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Text Messaging May Improve Abnormal Mammogram Follow-up in Latinas

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ABSTRACT

Purpose/Objectives: To develop and pilot test a text message notification process to reduce follow-up time for abnormal mammograms.

Design: Formative analysis; randomized trial with delayed intervention control group.

Setting: Federally qualified health center, Tiburcio Vasquez Health Clinic (TVHC).

Sample: Thirty-one Spanish-speaking Latinas with abnormal mammograms.

Methods: One Spanish text message was developed based on findings from two focus groups and five interviews with TVHC health care professionals. Fifteen women were assigned to receive text messages within 24 hours of receipt of abnormal mammogram by TVHC (intervention group), and 16 to receive text messages four weeks later (delayed intervention group).

Main Research Variables: Number of days between the abnormal mammogram and the return for follow-up appointment.

Findings: The median number of days between the abnormal mammogram report and the return for follow-up was 23 days for the intervention group and 59 days for the delayed intervention group ($p = 0.0569$).

Conclusions: Our study successfully developed a text message that, in Latinas, may decrease the time from receipt of an abnormal mammogram report to attendance at a follow-up visit.

Implications for Nursing: This simple low-cost approach could result in earlier detection of breast cancers, and thus lower morbidity and mortality among Latinas.

Knowledge Translation: Latina women had a high rate of cell phone ownership. Both focus group members and health professionals felt the text message should be short and refer the patient back to the clinic. A short text message added to usual care was associated with earlier return for follow-up appointment.

There is a significant need to improve follow-up care for Latina women who have received an abnormal mammogram. Although breast cancer incidence is lower for Latina women, they are more likely to be diagnosed with an advanced stage of breast cancer and are 20% more likely to die of breast cancer than non-Hispanic white women (ACS, 2012; Lantz et al., 2006). Foreign-born Hispanics are more likely than US-born Hispanics to be diagnosed at an advanced stage (Keegan, Quach, Shema, Glaser, & Gomez, 2010) and women of Mexican origin were found to be at high risk for early-onset, premenopausal breast cancer (Miranda et al., 2011). Latino Americans are more likely than European Americans, African Americans or Asian Americans to report diagnostic delays (Ashing-Giwa et al., 2010), which is highly relevant as over half of all women ages 50-69 have an abnormal mammogram result (Karlner, Patricia Kaplan, Juarbe, Pasick, & Perez-Stable, 2005). Timely initiation of diagnosis and treatment following abnormal breast exam results has been shown to improve survival, and may help lessen the mortality differences among racial/ethnic groups (Gorin, Heck, Cheng, & Smith, 2006). The population growth of Latinas in the United States, to over 128 million by 2060, makes diagnostic delays a significant public health concern (Bureau, 2012).

Follow-up on abnormal mammograms in specific populations is often poor for multiple reasons that may be based on system or individual barriers. Community health centers are often underfunded and over stretched, leading to up to 34% of abnormal results without adequate documentation for follow-up (Chen, Eder, Elder, & Hickner, 2010). Key drivers of follow-up are a physician documented plan and understanding of this plan by the patient (Poon et al., 2004). However, only 51% of women with a suspicious abnormality on mammogram understood their results to be abnormal (Karlner, et al., 2005). This percentage may be even greater among recent immigrants, and those with limited English skills and lower education levels. In particular, Hispanic ethnicity and low income have both been shown to be associated with longer wait times between the abnormal mammogram result and diagnostic follow-up compared to non-Hispanic white women (n= 6000 women) (Press, Carrasquillo, Sciacca, & Giardina, 2008). Among a group of 11,000 low-income women enrolled in a free statewide screening program, a retrospective case-control analysis revealed that of the 37% that required follow-up, 30% experienced delays of more than 60 days and Hispanic and African-American women were more likely than Caucasians to experience delays (Wujcik et al., 2009). Another study of 970 minority women showed that the median time to diagnosis was 183 days for BIRADS 3, and that income and not fully understanding the results of the mammogram were associated with significant delays (Perez-Stable et al., 2013). The medium of the message is also relevant, as women notified in person or by telephone have been found to be more likely than women notified in writing to understand their results (Karlner, et al., 2005). Patients particularly need clear messages about recommendations for abnormal screening follow-up when multiple providers are involved (J. G. Zapka et al., 2004), which is often the case in community care where mammograms may be referred to outside facilities.

Reminder systems have been shown to enhance the likelihood of attendance at mammography exams (Leirer, Tanke, & Morrow, 1992; Steele, 1999). Text messages improve compliance with medical guidelines (McBride & Rimer, 1999; Stehr-Green, Dini, Lindegren, & Patriarca, 1993; Taplin et al., 2000), and the majority of Americans have a mobile phone (Dang, Estrada, Bresee, & Phillips, 2013; Price et al., 2013; Smith, 2011 August 15; Union, 2012). However, there are no randomized trials reported in the literature testing interventions to increase follow-up of abnormal mammogram results (Bastani, Mojica, Berman, & Ganz, 2010).

Conceptual Framework

This research was guided by a modified and condensed version of the Precede-Proceed model (Green, 1991). This model looks to change health behavior through a systematic planning process that seeks to empower individuals with understanding, motivation, and skills and active engagement in community affairs to improve their quality of life. **There are** multiple steps involved in follow-up after an abnormal mammogram (Taplin, Yabroff, & Zapka, 2012; J. Zapka, Taplin, Price, Cranos, & Yabroff, 2010). Our **pilot** project intervened at the first point of result reporting **and, due to community input was designed to provide both study arms with an intervention.**

Methods

Focus Groups

To assess the patient perspective on the ABC message program acceptability, content and methods of implementation, we conducted two one-hour focus groups. Both groups were facilitated in Spanish by the Community Advisory Board (CAB) chair. Eight breast cancer survivors attended the first group. These survivors were members of an existing breast cancer support group. The second focus group was held with five women who had received an abnormal mammogram but had not been diagnosed with cancer. These women were referred by cancer survivors and the CAB. In addition to asking the women about linking their own behaviors to scheduling and attending an appointment to discuss their abnormal mammogram, we asked them open-ended questions in the following categories: 1. Response to Abnormal Mammogram, 2. Attitudes towards cell phone messages, 3. Content of cell phone messages, and 4. Supporting materials. Finally, focus group members were asked if they were willing to become "Rapid Testers" to receive and evaluate test text messages. The focus groups were recorded, transcribed and translated into English by a bilingual employee who also observed the groups in person. Dr. Oakley-Girvan and Ms. Davis reviewed the transcripts, coded and identified themes.

Rapid Testers

Five "test messages" were developed and tested by six focus group participants who had signed a consent form to participate as "Rapid Testers." Each Rapid Tester was contacted by telephone to remind her about the test message protocol. Subsequently, one text message was sent each day with specific instructions about providing feedback. After all text messages had been sent, each Rapid Tester was again contacted by telephone in order to provide verbal feedback (in Spanish or English) about the messages. We also obtained input from the CAB and TVHC in selecting the most effective of two messages identified by the Rapid Testers. This message was translated into Spanish by one of the CAB members and back translated by a CPIC bi-cultural, bi-lingual staff member.

Semistructured Interviews

We completed five semi-structured interviews with health care professionals at TVHC who had referred Latina women for mammography. The same interviewer completed all interviews, with three primary care providers, a medical assistant, and the supervising nurse. The interviews were conducted and recorded in English, and transcribed. Dr. Oakley-Girvan and Ms. Davis reviewed and coded the transcripts to identify themes.

Randomized Pilot Test

The prospective randomized pilot test comparing the text message identified through our formative research involved two groups, an Intervention Group and a Delayed Intervention Group that served as a pseudo control group. All patients at TVHC clinics were offered informed consent for text messaging and clinical care as part of the general consent form used at patient intake. This consent process was reviewed and approved by the CPIC Institutional Review Board upon which TVHC relied, as they did not have an IRB in place. The IRB determined that additional consent for women who had an abnormal mammogram to participate in the study was not necessary because no personal health information was transmitted from TVHC to CPIC, the standard TVHC consent for treatment already included consent to receive text messages related to their medical care by TVHC as their medical provider, and current usual care would continue to be provided for all participants. In addition, the IRB and the CAB felt that an additional consent process would serve as a reminder about the abnormal mammogram, and might compromise the study because the consent itself would potentially serve as an intervention.

Women eligible for the study needed to have a signed clinic and medical care consent on file at TVHC, be Spanish-speaking, Latina, and have received an abnormal mammogram report. Abnormal mammograms were considered BIRADs 3 and above. No changes were made in the clinic's current methods or usual care for notifying patients of their abnormal mammogram, nor in any of the mammography facilities' procedures for notifications. The text message was in addition to usual care notification procedures in place at the time of the study. An employee of TVHC checked daily for eligible women and assigned them a sequential study identification number (ID) according to the time of their abnormal report. This ID was used to assign them to the Intervention Group (odd numbered IDs), or the Delayed Intervention Group (even numbered IDs). The identical text message was sent up to four times according to the schedule in Figure 1 except when a weekend or holiday intervened, to avoid frustration on the part of recipients who attempted to respond to the message when the clinic was closed. Messages ceased as soon as the woman scheduled a follow-up appointment or she called and requested that they stop.

Data were transmitted from TVHC to CPIC with no Personal Health Information included. CPIC data contained only study IDs, eligibility criteria, and the number of days from the receipt of the abnormal mammogram report at TVHC to each event, including number of days to each message, and the number of days to the follow-up appointment.

Results

Focus Groups – breast cancer survivors or women that had an abnormal mammogram

Both focus groups were conducted in November of 2012. Focus group one (breast cancer survivors) had eight participants. The average age of participants was 47.5. The average number of years of school completed was 7.9. The second focus group (women that had an abnormal mammogram with no subsequent cancer) consisted of five women, with an average age of 46.3. The average number of years of school was 10.8. The majority of both groups were monolingual Spanish speakers from Mexico. One member of each group was bilingual; one member of each group was from a South or Central American country. Few participants recalled receiving a letter from the mammography facility. Participants in both focus groups wanted the text message to tell them that the mammogram was abnormal. Most participants wanted to meet with the doctor for further discussion about the abnormal mammogram results. Participants mentioned fear of cancer as soon as they heard about abnormal mammogram results, and mentioned the need for additional information in writing about an abnormal mammogram, including options for the next step.

Rapid Testers – subset of focus group participants

Six "Rapid Testers" were recruited from the focus groups for testing specific text messages. Three of these rapid testers had had breast cancer and 3 had an abnormal mammogram but no cancer. The six Rapid Testers preferred two of the messages. In order to decide between the two, the CAB and TVHC provided their perspectives. One message (The Tiburcio Vasquez clinic would like to speak with you about your exam results. Please call 510 471-5880 for an appointment) was selected for use in the pilot test and approved for use by the CPIC IRB in July 2013. The message was translated into Spanish by one of our CAB members and back-translated by a bi-cultural bi-lingual CPIC staff member for use in the pilot test.

Semi-structured Interviews with Health Professionals at TVHC

In the months of October and November 2012, we completed five semi-structured interviews with health care professionals at TVHC who had referred Latina women for mammography. All participants agreed that patients typically have access to cell phones and are familiar with how to use them, including retrieving text messages. Participants did warn that phone numbers may be changed frequently, because patients purchase inexpensive, "pay-as-you-go" phones, and do not notify TVHC when they obtain a new phone with a different number. Four of the five respondents felt that very little information should be provided in the text message, although one felt that the message could include information about the need for additional testing. Providers felt the message should include a specific phone number that patients could call to ask questions.

We found that two of the three primary health care providers preferred to have women return to see them for a face-to-face discussion about their mammogram results, particularly if the abnormal result indicated the possibility of breast cancer. We also found that the current process for notifying women of an abnormal mammogram varies by provider internally and externally. Some providers attempted to call patients themselves, or have their medical assistants contact the patient, but many noted difficulties in reaching the patient and the challenges in leaving a message that did not reveal personal health information. Providers noted that mammography facilities sometimes send letters directly to the patients, but the timeliness, language and literacy level of those letters varies by the facility where the patient received her mammogram (all TVHC patients are referred to other facilities for their actual mammogram).

Themes Identified in Focus Groups and Semi-Structured Interviews

Three major cross-cutting themes were identified from both the focus groups with patients and the semi-structured interviews with health professionals: 1. Detailed communications about abnormal mammograms should be provided by the clinician, ideally in person; 2. Latina women have access to cell phones; 3. The content of the text message should be very brief and should refer the woman to contact the clinic (see Table 1). One unexpected result was the need for additional information about what an abnormal mammogram is, as expressed by most focus group members and discussed by several providers. The patients described the anxiety and lack of information that they felt between the time that they received the results of their abnormal mammogram and when they were able to complete their follow-up procedures. One focus group member put it as follows, "During that two week period, I think back, ... the worry is so much. I think they should give some sort of follow up, information, mail a brochure....look don't worry because it could be this or this. Like when you have pre-diabetes they tell you these

are the risks, do exercise, do this do that, they give you follow up information, something you can actually do. With this (abnormal mammogram) they don't, they don't mail you anything, they just tell you to wait for the appointment, the worry is huge. I think they need to mail some sort of information or at least if you have questions go to this website, or call this number. There should be a number that you can call to get informed because you do worry a lot and you ask yourself a thousand questions."

Pilot Test

We enrolled 31 Spanish-speaking Latina women with abnormal mammograms into the study; 15 were assigned to receive text messages within 24 hours of when TVHC obtained the abnormal mammogram report (intervention group), and 16 were assigned to receive text messages four weeks later (delayed intervention group). The average age of women in the delayed intervention group was 51.9, compared with 53.1 in the intervention group. No additional demographics were collected from women enrolled in the study.

Two women in the intervention group had to be excluded from the study. One woman was excluded because she did not reapply for her health coverage and went elsewhere and the other because she had received adequate clinical input at her original appointment and there was no need for a follow-up visit. This resulted in a total of 13 women in the intervention group. Only one woman in each group was reached on a cell phone belonging to another member of the family, in both cases, a daughter. In all other instances the cell phone belonged to the woman herself.

The mean number of days between the receipt of the abnormal mammogram report and the follow-up appointment was 54.6 for the delayed intervention group, with a standard deviation of 31.9, and 31.6 days for the intervention group, with a standard deviation of 24.6 (see Table 2). On average, women in the intervention group returned for their follow-up appointment 23 days sooner than women in the delayed intervention group. The median number of days between the receipt of the abnormal mammogram report and the return for follow-up for the delayed intervention group was 59 with an inter-quartile range (IQR) from 35.5 days at the 25th percentile to 69.5 days at the 75th percentile. The median number of days for the intervention group was 23 with an IQR from 16.0 - 46.0 days. The difference between the two groups in the median number of days to return for the follow-up appointment was 36 days, $p = 0.0569$.

Discussion

To the best of our knowledge this is the first test of Spanish text messages designed to decrease the delay between an abnormal mammogram report and follow-up. In this study we pilot tested text messages to Spanish-speaking Latina women with abnormal mammograms who are patients at a Federally Qualified Health Center, Tiburcio Vasquez Health Clinic (TVHC). We found that Latina women had a high rate of individual cell phone ownership. We did not observe the concerns noted by health professionals that cell phones are shared by family members or that phone numbers change frequently. In agreement with other research (Davis & Oakley-Girvan, 2014) both focus group members and health professionals felt the text message should be short and refer the patient back to the clinic or doctor. We also documented that focus group members were anxious about results in the interim between the receipt of mailed abnormal mammogram results and completion of their follow-up appointment; the lack of information was stressful. This may be a particularly relevant factor to consider in this population as a study by Molina et al., found that Latinas experienced greater psychological distress and social withdrawal compared to non-Latina Caucasians (Molina, Beresford, Espinoza, & Thompson, 2014) with receipt of an abnormal mammogram. Moreover, a systematic literature

review and meta-analysis found that Hispanic cancer patients in the United States report significantly worse distress compared to Caucasians or other race/ethnic groups (Luckett et al., 2011).

Our study successfully developed a text message that, in a larger study of Latinas, or one with a control group that does not receive even delayed text messages, may show statistically significant decreases in the amount of time from receipt of an abnormal mammogram report to attendance at a follow-up visit with the healthcare provider. Although our pilot study results did not achieve statistical significance both our intervention groups experienced a much shorter median delay (23 days for immediate intervention and 59 days for delayed intervention) compared with a median time to diagnosis of 183 days for BIRADS 3 documented in a recent study (Perez-Stable, et al., 2013). Moreover, comparing our results to those from another study of urban minority women with abnormal mammograms in which 22% of the control group were still without a final diagnosis at 60 days (Ferrante, Chen, & Kim, 2008) provides reasonable indication that early intervention rather than delayed intervention is important. Although the p-value in our pilot study is not statistically significant, it is encouraging given the small sample size and the large difference in both mean and median days between the two groups. In sum, our ability to use early intervention text messaging to move follow-up appointments forward is encouraging. It is conceivable that implementation of simple low-cost text messaging could result in earlier detection of breast cancers, and thus lower morbidity and mortality among Latinas.

Strengths of this study include formative analysis to increase our understanding of concerns among Spanish-speaking women who have received an abnormal mammogram result and receipt of input to develop a text message for this population. We included a CAB with representation of organizations serving this population and conducted the research at a federally qualified health center that provides medical services to a low income, primarily Latino population. During the time period of the study, pre-Affordable Care Act, only one of the women experienced difficulties with health insurance.

Study Limitations

There are several limitations in the study. This was a pilot test of a text message, thus the sample was limited to 31 Spanish-speaking Latina women who had received an abnormal mammogram result. Women eligible for the study had to have an abnormal mammogram, but there was no additional information about whether it was screening versus diagnostic. However, given our randomization scheme it is unlikely there was differential distribution of diagnostic mammograms. We also used only one text message sent up to four times instead of a comparison of approaches or messages. The text message did not mention anything about an abnormal mammogram, due to the feedback from our health professionals, who felt that other members of the family occasionally read others text messages. Thus, some women may not have understood to which exam the text message referred.

Due to limited funding and a basic phone system set-up, we were unable to obtain the date on which women called TVHC to make a follow-up appointment after receiving the text message. This information would have helped us determine the immediacy of response but was not available using the phone system in place at TVHC. Difficulties in scheduling an appointment could have been a major factor in delays but we have no reason to believe a structural difference in scheduling between the immediate intervention and the delayed intervention group existed. We would have liked to collect income and education data, as well as other variables such as personal and family history of cancer, and other co-morbidities from our pilot test

subjects, but HIPAA confidentiality requirements and cost concerns prohibited this in our pilot design. The average age of subjects in the intervention and control groups was not statistically different, and women were alternately assigned to **the two** groups, so we expect that in terms of other demographic variables the groups were comparable.

Conclusions

This research addresses the understudied topic of **text** messaging reminder systems for Latina patients to ensure high-quality and timely follow-up of abnormal mammogram results. This approach was built in conjunction with the needs of overburdened, understaffed and underfunded health clinics such as TVHC. We hypothesized that harnessing the power of mobile applications to deliver reminder texts could reduce the observed health care gap and improve outcomes. Specifically, in this analysis, we found that a short text message **encouraged** earlier return for follow-up physician appointment suggesting that the message altered behavior resulting in shorter time to discussion of medical results. These findings are similar to others **described in a review of** mHealth that text messages can improve compliance with medical recommendations (Davis & Oakley-Girvan, 2014). **In this limited time frame pilot study** we did not explore whether this decreased time to definitive diagnosis. However, the results in this project provide **encouraging** support to investigate **whether** a tailored text messaging approach **in a larger sample can** reduce time to definitive diagnosis and thereby impact mortality. In this population, it may also be beneficial to investigate tailored text messaging **or other mobile health options** to improve education around breast cancer prevention **and what abnormal mammograms mean.**

Implications for Nursing Practice

Latinas frequently experience delays in definitive diagnosis following an abnormal mammogram report (Ashing-Giwa, et al., 2010)(Chen, et al., 2010; Press, et al., 2008). They often do not understand what an abnormal mammogram means (Karliner, et al., 2005). Possibly due to the lack of information and understanding about what an abnormal mammogram means, Latinas experience levels of anxiety higher than other ethnic groups after receipt of an abnormal mammogram report (Molina, et al., 2014). This pilot randomized study expands our understanding of Spanish-speaking Latinas who have received an abnormal mammogram report and contributes to the limited interventional research in this population. Results demonstrate that most Latinas use cell phones (Dang, et al., 2013; Price, et al., 2013) and are willing to receive text messages from a federally qualified health clinic. **For the first time,** this study provided **preliminary data** that text messages **may** reduce the number of days from the receipt of the abnormal mammogram report to attendance at a healthcare practitioner led follow-up visit. We recommend evaluating the time to definitive resolution among larger samples with the statistical power to test for interaction among key variables. There is also a need to provide more education related to breast cancer prevention and early detection, specifically, information about what an abnormal mammogram means in a culturally appropriate and linguistically acceptable manner. Adoption by healthcare practitioners of text messaging for appointment reminders and prompts to follow up on abnormal exams could **eventually** lead to decreases in breast cancer morbidity and mortality.

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