Reviewer's report

Title: Constructions of sex and intimacy after cancer: A Q methodology study of people with cancer, their partners, and health professionals

Version: 1 Date: 12 November 2012

Reviewer: Jennifer Reese

Reviewer's report:

I am highly supportive of these authors’ choice of topic, as sexuality continues to be a domain of QOL that is relatively understudied yet valued by cancer survivors. This manuscript has several strengths including the use of both patients and partners and the inclusion of patients with a range of cancer types, and is generally well-written.

However, I have substantial problems with the methodology and the conclusions the authors make using this methodology. A primary concern is that the Q sort items are in fact “a broadly representative sample of perspectives and viewpoints.” Many of the items they present are worded in the extreme, and as such seem to represent a sort of social desirability measure more than a measure of patients’ or providers’ actual viewpoints and certainly not behaviors. When faced with the item, “If a man can’t get an erection, there is no point in being intimate,” wouldn’t most respondents see the researcher’s intent here? Wouldn’t an item such as “Not getting erections can be frustrating and sometimes leads to stopping sexual activity” be more insightful into respondents’ actual attitudes? It seems to me that what they authors really may be tapping into with such items is the degree to which it is socially desirable to respond to particular items about sexuality in cancer.

While I completely agree with the concept and importance of renegotiating the concept of sex after cancer, I am concerned that the methods used here, and specifically the items used here seem poised to demonstrate the particular agenda of the researchers more than they provide a genuine exploration of the participants’ perspectives.

Perhaps even more problematically, by framing the study in this way, the result seems to be a marginalization of those patients and partners who do have sexual problems, who do have difficulty discussing sex, and who are distressed, as well as of those cancer providers who struggle with how to address sex in their patients. Where are the perspectives here of the woman with rectal cancer whose had vaginal atrophy after radiation therapy and is distressed about this? Where is the perspective of the couple having trouble talking about sex because one partner has an ostomy? By framing the items in such extreme terms (e.g., “when a person is diagnosed with cancer, sex becomes taboo”) it seems that the authors have inadvertently marginalized the perspectives of those patients/partners who feel that sex has become challenging –not taboo- but
challenging. It is that far more common, far less extreme, and far more complex perspective (i.e., of the patient/partner who has challenges and is working through them) that I am concerned is getting lost here.

My concern applies particularly strongly to the issue of patient-provider communication as “explored” here. What comes across is that providers are doing an excellent job communicating with their cancer patients about sex, when we know from mounting research that with the exception of prostate cancer, the majority of cancer patients receive little information or discussion with their providers about sex. Including in the provider sample so many psychologists and social workers, who are trained to discuss such sensitive issues, yet who serve a less primary role in many cancer patients’ care than their oncologists and nurses, potentially confounds the findings. These providers’ experiences and comfort level is certainly not the norm. Even if we were to take these providers’ attitudes as measured here as positive, we could not use it to infer anything about their actual behavior (i.e., to assume that because they say they are in favor of talking with their patients about sex that they actually do this). To do so (as I am afraid the authors imply in the discussion section) is to do a disservice to readers of this paper who could be misled to think that patient-provider communication is quite good with regard to sex.

My issue with inferring behavior from the attitudes measured here also pertains to patient-related items. In other words, because patients say that cancer patients should be able to use sex toys says nothing about patients’ actual sex toy use. The critical difference between attitudes and behaviors is not adequately acknowledged here, and I am afraid that the authors have occasionally inferred actual behaviors from self-reported attitudes.

Abstract

A couple typos in the first paragraph

Introduction

It was not clear how the authors were aiming to address the mismatch between patient and provider perspectives on sexuality in cancer here, as they state on p. 5, (given that patients and providers were combined into one larger group and therefore, it is not known whether their patterns of responding would have differed). I think it would have been quite interesting to separate patients from providers to examine whether the patterns differed, although I understand that by combining the patients and providers, the authors had enough of a sample size for the factor analysis and would have jeopardized this by splitting up the groups.

I did not feel that there was enough of a rationale behind what this study adds that is unique to the literature, given that there has been quite a bit of research in this area. Also, the authors state that little research has been conducted with partners and I am not sure what they mean by this since there are a number of interventions for couples with cancer that address sexuality. Perhaps they mean in qualitative type investigations? One way to frame this would be to discuss prior
research on attitudes about sexuality, since that is what this manuscript seems to do, and then discuss what is new about this method for assessing sexuality-related attitudes.

Methods

A more detailed explanation is needed of the use of Q sort methodology here and what makes it unique. Why was this chosen and what does it offer when compared with other methods?

The authors would benefit from simplifying their terminology and using less reified terms (e.g., “a systematic classification of constructions of sexuality in the context of multiple personal and professional perspectives”; “finite diversity”). What does this mean? This goes throughout the manuscript.

The authors should more clearly state what the inclusion criteria were of this smaller study. Moreover, the authors should discuss how they arrived at the final sample size from 698 patients and 175 partners as this is not clear currently.

Also, I am not clear on what happened to the individuals who participated yet were not included in the final three factors. Where did their data fall? If they fell out of the three factors, does that say something about the generalizability of the three factors that emerged?

While I appreciate the range of cancer types in the study there is no information on stage of disease or treatments, which would be important in understanding the types of problems likely to be experienced by this patient sample. If this is not available, it should be discussed in the limitations section.

It is unclear what the authors mean by “participants were strategically recruited with respect to their experience with cancer.” How so? Similarly, it is not clear what is meant by “further diversity was achieved…”

Results

With only six people in factor three how much weight can be given to this factor? Should this factor be considered as preliminary or more unique or less representative than the other two? No such discussion was given but it seems important to acknowledge.

Please define Centroid analysis.

The title of Factor 1 seems misleading as I don’t see much in this factor about dispelling myths while most of the items seem better classified under a title such as “strategies to support intimacy after cancer.”

Certain verbal quotes here from the provider (“who else is going to do it?”) appear quite unusual compared to my experience of discussion with many cancer providers (mostly oncologists) who tell me they feel uncomfortable discussing sex with patients and want someone else to do it. If I had to guess I would say that it was the psychologist or social worker who said this but such a
discussion needs to be given since different types of providers are likely to have vastly differing comfort levels.

The title of Factor 2 also seems to somewhat mischaracterize the content of this factor in that there is little about the cancer journey here (i.e., diagnosis, treatment, survivorship, advanced cancer and palliation), and in fact such information would be hard to discern given that there is no information about the stage or phase of the trajectory for patients.

However, the one quote that is offered here (“when we got the call…”) is very much discordant with my clinical experience with patients. Such a point of view seems to be the exception rather than the rule and should be acknowledged as such. Also, the endorsement of the importance of sex in advanced cancer had a rank of +1 which was not as strong as other items and to me suggests more ambivalence about this than is discussed here.

I would remove the quote using questionable language as I don’t think it’s necessary and has considerable shock value.

It seems a bit strange to describe 67% of 6 people. I would describe these in numbers and ratios rather than percentages.

While most would agree that a person should be allowed to be seen as a sexual person after cancer (an attitude), that doesn’t mean that many patients do feel like patients and lose their sexiness after cancer yet this experience is disappointingly absent here given the extreme wording of this item (p 17).

Discussion

What do the authors mean by “different shared subjective viewpoints”?

In general I find the discussion somewhat misleading in that it presents the view that the results in the study espouse the authors’ agenda of renegotiation of sex without adequately addressing the complexity of patients/partners/health professionals’ experiences with cancer. While many patients and partners are coping well through renegotiating sex, many are not, and it is not only because they are dying and in pain as shown in one of the few quotes given in this study illustrating difficulties.

Unclear what the authors mean by ‘bloody rapt’

Did not agree that this study showed that patients’ and provider perspectives are no longer mismatched. This would appear to be an overstatement.

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Acceptable
Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:
I declare that I have no competing interests.