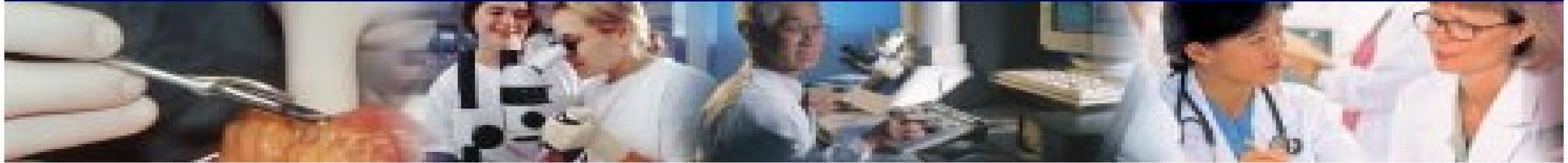

Women's experience of treatment for gynaecological cancer

May 2010

Dr Jo Wainer

Associate Professor Eileen Willis

Professor Judith Dwyer

Ms Kei Owada

MONASH University
Medicine, Nursing and Health Sciences

Agenda

- Aims and Method
- Pathway to care
- Treatment team
- In-hospital care
- Post-hospital care
- Rural women
- Pain management
- Outcomes
- Summary

Background and Aim

Gynaecological cancer affects 4000 women a year

It is a life threatening condition requiring immediate management

The aim was to document the experiences of some women in accessing and receiving diagnosis and treatment

Method

25 women were interviewed

- 3 Indigenous women
- 8 rural women
- 1 non-English speaking woman

Sites were:

- Monash Medical Centre, Darwin, Albury/Wodonga private, Royal Adelaide private & public, Flinders private

Pathways to Diagnosis

Symptom	Pathway	Number
Bleeding PV	To GP	8
Pain	To GP	6
PAP smear	By GP	4
Unwell (bowel, UTI, abdomen)	GP. ED, gastroenterologist	5

Women talked about their GPs being ‘very thorough’, ‘wonderful’, ‘ brilliant’, ‘very supportive’ and ‘marvelous’.

He’s brilliant. He got my diagnosis right from the beginning
I have a marvelous GP here who picked it up straightaway.

More than half the women (15/24) described how their GP made the diagnosis and referred them for further management.
GPs were included in the management team, contributed to their post-operative care, pain management and future cancer surveillance.

Treatment team

Treatment teams involved gynaecologist, gynaecological surgeon, anaesthetist, bowel surgeon, medical oncologist and radiotherapist. Follow up care was provided by the operating surgeon for the most part and general practitioners were involved in the post-operative team for a majority of women.

In-hospital care

Effective and high quality medical and nursing care

Team based care an effective model

Some failures in patient care

- Surgical mishap
- mixed sex wards
- pain management
- infection control

It was just that awful week where there was no help. There was no follow-up. There was nothing.

I gather it was just a young intern on the Saturday that said 'right, you're gone. You have nothing more to do with this hospital. Don't bother ringing if you have a problem, ring your GP'.

I rang my GP. He promptly informed me that he had no idea what I'd had done. There was no paperwork. There was no follow-up and he wouldn't make a house call and I was too sick to get out of bed…there should have been somebody that could have seen me that first week.

But nothing was offered

Post-hospital care

- This is where the system falls down
- Failure to engage GPs was the weakest link
- Half the women had unanticipated complications
- Some women had no-one to care for them either physically or medically (especially rural women)

Rural women

Same intra-hospital care

Different pre and post-hospital care

Metropolitan based care is very stressful for rural people

Some rural women felt abandoned as they were left to find their own way home

- discharged onto street, took train home
- no link to GP care

Rural services

Rural people are more likely to die of cancer within five years of diagnosis than urban people. They are diagnosed at a later stage and are more likely to die from cancers such as lung, cervical and uterine cancer the further they are located from large cities.

There are particularly poor outcomes for Indigeneous people with cancer.

Mapping Rural and Regional Oncology Services 2006

Good rural care

We've got a beautiful community nurse and GP; it's marvelous… They're outstanding here in the Eyre Peninsula, their care. That's all the allied health professionals; we've got the best GPs…. I believe I got more care because I was in the country. I had nurses popping in saying 'are you okay?' If' I'd had a bad morning they'd ring up or something 'are you all right?

Pain management

18 women had pain well managed

One quarter experienced unnecessary and distressing pain associated with treatment and post-operative care. Pain could be both awful and well managed, or not very present, and if present it could also be badly managed.

Pain was post-operative, and/or related to travel, chemotherapy and complications

Outcomes

All women were conscious that the interventions had been life-preserving, and grateful for that

Most women felt well cared for

Half the women had unanticipated post-operative complications

Some of these were serious

Some of these were not well managed

Outcomes

3 women had post-operative outcomes that left them with life-long disabilities

4 had post-operative infections including 1who was critically ill with septicaemia

2 had debilitating depression

1 had persistent intermenstrual bleeding

1 woman was dealing with a hernia four years later that was a result of the surgery

1 had morphine apnoea with possible cardiac arrest during surgery

Gynaecological cancer is uncommon, yet life threatening

Management includes radical surgery

Workforce is highly skilled and ageing

Women appreciate the high level of skilled care

Nearly half the women had unanticipated adverse outcomes

GP linkage and pain management are important gaps in care

Post-operative care for rural women is a challenge