



Self-Care for Parkinson's Care Partners: MEANING AND IDENTITY

MAY 19, 2021

KAITLYN (KATE) P. ROLAND PHD

UNIVERSITY OF VICTORIA

KROLAND@UVIC.CA





Caregiver/care partner

“There are only 4 kinds of people in this world. Those who have been caregivers, those who currently are caregivers, those who will be caregivers, those who will need caregivers.”

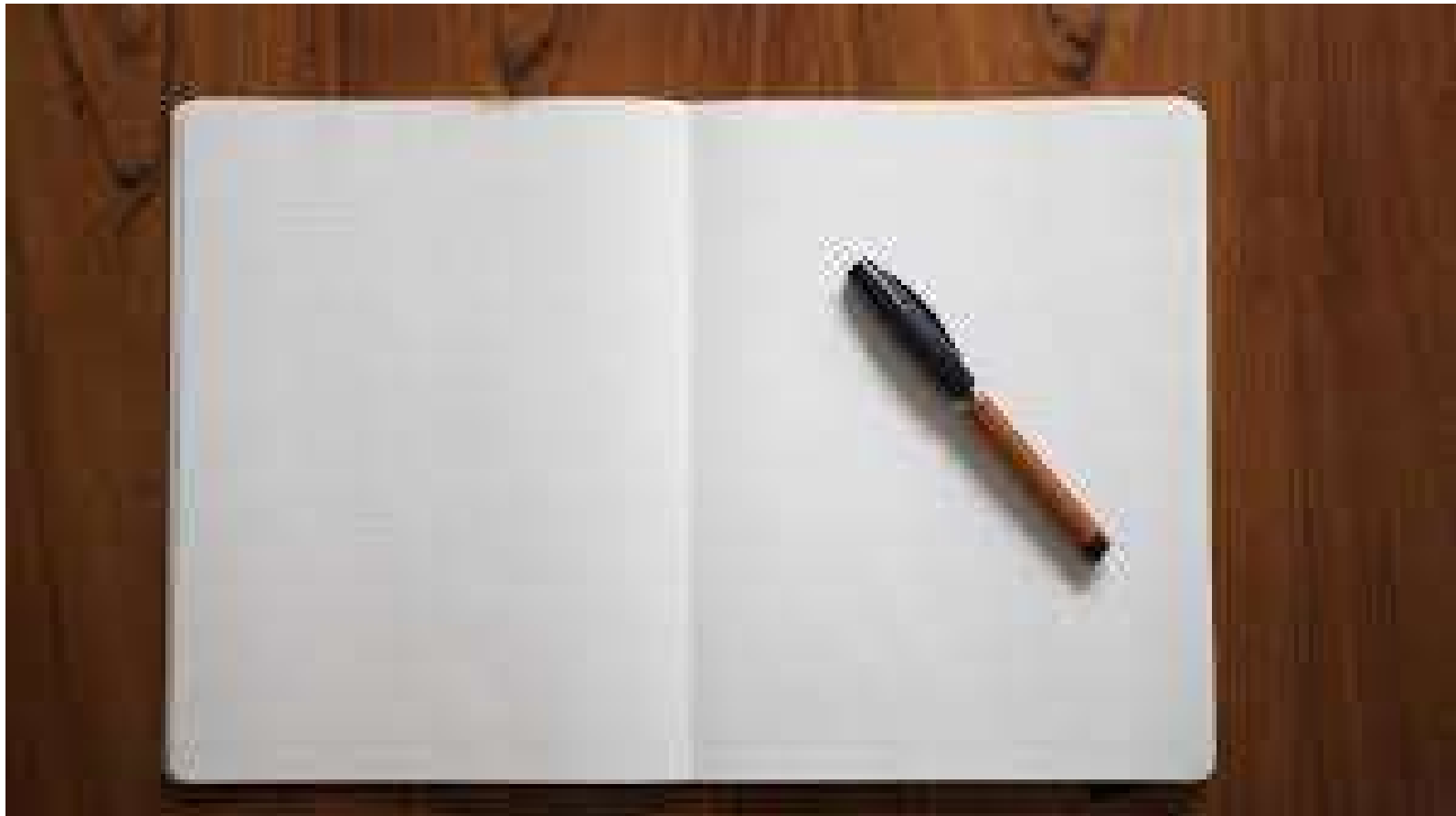
(Rosalynn Carter, 1st lady 1977-81)

A Caregivers Bill of Rights

I have the right:

- ▶ To **take care of myself**. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
- ▶ To **seek help** from others even though my loved ones may object. I recognize the limits of my own endurance and strength.
- ▶ To **maintain facets of my own life** that does not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- ▶ To get angry, be depressed, and **express other difficult feelings**.
- ▶ To **reject** any attempts by my loved one (either conscious or unconscious) to manipulate me through guilt, and/or depression.
- ▶ To **receive consideration, affection, forgiveness, and acceptance for what I do**, from my loved ones, for as long as I offer these qualities in return.
- ▶ To **take pride** in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.
- ▶ To **protect my individuality** and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
- ▶ To expect and demand that as new strides are made in finding **resources** to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

What Does It Mean To Be A Caregiver?




The Importance Of YOUR Health and Well-Being

Health is a **balance** of positive and negative aspects

- ▶ Being **prepared**, assuming the role and being realistic
- ▶ Good **relationship** quality
- ▶ Make it a **meaningful** experience





Who Supports Well-being For Caregivers?

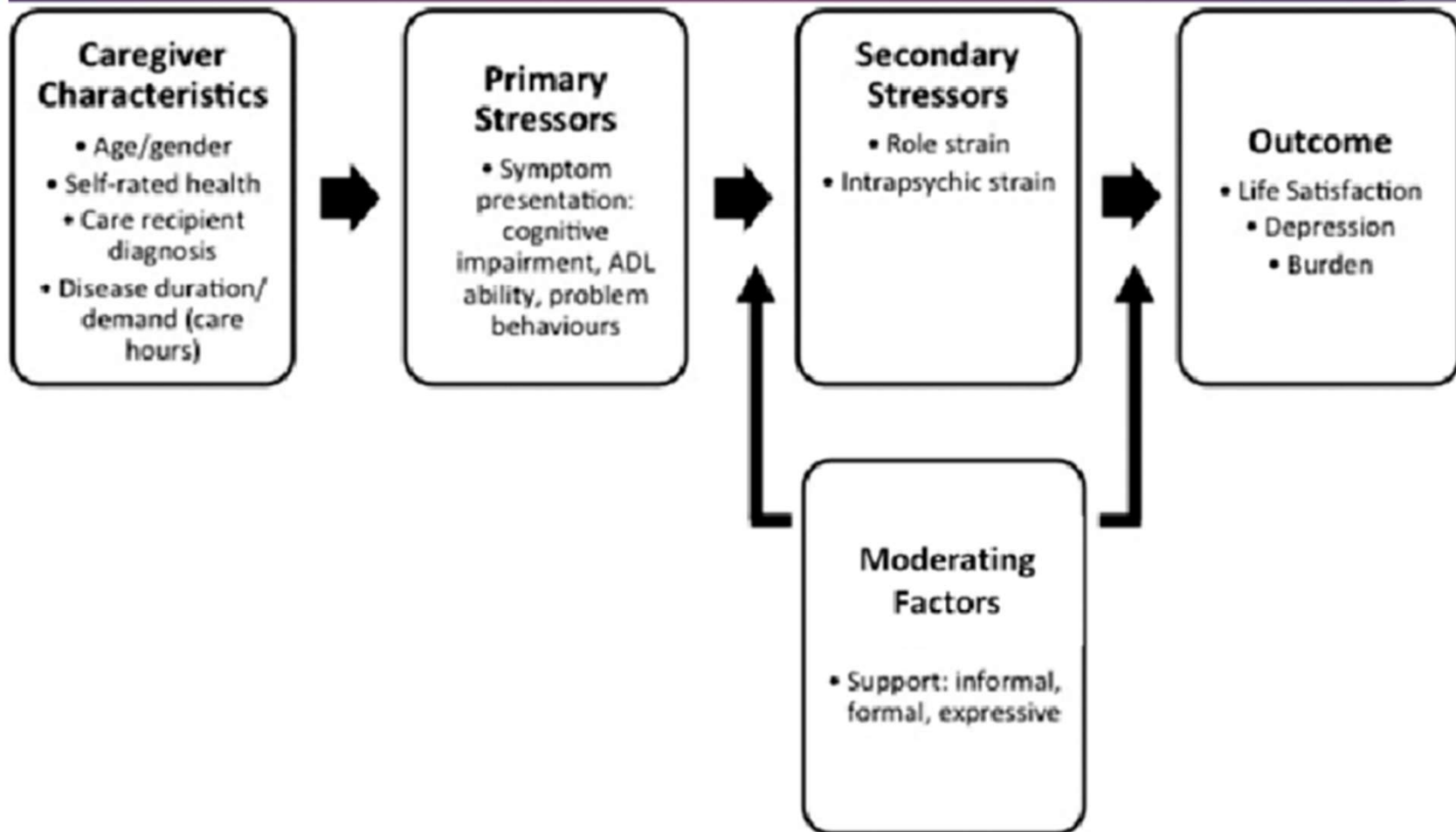
- ▶ FAMILY
- ▶ FRIENDS
- ▶ RESPITE SERVICES
- ▶ EDUCATION / TRAINING
- ▶ NON – PROFIT SOCIETIES
- ▶ COUNSELLING
- ▶ HEALTH CARE



What Is Coping?

- ▶ “**personal management** of a stressful situation that changes the meaning [of that stressor] and reduces the threat [of that stressor]”
 - ▶ (Pearlin, Mullan, Semple and Skaff, 1990)

What are stressors?



Adapted from Pearlin, Mullan, Semple, & Skaff, 1990



Burden

- ▶ Judgement of the caregiving experience
- ▶ Can take a toll on caregiver health and well-being
- ▶ “Not [to] overlook the negative aspect but all you hear is caregiver stress and this and that. If that’s all you hear, that’s what you’ll expect. But there are humorous times. There are positive things, and an opportunity to give back. So people should know that.”

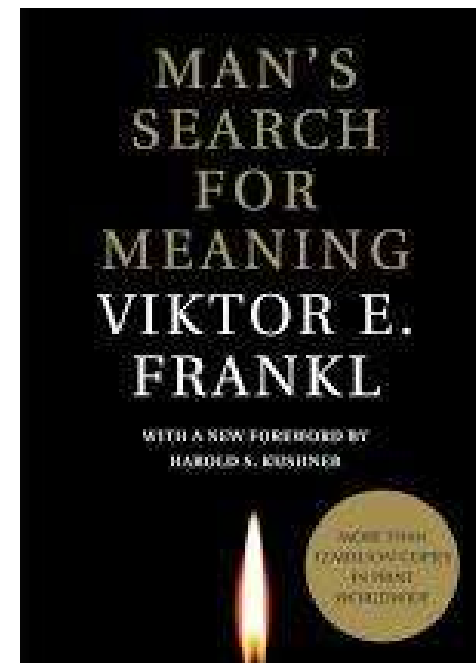


Finding Meaning In Care Giving

- ▶ Meaning = well-being
- ▶ The concept of finding meaning in caregiving has been proposed as a way of **cop**ing with the burden of caregiving

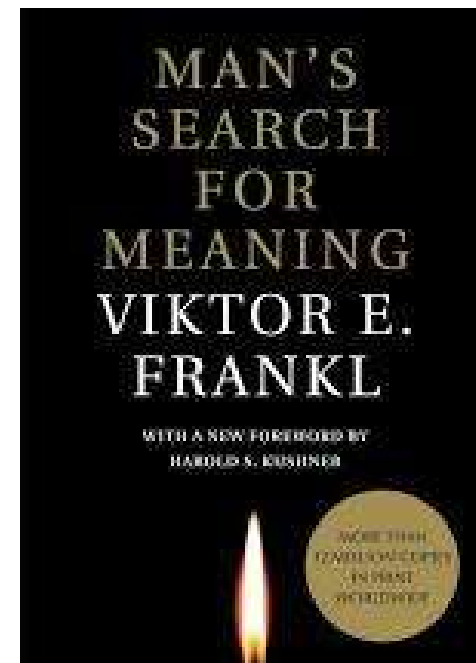
Finding Meaning

- ▶ What does it mean to 'find meaning'?
- ▶ Theoretical support for the construct "finding meaning," has primarily evolved out of Victor Frankl's (1963, 1978) personal and professional experiences.



Finding Meaning

- ▶ “Everything can be taken from a man but one thing: the last of human freedoms – to choose one’s attitude in any given set of circumstances, to choose one’s own way.”
(V. Frankl)



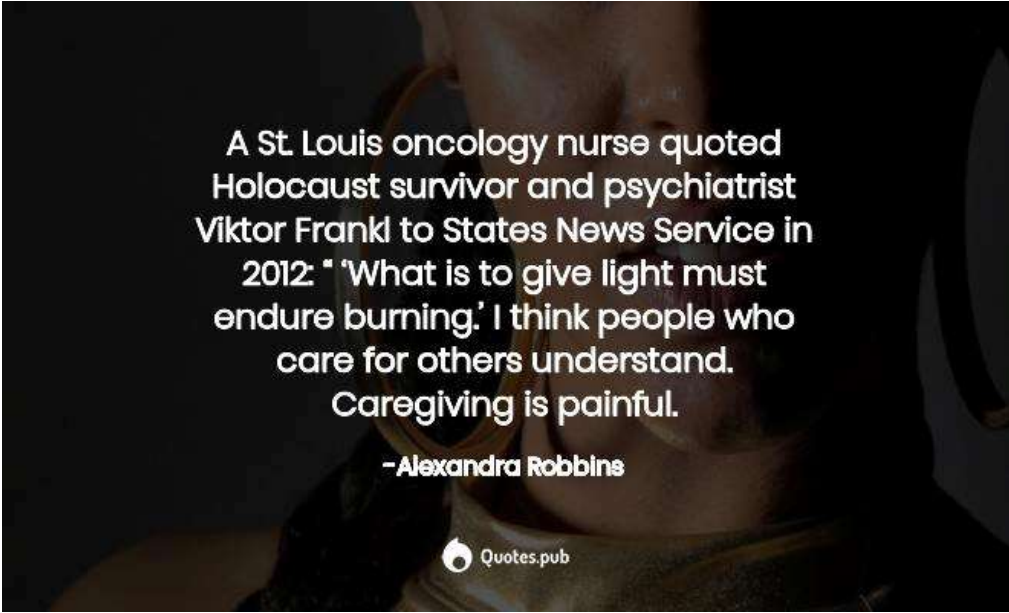


Aspects of Meaning

- ▶ Loss and powerlessness
- ▶ Provisional meaning
- ▶ Ultimate meaning

Loss and Powerlessness

- ▶ Missing the communication, companionship, abilities that my loved one had/did/provided in the past.
- ▶ Missing the time I used to have to do things of my choosing.




A St. Louis oncology nurse quoted Holocaust survivor and psychiatrist Viktor Frankl to States News Service in 2012: "What is to give light must endure burning." I think people who care for others understand. Caregiving is painful.

-Alexandra Robbins

Provisional Meaning

- ▶ Counting your blessings
- ▶ Recognizing your strengths



When we are no longer able to change a situation, we are challenged to change ourselves.

Viktor Frankl



Provisional Meaning

I enjoy having my relative with me; I would miss it if he/she were gone.

I count my blessings.

Caring for my relative gives my life a purpose and a sense of meaning.

I cherish the past memories and experiences that my relative and I have had.

I am a strong person.

Caregiving makes me feel good that I am helping.

The hugs and "I love you" from my relative make it worth it all.

I'm a fighter.

I am glad I am here to care for my relative.

Talking with others who are close to me restores my faith in my own abilities.



Provisional Meaning

Even though there are difficult things in my life, I look forward to the future.

Caregiving has helped me learn new things about myself.

Each year, regardless of the quality, is a blessing.

I would not have chosen the situation I'm in, but I get satisfaction out of providing care.

Every day is a blessing.

This is my place; I have to make the best out of it.

I am much stronger than I think.

I start each day knowing we will have a beautiful day together.

Caregiving has made me a stronger and better person.

Ultimate Meaning

- ▶ I will not be given more than I can handle
- ▶ I have faith in myself

Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom.
--Viktor Frankl

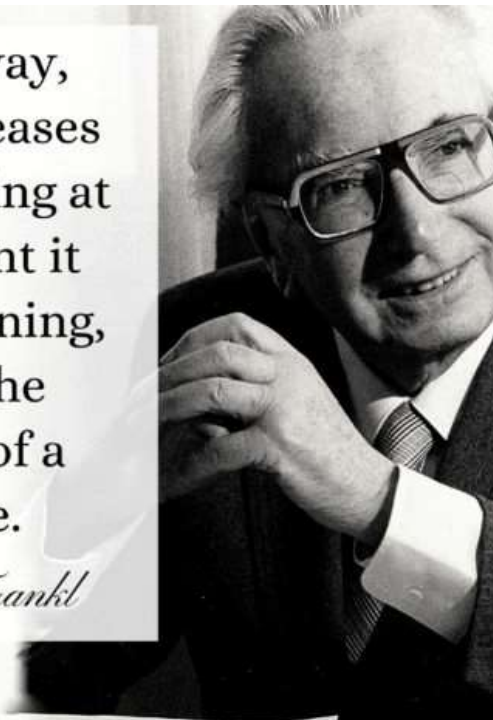


Meaning in Caregiving

- ▶ Growth in caring for another

In some way,
suffering ceases
to be suffering at
the moment it
finds a meaning,
such as the
meaning of a
sacrifice.

~Viktor E. Frankl



(B. Shim, 2020)



How Can Caregivers Find Meaning?

- ▶ Deciding to Care
- ▶ “First it was a question of do I want to do it or not. I solved that one. So that gave me the meaning. Second one is: Okay, I’m going to be a good husband and not [just] a caregiver.”

(B. Shim, 2020)



How Can Caregivers Find Meaning?

- ▶ Accepting the situation
- ▶ “But basically it has shifted from fighting a disease to accepting a disease [...] The sooner you accept that, the easier it is to do the rest.”

(B. Shim, 2020)



How Can Caregivers Find Meaning?

- ▶ Choosing a positive attitude
- ▶ “I could be very bitter, but I’m not going to be. I have a choice. What is my attitude going to be? What is my motivation for the day?”

(B. Shim, 2020)



How Can Caregivers Find Meaning?

- ▶ Focusing on the blessings
- ▶ “I learned that life does go on and you don’t even think about it after a while because you find good things [...] You can appreciate the more simple things of life [...] It’s like stopping to smell the roses.”

(B. Shim, 2020)



How Can Caregivers Find Meaning?

- ▶ Actively seeking resources
- ▶ “First of all joining a support group is very, very helpful. I made friends with one couple, we [...] but you don’t worry about it because these people know what you are going through.”

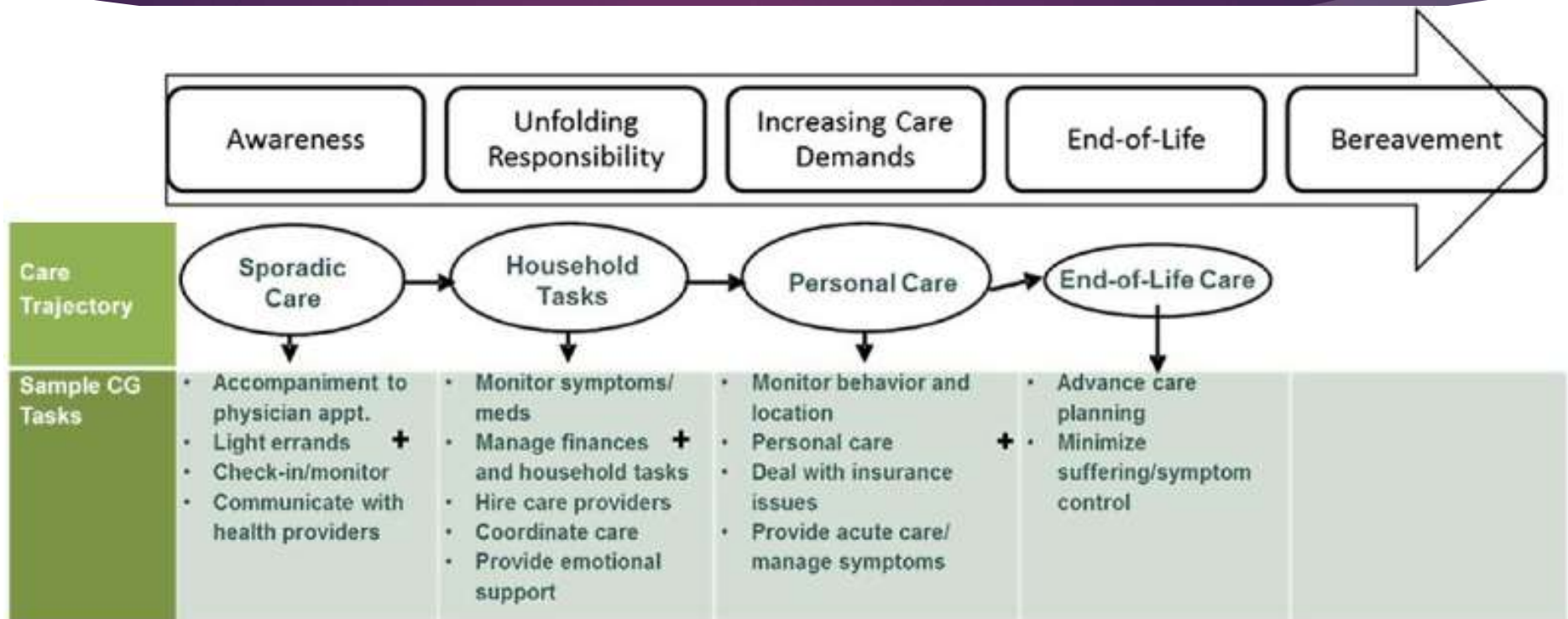
(B. Shim, 2020)



Finding Meaning Among Role Shifts and Transitions

- ▶ Multiple and evolving roles
- ▶ Multiple and evolving settings
- ▶ ... How do we continue to find meaning?

Caregiving Trajectory



Adapted from Gitlin and Schulz (2012) and Schulz and Tompkins (2010).

Caregiving Roles

Domain	Caregivers' Activities and Tasks	Caregivers' Activities and Tasks
Household tasks	<ul style="list-style-type: none"> •Help with bills, deal with insurance claims, and manage money •Home maintenance (e.g., install grab bars, ramps, and other safety modifications; repairs, yardwork) •Laundry and other housework 	<ul style="list-style-type: none"> •Prepare meals •Shopping •Transportation
Self-care, supervision, and mobility	<ul style="list-style-type: none"> •Bathing and grooming •Dressing •Feeding •Supervision •Management of behavioral symptoms 	<ul style="list-style-type: none"> •Toileting (e.g., getting to and from the toilet, maintaining continence, dealing with incontinence) •Transferring (e.g., getting in and out of bed and chairs, moving from bed to wheelchair) •Help getting around inside or outside
Emotional and social support	<ul style="list-style-type: none"> •Provide companionship •Discuss ongoing life challenges with care recipient •Facilitate and participate in leisure activities 	<ul style="list-style-type: none"> •Help care recipient manage emotional responses •Manage family conflict •Troubleshoot problems
Health and medical care	<ul style="list-style-type: none"> •Encourage healthy lifestyle •Encourage self-care •Encourage treatment adherence •Manage and give medications, pills, or injections 	<ul style="list-style-type: none"> •Operate medical equipment •Prepare food for special diets •Respond to acute needs and emergencies •Provide wound care
Advocacy and care coordination	<ul style="list-style-type: none"> •Seek information •Facilitate person and family understanding •Communicate with doctors, nurses, social workers, pharmacists, and other health care and long-term services and supports (LTSS) providers •Facilitate provider understanding 	<ul style="list-style-type: none"> •Locate, arrange, and supervise nurses, social workers, home care aides, home-delivered meals, and other LTSS (e.g., adult day services) •Make appointments •Negotiate with other family member(s) regarding respective roles •Order prescription medicines •Deal with insurance issues
Surrogacy and Decision making	<ul style="list-style-type: none"> •Handle financial and legal matters •Manage personal property •Participate in advanced planning •Participate in treatment decisions 	

Finding Meaning Among Role Shifts and Transitions

- Opportunities for redefining 'meaning' along the way





Breakout: Sharing Ideas

- ▶ What do you grieve? (i.e. what do you miss?)
- ▶ Where do you find joy? (i.e. what makes you happy?)
- ▶ Where do you find strength? (i.e. What are you good at?)
- ▶ How has the caregiving journey changed for you?
- ▶ What resonated with you today?
- ▶ What questions do you have on this journey?

