



Suffering in Advanced Cancer: A Randomized Control Trial of a Narrative Intervention

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Background

Advanced cancer often engenders existential angst and psychological suffering. "Being at peace" is associated with dying well; and its converse with a heightened distress and desire for hastened death.[1-3] Undergoing cancer treatment can thwart a sense of peace, and disrupt a sense of meaning in life. Narrative interventions, such as support groups, illness narratives, and life review manuscripts collected via bedside interviews have improved the wellbeing of in-patient hospice and palliative care patients,[4-7] but might not be feasible for widespread implementation. Our prior research suggested that pre-hospice patients could benefit from a life review/cancer narrative intervention.[8] *miLivingStory*, using a telephone interview to elicit the life and illness story and online tools to support revising and sharing the study-delivered story manuscript, was found to be acceptable to diverse, community-dwelling cancer patients and resulted in the addition of social networking tools.[9]

Specific Aims

1. Test *miLivingStory's* effects on wellbeing and distress
2. Explore use of and satisfaction with *miLivingStory*

Methods

Recruitment: Patients with Stage III or IV cancer, receiving therapy from the University of Wisconsin's Carbone Cancer Center

Randomization: 1:1 in blocks of 10, stratified by gender and race/ethnicity, after the baseline survey. The active control group received *miOwnResources*

Measures at baseline, 2 and 4 months: Peace and Meaning subscales of the Functional Assessment of Chronic Illness Therapies-Spirituality (FACIT-Sp) [8]. Anger, Depression, Tension subscales of the Profiles of Mood States-Short Form (POMS-SF). Both measures use a 0 to 4-point Likert scale to measure agreement. Use and satisfaction measured by survey with a 0-4 Likert scale.

Data analysis: Mixed Modeling, controlling for pre-test, tested for group comparisons of repeated measures at 2 & 4 months. Pair-wise comparisons tested for within- and between-group differences for the primary outcomes.

Interventions

My Living Story (intervention group):

1. An expert interviewer/writer:
 - a. Elicited the story by recorded telephone interview, asking:
 - Can you tell me a little about your life history?
 - What are the most important things you have done or accomplished?
 - How has cancer affected you/your life?
 - In 20 or 30 years from now, what would you want your family, friends or loved ones to remember about you?
 - What have you learned about life and that you'd like to pass along?
 - Is there anything about you, your hopes/dreams that you'd want to share?
 - b. Wrote a coherent story from the transcript
 - c. Delivered the Story in paper and e-formats to share with loved ones.
2. Online tools: Life review education; social media; and information, support and planning tools hosted on the National Cancer Institute and American Cancer Society websites.

My Own Resources (active control group):

1. NCI and ACS information, social support and planning tools

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Results

Baseline Characteristics: No between-group differences for this educated, primarily white, female sample with high well-being, especially for *Meaning*, and low distress.

	<i>miLivingStory</i>	<i>miOwnResources</i>	P-Value
Demographics	N = 49 ¹	N = 37 ¹	
Age, Range 35-80 Mean (SD)	57 (8.5)	57 (9.1)	.917
Female, n (%)	40 (82%)	28 (76%)	.345
White	45 (92%)	36 (97%)	-
Spouse/Partner	36 (74%)	28 (76%)	.744
Income > \$60,000	26 (53%)	19 (51%)	.509
Education > BA/BS	26 (53%)	17 (46%)	.348
Cancer, n (%)			
Metastatic	23 (47%)	13 (35%)	.122
CAM (meditation, support groups, art)	40 (86%)	27 (73%)	.486
Main Outcomes, Mean (SD)	0 - 4 Likert (0 = not at all ... 4 = very much)		
Peace ²	2.65 (0.81)	2.68 (0.65)	0.89
Meaning ⁴	3.49 (0.57)	3.34 (0.66)	0.28
Depression ³	0.60 (0.69)	0.59 (0.44)	0.92
Anger ³	0.48 (0.58)	0.51 (0.52)	0.81
Tension ³	0.74 (0.67)	1.02 (0.90)	0.11

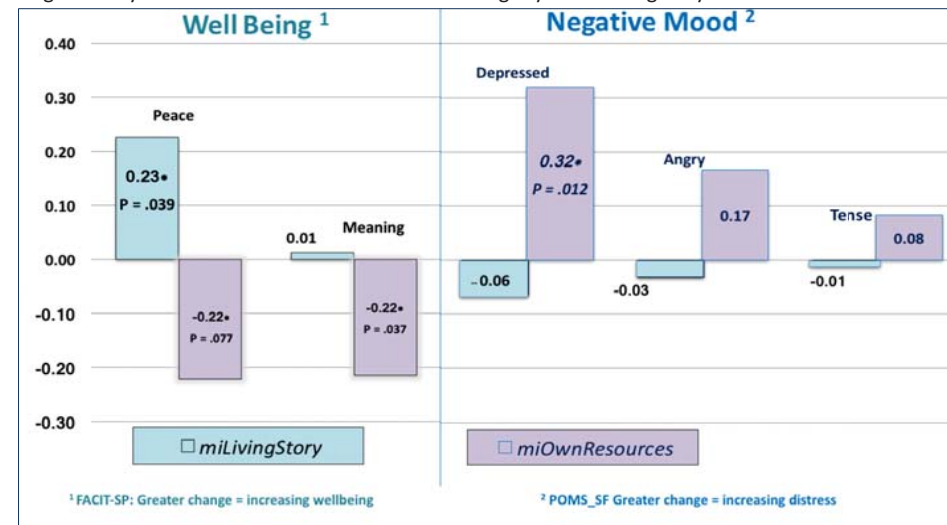
¹ 117 consented, 110 enrolled, 24 dropped out (Reasons: too ill, death, loss to follow-up)
² FACIT-Sp: Higher scores = Higher wellbeing; ³ POMS-SF: Higher scores = Higher distress

Intervention Effects at 2 and 4 months as measured from baseline.
There were no effects at 2 months. At 4 months *miLivingStory* had significantly greater *Peace* and trending effects for *Depressed Mood*.

		Primary Outcome Scores		Between-Group Differences ³	
		<i>miLivingStory</i> Mean (SE)	<i>miOwnResources</i> Mean (SE)	Mean Diff (SE) ³	p-Value
Peace ¹	2 Months	2.64 (0.89)	2.78 (0.66)	-0.14 (0.14)	.343
	4 Months	2.86 (0.84)	2.57 (0.93)	0.31 (0.14)	.029 ⁵
Meaning ¹	2 Months	3.39 (0.72)	3.44 (0.62)	-0.15 (0.13)	.266
	4 Months	3.40 (0.71)	3.22 (0.83)	0.18 (0.13)	.548
Depressed Mood ²	2 Months	0.83 (0.73)	0.45 (0.48)	0.16 (0.13)	.226
	4 Months	0.55 (0.70)	0.77 (0.75)	-0.22 (0.13)	.097 ⁵
Angry Mood ²	2 Months	0.49 (0.59)	0.47 (0.65)	0.02 (0.12)	.888
	4 Months	0.46 (0.50)	0.64 (0.79)	-0.18 (0.12)	.119
Anxious Mood ²	2 Months	0.79 (0.09)	0.77 (0.10)	0.02 (0.14)	.869
	4 Months	0.78 (0.73)	0.85 (0.10)	-0.07 (0.13)	.592

¹ Higher scores = Higher wellbeing; ² Higher scores = Higher distress;
³ *MLS minus MOR* at 2 and at 4 months, compared to baseline scores; ⁴ Significant at p < .05; ⁵ Trending at p < .10

Understanding effects at 4 (but not 2) months: Within-group changes between 2 and 4 months
Overall, the 4 *minus* 2 month showed that the *miLivingStory* group's wellbeing improved, while the *miOwnResources* group's wellbeing declined. *Peace* improved significantly for *miLivingStory*, and declined at a trending level, along with *Meaning*, for *miOwnResources*. *Depressed mood* increased significantly for *miOwnResources* and decreased slightly for *miLivingStory*.



Greater engagement increased satisfaction with telling and receiving the story.

<i>miLivingStory</i> (n = 49)	Edited Story Manuscript			Shared Story Manuscript		
	Yes (n = 24)	No (n = 23)	p-Value	Yes (n=15)	No (n = 30)	p-Value
Life Story phone interview ¹	3.00 (1.00)	2.37 (1.21)	0.090	3.00 (0.78)	2.17 (1.15)	0.018
Life Story manuscript ¹	2.46 (0.98)	1.82 (1.37)	0.070	2.80 (0.56)	1.84 (1.32)	0.010

¹ 0= Not at all helpful, 1=Somewhat helpful, 2=Helpful, 3=Quite helpful, 4=Very helpful

Comments:
I could never have done [the story] on my own.
Interviewer was very good. Allowed me to stay focused on my own thoughts and feelings and explore them.
Very nice to tell my story and to get it in written and audio form.
It helped to read My Living Story and get a perspective on my life.
I shared it with some very close friends. Allowed for deep and nurturing time.
My family is happy to know that my life story exists to be shared.
When you are dead and gone, it would be a great have a document like that!
To actually talk about your life and to see how it all relates to having an ongoing cancer--to put it into words. There really isn't another time to say what's in your heart.

In their own words...From their stories...

I can be sick, but my soul isn't. There's certain things my cancer won't do. It won't touch my memories. There's no way it can touch that. I can live off of them. It's just great. It can't touch my friends. I still have my friends that are my spirit, hope, and courage. Cancer can't touch any of that. (Excerpt. 057, Male age 60)

I have had a lot of loss and a lot of opportunities...I don't have a lot of material things. What I do have, I treasure. True blessings... I got pregnant at age 16. My parents put my daughter up for adoption against my will. ... I thought losing my daughter's was behind me. Then my 12-year old son was killed in a car crash. I knew I needed God's help to get through this... My estranged daughter came back before I had cancer. She has been just steadfast. Looking back, I would say the last five years have been the best part of my life. (Excerpt. 024, Female, age 64)

Discussion and Conclusions

miLivingStory significantly improved a sense of peace in patients with advanced cancer. Trends for lower depression the were due to declines in the *miOwnResources* group more than improvements the Story group. Thus, *miLivingStory* seems to have protected against increasing suffering in late-stage cancer. We had expected *miLivingStory* to increase a sense of meaning and decrease psychological distress, but baseline wellbeing was high and distress low. More exploration how the narrative intervention affects peace in patients with advanced cancer is needed.

Busy clinicians might benefit from receiving their patients' written life story. The William S. Middleton Memorial Veterans Administration's *My Life, My Story* program uses trained volunteers to collect and share veteran's stories with their clinicians. [10]

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