Editorial

When insight yields inaction: the role of implementation science in improving palliative care integration

Rubina Ratnaparkhi[1], **Lori Spoozak**[1,2]

[1]Department of Obstetrics and Gynecology, Division of Gynecologic Oncology, University of Kansas School of Medicine, Kansas City, KS, USA; [2]Department of Internal Medicine, Palliative Medicine Division, University of Kansas School of Medicine, Kansas City, KS, USA

Correspondence to: Lori Spoozak, MD, MHS. Department of Obstetrics and Gynecology, Division of Gynecologic Oncology, Department of Internal Medicine, Palliative Medicine Division, University of Kansas Medical Center, Kansas City, Kansas, 66160, 3901 Rainbow Blvd., KS 2028, USA. Email: Lspoozak@kumc.edu.

Comment on: Vetter VJ. Palliative care screening tools in the gynecologic oncology population: a narrative review. Ann Palliat Med 2022;11:3263-72.

Keywords: Palliative care; gynecologic oncology; implementation science; patient reported outcome measures

Submitted Dec 20, 2022. Accepted for publication Dec 30, 2022. Published online Jan 27, 2023.
doi: 10.21037/apm-22-1438
View this article at: https://dx.doi.org/10.21037/apm-22-1438

Introduction

Vetter's review summarizes outcomes for six screening tools for palliative care referral among patients with gynecologic cancers (1). The development of multiple screening methods in both inpatient and outpatient settings shows interest in expanding use of palliative care services for eligible patients. However, early palliative care uptake has increased only marginally in the past decade despite over ten randomized control trials demonstrating its efficacy and endorsements by multiple national oncology societies. A discussion on how to optimize screening gynecologic oncology patients for palliative care consult is incomplete without considering how to operationalize palliative care integration in gynecologic oncology more effectively.

Background

Temel *et al.*'s seminal 2010 trial showed that early palliative care improved mood and quality-of-life for lung cancer patients (2). The ENABLE III study even suggested a trend toward increased survival among advanced cancer patients with early integrated palliative care (3). Another large, randomized trial that included gynecologic cancer patients demonstrated increased symptom control, quality-of-life, and satisfaction with care for patients receiving early outpatient palliative care (4). In gynecologic oncology, both inpatient and outpatient palliative care visits have been shown to meaningfully improve symptom burden in terms of pain, nausea, fatigue, anxiety/depression, and appetite among gynecologic cancer patients (5,6).

This body of evidence led to formal recommendations for early and systematic integration of palliative care in oncology care from the National Comprehensive Cancer Network (NCCN), Society of Gynecologic Oncology (SGO), and American Society of Clinical Oncology (ASCO) (7-9). ASCO went on to propose eligibility criteria for automatic palliative care consult including stage III–IV disease, prior hospitalization within 30 days and/or recent hospitalization lasting longer than seven days, and/or active poorly controlled symptoms (10). Further, the recommendation was made to begin integration of palliative care within eight weeks of an advanced stage cancer diagnosis. However, the promise of early integrated palliative care has yet to be realized in practice in the ways in which it has been defined and recommended in theory. Prior studies in gynecologic oncology demonstrate that only 30–50% of eligible patients were seen by palliative care (11,12). Further, only 15–20% receive a "timely" palliative care consult in line with the recommendation of eight weeks by ASCO (12). As Albert Einstein once said, "In theory, theory and practice are the same. In practice, they are not". Screening gynecologic oncology patients by one or more of the methods presented by Vetter is only one piece of the process of implementing integrated palliative care. Two recent reviews by Salyer

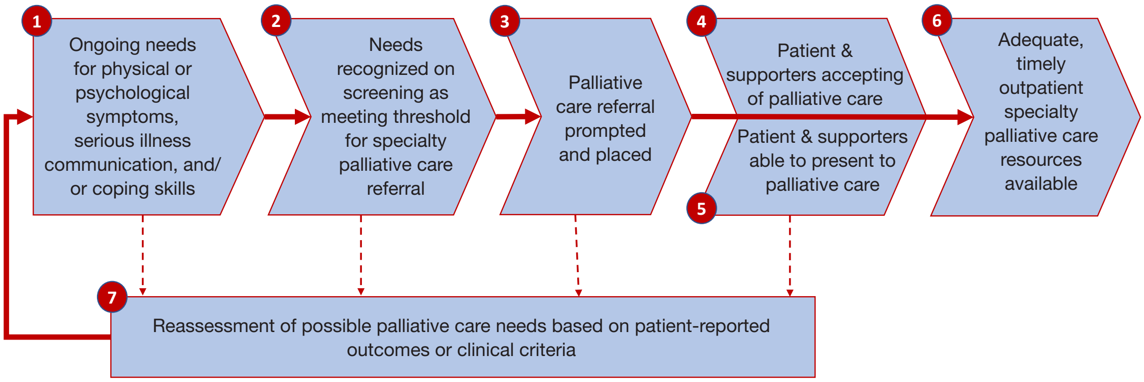

Figure 1 Process map with sequential flow diagram outlining steps required for identification, referral, and uptake of timely early integrated specialty palliative care.

et al. [2022] and Hui *et al.* [2022] highlighted the importance of designing interventions to increase palliative care uptake that are compatible with the operational model for palliative care delivery in a given healthcare system (13,14). Vetter's reported results describing existing palliative care screening tools in gynecologic oncology demonstrate the need to include implementation science metrics and methodology in future studies in this area.

Operationalizing palliative care delivery: toward a personalized yet systematic implementation framework

The screening methods analyzed in Vetter's review varied in three dimensions: (I) care setting (inpatient versus outpatient); (II) type of prompt for referral (e.g., prompt question versus presence/absence of clinical criteria versus symptom breadth/intensity score); (III) source of substrate data for screening (healthcare provider versus patient). Identified screening methods underperformed in terms of increasing palliative care utilization across the spectrum of practice settings. Salyer *et al.* [2022] proposed that palliative care will be implemented through one of three models based on whether a given institution has access to (I) primary palliative care only, (II) primary palliative care + inpatient specialty palliative care only, or (III) primary palliative care + inpatient and outpatient specialty palliative care (13). Hui *et al.* [2022] similarly suggested that given the scarcity of palliative care resources, screening should move beyond solving for early palliative care referral (i.e., how can we identify the entire universe patients who may benefit from integrated palliative care and get them evaluated by palliative care as expediently as possible?) and instead optimize for timely palliative care referral (i.e., how can we quickly identify patients with high supportive care needs and prioritize rapid integration of palliative care with ongoing oncologic care?) (14). The resource and care delivery model in a given institution will determine what screening method is most effective and feasible. A lack of standardized reporting on these factors limits our ability to evaluate the utility of existing screening methods.

Regardless of the specific delivery model, a patient's ability to obtain integrated palliative care relies on five components. (I) The gynecologic cancer patient must have a need for physical and/or psychological symptom management, serious illness communication, and/or coping skills/family management. (II) This need must be recognized (often by the oncologist) as meeting standardized criteria to be above the threshold for primary palliative care management alone and prompt referral to specialty palliative care. (III) The patient must have the willingness and the ability to present to the consultation and engage with palliative care services. (IV) There must be adequate and timely specialty palliative care services for patients to access. (V) We also need standardized flags to prompt reassessment of patients' needs for specialty palliative care for patients who do not screen in on initial assessment. Process mapping can improve uptake of care interventions by illustrating the activities and behaviors that support implementation of new processes (15). *Figure 1* shows a process map for palliative care referral in the outpatient setting.

A theoretical advantage of a standardized and systematic approach to patient evaluation for palliative care needs is the

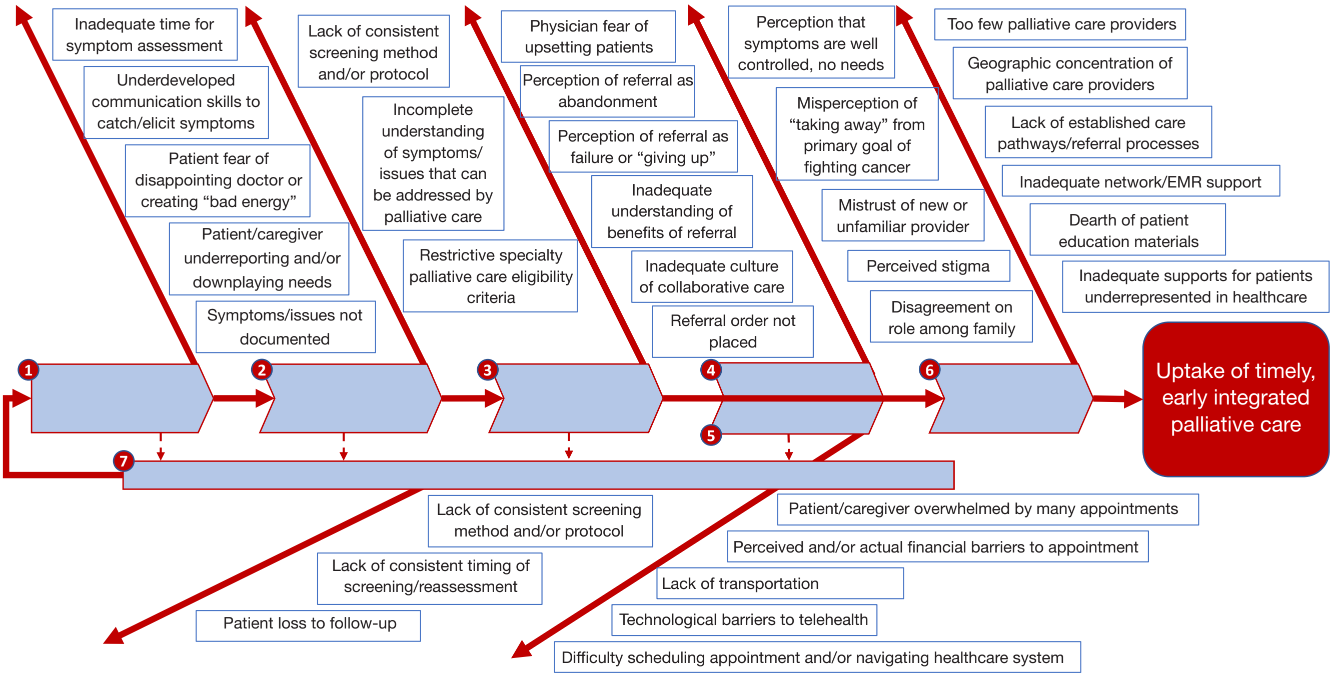

Figure 2 Example Fishbone Diagram mapping factors contributing to delayed specialty palliative care referral uptake.

opportunity to mitigate barriers and leverage facilitators to engagement with palliative care. Commonly, we attribute barriers to palliative care either at the level of patients and/or their support system, at the level of the oncologist, and/or at the level of the healthcare system. Barriers include inadequate knowledge of what palliative care is and its utility, misperceptions about whether palliative care enhances or compromises quality of medical care, stigma and perceived threat, logistical and financial barriers, biases about patient needs/values, and concerns about resource availability and allocation (16). Fee-for-service reimbursement for palliative care can also create undue burden for patients with co-pay out-of-pocket expenses and for palliative care practices by reimbursing only 20–60% of operating expenses (17). Facilitators of palliative care consultation can include positive experiences with palliative care among a patient’s social network, buy-in on role of palliative care from primary oncologist, integration of palliative care into multidisciplinary tumor boards and patient care conferences, and increased palliative care education among medical and surgical oncologists (13). Innovative membership-based reimbursement structures can also increase access and affordability of palliative care (17).

Past research limited analysis to grouping facilitators and barriers by themes, which omits the level of detail needed to accurately map the determinants of behaviors by patients and physicians in the process of obtaining palliative care in a particular practice setting (18). In *Figure 2*, we present an example of how an individual institution might explore where to target interventions or research to improve palliative care uptake. The diagram leverages principles of Theoretical Domains Framework of behavior change to explore how individuals’ behaviors contribute to implementation problems in an intervention (19). This exercise can facilitate a more thorough root-cause analysis as to the presence and impact of barriers to palliative care for individual patients and/or groups. Moreover, promoting specificity in naming and characterizing barriers can help avoid introducing generalizations and bias. For example, this permits more nuanced exploration of the etiologies of ongoing racial disparities in receipt of palliative care by acknowledging the many ways in which racism affects experiences within the healthcare system (20).

Reassessing screening methods from an implementation science lens

A review of key study results from an implementation science lens can provide further direction as to the next steps required to operationalize palliative care more broadly. One of the most widely used implementation frameworks is "RE-AIM", which evaluates five factors deemed critical for successful intervention implementation: (I) Reach: proportion of target population that participates in the intervention; (II) Effectiveness: positive and negative outcomes of intervention for the study population and healthcare providers/organization adopting the intervention; (III) Adoption: uptake of the intervention with other stakeholders/institutions, a form of active dissemination; (IV) Implementation: "the extent to which the program is delivered as intended" with intended effect and (V) Maintenance: intervention sustainability (21).

Vetter appropriately describes results separately for inpatient versus outpatient screening methods, acknowledging differences in implementation and risk of bias in very different care settings. In general, inpatient palliative care referrals occurred when gynecologic cancer patients met a set of criteria (either a "yes" to the "surprise question", or a set of 2–4 clinical criteria such as late-stage disease, poorly controlled symptoms, etc.) (1). Multiple evaluated prompts for referral yielded minimal to no change in palliative care referrals with up to 40% of patients eligible under stated criteria still not being referred to palliative care with limited understanding of persistent barriers and/or missed opportunities (1). We propose that limited gains in palliative care utilization in the inpatient setting reflects the fact that at the time of inpatient admission, we have already missed the window for "timely" palliative care integration. We anticipate greater potential for increasing palliative care utilization with a focus on identification and referral strategies in the outpatient setting. Additionally, all proposed inpatient prompts/criteria for referral required eligibility evaluations initiated and determined by physicians. This type of approach does not address implicit biases or reluctance to introduce palliative care, nor does it mitigate the known gating effect of the oncologist and/or primary care provider on palliative care access.

In contrast, in the outpatient setting, identified studies leveraged data generated from completion of instruments assessing patient symptoms, distress, and/or functional status. Two of the more effective studies by Gressel *et al.* [2019] in the U.S. (22) and Zimmerman *et al.* [2021] out of Canada (23) leveraged patient-reported outcome measures, effectively shifting agency for initiating and assessing palliative care needs from the physician to the patient. Importantly, both the study by Zimmerman and a related physician/nurse-administered palliative care referral protocol proposed by Paiva *et al.* [2020] noted that only a subset of patient and caregiver symptom and distress metrics were prevalent, and symptom endorsement appeared lower than expected (24). This suggests opportunities for refinement of instruments and enhanced patient and caregiver education about what palliative care is (and is not) and its role as part of timely, optimized, and high-quality care. Reasons cited for declining palliative care consult were adequately controlled symptoms, feeling overwhelmed by current appointments, and/or lack of interest (24). Importantly, in the Zimmerman *et al.* [2021] study, there was a subset of patients with advanced or recurrent cancer who fell consistently under the threshold for palliative care referral based on Edmonton Symptom Assessment System-revised (ESAS-r) who maintained high quality-of-life and mood scores without palliative care intervention (23). This further emphasizes the role of patient-driven needs assessment to identify a subset of the cancer patient population most likely to benefit from palliative care, particularly in areas where outpatient resources remain scarce. Of note, studies did not consistently report quality improvement outcomes such as percentage of palliative care referrals placed and percentage of patients who presented to at least one appointment. Increased reporting of these metrics would permit more rigorous evaluation of palliative care referral pathways.

Additionally, an ongoing challenge for assessing comparative effectiveness of palliative care screening and referral initiatives is the presence of multiple screening questionnaires and numerous, heterogeneous clinical criteria to prompt palliative care referral. A prior systematic review in 2016 revealed at least twenty published criteria assessing six functional domains (25). This includes multiple sets of "consensus criteria" introduced by NCCN, Center to Advance Palliative Care (CAPC), and an International Delphi consensus with further studies performed with adapted or modified versions of the consensus criteria (13,25). Similarly, multiple patient symptom screening instruments exist through ESAS-r and the Patient Reported Outcomes Measurement Information System (PROMIS®) (22,23). Future research could consider secondary factor analysis to hone in on which criteria/questions have greatest predictive value for utility of palliative care services. Ongoing reexamination of implementation outcomes for palliative care can improve the quality of patient care in gynecologic oncology.

Opportunities, challenges, and future directions

Taken together, these results suggest that including patient-reported outcomes and providing automated coordination support for palliative care referral may increase utilization of palliative care services. Though physicians can help identify patients with more subtle presentations who would benefit from palliative care and can educate patients about palliative care to bolster patient acceptance, improved implementation and effectiveness is achieved when physicians are not the sole gatekeepers/arbiters of palliative care introduction. Attention to implementation and quality improvement outcomes in study design and outcomes reporting is critical if we aim to finally achieve widespread adoption of palliative care. Future interventions would benefit from effective electronic medical record integration and meaningful use alerts tailored to the needs of specific institutions and delivery models.

Acknowledgments

Funding: None.

Footnote

Provenance and Peer Review: This article was commissioned by the editorial office, *Annals of Palliative Medicine*. The article did not undergo external peer review.

Conflicts of Interest: Both authors have completed the ICMJE uniform disclosure form (available at https://apm.amegroups.com/article/view/10.21037/apm-22-1438/coif). LS has received speaker fee from Total Health Conferencing and is the Vice Chair of the Society of Gynecologic Oncology Palliative Care Committee. The other author has no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

References

1. Vetter VJ. Palliative care screening tools in the gynecologic oncology population: a narrative review. Ann Palliat Med 2022;11:3263-72.
2. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 2010;363:733-42.
3. Bakitas MA, Tosteson TD, Li Z, et al. Early Versus Delayed Initiation of Concurrent Palliative Oncology Care: Patient Outcomes in the ENABLE III Randomized Controlled Trial. J Clin Oncol 2015;33:1438-45.
4. Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. Lancet 2014;383:1721-30.
5. Lefkowits C, Teuteberg W, Courtney-Brooks M, et al. Improvement in symptom burden within one day after palliative care consultation in a cohort of gynecologic oncology inpatients. Gynecol Oncol 2015;136:424-8.
6. Ruskin R, Rabow MW, Allen IE, et al. Outpatient palliative care consultation is associated with a decrease in symptom burden for women with gynecologic malignancies. Gynecol Oncol 2014;133:45.
7. Ferrell BR, Temel JS, Temin S, et al. Integration of Palliative Care Into Standard Oncology Care: ASCO Clinical Practice Guideline Update Summary. J Oncol Pract 2017;13:119-21.
8. Levy M, Smith T, Alvarez-Perez A, et al. Palliative Care Version 1.2016. J Natl Compr Canc Netw 2016;14:82-113.
9. Delivery of Palliative Care Services [Internet]. Society of Gynecologic Oncology. [cited 2022 Dec 13]. Available online: https://www.sgo.org/resources/delivery-of-palliative-care-services/
10. Smith CB, Phillips T, Smith TJ. Using the New ASCO Clinical Practice Guideline for Palliative Care Concurrent With Oncology Care Using the TEAM Approach. Am Soc Clin Oncol Educ Book 2017;37:714-23.
11. Nevadunsky NS, Gordon S, Spoozak L, et al. The role and timing of palliative medicine consultation for women with gynecologic malignancies: association with end of life interventions and direct hospital costs. Gynecol Oncol 2014;132:3-7.
12. Nitecki R, Diver EJ, Kamdar MM, et al. Patterns of palliative care referral in ovarian cancer: A single institution 5 year retrospective analysis. Gynecol Oncol 2018;148:521-6.
13. Salyer C, Littell RD, Pearl ML, et al. Palliative care in gynecologic oncology: a narrative review of current

literature and vision for the future. Ann Palliat Med 2022;11:3542-54.
14. Hui D, Heung Y, Bruera E. Timely Palliative Care: Personalizing the Process of Referral. Cancers (Basel) 2022;14:1047.
15. Kononowech J, Landis-Lewis Z, Carpenter J, et al. Visual process maps to support implementation efforts: a case example. Implement Sci Commun 2020;1:105.
16. Alcalde J, Zimmermann C. Stigma about palliative care: origins and solutions. Ecancermedicalscience 2022;16:1377.
17. Reed SM, Austin E, Colborn K, et al. Modeling of an alternative reimbursement method for palliative care. Am J Manag Care 2022;28:e221-7.
18. Powell BJ, Waltz TJ, Chinman MJ, et al. A refined compilation of implementation strategies: results from the Expert Recommendations for Implementing Change (ERIC) project. Implement Sci 2015;10:21.
19. Atkins L, Francis J, Islam R, et al. A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems. Implement Sci 2017;12:77.
20. Brown CE, Curtis JR, Doll KM. A Race-Conscious Approach Toward Research on Racial Inequities in Palliative Care. J Pain Symptom Manage 2022;63:e465-71.
21. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. Am J Public Health 1999;89:1322-7.
22. Gressel GM, Dioun SM, Richley M, et al. Utilizing the Patient Reported Outcomes Measurement Information System (PROMIS®) to increase referral to ancillary support services for severely symptomatic patients with gynecologic cancer. Gynecol Oncol 2019;152:509-13.
23. Zimmermann C, Pope A, Hannon B, et al. Phase II Trial of Symptom Screening With Targeted Early Palliative Care for Patients With Advanced Cancer. J Natl Compr Canc Netw 2021;20:361-370.e3.
24. Paiva CE, Paiva BSR, Menezes D, et al. Development of a screening tool to improve the referral of patients with breast and gynecological cancer to outpatient palliative care. Gynecol Oncol 2020;158:153-7.
25. Hui D, Meng YC, Bruera S, et al. Referral Criteria for Outpatient Palliative Cancer Care: A Systematic Review. Oncologist 2016;21:895-901.

Cite this article as: Ratnaparkhi R, Spoozak L. When insight yields inaction: the role of implementation science in improving palliative care integration. Ann Palliat Med 2023;12(2):274-279. doi: 10.21037/apm-22-1438