Latino Family Caregiving and Schizophrenia

Mercedes Hernandez, Ph.D., LCSW  
Assistant Professor  
Steve Hicks School of Social Work  
The University of Texas at Austin

Concepción Barrio, Ph.D., LCSW  
Associate Professor  
USC Suzanne Dworak-Peck School of Social Work  
University of Southern California

FSRTC SOS Conference  
June 11, 2018
Disparities in Mental Health Care

• Serious mental illnesses (SMI’s) are among the most debilitating conditions, affecting individuals’ ability to function in daily life

• SMI’s contribute to extensive burden of care and are the third most costly medical conditions in health care expenditure (Soni, 2009)

• Latinos underutilize mental health services particularly Mexican origin and Spanish-speaking Latinos (Alegria et al., 2007; Vega et al., 1999)

• Less is known about Latinos with SMI’s such as schizophrenia (Lopez et al., 2012)
Background and Significance

• Families play an important role in the lives of individuals with schizophrenia

• Family environment and Latinos (Lopez et al., 2004)

• By including family members in treatment we could address the needs of underserved groups
Culturally Based Intervention Development: The Case of Latino Families Dealing With Schizophrenia

Concepción Barrio† and Ann-Marie Yamada†

Abstract
Objectives: This article describes the process of developing a culturally based family intervention for Spanish-speaking Latino families with a relative diagnosed with schizophrenia. Method: Our iterative intervention development process was guided by a cultural exchange framework and based on findings from an ethnographic study. We piloted this multifamily group 16-session intervention with 59 Latino families in a randomized control trial. Data were collected on family- and client-level outcomes, and poststudy focus groups were conducted with intervention participants. Results: Preliminary evidence indicates that the intervention is effective by increasing illness knowledge and reducing family burden. Conclusions: This work can provide a model for how to integrate cultural factors into psychosocial services and enhance interventions in real-world settings for culturally diverse populations.

Keywords
cultural competence, Hispanics, ethnic minority families, severe mental illness, multifamily psychoeducation group intervention, family caregivers
Culturally Based Family Intervention for Mexican Americans (CFIMA)

• Roots in evidence-based elements of multifamily group psychoeducation
• Includes adaptations and new components for use with Spanish-speaking Latino families
• Takes into consideration sociocultural synchronicity with caregiving ideology of Latino culture
• Linguistically and culturally congruent with the needs, preferences and cultural learning styles of Spanish-speaking Latinos

Barrio & Yamada, 2010
Heuristic Model

Cultural Exchange Process

Latino Family Culture includes cultural resource domains, explanatory models, treatment needs and preferences. Provider Culture refers to treatment culture including explanatory models of existing intervention services.
Perceptions of subjective burden among Latino families caring for a loved one with schizophrenia

Perceptions of Subjective Burden Among Latino Families Caring for a Loved One with Schizophrenia

Mercedes Hernandez · Concepción Barrio

Received: 20 October 2014 / Accepted: 2 May 2015 / Published online: 8 May 2015
© Springer Science+Business Media New York 2015

Abstract The purpose of this study was to explore perceptions of subjective burden among Latino family members providing care for a loved one with schizophrenia. Data were collected from outpatient community mental health centers and featured 64 Latino family members who were primarily Spanish speaking and of Mexican origin. We used qualitative methods to examine subjective burden based on an open section of the Family Burden Interview Schedule. Five salient themes emerged capturing family members’ subjective burden experience: (a) interpersonal family relationships, (b) emotional and physical health, (c) loss of role expectations, (d) religion and spirituality, and (e) stigma. Overall, findings illustrated that families perceived numerous challenges in their caregiving. Implications for research and practice among Latino family members are discussed.

Keywords Serious mental illness · Hispanic · Community mental health · Family caregiving · Religion and spirituality · Stigma

Services 2009). Due to the impact of the illness, many consumers rely on family for various forms of support, including emotional, financial, and illness management (Awad and Voruganti 2008; Desai et al. 2013). Although providing direct tangible and emotional support may enhance the lives of consumers, it may also contribute to negative outcomes for families (Awad and Voruganti 2008; Gater et al. 2014; Maurin and Boyd 1990). A recent study found that when compared to families not caring for a family member with schizophrenia, those caring for a loved one with the illness were at greater risk of mental health and substance abuse disorders (DeVylde and Lukens 2013). Indeed, caring for a loved one with schizophrenia is often an overwhelming experience for family members and can contribute to burden.

The move from institutional care to community-based settings in the 1950s prompted many families to assume caregiving roles for family members with schizophrenia (Hatfield 1987; Maurin and Boyd 1990). Early researchers recognized that caring for a loved one with schizophrenia could pose unique challenges for families that may be conducive to greater burden. As such, there was interest in
Purpose of Study

(a) Expand understanding of subjective burden among primarily Spanish-speaking Latino family members caring for a loved one with schizophrenia

(b) Explore how these families perceived caregiving responsibilities and how they conceptualized subjective burden
Sample Characteristics

<table>
<thead>
<tr>
<th>Sample Characteristics</th>
<th>Family ($N = 64$)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, $M (SD)$</td>
<td>53 (13.45)</td>
<td>20–81</td>
</tr>
<tr>
<td>Education, $M (SD)$</td>
<td>7.5 (4.19)</td>
<td>0–15</td>
</tr>
<tr>
<td>Gender, $n (%)$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>53 (83 %)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11 (17 %)</td>
<td></td>
</tr>
<tr>
<td>Marital status, $n (%)$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>41 (64 %)</td>
<td></td>
</tr>
<tr>
<td>Separated</td>
<td>6 (9 %)</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>5 (8 %)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>5 (8 %)</td>
<td></td>
</tr>
<tr>
<td>Single, never married</td>
<td>5 (8 %)</td>
<td></td>
</tr>
<tr>
<td>Single, cohabitating</td>
<td>2 (3 %)</td>
<td></td>
</tr>
<tr>
<td>Relation to consumer, $n (%)^a$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>35 (55 %)</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>8 (13 %)</td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>8 (13 %)</td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>4 (6 %)</td>
<td></td>
</tr>
<tr>
<td>Son or daughter</td>
<td>3 (5 %)</td>
<td></td>
</tr>
<tr>
<td>Aunt</td>
<td>2 (3 %)</td>
<td></td>
</tr>
<tr>
<td>Other$^b$</td>
<td>4 (6 %)</td>
<td></td>
</tr>
</tbody>
</table>

$^a$ Percentages do not total 100 % due to rounding error

$^b$ Cousin, fictive kin, grandmother, or sister-in-law
Methods

• Data based on open-ended question on Family Burden Interview Schedule (FBIS)

  • In what other ways has the family suffered as a result of family member’s illness?
Fig. 1 Conceptual model of perceived subjective burden by family members dealing with schizophrenia in a loved one.
Family Interpersonal Relationship

Interpersonal relationship with family members

• “We are afraid that he will get upset or fight with others. We are always watching him and making sure that he does not do something during family reunions.” (Mother)

• “We don't do anything as a family anymore. For Christmas he only spent a little time with us. There's improvement--he ate with us. He did come out of his room.” (Mother)
Emotional/Physical Health

How the illness has affected families’ emotional/physical wellbeing

- “...high blood pressure...at times I have pain in my chest. I know that it is due to the sadness that I have, the pressure.” (Grandmother)

- “I also feel depression—I have cried, I have felt sadness seeing him like this.” (Mother)
Implications

• Families perceived numerous challenges in their caregiving experience
  • centered on emotional/physical health and family interpersonal relations

• Qualitative methods and use of bilingual and bicultural research interviewers may have facilitated participants’ disclosure of burden, may be a difficult topic to discuss given cultural views on caregiving

• Providers should consider that although many Latinos value a strong family orientation and interdependence, these families may experience limited social support and be at risk of burden.
Families and Medication Use and Adherence among Latinos with Schizophrenia

ORIGINAL ARTICLE

Families and medication use and adherence among Latinos with schizophrenia

Mercedes Hernandez and Concepción Barrio

School of Social Work, University of Southern California, Los Angeles, CA, USA

Abstract

Background: Medication nonadherence among Latinos with schizophrenia represents a significant treatment obstacle. Although some studies have examined patient and family perceptions of adherence, few have examined these perceptions together. However, such knowledge can provide a deeper understanding of how family processes may contribute to or impede adherence among underserved groups such as Latinos.

Aims: This study explored perceptions of medication and adherence among Latinos with schizophrenia and key family members.

Method: Purposive sampling was used to collect data from 34 participants: 14 patients with schizophrenia receiving community-based mental health services in an urban public setting and 20 key family members. Informed by grounded theory, semi-structured interviews were analyzed by bilingual–bicultural team members.

Results: Salient themes emerged indicating facilitators of and obstacles to medication use. Specifically, challenges centered on medication side effects, autonomy and choice, and illness insight, whereas facilitators focused on family support and holistic views of treatment and empowerment.

Conclusions: Because the majority of Spanish-speaking Latinos with schizophrenia live with family, it is important to examine family factors that may influence medication use. Findings suggest that patient and family perceptions of medication should be examined as part of the treatment process, particularly regarding issues of autonomy and choice.

Keywords

Serious mental illness, community mental health, Hispanic, treatment adherence, autonomy and choice

History

Received 29 February 2016
Revised 18 May 2016
Accepted 12 July 2016
Published online 26 September 2016
Purpose of Study

Explore the (a) perspectives of patients and family members regarding medication use and (b) how these perspectives contributed to challenges and facilitators of medication use
Methods

- Participants were part of a controlled multifamily intervention development study
- Follow-up study examining salient treatment outcomes
- Semistructured interviews
  - Asked about views of treatment
  - What treatment has worked best for you (family member)?
Sample Characteristics

<table>
<thead>
<tr>
<th>Patient and Family Member Characteristics</th>
<th>Patient (N = 14)</th>
<th>Range</th>
<th>Family (N = 20)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male, n (%)</td>
<td>11 (79)</td>
<td></td>
<td>4 (20)</td>
<td></td>
</tr>
<tr>
<td>Age, years, M (SD)</td>
<td>38 (12.00)</td>
<td>26-75</td>
<td>59 (8.48)</td>
<td>39-72</td>
</tr>
<tr>
<td>Education, years, M (SD)</td>
<td>11.50 (1.65)</td>
<td>9-14</td>
<td>7.30 (4.09)</td>
<td>2-14</td>
</tr>
<tr>
<td>Length of illness, years, M (SD)</td>
<td>16.38 (11.72)</td>
<td>7-50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship to patient – Mother, n, (%)</td>
<td>12 (60)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Country of birth, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>United States</td>
<td>8 (57)</td>
<td></td>
<td>1 (5)</td>
<td></td>
</tr>
<tr>
<td>Mexico</td>
<td>4 (29)</td>
<td></td>
<td>18 (90)</td>
<td></td>
</tr>
<tr>
<td>Interview Language – English, n (%)</td>
<td>8 (57)</td>
<td></td>
<td>2 (10)</td>
<td></td>
</tr>
</tbody>
</table>
Results

• **Themes**
  • **Challenges**
    • Side effects
    • Autonomy and choice
    • Illness insight
  • **Facilitators**
    • Family support
    • Holistic view of treatment
Results: Preliminary Model

Challenges
- Side Effects
- Autonomy and Choice

Facilitators
- Family Support
- Holistic View of Treatment

Illness Perceptions

Medication Perceptions

Adherence

Autonomy and Choice

Family
- Patient

Family

Autonomy and Choice

• “When I behave in that way all that they say is that we are going to go to the doctor ... and I tell them, ‘You know what, I am not a child,’ but I do recognize that I suffer from certain things.” (Patient)

• “Sometimes I see that he does not take it [medication] and he becomes irritated. Like with a sort of anxiety ... and then I begin to give it to him ... hidden. And I then see much change in him.” (Family Member)
"When I go by myself I don’t like it. It doesn’t feel good. Because I cannot …tell my own way out or like tell them, like what prescriptions…” (Patient)

“I told her [doctor], ‘I don’t know what is happening with [patient]’…She said that perhaps it was a side effect of the medication…perhaps it didn’t suit him well because he began to deteriorate…but he did not want to tell the doctor and that is why I had to go and tell her.” (Family Member)
Implications

• Family involvement as seen in treatment compliance provides support for key role of families in treatment outcomes (Kopelowicz et al., 2012)

• By including patient and family member perspectives can examine intersections and process of adherence

• Shared decision making critical to ensure patients’ needs and choices are met
Conclusion

• Role of families in treatment

• Protective factors and patient outcomes

• Families provide support to patients to compensate for disparities
Acknowledgements

• Study Participants
• NIMH R34 MH076087
• NIMH R36 MH102077
Questions?