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## Ethical Considerations for Involving Latina Adolescents in Mental Health Research

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### Abstract

**Topic**—U.S. Latina adolescents experience significant mental health disparities, such as depressive symptoms and suicidal ideation, and should be involved in research studies focused on minimizing these health disparities. However, researchers must consider the specific ways this population is vulnerable and provide adequate protections to reduce risks related to these vulnerabilities.

**Purpose**—The purpose of this article is to describe the different ways that Latina adolescents with mental health problems can be vulnerable research participants, identify strategies to protect this population during a research study, and describe steps taken to apply these strategies in an ongoing qualitative study examining depression in Latina adolescents.

**Sources used**—Kipnis's (2003) article describes seven ways that children can be vulnerable research participants. These seven vulnerabilities are used to describe the vulnerabilities of Latina adolescents with mental health problems. Specific strategies to protect this population are synthesized to provide a list of strategies that can be used by researchers to reduce the risks associated with the vulnerabilities of this group.

**Conclusions**—In order to minimize risks for Latina adolescents, researchers must be engaged in Latino/a communities, use culturally and linguistically appropriate consent processes, and implement strategies to protect the confidentiality of Latina adolescent participants.

### Keywords

Latina; Adolescent; Mental Health

### Introduction

The Latino/a population in the United States has more than quintupled in the last four decades, and currently composes 17% of the total population in the country (Pew Research Center, 2015). Although Latino/a adults and children account for a large percentage of the US population, they are often at a disadvantage with respect to health and healthcare services, with many experiencing health disparities and lacking access to adequate health

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services (Centers for Disease Control and Prevention [CDC], 2015). High rates of mental health problems, such as depressive symptoms, suicidal ideation, and suicide attempts, represent a significant health disparity among Latina adolescents living in the US (CDC, 2016).

Latina (female) adolescents experience significantly higher rates of depressive symptoms than Latino (male) adolescents and White and Black adolescent girls. In 2015, the Youth Risk Behavior Survey (YRBS) revealed that 46.7% of Latina adolescents reported feeling sad and hopeless on a daily basis in comparison to 24.3% of their Latino counterparts (CDC, 2016), 37.9% of White adolescent girls, and 33.9% of Black adolescent girls (CDC, 2016). Psychological vulnerabilities, such as depressive symptoms, contribute to the high rates of suicide attempts by Latina adolescents (Romero, Wiggs, Valencia, & Bauman, 2013; Zayas, Lester, Cabassa, & Fortuna, 2005). Data from the 2015 YRBS demonstrate that rates of suicidal ideation and suicide attempts among Latina adolescents mirror trends of depressive symptoms in this population. In the 2015 YRBS, 25.6% of Latina adolescents reported suicidal ideation, and 15.1% reported a suicide attempt in the past year (CDC, 2016). In comparison, 12.4% of Latino adolescents reported suicidal ideation, and 7.6% reported a suicide attempt in the past year. The rate of suicidal ideation in Latina adolescents (25.6%) was higher than in White (22.8%) and Black (18.7%) adolescent girls, and the rate of suicide attempts was also higher in Latina adolescents (15.1%) than in White (9.8%) and Black (10.2%) girls in the same age group (CDC, 2016).

In order to decrease these mental health disparities, there is a need to involve Latina adolescents in research studies to understand the reasons for these disparities and to develop interventions to decrease the prevalence of these mental health problems. Vulnerable groups of adolescents have been traditionally excluded from research, and because of this, a majority of the behavioral interventions currently used for adolescents have been derived from interventions with adult populations (Santelli et al., 2003). To mitigate this problem, the National Institutes of Health (2001) has mandated the appropriate inclusion of children, women, and minorities in research studies.

Latina adolescents with mental health disorders fall at the crossroads of several different vulnerabilities, due to their age, ethnicity, and mental health problems, so special ethical considerations must be taken to ensure that the rights of Latina adolescents are respected when engaging them in research studies. Yet, little has been written about how to involve Latina adolescents in social and behavioral mental health research in an ethical manner. The purpose of this article, therefore, is to: 1) describe the vulnerabilities of Latina adolescents suffering from mental health problems using the Kipnis (2003) taxonomy; 2) identify strategies to protect this population during the study; and 3) describe how these strategies are being applied in an on-going qualitative study examining depression in the Latina adolescent population.

## **Vulnerabilities of Latina Adolescents**

Latina adolescents suffering from mental health problems are vulnerable research participants in several ways. Kipnis (2003) described vulnerability as the ways by which

study participants can potentially be taken advantage of by others and developed a taxonomy for classifying the different ways children may be vulnerable as research participants. To understand how Latina adolescents experiencing mental health problems are vulnerable research participants, the seven types of vulnerabilities are reviewed in relation to this population.

Capacitational vulnerability is defined as deficits in the ability to understand information and make logical decisions for one's self (Kipnis, 2003). Although several studies have demonstrated that adolescents aged 14 and older have the capacity to consent to specific health services (Santelli et al., 2003), it should not be assumed that all adolescents have the capacity to weigh the risks and benefits of participating in a research study, as capacity can vary based on many conditions such as the patient's culture, level of health literacy, and degree of family involvement (Campbell, 2006). Similarly, individuals suffering from severe mental illness may not have the capacity to make logical decisions about participation in research studies (Campbell, 2006; Elliott, 1997). Therefore, Latina adolescents suffering from severe mental illness may be limited in their capacity to consent to participate in a research study.

Juridic vulnerability is defined as being liable to the authority of others (Kipnis, 2003). This juridic authority pertains to Latina adolescents as they are legally considered minors and are typically under the care of a parent or guardian. As minors, adolescents are vulnerable in that their parents or other adults have the right to make decisions regarding their research participation with which the adolescent might not agree.

Deferential vulnerability is defined as the tendency to defer to others who are more powerful (Kipnis, 2003). In the Latino/a culture, individuals who are in positions of power are often respected. If a researcher or medical professional asks an adolescent to participate in research, they and their parents may agree to enrollment in the study out of respect to the researcher even if they do not want to participate (Ojeda, Flores, Meza, & Morales, 2011).

Social vulnerability is defined as membership to a minority group whose rights have been socially devalued (Kipnis, 2003). Due to their ethnicity, Latino/a individuals are often discriminated against in school and community settings, and undocumented Latino/as are even more socially vulnerable as they may be taken advantage of by others who are aware of their documentation status. In addition to being an ethnic minority, Latina adolescents suffering from mental health problems might be further stigmatized because of their mental health problems. Due to these social vulnerabilities, Latinos/as are at risk for being coerced to participate in research, or they may hesitate to participate in any form of research out of fear that their documentation status or mental health problem may be exposed.

Medical vulnerability is defined as experiencing a serious health condition without having available treatment (Kipnis, 2003). Since many Latinos/as do not have access to affordable mental health services (Cummings & Druss, 2011), they may see mental health research as an avenue to receiving mental health services when there is no guarantee that the study will benefit them. For example, in a study by Lakes et al. (2012), Latina women did not see a distinction between the research study and the medical care they were receiving. Beliefs

such as these may lead individuals to participate in research under the assumption that they will receive a therapeutic benefit when that may not be the case, especially when they are recruited from clinic or hospital settings where they are receiving routine treatment (Fisher et al., 2002).

Allocational vulnerability is defined as lacking a social good that will be provided as a consequence of participation in research (Kipnis, 2003). Many adolescents lack financial resources, and thus a monetary incentive for participation may be coercive as Latina adolescents might choose to participate in research for the incentive when they would otherwise decline participation.

Situational vulnerability is defined as having to make a decision about medical treatment in an emergency situation without having sufficient time to consider the decision to participate in research (Kipnis, 2003). This particular vulnerability would not likely be relevant to Latina adolescents involved in social and behavioral mental health research, as mental health problems typically do not put adolescents at risk for needing emergency medical care that could only be provided within the context of a research study.

## **Strategies to Limit Vulnerability**

Latina adolescents are subject to six of the seven vulnerabilities as identified by Kipnis (2003). Because of this high level of vulnerability, there must be special considerations for recruiting this vulnerable population to participate in research studies. Strategies to reduce the risks associated with the vulnerabilities of this population include engaging with the local community, considering research team composition, obtaining parental permission and adolescent assent, providing culturally and linguistically appropriate consent materials, maintaining confidentiality, addressing emotional distress, respecting familial values, and providing appropriate compensation.

## **Community Engagement**

Community engagement is one strategy to address the social and deferential vulnerability of Latina adolescents who participate in research. In order to ensure that research procedures do not discriminate against or otherwise disadvantage this population, researchers are advised to better understand the communities from which their participants will be recruited by engaging with the community prior to, during, and perhaps following the research study (Lakes et al., 2012; Santelli et al., 2003). Such engagement can occur through networking with community leaders and residents, forming a committee of community stakeholders to advise the research team on recruitment, design, and human protection issues, becoming immersed in community activities, being visible at community events, and sharing study findings with the community at the end of the study (Ojeda et al., 2011; Villarruel, Jemmott, Jemmott, & Eakin, 2006; Wallace & Bartlett, 2013). These activities will not only result in a better understanding of community structures and practices that may affect Latina adolescents and their families (e.g., immigration concerns, discrimination experienced by minority groups, the effects of health disparities) but will also engender trust between the researchers and the community, something that is critical in minority communities that may have been taken advantage of by researchers in the past.

### Research Team Composition

Attending to the composition of the research team is another strategy to address the social vulnerability of Latina adolescents. While working with ethnic minority populations, the principal investigator should aim to have gender and racial/ethnic congruence between research team members and participants (Wallace & Bartlett, 2013). For Latina adolescents, the research team should include bilingual, Latina women if possible. Other non-Latino/a members of the research team should become well versed about Latino/a cultural values, norms, and traditions, as well as issues related to immigration (Ojeda et al., 2011). A diverse and informed research team, therefore, will reduce the risk of these Latina adolescents feeling devalued during the research process.

### Respecting Familial Values

Another strategy related to the social vulnerability of Latina adolescents is to respect Latino/a familial values throughout the research process. *Familismo*, or family connectedness, is one of the central values of the Latino/a culture. Researchers should appreciate that the decision to participate in a research study is not just an individual decision but a family decision as well (Lakes et al., 2012). To show respect for the Latino/a culture, researchers should involve parents in the decision-making process and allow enough time for the family to talk about the adolescents' participation in the study (Fisher et al., 2002; Quinn et al., 2012). By taking these steps, the researcher will also be demonstrating *respeto* (respect), another important Latino/a cultural value, to both the family and adolescent (Villarruel et al., 2006). While researchers should acknowledge the importance of family in the Latino/a culture, they must still keep in mind that if conflicts arise, the primary obligation for the researcher is to the adolescent participants rather than the collective family unit (Fisher et al., 2002).

### Obtaining Parental Consent and Adolescent Assent

Adolescents may experience risks during the consent process due to their capacitational and juridic vulnerabilities. Because adolescents, depending on their age, may face capacitational vulnerability, parental consent is typically sought to ensure that adolescents fully understand the risks and benefits of participation in research. Although parental consent is important, adolescents should also be actively involved in an assent process to ensure that they do not feel coerced to participate in the research (Kon, 2006). Therefore, obtaining parental permission for adolescents' participation in research decreases risks associated with their capacitational vulnerability whereas obtaining adolescent assent decreases risks related to juridic vulnerability.

### Providing for Language and Literacy Needs

Providing study materials that can be easily understood by Latino/a parents and adolescents can reduce risks related to capacitational and medical vulnerability. Because many families speak Spanish as their first language, the research team should include bilingual members or trained interpreters who can obtain parental consent and adolescent assent in Spanish if preferred by participants (Ojeda et al., 2011; Quinn et al., 2012). Other study materials should be available in both Spanish and English and reviewed verbally with the parents and

adolescents (Wallace & Bartlett, 2013). Because of lack of familiarity with the research process among many minority populations, providing study information in a variety of formats, such as brochures and videos, can improve their understanding of research risks and benefits (Quinn et al., 2012). Thus, providing study information based on participants' literacy and language needs will lessen the risk of Latina adolescents and their parents agree to participate in research without being fully informed about its benefits and risks. In particular, it is critical for them to understand that the research is separate from their routine mental health treatment and that there may be no direct medical benefit to participation.

### **Maintaining Confidentiality**

Adopting techniques to maintain confidentiality during the research study can lessen the risks associated with Latina adolescents' social vulnerability. Several studies have demonstrated that the biggest barrier to participating in research for Latinos/as is the fear that their documentation status will be exposed (Lakes et al., 2012; Ojeda et al., 2011; Quinn et al., 2012). Individuals may hold this fear due to misunderstandings about the US government's role in academic research and how the information collected in research studies will be used (Lakes et al., 2012; Ojeda et al., 2011). Participant concerns about privacy and confidentiality may be further exacerbated by the stigma of mental illness, especially in the Latino/a culture (Abdullah & Brown, 2011; Andrés-Hyman, Ortiz, Añez, Paris, & Davidson, 2006).

Researchers should therefore provide clear information to Latina adolescents and their parents about how their confidentiality will be maintained, the limits of their right to confidentiality, how any information they provide will be protected, and how their privacy will be ensured (Ojeda et al., 2011). Researchers must inform adolescents and their parents that while their confidentiality will be safeguarded, state laws mandate that certain information, such as the abuse of children, must be reported to the applicable authorities (Fisher et al., 2002). In some studies, it may be appropriate to obtain a waiver of documentation of consent to prevent linking participant names to sensitive information such as documentation status (Fisher et al., 2002). Researchers can replace personally identifiable information with identifiers on participant documents (Fisher et al., 2002). Depending on the nature of the study, researchers can apply for a certificate of confidentiality (CoC) that prevents forced disclosure of sensitive information in response to legal demands such as a subpoena (National Institutes of Health, 2016). While a CoC prevents the forced disclosure of private information, researchers should note that they are still ethically obligated to report suspected child abuse even if they have obtained a CoC (Paquette & Ross, 2014).

### **Addressing Emotional Distress**

Strategies to manage emotional distress that might arise from research participation are especially important given the additional social vulnerability Latina adolescents might experience if they have a mental illness. To ensure the safety of Latina adolescents, researchers will need to develop strategies to handle any psychiatric crises, including intended harm to self or others, that arise during the research process. Safety protocols have been developed to provide guidelines for researchers to protect research participants who have these experiences (Draucker, Martsof, & Poole, 2009; Fisher et al., 2002). These

guidelines often include procedures of assessment of imminent danger, having psychiatric clinicians available for consultation, and referral to local social service and mental health agencies, if indicated. For sensitive subject research with this population, it might be necessary to have trained mental health or medical professionals serve as data collectors so that they can conduct immediate safety assessments and make decisions about the appropriate level of intervention based on the immediacy of the crisis should one arise (Draucker et al., 2009).

### **Providing Appropriate Compensation**

A final consideration for working with Latina adolescents in a research setting concerns how much they should be compensated for their study participation due to their allocational vulnerability. Participation in a research study often requires a substantial amount of time and effort, thus compensation should be provided to adolescents (Ojeda et al., 2011). However, since adolescents typically do not have many financial resources, it can be difficult to determine the amount of the study incentive so that it appropriately compensates the participant for her time and effort while not being coercive (Wallace & Bartlett, 2013). To determine the most reasonable incentive, researchers should consult with community members to determine the appropriate level of compensation for time and travel based on the community and location (Fisher et al., 2002). By determining the appropriate compensation for participation, risks associated with allocational vulnerability can be reduced.

### **Application of Strategies to a Research Project**

The Latina Adolescent Depression Study (LADS) is an on-going grounded theory study examining how Latina adolescents develop, self-manage, and seek mental health services for their depressive symptoms over time. Latina adolescents and young adults are being recruited for this study from both community and outpatient mental health treatment settings in a large Midwestern city. Due to the vulnerabilities of Latina adolescents as described in this article, the LADS research team has instituted a number of the strategies discussed above to lessen the risk of study involvement for the participants. The steps taken by the research team to protect the Latina adolescent sample are described in Table 1 and discussed below.

The author of this article is the principal investigator of LADS, is bilingual in Spanish and English, and has networked extensively with the local Latino/a community. For example, before recruitment began, she met with leaders in the Latino/a community who work with Latina adolescents in community, academic, primary care, and mental health treatment settings. She asked these leaders for their input on recruitment strategies and study design and offered to present the findings of the research to groups of individuals working within these settings. Over the past two years, she has also participated in the development and implementation of several community-based summer and after-school programs for Latina youth from which participants will be recruited. Another member of the research team is Latina and bilingual, has served as a gatekeeper to the local Latino/a community, and has garnered investment in the study by other community leaders and members.

In planning the consent process, the research team considered the participants' risks due to their multiple vulnerabilities. The team decided to obtain permission from one parent and assent from the adolescent but to request a waiver of documentation of consent from the Institutional Review Board. The consent document is available in both Spanish and English and was written at an 8<sup>th</sup> grade reading level. The documents are reviewed verbally by the principal investigator with the parent and adolescent in their preferred language (Spanish or English). If the parent or adolescent wishes to have more time to consider participation, then they are offered the opportunity to contact the principal investigator at a later date to discuss the study. During the consent process, the principal investigator clearly explains that this is a research study and that the participant may not receive any direct medical benefits from participating in the project. The participants are informed that their participation in the study may help researchers and clinicians develop strategies that to prevent, identify, and treat depression in Latina adolescents. The principal investigator also makes it clear that the adolescent's information will be kept confidential unless there are any reports of abuse, harm to self, or harm to others. After consulting with the research team, which included community members, it was determined that a \$30 Walmart gift card would be appropriate compensation for an hour-long interview and travel. The participants will participate in just one interview, so the researchers will not need to retain their contact information, thereby further protecting the families' privacy.

Because the study focuses on depression and there is some likelihood that participants may experience acute distress during the interview, safety planning has been built into the study procedures. All interviews will be conducted by the principal investigator, a registered nurse who has been trained in responding to psychiatric emergencies. A standard safety protocol (Draucker, Martsolf, & Poole, 2009) that outlines procedures to be followed if a participant in a research study experiences acute distress or is in danger of harm to self or others has been modified for LADS. The protocol will ensure that participants will receive appropriate assessment and follow up care, such as referral to a psychiatric clinician in cases of acute distress or arrangement for immediate transport to the emergency room in cases of imminent danger of self-harm.

After data collection is complete, the research team will continue engagement with the local Latino/a community. The team will present the findings of the study in several primary care and mental health settings where Latina adolescents are commonly treated for depression. Based on the findings of the research, the team will work with clinicians in these settings to develop practical strategies to better identify and treat depression in a culturally sensitive manner for Latina adolescents. The research team will also collaborate with several Latino/a summer and after-school camps by presenting program staff with the findings of the research study and initiating conversations about how the findings might inform their primary prevention programs.

## Conclusion

Due to the high rates of mental health disparities faced by Latina adolescents in the United States, researchers must involve these individuals in research studies to reduce health disparities in this population. However, Latina adolescents suffering from mental health

problems may experience many of the vulnerabilities described by Kipnis (2003), including capacitational, juridic, deferential, social, medical, and allocational vulnerabilities. However, a number of strategies can be implemented to increase participation in research studies by reducing the risks that stem from these vulnerabilities. Among these strategies, several are being implemented in an on-going study of depression in the Latina adolescent population.

Successful participation of Latina adolescents in research studies calls for a comprehensive and flexible plan to reduce risks inherent in the vulnerabilities they face. All individuals have the right to be included in research studies if the results may potentially benefit their population. Therefore, researchers should not be deterred by the number of protections required to work with Latina adolescents. Finding solutions to mental health disparities is important for the health and well-being of many young Latina women in the US, and the recruitment and retention of these adolescents in research studies is crucial to finding solutions that prevent, identify, and treat mental health problems in this population.

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**Table 1**  
Types of Vulnerability, Protection Strategies, and Application for Latina Adolescents in a Mental Health Research Study

Vulnerability (Kipnis, 2003)	Definition	Protection Strategies	Application by LADS Team
<b>Capacitational</b>	Having deficits in the ability to understand information and make logical decisions for self	<ul style="list-style-type: none"> <li>Involve parent in the decision-making process</li> <li>Provide consent materials in Spanish and English at appropriate reading level</li> <li>Review consent documents verbally</li> <li>Provide alternative consent documents (pamphlets, videos)</li> <li>Allow extra time to make decision</li> </ul>	<ul style="list-style-type: none"> <li>Obtained parental consent</li> <li>Provided consent materials in Spanish and English at 8<sup>th</sup> grade reading level</li> <li>Used bilingual researcher to review documents verbally during consent process</li> <li>Allowed extra time to make decision about participation</li> </ul>
<b>Juridic</b>	Being liable to the authority of others	<ul style="list-style-type: none"> <li>Obtain adolescent assent</li> </ul>	<ul style="list-style-type: none"> <li>Obtained adolescent assent</li> </ul>
<b>Deferential</b>	Tending to defer to others who are more powerful	<ul style="list-style-type: none"> <li>Obtain adolescent assent</li> <li>Become involved in the local community</li> </ul>	<ul style="list-style-type: none"> <li>Obtained adolescent assent</li> <li>Participated in community activities with Latina youth before starting recruitment</li> </ul>
<b>Social</b>	Belonging to a minority group whose rights have been socially devalued	<ul style="list-style-type: none"> <li>Network with community gatekeepers to gain support and approval of the study</li> <li>Form a community advisory board</li> <li>Aim for gender and ethnic congruence with research team</li> <li>Incorporate Latino/a values into the consent process (<i>familismo, respeto</i>)</li> <li>Obtain waiver of documentation of consent or Certificate of Confidentiality</li> </ul>	<ul style="list-style-type: none"> <li>Accessed the population via gatekeepers</li> <li>Obtained letters of support from community members for the study</li> <li>Included bilingual women and Latino/a community gatekeepers on the research team</li> <li>Respected values, such as familismo, by involving parents in the decision to participate</li> <li>Obtained waiver of documentation of consent from IRB</li> <li>Will return results of the study back to the Latino/a community</li> </ul>
<b>Medical</b>	Experiencing a serious health condition with no treatments available	<ul style="list-style-type: none"> <li>Provide clear explanation of research during consent process</li> <li>Use acute distress and safety protocol</li> </ul>	<ul style="list-style-type: none"> <li>Explained the purpose of the research study and that there may be no direct benefits</li> <li>Developed distress and safety protocol to follow in the case of suspected abuse or self-harm</li> </ul>
<b>Allocational</b>	Lacking a social good that will be provided as a consequence of participation	<ul style="list-style-type: none"> <li>Consult gatekeepers to determine appropriate level of compensation</li> </ul>	<ul style="list-style-type: none"> <li>Consulted community members to determine appropriate level of compensation</li> <li>Provided \$30 Walmart gift card for an hour-long interview with travel</li> </ul>

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<b>Vulnerability (Kipnis, 2003)</b>	<b>Definition</b>	<b>Protection Strategies</b>	<b>Application by LADS Team</b>
<b>Situational</b>	Needing treatment in an emergency without having time to consider treatment options	<ul style="list-style-type: none"><li>• Not applicable</li></ul>	<ul style="list-style-type: none"><li>• Not applicable</li></ul>