Older Adults with Schizophrenia and Their Caregivers – An Often Invisible Population

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Often when we think of Serious Mental Illness (SMI) including schizophrenia, we do not think of older individuals. This exclusion is also apparent in the scientific literature as over 90% of the published papers on schizophrenia have ignored older persons with this disorder (Broadway & Mintzer, 2007). Although most older adults with schizophrenia experience onset of the illness at early ages, usually in the second or third decade of life (Wetherell & Jeste, 2004), approximately 23.5% of patients with schizophrenia developed the illness after the age of 40, and roughly 4% of persons with schizophrenia have onset after the age of 60. Community prevalence estimates for schizophrenia in individuals over the age of 65, ranges from only 0.1% to 0.5% (Broadway & Mintzer, 2007). This number, as well as the number of older adults with all mental disorders, is expected to increase as the older population grows, and as cohorts of middle-aged and younger individuals who are receptive to psychological services move into old age (Karel, Gatz & Smyer, 2012).

Unfortunately, inaccurate perceptions and stereotypes of aging can lead both health care providers and families of individuals with schizophrenia to have lower expectations for improvement among these individuals. Quite the opposite is true. Research on older adults with schizophrenia reveals that positive symptoms of schizophrenia do abate with age, use of illicit substances becomes less frequent, and mental health may improve (Depp , Loughran, Vahis, & Molinari, 2010; Harvey, Reichenberg, & Bowie, 2006). However, the stressful lives of those with schizophrenia takes its inevitable toll, especially due to hospitalizations for acute psychotic episodes, ingesting of multiple psychiatric medications, substance misuse, greater victimization, frequent incarcerations, and potential for homelessness. It is no wonder that those with schizophrenia's health status is often compromised at a relatively early age, and that they live 12-15 years less than their age matched peers with no SMI (Crump, Winkleby, Sundquist, & Sundquist, 2013).

The majority of older adults with schizophrenia live in community settings, with approximately one-third to one-half residing with family members (Cummings & Kropf, 2011; Lefley, 1987; Goldstein & Caton, 1983; Tessler & Goldman, 1982). This poses challenges for caregivers, as many of them do not fully comprehend the complexity of SMI and are ill-equipped to assist older adults with symptom management. For optimal mental and physical health outcomes for both older adults with schizophrenia and their caregivers, caregivers need to be knowledgeable about where to seek treatment and which specific interventions are culturally appropriate, evidenced based, and available within the community in which they reside.

Interventions for Older Adults with Schizophrenia

Older adults with SMI do benefit from both psychological and/or pharmacological interventions. Psychosocial interventions such as cognitive behavioral social skills training and Functional Adaptation Skills Training (FAST) are efficacious in improving functioning in older adults with schizophrenia (Jeste & Maglione, 2013). Adults aged 40 and over who completed this 24-week behavioral intervention that targeted six areas of everyday functioning, maintained improved living and social skills up to 3-months after completing the intervention (Patterson, Mausbach, McKibbin, Goldman, Bucardo, & Jeste, 2006). Mueser et al. (2010) developed Helping Older People Experience Success (HOPES), a program designed to reduce long-term medical burden and to improve psychosocial functioning in older adults with SMI living in the community. By adding a year-long social skills training component to the typical pharmacotherapy and case management regimen, older participants (aged 50+) with SMI improved more

in social skills, community functioning, negative symptoms, self-efficacy, and recreation. These improvements were sustained for at least three years (Bartels, et al., in press). The authors conclude that psychosocial rehabilitation (including health management and skills training) that is integrated with case coordination can benefit older adults with SMI who have long-standing functional impairments. Another program, Assertive Community Treatment (ACT) teaches living skills, and provides assistance with housing, family contact, medical care and medications, finances, counseling, and vocational rehabilitation for those with SMI. The services are provided 24 hours a day/7 days a week (wrap-around model). A recent randomized control trial tested the effectiveness of ACT for 62 older outpatients (60+ years) with SMI who were difficult to engage in psychiatric treatment. Relative to patients with treatment as usual, less older patients in ACT dropped out and more patients had a first treatment contact within three months. However, there were no differences found in mental health care use or psychosocial functioning scores (Stobbe et al., 2014).

It is also true that older adults with histories of chronic, SMI, including schizophrenia may benefit from providers with expertise in aging issues as they may experience additional age-related challenges such as cognitive impairment, medical comorbidity, polypharmacy, and end-of-life issues. In addition, psychotic symptoms associated with dementia are evident in up to 40% of patients, and the presence of psychosis predicts more rapid cognitive decline and institutionalization (Depp, et al., 2010). A provider is thereby required who is skilled in differentiating among the medical and psychiatric causes of hallucinations and delusions in schizophrenia versus dementia.

Unfortunately, in the United States, community programs often do not target older adults with schizophrenia, and assisted living facilities are not well regulated regarding mental health concerns. Even in the more regulated nursing home industry, training is sorely needed. Those with SMI make up approximately 10% of the nursing home residents (Becker & Mehra, 2005). These residents have their unique constellation of mental health needs and are unfortunately lumped together with those who have dementia with the expectation for cognitive decline. Nursing home residents with schizophrenia are more likely to be younger and male, and staff fear that they may behave aggressively towards frail women. The staff of the typical nursing home recognize the need and desire more training in the mental health arena (Molinari et al., 2008). A recent online training program showed positive results for formal caregivers in changing attitudes, improving knowledge, and gaining self-efficacy in dealing with mental illness in a long term setting (Irvine, Billow, Bourgeois & Seeley, 2013). Education and supervised training of staff in residential care settings may be keys to improved care for this vulnerable group.

Interventions for Informal (Family) Caregivers of Older Adults with Schizophrenia

Twenty-five percent of caregivers of adults 50 and older report that the care recipient they help needs care because of emotional/mental health issues (National Alliance for Caregiving, 2009). Family caregivers frequently assume supportive functions for an older adult with SMI because of the scarcity of community based housing alternatives and mental health services (Lefley, 2009). Indeed, individuals with schizophrenia who live with informal caregivers are less likely to have been hospitalized during the previous year compared to those without informal caregivers, perhaps because of the support that they receive (Tucker, Barker, & Gregoire, 1998). Assuming this responsibility doesn't come without cost, however. It has been reported that spouses of patients with mental illness are at high risk for developing a depressive disorder (Wittmund, Wilms, Mory, & Angermeyer, 2002).

Research on ethnic differences in caregivers' duties and burdens related to caring for family members with SMI is sparse. Similar to findings reported by family carers of older adults with other medical conditions, ethnic minorities report less feelings of burden and are more accepting of their caregiving role for family members with SMI compared to Whites (Guarnaccia & Parra, 1996; Horwitz & Reinhard, 1995). Although ethnic minorities are more apt to embrace the role of caregiver, they are less likely than

Whites to seek assistance from mental health professionals (Guarnaccia & Parra, 1996; Neighbors et al., 2008). Levels of understanding and perceptions of need vary among these groups. Primarily because receptivity is a major factor to successful outcomes, in order to engage and retain ethnic minority caregivers in mental health interventions a one size fits all approach should be avoided.

An online survey of family caregivers of older adults with SMI found four major areas of caregiver concern for future planning: worry that the health of the care recipient will get worse; worry that aging caregivers will be unable to sustain support over time; concern that social support will become less available for the loved one with SMI; and, increasing financial burden of care. Unfortunately, despite these legitimate concerns, few caregivers complete plans for future caregiving, and often they had not even discussed future caregiving with others (Corsentino, Molinari, Gum, Roscoe, & Mills, 2008). This may be understandable given the amount of day-to-day effort that is expended by the caregivers of individuals with SMI – they may have little time to spend thinking about the future in a concentrated way.

There is encouraging evidence for evidence-based practice in addressing the concerns and mental health needs of family caregivers of individuals with schizophrenia. Older family caregivers of adult patients with schizophrenia who completed a 10-session problem-solving intervention, consisting of psycho-education and information about schizophrenia, cognitive restructuring and stress management, behavior management, and planning to meet the future needs of the care recipient showed improved emotional well-being and life satisfaction, and reduced feelings of burden (Kauffman, Scogin, MacNeil, Leeper, & Wimberly, 2010). Family psycho-education also proved effective in reducing caregiver burden among families in a Latin American country (Gutiérrez-Maldonado & Caqueo-Urízar, 2007). Counseling services for family caregivers of individuals with schizophrenia were beneficial in allowing caregivers to express their feelings and concerns, to learn more about their loved one's illness, and to obtain guidance and advice related to caregiver issues (Bloch, Szmukler, Herrman, Benson, & Colussa, 1995). The National Alliance for the Mentally Ill (NAMI) has sponsored The Planned Lifetime Assistance Network (PLAN) to provide future care planning services which has yielded positive outcomes including decreased family stress, improved family relationships, and allowing parents to focus on their own lifespan needs (Obloy & Hutcheson, 2002). Family caregivers of persons with SMI can also benefit from respite care. Respite services are widely utilized by caregivers of dementia patients and have proven to significantly improve the caregivers' quality of life; however, while these services are desired and needed by caregivers of individuals with SMI they are not as prevalent for this population (Jeon, Brodaty, & Chesterson, 2004).

There are also a number of excellent online resources for caregivers of individuals with mental disorders. The American Psychological Association's Family Caregivers Briefcase, a 166 web page resource that contains facts, strategies for involving caregivers, interventions, and assessment tools for caregivers and care recipients across the lifespan, including for caregivers of individuals with mental disorders. One section of the Briefcase provides links to resources available for families and caregivers of individuals with SMI.

In closing, it should be noted that experts in schizophrenia who work with older adults often adhere to the principles of the Recovery Movement, maintaining the belief that we have been unnecessarily pessimistic in our outlook regarding the developmental course of schizophrenia. All health care professionals should encourage self-determination, honoring the rights of those with schizophrenia to make their own life decisions, to define their own quality of life criteria, and to live in the least restrictive environment (APA, 2009). In addition, health care providers and family caregivers must be strong advocates for government and organizational policies supportive of older individuals with SMI. The APA Family Caregiver Briefcase includes profiles of psychologists involved in such advocacy efforts.

We have moved in a positive direction in the last forty years from when many health professionals regarded family members of individuals with schizophrenia and bipolar disorder as harmful agents who may have had a role in the development of these chronic illnesses (APA, 2011). However, there continues to be a significant need for education to counter the belief that schizophrenia is caused by family behavior, and for increased availability of evidence-based programs to support family caregivers of older adults with schizophrenia and other serious mental illness.

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