



Original Article

Family-oriented dignity therapy for patients with lung cancer undergoing chemotherapy: How does it work better?



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ABSTRACT

Objective: This study aimed to examine the fidelity of intervention delivery and identify precursory factors contributing to the successful delivery and beneficial effects of family-oriented dignity therapy.

Methods: This was a process evaluation with quantitative and qualitative methods alongside a randomized controlled trial from March to May 2019. Nonparametric statistics were used to analyze how participants' demographics ($n = 45$ dyads) and process variables influenced the intervention effects. Fourteen patients, 11 family caregivers, and 11 nurses were interviewed to explore their perception of the intervention. Conventional content analysis was adopted to analyze the qualitative data.

Results: The fidelity was achieved with minor deviations from the protocol. Higher educational level and higher income were significantly correlated with lower levels of existential distress ($H = 12.20$, $P = 0.030$) and higher spiritual well-being ($H = -16.310$, $P = 0.031$), respectively. Higher levels of interest were significantly correlated with lower levels of existential distress ($H = 10.396$, $P = 0.035$) and peace of mind distress ($H = -16.778$, $P = 0.006$) and higher levels of life meaning ($H = -12.808$, $P = 0.047$). Patients who had higher response levels to the question were significantly correlated with lower levels of symptom distress ($H = -13.879$, $P = 0.035$). Four major categories were identified from the interview data: (1) benefits of the intervention, (2) risks of the intervention, (3) factors that enhance successful dignity-conserving care, and (4) difficulties and barriers to the delivery of dignity-conserving care.

Conclusions: Fidelity and precursory factors that enhance the beneficial effects of family-oriented dignity therapy were identified. Reinforcement strategies, such as using supplementary video, audio, and reading materials; developing a flexible approach to expressing feelings; and exploring lessons and achievements from various perspectives, are recommended for future research to enhance intervention effects.

Trial registration: The study was registered in the Chinese Clinical Trial Registry (registration number: ChiCTR1900020806).

Introduction

Lung cancer is the leading cause of cancer death, with an estimated 1.8 million deaths worldwide in 2020.¹ It is also the most commonly diagnosed cancer in China, with an estimated 820,000 cases in 2020.¹ Patients with lung cancer undergoing chemotherapy have not only several physical symptoms but also psychosocial distress, such as depression, death anxiety, hopelessness, helplessness, feeling of being a burden to others, and despair²⁻⁴. This distress greatly deprives them of a sense of meaning and self-value and undermines their sense of dignity.⁵

In health care settings, dignity is closely connected to one's principles, standards, and values, which can be jeopardized by various issues, such as deterioration of health, behaviors of others, physical setting, and one's own perspectives and behaviors.⁶ An undermined sense of dignity has been strongly associated with a high level of depression, low levels of spiritual well-being and hope, and an overall poor quality of life.^{5,7,8} Furthermore, a systematic review revealed that loss of dignity is the main reason for the desire to hasten death among patients with an incurable illness.⁹ Therefore, it is imperative to enhance the sense of dignity and to alleviate the psychological and spiritual distress faced by patients with

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lung cancer undergoing chemotherapy, thereby improving their quality of life.

Dignity therapy—a brief, individualized psychotherapeutic intervention—was developed to relieve dignity-related distress and enhance end-of-life experiences among the terminally ill.^{10,11} On the basis of an empirical model of dignity,¹² the therapeutic process begins with a framework of questions that help patients reflect on things that matter most to them or that they would most want to remember. A legacy document produced in dignity therapy is returned to the patients to read and share with their loved ones. A study provided robust evidence of the acceptability of dignity therapy among the terminally ill and its feasibility in some occident countries, such as Canada, America, and Denmark.¹³ However, the effects of the therapy are inconsistent. Juliao et al reported that dignity therapy significantly reduced anxiety and depression in patients with advanced cancer,¹⁴ whereas other studies have indicated that dignity therapy only nonsignificantly decreased anxiety and dignity-related distress.^{11,15} These studies focused on analyzing outcome-related distress and paid less attention to the delivery of the therapy, thus limiting the implications for future research and practice. A critical outcome analysis and intervention delivery evaluation are necessary to understand the effects of dignity therapy.

In 2010, the Medical Research Council published a framework for the process evaluation of complex interventions.¹⁶ The framework defines process evaluation as a study to examine intervention implementation and understand the functioning of an intervention. Fidelity—the consistency between plan and implementation—is the major concept of process evaluation. It may be compromised when the activities provided in real-world settings deviate from the original protocol. Consequently, delineating the process through which interventions are delivered and what is delivered in practice helps interpret the results of randomized controlled trials (RCTs). For example, nonsignificant results may contribute to a low level of fidelity rather than indicate problems with the intervention itself. In addition, a complex intervention is assumed to have an unequal effect on each patient because of the different characteristics and participation levels of the intervention individuals. The evaluation of these characteristics and participation levels helps identify the participants who would benefit most from an intervention. Another important aspect of process evaluation is the contextual factors of the intervention, which may influence intervention delivery and the functioning of the intervention. This process mirrors the complexity of the real-world situation and promotes intervention implementation. Process evaluation of the intervention fidelity, the participants' characteristics and participation levels, and contextual factors could help researchers understand the mechanism of action of the intervention and how to improve it, thereby building an evidence base to inform future practice and policy.

Several studies have explored the satisfaction of the participants with dignity therapy or the experiences of the participants and intervention facilitators.^{17,18} However, studies comprehensively evaluated the intervention delivery of dignity therapy are somewhat fragmented, preventing in-depth analysis of the intervention effects and hindering the promotion and clinical use of dignity therapy. Our team developed a family-oriented dignity therapy (FDT)¹⁹ and evaluated its effects on the Chinese population through an RCT.²⁰ In the present study, we evaluated the process of the intervention to (1) examine the fidelity of the intervention delivery and (2) identify precursory factors affecting successful delivery and effects of FDT. Our results are expected to provide strategies to improve FDT and end-of-life care in patients with lung cancer.

FDT and RCT

To enhance the sense of dignity and end-of-life experiences of patients with lung cancer undergoing chemotherapy, we developed an FDT based on several preliminary studies, including an integrative review of patients with cancer dignity perception,⁵ a systematic review of dignity therapy,²¹ a qualitative exploration of Chinese patients' dignity

perception,⁸ and a literature review of related theories, such as the empirical model of dignity and Erikson' theory of psychosocial development. Compared with dignity therapy, FDT is a family-centered intervention and highlights the effects of family support and communication on patients' sense of dignity.

Patients and one of their important family caregivers were invited to participate in the intervention. An additional sharing session was designed to promote communication and understanding. Therefore, FDT is a face-to-face psychosocial intervention with three sessions delivered by a trained intervention facilitator.¹⁹ Patients with lung cancer undergoing chemotherapy with one of their significant family caregivers were invited to reminisce important life events based on a question protocol. A legacy document titled "Spiritual Diary" was produced to record their memories, views, and thoughts. The patients and their family caregivers were invited to express their thoughts on the document and share their feelings with each other. An RCT involving 120 dyads of lung patients with cancer undergoing chemotherapy and family caregivers evaluated the effects of FDT and revealed that FDT significantly decreased dignity-related distress and depression and improved spiritual well-being.²⁰ In the present study, we focused on process evaluation to identify the fidelity of the intervention delivery and factors affecting its success.

Aims

To evaluate the implementation fidelity of FDT for patients with lung cancer undergoing chemotherapy and identify the precursory factors contributing to the successful delivery and beneficial effects of the intervention. On the basis of the results of the process evaluation, we also provided supplementary and complementary interpretations of the intervention effects.

Methods

Design

This process evaluation study adopted a combination of quantitative and qualitative methods. This is an adjunct study to an RCT²⁰ evaluating the effectiveness of FDT on psychosocial distress in patients with lung cancer undergoing chemotherapy from March to May 2019. That study randomly divided 120 patient–family caregiver dyads into the intervention ($n = 60$) or attention control group ($n = 60$). Repeated measurements of outcomes were performed at baseline (T0) and after completion of the intervention (T1). All recruited dyads completed the baseline assessment. The attrition rate was 21.7%, with 15 dyads in the intervention group and 11 dyads in the control group not completing the intervention or reassessment at T1.

This is an adjunct study to the RCT, and the demographic data and outcome variables in the intervention group were used in this substudy. We also designed a checklist to collect intervention delivery variables. The demographic data and intervention delivery variables were analyzed with the outcome variables in the intervention group to investigate how these variables impacted the intervention effects. Qualitative interviews were conducted with patients, family caregivers, and nurses to explore their perceptions of the intervention. Quantitative methods allowed statistical analysis of the impact of demographic and contextual variables on psychosocial outcome measures, whereas qualitative methods provided rich data to enhance the understanding of precursory factors affecting the intervention effects. This integration enabled us to supplement and complement the outcome-related results and enhance the validity of the findings. The Good Reporting of a Mixed Methods Study was used as a framework to report the study design and findings.²²

Participants

The participants were recruited from a university-affiliated public cancer hospital. The inclusion criteria were as follows²⁰: (1) adult

patients diagnosed as having lung cancer, (2) currently undergoing chemotherapy that would last for at least a month, (3) aware of their cancer diagnosis, (4) could read and communicate in Chinese, and (5) could identify one significant family caregiver to receive the intervention together. A dyad was excluded if the patient or the caregiver (1) had cognitive impairment, such as dementia, or was too ill to participate in the research, as determined by a physician; (2) was diagnosed as having a psychiatric illness; and (3) was currently participating in other psychosocial intervention studies.

Intervention

FDT is a face-to-face psychosocial intervention with three sessions. After an explanation session to introduce the intervention process and procedure, the intervention facilitator interviewed the patient and his/her family caregiver based on a question protocol, which was developed based on a series of studies on the perception of dignity from the patients' perspective. These questions were translated by two translators who are native speakers of Chinese and have a good command of English. This session aimed to help patients and their family caregivers reminisce the most important events of the patients. The interview process was audio recorded. The recording was transcribed verbatim and edited by the facilitator to produce a legacy document titled "Spiritual Diary." The patients and their family caregivers were arranged to share their thoughts during the third session. The detailed intervention development and delivery processes were described previously.²⁰

The first author, a registered nurse in mainland China with a 6-month experience of working in the oncology department, was the intervention facilitator. The author attended the workshop organized by Professor Harvey Max Chochinov, who developed the dignity model and therapy, in Winnipeg, Canada, in May 2018. Training included group teaching on a theoretical basis, dignity therapy demonstrations, product editing, and simulation exercises. The training lasted 2.5 days.

An RCT was performed to evaluate the effects of FDT from Match to May 2019 in a university-affiliated public cancer hospital in Changsha, a provincial capital in southern China. No significant between-group differences were observed in the baseline characteristics (including family caregiver characteristics) or outcome variable comparisons. General estimating equation analyses indicated that the intervention group had a significantly greater reduction in dignity-related distress (β : -3.347 , 95% confidence interval [CI]: -6.054 , -0.641 ; $P = 0.015$) at T1 than at T0. Significant between-group differences were also observed in secondary outcomes, including depression (β : -3.430 , 95% CI: -5.032 , -1.829 ; $P < 0.001$) and spiritual well-being (β : 3.705 , 95% CI: 0.599 , 6.811 ; $P = 0.019$).

Data collection

Participants' variables

Participants' characteristics, including age, gender, educational level, income, medical insurance, time of chemotherapy, and closeness between patients and their family caregivers, were obtained from 45 patients and their family caregivers in the intervention group who completed the intervention and outcome assessment.

Intervention variables

The major outcome variables of the RCT included patients' dignity-related distress, depression, and spiritual well-being. To conduct the process evaluation, a self-designed checklist was used to assess the intervention delivery process based on the literature review²³ (see Supplementary File) and further validated by an expert panel. The checklist includes four aspects: actual time spent on reminiscing and spiritual diary editing, difficulties or interruptions encountered in the intervention, participants' level of involvement in the intervention, and responses to the question protocol. The checklist was recorded and maintained by a

research assistant, who is a nursing postgraduate student, throughout the intervention.

The actual time spent on reminiscing and spiritual diary editing and difficulties or interruptions were recorded by the audio, intervention facilitator, and research assistant, respectively. The participants' level of involvement was assessed by recording their attention, participation, and interest in the intervention. Attention referred to how often the participants' engagement in the intervention was distracted by other issues. Participation referred to how participants actively reflected on the intervention, and interest referred to how much participants were willing to participate in the intervention. Participants' attention, participation, and interest were scored as "high," "moderate," "partial," or "low" by the research assistant based on the predefined criteria (see Table 1). The participants' responses to the question protocol were also recorded and assessed with low, partial, moderate, and high levels by the research assistant.

Perception of the intervention by stakeholders

Semistructured interviews were conducted to obtain the perception of the intervention by stakeholders among a convenient sample of the patients, family caregivers, and nurses. The patients and their family caregivers were invited to reflect on or comment on their experiences of receiving the FDT. Nurses have the most frequent contact with patients and are considered suitable facilitators of such psychosocial interventions in future research and practice. They were invited to express their comments and opinions on the intervention after a detailed introduction and explanation of the FDT. They are also expected to share their observations about the patients' responses to FDT. The interviews were conducted at T1 of the study.

Nineteen registered nurses worked in the study setting. Of them, four were excluded because of the minimal time they had spent with the patients and four declined because they felt that they lacked knowledge of the intervention or mental health or lacked interest. Finally, 11 nurses (all women) were interviewed individually in an office room. Forty-five patient-caregiver dyads completed the intervention, but only 16 dyads were eligible for face-to-face interviews because of discharge arrangements. Two patients and five family caregivers refused to participate in the interview because of a lack of interest or time and physical limitations. Consequently, semistructured interviews with 14 patients and 11 caregivers were conducted beside the bed or in an office room by a research assistant. Each interview ended when participants reported that they had exhausted their description. To ensure the credibility and authenticity of the data, a reflection and summary were provided at the end of the interviews to correct any misunderstanding. Each interview was audio recorded, transcribed verbatim, and proof-read. Field notes handwritten in a notebook were adopted to note and comment on impressions, environmental contexts, behavior, and nonverbal cues.

Ethical considerations

The study followed the principles outlined in the Declaration of Helsinki, and ethical approval was obtained from the Ethics Committees of the Joint Chinese University of Hong Kong-New Territories Ethical Committee (Approval No. 2018.400) and Central South University (Approval No. 2018017) before study commencement.

Data analysis

Data analysis was performed using IBM SPSS version 25.0. Demographic characteristics are presented as mean and standard deviation (SD), whereas participants' involvement and response levels are presented as frequency and proportion (percentage). In addition, the characteristics, the participants' involvement, and the response levels of the participants in the intervention were viewed as substantive factors to explore how these variables are related to the intervention

Table 1
Participants' involvement in the intervention.

Involvement	Level	Patients (n = 45)		Family caregivers (n = 45)	
		Frequency	%	Frequency	%
Attention to reminiscence	High	29	64.4	28	62.2
	Moderate	13	28.9	13	28.9
	Partial	3	6.7	4	8.9
	Not at all	0	0	0	0
Attention to sharing	High	26	57.8	23	51.1
	Moderate	9	20.0	16	35.6
	Partial	9	20.0	6	13.3
	Not at all	1	2.2	0	0
Participation in reminiscence	High	30	66.7	25	55.6
	Moderate	6	13.3	14	31.1
	Partial	9	20.0	6	13.3
	Not at all	0	0	0	0
Participation in sharing	High	27	60.0	24	53.3
	Moderate	10	22.2	15	33.3
	Partial	8	17.8	6	13.4
	Not at all	0	0	0	0
Interest in reminiscence	High	27	60.0	23	51.1
	Moderate	10	22.2	17	37.8
	Partial	8	17.8	5	11.1
	Not at all	0	0	0	0
Interest in sharing	High	24	53.3	21	46.7
	Moderate	12	26.7	19	42.2
	Partial	9	20.0	5	11.1
	Not at all	0	0	0	0
Interest in producing a Spiritual Diary	High	25	55.6		
	Moderate	9	20.0		
	Partial	11	24.4		
	Not at all	0	0		

Attention to reminiscence/sharing

High = Engaged in the reminiscence/sharing session without being distracted.
 Moderate = Occasionally distracted by other issues, excluding symptoms and feelings of discomfort.
 Partial = Attended to other issues during the reminiscence/sharing session.
 Not at all = Did not respond to the reminiscence/sharing session.

Participation in reminiscence

High = Actively talked about his/her life story and respond to facilitators' questions.
 Moderate = Present his/her life story in a question and answer manner.
 Partial = Required a considerable level of probing in talking about his/her life story and were reluctant to elaborate on the story.
 Not at all = Did not respond to the facilitator.

Participation in sharing

High = Read the entire Spiritual Diary carefully and actively shared his/her feelings.
 Moderate = Read the Spiritual Diary completely and present his/her feelings in a question and answer manner.
 Partial = Read the Spiritual Diary partially and required a considerable level of probing in sharing his/her feelings and were reluctant to elaborate on the story.
 Not at all = Did not read the Spiritual Diary completely and did not respond to the sharing.

Interest in reminiscence

High = Spontaneously disclose their life stories, with details of these stories described.
 Moderate = Required a certain level of probing to describe the details of life stories.
 Partial = Reluctant to elaborate on the details of life stories.
 Not at all = Did not respond to the facilitator.

Interest in sharing

High = Spontaneously disclose their feelings according to the Spiritual Diary.
 Moderate = Required a certain level of probing to express his/her feelings.
 Partial = Reluctant to elaborate on expressing his/her feelings.
 Not at all = Did not respond to the sharing.

Interest in producing a spiritual diary

High = Consistently happy during the reminiscence session and was eager to produce the Spiritual Diary.
 Moderate = Accepted the offer in producing the Spiritual Diary.
 Partial = Claimed that the Spiritual Diary was not necessary but accepted eventually after a further explanation on the purpose of the Spiritual Diary.
 Not at all = Did not want the Spiritual Diary to be produced.

effects. Nonparametric statistics were used because of the small sample size in the intervention group. Mann–Whitney U tests were performed to test for differences in variables between the two subgroups, such as sex. Kruskal–Wallis tests were conducted for variables among three or more subgroups, such as educational level, level of involvement, and response. Spearman's rank-order correlation was used to examine the association of continuous demographic variables, such as age, with the intervention effects. Because only the outcome variables in the intervention group were analyzed, we calculated the differences in the scores of the outcome variables between T0 and T1 to indicate the intervention effects.

Conventional content analysis with the inductive approach was adopted to analyze the qualitative data because it is generally used in a study design that aims to describe a phenomenon.²⁴ The interview data for patients and their family caregivers were pooled together for analysis as they were engaged in the intervention. Data analysis began with the first author repeatedly reading all the data to obtain an immersion and complete understanding of the transcripts. Next, the data were read word by word to derive codes by first highlighting the exact words (eg., negative emotions) from the text that appeared to capture key thoughts or concepts. Then, the author approached the texts by making notes of her first impressions, thoughts, and initial analysis. Labels for codes (eg., alleviating psychosocial distress) emerged that were reflective of more than one key thought. An initial coding scheme emerged that was reflective of more than one key thought. Finally, the codes were sorted into different subcategories using the inductive approach based on how the different codes were related and linked. These subcategories were subsequently classified based on their meanings. The analysis was repeated to identify nurses' perceptions of the intervention. The coding process was checked by another author. The final results, including categories, subcategories, and sample quotes, were translated by a researcher fluent in Chinese and English. Any disagreement was discussed and determined by the research team.

Results

Forty-five patients (mean age: 54.47, SD: 8.937; range: 32–73 years) and their family caregivers (mean age: 48.27, SD: 11.533; range: 25–70 years) completed the intervention and outcome assessment at T1. Most patients were men (62.2%), were married (97.8%), and were taken care of by their spouses (60.0%). Most patients had a monthly income of less than 1000 Chinese yuan (RMB; 55.6%). Most patients were diagnosed as having non–small–cell lung cancer (75.6%) and at the advanced stages of III and IV (86.7%). More than half of the caregivers were women (55.6%), and nearly half attended junior high school or above (48.9%) and had a monthly income of less than 1000 RMB (57.8%).

Features of intervention delivery

Deviations from the protocol were identified in the following aspects: reminiscence time, sharing session, and interruptions encountered in the intervention process. The average reminiscence time was 26.22 min (SD: 11.53, range: 8.24–56.36 min), less than the 1 h proposed in the protocol. The sharing session was scheduled after receiving the spiritual diary, and it was made flexible depending on the physical conditions and treatment of the patients. Face-to-face interviews were organized for 26 dyads, and 19 others (42.2%) were interviewed online through WeChat (a popular social media application in China). The reminiscence session for the two dyads was interrupted by friends' visits or noisy maintenance work conducted in the ward. Under these circumstances, the reminiscence session was terminated and rescheduled to another time for completion.

Association between participants' demographic variables and outcome measures

Patients with senior school education exhibited a significant decrease in existential distress compared with patients with primary school or lower education ($H = 12.20, P = 0.030$). The patients with a monthly income of more than 3000 RMB (USD 420) reported having better spiritual well-being than those with a monthly income of between 1000 and 3000 RMB (USD 140–420; $H = -16.310, P = 0.031$). The results revealed that patients' other demographic variables, including age, sex, primary caregivers, medical insurance, and chemotherapy duration, and family caregivers' characteristics, including age, sex, educational level, and income, did not significantly affect the intervention effectiveness (all $P > 0.05$).

Comparison of psychosocial outcomes in terms of process evaluation variables

Table 1 presents the involvement of patients and their family caregivers in the intervention, as recorded in the checklist. The patients who had high levels of interest in the sharing session had a significant decrease in existential distress ($H = 10.396, P = 0.035$) compared with those with moderate levels of interest. Moreover, the patients who had moderate levels of interest in the sharing session had a significant decrease in peace of mind distress ($H = -16.778, P = 0.006$) and an increase in life meaning ($H = -12.808, P = 0.047$) compared with those with partial levels of interest.

Table 2 presents the patients' and family caregivers' response levels

to the questions. The patients with a high response to Question 7 ("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, and others?") had a significantly decreased level of symptom distress than those with a moderate response ($H = -13.879, P = 0.035$). No other process evaluation variable was significantly related to intervention effectiveness.

Stakeholders' perception of the intervention

Four major categories were identified from the interview data: (1) benefits of the intervention, (2) risks of the intervention, (3) factors to enhance successful dignity-conserving care, and (4) difficulties and barriers to delivery of dignity-conserving care. Table 3 presents the primary categories and subcategories and the corresponding sample quotes.

The patients and their family caregivers reported similar perceptions of the intervention as they both participated in the intervention. However, the nurses expressed some different opinions regarding the intervention. Table 4 shows the main themes and subthemes of nurses, patients, and family caregivers. Specifically, the nurses reported different opinions on the theme of "risks of the intervention," "factors to enhance successful dignity-conserving care," and "difficulties and barriers in delivering dignity-conserving care."

Benefits of the intervention

Eleven nurses, 13 patients, and 10 family caregivers proposed several benefits of FDT. Three subthemes were generated from their opinions:

Table 2

Percentage distribution and the mean scores of response levels to the reminiscence questions of patients and family caregivers.

Questions	Patients (n = 45)					Family caregivers (n = 45)				
	High (n/%)	Moderate (n/%)	Partial (n/%)	Not at all (n/%)	Mean (SD)	High (n/%)	Moderate (n/%)	Partial (n/%)	Not at all (n/%)	Mean (SD)
1 Tell me a little about life history (of the patients), particularly the parts that you either remember most, or think are the most important. When did you (the patient) feel most alive? (childhood, before getting married, after the birth of the baby and after retired)	32 (71.1)	8 (17.8)	5 (11.1)	0 (0)	3.6 (0.688)	26 (57.8)	12 (26.7)	7 (15.6)	0 (0)	3.42 (0.753)
2 Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?	6 (13.3)	17 (37.8)	19 (42.2)	3 (6.7)	2.58 (0.812)	NA	NA	NA	NA	NA
3 What are the most important roles you (the patient) 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 (the patient) accomplished in those roles?	29 (64.4)	13 (28.9)	3 (6.7)	0 (0)	3.58 (0.621)	26 (57.8)	10 (22.2)	9 (20.0)	0 (0)	3.38 (0.806)
4 What are your (the patient's) most important accomplishments, and what do you feel most proud of?	28 (62.2)	9 (20.0)	8 (17.8)	0 (0)	3.44 (0.785)	26 (57.8)	9 (20.0)	10 (22.2)	0 (0)	3.36 (0.830)
5 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?	12 (26.7)	19 (42.2)	11 (24.4)	3 (6.7)	2.89 (0.885)	NA	NA	NA	NA	NA
6 How do you think about your loved ones at present of future? What do you expect of your loved ones?	16 (35.6)	17 (37.8)	10 (22.2)	2 (4.4)	3.04 (0.878)	NA	NA	NA	NA	NA
7 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? (for patients). What have you learned about life from the patient that guide your life (for family caregivers)?	26 (57.8)	7 (15.6)	12 (26.7)	0 (0)	3.31 (0.874)	25 (55.6)	14 (31.1)	6 (13.3)	0 (0)	3.42 (0.723)
8 Are there words or perhaps even instructions you would like to offer your family to help prepare them for the future?	15 (33.3)	16 (35.6)	13 (28.9)	1 (2.2)	3.00 (0.853)	NA	NA	NA	NA	NA
9 In creating this permanent record, are there other things that you would like include?	16 (35.6)	17 (37.8)	9 (20.0)	3 (6.7)	3.02 (0.917)	19 (42.2)	15 (33.3)	8 (17.8)	3 (6.7)	3.11 (0.935)

High = Responded spontaneously after the questions were asked and provided details of his/her story without probing.

Moderate = Required a certain level of probing to elaborate on their answers to the questions asked.

Partial = Not much information on his/her story was provided through questioning even after probing was exerted.

Not at all = Refused to respond to the questions asked or claimed to have no issues.

Table 3
Primary themes and subthemes and related sample quotes.

Themes and subthemes	Quotes
Benefits of the intervention	
Alleviating psychosocial distress	Communication serves as an outlet for patients to seek positive resources, such as how they have overcome difficulties in the past. This is also a form of confiding that helps regulate the negative emotions of patients and their families. (Nurse 2) The intervention lightens my mental burden to some extent and adjusts my mood. (Case 67) At this moment, we just need some psychological guidance; (we) need someone to care about our mood and adjust it. I think the intervention is very helpful for us. (Family caregiver of Case 11)
Improving personal relationship	The Chinese usually find it difficult to express their love. The intervention plays a connecting role between them, through which the family caregivers feel that they should take better care of their patients. Patients who receive encouragement and praise will also want to fight against the disease and live up to their family's efforts. (Nurse 3) It is a good way to improve the relationships between patients and healthcare providers and the satisfaction level of the hospital. (Nurse 2) This is a good form of communication; I will show it (the Spiritual Diary) to my wife. (It) can promote understanding; I think we don't communicate much in daily life. (Case 47) We don't usually talk about these things because we are (feeling) a little embarrassed. But it is good, and I know more about him now. (family caregiver of Case 92)
Increase confidence in recovery	It can improve patient adherence to treatment and confidence in the recovery. (Nurse 9) This is good for me and my family; it is a great help because (it) encourages me. I have more confidence to fight (the disease). (Case 86)
Risks of the intervention	
Triggering sad feelings	Recalling the past may bring up sad memories, just like opening a scar. (Nurse 6)
No risks reported by patients and family caregivers	I don't think such communication would have any adverse effect. If I feel unhappy, I will not participate. But I do benefit from the intervention (Case 52)
Factors to enhance successful dignity-conserving care	
Professional knowledge and skills	The effects of the intervention depend on the ability and communication skills of the facilitator. If the facilitator is not professional enough to understand the psychology of the patient or pays less attention to communication skills, it may cause negative effects. (Nurse 1)
Facilitators' characteristics	The facilitators are always required to be warm to patients; they also need well emotional adjustment ability to ensure the effects of the intervention. Thus, several nurses, maybe myself, cannot serve as facilitators. (Nurse 7) She (the facilitator) is very kind and always smiling and listening to my stories; it brings me in a good mood. (Case 19) She (the facilitator) is so nice and patient; I could sense that she cared about me and understood me during the communication, and it made me feel warm. (family caregiver of Case 11)
Appropriate intervention timeline	Newly diagnosed patients usually experienced a high level of psychological distress, thus the time diagnosed with cancer may be appropriate to deliver the intervention. (Nurse 7) (I think) It should be delivered at a late stage when the patient needs such care the most. (Maybe) near the death or the time that patients recognize their poor prognosis. (Nurse 5)
Support from the leaders	To do this intervention, I think a team is needed to solve an emergency or unexpected situation,

Table 3 (continued)

Themes and subthemes	Quotes
	so it is important to obtain support from managers. (Nurse 10)
Brief and flexible procedure	The study is very simple to participate in; we just communicated with each other (through which) to adjust the patients' moods. Killing time with small talk makes us happy. (Case 52)
Integrated with health education	I hope the intervention can be integrated with some health education, such as basic knowledge of the disease, advice on daily living and diet, and information on the treatment. (Case 20)
Difficulties and barriers to the delivery of dignity-conserving care	
Physical symptoms	When a patient is sick from vomiting or other severe complications, he doesn't have the energy to discuss it with anyone. (Nurse 3) For a long time, people thought that I was here to cure the disease and that my daily silence or unhappiness had nothing to do with the treatment. Several nurses and doctors feel that psychological care is nothing but a waste of time. (Nurse 2) It (psychology) is important for the treatment, but they (the patients) don't have enough awareness of psychology and regard it as useless. It is wrong. (family caregiver of Case 20) People may refuse to participate because they think it is useless or (it) is for psychiatric patients. (Case 109)
Underrecognition of psychosocial care	
Workload and time consumption	I am afraid that I don't have time to do it. The workload is too heavy now. The bed-to-nurse ratio is 13 to 1; if it becomes 4 to 1, maybe I can do it. (Nurse 11)

Table 4
A summary of the main themes and subthemes by nurses, patients, and family caregivers.

Themes	Subthemes	
	Nurses	Patients and family caregivers
Benefits of the intervention	Alleviating psychosocial distress Improving personal relationships Increasing confidence of recovery	Alleviating psychosocial distress Improving personal relationships Increasing confidence of recovery
Risks of the intervention	Triggering sad feelings	No risk reported
Factors to enhance successful dignity-conserving care	Professional knowledge and skills Facilitators' characteristics Appropriate intervention timeline Support from leaders	Facilitators' characteristics Short and flexible procedure Health education
Difficulties and barriers in delivering dignity-conserving care	Physical symptoms Underrecognition of psychosocial care Workload and time consumption	Underrecognition of psychosocial care

alleviating psychosocial distress, improving personal relationships, and increasing confidence in recovery. Alleviating psychosocial distress refers to the intervention of helping patients alleviate various types of distress related to existential, spiritual, and psychological issues. In addition, the intervention was regarded as a good bridge to promote communication and understanding between patients and their family caregivers, as well as with the facilitator, thereby improving interpersonal relationships. The spiritual diary also helped to promote

understanding and relationships in the family. Increasing confidence in recovery was mentioned. Specifically, the intervention encouraged the patients and their family caregivers and enhanced the patients' rehabilitation confidence.

Risks of the intervention

A potential risk was triggering sad feelings from the nurses' perspective. Three nurses were concerned about the sad memories or sharp contrast between the happiness of the past and the unhappiness of the present introduced during the reminiscence session. However, all patients and their family caregivers thought it had no adverse effects or risks.

Factors that enhance successful dignity-conserving care

Professional knowledge and skills, facilitators' characteristics, appropriate intervention timeline, support from leaders of the organization, short and flexible procedures, and health education were identified as factors enhancing successful dignity-conserving care. The facilitators' professional knowledge in psychology and communication skills were important to establish a comfortable conversation with the patients and their family caregivers and to provide positive guidance. Facilitators' characteristics to enhance successful dignity-conserving care require the facilitator to be nice, attentive, positive, friendly, and supportive to the patients and their family caregivers. An appropriate intervention timeline was important; nurses reported that newly diagnosed patients and patients with poor treatment prognoses or multiple complications usually needed more help than others. The intervention effects could improve when patients need it the most. Support from the leaders was mentioned by all 11 nurses. Leaders should have a high awareness of the importance of dignity-conserving care, provide professional training, and build a multidisciplinary team to offer continuous support.

A brief and flexible procedure was important for patients and their family caregivers to join the FDT. The intervention process should be brief and simple for the participants to understand. The sessions should be organized flexibly because the patients may have treatments and possible physical limitations during hospitalization. Health education was recommended by patients and their family caregivers to be integrated into the intervention to help them understand the disease, engage in rehabilitation, and relieve psychological distress. Health education on basic knowledge of the disease, advice on daily living and diet, and information on treatment were specifically mentioned.

Difficulties and barriers in delivering dignity-conserving care

Difficulties and barriers in delivering dignity-conserving care included patients' physical symptoms, underrecognition of psychosocial care, workload, and time consumption. Physical symptoms, especially severe complications after chemotherapy, such as vomiting, fatigue, and breathing difficulties, hindered the patients from communicating with others. Underrecognition of psychosocial well-being among patients, family caregivers, and health care providers was mentioned as one of the most important difficulties in delivering the intervention. Compared with physical symptoms, the patients usually underestimated the importance of psychosocial well-being and paid little attention to it. Furthermore, eight nurses mentioned the heavy workload and thought that the intervention was time consuming. Over half an hour of conversation with a patient would increase nurses' workload; transcription and editing would also be time consuming.

Discussion

A process-focused evaluation using quantitative and qualitative approaches was used to examine the fidelity of FDT and reveal a comprehensive picture of its effects. The fidelity of FDT was achieved despite minor deviations in the delivery process. Process evaluation results further indicated that FDT was more effective in patients with high educational level and high monthly income, as well as in those with high

levels of response to the reminiscence question and high levels of interest in sharing during the sessions.

The intervention fidelity was achieved despite deviations in the reminiscence time in the sharing sessions and interruptions of the intervention due to practical issues. The average time of the reminiscence session was 26.22 min, less than the approximately 1 h in similar studies in English-speaking countries.^{11,15} Despite the short time, the participants' responses to the questions were rich and deep around the following aspects: a brief description of the family, memorable stories, important roles, proudest achievements, life lessons, hopes and dreams, and things to share with family and family messages. The process checklist suggested that most patients and their family caregivers were highly or moderately involved in the reminiscence sessions and responded well to the questions. This may be because Chinese people tend to be introverted and rarely talk about their life events with others. Further studies should therefore offer a flexible approach for patients. In addition to face-to-face communication, responding to the questions by writing, phone calls, and voicemail messages may encourage the participants to express their feelings.

The main reason for the interruption during the intervention delivery process was the physical symptoms caused by chemotherapy, mainly weakness or tiredness, followed by nausea and vomiting. This scenario indicates the importance of flexibility in psychosocial interventions for patients with lung cancer undergoing chemotherapy. In addition, our study highlights the potential to deliver the intervention through a social platform, given that nearly half of the sharing sessions were successfully delivered through WeChat. Face-to-face psychosocial interventions are not always available and accessible because of time conflicts between the intervention and medical care, issues of geographic distance, and traffic problems.²⁵ Integrating social networking applications may help address such problems.

The quantitative analysis in the process evaluation helped to interpret the intervention effects. Comparisons of the intervention effect with the participants' characteristics indicated that FDT was more effective for those with higher educational levels. The intervention facilitator reported that all the participants could understand the questions with or without further explanation, whereas patients with higher educational levels usually expressed more information about the questions. The patients with lower educational levels usually reported that they were merely ordinary persons and expressed little about their important roles or accomplishments. The findings suggest that additional strategies are required to inspire patients with lower educational levels to narrate their stories and express their thoughts and feelings. The use of supplementary video, audio, and reading materials to present stories from those with similar situations may help them associate their important life events, views, and thoughts and motivate them to express themselves more when asked questions.

Our findings indicated that the patients' monthly income was associated with the intervention effects, reflecting the substantial economic burden imposed by lung cancer.²⁶ Patients with advanced lung cancer are usually unable to continue working, and many rely on family members for support during treatment or in the last phases of the disease. Economic burden was also reported in our preliminary research as an essential factor affecting patients' sense of dignity.⁸ The process evaluation further suggested that the economic burden might reduce the effects of FDT. Thus, its application in areas with high economic and medical burdens may be limited.

The patients who expressed high levels of interest in the sharing session benefited more from the intervention than their counterparts, implying that the sharing session after reminiscence is important to enhance the effects of FDT. High levels of interest during the sharing session reflected that the patients spontaneously disclosed their feelings to their family caregivers based on the legacy documents. Although some patients were interested in the spiritual diary, they were embarrassed to publicly disclose their introverted thoughts. Therefore, future research should consider providing a flexible approach, such as face-to-face

communication and writing letters or diaries to express their feelings.

The findings also indicated greater effects on patients who exhibited high response levels to the question “lessons learned about life that would pass along to others”. The question reflected the need to leave behind something that would last and transcend death, which was important for patients to sustain a sense of dignity. Future studies could help participants explore lessons and achievements from various perspectives, including work and life, or different life stages.

Qualitative interviews helped to interpret the effects of FDT and reveal how the intervention works. Qualitative analysis suggested that FDT improved personal relationships between patients and their family caregivers. The result was consistent with the original intention in the FDT development to improve communication by involving family caregivers in the intervention to enhance the patients’ sense of dignity. Modifications involving family caregivers were assumed to enhance the intervention effects by improving communication and personal relationships. Other similar studies have also highlighted the importance of communication between patients and their family caregivers in addressing patients’ psychological distress.^{27,28} Future studies are recommended to measure communication between patients and their family caregivers using a quantitative approach and identify whether it serves as a mediator between the effects and intervention activities.

The patients and their caregivers reported that the facilitators’ characteristics and simple and flexible procedures inspired them to actively enroll in the intervention. Compared with the professional knowledge and skills mentioned by nurses, patients and family caregivers highlighted the supportive, positive, and comfortable communication with the facilitator. In supportive psychosocial care, the facilitator is required to be nice, attentive, positive, friendly, and supportive to patients and their family caregivers. Creating an environment where patients feel respected, valued, and supported could make them feel free to talk about their achievements and possessions rather than loss, thereby reliving their feeling of being a burden to others and promoting their sense of dignity. A simple and flexible procedure was also seen as important for promoting participant involvement and compliance. The sessions must be scheduled according to the patients’ practical situations.

The qualitative data provided further implications for promoting the effects of FDT. The patients and their family caregivers suggested that adding health education to the intervention could help them cope with the physical symptoms encountered in the cancer trajectory. A comprehensive package of interventions addressing existential and symptom distress might enhance the effects on dignity to a large degree. Apart from physical symptoms, underrecognition of psychosocial well-being was the difficulty most frequently mentioned by nurses, patients, and family caregivers.²⁹ Although psychosocial distress such as depression, worries, or fears cause considerable suffering, health care providers, patients, and families underrecognized psychosocial care relative to disease treatment and symptom control, which resulted in unmet psychosocial needs of patients with cancer and families. Therefore, emphasizing the importance of psychosocial well-being and promoting psychosocial care for patients with cancer among health care professionals and patients is essential. Furthermore, the nurses mentioned that the intervention would increase the workload and be time consuming. Support from the leaders (eg., head nurses, directors) in workload arrangement, professional training, and cooperative psychosocial care teams are required to promote its implementation in clinical practice. The workload and time required to deliver FDT must also be reduced. Future studies can explore the feasibility of delivering FDT through mobile social media, such as WeChat, to use its automatic speech recognition technique and reduce transcribing time. Remote and online intervention may be acceptable and safe during the COVID-19 pandemic.

Limitations

This study has several limitations. First, stringent monitoring of the intervention facilitators and participants’ performance, such as

videotaping, was not conducted in consideration of privacy protection. The recording of involvement and response levels relied on the research assistant’s subjective judgment with a self-designed checklist. However, there is no validated or standard tool to evaluate the process of dignity therapy. We designed the checklist based on a previous similar study and further validated by an expert panel. The checklist described the standards clearly and make the rating of participation less subjective. Second, the small sample size in the quantitative analyses with nonparametric statistics may decrease the reliability of the results. Larger-scale studies are recommended to analyze how the process variables affect the intervention effects. Third, only 14 patients and 11 family caregivers were available for qualitative interviews because of various reasons, such as discharge, physical symptoms, and lack of time. This might limit the exploration of the participants’ perceptions of the intervention. Finally, although we discussed the quantitative and qualitative findings separately, these findings share the same purpose of enhancing the effects of FDT and promoting its clinical use. Integrating the quantitative and qualitative findings can help improve FDT.

Conclusions

The study provides rich and comprehensive information on the fidelity of the intervention delivery and the factors that contribute to the effective delivery of FDT and how these factors could be improved. A high degree of fidelity was achieved, with minor deviations due to the practical issues and some intended flexibility in the delivery of the intervention. Reinforcement strategies, such as using supplementary video, audio, and reading materials; developing a flexible approach to expressing feelings; and exploring lessons and achievements from various perspectives are recommended for future research and practice. We also identified the following factors contributing to successful dignity-conserving care: facilitators’ professional knowledge and skills, facilitators’ characteristics, appropriate intervention timeline, support from leaders of the organization, brief and flexible procedures, and health education.

Author contributions

All authors have made substantial contributions to the article. J.X. designed the study, analyzed the data, and drafted the article. K.M.C. and W.H.C.C. provided professional advice on improving the study design, supervised the research process, and critically revised the article. X.H., J.C., S.T., and G.W. critically revised the article. All authors read and approved the final article.

Declaration of competing interest

None declared.

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Ethics statement

The study followed the principles outlined in the Declaration of Helsinki, and ethical approval was obtained from the Ethics Committees of the Joint Chinese University of Hong Kong-New Territories Ethical Committee (Approval No. 2018.400) and Central South University (Approval No. 2018017) before study commencement.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.apjon.2022.100168>.

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