Published in final edited form as:

Support Care Cancer. 2014 September ; 22(9): 2401–2408. doi:10.1007/s00520-014-2194-3.

Caregivers as Healthcare Managers: Health-Management Activities, Needs and Caregiving Relationships for Colorectal Cancer Survivors with Ostomies

Carmit K. McMullen, PhD¹, Jennifer Schneider, MPH¹, Andrea Altschuler, PhD², Marcia Grant, RN, PhD³, Mark C. Hornbrook, PhD¹, Petra Liljestrand, PhD², and Robert S. Krouse, MD^{4,5}

¹The Center for Health Research, Kaiser Permanente Northwest, 3800 N. Interstate Ave., Portland, OR 97227

²The Division of Research, Kaiser Permanente Northern California, 2000 Broadway, Oakland, CA 94612

³City of Hope Hospital and Medical Center, 1500 East Duarte Road, Duarte, CA 91010

⁴Southern Arizona VA Health Care System, Surgical Care Line 2-112, 3601 S. 6th Ave., Tucson, AZ 85723

⁵University of Arizona, Tucson, AZ

Abstract

Purpose—While the burdens and rewards of cancer caregiving are well-documented, few studies describe the activities involved in cancer caregiving. We employed a social-ecological perspective to explore the work of cancer caregiving for long-term colorectal cancer (CRC) survivors with ostomies. We focused on healthcare management, defined here as the ways in which informal caregivers participate in healthcare-related activities such as managing medical appointments and information, obtaining prescriptions and supplies, and providing transportation to obtain healthcare services.

Methods—This ethnographic study included 31 dyads consisting of long-term CRC survivors (>5 years post-surgery) and their primary informal caregivers. Survivors were members of integrated healthcare delivery systems. We interviewed participants using in-depth interviews and followed a subset using ethnographic methods. Medical record data ascertained survivors' cancer and medical history.

Results—We classified families into a matrix of healthcare management resources (high vs. low) and survivors' healthcare needs (high vs. low). We found that patients' healthcare needs did not always correspond to their caregivers' management activities. CRC survivors with high needs had more unmet needs when caregivers and survivors differed in the level of caregiver involvement

Corresponding Author: Carmit K. McMullen, PhD, The Center for Health Research, Kaiser Permanente Northwest, 3800 N. Interstate Avenue, Portland, OR 97227, Camit.McMullen@kpchr.org, 503-335-6381, 503-335-6311 fax.

Conflict of Interest

None

they desired or regarded as optimal. This discrepancy was particularly evident in non-marital relationships.

Conclusions—As cancer survivors age and grow in number, it becomes increasingly important to understand how informal caregivers support survivors' well-being. Framing healthcare management as a component of caregiving provides a useful perspective that could facilitate future research and interventions to support survivors, particularly those with significant sequelae from their cancer treatment.

Keywords

long-term cancer survivors; colorectal cancer; intestinal ostomies; caregiving; ethnography; qualitative methods

Background and Purpose

While there are 11.4 million cancer survivors in the United States, healthcare providers have limited evidence on how to manage the care of survivors living with long-term and late effects of cancer and its treatment [1]. And despite the major contribution of family caregivers in managing the health and healthcare of loved ones [2–6], researchers are only beginning to document these efforts [7], especially for those who no longer receive acute cancer treatment.

To fill these gaps in the literature, we employed a social-ecological perspective to understand the work of cancer caregiving for long-term colorectal cancer survivors with ostomies [8]. This approach differs from psychologically oriented studies that frame caregiving as a form of stress [9, 10]. Social-ecological theorists in the field of gerontology study how physical and social environments shape individuals' aging, functional status, and health. In particular, Lawton's conceptualization of the person-environment fit suggests that the proximal environment (family and household) will impact how the sequelae of cancer treatment manifest as disabilities [11–17].

Social-ecology theory is well-suited to assessing colorectal cancer (CRC) survivors with ostomies and their caregivers. CRC survivors with permanent ostomies wear a pouch system that adheres to the skin around the stoma to collect fecal waste continuously. Managing an intestinal ostomy requires pouch emptying from one to many times per day. Individuals with ostomies also must periodically remove and change the skin barrier or entire appliance. Ostomy care requires time, consistent routines, the ability to see the stoma, manual dexterity, good cognitive functioning, and physical stamina and balance. Often, ostomies require clothing modifications to avoid constrictions on the pouch system from waistbands or tightly fitted clothing. Many people with ostomies also experience profound changes in social roles, expectations, and relationships [18].

Ostomy management may pose barriers to caregiver involvement and healthcare utilization. Our research sought to elucidate the role of informal caregivers in meeting the healthcare needs of CRC survivors with ostomies. This paper explores how caregiving relationships, activities, and survivors' level of need for help can promote or inhibit caregivers from taking an active role in managing CRC survivors' healthcare and ostomy-related needs. Building

upon Janzen's concept of "therapy management" [6] and Schumacher et al.'s transactional model [19] of family caregiving, which includes navigating the healthcare system as one of caregiving's key processes, we define "healthcare management" as the ways in which informal caregivers help with tasks such as managing medical appointments and information, obtaining prescriptions and supplies, helping with daily medications, and providing transportation to obtain healthcare services (Table 2). We focused on healthcare management to elucidate how the social environment shapes treatment-related sequelae among this group of cancer survivors.

Methods

We used qualitative research methods to capture participants' experiences with caregiving activities using in-depth, semi-structured qualitative interviews along with ethnographic fieldwork with a subset of families undergoing health and caregiving transitions. While we primarily drew from the interviews for this paper, we also used notes from the ethnographic fieldwork to validate interview findings.

The Institutional Review Boards (IRBs) at Kaiser Permanente Northwest (KPNW) and Kaiser Permanente Northern California (KPNC) approved this study and its activities. We obtained written informed consent from all participants and removed identifying information from transcripts and fieldnotes to protect confidentiality.

Setting and Recruitment

We identified potential survivor-caregiver dyads by searching tumor registries and administrative databases to recruit long-term colorectal cancer survivors with ostomies. Participants were members of KPNC or KPNW. Interview questions were designed to explore caregiving through a social-ecological lens, including questions about the home environment, health history, work and finances, the quality of family and caregiving relationships and personal values. We also conducted interviews in patients' homes so that we could directly observe the home environment and any particular areas (such as restrooms) that made ostomy care or other basic activities easy or difficult. We enrolled 31 of the 105 eligible survivor/caregiver pairs (29.5%). Recruitment methods are detailed elsewhere [8].

Measures

All participating dyads completed a baseline interview comprising open-ended questions and fixed-choice questions on social and demographic characteristics. We constructed the Charlson-Deyo Comorbidity index from inpatient and outpatient ICD-9-CM codes during the 12 months before we interviewed participants [20].

Data Collection

Three PhD-level ethnographers and one research assistant collected data. Two-person teams interviewed cancer survivors and caregivers in their homes, with the exception of one dyad we interviewed at a clinic. The research team developed a semi-structured interview guide to

increase consistency across interviews while allowing individual experiences to emerge [21, 22]. Interviews lasted approximately one hour and were digitally recorded.

Data Analysis

We transcribed, de-identified, and entered all baseline interview data into a qualitative dataset managed with NVIVO8 software. Using a template to highlight issues relating to the physical and social environment, pairs of researchers summarized information relating to caregiving and ostomies to represent each family's key challenges. We then employed a grounded theory approach [23, 24] to construct a codebook of themes relating to ostomies and caregiving. We applied these themes to all baseline interviews. After transcripts were coded, a second researcher reviewed coding to assure reliability. Discrepancies were resolved through discussion among the authors.

We also conducted "axial coding" to understand specific themes in more detail. This report focuses on the theme we labeled "caregiver in healthcare." Our findings on caregiver roles and healthcare management activities emerged from this iterative, analytic process [23, 25, 26].

Types of Healthcare Management

All caregivers participated in some form of healthcare management. We categorized caregivers as providing either high management or low management of survivors' healthcare by listing all healthcare management activities the caregivers in our sample performed (Table 1). Caregivers who engaged in high management (N=20) performed a wide range of activities, including participating in appointments and medical decisions, ordering supplies, and managing non-ostomy health concerns. Low-management caregivers (N=11) had a more limited role that included medication and supply management, contacting healthcare providers, and driving survivors to appointments. This care excluded medical decision-making and participating in in-person interactions with providers. High-management caregivers performed all activities of low-management caregivers.

We examined the sociodemographic characteristics of dyads with high vs. low management caregivers and found no apparent patterns.

Our next analytic step explored the relationship between caregivers' healthcare management and survivors' healthcare needs. We generated reports showing excerpts with the "co-morbidity" code, reviewing them for the level and type of healthcare need. We also reviewed each survivor's Charlson-Deyo score from medical records data. Because survivors told us about health problems that were not reflected in their Charlson-Deyo score, we categorized survivors as having either high or low healthcare needs after combining the qualitative data from the "co-morbidity" report along with the Charlson-Deyo score. We defined high healthcare needs as having at least one health problem in addition to the ostomy that impeded functioning and -well-being, and low healthcare needs as having stable health and few or no co-morbidities that impeded functioning.

Using "matrix coding," we explored interrelationships between healthcare management and healthcare needs. We used categories resulting from previous analyses to construct a matrix

of characteristics that distinguished the caregiving dyads. Describing the content of each cell in the matrix helped identify patterns or new themes that emerged from a sample-wide overview of the data [27, 28]. We describe the characteristics, challenges, and adaptations according to the matrix of high/low healthcare management vs. high/low healthcare needs below.

Results

Sample characteristics

The 31 dyads span living situations, income levels, and caregiving relationships. Most dyads (71%) were cohabitating spouses, and most caregivers (71%) were women. Non-spousal caregivers included children, daughters-in-law, and friends (Table 2).

High Healthcare Needs/High Healthcare Management (n=16)

These survivors were characterized by multiple co-morbidities beyond ostomy care that required caregiver assistance. Survivors in this group had Charlson-Deyo comorbidity scores that ranged from 0–6, and all but three survivors had a comorbidity score between 3 and 6. Survivors reported difficulties with mobility and balance (12), hearing (4), vision (4), ongoing cancer (5), hernias (3), chronic conditions like Parkinson's or diabetes (6), chronic pain (6), heart attack/stroke (4), and depression (1). In many cases, these survivors viewed ostomy care as the “least” of their health-related concerns.

This group also had numerous arrangements for receiving care. Six survivors had received or were receiving some form of paid assistance. Several additional families anticipated the need for future paid caregiving. All caregivers in this group participated in most, if not all, of the healthcare management activities (Table 3). These caregivers described their healthcare management activities as ongoing and consistent since the survivors' cancer diagnosis. Almost all caregivers who were spouses (11/13) were also involved in ostomy care. In contrast, none of the non-spousal caregivers helped with ostomy care, even though two of the three lived with the survivors.

In each of the 13 spousal dyads in this group, both survivor and caregiver generally agreed on the need and desire for caregiver involvement. This group viewed caregiving as part of the marriage commitment and a continuation of previous participation and support in each other's health. Spousal dyads acknowledged and accepted the need for collaboration maintained through open and honest communication. These participants also stressed the importance of teamwork in addressing healthcare needs. There was a distinct lack of discussion about the need for privacy or independence.

The three non-spousal dyads had a number of similarities to the spousal dyads, including the caregivers' commitment to assisting survivors. Survivors generally wanted assistance, and all members of the non-spousal dyads recognized the survivors' ongoing need for help. The main difference between spousal dyads and non-spousal dyads in this group was in their appraisals of the caregiving relationship. In spousal dyads, caregiving was viewed as mutually rewarding, non-invasive, and concordant with social roles. In non-spousal dyads,

survivors expressed concerns about maintaining independence and privacy, as well as feeling resentful or guilty about caregiving.

Low Healthcare Needs/High Healthcare Management (n=4)

Survivors in this group ranged from 0–2 on the Charlson-Deyo scale. While they reported health issues like hearing loss, declining vision, lymphedema in legs, and hernia, they characterized themselves as having generally good health. Even so, caregivers engaged in most, if not all, activities. All caregiving relationships were long-term family relationships, including spousal relationships and one dyad consisting of a daughter caregiver and her survivor mother.

Appraisals of caregiving roles varied among this group. Spouses felt that their participation was an extension of their marital partnership, duties, and roles. They also felt that participation was an expression of concern for their spouses' well-being. Everyone in this group expressed a desire to collaborate. The caregivers wanted to assist survivors, and the survivors expressed a complementary need for caregiver involvement. Mutual acceptance of ostomy and related care needs facilitated these partnerships, along with survivors not requiring privacy in relation to the caregiver. Concern for the survivors' ability to navigate the healthcare system also influenced many of these caregivers' high level of involvement. Caregivers felt that the survivors did not always understand all healthcare issues discussed at medical appointments and would not accurately relay the information. The one non-spousal dyad in this group expressed similar views.

In this group, while assistance with healthcare management activities was not necessary, both survivors and caregivers desired it. This attitude also extended to a range of personal-care and household-management tasks.

High Healthcare Needs/Low Healthcare Management (n=5)

This group included only one spousal dyad. Co-morbidities were high, both as reported by dyads and as measured by Charlson-Deyo comorbidity scores (2 survivors had scores under 3; 3 survivors' scored 5–6). All survivors had impaired mobility. Other health problems included difficulties with diabetes, breathing problems, mental health conditions, obesity, chronic pain, and congestive heart failure. Notably, the three survivors in this group with the highest levels of comorbidity lived alone or with a caretaker in a household where many other residents had high healthcare needs. No caregivers in this group provided ostomy care.

In this group, caregivers' healthcare management role was limited and included driving to appointments or "checking in" on the survivor from time to time. In the spousal dyad, the caregiver had health problems that posed significant barriers to being involved in healthcare management for her husband, which were compounded by a difficult relationship. Both survivors and caregivers in the three other dyads where family members provided caregiving voiced concerns about privacy and independence. Caregivers caring for parents expressed a desire to maintain their parents' privacy or hesitancy in negotiating privacy issues. These caregivers expressed anxiety and tension regarding the dual roles of being both a child and caretaker of a parent.

Healthcare management barriers in this group centered on notions of independence, autonomy, privacy, and the delineation of boundaries in the caregiving relationship, as well as limitations on caregivers' ability to be involved because of their own health problems.

Low Healthcare Needs/Low Healthcare Management (n=6)

These survivors viewed themselves as high functioning, independent, and competent, but reported problems with vision, arthritis, and post-operative hernias that required caregiving. Their Charlson Deyo scores ranged from 0–2, indicating fairly good health status. Caregivers in this group included four wives, one husband, and one daughter-in-law. Caregivers participated in healthcare management by ordering ostomy supplies or driving survivors to medical appointments, but not making or attending those appointments. Caregivers described being more involved during survivors' recovery from cancer surgery, and said their healthcare management roles declined as the survivors recovered and adjusted to life with ostomies. Caregivers played a limited and episodic healthcare management role and only occasionally engaged in additional caregiving activities.

Spousal caregivers in this group were employed full-time. Three of five spousal dyads positively appraised the relatively low level of healthcare management in their relationships. Both survivor and caregiver saw the survivor as independent, competent, and high-functioning. As a result, these dyads expressed no need for caregiver involvement in healthcare management and reported having an open, honest, and communicative relationship characterized by sharing decision-making and information.

Two spousal dyads expressed less agreement about the role of the caregiver. The survivor in one dyad wanted more support, but an established "routine" of being independent for many years posed a barrier to getting assistance from her husband. The survivor found it challenging to alter this established pattern and did not report asking for more help from her husband even though she wanted it. The survivor's husband, on the other hand, expressed a willingness to assist more in providing care, but had not altered his role: he assumed his wife had no need for increased assistance because she had not asked him for more help. In the other spousal dyad, the caregiver wanted to be more involved in her husband's healthcare because he had negative healthcare experiences that occurred during, and immediately after, ostomy surgery. The survivor, on the other hand, considered himself very capable and competent and did not want his wife to "over-manage" his healthcare.

In the non-spousal dyad with similar results, the survivor lived alone and described herself as very independent. The caregiver, a daughter-in-law, expressed concern that the survivor did not always understand or relay information from doctor appointments. The daughter-in-law felt that the survivor needed more assistance, but also felt that it was not welcome or appreciated. Tensions over issues unrelated to the survivor's healthcare management also appeared to play a role in their different views regarding healthcare management.

Discussion

As cancer survivors age and increase in number [29, 30], understanding the roles of informal caregivers in supporting survivors' physical, social, and emotional well-being will become

increasingly important. Survivors have many unique healthcare needs, including managing the sequelae of cancer treatment and monitoring for cancer recurrence. Living with an intestinal ostomy may entail ongoing or periodic difficulties that can be mitigated with the help and management of an informal caregiver. The socio-ecological perspective we employed highlights how the proximal physical and social environments in which caregiving activities take place can mitigate or exacerbate functional capacity and well-being. Elsewhere we have described how managing ostomy-related skin complications involves both direct provision of physical care and navigation of diverse healthcare resources, such as visiting ostomy nurses and acquiring new types of ostomy equipment, as well as consulting with surgeons, dermatologists, and primary care providers [8]. In this analysis, we explored a broader range of healthcare management activities. We found that healthcare management activities, which entail more cognitive work than direct physical care, can similarly span the home and healthcare settings, and are shaped by physical and social characteristics of individuals, living arrangements, relationships, and role expectations.

Our findings are consistent with studies that show how informal caregivers can act as healthcare managers to facilitate prompt and appropriate healthcare, especially when care recipients have high healthcare needs [2, 3]. While all caregivers in our study engaged in healthcare management, their activities were clustered into high or low levels of activity. High levels were characterized by more direct involvement in healthcare communication and management activities such as doctor visits and ostomy care.

Limitations

This study's limitations include our inability to draw quantifiable conclusions from this analysis. We also did not focus on caregivers' healthcare needs. Another limitation is that we did not study CRC survivors who were living in nursing homes, assisted living facilities, or adult foster care homes. Healthcare management for cancer survivors who are not living independently is an important topic for future exploration. Despite these limitations, our paper addresses the need for novel frameworks to articulate the processes underlying cancer caregiving [31]. Our findings and analytic framework should be further explored in other cancer survivor populations.

Implications for research and practice

The matrix of healthcare management resources (high vs. low) and survivors' health care needs (high vs. low) revealed patterns of benefits, conflicts, and unmet needs. The most salient findings for healthcare providers and researchers focus on the centrality of dyadic roles and relationships in shaping informal caregivers' participation in healthcare management activities. Our findings suggest that CRC survivors had more unmet healthcare management needs when they differed with caregivers on the desired level of assistance. Low healthcare management was also found in families with strong desires to maintain boundaries of privacy and autonomy. These issues were less common, but not absent in married/partnered dyads. While this was a satisfactory arrangement in some families, it nonetheless resulted in suboptimal healthcare coordination. Other families found that strong boundaries and discrepancies in desired involvement led to resentment and dissatisfaction.

Families' placement in the matrix of needs vs. management activities suggests different possibilities and priorities for intervention. Low needs/low management dyads were characterized by survivors and caregivers acting individually and not communicating with each other about plans, worries, or needs. Healthcare providers could encourage discussion about planning for increased caregiving support if health crises or further declines occurred. We found few potential difficulties in low needs/high management families. Consequently, these families may be better positioned to address future health challenges. High needs/high management families may have limited capacity to increase caregiving resources in times of crisis, and they may face challenges sustaining their level of caregiving over time. High needs/low management families in our study seemed at highest risk for poor outcomes, emotional difficulties, and limited capacity to manage any further health declines. They are the families who would likely benefit most from increased support from social work, nursing, or other supportive interventions.

Janzen's [32] and Schumacher's [19] descriptions of help-seeking and caregiving highlight the fluidity of relationships and roles that define caregiving as a process rather than a static trait. Our findings reinforce this view of caregiving activities and relationships as they affect healthcare management. Caregiver responsibilities and roles are sometimes in flux or transitory, depending on the patients' and caregivers' functioning. Cancer survivors are similarly juggling the implications of their role as "patient" or sick person, a well-documented balancing act with implications for relationships, social status, and help-seeking [33]. The emotional strain experienced by some families in our study was often due to this interplay of social and cultural contexts. Understanding these difficulties in terms of role conflicts (as opposed to personal shortcomings) could allow a productive and non-judgmental dialogue among providers, social workers, nurses, case managers, and family members.

Healthcare providers involved in teaching caregivers generally focus on survivors' physical needs. Other needs—emotional, knowledge, financial—are often unmet [34–36]. Our findings illustrate the importance of assessing the nature of the dyad relationship, the nature and amount of survivors' healthcare needs, and caregivers' interest in and ability to manage these needs, as well as caregivers' involvement in communication and healthcare decisions. With this information, clinical care could be tailored to survivor needs and the caregiver role. Healthcare management needs could include the practical issues of appointment management, transportation, and providing supplies and medications, as well as communication about care, goals, and problems. Finally, it is important to note that while our findings and other studies [37] demonstrate the benefits of partner or spousal caregiving, such relationships cannot be relied on for adequate caregiving. Moreover, because patient and caregiver healthcare needs and resources can change, repeated assessment is warranted to plan for appropriate and safe survivorship care [38, 39]. Having a social worker assist in this assessment and provision of support may be an efficient way to connect needs with available resources [36].

Acknowledgments

Support for this study was provided by Grant No. 1R21 CA129887 from the National Cancer Institute. The authors thank study participants for graciously welcoming us to their homes and speaking with candor about their challenges and adaptations as families surviving colorectal cancer. We also thank Kevin Lutz, MFA, for his assistance in preparing this manuscript.

Funding: Support for this study was provided by Grant No. 1R21 CA129887 from the National Cancer Institute.

Reference List

1. Bober SL, Recklitis CJ, Campbell EG, Park ER, Kutner JS, Najita JS, Diller L. Caring for cancer survivors: a survey of primary care physicians. *Cancer*. 2009; 115(18 Suppl):4409–4418. [PubMed: 19731354]
2. Feinberg, L.; Reinhard, SC.; Houser, A.; Choula, R. Valuing the invaluable: 2011 update, the growing contributions and costs of family caregiving. Vol. 2011. AARP Public Policy Institute; Washington, DC: 2013. <http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html> [Accessed 26 August 2013]
3. Levine C, Halper D, Peist A, Gould DA. Bridging troubled waters: family caregivers, transitions, and long-term care. *Health Aff (Millwood)*. 2010; 29(1):116–124. [PubMed: 20048369]
4. Coleman EA. Falling through the cracks: challenges and opportunities for improving transitional care for persons with continuous complex care needs. *J Am Geriatr Soc*. 2003; 51(4):549–555. [PubMed: 12657078]
5. Wolff JL, Roter DL. Hidden in plain sight: medical visit companions as a resource for vulnerable older adults. *Arch Intern Med*. 2008; 168(13):1409–1415. [PubMed: 18625921]
6. Bookman A, Harrington M. Family caregivers: a shadow workforce in the geriatric health care system? *J Health Polit Policy Law*. 2007; 32(6):1005–1041. [PubMed: 18000158]
7. Bowman KF, Rose JH, Deimling GT. Families of long-term cancer survivors: health maintenance advocacy and practice. *Psychooncology*. 2005; 14(12):1008–1017. [PubMed: 15818596]
8. McMullen CK, Wasserman J, Altschuler A, Grant ML, Hornbrook MC, Liljestrand P, Briggs C, Krouse RS. Untreated peristomal skin complications among long-term colorectal cancer survivors with ostomies. *Clin J Oncol Nurs*. 2011; 15(6):644–650. [PubMed: 22119975]
9. Brown MA, Stetz K. The labor of caregiving: a theoretical model of caregiving during potentially fatal illness. *Qual Health Res*. 1999; 9(2):182–197. [PubMed: 10558362]
10. Thomas C, Morris SM. Informal carers in cancer contexts. *Eur J Cancer Care (Engl)*. 2002; 11(3): 178–182. [PubMed: 12296834]
11. Lawton MP, Brody EM, Turner-Massey P. The relationships of environmental factors to changes in well-being. *Gerontologist*. 1978; 18(2):133–137. [PubMed: 640453]
12. Mendes de Leon CF, Gold DT, Glass TA, Kaplan L, George LK. Disability as a function of social networks and support in elderly African Americans and Whites: the Duke EPESE 1986–1992. *J Gerontol B Psychol Sci Soc Sci*. 2001; 56(3):S179–S190. [PubMed: 11316843]
13. Strauss, AM.; Corbin, JM.; Fagerhaugh, S.; Glaser, BG.; Maines, D.; Suczek, B.; Wiener, CL. Chronic Illness and the Quality of Life. Mosby; St. Louis, MO: 1984.
14. Izal M, Montorio I, Marquez M, Losada A. Caregivers' expectations and care receivers' competence Lawton's ecological model of adaptation and aging revisited. *Arch Gerontol Geriatr*. 2005; 41(2):129–140. [PubMed: 16085064]
15. Brandt, EN., Jr; Pope, AM. Models of disability and rehabilitation Enabling America : Assessing the Role of Rehabilitation Science and Engineering. National Academy Press; Washington, DC: 1997. p. 62-80.
16. Putnam M. Linking aging theory and disability models: increasing the potential to explore aging with physical impairment. *Gerontologist*. 2002; 42(6):799–806. [PubMed: 12451161]
17. Kahana, EA. A congruence model of person-environment interaction. In: Lawton, MP.; Windley, PG.; Byerts, TO., editors. Aging and the Environment: Theoretical Approaches. Springer; New York: 1982. p. 97-121.

18. McMullen CK, Hornbrook MC, Grant M, Baldwin CM, Wendel CS, Mohler MJ, Altschuler A, Ramirez M, Krouse RS. The greatest challenges reported by long-term colorectal cancer survivors with stomas. *J Support Oncol*. 2008; 6(4):175–182. [PubMed: 18491686]
19. Schumacher KL, Beidler SM, Beeber AS, Gambino P. A transactional model of cancer family caregiving skill. *ANS Adv Nurs Sci*. 2006; 29(3):271–286. [PubMed: 17139208]
20. Deyo RA, Cherkin DC, Ciol MA. Adapting a clinical comorbidity index for use with IDC-9-CM administrative databases. *J Clin Epidemiol*. 1992; 45(6):613–619. [PubMed: 1607900]
21. Patton, MQ. *Qualitative evaluation and research methods* 1990. Sage; Thousand Oaks: 1990.
22. Seidman, I. *Interviewing as qualitative research: A guide for researchers in education and social sciences*. Teachers College Press; New York, NY: 1991.
23. Strauss, A.; Corbin, J. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Sage Publications; Newbury Park, CA: 1990.
24. Erlandson, D.; Harris, E.; Skipper, B.; Allen, S. *Doing naturalistic inquiry: A guide to methods*. Sage Publications; Thousand Oaks, CA: 1993.
25. Lofland, J.; Lofland, L. *Analyzing Social Settings: A guide to Qualitative Observation and Analysis*. Wadsworth Publishing; New York: 1995.
26. Wolcott, H. *Transforming Qualitative Data: Description, Analysis and Interpretation*. Sage Publications; Thousand Oaks, CA: 1994.
27. Coeling HV, Biordi DL, Theis SL. Negotiating dyadic identity between caregivers and care receivers. *J Nurs Scholarsh*. 2003; 35(1):21–25. [PubMed: 12701522]
28. Knafl K, Ayres L. Managing Large Qualitative Data Sets in Family Research. *Journal of Family Nursing*. 1996; 2(4):350–365.
29. Horner, M.; Ries, L.; Krapcho, M.; Neyman, N.; Aminou, R.; Howlader, N.; Altekruse, SF.; Feuer, EJ.; Huang, L.; Mariotto, A.; Miller, BA.; Lewis, DR.; Eisner, MP.; Stinchcomb, DG.; Edwards, BK. SEER cancer statistics review, 1975–2006. National Cancer Institute; 2009. http://seer.cancer.gov/csr/1975_2006 [Accessed 1 October 2013]
30. Parry C, Kent EE, Mariotto AB, Alfano CM, Rowland JH. Cancer survivors: a booming population. *Cancer Epidemiol Biomarkers Prev*. 2011; 20(10):1996–2005. [PubMed: 21980007]
31. Blum K, Sherman DW. Understanding the experience of caregivers: a focus on transitions. *Semin Oncol Nurs*. 2010; 26(4):243–258. [PubMed: 20971405]
32. Janzen JM. Therapy Management: Concept, Reality, Process. *Medical Anthropology Quarterly*. 1987; 1(1):68–84.
33. Young JT. Illness behaviour: a selective review and synthesis. *Sociol Health Illn*. 2004; 26(1):1–31. [PubMed: 15027988]
34. Kim Y, Kashy DA, Spillers RL, Evans TV. Needs assessment of family caregivers of cancer survivors: three cohorts comparison. *Psychooncology*. 2010; 19(6):573–582. [PubMed: 19582798]
35. Yabroff KR, Kim Y. Time costs associated with informal caregiving for cancer survivors. *Cancer*. 2009; 115(18 Suppl):4362–4373. [PubMed: 19731345]
36. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology*. 2010; 19(10):1013–1025. [PubMed: 20014159]
37. Aizer AA, Chen MH, McCarthy EP, Mendu ML, Koo S, Wilhite TJ, Graham PL, Choueiri TK, Hoffman KE, Martin NE, Hu JC, Nguyen PL. Marital Status and Survival in Patients With Cancer. *J Clin Oncol*. 2013
38. Glajchen M. Physical Well-Being of Oncology Caregivers: An Important Quality-of-Life Domain. *Semin Oncol Nurs*. 2012; 28(4):226–235. [PubMed: 23107180]
39. Northouse LL, Katapodi MC, Schafenacker AM, Weiss D. The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Semin Oncol Nurs*. 2012; 28(4):236–245. [PubMed: 23107181]

Table 1

Caregiver Activities in High and Low Healthcare Management Roles

Healthcare Management Activities	High Management Role (n=20)	Low Management Role (n=11)
Makes healthcare appointments		
Drives survivor to appointments		
Prepares list of questions/concerns prior to appointment		
Attends and participates in appointments		
Asks questions during appointments		
Listens and helps to remember doctor recommendations / suggestions		
Calls or emails providers for questions outside of scheduled visits		
Tracks and orders ostomy supplies		
Prepares and organizes ostomy supplies		
Tracks issues and medications related to co-morbidities		
Gathers information on health problems		

Table 2

Participant Characteristics

Self-Reported Characteristics	Patient (N=31)	Caregiver (N=31)
Age		
45–70	10	16
71–84	15	10
85+	6	2
Not reported	0	3
Gender		
Female	17	22
Male	14	9
White or Caucasian	27	26
Annual Income (\$) ¹		
30,000 or less	6	
30,001 – 50,000	7	
50,001 – 75,000	7	
75,001 or more	5	
Not reported	6	
Impairment Level		
Needs help with basic activities ²	18	
Needs help with instrumental activities and/or ostomy care ³	13	
Survivor's living situation		
Lives with spouse	21	
Lives alone	5	
Lives with non-spouse caregiver	5	
Caregiver's relationship to survivor		
Spouse		21
Child		2
Other relative		6
Not related		2

¹ Caregiver income was not ascertained.

² ADL = Activities of Daily Living (e.g., bathing, dressing).

³ IADL = Instrumental Activities of Daily Living (e.g., driving, preparing meals).

Table 3**Matrix of Healthcare Needs**

	High Needs/High Management (N=16)	High Needs/Low Management (N=5)
Comorbidity status	Survivors have multiple co-morbidity issues beyond ostomy care.	High comorbidities, impaired mobility.
Caregiver participation	Six of 16 received/had received paid care. Caregiver provided ongoing, consistent care and participated in most care.	Limited. No ostomy care. Help included driving to appointment or “checking in” from time to time.
Relationship issues	Both groups acknowledged need for assistance. Collaboration key to maintaining relationship.	Barriers centered on independence and delineation of roles (e.g., child and caregiver).
Privacy	All spouses participated in ostomy care. Non-spousal providers did not participate in ostomy care and expressed need for privacy and independence.	Three of five dyads expressed concerns about privacy. Caregivers did not know how to navigate privacy issues.
Appraisal of caregiving	Spousal dyads saw care as part of marriage. Non-spousal dyads expressed concerns about independence, and guilt and resentment about caregiving.	Caregivers concerned with privacy and autonomy. Caregivers desire to maintain survivors’ privacy and dual roles.
	Low Needs/High Management (N=4)	Low Needs/Low Management (N=6)
Comorbidity status	Generally healthy, issues such as hearing loss and declining vision.	Low-vision impairment, arthritis, post-op hernias.
Caregiver participation	All long-term family relationships. Caregiver engaged in most, if not all, healthcare needs.	More involved earlier during recovery. As the patient recovered participation declined. Episodic management during worse health.
Relationship issues	Mutual acceptance of ostomy and needed care facilitated relationship.	Open communication facilitated relationship. Family tension complicated care for one dyad.
Privacy	Survivors did not express need for privacy.	
Appraisal of caregiving	While not necessary, care was desired by survivor and caregiver. Spouses felt care was extension of marriage. Other relatives felt it was an expression of concern.	Three of the five spousal dyads felt positive about low management.