



Psychosocial Impact of Ovarian Cancer Diagnosis in Young Women – A Case Study

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Acknowledgements

- Tetske Heijink, Radboud University, Netherlands
- Nigel Armfield, University of Queensland

The case

- 24 years old at time of diagnosis; 29 at time of interview
 - Has lived in Australia her whole life
 - Works as software & account manager
 - Previously married (throughout illness), then divorced
- No medical history, previously on the OCP
- Does not smoke, drinks alcohol rarely

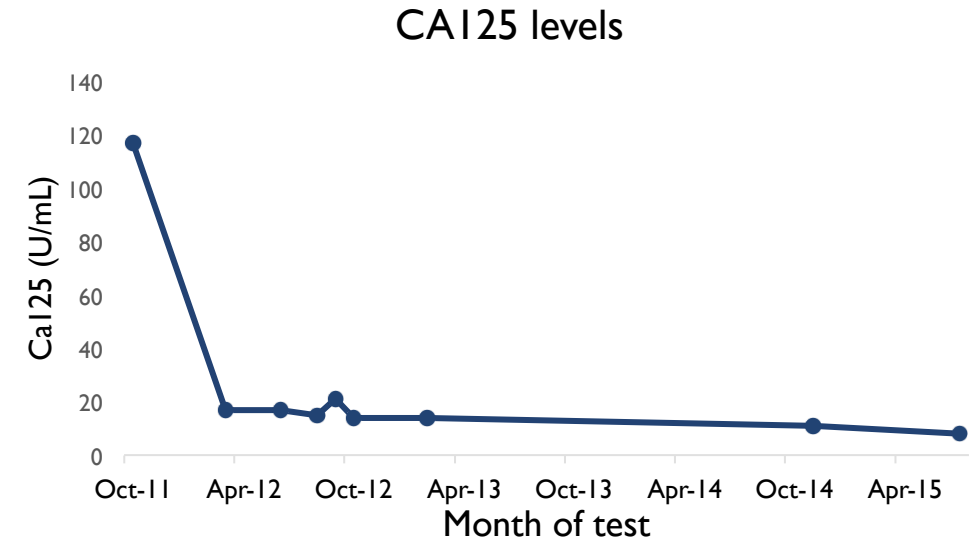
Medical history

- Presented with sore left hip in October 2011
- Vaginal examination → tenderness & fullness in right iliac fossa
- Trans-vaginal ultrasound & CT October 2011 → *complex, predominantly cystic lesion in right adnexa, frond-like projections of solid material into the cyst. Measures 54 x 26 x 21mm*

- 1st laparotomy November 2011

- Left ovarian cystectomy (80% of left ovary preserved) → frozen & paraffin sections – **borderline serous tumour**
- Right oophrectomy – borderline serous tumour with involvement of capsular surface
- Right external iliac nodes & left obturator nodes positive for borderline serous tumour
- Nil other evidence of metastatic disease → Stage pT1c pN1 pM0

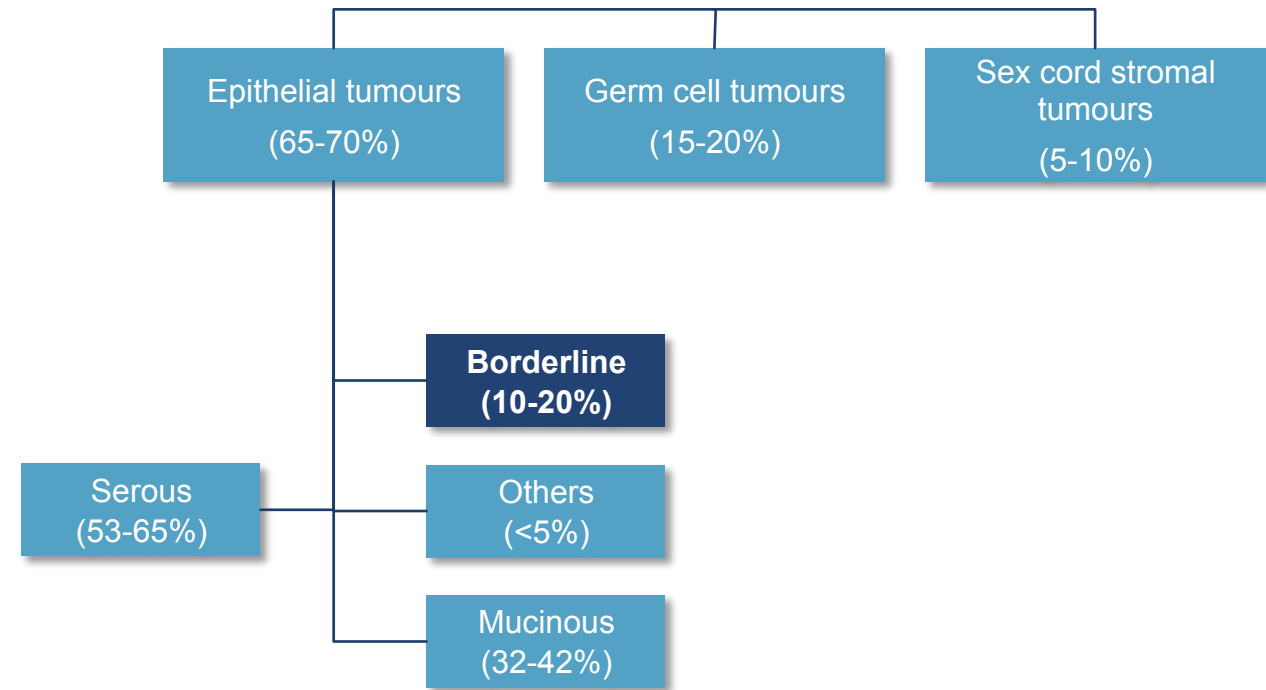
- 1st operation complicated by *Enterococcus* UTI & *S. aureus* wound infection (PO antibiotics)



Borderline ovarian tumours

- Epithelial ovarian tumour
- Incidence 4.8/100 000 [1]
- Average age of occurrence = 40 years (27-36% of cases occur in women younger than 40), compared with 60 years for average age of occurrence in invasive carcinoma [2]
- Serous tumours account for 55-65% of borderline ovarian tumours [2]

WHO Ovarian Tumour Classification



[1] Abascal-Saiz A, Sotillo-Mallo L, de Santiago J, Zapardiel I. Management of borderline ovarian tumours: a comprehensive review of the literature. *ecancermedicalscience*. 2014;8:403.

[2] Trope, C. G., Kaern, J., & Davidson, B. (2012). Borderline ovarian tumours. *Best Pract Res Clin Obstet Gynaecol*, 26(3), 325-336.

Medical history

- Fertility
 - After first operation, patient & husband expressed wishes to start a family
 - Concern noted about high dose IVF medications triggering recurrence
- March 2012 – Left iliac fossa pain episode – haemorrhagic corpus luteum
 - Cyst drained under ultrasound guidance, frank blood aspirated, cytology negative
 - Suggested patient goes on OCP for 3-4 months
- November 2012
 - Pelvic ultrasound (investigation for IVF), suspiciously concerning features
 - Options discussed = ovarian cystectomy vs salpingo-oophrectomy & hysterectomy
- 2nd laparotomy (Feb 2013) – **oophrectomy, salpingectomy & hysterectomy**
 - Histopathology – borderline serous tumour of left ovary

Patient's experience

Negative

Fear of dying, fear of future recurrences

Normal life has been 'taken' from her

Difficulty with making life-changing decisions quickly

Positive

Surprised by her own resilience

Role of religion for her

Awareness

Lack of awareness of ovarian cancer in young women → difficulty for family and friends in supporting her

Fertility

Married at time of initial diagnosis (age 24), went to IVF clinic after first operation to potentially freeze eggs
– recurrence of tumour was found on ultrasound at IVF clinic

AMH August 2012 (prior to 2nd laparotomy = 1.2)



Difficult decisions

“In hindsight, I probably would have made a different decision with the second operation”

Emotional impact

“You are surrounded by people of this age bracket who are having kids ... there is a constant reminder”

Relationship with pregnant friends

“One of my friends was falling pregnant at the time ... for them it was an uncomfortable situation - they didn't know how I would react”

Gynaecological cancer in young women

- Of all gynaecological cancer cases, young women comprise ^[3]:
 - 2% of cervix cancer cases
 - 5% of endometrial cancer cases
 - 12% of ovarian cancer cases
- Infertility following treatment has been recognised as a main quality-of-life concern in cancer patients ^[4, 5, 6]
- Gynaecological cancers & infertility
 - Oncologic treatments – chemotherapy with gonadotoxic agents, radiation therapy involving ovaries, uterus, vagina
 - Surgical treatments – removal of uterus, ovaries

[3] Siegel, R. L., Miller, K. D., & Jemal, A. (2016). Cancer statistics, 2016. *CA Cancer J Clin*, 66(1), 7-30.

[4] Rosen, A., Rodriguez-Wallberg, K. A., & Rosenzweig, L. (2009). Psychosocial distress in young cancer survivors. *Semin Oncol Nurs*, 25(4), 268-277.

[5] Partridge, A. H., Gelber, S., Peppercorn, J., Sampson, E., Knudsen, K., Laufer, M., . . . Winer, E. P. (2004). Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol*, 22(20), 4174-4183.

[6] Howard-Anderson, J., Ganz, P. A., Bower, J. E., & Stanton, A. L. (2012). Quality of life, fertility concerns, and behavioral health outcomes in younger breast cancer survivors: a systematic review. *J Natl Cancer Inst*, 104(5), 386-405.

Knowledge gap

- Many publications about surgical possibilities of fertility-sparing treatments ^[7]
 - Cervical cancer (FIGO Stage IA1, IA2, IB1): LLETZ or conization or radical trachelectomy
 - Endometrial cancer (FIGO Stage IA): Hormonal treatments by IUD for endometrial cancer
 - Ovarian cancer (FIGO Stage IA): unilateral oophrectomy
- Relative knowledge gap: psychosocial implications of a gynaecological cancer diagnosis, and potential infertility, for young women
- Guenther (2012) interviewed 11 women with ovarian cancer on their psycho-social experiences^[8]:
 - Only 1 woman was under age 35 when diagnosed
 - 23 years old, Stage IV ovarian cancer, no hysterectomy as she desired to have IVF in the future – no more mention of fertility
 - Common themes: Fear of recurrence, a new purpose to life, being taken aback by the diagnosis. Main feature of the paper was the frustration about a delayed diagnosis or mis-diagnosis for a long time

[7] Feichtinger, M., & Rodriguez-Wallberg, K.A. (2016). Fertility preservation in women with cervical, endometrial or ovarian cancers. *Gynecologic Oncology Research and Practice*, 3(1), 8.

[8] Guenther, J., Stiles, A., & Champion, J. D. (2012). The lived experience of ovarian cancer: A phenomenological approach. *Journal of the American Academy of Nurse Practitioners*, 24(10), 595-603.

Psychosocial implications of ovarian cancer during childbearing years [9]

- Purpose: “To understand what it is like to live with ovarian cancer during childbearing years”
 - 5 women with ovarian cancer, 3-4 in-depth interviews with each
 - ”Although each woman’s experience was unique, there were commonalities in their life words”
1. **Hysterectomy & infertility** → loss & emptiness, taking away opportunity & choice to go through pregnancy
 2. **Having to make quick decisions**
 3. **Unfairness of menopause** → are night sweats, bouts of crying, frequent urination from cancer, menopause or stress?
 4. **Uncertainty about where and how to find support** → complex changes in relationships with significant other & friends, support groups offered little, feeling abandoned by friends & coworkers
 5. **Being vigilant** → anxiety about recurrences

What can we learn from this?

- Increased psycho-social support for young women with gynaecological cancers
 - Ovarian Cancer Australia – **“Is it Just Me?” The Younger Women’s Resource**
 - Support groups - ?currently inadequate? – what is lacking? How can we improve this to better support young women?
- Education about fertility options before surgery
- Understanding: hysterectomy & infertility may represent loss, emptiness for some women
- Education about menopause & what to expect

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- [1] Trope, C. G., Kaern, J., & Davidson, B. (2012). Borderline ovarian tumours. *Best Pract Res Clin Obstet Gynaecol*, 26(3), 325-336.
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- [8] Guenther, J., Stiles, A., & Champion, J. D. (2012). The lived experience of ovarian cancer: A phenomenological approach. *Journal of the American Academy of Nurse Practitioners*, 24(10), 595-603.
- [9] Schaefer, K. M., Ladd, E. C., Lammers, S. E., & Echenberg, R. J. (1999). In Your Skin You are Different: Women Living with Ovarian Cancer During Childbearing Years. *Qualitative Health Research*, 9(2), 227-242.
- [10] Ovarian Cancer Australia (2017). Is It Just Me? The Young Women's Resource. In *Ovarian Cancer Australia Connect*. <https://ovariancancer.net.au/forums/forum/younger-women/just-younger-womens-resource/>