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Moya L. Alfonso

Georgia Southern University, malfonso@georgiasouthern.edu

Jaime Corvin

University of South Florida

Claudia Aguado Loi

University of South Florida

Isabella Chan

University of South Florida

Linda M. Callejas

University of South Florida

See next page for additional authors

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Authors

Moya L. Alfonso, Jaime Corvin, Claudia Aguado Loi, Isabella Chan, Linda M. Callejas, Dina Martinez Tyson, Maria Serrano, Phyllis Panzano, and Junius Gonzales



Latinos' views of co-morbid chronic disease and minor depression

Moya L. Alfonso¹, Jaime Corvin², Claudia Aguado Loi³,
Isabella Chan², Dina Martinez Tyson³, Linda M. Callejas⁴,
Maria Serrano⁵, Phyllis Panzano⁶, Junius Gonzales⁷

ABSTRACT

Background: There are notable health disparities among Latinos in the US associated with chronic diseases (e.g., diabetes) and depression. Further, chronic diseases and minor depression tend to co-occur among Latino populations. This paper reports findings from a community-based participatory research study using dyadic focus groups with Latinos who have chronic disease and minor depression and their family members (FM). The goal of this study was to better understand barriers and facilitators to chronic disease self-management among underserved Latinos living with both chronic illness and minor depression and their families using a socio-ecological approach. **Methods:** In total, five focus groups were conducted with individuals with the chronic disease ($n = 25$) and four with nominated FM ($n = 17$). All focus groups were digitally recorded and transcribed by a professional transcription agency in Spanish. Transcripts were imported into Atlas.ti V 6.2 software program and analyzed in Spanish by a team of bilingual researchers using content analysis. Qualitative results are presented thematically by the level of analysis or behavioral influence (i.e., individual, family, and community levels) and barriers and facilitators are discussed within each level. **Results:** Results revealed individual, family, and community-level barriers (e.g., transportation, expressed emotion, and lack of health care providers) and facilitators to managing chronic disease and minor depression (e.g., acceptance, family support, and Spanish speaking support groups). **Conclusion:** Findings have important implications for the understanding of chronic disease management for Latinos and emphasize the need to use evidence-based approaches that address barriers and facilitators across the social-ecological continuum.

¹Department of Community Health, Jiann-Ping HSU College of Public Health, Georgia Southern University, Statesboro, Georgia, USA, ²Department of Global Health, College of Public Health, University of South Florida, Tampa, FL, USA, ³Department of Community and Family Health, College of Public Health, University of South Florida, Tampa, FL, USA, ⁴Department of Child and Family Studies, College of Behavioral & Community Sciences, University of South Florida, Tampa, FL, USA, ⁵Hispanic Health Services Council, Tampa, FL, USA, ⁶Decision Support Services, Columbus, Ohio, USA, ⁷University of North Carolina, Chapel Hill, NC, USA

Address for correspondence:

Moya L Alfonso, Jiann-Ping Hsu College of Public Health, Statesboro, Georgia, USA. E-mail: malfonso@georgiasouthern.edu

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INTRODUCTION

Latinos now comprise the largest minority population (22%) in the state of Florida. The National Center for Health Statistics [1] identifies the cardiovascular disease (CVD) as the principal cause of death for Latinos in the United States [2]. Rates of diabetes are also reaching epidemic proportions

among Latinos, with more than 11.8% affected [3]. Chronic illnesses such as CVD, arthritis, and diabetes also commonly occur with depression, with rates of co-morbid depression and chronic illness ranging from 10% to 30% [4-8]. Additionally, "minor depression," a diagnosis that represents having two or more depressive symptoms for at least 2 weeks, is common in general health settings, tends to go undiagnosed, and is

associated with significant morbidity, disability and increased mortality [9-13].

Chronic disease self-management programs have been associated with healthy aging and several have been successfully adapted to meet the needs of specific populations [14-22]. However, data suggest the translation of strong evidence-based interventions for depression into routine practice has been disappointing and difficult [23]. Thus, in an effort to better understand these challenges and successes, especially when focusing on co-morbid chronic disease and depression, this paper presents findings from a multi-phase, community-based study of chronic disease and depression among Latinos. Specifically, data from the formative research phase of this study, which employed focus groups involving Latino individuals with chronic disease (ICDs) and their families to elicit a better understanding of barriers and facilitators to chronic disease self-management, are presented.

METHODS

Data Collection

Focus groups were conducted with Latino ICDs and their families in 2009-2010. Participants were recruited by a community research partner through local venues (e.g., clients, bodegas). Individuals who self-identified as Latino and met both study criteria were asked to participate. ICDs who agreed to participate were asked to recruit a family member (FM) who assisted with care to take part in Family focus groups. The study was approved by the Institutional Review Board of a large university in Florida.

A Community-Based Participatory Research (CBPR) Focus

CBPR provided the overarching approach to this study [24]. Community partners leveraged extensive contacts within the community and were responsible for the recruitment of all participants, and either led or co-led all focus group discussions.

Instrumentation and Translation

This study utilized a two-item screening tool, the PHQ-2 [25], to identify patients with minor depression. Kroenke *et al.* identified a score of 3 or higher (range 0-6) as an optimal identifier for depression. The PHQ-2 demonstrates adequate sensitivity (e.g., 83% for major depression), specificity (e.g. 92% for major depression), and predictive validity [25].

Two additional instruments were developed for the study a 23-item demographic survey and a focus group protocol. The focus group guide which addressed the following domains: Perceptions of living with chronic disease, risk, self-management of chronic disease, views on depression, competition, things that may alleviate symptoms, role of the family, and perceptions of chronic disease self-management programs. Parallel versions of

these tools were created for ICDs and FM so that perceptions could be compared. All instruments were extensively piloted and further refined prior to the start of formal data collection.

Analysis

All focus groups were digitally recorded and transcribed by a professional transcription agency in Spanish. Transcripts were imported into Atlas.ti V 6.2 software program and analyzed in Spanish by a team of bilingual researchers using content analysis. Each transcript was independently coded by a primary and secondary coder until 100% agreement was reached. The Community Advisory Board reviewed and verified the results.

Table 1: Phase 1 focus group demographics

	ICD	FM (n=17)
Age (mean/SD)	49.1 (8.4)	38.8 (14.06)
	<i>n</i> (%)	
Gender		
Males	15 (60.0)	4 (23.5)
Females	10 (40.0)	13 (76.5)
Highest level of education		
Less than high school	4 (16.0)	2 (11.8)
Some high school	1 (4.0)	1 (5.9)
High school graduate or GED	11 (44.0)	9 (52.9)
Vocational school or college	4 (16.0)	2 (11.8)
Graduate school/professional	5 (20.0)	3 (17.6)
Marital status		
Married/living with a partner	17 (68.0)	12 (70.6)
Single, never married	4 (16.0)	3 (17.6)
Separated/divorced	4 (16.0)	2 (11.8)
Income		
Unknown	1 (4.0)	4 (23.5)
<\$10,000	10 (40.0)	5 (29.4)
\$10,000 - \$39,999	14 (56.0)	6 (35.3)
\$40,000 - \$79,999	-	2 (11.8)
Country of origin		
Cuba	5 (20.0)	1 (5.9)
Dominican republic	3 (12.0)	5 (29.4)
Mexico	4 (16.0)	-
Puerto Rico	5 (20.0)	4 (23.5)
Other	6 (24.0)	5 (29.5)
The United States born	2 (8.0)	2 (11.8)
Length of time in U.S.		
<6 years	6 (24.0)	4 (24.7)
≥6 years and <25 years	12 (48.0)	8 (50)
>25 years	3 (12.0)	2 (11.8)
US born	2 (8.0)	2 (11.8)
Chronic disease*		
Cardiovascular disease	4 (16.0)	-
Diabetes	14 (56.0)	4 (23.5)
Depression	25 (100.0)	8 (47.1)
Hypertension	15 (60.0)	3 (17.6)
Other	9 (36.0)	5 (29.4)
Health insurance coverage		
No	14 (56.0)	10 (58.8)
Yes	11 (44.0)	7 (41.2)
English speaking ability		
Not at all	5 (20.0)	3 (17.6)
Not well	15 (60.0)	6 (35.3)
Well	5 (20.0)	8 (47.1)

Note: Percent may not add to 100% due to missing values, rounding, or having more than one type of chronic disease, FM: Family members, ICD: Individuals with chronic disease, SD: Standard deviation

RESULTS

Qualitative results are presented thematically by the level of analysis or behavioral influence (i.e., individual, family, and community levels). Within each level, barriers, and facilitators are discussed. Unless otherwise noted, “participants” refers to both ICDs and FM.

Participants

In total, five focus groups were conducted with ICDs ($n = 25$) and four with FM nominated by participating ICDs ($n = 17$). Table 1 provides a summary of demographic characteristics for each participant group. Participants were primarily foreign-born individuals though almost two-thirds had lived in the United States for at least 6 years. Most participants had at least a high school education, were married or cohabitating with a partner, and were low income. Diabetes and hypertension were the most frequently self-reported chronic illness in ICDs followed by CVD. Consistent with screening criteria, all ICDs screened for minor depression using the PHQ-2. While not screened for, almost half of all FM self-reported having a chronic disease. Additionally, almost half of the family sample screened positive for minor depression (47.1) with the PHQ-2. Access to health care and insurance was limited among study participants.

Individual Level

Barriers to managing chronic disease and depression: Two primary individual level barriers to chronic disease self-management emerged: (1) financial, physical, and personal accessibility and (2) health and wellness concerns, including physical and mental health issues. ICD and FM noted primary financial issue as lack of health insurance and money, which limited access to doctor visits and related treatment as a result of their prohibitive costs, ultimately affecting every aspect of health and wellness.

“...The most important medicine for me is insulin and (the insurance company) doesn't want to cover the cost. I'm not going to go without food... I know this might not sound right, but I will say it. I'm not going to pay \$200 for medicine when I have to pay my light bill. I'd rather die!” (Family member, Female).

Personal accessibility was also an identified barrier due to the lack of a personal patient-provider connection. ICDs described Latinos as hesitant to divulge personal information with people they do not know, particularly in regards to a problem. Moreover, male ICDs indicated that the family is the only entity with an understanding of what they are going through, and the only entity in which they could confide. As a result, male ICDs reported rarely seeking help for chronic illness, especially for depression, outside of trusted, familial circles.

Concerns regarding health and well-being also arose as barriers to self-management. According to participants, outcomes of living with a chronic illness have taken a great physical, emotional,

and mental toll on their quality of life, as well as causing or exacerbating other illnesses or syndromes including anxiety and stress, high blood pressure, stress-related heart attacks, crying spells, chest pain, insomnia, and numbness in legs.

“As of 5 years ago, I was found with this [diabetes] and then... a lot of discomfort...crying a lot, I didn't want to live, I felt lonely. alone, well, with my problems, and I felt that I was alone, that no one could help me nor did anyone help me. Right?” (ICD, Female)

Participants described chronic illness and depression as occurring in a cyclical pattern wherein depression is seen as stemming from chronic illness, which, in turn, can lead to other chronic illnesses. A number of ICDs reported that depression was often more debilitating than chronic physical illness, and some expressed that depression feels like dying a slow death and causes an inability to think clearly.

Facilitators to managing chronic disease and depression: Facilitators to self-management also arose on the individual level, including (1) self-care strategies, (2) spirituality and faith, and (3) self-acceptance. The use of self-care strategies was seen as an important to chronic disease management, with participants specifically identifying medication adherence, healthy and appropriate dietary changes, and regular exercise as effective self-care strategies.

“Well, I believe what has helped me is the following aspect, the aspect of Christianity... But, God has promised me something... the religious base... I have a religious base that I have hope because of my religion” (ICD, Male).

Family Level

Barriers to managing chronic disease and depression: In addition to the individual-level effects and their debilitating impacts, ICDs and FM also discussed the consequences of chronic disease and depression on the family and related challenges to self-management. Primarily, these related to (1) how individual mental health issues affected the family, especially with the occurrence of caregiver frustrations, and (2) the conflicting demands families face regarding self-care, dietary restrictions, time management, and financial concerns.

“A person (with depression is someone who) makes things more difficult every day. They lock themselves away and sometimes they don't come out of the room at all. They say that they don't want to bother anyone. They are people who let themselves go. Their lives become empty, and they will let themselves die...” (Family, Female).

Participants also noted that ICDs often suffered from mood swings characterized by agitation, sudden anger, and becoming easily irritated, especially with children who did not seem to understand the severity of their conditions. Both ICDs and FM noted that such interactions took a toll on the entire family. Some FM also discussed being frustrated by what they felt was

a lack of cooperation on the part of the ICD in successfully managing their disease. Others discussed the difficulties = in being separated from FM remaining in their home country, a perceived source of support. Additionally, the hardships faced by the distant family in home countries further aggravated ICDs' depression, increasing feelings of guilt and economic pressure.

Facilitators to managing chronic disease and depression: Overall, participants, especially ICDs, felt that support and social interactions with friends, family, support groups, and other people in the community made living with chronic disease and/or depression more palatable. More specifically, ICDs felt people who can help them cope with their conditions are those who are patient/tolerant, supportive, kind, empathic, compassionate, and non-judgmental. The two most frequently mentioned sources of social support were family and support groups. It is important to note, however, a number of participants noted that their social support networks were greatly reduced on moving to this country.

Community Level

Barriers to managing chronic disease and depression: At various points throughout the focus groups, participants discussed immigration related barriers to self-management, including adjusting to the US culture, under- and unemployment, and the higher cost of healthy foods. When discussing the reasons for migrating to the United States, the majority of participants noted that they did so in pursuit of a better quality of life. However, a number of individuals reported difficulty finding work, adjusting to US culture and customs, and learning English, barriers that ultimately negatively affect health.

"I do not work, but the day-to-day life is very hard here, starting with the customs, they're different. Having lived a short or long while ...in Colombia [you] know that if you are a professional...you work, you have an income, you are able to maintain the family; as a man you are valued there. Similarly, over there (Colombia), there are a variety of foods to manage one's illnesses, be it with carbohydrates, with one thing or the other, with medicine, but you maintain yourself." (ICD, Male).

Facilitators to managing chronic disease and depression: Support groups for people with depression were often discussed as a great help because they allow participants to share experiences and learn from each other and serve as a cathartic experience. Participants reiterated the importance of increasing the number of support groups available in the community to give ICDs an opportunity to talk with others facing similar conditions, as well as to increase their own self-worth through helping others. Reflecting their personal experiences, participants suggested that community support could be provided through group activities and other distractions.

"Also games like bingo and things like this, or some distraction. Look, you will see this week... we are thinking of forming a group to play bingo with other people who have these conditions - the word spreads and hopefully it will be full (the group gatherings)" (ICD, Female)

Table 2: Barriers and facilitators to chronic disease self-management

Level	Barriers	Facilitators
Community	Adjustment to US culture and norms	Support groups
	Increased cost of healthy food in US	Educational programs
	Unemployment or Underemployment	
	Lack of or limited accessibility to resources	
	Transportation	
Family	Language barriers	
	ICD withdraw from family activities	Social and emotional support
	Dealing with ICD mood swings	Interaction with family/friends
	Feelings of helplessness and depression in caregiver	Managing diet
	Stress of illness and depression on family	Increased awareness and self- management following episode
Individual	Caregiver frustration with the situation	
	Dietary restrictions	
	Impact of chronic illness and depression on the individual	Acceptance of the illness
	Being caught within the depression-Illness Cycle	Faith and trust in God
	Individual isolation from family	Self-care strategies
	Lack of health insurance and access to care	
	Cost	
	Employment	
	Lack of relationship with provider	
	Medication side effects	

DISCUSSION

Barriers and facilitators to chronic disease self-management, as expressed by ICDs and their FM are presented in Table 2.

Findings suggest the effects of chronic illness and depression carry across the multiple levels of health influence. For many, chronic disease and depression had taken a toll - physically, emotionally, and mentally - and further contributed to or promoted other illnesses and symptoms (i.e., high blood pressure, anxiety, and insomnia). Participants shared the effects of the depression-illness cycle, relating being depressed because of their chronic illness while acknowledging that depression made them unable to manage their disease, further exacerbating their condition.

Whereas studies highlights the importance of social support [26-28], our findings, corroborated by both members of the ICD-family dyad, indicate that the burdens related to chronic disease often result in a tendency toward isolation. For many ICDs, the disease burden(s) they experience were exacerbated considerably by cost, lack of health insurance, and issues accessing care, all variables widely cited in the literature [29,30]. Additionally, acculturative stress and a general inability to cope with the hardships associated with the downward mobility experienced following migration to this country were cited as additional challenges that often intensified disease burden(s).

As illness is central to the entire family, familial level issues were also evaluated. Overall, the negative effects of chronic

disease on the entire family emerged and were often discussed as a cause of tension in the dyad. The tendency on the part of ICDs to isolate themselves and their propensity for angry outbursts as a result of their condition was often identified as a source of stress for spouses/caretakers and a cause of breakdown in relationships, which may further reduce opportunities for social support. As a result of deteriorating communication and relationship tensions, FM reported feeling helpless. Further, a number of FM were coping with their own health conditions, making it increasingly difficult to help manage their spouse's/FM disease burden. Importantly, many spouses also noted that the stress from the ICDs chronic disease and/or the strain on their relationships often led to their own depressive symptoms. These findings highlight the importance of understanding the effects of chronic disease on the dyad and the inclusion of family in research of this nature.

In addition to the individual and family level impacts of chronic disease, community-society level barriers to chronic disease management emerged. Barriers most often identified by focus group participants were systemic, including a lack of health insurance, the cost associated with health care and/or management of chronic illness, including costs of medications and healthier foods, language barriers, and transportation challenges, findings consistent with those from studies examining barriers to health care access among Latinos [28]. In general, participants expressed a need for more culturally sensitive and language appropriate services, critiquing the impersonal nature of health care in the US when compared to their home countries, and expressing a desire for increased education and awareness campaigns targeted toward local Latino communities regarding the effects, management, and treatment of chronic disease, including depression. Despite the difficulties identified, facilitators to chronic disease management (e.g., acceptance, faith, family) were recognized.

Specific programmatic recommendations varied between the need for individual level facilitators (i.e., distractions and activities to increase feelings of self-worth) that would help ICDs to better manage their illness, family level (i.e., services that address the needs of the family and caregivers) facilitators, and community level facilitators (i.e., the need for more doctors that speak Spanish and an infrastructure to better help Latinos; [Table 3]). Support groups were seen as particularly important

Table 3: Recommendations for chronic disease self-management

	Recommendations
Community	Developing community activity centers More doctors Public education programs Helping others with chronic illnesses Increasing knowledge/awareness of chronic disease and depression Language appropriate materials Educating the children
Family	Addressing family concerns Free family support centers
Individual	Keeping mind off illness and depression Increasing feelings of self-worth

because participants consistently described the benefits of discussing their (or a FM) experience with the chronic disease. Participants also identified a need for neighborhood or community centers that could provide low-cost or free services designed to increase their level of physical activity and provide family-based services.

This study is unique in its dyadic approach to exploring Latino patients' and FM perceptions of minor depression and chronic disease and is characterized by multiple methodological strengths, including the use of existing reliable and valid measures to develop the focus group protocol and screen participants for minor depression, the inclusion of community members throughout the research process, and the triangulation of investigators and participant perspectives. Nevertheless, this study is not without limitations. The cross-sectional nature of the study and the small sample size limit the generalization of findings. Still these findings provide important insight into the potential needs of ICD-Family dyads in addressing the challenges of co-occurring chronic illness and depression.

CONCLUSIONS

The study suggests that to improve outcomes for Latinos with comorbid chronic disease and minor depression, attention must be focused on the ICD-Family dyad. Familism, defined as prioritizing one's family over oneself [31], is generally considered a core value in Latino culture [32]. Implicit in this value is the role of the family in the health and wellness. Thus, researching issues that impact health and wellness only at the individual level is outdated and overlooks the complex system of barriers and facilitators that influence health. This research, which examined the effects of chronic disease and minor depression as expressed by the ICD-Family dyad, allows for a better understanding of the impact these conditions have on the family unit and a more holistic approach to addressing factors influencing chronic disease self-management. Such research leverages both social and familial support in explaining health and wellness and identifies resources of social capital that allow evidence-based practices to better address the needs of the individual and the family unit.

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