

# Healing stories: Narrative characteristics in cancer survivorship narratives and psychological health among hematopoietic stem cell transplant survivors

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## ABSTRACT

*Objectives:* Survivors of hematopoietic stem cell transplant (HSCT) have experienced a life threatening and potentially traumatic illness and treatment that make them vulnerable to long lasting negative psychological outcomes, including anxiety and depression. Nevertheless, studies show that overcoming cancer and its treatment can present an opportunity for personal growth and psychological health (reduced symptoms of anxiety and depression and high levels of emotional well-being) through resilience. However, research has not yet clarified what differentiates HSCT survivors who experience psychological growth from those who do not. By analyzing recovery narratives, we examined whether HSCT survivors' interpretation of their experiences helps explain differences in their post-treatment psychological health.

*Methods:* Guided by narrative psychology theory, we analyzed the narratives of 23 HSCT survivors writing about their experience of cancer treatment. Psychological health was measured by: (1) emotional well-being subscale part of the Functional Assessment of Cancer Therapy Bone Marrow Transplant (FACT-BMT), (2) depression, and (3) anxiety subscales of the Brief Symptom Inventory.

*Results:* Findings revealed a positive relation between psychological health and a greater number of redemption episodes (going from an emotionally negative life event to an emotionally positive one) as well as fewer negative emotional expressions.

*Significance of the results:* Theoretical and practical implications of these findings are discussed, showing how narratives can inform interventions to assist cancer survivors with their psychological recovery.

**KEYWORDS:** Narrative, Cancer, Psychological health, Stress, Cancer survivor

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## HEALING STORIES: NARRATIVE CHARACTERISTICS IN CANCER SURVIVORSHIP NARRATIVES AND PSYCHOLOGICAL HEALTH AMONG HEMATOPOIETIC STEM CELL TRANSPLANT SURVIVORS

Survivors of hematopoietic stem cell transplant (HSCT) have experienced a life threatening disease and a physically and psychologically challenging treatment that can affect many areas of their lives. In addition to having to cope with their diagnosis (usually a hematologic malignancy), HSCT survivors undergo toxic treatment regimens that put their lives at risk (Copelan, 2006), including high dose chemotherapy. Studies of cancer survivors have emphasized the traumatic characteristics of cancer, including its sudden and unexpected onset and its uncontrollable nature (Tedeschi & Calhoun, 1995). Furthermore, research shows that HSCT precipitates responses consistent with psychological trauma (Mosher et al., 2009).

As a result, many studies of HSCT have focused on its negative emotional effects on survivors, including anxiety and depressive symptoms, diminished quality of life, and elevated generalized distress (Baker et al., 2003; Broers et al., 2000; Edman et al., 2001; Kettmann & Altmaier, 2008; Mosher et al., 2009). However, other studies suggest that HSCT can provide an opportunity for personal growth (Andrykowski, Brady & Hunt, 1993; Hefferon, Grealy & Mutrie, 2009; Tallman, Altmaier & Garcia, 2007). Research on personal growth following a traumatic experience has identified benefits such as development of the self, enhanced self-disclosure, emotional expressiveness in relationships, and a changed philosophy of life (Hefferon, Grealy & Mutrie, 2009; Tedeschi & Calhoun, 1995). However, research has not yet clarified what differentiates HSCT survivors who experience psychological growth from those who do not. The current study explores this question through the lens of narrative psychology theory, using the narratives of 23 HSCT survivors writing about their experience of the treatment. By analyzing these recovery narratives, we can examine whether HSCT survivors' interpretation of their experiences helps explain differences in their post-treatment psychological health.

Narrative psychology argues that the stories people tell about their lives are not mere recordings of life events but manifestations of the subjective ways they construct reality. Thus, narrative analysis offers an opportunity to understand emotions and psychological dynamics (McAdams, 1993; Raggatt, 2007; Singer, 2001). Examining the narrative characteristics of psychological growth and resilience after

cancer treatment can help guide interventions to promote psychological health among survivors.

Narratives consist of two dimensions: *content* (i.e., what is being said) and *form* (i.e., how it is being said). Content analysis focuses on the ideas, memories, events, and themes in the story; form analysis deals with the structure of the story, including the organization of its plot, the order of the events, and the progress of the narrative in time (Benish-Weisman, 2009; Lieblich, Tuval Mashiah & Zilber, 1998.) Form analysis differs from content analysis in two important ways. First, while narrators are usually highly aware of the content of their story, they may be less aware, and therefore less in control, of the story's form. Therefore, form analysis provides an opportunity to look at the deep and sometimes unconscious layers of the narrator's story. Second, content analysis tends not to focus on the timeline of a story, whereas form analysis does look at how an experience is discussed with respect to time elements, thereby adding a developmental point of view (Tuval-Mashiah, 2006).

For the most part, studies suggest that the content of a narrative is associated with the writer's psychological health, although evidence for a relationship between lower levels of psychological health and expression of emotional negativity remains unclear. That is, some studies suggest that narratives containing a large proportion of negative emotional words indicating sadness, fear, and unhappiness are negatively correlated with psychological health (Liehr et al., 2010; Pennebaker & Seagal, 1999). Others claim that the repression of negative emotions can lead to increased levels of anxiety and depression (Iwamitsu et al., 2003), therefore emphasizing the therapeutic effect of expression of negative emotional effect (Graf, Gaudio & Geller, 2008).

In addition, many studies suggest that the form of a narrative is associated with the writer's psychological health. The nature of the connection between the episodes of the story reveals the subjective way in which the cancer survivor interprets his or her illness and recovery. In a redemption sequence, for example, the storyteller describes episodes of transformation, going from an emotionally negative life event to an emotionally positive one (McAdams et al., 1997). It has been shown that redemption episodes are positively related to high levels of psychological health (McAdams et al., 2001). To our knowledge, this is the first study to examine form characteristics of narratives in HSCT survivors.

The current study hypothesizes that negative emotional expressions and redemption episodes in recovery narratives will differentiate survivors with poor psychological health from those with better psychological health. Specifically, we hypothesize that survivors with poor psychological health will

tell recovery narratives with a significantly different amount of negative emotional expressions (due to inconsistencies in the literature we do not specify direction) and fewer redemptive episodes than survivors with better psychological health.

## METHODS

### Participants and Procedure

Twenty three participants in the present study were recruited through screening for a parent study — a multi-site trial investigating a cognitive behavioral intervention for severely distressed HSCT survivors (described in DuHamel et al., 2010). Men and women were recruited for the trial's telephone-administered screening protocol through clinical databases at three medical centers in the northeastern United States. To participate in the trial's screening protocol, they had to be 1–3 years post-HSCT, English-speaking, and at least 18 years old. They were excluded if they were awaiting another transplant or receiving treatment for disease relapse, or if they had severe cognitive impairment, active psychosis, suicidal ideation, or substance dependence.

Participants who completed the trial's screening were approached for recruitment into this study if they were assessed as having at least elevated general distress and/or subclinical PTSD symptoms.<sup>1</sup> Those who agreed completed a pilot study of a psychosocial intervention that included three writing sessions, spaced one week apart, and a follow-up assessment 3 months after the last writing session (Smyth & Pennebaker, 2010). Because many HSCT survivors live far from their treatment site and have difficulty attending in-person study meetings, all pilot study procedures were completed by telephone using mailed materials. The writing sessions provided the narratives analyzed in the present study and the follow-up assessment provided the measures of psychological health. Using a telephone-based version of Pennebaker's emotionally expressive writing instructions (Pennebaker, 1997; Zakowski et al., 2004), pilot study participants were called for writing appointments and instructed to write continuously for 20 minutes about their deepest thoughts and feelings regarding their transplant experience. (A separate group of pilot study

participants wrote in a non-emotionally expressive way about their daily activities; however, their narratives were not appropriate for this study and therefore are not discussed.) Each writing session focused on a specified stage of transplant (i.e., before, during, and after hospitalization). After completing each writing session, participants returned their writing in a postage-paid envelope. All procedures were approved by the Institutional Review Boards of the two participating study sites. Participants were compensated for their time.

### Measures

#### *Psychological Health*

Three measures of psychological health were employed, assessing psychological aspects of health-related quality of life, depression, and anxiety. We assessed both cancer-specific and general psychological health outcomes as recommended by Mosher et al. (2009).

Psychological aspects of health-related quality of life were assessed with three items from the emotional well-being subscale part of the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT) Version 4, a well-validated self-report instrument. Responses to questions about events in the prior week (e.g., "I worry about dying," or "I worry that my condition will get worse") were provided on a scale from 0 (*not at all*) to 4 (*very much*). Responses were reversed and summed so that *higher* scores reflected a *higher* level of psychological health ( $\alpha = 0.73$ ).

Depression and anxiety were measured using the depression and anxiety subscales of the well-validated Brief Symptom Inventory (BSI, Derogatis, 1975). Each subscale included five items. Depression symptoms included "feeling blue" and "feeling no interest in things." Anxiety symptoms included "suddenly scared for no reason" and "feeling fearful." Respondents indicated how much discomfort each of these symptoms caused them in the past month on a scale from 1 (*not at all*) to 5 (*extremely*). A mean score for each subscale was calculated. Higher scores on these scales reflected higher levels of emotional distress. The internal reliability of each scale was  $\alpha = 0.73$  and  $\alpha = 0.66$ , respectively.

#### *Narrative Characteristics*

All the narratives of the 23 participants were coded by two trained independent coders. Initial training included studying the content of each coding category and discussing the optional inclusion/exclusion criteria. The unit of the coding could be a few words (as illustrated by the examples of negative emotional expressions, below) or an entire paragraph

<sup>1</sup>Patients met criteria for the study if (1) they were not eligible for the multi-site trial because they did not meet its distress criteria (probable illness-related posttraumatic stress disorder [PTSD], subclinical PTSD symptoms, or elevated general distress with some PTSD symptoms, assessed with validated measures; see DuHamel et al., 2010) or (2) they were eligible for the multi-site trial because they met these criteria but they refused to participate in the trial.

(as illustrated by the example of a redemption episode, below), dependent on the context. Nvivo, a qualitative analysis program was used for coding. The coders agreed 77% of the time. Cases of disagreement were decided by a third independent judge. The categories for coding were (1) negative emotional expression and (2) redemption episodes. Emotional expressions were coded as such if they contained explicit affect. Examples of negative emotional expressions that were found in our sample narratives included: “(I felt) sadness when thinking of my family if this had not worked out” and “I was scared, angry, overwhelmed.” The coding of the redemption episodes was based on the instructions in the Coding System for Redemption Sequences (McAdams, 1999). The redemption episodes were defined as explicit transformation in the story from a decidedly negative affect state to a decidedly positive affect state (McAdams et al., 2001). The transformation could take two forms: (1) a change from a negative affect state to a positive affect state, (2) the formation of a positive outcome out of a bad situation. For example, a 32 year old woman reflected on her healing experience as follows: “Finally in conclusion, I can say that this experience has definitely been an opportunity for me to reflect on my life and truly value the things that I normally would overlook, under normal circumstances. The challenges have made me think harder; appreciate the small things in nature and within me.” It is clear from this quotation that this survivor acknowledges the benefits of the hard experience she had. Moreover, from her perspective, the disease has improved her life.

## RESULTS

### Descriptive Statistics

Participants ranged in age from 26 to 76 ( $M = 56.6$ ,  $SD = 11.5$ ). Nearly half (45.8%) were women, 87.6% were white, and 70% were married. With respect to psychological health, their emotional well-being subscale scores from the FACT-BMT ranged from 14 to 24 ( $M = 20.87$ ,  $SD = 2.38$ ), their BSI depression subscale scores ranged from 0.01 to 0.15 ( $M = 0.28$ ,  $SD = 3.7$ ), and their BSI anxiety subscale scores ranged from 0.01 to 0.84 ( $M = 0.19$ ,  $SD = 0.27$ ).

### Hypothesis Testing

Our objective was to test the hypothesis that survivors who suffered from poor psychological health would tell recovery narratives with a significantly different number of negative emotional expressions and fewer redemptive episodes than survivors with better psychological health. First, we divided the

sample into different levels of psychological health by performing a cluster analysis using FACT emotional well-being scores, the anxiety subscale of the BSI, and the depression subscale of the BSI. Using a two-step cluster analysis with Schwarz Bayesian Criterion and Distance Measure Log-Likelihood, two clusters emerged. The first cluster ( $n = 19$ ) was characterized by a high score on the FACT emotional well-being scale ( $M = 21.64$ ,  $SD = 1.7$ ) and low scores on the depression ( $M = 0.15$ ,  $SD = 0.17$ ), and anxiety subscales of the BSI ( $M = 0.09$ ,  $SD = 0.14$ ). We named it the *high psychological health cluster*. The second cluster ( $n = 4$ ) was characterized by a low score on the FACT emotional well-being scale ( $M = 17.25$ ,  $SD = 2.3$ ) and high scores on the depression ( $M = 0.8$ ,  $SD = 0.58$ ), and anxiety subscales of the BSI ( $M = 0.67$ ,  $SD = 0.24$ ). We named it the *low psychological health cluster*.

In order to examine whether narrative characteristics differentiated between the two clusters, we conducted discriminant analysis, with redemption and negative emotionality episodes predicting membership in the two psychological health clusters. Discriminant Function Analysis is well-suited to identifying and mapping the narrative patterns that differentially characterize high and low levels of psychological health. The overall Wilk's lambda was significant ( $\Lambda = 0.67$ ,  $\chi^2[2, N = 23] = 8.06$ ,  $p < 0.05$ ), indicating that the predictors significantly differentiated the two psychological health clusters. To interpret this finding, standard discriminant loadings (or discriminant function coefficients) were examined. Discriminant loadings operate as factor loadings would in factor analysis (Burns & Burns, 2008). The positive coefficient for redemption episodes (0.7) and negative coefficient for negative emotionality episodes ( $-0.67$ ) were relatively large (i.e., over 0.5 (Burns & Burns, 2008)). In addition, the psychological health cluster group means on the discriminant loadings indicate that high numbers of redemption episodes and low numbers of negative emotionality episodes were related to high psychological health. The cross validation enabled 78.3% of the individuals in this sample to be classified correctly, which is regarded as an acceptable percentage (Burns & Burns, 2008). I would add a summary sentence here or the first in the discussion reminding people what we found— overall, consistent with our hypothesis, we found that the greater incidence of redemptive episodes and a the lower use of negative emotionality episodes predicted better psychological health.

## DISCUSSION

Living through HSCT can result in long-lasting and negative psychological outcomes for survivors. The

current study examined whether HSCT survivors' post-treatment psychological health was associated with the form of their recovery narratives. Findings indicated that, compared to survivors with poor psychological health, those with better psychological health were more likely to describe redemption episodes and less likely to use negative emotional expressions.

The fact that people with better psychological health used fewer negative emotional expressions suggests that HSCT survivors' expression of their stress and fear may not serve as a cathartic mechanism (Pennebaker, 2003). This finding contradicts traditional clinical psychology theories that encourage the expression of repressed negative emotionality in the belief that they can release the patient from his/her dark feelings (Murray, Lamnin & Carver, 1989), though it is consistent with more recent models of trauma and coping, which claim that encouraging expression of negative emotions and grief as an intervention strategy might not be helpful (Bonnano, 2004; Bonnano & Mancini, 2008). Although the correlational design of the study prevent us from making conclusions about causality, our findings are consistent with previous studies suggesting that ruminating on negative emotions might preserve or even aggravate negative mood (Bushman, 2002), thereby preventing an opportunity for change. For example, the expression of intense anxiety by breast cancer patients may contribute to and maintain feelings of helplessness (Lieberman & Goldstein, 2006). In other words, emotional discharge may not be enough for change in psychological adjustment (Nenova et al., 2011).

Our findings indicate that survivors who experience their recovery as built on negative points that turn into positive ones (redemption episodes) enjoy better psychological health. This is consistent with other studies that show that cognitive change through a reappraisal of the situation may be necessary in order to achieve better psychological health (Murray, Lamnin & Carver, 1989; Pennebaker, 1997). The ability to construct life events positively is related to well-being (King & Miner, 2000; McAdams et al., 2001; Taylor, 1989), and many studies show that optimistic or hopeful people have better mental health. We argue that HSCT survivors derive their present mental health in part from their former experience of illness. In other words, in their narratives they portray past difficulties as the reason for present psychological health, and their experience of the healthy present is intensified by their difficulties in the past.

Narratives open a window on the subjective experience and thus present an ideal opportunity to study people's experiences. However, the converse

is also true: narratives can affect experiences (Widderhoven, 1993). Through retelling, the feeling or evaluation of an experience may change. By putting experiences into words and by creating the possibility of looking at an experience from a distance, storytellers are able to process memories, feelings, and thoughts; they can reevaluate what happened or even have new insights. For HSCT survivors, naming amorphous and sometimes overwhelming experiences allows them to connect their stories to others (Frank, 2001), developing feelings of companionship and solidarity.

Findings from the current study should be evaluated in the context of the study's methodological limitations. First, the study has a small number of participants. Although intriguing and potentially clinically valuable, findings should be verified in a larger study examining the relation between narrative characteristics and psychological health in cancer survivors. Second, it includes HSCT survivors who are one to three years into their recovery. As longitudinal studies suggest (e.g., Hjerstad et al., 2004), psychological health changes over time. Therefore, future studies should investigate HSCT survivors at various points in their recovery. A longitudinal design would facilitate investigation of the plausibility of causal links between narrative structural elements and later psychological health.

Despite some limitations, the study makes a significant applied contribution. Our findings suggest detecting structural elements in HSCT survivors' stories may enable health workers and therapists to comprehend unspoken aspects of their recovery stories (Frank, 2001). Through the insight they derive, they may be able to help their HSCT survivor clients to do more than simply express their negative emotions, as these emotional expressions might have negative effects (Murray, Lamnin & Carver, 1989). Rather, they may be able to help their survivor clients interpret their stories more adaptively while retaining the facts. Moreover, a client's writing could provide a therapist with insight. For example, when a survivor's writing indicates a lack of redemption or highly negative affect, talk therapy could be used to move the individual to a more redemptive, positive understanding of the transplant experience. In addition, providing new interpretations of past events might allow the client and therapist to compose new endings to stories of suffering (Omer & Alon, 1997).

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