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Investigating Care Models to Support Older Adults with Depression and Health Comorbidities

Guidance Report

Peer Research Topic Priorities



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THE VALUE AND IMPORTANCE OF PEER CENTRIC RESEARCH

Recent years have seen an acceleration in patient-centered care and peer-centric research. The cornerstone of patient-centered care is emphasizing an individual's needs and desired outcomes when determining the best course of treatment and whether that treatment has been successful.

People with lived experience of mood disorders, referred to as peers, hold unique perspectives regarding the impacts of their condition, their experiences of care, and their treatment goals. Research reveals that these perspectives may not always align with clinician or researcher perceptions.

For example, one online survey of people with mood disorders and healthcare providers found that patients reported more mood, physical, and cognitive symptoms and a higher impact on psychosocial functioning in the post-acute and remission phases than the healthcare providers reported. These individuals also reported worse Quality of Life and greater levels of functional impairment than providers.¹

Additionally, traditional ideas on improvement based on symptom change may not adequately represent the perceived impact of treatment by

the individual. In one study, almost half of patients meeting the criteria for symptomatic remission did not subjectively consider themselves to be in remission.²

These results underscore the importance of peer-centric research grounded in the meaningful involvement of people with lived experience across the continuum of the research process, beginning with:

- identification of research questions, through
- shaping the design and conduct of research, all the way to
- dissemination of findings.

These discrepancies in perception prompted the Depression and Bipolar Support Alliance and the National Network of Depression Centers to partner on a project titled “Investigating Care Models to Support Older Adults with Depression and Health Comorbidities” to better understand peer research topic priorities. The Patient-Centered Outcomes Research Institute (PCORI) provided funding for this work through a Eugene Washington Engagement Award (EASC-23195).



1 Baune, B.T., Christensen, M.C., 2019. Differences in perceptions of major depressive disorder symptoms and treatment priorities between patients and health care providers across the acute, post-acute, and remission phases of depression. *Front Psychiatry* 10, 335.

2 Zimmerman, M., Martinez, J.A., Attiullah, N., Friedman, M., Toba, C., Boerescu, D.A., Rahgeb, M., 2012. Why do some depressed outpatients who are in remission according to the Hamilton Depression Rating Scale not consider themselves to be in remission? *J. Clin. Psychiatry*. 73, 790–795.

PROJECT BACKGROUND

Depression often co-occurs with late-in-life health conditions such as cancer, diabetes, and heart disease. Primary care providers have tested a few approaches to improving late-life depression and health comorbidities. These include IMPACT (Improving Mood Promoting Access to Collaborative Treatment) and PROSPECT (Prevention of Suicide in Primary Care Elderly – Collaborative Trial). While these models use clinical management and patient follow-up, they fail to address the importance of a holistic approach in supporting patients’ physical and mental health rooted in patient engagement and reducing isolation and self-stigma due to depression.

Patient-centered care aims to place individuals, their values, preferences, life, and health goals at the heart of the care process and to actively involve patients in care decisions. However, few comparative effectiveness research (CER) studies are specific to patient-defined outcomes for older adults with depression and health comorbidities.

Few comparative effectiveness research studies are specific to patient-defined outcomes for older adults living with depression and health comorbidities.

Recognizing the positive impacts of peer engagement in research, DBSA and NNDC convened the following stakeholder communities:

- peers and caregivers,
- clinicians and researchers, and
- patient advocacy organizations.

The goal was to elicit recommendations from these stakeholder communities on research topics and questions for future CER projects.

Patient-centered care aims to place individuals’ values, preferences, and goals at the heart of care decisions.



PURPOSE OF THIS DOCUMENT

Increasing stakeholder engagement in research has the potential to improve patient-centered care.

Twenty-eight individuals participated in a virtual convening held by DBSA and NNDC in August 2022. Invitations were extended to create an equal representation between the peer and patient advocacy communities and the clinician and researcher communities.

The convening agenda included sharing results from a survey of older adults living with chronic physical health conditions developed by DBSA and NNDC and distributed to older adults and caregivers. This session was followed by a presentation from Lokesh Shahani, MD, PhD, FACP, sharing work completed by the NNDC Geriatric Mood Disorders Task Group that illustrated the gaps between learnings from the survey and existing CER research.

During the presentation of the survey results, participants were asked to provide observations

about questions raised or thoughts about their personal experience as a stakeholder in real-time via online software. This feedback was used to develop questions for the small group discussions.

DBSA and NNDC elicited feedback from the stakeholder community through:

- large group discussions,
- breakout group discussions,
- reports from the breakout groups,
- individual lists of recommendations, and
- group voting on the individual recommendations.

This document is divided into three sections:

- High-level overview of the older adults living with chronic physical health conditions survey results,
- Gap analysis between peer and caregiver responses to the survey and existing research in this area,
- Recommendations from participants on future research topics.

Four research topic categories are presented for future researchers and funders to consider when designing and developing research proposals that can benefit older adults living with depression and chronic physical health conditions.

This report provides guidance derived from the generous input of the convening participants.



OLDER ADULTS LIVING WITH DEPRESSION AND CHRONIC PHYSICAL HEALTH CONDITIONS SURVEY

Survey respondents reported that depression had a more significant impact than the chronic physical health condition did on self-care.

To better understand the needs of older adults living with depression and chronic physical health conditions, DBSA and NNDC partnered on survey development. As the leading national peer-focused organization for people living with mood disorders, DBSA drew upon its expertise in developing similar surveys to create a draft questionnaire. A DBSA peer council of seven members representing older adults living with depression and chronic physical health conditions reviewed the survey for appropriate use of peer-centric language and to identify topic gaps that should be included.

The questionnaire was also shared with the Project Advisory Committee (PAC). The NNDC submitted an application to an institutional review board (IRB) and were informed that a formal human subjects review of the survey was not necessary. The NNDC Geriatric Mood Disorders Task Group's representatives reviewed the survey questions and made design recommendations.

The survey was distributed via DBSA social media and online newsletters. NNDC distributed through its member channels, and the PAC received a social media toolkit. At the time of the convening, 179 respondents met the inclusion criteria: over sixty years old and living with depression and a chronic physical health condition or being a caregiver of someone meeting that criteria. Respondents could either fit the definition of depression by identifying

with a formal diagnosis or indicating that they lived with symptoms of depression, such as prolonged sadness, low mood or energy, or feelings of worthlessness.

Among the initial responses, eighty-two percent identified as female, and forty percent reported being married, cohabitating, or in a domestic civil union. Fifty percent reported being or caring for someone in their 60s; thirty-one percent reported being or caring for someone in their 70s; three percent reported being or caring for someone 80 or older.

Respondents could select from a list of seventeen physical health conditions with no limit to the number selected. Eighty-eight percent of the respondents live with or care for someone with multiple physical health conditions. The most common health condition selected was high blood pressure, followed by arthritis and sleep disorders. Sixty-six percent of the respondents shared that they experienced depression before the reported chronic physical health condition(s). Fifty-eight percent of those respondents stated that the depression had worsened since experiencing the chronic physical health condition.

Survey respondents reported that depression had a more significant impact on self-care than their chronic physical health condition. Additionally, there was a greater impact on activities of daily living due to experiencing depression. Finances were also affected. Thirty-three percent indicated a significant impact on their finances or needing to choose between treating the depression or the physical health condition.

We sought to understand the prevalence of integrated care by asking respondents if their mental health and/or physical health care teams asked about their other conditions. More respondents reported that their mental health care team asked at every visit versus the physical health care team. Similarly, the mental health care team was more likely to ask about medication interference than the physical health care team.

GAPS IN RESEARCH

The NNDC works to change the national conversation surrounding mood disorders through large-scale collaborative studies, education, and outreach. This groundbreaking work occurs within multidisciplinary teams of leading clinicians and researchers from member institutions who devote their time and expertise to one or more initiatives related to diagnosing, treating, and preventing depressive disorders.

Incidence of Depression and Health Comorbidities in Older Adults

The association between depression and medical comorbidities in older adults is well established, but research is needed to provide a more nuanced or granular perspective. Aside from the lack of studies exploring the direction of the association (i.e., possible causality), the different contribution of specific medical conditions (e.g., cardiovascular vs. metabolic vs. neurologic) remains to be determined. Furthermore, little research has delved into the topic through either a diversity, equity, and inclusion prism or looked at the impact of COVID-19.

Impact of Depression & Health Condition(s) on Each Other

Depression has very complex pathophysiology involving multiple levels of distinct biological processes, such as neurotransmitters/neural circuits, inflammation, oxidative stress, and metabolism. This scenario is complicated in older adults by possible emerging neurodegenerative processes. While studies have investigated these different mechanisms in older adults with depression, they should be investigated in a framework that considers medical comorbidities.

The NNDC Geriatric Mood Disorders Task Group, which focuses on projects and research into mood-related disorders in older populations, undertook a literature review to identify potential research gaps related to the needs identified through the survey. The literature review uncovered seven potential gaps in research, as detailed below.

Integrated Behavioral Health Care Models to Treat Depression & Health Comorbidities in Older Adults

Studies have explored different healthcare models to treat medical comorbidities in people with severe mental illnesses, including schizophrenia and mood disorders. The literature on specific models to treat depression and medical comorbidities in older adults is minimal. Furthermore, the studies are heterogeneous in their measures (e.g., depression screening tools, primary outcomes), preventing comparison among them.

Models for Treating Depression and Health Comorbidities in Older Adults

There are limited data on the differential role played by distinct health professions (i.e., Primary Care Physician vs. Nurse Practitioner vs. Physician Assistant) in treating depression and medical comorbidities. Few studies have examined the accessibility and effectiveness of collaborative care models in culturally diverse and/or underserved communities.

Few studies have examined the accessibility and effectiveness of collaborative care models in culturally diverse and/or underserved communities.





58%

of survey respondents stated depression had worsened since experiencing chronic physical health condition(s)

GAPS IN RESEARCH (continued)

Peer Support for Depression and Health Comorbidities in Older Adults

The role of peer support in managing depression and medical comorbidities remains to be investigated. Besides exploring its potential benefit, issues such as technology literacy and cultural competency must be addressed.

Interest in Comparative Effectiveness Studies

As mentioned under the section Integrated Behavioral Health Care Models to Treat Depression & Health Comorbidities in Older Adults, effectiveness comparisons have been hampered by the heterogeneous nature of the available studies (e.g., samples differ regarding medical comorbidity, socioeconomic and racial/ethnic profile or enrolled participants, type, length and intensity of interventions, and outcome measures).

Other Related PCORI Studies

No definite conclusion can be reached due to the limited number of relatively small PCORI studies available. The PCORI studies reviewed included the following:

- Comparing Two Ways to Help Latinx Patients with Depression Who Are Age 50 or Older
- Comparing Two Treatments for Depression among Patients with Kidney Failure Receiving Hemodialysis -- The ASCEND Study
- Comparing Two Ways to Treat Serious Worry among Older Adults from Underserved, Racial or Ethnic Minority Communities
- Comparing Cognitive Behavioral Therapy versus Yoga for Helping Older Adults Address High Levels of Worry

RECOMMENDATIONS FOR RESEARCH TOPICS

After learning about the survey results and the gaps in research, the convening participants engaged in guided exercises designed to obtain feedback on recommendations for future research topics. These were designed to benefit the community of older adults living with depression and chronic physical health conditions, and focused on four key areas:

- Self-care
- Financial considerations
- Activities of daily living
- Collaborative medication management or reconciliation

The guidance below discusses these areas and provides a CER research topic recommendation.

Self-care

Peer-led health navigation to help patients meet their mental, social, and physical health needs

was identified as the number one CER research priority in this category. Included under this umbrella are topics on care coordination and learning from peers about how to recover and thrive. The effects of family engagement on self-care were also recognized as important.

Contributing to this recommendation was a discussion around providing peers and patients with support in identifying personalized health improvement goals, especially in the posthospitalization phase of recovery.

Activities of daily living

Discussion around this topic underscored the acknowledgment that researchers and the peer community often have different perceptions. Academic and policy-making institutions may have different definitions around the category of activities of daily living. Regardless, there was an overwhelming consensus that this category's top research priority is **integrating community-based services and supports with physical and mental health care**.

Personalization was a central theme during the guided discussion exercises. This theme incorporates the idea of “meeting people where they are” and a “one-size does not fit all” acceptance among the care teams. Training family members and/or using peer support specialists was recognized as possibly adding value.

Financial considerations

Using peer mentors, navigators, or peer support specialists to improve health outcomes and assist in navigating complex health systems

was the number one recommendation in this category. Discussions throughout the day that led to this recommendation included recognizing the financial impact re-hospitalization has on the individual and their family. Convening participants suggested that providing peer support to the patient, as well as the family, has the potential to address post-discharge challenges.

Collaborative medication management or reconciliation

Understanding models to assist people with cognitive impairment, including using allied professionals to manage medications, rounds out this last category. Discussion throughout the day focused both on medication management and reconciliation. It is essential to know the comfort level among patients and caregivers in addressing management and reconciliation. Beginning with this baseline understanding and insight has the potential to improve CER models.

Providing peer support to the patient as well as the family has the potential to address post-discharge challenges.

CONCLUSION

Older adults living with depression and chronic physical health conditions can face unique challenges to obtaining positive health outcomes. Many factors contribute to these challenges. Stigma around depression is just one barrier and is not isolated to the general population. Educating researchers about stigma experienced by patients, caregivers, and healthcare providers must be prioritized. Researchers should also be encouraged to work out in the community. Both concepts lay a foundation for improved stakeholder engagement in research. If we accomplish this, researchers will be in a better position to understand the self-care and financial considerations peers and caregivers face. This can ultimately provide them with the insights necessary for research project design, development, and implementation that best serves the population they seek to benefit.



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APPENDIX I

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