

Mental Health, Body Image, Intimate Relationships and Ostomies

Emily Brooke, LCSW

Digestive Health | Department of Health Social Work | Dell Medical School, Ascension Seton

Assistant Professor of Practice | Steve Hicks School of Social Work, The University of Texas at Austin

Format/Guidelines/Disclosures

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Part 1 Body Image & Mental Health

Part 2 Body Image in Relationships

- Interactive with questions and sharing
- This subject can be tough for any person with a body, hold space to honor and respect the vulnerability it takes to share

Who am I?

- licensed clinical social worker with Dr. Ivatury's office
- 10+ years of practice in therapeutic provision
- sibling of an ostomate

Body Image

Who has it? What impact does it have on my physical and mental health?

- About half (51%) of Americans say they feel pressured to have a certain body type.⁽¹⁾
- Negative thoughts and feelings about one's body are defined as body dissatisfaction, which is considered to be the most important global measure of stress related to the body.⁽²⁾
- Higher body dissatisfaction is associated with a poorer quality of life, psychological distress and the risk of unhealthy eating behaviours and eating disorders.⁽²⁾
- Body satisfaction and appreciation has been linked to better overall wellbeing and fewer unhealthy dieting behaviours.⁽²⁾
- Poor body image can be associated with higher levels of depression, anxiety and body dysmorphia
- "Stoma surgery creates a sense of alteration in body image and a change in awareness in both appearance and the function of an individual."⁽⁴⁾
- "Poor adaptation to alteration of body image was associated with younger age, overweight, and temporary stoma"⁽⁴⁾



What ostomates say...

...about how having a stoma impacted their body image

“Now I feel undesirable. Thinking, “Who wants to date a guy with a bag of shit hanging off his stomach?”⁽³⁾

“I went through months of depression and whenever I looked in the mirror or showered I did not see any beauty I did not see how a man could accept me with this bag connected to me.”⁽³⁾

“I missed how my body looked all the time. Then slowly appreciated how much better I felt.”⁽³⁾

“Body grief is real and it mimics other grief.”⁽³⁾

“I began to feel that my ostomy was something I was proud of – it was something that gave me life again.”⁽⁶⁾

“This journey of loving myself has not been a walk in the park...Embrace your scars, always.”⁽⁵⁾



What the experts want you to think about

- Hold your body and your feelings about your body in non-judgement, with self-compassion
 - We often call this body neutrality, the idea that our body is neither good nor bad, just as it is
- Having negative body image is a *normal* experience
- Who can you go vent to?
 - A friend? A fellow ostomate? A professional?



What ostomates say...

...about overcoming negative
body image

“ These scars didn’t represent the horrible things I had been through anymore. Instead, they represented how strong I was, how I had a drive for success, how I was a fighter, how I refused to ever settle or give up.” ⁽⁵⁾

“Anyone else just sit and think about how much they took their old body for granted? I used to hate my tummy, sometimes I did think it looked cute, but either way I was always self conscious to some degree.” ⁽³⁾

“When I feel self-conscious or gross it sometimes helps me to think that there are “normal” people out there who feel just as much disgust and self-loathing about their perfectly fine bodies (so maybe my body is also perfectly fine?). It kind of reminds me that it might not actually be the bag, just a very ugly thought pattern that lots of humans get.” ⁽³⁾

“It’s ok if you have self-confidence issues or body issues, but go to therapy.” ⁽³⁾

What have been your successes? Challenges?

What are your wonderings?

What ostomates say...

...about dating with an
ostomy

“Get out there and keep practising your social skills. Have fun. It will happen.” ⁽³⁾

“In my experience, if you’re understanding and upfront and confident about it, you will find most people can handle it... but if they can’t, don’t get down on them or yourself.... There are lots of people who won’t care about your ostomy, so don’t get hung up on the ones who do care.” ⁽³⁾

“Don’t feel the need to tell them as soon as you meet them, or before you meet them if your using dating apps. But at the same time, set a boundary for yourself that you will tell them before the relationship gets physical.”⁽³⁾

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Dating, Relationships

- **“Use of stoma-related humour enables the couple to ease tension around the stoma and ensure that not all conversations about the stoma are heavy or shameful.”⁽⁸⁾**
- **Move at your own pace- how you feel in your body, how you feel about dating is the best predictor of success**
- **Decide what, how much and when you want to disclose, your mileage may vary from other ostomates.**

Relationships

- Most Americans (62%) who have ever been in a relationship say they worry about what their partner thinks of how they look ⁽¹⁾
- Stoma patients with strong bonds with their partners returned to sexual activity more easily, led happier intimate lives and demonstrated a positive attitude towards their condition. Many patients also stated that the process of adapting to a stoma contributed to the growth and strengthening of their relationship with their partner. ⁽⁷⁾
- I vs We- how connected a couple is can help improve their communication, expectations and quality of relationship/sex.
 - “To varying degrees, all couples described fluctuations between a sense of ‘I’ and ‘We’ in their adjustment to RC and the colostomy” ⁽⁷⁾
- A commonly reported shift for couples was a request for personal physical space or privacy around the colostomy and its related activities. Needs for emotional space following diagnosis, treatment or a particularly stressful cancer-related event were also expressed ⁽⁷⁾

What this all comes down to is: communication

What ostomates say...

...about sex & sexuality

“I used to think nobody would find me attractive because of my bag. Now I realise I don't want to attract the kind of partner who has a problem with it.”⁽³⁾

“You start to forget, and they start to forget about your ostomy. It becomes like a tattoo at that point.”⁽³⁾

When get to a physical point, be confident.... Don't let your bag get in your head... you're having sex at that point so what does it matter?⁽³⁾



Ostomies and Sex: Practicalities

What might be help?

- Pelvic Floor Therapy
- Ostomy lingerie and stealth belts
- Ostomy care just before sex



Common Sexual Problems after Ostomy Surgery						
WOMEN						
Surgery	Decrease in desire <i>(may also be affected by pain, radiation, chemotherapy and medications)</i>	Painful intercourse <i>(can also be caused by vaginal dryness or a different position of the vagina after surgery)</i>	Problems having an orgasm	Less vaginal wetness <i>(can also be caused by menopause, hysterectomy or low estrogen)</i>	Infertility <i>(inability to produce eggs or carry a child; ovaries, vagina or uterus removed)</i>	
Removal of rectum	Seldom	Sometimes	Seldom	Often	Seldom	
Removal of bladder	Seldom	Sometimes	Seldom	Often	Sometimes	
Pelvic exenteration <i>(removal of bladder, rectum, ovaries, uterus, colon and sometimes all or part of the vagina)</i>	Sometimes	Sometimes	Sometimes	Always	Always	

Common Sexual Problems after Ostomy Surgery						
MEN						
Surgery	Decrease in desire <i>(may also be affected by pain, radiation, chemotherapy and medications)</i>	Problems with erection <i>(may also be affected by certain medications)</i>	No orgasm	Dry orgasm	Less orgasm <i>(may also be affected by age and certain medications)</i>	Infertility <i>(cannot produce sperm)</i>
Removal of rectum	Seldom	Often	Seldom	Often	Sometimes	Sometimes
Removal of bladder	Seldom	Often	Seldom	Always	Sometimes	Always
Pelvic exenteration <i>(removal of bladder, rectum, colon)</i>	Seldom	Often	Seldom	Always	Sometimes	Always

Real life relationships and sex

She said, “I’d much rather be next to a bag than a butthole. It’s clean and I know you won’t fart on me.” ⁽³⁾

“In another example, Natalie purchased ostomy-specific apparel to cover her stoma while being intimate with her partner, Bernard. However, his reaction to her concealing the stoma helped instead to re-assure her of her physical attractiveness in his eyes. Together, they described this interaction:

Natalie: I got on the Internet right away and I found this website called Ostomy Secrets. So it’s like Victoria Secrets ... they also showed a ‘vixen belt’ that you could wear for when you’re having sex [...] It was the prettiest little lace belt that I ordered right away. You know with visions that we, you know ... [laughs]

Bernard: So here’s the deal, here’s the deal. So the first time here’s the thing, it’s like ‘Ya, ya that’s cool’ whatever and all that. So then about like the [third] time and whatever. And then it’s like ...

Natalie: [imitating Bernard] ‘Don’t even wear it!’” ⁽⁸⁾

“You need to wait until you feel comfortable and ready. Explain that to your partner, it’s great that he doesn’t care about the bag, but he needs to understand and care that you need to feel comfortable in your “new” body first. ⁽³⁾

Relationship Sex

In fact, when faced with these changes in their sexual relationship, many couples reported experimenting with alternative sexual activities like masturbation, oral sex, use of toys or changes in sexual position. Many couples also remarked that their sexual relationship was not the focal point of their relationship as a couple, as one partner described, 'it's just enough to be together ... just clinch together and feel warm side by side. That experience is really the important thing in the relationship'.⁽⁷⁾

Ostomies, Sex, and Data

- Women (59%) who have had sexual relationships are much more likely than men (38%) who have had sexual relationships to say they think about how their body looks during sex. ⁽¹⁾
- One study found that 3 months after ostomy surgery, patients complained that their sexual satisfaction had decreased, but at 12 months there was improvement in both men and women ⁽⁷⁾
- The low self-esteem of patients adversely affected the quality of communication with their partner, frequency of sexual intercourse and sexual satisfaction. ⁽⁷⁾
- You need to wait until you feel comfortable and ready. Explain that to your partner, it's great that he doesn't care about the bag, but he needs to understand and care that you need to feel comfortable in your "new" body first. ⁽³⁾

What sex educators want you to know:

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- Only do what you feel comfortable with, only what you enthusiastically consent to
- Sex isn't the only way to be intimate
- Good sex and intimacy⁽⁹⁾ relies on
 - Connection
 - Alignment (wanting the same things)
 - Communication
 - Empathy
 - Authenticity
 - Vulnerability
- As humans we go through three phases around sex: do we expect it? Are we eager for it? Do we enjoy it?⁽⁹⁾ Sex sometimes doesn't have a yes to all 3 and that's often when we feel disconnected.
- Our bodies have a brake and an accelerator when it comes to sex⁽⁹⁾. Stimuli, relationships, context can all either tell our brains to hit the brakes or accelerate. Negative body image is often a brake.
 - How can you ease off the brakes?

What have been your successes? Challenges?

What are your wonderings?

Sources

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