

Promoting Evidence-Based Nursing Practice – SEXUALITY ISSUES FOR WOMEN LIVING WITH CHRONIC ILLNESS (PART 2)

INTRODUCTION

This is the second of a series of two newsletters where we highlight the changes to sexuality for women living with chronic illness. The dialogue in this newsletter also comes 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 2002). Women were aged between 30 and 65 years. Ethical approval was obtained for both inquiries.

WHAT IS SEXUALITY?

To summarize from the last newsletter, women who participated in these research projects perceived sexuality to mean desires, feelings or sexual expressions. Sexuality spanned the biological, psychological, social, emotional, and spiritual dimensions of their lives. 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, how they felt about their body and how they felt about sexual activities and behaviors. Their relationships with others included friendship, emotional intimacy, love, and/or sexual activities. Sexuality involved perceptions of people as sexual beings and 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.

WHAT WERE THE FINDINGS?

When a woman lives with chronic illness, sexuality is reshaped as is other aspects of her life. We have identified three emerging themes: the changing body, managing the needs of others and communicating sexuality. In this newsletter we specifically focus on the latter two themes.

MANAGING THE NEEDS OF OTHERS

For some women, changes to sexuality meant managing the sexual needs of their partner at a time when illness was causing turmoil and uncertainty in their lives. This was further compounded when the sexual needs of the woman was forced into the background as other illness issues took priority:

When my husband and I were together we had many arguments about sex. I always felt like we had just had sex and he felt like we never had sex. I think he was probably right. I know I was emotionally shut down...

Some women perceived it was the loss of their sexual desires or forced changes to sex practices that caused

negative changes in relationships. Changes to sexual desires and the inability to meet their partners sexual needs further compounded their loss of self-esteem and created a position of powerlessness within the relationship. The feelings of guilt were overwhelming for some women as they took on board guilt for elements of illness that were beyond their control such as changes to their appearance or changes to physical sensation. Some reflected that this was a time when their partner became abusive (physically and/or emotionally), as Rebecca explained:

I remember once my husband told me I was frigid. I never forgot what he said as it made me feel so inferior.

When Yolande was diagnosed with cancer, her partner aggressively resented the changes to her appearance that the planned treatments would cause:

She had worked extremely hard for her law degree and became enraged that I was sick right then and that the focus was on me and not on her achievement. She didn't want me to start treatment because she couldn't bear the idea that I would be bald at her graduation ceremony. I on the other hand was terrified and [felt I] needed to start treatment. Our relationship actually got violent a few times during this period.

Women also shared that their partners 'have been wonderful' and 'kids were just great', but it was common for them to protect others from their illness experience. The focus for women was towards minimizing disruption in the lives of those around them by continuing to meet the physical and emotional needs of others. Despite their efforts however, some relationships began to change, and this exacerbated mourning the loss of their lives that were before illness. Kerry reflected on the difficulty of coming to terms with the changes within her relationship:

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.

COMMUNICATING ABOUT SEXUALITY

Women who were unaccustomed to talking about their sexuality experienced difficulty when they needed to communicate with others about how illness had changed their sexual needs:

Having [this illness] has certainly had an impact on my sexuality and in the early days affected my relationship with my partner. I was depressed and I could not stand anyone touching me let alone feel like being

intimate. My partner took this to be that I was pushing him away. The antidepressants I take have had the side effect of causing me to be unable to climax... [Our relationship] has never got back to how it used to be.

Within many relationships there may not be conversations around sexuality. Sex may be something 'that just happens' between a couple. Pam said that:

...when young, we did not talk about sex and things' ... 'I was naïve'. 'If you like I didn't know what sexuality was ... it just has not cropped up before'. Sex was just one of those things in life, it was not an important issue. 'I just put up with it'.

To Pam, sex was a chore, a task that women performed as the duty of a wife rather than an act of mutual enjoyment. The broader societal attitudes to sexuality foster discomfort in talking about the topic. This issue is further complicated if there was no existing dialogue between a couple into which discussions about how illness and disability has changed sexual needs can fit.

For Vera, sex and sexuality loses its importance when she is feeling unwell, particularly when experiencing an exacerbation of Multiple Sclerosis. During the recovery phase, Vera makes a conscious effort to take notice of, and attend to her sexual desires/feelings and those of her partner. Sex is important to both parties but good communication is central. She described herself as happy and feels her sex life has been rescued through negotiation and talking with her partner about both the challenges of life with MS and the possibilities that the future holds for them.

Changes in body appearance also created problems and insecurities for women without a partner. The prospect of finding a partner and commencing a relationship was daunting because women were faced with concerns of when to tell a new partner they have a chronic illness. Fear of rejection, insecurities about the changed appearance of their bodies and lack of confidence about their sexual abilities within a new relationship may present formidable barriers to the development of new sexual relationships.

Women described the discomfort shown by 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. Other women had similar stories to tell of the obvious discomfort and the uncommon language that health professionals used when referring to sex and sexuality.

Health professionals have a powerful role to play in

addressing barriers to sexual fulfillment, which are a result of chronic illness and treatments.

HOW CAN DISTRICT NURSES MAKE A DIFFERENCE TO WOMEN?

Clearly, women's sexuality incorporates appearance, desires, feelings, or sexual expression and was more than coitus or the adequate functioning of genitalia. Issues of sexuality intruded on aspects of women's lives that they had been able to take for granted before the presence of illness. Illness became a constant presence in their lives, which created an unwelcome and uncomfortable awareness of their bodies. Through these inquiries we have come to understand that the construction of sexuality is different for each woman, but importantly it is a part of life. We challenge nurses to reject the myths and stereotypes of women who live with chronic illness as being asexual, and to develop understandings from an individual perspective, about how illness may impact on their sexuality. Permitting women time to tell their stories and to reflect on their sexual experiences may be the key for concerns about sexuality and sexual practices to be expressed.

When illness intrudes in a woman's life, sexuality is reshaped against a foundation of previous sexual experiences and expectations. We show that sexuality is a complex area that is more than physical responses and encompasses many facets of the individual. 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.



References

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