ORIGINAL ARTICLE

Resilience, preparedness, and distress among family caregivers of patients with advanced cancer

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Abstract

Objective Resilience has been proposed as a primary factor in how many family caregivers of patients with advanced cancer are able to resist psychological strain and perform effectively in the role while bearing a high load of caregiving tasks. To evaluate this hypothesis, we examined whether self-perceived resilience is associated with distress (anxiety and depressive symptoms), caregiver preparedness, and readiness for surrogate decision-making among a racially diverse sample of family caregivers of patients with newly diagnosed advanced cancer.

Methods Secondary analysis of baseline data from two small-scale, pilot clinical trials that both recruited family caregivers of patients with newly diagnosed advanced cancer. Using multivariable linear regression, we analyzed relationships of resilience as a predictor of mood, caregiving preparedness, and readiness for surrogate decision-making, controlling for sociodemographics.

Results Caregiver participants ($N = 112$) were mean 56 years of age and mostly female (76%), the patient's spouse/partner (52%), and White (56%) or African-American/Black (43%). After controlling for demographics, standardized results indicated that higher resilience was relevantly associated with higher caregiver preparedness (beta $= .46$, $p < .001$), higher readiness for surrogate decision-making (beta $= .20$, $p < .05$) and lower anxiety (beta $= -.19$, $p < .05$), and depressive symptoms (beta $= -.20$, $p < .05$).

Conclusions These results suggest that resilience may be critical to caregivers' abilities to manage stress, be effective sources of support to patients, and feel ready to make future medical decisions on behalf of patients. Future work should explore and clinicians should consider whether resilience can be enhanced in cancer caregivers to optimize their well-being and ability to perform in the caregiving and surrogate decision-making roles.

Keywords Family caregiving · Cancer · Resilience · Decision-making · Distress

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Introduction

The role of an unpaid family caregiver to a relative or close friend with advanced cancer is among the life circumstances that can challenge an individual's capacity to manage stress and perform under high pressure. Of the nearly 600,000 people who die from advanced cancer every year [1], most have been cared for by family caregivers who provided daily physical, emotional, and psychological support and complex medical care [2]. Family caregivers of individuals with advanced cancers perform numerous daily tasks to help support their relatives' day-to-day living and provide medical care for an average of 8 h per day [3], such as assisting with activities of daily living, coordinating care, and managing

the patient's medications and symptoms [2]. Performing these tasks can be taxing on a caregiver's mental health, as studies have reported this population experiencing high rates of anxiety and depression [4, 5]. Risks to a caregiver's mental health can be additionally heightened as patients approach the end of life and need medical decisions made on their behalf, especially if patients become unable to make decisions for themselves. Up to a third of family caregivers acting in this surrogate decision-making role experience post-traumatic stress months to years after the death of the patient [6]. Clearly, the family caregiving experience in the setting of advanced cancer from diagnosis to death and thereafter is suffused with numerous major life stressors that test an individual's ability to cope and maintain well-being.

Yet, many cancer family caregivers resist mental and physical strain while bearing a high objective load of caregiving tasks and mental and psychological challenges [7]. Studies in cancer and other caregiving populations, such as dementia and pediatric cancer, have proposed that one of the primary factors in these circumstances is resilience [8, 9]. Resilience is generally defined by the American Psychological Association [10] as the process of adapting well in the face of adversity, thus implying a relative state of well-being and ability to resist the negative effects of stress. However, coming to a consensus on finer definitions of resilience has been notably difficult [11, 12]. For example, resilience has been variously described as a relatively invariable set of innate personality characteristics; as a group of adaptive emotional, cognitive, and social coping resources; as the presence of a relatively positive physical or psychosocial outcome after a particular adversity; as the neurobiological response of an individual's central and peripheral nervous system; and as a multisystem, interactive process that spans the biological to the ecological system's level [9, 11, 13, 14]. While these and other conceptualizations highlight the diverse frameworks grounding resilience, existing conceptualizations inconsistently account for the domain-specific role that resilience might have on a family member's ability to perform in the caregiving role while facing numerous stressors, including acting as a surrogate decision-maker. Further, many fail to consider a caregiver's self-perception of their resilience, which can inform personal appraisals of stressors and one's ability to cope with them, thereby influencing one's emotions, mood, and behavior [15, 16].

We measured self-perceived resilience using the 10-item Connor-Davidson Resilience Scale (CD-RISC 10) [17, 18], defined by the developers as "positive adaptation in the face of stress or trauma." Two primary factors have been identified via factor analysis in the CD-RISC 10 that reflect respondents' self-perceptions of their resilience [17]. The first, *hardiness*, consists of items that refer to one's beliefs about their ability to cope with change, unexpected events, illness/injury/hardship, pressure, failure, and unpleasant feelings as well as using humor to cope with problems and seeing oneself as a strong person. The second, *persistence*, includes items asking about how one believes they give their best effort, achieve goals despite obstacles, and do not give up. Evident from the CD-RISC 10 items is the focus on an individual's beliefs about themselves and their self-perceived behavior under stress. These mental representations about one's resilience may inform appraisals of stressors, including potential future stressors one has not yet faced (as in the family caregiver's case of appraising potential future decisions about someone else's medical care) [15, 16]. These appraisals may consequentially affect actual coping behaviors in a live situation in the context of serious illness [19]. In the case of an individual perceiving themselves as highly resilient when faced with challenges, active coping strategies may be employed in response to these beliefs. Active coping strategies directly seek to alter or reframe the stressor in a way that promotes well-being in contrast to avoidant coping strategies that lead one to avoid or deny threatening stressors, thereby allowing stressors to persist in exerting negative effects [20].

In the context of cancer caregiving, an individual believing that they are resilient may exert more active coping towards both preparing for and executing caregiving tasks and challenging situations, such as effectively managing medications, monitoring a care recipient's symptoms, and coordinating care. They may be more actively engaged in communicating and problem solving with patients and their healthcare team. Caregivers who identify as resilient may also perceive potential future care tasks and decisions in a distinct way. Emerging frameworks of decision-making conceive of it as a health behavior process where decision behaviors (e.g., information seeking, leveraging social support, managing uncertainty) conform to a deliberation process that mentally projects a variety of potential future outcome scenarios based on options chosen [21, 22]. These mental projections consider a range of resilience-based beliefs about the individual themselves, including their self-perceived capacity to absorb, adapt, and recover from the process and/or outcomes of a decision as well as the maintenance of their self-concept/identity and relationships. Confidence in one's resilience in these future scenarios may also factor into one's present ability and motivation to pursue advance care planning for these future decisions (i.e., engaging with others in conversations about their values and preferences for future medical treatments) and to prepare for other potential caregiving tasks and situations.

Based on this proposed conceptual understanding of how resilience may factor into the context of cancer caregiving, the purpose of this study was to examine whether self-perceived resilience is associated with preparedness for caregiving and readiness for future decision-making. We also wanted to explore whether resilience was associated with caregivers'

level of distress. We hypothesized that higher resilience among caregivers would be associated with higher caregiving preparedness and readiness for future decision-making and with lower distress. The rationale for this analysis was that results could inform whether resilience might be a promising target of interventions to enhance outcomes for patients and families affected by advanced cancer.

Methods

This was a secondary analysis of baseline data from two small-scale, pilot clinical trials that both recruited family caregivers of patients with newly diagnosed advanced cancer (NCT03464188 and NCT03947606) [23, 24]. In both trials, family caregiver participants were identified and recruited in the outpatient oncology clinic of a large academic medical center and comprehensive cancer center. Participants in this analysis were recruited between October 2018 and September 2020, and completed questionnaires over the phone or by mail that assessed demographics, clinical data about their care recipients, self-perceived resilience, preparedness for caregiving, readiness for future surrogate decision-making, and distress. All study procedures were approved by the Institutional Review Board of the University of Alabama at Birmingham (IRB Protocol Numbers: 300000979 and 300003601). Informed consent was obtained from all participants.

Participants

The combined sample from both trials totaled 112 family caregivers defined as a close friend or relative 21 years of age or older who knows the patient well and is involved in medical care due to their cancer. Eligibility criteria for both trials further stipulated that the individual did not have to live with the patient and was not paid for their support. In both trials, patients of these family caregivers had to be 18 years of age or older and newly diagnosed within the past 60 days of initial screening with an advanced cancer, defined as metastatic and/or recurrent/progressive stage III or IV cancer. Patients were excluded (and by consequence, their family caregivers) if they had medical record documentation or provider report of active severe mental illness (e.g., schizophrenia, bipolar disorder), dementia, recent suicidal ideation, uncorrected hearing loss, and/or active substance abuse.

Measures

Predictor variables

Resilience was measured using the CD-RISC 10 [17]. The 5-point Likert scale measured the frequency of one's beliefs about coping with and persisting through adversity ($\alpha = 0.85$). Response options include the following: Not true at all, Rarely true, Sometimes true, Often true, and True nearly all of the time. Scores range from 0 to 40 with higher scores indicating higher resilience.

Outcome variables

Preparation for family caregiving was assessed using the 8-item Preparedness for Caregiving Scale (PCS) [25], which has demonstrated excellent reliability in prior work with cancer family caregivers ($\alpha = 0.91$) [26]. Domains of caregiving measured include providing physical care, emotional support, and arranging for in-home services. Scores range from 0 to 4 with higher scores indicating higher preparedness.

Readiness for potential future decision-making was measured using the 13-item Family Decision-Making Self-Efficacy Scale (FDMSE) [27]. On a 1-to-5 scale ranging from "Cannot do at all" to "Certain I can," respondents rate their confidence in being able to make potential future medical decisions about the person they care for should they become unable to. Items ask about decisions related to the person's comfort, where the person is cared for at the end of life, food and fluid, pain, resuscitation, avoiding suffering, and respecting dignity. Scores range from 13 to 75 with higher scores representing higher readiness for future surrogate decision-making ($\alpha = 0.85$).

Distress was assessed using the 14-item Hospital Anxiety and Depression Scale, with subscales measuring symptoms of anxiety (7 items) and depression (7 items) over the past week [28]. Subscale scores range from 0 to 21 with scores of 0 to 7 indicating normal mood and scores of 8 to 21 indicating caseness for anxiety or depression.

Sociodemographics and clinical data

Participants self-reported age, gender, race, marital status, highest level of education, employment status, religious affiliation, their relationship to the patient, and the number of days per week and hours per day providing care. The patient's primary cancer type was abstracted from the patient's medical record during screening.

Statistical analyses

We conducted unadjusted linear regressions to examine bivariate relationships between resilience and each outcome variable. Bivariate relationships between resilience and sociodemographics were then examined using independent samples *t* test, one-way analysis of variance, and Pearson correlation. We then conducted multivariable linear regressions to examine associations between resilience and each of the outcome variables, controlling for demographic

characteristics that demonstrated bivariate associations of $p < 0.20$ with the outcome variable. Standardized coefficients were estimated, and Cohen's guidelines [29] for interpretation of R^2 (small ~ 0.02, medium ~ 0.13, and large ~ 0.26) and the effect size r for standardized coefficients (small ~ 0.1, medium ~ 0.3, and large ~ 0.5) were used to aid in interpretation. Inference on control variables in the models was not presented as it might be biased due to data-driven selection. Ratio of coefficients to sample size in adjusted models was at least 1:10 to prevent bias from overfitting [30].
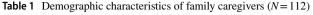
Results

Descriptive statistics

Caregiver participants were an average age of 56 years and mostly female (76%), married or living with a partner (62%), and Protestant (71%) (Table 1). Most of the sample was either White (56%) or African-American/Black (43%) with representative proportions of individuals along the spectrum of educational attainment and employment. Just over half of the family caregivers were the patients' spouse/partner (52%). Caregivers reported providing an average of almost 9 h/day of care and most caregivers (83%) reported providing care every day of the week. Patients had a wide range of stage III/IV cancers including breast, gastrointestinal, lung, head and neck, prostate, pancreatic, genitourinary, and other cancers.

Unadjusted linear regressions

In unadjusted analyses (Table 2), higher caregiver-reported resilience was associated with higher caregiver preparedness (beta = 0.49; standard error (SE) = 0.01; $p < 0.001$) and lower anxiety (beta = − 0.22; SE = 0.06; $p < 0.05$) and depressive symptoms (beta = − 0.22; SE = 0.05; $p < 0.05$). Resilience was not associated with decision-making readiness (beta = 0.13; SE = 0.11; $p > 0.05$). Among demographic variables (Supplementary table), higher self-perceived resilience was statistically significantly associated with younger age, being African-American/Black, and the patient not being the caregiver's spouse/partner or parent. Being African-American/Black compared to being White was associated with lower anxiety scores. Not being married/living with a partner was associated with lower depression scores. Caregivers who worked full time compared to those who were retired or unemployed were less prepared for caregiving. Being the patient's spouse or partner was associated with having a higher readiness for potential future surrogate decision-making.

Table 1 Demographic characteristics of family caregivers ($N = 112$)

Characteristic	N	% or standard deviation
Age, mean (SD), years	56.3	13.4
Gender, N (%)		
Female	85	75.9
Male	27	24.1
Race		
White	63	56.3
African-American/Black	48	42.9
Native Hawaiian or Pacific Islander	1	.9
Marital status		
Married or living with partner	69	61.6
Never married	15	13.4
Divorced or separated	20	17.9
Widowed	8	7.1
Education		
Some high school	5	4.5
High school or GED	24	21.4
Some college or technical school	44	39.3
College graduate or above	39	34.8
Employment status		
Full or part time	49	43.8
Retired	35	31.3
Not employed	28	25.0
Religious affiliation, N (%)		
Protestant	80	71.4
Catholic	8	7.1
None	4	3.6
Other	19	17.0
Missing/no response	1	.9
Relationship to patient (The patient is my…), N (%)		
Spouse/partner	58	51.8
Parent	20	17.9
Son or daughter	13	11.6
Sibling	11	9.8
Other (niece/nephew, aunt/uncle, friend/neighbor, etc.)	10	8.9
Days/week providing care, N (%)		
1 day or less/week	1	.9
2–3 days/week	6	5.4
4–5 days/week	10	9.0
6 days/week	2	1.8
Every day	93	83.0
Hours/day providing care, N (%)	8.86	7.5
Primary cancer site of patient		
Breast	21	18.8
Gastrointestinal	19	17.0
Lung	17	15.2
Head and neck	16	14.3

Table 1 (continued)

Characteristic	N	% or standard deviation
Prostate	11	9.8
Pancreatic	9	8.0
Genitourinary	5	4.5
Other	14	12.5

Multivariable linear regressions

In multivariable models (Table 2) controlling for demographic covariates, higher caregiver-reported resilience was significantly and strongly associated with higher caregiver preparedness (beta = 0.46; SE = 0.01; $p < 0.001$; adjusted $R^2 = 0.27$) and moderately associated with higher decision-making readiness (beta = 0.23; SE = 0.11; $p < 0.05$; adjusted $R^2 = 0.11$). Higher resilience was also moderately associated with lower anxiety (beta = -0.19; SE = 0.07; $p < 0.05$; adjusted $R^2 = 0.11$) and depressive symptoms (beta = -0.20; SE = 0.06; $p < 0.05$; adjusted $R^2 = 0.10$).

Discussion

In a racially diverse sample of 112 family caregiver trial participants of patients with newly diagnosed advanced cancer, we performed multivariable analyses showing higher caregiver-reported resilience to be associated with higher caregiver preparedness and readiness for potential future surrogate decision-making and lower anxiety and depressive symptoms. Along with other emergent research in this area [7, 31], these results suggest that resilience may play a critical role in how cancer caregivers provide effective support

to patients, feel ready to engage in future medical decisions on behalf of patients, and manage stress. Moreover, these results further the impetus for behavioral intervention developers to build frameworks and test interventions that seek to enhance resilience in caregivers of adult patients with advanced cancer.

When a patient is newly diagnosed with an advanced cancer, there can be a rapid and sustained accumulation of complex healthcare-related tasks required of family members, equating to a marked increase in stressors. Our results highlight the possibility that resilience may factor into relationships between the stress appraisal of these new and numerous tasks and the performance of those tasks. In this task-related context, a lack of resilience-based stress management skills has been associated with decreased work performance, including reduced situation awareness, stress tolerance, adaptability, and decision-making [32]. Inferring back to the task context of cancer caregiving, low resilience may be a direct cause of poor caregiving performance under stress, which might thereby affect the quality of patient care in the home. Future work should further investigate the role of resilience in caregiving task performance and its potential impact on patient care.

After controlling for demographic variables, higher resilience was associated with higher readiness for potential future surrogate decision-making. Interestingly, the association of resilience with decision-making was not significant in the bivariate test but was significant in the multivariable analysis after controlling for employment, relationship to the patient, and hours per day providing care. This suggests a suppressor effect of one or more of the demographic variables, such that their inclusion strengthened the relationship between resilience and decision-making [33]. While our cross-sectional data are unable to provide a clear causal pathway and explanation, there are several possibilities worth further exploration. Resilience might be a necessary

Table 2 Multivariable regression

Predictor variables	Caregiver preparedness			Decision-making readiness			Anxiety			Depression		
	B	SE	Beta	B	SE	Beta	B	SE	Beta	B	SE	Beta
Resilience (unadjusted)	.05	.01	.49***	.15	.11	.13	−.16	.06	−.22*	−.13	.05	−.22*
Adjusted R^2	.23			.01			.04			.04		
Resilience (adjusted)	.05	.01	.46***	.23	.11	.20*	−.13	.07	−.19*	−.12	.06	−.20*
Adjusted R^2	.27			.11			.11			.10		

Demographic covariates included in the adjusted model if demonstrating bivariate association with the dependent variable of $p < .20$, including age (anxiety, caregiver preparedness), gender (anxiety), race (anxiety depression, caregiver preparedness), marital status (depression), employment (anxiety, caregiver preparedness, decision-making readiness), relationship to patient (decision-making readiness), hours/day providing care (depression, caregiver preparedness, decision-making readiness)

*$p < .05$; **$p < .01$; ***$p < .001$

but not sufficient resource for feeling prepared for future decision-making on behalf of others. Other necessary components of feeling decisionally prepared might include certain knowledge or information, such as of the patient's values and preferences towards medical care at the end of life care or about the expectations of the surrogate decision-making role [34, 35]. Other components might be more affective and related to identity integrity, such as one's perception of filial obligations as a "good" spouse, partner, child, and so on to the patient by performing in the surrogate decision-making role [36]. Future work should seek to develop and test conceptual models of resilience in the caregiving and surrogate decision-making context that not only fully delineate the construct of resilience but also its orientation within a larger framework of stress, performance, and decision-making.

Higher resilience among family caregivers was also associated with lower distress, as indicated by lower anxiety and depression scores. Lower distress among family caregivers is a desirable end point clinically for this population [37], further signaling the potential of resilience enhancement as a promising target of intervention development. Furthermore, as mentioned above, lower distress may optimize a caregiver's ability to perform complex caregiving tasks and engage in prospective planning behaviors for future decision-making. Pertaining especially to the latter, intense distress has been found to profoundly affect cognitive abilities relating to deciding for others, including dampening the ability to remember and process information, limiting higher-order reasoning, biasing probability and risk assessment, and increasing susceptibility to projecting one's own values and beliefs onto others [21]. This raises the possibility that promoting resilience may optimize decision-making readiness in part by increasing one's stress management skills. Additional future work might also evaluate caregiving resilience in the context of the emotional and social dynamics between themselves and care recipients.

While not the central focus of this study, there were unexpected but noteworthy findings regarding differences in self-reported resilience in the demographic characteristics of our sample of family caregivers. First, family caregivers who were African-American/Black had higher self-perceived resilience in comparison to White individuals, which is consistent with other studies examining racial differences in resilience. Echoing others, this trend could be due to the consistent, lifelong social, cultural, and institutional adversity and racism faced by minority groups and their seasoned coping skills in appraising and managing the associated stress [38, 39]. Higher resilience among African-American/Black family caregivers may also explain why studies consistently report them having higher objective caregiving burden but less distress in comparison to Whites [40, 41]. Second, caregivers who were the spouse or partner of the patient reported less resilience compared to parental and

other caregiver relationship types. The context and stressors faced by spouses and partners of their seriously ill care recipient may be unique from other caregiver-care recipient relationship types such that their self-perceived resilience is being secondarily appraised in light of more ominous stressors (e.g., the loss of one's primary source of psychological, emotional, and material/financial support). These and other demographic differences in resilience can help inform researchers considering adaptive and/or culturally responsive interventions to support caregivers.

Our findings have important implications for clinicians who engage with families of patients with advanced cancer. Given the association between resilience and a caregiver's preparedness and readiness for future decision-making when a patient has been recently diagnosed, supportive care should be integrated early in the advanced cancer trajectory as is currently recommended by the American Society of Clinical Oncology [42]. This early support might specifically assess and promote a caregiver's resilience resources, which might include how the family member is coping with their situation, how they are managing stress, and how they are availing themselves of additional support from other family and friends and their community [43]. While our findings are not definitive, fostering resilience alone is likely not sufficient for adequately preparing caregivers for potential future surrogate decision-making and thus other advance care planning conversations and activities (e.g., living will completion) are still highly warranted as a complement to strengthening a family's resilience.

This analysis has several limitations. First, the analysis used cross-sectional data and hence cautious interpretation of findings is warranted, especially about causal pathways or changes in resilience in response to stressors. Longitudinal work could help inform the timing of potential resilience interventions [44]. Relatedly, longitudinal evaluation could help determine changes in a caregiver's resilience over time from the time of their care recipient's diagnosis and associated predictive factors. Second, the instrument used to measure resilience, the CD-RISC 10, while widely used, has been criticized for potential gaps in its content validity and unclear theoretical basis. It excludes measurement of other constructs that have been postulated as factors of resilience, such as resourcefulness, mastery, self-esteem, growth and thriving, and self-reliance [11]. This measurement issue also reflects the larger debate surrounding consensus (or lack thereof) on the definition of resilience [8, 44, 45]. Third, this sample came from a single geographical area and institution, limiting the generalizability of results. Conclusions and implications of our results would be strengthened by testing these hypotheses in a larger and more geographically diverse sample of advanced cancer family caregivers.

In conclusion, our analysis showed that higher self-perceived resilience among 112 caregivers of individuals

with newly diagnosed advanced cancer was associated with higher preparedness for caregiving tasks, higher readiness for potential future decision-making, and lower distress. Critical next steps in research include validating results in other cancer caregiving samples and formulating the construct of resilience within a wider stress process and decision-making framework. Intervention development and testing work can then ensue, potentially adapting resilience interventions being tested in other populations [46], that seek to optimize the outcomes, performance, and decision-making of family caregivers of the patients with cancer they care for from diagnosis to end of life.

Data availability The data that support the findings of this study are available from the corresponding author upon reasonable request.

Code availability Not applicable.

Declarations

Ethics approval and consent to participate This study was approved by the University of Alabama at Birmingham Institutional Review Board (IRB Protocol Numbers: 300000979 and 300003601) and was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments. Informed consent was obtained from all individual participants in this study.

Consent for publication Not applicable.

Conflict of interest The authors declare no competing interests.

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