Original Article

What we learnt from parents' death experience: A cross-sectional study of death literacy and parent's death quality among adult children in China

Xiang Li, M.A.P.[1] 🆔, Sok Leng Che, M.SC.[2] 🆔, Mingxia Zhu, PH.D.[1] 🆔 and
Wai I. Ng, PH.D.[1] 🆔

[1]Department of Education, Kiang Wu Nursing College of Macau, Macao SAR, China and [2]Nursing and Health Education Research Centre, Kiang Wu Nursing College of Macau, Macao SAR, China

Abstract

Objectives. This study aims at investigating the current status of death literacy and parent's death quality among adult children in China. A cross-sectional survey was conducted to explore the associations between death literacy and parent's death quality and to provide evidence for developing public policies for improving the quality of death and end-of-life care for the population in the Greater Bay Area (GBA) of China.

Methods. A cross-sectional design was adopted. Participants who experienced their father's and/or mother's death were recruited from 5 cities in the GBA of China in 2022. The Good Death Inventory (GDI) and the Death Literacy Index (DLI) were used to investigate the perceived quality of death of the parents of the participants and the death literacy of the participants.

Results. A total of 511 participants were recruited. Participants with higher GDI scores were positively associated with DLI scores ($p < 0.001$). Adult children who had close relationships before their parents' death also had higher levels of DLI.

Significance of results. This study investigated death literacy among bereaved adult children in China, filling a gap in the investigation of death literacy among Chinese residents. It found that parents' death experience can have a significant impact on the death literacy of adult children, which may affect their understanding and preparation for their own eventual death. Promotion of family discussion on death, development of community palliative care, and improving public death literacy are urgently needed in China.

Introduction

China's population aged 65 and over is expected to reach 487 million by 2050, accounting for nearly one-third of the country's total population (United Nations 2019). As China's population continues to age, this demographic shift has created a significant need for end-of-life care services, including hospice care, palliative care, and home-based end-of-life care. To address this issue, the Chinese government has launched several initiatives to improve end-of-life care. In 2016, the National Health and Family Planning Commission issued guidelines for the development of hospice care services, and in 2018, the Ministry of Civil Affairs announced plans to establish 1,000 hospice care facilities by 2020 (NHFPC 2017). In addition to government efforts, there has been a growing interest in end-of-life care among the general public. Recent studies conducted in China showed that the majority of people believed that palliative care and hospice care were necessary and expressed a willingness to receive such care (Leong et al. 2021; Lu et al. 2018; Zhang et al. 2022).

In 2015, a report on the quality of death index of 80 countries worldwide pointed out that the quality of death of residents in mainland China ranks 71st globally (Economist 2015). In another updated quality of death and dying survey in 2022, China ranks 53rd among 81 countries (Finkelstein et al. 2022). It can be seen that in China, general end-of-life care is underdeveloped, and the desire to achieve a good death in China is still a challenge (Lai et al. 2018; Shu et al. 2023). Another factor contributing to such a challenge is cultural attitudes toward death and dying. In traditional Chinese culture, death is often seen as a taboo. Although a good quality of death is desirable, many people are reluctant to discuss end-of-life care options. In China, "good death" is commonly understood as painless and is related to dignity and shared decision-making, which consists of practical preparation for the death and afterlife (Fu and Glasdam 2022). Accordingly, "managed pain and discomfort" was the most important indicator

of the quality of end-of-life care (Finkelstein et al. 2022). In both patients' and healthcare providers' perspective, the core elements of a "good death" consist of pain and symptoms control, clear decision-making, feeling of completeness, being treated as a person, preparation for death, and being still able to benefit others (Chen et al. 2022; Krikorian et al. 2020). However, the current situation reflects the opposite. Song and Su (2021) investigated that during the past 20 years in China, up to 89.68% of older adults received care from family members before dying, 87.31% of older adults died at home, and 37.29% of them died painfully rather than peacefully. A recent study also indicated that having control over the place of death is an indicator of a good death (Wiggins et al. 2019). It suggested that developing home and community care can optimize and support the geriatric care system, which could be beneficial to the population from the perspective of public health (Han et al. 2020).

From a family perspective, the quality of the dying process of parents has a significant impact on adult children's attitudes and preparedness toward their parents' death. Studies have found that when parents die after a prolonged illness, their adult children are more likely to have a better understanding of the dying process and to feel more prepared for their own eventual death (Gott et al. 2019). This may be because they had more time to process their emotions and to discuss end-of-life issues with their parents. A study in Japan showed that end-of-life discussions can increase patients' quality of death and help reduce depression and complicated grief in bereaved family members (Yamaguchi et al. 2017). Furthermore, the quality of care that parents receive during their dying process can also have an impact on their adult children's attitudes toward death. When parents receive compassionate and supportive care, their adult children are more likely to view death as a natural and peaceful process (Meier et al. 2016; Steinhauser et al. 2015). Death literacy was proposed to measure an individual's comprehension of end-of-life care options, which includes awareness, attitudes, values, communication skills, and medical decision-making. Leonard and colleagues found that there is a lack of awareness and communication skills related to death and dying among the Australian population (Leonard et al. 2022).

The Greater Bay Area (GBA) is a rapidly developing region in southern China that encompasses 9 cities in Guangdong province, as well as Hong Kong and Macao. It has become a hub for innovation, technology, and finance and has seen significant economic growth in recent years (Hui et al. 2020). However, the region also faces challenges related to social development, including healthcare and aging. Several recent studies have examined the development and highlighted the demand gap of palliative care in the GBA (Chung et al. 2021). Understanding the status of death literacy in the GBA can help identify gaps in current palliative care services and inform future policy decisions for the whole of China.

This study aims to investigate the current situation and relationships between death literacy and parent's death quality among adult children in the GBA and to provide evidence for developing public policies for improving the quality of death and end-of-life care for the population in the GBA of China.

Methods

Study design and participant recruitment

The study adopted a cross-sectional research design employing an anonymous online self-report survey. The participants were recruited from residents of 5 cities in the GBA of China, including Macao, Hong Kong, Guangzhou, Zhuhai, and Jiangmen, between October and November 2022. The inclusion criteria were as follows: (1) residents of those 5 cities at the time of the survey and of Chinese ethnicity; (2) aged 18–74 years; (3) whose father or/and mother was/were dead; and (4) was able to give consent and understand written Chinese. A convenient and snowball sampling method was applied via online advertisements and social media platforms such as Facebook, WhatsApp, and WeChat in the study. A detailed introduction of the study were displayed on the first page of the online questionnaire, the participants who read the introduction and met inclusive criteria were fully informed consent before starting to fill in the questionnaire. Participants were invited to forward the online questionnaire to their friends, families, and colleagues residing in the designated 5 cities. To ensure confidentiality and autonomy, data collection and analysis were conducted anonymously and without any identifying information.

Measurement instruments

The measurement instruments contained the Chinese version of Good Death Inventory (GDI) and Death Literacy Index (DLI) and sociodemographic data of participants, including age, gender, education level, marital status, religious beliefs, occupation, whether they had children or siblings, their closeness with parents, and their roles in caring for dying parents.

GDI was developed by Miyashita and colleagues and is widely used to evaluate the good death of a patient from the bereaved family member's perspective (Miyashita et al. 2008). The scale was with an internal consistency of 0.94 and reliability (Intraclass Correlation Coefficient, ICC) of 0.52. This study used the Chinese version, which was translated and validated in Taiwan (Tseng 2013). The scale consists of 54 items within 18 dimensions; each item is rated on a 7-point Likert-type scale from 1 (Completely disagree) to 7 (Completely agree); and the overall score ranges from 54 to 378. The higher scores indicate stronger agreement with the deceased parent's good death.

The DLI was originally developed by Leonard et al. (2022). The DLI consists of 4 subscales with 29 items in total, which is designed to assess levels of death literacy across multiple contexts, including at a community/national level, and to evaluate the outcome of public health interventions. Responses are on a 5-point Likert scale with scores from 1 to 5. There is no reverse coded item. Scores were calculated by summing items and scaling by the number of items in a subscale (with a range of scores between 0 and 10). The DLI was tested and validated in Australia, the United Kingdom, Turkey, and Sweden (Abacigil et al. 2019; Graham-Wisener et al. 2022; Johansson 2022; Johansson et al. 2023). The authorizations to use the GDI and the DLI in this study were obtained from the authors. In this study, we adopted the Chinese version of DLI translated by Che et al. (2023). Cronbach's alpha of the translated DLI was 0.88 for the total scale.

Statistical analysis

Analysis of the data was performed using SPSS V22.0 software. Descriptive statistics were used to understand the demographic data of the sample. Analysis of Variance (ANOVA) was used for group comparisons. Multiple linear regression was employed to examine the association between participants' characteristics, GDI, and DLI, with p-values less than 0.05 being considered statistically significant.

Table 1. Sociodemographic characteristics of participants and ANOVA of DLI (*n* = 511)

Variable	*n*	%	*M*	*SD*	*F/t*
Gender					−1.31
Male	98	19.2	6.75	1.37	
Female	413	80.8	6.95	1.38	
Age (year)					0.23
18–34	141	27.6	6.89	1.38	
35–54	243	47.6	6.89	1.44	
55–74	127	24.9	6.99	1.29	
Highest level of education					−0.81
High school or below	205	40.1	6.85	1.36	
College of above	306	59.9	6.96	1.40	
Marital status					−0.41
Married/cohabiting	325	63.6	6.90	1.37	
Single/divorced/separated/widowed	186	36.4	6.95	1.40	
Children					−0.08
Yes	330	64.6	6.92	1.39	
No	181	35.4	6.91	1.37	
Siblings					−0.80
Yes	431	84.3	6.94	1.40	
No	80	15.7	6.80	1.26	
Religion					−0.21
Yes	200	39.1	6.93	1.47	
No	311	60.9	6.91	1.33	
Income					−1.37
Below average	190	37.2	6.81	1.40	
Above average	321	62.8	6.98	1.37	
Occupation					3.95**
Medical professional and allied healthcare worker	185	36.2	7.15	1.32	1 > 3
Student	70	13.7	6.96	1.54	
Other	163	31.9	6.65	1.36	
Not working	93	18.2	6.88	1.36	
Hospitalized in the past year					−0.54
Yes	46	9.0	7.02	1.21	
No	465	91.0	6.91	1.40	
Survival status of parents					−0.33
Only one died	375	73.4	6.90	1.40	
Both parents died	136	26.6	6.95	1.33	

(Continued)

Table 1. (*Continued.*)

Variable	*n*	%	*M*	*SD*	*F/t*
Survival status of father					−1.68
Died	427	83.6	6.87	1.36	
Alive/don't know	84	16.4	7.15	1.46	
Supporter of father before death (*n* = 427)					−2.07*
Yes	143	33.5	7.06	1.38	
No	284	66.5	6.77	1.35	
Carer of father before death (*n* = 427)					−2.50*
Yes	129	30.2	7.12	1.34	
No	298	69.8	6.76	1.36	
Closeness with father before death (*n* = 427)					−4.57***
Not close/very not close/fair	162	37.9	6.49	1.28	
Close/very close	265	62.1	7.10	1.36	
Survival status of mother					1.61
Died	221	43.2	7.03	1.38	
Alive/don't know	290	56.8	6.83	1.38	
Supporter of mother before death (*n* = 221)					−1.26
Yes	97	43.9	7.16	1.42	
No	124	56.1	6.93	1.34	
Carer of mother before death (*n* = 221)					−2.96**
Yes	100	45.2	7.33	1.39	
No	121	54.8	6.78	1.32	
Closeness with mother before death (*n* = 221)					−3.33**
Not close/very not close/fair	46	20.8	6.44	1.33	
Close/very close	175	79.2	7.18	1.35	

*p < 0.05, **p < 0.01, ***p < 0.001.
ANOVA = Analysis of variance; *M* = Mean; *SD* = standard deviation.
Scaled mean ranged 1–10.

Results

Sociodemographic characteristics of participants

In this study, we received 511 respondents, and the results of their demographic data are shown in Table 1. The participants were mainly female (80.8%), aged between 35 and 54 years (47.6%), graduated from college or above (59.9%), and worked as medical professionals (36.2%). More than half of the participants were married (63.6%), and have children (64.6%) and siblings (84.3%).

Most of the participants had no religious beliefs (60.9%). A total of 375 participants (73.4%) reported that only one parent had passed away, while the remaining 136 participants (26.6%) stated that both parents had died. A large proportion of participants reported that their father died (83.8%), and 43.2% reported that their mother died. Regarding the caring role before their parents' death, about one-third of the participants reported they were financial supporters and carers before their father died, compared with about 40% before their mother's death. Most of the participants had close relationships with their parents.

The results of Analysis of Variance (ANOVA) showed that participants who had a medical professional background had significantly higher scores on DLI ($F = 3.95$, $p = 0.008$) when compared to other occupations. Furthermore, being the financial supporter ($F = -2.07$, $p = 0.04$) and carer ($F = -2.50$, $p = 0.01$) of father before his death and having a close relationship with father ($F = -4.57$, $p = < 0.001$) showed significantly higher DLI scores. While being the carer of mother before her death ($F = -2.96$, $p = 0.003$) and having a close relationship with mother ($p = -3.33$, $p = < 0.001$) also had significantly higher scores on DLI.

Results of participants' scores on GDI and DLI

This study calculated the mean (*M*) and standard deviation (*SD*) of GDI score in total and for each factor (Table 2). The mean GDI total score on father ($M = 246.14$, $SD = 45.17$) was higher than that on mother ($M = 239.47$, $SD = 44.30$). The highest mean score was on factor 9 "Be treated and respected as an independent individual" (Father: $M = 5.42$, $SD = 1.18$; Mother: $M = 5.32$, $SD = 1.16$). Whereas the lowest score was on factor 16 "Shameful" (Father: $M = 3.36$, $SD = 1.32$; Mother: $M = 3.42$, $SD = 1.32$). For the score of DLI, participants scored highest in "hands on support" under the practical knowledge subscale ($M = 7.77$, $SD = 1.98$) and scored lowest in the community knowledge subscale ($M = 6.22$, $SD = 2.28$) (Table 3).

Factors associated with participants' DLI

The results of multiple linear regression analysis revealed that DLI was significantly associated with occupation, perceived quality of the father's death, and closeness with the father before his death in individuals who had experienced the loss of their father. Participants with a non-medical-related job were 0.38 scores less than their counterparts with a medical-related job ($\beta = -0.38$, $p = 0.021$). In addition, with one score higher than the participants rated for the GDI of their father, they would have 0.01 scores higher in DLI ($p < 0.001$). Furthermore, those who had a close relationship with their father before father's death was 0.41 scores higher when compared to those who did not have close relationship with their father ($\beta = 0.41$, $p = 0.004$).

Regarding participants who experienced their mother's death, the perceived quality of the death of the mother and participants' closeness with the mother before her death were found to be associated with DLI. The DLI score would increase by 0.01 for each score higher of GDI of the mother ($p < 0.001$), and those who were close to their mother were 0.58 score higher than those who were not ($p = 0.02$). All other factors were not significantly correlated with DLI (Table 4).

Discussion

Our findings indicated that participants mostly agreed that the deceased were respected and lived peacefully with their family's

Table 2. Score of GDI of father ($n = 427$) and mother ($n = 221$)

Dimensions of GDI	Father died ($n = 427$)		Mother died ($n = 221$)	
	Mean	SD	Mean	SD
GDI total	246.14	45.17	239.47	44.30
Painless	3.97	1.75	3.78	1.76
Favourite place	4.53	1.73	4.36	1.73
Optimistic life	4.59	1.61	4.26	1.59
Trusted medical staff	4.59	1.45	4.62	1.51
Not other's burden	4.89	1.41	4.79	1.41
Family support	5.21	1.35	5.18	1.29
Physical activity independent	4.25	1.92	3.70	1.81
Live quiet without disturbance	5.17	1.44	4.98	1.48
Be treated and respected as an independent individual	5.42	1.18	5.32	1.16
Consummate life without regret	4.34	1.68	3.99	1.63
Adequate treatment	4.91	1.44	4.84	1.38
Dying naturally without over treated	4.93	1.42	4.74	1.42
Satisfied and grateful	4.78	1.37	4.67	1.34
Involved in medical decision-making	4.26	1.47	4.08	1.39
Know and think about dying	3.54	1.52	3.86	1.48
Shameful	3.36	1.32	3.42	1.32
Self-value	5.13	1.23	4.94	1.24
Belief	4.17	1.59	4.28	1.56
Average	4.56	–	4.43	–

GDI = Good Death Inventory; SD = standard deviation.

Table 3. Mean scores on DLI and its subscales

Subscales	Scaled mean	SD
Total DLI (29 items)	6.92	1.38
Practical Knowledge (8 items)	7.51	1.53
Talking support (4 items)	7.23	1.85
Hands on support (4 items)	7.80	1.97
Factual knowledge (7 items)	6.60	1.88
Experiential knowledge (5 items)	7.76	1.62
Community knowledge (9 items)	6.16	2.31
Accessing other's help (5 items)	6.25	2.41
Community support group (4 items)	6.05	2.61

DLI = Death Literacy Index; SD = standard deviation.
All scales ranged 0–10.

support. However, their deceased parents had not fully been aware of their own death and had not reflected on the coming of death before passing away. Furthermore, they had experienced physical and emotional pain before death. On the other hand, since our

Table 4. Results of multiple linear regression of DLI

Variables	Father died (n = 427)								Mother died (n = 221)							
						95% CI[a]								95% CI		
	B	SE B	β	t	p-Value	Lower	Upper	VIF[b]	B[c]	SE[d] B	β	t	p-Value	Lower	Upper	VIF
Constant	4.59	0.50		9.1153	0.00	3.60	5.58		4.80	0.72		6.7082	0.00	3.39	6.21	
Gender (ref.: Male)																
Female	0.25	0.17	0.07	1.45	0.15	−0.09	0.59	1.10	0.11	0.23	0.03	0.49	0.63	−0.34	0.56	1.16
Age (year) (ref.: 18–34)																
35–54	0.05	0.22	0.02	0.23	0.82	−0.39	0.49	3.13	−0.23	0.37	−0.08	−0.63	0.53	−0.96	0.49	4.13
55–74	0.35	0.26	0.12	1.38	0.17	−0.15	0.86	3.37	−0.09	0.38	−0.03	−0.24	0.81	−0.85	0.66	4.50
Highest Level of Education (ref.: High school or below)																
College of above	0.17	0.16	0.06	1.12	0.27	−0.13	0.48	1.50	−0.05	0.23	−0.02	−0.21	0.83	−0.50	0.40	1.63
Marital status (ref.: Married/cohabiting)																
Single/divorced/separated/widowed	−0.02	0.19	−0.01	−0.09	0.93	−0.39	0.35	2.00	−0.04	0.25	−0.02	−0.17	0.86	−0.54	0.45	1.88
Children (ref.: No)																
Yes	−0.12	0.20	−0.04	−0.59	0.56	−0.52	0.28	2.29	−0.05	0.27	−0.02	−0.20	0.84	−0.59	0.48	2.09
Siblings (ref.: No)																
Yes	0.02	0.18	0.00	0.09	0.93	−0.34	0.38	1.10	0.04	0.31	0.01	0.13	0.90	−0.58	0.66	1.28
Religion (ref.: No)																
Yes	0.05	0.13	0.02	0.39	0.70	−0.21	0.32	1.10	0.07	0.19	0.03	0.39	0.69	−0.30	0.45	1.13
Income (ref.: Below average)																
Above average	0.04	0.18	0.01	0.21	0.83	−0.31	0.38	1.81	0.24	0.25	0.09	0.99	0.32	−0.24	0.73	1.82
Occupation (ref.: Medical professionals and allied health workers)																
Student	0.14	0.33	0.03	0.42	0.67	−0.51	0.80	2.94	0.07	0.52	0.01	0.13	0.89	−0.96	1.10	2.95
Other	−0.38	0.17	−0.13	−2.31	0.02	−0.71	−0.06	1.53	−0.40	0.24	−0.14	−1.70	0.09	−0.87	0.06	1.56
Not employed	−0.21	0.22	−0.06	−0.99	0.32	−0.64	0.21	1.92	−0.19	0.29	−0.06	−0.66	0.51	−0.77	0.38	1.96
Hospitalized in the past year (ref.: yes)																
No	0.12	0.22	0.02	0.52	0.60	−0.32	0.56	1.05	−0.29	0.32	−0.06	−0.92	0.36	−0.91	0.33	1.14
GDI of father	0.01	0.00	0.22	4.56	0.00	0.00	0.01	1.07								

(Continued)

Table 4. *(Continued.)*

Variables	Father died (n = 427)					95% CI[a]		VIF[b]	Mother died (n = 221)					95% CI		VIF
	B	SE B	β	t	p-Value	Lower	Upper		B[c]	SE[d] B	β	t	p-Value	Lower	Upper	
Supporter of father (ref.: No)																
Yes	0.12	0.16	0.04	0.71	0.48	−0.21	0.44	1.51								
Carer of father (ref.: No)																
Yes	0.14	0.17	0.05	0.81	0.42	−0.20	0.47	1.51								
Closeness with father before death (ref.: Not close/very not close/fair)																
Close/very close	0.41	0.14	0.15	2.88	0.004	0.13	0.69	1.19								
GDI of mother									0.01	0.00	0.24	3.57	0.00	0.00	0.01	1.07
Supporter of mother (ref.: No)																
Yes									−0.27	0.23	−0.10	−1.18	0.24	−0.73	0.18	1.68
Carer of mother (ref.: No)																
Yes									0.44	0.24	0.16	1.85	0.07	−0.03	0.91	1.78
Closeness with mother before death (ref.: Not close/very not close/fair)																
Close/very close									0.58	0.25	0.17	2.30	0.02	0.08	1.07	1.30
R^2							0.12								0.15	
Adj. R^2							0.09								0.08	
F							3.41***								2.18**	
df							(17, 409)								(17, 203)	

**p < 0.01.
***p < 0.001.
[a]CI = Confidence Interval.
[b]VIF = Variance Inflation Factor.
[c]B = Beta.
[d]SE = Standard Error.

sample had caring experiences for dying parent, the death literacy of the participants was higher compared with the norm of Australia (Leonard et al. 2020), which targeted general community members. Participants in the current study felt most competent to provide hands-on care to dying people but lack community knowledge. Furthermore, having close relations and perceiving that parents had better death quality were associated with higher death literacy of adult children in the GBA of China.

Relationship with parents is important for death literacy

When investigating participants' evaluation of the good death of their deceased parent, our study found that they had the strongest agreement on dimensions "Be treated and respected as an independent individual," "Family support," and "Live quiet without disturbance." It aligned with the results in previous studies, which identified the importance of communication, symptom management, and emotional support in achieving a good death (Mignani et al. 2017; Smith-MacDonald et al. 2019). Recent research also showed that families with closer family relationships tend to experience a higher quality of death (Kajiwara et al. 2022), which may be due to the strong emotional bonds and support within the family. Families with close relationships may have better communication and shared meaning-making during the grieving process (Barboza et al. 2022). At the same time, patients who reported higher scores on GDI had better quality of life, symptom management, and emotional support and were more likely to die at home with their families and receive palliative care (Lee et al. 2019). Respecting and supporting parents were the key elements of filial piety under Chinese culture (Chungang 2015), which means taking others' interests into account with the aim of advancing their well-being (Voinea et al. 2022). The findings in our study also highlighted that closeness with parents is positively correlated to an individual's level of death literacy. Research has shown that families with strong parent–child relationships tend to have higher levels of death literacy among adult children after experiencing the death of their parents (Johansson et al. 2023), implying that experiencing the death of parents could be a learning process, particularly for those with close relationship with parents, in which one could develop a better understanding and acceptance of death through open communication and emotional support among family members. It can be seen that the inclusion of family support plays an essential role in achieving a good death. However, many families are not adequately prepared for the death of their loved ones, which can lead to poor quality of end-of-life care (Virdun et al. 2017).

From our results, there were far more participants who reported experiencing the death of a father (83.8%) than the death of a mother (43.2%). On the one hand, according to the National Bureau of Statistics of China, compared with 1981 and 2020, the average life expectancy at birth of Chinese males increased from 66.28 to 77.93 years, while that of Chinese females increased from 69.27 to 80.88 years, with a gender gap of 2.99–5.51 years (National Bureau of Statistics of China 2022). It can be seen that in the past few decades, Chinese males have consistently had shorter life expectancy than females, which could probably explain why a larger proportion of our participants have experienced the death of their fathers.

Discuss death in families and improve pain management is an urgent need

The items with the lowest death literacy reported by participants were "Know and think about dying" and "Painless." Although being informed about one's health condition is a basic right, families or healthcare professionals might have difficulties in discussing end-of-life issues with the dying parents of the Chinese adult children in the GBA. According to a study, only 50% of patients who died in hospitals had documented end-of-life discussions with their physicians (Teno et al. 2013), and the elderly who live in nursing homes lack opportunities to discuss their thoughts of life and preparations for death (Österlind et al. 2017). This lack of communication can lead to confusion and uncertainty about the patient's wishes and preferences. It is suggested that there is a need to improve clinicians' explanations about impending death, which could help families in preparing choice of interventions and advance care planning for patients' end-of-life care (Greenwood et al. 2018; Mori et al. 2018). Moreover, end-of-life discussions were positively associated with the quality of death (Yamaguchi et al. 2017). Healthcare providers should encourage patients and their families to have end-of-life discussions early on (Teno et al. 2013). It is suggested to develop an interview guideline and care model to facilitate the process of advance care planning for older residents in long-term care facilities and their families (Lee et al. 2019).

Meanwhile, pain management is another critical concern. Participants of this study expressed that they perceived a painless experience from the dying process of their parents. For many older people, the physical discomfort of dying may be avoidable if care is improved, and the quality of pain and symptom management are highly valued by patients and caregivers (Greenwood et al. 2018; Hughes et al. 2019). The Lancet Commission report emphasized that to alleviate the burden of pain at the end of life is a global health and equity imperative (Knaul et al. 2018). But the fact is that irrational cultural beliefs and inadequate knowledge about pain management persist at the end of life (Chakraborty et al. 2017; Chi and Demiris 2017). In a systematic review of the greater China region, up to 62.4% of patients in non-hospice settings reported pain; the prevalence of pain doubled compared with palliative care settings, and the palliative care intervention led to positive effects on pain relief (Chung et al. 2021). Scoping on the western countries, severe pain was reported in less than 1 in 5 of the studied population in Canada in the last month of life (Hagarty et al. 2020). End-of-life care in China still needs to make great efforts in pain management.

Need to develop community palliative care and improve public death literacy

In our study, participants scored the highest in practical knowledge subscale and the lowest in community knowledge subscale in DLI. Hands-on support under practical knowledge involves helping dying people with routine care, such as assisting feeding, bathing, or lifting them, whereas community support groups are community resources that can provide support to dying or bereaved persons. By comparison, the Australian population got the highest score in experiential knowledge scale and the lowest score in factual knowledge subscale, and the United Kingdom population showed lack of factual knowledge and accessing help (Graham-Wisener et al. 2022; Leonard et al. 2020). Some studies also highlighted caregivers' important role in daily care but facing an under-supported situation. Doherty et al. (2020) found that caregivers assist most in bathing, feeding, and administering medications in palliative care settings without adequate training. A study from the United States also showed that nearly half of older adults with documented challenges in bathing or toileting lack equipment to assist them (Lam et al. 2021).

Compared with the scores reported in the Australian population (Leonard et al. 2020), participants in this study had higher scores in every subscale of DLI. It may be because all participants

in this study had experienced the loss of one or both parents. Their bereavement increases the experience in dealing with death, and they might have gained a relatively higher level of death literacy. However, it is a high price to pay to gain our death literacy through the loss of our loved ones. It is important for dying patients and healthcare providers to know what options are available for end-of-life care. What is noteworthy about the results of this study is that adult children who work as "medical professional and allied healthcare worker" had significant higher score on DLI than those in other occupations. Healthcare professionals are more often exposed to death and dying in their daily work, which may contribute to their increased death coping abilities (Hayes et al. 2020; Rawlings et al. 2020). In addition, their professional training and experience may provide them with a better understanding of the healthcare system and the resources available to support end-of-life care (Kirkpatrick et al. 2019). It can be seen that the death literacy of the general public urgently needs to be improved. Practice to understand and support family needs, such as support for family decision-making, is essential for high-quality end-of-life care (Bloomer et al. 2022; Ramos et al. 2016). Most importantly, death literacy should be developed prior to the deaths of people and their loved ones and to improve the quality of death that will occur. This study found that it remains an important public health issue to develop sufficient end-of-life care services and education in the community and improve public awareness and accessibility of palliative care.

Regarding limitation, this study primarily examined the impact of experiencing parental death on one's own death literature, and therefore did not investigate factors that predict the quality of a parent's death. As the GDI was collected retrospectively from the participants and the death of participants' parent(s) occurred across different time periods, there may be recall bias among the participants when they reported on their parent's dying experience. In future studies, it will be of great practical significance to examine the perceived quality of death of parents of recently bereaved family caregivers and explore the factors that affect the death quality.

Conclusion

This study investigated death literacy among bereaved adult children in China. The result showed that they were confident with hands-on care but had inadequate access to community support resources. Positive bereavement experience, a good parent–child relationship, and holding a caring role before the death of parents had significant influence on one's death literacy. On the whole, in response to a rapidly aging population, focusing on the development of community palliative care, strengthening public education on death literacy, and making good use of end-of-life care resources are essential to improve the quality of death of the people.

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