Published in final edited form as:
Psychol Health. 2017 January ; 32(1): 94–109. doi:10.1080/08870446.2016.1247839.

Positive Changes among Patients with Advanced Colorectal Cancer and their Family Caregivers: A Qualitative Analysis

Catherine E. Mosher, Ph.D. [Associate Professor]
Department of Psychology Indiana University-Purdue University Indianapolis 402 North Blackford Street, LD 124 Indianapolis, IN 46202, USA

Rebecca N. Adams, Ph.D. [Postdoctoral Scholar]
Department of Pediatrics Stanford University School of Medicine 780 Welch Road, MC 5776 Palo Alto, CA 94304 Phone: 1-650-725-3954 rnadams@stanford.edu

Paul R. Helft, M.D. [Professor]
Department of Medicine Indiana University School of Medicine Indiana Cancer Pavilion 535 Barnhill Drive, Room 473 Indianapolis, IN 46202, USA Phone: 1-317-948-6942 phelft@iu.edu

Bert H. O'Neil, M.D. [Joseph W. and Jackie J. Cusick Professor of Oncology]
Department of Medicine Indiana University School of Medicine Indiana Cancer Pavilion 535 Barnhill Drive, Room 473 Indianapolis, IN 46202, USA Phone: 1-317-278-8845 bhoneil@iu.edu

Safi Shahda, M.D. [Assistant Professor]
Department of Medicine Indiana University School of Medicine Indiana Cancer Pavilion 535 Barnhill Drive, Room 473 Indianapolis, IN 46202, USA Phone: 1-317-278-4688 shahdas@iu.edu

Nicholas A. Rattray, Ph.D. [Research Scientist]
Center for Health Information and Communication Richard L. Roudebush VA Medical Center 1481 West 10th Street, 11H Indianapolis, IN 46202, USA Phone: 1-317-988-9762 nrattray@iupui.edu

Victoria L. Champion, Ph.D. [Distinguished Professor]
Indiana University School of Nursing 1111 Middle Drive, NU 340G Indianapolis, IN 46202, USA Phone: 1-317-274-4187 vchampio@iu.edu

Abstract

Objective—This study assessed positive changes in patients with advanced colorectal cancer and their family caregivers following diagnosis. We compared self-reported positive changes within patient-caregiver dyads as well as self-reports and patient reports of positive changes in caregivers.

Design—Individual, semi-structured qualitative interviews were conducted with 23 patients with advanced colorectal cancer and 23 caregivers. A theoretical thematic analysis of interview transcripts was framed by posttraumatic growth theory.

Results—Patients and caregivers described five positive changes: closer relationships with others, greater appreciation of life, clarifying life priorities, increased faith, and more empathy for

---

(corresponding author) Catherine E. Mosher, Ph.D. Phone: 1-317-274-6769 cemosher@iupui.edu.

others. Additionally, only caregivers reported better health habits following the cancer diagnosis, and a minority of patients and caregivers reported no positive changes. In about half of cases, patients reported at least one positive change that was identical to that of their caregiver. However, in most cases, patient and caregiver reports of the caregiver's positive change were discrepant.

Conclusion—Findings suggest that positive changes are a shared experience for many patient-caregiver dyads and obtaining both patient and caregiver reports of caregiver positive changes provides a more comprehensive understanding of their experience. Interventions may capitalize on positive changes to promote meaningful living in the context of advanced cancer.

Keywords

colorectal cancer; family caregivers; posttraumatic growth; benefit finding; positive changes; qualitative

Introduction

A large literature suggests that many cancer patients perceive positive changes related to their illness experience (Kolokotroni, Anagnostopoulos, & Tsikkinis, 2014; Shand, Cowlishaw, Brooker, Burney, & Ricciardelli, 2015; Stanton, Bower, & Low, 2006). Various terms have been used to describe these changes, including posttraumatic growth, stress-related growth, and benefit finding. Although the terminology differs across studies, the underlying concept is similar: people facing highly stressful life events such as cancer may experience both positive and negative outcomes (Tedeschi & Calhoun, 2004). Park's (2010) integrated meaning-making model suggests that perceived positive changes are the result of meaning-making, defined as cognitive and emotional processing to reduce the discrepancy between appraisals of a stressor and general beliefs and life goals. For example, a cancer patient who can no longer work outside of the home may initially evaluate the illness as a threat to his or her sense of meaning in life and identity. After processing the illness experience with loved ones and pursuing other meaningful goals, the patient may re-evaluate cancer as a catalyst for these positive pursuits and a new sense of identity.

According to Tedeschi and Calhoun's (2004) model of posttraumatic growth, some people experience profound changes in their perceptions of themselves, relationships with others, or philosophy of life following their struggle with a major life crisis such as cancer. The Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) has been widely used with cancer patients to assess aspects of this model, including relating to others, new possibilities, personal strength, spiritual change, and appreciation of life. The other commonly used measure of cancer patients' positive changes is the Benefit Finding Scale (BFS; Tomich & Helgeson, 2004), a unidimensional assessment of change in various attitudes and behaviours. Although the scales have shown some evidence of reliability and validity (Tedeschi & Calhoun, 1996; Tomich & Helgeson, 2004), limitations of the measures include the potential for recall and social desirability biases and overestimation of the degree to which positive changes are attributable to the crisis. Furthermore, although qualitative data suggest that some cancer patients and caregivers do not perceive positive changes (Ruf, Buchi, Moergeli, Zwahlen, & Jenewein, 2009), the positively phrased items in these measures may encourage reports of positive change.

Perceived positive changes have shown mixed associations with cancer patients' mental health and quality-of-life outcomes (Lechner, Carver, Antoni, Weaver, & Phillips, 2006; Shand et al., 2015; Tomich & Helgeson, 2012). Regarding mental health outcomes, a recent meta-analysis found that positive changes showed small negative associations with distress and depressive symptoms in cancer patients (Shand et al., 2015). Other research with cancer patients has found curvilinear relationships between positive changes and distress and quality-of-life outcomes, such that patients with high or low levels of positive changes had the best outcomes (Lechner et al., 2006; Tomich & Helgeson, 2012).

A small body of research suggests that family caregivers of cancer patients also perceive positive changes associated with the illness experience (Cassidy, 2013; Kim, Schulz, & Carver, 2007; Zwahlen, Hagenbuch, Carley, Jenewein, & Buchi, 2010). The level of change in caregivers has been found to be lower than that of patients, but most caregivers report some degree of positive change (Bishop et al., 2007; Zwahlen et al., 2010). Caregivers face a variety of challenges that may be catalysts for personal growth, including family role changes, occupational changes, financial and emotional strain, and altered household routines (Gaugler et al., 2005; Girgis, Lambert, Johnson, Waller, & Currow, 2013). Caregivers' perceptions of positive personal change following the patient's cancer diagnosis have shown mixed associations with their psychological adjustment (Bishop et al., 2007; Kim et al., 2007; Teixeira & Pereira, 2013).

To date, the psycho-oncology literature has largely focused on positive changes in early-stage breast cancer patients (Danhauer et al., 2013; Kolokotroni et al., 2014; Wang et al., 2015) and their spousal caregivers (Manne et al., 2004; Weiss, 2004). However, recent studies have examined positive changes in patients and caregivers coping with various cancers (Arpawong, Richeimer, Weinstein, Elghamrawy, & Milam, 2013; Moore et al., 2011; Salsman, Segerstrom, Brechting, Carlson, & Andrykowski, 2009; Thornton et al., 2012). These studies have consistently found that most cancer patients and caregivers report a range of positive changes following the illness. However, there are several gaps in our understanding of these changes. First, posttraumatic growth measures, such as the PTGI (Tedeschi & Calhoun, 1996), were developed to assess responses to general traumatic experiences, and little qualitative research has assessed whether these measures are capturing the range of positive changes experienced by cancer patients and caregivers. One mixed methods study found that, in addition to endorsing several changes included in posttraumatic growth measures, cancer survivors reported greater compassion for others and positive health-related changes at approximately 3 years post-diagnosis (Morris, Shakespeare-Finch, & Scott, 2012). Another key gap in the literature is the lack of observer reports of positive change in cancer patients or caregivers. One study found high agreement between advanced cancer patient and caregiver reports of patient posttraumatic growth (Moore et al., 2011), whereas another study found a weak correlation between primarily early-stage cancer patient and caregiver reports of patient benefit finding (Costa & Pakenham, 2012). To our knowledge, caregiver reports of positive personal change following the cancer diagnosis have not been corroborated by others. Agreement between individual and observer reports of positive change would support the validity of these changes. Finally, people coping with advanced cancers are understudied in the literature on positive changes, despite their high prevalence (American Cancer Society, 2016). One of the primary tenets of many theories of benefit finding and posttraumatic growth is that the stressor must be sufficiently severe to produce changes in the individual's worldview or priorities (Calhoun & Tedeschi, 2006). Advanced cancers qualify as a severe stressor, given their association with high symptom burden, distress, and poor prognosis.

To address these gaps in the literature, this qualitative study aimed to identify positive changes in patients with advanced colorectal cancer and their primary family caregivers since the diagnosis. In addition to reporting positive personal changes, patients were asked to describe any positive changes that their family caregiver had experienced. Thus, a second aim of this study was to compare self-reported and patient-reported positive changes in caregivers as well as self-reported positive changes within each patient-caregiver dyad.

Methods

Sample

All study procedures were approved by the Indiana University institutional review board and have been previously reported (Mosher et al., 2016). To summarize, patients with advanced colorectal cancer were recruited from the Indiana University Cancer Centre between September and December 2014. Eligible patients were adults (18+ years of age) who were at least 8 weeks post-diagnosis of advanced (stage III or IV) colorectal cancer and fluent in English. Initial eligibility was assessed via medical chart review and consultation with oncologists. Then a trained research assistant approached potentially eligible patients in clinic and asked them to identify their primary family caregiver (i.e., the person who provided most of their unpaid, informal care). Patients with a family caregiver were invited to participate in the study. With the patient's written consent, the research assistant approached the family caregiver in clinic or via telephone to screen for eligibility (i.e., English fluency and 18+ years of age) and obtain informed consent.

Of the 32 patients with advanced colorectal cancer who were approached about this study, all of them were eligible and 6 (19%) declined study participation. Primary reasons for declining were lack of interest and privacy concerns. Thus, 26 patients (81%) consented to participate in this study and allowed the research assistant to approach their primary family caregiver. Nearly all caregivers (25/26) consented to participate in this study; one caregiver could not be reached for the phone consent process. Additionally, two caregivers and one patient could not be reached for the telephone interview, and one patient withdrew following hospice enrolment. Interview data from one patient could not be analysed due to the quality of the recording. Following the analysis of data from 23 patients and 23 caregivers, the researchers jointly determined that thematic saturation had been achieved. Demographic and medical characteristics of the sample are found in Table 1.

Data collection

Telephone interviews were conducted by a doctoral student in clinical psychology who had experience interviewing cancer populations. The telephone modality was chosen in order to reduce barriers to participation for residents of rural areas and patients with physical impairments. Patients and caregivers were interviewed separately. Interviews ranged from 45 to 60 minutes and were digitally recorded. After reporting demographic information, patients and caregivers provided a detailed narrative of their cancer experience, including treatments received and tasks performed by the caregiver. The current analysis focused on patients' responses to the following question: “Some people talk about positive changes that have taken place since dealing with the illness. Have you experienced any positive changes since your diagnosis?” If the patient endorsed positive changes, the interviewer asked, “What changes did you notice?” Patients were then asked, “Has your [e.g., husband/wife, son/daughter] experienced any positive changes since your diagnosis?” Patients who answered affirmatively were then asked to describe these changes.

The present analysis also focused on caregivers' responses to parallel questions: “Some people talk about positive changes that have taken place since dealing with the illness. Have you experienced any positive changes since your [e.g., husband's/wife's, dad's/mom's] diagnosis?” If the caregiver endorsed positive changes, the interviewer asked, “What changes did you notice?” The caregiver was not asked to report positive changes that the patient had experienced because this study had a greater focus on family caregiving. Throughout the interview, the interviewer asked follow-up questions to obtain rich information regarding positive changes. Standardized questionnaires regarding positive changes were not administered because we aimed to capture patients' and caregivers' perceived positive changes that may or may not be included in these instruments. With patients' written consent, medical information was collected from their medical records in order to characterize the sample's cancer history. Each person received $25 for study participation as well as a brochure with contact information for mental health services at the cancer centre.

Qualitative data analysis

Interviews were transcribed verbatim and imported into Atlas.ti software for thematic analysis (Braun & Clarke, 2006). Thematic analysis is a method of qualitative analysis that involves identifying, analysing, and reporting patterns or themes across a data set (Braun & Clarke, 2006). We chose a theoretical approach to thematic analysis rather than an inductive one, as the analysis was framed by posttraumatic growth theory (Calhoun & Tedeschi, 2006; Tedeschi & Calhoun, 2004). More specifically, the analytic goals were to describe positive changes in patients with advanced colorectal cancer and caregivers based upon theory and to examine the data for changes not captured by current posttraumatic growth and benefit finding measures. Specifically, we examined the data for aspects of Tedeschi and Calhoun's (2004) model of posttraumatic growth, including relating to others, new possibilities, personal strength, spiritual change, and appreciation of life, but also sought to identify other positive changes or the absence of change. A clinical psychology doctoral student and a clinical psychologist who both specialize in psycho-oncology read all transcripts and generated initial codes. The codes were revised as the researchers independently coded the transcripts in Atlas.ti and met regularly (i.e., after the first two sets of transcripts for patients and caregivers and then every three sets thereafter) to review the codes and reconcile differences in coding for each transcript (Miles, Huberman, & Saldaña, 2014). At each meeting, the researchers jointly evaluated whether saturation had been achieved. Then the researchers sorted the codes into broader themes and compared these themes within each patient-caregiver dyad. Finally, the researchers checked their interpretations against data across transcripts to ensure that the themes were internally consistent and distinguishable from one another.

Results

Overview

Our thematic analysis identified five positive changes experienced by patients with advanced colorectal cancer and their caregivers: closer relationships with others, greater appreciation of life, clarifying life priorities, increased faith, and more empathy for others. In addition, only caregivers reported better health habits following the cancer diagnosis, and some patients and caregivers reported no positive changes. Each positive change is described below.

Closer relationships with others

The most common positive change for patients and caregivers was closer relationships with family, friends, and co-workers. Participants described receiving practical support, such as help with chores and gifts, as well as emotional and spiritual support from others. This support led to greater emotional closeness in their relationships. One female patient commented on these relational changes:

> I've been overwhelmed by the support from people at work as well as my family and friends…. I've had flowers and plants and cards galore of course and just little gifts here and there and people praying for me…. It certainly has made me more open with my feelings or telling someone, hey, you're a good friend of mine and I love you.

Other participants described a strengthening of the emotional bond with their spouse or partner, as illustrated by the following comment from a patient's wife:

> The closeness that we feel and the fighting it as a team, the whole all for one, one for all kind of thing…. The two of us I think we're closer than you can imagine … not leaving anything unsaid.

Greater appreciation of life

Another common positive change reported by patients and caregivers was a greater appreciation of life, especially time with loved ones. This appreciation stemmed from a greater awareness of life's brevity. As one patient's wife said:

> I think it's unfortunate that in the busy rush and just the general busyness of life … you think it's there for the taking whenever. I think [my husband] and I have learned to value and appreciate each and every day that we have together. We don't know that we have tomorrow. And that's no different than the way anybody else is in any given relationship. But in his case we know that time is probably more limited than what it would have been had it not been for this diagnosis.

A patient expressed a similar perspective following her diagnosis:

> I would say the positive is it just makes you appreciate life and your family. You cherish…. I always felt like I cherished my family, but you do even more.

Clarifying life priorities

Some patients and caregivers also stated that the cancer resulted in greater clarification of their life priorities. Participants often described prioritizing relationships over other aspects of life after the diagnosis. As one patient's wife said:

> [We] realize that life is precious, and our moments with people are precious. And that that is so much more important than all the little trivial, busy things of life.

One patient described a similar change in her priorities:

> I think I'm a little more light-hearted. I don't bog down too much on things. If something doesn't go right I'm like, you know what? It's not the end of the world and we'll get through this. Accidents happen or whatever it is. You know in the scope of things that's not important in life but [what is] important in life is being with your friends, your family, spending quality time, and I think those are changes that I consciously made.

Another patient stated that he and possibly his wife shifted their focus to meaningful relationships following his diagnosis:

> there's some relationships that you don't try to invest as much time or effort into them anymore maybe because they weren't that important and you realize you're better off investing that time or that effort into the relationship that's more meaningful to you. She [the wife caregiver] is probably going through the same thing, that's my guess.

Increased faith

Other patients and caregivers described a greater sense of closeness to God and the belief that the illness was “God's will.” As one female patient said:

> I think that God has given it [the cancer]--this is part of my life plan because I'm the right person to have had it. Now any positive change is that I feel more at peace…. You know God is working His ways in my life.

Other participants expressed a greater sense of trust in God and a changed opinion regarding “the power of prayer.” One patient's sister shared this viewpoint:

> my faith is different … I don't know if I believed in the power of prayer, but now I absolutely believe in it…. My family and friends, we all did a 24-hour prayer chain for [the patient] the Friday before she had that test on that last Monday…. I think the power of that prayer, of 24 hours of people thinking about [the patient]--everybody took a half-an-hour time slot--absolutely changed those results, you know? It made them even better than they were going to be.

Others reported renewed church attendance and other spiritual practices, such as regular devotional time.

More empathy for others

Increased empathy for others was another positive change reported by patients and caregivers. Participants noted a stronger connection to others who were suffering, as illustrated by a wife caregiver's comment:

> We've learned a lot of patience and tolerance for other people that we didn't have before, a lot more empathy that we have for people who have adversity whether it's cancer or any other kind of problem…. you feel a connection and an empathy for that, that we didn't have before.

One patient shared how his cancer experience fostered greater understanding of others' challenges and empathic communication via an on-line platform:

> Being able to get on this Facebook page and talk to people and help the people, I couldn't do it if I didn't have cancer. Now I can talk on all levels. I understand what they're trying to say they're going through and without the cancer I couldn't do that. I see myself as actually doing a service for a lot of people.

Better health habits

Only caregivers reported that they or their family members showed improved health habits following the patient's illness. These health habits included increased exercise, better diet quality, and medical check-ups, including colonoscopy. As one patient's husband stated:

> I've recommitted a little bit to exercise for me, because … I worry a little bit more about my health.

A patient's wife stated that her entire family adopted a healthier lifestyle following the illness:

> I feel we're trying to be healthier. I've taken a more active interest in trying to keep less junk in the house and to be more active. I think … we're trying to as a family be more active.

No positive changes

Some patients ($n = 3$) and caregivers ($n = 6$) did not report positive personal changes following the illness. In addition, seven patients reported that their caregiver did not experience positive changes. Some participants found the patient's suffering and uncertain prognosis or the caregiver's increased responsibilities to be a uniformly negative experience. One patient expressed this viewpoint regarding his wife caregiver:

> It's hard on her taking care of me. I'm here all the time. I'm sure she liked her freedom before and now I'm here…. I don't think there's any positives about this at all.

Other patients and caregivers believed that the illness did not change their general orientation towards life. As one male patient stated:

> But as far as physical changes or mental changes relative to dealing with cancer, I can't say that I've noticed much change in the way my wife or I approach life.

One patient's husband expressed a similar perspective:

> We've always been positive, so … I don't think that's changed. I think that it's stayed and we've still maintained that positive attitude towards everything about life.

Within-dyad comparisons

When examining self-reported positive changes between dyad members, about half of patients reported at least one change that was the same as that of their caregiver. However, when comparing patient and caregiver reports of the caregiver's positive change within each dyad, most of these reports were discrepant. The most common within-dyad difference (n = 5 dyads) was that the patient reported no positive changes in the caregiver, whereas the caregiver reported one or more positive changes. A representative sample of within-dyad comparisons of caregivers' positive changes is found in Table 2.

Discussion

This study provides rich, descriptive information on positive changes experienced by patients with advanced colorectal cancer and their primary family caregivers. Five key changes for patients and caregivers were identified: closer relationships with others, greater appreciation of life, clarifying life priorities, increased faith, and more empathy for others. In addition, only caregivers reported better health habits following the patient's cancer diagnosis, and a small minority of patients and caregivers reported no positive changes.

Our sample reported some positive changes that are captured by the widely used PTGI (Tedeschi & Calhoun, 1996) and endorsed by many cancer patients and caregivers in prior research (i.e., closer relationships with others, greater appreciation of life, clarifying life priorities, increased faith) (Arpawong et al., 2013; Moore et al., 2011; Salsman et al., 2009; Thornton et al., 2012; Zwahlen et al., 2010); however, other changes found in the current study (i.e., greater empathy for others and better health habits) are not subscales of this measure. These two changes were also identified in two studies of cancer survivors (Morris et al., 2012; Sears, Stanton, & Danoff-Burg, 2003), and better health habits were reported in qualitative research on adult children of cancer patients (Levesque & Maybery, 2012). In the current study, caregivers reported a variety of improved personal health habits, including more exercise, better diet quality, and preventive medical care, such as colonoscopy. In some cases, caregivers reported that their family had adopted a healthier lifestyle. Given their high disease burden and reduced life expectancy, advanced cancer patients may be less likely to improve their health habits than their family caregivers or other family members, a hypothesis that warrants examination.

Although many aspects of Tedeschi and Calhoun's (2004) model of posttraumatic growth were captured by participants' comments, greater personal strength was not reported by patients and caregivers. In this model, personal strength includes feelings of self-reliance and the discovery of inner strength. Given that patients and caregivers often become more dependent on family and friends for support as advanced cancer progresses, feelings of self-reliance may not emerge.

Another interesting finding is that a minority of patients and caregivers did not perceive positive changes associated with the illness. A similar finding was obtained in a qualitative study of head and neck cancer patients and their spouses (Ruf et al., 2009), but reasons for this finding were not reported. In the present study, some participants stated that cancer did not alter their worldview or attitude toward life, whereas others stated that cancer had been a uniformly negative experience and emphasized the physical and emotional suffering and poor prognosis or increased caregiving responsibilities. These results are consistent with Tedeschi and Calhoun's (2004) model of posttraumatic growth, which does not characterize growth as a ubiquitous outcome. The predominant questionnaires used to assess positive change in cancer patients [i.e., PTGI (Tedeschi & Calhoun, 1996) and BFS (Tomich & Helgeson, 2004)] allow for the reporting of no change; however, the uniformly positive wording of items may contribute to high rates of endorsing benefits of the cancer experience. It may be important to supplement these questionnaires with items assessing a perceived lack of change or negative changes related to the cancer experience in order to capture the full range of participant experiences.

When comparing changes within dyads, about half of patients reported at least one positive change that was the same as that of their caregiver. Shared experiences and coping strategies may account for similarities in positive change within dyads (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Traa, De Vries, Bodenmann, & Den Oudsten, 2015). However, reports of the caregiver's positive change were discrepant within most patient-caregiver dyads. The most common discrepancy was that the patient reported no positive change in the caregiver, whereas the caregiver reported at least one positive change. Similarly, a quantitative study found differences in thyroid cancer patients' and caregivers' reports of patients' positive changes (Costa & Pakenham, 2012).

Several factors may have contributed to discrepant reports of caregivers' positive change within patient-caregiver dyads. First, in previous studies, many cancer patients and caregivers have reported difficulty discussing the illness or avoidance of such discussions (Badr & Carmack Taylor, 2006; Lepore & Revenson, 2007; Manne, Ostroff, Winkel, Grana, & Fox, 2005). Thus, some caregivers in the current study may not have shared their positive cancer-related changes with the patient, and perhaps viewed this disclosure as insensitive. Second, cancer may serve as a catalyst for a number of positive changes; thus, for some dyads, both the patient and caregiver may have been reporting significant positive changes. Third, recall and response biases may have affected patient and caregiver reports. For example, some patients and caregivers may have been responding in a socially desirable manner, as the notion that personal growth arises from adversity is a strong cultural expectation.

Limitations of this study and directions for future research warrant mention. The present sample was primarily Caucasian and well educated, and, although participants had a wide age range, older adults were underrepresented. Regarding gender, the majority of patients were men and most caregivers were women, consistent with the gender composition of these populations (American Cancer Society, 2016; National Alliance for Caregiving, 2009). The transferability of study findings across gender, racial, and socioeconomic groups requires further research. In addition, most caregivers were spouses or partners of the patient; thus, the degree to which findings are transferable to non-spousal relationships should be examined in future research. This cross-sectional study provides an overview of positive changes to be explored further in future qualitative and quantitative research. A longitudinal design would help elucidate positive changes at different periods of the disease and treatment trajectory as well as factors contributing to these changes. Observer reports of positive changes and behavioural indicators of these changes would further establish their validity.

This study has important implications for future research and clinical practice. First, obtaining patient and caregiver perspectives on caregiver positive changes may provide a more thorough assessment of these changes. This assessment process may also involve increasing patient and caregiver awareness of the other person's perspective in order to strengthen communication and emotional closeness. Second, posttraumatic growth and benefit finding questionnaires may be expanded to incorporate subscales on increased empathy and health-related benefits. Indeed, Morris and colleagues (2013) added a subscale to the PTGI assessing newfound compassion and found evidence of its reliability and validity in a sample of prostate cancer survivors. Third, although links between positive changes and distress outcomes are equivocal at best (Shand et al., 2015), psychosocial interventions may build upon these changes (e.g., closer relationships with others, greater appreciation of life) to promote a rich and meaningful existence, even in the context of advanced disease. Additionally, prior research on cognitive-behavioural stress management for early-stage cancer patients suggests that perceived benefits of the illness may be a modifiable outcome (Antoni et al., 2001; Penedo et al., 2006). Whether such perceptions are modifiable in advanced cancer patients and caregivers requires further study. In sum, our results support the theoretical notion that a severe stressor such as advanced cancer may lead to a range of positive changes (Calhoun & Tedeschi, 2006). Capitalizing on these changes in psychosocial interventions may strengthen their efficacy among advanced cancer patients and caregivers.

Acknowledgements

This project was supported by a Project Development Team within the ICTSI NIH/NCRR Grant Number UL1TR001108. Catherine Mosher's work was supported by the National Cancer Institute under Grants K05CA175048 and K07CA168883. Rebecca Adams's work was supported by R25CA117865 (V. Champion, PI) from the National Cancer Institute. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Cancer Institute. The authors would like to thank the study participants and Danielle B. Tometich for her assistance.

References

American Cancer Society. Cancer facts and figures 2016. American Cancer Society; Atlanta, GA: 2016.

Antoni MH, Lehman JM, Kilbourn KM, Boyers AE, Culver JL, Alferi SM, Carver CS. Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. Health Psychology. 2001; 20:20–32. doi: 10.1037/0278-6133.20.1.20. [PubMed: 11199062]

Arpawong TE, Richeimer SH, Weinstein F, Elghamrawy A, Milam JE. Posttraumatic growth, quality of life, and treatment symptoms among cancer chemotherapy outpatients. Health Psychology. 2013; 32:397–408. doi: 10.1037/a0028223. [PubMed: 22563756]

Badr H, Carmack CL, Kashy DA, Cristofanilli M, Revenson TA. Dyadic coping in metastatic breast cancer. Health Psychology. 2010; 29:169–180. doi: 10.1037/a0018165. [PubMed: 20230090]

Badr H, Carmack Taylor CL. Social constraints and spousal communication in lung cancer. Psycho-Oncology. 2006; 15:673–683. doi: 10.1002/pon.996. [PubMed: 16287210]

Bishop MM, Beaumont JL, Hahn EA, Cella D, Andrykowski MA, Brady MJ, Wingard JR. Late effects of cancer and hematopoietic stem-cell transplantation on spouses or partners compared with survivors and survivor-matched controls. Journal of Clinical Oncology. 2007; 25:1403–1411. doi: 10.1200/JCO.2006.07.5705. [PubMed: 17416860]

Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006; 3:77–101. doi: 10.1191/1478088706qp063oa.

Calhoun, LG.; Tedeschi, RG. The foundations of posttraumatic growth: an expanded framework. In: Calhoun, LG.; Tedeschi, RG., editors. Handbook of posstraumatic growth. Lawrence Erlbaum Associates; New York, NY: 2006. p. 1-23.

Cassidy T. Benefit finding through caring: the cancer caregiver experience. Psychology and Health. 2013; 28:250–266. doi: 10.1080/08870446.2012.717623. [PubMed: 22928621]

Costa RV, Pakenham KI. Associations between benefit finding and adjustment outcomes in thyroid cancer. Psycho-Oncology. 2012; 21:737–744. doi: 10.1002/pon.1960. [PubMed: 21416554]

Danhauer SC, Case LD, Tedeschi R, Russell G, Vishnevsky T, Triplett K, Avis NE. Predictors of posttraumatic growth in women with breast cancer. Psycho-Oncology. 2013; 22:2676–2683. doi: 10.1002/pon.3298. [PubMed: 24136875]

Gaugler JE, Hanna N, Linder J, Given CW, Tolbert V, Kataria R, Regine WF. Cancer caregiving and subjective stress: A multi-site, multi-dimensional analysis. Psycho-Oncology. 2005; 14:771–785. doi: 10.1002/pon.916. [PubMed: 15750995]

Girgis A, Lambert S, Johnson C, Waller A, Currow D. Physical, psychosocial, relationship, and economic burden of caring for people with cancer: A review. Journal of Oncology Practice. 2013; 9:197–202. doi: 10.1200/jop.2012.000690. [PubMed: 23942921]

Kim Y, Schulz R, Carver CS. Benefit finding in the cancer caregiving experience. Psychosomatic Medicine. 2007; 69:283–291. doi: 10.1097/PSY.0b013e3180417cf4. [PubMed: 17420443]

Kolokotroni P, Anagnostopoulos F, Tsikkinis A. Psychosocial factors related to posttraumatic growth in breast cancer survivors: a review. Women and Health. 2014; 54:569–592. doi: 10.1080/03630242.2014.899543. [PubMed: 24911117]

Lechner SC, Carver CS, Antoni MH, Weaver KE, Phillips KM. Curvilinear associations between benefit finding and psychosocial adjustment to breast cancer. Journal of Consulting and Clinical Psychology. 2006; 74:828–840. doi: 10.1037/0022-006X.74.5.828. [PubMed: 17032087]

Lepore SJ, Revenson TA. Social constraints on disclosure and adjustment to cancer. Social and Personality Psychology Compass. 2007; 1:313–333. doi: 10.1111/j.1751-9004.2007.00013.x.

Levesque JV, Maybery D. Parental cancer: catalyst for positive growth and change. Qualitative Health Research. 2012; 22:397–408. doi: 10.1177/1049732311421617. [PubMed: 21890711]

Manne S, Ostroff J, Winkel G, Goldstein L, Fox K, Grana G. Posttraumatic growth after breast cancer: Patient, partner, and couple perspectives. Psychosomatic Medicine. 2004; 66:442–454. doi: 10.1097/01.psy.0000127689.38525.7d. [PubMed: 15184709]

Manne S, Ostroff J, Winkel G, Grana G, Fox K. Partner unsupportive responses, avoidant coping, and distress among women with early stage breast cancer: Patient and partner perspectives. Health Psychology. 2005; 24:635–641. doi: 10.1037/0278-6133.24.6.635. [PubMed: 16287411]

Miles, MB.; Huberman, AM.; Saldaña, J. Qualitative data analysis: A methods sourcebook. 3rd ed.. Sage Publications; Thousand Oaks, CA: 2014.

Moore AM, Gamblin TC, Geller DA, Youssef MN, Hoffman KE, Gemmell L, Steel JL. A prospective study of posttraumatic growth as assessed by self-report and family caregiver in the context of advanced cancer. Psycho-Oncology. 2011; 20:479–487. doi: 10.1002/pon.1746. [PubMed: 20878841]

Morris BA, Shakespeare-Finch J, Scott JL. Posttraumatic growth after cancer: the importance of health-related benefits and newfound compassion for others. Supportive Care in Cancer. 2012; 20:749–756. doi: 10.1007/s00520-011-1143-7. [PubMed: 21494782]

Morris BA, Wilson B, Chambers SK. Newfound compassion after prostate cancer: a psychometric evaluation of additional items in the Posttraumatic Growth Inventory. Supportive Care in Cancer. 2013; 21:3371–3378. doi: 10.1007/s00520-013-1903-7. [PubMed: 23928999]

Mosher CE, Adams RN, Helft PR, O'Neil BH, Shahda S, Rattray NA, Champion VL. Family caregiving challenges in advanced colorectal cancer: patient and caregiver perspectives. Supportive Care in Cancer. 2016; 24:2017–2024. doi: 10.1007/s00520-015-2995-z. [PubMed: 26530227]

National Alliance for Caregiving. National Alliance for Caregiving: Caregiving in the U.S. 2009. 2009Retrieved from http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf

Park CL. Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. Psychological Bulletin. 2010; 136:257–301. doi: 10.1037/a0018301. [PubMed: 20192563]

Penedo FJ, Molton I, Dahn JR, Shen BJ, Kinsinger D, Traeger L, Antoni M. A randomized clinical trial of group-based cognitive-behavioral stress management in localized prostate cancer: development of stress management skills improves quality of life and benefit finding. Annals of Behavioral Medicine. 2006; 31:261–270. doi: 10.1207/s15324796abm3103_8. [PubMed: 16700640]

Ruf M, Buchi S, Moergeli H, Zwahlen RA, Jenewein J. Positive personal changes in the aftermath of head and neck cancer diagnosis: a qualitative study in patients and their spouses. Head and Neck. 2009; 31:513–520. doi: 10.1002/hed.21000. [PubMed: 19132723]

Salsman JM, Segerstrom SC, Brechting EH, Carlson CR, Andrykowski MA. Posttraumatic growth and PTSD symptomatology among colorectal cancer survivors: a 3-month longitudinal examination of cognitive processing. Psycho-Oncology. 2009; 18:30–41. doi: 10.1002/pon.1367. [PubMed: 18481837]

Sears SR, Stanton AL, Danoff-Burg S. The yellow brick road and the emerald city: benefit finding, positive reappraisal coping and posttraumatic growth in women with early-stage breast cancer. Health Psychology. 2003; 22:487–497. doi: 10.1037/0278-6133.22.5.487. [PubMed: 14570532]

Shand LK, Cowlishaw S, Brooker JE, Burney S, Ricciardelli LA. Correlates of post-traumatic stress symptoms and growth in cancer patients: a systematic review and meta-analysis. Psycho-Oncology. 2015; 24:624–634. doi: 10.1002/pon.3719. [PubMed: 25393527]

Stanton, AL.; Bower, JE.; Low, CA. Posttraumatic growth after cancer. In: Calhoun, LG.; Tedeschi, RG., editors. Handbook of posttraumatic growth: Research and practice. Erlbaum; Mahwah, NJ: 2006. p. 138-175.

Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. Journal of Traumatic Stress. 1996; 9:455–471. doi: 10.1007/bf02103658. [PubMed: 8827649]

Tedeschi RG, Calhoun LG. Posttraumatic growth: Conceptual foundations and empirical evidence. Psychological Inquiry. 2004; 15:1–18. doi: 10.1207/s15327965pli1501_01.

Teixeira RJ, Pereira MG. Growth and the cancer caregiving experience: psychometric properties of the Portuguese Posttraumatic Growth Inventory. Families, Systems, and Health. 2013; 31:382–395. doi: 10.1037/a0032004.

Thornton AA, Owen JE, Kernstine K, Koczywas M, Grannis F, Cristea M, Stanton AL. Predictors of finding benefit after lung cancer diagnosis. Psycho-Oncology. 2012; 21:365–373. doi: 10.1002/pon.1904. [PubMed: 21254308]

Tomich PL, Helgeson VS. Is finding something good in the bad always good? Benefit finding among women with breast cancer. Health Psychology. 2004; 23:16–23. doi: 10.1037/0278-6133.23.1.16. [PubMed: 14756599]

Tomich PL, Helgeson VS. Posttraumatic growth following cancer: links to quality of life. Journal of Traumatic Stress. 2012; 25:567–573. doi: 10.1002/jts.21738. [PubMed: 23073975]

Traa MJ, De Vries J, Bodenmann G, Den Oudsten BL. Dyadic coping and relationship functioning in couples coping with cancer: a systematic review. British Journal of Health Psychology. 2015; 20:85–114. doi: 10.1111/bjhp.12094. [PubMed: 24628822]

Wang Y, Zhu X, Yang Y, Yi J, Tang L, He J, Yang Y. What factors are predictive of benefit finding in women treated for non-metastatic breast cancer? A prospective study. Psycho-Oncology. 2015; 24:533–539. doi: 10.1002/pon.3685. [PubMed: 25288217]

Weiss T. Correlates of posttraumatic growth in husbands of breast cancer survivors. Psycho-Oncology. 2004; 13:260–268. doi: 10.1002/pon.735. [PubMed: 15054730]

Zwahlen D, Hagenbuch N, Carley MI, Jenewein J, Buchi S. Posttraumatic growth in cancer patients and partners--effects of role, gender and the dyad on couples' posttraumatic growth experience. Psycho-Oncology. 2010; 19:12–20. doi: 10.1002/pon.1486. [PubMed: 19358228]

Table 1

Demographic and medical characteristics (*Ns* = 23 colorectal cancer patients and 23 family caregivers).

Characteristic	***No.* (%)**	**Mean (*SD*)**	**Range**
Caregiver's relationship to the patient			
Spouse/partner	18 (78)		
Other family member	5 (22)		
Patient gender—female	9 (39)		
Caregiver gender—female	20 (87)		
Patient race			
Caucasian	21 (91)		
Other race	2 (9)		
Caregiver race			
Caucasian	21 (91)		
Other race	2 (9)		
Patient marital status			
Married or marriage equivalent	20 (87)		
Unmarried	3 (13)		
Caregiver marital status			
Married or marriage equivalent	22 (96)		
Unmarried	1 (4)		
Patient age (years)		58 (11)	40 to 82
Caregiver age (years)		56 (12)	35 to 76
Patient education (years)		16 (3)	12 to 21
Caregiver education (years)		16 (3)	12 to 21
Patient annual household income (median)		>$100,000	>$10,000 to >$100,000
Caregiver annual household income (median)		>$50,000	>$30,000 to >$100,000
Months since the patient's colorectal cancer diagnosis		25 (21)	2 to 75
Cancer type and stage			
Stage III colon cancer	3 (13)		
Stage IV colon cancer	17 (74)		
Stage III rectal cancer	1 (4)		
Stage IV rectal cancer	2 (9)		
Treatment type			
Surgery	23 (100)		
Chemotherapy	23 (100)		
Radiation	20 (87)		
Chemoradiation	4 (17)		

Note. *SD* = standard deviation.

Table 2

Illustrative comparisons of patient and caregiver reports of caregivers' positive change.

Patient-caregiver relationship	Patient-reported positive change for the caregiver	Caregiver-reported positive change	Illustrative quote from patient and caregiver reporting caregiver's positive change
Patient = daughter Caregiver = mother	Closer relationships with others	Better health habits	P: “I think she has gotten the opportunity to be closer with some of her friends … communicating via phone or email has been important for her. I think one of the positives is that … we were pretty consistent with walking together and having some talks. I pick a topic and say tell me about the best things you remember about your childhood or let's talk about camping days or something like that and give us an opportunity to connect even closer.” C: “we [my family] can eat in a way to help prevent having cancer … we're becoming more aware of organic food and different ways to prepare food … I really feel that it's much more healthy for us. So that's been very positive for us.”
Patient = female partner Caregiver = female partner	Denial of benefits	Clarifying life priorities	P: “I don't think there's any positive change. I think she doesn't want me to go. She doesn't want to be without me.” C: “[I am] not worried about the yard anymore and what the neighbours think. It's like, you know what? The grass grows and it'll get cut eventually, [laughter] You have to evaluate what's important, what's really important to you.”
Patient = husband Caregiver = wife	Increased faith	Denial of benefits	P: “If there's anything positive, [it's] that we started going to church again. So I guess that's definitely a positive thing. I think it's definitely helped us.” C: “I can't think of anything positive in having to deal with cancer. I'm sorry. I wish I could. I wish somebody would find something.”
Patient = sister Caregiver = sister	Increased faith, greater appreciation of life	Better health habits, closer relationships with others	P: “I think it just made her even closer to God and even have more appreciation for each day … I'm sure she's very appreciative that she can just get up and go work on the farm or get up and do what she wants to do … after seeing me so sick … I'm sure it's probably made her more appreciative of everything that she has in her life.” C: “I am still trying to exercise more. Although she [the patient] was an exercise fiend and that didn't seem to matter…. Our family has always been close. I think we are even closer.”
Patient = husband Caregiver = wife	Closer relationships with others, increased faith	Closer relationships with others	P: “I think, me and my wife is closer together, closer than we've ever been before, and I think closer to God than we was before this happened, too. I know we are.” C: “I think we're [our family is] closer … [The illness has] jerked everybody's attention up in thinking, 'wow.'”

Note. P = Patient; C = Caregiver.