

# On Pins & Needles: Caregivers of Adults with Mental Illness

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International Carers Conference, Adelaide, Australia



# Report Sponsors

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- Allergan
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# Methodology

- **Conducted in partnership with the National Alliance on Mental Illness and Mental Health America**
- **Quantitative online interviews with 1,601 caregivers ages 18 or older**, currently providing care or cared in the year prior
- Targeted, non-probability-based design provides an **in-depth look** at a pre-identified population
- **Findings may underestimate challenges** as respondents were typically more educated and wealthier than the general public

# The Big Picture

- **8.4 million Americans** care for an adult with an emotional or mental health issue\*
- Caregivers have typically **provided care for 8.7 years**, while caregivers of an adult care for 4 years on average (any condition).
- Most care recipients (58%) are between 18-39 years; **most caregivers (45%) are parents caring for an adult child**, though other relationships can be impacted
- The main conditions requiring care are **bipolar disorder (25%), schizophrenia (25%), depression (22%), and anxiety (11%)**

\*from [Caregiving in the U.S. 2015](#), National Alliance for Caregiving and AARP Public Policy Institute

# Who are the caregivers?

- Most caregivers in sample were female (80%)
- They usually are caring for a relative (88%)
- Nearly half are caring for an adult son or daughter
- Most are between the ages of 45 and 64 (average age is 54.3 years old)
- 65% had a college education or more advanced degree
- 46% had a household income of \$75,000 or more
- 24% lived in rural areas

# Whom are they caring for?

- Average age is 46.3 years old but most are under age 40
- Almost half live in same household as caregiver (45%) or within 20 miles (27%)
- Three in ten have an alcohol or substance abuse issue
- Almost half are financially dependent on family and friends

## Male Care Recipients

- Comprise 51%
- 35% had schizophrenia vs. 14% for females
- 33% have a substance abuse issue
- 45% had at least 1 arrest
- 25% had been homeless

## Female Care Recipients

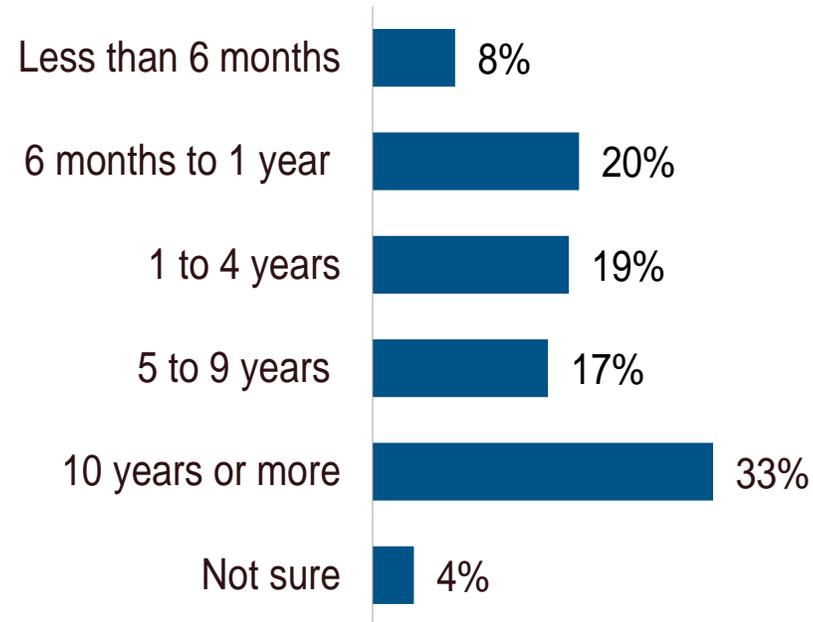
- 49% of care recipients were female
- 27% had diagnosis of depression vs. 18% of males
- 14% had diagnosis of anxiety vs. 7% of males
- 23% had a substance abuse issue
- 19% had been arrested
- 16% had been homeless

One-third  
of  
caregivers  
have cared  
for 10 years  
or more

## Figure 2: Duration of Care

*Q14. How long have you been providing/did you provide care to your [relation]?*

(n=1,601)

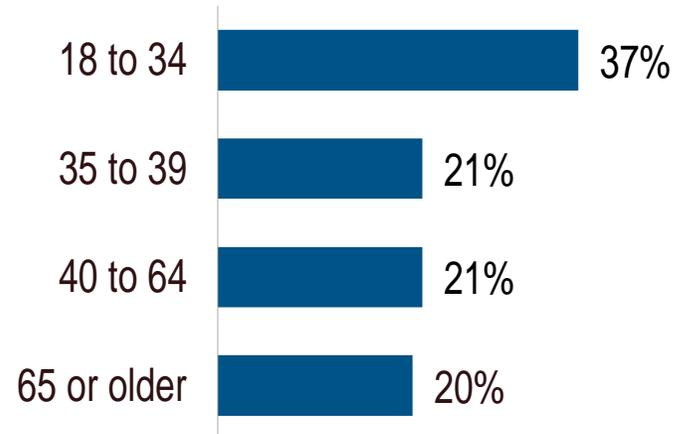


The majority of people receiving care were between 18-39 years old

## Figure 5: Care Recipient Age

Q13. How old is/was your [relation]?

(n=1,601)



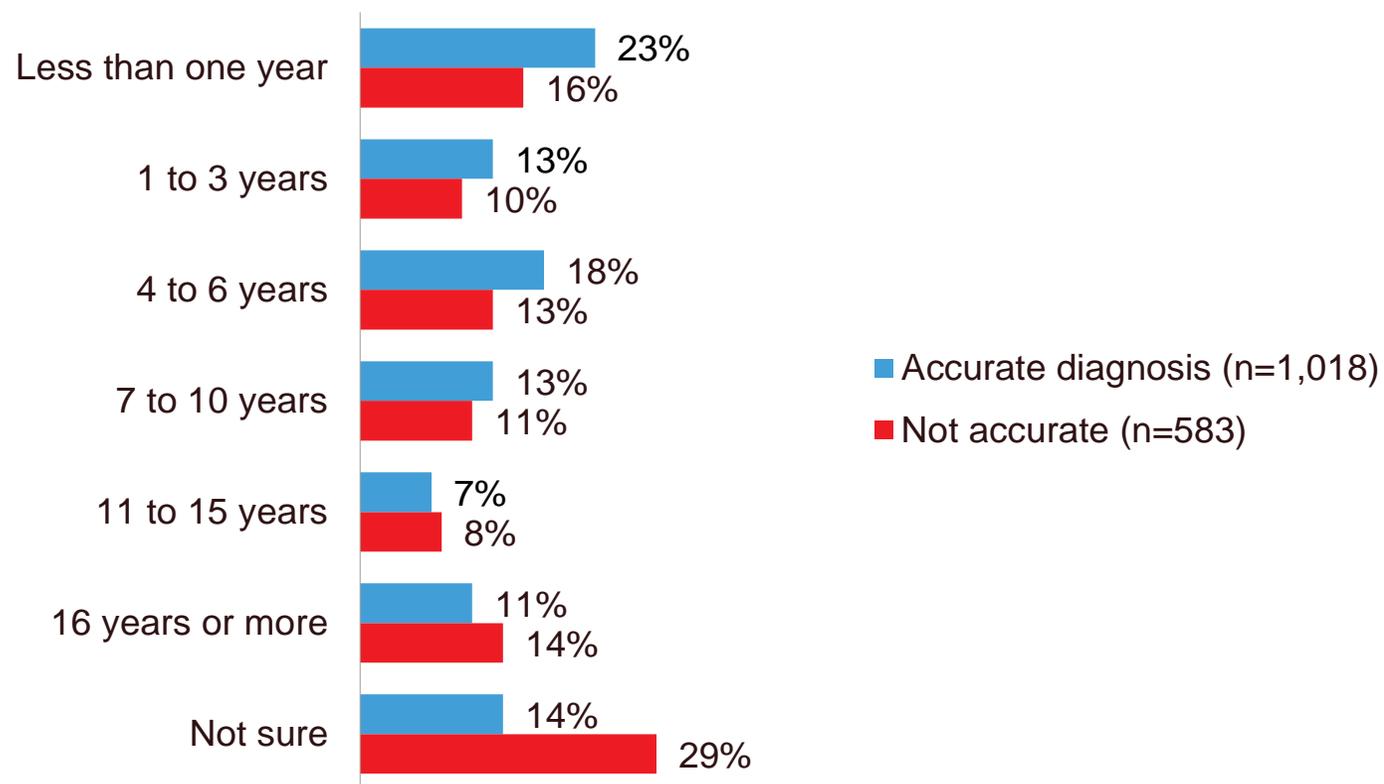
# Challenges: Time to Diagnosis

-Where families have an accurate diagnosis, it took 11.8 years on average to get there

-4/10 caregivers feel unsure that their loved one has an accurate diagnosis

**Figure 14: Time to Diagnosis**

*Q22. [If Accurate]: How many years did your [relation] display symptoms of an emotional or mental health issue before you felt he/she was accurately diagnosed/ [If Not Accurate]: How many years has/did your [relation] been trying/try to get an accurate diagnosis for his/her emotional or mental health issues?*



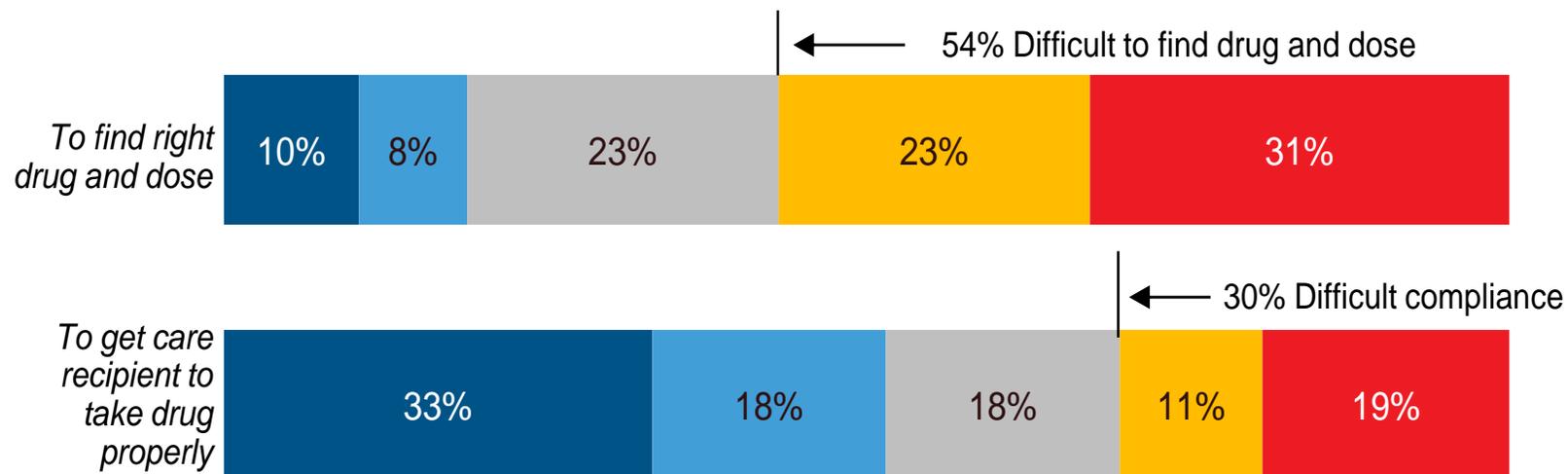
# Challenges: Medication Management

**Figure 12: Search for and Compliance with Prescription Medication**

*How difficult is/was it to...Q24a. find a specific drug and dosage that you feel works/felt worked for your [relation]'s mental health issue(s) / Q24b. get your [relation] to take his/her medication as prescribed (the right amount at the right time)?*

Caregivers whose recipient takes  
prescription medication  
(n=1,338)

■ 1 - Not at all difficult ■ 2 ■ 3 ■ 4 ■ 5 - Very difficult

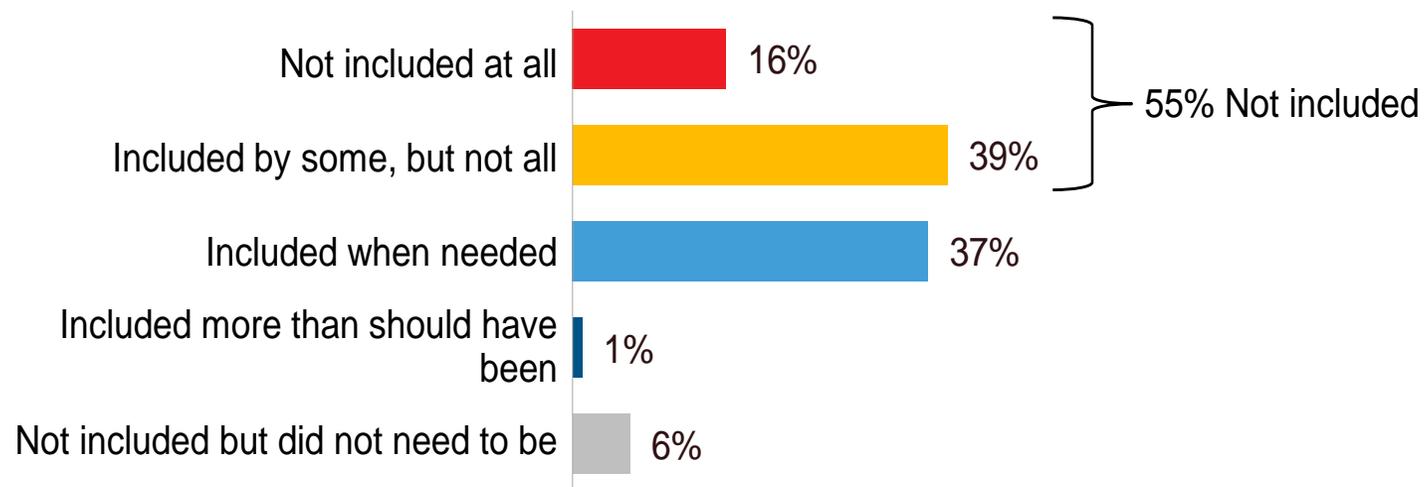


# Challenges: Caregivers often feel excluded from conversations with healthcare providers

## Figure 16: Conversations with Care Providers

Q33. To what extent do/did you feel care providers have/had included you in conversations about your [relation]'s care?

(n=1,601)

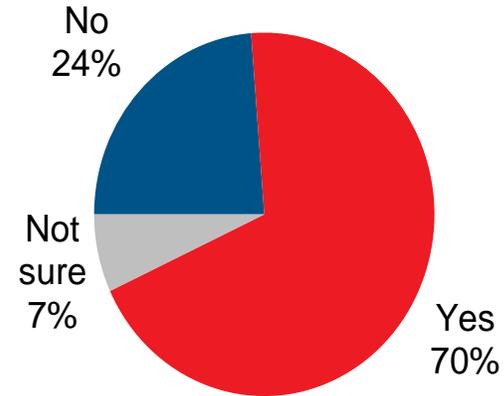


Challenges:  
Care recipients often discharged “too early” or “too quickly”

### Figure 23: Early Discharge in Crisis Situation

Q38. *Of all the times your [relation] went to an emergency room, hospital, or other facility due to an urgent mental health issue, do you feel he/she was ever sent home too early or too quickly?*

Caregivers whose recipient had crisis visit (n=1,256)

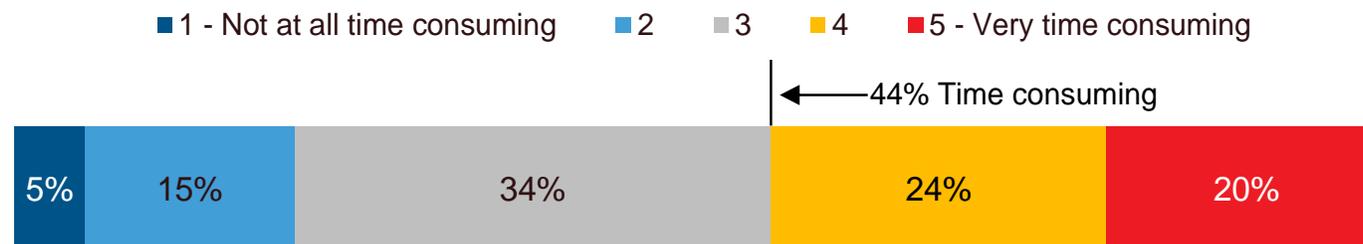


# Challenges: The “business of care”

## Figure 24: Time Spent Managing Paperwork or Finances

Q41. How time consuming is/was it for you to help your [relation] with his/her care paperwork or finances?

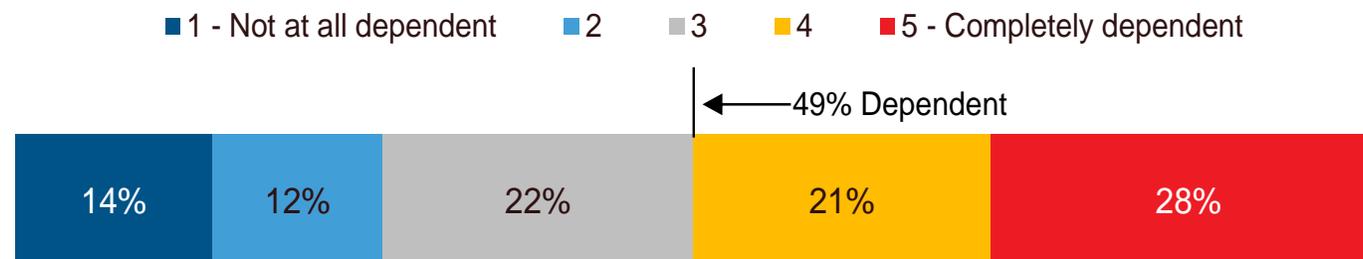
Those who manage recipient's finances  
(n=1,361)



## Figure 25: Care Recipient's Financial Dependence

Q43. How financially dependent is/was your [relation] on his/her family or friends?

(n=1,601)



## Other challenges

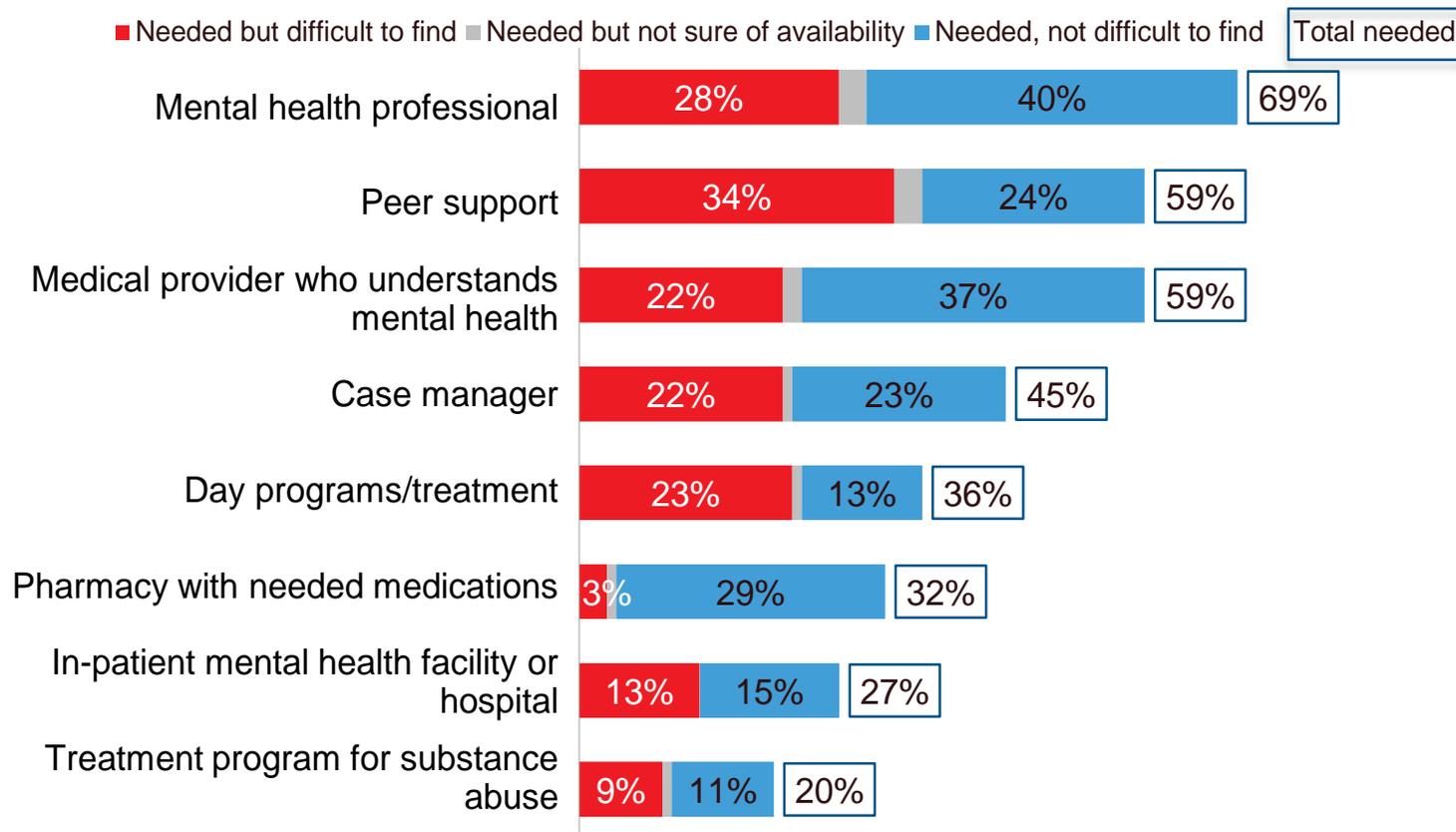
- **Arrest:** About one in three report their loved one has been arrested (32%)
- **Homelessness:** One in five caregivers report their loved one has been homeless for a month or longer (21%)
- **Self-Harm and Suicide:** Two-thirds of mental health caregivers are concerned their loved one will self-harm (68%) or die by suicide (65%)

# What social services would help with providing care?

## Figure 19: Service Needs and Availability

Q34. Select any care or support services you feel your [relation] needs/needed.  
 Q35. Which have been/were difficult to find in his/her area or community?

(n=1,601)



# Other findings

- Many caregivers express concern for the future, yet only half have made plans for their loved one's care
- Only 1 in 3 caregivers has guardianship or power of attorney. 40% would like more information
- 74% report that caregiving has been stressful
- 33% report their health as excellent or very good versus 27% who report it as fair or poor
- Yet, majority indicate that they feel closer to their relative (59%) and he/she appreciates the care they provide (55%)

# Public Policy Solutions

- **Integrate mental and behavioral health questions into all health care assessments,** and provide screenings.
- **Encourage treatment parity** for mental health issues with that of medical health issues.
- **Provide access** to a full array of high-quality behavioral and mental health services across the continuum of care.
- **Ensure patient access and reimbursement for appropriate medications** to treat mental illness.

# Public Policy Solutions

- Provide **assistance for both caregivers and patients in navigating the mental health system.** County and state providers can help.
- **Include caregivers as part of the health care team.**
- **Educate and provide resources** for caregivers of those with mental illness, especially around issues of stress and caregiver health.
- **Work to reduce the stigma of mental illness.**

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## Report Findings



Report available at:  
[www.caregiving.org/mentalhealth](http://www.caregiving.org/mentalhealth)