



Executive Summary of Gynecologic Cancer Survivorship Care: Patients – Survivors Survey

Gynecologic cancer survivorship care refers to the ongoing medical, physical, and emotional support provided to women who have been diagnosed and treated for gynecologic cancers, such as ovarian, cervical, uterine, vaginal, and vulvar cancer. This care is important to help women maintain their health, manage potential long-term side effects, and monitor for any signs of recurrence.

This survey was planned to understand the journey of gynecologic cancer patients with the intention to develop robust and effective Gynecologic Cancer Survivorship Care plans. This survey was prepared with multiple consultations among members of IGCAN to make it more inclusive with questions that are acceptable and answerable respecting social and cultural norms across geography.

This survey had 48 questions, divided into eight sections. A total of 407 responses were recorded from 34 countries.

Section 1: Demographic information

Out of 407 responses, the maximum number of respondents were from the USA (37.35%) followed by Italy (12.04%), India (8.35%), Canada (6.88%), Australia (6.63%), and Finland (5.16%). The uptake of this survey was more in developed countries because of the established concept of cancer survivorship in view of more patients becoming survivors.

Nearly 85% of the patients among respondents were either from urban (40.64%) or suburban (44.33%) whereas 15% of patients were from rural backgrounds. The majority (71.89%) of patients were in remission and were on follow-up and 28.11% of responders were patients undergoing cancer treatment. Ovarian cancer diagnosis was most common among responders with 56.58% followed by endometrial cancer (18.11%), cervical cancer (14.89%), and breast cancer (12.90%).

Section 2: Survivorship definition

IGCS defined the term "survivorship" as a cancer survivor is anyone living with a history of cancer from diagnosis through the remainder of life and 93.10% of responders agreed with this definition whereas 6.90% did not approve this definition among 377 respondents.

In a response to a question on "survivorship care" focuses on the health and well-being of a person living with and beyond cancer and when should this be started for a gynecologic cancer patient, 78.04% of respondents answered to start from cancer diagnosis onwards, followed by treatment initiation (10.32%), from remission (10.05%), from recurrence (1.06%), and end of life care (0.53%) in 378 patients.

Among 385 respondents, 65.19% did not receive survivorship care plans whereas 19.74% were offered and 15.06% were not sure about this. This low offering of the survivorship care plan to gynecologic cancer patients after the diagnosis necessitates the demand for an effective survivorship plan and makes it a part of a continuum of care.

Section 3: Awareness and Diagnosis

Cancer awareness is an important domain of cancer care that helps individuals to adopt safe practices and encourage them to present to the hospital for early diagnosis and better outcome. In our survey, 66.94% of patients did not know about the symptoms of the cancer they got diagnosed with whereas 19.51% and 13.55% of patients were somewhat knowledgeable and completely knowledgeable respectively.

Among 83 patients who were knowledgeable about gynecologic cancer symptoms, online (web research, social media) was the source of information for 42.17%, followed by television, radio, newspaper or magazines (30.12%), Healthcare provider (24.10%), and friends or the family in 20.48%.

Medical help was offered within one month of the onset of symptoms in 35.06% of patients followed by 1-2 months (28.16%), and 3-6 months (18.39%) whereas 6.03% of women waited for 7-12 months and 12.36% patients waited for more than a year to reach to a medical facility for further management.

Among 264 patients, 68.56% of patients expressed that knowing about symptoms before time would have helped them to present to the facility on time whereas 21.21% were not sure and 10.23% did not find it as a reason for the delay in presentation. There is a major issue of cancer diagnosis even after presenting to the hospital. In this survey, among 362 patients, 47.51% of patients were diagnosed within one month of presentation whereas 24.86% of patients took 1-2 months and 13.54% in 3-6 months. From cancer diagnosis to starting treatment is a resource-intensive process. In our survey population, 53.88% of patients received treatment within one month of cancer diagnosis, and nearly 85% of patients started treatment within two months.

In 363 answered responses, the most effective way of raising awareness about gynecologic cancers in your country was social media (e.g. Facebook, Twitter, Instagram, What's App) in 22.21%, healthcare providers in 15.70% and community events in 10.19% and Radio/TV in 8.54%.

Section 4: Needs and Support

When patients were asked about physical concerns during or after cancer treatment, fatigue was experienced by 84.93% of the patients followed by problems in memory and concentration (57.39%), neuropathy (51.59%), sleep disturbance (51.30%), pain (51.01%), weight changes (43.48%), nausea and vomiting (36.23%), and poor appetite (32.75%).

Among the psychological/emotional concerns, fear of recurrence (76.16%) and living with uncertainty (72.38%) were major concerns after the cancer diagnosis. Approx. 56% of patients defined a new sense of normal for them and managing emotions such as anger, fear, sadness, depression, guilt, and anxiety was difficult for 55.52% along with stress in 46% of the patients.

Among sexuality-related concerns during or after the treatment, loss of desire was a major concern (49.56%) followed by hormonal changes (41.94%), body image alteration (39.59%), and sexual dysfunction (36.07%).

Support was offered to cancer patients as a part of the treatment plan. Approx 47% of the patients received support for physical needs (treatment side effects, symptoms, lifestyle changes, etc.), 39.64% for psychological and emotional needs (counseling), 21.60% for peer support group, 11.54% for sexuality-related concerns, 10.06 from social support needs whereas 33.43% of patients were not offered any such support.

Peer group support was received by 22.82% of the patients whereas patient support or advocacy groups supported 27.52% of patients and 20.13% used websites to find support.

To find the choice of support services they will be requiring given an option, peer-to-peer support was required by 39.88% of patients, 26.28% therapy or counseling services, and 23.26% genetic counseling whereas 31.72% did not wish to participate in any services.

Among 163 respondents, the reason for not seeking support services was not being informed about the services in 41.72% of the patients, 19.63% did not want or felt the need for it, and 17.18% did not find any of these services in my area/region.

Among 345 patients who responded to financial concerns over treatment costs, 59.42% of patients did not have a problem managing finances for cancer treatment whereas 40.58% had it. On a question in reference to treatment delay because of financial concerns, 80.12% of patients did not find it a reason. The language barrier is an issue in a country where there are regional languages and, in this survey, only 6.47% of patients encountered a language barrier that made it difficult for them to receive the information needed throughout the treatment.

When it came to receiving support during and after cancer treatment, 46.43% of patients preferred to get it from healthcare providers followed by patient support/advocacy organizations (30.65%) and peer support groups (16.96%). Nearly 55% of patients were aware of a cancer-specific peer-to-peer support group in their country whereas 45% were not aware. Approx. 50% of patients were interested in joining a cancer-specific peer-to-peer support group if there was one whereas 39.17% were not sure and 10.39% refused to participate.

Section 5: Ongoing Healthcare

Follow-up is an important part of cancer care and patients are asked to visit the hospital on follow-up visits. In our survey, 89.58% of patients were offered assessments or follow-up appointments to monitor for recurrence or toxicities by their healthcare provider. Only 22% of this survey patients received individualized plans to support the transition out of treatment whereas 59% of patients were not offered individualized plans.

It is very important to monitor the changing need of cancer patients and 47.04% of patients preferred a named support worker who can be contacted between appointments whereas 33.64% of patients preferred telehealth (eg telephone or video appointments between hospital visits with a member of the healthcare team (eg a cancer nurse). Late side effects of cancer treatment were experienced by 60.53% of patients but only 50% of patients were warned about it and only 28% of patients were given support to help cope with late side effects. Late side effects affected your quality of life in 56.42% of patients whereas 15.22% of patients QOL were not affected. Approx 85% of patients who are on follow-up, were advised by their healthcare provider to return for regular cancer screenings to monitor for recurrence in the future.

Section 6: Palliative Care

Among 114 respondents who were asked about offering a referral to palliative care services for a loved one, 42.11% were referred when there were no further anti-cancer treatment options, 30.70% at the time of diagnosis, and 20.18% when they had difficult symptoms at any time.

Approx. 92% of patients think palliative care would be useful among 365 survey responders. Among those who responded in favor of the initiation of palliative care, 37.05% think the best time to initiate palliative care options is at the time of diagnosis followed by when a patient has difficult symptoms at any time (29.86%), when there are no further anti-cancer treatment options (27.34%), and, at time of recurrence (5.76%).

Section 7: Clinical Trial Awareness

Participation of patients in clinical trials is of utmost value to ensure better treatment options. In this survey, 54.56% of patients were neither offered nor did they seek to learn about or participate in a clinical trial whereas 24.84% of patients were informed about clinical trials by their healthcare provider. Out of 320 responders, 81.25% of patients did not participate in a clinical trial (or are currently enrolled in one) as a part of cancer treatment. The main reason for not participating in the clinical trial was not being offered the opportunity (47.81%), not eligible (17.88%), and did not want to participate (6.57%).

If the clinical trial was offered, 48.90% of patients would be interested in participating whereas 42.63% were not sure but 8.46% refused to participate. Of participants who were interested in participating in research projects that contribute to the improvement of cancer care, 80.50% of patients were ready to share data about treatment and outcomes, 51.08% for collecting tissue or blood samples but 15.79% were not interested in participating in research.

Section 8: Conclusions

When addressing gynecological cancer survivorship, several key deliverables and goals were aimed to support and enhance the well-being of survivors. These deliverables focused on various aspects of survivorship care and encompassed both medical and psychosocial components. The survey results emphasized the need for individualized survivorship care plans that outline the survivor's diagnosis, treatment received, potential long-term side effects, recommended follow-up care, and resources for support. These plans can serve as roadmaps for survivors and their healthcare providers to navigate ongoing care. Psychosocial support is needed for every patient through counseling services, support groups, and mental health resources to address emotional well-being, coping strategies, and adjustment to life after cancer to ensure a better quality of life.

Guidance and access to fertility preservation options prior to cancer treatment, as well as assistance and counseling for survivors facing fertility challenges should be an important consideration for young survivors. There is a need for better educational resources and programs to enhance survivors' understanding of their cancer journey, treatment options, potential late effects, and self-care practices. It is important to note that the specific deliverables may vary based on the healthcare system, resources available, and individual survivors' needs. The goal is to provide comprehensive and personalized care that addresses the unique challenges and concerns of gynecological cancer survivors.