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ORIGINAL ARTICLE

The effect of routine training on the self-efficacy of informal caregivers of colorectal cancer patients

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Abstract

Purpose Little is known about the degree to which caregiver training as part of routine clinical care influences caregiver self-efficacy. The objective of this study was to examine the relationship between training during routine clinical cancer care and self-efficacy among caregivers of colorectal cancer patients.

Methods Caregivers completed a self-administered questionnaire about their experiences with training for specific patient problems and about their task-specific and general caregiving self-efficacy. Associations between training and self-efficacy were examined for each problem using multivariate logistic regression adjusted for caregiver age, race, care burden, education, perception of patient's health, and patient stage of disease.

Results Four hundred seventeen caregivers completed the survey (70% response rate), of whom 374 (90%) were female and 284 (68%) were the patient's spouse/partner. Overall, 77 (38%) reported inadequate training for pain, 80 (38%) for bowel, 121 (48%) for fatigue, 65 (26%) for medication administration, and 101 (40%) for other symptoms. The odds of having low self-efficacy were significantly higher among those with perceptions of inadequate training across the following cancer-related problems: pain 10.10 (3.36, 30.39), bowel 5.04 (1.98, 12.82), fatigue 8.45 (3.22, 22.15), managing medications 9.00 (3.30, 24.51), and other 3.87 (1.68, 8.93).

Conclusions Caregivers commonly report inadequate training in routine colorectal cancer care. Significant and consistent associations between training adequacy and self-efficacy were found. This study supports the value of training caregivers in common cancer symptoms. Further work on how and when to provide caregiver training to best impact self-efficacy is needed.

Keywords Cancer · Oncology · Caregiver · Self-efficacy · Training

Introduction

Morbidity and treatment effects related to cancer often leave people needing physical and emotional support from informal caregivers. The prevalence of informal caregiving for cancer patients is high [1] and predicted to increase as age and cancer prevalence increase. Caregivers have been shown to have significant burden from caregiving tasks such as managing symptoms, physical cares, and medications, devoting a significant amount of time to these cares [1, 2]. Yet, caregivers report significant symptom burden themselves [3, 4], which can lead to poorer quality of life for the caregiver and patient [5]. Furthermore, studies show that caregivers often lack the training that they perceive as necessary to carry out these tasks [2, 6].

Self-efficacy in caregiving is defined as the caregiver's confidence in the ability to care for the patient's needs [5], and self-efficacy is central to health behavior theories due to its robust predictive capabilities of behavior performance, initiation, and persistence [7, 8]. Low self-efficacy in caregiving can lead to avoidance of care tasks and is associated with mental health symptoms such as strain, depression, and anxiety, which, in turn, can affect the quality of informal care provided [3–5, 9–12]. Higher self-efficacy has been

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associated with higher levels of hope in caregivers [13]. It is uncertain how routine training in caregiving relates to caregiver self-efficacy.

Due to the prevalence of caregiving and the significant gap in caregiver training, legislation has been recently adopted in multiple states requiring hospitals to train caregivers prior to patient discharge [14, 15]. Research has shown that additional interventions targeted at caregivers of cancer patients can improve caregiver self-efficacy [16, 17]. With the addition of legislation requiring training for caregivers in some states, it is likely that various forms of training within routine clinical care will be introduced to meet requirements in many states. However, health care organizations balance many priorities in their decision to invest resources and may be unsure of the actual impact of inadequate training. To date, there have been few studies of the relationship between caregivers' inadequate training in the health care context and their self-efficacy. This lack of information may weaken health care organizations' commitment to providing such training.

The primary objective of this study is to address this gap by examining the association between caregiver perception of the adequacy of training in care tasks received in the clinical setting where the cancer patient received care and their self-efficacy regarding their ability to provide care for common colorectal cancer (CRC) problems among patients with CRC receiving care at any Veterans Affairs (VA) facility.

Methods

Participants

Living patients diagnosed with CRC in 2008 and participating in a study assessing quality of VA cancer care [18, 19] were asked to nominate a primary and secondary informal caregiver to be invited to participate in a survey regarding their experiences in cancer caregiving. Between August and November 2009, nominated individuals were mailed a survey, information about the study and a $10 incentive. If primary caregivers did not respond to the mailed survey, the secondary caregiver nominee was invited to participate. Of the 1409 eligible patient respondents, 594 (42%) nominated a caregiver. Four nominees did not have addresses provided. Eight secondary caregivers were mailed a survey after no response was received from the primary caregiver. Of the 598 individuals who were mailed surveys, 417 (70%) valid responses were received. An additional 59 surveys were returned with 56 of them declining to participate, indicating they did not provide care to the patient and 3 returning the survey blank. To assess for any systematic differences between groups, the patients nominating a caregiver were compared with all patients in the 2008 VA CRC registry receiving a survey and the patients whose nominated caregivers completed a survey were compared to those whose caregivers did not complete the survey. This study was approved by the institutional review boards of the University of Minnesota and the Minneapolis VA Medical Center.

Materials

The survey was developed by a team of experts from the National Cancer Institute (NCI), VA, Department of Defense, and the University of Minnesota. Whenever possible, existing validated measures were used. New measures were written at an eighth grade reading level and underwent two rounds of cognitive testing with 10 caregivers of colorectal cancer patients. The resulting questionnaire was pilot-tested with 26 caregivers recruited through the University of Minnesota Comprehensive Cancer Center. Factor structure, internal validity, and criterion validity were calculated for new measures. Demographic characteristics were measured via self-report (see Table 1). Caregivers were asked to indicate if the patient experienced common problems or symptoms related to CRC: bowel problems, fatigue, pain, medication management, or other (dyspnea, insomnia, anorexia, nausea/vomiting, sore mouth, or dysphagia). For those patients who underwent colostomy or ileostomy, questions about bowel problems were skipped.

Independent variables

For each CRC-related problem endorsed as a problem for the patient, a measure of perceived training adequacy was assessed. No standardized training program existed for CRC caregivers in the VA at the time of study. The caregivers in this study were connected to patients treated in any facility in the VA; thus, the type of training delivered may have varied. To better characterize the training, caregivers were asked whether or not training was given by a VA doctor or nurse for each CRC symptom and the type of training received. As it is possible that training was received outside of the VA, we focused on the perception of training inadequacy for each symptom rather than solely the receipt of training. Caregivers were asked to indicate if they got less than, the right amount of, or more training than was needed or wanted in helping the care recipient with each problem. Answers were dichotomized to less than enough training compared with the right amount or more training than desired to assess the association of inadequate training with self-efficacy. In addition, a global measure of training inadequacy was created by creating a 3-level ordinal variable: no inadequate training, moderately inadequate training and extensive inadequate training. Caregivers were categorized as having moderately inadequate training if they reported inadequate training for any symptom but not all symptoms and extensive inadequate training if they reported inadequate training for all symptoms encountered.

Table 1 Caregiver demographic characteristics and clinical characteristics of patients ($N = 417$)

Characteristic	Mean (SD)	*N* (%)*
Age, years	60.7 (12.8)	
Sex		
Male		40 (9.7)
Female		374 (90.3)
Relationship with patient		
Husband or wife		247 (61.0)
Girlfriend, boyfriend, or romantic partner		37 (9.1)
Son or daughter		50 (12.3)
Mother or father		28 (6.9)
Sister or brother		18 (4.4)
Friend		12 (3.0)
Other		13 (3.2)
Percentage of patient care needs provided by caregiver		
I do less than half of the care		56 (14.4)
I do half the caregiving		23 (5.9)
I provide most of the help		119 (30.5)
I provide all of the care		192 (49.2)
Race/ethnicity		
Black		49 (12.1)
White, non-Hispanic		311 (76.6)
Hispanic		28 (6.9)
Other		18 (4.4)
Education		
>High school diploma		237 (58.7)
≤High school diploma		167 (41.3)
Caregiver perception of patient's health		
Excellent		23 (5.7)
Very good		118 (29.4)
Good		144 (35.8)
Fair		86 (21.4)
Poor		31 (7.7)
Cancer stage of patient at diagnosis		
I		121 (35.1)
II		122 (35.4)
III		72 (20.9)
IV		30 (8.7)

*Missing data not included in percentage calculation

Dependent variables

The symptom-specific self-efficacy of the caregiver for each of the common CRC-related problems experienced by the patient was assessed by asking, "How confident are you in your ability to help your care recipient with his or her pain/bowel/fatigue/medication/other problems?" with confidence rated on a scale of 1 "not at all" to 4 "very confident." This variable was highly skewed so scores were dichotomized to those indicating they were very confident compared with all others. In addition, we generalized task-related self-efficacy with three items from the preparedness subscale of the *Family Caregiving Inventory* [20–22] that measure how confident the respondent feels regarding caring for the patient's emotional needs, physical needs, and doing a good job as a caregiver. Respondents indicated level of confidence on a scale of 1 "not at all" to 5 "extremely." Factor analysis was performed and results indicated all the items loaded to one underlying factor. Internal validity of the self-efficacy scale was strong (Cronbach's alpha 0.87).

Covariates

Demographic characteristics of the sample, obtained by self-report, are found in Table 1. Dichotomous variables were created for race and education: black race vs. all other race categories and high school degree or less vs. more than high school degree. The relationship to the patient was dichotomized to compare those who were spouses or partners (girlfriend/boyfriend) with all other relationship categories (child, sibling, parent, friend, other). The caregiver's burden was dichotomized: whether they helped with most or all of their care recipient's needs (>50%) or if they helped with some needs or shared in care provision about evenly with another person (≤50%). To adjust for the patient's severity of disease, cancer stage at diagnosis was obtained from the VA Central Cancer Registry and dichotomized into stages I–II and III–IV. The caregiver's perception of the patient's health was measured with a single-item subjective indicator that was combined into a dichotomous variable representing excellent, very good, or good health compared with fair or poor health.

Statistical analysis

We calculated item response frequencies for all items and scales. Confidence limits on the prevalence of inadequate training per symptom were calculated using the Clopper-Pearson (exact) test. Chi-square tests were used to compare the demographic and patient factors of CRC patients who did and did not nominate a caregiver and of those whose nominated caregiver did and did not respond. Logistic regression was used to assess the association between having low self-efficacy and inadequate training. Five separate models were run for each symptom or problem experienced by the patient. Multivariate logistic regression was then used to adjust for potential confounding factors: age, race, care burden, level of education, stage of disease, perception of patient's health, and general confidence. Caregiver's relationship to the patient was found to be highly correlated with caregiver burden and was subsequently dropped to decrease covariance, with minimal effect to bias. To assess global confidence, we ran unadjusted and adjusted logistic regression with the global measure of inadequate training using the same potential confounders.

All analyses were performed by using SAS 9.4 software [23] and plots were made in R version 3.2.0 with ggplot2 [24]. Statistical comparisons were two-sided and were considered significant at the $p \leq 0.05$ level.

Results

Table 1 presents the demographic characteristics of the 417 caregiver respondents. The sample was 90% female and the vast majority (80%) was the patient's spouse or partner. Over three quarters (76.6%) of the sample was non-Hispanic white, 12% were black and nearly 7% were Hispanic, which is similar to the sample of VA patient respondents (14% black, 5% Hispanic) [18] and to the general VA patient population (12% black, 6% Hispanic) [25]. The average age of the sample was 60.7 years (SD = 12.8). Just over half (58.7%) of caregivers had education beyond high school. Less than a third of the CRC patients had stage III or IV disease at diagnosis. Most caregivers (70.9%) perceived the health of the patient to be excellent or good and 29.1% perceived the health of the patient to be only fair or poor. Compared to CRC patients who did not nominate a caregiver, those who nominated a caregiver were more likely to be married than those who did not (37 vs. 21%, $p < 0.0001$). There were no significant differences in age, sex, race, and stage of disease between those who did or did not nominate caregivers. Nominated caregivers of black (41.7 vs. 28.9% all others, $p = 0.01$) or unmarried (36.3 vs.26.6% married, $p = 0.01$) CRC patients were less likely to respond to the survey.

Caregiver reports of training adequacy and self-efficacy

Figure 1 shows the proportion of caregivers who reported inadequate training for each symptom with 95% exact confidence intervals (CI). Eighty (38%) reported too little training for managing the care recipient's bowel problems, 77 (38%) for pain, 121 (48%) for fatigue, 65 (26%) for managing medications, and 101 (40%) for other symptoms. The number of caregivers reporting they were not very confident in managing each of the care recipient's symptoms were 94 (41%) for bowel problems, 95 (35%) for fatigue, 81 (37%) for pain, 143 (55%) for managing medications, and 100 (37%) for other symptoms. For the global measure of inadequate training, 90 (26.0%) reported having moderately inadequate training, and 82 (23.7%) had extensive inadequate training.

As no standardized training program existed for caregivers at the VA and caregivers may have received training elsewhere, we sought to identify how many caregivers received training from the VA and the type of training delivered. Caregivers were asked if they received training from the VA for each symptom. Of these, 86 (35%) reported receiving training for bowel problems, 64 (23%) for fatigue, 97 (44%) for pain, 137 (52%) for medication management, and 119 (43%) for other symptoms. The training modalities used to train the 417 caregivers included face-to-face in the hospital or doctor's office 188 (45%), pamphlet or written instruction 93 (22%), telephone 47 (11%), face-to-face in the place where caregiver provides care 46 (11%), watching a video 13 (3%), or through a website 5 (1%).

Table 2 presents the relationship between training and self-efficacy for each symptom domain. Logistic regression models performed showed that among caregivers reporting inadequate training for each of the care recipient's symptoms, the odds of having low self-efficacy were consistently and significantly higher than those reporting adequate training. After adjusting for demographic and clinical covariates considered to be potential confounders, the odds ratio of having low self-efficacy and perceived lack of training remained clinically and statistically significant for each symptom: bowel problems 3.42, fatigue 5.40, pain 5.90, managing medications 6.85, and other symptoms 3.80.

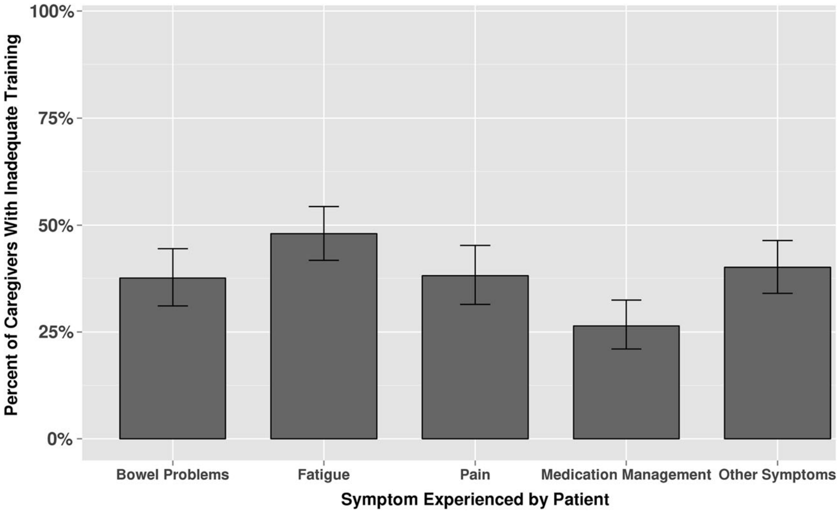

Fig. 1 Proportion of colorectal cancer caregivers reporting inadequate training for each symptom

Table 2 Logistic regression model analysis of the association between low self-efficacy and perception of inadequate training for each symptom domain

Dependent variable symptom domains					
Predictors	Bowel problems ($n = 208$) Odds ratio (95% CI)	Fatigue ($n = 251$) Odds ratio (95% CI)	Pain ($n = 201$) Odds ratio (95% CI)	Medication ($n = 243$) Odds ratio (95% CI)	Other ($n = 251$) Odds ratio (95% CI)
Unadjusted relationship: low self-efficacy and inadequate training	4.37* (2.29, 8.37)	3.77* (2.13, 6.66)	7.88* (3.71, 16.71)	6.32* (3.28, 12.17)	4.05* (2.26, 7.27)
Adjusted relationship[a]: low self-efficacy and inadequate training	3.42* (1.44, 8.12)	5.40* (2.37, 12.29)	5.90* (2.32, 15.04)	6.85* (2.73, 17.22)	3.80* (1.71, 8.40)
Age	1.00 (0.97, 1.04)	1.00 (0.97, 1.03)	1.01 (0.98, 1.06)	0.98 (0.95, 1.01)	1.00 (0.97, 1.04)
Black race	1.36 (0.36, 5.16)	0.69 (0.22, 2.16)	0.75 (0.22, 2.55)	0.67 (0.21, 2.19)	1.37 (0.44, 4.26)
Care burden ≤50%	5.33* (1.16, 24.54)	1.45 (0.45, 4.60)	1.64 (0.45, 5.97)	1.83 (0.66, 5.06)	0.91 (0.33, 2.55)
Education ≤high school	0.92 (0.39, 2.18)	0.61 (0.27, 1.38)	0.88 (0.36, 2.16)	0.62 (0.27, 1.45)	0.96 (0.43, 2.14)
Stage III–IV	1.80 (0.74, 4.36)	2.81* (1.22, 6.44)	2.14 (0.88, 5.22)	1.07 (0.49, 2.35)	1.99 (0.91, 4.35)
Health perception fair, poor	0.64 (0.25, 1.62)	0.81 (0.34, 1.92)	0.98 (0.39, 2.48)	0.47 (0.19, 1.15)	0.77 (0.34, 1.73)
Global confidence	0.30* (0.17, 0.53)	0.19* (0.10, 0.36)	0.26* (0.14, 0.50)	0.25* (0.15, 0.44)	0.25* (0.14, 0.44)

* Statistically significant coefficient ($p \leq 0.05$)

[a] Reference groups: race (all others), care burden (>50%), education (>high school), stage (I–II), and health perception (excellent or good)

We found a consistent relationship between training and self-efficacy when looking at overall training adequacy and global self-efficacy. Table 3 presents the associations. Similarly, the association between lack of adequate training and low self-efficacy remained significant with an adjusted odds ratio of 1.76 (95% CI 1.12, 2.74) for a one unit increase in the global measure of perception of inadequate training.

Discussion

Our findings support the value of adequate training in clinical care settings for colorectal cancer caregivers in managing common symptoms that may occur. While the majority of caregivers felt that they had adequate training, a significant minority reported that they did not receive sufficient training to adequately manage the symptoms of their care recipient, which is consistent with other studies [2, 6, 16, 17]. The lack of adequate training was associated with lower caregiver self-efficacy. We found significant and consistent associations between inadequate training and self-efficacy among specific symptoms and overall confidence domains, even when adjusted for other factors that could impact the self-efficacy of the caregivers. Care burden did show an independent association with low self-efficacy in managing bowel problems alone, even after adjusting for training inadequacy and other factors. The confidence interval was wide, however, denoting a small sample size. Age did not impact the association in any of the experienced symptoms. Although varying

Table 3 Logistic regression model analysis of the association between global caregiver confidence and perception of overall inadequate training

Predictors	Odds ratio	95% CI
Unadjusted relationship: low global confidence and overall inadequate training[a]	1.52*	1.07, 2.18
Adjusted relationship[b]: low global confidence and overall inadequate training[a]	1.76*	1.12, 2.74
Age[a]	1.05*	1.02, 1.08
Black race	2.5	0.68, 9.13
Care burden ≤50%	4.05*	1.24, 13.29
Education ≤high school	0.9	0.44, 1.82
Stage III–IV	0.89	0.44, 1.80
Health perception fair, poor	1.22	0.57, 2.64

* Statistically significant coefficient ($p \leq 0.05$)

[a] Odds ratio denotes a one unit increase on the continuous or ordinal scale

[b] Reference groups: race (all others), care burden (>50%), education (>high school), stage (I–II), and health perception (excellent or good)

patient and caregiver factors did not seem to strongly attenuate the association of training and self-efficacy, they may impact learning styles, so training programs should ideally be individualized to address the diverse needs of caregivers and patients.

This study is a robust survey of caregivers identified from a nationwide census survey of all patients diagnosed with CRC in a single year from the VA. There are several potential limitations. The study was cross-sectional so causal relationship cannot be established for training and self-efficacy. As the purpose of this study was to evaluate the routine training occurring in clinical care rather than the impact of implementing a particular training program, cross-sectional data were collected as the type and timing of training would have varied in each clinical location. There is no evidence that self-efficacy would affect the individuals' reporting of training, and so it is unlikely that reverse causation is a source of the noted association.

The survey was conducted of patients and their caregivers seeking care within the VA system, which is a unique health system, and may not be generalizable to other populations of patients and caregivers outside of the VA system. Caregivers were limited to those nominated by patients. CRC patients nominating caregivers were more likely to be married than those who did not nominate a caregiver and caregivers of black or unmarried CRC patients were less likely to respond, which could contribute to a response bias. Furthermore, while the majority of caregivers in the USA are women, in this sample, the percent of women caregivers was even higher because of the predominantly male patient population of the VA. As a result, we were unable to assess gender differences in the relationship between training and self-efficacy. Last, it is possible that further response bias could exist if caregivers with higher or lower self-efficacy were more or less likely to respond to the survey.

Given that improved caregiver self-efficacy can improve role performance and help protect from negative consequences in the caregiver and patient [5, 7, 26], it is important to identify ways to improve the self-efficacy of cancer caregivers. While previous studies have looked at the impact of a distinct training program on the self-efficacy of cancer caregivers [16, 17], this study identifies that the inadequacy of training occurring as part of routine clinical care is also associated with lower self-efficacy. These findings provide support for routine implementation of caregiver training in symptom and problem management. Further work is needed to delineate how and when to provide training to cancer caregivers that will provide the most impact. Furthermore, as training needs may change throughout the stages of disease and treatment, it would be important to iteratively assess for training needs among cancer caregivers in order to identify and address any gaps in self-efficacy.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

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