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Engaging Adolescent Mothers in a Longitudinal Mental Health Intervention Study: Challenges and Lessons Learned

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Abstract

Background—Little is known about recruiting and retaining adolescent mothers in research studies. Investigators who study adolescent mothers have been guided by trial and error, clinical experience, qualitative inquiry, literature of special populations or advice of stakeholders. This paper describes the challenges and lessons learned in engaging adolescent mothers in a longitudinal community-based mental health intervention study.

Methods—Audio-recorded data that describes the circumstances of five adolescent mothers lost to attrition were extracted from a longitudinal mental health intervention study.

Results—Adolescent mothers described a chaotic home environment with multiple demands, family conflict, health issues, limited access to a telephone, transportation, financial, and social support.

Discussion—Utilizing a multidisciplinary community advisory group, dedicated telephone, and free electronic media may assist in overcoming modifiable barriers to recruitment and retention of adolescent mothers. Exploring a waiver of informed consent and the engagement of mothers of adolescents in research are indicated.

Keywords

Adolescent Mothers; Mental Health; and Recruitment and Retention

Background

Inclusion of children (persons younger than 21 years of age) in research ensures that adequate data are available to support treatment choices for conditions that affect both

children and adults (National Institute of Health, 1998). In studies with particularly vulnerable populations, like adolescent mothers from a low socioeconomic level, researchers must balance the strong competing priorities of the recruitment and retention of adequate sample sizes with the strict adherence to ethical principles of informed consent free from undue influence. On one hand, there is tension to recruit and retain a sample that provides adequate statistical power and generalizability (Shadish, Cook, & Campbell, 2002). Alternately, the ethical principles for human subjects research outlined in the Belmont Report (1979) states that agreement to participate in research must be voluntary without an offer of excessive or improper reward. Attentions to context and individual situations are imperative; recommendations for appropriate recruitment methods for children and adolescents have been disseminated by professional organizations like the American Academy of Child & Adolescent Psychiatry (Hinshaw et al, 2004). Additionally, the scientific literature provides guidance on recruiting and retaining vulnerable populations. However, little is known about how to effectively recruit and retain adolescent mothers, who are at high risk for mental disorders and are often of low socioeconomic level.

Since little is known about the recruitment and retention of adolescent mothers in research studies, investigators who study adolescent mothers likely have been guided by trial and error, clinical experience, qualitative inquiry, use of the literature on other special populations or by heeding advice of stakeholders in a community advisory group. Our research team has extensive experience in studies with adolescent mothers and recently conducted a longitudinal mental health study with the population. For this study, we were guided by strategies used in recruiting and retaining special populations—minority, adolescents, and children (Topp, Newman, & Jones, 2008; Rice, et al., 2007; Flicker & Guta, 2008; Pierce & Hartford, 2004; Seed, Juarez, & Alnatour, 2009). Some strategies proposed by these scientists were effective in our research study. However we still encountered barriers to recruitment and retention, which are described in this paper. Thus, the purpose of this paper is to describe the challenges and lessons learned in engaging adolescent mothers in longitudinal community-based mental health intervention study. The circumstances of five adolescent mothers who enrolled in a longitudinal mental health intervention study, but were lost to attrition, are described. Their circumstances elucidate the challenges of engaging adolescent mothers in longitudinal research. We describe challenges and lessons learned within the context of competing tensions of recruiting and retaining an adequately sized adolescent sample while upholding the ethical principles of research.

Methods

Overview of Larger Longitudinal Mental Health Intervention Study

Complete results of the larger longitudinal mental health intervention study are reported elsewhere (Logsdon, et al., 2010). However, to provide context for this paper, a brief description of the study is provided. Adolescent mothers ($n = 97$) (13–18 years of age) were recruited from a Teenage Parent Program public high school and screened for symptoms of depression within four to six weeks post-delivery utilizing the Center for Epidemiologic Studies of Depression (CES-D) and Kiddie SADS (K-SADS). Participants who scored greater than or equal to 16 on the CES-D, or met the criteria for depression on the K-SADS received a telephone-based depression care management intervention. The purpose of the manualized intervention was to assist adolescent mothers in overcoming barriers to mental health treatment. Once assigned to the intervention, an experienced child/adolescent psychiatric nurse practitioner (the interventionist) delivered the telephone-based intervention to adolescent mothers with symptoms of depression. The interventionist was able to reach participants for 53% of calls. At baseline, the name, address, and five telephone numbers of social network contacts were supplied by participants. Participants received a \$15 retail card for screening at baseline (4–6 weeks post-partum), three months, and six months, but did not

receive compensation for enrollment in the intervention. All participants, regardless of initial depression symptom status, were screened for symptoms of depression at three and six months after the baseline screening. Although there was a trend for improved depression symptoms with the intervention, there were many feasibility issues in the conduct of this research study related to the complex life challenges experienced by adolescent mothers (Logsdon, et al., 2010).

Of the 97 mothers enrolled in the study, a total of 22 adolescent mothers were referred into the intervention. Thirteen adolescent mothers completed all telephone sessions of the intervention. Four adolescent mothers that were enrolled in the study and referred to the intervention, but were never able to be contacted by telephone and never received the intervention; thus, we have no qualitative data on these participants. Five adolescent mothers partially completed intervention; these five adolescent mothers received two to nine telephone sessions, but were lost to attrition during the intervention. Before these five participants were lost to attrition, the team collected qualitative data on adolescent mothers' life circumstances during the telephone intervention sessions.. This paper describes of cases of five adolescent mothers that were lost to attrition.

Data Collection

This paper reports data extracted from a larger longitudinal mental health intervention research study (Logsdon, Pinto-Foltz, Stein, Usui, & Josephson, 2010). For this paper, we examined audio-recordings of the intervention sessions of the five participants who were lost to attrition during the intervention.

Results

Five Case Studies

Andrea.*—(Names and demographic information have been altered to protect participants' identities) Andrea is a 15-year old adolescent who was four weeks post-partum at enrollment. During her first telephone intervention session, Andrea reported frequent “off and on conflicts” with her mother; although Andrea and her mother live together, they did not speak. At the second intervention session, Andrea’s mother answered the phone. At that time, the interventionist introduced herself and asked to speak to Andrea for the second intervention session. Andrea’s mother expressed her desire to speak to the interventionist first. Andrea’s mother was distraught about the frequent conflicts with her daughter and described Andrea as “out of control.” Andrea had a prior history of depression, but did not take prescribed medication. Andrea screened positive for depressive symptoms at four weeks post-partum and was referred to a mental health provider for further evaluation and treatment. Andrea never sought mental health treatment because of the inability to secure reliable transportation to a mental health provider and childcare for her baby. At the fourth intervention session, the interventionist had difficulty reaching Andrea by telephone; the interventionist called Andrea numerous times before making contact. Andrea was lost to attrition at the fifth intervention session. The interventionist exhausted all phone numbers provided at enrollment; these telephone numbers were for her mother, boyfriend, and brother.

Sarah—Sarah is a 17-year old female with a history of major depressive disorder at five weeks post-partum. Sarah has taken a Selective Serotonin Reuptake Inhibitor (anti-depressant medication) for three years, and recently terminated her weekly counseling sessions. Sarah reported that her “mother was too busy to take her (Sarah) to therapy sessions” and the therapist was not available at times when Sarah was available. During the first and second intervention sessions, Sarah reported to the interventionist a complicated

pregnancy. Since the baby's birth, she described life as "stressful with money, managing the baby, and school." Sarah described her baby as being "fussy" and "difficult to sooth because of his gastric reflux." Sarah complained of being "sleepy," but attributed her sleepiness to medication.

Sarah depended on her mother for use of the telephone and transportation. Sarah's mother's cell phone was Sarah's primary phone number. Sarah had restricted access to a telephone because Sarah's mother carried her cell phone to work in the evenings. The interventionist repeatedly had difficulty contacting Sarah for her intervention sessions. Sarah worked a part-time job at a local restaurant, but had little money for basic needs and no money for school or to attend college. Sarah was lost to attrition. The interventionist was able to talk with Sarah's mother, but Sarah's mother refused to provide the interventionist a contact number for her daughter.

Katie—Katie is a 16 year old female. At five weeks post-partum during data collection, Katie expressed thoughts of self-harm, and Katie was referred immediately for further mental health evaluation. Katie entered into the telephone-based intervention, and the interventionist further evaluated Katie's thoughts of self-harm. Katie told the interventionist that "I think I have post-partum depression, but I don't want to get treatment, medication or therapy. I think I'll get better on my own." Katie worked at a fast food restaurant, but did not possess adequate funds for mental health treatment. At the fifth intervention session, Katie reported that had been spending more time with her family and other friends who have babies and expressed a desire to pursue therapy and medication for her mood. After the fifth intervention session, Katie was lost to attrition. The interventionist exhausted all contact numbers for Katie, but was not able to reach Katie or determine if she ever received mental health treatment.

Leigh—Leigh is a 14-year old adolescent who was 4 weeks post-partum at enrollment. Leigh screened positive for post-partum depression and was referred for mental health treatment. However, one week after baseline measures, Leigh underwent an open cholecystectomy (removal of her gallbladder); she was hospitalized for surgical complications. Despite numerous calls from the interventionist, Katie could not be reached; she never began the intervention.

Allison—Allison is a 14-year old adolescent who was six week post-partum. Allison was lost to attrition after the third intervention session. During the interventionist's first call, Allison's mother answered the phone and said "Allison isn't ready to talk." Allison's mother however offered the information about her daughter; she thought "Allison was doing okay with being a new mom." A few days later, the interventionist was able to speak with Allison and learned that she was transferring from an all female public school for pregnant and parenting adolescents to a co-ed public high school. Allison lived with her mother and the baby. Before Allison was lost to attrition and at the third intervention session, Allison expressed no complaints about her mood and remarked that the baby's father was now visiting the baby on occasion. At the fourth intervention session, the interventionist made numerous calls, but the Allison could not be contacted.

Discussion and Conclusions

Results of these five cases elucidate the challenges faced by adolescent mothers within the first six months post-partum. Common threads of the adolescent mothers' circumstances include a chaotic home environment with multiple demands, conflict with their mothers, health issues (their own and/or their child), inconsistent access to a telephone and transportation, and limited financial and social support. There are some common threads

(barriers) to recruitment and retention can be addressed in future studies, while others are not easily modifiable. For example, the chaotic environment and competing demands described by adolescents may be inherent to the role of an adolescent mother. These factors may be complicated by a low socioeconomic level and residing in a single parent home; these barriers are not easily modifiable. Thoughtful strategies to overcome modifiable barriers to improve recruitment and retention of adolescent mothers can be gleaned from research with special populations—minority groups, adolescent, and children. Investigators describe overcoming modifiable barriers that likely were also barriers in this study. These barriers are skepticism and low trust, respondent burden, and inability to maintain contact with research participants. Given the guidelines of the recruitment site, we were unable to provide service during school hours. We employed face-to-face recruitment and followed up with phone calls to answer any questions of the adolescent mother and parent.

Overcoming Skepticism About Research and Building Trust

Recommendations to overcome skepticism about research and build trust are: (a) careful attention to terminology like using the word “project” and “study” opposed to “research” when the study is introduced to potential participants (Rice, et al., 2007); (b) use of a community research advisory group comprised of stakeholders and adolescents to inform provide formative assessments of study procedures, ensure ethical standards, and foster “buy in” from the priority population (Topp, Newman, & Jones, 2008; Flicker & Guta, 2008); (c) provision of service to the community prior to and after the study also facilitates trust and “buy in” (Topp, Newman, & Jones, 2008); and (d) use of face-to-face recruitment and the involvement of key stakeholders—teachers, school principals, nurses, social workers, and physicians, who have established trusting relationships with the priority population (Pierce & Hartford, 2004; Rice, et al., 2007).

In our research study, we used the terminology “project” and “study” in discussions with research participants. A community research advisory group reviewed study instruments, the intervention, procedures, and stipends. Our community research advisory group consisted of school personnel, medical professionals, social workers, adolescent advocates, and community leaders. In the future, we plan to include additional members to our community research advisory group include parents of adolescents, adolescent mothers, attorney, psychologist, medical anthropologist, and medical sociologist. We also plan to perform frequent formative assessments to identify recruitment and retention issues and so the team may develop timely solutions to problems that arise during the study.

Respondent Burden and Compensation

Adolescents often depend on their parents for transportation to and from study related activities. Thus, study participation should avoid loss of money and time (i.e. time off from work) for participants (Rice, et al., 2007). Whenever possible, inconveniences for participants should be avoided and minimized (Pierce & Harford, 2004). For example, if data are collected at community sites, like medical offices and schools, data should be collected when adolescents are at these sites for other reasons.

Compensation to offset respondent burden and incentivize participation should be age and developmentally appropriate, but not coercive (Kendall & Suveg, 2008). Opinions about appropriate compensation vary widely. A “wage-payment” model is considered developmentally appropriate for compensating adolescents for their time and effort (Bagley, Reynold, & Nelson, 2007). On average adolescents are compensated at a rate of \$26.61 per study session, but the range is \$2-\$1000/per session (Borzekowski, Ricker, Ipp, & Forenberry, 2003). Compensation type varies and includes cash, gift cards, items, and vouchers; Cash and gift cards are the most popular. Although compensation is important to

off-set respondent burden for study participation, adolescents and their parents often participate in research for non-monetary, altruistic reasons or because participants think they will benefit from the experience of peer interaction or from an intervention (Carroll, Marrero, & Swenson, 2007; Rice, et al., 2007). Compensation should be examined in the context of the population. Incentives may be coercive to some groups, but not considered coercive to others.

For this study, we attempted to minimize inconveniences for participants by collecting data during school hours and administering the intervention by telephone and at convenient times for the adolescent mother. Since we employed these procedures, we avoided the need for participants to secure childcare and transportation—both are common barriers for adolescent mothers. Adolescent mothers received a \$15 gift card to a discount retail store at each data collection point, but not for intervention. Our compensation was below the average identified by Borzekowski, et al. (2003). Adolescent mothers in our study frequently described stress related to inadequate financial resources. It is plausible that adolescent mothers choose to participate at baseline because they received a gift card immediately, but did not receive a gift card for each intervention session. For example, during a face-to-face recruitment with one adolescent mother, she said “I want to participate before next week. I need the gift card to buy diapers for my baby. She (the baby) will run out of diapers before next week, and I don’t have money to buy diapers.” In the future, compensation may need to be at a higher rate and more frequent increments, at each intervention session. It is plausible that a different compensation may be more appealing to potential participants. A community advisory group, that includes adolescent mothers, may provide guidance on other types of compensation.

Inability to Contact Participants After Enrollment

The inability to contact participants after enrollment is problematic and can result in attrition. In the last decade, implementation of the Health Information Privacy and Portability Act has provided additional protection to individuals’ health information, but also restricted the accessibility of information to investigators. As a result, some researchers have encountered barriers in recruiting, tracking, and retaining participants. To improve attrition, Menard (2004) recommends frequent contact with participants in the form of birthday/holiday cards and sending study notifications to foster a feeling of connectedness. Investigators have found that attrition can be lessened when they develop connections early in the study through friendly and personal interactions, prompt return of participant phone calls, and collection of multiple phone numbers to contact participants (Menard, 2002; Pierce & Hartford, 2004).

For our study, the inability to contact participants was time intensive and posed the greatest challenge. With the surge in cellular phone technology in the last decade, the research team did not anticipate inconsistent telephone access. Consistent telephone access was included in the study inclusion criteria and verified with each participant prior to enrollment at baseline. However, during the study, we discovered that phone access was inconsistent. Although we were able to retain the majority of participants, retention involved multiple phone calls and tracking adolescent mothers through the multiple social network contacts, which were provided by participants at baseline. We found adolescent mothers to be transient; many adolescents changed physical living locations and phone (landline and cell) were often disconnected within days of a previous contact. Another unanticipated problem was gatekeepers to phone access. Despite securing informed parental consent, mothers of research participants were often gatekeepers and posed as a barrier for the interventionist and tracking participants. In future studies, use of a dedicated cell phone for communication with the interventionist may enhance tracking and communication with research participants. Because phone access requires financial resources to maintain, use of social

networking accounts, like Facebook and MySpace that are free, may prove to be an effective means to communicate with research participants in the future. Among adolescents 12–17 years of age, 90% have internet access at home (Nielson, 2009). Of those adolescents without home internet access, 75% have internet access at school (Nielson, 2009). In 2009, roughly 45% used either Facebook or MySpace and most users updated their profile or status weekly (Nielson, 2009). Use of social networking for research is fairly new. The best methods to protect research participants and maintain confidentiality are unclear and currently debated in the scientific community (Friedewald, Wright, Gutwirth, & Mardini, 2010). Nevertheless, social networking appears to be a promising and naturalistic approach to maintain in contact with adolescent mothers in future research studies. The feasibility of this strategy is unknown, but is beginning to be used in research with adolescents (DiClemente, Ruiz, & Sales, 2010; Nwadiuko, Isbell, Zolotar, Hussey, & Kotch, in press)

Although parental consent was mandatory for study participation, some mothers of research participants posed barriers to maintaining contact with adolescents. Rojas, Sherrit, Harris, & Knight's (2008) naturalistic study illustrated that obtaining parental/guardian consent resulted in a heavily skewed, self-selected sample comprised of low risk participants. One could argue that self-selection of low risk research participants violates the ethical principle of justice, the fair sharing of risks and benefits (Santelli, et al., 2003). Upholding the justice principle is a relevant concern for two reasons. First, parents may not grant consent for their adolescents to participate in research, which may stem from the parent's general experiences as an adolescent or because of the study topic (Flicker & Guta, 2008); this may cause conflict between the adolescent and parent. Second, adolescents find some topics difficult to discuss with parents. As a result, they may not ask their parent to review and sign consent for participation in research (Flicker & Guta). Both scenarios are problematic because segments of the adolescent population, especially high risk adolescents whose voices need to be heard but are silenced, are excluded from participation in research that could improve their health (Flicker & Guta).

Federal guidelines allow adolescents to confidentially consent for medical care, like sexually transmitted diseases, and in some states, adolescent can confidentially consent for mental health care (English & Kenney, 2003). Parental/guardian consent is not always necessary, however the law is not interpreted consistently, which has resulted in ambiguity regarding consent for adolescents in research studies (Santelli, et al., 2003). In low risk research studies and when clinical care is not altered, researchers may argue that parental/guardian consent could breach confidentiality or may be impractical.

In our study, parental/guardian consent was required. Since adolescent mothers may be considered emancipated minors (in some states) or the requirement of parental/guardian consent may breach confidentiality, we will explore a waiver of parent/guardian consent in future studies. This may improve the generalizability of findings and assist researchers in overcoming barriers to maintaining contact with potential participants. If parental/guardian consent cannot be waived, engaging mothers of research participants may prove to be an effective method to retain and remain in contact with adolescent participants.

This study reports the cases of five adolescent mothers who were lost to attrition during the intervention phase of a longitudinal mental health intervention study. Given the small sample size and differing characteristics of the sample that may not have been captured by the investigators, we understand these findings may not be generalizable to other samples of adolescent mothers. Our purpose was to elucidate the circumstances of adolescent mothers in which we had detailed narrative data about their life circumstances. This type of narrative data, which is infrequently captured in intervention studies, serves as starting point to address the question of why adolescent mothers with depressive symptoms may be lost to

attrition. Knowledge of the circumstances of adolescent mothers can inform scientists' recruitment and retention strategies in future studies with adolescent mothers.

Adolescent mothers are a unique group who are challenging to recruit and retain in longitudinal mental health intervention studies. Adolescent mothers encounter numerous barriers with few resources and support. Based on empirical data, it is likely that adolescent mothers retained in research are a unique subsample of the overall population of adolescent mothers. Employing thoughtful strategies to improve recruitment and retention of adolescent mothers will enhance the generalizability of study findings that can inform policy, the allocation and provision of community services, and ultimately improve health outcomes of adolescent mothers.

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