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Understanding the Supportive Care Needs of Hispanic Men Cancer Survivors

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1. Introduction

Advances in cancer detection and treatment have led to an increase in the population of cancer survivors in the United States and globally (Hodgkinson et al. 2007, International Agency for Research on Cancer 2014, Fitzmaurice et al. 2015). Individuals who have been diagnosed with cancer continue to experience long term side effects and psychosocial concerns that extend well beyond the treatment phase (Adler and Page 2008, Martinez Tyson 2008, American Cancer Society 2012). Thus, it is critical that we develop a better understanding of the supportive care needs of this growing population. Supportive care is defined as the services/assistance provided to cancer patients and their families to help them cope with disease and enhance quality of life throughout the disease trajectory (Hui et al. 2013).

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Conflict of Interest

There is no conflict of interest to report.

In 2015, approximately 1.7 million people will be diagnosed with cancer in the United States (American Cancer Society 2015). About 125,900 of those new cancer cases are expected to be Hispanic (Siegel et al. 2015). When compared to non-Hispanic whites, Hispanics have disparate rates of 5-year cancer survival (Siegel, Naishadham, and Jemal 2013) and are vulnerable to cancer inequalities due to disproportionate poverty and other barriers to health care. For example, compared to other racial/ethnic groups, Hispanic cancer patients are the most likely to be uninsured and are generally more likely than non-Hispanic whites to be diagnosed at an advanced stage of disease (Halpern et al. 2008, Siegel et al. 2015). Compared to non-Hispanics, Hispanic men report significantly worse sexual and physical function, bowel bother, bowel function (Krupski et al. 2005), emotional well-being (Traeger et al. 2009), mental health (Gore et al. 2005), and overall QOL (Ramsey et al. 2007). Poor outcomes are exacerbated by lack of support, information, and skills to manage illness (Gore et al. 2005, Adler and Page 2008). Furthermore, men who have been diagnosed with cancer are less likely than women to use health and psychological supportive care services (Im 2008), and subsequently have significant unmet psychosocial and health information needs (Lintz et al. 2003).

Considering the number of Hispanic cancer survivors is growing (Siegel et al. 2015), it is critical to develop a better understanding of the supportive care needs of this at-risk population. Currently, limited research has been conducted to identify and explore the supportive care needs of Hispanic male cancer survivors (HMCS), which must be well-understood to properly develop or adapt interventions relevant to this population. The purpose of this paper is to provide a deeper understanding of the supportive care needs of HMCS living in the United States.

2. Methods

This paper reports on the qualitative segment of an exploratory sequential mixed methods study (Creswell and Clark 2007) whose overarching goal was to translate and culturally adapt the previously validated English language Cancer Survivors' Unmet Needs measure (CaSUN) (Hodgkinson et al. 2007) for Spanish-speaking HMCS. Qualitative methods (i.e. in-depth interviews and focus groups), which are appropriate for exploratory research, were used to understand the supportive care needs of HMCS (Bernard 2011). The project leveraged existing strong relationships of the Principal Investigator (DMT), the Tampa Bay Community Cancer Network (TBCCN), and community-based organizations that serve Hispanic cancer survivors in West Central Florida. Drawing from the principles of community-engaged research, a community advisory board consisting of bilingual cancer survivors, cancer survivorship experts, and Hispanic community members was convened and informed the research process by providing ongoing feedback from conceptualization of study concept to dissemination of findings.

2.1. Sample and Recruitment

Using purposive sampling, an approach appropriate for exploratory research (Bernard and Ryan 2010), Hispanic men of various national origins were recruited using the cancer registry from a local cancer center and through established relationships with community

organizations serving Hispanic cancer survivors via flyers and word-of-mouth. The inclusion criteria for study participants were: (1) self-identify as Hispanic/Latino, (2) Spanish-speaking, (3) 18 years of age and older, (4) have completed initial cancer treatment, and (5) between one to five years post-cancer diagnosis. Since the overarching purpose of this study was to culturally adapt the CaSUN measure which is designed to be used among adult cancer survivors of all ages, we felt it was important to be inclusive of adult survivors.

To include multiple perspectives of the survivorship experience of Hispanic men, we also conducted interviews with individuals who cared for and or treated HMCS in some capacity. Providers were recruited through established relationships with local cancer centers and community-based organizations.

2.2. Data Collection

The guides for the focus groups with HMCS and interviews with providers were similar in wording and content. The items were informed by literature, the biopsychosocial model (Novy and Aigner 2014) and the domains of the CaSUN (Hodgkinson et al. 2007). The focus groups sessions and interviews were divided into two parts. The first part included open-ended questions aimed at understanding the cancer survivorship experience of HMCS from the emic (cancer survivor) and the etic (provider) perspectives. Topics included HMCS's concerns and needs related to information, cancer care, quality of life, and social support. The second part included a review and discussion of the CaSUN (which are reported in a separate publication). The interview guides were reviewed and piloted with the project's community advisory board. A few minor adjustments were made to increase the face validity of the questions. The use of open-ended questions allowed unanticipated issues and topics to emerge. We used follow-up and probing questions to further illuminate topics and examples.

Two of the focus group sessions took place at a local cancer center and one took place at the university. The focus groups were conducted in Spanish by trained bilingual native Spanish speakers using established focus group procedures (Krueger and Casey 2009). HMCS generously shared their experiences and cancer stories openly. The facilitator and moderators recorded their field notes and observations and debriefed after each focus group session. All procedures were in accordance with the ethical standards of the University of South Florida Institutional Review Board (IRB). Informed consent was obtained from all participants.

2.3. Data Analysis

Data from focus groups with HMCS, interviews with providers, and debriefing sessions were transcribed verbatim in Spanish and/or English or any mixture of the two languages, and were analyzed concurrently using applied thematic analysis techniques (Guest, MacQueen, and Namey 2011). The members of the research team (DMT, PMR and CVO, all bilingual) read through the transcript from the first focus group session to develop the initial codebook following the focus group guide. The codebook included inductive and deductive codes. After PMR and CVO coded the first transcript independently, the codebook was discussed and revised as a team once a consensus on all codes was reached. The remaining

transcripts were coded independently by PMR and CVO. During the coding process, the team met regularly to review the coded transcripts and came to consensus if there was any disagreement. The data were coded using ATLAS.ti 7. Data saturation was achieved when no new themes emerged during the third focus group. When all the transcripts were coded, themes were analyzed and summarized using network views and thematic diagrams, which were developed and iteratively discussed by the research team. Once the illustrative quotes for the themes were selected they were translated to English by one of the members of the research team (NAB). The translation was reviewed by two of the other team members (DMT and PMR) to ensure accuracy. The findings were shared with the community advisory board who concurred with the interpretation of the results.

3. Findings

3.1. Sample characteristics

A total of 18 HMCS participated in the focus groups. Participant characteristics are summarized in Table 1. The mean age of the cancer survivors at the time of diagnosis was 60 (SD=8.7, range= 39–70). The majority of the cancer survivors had health insurance (83%) and were married or living with a partner (78%). Half of the participants worked during treatment (50%). At the time of the focus group most indicated having a household income of less than \$30,000 a year (53%) and more than half considered it to be barely or not enough to get by (59%). Most of the survivors born outside the US had been living in the country for at least 11 years (93%). Prostate cancer was the most common cancer (43%) reported by the survivors, and 28% indicated having more than one type of cancer. The cancer survivors represented five different Latin American countries: Puerto Rico, Cuba, Dominican Republic, Peru, and Colombia.

The sample of health providers was comprised of two men and three women (n = 5), all of whom were bilingual and had at least a college degree. Providers included a social worker, two oncologists, a patient navigator and a psychologist, all of whom have worked with Hispanic cancer patients across the different phases of the cancer trajectory. The workplace settings of the health providers included cancer treatment centers and private health clinics.

3.2. Emergent Themes

The four overarching themes reported below reflect the sentiments of HMCS and providers regarding the supportive care needs of HMCS. Thematic results from focus groups and interviews are presented concurrently. Provider perspectives are interwoven within each of the overarching themes and used to support or contextualize the needs of HMCS.

3.2.1. Need for Culturally Sensitive Cancer Care and Better Communication with Providers—During focus group discussions, HMCS spoke about various communication-related issues centered within the patient-provider context. Specifically they discussed issues related to English language proficiency, use of interpreters, and *confianza* (familiarity, trust based on rapport and personal relationships, the ability to confide in and connect with) that could be nurtured through a provider's willingness to listen and discuss certain topics (e.g., complementary medicine).

Language barriers related to patient's English proficiency: Most men in the focus groups, even those who were bilingual, expressed preference to communicate and receive cancer-related treatment information in Spanish (See Table 1). Participants expressed concern about not being able to fully comprehend what was said by providers and felt they did not have the ability (e.g., mastery of the English language) to fully communicate/articulate their worries, thoughts, and questions. As described in the following quote, the perceived inability to express themselves remained an issue even when an interpreter was available.

“There are questions that we as patients might want to ask, but we don't know how to, or we don't have the words/vocabulary to be able to do them, so it's a lot, I mean... I think it would be a lot better if that type of meeting was in Spanish...”
(Cancer Survivor)

Lack of trust and uncertainty using interpreters: There was consensus among the men that although interpreters were helpful, they were not always convinced that what interpreters said to the provider was exactly what they had wished to communicate. They also thought an interpreter could not express what they felt in the same way. The reservations they had towards using interpreters also affected their willingness to fully disclose their feelings and kept them from going into detail and asking follow-up questions. For instance, a focus group participant shared how he needed a letter from the oncologist for his employer because after his treatment he could no longer perform the manual labor required for his position. He told the interpreter, who then told the oncologist. The interpreter then flatly replied that this participant needed to get the letter from his primary care physician, providing no additional follow-up or guidance. The participant felt dissuaded from telling the interpreter that he could not get an appointment with his primary care physician for another month and that his boss had given him an ultimatum - if he did not have the letter by the end of the week he would lose his job. This man did not understand nor feel that a letter from the primary care physician was the proper course of action if the issue was related to his cancer treatment. He was distraught. The lead author, (DMT) asked the participant if he had shared his frustration or asked for clarification from the interpreter and his doctor. The participant said no, that he felt uncertain and did not feel comfortable or lacked the *confianza* to ask any additional questions or ask the interpreter to elaborate.

Providers interviewed also mentioned similar issues related to communication and Hispanic patients' comprehension of cancer-related information. Some providers perceived that the low educational level among some Hispanic men was an issue affecting communication. There was consensus among the providers that, in comparison to patients from other ethnic groups, they felt the need to spend more time with Hispanic patients as it took them longer to process the cancer diagnosis and make treatment decisions.

“Hispanics, I feel, are more emotional in dealing with their situation; they um... have more level of uncertainty and making a final decision and often times their first thought is to do as a doctor tells them... that takes a lot of conversation to educate them that they have to be part of the decision, they have to learn about their cancer and be part of the decision. So, that's the first challenge.” (Provider)

Another provider expressed similar concerns.

“Um, as an example I can see a patient for a 45 minute visit. It may turn out to be an hour and half [with Hispanic patient]. And that is usually more the norm than not. Because they do not know where they’re supposed to go next because they do not understand what their previous provider said to them. So, I feel sometimes obligated to assist them in those regards. Either to help them navigate to where they need to go next or to clarify misinformation that often they come to me with. So I have to look at the records, I have to read what they [other providers] wrote. I have to translate it to the patients or at least, um, help them understand what other providers tried before.” (Provider)

Time to build *confianza* (trust) and to process cancer information: Closely related to the previous themes, an important element that surfaced during the focus group discussions was the importance of having *confianza* (trust) and *personalismo* (friendly and personal relationship) with providers, which allows men to build rapport and be able to talk openly with providers. Many of the men mentioned the physician’s ethnicity and/or nationality, especially if the provider was Hispanic, when describing a trusting and positive relationship as illustrated by this quote (CS: cancer survivor):

CS₁- It is the treatment...what I mean is, doctor (physician’s Hispanic surname) was the one who took care of me, doctor (physician’s Hispanic surname) was very affectionate, very, very friendly, he is Puerto Rican, he is very caring, but one always need the nurses and others...

CS₂- Oh, no [affirmative no]

CS₁- to ask more questions, to be seen more like, not, not to be treated like a number that is what I mean by ... [treating us the Latino way]

If the cancer survivors perceived the provider to be empathetic, caring, warm and non-judgmental, they reported being more willing to discuss and less inhibited to disclose what they were feeling and doing to manage treatment side-effects and prevent cancer recurrence (e.g., using alternative or traditional remedies). However, providers discussed Hispanic men patients’ lack of engagement which they inferred based on a patient deferring to their wife or daughter. Providers explained how spouses/partners and/or daughters usually accompanied the men to medical appointments and tended to ask most of the questions and speak directly to them.

3.2.2. Need for more cancer treatment-related information and comprehensive survivorship care—Besides cancer recurrence, the major concerns and sources of stress discussed by participants were related to not having enough information about the treatment they received, the long-term side effects (e.g., impotency, incontinence, fatigue), and the availability of other treatment options and/or alternative/complimentary medicine. Several participants stated they knew little about the treatment they received. A few participants discussed that if they had known about the side effects of their treatment they might have opted for something else or have made a more informed decision. For instance, a prostate

cancer survivor explained that while providers allowed patients to make treatment decisions, insufficient information is provided about treatment options.

“They [the doctors] don’t pressure you to operate, but I think that person making the decision should have...it should be explained to him more clearly...the decision that [he] is making and if there is an option or another treatment...why not?”

HMCS also expressed concerns over not having information about what they needed to do after the treatment was over with regards to follow-up care. For instance, many of the men shared they did not know how often they needed to go back to see their provider nor what other types of follow-up care they might need (e.g., screenings for cancer). Overall, survivors felt cancer care needed to be more comprehensive and holistic, extending beyond the treatment phase and focus on maintaining overall health and wellbeing.

Among the cancer survivors there was a lot of discussion and interest in learning more about complementary medicine such as natural remedies (i.e. tea, natural pills), and nutrition. Many felt there was very limited, if any, dialogue with providers about this topic and that some providers were dismissive when they asked questions about complementary/alternative medicine. Thus, participants turned to the internet, natural food stores, or friends and relatives in their home country for advice. None of the providers mentioned the topics of nutrition and complimentary/alternative medicine in interviews.

3.2.3. Need to negotiate changing gender role expectations and still provide for their family—Cancer survivor participants worried how treatment side effects (e.g., impotency -a frequently mentioned side effect among focus group participants) could affect their relationship with their wives/partners and make them incapable of fulfilling their spousal obligations. From their discussions this obligation was less about their individual satisfaction but more about meeting their wife’s physical needs. Some men even expressed concern about their wife leaving them because of this. The following discussion between several focus group participants delineates this issue:

CS₁- The only problem that I have is erectile dysfunction because I ended up with erectile dysfunction...

CS₂- oh, yes me too

CS₃- I did too

CS₄- yes

CS₁- and that cost me a separation from...from my wife

Other side effects such as incontinence also had an impact on perceptions of masculinity. For instance, one participant talked about his experience and how it made him feel like a woman.

“... I was like that for over a year... Not able to just go to the bathroom and urinate. Why you ask? Because I did not have the urge, it would just leak out. I had pampers [diapers] and more pampers and more pampers... until today – the only improvement is that now I wear pads. I am like a woman on her period 24 hours a day... this has been my life for four years now... very uncomfortable and very

unsatisfied... I went to get treatments for it... some type of exercises and electrodes but it ended up that my insurance would not cover it and I could not keep doing that..." (Cancer survivor)

Changing roles and the ability to work and provide for the family: Related to the culturally mediated gender roles, men discussed how their role within their family changed after cancer diagnosis and treatment. Many of the men were accustomed to working outside the home and had been the primary breadwinner for their family. However, the treatment process (e.g., having to go in for radiation on a daily basis for several weeks), treatment itself (e.g., chemotherapy, surgery) and related treatment side effects (e.g., fatigue, weakness) negatively affected their ability to work or employment status (e.g., reduced hours, loss of job, inability to do the same type of work). After treatment most participants had difficulty working or keeping their jobs, especially those that worked in occupations such as construction, building maintenance, or other jobs requiring manual labor. Participants were concerned about the effects treatment had on their ability to work and provide for their families. This placed an even greater financial burden on their families. This was also stated by providers in our study, who mentioned how Hispanic men were often more concerned with how treatment would affect their ability to work rather than about the treatment itself.

"...but the fact "how long is the treatment, can I work while I'm doing it", that's a big concern for them [Hispanic men]. Those are the questions that come even before they ask about, you know, side effects or this and that; for them is like how long can I work because if they're not, then the family would suffer the economics." (Provider)

Closely related to this concern was the men's description of how their role at home had changed, in part due to their employment status, where now they spent more time at home and were able to contribute to doing chores around the house (i.e. cleaning the dishes, cooking). The discussion about having to do more household chores was discussed as a normal activity that resulted from spending more time in the house, and there was no discussion of any gender role-related stigma.

Concerns about burdening wives and daughters: Focus group participants mentioned they felt their wife, daughters and family members in general, needlessly worried about them as illustrated by the following comment, "...*imagine when, when my family found out that I had cancer they would call me every day as if I was... in my last days.*" Another cancer survivor went on to add "...*the person that is sick is the one who knows what they have but then there is the family, the family around you who think it is the worst [case] scenario.*" Many of the men were concerned about this and did not want to place a bigger burden on their wife and other family members or worry them further. They felt they needed to fulfill their role as provider and protector. Thus, they preferred not to disclose how they were feeling in order to protect their family, particularly their wives. The men also felt strongly that their wives needed some type of support. Interestingly, the day the focus groups were conducted, several men were accompanied by their wife. During the focus groups, the

wives waited outside and formed a mini-support group, voicing the need for programs to help them cope.

3.2.4. Need for support and to connect with other cancer survivors—During the focus groups, the men expressed the need to connect with other men who had gone through a similar experience. They wanted an opportunity to socialize and *distrarse* (to distract) with other survivors outside of the cancer context. They openly shared their experiences, talking about their needs and concerns without inhibition. The focus group gave them the opportunity to share their cancer story and to *desahogarse* (vent, get things off their chest). A few men disclosed that participating in the focus group was the first time they had met and talked with other Hispanic men, who have had cancer. As shared by one participant,

“I thought that the only one [Hispanic man] who had ... cancer treatment here had been me, and to me it is a surprise that there are three other people who have been through the same and I think they would be very pleased also to be able to communicate with others, and share experiences and talk about it and maybe meet, have a coffee, invite some ladies, dance merengue, do something ... (all laugh)”
(Cancer survivor)

At the end of each focus group and provider interview we asked participants what type of program or intervention would best address the supportive care needs of HMCS. Both providers and survivors discussed that a one-on-one type of program or intervention might not resonate well as men might feel they are forced to share and singled out. They suggested that a group environment or activity would be more acceptable and would also provide men with the opportunity to meet and connect with other cancer survivors.

4. Discussion

To date, there is a paucity of research and information on HMCS, who comprise part of the largest and fastest growing racial/ethnic minority group in the country (Siegel, Naishadham, and Jemal 2012). Male cancer survivors, in general, and Hispanic men especially, are underrepresented in the psychosocial and survivorship literature (Carrion, Nedjat-Haiem, and Marquez 2013), yet their unique needs must be addressed in order to ensure ideal supportive care.

The first group of themes relate to communication issues within the patient-provider relationship that are linguistically and culturally mediated and center on the participant's ability to communicate and understand cancer-related information. Communication-related issues also influence how participants feel about their providers. Providers (i.e., physicians, social workers, psychologists, nurses) who are better able to communicate in Spanish, build rapport with patients, and provide care in a culturally-sensitive manner were perceived more favorably. Embracing the Hispanic cultural value of *personalismo* (importance of warm, informal social relations) will help Hispanic patients develop *confianza* with their providers which will subsequently facilitate communication (Rojas 2008, Bracero 1998).

Sociocultural factors such as limited English proficiency, uncertainty about using interpreters, and lack of trust were intimately connected to issues of nondisclosure and

limited communication with providers. These issues provide additional insights into why providers may perceive Hispanic male patients to be less assertive and engaged, and require more time to understand and process a cancer diagnosis or treatment-related information compared to patients from other ethnic groups.

Patient-provider communication is, in part, mediated by wives and/or daughters, who are sources of support for HMCS. Wives and daughters played a key role in the patient-provider relationship by actively engaging in discussions with the provider and serving as advocates for their husbands/fathers. The high value of a wife's opinion regarding treatment-related decisions has been reported in the literature among both HMCS and men from other ethnic groups (Love, Thompson, and Knapp 2014, Rivers et al. 2012). In contrast to the dominant US culture that typically emphasizes individualism, especially within the context of health care, Hispanics may tend to place a strong emphasis on more family-centric values, often referred to as *familismo*, in which they value interdependence and involvement of the entire family in the decision-making process (Galanti 2003). Recognition of this by providers can help improve the patient-provider relationships as well as engagement with the entire family, subsequently improving patient satisfaction and adherence to care (Erwin et al. 2010).

The second set of themes vocalizes the need for holistic and comprehensive survivorship care to go beyond the treatment phase, an issue identified in the literature for cancer survivorship care overall, regardless of ethnicity (Rowland, Hewitt, and Ganz 2006). Our findings further highlight the need for a coordinated approach to survivorship care that focuses on the communication and transfer of information in a culturally and linguistically relevant manner.

Stress and concerns related to treatment and its side effects have been reported in the cancer survivorship literature (Linden et al. 2012). In our study, these concerns were exacerbated by the inability to satisfactorily communicate with providers and receive treatment-related information in Spanish – even among bilingual survivors. Other studies conducted with Hispanic cancer survivors also report the expressed need for more readily available treatment and health-related information in Spanish (Simon et al. 2013). We suggest that Hispanic men's concerns related to the need for treatment information stems in part from the inability to communicate directly with providers in their preferred language. While some portion of the information given by providers may be understood, not all of it is and this may lead HMCS to experience additional stress and worry regarding what to expect for the course of action for their care.

We propose that the combination of issues related to trust/*confianza*, *personalismo* and limited understanding of the information presented may lead to a disconnect between patient and provider communication which may also influence HMCS' willingness to disclose their thoughts and emotions or further inhibit them from asking questions making them seem less assertive and engaged (Schouten and Meeuwesen 2006). Furthermore, the men who described having a Hispanic or bilingual doctor had a more positive communication experience (Guarnaccia, Martinez, and Acosta 2005).

The third set of themes illustrate how the experiences of men are often embedded within culturally mediated beliefs related to masculinity which influence how men cope with disease and express personal needs (Liang, Salcedo, and Miller 2011). During illness, power relations and gender role expectations may change and impact psychosocial outcomes such as perceptions of masculinity (Arrington 2008, Courtenay 2000). Issues related to providing for a family and workability emerged and were discussed at length. Foremost, HMCS wanted to know how cancer treatment and its side effects would affect their ability to work. As reported in the literature, a majority of cancer patients encounter at least temporary changes in work hours, wages, and schedules and experience a decrease in their work ability (Mehnert 2011) that may last beyond the treatment phase. Persons from lower socioeconomic backgrounds, such as the majority of the men in this study, may experience an even greater decline in employment status (Mehnert 2011). Both providing sufficient income to meet household needs and the ability to work are closely tied to Hispanic masculine values of providing for and protecting one's family (Maliski et al. 2008). The inability to meet both of these gender role expectations may also contribute to the distress experienced by HMCS. Interestingly, the men we interviewed were able to renegotiate role changes within the home (e.g., now they were the ones doing household chores) which illustrates the fluidity of masculine identity in the presence of symptoms resulting from cancer treatment (Liang, Salcedo, and Miller 2011, Courtenay 2000).

Men cancer survivors also discussed concerns about their ability to care for their wife and deal with changes in sexuality, though few used the term erectile dysfunction (ED). Maliski et al. (2008) also found ED expressed as the inability to take care of one's wife and how this fueled fear of losing a partner after prostate cancer. HMCS also discussed keeping things to themselves because they did not want to worry or burden their wife and family. We suggest that perhaps this not only affects the disclosure of information within the household, but also how much information is shared within the patient-provider context if a wife or daughter is present.

The fourth group of themes centered on the need for support and to connect with other men cancer survivors which has also been reported in the literature (Trapp et al. 2013). Despite assumptions that Hispanic men may prefer to handle things privately or individually (Courtenay 2000) which is aligned with traditional Hispanic male gender roles, participants emphasized their appreciation for the opportunity to talk about their experience with other Hispanic men who had also experienced cancer. The men we interviewed were not inhibited and talked openly about sensitive issues, even with a female focus group facilitator. The men expressed the need to connect with others and preferred group-based, collective, connection-based support (Trapp et al. 2013).

5. Implications for Practice and Survivorship Care

Findings illustrate four broad areas that deserve attention in both clinical practice and research. When treating and working with Hispanic cancer survivors we need to be attuned to cultural variations in communication and conversation styles and recognize these are influenced by social norms that may affect where emphasis is placed. For example, Hispanics may be more contextually oriented and place more emphasis on paralinguistic

cues and the situational context than on the content of information provided (Schouten and Meeuwesen 2006, Simon et al. 2013). Furthermore, a patient's assertiveness, also informed by social norms, may affect how their level of involvement is perceived by providers. Recognizing the differences between collectivist and individualistic cultures may help us better understand the supportive care needs of HMCS. However, we must also consider that Hispanics are a heterogeneous group comprised of individuals and subgroups with variations in values and beliefs.

Providers (e.g., physicians, nurses, social workers) need to engage HMCS and their families throughout the cancer treatment and survivorship trajectory. In order to build rapport and trust we need to treat them with warmth and express personal interest in them (Guarnaccia, Martinez, and Acosta 2005). A way to build trust and open up communication between the provider and the cancer survivor is to use the explanatory models approach described by Kleinman (Kleinman 1978). Embracing the value of *personalismo* and *familismo* will help engage Hispanic cancer survivors (Ko et al. 2014). This can be done by getting to know and understand their viewpoint, expectations and what may be at stake for them (e.g., ability to work) as well as the stressors they are experiencing. Providers should ask their patients what is causing them the most stress, what their concerns are, and what are their treatment-related problems such as changes in roles at home and workability. Inquiries about what they are doing to cope, how they are managing side effects, and what they are doing to stay healthy – which may include the use of complementary and alternative therapies (e.g., teas, herbs, etc.), should also be included in the dialogue. Providers should listen with open-mindedness and respect, acknowledging what patients may already be doing (e.g. use of home remedies) and use this as an opportunity to build trust and enhance engagement. Hispanics may consult immediate and extended family before making a decision, thus providers should acknowledge the opinion of the patient's family members. Consequently, being perceptive and understanding of the needs of HMCS and what they most value in care and patient-provider relationships are important interpersonal skills that are invaluable tools for providers.

While some of the needs expressed by participants in this study may be unique to survivors from Hispanic background, e.g., importance of *personalismo*, these needs may also be globally applicable to survivors with limited English proficiency or other ethnic groups. For example, among African-American patients, Williams et al. (2008) found that an emphasis on effective communication, which includes getting to know and understand the patient and their family, is highly valued, and effective communication can ideally be executed through these patient-provider-family relationships.

Despite the need for improved patient-provider communication, we also recognize the provider's perspective regarding the difficulty of establishing rapport and a closer relationship with patients within the current healthcare system. Providers whether it be physicians, social workers and or psychologists working in oncology settings are rushed with patients, limiting their ability to show *personalismo*, something that Hispanic men may need in order to build rapport with their provider.

Medical interpreting services are invaluable in situations where providers are not fluent in the cancer survivor's language. However, it should be recognized that simply having an interpreter in the room may change the dyadic relationship and power dynamics between patient and provider [IMIA] (2007). This may be further exacerbated by age and gender differences between the interpreter and the patient, since men may feel inhibited to discuss intimate issues (e.g. ED) in front of younger and/or female interpreters. Hence, it is imperative to follow the recommendations of using trained interpreters whenever possible, and interpreters must provide assurance to patients that they are interpreting everything being said ([IMIA] 2007). We must also promote adequate training on proper interpreting procedures for providers to ensure appropriate knowledge and attitudes (e.g. always addressing the patient, explaining technical terms to the patient) when working with medical interpreters and non-English speaking patients.

6. Strengths and limitations

The use of focus groups and interviews in qualitative research provides the opportunity to explore the breath of the participants' experiences. Study findings contribute to the literature by presenting the needs of HMCS, a population that is under represented in the psychosocial and survivorship research. The use of purposive sampling limits the generalizability of the results of this study. However, a wide range of experiences were represented based on recruiting from both the general community and from a specialized cancer center, including men with a variety of cancer diagnosis sites and including provider perspectives. A limitation, though, is the relatively small number of patients and providers in this study. However, study findings were shared with the project's community advisory board who concur with the findings. Future research should focus on further exploring providers' perspectives when working with HMCS, in particular communication issues that might arise in the context of the patient-provider relationship. These insights could aid in the adaptation and/or development of interventions for the HMCS.

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References

- [IMIA], International Medical Interpreters Association. Medical Interpreting Standards of Practice. 2007. <http://www.imiaweb.org/uploads/pages/102.pdf>
- Adler, NE., Page, AEK. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: Institute of Medicine; 2008.
- American Cancer Society. Cancer Facts & Figures for Hispanics/Latinos 2012–2014. Atlanta: American Cancer Society; 2012.
- American Cancer Society. Cancer Facts & Figures 2015. Atlanta: American Cancer Society; 2015.
- Arrington, Michael Irvin. Prostate cancer and the social construction of masculine sexual identity. International Journal of Men's Health no. 2008; 7(3):299–306.

- Bernard, H Russell. Research methods in anthropology: Qualitative and quantitative approaches. Rowman Altamira; 2011.
- Bernard, H Russell, Ryan, Gery W. Analyzing qualitative data: Systematic approaches. SAGE publications; 2010.
- Bracero, William. Intimidades: Confianza, gender, and hierarchy in the construction of Latino–Latina therapeutic relationships. *Cultural Diversity and Mental Health*. 1998; 4(4):264. [PubMed: 9818515]
- Carrion, Iraida V., Nedjat-Haiem, Frances R., Marquez, David X. Examining cultural factors that influence treatment decisions: a pilot study of Latino men with cancer. *Journal of Cancer Education*. 2013; 28(4):729–737. [PubMed: 23881820]
- Courtenay, Will H. Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social science & medicine*. 2000; 50(10):1385–1401. [PubMed: 10741575]
- Creswell, John W., Plano Clark, Vicki L. Designing and conducting mixed methods research. 2007
- Erwin, Deborah O., Treviño, Michelle, Saad-Harfouche, Frances G., Rodriguez, Elisa M., Gage, Elizabeth, Jandorf, Lina. Contextualizing diversity and culture within cancer control interventions for Latinas: changing interventions, not cultures. *Social science & medicine*. 2010; 71(4):693–701. [PubMed: 20646810]
- Fitzmaurice, Christina, Dicker, Daniel, Pain, Amanda, Hamavid, Hannah, Moradi-Lakeh, Maziar, MacIntyre, Michael F., Allen, Christine, Hansen, Gillian, Woodbrook, Rachel, Wolfe, Charles. The Global Burden of Cancer 2013. *JAMA Oncology*. 2015; 1(4):505–527. [PubMed: 26181261]
- Galanti, Geri-Ann. The Hispanic family and male-female relationships: An overview. *Journal of Transcultural Nursing*. 2003; 14(3):180–185. [PubMed: 12861920]
- Gore JL, Krupski T, Kwan L, Fink A, Litwin MS. Mental health of low income uninsured men with prostate cancer. *J Urol*. 2005; 173(4):1323–6. S0022-5347(05)61090-7 [pii]. DOI: 10.1097/01.ju.0000152312.28002.ad [PubMed: 15758790]
- Guarnaccia PJ, Martinez IE, Acosta H. Chapter 2. Mental Health in the Hispanic Immigrant Community: An Overview. *Journal of Immigrant & Refugee Services*. 2005; 3(1–2):21–46.
- Guest, Greg, MacQueen, Kathleen M., Namey, Emily E. Applied Thematic Analysis. Sage; 2011.
- Halpern, Michael T., Ward, Elizabeth M., Pavluck, Alexandre L., Schrag, Nicole M., Bian, John, Chen, Amy Y. Association of insurance status and ethnicity with cancer stage at diagnosis for 12 cancer sites: a retrospective analysis. *The lancet oncology*. 2008; 9(3):222–231. [PubMed: 18282806]
- Hodgkinson K, Butow P, Hunt GE, Pendlebury S, Hobbs KM, Lo SK, Wain G. The Development and Evaluation of a Measure to Assess Cancer Survivors' Unmet Supportive Care Needs: The CaSUN (Cancer Survivors' Unmet Needs Measure). *Psycho-Oncology*. 2007; 16(9):796–804. [PubMed: 17177268]
- Hui, David, De La Cruz, Maxine, Mori, Masanori, Parsons, Henrique A., Kwon, Jung Hye, Torres-Vigil, Isabel, Kim, Sun Hyun, Dev, Rony, Hutchins, Ronald, Liem, Christiana. Concepts and Definitions for “Supportive Care,” “Best Supportive Care,” “Palliative Care,” and “Hospice Care” in the Published Literature, Dictionaries, and Textbooks. *Supportive Care in Cancer*. 2013; 21(3): 659–685. [PubMed: 22936493]
- Im EO, Chee W, Guevara E, Lim HJ, Liu Y, Shin H. Gender and ethnic differences in cancer patients' needs for help: An Internet survey. *International Journal of Nursing Studies*. 2008; 45(8):1192–1204. DOI: 10.1016/j.ijnurstu.2007.09.006 [PubMed: 17963769]
- International Agency for Research on Cancer. World Cancer Report 2014. Geneva: World Health Organization; 2014.
- Kleinman, Arthur. Concepts and a model for the comparison of medical systems as cultural systems. *Social Science & Medicine*. Part B: Medical Anthropology. 1978; 12:85–93.
- Ko, Linda K., Reuland, Daniel, Jolles, Monica, Clay, Rebecca, Pignone, Michael. Cultural and Linguistic Adaptation of a Multimedia Colorectal Cancer Screening Decision Aid for Spanish-Speaking Latinos. *Journal of Health Communication*. 2014; 19(2):192–209. [PubMed: 24328496]
- Krueger, Richard A., Casey, MA. Focus groups: a practical guide for applied research. Thousand Oaks, CA: Sage; 2009.

- Krupski TL, Sonn G, Kwan L, Maliski S, Fink A, Litwin MS. Ethnic variation in health-related quality of life among low-income men with prostate cancer. *Ethn Dis*. 2005; 15(3):461–8. [PubMed: 16108307]
- Liang, Christopher TH., Salcedo, Jime, Miller, Holly A. Perceived Racism, Masculinity Ideologies, and Gender Role Conflict Among Latino Men. *Psychology of Men & Masculinity* (12). 2011; (3): 201.
- Linden, Wolfgang, Vodermaier, Andrea, MacKenzie, Regina, Greig, Duncan. Anxiety and depression after cancer diagnosis: Prevalence rates by cancer type, gender, and age. *Journal of affective disorders*. 2012; 141(2):343–351. [PubMed: 22727334]
- Lintz K, Moynihan C, Steginga S, Norman A, Eeles R, Huddart R, Dearnaley D, Watson M. Prostate cancer patients' support and psychological care needs: Survey from a non-surgical oncology clinic. *Psychooncology*. 2003; 12(8):769–83. DOI: 10.1002/pon.702 [PubMed: 14681951]
- Love, Brad, Thompson, Charee M., Knapp, Jessica. Paper read at Oncology nursing forum. 2014. The Need to Be Superman: The Psychosocial Support Challenges of Young Men Affected by Cancer.
- Maliski, Sally L., Rivera, Steve, Connor, Sarah, Lopez, Griselda, Litwin, Mark S. Renegotiating Masculine Identity After Prostrate Cancer Treatment. *Qualitative Health Research*. 2008
- Martinez, Tyson D., Medina-Ramirez, P., Arriola, N., Vazquez-Otero, C., McMillan, S., Gwede, C. Combining Emic and Etic Perspectives to Translate and Culturally Adapt a Supportive Care Needs Measure for Hispanic Cancer Survivors. In press.
- Martinez Tyson, Dinorah. *Applied Anthropology*. University of South Florida; Tampa: 2008. The social context of stress and social support among immigrant Latinas diagnosed with breast cancer.
- Mehnert, Anja. Employment and work-related issues in cancer survivors. *Critical reviews in oncology/hematology*. 2011; 77(2):109–130. [PubMed: 20117019]
- Novy, Diane M., Aigner, Carrie J. The Biopsychosocial Model in Cancer Pain. *Current Opinion in Supportive and Palliative Care*. 2014; 8(2):117–123. [PubMed: 24690764]
- Ramsey SD, Zeliadt SB, Hall IJ, Ekwueme DU, Penson DF. On the importance of race, socioeconomic status and comorbidity when evaluating quality of life in men with prostate cancer. *J Urol*. 2007; 177(6):1992–9. S0022-5347(07)00276-5 [pii]. DOI: 10.1016/j.juro.2007.01.138 [PubMed: 17509278]
- Rivers, Brian M., August, Euna M., Quinn, Gwendolyn P., Gwede, Clement K., Pow-Sang, Julio M., Lee Green, B., Jacobsen, Paul B. Understanding the psychosocial issues of African American couples surviving prostate cancer. *Journal of Cancer Education*. 2012; 27(3):546–558. [PubMed: 22544536]
- Rojas, Tania P. *Hispanic Cultural Values and the Interpersonal Psychotherapy Model for Depression: A Critical Literature Analysis*. ProQuest; 2008.
- Rowland, Julia H., Hewitt, Maria, Ganz, Patricia A. Cancer survivorship: a new challenge in delivering quality cancer care. *Journal of Clinical Oncology*. 2006; 24(32):5101–5104. [PubMed: 17093270]
- Schouten BC, Meeuwesen L. Cultural differences in medical communication: a review of the literature. *Patient education and counseling*. 2006; 64(1):21–34. [PubMed: 16427760]
- Siegel, Rebecca L., Fedewa, Stacey A., Miller, Kimberly D., Goding-Sauer, Ann, Pinheiro, Paulo S., Martinez-Tyson, Dinorah, Jemal, Ahmedin. *Cancer Statistics for Hispanics/Latinos, 2015*. CA: A Cancer Journal for Clinicians. 2015; 65(6):457–480. [PubMed: 26375877]
- Siegel, Rebecca, Naishadham, Deepa, Jemal, Ahmedin. *Cancer statistics for hispanics/latinos, 2012*. CA: a cancer journal for clinicians. 2012; 62(5):283–298. [PubMed: 22987332]
- Siegel, Rebecca, Naishadham, Deepa, Jemal, Ahmedin. *Cancer statistics, 2013*. CA: a cancer journal for clinicians. 2013; 63(1):11–30. [PubMed: 23335087]
- Simon, Melissa A., Ragas, Daiva M., Nonzee, Narissa J., Phisuthikul, Ava M., Luu, Thanh Ha, Dong, Xinqi. Perceptions of patient-provider communication in breast and cervical cancer-related care: A qualitative study of low-income English-and Spanish-speaking women. *Journal of community health*. 2013; 38(4):707–715. [PubMed: 23553683]
- Traeger L, Penedo FJ, Gonzalez JS, Dahn JR, Lechner SC, Schneiderman N, Antoni MH. Illness perceptions and emotional well-being in men treated for localized prostate cancer. *J Psychosom Res*. 2009; 67(5):389–97. S0022-3999(09)00127-5 [pii]. DOI: 10.1016/j.jpsychores.2009.03.013 [PubMed: 19837201]

- Trapp, Stephen K., Woods, Jacqueline D., Grove, Alicia, Stern, Marilyn. Male Coping Processes as Demonstrated in the Context of a Cancer-Related Social Support Group. *Supportive Care in Cancer*. 2013; 21(2):619–627. [PubMed: 22903162]
- Williams, Sharon W., Hanson, Laura C., Boyd, Carlton, Green, Melissa, Goldmon, Moses, Wright, Gratia, Corbie-Smith, Giselle. Communication, decision making, and cancer: what African Americans want physicians to know. *Journal of palliative medicine* no. 2008; 11(9):1221–1226.

Table 1

Demographic characteristics of HMCS, N=18

	n (%)
Age	
41–64	10(56)
65+	7(39)
Missing	1(6)
Education Completed	
Less than high school	5(28)
High school	3(17)
College/Some college	7(39)
Graduate level	0(0)
Missing	3(17)
Heritage	
Puerto Rican	7(39)
Cuban	7(39)
Dominican	1(6)
Peruvian	2(11)
Colombian	1(6)
Marital Status	
Married/living with partner	14(78)
Divorced	1(6)
Widower	2(11)
Never married	1(6)
Current Employment Status	
At home	2(11)
Part-time	3(17)
Full time	4(22)
Retired	8(44)
Missing	1(6)
Current Household Income	
Less than \$10,000	5(28)
\$10,001 to 30,000	3(18)
\$30,001 to 50,000	4(22)
More than \$50,000	3(17)
Missing/Don't know	3(17)
Household Income is...	
Not enough	8(45)
Barely enough	2(11)

	n (%)
Enough	5(28)
More than enough	2(11)
Missing	1(6)
Health Insurance	
Yes	15(83)
No	3(17)
Age at diagnosis	
<40	1(6)
41–64	10(56)
65+	7(39)
Type of Cancer	
Skin and prostate	1(6)
Colon	4(22)
Prostate	3(17)
Prostate and lymphoma	1(6)
Prostate and pancreas	1(6)
Kidney	2(11)
Bladder	1(6)
Multiple myeloma	4(22)
Missing	3(17)
Worked during treatment?	
Yes	9(50)
No	9(50)
Language received cancer information	
English	10(56)
Spanish	1(5)
Both	7(39)
Language prefer cancer information	
English	0(0)
Spanish	12(67)
Both	6(33)