MULTIDISCIPLINARY USE OF DIGNITY THERAPY AND LIFE REVIEW WITH PATIENTS AND BEREAVED

Allison Jordan, MD, HMDC
Eileen Spinner, MA, LPC
BJC Hospice – Saint Louis, MO

ALLISON JORDAN, MD, HMDC

Allison Jordan is a board certified internist, psychiatrist, and palliative medicine physician. She is also a certified hospice medical director and has a certificate in medical education. She has lived across the country and is the medical director of palliative care services at Christian and Alton Memorial Hospitals in addition to Associate Medical Director at BJC Hospice. Her clinical interests include bereavement, pain management, and medical education.

EILEEN SPINNER, MA, LPC

• Eileen Spinner is a Licensed Professional Counselor was born and raised in Texas but now lives in St. Louis. She has worked for BJC Hospice for the past 11 years and feels it’s a calling and a blessing to serve patients and their families. She recently attended the Dignity Therapy Training in Winnipeg, Canada. She is proud to run a life review program that is informed by Dignity Therapy and primarily functions through the support of volunteers from the community.
OVERVIEW

- What is Dignity Therapy (DT)?
- How is Dignity Therapy done?
- Lumina Program at BJC Hospice
- Practical tips and ideas

HOW DO YOU SEE ME?

- Recognize the notion of “appearance”
- Patients are looking for a reflection of themselves in our eyes
- Are we being a skilled witness? Are we offering an affirming reflection?

“CARE TENOR”

- THE “FRAGRANCE OF CARE”
- THE TONE OF CARE
- ARE WE FULLY PRESENT WHEN WE ARE VISITING A PATIENT?
- WE CAN BE TECHNICALLY PERFECT BUT HAVE A TERRIBLE “TONE OF CARE”
- A PATIENT CAN BE SEEN BUT NEVER HEARD IF WE DON’T TREAT THEM WITH “DIGNITY CONSERVING CARE”
- HOW CAN WE MAINTAIN THEIR DIGNITY?

- CONSIDER THE MORE “INTIMATE DEPENDENCIES OF CARE” (BATHING/ DRESSING / INCONTINENCY)
- HOW DO WE PERSONALIZE THESE ISSUES? HOW DO WE KEEP THEIR PHYSICAL DIGNITY INTACT?
- WE WANT TO CREATE AN ETHOS AROUND THEIR PERSONHOOD – EVERYTHING ABOUT YOU IS IMPORTANT. TIME MATTERS. YOU MATTER. WHAT DO YOU WANT TO DO WITH THIS TIME YOU HAVE?

Dr. Harvey Chochinov
Dignity Therapy Workshop, 2016
DIGNITY THERAPY IS...
A brief therapeutic approach designed to decrease suffering, enhance quality of life, and bolster a sense of dignity for patients approaching death. It invites patients to discuss issues important to them and articulate things they would most want remembered as death draws near. DT has a growing evidence base, with positive outcomes for both patients and their bereaved family members. There is also research that shows that DT improves staff satisfaction when put into practice.

DIGNITY THERAPY IS...
- Dignity Therapy is about affirming personhood
- It’s about asking the patient, “What should I know about you as a person to help me better care for you?”

DIGNITY THERAPY PROTOCOL
1) Tell me a little bit about your life history; particularly the parts that you either remember most or are more important? When did you feel most alive? (Imagine a photo album of your life – what is the first picture you see? When you turn the page, what is the next picture you see?)
2) Are there things that you would want your family to know or remember about you?
3) What are the most important roles you have played in your life (family, work, community service, etc.)? Why were they important to you, and what did you accomplish?
4) What are your most important accomplishments, and what makes you feel most proud?
5) Are there things that you feel need to be said to your loved ones or things that you would want to say again?
6) What are your hopes and dreams for your loved ones?
7) What have you learned about life that you would want to pass along to others? What advice or guidance would you wish to pass along to your children, husband, wife, parents, other(s)?
8) Are there important words or instructions you would like to offer your family?
9) In creating this permanent record, are there other things that you would like to include?
THE EVIDENCE FOR DIGNITY THERAPY

Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life

Nancy Nee Niederhoffer, M.A., Thaddeus Park, M.A., Linda L. Aliprantis, Isaac E. Milligan, and Mike Miller

ABSTRACT

Purpose: This pilot study examined the feasibility and potential efficacy of a new psychotherapeutic intervention for patients near the end of life. The intervention, called Dignity Therapy, involves a therapist-facilitated discussion about a patient’s personal beliefs, values, and life goals.

Methods: Twenty patients with advanced illness participated in the study. They were randomly assigned to one of two groups: Dignity Therapy group and Control group. The Dignity Therapy group received the intervention, while the Control group did not.

Results: Patients in the Dignity Therapy group reported significantly greater improvement in quality of life, emotional well-being, and life satisfaction compared to the Control group.

Conclusion: Dignity Therapy appears to be a promising intervention for improving end-of-life care.

Dignity Therapy: Family Member Perspectives

Susan McClement, Ph.D., Harvey Max Chochrany, M.D., Ph.D., Thomas Park, M.A., Linda L. Aliprantis, Isaac E. Milligan, and Mike Miller

ABSTRACT

Purpose: This study explored the experiences of family members of patients who received Dignity Therapy. The goal was to understand the impact of the intervention on the family.

Methods: Families of 10 patients who received Dignity Therapy were surveyed. A semistructured interview guide was used to explore the family’s perception of the intervention.

Results: Families reported that Dignity Therapy improved communication with the patient, reduced feelings of isolation, and enhanced the patient’s dignity.

Conclusion: Dignity Therapy has the potential to provide important support for both the patient and the family.

Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial

Nancy Nee Niederhoffer, M.D., Thaddeus Park, M.A., Linda L. Aliprantis, Isaac E. Milligan, and Mike Miller

ABSTRACT

Purpose: The purpose of this study was to evaluate the effectiveness of Dignity Therapy in reducing distress and improving the end-of-life experience in terminally ill patients.

Methods: A randomised controlled trial was conducted with 100 patients with advanced illnesses. The intervention group received Dignity Therapy, while the control group received standard care.

Results: Patients in the intervention group showed significantly lower levels of distress and improved overall quality of life compared to the control group.

Conclusion: Dignity Therapy is a promising intervention for improving the end-of-life experience in terminally ill patients.
Dignity Therapy is...

A brief therapeutic approach designed to decrease suffering, enhance quality of life, and bolster a sense of dignity for patients approaching death. It invites patients to discuss issues important to them and articulate things they would most want remembered as death draws near. DT has a growing evidence base, with positive outcomes for both patients and their bereaved family members. There is also research that shows that DT improves staff satisfaction when put into practice.

BJC Hospice’s Lumina program is...

Informed by DT, it offers patients and their families the opportunity to review their lives as well as preserve stories, values, experiences, and life lessons in the form of journals, scrapbooks, memory boxes, letters to loved ones, and video or audiotaped statements. Interviews are conducted in the home by the program coordinator and/or intensively trained BJC Hospice volunteers.

REMEMBER...
RESEARCH SHOWS US DIGNITY THERAPY MAKES A DIFFERENCE!

Subjective and anecdotal. Fifty family members of deceased terminally ill patients who previously took part in Dignity Therapy completed a questionnaire to elicit feedback about the impact of Dignity Therapy on both the dying patient and themselves.

Results: Ninety-five percent of participants reported that Dignity Therapy helped the patient; 93% expected that it heightened the patient’s sense of dignity; 72% reported that it heightened the patient’s sense of purpose; 65% reported that it helped the patient prepare for death; 63% reported that it was an important part of the patient’s care; and 43% reported that Dignity Therapy improved the patient’s overall feeling of quality of life. Dignity Therapy increased feelings of well-being among the family members. There were also significant changes in patient outcomes after the provision of DT. Further research is needed to determine the impact on families' well-being. Dignity Therapy provides additional support for the needs of these individuals.

LUMINA SURVEY RESULTS ARE POSITIVE TOO!

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Lumen program positively impacted my family member on hospice.</td>
<td>71.79%</td>
<td>12.42%</td>
<td>2.56%</td>
<td>0.60%</td>
<td>0.00%</td>
<td>12.02%</td>
</tr>
<tr>
<td>The Lumen program gave my family a sense of meaning, purpose, and dignity.</td>
<td>66.67%</td>
<td>15.00%</td>
<td>9.33%</td>
<td>3.00%</td>
<td>0.00%</td>
<td>15.00%</td>
</tr>
<tr>
<td>The Lumen program was as important as any other aspect of hospice care.</td>
<td>75.00%</td>
<td>15.00%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>2.50%</td>
<td>7.50%</td>
</tr>
<tr>
<td>The Lumen program helped my family member leave a meaningful legacy for future loved ones.</td>
<td>77.50%</td>
<td>10.00%</td>
<td>2.50%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>10.00%</td>
</tr>
<tr>
<td>The Lumen program comforted surviving family members during our time of grief.</td>
<td>77.50%</td>
<td>7.50%</td>
<td>2.50%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>12.50%</td>
</tr>
<tr>
<td>It would recommend the Lumen program to other families.</td>
<td>82.50%</td>
<td>9.00%</td>
<td>2.50%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>10.00%</td>
</tr>
</tbody>
</table>

WHAT LUMINA PROVIDES

- Letters to loved ones
- Memory books/journals
- Scrapbooks
- Memory videos (using pictures/videos/music)
- Audio recordings
- Memory boxes
- Genograms (family trees)
- Lifelines (detailing life events)
- Memory pillows, bears, and quilts made from the patients’ clothing

All of these items can be created through life review with the patient, as well as through collaboration with the family and loved ones before and after the patient’s death.

LUMINA WITH MARTIN

Martin Schweig took time to reflect on his past and document his life through a book and video. He was happy to revive his own memories and give his children and grandchildren a better understanding of his history.

https://www.youtube.com/watch?v=P1JRmh1F164
LUMINITA WITH ZOEY

Zoey was born May 1st, 2014, with Trisomy 18 and died August 28th, 2014.

BEREAVEMENT SUPPORT TURNS INTO LASTING GIFTS

- Alma's Voice
- Mary's Memory Box for her husband
- Grandpa Song with music therapist
- Memory Pillows and Bears for daughters
- Nicole's ABC Books for her children

YOUR TURN!

Dear [NAME],

Today, I have thought a lot about you and how much I miss you.

I wish you were here right now, so I could hold you in my arms.

I hope you remember me and how much I love you.

I wish I could see you again.

I miss you so much.

Yours truly,

[Your Name]
EXAMPLES OF PROJECTS

MUST-HAVE COMPONENTS WHEN STARTING A DIGNITY THERAPY PROGRAM

• Volunteers are essential
  • Not a lot... just a few
  • Assess skills
  • Develop program around the strengths of your volunteers
• Staff "buy-in"
  • Resources: recorders, iPhones, voice memos, take notes, release form
• Time and Patience
• Supervision

SUMMARY

• Dignity therapy has been shown to improve patient and family quality of life, reduce sadness, depression, and give the patient a greater sense of well-being at the end of life
• The dignity therapy model is a lengthy process
• Use the dignity therapy model to create a system that will work for your organization
• START SMALL
• Volunteers are critical, and they will need ongoing supervision


