

## Newsletter

## In This Issue

People diagnosed with serious mental illnesses (SMI) including schizophrenia, bipolar disorder, major depression, and posttraumatic stress disorder, are at increased risk for physical health conditions and earlier mortality. Research suggests that the lifespan of people with SMI is reduced by as much as 10-20 years. Because of this increased likelihood of having medical conditions and early mortality, aging is thought to occur earlier in this population. The complex interplay between mental health symptoms and management of medical conditions in those with SMI places unique challenges on caregivers. While caregivers play a critical role in supporting older adults who live with SMI over the lifespan, little is known about SMI caregiving, and even less is known about SMI caregiving in older age.

November is National Family Caregivers Month and in this issue of the *E4 Center's Hot Topics Newsletter*, we highlight the latest research focused on caregiving for older adults with SMI. Typically, *Hot Topics* shares research published within the last year, however, due to the dearth of research on this important topic, we have highlighted publications over the last five years. Equally notable as the following research findings is the gap in knowledge in SMI, aging, and caregiving. A common theme shared by many of the following publications is a call to action for more research needed to support the wellbeing of older adults in this space and their caregivers.

For more information and resources, please check the **E4 Website** and **E4 Events Calendar**.



## Caregiving for Older Adults with Serious Mental Illness

Lived Experience-Led Research Agenda to Address
Early Death in People with a Diagnosis of a Serious
Mental Illness: A Consensus Statement JAMA Network
Open. May, 2023

Fortuna and colleagues report their findings and recommendations following the first virtual roundtable of its kind to address early mortality in people living with SMI. This two-day roundtable was comprised of forty members, most with lived experience of mental health and/or substance misuse, including peer support specialists, recovery coaches, family, and caregivers of people with SMI, researchers, clinicians, policymakers, and patient-led organizations. They used a virtual Delphi method to systematically discuss priorities for research and recommendations. The roundtable arrived at seven research and practice recommendations; advancing the role of family, extended families, and informal supporters was their second highest priority. Members emphasize the importance of family and caregiver involvement in treatments, caregiver education and training, as well as improving understanding on how to best support the unpaid care workforce.

Relationship Quality Among Persons with Serious
Mental Illness and Their Relatives: Rates and Correlates
Psychiatric Quarterly. May, 2024

Labrum and colleagues examined positive family dynamics in a community-recruited sample of 523 Americans with SMI. Theya examined the extent to which demographic variables, clinical characteristics, and types of relationship interactions were associated with relationship quality with a reference relative (RR; the adult relative with whom the participant spends the most time). Two-thirds of their sample reported high levels of relationship quality. Relationship quality was positively associated with frequency of contact, participants helping RR with activities of daily living, and care provided by the RR to participants. Participants whose RRs were romantic partners reported higher relationship quality than those whose RRs were parents or other family members. Better relationship quality was associated with less perceived emotional overinvolvement and psychological

abuse by RR toward the participant.

Mental health care for older adults: recent advances and new directions in clinical practice and research World Psychiatry. October, 2022

Reynolds and colleagues published a special article highlighting mental health care for older adults with an emphasis on dementia, major depression, schizophrenia, and substance use disorders, as these disorders are associated with more years lived with disability. The authors highlight the importance of positive elements of aging, including resilience, wisdom, and prosocial behavior, to combat stigma and improve mental health of older adults. Among several critical recommendations to improve care and mental health of older adults, the authors emphasize that care should not only be patientfocused, but also family centered. They emphasize that family caregivers play a large role in accurate clinical assessment and clinical interventions, leading to improved wellness and minimization of adverse events for the older adult. They call for more research to best support caregivers to older adults with mental illness.

Challenges, rewards, and lessons learned from family and community caregivers of individuals with serious mental illness and cancer Supportive Care in Cancer. July, 2023

Murphy and colleagues explored common challenges and rewards from qualitative interviews with thirteen caregivers (both family and community caregivers) to adults with SMI who were recently diagnosed with head or neck, breast, lung, or gastrointestinal cancers. Transcribed interviews were coded and analyzed to determine common themes. Common challenges included impact of mental health symptoms on timely diagnosis, treatment, care coordination, and resources available to SMI and cancer caregiving. Both family and community caregivers reported that they found it rewarding to be a part of a person-centered care model. Caregivers also highlighted the importance of tending to their own needs as well as advocacy and a team-based approach to combating mental health stigma and coordinating care.



Social isolation and loneliness in family caregivers of people with severe mental illness: A scoping review

American Journal of Community Psychology. August, 2023

Guan and colleagues conducted a scoping review aimed to characterize the current evidence and identify knowledge gaps in the topic of social isolation and loneliness in caregivers to adults with SMI. Fifty-one publications were included, over half with quantitative data. While definitions of loneliness were consistent, definitions of social isolation varied across studies. Risk factors and correlates of social isolation and loneliness were grouped into categories of sociodemographic factors, illness-related factors, health and wellbeing, and stigma. There was a lack of comprehensive measurements assessing social isolation and loneliness, few longitudinal studies, and few interventions addressing these constructs in this population. They also summarized findings in a cross-cultural lens and found that caregivers across nine countries reported that negative attitudes about SMI contributed to feelings of social isolation and loneliness, speaking to the importance of addressing mental health

Experiences and views of carers regarding the physical health care of people with severe mental illness: An integrative thematic review of qualitative research Journal of Psychiatric and Mental Health Nursing. October, 2021

Ho and colleagues conducted an integrated thematic review to synthesize experiences and views of caregivers on the topics of physical health care in SMI. In their search from publications from 2000-2021, five studies were included. Nine themes were identified across the categories of caregiver perceived facilitators, barriers, and roles in physical health care for people with SMI. They found that caregivers generally feel that receiving practical help, as well as having mental health nurses pay special attention to physical care needs, would facilitate care. Common barriers included lack of care coordination, poor communication and responsiveness, and limited-service access. They recommend revamping clinic models to better integrate mental and physical care needs. They also call for creating specialized roles for mental health nurses to specifically address caregiver concerns about physical health and medication side effects as well as identify ways to proactively support their goals to promote physical health in those with SMI.

## **Upcoming Events**

You can register for these events or learn more by going to our website at e4center.org/calendar

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Exploring Ethical Dilemmas in Capacity Assessments
Speaker: Peter A. Lichtenberg, PhD, ABPP
December 4 @ 12:00 pm - 1:30 pm CST