The point of no return: Beyond sexual functioning to sexual health assessment in oncology nursing

By Lorna Butler

Abstract
Disseminating research findings in a meaningful way is often a challenge. The topic of sexual health creates an even greater challenge. The work that numerous teams conducted within our research department had profound effects that altered the way in which we were practising cancer care. The Schering Lectureship provided the forum for our patients’ collective voices to be heard. Artists in the world of music who crossed the spectrum from classical to country helped us to focus. The sexual health message was entwined in their words. That message became a personal interpretation we had not been able to convey with words alone. Through the songs, each nurse found his/her own meaning. To our surprise, this lectureship became a powerful medium for patients to speak out and nurses to learn. The nurses conducting the sexual health studies thank CANO and Schering Canada. To each oncology nurse who spoke about the message heard, please know that your words touched our hearts. While it has been a challenge to put this lectureship into a manuscript, it is hoped the written words will convey a similar message.

Our experiences as men, women and couples are personal, and each individual’s perception of what occurs in his or her life is part of who he or she is - as it is viewed through only that person’s eyes. When our lives are touched at the very essence of who we are - how we define our reason for being - there is nothing more personal. The words you are about to read are about people - individuals with everyday lives - one of us. This article is the voice of many patients and their families, people we have encountered in our research, who have a message we as nurses need to hear, to pay attention to, and to rethink our practices. My purpose in writing this is to provide the opportunity for that voice to be heard. It is also a tribute to you - a way to say thank you. Thank you to that nurse who took the time to ask about me - the woman with breast cancer, the man with testicular cancer, we’re parents; partners. To you - that nurse, the only one who looked into the heart - my sensuality, my sexual well-being - thank you. My heart was whole, now it’s breaking. To CANO, we thank you for giving us the opportunity to be heard. We can’t go back. Our lives have been changed forever and we need your help. We’ve reached a point in our cancer journey that whatever way we go, there’s no turning back. If we step forward - do we walk alone? Should I follow? My heart is breaking - which way do I go? Will you extend your hand, give us the lift we need so we can soar? It’s the “point of no return”, nurse. Which way do I go?

This article reflects a lifetime of learning, yet so little known. It is a passionate story of people who have opened their hearts through our research. It is my way to try to disseminate a message I’m not sure I really understand. What I do know is that, as an oncology nurse, I cannot practise competently unless I look into the heart. Finding the right question to ask is not easy. Should we be asking women about chemically-induced menopause or how they view themselves as sexual beings? Only you can answer that question. As oncology nurses, it is your “point of no return”.

The introduction of sexual health into oncology practice in Canada has been a very stimulating experience. The reactions are varied, yet the discomfort, knowledge and values fairly consistent. Sexuality is a well-guarded secret that each of us holds near and dear to the heart. It is not discussed and very few are willing to expose who they really are; it just simply is no one’s business. Imagine the vulnerability one would feel. Because it has been difficult to open the discussions of sexuality, we have taken the approach that this aspect of one’s life is part of their overall health that requires assessment. Unfortunately, there is a perception that sexual health is sex. To measure sex, simply count the number of times someone has intercourse pre- and post-treatment. If that’s what is understood, and we’re certainly not about to discuss sex, then our patients are truly at the top of a mountain with no way down; they are out to sea with no land in sight... They ask for direction - subtly, but it’s there. If you missed the message - there’s no return: for them, or for you. Why would they seek you out again? Our experiences will all be different, our specialty areas will have their own unique features, and our patients will differ by cancer, gender and age. This may not really matter as much as we think, but the way the message gets delivered will matter.

When talking to women with breast cancer who were ages 50 to 70, the cancer was not the most important issue in their lives. Yet it was what I was caring for! The real issues were: children had grown and gone; retirement was close; some had marital discord; job loss; and now cancer. These responses were very upsetting and not what I wanted to hear, as I had no questionnaire for their lives, just for cancer. As nurses, our role is to help women with breast cancer find the right direction so they’ll know that pathway when they see it. These women had a message. Close your eyes and see - feel what’s in our hearts. But I didn’t understand. This was a path I had never really been on because I was afraid to go down their road. I never forgot those women and can still see their faces in my mind. A very special staff nurse in our hospital, Terry Sveinsson, CON(C) helped me to feel - to close my eyes and really see. That was a “point of no return” in my career. Another colleague, Monica Bacon at NCIC-CTG, helped me to soar and my feet haven’t hit the ground yet. These are powerful women, powerful as they had advocated for women before the feminist movement made it popular. Their specialty is gynecological cancer, but they don’t talk about pelvic resections, examinations and radiation. They talk about the effect on women.

In our work in gynecology, Terry learned that she was unique in her age group - 70 , the cancer was not the most important issue in their lives. Yet it was what I was caring for! The real issues were: children had grown and gone; retirement was close; some had marital discord; job loss; and now cancer. These responses were very upsetting and not what I wanted to hear, as I had no questionnaire for their lives, just for cancer. As nurses, our role is to help women with breast cancer find the right direction so they’ll know that pathway when they see it. These women had a message. Close your eyes and see - feel what’s in our hearts. But I didn’t understand. This was a path I had never really been on because I was afraid to go down their road. I never forgot those women and can still see their faces in my mind. A very special staff nurse in our hospital, Terry Sveinsson, CON(C) helped me to feel - to close my eyes and really see. That was a “point of no return” in my career. Another colleague, Monica Bacon at NCIC-CTG, helped me to soar and my feet haven’t hit the ground yet. These are powerful women, powerful as they had advocated for women before the feminist movement made it popular. Their specialty is gynecological cancer, but they don’t talk about pelvic resections, examinations and radiation. They talk about the effect on women.

In our work in gynecology, Terry learned that she was unique in her approach as a staff nurse. It was a lesson she was not too happy to experience. We have since also listened to women with breast cancer and after having had bone marrow transplants (BMT). These individuals were younger, but collectively they had a message that was profoundly distinct and unanimous. Some would argue that the site of the cancer is the determining factor, such that gynecological cancer could not be compared to breast cancer. Does gender make a difference? Our teams no longer believe that. We are trying to build a model that will support such an approach and help nurses understand the impact on one’s sexual health. For those who work in urology, reflect for a moment on the last time you asked a man what it felt like to hear the word impotence.

In relation to disease site, we have had the opportunity to compare two studies. Women with gynecological cancer in our own work talked about relationships - specifically issues of intimacy, support, reactions of health professionals and sensitivity to their concerns. They talked about knowledge, particularly the need for information...
What were the questions? Was the partner included? How did you differentiate alternatives are courageous and determined, but they also need. Often it is a devastating experience. The men who choose to explore the many interventions we can use, but what does the man experience? For men who do choose to have a radical prostatectomy for prostate cancer, sexual health is a major aspect of their continuing care. Referrals are made to attend sexual dysfunction clinics for men, but interestingly considering the emphasis placed on teaching, body functioning was referred to less often. What was noted by the women was the impact of fatigue and diarrhea on their ability and interest in sexual relations, particularly intercourse.

In Kansas, women with breast cancer reported similar results: they identified physical sexual functioning, relationship quality, psychological self and self as female as issues (Chamberlain Wilmuth & Alland Ross, 1997). The message here is that women are reporting issues that require us to think beyond toxicity levels and physical functioning. We must not negate the importance of either of these concerns, but at the same time not limit our focus to the body part being treated.

For men with prostate cancer, impotence was a major concern. Interestingly, they were not so focused on the interventions to aid erections, but what they had lost. They expressed: “My desire is the same but there’s nothing there.” “I’m afraid to hug my wife in case she expects more and I can’t give it to her.” “I didn’t know how much I would miss ejaculating.” “The orgasm is the same but the release is gone.” I’m sure many oncology nurses have explained to men following radical prostatectomy to expect to see cloudy urine as the ejaculate goes into the bladder. But what that means to a man and whether he will miss those feelings are rarely discussed.

These men and women are telling oncology nurses that their sexual well-being has been altered - something is different. Our reluctance to enter the sexual health discussion may soon be over, by force rather than choice. Popular magazines are doing stories on cancer that bridge the continuum from basic cellular issues to sexuality. Local and national newspapers are also beginning to focus on quality of life issues and sexuality has been addressed, particularly because women with breast cancer have made the public aware, and to some extent health professionals as well, through the same route. But, it is also a medium to poke fun. New pharmaceuticals for erectile dysfunction have opened the discussion much more than perhaps anyone realized. Talk shows on radio and local television are also discussing both male and female issues around sexual health and well-being.

For men who do choose to have a radical prostatectomy for prostate cancer, sexual health is a major aspect of their continuing care. Referrals are made to attend sexual dysfunction clinics for men, but interestingly their partners are not often included. Does this solve the problem? There are many interventions we can use, but what does the man experience? Often it is a devastating experience. The men who choose to explore the different alternatives are courageous and determined, but they also need support and guidance. Think about the last patient you worked with: What were the questions? Was the partner included? How did you explain the experience of attending a sexuality clinic, as opposed to providing information that a referral was made? We may need to pause and examine our own beliefs and bias. How judgmental are we in terms of who we think might have strong feelings around screening and sexuality issues?

Family-centered care is a concept nurses discuss and believe to be important in oncology nursing. Visualize in your mind your last encounter with the partner of the patient you were caring for. What were the fears, the uncertainty, the information needed to help him or her understand what was happening to the relationship? We tend to think of the most visible effects - a mastectomy-scarred chest, a shrunken scrotum post-orchectomy. But what about the invisible scars? For example, trying to respond when a young woman with cervical cancer who had a hysterectomy tells her partner she believes internally she is no different than any other guy; or an older man who has his prostate removed and believes his sexuality is gone. These are painful questions, but they are real. It is not during the acute phases of diagnosis and treatment that these questions traditionally arise, but later, three to six months after treatment, when life is getting back to normal. It is the partner who is then confronted by these questions, as there is no one else around.

The literature on sexuality refers to people as dysfunctional. Do you believe women with breast cancer or gynecological cancer are dysfunctional as sexual beings? Are men who have testicular cancer dysfunctional? What about hematological malignancies that do not discriminate by gender? Does BMT or Hodgkin’s render people as sexually dysfunctional individuals? Perhaps as nurses we do not really think in those terms. But these are our terms. If something is dysfunctional, then we (health professionals) fix it. What is the gadget we use for lost relationships, for partners who may not really comprehend what is happening, yet are deeply affected? What do you say to them? When thinking about intimacy, there is a tendency to visualize couples holding hands and walking into the sunset. Many couples have shared that, since their cancer, they have become closer and more intimate. Others have not. We have to assess what is happening and not assume that those who have never hugged each other will suddenly know how. Think about your own relationship, your parents’ and grandparents’, and whether or not the usual behaviour is to hold hands, to hug, to kiss each other. Yet we expect our patients to just express their intimacy in this way.

CANO has oncology standards that address sexual health. One of our teams interviewed oncology nurses in surgical oncology, medical oncology, ambulatory care, BMT and the cancer clinic. We asked registered nurses to respond to a questionnaire and then held focus groups in each practice area. The nurses reported that they were confident, usually comfortable and valued the inclusion of sexual health in their practice. When specifically asked about their practice habits, very few actually assessed sexual health. The exciting aspect of this study was nurses’ responses that they value the inclusion of sexual health in the care of patients and families with cancer. These findings suggest that this is a group of nurses with strong beliefs, a degree of comfort and some confidence in their knowledge of sexual health. What an important message! Nurses are telling us they value the problem is, they have not had opportunities to learn or to be exposed to mentors who translate those values into practice. What did we expect to find? For the last decade the literature has consistently reported these same findings. CANO has practice standards that demand a change. What is needed is that oncology nurse - you - the one who looked into the heart - the one who saw the woman, the mother, the man, the father, the partner. If I didn’t believe in the work of nurses, or think oncology nurses could make a difference in the sexual well-being of their patients, I would not have put a voice to what our research teams have learned, nor further exposed my patients’ vulnerabilities. If you truly believe and value the sexual well-being of your patients, if you see a man and not a dysfunctional penis; a woman and not a mastectomy scar, then this message is for you. Only you can decide. It’s your “point of no return”.

Acknowledgements

We are indebted to the patients and families who shared their lives with us and to those nurses who were also willing to talk about their oncology practice. Personally, I wish to thank each nurse who worked on our teams. They are my inspiration. They show me what it really means to be an oncology nurse. We thank Colleen Clattenburg for the countless hours dedicated to transcribing tapes, typing papers and keeping us organized.

References are found on page 114.

Editorial note: It is very difficult to convey the power of this presentation through the written word alone. Those present were treated to a tri-screen multimedia presentation featuring music, video, narration, novel lighting and audience participation. We commend Dr. Butler for her innovative presentation, which profoundly affected all in attendance.