Dementia Caregivers

Dementia by the Numbers

58% of dementia patients live in low- and middle-income countries, 68% by 2050

Total cost of dementia well over $1T US ($9.12 T by 2050)

~ ¼ of all people with dementia live in China: prevalence ~6.19% (2015) (7.1% in Canada)

Everyone with dementia requires care.

Dementia care is largely provided at home by unpaid caregivers

96% of people with dementia in lower- and middle-income countries live at home (Canada about 60%)

Global estimates of informal care (ADI, 2018)

annual global informal care hours: 82 billion (2015), ~ 6 hours per day. (40M FTE)

2015

2030

65 M FTE workers.

Implications of Data

- Dementia is a major public health challenge
- Most of the burden of care is in the Community
- Heaviest burden of care is on families – untrained, unsupported, vulnerable to physical and psychological impairment. Especially at risk are older women , living at home with PWD

What does it mean to be a Caregiver?

Video clip of Robert - about 3 minutes.

Doing the job -being Robert the Husband

- Alone and isolated
- Trudging through life at times
- Apologies and disappointment
- Unpredictability- can’t plan
- Constant daily tasks of intimate care- eating, managing apraxia (feeding and handing her the fork)
- time pressures

- No response or thanks
- Loss of continuity of shared memory
- Bewilderment – (we are at home)
- Frustration, conflict , anger
- Communication breakdown- no partnership love (when am I going home?)- Harsh communication

The Special Challenges of Dementia Caregiving

(Sadavoy, Sajedinejad et al 2020)

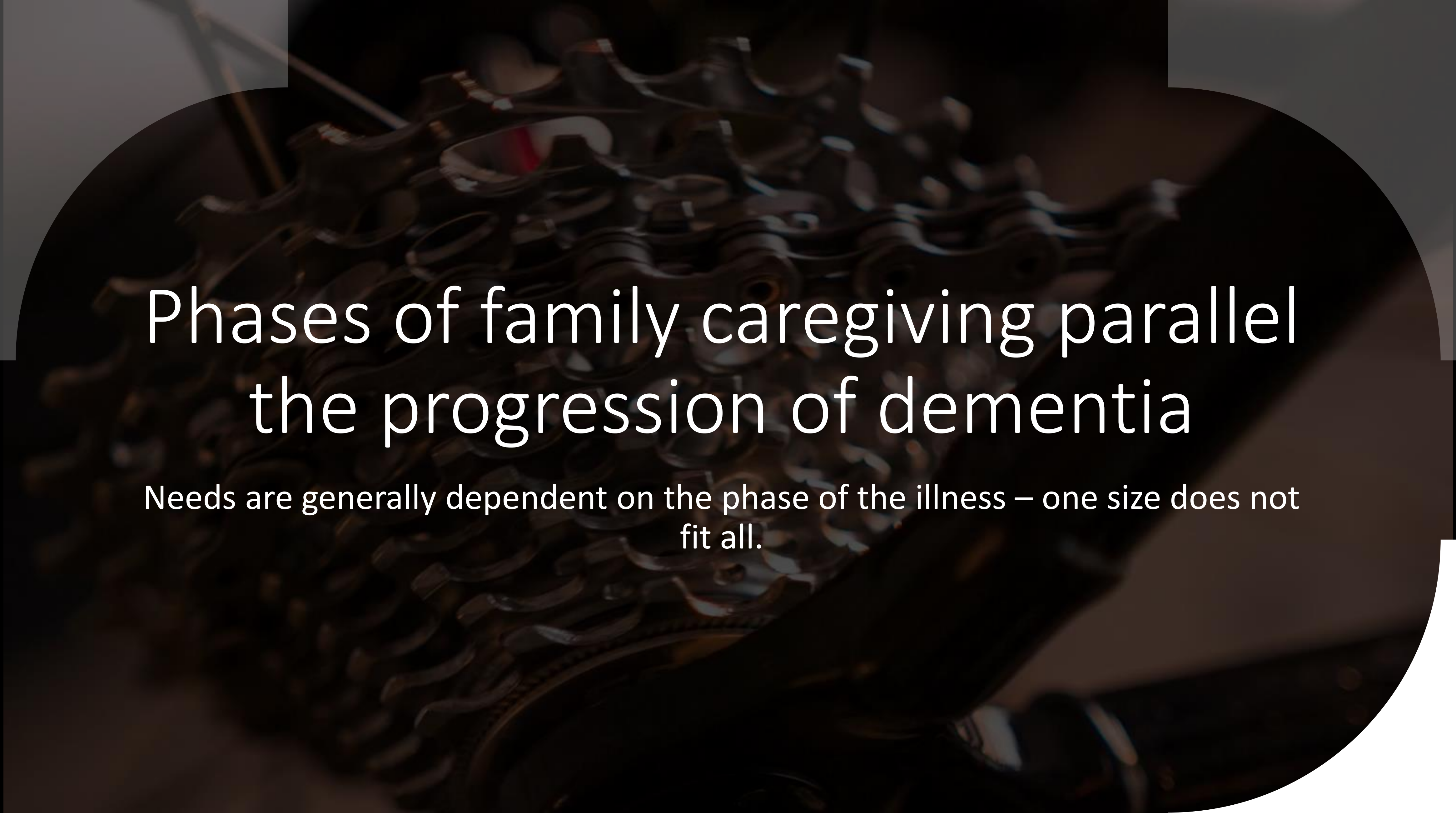
Most family caregivers (CG) caring for older adults, many with dementia, are employed out side the home (US data).

We conducted the first large scale study of employees focused on impact of dementia care

National Canadian Survey of employees (*N* = 1,839) who were concurrently providing informal care for an older adult with specific attention to dementia care

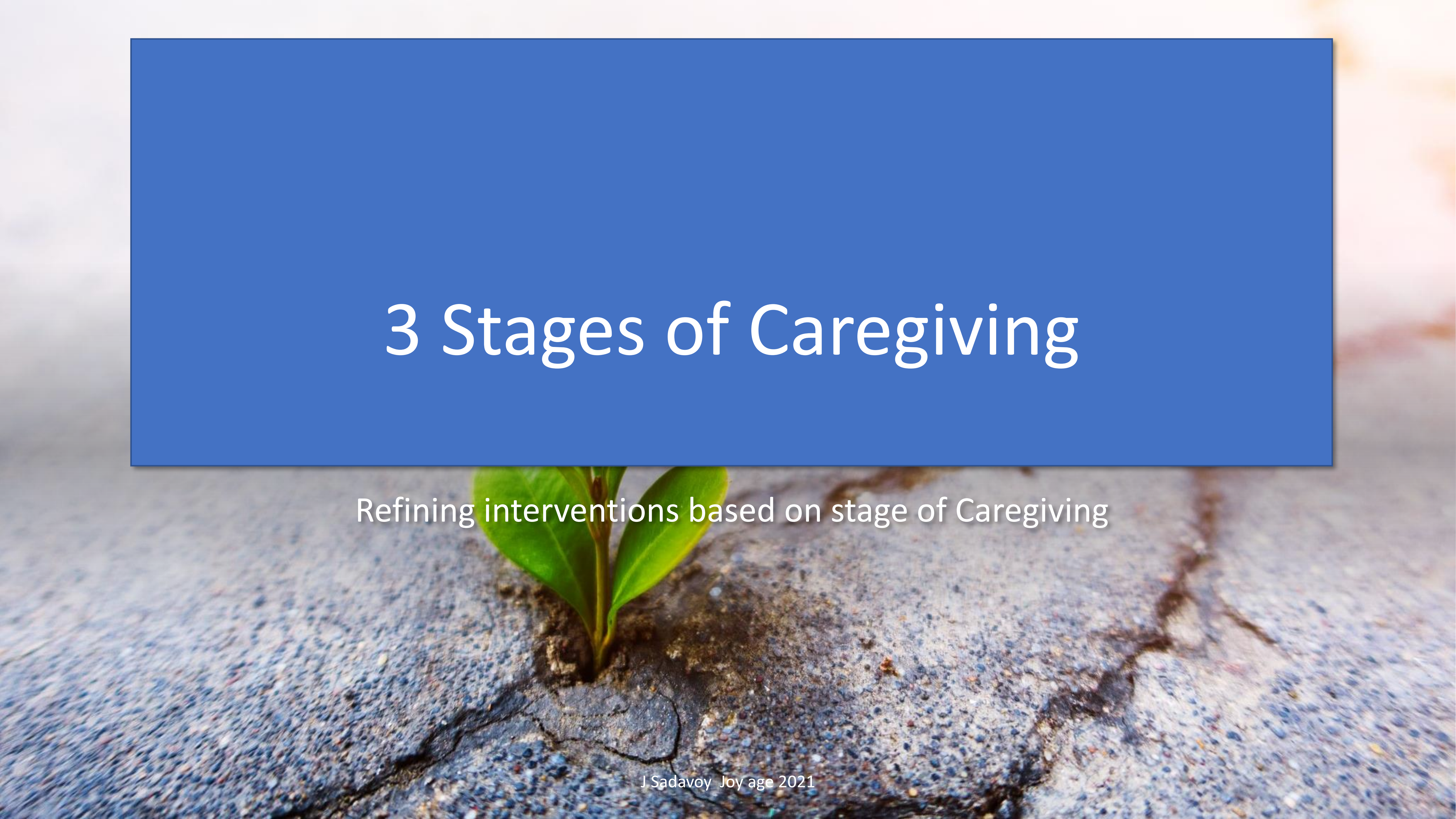
Results: **Employees concurrently caring informally for persons with dementia who pose moderate to high care demands experience significantly more difficulties than employees providing LDD or ND informal care**

How do we sustain caregivers through the years of dementia care?



Phases of family caregiving parallel the progression of dementia

Needs are generally dependent on the phase of the illness – one size does not fit all.



3 Stages of Caregiving

Refining interventions based on stage of Caregiving

J Sadavoy Joy age 2021

J Sadavoy Joy age 2021

Stage 1- Adjusted Coping

- **Diagnosis** new- adjusting to new information and uncertain future.
- **Relationship** – mild changes- core remains eg intimacy caring; irritation (doing it on purpose); confused
- **Communication** – relatively intact
- **Independent activity** (leaving him alone able to go out)
- **Safety concerns** – no major concerns
- **Daily activities** need little support or supervision
- **Coping** is adequate
- **Little need** for additional help
- **Few help seeking behaviours** and little need for system navigation

Stage 2 – marginal coping

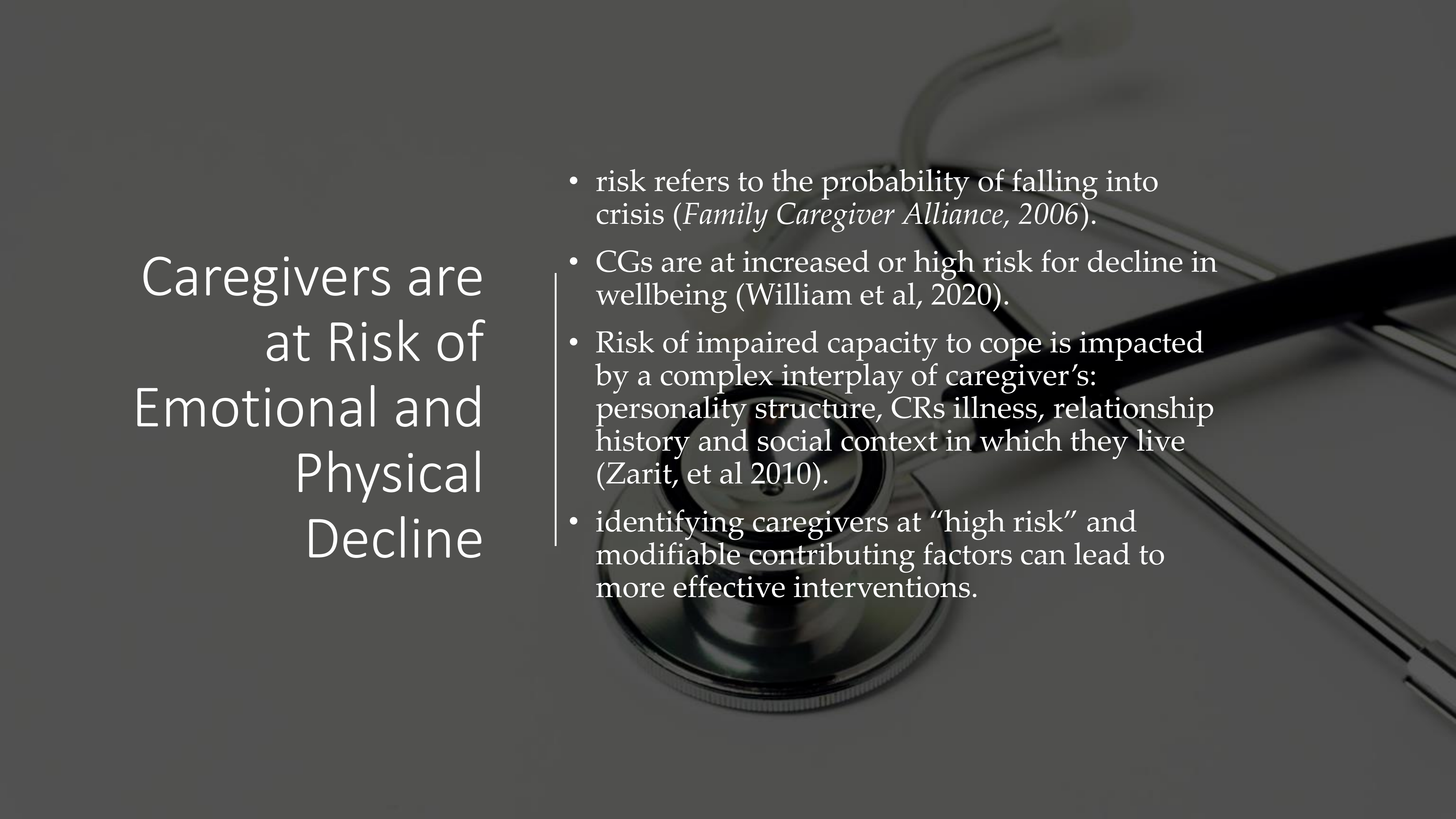
- **Diagnosis** and its meaning on life now clear- no uncertainty other than how long will this go on.
- **Relationship** is significantly impaired
- **Communication** intermittent often absent- "I forget what love is like"
- **Increasing responsibilities** for all duties at home- finances, shopping, medical decisions, diet, housing, travel etc
- **Dependency Supervision:** of many of all adl's, trapped at home- "I can't plan without him"
- **Social isolation** –actual/perceived
- **Additional help** necessary
- **Help seeking behaviours** and need for system navigation

"The silence was the worst. Silence not as in solitude or concentration but as in living with, eating with, waking up beside someone who has nothing to say to you." Rachel Hadas: Strange relationship: a memoir of Marriage Dementia and Poetry"

Stage 3- Overwhelmed coping - Terminal caregiving

- **Diagnosis** –focus on concurrent problems eg weight loss frailty
- **Relationship:** feelings of isolation and loss
- **Communication** mostly non-verbal
- **All decisions** activities and responsibilities are caregivers;
- **Overwhelmed** and no longer able to cope- fantasies of death of CR as a release
- **Independence** : Cannot leave at all unless fully replaced
- **Entrapment** induces hopelessness
- **Help seeking** focused on placement decisions

How do we clinically assess Caregivers?



Caregivers are at Risk of Emotional and Physical Decline

- risk refers to the probability of falling into crisis (*Family Caregiver Alliance, 2006*).
- CGs are at increased or high risk for decline in wellbeing (William et al, 2020).
- Risk of impaired capacity to cope is impacted by a complex interplay of caregiver's: personality structure, CRs illness, relationship history and social context in which they live (Zarit, et al 2010).
- identifying caregivers at "high risk" and modifiable contributing factors can lead to more effective interventions.

Clinical Assessment of Family Caregivers

The D-CIG: Dementia Caregiver Interview Guide

(Feldman et al Psych 2021)

Key Areas of CG Assessment (D-CIG)

- Years of Care
- CR factors: BPSD, cognitive and physical
- CG : entrapment, isolation, psych Hx, emotional reactions, relationship, psych Hx, coping style
- Knowledge of dementia
- Barriers to Change : stigma , denial
- Environment : support, respite and family relations, finances
- Barriers to accessing resources: eg culture language , isolation
- Protective factors: resilience, satisfaction in Cging
- Risk assessment : days when stretched to the limit in past week; rate global assessment of risk on 7 point likert scale

Theory of effective Intervention (1)

Build the caregivers “sense of coherence” i.e. internal sense of competence to face challenges,

Enhance “resources of resistance” (i.e personal capabilities) ” that enable coping such as education, social support and trained coping strategies. (*Turró-Garriga et al, Aging Ment Health, 2020*)

Incorporate understanding of invisible underlying personal characteristics: personality of Caregiver, relationship to CR, preexisting vulnerabilities like depression, or anxiety, substance use.

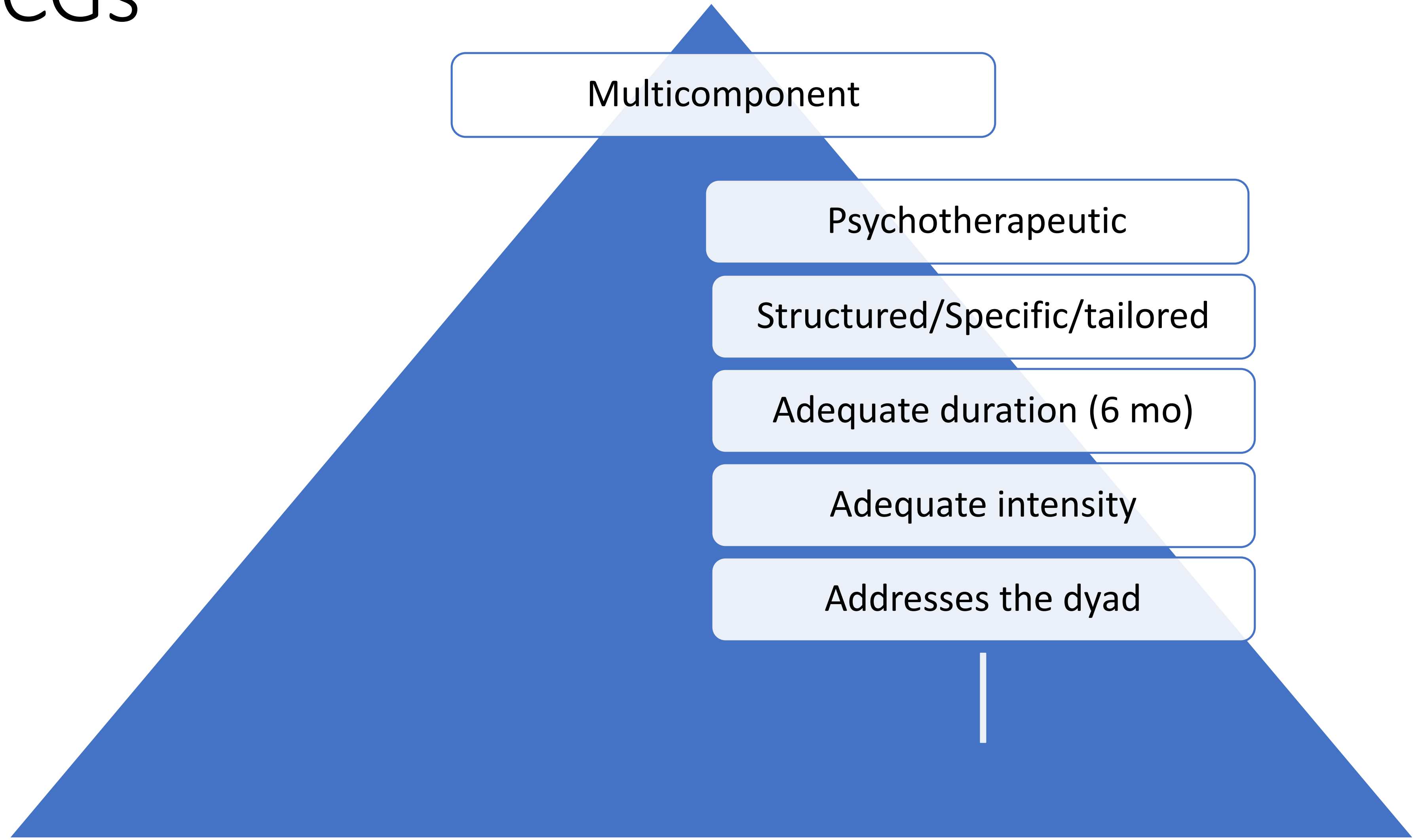
Theory of effective Intervention (2)

1. Enhance sense **of competence** to manage internal and external challenges
2. Enhance **realistic acceptance of the diagnosis, practical ability to manage** and **use resources**
3. Enhance **meaningfulness** of caregiving (worth doing)
4. Maintain sense of **inner identity, relatedness**
5. Address Interpersonal **conflict resolution and grief**
6. **Normalize, contextualize and promote connectedness**

What Works?

Multicomponent programs that include psychotherapeutic component

Principles of Effective models of Intervention for CGs



- Multicomponent
- Psychotherapeutic
- Structured/Specific/tailored
- Adequate duration (6 mo)
- Adequate intensity
- Addresses the dyad

Effective Programs that have been Scaled- USA and Canada

CARERS suite of multicomponent interventions

REACH, SMART, NYU and FAMILIES

All have Research data : most recent Sadavoy et al 2020,2021; Sperling et al FAMILIES, 2020

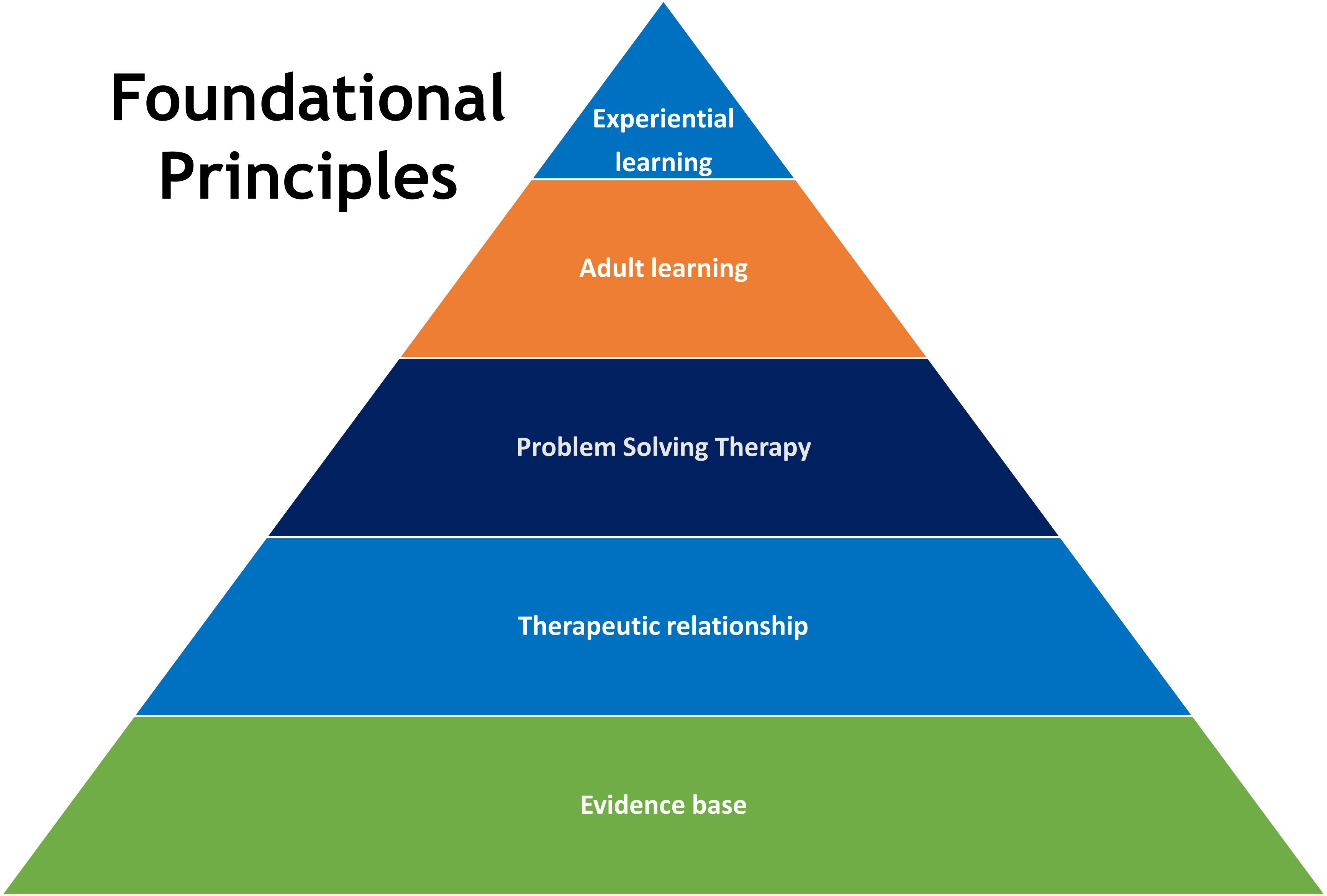
The CARERS Model of Intervention

Efficacy of CARERS

(3 studies- Chiu et al 2015, Sadavoy et al 2020, 2021)

- multisite trial of effectiveness of CARERS
- Intervention group : 264 CGs evaluated before and after completion of the 8-week CARERS
- Wait-list control group (*n* = 83)
- Results were adjusted for baseline CR measures (IADL/ADL and Revised Memory and Behavioural Checklist)
- CARERS was significantly superior to usual care on measures of perceived stress, depression, burden, competence, role overload, emotion and avoidance-focused coping.

Foundational Principles



Experiential learning

Adult learning

Problem Solving Therapy

Therapeutic relationship

Evidence base

Canada
This project is funded in part
by the Government of Canada

We begin with a thorough Assessment of Each Caregiver by a MH clinician

Our goal is to ensure that the program addresses the SPECIFIC and special needs of each CG

And we pay special attention to assessing EMOTIONS AND RELATIONSHIPS

The CARERS Manualized CG Group Psychotherapy Program Structure

8 weekly 2 hour sessions

- Week 1: Introduction, laying the foundation, dementia education and the caregiving experience
- Weeks 2 - 4 PST
- Weeks 5 - 7 Simulation (or PST if needed)
- Week 8 Simulation and closure

Individual support or referral as needed

What is CARERS PST?

CGs are taught a method to control emotions and convert abstract complex caregiving problems into a practical **solvable** form.

The focus is on caregiver issues **specific** to each caregiver

Goal: Re-establish sense of **mastery** and **competence**

What is Simulation?

Simulation is a guided re-enactment of a real recent incident in the caregiver's life

It makes use of a specially trained simulated patient who enacts the part of the person with dementia in the scenario; the caregiver is herself

During simulation emotional challenges, relationship challenges and gaps in knowledge, skills and attitudes are identified

Expert coaching helps the caregiver understand the relationship and emotions and learn new more effective approaches

Common Interpersonal Challenges Addressed Through Simulation Scenarios

- **paranoia/accusations**
- **Saying no to unreasonable demands**
- **behaviours like apathy, upset, confusion, agitation**
- **family tensions**
- **Telling others about the illness Asking for Help**
- **Talking to employers (working caregivers)**

Simulation demonstration video: Robert Struggles with his wife’s paranoia

- CG Robert
- Carers clinician Sarah
- SP Mary
- Group is not included in the video

Our challenge was to scale an intensive clinical program to address the needs of a large diverse population

Scaling the EC Program

- Acquire base funding
- Develop a network of program delivery partners in all regions
- Staff each site with trained clinicians
- Ensure and maintain quality and fidelity (MOU and job descriptions)
- outreach strategies to reach isolated or remote caregivers
- Address needs in urban and rural locations
- Maintain effective administration, communication and data collection
- Manage attrition, program failures and new development
- Effective use of technology

Enhancing Care for Ontario care Partners (EC): A Dementia Initiative program of the MOH Ontario Canada

RC is lead organization (direct services, training, administration, research, site support, new clinical program development, program maintenance new site).

12 satellite partner sites (ASs and hospitals) partners) delivering the program in 36 urban and rural communities in Ontario Canada, population 14.5 million.

Fun facts: Ontario 1.1 million Sq Km; about 1/9 size of China and US; twice as big as Germany, France or Spain.

Total number CGs served face to face (~ 3 years): ~2380