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Sexuality in palliative care: patient perspectives

Laurie Lemieux Division of Palliative Medicine, University of Calgary, Calgary, **Stefanie Kaiser** Tertiary Palliative Care Unit, Foothills Medical Centre, Calgary, **Jose Pereira** Alberta Cancer Foundation Professorship in Palliative Medicine, Calgary and **Lynn M Meadows** Departments of Family Medicine and Community Health Sciences, University of Calgary, Calgary

This qualitative study investigated the meaning of sexuality to palliative patients. Face-to-face interviews were conducted with ten patients receiving care in a tertiary palliative care unit, a hospice or by palliative home care services in their homes. Several themes emerged. Emotional connection to others was an integral component of sexuality, taking precedence over physical expressions. Sexuality continues to be important at the end of life. Lack of privacy, shared rooms, staff intrusion and single beds were considered barriers to expressing sexuality in the hospital and hospice settings. Only one subject had previously been asked about sexuality as part of their clinical care, yet all felt that it should have been brought up, especially after the initial cancer treatments were completed. Home care nurses and physicians were seen as the appropriate caregivers to address this issue. Subjects unanimously mentioned that a holistic approach to palliative care would include opportunities to discuss the impact of their illness on their sexuality. *Palliative Medicine* 2004; **18:** 630–637

Key words: cancer; palliative; qualitative; sexuality

Introduction

One of the primary goals of palliative care is improving quality of life.[1] As quality of life includes sexuality, a fundamental and enduring aspect of life,[2] it follows that palliative care should address this aspect of the human experience, even at the end of life.[3] As Stead *et al.* articulated, 'given the impact on quality of life, sexuality is just as relevant and important to inquire about as it is about bowel action and sleep.'[4] Despite its importance, sexuality receives little attention in the course of cancer care.[5,6] Sexual function is considered less important than treatments directed at the cancer. Health professionals find it difficult to discuss sexuality as an aspect of quality of life of their patients. MacElveen and McCorkle have commented that 'being treated as an asexual being because of age or illness by health-care providers can be a powerful experience for someone whose sexuality is already traumatized and vulnerable.'[7]

While sexuality has been extensively studied in cancer survivors and cancer patients who are earlier in the disease trajectory,[3,8–12] it has only recently started receiving attention in the palliative setting. Literature based on empiric data in this area remains sparse.[2,3,7,11,13–15] In a cross-sectional survey-based study, sexual function was affected more in palliative patients than in other cancer patients and a control group consisting of patients at a general practice clinic.[13] Palliative patients in that study were willing to talk about their sex lives and the impact of the disease on their sexuality. It appears that not much has changed in accommodating sexuality in palliative care and that meaningful change, guided by empirically based data, is needed.

Speculation continues about the significance of sexuality to palliative patients. We conducted a qualitative study to explore what 'sexuality' meant to palliative patients and how their illnesses had affected their sexuality. We were also interested in whether or not they had experienced institutional and personal barriers to expressing their sexuality and whether they wished to discuss their sexuality with their health care providers.

Methods

This study used a qualitative approach to naturalistic inquiry. This methodology was chosen because the objective was to discover and explore, rather than conduct hypothesis testing and prediction.[16] Ethics approval was obtained from the Conjoint Health Research Ethics Board of the Calgary Health Region and the University of Calgary. Palliative patients were recruited from a variety of settings: i) a 10-bed Tertiary (acute) Palliative Care Unit at a regional hospital affiliated with a provincial cancer care centre, ii) a

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Address for correspondence: Laurie Lemieux, Division of Palliative Medicine, University of Calgary, Palliative Care Office, Rm 710, 1403-29th Street NW, Calgary, Alberta T2N 2T9, Canada.
E-mail: llemieux@ucalgary.ca

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freestanding hospice, and iii) Palliative Home Care services. The researchers made the teams at the various settings aware of the study and explained the methods. Convenience sampling was used.[17] Potential participants were first identified by a health professional responsible for their care, and asked if they were willing to discuss the study with one of the researchers. When permission was given, one of the two interviewers (LL or SK) met with the patient and explained the study. Subjects were entered into the study when they provided consent.

Inclusion criteria included a cancer diagnosis, proficiency in English, ability to tolerate a 30-minute interview, and in a current relationship with a partner. The study was open to people of any sexual orientation. Exclusion criteria included an estimated life expectancy of less than one to two weeks and delirium (as assessed by the attending team based on their clinical assessments). As this was an initial exploration of the topic, partners of patients were not recruited as participants. Nevertheless, in three interviews, partners were present and participated in the discussion. Selected comments from partners have been included in the analysis.

Data were collected via face-to-face interviews using an open-ended interview guide. The guide was developed and pilot tested specifically for this study. Interviewer biases were declared at the start of the interview process to increase credibility. Initial questions were followed with probes as necessary. (See appendix A.) Participants' responses during the interviews were paraphrased and presented back to them for immediate feedback to increase the accuracy of the interpretations and hence internal validity. Interviews were audio recorded with permission, and transcribed verbatim. Field notes were taken. Interviews were evaluated by the interviewers for quality immediately afterward.[16]

Transcribed interviews were spot checked for accuracy. Immersion/crystallization method of data analysis was used.[16] This process involves reading and re-reading the interview text, as the analysis proceeds. Initially topics and issues are identified in each interview. As the process continues the context and contingencies of the emerging themes are examined, and comparisons made across all interviews. The data is then searched for disconfirming or contrary evidence. Finally, the connections between themes are identified. Several meetings were held to explore and confirm themes. The derived text was initially coded by two members of the research team (SK and LL), with a third member coding a subsample of the interviews. As we moved to the interpretation process the full team provided feedback on the analysis and contributed to the interpretation. Methods described by Crabtree and Miller and Meadows and colleagues were used to ensure study purposiveness (ensuring that study design is followed), verification and validity.[16,18]

Results

Recruitment ceased at ten participants when saturation of themes occurred. Five out of eight people approached at the hospice agreed to participate and two of five people in the tertiary palliative care unit agreed. Those who refused cited not feeling comfortable in speaking about the subject matter and a concern about physically tolerating the interview. Information about the number of people approached by the city's Palliative Home Care Co-ordinators was not available.

Table 1 is a summary of patient demographics. Patients' ages ranged from 44 to 81. Although the study was open to people of any sexual orientation, only heterosexual patients were available to participate during the duration of this study. Three spouses were present during the interviews and two of them provided input.

Table 1 Patient demographics

Subject no.	Age	Sex	Marital status	Setting of care	Time since diagnosis	Diagnosis and select treatments	Interval between interview and death
1	59	Female	Married	Tertiary Unit	8 months	Metastatic breast cancer, surgery, radiation, chemotherapy	5 weeks
2	65	Female	Married	Hospice	8 months	Orofacial cancer, regional spread, radiation	10 weeks
3	49	Male	Married	Tertiary Unit	5 years	Multiple myeloma, surgery, chemotherapy, radiation, stem cell transplant	12 weeks
4	51	Male	Married	Hospice	4 months	Renal cell cancer, radiation	6 weeks
5	49	Female	Married	Hospice	2 years	Metastatic colon cancer, surgery, chemotherapy	4 weeks
6	44	Male	Married	Home	6 months	Metastatic colon cancer, surgery, chemotherapy, radiation	6 days
7	71	Male	Married	Home	9 months	Metastatic lung cancer, surgery	Alive at end of study
8	81	Male	Married	Hospice	3.5 years	Metastatic lung cancer, surgery, radiation	4 days
9	72	Male	Married	Hospice	7 years	Metastatic prostate cancer, surgery, chemotherapy, radiation	6 weeks
10	47	Female	Married	Home	10 years	Metastatic breast cancer, surgery, chemotherapy, radiation	Alive at end of study

Some patients died within a few days of the interview. Three patients were receiving home-based palliative care, five hospice care and two tertiary palliative care.

Analysis of the data revealed five central domains: the meaning and expression of sexuality, sexuality and quality of life, barriers to experiencing sexuality in institutional palliative care, discussing sexuality and the study as a therapeutic intervention.

The meaning and expression of sexuality

Several aspects of experiencing and defining sexuality emerged. Emotional connection to others was an integral component of sexuality and an important source of validation during their illness experience. This took precedence over the physical expressions of sexuality.

> 'Sexuality means more than sexual intercourse. It's a broad, broad spectrum of feelings. . .closeness.'

> 'If my partner sees me as being sexual even though. . . you think you're deformed, but you're not. I think it's their attitude that helps me with my attitude about myself. See, I don't think sexuality is anything to do with the act of sex.'

People noted that the level of importance placed upon sexuality had changed minimally since becoming ill. They did remark, however, that the expression of sexuality had changed, and that they were less likely to express sexuality predominantly on a physical level. 'Intercourse is kind of tough when you got no energy to do that.'

Whether as a consequence of illness or the palliative stage of care, there was more emphasis on verbal and nonintercourse forms of intimacy.

> 'It's an eye across the room; it's a holding of hands.'

> 'It doesn't necessarily have to be lovemaking every night kind of thing. But just to be close or caressing each other.'

> 'We still do a lot of holding hands, hugging, kissing. It doesn't matter if it's in public or by ourselves. . . dancing to music in the elevators.'

> 'There was a pan flute player at [a store] when you come up the escalator and the next thing you know we're dancing.'

When specifically commenting on sexual intercourse, most interviewees described a progressive decrease in the frequency of sexual contact as a consequence of becoming ill.

> 'The frequency has gone right to the dogs. The illness has definitely put a cramp on things – it's changed me where I forget things. I can forget in the middle of fooling around. . .I feel inadequate after that.'

> 'It's still important, but. . .the frequency probably is not the same anymore. Sometimes I'm too tired.'

Decreased intercourse for fear of hurting oneself or the partner was expressed by some.

> 'What are you supposed to do when it says something is deadly when you get it [chemotherapy] on your hands, yet they're putting it inside your body – that's pretty scary. So you know it's floating around in your body so it can be passed on . . .but we went ahead anyway. We just went for it.'

> 'I had a bilateral mastectomy. . .and he was scared about hurting me at that time . . . he wasn't sure.'

Patients described how they had moved through a number of phases following the initial diagnosis of their illness being incurable.

> Patient: 'Yeah, let the shock wear off a little bit and then get into your normal life. It's going to evolve with everything.'
> Wife: 'The last thing you think of when someone tells you you have cancer is am I going to be able to have sex with him? You don't think that right away. That's later on.'
> Patient: 'That comes afterwards. . .but it does come'.

Sexuality and quality of life

Sexuality continues to be important at the end of life, especially for those who experience it as a way of connecting with their partner.

> '[Intimacy] . . .it's more important to me than basically anything in life.'

Some lamented the loss of sexuality. They saw it as another loss as a result of their illness.

> 'the other night I was sitting here waiting for [the nurses] to come get me into bed and . . .I thought of. . .how there's no sex in [the other patients'] lives anymore at all. . .well that's over, that's another thing that's over with in their life.'

For some, other facets of quality of life had taken precedence. For one woman, before admission to hospital, sexuality was paramount, but that had changed.

> 'You know what is important to me right now in my life?...At home I should be there for the family and be as loving as I can and I know that my disease is progressing and I don't have very much longer to live... I want to be as nice as I can as a mother, as a wife and daughter...'

The need to connect, to discuss important issues in comfort and privacy were important elements of maintaining togetherness and quality of life. Physical nurturing was seen as important to quality of life. Yet, several barriers to experiencing this were noted in the palliative care unit and hospice care (described further in next section).

Barriers to experiencing sexuality in institutional care

Lack of privacy, shared rooms with other patients (in the tertiary unit), uninviting physical space, intrusion by staff and the size of beds were considered barriers to expressing sexuality within hospital and hospice settings.

> Patient: 'the level of privacy in the hospital is way down... it was tough to find a place for us...to talk that was quiet and confidential and I think that had an effect on us.'
> Wife: 'He didn't feel safe. A nurse could walk in at any time – he would be interrupted – it's just not the same.'

> 'I could see that over that time period that having a bigger bed might have been something nice so we both could lie down together, and at least take a nap together.'

> 'Yeah while I was in the hospital and I was in that group of four or five patients there...I did not show my intimacy. We still held hands, but I would not try to grab her and kiss her and cuddle...But once we got our private room, things changed. She was sitting on the bed, we were holding, kissing, hugging...I could be more open, I could let my feelings go (crying)...in the private room, you can open up and be more yourself.'

When asked what could be done differently, one participant stated,

> 'I think that there's also a need for putting a priority on couples spending time together...It should be quality time and even if you had to shorten the visiting hours...there's an hour a day, two hours a day, that it's just strictly straight forward family time. And you and your family get together and we promise not to bring a pill or do a blood test during that time period.'

Discussing sexuality

Only one of the study participants had previously been asked about their sexuality in the course of treatment, yet they all felt that it should have been brought up as part of their care. One couple took the initiative themselves.

> 'We asked the doctor and we asked the nurse if it was ok because I was taking chemo. Never saw a doctor change to so many different colours of red in all your life. I think that we were the first person to ask that.'

> 'I think it's a part of who we are and if we're sick all of us is sick, not just a part...so yeah, I don't think it should be a problem with them asking about it.'

Home care nurses and physicians were seen as the appropriate caregivers to address this issue.

> 'I think it's probably the person you're the most comfortable with...and maybe there's more things I would tell the Home Care nurse than I would the doctor just because you've got a stronger rapport with them.'

Patients realized that the subject matter might be a difficult one for all involved.

> 'I am so shy to ask them and maybe the same with them. Maybe they are waiting for the patient to ask them...Sometimes the patient is shy and somebody has to bring it to their attention.'

> Wife: 'You would be bringing up something that might help another couple discuss something...some people won't have that ability to address it.'

They recommended a professional, forthright approach.

> 'You don't want to beat around the bush, it just makes everybody uncomfortable. If the person sees that you're uncomfortable, I'll be uncomfortable...simple as that'

> '...if it's put in a professional way...I might talk to them up to a point. I would only feel comfortable with something like that is if they would show a sincere concern...'

One participant felt that the onus for initiating discussions on sexuality is also on patients.

> 'However, you can't be shy either. You need to go bring concerns that you have as well. I mean it's as much onus on the doctors and nurses as it is on the

> patient. They can't help you if you don't tell them right?'

Interviewees unanimously urged a holistic approach to providing palliative care for themselves and for others in the future, including opportunities for them to discuss the impact of their illness on their sex lives and sexuality.

> 'Actually, it's something that I think a lot of people are nervous about, they shy away from it. And I think it's a good thing it's being brought up...I really do because it's part of who we are...yeah, it's not a dirty secret that everyone should be hiding away.'

When asked when would be the most appropriate time to discuss sexuality, some patients indicated that it would be after the initial treatments were completed.

> 'I would say more after treatment...cause then you deal with life – it's your life problems.'

> 'After your treatment is done and you know you're on the kind of mend.'

The study as a therapeutic intervention

Some patients described how the study itself was therapeutic and emotionally cathartic.

> 'At least whatever has been on my mind actually came out – I was able to talk to somebody about it – like you. I think that I have made my point and it makes me feel good that I have offered whatever is on my mind and told somebody. Lighten my load.'

Discussion

For patients in this study, sexuality was an important aspect of their lives, even in the last weeks and days of life. Sexuality encompassed many things but was centred on emotional connectedness. Their experience of sexuality changed over time, from expression that usually included sexual intercourse prior to the disease, to one of intimacy through close body contact, hugging, touching of hands, kissing, 'meaningful' eye contact and other nonphysical expressions of closeness and companionship. These expressions of sexuality were a key component of their quality of life. Although sexual intercourse continued to be among the preferred expressions of sexuality for some, for others it was no longer important. This is consistent with the findings of studies conducted in patients earlier in the cancer disease trajectory.[9,11,13,19]

All but one of the subjects interviewed in this study were unanimous in their views that sexuality and the impact of their illness on their sexuality should be addressed as an integral component of their care. It had been discussed previously with only one of the participants. Discussions would allow them to have their concerns validated and encourage exploration of other methods of expressing sexuality within the context of advancing disease. Information about the effects of chemotherapy and other treatments on their sex lives and methods to minimize physical harm during intercourse is needed earlier in the disease trajectory. These discussions should occur both earlier at the time of treatments and later when the illness is progressing. The suggestion by several of the interviewees that the study was in itself therapeutic speaks to the importance of providing palliative patients the opportunity to discuss the impact of the illness on their sexuality. They felt that their health care professionals, including their nurses and physicians, are appropriate persons to initiate discussions around this topic. Studies in other patient populations have echoed these findings.[4,13,20]

Subjects were very willing to discuss the impact of their illness on their sexuality. However, eight of the ten subjects had not previously discussed sexuality, even with their partners. Some were not comfortable discussing sexuality at the beginning of the interview, but by the end, had changed their minds. Only one patient expressed the opinion that it was not appropriate to discuss sexuality but acknowledged that it was appropriate to ask individual patients, in a sensitive way, whether or not they wanted to discuss the topic. These findings are consistent with those of Ananth and colleagues who noted that patients with cancer wish to talk about their sex lives and the impact of the disease on their sexual function. Addressing sexual problems earlier in the illness trajectory destigmatizes sexual difficulties and avoids embarrassment or aggravation of the problem later on.[13] It therefore appears important that patients and their partners should be given an opportunity to discuss concerns about their sexuality.

Lack of privacy and other physical barriers to opportunities to express sexual intimacy were noted in patients cared for in the tertiary palliative care unit and the hospice. Patients suggested private rooms and double beds as ways to address this as well as the setting aside of 'private time' without interruptions by nursing or other staff. Administrators and palliative care health providers should be made aware of these issues as should planners of palliative care units and hospices. Opportunities to have double beds in palliative care units and hospices should be sought recognizing that issues such as nursing care (e.g., turning patients who cannot turn themselves) and door widths (to accommodate double beds should there be need to wheel patients out of their rooms) should be addressed.

The limited number of subjects in this study prevents generalization of results to the entire palliative population. In keeping with qualitative principles however, there were sufficient numbers to saturate themes and to address the goals of the study. The convenience sampling may have skewed the identification of potential subjects as health care providers may have had their own biases as to who to approach for the study. It is also possible that only people who were open to discussing sex enrolled. Limited numbers and convenience sampling were the likely reasons that homosexual or bisexual persons were not represented. Future studies should provide a structure for all eligible patients to be approached and should be large enough to be fully representative of persons with various sexual orientations. However, despite differences in gender, age and ethnic background, common themes emerged early. Selection bias is another potential limitation.

This study and the study by Ananth and colleagues provide an empiric basis to further explore sexuality as part of the issues addressed in palliative care. Equipped with the definitions and themes from this study, we can now investigate how best to address sexuality within routine palliative care. Future studies may include a chart review for the documentation of discussions around sexuality and a survey of nurses', physicians' and other disciplines' attitudes toward patient sexuality in palliative settings. Sensitive methods or processes to routinely explore issues related to palliative patients' sexuality and their needs around sexuality should be identified and trialed.

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Appendix
Sexuality in palliative care interview guide

Open-ended question

1) What does sexuality mean to you?

Prompts

1) How important is your sexuality to you?
   a) Was it important to you before becoming ill?
   b) Is it important to you now?
2) How do you express your sexuality?
   a) How did you express your sexuality before becoming ill?
   b) How do you express your sexuality now?
3) Has your sexuality changed since becoming ill?
   a) How has it changed?
   b) When did it change?
   c) Have you been able to talk about it?
   d) If yes, with whom?
   e) If no, why not?
4) Are you interested in expressing your sexuality at the present time?
5) If you have a partner, what affect (if any) has your illness had on your partner's sexuality?

Semi-structured questions and probes

1) Do you currently have a partner?
2) Are the following barriers to your sexuality (if not at home)?
   a) No single room
   b) No double bed
   c) Intrusion by staff
   d) Not being interested in sex
   e) Not being able to get aroused
   f) Not being physically able to participate
   g) Not feeling desirable
   h) Fear of harming oneself during sexual activity
   i) Fear of passing on radiation, infection or cancer
3) Would you like the opportunity to express your sexuality in this setting (if not at home)?
   a) Would you like to have sex with your partner?
   b) Would you like to snuggle up in bed with your partner?
4) We would like to ask you a few questions about your experiences with health professionals. The term 'health professional' refers to your family physician, palliative care physician, nurses, occupational/physio therapists, social workers, chaplains, and other specialists. Have you ever brought up the subject of sexuality with a health professional?
   a) With whom?
5) Has any health professional ever asked you about your sexuality since you were diagnosed with your current illness?
   a) If yes, who asked you?
   b) When were you asked?
6) Is it appropriate (at any time) for health professionals to ask about your sexuality?
7) When would be the best time for health professionals to ask about your sexuality?
   a) At the time of diagnosis
   b) After the initial workup has been done
   c) After the treatments
   d) On admission to a palliative care facility
8) Is there a time when it would not be appropriate for health professionals to ask you about your sexuality?
9) Is it easy for you to talk about sexuality?
   a) If no, why is it not easy?

10) Could we make it easier for you to talk about sexuality?
    a) If yes, how could we make it easier for you to talk about sexuality?
11) Has this interview process been helpful at all?
    a) If yes, in what way?
12) May we meet again if any responses need to be clarified?