



Published in final edited form as:

J Child Adolesc Psychiatr Nurs. 2011 August ; 24(3): 137–149. doi:10.1111/j.1744-6171.2011.00288.x.

Increasing Participation in Prevention Research: Strategies for Youth, Parents and Schools

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Abstract

Topic—Subject participation is a critical concern for clinicians and researchers involved in prevention programs, especially for intensive interventions that require randomized assignment and lengthy youth and parent involvement.

Purpose—This paper describes details of an integrated approach used to recruit and retain at-risk high school youth, their parents and high schools to two different comprehensive “indicated” prevention programs.

Sources used—Parent and youth recruitment and retention data for the two studies is provided in support of the approach described. A coordinated, multi-level approach, organized around cross-cutting issues, is described in detail as a response to the challenges of including vulnerable populations in intervention research.

Conclusion—Methods are relevant to nurse clinicians who deliver prevention programs, and important to clinical research that relies upon adequate participation in research programs.

Keywords

indicated prevention; at-risk youth; recruitment; retention; family intervention

Introduction

Prevention research that is concerned with improving health outcomes among at-risk groups of vulnerable populations has increasingly become a priority in nursing research (McKinney, Weiner & Wang, 2006; Tingen, Andrews, & Stevenson, 2009; Troy & Clements, 2007). However, subject participation is a significant methodological concern for this type of research (Coday et al., 2005; Gottfredson, 2002; Harachi, Catalano, & Hawkins, 1997) and is particularly problematic for researchers conducting studies that involve random

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assignment to intensive interventions with longitudinal follow-up. Given public health mandates that just such studies be implemented to increase the availability of tested, effective intervention programs to at-risk populations, understanding how to best recruit and retain this population is critical (Biglan & Metzler 1999; Spoth, Kavanagh, & Dishion, 2002). Nurses, because of their clinical and research expertise, are uniquely poised to study and implement interventions with vulnerable populations, yet discussion of the recruitment and retention efforts required is limited in the nursing literature. In particular we lack guidelines to successful research participation that articulate a coherent approach and provide sufficient detail to guide other researchers.

There are a number of reasons why recruitment and retention of subjects is challenging for prevention programs with at-risk groups. This type of prevention, known as “indicated”, as opposed to universal (focused on a general population) or selective (focused on groups with potential risk) prevention, is designed for at-risk *individuals* and requires procedures for the identification of eligible participants who may be unaware of, or sensitive about, + their risk status. In addition, youth identified as at-risk, and their families, often share a number of barriers to participation, including personal and family hardships such as financial and family stress and instability, low social support and poor school or community bonds (Cohen & Linton 1995; Orrell-Valente et al., 1999; Sampson & Laub 1994). Any one of these barriers can diminish interest and ability to engage in programs either as individuals or as a family (Biglan & Metzler 1999; Conger et al. 1992; Conger et al. 1993; Prinz & Miller 1996; Sampson & Laub 1994;). Additional barriers may include mistrust of research programs (Yancey, Ortega, & Kumanyika, 2006) failure to see the relevance of programs (Redmond, Spoth, Shin, & Hill, 2004; Spoth, Redmond, & Shin, 2000), and fear of exposure or lack of privacy (Fox & Gottfredson, 2003; Spoth, Redmond, Hockaday, & Shin, 1996). Finally, the intensive indicated interventions, which often target multiple contexts in order to facilitate behavior change, and include lengthy follow up, place demands on both the participants and the systems that house them, thus creating further barriers to participation.

In this paper, we address a noted gap in the current literature by describing a community-based recruitment and retention approach designed to address these common barriers and increase the participation of high -risk adolescents and their families. Drawing on our experience with two large longitudinal indicated preventive intervention studies, we describe strategies congruent with this approach. Our experience suggests that an articulated program of strategies will maximize study participation and make it more likely the populations who might benefit from intervention will actually be assisted.

Background

Recruitment and retention of adequate numbers of research participants is crucial to the integrity of research, as valid, generalizeable results rely upon enrollment and retention of the targeted study population. At a practical level, when participants are not enrolled and/or retained, expensive research programs fail to reach the population for which they were designed. However, high-risk youth can be a difficult population to include in research. Rates for youth-only programs targeting risk behaviors, such as smoking or drug use, have been reported at 50% acceptance rates, with short- term retention in intervention studies at 50 to 80% (Biglan et al., 1991; Diviak, Wahl, O’Keefe, Mermelstein, & Flay, 2006; Hansen, Tobler, & Graham, 1990; Sussman, Lichtman, Ritt, & Pallonen, 1999; Sussman, Dent, & Stacy, 2002; Zand et al., 2006). Rates are even lower for minority youth, those with higher involvement in risk behaviors, and those involving families. Non-classroom based programs have reported intervention completion at less than 50% (e.g. Kazdin, 1996; Zand et al., 2006). Hansen and colleagues (1990) reported typical school-based prevention study retention of students at 81% at three months and 67% at three years. Sussman and

colleagues (2002) claimed their 65% retention at one-year post-baseline was typical for at-risk youth in a drug-abuse prevention program; parent rates are even lower (Biglan & Metzler, 1999; Spoth et al., 2002). These rates underscore the enormity of this challenge to research, with 65% youth study participation at one-year considered typical, as well as the need to intensify the research focus on participation strategies in order to meet and hopefully exceed these rates.

We find few strategy suggestions specific to indicated programs in the literature, however a recent advance in this field from the Behavior Change Consortium (Coday et al., 2005) described retention strategies for adults in indicated behavior change programs. While oriented to adults, many strategies described may be applicable to youth and parents, including: emphasizing benefits of participation, minimizing respondent burden, providing incentives and support, and maintaining a good tracking system. However, the consortium did not address how to tailor strategies to at-risk youth, their parents or their schools (Spoth et al. 1996). In the following sections we briefly discuss the strategy principles, derived from research literature specific to participation for those groups, which provide a foundation for the methods we detail later in this article.

Youth

Unfortunately, reports of recruitment to research have typically not included strategies for approaching and engaging at-risk youth, but involve for the most part group invitations in classrooms (Cline, Schafer-Kalkhoff, Strickland, & Hamann, 2005; Harrington et al., 1997) that are directed toward sending consent materials home to parents. The few reports that are specific to youth promote attending to interpersonal dynamics, such as patience, gentle persistence, effective communication, non-critical responses to challenges, and maintaining a pleasant demeanor and high level of engagement (Boys et al., 2003; Cotter, Burke, Stouthamer-Loeber, & Loeber, 2005; Prinz et al. 2001).

Parents

Lack of parent participation is a primary reason parent programs fail (Biglan & Metzler 1999); as few as half of targeted audiences in many programs for parents of non-risk youth actually enroll in studies (Heinrichs, Bertram, Kuschel, & Hahlweg, 2005; Orrell-Valente et al., 1999; Spoth et al., 2000). The recruitment and retention of families of at-risk youth is even more difficult (Tolan & McKay, 1996). In addition to scheduling difficulties and life stress, concerns about the study explanation, confidentiality, program relevance and perceived benefits were cited as key issues in engagement in universal programs (Orrell-Valente et al. 1999; Spoth et al., 2002), lending credence to a strategy focus on interpersonal dynamics (Capaldi, Chamberlain, Felrow, & Wilson, 1997; Dusenbury 2000; Prinz & Miller 1994; Prinz & Miller 1996; Prinz et al. 2001), such as thorough communication (Fox & Gottfredson 2003; Prinz et al., 2001), using collaborative language (Prinz et al., 2001), and issuing responsive, individualized invitations (Hogue, Johnson-Leckrone, & Liddle, 1999). Few descriptions of parent *retention* strategies exist; generally we see a focus on recruitment strategies thought to affect later retention (Fox & Gottfredson 2003; Hogue et al., 1999; Orrell-Valente et al., 1999; Prinz & Miller, 1994; Prinz et al., 2001; Spoth et al., 1996). As parents are not a “captive audienc”, they require continued efforts to sustain their attendance, particularly parents of older youth, thereby underscoring the equally important need for effective retention strategies.

Schools

Schools are usually viewed as the setting for research studies rather than the subject of recruitment efforts; however a cooperative relationship between schools and research partners is essential to sustaining school-based research programs, especially when programs

address non-academic issues. A central tenet in any community-based research study, including school-based, is the establishment of mutually respectful relationships with key stakeholders (Yancey et al., 2006). The limited literature available emphasizes general principles such as thorough communication at all levels, having “insider connections”, material incentives for staff, respecting teacher time and respecting the school priorities (Blinn-Pike, Berger, & Rea-Holloway, 2000; Harrington et al. 1997).

A community-based recruitment framework

All levels of research can benefit from an ecological framework that is inclusive of individual and social context risk factors, and which includes participation strategies tailored to those contexts. In addition to tangible support for participation (incentives, babysitting, etc.), the studies reviewed emphasized strategies related to interpersonal connections which, being less tangible, are more difficult to stipulate, much less maintain consistently throughout a lengthy study. The strategy principles include regular one-on-one interaction, conveying respect, and responsiveness to individual needs; these principles underlie the different yet complementary strategies for each domain involved (youth, family and school). The advantage to both clinicians and researchers of working with a multi-level framework is that efforts made in each domain can influence a potential participant’s decision in another domain, and thereby facilitate program or research activities. The key to a coherent integrated strategy that extends across domains is identifying the cross-cutting issues and how they are expressed and translated for each group. This can be particularly true for indicated prevention studies whose potential participants may be less interested or trustful of university researchers or research involvement (Yancey et al., 2006).

In this paper we describe the principles and techniques utilized by the Reconnecting Youth Prevention Research Program to recruit and retain youth, parents and schools to two successful high school-based, indicated prevention programs for at-risk youth—Parents and Youth with Schools (PAYS) (Eggert, 1996) and Promoting CARE (CARE) (Randell, 1999)—to illustrate how guidelines may be generated from principles in order to define and guide recruitment and retention efforts. The Reconnecting Youth Prevention Research Program is a program of research devoted to developing and evaluating preventive interventions for high school youth at risk for school drop-out and suicide. Although the programs differed, the same strategy was implemented in both studies to address typical participation barriers by attending to and reducing participant burden; demonstrating relevance of the programs and regard for the participants; and, by assuring participants that both they and their privacy were respected. Both studies demonstrated participation rates that met or exceeded rates reported for similar populations invited to intensive interventions: between 69% and 80% of invited youth said ‘yes’, close to 90% of recruited students completed their intervention program, and over 90% of youth completed their post-intervention data collection with over 80% still providing data at 15-months post-baseline.

The Pays and CARE Studies

PAYS and CARE projects were comprehensive and high-dose randomized controlled intervention studies, involving at-risk high school youth, parents and schools and are described in depth elsewhere (Eggert, Thompson, Herting, & Randell, 2001; Hooven, Herting, & Snedker, 2010). The PAYS and CARE projects are presented as exemplars because the two targeted populations were both challenging and known to be reluctant to engage in intervention research (older adolescents at suicide and/or school drop-out risk). Both populations, and notably suicide-vulnerable youth, may avoid or resist intervention (Carlton & Deane, 2000; Garland & Zigler, 1994). Although school-based, neither the intervention nor data collection was brought into an existing classroom but required that

youth, family and schools use out of class time, or, in the case of RY, an additional, special class.

PAYS addressed individual, family, peer and school risk and protective factors known to influence adolescent drug involvement, aggression/depression and school deviance. Students were identified from the school district database as at risk for school dropout, based upon risk behaviors such as poor grades, low attendance, suspensions and/or failure to progress with high school credits (Herting, 1990); potential participants were selected at random from these eligible students. The program was comprised of a year-long intensive intervention focused on students and parents. Students participated in a semester-long daily class (RY I), with a second semester option (RY II). A considerable challenge was that students had to be recruited the spring before the fall program in order to be scheduled for the class before fall semester. Parents participated in a 15-session program (Parents as Partners), comprised of four home visits and 11 small group sessions interspersed over the school year (see Table 1).

The purpose of the CARE study was to evaluate the effectiveness of three brief suicide prevention protocols. Eligible youth were randomly assigned to one of four study conditions: intervention as usual control group (IAU), Counselors-CARE (C-CARE) for youth, Parents-CARE (P-CARE) for parents, or Counselors- & Parents-CARE (parent and youth intervention combined). C-CARE provides assessment and intervention to teens, while P-CARE involves coaching of parents/guardians to deliver support and skills training to their teen. C-CARE is a 2-hour intervention, followed 10 weeks later by a booster assessment and intervention, while the parent intervention (P-CARE) is presented in two 2-hour home visits. In both studies, parents and students were compensated for their time.

Recruitment Methods

Based upon research experience and literature review related to both strategies and participation barriers, principles were identified to guide the RY approach to research participation, and translated into specific procedures for each domain (youth, family and school). The primary cross-cutting issues were relevant and applicable to both studies: maintaining one-on-one interactions (i.e. build relationships), thinking “youth first” (it is developmentally appropriate to respect autonomy and privacy), conveying respect for individuals (e.g., non-judgmental, respectful of boundaries, honest, collaborative vs. expert, use individualized interactions), and being flexible with interventions and data collection to minimize burden (e.g., timing and locations of sessions, sequence and type of activities). The methods used for participants in each domain vis a vis the cross cutting issues are described below, for three spheres of research activity (recruitment, overall communication, and retention).

Youth First

Recruitment—Invitations to youth were tailored to meet the developmental and social needs of adolescents. “Inviters” were relatively young, usually undergraduate or graduate students, carefully selected for their interest and experience in working with teens (Boys et al., 2003) and their enthusiasm for presenting to adolescents the opportunity to learn life skills. One-on-one individual verbal invitations to students, prior to parent consent, were considered critical for recruiting the targeted older at-risk youth. This is not only developmentally appropriate, but it is important for adolescent “buy in” that they make the initial decision to participate. This rationale was presented to schools, and to our Institutional Review Board, which gave its approval. While students’ formal (i.e., written) assent could not be received without parent consent, students were verbally invited to the study before their parent(s) were invited so that their interest in participating preceded parent contact¹. Allowing the student to be the “gatekeeper” who provided entrée to the family, and

determined whether his/her participation was discussed further with parents, built trust that formed the foundation of the proposed partnership. Interested students were given the study brochure and consent form and asked to share the information and their interest with their parents. This student-first philosophy also has ethical justification; a well-meaning parent was not put in the position of insisting or convincing a student to participate in the research project, if a student did not want to participate.

Communication—Student recruitment was viewed as the opportunity to extend and receive an invitation. The notion of belonging, important to everyone, but perhaps of greater concern for at-risk individuals in a high school environment, underlies the invitation process. Staff manner with students was convivial and appropriately humorous, and conversations were collaborative and appreciative: students were reminded that they were the inside expert on the high school experience and commended for considering an opportunity to possibly improve the high school experience for future students as well as for being open to the possibility of learning something about themselves.

Inviting also meant that students had control over the interaction and outcome. Student permission was sought to tell them about the study. RY inviters were trained to appreciate a student's ability to say "no", which was helpful in establishing a relationship based on mutual respect. Thus, when students who declined (or were unsure about) participation were asked if we could invite them to a later wave of the study, most said yes.

In all instances, students were told why they were invited. For example, students in PAYS who were pre-selected for eligibility were told that they had been chosen from among a group of students who "may have had a less than positive experience with grades or attendance recently". For CARE, initial invitation by research staff was to randomly selected students. However, after students were screened, those eligible were contacted to continue in the study by clinicians, and specific concerns were detailed. These interactions were well-received, likely because information was conveyed in a nonjudgmental, matter-of-fact manner. It is important to note that while PAYS students were invited because they met criteria for potential high school dropout, the research staff inviters were blind to a student's individual status or situation (and this was conveyed by the tentative "may have had").

Because many potential participants in these indicated prevention studies were experiencing problems with school attendance or grades (all of PAYS and half of CARE participants were at risk for drop-out), finding students in order to issue the invitation could be challenging. Research staff members were trained to persist and problem solve in order to locate potential participants by using resources such as classroom teachers, school staff, school security personnel and other students, and by learning where students who were skipping a class congregated (parking lots, outdoor benches). We benefitted from the positive reputation the study held among students and school staff. Research staff had been an obvious presence during invitations, wearing colorful badges and engaged in friendly one-on-one conversations. Students knew they were being sought for "something interesting, and not because of a problem". Helping the university was seen as "cool", and students who heard we were looking for them often sought us out on their own.

Intervention and Longitudinal Retention—Recruitment and retention strategies were integrated throughout the study using the same principles of attending to one-on-one relationships, individual autonomy, respect and flexibility. For instance, continued

¹In later studies (post 2007) some school districts required that we send letters to parents, signed by school principals, that described study in general and stated students "might be invited" in order to allow parents to opt out of having their child be invited. There were very few opt outs.

participation and increased connection to the project were promoted by consistent study staff who became known to students; conducting interventions one-on-one or in small group settings, with highly trained leaders; using special youthful “locators” (re-inviter) who were hired to find and remind students who were missing from a session; and by advocating for students with teachers and at school disciplinary meetings. Designated study staff were available individually to students via cell phones and/or pagers throughout the intervention period, and at follow-up data collection, for questions, support and crisis intervention.

Continued respect for youth privacy and autonomy were considered key to retention: parent and youth interventionists did not cross-share information about parents and youth unless there was a crisis. At recruitment stage, it was made clear to all partners that youth confidentiality would be respected unless safety was involved. It was made clear to youth what would and would not be shared with parents (particularly around suicide vulnerability). Questionnaire responses that were concerning were followed immediately by a one-on-one interview so that youth and research staff could discuss any further disclosures. If, during the course of an interview or intervention it was necessary to contact a parent or school staff member to resolve a student issue, we worked collaboratively with the student about how we would contact that person. Much care was taken when conveying knowledge of youth to parents so that parents (and school staff) would not feel excluded, but also that youth not feel betrayed or labeled².

Some youth had an intermittent relationship with their high school; therefore data collection might take place individually in libraries or coffee shops, or even over the telephone. If a youth was resistant to scheduling questionnaires, in spite of our flexibility with times and locations, staff were trained to back off and allow a youth to decline or delay, rather than placing an ambivalent youth in a position where they either had to decide to participate now or drop the study. Usually participants who declined a questionnaire did not want to leave the study. We abided by a “open window” approach to difficult data collection (Meyers, Webb, Franz, & Randall, 2003) which sometimes meant data collection was less timely, but often meant a youth was available, ready and willing for the next study contact.

Parents

The Recruitment Call—In addition to agreeing to their student’s participation, both studies asked parents to agree to considerable involvement on their own part, including random assignment to a parent intervention program. Knowing that parents are more likely to enroll in a program when the problems it addresses appear relevant to the child (Spoth et al., 2002), both studies included a “screening” aspect that demonstrated the appropriateness of the program for the teen, e.g. school problems or suicide risk (see Methods). Parents often said they were motivated to hear that their teen had already expressed interest in participating. Finally, typical physical hurdles to attending program activities had been previously identified using pilot study interviews, and were planned for in the current parent programs (childcare, meals, flexible scheduling, etc.). Consequently, the study described to parents was “parent friendly”.

After a student had expressed interest in the study, parents were called the same or the following day. In addition to providing written consent, all parents took part in a (approximately) 20-minute one-on-one conversation to discuss the study and give their verbal consent to their own and their teen’s participation. The study was thoroughly described and parents were invited to ask questions in order to ensure recruitment numbers

²For example, to limit, focus and collaborate around necessary information sharing: “when we asked ____ if he/she was experiencing ____, he/she said _____”.

were not achieved at the expense of lower retention, which can happen when parents are later surprised by study expectations (Fox & Gottfredson, 2003). As with students, random assignment was explained in detail,³ and while parents were interested in what it meant, once it was understood, few gave random assignment as a reason for refusal. To further enhance study credibility and connection, the callers who invited parents to the study were older than those who invited students, with more mature voices and broader experience working with adults; therefore responses to parent concerns demonstrated understanding of the parent perspective, and set the stage for future relationships with study staff.

Communication—Unless a youth told his/her parents about their program invitation, the call home was essentially a “cold call”. It began with an explanation to the parent of how we obtained their phone number (i.e., from the student not the school) and words of appreciation about their teen. Callers used language that showed respect for parent expertise and deference to the parent’s knowledge of their teen such as, “that is something a parent would know more about than we would” or “parents have told me that this is a concern”. We did not oversell. If parents indicated they had unrealistically high expectations of their child’s issues being “fixed”, they were encouraged to see the study from a strength-based but more realistic perspective (e.g., as one more positive resource in their child’s life; or, as an opportune moment to capitalize on their teen’s interest in making changes). Paradoxically, being more realistic about expectations often led to consents. In the same spirit, the described goals of the parent program were to support strengths rather than address parent deficits (“parent sessions discuss keeping up good communication, even in tough times” rather than “parents learn to communicate better”).

Respect for parents was conveyed in conversation process and language. Questions were answered when they were asked, not when the “study script” came to it. Callers had no personal knowledge of individual student behaviors, and let that be known. They consciously avoided language that suggested “labeling” of youth or parents by using the same care with language used with youth when describing study focus, e.g. “Students invited may have experienced...etc.” As both studies had several ways to achieve study eligibility, no caller could know specifically why an individual student was selected.

Intervention Retention—The bonds with parent interventionists, based on the principle of parents as partners, are the cornerstone of our parent retention strategy. Parent interventionists were skilled, mature clinicians and teachers who were also selected for their interpersonal skills, their willingness to be persistent and their understanding of delivery challenges in community-based programs. Interventionists were carefully supportive and non-judgmental, not easily discouraged, trained to work around and normalize parent and parenting difficulties, and available to consult on a wide range of issues. At the same time, interventionists monitored the level of parent disclosures, in order to demonstrate respect for privacy and protect participants from over-disclosing too early in the study process, or too publicly later in the group settings.

Session material was individualized to actual parent experiences, and emerged from group discussions rather than “top down” in lecture format. Room was made to discuss current parent concerns. Program content was deliberately structured so that parents were able to discern progress in their teen early on (e.g. monitoring progress), which served to reinforce the intervention success and facilitate program retention. Retention was enhanced by building in responsiveness to parent interests. For example, PAYS parents indicated that they were interested in joint sessions with their teens and in learning more about the teen

³“like flipping a coin, but we use a computer”

program. As a result, at key retention points (e.g., after a break) over the course of the 15 sessions, parent sessions included teens and RY teachers. Finally, relationships were encouraged within the group: leaders were trained to empower parents to increase the sense of overall “belonging.” Parents were not only publicly praised for their skills and commitment, but were encouraged to assist each other and share responsibility for group cohesion (phone trees, assist with make-ups, brainstorm advice, paired for discussions, etc.) and to participate in group decision-making.

High Schools—While not the intervention focus, the high schools were integral to the success of the RY studies. The implementation of intervention research in high schools places demands on systems that may already be overtaxed and burdened. For both projects, schools supported one-on-one recruitment invitations and a series of data collection and videotaped intervention activities. It was important that schools and teachers understood and supported the necessity and appropriateness of having students leave class for individual invitations, as well as for later lengthier data collection and intervention activities.

The demand on school capacity was considerable for the PAYS study. School personnel delivered the intervention, a 2-semester course that met daily and was part of the teacher’s and the students’ regular schedule, and participated in ongoing training and weekly supervision. Other staff were selected for their willingness to be a student’s “support person”. The demands on the school by the CARE project were less, but were evident. While the intervention was brief, the focal issues were sensitive and sometimes controversial, involving multiple suicide-risk screenings and a pull-out program with follow-up assessments. School counselors and/or school nurses were involved at each assessment as an explicit source of support for those students who had been identified as suicide vulnerable. While these procedures asked more of busy staff, they were also a source of positive connections between the study and school: school staff were frequently acknowledged and praised for their support to study youth.

At initial recruitment meetings principal investigators and senior staff (at least two persons) presented the project to the school administrative teams. These initial meetings were two-way, and included not only discussions about the study but also about the school culture, student characteristics and staff concerns about students. It was especially important that the study’s alignment with school goals was demonstrated (how academic aims will be affected), and that schools understood the study confidentiality agreements. These recruitment meetings concluded with the principal and researchers signing a letter of understanding that detailed the benefits and responsibilities for both parties. Once this agreement was reached, communication with the larger school community began. Details about the studies, including very concrete descriptions of the study activities, were communicated via smaller team planning meetings, informational brochures, staff bulletins, parent newsletters, e-mail announcements and a presentation at full faculty/staff meetings⁴. Meetings were important, allowing everyone an opportunity to ask questions, feel included and understand the project. A primary contact person at the school was determined, as well as a mailbox among the faculty and staff boxes—to facilitate our integration into schools and to ensure that communication between school and study would be easy for school staff.

Sustaining day-to-day communication required consistent attention. Consistent research staff came to a school and learned the names of front office staff, the registrar, the school nurse, counselors and principals. Research activities were announced in advance (approximately

⁴A concrete description of what the study “looks like” when it is being implemented was provided: “Staff with badges will leave notes, ask students to leave class, and invite them to the study individually. You will see them in the halls talking to students during the second week of September, and we will remind you again just before we begin the invitations”.

two days ahead) by placing reminders in staff mailboxes, allowing staff time to respond if necessary. Study stationery was bright and recognizable, with identifiable study logo. The school calendar was checked well in advance of scheduling activities to avoid conflicts and study staff deferred to school staff (and waited or returned another time) if a space or student was double-booked. We learned, recorded and abided by school rules as well as informal building practices (e.g., which tables were reserved in staff rooms). Special acknowledgments (notes, treats) were given at times when research activities had been unusually noticeable or school staff had provided extra support.

Recruitment and Retention Rates

Recruitment and retention data for PAYS and CARE studies are provided in the flow charts (see Figures 1 and 2), that show the percent reached or consenting of those eligible at each step. Student acceptance rates were quite high, particularly for at-risk youth invited to behavior change interventions, with 80% (4231 out of 5317) of those invited to CARE and 69% (1591 out of 2301) of students invited to PAYS saying “yes” to invitation. When parents were invited to participate, the acceptance rate was also high, 74% for PAYS and 81% for CARE. The primary reason for declining participation, for youth and parents, was cited as lack of interest in the study or intervention.

Over one thousand students and their families were involved in the two studies (Table 1). As described previously, student participation included questionnaires and brief interviews, and, for intervention students, the C-CARE intervention or the RY class. For parents, activities included questionnaires, phone call “connections,” and for intervention participants, parent home visit and/or group sessions (i.e., P-CARE or Parents as Partners). Regardless of study or whether the participant was a parent or youth, more than 90% of those who were assigned to an intervention attended some portion of the intervention.

The ages of youth and parents involved in the two studies were nearly identical, as were number of children in the households. The mean age for participating students in the PAYS study was 15.98 years while the mean age for CARE participants was 15.96 years. Youth and family involved in the studies were representative of the school and area demographics. Some differences between the two study populations may be attributable to the demographic differences in the study specific participating schools and communities. PAYS drew primarily from urban schools, while CARE included urban, suburban and rural communities. While high school enrollment numbers and socioeconomic levels were similar, youth in PAYS were more diverse ethnically, reflective of the large urban population from which participants were drawn. Other differences are likely related to the study focus. PAYS recruited specifically from students at risk of school dropout which likely accounts for the slight over-representation of males. The CARE study included only youth who evidenced direct suicide-risk behaviors and/or depressed mood; given that these behaviors are generally over-represented in girls it is not surprising that this sample had slightly more females.

All schools sustained their participation subsequent to enrollment. For high school students, retention in the one-semester RY I intervention was 88% completing the class, with 88% of these going on to subsequently enroll in a second semester intervention booster (Table 3). Completion of the two-session CARE youth intervention was also 88%. Data collection numbers were higher. Ninety-five percent of RY students completed the post-RYI data collection, 88% of all youth in the PAYS study completed data collection at the end of the intervention year (at nine months), and 84% were participating in data collection at 15 months follow-up. Ninety-two percent of CARE participants completed data collection throughout the intervention period, and 83% were participating at 15 months follow-up.

Youth study dropout was not associated with intervention vs. control/comparison condition in either the PAYS or CARE studies. When each condition was compared to the other conditions, there were no significant differences in the PAYS study. In the CARE study, those in the P+CCARE condition were more likely to drop out of the study than those in the other conditions. In PAYS, the only two baseline variables related to study drop-out at 15 months were living in a non-parent household and higher drug use; in CARE there were no significant links between study drop-out and baseline variables. Parent participation rates for the home visit format were high overall, with participation rates at the initial home visit sessions higher for PAYS parents than for CARE parents (perhaps related to greater ease with topic of school performance versus depression and thoughts of suicide). PAYS parent participation declined when the intervention transitioned to group format, with 63% attending groups at the end of first semester (up to and including session nine). Sixteen parents (10%) who dropped out during the first semester stopped attending because their teen no longer attended RY (and had also left their high school). The average number of sessions out of 15 attended by all eligible parents, including those who never attended, was 8.1, over half of the sessions.

Discussion

There are no published blueprints for recruiting and retaining multiple participant domains into indicated research studies. For the most part, researchers rely upon an accumulation of strategies gleaned from their own experience or that of other researchers. In the methods used in the PAYS and CARE studies, concerted efforts were made to address the difficulties of recruiting and retaining at risk youth, their parents and schools, by articulating a coherent system of strategies. These are likely to be even more effective for youth and families with lower risk. A unique aspect of our approach in these studies was an ecological framework which guided our work and identified not only the multiple audiences that needed to be addressed to maximize outcomes, but also the fact that the contacts needed to occur simultaneously to optimize enrollment rates. Coordinating recruitment efforts for youth, parents and schools complicated study procedures, but at the same time we benefitted from the heightened attention to detail, communication and documentation that was required to synchronize recruitment teams and intervention efforts, critical in complex and intense interventions such as PAYS and CARE. Having an established set of guidelines, and abiding by their underlying principles, also provided a kind of yard stick with which to judge our responses to the unexpected events that will inevitably occur in a complex study.

While an ideal participation rate would be 100%, and this number is sometimes approached in studies of low-need populations, our participation rates exceeded those of many programs with at-risk youth. By using strategies that addressed barriers and facilitated connection to the study, we were addressing what we called “preventable” study refusal and attrition. Even while striving to maintain participation, we acknowledged that attrition is not only inevitable at times, but may also be appropriate. Long interventions mean that we lose participants to moves during the school year, to life events, and to changes in priorities and crises unrelated to the study. It is not surprising that retention for the PAYS parent program (Parents as Partners) was lower than that of the other programs (RY and CARE for youth, and P-CARE for parents) – it was long, at school, and intermittently spaced over the year. The CARE intervention for both youth and parents was brief, and administered immediately post-screening. Although the PAYS youth intervention was long, it involved enrollment in a daily school class, and benefited from school structure and support for intervention retention thereby facilitating the better retention. PAYS parent participation was high early in the program, higher than P-CARE participation for the first two sessions, but parent retention had decreased to 63% by the end of the first semester, and attendance by some parents was sporadic. Nonetheless, rather than quit, many parents came when they could, and 74% of

parents whose teen was in RYII at end of spring semester, attended at least one of the last two sessions. These results show parent willingness to stay enrolled for a long intervention, but suggest difficulty with the pragmatics of regular attendance.

The recruitment flowcharts (Figures 1 and 2) indicate losses that occurred during the recruitment process, some of which were anticipated. In PAYS, study retention faced an additional challenge: we were required to recruit the spring before the program began, knowing we would lose students to natural and non-malleable factors such as household mobility and unanticipated school schedule conflicts. In retrospect, and in line with study principles, for those students who lost interest over the summer, perhaps summer study activities would have facilitated a bond with the study that could have prevented some attrition. In the CARE and PAYS studies, we lost participants who had consented verbally, but either did not bring written consents, or were not available (i.e., not at school) for the first study questionnaire. Sometimes we received written consent, but were not able to contact parents. While we were not mandated by IRB to obtain parent verbal consent as well as written consent, we chose to require it, so that parents could discuss intervention intensity and the sensitive nature of some topics. This early loss of more difficult-to-reach participants, which includes students with erratic attendance, may have had an enhancing effect on subsequent retention.

Strengths and Limitations

The successful implementation of two complex, comprehensive indicated intervention research projects, accompanied by detailed documentation of recruitment, retention and attendance, is noteworthy, and a rich source of participation data. However, consideration of study limitations is warranted. The descriptive nature of this report means that we cannot claim the specific strategies we used accounted for our recruitment and retention rates. Using the described strategies we were successful at involving at-risk youth, their families and their schools in research, but we did not test different approaches for success. Furthermore, while we believe the described procedures can be tailored to a range of studies with adolescents, the two studies described here involved at-risk high school youth invited to intensive, comprehensive, school-based programs in the Pacific Northwest, both using recruitment efforts that were systematically integrated across study domains. We selected two specific populations of at-risk high school youth, those at risk of school failure and those at risk of suicide, and we saw similar recruitment and retention rates with both populations. Given that adolescent school problems and risk of suicide tend to co-occur with mood and substance use problems, we hypothesize that we would see similar participation results if we had selected youth based upon these behaviors.

Implications for Future Nursing Research

This study has implications for future research in two major areas — for studies of recruitment and retention strategies, and for the adaptation of prevention programming to increase the likelihood and effectiveness of program participation. Related to the former, this study reinforces the nursing research priority of attending to participation by developing protocols, and adhering to them, for interacting with potential participants. As a next step, however, it is suggested that we move to actual studies of strategies that will increase participation success. With the increased focus in nursing research on evidence-based practice, examinations of differential effects of recruitment and retention strategies are an important step for augmenting the success of programs as well as the research that validates their success. In addition, future studies might examine features of programs, and not just of individuals, that enhance study participation. Maximizing participation means making programs accessible to people who might struggle to participate, which will help us address the disparities often seen in health resource allocation in both clinic and research settings.

The adaptation of programs to individual needs is also a promising direction for increasing study participation. Some individuals may not be able to participate in each aspect of complex, multi-faceted research interventions, regardless of our strategies. For these individuals, programs should be flexible, welcoming to, and even embracing intermittent participation; stringent rules on who is excluded on the basis of resultant participation alone are likely to stymie any progress in indicated prevention research and/or programs. The Parents as Partners curriculum, with its reliance on basic parenting principles applied to a range of situations, was amenable to intermittent attendance; it was felt that both parents and youth benefited from parents' continued sense of belonging to the group and access to resources even when attendance at every session was not possible. Similarly, and commensurate with the "open window" approach (noted in recruitment methods section), encouraging and promoting, but not insisting, on timely attendance or data collection modeled a flexible and accepting attitude that prevented premature attrition. Rather than drop out of a program because they felt pressured to comply, a participant knew his/her next opportunity to participate would be greeted positively. Likewise, a youth who was not available for one questionnaire was frequently available for the next. This leads to the consideration of adaptive or tailored programs, which allows participants to select or be selected for aspects of an intervention that are most interesting and relevant to their particular situation. Related to this, analytic strategies in research will need to take into account the "dose" received by participants; deletion of cases when the full intervention is not received can result small sample sizes and misleading impressions about participation failures.

Recruitment and retention into prevention studies and programs will always be challenging. It is the nature of conducting research with behavioral interventions — we are working with people who have multiple demands on their lives. Generating strategies from a framework of guiding principles for recruitment and retention that are sensitive to the competing demands in peoples' lives, but that can maximize their potential for program participation, will result in an articulated, deliberate and systematic plan that is likely to increase the chances of successful recruitment and retention in this important work.

Acknowledgments

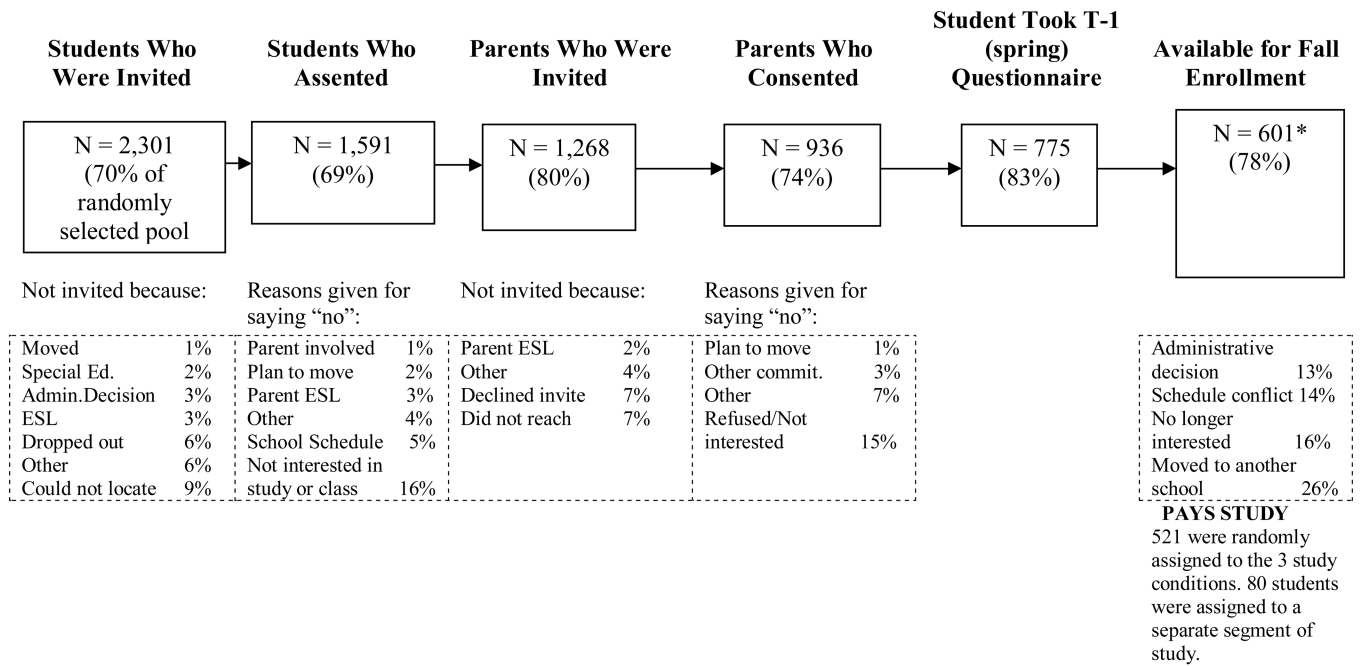
This study was funded by the National Institute of Nursing Research (NR04933), and the National Institute on Drug Abuse (DA10317). The authors gratefully acknowledge the wisdom, support, and training by Dr. Leona Eggert and Ms. Liela Nicholas that was the foundation for the recruitment strategies described in this paper.

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*Of the 775 students who took a TIQ in the spring of their cohort year, 601 were available for intervention enrollment in the fall. Based upon baseline data, there were no systematic differences for demographic or outcome variables between those did and did not drop out over the summer.

Figure 1.
Flowchart: PAYS Recruitment from Spring to the Following Fall

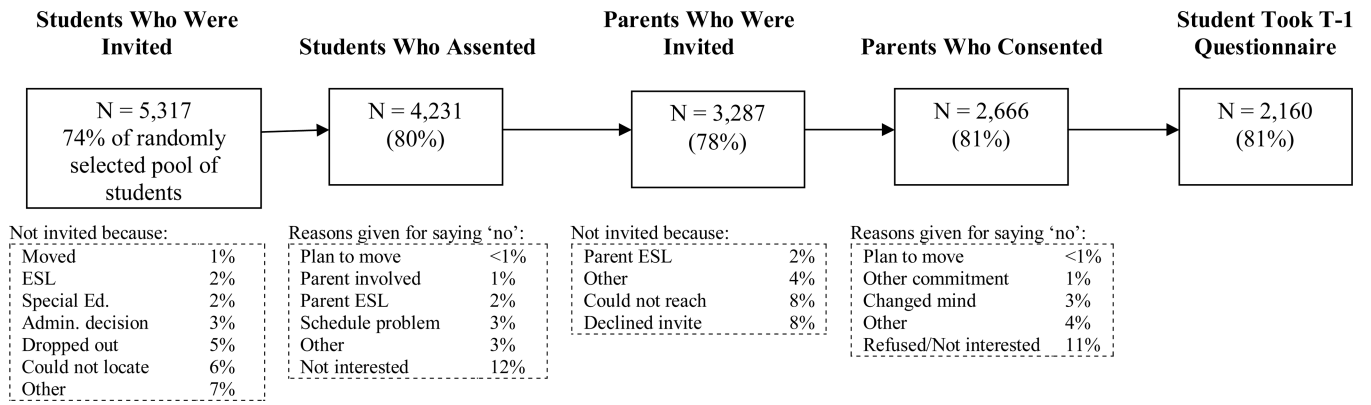


Figure 2.
Flowchart: CARE Recruitment

Table 1

Parent and Student Enrollment by Study Condition

Participants	Study			
	Parents and Youth in Schools (PAYS)		Promoting CARE (CARE)	
Households Involved (Overall)	521 at-risk for drop-out students enrolled in one of 3 conditions		615 suicide vulnerable students enrolled in one of 4 conditions	
Students	School as Usual (Control)	(N = 153)	Intervention as Usual (Control)	(N = 143)
	RY Class only	(N = 203)	Counselors-CARE only	(N = 153)
	RY + Parents as Partners	(N = 165)	Parents-CARE only	(N = 155)
			Counselors & Parents CARE	(N = 164)
Parents	<i>Parents as Partners</i>		<i>Parents CARE</i>	
	Eligible households	(N = 162)	Eligible households	(N = 319)
	Participating households	(N = 160)	Participating households	(N = 290)
	Participating Parents	(N = 221)	Participating parents	(N = 331)

Table 2

Recommended Recruitment and Retention Strategies

	Youth	Parent	Schools
Approaching Potential Participants	<ul style="list-style-type: none"> • One on one, private • Students invited before parents (“gatekeepers”) • Student choice to be invited • Students are helping us out • Told why invited 	<ul style="list-style-type: none"> • Telephone contact using contact info from youth • Call at parent convenience • Praise youth • Thorough study description • Demonstrate study relevance for family 	<ul style="list-style-type: none"> • Meet with principal, administrative staff first (usually two meetings) • Use and leave attractive brochures and visual aids • Assign roles/ rehearsed talk • Speak at faculty and team meetings • Formal “letter of agreement”
Recruiter Characteristics	<ul style="list-style-type: none"> • Young, positive, friendly, easily identified as study staff • Highly trained • Older supervisors 	<ul style="list-style-type: none"> • “Parent age”/ mature • Able to speak to details of research as well as parenting topics • Offer links to resources 	<ul style="list-style-type: none"> • Principal investigators/ supervisors (take two persons) • Senior staff who are “study savvy” • Knowledgeable about schools
Communication Principles (One-on-One)	<ul style="list-style-type: none"> • Two-way • Thorough • Appropriately humorous • Respectful of youth expertise • Appreciative • Students given cards with staff contact and pager numbers 	<ul style="list-style-type: none"> • Collaborative, defer to parent expertise • Focus on listening • No labeling of youth • Parent is called every time study staff interviews a student • Parents have access to study staff (phone #) • Honor parent knowledge & commitment 	<ul style="list-style-type: none"> • Communicate with all staff persons – at all levels • Describe: “What we do, why, and what we look like when we are doing it” • Regular check in’s with administrative staff • Always ask permission • Apologize readily • Find opportunities to praise staff for their service to youth
Facilitating Continued Participation	<ul style="list-style-type: none"> • Interventions occur at school, during day • Acknowledge youth strengths • Respect for privacy • Many reminders • Locate (re-invite) missing students 	<ul style="list-style-type: none"> • Interventions at home or school - convenient • Flexible scheduling • Topics individualized to teen and parent • Modest incentives 	<ul style="list-style-type: none"> • Flexible approach to scheduling times and spaces • Learn school staff names • Consistent and easily identified research staff • Frequent thank you’s (sometimes cards, flowers)

For groups:

Youth	Parent	Schools
<ul style="list-style-type: none"> • “Open window”: i.e. flexible scheduling • Snacks/drinks • Incentives 	<ul style="list-style-type: none"> • Attention to “belonging” • Including adult topics • Substantial snacks • Joint parent-teen groups 	<ul style="list-style-type: none"> • Doing all study-related ‘chores’ oneself (& clean up) • Always on time • Schedule all events ahead

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Table 3

Intervention Participation

PAYS Study		CARE Study	
Students (n = 368)	Parents (n = 162 eligible households)	Students (n = 615)	Parents (n = 319 eligible households)
2 semester class [1 st semester = RY 1 2 nd semester = RY 2]	15 sessions total (4 Home Visit sessions & 11 2-hour group sessions) ^a	2 C-CARE individual sessions (2 hours & 1 hour) (n = 317) [P+CCARE & C-CARE] OR 1 brief individual session 'control' (n = 298) [P-CARE or IAU]	2 Home Visit sessions (1 ½ hour each) [P-CARE & P+C- CARE]
Intervention Completion		Intervention Completion	
Students	Parents	Students	Parents
RY 1: 88% RY 2: 70%	HV 1: 98% HV 1 + 2: 88% HV + 1 or more groups: 78%	1 C-CARE individual session: 99% 2 C-CARE individual sessions: 88% 1 brief 'control' session: 100%	Home Visit 1: 91% Home Visits 1 + 2: 81.5%

^a9–11 of the sessions occur in the first semester; average number of sessions attended = 8.1