







# Caregiver Engagement Practices in National Cancer Institute Clinical Oncology Research Program Settings: Implications for Research to Advance the Field

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**BACKGROUND:** Supportive care interventions have demonstrated benefits for both informal and/or family cancer caregivers and their patients, but uptake generally is poor. To the authors' knowledge, little is known regarding the availability of supportive care services in community oncology practices, as well as engagement practices to connect caregivers with these services. **METHODS:** Questions from the National Cancer Institute Community Oncology Research Program (NCORP)'s 2017 Landscape Survey examined caregiver engagement practices (ie, caregiver identification, needs assessment, and supportive care service availability). Logistic regression was used to assess the relationship between the caregiver engagement outcomes and practice group characteristics. **RESULTS:** A total of 204 practice groups responded to each of the primary outcome questions. Only 40.2% of practice groups endorsed having a process with which to systematically identify and document caregivers, although approximately 76% were routinely using assessment tools to identify caregiver needs and approximately 63.7% had supportive care services available to caregivers. Caregiver identification was more common in sites affiliated with a critical access hospital (odds ratio [OR], 2.44;  $P = .013$ ), and assessments were less common in safety-net practices (OR, 0.41;  $P = .013$ ). Supportive care services were more commonly available in the Western region of the United States, in practices with inpatient services (OR, 2.96;  $P = .012$ ), and in practices affiliated with a critical access hospital (OR, 3.31;  $P = .010$ ). **CONCLUSIONS:** Although many practice groups provide supportive care services, fewer than one-half systematically identify and document informal cancer caregivers. Expanding fundamental engagement practices such as caregiver identification, assessment, and service provision will be critical to support recent calls to improve caregivers' well-being and skills to perform caregiving tasks. *Cancer* 2021;127:639-647. © 2020 American Cancer Society.

**KEYWORDS:** assessment, cancer, caregiving, oncology, supportive care.

## INTRODUCTION

There are at least 2.8 million informal (unpaid) caregivers in the United States who provide care to adult patients with a primary diagnosis of cancer.<sup>1</sup> These caregivers report many unmet needs across psychosocial, medical, daily activity, and financial areas, and those with unmet needs report poorer mental health.<sup>2</sup> Despite performing complex care tasks such as administering medications, managing patients' symptom burden, and coordinating patient care, caregivers typically are not prepared and are undertrained.<sup>1,3,4</sup> Anxiety and depression are common in cancer caregivers (40% and 39%, respectively)<sup>5</sup>; compared with population norms, cancer caregivers have worse mental and physical well-being.<sup>6</sup>

In 2015, the National Cancer Institute (NCI) and the National Institute of Nursing Research (NINR) issued 4 recommendations for advancing cancer caregiving science: 1) improve the assessment of the prevalence and burden of informal cancer caregiving; 2) improve interventions targeted at cancer patients, caregivers, and patient-caregiver dyads; 3) facilitate further integration of caregivers into formal health care settings; and 4) maximize the positive impact

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of technology on informal cancer caregiving.<sup>7</sup> However, a critical first step toward achieving these recommendations is to better understand current caregiver engagement practices in oncology settings, in which supportive care largely has focused on patients.

Supportive care services for patients, such as psychosocial oncology care, pain management, integrative medicine, nutrition, and rehabilitation, are considered essential comprehensive oncology care components. These services also are critical for caregivers because supportive care interventions for cancer caregivers are reported to decrease burden and depression and improve well-being, satisfaction, knowledge, and skills.<sup>8</sup> However, to our knowledge, little is known regarding the availability of supportive care interventions for caregivers in general oncology practice. To our knowledge, most of the literature to date has reported unmet supportive care needs and service use using caregiver reports.<sup>9</sup> There is a paucity of system-level data clarifying service availability and how oncology practices identify caregivers who are in need of services. This gap is a major barrier to advancing the routine integration of supportive care for caregivers. One previous study examined supportive care resource availability for patients and family caregivers at 31 NCI-designated comprehensive cancer centers and observed that service quantity and quality had improved since 1994.<sup>10</sup> For example, approximately 88% of institutions offered nutritional services for patients and 96% offered spiritual services. In addition, approximately 65% of institutions offered caregiver education programs and 84% offered some type of family caregiver program, but to our knowledge the types and scope of caregiver services were not reported.

A recent systematic review<sup>11</sup> concluded that cancer caregiver interventions demonstrate limited capacity for translation into practice. Intervention delivery required a median time commitment from staff of 180 minutes, and the majority of studies failed to include key components to support future implementation (eg, acceptability, potential adoption).<sup>11</sup> Similarly, a meta-analysis highlighting the research-to-practice gaps suggested that evidenced-based supportive care interventions for caregivers rarely are implemented in practice and identified system-level and provider-level barriers to the implementation of caregiver interventions.<sup>12</sup> Cited barriers include insufficient provider awareness of caregivers' needs, suboptimal provider training, emphasis on medical care, and cost<sup>12</sup>; these barriers may be particularly evident in community oncology practices, in which resources often are limited. To the best of our knowledge, no studies to date have assessed caregiver service availability in community

oncology clinics or the presence of caregiver identification and assessment practices.

As part of a larger effort to examine cancer care delivery research capacity and priorities, our team conducted what to our knowledge is the first assessment of cancer caregiver engagement practices in community oncology practices, and reported the percentage of oncology practices that: 1) identify and document caregivers; 2) assess caregiver needs; and 3) have supportive care services available for caregivers. This study also examined variations in these caregiver engagement practices by practice-level characteristics. These data will provide a benchmark with which to monitor future progress in supporting cancer caregivers in the United States who are providing care for patients receiving treatment in the community oncology setting and provide a better understanding of how gaps in caregiver engagement practices vary so that interventions can be targeted appropriately.

## MATERIALS AND METHODS

### Overview

The NCI-funded Community Oncology Research Program (NCORP) supports the recruitment of patients to clinical trials from a national network of community oncology clinics.<sup>13</sup> Data for the current study were obtained from NCORP's Cancer Care Delivery Research (CCDR) 2017 Landscape Survey. This survey solicited information regarding community site infrastructure and capacity for CCDR among NCORP clinics. CCDR is a multidisciplinary science that aims to improve the health and well-being of patients with cancer and cancer survivors by intervening on multilevel factors that influence care delivery.<sup>14</sup> The development and distribution of the Landscape Survey to NCORP components and/or subcomponents (component/subcomponent) has been described previously.<sup>15,16</sup> The term "component/subcomponent" in the NCORP network refers to the specific community oncology practice group. Administrators and research staff at NCORP clinics answered questions via internet-based surveys on topics related to health care delivery and clinical trials. As described previously,<sup>15,16</sup> oncology clinics were allowed to respond as a practice group, indicating that multiple clinics shared providers, patients, and infrastructure using a common electronic health record. The current study focused on 3 independent questions from the Landscape Survey: 1) systematic caregiver identification and documentation; 2) assessment of caregiver needs; and 3) availability of supportive care services for caregivers. The current study was determined to be

exempt by the institutional review board at the Wake Forest School of Medicine in Winston-Salem, North Carolina.

### Measures

Caregiver engagement practice questions used for the current study included: 1) Does your component/subcomponent have a mechanism in place to systematically identify and document a primary family or other informal (unpaid) caregiver for cancer patients? (response options were yes; no; or no, but planning in progress); 2) Are assessment tools, such as rating scales or screening questions, used to identify the needs of informal or family caregivers at your component/subcomponent? (response options were yes, routinely collected for the majority of caregivers; yes, sometimes; or no, not at all); and 3) Are supportive care services available specifically for family or other informal caregivers at your component/subcomponent? (response options were yes; no; or no, but planning in progress). A follow-up question asked participants to specify what caregiver services were offered from a list of services (response options were yes or no). We developed a modified list distinguishing 5 supportive care service types assessed in prior studies,<sup>10,17,18</sup> including: 1) caregiving training or education classes (eg, assistance with activities of daily living, medical or nursing tasks); 2) individual psychosocial (eg, coping support, counseling) or behavioral (eg, smoking cessation, stress management) services for caregivers; 3) group psychosocial services for caregivers (eg, support group, other psychosocial or psychoeducation group); 4) self-care classes (eg, healthy behaviors, diet and/or nutrition, exercise, sleep); and (5) respite care (eg, help in getting access to community resources and/or services to provide caregiver relief). In addition, we included a free-text option allowing respondents to report other supportive care services offered.

We also reported on a subset of practice characteristics for each component/subcomponent including the number of new cancer cases per year (a proxy for practice group size), the organization of cancer care services (inpatient services, outpatient clinic in or on a hospital campus, and a free-standing outpatient clinic or private group and/or practice), American College of Surgeons Commission on Cancer accreditation status, safety-net hospital status, and whether the practice group was affiliated with a critical access hospital. We excluded practice groups that served solely pediatric patients because this group and practice environment have distinct supportive care needs and infrastructure, respectively. Due to sample size restrictions and to preserve respondent anonymity,

practice groups were classified into the 4 US Census regions, including West, Midwest, Northeast, and South,<sup>19</sup> for analyses.

### Statistical Analyses

Frequency statistics summarized practice group characteristics and the prevalence of the following primary outcomes: caregiver identification practices, caregiver assessment practices, and supportive care service availability for caregivers at practice groups. We also calculated the prevalence of practice groups offering each of the 5 supportive care services (training or education classes, group psychosocial services, individual psychosocial and/or behavioral services, respite care, and self-care classes) and the most common co-occurring caregiver engagement practices. Logistic regression models were used to examine the relationships between the primary outcomes and practice group characteristics. For caregiver identification practices and supportive care service availability, answers of “no” and “no, but planning in progress” were combined to compare “yes” and “no” responses in the logistic regression models. For caregiver assessment practices, “routinely collected for the majority of caregivers” was compared with “sometimes” or “not at all.” Backwards selection was used to identify final models for each outcome. A significance level of .15 was used for a predictor to remain in the model. All analyses were conducted using SAS statistical software (version 9.4; SAS Institute Inc, Cary, North Carolina) with a 2-sided  $\alpha$  level of .05 used to indicate statistical significance.

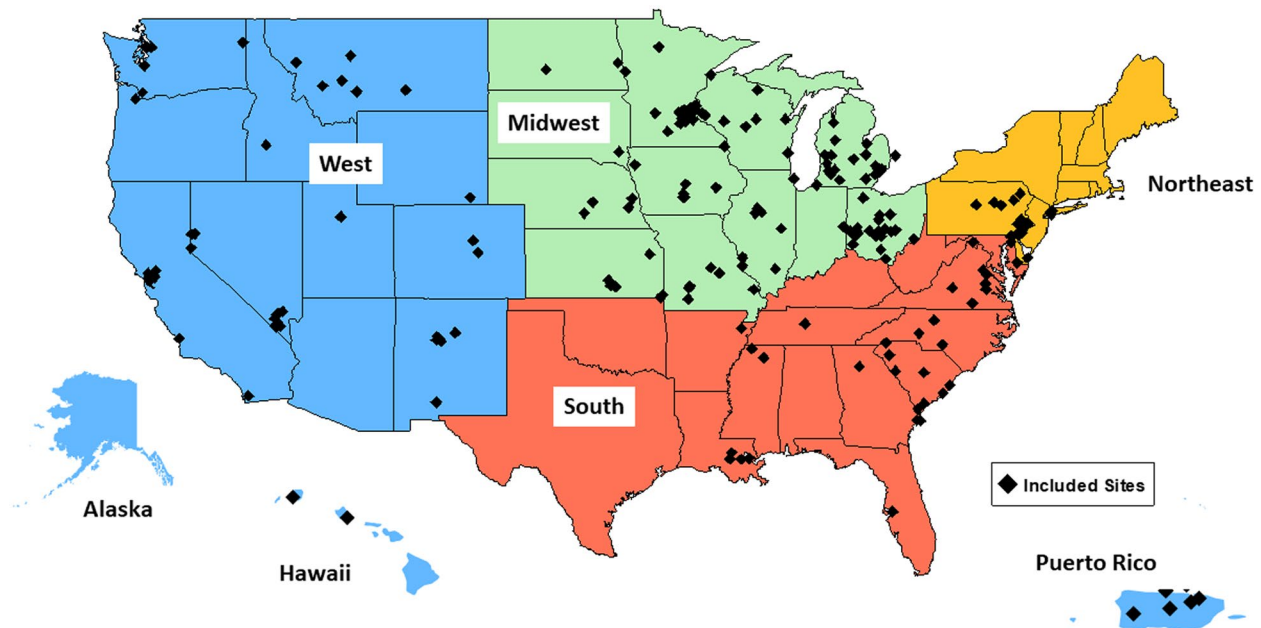
## RESULTS

### Practice Group Characteristics

Of the 943 discrete NCORP practice locations, 504 (54%) responded to the survey, corresponding to 227 practice groups; 17 locations were excluded because they served pediatric patients only. Of the remaining 210 practice groups, 204 responded to each of the primary outcome questions (Fig. 1). A total of 106 practice groups (52%) were located in the Midwest, 43 groups (21.1%) were located in the West, 42 groups (20.6%) were located in the South, and 13 groups (6.4%) were located in the Northeast. See Table 1 for additional practice group characteristics.

### Caregiver Identification and Needs Assessment Practices

Only 40.2% of community oncology practice groups (82 groups) reported that they had a process in place to



**Figure 1.** A total of 204 National Cancer Institute Clinical Oncology Research Program (NCORP) practice groups throughout the United States participated.

**TABLE 1.** Characteristics of Participating Practice Groups (N = 204)

Region, no.	
Midwest	106 (52.0%)
West	43 (21.1%)
South	42 (20.6%)
Northeast	13 (6.4%)
Median no. of new cancer cases per y (IQR)	843 (412-1690)
Service organization, no.	
Inpatient services	168 (82.4%)
Outpatient clinic in or on hospital campus	168 (82.4%)
Free-standing outpatient clinic or private group/practice	123 (60.3%)
COC accreditation, no. <sup>a</sup>	142 (86.1%)
Safety-net hospital, no.	48 (23.5%)
Affiliated with critical access hospital, no.	43 (21.1%)

Abbreviations: COC, American College of Surgeons Commission on Cancer; IQR, interquartile range.

<sup>a</sup>Only asked for those practices with inpatient services.

systematically identify and document informal caregivers (Fig. 2). The majority of practice groups (155 groups; 76%) reported routinely using assessment tools to identify caregiver needs (Fig. 2).

#### Caregiver Supportive Care Service Availability

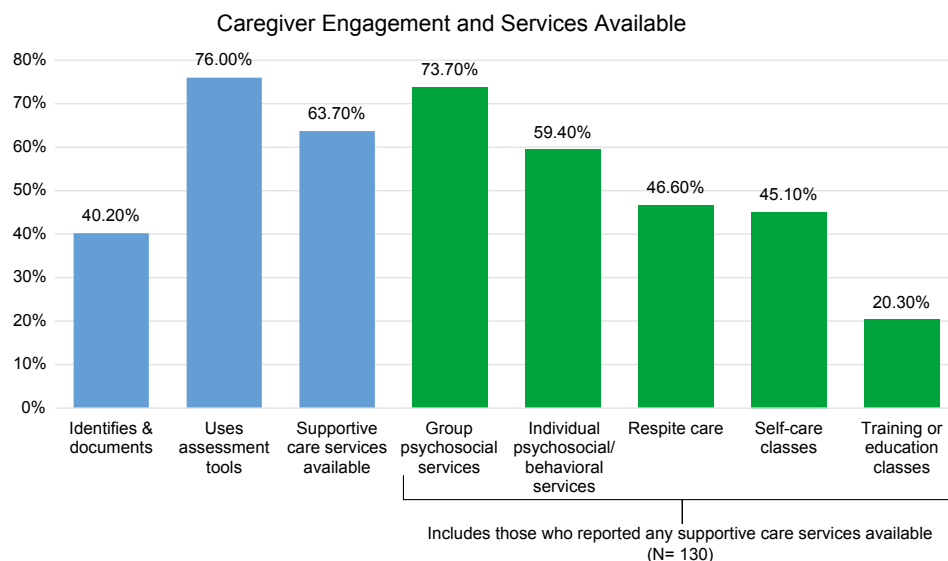
The majority of practice groups (130 groups; 63.7%) had supportive care services available to caregivers (Fig. 2). The most common services included group psychosocial services (98 groups; 73.7%) and individual psychosocial and/or behavioral services (79 groups; 59.4%) (Fig. 2).

Fewer than one-half of the practice groups had available respite care programs (62 groups; 46.6%) and self-care classes (60 groups; 45.1%); <25% of practice groups had available general training or educational classes for caregivers (27 groups; 20.3%). Among the practice groups with available supportive care services, these groups most commonly had 2 types of services (36 groups; 17.6%); few practice groups (12 groups; 5.9%) had all 5 services and only 2.9% of groups (6 groups) reported that they did not offer any of the services. Among practice groups reporting “routinely” or “sometimes” using assessment tools for caregivers, an average of 2 services (SD, 1 service) were available. Patterns of caregiver practices varied, with only 23.5% of practice groups (48 practice groups) engaging in all 3 practices (ie, identifying, assessing, and having available services), whereas 7.8% of the practice groups (16 groups) only identified and assessed needs in caregivers.

#### Practice Group Differences With Regard to Caregiver Practices and Services

As shown in Table 2, caregiver practices varied by practice characteristics. Specifically, caregiver identification practices were more common in sites affiliated with a critical access hospital (odds ratio [OR], 2.44;  $P = .013$ ). Assessment practices were less likely to be conducted in safety-net hospitals (OR, 0.41;  $P = .013$ ). Finally, supportive care services were more commonly available in the





**Figure 2.** Percentage of National Cancer Institute Clinical Oncology Research Program (NCORP) practice groups with informal cancer caregiver supportive care services (204 groups).

**TABLE 2.** Associations Between Oncology Practice Group Characteristics and Cancer Caregiver Engagement Practices (N = 204)

Variable	OR (95% CI)	P
Identifies and documents caregivers		
Free-standing outpatient clinic or private group/practice (yes vs no)	1.77 (0.97-3.23)	.061
Affiliated with critical access hospital (yes vs no)	2.44 (1.21-4.91)	.013
Supportive care services available for caregivers		
Region		
Midwest vs West	0.60 (0.26-1.41)	.044
Northeast vs West	0.19 (0.05-0.76)	
South vs West	0.33 (0.12-0.89)	
Free-standing outpatient clinic or private group/practice (yes vs no)	1.76 (0.89-3.45)	.102
Inpatient services (yes vs no)	2.96 (1.28-6.89)	.012
Affiliated with critical access hospital (yes vs no)	3.31 (1.34-8.20)	.010
Uses assessment tools		
Safety-net hospital (yes vs no)	0.41 (0.20-0.83)	.013

Abbreviations: 95% CI, 95% confidence interval; OR, odds ratio.

Western region of the United States, in practices with inpatient services (OR, 2.96;  $P = .012$ ), and in practices affiliated with a critical access hospital (OR, 3.31;  $P = .010$ ).

**DISCUSSION**

To the best of our knowledge, the current study is the first to assess the prevalence and correlates of caregiver engagement practices in a national sample of community oncology clinics. The findings support and advance recommendations from the 2015 NCI/NINR cancer

caregiving meeting to improve caregiver assessment, interventions, and integration within the health care setting.<sup>7</sup> Greater than one-half of practice groups surveyed in the NCORP Landscape Survey reported not identifying and/or documenting informal caregivers. Suboptimal identification suggests a critical need for education and technical assistance to implement caregiver-tailored services. Policy support through legislations such as the Caregiver Advise, Record, Enable (CARE) Act may further efforts to identify and document caregivers as part of routine cancer care. The CARE Act, sponsored by AARP (formerly called the American Association of Retired Persons),<sup>20,21</sup> in part mandates hospitals to record family caregivers' names at the time of the patient's hospital admission. Most recent available reports from June 2019 have indicated that the CARE Act has become law in 42 states<sup>22</sup>; however, the timeline for implementation of caregiver identification strategies and relevance for outpatient oncology is unclear. Nevertheless, the CARE Act demonstrates national recognition of the importance of documenting the caregivers of inpatients.

One strategy to advance aspirations of the NCI/NINR's recommendation to improve caregiver assessment is to incorporate risk stratification strategies to identify highly stressed patients and caregivers. Although the current study observed only 40% of practice groups reporting systematic caregiver identification and documentation practices, surprisingly, approximately 76% of practice groups reported assessing caregivers' needs.

These findings suggest that assessment is not occurring systematically but rather appears to be performed in an opportunistic manner. Before providing specific recommendations to implement risk stratification processes, more information is needed regarding current caregiver assessment processes, specific assessment instruments and their validity, and ultimately the impact of assessment efforts. For example, it is possible that caregiver needs assessment tools are being used only for caregivers who present for supportive care services or those who proactively seek services. Although patient distress screening was recognized by the Institute of Medicine in 2008 and the National Comprehensive Cancer Network in 2018 as a critical component of high-quality, comprehensive cancer care delivery and consequently has been largely implemented in the oncology health care setting as the sixth vital sign, to our knowledge caregiver distress screening has not.<sup>23,24</sup> Implementing the routine assessment of cancer caregiver needs may support risk stratification processes targeting the most vulnerable caregivers with the greatest needs and distress.<sup>7,12,25,26</sup> One recent study supported the feasibility and acceptability of conducting distress screening among caregivers in a surgical oncology setting.<sup>27</sup> The findings of the current study have suggested that community oncology health care may have the infrastructure with which to support routine caregiver assessment, although further information is needed to guide implementation.

The majority of practice groups in the current study (64%) reported that they have at least one type of supportive care service available for caregivers. Although promising, to our knowledge it is not clear if and how caregivers are being connected to these services, especially because only approximately one-half of the practice groups systematically identified caregivers. Indeed, studies have demonstrated that caregivers have significant unmet needs and suboptimally use supportive care services.<sup>28-31</sup> In addition, because patients remain the primary focus in oncology care settings, it is not clear what types of funding support caregiver supportive care services, thus augmenting concerns regarding caregiver care access. Community organizations may provide caregiver services and national-level resources often are available (eg, the American Cancer Society). However, without education regarding such services and targeted referrals, caregivers shoulder the burden of seeking services in the midst of juggling patient care, work, and other home obligations. One study demonstrated that among a national sample of informal caregivers, approximately 73% accessed online health-related information for themselves, suggesting that

caregivers demonstrate the initiative to seek resources, at least online; however, this study was not cancer caregiver-specific.<sup>32</sup> Advocates have described cancer caregiving as a particularly intense and episodic experience with a high prevalence of burden,<sup>1</sup> ultimately challenging caregivers' abilities to meet their own needs.

The results of the current study also highlighted variability in the types of supportive care services available in the oncology setting with group psychosocial and individual psychosocial and/or behavioral services most commonly available and training or education classes found to be provided infrequently. Because psychosocial and self-care challenges are highly prevalent among cancer caregivers,<sup>1</sup> it is reassuring that the majority of sites provided some type of psychosocial (eg, coping support, counseling) or behavioral (eg, smoking cessation, stress management) services for caregivers to address those needs. A critical next step is to ensure a more systematic planning approach in oncology care settings to ensure available services match caregivers' needs. In particular, the findings of the current study demonstrated that <25% of practice groups offered training or educational services for caregivers. This is consistent with prior findings demonstrating that caregivers report receiving little to no training, and feeling unprepared for their caregiver role.<sup>1,3</sup> These findings are concerning because caregivers frequently endorse a need for or an interest in training and/or educational resources.<sup>33-35</sup> The need for caregiver education likely is increasing as developments in cancer treatment (eg, oral agents, immunotherapy) may place an even greater demand on caregivers to understand and manage complex treatment regimens at home, with less frequent clinic visits.<sup>36,37</sup> Caregiver support strategies can assist those caregivers who are monitoring their loved ones' treatment and disease trajectory. Caregivers overseeing patients being treated with oral agents and immunotherapy in particular may benefit from research testing technology-supported interventions to facilitate caregiving (eg, self-management, remote symptom monitoring, or medication adherence tools).

The results of the current analyses demonstrated some variability in caregiver practices by site characteristics. A clear pattern of caregiver practices according to site characteristics was not evident in the current study. In some instances, it was counterintuitive. For example, critical access hospitals were more likely to identify and/or document caregivers and offer supportive services. Critical access hospitals often are underresourced, and therefore it is surprising that they were more likely to report caregiver engagement practices. These findings could

reflect practice groups' recognition of the critical role cancer caregivers play in facilitating care with vulnerable populations.<sup>38-40</sup> However, additional research is warranted to describe the specific ways practices engage and care for caregivers, including the depth and timing of assessment and services, as well as reimbursements amenable to service provision.

Limitations of the current study should be considered when interpreting the results. First, although NCORP sites include a wide variety of oncology settings across the country, there was a lack of data with which to compare participating Landscape Assessment practices with nonparticipating practices. Second, NCORP sites may lack generalizability to oncology practices nationwide. Both the NCORP network and this Landscape Survey's subsample contain fewer practice groups from the Northeast than observed nationally. This limited our ability to draw strong conclusions regarding regional differences. Third, because these questions were embedded in a larger assessment of cancer care delivery capacity among NCORP practices, we were unable to collect complementary data from patients or caregivers. In addition, although we solicited information regarding several types of common supportive care services, we did not exhaust all possible service types. However, our survey included a free text box that allowed respondents to document services our questions failed to capture.

### Conclusions

The current study focused on characterizing practices in the oncology setting to assess and address the needs of cancer caregivers, and was strengthened by undertaking a nationwide assessment of community oncology clinics, in which the majority of patients with cancer receive care.<sup>41</sup> To the best of our knowledge, the current study is the first to collect these types of data, thus serving as a resource for those invested in advancing cancer caregiving research, particularly within the NCORP network. The current study also has provided baseline data from which to consider any subsequent practice changes.

Although the current study has provided what to our knowledge is the first evidence of caregiver identification and/or documentation and assessment practices, as well as supportive care services available to caregivers within community oncology practice groups, additional research is needed to provide a more comprehensive understanding of effective strategies with which to perform these engagement practices to guide the development of feasible interventions to efficiently link caregivers to needed resources. It also will be important to conduct additional

research to characterize provider-level, clinic-level, and policy-level factors and their impact on caregiver engagement practices and provider recommendations for, willingness to, and barriers to engaging with caregivers. Additional research directions include the identification of optimal technology modalities to support caregivers in community oncology practices.<sup>7</sup> A more in-depth assessment of barriers and facilitators to reaching caregivers, such as those suggested by Northouse et al<sup>12</sup> (eg, provider training, cost for services) would provide key information with which to guide interventions addressing system, provider, and caregiver barriers, and incorporating technology in alignment with previous recommendations.<sup>7</sup> Addressing barriers at multiple levels is critical for the successful implementation and sustainability of supportive care services in community oncology practices. System-level approaches<sup>42</sup> are needed to comprehensively address caregiver needs over time in the dynamic oncology setting. With a better understanding of current strategies for, and barriers to, caregiver identification, assessment, and supportive care service availability, we can develop best practices to reach caregivers in diverse oncology treatment settings.<sup>12</sup>

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## AUTHOR CONTRIBUTIONS

**Chandlyen L. Nightingale:** Conceptualization, methodology, visualization, writing—original draft, and writing—review and editing. **Katherine R. Sterba:** Conceptualization, methodology, visualization, and writing—review and editing. **Laurie E. McLouth:** Writing—review and editing. **Erin E. Kent:** Methodology and writing—review and editing. **Emily V. Dressler:** Data curation, formal analysis, software, and validation. **Alexandra Dest:** Visualization, writing—original draft, and writing—review and editing. **Anna C. Snavely:** Data curation, formal analysis, software, and validation. **Christian S. Adonizio:** Writing—review and editing. **Mark Wojtowicz:** Writing—review and editing. **Heather B. Neuman:** Project administration and writing—review and editing. **Anne E. Kazak:** Project administration and writing—review and editing. **Ruth C. Carlos:** Project administration and writing—review and editing. **Matthew F. Hudson:** Writing—review and editing. **Joseph M. Unger:** Visualization, project administration, and writing—review and editing. **Charles S. Kamen:** Project administration and writing—review and editing. **Kathryn E. Weaver:** Conceptualization, methodology, visualization, project administration, funding acquisition, supervision, and writing—review and editing.

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