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#### Review

## Survivorship planning in gynecologic cancer patients



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#### HIGHLIGHTS

- Survivorship care plans following primary treatment may improve coordination of care amongst providers caring for women with gynecologic malignancies.
- Late and long-term effects in survivors commonly include psychological distress, fatigue, menopausal symptoms, sexual dysfunction, pain, cognitive and sleep disturbances.
- · The cancer survivorship period provides a teachable moment on improving lifestyle behaviors and promoting health.

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#### ABSTRACT

*Objective.* There are over one million survivors from gynecologic malignancies currently living in the United States and this population is expected to increase by 33% over the next decade. Identifying the needs of these cancer survivors is often understudied and overlooked.

*Methods*. A literature review using MEDLINE was searched for research articles published in English from 1967 to 2013 focusing on survivorship care in women with gynecologic malignancies.

Results. For women with gynecologic malignancies, the survivorship period requires management of several aspects of care. Improved coordination of care between providers that may be addressed with the use of survivorship care plans and should include surveillance recommendations. Providers should conduct a focused evaluation of late and long-term effects of cancer that may continue to effect patients during and after treatment. Opportunities to improve lifestyle behaviors and continue general health maintenance should also be maximized.

Conclusions. The survivorship period incorporates the following: prevention of new cancer diagnoses, surveillance for recurrence, assessment and management of side effects from cancer and cancer treatment, and the coordination of care between patients and healthcare providers. Focusing on these components may improve quality of life as it allows for a seamless transition for cancer survivors and their caregivers.

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#### Introduction

Currently, it is estimated that there are over 7 million female cancer survivors in the United States and over one million survivors of gynecologic malignancies [1]. Due to increasing age and cancer incidence, advances in diagnostic tests and improved therapies, this number is estimated to increase by an additional 33% over the next ten years [2]. As this population grows, it is important to recognize the long-term management of the effects of cancer and therapy on gynecologic cancer survivors and their caregivers and families. However, many survivors continue to be unaware of the increased risk for late effects of their diagnosis and often do not even receive the basic required care. Along these same lines, despite a willingness to provide follow up care for cancer survivors; many primary care physicians (PCP) are often undertrained on specific needs of survivors [3,4]. This is in part due to evolving and changing needs of patients and a lack of provider education and evidence-based clinical practice guidelines.

In order to address some of these needs, in 2005, the Institute of Medicine (IOM) report "From Cancer Patient to Cancer Survivor: Lost in Transition" has highlighted the unique needs that patients experience related to both the effects of cancer and those of treatment [3]. Though not universally accepted, survivorship is often defined as beginning at the time of cancer diagnosis. The components of survivorship care should include the following: 1) prevention of new and recurrent cancer, 2) surveillance for cancer spread or recurrence, 3) evaluation of cancer and treatment side effects, and 4) and coordination of follow up regarding all aspects of care [3].

Despite this report, practices have been slow to evolve and provide the necessary evaluation and services. Survivorship data in breast cancer has provided a foundation for other disease sites, yet research on survivors of gynecologic malignancies is only in its infancy [3]. As it is well known that gynecologic malignancies can leave a significant impact, emotionally, physically, and financially, identifying needs and services may assist in the transition to wellness [5]. Ensuring that survivors' needs are also shared with caregivers and PCPs will also enhance survivorship care. The purpose of this review is to provide the most up-to-date research and resources available for those who take care of survivors of gynecologic malignancies.

#### Survivorship care plans (SCP)

After the completion of primary treatment; transition to routine medical care is rarely seamless. Furthermore, following completion of treatment, cancer survivors remain unaware of future health risks and opportunities to address these and other issues are often overlooked [6]. Patients and providers must not only be aware of signs and symptoms of recurrent disease, but must also be aware of the long term and late complications of treatment. In the IOM report,

the need to improve coordination of care for survivors was highlighted. The recommendations include the creation of a survivorship care plan – incorporating components of cancer diagnosis, treatment, and complications – for both the patient and the PCP. Furthermore, scheduled follow up visits, surveillance recommendations, and routine health maintenance should also be included. This is consistent with a study regarding needs assessment of gynecologic cancer survivors who stated that receiving medical information, via pamphlet or provider discussions, regarding their care was considered a high priority and that these efforts may reduce anxiety and empower patients and caregivers [7]. Unfortunately, few survivors and providers receive this information, resulting in a compromised quality of care [8].

In a recent study of gynecologic cancer survivors, the provision of an SCP did not result in the perception of increased quality of care or satisfaction compared to those who did not receive an SCP [9]. Though this may be attributed to high satisfaction in both groups, the role of SCP to communicate amongst providers has demonstrated improved coordination of care. For example, PCPs reported higher adherence to appropriate screening tests in patients following a cancer diagnosis when provided a SCP [10,11]. As patients report that they receive follow up care from their oncologist (53%), PCP (13%), and a combination (32%), communicating the SCP is critical [12]. However, only 28% of cancer survivors felt that their PCP and their oncologist communicated well, and over 50% of PCPs reported the need for additional communication regarding the transfer of care for cancer survivors [13,14]. Since practice regarding post-treatment care and assessment for recurrence differs significantly between the oncologist and PCP, ensuring that all providers know the follow-up plan will, undoubtedly, enhance survivorship care [8,15]. Typically, the focus of follow up care has been on surveillance for the detection of recurrent disease. However, in addition to surveillance, survivorship care should also encompass the following components: 1) chronic effects of cancer and its treatment, 2) continuing routine health maintenance, and 3) preventative and risk reducing care. Furthermore, the SCP should identify the responsible providers for each aspect of care and provide patients with signs and symptoms that should prompt point of access care.

Recently, the Society of Gynecologic Oncology created modifiable survivorship care plans and pocket cards to help enhance this communication, which is available at https://www.sgo.org/clinical-practice/management/survivorship-toolkit/. These documents have been customized based on site of disease and can be used as an abbreviated SCP for patients and other providers (Fig. 1).

#### Surveillance

An important component of cancer survivorship, often the focus, is surveillance for cancer recurrence. Unfortunately, surveillance recommendations are often based on anecdotal evidence and practices

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