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Promoting mammography adherence in underserved women: The telephone coaching adherence study

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Abstract

Background—Despite interventions to promote regular mammography, underserved women face barriers to mammography. This is evident in high no-show appointment rates in community-based clinics. Understanding why women fail to follow-through with appointments may help improve adherence.

Objectives—We conducted a focus group with women who were non-adherent to mammograms to evaluate psychosocial and structural barriers and design intervention messages. In phase two we conducted a small randomized controlled trial (RCT) to pilot test a brief telephone coaching adherence intervention (vs. control) to address barriers.

Method—Eligible women were non-adherent to their mammography screening appointment at a community-based setting. Psychosocial factors and perceptions of barriers were measured via a baseline survey and used to tailor the telephone coaching session. In the RCT, the primary outcome was whether women rescheduled and kept their appointment (yes vs. no). Descriptive statistics were used to summarize the results.

Results—Fifty-four women participated in the study (17 in phase 1 and 31 in phase 2); 89% were Black and 11% were Latina. Overall, prior to the intervention, women had low perceptions of risk ($m=4.2$; $SD=2.4$) and cancer worry ($m=4.2$; $SD=2.6$) and these characteristics informed the telephone coaching. After the intervention, most women (94.5%) rescheduled their missed appointment. More women in the intervention group kept their appointment (54%) than those in the usual care group (46%).

Conclusion—It appears feasible to implement a RCT in non-adherent underserved women. Addressing psychosocial and structural barriers in a brief telephone intervention may reduce non-adherence. Future studies that will test the efficacy of this approach are warranted.

Keywords

Mammography; Low-income; Minority; Breast cancer; Disparities; RCT

1. Introduction

Screening mammography has proven to decrease breast cancer mortality [1–4], yet population-based research shows that adherence to screening mammography in the US is far from universal [5,6]. In recent national reports [7] approximately 70% of women report having had a mammogram in the past 2 years. Screening rates can be even lower in under-insured or uninsured minorities [8,9]. Some factors that have been found to increase mammography use include improved access to imaging (e.g. onsite mammography vans), free/low cost mammograms, home visits and peer educators/patient navigation [10]. Improvements in mammography adherence have ranged from 1% (e.g., letter or video interventions) to 33% (interventions with behavioral and cognitive strategies) [11,12]. Moreover, studies suggest that multiple strategies, such as tailored interventions combined with reminders (phone and/or letters) are generally more effective than single strategies for increasing mammography use in underserved women [10,13,14]. While there is no universal definition of “underserved,” for the purposes of this investigation “underserved” was conceptualized as women without health insurance or those who have low-income and met eligibility criteria to be covered by publicly subsidized insurance [15].

Despite the wealth of information about interventions to improve mammography rates, many low-income women continue to suffer from low adherence to mammography screening guidelines. The impetus for this study was drawn from the applied and clinical experience from within a community-based screening facility, Georgetown University's Capital Breast Care Center (CBCC) that serves a large proportion of the District of Columbia's (DC) low-income female residents. For example, low-income women served by Medicaid, receive many of the aforementioned access interventions, such as transportation and reminder phone calls from patient navigators, in addition to monetary incentives to attend scheduled appointments. However, adherence to appointments still remains very low (50%) [16]. Thus, it is possible that a woman's self-efficacy, i.e. her confidence in her ability to follow-through with her mammography appointments and her ability to overcome various barriers to screening, and other psychosocial or subjective and cultural norms may prevent some of the underserved women from having a mammogram [17,18].

Many studies have evaluated logistic barriers to screening in minority populations including: lack of health insurance, absence of social support, lack of child/family care, and lack of transportation and scheduling [19–27]. However, the relationship between psychosocial factors and following through mammography appointments among minority women is less understood [27–29]. In this paper, we take advantage of an ideal setup to describe potential psychosocial (e.g., perceived risk) and access barriers (i.e., transportation) for a group of underserved women who have access to several system level accommodations (i.e. free mammogram screening programs, free transportation to the screening appointments) to reduce barriers to screening but yet their adherence to appointments remains low. In this report we report on the feasibility of conducting a randomized control trial (RCT) within a community-based setting. The aims of this report are to: 1) describe psychosocial and access barriers to mammography among women who are non-adherent to mammography appointments and 2) describe a brief motivational telephone intervention randomized trial to promote adherence to mammography appointments. A better understanding of ways to facilitate adherence for underserved women will be important for the providers that serve this group.

2. Material and methods

2.1. Overview

A mixed method descriptive design was employed in this study. To guide our approach, we chose to adapt Social Cognitive Theory (SCT) as the conceptual framework [30]. The SCT posits that behavioral change comes from observational learning (i.e., modeling), use of reinforcement, improvement of behavioral capacities (knowledge, attitudes, and skills), the values a person puts on performing the behavior (outcome expectancies), and self-efficacy to perform the behavior. Our intervention and measures target these SCT constructs.

Approval was received from the Georgetown University Oncology Institutional Review Board. The setting was the Georgetown University Capital Breast Care Center (CBCC) that provides culturally sensitive comprehensive breast cancer services to women in the Washington, DC area regardless of their ability to pay. Fig. 1 depicts the study schema. The primary purpose of the qualitative phase was to identify psychosocial and structural barriers that could inform the development of brief messages for non-adherent women while assessing the feasibility of reaching non-adherent women. In the second phase, we conducted a RCT to pilot test a brief motivational telephone intervention “Telephone Coaching Adherence Project” (T-CAP). The section below describes the methods and results for each phase of the study.

2.2. Phase I

In the first phase, we collected formative data to identify access and psychosocial factors relevant for underserved Black and Latina women in our patient population in order to inform the data collection tool and develop the intervention script. Women who made appointments at a CBCC but failed to show up for their appointment over a period of 12 months, and who had not had a mammogram elsewhere were eligible. The non-adherence refers to women not adhering to the American Cancer Society annual mammography

screening guidelines [31]. A detailed review of clinical records identified 90 women within one month who had been non-adherent. We were able to reach 25 women who consented by phone; 17 of them participated in two focus groups. Given the information in the literature about barriers to mammography screening in minority and underserved women, the focus group guide included questions to understand women's general awareness, feelings, experiences, and decisions about getting mammograms that were in line with our conceptual framework; Social Cognitive Theory (SCT).

Two female researchers trained in qualitative techniques obtained informed consent and moderated focus groups in English. Women shared their experience seeking mammography screening and provided suggestions to encourage other women to get their mammograms. Sessions were audio taped and transcribed verbatim by an experienced transcriptionist.

Analysis followed established qualitative methods [32]. Two investigators independently read transcripts and extracted key comments associated with women's mammography beliefs, attitudes, and care seeking experiences. Data relevant to each category were examined using a constant comparison process. Categories were added to reflect as many nuances as possible in the data. Categories were further refined and reduced in number by grouping them together. Disagreements about themes led to refinement of codes though consensus by the two researchers. Building upon the large literature regarding mammography intervention in clinical settings we used formative data to inform brief motivational messages that could be delivered by phone during a routine reminder call [33].

2.3. Phase II: Pilot trial of T-CAP

The purpose of the second phase of the study was to test the feasibility of administering the T-CAP intervention in non-adherent patients within the CBCC facility. A two-arm randomized controlled trial (RCT) was employed. Eligible women were those who had failed to show up for scheduled annual appointments over a period of 12 months, and who had not had a mammogram elsewhere. Duplicated names in clinic lists were checked and subsequently removed. Confirmation regarding their appointment was obtained from clinic medical records. After cleaning the list, there were a total of 90 women identified as non-adherent. The participants from the list were randomized to either the intervention or control group using a simple randomization technique based on generating uniform random numbers. CBCC staff and all study team members, except the biostatistician and the interventionists, were blinded to arm assignment. Participants were not blinded to their study assignments since the intervention was delivered immediately after the survey while on the phone for those in the intervention arm. Contamination between the two arms was prevented by having the survey and intervention delivered via the telephone in one session. Attention was not an issue for this same reason.

A total of 90 women were called during the six month data collection time-frame. Of this number 24 had disconnected phones, 15 were not reached (e.g., messages were left but no contact was made), and 14 refused participation. The final sample consisted of 37 women (41% consent rate). These 37 women were randomized to receive either the usual care (n = 15) or the intervention (n = 22).

A trained research assistant obtained consent, confirmed eligibility, and administered the survey via telephone. The survey included information pertaining to perceived risk, knowledge, self-efficacy and socio-cultural factors (fear, fatalism, etc.). Results from the survey were used to tailor the T-CAP intervention which was delivered immediately to women in the intervention group.

Intervention outcomes—The primary outcome measures of interest were: 1) whether or not women rescheduled their appointment (yes vs. no), and 2) whether they kept their rescheduled appointment (yes vs. no). These data were drawn from the electronic medical records which were monitored to assess whether the women kept their appointment. Additionally, for women referred from publicly subsidized programs, non-receipt of mammogram was verified by from the program (i.e., local CDC program).

Survey measures—Survey measures were chosen based on our formative research, conceptual framework, brevity, and prior use in underserved groups. *Self-efficacy*. A woman's confidence in her ability to follow-through with her mammography appointment and ability to overcome various barriers to screening was measured on a five-item Likert scale with responses varying from “not at all confident” to “very confident” [17,34]. The study conducted by Tolma and colleagues shows high reliability ($\alpha = .852$) for the self-efficacy scale; scores below the average are considered as demonstrating lower self-efficacy. *Cancer worry*. We assessed cancer worries using a two-item subscale from previous research [35] (e.g. “How worried are you about getting breast cancer in the next 10 years/in your lifetime?”). Responses ranged from “not at all worried” to “very worried” (scored 1–5) and scores above the average are regarded as high and those below the average are regarded as low. *General distress*. We used the Center for Epidemiological Studies Depression Scale (CES-D-20) to assess general distress [36]. The scores range from 0 to 60 with a cutoff score of 16 representing mild or significant depressive symptomatology [37]. *Perceived risk of breast cancer*. Three levels of perceived risk were assessed. First, we assessed comparative risk by asking participants to rate their risk relative to an average woman their age in the next ten years/in your life time on a 1–5 Likert-type scale that ranged from much below average to much above average (comparative perceived risk) [35,38,39]. Next, we asked women to rate their overall qualitative risk of getting breast cancer in the next ten years/in your lifetime using a Likert-type scale with the anchors “very unlikely”, “unlikely”, “50–50 chance”, “likely”, and “very likely.” Again, this method has been used previously [35,40]. Scores above average were considered high. *Subjective norms*. Factors included normative beliefs about whether referent members (e.g., partner, significant others, and friends) approve of mammography screening and women's motivation to comply or do what each referent thinks about mammography [41]. *Socio-cultural factors* included items such as fatalism, collectivism, religiosity, and distrust and were measured using items from prior research with this type of population and our previous research work [42–44].

Statistical analysis—Descriptive statistics were calculated including means and standard deviations for the continuous variables and counts and percentages for the categorical variables.

3. Results

3.1. Phase I qualitative results

As described above we conducted focus groups to examine psychosocial and structural barriers that were prevalent among underserved women to inform intervention messages. Fifty-three percent was Black and the rest was Latina with an average age of about 53 years.

Overall, women's failure to show for scheduled mammography appointments was related to their perceptions of access (e.g., convenience, appointments) knowledge factors (e.g., understanding about screening guidelines), and psychosocial factors (e.g., motivation, fear, self-efficacy). Most notably, for many participants, keeping their appointment was not a major priority given other life priorities and their self-efficacy regarding how to manage competing priorities was a concern. Mixed knowledge about screening guidelines and where and when to have mammograms was problematic for some women. For example, a few women did not know that mammography appointments had been scheduled by their insurer on their behalf. Other women were unsure where to go for their appointments because sometimes, their insurer would send them to different locations for screening. Thus, as one woman stated, "maintaining consistency" in mammography location was important. Fear was also a common theme among participants. As one woman stated, "I have been told that the machine is cold and that a mammogram hurts." Based on this participant's comment, it appears that she had never had a mammogram; this may have been in part because of what she had heard about them.

Participants also suggested the need for more incentives to facilitate adherence. Incentives beyond transportation, childcare, and cash were needed, although participants didn't have specific suggestions of incentives. When asked to summarize and rank suggestions to help women adhere to scheduled appointments, women provided a list of items that address both psychosocial and structural barriers. Suggestions to increase adherence included reminder phone calls the night before to explain the procedure, transportation, extended time of clinic operation, free mammograms, receiving information about other facilities, or inviting a friend to the mammogram appointment. Taken together, these suggestions were used to frame and tailor the intervention messages and were offered as appropriate to intervention participants (e.g. suggesting they bring a friend to the appointment).

Development of the intervention (T-CAP)—By developing a brief motivational telephone intervention we were able to leverage existing navigation services within the CBCC. Informed by our conceptual framework, SCT, the intervention consisted of three messages derived from the key themes that emerged from the qualitative data. These messages were: 1) Self-efficacy and personal responsibility, 2) Psychosocial issues, and 3) Problem-solving regarding access issues. Participants' responses to the brief baseline survey that tapped in to those themes (see Material and Methods Section) were used to tailor intervention messages or to provide resources as necessary, paying special attention to extreme values (i.e., high, low, etc.) on the measures described above. For instance, in relation to self-efficacy and personal responsibility components, in accordance with the protocol, a women with low self-efficacy scores (less than the average), received additional suggestions on how to overcome potential barriers that were identified (e.g., transportation

and fear) to boost her confidence in following through with her appointment and get a mammogram. Psychosocial issues discussed in the focus group included fear of pain during mammography and perceived risk of breast cancer. Because the clinic has a “softer” mammogram, this information was delivered in a conversational tone. For example, “many women don't have regular mammograms because of concern about it being painful. If you don't already know let me tell you about our ‘soft mammogram’ (i.e. machine with soft pads to cushion breast)”. Perceptions about breast cancer risk were also used to tailor the telephone session. For example, for women with low perceptions of breast cancer risk we provided breast cancer facts to increase awareness of the importance of engaging in early detection. For women with high risk perception that overestimated their chances of having breast cancer we gave them information about breast cancer prevalence and importance of early diagnosis to manage the fear that could be preventing them from getting a mammogram.

Also, women with high levels on the depression measure (score 16 and above) were provided with information about psychological resources and, if they agreed, the navigator followed-up with her to assist her in accessing those services. For ethical considerations, this procedure for mental health referrals was also followed for women in the control group.

3.2. Phase II: Results of pilot RCT

Most interviews were conducted in English and only two were in Spanish. Table 1 displays characteristics of the participants ($n = 37$) by study arm. The majority of women were Black and the average age was 50 years old ($SD = 9.4$).

Sixty-five percent of participants reported at least one barrier to breast cancer screening care ($m=1.6$; ranging from 0 to 5). Several of these barriers were related to structural aspects of care (e.g., hours of operation). Regarding psychosocial factors, a substantial proportion of women experienced distress in the sample ($m=14.7$; $SD = 9.1$). About 43% of the sample had a score above the mean suggesting potential psychological morbidity. However, women's perceptions about their lifetime risk of breast cancer compared to other women in the general population who were their same age ($m = 4.6$) or who were their same race ($m = 13.5$) were relatively low. The worry about breast cancer was low in the sample ($m = 4.7$). Using a structured script, interventionists tailored the delivery of messages according to participants' baseline responses to psychosocial and structural factors.

Intervention outcomes—All women randomized to the intervention group ($n = 22$) were willing to remain on the phone for the coaching session and to complete the intervention. The T-CAP took about 10 minutes. No differences were noted in delivery time between English or Spanish speaking women. Almost all women (94.5%) scheduled another mammography appointment (100% T-CAP group, 86.6% usual care group). Because all women were non-adherent at the start of the study, non-adherence dropped from 100% to 63% (37% improvement) in this sample. Additionally, the rate of adherence to scheduled appointments in the intervention group (54%) was higher than that in the usual care group (46%).

4. General discussion

The overall goal of this study was to better understand and address non-adherence to mammography appointments in an urban low-income population. This study is innovative in that we intervened with women who would be expected to be less likely to participate in a research study — those who were no-shows to their scheduled appointment and who had failed to reschedule their appointment within 12 months. Additionally, the T-CAP intervention was delivered within a clinical setting that focused on women who were underinsured or uninsured. Overall, we found that contacting women by phone took multiple attempts but that women were willing to consent to participate in a research study and that 94.5% made new appointments (100% T-CAP group). Most importantly, we found that women in the T-CAP group had a higher adherence rate to their mammography appointments than those receiving usual care.

We identified that self-efficacy and personal empowerment are important aspects of follow-up for mammography appointments for some underserved women and that a brief telephone coaching intervention that tailors sessions based on baseline psychosocial factors and perceived barriers may improve appointment adherence. We contribute to the literature by showing how “real world” intervention approaches can be implemented within such settings and how they may improve motivation for screening by facilitating adherence to mammography appointments. Additionally, the fact that the intervention was implemented during a routine reminder call suggests the feasibility of conducting other surveys or interventional research within this population.

Our findings suggest that a brief telephone coaching intervention that involves flexibility to tailor messages according to pertinent psychosocial and structural factors may facilitate improved adherence in low-income women. Mandelblatt and colleagues [45] suggest that rather than large investments in general education efforts to promote mammography, mammography interventions that are targeted to defined underserved groups of unscreened or under-screened women may be more cost-effective. Our study focuses on such a population — low-income women who have shown non-adherence to scheduled mammography appointments. Rather than waiting for women to become non-adherent, another approach may be to collect baseline data when women make an appointment and then use such data to tailor reminders. Because women in the current study had already received a reminder as part of usual care, a reminder alone may be insufficient and we are uncertain upfront which factors may distinguish which women will or will not be non-adherent.

One of the most effective strategies for increasing mammography screening among low income women includes the deployment of peer educators to deliver health messages as they are more likely to understand the life circumstances of their counterparts and thus may more readily identify barriers to optimal health behaviors [13,46,47]. These programs are often costly, however, and are not always easily integrated into non-public health settings [48,49]. The use of in-depth reminder calls, on the other hand, has also been effective in low-income women as these calls can address individual barriers, provide an opportunity for patients to raise other concerns and are excellent for women with low literacy [46,50]. We were

intrigued that participants who were non-adherent felt that additional “incentives” (beyond transportation, childcare, etc.) may help women to show up for their appointments. This finding helped shape messages described earlier regarding personal responsibility. More research is needed to ensure that interventions facilitate but do not hinder a woman's sense of empowerment to be proactive about her health.

Overall, this study allows us to delve into the psychosocial reasons for non-adherence while accounting for a number of structural issues that have been found to hinder adherence in other investigations. Ultimately, being able to successfully address these barriers proactively may lead to increased utilization of screening mammography, therefore, informing future interventions aimed to reach similar priority populations. We also avoided issues with contamination across study arms given that the intervention was delivered by phone and in one session.

While this study provides insight that may be useful to community-based screening programs that serve low-income women, there are several limitations of our study. First, the small sample size restricts our study to only providing descriptive statistics. Additionally, the inclusion of Black and Latino minority women who reside in urban areas may limit generalizability. In the future, samples that include women from other racial/ethnic groups may be useful to assess the influence of the intervention in these subgroups. Next, we only captured information about psychosocial (e.g., perceived risk) and structural factors at baseline so we do not know to what extent there were changes in these factors after the intervention. Future studies should balance the need of measuring psychosocial factors at multiple time points (e.g. before and after the intervention), the time constraints of the phone session, and the resources of the clinic. Because we found that 59% of phone numbers were invalid in this sample, provisions for additional contact or estimates of potential loss to follow-up are important future considerations.

Another limitation is that the number of focus group participants was small and it is likely that saturation was not reached. However, the purpose of the pilot was to build upon our team experiences and prior efforts in this population to specifically examine reasons for non-adherence in light of previous interventions. Thus, we elected to maximize existing resources by building upon prior knowledge, and focusing only on women who were non-adherent. Future in-depth qualitative studies will be useful to delve into underpinnings of non-adherent behaviors. Additionally, though not the aim of this investigation, including adherent women maybe useful for future work in order to contrast them with non-adherent women and to build upon identified facilitators of screening as well as barriers. On balance, this study provides useful information about the conduct of a RCT within a contemporary clinical care setting that has relevance for future interventions with patients served in settings geared towards low-income minority patients.

5. Next steps and conclusions

It is clear that additional resources are necessary to effectively reach women who are underserved. Rather than focusing on interventions with those who are non-adherent, it may be proactive to conduct brief interventions when making reminder calls to address

psychosocial issues that are prevalent in low-income groups. The rate of distress in this sample suggests the need to further identify and address psychosocial issues. Also, while there are likely similar factors that can be generalized to low-income women in general, providers in community-based sites that serve low-income women can collect brief data from their patient populations to ensure that messages are indeed relevant to their patients. Next, our intervention results showed that a more detailed follow-up with women who do not show for appointments further increases adherence. We plan to test the intervention in a larger sample of women and integrate the intervention within the routine delivery of care that includes reminder calls. Given that all services are provided at low or no cost and the clients of the center continuously rate the care they received as excellent, women experience barriers that were beyond the financial or insurance barriers that are typically described in the literature. Finally, a better understanding of how to achieve the balance between reducing barriers without reducing the impetus for personal accountability will have implications for future trials to improve mammography adherence.

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Fig. 1.
Study schema.

Table 1

Demographic and psychosocial characteristics of the participants (n=37).

Demographic characteristics	Total (n=37)		Intervention (n=22)		Control (n=15)	
	n	%	n	%	n	%
Age (mean, SD)	50.3 (9.4)		50.6 (11.4)		49.9 (5.7)	
<50	23	62.2	13	56.5	10	43.5
50	14	37.8	9	64.3	5	35.7
Education						
High school	29	80.6	16	55.2	13	44.8
Some college	4	11.1	2	50.0	2	50.0
Bachelor and above	3	8.3	3	100.0	0	0.0
Marital status						
Married	1	2.7	1	100.0	0	0.0
Divorced/separated/widowed	9	24.3	6	66.7	3	33.3
Single/never married	25	67.6	14	56.0	11	44.0
Other	2	5.4	1	50.0	1	50.0
Employment						
Employed full time/part-time	18	48.6	11	61.1	7	38.9
Unemployed/retired	19	51.4	11	57.9	8	42.1
Race ¹						
Black	33	94.3	19	57.6	14	42.4
Latina	2	5.7	2	100.0	0	0.0
Ever had mammogram						
Yes	30	81.1	16	53.3	14	46.7
No	7	18.9	6	85.7	1	14.3
Frequency of mammogram test ²						
Yearly	20	69.0	12	60.0	8	40.0
Every two years	4	13.8	2	50.0	2	50.0
>Every two years	5	17.2	2	40.0	3	60.0
Tailoring variables	Total (n=37)		Intervention (n=22)		Control (n=15)	

Demographic characteristics	Total (n=37)		Intervention (n=22)		Control (n=15)	
	n	%	n	%	n	%
Self-efficacy (mean, SD; range)	7.7 (2.1); 4–12		7.7 (2.1); 4–12		7.7 (2.2); 4–12	
Religiosity (mean, SD; range)	28.2 (4.5); 19–36		28.2 (4.0); 19–36		28.3 (5.4); 21–36	
Subjective norms (mean, SD; range)	6.5 (1.0); 4–8		6.4 (1.0); 5–8		6.6 (1.0); 4–8	
Depression (mean, SD; range)	14.7 (9.1); 0–41		13.3 (10.2); 3–31		16.7 (7.1); 0–41	
BC worry (mean, SD; range)	4.7 (2.6); 2–10		4.6 (2.6); 2–10		4.8 (2.7); 2–10	
Perceived BC risk (mean, SD; range)	4.6 (2.5); 1–10		4.8 (2.7); 2–8		4.3 (2.1); 1–10	
BC comparative risk (mean, SD; range)	13.5 (2.3); 7–16		13.0 (2.8); 12–16		14.3 (1.1); 7–16	

¹Two persons did not identify their race.
²Only computed for people over 40 years old.