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Transitioning from Active Treatment: Colorectal Cancer Survivors' Health Promotion Goals

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Abstract

Objective—The purpose of this study is to describe the post-treatment goals of colorectal cancer (CRC) survivors. We sought to determine whether goals were a salient concept during the period immediately following treatment and whether a goal-setting intervention might be feasible and acceptable to these patients.

Methods—Semi-structured qualitative interviews were administered to a convenience sample of 41 CRC patients who were 0–24 months after treatment. Topics discussed included expectations and goals for future health, cancer prevention awareness, health-promoting behavior-change goals, and post-treatment cancer issues. Content analysis was used to explore emergent themes.

Results—Overall, participants' health-related goals were being healthy, getting back to normal, and not having a cancer recurrence. Most of the CRC survivors reported being proactive with their health by maintaining healthy behaviors, making healthy behavior changes, or had goals to change their behavior. All respondents had plans to maintain follow-up care and regular screening appointments. Some patients were managing treatment side effects or non-cancer issues that limited their functional abilities. Many respondents were satisfied with the care they received and felt it was now their responsibility to take care of the rest.

Conclusions—CRC survivors talk about goals and many of them are either making or have an interest in making health behavior changes. Self-management support could be an appropriate strategy to assist patients with achieving their health goals post-treatment. Patients may need help addressing lingering treatment side effects or non-cancer issues. Healthcare providers should consider assessing patients' goals to help patients resolve post-treatment issues and promote healthy behaviors.

Keywords

colorectal cancer; survivorship; health promotion; goals; post-treatment

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INTRODUCTION

Engaging in health-promoting behaviors, such as healthy eating, physical activity, and follow-up care, improves physical and psychological functioning (Berglund et al., 1994; Knols et al., 2005; Kuchler et al., 2007; Osborn, 2006), health status (Berglund et al., 1993), risk of recurrence (Meyerhardt et al., 2006), and overall survival (Kuchler et al., 2007; Meyerhardt et al., 2006) in colorectal cancer (CRC) survivors. Evidence suggests self-management programs both help individuals change behaviors (Von Korff et al., 2002) and improve clinical outcomes (Chodosh et al., 2005; Newman et al., 2004). Such programs have been used successfully in chronic disease management (Chodosh et al., 2005; Newman et al., 2004; Norris et al., 2001; Warsi et al., 2004) and lifestyle modification interventions, such as dietary change (Gillis et al., 1995) and physical activity (Van Weert et al., 2005). A few studies (Braden et al., 1998; Turton & Cooke, 2000; Cimprich et al., 2005; Korstjens et al., 2008) have used self-management strategies with cancer survivors that show promise in stimulating adoption of a healthier diet (Turton & Cooke, 2000), increased physical activity (Cimprich et al., 2005) and improved quality of life (Korstjens et al., 2008). The theory of self-regulation suggests people can regulate their own behavior through an iterative process of monitoring behavior, judging effectiveness of behavioral strategies against a goal or standard, setting or revising goals and plans, implementing the plans, and returning to monitoring in order to evaluate the implemented strategies (Bandura, 1991; Maes & Karoly, 2005; Bandura, 2005).

The end of cancer treatment is conceivably a “teachable moment” (Demark-Wahnefried et al., 2005; Ganz, 2005) as patients have an opportunity for setting goals for their self-management as survivors (Stanton et al., 2005; McCorkle et al., 2011). Previous studies conducted with breast and prostate cancer survivors indicate that they want to improve or maintain their physical health by engaging in physical activity, managing or losing weight, and eating a healthy diet (Demark-Wahnefried et al., 2000; Lauver et al., 2007).

Goal-setting is a way of helping patients make disease-related behavior changes (Gollwitzer & Oettingen, 1998; Bradley et al., 1999), however little is known about the goals of CRC survivors once they complete treatment. CRC survivors make up 11% of the cancer survivor population, have high rates of survival, receive ongoing surveillance related to cancer and co-morbidities, and the majority are over the age of 65.

To assist post-treatment CRC survivors to engage in health-promoting behaviors, we must understand their goals (Rasmussen et al., 2006). The purpose of this study was to identify and describe the health goals of CRC survivors who have completed cancer treatment.

METHOD

Participants

The first author conducted semi-structured in-depth interviews that were completed between August 2008 and August 2009 with a convenience sample of 41 adult CRC patients attending three clinics in Houston, Texas. Eligible study participants met the following criteria: diagnosed with colon or rectal cancer at stages 0-III, 0 to 24 months post-treatment and currently cancer free.

Recruitment and Data Collection

Eligible participants were identified through each clinic’s medical record system or cancer registry. Invitation letters were sent to potential participants at two clinics. Patients were approached during their clinic appointment, with the approval of their oncologist and/or if the patient had not declined participation or further contact. Patients at one clinic were contacted by phone to confirm their interest and eligibility and schedule a time to complete the interview.

Study participants received clinic site-specific informed consent forms. Once informed consent was obtained, a 30- to 60-minute interview was conducted the same day by the first author, in a private room at the site. Study participants received a $15 gift card. All procedures were approved by each partnering institution's institutional review board, and the University of Texas–Health Science Center at Houston.

Interview Guide

The research team developed the semi-structured in-depth interview guide (Table 1), based on theories about goal-setting (Locke et al., 1990; Locke, 1996; Bradley et al., 1999; Strecher et al., 1995) and self-regulation (Bandura, 1991; Maes & Karoly, 2005; Clark et al., 1991), prior research in cancer survivorship (Turton & Cooke, 2000; Cimprich et al., 2005; Korstjens et al., 2008), and research conducted by team members (Morrow et al., 2008; Brown et al., 2007; Schulman-Green et al., 2006). Topics of discussion included patients' expectations and goals for their health, cancer prevention awareness, goals regarding cancer prevention behavior, unaddressed issues related to their cancer experience, and goals for health-behavior change. Verbal probes were used to ensure comprehensive data collection and to clarify responses.

Data Analysis

Each interview was digitally recorded, transcribed verbatim, reviewed for accuracy, saved and transferred into ATLAS.ti (Muhr, 1997) – a qualitative analysis software program – for coding, sorting, retrieval, and evaluation.

The first author reviewed 15 transcribed interviews to develop a code key. The code key was reviewed and 15 interviews were coded independently by a research assistant with qualitative research experience. Consensus was reached between the first author and the research assistant's individual codes to finalize the code key. Any differences in codes were discussed with the co-authors for clarification and finalization (Miles & Huberman, 1994). Once the code key was finalized, all transcripts were coded by the first author.

The goal of the analysis was to identify and group themes that emerged from participants' responses. Identified codes were compared and grouped into themes according to a common element. Emergent themes were further examined using a matrix, to note any relationships or patterns across patient characteristics, such as gender, stage at diagnosis and time since treatment end.

RESULTS

Overview

The sample was predominately male, White, and well-educated (Table 2). Colon cancer was the principal diagnosis, with the majority diagnosed at stage III. All participants had surgery and most also had chemotherapy, radiation, or both.

Goals

General Goals—CRC survivors most commonly expressed an overarching goal to be healthy. This goal was typically described as a hope to remain cancer free. Many CRC survivors described their goal as getting back to normal or getting back to their regular pre-diagnosis activities. When asked about health goals, one woman said her goal is "To live my life, to get back to normal. To be able to do and go and what I did a year ago before all this happened. … Just work on physically getting back where I was and hopefully getting my life back" (57 year old White female, stage IIIB colon cancer, 5 months post-treatment).

Some patients also discussed being healthy in conjunction with a general action plan, such as keeping up with medical appointments. One man explained his plan to "…try to figure out the things that I need to do to stay healthy so that this will not happen again, lose weight, and become physically fit, stay around a little bit longer so I can take care of my family, and see my grandkids grow up" (57 year old Hispanic male, stage IIA colon cancer, <1 month post-treatment).

Health Behaviors—Many survivors discussed specific health behaviors as ways to maintain or achieve their overarching goal to be healthy (e.g., diet, physical activity, weight management, follow-up care, and quitting smoking). These behaviors were usually stated in combination with one another:

> I think I'd like to get more handle on my weight and my exercise issues. … I think if I could lose some weight and get more exercise that would improve my health and it may improve my chances on cancer too. (65 year old White male, stage IIIA colon cancer, 15 months post-treatment)

Some patients with health promoting goals also discussed brief action plans to achieving their health goal:

> I like to bake and I eat sweets, which is a big problem, but I'm going to cut that out. I'm going to stop baking as much, and the things that I know I cannot handle I won't even keep them in the house. I don't even keep ice cream in the house. (65 year old Black female, stage IIA colon cancer, 1 year post-treatment)

Additionally, some respondents had goals to maintain various health behaviors in which they were already engaged. When queried, these patients typically disclosed they engaged in health promoting behaviors prior to their diagnosis of cancer.

Managing Residual Effects of Cancer—Many survivors had goals specifically related to dealing with or managing the residual effects of their cancer treatment. For example, patients with ostomies had goals for management or reversal of a colostomy or ileostomy. One man discussed how his ostomy limited his physical function and his plan to get it reversed:

> As long as I got the ileostomy I can't really do much weightlifting…. As soon as they figure that the pressure had gone down on the liver, they're going to try to set up a schedule to reverse it. (62 year old Hispanic male, stage IIIA colon cancer, 4 months post-treatment)

A few patients went beyond the physical impact and discussed how ostomy affected them emotionally, their self-image and required support for dealing with a lifelong appliance:

> …I was worried….How am I going to put people in my car and I've got a colostomy bag on. Cuz I just knew it was gonna be odors and embarrassing and things were gonna happen in front. I figured my life was over. … Cuz you think you're Mr. Tough Guy and then somebody tells you you're going to wear a bag on your stomach the rest of your life and you break down in tears. I mean that's what I did. And I know I'm not the only one. So there needs to be a little bit of a support group for people. (55 year old White male, stage IIIB rectal cancer, 11 months post-treatment)

Additionally, several survivors had goals of mitigating treatment side effects, for example neuropathy. Patients expressed these as priority goals if they felt the condition was impeding their physical functioning:

> I want the neuropathy to go away. My feet just hurt. … I try to convince myself the fact that they hurt is meaning that the nerves are building back. …in December I want to be able to walk and not have to worry about the cold weather and the different things that happen with neuropathy. … I just want to be able to get around without my feet hurting. (52 year old White female, stage IIIB colon cancer, 13 months post-treatment)

Many of these patients with goals to manage or resolve residual cancer effects were competing with their goals of engaging in physical activity or eating a healthy diet. For example, a patient with an ostomy states:

> I think diet has a big part to do with how you feel, and I'm looking forward to having this reversal. I'm looking forward to being able to eat a normal healthy diet. … I can't have the fiber and all the vegetables. I can't eat nuts and different fruits and things. I can't have what might make things complicated. (52 year old White female, stage IIIB rectal cancer, 1 month post-treatment)

In contrast, several patients saw residual side effects as being unresolvable or out of their control. For example, a patient who had neuropathy felt she could do nothing to fix the problem and she simply needed to be patient and allow it to wear off with time. Overall, many survivors described the residual effects of cancer as things to manage or resolve and barriers to overcome.

Co-morbid Conditions—There were a few patients whose goals were not influenced by their cancer experience; instead their goals were inspired by co-morbid conditions. These patients were typically further past their last cancer treatment:

> I'm overweight and I do have diabetes, and I've kind of ignored that for the last two or three years. In fact, I'm totally off the medicine right now. Every time I come in, I get a lecture about what damage could be happening that I need to get under control, so I've got to convince myself that I need to get back on the diabetes medicine. I've been putting that off for a long time. (55 year old White male, stage IIIB rectal cancer, 11 months post-treatment)

Similar to patients with residual cancer side effects, patients dealing with non-cancer health issues (i.e., diabetes and chronic back pain) also had goals to resolve these issues that were competing with their other health-promoting goals:

> [My goal is] getting better and getting rid of the pain, and not from the cancer but from the lower back….That's definitely gonna be my biggest goal. And then once I can walk around, I'll take care of the rest….exercise. If ever I could get some pain relief I'd definitely be able to do that. (55 year old white male, stage O colon cancer, 3 months post-treatment)

Barriers and Resources

When asked specifically about barriers to achieving their goals, most patients acknowledged themselves as the only thing that could hinder their achievement. Survivors were quick to take personal responsibility for their actions and success:

> A doctor already gave me a suggested diet…the things that are good for me and the things that are not, but that's about all I need….I just come back for my checkups….I am determined, and usually if I'm determined to do something, I do

> it, I finish it...health-wise or anything else. (65 year old Black female, stage IIA colon cancer, 12 months post-treatment)

When asked about resources that would be helpful, most patients could not identify anything that could help them achieve their goals. Instead, most survivors talked about how satisfied they were with the care they received and how now it is their personal responsibility to maintain or improve their health.

In addition, many respondents talked about the potential benefits of support from their peers, whether one-on-one or in a group. Typically these same people were willing to return the favor to a future cancer patient:

> It’s one thing to hear it from the doctor that you’ll be doing these things, but it’s another thing to talk to somebody who’s gone through the treatment, who’s gone through the process,…so that they hear firsthand from somebody… (54 year old Hispanic male, stage IIIB colon cancer, 21 months post-treatment)

Characteristics of Goals

None of our CRC survivors’ goals included characteristics of being specific, measurable, achievable, and realistic or timed (Wade, 2009). A few participants’ goals did include action plans or steps to achieve their goals. For example, one survivor discussed how he is maintaining physical activity by walking a mile each day and tries to go a little bit farther every time. In another example, one survivor shared what he is doing to improve his diet, including using substitution.

> Try to eat a little bit better. You know, I don’t watch what I eat…, but I’m trying to learn how to eat some vegetables and things of that sort, taking a lot more vitamins, drinking orange juice instead of coffee. (41 year old Hispanic male, stage IIA colon cancer, 22 months post-treatment)

Relationship between Goals & Patient Characteristics

Patients with specific medical issues discussed their goals in relation to resolving or managing a specific issue. Additionally, participants who completed treatment within the previous six months most often discussed goals associated with their cancer experience, for example coping with or resolving treatment side effects and getting back to normal.

> Since the surgery I’ve lost a few pounds, because of my appetite, but that’s one of my goals now is to get back and formulate a really good eating habit to protect my diet again, you know, to eat the right kinds of food, and to get back 100% within the next three weeks. (57 year old Black male, stage I rectal cancer, <1 month post-treatment)

DISCUSSION

We found that patients’ goals were often diffuse or broad, and can be viewed as hopes or desires more than motivating goals or action plans. Patients expressed their goals in the way they wanted to ‘be’ (e.g., be healthy) versus the things they needed to ‘do’ (e.g., exercise or eat healthy) (Rasmussen et al., 2006). These goals can be seen more as outcome goals versus behavior change goals. Patients also had goals that may be more related to an acute care context in which they want to return to normal or their pre-cancerous state once treatment ends. Patients don’t seem to acknowledge having been transformed in permanent or long-term ways by the cancer and its treatment – a transformation that may mean “getting back to normal” is not an option. Instead cancer survivors may need to adjust to a “new normal.” Additionally, when patients did discuss behavior changes, their aspirations and action plans were expressed as generalities. These general goals may not be as helpful in managing the changes brought about by cancer and non-cancer co-morbidities as would more specific goals and action plans.

The most useful or effective goals for achieving health behavior changes are fairly specific, moderately challenging but attainable, have a time frame, and also are accompanied by very specific plans (Wade, 2009; Bovend'Eerdt et al., 2009; Doran, 1981; Gollwitzer & Oettingen, 1998). Oettingen and Gollwitzer (2002) suggests that people with broad goals or desires will not be stimulated to act on the goal, but need to take steps to turn these broad desires into specific, motivating goals. Bodenheimer and Handley (2009) further describes goals as being distal (general) or proximal (specific); the more specific the goal the more likely the patient will achieve it. While patients' broad goals were pertinent, they did not have the characteristics of goals that lead to motivation and planning (Bovend'Eerdt et al., 2009; Locke & Latham, 2002; Lorig & Holman, 2003).

McCorkle and colleagues (2011) suggest that behavior change goals in cancer survivorship should be in the chronic care context and include behaviors across the cancer continuum. Using goal-setting and self-management in chronic care could be a viable option for helping cancer survivors set realistic goals and action plans that will help change their behavior and improve their health outcomes. These goals would include managing sequelae of the cancer and its treatment, maintaining cancer screening and medical care follow-up to find recurrence or a new cancer early, and managing other chronic illnesses.

In this study, survivors reported three types of health-related goals related to the sequelae of their cancer treatment, the management of other chronic illnesses, and general health promotion. Individuals who completed treatment more recently or who had significant residual treatment effects often had goals related to those residual issues (e.g., ostomy appliance or neuropathy). For some patients, these issues competed with their goals by serving as barriers to achieving other health-promoting goals, such as engaging in physical activity. This was also found in patients with non-cancer issues (e.g., back pain). Patients who discussed treatment side effects or complications in terms of chronic conditions seem to have a different perspective. These patients seem to recognize the need to balance competing goals (e.g., adjust to or reverse ostomy before moving forward with physical activity). They also seem to understand that survivorship is different from simply "returning to normal." These patients may require additional assistance in prioritizing their goals to minimize conflicts, setting realistic goals, and making action plans for managing chronic conditions or overcoming residual treatment effects. In caring for cancer survivors, special attention may be required for patients with residual treatment side effects and non-cancer issues. For example, a patient with neuropathy may have trouble walking, which would hinder physical activity, and they would need a recommendation for an alternative exercise option such as yoga.

Our respondents consistently see themselves as being responsible for their health once treatment ends, however chronic care research (Von Korff et al., 1997) suggests that a collaborative approach between patient and provider leads to goal achievement and better health outcomes (Wagner, 2000). In addition, it is not typical of healthcare providers to explicitly help patients define goals and make strategic plans to work toward them because (1) the acute problem was resolved and the patient should return to 'normal,' and (2) there is a lack of time, interest, and training regarding goal assessment and goal-setting (Schulman-Green et al., 2006).

The chronic care model of our cancer care infrastructure largely excludes post-treatment cancer survivors. Post-treatment cancer survivorship programs can align themselves with models that incorporate chronic care and self-management, including enhancing patients' confidence in their ability to be proactive and empowered patients, and facilitate patient-provider communication and collaborative healthcare (McCorkle et al., 2011; Cimprich et al., 2005). Patient-provider communication has been associated with improved performance in other chronic diseases, such as diabetes (Heisler et al., 2002), and has been linked to better continuity of care, preventive services, and optimal self-care (Sevick et al., 2007).

Collaboration between patients and providers is increasingly important among cancer patients due to the complexities of medical care and self-care during and after treatment, including planning and maintaining follow-up care, managing residual treatment side effects, maintaining care for co-morbid conditions, and dealing with psychosocial issues (Hack et al., 2005). Studies have shown healthcare providers have a significant effect on health promotion behavior change in cancer patients with even modest interventions (Jones et al., 2004). Other studies show that healthcare providers can also be trained to help patients set goals and create action plans that foster behavior change (Langford, 2007; Handley et al., 2006; MacGregor et al., 2006; Naik et al., 2008). Healthcare providers, especially non-physician providers (e.g., oncology nurses, case managers, social workers, and rehabilitation specialists), play a big role in chronic care, and requires a team approach (McCorkle et al., 2011; Miller, 2008; Fenlon & Foster, 2009)

Results from this study are similar to other studies that indicate cancer patients do have health-related goals and some are even taking steps to achieve those goals, even patients not far removed from treatment (Stanton et al., 2005; Demark-Wahnefried et al., 2000; Lauver et al., 2007). This indicates that self-management with goal-setting and action planning could be appropriate and well received by patients who are completing or have completed treatment. Self-management and goal-setting has been successful in changing behaviors and improving health outcomes in patients with chronic diseases (Chodosh et al., 2005; Handley et al., 2006; Barlow et al., 2002; DeWalt et al., 2009). A few studies (Cimprich et al., 2005; Stanton et al., 2005; Damush et al., 2006) indicate the same potential in post-treatment cancer survivors, and across the cancer continuum (McCorkle et al., 2011). Additionally, as seen in our study, patients' goals are specific to the individuals and their circumstances because each person will have unique physical and psychosocial issues after treatment. That individuality gives credence to the appropriateness of self-management and tailored interventions for cancer survivors.

Our study has a few limitations. The respondents comprised a convenience sample of CRC survivors, mostly White males with at least some college education. However, efforts were made to recruit a diverse sample by recruiting in three diverse clinic settings, resulting in 36% minorities, which is fairly consistent with the Houston, Texas population. Additionally, assessing healthcare providers' perspectives, as well as families and friends of cancer survivors, could have been informative considering the importance of patient-provider communication and social support (Gallant, 2003).

Our study suggests cancer survivors need help developing goals that lead to behavior change. Our findings also suggest that cancer survivors needs and goals vary and require a tailored approach. Patients being seen for follow-up care appointments with their oncologists or those who have returned to their primary care providers could benefit from a brief intervention with a healthcare provider (Fleming & Manwell, 1999), not limited to their physician. An intervention may include assessing the patient's goals and the provider's goals; a discussion to set a mutually acceptable goal; and then an action plan for achieving the goal. Throughout the process, the patient and provider should have follow-up visits or consultations to assess progress, identify barriers, problem-solve, and provide resources.

Many cancer survivors have co-morbid conditions that may be barriers to achieving their health-related goals (Rodriguez-Bigas et al., 2007; Courneya et al., 2005). Future studies should focus on these patients, who may have varying needs to address. Overall, cancer survivors' needs and goals vary and require more tailored programs.

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Table 1

Semi-Structured In-depth interview Guide

Expectations and goals for future health:

- What are your expectations/concerns for your health in the future?
- Over the next 6–12 months, what are your goals in terms of improvements in your current symptoms or limitations due to your cancer and/or treatments for your cancer?
- Over the long term, what are your goals for your health, your career, and life in general?

Awareness of cancer prevention:

- What have you learned or heard about that you think might help improve your general health?
- Are there things you specifically believe might help you prevent a new cancer or a return of your cancer?
- How has your cancer and cancer treatment affected your other health conditions?

Cancer prevention behavior changes:

- So you talked about …., would you like to change any of this (*previously mentioned goals*)?
- Do you have any specific goals in mind about (*previously mentioned goals*)? *if so, please explain/describe.*

Remaining cancer related issues:

- Is there anything that came up during your cancer experience that you feel like you still need to deal with or manage now that treatment has ended?

Help with goals and changes:

- Are you doing anything now to actively work on (whatever goals were previously mentioned)
- What goal is your highest priority?
- Can you imagine anything your doctors or the cancer center might be able to do or give you to help you work on your goals?
- What barriers do you think you might encounter when trying to work on your goals?

Behavior change history:

- Have you ever tried to make any behavior changes in the past? *If so, please explain/describe.*

Note: Additional probing questions were asked for clarification or elaboration, in relation to specific goals identified by the study participant.

Table 2

Participant Demographic and Clinical Characteristics

(N=41)	Mean ± SD	(range)
Age	61 ± 11	(33–87)
Time since treatment (*months*)	8.6 ± 6.4	(0.4–22.4)
	Frequency	(%)
% Male	32	(78)
Race/ethnicity		
White / Caucasian	26	(63.4)
Black / African American	11	(26.8)
Hispanic	4	(9.8)
Education		
< High school	4	(9.8)
High school	5	(12.2)
Some college	13	(31.7)
College degree or more	19	(46.3)
Type of cancer		
Colon	23	(56.1)
Rectal	15	(36.6)
Both	3	(7.3)
Stage at diagnosis		
0	1	(2.4)
I	8	(19.5)
IIA	9	(22)
IIIA	5	(12.2)
IIIB	17	(41.5)
IIIC	1	(2.4)
Type of treatment		
Surgery Only	10	(24.4)
Surgery & Radiation	2	(4.9)
Surgery & Chemotherapy	15	(36.6)
Surgery, Radiation & Chemotherapy	14	(34.1)
Clinic Site		
VA Medical Center	14	(34.1)
Multi-Specialty Physician Group	12	(29.3)
Comprehensive Cancer Center	15	(36.6)