Ethics and Family Caregiving in Geriatric Medicine

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Welcome

I have nothing to disclose.

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Learning Objectives

1. Discuss ethical dilemmas encountered in family caregiving for geriatric patients, including conflicts related to autonomy, informed consent, and care priorities.

2. Identify strategies to promote effective communication and decision-making among family members, caregivers, and healthcare providers in ethically challenging situations.

3. Appreciate the shortcomings of our current healthcare system's approach in engaging family caregivers.

“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers”.

-Rosalynn Carter, Former First Lady

August 18, 1927 – November 19, 2023

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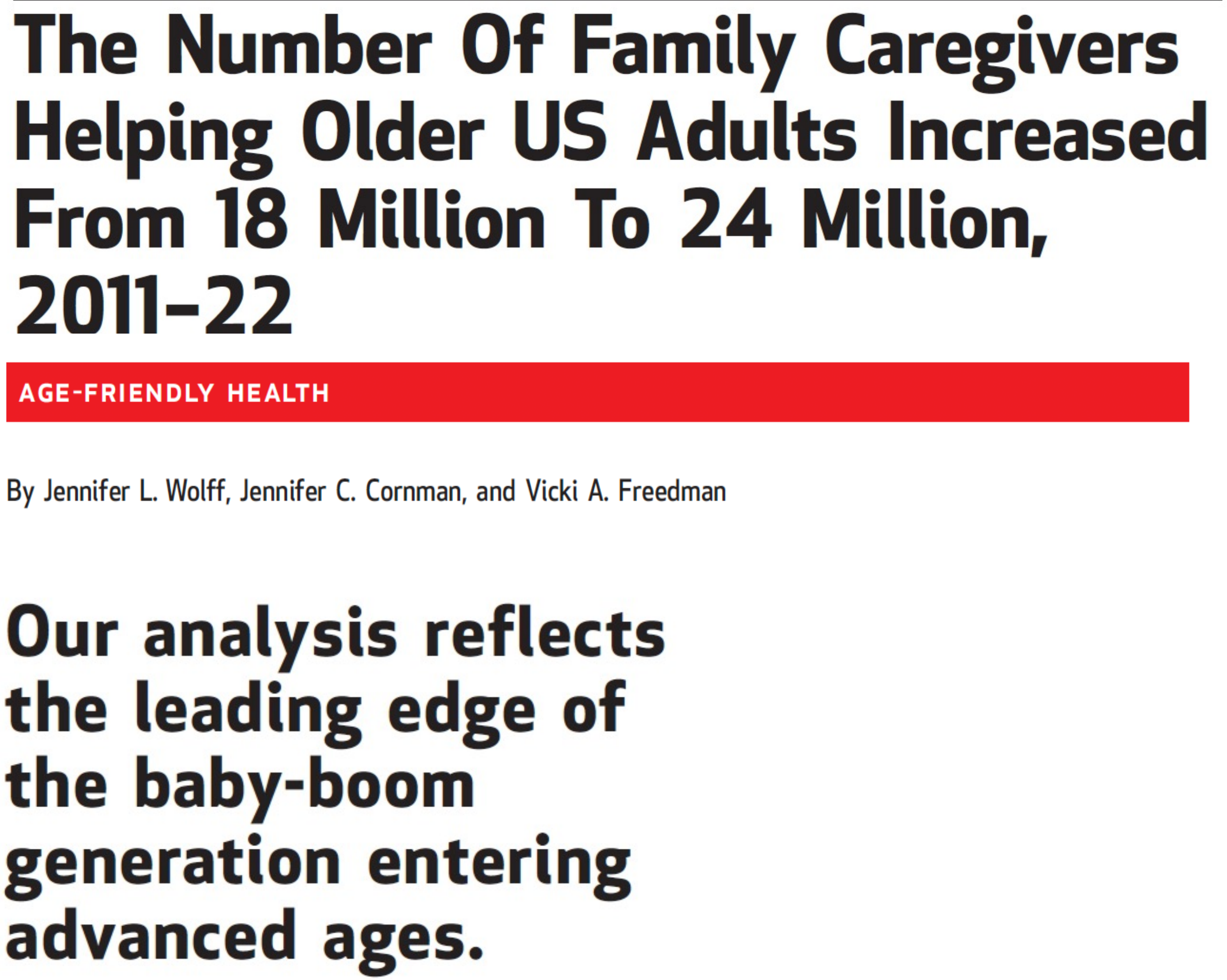
Background

Background

- Approximately 53 million provide unpaid care (21.8% increase from 2015).
- 34.2 million provide care to an adult aged 50 or older.
- Average intensity of care (~20 hours/week).
- Majority of caregivers are female (61%).
- Majority of caregivers are over 40 years old (63%).
- 28-30% of family caregivers who care for relatives also have children under 18 years.
- Economic value of family care: approximately $470 billion

(Family Caregiver Alliance, 2020)

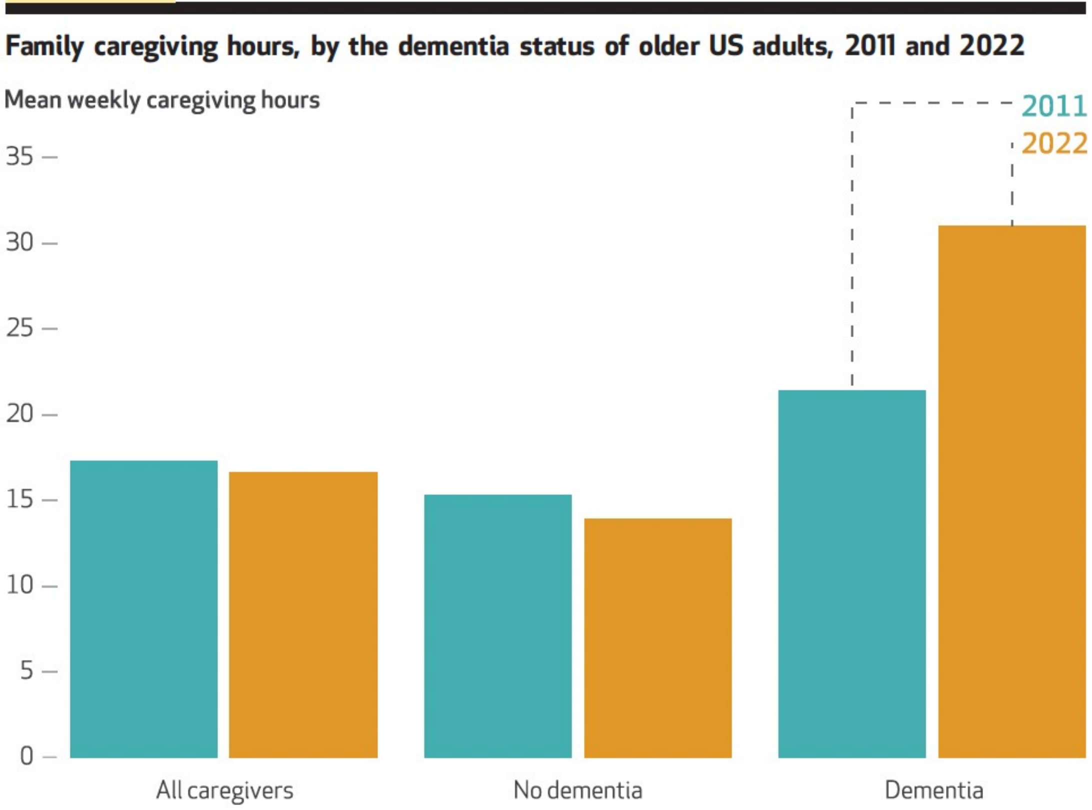


The Number Of Family Caregivers Helping Older US Adults Increased From 18 Million To 24 Million, 2011–22

AGE-FRIENDLY HEALTH

By Jennifer L. Wolff, Jennifer C. Cornman, and Vicki A. Freedman

Our analysis reflects the leading edge of the baby-boom generation entering advanced ages.



Family caregiving hours, by the dementia status of older US adults, 2011 and 2022

SOURCE Authors' analysis of data from the 2011 and 2022 National Study of Caregiving. **NOTE** $p < 0.001$ for difference between 2011 and 2022 for dementia.

(Wolff et al. , 2025)

Categories of Caregivers

Family caregivers (informal)

- Provide help to a family member/loved one.
- They often believe it's their responsibility.

(Reinhard et al., 2019)

Professional caregivers (formal)

- Receive payment for providing care.
- Usually employed by a health care agency.
- Typically, not related to the patient.

(Wilde-Larsson et al., 2015)

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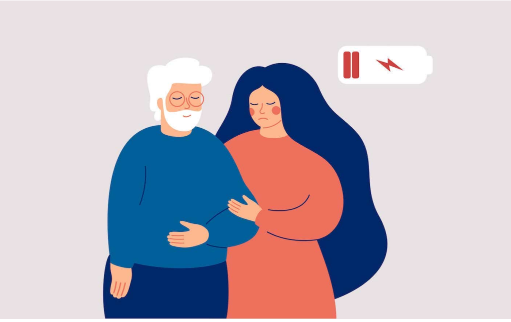
Costs of Caregiving (Caregiver Burden)



Physical Health

- Sleep disturbances
- Fatigue
- Reduced Energy
- Chronic conditions
- Ill health
- Early Death
- Weight Gain/Loss
- Increased Cortisol

Mental Health

- Depression
- Anxiety
- Fear
- Apprehension
- Suicidal ideation
- Anger & resentment
- Hostility
- Lack of Intimacy

Social Health

- Social Isolation
- Financial insecurity
- Increased Smoking
- Poor diet
- No exercise
- No rest
- Poor quality of life
- Poor Coping Skills
- Less self-care

(Adelman et al, 2014; Wittenberg et al, 2017; Zarit et al., 1986)

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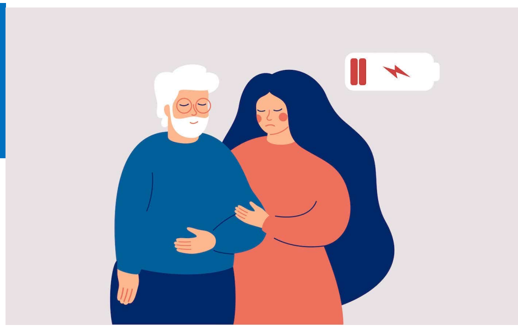

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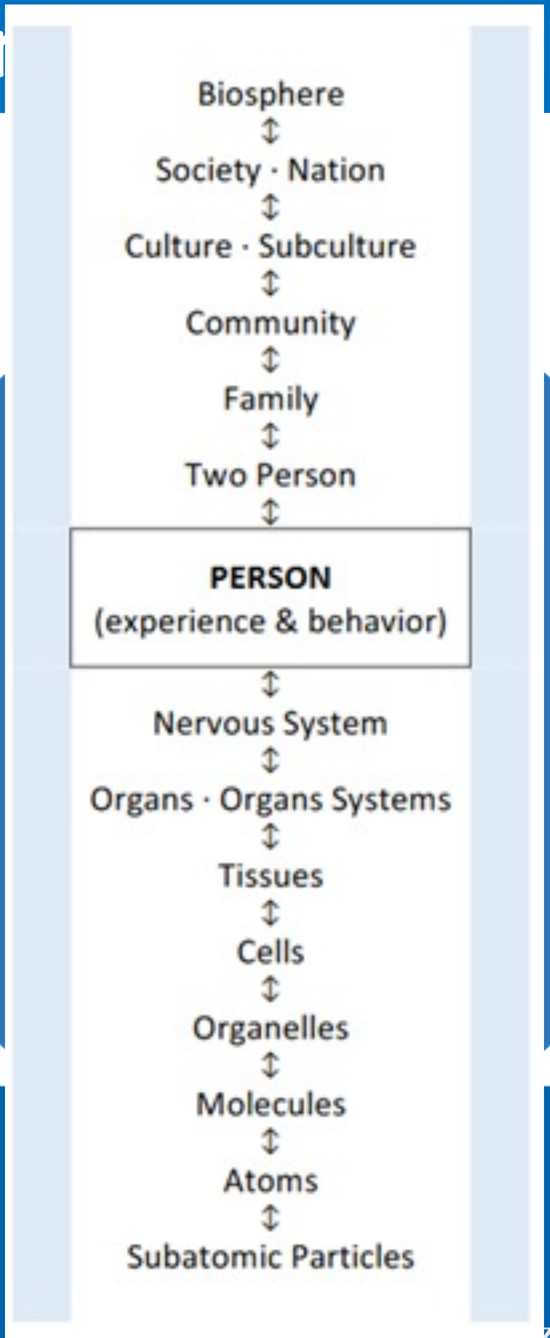

Biosphere
↕
Society · Nation
↕
Culture · Subculture
↕
Community
↕
Family
↕
Two Person
↕
PERSON
(experience & behavior)
↕
Nervous System
↕
Organs · Organs Systems
↕
Tissues
↕
Cells
↕
Organelles
↕
Molecules
↕
Atoms
↕
Subatomic Particles

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Roles of the Caregiver

Promotes good communication and builds self-esteem

Benefits of caregiving (caregiver esteem)

Interpersonal

- Close relationship with family member.
- Lessons can be applied to other interactions
- View of caregiving as a privilege rather than an obligation.

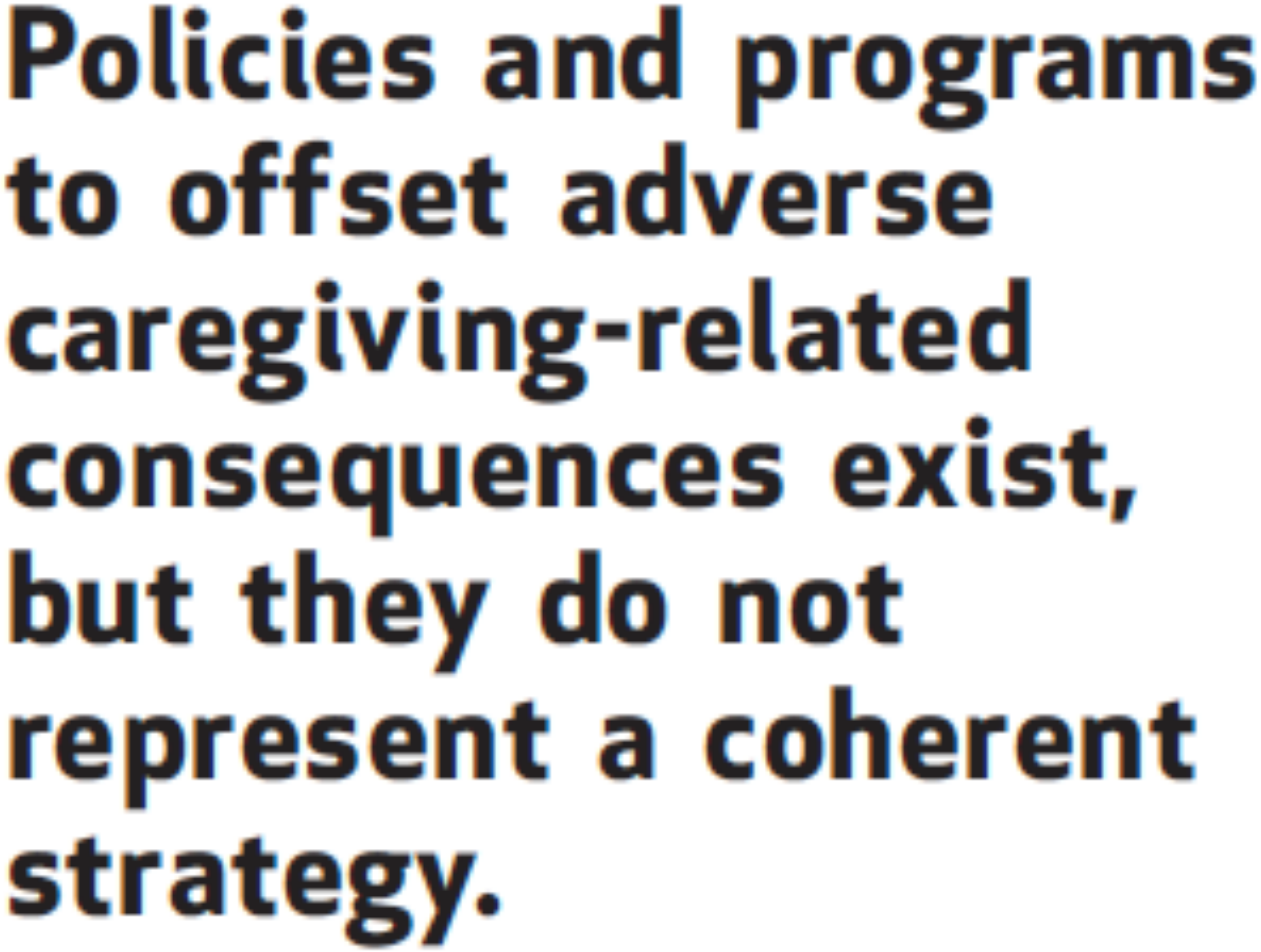
Other

- Financial benefit for providing care at home over assisted-living.
- Well-informed on care recipient’s condition and treatment.
- Feelings of fulfillment.

In some states, caregivers can receive payment from Medicaid through consumer directed programs.

(Cohen et al., 2002; Grant et al., 1998; Hastings & Taunt, 2002; Sheldon et al., 2020).

Resources and Policies for Caregivers and their Loved Ones



Policies and programs to offset adverse caregiving-related consequences exist, but they do not represent a coherent strategy.

Wolff et al., 2025

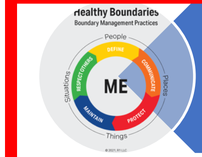
Ethical Issues in Family Caregiving

Case Discussion - RG

RG is an 89-year-old male with a history of end stage renal disease on hemodialysis, atrial fibrillation, CVA with residual left-side hemiparalysis, type 2 diabetes, congestive heart failure on home oxygen, pacemaker, dysphagia status post PEG tube, hyperlipidemia, hypertension, who was admitted for lethargy and altered mental status. Found to be hypoxic and intubated/extubated several times for airway protection due to hypercarbic respiratory failure. RG underwent a bronchoscopy and was found to have significant mucous plugging causing complete opacification in the left hemithorax. ID following for aspiration PNA and bacteremia.

This is the patient's 5th hospitalization over the prior 3 months with only a couple days in between hospitalizations. Due to his recurrent need for respiratory support, a tracheostomy and going to a subacute rehab was recommended however, the family, mostly RG's wife AG, wishes to take the patient home **and** does not want the tracheostomy. Logistics for caring for RG on hemodialysis and ventilator support at home were discussed and the family expressed understanding that this will be challenging for them. Home hospice was discussed however once the family were told about the need to stop dialysis the family did not want to pursue hospice.

Ethical Issues in Family Caregiving



Absence of boundaries for the potential response of family caregivers

Need for informed choice-making

Decisional autonomy and independence in the care relationship

Power dynamics in the care relationship

Relations with formal/professional caregivers (healthcare personnel)

Barret et al., 2016

Boundaries of Care Relationships

- Family care, unlike formal/professional care, has a notable absence of boundaries.

- Since informal care is given to single individuals who are connected in some way with the caregiver, this relationship is troubled from the outset by the fact that there are no boundaries for the potential response (Levinas, 1989).

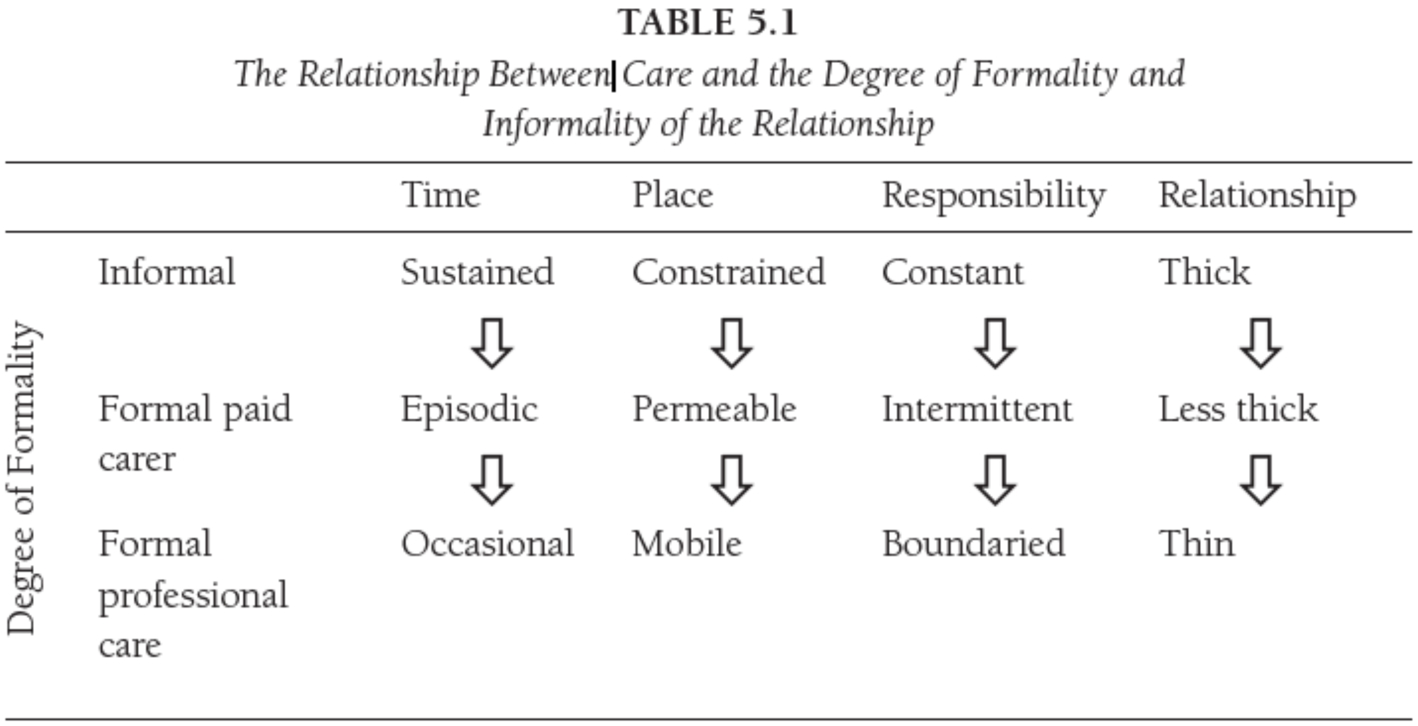


TABLE 5.1

The Relationship Between Care and the Degree of Formality and Informality of the Relationship

		Time	Place	Responsibility	Relationship
Degree of Formality	Informal	Sustained	Constrained	Constant	Thick
		⇩	⇩	⇩	⇩
	Formal paid carer	Episodic	Permeable	Intermittent	Less thick
		⇩	⇩	⇩	⇩
	Formal professional care	Occasional	Mobile	Boundaried	Thin

Barret et al., 2016

Motivations and Willingness – NOT the same.

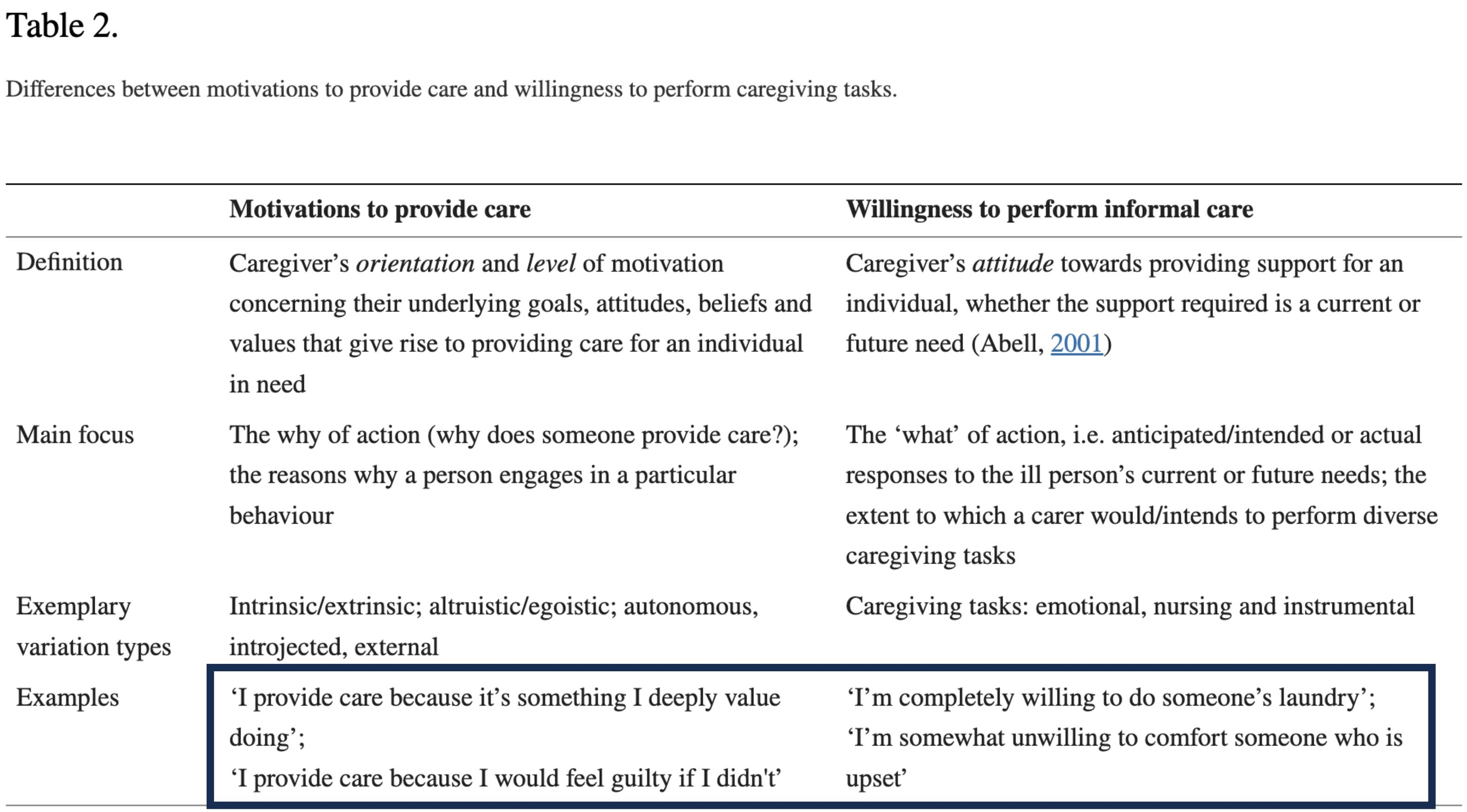


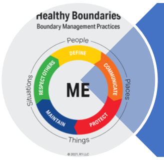
Table 2.

Differences between motivations to provide care and willingness to perform caregiving tasks.

	Motivations to provide care	Willingness to perform informal care
Definition	Caregiver's *orientation* and *level* of motivation concerning their underlying goals, attitudes, beliefs and values that give rise to providing care for an individual in need	Caregiver's *attitude* towards providing support for an individual, whether the support required is a current or future need (Abell, 2001)
Main focus	The why of action (why does someone provide care?); the reasons why a person engages in a particular behaviour	The 'what' of action, i.e. anticipated/intended or actual responses to the ill person's current or future needs; the extent to which a carer would/intends to perform diverse caregiving tasks
Exemplary variation types	Intrinsic/extrinsic; altruistic/egoistic; autonomous, introjected, external	Caregiving tasks: emotional, nursing and instrumental
Examples	'I provide care because it's something I deeply value doing'; 'I provide care because I would feel guilty if I didn't'	'I'm completely willing to do someone's laundry'; 'I'm somewhat unwilling to comfort someone who is upset'

Zarzycki & Morrison, 2021

Ethical Issues in Family Caregiving



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Informed Consent

Informed consent occurs when communication between a patient and clinician results in the patient's authorization or agreement to undergo medical interventions (AMA).

Primary tool for the maintenance of patient autonomy.

~~How~~ Do we discuss with family caregivers, current and future, about what *their* lives will look like serving in this role?

How we approach caregivers

Teaching *how* to care for the individual

- Medication Management
- Lifting/Moving
- Follow-Up
- Wound Care

We ask about resources and financial information

- What can *they* provide *us?*
    - Normally so we can ensure they receive the right resources to be successful – “safe discharge”.

We might provide information on community resources

- If available, we can provide information about community resources that can aid the patient and caregiver.

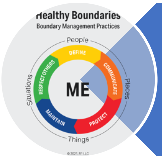
Informed Choice-Making in Family Care

Many caregivers feel ill-prepared for their role, lacking information and basic preparation skills (Nolan et al., 2001).

"Being forced to take on responsibilities that exceed capacity… leads to situations of unsustainable caregiver burden. Being an active agent indicates the possibilities of choice, and choices include to not [provide] care, to [provide] care, to have help, to be in the workforce outside the home, and to recognize care at home in terms of work, rather than solely in terms of family duty, love, and affection." (Barrett et al., 2016).

Caregiver support can [and should] include interventions that assist caregivers to take up, *or not take up,* the caring role, *continue* the caring role, or *give up* the caring role (Askham, 1998).

Ethical Issues in Family Caregiving



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Autonomy and Independence in the Care Relationship

1. Caregivers play a significant role in *patient decision-making*.

- Professional caregivers often expect the family caregiver to take on the role of decision-maker.

2. Caregivers become the *persuader*.

- Caregivers persuade care recipients to consent (or decline) medical interventions. Healthcare professionals may elicit help from the caregiver to *gently persuade* the patient.

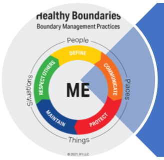
3. The need for caregiving impacts the care recipient's *independence*.

- A fundamental change in familial roles (i.e. an adult child providing care for a parent) can cause tension. Decisions need to include how it impacts the caregiver *and* the care recipient.

4. The caring relationship brings up question of *authority*.

- Who does have the authority in the relationship? What role does *shared decision-making* have?

Ethical Issues in Family Caregiving



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Power Dynamics in the Care Relationship

- **Power dynamics, specifically questions over authority and control, of been have been a key concern from those in the disability community (Kröger, 2009).**
    - Historic practices reinforce the narrative that care recipients are dependent, non-autonomous people.
    - Care recipients are assumed to have less agency.
- The word “care” has an alternative meaning as a contractual obligation rather than the relationship connotation.
- Buildup of tension between family caregivers and care recipients if there are choice differences and issues of control.

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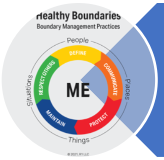
Ethical Issues in Family Caregiving



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A tale of two perspectives

“Good” Relationship with the Formal Care Sector

- Family caregivers have detailed knowledge about the patient which can help in shared decision-making.
- Health professionals can (and do) ask for input.
- Can be confident that the patient’s discharge will be safe.

“Bad” Relationship with the Formal Care Sector

- The family member ”dictating care”.
- “You’re not doing this right.”
- Trust, in both directions, can be impacted.
  - Family caregiver loses trust in the system.
  - Formal caregiver may invest little-to-no time to become involved with the family care situation.

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Note about Situations where the Family Caregiver *IS* a healthcare professional

- **Patients whose family caregivers are in the healthcare field can present unique ethical challenges.**
- Anecdotally, healthcare professional family caregivers (HCP-FC) are spoken to as colleagues rather than family members.
    - *"She (the daughter) is a physician, she should understand how serious this is."*
    - *"The patient's son is a cardiac anesthesiologist; he should know that the risk is not worth taking."*
    - *"The daughter is a veteran nurse; discharge home shouldn't be an issue."*
- HCP-FCs report increased role struggle during interactions with colleagues and fellow health care professionals (Bristol et al., 2021). If they are new at the family caregiver role, they struggle with role transition and role shifting.

Ethics Case Revisited

Case Discussion - RG

RG is an 89-year-old male with a history of end stage renal disease on hemodialysis, atrial fibrillation, CVA with residual left-side hemiparalysis, type 2 diabetes, congestive heart failure on home oxygen, pacemaker, dysphagia status post PEG tube, hyperlipidemia, hypertension, who was admitted for lethargy and altered mental status. Found to be hypoxic and intubated/extubated several times for airway protection due to hypercarbic respiratory failure. RG underwent a bronchoscopy and was found to have significant mucous plugging causing complete opacification in the left hemithorax. ID following for aspiration PNA and bacteremia.

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The Ethics Consult – for RG

Consult purpose: Assist the team in the ethical dilemma posed by an 89-year-old male with a complex medical history regarding goals of care.

Several weeks of having goals of care discussions between critical care and palliative care. The conclusion was that the “*patient would want to be in this position for AG (the spouse).”*

Held an interdisciplinary team-family meeting. Found to have a severe lack of understanding about advance directives, advance care planning, logistics of his care.

AG (patient’s spouse) spoke some English but would frequently shift to Italian when getting emotional. Family translate one phrase during the meeting – *la cura è amore* or “to care is to love”.

Patient eventually died in the hospital.

Case Discussion - LB

LB is an 82-year-old female with a history of advanced Alzheimer’s dementia, s/p PEG placement 6 years prior, HFrEF (38%), and DM2. Patient has lived at home except for one physical rehab stay following a hip replacement in her mid 70s. LB’s current hospitalization is following an aspiration event during PEG feeding, which has happened only once before since PEG placement. She required 5 days of intubation/mechanical ventilation and will be ready for discharge following a course of antibiotics.

LB has two children: FO, her daughter who lives with the patient and HB, her son who lives about 20 minutes away in a different neighborhood. LB receives some homecare services, but much of her care is provided by FO. HB visits on weekends and some weeknights but has a full-time job and is married with three children. FO was married at one time but is now divorced (unknown when that happened). Neither child is a named healthcare proxy and LB has no advance care plan.

The Ethics Consult – for LB

Consult purpose: Assist the team in the ethical dilemma posed by an 82-year-old female whose children disagree about discharge.

FO wants the patient to come home with her, and HB feels mom would be better in a nursing home. FO claims that “Mom made me promise to never put her in a home, so I won’t”. HB feels that FO has sacrificed a lot in her life and her health has taken a hit in the 6+ years she’s been a family caregiver.

No concerns over the patient’s safety going home. Just some family disagreements.

Overall, there was a discussion with the children who agreed home hospice would be the best option for mom.

Practical Responses to Ethical Issues in Family Care

1. **Acknowledge the caregiver burden and caregiver esteem can co-exist (Scorgie & Sobsey, 2000):** much of the literature and interventions are focused on caregiver vulnerability. It's important not to assume that a family caregiver is automatically or solely burdened.
2. **Recognize the needs of the caregiver:** being included in discussions for the care recipient will assist the family caregiver in feeling valued. Take time to properly inform the caregiver about what they can expect for themselves and **not** just what techniques they can use to support the patient.
3. **Call for help:** when it becomes clearer that there are dilemmas and issues that involve conflicting values, allow the ethics consultation team or other services to assess and mediate when necessary. **Do not turf.**
4. **Empathize:** 1) reflection, 2) legitimization, 3) exploration, and 4) partnership.

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Thank you!

Questions and Discussion