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Using Participatory Methods to Enhance Youth Engagement in Substance Use Research

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Abstract

Youth engagement in substance use research is critical to the understanding of correlates that lead to detrimental health and social outcomes for adolescents. In addition to the documented challenges related to youth recruitment for substance use research, Latinx youth living on the U.S.–Mexico border may be difficult for researchers to engage in substance use research because they could face retributory harm if they identify their experiences to any entity perceived as an authority (e.g., researchers). Empirical findings that posit viable strategies to engage marginalized youth in substance use research are lacking. Participatory approaches show promise in increasing participation of historically underrepresented youth in research. Building on previously published work on our youth participatory action research mixed-methods study, this article discusses the youth-led participatory approach used to (1) develop and pilot test a culturally, regionally, and linguistically tailored substance use instrument and (2) engage 445 Latinx youth to participate in a cross-sectional study to assess epidemiological patterns of youth substance use on the U.S.–Mexico border. We share lessons learned related to the youth-led instrument design, youth-led recruitment strategy, and assuring participant confidentiality.

Keywords

child/adolescent health; health disparities; health research; community-based participatory research; Latino; minority health; partnerships/coalitions; rural health; school health; substance use

BACKGROUND

Youth engagement in substance use research is critical to the understanding of correlates that lead to detrimental health and social outcomes for adolescents. Challenges to engaging historically marginalized youth, including youth of color and immigrant youth, as participants for research include housing and transportation instability, low socioeconomic status, race/ethnicity, cultural norms, and safety and legal concerns (Bradley et al., 2019). Latinx youth in high-risk settings may be difficult for researchers to engage in substance

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use research because they could face retributory harm if they identify their experiences to any entity perceived as an authority (e.g., researchers). Latinx youth living on the U.S.–Mexico border may experience perceived disordered neighborhood stress, drug trafficking, militarized border security, disproportionately punitive drug and immigration enforcement, and racial profiling (Valdez et al., 2019; Valdez et al., 2021). Thus, Latinx youth living on the border may be unwilling to engage in substance use research that elicits information of personal substance use history or sharing knowledge of personal or familial experience in the drug trade due to substantial fear for their personal safety or social repercussions. Empirical findings that posit viable strategies to engage marginalized youth in substance use research are lacking.

Participatory approaches show promise in increasing participation of historically underrepresented youth in research (Ozer, 2016). This article discusses the youth-led participatory approach used to (a) develop and pilot test a culturally, regionally, and linguistically tailored substance use instrument and (b) engage 445 Latinx youth to participate in a cross-sectional study to assess epidemiological patterns of youth substance use on the U.S.–Mexico border.

METHOD

Partnership Development

A local youth health coalition and the principal investigator (PI) engaged in a youth participatory action research (YPAR) project to examine the environmental factors that influence substance use among youth in a community on the U.S.–Mexico border. YPAR is a form of participatory research whereby youth learn how to conduct research and use their findings to engage in social action at the local community and policy levels (Ozer, 2016). The research team consisted of the PI, the youth coalition, and the youth coalition coordinator. Faculty from the University of Arizona and mentors of the PI, a doctoral candidate, had fostered a long-standing relationship with this specific border community and the youth coalition. Because the PI was a white academic outsider, it was important to work closely with the youth coalition coordinator, who was a bicultural, bilingual, and civically engaged member of the community. The youth coalition's primary focus was tobacco prevention policy in the border community, and a focus on substance use in general, therefore, fell within the scope of their purview. The coalition consisted of 25 Latinx youth aged 14 to 18 years from the community, who provided parental consent and assent to participate in the study. The research team met several times to build rapport; develop bilateral goals of the project outcomes, processes for accountability; and establish data ownership agreements prior to the study (Minkler & Wallerstein, 2011). This study received human subjects approval from the University of Arizona's Human Subjects Protection Program.

Study Design

In Stage 1, the academic–community collaborative team used a photovoice process to examine the perceived environmental factors that increase risk of, or protect against, substance use among adolescents living at the border. The youth were responsible for data

collection, analysis and parts of the dissemination for the photovoice phase of the research (Valdez et al., 2019).

In Stage 2, the academic–community research team developed and pilot-tested the Border Adolescent Substance Use Survey (BASUS). We used the overarching themes, relevant terms, and definitions identified in the photovoice process to identify existing validated instruments to measure select variables. For those novel variables not represented in the literature, the research team developed new questions for the BASUS. The PI crafted the questions and presented the questions to the youth coalition for approval. Finally, the PI pilot tested the BASUS with the youth coalition.

In Stage 3, we developed a recruitment strategy to recruit students from the local high school to participate in the cross-sectional study using the BASUS. One week prior to data collection, the lead author described the study to 10 math classes composed of freshmen, sophomores, juniors, and seniors in order to get a representative sample of youth aged 14 to 18 years in the community. Students provided parental consent and assent prior to participation. The research team delivered the BASUS during math class at the school computer lab. As an incentive to participate, BASUS participants received 10 student dollars (to be used in the high school’s student store) for submission of the parental consent and participant assent forms, and five student dollars for completion of the BASUS. A total of 597 students received invitations to participate, and 445 eligible consented participants completed the BASUS. We achieved 100% of our recruitment goal ($n = 400$) and a 75% response rate overall out of 597 youth (Valdez et al., 2021).

KEY LESSONS LEARNED

Youth-Led Instrument Design

The youth coalition provided critical insights on the design of the BASUS (Stage 2), particularly the phrasing of the questions. They expanded the definition for youth involvement in drug trafficking to include store, sell, or transport drugs. They also identified a theme that was not adequately queried by existing questions and proposed additional questions, including, “In my community, music that glorifies drug trafficking or the narco lifestyle, like corridos, hip-hop, reggae, and bachata, influences adolescents to get involved in moving, selling or storing drugs.” Youth contributed their regional, cultural, and linguistic expertise to develop a community-tailored substance use instrument.

Youth-Led Recruitment Strategy

The youth coalition suggested that the BASUS data collection should be at the local high school (Stage 3). The PI met with the school board, the principal, and the school superintendent to determine their level of interest and engagement with the study. All parties agreed that the data collected would be owned by the community and used to better understand the youth in the community, develop tailored prevention strategies, and apply for grants to support prevention initiatives. The youth coalition advocated that the recruitment messaging should frame the data as being beneficial to the youth (i.e., data could be used to apply for grants, allocate local resources to a youth center). The youth coalition also

provided unique insight regarding the general culture of the student body, who to partner with, and how to incentivize participation. We determined that more students would return parental consent forms and participate in the study with student store dollars as an incentive, paid for with grant funds. Student store dollars are used to purchase snacks and other school promotional items (e.g., T-shirts) from the student store. The decision to use student store dollars resulted in an 83% submission rate for consent/assent forms. This particular success illustrates the importance of partnering with the youth coalition to enhance recruitment.

Assure Participant Confidentiality

The youth coalition determined that students might not want to participate in the study due to legal and personal safety concerns. Illustrating the youth coalition's concerns, during one class presentation a student declared, "I'm not doing that. I ain't no snitch." Thus, we took a number of steps to emphasize participant confidentiality. We obtained a Certificate of Confidentiality from the National Institutes of Health. Furthermore, we assured students that their responses would be deidentified, locked in a safe place, and would not be released to school officials or parents. As an additional security measure, the research team use the online REDCap (Research Electronic Data Capture) platform, which guarantees data safety and participant confidentiality. The team carefully conveyed this information to participants both verbally and written at two time points. We believe that by emphasizing participant confidentiality and safety, as suggested by the youth coalition, students felt sufficiently safe and comfortable to respond to the BASUS.

CONCLUSIONS

Our lessons learned illuminates that using participatory methods (e.g., YPAR) can enhance instrument design and recruitment efforts to increase underrepresented youth engagement in in substance use research. Future substance research should prioritize more fully engaging youth in the research process, particularly when trying to reach historically marginalized populations.

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