At-risk adolescents as experts in a new requirements elicitation procedure for the development of a smart phone psychoeducational trauma-informed care application

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At-risk adolescents as experts in a new requirements elicitation procedure for the development of a smart phone psychoeducational trauma-informed care application

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ABSTRACT

Background/Purpose: Adolescents from urban, socioeconomically disadvantaged communities of color encounter high rates of adverse childhood experiences. To address the resulting multidimensional problems, we developed an innovative approach, Experiential Participatory and Interactive Knowledge Elicitation (EPIKE), using remote experiential needs elicitation methods to generate design and content requirements for a mobile health (mHealth) psychoeducational intervention. Methods: At a community-based organization in a northeastern city, the research team developed EPIKE by incorporating elicitation of input on the graphics and conducting remotely recorded experiential meetings and iterative reviews of the design to produce an mHealth smartphone story application (app) prototype for the participants to critique. The 22 participants were 13- to 17-year-olds, predominantly African American and female, from underresourced communities. Results: The four goals of the design process were attained: 1) story development from participant input; 2) needs-elicitation that reflected the patient-centered care approach; 3) interactive story game creation that accommodates the participants’ emotional and cognitive developmental needs; 4) development of a game that adolescents can relate to and that which matches their comfort levels of emotional intensity. Conclusions: The EPIKE approach can be used successfully to identify the needs of adolescents across the digital divide to inform the design and development of mHealth apps.

Introduction

As use of mobile phones among adolescents continues to increase, access to mobile health (mHealth) applications (apps) has potential to facilitate self-management of both behavioral and physical health (1). An estimated 88% of adolescents in the United States have a mobile phone, with three-quarters owning smartphones (2). Among young African Americans, mobile phones play prominent roles in their social and sexual lives (3). A recent Pew study reported that mHealth interventions are expected to capitalize on prevalent adolescent mobile phone use (4).
**Background**

To date, mHealth apps have been designed to deliver HIV educational content (5), monitor chronic disease (6), or modify behaviors that have easily understood discrete metrics, such as medication administration (7), smoking cessation (8), diabetes control (9), or weight management (10). Such apps, however, do not address the psychobehavioral aspects intrinsic in the personal management of behavioral health, especially for adolescents whose everyday lives are framed by adverse childhood experiences (ACEs) (e.g., negligence and violence). In such cases, a design team cannot take for granted that users are able to even assess or report their own behavioral and emotional responses to stimuli. These adolescent users need to first learn how to reflect upon, label, narrate, and evaluate their emotional and behavioral responses to stressful events before they can learn how to control and manage their reactions to such events (11,12). In general, mHealth apps tend to be designed for people who resemble the educated and professional developers (13,14), despite the need for health management on the other side of the digital divide (15).

For adolescents from urban, socioeconomically disadvantaged communities of color, there is a pressing need to extend the reach of personal behavioral health management, such as trauma-informed health care services. These adolescents, who encounter high ACE rates, often engage in various high-risk activities including unsafe sexual behavior, which could result in increased rates of communicable and chronic diseases and untimely death. Each year, almost half of all reported sexually transmitted infections (STIs) occurred among 15- to 24-year-old young adults, with persistent disparities among marginalized populations, especially African Americans (12% of the U.S. population accounting for 50% of cases) (16). In fact, living with multiple ACEs has been identified as the largest cause of many of the nation’s worst health and social problems (17,18). Given their elevated risk, it is critical to target young, minority ACE survivors to help them avoid the behaviors that put them at risk for STIs.

ACE survivors are at greater risk for sexual risk-taking due to their impulsive decision making, coping styles, and problems with self-regulation and self-understanding (19), as compared to adolescents in the general population who tend to exhibit poor decision making (20). Underserved minority youth are especially vulnerable to this elevated risk due to their ecological conditions such as disorganized communities and dysfunctional families (21,22). Relationship difficulties among ACE survivors may involve engaging in unprotected sexual intercourse, having superficial or multiple sexual partnerships, or experiencing adolescent pregnancy (23).

Addressing this risk factor of risky decision making among adolescent ACE survivors is a necessary component of a successful intervention that can reduce contracting STI or HIV or being in a relationship that includes an unplanned pregnancy. Proven elements of trauma-informed care interventions that target the decision-making mechanism have been outlined in the literature (24,25). All interventions reviewed included development of safety skills (i.e., injury to and from others and to self and perceived and real threats) and self-management as a foundation (24). However, current trauma-informed care interventions (25–28), being paper-based and therapist-delivered, have dissemination barriers in marginalized communities due to access issues and mental health stigma (29,30). Mental health resources in these communities are often inaccessible or unavailable (31). Moreover, those psychobehavioral services that are available are underutilized due to two common factors: 1) the scarcity of developmentally appropriate treatment modalities for this population; and 2) adolescent concerns about stigma (32).

Given the prevalence of ACEs and the barriers to access among adolescents in urban communities, the availability of treatment interventions needs to be expanded. These should include multiple contact portals, especially ones that can address their developmental needs and mitigate the stigma associated with psychobehavioral services. An intervention should address (i.e., manage and/or overcome) the cognitive limitations. These need to include assistance with difficulties organizing information, emotional distancing, and reactivity (33–35) and psychological resistance to treatment that adolescent ACE survivors often present.
One promising intervention is use of mHealth story and game apps to improve the personal behavioral health management of adolescents from marginalized cultures and communities. There is evidence that game behaviors translate to real-world sexual risk behaviors (1,33). Games, as stories, use narrative that provides an organizing design for decision making, emotions, and outcomes that can facilitate self-regulation (34). The interactive narrative enhances a player’s feeling of “being there” socially and physically, requiring a player to do more than just observe, taking a more active role in the decision-making process (34). Games can provide immediate feedback, thereby increasing player engagement (1). The repetitive nature of games enables reinforcement of the player’s learning (1). These features enable the game player to have the experience and see the consequences, thereby supporting the subsequent transfer of the experienced skills to real life (34). However, existing game-based behavioral tools (5,35) do not address (i.e., manage and/or overcome) safety, impulsivity, and self-regulation related to risky decision making. Nor are these mHealth interventions designed for adolescent ACE survivors from underresourced communities (1,33).

Creation of an interactive story can follow software developmental processes that integrate users for iterative, user-centered design of apps. Iterative design of user interfaces enables designers to refine versions by fixing multiple usability problems in each new version and to subsequently address new problems that appear when old ones are fixed (36). An innovative approach to user-centered design is partnering with a community-based organization (CBO) using a participatory design approach. This method has been shown to be effective with older adults as design partners in integration of potential community-based consumers of an internet application (37).

Objectives

The aims of study were to: 1) develop and employ an innovative approach, Experiential Participatory and Interactive Knowledge Elicitation (EPIKE), which uses iterative, remote experiential needs elicitation methods to generate design and content requirements for a psychoeducational mHealth intervention; and 2) assess whether the use of EPIKE resulted in the design of an interactive story that representatives from the intended audience found desirable and usable.

Methods and procedures

Research design

This study is a needs assessment designed as an iterative participatory process with qualitative evaluation. This approach to needs assessment research was designed to maximize participants’ expression of expertise in order to heighten the effectiveness of a health care prevention tool. The Drexel University Institutional Review Board approved the study proposal for the ethical conduct of human research.

Research setting, team, participants

Between October 2013 and December 2014, our multidisciplinary team partnered with a CBO in Albany, New York, that has focused on delivering HIV/STI/pregnancy prevention education to adolescents from underresourced communities. The CBO, Alliance for Positive Health (formerly AIDS Council of Northeastern New York) offers after-school activities in community settings.

The team included: 1) two public health informaticians (PS,YS), one of whom has expertise in designing user–computer interfaces especially for people with low literacy and low health literacy (YS); 2) a medical anthropologist (SS) and a psychiatrist (SB) who work with trauma survivors; and 3) a gaming and digital media researcher (JZ) with expertise designing interactive narrative stories.

Our principal CBO partner was the project manager (TJS) who was responsible for enlisting the adolescents, obtaining a signed parental consent form, and supervising the CBO’s health educators who
moderated meetings with adolescents. All 13- to –17-year-old English-speaking adolescents who participated in CBO activities and who provided both signed parental consent and signed participant assent forms were eligible to participate. The project manager recruited adolescents from their existing programs. The rationale was that the CBO incorporated this study into their funded initiative, as this study met their funded grant requirements. Typical eligible participants were African Americans and/or Latinos who came from an environment with a high prevalence of multiple ACE risk factors and high susceptibility to comorbid risk-taking behaviors (e.g., substance use and unprotected sex). Eligible adolescents participated in the five sessions based on their availability. The CBO held the sessions at the CBO offices, schools, a YMCA, and a Boys and Girls Club.

**EPIKE**

The EPIKE design approach to elicit design requirements is based on principles of both community-based participatory research (CBPR) and patient-driven participatory research (PDPR). (Here we use patient and consumer interchangeably to refer to the population who live with a condition; the term ‘patient’ identifies a consumer when he or she is actively participating in the health care system.) CBPR is defined as a: “systemic inquiry, with the participation of those affected by the issue being studied, for the purpose of education, and taking action or affecting social change” (p. 420) (38). CBPR, used in urban settings to address health disparities (39), is a powerful tool for engaging marginalized populations (40). The EPIKE approach is based on CBPR characteristics of community participation and taking action—specifically building on the resources and strengths of the community, promoting a co-empowering and co-learning process, and empowering collaborative partnerships (37). For example, research team members have demonstrated that they were successful in building a trusted relationship with the CBO’s executive director and project manager. This approach facilitated engagement of their staff and program participants in an iterative, interactive process to design the interactive story.

The PDPR approach includes use of focus groups and participatory design sessions to derive users’ needs, which contribute directly to the development and design of a software system (37). Inclusion of these PDPR principles in our approach shifted the focus to health care and provided greater detail about the roles of the designer and the patient/consumer. That is, the designer involved patients in the identification of their own needs; thus, the designer would understand and specify the context of patient use of the software and the patient-centered functionality, as shown in Figure 1 (41).

Unlike the CBPR and PDPR approaches, which have used face-to-face focus groups to elicit subject matter knowledge from participants, the EPIKE approach relied on remotely recorded experiential

![Diagram indicating designer involvement of patients in the identification of the patient needs, adapted from Arsand and Demiris (41).](image-url)
meetings. While both PDPR and EPIKE used participatory design sessions, the content of these sessions differed. The PDPR elicited content focused on three topics: 1) intended audience characteristics; 2) proposed system software functions; and 3) anticipated software use patterns. The developers then used that elicited content to design the look and feel, as well as functionality of the software system. In contrast, the EPIKE approach elicited subject matter knowledge which the developers incorporated directly into the scenes and dialogue of the interactive story. The EPIKE subject matter content focused on the scenarios and dialogue, as participants responded to prompts and “what-if” scenarios. In both the PDPR and EPIKE approaches, the iterative process involved participatory design sessions followed by prototype development and display of the prototype to elicit participant feedback.

EPIKE features
The EPIKE approach comprises a number of remotely recorded experiential meetings and the research team’s iterative review of the design sessions to develop an app prototype for the adolescents to critique, as shown in Figure 2. The researcher team’s high-level design requirement was to create an interactive story app as a psychoeducational intervention designed specifically for those who are living with multiple ACEs. The four design requirements were to: 1) develop the story from participant input; 2) use an experiential needs-elicitation process that reflects the patient-centered care approach (42) that is responsive to patient/community needs and values; 3) accommodate the emotional and cognitive developmental needs of the adolescent with developmentally appropriate language and time frames that match their attention span; and 4) manage resistance to the

![Figure 2. Schematic of EPIKE stages in study.](image-url)
psychoeducational intervention by developing a game that adolescents can relate to and that matches the users’ comfort levels of emotional intensity to maximize interest in and usability of the game.

The app would help the player build skills related to making herself safe in a relationship (e.g., how to leave the relationship safely if the partner is violent). The interactive storytelling function would enable users to choose among behavior alternatives as the story progresses (decision points) and select outcomes in the storyline that reflected the users’ choices. The intent was that adolescents who are thinking about changing their behavior would see the effect of different actions and outcomes (i.e., branches of the interactive story). Moreover, based on the Transtheoretical Model of Behavior Change (43), when playing the game, they would see themselves in that story and be motivated to make change in their own lives. At decision points, material from the psychoeducational intervention SELF (Safety, Emotional management, Loss, Future), a paper-based psychoeducational intervention for trauma survivors based on a group psychotherapy model (11), was integrated into the advice provided by nonplayer characters representing voices of helpers or agitators in the community who offered alternative solutions to problems. Use of SELF guided the researchers toward the important messages about safety to impart to at-risk adolescents. For example, we addressed vulnerabilities of revictimization in the dialogue of the trusted aunt, a recognizable and respected persona within the character’s community. The aunt says, “Just you don’t let him make you forget it just cause he slick,” empowering the main character to make the choice to keep herself safe. The app does not disguise the therapeutic aspect of the game, rather it merely makes it less institutionalized and more consistent with the adolescents’ social and cultural practices. To maximize interest and accommodate the emotional and cognitive needs of adolescents (i.e., design requirement #3), the researchers communicated the messages from SELF using the adolescents’ own language style through a figure who they would recognize and respect, the trusted aunt.

**Experiential meetings: Preparatory work**

During the preparatory work phase, the research team made decisions to guide the development of the interactive story. These decisions were: 1) deciding how best to conduct elicitation of requirements, 2) defining the structure and scope of the script, and 3) choosing the mHealth development platform. The research team communicated via regular telephone conference calls to arrive at a consensus on each decision. Meeting minutes that documented each decision were circulated to the team following each meeting.

The elicitation process was organized as experiential meetings at the CBO (i.e., design requirement #2). Rather than having adolescents sit down and write out a script, we used active and spontaneous role play to elicit dialogue for script development. In this way, the adolescents were framed as expert informants whereby the look, language, and plot would be familiar and authentic to their experience (i.e., design requirement #1).

In order to minimize the research team’s interference with the established rapport between the adolescents and the CBO’s program staff, these meetings were recorded for the researchers to view offsite. The CBO uploaded the video recordings to a secure server with secure transmission modality to enable the researchers to view the recordings on the server. To maintain confidentiality, researchers were not able to download the recordings from the server to another device.

The research team: 1) delineated the scope of the story for presentation to the adolescents; 2) identified the focus of the story line; and 3) ascertained characteristics related to the ‘size’ of the game (i.e., the number of decision points, number of iterations through the game, and use of advice-giving nonplayer characters). The story was circumscribed to have a single player navigating four decision points: 1) deciding whether or not to be in a relationship that has multiple outside partners; 2) deciding if the partners use condoms consistently and correctly each time they engage in sex; 3) deciding how to approach the first real argument, which is about substance abuse; and 4) deciding, before the partners have sex (or have sex again), how to engage in a conversation about getting tested for HIV/STIs. The story focus was the “Pick Me” card game, developed by the CBO, in which players managed an imaginary romantic relationship, as shown in Figure 3. The game was designed for both
PICK ME!

Identify yourself

CHOOSE A PERSON THEY THINK THEY MIGHT WANT TO HAVE AN IMAGINARY RELATIONSHIP WITH FOR AT LEAST 3 MONTHS

Why do you think you were asked to choose based on a picture?

How did you decide on this person?

If your partner is much older/younger than you, what kind of differences will this make in a relationship?

What process did you use?

What clues were there in the pictures that suggest what type of person he/she is?

Can you identify any values you hold based on what we’ve discussed so far? (e.g., if the participant chose the “bookish” looking person, do they value education?)

CHOOSE A NAME FOR YOUR PARTNER

Does the name influence your decision to be with this person at all?

If so, how and why?

What if you don’t like your partner’s name?

Do you want to choose another partner?

WHERE WE MET

Where are some good places/bad places to meet someone?

Why are they good/bad places?

Do you want to change your mind based on where you met and choose someone else?

How do you met influence your decision to be with this person?

What clues are there in how you met that suggest what type of person he/she is?

WHAT KIND OF INTERESTS DOES YOUR NEW PARTNER HAVE?

Do you want to change your mind based on your partner’s interests and choose a new partner?

How do the interests influence your decision to stay/not stay with this person?

What clues are there in your partner’s interests that suggest what type of person he/she is?

HOW DOES YOUR PARTNER FEEL ABOUT DRUG/ALCOHOL USE? HOW WOULD YOU FIND OUT?

Based on your partner’s feelings about drugs/alcohol, do you want to choose another partner?

How does your partner’s feelings about drugs/alcohol influence your decision to stay/not stay with this person?

Figure 3. Pick me romantic partner game.
<table>
<thead>
<tr>
<th>WHAT CLUES ARE THERE IN YOUR PARTNER’S FEELINGS ABOUT DRUGS/ALCOHOL THAT SUGGEST WHAT TYPE OF PERSON HE/SHE IS?</th>
</tr>
</thead>
<tbody>
<tr>
<td>If you choose not to use drugs/alcohol, how does your partner’s behavior impact on your decision?</td>
</tr>
<tr>
<td>Can you make your partner behave differently? Why/why not?</td>
</tr>
<tr>
<td>Do you want a new partner?</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>HOW DOES YOUR PARTNER FEEL ABOUT SEX AND CONDOM USE?</th>
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<tbody>
<tr>
<td>Do your partner’s attitudes about sex/condoms influence you to stay/not stay with him/her?</td>
</tr>
<tr>
<td>What are the benefits to using condoms every time?</td>
</tr>
<tr>
<td>What are the barriers to consistent and correct condom use?</td>
</tr>
<tr>
<td>What if you don’t want to have sex until marriage—how would you tell your partner?</td>
</tr>
<tr>
<td>What if your partner tries to force you to have sex and you don’t want to? (discuss date rape)</td>
</tr>
<tr>
<td>If your partner feels this way about sex/condoms with you, has he/she been that way with other people also? How do you know or how would you find out?</td>
</tr>
<tr>
<td>Do people ever lie to get what they want? Why might this person lie about his/her feelings about sex/condoms?</td>
</tr>
<tr>
<td>What clues are there in his/her feelings about sex/condoms that suggest what type of person he/she is?</td>
</tr>
<tr>
<td>Based on all that you know (or think you know) so far, do you want to choose a new partner?</td>
</tr>
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<table>
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<tr>
<th>WHAT TYPE OF RELATIONSHIP IS YOUR PARTNER INTERESTED IN?</th>
</tr>
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<tbody>
<tr>
<td>Does your partner want the same type of relationship as you? How will this impact on your relationship?</td>
</tr>
<tr>
<td>If you have already had sex with your partner, how would your choice to use or not use a condom impact on your risk based on what you now know about your partner?</td>
</tr>
<tr>
<td>What are the positive and negative consequences of having a sexual relationship at this point?</td>
</tr>
<tr>
<td>What types of things might happen if you want one type of relationship and your partner wants a different type?</td>
</tr>
<tr>
<td>How would you tell your partner you are interested in a monogamous (just the two of you) relationship?</td>
</tr>
<tr>
<td>Based on what you know, do you want to choose a new partner?</td>
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<table>
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<tr>
<th>HOW DOES YOUR PARTNER BEHAVE DURING YOUR FIRST REAL ARGUMENT?</th>
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<tbody>
<tr>
<td>Are there any signs that this might be an abusive relationship? If so, what are they?</td>
</tr>
<tr>
<td>What is your behavior usually like during a disagreement/argument?</td>
</tr>
<tr>
<td>Are there any signs in your real life that you might be or might have been abusive to your partner(s)? How does that impact on your relationships?</td>
</tr>
<tr>
<td>What resources are available to help people who are being abused or are abusing others?</td>
</tr>
</tbody>
</table>

In a healthy relationship, both partners have a say in what happens and neither one tries to make the other person do what they want—either
<table>
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<tr>
<th><strong>through words or actions. Is your “relationship” healthy?</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you think this might have to do with HIV/AIDS/STDs?</td>
<td></td>
</tr>
<tr>
<td>Based on what you know, do you want to choose a new partner?</td>
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</table>

**DURING YOUR LONG, ROMANTIC TALKS, YOUR PARTNER TELLS YOU HOW MANY PARTNERS HE/SHE HAD IN THE PAST.**

<table>
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<tr>
<th>How would you start this discussion? When? Where? Why?</th>
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<tbody>
<tr>
<td>What are the risks of asking your partner about how many partners he/she had in the past?</td>
<td></td>
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<tr>
<td>If your partner “uses” the information against you in some way (insulting you, for example), it is unhealthy. How do you think you might react to this type of situation?</td>
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<tr>
<td>Does the number of partners your new partner had in the past influence you to stay/not stay with him/her? How many is too many? What if you’ve had more than your partner?</td>
<td></td>
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<tr>
<td>How might the number of partners your new partner had in the past put you at risk for HIV/STDs or reduce your risk for HIV/STDs?</td>
<td></td>
</tr>
<tr>
<td>What are some ways you can ask your partner about whether or not he/she used condoms consistently and correctly with all previous partners?</td>
<td></td>
</tr>
<tr>
<td>Is there any clue in the number of partners he/she had in the past as to whether or not he/she has been honest with you all along?</td>
<td></td>
</tr>
<tr>
<td>Based on everything you know so far, do you want to choose a new partner?</td>
<td></td>
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</tbody>
</table>

**YOU’VE NOW BEEN IN THE RELATIONSHIP FOR ONE MONTH. LET’S FIND OUT HOW LONG IT’S BEEN SINCE THE LAST TIME YOUR PARTNER HAD SEX.**

<table>
<thead>
<tr>
<th>Based on this new information (or lack of information), do you want to stay with this partner or choose a new one?</th>
<th></th>
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<tbody>
<tr>
<td>Does your partner’s sexual history put you at any risk for HIV/STDs?</td>
<td></td>
</tr>
<tr>
<td>Have you discussed mutual monogamy (just the two of you and no other partners) with your partner yet? Why/why not?</td>
<td></td>
</tr>
<tr>
<td>Based on everything you know so far, has your partner been honest with you?</td>
<td></td>
</tr>
<tr>
<td>How do you decide if you want to stay with this person or not?</td>
<td></td>
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</tbody>
</table>

**YOU’VE BEEN WITH YOUR PARTNER FOR NEARLY 3 MONTHS.**

| Have you had sex already? |  |
| Have you used condoms consistently and correctly every time? Why/why not? |  |

**BEFORE YOU HAVE SEX (OR HAVE SEX AGAIN), YOU DECIDE TO HAVE A CONVERSATION ABOUT GETTING TESTED FOR HIV/STDs.**

| How would you bring that up? |  |
| What are the benefits to getting tested before you have sex? |  |
| What are the barriers to getting tested before you have sex? |  |

**Figure 3.** (Continued)
genders to play. To accommodate the narrow scope and the need for fast development of the app prototype due to time and resource constraints, the plot was limited to a female player and one romantic male partner and was intended to be played once, not repeatedly.

The team decided to use a webpage-based system for the initial prototype instead of a commercially available development platform. The reasons to use the webpage-based system were that it could: 1) have all the desired features; 2) be easy and quick to test; and 3) be accessible to everyone who has a smart phone. The reasons not to use the commercial platform were that its use required obtaining official approvals from Apple and Android, and it would be difficult to find proficient programmers, as the software was very new at the time.

Participatory design sessions

Following the preparatory work phase, the team conducted participatory design sessions with adolescents at the CBO. The purpose of the participatory design sessions was to elicit content knowledge that adolescents related to the graphics and the script from these adolescent subject matter experts.

Iteratively and concurrently with script development, the participants and researchers determined the graphics style. Over the course of several emails, the gaming and digital media researcher communicated with the CBO’s project manager to elicit design recommendations from participants. The project manager showed the adolescents preliminary sketches and asked them about the style and content for the characters and background graphics. She communicated their responses to the gaming researcher who incorporated the changes and sent the revised graphics back to the project manager to show to the participants.

CBO session moderators who had previously developed relationships with the adolescents conducted the recorded experiential meetings. The exercise began with a group of adolescents playing the Pick Me card game to focus participants’ attention on the romantic relationship topic. During
the following two meetings, the groups developed the script in a conversation with moderators who provided prompts related to the decision points and subsequently probed the participants’ responses. The moderator sets the scene, and the adolescents described how they would react to these situations in their lives.

After each design session, a researcher (PS) viewed the session recordings and documented the scenarios and dialogue in field notes. The purpose was to segregate and organize dialogue related to each decision point. In accordance with the design goal of using the participants’ own language to develop a story that the player could relate to, we did not conduct content analysis that would alter or not include the participants’ own words. We organized the dialogue using a manual process, without the use of software, due to the sample size (i.e., number of design sessions conducted). The researcher mapped each dialogue grouping to a decision point identified in the preparatory work. The researcher assessed whether the mapped dialogue needed further development sufficient for the planned speech bubbles. The researcher sent the list of decision points that needed initial or further development to the project manager to discuss with the moderators in preparation for the next design session.

**Script development**

To develop the script for the prototype interactive story, the researchers referred to a schematic of the decision points to organize the dialogue, add advice-giving characters, and reduce the script to speech bubbles. Researchers (PS, SS) viewed the recordings and organized the dialogue into a script around the identified decision points to fit the project scope. To help organize the script for programming, the gaming and digital media researcher (JZ) provided a schematic of the branching logic; Figure 4 shows the schematic of the resulting story with two decision points. JZ translated the schematic into the script structure with sample dialogue and characters. Subsequently, a team member knowledgeable about implementing SELF (SS) added script for the advice-giving, nonplayer characters. This researcher also referred to the schematic to suggest the sequential placement of the nonplayer characters’ interactions with the main character. This script structure was given to a CBO session moderator who filled out the script using the language and emotion familiar to him from working with the participants and reviewed the script’s literacy level.

**Game development**

To further reduce and reorganize the script, the gaming and digital media researcher and media designer (JZ) and her research assistant (NL; see Acknowledgments) referred to the schematic to identify the placement of scenes. Next, they looked for dialogue organized around decision points that matched the scenes among the episodes in the script. The developers’ next step was to reduce the number of words in the script to fit into speech bubbles. They studied the language in the script to replicate the vocabulary and terms in the speech bubbles, following the patterns they discerned.

**Feedback from the intended audience**

Following completion of the interactive story, the researchers elicited from the adolescent subject matter and content experts their feedback on the prototype. The intent was for the researchers to incorporate this feedback during the next iteration to further refine the interactive story to manage any resistance to the psychoeducational intervention (i.e., design requirement #4). Following development of the interactive story, a total of nine adolescents, in each of two groups, participated in the feedback sessions based on their availability. The groups included some adolescents who participated in script development. Each group viewed the story on a single laptop. The groups navigated the story, from beginning to end, making choices at each decision point while giving their input along
the way. The moderators did not provide prompting prior to or during these feedback sessions. Moderators transcribed the feedback during the sessions instead of using video recording. Researchers (PS, SS) manually identified themes.

Results

The results are organized by the stages of the EPIKE participatory design of the interactive story development displayed in Figure 2: graphics, nonplayer characters, participatory design sessions, script development, game development, and feedback. We summarized each stage using broad descriptions that best represented in words the essence of the outcomes. Overall, 22 program participants participated in the study: 15 female and 7 male adolescents. They were Black and/or Latino.

Participatory design sessions

Graphics

The participants made three graphics decisions: 1) the style of the characters, 2) the background, and 3) the display of the characters’ speech. We initially proposed a graphic representation style close to Japanese anime as shown in Figure 5. The feedback we received from the participants was that the anime style did not appeal to them and that use of light-skinned anime characters would be very “off putting.” Instead, they chose a soft, sketchy style, similar to the Boondocks comic strip style, as shown in Figures 6 and 7. Another central issue to the participants was the body shape of the

![Figure 4. Schematic of planned interactive story branching logic.](image)
characters. They did not identify with the skinny body and tight waistline, a style commonly used in anime and comics in general.

Participant feedback clearly suggested that the representation of ethnicity played an important role for their identification with the characters. Our character and environment artist (DL—see Acknowledgments) then followed the participants’ suggestion to emphasize features associated

Figure 5. An early version of graphic design showing anime character style and bedroom with accessories.

Figure 6. Interactive story graphic of characters in school classroom.

Figure 7. Interactive story graphic with gender-neutral bedroom background and example of speech bubble containing vernacular language that participants questioned.
with Black and/or Latino characters. Next, in response to the artist’s request for advice for the main character descriptions (e.g., hair style and clothing), the participants provided strong guidance on a graphic design that reflected the people in their social networks.

We initially had included an example of an “upscale” bedroom with an ocean view as an option for the background environment. The participants responded that this background was not reflective of the places where they live and socialize; instead, they suggested using the bedroom shown on the adolescent’s website (44), which appeared to be minimally decorated, with a blind over the window. The website bedroom also appeared to be gender-neutral. In response, the artist requested photos for female adolescents’ bedrooms, which she used as the basis for the final environment, a bedroom of indeterminate décor style.

The decision of how to represent the characters’ conversations began with presentation of examples of two common approaches, textboxes, and speech bubbles, with the advantages and disadvantages of each approach. The participants indicated their preference for speech bubbles on the top, though the CBO noted that many of the adolescents had literacy issues. The CBO pointed out that displaying information at the bottom in text boxes, in addition to the speech bubbles, could be too busy for the adolescents with limited attention spans and literacy concerns. As a result, the adolescent audience might miss information. The final design was to use speech bubbles at the top and text boxes at the bottom, which were limited to decision point choices and the “next” button for advancing the story.

**Other characters (nonplayer characters)**

During the preparatory stage, the CBO project manager, whose knowledge is based on many years of direct experience working with these at-risk adolescents, identified three main character types that the adolescents often mentioned as supports or challenges as they made important decisions in their lives. Based on this guidance, the research team developed the personality profiles of three characters with whom the player could interact. These were the “trusted aunt” character, a common authority figure in the target audience’s social environment, and a “good friend” who would provide consistently good advice. The jealous girlfriend (also a common challenge in the audience’s social world) would provide unreliable advice.

**Experiential meetings to develop script**

There were three participatory design session meetings. Participants attended these sessions based on their availability. The three groups were of different sizes, and each group included no more than six adolescents. Some participants attended more than one session. During the first group meeting, the exercise began with the participants playing the Pick Me card game. Next the participants described the male partner characteristics, identified aspects of the backstory to the relationship, and began to build the plot line identifying three decision points. The participants decided to omit the decision point about substance abuse, which had occurred at the first real argument.

During the second and third group meetings, in response to moderators’ queries about how the adolescents would react to scenarios, the participants reported what they would say, or they acted out their reaction. Participants determined that decision point #2, the use of a condom, was the first chronological decision point in the script. The scenario was that the male partner did not have a condom and tried to convince the female partner they did not need condoms, saying that she was the only one with whom he was in a relationship. Decision point #1, remaining in a relationship in which the partner had outside partners, was the second decision point in the script. The scenario was that after the female partner looked at the male partner’s phone and saw messages from other girls that were highly sexual and suggestive, she confronted the male partner, both physically and verbally. Due to time constraints related to participants’ limited attention spans and lack of availability, the script ended before decision point #4, getting tested
for HIV/STI, was discussed. Figure 8 indicates on the schematic the decision points included in the current version of the interactive story.

**Script and game development**

The game developers shortened the backstory material at the beginning of the script to produce a game that would commence as soon as the player started the game. The story opens with an introduction of the main character and a brief description of her relationship with her romantic partner. The player then selects among the three advice-giving, nonplayer characters and decides which person to visit first. The plot then shifts to the main character and her partner in a bedroom...
where they discuss their relationship and use of a condom. The conversation stops when she sees a text message on his phone from another girl, and she decides how to proceed with the relationship.

Feedback from the intended audience

Nine participants, six female and three male, divided between two groups provided feedback. Both participant groups thought the game was good; there were no statements that the game was not liked. A theme that focused on the characters was that the participants found the characters realistic and related to their experiences. They were enthusiastic about the nonplayer characters and could easily relate to them: “Sounds like my aunt and what I say to her.” A second theme was that the actions in the story resonated with the participants. They felt the main character’s outcome of finding the text message was realistic and mirrored some of their own personal experiences. The participants said that the game reinforced the decision-making advice of the trusted aunt who had been the cultural mediator of SELF and reinforced the adolescents’ real-life capability, as evidenced in remarks such as, “Stay strong, girl.” The participants immediately wanted to go back through the game again to see all the options. While enthusiastic, they felt the story was incomplete and are waiting for the rest of the game. The participants wanted to be able to download the app immediately to share the game with their friends and family asking, “Can we download this app right now?” and were disappointed when told they could not do so.

The participants’ vernacular language in the speech bubbles was an issue (e.g., see Figure 7) raised by some in the second group of participants. Their responses included: “Language makes us sound dumb” and “We don’t talk like that” (i.e., the slang is old). The participants thought the language issues were grammar or incorrect typing issues.

Discussion

Unlike participatory design approaches used with adults (37,40), our EPIKE approach can address the challenges of designing mHealth games for adolescents across the digital divide. In this study, we addressed four design requirements: 1) story development from participant input; 2) use of an experiential needs-elicitation process; 3) accommodation of the adolescents’ language and time frames; and 4) management of adolescents’ resistance to the intervention.

The design and development activities of mHealth apps intended for support and self-care are often conducted by developers working in isolation who do not resemble the potential consumers of personal behavior management apps who reside in underresourced communities. Instead, user-centered design should identify and focus on these consumers to assure that their needs are fully understood and incorporated into the overall design (13). Our innovative approach to engage adolescents from high ACE-prevalent neighborhoods in interactive, experiential activities was successful in the elicitation of their reactions to inform development of each iteration of the interactive game prototype. The important difference between the EPIKE approach and other CBPR or PDPR approaches in the engagement of community members as design partners (37) is the use of technology for remote communications to avoid disrupting the moderators’ rapport with the participants, as well as experiential group meetings instead of developmentally inappropriate focus groups. This engagement contributes to mHealth development that is based on real-world experiences.

Researchers working with at-risk populations must face the ethical dilemma posed by the imbalance of power that is inherent in the situation. Instead, the EPIKE researchers worked with these adolescents as equal partners in research engaging them to assure that they would be represented in the way they want to be represented. That is, the participants were active agents in their own self-representation. Therefore, the researchers have engaged the participants as experts in the needs elicitation process, as well as leaders in the app evaluation process.
This study had a number of strengths, as well as some challenges. Engaging adolescents from underresourced communities allowed us to incorporate developmental, social, and cultural considerations into the design and development of the mHealth game. This engagement was made possible based on the researchers’ collaboration with the CBO, which was a strength of the study. The participants’ responses indicated they were actively involved and emotionally engaged in the design process. The adolescents were not drawn to participate based on any incentives (there were no tangible incentives), yet they remained involved in the project.

Another strength of the approach was that the CBO moderators’ relationships with the participants enabled the moderators to have productive participatory design sessions. The researchers did not interrupt the trusting relationship and rapport that was so important to eliciting the adolescents’ input on sensitive topics. A challenge was participants’ hunger and shortened attention spans during these after school sessions. Future research may benefit from providing participants with healthy snacks at the start of the participatory design sessions, which may enable them to concentrate longer and promote more productive sessions. Despite this challenge, researchers were able to obtain relevant information and language that they could not have predicted prior to engagement with the study participants, due to the open-ended nature of the needs elicitation and assessment processes.

The CBO’s prior experience developing educational media for social networks was another study strength. Drawing on the CBO’s experience, we circumscribed the study scope, due to resource constraints, such that the interactive story had a single plot line navigated by one female main character with one male romantic partner. Future research would have the participants suggest additional plotlines. Researchers and the CBO anticipated that four decision points could be discussed during the participatory design sessions. However, participants’ availability, school holidays, and a hard winter limited the number of meetings. Future research should plan for more participatory design sessions when working with a CBO with less media development experience as well as when creating multiple plotlines, characters, and players.

The researchers and CBO had intended the interactive game to be designed as gender-neutral. However, study participants were predominantly female. Their perspectives are reflected in the interactive story’s female main character, female avatars, and framing of decision point scenes. In future studies, researchers may want to decide to develop a game for one or both genders and purposefully recruit adolescents to meet that goal.

In this study, script development entailed 1) participants providing dialogue in response to scenarios posed by moderators, and 2) a CBO moderator and a researcher developing the script. In future research, we would plan for increased adolescent participation in script development. More participatory design sessions and more productive sessions may enable moderators to use techniques that could include story-boarding to draw thumbnail sketches of the scenes as well as role-playing of the dialogue.

Another challenge related to script development concerned the extraction of language that was authentic to the participants’ community. Unlike the process for designing the graphics, researchers did not ask the participants about their preferences for presentation of the language in the speech bubbles. Adolescents have different attitudes about how their language is portrayed in writing. As stated in a recent study, “In certain settings, you should speak as you want to, but when you are in different settings, like school and on the job, you shouldn’t speak that way because it is not standardized and people are still racist” (45). In our mHealth game study, the adolescents’ responses demonstrated that it is important to elicit feedback about language presentation.

Regarding methods, researchers conducted qualitative analysis of the feedback sessions to identify important themes. However, due to the lack of video recording of these sessions, quantitative evidence for the adolescents’ expressions of opinion is not available. This absence speaks to the value of remote recording as a strength of the EPIKE method.

Considering the small sample size, the researchers are aware that these adolescents viewed the interactive story game as a group and that the dynamic of a group is different from the dynamic of
an individual. The initial videotaped group was a mix of adolescents from several different community settings and most participants did not know each other. The subsequent videotaped groups had members within the group who knew each other. The responses indicated that when a group of adolescents are motivated to participate in the development of the game, researchers could expect less resistance. It is also possible that when members of a group know each other, the resulting group dynamic may counteract individual resistance. Therefore, we expect that other adolescents in the larger population who resemble these study participants will also be engaged. Considering the study findings, the researchers have concluded that the remote, participatory approach was successful due to its numerous strengths and few weaknesses. Furthermore, they can recommend this approach to developers designing personal behavioral health management apps for vulnerable adolescents.

The interactive story is, to the best of our knowledge, the first psychoeducational mHealth app for adolescent trauma survivors’ personal health management. We plan to refine the interactive story described above to be an interactive game with a branching story, with multiple decision points. We expect that by continued use of the EPIKE approach during further app development, these adolescents will find the games sufficiently engaging and compelling and that their experiences would facilitate their dissemination of these apps throughout their social networks. This game is likely to be distinctly different from games developed for those who resemble the educated and professional developers. In designing and developing mHealth apps that this audience is likely to use and share, it is vital to maximize the engagement of the intended adolescent audience in the mHealth app development process.

Conclusions

The EPIKE approach can be used successfully to identify the needs of adolescents across the digital divide to inform the design and development of mHealth apps. Interactive game apps, such as the prototype developed in this study, can increase mental health care access and quality of care among vulnerable and marginalized populations by making actionable resources available (46). The research team developed a remote, experiential, community-centered participatory design approach that is focused on consumers’ needs. In addition, it is focused on core public health functions and outcomes such as spurring community partnerships to address health problems; improving access to needed health care; and conducting research to develop innovative solutions and new insights into health problems (47). The EPIKE approach provides community-based as well as public health organizations, researchers, and mHealth designers with a systematic and theoretically informed method to develop consumer-oriented mHealth innovations.

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Declaration of interest

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