



# When Behavioral Health Leaders Are Also Behavioral Health Family Caregivers

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## ■ LEARNING OBJECTIVES

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- + Understand the burgeoning phenomenon of family caregiving in America**
- + Find out how BH professionals are impacted by their own personal family caregiving experiences in both positive and potentially negative ways**
- + Learn three effective strategies BH professionals can employ to manage their own emotional reactions to interactions with clients and staff members**

- + Family caregiving in America
- + Mental health caregiving
- + Advantages and challenges for BH clinician-caregivers
- + Defining and negotiating roles
- + Working toward ideal collaboration





- *If you have been a family caregiver to a relative with a behavioral health disorder, what was your loved one's diagnosis?*
- *On a 1-10 basis, for which 1 is "not stressed" and 10 is "highly stressed," how would you rate your family caregiving experience? Why?*
- *(If you haven't been, then please think about how a colleague or supervisee may have coped.)*

- *In one or two sentences, how has being a behavioral health family caregiver affected your work as a behavioral health leader and/or clinician?*
- *(How has BH caregiving affected your BH staff?)*





# Family Caregiving in America

- 53 M Americans engage in some form of caregiving activity in a year (NAC/AARP, 2020)
- 40 M for adults over 50; 9 M for children
- Prevalence: 21.3% (18.2% in 2015)





- 60% women/40% men
- ¼ Millennials; ¼ Gen-Xers
- Average family caregiver:  
A 49-year-old woman  
still working at least part-  
time and also caring for  
children—"sandwich  
generation"

# Family Caregivers' Healthcare Roles (Wolff, Jacobs, 2015)

- Attendant
- Administrator
- Companion
- Driver
- Navigator
- Technical Interpreter
- Patient Ombudsman
- Coach
- Advocate
- Case Manager
- Healthcare Provider

- **Schulz:** dementia caregiving associated with insomnia, depression, musculoskeletal problems, increased mortality



- **Roth:** caregiving associated with increased lifespan, *enhanced sense of purpose*

# Mental Health Caregiving

- 2016 NAC/NAMI study of over 1600 mental health caregivers:
- 8.4 million MH caregivers
- 45% care for an adult child; 64% financially dependent
- 62% say caregiving has made their own health worse
- 48% say stigma prevents them from talking about their loved one's condition
- 28% say their loved one can't find right BH services



## ON PINS & NEEDLES

*Caregivers of adults with mental illness*



February 2016



- ***Any surprises here?***
- ***Please type your thoughts in the chat box***



## Working Triangle



## Advantages for BH Clinician-Caregivers

- Expert knowledge of condition
- Insider understanding of the care delivery system
- Rapport with specific providers
- Enhanced standing within own family

# Challenges for BH Clinician-Caregivers

- Hard to have objective perspective
- Role uncertainty vis-à-vis patient
- Role uncertainty vis-à-vis treatment professionals
- Emotional impact of personal experiences on professional role
- Self-, family-, and (sometimes) team-imposed expectations/responsibilities→  
**GUILT!!!**



# Lack of Objectivity

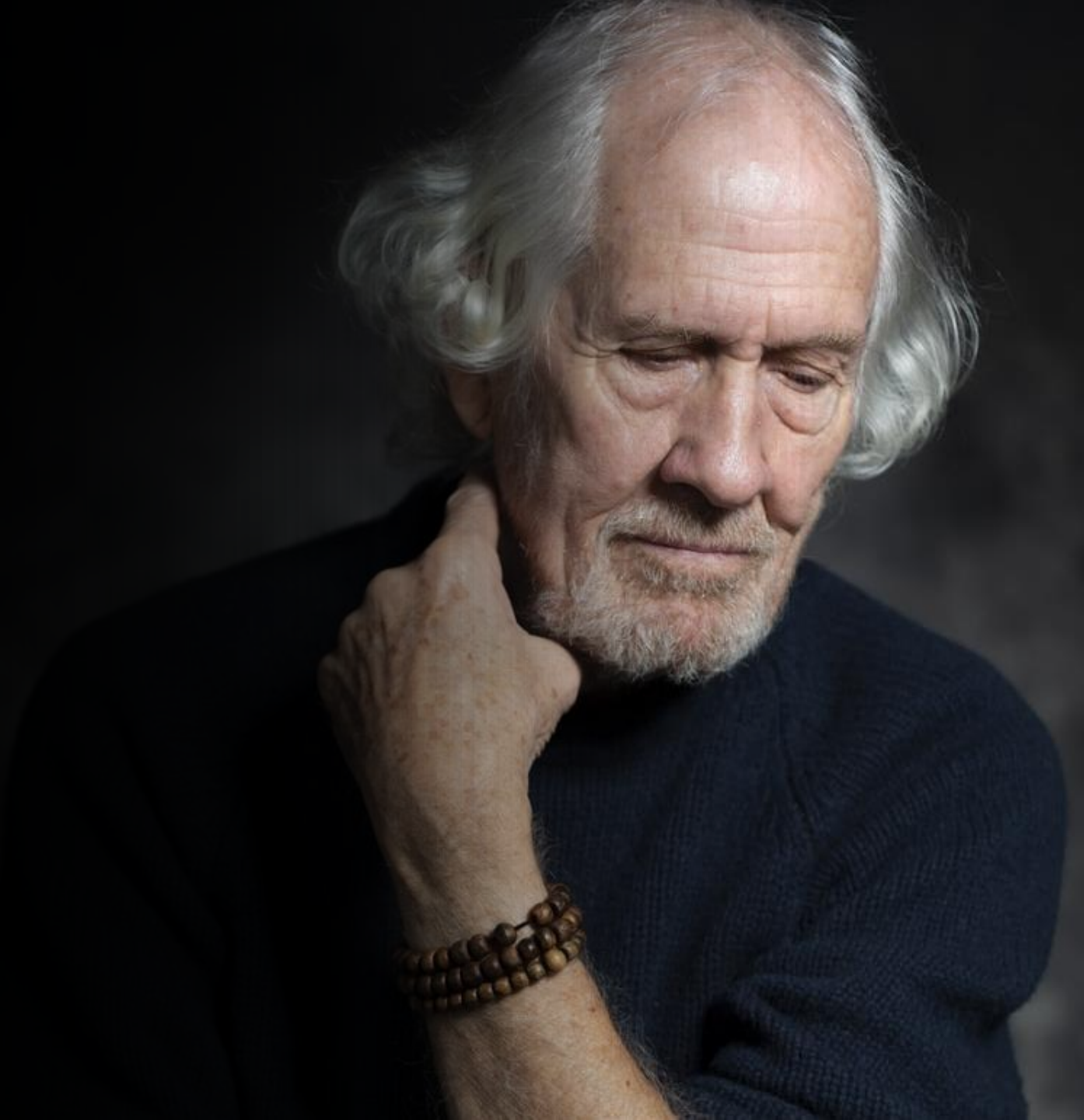
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- Ethical principles: No (or limited) treatment of family members allowed because of emotional ties clouding judgment
- But family caregivers have opinions about what their loved ones' need
- Shouldn't BH family caregivers who are BH providers use their informed opinions to guide care?
- ***Thoughts?***

## Role Uncertainty with Family Member

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- Authoritative guide? But what if your guidance steers care receiver in wrong direction? And what if care receiver thinks you don't trust his judgment?
- As-needed expert? But what if you are never called upon when you think you should be?
- Hands-off supporter? But will the care receiver think you are neglecting him?







## Role Uncertainty with Treatment Team

- Part of treatment team? Or seen as potential critic of the treatment team's plan and performance?
- As-needed informed observer and resource? And what if they don't want your observations?
- Hands-off supporter? Or will the treatment team try to pull you into its discussions?



## Impact of Personal Experiences on Professional Role

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- Potential for increased capacity for empathy, stronger basis for therapeutic alliance
- Countertransference:
- Is it harder to use non-directive techniques (e.g., Motivational Interviewing) when you've been personally hurt by a family members with an addiction?
- Increased stridency
- Decreased capacity for instilling hope



## Dealing with (Possibly Unrealistic) Expectations

- Increased pressures in this role as a family member with special knowledge
- Fear of failing, letting yourself and others down
- Family caregivers are often riven with guilt. BH leaders/clinicians may have it worse

- ***As a BH family caregiver, how do you decide the role you want to play—or believe you are required to play?***



# Defining BH Caregiver's Desired Role

- We have blind spots. We need others' input about right course
- Our special knowledge may or may not be pertinent to our loved one's care
- We are well advised to confer with confidants, colleagues, or therapists to remove countertransference, including anger and guilt, from decision-making





## Negotiating Expected Role

- Not all “help” is helpful
- Negotiate role with family member with BH disorder (as best as possible)
- Set limits on what you are willing and able to do
- Have explicit conversation with BH treatment team about roles you could play that would not violate confidentiality
- Be diplomatic. See “advocating” in context
- Be flexible and change roles as conditions change over time



- ***What would an ideal collaboration among BH clinician-caregivers and clinical team members look like?***
- ***Please type your thoughts in the chat box***

# The Ideal Collaboration

- ***Mutual respect and appreciation all around:***
- Clinician-caregiver respects autonomy of family member
- Family member (patient) appreciates clinician-caregiver's input for collaborative team
- Clinician-caregiver's input is welcomed by the collaborative team as informed observation
- Clinician-caregiver respects the perspectives and expertise of the collaborative team

- ***What other ideas do you have for overcoming the challenges of being a clinician-caregiver?***
- ***Please type your responses in the chat box***

# Upcoming webinars

*The series, Exploring the Landscape of Behavioral Healthcare, will take place from April to August and explore central themes ranging from the impact of COVID-19 to the future of child welfare and behavioral health equity.*

- COVID Response to Behavioral Health Needs
- CCBHC: “Waiting is the Hardest Part” (*What to do while waiting for your CCBHC-E grant, and once you are awarded*)
- Conducting Virtual Supervision in the Telehealth World
- Advancing Health Justice for Medicaid Members with Disabilities, Including Persons with Mental Illness and Substance Use Disorder (SUD)
- Children’s Behavioral Health and the Intersect with Medicaid and Child Welfare
- How Child Welfare and Behavioral Health Systems Can Support and Enhance Family Engagement and Collaborate on Child Welfare Prevention
- Using Substance Use Navigators (SUN) in Emergency Departments to Engage and Connect Patients to Treatment
- Best Practices for Working with Patients with Stimulant Use Disorder
- Addressing Best Practices in Addressing Perinatal Substance Use: Keeping Moms, Families and Babies Together
- Addressing the Variability in How Child Welfare Departments Address Perinatal Substance Use Disorder





Questions? Last  
thoughts?

## Contact us



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