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Recruiting Urban Latina Adolescents and Their Families: Challenges and Lessons Learned in Suicide Attempts Research

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Abstract

Recruiting samples with unique characteristics dispersed across services and geography is hard to identify because of legal status and stigma create research challenges. Public health, however, requires sustained recruitment efforts. We describe challenges and solutions in recruiting urban adolescent Latinas who had attempted suicide. Procedures for recruitment and human subject protections were established, yet logistic obstacles emerged. Program directors failed to support the research; therapists were slow to identify subjects and to meet inclusionary criteria; numbers of prospective participants were lower than originally calculated; girls and parents were hard to reach; and interview appointments were missed. From challenges came solutions: to use fewer agencies, do better participant surveillance, monitor staff participation, and build rapport and relationships with staff. In-service research training to develop agency research infrastructure generated support among providers and administrators. Our experience may be helpful to other researchers conducting studies with similar populations.

Keywords

subject recruitment; field methods; adolescent suicide attempts

Recruiting special populations that are not likely to appear on the “radar screen” of clinical epidemiologists and services and behavioral science researchers often poses special challenges. Unlike samples contained within institutions and communities (e.g., college students, in-patients, parent-teacher-student associations) or that are convenient to engage, populations with unique characteristics that do not typically lend themselves to easy recognition by researchers are often less accessible (Domenech Rodriguez, Rodriguez, & Davis, 2006). In seeking them, many challenges await us.

While recent reports suggest that Hispanics¹ are as willing to participate in health research as non-Hispanics (Wendler, Kington, Madans, Van Wye, Christ-Smith, Pratt, Brawley, Gross, & Emanuel, 2006), in the case of populations at risk, such as adolescent suicide attempters, there

¹We use the terms Latino and Hispanic interchangeably in this paper.

are ethical, diagnostic, and practical issues that make recruitment of adequate numbers of participants especially difficult. Working with adolescents requires special effort to guarantee voluntary recruitment, and the most frequently reported difficulty is obtaining parental consent (Diviak, Currt, Emery, & Mermelstein, 2004). Parents also strongly influence their adolescents' decisions to participate in research (Broome & Richards, 2003). Therefore, the ability to establish a good relationship with the parents is essential for recruitment of the adolescents.

However, adolescent suicide attempters tend to be dispersed in the population under care in the mental health system and administrative data often categorizes them by diagnosis rather than symptom (i.e., suicide attempt). Unlike persons with other health problems, such as tuberculosis, diabetes, renal dialysis, human immunodeficiency virus (HIV) or mental disorders (e.g., schizophrenia), who are often identified early, sorted into specialty clinics, and monitored extensively, suicide attempters might find themselves in a variety of differing situations. While they might be seen in an adolescent psychiatric clinic, the number of attempters a clinic might be serving at any given time (and how many might fit research inclusionary criteria) varies. Also, the treatment plans for many suicide attempters often include some time in an inpatient unit followed by outpatient treatment through a different organization, and the amount of time spent in each depends on the individual and the providers. Hispanic adolescent females with histories of suicide attempts are one such group that typifies some of the recruitment challenges researchers face, especially when studying culturally influenced phenomena of clinical significance among populations not easy to access.

Social and behavioral science textbooks, for the most part, have very little to say about recruiting these elusive populations. More often, they detail how to go about identifying the population, computing the size needed for statistical power, and stratifying the sample (Monette, Sullivan, & DeJong, 2005; Neuman, 2006; Rubin & Babbie, 2007), but do not address the logistical challenges of accessing the population to be studied. Some attention has been given to recruitment and retention of minority research participants and to the need for publications that report on the challenges inherent in recruiting and conducting research with ethnic minorities in community-based settings (e.g., Domenech Rodriguez et al., 2006; Gilliss, Lee, Gutierrez, Taylor, Beyene, Neuhaus, & Murrell, 2001; McMiller & Weisz, 1996; Miranda, Azocar, Organista, Muñoz, & Lieberman, 1996; Villarruel, Jemmott, Jemmott, & Eakin, 2006). Other reports on the challenges of conducting intervention research in real-world community settings (e.g., Hohman & Shear, 2002; Zayas, McKee, & Jankowski, 2004) have appeared to help researchers in the fluid, dynamic environments of community-based research. In this paper, we hope to contribute to this growing body of literature.

The purpose of this paper is to describe the challenges that we faced in finding, recruiting and enrolling adolescent Latinas from an array of service settings in New York City for a mixed-method study of their suicide attempts. By describing our experiences and how we managed them—sometimes effectively and sometimes ineffectively—and the lessons we learned, we want to help other researchers avoid similar pitfalls.

Our Study

Our federally funded project on adolescent Latina suicide attempters had as its aims to explore the phenomenology of the suicide attempts; parents' understanding of their daughters' suicide attempts; and familial, developmental, and sociocultural experiences that distinguish adolescent Latina attempters and their parents from Latina non-attempters and their parents. The research design involved recruiting a sample of one hundred Hispanic adolescent females, between eleven and nineteen years of age, who reported at least one suicide attempt in the previous six months, and who were receiving mental health services in any of the clinics or

hospitals that had volunteered to serve as recruitment and data collection sites. Our exclusionary criteria included a history of severe mental health illnesses (e.g., schizophrenia, bipolar disorder, psychotic disorder), foster care, and mental retardation. A comparison group was comprised of one hundred adolescent Hispanic girls with no history of suicide attempts, severe mental illnesses, or mental retardation, who were recruited from non-clinical programs at the same recruitment sites, other organizations in the same communities, such as prevention or after school programs, etc. One or both parents of the attempters and non-attempters were invited to participate in the study, but a parent could not participate if his/her daughter was not interviewed. Participation by girls and parents entailed a ninety minute meeting with a researcher in which a questionnaire and in-depth interview were administered, after which the individual was paid for her or his participation. All procedures for participation were approved by our university's institutional review board to ensure the protection of the human subjects and the participating agencies and hospitals.

A diverse selection of mental health services were identified as potential recruitment sites (i.e., community mental health clinics, prevention programs, in-patient psychiatric units, outpatient psychiatric services, after school programs, pediatric clinics). Five institutions agreed to permit recruitment in their clinics, totaling nine individual sites. One institution did not proceed with their IRB application and was dropped after several months. Two others completed their IRB process and two designated our university's IRB as the responsible one. Some institutions provided exclusively suicide attempters; others provided both attempters from their clinical programs and non-attempters from non-mental health primary care, youth development, and prevention programs.

Moving through the identifying and recruiting procedures to the point of actually interviewing participants was a highly complex process. Each institution had its own protocols and each subsystem or clinic of larger organizations its own culture, which necessitated that the procedures be adapted specifically to the nature of each site. As per IRB regulations, we were particularly cognizant of the potential coercion of our vulnerable participants. According to the Belmont Report (1979), "Coercion occurs when an overt threat of harm is intentionally presented by one person to another in order to obtain compliance." Our basic procedures for obtaining informed consent consisted of six steps, modified slightly for individual settings. In the *identification* step, the agency intake supervisor identified girls who met inclusionary criteria. In the *assent* step, the agency staff told girl and parents briefly about the study to assess interest. If family declined, there was no further attempt to recruit them. If the family indicated interest, the staff member informed the family that the girl's therapist would have to grant approval for her to participate. If there was any indication of coercion, this was noted for the therapist for the next step, *clinical clearance*. With the family's agreement, the girl's therapist assessed her clinical readiness to participate, any potential risks involved, and the presence of coercion, especially if flagged earlier. If the therapist approved of her participation, the girl was *referred* to the study and the researchers were then able to contact her and her parents. The *informed consent* step began with the research interviewer describing the study (and assessing for coercion). Once more, the family could opt out. If the girl agreed to participate and no coercion was evident, she (and her parents if she was under 18 years old) signed the consent form. Parents decided to provide consent to participate in their own interviews or not. If coercion of the girl was present in this step, she and her parents were redirected to the clearance step, thus providing added protection. After obtaining informed consent, the next step was to schedule the *interview* and collect data. Participants were then compensated for their interviews with \$50, for which they signed a receipt and were given a copy.

Challenges, Solutions, and Lessons

Several recruitment challenges emerged during the first 30 months of recruitment. We grouped challenges into categories associated with the initial start-up of the project, working with multiple agencies and providers, human subject protection, and recruiting adolescent Latinas and their parents. Developing a successful recruitment strategy was costly and time consuming. However, as a group of researchers with diverse backgrounds, we were able to overcome the challenges. From this experience, there are several lessons that may be helpful to other researchers investigating populations with similar social and psychiatric problems.

Challenge: Discrepancy between expected and actual numbers of potential participants

Not unlike the experiences of other community-based researchers, we encountered agencies that were very enthusiastic about participating and optimistic about the recruitment of adolescent Latinas with a recent history of suicide attempts. Calculations of the number of potential participants for the study were often based on impressions of past and current caseloads and, in only a few instances, on actual data. However, when the recruitment procedures were actually implemented in the sites, we found that the rate of referrals was much lower than what had been previously predicted. For more than a year, considerable effort went into enlisting institutions and ascertaining that the participants could be identified and recruited. However, the numbers were below our estimates due in part to difference between agency perspectives on who would be eligible and the study's criteria for inclusion. Thus, the project was delayed in its initial stages, a cause for alarm among our research team.

One solution was to *move quickly to close gaps*. Most of the challenges encountered early on represented issues of time constraints. That is, whether it was recognizing that some providers or sites were not generating sufficient numbers of referrals, or that financial decisions had to be made, we learned that the best approach was to address the problem promptly and make decisions rapidly to prevent the continued loss of time or money. Sometimes these decisions were based on incomplete information but they were the best possible choices under the circumstances. So, we discontinued interviewers or dissolved agreements with institutions when it was clear that recruiting sufficient participants in a timely manner did not look promising. It was not always pleasant parting company, but everyone involved understood the situation we all faced.

Challenge: Engaging agencies and providers

Because we were guests of the different organizations that referred participants and our access to case records and potential participants was constrained by privacy policies, our research team had to develop individualized working plans. Each institution had its own culture and climate, and different IRB requirements had to be satisfied. In so doing, our researchers had to develop relationships with individual managers, clinicians and general staff, learning the nuts and bolts of the organization, and recognizing the potential problems in the organizational landscape. The assertive diplomacy and relationship-building skills of our project manager and principal investigator were instrumental in gaining the trust and engaging the program directors and providers.

As we learned that no single agency could provide the full number of attempters needed or the diversity of sample that we hoped for, it was necessary to act aggressively to find new sites. Through contacts in the city and as the study gained more publicity, numerous potential recruitment sites were identified. Some were discarded summarily because of their service orientation or population. Others were contacted and collaboration was discussed, which resulted in several agencies becoming faithful partners. With others, we progressed toward collaboration only to find soon enough that the complexities of their approaches, or the

expectations they had of the project (often in the form of monetary payment or unlimited access to our data) were unreasonable. Of about twelve agencies considered, only four became sustainable research partners.

Our first resolve was to understand and encourage *staff flexibility and patience*, both research and agency staff. A key lesson was inculcating in interviewers and research staff the need to keep flexible schedules when arranging interviews. Whether participants arrived late or not at all, or interviews ran longer than expected, interviewers had to remain poised and accommodating to both agency and participants. To achieve higher levels of engagement we found it advantageous to adjust the interviewing process to the parents' requests, especially. Interviewing on weekends or in the evenings, obtaining consent in the participants' homes, and providing childcare during these interviews were all crucial to increase our rate of data collection.

Challenge: Staff buy-in and locating participants

Still, despite oral assurances of their cooperation, often in the presence of upper level agency directors, clinicians and program directors did not always come around easily. In fairness, most clinicians in community settings are overworked and carry large caseloads, and requesting their assistance with our research translated into more tasks (e.g., staying in contact with the project manager, completing forms, learning the recruitment protocol and the requirements for human subjects protection); and there were few incentives for their help. Some clinicians showed their reluctance by denying researchers access to patients. In some cases, in spite of written and oral encouragement from the administration, some program or clinic directors were not enthusiastic about participating and their reluctance was often a politically motivated response to the agency climate.

Our first step to incentivizing agency staff was to select and train them as research interviewers. They received monthly supplements to their salaries, but it soon became apparent that this was insufficient incentive to find, enroll, and interview participants from their agencies. This was largely due to the fact that the incentive was guaranteed and did not depend on productivity. We then undertook negotiations with the institutions ensued and we agreed to pay interviewers as consultants to the project ("freelance" as it became known), a move which resulted in much faster accrual of participants. This arrangement also made it clear which staff members were more motivated than others, not just by finances but also by a real interest in the research process. Freelance interviewers from within the agencies became excited and appreciated the professional development they gained by acquiring new research skills. They became more eager to help develop the research infrastructure in their agencies, a well-received by-product of the change in compensation structure.

Freelance interviewers and incentives proved to be the best way to stay aware of real cases in each location. These freelance researchers were clinicians in managerial positions who had access to agency intake records and contact with all of the other clinicians in the agency. They were able to identify cases and follow those that qualified for the study. The constant presence of the research staff and the continual search for creative ways to work within the system helped in the long term to achieve the study's goals.

Challenge: Multiple recruitment sites, multiple informed consents

Completing the requisite human-subjects protections process did not guarantee success in the recruiting process, and the research was affected by the rotation of agency staff and the need to train newcomers. This process was very expensive in both time and money, an expenditure that was not anticipated in the original budget or timeframe for data collection and analysis. By the time all arrangements were in place, we were using seven sets of forms (assent for

attempters, assent for non-attempters, parental consent for attempters, parental consent for non-attempters, consent by adolescent attempter, consent by adolescent non-attempter, parental consent for self) in both English and Spanish (N = 14 forms). Further, each institution had some variation on forms (e.g., slight changes in wording, requiring agency logos on consents). Four agencies each used fourteen forms, requiring the maintenance of 56 separate forms.

With those agencies that became data collection sites for this project, we made special efforts to maintain the interest and participation of staff and administrators in the recruitment process. Providing departments and agencies with training opportunities, gift certificates, and subscriptions to professional journals acknowledged the value of their collaboration. Research co-investigators who were skilled clinicians delivered workshops, lunch talks, grand rounds, and cultural competency training sessions that bolstered staff support.

Solution: *Establishing and maintaining rapport*—Having at least one full time researcher who can serve as the point of contact for both the managers and clinical staff in the various sites was extremely helpful in building good rapport and securing strong relationships. The most success came at the stage after assent, when girls and parents met with research staff. We had no instances of declinations at that point. This seemed to be a combination of families' motivation to participate and the sensitive interpersonal skills of the research staff, all of whom were bilingual Latinos. Taking into account practical barriers was important to successful recruitment (Gallagher-Thompson, Solano, Coon, & Areán, 2003). Our task was to work assiduously to make our IRB issues seem invisible to agency staff. Despite our frantic efforts in the background to accommodate and meet all mandates for human subjects protections, we managed these without worrying agency staff and supervisors. Once the issues were settled, we worked with staff to introduce the changes to research protocols.

Challenge: Recruiting girls and their parents

“Word of mouth” was reported as a useful tactic by Domenech Rodriguez et al. (2006) in their recruitment of rural Latino parents. However, in the context of a mental health, where confidentiality and privacy are necessary, this type of recruitment was not feasible (although it was used in recruiting the non-attempters). Stigma, shame, and legal status were other obstacles toward a more aggressive outreach.

The vulnerability of our population we study raised the level of vigilance that we had to keep on issues of coercion. At every step in the recruitment of girls and their parents, we were attuned to potential coercion: that therapists encouraged a little too much, that the girl felt the need to please her therapist or other staff, that parents might be applying pressure to the girl because of the compensation offered.

The challenges of identifying and recruiting minors (following all ethical guidelines for research with this vulnerable population), interacting with parents, managing a multilingual sample, coordinating multiple sites, deploying interviewers, and accounting for payments to participants and interviewers became pronounced, demanding a great deal of project staff time. Because many parents participating in the study were single parents and were solely responsible for childcare in their households, we frequently encountered scheduling conflicts between their availability and the clinics' working hours. Requests for childcare and transportation arrangements were frequently difficult to fulfill, especially for a geographically dispersed population.

Compounding these issues was the fact that some of the study's participants were undocumented immigrants, particularly the parents. Hesitation about participation was evident in parents' replies to our invitation, and they expressed interest very tentatively until trust was established. Many live below the poverty line and leave the health and social service system

quickly and frequently. In some cases there was no telephone in the household, an economic reality of low-income urban life. Assuring participants of the privacy and confidentiality of the study, including our federal certificate of confidentiality, was not always easy with persons with marginalized financial, educational, or immigration status.

It was not unusual that after a clinician approved that a teenage client be referred to the study, the girl agreed to be contacted without much hesitation. This was followed by sometimes strenuous efforts to arrange for the consenting process with the parents, to schedule the interview appointment, and to obtain access to agency offices for the interviews (especially on weekends). Additionally, often two interviewers set their schedules to conduct two to three interviews in a day only to have participants fail to show up without notifying the interviewers. Renewed efforts to engage the participants were made until the interviews were rescheduled and completed. Ultimately, coordinating parents', teenagers', therapists' and researchers' schedules while maintaining reasonable timetables to achieve our goals necessitated being alert and flexible. The closer the interview was to the time of the initial contact, the better the quality of the data collected. Time lapses meant lost opportunities.

Conclusion

Although the Centers for Disease Control and Prevention (2006) report that 15% of adolescent Latinas report having attempted suicide—a rate higher than their non-Hispanic counterparts—this rate does not translate into a population easily accessible to researchers. Study the reasons that adolescent Latinas attempt suicide calls for research designs that locates participants across a diverse service network and broad urban geography. Unlike other public health populations, there is no naturally occurring concentration of Latinas with suicidal behaviors. Because of these challenges, every effort was to be made to recruit, enroll, and retain participants. Our multi-site model covered an ample spectrum of locations and care levels, all within the metropolitan area, and helped generate a diverse sample, lending strength to the quality of the data. But these very same strengths brought with them numerous logistical challenges in the field. Often research reports and texts report the study methods without attention to the logistical challenges, obscuring the story behind the research story (Domenech Rodriguez et al., 2006; Gilliss et al., 2001; Ness, Nelson, Kumanyika, & Grisso, 1997). This paper adds to a growing body of literature that tells the untold struggles of community-based research with vulnerable groups.

In recruiting adolescents and parents, we were able to develop strategies to approach the participants in their own language, to offer multiple scheduling opportunities, to adapt informed consent to institutional requirements, and to maintain flexible interviewing schedules, while staying faithful to our protocol. The team found that being cognizant of the uncertainties and fears faced by undocumented immigrants and stressing the confidential and volunteer nature of their participation eased the informed consent process. Finally, our interviewers' expression of genuine interest in the families' stories was the best tool in engaging the adolescents and their parents.

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