INTIMACY AND SEXUALITY POST STROKE

Why it Matters

Robert S. Djergaian, MD
DISCLOSURES

CARF Surveyor
UDS Consultant
OBJECTIVES

List at least three impairments post stroke that can adversely affect intimacy and sexuality.

Describe various ways successful return to intimacy and meaningful sexuality can contribute to maximizing quality of life post stroke for survivors and partners.

Discuss how a stroke rehabilitation center of excellence can best integrate programmatically issues related to sexuality into their stroke rehabilitation continuum of care.
Rehabilitation of people with disabilities is a process aimed at enabling them to search and maintain their optimal physical, sensory, intellectual psychological and social functional levels.

World Health Organization
The goals of rehabilitation are to help survivors become as independent as possible and to attain the best possible quality of life

US Department of Health and Human Services
Quality of life is an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

World Health Organization
Quality of Life

The overall enjoyment of life

This includes an individual’s sense of well being and ability to carry out activities of daily living
The job of any doctor is to support quality of life, meaning two things...as much freedom from the ravages of disease as possible and the retention of enough function for active engagement in the world.

Juergen Bludau, MD
The purpose of our life is happiness

If you approach others with compassion it creates a feeling of affinity, a kind of connectiveness

The Art of Happiness
Dalai Lama
Howard Cutler, MD
Intimacy is the experience of connectivity.

“The Art of Intimacy”
Thomas Malone
Patrick Malone
Latin intima – inner or innermost

The desire for intimacy is the desire to share one’s innermost self with others.

Dr. Dan McAdams
Intimate attachments to other human beings are the hub around which a person’s life resolves. From these intimate attachments a person draws his strength and enjoyment of life.

John Bowlby
British Psychoanalyst
Well being is all about relationships

Quality of life is all about relationships

Dr. Dan Gottlieb
Humankind’s most basic fear is the threat of being separated from other humans and the experience of separateness is the source of all anxiety in human life.

Erich Fromm
Human sexuality is the way people experience and express themselves sexually. This involves biological, erotic, physical, emotional, social or spiritual feelings and behavior.
Sexuality is about who you’re attracted to sexually and romantically.

Sexuality is shaped by many things including:

- Values and beliefs
- Attitudes
- Experiences
- Physical attributes
- Sexual characteristics
- Societal expectations
Stroke is the fifth leading cause of death and leading cause of disability worldwide.

Rodrigues et.al
International Archives of Medicine
2016
Most stroke survivors identify sexuality as an important issue in their post-stroke rehabilitation.

Individuals with strokes are not satisfied with how the rehabilitation community addresses sexual dysfunction.

Rodrigues, et.al
2016
Patient Counseling Preferences

71% identified sexuality as moderate to very important
47% indicated sexual function declined post stroke
81% reported receiving insufficient information
26% wanted counseling prior to discharge
71% wanted counseling within one year

Stein, et.al
Disabil Rehabil 2013
Common myths regarding sexuality

People with disabilities are less sexual than persons without
Sex means sexual intercourse
Talking about sex is not natural, proper or necessary
Sex is for younger people
Men should initiate sexual activity
Sex should be spontaneous
A firm penis is a requirement for satisfying sex
Quality sex ends with an orgasm

Milton Klein, DO
Medscape, October 2018
Pertinent Post Stroke Impairments

Paresis  
Sensory loss  
Visual loss  
Contractures  
Pain  
Cognitive deficits  
Communication deficits  
Incontinence  
Depression/anxiety  
Fatigue  
Erectile dysfunction  
Lubrication issues  
Orgasmic problems  
Pain
Location of stroke matters

frontal lobe – disinhibition

temporal lobe – libido, arousal, pragmatics

R brain – attention, memory, executive function

bilateral temporal – hypersexual

L brain - language
Medication Sexual Side Effects

Decreased libido, sexual desire
Erectile dysfunction
Difficulty achieving orgasm
Diuretics
Antiepileptics
Beta Blockers
SSRI/SNRI
Alpha blocker
Tricyclics
Opioids
Anxiolytics
Alcohol/Drugs
Female issues

Pregnancy/birth control
Menopause/estrogen
  Avoid estrogen > 10 years post menopause
Aging

Changes over time
Psychosocial/economic stress
Anxiety
Isolation
Body image concerns due to hemiplegia, language issues, facial droop, role change. Survivors feel unattractive and unappealing
Insecurity, Fear, Doubt
A common cause of concern for survivors and caregivers is fear of causing another stroke.

Making love takes about as much energy as walking up 1-2 flights of stairs.
Role Changes

Caregiver → lover
Prior sexual roles
Provider/homemaker changes

Effects on self esteem
Role Changes

Masculinity linked to physical function
Provision of protection and security
Femininity linked to bodily aesthetics, maternal role
LGBQT
Struggle to communicate
Not wanting to cause stress
Survivor is not capable or interested
Fear of rejection
Loneliness/isolation – lost partner
Two major themes were central to the experience after stroke

Sexuality is silenced
Sexuality although muted and sometimes changed is not forgotten

McGrath, et.al
For many, this means sexuality is lost, potentially leading to increased incidence of anxiety, depression and poor quality of life outcomes.
Increased risk of stroke with depression, anxiety and stress

Increased inflammatory factors
You need to understand your past, cultural and family issues. Some cultures are free; some are closed. Some families educate. Some cultures have a strong male head; others female. Some religions don’t support masturbation or birth control.

Spectatoring

Masters and Johnson
Communication and openness is the secret to good sex. If you are unable to communicate and be honest with yourself about your fears and beliefs, it is hard to share with a partner. Conversely if you have good internal communication but are unable to share with your partner. Then having a good sexual relationship becomes difficult.

Sexual Sustainability
Marcalee Alexander, MD
I would rather know what sort of person has a disease than what sort of disease a person has

The outcome of tuberculosis had more to do with what went on in the patient’s mind than what went on in his lungs

Sir William Osler
PLISSIT Model

Permission
Limited information
Specific suggestions
Intensive therapy
Communication (verbal/nonverbal)

Patience

Perseverance
Medication review
Lubrication
BC/protection
Masturbation
Vibrators/toys
Positioning
Mindfulness
Counseling
Peers
Timing
Hygiene
Bowel/bladder
Environment/mood
Planning
Communication
  Pre
  During
  Post
Start slow but start
Closeness
Cuddle
Humor
Say what feels good
Kiss, touch, hug
It’s not just about vaginal penetration
All stroke survivors and their partners should be asked about intimacy and sexual function at the time of the stroke and at regular intervals during follow-up.

Sexual activity is reasonable for patients after stroke.

To reduce the psychological sequelae associated with stroke, sexual counseling can be useful for most patients and their partners.

Kautz, VanHorn
International Journal PM&R 2014
Rehabilitation Center of Excellence and Significance

Comprehensive
Connected
Continuum

Coordination
Communication
Community
PCP
Neurology
OB/Gyn

PM&R
OP staff
Urology
Administration

Acute Rehab
SNF
Assisted Living
Continuum
Timing of intervention
Follow up
Telerehab
Active evaluation/intervention
Roles
Please remember that information doesn’t change anyone. Inspiration does. Find your reason to live. Be inspired by it and undergo revelation and transformation. I have found only one bit of information that could help change you: It is that you are mortal and will die some day. Therefore, don’t do things to not die but do things to enhance the quality of your life and you may be surprised by how long you do live. Accept that you will die and made decisions about how you want to spend the limited amount of time you have.

Love, Medicine and Miracles
Bernie Siegel, MD
We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it’s larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive.

Being Mortal
Atul Gawande
Behind mountains are more mountains

Haitian proverb
The answer lies not in return but in transformation.

We can only go forward to what we can be.

Rabbi David Wolpe
Making Loss Matter
“My experience throughout my recovery is that life unfolds in ways we can’t predict. If you encounter a difficult challenge in your own life. I hope you’ll remember that this challenge doesn’t have to define or limit you. You hold an amazing power to influence the course of your own life. How you respond to the challenges of your life can become your opportunity to discover just how much you have to give to yourself, this world and the people in it.”

Alison Bonds Shapiro
Healing into Possibility
Thank you