

Patients with ovarian cancer – knowledge and awareness of their disease, treatment, and possible complications

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Abstract

Introduction: Ovarian cancer is one of the most common cancers in Sri Lankan women and the third most common cancer among them. Health care workers as a team should be involved in patient education and counseling which must be customized according to the medical, psychological, social, financial, and spiritual background of the patient concerned.

Objectives: To assess patient awareness and knowledge about ovarian cancer, its treatment, and possible complications. To evaluate patients' concerns about how they were educated and counseled. Identify shortcomings and drawbacks and suggest measures to improve patient counseling and education.

Method: A prospective cross-sectional study was done with 178 patients to evaluate their knowledge about their disease, treatment, and possible complications of ovarian cancer. Assessment was done through an interviewer administered questionnaire. Assessment of the stage of the disease at diagnosis was done by comparing patient's description with patient's notes.

Results: 112 (63%) patients had satisfactory knowledge of the correct diagnosis of their disease whereas 56 (31%) patients had poor knowledge. 133 (74%) patients had good knowledge about the stage of the disease whereas 35 (20%) had poor knowledge. Concerning the treatment options, 133 (74%) had good knowledge but 33 (19%) patients had poor knowledge. Regarding the possible complications of the disease and possible complications of treatment 97 (54%) and 69 (39%) patients had good knowledge respectively, whereas 82 (46%) and 109 (61%) had poor knowledge respectively. 154 (87%) patients were satisfied with the education and counseling they had and 24 (13%) were unhappy.

Conclusion: Patient knowledge about their disease, treatment, and complications is not satisfactory and needs improvement. A counseling model needs to be developed and audited regularly.

Key words: ovarian cancer, knowledge, awareness, counseling

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Introduction

Ovarian cancer is one of the most common cancers in Sri Lankan women and the third most common cancer among them¹. The first and second most common cancers are breast cancer and cervical cancer respectively¹. Ovarian masses are common in premenopausal women than in postmenopausal women. But ovarian cancer is more common in post-menopausal women¹. The majority of ovarian cancers are asymptomatic until advanced stages. Therefore at diagnosis, 80% of cases are at an advanced stage³. The overall five-year survival rate for ovarian cancer remains 35-40%^{3,4}. Treatment depends on the stage at diagnosis, cancer type and cancer grade, fertility wishes, comorbidities, and patient's wishes⁵. As a general rule surgery is preferable in the early stages and may be the only form of treatment in some early-stage disease. In advanced stages, surgery may be supplemented by chemotherapy in the form of adjuvant chemotherapy which is given post-operatively, or neoadjuvant chemotherapy which is started pre-operatively to shrink the tumor with or without post-operative chemotherapy. Some cases of advanced-stage diseases are inoperable and hence chemotherapy or palliative care would be the treatment of choice³. Follow up after treatment is extremely important as it allows detection of disease recurrence and disease complications.

Patient counseling plays a key role not only in ovarian cancers, but also in other cancers as well as in other non-cancerous diseases. Patient awareness and education of their disease, its treatment, and possible complications play a major role in patient management as it directly affects patient compliance towards the treatment and follow up which plays a pivotal part in proper patient management. Patient education and counseling has been incorporated into the formal legislation system and is tightly regulated in some countries⁶. Health care workers as a team should be involved in patient education and counseling which must be customized according to the medical, psychological, social, financial, and spiritual background of the patient concerned. The quality of life (QOL) of a patient also relates to the patient's education and understanding of the disease and treatment^{7,8}. On the other hand, the quality of life of patients with ovarian cancer can be enhanced by improving patient education and counseling^{9,10}. It is a challenge to meet the requirements of proper patient education and counseling in a busy government health care system but neglecting which is not acceptable. Our objective was to evaluate patient

knowledge and awareness of their disease, treatment, and possible complications in patients with ovarian cancer and identify drawbacks and make suggestions to improve patient education and counseling.

Materials and method

A prospective cross-sectional study was done including 178 patients with ovarian cancer at the gynecological oncology unit at Apeksha Hospital Maharagama for six months between 1st of December 2017 and 31st May 2018. Ethical clearance was obtained by the Medical Research Institute (MRI) before commencing the study. Patients with a diagnosis of ovarian cancer within six months and who were waiting for treatment or who completed treatment and was on follow-up were included. Written consent was taken before the study from all participants. Those who were diagnosed to have benign ovarian masses were excluded. Those who had their established ovarian cancer diagnosis older than six months were also excluded as the ability to recall incidents at the diagnosis may be poor.

After fulfilling the eligibility an introduction was made to the patient about the study by one of the investigators and patients who consented to participate were interviewed through an interviewer-administered questionnaire. The questionnaire was designed to acquire information related to the patient's social background, monthly income, educational status, knowledge of the diagnosis, knowledge of the disease and its stage, and knowledge of complications of the disease. Patient's responses were recorded separately. Patient's response regarding the stage was compared with the actual stage at diagnosis and accuracy was determined subjectively. Patient's knowledge was assessed by an interviewer administered questionnaire. At the end of the interview if a patient required more information about their disease, stage, complications, or anything related to the disease, it was given to the patient after going through the clinical records. All questionnaires were entered into a Microsoft excel datasheet and analysis was done at the end of the study.

Results

The total number of subjects was 178. Age ranged from 22 years to 76 years with an average of 58.7 years. Out of 178 patients, 138 patients (77%) were post-menopausal and only 40 patients (23%) were premenopausal. Out of 178 subjects, 157 (88%) had children and only 21 (12%) were nulliparous. Sixty-

one subjects (34%) were never employed and 117 subjects (66%) were currently employed or retired after employment. Educational level was stratified into three categories as advanced level (A/L) or above, ordinary level (O/L) education, and below ordinary level education. Only 41 subjects (23%) had an education level of A/L or above whereas 96 patients (54%) had education up to the ordinary level only. Forty-two subjects (23.5%) had an education level below O/L (Figure 1).

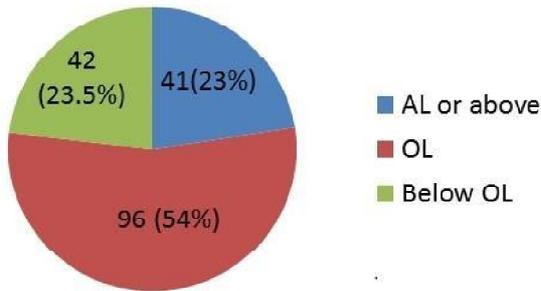


Figure 1. Distribution of education level of the study population.

Family income level was stratified into four categories, less than Rs. 20,000 per month, between Rs. 20,000-50,000 per month, between Rs. 50,000-100,000 per month and more than Rs. 100,000 per month. Only six subjects (3.5%) had family income above Rs. 100,000 and only 8 subjects (4.5%) had family income below Rs. 20,000. Eighty-four patients (47%) had family income between Rs. 50,000-100,000 whereas 80 patients (45%) had income between Rs. 20,000-50,000.

The stage at diagnosis of ovarian cancer was stratified according to FIGO staging of ovarian cancer. About 49% of patients (87 out of 178) were at FIGO stage III at the diagnosis and only 41 patients (23%) were at FIGO stage I at diagnosis. Thirty-four (19%) and 16 (9%) patients were at stages II and IV respectively at diagnosis. The distribution of the FIGO stage at diagnosis is shown in Figure 2.

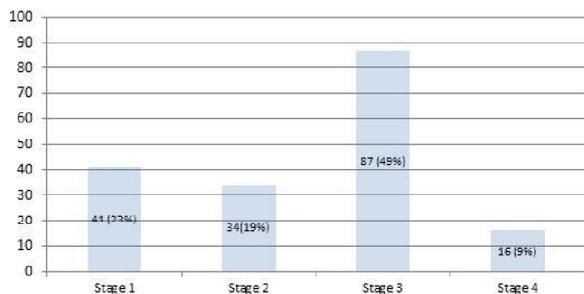


Figure 2. Distribution of FIGO stage at diagnosis.

The level of the knowledge was assessed separately about the diagnosis (which is ovarian cancer), how the diagnosis was made, stage of the disease at diagnosis and about the treatment options of the disease and was categorized into three ordinal categories as excellent, good and poor. Categorization was done subjectively. Graphical representation is given below along with the figures of assessment.

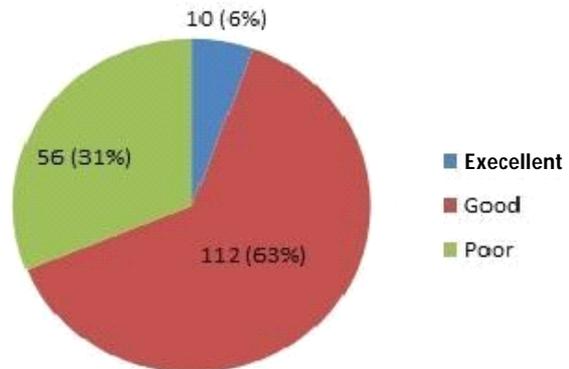


Figure 3. Knowledge about the diagnosis.

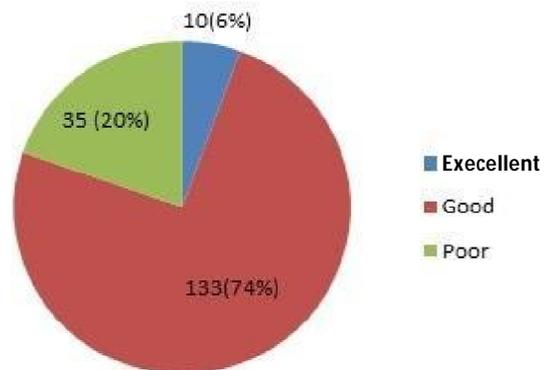


Figure 4. Knowledge about the stage at diagnosis.

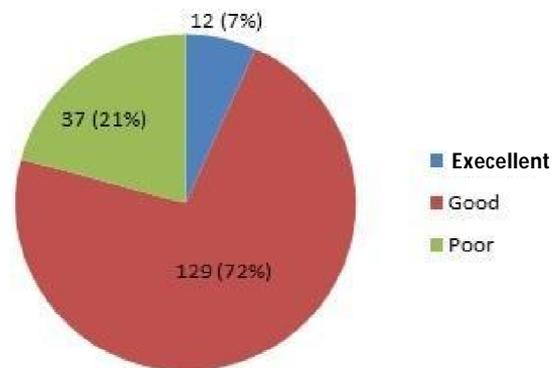


Figure 5. Knowledge about how the diagnosis was made.

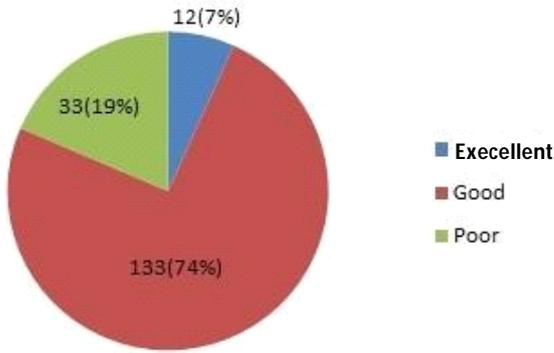


Figure 6. Knowledge about the treatment options.

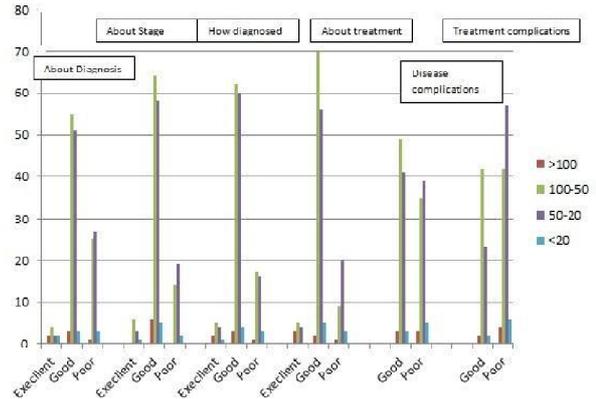


Figure 8. Financial status and knowledge.

The level of knowledge was assessed about complications of both the disease itself and complications arising from treatment. Two ordinal categories of good and poor were made when assessing level of knowledge for complications. Classification was made subjectively. Knowledge about complication of the disease was good in 97 subjects (54%) whereas in 82 subjects (46%) it was poor. Sixty nine patients (39%) had a good knowledge about possible complications of treatment while 109 patients (61%) had a poor knowledge. About the education of the patients only 43 patients (24%) were educated by a consultant and 129 (73%) and 6 (3%) patients were educated by a medical officer and nursing officer respectively. Twenty four patients (13%) were not happy about the education they had and 154 (87%) patients were happy. Twenty eight patients (16%) did not ask for further information of their disease while 150 (84%) were interested in having further information. All the parameters were analyzed about educational status and economic status and graphical representation with data is given below.

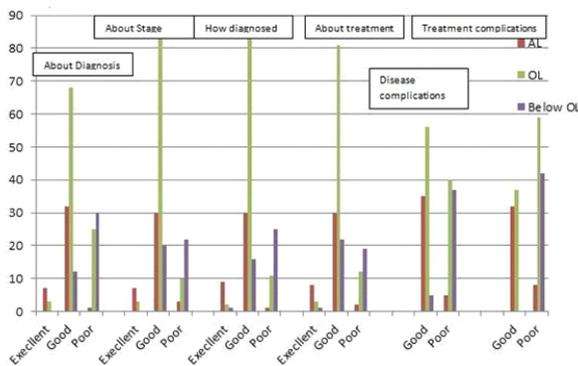


Figure 7. Education level and knowledge.

Discussion

Epidemiologically, data observed in the study is comparable with global statistics about the mean age of ovarian cancer and its post-menopausal predominance. Data differs significantly from national data with regards to income level and education when compared to the National Household and Expenditure Survey 2016 by Department of Census and Statistics, Sri Lanka¹¹. However comparison of such data is beyond the scope of this study.

When concerning the knowledge about the diagnosis, a shocking feature is that nearly one third of the study population had a poor knowledge about the exact diagnosis. We, as health care workers need to think twice if a patient does not know what the disease he or she is having and for what condition they are being treated for. When analyzing in detail the data of patients who had poor knowledge about the diagnosis, some of them thought that they had a cancer inside the abdomen, stomach, a cancer inside the uterus or a cancer in the bowel. This may be a result of either not having proper counseling or they may have forgotten what they were told over the time. Recalling symptoms is poor over the time with cancer patients¹². Nobody has been given written information which could have prevented such a poor result. Another factor is that not all were counseled along with a relation or friend who can retain the details given when the patient is under a stressful environment during breaking bad news. Most of them have attended subsequent clinic visits but still showed lack of knowledge.

However knowledge about the stage at diagnosis is poor only in 20% of subjects. The expectation about the knowledge of stage at diagnosis was basic and that can be the reason for not having a higher number

of failures compared to the knowledge of the diagnosis. The majority of the patients knew whether their disease was at an early stage or advanced stage and interestingly, that information seemed retained far better than the information about precise diagnosis. Even in developed countries like the United Kingdom awareness of ovarian cancer among the general public is low as shown by recent ovarian cancer pathfinder study¹³.

The final and exact diagnosis of ovarian cancer is only made after histological analysis and about 20% of patients were not aware of it. Some patients thought that the diagnosis was made after a CT scan or after ultrasound scan. Few patients thought that it was made after abdominal palpation alone. This denotes lack of medical knowledge of the patients and needs addressing.

When it comes to the topic of treatment options it is very important that the patient is well aware of the available treatment options and it plays an essential part in patient counseling. However, irrespective of much effort, unfortunately about one fifth of patients were not aware of treatment options that were available to them or that are available to them depending on the case. No written information was given explaining treatment options. However 80% of patients had a fair knowledge of treatment options. They either discussed with doctors or explored the subject by personal contacts or through newspapers, articles or the internet.

Both the levels of knowledge about complications arising from the disease itself and possible complications of the treatment were poor among the study population, and were 46% and 61% respectively. Majority could not recall the possible complications that they could have and some of them were not aware about it at all. Those who had complications knew about it and its management better than those who had no complications. Specially, those who had complications of chemotherapy had a good knowledge about it. Those who had surgery alone had a poor knowledge of possible complications compared to those who had chemotherapy. For a standard practice knowledge should be given about the possible complications before embarking on any kind of treatment and informed consent for such a treatment is pivotal. However documentations were noted in clinical notes about such discussions but the problem was that patients did not retain the information provided. It is evident as much as 84% of patients were interested in further discussion about their disease and treatment. Patient education

models are known to be poor especially in south asian countries¹⁴.

When analyzing the parameters against education level and financial status, it is evident that the majority of “poor knowledgeable” patients belong to low education levels and low income levels. Therefore we should pay much attention when we counsel such patients as the tendency is lack of retaining information in the long run.

Even though sexual health concerns were not addressed in the study it was noted that a significant number of patients had sexual health problems. Main areas of concern were effects of cancer for the sexual life, contraception issues for premenopausal women and sexual dysfunction issues in those who had extensive surgery and chemotherapy. Since it has been shown that sexual health concerns are one of the main features that determine quality of life¹⁵, we believe that sexual health concerns should be incorporated into the patient counselling.

Genetic counselling for ovarian cancer is not considered routine in current practice in Sri Lanka. However, advanced genetic mutation detection tools are currently available and are used in genetic counselling in other countries¹⁶.

Conclusion and recommendations

In summary, knowledge, and awareness of diagnosis, treatment, and complications of ovarian cancer among patients with ovarian cancer is not satisfactory and there is plenty of room for improvement. The main pitfalls identified are, being unable to recall what has been discussed, lack of written information, lack of proper counseling sessions with the involvement of relations, and lack of regular assessment of knowledge and understanding. The majority of patients are happy with the counseling they had but recalling of the facts is poor. We strongly recommend providing written information when counseling in the form of leaflets or booklets so that the patients can read them at home when their mind is ready to absorb information. Standard leaflets about not only ovarian cancer, but also other cancers can be developed as in many other developed countries. The leaflet should contain a precise diagnosis, basic anatomy, possible complications of the disease spread, stages of the disease, treatment modalities available, and its possible complications. It should also contain how to find more

details if they wish to and services available to them for their possible needs. We also recommend regular auditing to maintain standards as no audit program is designed with regard to this aspect. A proper counseling model can be developed and implemented with the areas of address, people involved and with a plan of management. The patient's education level and financial status should be considered when offering counseling as patients with low education levels and low income tend to fail in absorbing facts in counseling sessions. We hope we can improve parameters by implementing what we have recommended and formulating a follow-up mechanism in the form of an audit.

Author declarations

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