Published in final edited form as:
J Mens health. 2011 October ; 8(3): 185–191. doi:10.1016/j.jomh.2011.06.001.

Living with a `women's disease': risk appraisal and management among men with osteoporosis

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Abstract

Background—There is clear evidence that men suffer from osteoporosis (OP) in increasing numbers, but that men commonly remain underdiagnosed, undertreated and experience poorer outcomes than do women. The widespread sociocultural association of OP with postmenopausal women reflects their greater risk for developing the disorder, but the sexing of OP as a women's disease disadvantages at-risk men.

Methods—This paper reports on qualitative data gathered from 23 community-residing men who have an OP diagnosis.

Results—Interviews with men reveal that the sexing of OP as a female disease may affect men's risk appraisal. Men clearly associate OP risk factors with women and accordingly may feel protected from the disorder. Subsequent to diagnosis, men's OP-related risk management strategies reveal that men's gender identity constrains their ability to enact risk-reducing behavior.

Conclusions—Men may internalize the association of OP with women and incorporate it into a sense of perceived invulnerability to the condition, which, in turn, contributes to delayed diagnosis and treatment. Limited male-specific treatment and support options as well as social expectations of male gender performance play roles in men's health behavior.

Keywords

Risk assessment; Risk management; Risk reduction behavior; Qualitative research; Male breast cancer; Osteoporosis; Men

Introduction

Postmenopausal women's vulnerability to osteoporosis (OP), osteoporotic fracture, and their negative psychosocial consequences are well documented in the clinical and social science literatures (1,2). As feminist scholars have noted (3) the emphasis upon women's risk for OP carries messages that reproduce the larger cultural discourse of women's inherent vulnerability, weakness, and need for protection. While it is clear that postmenopausal women suffer enormously from OP and fractures, and that they do so *as women*, how men suffer from OP is less clear (4,5). This qualitative study sought to describe how men suffer

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from OP *as men* and explores the impact of the “sexing” of OP as a diagnostic category by examining the illness narratives of men living with this condition.

Attention to the relational nature of masculinity and health behavior in men is increasing, but relatively spare (6). Thus far, we understand that men mitigate perceived health risks differently than do women (7). Not only might men actively resist health promotion activities because of their association with femininity, men may seek to participate in risky behaviors to bolster their masculine identity (8,9). In fact, there is emerging evidence that men who adhere to masculine norms indeed perform fewer health-promoting behaviors (9). The bidirectional nature of the sexing of disorders is amplified in the context of cross-gender diagnosis; men who are diagnosed with “women's diseases” contend with a complex set of social demands as they come to make sense of their somatic condition and limited treatment options.

Sexed disease, gendered response

The power of clinical discourses to shape perceptions of risk are perhaps most clear in the case of male breast cancer (MBC). MBC patients across several studies defined it as a “woman's disease” and this working definition likely delayed the recognition of their symptoms by themselves and care providers alike (10–12). Men are diagnosed with MBC at a later age, with more advanced cases, and have poorer 5-year outcomes than do women (12). Men who do recognize early signs of MBC may be reluctant to share their suspicions because of the fear of stigma associated with having a “women's disease.”

Once diagnosed, MBC patients were unlikely to find gender relevant advocacy or patient literature, nor were they able to locate appropriate support groups should they have desired one (11, 13). The treatment of MBC is derived from knowledge of female patients, and so the safety and long-term psychosocial outcomes of mastectomy or the drug of choice, tamoxifen, are not well documented for men. Recent work with MBC patients shows that mastectomy scars can alter body image, leading men to conceal their diagnosis and surgical sites (10).

Diagnosing the “silent disease”

Although the embodiment of breasts is arguably more intensely gendered than for bones, men's experiences with OP reveal how sexing OP as female contributes to suffering within the illness experience. Similarly to MBC, men with OP face constraints to timely diagnosis, well validated treatment, and social support. Men and providers alike have poor knowledge of risk factors (14–18). Studies of OP diagnosis in men commonly report that men are infrequently screened and remain underdiagnosed and undertreated (16, 19–21).

The promise underlying the Health Belief Model (22) so frequently used in interventional work – that effective communication of risk to the appropriate at-risk population, who are thus equipped and ready to engage with this information, will result in at-risk persons taking actions to reduce health risks – is unrealized in OP due to its asymptomatic nature and gender norms. After diagnosis, bone mineral density (BMD) may be assessed on an annual or biannual basis, creating large periods of time in between any stimulus to change events, and fostering reliance upon external measures to ascertain wellness. Recent studies with OP diagnosed women illustrate that dependence upon BMD as an indicator of health may contribute to a sense of vulnerability or lack of control over one's health (23). Furthermore, if we are to examine factors affecting men's self efficacy and ability to change, the fact that men are treated with medications largely designed for and tested in female populations (21) and that they are diagnosed most often post fracture and with greater impairment, may not foster confidence in treatment efficacy or appropriateness.

Methods

Subjects

Men were asked to participate in a mixed methods study of their experience of living with OP. This study was comprised of three interrelated components: a mailed, self-administered health-related quality of life instrument, the Male Osteoporosis Assessment Questionnaire (Male OPAQ™); and an interview composed of two parts – a structured interview on men's explanatory models for OP and an open-ended interview on men's illness narratives for the disorder. The MALE OPAQ™ was tested for reliability and validity and is reported elsewhere (24). The explanatory models interview was conducted to present men's framework for seeking treatment, responding to diagnosis, persisting with treatment, and understanding OP as a chronic disorder. Those data, a detailed description of subject recruitment, and data collection procedures are reported elsewhere (5). This article reports on the open-ended interviews, which connect men's explanatory models with health behavior.

Briefly, men aged 50 years or older with a diagnosis of OP, spoken and written English literacy, and attending a bone health clinic located in the southern United States were invited to participate. Diagnosis was defined as a BMD t score of < -2.5 in the spine or hip or a history of osteoporotic fracture. Potential subjects were referred to the study by a physician, and 23 men agreed to participate. As discussed elsewhere (5, 24), 38 men were approached and 14 declined to participate. Signed informed consent was obtained from subjects by the author. The Duke University Medical Center Institutional Review Board approved the study protocol. All subjects were offered an honorarium.

Procedures and analyses

In order to elucidate the relationship between masculinity and men's experience of OP, men were asked individualized, open-ended questions during audio-recorded interviews. The interviews were semi-structured and composed of two parts. Part 1 invited subjects to respond to focused questions aimed at collecting subjects' explanatory model (25) for OP. Part 2 was open-ended and consisted of investigator-driven prompts to clarify salient themes from men's models. The explanatory models, which focus on the etiology, diagnosis, treatment, course, and nature of OP, provide a structured way of comparing men's working definitions for OP but do not, in and of themselves, focus upon men's social worlds or masculinity, *per se*, and are reported elsewhere (5). Related, open-ended, inductively derived follow-up questions were explored during the second portion of the interview.

At the conclusion of data collection, the interview recordings were transcribed and transcripts provided to subjects for verification and as a courtesy. Interview transcripts were imported into an NVivo project to enable rapid indexing and coding. The transcripts were coded for content and an inductive model was used to organize salient themes as they were identified.

Results

Men's average age was 70 years (range 53–86), all but one reported “white” race, 19 were married, only 2 men reported incomes of less than $25,000 per year, 13 had a history of fracture, and 17 were taking an OP medication. Men's responses to unstructured inquiry were characterized by a recurring focus on risk, which was further delineated into two overarching themes – *risk appraisal* and *risk management*. Risk appraisal incorporates both internal and external perspectives. Internal risk appraisal refers to how men identify their vulnerability to OP, drawing on their knowledge of the disorder and their ability to see symptoms in their own body and connect those symptoms to an OP diagnosis. External risk appraisal refers to the impact of other people's assessment of men's vulnerability to OP and includes both social contacts and medical providers. After diagnosis, risk management addresses men's experiences and thoughts on how to identify and mediate risk in daily life.

Risk appraisal

As is clearly illustrated in men's explanatory models for OP (5), prior to diagnosis even men who had early symptoms of bone loss did not consider themselves to be at risk because they defined OP as a disease of women. The sexing of OP was linked to a sense of invulnerability, as reflected in these comments:

> "Osteoporosis? I ain't no postmenopausal woman!"

> "My idea of [*OP*] was that it was something that women had and I didn't have to worry about it. Until [*my doctor*] informed me that I did have to worry about it."

It was also evident in men's expectations of the disease. Some men assumed that OP was not life threatening nor of immediate concern because they knew women lived with it, and so by extension it could not be that severe.

> "… It wasn't great news but it wasn't something that I was scared of. … I mean you know grandmothers have it and live through it. … I guess it's hard to understand what that's like, the constant pain until you have it. So no, I wasn't excited or upset or anything about getting it."

> "Until [*it was confirmed*], I never really thought about [*OP*]. It's not life threatening that I know of. It's just one of these deals. Old women have it all of the time and you don't see them complaining too much about it."

In a related vein, others expressed frustration with the marketing of OP as a female concern, and they advocated for a more balanced approach:

> "I hope that the male OP thing becomes more prominent in people's minds. Because I think it's very important when I see guys walking around that are worse off than I am. And they are not [*diagnosed*]. And you know there's no [*advocacy for men*]. Women's OP, everybody's hopped on them. You've got advertising on television and everything else about OP. So there's a big red light, everything else going on with this OP with women but there's very little about men."

Men's healthcare providers' actions reveal a potentially similar sex-based assumption. Eight of the 23 men identified their risk factors and followed up on these suspicions with their family doctor. While these men reported that their primary care provider did then order BMD screening, several had to persuade their doctor to do so. For example, one gentleman was attending a community health fair where BMD testing was available. The technician told him that the results indicated OP, but that the machine was calibrated for women and so he should seek the care of his family physician. When he reported the test results and his ongoing back pain to this physician, his doctor was not immediately concerned.

> "[*My doctor*] said that is was very unlikely that a guy would have it. But he referred me to the specialist. That's how I was able to get the test done. I showed [*my doctor*] the results. So I think that he had to have that [*to be convinced*]."

Other men reported dissatisfaction with health care providers who, in their opinion, seemed to have missed obvious symptoms, such as decreased height or the consequences of long-term androgen deprivation therapy (5).

Risk management

As men made sense of being diagnosed with a “women's disease” they encountered the sexing of the disorder in several ways, most notably in their efforts to follow medical advice and decrease fracture risk. Men were dismayed by the lack of male-specific data.

> “In women, presumably, we have a fairly good handle on what it is because there are ample medications that ladies do take that tend to minimize the problems that OP presents. But with men since we know so little and therefore it is really – there really are no medications. The medication that I'm taking was developed for ladies.”

Comments such as this focused on the limited knowledge concerning men's treatment, yet did not make an explicit connection between masculinity and taking “women's” medicines.

In addition to medications, men were frequently advised to avoid physical activities that would increase their fracture risk. This advice included weight restrictions for lifting, avoiding movements that twisted the spine, and reducing movements that increased the likelihood of falling. The ways in which men incorporated these domains into their health maintenance behavior revealed the importance of gender performance to daily activities.

Men who reported weight-lifting restrictions felt that they were impractical. This impracticality was both procedural and gender-based, as the following comment demonstrates:

> “When I was young I'd lift these one hundred pound sacks of fertilizer occasionally. Of course I shouldn't have done that when I was young. … But to [*have trouble lifting*] a 4 pound weight in each hand when you're seated. I mean it seems like it ought to be child's play. You know, women pick up babies that weigh more than that …I mean I couldn't do that and that sort of thing troubles me. But I'm stubborn and I still I go out I take care of my lawn and I'll drag bags of fertilizer out and so on…Well I do it. I usually pay a price, but I do it anyway.”

Men discussed several activities that can stress the spine, such as bowling, golfing, or fishing and their behavior seemed to simultaneously respond to and ignore risk. One man admitted that there was “*no such thing as a safe golf swing*”, and went on to describe how he is working with staff at the golf course to develop a more protective golfing style. Another man discussed fishing:

> “[*laughs*] Well, the funniest thing about it is that I love to fish. I see [*my doctor*] once a year. [*Last year*] he said `I hope you don't catch a big fish.' I said, `Well…' He said, `You know, you really should watch yourself pulling on a fish like that.' When I catch [*a big fish*] I really have to watch myself. So I hold on to it and let him play and get tired before I have to pull him in. [*laughs*]. If I've got something on there that I think is really going to tear me up I cut the line.”

Management of risk overall seemed to stress awareness rather than active prevention. For example, when I asked another gentleman in his 70s, “How is this 20 pound weight limit affecting things you do around the house?” he responded:

> “Well around the house it really doesn't affect it. Because I ignore it. If something has to be done I have to do it. And like cutting the grass – I've got a riding mower for that, but that works on me because the bumping and everything in the yard. That wears me out. My back would be tired from that. But grass – it's going to grow regardless so it's going to get cut regardless. … I'm more conscious that if I fall I might break something. So I think that plays in the back of my mind when I climb up on [*the roof*]. I clean my gutters. My wife has a hissy fit.”

This emphasis on awareness was not solely a product of men's internal dialogue; men reported that other's perception of masculinity could limit men's ability to decrease their fracture risk. The invisibility of an OP diagnosis, vertebral fracture, and pain, intensified men's quandary in avoiding risk because other people could not see that these men were physically limited as they strove to maintain social markers of masculinity. This was a major theme for one man in his mid 50s.

> "I had my nephew go with me to the dump and we're unloading a truckload of shingles and wood and it's like the [*employee is*] telling me `There's people waiting. You need to help him.' Now am I supposed to get out my handicapped sticker and wave in his face or say `No, I ain't going to do that'? … I take a real high risk of hurting myself and doing more damage, but I get back to the point where, you know, I want to do it."

Later in the interview he commented:

> "Yeah… it's a different attitude whether it's bad or not I don't know. It is different for male and female. It's just the way that society expects for a man – I mean, I don't expect for my wife to go out there and build a tree house for my grandkids. But my daughter would think that that would be an awful nice thing for grandpa to do. But not for grandma. You see that there's a difference for what's expected of a man and what there is of a woman…. Of course women [*work hard*] but here is a difference because it is expected of a man to be able to drag his own deer out of the woods [*when hunting*]. It may not be expected of a women to do that even though they can. It's like, `Well you're able enough to go hunting. You ought to be able to drag our own deer out of the woods."

Finally, some men faced the challenge of avoiding risk when fractures seemed to occur for no reason at all.

> "I can't remember exactly when [*the fractures*] happened, but I got a vertebrae cracked when I was trying to open a window. I got another vertebrae [*fractured*] when I walked a little too far too fast when I wasn't used to it. A few other weird things. They were `nothing' events but very painful I'm afraid. … Oh, I walked up some stairs too fast one time."

For these men, the connections between gender and risk management were less explicit, but the impact of OP on their quality of life was apparent.

Discussion

Feminist critiques of the medicalization of older women's bodies have taken to task the social and medical reproduction of the weak woman, but older women are at substantively greater risk of OP and fractures than are men. In an unfortunate turn, it is precisely the sexing of OP as a women's disease that ultimately serves to give men a false sense of security, decreased access to care and treatment, and poorer outcomes. Men with OP in this study share many of the challenges documented among MBC patients. Prior to diagnosis men clearly knew what OP was and considered themselves to be safe because they were men. Some men reported that their family doctors were unaware of men's risk for OP, while other men's narratives implied a sense of emasculation in the eyes of others who questioned why a man would be diagnosed with a "woman's disease." After diagnosis, men's efforts to manage risk were embedded in gender performance and their behavior was constrained by the tension between masculinity and physical ability and by other people's expectations of manly performance.

These results reinforce others' findings of a generally low perceived susceptibility to OP among older men (18, 26) and underscore the importance of incorporating patient constructions of risk into programs to improve risk reduction behaviors (15, 26,27). It also echoes the findings of Gaines et al. about men's limited knowledge of OP risk factors and prevention behaviors in a largely middle class Caucasian sample (15). The men who participated in this study were largely well positioned with regard to social and economic status. This bias and the small sample limit the generalizability of these findings, but also implies that men who are less privileged may suffer additional effects. It is important to note that participants represent a variety of voices on masculinity. While some may actively perform masculinity by engaging in risky behaviors, others' expressed interests in prevention are quashed by the lack of male relevant resources. Thus, while the risk narratives and diagnostic encounters of these men may not reflect the full range of experience, they support the broadening of our attention from masculinity to a deeper attention to *masculinities* and demonstrate how the sexing of disease has consequences for both diagnosis and gender continuity in later life. Individual men perform masculinity from unique sociohistorical locations that should be taken into account when designing research or interventions. Men's narratives of risk appraisal and risk management highlighted the sustained need for clinical vigilance for OP diagnosis and gender-sensitive treatment protocols.

Acknowledgments

The author thanks the men who participated in this study. S.L.S. is currently a Health Research Scientist Specialist in the Center for Comprehensive Access and Delivery Research & Evaluation (CADRE) at the Iowa City VA Health Care System, which is funded through the Department of Veterans Affairs, Veterans Health Administration, Health Services Research and Development Service. The views expressed in this article are those of the author and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government. The Center for the Study of Aging and Human Development at Duke University Medical Center provided facility support, and institutional postdoctoral support for this research was provided by The National Institute on Aging (5T32 AG00029-31). The author extends her appreciation to Deborah T. Gold, PhD for ongoing mentoring and to Dr Thomas J. Weber for his assistance with subject recruitment.

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