



Caregiver Journeys: New Pathways for Support



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01

Introduction

Qualitative Research Study: *Caregiver Experiences and Perceptions of Declining Health*

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 **Innate Motion**

NPHI *National Partnership
for Healthcare and
Hospice Innovation*



June 2023

People Over Profits

*A Values-Based Movement
for Declining Health*

NPHI *National Partnership
for Healthcare and
Hospice Innovation*

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Research Methodology

Format:

- 6 virtual **1:1** interviews (1.5 hours each)
- 6 virtual group Interviews with **3 participants** per group (2 hours each)

Participants:

Diverse set of **31 caregivers** recruited from around the country:

- Approximately census-balanced mix of race and ethnicity
- Gender skewed female, reflecting national trends in caregiver status
- Representation of a range of health issues (dementias, cancers, and heart failure were most common)
- Mix of relationships to patient, including spouses, children, parents, and other relatives
- 1 caregiver of a pediatric patient (recruiting for this category posed serious challenges, a key learning for future research)

Content/Discussion:

- Moderators followed a discussion guide with detailed questions around key facets of the caregiver experience and their “journey” through the healthcare system
- Key themes included: practical considerations, interactions with healthcare system, social and interpersonal dynamics, religion and spirituality, financial challenges, caregiver health and wellbeing, and more
- Participants were asked to imagine the ideal healthcare experience for themselves and their loved one, with moderators probing on key terminology (e.g. “comfort,” “advanced illness,” “palliative,” “hospice,” etc.)



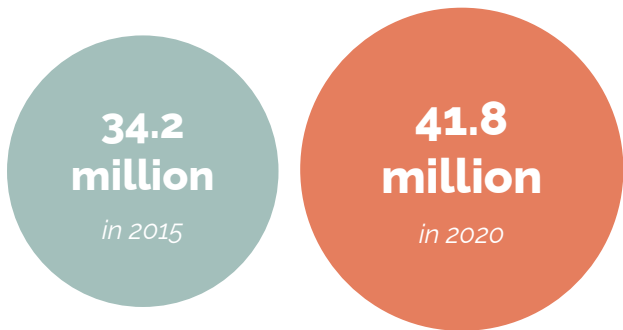
02

Caregiver Burden

Caregiver Burden: By the Numbers

41M+

unpaid caregivers of adults
over 65



16M

care for someone who has
Alzheimer's or other dementia

More than

half

say they did not have a choice
in becoming a caregiver

25%

say caregiving has made
their health worse

40%

have 2 or more
chronic conditions

26-57%

experience
depression

\$7,200

average annual out-of-pocket cost
for caregivers

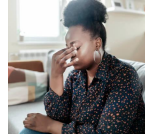
\$9,000

per year for caregivers of someone
with dementia

Two Sides of Caregiving

The Weight

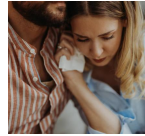
Forced into an imposed destiny



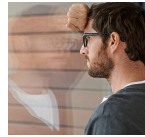
Trapped in the red tape



Drowning in emotions



Isolated in a lonely journey



Neglecting their own health



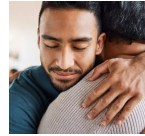
The Beauty



Rise to the occasion



Find comfort in faith & purpose



Honor the sacrifice and privilege



Heal together



Gain perspective

An elderly couple is shown from behind, embracing each other on a grassy hillside. The man is on the left, wearing a grey jacket, and the woman is on the right, wearing a dark blue jacket. They are looking out over a vast, hazy valley with a winding road and a small white building in the distance. The scene is captured in a soft, natural light, suggesting a misty or overcast day. The overall mood is peaceful and intimate.

03

Caregiver Archetypes

Human Framework: Caregiver Archetypes

PROACTIVE PROBLEM-SOLVERS

EMOTIONAL EXPERIENCE:

DETERMINATION. Ready to face and tackle the challenges ahead with energy and perseverance, their experience is the most positive, driven by a feeling of usefulness and even pride.

APPROACH TO CARE:

OWNERSHIP. Their commitment is more "chosen" and they view caregiving as a problem to be solved. They want to take destiny into their own hands, so they are proactive, well-informed, and open to seeking external support.

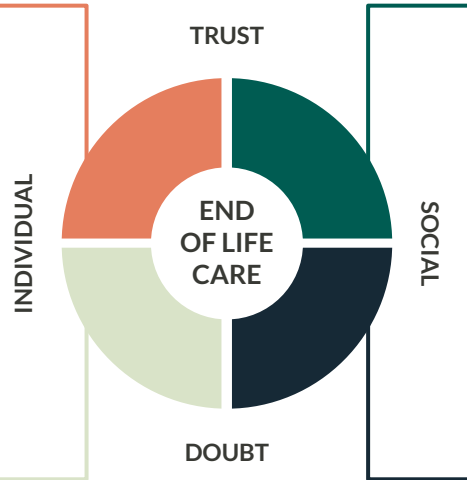
EFFECTIVE COORDINATORS

EMOTIONAL EXPERIENCE:

PRAGMATISM. They have a rational attitude towards the situation and want to feel in control. They are in close supervision of their loved one. They strongly believe in their ability to positively impact the condition of their loved one through top-notch treatments and services.

APPROACH TO CARE:

CONTROL. They have found a way to manage the situation despite the sometimes-severe loss of autonomy of their loved one, thanks to solid relational, emotional and financial resources, and the more frequent use of professional help.



BALANCED EMBRACERS

EMOTIONAL EXPERIENCE:

ACCEPTANCE. They take their situation with more perspective, accepting that the end of life is a natural part of it. Out of love, respect, and tradition, they try to live in the most harmonious possible way and put their loved one's needs first.

APPROACH TO CARE:

HONOR. They take their role as an honor to give back what their loved ones had given to them. Knowing their time is finite, they want to enjoy the time left to the fullest with no regrets. Being part of a tight community is a great source of emotional and organizational support.

DEVOTED GIVERS

EMOTIONAL EXPERIENCE:

DEVOTION. They commit themselves almost full-time to the care of their loved one. Often desperate and overwhelmed by the situation, they have a very difficult time coping with their situation, suffering from a feeling of powerlessness and a heavy mental burden that can be aggravated by the lack of financial resources.

APPROACH TO CARE:

SACRIFICE. Giving, they are willing to put themselves at the service of their loved one. They tend to delay seeking external support.

Proactive Problem-Solvers

Health Status Skew



MODERATE HEALTH ISSUES

Those with moderate or early-stage health issues **require less supervision** and experience a gradual decline.

Relationship Status Skew



SIBLINGS OR GRANDCHILDREN

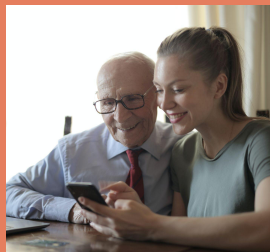
They are **emotionally resilient** and function successfully while providing long-term care for their loved ones.

EMOTIONAL EXPERIENCE:

DETERMINATION. Ready to face and tackle the challenges ahead with energy and perseverance, their experience is the most positive, driven by a feeling of usefulness and even pride.

APPROACH TO CARE:

OWNERSHIP. Their commitment is more "chosen" and they view caregiving as a problem to be solved. They want to take destiny into their own hands, so they are proactive, well-informed, and open to seeking external support.



Mini Story: Michelle

Michelle takes care of her grandfather, recently diagnosed with dementia. There is **no time to stop and think** as there are so many things to plan and do. She knows she also needs to **take care of herself** and her own family in order to stay mentally and physically healthy and to **keep going**. Every day is a new challenge but she is ready to take it one day at a time.

Effective Coordinators

Health Status Skew



GRADUAL HEALTH DECLINE

With a gradual decline, there is more **time to prepare** and anticipate the challenges ahead.

Relationship Status Skew



CHILDREN

Despite a high emotional toll, these **high-functioning individuals** are adept at managing multiple responsibilities.

EMOTIONAL EXPERIENCE:

PRAGMATISM. They have a rational attitude towards the situation and want to feel in control. They are in close supervision of their loved one. They strongly believe in their ability to positively impact the condition of their loved one through top-notch treatments and services.

APPROACH TO CARE:

CONTROL. They have found their way to manage the situation despite the sometimes-severe loss of autonomy of their loved one, thanks to solid relational, emotional and financial resources, and the more frequent use of professional help.



Mini Story: Ella

Ella, a mother of two and full-time director of partnerships, faces the challenge of caring for her mother with early dementia in Florida from New York. Despite disagreements and difficulties within the family, Ella takes on the responsibility as the **family organizer**, handling tough situations with a **level-headed approach**.

Balanced Embracers

Health Status Skew



ALL HEALTH ISSUES

This factor is of **limited relevance**, as respondents in this category cared for a diverse mix of loved ones.

Relationship Status Skew



CHILDREN AND GRANDCHILDREN

Kin caring for their elders, **embracing the circle of life**, and giving back to the community.

EMOTIONAL EXPERIENCE:

ACCEPTANCE. They take their situation with more perspective, accepting that the end of life is a natural part of it. Out of love, respect, and tradition, they try to live in the most harmonious possible way and put their loved one's needs first.

APPROACH TO CARE:

HONOR. They take their role as an honor to give back what their loved ones had given to them. Knowing their time is finite, they want to enjoy the time left to the fullest with no regrets. Being part of a tight community is a great source of emotional and organizational support.



Mini Story: Mandip

Mandip, born in India and raised in the US, finds **great reward and honor in caring for her loved ones**, including her parents, in-laws, cousins, and community. Being part of a close-knit **Indian community** brings immense support, with others readily stepping in to help if she is unable to make an appointment or pick up a prescription.

Devoted Givers

Health Status Skew



RAPIDLY DECLINING HEALTH CONDITIONS

Associated with the imminent reality of death, they grapple with **fear, grief, and regrets** related to mortality.

Relationship Status Skew



SPOUSES AND CHILDREN

Typically observed among spouses and children, they are characterized by a profound **emotional bond** and close connection.

EMOTIONAL EXPERIENCE:

DEVOTION. They commit themselves almost full-time to the care of their loved one. Often desperate and overwhelmed by the situation, they have a very difficult time coping with their situation, suffering from a feeling of powerlessness and a heavy mental burden that can be aggravated by the lack of financial resources.

APPROACH TO CARE:

SACRIFICE. Giving, they are willing to put themselves at the service of their loved one. They tend to delay seeking external support.



Mini Story: Diamond

As a young woman balancing school, work, and motherhood, Diamond faces the challenging role of caring for her mother in the final stages of cancer. Despite **emotional ups and downs**, frustration over not being able to fulfill her mother's wish to stay out of the hospital, and **concerns about the quality of care**, Diamond finds strength in her son's unwavering joy.

Human Framework: Caregiver Archetypes

PROACTIVE PROBLEM-SOLVERS

EMOTIONAL EXPERIENCE:

DETERMINATION. Ready to face and tackle the challenges ahead with energy and perseverance, their experience is the most positive, driven by a feeling of usefulness and even pride.

APPROACH TO CARE:

OWNERSHIP. Their commitment is more "chosen" and they view caregiving as a problem to be solved. They want to take destiny into their own hands so they are proactive, well-informed, and open to seeking external support.

EFFECTIVE COORDINATORS

EMOTIONAL EXPERIENCE:

PRAGMATISM. They have a rational attitude towards the situation and want to feel in control. They are in close supervision of their loved one. They strongly believe in their ability to positively impact the condition of their loved one through top-notch treatments and services.

APPROACH TO CARE:

CONTROL. They have found a way to manage the situation despite the sometimes-severe loss of autonomy of their loved one, thanks to solid relational, emotional and financial resources, and the more frequent use of professional help.

BALANCED EMBRACERS

EMOTIONAL EXPERIENCE:

ACCEPTANCE. They take their situation with more perspective, accepting that the end of life is a natural part of it. Out of love, respect, and tradition, they try to live in the most harmonious possible way and put their loved one's needs first.

APPROACH TO CARE:

HONOR. They take their role as an honor to give back what their loved ones had given to them. Knowing their time is finite, they want to enjoy the time left to the fullest with no regrets. Being part of a tight community is a great source of emotional and organizational support.

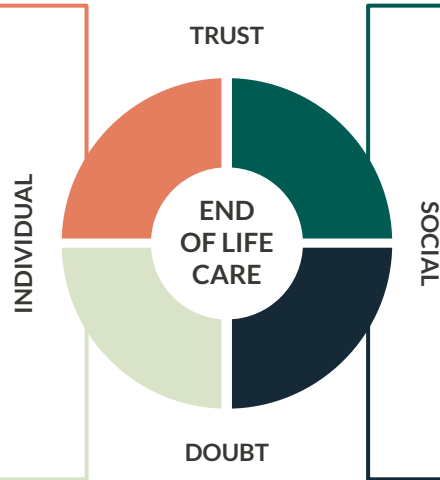
DEVOTED GIVERS

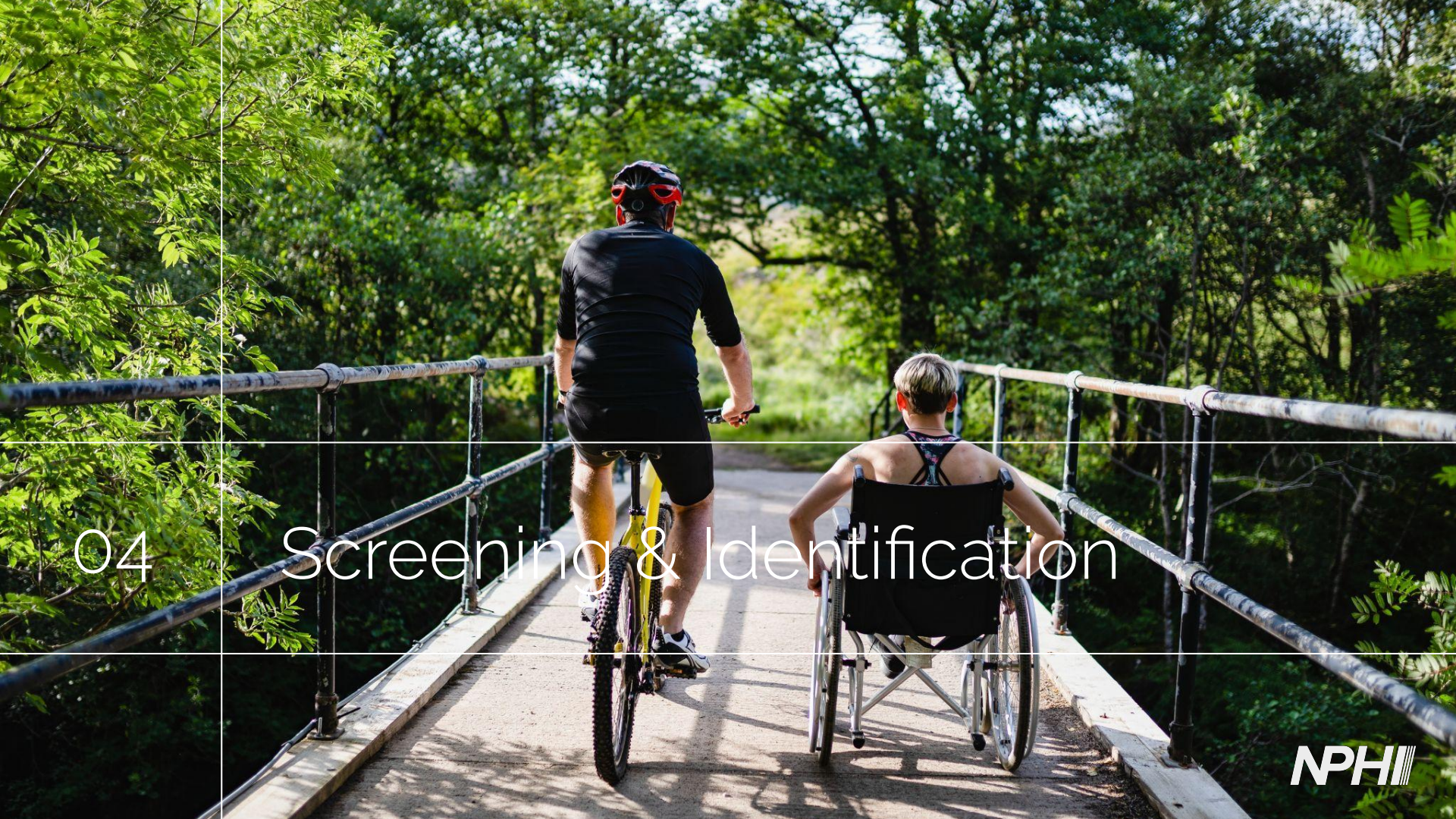
EMOTIONAL EXPERIENCE:

DEVOTION. They commit themselves almost full-time to the care of their loved one. Often desperate and overwhelmed by the situation, they have a very difficult time coping with their situation, suffering from a feeling of powerlessness and a heavy mental burden that can be aggravated by the lack of financial resources.

APPROACH TO CARE:

SACRIFICE. Giving, they are willing to put themselves at the service of their loved one. They tend to delay seeking external support.





04

Screening & Identification

Caregiver Archetype Screening Tool: Overview

Based on this study and a review of existing literature about caregiver experiences, we have developed a short screening tool to help care teams identify caregiver archetypes.

This screening tool could be given to a caregiver as part of the intake process for new patients.

- *Right away, this signals to the caregiver that **you are interested in their needs and experiences**, and will be available to support them alongside their loved one.*
 - *The act of thinking through these questions can also **help clarify the caregiver's own feelings about the experience**, which they may not have had time or space to think about.*
-

Include the completed form and the caregiver's archetype in the case file, so that the full care team is aware of the caregiver's attitude and approach.

- *Examples of ways to tailor service offerings and communication style to specific archetypes are included in the next section.*

Caregiver Archetype Screening Tool: Questionnaire

Caregiver Experience Questionnaire: For Caregivers

NPIH

Caregiver Experience Questionnaire

Introduction

Thank you for volunteering with the care of your loved one. This questionnaire is designed to help us better understand your unique situation as a caregiver, so that we can provide the most effective support tailored to your needs. Please be assured that your responses will remain confidential and will not be shared with your loved one. By learning more about you, we can better recommend care for caregivers and services that may be beneficial to your ongoing journey. Thank you for taking the time to help us enhance the care and support we offer.

Questions

1. Emotional Experience

When you think about caring for your loved one, which of the following statements resonates with you most?

- Frustration - I understand the situation for what it is, but I'm willing to take charge of my loved one's care.
- Determination - I know that with perseverance, caring for my loved one is something I can do long.
- Devotion - Even though it often feels overwhelming, I'm committed to doing everything I can for him.
- Acceptance - I understand that the end of life is a natural part of it. This perspective helps me cope.

2. Approach to Care

Which of the following most accurately describes your personal approach to care?

- Sacrifice - I'm volunteering, I'm willing to go above and beyond the services of my loved one's master plan.
- Ownership - Caring for my loved one is my decision. I take initiative into my own hands and work to accomplish my own goals.
- Honor - It's an honor to do care of my loved one. I want to bring the time we have left together with no regrets.
- Control - Despite my loved one's loss of independence, I've found a way to manage the situation and have help and resources that can assist.

3. Strength

Which of the following words would you say is your biggest strength in caregiving?

- I'm focused.
- I'm proactive.
- I'm patient.
- I'm organized.

NPIH

11. Open-ended 1

By your own opinion, what could we do to support you the most?

14. Open-ended 2

Which specific aspects of caring for your loved one do you need the most help with?

15. Open-ended 3

Is there anything else you want us to know about you as a caregiver?

What happens next?

Once you have completed this questionnaire, all information will be sent to your care manager. They will carefully review your responses and get in touch with you to discuss and recommend tailored services and programs that can support you in your caregiving role. We aim to ensure that you receive the most appropriate and helpful resources to meet your needs and enhance your ability to care for your loved one. Thank you for your collaboration and openness.

Caregiver Experience Questionnaire: For Case Managers

NPIH

Caregiver Experience Questionnaire for Case Managers

Background

This caregiver questionnaire was developed based on insights from the NPIH best practices Caregiver Experiences and Priorities (CAREx) study. The questionnaire is designed to help you identify the caregiver archetype of the individual you are working with. The goal is to tailor your service offerings and communication style to each caregiver's unique perspective.

Scoring Instructions

- To utilize this questionnaire, complete the caregiver experience statements identified by the "Scoring Rubric" below. Every answer is associated with a particular archetype - indicated by an acronym and the letters PPE, BE, and DC.
- As you go through the results, mark a tally in the "Scoring Results" column that corresponds with the caregiver archetype.
- Add up the tally for each type of response the caregiver gave - e.g. PPE, BE, DC, BE, DC, DC, DC. The tally that indicates the archetype most closely aligns with the caregiver, with the most total responses checked, providing added context.
- While not a definitive scientific assessment, respondents will likely identify answers on a scale of the responses more than the others. In cases where answers are truly split evenly, you may need further dialogue to clarify what would be most useful for them.

Scoring Rubric:

Emotional Experience

When you think about caring for your loved one, which of the following statements resonates with you most?

- Frustration - I understand the situation for what it is, but I'm willing to take charge of my loved one's care. (PPE)
- Determination - I know that with perseverance, caring for my loved one is something I'm capable of doing. (PPE)
- Devotion - Even though it often feels overwhelming, I'm committed to doing everything I can for him. (DC)
- Acceptance - I understand that the end of life is a natural part of it. This perspective helps me cope. (BE)

NPIH

Scoring Results

Answers	Effective Coordinators (EC)	Balanced Enthusiasts (BE)	Devoted Owners (DO)
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Interpreting the Questionnaire: Four Caregiver Archetypes

Effective Problem Solvers (PPE)

These caregivers are determined and proactive. Their commitment is "strong" and they view caregiving as a problem that can be solved. They have the most control about their role as a caregiver, and their role grows as well as needed. Often motivated by a desire to maintain a high functioning status, they can still be open to accepting outside help. While their practical skills make them more adept at handling the logistics of systems than others, this group has the most proactive challenges over emotional or spiritual ones.

Appropriate Services

Emotional resources specific to the caregiver's condition (e.g. NPIH's Dementia Care Kit, Caregiver Support).

Communication Style

Direct and authoritative. They are well informed and direct. Taking charge or demonstrating expertise, including health advice.

High Functioning (BE)

Often described as "low burden" or "high functioning," these caregivers strongly believe in their ability to help their loved one "right" through their own efforts and skills. They will be able to access financial resources, often through frequent use of professional help. Often in close contact with their loved one, they have a more direct role in care. Because of their high function in handling the best possible care, this group tends to be less collaborative with other family members and less likely to describe the experience as a stressor or burden for their role.

Appropriate Services

Emotional and program information that can help them understand their role and how to best support their loved one. Supplement and augment care provided for your team.

Communication Style

Direct and efficient. This group needs to know their role and what the parts of care are. Supplement and augment care provided for your team. They may need to be educated to take care of themselves, too.

Caregiver Experience Questionnaire: Questions

Emotional Experience

When you think about caring for your loved one, which of the following statements resonates with you most?

- Pragmatism - I understand the situation for what it is, so I'm willing to take charge of my loved one's care. (EC)
- Determination - I know that, with perseverance, caring for my loved one is something I'm capable of doing. (PPS)
- Devotion - Even though it often feels overwhelming, I'm committed to doing everything I can to help. (DG)
- Acceptance - I understand that the end of life is a natural part of it. This perspective helps keep me going. (BE)

Caregiver Experience Questionnaire: Questions

Approach to Care

Which of the following most accurately describes your personal approach to care?

- Sacrifice - I value giving. I'm willing to put myself at the service of my loved one no matter what. (DG)
- Ownership - Caring for my loved one is my decision. I take destiny into my own hands and view it as something we can solve. (PPS)
- Honor - It's an honor to take care of my loved one. I want to enjoy the time we have left together with no regrets. (BE)
- Control - Despite my loved one's loss of independence, I've found a way to manage the situation and have help and resources that I can rely on. (EC)

Caregiver Experience Questionnaire: Questions

Strength

Which of the following words would you say is your biggest strength in caregiving?

- I'm devoted. (DG)
- I'm proactive. (PPS)
- I'm present. (BE)
- I'm organized. (EC)

Caregiver Experience Questionnaire: Questions

Needs

Which of the following describes where you need the most support?

- Help honoring my loved one and enjoying the time we have left together. (BE)
- Help supporting my loved one without losing hope. (PPS)
- Help determining the right course of action. (EC)
- All around help. (DG)

Caregiver Experience Questionnaire: Questions

Burden

What's the hardest part about being a caregiver?

- Feeling like I'm in over my head no matter how hard I try. (DG)
- All the responsibilities I have to manage. (EC)
- All the interferences that take me away from spending time with my loved one. (BE)
- Staying strong for my loved one when times get tough. (PPS)

Caregiver Experience Questionnaire: Questions

Anticipatory Grief

When you think about your loved one dying, what comes to mind?

- I can't think about that right now. (DG)
- I just want to know that I did everything I could for them. (EC)
- I know it's inevitable, but for now I just take it one day at a time. (PPS)
- I know death is a part of life, but it'll be hard not having them here. (BE)

Caregiver Experience Questionnaire: Questions

Support Systems

Which of the following statements best describes your access to support systems?

- I'm proactive about seeking support. I try my best to stay well informed and I'm open to asking for help. (PPS)
- I tend to delay seeking support until it's absolutely necessary. My financial resources are limited, which constrains my options and acts as a source of stress. (DG)
- I have reliable access to resources and support, which allows me to rely on professional help more frequently. (EC)
- I have a tight-knit and supportive community around me, which is a big source of emotional and organizational support. (BE)

Caregiver Experience Questionnaire: Questions

Hypothetical

Say you get new test results back regarding your loved one's health. What's the first thing would you do?

- Contact family members to update them and get advice. (BE)
- Find the most qualified professional to help. (EC)
- Do some research to learn more. (PPS)
- I'm not sure. (DG)

Caregiver Experience Questionnaire: Questions

Asking For Help

How comfortable are you asking for help?

- I often do things myself, but I'm comfortable seeking support. (PPS)
- It's usually hard for me to ask for help. (DG)
- I usually turn to family and community members for support. (BE)
- I frequently seek professional help. (EC)

Caregiver Experience Questionnaire: Questions

Motivations

The biggest thing motivating me to care for my loved one is:

- I want to make sure my loved one gets the best treatments and services available. (EC)
- I want to be useful to my loved one. I choose to help and I'm proud to do so. (PPS)
- I do it because, if I don't, who will? Even though it's hard, I do it no matter the sacrifice. (DG)
- Love, respect, and tradition. I want to give back what my loved ones had given to me. (BE)

Caregiver Experience Questionnaire: Questions

Drive

We know that caregiving can be hard work. What keeps you going when it gets tough?

- My emotional bond and connection with my loved one is what keeps me going, no matter how hard it is for me. (DG)
- Perspective keeps me going. I embrace the circle of life and know I'm doing the right thing by giving back. (BE)
- Despite all the emotions and responsibilities I juggle, I have to keep a level head in order to make sure everything goes according to plan. (EC)
- I remind myself that, with hard work, I can do it. I try to take care of my own health in order to remain strong for my loved one. (PPS)

Caregiver Experience Questionnaire: Questions

Reward

Which of the following would you say is the most rewarding part of caring for your loved one?

- Knowing I gave it my all. (DG)
- Quality time with my loved one. (BE)
- Making sure my loved one has the best experience. (EC)
- Knowing I did the right thing. (PPS)

Caregiver Experience Questionnaire: Questions

Open Ended Questions

- **In your own opinion, what could we do to support you the most?**

- **Which specific aspects of caring for your loved one do you need the most help with?**

- **Is there anything else you want us to know about you as a caregiver?**

Caregiver Experience Questionnaire: Scoring

Scoring Rubric: For Case Managers

- To score the questionnaire, compare the caregiver's responses to the acronyms identified in the rubric below. Every answer is associated with a particular archetype – indicated by an acronym on the rubric. As you go through the results, mark a tally in the score chart quadrant that corresponds with the acronym associated with each answer given.

- Add up how many of each type of response the caregiver gave – e.g. PPS (7), EC (2), BE (2), DG (1). The top choice indicates the archetype most closely aligned with the caregiver, with the second most common choice providing added context.

- While not a definitive scientific assessment, respondents will likely skew towards one or two of the responses more than the others. In cases where answers are truly split evenly, you may need to probe further to clarify what would be most useful for them.



05

Archetype-Informed Intervention

Proactive Problem-Solvers



Appropriate Services:

Educational resources specific to the loved one's condition (e.g. NPHI Dementia or Cardiac Care guides).



Communication Style:

Respectful and complimentary of their approach to caregiving. Acknowledge that they are well-informed and avoid "talking down" or oversimplifying when discussing medical issues.

Effective Coordinators



Appropriate Services:

Information about volunteer-led programs offered by your hospice and/or local third party services to supplement and augment care provided by your team.



Communication Style:

Detailed and thorough. This group wants to know everything they can and is more likely to do their own research, but may need to be reminded to take care of themselves, too.

Balanced Embracers



Appropriate Services:

Connection to a Death Doula or Chaplain who can assist with legacy projects and help make the most of time together.



Communication Style:

Empathetic and optimistic. While they may be emotionally and spiritually resilient, they may need more help with practical considerations like medications, bathing, and administrative tasks.

Devoted Givers



Appropriate Services:

Respite care, connection to caregiver and grief support groups, and connection to potential social supports such as food programs or childcare.



Communication Style:

Patient and compassionate. Recognize that this group may feel “in over their heads” but less willing to accept outside help. Remind them that it's ok to take time for themselves, and that they'll be a better caregiver for their loved one if they're well cared for themselves.

Supplemental Caregiver Research

Article Link:

- Family Caregiver Communication Tool

Article Link:

- Screen for Caregiver Burden (SCB)

Article Link:

- Types of Caregiving Experience and Their Association With Caregiver Depressive Symptoms and Quality of Life

Thank you!



Contact: nphi@emergence-creative.com



NPHI *National Partnership
for Healthcare and
Hospice Innovation*