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Talking with Others About Stigmatized Health Conditions: Implications for Managing Symptoms

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Abstract

We investigated the influence of social ties on symptom management and help seeking, using urinary symptoms as a case study. Talking with others about these symptoms was common and both facilitated and hindered symptom management and help seeking. In some cases, talking with others resulted in gaining a sense of identification with others suffering the same symptoms, receiving assistance to ease the burden of symptoms, obtaining suggestions to help manage symptoms, and learning information about available treatments. In other cases, talking with others served to normalize symptoms to such an extent that individuals saw no need to manage their symptoms differently.

Keywords

communication; interviews; health seeking; relationships; symptom management

The relationship between social connections and health is well established (Berkman & Breslow, 1983; Berkman, Glass, Brissette, & Seeman, 2000; Blazer, 1982; Cobb, 1976; Cornwell & Waite, 2009; House, Landis, & Umberson, 1988; Pearce & Smith, 2003; Umberson & Montez, 2010). However, we still do not fully understand the mechanisms through which social relationships affect health (Fremont & Bird, 2000). In this analysis, we investigate how one aspect of social relationships, talking with others, influences how individuals manage symptoms of a stigmatized health condition.

Conceptually, one's social relationships or ties are considered a social network with structural properties, such as the number of ties and frequency of contact (Barrera, 1986; Lin & Westcott, 1991; Thoits, 1995; Wellman & Wortley, 1990). Social networks can be the source of social support in the form of instrumental, informational, and/or emotional assistance (James House & Kahn, 1985; House et al., 1988). The type of support received is influenced by the structural properties of one's social network, including the type and strength of the ties or relationships. While the strong ties of close relationships with frequent contact often result in provision of support, research has also shown that weak ties can be influential. Granovetter (1973) provided evidence of the importance of weak ties (ties with less intensity, intimacy, and contact) in finding employment. Evidence supporting the "strength of weak ties" has also been reported for health outcomes (Langlie, 1977). These

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findings remain highly relevant and suggest that who one talks to about health conditions might be important for understanding how this social contact has an effect on coping with or managing symptoms.

Talking with others about health conditions provides an opportunity to gain information, instrumental assistance, and/or emotional support. Other scholars have shown that talking with others has been a source of social support for new mothers (Dahlen, Barclay, & Homer, 2010) and an important facilitator of emotional adjustment after breast cancer diagnosis (Mallinger, Griggs, & Shields, 2006). Other researchers have addressed the influence of talking with others on seeking health care or pursuing a particular line of treatment (Kinchen et al., 2003; Rodrigue, Cornell, Kaplan, & Howard, 2008; Wolters, Wensing, Van Weel, Van Der Wilt, & Grol, 2002). While these scholars have provided important insight into the association between talking with others and help seeking, we still do not fully understand the process of how talking with others operates to facilitate or hinder health status and outcomes (Umberson & Montez, 2010). Understanding how people talk about their symptoms with friends, family and other members of their social networks can offer insight into the mechanisms by which social ties and resulting social support promote health and wellbeing. We also need to better understand the relationship between social ties and health in diverse populations.

Our objective in this analysis was to investigate in a diverse population how talking with others influences symptom management, using urologic symptoms as a focus case. Urologic symptoms provide a useful case for exploration of how individuals talk with others about health conditions. Urologic symptoms include problems such as daytime frequency, urgency, nocturia, and incontinence, and are common, affecting nearly one in five adults (Kupelian et al., 2006). Research indicates that many people suffering such symptoms do not seek medical care for symptom relief (Burgio, Ives, Locher, Arena, & Kuller, 1994; Harris, Link, Tennstedt, Kusek, & McKinlay, 2007; Jacobsen et al., 1993).

Urologic symptoms are associated with feelings of stigma, making it challenging for individuals to talk with doctors about their condition (Elstad, Taubenberger, Botelho, & Tennstedt, 2011; Roberts et al., 1994). When individuals experience stigma in connection with a health problem, they are more likely to delay care (Ahmad, Driver, McNally, & Stewart, 2009). While other studies have investigated the importance of social support for help seeking among those suffering nonstigmatized conditions (e.g., coronary artery disease) (Boutin-Foster, 2005) or cancer (Hilton, 1994; Mallinger et al., 2006), the case of urinary symptoms allows an investigation of the influence on symptom management of talking with others about a stigmatized condition. We address two main questions in this analysis: (a) Who reports talking to others about their symptoms and to whom do they talk; and (b) How does talking to others facilitate or hinder symptom management and help seeking for these symptoms?

Qualitative data offer the advantage of moving beyond the confirmation of an empirical association between social support and help seeking. Qualitative data can illuminate the process of how social support operates to improve health and wellbeing. One other qualitative study of communication about urinary symptoms was limited to sexual functioning and communication among couples (Badr & Taylor, 2009) and did not focus on strategies of symptom management.

Methods

We rely on data collected during in-depth interviews with a subsample of participants in the Boston Area Community Health (BACH) Survey. BACH is a population-based, random sample epidemiologic survey (n=5503) of a broad range of urologic symptoms. For this parent study, the investigators used multi-stage, stratified cluster sampling to obtain roughly equal numbers of Black, Hispanic and White men and women between the ages of 30 and 79; that is, 3202 women and 2301 men; 1767 Black, 1877 Hispanic, and 1859 White people. McKinlay and Link (2007) have described the sampling design and study methods elsewhere.

The target sample size for this qualitative study was 150, or 25 participants in each of the six subgroups. Participants in the parent study who reported one or more urologic symptoms (n=2,799) were eligible for participation. We randomly ordered these participants within respective subgroups (cells) and approached them for enrollment until all cells were filled. For this analysis, we include responses from 25 Black women, 23 Black men, 25 Hispanic women, 22 Hispanic men, 23 White women, and 26 White men (total=144). We excluded seven study participants from this analysis because there was not sufficient data about their discussions with others to sufficiently determine if they had discussed their symptoms with others, nor the nature of that discussion.

Trained qualitative interviewers conducted in-depth interviews using a structured guide that focused on a broad range of topics, including description and characterization of symptoms; impact on daily life; feelings associated with and understanding of symptoms; norms; coping and management; and help seeking (from both family/friends and health care providers). We focus our analysis here on the questions asking respondents to describe their discussions with others about their urinary symptoms. Specifically, interviewers asked respondents: “Have you ever talked with your family or friends about your bladder, pelvic or urinary symptoms?” If they responded “yes”, the interviewer went on to ask, “Who do you talk to about your symptoms?” The interviewer also asked, “What has [PERSON] told you to do about your problem?” If the respondent indicated they had not talked with someone about their symptoms, they were asked to explain why they had not. The interviews were conducted in respondents’ homes in their preferred language, either English or Spanish. To facilitate consistency, all interviewers completed the same project-specific training. The 60 minute interviews were digitally audio-recorded and transcribed verbatim, and Spanish interviews were translated into English.

The research team used an inductive approach to the analysis (Strauss, 1998). During an “open coding” phase of data analysis, members of the research team read the transcripts to generate a “start list” of codes related to talking with others. Transcripts were read a second time to refine the coding structure. Transcripts were coded using Atlas.ti 5.6 qualitative data analysis software (Muhr, 2004). Following coding, Jackson conducted a thematic analysis to identify common issues related to who participants talked with about their symptoms and what was gained from talking with others. During analysis, Jackson made comparisons of categories across gender and ethnic/racial groups to incorporate any differences into emergent themes. In this analysis, we focused on talking to family, friends, coworkers, neighbors and so forth, we did not include discussions that respondents had with professional health care providers. We intended our analysis to focus on individuals’ social ties, not their interactions with the health care system.

The New England Research Institutes’ (NERI) Institutional Review Board approved this qualitative study and the parent epidemiological study. Interviewers informed study participants about the purpose of the study, and the risks and benefits involved in their participation. Interviewers assured participants of confidentiality of the information provided. All participants provided written informed consent prior to participation in the qualitative study.

Results

Talking to Others about Symptoms Differs by Race and Ethnic Background

As shown in Table 1, nearly three-quarters (73%) of respondents reported that they had talked with others about their urinary symptoms. Talking with others about these symptoms was common across all subgroups in the sample, although some groups were more likely than others to do so. For example, the vast majority of Hispanic men (95%), Hispanic women (80%), and White women (83%) had talked with others about their urinary symptoms, whereas only 56% of Black women, 61% of Black men, and 65% of White men did so.

For those 105 respondents who reported discussing these symptoms with someone, it was usually with close women relatives (mother, daughter, sister) (43%), followed by friends (37%), or a spouse (34%) (see Table 1). Many respondents (n=44; 42%) talked to more than one type of listener. Men were just as likely as women to report talking with a woman about the symptoms. This was often their spouse. The likelihood of talking with a spouse was similar for White men and women but not so for the other race/ethnic groups. Black and Hispanic women were less likely to talk with their husbands about these symptoms, although the men in these subgroups did talk with their wives.

Social Ties are Supportive but do not Always Lead to Help Seeking

Respondents identified a variety of ways in which talking with others not only facilitated management of their symptoms but also hindered it. Respondents reported: (a) taking comfort in knowing that others also have these symptoms; (b) learning about specific strategies and treatments to manage symptoms; (c) obtaining instrumental assistance and support; and (d) normalizing their symptoms.

A number of respondents described the importance of knowing they were not the only ones with urinary symptoms and the comfort they felt because of gaining this understanding. For example,

> There’s a guy I work with. Sometimes we talk about things like that … He’s younger than I am, but it’s sort of a common thing sometimes. It’s good to talk to someone your own age, and also it gives you some confidence that you’re not the only one (White man)

Many respondents reported that talking with others about their symptoms resulted in learning strategies to manage their symptoms. For example, this man described learning about managing fluid intake.

> Yeah. I always talk to my sister and them about it, … She told me, she said after 6 o’clock … don’t drink no water. Test yourself and see if you go. And I did that and I didn’t go. And I told her that. And she said, well; just don’t drink water after 6. (Black man)

Others described hearing advice about timed voiding and learning about products to help manage these symptoms. For example, this woman describes learning about incontinent aid products from another friend:

> Oh, my best friend, like I said, she was the one that told me to buy the pads … So, I did. I went and bought the pads she showed me. And sometimes I do go out with my other friend. We go a little bit food shopping that she takes me, and I do wear my pad. And sometimes I wear it and I don’t even have to go. But I am ready (Hispanic woman).

These conversations sometimes resulted in shared advice. Some respondents described providing in addition to receiving advice:

> You learn a great deal. Somebody else will learn from you … And I do feel that if I can help somebody else by learning about it. And I can learn about it too by asking … So you learn a great deal. (White woman)

Many respondents reported receiving advice to see a doctor. This advice was both nonspecific and specific. Nonspecific recommendations included reports such as: “Yes, she tells me to explain everything to the doctor” and “All she told me to do is to go to the doctor”. As an example of a more specific recommendation, this woman described how she learned about surgical treatment options from a neighborhood friend:

> … she says I had to get a cradle, she called it. And I said, what do you mean a cradle? … and that’s when she told me about it…. [She] couldn’t go like anywhere. She said, I had to wear pads all the time … And she says they did that. It was like an in and out. I mean it wasn’t overnight or anything. And they put like some kind of cradle or a cap or something. And she said she felt great and it worked good…. I said, geeze, I pee all the time too. You know, so she said, well, keep that in mind, because she said if it gets worse; she said, I kept putting it off and putting it off, because you know I didn’t want to have to go into the hospital for that (White woman).

In this case, talking with a friend provided the opportunity to learn about a specific treatment that she might not otherwise have known about.

In some cases, talking with others about symptoms led to receipt of instrumental assistance to help manage their symptoms. Friends and/or family members offered to help by picking up medicines, providing transportation to medical appointments, helping to locate bathrooms, or preparing foods recommended by doctors. For these individuals, sharing of information and experiences regarding their urinary problems provided the opportunity for others in their social network to provide this instrumental support and assistance.

Talking with others about urinary symptoms also provided the opportunity for these respondents to receive emotional support from friends and families, and they reported feeling better because of sharing these experiences. For example, this woman describes the consideration offered by her family members once they knew she had these symptoms.

> They know if they take mama anywhere, you better make sure there’s a bathroom close by or they’ll turn around and say we’re going out for three or four hours, do you think you can make it or what is your opinion. They’re pretty interested and concerned about how mama is going to feel or take the trip that we’re going to do or go anywhere (White woman).

The illustrations presented above highlight how talking with others was supportive and could serve to facilitate symptom management strategies. However, in other cases talking with others about symptoms normalized participants’ symptoms or resulted in their accepting symptoms as not a problem in need of treatment or management. In these cases, talking with others inhibited taking action to manage symptoms. For example, the women below described talking with others about their shared symptoms and concluding that their symptoms are just a part of the aging process.

> Like when I’m with a group of my friends, we all, we sit around and we joke about how before we’d talk about a whole different category. Now it’s about everybody’s aches and pains. I mean, it’s like; Sure, we joke about everything, yeah. I mean, we

> just make light of it. It's nice to know we have something, you know, it's not just me or, you know? It's just something that happens (White woman).

For this woman, defining the cause of her symptoms as something "natural" was a mechanism by which talking with others hindered help seeking.

> I have some good friends, and my daughter…. Well, they have the same problem…. It's age. That's all we boil it down to is the age. Nothing you can do about it (Black woman).

As the response below displays, some other respondents experienced relief simply by knowing others have the same problem.

> You know, I mean I talk to a lot of people about this and we laugh about it, because they said it's happened to them too. You know? … they say, 'Damn, I have that same damn problem.' I mean we'll be a group of guys talking and we come up to the same thing. And I said, damn, I don't feel bad then … I ain't the only one … so I say, if they feel comfortable with it, I feel comfortable with it now, because it don't bother me now … I was scared. I thought I was the only one having this [problem] (Black man).

This man's description of the meaning he made out of discussing his symptoms with others suggests that normalizing is one of the mechanisms by which talking with others can hinder symptom management.

For some, identifying others with the same problem provided the opportunity to assess their condition relative to others with the same condition. In most of these cases, people expressed relief that their symptoms were not as severe as those of the people to whom they were talking and they therefore did not seek help.

> I've listened to people who have had a problem that's probably much more severe than mine. And that's why I was telling you the story about the guy who I know, he can't control his urination, uses Depends. And now he had a situation where he had surgery where his prostate was removed. I've listened to other guys, because I work with a network of prostate cancer survivors, and I listen to them talk about some of their issues with frequent urination. So I'm aware of some of the techniques, some of the medicines out there. But I don't think mine is at that level where it even needs to be treated medically or it certainly isn't painful (Black man).

Based on this description, we illustrate a third mechanism by which talking with others can inhibit symptom management and treatment seeking. These discussions were used by some to gauge the severity of their symptoms. When they concluded that their symptoms were not as bad as someone else's, they concluded they did not need to seek treatment or pursue remedies to manage their symptoms

Discussion

In this study, we found that talking with others about urinary symptoms is a common practice across social groups and is particularly widespread among Hispanic men and women and White women. We consider this finding somewhat surprising given the stigma associated with urinary symptoms (Elstad et al., 2011). Despite the stigma, most respondents utilized social ties (measured by talking with another person about urinary symptoms and who respondents talked with) in managing their urinary symptoms. Moreover, these ties functioned as social support regarding the experience of urinary symptoms but did not always lead to help seeking for those symptoms.

Prior researchers have documented that Hispanic women are less likely to access health information online and through other information sources (Jackson, Botelho, Joseph & Tennstedt, under review; Lorence, Park, & Fox, 2006). In this study, we found that talking with others might be an important resource for Hispanic women who are less likely to obtain health information from other sources. We also found group differences in who talked with others about symptoms as well as what they gained from those conversations that might reflect cultural conventions regarding what is socially acceptable to discuss with others.

What we learned about whom respondents talked with about their symptoms replicated prior findings that women are more often a source of social support compared to men (Belle, 1982; Cutrona, 1996; Schulz & Schwarzer, 2004; Antonucci & Akiyama, 1987; Kiecolt-Glaser & Newton, 2001; Shumaker & Hill, 1991). When respondents in our study reported discussing their symptoms with a spouse, it was more likely to be a man talking with his wife than a woman talking with her husband, suggesting that men in our sample received more spousal support than did the women. In addition, women relatives (mother, daughter, sister) were more likely than men relatives (brother, father, son) to be a resource with whom participants reported talking about their symptoms.

These findings contribute to the understanding of how social networks impact health status. Prior research has established that not all members of a social network contribute equally (Granovetter, 1973; Langlie, 1977). Weaker ties can sometimes be more useful than stronger ties because of the exposure to a broader range of information that comes from these weaker connections. Strong ties are more likely to operate within the same social network so that there are few opportunities to learn new information. In our study, women relatives were the most commonly reported outlet for discussing health symptoms, followed by friends. Overall, respondents turned to women relatives and friends more than to closer men relatives for discussions about their symptoms. However, this varied by race/ethnicity and gender. For example, whereas Black and White women relied on friends more than any other source, Hispanic and Black men were more likely to talk with their spouses. The impact of strength of connection on health is not uniform across all social groups, but varies by race/ethnicity and gender.

Talking with others can both facilitate and hinder symptom management and help seeking. Respondents described a range of ways in which talking with others facilitated symptom management and help seeking. In some cases, talking with others provided the opportunity to know they are not the only ones suffering with these symptoms, reducing the sense of isolation that can accompany a stigmatized health condition. In many instances, family members and friends responded with instrumental advice about managing these symptoms or encouraged a visit to the doctor. In other cases, talking provided the opportunity to communicate a need which friends and family were then able to accommodate by providing direct instrumental assistance such as picking up medication or providing transportation for provider visits. Finally, respondents reported receiving emotional support through their discussions with friends and family about their symptoms.

For a small group of other respondents, learning that others had the same symptoms provided them a sense that their symptoms are normal, are perhaps not in need of treatment, or might be challenging to treat. For these individuals, talking with others served to normalize their symptoms in ways that facilitated a notion that their symptoms are not problematic or there might not be benefits to seeking medical treatment. For this group, sharing symptoms within a social network limited the range of self-management strategies and recommendations for seeking health care for urinary symptoms. These findings contribute to a growing literature that illustrates how social ties can have negative as well as positive effects on health (Christakis & Fowler, 2007; Kelsey, Earp, & Kirkley, 1997). This is consistent with Granovetter's theory (1973) in that strong ties can be supportive yet limit motivation to access information that would facilitate effective symptom management.

Limitations

We provide new evidence of the implications of talking with others for a stigmatized health condition, but there are some limitations to consider. First, we conducted our study in Boston, MA in the United States. Therefore, although the sample is large for a qualitative study and is socio-demographically diverse, researchers in other geographical areas or interviewing other race/ethnic groups might obtain different results. Second, we cannot eliminate the possibility that some intended meaning was lost in the translation of interviews from Spanish to English. Finally, our interview schedule did not include explicit probes to ascertain how individuals made decisions about with whom they discussed health symptoms. We are limited in our ability to specify the conditions under which social ties might result in improved outcomes for symptom management. These are two promising areas for future research.

Conclusion

Talking with others about health conditions and symptoms is one of the ways in which individuals can leverage their social connections to impact health and wellbeing. Using urinary symptoms as a case, we contribute evidence to better understand who talks with others about health conditions, and how conversations can facilitate and hinder health promotion strategies. Confirming findings of prior studies, we found important differences along lines of gender in who provides social support. For men, spouses are an important source of support whereas women rely on friends and other (mostly women) relatives. We also add to the literature regarding sources of support and information about health conditions for men and women in minority groups.

Our participants shared information that has implications for clinical practice. Clinicians would benefit by knowing more about how their patients' symptom management strategies are shaped by conversations that occur outside of provider visits and health care settings. Clinicians could enhance their patient counseling by talking with them about their sources of health information and how this information affects how they think about their symptoms and what they do about them.

Our results contribute to the literature on social networks and social support by providing evidence of how talking with others can both facilitate and hinder strategies of symptom management. In some cases, talking with others resulted in gaining a much needed sense of identification with others suffering the same symptoms, receiving tangible assistance to ease the burden of symptoms, obtaining informative suggestions to help manage symptoms, and learning important information about available treatments. However, in other cases, talking with others served to normalize symptoms to such an extent that individuals saw no need for symptom remedy.

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Table 1

With Whom Respondents Talked by Race/Ethnicity and Gender

	Black women	Black men	Hispanic women	Hispanic men	White women	White men	Total
Have talked to someone [*]	14 (56%)	14 (61%)	20 (80%)	21 (95%)	19 (83%)	17 (65%)	105 (73%)
Talked with: [**]							
Close women relative (daughter, sister, mother)	11 (79%)	6 (43%)	15 (75%)	3 (15%)	7 (37%)	3 (18%)	45 (43%)
Friends	7 (50%)	4 (29%)	5 (25%)	6 (29%)	9 (47%)	8 (47%)	39 (37%)
Spouse	0	6 (43%)	3 (15%)	12 (57%)	6 (32%)	7 (41%)	34 (32%)
Men relative (brother, son, father)	1 (7%)	4 (28%)	0	4 (20%)	1 (5%)	4 (24%)	14 (14%)
Other relative	3 (21%)	0	3 (15%)	0	2 (11%)	1 (6%)	9 (9%)

[*] percents based on total sample

[**] percents based on 105 respondents who talked with others about symptoms