

'Ovarian Cancer and the Psychological Impact.'

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Key learning points

1. A woman's journey to a diagnosis of ovarian cancer is often a difficult one.
2. Treatment and the heavy symptom burden are hard to endure and women experience significant levels of psychological distress.
3. Primary care nurses have a role to play in providing psychological support throughout the cancer trajectory, beyond treatment to survivorship.

Introduction

Ovarian cancer is the sixth most common cancer in women in the UK and the most lethal of gynaecological cancers (1). The only proven method of prevention is the removal of the ovaries and fallopian tubes before cancer develops. This strategy is not recommended for women in the general population, but is available for women who are known to be at increased risk of developing ovarian cancer because of a genetic predisposition. Ovarian cancer screening aimed at reducing mortality through early detection is not available on the NHS, due to the lack of a convincing evidence base.

The generic term 'ovarian cancer' encompasses a group of cancers that includes the ovaries, along with primary cancers of the fallopian tube and peritoneum. It is not a single disease entity but different diseases with different risk factors, precursor lesions, patterns of spread, response to chemotherapy and prognosis (2, 3). Most patients (80%) present with aggressive high-grade serous carcinoma at an advanced stage and overall 5-year survival is less than 35%. This poor outcome reflects the high risk of recurrence after initial treatment. The psychological impact of this disease can be profound.

Risk Factors and Presentation

Healthcare professionals in primary care may only see one or two cases of ovarian cancer in their working life. The lifetime risk of ovarian cancer is 2% (England, Wales). A woman's risk of developing ovarian cancer increases with age and most occur in women aged 65 years and older. The strongest risk factor

is a family history of ovarian cancer and other cancers seen in inherited cancer syndromes (breast, bowel). Up to 15% of high-grade serous ovarian cancers are associated with a mutation in a tumour suppressor or mismatch repair gene. Lifestyle factors that reduce the total number of ovulations, such as use of the oral contraceptive pill and breast feeding, are associated with a lower risk.

Symptoms are non-specific and often mistaken as non-threatening by both patients and healthcare providers. Women diagnosed with ovarian cancer often have a history of presenting with vague symptoms including fatigue, constipation and back pain (4). The GP may have decided on a wait and see approach or the patient may have been referred to a non-gynaecological oncology specialist for investigation (typically gastrointestinal or bowel). Some women report feeling exhausted by the struggle to get a correct diagnosis. NICE guidelines list 4 red flag symptoms that may indicate the presence of ovarian cancer when experienced persistently or frequently: abdominal bloating, loss of appetite, pelvic/abdominal pain, and urinary urgency/frequency (5).

Diagnosis, Treatment and Management

The first test for ovarian cancer is the serum CA125 blood test and if the result is concerning an abdominal/pelvic ultrasound scan to identify a suspicious mass. If ovarian cancer is suspected, women should be urgently referred to a specialist centre with expertise in the treatment and management of ovarian cancer, where the best outcomes are achieved (6). Formal diagnosis is based on cytology or histopathology.

Over the past 10 years changes in surgical practice aimed at achieving zero residual disease and the use of platinum-based chemotherapy treatments have led to improvements in survival. Unfortunately while the majority of women initially respond well to treatment, most will experience a recurrence of disease necessitating repeated surgery and cycles of chemotherapy aimed not at cure, but improving the quality of life and palliation.

Psychological Impact

The journey to a diagnosis of ovarian cancer is often difficult. It may be abrupt following an emergency presentation reflecting advanced disease, or involve a protracted struggle for symptoms to be appropriately investigated. The initial psychological impact can range from one of shock in women who have been unconcerned about non-specific symptoms, to relief at confirmation of the reason for symptoms, or disappointment and anger at missed opportunities to diagnose the cancer earlier when reported symptoms have been misattributed to other less serious conditions and delay may have compromised survival.

Extensive surgery with major tissue debulking and repetitive cycles of toxic chemotherapy are debilitating and challenging to endure. Younger women also have to contend with the loss of fertility and a premature menopause. The quality of women's lives is often severely compromised by psychosocial issues including personal and family distress at the initial diagnosis, along with fear about future diagnostic tests (7). Women may be aware that their doctor is expecting the cancer to return and there is uncertainty about when, or if, further

treatment will begin. Concomitant psychosexual problems are often not addressed and there may be concern that relatives will be diagnosed with cancer if there is a heritable component. The prospect of a cure is rare and most face the very real possibility of dying (8). Disease progression is often accompanied by pain (peripheral neuropathy after intense chemotherapy) and the heavy symptom burden can lead to changes in body image (abdominal distention caused by ascites), difficulty eating and bowel obstruction, reduced mobility and activity, and a loss of confidence leading to social isolation.

Through all of this, a woman's cherished relationships come under strain as the disease process interferes with her social roles as a mother (particularly if her children are young), wife, sister, grandmother and friend. Women face the loss of femininity, sexuality, loved ones and the trauma of confronting an early death.

Psychological Support

Primary care nurses are a potential source of long-term psychological support to women diagnosed with ovarian cancer. While input from other specialist practitioners may come and go throughout the patient's cancer journey, the primary care nurse remains a constant presence.

Adjusting to cancer is a normal psychological process that occurs over time as a woman and the people she is close to come to understand and adapt to the changes caused by the illness and its treatment (9). Inevitably, a life-threatening diagnosis confronts women with their own mortality. For some, this can lead to a period of healthy personal growth with revised priorities and lifetime goals. However, maladaptive adjustments (loss of meaning, helplessness and despair) can result in a depressive illness or anxiety. Both are common in ovarian cancer patients (10), along with a degree of post-traumatic stress disorder (11).

Women should be screened for psychological distress at the beginning of the cancer pathway. As part of a Holistic Needs Assessment and Care Plan (12) women complete a brief assessment checklist at strategic points along the cancer trajectory, highlighting issues causing the greatest distress and immediate support needs. This may prompt further evaluation by a psychology member of the clinical team or clinical nurse specialist. Self-report measures, such as the Hospital Anxiety and Depression Scale (HADS) (13), are used to identify women requiring specialist input from a psychologist or counsellor (trauma focused cognitive behavioural therapy, mindfulness stress reduction).

More women are surviving and living beyond cancer and their psychological wellbeing is an integral part of a survivorship care plan. The primary care nurse is at the heart of this process (14) offering proactive advice to enhance emotional support and practical strategies for dealing with stress and low mood, difficulty sleeping, lethargy and a lack of concentration. Encouraging women to set goals for the future can restore a measure of self-control that is integral to a sense of security and self-esteem. The simple step of signposting women on to further sources of information (Cancer Research UK, Citizens Advice Bureau) and

support (Relate, and charity-run helplines for ovarian cancer) can also be helpful.

A one size fits all approach to any intervention which fails to address women's innate preferences for emotional support in response to a life-threatening illness is unlikely to achieve the maximum benefit (15). Early experiences of receiving emotional support during infancy form a template for preferences in later adult life. Individuals can be broadly categorized as secure (60% of the population) or insecure in their willingness to seek support. The securely attached feel comfortable asking for support in the confident expectation it will be given. This contrasts with the insecurely anxious who crave support but worry it will not be forthcoming, and the insecurely avoidant who feel most comfortable with emotional distance and self-reliance. More anxiously attached women may welcome frequent short contact and an opportunity for intense emotional expression. The compulsively self-reliant avoidant woman may feel more comfortable with interpersonal distance and less frequent contact perhaps by telephone rather than face-to-face. Being sensitive to these differences and tailoring psychological interventions to address them is likely to be most effective (16).

Primary care nurses play a key role in linking the support and care provided by GP practices and hospital-based oncology and palliative care services, along with coordinating community based services. Developing a consistent approach to managing the psychological impact of ovarian cancer can be achieved through good communication amongst healthcare professionals working as a team and sharing insights into patients' support needs.

What the Future Holds

Managing the consequences of cancer and its treatment in primary care is set to increase in an ageing population. Primary care nurses will need to undergo education and training, to enable them to fulfil this changing role. The Macmillan toolkit is a useful online resource (www.rcgp.org.uk/coc). A body of research is developing that will provide the evidence base to design clinical practice guidelines on psychological interventions (17). It is hoped that this work, along with a better understanding of the sub-types of ovarian cancer and progress in biomarker discovery, will lead to improvements in earlier diagnosis, improved survival, and a better quality of life for those affected by ovarian cancer.

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