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Clinical Commentary

Cancer care delivery research in gynecologic oncology☆

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1. Introduction

Innovative cancer treatments cannot benefit patients they do not reach. Furthermore, significant demographic, social and geographic disparities exist in access to standard cancer care. Cancer care delivery research (CCDR) is an umbrella term for investigations that examine “how social factors, financing systems, organizational structures and processes, health technologies, and healthcare provider and individual behaviors affect cancer outcomes, access to and quality of care, cancer care costs, and the health and well-being of cancer patients and survivors.” [1] CCDR encompasses a continuum of process- and outcomes-based questions, and draws on multiple scholarly disciplines, including health services research, patient-centered outcomes research, dissemination and implementation sciences, and epidemiology. In 2015, the National Cancer Institute (NCI) strengthened its emphasis on CCDR through the creation of the Healthcare Delivery Research Program within the Division of Cancer Control and Population Sciences and established a CCDR Steering Committee to review and prioritize cancer care delivery research concepts [2]. Accordingly, the member groups of the NCI’s National Clinical Trials Network (SWOG, Alliance, ECOG-ACRIN, COG, and NRG Oncology) now set strategic priorities for CCDR alongside traditional disease site-specific agendas.

While identifying and improving patient, clinician and organizational factors that affect the delivery of cancer care have always been of interest, these new, national priorities offer unprecedented opportunities for support for CCDR and incentivize standardization of terminology and research methods. In this article, we outline a framework for cancer care delivery research in gynecologic oncology. We hope this framework will clarify the scope of CCDR and will guide the systematic development of investigations into implementation of high-quality care for gynecologic cancers.

The continuum of care for gynecologic malignancies may be divided into 4 distinct phases: Phase 1 (Pre-Diagnosis) ends when a cancer diagnosis is made; Phase 2 (Pre-Treatment) begins after diagnosis and ends with initiation of treatment; Phase 3 (Treatment) begins with initiation of treatment and ends when treatment has been completed; Phase 4 (Post-treatment/Survivorship) begins after completion of treatment and ends with resumption of treatment or death (Fig. 1). While the specifics of studies focusing on different disease sites may vary, these

phases are useful to categorize general elements of cancer care delivery (e.g., uptake of cancer screening [Phase 1], access to specialty care after diagnosis [Phase 2], adherence to best-practices guidelines for treatment [Phase 3], and implementation of recommended surveillance schedules during survivorship [Phase 4]).

Successful cancer care delivery depends on collaboration between oncologists, patients and healthcare organizations (e.g., cancer centers, physicians’ offices and insurers). Accordingly, in developing CCDR research projects, investigators should consider each party’s contribution to the target outcomes. For example, if utilization of intraperitoneal (IP) chemotherapy is of interest, it is critical to consider factors influencing physicians’ recommendation of an IP regimen, patients’ preferences for IP chemotherapy over other alternatives, the organizational capability of treatment centers to deliver IP therapy (e.g., adequate nursing support), and insurance coverage for this intervention.

Following below is a detailed discussion of each phase within the continuum of care for gynecologic cancers. Each discussion contains examples of patient, clinician, and organizational elements related to cancer care delivery, and cites example investigations where possible. Importantly, some aspects of cancer care may span multiple phases. For example, the “financial toxicity” of cancer care [3] may affect patients and caregivers at any time from initial presentation to the end of life. Nevertheless, it may be helpful to understand these processes in the context of the specific phases in which they occur.

1.1. Phase 1: pre-diagnosis

The pre-diagnosis phase of cancer care delivery refers to the time frame preceding a cancer diagnosis, and encompasses issues related to primary cancer prevention, screening and diagnosis. Patient-related elements may include awareness of and timely presentation for evaluation of cancer-related symptoms [4], and adherence to recommendations for screening or diagnostic tests (e.g. imaging, cytology or biopsy) [5]. Clinician-related elements may include implementation of evidence-based cancer screening protocols [6], avoidance of low-value testing for screening purposes [7], and recognition of signs or symptoms concerning for malignancy with timely performance of diagnostic testing. Organizational elements may include the effect of ease of appointment scheduling and facility comfort/accessibility on patient adherence [8], and support for timely communication of abnormal results (i.e., radiology, pathology, etc.) to physicians and patients.

1.2. Phase 2: pre-treatment

The pre-treatment phase of cancer care delivery begins with a diagnosis of cancer and ends with the initiation of treatment. For many women with gynecologic cancers, the diagnosing physician (e.g., primary care provider or obstetrician/gynecologist) is different

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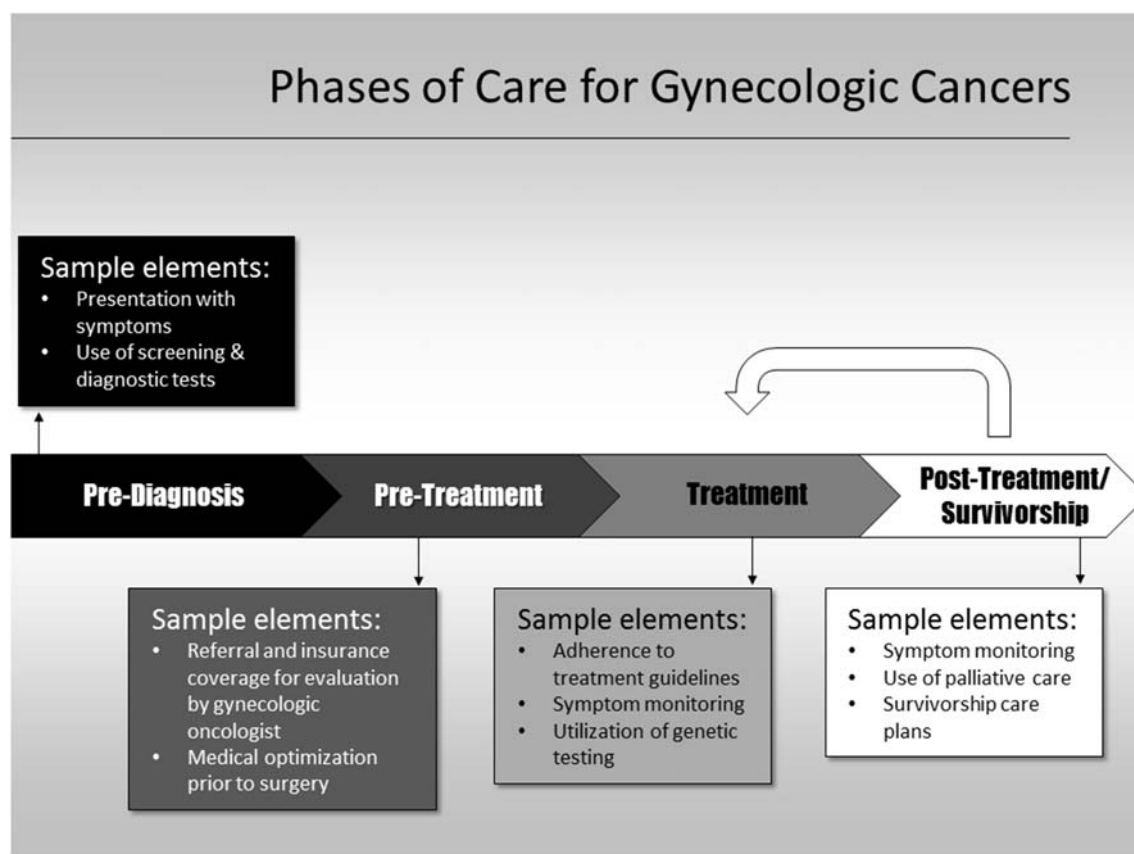


Fig. 1. Phases of care for gynecologic cancers.

from the treating physician (e.g., gynecologic oncologist, medical oncologist, or radiation oncologist). For these patients, referral and transfer of care may occupy the majority of time spent in this phase. Other patients may undergo subspecialty evaluation rapidly, but incur treatment delays by requiring significant medical optimization prior to initiation of medical, surgical or radiation therapy. Patient-related elements may include social, psychological, financial and geographic barriers to seeking specialty cancer care after diagnosis [9], and adherence to recommendations for pre-treatment medical optimization. Clinician-related elements may include timeliness of referral to treating physicians after diagnosis [10], and evidence- or value-based utilization of preoperative testing [11]. Organizational elements may include availability of insurance coverage for subspecialty referral and care, the availability of appointments in subspecialty and perioperative clinics, and geographic access to care [12].

1.3. Phase 3: treatment

The treatment phase of cancer care delivery begins with the initiation of treatment and ends when treatment is complete. Treatment for gynecologic cancers may include medical, surgical and radiotherapeutic modalities, alone or in combination. Importantly, trials comparing different treatment approaches using traditional clinical outcomes such as survival or morbidity do not fall within the scope of CCDR; rather, CCDR focuses on factors influencing the implementation and use of evidence-based practices in cancer care. Patient-related elements may include monitoring and reporting disease- and treatment-related symptoms during treatment, utilization of healthcare resources (e.g., evaluation and treatment in the inpatient and emergency department settings), and adherence to prescribed treatment schedules. Clinician-related elements include adherence to treatment guidelines for surgery and chemotherapy [13], factors underlying selection of

primary versus interval cytoreduction [14], and use of genetic testing [15]. Organizational elements include factors influencing timeliness of adjuvant therapy [16], methods to evaluate and manage treatment remotely [17], and institutional factors associated with improved outcomes [18].

1.4. Phase 4: post-treatment and survivorship

The post-treatment and survivorship phase of cancer care delivery begins when treatment is complete and ends either with re-initiation of treatment for recurrent disease or at the time of death. Consequently, cancer care delivery in this phase largely involves surveillance for recurrence, care transitions between treating oncologists and other clinicians who share responsibility for surveillance, and utilization of palliative and hospice care towards the end of life (though these last interventions are often best begun during the treatment phase). Patient-related elements include reporting of symptoms concerning for recurrent disease [19], and factors related to families' participation in caregiving across multiple phases of care [20]. Clinician-related elements include evidence-based surveillance after treatment is concluded, avoidance of low-value routine surveillance imaging/testing [7,21], and timely implementation of palliative care [22]. Organizational elements may include insurance coverage and system capacity for hospice/palliative care services, and processes that improve communication between oncologists and other clinicians involved in surveillance (including implementation of survivorship care plans) [23].

1.5. Research design and outcomes

A variety of study designs fall under the umbrella of CCDR (Box 1). Traditional epidemiologic methods, including analysis of large datasets, may be optimal for identifying the presence and scope of suboptimal

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