Latino Men and Familial Risk Communication About Prostate Cancer

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rothers and sons of Latino men with prostate cancer (PCa) are an unsuspecting at-risk group for PCa. Shared decision making ideally includes a discussion of familial risk. However, this assumes that families communicate risk and cancer histories and that relatives have regular access to preventative care. Few studies exist that focus on familial risk communication and screening decision making for men with PCa, much less Latinos (Tilburt et al., 2011). How families do or do not spread information about risks through their social networks and the implications this has for at-risk relatives' informed decision making about screening choices should be investigated (Palmquist et al., 2010). Several studies with the general population show that perceiving risk is not enough to prompt preventative behavior or screening (Beebe-Dimmer et al., 2004; McDowell, Occhipinti, Gardiner, Baade, & Steginga, 2009). McDowell et al. (2009) pointed out that if a relative's diagnosis of PCa acts as stimulus for screening, health promoters need to capitalize on the opportunity to inform both the affected man and the family about familial risk and screening options.

Evidence has shown that men with a first-degree relative (i.e., brothers or father) diagnosed with PCa have increased risk of developing PCa compared to men without a family history of PCa (Brandt, Bermejo, Sundquist, & Hemminki, 2010; Bratt, 2007; Colloca & Venturino, 2011; Madersbacher et al., 2011). Firstdegree male relatives (FDMRs) of men with PCa are more likely to undergo screening, which, in turn, may inflate the number of first-degree relatives who are diagnosed (Brandt et al., 2010). Still, a general consensus exists that unaffected FDMRs of men with PCa are an at-risk group in need of education and informed decision-making support (Brandt et al., 2010; Ola Bratt, 2007; Colloca & Venturino, 2011; Madersbacher et al., 2011). This is particularly true in the context of uncertainty about screening efficacy. Scientists do not **Purpose/Objectives:** To investigate how familial communication about prostate cancer (PCa) risk and screening affects sons of men with PCa.

Research Approach: Qualitative grounded theory.

Setting: Southern California.

Participants: 17 Latino sons of PCa survivors.

Methodologic Approach: The team conducted semistructured interviews and follow-up interviews. Therefore, the sample includes 25 transcripts. Data were analyzed with a mix of a priori topical codes and grounded theory techniques.

Findings: Sons were in need of information about familial risk and screening options. They became sensitized to PCa, desired information, and held protective intentions. Hopeful intentions came up against cultural taboos around sex, reproductive health, and intimacy that limited discussions between fathers and sons. Fathers were a valued source of information but play various roles, which affect sons' screening intentions. Open communication between father and son promoted awareness of screening and familial risk.

Conclusions: Uncertainty about familial risk and screening options, especially early detection strategies, was exacerbated by cultural taboos around PCa. Fathers could have been primary and credible advocates for shared decision making, but sons had difficulty learning from their fathers' experience.

Interpretation: Findings from the study can help inform community-based interventions with Latino families, help to culturally tailor health messaging, and sensitize clinicians to a group that needs concerted counseling about PCa risk and screening.

Key Words: prostate cancer; Latino; familial risk; taboo; screening

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agree on therole PCa screening should play, and that uncertainty trickles down to clinicians and men seeking information. Current guidelines in the United States advise men at average risk of developing PCa to engage in shared decision making at age 50 years or older, whereas men with higher-than-average risk of developing PCa should engage at ages 40–45 years depending

on their risk factors (Qaseem, Barry, Denberg, Owens, & Shekelle, 2013).

Risk and screening awareness is particularly important for Latino men because they are disproportionately diagnosed with non-localized PCa requiring aggressive intervention (American Cancer Society, 2014). PCa is the leading cancer diagnosed in Latino men, with 29% of new cancer cases in 2012 (American Cancer Society, 2014). Although incidence of PCa are lower for Latinos than non-Hispanic Caucasians, Latino men are diagnosed with later-stage disease than non-Hispanic Caucasian men (American Cancer Society, 2014; Bradley, Given, & Roberts, 2003; Gilligan, 2005; Klein, Nguyen, Saffore, Modlin, & Modlin, 2010). McFall (2007) studied race and ethnicity as a factor in screening rates and found that awareness was a determining factor in current and lifetime use of PCa screening test, independent of race and ethnicity. However, Latinos were less likely to be aware of the PCa screening test than non-Hispanic Caucasian men (McFall, 2007).

Therefore, increasing awareness about screening options among Latino men is critical to engage them in shared decision making. The diagnosis of Latino men at more advanced stages of the disease is a disparity that is not well understood. The current study sheds light on how health risks are talked about between fathers and sons.

Methods Participants

The data were collected as part of a larger study, which included men with PCa and a separate group of FDMRs of PCa survivors. The men with PCa and FDMRs who participated were not necessarily related; each group was recruited separately, meaning that no correspondence occurred between accounts from men affected by PCa and sons whose fathers experienced PCa.

After receiving approval from the University of California, Los Angeles (UCLA), Office for the Protection of Research Subjects, men with PCa were recruited from the men's health study, a longitudinal survey conducted by the UCLA Department of Urology. In this recruitment group, the authors' criteria were local men who were treated for PCa, self-reported as Latino, and had at least one FDMR. In the second recruitment group, the criteria were local men who were FDMRs of a man treated for PCa and self-reported Latino. These men were recruited through community advertisements. The analysis of data from men diagnosed with PCa focused on disclosure networks and was reported previously by Maliski, Connor, and Litwin (2012).

The current analysis includes 25 transcripts from 17 sons whose fathers were affected by PCa. An effort

was made to interview each son twice to help with member checking and confirmability. Of the 17 men who completed a first interview, eight completed a second interview. Follow-up interviews were completed an average of seven months after the baseline interviews.

Procedure

Data were gathered using semistructured, in-depth interviews, which varied in length from 30-45 minutes. Patients were contacted by phone, and, when consent was given, an interview was scheduled. In person, bilingual male interviewers obtained written consent and interviewed participants in the language of their preference (Spanish or English) in participants' homes. Demographic data, not including insurance status, were collected with a brief questionnaire. Interviews were recorded and transcribed verbatim in the language conducted, and the team translated Spanish transcripts to English. Ten participants were interviewed in Spanish and seven in English. The follow-up interviews were a convenience sample to help the interviewers focus more on the sons' decisionmaking processes about their own health. An effort was made to follow-up with each participant, but only eight were available. The follow-up interviews used the same interview guide, but stressed questions about the sons' personal health behaviors, knowledge, and decision making. The interviewers then followed up with each man based on topics from the baseline interview (see Figure 1).

Analysis

The research team did line-by-line coding to capture important actions expressed in the data. The team used broad a priori codes to assess sons' general knowledge of screening practices and familial risk. These two a priori topical codes were determined based on the previous analysis of data from men with PCa who had FDMRs (Maliski et al., 2012). These men expressed a great desire to promote screening to their FDMRs. Using Atlas.ti 7, the first author coded the transcripts into categories identified from the topical coding using grounded theory techniques. The first author identified categories such as information sources, screening knowledge, screening intentions and actions, facilitators and barriers, and areas of uncertainty and desired information. During debriefing sessions, in which summaries of the category coding were reviewed by the senior author, the research team saw complex relationships emerging between the level of family communication, knowledge of familial risk for PCa, knowledge about early detection, and screening actions. After creating analytic tables to track primary sources of communication and awareness of familial risk and screening, the team found that fathers were a critical figure in the narratives. A team decision was made to focus theoretical coding on communication between fathers and sons. The research team refined ideas through debriefing meetings and memoing. Memoing was done in Atlas.ti 7 and used three types of memos: theoretical, commentary, and audit trail.

Results

The sons in this study were mostly Mexican Americans who had lived in the United States since childhood, were middle class, and were younger than men targeted for early detection. Demographic data from 3 of the 17 sons were not available. Great variability exists among the 14 sons who were administered the demographic survey. The sons had a median age of 37 years at the time of interview, ranging from 25-43 years old. The median income per household of the group was \$60,000, ranging from \$21,600-\$120,000. The large range in income is attributed to a range in education and the amount of people living in one household. Households ranged from 3-7 occupants. Data were not collected about whether the sons were married. Five sons had not received any post-secondary education, whereas eight had some college or were college graduates. Sixty-four percent of sons were born in a Latin American country, with Mexico the most dominant country of origin. Sons showed a high degree of acculturation, with 76% spending their early childhood in the United States. Sons largely had diverse social networks that were comprised of Latinos and other ethnic groups, and the great majority of sons reported being able to speak and read in both Spanish and English. The authors did not find important differences in the transcripts based on the interview language.

Follow-up interviews were analyzed for changes in awareness, information seeking, and father-son communication because the sons were sensitized to familial risk and screening through the baseline interviews, but this did not seem to be a theme. The follow-up interviews reinforced and deepened themes from the baseline interviews.

Connecting Familial Risk to Screening

Each participant's (a) understanding of familial risk, (b) knowledge of screening actions, and (c) screening actions (past history of screening, scheduling check-up appointments, intention to bring up early detection with their doctor, or setting an age at which to start screening) were characterized. Classifications emerged for the three topics, and the research team identified shared concepts in each class for each topic. The classifications used for each topic, the amount of participants who fit each classification, and the shared concepts are delineated (see Table 1).

Please talk about what your father's PCa experience meant for you.

- What had you heard about PCa?
- How does your father's diagnosis and PCa relate to you?
- What do you think your father's PCa means for your chances of having PCa?

Now, what would you tell me about what you have heard or know about PCa screening?

- What does that mean for you?
- Describe what happens during PCa screening.
- How do you feel about that?

Please talk about how you have or how you might decide on whether or not you would go for PCa screening.

- What kinds of things would you consider when deciding about screening?
- Who would you talk to about screening?
- What made it or would make it difficult to make a decision?
- Who or what would be helpful in making a decision?

After making a decision, you then have to think about carrying out that decision. Please tell me about what would affect whether you would be able to carry out your decision about having PCa screening or not.

- · What kinds of things would make it easier? Harder?
- Who might influence whether you follow-through on your decision or not?
- What might make you change your mind about your decision?

PCa—prostate cancer

Figure 1. Abbreviated Interview Guide

The current authors compared the sons' levels of awareness to their intentions and actions. Four sons understood their familial risk and engaged in screening actions. Four of six sons who did not understand their familial risk did not enact any screening behaviors. One of the men who understood familial risk was so scared of having PCa that he avoided screening. Nine men, who were uncertain about or did not understand familial risk, did not enact screening behaviors. The current sample suggests that sons who understand familial risk take screening actions more seriously than sons who do not, although variability does exist.

Interestingly, when assessing sons' reported general knowledge of PCa and screening, a link between having a high degree of information and enacting screening behaviors does not exist. Several topics were studied, and the five men who enacted screening behavior had varying levels of knowledge about screening examinations. Men who were aged 40 years or older had more screening actions, but some of the youngest in the sample had good information about screening and familial risk.

Risk Communication

How the sons' fathers were diagnosed influenced the sons' beliefs about when and why they should be screened. Twelve fathers were diagnosed because they

Risk Topic and Classification	n	Shared Concepts
Familial Risk Awareness		
Understood increased familial risk	7	Concern about personal risk Desire to take action Consultation with family, social network, and healthcare providers
Uncertain about increased familial risk	5	Vague beliefs about PCa being "inherent" It is probable that he will have it; his father had it. Expressions of inevitability or fatalism
No awareness of increased familial risk	5	PCa is very common. Anyone can get it. It is because of bad luck that people get PCa.
Screening Awareness		
Knowledge of both the PSA and DRE examinations	5	Awareness of the need for early detection to prevent diagnosis at an advanced stage Advice from healthcare providers
Knowledge of either the PSA or DRE examinations, but not both	6	DRE is known about through social networks, often jocularly. PSA is learned about through healthcare providers and fathers.
No knowledge of either PSA or DRE examinations	6	Symptoms will tell him if he has PCa.
Action		
Engaged in screening actions	6	Age (40 years old or older) Awareness of early detection and familial risk
Engaged in lifestyle protective behaviors	5	Eating healthy Avoiding smoking or drinking
Engaged in information seeking	11	Vague awareness of familial risk and intention to understand his personal risk

had symptoms such as an inflamed prostate or urinary distress. Three fathers were diagnosed via an annual checkup. How the remaining three fathers were diagnosed is unknown.

Seven men believed that having symptoms would prompt them to go for screening. Seven men believed that they needed screening when they reached 40 years of age. Two sons, whose fathers were diagnosed with PCa via a regular annual examination, were committed to preventative checkups and talking to their doctor about PCa. Only one son mentioned screening at a young age as a possibility. Of concern, five of the sons whose fathers were diagnosed because of symptoms continued to believe that they would engage in prostate screening only if they develop symptoms. The sons who did not know anything specific about PCa screening associated screening with symptoms, as illustrated by a son who had little knowledge of familial risk or screening options.

What would make me consider [getting screened]? Wow, I guess it may be the basic obvious, like plac-

ing [symptom], which is, like, what happened with my dad, is, like, I got to go to the rest room, and I can't hold it. We have a problem and we need it to get it fixed.

Based on what the sons recounted of learning about their fathers' diagnosis and treatment, the research team carefully characterized each of their fathers' role in risk communication. Three father roles emerged: educator (n = 3), partner (n = 4), or ascetic (n = 9). The fathers who acted as educators unilaterally communicated their diagnosis and treatment plan to their sons. Fathers and sons did not engage in discussions about PCa, and sons did not ask many questions or participate in the treatment or recovery process. Fathers who acted as partners discussed their cancer with their sons, and the sons were actively engaged in the process (e.g., accompanying their fathers to doctor's appointments, translating). The sons understood their increased risk and enacted screening actions. The fathers who were ascetic kept the details of their PCa private. Their sons knew they had PCa but very little more.

Open communication (characterized by the son asking questions or being privy to the PCa experience) between father and son was the common denominator for screened men or men with a screening plan. Seven sons reported that their father's advice or observation of his experience influenced their screening decisions. In addition, the most proactive men (n = 4) had multiple information sources within their social network with whom they talked about PCa (e.g., mom, sister, colleagues, friends). These other information sources were much less prevalent and salient than fathers. Some of the sons who were married only rarely discussed wives as people who would influence decision making. Sons who had little contact with their family members (n = 2) had little information about screening or familial risk and, therefore, few screening intentions.

Cultural Taboos

A father with PCa emerged as a powerful, but double-edged, information source. The following excerpt from one son showcases the tension between wanting advice from his father and being concerned about insulting his father by transgressing a cultural taboo. The son says that he cannot talk to his family, particularly his father, about sex or erectile dysfunction; however, directly following this statement, he identifies his father as having the biggest influence on his screening behaviors.

Participant: For my family, for most families, and all Latinos, you stay away from that conversation about sex and all the stuff, impotence and all that, [particularly] with my dad. I wouldn't dare talk about that with my dad. It would be kind of, not insulting, but I have always been told that that's not the line you cross with parents. I mean, we don't talk about it. I don't think a lot of males talk about it with their family members, we sure Latinos, we feel uncomfortable.

Interviewer: Is there anyone, or something else, that may influence . . . your decision to go to the screening?

Participant: [I am] thinking the encouragement of my dad probably will be the biggest thing.

Several sons commented on the repercussions of little family communication. Many were frustrated by their lack of knowledge and sought out information from friends, colleagues, and the Internet. The sons talked about cultural taboos in the context of questions about with whom they talked to about their fathers' PCa and who or what would influence their screening decisions. In a follow-up interview, a participant summed up the tension between respecting taboos, but needing the family to be a source of information and protection.

So, the ability to speak frankly, one has to get rid of whatever taboo because it is simply a topic of health. Meanwhile, other studies . . . speak with clarity, that the families [who] do not talk about those topics are those that are more commonly in the second stage or the third stage. The families that have more open communication, they are the ones that at the early stage they realize. So, that is the benefit of dialogue. The more dialogue in a family, the more possibilities to find it in initial stages, about prevention, and, in that, [the family] can help you a lot.

Half the sons associated lack of communication about PCa in their family to Latino cultural taboos about discussing sex, intimate body parts, and reproduction. One participant was asked specifically why he did not communicate much with his family about PCa. He answered,

Well, the taboo in our family is, is that for some reason, we don't talk about our body parts. We don't talk about literally anything that, that our clothes cover, we don't. So, it's, it's very typical, our, our culture we just don't communicate very well.

Another participant also thought that lack of familial communication occurred because of Latino cultural values. He described Latinos as very diverse socioeconomically, but having in common a taboo around intimate body parts: "These issues related with sex or, or reproductive organs within our, within our system are very taboo within our population."

Many sons did not know about a family history of PCa until their father was diagnosed. A son recounted how startled he was to learn that many people in his extended family had been affected by PCa.

Participant: We went to Mexico, and every time [extended family members] call the house, and they told me that they had it, and they turned out [okay]. All these stories kind of pop up as soon as someone focuses [on PCa] . . . all these stories start popping up, from my uncle and family members.

Interviewer: So they had the screening?

Participant: They had the screening before—the logistics don't go into it because it is a whole male thing.

Eleven of the 17 sons talked about the taboo associated with the digital rectal examination (DRE). Most of the men heard about the DRE through jocular, informal encounters in their social networks. The sons acknowledged the taboo, but countered it with arguments about how it was important to overcome their discomfort and do the examination. One participant gave a bald summary of the way his peers interpret the DRE examination.

There's a whole . . . misconception that deals with, uh, the sexuality of a male. You can hear . . . the

Knowledge Translation

Latino sons of prostate cancer (PCa) survivors need concerted counseling about their increased risk and the protective action they can take.

Nursing interventions can use Latino cultural values, such as familismo, to counteract cultural taboos that limit communication about PCa, particularly the digital rectal examination.

Nurses can clarify with Latino men that symptoms are not necessary to diagnose PCa.

guys talking about "I don't wanna, I don't wanna, I don't wanna give up my virginity." They say that they're gonna be raped [because] there is an insertion of the finger . . . and they still have this discomfort . . . of being penetrated with the finger . . . fear, fear of the unknown and fear, lack of information, as well.

The peer pressure of the taboo is so strong that the same participant, who had been screened, commented,

I always laugh about it; I participate within, within the jokes and within the whole discussion of, of uh, uh getting checked by doctors. I become part of it within the group. But, inside of me, I, I'm just playing with them . . . to be part of the group. But I don't feel comfortable. . . . I look at it as, uh, routine. A normal routine that I have to have in order for my own survival.

That example from a son who played along with the public stigmatization of PCa screening, while privately committing to regular screening, is a testament to the durability of the taboo, even if it did not prevent him from getting screened.

Discussion

Men at higher risk of PCa because of family history need to engage in shared decision making. Latino sons of men treated for PCa may have less opportunity or awareness of how to engage in shared decision making and may not have the information necessary to alert clinicians to their increased risk. This research identifies community health promotion opportunities to increase informed decision making about screening for PCa among Latino men. The current study extends previous work on familial communication about risk and the importance of culture (Bratt, Emanuelsson, & Grönberg, 2003; Christophe, Vennin, Corbeil, Adenis, & Reich, 2009; Harris et al., 2010; Lagos et al., 2008; Palmquist et al., 2010; Shaw, Scott, & Ferrante, 2013; Vadaparampil, McIntyre, & Quinn, 2010; Wakefield et al., 2008). It follows up on the previous research of men

with PCa about their disclosure patterns and communication with unaffected FDMRs (Maliski et al., 2012). Finally, a dearth of research exists specific to Latinos and PCa despite the disparities observed in screening and stage at diagnosis, which needs to be addressed.

Sons of men diagnosed with PCa have heightened interest in information regarding PCa but low awareness of familial risk and screening options. Many sons in this study were younger than the target group for regular screening; however, previous research with Latino men and their wives suggested that a PCa diagnosis heightens interest and desire in adopting a range of health behaviors. In addition, the men with PCa who have FDMRs were very committed to promoting screening with their FDMRs. The authors of the current article propose that family members' (particularly fathers') diagnoses of PCa can be a window of opportunity to increase awareness in Latino families. This is supported by the current study in two ways: (a) Young sons (even the 25-year-old son) went out and found information about screening, and (b) some of the most poorly informed men in the study were approaching age 40 years, which, depending on a variety of factors, could be the age at which they engage in shared decision making with physicians about screening. The current study found that cultural taboos around PCa diagnosis and survivorship, as well as with PCa screening, have an adverse effect on Latino men's willingness to communicate risk within their families. On the other hand, sons sensitized to PCa desire information and intend to enact protective behavior.

The sons' perceptions presented here are an interesting rejoinder to the previously reported findings with men affected by PCa with FDMRs. Maliski et al. (2012) found that men affected by PCa with FDMRs hoped to communicate the importance of early detection to their FDMRs, but were highly selective about the depth of information disclosed, even to their adult children. The men with PCa stated that they appreciated "respectful silence" from their relatives because they considered PCa an intimate issue. However, in the current study, sons wanted more information and felt frustrated by cultural taboos that barred them from open conversations with their fathers. Ultimately, the sons in this study often did not have actionable information about risk or screening.

Sons see their father as an advisor, but get very few details about screening. Most notably, in the current sample, the fathers' diagnosis experience greatly influenced the sons' beliefs about screening, which leads many of the sons to believe that screening occurs because of symptoms, limiting early detection. The finding that over half of the men in a diverse socioeconomic sample all spoke about DRE taboos is concerning. Although sons in the current study attested that

they overcame the taboo, communication barriers are evident in their social networks. Several sons linked Latino culture, particularly in their father's generation, to poor communication about PCa and screening specifics. Although discomfort with screening is not unique to Latino cultures—men across ethnic groups are uncomfortable with the DRE (Shaw et al., 2013)—understanding cultural aspects of how information is presented and disseminated through social networks is critical to address taboo and stigma (Consedine et al., 2007; Consedine, Morgenstern, Kudadjie-Gyamfi, Magai, & Neugut, 2006; McFall, 2007).

Getrich et al.'s (2012) conceptualization of the term machismo is helpful in the context of this study because it captures a similar tension in masculine performances amongst Mexican and Mexican American men around colorectal cancer screening. Although the sons did not use the term machismo very often, the concept is valuable for thinking through cultural-specific masculinities between father and son. Getrich et al. (2012) pointed out that machismo, which is a cultural construct used by Mexicans and Mexican Americans, can be seen as a barrier; it can be linked to homophobia, dominance, and stoicism. On the other hand, it is linked to a strong sense of family, protection, and responsibility (familismo) (Getrich et al., 2012). Machismo can prevent openness about intimate health topics, but the values of familismo could facilitate awareness from within social networks, possibly having a greater impact. McFall (2007) pointed out that if awareness is a pivotal factor in screening behavior, then continuing outreach through existing mechanisms may not address existing racial or ethnic disparities. The current article's research team posits that working intergenerationally through familismo is another approach.

Implications for Nursing

For some Latino men, cultural taboos exacerbate an awareness deficit. The ambiguity about screening guidelines, combined with under-informed men and little communication about PCa within their social networks, heightens the decisive role that healthcare providers, particularly nurses, play. Nurses can alert sons to increased risk and provide actionable knowledge about risk and screening. Healthcare providers played an invaluable role as credible information sources when the sons encountered them. Interventions that empower fathers as mentors may give fathers a sense of efficacy while promoting informed decision making for sons. Nurse-provided education needs to include not only the man with PCa and his spouse, but also his adult children. Nurses can use familismo to facilitate informed decision making through routine practice and interventions in this population.

Limitations

The Latino men recruited in this study come from a predominately Mexican or Mexican American background and findings cannot be generalized to other Latino ethnicities. In addition, because fathers and sons were not recruited as dyads, the current authors were not able to see the direct link between a man and his son.

Conclusion

Sons whose fathers were diagnosed with PCa were both in need of and potentially receptive to actionable information in light of increased familial risk. For sons in this study, a cultural taboo surrounding sexual and reproductive health and the DRE is in tension with their desire for meaningful first-person familial accounts about PCa. Health advocates have the opportunity to work with families to increase risk awareness and shared decision making about screening.

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For Further Exploration

Use This Article in Your Next Journal Club Meeting

Journal club programs can help to increase your ability to evaluate literature and translate findings to clinical practice, education, administration, and research. Use the following questions to start discussion at your next journal club meeting. Then, take time to recap the discussion and make plans to proceed with suggested strategies.

- 1. This study interviewed men with prostate cancer and an unrelated group of sons whose fathers had been diagnosed with prostate cancer. How might this have influenced the results?
- 2. Some of the men with prostate cancer and the unrelated sons were supportive of early prostate-specific antigen test for prostate cancer detection. How does this comply with the most recent guidelines of the American Cancer Society and the American Urologic Association?
- 3. "Machismo" is a well-known cultural concept. How do you deal with a patient who displays this behavior when it prevents honest communication within the family and in the healthcare setting?
- 4. What are the risks and benefits of family communication about disease risk and health beliefs?

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