

Exploring the Relationship Between Health–Illness Transition Experiences and Distress Among Patients With Pancreatic Cancer

Jessica I. Goldberg, PhD, RN, Jessica R. Flynn, MS, Raymond E. Baser, MS, Judith E. Nelson, MD, JD, Elizabeth Capezuti, PhD, RN, FAAN, and Dena Schulman-Green, MA, EdM, MS, PhD

OBJECTIVES: To explore the correlation between health–illness transition (HIT) experiences and distress among patients with pancreatic cancer.

SAMPLE & SETTING: 55 patients with a diagnosis of pancreatic cancer receiving chemotherapy at a tertiary cancer center in New York.

METHODS & VARIABLES: A prospective correlational study was performed to explore the frequency, extent, and management of HITs. HITs were evaluated using the Measurement of Transitions in Cancer Scale, and distress was measured with the National Comprehensive Cancer Network Distress Thermometer.

RESULTS: All patients experienced at least one HIT. The extent of HITs decreased over time. Patients reported that they managed HITs moderately well. There was a significant correlation between unmanaged HITs and distress. As distress increased, the extent of the physical and emotional HITs increased and management worsened.

IMPLICATIONS FOR NURSING: HITs are ubiquitous among patients diagnosed with pancreatic cancer. Associated distress inhibits management. Nurses are well suited to assess for potential HITs and to support self-management of HITs.

KEYWORDS health–illness transitions; distress; pancreatic cancer

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Health–illness transitions (HITs) are shifts that patients experience in life situation or status that are triggered with the diagnosis of an illness and bring about subsequent changes in roles, behaviors, and relationships (Schumacher & Meleis, 1994). The study of HITs is guided by transitions theory, which describes the fundamental components of the transition experience, including the nature of the transition (i.e., time span, management, awareness, and engagement), facilitators and barriers to the transition, and patterns of response (i.e., mastery, coping, and distress) (Meleis et al., 2000). Much of the research on transitions focuses on a narrow aspect of the transition experience, describing either a transition in goals of care (e.g., from curative intent to palliative intent) (Fitch et al., 2020; Kitta et al., 2021) or a transition in site of care (e.g., from care in a hospital to care at home) (Coleman et al., 2005; Lorenzini et al., 2020; Smith et al., 2019). However, patients with cancer describe HITs as a complex, multifaceted series of events associated with illness-related time points such as diagnosis, start of treatment, and recurrence, which have the potential to profoundly influence their sense of identity, psychological health, and quality of life (Chao et al., 2020; Madsen et al., 2019; Schulman-Green et al., 2011, 2012).

Much of what is known about the cancer-related HIT experience is derived from research focused on female patients with a diagnosis of breast and ovarian cancer (Chao et al., 2020; Goldberg et al., 2016; Schulman-Green et al., 2011, 2012). These patients describe HITs as including personal transitions (changes in physical, emotional, social, or spiritual status) and care transitions (changes in cancer status,

treatment, or approach to care) (Schulman-Green et al., 2017). Examples of personal transitions include changes in energy level (physical), changes in anxiety (emotional), changes in employment (social), and changes in a relationship with a higher power (spiritual). Care transitions include changes in prognosis (cancer status), changes in chemotherapy regimen (treatment), and changes in the goal of the treatment (approach to care). Patients with breast and ovarian cancer undergo multiple, overlapping transitions (Geary & Schumacher, 2012) throughout their disease course and report that transitions can create a sense of uncertainty (Duggleby et al., 2010), increased vulnerability (Bohner, 2017), and psychological distress (Schulman-Green et al., 2011, 2012).

Poorly managed transitions can lead to worse health outcomes (Meleis et al., 2000). For example, a patient experiencing increased pain (physical transition) that is not well managed with medications may find it difficult to leave the house, thereby causing the patient to feel socially isolated and depressed. However, the ability to successfully navigate or manage a transition helps patients reduce suffering and discomfort while achieving a sense of well-being and mastery of the new behaviors associated with the change (Kralik et al., 2006; Schumacher & Meleis, 1994). For these reasons, management of transitions is a vital skill in cancer self-management because successful management can contribute to patients' experience of effective coping, management of their emotions, and self-confidence (McCorkle et al., 2011; Schumacher & Meleis, 1994).

Patients with pancreatic cancer have a poor prognosis, and pancreatic cancer remains the third leading cause of cancer-related deaths in men and women (Siegel et al., 2023). In these patients with a limited life expectancy, often measured in terms of months, the experience of multiple overlapping transitions may prevent healthy self-management practices, therefore leading to worse outcomes, including high levels of distress (Lelond et al., 2021). Patients with a pancreatic cancer diagnosis are at elevated risk for experiencing distress, which may influence quality of life (Marte et al., 2022) and mortality (Wang et al., 2020). To the authors' knowledge, there are no previous studies examining HITs and their relationship with distress in this particularly vulnerable population. Therefore, the purpose of this study is to identify the frequency, extent, and management of HITs and to explore the relationship with distress among patients with pancreatic cancer who are receiving chemotherapy.

Methods

Design

This prospective correlational study was approved by the institutional review board at Memorial Sloan Kettering Cancer Center and the Hunter College Human Research Protection Program. Consenting patients were asked to complete paper versions of the Measurement of Transitions in Cancer Scale (MOT-CA) (Schulman-Green et al., 2017) and the National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) (Roth et al., 1998) at the following two time points: baseline (time 1) and a follow-up visit four to six weeks later (time 2). The follow-up time interval was chosen to allow sufficient time for patients to have experienced a transition but not long enough to have significant attrition in this population of patients with a poor prognosis.

Sample

The clinic census for one medical oncology practice was reviewed daily to identify eligible patients. The authors approached consecutive eligible patients to seek their participation between July 2020 and March 2021. The inclusion criteria for this study were adult patients (aged 18 years or older) who could read and understand English, had a biopsy-proven diagnosis of pancreatic (adenocarcinoma or neuroendocrine) cancer, and were within three months of initiating a chemotherapy regimen at the Memorial Sloan Kettering Cancer Center location in New York City. Patients with a previous history of cancer were excluded.

Measures

The authors measured transitions with the MOT-CA (Schulman-Green et al., 2017). This tool measures seven transition domains that are characterized as either personal (physical, emotional, social, spiritual) or care (cancer status, treatment, approach to care) transitions. The only published use of this tool has been in patients with a diagnosis of breast cancer (Goldberg et al., 2016; Schulman-Green et al., 2023). The MOT-CA has content and convergent validity for the personal (eigenvalue = 2.994) and care (eigenvalue = 1.444) transitions (Schulman-Green et al., 2023). There are seven items corresponding to each of the seven transition domains. Patients were provided with examples to describe the transition domains (e.g., cancer status transition is change in prognosis, approach to care transition is a change in the goal of the treatment). Each item has two parts scored on a numeric rating scale. For part A, patients describe the extent of the transition, or how much

change they have experienced in the past month, from 0 (no change) to 10 (a lot of change). For part B, they report how well they have dealt with the transition, from 1 (not well at all) to 10 (very well). On part A, a score of 1–3 corresponds to little transition, 4–6 corresponds to moderate transition, and 7–10 corresponds to much transition (Schulman-Green et al., 2017). For part B, the score was inversely related to how well the transition was managed.

For each MOT-CA transition domain, the proportional need for improvement (NFI) is a composite index that combines a patient's part A (extent of transition) and part B (management of transition) scores into a single index representing the degree of unmanaged transition. The NFI is the preferred method to evaluate associations between the MOT-CA transition domains and other outcomes (Jeon et al., 2019). The NFI is calculated as $[(10 - \text{management of transition})/10] \times \text{extent of transition}$. A score of zero reflects either fully successful management of a transition or absence of a transition. The higher the NFI score, the greater the need for improved management, or the greater the presence of unmanaged transitions.

The authors calculated sample size for the primary outcome using the MOT-CA (Schulman-Green et al., 2017), with a two-tailed Wilcoxon signed-rank test and an alpha adjusted for multiple (seven) comparisons ($\alpha = 0.008$) (Faul et al., 2007). A sample size of 55 had 80% power to detect a difference of 0.5 SDs on any one of the seven MOT-CA domain scores between the two time points at the $p < 0.008$ significance level.

The authors measured distress with the NCCN DT (Roth et al., 1998). The DT is frequently used to measure cancer-related distress (Donovan et al., 2014), and its reliability and validity have been demonstrated in a mixed population of patients with cancer (Chambers et al., 2014; Gessler et al., 2008; Wiener et al., 2017), although to the authors' knowledge, never specifically in a pancreatic cancer population. The NCCN DT consists of one item and uses an 11-point visual analog scale. Patients report their level of distress within the past week, ranging from 0 (no distress) to 10 (extreme distress). Scores of 4 or greater reflect clinically significant distress (Holland, 2013).

The demographic and clinical data were manually extracted from the electronic health record and included the following variables: age, gender, race, date of diagnosis, primary tumor histology, chemotherapy regimen, date of initiation of chemotherapy, and site of metastatic disease. The data were de-identified and stored in a REDCap database.

Data Analysis

The primary variables of interest were as follows: (a) the frequency of transitions, (b) the extent of transitions, (c) the management of transitions, and (d) distress. The frequency was calculated for each of the seven transition domains on the MOT-CA. The extent of each transition domain reflected part A and the management reflected part B on the MOT-CA. Distress was defined as any nonzero response on the NCCN DT.

The authors included patients in the data analysis if they completed both measures at the two study time

TABLE 1. Demographic and Clinical Sample Characteristics (N = 55)

Characteristic	Median	Range
Age (years)	70	48–82
Months from diagnosis to consent	4	0–50
Characteristic	n	
Sex		
Female	28	
Male	27	
Race		
Asian	6	
Black	1	
White	48	
Tumor type		
Adenocarcinoma	54	
Neuroendocrine	1	
Stage		
II	10	
III	4	
IV	41	
Surgery		
No	43	
Yes	12	
Chemotherapy		
FOLFIRINOX	25	
Gemcitabine/paclitaxel	17	
FOLFIRI	7	
FOLFOX	4	
Gemcitabine/capecitabine	1	
Gemcitabine/cisplatin/paclitaxel	1	
FOLFIRI—folinic acid, 5-fluorouracil, and irinotecan; FOLFIRINOX—folinic acid, 5-fluorouracil, irinotecan, and oxaliplatin; FOLFOX—folinic acid, 5-fluorouracil, and oxaliplatin		

TABLE 2. Frequency, Extent, and Management of Health-Illness Transitions

MOT-CA Transition Domain	Frequency		Extent ^a				Management ^b			
	Time 1	Time 2	Time 1		Time 2		Time 1		Time 2	
	n	n	\bar{X}	SD	\bar{X}	SD	\bar{X}	SD	\bar{X}	SD
Approach to care	16	5	5.25	3.36	3.2	2.17	5.94	1.69	4.8	1.79
Cancer status	28	16	7	3.2	4.44	2.53	4.46	1.93	6.19	2.23
Emotional	51	53	4.73	2.5	4.43	2.37	5.94	2.1	5.98	2.15
Physical	52	53	5	2.14	4.7	1.85	6.04	1.98	6.02	1.9
Social	44	39	4.14	3.15	2.72	2.05	6.91	1.91	6.77	1.95
Spiritual	24	19	2.88	2.05	2.42	1.64	7.58	1.35	7.68	1.25
Treatment	32	8	8.75	2.14	8.38	2.83	5.59	1.98	4.62	2

^a Higher scores indicate more transition.

^b Higher scores indicate better management of transitions.

MOT-CA—Measurement of Transitions in Cancer Scale

Note. The range for each score is 0–10.

points. To summarize the demographic and clinical characteristics of the sample, the HIT variables, and the distress scores at both time points, the authors used frequencies and percentages for categorical variables and medians and ranges or means and SDs for continuous variables. The authors tested differences in the MOT-CA transition domain NFI composite scores between the two time points using a two-tailed Wilcoxon signed-rank test. Associations between NFI composite scores and distress were evaluated using Spearman's correlation coefficients and tests. All analyses were performed using R, version 4.1.0.

Results

Enrollment

The authors screened 154 patients, among whom 58 were eligible and 56 consented to participate in the study and completed the measures at time 1 (baseline). One patient died before the time 2 assessment and was not included in the final analysis. In total, 55 patients completed the measures at the two time points.

Demographic and Clinical Characteristics

The sample was fairly evenly divided by gender and was mostly White ($n = 48$), aged older (median = 70 years), and diagnosed with stage IV ($n = 41$) pancreatic adenocarcinoma ($n = 54$). Patients were enrolled at a median of four months (range = 0–50) after diagnosis (see Table 1).

Frequency of Transitions

All patients experienced at least one transition. At time 1, the frequency of transitions ranged between 29% and 95% for all seven domains. More than half of all patients reported experiencing some degree of physical, emotional, social, cancer status, and treatment transitions. By time 2, the frequency of transitions was between 9% and 96% for all domains, with 50% or more of patients reporting physical, emotional, and social transitions (see Table 2).

Extent of Transitions

Among patients who experienced at least one transition, the extent was reported between 2.88 and 8.75 (time 1) and between 2.42 and 8.38 (time 2). At time 1, the cancer status and treatment transitions were reported at the highest extent (\bar{X} score = 7 or greater). However, by time 2, only the treatment transitions remained within the much transition range. Patients experienced moderate (\bar{X} score = 4–6) amounts of physical and emotional transition and little (\bar{X} score = 1–3) spiritual transition at both time points.

Management of Transitions

Among patients who experienced a transition, the management was reported as 4.46–7.58 (time 1) and 4.62–7.68 (time 2). At both time points, patients managed all seven transitions at least moderately well, although the personal transitions (physical,

emotional, social) were consistently reported as better managed.

Presence of Unmanaged Transitions

The NFI ranged from 0.29 to 2.35 (time 1) and from 0.17 to 2.12 (time 2). The presence of unmanaged transitions, as measured by the NFI, significantly decreased between the two time points (see Table 3).

Distress and Transitions

The overall level of distress reported by patients at the two study time points was unchanged (time 1: \bar{X} = 4.07, SD = 2.15; time 2: \bar{X} = 4.02, SD = 2.04; $p > 0.9$). At both time points, there was a direct relationship between the presence of unmanaged physical, emotional, and cancer status transitions and distress.

Having observed little difference between distress reported at times 1 and 2, the authors stratified patients into distress categories (minimal: 0–3, moderate: 4–7, and severe: 8–10) based on the NCCN DT score at time 1. For all patients, the extent of the physical, emotional, and social transition domains increased for each of the distress categories (see Table 4). Similarly, the management of the physical, emotional, cancer status, and treatment transition domains decreased as the distress level increased (see Table 5).

Discussion

This study provides new information on the HIT experience of patients with pancreatic cancer. These patients reported multiple overlapping HITs; the physical, emotional, and social transitions were reported most frequently. For many patients, the extent of all seven transitions decreased between the two time points. On the whole, the sample of patients described moderate management of transitions, although the personal (physical, emotional, social, spiritual) transitions were managed best. This difference in management may reflect that personal transitions are more likely to be under the patient's control and potentially be acted on. The patients experienced clinically significant distress, with a correlation between unmanaged transitions and distress at both time points.

An unexpected finding from this study was that in this sample, the proportion of patients reporting frequent transitions was smaller than expected; most reported experiencing only moderate levels of transition. The rates reported by patients with pancreatic cancer in this study are similar to those reported by a sample of patients with nonmetastatic breast cancer (Schulman-Green et al., 2017). Patients with pancreatic cancer, in comparison to other tumor types, are at increased risk for developing psychological distress (Carlson et al., 2019), and it is possible that the poor

TABLE 3. Correlation Between Unmanaged Transitions (NFI) and Distress

MOT-CA Transition Domain	Unmanaged Transition (NFI) ^a					Correlation Between NFI and Distress	
	Time 1		Time 2		p ^b	Time 1	Time 2
	\bar{X}	SD	\bar{X}	SD		r _s	r _s
Approach to care	0.66	1.39	0.17	0.73	0.028	0.21	0.21
Cancer status	2.12	2.68	0.56	1.37	< 0.001	0.28*	0.48**
Emotional	2.08	2.01	2.12	2.03	0.8	0.6**	0.82**
Physical	2.15	1.77	2.07	1.67	0.6	0.4**	0.59**
Social	1.18	1.7	0.83	1.34	0.1	0.19	0.71**
Spiritual	0.29	0.56	0.21	0.5	0.4	0.09	0.49**
Treatment	2.35	2.52	0.67	1.88	0.002	0.06	0.33*

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

^a Higher scores indicate greater unmanaged transitions.

^b p value from Wilcoxon signed-rank tests

MOT-CA—Measurement of Transitions in Cancer Scale; NFI—need for improvement

Note. The possible range for NFI is 0–10.

TABLE 4. Extent of Transition by Distress Level Among Patients Reporting Transition

MOT-CA TD	Mild Distress (N = 24)						Moderate Distress (N = 24)						Severe Distress (N = 7)					
	Time 1 ^a			Time 2 ^a			Time 1 ^a			Time 2 ^a			Time 1 ^a			Time 2 ^a		
	n	\bar{X}	SD	n	\bar{X}	SD	n	\bar{X}	SD	n	\bar{X}	SD	n	\bar{X}	SD	n	\bar{X}	SD
Approach to care	5	5.6	4.3	5	2	NA	7	5	3.8	7	3	2.7	4	5.3	1.7	4	5	NA
Cancer status	12	6.3	3.9	12	4.8	2.8	11	7.2	2.5	11	4.1	2.6	5	8.4	2.6	5	4.7	2.9
Emotional	20	3.1	2	20	3.4	1.9	24	5.3	2.1	24	4.9	2.4	7	7.3	1.9	7	6.3	2.3
Physical	22	4	1.9	22	4.4	1.8	23	5.4	2	23	4.6	1.9	7	7	2.1	7	5.9	1.9
Social	20	3.8	3.3	19	2	1.1	18	4.3	2.9	18	3.2	2.5	6	4.8	3.7	6	3	2.1
Spiritual	11	2.6	2.1	11	1.7	0.5	10	2.6	1.8	10	3	2.1	3	4.7	2.5	3	2	1.4
Treatment	13	8.6	2.7	13	7.3	3.8	16	8.8	1.8	16	9.3	1.2	3	9	1.7	3	10	NA

^a Scores range from 0 to 10, with higher scores indicating more transition.

MOT-CA—Measurement of Transitions in Cancer Scale; NA—not available; TD—transition domain

Note. Mild distress = 0–3, moderate distress = 4–7, and severe distress = 8–10 on the National Comprehensive Cancer Network Distress Thermometer at time 1.

psychological health and the need to acknowledge the heightened risk of mortality in these patients leads to difficulty accepting the pancreatic cancer diagnosis and its sequelae (Czerw et al., 2020). Such emotions may have influenced the study participants so that they were unaware of or unwilling to acknowledge the presence of a transition.

There may also have been a difference between unconscious and conscious transitions (Fringer et al., 2018), whereby only the conscious transitions were accurately captured by the MOT-CA. Transitions theory highlights the importance of one's awareness of undergoing a transition (Meleis et al., 2000); however, the full transition experience for patients with a diagnosis of cancer is likely more accurately captured with input from the clinician (Collins et al., 2018) and caregiver. The involvement of the clinician and caregiver in the description of the HIT experience has not yet been explored in the literature.

This study adds to previous research among a sample of patients with breast cancer, which demonstrated an inverse relationship between the extent of the physical and emotional transitions and the level of self-management of the changes (Schulman-Green et al., 2017). However, in this sample of patients with pancreatic cancer, it became clear that as the level of distress increased, the extent of the transition was

greater and the management was worse. This finding is understandable because as patients experience more distress and physical and emotional changes, they likely find it more difficult to navigate these transitions.

Limitations

The current study has some limitations, including that Black patients were not well represented in the sample, although the incidence of pancreatic cancer is higher among Black individuals than any other racial group in the United States (Zavala et al., 2021). In addition, eligibility was limited to patients receiving chemotherapy. As the treatment options for pancreatic cancer evolve beyond traditional chemotherapy regimens to the use of immunotherapy and targeted treatments (Sohal et al., 2020), patients may have different HIT experiences. The current results may also have been influenced by the interval between assessments. The timing of the follow-up assessment was primarily selected to limit attrition; this interval may have been too short for some patients to experience or to acknowledge the presence of a transition. The current results may also be limited by the small sample size and the fact that it was not powered to detect a difference in the relationship between unmanaged transitions and distress. Finally, the contemporaneous COVID-19 pandemic may have influenced patients' capacity for and participation in

self-management, their experience receiving chemotherapy, their relationship with healthcare providers, or involvement of family caregivers.

Implications for Nursing

The role of the nurse is a central component of transitions theory. The patient–nurse relationship is often most important during a time of transition (Harrison, 2004; Meleis et al., 2000) because it is the nurse’s role to assist patients in navigating expected and unexpected transitions. Nurses need to be able to identify potential sources of transition and to support patients through these times of uncertainty and distress. The nurse has the opportunity to influence the frequency and severity of unmanaged transitions, to promote good health, and to teach self-management skills (Schumacher & Meleis, 1994). Oncology nurses are “transition specialists” (Ferrell, 2021, p. 109) and are well suited to guide patients through the transition experience.

As understanding of the HIT experiences of a diverse population of patients with cancer continues to evolve, nurses will be better equipped to know when and how best to intervene in the HIT process. Although the specifics of how and when the oncology nurse should intervene have not yet been elucidated, there are concrete lessons that can be learned from

KNOWLEDGE TRANSLATION

- Patients with a diagnosis of pancreatic cancer experience multiple transitions and significant distress.
- Distress was found to interfere with self-management; as patients’ experience of distress increased, they underwent more transitions and were not able to manage them well.
- These findings can inform nurse-led interventions to improve self-management of transitions; nurses have a responsibility to assist patients in preparing for, recognizing, and processing the transition experience.

these data. The results from this study recognize the presence of a clinically meaningful relationship between unmanaged transitions and distress. With this knowledge, the nurse should provide education to patients about the types of HITs, assess for changes in distress level, and offer self-management strategies.

Conclusion

The findings from this study describe the HIT and distress experience of patients with a diagnosis of pancreatic cancer. The authors found that all patients with pancreatic cancer in the current cohort

TABLE 5. Management of Transition by Distress Level Among Patients Reporting Transition

MOT-CA TD	Mild Distress (N = 24)						Moderate Distress (N = 24)						Severe Distress (N = 7)					
	Time 1 ^a			Time 2 ^a			Time 1 ^a			Time 2 ^a			Time 1 ^a			Time 2 ^a		
	n	\bar{X}	SD	n	\bar{X}	SD	n	\bar{X}	SD	n	\bar{X}	SD	n	\bar{X}	SD	n	\bar{X}	SD
Approach to care	5	6.4	2.5	5	6	NA	7	5.4	0.8	7	5.3	1.2	4	6.3	1.9	4	2	NA
Cancer status	12	5.6	2	12	7.4	2.2	11	4.3	1	11	5.9	2.3	5	2.2	1.3	5	5	1.7
Emotional	20	6.9	2.1	20	7	1.9	24	5.6	1.9	24	5.7	2	7	4.6	1.8	7	3.9	1.7
Physical	22	6.6	2	22	6.7	1.8	23	5.9	1.9	23	6	1.8	7	4.9	1.6	7	4.1	1.2
Social	20	7.6	1.7	19	7.8	1.4	18	6.2	1.7	18	6.3	2.2	6	6.7	2.5	6	5.7	1.5
Spiritual	11	7.8	1.5	11	8	1.2	10	7.2	1.4	10	7.7	1.3	3	8	-	3	6.5	0.7
Treatment	13	6.1	2.3	13	5.3	2.2	16	5.3	1.9	16	4.3	2.1	3	5	-	3	3	NA

^a For each MOT-CA TD, these columns summarize the ratings of the management of transition experienced only among patients who experienced the transition (see the n columns for the number of patients included) separately for time 1 and time 2. Higher scores indicate more transition. MOT-CA—Measurement of Transitions in Cancer Scale; NA—not available; TD—transition domain

Note. Scores range from 0 to 10. Mild distress = 0–3, moderate distress = 4–7, and severe distress = 8–10 on the National Comprehensive Cancer Network Distress Thermometer at time 1.

experienced at least one transition and that the extent of transitions, which were managed moderately well, decreased over time. However, as patients' level of distress increased, the extent of the transitions experienced was greater and their management was worse. Ultimately, there is a need to better understand the factors that influence the success of self-management of HITs and, in turn, the experience of distress, not only for patients with pancreatic cancer but also for patients with other malignancies.

Jessica I. Goldberg, PhD, RN, is a supportive care service nurse practitioner and **Jessica R. Flynn, MS**, and **Raymond E. Baser, MS**, are research biostatisticians in the Department of Epidemiology and Biostatistics, all at Memorial Sloan Kettering Cancer Center; **Judith E. Nelson, MD, JD**, is a supportive care service attending physician at Memorial Sloan Kettering Cancer Center and a professor of medicine in the Weill Cornell Medical College at Weill Cornell Medicine; **Elizabeth Capezuti, PhD, RN, FAAN**, is a professor and the William Randolph Hearst Foundation Chair in Gerontology in the Hunter-Bellevue School of Nursing at Hunter College of the City University of New York; and **Dena Schulman-Green, MA, EdM, MS, PhD**, is an associate professor in the Rory Meyers College of Nursing at New York University, all in New York, NY. Goldberg can be reached at goldbej3@mskcc.org, with copy to ONFEditor@ons.org. (Submitted January 2023. Accepted May 12, 2023.)

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