The Dementia Caregiver*

(*unpaid family or friend)

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CarePartner x 8 yr, Survivor x 5 mo

ECHO-Dementia October 13, 2023

Learning Objectives

1. Expand curiosity about dementia caregivers' experiences, and increase the ability to interview and engage with them.
2. Review quantitative data and qualitative findings from recent dementia caregiver research.
3. Identify validated assessment tools to measure and track caregiver burden and also gratification.
4. Distinguish various Primary Care practice model innovations intended to create more integrative and satisfying dementia care.
5. List resource options to discuss with dementia caregivers.
6. State one practice change you can implement next week.

Note: Caregivers = Care Partners for this presentation

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Clinic Visits:

What's Behind the Curtain?

USA Today

Which one of these caregivers is coping?

koimoi

Clinic Visits

- Caregivers have an Internal Conflict re: how we present
  - Wanting to look like we're on top of it & serving our loved one well vs. Wanting our distress to be acknowledged & addressed
- Caregiver's knowledge, burden & creativity are unseen when HCPs continue pre-dementia patient autonomy norms (Chanesian 2023; Hao 2020; Weisbrod 2022)
  - The person with MCI or dementia is often not a reliable historian – may answer questions confidently but incorrectly
  - Even in later stages, the patient may do 'Showtime' during clinic visits – super frustrating!
  - The patient's interests are existentially 'intertwined' with those of the caregiver's

freevector.com

- Medications are *frequently* misunderstood
  - The 'losing-ground' and polypharmacy aspects are intimidating, depressing, and muddled, even for caregivers who are HCPs (Weisbrod 2022)
  - Caregivers turn to peers for answers who can speak to them from the trenches, but n=1 and advice is anecdotal (and often international)
  - Risk-benefit ratios change (especially with psych meds & pain management) → CGs need ongoing evolving medication appraisal and education (Gench 2021; Sawan 2021)

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Clinic Visits

- Things we don’t or won’t tell you for fear of discomfort, disapproval, misunderstanding
    - Accessing & managing ‘outside help’ is often more burdensome than going it alone – CGs get “trained” to stop asking for help when we’ve had bad experiences, and refusal might appear obstinate or ungrateful
    - Use of other providers and trying herbs, cannabis, foods, supplements, LED light therapy, crystals, treatments for chronic Lyme disease, exorcism, etc, …
    - The Dark Secrets – ‘inappropriate’ sexual behaviors, or abuse we suffer or perpetrate [esp spouses (Steinsheim 2023)]
    - Fears of isolation, financial ruin, & disability/mortality (Scheeres-Feitsma 2023)
        - thoughts of homicide-suicide as a loving desperate act

- CGs may not recognize that we need resources, don’t know what’s available/ appropriate, or sometimes aren’t ‘ready’
    - When we say “No” to your offers: *“Do you need additional resources?” “Is there anything more I can offer you today?”*, it may be a lack-of-insight declination [frog in the pot]
    - Palliative care consultation and hospice on-boarding are often eye-opening re: what resources have been ‘out there’ all along, but now access comes too late [esp. respite care]

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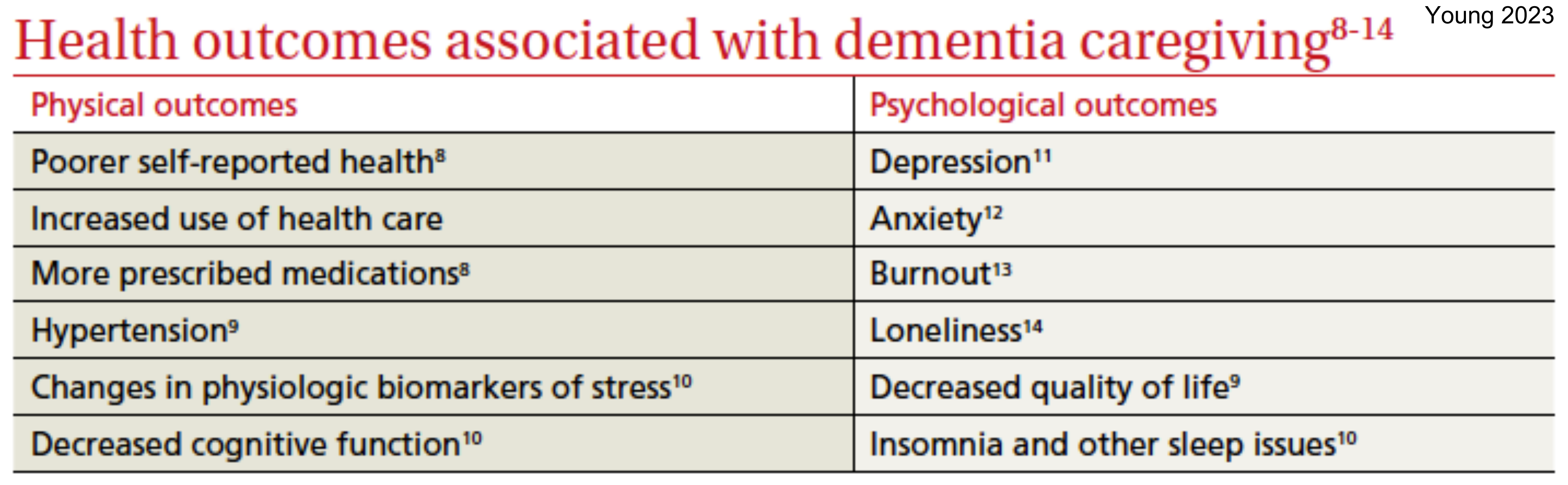
What Does the Research Say about Caregivers?



Young 2023

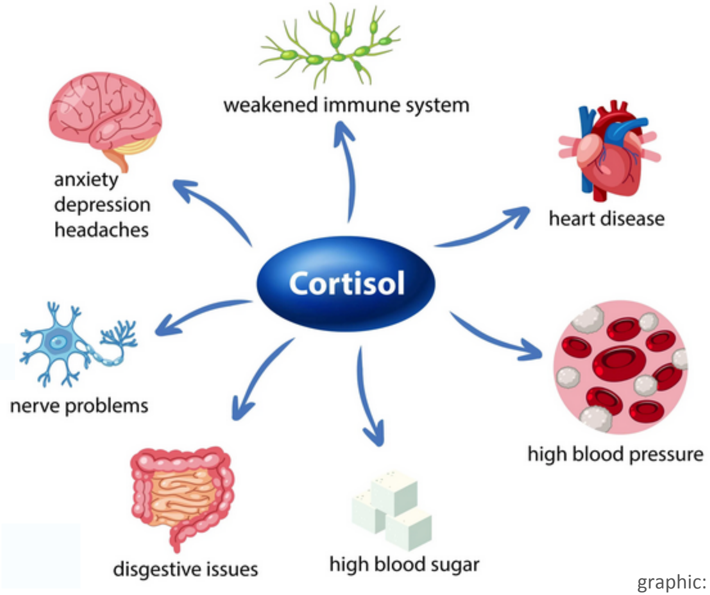
Health outcomes associated with dementia caregiving[8-14]

Physical outcomes	Psychological outcomes
Poorer self-reported health[8]	Depression[11]
Increased use of health care	Anxiety[12]
More prescribed medications[8]	Burnout[13]
Hypertension[9]	Loneliness[14]
Changes in physiologic biomarkers of stress[10]	Decreased quality of life[9]
Decreased cognitive function[10]	Insomnia and other sleep issues[10]

Facts & Data about Family Caregivers

- >25% of dementia caregivers are 'sandwich generation' (alz.org 2020)
  - And the majority are women – caring for elders AND youngsters, and also sometimes a disabled spouse

- The disease stage does not necessarily correlate with caregiver's stress level
  - Initial diagnosis & early months of accepting (or denying) the diagnosis might be most disorienting and distressing
  - Denial & secrecy are setups for bigger problems and crises down the road (e.g., driving!)
  - Rapid declines upend everything at any stage of disease



graphic: ATPscience

- Different types of dementias create different types of burdens
  - LBD (Bentley 2021; Yuuki 2023), FTD (Tookey 2021), PPA (Seckin 2023), early onset (Gomez 2023; Kilty 2023)
  - Anosognosia is demoralizing for CGs – caregiving is seen as unnecessary and intrusive by the person with dementia who doesn't recognize or admit their deficits (Vignolo 2021)

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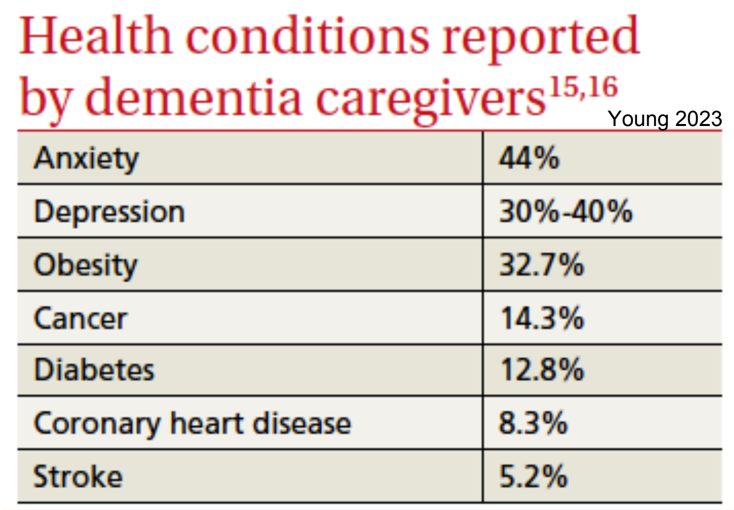
Facts & Data about Family Caregivers

- Financial anxiety & peril is common
  - Lost current income (Goto 2023; Mattingly 2022)
    - caregiving requires an average 30 hrs/wk (up to 80+) (alz.org 2020; vanHezik-Wester 2023)
  - Impoverished future – especially affects the surviving spouse
    - depleted savings, reduced Social Security wages, reduced and delayed retirement contributions (>$300,000 lost)
    - selling off assets (e.g., house to pay for LTC)
  - What does it really cost to care for a person with dementia?
    - Unpaid informal caregivers represent 40-75% of the total costs of caring for a person with dementia (Angeles 2021, Mattingly 2022)

- Caregiver may become disabled, or die, before the patient
  - Quoted range for predating death is 18%-70%, but it's difficult to tell where these numbers come from
  - Primary CG role averages 4 years (a few months to more than a decade)
  - Black & Latinx caregivers endure more intensive CG years and use fewer outside resources (Young 2023)

Voices of Caregivers / Care Partners



Health conditions reported by dementia caregivers[15,16]

Young 2023

Anxiety	44%
Depression	30%-40%
Obesity	32.7%
Cancer	14.3%
Diabetes	12.8%
Coronary heart disease	8.3%
Stroke	5.2%

Sleep disturbances (Brewster 2022; Gibson 2013; VanHourt 2023)

Voices of Family Caregivers

- "Mantle of responsibility" cannot be paused
  - Burden of 24/7 loss, grief, guilt, resentment, isolation, loneliness, lack of agency → exhaustion, depression, anxiety (Duplaintier 2023)
- CG's mental, emotional, social, physical, & financial well-being are progressively de-prioritized
  - More common for in-home family caregivers & spouses (esp. female) (Duplaintier 2023; Gomez 2023; Mank 2023; Steenfeldt 2021; vandenKieboom 2020)
  - Watch for CGs who are always in 'crisis mode'
  - Watch for CG shift to 'survival mode'

- Bringing in helpers can unpredictably increase caregiver burdens

  They are fantastic and life-saving when a good fit and affordable, but …
  - They can be expensive, unreliable, poor fit, not dementia trained, apathy, constant direction & training, on their phones/headphones, theft (&/or paranoia of theft), minimal skills (e.g., can't give meds or drive the person); they're stressed out too!
  - Agencies vs registries vs independent freelance aides have different scheduling and financial/tax chores and challenges. Geriatric care managers charge $125-$250/hr.

Voices of Family Caregivers

- *"Care for me, too"*- 4 major CG support needs identified (Burgdorf 2023)
    - navigating insurance/coverage
    - skills training
    - respite referrals
    - disease progression anticipatory guidance

- 8 CG Self-Efficacy (Confidence) Attributes (Khan 2021)

    (1) ability to manage behaviors
    (2) control upsetting thought
    (3) acquire medical information
    (4) manage medical issues
    (5) obtain self-care
    (6) access community supports
    (7) assist ADLs & other care
    (8) maintain good relationship w/ person w/ dementia

- Diversity literature – *Caregiving in the US 2020* fact sheets (www.caregiving.org)

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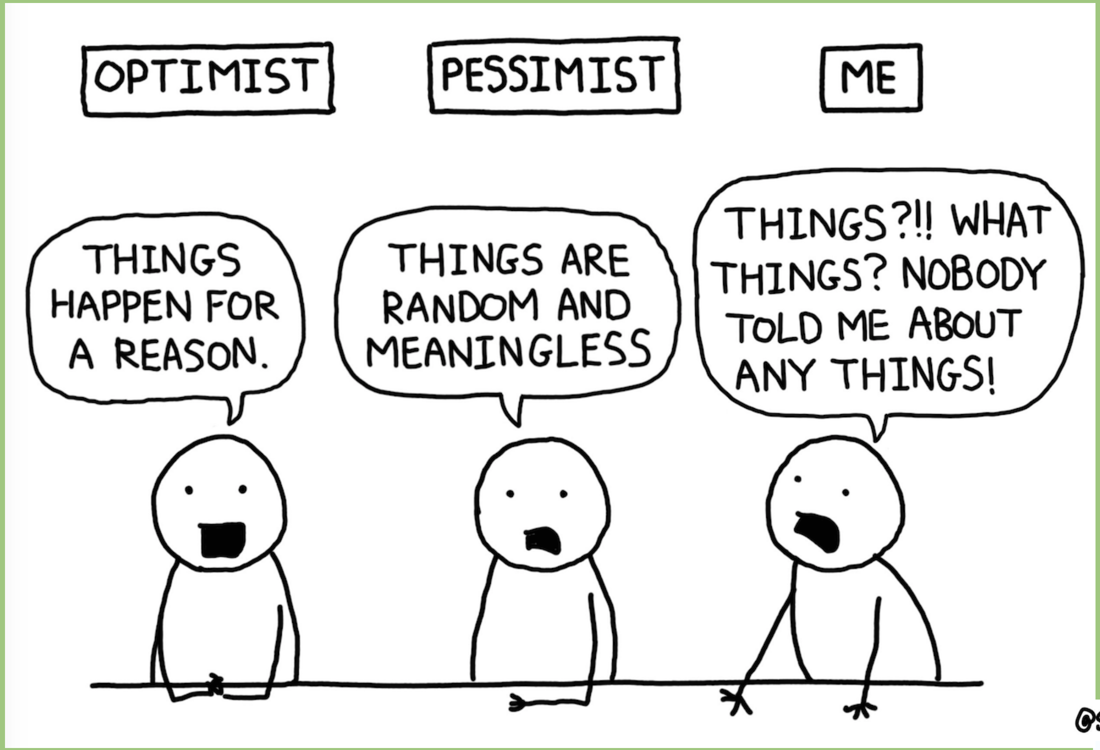
Caregiver Assessment Tools



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Caregiver Assessment Tools

- *"This field of research remains in its infancy"* (Gerain 2023)

- **Validated* Assessment Tools** to measure caregiver burden

  (Tu 2022; Zhi-Xiang 2023)

  - Zarit Burden Interview https://wai.wisc.edu/wp-content/uploads/sites/1129/2021/11/Zarit-Caregiver-Burden-Assessment-Instruments.pdf
  - Screen for Caregiver Burden https://psycnet.apa.org/record/1991-23257-001
  - Caregiver Burden Interview https://dementiasherpa.com/wp-content/uploads/2018/12/FTLDA-CARGIVER-BURDEN-SCALE.pdf
  - Burden Scale for Family Caregivers https://www.virtualhospice.ca/Assets/BSFC_english_o%20(Caregiver%20Burden%20Scale-Original)_20170306132227.pdf

- **'Positive Aspects of Caregiving' tools** (Nemicikova 2023; Smalling 2021)

  measure happiness, learning, gratification, closer relationships…

  https://onlinelibrary.wiley.com/doi/epdf/10.1111/ggi.14210

  - Positive Experiences Scale (PES)
  - Gain in Alzheimer's Care Instrument (GAIN)
  - Positive Aspects in Caregiving Measure (PAC) (see also Cheng 2023; Cousins, 2023; Quinn 2019)

**Validated for diverse cultural, language, ethnic/racial groups?*

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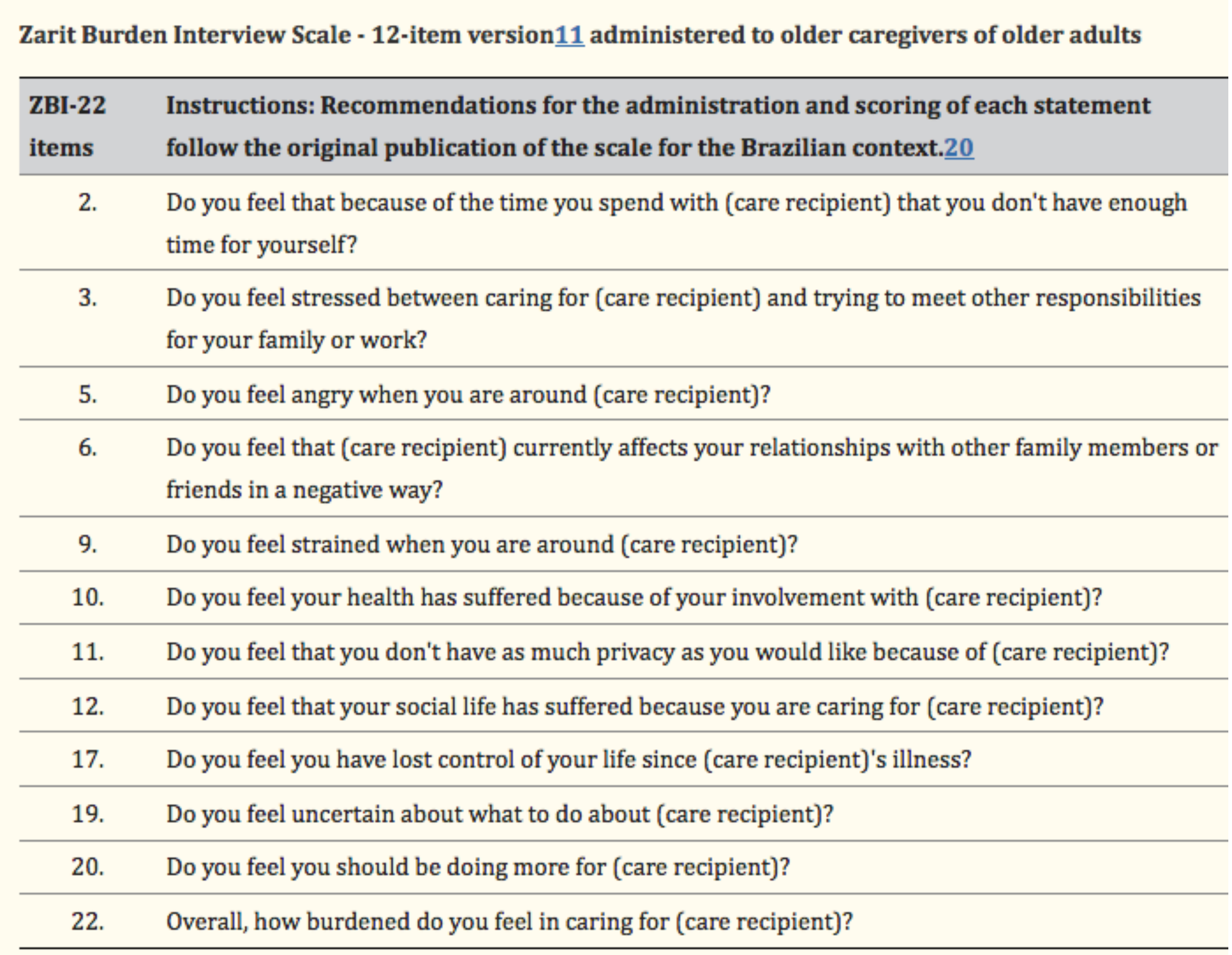
Example of a Caregiver Burden Scale



Zarit Burden Interview Scale - 12-item version11 administered to older caregivers of older adults

ZBI-22 items	Instructions: Recommendations for the administration and scoring of each statement follow the original publication of the scale for the Brazilian context.20
2.	Do you feel that because of the time you spend with (care recipient) that you don't have enough time for yourself?
3.	Do you feel stressed between caring for (care recipient) and trying to meet other responsibilities for your family or work?
5.	Do you feel angry when you are around (care recipient)?
6.	Do you feel that (care recipient) currently affects your relationships with other family members or friends in a negative way?
9.	Do you feel strained when you are around (care recipient)?
10.	Do you feel your health has suffered because of your involvement with (care recipient)?
11.	Do you feel that you don't have as much privacy as you would like because of (care recipient)?
12.	Do you feel that your social life has suffered because you are caring for (care recipient)?
17.	Do you feel you have lost control of your life since (care recipient)'s illness?
19.	Do you feel uncertain about what to do about (care recipient)?
20.	Do you feel you should be doing more for (care recipient)?
22.	Overall, how burdened do you feel in caring for (care recipient)?

https://wai.wisc.edu/wp-content/uploads/sites/1129/2021/11/Zarit-Caregiver-Burden-Assessment-Instruments.pdf

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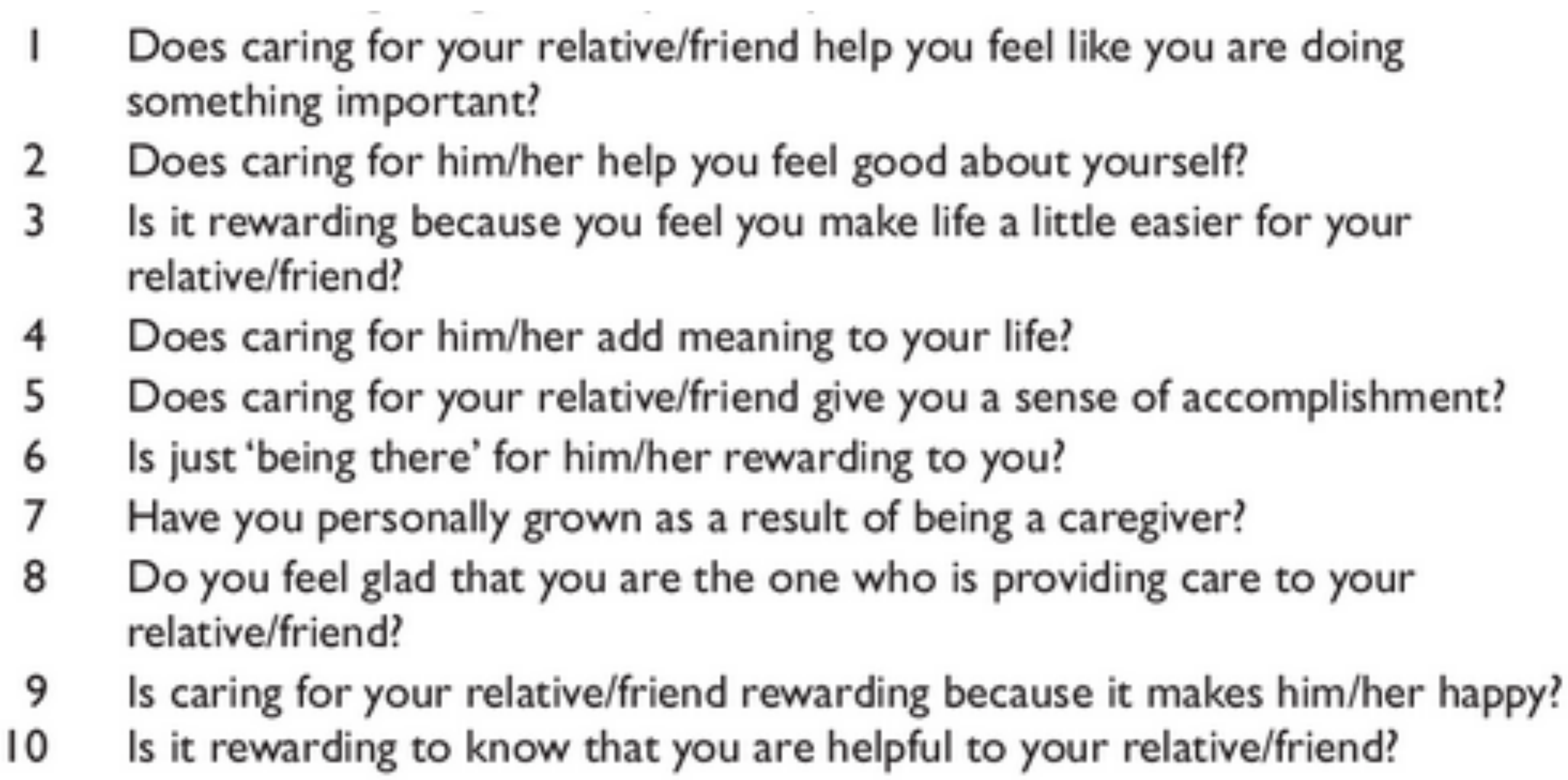
Example of a Caregiver Rewards Scale



1 Does caring for your relative/friend help you feel like you are doing something important?
2 Does caring for him/her help you feel good about yourself?
3 Is it rewarding because you feel you make life a little easier for your relative/friend?
4 Does caring for him/her add meaning to your life?
5 Does caring for your relative/friend give you a sense of accomplishment?
6 Is just 'being there' for him/her rewarding to you?
7 Have you personally grown as a result of being a caregiver?
8 Do you feel glad that you are the one who is providing care to your relative/friend?
9 Is caring for your relative/friend rewarding because it makes him/her happy?
10 Is it rewarding to know that you are helpful to your relative/friend?

https://www.semanticsscholar.org/paper/Adaptation-and-psychometric-evaluation-of-the-for-a-Henriksson-Andershed/8f48c4fa0a1a2ed887818f7a90efd33797d925ed

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Primary Care Practice Models


UTphysicians.com

Primary Care Practice Models

- Family Practice is a key provider “focusing on the family” (Young 2023)
    - Continual assessment for changing burdens, gratifications & needs – how CG is adapting to caregiver role, dealing with denial, managing stress, finding or creating joy & satisfaction
    - Continual scanning & sharing local + online resources (including peer support within your clinic/health system if that’s been organized)

- Care Models systematic reviews
    - Inconclusive evidence (Frost 2020):
        - PCP led +/- specialists
        - PCP case management partnerships
        - Integrated models
    - Some effectiveness
        - Collaborative care (Heintz 2020)
        - Family Centered care (Hao 2020)
        - Integrative care (Cheng 2022; Warren 2023) models
    - Showed ‘promise’
        - Patient navigators model (Kallmyer 2023)

Primary Care Practice Models

- Palliative care model (Weisbrod, 2022)

  Valued aspects:
  - “high quality communication while sharing a diagnosis,
  - counseling the patient and CG through progression of illness & prognostication, and
  - referral to hospice when appropriate”

- Care models & efforts for specific demographics*
  - Multilingual & Migrants – Demanes 2021; Garcia 2023; Stenberg 2023
  - Latinx / Hispanic – Dessy 2022; Fink 2023; Mage 2023; Ramirez-Gomez 2023
  - Black / African American – Duren 2023; Moon 2022
  - East Asian – Wang 2023
  - Women – Derreberry 2019
  - Rural vs Metro, different races/ethnicities – Kindratt 2023
  - Veterans – Koufacos 2023

**Not an exhaustive search*

Resources to Consider

galenaparkisd.com

NIH: National Institute on Aging

Resources – best if specific for dementia stages

- Disease specific national associations, websites, books
  - And Caregiver Action Network; Family Caregiver Alliance; Family Caregiving 101; National Alliance for Caregiving; Well Spouse Association

- OT / PT / Speech T / Neuropsychologists (DelBene 2023) etc.
  - any accessible reimbursed referrals

- Palliative Care → Hospice (Chan 2023; Hamilton 2023; Weisbrod 2022)
  - Most regret referral came 'too late', average time on hospice = 2 wks
  - For hospice referral look for rapid decline, weight loss, swallowing difficulties

- Research study participation (disease specific registries)

- Legal & Financial Services

  Must do during MCI or early dementia when they can still sign paperwork
  - DPOAs, Advanced Directives for dementia, Estate Planning, successor caregiver (elder law attorneys)
  - Proper naming of and access to accounts & beneficiaries, property titles, etc.
    - prevent accounts, credit, online access, and utilities from getting frozen/deleted after death
  - Protect assets from abuse

Resources (cont.)

- **Local Community aging/dementia places & activities** (Maffioletti 2019)
  - may need repeated encouragement to try these; arrange a warm hand-off by a peer
  - problematic for young-onset and for introverts

- **Peer Support** – disease & stage specific most helpful
  - formal, informal, in person, online, 1:1, group → CGs find chosen peers within support groups
  - identify CG peer leaders in your practice, encourage them to stay involved post caregiving

- **Assistive Technologies** – "smart" stuff, home sensors, wearables; these are not for everyone

- **Programs & Training for Dementia Caregivers**
  - >30 meta-analyses & systematic reviews from 2020-23
    - primary outcomes: knowledge, QoL, self-efficacy, depression, anxiety, burden, …
    - only a few focused on racial/ethnic, SES, or gender marginalized populations
  - The research on CG programs and training endorses:
    - psychoeducation; behavioral/empathy training; CBT/ACT (acceptance, commitment); exercise; mindfulness
    - BUT, effects are small to moderate & contradictory: multi-component interventions better; group/peer-based often better, no conclusions on online/mobile/remote support & in-home tech

Recommendations

to implement today

and reinforcement for
what you're already doing!

NIH: National Institute on Aging

Recommendations

- At each visit, say at least 1 of these
  - *“What’s the hardest thing right now?”* inquiry (see Burden Scale questions) and
  - *“Has there been anything positive about caregiving?”* (see Rewards questions), and
  - A praise phrase (*“They’re lucky to have you.” “I’m so impressed.” “You’re doing a good job.”*)

- Ask *HOW* the caregiver is doing the medication procedures, not just *IF* the patient is taking their medications
  - Ask about what is most difficult
  - Be genuinely interested in the non-medical therapies they might be trying

- Provide written take-home material (handouts, sticky notes) (Burgdorf 2023)
  - And/or have a staff person help make calls if possible

- Encourage participation in research studies
  - The earlier the better, many studies are online

Recommendations

- Don’t misinterpret “Showtime” as the usual capabilities of the person with dementia
  - Be curious with the CG about behaviors, abilities, and decline noticed at home
  - Believe the CG when they tell you how “bad” the patient is doing (Burgdorf 2023)

- CGs want to be an ‘additional patient’, not an ‘invisible patient’
  - All visits should include the primary caregiver
  - If the caregiver can also be your patient, book back to back visits so you can spend more time with the duo, and so you have dedicated (reimbursed) time to spend focused on the CG

(Burgdorf 2023; Duplantier 2023)

- Narrative documentation in the medical record about both
  - CGs (like all patients) want good healthcare team communication (Burgdorf 2023)
  - Make notes about CG, too – patient’s well-being & functionality is inexorably intertwined with those of the caregiver, a role unique for dementia diagnoses d/t lack of patient autonomy, in contrast with other chronic diseases (Chanesian 2023; Hao 2020; Weisbrod 2022)

Conclusion

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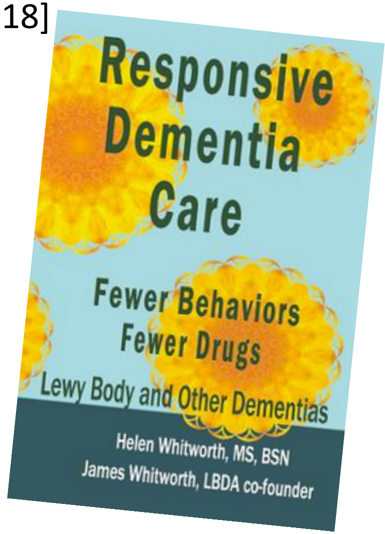
Conclusion: 3 Take Home Messages

- **‘Everything changes’** all the time (Frewer-Graumann 2020)
  - Dementia caregivers ‘enter unknown territory’ every month, week, day, hour
  - Understanding each caregiver’s individual needs and ‘grasping how to support those needs is crucial’ (Steenfeldt 2021; Waligora 2019)

- Initiate **meaningful helpful conversations**

  Be curious, brave, and focus on one or more of the 8 self-efficacy areas (Khan 2021)

  (1) managing behaviors [book recommendation *Responsive Dementia Care* by Whitworth^2 2018]
  (2) controlling upsetting thoughts
  (3) acquiring medical information
  (4) managing medical issues
  (5) obtaining / performing self-care
  (6) accessing community supports
  (7) assisting with ADLs & other care, and getting help when needed
  (8) maintaining good relationship with the person with dementia



- **Continually assess** as the dementia progresses
  - Remember that **the stage of disease may not correlate with the level of CG distress and burden**
  - However, facilitate **peer support** that <u>is</u> related to disease stage

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