


# A comparison of Dignity Therapy narratives among people with severe mental illness and people with cancer

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## Funding information

Università degli Studi di Ferrara

## Abstract

**Objective:** To examine Dignity Therapy (DT) narratives in patients with severe mental illness (SMI) and a control group of cancer patients.

**Methods:** 12 patients with SMI (schizophrenia, bipolar disorders, severe personality disorders) and 12 patients with non-advanced cancer individually participated to DT interviews. DT was tape-recorded, transcribed verbatim and shaped into a narrative through a preliminary editing process. A session was dedicated to the final editing process along with the participant, with a final written legacy (generativity document) provided to the participant. Interpretative Phenomenological Analysis was used to qualitatively analyze the generativity documents.

**Results:** Patients with SMI and patients with cancer presented similar main narrative categories relative to dignity, such as "Meaning making", "Resources", "Legacy", "Dignity"; in addition, inpatients with SMI "Stigma" and inpatients with cancer "Injustice" emerged as separate categories. Patients in both groups strongly appreciated DT as an opportunity to reflect on their life story and legacy.

**Conclusions:** The study showed that DT is a valuable intervention for people with SMI, grounded in a practical, person-centered approach. All patients found DT as an opportunity to describe their past and present, highlighting changes in the way they relate to themselves and others. These results can guide implementation of DT in mental health settings for people with SMI, as it is for people with cancer.

## KEYWORDS

bipolar disorders, cancer, Dignity Therapy, psycho-oncology, schizophrenia

## Key points

- This study analyzed the narratives in patients with severe mental illness (SMI) and a control group of cancer patients
- All patients completed Dignity Therapy (DT), including creating a generativity document
- Patients with SMI and patients with cancer presented similar main narrative categories relative to dignity, such as "Meaning making", "Resources", "Legacy", "Dignity"; in addition, patients with SMI included "Stigma" and patients with cancer "Injustice"
- Results can guide implementation of DT in mental health settings for people with SMI

## 1 | INTRODUCTION

Dignity has been defined as a basic human dimension, which should be a routine part of a comprehensive person-centered approach in medicine.<sup>1,2</sup>

Dignity Therapy (DT) has been developed in palliative settings as a brief, empirically based therapy that offers participants an opportunity to reflect upon crucial existential and relational issues and review aspects of their lives that they wish to be remembered.<sup>3</sup>

DT has been applied in randomized clinical trials (RCTs) within a variety of clinical settings (e.g. oncology, neurology, geriatrics, palliative care), with reviews confirming that it improves the patients' quality of life, validates personhood, enhances the sense of meaning and purpose, and decreases the levels of demoralization and existential suffering.<sup>4</sup>

In people with severe mental illness (SMI; e.g., schizophrenia, bipolar disorders), although stigma, discrimination and disrespect of human rights have been underscored as factors eroding the patients' dignity,<sup>5</sup> a few studies investigated the use of DT. Only three DT case reports of patients with psychiatric disorders (e.g. schizoaffective disorder,<sup>6</sup>) and a RCT involving fifty-eight patients with major depression disorder are available.<sup>7</sup>

Within this background, the aim of this report was to conduct a qualitative analysis of dignity narratives emerging in DT in patients with SMI and to compare them with patients with cancer.

## 2 | METHODS

### 2.1 | Subjects

Patients with SMI (group 1) were recruited from one Psychiatric Rehabilitation Inpatient Unit; patients with cancer (group 2) were recruited from the Psycho-Oncology Unit, both units belonging to University Integrated Department of Mental Health and Pathological Addictions in Ferrara, North-Eastern Italy, where DT is routinely conducted as a clinical intervention. Group 1 criteria for participation in DT were: age between 18 and 65 years, not to be in an acute phase of illness (Brief Psychiatric Rating scale score <53, cut off for markedly ill patients), to be cognitively intact; group 2 criteria were: age between 18 and 65 years, not to be terminally ill, to be cognitively intact and in a good performance condition (Karnofsky score  $\geq 80$ ).

We followed the DT protocol, with therapists (L.G., H.O., M.G. N) individually meeting each participant, showing the DT questions and asking him/her to consider what he/she might wish to speak about during the session. About a week later, DT interviews were carried out and tape-recorded, then transcribed verbatim and shaped into a narrative through a preliminary editing process. A session was dedicated to the final editing process along with the participant, with a written legacy (generativity document) provided to the participant.

### 2.2 | Statistical analysis

The sample size (at least 12 per group) was based on achieving saturation criteria as required by qualitative analysis. NVivo V.11 software package<sup>8</sup> was used to qualitatively analyze the generativity documents, within the Interpretative Phenomenological Analysis framework.<sup>9</sup> Narratives underwent a bottom-up analysis that required reading, identifying the thematic categories and drawing the units of meaning in order to have accurate descriptions of personal accounts.

## 3 | RESULTS

Socio demographic and clinical characteristics of the patients are reported in Table 1. Qualitative analysis of DT narratives among participants with SMI (12 subjects: 7 males and 5 females) and with cancer (12 female subjects) yielded similar categories, namely "Meaning" (e.g., "vitality", "self-evaluation", "pride", "evolution of self", "support"), "Resources" (e.g., "support", "resilience", "family", "encounters"), "Legacy" (e.g., "bequest for others", "time to say"), and "Dignity". As further categories, "Stigma" emerged in patients with SMI, while "Injustice" in cancer patients (Table 2).

With respect to "Meaning", many patients with SMI described their condition as a significant milestone and a source of pride. Such an appraisal of the illness experience (e.g. opportunity for personal growth, authentic and meaningful life) was also common in cancer patients' narratives.

The theme "Resources" was a significant dimension emerging in both psychiatric and cancer settings. Most participants with SMI depicted their experience as a significant biographical turning point leading to personal growth, empowerment and resilience.

"Dignity in illness" was a thematic category identified in both settings. According to cancer patients, dignity was primarily based on physical autonomy and cognitive integrity, while patients with SMI raised the thorny issue of dignity and stigma as the two sides of the same coin.

Regarding "Legacy", participants elicited the dimension of time, that was experienced differently in the two groups. Patients with SMI appraised the future as an opportunity to rise again and fulfill themselves, to go beyond their present condition, make future plans, and settle future goals. Cancer patients referred to uncertainty about the future and fear of death and indicated that living fully within the present is a life value and a way of facing such a time-limiting condition.

In few instances, SMI was appraised as an obstacle, preventing patients from self-determination, since the illness may preclude them from assuming significant roles or satisfying social interactions with others ("Stigma" category). These themes did not emerge in cancer patients, who instead indicated a sense of betrayal determined by the disease ("Injustice" category).

Patients in both groups strongly appreciated DT as an opportunity to reflect on their life story and legacy.

TABLE 1 Characteristic of the patients

Severe mental illness	Cancer
12 participants: 7 males and 5 females	12 participants: 12 females
Mean age 43.8 years (SD 10.4; range 31–60)	Mean age 60.91 years (SD 7.49 range 46–73)
Diagnosis: Schizophrenia/psychotic disorder ( $n = 10$ , 83.3%), bipolar ( $n = 1$ ) and severe mood ( $n = 1$ ) disorders	Diagnosis: Breast ( $n = 5$ ), digestive ( $n = 2$ ), thyroid, pulmonary, ear, nose and throat, dermatologic cancer)
	Stages: Loco/regional, $n = 6$ ; advanced cancer, $n = 3$ ; under treatment or follow up, $n = 3$

TABLE 2 Examples of narratives in the main thematic Dignity Therapy (DT) categories among patients with severe mental illness (SMI) and patients with cancer

Severe mental illness	Cancer
<u>Meaning</u>	
<i>"Being with people suffering from a psychiatric condition made me grow. It made me realize that there was a more sensitive world out there, broader than what we might be able to see: a really more important world. Such experience has enriched me"</i> (Marta)	<i>"This experience was meaningful because it made me stronger temperamentally. I wasn't aware of being a strong person, supported by the love of my son and the wish of being a guiding example for him. This makes me proud of myself"</i> (Barbara).
<i>"Being part of the group within the psychiatric rehabilitation center and pursuing that activity, meant finding a meaning to my life, a meaning that I have lost beforehand"</i> (Fabio).	<i>"[...] having managed to change the way I deal with everyday living problems. Before, they seemed insurmountable mountains to me. Now, I rather believe that there is a solution for everything"</i> (Anna)
<u>Resources</u>	
<i>"The ability to react positively to obstacles or negative events. Like a tree, if the wind comes, my branches move, but they don't break and I keep my fruit on the branches"</i> (Marta).	<i>"I found a place where I could take care of myself and the world within a network of welcoming bonds that draped me as a new skin; a place where room has been made to words- a cure to me- to gesture and silence"</i> (Marianrosa)
<u>Dignity</u>	
<i>"Dignity means conserving one's own integrity, being respected and at the same time respecting the others, being treated equally and especially preventing stigmatization"</i> (Giorgio).	<i>"I think about dignity in illness. I repeat that the tumor I had was not as impactful as it might be when it requires heavy treatments. Thus, I have not experienced the inability of doing things or the need to lean on others. In the case of advanced illness. It is obvious that it becomes really awful not to be autonomous any longer."</i> (Giulia)
<i>"Living with dignity means to have values to express. Everyone has an intrinsic value to express. It only needs to be brought out"</i> (Marco).	
<u>Legacy</u>	
<i>"I would like to convey this message: you must always have hope in the future, never let yourself go. Be calm because there is always a way out"</i> (Marianna).	<i>A life lesson could be loving what we feel does really belong to us, and letting go with serenity, driving away from us people, situations, things that no longer give us love [...]"</i> (Giovanna).
<i>"What is important is that, even if you have failed, you should know that it does not last forever. You can! It's wonderful to have the opportunity and the possibility to say: "I am making it. I want to get back on track and find back the path that I have lost in past"</i> (Paolo)	<i>"I wish my son could see and remember the image of a mum surrounded by positive relations, determined and fragile at the same time, a mum who loves life because it is full of possibilities, opportunities, occasions, light to catch".</i> (Linda)
<u>Psychiatric illness experience (Stigma)</u>	<u>Cancer experience (Injustice)</u>
<i>"[...] Sometimes, the others treat me as if I were a sick person (a patient) and this makes me suffer. I say: "I am not (only) a sick person, I am a person who has a few issues but I am not (only) sick"</i> (Valentina)	<i>"[...] I have never smoked nor drank alcohol. When I got diagnosed with cancer, I discovered I had a tumor at a metastatic stage that had spread to brain"</i> (Maria).
<i>"My mum is not happy that I am sick. [...] She does not easily accept my illness with mental (psychiatric) features. People in general do not accept that and treat us like aliens"</i> (Fabio)	<i>"I hope I am finished with this illness because I think I have done enough if I had to expiate for something. If we might all go through suffering and illness, I think I am ok; I already got my part".</i> (Arianna)

## 4 | DISCUSSION

The thematic analysis of participants' generative documents indicated similar DT categories among patients with SMI and patients with cancer, namely Meaning, Resources, Dignity and Legacy. Both groups considered their illness experience as an opportunity for personal and biographical growth and as a lesson to be passed to others. Participants considered themselves as persons rather than patients, whose experience determines the need to re-appraise moments of life and to give new meanings. These results are consistent with the literature regarding recovery process that favors personal growth perception, the strengthening of personal resources, and the expansion of the social network and interactions in patients with SMI.<sup>10</sup> The experience of illness however was also described as a limitation and obstacle suggesting that SMI is the polar opposite of dignity (Stigma). In cancer patients, the experience of illness was more centered on the body and the sense of invasion and betrayal (Injustice), rather than on being marginalized by others.

In conclusion, our study showed that DT is a valuable intervention for people with SMI, grounded in a practical, person-centered approach. All patients underlined the fact that DT was an opportunity to describe their past and present, highlighting changes in the way they relate to themselves and others.

### 4.1 | Study limitations

The main limitation of the study is the small sample size limiting generalization of our results. Also the sampling consisted of patients that receive DT as a form of routine treatment in our settings. As such, these patients had to meet eligibility criteria for DT and are not representative of the entire patient population. A further limitation is that the study involved only one center. A wider sampling frame may have given not only a larger sample, but a broader diversity of experience amongst people with SMI. Also, a DT randomized clinical trial with quantitative measures, as done in end-of life settings, is recommended.

### 4.2 | Clinical implications

From the clinical point of view, our findings highlight that DT offers patients with SMI a structured, dialogic space in which they express the importance of being treated as equal human beings, with the potential to experience self-worth, meaning and purpose, despite suffering the consequences of mental illness. Although DT has been implemented in end-of-life care and geriatrics, our findings suggest to introduce this treatment psychiatry as well as in oncology, that is in

patients not in terminal illness. This supports the need to have a wider concept of palliative care (i.e. as supportive intervention to palliate every form of suffering in chronic conditions). Further studies are needed to confirm and evaluate its efficacy, by way of randomized clinical trials among patients with SMI.

### ACKNOWLEDGMENTS

University of Ferrara local research funds.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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**How to cite this article:** Grassi L, Nanni MG, Caruso R, et al. A comparison of Dignity Therapy narratives among people with severe mental illness and people with cancer. *Psychooncology*. 2022;31(4):676-679. <https://doi.org/10.1002/pon.5913>