

**PERSPECTIVES OF PROSTATE CANCER SUPPORT
GROUP MEMBERS ON MEN'S HEALTH ISSUES
AND MASCULINITY***

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ABSTRACT

There is growing evidence that men are in trouble with their health, and that conceptions about masculinity are implicated in this trouble. But there has been little investigation about the perspectives of men themselves regarding these issues. In this article, findings of interviews with veteran prostate cancer patients who have been involved with cancer support groups are reported. Participants agreed that most men are poorly prepared for acting proactively to ensure good health or for dealing with a health crisis, thereby providing confirmation for recent writing in men's health. Chief among the problems cited is men's habitual tendency to avoid communicating with family and friends about personal health matters. Despite verbal acknowledgment of the need for change, some individual men judged themselves as falling short as communicators. After viewing an educational drama about couples facing prostate cancer, many men reported new insights about the difficulties experienced by their spouse.

There is a growing recognition that men are in trouble with their health. Evidence shows that men die younger, on average, than do women and have higher death rates from most of the leading causes of death (U.S. Department of Health

Services, 2000). Given that many deaths are preventable (or, more accurately, can be postponed) through changes in individual behavior, it's a good guess that men's poorer health may be largely due to how they behave. Numerous studies from many countries reveal that men engage in more behaviors that damage health than do women, and fewer behaviors that improve health (Courtenay, 1998; Holtzman, Powell-Griner, Bolen, & Rhodes, 2000; Reime, Novak, Born, Hagel, & Wanek, 2000; Stronegger, Freidl, & Raky, 1997; Uitenbroek, Kerekovska, & Kessler, 1996). Men are also less interested in making positive health changes (Gabhainn et al., 1999). And they are less active in seeking health-related information—which is likely linked to the reality that men, as a group, are less knowledgeable about health and illness issues than are women (Bostick, Sprafka, Virnig, & Potter, 1993; Mermelstein & Riesenber, 1992; Polednack, 1990; Zuckerman, 1994).

Men tend to underestimate the risks involved with various threats to health, such as drinking, smoking, or exposure to the sun (Boehm et al., 1993; DeJoy, 1992). They are less alert to changes in their bodies and less likely to investigate bodily changes that they might notice (Gijsbers van Wijk, Huisman, & Kolk, 1999; Koh et al., 1992; Stoverinck et al., 1996). Most men do not have regular check-ups with physicians (Schappert, 1999). When men get seriously ill, they often cope more poorly than do women (Fife, Kennedy, & Robinson, 1994; Greimel, Padilla, & Grant, 1989). And they are less likely to access supportive care services that might assist them in coping with illness (Fergus, Gray, Fitch, & Hollenberg, 2002; Levant, 1996). Both in the illness context, and more generally, men have smaller networks of informal support than do women (Babchuck, 1978; Longino & Lipman, 1982). They seek help from others less during health crises and talk about their experiences less openly with peers (Courtenay, 1998; Prosser-Gelwick & Garni, 1988).

In considering why men seem to do so much worse than women in relation to their health, men's health writers have been focusing on how masculinity is constructed for and lived by men (Courtenay, 2000; Lee & Owens, 2002; Nicholas, 2000; White, 2002). The emerging literature on masculinity discusses how men's health, individually and collectively, arises out of, and is intimately connected to, how they learn to understand themselves as men. The cultural ideal of masculinity—with characteristics like being tough, competitive, emotionally inexpressive, public, active, aggressive, and autonomous—is argued to work against possibilities for sustaining good health (White, 2002).

While the evidence continues to mount that men are in trouble with their health, and that notions of masculinity are implicated in this trouble, little is known about the perspectives of men about these concerns. Are men that are not professionally immersed in health issues aware of the so-called crisis in men's health? If aware, do they share the concerns of "experts"—that idealized notions of masculinity are largely to blame for men's poor health performance? Or do they understand these issues on different terms? Are there groups of men

that are motivated to change the status quo around their health, and more fundamentally, to their way of being in the world.

This article reports on findings of interviews with “veteran” prostate cancer patients, who have been involved with support groups for men with prostate cancer. This particular group provides a unique perspective—older men that by and large have subscribed to traditional notions of masculinity throughout their life, but who then had to face a major health crisis. Their reflections on their own and other men’s approaches to health and illness have thus been shaped through experiences that tested the viability of such approaches. As a group, they provide a window for viewing how the issues identified by men’s health writers are being played out in the everyday lives of men forced to deal substantively with health issues. In this study, there was an added opportunity to assess how an educational intervention, focused on illuminating men’s experiences with cancer, further influenced prostate cancer survivors’ thinking about men’s health issues.

METHODS

Accrual and Procedures

Potential participants for this study indicated, in advance, that they planned to attend an educational drama, entitled *No Big Deal?* (Ivonoffski & Gray, 2000), about issues facing men with prostate cancer and their spouses. Contacts with potential participants were made through the leadership of prostate cancer support groups in Ontario, Canada communities where the production was to be performed. Group leaders volunteered themselves and/or recommended other men planning to attend the performance. There were no refusals to participate. Individuals were interviewed by telephone prior to the performance, and also after the performance. Interviews followed a semi-structured format and were approximately 45-60 minutes in length. In the initial interview, men were asked a variety of questions about their experiences with prostate cancer since their diagnosis, including their perspectives on how they and other men deal with health issues and how this might differ from women’s coping. In the post-performance interviews, men were asked about how the drama influenced their understanding of men’s health and illness experience, as well as how it may have influenced their perspective on their spouse’s experience.

Participants

A total of 26 men with prostate cancer completed interviews prior to and following the educational drama. The mean age of study participants was 67 years, with a range of 53 to 82. They were a relatively educated group (13 completed college or university, 10 secondary school, and 3 primary school). On average, it had been 5.7 years since their cancer diagnosis (range = 2 to 16 years),

and they had experienced a variety of treatment modalities (surgery = 15; external beam radiation = 11; hormone therapy = 7; other = 5).

Intervention

The educational drama *No Big Deal?* is based upon a research study, undertaken by our team at the Toronto Sunnybrook Regional Cancer Centre, about the experiences of men with prostate cancer and their spouses (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). The script was constructed to represent study findings, and to provide an educational tool that would illuminate the issues facing prostate cancer patients and their families. The play is structured as a series of vignettes, each one revealing another challenge faced by a man with prostate cancer and/or his wife. There are two couples in the play, an older and a younger one, and many scenes reveal tensions that develop between husbands and wives. The cast portrays the shock of diagnosis, the difficulties in getting and integrating information and making treatment decisions, the concerns about who to tell about the diagnosis and how much to say, the worries and impatience accompanying recovery after treatment, and the coping with incontinence and impotence. Battle scenes are scattered throughout the play, as are appearances by the madcap “Professor Joker,” who tries to explain the complexities of prostate cancer but only manages to confuse everyone. While the topic is serious, the performance is full of humor. Most of the words in the script are drawn directly from interview transcripts.

Excerpt from *No Big Deal?*

In order to provide a sense of the flavor of the performance, an excerpt is provided below, focusing on the post-surgical period where men are often irritable about their incapacitation and the slowness of recovery.

Man 3 (Professor Joker): Today we’re going to demonstrate the Grumpy Bear Syndrome. This post-treatment syndrome is generally found in males, although it can be contagious when two people live in close quarters. The syndrome is characterized by: 1) periods of silent brooding, broken only occasionally by bear like grunts; and 2) pronounced irritability. Our first example is a couple with fairly mild symptoms.

Woman 1 (Miriam): I thought I heard you stirring. Here’s your tea, dear.

Man 1 (Fred): Hmm.

Miriam: Did you have a nice nap?

Fred: MmmHmm.

Miriam: Freddie called to see how you were getting on.

Fred: Hmm.

Miriam: He and Jill are going to drop by for lunch tomorrow. Won't that be nice?
(*Fred sips his tea*)

Fred: Tea's cold.

Miriam: All right, I'll get you another. (*starts to leave*)

Fred: I can do without.

Miriam: No, no, it's my fault. (*martyred tone*) I should have brought it right up to you instead of putting in a load of laundry.

Fred: Miriam?

Miriam: Yes? (*sounding exasperated*)

Fred: I'm sorry. I do appreciate all that you're doing. It's just that I feel like such a lump.

Miriam: Well, I understand dear. (*moving over to hug him*) Just try to be a more cheerful lump.

Professor Joker: Our next couple shows some of the more serious symptoms of the grumpy bear syndrome. They have reached the well-known "mollycoddling crisis point," which appears predictably at this high point in the irritability graph, about 6 to 8 weeks post-treatment. Men are still relying on their wives for support but are also impatient to get back to normal. And women are starting to feel they're being taken for granted.

(*Jack starts to cross the stage and Susan follows him*)

Woman 2 (Susan): Jack! Where are you going!

Man 2 (Jack): We've got to get some wood in.

Susan: I don't need you to do that. That's all I need on top of everything, for you to get a hernia!

Jack: Well, we're low on wood.

Susan: I'll get some later. It's not like I'm loafing around you know. I just haven't gotten around to it.

Jack: I'm perfectly capable of doing this. I'm fine now. (*both getting increasingly angry*)

Susan: Sure you are. And I suppose you weren't tossing in your sleep moaning with pain last night.

Jack: I was not!

Susan: Oh yeah? Well, tonight I'll record you.

Jack: (*pointing his finger aggressively at Susan*) You do that. But in the meantime stop hovering over me!

Susan: Fine! You want to do something useful—well how about doing the dishes, or folding the laundry. (*she throws laundry basket at Jack*) I'm going to take the garbage out and shovel the snow. And then I'll split the wood.

Jack: Oh, Susan! (*he follows as she exits stage left*)

Professor Joker: As you can see, this grumpy bear syndrome can be very serious business. To help prevent things from getting really bad, our research team has compiled a list of **8 Things to Do While Your Man is Recovering from Surgery . . . Not!!!**

(*actors line up across the stage*)

Woman 1: Every 5 minutes, ask how he's feeling or if he's in pain, morning to night.

Man 2: If he says one revealing thing about what he's thinking or feeling, immediately follow up by asking about the top 5 things you've always wanted him to open up about.

Woman 2: Suggest that this might be a good time for him to retire, or give up smoking, or go on a diet, or take up yoga.

Man 1: Invite all his friends and acquaintances around to the house for a bedside visit to help him overcome being such a stick-in-the-mud.

Man 2: Cancel the subscription to the Television Sports Network.

Woman 1: Stay by his side at all times, and remind him to be careful every time he gets up from his chair.

Man 1: While he's bed-ridden, use the opportunity to explain to him about steps that could be taken in your marriage to ensure a more equal distribution of power.

Woman 2: Let him get away with treating you like a servant or nursemaid. Some men . . . ok most men, will use any excuse at all.

Analyses

Initially, members of the research team met to discuss themes that were emerging from the first few interviews. Then team members independently reviewed and coded several transcripts and developed preliminary coding schemas. These were then used to develop a single coding schema, which was subsequently refined and modified as new data emerged from other transcripts. A single member

of the team (ML) undertook the remaining coding of the transcripts, consulting as necessary with the study's primary investigator (RG) about controversial issues.

The computer software Non-numerical Unstructured Data Indexing, Searching, and Theorizing (NUD*IST), was used to assist with data management for this study.

RESULTS

Interview results are organized under two broad categories: 1) men's perspectives prior to the educational intervention; and 2) impact of educational intervention on men's perspectives.

Prior to Educational Intervention

Most of those interviewed had negative things to say about how men typically deal with health and illness. Overwhelmingly, these men agreed that the hesitancy to reveal what is happening compromises men's coping and imperils those surrounding them.

I get angry and pissed off because men need to know that doing it alone is not the way to go. It's best if you talk to someone else that has experience and ask questions of them and find out where they're at. To gather support around yourself. PT 8

Men are less likely to talk about it. Some go into a shell. Sometimes they do that, nursing this or that and letting it go too long, and when they finally decide to do something, it's too late. . . . If they were better communicators, better listeners, not afraid to speak how they feel to somebody, to share their problems, they would be better off. PT 10

Men's frequent inability to speak about what is happening with their health was negatively contrasted with women's approach to dealing with things.

Men tend to keep it to themselves. They don't talk about it or they don't believe in bringing it out into the open. Women, in general, have better support. PT 5C

I would say that we don't talk as much as girls might. You know, they will confide in each other, whereas fellows, we even have a hard time talking to our brothers. PT 6

The importance of better and more communication was linked for some study participants to a need for more attunement to the emotional side of life.

They won't talk about it and get their feelings out in the open where they might see that a lot of their thoughts aren't realistic. Men are just so frightened, but they don't want anyone to see them being frightened. Women are far more open. PT 19

Men tend to be more stoical. They hold their feelings in and get mental stress out of that. I see it in the support group, certain men seem to have reached peace with themselves, and then I hear from other sources that things are not at peace, that they're having problems which haven't been resolved and causing marital stress. PT 4

A number of participants referred to how men's expectations for themselves (as men) created a barrier to positive action and adaptation at the time of diagnosis.

Men think they're invincible so it's more of a shock for them to be told they have cancer. I think they react pretty badly to it, most of them. It's like, "I'm a man, I'm supposed to be strong. Why is this happening to me?" Sickness isn't supposed to be on the agenda. PT 15

While socialization to be tough was a common explanation for men's difficulty adapting to illness, other participants seemed to believe that men were simply less hardy than were women.

Women, I believe face facts and do things, whereas men are like dogs, they go to the corner and lick their wounds and hope it's all going to go away. PT 24

I usually find that women are stronger than men. Men sometimes psychologically can't quite handle it. But that's certainly not always the case. PT 5

Some participants pointed out that men often had inadequate preparatory experience with health professionals and health settings, making them less capable to address issues. One man argued that lack of information about men's health contributes to individual men being poorly prepared for managing a crisis.

I think women have been brought up a little more aware of themselves from a medical point of view. Because of reproductive issues or whatever. Whereas men have been able to sail along and not have to deal with that aspect of their life. And so when it comes along, their modesty is probably detrimental to them. PT 23

I think it's more shocking to men. But if they got more information about prostate cancer it wouldn't be as shocking. I think that women have been more aware of breast cancer risks, so they probably deal with it much better than men. PT 21

Study participants were adamant that most men needed to have better attitudes about doctors. Many had avoided going to doctors, sometimes resulting in delayed diagnosis. And participants noted that they and other men were too quick to defer to the authority of doctors about their health. Important questions were often not asked; decisions made too quickly.

I think men have a tendency to not want medical help. You know, I don't need a doctor or I'm fine and everything's great, until in a lot of cases it's too late. PT 14

I believe men's usual reliance upon their doctor's advice only can lead to less than optimum treatment. PT 11

Unfortunately, many men still expect that the doctor should make the decision for them as to which kind of medical support they're going to get. PT 1

During interviews, participants were asked about possible positive aspects of men's ways of dealing with health and illness. While a few mentioned the usefulness of a pragmatic, problem-solving orientation, most men could see little to recommend the cultural ideal for masculinity.

I suppose, generally we try to muddle through perhaps more than a woman would. You know you get the job done and that's good. But denying it and trying to cover it up is not good. PT 13

I guess in some ways men's avoidance of things can be a benefit because you try and put it out of your mind and forget about it and carry on a normal life and act normal. It may not be the best for the long term for the man, but in the short term it works. PT 14

I really can't think of anything positive about how men deal with illness. Because you're suppressing so much in you emotions and your whole system . . . your immune system just doesn't respond properly. PT 19

While the men in the study were fairly consistently caustic about the approach that men often take to health and illness, they were nevertheless sensitive to the difficulties that individual men have in trying to mobilize personal change.

I think we have to be compassionate with a man who does not open up. It's a hard thing to do, because we were all taught to keep things private. PT 26

Post-Intervention Data

Based on qualitative research, the play *No Big Deal?* displays how many men with prostate cancer deal with illness, including how they engage with spouses during a health crisis. For about half of the men in our sample, the scenes they saw on stage confirmed but did not add to their existing perceptions about men's health issues.

It just reinforces that I need to be vocal with men. And not secret about prostate cancer. And speak my life experience. PT 8

It's kind of reassuring to know that your experiences were pretty much the same as everybody else. So you see it on stage and you think, "yeah, that's me." PT 9

Other men had fresh insights about the importance of communicating with their spouse, past and/or present.

I think, from watching the play, I've come to the realization that it's good to open up a bit more. It's a 2-way street, communication's got to be back and

forth. I think in general my attitude was “Ok, it’s no big deal.” . . . And the whole macho thing kicks in and you kind of exclude the family, the wife and kids from it. PT 5

I don’t think I clammed up too much, but I might have. I tried to be open at the time but maybe I wasn’t. Who knows? PT 4

The strongest learning from the educational drama for the men was not about how men deal with health and illness, but about the impact of men’s illness on the women who love them. Many of those interviewed described how seeing actors portray women’s perspectives opened their eyes in new ways, making them realize that the impact of disease was not limited to them.

I appreciate the fact that they go through it in a larger sense than what I’d realized. Now I see that they go through a tremendous amount of emotion and anxiety that I wasn’t aware of initially. PT 10

It reinforced that in some cases she is probably suffering more than I am and worrying more than I am, yet trying not to show it at all because she doesn’t want to upset me. I can relate better to her feelings now. PT 14

The realization that women were more affected than many men had believed was the source of consternation for some.

I was so focused on myself, rather than even thinking of her or looking at her and what her emotional turmoil must be. I was sad that I didn’t pick that up. You know that I could not see the larger picture and how supportive she was. I knew she was making phone calls and getting information for me but I wasn’t aware of the emotional part of what was going on. To see that was a big awareness for me. And now I want to tap into that. You know, be more supportive of her in emotional times. PT 8

Men also spoke about the value of the drama for wives who attended it, pointing at the possibility that they did not always feel well understood in what they were going through.

I think it opens the door for wives to see another side. It could let them realize that, yeah, men generally keep everything within themselves, but they do have feelings and emotions that they’re running through also. PT 10

There’s probably a better understanding of what the man is going through. Even though you may not be happy with what his response to you may be, at least you might have a better understanding of that. And that always makes it easier. PT 3

DISCUSSION

The men interviewed for this study share characteristics which make them important commentators on men’s health issues, but which distinguishes them as different from most older males, including most men with prostate cancer.

Experience with prostate cancer has provided them with intimate, first-hand knowledge of how traditionally male approaches to health and illness work (or not). Experience with prostate cancer support groups extends their knowledge about men's coping patterns to include many other individuals in similar circumstances. Group participation also provides experiences that challenge, or at least extend, men's usual ways of coping, by engaging the men in discussion with each other about difficult life issues. Clearly, this sample should be understood as key informants of a particular kind, rather than as representative of older men's perspectives on men's health issues.

Study participants believe that men are poorly prepared for acting proactively to ensure good health or for dealing with a health crisis. This understanding arose directly out of the men's individual experiences, thereby providing important confirmation for recent academic writing about men's health issues. Prostate cancer veterans described how they and other men were prone to avoid health issues and doctors, and often performed in self-defeating ways when they engaged with the health system. In response to this recognition among patients, there has been substantial activity in cancer support groups whereby men encourage other men to be more proactive in dealing with health professionals and to take more responsibility for their own bodies.

The veterans of prostate cancer interviewed for this study shared the understanding of leading men's health writers about why men perform poorly in relation to their health. While most did not discuss issues in the more abstract forms familiar to academics—e.g., “culturally ideal” or “hegemonic” masculinity—they nevertheless spoke about specific features of traditional masculinity that negatively affected men's capacity to engage positively with their health. Chief among the problems cited was men's habitual tendency to avoid communicating with family and friends about personal health (and other) matters. These men had learned, through their association with cancer support groups, that it can be helpful to be more open about one's experience. And many had consequently become advocates for better communication, at least in the domain of illness, and often more broadly.

Despite the overwhelming endorsement from study participants for men to be more open and communicate better about their lives, there was evidence that such shifts in behavior were not easily achieved. Some men who viewed the *No Big Deal?* play, in which communication issues were highlighted, subsequently questioned whether they were doing as well on this front as they intended. A few men, despite their prior experience with support groups, were only newly convinced that they should be open with family members about their illness. These findings suggest that the rhetoric of improved communication espoused in support groups may not always be taken seriously, or even necessarily absorbed, by individual members.

It is interesting that the strongest impact for study participants of viewing a research-based drama about prostate cancer issues was to have greater insight into,

and empathy for, their spouse's experience. While most of the men, to at least some degree, had made efforts to talk about their own struggles, many had failed to fully appreciate the struggles undergone by their primary support person. It could be argued that for some men the focus on communication was mostly on expressing, much less on listening (or eliciting unspoken reactions)—resulting at times in failures of empathy. This finding speaks to the limitations of a narrow, skill-building framework for expanding men's approach to health and illness. While it can be important for men to be more open about their lives, the larger context for meaningful support is interpersonal intimacy that involves reciprocal sharing and listening.

Previous studies of prostate cancer support groups have revealed that the primary emphasis tends to be on disseminating medical information (Coreil & Behal, 1999; Gray, Fitch, Davis, & Phillips, 1996; Manne, 2002). But the findings of the present study show that other agendas are relevant, including challenging prevailing notions of masculinity, especially as they contribute to sub-optimal approaches to health. Veteran patients are advocates for more proactive health practices and for the undoing of men's attachment to privacy, stoicism, and aggressive independence. While not necessarily perceiving themselves as having a radical agenda, prostate cancer support groups (including interact discussion groups) carry a grassroots message aimed at undermining the practices of hegemonic masculinity and supporting improved health practices.

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