



## Caregivers And End-Stage Ovarian Cancer Survivorship- A Correlation

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### Abstract

A support and comprehensive care for a ovarian cancer survivor is meant by providing them information pertaining to their disease , treatment and end results . Its aimed at educating them for self care and motivating attendants and training them for providing continuous, physical, emotional, financial, psychological support, Still, regular follow-ups can also help understand their concerns and address them immediately before they impact. Questionnaires have been the best way so far, to evaluate caregivers' satisfaction levels, lack of information, and attention. With this approach, the common hindrances can be cleared before impacting the caregiver's mental and physical health.

**Keywords:-** Comprehensive Care, Psychological, Ovarian Cancer.

## INTRODUCTION

Ovarian cancer is the third most common but deadliest cancer. The first and most common cancer in females is breast cancer, following cervical cancer. In recent years, Ovarian cancer has emerged as a fatal malignancy affecting women in India. The recent reports denote that ovarian cancer is the 7th cause of death and morbidity in women. Trends published in reports have stated that ovarian cancer is a complex neoplastic assembly, significantly affecting women over 65 years. Ovarian cancer grows in the cell's DNA through a mutation that causes mass production of cells that fail to survive as healthy cells die.<sup>[1]</sup> It starts from the ovary (a female organ that produces eggs) and can spread to or damage the nearby areas or tissues of the mother tumour.

Numerous reports published in various journals have stated that nearly 1 out of 75 women are at the risk of developing ovarian cancer, and 1 in 100 will be at the risk of death from this lethal condition.<sup>[2]</sup> The instances of ovarian cancer in India (age-adjusted for 100,000) were 1.7 to 15.2% starting from 2012 to 2014. In India, Ovarian cancer is expected to increase to 371,000 (55%) by 2035, while the death rate caused by ovarian carcinoma has been estimated to grow by 64% (254,000).

The highest risk of ovarian cancer is observed in White Women (non-Hispanic) around 12/100,000 = 0.00012%, Black (non-Hispanic) 9.4/100,000 = 0.000094%, and Asian Pacific Islander women 9.2/100,000 = 0.000092%. In the United States, the American Cancer Society estimates that in 2022, about 19,880 new cases of ovarian cancer will be diagnosed.<sup>[3]</sup> While



around 12,810 women are estimated to die of ovarian cancer by the end of 2022. This figure can give an overview of current reports on ovarian cancer worldwide.

### **Ovarian cancer burden- End-stage disease**

Diagnosis of ovarian cancer starts with abdominal washing cytology and peritoneal biopsies and also includes bilateral salpingo-oophorectomy, pelvic lymph node dissection, and para-aortic lymph node dissection. Reports have stated that just 20% of the women having symptoms of ovarian cancer are diagnosed at the early stage [stage IA and stage IB]. Cancer is usually confined to the ovary in these two stages, and treatment is also possible with 90-100% of cure at this point. However, nearly 60% of the total ovarian cancer patients are diagnosed at the advanced level stage [level III or IV], and the outcomes are much graver than those diagnosed at the stage IA or IB.<sup>[4]</sup>

Few reports have shared the recent data, which shows that about 36% of women with III-stage ovarian cancer survive for just five years after being diagnosed, and only 18% of the IV stage patients survive for this long. If cancer spreads beyond the ovary, it will damage the total abdominal hysterectomy and bilateral salpingo-oophorectomy as ovarian cancer staging starts with it.

Women with advanced diseases survive longer, and data from a cancer institute shows improvement in five-year survival in patients at the III or IV stages. However, most women diagnosed with advanced level ovarian cancer require complicated oncologic care, usually for a more extended period of time.<sup>[5]</sup> Besides common treatment side effects such as pain,

infection, fatigue, anaemia, vomiting, etc., women with end-stage ovarian cancer might have serious health complications, including ascites, bowel, and bladder, obstructions, etc. People at the end stage of ovarian cancer might feel stressed & overwhelmed and need emotional care. It is also normal for patients in the advanced stage to feel anxious, afraid, angry, or depressed. Plus, cancer treatment might cause them to have trouble concentrating or remembering things. These issues make it hard for them to perform even their day-to-day activities, and thus they need a caregiver throughout the cancer treatment.

### **Strategise the patient needs and care needed**

Giving care to end-stage ovarian cancer patients can be challenging. Many caregivers forget everything, put their own needs aside and just focus on the person with cancer. This can lead to burnout which might have prolonged physical and psychological effects. Though the concept of caregiver burden has been discussed in several studies around the world, caregiver burden can be referred to as multidimensional biopsychosocial reactions and their personal time, social interactions, physical and emotional states and multiple roles that they fulfil.<sup>[6]</sup>

Researchers are constantly studying to evaluate the burden experienced explicitly by the caregivers of patients with ovarian cancer. An Ovarian Cancer Research Alliance report denotes that the anxiety rate in ovarian cancer end-stage patients was 15%, while depression among patients was 6%, almost double the community norm.<sup>[7]</sup> In contrast, around 42% of the cancer patient caregivers reported extended anxiety levels, 19% at the clinical level and 5% at clinical depression. Lower social support,

communication and a complete cut-off from the outside world were the major reasons for depression and anxiety in caregivers. Another study evaluated the caregiver's quality of life while caring for ovarian cancer patients in the end-stage, showing that caregivers' mental and physical well-being deteriorates over time.<sup>[8]</sup>

The primary reason for this poor quality of life for caregivers is a lack of communication and social support. Although some caregivers have displayed a stable level of psychological distress, most diseased families have high levels of stress, mainly the younger age female gender, that show pre-morbid mental health issues. Significant challenges that caregivers face are balancing between full grieving about the loss and adjusting to life without the diseases.

The unmet needs of caregivers are defined in fulfilling the loss of the deceased and making adjustments to the bereavement during the long-term survivorship phase.<sup>[9]</sup> Primarily the unmet needs for adjusting to a loss were strong predictors of intense emotional reaction to the loss; grief and post-traumatic stress are also common challenges for caregivers. The findings call to address these challenges faced by the caregivers and suggest a revolution for sustainable cancer care. Greater technology can produce noble therapies to address the unmet needs of caregivers of women with end-stage ovarian cancer.

### **Empowering ovarian cancer caregivers: creating the next line of unsung warriors**

Reports have suggested that minimal guidance is provided to caregivers about the role they are about to undertake. The anxiety level in cancer patient caregivers is estimated at approximately

47%.<sup>[10]</sup> Cancer patients do not fight alone; caregivers undergo the same complications, not physically but emotionally. Behind every cancer patient, there is likely to be an overlooked caregiver. Caregivers positively impact patients' lives by educating them about their disease and treatment decisions. While half of the ovarian cancer cases are diagnosed in women older than 60 years, most caregivers are likely to provide care for older ovarian cancer patients. At the end stage of ovarian cancer, it becomes emotionally and physically challenging to take care of older ones. While caregivers spend time caring for cancer patients, supporting and empowering cancer patients should be normalised.<sup>[11]</sup>

The concept of caregiver burden has been highlighted in many studies worldwide. This burden can even exacerbate when a close friend or family member takes on the role of caregiver. A survey on caregivers of ovarian cancer patients revealed that low income and a distressed relationship between caregivers and patients often lead to high caregiver burden levels.<sup>[12]</sup> The exploration of caregivers involved in looking after the end-stage ovarian cancer patients identified that depression and anxiety are common concerns associated with the caregiver's burden. In another study around caregivers of ovarian cancer patients with a terminal illness, the burden on caregivers increases when required care imposes greater economic hardship on families, especially when the caregiver is from the family itself. Increased levels of depression and burden are reported in caregivers associated with the care of older and dying patients in the very end-stage of ovarian cancer.



While cancer caregivers are highly vulnerable to mental and physical health issues, these efforts should be made toward the multidimensionality of the caregiver experience.

### **Formalise educating the caregivers**

The most practical approach to better preparing the caregivers to render multidisciplinary care is delivering education. Though every patient responds to treatment differently, patients with advanced ovarian cancer might encounter severe complications.<sup>[13]</sup>

Chemotherapy destroys the rapidly increasing cancer cells in your body, destroying many healthy cells. Many healthy blood cells are also damaged, especially white blood cells. Moreover, advanced ovarian treatments may also damage the platelets that make your blood thick and prevent bleeding. Nearly 20% of the caregivers said that they were not well informed before taking on the care of ovarian patients. The same study also reveals that as caregivers' burden increases, perception also gets changed, and so does the requirement for education.

Direct communication with medical teams, friends and families can also help a lot. Moreover, technological advancements can help caregivers better understand the disease and render care that has a lasting impact.

### **Empower and strengthen caregivers to render holistic care**

The majority of ovarian cancer patients at the end-stage show the need for holistic care that primarily focuses on psychological well-being.<sup>[14]</sup> Delivering care to end-stage ovarian cancer patients is different and challenging.

Ovarian cancer treatment might have diverse effects both mentally and physically. End-stage ovarian cancer patients struggle with fatigue, nausea, and pain, making it unbearable to do anything or leading to frequent mood swings.<sup>[15]</sup> While caregivers have to undergo similar things with patients, they should be enlightened about acupressure and various massage techniques to normalise holistic care. Studies have suggested that incorporating multimodality care to reduce the symptoms in cancer patients has significantly improved the confidence and self-efficacy of caregivers.

### **Improve the health delivery model**

The steps toward chemotherapy or orally administered medication are associated with a few meetings between the patients/caregivers and the medical team looking forward to starting the treatment.<sup>[16]</sup> A change in the condition of cancer caregivers can be driven by accelerating this process of bringing caregivers and medical teams together. One random study on patients with Alzheimer's puts light on a care delivery model that heavily focuses on the education of caregivers. The model focuses on including a few points of contact with providers and regular assessments of caregivers' physical health frequently. A similar approach is followed towards treating chronic health issues, primarily with new nursing facilities.

### **Support self-care of caregivers**

One of the ways to support cancer caregivers is to give them information or educate them. Still, regular follow-ups can also help understand their concerns and address them immediately before they impact. Questionnaires can be used to evaluate caregivers' satisfaction levels, lack of

information, and attention. With this approach, the common hindrances can be cleared before impacting the caregiver's mental and physical health.

Several studies have found that the quality of life and physical well-being of caregivers of patients with ovarian cancer has deteriorated over time.<sup>[17]</sup> The primary reason for this distress is the lack of social support from families and friends, and the cancer care team. Studies focusing on empowering the caregivers also suggest improving communication between medical teams, families and caregivers to ensure transparency and deliver better patient care.

### **Education and counselling of family members**

Ovarian cancer patients who live at home often require assistance with day-to-day activities, basic medical care, social needs and, most importantly, emotional support. Most of that support comes from family and friends turned caregivers. These family members and friends do not come with experience in caring for cancer patients, so they also require education and support to maintain a balance between patient care and their well being effectively.<sup>[18]</sup>

Millions of people are involved in caring for someone with cancer. These caregivers, too often, spouses, family members, and friends, are not prepared for a crucial role that takes a toll on their psychological well being.

At-home caregivers usually provide ovarian cancer patients with four types of assistance; daily living activities (meals, transportation, bathing); medical care (injection, wound care management); social support (companionship, encouragement, communication with family &

friends); advocacy with providers and payers.<sup>[19]</sup>

A family caregiver's work can be full time - an average of 8.3 hours per day for 13.7 months. This can extend to 66 hours per week during the last years (end-stage) of a patient's life. Ovarian cancer end-stage is crucial for both patients and caregivers. It is linked to diminishing the quality of life, depression, impaired immunity, heart disease, and early death of at-home caregivers.<sup>[20]</sup> The psychological burden may be even more significant for family caregivers because they stay around the patient, and complications are greater with female than male caregivers. A 2020 report calls for proper education and counselling at-home caregivers and other family members to achieve family-centred care.

### **Empowering the at-home ovarian cancer caregiver**

Family caregivers fall into two categories. One group takes care of patients with advanced cancer that is unlikely to be cured but demands chronic management and care.<sup>[21]</sup> Another group is involved in taking care of patients with stable conditions but interpreted with high-stress, high-need spikes – irreversible decline. The psychological and emotional toll may be intense for families of patients who undergo induction therapy for leukaemia, autologous stem cells or complex multimodality care.<sup>[22]</sup> Here are a few approaches to support both family caregivers and patients for better patient care.

### **Assessment**

The first step is to render the structure of family caregivers in a practical way and link with the



medical team and caregivers' network to communicate efficiently. A comprehensive assessment of family caregivers is used to plan the treatment in accordance with the family caregivers because, ultimately, they have to look after the patient.<sup>[23]</sup> Caregivers' assessment should focus on employment status, family responsibilities, community activities, competency, caregiving experience, medical skills, mental stability, and patient family dynamics.

### Education

Preparing family caregivers for their role in taking care of advanced ovarian cancer patients involves education, including skill training. Large institutions might have a caregiver curriculum with standard offerings regarding medication management, treatment of adverse effects, symptom management, nutrition and stress management, etc.<sup>[24]</sup> Specialised offerings should be tailored to caregivers' needs (financially, community resources, behavioural counselling, etc.)

### REFERENCES

1. Bast RC Jr, Hennessy B, Mills GB. The biology of ovarian cancer: new opportunities for translation. *Nat Rev Cancer*. 2009;9(6):415-28. doi: 10.1038/nrc2644.
2. Torre LA, Trabert B, DeSantis CE, Miller KD, Samimi G, Runowicz CD, et al. Ovarian cancer statistics, 2018. *CA Cancer J Clin*. 2018;68(4):284-296. doi: 10.3322/caac.21456.
3. Armstrong DK, Alvarez RD, Bakkum-Gamez JN, Barroilhet L, Behbakht K, Berchuck A, et al. Ovarian Cancer, Version 2.2020, NCCN Clinical Practice Guidelines in Oncology. *J Natl Compr Canc Netw*. 2021;19(2):191-226. doi: 10.6004/jnccn.2021.0007.
4. Stewart SL, Rim SH, Richards TB. Gynecologic oncologists and ovarian cancer treatment: avenues for

### Empowerment

Empowerment is usually referred to as training employees, but it is different and very much relevant to the ongoing role of family caregivers. Empowering caregivers is a must to ensure they feel confident in their tasks & duties, are responsible for performing well, and are listened to and responded to, contributing to a better society. Empowering also includes being educated and informed about what is happening and coming next.<sup>[25,26]</sup>

### CONCLUSIONS

More than any other disease, Ovarian cancer requires ongoing formal care and support to align the efforts of medical teams. Because many caregivers are not as experts as their family members. Regular communication and counselling, open discussion, problem-solving, and appreciation can help them achieve their goals.

improved survival. *J Womens Health (Larchmt)*. 2011;20(9):1257-60. doi: 10.1089/jwh.2011.3053.

5. Cryer L, Shannon SB, Van Amsterdam M, Leff B. Costs for 'hospital at home' patients were 19 percent lower, with equal or better outcomes compared to similar inpatients. *Health Aff (Millwood)*. 2012;31(6):1237-43. doi: 10.1377/hlthaff.2011.1132.
6. Williams AM. Education, Training, and Mentorship of Caregivers of Canadians Experiencing a Life-Limiting Illness. *J Palliat Med*. 2018;21(S1):S45-S49. doi: 10.1089/jpm.2017.0393.
7. Wu AH, Pearce CL, Tseng CC, Pike MC. African Americans and Hispanics Remain at Lower Risk of Ovarian Cancer Than Non-Hispanic Whites after Considering Nongenetic Risk Factors and Oophorectomy Rates. *Cancer Epidemiol Biomarkers Prev*. 2015;24(7):1094-100. doi: 10.1158/1055-9965.EPI-15-0023.



8. Petricone-Westwood D, Stragapede E, Galica J, Hales S, Lebel S. An investigation of fear of recurrence, attachment and caregiving experiences among ovarian cancer partner-caregivers. *Psychooncology*. 2022;31(7):1136-1143. doi: 10.1002/pon.5901.
  9. Kim Y, Carver CS, Ting A. Family Caregivers' Unmet Needs in Long-term Cancer Survivorship. *Semin Oncol Nurs*. 2019;35(4):380-383. doi: 10.1016/j.soncn.2019.06.012.
  10. Geng HM, Chuang DM, Yang F, Yang Y, Liu WM, Liu LH, et al. Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. *Medicine (Baltimore)*. 2018;97(39):e11863. doi: 10.1097/MD.00000000000011863.
  11. Macpherson AM, Barry SC, Ricciardelli C, Oehler MK. Epithelial Ovarian Cancer and the Immune System: Biology, Interactions, Challenges and Potential Advances for Immunotherapy. *J Clin Med*. 2020;9(9):2967. doi: 10.3390/jcm9092967.
  12. Vang R, Shih IeM, Kurman RJ. Fallopian tube precursors of ovarian low- and high-grade serous neoplasms. *Histopathology*. 2013;62(1):44-58. doi: 10.1111/his.12046.
  13. Institute of Medicine (US). Evidence-Based Medicine and the Changing Nature of Healthcare: 2007 IOM Annual Meeting Summary. Washington (DC): National Academies Press (US); 2008.
  14. Ozga M, Aghajanian C, Myers-Virtue S, McDonnell G, Jhanwar S, Hichenberg S, et al. A systematic review of ovarian cancer and fear of recurrence. *Palliat Support Care*. 2015;13(6):1771-80. doi: 10.1017/S1478951515000127.
  15. Lewis FM, Fletcher KA, Cochrane BB, Fann JR. Predictors of depressed mood in spouses of women with breast cancer. *J Clin Oncol*. 2008;26(8):1289-95. doi: 10.1200/JCO.2007.12.7159.
  16. Yoshino K, Enomoto T, Fujita M, Ueda Y, Kimura T, Kobayashi E, et al. Salvage chemotherapy for recurrent or persistent clear cell carcinoma of the ovary: a single-institution experience for a series of 20 patients. *Int J Clin Oncol*. 2013;18(1):148-53. doi: 10.1007/s10147-011-0357-5.
  17. Ferrell B, Smith SL, Cullinane CA, Melancon C. Psychological well being and quality of life in ovarian cancer survivors. *Cancer*. 2003;98(5):1061-71. doi: 10.1002/cncr.11291.
  18. Hennessey BT, Coleman RL, Markman M. Ovarian cancer. *Lancet*. 2009;374(9698):1371-82. doi: 10.1016/S0140-6736(09)61338-6.
  19. Kim A, Ueda Y, Naka T, Enomoto T. Therapeutic strategies in epithelial ovarian cancer. *J Exp Clin Cancer Res*. 2012;31(1):14. doi: 10.1186/1756-9966-31-14.
  20. Ramakrishnan S, Subramanian IV, Yokoyama Y, Geller M. Angiogenesis in normal and neoplastic ovaries. *Angiogenesis*. 2005;8(2):169-82. doi: 10.1007/s10456-005-9001-1.
  21. Liekens S, De Clercq E, Neyts J. Angiogenesis: regulators and clinical applications. *Biochem Pharmacol*. 2001;61(3):253-70. doi: 10.1016/s0006-2952(00)00529-3.
  22. Given CW, Given B, Stommel M, Collins C, King S, Franklin S. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health*. 1992;15(4):271-83. doi: 10.1002/nur.4770150406.
  23. Petricone-Westwood D, Hales S, Galica J, Stragapede E, Lebel S. What do partners of patients with ovarian cancer need from the healthcare system? An examination of caregiving experiences in the healthcare setting and reported distress. *Support Care Cancer*. 2021;29(3):1213-1223. doi: 10.1007/s00520-020-05599-3.
  24. Price MA, Butow PN, Costa DS, King MT, Aldridge LJ, Fardell JE, et al. Prevalence and predictors of anxiety and depression in women with invasive ovarian cancer and their caregivers. *Med J Aust*. 2010;193(S5):S52-7. doi: 10.5694/j.1326-5377.2010.tb03929.x.
  25. Angioli R, Capriglione S, Aloisi A, Miranda A, de Cicco Nardone C, Terranova C, et al. Economic Impact Among Family Caregivers of Patients With Advanced Ovarian Cancer. *Int J Gynecol Cancer*. 2015;25(8):1541-6. doi: 10.1097/IGC.0000000000000512.
  26. Marzorati C, Bailo L, Mazzocco K, Pravettoni G. Empowerment from patient's and caregiver's perspective in cancer care. *Health Psychol Open*. 2018;5(2):2055102918815318. doi: 10.1177/2055102918815318.
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