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“I Didn’t Feel Like I Was a Person Anymore”: Realigning Full Adult Personhood after Ostomy Surgery

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Abstract

Colorectal cancer (CRC) is the third most common cancer in the United States. For some CRC patients, cancer treatment involves creating a permanent or temporary intestinal ostomy. Having an ostomy often results in complex social and physical concerns—including unpredictable and at times publicly noticeable bowel output. In this article, we discuss findings from 30 in-depth interviews with female CRC survivors with ostomies in the western United States. We highlight how having an ostomy disrupts culturally sanctioned practices of continence that mark the attainment of full-adult personhood. We discuss how survivors reclaim a sense of full personhood after ostomy surgery through a process of realignment that entails both learning how to manage ostomy equipment to conceal bowel activity and reappraising their illness and suffering. We suggest that the anthropological categories of personhood and personhood realignment be incorporated into research and interventions aimed at increasing support among cancer survivors living with bodily impairments.

Keywords

cancer survivorship; personhood; continence; adaptation

Introduction

Colorectal cancer is the third most diagnosed cancer and the third leading cause of cancer death in both men and women in the United States (ACS 2011–2013). The five-year relative

survival rate for CRC has increased from 51% for cases diagnosed in the mid-1970s to 67% for cases diagnosed in 1999–2006 (ACS 2011–2013:7). Significant advances in treatment have reduced mortality rates by as much as 30% (ACS 2011–2013). Some long-term CRC survivors (5 years) will need to have temporary or permanent ostomies created surgically. This procedure involves the removal of the diseased part of the small or large intestine and attaching the remaining intestine to an opening in the abdomen through which feces are discharged—most often into a pouch appliance.

As more CRC patients survive their initial cancer treatments, research has documented ongoing treatment-related challenges among survivors, especially those with ostomies (5 years) (Grant 1999; Krouse et al. 2007; Nugent et al. 1999; Ramsey et al. 2000). Having an ostomy often results in complex emotional, social, and physical concerns—such as managing unpredictable and uncontrollable bowel functioning (Kelly 1992; Klopp 1990; Manderson 2005; Notter and Burnard 2006). Many CRC survivors living with an ostomy undergo an adjustment process akin to a second period of toilet training, which potentially compromises the very foundation of adulthood (Kelly 1992; Rozmovits and Ziebland 2004).

We use Luborsky’s (1994:239) formulation of “full adult personhood” to expand on previous research that has examined how living with an ostomy assaults the cultural category of personhood. As colorectal cancer patients’ long-term survivorship issues are still insufficiently understood and addressed (McMullen et al. 2008:176; Sapp et al. 2003), we examine how female CRC survivors in the United States articulate their experience living with an ostomy as an erosion of full adult personhood. We then discuss various technical and narrative strategies that helped realign these CRC survivors with ostomies back into the cultural category of full-adult persons.

Continence, Competence, and Personhood

Having an intestinal ostomy dramatically disrupts bowel function as it is no longer under the individual’s direct muscular control, and defecation can occur at unpredictable times and places (Kelly 1991). Research examining the social contours of incontinence, including living with a colostomy and ileostomy, has revealed the close linkages this impairment has with dirt, pollution, and stigma (Kelly 1992; MacDonald 1988; Manderson 2005; Mitteness and Barker 1995; Roszmovits and Ziebland 2004). Feces carried and handled outside of the body or worse—defecation that occurs in public—can be understood as the very essence of “matter out of place” (Douglas 1966).

Being able to excrete when the need arises, and the ability to control one’s body so that it does not excrete at culturally inappropriate times and locations, is a process Lea calls “embodied self-control” (1999:12). Given that urinary and fecal control are part of the earliest and most basic processes of socialization, surviving CRC with an ostomy can disrupt the very foundation of an individual’s identity as an adult human because it involves “a loss of embodied self-control” (Lea 1999; Rozmovits and Ziebland 2004). Culture mandates particular bodily waste management practices, which, for the current discussion, can be thought of as fecal habitus (Bourdieu 1984; Inglis 2000). In the United States, culture mandates a fecal habitus not only of embodied self-control that ensures absolute privacy for

defecation, but also complete self-reliance whereby continence and personhood competence are often conflated (Mitteneess and Barker 1995). Therefore, the inability to eliminate at only appropriate times and places is a symbolic—and literal—negation of personhood (Peake et al. 1999:276).

Luborsky (1994) contends that full-adult personhood is bestowed by society and is earned by achieving and maintaining expected social roles and ideals at particular times in the life cycle. Personhood is not an intrinsic property of an individual nor can it be seized by individual fiat—it must be socially legitimated. Impairments that interfere with valued social roles and ideals represent assaults to the cultural category of personhood and can be understood as a cultural adversity. Luborsky further notes that examining individual efforts to cope with impairment and disability that have traditionally been viewed as psychological coping mechanisms can now be viewed as addressing cultural concerns—foremost of which is the preservation—or realignment—of one’s identity as a “full-adult” person. This framework provides a useful way to understand the adaptations made by CRC cancer survivors living with ostomies.

Adaptation and Realignment in Response to Chronic Illness and Disability

Having a changed body as a result of cancer treatment often provokes painful identity crises due to the loss of body parts and changed bodily functioning (Manderson 2011; Piot-Ziegler et al. 2010; Rasmussen et al. 2010). Linda Hunt asserts that cancer “may present the afflicted with permanent challenges to their identity: it does not permit one to go on living in an undisputed, familiar world” (Hunt 2000:88). Cancer scholars have noted that North American discourses of rehabilitation and survivorship are inflected with many of the cultural mandates representative of the most valued aspirations of human conduct in Western culture today: hope, positive thinking, lifestyle change, and self-responsibility (Delvecchio Good et al. 1990, Ristovski-Slijepcivic 2011; Sinding and Gray 2005). Efforts to rehabilitate the cancer-damaged body back into a particular social and cultural world may overlook the more enduring and existential dimensions of having contended with a life-threatening disease such as cancer (Hansen 2007; Hansen and Tjørnhøj-Thomsen 2008; Rasmussen et al. 2010).

Medical anthropologists and sociologists have examined how individuals contend with bodily impairments and their attendant cultural assaults as a process of realigning body, self, and society (Becker 1994; Charmaz 1995; Luborsky 1994; Murphy 1987; Williams 1996). Michael Kelly (1991, 1992), using Goffman’s (1963) classic framework of stigma and spoiled identity, examines how individuals living with an ostomy engage in a process of identity management whereby they may be rendered “ordinary” or “normal” if the appliance and its function are kept from public view via the technical management of bodily waste.

Much important scholarship has been devoted to examining how narrative reorders suffering and enables afflicted individuals to create a sense of continuity that reconnects them to their social and cultural worlds (Becker 1994; Gregg 2011; Kelly 1991; Kleinman 1988; Mattingly 1988; Mattingly and Garro 2000). The use of metaphor, even stigmatizing metaphors, allows the sufferer to maintain a connection to a particular gendered social order

(Gregg 2011). Kelly (1991) notes a shared vocabulary of coping and the verbal art of appraisal and reappraisal of events, at times “normalizing” illness, which maintains a “sense of coherence” in the face of biographical disruption (Bury 1991; Kelleher 1988). Similarly, Williams (1996:38) contends that the chronically ill “negotiate settlements” whereby they realize that they are never going to be who they once were but attempt an approximation of their former selves through narrative reappraisals that reposition suffering, making the threats and losses they have endured more bearable.

As cancer treatments often include changes to bodily functioning and the loss of various body parts, it is important to recognize the cultural dimensions of these impairments such as the erosion of personhood, which is not well understood (Luborsky 1996:243). Examining how individuals contend with assaults to personhood can perhaps provide insights into enhancing support for other long-term cancer survivors.

Methods

The first author (MR) conducted in-depth, semi-structured interviews with 30 female members of an integrated health care delivery system who previously had participated in a National Cancer Institute (NCI) funded study examining health-related quality of life among long-term CRC survivors (5 years). This qualitative portion of the study focused on issues related to sexuality, but interviews included general questions asking women to reflect on their experiences of living with and adjusting to having an ostomy. Nineteen women resided in northern California and 11 in Oregon. Eligible participants were women with ostomies who had survived at least five years since their cancer diagnosis. Participants received a recruitment letter inviting them to participate in an hour-long interview to discuss their experiences of living with an ostomy.

Members of the project team identified minority patients in the pool of eligible participants to ensure some degree of minority representation. The interview guide was created by the interdisciplinary research team and examined issues regarding body image, personhood, gender, and sexuality. Informants were given the choice of being interviewed in their homes, their nearest medical facility, or some other convenient location. Most women chose to be interviewed in their homes. Informed consent was obtained from all study participants, who received a \$25 gift certificate after completing the interview. Interviews were audio-taped or digitally recorded and transcribed verbatim by a professional transcription service. The health care system’s Institutional Review Board approved all study materials and protocols.

Data Analysis

Four of the six authors coded the transcribed interviews during the preliminary stages of data analysis. At least two authors independently reviewed and coded each transcript for major themes. Codes included medical co-morbidities, diet, body image, ostomy care, sexuality and gender, and relationships with spouses. The authors met weekly to discuss coding. During the team coding process, the first author noted that the participants discussed the ostomy as an assault to the self and body, but also described ways in which they were able to cope with these assaults. Auerbach and Silverstein (2003) have developed a model that allows researchers to use interview data to develop a theoretical narrative about trauma and

recovery. At this stage, MR read the transcribed interviews with the following research questions in mind (Salick and Auerbach 2006): How does having an ostomy assault core notions of personhood among cancer survivors? What strategies did they employ to help mitigate these assaults? MR then created a table that listed how participants discussed the ostomy as an assault to personhood and the strategies that helped them cope with this impairment.

Findings

Participant demographics are listed in Table 1. Less than half (40%) were married or partnered, the majority were white, and half of the group had some college education. Further, as this study explored post-surgical experiences of sexuality, all participants indicated a heterosexual sexual orientation.

The following sections provide illustrations from our interviews about how living with an ostomy assaults full-adult personhood by disrupting fecal habitus. We examine technical and narrative realignments that served to reposition these cancer survivors back into the cultural universe of full-adult personhood (Luborsky 1994). The women in this study share with many other cancer survivors a feeling that they were no longer the same person they were before the disease and treatment (Manderson 2011; Piot-Ziegler et al. 2010; Rasmussen 2010). For example, a white, 80-year-old widowed woman living in a comfortable northern California home, who had survived cancer for many years, and whose husband and family had been very supportive still felt as if she did not belong in her cultural world. Her changed body disrupted her sense of being a whole person. When discussing other people she knew who also had an ostomy, she described it as a “mental thing.” When asked to clarify what she meant by this, she stated: “That you’re not complete. How do you put it? ... That you’re different and it’s not what it should be. You’re not the same whole person that you were. From feeling that way, you feel like you’re not a part of ... everybody else’s thinking and social things.”

This statement demonstrates that cancer and its attendant bodily changes assault the body–self–society nexus of personhood to such a significant degree that even after years of what can be considered successful adaptation, there is a persistent sense of alienation from one’s cultural world. One of the central ways that these women felt that they were not a part of everybody else’s thinking and social things was their changed body in relation to fecal habitus. A common theme among the stories, particularly when reflecting on the early days of their surgical recovery, was an initial period of equipment failures and accidents that severely encumbered social participation. A 62-year-old divorced, ethnically mixed Filipina woman (Filipina and Native American) who lived in a comfortable mobile home discussed the difficulties she encountered while going out with her former husband:

I didn’t feel like I was a person any more. I felt more like a non-person, you know, because you’ve got these things on you and then you’ve got this attachment, and not knowing how to care for this. We’d go places and we’d have to come home because I’d like overflow. ... I guess that’s all in not knowing how to care for it.

The inability to control the ostomy and its function led to profound assaults to personhood for this woman, and she was not unique in her description of a problematic relationship with

the ostomy appliance, especially in the initial phases of living with it. Nearly every woman in the study had an “accident” story in which they spoke in detail about an appliance failure or a bout of diarrhea that essentially led to defecating in public, which was described as a traumatic and humiliating event.

Noises and odors that can emanate from the pouch appliance are other troubling aspects of having an ostomy that also threaten to expose the individual as “non-ordinary” (Goffman 1963) (i.e., incontinent and therefore incompetent) (Mittiness and Barker 1995). Accidents, odors, and noises render this otherwise invisible impairment visible, and if it becomes evident that a person with an ostomy can no longer control where and when to defecate, this once again threatens to remove the individual from the cultural category of full-adult personhood. Therefore, one of the key strategies employed to contend with these assaults at least initially, was learning how to care for the ostomy appliance and its function, essentially learning a new fecal habitus.

Strategies for Personhood Realignment after Ostomy Surgery

Learning a New Fecal Habitus—Wearing an appliance, keeping it on, and changing it are the basic skills necessary when coping with an ostomy. These skills are the foundation for a return to what Kelly (1991) calls a “normal life” or what we are calling realigning full-adult personhood. However, many women described a steep learning curve when initially attempting to learn a new fecal habitus. A 64-year-old woman living in comfortable northern California home, married to a man 13 years her junior, described the following:

The first couple of months were a disaster. Your whole system changes and I was constantly having the runs ... the bag was breaking. I thought, what am I gonna do? I just thought I couldn't live like this, and it took almost two years. I hardly left the house. I was afraid to leave the house because I had a couple of accidents. But finally you adjust. Finally you learn what your body needs and doesn't need, and what works and what doesn't work. But it takes time. So does anything—you break your arm or you hurt yourself, you learn how to use it.

Women talked at length about the technical difficulties they initially experienced, but over time and through trial and error, they discovered various techniques that became a part of their new fecal habitus. A major theme that emerged in virtually every woman's story was the quest to find the right equipment. For most women, the equipment they initially began their ostomy journey with was not the equipment that they ended up with. Some women liked a particular kind of clip for their appliance, whereas others had tried clips but found them to be unreliable. Another participant started out with a one-piece appliance, found it inadequate in maintaining bowel function, but is now reasonably content with her opaque, two-piece appliance because excreta can be more efficiently removed from it while also keeping its contents less visible.

Irrigation was another technique that became a part of some participants' new fecal habitus. This process entails using an enema to instill tap water into the colon via the ostomy to literally wash out feces. This technique requires skill and patience as it can take up to an hour and is not always successful. Gas and other digestive issues can interfere with the

process. If successfully implemented, it can provide a degree of control over the timing and location of defecation; for some participants, this was the primary means by which they were able to reintegrate into social life. A white, retired factory worker in her fifties explained that she would not have been able to adapt to an ostomy if she had not been able to irrigate, stating: “Thank God I can irrigate, because I wouldn’t have made it the other way.” This woman discussed an elaborate irrigation ritual that she conducted every morning, which allowed her to feel that she could be “in charge just the same as yourself or anybody else.” Of all the women interviewed, this participant expressed the greatest aversion to her ostomy—she used feminine hygiene spray to “blast that sucker” and said that when she dies, she wants to be cremated because she wants her ostomy “burned up and gone!” In spite of this, she was able to return to work, go dancing, and carry on a sexual relationship for several years after the surgery, all of which she attributed to her ability to irrigate.

For a 77-year-old retired African American participant who had worked as a house cleaner, irrigation was also a means for her to continue full social participation, in part because irrigating allowed her to wear a gauze patch over her ostomy, rather than wearing a bag:

I cleaned houses. That was my job. I loved it. ... I was just thankful that I could do all of these things. You’ve got to make friends with the things that are kept in your body. I went dancing. I played bridge with the other girls. I was out doing different things. ... I wasn’t sitting at home with the bag over me, or anything like that, because I didn’t wear it. [Chuckles.] I did everything anybody else did.

This woman felt very strongly about not wearing an appliance, which seemed to be synonymous with staying at home and not engaging in the social world. “Making friends” with her new fecal habitus, allowed her to have control over defecation. Both participants noted that irrigating their ostomies made them feel just like anybody else, highlighting a degree of realignment with the ordinary world of basic continence and personhood competence.

Although irrigation was a successful strategy for some participants, others noted that the process was not helpful in controlling bowel function. A white woman, living with her disabled daughter in northern California, mentioned that after her surgery she was shown an educational film about using irrigation to regulate defecation and thought, “I’ll still have control. I won’t have it coming out any old time and embarrassing me.” She indicated that it was misleading to tell people that they would be able to regain control of their bowels by irrigating once a day, because ultimately feces “comes out whenever it wants to: You’re sitting there talking to somebody and all of a sudden—there it is.” However, she discussed other bodily techniques that helped her regain control:

When I was working, the way that I dealt with it was that I didn’t hardly eat anything during the day. [Laughs.] I would take Imodium every night. ... Usually I didn’t have anything happen while I was at work. I was teaching until 3:00. Usually in the evenings everything would happen. I was taking care of it in the evenings when I was at home. I had my body regulated at least.

In addition to regulating the timing of foods consumed, dietary modifications such as controlling the types of foods eaten were regularly featured in the technical strategies to control an unpredictable bowel cycle.

Regaining a degree of embodied self-control via the technical mastery of the ostomy and its appliance was a central feature in the participants' ability to cope with this impairment. For one woman, this technical mastery was made evident when she no longer needed to bring an extra set of clothing in the car: "I would take an extra set of slacks and underpants, just in case. We did that for a long time. I went for months and didn't need them and I finally said, 'Well, thank you, but I think we can take those out of the car now.'"

The child-like state of needing an extra set of clothing just in case there was an "accident" was something this woman felt confident to leave behind. The techniques employed by the women in this study served to keep the ostomy and its function a private matter—so much so that many claimed "most people don't know I have it." The more closely these women could approximate socially sanctioned fecal habitus, the more closely aligned they became with the cultural category of full-adult personhood.

Narrative Reappraisals

Youth, Sex, and Pollution: A Gendered Lifecourse Reappraisal—While concealing the ostomy was necessary to maintain one's public identity as an ordinary, continent, and competent full-adult person, it became evident that this "hidden-ness" presented particular difficulties for women as they navigated the complex terrain of heterosexual sexuality. Colorectal cancer most commonly affects older adults—the average age of the women in this study was 70, and the average age of women when they underwent their surgery was 69. When reflecting on the difficulties of surviving cancer with an ostomy, many women believed that the experience would have been much worse if they had undergone the surgery as a young, single woman. What appeared to be particularly troubling about the prospect of living with an ostomy at this stage was the idea of having to disclose the ostomy to a potential sexual partner. A widowed white woman, who reported a great deal of support from her husband when he was alive, nonetheless wondered when a young, single woman would tell a potential sexual partner about her impairment:

And when do you tell them? ... You don't walk up and say, 'Hi, I'm so and so. I have a colostomy bag.' [Both laugh.] So when is it that you tell somebody? What is their reaction when they're told? Do they suddenly lose interest? ... I think, okay, if you were missing a leg and you had an artificial leg ... but that is obvious to somebody.

According to this woman, having an ostomy could potentially be more problematic than missing a limb when meeting a potential romantic partner because a missing limb is publicly visible and therefore does not require disclosing an unexpected or "spoiled" identity (Goffman 1963).

Another white, widowed participant was concerned about what a young, single woman would do when initiating a sexual relationship and noted that telling a potential partner about the ostomy would be akin to revealing that you have AIDS:

If you get to know someone well enough that you decide to be intimate, it's kind of like saying I have AIDS. You know, how do you tell them and discreetly let them know? It would have to be somebody that you really knew well and would have to be understanding.

This woman's mention of AIDS in relation to her ostomy demonstrates a belief about the ostomy's metaphorical link with stigma and pollution. In her estimation, someone would have to reveal an unknown or unexpected impairment as well as one linked with a current ultimate signifier of stigma, if not death.

Finally, a white married participant who underwent surgery at age 52 indicated that it would have been extremely difficult to imagine a new romantic relationship as a younger, single woman and became very emotional when talking about the issue:

I: Why do you think it would have been harder as a younger woman as opposed to a 52-year-old woman?

R: Well, now you're really getting to the crux of it. I can't imagine wanting to ever be seen naked. I can't imagine falling in love, making love and I have an appliance. It wouldn't work. While I say that, I wasn't in that position. ... It would have been very awful for me. [Participant very emotional, near tears.] That would have been really hard.

What is striking about these accounts is that all of these women actually had very supportive husbands, at one time or another, who accepted their changed body and who maintained a loving relationship with them after their surgery. However, they could very easily imagine how difficult it would be for a woman who did not have this support and they wanted to know how a young, single woman would go about negotiating her impairment in a new sexual relationship with a man. Having an ostomy poses a particularly difficult dilemma for sexual intimacy: If successfully concealed, one's identity as normal or ordinary can be legitimized (Goffman 1963; Kelly 1991). However, sexual intimacy requires potentially revealing a nonordinary or "spoiled identity" to a new partner and risking rejection, and it appears that this fear is not entirely unwarranted.

Nearly one-third of the women interviewed did not have a partner at the time of their surgery and did not feel comfortable with the idea of embarking on a new sexual relationship with a surgically altered body. Some of the women were elderly and widowed when they underwent the surgery and felt that a new sexual relationship stage of their life had since passed. Others felt that they would not be able to cope with the reaction of a new sexual partner when disclosing the impairment (Ramirez et al. 2009). One woman did manage to venture into the heterosexual dating arena after her surgery. She talked about dating a man for three months even having sex one time without him discovering her ostomy appliance. After the sexual encounter, the participant believed that the relationship was getting serious, so decided that she should disclose her impairment: "As soon as I told him. ... And, I mean he's telling me that he's fallen in love with me. As soon as I told him this, I didn't see him again. I thought, what is wrong with this guy? I said, well, it's his loss. But it really crushed me."

This participant wanted to blame this rejection on the flawed character of her would-be suitor and assuage the rejection with the time honored “It’s his loss,” while also revealing that the incident “crushed her.” This woman underwent ostomy surgery as a single woman and experienced the kind of rejection the married-at-the-time-of-surgery participants could only imagine as being painful and humiliating.

Refusing Assaults to Personhood-Culture and Metaphor—Most of the women in this study provided lengthy accounts of how the ostomy had fundamentally altered their sense of self and personhood, but some women refused the idea that the ostomy meant a lesser role for themselves as adult members of society, or that the ostomy had somehow compromised some essential part of their personhood. One woman, a 56-year-old retired engineer originally from India, attributed this refusal to her cultural background: “I guess there’s a difference I think in the cultural sense too. I find that the Western women are much more into their body thing ... and maybe it’s just the Asian culture, but we take these things as more of a karma kind of thing.”

This participant attributes her equanimity about her impairment to her culture that deems this kind of adversity to a karmic process, which she distinguishes from Western women’s attitudes about “their body thing.” In her estimation, Western women may be more vulnerable than she is to personhood assaults because of different cultural understandings of the body and adversity. The participant also discussed how she did not hide the fact that she has an ostomy from people that she worked with; in fact, she made it known to her work colleagues that she was a resource for others who were dealing with cancer. This is in part because she feels that “it was nothing to be embarrassed about” because it is after all “a medical condition.” Later in the interview, when asked if there was any advice that she might give someone who was about to undergo ostomy surgery, she stated:

There is no need to feel any less than what you are. This little thing on your stomach doesn’t determine the person you are. It doesn’t. Why feel anything different? To me, it’s a very shallow thing if somebody thinks that their whole life force depends on this thing on their stomach.

Most women in the study described profound distress at the bodily and cultural implications of having an ostomy, but this participant characterized it as merely “this little thing on your stomach,” which for her has no relation to an individual’s “life force.”

Another participant, a white woman living in San Francisco, in her early eighties in very good health, who has been married to her husband for 59 years, did not want to recount a tale full of trauma and embarrassing accidents when discussing her surgery and treatment. For her, it was important to deal with the situation at hand with stoicism and practicality. Interestingly, both this woman and the participant discussed above used plumbing metaphors to describe their transformed bodies:

I: Do you feel that having a stoma has affected the way that you feel about your body?

R: No. ... No, I don’t. I just think of it as in front instead of in back. It’s still the same plumbing. [Both laugh]. [Pause.] It hasn’t affected anything.

Both of these women used mechanical metaphors to describe their changed bodies and denied any profound existential distress over the ostomy. They insisted that the ostomy had not disrupted their personhood, even while acknowledging that for others the condition might “determine the kind of person you are.”

Discussion

Living with an ostomy can indeed present many profound challenges to the cultural category of full-adult personhood in a U.S. cultural context, stemming from the conflation of incontinence with incompetence (Mittiness and Barker 1995). Tracing the origins of current Western defecatory aesthetics, David Inglis (2000) contends that toiletry technologies are subject to socio–historical mediation, with different characteristics possible at different times and places. In the United States, as in many other advanced industrialized nations, the cultural ideology anchored in the body regarding elimination requires that excretory functions be performed in absolute privacy due to increasingly less tolerant attitudes about the body and its products (Lea 1999). Elias (1978) discusses a process in Western Europe by which the threshold of disgust and embarrassment was raised gradually over the centuries, necessitating ever-increasing containment of the body. Moreover, being “civilized” is contingent on the appropriate management and the degree to which bodily waste and functions are hidden from public view (Elias 1978).

Although the dominant form of fecal habitus is culturally and historically mediated, it is nonetheless internalized and embodied by competent social members (Akpan et al. 2006; Bourdieu 1984; Inglis 2000; Lea 1999; Mittiness and Barker 1995). And if the body is the starting point for our apprehension and construction of the world, indeed the core symbolic system through which people come to understand the relation of the self to society (Csordas 1990; Douglas 1982; Lock and Scheper-Hughes 1990; Merleau-Ponty 1962), we can begin to further appreciate the distress experienced by individuals when their bodies transgress this most fundamental tenet of cultural personhood. The technical mastery of the ostomy, particularly in the case of irrigation, can be understood as purification rituals that serve to realign the body within a culture that mandates that the body’s polluting substances be kept from public view, maintaining one’s identity as an ordinary, and continent, therefore competent person (Douglas 1966; Goffman 1963; Mittiness and Barker 1995). The closer the women in this study could approximate cultural norms for absolute privacy through the technical mastery of their new fecal habitus, the more closely aligned they became with the cultural category of full-adult personhood (Luborsky 1994).

Another key feature in realigning personhood were the stories women told about how they were able to mediate adversity through narrative reappraisals (Becker 1994, 1999; Kelly 1991; Williams 1996). In this study, one reappraisal came in the form of: “If I had been younger and unmarried, living with an ostomy would have been much worse than what I have endured.” It was in the realm of youthful sexuality that the ostomy seemed particularly treacherous because of the possibility of romantic or sexual rejection, which, in sociological terms, means that one’s identity as normal or ordinary is not legitimated (Kelly 1991:121).

Sexual rejection can be a painful experience for anyone, but the idea of being rejected because of a bodily impairment may be especially troubling for women in a U.S. cultural context, in which a woman's prestige is often derived largely from the treatment they receive from men, which is formative of and responsive to her attractiveness (Holland and Eisenhart 1990). Or, as one participant in this study succinctly noted: "I think that as women, we value ourselves a lot ... according to how men value us." This sentiment encapsulates an assertion made by many second-wave feminists—in a heterosexist society, a woman's authenticity is derived from their relation to men and their desirability by men, what later feminists refer to as the power of the "male gaze" (Kaler 2006:65).

By articulating a concern about single women facing life with an ostomy, these women express an understanding and perhaps a tacit acceptance of cultural gendered norms and thus their continued membership within this culture (Gregg 2011:80). Being married to men who found these women desirable in spite of their impairment meant that they could still claim significant membership within a heterosexist cultural order. However, visions of a young single woman with an impairment associated with stigma and pollution, in a cultural milieu that links a woman's prestige and value with how desirable a man will find her, provoked painful imaginings about what it might be like to be an unacceptable woman within this very same cultural universe. Therefore, some women imagined that having an ostomy could have assaulted or "crushed" the very core of a heterosexual woman's gendered identity, especially if the participant had been younger and single, negotiating a new romantic/sexual relationship. This revealed assaults to gendered personhood that some CRC survivors with ostomies were relieved that this, at least, was one cancer-related indignity they had been spared, thus reappraising the threats and losses they had endured as more bearable.

Another narrative form used by the women in this study was a process sociologists refer to as "normalizing" (Kelleher 1988:147). This entails maintaining a feeling of personal worth and a "sense of coherence" or potency in the face of disruption—so that the impact of the illness and its effects on the person's identity remain relatively slight—or regarding the illness or treatment regimen as normal to incorporate it more fully into the person's identity (Bury 1991; Kelleher 1988; Williams 1996). In this study, some women's narrative appraisals excluded accounts that described the ostomy as compromising some core part of their personhood, such as the South Indian woman who believed this attitude was part of her cultural heritage. In the language of public health, one could view this woman's description of her cultural background as being "protective" against assaults to personhood. More research is necessary to see if this is borne out, but what is evident is that cultural identity was one of many resources marshaled by participants to confront assaults to personhood (Luborsky 1994).

Mechanical metaphors were also used to normalize the ostomy and to mediate assaults to personhood. Two women chose to describe the ostomy as simply a matter of altered plumbing. Mathews and colleagues (1994:794) note that metaphors provide a set of images and characteristics that can be used to conceptualize illness in a concrete way, allowing individuals to predict likely entailments. Becker notes that metaphor serves as a mediator for change, enabling individuals to reestablish a sense of connection with cultural norms and the social order while "obscuring cultural paradoxes and unresolvable dilemmas" (Becker

1994:404). Living with an ostomy can indeed present CRC survivors with many unresolvable dilemmas regarding the continence-competence conflation with personhood. Using a mechanical metaphor like plumbing while relying on the Western tendency to view the body as a machine (Martin 1992) may metaphorically unite the individual within a cultural universe that views the body as such—my body has plumbing, just like every other body in my cultural world.

Limitations

All the women who agreed to participate in this study managed to negotiate some kind of settlement with regard to their new fecal habitus, although for some there was a persistent sense of not belonging in this cultural world. It is possible, however, that women who have not been able to cope with the myriad challenges of living with an ostomy may not have been as willing to share their experiences. This discussion can therefore be understood to only partially represent the experiences of some CRC survivors with ostomies who have been able to reorder their lives and reappraise their illness in ways that reconnected them to the social world of full-adult personhood.

One reason for low minority participation in the parent study could be that the original survey (from which these study participants were recruited) was only administered in English. Therefore, the resulting low minority participation in this study makes it difficult to formulate any claims regarding whether particular adaptations to ostomy surgery differed by race/ethnicity. To augment minority participation in the future, strategies could include surveys in multiple languages and outreach to community-based organizations that serve particular minority groups (Mendez-Luck et al. 2011). Given that identity is constituted in complicated ways including age, race, sexuality, and gender, future research should explore the experiences of men and non-heterosexual women. Looking at both of these groups could contribute to a more nuanced understanding of how this particular impairment affects gendered personhood and personhood realignment. Future research could also examine how different cancers produce similar or divergent personhood realignments at various life course stages. Given the extensive literature on how breast cancer surgery can impact women's gender identity and personhood, comparisons between breast and colorectal cancer survivors could be very instructive (Petronis et al. 2003; Piot-Ziegler et al. 2010).

Conclusion

Although many women in this study successfully confronted erosions to personhood, others still faced a persistent sense of not fully belonging in their cultural world. Some women claimed a personhood that transcended the limits of the flesh, while others were still bound by its physical and cultural weight. Cultural ideologies anchored in the body, such as fecal habitus, provide a lens through which to view the body as fundamentally cultural, securely anchored in a particular historical moment (Scheper-Hughes and Lock 1987). Thus, transgressions of habitus—such as the ostomy—provide key insights into the gendered, cultural, and moral universe where the body resides and can further illuminate why living with an ostomy can assault the essence of personhood in a U.S. cultural context. Nonetheless, individuals struggle against devaluation through the technical mastery of their

ostomy appliance and negotiate settlements that reappraise the meaning of their illness and suffering while also making the threats and losses endured more bearable. We suggest that the anthropological category of personhood and the adaptive process of realigning personhood can be fruitfully incorporated into research and interventions aimed at increasing support among cancer survivors living with bodily impairments. Such an approach, grounded in the phenomenological and social body, could inform rehabilitation efforts that pay heed to the enduring and existential concerns and suffering related to surviving cancer, which, according to Rasmussen and colleagues (2010:158), appears to be a dynamic and life-long process.

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Table 1Participant Demographics ($N=30$)

Age	44–93 (average age 70)
Average age at ostomy surgery	69
Marital Status	
Married (or partnered)	12
Widowed	10
Divorced	5
Single	3
Race/Ethnicity	
White	22
Asian	3
Pacific Islander	2
African American	2
Hispanic	1
Education	
<High School	1
High School/GED	5
Vocat/Secctrl/Busin	4
Some College	13
Grad College	4
Some Grad	1
Grad Degree	2

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