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The Influence of Husbands' or Male Partners' Support on Women's Psychosocial Adjustment to Having an Ostomy Resulting from Colorectal Cancer

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Abstract

Objective—Some patients with colorectal cancer (CRC) require a permanent ostomy, which changes bodily function and can create psychosocial distress. However, little is known about the influence of men's support on women's psychosocial adjustment to having an ostomy as a result of CRC.

Methods—Participants initially completed the City of Hope-CRC Quality of Life questionnaire. We then conducted in-depth interviews with 30 female participants. Interview questions focused on body image, gender, and sexuality. Interviews were recorded and transcribed. We used qualitative methods to analyze the interview data and compared global HRQOL quartile scores to the overall ways that women discussed husbands' or partners' support regarding psychosocial adjustments to having ostomies.

Results—Of 30 participants, 22 were married or partnered at the time of surgery and 8 were single. The non-partnered respondents are not included in this analysis. Of the 22 married/partnered women, 17 described positive support from husbands being central to their psychosocial adjustment, 3 described a lack or withdrawal of support negatively affecting adjustment, and 2 described support as neither positive nor negative. In 17 cases, women's high or low quantitative HRQOL scores matched the positive or negative qualitative findings. There were 3 cases in which there were positive qualitative data and low HRQOL scores, but each of these cases, women reported serious current comorbidities.

Conclusions—These findings suggest that the provision or withdrawal of husbands' or partners' support can have a considerable impact on the psychosocial adjustment of female CRC patients with ostomies. These findings appear to be both short- and long-term. Survivorship assessments should include appraisals of women's relationships to spouses/partners.

Introduction

In the past several years, researchers and clinicians have begun to turn their attention to the impact of spouses on cancer patients' and survivors' psychosocial status and quality of life. These studies have focused primarily on prostate cancer for male patients and breast cancer for female patients. Recent work has included both pilot studies and randomized controlled trials. In general, these studies have found that spouses have the potential to have a positive effect on patients' psychosocial status and quality of life regarding such domains as communication and feelings of certainty [1], hopelessness and self-appraisal of their illness [2], general feelings of social support [3], and mood and anxiety [4]. Nevertheless, spouses can have negative effects as well [5]. While preliminary research on patients with colorectal cancer and their spouses has been reported [6-7], additional research is needed. Additional studies are particularly important in this population because, unlike many other cancer patients, some colorectal cancer (CRC) survivors must also contend with a significant change in body function (having an ostomy) in addition to coping with the more typical physical and psychosocial sequelae of cancer survivorship.

A permanent ostomy is sometimes required for CRC patients. For some patients, ostomy becomes routine and fairly problem-free, while for others it remains problematic long after surgery [8]. It is estimated that there are between 750,000 and 1,000,000 persons living with an ostomy in the US, and a significant proportion undergo ostomy surgery as a result of CRC [9]. Living an ostomy necessitates changes in daily habits for affected individuals. Managing an ostomy can cause distress by limiting activities, and negatively influencing the woman's sense of self, body image, and sexuality [10-19]. While the challenges of cancer recovery are becoming well recognized and addressed [20], CRC patients with permanent ostomies have additional long- and short-term physical and psychosocial challenges to face in survivorship.

This article reports part of an ongoing, mixed method, multi-site project examining health-related quality of life (HRQOL) in CRC patients with ostomies [21]. We investigated the ways in which husbands and male partners affect psychosocial adjustment and HRQOL of female CRC patients with permanent ostomies. To better understand how a range of aspects of intimacy and sexuality are affected by having an ostomy as a result of CRC, we conducted in-depth, semi-structured interviews with 30 female CRC survivors with ostomies who were at least five years post-surgery. The focus of this project was on women because women's intimacy and sexuality post-CRC surgery remains an understudied area as compared to that of men's. We then explored relationships between women's perceptions of their husband's or partner's support and their global HRQOL following ostomy surgery.

Materials and Methods

In the parent study of the project reported here, we conducted a mailed survey on CRC related HRQOL in 284 long-term CRC survivors with ostomies, 117 of whom were women. Women who chose to participate in this interview study previously completed the survey. We have published details about the survey methodology elsewhere [21]. Study sites for the parent study are three Kaiser Permanente Regions: Northern California (KPNC), Northwest (KPNW), and Hawaii (KPH). The study was coordinated at the Southern Arizona VA Health Care System/University of Arizona site. The City of Hope Quality of Life for Ostomy survey provided the framework for the parent study's overall design. The thirty women interviewed for the present study were patients from either KPNC or KPNW only.

We used a comprehensive sampling strategy to identify participants for the initial survey. All colon and rectal cancer survivors (at least five years post-diagnosis) with permanent ostomies

who were identified from NCI-certified tumor registries in Kaiser Permanente Hawaii, Northern California, and Northwest during the years 2000-2006 were eligible. Members of the interdisciplinary research team collaboratively created the semi-structured, open-ended interview guide that examined issues regarding body image, gender, and sexuality in female CRC survivors with ostomies. The interview guide is shown in Table 1. The KPNC, KPNW, and University of Arizona IRBs approved all study materials and protocols.

Study Sample and Recruitment

Women were recruited from the parent CRC related HRQOL study for this project. We contacted women in waves of recruitment from each site until the intended sample of 30 was filled. We initially contacted participants by letter and then by telephone to assess their interest and eligibility. Potential participants for this study received a recruitment letter inviting them to participate in an hour-long interview to discuss how having an ostomy have affected them in terms of intimacy and sexuality. Potential participants then received a follow-up call from the second author/interviewer to confirm eligibility and interest and to schedule an interview, if appropriate. We used electronic medical records to identify minority patients in the pool of eligible participants to ensure some degree of minority representation among research participants. We also focused our recruitment on younger women (< 60 years of age) to ensure a wide variety of experiences would be represented. Because the study was descriptive in nature, and the aim was to generate rather than test hypotheses, we recruited respondents to represent as full a range of patient experiences as possible.

Measures and Qualitative Analysis

Participants were interviewed in either their homes or local medical facilities depending upon their preferences. Women received a \$25 gift card to thank them for their participation in the interview. Interviews were audio taped or digitally recorded and transcribed verbatim by a professional transcription service. At least two authors independently reviewed and coded each transcript for major themes. The first, second, third, and seventh authors each coded the transcripts independently, and then met as a group to discuss the different sets of coding. Codes addressed issues such as medical problems, diet, body image, ostomy care, sexuality, the nature of relationships with spouses, and sense of self and femininity. When coding disagreements arose, these four authors discussed the responses and came to consensus on the most appropriate codes for each response. The research team came to consensus that sufficient diversity of experience had been explored after 30 interviews.

Based on the initial coding of the interviews, it became apparent that throughout individual interviews, married women, or women in long-term, non-married relationships, described husbands or partners in one of three general ways: giving positive psychosocial support, withdrawing support and/or leaving the relationship, or a mix of support and withdrawal of support at different times in the relationship. We then assigned each of the 22 interviews with married or partnered women a global code of positive, negative, or mixed regarding husband/partner support. We coded interviews as positive when women reported men's emotional and/or instrumental support as being central to their psychosocial adjustment. We coded interviews as negative when women reported that men were particularly negative in their behavior toward them after surgery and/or left the relationship. We coded interviews as mixed when women reported that men's behavior had both positive and negative components regarding their adjustment.

Measures and Quantitative Analysis

We calculated an individual, global HRQOL score for each survey respondent. The City of Hope Quality of Life-Ostomy (COHQOL-Ostomy) questionnaire consists of socio-demographic items, as well as scaled and non-scaled HRQOL-related items. Using the City of

Hope four-dimensional framework [22], the COHQOL-Ostomy questionnaire provides scale scores for the following quality of life domains: physical well-being (11 items), psychological well-being (13 items), social well-being (12 items), and spiritual well-being (6 items). In addition, an overall HRQOL score can be calculated by combining these domains. Once we calculated a global HRQOL score for all survey participants, we divided the scores into lowest to highest quartile scores. We then compared each interview respondent's global HRQOL survey quartile score (lowest quartile, second lowest quartile, second highest quartile, highest quartile) to their global qualitative code of positive, negative, or neither positive nor negative regarding husband support.

Results

The response rate to the initial mailed HR-QOL survey was 52%. The median age of female survey respondents was 74; years since diagnosis was 12 and years since surgery was 11. We contacted 73 female survey respondents for the interview study, and 30 were interviewed (41% response rate). Non-respondents stated that they did not have the interest or time to participate, or could not be reached during phone follow-up. The second author interviewed 19 women in Northern California and 11 in Oregon. While most interview participants were White Non-Hispanic (N=22), other racial/ethnic groups were represented including Asian/Pacific Islander (N=5), African American (N=2), and Hispanic (N=1). Participants ranged in age from 44 to 93 (mean=70). All of the women interviewed were in heterosexual relationships at some point during their lives. None said they had ever been in a same-sex sexual relationship. Married or widowed women mainly reported marriages of long duration, typically 20 years or more.

Of the 30 respondents, 22 were married or partnered at the time of surgery or shortly thereafter (20 were married, 2 were partnered), and 8 were single at the time of surgery and continued in that status after the surgery. The eight non-partnered respondents are not included in this analysis. Of the 22 married or partnered women, 17 described positive or highly positive support from their husbands as being central to their psychosocial adjustment, 3 described how a lack or withdrawal of support from husbands or partners negatively affected their adjustment, and 2 described their husband's or partner's support as exerting a mixed effect (Table 2). In 17 cases, women's high (top two quartiles) or low (bottom two quartiles) quantitative HRQOL scores matched the positive or negative qualitative findings. There cases had positive qualitative data and low HRQOL scores, but each of these three women had serious current co-morbidities they discussed during the interviews that were described as negatively impacting their lives (Table 3).

Positive support from husbands

Only husbands were reported by women as giving fully positive support; no participants reported an unmarried partner giving positive support. Respondents shared that husbands provided both instrumental and emotional support, but it was the emotional, psychosocial support that was described as most meaningful as women adjusted to having an ostomy and feeling "normal" again. This positive support appeared especially apparent when women discussed their husbands' words and actions that expressed that having an ostomy did not change their feelings for their wives. For example, one woman said that her husband changed her ostomy bag on a weekly basis as a way of sharing her experience of having an ostomy, but it was his expressions of sharing and empathy that appeared most important:

"Oh, he was something else. He said, I'm gonna be part of this. I want to know what you're going through. Not many men would do that (change the bag on a weekly basis). He did. Well, he was just a part of it. He didn't go ugh...ugh, or anything like that. He just said, well, this is part of you now and I'm going to be part of it. He was a wonderful man."

What was particularly notable were the ways in which women described their husbands showing that they still loved them equally post-surgery, and that having an ostomy did not diminish their “value” as a woman:

“...my husband says, you've got a wonderful body. You always want to hide it, whatever. He has actually been very helpful with that. He really has, because I know a lot of men might turn away from it. I mean, here I've got this bag hanging from me and it's like it's not that big of a deal for him. So, he has been a big factor.”

Some husbands' very matter-of-fact language was very comforting in assuring women that they were the same people they were before having an ostomy:

“My husband was phenomenal. He just said, ‘it's just a change in the plumbing.’ But as far as the body and the stoma itself, he just finds that's just fine. He says, ‘you know, I've got you.’ So, how can you top that?”

Some women even explained that their husbands appeared to adjust to the ostomies better than they did themselves:

“My husband adjusted much better than I did, because...I was wondering how he was gonna react. I was worried about how he was gonna react to the surgery and to the colostomy. But he never seemed too worried. He adjusted really well.”

Even for women whose husbands weren't as highly supportive as the ones described above, having their husbands' support was an important aspect of their adjustment:

“Well, my husband is very good to help if I ask. He's not very good to think of it himself, but if I say I need help with this, he's right there and so he was good to do that.”

Withdrawal of support from husbands or partners

In contrast to the husbands who offered positive support, women reported that husbands or partners who withdrew their support or presence altogether experienced a negative impact on their adjustment to having an ostomy and their lives in general. These men made it clear that they no longer wanted to share their lives with the women who formerly had been their partners or wives. In the interviews, women described spouses or partners who lacked the desire and/or ability to provide either instrumental or psychosocial support once they had ostomies and left the relationships:

“Yeah. His thing was, I'm tired of taking care of you, were his words. And so, it wasn't monetarily, because I had more income than he did. I said, we're together, and...we're taking care of each other. I said, ‘I don't understand what you mean taking care of me, because you're not.’ I realize that I wasn't fulfilling the sexual part of it, but it didn't seem to bother him at the time. I had all of these physical problems, and I think that's what he was saying is all of these things combined was why he didn't want to take care of me. I needed more accommodations than he was willing to do for us. So it just wasn't working.”

The burden of caregiving, which is evident in the quotation above, is even clearer in the response below, in which the woman was already aware that should she get sick again, there would be a highly negative reaction from her partner:

“And then I told him, my cancer is back. I thought if I told him it would crush him, because he always told me if I ever got cancer again, it would just kill him. And...he took off with another woman and sold his house. He used to help me. He used to drive me to appointments and be my moral support. And he made a lot of promises to me,

so it's like I'm dealing with cancer and that loss too. I don't know, I must have been awfully bad on this earth, the Lord's getting me good."

Mixed support from husbands or partners

In these cases, women described their husbands and partners as offering some degree of support, but the level of support was less than those categorized as offering positive support. These women also described their husbands or partners withdrawing, or being somewhat supportive, but not in a fully sincere or unconditional manner:

"It (the ostomy) was a little horrifying for him. He's an older man. He was a military man, a very kind of straight-laced man. I don't know, a conservative man. I think it was hard, although he did come to the hospital when I had the surgery and we did resume a sexual relationship. I think, really, I might have gone through the surgery sooner if I hadn't been in a relationship with him and knew how much he would be opposed to the idea (of the surgery and possible ostomy) and how much he would be not able to handle it."

A younger woman who had been with her husband since she was a teenager found that having an ostomy compounded marital problems she and her husband had experienced intermittently for many years. In contrast to the married women who felt fully supported by their husbands, this woman who had been with her husband for 26 years, felt sporadic support and withdrawal of attention, but felt emotionally tied to him and had no plans to leave the relationship:

"If I had been healthy probably before all this [husband's affair] happened, then maybe I could have had the strength to leave. But it's like at this point, I wouldn't feel comfortable with anybody else...he still feels like the other half of my soul. We've been together so long, it's a comfortable relationship."

Discussion

These findings suggest that husbands' or partners' demonstration of support or lack thereof can have a considerable positive or negative impact on the psychosocial adjustment of female colorectal cancer patients with ostomies. In discussing their adjustment to their ostomy surgery that took place anywhere from 5 to over 30 years ago, these primarily older women (mean age 70 years), described ways in which their husbands' support was central to their psychosocial adjustment to having an ostomy. In discussing their husbands' support, women recalled and described support that occurred both in the immediate aftermath of having an ostomy as well as support that lasted for years after that made them feel normal and whole, and not diminished as women in their various roles.

These findings also suggest that assessment and counseling regarding the potential impact of husbands' support could be a standard element of pre-surgical preparation for female colorectal patients facing ostomy surgeries. Northouse's investigation of colorectal cancer patients and their spouses demonstrates that women, whether patients or spouses, appear to fare worse within various psychosocial domains than do men [6]. It would be important to establish if this is true for CRC ostomy patients as well, and design interventions accordingly.

It is notable that in this sample, women reported that only husbands, and not unmarried partners, provided positive support. It could be inferred that the long-term duration of most these women's marriages and the commitment implied by marriage, as opposed to a less binding relationship, provided the stability and assurance that helped these women adjust, as opposed to the women who were in less binding relationships. However, in recent work, Nichols and Reimer demonstrate the implications of any kind of long-term stable relationship for ostomy patients. Their analysis demonstrated that ostomy patients without a stable spouse or life partner

pre- and post-surgery were nearly twice as likely as those patients with stable spouses or partners to report nonpositive life satisfaction scores [23]. This finding underscores the importance of any type of long-term committed relationship. These somewhat differential findings suggest the need for further research into the dynamics of marriages versus other long-term stable relationships.

In either case, both sets of findings suggest that educational and counseling materials and interventions could be developed to teach partners or husbands skills to provide support. This would be anticipated to be especially helpful for women whose relationships might not be particularly supportive, as was evident for women whose husbands or partners withdrew or both gave and withheld support. It might also be beneficial to provide anticipatory guidance to women that psychosocial support is less likely to be provided by an unmarried partner.

The study has several strengths and limitations. As a qualitative study, there were only a small number of participants, which allowed us to explore a range of responses, and develop broad themes from which one could develop hypotheses. The predominantly older age of respondents, many of whom were involved in relationships spanning years or decades, may limit application of findings to younger women. The low response rate, although troubling, is understandable in light of the highly sensitive nature of the questions and the older age of many in the target population. However, triangulation and confirmation of the qualitative findings with HRQOL scores strengthens the qualitative findings reported here. These combined findings shed important light on the spectrum of recovery of women with CRC-related ostomies.

Additional research should be undertaken to validate these findings in a larger sample. A next step would include describing the experience from the spouses' perspectives, and developing and testing intervention programs for both patients and their spouses/significant others, as has happened for patients and spouses affected by breast [2,4,24] and colon [1] cancers. It is also important to investigate whether lesbian partners have the same effect on psychosocial adjustment, and whether individuals who have close emotional bonds but who are not spouses or partners could provide the same positive support as did husbands in this study.

A small number of participants in our study did not have husbands or partners at the time of their ostomy procedures or afterward. The possible positive effect of some sort of partner support should also be considered in this population as well. While it is not possible to arrange an intimate partner for a patient, consideration for finding others, possibly other CRC survivors with ostomies, who could provide support for a partner-less CRC survivor may be an area of future study and intervention.

This study shows that husbands and partners exert dramatic effects on psychosocial adjustment of female CRC survivors with intestinal stomas. Our findings strongly suggest that social history must be considered by practitioners in the holistic care of CRC cancer survivors. In this way, clinicians can be aware of problems and potentially improve these patients' overall HRQOL.

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Table 1
Interview Guide

Questions	Probes
1. How long ago did you have the surgery?	<ul style="list-style-type: none"> How old were you?
2. Does anyone help you with your personal care?	<ul style="list-style-type: none"> How do you feel about letting others take care of you?
3. How has having a stoma affected the way you feel about your body?	<ul style="list-style-type: none"> How would you describe your body before you had the stoma? How would you describe it now?
4. How has the surgery affected the way you think or feel about yourself as a woman?	<ul style="list-style-type: none"> How has it changed how others perceive you as a woman?
5. What does sexuality mean to you?	<ul style="list-style-type: none"> What did it mean to you before the colostomy/ileostomy surgery? What does it mean to you now?
6. How important is your sexuality to you?	<ul style="list-style-type: none"> Was it important to you before your stoma surgery? Is it important to you now?
7. How has your sexuality changed since you've had a stoma?	<ul style="list-style-type: none"> In what ways has it changed? How do you express sexuality and/or intimacy? How did you express your sexuality before the stoma surgery? How do you express your sexuality now? Have you had to make any adaptations to your sexuality/sex life/sexual repertoire since you've had the stoma? If yes, could you describe them? How important are things like cuddling, holding hands, massage, and touching for you?
8. Are you interested in expressing your sexuality at the present time?	<ul style="list-style-type: none"> If no: Is there anything you miss about sex? If yes: How easy or difficult for you to express you sexuality at the present time?
9. What kinds of physical changes have you experienced:	<ul style="list-style-type: none"> Is sexual intercourse painful? If so are there reasons why you think it is painful? (lubrication)
10. If you had a close friend or family member who was going to have a colostomy/ileostomy:	<ul style="list-style-type: none"> What advice based on your experiences would you give her/him about coping with a colostomy/ileostomy? What advice would you give them about sexuality?

Table 2
Global codes and Sub-codes

Global Code	Sub-codes
Positive support	Instrumental <ul style="list-style-type: none"> • Changing bag • General help with ostomy care
	Psychosocial <ul style="list-style-type: none"> • Displays of empathy • Assurance that still the same person/value as person • Not displaying worry • Assurances of normalcy • Assurances of beauty
Withdrawal of support	<ul style="list-style-type: none"> • Lack of demonstration of support • Diminishing level of care • Diminishing level of intimacy • Leaving relationship
Mixed support	<ul style="list-style-type: none"> • Displays of psychosocial support • Withdrawal of support • Additive to existing relationship problems

Table 3
Comparison of global qualitative coding and quantitative scores for married/partnered women

HR-QOL global quartile score → Global qualitative code ↓	1 Lowest	2	3	4 Highest	TOTAL
	N (%)	N (%)	N (%)	N (%)	N (%)
Positive	1 (4%)*	2 (9%)*	9 (41%)	5 (23%)	17 (77%)
Mixed	3 (14%)				3 (14%)
Negative	2 (9%)				2 (9%)
TOTAL	6 (27%)	2 (9%)	9 (41%)	5 (23%)	22 (100%)

* current co-morbidities present