

ORIGINAL ARTICLE

Supporting the support person: Oncologists' roles in reducing support people's uncertainty and facilitating psychological adjustment

Elizabeth Broadbridge¹  | Maria K. Venetis¹  | Katie A. Devine²  |
Lauren E. Lee¹  | Smita C. Banerjee³  | Kathryn Greene¹ 

¹Department of Communication, Rutgers University, New Brunswick, New Jersey, USA

²Division of Pediatric Hematology/Oncology, Rutgers Cancer Institute of New Jersey, New Brunswick, New Jersey, USA

³Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, New York, USA

Correspondence

Elizabeth Broadbridge and Kathryn Greene, Department of Communication, Rutgers University, 4 Huntington Street, New Brunswick, NJ 08904, USA.
Email: liesl.broadbridge@rutgers.edu and klgreene@rutgers.edu

Funding information

Rutgers University School of Communication and Information

Abstract

Objective: Support people of cancer patients are at significant risk for psychological distress. Additionally, cancer patients' well-being is reciprocally associated with support peoples' psychological well-being. Informed by Uncertainty in Illness Theory, this study tests whether support person psychological well-being is influenced by provider communication and uncertainty reduction.

Methods: We tested a multiple mediation model to investigate how empathic communication facilitates psychological adjustment in support people of cancer patients and how this process is mediated by support peoples' illness uncertainty and caregiver burden. Support people of cancer patients ($N = 121$; including spouses, adult children, etc.) completed an online questionnaire about their perceptions of oncologists' empathy, uncertainty about the cancer patients' illness, perceived caregiving burden, and their psychological adjustment to diagnoses.

Results: Path analysis revealed that (1) more perceived oncologist empathy was associated with less illness uncertainty, (2) more illness uncertainty was associated with worse psychological adjustment and more perceived caregiver burden, and (3) more burden was associated with worse adjustment ($\chi^2(2) = 1.19, p = 0.55$; RMSEA < 0.01 ; CFI = 1.00; SRMR = 0.02).

Conclusions: Given the reciprocal nature of well-being between cancer patients and their support people, it is critical to understand and bolster support people's psychological well-being. Results demonstrated how empathic provider communication can support psychological well-being for support people of cancer patients. Additionally, this study offers theoretical contributions to understandings of illness uncertainty in caregiver populations.

KEYWORDS

cancer, caregiver, communication, psychological well-being, psycho-oncology, uncertainty

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1 | INTRODUCTION

Patients diagnosed with cancer are at high-risk for psychological distress throughout the illness trajectory.^{1,2} To manage their psychological well-being, cancer patients often turn to their social support network, including spouses/partners, family members, and/or close friends (e.g., support people).³ Importantly, these individuals are also at-risk for psychological distress in their role of supporting the cancer patient, with worse psychological well-being of patients associated with worse psychological well-being of their support person.⁴ Given the interconnectedness of patients' and support peoples' well-being, efforts to improve patient psychological well-being of must be extended to support people.¹ Informed by Uncertainty in Illness Theory⁵ (UIT), this study explores the extent to which the psychological well-being of people supporting cancer patients can be facilitated through increased empathic provider communication and reduced support person uncertainty. Further, this study extends UIT by considering how perceived burden of being a support person may mediate the relationship between uncertainty and psychological well-being. This study offers pathways for addressing and bolstering support people well-being.

1.1 | Cancer and uncertainty

Illness uncertainty is a cognitive and emotional state in which people struggle to make meaning of illness-related events due to the novelty, complexity, and/or ambiguity surrounding the event.⁵ Illness uncertainty can present throughout the cancer experience including from initial biopsies, treatment decisions, and into the post-treatment phase where recurrence concerns may arise.^{6,7} For example, support people of cancer patients report high levels of uncertainty about both the future and information about treatment side effects.^{8,9} Although not all uncertainty has negative consequences (e.g., providing hope), we focus on the potential negative effects of illness uncertainty. One potential consequence of this uncertainty is psychological distress for both patients and support people.⁶

1.2 | Cancer and psychological distress

A cancer diagnosis can elicit psychological distress for both patients^{1,2} and support people.⁴ Moreover, evidence points to an interdependence between the psychological well-being of cancer patients and their primary support person,^{10,11} underscoring the importance of attending to the psychological needs of both patients and their support people. For example, support people having more unmet needs (e.g., emotional, relationship) is associated with higher cancer patient anxiety and depression.¹⁰ One marker of psychological well-being is the concept of psychological adjustment, or the idea that people can eventually manage the diagnosis without

significant psychological distress.¹² For breast cancer patients, a robust relationship has been demonstrated between illness uncertainty and psychological adjustment such that more uncertainty predicts worse psychological well-being.^{13,14} However, the connection between uncertainty and psychological adjustment has been understudied among support peoples' experiences with cancer caregiving.

Research suggests that, among support people, increased uncertainty may indeed be associated with increased psychological distress. Specifically, higher levels of uncertainty in parents of children with pediatric cancer are associated with more parental symptoms of depression and anxiety.¹⁵ However, less is known about whether this pattern persists for support people of adult cancer patients. Understanding that illness uncertainty is present throughout the cancer trajectory, and that support people may be at risk for developing symptoms of anxiety and depression due to the uncertainty they face, bolstering psychological adjustment to these symptoms is critical for facilitating holistic cancer care. To explore the connection between illness uncertainty and psychological adjustment for support people of cancer patients, the following hypothesis is proposed:

H1 *Support peoples' illness uncertainty will be negatively associated with their psychological adjustment to the cancer diagnosis.*

1.3 | Uncertainty in Illness Theory

Uncertainty in Illness Theory (UIT) provides a framework for understanding how various factors influence patient illness uncertainty and the consequences of illness uncertainty on coping and illness adaptation.⁵ UIT posits that *illness uncertainty* is affected by patients' perceptions of/familiarity with symptoms and symptom patterns (called the *stimuli frame*) such that less familiarity is associated with more uncertainty. Stimuli frame effects are influenced by external factors (called *structure providers*) such as perceived provider credibility and/or provider communication such as providers' offering tailored education about the health-related event. Finally, UIT posits that illness uncertainty elicits an *appraisal process* that can result in successful or unsuccessful *adaptation* to the illness, such as improved or reduced psychological adjustment.

UIT has been applied within many patient populations including breast and prostate cancer,^{13,16,17} genomic tumor profiling,¹⁸ and chronic illnesses.¹⁹ Although support peoples' uncertainty can make caring for patients more challenging,²⁰ little research exists attempting to connect support person uncertainty with health outcomes of the support people themselves. This study applies UIT to include support people of patients with cancer, providing an important theoretical contribution to the theory's utility. Below we detail how, within the support person context, the theoretical concepts of uncertainty appraisal and structure providers require extensions beyond the original definitions.

1.3.1 | The role of empathic communication

UIT explains that structure providers are external factors that influence illness uncertainty; examples include provider credibility and provider communication and education efforts.¹³ Specifically, empathic provider communication has been related to breast cancer patients' illness uncertainty and psychological adaptation, consistent with UIT hypotheses.¹³ In other words, for patients, more perceived provider empathy is associated with less illness uncertainty and better psychological adjustment. Given the interdependence of support person and patient psychological well-being, and the understanding that support people experience illness uncertainty, uncertainty may exacerbate psychological distress in similar ways for support people as it does for cancer patients. Thus, the following hypothesis is proposed:

H2 *Perceived provider empathic communication with support people will be negatively associated with support peoples' illness uncertainty.*

1.3.2 | Experiencing uncertainty

The uncertainty appraisal process in UIT is oriented to how patients experience illness uncertainty and how they appraise the uncertainty either as an opportunity (called an *illusion appraisal*) or as a danger (called an *inference appraisal*).⁵ This appraisal is posited to affect patients' capacity for coping and adaptation. In the context of support people, we propose an additional appraisal of uncertainty as perceived *burden appraisal* that can likewise affect support peoples' capacity for coping and adaptation (Figure 1A). Consistent with this argument, support people who view the patient's health as uncertain experience more difficulties such as burden. Caregiver burden² is defined as the "distress that caregivers feel as a result of providing care" (p. 221).²¹ Caregiver burden is a stressor distinct from anxiety or depression, but can result in such stressors.²¹ In a study of breast

cancer patient caregivers, perceived caregiver burden was the most significant psychological well-being predictor.²² In addition to psychological distress, caregiver burden can manifest in physical,²³ social,²⁴ and financial burdens.^{23,24} In contexts outside of cancer, illness uncertainty has been associated with caregiver burden such that more illness uncertainty is associated with more caregiver burden.²⁵ Although this relationship has not been explicitly addressed in the cancer context, to our knowledge, a study of caregivers of advanced-stage lung cancer found that illness uncertainty was associated with more anticipatory grief, which was separately associated with more caregiver burden.²⁶ Given the empirical data supporting the connection between illness uncertainty, caregiver burden, and psychological well-being, the following hypotheses are proposed:

H3 *Support peoples' illness uncertainty will be positively associated with their reports of caregiver burden.*

H4 *Support peoples' reports of caregiver burden will be negatively associated with their psychological adaptation.*

2 | METHODS

2.1 | Sampling and procedures

This study was conducted as part of a larger data collection effort that occurred between June 2020 and December 2022. Participants ($N = 121$) were recruited through the Love Research Army®, a research registry hosted by the Dr. Susan Love Foundation for Breast Cancer Research, to complete an online cross-sectional survey about their experience as a support person of someone with cancer and their communication with the oncology care team during visits. Eligible individuals were 18+ years old, able to read English, have Internet access to connect to the survey, able to provide informed consent, and sometimes or regularly attended oncology visits with a cancer patient. Participants had the opportunity to enter a drawing for one of three \$50 gift cards. This study was approved by the Rutgers University Institutional Review Board (IRB #E17-664).

2.2 | Measures

2.2.1 | Perception of empathic communication

Participant perceptions of the oncologist's empathic communication (H2) were assessed using the 10-item Consultation and Relational Empathy (CARE) questionnaire.²⁷ Participants rated statements about the oncologist's communication on a 6-point scale (*really poor* to *excellent*) based on the prompt, "How was the oncologist at...". An example item includes, "Showing care and compassion." Final composite scores had high reliability ($\alpha = 0.97$). Higher scores indicate perceptions of more empathic provider communication.

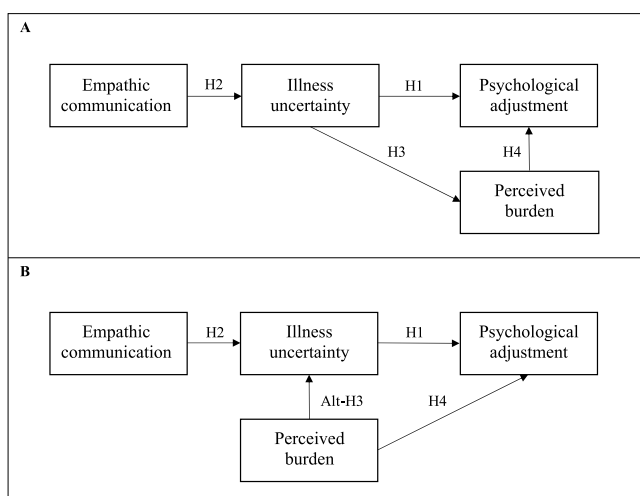


FIGURE 1 (A) Hypothesized model and (B) alternative model.

2.2.2 | Illness uncertainty

Illness uncertainty (H1, H2, H3) was assessed using a 3-item scale derived from the Uncertainty in Illness Scales,²⁸ with prior use in cancer patient populations.¹³ Participants rated the degree to which they agreed with statements about their uncertainty on a 5-point scale (*strongly disagree* to *strongly agree*). An example item is, "Because of the unpredictability of the patient's cancer, I cannot plan for the future." Final composite scores had acceptable reliability ($\alpha = 0.70$). Higher scores indicate perceptions of more illness uncertainty.

2.2.3 | Perceived caregiver burden

Perceived caregiver burden (H3, H4) was assessed using a 10-item caregiver burden scale²⁹ plus an additional four items created by the research team based on prior research.³⁰ Participants rated their agreement about how caring for the patient affects their own well-being on a 5-point scale (*none of the time* to *all of the time*). An example item is, "I am concerned that I am/was helping [the patient] beyond my capacity." Final composite scores had high reliability ($\alpha = 0.93$). Higher scores indicate perceptions of more perceived caregiving burden.

2.2.4 | Support person psychological adjustment

Psychological adjustment (H1, H4) was assessed using an 8-item index derived from the Mini-Mental Adjustment to Cancer scale.³¹ Two items from each of four subscales were included based on a combination of face validity as assessed by the research team and factor loadings in a previous study³² in a cancer population. Participants rated their agreement with statements about their psychological adjustment on a 5-point scale (*does not apply to me* to *very strongly applies to me*). Items did not initially load on a single factor. The index was further refined by iteratively removing single items based on factor loading and reevaluating dimensionality. The final index consisted of four items from three subscales with acceptable reliability ($\alpha = 0.72$). The items were, (1) "I am very optimistic", (2) "I feel completely at a loss about what to do", (3) "I feel there is nothing I can do to help the patient", and (4) "I suffer great anxiety about the patient having cancer." Higher scores indicate better psychological adjustment.

2.3 | Statistical methods

After data screening, mean scale replacement was used for individual items if the participant was missing two or fewer items per scale ($n = 12$ replacements, $<1\%$ of items). Initial analyses included one-tailed bivariate correlations with Bonferroni-adjusted significance levels across model variables (Table 2). Path analysis was conducted

to assess the overall fit of the proposed model using composite average scores from the scales above. An alternative model was tested to investigate whether alternative directionality might be possible given that these data were cross-sectional (Figure 1B). Alternative model fit was compared to the fit of the hypothesized model. Model fit was assessed using a combination of fit statistics including chi-square (χ^2), root mean square error of approximation (RMSEA), confirmatory fit index (CFI), and standardized root mean square residual (SRMR). Good fit was considered at RMSEA < 0.06 , CFI > 0.95 , and SRMR < 0.08 .³³ Data were analyzed using STATA (version 17.0).

3 | RESULTS

3.1 | Participant characteristics and initial analyses

In total, 148 survey responses were collected from support people. Participants were excluded if they did not respond to more than two items per scale measure ($n = 27$) for a total of 121 complete responses retained for analyses. Most participants reported being a support person to a breast cancer patient ($n = 78$). Because the Love Research Army is not limited to those affected by breast cancer, support people in our sample also represented other cancer types ($n = 44$). Other cancer types that three or more participants reported included lung cancer, lymphomas, colorectal cancers, and pancreatic cancer (Table 1). Bivariate correlations across model variables revealed statistically significant correlations among all variables (Table 2).

3.2 | Path analysis

Overall, the hypothesized path model was well-supported by the data ($\chi^2(2) = 1.19$, $p = 0.55$; RMSEA < 0.01 ; CFI = 1.00; SRMR = 0.02) (Figure 2A). All paths were statistically significant ($p < 0.01$), with path directionalities consistent with the hypothesized relationships (H1-H4 supported). That is, support people who reported that the oncologist had more empathic communication reported less illness uncertainty (H2; $B = -0.50$). Participants who reported more illness uncertainty had worse psychological adjustment (H1; $B = -0.44$) and reported more perceived burden (H3; $B = -0.33$). Finally, participants who reported more perceived burden had worse psychological adjustment (H4; $B = -0.26$).

3.3 | Alternative model

An alternative model was run to explore potential deviations from our hypothesized model. A single modification was made to the model: the path from illness uncertainty to perceived caregiver burden was reversed (H3). Overall, the alternative model was also a good fit to the data ($\chi^2(1) = 1.06$, $p = 0.30$; RMSEA = 0.02;

TABLE 1 Support person demographic information and descriptive statistics ($N = 121$).

	Participants	
	<i>n</i>	%
Age - mean (<i>SD</i>)	60.47 (12.52)	
Gender		
Female	107	87.7
Male	14	11.5
Education		
High school graduate	2	1.64
Vocational, technical, business, or trade school certificate or diploma	6	4.92
Some college	18	14.75
Bachelor's degree	39	31.97
Master's, professional, or doctoral degree	57	46.72
Race		
White	113	94.17
Asian	3	2.50
Other	4	3.33
Ethnicity		
Hispanic/Latino	10	8.20
Marital status		
Single	13	10.66
Married/living as	89	72.95
Divorced	9	7.38
Widowed	10	8.20
Separated	1	0.82
Relationship to patient		
Partner (spouse/boyfriend/girlfriend/husband/wife/romantic partner)	47	38.5
Companion (sibling, child, neighbor, other family, friend, etc.)	74	60.7
Patient cancer type		
Breast	78	62.93
Colorectal	5	4.10
Lung	10	8.20
Lymphoma	7	5.74
Pancreatic	3	2.46
Other	19	15.57

CFI = 1.00; SRMR = 0.02) (Figure 2B). All paths were statistically significant ($p < 0.01$), and path directionalities were consistent with the hypothesized relationships where applicable (H1, H2, H4 supported). As with the hypothesized model, support people who

reported that the oncologist had more empathic communication reported less illness uncertainty (H2; $B = -0.45$) and participants who reported more illness uncertainty had worse psychological adjustment (H1; $B = -0.44$). Participants who reported more perceived burden reported more illness uncertainty (alternative path; $B = 0.25$) and worse psychological adjustment (H4; $B = -0.26$). The alternative model did not fit the data significantly better than the hypothesized model ($\Delta\chi^2 = 0.13$, $\Delta df = 1$, $p = 0.72$).

4 | DISCUSSION

Overall, this research explored how the relationships hypothesized by UIT function within a support person population, providing extensions to UIT in two distinct ways. First, results support the relational concepts of the model within a support person rather than patient population. Previous applications of UIT for support people have focused primarily on parents of young children and how parent uncertainty affects child uncertainty.^{34,35} This study adds a unique population of adult support people and a focus on support peoples' well-being as the outcome of uncertainty. Second, results extend the appraisal process to include perceived caregiver burden. This study adds to the growing literature on support peoples' experiences in the cancer context^{36,37} by exploring the interdependence of cancer patient and support person well-being.

Support people have significant roles in cancer patients' illness journeys,²¹ and supporting their psychological well-being is critically important for the successful care of patients with cancer. Study results revealed that empathic communication from cancer providers help to address support people's illness uncertainty, aligning with research among cancer patients.¹³ More uncertainty was associated with more perceived burden, and more perceived burden was associated with worse psychological adjustment. Importantly, empathic provider communication was associated with decreased uncertainty for support people in this study. The indirect relationship between more perceived empathic communication, illness uncertainty, and better psychological adjustment is novel to the support person context but is also supported in the patient literature.^{13,38}

4.1 | Study limitations

This study investigates possible mechanisms for influencing the well-being of support people of cancer patients, an important and less-well understood population in the psycho-oncology literature. Results provide evidence towards the validity of UIT when used as an explanatory mechanism for psychological outcomes in support people contexts, in addition to patient contexts. Additionally, this study adds to the growing literature that recognizes using provider communication behaviors as part of the conceptualization of structure providers¹³ and an important antecedent of psychological well-being.

TABLE 2 Descriptive statistics for study variables.

Variable	M	SD	α	Correlation			
				(1)	(2)	(3)	(4)
(1) Perceived empathic communication	3.31	1.39	0.97	1.00			
(2) Illness uncertainty	2.48	1.01	0.70	-0.50**	1.00		
(3) Perceived caregiver burden	1.85	0.81	0.93	-0.19*	0.32**	1.00	
(4) Psychological adjustment	3.71	0.84	0.72	0.34**	-0.52**	-0.41**	1.00

Note: Two-tailed significance levels. Degrees of freedom = 120 across all variables.

Abbreviations: α , Cronbach's alpha; M, mean; SD, standard deviation.

* $p < 0.05$; ** $p < 0.01$.

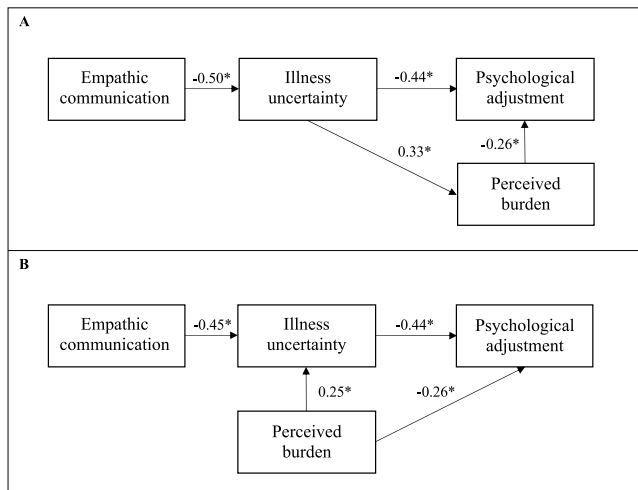


FIGURE 2 Path analysis results for (A) the hypothesized model and (B) the alternative model. Parameter estimates are standardized. (A) Model fit indices $\chi^2(2) = 1.19$, $p = 0.55$; RMSEA < 0.01 ; CFI = 1.00; SRMR = 0.02. (B) Model fit indices $\chi^2(1) = 1.06$, $p = 0.30$; RMSEA = 0.02; CFI = 1.00; SRMR = 0.02. Model fit not significantly different across models ($\Delta\chi^2 = 0.13$, $\Delta df = 1$, $p = 0.72$). * $p < 0.01$.

Despite these strengths, there are also several limitations worth noting. First, this study utilizes a cross-sectional survey design, which limits the extent to which causality can be inferred. Although our model was grounded in theory and past empirical data to suggest directionality, additional models may also fit these data. Further, it is possible that constructs outside of the scope of this study, such as extent of support responsibilities or cohabitation with the cancer patient, may moderate our models, and further research is needed to address these relationships. The study design also limits the extent to which perceptions of oncologists' empathic communication represents actual communication behaviors within individual cancer care appointments, because responses represent perceptions of communication behaviors and not observed interactions. Future research should address this limitation through observation and/or video analysis of the medical interaction to understand how support people's perceptions align with or diverge from actual communication of the provider. A second limitation is that the population of support people that were recruited represent a specific subset of cancer

support people in the United States. Participants were majority white (93%), female (88%), had some college education (93%), earned $> \$75,000$ per year (75%), and were at least somewhat digitally literate (100% completed the survey online). They also represented a range of relationships with the patient (i.e., spouse, sibling, child). The homogenous demographic characteristics of the study sample limits the extent to which the study results will be generalizable to the broader population of cancer patient support people. Further research is needed to understand whether the study findings replicate among other support people populations. Of particular importance are support people with lower health and/or digital literacy who may be most affected by illness uncertainty, and thus potentially most likely to benefit from empathic communication from their providers. Despite these limitations, this study contributes to the broader literature on empathic communication, illness uncertainty, and psychological adjustment of support people of cancer patients.

4.2 | Clinical implications

Results from this study suggest a relationship between health care provider communication and support persons' psychological well-being. Support people who rated the provider as more empathic had less illness uncertainty and better adjustment. Empathic communication behaviors included communication that helped the support person feel listened to, understood, and empowered to help the patient they care for. This aligns with previous calls for ongoing empathic communication skills training for clinicians.^{13,39,40} This study provides a targeted area of empathic communication skills training for clinicians. Specifically, cancer care providers should attend not only to patient concerns, but also to the potential uncertainty support people experience by eliciting questions and concerns from support people and responding to this uncertainty with empathy. Although uncertainty may not be readily apparent, asking questions about what remains unclear, what support people are still worried about, expectations about treatment plans or recurrence risk, and/or other illness-related topics may help clinicians identify moments for addressing uncertainty with empathy. This might be accomplished by adding a focus on support persons to existing provider communication trainings, though future research is needed to determine the most effective strategies.

This study also supports continued focus on support persons' psychological adjustment while caring for a cancer patient. Support people displayed a degree of illness uncertainty and caregiver burden. Clinicians should be aware of these potential challenges and regularly assess cancer support peoples' own support needs, providing referrals to social work or other services as needed. Recognizing the direct relationship between support person well-being and patient well-being in the cancer context,^{10,11} it is critical that both individuals are supported by the health care team.

4.3 | Conclusions

Support people have a critical role within cancer patients' healthcare experiences. Psychological consequences of caregiving can have detrimental effects on support people and cancer patients. This study provides a mechanism through which clinicians can help bolster support person well-being. Provider empathic communication was seen to be associated with less illness uncertainty and better psychological adjustment among support people. Continued attention on provider communication training is needed for bolstering empathic communication skills and strategies for effectively involving support people throughout the cancer care experience.

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CONFLICT OF INTEREST STATEMENT

The authors declare no competing interests.

DATA AVAILABILITY STATEMENT

The deidentified data that support the findings of this study are available from the corresponding author.

ETHICS STATEMENT

This study was approved by the Rutgers University Institutional Review Board (protocol and approval #E17-664).

ORCID

Elizabeth Broadbridge  <https://orcid.org/0000-0003-4121-3697>

Maria K. Venetis  <https://orcid.org/0000-0002-6710-1776>

Katie A. Devine  <https://orcid.org/0000-0002-1003-8905>

Lauren E. Lee  <https://orcid.org/0000-0002-6579-7466>

Smita C. Banerjee  <https://orcid.org/0000-0001-5479-5978>

Kathryn Greene  <https://orcid.org/0000-0002-3362-4982>

ENDNOTES

¹ The term "caregiving" is often used to encompass support roles that range in spectrum of involvement. We use the term "support people" to be more inclusive of people identified by the cancer patient as someone

who attends visits with them and provides support, regardless of the extent to which they are caregiving in other contexts external to the healthcare interaction.

² The term "caregiver" is used here instead of "support person" because this is the term typically used to describe and measure the burden that these individuals face.

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