# Greater awareness is the first step in the fight against Ovarian Cancer in Jordan

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### Abstract

Objective: This study was undertaken to assess the awareness of the risk factors, signs, and symptoms of Ovarian cancer, among health care professionals. And to evaluate possible measures to enhance ovarian cancer care in Jordan. Methods: Real time surveys were completed by 75 family medicine trainees from Jordan's Ministry of Health, and 75 final year medical students from Jordan University of Science and Technology. The survey included a case scenario with three extended match questions to cover diagnosis, initial investigations and referral to a specialised cancer unit for further review and management. Results: Only 5 (6.7%) family medicine trainees and 2 (2.7%) final year medical students managed to answer the three questions correctly. 60% of family medicine trainees and 40% of final year medical students correctly answered the first question on cancer diagnosis, 8% of family medicine trainees and 3% of final year medical students correctly answered the second question on the initial investigations in the primary care. 35% of family medicine trainees and 40% of final year medical students correctly answered the third question on the referral to cancer unit for further management and review. Conclusion: There is an obvious need to improve awareness of risk factors, signs and symptoms of ovarian cancer, to implement a robust ovarian cancer reporting system, cancer networks, and to develop a country-wide strategy to enhance ovarian cancer care in Jordan.

# Clinical Article

#### Title:

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#### Abstract :

**Objective**: This study was undertaken to assess the awareness of the risk factors, signs, and symptoms of Ovarian cancer, among health care professionals. And to evaluate possible measures to enhance ovarian cancer care in Jordan.

**Introduction**: Ovarian cancer is the sixth most frequently diagnosed cancer in women.[10] It is the most common cause of death from gynaecological malignancy with a lifetime risk of 1:50. Unfortunately, as there

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is no effective screening program;70% of women are diagnosed with an advanced stage, with a 5-year survival of only 40%. [1,3] Based on an estimated population of approximately 10 million; it is expected to have around a 1000 ovarian cancer cases diagnosed per year in Jordan. However, in 2015 there were 86 ovarian cancer cases have been registered, with an average of less than 90 cases annually over the previous years according to the Ministry of Health cancer registry.[2]

**Methods**: Real time surveys were completed by 75 family medicine trainees from Jordan's Ministry of Health, and 75 final year medical students from Jordan University of Science and Technology. The survey included a case scenario with three extended match questions to cover diagnosis, initial investigations and referral to a specialised cancer unit for further review and management.

**Results**: Only 5 (6.7%) family medicine trainees and 2 (2.7%) final year medical students managed to answer the three questions correctly. 60% of family medicine trainees and 40% of final year medical students correctly answered the first question on cancer diagnosis, 8% of family medicine trainees and 3% of final year medical students correctly answered the second question on the initial investigations in the primary care. 35% of family medicine trainees and 40% of final year medical students correctly answered the third question on the referral to cancer unit for further management and review.

**Conclusion**: There is an obvious need to improve awareness of risk factors, signs and symptoms of ovarian cancer, to implement a robust ovarian cancer reporting system, cancer networks, and to develop a country-wide strategy to enhance ovarian cancer care in Jordan.

# Introduction:

Ovarian cancer is the fourth most frequently diagnosed cancer in women with a life-time risk estimated around 1:50. It is also the most common cause of death from gynaecological malignancy. The 5 years survival is around 90% in the first stage, with total survival for all stages estimated around 40%. As there is no established effective screening programme for ovarian cancer yet; 70% of ovarian cancer cases are diagnosed with an advanced stage.[1,3,4]

A prospective cohort study within the UK collaborative trial of ovarian cancer screening (UKCTOCS) that included more than 200,000 women; revealed an overall 20% mortality reduction in years 7–14, however, further follow-up is needed before firm conclusions can be reached on the efficacy and cost-effectiveness of ovarian cancer screening.[9]

The majority of ovarian cancers are epithelial and sporadic. Familial and genetic mutations account for around 10% of the cases; BRCA1,2 and HNPCC.[11] Women with BRCA1& BRCA2 genetic mutation have around 40%, 10-20% risk of developing ovarian cancer respectively.[11,12] Its recommended to offer risk reduction surgery to remove both ovaries after completion of family to reduce risk of developing ovarian cancer.

Risk factors of ovarian cancer include; Age with a peak incidence above 60 years, nulliparity, infertility (especially with the use of fertility drugs), and Endometriosis.[1,5]

Protective factors include; pregnancy and usage of combined hormonal contraception. Usage of combined pills for more than 10 years reduces the risk of ovarian cancer by 40%.[1,5]

Many years ago, ovarian cancer was thought to be a silent killer. However, most recent evidence revealed that ovarian cancer always gives symptoms, but healthcare professionals should listen carefully.[1,3] Symptoms of ovarian cancer include abdominal pain, bloating, change in bowel habit, urinary symptoms, and pelvic symptoms. Signs of ovarian cancer include abdominal mass/cyst, weight loss, and reduced appetite. Additionally, ovarian cancer can be diagnosed incidentally during routine investigation.[5]

Recognition of risk factors, symptoms and signs besides greater awareness among people and health care professionals are essential and has an important role in diagnosing ovarian cancer in a relatively early stages where the prognosis and survival is better.

# Method:

75 ministry of health family medicine trainees and 75 final year medical students from Jordan university of science and technology participated in this study. Participants were given a case scenario about ovarian cancer and were asked to answer three questions.

# The clinical Scenario:

A 60 year old, nulliparous lady, with history of 5 previous failed IVF cycles, diabetic on Metformin and diet, but otherwise normally fit and well. Presented to primary care with 3 months history of constant bloating, lower abdominal discomfort and altered bowel habits. Examination was limited due to body habitus, examination revealed raised BMI with no obvious palpable masses.

- Q1. Based on risk factors and symptoms she is at risk of?
- Q2. What is the next relevant investigation required in primary care setting?
- Q3. If pelvic mass is palpable, the next most appropriate action is?

#### Answers:

Based on the patient's age, risk factors and symptoms, the clinical scenario is in keeping with ovarian cancer. It is recommended, and crucial for the healthcare professionals to investigate and rule out ovarian cancer. The initial relevant investigations in a primary setting should be focused on testing for Tumour marker (CA125) followed by an urgent pelvic ultrasound for abnormal result. If a pelvic mass is identified during the examination, this should trigger an urgent suspected cancer referral to cancer unit.

One useful tool could be used to assess and triage women presented with ovarian cysts especially for post-menopausal women called Risk of Malignancy Index (RMI) Tables 1& 2.[1]

RMI can be calculated according to this formula. RMI= M (Menopausal status) XCA125X Ultrasound score.

M equal 1 for pre-menopausal women, 3 for post-menopausal women.

CA 125 is a surface antigen on a high molecular weight glycoprotein recognised by a monoclonal antibody (produced using an ovarian cancer cell line). It is most useful as a marker for non-mucinous ovarian epithelial cancer, and indeed is present in up to 80% of cases of advanced ovarian cancer.[4,5]

Ultrasound score will be calculated based on the cyst's characteristics. Patients can be counselled and referred according to their cancer risk.[1,5]

Clinical scenario was given to participants, answers were collected on a spread sheet and analysed.

# Results:

Out of 150 participants, 60% of family medicine trainees and 40% of final year medical students correctly answered the first question on cancer diagnosis, 8% of family medicine trainees and 3% of final year medical students correctly answered the second question on the initial investigations in primary care. 35% of family medicine trainees and 40% of final year medical students correctly answered the third question on the referral to cancer unit for further management and review.

Only 5 (6.7%) family medicine trainees, and 2 (2.7%) final year medical students managed to correctly answer all three questions.

# Discussion:

There are around 7,400 new ovarian cancer cases in the UK every year, that's 20 every day (2015-2017) with a 10 years survival of 35%. Ovarian cancer is the 6th most common cancer, with around 7,300 new cases in 2017.[10]

The estimated population of a country like Scotland is around 5.5 million with an average of 600 Ovarian cancer cases diagnosed each year.[5,10]

In comparison the estimated population of Jordan is around 10 million with an average of lass than 90 Ovarian cancer diagnosed each year according to the ministry of health cancer registry.[2]

Table 3 summaries some demographic, Ovarian cancer risk factors and cancer care differences between the 2 countries.

Based on the population, risk factors and the world wide 1:50 women life time risk of developing Ovarian cancer, it is expected that Jordan should register more than a 1000 ovarian cases annually. However, according the ministry of health cancer registry, on average there are less than 90 Ovarian cancer registered. [2]

It is obvious that we have a gap between the expected and the registered cancer numbers.

How can we explain this gap? And what are the possible reasons responsible for this gap?

Possible causes and suggested measures to enhance ovarian cancer registration and care in Jordan:

Lack of awareness among health care professionals. This study revealed a need to improve awareness among healthcare professionals about risk factors, signs and symptoms of ovarian cancer. This can be achieved through organising regular joint meetings, workshops and study days for the primary care general practitioners and family medicine doctors. Primary health care systems in many developed countries established a clear guidelines to their health care professionals to role ovarian cancer with tumour marker and pelvic ultrasound for women over 50 years of age who present with symptoms suggestive of ovarian cancer. [13]

Lack of community awareness: Ovarian cancer always gives symptoms. [1,13] Unfortunately, these symptoms are often non-specific and could be put down to many benign conditions like Irritable bowel syndrome, until cancer develops into a more advanced stage resulting in a poor prognosis. Several measures can be utilised to raise women's and public awareness of risk factors and symptoms of ovarian cancer. Regular educational programmes to raise awareness can be broadcasted through national and other media channels including social media. In addition, informative leaflets and posters can be made available in hospitals, universities and other healthcare institutions.

Under-reporting: There are several healthcare systems and independent health care institutions in Jordan; Ministry of Health' hospitals, Royal Medical Services' hospitals, university-based hospitals, and a large private sector. There is no standard robust cancer reporting system in place to ensure all ovarian cancer cases are being reported and registered in one single cancer registry. Reporting forms should be available electronically, and completed by designated cancer accountable healthcare professionals on monthly basis. Most health boards in many developed countries developed national cancer registration and analysis services responsible for cancer registration and to support cancer epidemiology, public health, service monitoring and research.[15]

Lack of standard timely cancer referral pathways: Delivering timely cancer pathways is crucial for the following reasons: Despite improving survival rates, cancer is the fourth leading cause of death in the UK; Patients continue to present late to their doctors with their symptoms, resulting in delayed referral; Once a patient has been referred, they want to be told "It's not cancer" as soon as possible or have their treatment planned in a timely manner; Where the diagnosis is cancer, a speedy diagnostic pathway is critical for 62 day compliance. Achievement of the national cancer waiting times standards is considered by patients and the public to be an indicator of the quality of cancer diagnosis, treatment and care.[1,3,16,17] Unfortunately, there is no equivalent standard referral pathways in Jordan. This could result in some of patients having to wait for prolonged periods, or not being referred to cancer units at all. Implementing these standard pathways will contribute to enhancing patient's referral and care.

Lack of cancer tracking system: Cancer tracking is crucial to ensure that cancer patients receive their care in a timely manner. It is good practice for organisations to have in place staff, systems and processes to 'pull' cancer patients along their diagnosis and treatment pathways. Tracking list should enable tracking staff to see clearly where each patient is in their cancer pathway, what next step(s) each patient is awaiting and the deadline by which it needs to be done. It should be clear which patients are currently at risk of missing a milestone on their pathway[16]. Ovarian cancer patients in Jordan receive their management, or parts of their management, in several hospitals, and in different health sectors based on the availability of the infrastructures and resources. Some patients will need to be referred between these sectors with no single authority tracking the care of these patients. Thus, increasing the risk of patients being lost between these healthcare institutions.

Lack of cancer clinical networks: Linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner to ensure equitable provision of high quality clinically effective services. Cancer networks play a key role in reconfiguring cancer services with improvement of survival figures and patient experience.[18] Having this structure of networking will have a positive impact on cancer patients care in Jordan.

# **Conclusion:**

Ovarian cancer is no longer a silent killer. It always gives symptoms which healthcare professionals should be attentive to.

Enhancing cancer care and improving ovarian cancer survival comes down to greater awareness, education, early diagnosis and treatment.

It is essential to improve community and healthcare professionals' awareness of risk factors, symptoms and signs of ovarian Cancer.

Women diagnosed with ovarian and breast Cancer should be referred to genetic clinics for genetic counselling and BRCA, HPNCC testing.

Risk reduction surgeries to remove ovaries should be offered to women who carry genetic mutations.

There is a need to establish cancer networks; to ensure a multidisciplinary approach, clear, timely 2 weeks cancer referral pathways with easy and free access.

There is also a need to set a robust national cancer tracking with standard investigation and treatment targets. A simple blood test of CA125 should be available in all primary care clinics. Fertility drugs should be given with caution and only in women specialised fertility clinics.

We need to develop a country-wide strategy to enhance ovarian cancer care through establishing cancer networks and links, referral pathways with cancer tracking system to enhance ovarian cancer care in Jordan.

Table 1. Calculating the risk of malignancy index (RMI); these are modifications of the original RMI using modified scores

 $RMI = U \times M \times CA125$ 

U = 0 (for ultrasound score of 0); U = 1 (for ultrasound score of 1); U = 3 (for ultrasound score of 2–5) Ultrasound scans are scored one point for each of the following characteristics: multilocular cyst; evidence of solid areas; evidence of metastases; presence of ascites; bilateral lesions.

M = 3 for all postmenopausal women dealt with by this guideline

CA125 is serum CA125 measurement in u/ml

 $\textbf{Table 2.} \ An example of a protocol for triaging women using the risk of malignancy index (RMI); data from validation of RMI by Prys Davies \textit{et al.}^{16}$ Risk RMI Women (%) Risk of cancer (%) Low 40 < 3 Moderate 25-250 30 20 30 > 250 75 High

Table 3

	Jordan	Scotland
Population	10 million	5.4 million
People>65 years	3.5%	20%
Child birth per women	3	0.06
CHC* use	Not popular	Popular $> 20\%$
Fertility drugs	Out of control	Specialised fertility clinics
Health care system	Multiple	Single
2 weeks referral pathways	Not implemented	Implemented
National Cancer tracking system	Not implemented	Implemented
National cancer treatment targets	Not implemented	Implemented
Cancer networks	Not established	Established

\*CHC: combined hormonal contraceptives

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Othman Beni Yonis: Analysis of data Ahmad Abdulla: Collection of data

Nail Obeidat: Analysis and editing manuscript

Keywords: UKCTOCS, BRCA1,2, RMI, CANCER NETWORKS, REFERRAL PATHWAYS

# Selected References:

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