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Bringing Advanced Directives and Symptom Assessment and Management to Community Oncology Practices

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Abstract

Palliative care services are not available in most outpatient oncology practices. A program training 11 mid-level providers from oncology practices on advanced directive discussions and supportive symptom assessment and management performed by palliative care specialists was completed. A follow-up session 9 months later identified barriers to implementation. Of the 11 mid-level

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providers, 8 participated in the follow-up session, and 9 of the 11 providers implemented advanced directive's discussions and symptom assessment and management for patients with metastatic cancer. Main barriers included uncertainties about reimbursement, patients' lack of knowledge about palliative care, and lack of access to supportive services. This program successfully promoted advanced directive discussions and supportive/palliative care symptom assessment and management to community oncology practices, which will hopefully translate into improved quality of life for patients with metastatic cancer.

Keywords

palliative care; quality of life; metastatic cancer; outpatient oncology practices; mid-level providers; supportive services; community oncology practices

Introduction

In 2010, the Florida Society of Clinical Oncology (FLASCO) Ad Hoc Committee on Payer Relations met in person or by conference call with medical directors and other payer staff from national insurance companies. There was great interest from the leaders of the insurance companies on the development of programs that address issues related to end-of-life care of patients with cancer. The FLASCO leadership expressed interest in assuming a leadership role in the development of palliative care intervention programs aimed at improving the quality of life of metastatic patients with cancer and potentially minimizing futile therapeutic interventions in patients with end-stage cancer. The insurance companies' leaders challenged FLASCO leadership to develop these programs with the promise of potentially funding studies that measure the effectiveness of these interventions.

At the national level, a provisional clinical opinion by the American Society of Clinical Oncology (ASCO) in 2012 supports strategies aimed at optimizing concurrent palliative care and standard oncology care and research evaluating its impact on important patient and caregiver outcomes and society.¹ These recommendations are supported by recent studies that demonstrated the value of multidisciplinary palliative interventions delivered concomitantly with standard oncologic care, in improving the quality of life and potentially the overall survival of patients with metastatic cancer.^{2,3} Both of these studies were based at academic medical centers with well-developed, well-established, multidisciplinary palliative care teams. Most (85%) of the cancer care in the United States takes place at outpatient community medical oncology practices that do not include palliative care specialists or specialists in other supportive disciplines, such as psychology, pain management, and nutrition. Therefore, most patients with cancer do not have ready access to these important palliative interventions. The main focus of the oncology patient care team is on delivering effective, cancer-directed, therapeutic interventions; and as a result of this, the management of other related symptoms (depression, pain, spiritual needs, transportation and financial issues, and caregiver needs) comes second and is frequently not addressed adequately. It is not until all cancer treatments are exhausted and the patients are referred to hospice that palliative care interventions are reviewed in detail and brought to the forefront, and many opportunities to impact and improve the quality of life of the patients have already been lost.

This can also lead to the inadequate establishment of the patients' and families' wishes regarding advanced directives and end-of-life care issues.

The significance of this problem in Florida was confirmed with a survey of the members of the FLASCO executive committee, which represents leaders from small and large oncology practices from throughout the state. None of the surveyed oncologists in their practices reported the availability of formal outpatient-based early palliative care consultations for patients with metastatic cancer (aside from referral to hospice services once cancer treatments are stopped) or the availability of palliative care trained personnel within their practices. None of them stated that they were aware of advanced directive forms approved for use in the state of Florida in the outpatient setting or that they had used any of these forms in that setting (including the Five Wishes form) with any of their patients.

Recently, the Mayo Clinic in Jacksonville, Florida, completed a randomized pilot study, PAL-1 study, which demonstrated the effectiveness of an Advanced Registered Nurse Practitioners (ARNPs)-coordinated early palliative care intervention in improving the emotional quality of life of patients with metastatic cancer.⁴ The palliative interventions included advanced directive's discussions utilizing the Five Wishes tool, an advanced directive tool developed by a national nonprofit organization, and Aging with Dignity that has become the most popular living will in the United States. It has been translated into 26 languages and meets the legal requirements as a living will in 42 states, including Florida.⁵ The Five Wishes document was well received by all the PAL-1 study participants. None of the patients who participated in this study were aware of the existence of that tool. This study also included specific pre- and postintervention assessments for the benefit of the interventions using the validated Functional Assessment of Cancer Therapy-General tool (FACT-G) tool. The FACT-G is a validated tool first used in 1993 and is a questionnaire that measures health-related quality of life for patients with cancer.⁶ Statistically significant improvements in the emotional well-being of patients in the intervention arm were observed.⁴

Potential barriers to the successful development of an early palliative care intervention program for patients with metastatic cancer in the outpatient community and academic medical center settings may include lack of an adequate number of health professionals trained in palliative care, lack of awareness of recent data establishing the benefit of palliative care interventions, financial barriers, and lack of tools to effectively implement and measure the outcomes from palliative care interventions. In order to address these barriers, a grant proposal to ASCO for a state affiliate grant was funded, and this is a report of the findings. This project addressed these barriers by educating and training personnel who are an integral part of the care of patients with metastatic cancer in the outpatient community and academic oncology practices, namely the oncology ARNPs, physicians assistants (PAs), and licensed clinical social workers (LCSWs), and by bringing the tools needed for the assessment of these programs into the hands of the oncology team that is coordinating the care of the patients with cancer. This project successfully brought palliative care interventions including advanced directive discussions and palliative symptom assessment and management to the participating practices.

Methods and Materials

Goal

The main goal of this project was to educate and train mid-level providers (ARNPs, PAs, and LCSWs) from 3 to 4 community-based medical oncology practices and from 2 to 3 academic medical centers on the principles of palliative care for patients with metastatic cancer and on the presentation of the Five Wishes document⁷ to these patients in the outpatient setting, with the ultimate goal of providing these palliative care interventions within their respective oncology practices. The opportunity to participate in this program was presented to all 375 FLASCO members via e-mail. A total of 11 practices volunteered to have their mid-level providers participate including 9 ARNPs, 1 PA, and 1 LCSW from 8 community oncology practices and 3 academic medical centers. A decision was made to accept all 11 participants. The project was deemed exempt from institutional review board, since this was a survey for practitioners, which did not include the dissemination of individual patient data.

Training and Consultative Forms

Before the first meeting, the participants completed a pretraining evaluation form that assessed the type of information that the participants hoped to gain from the training and inquired about the types of palliative care consults (if any) that were currently performed in their practices. Their current use of the Five Wishes form was also evaluated.

Training Programs

The training program took place on July 15, 2011, at the Mayo Clinic Simulation Center in Jacksonville, Florida. The program was directed by trained palliative care physicians and ARNPs from Mayo Clinic and the University of Florida. Trainers included a palliative care fellowship program director, the principal investigator for the PAL-1 trial, a director of a palliative care program, a chaplain, a palliative nurse practitioner expert, an expert on quality-of-life assessment, and a specialist in communications. The training program included lectures that provided an overview of palliative medicine, incorporating the different domains of care, discussions on the results of recent randomized clinical trials on palliative care interventions, a review of the FACT-G quality-of-life assessment tool, and a discussion of the Mayo Clinic PAL-1 study, the randomized study that forms the basis for this intervention. Interactive sessions during which the participants received one-on-one coaching on the performance of video-recorded advanced directive discussions and FACT-G-driven symptom assessment and management were completed.

The trainees were asked to implement these palliative care interventions on their patients with metastatic cancer upon return to their practice. In order to assist in the transition to this new method of care, several forms were given to the participants to use during the consultations, such as the Intervention Record (Figure 1) and Was It Worth It forms (Figure 2). The Intervention Record lists potential palliative interventions that were utilized in the PAL-1 study. The Was It Worth It form assesses patients' satisfaction with the interventions. The participants were asked to use the Five Wishes form or other advanced directives forms

of their preference. The FACT-G form was used to assess the patients' quality of life and to direct the need for suggested interventions listed in Figure 1.

Analysis

A follow-up training session took place on March 23, 2012, during which the trainees discussed their experience including barriers to implementation. Open-ended questions were used to guide the discussions. Analysis of the data discussed and presented by the participants was purely descriptive.

Results

Pretraining Session Survey Results

Although 7 of the 11 participants were familiar with the Five Wishes document, only 3 actually utilized it in their practice. All of the participants expressed interest in learning about the different aspects of palliative care, including grief assessment, facilitation of advanced care planning, and existential/spiritual concerns.

Posttraining Session Results

Out of the 11 trainees, 8 returned for the posttraining session. Three trainees did not return because of personal reasons. One of the trainees who did not return had changed her job recently, although she reported that she was able to implement the program prior to changing her job. All of the trainees who returned reported that they were able to implement the palliative care interventions in their practices. The patients that were offered these services reported that they found them useful and informative; several of them commented that they had never discussed end-of-life issues and advanced directives.

Most of the barriers to implementation mentioned by trainees could be grouped into patient-related barriers and practice-related barriers (Table 1). The main patient-related barrier was the patient feeling that engaging in palliative care discussions meant that they will have to give up hope and not be able to continue chemotherapy treatments. Unfamiliarity with the term "palliative care" was seen as a patient-related barrier because they were not able to differentiate between palliative care and hospice care. It was suggested that indeed the term "supportive care" may represent the program better, as suggested by our colleagues at MD Anderson Hospital.⁸

The main practice-related barrier was the lack of dedicated time for this effort, with most participants stating that they had to carry out these initial palliative care interventions afterhours and on their own time. Another practice-related barrier involved uncertainties about reimbursement for these services. Most of the trainees billed for the palliative interventions based on the time spent on face-to-face consultation, some billed for consultation visit.

Trainees commented on how surprised they were at the profound effect that giving the patients 30 minutes to discuss palliative care issues had. One observation by several trainees was how different their perception of the patient's quality of life was compared to the patient's perception. They discussed the more intense levels of disclosure that the patients

expressed during this time, many of them revealing issues that had never surfaced during their follow-up treatment visits. One very telling example of this was a patient with metastatic ovarian cancer hospitalized for 4 weeks who, during the palliative care intervention visit, explained her love of gardening. This led to an intervention of taking her outside of the hospital for short periods of time to explore the grounds; the profound effect on her well-being was noted by the nurses following the intervention.

The patients felt that the Five Wishes document was useful. Five of the trainees completed the FACT-G surveys with their patients and found them useful in identifying the areas in need of intervention and to facilitate the discussion. The Intervention Record form facilitated the identification of possible useful interventions (Figure 1). One of the participants utilized the Was It Worth It form, with 4 of the 5 patients stating that their participation in this program was worthwhile (Figure 2).

Several of the recommendations from the trainees that they considered essential for positive results include having the palliative care consultation in a different room from the patient examination room or chemotherapy rooms, with the family present, and having the discussion during a separate time fully dedicated for palliative care interventions. The participants also reported the importance of the “unit of care,” consisting of not only the patients but also their caregivers and families. In some cases, the patient’s goals differ from his or her families’ goals that can contribute to the stress of the patient. Therefore, it is important in those individual cases to interview the patient without the family members present and to assist the patient and his or her family in resolving their conflicts.

Support from the physician practice leader was critical to the success of the implementation of palliative care interventions. Referral of patients for the palliative interventions was required and would not have taken place without the support of the physicians. In some of the practices, the patients referred for the palliative care interventions came from only a limited number of physicians.

Having a separate, dedicated time for the palliative care interventions was deemed as ideal. Some of the trainees perform multiple functions within their practices including marrow aspiration and genetic counseling in addition to evaluation of returning patients.

Several of the trainees mentioned their need for ongoing training. Their success in helping their patients was dependent on them creating a multidisciplinary palliative team composed of a chaplain, nutritionist, psychologist, and a social worker, among others. Creating a community-based listing of providers of these services helped facilitate these services. Several expressed frustration over their inability to provide satisfactory answers to patients in need of financial assistance.

One of the most significant benefits of this initiative, as reported by several of the trainees, was the identification of resources, of which they were previously unaware, which will benefit many of their future patients with cancer. Identification of psychology counselors, pain management specialists who provide home services, and chaplains who provide outpatient consultation services were some of the services recognized by this initiative.

The trainees mentioned that the repetitions of the palliative interventions led to an increased level of comfort. This familiarity also enhanced confidence in their ability to identify the community resources that would best address their patients' needs. All of the trainees felt the most significant benefit was the witness of patients and their families as they shared their life story with the health providers. The privilege of getting to know their patients and their families better and recognizing what things were especially important to them was priceless.

Discussion

This training program was well received and enabled mid-level practitioners to implement palliative care interventions including symptoms assessment and management and advanced directive discussions within their respective oncology practices. The palliative care intervention sessions provided the time needed for the trainees to learn from their patients, which led to personal growth. The finding of new resources within their communities was an added benefit that will help their future patients with cancer.⁹ The FACT-G questionnaire and the Five Wishes were deemed very helpful.

Hui et al assessed the availability and integration of palliative care at the US cancer centers and described similar practice-related barriers as the ones described in this project.¹⁰ Other prominent barriers identified in our study included the patients' lack of knowledge of these services and lack of physician referrals. These 2 barriers have also been reported by Kumar et al¹¹ and are consistent with the barriers identified for hospice consultations.^{8,11,12}

This study has several limitations including the qualitative nature of data analysis. Formal instruments were not used to analyze the data. Specific information on the total number of patients served and their diagnosis was not collected. The small number of participants limits the validity of the observations. Most of the participants were nurse practitioners, with only one of the participants being a Licensed Clinical Social Worker, so analysis of the differences in effectiveness between different mid-level providers was not feasible.

One of the chief obstacles in implementing this program on a larger scale is the lack of knowledge about or misconceptions about the nature of palliative care. This seems to be one of the root causes of patients' and physicians' lack of endorsement. This program demonstrates the interest of medical oncologists in the incorporation of outpatient palliative care services into their practices, and the capability of mid-level providers to become enthusiastic leaders in the provision of advanced directive discussions and symptom assessment and management and in organizing multidisciplinary palliative care teams with community resources. Continuation of this program, with the training of additional mid-level providers is recommended. The national expansion of this program is likely to lead to the improvement in access of patients with metastatic cancer to beneficial palliative care interventions early in their clinical course, in the outpatient setting, as an integral part of the care delivered by community oncology practices.

Conclusion

An educational program that trains mid-level providers (ARNPs, PAs, and LCSWs) on palliative care successfully brings advanced directive discussions and palliative symptom

assessment and management to outpatient oncology practices. Adoption of this training program on a national level could lead to more comprehensive care of patients with metastatic cancer and improved quality of life for our patients.

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	Palliative Care Interventions to be Offered	Date Offered	Date Implemented	Comments
1	Exercise and light weight lifting rehabilitation programs			
2	Yoga			
3	Review and optimization of antiemetic regimens			
4	Assessment of family needs with deployment of programs of social and financial assistance			
5	Pain management with goal of zero pain			
6	Detailed assessment of side effects of treatment with tailored program to mitigate them			
7	Assessment of home accessories to promote mobility and activities			
8	Creation of computer-based social networking tools (Care Pages)			
9	Assessment of family and friends support with pro-active attempts at improving support structure			
10	Family and patient psychological counseling			
11	Home visit by the ARNP to assess home situation and support structure (all patients)			
12	Sex life consultation and medication intervention			
13	Assessment of depression status and psychological and/or pharmacological interventions			
14	Coping skills and goal setting training			
15	Five Wishes and living will completion			
16	Stress management and other therapeutic interventions			
17	Creation of life story with family members and incorporation of this into electronic social networking tool			
18	Pharmacological and other measures to aggressively improve sleep impairment			
19	Occupational training: knitting, photography and others with incorporation of progress in electronic social network tool			
20	Spirituality assessment and assistance			
21	Participation in cancer support groups			
22	Referral to nutrition/dietician services			
23	Integrative Medicine			

Figure 1.

The mid-level provider used this form as a fairly exhaustive list of potential palliative care services. After talking with the patient, the participants using the Functional Assessment of Cancer Therapy–General (FACT-G) survey tool decided which intervention would be the most effective depending on the patients' needs and implemented them accordingly.

Was It Worth It (WIWI) Questionnaire

Participating in a clinical trial/research study is a personal choice and an individual experience. We would like to get your feedback on your experience in this research study.

Directions: Please answer each question by circling Y (for yes), N (for no), or U (for uncertain).

1. Was it worthwhile for you to participate in this research study?

Y N U

2. If you had to do it over, would you participate in this research study again?

Y N U

3. Would you recommend participating in this research study to others?

Y N U

4. Overall, did your quality of life change by participating in this research study (circle one response)?

It improved

It stayed the same

It got worse

5. Overall how was your experience of participating in this research study (circle one response)?

Better than I expected

The same as I expected

Worse than I expected

Figure 2.

This form was given to the participants in order to evaluate the patients' experience of the palliative care consultations and services for the purpose of improving the program for future patients.

Table 1

Barriers to implementation of a mid-level provider-directed palliative care consultation program

Patient-related Barriers	Practice-related Barriers
Concern that cancer treatments will need to be discontinued	Lack of time
Lack of knowledge about the benefits of palliative care.	Lack of ancillary services
Confusion of palliative care with hospice care	Uncertainties about re-imbursement for services