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Development of the pediatric family-based dignity therapy protocol for terminally ill children (ages 7–18) and their families: A mixed-methods study

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Abstract

Objectives. Dignity therapy (DT) is well-established in adults, and it might potentially benefit the younger population. This study aims to develop a pediatric family-based dignity therapy (P-FBDT) protocol for terminally ill children and their families.

Methods. A parallel mixed-methods design was used. The P-FBDT protocol was developed based on the adult DT, and meanwhile by taking children-specific dignity characteristics and Chinese family-oriented culture into consideration. The protocol was then evaluated and modified based on the quantitative and qualitative feedback from 2-round surveys of 14 pediatric oncology or pediatric palliative care experts.

Results. The P-FBDT involves terminally ill children and their families in meaningful interactions including a series of conversations and creative activities, which will be recorded and then edited into a document-based generativity entity. The P-FBDT protocol was recognized as highly reasonable and the P-FBDT interview guide was endorsed as important, acceptable, clear, comprehensive, and suitable to be used in pediatric palliative care practice in Chinese culture (>90%). Potential benefits, possible challenges, and practical considerations of the P-FBDT were also proposed.

Significance of results. The P-FBDT was perceived to be potentially beneficial to terminally ill children and their families by engaging in a series of meaningful family interactions and creating a lasting memento to be preserved. The protocol needs to be pilot tested among terminally ill children and families for feasibility and potential efficacy in practice.

Introduction

Dignity, an integral part of human beings, has always been one of the central pillars of life quality not only for adults but also for children with terminal illnesses (Poles and Bousso 2009). To understand and maintain patient dignity, Chochinov et al. (2002) developed an empirical dignity model through interviewing 50 terminal adults on their understanding of dignity. The dignity model provides a framework for the development of dignity therapy (DT) by informing its form, content and therapeutic tone. DT is a brief, individualized, psychotherapeutic intervention in palliative care, which provides terminal patients with opportunities to convey memories and essential discourses, and finally formulates a generativity document to share with or bequeath to individuals of their choice (Chochinov et al. 2005). DT has been demonstrated to be helpful in addressing the dignity-related needs of adult patients by reinterpreting the meaning in life, maintaining self-integrity, and creating value beyond their own death (Zhang et al. 2022).

The concept of dignity is culturally sensitive and the implementation of DT could be influenced by different cultures (Linet al. 2022a). In traditional Chinese culture, the family rather than the individual is viewed as the basic unit of life, and family support is a cultural-specific meaning of dignity in dying (Liu et al. 2021). Meaningful family interactions at the end of life including communicating gratitude, affection, forgiveness, and farewell in families are significant to achieve a dignified death for Chinese patients. Taking these Chinese cultural

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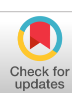

characteristics into consideration, we developed a family-based dignity therapy (FBDT) with cultural-specific questions regarding "family support," "apology and forgiveness," and "gratitude and appreciation" being added to the DT interview guide. In FBDT sessions, patients and family members would be invited to converse on shared topics guided by the interview guide (Chen et al. 2022). The FBDT has been conducted with advanced cancer patients in mainland China, and it has been shown to potentially relieve patients' dignity-related, psychological, and spiritual distress and improve their family function (Lin et al. 2023a).

Compared with adults, children with serious illnesses and poor prognoses might have more fear and resistance to death due to their underdeveloped understanding of death and illness (Peng and Hu 2019), and they might be more vulnerable to diminished dignity due to their powerlessness and lack of control over what happens to them (Reed et al. 2003). In previous studies, an empirical pediatric dignity model with a series of children-specific characteristics based on the framework of the Chochinov dignity model was developed (Cai et al. 2023; Lin et al. 2022b). The dignity needs of terminal children are intimately bound to the cognitive and psychological developmental stages, which could trigger complicated dignity-conserving care dilemmas. Maintaining terminal children's dignity needs particular attention, but currently it is underappreciated in pediatric palliative care. There are few non-pharmacologic interventions designed to address dignity-related issues for terminal children besides that a few studies adapted DT to the young population (Julião et al. 2020a, 2020b; Schuelke and Rubenstein 2020). A case-series report on DT modality described a novel implementation of DT by proxy of children and showed its feasibility and acceptability in pediatric palliative populations (Schuelke and Rubenstein 2020). The DT question framework also has been adapted to Portuguese adolescents (ages 10–18) based on inputs from an expert committee panel familiar with DT (Julião et al. 2020a), and various facilitating techniques consisting of metaphors, tasks, and support phrases were explored to make it more developmentally appropriate (Julião et al. 2020b). However, in comparison to the well-established DT for adults, there is a clear gap in the development and evaluation of an empirical DT for children (Rodriguez et al. 2018), and DT has never been adapted to be used among children in mainland China to the best of our knowledge. Taking both children-specific dignity characteristics and the Chinese culture into consideration, we have developed a pediatric family-based dignity therapy (P-FBDT) aiming to provide psychological support to terminal children and their families in pediatric palliative care. This study described how the P-FBDT protocol was developed and modified from the perspective of pediatric care professionals.

Methods

Study design

This study was conducted according to the ADAPT guide for adapting interventions to new contexts (Moore et al. 2021). After obtaining permission to adapt the adult DT for children from Harvey Max Chochinov who developed the original DT, we developed the P-FBDT protocol based on the development process of the original DT and FBDT (Chen et al. 2022; Chochinov et al. 2005). A combination of the children-specific dignity characteristics, the pediatric dignity model, and Chinese cultural considerations in FBDT informed the form, tone, and content of P-FBDT. See Figure 1 for the development process of the P-FBDT protocol.

For the form of the P-FBDT, inspired by the new themes including "the company of important people" and "a sense of security" emerged in the pediatric dignity model (Cai et al. 2023), children and their families would be invited as a unit to engage in the P-FBDT session to converse on shared topics and together create the final legacy. The co-participation of children and families aims to increase the sense of security of children to maximize the potential benefits of P-FBDT to the child–family unit. Meanwhile, considering that terminal children's social dignity is damaged due to the long-term treatment in hospitals that deprives them of hobbies, daily life and social activities and their dignity needs vary according to different developmental stages (Lin et al. 2022b), children would be invited to conduct a series of creative activities such as hand-crafting and photography based on their age groups and preferences in the P-FBDT session. For the tone of the P-FBDT, besides following the care tenor of empathic, non-judgmental, mutual caring, encouraging, and respectful attitude and manner, the new themes of stigma and fairness in the pediatric dignity model were also taken into consideration. The content of the P-FBDT is the interview guide consisting of 11 topics with paired questions under each topic. The topics of important memories, things about yourself, special roles, merits and achievements, wish list, hopes and dreams, and suggestions for the future in the P-FBDT interview guide were respectively informed by the themes of continuity of self, role preservation, maintenance of pride, realizing unfinished wishes, hopefulness, and aftermath concerns in the pediatric dignity model (Cai et al. 2023). The topics of gratitude and appreciation, apology and forgiveness, and family support were informed by the Chinese tradition of four important things in life and the Chinese family value, which followed the cultural considerations of the FBDT interview guide (Chen et al. 2022).

Besides the intervention form, tone, and content of the P-FBDT, the suitable participants, setting, timing, and intervention team were identified by the research team based on their expertise and clinical experience in caring for terminal children. The preliminary P-FBDT protocol was reviewed by Harvey Max Chochinov and other 2 experts in pediatric palliative care who have a deep understanding of both DT and the pediatric dignity model to ensure that the P-FBDT has captured the essence of DT and the fundamental elements of the pediatric dignity model, and then was adjusted based on the Delphi expert consultation (Lin et al. 2023b). Meanwhile, an expert panel including healthcare providers or researchers in pediatric oncology or pediatric palliative care was invited to evaluate the P-FBDT protocol through a parallel mixed-methods design. Quantitative data (endorsement rates) and qualitative data (perceptions on P-FBDT) were collected simultaneously by an evaluation questionnaire including a rating sheet and a list of open-ended questions. Priority was given to both forms of data.

Participants and setting

Between November 2022 and January 2023, purposive sampling was utilized to recruit pediatric oncology or pediatric palliative care experts including physicians, nurses, social workers, and researchers from tertiary hospitals across northern, southern, and central China to maximize professional and regional variation. Eligible participants had to be involved in pediatric oncology or pediatric palliative care for at least 5 years, receive at least once DT training/lecture or conduct at least once DT/FBDT, know about or be familiar with DT, and be willing to participate in this study.

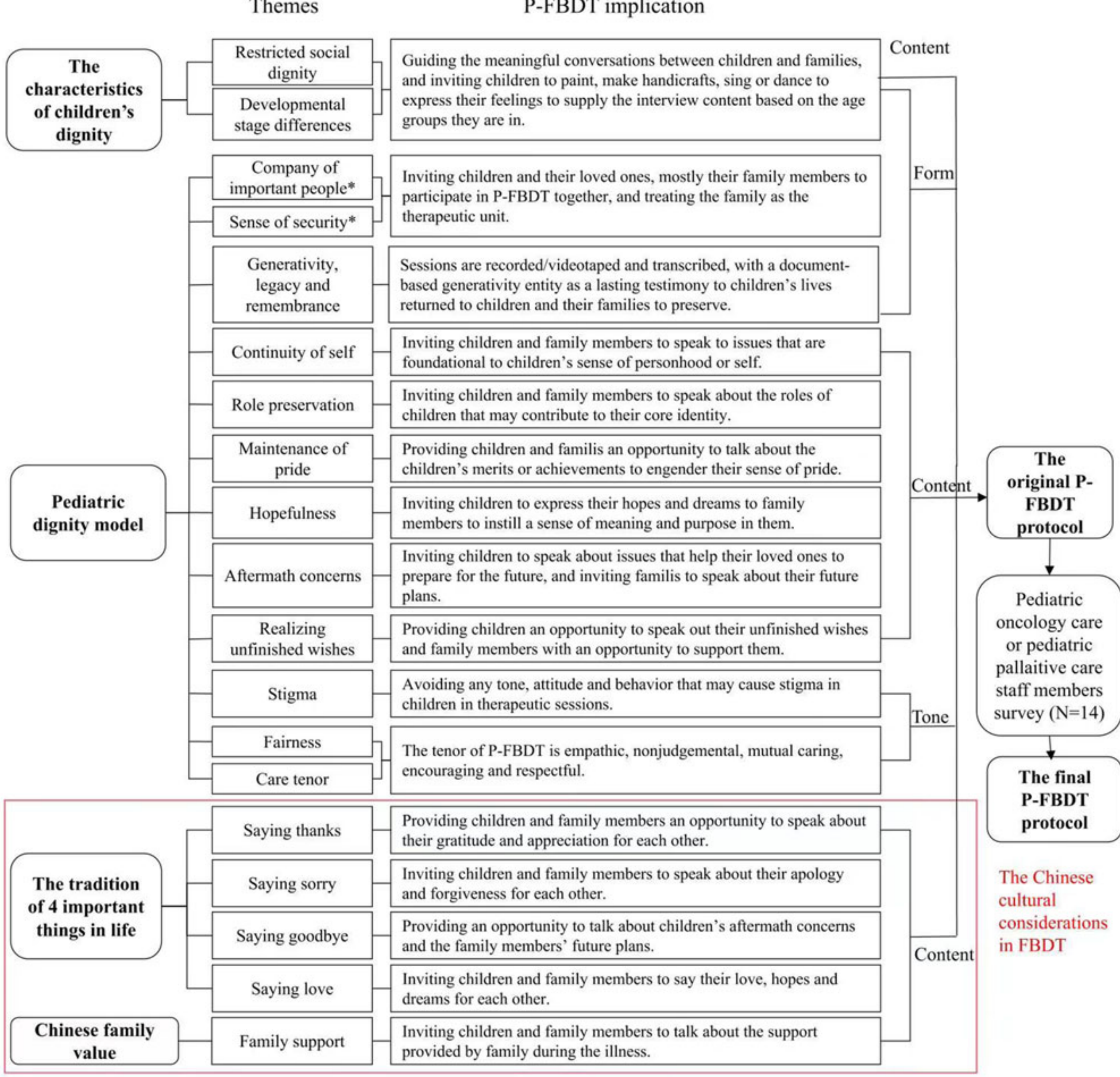

Figure 1. The development process of Pediatric Family-based Dignity Therapy protocol.

Data collection

Fourteen participants were invited via WeChat (a social software) and were briefly introduced the P-FBDT by 2 authors (XZ and HL). After obtaining the signed informed consent and demographic information from each participant, the first author (JL) sent a self-designed evaluation questionnaire to them via WeChat. In particular, the self-rated degree regarding knowledge of DT ranging from 1 (not all) to 5 (very much) was obtained from each participant, and those who scored 4 and over were included in the study.

The participants were invited to do the following tasks: (a) evaluate the form, tone, suitable participants, setting, timing, and intervention team of the P-FBDT in terms of rationality, with each item rated from 0 (not all) to 5 (very much); (b) evaluate the content of P-FBDT, that is each question for children and families in the P-FBDT interview guide in terms of importance, acceptability, comprehensibility, clarity, and cultural sensitivity, with each item rated from 0 (not all) to 5 (very much); and (c) provide comments and amendments for each part of the protocol. The qualitative data meantime was obtained from participants through open-ended questions regarding the perceived benefits, challenges, and practical considerations of implementing P-FBDT in clinical practice.

Based on the participants' quantitative and qualitative feedback, the research team revised the P-FBDT protocol, which then was sent to the participants to re-evaluate. To resolve any discrepancies, at least 90.0% endorsement rates among participants for each part of the P-FBDT protocol were preferred.

Data analysis

Quantitative data entry and analysis were performed using SPSS 25.0. Descriptive statistics were used to describe the demographic

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Table 1. Demographic characteristics of the participants ($N = 14$)

Age (years)	
Range	32–58
Mean (SD)	44.93 ± 6.98
Gender	
Male	2 (14.3%)
Female	12 (85.7%)
Educational level	
Bachelor's degree	6 (42.9%)
Master's degree	7 (50.0%)
Doctor's degree	1 (7.1%)
Profession	
Physician	6 (42.9%)
Registered nurse	5 (35.7%)
Social worker	2 (14.3%)
Researcher	1 (7.1%)
Specialized fields	
Pediatric palliative care	5 (35.7%)
Pediatric oncology	9 (64.3%)
Years in specialized fields	
Range (years)	5–36
Mean (SD)	17.14 ± 11.03
The region of working	
Beijing (Northern China)	10 (71.4%)
Cangzhou (Northern China)	1 (7.1%)
Nanjing (Central China)	1 (7.1%)
Shenzhen (Southern China)	2 (14.3%)

characteristics of the participants. The data evaluating the P-FBDT protocol were described using mean and standard deviation and endorsement rate. The qualitative data were analyzed by 3 authors (JL, QG, and SC) using content analysis (Elo and Kyngäs 2008). The emerging themes were constantly compared and discussed by the whole research team until reaching a consensus.

Results

Demographic characteristics

The participants comprised 14 pediatric oncology or pediatric palliative care experts including 6 physicians, 5 registered nurses, 2 social workers, and 1 researcher. The demographic characteristics are shown in Table 1. The average score on the degree of knowledge of DT/FBDT was 4.36 ± 0.23, indicating that the participants had a decent understanding of DT/FBDT.

Quantitative evaluation of the P-FBDT protocol

Table 2 presents the endorsement rates for the rationality of the P-FBDT protocol. The endorsements of rationality for each part of the P-FBDT protocol on the first and second rounds of the survey were higher than 85.0%.

Table 3 presents the endorsement rate for each question in the P-FBDT interview guide regarding its importance, acceptability, comprehensibility, clarity, and cultural sensitivity. In the first-round survey, the endorsements of importance and acceptability for each question were higher than 85.0%. However, the comprehensibility, clarity, and cultural sensitivity of the questions for children and family regarding "special roles," and the clarity of the question for children regarding "family support" received less than 80.0% endorsements. After revising the original P-FBDT interview guide based on the feedback of participants, all items received over 90.0% endorsements in the second-round survey.

Revision of the P-FBDT protocol

Each part of the preliminary P-FBDT protocol including suitable participants, form, setting, timing, intervention team, and the P-FBDT interview guide were retained due to high endorsement rates for each item in the first-round survey. Based on the suggestions of participants, the specific statements of the P-FBDT protocol were modified. In particular, the questions in the P-FBDT interview guide regarding the topics "special roles" and "family support" were rewritten and modified based on suggestions derived from 2-round survey, to be more comprehensive, clearer, and more culturally sensitive. Table 4 shows the some participants' suggestions for the improvement of the P-FBDT interview guide. Tables 2 and 5 present the final version of the P-FBDT protocol and the P-FBDT interview guide separately.

Pediatric oncology or pediatric palliative care experts' views on P-FBDT

Three themes have emerged by analyzing qualitative input on the P-FBDT protocol from participants, including perceived benefits of P-FBDT, possible challenges, and practical considerations in implementing P-FBDT.

Perceived benefits of the P-FBDT

Facilitating dignity conservation for terminal children. Participants in this study stated that P-FBDT could offer an opportunity for terminal children to systematically speak out their inner feelings and thoughts, thus potentially helping caregivers to know their dignity-related needs and providing them with targeted dignity-conserving care.

> It could potentially help us to know the real needs of children, especially the older ones who have developed a stronger sense of dignity, thus we can try to satisfy their needs and wishes, helping them to achieve dignified death with no regret. (S2)

Enhancing emotional connections in family. Participants mentioned that P-FBDT focused on meaningful communication on inner emotions and feelings between children and family members, through which, they could feel love and support from each other, thus strengthening emotional connections in the family.

> The P-FBDT could be an effective communication prompt for children and families to exchange their feelings and love with each other, which might have been ignored, or hard to express in daily life. (S9)

Relieving family grief in bereavement. Some participants emphasized the benefits of family interactions in P-FBDT and the P-FBDT

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Table 2. Endorsement rate by participants ($N = 14$) and the final version of the P-FBDT protocol

Part	Endorsement rate for rationality (%)		The final version of the P-FBDT protocol
	In the first round	In the second round	
Suitable participants			
Children	85.7	100.0	The ones whose ages range from 7 to 18 years, are diagnosed with terminal illness, and have a life expectancy of less than 1 year.
Family members	92.9	100.0	The ones who undertake the main caring tasks and have intimate relationships with the child.
Intervention form	100.0	100.0	• A therapist-facilitated psychotherapeutic intervention centered on the child–family unit. • Both children and their families are invited together to engage in family interactions including conversations and creative activities in the therapeutic session which would be audio/video-recorded based on the participants' preferences. • Each P-FBDT session could last about 1 hour; however, the specific length and times of the therapeutic sessions depend on the physical conditions of the children and the narrative richness of conservation between the children and their family members.
			• The recorded sessions would be transcribed and edited into a generativity document. The narrations of both children and families could be co-presented under each shared topic in a singular document or the narrations of children and families could be separated into 2 documents, depending on the preferences of participants. • The final form of P-FBDT is a generativity entity, which includes a generativity document as the main body, supplemented with various memorable items such as crafts or photos if participants would provide any. • The generativity entity would be returned to children and families to preserve.
Intervention tone	100.0	100.0	The therapeutic tone of P-FBDT is empathic, nonjudgmental, mutual caring, encouraging and respectful; any tone, attitude, and behavior that may cause stigma to children in therapeutic sessions should be avoided.
Intervention setting	85.7	100.0	Where to conduct the intervention should be identified based on the preferences of children, including home, private meeting rooms, and so on, with their favorite things such as pets or flowers at present.
Intervention timing	92.9	100.0	Starting at any time after therapists establish trust relationships with children and their families.
Intervention team	85.7	100.0	The therapist can be a healthcare provider such as a physician, nurse, psychologist, social worker, or hospice volunteer, who has over 3-year experience in pediatric palliative care and has received P-FBDT training including theoretical basis, implementing procedures and skills.
Intervention content (P-FBDT interview guide)	See Table 3		See Table 4

P-FBDT = pediatric family-based dignity therapy; CQ = question for children; FQ = question for family members.
Endorsement rates for rationality were calculated by the proportion of scores above 3 (ranging from 1 to 5).

generativity entity to the family, which could help to potentially relieve family grief in bereavement.

> The love for each other they felt in the therapeutic process could potentially help the bereaved family to recover from the grief of losing a child, and the generativity entity could comfort the whole family through bereavement. (S12)

Enriching pediatric palliative care practice. Participants stated that P-FBDT is an innovative and meaningful psychological intervention in pediatric palliative care, which could provide a practical approach to satisfying the dignity-related needs of terminal children and their families.

> Dignity is the central goal of palliative care, however, there are few practical interventions to conserve the dignity of terminal children. P-FBDT with distinctive children-specific characteristics is different from DT for adults, which could enrich the practice of pediatric palliative care. (S4)

Possible challenges of implementing P-FBDT

Difficult initiation of the invention with children's families. Participants mentioned that the family is viewed as the gatekeeper for children's care. Most families in China could not entirely accept the fact that the death of their children is approaching; thus, it might be difficult to initiate discussions in P-FBDT that may involve dying- and death-related topics.

> The initiation of P-FBDT depends on the family's acceptance of the diagnosis of the child. Families tend to insist on searching for possible treatments to cure their child, even if the disease is incurable. It is hard to initiate these topics with them in such a situation. (S13)

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Table 3. Endorsement rate for original P-FBDT interview guide by participants ($N = 14$)

Topics	Questions	Endorsement rate[a] (%)					Overall endorsement rate[c] (%)
		Importance[b]	Acceptability[b]	Comprehensibility[b]	Clarity[b]	Cultural sensitivity[b]	
1. Important memories	CQ	100.0	100.0	100.0	92.9	85.7	95.7
	FQ	100.0	92.9	100.0	85.7	100.0	95.7
2. Things about yourself	CQ	100.0	100.0	85.7	92.9	92.9	94.3
	FQ	100.0	100.0	100.0	100.0	100.0	100.0
3. Special roles	CQ	85.7	85.7	71.4	64.3	64.3	74.3
	FQ	85.7	85.7	71.4	71.4	57.1	74.3
4. Merits and achievements	CQ	100.0	100.0	92.9	100.0	100.0	98.9
	FQ	100.0	100.0	100.0	100.0	92.9	98.6
5. Family support	CQ	92.9	85.7	85.7	64.3	85.7	81.4
	FQ	100.0	100.0	100.0	100.0	100.0	100.0
6. Wish list	CQ	92.9	100.0	100.0	100.0	100.0	98.6
	FQ	100.0	100.0	92.9	100.0	100.0	98.6
7. Gratitude and appreciation	CQ	100.0	92.9	100.0	92.9	92.9	95.7
	FQ	100.0	100.0	100.0	100.0	100.0	100.0
8. Apology and forgiveness	CQ	100.0	100.0	100.0	92.9	100.0	98.6
	FQ	100.0	100.0	100.0	100.0	100.0	100.0
9. Hopes and dreams	CQ/FQ	92.9	100.0	100.0	100.0	100.0	98.6
10. Suggestions for future	CQ	100.0	100.0	92.9	92.9	92.9	95.7
	FQ	100.0	100.0	100.0	100.0	100.0	100.0
11. Others	CQ	92.9	92.9	100.0	100.0	100.0	97.2
	FQ	92.9	92.9	85.7	85.7	85.7	88.6
Overall endorsement rate[d] (%)		97.0	96.3	94.2	92.2	92.9	

P-FBDT = pediatric family-based dignity therapy; CQ = question for children; FQ = question for family members.
[a]Endorsement rates for importance, acceptability, comprehensibility, clarity, and cultural sensitivity were calculated by the proportion of scores above 3 (ranging from 1 to 5).
[b]Importance: Is it easy to understand? Acceptability: Do children and their families accept to talk about this topic? Comprehensibility: Is it easy to understand for children/families? Clarity: Is it clear in expression? Cultural sensitivity: Does it confirm to the Chinese cultural expression?
[c]Overall endorsement rate refers to the average endorsement rate on importance, acceptability, comprehensibility, clarity, and cultural sensitivity of each question.
[d]Overall endorsement rate refers to the average endorsement rate on importance, acceptability, comprehensibility, clarity, and cultural sensitivity of the whole P-FBDT interview guide.

The uncertainty of the children's compliance to the intervention. Based on the participants' clinical experience, they indicated that children's compliance to P-FBDT might be varied and uncertain based on their stages of cognitive development and understanding levels.

> It is more challenging to implement P-FBDT among younger children with underdeveloped understanding; they may lack concentration during the therapeutic process. Older children may be too rebellious to cooperate with their families or therapists. (S6)

Emotional challenges of participating in P-FBDT. Participants also spoke of their emotional concerns for those participating in P-FBDT, including the children and their families, and even the therapists, as the interview could possibly evoke emotional fluctuation among them.

> The life of advanced cancer children is incomplete so they might have much regret in life. While recalling the happiness in the past, the contrast to the present sufferings may cause emotional fluctuation in children and families. (S13)

> Implementing P-FBDT might bring emotional challenges to the therapists. They may be empathetic to the sufferings of children and families, and need to maintain an intense attentiveness to cope with unexpected events during the session. (S3)

Practical considerations in implementing P-FBDT

Establishment of trust relationships between the child, family, and therapist. Participants suggested that therapists should try to establish trusting relationships with children and their families before the intervention starts, which could help to smooth the P-FBDT process.

Table 4. Suggestions for improvement to the pediatric family-based dignity therapy (P-FBDT) interview guide

Aims	Suggestions	Quotes
To improve the cultural sensitivity of questions.	The statements for some questions should be reparaphrased to be suitable for Chinese families.	• For the topic of gratitude and appreciation, it is better to invite children to express their thanks to loved ones in their ways rather than directly invite them to say "I love you", considering the introverted personality of the Chinese in family interactions. (S6) • The questions for children and family under the topics of hopes and dreams should be stated with great care, as these questions might trigger ominous thoughts under the Chinese death-taboo culture. (S4)
To increase the clarity of questions to ensure them to be easier to answer.	Using plain language and concrete expression rather than broad statements.	• The word "play a role" may be difficult to understand for children and families. It seems too formal and blunt. The specific role such as a son/daughter should be pointed out when asking the question of "special roles" in the interview. (S7) • The statement "What is your hobby?" is a little bit broad, which could be stated as "what kind of game/book/TV programme.. do you like to play/read/watch.." (S3)
To improve the comprehensibility of the questions for children.	The children's questions should be delivered using diversified, vivid expressions, and giving examples in questions.	• The question for children "what are your important memories in your life" could be replaced by such statement "What fun things have you done before.." (S9) • For the topic "things about yourself", asking "What kind of kid do you think you are" may be too ambiguous to answer; taking some examples such as "Are you a brave/kind.. kid?". (S1)

> Therapists need to build good relationships with the children and their families by accompanying and understanding them, being empathic with their emotions, and helping to meet their practical needs. (S9)

Sufficient preparations before implementing P-FBDT. Participants mentioned the significance of therapists' preparations before the intervention in terms of obtaining sufficient personal and familial information and fully relieving the physical symptoms of children.

> The therapists should communicate with the children's family to get familiar with their psychological and physical conditions, family relationships, religious beliefs, and so on, helping them to build a basic life framework for the family and make contingency plans for implementing P-FBDT. (S6)

> The precondition of implementing P-FBDT includes adequate symptoms control as physical comfort is the foundation for satisfying other needs. (S2)

Flexible use of the P-FBDT protocol in practice. Participants stated that the P-FBDT protocol for children should be flexibly used in practice based on children's developmental stages and individual preferences, including whether or how to involve the family or child in P-FBDT sessions, and how many sessions will be needed or how long a session will be lasting.

> Some adolescents are sensitive to their parents' emotions, and they may be reluctant to express themselves in the presence of their parents. In that case, therapists can interview the child alone. The forms of implementing P-FBDT could be flexible and follow the wishes of participants. (S7)

> During the P-FBDT interview, there may be a series of unexpected events such as emotional fluctuations of children or families, thus the P-FBDT session cannot be completed in 60 minutes. It is possible to conduct several times of sessions. (S3)

Discussion

The P-FBDT was developed empirically as a family-based psychotherapeutic intervention in pediatric palliative care. It involves terminally ill children and their families in a series of meaningful family interactions facilitated by therapists, and prepares a multiform generativity entity including a generativity document supplemented with various memorable items as a testimony to children's life. The P-FBDT could potentially facilitate dignity-conserving care of children, enhancing emotional connections in the family, and relieve family grief in bereavement.

The endorsement rates for the rationality of the P-FBDT protocol and the importance and acceptability of each question in the P-FBDT interview guide were over 80%, indicating that P-FBDT was highly recognized by pediatric oncology or pediatric palliative care experts as an acceptable and significant intervention for terminal children and families, and the P-FBDT interview guide could be viewed as a practical framework for the therapist to elicit family interactions in the P-FBDT session. However, it is worth noting that the statements of all questions in the interview guide should be flexibly adjusted to be easier understood by children in various developmental stages and with different personality characteristics. It is the latitude and responsibility of trained therapists to shape individualized P-FBDT sessions (Schuelke and Rubenstein 2020).

Different from adults, children usually do not accumulate enough contributions, wealth, and knowledge that could benefit others; thus, their generativity needs might lie on leaving a sign that they have ever existed in the world and being held in the memory of those left behind (Cai et al. 2023). The therapeutic process of P-FBDT involves a series of family interactions including conversations supplemented with handcrafting, photography, and other creative activities, which could help to create a lasting testimony to children's lives. Therefore, enabling the preservation of memory might be the crucial value of P-FBDT for terminal children (Chochinov and Julião 2021). Besides, the P-FBDT interview guide could serve as a communication prompt for children and their families, with which families could deepen their understanding of children's needs and preferences (Poles and Bousso 2009). Therefore, the P-FBDT was assumed to potentially improve the dignity-conserving care for terminal children, which also was mentioned by the study adapting DT for adolescents (Julião et al. 2020a). Nevertheless, whether children's dignity could be enhanced by P-FBDT still needs to be further explored from the children's perspectives.

Notably, participants emphasized the benefits of family interactions and the final generativity entity to children's families

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Table 5. The final P-FBDT interview guide

	Topics	Questions
1	Important memories	CQ: What are the funniest things that you have done? What are your favorite places you have been? FQ: What are the things you remember the most about the child?
2	Things about yourself	CQ: What kind of … (activities, toys, cartoons, books, etc.) do you like? What kind of kid you are? (namely personalities, qualities, characteristics, etc.) FQ: How do you think of the child (namely personalities, qualities, characteristics, etc.)?
3	Special roles	CQ: What roles have you undertaken in your family or school? Such as daughter/son, younger or older brother/sister, etc. As … (a certain role), what things have you done that make you and others happy or satisfied? FQ: What important roles do you think the child has undertaken in family or school? As … (a certain role), what are the meaningful and important things he/she has done for others?
4	Merits and achieve-ments	CQ: What are you good at? What things have you done that you or others are proud of? FQ: What are the merits of the child? What are the things has he/she done that you are proud of?
5	Family support	CQ: Since you were ill, how has your family (namely parents/grandparents, etc.) cared for you, and how have your siblings comforted you? FQ: How have you cared for the child since he/she became ill?
6	Wish list	C: Now make a wish. Is there anything you want to do, say, or have? F: What do you want to do or say for the child?
7	Gratitude and appreciation	CQ: Are there things about your family that you feel grateful for? How do you want to express your gratitude, such as saying, writing down or doing something for them? FQ: Are there things about the child that you feel grateful for? How do you want to express your gratitude to him/her?
8	Apology and forgiveness	CQ: Are there things that you want to apologize to your family? Are there things your family has done that make you feel wronged, and have you forgiven them for these things? FQ: Are there things that you want to apologize to the child or forgive?
9	Hopes and dreams	CQ/FQ: What are your hopes and dreams for each other?
10	Suggestions for the future	CQ: How do you want your loved ones (such as your parents, etc.) to get along with each other, and in your imagination, what is their life like in the future? FQ: What are your future plans? Is there anything you want to say to your child to make him/her feel more peaceful?
11	Others	CQ: Do you want to paint a picture/sing a song/do a craft/dance/write a few words (or anything you want to do) to your parents or other loved ones? FQ: In creating this family document, are there other things that you would like to include?

CQ = question for children; FQ = question for family members. P-FBDT = pediatric family-based dignity therapy.

extending to bereavement. Within the child–family dyad, meaningful interactions in P-FBDT allow them to construct memories, and feel love and support from each other, thus enhancing their emotional attachment, which could help the family to better prepare for the children's impending death. The everlasting memento that represents the continuing bonds between the deceased and the bereaved could be viewed as resources for the family to cope with mourning in bereavement (Akard et al. 2015). Therefore, the extensive value of P-FBDT to the family might be vital, which needs to be further explored in future studies.

A series of challenges were proposed in this study, one of which is the difficult initiation of P-FBDT due to the gatekeeper role of the family members. A Western study mentioned that parents may be reluctant to have their children think and talk about serious life situations, thus setting a barrier to initiating DT for children (Julião et al. 2020a). Similarly, Chinese family members are unwilling to talk about dying and death-related issues that P-FBDT sessions might involve due to their low acceptance for their children's impending death, since that the Chinese family tend to insist on fighting the illness of their child at any cost even in vain (Cai et al. 2020). Therefore, death education is urgently needed for Chinese families, and appropriate techniques need to be further explored to make the initiation of P-FBDT unoffensive to Chinese families. A trusting relationship between the children, families, and therapists is fundamental to meaningful therapeutic interactions, which might be helpful to initiate and smooth the P-FBDT process. Moreover, participants also mentioned the emotional concerns that conducting P-FBDT might bring to therapists, suggesting that self-care skills for coping with emotional challenges should be given particular attention in future therapist training (Lin et al. 2022a).

To the best of our knowledge, this is the first study to develop an FBDT protocol targeting the child–family dyad in pediatric palliative care. The P-FBDT mapped onto the family-centered tenet of pediatric palliative care and had the potential to benefit terminal children and families with Chinese cultural context in and outside China. However, the protocol has not been evaluated from the perspectives of terminal children and their families, which will be done in future feasibility and pilot studies. Besides, participants in this study were predominantly female, which is representative for the pediatric palliative care workforce dominated by women in China (Cai et al. 2021); however, how male perspectives could inform the study findings needs to be addressed in future studies.

Conclusions

The P-FBDT protocol is designed to facilitate meaningful interactions between terminally ill children and their families, and finally create a lasting testimony to children's lives. It was highly endorsed as a promising palliative care intervention to benefit terminal children and their families extending to bereavement. Future studies will be needed to test its feasibility and efficacy in practice.

Data availability statement. The data that support the findings of this study are securely stored under lock and key at the School of Nursing, Capital Medical University. The authors do not have permission from either the Research Ethics Board at the university or consented research participants to release or share the data; thus, they cannot make it available in the public domain.

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Resources. HL: Investigation, Data curation, Resources. SC: Investigation, Data analysis. All authors approved the final submitted manuscript and have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

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Ethical approval. This study was approved by the institutional review board at Capital Medical University (No. Z2023SY056) and was conducted in accordance with principles embodied in the Declaration of Helsinki. Each participant was given a numerical identification number (e.g. S1) to protect personal information.

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