

# Getting Creative with a Coached Writing Intervention to Improve Outcomes in Patients with Advanced Cancer: A single arm, rural academic medical center pilot study

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# Background

Expressive Writing (EW) has a positive impact on psychological response, illness behaviors, and QoL<sup>1</sup>

*Private writing for 20 minutes 4 days in a row about one's deepest thoughts and feelings regarding a past traumatic event<sup>2</sup>*

1. Frattaroli J. Experimental disclosure and its moderators: a meta-analysis. Psychol Bull 2006; 132(6) 823–65.
2. Pennebaker JW, Beall SK. Confronting a traumatic event: toward an understanding of inhibition and disease. J Abnorm Psychol 1986; 95(3): 274–81.

# Background

Minimal data on EW in seriously ill patients.

Seriously ill patients are living in a traumatic experience.

EW may cause psychological harm<sup>3</sup>.

# Background

Writing coach can guide patients in choosing goals, mode, genres, and content of activities influenced by EW, positive psychology, and dignity therapy with emphasis on the patient being the locus of control.

# Aims

1. Assess the feasibility of a writing coach working with incurable cancer patients
2. Gather initial data on grief, resilience, coping, existential distress, mood, and illness acceptance

# Methods

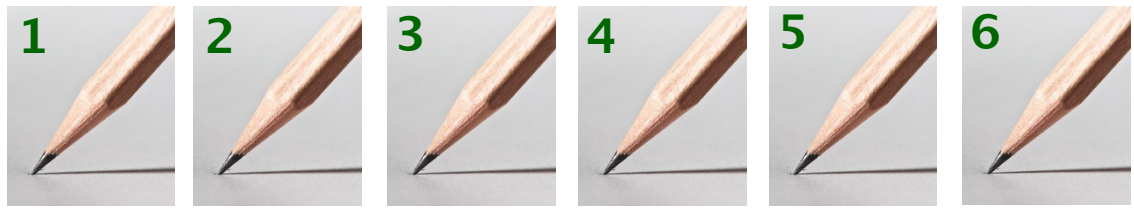
## MEASURES

ALL  
OD  
D  
EVEN

- |      | Baseline  | 3 Months   | 6 Months   | 9 Months   |
|------|---|--|--|--|
| ALL  | <ul style="list-style-type: none"> <li>➤ Clinical/Demographics</li> <li>➤ Performance Status</li> <li>➤ Anxiety, Depression, Distress, Physical Symptoms, Prognostic Awareness</li> </ul> | <ul style="list-style-type: none"> <li>➤ Writing Practices Survey</li> <li>➤ Performance Status</li> <li>➤ Anxiety, Depression, Distress, Physical Symptoms, Prognostic Awareness</li> </ul> | <ul style="list-style-type: none"> <li>➤ Writing Practices Survey</li> <li>➤ Performance Status</li> <li>➤ Anxiety, Depression, Distress, Physical Symptoms, Prognostic Awareness</li> </ul> | <ul style="list-style-type: none"> <li>➤ Writing Practices Survey</li> <li>➤ Summative Writing Feedback</li> <li>➤ Performance Status</li> <li>➤ Anxiety, Depression, Distress, Physical Symptoms, Prognostic Awareness</li> </ul> |
| OD   | <ul style="list-style-type: none"> <li>➤ Post-Traumatic Growth, Existential Distress, Grief</li> </ul>  | <ul style="list-style-type: none"> <li>➤ Post-Traumatic Growth, Existential Distress, Grief</li> </ul>   | <ul style="list-style-type: none"> <li>➤ Post-Traumatic Growth, Existential Distress, Grief</li> </ul>   | <ul style="list-style-type: none"> <li>➤ Post-Traumatic Growth, Existential Distress, Grief</li> </ul>   |
| D    |   |  |  |  |
| EVEN | <ul style="list-style-type: none"> <li>➤ Coping, Resiliency</li> </ul>  | <ul style="list-style-type: none"> <li>➤ Coping, Resiliency</li> </ul>   | <ul style="list-style-type: none"> <li>➤ Coping, Resiliency</li> </ul>   | <ul style="list-style-type: none"> <li>➤ Coping, Resiliency</li> </ul>   |



- Inclusion**
- 18 years old
  - Non-curable solid tumor
  - Cognitively intact
  - English speaking
  - Access to telephone



## INTERVENTION

# Coached Writing - Goals

Strengthen Patient Autonomy via Choices  
Process Difficult Experiences and Emotions  
Increase Wellbeing  
Share My Stories  
Communicate with Others  
Help Others

# Results

**Table 1. Patient Characteristics**

Age	61.4 yrs (range 33-84yrs)
Sex (M/F)	35% (n = 7)/ 65% (n = 13)
Race	
Caucasian	90% (n = 18)
American Indian/Alaska Native	5% (n = 1)
Highest Level of Education	
Up to some college	25% (n = 5)
Completed college or more	75% (n = 15)
SES (annual income)	
\$0-49,999	45% (n = 9)
More than \$50,000	55% (n = 11)
Marital Status	
Married/Significant Other	75% (n = 15)
Divorced/Separated	15% (n = 3)
Never Married	5% (n = 1)
Living Situation (Home)	100% (n = 20)
Median Survival	9.6 months

**Table 1 (continued)**

Religion	
Catholic	15% (n = 3)
Protestant	35% (n = 7)
Other	20% (n = 4)
None	25% (n = 5)
Jewish	5% (n = 1)
Religious Importance	
Not at all	20% (n = 4)
Somewhat/Very	80% (n = 16)
Primary Cancer	
Lung	20% (n = 4)
Pancreatic	10% (n = 2)
Other	70% (n = 14)
Goals of Treatment	
Cure	10% (n = 2)
Life Prolonging	75% (n = 15)
Improving quality of life	25% (n = 5)
Prognostic Disclosure (Y)	85% (n = 17)
Advance Care Planning	
Advance Directive	60% (n = 12)
	20% (n = 4)



# Results - Feasibility

**Table 2. Feasibility Outcomes**

Enrollment rate	35% (n = 22)
Completed Sessions	
One	91% (n = 20)
Two	86% (n = 19)
Three and Four	82% (n = 18)
Five	68% (n = 15)
Six	41% (n = 9)
More than 6	23% (n = 5)
Reasons for Not Completing	27% (n = 6)
Progressive illness/Death	9% (n = 2)
Logistical issues	5% (n = 1)
Pre-existing depression	
Elevated HADS*	27% (n = 6)
None attributed to the writing intervention	

# Coached Writing - Description

Method	Writing (n = 12) Dictation (n = 4) Writing and Dictation (n = 4)
Genre	Poetry (n = 11) Autobiography (n = 9) Journaling (n = 8) Essays/Letters (n = 5)
Additional Writing	Writing during sessions & at home (n = 9) Write only during sessions (n = 8) Use sessions for planning & feedback; write at home (n = 3)

# Results – Potential Impact

	Coefficient	Standard error	P-value	95% CI
<b>Prognostic Awareness (PA)</b>	0.266	0.144	<b>0.071</b>	(-0.024, 0.556)
<b>Coping Self-Efficacy (CSE)</b>	11.628	5.123	<b>0.036</b>	(0.842, 22.414)
Resilience (CD-RS 25)	1.839	2.687	0.504	(-3.898, 7.576)
<b>Traumatic Growth (PTGI)</b>	<b>-5.181</b>	<b>2.415</b>	<b>0.051</b>	<b>(-10.398, 0.036)</b>
<b>Grief (PGAC)</b>	4.821	1.754	<b>0.015</b>	(1.081, 8.560)
Distress (DT)	0.220	0.712	0.759	(-1.215, 1.656)
<b>Anxiety (HADS-anx)</b>	-1.315	0.656	<b>0.052</b>	<b>(-2.639, 0.009)</b>
Depression (HADS-dep)	-0.309	0.502	0.541	(-1.323, 0.704)
HADS total	-1.497	1.031	0.154	(-3.579, 0.586)
<b>Existential Distress (FACIT-Sp-Ex)</b>	5.204	1.814	<b>0.013</b>	(1.286, 9.124)

# Patient Feedback

Most difficult parts of the writing?

Taking the time and getting started

Most helpful parts of the writing?

Working with the coach

Prompts, help with getting started

Reflecting on life, sharing legacy

How did the writing help?

Expressing difficult experiences and emotions

Being heard

Better understanding myself and my situation

Most surprising about the writing?

Easier/more enjoyable than I expected

# Patient Comments

*Expressing feelings about this illness - being open, sharing with others in non-judgmental atmosphere, allowing self to dig deep into grief, with words allowing a vehicle to leave a legacy to my grandchildren - a bit of who I am/was.*

*Helped me to 'play' with writing and ... woke up the part of me that writes poetry.*

*[I was surprised] that I could be more creative than I expected. That I had more ability to cope than I thought. Writing gave me a powerful tool to understand who I am.*

*Learning to free flow - let go. Nothing is wrong. Freeing.*

# Conclusions

- Coached Writing Interventions are feasible, even with patients near the end of life
- Four sessions seem to be the most feasible
- Coping, Grief, Anxiety, and Existential Distress were all improved over time in this study

# Limitations

- Traumatic Growth worsened; may be due to the framing of the questions
- Small sample size/single center
- Enrollment bias
- No control arm; changes may be due to time or other unmeasured factors (e.g. pall care involvement)