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Caregiving and mutuality among long-term colorectal cancer survivors with ostomies: qualitative study

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Abstract

Purpose—The cancer caregiving literature focuses on the early phases of survivorship, but caregiving can continue for decades when cancer creates disability. Survivors with an ostomy following colorectal cancer (CRC) have caregiving needs that may last decades. Mutuality has been identified as a relationship component that can affect caregiving. This paper discusses how mutuality may affect long-term ostomy caregiving.

Methods—We conducted semi-structured, in-depth interviews with 31 long-term CRC survivors with ostomies and their primary informal caregivers. Interviewees were members of an integrated health care delivery system in the US. We used inductive theme analysis techniques to analyze the interviews.

Results—Most survivors were 71 years of age or older (67%), female (55%), with some college education (54%). Two-thirds lived with and received care from spouses. Caregiving ranged from minimal support to intimate assistance with daily ostomy care. While some survivors received caregiving far beyond what was needed, others did not receive adequate caregiving for their health care needs. Low mutuality created challenges for ostomy caregiving.

Conclusions—Mutuality impacts the quality of caregiving, and this quality may change over time, depending on various factors. Emotional feedback and amplification is the proposed

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Compliance with Ethical Standards

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Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

I have full control of all primary data and agree to allow the journal to review the data if requested.

mechanism by which mutuality may shift over time. Survivorship care should include assessment and support of mutuality as a resource to enhance health outcomes and quality of life for survivors with long-term caregiving needs and their caregivers. Appropriate questionnaires can be identified or developed to assess mutuality over the survivorship trajectory.

Keywords

colorectal cancer; ostomy; caregiving; mutuality; emotional amplification

Introduction

Just as having cancer can have profound emotional, if not existential effects on individuals [1-3], so too can cancer caregiving impact a dyad, most often a married couple [4-6]. As Dumont [7] points out, caregiving often is a multi-faceted endeavor that can entail both instrumental and affective support. Over the past decade, the cancer caregiving literature has grown as patients' and partners' needs and quality of life (QoL) have become a focus of concern [8-11]. Numerous researchers have designed interventions to improve the situations of couples undergoing the stress of cancer diagnosis and ongoing treatment [12-14].

Long-term colorectal cancer (CRC) survivors who require a colostomy or ileostomy as part of treatment are a somewhat unique population regarding caregiving. Having an ostomy,¹ that is, the exteriorization of the large or small intestine to the abdominal wall, does not necessarily require any ongoing caregiving. However, certain physical capabilities, such as manual dexterity, eyesight, and balance are key to successful ostomy management. When such abilities and function diminish with age or illness, ostomy care can be more easily accomplished as a two-person task [15-16]. If the need for ostomy related caregiving lasts for years, and possibly the rest of a survivor's life, long-term caregiving can be complicated by the fact that it involves intimate body functioning. For these patients, stool is highly visible, frequently with an attached odor and thus crosses the taboo of "matter out of place" as conceptualized by anthropologist Mary Douglas in her discussion of how what each society considers "unclean" is deeply reflective of that society's overall cultural norms. [17]. As the number of cancer survivors in the population aged 65 and above grows larger [18], the issue of caregiving for older CRC survivors with ostomies, as well as older cancer survivors generally, becomes increasingly salient.

In contrast to individuals who receive long-term caregiving for dementia or Parkinson's disease, CRC survivors with ostomies may regain their overall health status. After a period of postoperative recovery, being a cancer survivor with an ostomy does not de facto change one's overall physical and/or mental capabilities. However, the survivor with an ostomy is a changed person in both having had cancer and in having had their body radically transformed in its anatomical functioning and appearance. In our previous work, we have explored the impact of this change on individual women and couples' relationships [19-21]. A rich literature describes and analyzes the unique challenges and stigma associated with having an ostomy as a result of CRC or other medical conditions insofar as the process of

¹We use "ostomy" to refer to colostomy and ileostomy.

fecal elimination is transformed from a private bodily process to one that must be managed in an entirely different manner that can cause diminished quality of life [22-23, 46-49]. While the quality of couples' relationships has been examined as a factor in dyads' well-being in long-term caregiving for Alzheimer's Disease and dementia [24-25], Parkinson's Disease [26-27], and stroke [28-29], we are unaware of such an examination among a long-term cancer caregiving population.

In this analysis, we expand upon our group's previous work to explore how mutuality, the positive quality of a dyad's relationship [30], impacts the experience of caregiving for long-term CRC survivors with ostomies. Hirschfield [52] more expansively defined mutuality in this context as the caregiver's ability to maintain a positive relationship with the person she or he is caring for; find meaning in their caregiving; and perceive that their relationship with the person receiving care is still reciprocal. This conceptualization was part of the growing attention paid in nursing and social work to women's long-term caregiving in families and its negative consequences for women's health, which was commonly discussed in terms of caregiver stress, burden, or strain [53-55]. Hirschfield drew attention to the positive aspects of dyads' relationships, i.e., mutuality, which allows individuals to continue providing long-term care to loved ones and not suffer as many negative consequences as others who have less positive relationships with family members.

Based on our previous work, we were especially interested in better understanding the factors that affect why long-term survivors and their close caregivers respond very differently to the experience of living with an ostomy. For some dyads, learning to live with an ostomy is a surmountable challenge, and life resumes its course, perhaps even in an enriched manner. For others, ostomy management becomes an ongoing, if not severe problem with profoundly negative impacts [16, 20, 21]. While comorbidities and surgical outcomes affect long-term outcomes in this population [31-32], in this paper we explore relational and emotional aspects of long-term CRC survivorship and further conceptualize mutuality and cancer caregiving.

Methods

We recruited participants from Kaiser Permanente, an integrated healthcare delivery system, in Northern California and Oregon. Participants were identified by searching the organizations' tumor registries and administrative databases. All long-term CRC survivors with ostomies (five or more years post-diagnosis) living within 100 miles of the research offices (N = 307) were identified. We invited individuals to participate by mail, and then contacted them by phone for an eligibility interview. We confirmed that 105 survivors met inclusion criteria which included having a permanent ostomy, receiving at least one hour of unpaid caregiving of any kind per week because of a health problem or functional impairment, and had no exclusion criteria: cognitive, speech, or hearing impairments that would preclude participation in an in-depth interview. If participants were found to be eligible and decided to enroll in the study, they answered questions regarding their impairment level, relationship to their caregiver, and household status during the recruitment/enrollment phone call. We first recruited survivors, and then recruited informal caregivers, who were identified by survivors.

It was our initial intent to have a purposive sample with regard to caregiving and demographic diversity, but because of the relatively small size of the number of eligible long-term survivors, we enrolled all patients who were eligible and agreed to participate. Based on the authors' previous experience with qualitative research and published work on saturation (50-51), we estimated that 30 interviews would allow us to reach thematic saturation in this population, which we were able to achieve. Recruitment and interviews took place between Summer 2008 and Spring 2009. All study activities were approved by both Kaiser Permanente regions' Institutional Review Boards.

All patients and caregivers participated in an in-person, private, semi-structured interview that lasted about an hour, and completed a basic demographic questionnaire. The first, second, and senior authors, in addition to a research associate in Oregon conducted the interviews. The first (AA), second (PL), and senior authors (CM) are all experienced, PhD level qualitative social scientists, and the research associate had extensive experience interviewing frail, older patients in their homes for previous studies. Before the interviewing began, they all met as a group with the other authors to discuss their approach to conducting the interviews. We interviewed the dyads in two-person teams by interviewing the cancer survivors and caregivers separately in their homes. The interview guide included topics related to survivors' medical history, ostomy-related issues, needs for caregiving, and caregiving activities. All interviews were recorded and transcribed verbatim. After each interview, we wrote field notes composed of interview summaries and conceptual categories.

We managed the transcribed data and analysis with NVivo 8 software [34]. The investigator team discussed the social, caregiving, health system, and clinical issues topics that arose in the interviews during weekly phone meetings. We used inductive theme analysis techniques [35] as well as the original questions we asked participants to develop codes focusing on themes related to ostomies and caregiving and applied these codes to all interviews. We followed recommended techniques and reporting guidelines to ensure that data analysis was systematic and verifiable: consistent use of the interview guide, audio-recording and independent professional preparation of the transcripts, standardized coding and analysis of the data, and the creation of an analysis audit trail to document analytic decisions [36]. Two interviewer-investigators (different pairs for each interview) initially coded each interview, met to discuss coding, and identified disagreements. Disagreements, approximately 15%, were resolved by consensus during weekly calls. For the current paper, the first author (AA) returned to the transcripts and field notes and coded them for additional passages germane to the nature of dyads' relationships and reviewed additional coding with the senior author (CM). We developed our findings on mutuality and caregiving based on this iterative, analytic process [35, 56].

Results

Of the 105 eligible survivor-caregiver pairs, 31 (30%) participated. The remaining 70% declined to participate for a variety of reasons including failing health, or lack of time or interest. Participants represented various living situations and caregiving relationships (Table 1).

Survivors received various types of assistance, including personal care, help with household tasks, and driving and managing finances. About half the survivors received no help with ostomy care, and 75% of these survivors lived with non-spouses or alone. Seventeen of the 21 survivors living with spouses received ostomy-related care of some kind. Survivors and caregivers reported a range of caregiving from minimal support, such as assistance with laying out supplies needed for routine ostomy care, to daily ostomy care which can involve emptying the fecal contents from the ostomy bag. When survivors required help with daily ostomy care, it was mainly due to stoma-related hernias, poor vision, obesity, poor manual dexterity, cognitive impairment, and weakness. This range of caregiving illustrates both quality of the dyads' relationships and severity of the survivors' health conditions. As we have done in other analyses, we turned our attention to dyads that demonstrated congruence versus incongruence in the constructs we were seeking to understand – in this case, mutuality and caregiving related to their ostomies. In the following paragraphs, we provide examples of these constructs relating to mutuality and caregiving.

Low caregiving need, high mutuality

For example, there were survivors who received caregiving but didn't require it from a functional point of view. There were eight cases in which the survivor suffered no infirmity as a result of their ostomy or overall health status, but their partner provided on-going ostomy care. This care was given in two ways – by helping with preparation for ostomy care, for example, making up daily ostomy care packs containing cleansing wipes, or minor assistance in helping place the device on the survivor's stoma two times a week. In these cases, survivors were sometimes still in the workforce, or if retired, reported living full lives not impacted by having an ostomy. Each member of the dyad, always a married couple, reported that while undergoing the experience, if not horror of cancer surgery and recovery was some degree of challenge, the experience actually served to make their bond stronger, and make them realize their love and appreciation for one another. We characterized these couples as having high mutuality and low functional need for caregiving. In speaking about her already retired husband as caregiver, one woman in her early 60s who was still working full-time, responded:

Q Does that sort of follow through the rest of your relationship? Is he the main caregiver?

A Yeah. Definitely. And I think that makes it (having the ostomy) easier for me, because you know, I'm still a little self-conscious...having it. And, you know, I live with it every single day.

And so I think it makes you closer, that he understands it.

Q And it's so interesting, because with the self-consciousness, a lot of people keep it private, and they don't want the partner to see.

A Yeah. I could see how that could happen. But I think it makes you closer. I mean, if you can.

In describing how caregiving has affected their relationship, one man in his early 70s reported the following regarding his wife, who also was in her early 70s:

Q What are some of the good things that have come from taking care of (your wife)?

A Probably a realization of how important she is to me. I don't know if you'd say that it's made us closer, but we probably appreciate each other more. That's the best I could put it. I don't complain as much about her watching football and basketball. Oh, I probably complain about basketball, but that's just a nonsensical activity. (Note: This couple did not conform to gender stereotypes regarding sports.)

High caregiving need, low mutuality

In contrast, there were six dyads in which survivors were clearly in need of more help with ostomy care than they were receiving. In these cases, survivors and caregivers discussed the ways in which there currently was a negative impact on their relationship as a result of intensive caregiving. In these dyads, two of which were long-married couples, both survivors and caregivers reported problems with ostomy care. Problems included skin break-down at the ostomy site caused by the survivor's and/or caregiver's inability to manage ostomy care themselves. In these dyads, unmet caregiving needs often were compounded by fairly severe comorbidities such as Parkinson's Disease and stroke sequelae. For example, several survivors had problems with their ostomy bags regularly leaking. This problem caused them to be homebound to varying degrees to prevent the embarrassment of fecal matter draining out of their ostomy bag in public. For these survivors and caregivers, QoL was negatively impacted by the ostomy. We characterized these dyads as having low mutuality and high functional need for caregiving. The following quotes from a married couple, in their mid-70s, in which the wife is the survivor (first quote) and the husband is the caregiver demonstrate this dynamic:

A ...that's had me concerned when he gets a little bit upset. You know, he's with me all the time, and he gets a little bit angry at times, with me. He thinks that I should do more than I do, but I can't, I just can't. So, that's very hard. And it's hard for him also.

Q Does it just happen [that husband gets upset]?

A Yes, it just happened, and that's it. And I talked to the doctors about that too. And of course, I talk to my children about it, and they understand. They think that he needs some more time to himself, so they would like us to have somebody in the house every day, but I can't—we can't afford that, so that is out of the question.

From the husband's perspective:

A Well, I have—I think I mentioned to you—I have a bit of a temper, short fuse... And I—there are times I feel like a dog a little for the way I've spoken, or yelled and stuff like that. I get... It's one of those things, I... I'll do anything I can for my wife, but sometimes, it really—I lose my temper. I lose my cool, as they say—if I ever had any. And my kids are concerned about that... You know... It's difficult for my wife, and it's difficult for me—

there's no doubt about it. She says, "I wish you didn't have to do this." And I say, "Well, you know, I'm here, I want to do it." I want to help her any way I can. But it gets frustrating, especially when we have an accident. That's frustrating as hell.

Low caregiving need, low mutuality

There were dyads between these extremes of health status and caregiving who reported less polarized relationships. In some cases, there wasn't a current need for ostomy caregiving, but if such a need arose, both survivors and caregivers anticipated that they could face difficult situations as described above. One woman in her mid-50s who was losing her eyesight anticipated needing ostomy help in the future from her husband, also in his mid-50s:

Q ...is (your husband) resistant about helping with your ostomy?

A No, in fact, he says he wants to help me. He wants to be a caregiver.

Q Oh, that's great. So he's not at all resistant.

A He might be a little—let's see. How would I say this? I don't know that he knows how to be compassionate...He's learning very slowly, and I guess I'm hoping that, by the time I really do need help, that I will have trained him well enough, not just to do the physical things, but to be there for me emotionally.

Q In terms of ...?

A Just the emotional support. And maybe I'm wrong.

Similarly, a daughter-in-law in her mid-50s spoke about existing tension with her mother-in-law who was in her early 80s that could make ostomy care difficult in the future:

(There's)... a level of comfort that also invites friction more so now than... if my husband and I lived in another state. Those few occasions that we would see her—would be in that sort of formalized, family way. Whereas now, the dirt all comes out, and there are times when the conversation builds to a level of annoyance or irritation, and so that happens.

High caregiving need, high mutuality

In our sample, no participants described currently having this level of need and mutuality related to ostomy caregiving. However, nearly all the dyads spoke of these levels during the post-operative period when they were adjusting to the radical changes brought about by colorectal cancer surgery followed by permanent ostomy placement.

In summary, while some survivors had low functional needs for caregiving, they received caregiving far beyond what was needed. In these cases, survivors' overall good health, and lack of serious caregiving need served as a means to deepen and improve relationships. Conversely, others who had significant caregiving needs did not receive all the caregiving that was indicated, and such situations were often made more problematic by negatively

charged emotions that resulted because of survivors unmet caregiving need. Relationships that could be characterized as having low mutuality, often as a result of intensive caregiving, appeared to create challenges for caregiving, especially if the caregiver was not the spouse of the survivor. Conceptually, it is possible to see the end-points of a mutuality continuum and their relationship to caregiving need as a two by two table (Table 2):

Conclusions

This analysis supports previous findings that surviving cancer can enhance or diminish QoL and meaning in one's own life [1-3], and extends findings particular to long-term CRC survivors with ostomies and their caregivers. That is, these findings suggest that survivors in high mutuality relationships who do not need care related to their ostomy may benefit emotionally from caregiving that is not medically necessary. But others, who have functional limitations and are in low mutuality relationships, may suffer from a lack of caregiving related to ostomy needs. This caregiving need and low mutuality may then be intensified and reinforced as relationships are strained by ongoing caregiving. This amplification of caregiving need and low mutuality seemed more evident among people who received care from non-spouses, but receiving care from a spouse did not seem to assure that needed caregiving was always provided in a loving, positive manner.

This caregiving-mutuality amplification cycle that can affect how mutuality may increase or decrease over time can be illuminated by Hallett's concept of emotional feedback and amplification [37]. According to Hallett, "ongoing interactions provide the means for the situational evolution of emotions, for the increasing development of emotions through a process of feedback and amplification." This conceptualization frames how emotions develop and change in the context of social interactions over time. Mutuality provides a conceptual framing for the affective nature of a dyad's relationship. Emotional feedback and amplification conceptualizes the mechanism by which mutuality may increase or decrease over time, depending on the changing course of interactions, and provides the means by which mutuality can be seen as a fluid dynamic, rather than a static characteristic of dyads' relationships. In describing the nature of their relationships, interviewees demonstrated how ongoing interactions around caregiving may serve as feedback and amplify positive and negative emotions and thus may increase or diminish a dyad's mutuality over the course of long-term cancer caregiving, and perhaps, the quality of caregiving given and received.

While Hallett's work is based on emotion management in the workplace, the notion of a situational evolution of an individual's emotions in a particular role is germane to this most intimate of caregiving relationships. Hallett notes that "interactions provide an additional stimulus that feeds back into the initial emotion, amplifying it." (p. 705) Hallett's conceptual framing that ongoing interactions can serve to amplify emotions, thereby making the positive better, and the negative worse, can also apply to dyads in the context of ostomy care, or any kind of caregiving. Thus, if dyad members, especially in the context of a long-standing marriage, have relatively good health, love for one another, low need for care, and manageable medical and surgical outcomes, they may be more likely to have positive interactions in their caregiving. Such positive interactions and emotions may be likely to reinforce and amplify over time, which can improve and deepen the quality of their

relationship. If a dyad is not a married couple, or a married couple with a less positive emotional relationship, and the patient has problematic issues related to their ostomy, interactions may deteriorate and become problematic over time, both emotionally and in terms of the caregiving needed by the survivor. This concept of amplification could help inform a more robust conceptualization of cancer caregiving's long-term trajectories framed in terms of the impact of stress upon emotional relationships [38].

These qualitative findings could be the basis to generate hypotheses for future studies on cancer caregiving. Because many people with caregiving needs are not in relationships with high levels of mutuality, such unmet caregiving needs could be better addressed by the growth of survivorship care planning [39-41]. Initial survivorship care could include assessment and support of mutuality as a resource that can enhance QoL and adaptation over time for all survivors with long-term caregiving needs and their caregivers. Survivors and their presumed caregivers could complete standardized questionnaires that would indicate the degree of congruence regarding mutuality. Results from such questionnaires could alert practitioners to a possible need for intervention. Questionnaires such as the Decision Making Involvement Scale [42], or the Care Values Scale [43] may be good instruments to assess mutuality. It also might be beneficial to use a questionnaire focused simply on mutuality, and not mutuality within the context of caregiving [44].

Assessments could take place periodically in the survivorship trajectory to measure possible changes and new needs for support or intervention. Changes in survivors' and caregivers' health status and other life event changes could affect the caregiving dynamic and negatively impact survivors' (and caregivers') health status and QoL. For survivors who are found to have primary relationships with low mutuality but high caregiving needs, home health interventions could be designed to address survivors' caregiving needs. Additionally, appropriate psycho-educational and/or mental health referrals could be made to assist survivors and caregivers more effectively cope.

This study has strengths and limitations. Our sample was predominantly white, non-Hispanic, so may not reflect situations of all CRC survivors and caregivers. However, one research team has suggested that cancer caregiving may constitute its own cultural construct and not be bounded by race/ethnicity [45]. As a qualitative study, our sample was relatively small, non-random, had a low recruitment rate, and therefore is not generalizable. However, our open-ended interview guideline allowed participants to share concerns and issues in a way that is not possible with quantitative assessments. Additionally, our sample included survivors from across the income and education continuum. Our findings also suggest further avenues for research with testable hypotheses and possible strategies for long-term cancer survivors' and caregivers' support.

Colorectal cancer survivors with ostomies face a range of possible outcomes – some of which may require no caregiving at all, while others may require intensive assistance. Over time, existing emotions and behaviors between survivors and caregivers may become amplified in a kind of feedback loop that can improve positive interactions and intensify those that are problematic. This conceptualization could assist survivors, caregivers, and clinicians to improve medical and QoL outcomes for survivors and caregivers. Such

acknowledgement could pave a way to more accurate anticipatory guidance and intervention over the survivorship trajectory for CRC survivors with ostomies and their caregivers, or for that matter, any dyad facing long-term caregiving.

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Table 1

Demographics

| | Survivors N=31 | Caregivers N=31 |
|--|-------------------|--------------------|
| Age | | |
| 45–70 | 10 (32%) | 16 (52%) |
| 71–84 | 15 (48%) | 10 (32%) |
| 85 or older | 6 (19%) | 2 (6%) |
| Missing | 0 | 3 (10%) |
| Female | 17 (55%) | 22 (71%) |
| Caucasian | 27 (87%) | 26 (84%) |
| Household income | | |
| 30,000 or less | 6 (19%) | |
| 30,001–50,000 | 7 (22%) | |
| 50,001–75,000 | 7 (22%) | |
| 75,001 or more | 5 (16%) | |
| Missing | 6 (19%) | |
| Education | | |
| High school, GED, vocational school, or less | 13 (42%) | 5 (16%) |
| Some college | 11 (35%) | 17 (55%) |
| Some graduate school | 6 (19%) | 5 (16%) |
| Missing | 1 (3%) | 4 (13%) |
| Impairment level | | |
| Needs help with activities of daily living (ADL) (e.g., bathing, dressing) | 18 (58%) | |
| Needs help with instrumental ADL (e.g., driving, preparing meals) or ostomy care | 13 (42%) | |
| Received ostomy care | 17 (59%) | |
| Received ostomy care only (subset of group above) | 5 (16%) | |
| Household status | | |
| Lives with spouse | 21 (68%) | |
| Lives alone | 5 (16%) | |
| Lives with non-spouse | 5 (16%) | |
| Caregiver relation to patient | | |
| Spouse | | 21 (68%) |
| Child | | 2 (6%) |
| Other relative | | 6 (19%) |
| Not related | | 2 (6%) |

Table 2

Effect of mutuality on long-term ostomy caregiving and relationships

| | Low mutuality | High mutuality |
|----------------------|--|--|
| Low caregiving need | Minimal caregiving; quality of relationship stable or deteriorates | Caregiving needs fulfilled; quality of relationship improves |
| High caregiving need | Caregiving needs tended to at minimal to basic level; quality of relationship stable or deteriorates | Caregiving needs fulfilled; quality of relationship stable or improves |

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