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Developing a Peer-to-Peer mHealth Application to Connect Hispanic Cancer Patients

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TITLE: Developing a Peer-to-Peer mHealth Application to Connect Hispanic Cancer Patients

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Abstract

Purpose: Cancer and its treatment can significantly impact health-related quality of life (HRQOL) [29, 4], particularly for Hispanics [8, 17]. Moreover, providers of cancer support for this population may encounter unique challenges. Grounded in social capital theory, this study identified Spanish-speaking, Hispanic breast cancer survivor support needs and preferences for a mHealth intervention. **Methods:** A user-centered, community-engaged research design was employed, consisting of focus groups made up of constituents from a local Hispanic-serving, cancer support organization. Focus group audio-recordings, translated into English, were coded using a grounded theory analytic approach. First, lead researchers read the complete transcripts to obtain a general sense of the discussion. Next, coding rules were established (e.g., code at the most granular level; double and triple code if necessary, code exhaustively) and initial codebook was created through open-coding. Three new coders were trained to establish requisite kappa statistic levels ($\geq .70$) for inter-rater reliability. With training and discussion, kappa estimates reached .81-.88. **Results:** Focus group (n=31) results revealed a mHealth intervention targeting Hispanic cancer patients should not only offer information and support on disease/treatment effects, but also respond to the individual's HRQOL, particularly emotional and social challenges. Specifically, participants expressed a strong desire for Spanish content and to connect with others who had gone through a similar experience. Overall, participants indicated they would have access to and would use such an intervention. **Conclusions:** Findings indicate positive support for a mHealth, tool, which is culturally tailored to Spanish-speakers, is available in Spanish, and connects cancer patients with survivors.

Introduction

Cancer and its treatment can have a significant impact on health-related quality of life (HRQOL)[26]. HRQOL is the impact of a disease and/or its treatment on one's physical, emotional, cognitive, social, functional and spiritual wellbeing [29, 4]. Hispanics diagnosed with cancer are at greater risk for decreased HRQOL than other ethnic groups [8, 17], particularly as it relates to psychosocial wellbeing. In a recent review, Weiss et al. found Hispanics were at greater risk for psychological distress and psychosocial service needs compared to Caucasian and African Americans [28]. Similarly, Clauser et al. found Hispanics diagnosed with cancer reported poorer physical and mental health [8]. In a meta-analysis of 37 breast cancer studies, Lopez-Class et al. reported that Hispanics expressed significantly worse psychological and emotional well-being compared to other racial and ethnic groups [17]. Finally, in a study of 703 breast cancer survivors, Ashing-Giwa and Lin (2011) found Latinas were more likely to report poorer mental health compared to other racial/ethnic groups. Given these findings, Hispanics diagnosed with cancer might be in greater need for social and emotional support.

Providers of cancer support services face unique challenges and limited resources when their clients are Hispanics born outside of the United States (U.S.). The heterogeneity of this population can make it difficult to provide adequate support and develop health appropriate interventions [1]. Hispanic sub-groups vary greatly in terms of education, acculturation, prevention behaviors, immigration status, risk behaviors, and access to care. These variances make it disadvantageous to expect a one-size-fits-all intervention or mechanism of support. Fortunately, flexible and tailor-friendly forms of cancer support increasingly are available, such as mHealth technologies [7, 22, 20]. mHealth, which are mobile technologies for computing and communicating in health care and public health[12], lend themselves well to addressing

disparities affecting Hispanics in that they can be designed to target diverse audiences with specific needs in different situations [14].

In a published review article focusing on mHealth use among Hispanic patient populations, the authors highlighted the increasing use of technology-enabled health communications and health information acquisition solutions within this demographic. For example, over 80% of Hispanics report getting health information from different technologies, particularly those who do not have a regular health care provider [21]. According to the Pew Research Center, 21% of U.S. Hispanics use their cell phones to look for health information compared to 13% of Caucasians and 15% of African Americans [13]. Moreover, Hispanics use social media more frequently than other groups, quadrupling since the mid-2000's [24]. This trend is attributed to the growing number of local, personal, and culturally-tailored Spanish language social media sites. It can also be attributed to social media's underlying collectivist norms, which also are found in Hispanic culture. Hispanics, more so than other racial/ethnic groups, depend on family and social networks to look after them in valued ways, including healthcare tasks and decisions [21].

Growing use of social media among Hispanics is illustrative of social capital theory. Social capital theory is based on the premise that social networks have great value through their inherent qualities of cooperation, trust, support, reciprocity and information [23]. Social capital encompasses the cohesive structure of communities and their social networks, as well as the individuals who draw upon these resources to achieve their own needs [16]. According to Carpiano, social capital encompasses aspects of social support, social leverage, social control and social participation.[3] From this perspective, emphasis is placed on understanding

community and social context as determinants of health. In public health, social capital has been associated with reduced psychological morbidity [25] and improved health behaviors [10, 5].

Despite the increase in social media use among Hispanics, and its natural underpinnings in social capital theory, there is a noticeable absence of research leveraging these areas to address HRQOL inequities [6]. The purpose of this present study was to learn from Spanish-speaking breast cancer survivors about their personal experiences coping with cancer, interactions with medical environments, and desired support. Also, the research team (authors JB, DV, SG, EC) sought to identify ways mHealth technologies, based in a social media context, could extend the type of psychosocial support obtained in a face-to-face cancer support group setting.

Methods

Participants

The study was approved by the Institutional Review Board at Northwestern University and at Northeastern Illinois University. Participants were recruited from the Chicago and surrounding community, primarily through posters and referrals from a partnering Hispanic-serving, cancer support organization called ALAS-WINGS (www.alas-wings.org). Potential participants were invited to attend a brief informational/consenting session conducted by the study coordinator (author SG) 15 minutes prior to the start of the focus group, during which the research study and focus group were explained in detail and participants were given the opportunity to ask questions. Verbal consent was provided by all participants interested in focus group participation, and their socio-demographic information is provided below.

Thirty-one Spanish-speaking, Hispanic individuals, one male caregiver and 30 cancer survivors (28 female, 2 male), with a mean age (\pm SD) of 54.6 ± 11.0 years participated in the focus groups (Group 1, $n = 10$; Group 2, $n = 11$; Group 3, $n = 10$). Of the 30 cancer survivors,

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cancer diagnoses included breast (86.7%), cervical (3.3%), Hodgkins lymphoma (3.3%), leukemia (3.3%), and multiple myeloma (3.3%). Most participants (81%, n=25) were born in Mexico, in the following locations: Federal District, Guanajuato, Michoacán, Jalisco, Guerrero, or Durango. Four people did not specify where in Mexico they were born. Five participants (16%, n=5), indicated one of the following as their country of origin: Guatemala, Cuba, Ecuador, and Nicaragua. One participant (of Mexican descent) was born in the United States. Among foreign-born participants, 20 reported living in the U.S. a mean (\pm SD) of 25.3 ± 15.9 years. Twenty-one participants provided additional socio-demographic information. Ninety-five percent reported Spanish as the primary language spoken at home. Most were married (57%) or never married (24%). More than half of participants (52.4%) reported a highest educational attainment of 8th grade or less, with an additional 23.8% reporting some or completion of high school/GED. A smaller percentage reported some college (19.0%) and college completion (4.8%). For 43% of participants, the reported annual household income was less than \$5,000. Annual income was between \$5,000 and \$9,999 for 19%, and between \$10,000 and \$19,999 for 33%.

Procedure

Study Design. The research team engaged in an iterative, user-centered design approach rooted in community-based, participatory research principles (CBPR) [11]. A user-centered design approach, which values end-user feedback, is very similar to CBPR, which values bidirectional, equitable partnerships with community members ultimately affected by or who are the focus of the research [18]. Given our interest in a mobile application to support HRQOL needs among Hispanic breast cancer patients, a combined user-centered /CBPR approach seemed prudent. To do this, we developed a partnership with a local Hispanic-serving cancer support organization called ALAS/WINGS. This partnership has consisted of bringing their founder (author JG) on as

a co-investigator, establishing a memorandum of understanding, and working closely with the organization's constituents.

Focus Groups. Focus groups took place at collaborating Chicago area community organizations that provide Spanish-language support groups to cancer survivors and their families, and were 1.5 hours in duration. Interested individuals were instructed to arrive 15 minutes early for consenting, and focus groups began promptly afterward. Groups were co-facilitated in Spanish by authors (SG and JG) and audio-recorded for data collection. Each participant received a \$25 stipend after the focus group session.

Focus Group Guide. To prepare for the focus groups, one of the lead researchers (DV), who is familiar with user-centered design, CBPR, and qualitative methods, trained the research team on Hispanic cultural and linguistic considerations (e.g., role of family, respect, the importance of relationships, and trust) and on how to conduct focus groups. This training facilitated the design of a semi-structured focus group guide translated into Spanish. Discussion questions included: 1) How has your life been affected by cancer? 2) What kinds of side effects were the most common for you? 3) How did you deal with or manage your side effect? 4) What was your experience like getting medical support to help you manage your side effects? 5) In what ways have you used technology or social media to cope with or manage your cancer experience or health in general? This manuscript will focus primarily on participants' comments related the fifth discussion question, how participants used technology or social media to manage their cancer or health.

Data Analyses

The audio recordings were first transcribed in Spanish and then translated into English using a professional translation and transcription service. All participants were de-identified. A bilingual, expert reviewer (JG) confirmed and reconciled the accuracy of the Spanish and

English transcriptions. The research team (DV, JB, SG, EC) used the qualitative analysis software Dedoose to analyze and code the English transcripts using a grounded theory analytic approach [9]. A multi-step process guided the analysis. First, all coders read the complete transcripts to obtain a general sense of participants' experiences. Next the research team established coding rules (e.g., code at the most granular level of meaning that can stand alone as an understandable passage; double and triple code the same passages if necessary, code exhaustively). Then the research team created an initial codebook through open-coding. This involved the two lead researchers (JB and DV) assigning codes to words, phrases, and text passages for one of the transcripts. From this initial codebook, code definitions were created and three new coders were trained to establish requisite kappa statistic levels ($\geq .70$) to assure inter-rater reliability. During initial code application training, kappa estimates ranged from .52 to .67; however, upon additional training and discussion, these levels increased to .81 to .88. Once inter-rater reliability was achieved, coders engaged in a process of axial (selective) coding, in which established codes were applied to the remaining two transcripts. Finally, the research team examined data saturation, the point at which no new codes emerged.

Results

In total, the research team identified 48 unique codes in the focus group data, all of which were applied in the first focus group; therefore, with no new information identified in the second or third focus groups, saturation of the data may have been achieved. See Table 1 for codes, descriptions, and evidence of saturation.

INSERT TABLE 1 HERE

The research team organized codes into four overarching themes: 1) disease and treatment effects, 2) psychosocial effects, 3) coping processes, and 4) health communications and

preferences for technology use. To assess which thematic clusters received the greatest attention, the authors summed the total number of times the thematic codes were assigned in the transcriptions and then calculated a percentage by placing that cluster's number over the total number of times all of the codes were recorded. Below are descriptions of the themes and their percentage of application.

Disease and treatment effects. Fifteen codes (11.1% of all codes) comprised this theme: appetite problems, bone pain, chemo brain, disease symptoms, general pain, hair loss, headaches, hot flashes, menses cessation, mouth sores, nausea and vomiting, not feeling well, skin irritation, swallowing problems and weight loss.

Psychosocial effects. The research team divided this theme into positive and negative effects. Positive effects comprised six codes (16% of all codes): appreciation, feeling better, positive affect, sense of control, sense of purpose, and social/emotional support. Negative effects comprised 14 codes (13.1% of all codes): cancer related distress, caregiver burden, depression, hopelessness, identity changes, lack of social support, loss of interest, overwhelmed, pre-cancer life stress, role interference, sense of doom, sleeping problems, stigma, and uncertainty.

Coping processes. This theme was comprised of seven codes (14.0% of all codes): centering on coping, information seeking, perspective-based coping, religious coping, self-advocacy, and warrior coping.

Health communications and preferences for technology use. This theme was made up of six codes (45.8% of all codes): communication with doctor, information preferences, lack of information, side effects education, treatment information, and use of health technologies. Due to this study's focus on how participants use technology or social media to manage their cancer or health in general, we expand upon this theme in greater detail. (Authors' note: While there was

an interview script, conversations varied from one focus group to the next. When a number or percentage that does not include responses from all groups is reported, it is noted as such).

Technology access and use. Despite lower socio-economic status, many participants reported having access to and engaging in a wide variety of information technology practices, most at home, and some at work. While most had access to computers at home ($n=17$ or 77% of participants from focus groups 2 and 3), level of knowledge or ability in using them varied (e.g. $n=8$ or 47% of these participants with computers at home know how to use them). Some participants ($n=9$ or 29%) reported using the Internet to search for information about their cancer and treatment from computers and mobile phones. The following exchange supports this:

Participant 1: *Yes, of course [I use the Internet]. I read a lot about cancer. Sometimes I'll read about people who write about cancer. I research.*

Participant 7: *I research things like cancer, what is good to eat.....*

Participant 9: *When I'm on the bus, I'll start doing research too.*

Participant 5: *I researched before starting chemotherapies; I found information on what would happen depending on the type of cancer.*

Diversity of technology use. In addition to using the Internet, nearly everyone reported having a mobile phone. For example, one participant said, "*I use it [mobile phone] when I'm at home and I'm feeling lonely and depressed. I talk to my friends who have gone through the same thing.*" Several participants reported only using their phones to talk, while others said they texted ($n=18$ or 58%) and used social media ($n=8$ or 38% from focus groups 2 and 3). For example, another participant reported, "*I don't have a computer, but I do have a phone without service but has Facebook once in a while.*"

Technology preferences. In focus group 3, when discussing preferred technology platforms to receive information, all 10 of the participants reported a preference for video-based information and educational material so that they could review information if they forgot it. In this same session, all 10 participants reported a preference to video-conference with members of their medical team. For example, one participant reported, *“Skype...would be perfect because it would be more practical. Now if they would do it like in the movies, where you see where it looks like a transparent screen, where you dial and the doctor comes out or whoever you’re talking to and all that. That would be better. All you do is carry your phone and you push and the doctor’s image appears or whoever you want to talk with.”* Another participant said the waiting room at her cancer center or the room in which she receives chemotherapy could be places to receive information on a monitor/television. She said, *“When you’re waiting for the oncologist, where sometimes they take up to half an hour, 20 minutes, an hour, [I could be] sitting there watching [a] program with information about what oncology is. How do you overcome? What do you feel? And as far as chemotherapy ... you sit for hours.”*

Of all topics, peer support, received the most attention. Nearly everyone ($n=19$ or 90% of participants from focus groups 2 and 3) preferred a call from someone going through the same thing. One participant said, *“I have given my phone number to many people... I lift their mood...because what [they] are going through I’ve already been. And they say, ‘That’s exactly why I want to keep talking to you, because no one understands me more than you do.’”*

Finally, almost all participants, excepting those who also spoke English, reported on the frustration and barriers they face because of their non-English speaking status. One participant’s statement captures this sentiment: *“When you are Hispanic and don’t speak English and they give you English brochures...I don’t know anything. And you ask [questions], but the doctor*

speaks English, the nurse speaks English. What is left? Nothing.” In another focus group session, one participant said she went to the library and found only two books in Spanish and no videos. She shared, *“I kept thinking, wow, this disease is advancing more and more each day, and there isn’t much information out there. There is in English, but not much in Spanish.”* Another participant concurred and said, *“For those that can speak English, it’s easy for them. They go in the computer and that’s it.”* These comments reflect the need for content and support to be available in Spanish, as well as English.

Discussion

Given the greater number of codes applied to areas such as distress, burden, depression, hopelessness, and feeling overwhelmed, compared to other disease and treatment side effects like hair loss, hot flashes and nausea, it is apparent that mhealth interventions designed to positively impact this population’s HRQOL should not only offer information on disease and treatment effects, but also respond to the emotional and social challenges. Participants expressed the desire for synchronous/asynchronous video communication options involving support from peers (and even possibly medical team members). Participants also indicated they have access to, and engage in a wide variety of information technology practices and behaviors, despite their relatively lower SES. Some caveats included limited knowledge of computer use; but overall, they were receptive to a mHealth intervention provided that the content was in Spanish.

Struck by the Hispanic population’s psychosocial needs and our participants’ interest in connecting with others who have experienced the same thing, the research team has conceptualized a social media, mobile application tool called MAESTRA, which stands for *MAESTRA: mHealth Application to Enhance Support, Treatment Readiness & Adjustment*. MAESTRA means “teacher” or “mentor” in Spanish, which is the essence of this new tool – to

pair newly diagnosed individuals with *mentors* who have been through something similar, as a means to foster communities of care and to assemble community intelligence.

Healthcare information and support is no longer a one-way flow from the physician to the patient [27]. Moreover, *communities of care*, a collective of individuals who care about and care for each other, are increasingly becoming a means by which patients obtain receive support [27]. Such communities, be they face-to-face or via online (e.g. chat rooms, listserv, etc), are also sources of, and catalysts for community intelligence. Per Hesse et al., *community intelligence* describes how Web 2.0 technologies, via a “bottom up” approach, support collective knowledge to improve health outcomes in a community [15].

The notion of communities of care and community intelligence is consistent with Carpiano’s definition of social capital, particularly the components of social support and social leverage. MAESTRA would be grounded in these components, harnessing the collective intelligence of the Spanish-speaking cancer community. Also, it would address the psychosocial well-being and adjustment HRQOL disparities experienced among U.S. Hispanics diagnosed with cancer [2]. While there is a growing body of research to support the benefits of social capital, there is little to no research on the use of a social media, mobile application specifically designed to positively impact the quality of life for Hispanics diagnosed with breast cancer.

The authors are mindful that success rests with a thoughtfully planned application [19]. Putland et al. found long-term vision and commitment, sectors working together, building effective relationships, and generating knowledge about what works as factors to consider when applying social capital theory in public health [19]. The research team will continue to apply CPBR approaches in the design of a first prototype, as well as in the implementation and evaluation phases.

Limitations

There are several significant limitations to this study underscoring the importance of generalizing the findings with caution. First, the study only included two male cancer survivors. Their opinions may not be representative of other Hispanic men with cancer. It also included four cancer survivors with non-breast cancer diagnoses and one male caregiver. Second the sample was small and the diversity of this study's Hispanic sub-groups was limited, with 84% being of Mexican descent. Data was not gathered to document differences within Hispanic subgroups, and among such factors as acculturation, English/Spanish language proficiency, income, education, occupation, occupation, and so forth. Fourth, since the technology cluster accounted for half of the codes, it is possible the research team facilitated a bias in this direction given their desire to understand how the participants would respond to technology because of the implications for the mHealth application being developed. Finally, the research team did not analyze variances in responses as they related to technology proficiency. It is possible that those who are more technology proficient are more apt to use a mHealth breast cancer support tool.

Conclusion

In light of the heterogeneity of Hispanic sub-groups, knowing how best to target cancer care support needs can be challenging. Seizing the potential of flexible, tailor-friendly, mobile applications and with the intent to reduce the HRQOL disparities among Hispanics, in this paper the authors described how they are using a user-centered, CPBR approach to support the formative development of a mHealth support tool for Spanish speakers diagnosed with breast cancer. While this study focused primarily on breast cancer survivors, whose primary country of origin was Mexico, the authors believe the findings point to a need to investigate further the technological opportunities with other Hispanic groups and with other forms of cancer. In this

way, the research team can begin to address the cancer-related, lower HRQOL factors experienced by this population.

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