

Sexuality... the Forgotten Issue

BY FAITH ROBERTS, RN, BSN, CRRN

For 21 years sexuality has been a topic that I have studied, written and presented in numerous venues. I am amused that when I say the topic is sex people shy away. However, if I re-title the program with the word sexuality somehow that softens it and people swarm in for the talk.

Unfortunately, for all of those 21 years sexuality remains the topic least discussed or even mentioned during recovery from trauma/illness. Most of the time it is covered in such vague generalities that the person asking the question or needing the information leaves the encounter thinking "Yeah...OK...but I just wanted to know...Can I do it?" These four words sum up so much more than the physical mechanics. They represent the individual's query: Do you see me as attractive? Am I still me? Will anyone love me again?

As a novice nurse in Iowa a 74-year-old male stroke patient called me one night during my shift in this manner, "Psst! come here. Do you know if I can 'do it'?" Somehow even then I just knew what he was talking about. What followed over the next 24 hours was a series of events that were at times comical and frustrating as I checked with nurse colleagues, physicians, faculty and others only to find out no one knew. Oh sure, they could TALK about it, around it, above it and below it, but no one could answer the question "can I do it?" Finally after a lot of hard work I found a pamphlet put out by the American Heart Association that not only discussed sex openly but even had diagrams to illustrate positions that would be better for a person post stroke.

That one patient and his question triggered in me a desire to always get accurate information to the person asking the questions; to get the subject of sexuality out from between the covers of the discharge folder and into the everyday discussions between survivor and health care provider. Hopefully, to see sexuality talked about with the same ease that

colleagues have when discussing pain control, graft sites, release surgeries and insurance coverage.

A favorite definition is this one: Sexuality is who you are: unique and alive, sex is what you do. I am a heterosexual female. Many of you reading this article are heterosexual females but no one has my sexuality. It is what makes Faith... Faith. Sexuality is very closely intertwined with spirituality as one of the most intimate areas of our life.

I get a kick out of how many times I hear a colleague say, "OK, that's it! I do a lot of things but I am not talking about that, it is just too private! It is none of my business. It is too intimate." Then I watch that same colleague enter the patient's room, lean over the bed and say, "Did you have a bowel movement today?" My point is -- most people do not discuss their bowel movements with others. For too long in health care we have blurred the lines of intimacy so we do not know what is truly intimate.

During recovery from a burn injury, often times the person is exposed. This maybe especially embarrassing when the burned skin includes areas of the body that are usually covered in our culture. For young adolescents entering or just beginning to enter puberty this can be especially dehumanizing. Being able to understand that all of us are sexual beings and at least speaking to that issue can reassure the patient that you realize this is an awkward situation for them.

From survivors to partners the questions post-burn are ever present: "Will the burned/scar area be more sensitive?" "Will I be able to touch or be touched the same way?" "How does this affect who I am?" The most common is, "I am just too tired for that now." A common refrain from partners is, "I am just so glad you are alive and still here. I don't need anything else." Often these questions are never verbalized because many individuals do not feel comfortable talking about sexuality.

It does not help to hear, “We cover it in the pamphlet.” “It is in our discharge booklets.” “It is not just sex it has so much to do with body image.” Blah, blah, blah.... This does not support the patient and encourage dialogue. In reality such vague generalities only reinforce that sex is a topic no one wants to talk about. As a nurse I do not ask the patient about their sexual activity, all I do is let them know information is available.

How do I do it? When I enter the room to meet the patient I say, “Hi. I’m Faith and I’ll be your nurse this evening. While here on the unit we will be teaching you a great deal about your injury, therapies and medications. We also have information on sexual activity post-burn. If you ever have any questions feel free to ask any of us here on staff.” That’s it.... nothing else. All I do is open the door. Maybe they don’t want to ask me anything because they would feel more comfortable asking Andy from PT or Pat from Social Work. Maybe right now they are dealing with so much pain that just getting through the next hour is all they can think about. All I do is let the person know that this is a subject we are open to discussing. It may be a year later in a follow-up visit or a pre-surgical consult before the client brings it up. It is the willingness of all providers to address the issue of sexuality that empowers the client to follow through with questions or comments.

The issues differ widely for those who were in an active sexual relationship pre-injury vs. those who were not. In the first situation partners will examine previous patterns for what will work now. The survivor will spend a lot of time trying to redefine who they are as they assimilate their new image. In conversations with couples who are sexually active post burn this has been a common theme. As recuperation progresses and couples get comfortable with physical intimacy the survivor often mentions, “I am the same person, I guess I forgot that.”

For those survivors not in a relationship at the time of the injury their scar will be part of who they are and what they bring to a new relationship. Remember that for many, the ability that a partner would have to be able to kiss “my scar” means that love transcends everything, including the injury. For some people, it is very important to keep that scar covered. For other people, it is a moment of sheer intimacy when you can

allow your whole body to be viewed. Burns in the groin area are not the only image changing injuries. Reconstructive surgery around the oral mucosa may diminish sensation in the mouth which is often viewed as the gateway to sexual pleasure. Whether or not you feel like a sexual being does not ever negate the fact that you are an individual, unique and alive. What you do with your body and how you feel is important to recovery.

When a person talks about the sex act itself, he/she may be saying: I want to be able to share my life with another human being in the most intimate way known. In 2003 we live in a society where sex is often the cheapest stimulant out there. It is not about making love. It is not about building a relationship; it is not about true-shared intimacy. For many people post-trauma, being intimate means that the last barrier has finally been broken. Survivors need to be able to say to physicians, nurses, therapists – this isn’t working and can you help? We all need to be open to sharing whether in support groups or in conversation. The chance for a couple to hear another couple say, “You know what, being intimate was the last hurdle for us but we got there.” Hearing this allows others to think, “it took a year for them and that’s okay.” Everyone’s wondering....when? You know what? For some people, resuming their sexual expression happened post injury while still in the hospital. And for some people it was years later.

It is important to remember what is derived from a healthy sexual relationship: A feeling of safety and security, a feeling of closeness and warmth and a feeling of love. When viewed from that perspective it is easier to see why in days leading up to a release surgery a person may not want pressure on the affected area but may need to cuddle, caress and be held. Anxiety that comes to anyone pre-surgically dissipates when replaced with feelings of closeness, security and love. Remember sensation, excessive scar tissue – that will never change who you are as a human being – unique and alive. That is what your sexuality is....that is YOU!

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