

CASE REPORT

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Challenges of Managing Advanced Cancer Patients Through Phone Triage at an Outpatient Supportive Care Clinic: A Case Series of Palliative Care Patients

Lindsey E. Pimentel, Sriram Yennurajalingam, Elizabeth D. Brown and Debra K. Castro

The University of Texas MD Anderson Cancer Center. Corresponding author email: syennu@mdanderson.org

Abstract: Palliative care strives to improve the quality of life for patients and their families by impeccable assessment and management using an interdisciplinary approach. However, patients with cancer-related pain and other symptoms tend to be undertreated because of limited follow-up visits due to late referrals and logistics. Thus, patients who present to the outpatient Supportive Care Center at The University of Texas MD Anderson Cancer Center often experience severe physical and psychological symptoms. The two case reports presented highlight the challenges of managing distressed patients with advanced cancer in the outpatient setting. These descriptions focus on addressing patient needs over the phone to enhance the care patients receive at the Supportive Care Center. Future prospective studies are needed to measure the effectiveness of using phone triaging in conjunction with standard outpatient palliative care.

Keywords: ambulatory palliative care, telephone triage, telephone counseling, outpatient cancer care, cancer

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Introduction

The goal of palliative care is to improve the quality of life of patients and their families who are facing a life-threatening illness, such as cancer, by preventing and relieving suffering by means of early identification, assessment, and treatment of pain and other problems—physical, psychosocial, and spiritual.¹ The most important aspect of providing quality care to these patients and families is communication.¹⁻³ By enabling a relationship of trust to develop with the professional care team, timely communication enables seamless delivery of palliative care to suffering patients and caregivers.³

Provision of palliative care to patients with advanced cancer, who tend to have high levels of symptom distress due to the severity of their physical and psychological symptoms,⁴⁻⁷ can be challenging. Patients with advanced cancer who are outpatients pose additional challenges because of limited follow-up visits due to most referrals to outpatient palliative care clinics being made late in the trajectory of the disease and due to the logistics of receiving care away from home. These patients often have only one or two follow-up visits to a comprehensive cancer center.^{8,9}

Previous studies revealed the need for patients to have an available resource aimed at providing medication education, assurance of the quality of care in the home setting, and emotional support.¹⁰⁻¹³ Telephone consultation is an option for providing such resources and timely care to outpatients. The University of Texas MD Anderson Cancer Center has extended this concept by initiating daily triaging by clinical nurses of the outpatient Supportive Care Center (SCC) via the phone. This “phone care” was designed to address the needs of both outpatients and their at-home caregivers.⁸ The program provides a daily resource for addressing symptom burden, family and patient distress, and other concerns or questions.

The MD Anderson Supportive Care Center Phone Triage Program

The MD Anderson Cancer Center’s Department of Palliative Care and Rehabilitation Medicine has an outpatient center, the SCC, dedicated to continued patient care. The SCC schedules patients for routine follow-up visits to the cancer center to ensure

adequate symptom management; family, patient, and caregiver support; and constant communication between families and the department’s interdisciplinary team (IDT). Each week within the SCC, the registered nurses are designated to a phone triaging day to address patient concerns during clinic hours.

The palliative care of patients across all care settings follows a standardized management plan.¹⁰ When a patient with advanced cancer is seen in the SCC, the concept of phone triage is explained to the patient and family, who are encouraged to use it between visits to enable continuity of care by the SCC. This procedure has been proven to increase use of out-of-hours services.¹¹ Outside of clinic hours, a dedicated on-call physician is available for urgent issues and concerns.

Between regularly scheduled visits to the outpatient SCC, patients and caregivers are able to call the phone triage line with questions or concerns. The triage nurse can access patient information immediately. Nurse autonomy is practiced, but the patient’s dedicated physician is contacted when necessary for updates on the patient’s condition and for recommendations. In addition, if during an outpatient visit to the SCC a patient expresses a high symptom burden, within the following days the phone triage nurse can initiate contact with the patient to assess symptom control at home.

Published data on using a phone care program to manage the needs of outpatient palliative care are limited. In the following case reports, we provide background information and discuss the challenges of addressing the needs of these patients and their caregivers via MD Anderson’s SCC phone care program. These case reports will provide better understanding of the degree to which ongoing communication and expressive supportive counseling over the phone help us provide our patients with the most comprehensive care possible. The reports will also demonstrate the need for further research on this approach to palliative care.

Edmonton Symptom Assessment Scale

The Edmonton Symptom Assessment Scale (ESAS) is a formalized symptom assessment tool used at the SCC to capture patients’ subjective measurement of symptoms.



At each clinic visit, patients are asked to complete the ESAS and rate their symptoms by using the numerical 0 to 10 rating scale. At every visit, a nurse trained in palliative care explains the ESAS to the patient and caregivers to ensure the scale is understood and properly filled out. Symptoms included on the ESAS are pain, fatigue, depression, nausea, anxiety, drowsiness, best appetite (with a score of zero signifying no subjective report of appetite issues), best feeling of well-being, no shortness of breath (SOB), and best sleep. While the ESAS is not systematically used with each phone call, the numerical 0 to 10 rating scale is also used to assess current patient distress. The phone triage nurse has access to previous ESAS scores through the patient's medical record to determine the patient's goals for pain control, recent symptom scores, and recent changes in medication regimen. ESAS scores are included in this report for the two case studies to illustrate the effects of continued patient contact between as well as after clinic visits in abetting an overall decrease in symptom distress.

Case 1

Background

A 71-year-old female had been diagnosed with chondrosarcoma of the left lower extremity 8 years prior to consultation to the SCC. The initial intervention had been debulking surgery, but due to recurrence, 2 years later a left below-knee amputation had been required. Two years after the amputation, advanced disease had been discovered in the presence of newly developed lung metastases. After the patient had completed subsequent chemotherapy and radiotherapy due to progression, she had presented to MD Anderson's Targeted Therapy outpatient clinic and had begun cancer treatment. However, treatment had been discontinued due to uncontrolled nausea, vomiting, and diarrhea. The 3-month follow-up with the targeted therapy team had revealed progressive pulmonary metastatic disease and hospice had been recommended.

Supportive care

The patient deferred hospice at that time and was referred to the SCC for symptom control and eventual hospice enrollment. Symptoms addressed at the initial supportive care consultation included pain, constipation, nausea, dry cough, and weight loss. Initially, the patient was reluctant to take opioid

medication because she was afraid of the potential side effects and addiction.

During the initial consultation, the patient and her husband revealed they were raising their 10-year-old grandson. With the IDT members, the patient and her spouse were able to address concerns about discussing her illness with the grandchild and his fears concerning end-of-life symptoms and care.

The patient was seen in the SCC routinely and used the SCC's phone care program to maintain access to clinic staff between visits to discuss concerns and ensure optimal symptom control.

At the following visit to the SCC, the patient noted increasing SOB. Oxygen was prescribed for comfort, and the use of opioid therapy for control of pain and SOB was discussed; extensive patient education was provided to address her fear of using opioids to manage pain and SOB. Through continued patient education during follow-up visits and conversations with the phone triage nurses of the SCC, the patient eventually agreed to the use of oxycodone liquid to help control the pain and persistent SOB.

Three months after the initial consultation with the Supportive Care Center, the patient contacted the phone triage nurse to announce her decision to consult home hospice. The patient's SOB continued to worsen but was ably managed by the hospice team and the patient's family. One month later the patient passed away comfortably at home.

ESAS results

The first ESAS consultation revealed a high symptom burden. Initial management of symptoms focused on pain, nausea, appetite, anxiety, and sleep. Time from the first consultation to the final clinic visit was 2 months, at which time symptom burden had decreased overall. Phone conversations between the SCC nurses and the patient took place between visits and continued after her final visit and until her ultimate decision to transition to hospice care. Because the patient's subjective feeling of SOB increased with disease progression, home oxygen and short-acting opioid therapy were introduced to lessen her distress; subsequent follow-up phone calls with SCC nurses noted a decrease in symptom burden and an increased sense of comfort and control with self-managing care at home. Figure 1 shows ESAS scores at the initial and final visit for the patient described in Case 1.

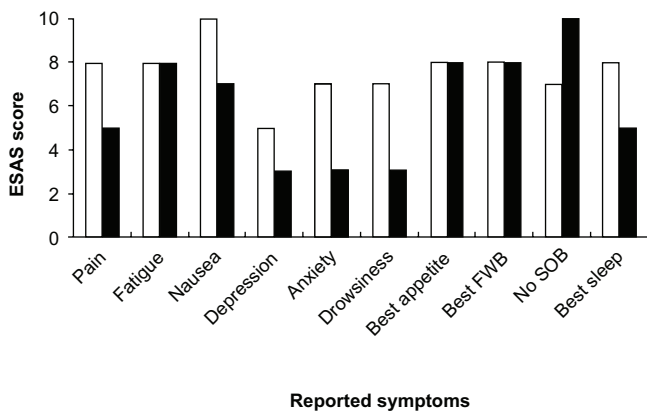


Figure 1. ESAS scores from initial SCC consultation (white) and final follow-up visit (black) for patient in Case 1.
Abbreviations: FWB, feeling of well-being; SOB, shortness of breath.

Case 2 Background

A 23-year-old female with hepatocellular carcinoma metastatic to the lung had had a history of significant nausea, pain, fatigue, and weight loss over recent months with her treatment regimen. The patient had presented to MD Anderson for a second opinion regarding treatment options, and chemotherapy and palliative radiotherapy had been initiated at MD Anderson. Two months later, the patient had been referred to the SCC.

Supportive care

The initial consult focused on the psychological distress experienced by both the patient and family related to coping with advanced illness. The patient attended one follow-up visit at the SCC for physical and emotional symptom management. During the follow-up visit, the patient expressed her wish to return home. Although open dialogue regarding the patient’s disease and poor prognosis had taken place, the family was largely unaware of the patient’s terminal health status. During that follow-up visit, an end-of-life discussion ensued between the IDT members (specifically the palliative care-trained physician, nurse, and social worker), the patient, and her family; the latter were counseled on and prepared for the psychological distress if the patient died on the long trip home.

After the patient’s second and final visit to the SCC, ongoing communication via the phone care

program occurred between the patient, her family, and phone triage nurses throughout her journey home. Frequent phone conversations occurred between the patient’s mother and clinic nurses solely to validate her fears and concerns, ensure adequate pain control for the patient, and receive supportive counseling. The patient died as an inpatient at a local hospital 4 months after her initial contact with the SCC. Following the patient’s death, communication with her mother continued; she was grieving appropriately and voiced appreciation for the continued communication and patient care.

ESAS results

At the initial contact with the SCC, the patient’s most distressing ESAS symptoms were fatigue and emotional symptoms (ie, anxiety, depression, and sleep) associated with newly diagnosed advanced disease. The time frame from initial consult to final visit was 1 month. As is frequently the case with the patient population referred to the SCC, the most limiting factor associated with patient care is time.⁹ However, within this 1-month time frame, follow-up visits and the use of the phone triaging program allowed a trust to form between this patient, her family, and clinical staff. Significant decrease in emotional distress was noted between visits, as fatigue, depression, anxiety, and feeling of well-being significantly improved within the short time of caring for the patient. Figure 2 shows the ESAS scores at the initial and final visit for the patient described in Case 2.

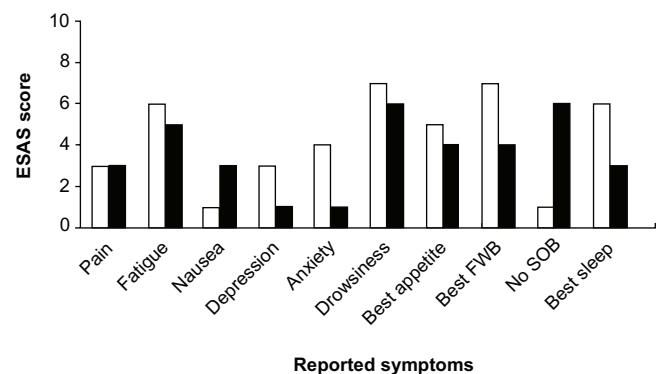


Figure 2. ESAS scores from initial SCC consultation (white) and final follow-up visit (black) for patient in Case 2.
Abbreviations: FWB, feeling of well-being; SOB, shortness of breath.



Comment

In both cases, the patients and caregivers required continued education, reinforcement regarding medication administration and management, and emotional support between and after visits to the SCC. Providing this support would not have been possible if not for the availability of the SCC's phone triage program. Education initiated during visits to the center was emphasized over the phone, which aided in medication compliance and optimal symptom management. In addition, the supportive counseling and emotional validation provided via these conversations increased the patients' and families' confidence regarding independent care at home.

Challenges presented in Case 1 included addressing the patient's reluctance to use opioid medications, need for ongoing patient and family education, and end-of-life concerns. The phone triage nurses met these challenges with ongoing communication, facilitating confidence in medication use and symptom management at home. Symptoms reported as distressing to the patient (eg, constipation, worsening SOB, and pain) were frequently addressed during phone interactions. Questions and concerns regarding hospice information were also addressed, and patient education was provided frequently. The patient and her husband were also prepared to address questions regarding end of life with their grandson. Moreover, communication via the phone care program facilitated the transition to hospice. This case highlights the importance of a designated phone triaging program within the outpatient center as a means of providing continuous communication between scheduled clinic visits.

The challenge in Case 2 involved addressing end-of-life issues with a young adult patient and her mother within a limited time frame. The patient returned home only 1 month after the initial consultation in the SCC. Although the patient did not receive hospice care, frequent communication via the phone care program ensured the patient's wishes were addressed and met. The mother received timely education and reinforcement along with validation of her feelings and concerns as her daughter's death neared. The importance of having a phone triaging program is apparent, as meeting these challenges would not have been possible without the continued communication provided by the phone triage nurses.

Currently, only 66% of comprehensive cancer centers and 29% of regional cancer centers in the United States offer outpatient palliative care services.² Because outpatient care services are less common—even though they are essential for providing early palliative care³—there is a very limited amount of published data regarding best practices, recurring patient themes, and communication methods that could help improve the phone care programs that do exist for palliative care. Bakitas and colleagues recently published findings from a nursing-led intervention program that included monthly phone calls in palliative care.¹⁴ That intervention was found to be beneficial in addressing patients' physical, psychosocial, and care coordination concurrently with the oncology team.⁴ Compared with the model used by Bakitas et al,¹⁴ the phone care program at MD Anderson's SCC is incorporated as standard of care.⁵ Similar to the study by Bakitas et al, nurses within the SCC utilized phone triaging to proactively contact patients and assess symptom control between clinic visits. In turn, patients are able to access the phone triage nurses in the SCC daily. In a study of 405 patients who had depression and cancer-related pain, centralized telephone-based care management coupled with automated symptom monitoring resulted in improved pain and depression outcomes.¹⁵ Similar to phone triaging by the specialized nurses in the SCC, in this study, the nurse care manager trained in symptom control managed the symptoms for the study. However, unlike the usual practice in the SCC phone triage program, the nurse care manager reviewed cases with a psychiatrist who specialized in pain and was assisted by the triggered phone calls by automated symptom monitoring. Also, there were no in-person visits to the supportive care or palliative care centers.

Based on prior studies and our case presentations, it is clear that using nurse telephone triage to enhance supportive care is acceptable, appropriate, and safe.^{4-7,14,15} Future prospective studies should evaluate the feasibility and effectiveness of supportive care outpatient consultation and follow-up with and without nurse triage in providing patients with optimal quality of life and symptom control. It may also be worth evaluating the impact of a nurse triage program in terms of quality of care metrics and the



clinical practice guidelines for quality palliative care, such as reductions in inappropriate emergency room visits, intensive care unit admissions, length of hospital stay, and enrollment into hospice.^{13,15,16}

Conclusion

The information from the two case reports presented, as well as our experience with other patients regarding the importance and effectiveness of an outpatient palliative care phone triaging program staffed by designated nurses, is limited. Nevertheless, the results suggest that patients, as well as their family members and at-home caregivers, benefit from having this resource available to discuss questions and concerns regarding symptom management and emotional support throughout their cancer journey. Further studies of the effectiveness of such a program are warranted.

Author Contributions

Conceived and designed the experiments: SY, LEP, DC, EB. Analysed the data: SY, LEP, DC, EB. Wrote the first draft of the manuscript: SY, LEP, DC, EB. Contributed to the writing of the manuscript: SY, LEP, DC, EB. Agree with manuscript results and conclusions: SY, LEP, DC, EB. Jointly developed the structure and arguments for the paper: SY, LEP, DC, EB. Made critical revisions and approved final version: SY, LEP, DC, EB. All authors reviewed and approved of the final manuscript.

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Competing Interests

Author(s) disclose no potential conflicts of interest.

Disclosures and Ethics

As a requirement of publication author(s) have provided to the publisher signed confirmation of compliance with legal and ethical obligations including but not limited to the following: authorship and contributorship, conflicts of interest, privacy and

confidentiality and (where applicable) protection of human and animal research subjects. The authors have read and confirmed their agreement with the ICMJE authorship and conflict of interest criteria. The authors have also confirmed that this article is unique and not under consideration or published in any other publication, and that they have permission from rights holders to reproduce any copyrighted material. Any disclosures are made in this section. The external blind peer reviewers report no conflicts of interest. Provenance: the authors were invited to submit this paper.

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