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Cancer Worry Among Urban Dominican: A Qualitative Study

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Abstract

Background—Two thirds of respondents of a recent survey, primarily self-identified urban immigrant Dominican females, indicated that cancer was the health problem they worried about the most.

Purpose—The purpose of this qualitative study was to gain a greater understanding of the cancer worry experienced by Dominican women.

Design—Giorgi's descriptive existential phenomenological framework and methodology guided the study. Setting: Washington Heights/Inwood community, New York City, New York.

Participants—Thirty-eight urban Dominican immigrant women were included in the study.

Method—Data were gathered using focus group interviews. All interviews were digitally recorded, transcribed verbatim from Spanish to English. The transcripts were analyzed using Giorgi's existential phenomenological data analysis process.

Findings—Four essences unfolded: Cancer as Destiny, Faith, Influential Relationships and Knowledge Acquisition.

Conclusion—New knowledge was generated on the contextual factors that influence cancer worry among a major Hispanic subgroup. Implications for nursing research and practice are described.

Keywords

Hispanic; Dominican immigrants; cancer worry; community participatory research; WICER Project; Giorgi's phenomenological framework and methodology; focus group interviews; qualitative study; transcultural health; urban setting

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Declaration of Conflicting Interests

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¹Although there is no single "Hispanic culture," there are overarching values that are shared by a variety of Hispanic cultures (Flores, 2000).

Introduction

In Hispanic communities, cancer worry related to diagnosis, risk, and recurrence, both abroad and in the United States (US), is rated as one of the top health problems most worried about (Consedine, 2012; Cottler et al., 2013; Fernández et al., 2015). Consequently, qualitative and quantitative studies have been conducted to learn more about this phenomenon. A recent correlational study found that nearly two thirds of a sample of self-identified urban Dominican immigrant females indicated that cancer was one of the top three health problems they worried about the most (Pacsi-Sepulveda & Bakken, 2016). The purpose of the current study was to explore and gain a greater understanding of the cancer worry experienced among urban Dominican immigrant women. The research question was “What is the lived experience of cancer worry among Dominican immigrant women residing in an urban community?”

Background

Dominicans are a Hispanic subgroup that make up 25.3% ($N = 605,840$) of the overall population of New York City (NYC) ($N = 2.3$ million) and this percentage is increasing (Center for Latin American, Caribbean & Latino Studies, 2011). Nearly 8 out of 10 Dominicans in the United States reside in the northeast (78%) and 48% of these reside in New York City (Brown & Patten, 2013; Pew Hispanic Center, 2013). Less than 50% are proficient in English (Brown & Patten, 2013; Pew Hispanic Center, 2013; U.S. Census Bureau, 2010). Twenty-eight percent self-reported living in poverty compared with 16% of the U.S. general population (Pew Hispanic Center, 2013). Approximately 21% of Dominican residents do not have a primary health care provider that they see on a regular basis due to lack of health insurance, compared with 15% of the general population (Brown & Patten, 2013; Pew Hispanic Center, 2013; U.S. Census Bureau, 2010). There have been several studies of the correlates of cancer worry in various racial and ethnic groups that have examined sociodemographics, acculturation, cancer screening, genetic risks, and recurrence among Caucasian, African American, Asian, and Hispanic populations. In these studies, ethnicities tend to be viewed as homogeneous groups and most of them cluster subgroups of Hispanics together (Han et al., 2011; Jacobs et al., 2014; McBride et al., 2007; Mellon et al., 2008; Morrison et al., 2012). This is problematic as Hispanics are not monolithic. Therefore, it would be more beneficial to study subgroups to learn what experiences influence their cancer worry. Few studies have been conducted with Dominicans.

Recent correlational studies have been conducted which examined factors associated with online health information-seeking behaviors of Hispanics from the northern Manhattan community of Washington Heights, as part of the Washington Heights Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER) Project. Two thirds of the survey respondents, primarily self-identified urban Dominican immigrant females, indicated that cancer was one of the top three health problems they worried about the most. Additionally, data analysis found that four variables significantly increased the likelihood of identification of cancer as a worrisome health problem: married marital status, younger age, less depression, and a diagnosis of cancer and addressed the knowledge in this community (Lee, Boden-Albala, Larson, Wilcox, & Bakken, 2014; Sepulveda-Pacsi & Bakken, 2016).

Results from the above studies were used to study cancer worry specifically in urban Dominican immigrants and inspired the current study.

Methods

Research Design

For the current study, Dominican female participants from the original WICER study were interviewed using focus groups. Although there has been debate about the validity of using group methods to analyze individual experience (cf. Bradbury-Jones, Sambrook, & Irvine, 2009; Webb & Kevern, 2001), we believe that using focus groups leads to improved phenomenological findings because it (a) enable's researchers to reduce the influence of prejudice and helps them bracket their assumptions (Halling, Kunz, & Rowe, 1994; Halling & Leifer, 1991), (b) stimulates discussion and reflection by the individual participants (Bradbury-Jones et al., 2009; Krueger & Casey, 2000), while (c) enabling more viewpoints and voices to be heard. This format enabled the author to explore and gain a greater understanding of multiple women's perceptions, beliefs, and personal experiences, which enhanced the trustworthiness of the findings.

Transcripts of focus groups were analyzed using the descriptive existential phenomenological framework of Giorgi (1999, 2005). The use of Giorgi's framework (1999, 2005; Husserl, 1913/1972) was used to reveal the phenomenological meaning of cancer worry through the identification of essential themes in a way that was free of assumptions and interpretation (Bradbury-Jones et al., 2009).

Ethical Considerations

The study was approved by the Institutional Review Board (IRB) at Columbia University Medical Center (CUMC). Written consent was obtained from the study participants, including permission for digital audiorecording of the focus groups. Ethical standards were observed to maintain participants' confidentiality prior to participating in the study research protocol and Health Insurance Portability and Accountability Act forms were explained and discussed with each participant.

Recruitment

Two bilingual community health workers, who were part of the research team, reviewed the WICER database, identified potential participants, and telephoned them to inform them of the study using a script. Individuals who agreed to participate were assigned to a focus group. Participants were allowed to choose the language of the focus groups, and all participants chose their native language, Spanish. Each participant received a \$50 coupon to compensate them for the time, possible expenses, and inconvenience of taking part in the study.

Sample

The data collection was based on the principle of saturation (Mason, 2010; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Munhall, 2010). Therefore, the number of participants was not predetermined. A total of 178 potential participants were invited to participate in the

study. Of these, 56 accepted the invitation and 38 self-identified urban Dominican immigrant women met the inclusion criteria (Table 1) and participated. The average age was 53 years and ranged from 32 to 62 years (see Table 2 for more demographics).

Setting

The focus groups took place at a storefront community engagement resource center of the Irving Institute for Clinical and Translational Research, located in the Washington Heights area of NYC. The participants signed consent forms and completed the demographic questionnaire in a private room. The focus group interviews took place in a conference room. Participants were seated at a rectangular table and each had eye contact with the others in the group and with the facilitator and note taker. This seating arrangement promoted group discussion and decreased the potential for any one participant to dominate (Krueger & Casey, 2000). Refreshments and sandwiches were served which created a more relaxed and social environment.

Data Collection

The first author (FA) served as the facilitator and a research assistant served as note taker. Both were fluent in English and Dominican Spanish. Eight focus groups comprising 35 participants were convened. The average focus group size was four to five members. Saturation was reached after eight focus groups. The FA then held one additional focus group, consisting of three participants, to confirm that saturation had been reached. The sessions lasted 90 minutes and field notes were taken.

All members of the research team were experienced in conducting focus group interviews. Participants were encouraged to speak freely which increased group interaction (Krueger & Casey, 2000). The interview began with the facilitator asking each participant, “What is it like to worry about cancer?” Additional questions were posed to clarify or seek more information (“What is it like not to worry about cancer? Can you tell me more about that?” “What do you mean by ... ?” “How did you feel when ... ?”). The sequence of questions centered on cancer worry, its presence or absence, and descriptions. Acknowledgement, clarification, mirroring, and reflection were used to explore the participants’ beliefs as to why they did or did not worry about cancer.

Data Analysis

The digital audio-recordings were transcribed verbatim by the FA within a couple of days post focus groups. The data were analyzed using a five-step descriptive phenomenological existential methodology (Giorgi, 1999, 2005). These five steps prepared the researcher to view the data objectively within their own context without being judgmental. The five steps were the facilitator (1) listened to and read the naïve narratives/transcripts of the participants; (2) reread all the naïve transcripts line by line and systematically determined each instance that a transition in meaning took place. Common ideas (in the participants’ words) were clustered and identified as meaning units. Next, the facilitator (3) examined the meaning units for clarification, redundancies, and elaboration by relating them to each other to get a sense of the whole; (4) reflected on the data and created the synthesized transformed

meaning units, which were used to define the essences of the participants' experiences; and lastly (5) formalized a description of the overall meaning and structure of the phenomenon.

This methodology provided a systematic, structural, and rigorous analytic approach, and enabled the FA to assume a phenomenological frame of mind, which enabled her to bracket (*epoché*) her biases, ideas, personal knowledge, beliefs, and preconceptions of the phenomenon under study. This enabled her to view and reflect on the content of the naïve narratives using the participant's viewpoint or perspective (Giorgi, 1999, 2005; Husserl, 1913/1972; Karlsson, 1993) and to extract the themes inductively, resulting in a greater breadth of understanding of the phenomenon under study. Additionally, the FA had two other researchers, experts in their field, read the narratives. The purpose for this was not simply to obtain consensus but also to create a broader analytical space (Pacsi, 2015).

Findings and Discussion

Twenty meaning units were identified from the analysis of the recordings and transcripts. From these, the synthesized transformed meaning units were formed, and four key essences unfolded: Cancer as Destiny, Faith, Influential Relationship, and Knowledge Acquisition. The following quotations reflecting the above essence are coded with group number and participant's number: for example, (Group) 1/8 (participant).

Essence 1: Cancer as Destiny

Cancer as destiny is based on participants' belief that getting cancer is predetermined. This perception is rooted in their belief that one has no control of "coming down with cancer." In the six focus group sessions, participants agreed that whether one got cancer was out of their control, but they felt some sense of control of their destiny, for example, by getting cancer screenings or participating in other ways in their medical treatment. Five participants who did not have cancer commented:

4/3 "The bottom line is that having a familial cancer history or not, if you are predetermined to get it you cancer you will."

5/3 "Getting cancer is out of our control."

Two participants who were cancer survivors stated:

2/2 "After being diagnosed with cancer. I stay on top of my follow-up visits. The health care team always emphasis what I can and can't do to not have the CA come back. That and having my children stay helps me stay on top of what I'm doing stay healthy. And despite my cancer diagnosis, so far so good. I do have to agree I often worry that the cancer may come back again."

4/3 "Cancer, after having lived through it with my mother, does not mean death. It's just a new way of living. Do we worry? Yes. Do we stay on top of her checks-ups? Yes."

Previous studies have examined cultural factors, cancer worry, fatalism, and the likelihood of screening. Researchers found that knowledge of cancer risk and screening, fatalistic beliefs, defined as lacking the power to control the onset or progression of cancer among Hispanics,

evoked a sense of helplessness, particularly believing that cancer risk cannot be reduced (Consedine, 2012; Jonnalagadda et al., 2012; Ramírez, 2014). In the current study, the women expressed that cancer was predetermined or destiny. However, they did not lose their sense of hope; instead, they used their cancer worry and fatalism to be proactive. Additionally, despite their cancer worry, they believed they were in control. The participants believed that if diagnosed with cancer, they could control the outcomes with a proactive approach toward treatment, screening, and working with their health care providers.

Essence 2: Faith

Participants defined faith as that which gave them a sense of hope and spirituality and was rooted in a strong belief and trust in God. They stated their faith enabled them to be proactive in changing their behavior and participating in cancer screening practices.

3/5 “I do get my regular check-ups, exercise, eat well then I let go and let God take care of the rest.”

5/2 “I was diagnosed with cancer 2 years ago and I’m fine. And I have belief in God that all will turn out well because I follow the treatment plan exactly how the doctor tells me to.”

4/5 Believing in God and in the doctors. Science is very advanced and you have to be up to date, and put yourself in the hands with God and with the doctors. God is the only one that knows and the doctors.”

In one study conducted among Southern European cancer survivors (Travado et al., 2010), researchers found significant associations among a fighting spirit, fatalism, and avoidance. They also found that faith served as a protective mechanism and reduced psychological morbidity. These findings are consistent with the current study, despite differences in population, and suggest that across different cultures, participants with faith are more likely to participate in screening and health promotion.

Essence 3: Influential Relationship

The meaning of influential relationship consisted of *personalismo* (personalism) and *familismo* (familism). *Personalismo* is defined as treasuring and developing personal relationships as opposed to institutional relationships (Antshel, 2002)) which emphasizes pleasantness and politeness in social interactions, and mutual respect. *Familismo* refers to maintaining close relationships with and loyalty to nuclear and extended family members (Flores, 2000). All participants referred to these concepts as essential to their behaviors related to cancer screening, early detection, and treatment.

4/3 “I trust my doctor because he answers my questions and just doesn’t see me as a number. He addresses my cancer worry, sets up the tests I need and discussed results with me and my daughter.”

2/4 “To my doctor and his health care team I’m not just a number. I’m a person. If I have any concerns regarding my health, for example, I had a lump in my breast. I immediately called him and he orders the appropriate tests. I trust her implicitly.”

5/5 “My health care providers give me the information I need to make an informed decision. They put all the options on the table and give me time to think.”

7/2 “My doctor and nurses know that I’m the pilot and they are the co-pilots, in good or bad times, they have my back.”

Throughout the interviews, *familismo* played a specific role in reinforcing their proactive stand on cancer screening. Participants agreed that it was extremely important for them to maintain their health. Those with dependents talked about the critical role they played in the family as primary care givers.

5/3 “I am the nucleus in my family. It’s vital I maintain my health so I can take care of my children.”

2/3 “If I were to get cancer and not get better, what would happen to my family, who will take care of my children? ... I rather prevent or be diagnosed early than delay and as a result cause my family undue sadness.”

7/2 “I have to stay healthy for my children. So if screening and leading a healthy life style will help; I’m there!”

Moreover, all group members agreed that having a trusting relationship with their physicians and the other health care team helped them make informed decisions related to cancer prevention and overall health screening. Although these women emphasized the positive impact of their doctor–patient relationship, the effect of cultural factors in the doctor–patient relationship has been shown to have both positive and negative impacts on the care they receive (Gallo et al., 2009; Yanez, McGinty, Buitrago, Ramirez, & Penedo, 2006).

Essence 4: Knowledge Acquisition

Knowledge acquisition was described by participants as consisting of two categories: objective knowledge and subjective knowledge. Objective knowledge referred to information derived from their primary and/or gynecological physicians, other health care providers, pamphlets obtained from health care centers, community health fairs, television commercials.

Participants indicated the following:

8/2 “I get my information from my primary doctor, television, radio, and the pamphlets at the doctor’s office.”

5/3 “My doctor went over with me in detail the cause and risk factors for Human Papilloma Virus (HPV) and what can happen if it’s not taken care of. As a result I now know what to prevent and look for. I can’t say the same for the other cancers.”

2/4 “I get my cancer information from my doctor and his health care team.”

5/5 “I don’t know all the cancer facts. There is a lot of information out there but it’s hard to figure it all out.”

Subjective knowledge was described as their personal and/or family members’ experiences of living with this illness. Participants stated:

6/2 “Cancer is an illness that is very invasive and eats you up slowly. I saw and lived it when my mother and cousin got cancer; it was terrible to witness.”

3/3 “I have had personal experience seeing my friends and family who have suffered with cancer. Life has taught me what cancer is and it’s not pretty.”

In the present study, participants indicated that their knowledge of cancer was based on life contexts. This led the need to be addressed regarding cancer, etiology, and genetic and behavioral risk factors. All participants agreed that additional information related to cancer and screening guidelines would be helpful.

This is consistent with other studies conducted with other Hispanic subgroups, mostly Mexican immigrants, of similar age and socio-economic status as the current sample, which found that one factor inhibiting colorectal screening was participants’ lack of knowledge (along with health literacy, risk perceptions, self-efficacy, poor access to health care, lack of insurance, and fatalism) (Ashing-Giwa et al., 2004; Fernández et al., 2015; Flórez et al., 2009; Lumpkins et al., 2013; Shelton, Jandorf, Ellison, Villagra, & DuHamel, 2011).

Overall, in all the group sessions, the participants used words such as “anxiety,” “destiny,” “fear,” and “fatalism” when speaking of information provided by media, and families’ and friends’ experiences with cancer. Additionally, the majority believed that once diagnosed with cancer, recurrence was inevitable and cancer equaled death if one did not take proper care of oneself. The women emphasized the impact faith and hope had on the outcomes of cancer diagnosis and believed that trusting in God gave them free will to make decisions despite destiny. For them the key was to trust in God. They expressed the importance of *destino* (destiny), *confianza* (faith), *familismo* (familism), and *personalismo* (personalism) in the relationship they had with their health care providers and the role this played in dealing with their cancer worry. These factors helped them cope effectively with their worry, such as being proactive with screening. This is consistent with other findings in the literature which found that worry about cancer in general is associated with greater screening behavior (Hay, Buckley, & Ostroff, 2005).

Our findings are also consistent with those of researchers at City of Hope, who conducted a qualitative study determining the relevance, content, cultural congruence, and linguistic appropriateness of their patient education program for breast cancer survivors (Juarez, Mayorga, Hurria, & Ferrell, 2013). Participants from Central, South, and North America provided feedback about the cultural context of the education program. The Hispanic cultural values used to develop the program were *familismo*, *personalismo*, *respect* (respect), *simpatico* (kindness), and *confianza*, and it was considered vital to the effectiveness of the program. In other previous studies, researchers noted that *familismo*, particularly among women with dependent children, was an impetus to maintaining optimum health despite identifying that cancer was their primary health care worry (Carteret, 2011; Contreras, Magelsdorf, Rhodes, Diener, & Brunson, 1999; Hall, Hall, Pfriemer, Wimberley, & Jones, 2007; Pacsi, 2015; Sue & Sue, 2012).

Overall, the structure of this group of Dominican women’s experience with cancer worry is multifaceted and based on essences of Cancer as Destiny, Faith, Influential Relationships,

and Knowledge. These essences can be seen as having roots in and connections to Dominican cultural values. These values influence their belief that cancer may be part of one's destiny. Their faith and trust in God gives them the strength to participate in prevention and treatment measures. This is further influenced by their relationship and shared decision making with their health care providers and family. Their culture also influences the knowledge, objective or subjective, that guides their worry about cancer and related health care decisions. The centrality of these essences is consistent with a model by Yanez et al. (2006). Their model posits interrelationships between cultural context (e.g., cultural values, such as Destiny and Faith), psychosocial factors (such as Knowledge and Screening Behavior), health care factors (e.g., patient-provider communication, an aspect of the Influential Relationship between patient and doctor), all of which contribute to cancer outcomes.

Limitations and Strengths

This study had both strengths and limitations. Its strength is that it is a culturally and ethnically based study, studying an understudied population, with a relatively large sample size for a qualitative study. The limitations were that (a) this was a convenience study, (b) composed only of women, (c) all the group sessions were held in Spanish, and (d) participants represented a subgroup of Hispanics residing in the Washington Heights/Inwood community. Therefore, consistent with qualitative methods, this study's results cannot be generalized.

Implications for Nursing Practice

The findings have implications for developing strategies for nursing practice, using a multidisciplinary approach, to increase knowledge, decrease worry, and promote health by integrating urban Dominicans immigrants' faith and cultural beliefs regarding cancer (Pacsi, 2015). All strategies should target families, not just individuals. Additionally, it would be beneficial to engage community stakeholders, faith-based groups, and the community, to offer easy to understand informatics-based tools in Spanish to assess and provide culturally relevant information about risks for various cancers. In addition, given the Hispanic cultural values of *destino*, *familismo*, *confianza*, and *personalism*, it is important that these be incorporated in the development of interventions to address cancer worry in order to establish a trusting relationship with the urban Dominican immigrant community residing in Washington Heights/Inwood community.

Culturally appropriate informational programs should also be created for television, video, and face-to-face group chats that can provide a forum to ask questions and express concerns about cancer, early detection, and screening practices. Moreover, given that this community (and Hispanics in general) is more likely to access the Internet through mobile phones, and the prevalence of cell phones over landlines, it is important that cancer-related informatics be suitable for mobile technology.

Conclusion

Dominican women's experience with cancer worry is multifaceted and rooted in their culture. All participants expressed the belief that they are in control of their destiny and that faith gives them the strength to participate in prevention and treatment measures. This is further influenced by the relationships and shared decision making with their health care providers and family. Their knowledge about cancer, both objective and subjective, guides their worry about cancer and related health care decisions. However, our findings suggest there is a knowledge gap in this population regarding the objective meaning, etiology, genetics, and behavioral risk factors of cancer. As in other studies, Dominican women's lack of knowledge appears to increase their cancer worry but also serves as an impetus for increased screening (Consedine, Magai, & Neugut, 2004; Flórez et al., 2009; Garbers, Jessop, Foti, UribeArrea, & Chiasson, 2003).

Future qualitative studies should be conducted to assess the role that knowledge, relationships, destiny, and faith play in the cancer worry of Dominican women, as well as other Hispanic women of diverse backgrounds, and to increase understanding of how these contribute (both positively and negatively) to cancer-related outcomes. These studies would lead to creating culturally congruent strategies to assess and intervene with cancer worry more effectively and help this population make informed decisions based on facts regarding cancer prevention practices, which will improve outcomes (Flórez et al., 2009; Pacsi, 2015; Schumacher, 2010).

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Table 1

Sample inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> a. self-identified urban immigrant Dominican woman b. residing in the Washington Heights/Inwood Community c. able to speak and understand English and/or Spanish d. a previous participant in the WICER survey e. on record as signing the original study consent form indicating willingness to be contacted for future studies f. agreed to data linkage g. between the age of 30 and 60 during the initial WICER study h. able and willing to provide informed consent 	<ul style="list-style-type: none"> a. residing outside the Washington Heights/Inwood Community b. not a previous participant of the WICER study c. participated in the WICER study, but did not agree to data linkage d. less than 30 or more than 60 years of age during the WICER study e. cognitively impaired

Table 2

Demographic characteristics of the sample

Factor		N=38
Age		
	30–39	3
	40–49	8
	50–59	23
	60–69	4
Income		
	0	32
	1–19,999	3
	20,000–29,999	1
	30,000–39,999	1
Number of Children		
	1	5
	2	14
	3	14
	4	2
	5	3
Sex		
	Female	38
Insurance		
	Medicare	1
	Medicaid	29
	Private	3
	None	2
	Other	3
Marital Status		
	Single	10
	Married	14
	Divorced	10
	Widowed	2
	Cohabiting	2
Education		
	High School	30
	College	8
Working Status		
	Full Time	9
	Part Time	5
	Unemployed/Disabled	24

Factor		N=38
Cancer Diagnosis		
	Yes	2
	No	36
Family History of Breast Cancer		
	Yes	3
	No	26