

Promoting Evidence-Based Nursing Practice – SEXUALITY ISSUES FOR WOMEN LIVING WITH CHRONIC ILLNESS

INTRODUCTION

The aim of this newsletter is to illustrate that sexuality is an important health issue for women living with chronic illness and to offer ways that nurses may facilitate sexuality issues for women. Our research has been with women but we are currently seeking funding to also explore sexuality issues with men living with multiple sclerosis. The dialogue in this newsletter is from women who participated in Debbie Kralik's doctoral inquiry (Kralik 2000; Kralik, Koch and Telford 2001) and a participatory inquiry with 12 women living with Multiple Sclerosis (Koch, Kralik and Eastwood in press). Women were aged between 30 and 65 years. Ethical approval was obtained for both inquiries.

WHY RESEARCH SEXUALITY?

In both inquiries, women talked about sex and sexuality within the context of their daily lives with long term illness. Women revealed that issues of sex and sexuality were rarely topics of discussion with health professionals. Kerry recalled her experience of anxiously wanting to discuss her sexual functioning with her doctor following her first symptoms of Multiple Sclerosis:

I could hardly walk. My body was numb from the waist down and I was desperate to talk to someone about the likelihood of being able to enjoy sexual activity again. But when I raised the subject with my neurologist he replied "For Goodness sake we've got to get you walking before we need worry about that". I was left feeling even more alone with my fears and almost guilty for making my sexuality a priority when there were other major health issues to be addressed.

Women were mindful of the discomfort shown by some health professionals when talking about sex and sexuality. Such discomfort was not conducive to women disclosing their experiences and in some instances effectively closed off any further communication about sex. One woman recalled with humour how her doctor had uncomfortably asked how were her 'relations'. She responded that they were fine, thinking he was inquiring about family members. It was later that she realised it was the doctor's way of asking about her sexual functioning and practices. Health professionals do not often deal with sexuality issues very well, hence this research. In addition, we also found that literature that focused on the way in which women experience changes to sexuality when living with chronic illness was scarce.

WHAT IS SEXUALITY?

Women perceived sexuality to mean desires, feelings or sexual expressions. Women revealed that sexuality began with the relationship they had with themselves and extended to their relationships with others. The relationship with themselves included how they felt about themselves as sexual beings and how they felt about their body. The body is heavily inscribed with meaning and a great deal of that meaning is sexual. Constructions of sexuality encompassed physical sexual responses, perceptions of appearance and attractiveness to self and others, communication and relationships, self-image and self-esteem, and the sense of affirmation and acknowledgment that women experienced from others in their everyday lives. Their relationships with others included friendship, emotional intimacy, love, and/or sexual activities.

Note: This newsletter is the first of a two part series that focuses on sexuality issues for women living with chronic illness. Watch out for the June newsletter – Part Two.

WHAT WERE THE FINDINGS?

When chronic illness intrudes in a woman's life, sexuality is reshaped against a foundation of previous sexual experiences and expectations. Although we have uncovered three emerging themes: the changing body, managing the needs of others and communicating sexuality, we are able to talk about just one theme in this newsletter but the June newsletter will focus on the other two themes.

THE CHANGING BODY

There is a lot of sexual importance placed on the female body and it is clear that in our western society the ideal for women's bodies is to be thin, fit, and healthy. The reality, however, is that women wear an assortment of body shapes, and illness can further reshape the female body. Learning to live with chronic illness was largely about acknowledging the changing perceptions of self. Women described fearing the change in the familiar self and often compared themselves in illness with their previous self. Kerry recalled:

For a long time I kept a photo of myself taken prior to illness on my mirror to remind myself of how healthy, fit and vital I had been. I was rapidly losing the body and abilities I had ... and I didn't want to lose that healthy vision of myself. In retrospect it was not a constructive thing for me to do. I was giving myself a hard time for not being the person I used to be.

There were times when women felt elements of their familiar selves were lost and for some, it seemed that illness had intruded on every aspect of their lives including their perception of themselves as sexual beings:

The thing I was most bitter and angry about and the thing that made my grieving so painful was the loss of my physical abilities, lifestyle and quality of life. Like the ability to walk without pain and with a 'normal' gait, to run, skip, hop, jump, do aerobics, play squash, be spontaneous. The ability to control my bladder ... to feel with my feet and achieve orgasm.

When the illness or treatments made visible changes to their bodies it was evident that those changes dominated and shaped their illness experience. Their perception was that a beautiful, sexual body was a body without illness. The presence of illness exacerbated the need for women to compare themselves with 'beautiful people' at the expense of positive feelings towards themselves. Deirdre wrote:

I just want me back. I see women with hair and spunk and I want it back. I watched ... TV last night. Beautiful people with hair and breasts. I want to be normal again with hair and breasts.

Women did not usually perceive the changes to their bodies caused by illness to be either enhancing or attractive. Raelene explained:

I don't like the visible changes [Rheumatoid Arthritis] has caused muscle wastage, oversized knuckles, distorted fingers, turned in knee and not to mention the scars from joint replacements. Rarely will I look at myself in a full-length mirror (I don't like what I see) because every time I do I notice another change in my body. As you can see, my feelings towards my body have changed dramatically. It's not me the person I dislike, it's the body. I think I feel this way because I feel powerless to stop the changes. Prior to the visible changes, I was more accepting of my body, despite the pain, as I couldn't see the destruction that was happening within.

Women described a changing relationship with their own bodies and how they perceived others experienced their bodies, which shaped self-image and exacerbated feelings of insecurity and vulnerability. Donna revealed how important it was for her to hear her new partner say that he saw the person beyond her psoriasis:

I went out with a great-looking guy once. I asked him if my spots bothered him before we slept together. "What spots?" was his reply. I'll always love him for that. It was what I needed to hear so badly!

Kerry described how her changed body altered the meaning of sexual experience because illness forced changes to both sexual practices and her response to intimacy:

Sex used to have a whole lot of positive associations for me of pleasure, fun, passion and intimacy. I felt it was the lifeblood of our relationship. Constant pain, spasticity, areas of numbness and hypersensitivity now mean touch that was once pleasurable is now unpleasant or not felt and positions that I once enjoyed are now painful. Much of the dialogue around sex that used to be erotic and sensual is now focused around ensuring I am as comfortable as possible and negotiating the difficulties imposed by a body that does not function properly.

Women found it difficult to come to terms with effects of illness and treatments such as insomnia, fatigue, depression, alopecia, skin rashes, weight loss or weight gain, scars, dis-functioing and distorted body parts. Changes in the way women experienced their bodies were entwined with feelings of sexual attractiveness.

For many women sexual identity was largely located in the appearance of their bodies and incorporated dressing in a way they felt was attractive. Visible changes to their bodies dictated what clothes they would wear. Scarves, wigs and hats to cover hair loss, rashes, psoriasis, open toed orthopaedic shoes for toes disfigured by arthritis, long sleeves and pants even on warm days, and baggy shirts all served to hide the 'offensive' body part. Women perceived that to be seen by others as damaged by illness was humiliating so they hid from others that they were 'less than perfect':

In summer even when it was unbearably hot, I always wore stockings and a cardigan, despite all the jibes I got. I never undressed in front of my husband unless it was pitch black.

For years I struggled to keep doing all the things I had done prior to illness because I feared my partner's realization that I was becoming less of a partner in the relationship. Accepting my need to increasingly depend on my partner for some things has been one of the hardest things I've had to come to terms with, and for him too I think. Although he is very supportive he has had to change his perception of me as a partner as well. I am not able to contribute to this relationship in the way that I used to but I still want to be seen as an equal partner. Managing to maintain my personal power in a relationship alongside increasing disability is a very fine line to tread and one I am constantly grappling with.

WHAT CAN NURSES LEARN FROM THIS RESEARCH?

Community nurses have a powerful role to play in addressing barriers to sexual fulfillment, which are a result of chronic illness and treatments. Kerry wrote about receiving guidance, reassurance and validation of her experiences with incontinence from a Continence Nurse Advisor:

Loss of bladder control undermines my sense of competence and freedom in the world. To feel safer about

having sex without being incontinent I need to follow a routine before and after sex, which interrupts the flow of emotions involved in arousal and intimacy. I would love to be able to just go with my feelings at the time but I'm afraid to ... the embarrassment of being incontinent during sex is too great a risk. I would hate the shame of it. I had the good fortune of meeting a continence nurse who approached the subject of sexuality with me in a safe and comfortable manner. Through exploration of the difficulties I was experiencing with sexual activity and the suggestion of helpful strategies... I managed to resume a level of sexual activity that I previously thought was lost forever. I have an endless well of gratitude within me for that continence nurse.

The constant contact that nurses have with clients provides them the opportunity to facilitate communications about sexuality and to ensure that sexuality is provided the same priority as other health issues. In doing so, a foundation of acceptance and respect for the whole person is established which provides women permission to ask questions or seek assistance with sexuality issues. The acknowledgement of the sexual aspect of a person by a nurse, and the willingness to assist in this area is extremely affirming for women who are coming to terms with the effects of chronic illness.

Sexuality is a sensitive and value laden area, and as such individuals are diverse in both attitudes and comfort levels with regard to sexuality. It is important that nurses develop an awareness of their own values about sex and sexuality in order to facilitate open communications. Creating a comfortable environment and the use of lay sexual terms are effective ways of communicating about sexuality.

We have revealed that the ways women respond to illness, disability and sexuality are diverse but central to their well being. Women who participated in these inquiries would have benefited from health professionals who were prepared to confront and explore sexuality issues and the relationship to other aspects of their lives. The willingness to listen and understand what women are experiencing has therapeutic benefit. With knowledge of resources and services in the sexuality health area the woman can be facilitated towards expanded opportunities for appropriate assistance and support.

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