Central Lancashire Online Knowledge (CLoK)

Title	Development and evaluation of the Dignity Talk question framework for palliative patients and their families: A mixed-methods study
Type	Article
URL	https://clok.uclan.ac.uk/20777/
DOI	https://doi.org/10.1177/0269216317734696
Date	2018
Citation	Guo, Qiaohong, Chochinov, Harvey Max, McClement, Susan, Thompson, Genevieve and Hack, Tom (2018) Development and evaluation of the Dignity Talk question framework for palliative patients and their families: A mixed-methods study. Palliative Medicine, 32 (1). pp. 195-205. ISSN 0269-2163
Creators	Guo, Qiaohong, Chochinov, Harvey Max, McClement, Susan, Thompson, Genevieve and Hack, Tom

Original Article

PALLIATIVE MEDICINE

Palliative Medicine
2018, Vol. 32(1) 195–205

DOI: 10.1177/0269216317734696
journals.sagepub.com/home/pmj
SAGE

Development and evaluation of the Dignity Talk question framework for palliative patients and their families: A mixed-methods study

Qiaohong Guo[1,2,3], Harvey Max Chochinov[2,3], Susan McClement[2,4], Genevieve Thompson[2,4] and Tom Hack[4,5]

Abstract

Background: Effective patient–family communication can reduce patients' psychosocial distress and relieve family members' current suffering and their subsequent grief. However, terminally ill patients and their family members often experience great difficulty in communicating their true feelings, concerns, and needs to each other.

Aim: To develop a novel means of facilitating meaningful conversations for palliative patients and family members, coined Dignity Talk, explore anticipated benefits and challenges of using Dignity Talk, and solicit suggestions for protocol improvement.

Design: A convergent parallel mixed-methods design. Dignity Talk, a self-administered question list, was designed to prompt end-of-life conversations, adapted from the Dignity Therapy question framework. Participants were surveyed to evaluate the Dignity Talk question framework. Data were analyzed using qualitative and quantitative methods.

Setting/participants: A total of 20 palliative patients, 20 family members, and 34 healthcare providers were recruited from two inpatient palliative care units in Winnipeg, Canada.

Results: Most Dignity Talk questions were endorsed by the majority of patients and families (>70%). Dignity Talk was revised to be convenient and flexible to use, broadly accessible, clearly stated, and sensitively worded. Participants felt Dignity Talk would be valuable in promoting conversations, enhancing family connections and relationships, enhancing patient sense of value and dignity, promoting effective interaction, and attending to unfinished business. Participants suggested that patients and family members be given latitude to respond only to questions that are meaningful to them and within their emotional capacity to broach.

Conclusion: Dignity Talk may provide a gentle means of facilitating important end-of-life conversations.

Keywords

Dignity talk, palliative care, palliative patients, family members, communication, mixed methods

What is already known about the topic?

- Effective patient–family communication is foundational to relationships anchored in mutual support and understanding, which can buffer emotional distress for both patients and families.
- Patients with life-limiting illness and their family members often experience great difficulty in communicating their true feelings, concerns, and needs.
- Numerous interventions have been developed to facilitate communication between patients and healthcare providers; however, interventions aimed at facilitating communication between palliative patients and their families are limited.

---

[1] School of Nursing, Capital Medical University, Beijing, China
[2] Manitoba Palliative Care Research Unit, CancerCare Manitoba, Winnipeg, MB, Canada
[3] Department of Psychiatry, Rady Faculty of Health Sciences, University of Manitoba, Winnipeg, MB, Canada
[4] Rady Faculty of Health Sciences, College of Nursing, University of Manitoba, Winnipeg, MB, Canada
[5] University of Central Lancashire, Preston, UK

Corresponding author:
Harvey Max Chochinov, Manitoba Palliative Care Research Unit, CancerCare Manitoba, 3017-675 McDermot Avenue, Winnipeg, MB R3E 0V9, Canada.
Email: hchochinov@cancercare.mb.ca

What this paper adds?

- Interventions developed to facilitate end-of-life communication typically focus on patient and clinician exchanges. This study developed a list of question prompts coined Dignity Talk that may provide a viable means of facilitating important, sensitive conversations between palliative patients and their families.
- Palliative patients, family members, and healthcare providers perceive Dignity Talk would be valuable in enhancing family connections and relationships, enhancing patients' self-worth and dignity, promoting effective interaction, and attending to unfinished business.

Implications for practice, theory, or policy

- Dignity Talk may be useful in clinical practice as a communication prompt between patients and families for important and meaningful end-of-life conversations.
- Dignity Talk has the potential to enhance end-of-life experience by engendering a mutual sense of meaning for palliative patients and their families through the sharing of memories, gratitude, forgiveness, wishes, and hopes.

Introduction

Patients with life-limiting illness and their families encounter a complex array of challenges and concerns that threaten their psychological, existential, and spiritual integrity.[1,2] Poor family communication can increase feelings of loneliness and hopelessness in patients with advanced cancer, resulting in increased psychosocial stress.[3,4] Family connectedness can bolster patient well-being toward the end of life;[5] however, terminally ill patients and their family members often experience great difficulty in communicating their true feelings, concerns, and needs because of the desire to protect each other from being exposed to emotional distress.[4,6]

The quality of patient–family communication affects family members during the final phase of the patient's illness and in the bereavement period.[7] A phenomenological study of the experience of spousal grief and bereavement suggests that meaningful communication between patient/family member dyads is important, and remembering and constructing memories during the patient's illness is a way of helping families make sense of their experience.[8] A study of family members who had a loved one die in hospice identified regret and frustration when their loved one's condition precluded communication.[9] Similar findings were reported in another study, which indicated that family caregivers reflected positively on their grief experience when they had been able to communicate effectively with the patient and enjoy their company despite the ravages of disease.[10]

Numerous interventions such as question prompt lists and communication support programs have been developed to facilitate end-of-life communication. However, most of them are designed to facilitate communication between patients with cancer and their healthcare providers (HCPs) regarding illness and treatment,[11,12] prognosis,[13,14] decision making,[15] and psychosocial and spiritual issues.[11,16] These interventions prompt patients to ask questions and satisfy their information needs; few demonstrate influence on psychological outcomes.[11,15,17–20] Several studies have used question prompt lists to encourage HCPs and family caregivers to discuss end-of-life issues.[21,22] Recently, a Serious Illness Conversation Guide was developed to guide patient/family–clinician communication about end-of-life care goals and decisions.[23] However, interventions aimed at facilitating communication between palliative patients and their families are rarely examined. Mowll et al.[24] used the Patient Dignity Inventory (PDI) to guide couples in conversations about living with advanced cancer. The PDI-Couple Interview enabled couples to express their concerns to one another, identify differences in understanding, gave permission to speak with each other, enhanced closer communication, and helped prepare them for the challenges ahead.

Patients report that sharing their palliative care experience with supportive family members enhances their relationship and strengthens bonds.[25] The desire to feel valued by and connected to others is very important.[26] However, palliative patients and their family members are often afraid to share their feelings and needs, resulting in profoundly important issues not being broached. To help patients and their families with these challenges, we developed a self-administered intervention coined Dignity Talk, to facilitate meaningful conversations between palliative patients and their families. In this article, we described how Dignity Talk was developed and evaluated by a group of palliative patients, family members, and HCPs.

Methods

Research design

Our research team developed a list of question prompts, using the Dignity Therapy question framework as an initial template. Dignity Therapy is a brief, individualized psychotherapy, engaging terminally ill patients in a

Table 1. A comparison of Dignity Talk with Dignity Therapy.

	Dignity Therapy	Dignity Talk
Aim	To promote generativity, by creating a legacy document, with the purpose of instilling a sense of meaning for participants	To engage dying patients and their families in mutually beneficial conversations intended to enhance end-of-life experience by decreasing feelings of isolation, despair; and enhance communication and connectedness
Theoretical framework	The model of dignity in the terminally ill	The model of dignity in the terminally ill
EOL intervention	Enhance EOL experience	Enhance EOL experience
Format	A semi-structured interview facilitated and recorded by a therapist	An intimate and private conversation between patients and their family members
Application	Therapist-facilitated	Self-administered
Primary recipient	Terminally ill patients	The patient–family dyad
Primary role of family member	Recipient of the generativity document	Co-participant and therapeutic beneficiary
Question protocol	A guide for a therapist-facilitated conversation	Conversation prompts for patients and family members
Audio record	Yes	No
Therapist input	Needed	No therapist is needed, although ideally they are available before or after Dignity Talk for added support
Final product	A summary generativity document	NA

NA: not applicable; EOL: End-of-life.

therapist-facilitated conversation designed to invoke a sense of meaning and purpose, provide patients a sense of affirmation and continued sense of worth, and fulfill generativity needs.[27] The prototype for Dignity Talk came about by way of reviewing the Dignity Therapy questions, and restating each question in a fashion that would lend itself to self-administration, hence enabling patients and families to engage in conversations. Feedback on this initial prototype was sought from five patients, six family members, and four healthcare professionals. On the basis of their input, two questions including 'what we have meant to each other' and 'regret and forgiveness' were added to the protocol. A separate set of paired questions were developed, with one version meant for the patient and the other for the family respondent. Key differences between Dignity Talk and Dignity Therapy are shown in Table 1.

A convergent parallel mixed-methods design was used for the study.[28] The Dignity Talk guidelines and questions were evaluated using both quantitative and qualitative data. Data were collected simultaneously and priority was given to both forms of data. Convenience sampling was used to recruit participants, including palliative patients, family members, and HCPs. Patients and family members were recruited from two inpatient palliative care units within the Winnipeg Regional Health Authority and were identified by staff members on the units between June and November 2013. Eligibility criteria for patients included being 18 years of age or older, able to speak and read English, having a life-limiting illness with approximately 6 months or less to live, able to provide informed consent, and showing no evidence of confusion or delirium based on clinical consensus. Eligible family members were 18 years of age or older, able to speak and read English, able to provide informed oral and written consent, and able to provide meaningful and coherent feedback regarding Dignity Talk. Eligible HCPs had to be employed on one of the two participating study units and be directly involved in clinical care. They were recruited by emails, posters, and individual invitation by the research nurse.

Data collection

Ethical approval was obtained from the University of Manitoba Health Research Ethics Board and site access from the Research Access Committee at the participating institutions. Written informed consent was obtained from all participants.

Patients and family members were interviewed individually either in person or by phone. The research nurse read each of the Dignity Talk questions to patients and family members and asked them to evaluate its clarity, sensitivity, relevance, and importance. Open-ended questions were asked to elicit concerns about Dignity Talk, suggestions for improvement, and comments about its perceived impact on patient and family experience.

Six focus groups were conducted with interdisciplinary groups of HCPs who were invited to share suggestions for improving Dignity Talk and raise concerns about its use. Each focus group consisted of 3–11 members of the interdisciplinary team, including physicians, nurses, social workers, and healthcare aides. Demographic information

Table 2. Demographic characteristics of patients (*N* = 20) and family members (*N* = 20).

Characteristics	Patients *N* (%)	Family members *N* (%)
Age (years)		
Range	59–95	27–83
Mean (SD)	77.7 (12.0)	56.6 (15.3)
Gender		
Male	7 (35.0)	7 (35.0)
Female	13 (65.0)	13 (65.0)
Marital status		
Never married	1 (5.0)	4 (20.0)
Married	6 (30.0)	14 (70.0)
Common law/cohabitating	4 (20.0)	0 (0.0)
Separated/divorced	2 (10.0)	1 (5.0)
Widow(er)	7 (35.0)	1 (5.0)
Education		
Some elementary/high school	4 (20.0)	3 (15.0)
High school	9 (45.0)	3 (15.0)
Some university/college/technical	3 (15.0)	1 (5.0)
Undergraduate degree	2 (10.0)	11 (55.0)
Postgraduate degree	2 (10.0)	2 (10.0)
Diagnosis		
Cancer	13 (65.0)	
Non-cancer	7 (35.0)	
Relationship to patient		
Spouse/partner		9 (45.0)
Adult child		11 (55.0)
How long have you known the patient? (years)		
Range		27-63
Mean (SD)		46.1 (12.4)
NA/missing		8 (40.0)
How often do you visit the patient?		
Every day		17 (85.0)
Missing		3 (15.0)

SD: standard deviation; NA: not applicable.

was collected for all participants. Patient diagnostic information was collected from the medical chart by the research nurse. Answers to open-ended questions were audio-recorded, transcribed verbatim, and summarized.

Data analysis

Descriptive statistics were used to describe demographic data. Feedback obtained from patients and family members regarding clarity, sensitivity, relevance, and importance of Dignity Talk questions were analyzed quantitatively (endorsement rate). Chi-square analysis was employed to compare the overall endorsement rate by patients and family members. Qualitative data were analyzed line-by-line using the constant comparative techniques to identify recurrent themes by the first two authors.[29] Quantitative and qualitative results were finally merged and interpreted, based on which the Dignity Talk question framework was revised. An audit trail, documenting the logic of the researchers, processes of data collection and analysis, and personal notes, was created. All authors discussed the audit trail and the emerging themes until consensus was reached. The research team included members from psychiatry, psychology, and nursing, as well as research personnel.

Table 3. Demographic characteristics of healthcare providers (*N* = 34).

Characteristics	*N* (%)
Gender	
Male	14 (41.2)
Female	20 (58.8)
Age (years)	
Range	25–65
Mean (SD)	48.3 (12.3)
Professional affiliation	
Physician	7 (20.6)
Medical resident	4 (11.8)
Registered nurse	12 (35.3)
Social worker	4 (11.8)
Healthcare aide	5 (14.7)
Chaplain or spiritual care provider	2 (5.9)
Employment	
Full-time	21 (61.8)
Part-time	13 (38.2)
Number of years in healthcare (years)	
Range	1.5–35
Mean (SD)	20.2 (12.2)
Number of years in palliative care (years)	
Range	0–35
Mean (SD)	9.5 (10.0)

SD: standard deviation.

Results

Demographic characteristics

The final sample comprised 20 patients, 20 family members, and 34 HCPs. A total of 12 patients and 10 family members declined citing reasons of being too sick to take part, or not interested. Participants' demographic characteristics are shown in Tables 2 and 3.

Endorsement of Dignity Talk questions

Table 4 shows the endorsement rate by patients and family members for each Dignity Talk question regarding clarity, sensitivity, relevance, and importance. In terms of clarity and sensitivity, all questions were endorsed by 85.0% or more of either patients or family members. In total, 10 out of 11 questions had been discussed previously by 70.0% or more of either patients or family

Table 4. Dignity Talk framework endorsement rates by patients ($N = 20$) and family members ($N = 20$).

Initial questions	Endorsement rate (%)[b]										Overall endorsement rate (%)[c]		
	Clarity[a]		Sensitivity[a]		Relevance[a]				Importance[a]				
					(have discussed)		(would discuss)						
	Patient	Family	Patient	Family	Patient	Family	Patient	Family	Patient	Family	Patient	Family	p
1. Are there particular memories or important moments from the past that you would like us to talk about?	95.0	85.0	95.0	85.0	90.0	95.0	80.0	65.0	95.0	70.0	91.0	80.0	0.027*
2. Are there things about yourself that you might like us to talk about?	100	70.0	95.0	95.0	70.0	50.0	50.0	40.0	50.0	45.0	73.0	60.0	0.051
3. Are there special or important roles that you have played in life that you might like us to talk about?	100	100	95.0	90.0	80.0	50.0	60.0	35.0	65.0	55.0	80.0	66.0	0.026*
4. Would you like us to talk about things we feel grateful for?	100	100	100	100	85.0	80.0	85.0	65.0	80.0	60.0	90.0	81.0	0.071
5. Would you like us to talk about what we have meant to each other?	95.0	100	100	95.0	80.0	70.0	75.0	60.0	80.0	75.0	86.0	80.0	0.259
6. Would you like to talk about regrets or forgiveness?	95.0	100	95.0	85.0	60.0	35.0	50.0	40.0	45.0	55.0	69.0	63.0	0.370
7. Would you like to talk about hopes and dreams for people who are important to us?	95.0	100	90.0	95.0	70.0	90.0	65.0	85.0	65.0	80.0	77.0	90.0	0.013*
8. Would you like to talk about the important things that life has taught us; or perhaps the things we have taught one another?	95.0	100	95.0	100	70.0	50.0	60.0	45.0	50.0	60.0	74.0	71.0	0.635
9. Would you like us to talk about words of advice or guidance that might be important to share with special people in our lives?	85.0	85.0	85.0	90.0	85.0	60.0	70.0	55.0	60.0	60.0	77.0	70.0	0.262
10. Are there things that we still need or want to discuss with each other?	90.0	100	100	95.0	80.0	70.0	80.0	70.0	65.0	70.0	83.0	81.0	0.713
11. Are there things we want or need to say to each other once again?	90.0	90.0	95.0	95.0	90.0	70.0	90.0	60.0	85.0	70.0	90.0	77.0	0.013*

[a] "Clarity": Is it easy to understand?
"Sensitivity": Is the wording sensitive, gentle, non-confrontational?
"Relevance": Is this a topic you have discussed with your family member? Would you personally choose to talk about it?
"Importance": Is this topic important for you and your family?

[b] "Endorsement rate" for clarity, sensitivity, relevance, and importance were calculated by the proportion of participants who chose "yes" from responses choices including "yes," "no," "somewhat," or "unsure."

[c] "Overall endorsement rate" refers to the average endorsement rate on clarity, sensitivity, relevance, and importance. Chi-square analysis was employed to compare the overall endorsement rate by patients and family members.

*$p < 0.05$.

Table 5. Examples of critiques for Dignity Talk questions.

Clarity
"No. (question 2 is) a little vague, wouldn't know where to start." (Family member 34)
"No (question 9). Too many words. Would you like us to talk about words of advice or guidance for others?" (Patient 27)
Sensitivity
"No. 'As you look back on life' (in question 1)—terminal words, not comfortable." (Family member 36)
"Yes, (question 10) could be a little sensitive. Tone is kind of the end of it all and may not have another chance." (Family member 23)
Relevance—have discussed
"No. I don't think it (question 6) is a question we would talk about. Don't dwell on regrets—past is past. Forgiveness is more internal than external. I don't believe in grudges. Forgiveness is a necessity—don't need to discuss." (Family member 39)
"No (question 8). Never been one to look for something better. I am very plain." (Family member 20)
Relevance—would discuss
"No. It (question 3) would get emotional for mum and that would not be comfortable for her." (Family member 23)
"No (question 5). We're not that kind of family, it is awkward for me to talk to dad. Had this conversation with mum (who died 3 years before)." (Family member 28)
Importance
"Somewhat important. Some people would want to talk about it (question 2). He (the patient) was not a person who shares his emotion … Son knows he loves him but patient never says it." (Family member 20)
"Somewhat. If it (question 6) comes up in conversation, wouldn't ask directly this question." (Patient 27)

members; 7 out of 11 questions would be discussed by 70.0% or more of either group. Six out of 11 questions were considered important by 70.0% or more of either patients or family members. In all, 10 out of 11 Dignity Talk questions received overall endorsed from 70.0% or more of patients; 8 out of 11 by 70.0% or more of family members. Question 6 regarding regrets and forgiveness was the only item receiving less than 70.0% overall endorsement by both groups.

Higher overall endorsement was obtained from patients compared to family members for nearly all Dignity Talk questions. There was significantly higher endorsement among patients for question 1 regarding the sharing of memories (91.0% vs 80.0%; $p=0.027$); question 3 pertaining to important roles (80.0% vs 66.0%; $p=0.026$); and question 11, asking if there are still things that need to be said (90.0% vs 77.0%; $p=0.013$). Family members were significantly more likely than patients to endorse question 7, inquiring about hopes and dreams for important people (90.0% vs 77.0%; $p=.013$). Example reasons for non-endorsement are shown in Table 5.

Suggestions for improvements

Participants were asked to provide suggestions for ways to improve the Dignity Talk question framework. Qualitative analysis identified four main themes.

Appraisal of the Dignity Talk guidelines. Patients, family members, and HCPs raised three points that need to be addressed in the Dignity Talk guidelines:

> *Explanation of the title "Dignity Talk"*:
>
> A brief explanation regarding what Dignity Talk is. i.e. "Dignity Talk is a new intervention/approach developed by our research group … this will help to tie things together." (HCP focus group 6)
>
> *Flexibility in use*:
>
> In guidelines may be helpful to highlight you can talk about as many or as few questions as you like. [HCP focus group 4]; "In terms of guidelines, I like the statement regarding 'either of you may decide to stop a conversation.'" (Patient 42)
>
> *Role of the patient/family*:
>
> Who is taking lead, patient or family? Have to make it abundantly clear that these questions are for everybody to dialogue. (HCP focus group 6)

Conciseness and clarity. To ensure the conciseness and clarity of the Dignity Talk questions, HCPs suggested keeping questions simple and using as few phrases as possible. In addition, some patients and family members proposed that certain questions were too general or broad to respond to, while others pointed out it is good to be broad so that people can respond, but avoid things they don't want to talk about:

> A general concern, keep it simple, less phrases are better. (HCP focus group 2)
>
> The question (question 2) is big enough to be vague so people could avoid some things. (Patient 11)

Wording and tone. HCPs stated that the Dignity Talk framework was worded in a respectful tone. The Dignity Talk questions were regarded as straightforward in opening up delicate and personal conversations, enabling patients and families to respond according to their own needs and preferences. The importance of using "plain language" was highlighted, so that it could be understood by participants of all educational levels:

> Would someone with less education understand the question? It is important to have guidelines in plain language. (HCP focus group 1)

> (Question 2) wording very good. Doesn't infer that holding secrets but possibly invokes a response. (Family member 31)

Style and presentation of questions. Considering that Dignity Talk is designed to elicit patient–family conversations, participants felt that questions need to be presented less like an interview and more like an invitation to a conversation. HCPs said that numbering questions makes the questions framework seem rigid and implies they need to be gone through in order. They encouraged sensitivity to arranging questions based on how emotionally evocative they might be and starting with less evocative questions as a way of moving gently into a conversation:

> Numbering questions makes it seem hierarchical—i.e. some questions are more important or have to go through the list… Perhaps thematic or groupings. (HCP focus group 2)

> Questions 1, 8, 9 seen as easiest for people to answer—therefore maybe have them earlier in list. Don't start with regrets/forgiveness. (HCP focus group 5)

> Questions would need to be presented with great care. (Family member 30)

Perceived benefits of Dignity Talk

Participants felt that Dignity Talk could serve as a conversation prompt, enhance family connections and relationships, enhance personal value and dignity, promote effective interaction, and help attend to unfinished business.

Conversation prompt. Participants stated that Dignity Talk could offer the patient and family member a chance to talk about important things, especially for those more reticent to broach some of these issues:

> Every single question was amazing. I would not be able to talk about these without the prompts of the question sheet. (HCP focus group 3)

> Talking points are helpful and I suspect most people do not talk about these things, therefore they need something like this. (Family member 30)

Enhancing family connection and relationship. Patients and family members stated that Dignity Talk could enhance family relationships by offering a chance to share stories and feelings, learn from each other, or just be together:

> Very very important because you hear so many occasions where families haven't spoken really for years and this may or may not bring them together. (Patient 36)

> It brings family members together and brings common memories for future. (Family member 9)

Enhancing personal value and dignity. Several patients stated that Dignity Talk could offer an opportunity to pass on their memories, life learning, hopes, and advice to their family members. Family members felt that Dignity Talk could help create memories that family members can carry into bereavement:

> You have walked yourself and had experiences as to what have worked best [in your life]. My children want to know about my life, particularly important if young people who don't know which way they are going in life. (Patient 2)

> This is important because the person is gone but their (words of advice or guidance) keep memories alive in our heart. (Family member 3)

Promoting effective interaction. Patients and families felt Dignity Talk could promote emotional interactions. They saw value in the opportunity to show appreciation to their loved ones:

> It is important to know how you feel about them (family). For example, my macho brother—kind and caring, I tell him how much he means to me even if it makes him uncomfortable. (Patient 36)

> … continue to tell each other how much we care for each other and need each other and appreciate each other. (Family member 19)

Attending to unfinished business. Patients and family members felt Dignity Talk could help them attend to unfinished business and hence die with no regrets. Similarly, HCPs felt that Dignity Talk offered patients and families an opportunity for introspection:

> When you know the end is inevitable like in my case, nothing is worse than someone passes away and things not clear—i.e. legal. Prepare ones that are left. (Patient 25)

> It (question 6) does help to have permission and allows some soul searching. (HCP focus group 5)

Perceived concerns and challenges of Dignity Talk

Concerns and challenges included applicability of some of Dignity Talk questions, patient and/or family preparation for Dignity Talk, and the potential for questions to elicit information that might be difficult to deal with emotionally.

Applicability of Dignity Talk. While the Dignity Talk questions were considered important and meaningful, not all questions are applicable to every patient or family, depending on various factors such as individual or relational characteristics, culture, or health status:

> Men in my culture are prideful, it is a matriarchal background. Hard for us (son and father) to share (memories). (Family member 28)

> Heath characteristics can impact as well—have a stroke may impact memory of events. (Patient 25)

Preparation for Dignity Talk. Although Dignity Talk is designed to be self-administered, HCPs suggested that participants will need to be well prepared prior to implementation, in terms of having a clear understanding of the intervention and how to start these conversations:

> Before family (and patient)gets the questions it will be important to prepare them and talk with them … They need time to "chew on it." (HCP focus group 3)

> A lot of people need help opening the door … Maybe the HCP can offer support for this framework. (Family member 30)

Difficult situations. Participants noted that some questions, in some instances, could be emotional or elicit potentially harmful or difficult information. HCPs felt it was very important that participants be given complete latitude to respond only to questions that were meaningful and within their emotional capacity to engage in:

> I might hesitate to ask (question 10) because of what might be brought up e.g. negative. (Family member 34)

> … potential to be comforting for both patient and family. However, there may be potentially hurtful things that come out—may not be time for resolution—important to be mindful of this and offer safety. (HCP focus group 1)

Revision of Dignity Talk guidelines and questions

Dignity Talk was revised based on participant feedback. Revisions included a statement about the definition of dignity; an explanation that *Dignity Talk* is a list of questions that is intended to open up meaningful conversations between patients and their families; and a caution that some questions might be emotionally evocative. Guidelines were also revised to reflect that participants can choose to talk about as many or as few questions as they like; and that they can deviate from the question framework to talk about anything else the conversation might lead to. A statement was added instructing participants to pace themselves and take breaks as needed. Details about the time frame for completing Dignity Talk were included, stating that Dignity Talk is meant to be flexible, and can be returned to when the time feels right. To optimize emotional comfort and safety, the guidelines explicitly state that either party can decide to set aside or defer questions. Finally, the guidelines were revised to include contact information for supportive counseling following Dignity Talk, should participants feel the need to pursue this.

The original Dignity Talk question list was revised in response to feedback, rewording questions to make them less prescriptive. The final Dignity Talk communication prompt includes 12 questions. All original questions were retained, with question 6 regarding regrets and forgiveness being divided into two distinct questions: one about regrets and the other about forgiveness. Even though question 6 was endorsed by fewer than 70.0% of patients and family members, it was retained based on the feedback from HCPs such as "Question 6 is a powerful and important question and should be included, cannot have an intimate conversation if this is not on the table" (HCP focus group 4). Dignity Talk questions were re-written in plain language to assure clarity and broad accessibility. Instead of numbering, each question was labeled with a theme so that the participant can easily scan the topics and pursue those that fit best with them. While there had originally been a separate version of Dignity Talk for patients, and another for families, the feedback and refinement saw these combined into one final version of Dignity Talk suitable for both (see Table 6).

Discussion

Main findings of the study

Dignity Talk was generally well endorsed by participants, who felt it would be a valuable means of promoting family conversations, enhancing family connections and relationships, bolstering sense of value and dignity, promoting effective interaction, and attending to unfinished business. The vast majority of patients and families reported that the Dignity Talk questions were clearly stated and sensitively worded. While the rate of endorsement on relevance and importance varied across individual questions, all but one question was more highly endorsed by patients versus family members. Patients nearing death may see Dignity Talk as a final opportunity to address issues that matter most to them, speak to things they would want remembered, and complete unfinished businesses, thus achieving greater peace of mind.[27] The one exception, question 7 regarding hopes and dreams for people was more highly endorsed by family members than patients. This might reflect family members' urge to seek guidance and input regarding the lives of people who are soon to be bereft. The question regarding forgiveness and regrets received the least endorsement, from patients and families alike, while HCPs in particular deemed it important and necessary for inclusion. That impression is supported by evidence that expression of

Table 6. Dignity Talk guidelines and questions.

[Side 1 of laminated card]

Dignity is so much about feeling appreciated and understood for who you are as a person and what you feel is or has been important in your life. *Dignity Talk* will give you a chance to talk about these things, to put into words how you feel about them and for someone to hear what you have to say.

Dignity Talk is a list of special questions that are meant to open up conversations. Some questions may have more meaning than others and some may feel more emotional than others. Please talk about as many or as few of these questions as you like. Some conversations you may choose to have; others you may decide to skip altogether. There are no right or wrong answers. The questions do not need to be talked about in any particular order. It is also perfectly fine if the conversation becomes extended or moves into a different direction entirely.

Please pace yourselves; take breaks when you need to. The time you take to do *Dignity Talk* is meant to be flexible. You may choose to answer most questions in a single sitting OR you might decide on shorter and more frequent sessions spread over more time.

These conversations are meant to provide you with comfort. If they feel too demanding, it is okay to move onto another question or set these questions aside. Some conversations may feel easier than others. Just because a conversation might be emotional or difficult does not necessarily mean that it should be avoided. You know each other best. Where you choose to take conversations and what areas you choose to avoid is best left up to both of you. Either of you may decide to stop a conversation if you find yourself unable or not wanting to proceed. What you do with the information that comes out of *Dignity Talk* is also very personal. We hope that the conversations and the memory of the conversations will be of benefit to you.

Should you have any questions, encounter any challenges, want to talk to a counselor, or just want some further help with *Dignity Talk*, please speak with your healthcare providers.

[Flip side of laminated card]

MEMORIES	Looking back on life, are there particular memories or moments we might want to talk about?
THINGS ABOUT YOURSELF	Are there things about yourself that you want us to talk about?
SPECIAL ROLES	Are there special or important roles in your life that you would like to talk about? (What made those roles special? Which of those roles made you feel proud?)
WHAT YOU MEAN TO ME	Would you like to talk about what we mean or have meant to each other?
REGRETS	Would you like to talk about any regrets?
FORGIVENESS	What about forgiveness? Are there things you want to forgive, or be forgiven for?
GRATITUDE	Would you like to talk about things we feel grateful for?
HOPES AND DREAMS	Would you like us to talk about hopes and dreams for people who are important to us? (Family, friend, others?)
WHAT WE'VE LEARNED	Would you like to talk about the things life has taught us, or perhaps what we have taught one another?
ADVICE	Are there words of advice you might like to share with special people in our lives? (Family, friend others?)
MORE TO DISCUSS	Are there things that we still want or need to discuss with each other?
MORE TO BE SAID	Are there things we still want or need to say to each other?

forgiveness and regrets can improve emotional status, decrease depression and anger, improve hope and facilitate completion of life tasks for terminally ill patients, and ease bereavement for family members.[30–32]

The fact that the majority of questions had already been broached by 70% or more of either patients or family members suggests that these questions are salient for patients and families anticipating end of life. The broad nature of these questions could see patients and families wanting to revisit these conversations at different points in time. On the other hand, it could be the case that a smaller minority of patients and families will use Dignity Talk to broach issues they are otherwise avoiding or find too difficult to initiate without a prompt. Enhanced communication is foundational to relationships anchored in mutual support and understanding, hence buffering emotional distress for patients and families alike.[33] Family caregivers seek existential meaning in their relationships with dying loved ones.[34] Dignity Talk offers a strategy to help them support their family member in the enactment of their caregiver role and achieve meaningful involvement.[35]

Strengths and limitations of the study

Strengths of the study include Dignity Talk being developed and modified based on both qualitative and quantitative data. It is one of very few psychosocial interventions targeting patient/family dyads[36] and is meant to be self-administered by patients and families. Limitations include a relatively small sample size, although rich qualitative data were collected. Participants were recruited from two mid-western Canadian institutions; the attitudes of participants may not be representative of attitudes toward conversations elicited by Dignity Talk in other settings or cultural contexts. Collecting dyads in palliative care research is challenging, particularly given that patients are very ill and family is often preoccupied by concerns and tasks related to supporting their loved ones.

What this study adds

This study developed the Dignity Talk question framework, designed to facilitate important conversations between terminally ill patients and their family members. To confirm its role in palliative care, a Phase II clinical trial of Dignity Talk will be needed, recruiting patients and family members to examine its feasibility, benefits, and perceived value.

Acknowledgements

We would like to thank the patients, family members, and healthcare providers for their time and thoughtful insights. We would also like to thank our research nurse, Katherine Cullihall, for her assistance in participant recruitment and data collection. H.M.C. contributed to the conceptualization and design of the study. Q.G. and H.M.C. contributed to data analysis and interpretation of data with main contributions from Q.G. Q.G. drafted the manuscript, and H.M.C., S.M., G.T., and T.H. revised it critically for important intellectual content. All authors approved the final manuscript and have participated sufficiently in the work to take public responsibility for appropriate portions of the content. Registration: ClinicalTrials.gov Identifier: NCT01883375; data of registration: 11 February 2013.

Data management and sharing

Our study data are securely stored under lock and key in the Research Institute of Hematology and Oncology, CancerCare Manitoba. We do not have the permission from either the University of Manitoba Health Research Ethics Board or consented research participants to release or share our data, thus we cannot make it available in the public domain.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Canadian Institutes of Health Research Operating Grant (grant number MOP-123473).

Research ethics and patient consent

This study was approved by the University of Manitoba Health Research Ethics Board (H2013:024) and all participants provided informed consent.

References

1. Chochinov HM. Dying, dignity, and new horizons in palliative end-of-life care. *CA Cancer J Clin* 2006; 56: 84–103.
2. Chochinov HM, Hassard T, McClement S, et al. The landscape of distress in the terminally ill. *J Pain Symptom Manage* 2009; 38: 641–649.
3. Kristjanson LJ and Aoun S. Palliative care for families: remembering the hidden patients. *Can J Psychiatry* 2004; 49: 359–365.
4. Zhang AY and Siminoff LA. Silence and cancer: why do families and patients fail to communicate? *Health Commun* 2003; 15: 415–429.
5. Lin HR and Bauer-Wu SM. Psycho-spiritual well-being in patients with advanced cancer: an integrative review of the literature. *J Adv Nurs* 2003; 44: 69–80.
6. Salander P and Spetz A. How do patients and spouses deal with the serious facts of malignant glioma? *Palliat Med* 2002; 16: 305–313.
7. Braithwaite M, Philip J, Tranberg H, et al. End of life care in CF: patients, families and staff experiences and unmet needs. *J Cyst Fibros* 2011; 10: 253–257.
8. Duke S. An exploration of anticipatory grief: the lived experience of people during their spouses' terminal illness and in bereavement. *J Adv Nurs* 1998; 28: 829–839.
9. Kehl KA, Kirchhoff KT, Kramer BJ, et al. Challenges facing families at the end of life in three settings. *J Soc Work End Life Palliat Care* 2009; 5: 144–168.
10. Dumont I, Dumont S and Mongeau S. End-of-life care and the grieving process: family caregivers who have experienced the loss of a terminal-phase cancer patient. *Qual Health Res* 2008; 18: 1049–1061.
11. Brown R, Butow PN, Boyer MJ, et al. Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking. *Br J Cancer* 1999; 80: 242–248.
12. Kahana E and Kahana B. Patient proactivity enhancing doctor–patient–family communication in cancer prevention and care among the aged. *Patient Educ Couns* 2003; 50: 67–73.
13. Butow PN, Dunn SM, Tattersall MH, et al. Patient participation in the cancer consultation: evaluation of a question prompt sheet. *Ann Oncol* 1994; 5: 199–204.
14. Walczak A, Mazer B, Butow PN, et al. A question prompt list for patients with advanced cancer in the final year of life: development and cross-cultural evaluation. *Palliat Med* 2013; 27: 779–788.
15. Butow PN, Devine R, Boyer M, et al. Cancer consultation preparation package: changing patients but not physicians is not enough. *J Clin Oncol* 2004; 22: 4401–4409.
16. Schwartz C, Merriman MP, Reed G, et al. Evaluation of the Missoula–VITAS Quality of Life Index-revised: research tool or clinical tool? *J Palliat Med* 2005; 8: 121–135.

17. Brown R, Butow PN, Dunn SM, et al. Promoting patient participation and shortening cancer consultations: a randomised trial. *Br J Cancer* 2001; 85: 1273–1279.
18. Bruera E, Sweeney C, Willey J, et al. Breast cancer patient perception of the helpfulness of a prompt sheet versus a general information sheet during outpatient consultation: a randomized, controlled trial. *J Pain Symptom Manage* 2003; 25: 412–421.
19. Clayton JM, Butow PN, Tattersall MH, et al. Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *J Clin Oncol* 2007; 25: 715–723.
20. Glynne-Jones R, Ostler P, Lumley-Graybow S, et al. Can I look at my list? An evaluation of a "prompt sheet" within an oncology outpatient clinic. *Clin Oncol* 2006; 18: 395–400.
21. Hebert RS, Schulz R, Copeland VC, et al. Pilot testing of a question prompt sheet to encourage family caregivers of cancer patients and physicians to discuss end-of-life issues. *Am J Hosp Palliat Med* 2009; 26: 24–32.
22. Walczak A, Henselmans I, Tattersall MH, et al. A qualitative analysis of responses to a question prompt list and prognosis and end-of-life care discussion prompts delivered in a communication support program. *Psychooncology* 2015; 24: 287–293.
23. Bernacki R, Hutchings M, Vick J, et al. Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention. *BMJ Open* 2015; 5: e009032.
24. Mowll J, Lobb EA, Lane L, et al. A preliminary study to develop an intervention to facilitate communication between couples in advanced cancer. *Palliat Support Care* 2015; 13: 1381–1390.
25. Murray C, McDonald C and Atkin H. The communication experiences of patients with palliative care needs: a systematic review and meta synthesis of qualitative findings. *Palliat Support Care* 2015; 13: 369–383.
26. Kutner JS and Kilbourn KM. Bereavement: addressing challenges faced by advanced cancer patients, their caregivers, and their physicians. *Prim Care* 2009; 36: 825–844.
27. Chochinov HM, Hack T, Hassard T, et al. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol* 2005; 23: 5520–5525.
28. Creswell JW and Plano Clark VL. *Designing and conducting mixed methods research*, 2nd ed. Thousand Oaks, CA: SAGE, 2011.
29. Strauss AL and Corbin JM. *Basics of qualitative research: techniques and procedures for developing grounded theory*, 2nd ed. Thousand Oaks, CA: SAGE, 1998.
30. Exline JJ, Prince-Paul M, Root BL, et al. Forgiveness, depressive symptoms, and communication at the end of life: a study with family members of hospice patients. *J Palliat Med* 2012; 15: 1113–1119.
31. Steinhauser KE, Alexander SC, Byock IR, et al. Seriously ill patients' discussions of preparation and life completion: an intervention to assist with transition at the end of life. *Palliat Support Care* 2009; 7: 393–404.
32. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476–2482.
33. Roberts KJ, Lepore SJ and Helgeson V. Social-cognitive correlates of adjustment to prostate cancer. *Psychooncology* 2006; 15: 183–192.
34. Milberg A, Strang P and Jakobsson M. Next of kin's experience of powerlessness and helplessness in palliative home care. *Support Care Cancer* 2004; 12: 120–128.
35. Andershed B and Ternestedt BM. Development of a theoretical framework describing relatives' involvement in palliative care. *J Adv Nurs* 2001; 34: 554–562.
36. Harding R, List S, Epiphaniou E, et al. How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliat Med* 2012; 26: 7–22.