ORDER OF MALTA - AMERICAN ASSOCIATION, USA

ST. BERNADETTE MINISTRY

SUPPORTING THE DIGNITY OF CARE FOR THE ELDERLY, FRAIL, SICK, AND TERMINALLY ILL

A Christian Response to the Culture of Death, Physician Assisted Suicide and Euthanasia, Loss of Dignity and Denial of Personhood

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My Life Story: A Legacy Project

Life is a Gift, a Symphony to be Celebrated and Shared

Overview

The St. Bernadette Ministry's focus is to serve those who are near or at the end of life, the frail elderly living in nursing homes or at home, individuals who are experiencing loss of dignity, or those whose life is nearing sunset. As a ministry specifically for the sick, we serve those who are terminally ill, in particular our malades, malades-in-spirit, and our members.

The Work

Everyone has a beautiful story to tell and to share in the preciousness of passing on wisdom. *My Life Story: A Legacy Project* is a way to remember and be remembered, it's one's important moments, a history as an autobiographical poem in prose in the storyteller's own words. This, as a legacy document, is for them to share with and leave for their family and friends.

Background & History

This Biographical Legacy Project of the American Association of the Order of Malta is based on two programs. One is the clinical model developed by Dr. Harvey Chochinov's *Dignity Therapy* which is now used to give patients in hospices and in hospitals who are on palliative care the opportunity to talk about their lives and preserve their history.

The second model is from the *Eastern Palliative Care*, which is a partnership between Outer East Palliative Care Service, Order of Malta and St. Vincent's Hospital in Melbourne Australia offering home-based integrative palliative care. Their volunteer services include, yet are not limited to, companionship, respite, transportation, and the Biography Project.

Research on Dignity in Dying

Research with terminally ill patients showed that one's sense of dignity literally made the difference between one's desire to live or die. In areas where physician-assisted suicide was legal, the loss of dignity was more than any other reason to die, while pain was only 5%.

Preserving Dignity

Dr. Harvey Chochinov of the Manitoba Palliative Care Research Unit in Canada, in collaboration with researchers from Australia, England, and the United States found a range of factors that either supported or undermined a person's sense of dignity. Out of the research, they developed a *Dignity in Care Model* that offers a repertoire of dignity conserving interventions as a new model for palliative care.

A Dignity Intervention

One of the interventions found to be most effective was a psychotherapeutic intervention that addressed generativity and legacy, one of the factors related to a person's sense of dignity. Patients were offered an opportunity to talk about their life using open-ended questions.

Different from a *Life Review* that is a historical recounting of events –this intervention supports the patient in recounting those ideas, memories, and events that are relevant and meaningful for them and what they desire to pass along to others. The term Dignity Therapy was applied to this intervention. These 30-60 minute sessions with the clinician were taped, transcribed, and edited by staff then offered to the patient to make changes before a final document is published as a legacy.

The process is initially an hour using targeted questions to stimulate memories. The sharing interview is transcribed into a draft and then a formal document. Patients have reported immense value as it provided the time and space to reflect on their lives, both the successes and challenges and to share these thoughts with those they care about. The patients receive a bound transcript of the interview to keep or give away.

Clinical Results

Dignity Therapy was shown to promote spiritual and psychological well-being. It helps one get in touch with what was most meaningful in their experiences and accomplishments that made them unique and valued and to do something for loved ones that will endure beyond one's own life.

Palliative Care Committee

Active committee members presently are those with experience as health care providers or as hospital chaplains.

Donna E. Coletti, MD, DM – Committee Chair
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The Order of Malta Model

Steps in the Legacy Project

- Introduction to the Facility and Recipient
- Interview
- Transcript
- Editing
- The Review with Recipient
- Final Document

Resources

- Training Manual
- Downloads
- Recording Equipment & Transcription Service
    - SEANME H-26 or TASCAM DR-05X hand Held Voice Recorder
    - Rev.com transcription service

Reference Materials

- USCCB Pro-Life Activities
  https://www.usccb.org/prolife/assisted-suicide-euthanasia

- "*The Richness of Many Years of Life*" International conference on the Pastoral Care of the Elderly, Vatican
  http://www.laityfamilylife.va/content/dam/laityfamilylife/Eventi/ricchezzadeglianni/PROGRAMMA_EN_online.pdf
  http://www.laityfamilylife.va/content/laityfamilylife/en/eventi/2020/la-ricchezza-degli-anni.html

- Dignity in Care
  https://dignityincare.ca/en/
  https://dignityincare.ca/en/toolkit.html

- Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life
  https://pubmed.ncbi.nlm.nih.gov/16110012/

- Sauro Antonelli, KM Training Manual

PRAYER FOR THE ELDERLY

Lord Jesus Christ,

You gave us life by making it shine with Your divine reflection and

You reserve a special gift to the elderly who benefit from a long life.

We entrust and consecrate them to You: make them witnesses
of the Gospel values and devoted custodians of Christian traditions.
Protect them and preserve their spirit with Your loving gaze and Your mercy.

Make them sure of Your faithfulness, messengers of Your love
humble apostles of Your forgiveness, welcoming and life-giving arms
for children and young people who seek in the eyes of their grandparents
a safe guide in their pilgrimage to eternal life.

Make us capable of giving them the love, care and respect
they deserve in our families and communities.

And grant each of us the blessing of a long life
in order to one day be able to unite with You, in Heaven
You who live, and reign in love forever and ever.

Amen

MATCHING INTERVIEWER/BIOGRAPHER AND RECIPIENT

2 level matching recipients to biographer/interviewer skills.

Clinically Experienced Members	Dignity Therapy Model (Dr. Chochinov)
Members	Biography Model

Malta volunteers are to be matched by skill set with the recipient's clinical situation.

Professionals with clinical interviewing skills may be matched to those recipients with advanced disease to provide a therapeutic intervention of psychological comfort using the Chochinov model; while other Malta members would be matched with those recipients with higher functional abilities using the biography model. Both models provide dignity and a spiritual/social prayer filled presence.

Those with clinical interviewing skills who are able to provide a therapeutic intervention will be performing the interviews on their own. Non-clinically experienced members will be provided assistance initially by skilled members.

Since we are moving from clinical language to a conversational tone in our encounters, the ultimate goal is to provide the same person-centered (therapeutic) life-giving benefit to bring dignity and hope through our presence and actions as Christ's hands extended.

Interview Model Cards

Therapeutic Interview Model Card Example #1

Side A:
Life is a love story lived for and with others in shared memories of gifted moments. Everyone has a beautiful story to tell and share in the preciousness of passing on wisdom. My Life Story: A Legacy Project is a way to remember and be remembered, it's one's history, as an autobiographical poem in prose in the storyteller's own words.

Side B:
1. "Tell me a little about your life history, particularly the parts that you either remember most, or think are the most important. When did you feel most alive?"
2. "Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?"
3. "What are the most important roles you have played in life (family roles, vocational roles, community service roles?
4. Why were they so important to you, and what do you think you accomplished in those roles?"
5. "What are your most important accomplishments, and what do you feel most proud of?"
6. "Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?"
7. "What are your hopes and dreams for your loved ones?"
8. "What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, closest friends, others)?"
9. "Are there words or perhaps even instructions you would like to offer your family and closest friends to help prepare them for the future?"
10. "In creating this permanent record, are there other things that you would like included?"

Therapeutic Interview Model Card Example #2

Side A:
We are but a composite of our life's experiences which through this interview process comes together in a narrative tapestry. The interviewee is given the ability to reflect and share thoughts on what gave their life meaning, purpose and joy as well the challenges they suffered. They may want to detail many of these issues in order to express feelings of love, forgiveness and closure.

Side B:
Overview: Life Chapters, Key Scenes, Future Script, Challenges, Personal Ideology, Life Theme, Reflection High Point, Low Point, Turning Point, Continuity, Earliest Memory, Childhood Event (<13), Adolescent Event (13-19), Morality, Decisions and Goals.

Biography Model

Telling Your Story: Biography Program is a project of the Eastern Palliative Care Program of Melbourne, Australia, co-sponsored with the local Order of Malta.

The biography program begins with an introduction to the patient by one of the visiting care team members, where then a trained volunteer is assigned to work with the client. Patients are selected based on their current health status, timeline, and ability to focus on tasks. In using a standardized template as a guide, the biographer and the client meet over several sessions to gather the details of one's life and precious memories, along with photos and other memorabilia to be added in. The final document is a bound booklet containing the story of one's life.

Biography Model Card

The downloadable Template Guide is available. It contains a timeline layout and a list of suggested questions under each section.

The interview approach for this model is more of a conversational type which starts with the basics (name, age, and where they live). It then evolves into a narrative arc of their life by recalling their early years, family life, values instilled, and background as well as detailing their view of themselves, the important relationships (personal and professional) and careers they've had as well as the positive and possibly negative events which have shaped their life. Their perspective on life events, illness, aging, specific holidays, vacations, and what gave them joy, satisfaction, sadness, and acceptance of how their life turned out can be explored.

BOOK: DIGNITY THERAPY - FINAL WORDS FOR FINAL DAYS

by Harvey Chochinov, MD

CHAPTER 1: DIGNITY AND THE END OF LIFE

Individual psychotherapy for those with life threatening/life limiting conditions
Definition of Dignity: To be worthy of honor, respect or esteem

Why DT:

- Empirical research (JAMA'02) demonstrated that DT promoted spiritual and psychological wellbeing, engagement providing meaning and hope that could enhance EOL experience.
- Assist to prepare and provide comfort for those w/ limited time
- Meaning, purpose & affirmation lessen EOL distress: physical, psychological & existential sources of suffering
- Loss of dignity: associated w/ bowel function and preoccupied w/ appearance and QOL
- Being respected is related to dignity
- Being a "Care Receiver": In spite of dependency, patients still feel in charge

Physician Assisted Suicide (PAS):
Patients note Depression, Hopelessness, Being a Burden, Loss of Dignity >> Pain alone
Loss of hope has greater association w/ suicidal ideation than depression

Perception of being a burden:
Associated w/ loss of will to live, desire for death & request for PAS/euthanasia, depression, hopelessness and QOL but DID NOT correlate w/ ACTUAL debility so it is psychological response to the illness because depression & despondency conflate loss of value, neediness and feelings of being a burden.

Pain: Interpretation of pain determines what meaning is ascribed to it.
Pain and symptoms in control: Patients feel supported and help to dignity
Pain out of control: Assoc w/ Anxiety, Depression and Fear of dependency

DT Model:
A. Illness-Related Concerns (Physical & Psychological Response)
  a. Level of Independence (cognitive activity, functional capacity)
  b. Symptom distress (physical and psychological)

B. Dignity Conserving Repertoire (Psychological and Spiritual Factors: Outlook of Who NOT What)
  a. Continuity of self
  b. Role preservation: Survival is equal parts mental/physical fortitude & retained physical capacity
  c. Generativity/legacy (guidance for next generation)
  d. Maintenance of pride (positive self-regard, self-respect)
  e. Hopefulness: Usually assoc. w/ "a future"; @ EOL its assoc. w// meaning and purpose.
  f. Autonomy/Control: Loss of Autonomy=loss of personhood
  g. Acceptance (often easier for the elderly; comes in steps; denial provides psychological space)

h. Resilience/fighting spirit

C. Dignity Conserving Practices
a. Living in the moment
b. Maintaining normalcy
c. Seeking spiritual comfort

D. Social Dignity Inventory (Environmental/External factors)
a. Privacy boundaries
b. Social support
c. Care tenor: Mirror back to patient either “illness or personhood”; Quality NOT amount of time spent
d. Burden to Others
e. Aftermath concerns

CHAPTER 2: MOVING DIGNITY INTO CARE

OVERVIEW

- Dignity Model: First time that researchers have tried to study the concept of dignity with dying patients
- The Model represents current understanding of what might influence a dying patient's sense of dignity
- Dignity Model: three primary areas address: physical, existential/spiritual, and social considerations
- Book focuses on Dignity Therapy as a clinical intervention to address generativity & aftermath concerns
- Various elements of Dignity Model provide rationale for each facet: form, tone, content

HOW THE DIGNITY MODEL INFORMS DIGNITY THERAPY

- Form
    - Key subtheme is generativity/legacy
    - Prolonging influence/extending aspects of self/sustaining the memory
    - Expressions of legacy can mitigate sufferings/something that will transcend
    - Written word ideal mode of generativity/legacy
    - Conveys profound regard for disclosures patients share; captures and preserves for posterity
- Tone
    - Must convey respect and tone of sincere affirmation
    - Care tenor, or tone of care, has profound influence on sense of dignity
    - Convey appreciation, respect, and kindness
    - Like Client-Centered Therapy (CCT): 3 critical attitudes – genuineness, unconditional positive regard, empathic understanding
    - Must remember, important/unique story to tell; feigned interest readily transparent, nothing more important to storyteller than engaged listener
- Content
    - Dignity Therapy facilitated by series of questions; theme for questions from dignity conserving perspectives/aftermath concerns
    - Sub Themes include: continuity of self, role preservation, maintenance of pride, hopefulness, and autonomy/control
    - Aftermath concerns; provide openings to discuss these delicate areas

DIGNITY THERAPY REVEALED

- Patients invited to: engage in conversations, addressing important issues/memories for those who will outlive them
- By recording, transcribing, editing, printing creates something that will last; something that will influence after death; voice to be heard for generations
- Role of interviewer is to imbue therapeutic interaction with dignity; help patients feel accepted, valued, and honored

THE FIRST CLINICAL TRIAL IS PUBLISHED

- Aug 2005 results of first clinical trial published; Journal of Clinical Oncology
- Hailed as major breakthrough for palliative care
- Over 2 year period, 100 patients completed study; participants from Australia/Canada
- Most w/ advanced end-stage cancer; medium survival 51 days from point of contact until time of death
- Of 100 who completed
    - 91% felt satisfied of highly satisfied
    - 86% felt helpful/very helpful
    - 76% felt heightened sense of dignity
    - 81% reported it had already helped, or would help their families
- DT used in a variety of ways
    - Affirm their love for friends and family members
    - Opportunity to recount memories of special life events/moments of celebration or tragedy; often moments that had changed, defined, or shaped their lives
    - Theme of generativity; bring it all together for others
    - Others expressions of regret
- Measures of suffering/depression also showed significant improvements
- Improved feelings their life was meaningful, heightened sense of purpose, and will to live
- DT bolsters sense of meaning & purpose within framework that is supportive, nurturing, and accessible;
- Viability of DT as end of life intervention fully supported by results of first study

WHAT ABOUT FAMILIES

- Families deeply affected by experience of anticipatory loss and impending death
- Factors that affirm patient dignity often have similar effect on families
- Interviewed family members 9-12 months later; 60 family members provided feedback
- Group mainly consisted of spouses and grown children
    - 95% felt DT helped their loved one;
    - 78% felt DT heightened loved one's sense of dignity
    - 72% felt enhanced loved one's sense of purpose
    - 65% felt it helped love done prepare for death
    - 65% felt DT one of the top components to overall palliative care interventions
- Benefits expressed in variety of ways
    - Affirmed sense of purpose; feelings of having lived worthwhile life
    - Influenced grief and accommodation to loss
    - DT doc helped them in time of grief and DT doc remained a source of comfort
    - Presence of family member at interview provides quality assurance, helps keep responses consistent, offer suggestions to assist in recall meaningful disclosures

GOLD STANDARD EVIDENCE

- The status quo is difficult to change! Commonly held practices hard to displace w/o convincing evidence
- The way care providers behave toward patients – their ability to affirm the whole person, is a powerful mediator of overall satisfaction
- With funding from NIH, conducted 3 country, three-arm randomized controlled trial
- Patients met strict protocols and were randomly assigned to one of three study arms
    - Dignity Therapy
    - Client-Centered Care (here and now discussions)
    - Standard Care
- August 2011 research group published findings in Lancet Oncology
- 326 patients with terminal prognosis randomized across 3 study conditions
- DT was significantly more likely to have been helpful; improve quality of life, increase sense of dignity, change family dynamics
- DT dramatic improvement in spiritual well-being; lessening of sadness/depression
- Many examples/anecdotes of the value of DT and its ability to help share stories of simple wisdom that people wish to pass along to their loved ones
- Time after time, DT captured pivotal moments in life, when time stood still, and memories were indelibly etched

TIME TO MOVE ON

- DT can enhance life experience for those nearing death
- DT can improve spiritual well-being, and quality of life, sense of dignity
- DT can help cope with disappointments, process the reality of leaving loved ones behind, and deal with sadness, loss, and isolation
- DT can help consider personal priorities and resolving outstanding conflicts
- DT stands on solid empirical ground; treatment is evidence based; supporting data very strong
- DT helps mitigate various kinds of stress and suffering for patients and families

CHAPTER 3: INTRODUCING DIGNITY THERAPY TO PATIENTS AND FAMILIES

STEP 1

Discussion points:

1. Introducing DT to patient and families
2. Referral has to be made from someone who knows the patient, but also knows something about DT—A conundrum
3. What signs does an observer look for to think about referring a patient for DT?

Total Pain-Cicely Saunders

Total pain describes the subtle, existential, almost insurmountable distress a dying patient can be experiencing even though they appear comfortable. Physical appearance does NOT always mean inner peace.

She identified the need a dying patient has to give meaning to a life lived. Her patient, David, did not know what she knew as she was his nurse, namely that he was dying of an advanced cancer. She became his friend, identifying his tremendous need to give some meaning to his life. Dying at the age of 40, he had to define who he was. He left her money to start a hospice.

What does the typical patient look like?

1. Person in final months, weeks or at times days.
   Use DT as a foil against a mounting sense of futility.
   The patient has to acknowledge that there is less life than one would have expected without the illness, whatever the diagnosis may be.
   The first step is to determine which patients might benefit from DT. This means understanding eligibility criteria and knowing which patients should not take part.

2. Need a motivated patient. It takes awareness of self and someone who wants to help themselves and help their family. It is not for everyone. The therapy as any therapy can have adverse effects.

3. The patient needs to have the energy to do it and therefore advanced disease may be too overpowering. You should have at least 2 weeks to complete the project. Impaired cognitive ability can be a problem.

4. If there is a dissonance between what the patient says and what the family perceives, the recipient of the journal may want to hold it back.

STEP 2

Once eligibility has been determined, DT can be formally introduced to the patient and family. Communication skills in DT as in palliative care involve talking balanced with listening.

Caveat:

1. Don't start by saying: "This is something good to do as you are nearing the end".

2. Start with the patient, but include the family. This therapy can help many people comprehend how they feel about themselves and their circumstances, and even improve their quality of life. It can also have benefits for their family members.

Mechanics:
DT usually only takes one session, sometimes two.
These conversations are audio recorded, transcribed and edited
The final product is a type-written document or paper, which is returned to the patient.

STEP 3
Once DT has been introduced, answer any questions that the patient might have.

Nine Common Questions:

1. Why does it work?
DT is meant to help people, especially those who are feeling particularly unwell, maintain the sense that they still have something important to do. Most people find the experience very meaningful and take comfort in knowing that the document is for them to keep and something they can share with people they care about.

2. What sort of questions will I have to answer?
There are no specific questions that have to be answered. The document belongs to the patient.

3. What kinds of questions will you ask me?
Leave a copy of the questions—Most patients who do **DT do not have a particular content in mind**

The message can be constructed around a particular area that patient may want to elucidate, e.g. the secret of how she was successful in business

The patient can spontaneously offer important content or use question protocols to reflect on specific content.

4. What if I get started and I just don't know what to say or how to continue?
It is the **leader's job**, using their skills, to help the patient out of these sticky areas. The therapist can interject prompts or point out possible connections.

5. What if I get tired or just start feeling too unwell to continue?
Sessions should be 45-60 minutes, take breaks at any point. The therapist can call the shots. DT can energize.

6. Why does it have to be audio recorded; what if I don't feel comfortable with the tape recorder?
You eventually forget about the tape recorder and realize that you are "generating" something that will outlast you for the benefit of those left behind. The patient's words transcend death. This technique **gives the ability to leave something behind.**

The final document is a refined piece of work, **a distillate of emotion**. One patient reported having asked for the original unedited tape. After hearing it he felt that it was "too raw and too painful to listen to". Everyone has the generativity document which was and continues to be a source of comfort".

Words are more easily malleable

7. **What if I just don't get it right?**
Remind the patient that the transcript can be edited.
There can be two versions-One for the family and one for friends.

8. Is DT just for patients who are dying?
DT usually brings comfort. Originally for people in palliative care. It can help people who are facing the challenges of getting older or who are facing significant health problems.

9. How do I know if it is right for me?
The story belongs to the teller. No two lives are the same. There is **no particular type of person that qualifies for DT.** If it sounds appealing and meaningful, you should give it a try.

It can heighten a sense of meaning and purpose and improve quality of life. You can have someone with you during the interview.

STEP 4
After the patient's questions have been answered, offer him or her a copy of the basic DT question protocol.

Caveats:
1. The questions are not arbitrary or haphazard. They evoke a sense of meaning and purpose. They connect with memories and thoughts. They resonate with the core sense of self.
2. Each question elicits some **Aspect of Personhood**; elements of self that were or may remain meaningful or valued.
3. The patient's core self is being acknowledged. The patient feels a sense of meaning, purpose, and dignity. **The therapist is the facilitator.**

STEP 5
Once the patient has agreed to take part, collect basic demographic information
Demographics place the patient in context.

STEP 6
Arrange an appointment with the patient (with or without a friend, family member, or loved one) to conduct the DT interview.

Caveat: ONE to THREE days **after** the introduction, review the questions.

CHAPTER 4: DOING DIGNITY THERAPY

I. First Meeting- Preparation BEFORE the session

- Dignity Therapy has been explained to the patient. Patient has agreed to participate.
- Patient has been given a copy of the DT Question protocol
- Patient has determined the recipients of the finished document
- Patient has decided whether to do DT alone or accompanied by friend or family member
- Therapist has established the "frame" for DT (example, name, how they wish to be addressed, age, marital status, names of significant others, family members, vocation, current illness and condition)
- Plan the therapy itself. (patient may address content themes or issues to be covered).
- Arrange the therapeutic setting

II. Setting up the DT Sessions.

- Be prepared to review things again.
- Answer remaining questions
- Explain the two components: guided conversion b/w the patient & therapist; and creating the document
- Setting the room for privacy and comfort
- Discuss use of an audio recorder. Reassure patient that anything can be edited, changed or deleted
- Be mindful of the family or friend participant who may also have questions

III. THE ROLE OF THE DIGNITY THERAPIST

At all times, the therapist must be a highly engaged, active listener.
Knowing when to guide them, even actively redirect them is the Essence.

- At all times, for all patients, and in all circumstances, the therapist must assume a dignity-affirming stance.
  - To be a caring active listener
  - To understand that patients look to the therapist for affirmation and some indication of their inherent worth.

- Provide the necessary structure and guidance to help patient construct his/her generativity document Take an active role to engage and guide the patient

- Place meaningful, easy to follow "DOTS"
  - To help them draw their own legacy document
  - Open-ended questions to start
  - Eliciting detail, laying the "Next DOT"

Sit side-by-side with the patient, looking through a metaphorical photo album of their life

- Be mindful that there are different kinds of stories or types of disclosures that patients will share; Essentially, there are **three types**:
  - "The Good" (easier to hear; recall a good life well lived)
  - "The Sad" (may recall personal tragedy, regrets or failures, or seeking forgiveness)
  - "The Ugly" Know **how to manage and respond to the "Ugly" stories:**
    - They may have a potential to harm the recipient(s) of the generativity document
    - Therapist's responsibility: manage these stories along w/ a duty to care for both patient & recipient

- Help patients provide clarity about the details of their stories
  - Want the document to read well for loved ones
  - Time sequencing in a chronological context

- Follow the patient's affect as a way of identifying areas to be included in the DT
  - Follow the emotional energy of the interview
  - Clinical judgement and experience will help guide

- Establish critical momentum and maximize disclosure with minimal expenditure of energy.
  - Use of the photo-album metaphor for example

- Look for therapeutic balance between providing open-ended questions and/or imposing more structure
  - Example; patient fatigue or disorganization; helped by more structure
  - Start with broad questions, then narrow down in detail

- Understand that some stories may be too painful to tell; give patients permission to withhold recollections that may cause them to feel too vulnerable.
  - Therapist is respectful of the patient's defenses

- Remind the patient that the "time is now".
  - ie: "If this was your chance to say all the things that need saying, what would you say to whom?"

- Pace the therapy to best match the patient's needs and abilities.
  - Keep track of the time and monitor the patient's fatigue and mental ability.
  - Assess whether a second session may be needed

Before turning off the Audio Recorder, ALWAYS provide the patient a chance to get in a final word.

Be sure to leave some time for a debriefing with the patient; "How was that for you?"

- **Review Next Steps of DT Protocol-**
  - Audio recording to be transcribed
  - Therapist will then edit the document

- **Third Meeting-** Review the edited transcript with the patient
  - Opportunity to determine if any corrections are needed
  - Patient may want to make changes

- **Fourth Meeting**- Patient presented with the Final Document

THANK THE PATIENT FOR THE HONOR & PRIVILEGE OF SHARING THEIR WORDS WITH YOU

CHAPTER 5: THE GENERATIVITY DOCUMENT

This chapter discusses questions regarding the task of editing the verbatim transcript.

Is it right to edit or change the verbatim transcript in any way? What is the rationale for doing it? How does one know if editing isn't keeping with the patient's wishes? These are legitimate questions.

The Rationale for Editing Dignity Therapy Transcripts

To begin the discussion, it is helpful to return to the therapeutic contract established with dignity therapy participants. The role of the therapist is to encourage the patient to accomplish something that could not be done without therapeutic assistance and guidance.

Those enrolled in the therapy are facing life-threatening in life limiting circumstances and not only do they lack the energy and at times mental capacity even without those limitations many feel intimidated at the prospect of trying to document some of their most heartfelt thoughts and feelings knowing these words will achieve longevity beyond their own days.

We want to be heard correctly and hope our words will accurately reflect what we feel for it is a permanent indicator of who and what we are or were. We want our own words to be worthy of our thoughts, feelings, and recollections to be an accurate reflection of ourselves. In essence the relationship is together we can do this and we could do it right.

This means that disordered or distractive thinking is not treated as sacrosanct, simply because it happens to be part of the patient's narrative. Polishing and compensating for disorganization, and eliminating extraneous content that might diminish their words, yet the editorial procedures judiciously applied will yield a final generativity document where the patient could have produced if they had been feeling well enough to do so.

Transcribing the Audio Recorded Interview.

The transcript provides all the raw material available to construct the edited document. Details regarding how it is produced is important. Whoever does the transcript must be ready and prepared to listen to the type of content that would have such words as love, regret, anguish, longing, and grief and the vast panorama of human experience. Transcribing should be done within 1 to 3 days of the interview. Depending upon the length of interview the time required for each individual transcription, it ranges from 2 to 3 hours, a verbatim transcript usually takes 2 to 3 times the length of the actual interview to complete. One hour interview = 2-3 hours of transcription.

In the process of transcribing there are several points to consider: its overall approach, its timing, and confidentiality.

Layout: The transcript should read like a conversation between the interviewer and the patient; each new exchange of dialogue should be labeled to indicate the current speaker.

Good quality transcription equipment is essential. Partial documentation of what was said is better than none and that will allow the editor/therapist to reconstruct the essence of the patient's intended words. It's important for the editor/therapist to remember those feelings or highlights where they will reconstruct if need be.

Word processing and program compatibility, where the dignity therapy documents should be able to be viewed in 3 versions: 1) the original edited a transcription, 2) the track changes and edited version that displays all additions and deletions, and 3) the final edited version.

Editing the Verbatim Transcript

The words and legacy of the patient is literally in the hands of the editor/therapist. The therapist may recall words the transcriptionist missed or remember the patient's intended message what was meant to be emphasized.

Editing takes twice the amount of time required for the interview itself. One hour interview should take about two hours to edit.

Suggested fonts would be Garamound font number 14, with line spacing of 1.5 to 2 along with left and right margins to be set at 1.5 cm that will allow the tracking function to assist you and others in reviewing the changes.

The editing process is divided into *four primary tasks or stages, the* sequence not critical they are: 1) cleaning up the transcript, 2) clarify in the transcript, 3) correcting times sequence, 4) finding a suitable ending. Editors must be sensitive to what they cut or add to always be true to the participants' words and wishes. It's like putting a puzzle together once you have all the pieces together, fit them so that they tell the patient story in the best way possible.

1. **Cleaning up the transcript**

   The first task of editing is to clean up the manuscript so it reads more like prose than a recorded conversation. You could take out such words as "you know". Anything in the transcript can be edited, certainly words that the patient might later deem embarrassing, or words they regret saying, or anything that could be damaging to the surviving loved ones; this can be easily and readily dealt with in the editing process.

2. **Clarifying the transcript**

   Patients may say something they perceive to be quite obvious but later reads less clear editing such may require a phrase being incorporated with another or you may have to combine sentences or paragraphs may need to be moved for clarity or chronological coherence.

3. **Correcting times sequence**
   Patients do not talk in the sequence not when things occurred but rather in the order that they happen to recall them. Spontaneous recollection is often accompanied by optimal energy and engagement. Once the editing process has been cleaned up and clarified correctly in time sequences is relatively easy. This helps make the patient's story much more coherent and readable and it underscores the importance of clarifying details regarding time in the sequence of events

4. **Finding a suitable ending**
   The editor is to be mindful when someone says something that is quite poignant and lovely when they know the opportunity record their words is coming to a close. However, often what is said during the end of an interview session is usually anti-climactic compared to the often profound, poignant, or emotional issues that have been raised during the course of the interview. With that in mind during editing it's important to watch for a statement that might make an appropriate ending such as "It's been a good life".

The Patient Has The Final Say

When the manuscript has been shaved and polished to the best of the therapist/editor ability; it is returned to the patient for final approval. The critical element of editing requires the therapist to read the entire edited manuscript to the patient allowing for any final corrections (some patients choose to read the manuscript by themselves). Hearing a summary of their reminiscence, thoughts, feelings, and wishes can be deeply moving for patients. Changes can be small or changes can be large. The therapist wants to assure the patients that the editing was accurate and true to the patient's words.

CHAPTER 6: FROM START TO FINISH

I. Introduction

A. Two simulated DT interviews presented:
   1. Presented verbatim, from start to finish.
   2. Conducted for a live audience during DT workshops with actors playing the role of patients.

B. Methodology
   1. Patients were provided the DT question framework in advance of the interview.
   2. Patients answered a few questions to provide the "FRAME" (see chapter 3) of basic demographic information.

II. DT Interview #1: Dave

A. Frame: Dave is a 57- year- old married man and father of 3 children, 1 son and 2 daughters. Prior to being diagnosed with advanced colorectal cancer, Dave ran his own outdoor landscaping business.
B. First part of interview focused on:
   1. Putting patient at ease
   2. Making sure the patient understands the process.
   3. Reassure the patient that they have full control over what is included.
   4. Interviewer: Calm tone, reassuring responses.
   5. Review what is unclear, clarify misunderstanding, answer questions.

Example:

"I'm just a Canadian bloke so you're going to have to fill me in and tell me when things I'm asking don't quite work for you and when they do."

This comment is meant to make Dave feel that the interview should be comfortable and that a certain amount of casualness and levity is appropriate**.**

C. Exquisite care in choosing words.
   1. Euphemistic language such as "this will let me share stories with people I love" leads the interviewer to use more euphemistic language as well.
   2. Patient has mentioned that the document will be passed on "when he is gone" so this provided implicit permission for the interviewer to use similarly explicit vocabulary.
D. Obtain clarity (e.g., clarify names and relationships, asking the age of the patient during that story to clarify chronology.)

   Example:

   Patient: "When Jean and I were first together…"

   Interviewer: "So, Jean is your wife?"

E. Use of the metaphor of photographs.
   1. Can be useful and evocative.
   2. Connects the memory to a concrete visual image.

3. Allows patients to describe the recollection more easily.
4. Interviewer can enquire about details contained within these pictures.
5. Detailed memory description makes the document unique to the life of the memory's creator.

Examples:

"I get the sense there are some particular memories or images that come to mind as you share this story. If it's not too difficult, would you be able to share some of those pictures that you are seeing in your mind's eye?"

Later on, after one photograph is shared, ask if there is another memory that comes to mind allowing the patient to make a conscious choice about where to proceed next.

"Now that you've shown me the photo of the Solomon Islands, are there others that come to mind, moments that you would want people to know about you, or to somehow be able to share?"

F. Pursue affect
1. Help patient connect to a memory to elicit rich detail for the generativity document.
2. DT uses the "pursuing affect" approach rather than "insight-oriented" approach used by psychotherapists.

Example:

"I notice as you talk about it, Dave, it seems a happy memory; but it seems to evoke a lot of emotion. Is that something that you wanted to talk about?"

G. Occasionally Summarize
1. Illustrates that the patient is being carefully listened to.
2. Indicates that the patient's words matter.

Example:

"This thread of the outdoors is something we can trace in each of the three images that you've shared, from the golf course, to mountain climbing, to the Solomon Islands."

H. Timekeeping
1. Interviewer must be mindful of timekeeping.
2. Advanced illness means a patient rarely has energy to extend a session beyond an hour.
3. First half of the interview is devoted to personal memories and recollections.
4. At the 20-minute mark, point in the direction of discussing any remaining key relationships.

I. Uncomfortable relationships with others
1. Friction between patient and others may be important family issues but may or may not be something the patient wants to address in DT.
2. It is not required content for DT.
3. Only the patient can determine what content finds its way into the document.

4. Interviewer needs to monitor the so-called "ugly" stories, content that might prove harmful to generativity document recipients.
5. Facilitate sharing of end- of- life reflections for generativity relevant content.
    a. Interviewer acknowledges the implied pain in a relationship.
    b. Points toward generativity relevant content

Example:

"People often use DT to say things that they want said. If this is one chance for you to say to X the things that you want him to know, what would you say?"

J. Important roles, pride, and accomplishments
1. Ask about the personal connection to an affiliation.
2. Avoid redundancies if the patient has already described these sufficiently earlier in the interview.
3. Ask about roles not yet described.
4. Create opportunities that might lead the patient to a rich, balanced, and overall complete DT.
5. Gently encourage patients to move from generalizations and platitudes to specific, personal perspectives or experiences.

Examples:

"I have a sense of how you might answer this, but are there particular roles and accomplishments that you feel most proud of?"

"What makes that an important connection for you? I mean, why that particular association? Affiliation? Accomplishment?"

"Besides the vocational and community roles you've shared, are there others? For example, what about family roles?

"So, when you describe being a good Dad, can you put words to what that means to you?

K. Possibility of healing
1. Empathic connection between interviewer and patient.
2. DT may be healing for the people the patient loves.

L. Concluding the Interviews
1. Ask patients about Hopes, Wishes, and Dreams
2. Ask about final words of advice or instructions.

Example:

"None of us know how much time we have. In thinking about the future and in helping them to prepare for a future that you might not be a part of, are there words of advice, or instruction that you would want to leave with them to help them with whatever lies ahead?"

III. Generativity Document

A. Use of italics and boldface type
   1. Use sparingly to indicate where the patient has placed emphasis.
   2. Italics imply soft emphasis; Boldface implies strong emphasis.

B. Use wording particular to the patient for a voice distinct to the patient.
   1. Patient will read or hear the edited document in its entirety & has the opportunity to remove words.
   2. Colloquialisms (e.g. "bucks") need not always be eliminated; they capture the speaker's authentic voice.

C. Correct errors in transcript (e.g. Saltzman Islands corrected to Solomon Islands)

D. Re-order patient's sharing to improve sense of chronology, enhance picture patient is describing or help transcript to read as prose not dialogue. (e.g. moving demographic information regarding children to the section in which patient talks about family)

E. Condense and eliminate words of therapist when possible.

F. Unnecessary to include all the interviewer's questions if one captures the main line of inquiry.

G. Suitable and dignified ending
   1. Might be found anywhere in the transcript.
   2. Often appear toward the end of the interview during "words of advice" and "wishes or dreams" discussion.

H. Grammar and punctuation are not entirely perfect or formal
   1. Edit to capture the fashion in which the patient uses speech and language.
   2. Goal is for authenticity specific to the patient.

IV. DT Interview #2: Bill

Bill is a 69-year- old man with end-stage cancer. He has been told he has only a few months left to live. He and wife have been married for 45 years. They have 3 children and 5 grandchildren. Until he got sick, Bill worked as an accountant.

A. Interviewer orientating to chronology of patient's story.

   <u>Examples:</u>

   "How old would you have been when you started into accounting?"

   "How old were you when you got married?"

B. Vague and sweeping responses.
   1. Typical when someone is feeling unwell and has limited energy.
   2. Interviewer tries to elicit more detail on important issues.

3. Return to the important issue mentioned.
4. Use photograph metaphor to encourage further details or additional anecdotes.

Examples:

"Maybe we could back up for a moment. You were talking about meeting your wife Janet. I'm wondering if you can tell me how that happened?"

"Let's imagine that you and I are looking through a photograph album of your life. There you find a picture labeled "meeting Jane." Can you tell me what that photograph looks like?"

"Perhaps I've asked this already, but were there things about Janet that drew you to her, maybe something about her way of being?"

C. Interviewer as attentive listener, in synch with patient's story
1. Use the patient's words and language.
2. Explore whether there are earlier memories the patient might wish to address.
3. Invite patients to recount as much detail as possible.

Examples:

"Turning back a few pages in this album, are there some earlier memories or earlier photographs that you and I might glance at?"

"Tell me about the cars you just mentioned. What do you remember?"

D. Stories that hold pain for the patient
1. When a patient retells a sorrowful story, acknowledge it with empathic connection.
2. Offer patients a choice on how to proceed regarding an unhappy/unpleasant life experience.
3. Patients have permission to include only those memories and recollections that they wish to share with others.

Examples:

"You suggested that there are a lot of things about those early years that you don't particularly want to talk about. If there are things you would just as soon not look at, we don't need to. But if there are things that you want to recount or you think are important to share, this would be the time to do it."

"It feels like we are scratching on the surface of a lot of pain."

E. Concluding the interview:
1. Ask patients about Hopes, Wishes, and Dreams.
2. Ask about roles played in life and things that the patient takes pride in.
3. Ask about formative experiences, relationships, places, events that have made them who they are.
4. Emphasize that this is the time to say things that need to be said.
5. Ask about final words of advice or instructions.

Examples:

"Are you able to say what Jane and your marriage helped you to achieve?"

"Why don't you share some of those memories with me, memories of fatherhood and being a young husband, and what it was like learning how to love?"

"Are there things that you learned while "walking through the minefield of raising teenagers", as you said, that you think are worth putting into words?

"How would you describe yourself as a father, or how do you think your children would describe you as a father?"

"Not having come from a place where you could learn about these kinds of loving relationships, how do you think you learned to be the kind of father and grandfather that you are?"

"You have the opportunity to talk about things you want to talk about; perhaps to say things you feel need to be said. Are there things that you feel still need to be said or perhaps you want to say again?"

V. Generativity Document

A. Verbatim transcripts provide the raw material for what the editor then turns into a pristine narrative.
   1. Each editor makes a different decision in determining how to shape the document.
   2. Adherence to basic principles of editing (chapter 5) will help ensure that the story and the essence of the message that the patient wants to convey remains unchanged.
   3. The original and final generativity documents will be different from one another.

B. Cleaning up the transcript

   1. Combine several segments of dialogue and move segments to a different place in the document than where they occur in the transcript to achieve a more streamlined, chronologically coherent document.

   2. Edit to add clarity such as adding the word "light" to "switch".

   3. Eliminate sentences that add nothing by way of clarity or content.

   4. Determine when to include often repeated words such as "basically" or "you know" to maintain the patient's unique voicing and when for the sake of clarity and flow to delete them.

   5. Distill and condense content when appropriate

   6. Editor uses discretion regarding retention of colloquialisms.

CHAPTER 7: MOVING FORWARD

Is There Currently Sufficient Evidence to Support the Application of DT

Multiple uses throughout the world (Japan, Korea, Denmark, Copenhagen, Quebec) include: research, clinical, grad course in therapeutic communication and health professional teaching Mercy Hospice (Aukland): question structure used to assist pts at EOL that can't participate in multiple interview life story process not possible, create personal stories San Diego Hospice (Lori Montross)

Copenhagen study: patient felt the DT helped them & relatives, heightening patient's sense of purpose, dignity and will to live. Dignity and meaning, measures of existential well being carried into a 1 month survey after release of the document and despite patient's decline.

Quebec Study: improved the patient's sense of meaning, purpose, & overall dignity suggesting it to be a valuable asset as a bereavement intervention.

Caution: DT hasn't been used in cases of marked distress only for general PC pop. Can be used along with conventional therapy but not in place of it. Depression, suicidal ideation or euthanasia seekers are not advised despite often having lost meaning & purpose because of no evidence of efficacy in these groups.

How Do I Become Skilled enough to Implement and Improve My Abilities to Deliver DT?

Acquire skills: Workshops www.dignityincare.ca, experience, being supervised, peer-to-peer support

Self-check via audio record of one's delivery of DT & editing process provides a paper trail. Unedited, tracked edited and final edited can be shared and reviewed w/ peers (FTF, video) in addition to virtual communities (boards, blogs, FB).

How Much Does DT Cost and How Can Resources to Support It Be Found?

For traditional therapist's interview time, editing and transcriptionist fees, it is estimated to be between $400-500 per transcript. In a hospital setting, compared to the costs of a new pharmaceutical drug or other therapeutic interventions, like palliative chemotherapy or radiation, it is an inexpensive treatment. Funding is suggested to be by hospital's absorbing the costs, or the engagement of philanthropic or hospice foundations.

What If Family Members or Volunteers Want to Take On This Work? Is That an Option?

Many of the questions within DT affirm a person's "personhood" and require the interviewer to be present, attentive, and appreciative of the disclosures. As these questions provide a framework, the therapist must be **highly skilled** at eliciting responses, identifying important issues, engaging the patient with the process, mitigating possible negative outcomes and making these disclosures into a cohesive and meaningful document.

Family members may find it difficult to do DT with loved ones due to the "balancing act" of being an interviewer. The intense emotions that arise when watching a loved one die eliminates objectivity from the experience. There are the basic challenges of keeping the patient within time frames and on topic and in addition to understanding the psychology of how these legacy documents are rooted in conflicted relationships or unresolved interpersonal relationships. A skilled interviewer can conduct this interview recognizing opportunities for the patient to feel empowered to honestly express themselves.

Can DT Be Done By a Therapist Who Knows the Patient Well?

Unlike research interviewers, knowing the person well may offer the therapist clear advantages such as having mindful insights that can direct patients toward meaningful disclosures and not overlooking recollections that the patient feels are important. Although, there can be an inherent bias in offering DT to those who had "good stories" to tell rather than those who had a complex or a hard life.

Furthermore, the recording of the session in a person's own words adds a dimension to the experience that is permanent and less interpretative that requires a therapist the unique experience to transcend the "here and now" of the session and expand it to a broader audience and beyond their death.

A critical issue is the ability of the therapist to choose between further exploring profound and unexpected disclosures, such a trauma and moving forward with the interview. It requires the need for affirmation of what the patient wants to include in the document and proceeding according with that goal, ie: whether to further explore these issues and/or include them in the document.

Are There Still Things About DT Worth Studying? If So, How Might Researchers Take Up This Work?

The following needs to be further explored: "Who is DT most likely to benefit?", "What is the nature of the therapeutic effects wielded by DT?", ``How can one measure the influence and benefits of DT?"

Because the themes and subthemes of DT are universal, including influences on the body, social environment and the psyche and spirit of patients near death, the above questions imply that DT extends beyond end-stage cancer and even end-of-life and may resonate across a broad spectrum of the human

experience. DT has been used for ALS patients and piloted in the elderly and frail living in LTC and shown to operate differently in those who are "moving closer toward the end of life" rather than the actively dying.

The challenge remains for determining qualitative outcome measures in patients with long-term illness and low base rates of distress. A focus on how examples of witnessing and affirmation are used to demonstrate a healing rather than on fixing and curing is advised when addressing issues of self-worth, sense of peace, dignity, meaning, spiritual well-being and existential angst.

What About Other Modes of Generativity?

The legacy document should not replace other modes of generativity such as video, audio recordings, diaries, letter writing and art work that may also reflect a person's individualistic way of representing themselves.

What About Dying Children? Does DT Have A Role To Play?

The Dignity model has been developed for those 18yrs and older with end-stage cancer and one cannot assume it would apply to those beyond that demographic. The need for insight and generativity needs are key parts of the Dignity model so age and developmental modifications would need to be developed for children.

What About the Issue of Culture and DT?

Sensitivity to different cultural norms is critical such as in Denmark where endorsing a sense of taking "pride in oneself" is considered to be crass and immodest. Thus, the language of questions would be changed to asking about what they consider to be important or meaningful accomplishments. Hong Kong residents have noted the need to preserve self-respect and self-identity or "face" which will also impact one's approach and framework of the DT questions. In both instances, it is the flexibility of the questioning with respect to social norms which needs to be addressed.

How Should DT Be Evaluated?

It is advised that a tracking method be employed such as how often DT is used, the circumstances of patient participants, and the responses of both the participants and family. This data can then be used for funding purposes and to share with the wider DT community @ www.dignityincare.ca.

Closing Thoughts

Dr. Chochinov shared the story of his first DT patient who regretfully noted that "if he were in Europe" that he could and would "push a button". Yet after being told about DT and asked if he still wanted to "push a button" his answer was "No, I'd like to do this first". It resulted in the patient being energized and enthusiastic about the retelling of his life and offering love, blessings and comfort to his family.

When Dr. Chochinov returned to review the document with the patient, he found him further deteriorated and unable to respond. However, his wife at the bedside was tearful and most grateful, accepting the document as a "blessing" for their family.

This experience changed Dr. Chochinov's career for the next 7yrs. Prior to starting DT, it would have struck him "as entirely unfathomable that "a brief psychotherapeutic intervention might enhance a patient's sense of meaning, purpose and dignity, offer comfort to the bereft and have the potential for multigenerational impact." Furthermore, DT opens up "opportunities to provide comfort, mitigate suffering, and promote healing that are unique and effective".