

The Need to Be Superman: The Psychosocial Support Challenges of Young Men Affected by Cancer

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For many cancers, young adult survival outcomes have not improved in decades (Bleyer, 2011), and general consensus is that this lack of improvement stems from a combination of biologic, medical, and social influences (Bleyer, 2011; Fernandez et al., 2011). As a result, the psychosocial aspects of the young adult cancer experience are receiving increased focus (Morgan, Davies, Palmer, & Plaster, 2010; Zebrack, 2008), including consequences for quality-of-life indicators (e.g., relationships with partners and family, [in]ability to engage in daily activities, fertility issues) (Clinton-McHarg, Carey, Sanson-Fisher, Shakeshaft, & Rainbird, 2010).

Through several mechanisms, psychosocial support can affect health and well-being (Fernandez et al., 2011). Clinician-patient communication has been linked to health and well-being through proximal outcomes of agreement, trust, and understanding, as well as increased adherence and enhanced self-care (Street, Makoul, Arora, & Epstein, 2009). Considering the importance of psychosocial support, young adults reporting age group-appropriate support as a consistent unmet need in various facets of their lives, including mental health and relationships, is troubling (Zebrack, 2008).

Adding to the challenge is that men are less likely to seek support and information than women, more reluctant than women to consult their doctors, less knowledgeable about health, and show poorer psychosocial adaptation to cancer than women (Chapple & Ziebland, 2002; Galdas, Cheater, & Marshall, 2005; Nicholas, 2000). Disparities in men's and women's health outcomes are, in large part, attributed to men's beliefs that they should be independent and not seek help (Chapple & Ziebland, 2002; Nicholas, 2000). These beliefs are a ubiquitous feature of social life created by and through individual interactions with others (Courtenay, 2000; Moynihan, 1998; Oliffe, 2007). In the context of health, these displays of masculinity put men at greater risk and create challenges to identity reconstruction (Courtenay, 2000; Gurevich, Bishop, Bower, Malka, & Nyhof-Young, 2004).

Purpose/Objectives: To investigate how gender-specific issues shape the experiences of young adult men with cancer and what they report to be problematic.

Research Approach: A qualitative, descriptive approach.

Setting: Website, focus group in the southwestern United States, and phone interviews throughout the United States.

Participants: Text from an online forum (N = 3,000 posts), focus group of six men, and separate interviews with four men.

Methodologic Approach: Data analysis took place over two months through constant comparison of online text as well as a focus group and interview transcripts.

Findings: Men face challenges being both a receiver and provider of support in relationships with their peers, romantic partners, and children. Cultural expectations to "be strong" drive their support-seeking beliefs and behaviors.

Conclusions: Men report conflict between desires to show strength and to be honest that present a barrier to support, as well as contribute to inadequate relationships with male peers and greater difficulty in exchanging support with romantic partners.

Interpretation: The authors identified attitudes about and barriers to men's experiences with social support, which healthcare providers, such as nurses, should be sensitive to when developing and providing support.

Key Words: young adult cancer, men, masculinity, social support

How men with cancer view their own masculinity is not only influenced by cultural ideals about what a man is and should be (i.e., stoic and independent) (Moynihan, 1998), but also is constrained by the inherently chaotic and emotional experience of cancer (Becker, 1997). Research on men with testicular and prostate cancers is focused mostly on older men and illustrates the tension between appearing strong and feeling ill, being independent and needing help (Gurevich et al., 2004; Oliffe & Thorne, 2007; Oliffe, Ogrodniczuk, Bortorff, Hislop, & Halpin, 2009). Importantly, this research

draws attention to the poorly studied dilemmas and complexities of providing support to young men with cancer, arguing for a more gender-sensitive approach to men's support and care (Chapple, Ziebland, & McPherson, 2004; Singleton, 2008).

Although more research is focusing on men's lived cancer experiences (Cayless, Forbat, Illingworth, Hubbard, & Kearney, 2010; Wall & Kristjanson, 2005) and awareness of risks (Moore & Topping, 1999), additional examination is needed to identify what makes cancer particularly disruptive for young men and to describe why men have difficulty overcoming these challenges and discussing their cancers (Chapple et al., 2004; Sandén, Larsson, & Eriksson, 2000).

Lack of knowledge about supporting young men with cancer is particularly problematic because the literature on masculinity and health focuses on cancers that affect older men (e.g., prostate) (Chapple & Ziebland, 2002; Oliffe, 2007; Oliffe, Ogrodniczuk, et al., 2009). Building from earlier research showing that men affected by chronic illness face particular challenges, and that gender-specific care could impact outcomes, the researchers' guiding question was, "In the context of young adult cancer, what unique challenges do men report?" The current study helps to fill that gap and informs the call for more personalized care for patients with cancer (Fernandez et al., 2011; Oliffe, Davison, Pickles, & Mroz, 2009; Zebrack, 2008) by investigating how age- and gender-specific issues shape the experiences of young adult males with cancer.

Methodologic Approach

To better understand the unmet psychosocial needs of young adult men affected by cancer, the researchers employed qualitative methods involving several sources. The investigation began with an online forum for young people affected by cancer; then, to inform, substantiate, and confirm emerging themes, data from a male-only survivors' focus group and key informant interviews were used. All recruitment and data gathering received institutional review board approval from the University of Texas at Austin, and participants completed informed consent forms.

Online Forums

The researchers reviewed text from 3,000 posts in a young adult cancer-focused online support forum (a few family members or caregivers were present), where members self-identified as male or discussed men and support. Members discussed cancer as a lived, first-person experience as opposed to writing about others' experiences.

Because de-identified preexisting posts were analyzed, precise demographic information about the men

in this study could not be gathered. Based on the age question at registration and the content, the researchers inferred that participants are within the accepted young adult age range of 18–39 years.

The forum was a preexisting English-language forum open to any young adult affected by cancer from diagnosis to post-treatment. The online community maintains several thousand users, predominantly from the United States, and receives nearly 20,000 monthly visits. Registration for the online community notes that content may be used for research purposes and includes a statement that content can be used for "well-behaved," non-commercial efforts, subject to the definition and discretion of network administrators. Following institutional review board approval, administrators provided text-only files with user names, and identifying information was replaced by randomly generated alphanumeric codes.

Posts were selected based on relevance to men's needs. Researchers read a subsection of the threads to determine search terms, including *men*, *male*, *gender*, *sexual issues*, and *masculine*. The initiating post did not have to concern men. Instead, male-specific concerns only needed to be part of the conversation (e.g., present in subsequent comments in the thread). Selecting posts this way allowed for men's needs to appear naturalistically in conversation and provided context in line with how individuals experience cancer trajectories. The final sample included 253 posts from 50 threads (initiating post and ensuing comments) from February 2008 to August 2010.

Focus Groups

A focus group was conducted consisting of five male survivors, aged 21–36 years ($\bar{X} = 28$). Four of five participants identified as Caucasian, employed, and with a college education. Different cancers were represented, including testicular, brain, and soft-tissue sarcoma. Length of time since first diagnosis ranged from less than six months to more than 12 years ($\bar{X} = 7.1$, $SD = 4.67$) (see Table 1).

Recruitment took place through advertising in newsletters and websites of local chapters of cancer support organizations in a large Southwestern metropolitan area. In addition, notices were posted on social media, such as Facebook and Twitter, twice a week for a month. Survivors aged 18 years and older were invited to participate at one of four times convenient for them. Informed by other research indicating the range of psychosocial responses to cancer (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992), the intent was to recruit a range of survivors. Recruitment materials requested young adult cancer survivors willing to talk about their experiences, their communication with family and friends about cancer, and their use of media. Data from only the exclusive male group are employed here; the other groups included women and produced data

for other research. Sessions were audio recorded and transcribed, and participants received a \$25 gift card.

The focus group interview lasted about 90 minutes and occurred in the conference room of a support-focused cancer nonprofit organization. The session followed a semistructured interview guide that allowed researchers to explore and verify themes related to the experience of being a young man affected by cancer, while also encouraging participants' own narratives and important topics (Krueger & Casey, 2009; McAdams, 1993). Topics included information needs and resources, peer support, relationship management, disclosure, and advice for loved ones and peers.

Informant Interviews

Four key informants aged 25–39 years ($\bar{X} = 31$) were interviewed. Interviewees were different individuals than focus-group participants. Interviewees identified as Caucasian, college-educated, and employed. Cancers represented included testicular, brain, and soft-tissue sarcoma. Length of time since diagnosis ranged from 5–15 years ($\bar{X} = 9.5$, $SD = 4.4$).

Recruitment for key informants occurred through an advertising flyer placed in a prominent position during check-in at a young adult-focused cancer conference. Interested men could contact the first author to set up an in-person or phone-based interview. All interviewees had participated in leadership roles for support organizations relevant to needs of young adult men, demonstrating involvement with the issues. Sessions were audio recorded and transcribed, and participants received a \$25 gift card.

Interviews mirrored the focus group methodology; a semistructured format was followed and covered the same topics. Interviews were conducted via telephone and ranged from 35–61 minutes (averaging 45 minutes).

Thematically, responses matched the focus group with one exception, likely because of participants' leadership roles. Like those from the focus group, interview participants addressed the cancer experiences of young adult men in relation to social support. However, interviewees often added content about policy and standard changes, which was useful, but not related to the research question.

Data Analysis

During three phases, researchers worked to understand stated experiences, motivations, and unmet needs of young men in the cancer context. The data were analyzed using grounded theory and constant comparative techniques (Strauss & Corbin, 1990) to extract information embedded in experiences (Michallet, Le Dorze, & Tétreault, 2001). Researchers worked independently and met to discuss themes and establish consensus, occasionally using a peer debriefer for validation.

Table 1. Focus Group Characteristics (N = 5)

Characteristic	\bar{X}	SD
Age (years)	28	5.61
Time since diagnosis (years)	7.1	4.67

Characteristic	n
Married	2
Employed	4
Cancer diagnosis	
Brain	1
Soft-tissue sarcoma	1
Leukemia	1
Melanoma	1
Testicular	1

Over the course of a month, researchers independently examined the online content for relationships among gendered experiences and cancer trajectories. Such analysis produced initial concepts that then were discussed among the authors as is usual with continuous data collection and analysis (Charmaz, 2003). The constant comparison employed the online text in increments to allow for ongoing discussion of findings, and so that ideas could be checked during follow-up readings (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Reliability was established through discussions, and findings were based on author agreement (Charmaz, 2006). In addition, a peer debriefer specializing in qualitative research examined the data and findings and verified that the themes were supported (Lindlof & Taylor, 2002).

Following analysis of the transcripts of the online posts, the focus group transcript was read for insight and confirmation of previously noted themes. The first author and the peer debriefer analyzed the interviews for the same purpose.

Findings

Across data sources, the consistent need for discreet and appropriate emotional support stands out as the most discussed area, but its use is severely hindered by cultural expectations of masculinity. Perceived cultural expectations to maintain an image of strength in line with stereotypical gender roles stands out as the dominant theme throughout the texts, and this, in turn, differentially impacts peer support, partner relationships, and the ability to care for children.

The Need to “Be Strong” as a Barrier to Support

Although other issues (e.g., fertility, treatment, information resources) surfaced in the analysis, the frequency and salience with which men reported perceived

masculine cultural expectations to “be strong” or maintain a “stiff upper lip” prompted the focus on emotional support through social channels. Men describe the pressure to be strong as an overarching barrier that prevents them from receiving and offering emotional support, particularly in relationships with peers, partners, and children, which is consistent with research on other age groups (Moynihan, 1998; Nicholas, 2000; Oliffe, 2007). For example, one member wrote the following online.

Being a man, you always have to cover up your suffering as much as possible. “Never let them see you hurting” is something that always went through my head. . . . I felt like I had to be strong for everyone else. Well, that’s probably one of the mistakes I made. Maybe letting others see the suffering I was going through might have made them stand up and help carry me along.

Conflicting goals between being strong and being honest about his emotional state acted as a barrier to his ability to seek and receive support. The emotional balance is so delicate that one focus group member even advocated having a loved one “freak out on your behalf because then you can also feel like you’re being the strong one.” He discussed such a relationship as allowing him to maintain his perception of strength while being in an environment where open emotional concern is accepted.

Another focus group member, who used mental health services several years post-treatment, detailed that internal barriers about being open with his feelings initially stood in the way of therapy.

I always believed in therapy, but I was too proud or too something to really pursue it. I’m not struggling with depression or anything. I feel like I’m a pretty well put together guy. However, I’ve seen the service [therapy] and it made me realize like, “Wow. Even though I thought I had everything put together, I could be better.”

However, according to participants here and in other research, personally acknowledging weakness would hurt perceptions of masculinity (Winnett, Furman, & Enterline, 2012).

Peer support: Men in this study remarked that the social support they receive from other males is inadequate or nonexistent as a result of masculine gender expectations. They reported discord between masculine strength and the perception or experience of illness leading friends to create distance. In the interviews and focus group, men strongly asserted the importance of peer support, despite its rarity.

Even if there are less-than-ideal circumstances that wind up being a result of it [a cancer diagnosis], you can deal with it. Having that support structure

will help you get through. If it works out and you’re cancer free for the rest of your life, fantastic. If you have to struggle through it, it sucks, but at least you’d have friends.

At the same time, many participants lamented the loss of friends because of their cancer experience. One online forum member discussed peer support during his cancer.

There is always that lack of brotherhood. People that may not know exactly what you are going through but can make fun of you all the same. Punch you in the port. Slap you on the stitches. The ones that are willing to stick by even if the thought of losing you is too unbearable.

Men value and desire friendships during this difficult time, in part because even just the opportunity for peer support is valued (Chapple & Ziebland, 2004).

[Y]ou get what you get, and you don’t have to listen to certain people, or you can listen to certain people. You’re given an opportunity. And, at least in my opinion, it’s better to be given the option than to not even know it’s there in the first place.

However, gendered support notions can drive inadequate interactions with other males.

The others, generally speaking, are in some combination of denial and “chin up, buck” attitude. To make things worse, I think other guys use inappropriate humor to deal with their discomfort on the topic. I find I have to do some serious reading between the lines to figure out what the hell they are trying to tell me.

Partner support: Another prominent area of support challenges stemming from perceived expectations of masculinity involves romantic relationships. Effective support for male survivors seems to come from spouses and romantic partners who view the cancer experience as a joint effort.

One focus group member described a situation with his partner, where they sought a diagnosis for his as-yet-unexplained symptoms together. “[M]y partner was a little bit excited like, ‘Cool! It’s cancer. It’s kind of dangerous, but they know how to treat it now.’” He reported benefitting from the joint approach with his partner and the partner’s optimistic outlook. Another focus group participant discussed the importance of having each care provider always deliver information to him and his wife as a couple, so that they are “able to digest it at the same time, [and] be there for each other.”

One popular topic in the online forum was the need to set aside conversational time explicitly dedicated to not discussing cancer.

The other thing that we've been doing is, while we're spending time together, take an hour or two off from talking about cancer. It's amazing how hard that is at the moment, but it's also helping us remember what we're like together.

Supporting children: Men with children added concerns about providing emotional support for his existing family despite how perceptions of masculinity can initially prevent effective family communication. Information, support, or strategies concerning how to explain and share the cancer experience with children stood out as a little-addressed family issue.

Unfortunately, no one seems to have straight forward advice about what to do in this situation. There were times when it was impossible to shield [son] from things, and we've had to explain a few things that no preschool kid should ever need to know about. . . . I think, though, that by including him in the situation, rather than having someone care for him or something like that, that he felt more connected to us.

One interviewee put this need to focus on family in all aspects of the cancer experience as, "I think it's becoming almost more tribal. People are flocking toward the pack that they trust." For some men in the online forum, their outcomes were better connections to loved ones, findings similar to earlier research that examined young men facing masculinity-threatening fertility issues (Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002).

It's very humbling to have to admit this, but I really am becoming a better dad and husband through this. And yes, I just wish that it could of happened another way.

Discussion

Consistent with literature concerning the gendered experience of cancer, researchers found that notions of masculinity impact men's ability to seek, give, and receive emotional support (Courtenay, 2000; Evans, Blye, Oliffe, & Gregory, 2011; Moynihan, 1998). Not only do men find it difficult to ask for help, but they often believe that they cannot, and should not, go to others for support. Moynihan (1998) stated that men with cancer "wept in private far away from their families, and often in their cars where they felt 'enclosed and safe'" (p. 1,074).

Young adult men are acutely aware of the masculine image they are expected to uphold and lament a lack of received support from what they attribute to enacted cultural expectations. The negotiation of masculinity (e.g., strong, sturdy, reserved) with the inherently chaotic and emotional experience of cancer has implications for personal relationships (Becker, 1997; Cayless et al., 2010).

Knowledge Translation

Encourage young men to find ways to express feelings without violating masculine identity expectations.

Suggest activities apart from the anonymity of online support groups that connect men through activities not explicitly identified as support (e.g., sports, exercise, faith groups).

Encourage time set aside for noncancer-focused interaction with loved ones.

In the current data, masculinity was a barrier to support that affected peer, romantic, and family relationships. Peer connections suffered from increased social distance. Romantic relationships operated optimally as cancer partnerships, requiring extensive conversation and, often, communication training with significant others to share emotional and illness-work burdens, consistent with other chronic illness findings (Michallet et al., 2001). Family interactions stand out as an unaddressed issue that initially presents a challenge, but can turn into opportunity for deeper relationships.

Implications for Nursing Practice

Despite frustrations stemming from expectations of masculinity, some men discussed examples of effective support that could be modeled by nursing practitioners. First, men need to find outlets to express feelings, which might be a challenge for those lacking appropriate communication skills or support networks. Speaking out risks losing other men's emotional support, but the resulting catharsis seems to outweigh the cost; men who do seek the help of others praise the experience. Responses suggest that an ideal scenario would include ways for men to express feelings without threatening masculine identity; for example, using humor to introduce the topic and promote coping during support exchanges (Chapple & Ziebland, 2004; Oliffe, Ogradniczuk, et al., 2009). Of course, dealing with cancer as a joint effort requires extensive conversation and sharing. Communication training and handouts encouraging men to discuss difficult topics have served as successful prompts among older men diagnosed with prostate cancer and may do the same for younger men (Kripalani et al., 2007; Nelson & Kenowitz, 2013).

The openness of men in the online forum suggests that expressing thoughts and feelings may be easier through the relative anonymity of digital media, a strategy that nurses can proactively recommend. Consistent with prior work (Chapple, Salinas, Ziebland, McPherson, & Macfarlane, 2007; Seale, Ziebland, & Charteris-Black, 2006), the online data indicate that

sensitive issues, such as sexuality and emotions, benefit from online anonymity and can meet the desire for opportunities to discuss sensitive topics.

Connecting men through other activities, not explicitly connected with cancer, such as sports or exercise (Carless & Douglas, 2008) and religious groups (Tarakeshwar et al., 2006), received strong support in the interview and focus group findings in accordance with research demonstrating positive connections between activity and mental-health outcomes (Hefferon, Mallery, Gay, & Elliot, 2013; Mason & Holt, 2012), as well as spirituality and well-being in men and young adult survivors (Krupski et al., 2006; Park, Edmondson, Hale-Smith, & Blank, 2009). The focus, then, is not on men's cancer experiences, but on a shared interest that can be a conduit for cancer-related conversation and, therefore, gender- and age-appropriate support.

Limitations

Limitations of the current study include a primary data set of de-identified text that existed prior to the study, removing the ability to probe. Although the researchers worked to address this through interviews, digitally reported behaviors and motivations were not subject to exploration. In addition, individuals living in households earning less than \$30,000 per year and Spanish-dominant Hispanic adults living in the United States are less likely to use online support (Zickuhr & Smith, 2012), and these groups were not present in the

focus group or interviews. For participants far removed from diagnosis and treatment, subsequent aging may have influenced their views on masculinity. Therefore, the data offer a piece of the young adult male cancer experience but cannot be applied to all demographics or diagnoses.

Conclusion

In the context of young adult cancer, perceived cultural expectations of masculinity affect young men's abilities to use and benefit from social support. Qualitative findings based on online community discussions, interviews, and a focus group show how the barrier presented by expectations of masculinity affects peer, romantic, and family relationships differently. The results offer ideas to better support men in their cancer journeys through communication training and non-cancer-focused activities.

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