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A Content Analysis of Functional Recovery Strategies of Breast Cancer Survivors

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Abstract

Seventeen breast cancer survivors completed a six-week, telephone-delivered, Behavioral Activation/Problem-solving intervention designed to reduce participation restrictions. A content analysis of the session data was conducted to identify the goals and patterns of goal attainment, in order to understand what women were trying to achieve in their recovery. The 17 women set 141 goals. Sixty-six (47%) of the goals reflected a desire to add a new activity to their routine and 75 (53%) of the goals reflected a desire to perform a routine activity more efficiently. The women set goals to address challenges in exercising (24%), work (13%), nutrition (11%), instrumental activities of daily living (IADLs; 10%), stress management (9%), and social activities (9%). The women set an average of 8 goals and met 71% of their goals. The intervention shows promise in helping women set and achieve a number of functional goals as part of breast cancer recovery.

Keywords

cancer; descriptive study; breast neoplasm; occupational therapy; rehabilitation

At the start of 2012, 2.9 million women living in the United States had a history of breast cancer (American Cancer Society, 2013). Survival has improved, but cancer and its treatment can have long-lasting or late effects that can influence a woman's ability to fully participate in many occupations. A recent review noted a dearth of interventions that directly target participation restrictions in cancer survivors (Egan et al., 2013). Participation restrictions refer to challenges people face engaging in their self-care, productive, and leisure activities within their homes and communities (World Health Organization, 2001). Satisfaction with the ability to perform daily activities, also known as functional well-being, is one aspect of quality of life (Cella & Nowinski, 2002). Recent studies found that reduced functional well-being predicted shorter overall survival in women treated for breast cancer (Braithwaite et al., 2010; DiSipio, Hayes, Battistutta, Newman, & Janda, 2011). The ability to perform daily activities and routines to one's satisfaction is, therefore, implicated in both quantity and quality of life.

Younger breast cancer survivors may have a heightened risk of experiencing participation restrictions after cancer treatment. In a study of 2,910 cancer survivors, younger and female respondents reported the most physical and emotional post-treatment concerns and were least likely to have received post-treatment care (Beckjord et al., 2013). This echoes other work that found younger breast cancer survivors at greater risk of disability, likely due to responsibilities for which physical effort is required such as child care, paid employment, and household maintenance (Ganz et al., 2002; Irwin et al., 2003; Kroenke et al., 2004; Mackenzie, 2014; Ness, Wall, Oakes, Robison, & Gurney, 2006; Thewes, Butow, Girgis, & Pendlebury, 2004). Age-related demands of working and child rearing may also make it difficult for younger breast cancer survivors to access traditional rehabilitation services (Miedema & Easley, 2012).

In a series of studies (Hegel et al., 2011; Lyons et al., 2014), we have developed and evaluated a flexible, telephone-based, rehabilitation intervention using the structure of Behavioral Activation and Problem-solving Treatment (BA/PS; Cuijpers, van Straten, & Warmerdam, 2007a; Cuijpers, van Straten, & Warmerdam, 2007b; Hegel & Arean, 2003; Lejuez, Hopko, LePage, Hopko, & McNeil, 2001). The BA/PS intervention is designed to reduce participation restrictions and improve the quality of life of young- to middle-adult breast cancer survivors. In a recently submitted manuscript, we described the feasibility and potential efficacy of the intervention as implemented in two pilot studies (Lyons et al., 2014). In sum, the pilot studies indicate that the intervention 1) is feasible and acceptable to participants, 2) helps women to meet their short-term functional goals, and 3) may increase active coping, planning, and quality of life. The current analysis uses intervention data from the second pilot study in that report. The experiences of women participating in the intervention offer insight into the types of challenges women face in cancer recovery. In this manuscript we present a content analysis of the intervention data: what the women chose to address during the intervention, what they were trying to accomplish, and the patterns of goal attainment experienced by the sample. These data will help us to understand the participants' needs and identify opportunities for improving the intervention.

Method

Study Design

There were two phases in this pilot study. In phase one, we delivered the intervention to six women, revising the treatment manual after the first and the last three women had completed the intervention and provided feedback regarding what they found most and least helpful about the intervention and the workbook. Seventeen women enrolled in the second phase of the study, however, two withdrew before completing the baseline assessment and three withdrew during the six week no-treatment run-in period that was used to assess the persistence of participation restrictions. Twelve women began the intervention but one woman withdrew after one session, reporting an inability to fit the intervention into her schedule. The remaining 11 women completed the six sessions of the intervention. This analysis uses session data from the 17 women who completed the intervention (six of them participating in phase one, and 11 of them participating in phase two).

Women were eligible for the study if they had stage I – III breast cancer, were between 18 and 59 years of age, had completed definitive breast cancer treatment (i.e., subsequent to loco-regional surgical treatment and completion of adjuvant or neo-adjuvant chemotherapy with or without radiation) within the past 6 months, spoke English, and screened positive for a moderate or worse level of participation restriction (i.e., score > 10 on the Work and Social Adjustment Scale [WSAS]; Mundt, Marks, Shear, & Greist, 2002). The WSAS was chosen as a screening tool as it offers a 5-item measure of self-reported impairment in work, self-care, and leisure and has been shown to correlate with depression ($r = 0.76$) and be sensitive to disease severity and treatment-related change. A research assistant worked with the oncologists to identify women who were completing chemotherapy for stage I-III breast cancer. She then screened them in the clinic and initiated informed consent procedures (i.e., ongoing discussion of study risks, benefits, rationale, expectations, etc. and documented in a signed consent form) with women who were eligible and interested in participating. A full description of the study design can be obtained from the first author. The study design and procedures were approved by the Dartmouth College Committee for the Protection of Human Subjects (Institutional Review Board) and were consistent with the revised (2000) Helsinki Declaration.

Intervention

The BA/PS intervention was adapted from two manualized, evidence-based interventions that were originally designed to treat depression: Behavioral Activation (BA) (Cuijpers, van Straten, & Warmerdam, 2007a; Lejuez, Hopko, LePage, Hopko, & McNeil, 2001) and Problem-solving Treatment (PST) (Cuijpers, van Straten, & Warmerdam, 2007b; Hegel & Arean, 2003). Both interventions use structured formats to teach people ways to adapt to and cope with stress by finding practical solutions to daily challenges in life. By carefully and systematically identifying barriers to participation, brainstorming possible adaptive strategies, and creating a comprehensive action plan, women are able to make realistic and progressively larger changes to their daily routines and activities, in a way that promotes functional recovery and quality of life.

Behavioral Activation (BA) involves three steps: identifying what makes the activity challenging, setting a goal for the week that is behavioral, measureable, and achievable within the next seven days, and developing a specific action plan that details when, where, and how the goal will be met. BA is a parsimonious and efficient method of setting goals when the woman knows exactly what she wants to accomplish and primarily needs to create an adaptable action plan. For example, women often reported that they used to attend a gym but had not been exercising since treatment due to being busy or fatigued. If they knew that they wanted to resume their previous gym activities, then BA allows them to examine their personal challenges (e.g., identify patterns of fatigue, level of motivation, contextual factors like child care or body image concerns that can affect gym attendance), set a goal, then specify an action plan that includes things such as identifying days and classes she will attend, the availability of resources such as gym clothes and childcare, and whether another person's involvement would be helpful. Each woman is also prompted to identify a "plan B" of how she can get to the gym or get another form of exercise if a child becomes ill, a workout buddy cancels, or a class is cancelled.

Problem-solving utilizes the same steps as Behavioral Activation, but adds the steps of brainstorming solutions and weighing their advantages and disadvantages. For this reason, problem-solving takes longer to deliver than Behavioral Activation, but is better suited for situations when a woman does not know exactly what it will take to meet her goal. For example, in the current study one woman wanted to stop smoking. She knew that she wanted to identify an activity she could do when coming home after work that would take the place of sitting down to smoke, but was not sure what activities would be most effective. After identifying her challenges and setting a goal to initiate a replacement activity each day after work, she used the brainstorming step of problem-solving to generate four “replacement activities” for smoking: going for a walk, knitting, journaling, or doing a puzzle. She then evaluated the advantages and disadvantages of each in terms of how well they would engage her mind and body. For example, the advantages of walking are that it would get her moving and away from where she usually smokes and that it is very dissimilar to sitting and relaxing on the deck with a cigarette. However, the disadvantages of walking as a replacement activity were that it might take more time and energy than she has after work and she might be disinclined to walk in bad weather. By similarly weighing the other options, she was able to choose the activity she thought would help most and generate an action plan to help her meet her goal.

The BA/PS intervention was individually delivered by an occupational therapist over the telephone in six weekly sessions. The women received a workbook (written at a seventh-grade reading level) that contained background information and worksheets to use when setting and monitoring weekly goals. During the first session the interventionist explained: a) the structure and rationale of the intervention, b) the relationship between activity engagement and health, and c) the benefits of regular exercise and effective stress management techniques during cancer recovery. Each week, women were asked to set at least one goal related to an activity that they wanted to do in the next seven days but found challenging.

Data Collection

Both the occupational therapist and the participant used a worksheet to record the details of each telephone BA/PS session. The therapist took notes on the worksheet during the session, and attempted to use the participant’s words to record what was discussed. After each session, the therapist transcribed and summarized the following participant-reported information into a database: the activity topic, the goal, whether the goal was attained, the participant’s degree of satisfaction with the effort expended on the action plan (on a zero to 10 scale, with “0” being “not at all satisfied” and “10” being “completely satisfied”), reasons for unsuccessful goal attainment and whether the goal was set using behavioral activation alone or with problem-solving.

Analysis

Goal Attainment

Goal attainment was calculated on two levels. First, the therapist recorded the participant’s report of whether the goal was “met” or “not met.” The therapist then calculated and

recorded the degree of goal attainment by assessing the number of actions that were taken to meet the goal. For example, if the woman's goal was to exercise four days in a week and she exercised three days, then the goal was "not met" and the therapist recorded "75%" for the degree of goal attainment.

Coding

The 17 participants generated 141 goals. Three coding structures were used in this analysis. First, the therapist categorized the activity topic using a coding structure developed in an earlier study (Lyons, Erickson, & Hegel, 2012). That structure was developed for another content analysis in which we were also trying to summarize the types of activities that participants wanted to address within a behavioral intervention to reduce disability. Second, the therapist developed codes to describe the type of goal and the reasons for non-attainment. The goal codes represented "in vivo" codes (Glaser & Strauss, 1967) developed from multiple readings of the worksheets, as opposed to the "a priori" activity topic codes determined by the previous coding structure. After coding all of the goals, the operational definitions for the activity topic, the goal type, and the reasons for non-attainment were given to a research assistant (second author) who independently coded the goals. The therapist and assistant then met to review the coded data and discuss the coding scheme. The operational definitions were subsequently refined and the therapist and assistant met once more to review each goal and determine the appropriate code. The codes were determined by consensus, with the pair reviewing the original worksheets to resolve any discrepancies.

The final coding scheme included 13 activity topics, two types of goals, and five reasons for unsuccessful goal attainment. The 13 activity topics included exercise, work, nutrition, instrumental activities of daily living (i.e., housecleaning, yard work, meal preparation, shopping, and managing finances) stress management or relaxation activities, social activities, child care, leisure, habits (i.e., weighing self daily, hanging up coats and clothes daily, and taking medications with food), smoking cessation, arm exercise or stretching, cognition (i.e., doing memory exercises or establishing memory aids), and sleep. When the woman was trying to add a new activity to her routine or increase the time spent doing the activity, we described this type of goal as "doing more." For example, this code was applied when the woman wanted to start an exercise program or wanted to increase her hours at work. In these cases, the minutes spent in activity engagement would increase. When the woman was already doing the activity in some fashion but was trying to make the activity more efficient, easy, enjoyable, or effective then we coded this type of goal as "doing differently." For example, this code was applied when the woman wanted to use energy management techniques during housecleaning, or wanted to have her children prepare their own lunches, or wanted to use memory aids to function more efficiently at work. In these situations a woman might be introducing a new discrete behavior but in the spirit of actually decreasing the amount of time or energy spent doing an activity.

The reasons for unsuccessful goal attainment were categorized into five codes. First, there were sometimes "*unexpected events*" such as the flu, a back injury, or a surprise visit from an out-of-town friend that made goal attainment impossible or undesirable. More often, there were "*expected barriers*" which were typical hassles that come up in life that make

goal attainment challenging, such as feeling tired or feeling stressed. In the third code, participants explicitly noted that a “*reduced effort*” was put into executing the action plan, saying that they did not take the time to attempt the action plan or that “it fell off the radar.” The fourth code was used when a woman “*came close*” to meeting her goal. This was applied when the woman’s degree of attainment was 80% or higher. Finally, the last code was applied when a woman put effort into attempting the action plan but explicitly “*changed her mind*” and downgraded the standard needed to attain a particular goal, deciding during execution that the goal was too aggressive or inappropriate. For example, upon execution one woman decided that having her children pack their lunch every day was not necessary, but their packing it two days a week would be helpful.

Descriptive analysis

Means and frequencies were calculated for participant demographics. Using the participant as the unit of analysis, we calculated the mean number of goals set and attained by each woman, b) the number of activity topics covered by each woman and c) the proportion of women who addressed each activity topic with at least one goal. Using the goal as the unit of analysis, we calculated frequencies of behavioral activation versus problem-solving, the activity topics and types of goals, goal attainment, and reasons for unsuccessful goal attainment. We calculated the mean degree of goal attainment and the level of satisfaction with effort.

Results

Participants

Demographics of the 17 women who completed the six session intervention are presented in Table 1. The women ranged in age from 37 to 55, with a mean of 47.9 years ($sd = 6.1$). All women were Caucasian and non-Hispanic, and most were married (71%) and working full (59%) or part-time (18%). Most women had received a mastectomy (82%) and radiation (71%) and all had completed chemotherapy.

The women addressed an average of 3.8 ($sd = 0.8$; range = 2 to 5) different activities. Most of the women chose to address challenges in exercise (71%) and many women set at least one goal to address challenges in work (41%), social activities (41%), and instrumental activities of daily living (41%). The proportion of women addressing each type of activity at least once is displayed in the second column of Table 2.

The women set a minimum of 5 goals (one for each of the sessions excluding the first) and a maximum of 15 goals over the six sessions (mean = 8.3, $sd = 3.0$; median = 7). On average, the women met 71% of the weekly goals that they set. Eight women met at least 80% of their weekly goals, with three of them meeting all of their weekly goals. One woman met only 25% of her weekly goals, another met 40% of her weekly goals, and the remaining seven women met at least half (but less than 80%) of their weekly goals.

Recovery Goals

Topic and type of goal—The seventeen women set 141 goals over their six BA/PS sessions. Eighty-seven percent of goals were set using behavioral activation and 13% were set using problem-solving. The first column in Table 2 displays the proportion of goals addressing each activity type. Women most frequently set goals to address challenges in exercising (24%), work (13%), nutrition (11%), instrumental activities of daily living (IADLs; 10%), stress management (9%), and social activities (9%).

All of the goals were active in that they required the woman to initiate a behavior to accomplish the goal. Sixty-six goals (47%) reflected a desire to “do more” by adding a new activity to a routine e.g., start exercising or make time for a “date night” or “girls’ night.” For 75 of the goals (53%), the objective was to perform a routine activity more efficiently, effectively, or enjoyably e.g., use energy management techniques during housecleaning, eat more vegetables, or communicate better at work.

Goal attainment and satisfaction with effort—Goal attainment data is available on the 121 goals that were set during the first five sessions (women often set a goal during session six, but the occupational therapist did not contact participants in the following week to determine if the goal was met). The participants met 83 of their goals (69%) and, on average, rated their satisfaction with these met goals as 8.5 out of 10 ($sd = 1.7$). Of the goals that women met, 60% were goals in which they were trying to perform a routine activity in a different manner (“do differently”) and 40% were goals in which they were trying to add a new activity to their usual routine (“do more”).

Conversely, the women did not meet 38 of their weekly goals (31%). Their satisfaction with the effort they took to meet these unmet goals was 5.1 ($sd = 2.8$). Partial goal attainment occurred for 24 of the 38 unmet goals (63%) and five of those goals “came close” to being met (13%). The reasons for the lack of goal attainment were attributed to expected barriers (42%), reduced effort (18%), and unexpected events (16%). On four occasions (11%), the women changed their mind about meeting the goal.

Discussion

We undertook this content analysis to increase our understanding of what women were trying to accomplish in their functional recovery from cancer treatment and how the intervention could be enhanced to better meet their needs. When looking at the participant-level data, it is apparent that these breast cancer survivors focused on participation restrictions in a variety of activity domains. Most women set goals in four different activity domains and the most frequently addressed activities included exercise, work, social activities, and instrumental activities of daily living. None of the participants had only one area of concern or addressed only one type of activity, indicating that women typically have rehabilitative needs that span multiple domains. This mirrors other literature indicating that breast cancer survivors need to manage multiple demands in different domains of life (Ganz et al., 1996; Pauwels, Charlier, De Bourdeaudhuij, Lechner, & Van Hoof, 2013; Thewes et al., 2004), frequently re-negotiating a balance between health promotion, work, and family responsibilities (Mackenzie, 2014).

The majority of the participants was able to meet most of the weekly goals and reported high levels of satisfaction with the effort that they expended. Adding a new routine to an already busy schedule and modifying an activity that they were already doing were equally important (47% and 53% of goals, respectively). While many women reduce activity levels during treatment (Irwin et al., 2003), recovery is not simply a matter of increasing activity levels until the pre-morbid level is reached. Instead, the experience of cancer can lead women to re-evaluate their lifestyles and routines and find ways to make large or subtle changes in their daily activities (Shannon & Shaw, 2005; Wilkinson, 2000).

While expected and understandable, the variation in the number of activities addressed and the intention of the goal poses a measurement challenge. Each woman has an idiosyncratic profile of challenging activities and varies in whether she is ultimately trying to increase or decrease her minutes of activity engagement. Instruments that measure the number of minutes in activity engagement or the level of independence may not be sensitive to subtle changes in routines and lifestyle that could ultimately be health-promoting for a given woman. It may appear prudent to revise the intervention to focus on one particular impairment or activity e.g., use BA/PS to help women increase hours at work or minutes spent exercising. Despite the logic and appeal of a more tightly specified intervention, it could decrease the clinical and practical utility of the intervention. Issues related to various domains may overlap (Mackenzie, 2014) and it may be more helpful to address multiple issues with one format. The advantage of the BA/PS intervention lies in its ability to offer one structure that women can learn and internalize, and then use to address various practical challenges in daily life.

The women often encountered “expected” barriers in their attempts to meet goals, e.g., a child needs attention, something comes up at work, or a woman felt too tired or stressed to exercise. These are events that should be anticipated in the action planning stage of BA/PS. The women usually had at least partial success with these goals and often re-visited the goal in a subsequent week with some degree of success. These patterns suggest that the intervention may be enhanced by a revision to the treatment manual. Only 13% of goals were set using problem-solving. If the participant does not meet a goal due to experiencing expected barriers, the therapist should explicitly encourage the use of problem-solving when re-visiting the goal. It may be that the women needs to step back and creatively generate new responses to typical barriers as the initially identified plan may be inadequate.

The other reasons for unmet goals similarly suggest other treatment manual modifications. When a woman reports reduced effort towards meeting a goal, she may benefit from motivational interviewing (Miller & Rollnick, 2012). A woman who came close to meeting a goal might need to ascertain if the goal was overly ambitious or if the action plan needs enhancing. In cases where an unexpected event occurred that made it impossible or undesirable to meet the goal, the therapist needs to help the woman determine if the time is right to revisit the goal and if the initial action plan will suffice, given the events lined up for the coming week.

Limitations and Directions for Future Research

The findings from this study should be interpreted with caution in light of the following issues. First, the codes were developed by studying the worksheets of the occupational therapist. The therapist completed the worksheets during the telephone sessions and, as such, the notes likely reflect the words spoken by the participant. However, it is possible that analysts listening to transcripts of the sessions could have generated different coding schemes. Second, these results only reflect the perspectives of this convenience sample of women. The sample was somewhat homogeneous in the sense that more than 75% of the sample had some level of college education, all were Caucasian and non-Hispanic, and most had undergone both mastectomy and radiation in addition to their chemotherapy treatment. Furthermore, the women who began the intervention first completed a baseline study assessment, experienced a six week no-treatment run-in phase, and then completed another study assessment. We do not have a clear picture of how these women differ from the women who withdrew from the study before beginning the intervention, except to say that the women who withdrew typically cited being too busy to continue, as opposed to saying that they no longer needed the intervention.

The next step for our research is to make modifications to the BA/PS intervention based on these data to enhance the rates of goal attainment (e.g., more sessions, inclusion of motivational interviewing, and increased use of problem-solving after a goal is not met with Behavioral Activation alone). In future studies we will assess the degree to which weekly goal attainment leads to long-term improvements in participation and quality of life and the ways in which the intervention can be tailored to meet the needs of women with lower levels of literacy. We also plan to investigate the feasibility and utility of individualized outcome measures such as goal attainment scaling (Turner-Stokes, 2009) and the Canadian Occupational Performance Measure (Law et al., 2014) for breast cancer survivors. Such instruments may help to track each woman's progress towards the idiosyncratic changes that she feels will most enhance her health and recovery. After establishing an individualized measure of participation, BA/PS will be ready for a large-scale randomized controlled trial to assess its efficacy in reducing participation restrictions and facilitating recovery in breast cancer survivors. Should the intervention prove efficacious, it could be adapted to meet the needs of survivors of other cancers that frequently occur at early to middle adulthood, such as Hodgkin's disease or testicular cancer. The ultimate goal is to provide an evidence-based intervention that occupational therapists can use to ameliorate participation restrictions faced by persons with cancer, at all stages in the illness experience (Egan et al., 2013; Feuerstein, 2009).

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Table 1

Participant Characteristics (N = 17)

Characteristics	Mean (sd)	n (%)
Age in years	47.9 (6.1)	
Stage		
1		5 (30)
2		6 (35)
3		6 (35)
Surgery		
Mastectomy		14 (82)
Lumpectomy		3 (18)
Axillary node dissection		15 (88)
Number lymph nodes dissected	11.1 (8.2)	
Received radiation		12 (71)
Race and Ethnicity		
White and Non-Hispanic		17 (100)
Marital status		
Never married		1 (5)
Married		12 (71)
Living with a partner		2 (12)
Divorced		2 (12)
Living with children < 16 years old		6 (35)
Employment		
Full time		10 (59)
Part time		3 (18)
Not working		4 (23)
Income		
Less than \$40,00 per year		9 (53)
\$40,000 or more per year		8 (47)
Education		
High school graduate/GED		4 (24)
Some college/technical school		5 (28)
College graduate		4 (24)
Graduate degree		4 (24)

Table 2

Domains addressed during the BA/PS sessions

Code	Number of goals addressing the domain (N = 141) n (%)	Number of participants addressing the domain (N = 17) n (%)
Exercise	34 (24)	12 (71)
Work	18 (13)	7 (41)
Nutrition	16 (11)	5 (29)
Instrumental activity of daily living	15 (10)	7 (41)
Stress management/relaxation	13 (9)	6 (35)
Social	13 (9)	7 (41)
Child	8 (6)	5 (29)
Leisure	7 (5)	4 (24)
Habit	6 (4)	3 (18)
Smoking cessation	5 (3)	2 (12)
Arm exercise/stretching	2 (2)	2 (12)
Cognition	2 (2)	2 (12)
Sleep	2 (2)	2 (12)