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From diagnosis through survivorship: health-care experiences of colorectal cancer survivors with ostomies

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Abstract

Purpose—The journey from diagnosis through treatment to survivorship can be challenging for colorectal cancer (CRC) survivors with permanent ostomies. Memories of both the positive and negative health-care interactions can persist years after the initial diagnosis and treatment. The purpose of this paper is to describe the health-care experiences of long-term (>5 years) CRC survivors with ostomies.

Methods—Thirty-three CRC survivors with ostomies who were members of Kaiser Permanente, an integrated care organization, in Oregon, southwestern Washington and northern California

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participated in eight focus groups. Discussions from the focus groups were recorded, transcribed, and analyzed for potential categories and themes.

Results—Health-care-related themes described CRC survivors' experiences with diagnosis, treatment decision-making, initial experiences with ostomy, and survivorship. Participants discussed both positive and negative health-care-related experiences, including the need for continued access to trained nurses for ostomy self-care, access to peer support, and resources related to managing persistent, debilitating symptoms.

Conclusions—Long-term CRC survivors with ostomies have both positive and negative health-care experiences, regardless of health-related quality of life (HRQOL) and gender. Long-term support mechanisms and quality survivorship care that CRC survivors with ostomies can access are needed to promote positive adjustments and improved HRQOL.

Structured abstract—The current literature in CRC survivor-ship suggests that HRQOL concerns can persist years after treatment completion. The coordination of care to manage persistent late- and long-term effects are still lacking for CRC survivors living with an ostomy. Findings from this qualitative analysis will aid in the development of support strategies that foster more positive adjustments for CRC survivors living with an ostomy and support their ongoing ostomy-related needs.

Keywords

Colorectal cancer; Survivorship; Ostomy; Quality of life

Introduction

Approximately 143,000 individuals in the USA will be diagnosed with colorectal cancer (CRC) in 2013 [1]. CRC remains the third leading cancer type for all new cancer cases [1]. Treatment advances made in the past few decades have resulted in a gradual decline of CRC mortality rates, and the current 5-year relative survival rate is 64.3 % [2]. An estimated one million individuals with a history of CRC are alive today, and this group constitutes one of the largest cancer survivor populations in the USA [3]. To date, few studies have explored the needs and experiences of long-term survivors (>5 years post-treatment), particularly with respect to health-care services [4]. However, CRC survivors' health-related quality of life (HRQOL) concerns can persist years after the completion of treatment [5–7]. Published findings from our research group have found common and persistent deficits in HRQOL for long-term (≥5 years) CRC survivors with ostomies, and these survivors have persistent health-related concerns and unmet needs [8–16]. An emerging literature is documenting long-term cancer survivors' needs and experiences relating to persistent long-term effects of their cancer and treatments, and that coordination of care to manage these long-terms effects are still lacking [4, 5, 17, 18]. Responding to the care coordination needs will help in the design of patient-centered survivorship care. Toward that goal, this article describes the health-care-related experiences of long-term CRC survivors with ostomies who participated in a community-based study with focus groups.

Focus group methods

The description of the design and methods for this mixed methods study has been published elsewhere [11, 14, 16]. The overall aim of this study was to describe HRQOL in 282 long-term CRC survivors with an intestinal ostomy, using a mixed-methods approach. Survivors were members of the Northwest (Oregon and southwest Washington), Northern California, or Hawaii Regions of Kaiser Permanente (KP). KP is a large integrated care delivery system operating in eight regions of the USA. In the three regions included in this study, care is capitated, and the Kaiser Foundation Health Plan owns the hospitals, medical offices, pharmacies, imaging facilities, and laboratories used by its members. It also has an exclusive contract with the Permanente Medical Group for physicians' services.

In the questionnaire portion of the study, HRQOL was assessed using the modified City of Hope Quality of Life Ostomy-specific (mCOH-QOL-Ostomy) questionnaire [11, 14]. We formed focus groups from the questionnaire respondents to make a qualitative assessment as well as to help identify and assess long-term CRC survivors' experiences and challenges of living with an ostomy and factors that influence positive or negative adaptations, which were largely unexplored in the current literature. We chose to use focus groups because they allow and encourage participants to share and explore common experiences [14].

To determine the number of focus groups to explore these shared issues adequately, we divided potential participants by gender and quantitative QOL scores so that participants would be in a group with others of similar experiences, and thus would have common issues to share and discuss. We recruited patients with the highest and lowest quality of life scores so that we would be able to best understand the issues germane to patients who, based on quantitative questionnaire scores, reported high or low health-related quality of life, our major outcome of interest [14, 19]. Thus, this distinction helped with including participants who successfully adapted (higher HRQOL score) as well as those who experienced extreme challenges with ostomy management (lower HRQOL score). Gender was the second variable that we used to recruit for the focus groups, based on our experience that factors such as adjustment may differ by gender [14].

The University of Arizona and Kaiser Permanente Northwest and Northern California Institutional Review Boards reviewed and approved all study procedures and protocols, including focus group procedures and the written informed consent. Participants were mailed an invitation with return postage declaring their interest in attending the focus groups, and these interested individuals were subsequently contacted by research assistants with information about time and location for each focus group. All participants signed an institutional review board-approved written informed consent. Approved informed consent included assurances of the anonymity of participant's disclosures during the focus groups [14].

All focus groups were audiorecorded and transcribed. A discussion guide was developed and used to guide each focus group. The discussion guide included several questions related to health-care experiences, and they were presented in an open-ended fashion [14]. Health-care experiences-related open-ended questions included:

- After you had the surgery, which medical staff (nurses, doctors, social workers, anyone else?) was least helpful to you in learning to live with your stoma?
- What else would you have liked them to have done for you/told you?
- How has your medical system not helped with your ostomy care?

An experienced group facilitator (MG) moderated each focus group. The group facilitator used prompts for each of the open-ended questions to explore discussion topics as well as topics that arose spontaneously [14]. One research team member (RSK) served as a silent recorder for each focus group, and he documented field observations related to focus group participants' behavior and recorded statements to aid in transcription clarifications. Focus groups lasted for about 2 h in order to provide sufficient time for discussions.

Transcripts review and analysis

Qualitative data derived from each of the eight focus groups were transcribed into text and analyzed using HyperRESEARCH™. Investigators experienced in qualitative analysis (Sun, Grant, Krouse, and McMullen) independently reviewed all focus group transcripts to identify potential categories and themes. A QOL framework was used and included the following domains: physical well-being, psychological well-being, social well-being, spiritual well-being, ostomy-specific content, and health-care issues. This paper describes qualitative findings from the health-care-related issues domain only. A second, separate group of investigators conducted a final validation review of the themes to ensure consistency and clarity. Investigators discussed discordantly coded data (10–15 %) for refinement and consensus, and a unanimous decision was made by the entire group for all discordantly coded data [14].

Results

A total of 33 survivors who completed the QOL questionnaire survey took part in one of eight focus groups (16 women and 17 men). The sociodemographic and clinical characteristics of these 33 survivors have been published elsewhere and are summarized below [20]. The mean ages for the focus groups' participants ranged from 63 to 76 years. On average, the survivors were 8 to 19 years past their actual cancer diagnosis. They were primarily Caucasian, had either a high school or college degree, and were retired. Five prominent themes (diagnosis, treatment decision-making, treatment initial experience with ostomy, and interaction with providers) emerged. Overall, there were no differences in the qualitative findings by HRQOL score or gender, on health-care experiences except that there were more comments from the lower HRQOL quartile groups related to treatment toxicities. Representative quotes related to health-care experiences across the cancer trajectory are shown in Table 1.

Diagnosis

In general, comments related to the survivors' experiences at diagnosis were confined to how the cancer was discovered and how the diagnosis was communicated to the survivors.

The detailed descriptions of the events surrounding the discovery and diagnosis of the tumor suggest that even after many years the memory of the experience was still vivid.

Treatment decision-making and treatment-related toxicities

Survivors discussed treatment decision-making, treatment toxicities, and initial experiences with having an ostomy. The treatment decision-making process, as several survivors described it, was an intense time they focused on getting the recommended treatment as quickly as possible. Survivors perceived that there was no time to lose, and therefore there was no time to learn about and make an informed choice. In the area of decision-making about treatment, focus group participants talked about desiring a sense of control over the decision-making process. For example, one survivor said, “So, I had everybody I know check out who was the best surgeon.” Participants said that positive interactions with their physicians, such as being told the history of the type of surgery planned, provided a sense of control. Being given information on what to expect during and following treatment was also helpful. Survivors described having lingering doubts about whether they had made the right choice in terms of treatment, and some sought confirmation with their physicians as to whether they had “made the right decision.”

The treatment decision-making process, as several survivors described it, was an intense time they focused on getting the recommended treatment as quickly as possible. Survivors perceived that there was no time to lose, and therefore there was no time to learn about and make an informed choice. In some situations, the decision-making was swift because the physician recommended surgery right away. In these intense moments, survivors reported that they just “went along with it.” In other situations, surgery may not have been warranted, but the survivors insisted on having the cancer “taken out,” as they believed that this was the only way to know that the cancer was “gone.”

Narratives related to treatment toxicities were also common. Survivors described the negative consequences of treatment-related toxicities, mostly from chemoradiation or adjuvant chemotherapy. They spoke about common toxicities such as fatigue, weight loss, diarrhea, bowel obstructions, and peripheral neuropathy. Survivors noted the debilitating effect of fatigue on daily activities, as one survivor described, “You’re just weak…you’re weak, you’re shaking and your whole world just fell apart.” They also described how the treatments affected other comorbidities or resulted in other complications, such as making osteoporosis worse, or being “thrown into menopause” at an earlier age.

Initial experience with ostomy

Survivors described their initial experiences of learning how to live with an ostomy, including initial teachings about ostomy self-care following the surgery, teaching “failures,” home visits, peer education, and accessing the internet and ostomy association newsletters. Survivors recounted both positive and negative experiences while learning to manage their ostomies. Positive experiences were largely related to interactions with helpful and experienced nurses, and survivors talked about the importance of having experienced nurses who taught them how to manage an ostomy. Almost all narratives related to negative learning experiences involved interactions with a nurse who “did not know how to do it.”

These negative experiences were frustrating for survivors, and most importantly they did not help make the adjustment easier. In these initial encounters, survivors also described how they did not know what questions to ask or who to ask about managing their ostomies. Although some survivors went to the internet to research information on ostomy care, they found that most information on the internet was basic, and did not give them the “little tricks of the trade” that make ostomy self-care successful. Survivors also endorsed the value of having peers provide education and share their own experiences with what types of ostomy equipment that worked or failed.

Survivorship

Focus group participants described interactions with providers, seeking support through community resources and long-term ostomy care in their comments about health-care experiences during the survivorship phase. Some described poor communication experiences with providers who lacked “people skills.” Others described being cared for by new providers who were not familiar with the survivors’ cancer history and were not aware that the survivor had an ostomy. Survivors continued to seek information about ostomy care throughout the years, but found that judging the quality of the information was challenging. Others talked about resisting changes to the type of ostomy products they used because they had grown accustomed to their current appliances. Survivors also found resources such as support groups helpful in their long-term adjustment.

Discussion

In this study, we explored the health-care experiences of long-term CRC survivors with ostomies. We found that CRC survivors expressed common health-care needs regardless of gender or their long-term HRQOL outcomes. Highly charged, detailed description of the diagnosis phase suggests that a cancer diagnosis is a vividly remembered event for survivors. The memory of the events surrounding a cancer diagnosis can be recounted vividly by survivors years after the initial disclosure. Current research exploring the psychological impact of a cancer diagnosis suggests that the diagnosis phase results in enormous psychological distress for patients and their families, where fear of death, anxiety, and uncertainty can be prevalent [21–24]. Our research suggests that, at least for CRC survivors with ostomies, the long-term impact of early communications and health-care interactions during diagnosis should not be overlooked.

The cancer treatment phase involves the decision-making process for selecting the best treatment option as well as receiving the selected treatments. There is a growing emphasis on the need to include patients in the decision-making process and provide them with the information necessary for them to actively participate in the process. For CRC survivors with ostomies, the decision-making process for treatment also involves discussions related to the pros and cons of living with a permanent ostomy. In general, CRC survivors in this analysis described the importance of having a sense of control over the decision-making process. Studies have shown that cancer patients who perceived they had good communication with physicians, and had adequate information, had better experiences with treatment decision-making [17, 25]. Our CRC survivors also described the importance of having adequate support during their initial experiences with an ostomy. Our previous research shows that effective solutions to ostomy care, such as positive interactions with ostomy nurses and having access to peer ostomates, are important for CRC survivors living with permanent ostomies to make positive adjustments [15, 16]. Although we acknowledge that not all nurses are trained to teach ostomy self-care, all nurses should be aware of resources that help CRC survivors with learning how to manage their ostomies. Health-care providers should be aware of the importance of adequate support and teaching in assisting CRC survivors to adjusting to life with an ostomy.

The need for comprehensive care that can fully address long-term survivorship issues has been the subject of numerous reports and recommendations from the NCI, the National Coalition for Cancer Survivorship (NCCS), the Institute of Medicine (IOM), and the American College of Surgeon’s Commission Cancer [26, 27]. In its new report on delivering high-quality cancer care, the IOM recommends that care teams should collaborate with patients to develop care plans that reflect patients’ needs, values, and preferences [28]. A primary goal of comprehensive survivorship care is to improve care coordination and communication for cancer survivors following treatment completion. Implementation of the recommendations should result in more patient-centered care and improved patient-centered communications [28, 29]. Our findings suggest that CRC survivors’ concerns may be more focused on ostomy care, which points to the need for the development of disease-specific survivorship care programs that can address the specific care needs of CRC survivors’ with ostomies. Currently, there is a lack of evidence-based survivorship care that focus on the unique needs of long-term CRC survivors with ostomies [30]. As suggested by our findings, survivorship care should also include ongoing assessment or re-evaluation by a trained ostomy nurse and having access to peer support. Providing information about survivorship care for CRC survivors with ostomies could potentially foster more positive adjustments to living with an ostomy and support their ongoing ostomy-related needs.

Limitations of the present study included the lack of wide racial/ethnic or cultural diversity within the study population and the small subset of survivors who participated in the focus groups; thus, findings may not be generalizable. Further research is needed to replicate the findings in a more diverse population of CRC survivors with ostomies.

Findings from the current analysis provide valuable information for health-care providers who routinely care for CRC survivors with ostomies. Descriptions by CRC survivors regarding their health-care experiences from diagnosis to long-term survivorship have revealed specific needs that must be addressed from diagnosis through survivorship. Most importantly, CRC survivors are also in need of adequate support and communication in both primary and oncology settings during survivorship, specifically the need for support mechanisms that can foster positive adjustments and adaptations to life as a cancer survivor living with permanent ostomies.

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Table 1

Selected quotes related to health-care experiences

Theme	Selected quotes
Diagnosis	The doctor just looked at me. And I'm telling you that, if it wasn't for him, I'd probably be gone by now. And I'll never forget he said this. He told the nurse, he said, "Something's wrong with her." So the nurse got me on a gurney. So he did the rectal, and I'll tell you from there is where my story started. That doctor barely put his gloved hand, you know, one finger in my rectum, and I could feel something happen, and I was so embarrassed. I figured it was stool. So he said to me, "what you feel here, it's not what you think it is. It's blood. I just touched something, just barely, with the tip of my finger, and it ruptured. And I'm taking you personally on this gurney to the surgical room, and we're going to see what you have down there."
	I was going to bed after watching the 11:00 news. Maybe about 10 min before the end of the program, I could feel that I had to go to the bathroom. As far as I remember, I didn't even touch the seat, but just as I was lowering myself, all this blood rushing out. At the emergency room I had the urge to go again to the bathroom. They took me up and wanted me to stay for the night. So I was there taking all those tests for, I think it was, 5 days. They came back, and it was just that one spot.
	I come from a family where there's a history of cancer. My mother and sister both died in their fifties. I was sixty-two with a black cloud over my head. I noticed blood in my stool 1 day. I couldn't see my doctor for a couple of weeks. The next day I still had more blood and I had a friend who was a surgeon. So I called him and he said, you get down to my office tomorrow. So I went down. Anyway, I saw it so early because it was so close to the rectum.
	I had a requisition to go get a sigmoid—and I was hesitating to go—my own fault. I was busy taking care of my mother and my daughter. My daughter's disabled, and my mother had Alzheimer's. And I put it off, which was my own fault. So, they could tell right away, when I had the sigmoid, that I had cancer.
	I had just turned 50 and I just had had trouble off and on for several years of bleeding off and on. And then I had gone to a surgeon, just a couple of years before they found the cancer and they said they couldn't find anything. And then I got to where it was just bleeding all the time and I went back and they were able to find it.
	Mine was a fluke, just thinking I had one thing and actually found out it wasn't that, it was something totally different. And asking a question and having a doctor that actually cared enough to send me for more stuff.
Treatment decision-making	When they say you're going to get this surgery—you're going to have this surgery right away. You want it tomorrow or the next day—you really have no time to think if you really need surgery.
	I went in on a Friday, and they said they needed surgery from me on Monday. And I didn't feel there was any reason not to have it, because my back was to the wall at that point. So from there, I just went with it, and I've gone with it ever since, and I have no problem with it.
	What I did was I had looked into physicians—what I know about medicine that says that there are some doctors who are better than others. They're not all the same. So, I had everybody I know check out—checked out who was the best surgeon.
	The surgeon kind of indicated it was easier to do surgery before the radiation had caused scar tissue. So we had surgery, and then following that was radiation and chemo at the same time.
	They probably wouldn't have had to do that surgery, but I opted for that even though he said, well, I probably get chemo and radiation and stuff, but with my family history, I said, take it out. I've never been sorry.
	I don't think anybody meant any harm by postponing. I think they really thought they could put me back together without resorting to that. Nobody knew; I don't think you can always know everything. Of course, on the other hand, when he put me back together, and I woke up, and I didn't know if I had a colostomy, I said, "Do I have a bag?" …. they tried to put me back together twice without resorting to it. And they thought they were doing the right thing. And this was one of the cases where you really couldn't do that—then I can say I didn't have any control.
	It was starting already to travel into the muscle wall. I asked him later, did I make the right decision? And he said, there's really no way to know. There's no way to know how long you've had this. There's no way to know if it was, but the only true point of knowing it's gone is to remove it. So the only choice I thought I had at the time was that.
	I had a doctor tell me the history of my surgery. He said it was done in 1917—and it really sounded good to me because it might mean it's successful. And he said that when they first used it, they had to do the surgery in three-quarters of an hour or the person would die from loss of blood. And now, they take their time, and they have clamps to clamp off the blood flow and all that—so they can do a better surgery in more time. And that relieves me quite a bit—just to tell the history.
	He (surgeon) spent a lot of time with me, and he told me exactly what to expect. And, you know, he said, "This is not going to be reversible," as sometimes it is, colostomy. And he said, "You can't expect that." And he explained why and so forth.

Theme	Selected quotes
	And then eventually I had the surgery, about 10 years ago, and I've had chemo and radiation. I always thought, years ago, "Oh, the worst thing that can happen to a person medically is to have to have a colostomy. Wouldn't that be awful?!" And it's not awful at all. I'm just very grateful that I'm here.
	When the doctor called me to say it was cancerous, I kind of joked and said, "Oh, well, they're just going to cut it out and sew me back together again." "No," he said, "You're going to have a colostomy." I mean, I knew some basic things about it, but I really didn't know all the ramifications.
	They realized they were going to have to do the colostomy. I was a teacher and I just said, "Could you just wait until June?" And they said it was very slow growing, so I just asked them if they'd wait until June, until school was out—which they did. So I had it at the end of June.
Initial experience with ostomy	We had the greatest ET nurse. And sometimes I think if it wasn't for her, I would have been in a looney bin.
	Ten days later I woke up…had this thing on the side of my body and I was not too happy with what was going on, but she said not to worry about it. Before I even left the hospital, she showed me how to irrigate and to cleanse myself, and that type of thing. A couple of times we did that and then I went home and 3 days later I called her and said, HELP! So she came out to the house and we went through it again.
	Then when it was time to show me how to irrigate, this really lovely nurse brought her student nurses with her. Well, not only did she not know how to do it, but obviously they didn't know how to do it. That was a charming, charming experience. So the doctor came in the next day and said, now did you learn how to do this, this, and this? I said, I didn't learn anything. They gave up and went home, I guess. So he sent somebody else in that did know.
	They act a little embarrassed about it—the nurse that came—she acted embarrassed. And it's like, "Well, wait a minute, you're a nurse." You know? Please don't make it worse. I guess she's doing the best she can. And if you've never had any experience with it, how do you know? What do you know to tell people?
	When I came home from the hospital with the colostomy, they sent me help. She was an RN, and she would take my blood pressure. And I said to her, "What I really want to know is about colostomies." And she said, "Oh, I don't know anything about that." And I said, "Well, don't come anymore." And she said to me, "What do you care, you're not paying for it."
	I think in a perfect world, you would have a nurse who has had a lot of experience. And I think most nurses do—not all of them. At the hospital my daughter works, there's no ET nurse. But sometimes, when you want to change a product, and it's that the nurse may not be available immediately, there may be a communication problem in terms of what the appliance that you're looking for—whether it's there or not. Or you even don't know what may be available. These are things that need to be worked out, I think.
	That male nurse in the hospital. He's the one that first…showed me how to change…And it was a one-piece at the time that they had me on, which I didn't know anything other than that. But he showed me how to clean it, how to make sure it was dry before I put the ostomy part on and…if it hadn't have been for him, I probably wouldn't have been as good as I was when I went home. But the second gal that I connected with, and with the two piece system kind, said this is another way to do it. And when I connected the two-piece and put in the wafer and using the bag like a Tupperware thing, that was just totally like, why can't they have given me this to begin with? It would have been SO much easier.
	They sent me a nurse at home. But when I would ask her real practical things—like, how do I clean this thing out—I got more information from the woman who called me, who had one—who said that you have to take a big cup of water, and fill it up…You know, real practical things, like how do you clean out this thing? What do I do? I take it off and clean it out in the sink? Well, how do I clean this thing out, you know?
	It's just the availability of information. Because at the time my surgery was coming through, they didn't think it was…that they'd have to do it. But I didn't even know what it was. And the people that were around at the point, I didn't know who to ask. It was after the fact of the surgery, and even a couple of weeks after that, and one of my first checkups with my surgeon that I actually met up with the ostomy nurse. And she had a huge book and it was like, well, here's the products. But it was like, okay, what am I supposed to be doing that I'm not doing already. It was like my questions weren't totally being answered.
	When I was in the hospital, I did have a visit from somebody who just kind of stopped in and said, do you have any questions? And at the time I knew nothing to ask.
	A friend of the family had someone that she knew that had a colostomy and came in and talked to me and told me about the two piece systems, so that's what I've been using ever since.
	When I got home, after the surgery, I spent a lot of time on the internet and did a lot of research there. It gives you a lot of basic information, but it doesn't give you the little tricks of the trade. All those you learned over the course of time.
	Just the whole thing of adjusting to it—was really helpful, to have somebody who'd been through it, giving me some ideas about how she adapted to it—clothing-wise. She told me she wore jackets a lot. She gave me quite a few hints on the clothing. And it was really helpful, to have her call me.
Survivorship	And I asked the doctor later, "Do you think because we did that experimental chemo protocol that almost killed me—do you think that's what saved me?" Because the cancer was in the lymph nodes and stuff. And he said, "Oh, it's just the luck of the draw." He was a fine oncologist. He just wasn't a people person.

Theme	Selected quotes
	Well, you know what's happened with my experience is my great primary doc left. I'm on my third primary doc since the surgery, and she doesn't know me. I mean, all she knows is this healthy woman who walks in and, obviously, I have an ostomy.
	They have to study your chart once in a while. I've had doctors that I go, and they want to put a finger up my rectum. And I don't have one!
	I got into an ostomy group. It was a VERY open informative group. We had a couple of ET nurses that came in and offered help.
	There's a lot of products out there, a lot of companies. But I really didn't want to change because I'm so used to this—and I do not want to make any changes. So, I just kept with what I've got.
	There's all kinds of information there. It's just judging what's right…you've got to read it all and just evaluate it for what's going to work for you.