

Modifying and Adapting EBPs: The Family Psychoeducation Project in Three Diverse Communities

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*Lessons Learned: Embedding Evidence-Based Practices
in Statewide Transformation*

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Presentation Overview

- Background: NYS Context
- The SAMHSA Grant: Aims, Methods, Challenges
- Select Findings and Lessons Learned



PART I: **Background**



Background: NYSOMH Context

- 2001 - Family psychoeducation (FPE) was selected as one of 3 priority EBPs for adults with SPMI
- 2001 - New ACT regulations require implementation of FPE
- 2002 - The Family Institute for Education, Practice, and Research (FIEPR) was founded
 - Partnership between OMH and the University of Rochester
- 2003 - NYS FPE Initiative - 35 sites participate in Phase I of statewide implementation project
- Diversity is added to OMH's top strategic plan priorities



PART II:
The SAMHSA Grant:
Aims, Methods, Challenges



Grant Aims

- Adapt FPE toolkit and training for clinical staff in three communities—African American, Chinese, and Latino
- Implement FPE in these communities
- Evaluate the implementation of the adapted toolkits:
 - FPE Fidelity
 - Cultural competence (CCAS)
 - Implementation barriers/strategies (qualitative)
- Evaluate clinical outcomes and satisfaction with services



Cultural Adaptation Methods

■ Initial Adaptation:

- Define model components
- Use multiple data sources to support adaptation:
 - Literature review
 - Focus groups (consumers, families, providers/community members)
 - Key Informant Interviews (cultural and FPE experts)
- Work group develops draft of revised toolkit materials based on consensus of the data
- Revisions based on stakeholder and expert feedback: Scientific Advisory Board, culture specific advisory board, OMH's Multi-cultural Advisory Committee, and key informants

■ Field Testing

■ Final Revision:

- Data Sources: site visit data collected field testing, and second round of focus groups with participants
- Final stakeholder and expert review



Focus Group Methods

- Three focus groups held for each community
- Clinics recruit participants
- Focus groups conducted in primary languages
- Focus groups transcribed and translated into English
- Two to three observers take notes
- Content of focus groups analyzed in primary language by one or two raters, and in English by three raters
- Final ratings determined by consensus
- Themes, considerations, and recommendations summarized and presented to stakeholders for review



Challenges

- Defining culture, given the heterogeneity of African American, Chinese, and Latino communities
- Using prior research to guide adaptations: paucity of research
- Using expert opinion to guide adaptations; finding experts in both FPE and cultural considerations; addressing differences of opinion and determining consensus
- Using qualitative data to guide adaptations: finding bilingual/bicultural qualitative researchers and focus group leaders; getting meaningful feedback from stakeholders who are not familiar with FPE
- Tailoring the model for diverse groups without compromising its basic integrity
- Defining the model – explicit and implicit assumptions

FPE Model Overview



ENGAGE- MENT

In sessions with consumer, and outreach phone calls to families

Multiple outreach efforts made over time

JOINING

Family and consumer meet with clinician separately

3 one-hour meetings each

EDUCATION WORKSHOP

Families attend; consumer attendance optional; diagnosis-specific

1 full day


ONGOING SESSIONS

Multiple families; all consumers attend ongoing meetings together

Group lasts 9 months - 5 years

Defining Model Components: Explicit and Implicit Assumptions

- Explicit - core components:
 - Included in fidelity measure
 - Examples: All families engaging in FPE should start out with a series of joining sessions with the group leader
- Explicit – minor components:
 - Not part of a fidelity measure, but described in FPE literature
 - Examples:
 - Serve food at MGF meetings
 - Ideally the MFG leader is also the consumer's therapist
- Implicit Assumptions
 - Sharing experiences and struggles with mental illness will be helpful/ healing
 - Families believe child rearing is a cause of illness; neurobiological explanations of mental illness will reduce stigma/guilt for families



Defining Model Components: Structure, Process, Content

- Core components can be broken down in to:
 - Structure: Where, when, who
 - e.g. The educational workshop should last all day, and all family members should attend
 - Process: How
 - e.g. The workshop should be conducted like a classroom
 - Content: What
 - e.g List of specific topics that should be covered during the workshop (history and biology of mental illness, treatments, outcomes, typical reactions to mental illness in the family, etc.)



PART III:
Select Findings and Lessons
Learned



Select Findings

- Although some findings were observed across all cultures, those discussed here have been chosen to highlight the distinctiveness of findings in particular cultures, or the contrast in findings across cultures
- Since findings reported here are to some extent site-specific, and are not intended to represent the entire cultural group



African American Community: Themes

- TRUST
- RESPECT
- BENEFITS



African American Community: TRUST

- Engagement:
 - Be up-front and explicit in describing the program and its requirements at the point of first contact
 - It may take time for families to “hear” you; be prepared to repeat information as trust develops and families become more open and comfortable talking with you
 - Stress the confidential nature of information to be discussed with the clinician and other families
- Workshop:
 - Deemphasize “therapy”-related language; talk instead about “getting help for mental health problems”
 - Due to mistrust of authority, deemphasize idea of “following doctor’s orders”; talk about “consulting expert opinion” and “using medication effectively”



African American Community: RESPECT

■ Workshop:

- Standard discussion of families' experiences with mental illness should be moved up in the agenda, and address culturally specific experiences and norms, e.g.:
 - African American experiences with mental illness and treatment (stigma, racism, mistrust of mental health system, etc.)
 - Family structure and support (kinship networks, community associations)
- Show respect for natural and existing supports and resources outside of the treatment setting—e.g., spiritual help

■ Multifamily groups:

- Demonstrate respect for and understanding of their busy lives by helping families work around practical barriers to attendance—e.g., transportation, childcare, busy schedules



African American Community: BENEFITS

- Engagement:
 - Be concrete and practical when discussing benefits of the program and resources the clinic can offer
 - Emphasize the free, no-obligation nature of the service to families
- Workshop:
 - De-emphasize or eliminate standard 1st section on History of Mental Illness; instead emphasize practical information that can help families now
- Multifamily groups:
 - Emphasize recovery from the very beginning rather than the standard model where recovery is the focus of year 3 of MFG



Chinese Community: Themes

- FAMILY
- GUAN XI (*building personal relationships and trust before engaging in professional interactions*)
- PRACTICALITY



Chinese Community: FAMILY

- Engagement:
 - Take into account the input of multiple caretakers, since there may be conflicts among them regarding treatment methods
 - Understand families' structures; in particular, realize that the decision-makers—e.g., father or eldest brother—may not necessarily be the ones who provide day-to-day care—e.g., daughter, mother, younger sibling
- Joining:
 - Confucian and Buddhist cultural traditions may impact how families respond to the burden of mental illness. Consider bringing up family burden if they do not raise it spontaneously.
 - Cultural belief in karma may impact how families view mental illness.
- Multifamily groups:
 - Family and cultural expectation that consumers will work and send money back to China, or give money to family here is a major source of stress for consumers – use MFG to problem solve



Chinese Community: GUAN XI

- **Joining:**
 - Allow families to reveal information at their own pace, due to concerns they may have regarding personal disclosure to clinicians
- **Multifamily groups:**
 - Consider separating families and consumers for the first two meetings, due to the desire to save face
 - Consider using a more general problem-solving format that does not focus on one family, until families have become more comfortable with one another



Chinese Community: PRACTICALITY

■ Engagement:

- Mention positive treatment outcomes related to employment and decreasing family distress
- Ask families to commit to six months; later encourage them to renew their commitment
- Emphasize the role of the clinician as both a helper and a representative of a mental health center
- Highlight doctors' endorsement of the program

■ Joining:

- Condense into two sessions



Latino Community: Themes

- **FAMILISMO** (*strong identification with and loyalty to family*)
- **PERSONALISMO** (*personal/friendly element added to formal/professional interactions*)
- **BENEFICIOS** (*benefits or positive outcomes*)



Latino Community: FAMILISMO

- Engagement:
 - Respect gender hierarchy in family
 - Some family members have made great sacrifices in their carer role, and view themselves as experts in managing their loved ones illness. Reinforce the notion of families' learning useful information from the program and adding to their expertise
- Multifamily groups:
 - Be aware that close family involvement may influence treatment in a number of ways both negative—e.g., being hypercritical or overly sensitive—and positive—e.g., being supportive and loving



Latino Community: PERSONALISMO

- Engagement:
 - Address families respectfully; make proper use of surnames, titles, and person
 - Emphasize the individual relationship of the clinician with the family, rather than the clinician's place in an institutional context
- Joining:
 - Show interest in and respect for alternative remedies families have tried, e.g. consulting a spiritualist, herbal remedies, etc.
- Workshop:
 - Add guidelines “Keep it warm” and “Take care of yourself”



Latino Community: BENEFICIOS

- Engagement:
 - Make it clear to families that the program focuses primarily on the consumer's goals and needs, though acknowledge that the family will get something out of the program indirectly—e.g., they may be helped by their loved one's being helped
- Multifamily groups:
 - Brief phone contacts in between groups may be helpful in promoting continued engagement; Encourage them to keep coming, reminding them of progress made, and benefits of continued participation



Final Thoughts

- Universal experiences and needs are refracted through different lenses
 - Race/ethnicity/culture/language
 - Gender
 - Socioeconomic status
 - Comorbid conditions—e.g., substance abuse
 - Personal experiences