Published in final edited form as:
Ann Hum Biol. 2013 ; 40(6): 485–495. doi:10.3109/03014460.2013.806590.

Attitudes and beliefs toward biobehavioural research participation: voices and concerns of urban adolescent females receiving outpatient mental health treatment

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Abstract

Background—Biobehavioural research methodology can be invasive and burdensome for participants—particularly adolescents with mental illnesses. Human biological researchers should consider how methodological impositions may hinder adolescent research participation. However, literature on adolescent's voices and concerns toward biobehavioural research participation is virtually non-existent.

Aim—This study was designed to determine adolescents' perceptions of participation in research involving the collection of biomarkers via blood, saliva and/or urine samples.

Subjects and methods—Urban adolescent females (aged 12–19) receiving outpatient mental health treatment (*n* = 37) participated in focus groups with concurrent survey administration to explore attitudes, beliefs and willingness/intentions toward biobehavioural research participation.

Results—Participants had favourable attitudes toward biobehavioural research and were amenable to provide each specimen type. Mistrust for research emerged, however, and concerns related to privacy and confidentiality were expressed.

Conclusion—Participant recruitment is a critical component in study design and implementation; this includes knowledge of population-specific recruitment barriers and facilitators. This innovative paper provides a context for the research participants' decision-making process, strategies to allay fears and concerns and concrete areas to target in research-related interventions. Although the findings are from a specific, US-based sample, the implications warrant replication of the research in other geosocial settings.

Keywords

Biological specimens; research subject recruitment; research ethics

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Declaration of interest
The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Introduction

Identifying and addressing mental illnesses among adolescents is a public health priority. Globally, neuropsychiatric disorders account for 45% of the years lost because of disability among youth aged 10–24 and this impairment is most prominent among those aged 15–24 (Gore et al., 2011). Adolescents living in resource-limited environments are at even greater risk for mental illness and suffer more severe consequences (Dashiff et al., 2009). Further, mental illnesses in vulnerable adolescents have been associated with poor interpersonal relationships and physical health (Guajardo et al., 2011; Katon et al., 2010; Luppino et al., 2010; Vujeva & Furman, 2011), as well as other risk behaviours, including substance use, involvement in physical violence and sexual risk behaviours (Brawner et al., 2012b; Brooks et al., 2002; Brown et al., 2006; Katon et al., 2010; Shrier et al., 2009).

A comprehensive understanding of mental illnesses, as well as other biologically-based health problems in adolescents, requires a closer examination of integrated biological and behavioural health indicators (Uher & McGuffin, 2008). The National Institutes of Health defines a biomarker as ‘a characteristic that is objectively measured and evaluated as an indicator of normal biologic processes, pathogenic processes or pharmacologic responses to a therapeutic intervention’ (Atkinson et al., 2001); this is one of many definitions of the term and is not all-inclusive. Biomarkers are used to determine genetic pre-disposition for diseases (Goudriaan et al., 2004; Li et al., 2011; Marenberg et al., 1994), confirm participant self-report (Hewett et al., 2008), prospectively examine health complications (Baum & Posluszny, 1999; Latendresse, 2009; Perera et al., 2011) and guide the development and evaluation of targeted interventions (Andersen, 2002; Boyce et al., 2006; McBride et al., 2012; Rogers et al., 2009). Triangulating various biomarkers with other methods such as genotyping and behavioural assessments may be most effective in predicting pathology (Juster et al., 2010). Generation of this knowledge necessitates the examination of disease biomarkers, a continuously emerging field in adolescent mental health research (Williams et al., 2002).

Although definitive biomarkers of psychiatric illnesses have not been identified, evidence suggests that it is most often influenced by both pathophysiological and environmental factors (Tsankova et al., 2007). Epigenetics refers to the normal functioning of the genome through the regulation of the DNA sequences (e.g. transcription), while maintaining the base genetic code (Ptak & Petronis, 2010; Tsankova et al., 2007). Researchers, reviewing the role of epigenetics in psychiatric disorders, purport strong evidence that epigenetics mechanisms have an influential role in the developmental of psychiatric disorders, in which environmental context and stress contribute (e.g. depression) (Bredy et al., 2010; Tsankova et al., 2007). Furthermore, epigenetic research using biological specimens introduces potentially therapeutic tools in the treatment of mental illness (Bredy et al., 2010).

Although the scientific and general community understanding of biological roots/correlates of mental illnesses and their treatment has increased (Schomerus et al., 2012), geographical and cultural differences exist in the recognition of the relationship between human biology and mental illness. For example, Blacks in the US may be less likely than Whites to believe in a biological aetiology of mental illness; this may be tied to a history of racial marginalization and eugenic arguments of Black inferiority (Schnittker et al., 2000). This is one of many examples where biobehavioural research may be warranted and effective, yet individual-level attitudes and beliefs based upon historical biases could preclude participant interest and consent.

Several ethical and methodological issues are important to consider in human biological lines of inquiry. This is particularly pertinent among minors with mental health diagnoses, where both developmental and cognitive competency to provide consent or assent can be called to question. Despite the advanced knowledge and improved health outcomes that stem from biobehavioural research, the methodology can be invasive and burdensome for participants, potentially hindering their participation. In a study of child and parent refusal to enrol in clinical research, Gattuso et al., (2006) discovered that the burden of research methods was the most commonly reported reason for refusal. A fair number of studies have examined adolescents' perspectives on research participation (DiClemente et al., 2010; Fisher et al., 2002). However, literature voicing adolescent concerns (with or without mental illnesses) toward biobehavioural research participation is virtually non-existent.

Specific investigators have identified barriers to research participation in adolescents, including insufficient understanding and mistrust of research (DiClemente et al., 2010). Furthermore, there has been a concentration in the topical areas of parental and adolescent consent (Pasternak et al., 2006a; Vitiello et al., 2007). However, the introduction of biomarkers into research often requires more invasive and burdensome procedures. Therefore, specific attitudes, beliefs and willingness/intentions to participate in biobehavioural research must be uncovered. Adolescent research experts purport that it is essential to elicit the opinions of individuals with specific cultural knowledge and experience including those that are the target of an investigation or interventions (Fisher et al., 2002).

Biobehavioural research can expand our understanding of biological influences on behaviour and health. Adolescent involvement in this research is a key factor in generating developmentally-appropriate knowledge (DiClemente et al., 2010; Duck-Hee et al., 2010). Research on biomarkers in adolescents, particularly minority and urban adolescents with mental health diagnoses—who are often most vulnerable— however is limited (Kattan et al., 2010; Sacheck et al., 2011; Shafii et al., 2007; Worthman & Costello, 2009). As mental illness is experienced at twice the rate for females than males, more information is needed concerning the pre-disposition to mental illness experienced by females. Compounding this disparity, adolescent females receiving outpatient mental health treatment in resource-limited environments are even more vulnerable and are an important population that could benefit from biobehavioural research developments. For example, biomarkers could be used to disentangle the relationship between clinical depression and sexual risk behaviours, markers of inflammation, genetic polymorphisms, heart rate variability and/or sex hormone variability (Brawner et al., 2012a; Gold & Irwin, 2006; Hamer et al., 2009; Hughes & Stoney, 2000; Larson et al., 2001; Naninck et al., 2011). To evaluate the feasibility of conducting biomarker research in this often-silent population, it is imperative that we evaluate their perception, by ascertaining their beliefs, attitudes and intentions about such research.

This study was designed to determine adolescents' perceptions of participation in research involving the collection of biomarkers via blood, saliva and/or urine samples. The sample included urban adolescent females aged 12–19 years receiving outpatient mental health treatment (*n* = 37). The population was selected based on the need for additional biobehavioural research within that demographic group. This innovative knowledge can be used more broadly to develop research-related educational materials and enhance recruitment of heterogeneous populations in biobehavioural research. Although the findings are from a specifically defined, US-based sample, the implications warrant replication of the research in other geosocial settings and populations.

Theoretical framework

This study was guided by the Theory of Planned Behaviour (TPB) (Azjen, 1991). The TPB postulates that relevant attitudes, beliefs and intentions guide behaviour (Ajzen, 1991, 2002); see Figure 1. These theory-based predictors of behaviour are critical to understanding and changing behaviour, most frequently behaviour under the voluntary control of an individual (Ajzen, 2002). Attitudes are defined as an individual's evaluation of their ability to perform a particular behaviour. Beliefs are distinguished into behavioural, normative and control beliefs. Behavioural beliefs are defined as the individual's perceptions about consequences of a particular behaviour. Normative beliefs are the individual's perception of those close to them regarding the behaviour and social norms of the behaviour. Control beliefs are the individual's perceptions of their ability to perform the behaviour. Intentions are defined as an individual's readiness to perform a particular behaviour. The theoretical framework was selected due to the strong evidence it has in elucidating knowledge predictive of adolescent behaviour (Hutchinson & Wood, 2007; Jemmott et al., 2001; Martin et al., 2010).

Methods

Study design and sample

An investigator-developed survey and focus group guide, informed by the TPB, were used to accomplish the study aims. The research team conducted face-to-face recruitment of a convenience sample of adolescent females aged 12–19 (*n* = 37) and parents/guardians of adolescent females aged 12–19 (*n* = 23) from outpatient mental health treatment settings in the Philadelphia, PA and Hampton, VA; this was done to provide geographically-relevant information for future studies of the investigative team. Findings from the parent/guardian focus groups are discussed elsewhere (Authors). This paper solely focuses on the adolescents, in an effort to highlight the unique voice adolescents provide to the research recruitment process. To mirror the diverse nature of the participant population, the research team consisted of young adult and adult African American (*n* = 5), Caucasian (*n* = 2) and Filipino (*n* = 1) females. None of these individuals were involved in the psychiatric treatment of the participants.

Flyers and palm cards (recruitment informational card the size of one's hand), staff referrals, waiting room encounters and participant referrals were all methods of recruitment. Inclusion criteria were: (1) adolescent females aged 12–19 years old, (2) currently receiving outpatient mental health treatment and (3) able to speak, read and write in English. Adolescent girls that were diagnosed with a cognitive or psychiatric condition that would prohibit the participants' ability to complete the study procedures (e.g. cognitive deficits or active psychosis) were excluded; this was ascertained by trained research staff at the time of screening. A total of eight focus groups were conducted with three-to-eight participants per group. Two staff members were present during each focus group session; one facilitated the group discussion while the other took detailed notes.

Two adolescents also participated in individual interviews instead of focus groups due to poor focus group session attendance on repeated occasions. In the case of individual interviews, only one staff member was present. Data collection occurred from October 2010 through August 2011.

Measures

The study questionnaire and semi-structured focus group guide were designed to assess theoretical mediators of research participation in accordance with the TPB (Azjen, 1991). Specifically, we sought to uncover participants' attitudes and behavioural beliefs (what is good/bad about research participation), normative beliefs (who would approve/disapprove of research participation), control beliefs (how easy/hard would it be to participate in a research study) and research participation intentions (I plan/do not plan to participate in a research study).

Surveys—In the 52-item paper-and-pencil survey, participants were asked closed-ended questions about their attitudes, beliefs and willingness/intentions regarding research participation that would involve providing samples of blood, saliva and/or urine. Sample 5-point Likert scale items included: 'How likely is it that you would participate in a research study if we had to use a needle in your arm to give blood?' (response options were very likely, likely, in the middle, unlikely and very unlikely) and 'Would most people who are important to you approve or disapprove of you participating in a research study where they collected information about your genes?' (response options were strongly approve, approve, in the middle, disapprove and strongly disapprove). The survey also included questions on participant perceptions of adequate compensation for biobehavioural studies. These questions were designed to determine whether participants thought more compensation should be offered for the different sample types, as well as the type and amount of compensation they believed was adequate. Closed-ended questions were selected to allow for group consensus on specific topics, such as incentive payment, that are important in designing ethical research studies that request biomarkers.

Focus group guide—The focus group guide expanded on the questionnaire items to further probe participants' attitudes, beliefs and willingness/ intentions regarding biobehavioural research. The guide consisted of a series of open-ended questions such as: 'What would be a good thing about participating in a research study where you had to give blood?' and 'What would make it hard to participate in a study where you had to pee in a cup to provide a sample of urine?' Specific probes were also included to determine participants' willingness to provide multiple biological samples. Regarding compensation, participants were asked to share the most important factors in determining adequate compensation amounts (i.e. time spent in the study or experience of pain), as well as the specific types and amounts of compensation for each biological sample. Participants were also asked questions to inform recruitment strategies for biobehavioural research projects.

Procedures

After approval by the University of Pennsylvania's Institutional Review Board, adolescent females were approached and screened for eligibility. Informed consent was obtained from eligible participants. Participant assent and verbal parent/guardian permission were obtained for adolescents under age 18. The focus groups and interviews took place at the recruitment site. Prior to the start of the discussions, participants completed the brief 10–15 minute survey. Immediately upon survey completion by all group participants, the 2-hour focus group discussion or interview began. In accordance with the TPB, it is appropriate to administer surveys prior to the group to better acquire data on participant's salient beliefs. This approach has been used in other studies involving use of the Theory of Planned Behaviour (Harrison & Liska, 1994; Randall & Gibson, 1991). Focus groups and interviews were audio-recorded and transcribed and staff took detailed field notes during the discussions. All participants were provided with $20 to compensate for their time.

Data analysis

Over the course of the study, data collection and analysis activities overlapped. The quantitative data were dual entered into SPSS 18 and cleaned. Inconsistencies were verified with the hard copy of the survey and changes were made accordingly. Analyses consisted of descriptive statistics conducted to describe the sample and frequency counts to explore the reported attitudes and beliefs.

Qualitative data included focus group transcripts and researchers' field notes. Each transcript was put in line-numbered form and read and analysed in detail using NVivo9 software. All recordings and corresponding transcripts were independently reviewed by a trained research assistant in order to correct inconsistencies and ensure validity. Descriptive content analysis was based on a deductive coding structure derived from TPB concepts. The two co-principal investigators independently assigned codes to the data and included their definitions of the codes that were developed to minimize confusion. They then conferred together to determine the final coding structure for the analyses and went back through the transcripts applying the agreed-upon structure. The authors cross-analysed the data for consistent themes (Bradley et al., 2007). Study rigour was ensured through validation of transcripts, double coders and through field note verification. The average Kappa coefficient and percentage agreement were determined by exporting coder comparison queries from NVivo 9 to Microsoft Excel for analysis as outlined by the software developer (QSR International). The Kappa statistic for inter-coder reliability was 0.77 and there was 91% agreement; Kappa values greater than 0.75 indicate excellent agreement (Landis & Koch, 1977).

The focus group/interview and survey data were mixed during data analysis and interpretation. The investigative team simultaneously reviewed the transcripts and survey data which allowed the weaknesses in either the qualitative or quantitative method to be minimized by the strengths of the other. More specifically, the survey data were used to explore the prevalence of beliefs, attitudes and intentions within the sample and transcripts provided context for these factors. The TPB served as the overarching framework to guide the analyses and interpretations.

Results

Sample description

Table 1 depicts the study sample. Participants were predominantly African American (73%), and the average age was 15 ± 2 (*M* ± SD). Eighty-nine per cent of the participants were currently in school; two had graduated from high school. There was an average of 2 ± 1 adults and 3 ± 1 children per household. Eighty-one per cent of the participants lived with their mother or father and 19% lived with an adult other than a parent. The majority of the sample (65%) had not participated in a research study prior to our survey and focus group study.

General research attitudes, beliefs and intentions

The majority of the sample had favourable attitudes toward research. They believed that participating in a research study would be a good or very good idea (behavioural beliefs) (87%); that participation would be easy or very easy (control beliefs) (89%); that most people important to them would approve or strongly approve of their participation (normative beliefs) (89%); and that, if asked, they would agree or strongly agree to participate (intentions) (87%). Sixty-five per cent also indicated that they planned to participate in a research study in the next 3 months. Some participants, however, reported skepticism toward research and researchers. Twenty-seven per cent indicated that they were ‘in the middle’ about whether they would trust they were being told about what would be done to them as a participant in a research study. Others agreed (8%) or were ‘in the middle’ (38%) about their trust for researchers and how their information would be used once the data were collected.

During the focus groups, adolescents shared previous experiences with survey and clinical research participation. They frequently associated research with terms such as ‘experiments’, ‘questions’ and ‘surveys’, but they were also able to altruistically discern the benefits of research participation. For example, they shared that, ‘[research] is about finding solutions’ and ‘you can, like, help with a cure for something’. The overall consensus across the group was that research was a means to learn new information and that this information would not only help themselves, but also others in need. Participants believed that peers would want to participate in research because it would give them something to do, keep them out of trouble, while allowing them to help others. When asked if anything would prevent them from participating in a research study, most talked about confidentiality (focus group numbers are referenced by ‘[FG number, City]’):

> If we was talking about girl stuff and they brought a man in here, that would be hard (chuckles) [FG 2, Hampton]. Making them actually put out their information, telling them like they have to put they real name and stuff like that because it could make them feel insecure about what's going on [FG 6, Philadelphia].

They confirmed skepticism indicated on the survey questionnaire results with statements such as 'you don't know where the information's going' and 'you don't know what that person [the researcher] might do with your information'. There was also concern about dissemination of results and how the data/statistics would be used to portray adolescents: '[Research can] make us a statistic about bad things'. Although overall attitudes toward research participation were positive, discrepancies arose when discussing the different sample types that might be collected for biobehavioural research.

Attitudes, beliefs and intentions toward blood samples

Blood samples, through either antecubital venipuncture or finger stick, were perceived to be the most burdensome samples to provide; see Table 2. Near equal numbers of participants indicated they would be likely or very likely to get a needle in their arm (41%) or have their finger stuck (42%) to provide a sample of blood. More participants, however, believed venipuncture would be hard or very hard compared to a finger stick (38% vs 22%, respectively). Many (41%) were 'in the middle' as to whether people who are important to them would approve or disapprove of them participating in a study where they had to give blood; however, many more believed that referent others would approve or approve strongly (35%) than disapprove or disapprove strongly (24%).

Controversy arose as most participants shared their fear of needles and indicated that they would be hesitant to provide blood samples because 'people are squeamish of needles'. However, surprisingly, a few either were not afraid of needles ('I don't have a problem with seeing blood, giving blood') or viewed blood draws in research the same as for tests through their primary care providers, which were not difficult. As one participant shared, 'I had it done before when I went to the doctor's, so, like, it don't hurt'. There were mixed feelings on whether participants would prefer to give blood through venipuncture or a finger stick. Some preferred the finger stick because it wouldn't hurt as much, while others felt this could interfere with their ability to draw or write and preferred the venipuncture.

Concerns about potential nerve damage were expressed for both venipuncture and finger stick samples. Fear of the use of a 'dirty needle' also emerged, with participants concerned that research participation requiring a blood draw could give them HIV or another infection. They also shared hesitancy about giving a blood sample because they perceived it could be used to test for something else without their knowledge: 'People might be scared, like, if they test them for, like, STDs or AIDS or something with their blood, when they get their blood'. Some participants were also concerned about whether they would physically be able to provide blood in a research study, 'I don't think I would actually have to give blood because pretty much I don't have enough iron in my body'. Or, they wondered if it was possible for 'too much blood' to be taken. Conversation also developed about the possibility for researchers to 'mix up' participants' samples and give false diagnoses or lab results:

> like if they take a test on my blood and they give me the wrong stuff … And I'm like, 'No, I never heard of this'. And they saying this and that. And, um, so I go to the doctor and I tell them … and they check my blood and they saying that you don't have this. 'So who told you you had it?' And they're [the researchers] like, 'Oh, I got your, your thing mixed up. Oh, I'm so sorry' [FG 3, Philadelphia].

Attitudes, beliefs and intentions toward urine samples

Compared to blood samples, fewer participants reported that they would be likely or very likely to provide a urine sample (30%); see Table 3. Nearly one-third (32%) were in the middle about whether it would be easy or hard to provide a urine sample. Nearly half (49%) were 'in the middle' about whether referent others would approve or disapprove of participation in a study that involved collection of urine. The majority, however, believed it would be easy or very easy (51%) to provide a urine specimen.

During the group discussions, however, participants were more in favour of providing urine samples than they reported on the questionnaires. Thus, individual participants had mixed feelings as to the comparable acceptability of urine or other types of samples. Some stated, 'peeing in a cup is better than giving blood because like it doesn't involve pain'. Others noted, they 'always feel uncomfortable urinating in a cup'. Before the research team explained what a urine sample might be used for, most participants assumed the urine would be tested for pregnancy, sexually transmitted infections (STIs) and/or testing for drug use. In multiple focus groups, angst about their parents/guardians receiving the results from their laboratory findings surfaced. Participants also shared how the possibility of parent/guardian and legal system access to their research information could be a barrier toward their participation consent:

> because, like, if they do got something [an STI], like, they [parents] would, you know, like want to know. But they wouldn't want to have to tell they parents [FG 8, Hampton].

> what if it, like, just pop up and the cop, like, just like, pops up, like, and he finds out, like, he sees that somebody's taking drugs [FG 4, Philadelphia].

The participants expressed apprehension about having to see and smell their urine, 'missing the cup' and soiling their hands and not wanting to provide a urine sample if it's their 'time of the month'. Most, however, equated urine specimens with 'peeing in a toilet' and believed it would be easy to do if they were offered gloves and a private location to provide the sample. One participant discussed the research benefits of collecting urine samples:

> urine is like 10-times more advanced than blood because urine actually has the proteins and like all the stuff that's in your body … you can use urine to like even diagnose diseases and stuff. So, I mean, urine has like good information in it [FG 1, Philadelphia].

Attitudes, beliefs and intentions toward saliva samples

As seen in Table 3, 49% reported they would either be likely or very likely to provide a saliva sample. The majority (65%) believed it would be easy or very easy to do. Fifty-one per cent, however, were in the middle as to whether referent others would approve or disapprove of this type of research. More believed that referent others would approve or strongly approve (38%) than disapprove or strongly disapprove (11%).

In the group discussions, no consensus was achieved regarding whether the mouth swab or spitting into a collection container was the preferred method of saliva collection. For example, some participants believed that ‘spitting is disgusting’ and ‘nasty stuff’ and preferred the mouth swab. Others had issues with a swab being placed in their mouths and shared, ‘I don’t want anything in my mouth’ and ‘you can spit in the cup instead of going in your mouth’. Despite the collection method, some were skeptical about the type of information that could be gained from a saliva sample and how it would be used. One participant noted:

> spit is the easiest to give, some people might be gullible because spit doesn’t sound as serious as urine or blood. And if somebody said, ‘Let me get a spit sample’, they’ll just, like, spit on a Petri dish or something. And they don’t know what they just did. So because you feel comfortable doing that, you don’t think anything bad can come from it [FG 5, Hampton].

Attitudes, beliefs and intentions toward genetic research

Nearly half (49%) indicated they would be likely or very likely to provide a genetic sample through saliva (see Table 3). Fifty-nine per cent said it would be easy or very easy to give a genetic sample and many (46%) believed people who are important to them would approve or strongly approve of them participating in this type of study; a large portion (43%), however, were ‘in the middle’ about whether referent others would approve or disapprove.

Participants indicated that genetic research was appealing because they could learn things about themselves or their families. Some even believed that the information could be used to trace their family tree, as one shared, ‘I want to know about my history with my parents’. Suspicion surfaced in groups where participants talked about the implications of DNA in the wrong hands. ‘They could take your DNA and put it out somewhere and get you framed for something’, ‘it makes me think criminal-wise, putting you in the system and stuff’ and ‘they can try to clone you’.

Attitudes and beliefs about participant compensation

When asked what they believed adolescent females should receive for providing blood, urine and/or saliva samples in a research study, a majority of the participants indicated a preference for cash for each activity (97%, 56% and 53%, respectively (see Table 4). Some believed that blood was the only sample that would require compensation because of the pain and effort. As one participant reasoned, ‘your urine, you don’t have to work to get it. You peeing, you get on the toilet every day. You spit or you make saliva every day. You can give them that for free’. Others viewed research participation as altruistic and required minimal compensation, ‘with certain people you have to bribe them or some other people … might be interested because they want to learn more or maybe … it could help your community’.

Most agreed or strongly agreed that the amount of money or other items they would want to receive would vary depending on the amount of time they would have to take out of their day (56%), whether or not they could get hurt or feel pain from participation (57%) or how much of their own money they would have to spend to participate (47%, e.g. transportation). Across venipuncture and finger stick blood draws, urine and saliva for genetics, there was wide variation in how much participants believed biobehavioural research participants should receive. Larger proportions indicated that both blood samples would require the highest compensation (34%, $21–$40) and saliva for genetic testing would require the lowest compensation (38%, $0–$20). In the focus groups, participants were also probed about incremental compensation for multiple study visits. Having the compensation increase over time for multiple sample collections was the preferred structure compared to one time or standing payments. They also discussed cash or pre-loaded credit cards as preferred methods of compensation, ‘I would say a money gift card because, like, you may give someone a certain gift card to a certain place but they probably won’t shop there’.

Recommended strategies for biobehavioural research agendas

‘Pep talks’ from the research team and social support were identified as strategies to help participants feel comfortable if asked to give samples of blood, urine or saliva. Suggestions were made to have mothers or friends attend the data collection visit with them or to participate in the study with peers. Assurance that privacy and confidentiality would be maintained, with the research team and others (i.e. parents/ guardians and police) blinded to laboratory results, were also promoted. The large majority of the participants requested detailed, thorough information (above standard consent language) on what they would be asked to do and how samples would be used. This process is sometimes cumbersome for participants and it was believed that if there was an easy-to-follow guide, in addition to the consent form, the requirements and process could be more easily understood and followed.

> … just taking me through, like, everything, what’s going to happen. Like what we’re using it for, what’s going to happen… Make sure everything’s clean, everything is right; and then I just, that should be, like, that’ll be enough for me [FG 6, Philadelphia].

Others even talked about wanting to know their research results before the rest of the research team:

> Showing me the … information, that they let everybody else see. If it’s, you know, if I feel comfortable with letting everybody else see it. But just basically letting me see it first. Going through everything with me [FG 7, Hampton].

Participants shared strategies for recruiting adolescent females in biobehavioural research. Across the groups, social networking media including ‘Facebook’ was the most commonly suggested recruitment strategy. Word of mouth (i.e. respondent driven and snowball sampling) was also noted to be popular in gaining interest among peers. They believed that hearing about a research study through their social networks would increase participation interest. Further, they suggested that, when applicable, researchers should stress that participants could learn new information about their health or determine if ‘there’s something wrong with them’ through study enrolment. Unprompted, some Black participants discussed racial and ethnic insider–outsider issues and indicated they might not trust ‘a Caucasian person who was trying to just make [them] a statistic’. Participants noted that it was most important to them that researchers were upfront and provided as much detail as possible on expectations and procedures.

Discussion

Before investigators can respond to the call to develop targeted biobehavioural science and human biological studies, they must take a step back to hear the voices of potential participants. These novel findings contribute to the published literature by providing context for the research decisionmaking process, strategies to allay fears and concerns and concrete areas to target in research-related educational interventions. The adolescents viewed biobehavioural research participation as a way to learn about their health; this included favourable (i.e. family heritage) and unfavourable (i.e. disease diagnosis) findings (Long et al., 2011). Thus, mixed feelings emerged about whether or not they should participate in studies involving blood, urine and saliva samples. However, the majority agreed it would be better to enrol and find out additional procedural information (Segal et al., 2004), while there was still time to take action. In these focus groups altruistic motivations also emerged, consistent with the literature (Harel et al., 2003). They also shared that, even if there was no direct benefit, they would still participate to help someone else and possibly ‘save a life’.

A common assumption was that a fear of needles would prevent adolescents from participating in a study that involved blood samples. However, consistent with the TPB, results demonstrated that beliefs or being informed about the research process and knowing how the information would be used could trump adolescents’ fears. Further, some participants reported they would be more likely to give blood samples than urine. Given the sensitive nature of such testing, researchers must be explicit about research that involves urine samples for purposes other than pregnancy, STI or drug testing, clearly stating whether or not those factors will be tested, to assuage concerns.

Consistent with previous studies assessing genetic testing knowledge and health applicability (Catz Ds Fau - Green et al.,), many participants did not have a concept of how genetic information could be used to benefit them and many did have misguided fears related to misuse of genetic data (Harel et al., 2003; Catz Ds Fau - Green et al.,) such as with cloning and possible false criminal implication, therefore it is important to provide a detailed explanation of the procedures to be conducted along with defined outcomes during the consent/assent process. However, according to the adolescents, it is important for researchers to clearly express to participants what will take place over the course of the study, how their information will be used (Harel et al., 2003) and any plans for sharing their samples (whether they are de-identified or not) with other researchers. Although this is standardized in the consent process, the participants want to hear from the primary researchers over the study’s course to ease their concerns. To prevent misconceptions, researchers also need to make sure that participants clearly understand what will—and will not—be learnt as part of the study. If these factors are unspoken, assumptions may be made and can result in disappointment and further mistrust.

Research that involves minors presents unique challenges. In many cases, consent must be obtained from at least one parent or legal guardian. Almost one-fifth of our sample did not live with their mother or father. Thus, researchers working with similar populations may need to navigate through legal, familial and organizational barriers as identified in a review of HIV biobehavioural research (DiClemente et al., 2010). Additionally, when conducting research with adolescents in particular, significant attention should be given to how much, if any, information will be shared with their parents/guardians. As confirmed through the narratives in this study, the adolescents' confidentiality and privacy were highly guarded and important. Research has indicated that many adolescents and parents/guardians have different opinions about requirements surrounding research disclosures to adolescent participants'; parents often want to receive their children's research information, but adolescents may want to withhold private and sensitive findings.

It was discovered that the focus groups served as a source of information for participants. The majority of the participants had never been involved in research and, hence, did not have a frame of reference to understand what it entailed. Through the focus groups they learned these details, which challenged many of their pre-conceived notions. This highlights the need to provide education at the community-level to ensure that individuals can make informed decisions about research participation (Long et al., 2011). Researchers have a responsibility to present the facts about research and conduct ethical investigations while challenging misconceptions. Based on this study's findings and in conjunction with the investigators' youth community advisory board, a biobehavioural research educational brochure was developed to seek to fill this gap in the research process (Authors).

Limitations of this work must be acknowledged. Due to difficulty in co-ordinating participants' focus group availability and small group attendance, the methodology had to expand to include smaller focus groups and interviews. The semi-structured focus group script helped to ensure that each focus group and interview participant was guided in the discussion of standardized topics. However, it must be acknowledged that smaller focus groups and interviews could have affected the flow of ideas during those sessions. Future studies could brainstorm attendance barriers with eligible participants and ask them to identify strategies to overcome those barriers prior to the scheduled group. Although the practice aligns with procedures for implementing the TPB, administration of pre-focus group surveys may have a priming effect, which could shape the subsequent focus group discussion. The findings should be viewed with recognition of this potential bias. The small sample size, alternation between focus groups and interviews and geographical locations of the study activities limit the generalizability of these data. Additionally, the investigators did not collect data on the participants' diagnoses or their level of impairment. This limits the ability to ascertain the applicability of the findings for adolescents with serious mental illnesses or to explore variations in attitudes and beliefs across diagnoses. The findings do, however, provide targeted points to understand attitudes, beliefs and willingness/intentions toward biobehavioural research in urban settings with a predominantly minority population undergoing mental health treatments.

Conclusion

While important to scientific advancement and improved health outcomes, biobehavioural research presents a significant burden to potential participants. A better understanding of attitudes, beliefs and willingness/intentions toward participation in research that involves collection of biological samples is important for study design and participant accrual and retention. Future studies can explore these factors in larger, more representative samples and develop and test programmes to increase research awareness and education.

Acknowledgements

This research was supported by the Distinguished Postdoctoral Fellowship at the University of Pennsylvania awarded to Dr Bridgette M. Brawner and the NIH Award Number T32NR007100, Research on Vulnerable Women, Children and Families from the National Institute of Nursing Research to Drs Volpe, Stewart and Gomes. The authors thank the participants for generously giving of their time to participate in the study. The authors also wish to acknowledge Ehriel Fannin, Kristine Quiambao, Janaiya Reason, Jazz Robinson, Margaret Tait and Danielle Stevenson for their assistance with data collection.

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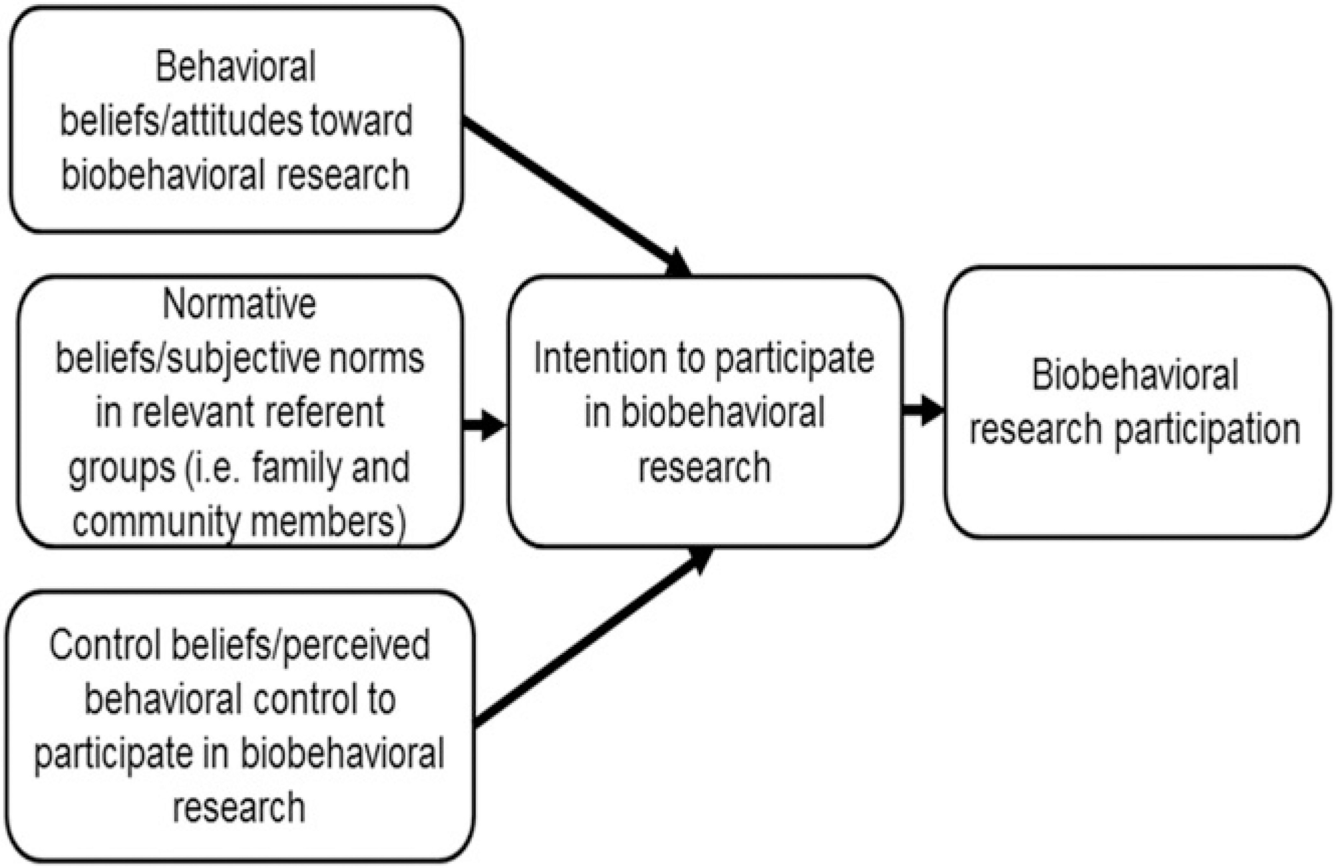

Figure 1.
Theoretical model depicting the relationships among attitudes, beliefs and intentions and biobehavioural research participation.

Table 1

Sample characteristics of focus group participants (*n* = 37).

	M **(SD)**	**% (*n*)**
Age	15 (2)	
Number of adults per household	2 (1)	
Number of children per household	3 (1)	
Race		
Black/African American		73 (27)
Mixed race/ethnicity		24 (9)
Native American		3 (1)
Currently in school		89 (33)
Last grade completed		
Less than 9th grade		22 (2)
9th grade		33 (3)
10th grade		22 (2)
12th grade		22 (2)
Parents/guardians currently married		25 (9)
Parents/guardians ever married		33 (12)
Live with mother and father in same household		9 (3)
Not living with parents		19 (7)
Live with grandmother/grandfather		43 (3)
Live with aunt/uncle or other relative		29 (2)
Live with adoptive/foster parents		29 (2)
Mother work		58 (19)
Mother completed high school		77 (26)
Father work		47 (14)
Father completed high school		35 (12)
Guardian work		85 (11)
Participant work		9 (3)
Ever participated in a research study		
Yes		30 (11)
No		65 (24)
Don’t know		5 (2)

Table 2

Attitudes, beliefs and intentions toward blood samples (*n*= 37).

	Venipuncture	Finger Stick
How likely is it that you would participate in a research study if we had to get blood?		
Very unlikely	19 (7)	14 (5)
Unlikely	19 (7)	14 (5)
In the middle	22 (8)	31 (11)
Likely	30 (11)	28 (10)
Very likely	11 (4)	14 (5)
How easy or hard would it be for you to give blood?		
Very hard	19 (7)	11 (4)
Hard	19 (7)	11 (4)
In the middle	16 (6)	27 (10)
Easy	30 (11)	32 (12)
Very easy	16 (6)	19 (7)
Would most people who are important to you approve or disapprove of you participating in a research study where you had to give blood?		
Disapprove strongly	5 (2)	
Disapprove	19 (7)	
In the middle	41 (15)	
Approve	30 (11)	
Approve strongly	5 (2)	

Values are percentages (*n*). Data were missing from one participant for likelihood to participate, the denominator is 36. Referent other approval or disapproval encompassed both venipuncture and finger stick.

Table 3

Attitudes, beliefs and intentions toward urine, saliva and genetic samples (*n*= 37).

	Urine	**Saliva**	**Genetic**
How likely is it that you would participate in a research study if we had to get …			
Very Unlikely	8 (3)	3 (1)	3 (1)
Unlikely	14 (5)	19 (7)	8 (3)
In the middle	49 (18)	30 (11)	41 (15)
Likely	30 (11)	30 (11)	35 (13)
Very Likely	0	19 (7)	14 (5)
How easy or hard would it be for you to give . . .			
Very hard	3 (1)	3 (1)	5 (2)
Hard	14 (5)	8 (3)	5 (2)
In the middle	32 (12)	24 (9)	30 (11)
Easy	46 (17)	49 (18)	43 (16)
Very easy	5 (2)	16 (6)	16 (6)
Would most people who are important to you approve or disapprove of you participating in a research study where you had to give . . .			
Strongly Disapprove	3 (1)	3 (1)	5 (2)
Disapprove	16 (6)	8 (3)	5 (2)
In the middle	49 (18)	51 (19)	43 (16)
Approve	32 (12)	35 (13)	38 (14)
Strongly Approve	0	3 (1)	8 (3)

Values are percentages (*n*). Questions related to saliva were based on providing the sample via mouth swab.

Table 4

Attitudes and beliefs about participant compensation in biobehavioural research (n= 32).

	Blood		Urine	Saliva for genetics
Type of incentive for giving …				
Cash	97 (31)		56 (18)	53 (17)
Gift card	3 (1)		41 (13)	34 (11)
T-shirt with project logo	0		3 (1)	13 (4)
Amount of compensation to be provided for …	VP	FS		
$0–$20	13 (4)	22 (7)	31 (10)	38 (12)
$21–$40	34 (11)	34 (11)	28 (9)	16 (5)
$41–$60	22 (7)	28 (9)	25 (8)	16 (5)
$61–$80	19 (6)	3 (1)	3 (1)	16 (5)
$81–$100	13 (4)	9 (3)	13 (4)	13 (4)
The incentive offered depends on time taken out of one’s day to participate				
Strongly Disagree	9 (3)			
Disagree	9 (3)			
In the middle	25 (8)			
Agree	47 (15)			
Strongly Agree	9 (3)			
The incentive offered depends on whether or not participant could get hurt or feel pain				
Strongly Disagree	6 (2)			
Disagree	9 (3)			
In the middle	28 (9)			
Agree	38 (12)			
Strongly Agree	19 (6)			
The incentive offered depends on how much would have to be spent to participate				
Strongly Disagree	6 (2)			
Disagree	3 (1)			
In the middle	44 (14)			
Agree	34 (11)			
Strongly Agree	13 (4)			

Values are percentages (n). Items on compensation were added to the study instrument after data collection began, five participants had already completed the study activities and thus the final sample for compensation-related questions was 32. VP, venepuncture; FS, finger stick.