Communication-Focused Technologies for Improving the Health of Young African-American Women

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Final Report

Communication-Focused Technologies for Improving the Health of Young African-American Women

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Preface

This project was funded as an Accelerating Change and Transformation in Organizations and Networks (ACTION) task order contract. ACTION is a 5-year implementation model of field-based research that fosters public–private collaboration in rapid-cycle, applied studies. ACTION promotes innovation in health care delivery by accelerating the development, implementation, diffusion, and uptake of demand-driven and evidence-based products, tools, strategies, and findings. ACTION also develops and diffuses scientific evidence about what does and does not work to improve health care delivery systems. It provides an impressive cadre of delivery-affiliated researchers and sites with a means of testing the application and uptake of research knowledge. With a goal of turning research into practice, ACTION links many of the Nation's largest health care systems with its top health services researchers. For more information about this initiative, go to http://www.ahrq.gov/research/action.htm.

This project was one of three task order contracts awarded under the *Communication-Focused Technologies* request for task order (RFTO). The goal of this RFTO was to develop and test proof-of-concept projects that leverage innovative communication-focused technologies to improve access to care, service quality, or patient safety in ambulatory settings. Of particular interest were projects that made innovative use of communication-based technologies, were person-centered, focused on hard-to-reach populations, and addressed ambulatory care issues.

Structured Abstract

Purpose: To adapt an existing clinical patient education system—the Virtual Patient Advocate (VPA)—to deliver a behavior change intervention about preconception health for young African-American women.

Scope: In the United States, substantial disparities in birth outcomes among racial and ethnic groups remain a major public health concern. Despite efforts to improve prenatal care, in 2005, the infant mortality rate for black women (13.6 per 1,000 live births) was more than double that of white women (5.8 per 1,000).[1] Therefore, prenatal care may be too little, too late. Despite the growing interest in preconception care, there has been only modest progress in translating what is known into clinical practice.

Methods: Focus groups and individual interviews were conducted to inform development. An existing system, called a VPA, was adapted by creating a new character and writing content specific to preconception care. Fifteen pre-testers used the system and completed an interview in our lab; updates were made to the system based on feedback. Nine pilot testers used the system for 2 months. Outcome data was collected at 2 months through telephone interviews.

Results: In the pilot, six out of nine participants used the system at least once. Of those six participants, 128 risks were identified; 67 were discussed with Gabby and participants added 43 to their "My Health To-Do Lists." At followup, participants reported they resolved or took action for 83 percent of the risks added to their lists.

Key Words: preconception; health risk assessment; clinical information technology systems

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Purpose

In response to the Agency for Healthcare Research and Quality's (AHRQ's) ACTION Request for Task Order #7 "Communication-Focused Technologies," this project adapted an existing clinical patient education system—the Virtual Patient Advocate (VPA)—designed to deliver a behavior change intervention about Preconception Health for African-American women (15 to 25 years old) and tested it in a "proof of concept" pilot study.

The specific objectives for this task order are as follows:

1. Design a new VPA, for use in a Web-based behavior change and patient activation system that is informed by qualitative research with the target audience.
2. Develop VPA dialogue for African-American women (15 to 25 years old) to: (a) deliver tailored personalized health promotion; (b) assess 12 domains of preconception risks; and (c) deliver interventions (according to transtheoretical stage) designed for each risk identified.
3. Develop relational database backend and "workstation" interface that will let study clinical personnel enroll new subjects, including demographic information and limited history.
4. Develop report system to accompany the intervention to produce a 'Reproductive Life Plan' for VPA users and a report of health risks for the primary care physician.
5. Develop interface to permit Web-based VPA users to submit personal stories of behavior change to be used with other VPA users. This feature will include administrative review to let study personnel assess submitted stories for appropriateness prior to use.
6. Develop social networking interface to allow users to recommend other users who they think could benefit from the intervention.
7. Develop the Web-based VPA to assess progress of participant's behavior change in identified risk areas.
8. Perform a proof of concept test of this new system to improve the health of African-American women (15 to 25 years old).
9. To analyze the impact of the newly designed system, we will evaluate: (a) enrollment rate; (b) dose of exposure; (c) attrition rate; (d) fidelity; (e) content of communication to PCP; (f) patient satisfaction; (g) qualitative evaluation of the VPA with target users; and (h) assess impact of the new technology on the participants 2 months after enrollment by assessment of knowledge of individual risks and 'stage of change' for identified risks.
10. Modify the system based on user feedback.
11. Disseminate this new technology to at least two other academic medical centers and through presentations at AHRQ, national research meetings, publications in the medical literature, and through the media.

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Scope

Background

Infant mortality has long been considered a measure of a Nation's health and well-being, so leaders in the United States were alarmed in the early 1980's when it was revealed that the country's ranking in infant mortality among developed countries had slipped from 12th in 1960 to 19th in 1980.[2,3] Health and public policy leaders initiated national programs to improve poor pregnancy outcomes, with much of the effort directed towards caring for women during pregnancy and assisting women to enter early prenatal care.[4,5] With the implementation of these initiatives, the percentage of U.S. women accessing early prenatal care and those receiving adequate prenatal care increased, growing from 76.3 to 83.9 percent in 2004.[2]

Yet, the increase in access to and utilization of prenatal care has not eliminated the disparities in birth outcomes between racial groups, especially between blacks and whites. The work of Collins et al. has elevated awareness of the impact of direct effects of racism and class on maternal and child health (MCH) disparities. Their research on racism and birth outcomes found that African-American women who perceived racial discrimination were between 1.9 and 3.2 times more likely to have a very low birth weight preterm infant than those who did not perceive discrimination.[6] This study, along with the work of Rich-Edwards[7] and Rosenberg,[8] helps illuminate the importance of interpersonal and societal racism on birth outcomes and may explain some of the disparities observed between whites and African Americans. Collins' studies on class effects conducted among multiple generations of white and African-American women in Chicago found the risk of low birth-weight (LBW) was 23.6 percent for African Americans who had a lifelong residence in low-income neighborhoods compared to 1.6 percent risk for whites in low-income neighborhoods.[9] The weathering hypothesis described by Geronimus focuses on the "cumulative impact of repeated experience with social, economic, or political exclusion" as a way to explain the disparities in health between white women and African-American women.[10] Recently the "Life Course Perspective," which emphasizes the importance of comprehensive interventions appropriate for all women, has been articulated by Michael Lu and others.[11]

In order to begin to better define and understand the issue of preconception care, in November 2004, the CDC Workgroup on Preconception Health and Health Care launched the Preconception Health and Health Care Initiative, convening a group of national experts—the Select Panel on Preconception Care. The guiding principles, vision, and recommendations for preconception health and health care were published in April 2006.[12] The panel's vision is that all women of childbearing age and all men have high reproductive awareness, all pregnancies are intended and planned, and all women of childbearing age have health coverage and are screened prior to pregnancy for risks related to adverse pregnancy outcomes. The panel's guiding principle called for improving women's health by emphasizing individual behavior and responsibility. In June 2006, the CDC established five implementation workgroups—(1) clinical, (2) public health, (3) consumer, (4) policy and finance, and (5) research and surveillance—to develop strategies for implementing the recommendations. The clinical workgroup (co-chaired by Dr. Jack) completed a 2-year project to define the clinical content best practices for preconception care, which is now the standard used across the United States.[13]

Context

Intervention studies that deliver timely, comprehensive and expanded *prenatal care* have not been shown to improve persistent disparities in PTB and LBW.[14–16] While interventions consisting of augmented, comprehensive prenatal care that focused on risk awareness and behavior improvement showed improvement in patient satisfaction and risk knowledge, they did little to improve birth outcomes. In a study by Klerman et al., there were no significant differences in outcomes related to birth weight, gestational age, child health status, or maternal health status.[14] Thus, it is possible that prenatal care is indeed too little too late and that comprehensive interventions beginning before pregnancy are needed. Many women enter pregnancy at risk for poor pregnancy outcomes because of preexisting medical conditions or exposures to teratogenic factors, or because proper, scientifically based preventive action (such as folic acid supplementation) has not been taken to prevent adverse pregnancy outcomes.[17,18] Moreover, millions of women remain at risk for unintended pregnancy. If we want to achieve improvements in maternal and infant pregnancy outcomes, we must act before pregnancy using a paradigm of "prevention and health promotion" before pregnancy and throughout a woman's lifespan.[3,5,19–31]

Despite this broad interest in preconception care, there has been only modest progress in implementing these concepts into clinical practice and developing research studies to translate what is known into clinical practice. Existing research indicates that most women realize the importance of optimizing their health before pregnancy, whether or not the pregnancy is planned,[32] and that most physicians think preconception care is important;[33] however, most providers do not routinely recommend or provide preconception care to their patients.[34] One RCT found that, even when given specific training, physicians failed to take action on risks identified at the time of a negative pregnancy test.[35,36] National surveys indicate that 84 percent of women, 18-44 years of age, have had a health care visit during the past year, and that most women of reproductive age obtain preventive health services any given year, all offering opportunities to deliver preconception care.[37] However, only about one in six obstetricians/gynecologists or family physicians provide preconception care to the majority of the women for whom they provide prenatal care.[37]

Incidence

In the United States, substantial disparities in birth outcomes among racial and ethnic groups remain a major public health concern, despite over 30 years of research and policy work in this area. As of 2005, the infant mortality rate for black women (13.6 per 1,000 live births) was more than double that of white women (5.8 per 1,000).[1] While the United States has pushed forward advances in medical technology, the gap between whites and non-whites in birth outcomes continues to widen. LBW due to pre-term delivery (PTD) and intrauterine growth restriction is a leading contributor to both infant mortality and childhood physical and developmental problems and their resulting health care costs. Black women are approximately twice as likely to deliver a LBW infant as white women (14 percent and 7.3 percent, respectively).[1]

Methods

Study Design

Qualitative Work

Predevelopment qualitative work included focus groups and individual interviews. Leanne Yinusa-Nyahkoon, M.S., Sc.D., conducted focus groups of the target population—African-American women ages 15-21. For later phases of the project the target audience was extended to ages 15-25. Focus group participants were recruited from the local Boston community, through flyers distributed in local stores and restaurants and advertisements in Boston's *Metro* newspaper, college employment centers, Craigslist, and word-of-mouth from participants themselves. Participants contacted the program manager via telephone, at which point the study was explained to them and they were screened for eligibility. We enrolled 31 focus group participants and conducted eight focus groups, with no more than eight participants per session. Participants were also invited to schedule an individual interview with another qualitative researcher on our staff, in order to conduct a more in-depth discussion about attitudes towards family planning, pregnancy, unintended pregnancy, and interactions with providers.

Development

First, based on work previously done by the investigators,[35,36] as well as information from qualitative work (focus groups and key informant interviews), the research team developed the content for: (1) a personalized and comprehensive Online Risk Assessment Tool of Preconception Risks (Appendix A); (2) scripts with culturally appropriate health promotion and behavior change messages; and (3) a library of stories to pre-populate the system, to later be expanded upon with participant-generated stories. The evidence-base for the content was from the work of the clinical workgroup of the CDC's Select Panel of Preconception Care, recently published in 2008 as a supplement to the *American Journal of Obstetrics and Gynecology*. Second, the research team outlined the text for the supporting framework of the system, such as for the Stages of Change assessment, response buttons (for participants to click in response to Gabby), and the "My Health To-Do List."

Dr. Bickmore and his team at Northeastern were responsible for the programming of all components of the system and the VPA using the preconception care content and scripts developed by the Boston University Medical Center (BUMC) team. Both teams met weekly as the working group to discuss the scripting and programming of the VPA system, which we refer to as the "Gabby system."

Pretesting

Following the first round of development of the system, we enrolled fifteen participants (who met the enrollment criteria described in the Participants section below) to come to our research lab. We recruited participants through flyers posted in clinics at Boston Medical Center (BMC), a registry of BMC patients who are interested in participating in research (the ReSPECT Registry), and via referrals from past focus group participants.

During each 90-minute session, each participant completed the Online Risk Assessment Tool, heard about approximately six health risks from Gabby, then filled out a quantitative survey about her reactions to the system and participated in a qualitative interview with one of the our researchers for approximately 30 minutes. Of the 15 participants, 11 heard about their own personal health risks, based on their answers to the Online Risk Assessment Tool. The first four participants heard about common, pre-selected risks, as programming was not complete and the risk assessment was not yet linked to the scripts.

Pilot Testing

We enrolled nine pilot-testing participants through the Office of Minority Health's (OMH) Preconception Peer Educator (PPE) training at Northeastern University in February 2011. The initial study design called for 50 pilot-testing participants, but this number was reduced due to Office of Management and Budget (OMB) guidelines. All trainees in the PPE program were informed of the opportunity to participate in the study prior to the start of the training, and invited to attend an extra half-day event for enrollment and introduction to the Gabby system. BUMC investigators screened for eligibility and obtained consent; once the consent form was signed, investigators collected basic demographic and contact information. Participants were each given a username and password to log in securely to the Gabby system. During the session, each participant logged on, completed the Online Risk Assessment Tool, and then completed a demo version of the Gabby system. We did not have participants listen to their own personal health risks during the training session, as this would put their privacy at risk. The demo version provided them with the opportunity to learn how to use the different functions of the system, such as the story-authoring tool, before using the system from home. All participants were given an instruction sheet with contact information of the Program Manager, to use if they had any questions about the system during the 2 months of the pilot.

At 2 months after enrollment, investigators contacted each participant via email to schedule a time for a 30 minute follow-up phone call. Investigators then called each participant at the scheduled time and conducted the interview using the 2-Month Follow-Up Telephone Interview Guide.

Participants

All participants for the four phases of this project—focus groups, individual interviews, pretesting and pilot-testing—were enrolled at BMC, colleges and universities in Boston, or from advertisements in Boston stores or from the *Metro* newspaper, which is a popular newspaper for individuals using public transportation in Boston. Specific recruitment methods and differences in enrollment criteria for each phase are described below.

Focus Groups

There were 34 participants in the focus groups; all were female, self-identified as African American or Black, between the ages of 15-21, spoke English and were self-reported not pregnant at the time of enrollment in the focus group. Responses from the Focus Group Questionnaire showed that 84 percent were enrolled at a college or university, 87 percent have an assigned primary care physician, 71 percent reported using the Internet five or more times a day,

84 percent have access to the Internet via a home computer or laptop, and 61 percent have access to the Internet via a cell phone.

Individual Interviews

There were 15 participants for the individual interviews, who were recruited through the focus groups or by word of mouth. All self-identified as African American or Black, were between the ages of 18 and 25 and spoke English. A focus of the individual interviews was the topic of unintended pregnancy; therefore, we chose to enroll women ages 18-25, as this age group has the highest risk for unintended pregnancy.

Pretesting

We enrolled 15 Pretesting participants, who were all female, self-identified as African American or Black, between the ages of 15-25 (average age was 20 years), spoke English and were self-reported not pregnant at the time of enrollment for Pretesting.

Pilot Testing

We enrolled nine pilot-testing participants, who were all female, between the ages of 15 and 25, spoke English and were self-reported not pregnant on the day of enrollment for pilot testing. We enrolled pilot testing participants through the Office of Minority Health's Preconception Peer Educator program (PPE), at a training session held at Northeastern University. Due to the demographics of that particular training site, we were not able to limit our enrollment to only African American or Black participants, and opened up enrollment to young women of all races and ethnicities, who met the other enrollment criteria.

Data Sources/Collection

Data Collection 1, Focus Groups

It is important to determine if the IT system is accepted by participants. Assessment included qualitative evaluation with potential users, conducted by Dr. Leanne Yinusa-Nyahkoon. Group interviews are particularly useful for adolescents and young adults as they are more inclined to engage in conversations about sensitive topics when they are joined by their peers. Also, their conversation reveals common language used to discuss the issue and provides insight into the group's acceptance of or sensitivity to the issue and its sub-topics. Focus groups contained no more than eight participants and were held in a private room at Boston Medical Center. Focus groups were facilitated by an African-American, female investigator because it is easiest to establish an effective interviewing relationship when participants and investigators share demographic characteristics. Dr. Yinusa-Nyahkoon facilitated using a semi-structured interview guide.

All focus groups were audio recorded and transcribed by a professional transcription agency. BUMC investigators reviewed the transcripts to remove any identifiable information. Then, Dr. Yinusa-Nyahkoon and other BUMC qualitative team members coded the transcripts, to ensure

trustworthiness and credibility of the findings. After all of the focus groups were completed, data analysis transitioned to organizing codes into specific categories. Then, in-depth comparison analysis across categories identified common themes emerging from the focus group data. During this stage of data analysis, participant quotes and supporting evidence from focus group transcripts were reviewed with research team members to corroborate analytic categories and emerging themes. These categories and themes were shared with the technical team and integrated into the content and design of the Web-based educational program.

Data Collection 2, Key Informant Individual Interviews

We employed a purposeful sampling method and selected homogenous participants who were all young Black women. Young women were also recruited using snowball sampling techniques, with enrolled participants recommending other potential candidates for the study. Participants were recruited primarily through focus groups.

Research staff transcribed all interviews verbatim and analyzed the data using qualitative analytic techniques informed by grounded theory. Qualitative methods allowed for themes to emerge and understanding of these young women's conceptualization of pregnancy prevention and experiences in receiving family planning care. These research questions were well suited for qualitative methods, given the goal of understanding the patients' perceptions of pregnancy, use of contraception and their interaction with providers to further develop theories about how patient-provider interaction are associated with patient health behavior and outcomes and create tailored, effective interventions. Given the dearth of research in this area, this study was necessarily exploratory and thus a design that allowed participants' views to emerge about these concepts was ideal. Qualitative analysis was facilitated by using HyperResearch software (ResearchWare, Inc., MA, version 2.8.3).

Data Collection 3, Pretesting Data

Pretesting participants were the first to use the complete Gabby system; in addition to providing valuable data about the usability of the system (i.e., the length of time it takes, on average, for a participant to complete the Online Risk Assessment Tool), each participant filled out a quantitative questionnaire about the system and took part in a one-on-one interview with a BUMC qualitative investigator, which took approximately 30 minutes.

Data Collection 4, Pilot Testing Intake Data

At enrollment, we collected basic demographic data and contact information from each pilot-testing participant. Then, similarly to the pretesting phase, pilot testers completed a session with Gabby, including the Online Risk Assessment Tool, and filled out a quantitative survey about their experiences.

Data Collection 5, Pilot Testing Outcome Data

Outcome data was collected at 2 months after enrollment via a telephone interview that took approximately 30 minutes. Assessment variables include—

1. Enrollment rate in the study
2. Dose of exposure
3. Attrition
4. Fidelity of exposure
5. Participant satisfaction with the VPA
6. Participant satisfaction with the virtual social networking function, to be measured quantitatively at an exit interview with questions relating to the personal change narratives authoring tool and the experience of hearing other participants' narratives
7. Evaluation of the virtual social network function by examining the number and content of personal change narratives participants have added to the system.

In addition, at 2 months we reassessed each risk that was on each participant's original list of preconception health topics, by checking to see if it was still a risk, if any progress had been made, or if the risk had been resolved. We reassessed the participant's stage of change for that risk, to compare to the stage identified 2 months prior.

Interventions

Pretesting and pilot testing participants received the intervention, which includes the Online Risk Assessment Tool and the Gabby system: health information, "My Health To-Do List," and stories.

Online Risk Assessment Tool. Using the recommendations from the *American Journal of Obstetrics and Gynecology* (AJOG) supplement on preconception care,[12] as well as screening tools previously developed by the principal investigator,[35,36] we developed an online preconception risk assessment that covers over 100 health risks in twelve domains of preconception health (Appendix A). The Online Risk Assessment Tool is self-administered; based on pretesting and pilot-testing data, it takes approximately 12 minutes to complete, on average.

Gabby System. Research team members developed "scripts" so that Gabby can discuss each preconception health risk. The content is based on the recommendations from the AJOG supplement.[13] Young women using the system can choose to hear information under the headings of: "What is it?," "Why does it matter to me?," and "Why does it matter for pregnancy?" The information is written at a sixth- to eighth-grade reading level; users can also have Gabby repeat each segment of "script" as many times as necessary to aid with comprehension. Each participant is presented with her list of risks identified from the Online Risk Assessment Tool, and then has the opportunity to hear Gabby share information about each topic, in the order they are presented in the list; the order was based on rankings given in the AJOG Supplement.[13] After listening to all or some of the information (or after deciding not to listen to any information) the participant can choose whether or not to add the risk to her "My Health To-Do List." If she decides to add it to her list, she can also select an action to take to help her resolve the risk. At different points in the interaction, Gabby offers stories from other users and asks the participant if she would like to leave her own story. When participants log online for later sessions, Gabby reviews the "My Health To-Do List," at which point participants can check off the tasks that they have completed. Gabby encourages participants to share the "My Health To-Do List" with family, friends, and health care providers in order to get the help and support needed to resolve the health risks.

Measures

Focus Groups. We collected demographic data and had focus group participants answer questions about their perception of health care and use of the Internet. The focus group moderator used a semi-structured interview guide. All focus groups were professionally transcribed, and members of the research team coded the transcripts and created a coding dictionary.

Individual Interviews. The interviewer followed an interview guide and recorded each interview. Research staff transcribed each interview verbatim, first by reading and re-reading transcripts as a whole, several times prior to coding. Coding started with a line-by-line approach and created codes that conceptually matched the data. Next, staff engaged in axial coding to sort and classify codes into major themes throughout the narratives and analyze relationships among themes to identify larger concepts. Within these concepts, they grouped lower level themes accordingly.

Pretesting. Participants in the pretesting phase completed the Online Risk Assessment Tool (Appendix A) and tested all aspects of the Gabby system, including: listening to informational scripts, creating a "My Health-To Do List," listening to existing stories, and writing personal stories. Each participant then filled out a questionnaire to measure her opinions on the Online Risk Assessment Tool, the character "Gabby," the information provided by Gabby, the "My Health To-Do List," stories, and the story-authoring process. Research staff completed the "Health Topic Sheet," recording each health risk that appeared on the participants' list of risks to discuss, and participants filled out the chart about their current attitude toward each risk: for example, whether they believe it is a risk and whether they have ever talked to a doctor about it before. Finally, pretesting participants completed a 30-minute one-on-one interview with a member of the research team; each interview was audio recorded and transcribed verbatim by a member of the research team, and were coded following the same protocol as focus groups transcripts.

Pilot Testing. Research staff completed an eligibility form for each participant, and collected basic demographic information and contact information. Participants then completed the Online Risk Assessment Tool (Appendix A), completed a demonstration of the Gabby system, and filled out the same survey as was used in pretesting. During the next 2 months, participants were able to log on to the Gabby system; the system sent reminder emails each week to participants who hadn't logged in for a week or more. After 2 months, a member of the research team called each participant and completed the Telephone Follow-up Assessment: 2-Months Post-Enrollment and the Identified Risks Chart.

Limitations

A significant limitation to our results is the sample of the pilot-testing phase. Due to restrictions in recruitment levels set by the Office of Management and Budgets (OMB), we were limited to nine pilot-testing participants. Therefore, our sample size is limited and data from these nine participants is difficult to analyze. Additionally, only six participants used the system from home, and only seven completed the 2-month follow-up phone call. Our enrollment population pool at the Preconception Peer Educator (PPE) program had very few African-

American women; this was not expected as most PPE training sites have a very high percentage of African-American attendants. Therefore, we had to expand our enrollment criteria to include all races and ethnicities; we enrolled one African-American, five Caucasian, and three Asian participants for the pilot-testing phase. We believe that, as a pilot study, the sample still provided valuable insight into the usability of the system and the data and feedback will help us improve upon the system for future projects. Pilot testers were the first group to use the system from home, and over an extended period of time; we were able to learn about how to address technical issues such as password problems and server downtime. During the 2-month pilot, six out of nine participants sent the Program Manager an email with questions about access or to report programming issues with the system, which we were able to address promptly with programming fixes. However, participants during all phases of *development* of the system (focus groups, individual interviews, and pretesting) self-identified as African American. Their feedback and ideas informed all development decisions for the Gabby system; therefore, the Gabby system has been designed for young African-American women and future studies will exclusively target that audience.

Another limitation is that all of the health information collected from each participant is self-reported; participants could have inaccurately reported their health risks and behaviors because of a lack of knowledge or because they did not feel comfortable sharing their health information with the computer or with the researcher during the 2-month follow-up phone call. In the future, a validation study, comparing responses given to the Online Risk Assessment Tool to those given to a trained interviewer, and then comparing to medical charts, would demonstrate the accuracy of the Online Risk Assessment Tool.

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Results

Principal Findings

Focus Groups

Participants provided recommendations for Gabby's name and physical appearance. These recommendations confirm a previous research finding that African Americans prefer a VPA who is their same race and gender.[38] Focus group findings confirmed that our Web-based system is a familiar and viable method for delivering a health risk assessment and interventions, as focus group participants all reported to have Internet access via their home computer/laptop, smartphone, or both, and described accessing the Internet an average of 6 times per day.

Early focus groups focused on the development of the VPA character. The focus group moderator presented participants with a series of six characters and asked them to discuss which character they would want to deliver personal health information. Participants told us that they want someone they can relate to; after viewing one character who looked older than our target audience, a participant said, "It looks like Michelle Obama. We don't want Michelle Obama. Not if we're going to relate to her for this. Not for these purposes." Participants ultimately decided on the character we have chosen, who is female, African American, and looks young; later focus groups decided upon the name "Gabby."

Participants provided valuable feedback about the health risk assessment, health promotional messages, storytelling function, and "My Health To-Do List" components of the system. For example, participants reported that the wording used throughout the risk assessment was understandable, but suggested that a function that allowed users to complete the questionnaire in multiple sessions and visually monitor their progress completing the questionnaire would improve usability. Participants edited educational messages the system provides about 12 clinical domains related to preconception care (Appendix A), and made specific recommendations to improve the language, length, and content of these scripts. For example, participants communicated that when Gabby makes a recommendation to help address a health issue, she should present the pros and cons of that action, so that the user will be able to make an informed decision.

The story-authoring tool and example stories were a priority in focus group discussions. Participants also suggested various authoring methods, writing supports, and reader approval mechanisms to facilitate simplicity and encourage use of the storytelling feature of the system. They also gave specific advice on how stories should be written; they agreed that stories should be in the first person, should avoid slang or negative language, and should include a lot of contextual details and a realistic ending.

Finally, participants designed a user-friendly format of the "My Health To-Do-List," featuring a simple design with boxes to check off each task and an option to print or to keep it online. A sample of direct participant quotes, illustrating their suggestions and feedback, is in the box below.

Table 1. Focus group participant quotations

Relationship with Health Care Provider
"My primary care physician never asks about psycho-social stuff. It's all like medical stuff. But with my gynecologist, she's the one to always ask, so are you with the same partner as last time? How is school? Like stuff like that." *(Focus Group #2, Line 372)*
"Yeah, I think I kind of lie to my doctor sometimes. I don't want him to judge me, because he'll be like, 'Oh, how sexually active are you? Or how much do you drink?' It's like, 'Well, um. Not at all, or I don't really do anything.' Because it's like an awkward-- because what if my mom finds out or the doctor-- because like me and my mom share the same doctor so what if the doctor's like, 'Oh by the way, your daughter blah, blah, blah, did this, this and that.' Yeah, I wouldn't." *(Focus Group #3, Line 2319)*
"My Health To-Do List"
"It ["My Health To-Do List"] should just kind of be like an outline of things that we should discuss with your doctor. Because sometimes you'll start talking about one thing, and you'll keep going on and on about it. You might forget about other things that should be addressed." *(Focus Group #2, Line 1717)*
"I would [print the "My Health To-Do List"] maybe if it was like the night before I'm going to the doctor. But if it was like a month before, I'd forget." (*Focus Group #2, Line 1750*)
"Yeah, I actually think that would be really helpful now that I think about it. Because I'm always sitting in the office, like, "I know there's something else I need to talk about." But they just make me feel so pressured and rushed, that something like that would actually be nice." *(Focus Group #2, Line 1836)*
Privacy/Access
"I feel like it should be available at home too where I can access it if I'm just sitting on the couch or something. Just because I don't know if I would really want to talk about all of that just standing in a doctor's office. Because I would feel like, are other people listening?" *(Focus Group #2, Line 1728)*
Technology
"I would like [a daily health reminder] electronic because everything is going green now. I'd rather [pause] when I set appointments, I don't do it in a planner, I do it on my computer, like on a calendar on my computer. So an e-book, like an e-online thing would be great. And our generation is so about being green." *(Focus Group #3, Line 2691)*
Advice for Content
"I don't like people telling me what to do. With me, when people tell me to do something, I do the opposite, just because. So, if they just give me ideas, they're going to be in the back of my head. And, I'll think about them. And, chances are, I might do them." *(Focus Group #4, Line 399)*
"You know what I think? I think that list that you gave us right there, with all the 12 different topics, I think if those are the 12 most important ones, then the doctor should give you those 12, like you're doing right now, and go through them one-by-one. Because I think all of them really need to be touched on." *(Focus Group #4, Line 500)*

Individual Interviews

Participants discussed topics salient to them in the context of family planning: sexual responsibility/self-efficacy in pregnancy prevention and the role of health care providers. Throughout their narratives, women constructed themselves as responsible actors in control of their contraceptive decisionmaking and practices. Many viewed their life plan, to finish school and gain financial stability, as crucial to their resolve to use contraception. Some noted that friends had intended pregnancies, as a result of being lonely, without other goals or opportunities or in accordance with a new social trend. The majority maintained a sense of pride in not being pregnant, and believed others who did get pregnant were lazy and irresponsible for not using contraception. Most had limited expectations of providers and considered in–depth conversations about sexual behavior or details of contraceptive use to be unnecessary. However, several

participants described their interaction with providers as positive and helpful, as opposed to others who described not trusting doctors.

Participants valued contraceptive information from different sources for distinct reasons. Information from health care providers was perceived as personalized to patients' specific context and a credible source of information. In addition, the Internet was valued because of its convenience, speed, and anonymity. Information from both sources allowed for exposure to multiple perspectives and the ability to validate information gained. These young women generally requested Web site information to help them making an informed decision as to the most appropriate method for their situation. They requested information about who was taking certain birth control methods, what are their options, side effects and efficacy, where one could obtain contraceptives, and how each method functioned.

Table 2. Individual interview participant quotations*

Perceptions of Pregnancy and Parenthood   "Well, these days you never know what these girls want to do….I think like having babies is a new handbag. Everybody is doing it." (Shonelle, age 20).   "I feel like, as a person who's about to be 21 years old, I got a lot of these girls beat because I haven't had a kid yet. But I feel like I do. I don't feel like, I don't know, like certain girls I think they might be out here to get pregnant-there's a lot of us who are not." (Shonelle, age 20)   "I think that majority of the youth my age or females I should say, they don't want to get pregnant. They want to go to college, get an education, get be successful in life before they start a family. Like a lot of people I know we want to get married before we have kids and have our kids at a decent age where we're like stable in life." (Dena, age 18)
Opinions of Health Care System   "I guess to some degree I don't completely trust doctors….Yeah I don't like taking medicine and I'm afraid of needles and I guess I'm just afraid of getting treated for something that I don't really need…..I think like my view of doctors is heavily influenced by my family and that's where the cultural aspect comes in…it's just that we're all from Haiti. And in Haiti you only go to the doctor if something's wrong with you. Or at least from our neighborhood, you only go if something's wrong with you not like for regular checkups and what not." (Michelle, age 20)
Relationship with Health Care Provider   "I think that would be helpful for a lot of people because a lot of people don't want to tell their doctor or ask their doctor questions but they'll sit there and ask somebody that doesn't know them at all….Some people don't know how to make it come out right. And some people just I don't know they don't – they just don't want to talk about it. And it's like for me when I'm like texting or like talking online or something like that it's so much easier asking them a question online. But for me to actually ask somebody face to face if I'm not comfortable with them I won't ask them. And a lot of it too is so that they won't be judged." (Sasha, age 22)   "She (nurse practitioner) basically asked me like what's my relationship like and I told her I was with the same person for 5 years so she assumed like oh I'm taking care of myself. And she asked me have I ever been pregnant before and I was like 'no'. So. And anytime that I go there she asked me oh do I need a refill or anything like that but nothing too serious." (Joanne, age 21)
Health Technology   "I feel like convenience is always the best policy with things like that. I think they'd rather use a Website. Because it's all about the convenience…I know the convenience would be the biggest thing. Because like students and young adults they just like want everything to go- like 'can I just find it out myself and do it that way' instead of waiting and waiting. We're the impatient generation." (Monica, age 20)   "I'm one of those people who'll do things on my own. So I'll just go on WebMD and I'll look for all the um warning signs. You know mostly with doctors they'll just give you a pamphlet which basically says the same thing as when you look up something from the Internet so. And so I did. Just to be able to identify it when I see it." (Jaime, age 18)

*all names are pseudonyms

Pretesting

Participants tested the Gabby system by taking the Online Risk Assessment Tool, listening to informational scripts provided by Gabby, and hearing stories and authoring their own stories. We collected quantitative data with the Pretesting Questionnaire (data in Appendix B), with questions mostly on a seven-point scale. Key findings include that: (1) For the Online Risk Assessment Tool, the majority of participants felt that it was useful (80 percent), easy to complete (90 percent), and took an appropriate amount of time (67 percent); (2) In regards to the character Gabby, 80 percent of participants felt that it was easy to talk to Gabby; 73 percent trust Gabby, and 87 percent felt comfortable telling Gabby everything about their health; 80 percent would use health information from Gabby to improve their health, and 87 percent felt that Gabby did a good job answering their questions; 73 percent felt that the session with Gabby was just the right length; (3) 80 percent of participants reported that they would use their My Health To-Do List; and (4) 67 percent indicated that they would write their own stories from home if they could continue using the system. Average scores from the PCC Pretesting Survey can be found in Table 1. In addition to survey findings, it was significant to learn that pre-testers took less than 12.5 minutes to complete the Online Risk Assessment Tool on average, and that the average number of health risks identified per participant was almost 23.

Table 3. Pretesting quantitative feedback, n=15

Questions	Average Score	Scale
1. How useful was the health survey that you took at the beginning?	2.60	Very Useful = 1, Not Useful At All = 7
2. How easy or difficult where the questions to answer?	1.87	Easy = 1, Difficult = 7
3. Did you feel that the health survey was (too short…just right…too long)?	4.13	Too short = 1, Just Right = 4, Too Long = 7
4. To see if your health risks have changed, would you be willing to take the health survey in:	2.36	1="A month" , 2= "3 months," 3 = "6 months," 4 = "A year or more," 5= "Never
5. How easy was it to talk with Gabby?	2.40	Easy = 1, Difficult = 7
6. How much do you trust Gabby?	2.93	Very Much = 1, Not At All = 7
7. Did you feel your session with Gabby was (too short...just right...too long)?	4.27	Too Short = 1, Just Right = 4, Too Long = 7
8. Do you think that you will use some of the information from Gabby to improve your health?	2.40	Definitely Yes = 1, Definitely No = 7
9. Please answer "Yes" or "No" to this statement: "There are some things about my health that I did not feel comfortable telling Gabby."	0.13	1=Yes, 0=No
10. How well did Gabby answer any questions that you had?	2.67	Very Well = 1, Not At All = 7
11. To what degree would you rather have talked to a doctor or nurse than Gabby?	3.93	Definitely Doctor or Nurse = 1, Definitely Gabby = 7
12. Would you like to interact with Gabby again?	2.80	Definitely Yes = 1, Definitely No = 7
13. Would you recommend Gabby and the computer system to someone you know?	0.92	1=Yes, 0=No
14. Do you think that you will use your "My Health To-Do List?"	2.67	Definitely Yes = 1, Definitely No = 7
15. How helpful was the story (or stories) that you heard?	4.00	Very Helpful = 1, Not At All Helpful = 7
16. If you were using the computer system from home, would you share your stories with Gabby?	3.13	Definitely Yes = 1, Definitely No = 7
Minutes to Complete Online Questionnaire	12.33	
Number of Risks Identified	22.91	

After testing the system, each participant also completed a one-on-one interview with a member of the research team, using a semistructured interview guide. Participants were given the opportunity to share their overall reaction to the system and Gabby, and to answer specific questions about usability, accessibility, and functionality of individual system components (i.e., "My Health To-Do List," story-authoring interface). The overall reaction to the system was positive; most participants indicated that they liked and could see themselves using at least certain components of the system. Although some would have liked to also have text to read while Gabby was talking, most enjoyed listening without needing to read. Almost all participants thought that the Online Risk Assessment Tool was easy to take and an appropriate length. When asked whether they would prefer to talk to Gabby or talk to a doctor, the response was mixed: some favored Gabby, for the anonymity, lack of embarrassment, and convenience. Others did not think that Gabby could give them enough in-depth, personalized information. However, many viewed Gabby as a valuable addition to their doctor's visits, either as a way to prepare for an appointment, or a way to review and reinforce the information after an appointment. Two participants believed that the Gabby system would be a helpful tool for middle school or high school students, as a more personalized, private alternative to health classes taught in school.

The concept of the "My Health To-Do List" was familiar and well received; most participants said that they make to-do lists for themselves, and like that Gabby compiles a list throughout the interactions. Preference for how to use the "My Health To-Do List" was mixed between those who would prefer to print it out and other who would want to only access it on-line. Of those who would print it out, some would give the list to their health care provider directly, while others would keep the list as a reminder of topics to bring up during the appointment. Overall, the discussion about the "My Health To-Do List" indicates that young women need options so that they can use the tool in a way that works for them.

Pilot Testing

At intake, participants took the Online Risk Assessment Tool; on average, it took them just over eleven minutes to complete and it identified 21.44 risks per participant. They were given access to the Gabby system for 2 months, with a unique username and password. A similar quantitative survey to the one used in pretesting was used both at intake and 2 months; the results from both points of measurement are in Table 2, below. Highlights include that, on average, participants reported it was easier to talk to Gabby after the 2 months than it was at intake (2.33 at 2 months and 3.11 at intake, where 1= Easy and 7= Difficult), but that participants thought that the stories were not as helpful when asked at 2 months (5.33 at 2 months and 4.57 at intake, were 1= Very Helpful and 7 = Not At All Helpful) (table below and charts in Appendix C).

Table 4. Pilot testing quantitative feedback; mean scores reported at intake and followup

Question (Scale 1-7)	Scale	Pilot Testing Intake	Pilot Testing 2 Months	n at 2 months
1. How easy was it to talk with Gabby?	1=Easy, 7= Difficult	3.11	2.33	n=6
2. How much do you trust Gabby?	1= Very Much, 7= Not At All	2.78	3.5	n=6
3. Did you feel your session with Gabby was (too short...just right...too long)?	1= Too Short, 4 = Just Right, 7= Too Long	4.44	4	n=6
4. How well did Gabby answer any questions that you had?	1= Very Well, 7= Not At All	3.43	4.17	n=6
5. To what degree would you rather have talked to a doctor or nurse than Gabby?	1= Definitely Doctor/Nurse, 7= Definitely Gabby	3.33	3.5	n=7
6. Would you like to interact with Gabby again?	1= Definitely Yes, 7= Definitely No	2.78	3.5	n=6
7. Do you think you will use your "My Health To-Do List"?	1= Definitely Yes, 7= Definitely No	2	N/A	N/A
8. How helpful were the stories that you heard?	1= Very Helpful, 7= Not At All Helpful	4.57	5.33	n=6
9. Where there any other topics that you wish you could have heard stories about?	1= Definitely Yes, 7= Definitely No	N/A	6.83	n=6
10. If you were using the computer system from home, would you share any stories with Gabby?	1= Definitely Yes, 7= Definitely No	2.89	N/A	N/A
11. Do you think you will use some of the information from Gabby to improve your health?	1= Definitely Yes, 7= Definitely No	2.56	N/A	N/A

During the 2-month pilot, six out of the nine pilot testing participants logged in to the Gabby system at least once. For those six participants, there were a total of 63 sessions during the 2-month trial, an average of seven sessions per user and maximum of 18 sessions. The average session lasted 12 minutes, with a range from 2 to 32 minutes. Two participants reviewed all of their risks; on average, each participant who logged in to the system as least once reviewed 11 risks. There were 128 total risks identified; 67 were discussed with Gabby (53 percent). Of the 67 risks discussed, participants chose to add 43 to their "My Health To-Do List," which is an average of 7.2 risks per participant. At the 2-month follow-up phone call, when asked about the risks that were added to the "My Health To-Do List," participants reported that 83 percent were either resolved or the participant had taken some action towards resolving them.

Risks Identified by Domain - Pretesting and Pilot Testing Combined

Identified risks (n=449) were distributed across the twelve domains as shown in Figure 1 below. Nutrition accounted for the most risks, at 113 (26 percent), followed by Infectious Diseases at 94 (21 percent). Forty-two genetic risks were identified (8 percent) and 38 risks (8 percent) in the Environmental Domain. Reproductive History, Immunizations, and Chronic Health Conditions and Medications all accounted for approximately 6 percent of the risks identified. Healthcare Access and Programs, Emotional and Mental Health, and Illicit Substances followed at 4 percent. Finally, Men and Healthcare, and Relationships each made up 3 percent of the total risks. The frequency of specific risks identified is listed in Table 5.

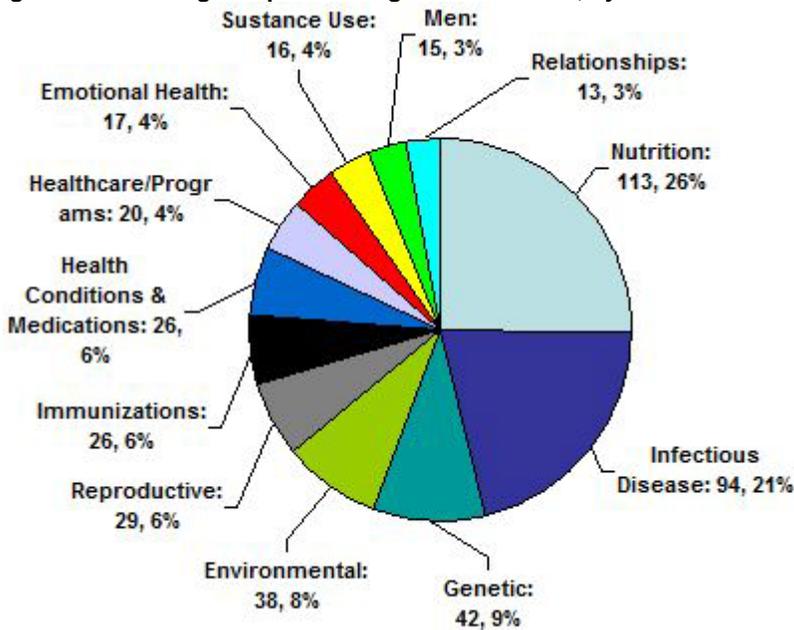**Figure 1. Pretesting and pilot testing risks identified, by domain**

Pie chart showing:
- Nutrition: 113, 26%
- Infectious Disease: 94, 21%
- Genetic: 42, 9%
- Environmental: 38, 8%
- Reproductive: 29, 6%
- Immunizations: 26, 6%
- Health Conditions & Medications: 26, 6%
- Healthcare/Programs: 20, 4%
- Emotional Health: 17, 4%
- Substance Use: 16, 4%
- Men: 15, 3%
- Relationships: 13, 3%

Table 5. Frequency of risks identified in pilot-test (self-report, via on-line risk assessment)

Risk	# Participants	Risk	# Participants
Multivitamin with Folic Acid	9	Personal History of Health Condition	3
Hepatitis C Risk	9	Vitamin A Toxicity	3
Ethnicity-Based Health Risk	9	Weight loss or sports supplements	3
Health problem that runs in the family	8	Cytomegalovirus (CMV)	2
Calcium Deficiency	7	Depression	2
Over-the-Counter Medicines	7	Drugs	2
Tuberculosis (TB) Risk	6	Lead Exposure	2
Caffeine	6	Medicines	2
Listerosis	6	Omega-3 Fatty Acid Deficiency	2
Mental Illness in the family	6	Tetanus (Td) Vaccine	2
Plastic Water Bottles	6	Periodontal Disease	2
STI Risk	5	Physical or Sexual Abuse	2
Bad diet or food choices	5	Plastic lining of canned foods	2
Vitamin D Deficiency	5	Hepatitis B Risk	1
Not been tested for an STI	5	Don't have a PCP	1
Partner has not talked to doctor about his Reproductive Life Plan	5	Exercise	1
Mother was Born Low Birth-Weight or Preterm	4	Mercury Exposure	1
Iron Deficiency	4	Inadequate Health Insurance	1
Toxoplasmosis	4	Household chemicals	1
Workplace chemicals and dangers	4	Tdap Vaccine	1
Anxiety	3	Family health history unknown	1
Malaria Risk	3	No Birth Control	1
Don't feel safe	3	Not born in the United States	1
Emotional or Verbal Abuse	3	Overweight	1
Herbal and Weight Loss Supplements	3	Partner does not have a doctor (PCP)	1
Flu Vaccine	3	Inadequate Financial Resources	1
HPV Vaccine	3	Underweight	1
Partner has not been to doctor in last year	3		

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In regards to the stage of change assessment, we assigned numbers to each stage (Pre-contemplation= 1, Contemplation= 2, Preparation= 3, Action/Maintenance= 4) and totaled the rankings across the 43 risks added to the "My Health To-Do List" at initial assessment and at the 2-month follow-up: cumulatively, participants took nine "steps" forward in the Stages of Change. A "step" means that the participant progressed to the next stage of the Stages of Change. For example, a participant who was identified to not be using birth control regularly and was precontemplative at intake and then at the 2-month follow-up reported that she planned to start taking birth control in the next month ("planning" stage) would have moved forward two steps. Someone who was contemplative at intake for the same risk but was precontemplative at 2 months would have moved backwards one step. A participant who was at the same stage at intake and the 2-month follow-up was recorded as "Same." Of the 43 risks added by the 6 participants who used the system and completed the 2-month follow-up call, 16 risks moved Forward, 12 moved Backward, 14 stayed the Same, and one was reported at 2 months not to be a personal risk. Of the 12 that moved Backward, 10 began at the Preparation stage at initial intake, indicating that our intervention was not effective for individuals in that stage. However, 8 out of 11 in Contemplation moved Forward, showing that the intervention was more effective for that group. Furthermore, out of the risks added to the "My Health To-Do List," 73 percent that started at Contemplation ended at the Action/Maintenance stage. Almost 92 percent of risks that started in Action/Maintenance remained in Action/Maintenance. Detailed Stage of Change data can be found in Appendix D, and an overview of the Stage of Change data is in Appendix E.

Story-Authoring Tool

Development of the story-authoring tool began during focus groups, where examples of stories were presented to participants; they reported that our initial drafts were too long and didn't sound like they were written by a young African- American female. Research team members wrote new stories, using feedback from the focus groups as guidance, and the new drafts tested more positively with later focus groups. However, when asked "How helpful were the stories that you heard?" pre-testers chose "Neutral" on average, indicating that improvements will still need to be made to the system. Of note, our library of stories for this project was almost exclusively written by research team members; as more participants are enrolled in future trials, the participants themselves will supply the stories. The protocol for pretesting may have also contributed to the unfavorable responses; if a participant was nearing the end of her session and had not heard a story, she was instructed by a research team member to listen to a story for the next risk. Thus, some participants listened to stories about risks that they may not have been interested in. Still, it was encouraging that seven out of fifteen participants said that the stories were helpful (Figure 2).

Figure 2. How helpful were the stories you heard?
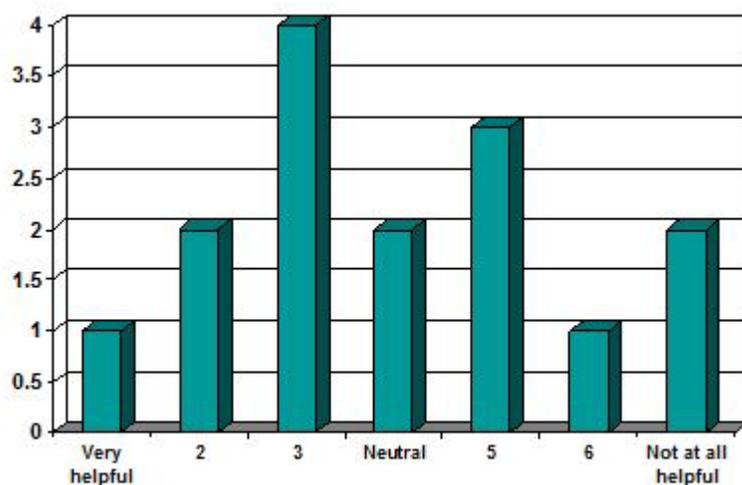
Pilot testing participants listened to a preselected story when they completed the demo session on the day of enrollment. Then, they had the opportunity to listen to stories for their own health risks during the 2-month pilot. Table 4, question seven (How helpful were the stories that you heard?) shows that the average rating was above neutral at both enrollment and 2 months, increasing from 4.57 to 5.33, where 1= Very Helpful and 7 = Not At All Helpful. While this could be partially attributed to our sample, who were all nursing students and of various races and ethnicities, it indicates that the story-authoring tool needs more testing. A study specifically focused on improving the story-authoring tool is warranted, as we believe that it has the potential to have a significant impact on behavior change in our target population.

Discussion

Overall, our results show that an on-line, tailored health risk assessment and education system is a promising method for delivering preconception health information to young African-American women. Qualitative findings confirmed that this population is comfortable with and receptive to health information technology, and that they do not always feel confident in initiating sensitive conversations with their health care providers. However, an on-line system was seen as more anonymous and therefore a venue for getting information about sensitive topics. Focus groups also confirmed that young African-American women prefer to receive health information from a VPA of their same race and gender. Finally, participants provided detailed feedback on individual components of the system, such as stories, the "My Health To-Do List," and the Online Risk Assessment Tool.

Pretesting provided a critical opportunity to test the system on real users under the watch of research team members, who could identify and remedy technical issues quickly. For example, if an early pre-tester indicated that she believed that a health risk was incorrectly included on her list, the programming for all related questions would be reviewed and fixed, if necessary, before the next pretesting session. Pretesting also gave a first-look into the usability and acceptability of the system; for example, by observing during On-Line Risk Assessment Tool, we found that, on

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average, pre-testers completed all of the questions within 12.5 minutes, which they reported to be a reasonable length. However, by observing participants' frustrations during the story-authoring process, we determined that the tool as designed was not intuitive for the target population, and were able to redesign in prior to pilot testing.

The pilot-testing subjects were the first to have the opportunity to use the system from home and to log in multiple times and track their progress on their "My Health To-Do List." Key findings include that: (1) Six out of nine participants used the system and logged an average of 17.5 sessions each during the 2-month trial; (2) the On-line Risk Assessment Tool identified 21.44 risks per participant; (3) Participants reported it was easier to talk to Gabby after the 2 months than it was at intake; (4) Participants who used the system discussed an average of 11 risks with Gabby, which is just over half of the risks that were identified; and (5) 43 risks (7.2 per participant) were added to the "My Health To-Do List"; 83 percent were either resolved or the participant had taken action towards resolving them at the 2-month follow-up.

Another group has developed an online preconception risk assessment tool and has demonstrated that it is a viable way to identify preconception health risks in a way that saves time during health care visits. In the Netherlands, researchers from Erasmus Medical Center, the Dutch National Genetic Resource and Information Center, and the Dutch Genetic Alliance have developed an on-line questionnaire (www.zwangerwijzer.nl); the questionnaire covered similar domains to our Online Risk Assessment Tool, such as Chronic Health Conditions, Prescription and Over the Counter Medications, Illicit Substances, Nutrition, and Environmental Risks. However, a notable difference is that for immunizations, www.zwangerwijzer.nl only included Rubella, while our Online Risk Assessment Tool lists all immunizations recommended in the United States. Overall, the online questionnaire showed a high level of agreement when compared to the interview conducted by the trained interviewer. The authors were able to identify some risks that did not correlate well (e.g., use of over-the-counter drugs, partner's family history) and questions that participants indicated were too vague (e.g., "uterine or cervical anomalies.")[39] Based on these results and qualitative feedback, they plan to re-phrase questions. This study provides a model for our future validation efforts.

The Pregnancy Risk Assessment Monitoring System (PRAMS) is an ongoing surveillance system, conducted in 37 states, one tribal-state collaborative project, and one city, to monitor maternal risk factors during the preconception and interconception periods.[40] Although it is a paper-based assessment, it is similar because it is self-administered and assesses for many of the same health risks as our Online Risk Assessment Tool, and can therefore serve as a comparison to help validate our screening results. The PRAMS also stratifies data by age group and race/ethnicity, allowing for comparisons between similar samples. This will be more useful in our future studies when our sample size is larger; however, even in our sample of 20 (nine pilot-testing participants plus eleven pretesting participants who reviewed their own health risks) it can be useful to compare our findings to a national program. For example, in the PRAMS survey, tobacco use, which is a critical preconception health risk, was common in younger women: 31.1 percent in women under 20 and 24.0 percent in women ages 20 to 34.[40] However, only 10 percent (two participants) of our sample indicated that they use tobacco. This is closer to the PRAMS findings that 16.6 percent of Black women used tobacco prior to pregnancy. [40] In examining health conditions, 2.0 percent of women under 20 years old and 1.6 percent of women 20 to 34 years old had diabetes prior to pregnancy, according to the PRAMS.[40] In our sample of 20 young women, none indicated that they had diabetes. This is an example of an instance where a larger sample size in a future study will allow for a more accurate comparison.

As a pilot study, this study was successful in translating preconception care guidelines into a tool that can be disseminated on a large scale, so that young women can benefit. Using health information technology, we developed a comprehensive Online Risk Assessment Tool that screens for over 100 health risks, allowing the educational component of the system to be tailored to the woman's individual health concerns. Our qualitative work directed development, so that the system—including the VPA character Gabby—is well-received by our target audience; feedback collected during testing of the system will be factored into future development so as to continue to improve upon Gabby. Perhaps the most important finding was that pilot-testing participants either resolved or took action towards resolving 83 percent of the risks that they chose to add to their "My Health To-Do Lists." If future studies show similar results, the Gabby system could have a significant impact on preconception health status.

Implications and Significance

Although this was a "proof of concept" pilot study, the results indicate that more research is warranted in the area of health IT in the field of preconception care. Our qualitative findings revealed potentially effective means of disseminating the system to our target audience, through health classes in middle school and high school or social networking sites such as Facebook. Results from the pilot study show that this system could have a significant impact on reducing preconception health risks; 53 percent of risks that were added to the "My Health To-Do List" were reported to be resolved at 2 months follow-up, and participants had taken action towards resolving another 30 percent.

List of Publications and Products

Our team will develop three publications to disseminate our findings from this task order; the general topic, name of first author, and proposed title are listed below:

1. Health Information Technology – Ring, Lazlo. "Development of an Embodied Conversational Agent for Preconception Care Program"
2. Clinical Results: Gardiner, Paula. "Development of an On-Line Preconception Care Risk Assessment and for Young African American Women"
3. Qualitative Results: Yinusa-Nyahkoon, Leanne. "Internet-Based Preconception Care: Perspective of Young, African American Females"

Future Work

To build upon the progress made through this contract, our team will fine tune the current system and develop additional functionality. Based on data and observations from the pilot study, we will fix remaining bugs to the Online Risks Assessment Tool and Gabby intervention. Analysis of the risks that participants chose to add to their "My Health To-Do Lists" versus those that were repeatedly not added provides insight into questions that may have been overly sensitive and need to be reworded. Some questions may have been programmed incorrectly; our technical team can fix those issues prior to future studies. Once the On-line Risk Assessment Tool has been refined, a significant future project would be to conduct a validation study, comparing results from our on-line, self-administered version to results from the same risks assessment administered by a trained interviewer and a medical record review.

The current intervention delivered by Gabby is limited in scope and does not lend itself well to long-term behavior change. Through funding we have received from HRSA's Maternal and Child Health Bureau, we will greatly expand Gabby's capabilities using Longitudinal Multi-Factor Behavior Change. Gabby will take an integrative approach to intervene on multiple behaviors, identifying and focusing on common factors whenever possible. She will also regularly assess the participant's stage of change for each risk, and will adjust her approach based on the current stage. The implementation of this dialogue software follows work Dr. Bickmore has conducted on NIH National Library of Medicine grant 1R21LM008995, in which a general-purpose, parameterized software framework for developing health behavior change counseling systems has been developed. The objective of this work is to allow new health behavior change counseling systems to be developed with minimal effort by instantiating a relatively small set of variables, such as the behavioral criterion to be achieved, a list of the most common barriers to change, and other factors. The use of this framework will enable the rapid construction of counseling functionality in several behavioral component areas. For example, removing barriers to medical care will impact immunization and chronic disease management behaviors or removing environmental stimuli that trigger alcohol consumption may also reduce risk for STIs. We will also intervene on general health attitudes and provide counseling on general health behavior change skills that may enable patients to more effectively address all of their risk factors.

Grants Received or Submitted

Heath Resources and Services Administration (HRSA), Bureau of Maternal and Child Health (B-MCH), February 1, 2011 – January 31, 2014

National Institute of Minority Health Disparities – April 2012 – March 2017 (submitted 6/13/2011)

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