

Podcast Interview Transcript

Erin Kobetz, Joan Bloom, Irma Robbins, Kim Engelman

Welcome to Progress in Community Health Partnerships' latest episode our Beyond the Manuscript podcast. In each volume of the Journal, the editors select one article for our Beyond the Manuscript post-study interview with the authors. Beyond the Manuscript provides the authors the opportunity to tell listeners what they would want to know about the project beyond what went into the final manuscript. The associate editor who handled the articles conducts our Beyond the Manuscript interviews. In this edition of Beyond the Manuscript, Associate Editor Erin Kobetz interviews Irma Robbins, Joan Bloom, and Kim Engelman, authors of "Targeting and Tailoring Health Communications in Breast Screening Interventions."

Erin Kobetz: Hi everyone. My name is Erin Kobetz and I am an Associate Editor for the Progress in Community Health Partnerships and I'm honored to talk to you today about your manuscript, "Targeting and Tailoring Health Communications in Breast Screening Interventions."

The first question that I have is for Dr. Joan Bloom from the Alameda County Network Center to Reduce Cancer Disparities. Joan, I'm interested if you could tell me a little bit more about the third component of your intervention design. I was really curious when a husband could be invited, and whether you could explain that in further detail. I was curious whether this was only the choice of the participant and what you did if a woman wanted her husband to come but the husband himself refused participation.

Joan Bloom: Some of those eventualities did not occur. The reason why we decided to ask the wife if the husband would be on it was because in the Muslim religion there's a real division in roles. And we wanted to make sure that it was okay with the wife for the husband to participate and that she would be the best person to ask him first before we contacted him officially. As it turned out none of the women refused their husbands to participate, so that turned out to be a non-issue. But we didn't know that when we got started.

Erin Kobetz: I'm wondering if it would be useful for our readers if you just want to give two or three sentences background about what your research was hoping to accomplish before I ask any additional questions. I probably should have started with that, and I apologize for not doing so.

Joan Bloom: Our project focused on Afghan women who are generally Muslim. In fact, I think it's almost 100 percent Muslim. And we were focused clearly on the religion and the religious precepts and those are somewhat different. The Muslim culture is a lifestyle as well as a religion and so we've been very sensitive to that and most of my colleagues working on the project are Muslim so that has been foremost. Our project was to increase breast cancer screening among Muslim women and so that was our main focus of the project.

Joan Bloom:

And the intervention—we had three interventions, essentially—our main intervention and two follow up interventions. The main intervention was an education program that lasted two hours and was run by lay health educators who we trained to run the education session. Most of the Muslim immigrant women that participated do not speak English or have very limited English ability, even though some of them have been here as many as 30 years. And they mostly have very low education levels so they are illiterate in their own language. So the intervention consisted of a lot of activities that they could participate in, including story-telling, looking at a breast model to see if they could feel for the lumps even though we weren't teaching that particular skill but just to give them the vision of that. And often these women never looked at their own breast in the mirror so they never looked at themselves without their clothes on, so it's a very different kind of culture.

In addition to that, we had community health educators, also lay members of the community who we trained—navigators—to help them make appointments. Appointments for medical appointments, we helped them with transportation, with childcare, if they needed that as well. And at the end of the intervention, those women were asked whether they wanted to have a navigator, as well as if they wanted to have their husband participate in a men's health group.

The reason why we had the second part, the men's health group, was because many of the men can act, although as it turned out they didn't act, as gatekeepers for the women getting healthcare because they are the ones who are more likely to speak English but they are the ones who can make the appointments and provide transportation. And because some of them are working or because their relationship with their wife is not good, they may not be supportive of that. So that's why we decided to have an education session for the men to get them to become advocates for the wives' health. As one of the precepts of the Muslim religion, it was that the men were responsible for the health of their family.

Erin Kobetz:

Thank you for those answers. You did such a good job that you actually answered most of the other questions that I had for you. And I think this is implicit, the answer to the next question I have is implicit in some of what you just beautifully described. You mentioned in the article that the intervention design was based on focus groups of key male informants and male physicians. And I'm assuming the reason why this was the case was because of the literacy in English and the fact that men are traditionally gatekeepers and make critical decisions for women in the Muslim community with regard to health prevention. Is this the case or is there another reason why the focus groups were done with men alone?

Joan Bloom:

I read over the article or at least the draft that I had and I think it's just a placement – the intervention for the women was really based on 53 interviews with women. The intervention for the men was based on a focus group. And the reason why women were not included in the men's focus group is because we wanted to find out about their interests in health, which we discovered that they were quite interested in health and the discussions were quite lively.

And we had, as I said, a male Afghan physician lead the group and we had a group of key informants help us design the men's intervention. But the men were not involved in the women's intervention. And as I look back at the articles they said it was probably based on how that was said, we were trying so hard to get the numbers, the number of words down to what our journal required that we may have slipped up on that.

- Erin Kobetz: I think that clarification is important. I think the work that you've done is really tremendous and it's really clear even in this article, despite short word limits, about the commitment that you had to the community in ensuring that the cultural appropriateness of your intervention design by engaging community members throughout the research continuum, so thank you very much.
- Now we're going to speak to the Kansas City Community Cancer Disparities Network and on the phone we have Irma Robbins, who is a community member as well as Dr. Kimberley Engelman. And my question for you is: at the end of your intervention the participants received a printout detailing individualized steps for screening. As part of this, were they offered any navigation support?
- Irma Robbins: Yes, absolutely. And each woman who participated receive a personal printout detailing all their individual steps. And the promotoras then to sign the plan and suggest that they put in a place where they could see it and remind them to follow up with a doctor. If the participants had a question about where they could go to get their screening that depended. If they had insurance then the promotoras will give them information in that case, how to start, where to go, et cetera. And if they didn't have insurance and then the promotoras will give them information about the state program for at-risk screening, along with a brochure with a toll-free number.
- Erin Kobetz: Wonderful. I was also curious, because you were working with a population of older women, many of whom have limited English proficiency, whether you ran into any difficulties using computers as your main tool for intervention?
- Irma Robbins: Yes and I'm going to give you some points there. When the promotoras had an eligible woman, they asked them first if they will feel comfortable using the computer. And some say yes, some say no. If they said yes, that they felt comfortable with that, then the promotoras explained to them that they would be nearby to be available in case they needed help.
- And some women said that they never used a computer before and they wouldn't feel comfortable using it. In that case then the promotoras explained to them that they would sit next them to help them navigate through the whole program. This made the women feel very comfortable completing the program.
- Also, we have some women say that they had poor reading skills and the promotoras read all the questions to them, providing information, asking the questions, in getting the participants response. Of course, always making sure that each participant was comfortable with that.
- There were a lot of women in the Latino community who needed the help of the promotora.
- Erin Kobetz: Wonderful. Dr. Engelman, do you have anything else you want to add?
- Kim Engelman: Yes, thank you very much. Irma that was a wonderful description. I also want to point out that we not only developed and deployed our program at community events that were focused in Latino communities with Latino women, but we also worked in an area of northeast Kansas where there a larger population of communities of American Indian women. And so this project was dually focused and we did not see as many difficulties with using the computer program in our American Indian communities as we did with our Latinas.

- Kim Engelman: And likely, for obvious reasons for one, there may be an acculturation barrier. The program was available in English and in Spanish, so our Latina participants had a choice. But nonetheless, using the mouse appeared to be difficult skill for some, they were used to it and maybe some had never seen actually a mouse on a computer. And so that was a little bit more difficult in our Latina community members, in terms of engaging with the program than it was for our American Indian community members.
- Erin Kobetz: It's really interesting work that all three interventions describe in this manuscript cover. And I'm hoping that all of you can comment on a little bit more on your experience, but specifically with tailoring and targeting. So the unifying focus of the work reported on in this manuscript is one, that it's all community based participatory research. Two, that it was part of a community network program funded by the National Cancer Institute and three, that this work really emphasized targeting and tailoring communications about breast cancer to engage medically disenfranchised communities in breast cancer early detection.
- How do you think the same principles can be implemented in other communities and potentially with other screening techniques?
- Joan Bloom: You want each of us to comment on that?
- Erin Kobetz: Please.
- Joan Bloom: This is Joan Bloom and first of all, I think that the two principles targeting is really defined as focusing on a specific patient population. In the case of the Afghan women that was a specific population in the fact that they were Muslim, had limited English proficiency, and were possibly illiterate was the focus of our targeting. So we were targeting to that particular population.
- And the tailoring aspect is looking particularly at some of the particular characteristics of that population. So moving from the population to the individual level and one could tailor based on special population cultural characteristics of the population or on other kinds of information that you might have about them. And I think that and maybe Kimberly and Irma could talk more about that, but in their intervention I think that they really spent a lot more of the emphasis was on the tailoring aspect. That was maybe less clear in the other two interventions.
- Kim Engelman: This is Kim. We tried to strictly adhere to community based participatory research principles in the development and roll out of our intervention. And so by that I mean that our community members, both Latina and American Indian, were involved in the complete development of the computer program. We had advisory board members who sat down with us and helped us to develop questions, helped us with the look and the feel and the layout of the computer program, and then helped us to recruit participants—or actually pilot test—and then recruit participants as well.
- And as we finish up our results for this particular project, they will also help with our understanding those results, contextualizing the results, and then also disseminating them to their community members. And we'll be disseminating them to the scientific community. It was critically important to have this input from the beginning and we had the input both on the tailoring side with our community members and then also the targeting side.

Kim Engelman:

We found many different similarities between our two focused communities and then also some differences as well that we try to take into account in the program. We did end up with one program for both communities and they were the questions and the wording was exactly the same for each of the programs. The one thing that was different was for American Indian program we did have some photos and different images that were a little bit more culturally appropriate and tailored for that particular community.

But all that being said, I think it's critically important to have community member input, in our particular situation and many others. It helps to build trust in the program. I think that we had a great recruitment because of that and our program was being talked about in a positive manner in both communities. We also had community members in the front lines of recruitment, both Latina and American Indian. And that was critically important as well. So it wasn't the PhD PI of the research program at the front line of recruitment, it was an actual American Indian or Latina community member. That was very important, too.

And so when you're looking at rolling out, targeting, and tailoring a program for cancer screening or other preventive health behaviors, I think focus number one on including community members providing real and important and meaningful input that is understood and put into action by the research team. Including the community members as parts of the research team is absolutely critical.

I do think that what we've done in Kansas and what has been done by the other programs can be relayed as well to other cancers very easily. We've used some of the same principles in our program--it's called implementation tension theory—into colorectal cancer screening with rural populations and inner city populations with some success as well.

Erin Kobetz:

That's wonderful. I really appreciate all of your answers. Irma, I don't know if you wanted to chime in before we end the interview.

Irma Robbins:

No, that's fine. I agree with Dr. Engelman, I mean she's amazing the way that she speaks and explains everything so no, I'm fine. Thank you.

Erin Kobetz:

Thank you all for your time and for your contribution to Progress in Community Health Partnerships. I think this manuscript will be of great interest to our readers who have much to learn from your experience working with diverse communities to address issues of cancer disparity. Thank you.