



Conversations on Caregiving, Ethics, and Elder Mistreatment

November 6, 2024

The National Center on Elder Abuse

NCEA
National Center on Elder Abuse

The National Center on Elder Abuse (NCEA) provides up-to-date information regarding policy, research, training, best practices, news and resources on elder abuse, neglect and exploitation for policy makers, professionals in the elder justice field and the public.



Panelists



Georgia J. Anetzberger, PhD, ACSW, FGSA

Consultant in private practice
Adjunct Faculty, Case Western Reserve University



Nicholas R. Mercado, DrPH, MCHES, HEC-C

Clinical Ethicist, Director of Health Humanities and Bioethics
Undergraduate Medical Education & Assistant Professor, Department
of Health Humanities and Bioethics University of Rochester School of
Medicine & Dentistry



Donna Benton, PhD

Director, Los Angeles Family Caregiver Resource Center
Professor, USC Leonard Davis School of Gerontology



Candace Heisler, JD


Author, Trainer, & Consultant
Retired Assistant District Attorney, City and County of San Francisco



Pamela Teaster, PhD, MA, MS

Professor of Human Development and Family Science, Virginia Tech
Director, Virginia Tech Center for Gerontology

Housekeeping Items

- All attendees will enter the meeting in listen-only mode.
- Please utilize the Q&A function to submit questions or comments to panelists.
- To enable the Live Transcript feature, click the  button.
- Recording & presentation materials will be made available via the National Center on Elder Abuse.
- Your feedback matters! After we conclude today's webinar, please follow the link to complete our survey.

Caregiving



**Conversations on
Caregiving, Ethics,
and Elder Mistreatment**

 November 6  10:00 - 11:15AM PT



Ethical Issues in Family Caregiving

A primer and start to a crucial conversation

Nicholas R. Mercado, DrPH, MS, MCHES, HEC-C

Assistant Professor of Health Humanities and Bioethics

Director, Health Humanities and Bioethics Undergraduate Medical Education

Clinical Ethics Consultant

University of Rochester School of Medicine and Dentistry

November 6th, 2024



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

Learning Objectives

1. Discuss the ethical issues in family caregiving.
2. Describe at least three (3) methods for addressing ethical issues involving patients and 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



UNIVERSITY of
ROCHESTER
MEDICAL CENTER
8

Background

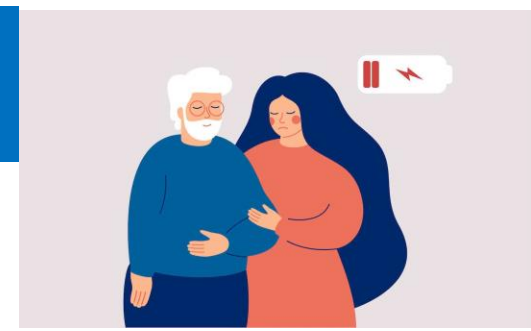
- ❖ Approximately 53 million people provide family care in the United States (21.8% increase from 2015).
- ❖ 34.2 million provide care to an adult aged 50 or older.
- ❖ Average intensity of care (~20 hours/week).
- ❖ Majority of caregivers are female (61%).
- ❖ Majority of caregivers are over 40 years 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)



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

Biopsychosocial Issues in Family Caregiving



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



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).

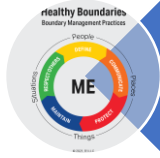


Ethical Issues in Family Caregiving



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

Ethical Issues in Family Caregiving



Absence of boundaries for the potential response of family caregivers



Need for informed choice-making



AUTONOMY

Decisional autonomy and independence in the care relationship



Power dynamics in the care relationship

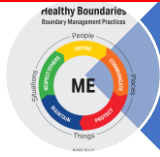


Relations with formal/professional caregivers (healthcare personnel)

Barret et al., 2016



Ethical Issues in Family Caregiving



Absence of boundaries for the potential response of family caregivers



Need for informed choice-making



AUTONOMY

Decisional autonomy and independence in the care relationship

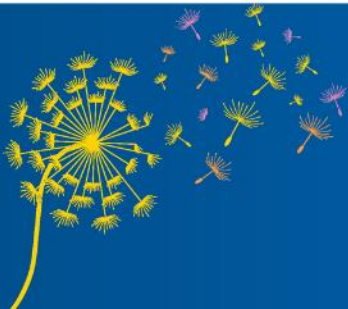


Power dynamics in the care relationship



Relations with formal/professional caregivers (healthcare personnel)

Barret et al., 2016



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

Boundaries of Care Relationships

- Family care, unlike formal/professional care, has a notable absence or diminution of boundaries.
- Since family 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, as cited by Barret et al., 2016).

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



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

Motivations and Willingness – NOT the same.

Table 2.

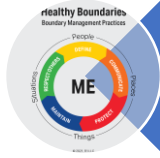
Differences between motivations to provide care and willingness to perform caregiving tasks.

| | Motivations to provide care | Willingness to perform informal care |
|---------------------------|---|--|
| Definition | Caregiver's <i>orientation</i> and <i>level</i> of motivation concerning their underlying goals, attitudes, beliefs and values that give rise to providing care for an individual in need | Caregiver's <i>attitude</i> 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



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



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?



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

How we approach family 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).



Practical Responses to Ethical Issues in Family Caregiving in the clinical setting.

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 as persons with their own value, needs, and agency.
3. **Call for help:** when it becomes clearer that there are conflicts and issues that involve values, leverage resources where available (ethics, social work, palliative care, chaplaincy, child life, etc.). **Do not turf.**
4. **BONUS: Empathize:** 1) reflection, 2) legitimization, 3) exploration, and 4) partnership.





Thank you!

Panel discussion up next!

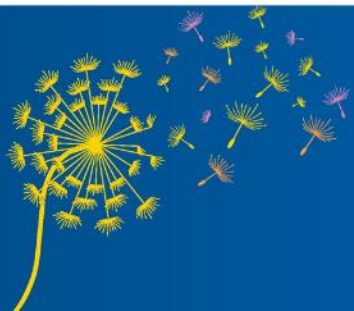
Nicholas_mercado@urmc.Rochester.edu



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

References

- AARP. (2020). *Can I get paid to be a caregiver for a family member?* <https://www.aarp.org/caregiving/financial/legal/info/2017/you-can-get-paid-as-a-family-caregiver.html>
- AARP. (2022). *1 in 5 Americans now provide unpaid family care.* <https://www.aarp.org/caregiving/basics/info-2020/unpaid-family-caregivers-report.html>
- AARP, National Alliance for Caregiving. (2020). *Caregiving in the United States 2020.* <https://www.aarp.org/ppi/info/2020/caregiving-in-the-united-states.html>
- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *Jama*, 311(10), 1052-1060.
- Askham, J. (1998). Supporting caregivers of older people: an overview of problems and priorities. *Australasian Journal on Ageing*, 17, 5-7. <https://doi.org/10.1111/j.1741-6612.1998.tb00845.x>
- Barrett, P., Butler, M., & Hale, B. (2016). Ethical issues in family care today. *Annual Review of Nursing Research*, 34(1), 67-87. <https://doi.org/10.1891/0739-6686.34.67>
- Bristol, A. A., Martin-Plank, L., & Crist, J. D. (2021). Health Care Professionals' Experiences as Family Caregivers During Intra-Hospital Transitions. *Journal of Gerontological Nursing*, 47(2), 31-36. <https://doi.org/10.3928/00989134-20210113-02>
- Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry*, 17(2), 184-188. <https://doi.org/10.1002/gps.561>
- Cooper, S., Schmidt, B., Sambala, E. Z., Swartz, A., Colvin, C. J., Leon, N., . . . Wiysonge, C. S. (2019). Factors that influence parents' and informal caregivers' acceptance of routine childhood vaccination: A qualitative evidence synthesis. *Cochrane Library*, 2019(2) <https://doi.org/10.1002/14651858.CD013265>
- From, I., Wilde-Larsson, B., Nordstrom, G., & Johansson, I. (2015). Formal caregiver's perceptions of quality of care for older people: Associating factors. *BMC Research Notes*, 8(1), 623. <https://doi.org/10.1186/s13104-015-0597-X7>
- Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: Towards a refined model of caring and coping. *Journal of Intellectual Disability Research*, 42(1), 58-71. <https://doi.org/10.1046/j.1365-2788.1998.00079.x>
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal of Mental Retardation*, 107(2), 116-127. [https://doi.org/10.1352/0895-8017\(2002\)107<0116:PIFOC>2.0.CO;2](https://doi.org/10.1352/0895-8017(2002)107<0116:PIFOC>2.0.CO;2)
- Johnson, K. L., Lin, M., Cabral, H., Kazis, L. E., & Katz, I. T. (2017). Variation in human papillomavirus vaccine uptake and acceptability between female and male adolescents and their caregivers. *Journal of Community Health*, 42(3), 522-532. <https://doi.org/10.1007/s10900-016-0284-X5>
- Kröger, T. (2009). Care research and disability studies: Nothing in common? *Critical Social Policy*, 29(3), 398-420. <https://doi.org/10.1177/0261018309105177>
- Kurup, L., Shorey, S., Wang, W., & He, H. (2017). An integrative review on parents' perceptions of their children's vaccinations. *Journal of Child Health Care*, 21(3), 343-352. <https://doi.org/10.1177/1367493517722864>
- Nolan, M., Davies, N., & Grant, G. (2001). *Working with older people and their families*. McGraw-Hill Education (UK).
- Reinhard, S., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019). *Valuing the invaluable 2019 update: Charting a path forward.* <https://www.aarp.org/ppi/info/2015/valuing-the-invaluable-2015-update.html>
- Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental retardation*, 38(3), 195-206. [https://doi.org/10.1352/0047-6765\(2000\)038<0195:TOAWPC>2.0.CO;2](https://doi.org/10.1352/0047-6765(2000)038<0195:TOAWPC>2.0.CO;2)
- Sheldon, J. P., Oliver, M., & Yashar, B. M. (2020). Rewards and challenges of parenting a child with down syndrome: A qualitative study of fathers' perceptions. *Disability and Rehabilitation, ahead of print*(ahead of print), 1-12. <https://doi.org/10.1080/09638288.2020.1745907>
- Wittenberg, E., Kravits, K., Goldsmith, J., Ferrell, B., & Fujinami, R. (2017). Validation of a model of family caregiver communication types and related caregiver outcomes. *Palliative & Supportive Care*, 15(1), 3-11. <https://doi.org/10.1017/S1478951516000109>
- Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist*, 26(3), 260-266.
- Zarzycki, M., & Morrison, V. (2021). Getting back or giving back: Understanding caregiver motivations and willingness to provide informal care. *Health Psychology and Behavioral Medicine*, 9(1), 636-661. <https://doi.org/10.1080/21642850.2021.1951737>



Case Scenario #1

Nearly every state, as well as the District of Columbia and US territories, mandate that certain professionals report incidents of suspected elder mistreatment to reporting agencies, including Adult Protective Services (APS). Statutes vary regarding the types of individuals required to report, and the type of abuse that must be reported. Depending upon the jurisdiction, mandated reporters may include healthcare professionals, law enforcement, social services staff working with older adults and/or adults with disabilities, caregivers, clergy, and financial institutions, among others.

A caregiving daughter is frustrated with her mother's inability to "listen." She shouts at her when she refuses to take a shower, eat, or go to sleep at a certain time. **Is this abuse? What additional information do you want to know? As a mandated reporter, do you make a report to APS or give the daughter a grace period?**

Case Scenario #2

My 78-year-old mother has moderate dementia and experiences depression, anxiety, agitation, and sleep disturbance. Her doctor recommended a low-dosage CBD/THC gummy to reduce these concerns. She takes one a day, in combination with other therapies. She now experiences more stable moods and better sleep.

Is it wrong to give my mother a drug that she would never have agreed to take on her own? (*NYT The Ethicist*)

Case Scenario #3

An older victim of financial abuse obtained a restraining order, prohibiting her son who has been stealing her money, from having any contact with her. After several weeks, she misses him and wants to have regular visits, as well as his help with medical appointments, grocery shopping, etc. as he had done in the past. The son comes to visit her, thereby violating the restraining order and potentially exposing the mom to further financial abuse.

How do we balance mom's desire for emotional connection and support while protecting her from financial exploitation?

Case Scenario #4

My mother has advanced dementia. I manage her finances, including making annual donations in her name. One of her caregivers has asked me to donate to her church (caregiver's). I agreed, but when I looked up the church, I noticed they oppose same-sex weddings and believe homosexuality is a sin. As a gay man, I don't support any organization that doesn't support me.

While my mother's money is not mine, is it wrong of me to deny her caregiver's request? (*NYT The Ethicist*)

Tips & Tools:


- [Providing Safe and Supportive Caregiving](#)
- [Providing Culturally Competent and Responsive Care to Older People who Experience Abuse](#)

NCEA National Center on Elder Abuse

TIPS & TOOLS

Tips and Tools for Safe and Supportive Caregiving

Most people either are caregivers, know a caregiver, will become a caregiver, or will need care during their lives.¹ Caregiving, and in particular caregiving for a close family member, chosen family, partner, or friend, can be a very rewarding and meaningful role. It can also be a challenging one.



What challenges do family caregivers face?

- As a loved one's medical needs increase and caregiving duties expand or continue over time, unexpected physical, emotional, and/or financial hardships may arise.
- Family carers may not identify themselves as caregivers. They may not recognize that their roles are being redefined as the demands of the situation change.
- It may be difficult for some caregivers to accept that they are now responsible for parents who raised and cared for them.
- Most people are surprised to take on the new roles and few know where to turn for financial, legal, medical, and emotional support.
- Shifting roles may become more complicated for families with histories of unresolved conflict. Caregivers harboring residual anger may respond to a loved one inappropriately and without fully understanding the changes that have occurred.
- Family caregivers may feel guilty about having any negative feelings. They may not have someone to talk with who understands their experience.

What is the impact of caregiver challenges on the care recipient?

- The demands of caregiving may get in the way of providing proper, quality care. For example, a caregiver may desire a break and leave an adult who is unable to care for themselves alone.
- Caregivers who have not acknowledged their caregiving role or are new to the challenges of caring for a loved one may lack knowledge and skills to adequately meet their needs. This may lead to failing to assist a loved one who can't remember to take their medication.
- Unprocessed feelings of anger held from childhood or adolescence may result in caregiver ambivalence and poor care. A reluctant caregiver may threaten to move the family member into a long-term care facility, a fear for many older adults.
- Family conflict among siblings and other relatives about their caregiving roles and responsibilities may negatively impact care for their loved one.
- Without appropriate supports in place, unchecked caregiver challenges could potentially lead to elder mistreatment.
- On the other hand, these new roles can help with learning resilience, patience, and problem-solving. Caregivers and care recipients understand and can promote the value of care, and model roles for future generations.

¹ Paraphrasing a quote by Rosalynn Carter

NCEA Tips and Tools for Safe and Supportive Caregiving, 2023

1

NCEA National Center on Elder Abuse

TIPS & TOOLS

Tips and Tools for Providing Culturally Competent and Responsive Care to Older People who Experience Abuse

Culture often impacts our definitions, perceptions of, and responses to mistreatment. It also influences our willingness to report harm and ability to seek and access appropriate assistance in the aftermath of abuse. Culturally competent and responsive engagement is essential to meet the unique needs of our diverse older population and are critical to abuse prevention, harm reduction, and meaningful intervention.

What is culture?


Culture embraces many factors, including our thoughts, attitudes, beliefs, language, communications, behaviors, customs, experiences, values, societal institutions, and norms.

What are cultural competence, cultural humility, and cultural responsiveness, and how do they intersect?

Cultural competence is the ability to respectfully embrace and engage with individuals whose beliefs, values, and cultural backgrounds differ from your own. Cultural humility is the exercise of self-reflection, self-awareness, genuine interest, and inquiry to better understand and learn from others. Cultural responsiveness is applying cultural competence and humility into practice and daily interactions.

Why are culturally responsive interactions important to older people who experience abuse?

Older people who experience abuse may be unlikely to report harm and reach out for appropriate services. Since many offenders are family members, chosen family, or trusted others, elders may be reluctant to reveal maltreatment by those closest to them. Cultural considerations may impact an individual's response to abuse. Individuals may feel shame and embarrassment, fear the offender will retaliate. Some diverse elders may be resistant to reporting their loved one due to historical and ongoing discrimination by authorities and systems. Understanding and acknowledging the cultural and contextual factors that can encourage or inhibit disclosure are critical to facilitating engagement.



Tips and Tools for Providing Culturally Competent and Responsive Care to Older People who Experience Abuse

1

USC Leonard Davis
Family Caregiver Support Center

LACRC
LOS ANGELES CAREGIVER RESOURCE CENTER
A Program of the USC Family Caregiver Support Center

<http://losangelescrc.usc.edu>

1-800-540-4442



#USCFCSC #LACRC

CAREGIVING RESOURCES

Caregivers Are Learning More (C.A.L.M.)

<https://losangelescrc.usc.edu/caregiver-month-celebration-2024/>

Family Caregiver Alliance

<https://www.caregiver.org/>

Administration for Community Living, National Family Caregiver Support Program

<https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>

Administration for Community Living, National Alzheimer's and Dementia Resource Center

<https://nadrc.acl.gov/home>

Alzheimer's Association

<https://www.alz.org/>

NCEA

National Center on Elder Abuse

ncea.acl.gov

ncea-info@acl.hhs.gov

855-500-3537

