

Original Article

Cite this article: Bylund CL *et al.* (2022). Empathic communication in dignity therapy: Feasibility of measurement and descriptive findings. *Palliative and Supportive Care* 20, 321–327. <https://doi.org/10.1017/S1478951521001188>

Received: 13 December 2020

Revised: 27 June 2021

Accepted: 11 July 2021

Key words:

Dignity therapy; Empathy; End of life

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Empathic communication in dignity therapy: Feasibility of measurement and descriptive findings

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Abstract

Objective. Dignity therapy (DT) is a guided process conducted by a health professional for reviewing one's life to promote dignity through the illness process. Empathic communication has been shown to be important in clinical interactions but has yet to be examined in the DT interview session. The Empathic Communication Coding System (ECCS) is a validated, reliable coding system used in clinical interactions. The aims of this study were (1) to assess the feasibility of the ECCS in DT sessions and (2) to describe the process of empathic communication during DT sessions.

Methods. We conducted a secondary analysis of 25 transcripts of DT sessions with older cancer patients. These DT sessions were collected as part of larger randomized controlled trial. We revised the ECCS and then coded the transcripts using the new ECCS-DT. Two coders achieved inter-rater reliability ($\kappa = 0.84$) on 20% of the transcripts and then independently coded the remaining transcripts.

Results. Participants were individuals with cancer between the ages of 55 and 75. We developed the ECCS-DT with four empathic response categories: acknowledgment, reflection, validation, and shared experience. We found that of the 235 idea units, 198 had at least one of the four empathic responses present. Of the total 25 DT sessions, 17 had at least one empathic response present in all idea units.

Significance of results. This feasibility study is an essential first step in our larger program of research to understand how empathic communication may play a role in DT outcomes. We aim to replicate findings in a larger sample and also investigate the linkage empathic communication may have in the DT session to positive patient outcomes. These findings, in turn, may lead to further refinement of training for dignity therapists, development of research into empathy as a mediator of outcomes, and generation of new interventions.

Introduction

Nearly 500,000 older Americans die a cancer-related death each year (Xu *et al.*, 2018). Maintaining human dignity is central to the quality of life for patients with advanced illnesses (Chochinov *et al.*, 2016), including serious cancer diagnoses. Patient dignity can be fostered through empathic patient-provider communication, which promotes rapport, shared decision-making, and patient preparation for health decline (Cripe and Frankel, 2017). Oncology patients, however, do not always experience empathic communication during interactions with providers (Pollack *et al.*, 2007).

Dignity therapy (DT) (Chochinov, 2002) is a validated and acceptable intervention to improve dignity for seriously ill patients (Martinez *et al.*, 2017). The DT process involves reviewing one's life story (Chochinov *et al.*, 2005), affording patients individualized psychosocial support through encounters with a dignity therapist. We use this term, *dignity therapist*, to describe providers (e.g., nurses, chaplains, and mental health therapists) who receive standard training and use explicit interview tools (e.g., Guiding Questions, see Table 1) to facilitate the patient's feeling that their life has had meaning and their accomplishments and experiences are uniquely valued (Pasupathi and Rich, 2005).

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Table 1. DT protocol: questions guiding the session

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?
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?
What are the most important roles you have played in life (family roles, vocational roles, community service roles, etc.)? Why were they so important to you, and what do you think you accomplished in those roles?
What are your most important accomplishments, and what do you feel most proud of?
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?
What are your hopes and dreams for your loved ones?
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, others)?
Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future? In creating this permanent record, are there other things you would like included?

Note. Items taken from the original DT protocol for Guiding Questions (Chochinov et al., 2005).

DT has been implemented in seven countries and established as an intervention for improving outcomes such as increased hopefulness (Hall et al., 2011) and decreased anxiety (Juliao et al., 2013). Though patients report effectiveness of DT (Julião et al., 2015; Dose et al., 2017), research using independently-assessed outcomes has been mixed, calling into question how, for whom, and in what ways DT is most effective (Martinez et al., 2017). One unexamined area that may help to clarify the mixed findings of DT is the interpersonal, *therapeutic processes which occur during DT, including provider empathic responses to patient disclosures.*

In line with the goals of patient-centered care (Clayton et al., 2011), we propose empathic patient-provider communication as a potential interpersonal mechanism of effective DT. Empathic communication is an interactive process mutually constructed by patient and provider (Bylund and Makoul, 2002). The importance of empathy in clinical interactions, particularly in oncologic care, has been rigorously established (Neumann et al., 2009). A substantial body of research has demonstrated positive patient outcomes as a result of empathic communication during clinical visits (Epstein and Street, 2007; Street et al., 2008; Zolnieriek and Dimatteo, 2009; Derksen et al., 2013; Yuguero et al., 2017; Howick et al., 2018; Dambha-Miller et al., 2019). Research on life story sharing (Habermas and Bluck, 2000; McAdams and McLean, 2013) also suggests that the listener plays a crucial role in shaping how individuals recall and evaluate their personal past (Pasupathi and Rich, 2005), as occurs centrally during DT. It follows that empathic communication should be central in DT. Dignity therapists' engaged, respectful listening, acknowledgment of patients' experiences and emotions, and personalized guidance likely enhances patients' ability to authentically narrate their life story.

The Empathic Communication Coding System (ECCS) (Bylund and Makoul, 2002, 2005) was designed to measure empathic communication in the clinical setting and has been used in a variety of healthcare contexts, including primary care, diabetes, medical interpretation, and virtual patients and students (Goodchild et al., 2005; Bonvicini et al., 2009; Parkin et al., 2014; Foster et al., 2016; Pehrson et al., 2016; Krystallidou et al., 2020). Most relevant are applications of the ECCS to encounters between

oncology patients and providers (Pehrson et al., 2016; Shen et al., 2019) and to hospice team members' interactions with informal family caregivers (Wittenberg-Lyles et al., 2012). The ECCS has always been used in a setting where a clinician or trainee was providing medical care and consultation to a patient; it has yet to be used in psychologically therapeutic settings. *Guidelines for empathy in psychotherapy, however, share many of the same qualities outlined by the ECCS, including encouraging therapist responses that attune the therapist to the patient's experiences and validate those experiences such as reflective listening, shared experiences* (Greenberg, 2004; Wynn and Wynn, 2006; Muntigl et al., 2014; Elliott et al., 2018). As *DT sessions bridge palliative medical care with psychological therapy, the ECCS is an optimal tool for assessing empathic communication within DT.* The aims of the current study were: (1) to assess the applicability and feasibility of the ECCS in DT sessions; (2) to describe empathic communication as a process in DT.

Methods

Study design

The current study is a secondary analysis of 25 DT sessions collected as part of a: a six-site randomized, controlled 4-step, stepped-wedge design comparing effects of usual outpatient palliative care to DT (Kittelson et al., 2019). For this analysis, we examined DT sessions only from the first two sites that stepped up to provision of the DT intervention. All study procedures were approved by the University of Florida Institutional Review Board.

Eligibility

Eligibility requirements for the parent study included: (1) having a cancer diagnosis, (2) receiving outpatient palliative care, (3) being 55 years or older, (4) being able to speak and read English, and (5) being physically able to complete the study. Participants completed demographic and descriptive surveys before engaging in DT so that study teams could assess eligibility. For example, all participants completed the Edmonton Symptom Assessment Scale (i.e., ESAS) (Watanabe et al., 2012) and the Palliative Performance Scale (Anderson et al., 1996) so the study team could determine their symptom severity.

DT sessions

Each outpatient participant engaged with dignity therapists (nurses and chaplains) at the medical center where they received care. The dignity therapist contacted the patient by phone to establish initial rapport. Approximately a week later, the one-on-one interview occurred, guided by a well-established DT protocol (Chochinov, 2002; Kittelson et al., 2019), including Guiding Questions (see Table 1). These interview sessions were audio-recorded and transcribed for empathy interaction analysis. They lasted an average of 42.6 min (range = 23–57 min; SD = 10.5). Following the DT session, the patient was provided with an edited version of their responses which captures the essence of their life story narrative (e.g., Legacy Document), to which they were able to make changes and give to their loved ones.

Empathic communication coding process

Original form of the ECCS

The original ECCS is applied to either transcriptions or recorded sessions using two steps. First, coders unitize the interaction into

empathic opportunity (EO) idea units which are determined through identification of a specific expression of emotion, progress, or challenge from the patient. Second, coders categorize the healthcare provider's response to each EO into one of seven hierarchical categories (Bylund and Makoul, 2005).

To test the feasibility of the ECCS with DT sessions, we followed these steps: (1) The first and second author conducted an initial trial of applying the ECCS to several DT sessions, concluding in the realization that the coding system would need revisions to be feasible in the DT context (e.g., revision to the process of creating idea units, and to the categories of empathic responses; N). (2) Subsequently, we open-coded a portion of the transcripts ($n = 15$) using an inductive qualitative thematic analysis process (Braun and Clarke, 2006). We reviewed the results and attempted to map them on to the original response codes from ECCS. Through this process, we discovered that the response codes from the original ECCS did not perfectly correspond with the empathic responses from the dignity therapists. We discussed findings with the third and senior authors and made changes to the coding system accordingly (See Results.)

Revised form: ECCS-DT

The first and second authors applied the ECCS-DT to 20% of the total sample of 25 patient-provider transcripts. The revised version included four types of empathic communication response categories: *acknowledgment*, *reflection*, *validation*, and *shared experience* that were coded as present or absent within each idea unit. Overall inter-rater reliability ($\kappa = 0.84$) and inter-rater reliability for each of the four codes (acknowledge: $\kappa = 0.77$; reflection: $\kappa = 0.73$; validation: $\kappa = 0.85$; shared experience = 1.00) were acceptable. After reliability was established, the two coders independently coded the remaining 20 transcripts.

To create an overall score for each patient, the number of times any empathic communication category was coded as present in an idea unit was summed across the entire DT session and then divided by the number of idea units in that session. Possible scores for overall empathic responding thus ranged from zero to four. That is, if empathic responses never occurred, the DT session would receive a score of zero. If all idea units included all four types of empathic response, the session would receive a score of four. Therefore, the higher the score, the more variability of types of responses demonstrated by the dignity therapist, known as "breadth" of communication skill (Bylund et al., 2018).

Results

Participants

Participants were 25 cancer outpatients who were recruited consecutively from cancer centers of two large US academic medical centers as part of a larger study (Kittelton et al., 2019), and who participated fully in DT (i.e., met with the provider for the initial meeting, the DT session, and to receive and review their Legacy Document). Six dignity therapists (4 at one site, 2 at the other site) conducted the interviews. The patients were aged 55–75 ($M = 63.1$; $SD = 5.7$; 52% women). They received \$50 for study completion. The majority (72%) identified as White, 16% as Black or African American, 4% as American Indian/Alaskan and 8% as "other race." About half (48%) held a Bachelor's degree or higher. The other half (52%) had some college or less.

Participants reported mild-to-moderate illness-related symptoms ($M = 3.48/10$; $SD = 2.95$). Most (88%) had Palliative

Table 2. Patients' cancer diagnosis and stage

Diagnosis-Stage	No. of patients
Pancreas-2	4
Pancreas-4	1
Lung-3	1
Lung-4	4
Ovarian-1	2
Ovarian-4	1
Rectal-4	2
Breast-4	2
Bone Marrow-2	1
Liver-4	1
Stomach -4	1
Esophageal-4	1
Thymoma-4	1
Prostate-4	1

Note. One patient had a non-staged cancer.

Performance scores between 60% and 80%, indicating some illness-related problems with normal activity, full or somewhat reduced ability to care for themselves, and full daily consciousness. Table 2 shows patients' cancer diagnoses and stages.

Aim 1: feasibility of the ECCS for coding DT

In our application of the ECCS to DT sessions, we quickly realized that there were unique characteristics about DT that distinguished EOs and responses from those in previous work with the ECCS. First, the nature of DT made identifying discrete EOs impractical. DT sessions could arguably consist of continuous EOs, making coding the dignity therapists' responses to specific EOs not feasible. The DT session was different from most physician-patient interactions, where EOs are discrete and easily identifiable. The new ECCS-DT thus entails defining idea units through the identification of DT providers shifting from one topic to the next through asking a new Guiding Question of the patient. Idea units were delineated within each transcript prior to coding.

Second, we realized that because the DT session focuses on the participant's review of their life experiences, rather than being a medical information exchange as occurs in a clinical interaction, the original ECCS response categories were not exhaustive. *The original ECCS has four empathic communication response categories* (Shen et al., 2019). *Our subsequent open coding of 15 transcripts, as described above in the Methods, led us to add a new empathic response category to the ECCS-DT, reflection, in which the therapist uses their own words to reflect their understanding of the participants' view. We also chose to remove the response category called pursuit, given that the scripted DT questions would have always been coded as this, not providing any variance.*

Aim 2: descriptive findings

Across the 25 DT sessions, there were a total of 235 idea units. Idea units within individual DT sessions ranged from 4 to 19 ($M = 9.40$; $SD = 4.19$). All DT sessions included identifiable

empathic responses. Of all the idea units, 198 units had at least one empathic response present. As it was possible for more than one type of empathic response to occur in each idea unit, a total of 417 empathic responses were recorded across the 235 idea units. Of the total 25 DT sessions, 17 had at least one empathic response present in each idea unit. Total empathic communication scores ranged from 0.22 to 2.79 ($M = 1.80$; minmax: 0–4). Of the six therapists, four utilized all four types of empathic responses, and two utilized only three types. Below we present each of the four empathic response types with their frequencies and illustrative examples from the transcripts.

Validation

We used the code *validation* to note when dignity therapists said something that indicated the patient's emotion or experience was appropriate or reasonable, confirming the patient's comment. The code *validation* could also be achieved by normalizing the patient's experience or praising their efforts. Dignity therapists demonstrated the empathic communication response of *validation* in 64% ($n = 150$) of the units. For instance, in answer to a question about her roles in the community, one individual discussed how she likes to talk to people and be social.

Participant: I'll talk to a stranger now at the drop of a dime, just talk to them. It doesn't matter who they are... This may be the best person you ever met in your whole life. Why would you put that opportunity in front of you and throw it to the side?

Dignity Therapist: I love that. I love what you just said. (DT session with Participant 9)

In this example, the dignity therapist validated the participant's description of a new approach to being social with a positive, reinforcing reaction.

Near the end of another session, a different participant expressed some difficulty in fully expressing themselves.

Participant: I wish I could give you more, but it's hard to put in words, but I know what I feel in my heart.

Dignity Therapist: Yeah, well, I think you expressed yourself pretty well and your heart, at least for my eyes, is seeing very clearly and so, I really appreciate your time. (DT session with Participant 13)

The therapist's response is validating, as it provides praise for the participant's expressive ability and willingness to spend time together.

Exemplifying a different type of validation, one participant spoke about having a difficult childhood.

Participant: There's probably not much in there that I would say made me feel real great or something that's really outstanding. It was just a nasty childhood.

Dignity Therapist: A lot of people feel that way, but for all kinds of different reasons. (DT session with Participant 11)

By normalizing the participant's difficult experience, the therapist validated the response.

Reflection

We used the code *reflection* to note when dignity therapists used *their own words* to interpret and state back to the participant what they understand from what the participant shared. Central to the use of this code is that there is some interpretation happening on the part of the therapist. Dignity therapists used the empathic communication response of reflection in 60% ($n = 142$) of the units.

In the following example, a participant spoke about her experiences serving others in her community. The therapist used the word *server* here to indicate someone who provides community service.

Dignity Therapist: You were mostly very comfortable being a server then?

Participant: Oh yeah. I never sought a big name or anything like that.

Dignity Therapist: Because with the education and the experiences that you've had, it would've been really easy for you to take a leadership role, but just seemed like you were perfectly satisfied being a server. (DT session with Participant 6)

In this example, the therapist stated back to the participant an understanding that being of service was important to them, based on things previously said in the interview.

A common phrase indicating *reflection* was for the therapist to say, "It sounds like...." We see this in the following example of a participant talking about someone who helped him during his childhood.

Participant: You gotta understand the childhood that I had. There were six months I lived in the backseat of an old car. I finished school, took showers in truck stops and what have you, but I had enough stamina. I had a part-time job. I could eat. I could buy a few clothes. I could take showers and stay clean in the truck stop and then [my friend] would pick me up and take me to school, bring me home in the afternoons and then eventually, [his] dad says, "...why don't you just move in? We've got an attic that we could turn into a bedroom for you," and so—

Dignity Therapist: It sounds like you met a lot of trials early on and overcome them all thanks to [your friend]. (DT session with Participant 13)

In a final example of reflection as an empathic response, the participant had talked about being a mentor as an important accomplishment in life, but also being willing to learn from others. The dignity therapist responded by saying:

It sounds like you were a mentor, but on the other hand, you were open to learning from people who didn't have as much experience as you. You know, a brand new set of eyes. Is that fair to say? (DT session with Participant 24)

Here, not only did the dignity therapist state back an understanding of the individual's experiences, but also checked with the participant to see if it is correct.

Acknowledgment

We used the code *acknowledgment* to note when dignity therapists said something that indicated the recognition of patient's emotion or experience. This code is used to demonstrate that the dignity therapist is listening or heard the patient. This can take the form of repeating back what the patient said using the patient's words, unlike *reflection* which requires the therapist to use their own words and offer some interpretation of the patient's expression. *Acknowledgment* is also coded if the therapist said something else that indicated they heard the patient, detached as compared to *validation*, as it did not denote agreement with the person speaking. We did not code *acknowledgment* when the dignity therapist simply used general responses, such as "yeah" and "uh-huh." Dignity therapists used the empathic communication response, *acknowledgment* in 46% ($n = 109$) of the units.

In the following example, the participant was telling the dignity therapist about what caused them to relocate many years ago to their current home.

Participant: It was an opportunity. That's what brought me down here. I seen that it was more opportunity for people of color down here than it is up north ... there was a lot of opportunity down here than it is up there you see for black people. Because you can walk in a bank up there and can't come out with a business loan and start your own business. Somebody go right behind you that you know that they poorer than you, dirt poor too, and go in the back and come out with their loan and they start a tree business and all this kinda stuff. You understand?

Dignity Therapist: I hear you. (DT session with Participant 16)

The therapist shows acknowledgment by indicating that they understand what the participant means.

As a final example, in the quote below, the dignity therapist asked a question and referred to something the participant said earlier.

Dignity Therapist: What do you think you accomplished as you participated in the role of raising your children? "Cause I noticed you said that one son and you have a pretty good relationship? (DT session with Participant 3)

This example demonstrates how an empathic response might be embedded in another comment or question.

Shared experience

We coded shared experience when the dignity therapist disclosed something about him or herself as a way of relating to the participant. This was the least used empathic communication strategy, with dignity therapists using "shared experience" in only 7% ($n = 16$) of the units. Whereas all dignity therapists used the first three types of empathic responses, four of the six dignity therapists used shared experience.

In the following example, the participant told the therapist about his partner.

Participant: We've been together for 24 years.

Dignity Therapist: Oh, my word.

Participant: We hadn't gotten married but we've been together for 24 years.

Dignity Therapist: Mm-hmm. My son's been with his girlfriend 20 years.

Participant: Oh, yeah.

Dignity Therapist: Yeah. They just don't see a real need for gettin' married so I appreciate that.

Participant: Yeah. We just hadn't gotten married but we still are together. (DT session with Participant 1)

Here we see how the therapist related to the participant based on her son's experience being similar to his.

In another example, near the end of one interview, the participant was talking about their travel experiences and the dignity therapist agreed that travel is important. The therapist then went beyond that to offer some information about herself:

Dignity therapist: Yeah. My husband was born in a small mountain town in [country]. (DT session with Participant 22)

By sharing this, the dignity therapist opened up a topic for further conversation about their shared love of travel and visits to a specific country.

Discussion

Patients' dignity can be challenged, as they navigate their diagnosis, experience health decline, and consider their future. DT is a

well-accepted intervention for enhancing or maintaining dignity in seriously ill patients. Despite the adoption of DT in cancer care, there has been little exploration of the therapeutic processes, such as empathic communication, that occur during DT sessions. The current study had two aims: to test the feasibility of the ECCS for DT sessions and to provide a rich description of the process of empathic communication during the interaction between the dignity therapist and participant during a DT session.

The adjustments made to create the new ECCS-DT were necessary to capture the unique context of communication during DT. The coding system was originally designed for a physician-patient interaction, where EOs are quite distinct and relatively infrequent (Bylund and Makoul, 2005). In contrast, the process of guiding and engaging a patient in narrating their life story during DT involves a much more complex interaction in which there are numerous EOs that are difficult to differentiate. Choosing to use an idea unit as our unit rather than EO (e.g., expressions of emotion, progress, or challenge) allowed us to capture the many ways in which a dignity therapist might show empathy within their session with a patient. Furthermore, we added a code of *reflection* that was not present in the original coding system as a result of open coding of 15 transcripts and finding this to be a common means of responding empathically to participants in the DT setting.

We found three types of empathic responses (i.e., validation, reflection, and acknowledgment) to be used by all six dignity therapists and to be fairly common throughout the DT session transcripts. The examples presented demonstrate how these three types of empathic communication served to connect the therapist with the participant: to show the participant that the dignity therapist is listening in a caring manner and trying to understand the patients' perspective. These types of narrative responses exemplify the concept of *clinical empathy* as defined in the healthcare communication literature (Goodchild et al., 2005).

Shared experience was seldom present in the coded transcripts. There is controversy over whether self-disclosure is appropriate in clinical (Beach et al., 2004) and therapeutic environments (Henretty and Levitt, 2010). A therapist's choice to disclose their own experiences often takes the focus off of the patient. A shift in the focus of the DT session may needlessly halt the participant's attempts to narrate a cohesive life story, integrate life experiences, and make meaning of disclosed information, processes that are central to psychologically therapeutic experiences, including DT (e.g., Fitchett et al., 2015). As such, future research should critically consider the role of shared experiences from provider in DT sessions by, for example, examining whether shared experiences suppress narrative cohesiveness, integration, or richness of meaning-making. Evidencing specific guidelines for dignity therapists about when and how to express their own shared experiences in DT sessions is likely to lead to improvements in patient experiences during DT.

This feasibility study is an essential first step in our larger program of research. These elements of empathic communication were present in the interviews, they varied across interviews, and the ECCS-DT was able to capture them. Next, we aim to replicate findings in a larger sample and examine whether empathic communication in the DT interaction can be linked to positive patient outcomes such as narrative richness in the life story, enhanced feelings of dignity, and higher quality of life at the end of life. These findings, in turn, may lead to further refinement of training for dignity therapists.

Limitations of this study include coding empathic communication using only the DT transcripts without audio or visual cues

that may provide a fuller picture of therapist–participant sessions. Furthermore, the limited sample size of this preliminary study and lack of access to descriptive information about the DT providers (i.e., as the parent study is currently in progress) prohibited exploration of differences in empathic communication (e.g., type of response and frequency of response) across different therapists. Variation in training opportunities and discipline may promote different empathic communication tendencies across providers and should be investigated in future work. Finally, the study was completed with outpatient participants who would have likely been experiencing milder symptoms than inpatient participants. The extent and type of empathic response from therapists may vary based on the participant's condition during the session. Future work should examine symptom severity and proximity to death as potentially related to empathic communication during DT.

Funding. This research was made possible by Grant No. 1R01CA200867 from the National Institutes of Health (NIH), National Cancer Institute (NCI). The information in this article is solely the responsibility of the authors and does not necessarily represent the views of the NIH or NCI. The final peer-reviewed manuscript is subject to the National Institutes of Health Public Access Policy. This research was also funded by a pilot project grant from the University of Florida Health Cancer Center.

Conflict of interest. There are no conflicts of interest.

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