

# Exploring women's reactions to a diagnosis of endometrial carcinoma: a pilot study of Australian women

## AUTHORS

### Wendy Linford

BN, RM

Associate Unit Manager, Gynaecology/Oncology Unit, Mercy Hospital for Women, Heidelberg, Victoria, Australia. wlinford@mercy.com.au

### Della Forster

RN, RM, DipAppSci, BHealthSci, Mmid, PhD

Senior Research Fellow, La Trobe University, Melbourne, Victoria, Melbourne, Australia. d.forster@latrobe.edu.au

## Acknowledgements

*The researchers would like to thank the women who took part in piloting the questionnaire; the women who participated; colleagues who helped with questionnaire piloting; and the support from those who work on the gynaecology/oncology ward at the MHW; all of whose contributions were invaluable throughout the research project.*

## KEY WORDS

cancer nursing, endometrial cancer, gynaecological cancer, women's views, semi-structured interviews, pilot study.

## ABSTRACT

### Objective

Endometrial carcinoma (cancer of the uterus) is the fifth most common cancer in women world wide and the most common gynaecological cancer. Each woman confronted with such a diagnosis will respond in different ways, as will their family and friends;

therefore each will vary in their supportive needs. This study aimed to acquire some insight into the initial impact of a diagnosis of endometrial carcinoma on women and factors relating to support for them.

### Design

Semi-structured interviews were used to collect in-depth data on women's views. Interviews were audio-taped. Demographic data were collected prior to interview by structured questionnaire.

### Setting

The setting was a tertiary women's hospital in Melbourne, Victoria, Australia.

### Subjects

The subjects were seven women with newly diagnosed endometrial carcinoma.

### Main outcome measures

Interviews were transcribed verbatim and coded into themes.

### Results

The findings include an acceptance of the diagnosis and adequate friend and family support. Some women experienced initial denial from immediate family members; for others the diagnosis led to a new appreciation of life and values. Most women received adequate education regarding endometrial carcinoma, while others used varied means including the internet to find further information. Health care facilities for rural versus urban women; the means by which women were told of their diagnosis; and appropriate follow up and support, were issues that arose which require further exploration.

### Conclusions

The needs of a woman diagnosed with endometrial carcinoma will vary between individuals. Further research in the area of psychosocial care for women newly diagnosed with endometrial carcinoma would be of value. Women need individualised and accessible education. If women are provided with a variety of educational tools, they can individualise the information they need for themselves.

## INTRODUCTION

Endometrial carcinoma is the most common gynaecological malignancy in the developed world with approximately 1400 new cases diagnosed each year in Australia and approximately 260 deaths as a result (Queensland Institute of Medical Research 2005). The median age at diagnosis is 65 years (Lancaster and Nattress 2005) and an average of one in eighty women are diagnosed by the age of 75 years (Robertson 2003). In Victoria each year there are approximately 350 women diagnosed with cancer of the uterus (The Cancer Council of Victoria 1999). At the Mercy Hospital for Women (MHW) in Victoria, Australia, 84 women were diagnosed with endometrial carcinoma in 2005 and underwent surgical treatment (Admission Register Gynaecology/Oncology Unit MHW).

The most common presentation of endometrial carcinoma and the main reason for its early detection is postmenopausal vaginal bleeding (Otto 2001). About 80-90% of women diagnosed with endometrial carcinoma will have noted an abnormal vaginal discharge (Barakat et al 2003) and approximately 15% of all postmenopausal women presenting with abnormal bleeding will have endometrial carcinoma (Barakat et al 2003). Other signs can be: irregular, excessive or prolonged premenopausal bleeding; pyometria, causing a yellow/watery vaginal discharge; accretion of blood in the uterus: and/or pain in the pelvic regions (Otto 2001).

There is no cost effective and accurate public health screening device to assist early detection of endometrial carcinoma, therefore women are encouraged to seek immediate medical attention if any of the above symptoms occur (Robertson 2003). Once diagnosed with endometrial carcinoma treatment usually includes surgery (Creasman et al 2001) and may involve radiotherapy, chemotherapy and hormone therapy (American Cancer Society 2005).

No Australian literature was identified that discussed the psychosocial issues associated with a new diagnosis of endometrial carcinoma. Ersek et al

(1997) found depression and anxiety often follows an ovarian cancer diagnosis. A study of women newly diagnosed with breast cancer by Landmark et al (2001) found the 'life and 'fight for life', and 'stubbornness of attitude' emerging as common themes. Luker et al (1996) found that women with recently detected breast cancer see their diagnosis as a 'challenge', while Watson et al (1984) found that women were more likely to have feelings of denial toward their breast cancer prior to their surgery and this assisted them through the initial process. In general, high levels of psychological distress and adjustment problems can be seen in newly diagnosed cancer patients regardless of their prognosis (Lev et al 1999).

The aim of this pilot study was to gain an initial understanding of how women responded to a diagnosis of endometrial carcinoma. Specifically the study endeavored to understand how life changed for the women. Each woman was asked about their symptoms, about seeking help, how this diagnosis affected their family and friends and what support was available to them during this time. The study also explored whether the support offered to the women was adequate and how the health care system could have further assisted them.

This study was approved by the Research Ethics Committee at Mercy Health and Aged Care Victoria, Australia.

## METHODS

### Sample and Setting

MHW is a public tertiary women's hospital. All women (private and public) admitted to the gynaecology/oncology ward with operable endometrial carcinoma between 1 March and 30 June 2006 were invited to participate in the study. A sample size of approximately 15 women was set based on other similar research and in order to reach data saturation. Women were approached five to seven days after their primary surgery. This was to firstly to ensure the exact diagnosis was known; and secondly, to allow women some time to adjust and recover from their surgery. The study was explained, questions answered and deliberating

time given. Willing participants signed consent forms and completed demographic questionnaires prior to interview. Women were excluded if they were inpatients at a time the researchers were unable to interview them; they could not speak English; or were unable to give informed consent as assessed by the research team.

### Data collection

Demographic data were collected by a brief self administered survey and semi-structured interviews were used to obtain the main data for analysis.

The interview comprised a series of eight questions initially. After piloting two questions were added. The question areas were: symptoms and action; initial diagnosis reactions; views on life and their future; and support (educational and emotional). Health system limitations/barriers were also explored.

Interviews were undertaken by the same researcher and took 20 minutes on average (although the longest was 45 minutes) and were undertaken in a private location. Interviews were audio-taped and field notes recorded later. Demographic data were entered onto an Access Database (Microsoft Corporation 2000) and descriptive statistics used to describe the data. Interviews were transcribed verbatim and coded into themes. Both investigators read through all transcripts, came up with themes independently, and explored areas where there was no consensus. In all cases agreement was reached. Illustrative quotes have been used to help describe the data. Pseudonyms (with actual ages) are used for all participants.

## RESULTS

Recruitment was limited by the researchers having a 12 month time span for this project and that fewer women than anticipated presented for surgery for endometrial carcinoma during that period. Sixteen women were approached during March and June 2006, with seven of these women agreeing to participate. A further two were missed as a result of earlier than expected discharge from hospital. Two others were ineligible as one of the researchers was on leave during their admission. Relatives were

not excluded from the interview if the participant wanted them to stay, although the researchers did not seek to have a relative present. One woman's husband attended an interview with her and a daughter and granddaughter attended another woman's interview.

The average age of participants was 65 years, (range 49-78). Five women were married or widowed, one was single and another separated/divorced. Three women currently lived with their husband/partner, three lived alone and one woman lived in a religious community. Four had completed secondary school to year 12, and three attended but did not complete secondary school. Two women had completed a degree, one an apprenticeship/traineeship and another had completed a diploma. The average household income before tax was \$40,000(AUD). Four women said a pension was their main income. Two women were born in the United Kingdom; the others were born in Australia. Six women were of a Christian religion. No women currently smoked tobacco. One was an ex-smoker of five-six years. Two of the seven women had never been pregnant.

Of the seven women interviewed, six had had spotting of blood or an episode of a heavy 'period type' bleed. Two of these women said their discharge was somewhat normal for them due to menopausal changes and the altering of their hormone replacement therapy (HRT), with the general feeling of being unwell being the reason for investigations. One participant had spotting of blood then a watery discharge two months later. Another participant stated her only symptom was spotting of pale, watery discharge. Five women investigated their symptoms straight away, contacting their local general practitioner (GP) and were then referred to a specialist. One woman did not investigate her symptoms until about a year later, while another waited three months until her next planned appointment with her doctor.

Six out of the seven participants were told they had endometrial cancer over the phone; three of these women were alone at the time. One participant was told during a consultation at her gynaecologist's rooms.

### Women's responses to their diagnoses

There was a range of responses from the women when asked how they felt about their symptoms being due to endometrial carcinoma. One participant found it too hard to describe; another felt she was prepared for it, due to already being told there was a chance of it being cancer, stating:

*Well I think I was prepared for it because you know he said that there was a chance, and he really reassured me - but you still sort of have that feeling (Emma 73 yrs).*

*I was shocked because it wasn't something that I was expecting because it was just an incidental thing that the doctor did (dilation and curettage) (Lola 49 yrs).*

The above participant presented with a general unwell feeling which was firstly thought to be due to a gallbladder complaint. A dilation and curettage was performed only due to the long time span of taking hormone replacement therapy.

One participant stated she felt upset by the news, but was more worried she may die during the operation from a complication due to her other health problems. Another stated the word cancer "is a frightening one" (Kate 52 yrs). Two women felt they took the information very well. One said:

*Probably going to Melbourne was a bigger issue than having endometrial cancer, um, ah, how did I feel, well I guess I think I coped with it reasonably well, more so than the people around me (Lola 49 yrs).*

The women were asked to identify any changes to their views regarding life and the future since their diagnosis. Three women stated there had been no change to their views at all. One said:

*Not really, I think when you get to our age, you want to make the most out of what you have got left anyway (Alice 74 yrs).*

Three women felt it had changed their outlook on life. One woman suggested it had helped her to "look on the bright side" (Judy 78 yrs), while another said her son told her that his whole outlook on life had changed:

*He said, um, it makes you realize that what you worry about is nothing when something like this comes out... material things aren't anything are they, it doesn't matter (Kate 52 yrs).*

Quotes from the participants that suggested a change in existential views included:

*When I go back I think I'll have to go through a lot of things (laugh), and sort some things out, get rid of stuff that I don't need and so forth, but ah, it does make you think a bit more, yeah (Mavis 74 yrs).*

*Ah yes, life's very precious, your whole outlook changes... I mean, do what you want to do if you can do it, do it! (Kate 52 yrs).*

### Responses of family members and friends

The general reactions of family members toward the participant's diagnosis were concern, upset and worry. Some examples include:

*He [husband] was very upset... but he remained positive for my sake, um, and he helped me though, he was very, very good (Lola 49 yrs).*

*Well I, I didn't want them to be worrying about it when, ah, when I'd be worrying about it - I didn't really know what anyone thought, I didn't want, I said I don't want to talk about it, I don't want to hear anything about it (Judy 78 yrs).*

Three participants felt the initial reaction of one of their relatives: son (n=2); brother (n=1); and sister (n=1) was state of denial and not coping, stating:

*He obviously didn't think it was anything anymore than what I had before... I think he blocked it out (Kate 52 yrs).*

*My brother was probably in denial, both brothers went quiet (Dina 56 yrs).*

Another said:

*She [sister] just didn't want to admit that it was cancer (Emma 73 yrs).*

Some positive outcomes were also evident with two participants stating family relationships seemed stronger after the diagnosis than before, a husband of one women quoting:

*I think it's brought them [the family] together a bit... there's a bit more contact and communication now (husband of Alice 74 yrs).*

There were mixed responses from friends of the participants. One woman stated what a shock to her friends it was, while two participants said how positive and understanding their friends had been. One woman said her friends expressed their concern, while another found out later that her friends were devastated, but did not initially inform her of this. Supportiveness was a definite theme throughout the interviews with quotes such as:

*They've been very supportive, very good and everybody's been very good really, very supportive - our friends have been absolutely brilliant (Kate 52 yrs).*

Family and friends proved to be the main emotional support for six of the participants. One woman said:

*They've been pretty good actually, haven't they, the family, family and friends, they have all been good, my main support obviously - very strong emotional support (Alice 74 yrs).*

Two women stated they also valued support from their church while another participant considered herself to be her own main support.

#### **Responses to supports received/perceived**

The research also explored the adequacy of the support the hospital provided. All women felt the hospital had provided support to them through this journey. Four participants could not think of any additional support the hospital could offer other women in the future. One woman suggested better diagrammatic information and more time available to talk to doctors, while another firstly stated there was nothing else the hospital could have offered her to help her through her diagnosis, however was still unsure about one thing:

*But I guess my big question is with menopause, how do you know what's an abnormal bleed? Or how do you know what's abnormal? - I guess for me it was the watery discharge, and I mean the doctor said*

*you've got a cyst, it looks like a cyst, I went ok, um, not having had one before, um I didn't think anything more of it (Dina 56 yrs).*

Regarding the type and suitability of endometrial carcinoma education the participants received, there were mixed responses. Five of the seven women received a booklet published by the Anti-Cancer Council of Victoria (1999). Two women stated this was enough and did not seek any further information. One woman said:

*No, that was enough (laugh), you hear about it at any rate you, you don't want to hear more than you have to (Mavis 74 yrs).*

*The pamphlet was standard information which is fine but it, it doesn't have a voice, you know, you need to be able to ask questions (Lola 49 yrs).*

Another said:

*It's very hard when, you know, you're in the country and your getting all the information from here (Emma 73 yrs).*

Four women stated their consultation with the oncologist helped to inform them, with diagrams also aiding this process. Three women sought out more information, with two searching on the internet. One of these women stated:

*I went on the internet as well, had a look to see, yeah, I mean I wanted to know, but I didn't want to know too much either you know, I suppose that sounds strange, I just wanted what I could handle for that time sort of thing (Kate 52 yrs).*

Three women found talking to friends who either used to be nurses or had undergone hysterectomies themselves to be a useful source of data. One participant did not want any information; when asked if she was given a pamphlet regarding endometrial carcinoma she said:

*No, and I don't want it...No, I didn't want that before I come down here and I wouldn't have been reading it anyway, hidden it in a book somewhere - before I came down all you got on the television and the radio was diabetes and cancer, and I shut it off, you're at home*

*but when you know that you've got to come, seemed to be on everyday, every hour (Judy 78 yrs).*

One woman stated she did not receive enough information and did not have time to seek out more due to her speedy admission. She stated:

*Just incidental discussions with people, it's been incidental information rather than anything written or diagrammatic (Lola 49 yrs).*

When asked if she is going to look for more information when she gets home she said:

*Well, not when I go home 'cos (sic) I know I won't find it, in the bush, it's just not there - well there might be something in the library, gee the books are pretty old (laugh) (Lola 49 yrs).*

Women were asked to describe any services they thought were lacking in the health care system. Five thought there was nothing more the system could have done to help them through their journey so far; another who was told of her diagnosis over the phone stated:

*Not really, the only thing was the way I was told I suppose, that's the only...but I'm not blaming anybody, it must be a very difficult thing to do, and I don't know how you would do it (Kate 52 yrs).*

Another woman from a rural area said:

*I think you're much more likely to have assistance down here that you can get in rural and regional Victoria - rural Victoria needs um, a great deal of funding and medical facilities, and it also needs ah, a wide range of highly skilled professional, medical people...the access to people is, is a problem (Lola 49 yrs).*

## DISCUSSION

The aim of this pilot project was to gain some preliminary understanding of how a diagnosis of endometrial carcinoma affected women and their families, the support that was needed both educationally and emotionally, and to start exploring areas of the health care system these women felt were lacking. Health care providers can only provide

appropriate care and adequate and holistic support if there is an understanding of women's needs.

Although a limitation of the study is its small sample size, the women in this pilot were similar in many ways to what was reported in the literature, including the variety of presenting symptoms and the range of response times in seeking medical attention. While we can not generalise, it may be that further education regarding endometrial carcinoma is needed in the community.

A person's response to a cancer diagnosis will always be individual and the women in this study demonstrated this. However most were told of their endometrial carcinoma diagnosis over the phone, often without support people present. Given that reactions are likely to vary and that many women may need support when hearing their diagnosis, an improved strategy may be to at least give the woman an option regarding how and where they are informed of their results.

Mor et al (1994) suggest that relatives of people who receive a cancer diagnosis experience similar if not greater negative psychological responses than the patient themselves. Concern, upset and worry was how women perceived their family and friends' reactions, despite the fact that most stated their main support arose from these sources. The uncertainties and fears experienced by a person newly diagnosed with cancer are likely to enhance the need for social support (Dunkel-Schetter 1984). Three women in our study felt family members could not cope and that they were in denial initially, a response identified by Watson et al (1984) in women diagnosed with breast cancer. Lewis (1986) found there is evidence that a cancer diagnosis in one family member causes existential concerns in the other family members and that tension occurs in the early diagnostic and treatment period within family units. These responses did not seem very evident within this project. Endometrial carcinoma information leaflets specifically detailed for close acquaintances of the affected women may be a tool to assist them through this whole process and further enable them to provide support for the women diagnosed.

Ersek et al (1997) reported that some women had more positive views on life after a diagnosis of ovarian cancer, including a new appreciation of life and adoption of a 'live for the moment' philosophy (Ersek et al 1997). In our study three women stated their views on life and their future did not change during their initial diagnosis stage, whereas three others reported it had challenged their outlook, saying their whole views on life changed.

The research was particularly interested in whether women's informational needs were met and found mixed responses regarding this issue, with some women requiring more information and others seeking information from a variety of sources. It is important women have access to appropriate and adequate educational information and this can only be achieved by understanding what information is appropriate and in what context and tailoring tools based on this. A 'take home' kit with a range of educational information from diagrams, booklets, details of support groups available and appropriate websites may help ensure women have a thorough knowledge base available to them if they wish. A follow up phone call by an oncology nurse after the gynaecologist/oncologist consultation to discuss further questions prior to their admission to the ward could also be of benefit.

Most of the women stated they could not think of any additional services the health care system could provide to assist them through their diagnosis of endometrial carcinoma. One woman suggested further resources were needed in regional Victoria and that there was a lack of medical professionals and lack of educational resources at the local library. While this is only one woman's view and relates to one regional area, it is important to note.

This study was a small pilot with acknowledge limitations. The research was limited by the number of women available to recruit to the study as well as by the time constraints of the project. The research aim was to gain some preliminary understanding of how a diagnosis of endometrial carcinoma affected women and their families and to explore whether the particular health system was meeting the needs

of this group of women. While these data are not generalisable they do provide insight into the lives and views of these women's views and feelings following a diagnosis of endometrial cancer.

## RECOMMENDATIONS

Given that the needs of a woman diagnosed with endometrial carcinoma will vary between individuals, further research in this area of psychosocial care of women newly diagnosed with endometrial carcinoma would be of value. In terms of practice, it is important to be aware that women need individualised and accessible education. If women are provided with a variety of educational tools, they can individualise the information they need for themselves. It is possible that for women who are newly diagnosed with endometrial carcinoma, the allocation of a 'primary nurse' for initial and ongoing contact may be a method worthy of exploration. This very small pilot study suggests a lack of facilities and medical staff in rural areas which may lead to inequities in access. This is a topic that requires further exploration and consideration.

## REFERENCES

- American Cancer Society. 2006. Overview: endometrial cancer. How is endometrial cancer found? Available from: [http://www.cancer.org/docroot/CRI/content/CRI\\_2\\_2\\_3x\\_How\\_Is\\_Endometrial\\_Cancer\\_Found.asp](http://www.cancer.org/docroot/CRI/content/CRI_2_2_3x_How_Is_Endometrial_Cancer_Found.asp) (accessed August 2008).
- Barakat, R., Bevers, M. and Gershenson, D. 2003. *Handbook of gynaecologic oncology*. Martin Dunitz: London, UK.
- Creasman, W., Odicino, F., Maisonneuve, P., Beller, U., Benedet, J., Heintz, A., Ngan, H., Sideri, M. and Pecorelli, S. 2001. Carcinoma of the corpus uteri. *Journal of Epidemiology and Biostatistics*, 6(1):45-86.
- Dunkel-Schetter, C. 1984. Social support and cancer: findings based on patient interviews and their implications. *Journal of Social Issues*, 40(4):77-98.
- Ersek, M., Ferrell, B., Dow, K. and Melancon, C. 1997. Quality of life in women with ovarian cancer. *Western Journal of Nursing Research*, 19(3):334-350.
- Lancaster, T. and K. Nattress 2005. *Gynaecological cancer care: a guide to practice*. Ausmed Publications Pty Ltd: Melbourne, Victoria, Australia.
- Landmark, B., Strandmark, M. and Wahl, A. 2001. Living with newly diagnosed breast cancer - the meaning of existential issues. A qualitative study of 10 women with newly diagnosed breast cancer, based on grounded theory. *Cancer Nursing*, 24(3):220-226.
- Lev, E., Paul, D. and Owen, S. 1999. Age, self-efficacy and change in patients' adjustment to endometrial cancer. *Cancer Practice*, 7(4):170-175.

Lewis, F. 1986. The impact of cancer on the family: a critical analysis of the research literature. *Patient Education and Counseling*, 8:269-289.

Luker, K., Beaver, K., Leinster, S. and Owens, R. 1996. Meaning of illness for women with breast cancer. *Journal of Advanced Nursing* 23(6):1194-1201.

Microsoft Corporation (2000). Microsoft © Access 2000.

Mor, V., S. Allen, S. and Malin, M. 1994. The psychosocial impact of cancer on older versus younger patients and their families. *Cancer*, 74(Suppl.7):2118-2126.

Otto, S. 2001. *Oncology Nursing*. Mosby Incorporated: St Louis, Missouri, USA.

Queensland Institute of Medical Research. 2005. *Endometrial Cancer*. Available from: <http://www.qimr.edu.au/research/topics/endometrial.html> (accessed August 2008).

Robertson, G. 2003. Screening for endometrial cancer. *Medical Journal of Australia*, 178(12):657-659. Available from: [http://www.mja.com.au/public/issues/178\\_12\\_160603/rob10833\\_fm.html](http://www.mja.com.au/public/issues/178_12_160603/rob10833_fm.html) (accessed August 2008).

The Cancer Council of Victoria. 2007. Cancer of the uterus: a guide for women, their families and friends. Available from: [http://www.cancervic.org.au/about-cancer/cancer\\_types/uterine\\_cancer](http://www.cancervic.org.au/about-cancer/cancer_types/uterine_cancer) (accessed August 2008).

Watson, M., Greer, S., Blake, S. and Shrapnell, K. 1984. Reaction to a diagnosis of breast cancer: relationship between denial, delay and rates of psychological morbidity. *Cancer*, 53(9):2008-2012.