et al. Disabil Rehabil 2013;35:315-24



# Timing It Right Phases

- |                    |   |             |
|--------------------|---|-------------|
| 1. Event/diagnosis | } | Acute Care  |
| 2. Stabilization   |   |             |
| 3. Preparation     | } | Acute/Rehab |
| 4. Implementation  |   |             |
| 5. Adaptation      | } | Home        |
|                    |   |             |

Families' have different support needs across these phases

# Caregivers are not a Homogenous Group

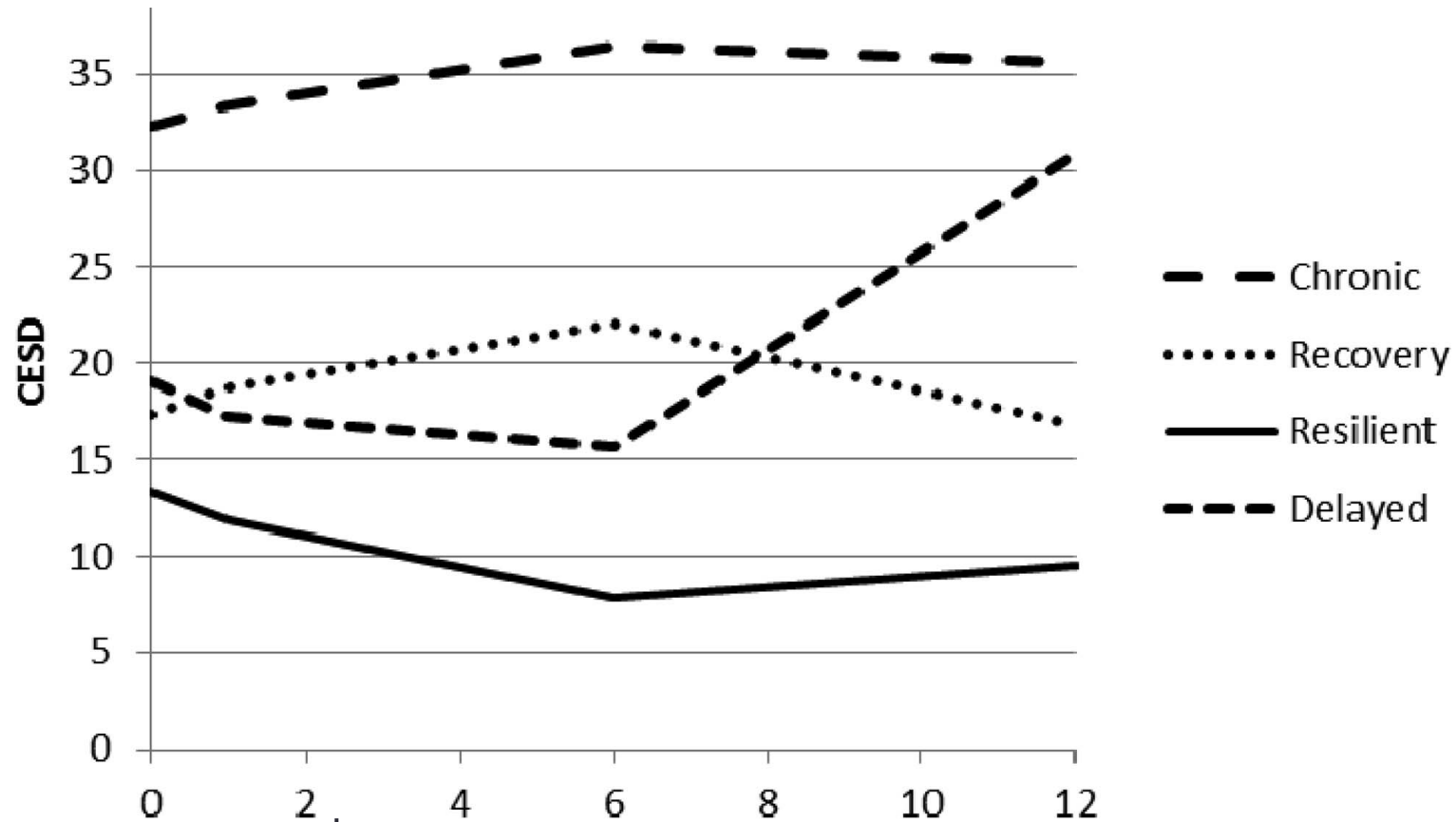


Figure 1. Trajectories of depression in the initial year of caregiving.

CESD - Center for Epidemiological Studies Depression Scale. (Elliot, TR, et al, 2014)

# Caregiver Experiences Vary by Sex, Gender, and Relationship

- Researchers encouraged to examine findings by sex and gender (CIHR)
- Thorough examination of sex and gender on caregiver experiences in the context of Alzheimer's Disease across illness trajectory
- Qualitative grounded theory study with spousal (10 husbands and 10 wives) and adult children (10 sons and 10 daughters) caregivers
- **Key findings:**
  - The experiences of caregiving, examined through a gender and relationship type lens, are complex and variable.
  - The caregiving experience was not related to gender or relationship type alone, but often to a combination of the two.

(Kokorelias et al, *Dementia*, 2021)

# Specific Interventions may not be the Solution

Dalton J, Thomas S, Harden M, Eastwood A, Parker G. *Updated meta-review of evidence on support for carers*. J Health Serv Res Policy. 2018;23(3):196-207.

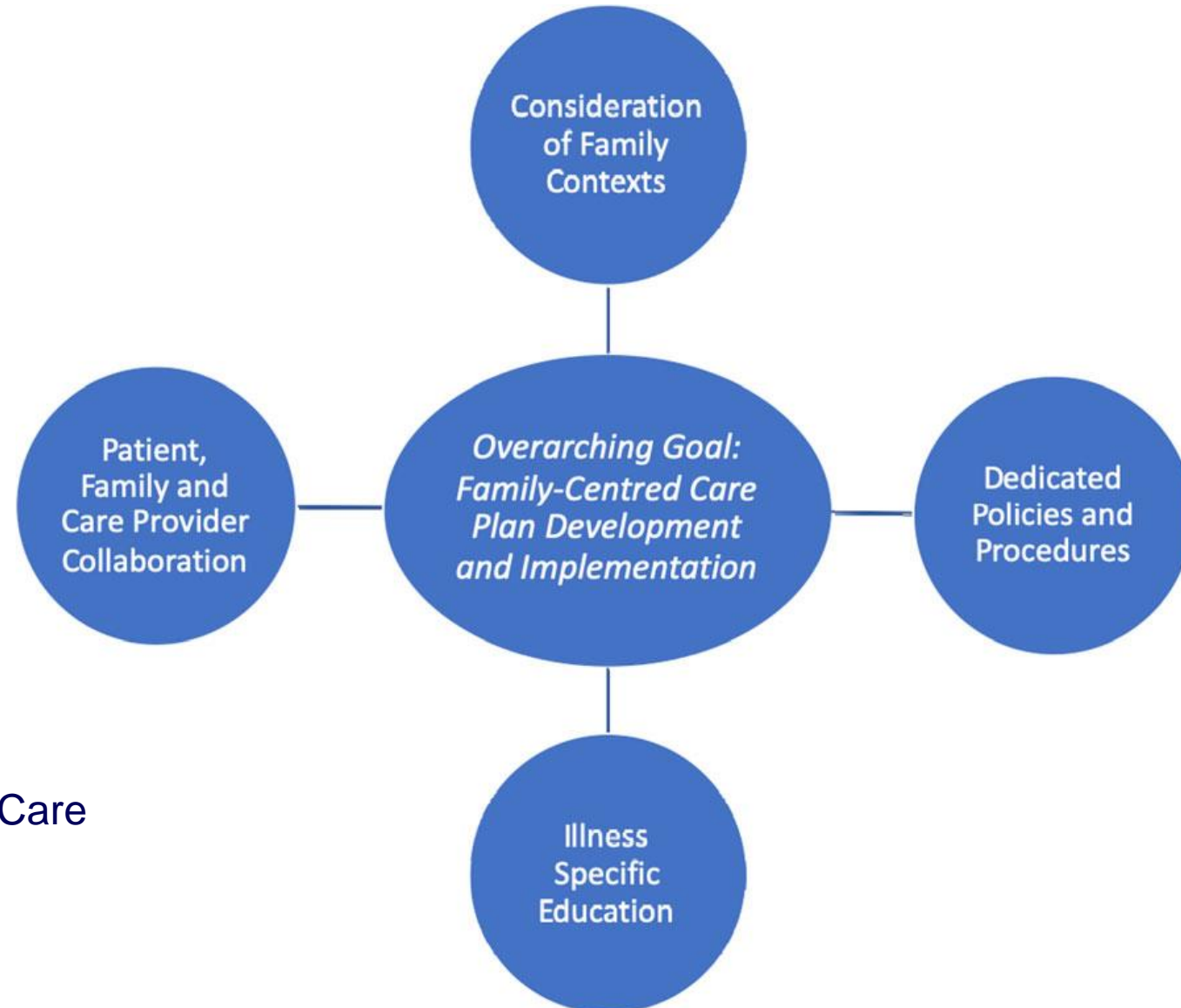
- A meta-review of 61 systematic reviews of interventions for caregivers
  - reported mixed results
  - **concluded there is no “one size fits all” intervention**
  - suggesting that needs vary as do their abilities to benefit from different types of interventions
- Bakas, T., McCarthy, MJ, Miller, EL. Systematic Review of the Evidence for Stroke Family Caregiver and Dyad Interventions. Stroke 2022;54(6)
  - Few studies, small sample sizes
  - Some positive outcomes for people with stroke, decreased burden for caregivers, limited further results

# Person AND Family Centered Care may be a solution

**Objective:** to determine the key model components and to identify aspects that are universal across illness populations, and care contexts and aspects that are illness- or care-context specific

- 55 articles included
- 40 included models for pediatric populations
- 15 included a variety of adult conditions including unspecified

Towards a Universal Model of Family Centered Care  
(Kokorelias, et al 2019)





# Person and Family Centered Care Study

- Looking for Participants!!
- People with stroke who identify as male
- Caregivers who identify as male
- Health care professionals involved in stroke care
- 45–60-minute telephone or virtual interview
- Email Meera @ [caregiving.study@utoronto.ca](mailto:caregiving.study@utoronto.ca)



