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Rural Community Engagement for Mental Health

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INTRODUCTION/BACKGROUND

Community engagement has been defined as "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people"[1]. Several research models have been used to apply the principle of community engagement. Patient Centered Outcomes Research (PCOR) and Community Based Participatory Research (CBPR) have common principles of involving the subjects of research, or stakeholders, throughout the research process and should be thought of as complementary approaches[2,3]. CBPR is one of the most well-known models of Community Engaged Research (CEnR) and focuses more broadly on a community's health. PCOR, which is a more recently proposed framework, focuses more on patients and medical problems[4]. Community-engagement strategies have been used successfully in mental health research and have been proposed as ideal for addressing stigma associated with mental illness[5,6,7,8,9]. However, little has been published about using a community-engaged approach to address mental health and associated stigma in rural communities.

Using community-based participatory research (CBPR) and patient-centered outcomes research (PCOR) principles, we aimed to develop a mental health patient-centered research community and advisory board for two rural communities in the Midwest with the long-term goal of improving mental health care, self-management, and outcomes in these communities. Focus groups and the development of a mental health research advisory committee (MHRAC) were used to engage the community. We outline the process of conducting focus groups and developing MHRAC, as well as forming a partnership between a major academic institution and its neighboring communities. We discuss lessons learned from this process and demonstrate the quality of work that can be created through successful partnerships.

STUDY DESIGN/METHODS

Focus Group (FG) Recruitment (September-November 2016):
- Rural adults in the Midwest
  - Direct mental health care providers
  - Community members
  - Adults with mental health concerns and their supporters
- Recruitment
  - Flyers
  - Social media
  - Networking
  - Word of mouth
- Five 90-minute FG; 12 adults/FG
- Compensation: $25 Visa gift card and meal

Discussion Topics
- Mental health stigma
- Self-management and mental health care
- Access to care
- Financial education
- Emergency room care
- First responder issues

Mental Health Research Advisory Committee (MHRAC)
- Two-hour monthly meeting (Jan-April 2017)
- Compensation: $20 Visa gift card per meeting and dinner
- Reviewed, summarized, and de-identified the focus group transcripts

Table 1[2,11]. Application of Community Engagement Principles

Patient-Centered Outcomes Research (PCOR) Strategy Kwon et al., 2018	Community-Based Participatory Research (CBPR) Principles Kwon et al., 2018	Application in this Project
Research with patients as full partner Researcher and patient stakeholders share control equally	Collaborative, equitable partnership in all phases of research -- from identifying priorities to design to intervention development and implementation to evaluation to dissemination	Stakeholders involved throughout process, including participation in the focus groups and in developing the focus group summaries
Patients as participants and collaborators	Community is the unit of identity -- focus is on the community	Creation of a Mental Health Research Advisory Committee (MHRAC) that represents the different perspectives of the community
Uses an asset-based approach to developing interventions building on assets in patient, caregivers, family, and provider settings	CBPR builds on strengths and resources of community	Worked with local health services groups in identifying focus group participants and disseminating the focus group summaries
Researchers and stakeholders work together to help build community capacity	CBPR fosters co-learning and capacity building	Academic partners offered ongoing support for Mental Health Research Advisory Committee meetings and stakeholders outlined a strategy for continuing patient and community engagement in mental health research
Researchers and patient stakeholders identify at the onset their expectations and goals of the research to be conducted and determine the practical benefit for patient stakeholders in engaging research	Balance between knowledge generation and benefit for community partners	Project prioritized community benefit and developing engaged community partners. Project was not designed primarily as research but as a path leading to mental health research in the communities
Stakeholders identify problem or works with researcher to identify problem	CBPR focuses on problems of local relevance --communities determine the priorities	Focus groups used to identify community's priorities
Goal of the research is not only about advancing knowledge but includes a process that allows for reflection, quality improvement, and actions related to improving engagement and sustainability that includes ongoing assessments of successes and challenges	CBPR occurs through a cyclical and iterative process	Mental Health Research Advisory Committee wrote the summaries from the focus groups transcripts in an iterative process
Data is shared, researchers and patient stakeholders decide its use and dissemination	CBPR disseminates results to all partners and involves them in wider dissemination of results	All community partners and participants received the focus group summaries
Sustainability is an ongoing goal to strive towards	CBPR involves a long-term process and commitment to sustainability	Project was designed to empower local groups with academic and non-academic partners

RESULTS

Successful Community Engagement in rural communities
- ***Focus Group Attendance (goal=12 participants/FG)***
  - 38 participants
  - Direct mental healthcare providers and community members
    - FG1 (N=8)
    - FG2 (N=9)
    - FG3 (N=12)
  - Adults with mental health concerns and their supporters
    - FG4 (N=4)
    - FG5 (N=5)
- ***Mental Health Research Advisory Committee (MHRAC):***
  - 24 volunteers
    - Adults with mental health concerns (N=7)
    - Supporters of adults with mental health concerns (N=4)
    - Community members (N=7)
    - Researchers (N=4),
    - Mental Health Clinicians (N=3)
    - Stakeholders (N=5)
- ***High quality discussions***
  - FG transcripts: *"It's not talked about": Mental Health in Rural Communities*[10] (250 pages)
  - MHRAC summary (28 pages): distribution within the communities

Comparison between FG transcripts and MHRAC summaries
- Transcript topics adequately mentioned in the summaries
- However, the transcript narrative may have expressed stronger sentiments than presented in the summaries (FG4/5).

DISCUSSION/CONCLUSION

Focus Group Saturation
- Lower saturation in FG4/5
- Possible reasons include stigma, risk of disclosure and the academic partners being a new mental health entity in the community

Focus Group Summary Discrepancies
- There may be biases among adults with mental health concerns and their supporters (FG4/5) and what they report as challenges to accessing mental healthcare
- *Possible Hypotheses for biases*
  - Need to preserve the reputation of the health care providers or community
  - Stigma
- Despite these limitations, the need for improved access to mental health care was uniformly reinforced throughout focus group transcripts and summaries.

Impact
- Transcript summaries distributed throughout the community
- Identified themes continue to be addressed within the community
- MHRAC email distribution list and website
- Responsibility for ongoing dissemination of findings in a way that honors participants and reduces mental healthcare stigma

REFERENCES: