Support Care Cancer (2016) 24:929–932
DOI 10.1007/s00520-015-2862-y

ORIGINAL ARTICLE

Implementation of NCCN Palliative Care Guidelines by member institutions

Alexandra Albizu-Rivera [1] · **Diane G. Portman** [1] · **Sarah Thirlwell** [1] · **Shirley N. Codada** [2] · **Kristine A. Donovan** [1]

Received: 9 April 2015 / Accepted: 17 July 2015 / Published online: 31 July 2015

Abstract Increasingly, evidence suggests the integration of palliative care (PC) with standard oncologic care can yield substantial benefits. As part of an effort to improve the PC of cancer patients, the National Comprehensive Cancer Network (NCCN) has developed clinical practice guidelines for PC that promote access to quality, evidence-based PC. This study sought to characterize current implementation of the guidelines by NCCN member institutions. Institutional representatives appointed to the NCCN Palliative Care Guidelines Panel were asked to complete an online survey in the spring of 2014. The survey focused on availability of PC services, screening and referral practices for PC, PC education, and quality improvement programs. The survey was completed by representatives from 21 of 25 NCCN member institutions (84 %). A majority routinely provides PC services via interdisciplinary teams; 52 % routinely inform patients of the availability, elements, and benefits of PC. The guidelines are most often used to guide clinical practice; only 10 % reported using the guidelines to formally screen for PC needs and/or make referrals to PC specialists. Among the 62 % of institutions that screen any patients using any available criteria, when a patient screens positive for PC needs, a referral to a PC specialist is made less than half the time. Implementation of PC Guidelines is incomplete and various aspects of the guidelines, such as the recommendation to screen all patients for PC needs, are applied inconsistently. Despite this, most institutions provide PC services in a manner consistent with the guidelines. Greater implementation of the guidelines' recommendations is needed.

Keywords Palliative care · Clinical practice guidelines · Integration of palliative care

Introduction

Increasingly, evidence suggests that the integration of palliative care (PC) with standard oncologic care throughout the disease trajectory can yield substantial benefits for patients and their caregivers and reduce the overall burden of costs to the health care system [1]. In the late 1990s, the National Comprehensive Cancer Network (NCCN) convened a panel of multidisciplinary professionals with representatives from member institutions to formulate clinical practice guidelines for PC. The NCCN Palliative Care Guidelines (hereafter referred to as PC Guidelines) were first published in 1999 [2] and are updated annually [3]. The purpose of the PC Guidelines is to offer an evidence-based framework that serves as a primary resource for PC for primary oncology teams and other cancer care professionals. The guidelines are designed to promote access to quality, evidence-based PC, and thus, meet the goals of PC to help cancer patients experience the best quality of life (QOL) possible throughout the course of illness.

The PC Guidelines serve to define PC, describe the criteria for referral of oncology patients to PC, delineate best practices in PC delivery and practice, and provide guidance on improvement of PC effectiveness and efficiency through education and quality improvement initiatives. For example, the guidelines recommend early collaboration with a PC specialist for all cancer patients and specify processes that should be in place to integrate PC into standard oncology care. An important step toward achieving PC integration includes conducting routine

---

✉ Kristine A. Donovan
kristine.donovan@moffitt.org

[1] H. Lee Moffitt Cancer Center and Research Institute, MRC-SCM, 12902 Magnolia Drive, Tampa, FL 33612, USA

[2] Emory University Hospital, Atlanta, GA, USA

screening to identify patients with PC needs. Thus, the guidelines provide criteria for screening and referral to a PC specialist and recommend that all patients be screened and re-screened at appropriate intervals for PC needs. Criteria include patient characteristics such as the presence of symptoms, including pain, that are not well controlled with conventional management, high-symptom burden, high distress, severe comorbid conditions, frequent and/or complex admissions and limited treatment options. The guidelines also include standards of care for symptom assessment and symptom management and specify clinical pathways that provide detailed recommendations related to PC interventions and PC service delivery.

In the last several years, a number of national and international organizations have published guidelines regarding PC services for cancer patients [4]. Few studies have evaluated the extent to which these guidelines have been implemented or have helped to create a standard for PC services [4, 5]. To our knowledge, no studies have evaluated progress in implementing the NCCN PC Guidelines. The purpose of the current study was to assess implementation of key aspects of the PC Guidelines by NCCN member institutions.

Methods

In April 2014, a letter of invitation to participate in an online survey was sent via electronic mail to each institutional representative appointed to the NCCN PC Guidelines Panel. For institutions that had more than one representative on the panel, a single representative was selected to receive the invitation. The letter contained a link to a web-based survey formatted by the Moffitt Cancer Center Survey Methods Core. Multiple reminders were sent via electronic mail between late April and early June 2014 to institutional representatives who did not complete the survey in response to the initial request. In instances in which an institutional representative did not reply or the organization had only recently become a NCCN member institution, attempts were made to identify and contact an individual who is involved in the delivery of PC services at the institution who could complete the survey. Survey items focused on the availability of PC services screening and referral practices for PC, PC education, and quality improvement programs. Additional survey items focused on institutional knowledge and attitudes toward the provision of PC and barriers to the delivery of PC services. More specific information about item content is presented with the results, and a copy of the survey is available upon request.

Results

Responses were received from 21 of the 25 NCCN member institutions, reflecting a response rate of 84 %. The initial set of survey items inquired about the availability of PC services and service delivery. All 21 institutions responding (100 %) provide some form of PC; 20 of 21 (95 %) reported a formal PC program or department. Eleven out of 21 (57 %) offer specialty PC services for select groups. Nine (43 %) offer speciality PC services for pediatrics, eight (38 %) for adolescents and young adults, and nine (43 %) for senior adults. Five (24 %) respondents and one (5 %) respondent offer specialty PC services to select cancer types (e.g., gynecologic cancers) and specific treatment modalities (e.g., patients receiving radiation), respectively.

Consistent with the PC Guidelines, nearly three fourths (71 %) deliver PC services via an interdisciplinary team. All 21 of the institutions (100 %) reported the participation of physicians board-certified in hospice and palliative medicine, as well as advanced practice professionals such as nurse practitioners and physician assistants. Other disciplines formally involved in providing PC include registered nursing (67 %), social work (86 %), chaplaincy (76 %), psychiatry (24 %), and psychology (48 %). The guidelines recommend that PC be initiated by the primary oncology team. Consistent with this, 20 of 21 institutions (95 %) indicated that referrals to PC are made by the attending oncologist. Ninety-five percent also allowed referrals to be made by any physician involved in a patient's care while 67 % allowed referrals by advanced practice professionals, 29 % allowed referrals by registered nurses, 19 % allowed referrals by social workers, and 14 % allowed referrals by psychologists. Fifty-two percent of institutions responding allow patients to self-refer to PC. Nine institutions (43 %) reported having institutional guidelines or triggers in place to facilitate the utilization of PC services while five (24 %) indicated this effort as in progress. Approximately half of the institutions (52 %) responding indicated that patients are routinely informed of the availability, elements, and benefits of PC.

The next set of survey items focused on quality improvement. Eleven of 21 (52 %) institutions indicated having some type of quality improvement initiative in place to monitor the quality of PC provided, and another six (29 %) indicated that they are in the process of developing one. Eight of the 20 institutions (40 %) that have a formal PC program or department have earned accreditation or certification. Ten of 21 (48 %) institutions reported that they submit data to the National Palliative Care Registry [6], a registry created by the Center to Advance Palliative Care that collects operational data on PC programs to promote standardization and improve the quality of PC in the United States. The guidelines recommend instituting educational programs for health care professionals to improve effective PC service delivery. Sixty-seven percent of respondents reported having a formal educational/training program in place while an additional four (19 %) indicated that they are in the process of developing such a program.

The next set of survey items referred to the extent to which the guidelines are used to guide PC. Nineteen percent use the guidelines to guide patient assessment and almost half (43 %) use them to guide clinician practice. Eight institutions (38 %) indicated that the guidelines are not used in PC service delivery. Only 10 % of respondents reported using the guidelines to screen for PC needs and/or make referrals to PC. Specific criteria considered while screening include the following patients: with uncontrolled symptoms or high-symptom burden (85 %), with metastatic or locally advanced disease (54 %), with limited treatment options or at the end of life (62 %), with specific types of cancer (15 %), who are undergoing specific treatments (15 %), and who are inpatient (54 %). When a patient screens positive for PC needs, a referral is made to PC services only approximately half the time (46 %). Although most institutions do not expressly use the guidelines to screen patient characteristics for PC needs or a PC referral, 13 of 21 institutions (62 %) indicated they screen at least some (but not all) patients in some manner (but not usually with the PC Guidelines) to determine whether PC services are appropriate. Among those who do screen, the majority (62 %) indicated that patients are not routinely rescreened for PC needs.

In the penultimate set of survey items, respondents were asked to gauge their institution's knowledge of, and attitude toward, PC services (see Table 1). Most respondents indicated that overall, provision of PC at their institution is consistent with the goals of PC as outlined by the NCCN PC Guidelines. However, there is less agreement on the benefits of PC and appropriate recipients and timing of PC. Finally, the last set of survey items asked respondents about perceived institutional barriers to providing quality PC services. As shown in Table 2, the two most frequently cited barriers were attitudes toward PC and insufficient staffing; only 5 % cited regulatory or administrative issues as a barrier.

Table 1 Institutional knowledge of, and attitude toward, palliative care services

At my institution	Strongly agree or agree (%)
Providers agree on what palliative care is	43
Providers agree on the elements that constitute palliative care	67
Providers agree on who should receive palliative care	29
Providers agree on the benefits of palliative care	43
Palliative care is done in a manner consistent with the goals of palliative care as outlined by the NCCN PC Guidelines	81
There is someone championing the palliative care service effort	95
Referrals to palliative care services occur in a timely and efficient manner	43
Providers agree that early integration of palliative care should occur for all oncology patients	19

Table 2 Perceived institutional barriers to providing quality palliative care services

The following hinders my institution's ability to provide quality palliative care services	% Endorsing
Attitudes toward palliative care	71
Insufficient staffing	67
Limited financial resources	57
Lack of awareness of the need for palliative care	48
Time constraints	48
Lack of effective leadership	10
Regulatory or administrative issues	5

Discussion

The survey results demonstrate variable implementation of the PC Guidelines by member institutions. Broad adoption of PC is indicated by widespread availability of services at member institutions as all but one have a formal PC program or department. The offering of specialty PC services to patient groups, such as adolescents and young adults and senior adults, by a majority, indicates attention to needs distinct from the general adult oncology population. There seems to be general agreement among member institutions about the constituents of PC and its benefits, as well as commitment to educational programming for health care professionals to improve PC delivery. Dedication to program quality improvement is indicated by a high rate of participation in data submission to the National Palliative Care Registry and the promotion of PC services overwhelmingly supported by individual championing of PC service efforts at member institutions.

Rather than rely on national guidelines or standards, many member institutions have institution-specific triggers in place to facilitate the use of PC services; in 76 % of cases, referrals are made simply at the discretion of the oncologist and/or primary oncology team. The PC Guidelines themselves are more often used by member institutions to inform clinical practice. Although only a few member institutions use the PC Guidelines to screen for PC needs and/or make referrals to PC services, a majority perform at least partial screening of some patients for PC needs. In addition, the screening criteria considered the following: uncontrolled symptoms, high-symptom burden presence of locally advanced or metastatic disease, and limited treatment options, for example are generally consistent with the criteria recommended in the PC Guidelines. Whether these are the ideal criteria remains to be determined as research evaluating the accuracy and utility of these screening criteria is limited [7, 8].

Despite significant achievements, limitations in implementation of the PC Guidelines continue to impact member PC services. The interdisciplinary team construct, a mainstay of PC, and formal quality improvement efforts to monitor the quality of PC provided are still not universally employed. Relatively few use the PC Guidelines to screen for PC needs, and when a patient screens positive for PC needs using other guidelines or triggers, a referral to PC services is not prevalent. The primary oncology team may not refer the patient for PC services, and patient self-referral capability is also restricted. This may be due, at least in part, to institutional attitudes about the integration of PC in standard oncology care and/or limited resources available to provide PC services.

Although informative, this study has noteworthy limitations. First, some NCCN member institutions did not participate in the survey. Although 84 % is a high rate of participation, findings are only representative of the subset of institutions that responded to the survey. Similarly, the responses correspond to the views of the institutional representative who completed the survey. Whether an on-site audit of PC at each institution would yield similar results is unknown. Second, during the conduct of the survey, three institutions were named NCCN Comprehensive Cancer Centers, increasing the total number of member institutions from 22 to 25. The survey was made available to representatives from each of these institutions; however, these institutions are not (yet) represented on the PC Guidelines Panel. It may be the case that participation on the PC Guidelines Panel, or any other NCCN panel, for that matter, will have some bearing on an individual's responses on behalf of their institution to a survey such as this.

The results of the current survey suggest several future directions for examining implementation of the NCCN PC Guidelines. The extent to which the PC Guidelines have been implemented in National Cancer Institute (NCI)-designated cancer centers is not known. The NCI-designated cancer centers represent most of the leading cancer centers in the United States, and it would be informative to examine whether they have implemented the PC Guidelines. Similarly, it would be informative to examine implementation of the PC Guidelines in community-based cancer centers. Given the documented lack of standardized PC care in cancer clinical trials, [4] it would be interesting to assess the PC resources actually available in community-based cancer centers who participate in NCI's cooperative oncology groups. Finally, given the increasing acceptance of the need to integrate PC with standard oncology care, it would be informative to resurvey the NCCN member institutions at some later date to determine whether progress has been made in implementing the PC Guidelines.

Participants' responses to our questions about institutional attitudes toward PC and barriers to PC service delivery suggest ways to both promote greater implementation of the guidelines, and advance the integration of PC with standard oncology. The majority of respondents indicated that there is no agreement on the benefits of PC, on who should provide it and who should receive it and when. As the empirical evidence in support of PC services throughout the disease trajectory continues to accumulate, and the adoption of standardized needs assessments and referral criteria for PC utilization evolves, we should anticipate more agreement among busy oncology care providers on the role of the PC specialist and the value of PC.

Conflict of interest The authors have no financial interest, arrangement, or affiliation to disclose. Dr. Codada has disclosed that she was a member of the NCCN Palliative Care Guidelines Panel at the time of the study.

References

1. Smith TJ et al (2012) American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care. J Clin Oncol 30:880–887
2. Levy MH (1999) NCCN Task Force reports: supportive and palliative care. Oncology 13:517–522
3. Network, N.C.C. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines (R)). Palliative Care 2014 [cited August 22, 2014
4. Zafar SY et al (2010) Standards for palliative care delivery in oncology settings. Cancer J 16:436–443
5. Hui D et al (2012) The lack of standard definitions in the supportive and palliative oncology literature. J Pain Symptom Manage 43:582–592
6. Registry, N.P.C. National Palliative Care Registry. 2014 [cited August 22, 2014]; Available from: https://registry.capc.org/cms/Home.aspx
7. Glare PA et al (2011) Palliative care in the outpatient oncology setting: evaluation of a practical set of referral criteria. J Oncol Pract 7: 366–70
8. Glare P et al (2013) Study using the NCCN guidelines for palliative care to screen patients for palliative care needs and referral to palliative care specialists. J Natl Compr Cancer Netw 11:1087–96