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Mapping the Views of Adolescent Health Stakeholders

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A B S T R A C T

Purpose: Health research that includes youth and family stakeholders increases the contextual relevance of findings, which can benefit both the researchers and stakeholders involved. The goal of this study was to identify youth and family adolescent health priorities and to explore strategies to address these concerns.
Methods: Stakeholders identified important adolescent health concerns, perceptions of which were then explored using concept mapping. Concept mapping is a mixed-method participatory research approach that invites input from various stakeholders. In response to prompts, stakeholders suggested ways to address the identified health conditions. Adolescent participants then sorted the statements into groups based on content similarity and rated the statements for importance and feasibility. Multidimensional scaling and cluster analysis were then applied to create the concept maps.
Results: Stakeholders identified sexually transmitted infections (STIs) and obesity as the health conditions they considered most important. The concept map for STIs identified 7 clusters: General sex education, support and empowerment, testing and treatment, community involvement and awareness, prevention and protection, parental involvement in sex education, and media. The obesity concept map portrayed 8 clusters: Healthy food choices, obesity education, support systems, clinical and community involvement, community support for exercise, physical activity, nutrition support, and nutrition education. Ratings were generally higher for importance than for feasibility.
Conclusions: The concept maps demonstrate stakeholder-driven ideas about approaches to target STIs and obesity in this context. Strategies at multiple social ecological levels were emphasized. The concept maps can be used to generate discussion regarding these topics and to identify interventions.

IMPLICATIONS AND CONTRIBUTION

Research that includes youth and family stakeholders increases the contextual relevance of findings, yet participatory research with adolescents is an underutilized strategy. This study reports that the most common health concerns of stakeholders in adolescent health include STIs and obesity. The results further describe stakeholder-recommended approaches to target these concerns.

Youth health research that includes adolescents and families increases the contextual relevance of findings [1]. Participatory approaches can engage local youth and families in research to address problems of interest to the stakeholders involved. Benefits of participatory research include increased relevance of the research to both the various stakeholders and the academic partners, and development of interventions that are informed by the lived experience of the stakeholders involved [2].

Participatory approaches to research have become increasingly commonplace, particularly regarding adult health [3].

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Children and adolescents are uniquely situated to benefit from participatory research approaches that emphasize multifactorial elements affecting health and illness [3]. Although children and adolescents are especially impacted by health conditions with social and environmental etiologies [3], youth engagement in health research using participatory approaches remains less frequent than among adults [3]. Participatory research is also particularly important among marginalized populations [1], including minorities and populations of low socioeconomic status [3].

Youth are less often actively engaged in health research than are adults [3], although several studies do report youth involvement. Ginsburg et al. [4] report on services desired by youth and their preferences regarding health care provision. Mathews et al. [5] describe a project designed to reduce health disparities in which adolescent girls assessed community needs and designed an intervention. Reis et al. [6] describe youth impressions of factors affecting physical activity. Recently, an issue of the *American Journal of Community Psychology* was dedicated to the topic of participatory research with children [7]. The participatory work described within ranges from examination of school recess [8] to work on youth mental health issues [9]. Similarly, an issue of *Family & Community Health* dealt with youth-involved community-based participatory research work ranging from substance abuse prevention [10] to issues affecting immigrant youth [11]. However, relatively little information exists about adolescents' health priorities. As Reich et al. [12] state, "Youth are rarely involved in the process of identifying or addressing their own needs". Yet, this information is significant because interventions have the potential to be more successful if they target concerns of the affected population of youth [13].

Concept mapping (CM) is a stakeholder-driven, mixed-method research approach that is particularly well suited to the evaluation of health issues within the local community context [14]. CM has been used with adults and, to a more limited extent, with youth in conducting health research [3,15]. CM has been used to examine coping strategies among high-risk youth [16] as well as youth perceptions of physical activity [6] and bullying [14]. A singular strength of CM is that it moves beyond the mere identification of priority health conditions by offering youth the opportunity to become directly involved in discussing strategies to address those health conditions. Typically, interventions are expert driven and/or selected from existing evidence-based practices without seeking any youth input [14]. Strategies created with input from youth are desirable because they are more contextually relevant, which can improve the "translational capacity" of this research [17]. Prior research suggests that outcomes are improved when the target group is involved in identifying the problems to be targeted [12]. This study sought to identify youth, family, clinical health care worker (HCW), and public health worker adolescent health concerns and subsequently use CM to explore strategies to address those health concerns.

Methods

Study setting and participants

Participants included a convenience sample of adolescents aged 12–22 years seeking primary care in an urban, hospital-based adolescent medicine clinic; parents/guardians of clinic patients; HCWs; and public health workers. Youth aged 12–22 years were included in an attempt to obtain the fullest range possible of the adolescent voice; youth aged 12–22 years are seen in the clinic from which participants were recruited, thus youth of these ages were included in the study. Clinic patients live primarily in urban areas of a mid-sized midwestern city; 74% of patients identify themselves as African American and most patients are covered by public insurance. Community physicians from the hospital's mailing list, physicians employed by the hospital, and public health professionals from local institutions were identified and invited to participate via email. Academic and community clinicians and public health workers from various institutions participated. Patients and caregivers were approached during clinic visits, and any or all eligible parties could participate.

This study was approved by the Institutional Review Board of Cincinnati Children's Hospital Medical Center in Ohio. Participants provided informed consent verbally; the need for written documentation of informed consent and the need for parental consent were both waived.

Study methods

In step 1, stakeholders identified health topics that they perceived to be important to adolescent health. In steps 2 through 4 and data analysis, CM methodology as described previously by Trochim and Kane [18,19] was used. CM is a multistep, mixed-method participatory research approach. It uses multiple steps including idea generation or brainstorming and statement sorting followed by statistical analysis using multidimensional scaling and hierarchical cluster analysis. Participants were recruited separately for each step in an iterative fashion; data analysis from each step was necessary before proceeding to the following step.

Step 1: Health topic identification. We planned to recruit 150 total participants, ideally evenly distributed among adolescents; HCWs; and other participants. Youth participants were asked "Thinking about adolescents (people ages 12–22 years), what do you think are the three most important health problems affecting adolescents in your neighborhood, your school, and/or your group of friends?" Parents, public health workers, and HCWs were asked appropriately modified versions of the same question. Responses were coded by researchers (L.E.).

Step 2: Idea generation. We aimed to recruit sufficient participants to generate 50–100 distinct ideas after editing. Participants were provided with a focus prompt regarding health conditions identified in step 1, for example, "In order to address obesity among teenagers and young adults, I believe we need to…" and asked to provide 3 to 5 ideas in response to each prompt.

Step 3: Statement editing. In CM, responses obtained from the idea generation phase constitute the basis for the statement sorting and rating step. Statements should be easily understandable to participants and relevant to the focus prompt; therefore, researchers (L.E., L.V.) edited the statements for clarity. Additionally, prior work in CM has shown that the ideal number of statements for use in the sorting phase is <100 [19] but generally >50 so as to represent sufficiently the diversity of ideas. Researchers edited the statements for clarity and eliminated redundant statements and those that did not seem to