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## Pearls and Pitfalls of Community-Based Group Interventions for Adolescents: Lessons Learned from an Adolescent Asthma Camp Study

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### Abstract

This paper explores specific challenges in implementing community-based group interventions with adolescents and makes practical suggestions to researchers who contemplate the group approach. Group interventions have important implications for adolescent research and program development in the areas of chronic illness. They have a capacity to address participants' psychosocial needs as well as to offer a cost and time-effective opportunity for disease-specific education. A group intervention encompasses an array of pragmatic challenges that need to be addressed through meticulous preparation. Based on the authors' firsthand experience with a group intervention for adolescents with asthma, this paper describes potential difficulties and logistics pertaining to recruitment, planning and implementation of a group intervention targeting adolescents and suggests general strategies that can be adopted.

### Keywords

group intervention; community based; adolescents; camp study; asthma

Adolescence is a time of transformation that is accompanied by dramatic growth and changes in biological, emotional, cognitive and social domains (Williams, Holmbeck, & Greenley, 2002). Adolescents with chronic health conditions must deal with the same developmental stresses as their healthier peers: body image, identity, peer acceptance, emotional and financial independence and emerging sexuality. Chronic health conditions can further complicate adolescents' journey into adulthood through both physical and social challenges. Age-appropriate interventions are needed for these adolescents to facilitate optimum development amidst the challenges imposed by chronic conditions. Existing literature has supported that psychosocial factors exert a powerful influence on adolescents' motivation in adopting healthy behaviors (Williams et al.).

Peers constitute an essential component of psychosocial experiences for adolescents. Adolescents often look to their peers for benchmarks of normalcy (Gibson, 2000) and strive to obtain peer approval by conforming to peer-defined attitudes, values and behaviors. Peer networks are of particular importance for adolescents with chronic health conditions as they deal with both developmental tasks and disease-related challenges (Kyngas, Hentinen, & Barlow, 1998; Logan, Zelikovsky, Labay, & Spergel, 2003; Weissberg-Benchell, & Antisdel, 2000). Peer support enhances adolescents' ability to surmount health challenges (Kyngas & Rissanen, 2001) and helps reduce the stigma and anxiety of carrying out self-managing

behaviors such as taking medications (Berg, Tichacek, & Theodorakis, 2004). Adolescents with chronic conditions are twice as likely to adhere to medical treatment when they perceive support from friends (Kyngas & Rissanen, 2001). As such, optimal management of chronic illness in adolescents can be facilitated by positive peer relationships (Butler & Cooper, 2004). Therefore, it appears natural that interventions designed to assist adolescents with chronic conditions should adopt an approach taking advantage of peer dynamics to maximize effectiveness.

Interventions using a group format are potentially beneficial in adolescence in terms of their capacity not only to offer specific topics of interest, but also to address the participants' psychosocial needs such as attaining peer approval and fostering a sense of belonging. Despite the anticipated advantages, group interventions have been underutilized and the literature is limited in identifying and describing caveats and logistics for using group approaches with this population. Thus, the purpose of this article is to explore pragmatic issues and challenges in planning research with adolescents using a group format. In addition, we offer practical suggestions to address those identified issues.

Traditionally, group interventions with children or adolescents have taken place primarily in school settings (Gerald et al., 2006; Lukacs, France, Baron, & Crane, 2002); however, accessibility to school settings for research purposes has become challenging for a variety of reasons. The increasing concern for students' privacy and security is an issue as is school personnel's time commitment. The school day is already fully utilized and finding extra time for students to be available for research activities during regular school hours is virtually impossible. Therefore, there is a need for alternative settings that allow researchers to conduct group interventions for children and adolescents within the community.

As an option, existing literature has explored the potential use of camp settings for group interventions for children with chronic health conditions. Camp is a natural setting where children can interact with peers with similar health conditions and the formation of supportive peer relations is facilitated. Camps provide opportunities to promote intensive illness-related learning within a structured yet enjoyable environment while addressing the psychosocial needs such as social adaptation (Plante, Lobato, & Engel, 2001). Existing literature is scarce in the pragmatics of implementing group interventions within community settings such as camps for adolescents with chronic illness. Based on our experiences with a teen asthma camp project, we discuss practical issues and challenges that researchers need to consider in planning and undertaking a group-based intervention with adolescents. This paper provides useful practical information not only for camp projects but also for community group interventions targeting adolescents in general. The issues covered in this paper range from recruitment to the implementation of a group intervention.

## Challenges to Adolescent Research Using Group Intervention

### Recruitment

Subject recruitment and retention is a challenge for many research projects regardless of the particular research methods. Adolescent studies present additional difficulties in recruitment, particularly with regard to communication about studies. In implementing the Teen Asthma Project, we utilized multiple avenues to reach out to potential participants including flyers, clinician referrals, newspaper ads, and partnerships with school health providers. Of these strategies, newspaper ads were found to be the least effective, yet most expensive. The cost of an one-time local newspaper ad covering 4 counties was \$248, yet only one parent responded to the ad. Thus, when a project operates with limited fiscal resources, this may not be an ideal option to pursue. Alternatively, e-ads on popular websites for adolescents may be considered as an avenue to communicate to target populations directly. Flyers also appear to not excite

adolescents' interest much unless accompanied by verbal encouragement and reinforcement from respected adults (e.g., teachers, clinicians). Only 11% of our study sample spontaneously responded to the flyers placed in school clinics and private practices.

We adopted a more active recruitment strategy that health care providers communicate study opportunities with patients through face-to-face contact and mailing. This method resulted in far more encouraging results yielding 36% of our sample. Utilizing this option necessitated partnership with clinicians. However, securing sustainable commitment from clinicians was challenging because of their clinical overload. In addition, direct mailing from our study team was not feasible due to the restrictions imposed by Health Insurance Portability and Accountability Act (HIPAA) which prevented us from obtaining patient contact information (e.g., mailing address). Given these barriers, it was pivotal for us to establish and maintain collaborative relationships with practitioners. We made frequent contacts with clinicians via telephone and emails as well as site visits to introduce the study to the providers. We also assured clinicians that the research team would be responsible for financial costs incurred in the process of mailing including reimbursing clinical staff time and postage.

As an alternative, we disseminated study information through the school system, which required prior approval from school boards. In many cases, we noted that students misplaced or forgot to share information with their parents. In order to address this problem, we mailed information directly to eligible families. As in clinical settings, due to privacy issues, most schools are not permitted to share mailing addresses with the study team, so we had to work with school personnel who were willing to distribute information on the study teams' behalf. We also utilized school e-news or newsletters that many schools already have in place as a means of communication with parents. The Teen Asthma Project worked closely with school physicians and nurses who partnered with the research team as they foresaw the potential benefits of the offered asthma program for their students. Particularly, school nurses played pivotal roles in coordinating procedural steps necessary for implementing each recruitment strategy. We managed to draw 39% of our study sample from the concerted efforts targeting school systems.

It is important that researchers remember that parents are not the sole decision makers related to their teens' research participation. As a rule, the Internal Review Board requires researchers to document adolescent assent along with parental consent to enroll adolescents in a research study. Securing adolescent assent is an important procedure in studies not only because it addresses human subject protection but because it signifies the researchers' developmental sensitivity respecting adolescent individuality and independence. From our own experience, most parents expressing an interest in having their adolescents participate in the study were reluctant to commit to participation until having a discussion with their adolescents. It was important for us as the research team to establish rapport with both parents and their teens. Follow-up contacts with adolescents, however, create an additional challenge as many parents are unaware of their adolescents' detailed schedule besides their routines and special events. As a result, we had to make multiple contacts with adolescents and parents until enrollment was complete. In our study, it took an average of 5 (range 2–17) attempts of phone contact before the confirmation of enrollment.

Another challenge related to communication is posed by the preferred methods of contact requested by adolescents. Most adolescents have their own mobile phones and e-mails and provide that contact information to researchers. However, we noted that mobile phones and internet use are often considered an earned privilege that can be taken away by their parents as a consequence of negative behavior/academic performance or misuse of such communication technology. Such circumstances directly restricted our ability to contact adolescents enrolled or pending enrollment. Therefore, it is important for researchers to

anticipate the extended time and increased number of attempts needed to communicate for recruitment and beyond in adolescent studies.

### Planning the Group Intervention

Timing is a crucial consideration in planning a group intervention. Group interventions require a great deal of coordination in scheduling the time for the intervention in order to accommodate the availability of a group of participants. Many adolescents have multiple demands on their time including school, after school activities, sporting events, part-time employment or church-related expectations. It is important to factor the predictable conflicting events or commitments that could affect the availability of a large proportion of the sample and to make every attempt to avoid the conflict. For example, in the United States, high school juniors (and sometimes sophomores) seeking National Merit Scholarships or anticipating college application are expected to complete a College Board Test, such as the Preliminary SAT<sup>®</sup>/National Merit Scholarship Qualifying Test. This exam is offered on limited dates in October. Unfortunately, the offering of that exam happened to coincide with the previously-planned date of our camp program resulting in the attrition of six subjects. Summer months may be tempting to plan group interventions; however family vacations and summer school or employment can also interfere with availability to participate in a research study. Determining the best timing is a challenge, yet careful consideration of anticipated conflicts germane to situations involving the majority of adolescents can assist researchers in making informed decisions in that regard.

Although some time-related difficulties can be anticipated, weather conditions tend to be more unpredictable. Some community-centered group interventions involving outdoor activities (e.g., camp studies) are more susceptible to weather situations. Even when group interventions take place indoors, weather conditions can still affect participants' motivation and ability to attend the group sessions. The weather condition that we encountered was unusually mild for the season (i.e., late October in Northwest New York), and engaging participants in the intervention program was a challenge as many were tempted to play outside instead. Therefore, researchers need to take into consideration potential weather effect in scheduling and be flexible in modifying the intervention sites, dates and planned activities as needed. If outdoor activities are written into the protocol, an indoor facility should be available as a back up in case untoward weather conditions interfere with the original plan.

In planning a group intervention, researchers need to make a decision regarding how to space the program – a one day session of consecutive long hours or multiple sessions spread out over several days. Either option presents its own pros and cons. Our camp intervention was a single day program offered from 9 am to 5 pm. By adopting this strategy, we were able to address concerns for subject attrition or inconsistent attendance patterns that might have been inevitable if offered over several days. A single full-day session requires less coordination on the part of both researchers and participants and most importantly affords a natural opportunity for interactions among participants. We observed active group dynamics and informal social networks being established among participating adolescents as they engaged in the program throughout the day. However, we anticipated that the full-day option might cause participant boredom or fatigue potentially diminishing the intervention effect. Thus, we arranged sessions of an entertaining nature to sustain participant interest and attention such as a musical performance (“mini concert”) and recreational activities (“drum class” and “arts & crafts”). Although we spent a significant amount of our budget on these activities, some participants verbalized dissatisfaction with available options due to their diverse range of interest and preferences. To maximize participant satisfaction within a limited budget, a thorough survey of their entertainment preferences in advance is recommended. In that regard, requiring a group of adolescent to attend multiple short sessions over several days may seem advantageous. The option of multiple sessions results in less subject boredom, thus eliminates the needs for the

costly “extra-curricular” programs. Multiple group sessions can be preferred in cases when subject attrition is less of an issue as in school-based interventions or when intervention effects depend less on group interactions. Researchers should carefully weigh the pros and cons of each option based on a thorough understanding of the sample characteristics and goals of the intervention.

### **Location of the Group Intervention**

Selecting a location for the group intervention is the most important yet agonizing process. Viability of the intervention depends, if not entirely, on the atmosphere that produces conduciveness to learning and group interactions. When a goal of the intervention is to capitalize on group dynamics among participants, settings of an informal nature such as camps or recreation centers are desirable instead of schools, churches or governmental facilities. It is crucial to have access to the intervention space in advance for planning logistical details. In fact, our research team made three field trips to the camp site prior to the camp day to become familiarized with the facility and to ensure the proper set-up including audio-visual equipment, seating arrangements, parking access, participant drop-off and pick-up, and other details. We rehearsed the entire process using role-play from check-in to check-out for a seamless flow of the process. For effective interaction with the facility administrators who authorized the study team’s pre-access to the camp site, we hired a camp coordinator as a liaison. (Specific roles of the camp coordinator are discussed further in the personnel section.) The camp coordinator communicated with the facility staff and arranged for access to the camp site in advance which allowed plenty of opportunities to attend to the details in relation to preparing the intervention site.

Distance to the intervention site can be perceived as a barrier to adolescent participants and their parents. Therefore, geographic proximity of the location is always an advantage; thus boosting participation rate. We used the camp site that was located within 30 minutes of driving distance for the majority of participants, which appealed to parents who otherwise might be reluctant to participate. A reasonable distance has an economic advantage for researchers as well, reducing the cost in mileage reimbursement for private transportation methods (self or parents driving to the camp site).

Geographic proximity and travel reimbursement do not completely address transportation issues. Some of the families had difficulty in arranging private transportation due to limited financial resources. From scientific rigor and ethical standpoints, we had an obligation to provide transportation to those who otherwise might be unable to participate. However, arranging transportation brought an array of challenges ranging from liability issues to vendors to competitive rates. We identified the transportation needs of participants as soon as possible after enrollment. This early needs assessment allowed sufficient time for us to secure the service. Another important issue related to transportation is about how and where participants are picked up and dropped off. Because many of our participants requiring transportation resided in locations presenting a safety concern, we found it necessary to offer door-to-door transportation. Thus, it was important that we communicate with a selected vendor regarding their ability to accommodate such need before we signed the contract. When planning the budget, we suggest that researchers allow flexibility to accommodate the high cost of the door-to-door service, should it be deemed necessary.

### **Coordinating Personnel and Other Logistics**

Implementing a group intervention requires tremendous personnel support (“manpower”) in addition to the regular research staff. Because of the complexity and anticipated heavy workload for research staff, we found it efficient to utilize a “camp coordinator” who was responsible for arranging and organizing activities and details for the group event. The



coordinator had many years of experience coordinating and leading community group events for adolescents. The coordinator's familiarity with adolescent preferences in terms of food and entertainment activities and her extensive community networks were an invaluable asset to the project. Therefore, it is worth considering utilizing extra personnel entirely devoted to the group event, which allows time for researchers to focus on the scientific aspects of the group intervention.

Behavior issues (e.g., violence, smoking, sexual behavior) are a salient safety concern for adolescents participating in a group intervention. In order to reduce the risk and ensure a safe environment for all, we strengthened adult supervision by utilizing adult volunteers (four graduate nursing students in addition to regular research staff) and by providing maximal structure in scheduling in order to minimize unsupervised "down" time. We set and reinforced a code of conduct that all participants were expected to abide by. Participants were also informed that any violation of the code could result in the termination of participation. Thanks to the precautionary efforts, no incidence of a serious nature occurred during our camp program.

Group interventions conducted in a facility involving outdoor settings (e.g., camps) need to pay particular attention to another safety issue involving accidents. In outdoor environments, participants could be injured whilst engaging in physical activities or their existing health conditions (e.g., asthma) could be exacerbated by outdoor triggers. Having recognized the potential risks, we ensured that the camp site was equipped with basic medical supplies (e.g., First Aid Kit) and devices (e.g., automated external defibrillator, nebulizer, oxygen tanks, etc.) and medical personnel who were able to manage potential medical situations on site. We also located an emergency department close to the camp site. Prior to the scheduled intervention, we obtained a signed "emergency medical treatment agreement" form from the parents along with basic questions in relation to participants' preexisting health conditions, allergies and routine medications. The agreement permits research personnel --licensed health professionals-- to treat participants when needs for medical care arise during participation.

Often visual images are the most vivid way of conveying energy and atmosphere of research events to outside audiences. Thus, photos and videotapes are frequently used in presentations and less frequently in publications. To take photos or video-tape of the group activities for reporting or publicizing purposes, IRB may require "photo consent" from parents, which we were not aware until later. As a result, we had to submit an additional IRB amendment for inclusion of this procedure in the research protocol. In addition to the photo consent, we were advised by an IRB specialist to take precaution to protect the privacy of participants. Precaution included taking pictures of groups rather than a small number of individuals and capturing participant images from the back or sides. Should these pictures be posted in study websites for the view of participants, it may be necessary that the photo sites be password protected to ensure that only legitimate users have access.

### Managing the Group Intervention

Gaining and sustaining adolescents' attention during the delivery of a group intervention is not an easy task. We found it challenging for a single person (i.e., a group instructor) to manage a group of adolescents effectively. This was the case especially when the group primarily consisted of younger participants or when the group dynamic was disrupted by a few participants with behavioral issues or a lack of motivation. We were able to prevent the disruption to some degree by assigning seating placements in a way that the participant of concern was seated in proximity to the instructor. A certain level of structure such as seating arrangement provided by the instructor was found to be beneficial in managing difficult participants and thus maximizing the learning experience of the rest. When the intervention is provided within the context of a rather large group (over 20 participants) or several small groups

(10 or fewer in each group), it could be beneficial to assign additional personnel (e.g., co-instructor) in the audience to facilitate the group leader and to assist participants.

Researchers can utilize adolescents as co- or instructors for the group intervention. Literature has supported the approach of peer education (counseling) particularly in programs targeting adolescents given its developmental relevance (Backett-Milburn & Wilson, 2000; Mellanby, Rees, & Tripp, 2000; Ozer, Weinstein, Maslach, & Siegel, 1997). In fact, the core of our teen camp project was to examine the feasibility of an asthma education program utilizing peer leaders. The peer leader approach is developmentally salient and has important implications for group interventions targeting adolescent populations. Nonetheless, selection of peer leaders was a scrutinizing process as we ensured their basic qualification to present themselves as role models as well as group leaders. In our study, good academic standing (average grade B or above) was required along with adult nomination attesting to the teens' leadership skills. In the process of recruitment, however, we encountered challenges in attracting male peer leaders and qualified minority candidates. Of 12 peer leaders, we enrolled only two males and two African-American adolescents as peer leaders. Specific strategies to recruit qualified peer leaders from these groups are needed.

To translate the leadership qualification into intervention success, we implemented peer leader training sessions where the scientific rigor of the program was reinforced. Training strategies involved didactic sessions, discussion, demonstrations, role plays and field trips. The training required a significant commitment of resources including personnel, financial cost and time (for both researchers and peer leaders). We hired a "peer leader trainer" who had expertise in asthma and experiences working with adolescents. Our selected peer leaders completed 3 training sessions (over 12 hours in total) offered by the peer leader trainer.

At the camp, each pair of peer leaders was assigned to a small group of 6–10 teen participants by age (younger vs. older) and gender. Each age group was divided into three subgroups by gender (female only, male only and mixed-gender). Younger peer leaders ages 16–17 led gender-matched younger campers (13–14 years). Older peer leaders, 18–20 years, were assigned to older campers (15–17 years). Because we had no male peer leaders between 18–20 years, the three groups of older campers were all led by 3 pairs of female peer leaders. Our preliminary analysis of the camp evaluation demonstrates that adolescents are in favor of the asthma camp led by peer leaders (who also have asthma) compared to the camp led by adult instructors ( $t=2.49$ ,  $df=88$ ,  $p=.01$ ). Nonetheless, the extent to which participants' positive perception of the peer led program is translated into the effectiveness of the program remains to be analyzed. We found that the peer leaders virtually eliminated the need for additional research staff to manage the camp program and to ensure the safety of participants. The peer leader program primarily capitalized on adolescents' heightened receptiveness to peer influence and their desire for independence (i.e., adolescent governed program format). We anticipate that observed participants' satisfaction with the program could ultimately produce desirable outcomes of the intervention such as improvement in asthma morbidity and quality of life.

## Conclusion

Given the importance of peer interactions in many aspects of adolescent life, a group approach that capitalizes on group dynamic and promotes constructive interactions among participants could be a viable option for research and program development of adolescents. Despite its theoretical advantages, a group intervention encompasses an array of pragmatic challenges that can be addressed or overcome through scrupulous planning. This paper described some of potential difficulties and logistics pertaining to a group approach targeting adolescents and suggested general strategies that can be adopted in undertaking such projects. Challenges

include: selecting the most effective and efficient recruitment strategies, establishing effective communication channels with adolescents and parents, deciding on the group format (i.e., small or large groups), selecting a location and coordinating personnel resources. Logistic details including arranging transportation, training research staff and ensuring a safe environment must be meticulously heeded in the planning stage of a group intervention for adolescents. When these challenges and caveats are adequately addressed, group approaches not only afford researchers an exceptional opportunity to augment treatment effects but also provide adolescent participants with a safe milieu where they can actively engage in establishing a social network.

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