Using the Arts and Humanities to Support the Dying, Bereaved and Ourselves

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1. “Art can permeate the very deepest part of us, where no words exist.”

   “I create beautiful art, so I can look back on the life my body fell short of in such a way that it brings me peace.” Nikki Rowe: Once a Girl, Now a Woman

2. Themes
   - What does this mean at the bedside
   - Moving beyond “angst” and distress
   - Assisting people to design their “good death” experience
   - Peace at the time of death
   - Conscious living and dying
   - Saying goodbye

3. Theoretical Frameworks and Interventions
   - Guided Imagery
   - Cognitive behavioral Therapy
   - Mindfulness
   - Motivational Interviewing
   - Person-centered approach to assisting people to articulate goals and plans they are actually motivated to achieve
   - The TOD POC

4. Personal insight and resilience
   - What thoughts and feeling have come up for you during this session?
   - What are you learning about yourself while doing this work?
   - Is this work about you? Not about you? Only about patients/families?
   - Are you resilient? What do you need to do to become more resilient as you move through life?
   - How often do you think about your own death?
   - What would “great hospice care” look like if you or your loved one were to be the patient/family?
   - In the years you have lived so far, what have you learned that will assist you to have a “good death”? What do you still need to learn?

5. This is a test to see if your mission in this life is complete, if you are alive, it isn't.
   Richard Bach, quote from Illusions
Why Arts and Humanities

Science may give us the tools for curing, but the arts give us the tools for caring.

Since the beginning of time the arts have always been indispensable voices for both protest and solace of trauma. In every era artists—be they poets, dancers, musicians, sculptors, painters, cartoonists, filmmakers—have crafted in various forms or media, their responses to life-cycle and tragic events. Today it is more timely than ever as people around the world struggle with the impact of the pandemic, loss and social isolation. Each of us needs periodic re-inspiration to invigorate our imaginations and souls. A painting, poem, lyric or cartoon may be just the prod to shake us out of the ruts of ordinary perception to approach suffering and the unbearable in fresh and strangely bracing ways. The arts and humanities challenge, instruct and support us in our endeavor to stay present with another’s suffering, and to better understand our own. Hopefully as we laugh, cry and most importantly connect—albeit virtually—our humanity is affirmed as our heads and hearts are resuscitated.

(Further resource materials also will also be available upon request.)

I. Introduction -Why Arts?

-Bertman's Premise: “Engaging in the arts and expressive therapies as initiator or observer is in itself a creative act, often catalyst enough to enable grief, assist in the search for meaning, and initiate change. The engagement (be it reading or writing, viewing or drawing, listening or enacting) to varying degrees involves attention, analysis, identification, catharsis and insight. The beauty of the process is its openness to interpretations, to the way any of us—therapist, staff, patient, client, colleague, family member, friend—takes it in and uses it for oneself, in personal and professional contexts.” (adapted from Bertman, Grief and the Healing Arts: Creativity as Therapy 1999, p.3)
Place yourself in the image. On which side of the bowl are you? Are you the giver or receiver? What’s in the bowl?

!! Visual Case Studies: Some Prompt Triggers for Discussion.

Reflect on the image in silence.
- What’s going on in this picture?
- Why do you see that makes you say that?
- What else do you see?

Place yourself in the image. ***
- How would you change the image?
- How does it relate to your experience?

What are your feelings?
If so moved, create a title, dialogue, poem, haiku.

These probe questions unexpectedly accelerate shifts in thinking especially when being exposed to responses of team or group members (all the while improving critical thinking and observational and listening skills). With each new interpretation community is enhanced as the group becomes more comfortable with ambiguity, experiences the validity of other ways to make meaning, and delightfully realizes that there is always more to see.

Should you care to share your reflections on any or all of these visuals, we will provide a compilation of response to the images. (see page 15)
III. The Moment of Death:

-Loss teaches you very fast what you cannot go without saying.
-The healing power of hope, faith, prayer, environment, humor, grief, love.
-THE time to do bereavement work.

IV. The humanities are, after all, what makes us human, because they allow us to make meaning of our experiences in the world at our best and at our worst moments.

This being human is a guest house,
Every morning a new arrival,
A joy, a depression, a meanness,
some momentary awareness comes
as an unexpected visitor.
Welcome and entertain them all!
Even if they're a crowd of sorrows,
who violently sweep your house
empty of its furniture,
still, treat each guest honourably.
He may be clearing you out
for some new delight.
The dark thought, the shame, the malice,
meet them at the door laughing,
and invite them in.
Be grateful for whoever comes,
because each has been sent
as a guide from beyond.    Rumi, *The guesthouse*

The Time of Death Plan of Care

Goals: Time-of-Death (TOD) See codes below

1. Assist the person who is ill and/or members of this person’s circle of support to develop a plan for life as death draws near. [A, B, C, F, G, H, I, J, K, L, N, O, P, Q, R, S, T]

2. Guide the person who is ill and/or members of this person’s circle of support through an understanding of services offered/not offered at TOD. [E, I, P, Q, R]

3. Assist the person who is ill and/or members of this person’s circle of support with understanding of processes at TOD. [C, D, n, O, P, Q, R, S, T]

4. Guide carers through communication methods/skills that will be helpful as death draws near. [A, B, C, D, E, F, G, H, L, N, Q, T]

5. Provide initial and ongoing coaching re: communication/interaction techniques/skills that will be helpful during the dying phase. [A, B, C, D, E, F, G, H, L, N, Q, T]

6. Assist the person who is ill and/or members of this person’s circle of support to consider anticipatory grief processes. [A, B, C, F, G, H, N, O, Q, R, S, T]

7. Assist with an understanding of and acquiring coping strategies. [C, D, E, F, G, H, R, T]


9. Provide guidance to develop and plan for preferences re: death process and time period prior to death. [C, D, E, F, G, H, N, O, P, S, T]


Interventions:

A. Explore hx of coping patterns.
B. Assess barriers that could inhibit effective coping now and at TOD.
C. Provide counseling.
D. Explore and develop support systems.
E. Refer to agency/community resources (full team participation, 11th hour program, tuck in program, caregiver support, church/community services, etc.)
F. Explore cultural influences.
G. Explore religious/spiritual influences.
H. Encourage expression of feelings through alternative methods: Music, journaling, life review, etc.
I. Discuss burial/cremation options.
J. Assess status of funeral arrangements.
K. Initiate conversation re: funeral arrangements.
L. Encourage family discussion re: funeral arrangements.
M. Assist Pt/PCG to complete funeral arrangements.
N. Facilitate family discussion re: dying.
O. Assess pt/family desires/needs at TOD.
P. Provide information re: agency processes at TOD.
Q. Provide individualized education/resources re: effective coping skills.
R. Provide individualized education/resources re: grief experience/anticipatory grief reactions.
S. Provide information to pt regarding emotions surrounding death and dying.
T. Encourage Pt/PCG/Family to discuss feelings related to dying and death.

Counseling: **Motivational Interviewing**

**Motivational Interviewing - Strategies and Techniques**

**Transitional Summary**

Transition into the conversation about this topic or this particular goal by providing a summary of where this person is up to this point.

**Ask Evocative Questions or Leading Statements:**

Ask open questions that will likely lead to conversations about goals.

- “What kinds of things are most important to you these days?”
- “I can see you have been thinking a lot about your family and their needs.”
- “The relationship with your daughter seems strained or is that my imagination?”
- “It appears you want to do what is best for your husband Bob. I am wondering if you know what Bob wants for you right now?”

**Explore Decisional Balance:**

Ask for the pros and cons (positives/negatives) of specific goals, especially those that feel frightening or where there is apprehension.
➢ “You said you would like a feeding tube in any situation if you are unable to eat. Certainly the thought of not getting nourishment can be frightening. Can you think of a situation where it might be best to stop that type of feeding?”
➢ “Let’s talk a moment to look at this from both sides.”

Ask for Elaboration/Examples

When a potential goal emerges, ask for more details.
➢ “What might that look like for you?”
➢ “Can you give me an example of how you might go about that?”
➢ “You said you would like it if you could speak with your daughter about this. Can you tell me more about that?”

Look Back

Ask about times before this goal.
➢ “Was there a time in the past when you experienced something like this and what happened then?” “What did you do at that time and was it successful?”
➢ “How were things different/better/worse?”

Look Forward

Ask about what may happen if things stay the way they are.
➢ “If you are 100% successful in speaking with your husband about this, how will things be different?” (The miracle question)
   o How will it look?
   o What will you be doing?
   o What will be happening?
   o How will you be feeling?

Query Extremes (troubleshooting)

➢ Ask about the worst/best things that could happen?
➢ “If the worst occurs, what will you do then?” Utilize role-playing (for example) to rehearse possibilities and assist people to explore options if “the worst” or problems arise.

Use Change Rulers

➢ “On a scale from 1 – 10 (1…not important and 10…very important) how important is it that you achieve this goal?”
➢ “How confident are you?”
➢ “How likely is it that you will succeed?”
➢ “How likely is it that this will occur?”
Explore Goals and Values

Ask about the person’s values that guide the setting and achievement of this goal.
➢ “Most of us make choices based on certain values. What would you say are your top 2 or 3 values or guiding principles?”
➢ “How might these values guide you in making this decision?”
➢ “What goals would you like to create for this situation based on these values?”

Come Alongside

Side with the negative in order to explore motivation.
➢ “Perhaps speaking with your husband is less important than keeping things ‘safe’ or the way they are right now?”
➢ “Sometimes it feels like not resolving this situation is preferable for you.”
➢ “I can see that if you do not confront your husband you will not have to risk his response.”

Adapted from http://www.nova.edu/gsc/forms/mi_rationale_techniques.pdf “Motivational Interviewing Strategies and Techniques”

Exploring Decisional Balance

<table>
<thead>
<tr>
<th>Benefits/Pros</th>
<th>Costs/Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making a change</td>
<td>Not making a change</td>
</tr>
<tr>
<td>Having a caregiver would make life easier for me</td>
<td>I don’t have to face his response</td>
</tr>
<tr>
<td>It could upset my husband and cause him to feel he is a burden to me</td>
<td>My health</td>
</tr>
</tbody>
</table>

Exploring Decisional Balance - The Conversation

Case Example:
The person who is ill lives alone and is struggling with whether or not to seek SNF options. She is unclear about what she wants and has been hesitant to talk with you about it.
Exploring Decisional Balance:
1. Maybe it is better if we do not talk about this at all? Are there reasons that you feel avoiding this topic altogether would be good? (Benefits of not changing)
2. Can you think of a reason why not exploring your options could create problems for you in the future? (Costs of not changing)
3. Could there be a downside for you to explore your options at this time? (Costs of change)
4. I wonder if there were times in the past when you felt better knowing that you were prepared for any outcome. (Benefits of change)

5. Just thinking here, and you don't have to decide now, (paradox) would there be an advantage to putting a plan together knowing you can change it at any time? (Benefits of change)

Goals of pursuing decisional balance:
- Shine a light on ambivalence
- Explore resistance
- Using the clients own arguments for change
- Explore motivation and accessing motivation

Motivational Interviewing for Exploring Person-Centered Goals

Case Example: Sarah is 73 years old and has been married to Bob for 50 years. Bob is on your hospice program and his care has been difficult for Sarah. There has been talk about asking their adult daughter Judith to move in for a while to help out. The relationship up to this point has been strained but Judith has offered, especially considering she is being evicted from her apartment. Bob sleeps most of the time and is lucid off and on.

<table>
<thead>
<tr>
<th>Hospice worker</th>
<th>Sarah, it sounds like things have been very difficult for you for these last 8 months starting with Bob’s diagnosis. You have been busy with doctors and treatments and hospitals and emergency rooms. You have done this all on your own. I so admire you for your dedication to Bob. And now I can see you are exhausted.</th>
<th>Transitional summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>I am exhausted. There are times when I am not sure I can go on. I hurt my back yesterday trying to get Bob to the bathroom. I am worried that one day I will be unable to help out at all and we don’t have money for assistance. The nursing assistants have been a big help but they are not here 24 hours. I have to do something.</td>
<td>Sarah confirms exhaustion, provides feedback and helpful information.</td>
</tr>
<tr>
<td>Hospice worker</td>
<td>It sounds to me like you are ready to get help but maybe you are not quite sure what to do next. Is that correct?</td>
<td>Continues summary and initiates exploration of Sarah’s motivation to seek assistance.</td>
</tr>
<tr>
<td>Sarah</td>
<td>Yes, I could really use some help. Especially with the heavy work and at night. I am afraid my own health has suffered terribly. Is there anything I can do?</td>
<td>Sarah is asking for assistance</td>
</tr>
<tr>
<td>Hospice worker</td>
<td>Let’s talk about that. First, I remember you mentioning your daughter Judith in a previous conversation but I remember there were potential problems with that option. Is it possible there are</td>
<td>Sarah has mentioned before that Judith might be available to help but that the relationship is</td>
</tr>
</tbody>
</table>
other family members, friends or even people from your church who would be willing to help out? One option is that we can assist you to coordinate help from several people by checking out their availability and putting together shift schedules so you will not have to do that.

| Sarah | Bob and I have kept to ourselves for many years. I don't know of anyone who would be willing to help. |
| Hospice worker | I hope this does not seem too personal and I want to remind you that you do not have to answer at all or offer any information that would make you feel uncomfortable. You used the word “strained” when talking about the relationship with Judith. I am wondering how strained and in what way it is strained. |
| Sarah | Let's just say that Judith did something many years ago that led to Bob and I feeling we needed to distance ourselves from her. We have talked off and on throughout the years but not much. The relationship is still very strained, especially for Bob but I know Judith has to move out of her apartment now. |
| Hospice worker | Let me see if I can boil all this down just to see if Judith coming to help out could be added to the list of possibilities for you. The relationship is strained but you have spoken a bit throughout the years so it is not as if there has been no contact at all. You need assistance and Judith needs a place to stay for a while. Judith has told you she would be willing to help with Bob’s care while she is there. Bob may or may not be agreeable. Does this sound right? |
| Sarah | That is correct. And yes, I don't know what Bob would say. |
| Hospice worker | Setting up decisional balance and looking forward. |
| Sarah | Okay. Certainly it will be helpful if she is here and all goes well: she can help with the care, we will... |

strained. Instead of moving in this direction first the hospice worker explores other options.

Sarah provides useful information

Reinforcing informed consent and asking evocative question. ("Evoking further discussion of possibilities)

Additional information

Summary statement and from a person-centered perspective allowing Sarah to explore this as just one possibility without coercion.

Agreement and the addition of another area to explore…Bob’s response.

Beginning to contemplate how a
all get along and no one will talk about the past – that would be very nice. The downside is if she comes here and wants us to apologize for something or if she starts blaming us and opens a can of worms. Also, Judith moving here for good is not an option. I would want her to know that she needs to look for work and her own place to live.

<table>
<thead>
<tr>
<th>Hospice worker</th>
<th>I know this is just guess work at this point but how likely do you feel it is that the things you listed as concerns would actually occur?</th>
<th>Query extremes (Initiating troubleshooting)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>I just don’t know but I would want to make things clear with Judith before we ever say yes to this.</td>
<td>Sarah initiating the possibility of a first goal. Speaking with Judith to set some clear boundaries and get upfront commitment/agreement.</td>
</tr>
<tr>
<td>Hospice worker</td>
<td>That would certainly be very important. Let me just say before we go on, maybe it would be better to leave this whole thing with Judith alone and see if we can find another option. Maybe it isn’t worth bringing the past into your lives at this time.</td>
<td>Coming alongside</td>
</tr>
<tr>
<td>Sarah</td>
<td>Honestly, I would love to have Judith back in my life. As we have been talking I have thought about how nice it would be if things were to work out. I am not sure how Bob feels and I guess there is a possibility that he would forbid it.</td>
<td>Beginning to hear that Sarah has some degree of motivation to at least take the first step in determining if this is an option.</td>
</tr>
<tr>
<td>Hospice worker</td>
<td>So what happens now? Do want to see if you can speak with Bob first and then give Judith a call? Are you ready to talk about that now?</td>
<td>Moving towards clarifying the goal. Again, from a person-centered perspective, giving Sarah the choice to continue or not. This is also another way to determine her level of motivation.</td>
</tr>
<tr>
<td>Sarah</td>
<td>Bob might be the biggest hurdle but again, I am not sure Bob is even in a place where he will comprehend any of this. Yesterday I mentioned Judith and he did not even know who that was. This morning he seemed clearer though. I feel nervous about speaking with Judith.</td>
<td>Beginning to hear some reluctance or hesitance about speak with Judith.</td>
</tr>
<tr>
<td>Hospice worker</td>
<td>Are you saying it would be best to first see if Bob is able to participate in making this decision and see if you can get an idea about how he feels??</td>
<td>Clarifying the goal</td>
</tr>
<tr>
<td>----------------</td>
<td>-------------------------------------------------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Sarah</td>
<td>Yes…I need to start there.</td>
<td>There is the goal (for now)</td>
</tr>
<tr>
<td>Hospice worker</td>
<td>Since Bob seems clearer today, would you want to see if you can have this conversation with him before tomorrow?</td>
<td>Moving towards specifics</td>
</tr>
<tr>
<td>Sarah</td>
<td>Yes. Could I do it now? Would you mind waiting for me out here?</td>
<td>Sarah has made the decision to act now</td>
</tr>
<tr>
<td>Hospice worker</td>
<td>Absolutely. Before you go though, let’s just talk briefly about how you think this could play out. What do you think might happen if Bob clearly understands what you are saying and that leads him to become upset? How might you respond?</td>
<td>Troubleshooting</td>
</tr>
</tbody>
</table>

**Motivational Interviewing**

**Video Demonstrations of MI Sessions**

*Motivational Interviewing - Building Confidence* (video)
http://www.youtube.com/watch?v=Cfl4d-qQ-co

*The Effective Physician – Motivational Interviewing Demonstration* (video)
http://www.youtube.com/watch?v=URiKA7CKtfc

*Motivational Interviewing in Primary Care* (video)
http://vimeo.com/18577370

*Modifying Automatic Thoughts* (video)
http://www.youtube.com/watch?v=a0YyC1iS8Rc

*Patient-Centered Collaborative Care* (video)
http://www.youtube.com/watch?v=h7jHp5ooNec

**Books**


*Building Motivational Interviewing Skills – A Practitioner Workbook* by David Rosengren., the Guilford Press, New York, 2009
Motivational Interviewing in Nursing Practice by Michelle Dart, Jones and Bartlett, Sudbury, MA, 2011


Cognitive Behavioral Therapy


Modifying Automatic Thoughts (video) 
http://www.youtube.com/watch?v=a0YyC1iS8Rc

A Therapist’s Guide to Brief Cognitive Behavioral Therapy 

Books


Mindfulness and Relaxation

Relaxation Therapy 
Susan G. Komen 
http://ww5.komen.org/BreastCancer/Relaxationtherapy.html 

6 Mindfulness Exercises You Can Try Today 
Pocket Mindfulness 
http://www.pocketmindfulness.com/6-mindfulness-exercises-you-can-try-today/ 

Mindfulness Exercises 
Living Well 

BOOKS


Using the Arts & Humanities
Selected sources/reproductions, quotations of many citations and illustrations used in today's presentation.


Bertman, S. (2015). Using the arts and humanities with the dying, bereaved…and ourselves. In


*Boys in the Street* animation [https://vimeo.com/158769251](https://vimeo.com/158769251)

Clary, P. (2010). *Poetry and Healing at the End of Life,* JPSM, 40(5)796-800.


Prima Ballerina with Alzheimer’s listens to Swan Lake and starts to remember [https://www.youtube.com/watch?v=6j5yeRDBaU](https://www.youtube.com/watch?v=6j5yeRDBaU)

See also downloadable articles, DVDs etc., [www.sandrabertman.com](http://www.sandrabertman.com)

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LOOK AGAIN! Invitation: If you would please (1) Jot down your reflections and responses to any image (pps. 3-5) and/or (2) Place yourself in the image (Where? Why? How? What would you say or do?) We would provide a compilation of our work.

If you would like your name* and affiliation to be used in print, please indicate how you would like to be credited: *Otherwise, all commentaries shall appear anonymously.*

ID (code or name)*________________________________________

Profession/Occupation______________________________________ Age____ Sex___ Image #________

Please e-mail your responses to sbertman@gmail.com
We’ll share this compilation of responses by mid-December. [www.sandrabertman.com](http://www.sandrabertman.com)

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