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Resilience and coping styles in family caregivers of terminally ill patients: A cross-sectional survey

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Abstract

Objectives. Coping styles can be improved by dyadic palliative care interventions and may alleviate patients' and family caregivers' distress. Moreover, family caregivers' preloss resilience protects against depression after bereavement. This study aimed to determine the types of coping styles can be encouraged to increase resilience.

Methods. A self-reported questionnaire survey was administered to family caregivers at the 4 palliative care units, and their resilience was assessed using the Connor–Davidson Resilience Scale (CD-RISC) and their coping styles were assessed using the Brief Coping Orientation to Problem Experienced, as well as their background characteristics.

Results. Among 291 caregivers with a mean CD-RISC score of 56.2 (standard deviation: 16.13), internal locus of control, educational level, and history of psychotropic drug use were associated with resilience. After adjusting for the aforementioned factors, more frequent use of positive coping styles such as active coping (Spearman's $\rho = 0.29$), acceptance ($\rho = 0.29$), positive reframing ($\rho = 0.29$), planning ($\rho = 0.24$), and humor ($\rho = 0.18$), was found to be associated with higher resilience. On the contrary, more frequent use of negative coping styles such as behavioral disengagement ($\rho = -0.38$), self-blame ($\rho = -0.27$), and denial ($\rho = -0.14$) was found to be associated with less resilience.

Significance of results. By assessing internal locus of control, educational level, and history of psychotropic medication use of family caregivers, as factors associated with their respective resilience, may help identify less resilient family caregivers who are at risk for developing major depression after bereavement. In addition, coping skill-based educational interventions targeting patients and their family caregivers that focus on specific coping styles associated with resilience may increase family caregivers' resilience, resulting in less emotional distress and a lower risk of major depression after bereavement.

Introduction

Family caregivers have experienced a variety of emotional distresses throughout the illness trajectory of patients with advanced cancer and the dying process. Previous studies reported that family caregivers of patients with advanced cancer had more health problems and psychological distress (Choi et al. 2016; Emanuel et al. 2000; Garrido and Prigerson 2014; Hudson et al. 2011; King et al. 2013; Latham and Prigerson 2004; Song et al. 2011; Tomarken et al. 2008; Utne et al. 2013). In Japan, 41–47% of family caregivers of patients with cancer in palliative care units (PCUs) had depressive symptoms severe enough to warrant a diagnosis of a major depressive disorder (Sachida et al. 2016; Shimizu et al. 2022).

Coping supports are important in palliative care practice because they improve quality of life (QoL) and depression (Greer et al. 2020, 2018; Nipp et al. 2016a). Furthermore, these supports are available not only to patients but also to family caregivers (Greer et al. 2020; Nipp et al. 2016b). To cope with stressful situations, patients with advanced cancer and family caregivers use a variety of coping styles with various outcomes, including QoL, depressive and anxiety symptoms, and illness understanding (Greer et al. 2020). Some coping styles contribute to positive outcomes, while others do not (Greer et al. 2020). In the early palliative care interventions,



Figure 1. The research framework of this study. (1) (von Heymann-horan et al. 2019); (Northouse et al. 2013) (2) (Shimizu et al. 2022)

the use of adaptive coping styles is encouraged, which improves outcomes such as QoL and depression (Greer et al. 2020). Furthermore, family caregivers' coping styles are important, as patients' and family caregivers' coping styles influence each other's outcomes (Greer et al. 2020; Nipp et al. 2016b). Therefore, it is important to consider which types of coping are appropriate to encourage in order to alleviate the distress of family caregivers.

Resilience is an important concept related to coping styles in stressful situations. It is the dynamic capacity of an individual to maintain or regain mental health following a stressful or traumatic experience (Rutter 1993). Factors related to resilience among the caregivers of patients with cancer include caregivers' social support (Chen et al. 2021; 2020; Hwang et al. 2018), caregivers' family function (Hwang et al. 2018; Wang et al. 2021), patients' performance (Chen et al. 2020; Hwang et al. 2018), caregivers' age (Simpson et al. 2015), caregivers' health status (Hwang et al. 2018), caregivers' self-esteem (Hwang et al. 2018), caregivers religious (Krok et al. 2021), caregivers hope (Krok et al. 2021), caregivers positive/negative affect (Krok et al. 2021), patients age (Chen et al. 2020), caregivers level of education (Chen et al. 2020), and caregivers financial problem (Hwang et al. 2018).

In a previous study, we found that higher preloss resilience reduced the impact of preloss emotional distress on bereavement outcomes, such as complicated grief and depression (Shimizu et al. 2022). In general, adaptive coping styles are associated with higher resilience (Connor and Davidson 2003; Haglund et al. 2007; Southwick et al. 2014; Southwick and Charney 2018; Stewart and Yuen 2011). Therefore, enhancing resilience by providing support that encourages specific coping styles may help alleviate emotional distress. Adaptive coping is positively correlated with higher resilience in medical students (Beg et al. 2024), in patients with breast cancer (Wu et al. 2016), in primary caregivers of patients with schizophrenic (Wu et al. 2021), in caregivers of patients with hematopoietic stem cell transplantation (Luo et al. 2020), and in cancer survivor couples (Lim et al. 2014), while avoidant and emotionally focused coping is negatively correlated with lower resilience in medical students (Beg et al. 2024). To the best of our knowledge, no reports have identified an association between resilience and specific coping in family caregivers of terminally ill patients with cancer. Therefore, the relationship between resilience and coping style needs to be clarified. The research framework we developed is shown in Fig. 1.

The aims of this study were to investigate the relationship between resilience and coping styles in family caregivers of terminally ill patients with cancer.

Methods

This is a cross-sectional questionnaire survey of family caregivers of terminally ill patients with cancer who treated in 4 PCUs from December 2016 to January 2018. The participants served as the baseline for the cohort study to determine the impact of preloss resilience on changes in depression before and after bereavement (Shimizu et al. 2022).

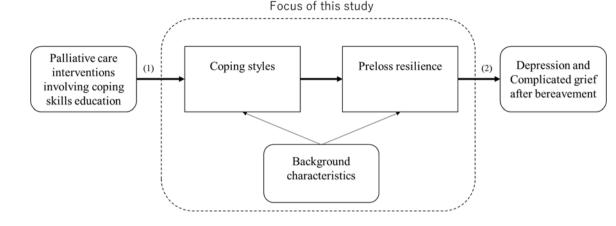
Participants and procedure

Primary family caregivers of terminally ill patients with cancer who were admitted to 1 of the 4 Japanese PCUs were eligible to participate. The inclusion criteria were as follows: (1) primary family caregivers, who responded to be the family member most involved in the patient's care during the last few weeks of life; (2) patients and family caregivers aged 20 years or older; and (3) patients admitted to the PCUs before January 29, 2018. The exclusion criteria were as follows: (a) family caregivers who were considered unfit to participate in the study by the primary physician due to serious psychological symptoms; (b) family caregivers unable to complete the self-report questionnaire due to linguistic and health issues (e.g., cognitive impairment or visual deficit); and (c) a length of stay of <48 h. All participants provided written informed consent prior to study inclusion. They were asked to return their completed questionnaires to the research office *via* mail.

The study was approved by the institutional review boards of Tohoku University School of Medicine (IRB approval ID: 2016-1-409, 2017-2-236-1) and all participating institutions (St. Luke's International Hospital, Gratia Hospital, and National Cancer Center).

Measurements

The questionnaire was developed based on a literature review and several multidisciplinary focus group discussions with nurses, psychologists, psychiatrists, and researchers, followed by cognitive interviews with the 10 participants after they completed the questionnaire.



Resilience: Connor-Davidson Resilience Scale-25

The 25-item Connor–Davidson Resilience Scale (CD-RISC) (Connor and Davidson 2003; Ito et al. 2010) is a widely used scale in which each item was rated on a 5-point Likert scale ranging from "0" (not true at all) to "4" (true nearly all of the time); the higher the scores, the greater the resilience (range, 0–100). The scale was rated based on how the respondent felt about functions, such as: "Able to adapt to change," "Can deal with whatever comes," "See the humorous side of things," in the previous month (Connor and Davidson 2003). This scale, as well as its Japanese version, has been proven to be reliable and valid (Connor and Davidson 2003; Ito et al. 2010). Cronbach's alpha coefficient is 0.95 for general and 0.90 for university students in Ito et al.'s study (Ito et al. 2010).

Coping styles: Brief Coping Orientation to Problem Experienced

The Brief Coping Orientation to Problem Experienced (B-COPE) is a 28-item questionnaire that assesses 14 conceptually different coping styles: active coping, planning, positive reframing, acceptance, humor, religion, emotional support use, instrumental support use, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame (Carver 1997; Otsuka et al. 2008). Each coping subscale consists of 2 items on a 4-point Likert-type scale ranging from "1" (I haven't been doing this at all) to "4" (I have been doing this a lot). This scale, as well as its Japanese version, has been proven to be reliable and valid (Carver 1997; Carver et al. 1989; Otsuka et al. 2008).

Locus of control: Health locus of control scale

From the existing Japanese version of the Health Locus of Control Scale (Horike 1991), 1 item related to the chance locus of control, 1 item related to the God locus of control, which means attribution to God, Buddha, and other deities, and 1 item related to an internal locus of control were extracted and used. Specifically, the following questions were asked: "Do you think you are lucky to be in good health?"; "Do you think that if you make offerings to God and Buddha and ask for their protection, they will protect you from illness?"; and "Do you think it depends on your own efforts whether your illness gets better or not?" and they were rated on a 4-point Likert scale ranging from "1" (disagree) to "4" (agree). Higher scores indicate a proclivity to attribute to the relevant locus of control.

Family caregivers' characteristics

Participants were asked to provide their own sociodemographic information such as age, sex, relationship with the patient (partners, children, etc.), whether they lived with the patient, educational level, religious belief, frequency of worship or visiting religious places, belief about staying with them in the patient's spirit after bereavement, whether he or she lived with the patient, attendance frequency, history of psychotropic drug use, and history of psychiatric visits and perceived social support (feelings of being loved and cared for and perception that their concerns or problems are being recognized). Participants were also asked to provide the patient's background characteristics, such as age, sex, primary tumor site, time intervals since cancer diagnosis, number of people living with the patient, marital status, and household income.

Statistical analysis

First, descriptive analyses of demographic characteristics, individual resilience degree as assessed by the CD-RISC, and frequency of use of each coping style as assessed by the B-COPE were performed. Next, to clarify factors associated with resilience among family caregivers of terminally ill patients with cancer, Spearman's rank correlation coefficients were calculated for each item on the CD-RISC total score, including family caregivers' characteristics and the health locus of control. Furthermore, to identify coping styles that family caregivers with higher resilience tended to use, Spearman's rank correlation coefficients for resilience and coping styles were calculated. After that, the partial Spearman's rank correlation coefficient was calculated and adjusted for the factors that were significantly correlated with resilience. All analyses were performed using the statistical package SAS, Version 9.4 (SAS Institute Inc., Cary, NC). The significance level was set to a *p*-value of <0.05 (2-tailed).

Results

Of the 417 family caregivers who met the selection criteria, the questionnaires were distributed to 317 caregivers (76.9%) who provided consent, and 291 of them (69.8%) were returned (Fig. 2). Table 1 summarizes the background data of the patients and their family members.

Resilience among family caregivers and its association with other factors

The mean CD-RISC score was 56.2 (standard deviation: 16.13). In correlation analyses (Table 2), higher resilience was associated with an internal locus of control (Spearman's $\rho = 0.13$, p = 0.035), higher educational levels ($\rho = 0.13$, p = 0.039), and no history of psychotropic drug use ($\rho = -0.13$, p = 0.041).

Relationship between resilience and coping styles among family caregivers

As summarized in Table 3, the higher resilience was associated with more frequent use of some positive coping styles such as active coping ($\rho = 0.29$, p < 0.001, adjusted p < 0.001), acceptance ($\rho = 0.29$, p < 0.001, adjusted p < 0.001), positive reframing ($\rho = 0.29$, p < 0.001, adjusted p < 0.001), planning ($\rho = 0.24$, p < 0.001, adjusted p < 0.001), and humor ($\rho = 0.18$, p = 0.003, adjusted p = 0.001). The higher resilience was associated with less frequent use of negative coping styles such as behavioral disengagement ($\rho = -0.38$, p < 0.001, adjusted p < 0.001), and denial ($\rho = -0.14$, p = 0.029, adjusted p = 0.015).

Discussion

In this study, we identified factors associated with resilience in family caregivers of terminally ill patients with cancer and found that those who used positive coping styles such as active coping, acceptance, positive reframing, planning, and humor were more resilient, while those who used negative coping styles such as behavioral disengagement, self-blame, and denial were less resilient.

A higher internal locus of control was associated with greater resilience. People with a high internal locus of control attribute

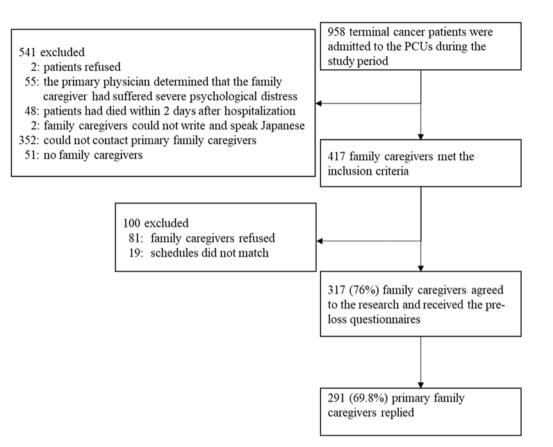


Figure 2. Study flow chart of family caregivers of patients with cancer.

their current situation and the causes of events that occur to their own abilities and efforts, which lead to proactive problemsolving coping with subsequent higher learning ability, stress tolerance, and resilience (Brosschot et al. 1994; Rotter 1966). We also found that higher educational levels were associated with greater resilience, as previously reported in qualitative studies (Giesbrecht et al. 2015). Higher educational levels may be related to socioeconomic backgrounds because students with higher socioeconomic status tend to get better educational achievement (Thomson 2018). Further studies are required to determine whether educational levels, socioeconomic backgrounds, or both associate with resilience. In this study, family caregivers with a history of psychotropic drug use had relatively low resilience, which may be due to the fact that those with lower resilience are more likely to develop mental problems (Hu et al. 2015).

Among family caregivers of terminally ill patients with cancer, those who frequently used active coping, acceptance, positive reframing, planning, and humor were more resilient, while those who frequently used behavioral disengagement, self-blame, and denial were less resilient. Greer et al. found that early palliative care interventions significantly increased patients' use of approach-oriented coping styles such as active coping, positive reframing, and acceptance, while slightly reducing their use of avoidant coping styles such as denial and self-blame (Greer et al. 2020). In addition, Northouse et al. and von Heymann-Horan et al. found that specialized palliative care intervention associates with dyadic coping styles (Northouse et al. 2013; von Heymann-horan et al. 2019). Thus, palliative intervention involving coping skill education for patients and family caregivers may increase family caregivers' use of effective coping styles while decreasing their use of ineffective coping styles. Because the current study found an association between resilience and the coping described above, palliative care interventions may improve coping and thus increase resilience. Rosenberg et al. reported the effects of skill-based educational interventions involving coping skills on resilience and psychological outcomes in children, adolescents, or young adults with serious illnesses (Rosenberg et al. 2018, 2015). Resilience is thought to be more likely to develop at younger ages when neural plasticity is higher, (Haglund et al. 2007; Southwick and Charney 2018) and it is unclear whether it can be adapted in older subjects. Previous studies have reported that resilience mediated the relationship between positive coping styles and post-traumatic growth (PTG) in family caregivers of patients with schizophrenia (Wu et al. 2021) and those of patients with hematopoietic stem cell transplantation (Luo et al. 2020). Thus, a palliative intervention that educates patients and family caregivers about coping skills may promote their PTG through positive coping and resilience.

Study limitations

The current study has several limitations. First, the participants were recruited from 4 PCUs, which are member facilities of the Japanese Hospice Palliative Care; therefore, the findings may not represent the entire population. Second, because of the risk of harm, potential participants who were unable to complete the survey due to extremely severe mental conditions were excluded, which may influence the results. Third, a limitation of the cross-sectional design must be considered while interpreting the causality of the present results.

Table 1. Characteristics of patients and family caregivers

Patients, n		291	
Age, years	Mean (SD)	71.5	(12.3)
Sex, n (%)	Male	153	(52.9)
	Female	136	(47.1)
Primay tumor sites, <i>n</i> (%)	Lungs	55	(18.9)
	Pancreas, liver, or bile duct	57	(19.6)
	Stomach or esophagus	39	(13.4)
	Colon or rectum	40	(13.7)
	Head and neck	16	(5.5)
	Uterus or ovary	14	(4.8)
	Breast	27	(9.3)
	Kidney or bladder	10	(3.4)
	Hematologic malignancy	5	(1.7)
	Other	28	(9.6
Time interval between cancer	\geq 3 years	91	(31.8
diagnosis and study, n (%)	\geq 1 year and $<$ 3 years	94	(32.9)
	\geq 6 months and $<$ 1 year	38	(13.3)
	\geq 3 months and $<$ 6 months	23	(8.0)
	<3 months	40	(14.0
Number of people	No	65	(22.4
cohabitating in the same household, <i>n</i> (%)	One	111	(38.3
	Two or more	114	(39.3
Marital status, n (%)	Married	203	(70.5
	Unmarried	20	(8.9
	Widowhood	45	(15.6
	Divorced	20	(6.9
Household income, n (%)	<1 million yen	27	(9.9
	≥1 million yen and < 2 million yen	45	(16.5)
	\geq 2 million yen and < 4 million yen	95	(34.8
	\geq 4 million yen and $<$ 6 million yen	50	(18.3
	≥6 million yen and < 8 million yen	32	(11.7
	\geq 8 million yen	24	(8.8)
Family caregivers, n		291	
Age, years	Mean (SD)	59.8	(13.7)
Sex, n (%)	Male	72	(25.1)
	Female	215	(74.9)

Table 1. (Continued.)

Patients, n		291	
,	Partner	139	(48.4)
Relationship, n (%)	Child	139	
		22	(36.2)
	Sibling		(7.7)
	Son- or daughter-in- law	7	(2.4)
	Parent	7	(2.4)
	Other	8	(2.8)
Whether caregiver lives with the patient, <i>n</i> (%)	I lived with the patient	197	(68.6)
	I did not live with the patient	90	(31.4)
Educational level, <i>n</i> (%)	Elementary to junior high school	21	(7.4)
	Middle school to high school	95	(33.6)
	College or vocational school	82	(29.0)
	University	77	(27.2)
	Graduate school	8	(2.8)
Attendance frequency, n (%)	Everyday	167	(58.8)
	Within 4–6 days/week	60	(21.1)
	Within 1–3 days/week	45	(15.9)
	Not at all	12	(4.2)
Person who attended to the	Presence	197	(68.9)
patient in turn, <i>n</i> (%)	Absence	89	(31.1)
Religious belief, n (%)	None	146	(52.1)
	Buddhism	104	(37.1)
	Christianity	10	(3.6)
	Shinto	6	(2.1)
	Other	14	(5.0)
Frequency of worship or	Regularly	36	(12.7)
visiting religious places, n (%)	Sometimes	135	(47.5)
	Rarely	79	(27.8)
	Never	34	(12.0)
History of psychotropic drug	Never	247	(86.4)
use, n (%)	Yes	39	(13.6)
History of psychiatric visits,	Never	253	(88.8)
n (%)	Yes	32	(11.2)
How much do the people	A great deal	88	(30.7)
around you make you feel loved and cared for? <i>n</i> (%)	Quite a bit	115	(40.1)
	Somewhat	76	(26.5)
	A little	7	(2.4)
	Not at all	1	(0.4)
		((Continued

Table 1. (Continued.)

Patients, n		291	
How willing are people to listen when you need to talk about your worries or problems? <i>n</i> (%)	A great deal	90	(31.4)
	Quite a bit	108	(37.6)
	Somewhat	79	(27.5)
	A little	9	(3.1)
	Not at all	1	(0.4)
Do your loved ones stay with	Strongly agree	92	(32.4)
you in spirit after death? n (%)	Agree a little	94	(33.1)
	Disagree a little	63	(22.2)
	Strongly disagree	35	(12.3)
God LOC: The perception	Strongly agree	27	(9.5)
that good health is attributed to offerings to gods, <i>n</i> (%)	Agree a little	102	(35.9)
	Disagree a little	89	(31.3)
	Strongly disagree	66	(23.2)
Chance LOC: The perception	Strongly agree	44	(15.4)
that good health is attributed to a chance factor, <i>n</i> (%)	Agree a little	108	(37.9)
	Disagree a little	85	(29.8)
	Strongly disagree	48	(16.8)
Internal LOC: The perception	Strongly agree	34	(11.9)
that good health is attributed to their own effort, <i>n</i> (%)	Agree a little	125	(43.9)
	Disagree a little	100	(35.1)
	Strongly disagree	26	(9.1)
CD-RISC; <i>n</i> = 285	Mean (SD)	56.2	(16.1)
B-COPE; <i>n</i> = 285			
Active coping	Mean (SD)	5.7	(1.1)
Planning	Mean (SD)	5.7	(1.3)
Positive reframing	Mean (SD)	5.3	(1.2)
Acceptance	Mean (SD)	6.1	(1.0)
Humor	Mean (SD)	3.8	(1.3)
Religion	Mean (SD)	3.7	(1.5)
Emotional support use	Mean (SD)	4.9	(1.5)
Instrumental support use	Mean (SD)	5.1	(1.4)
Self-distraction	Mean (SD)	4.7	(1.3)
Denial	Mean (SD)	3.2	(1.2)
Venting	Mean (SD)	4.3	(1.3)
Substance use	Mean (SD)	3.1	(1.6)
Behavioral disengagement	Mean (SD)	3.6	(1.1)
Self-blame	Mean (SD)	4.1	(1.3)

B-COPE, Brief Coping Orientation to Problem Experienced; CD-RISC, ConnorDavidson Resilience Scale-25; LOC, locus of control; SD, standard deviation.

Clinical implications

Among family caregivers of terminally ill patients with cancer, internal locus of control, educational level, and history of
 Table 2. Results of the correlation analysis between resilience and background characteristics

		ρ	p
Age, years	262	-0.04	0.475
Gender	262	-0.05	0.421
Education level, <i>n</i> (%)	259	0.13	0.039
Religious belief, n (%)	256	-0.06	0.365
Frequency of worship or visiting religious places, <i>n</i> (%)	259	-0.03	0.630
Do your loved ones stay with you in spirit after death? n (%)	260	-0.07	0.273
History of psychotropic drug use, n (%)	261	-0.13	0.041
History of psychiatric visits, n (%)	260	-0.08	0.220
Internal LOC: The perception that good health is attributed to their own effort, n (%)	261	0.13	0.035
External LOC: The perception that good health is attributed to a chance factor, n (%)	260	-0.08	0.193
External LOC: The perception that good health is attributed to offerings to Gods, n (%)	260	-0.08	0.178

 $\rho = \mbox{Spearman's rank}$ correlation coefficient.

LOC, locus of control.

Table 3. Results of the correlation analysis between resilience and coping styles

		Crude		Partial
Coping style	n	ρ	р	p
Active coping	263	0.294	<0.001	< 0.001
Acceptance	261	0.288	<0.001	< 0.001
Positive reframing	260	0.286	<0.001	< 0.001
Planning	261	0.237	<0.001	< 0.001
Humor	261	0.184	0.003	0.001
Behavioral disengagement	261	-0.377	<0.001	< 0.001
Self-blame	261	-0.271	<0.001	< 0.001
Denial	261	-0.136	0.029	0.015
Substance use	263	0.053	0.393	0.583
Instrumental support use	262	-0.036	0.56	0.419
Emotional support use	263	0.047	0.445	0.814
Self-distraction	263	0.032	0.609	0.775
Venting	261	0.011	0.865	0.946
Religion	261	0.005	0.934	0.962

Partial correlation coefficients adjusted for educational level, history of psychotropic drug use, and internal locus of control.

 $\rho=\mbox{Spearman's rank}$ correlation coefficient.

psychotropic drug use were associated with resilience. Assessing these factors may help to identify family caregivers with lower resilience who are at risk of developing major depression after bereavement.

In addition, coping skill-based educational interventions targeting patients and their family caregivers that focus on specific coping styles associated with resilience may increase family caregivers' resilience, resulting in less emotional distress and a lower risk of major depression after bereavement. Further research on the mechanisms in this area is needed.

Conclusion

Among family caregivers of terminally ill patients with cancer, we identified factors associated with resilience and found that those who used positive coping styles such as active coping, acceptance, positive reframing, planning, and humor were more resilient, while those who used negative coping styles such as behavioral disengagement, self-blame, and denial were less resilient. To increase resilience, dyadic palliative care interventions focused on coping skill education may be needed.

Data availability statement. The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Competing interests. The authors declare none.

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