

Nurse led telephone follow up in ovarian cancer: A psychosocial perspective

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### **Abstract**

Survivorship is a relatively new concept in ovarian cancer due to improvements in diagnosis, surgery and chemotherapy. As more women require long term follow up for ovarian cancer the pressure on outpatient services is increased and the question of how best to care for these women long term needs to be addressed. This paper considers the results of a pilot study of nurse led telephone follow up in ovarian cancer from a psychosocial perspective. Fifty-two women received telephone follow up over a 10 month period, one aspect of this intervention was the opportunity for women to discuss psychosocial concerns with the clinical nurse specialist. A nurse database held records of patient discussions, and patient feedback regarding the service was collected using a satisfaction and experience with follow up questionnaire. Thirty-three women were recorded as discussing psychological concerns with the nurse, 42% discussed feelings of anxiety or depression and 33% discussed fear of disease recurrence. Thirty-nine women were recorded as having discussed social concerns with the nurse, 56% discussed their family (husband, children etc), 51% discussed work and/or finances, and 41% discussed sexual intimacy. The majority of women (73%) expressed a preference for nurse led telephone follow up, the main advantages were reported as the relationship and discussions between the patient and the nurse, and the convenience of having follow up appointments over the telephone instead of attending clinic. This pilot study suggests that nurse led telephone follow up offers an acceptable opportunity for psychosocial support for women with ovarian cancer.

## **Introduction**

The focus of follow up care has traditionally been the detection of recurrent disease and symptom management but it is also imperative that the psychosocial concerns of patients are addressed throughout the patient pathway (NICE 2004). The NHS Executive (NHSExecutive 1999) defines the follow up of women with gynaecological cancers as (i) the prompt detection of recurrent disease, and (ii) the identification and management of physical and psychological morbidity. Ovarian cancer is the fourth most common cause of cancer related death in women in the UK. Cancer Research UK reported 6,906 new cases of ovarian cancer in 2003 and 4,434 deaths from the disease in 2004 (CancerResearchUK 2007). During the past 30 years, survival has increased owing to improvements in diagnosis, surgery and chemotherapy. Survivorship is a relatively new concept in this area and consequently the needs of these women lack exploration (Lockwood-Rayerman 2006).

Research conducted for Macmillan Cancer Support (MacmillanCancerSupport 2006) highlights that 45% of patients with cancer cite the emotional effects of cancer as the most difficult to cope with, but overstretched oncology clinics may not provide an adequate opportunity for these concerns to be discussed. Health care professionals currently overestimate the psychological benefits of traditional gynaecological follow up for their patients (Kew et al. 2007) and guidelines are urgently required to improve the psychosocial support offered to these women.

A recent study by Cox and colleagues (Cox et al. 2006a) examined the information needs and experiences of UK cancer patients, including a sample of 67 patients with gynaecological cancer. The results of this study highlighted that only 17% of patients with gynaecological cancers reported discussions concerning family history ('will my children inherit my disease') and only 49% of patients recalled a discussion on how their treatment may affect their body image/sexual well-being. Discussions regarding social wellbeing and emotional wellbeing were reported by 56% and 66% of patients respectively, this supports the report by Macmillan Cancer Support which found 41% of patients were unable to gain information on the emotional aspects of a cancer diagnosis and 49% were unable to gain information on the impact of a cancer diagnosis on relationships (MacmillanCancerSupport 2006). These are important concerns to patients, in a study of ovarian cancer survivorship (Wenzel et al. 2002), 43% of respondents expressed a willingness to participate in a counselling program to discuss psychosocial issues raised by having had ovarian cancer. New approaches to follow up need to be implemented to ensure women have an opportunity to discuss the impact of ovarian cancer on all aspects of their life.

Nurse led follow up of patients with cancer is arousing considerable interest. There is a belief that nurse led services are a cost effective method of addressing the increasing pressure on follow up services (Faithfull et al. 2001). However, discussions considering service redesign should primarily focus on improving the quality of service provision and the potential of nurses to enhance aspects of patient care. The acceptability of nurse led follow up has been demonstrated in a range of cancer sites including lung (Moore et al. 2002; Cox et al. 2006b), breast (Koinberg et al. 2004), and prostate cancer (Faithfull et al. 2001; Booker et al. 2004). A qualitative breast cancer study of patient perceptions of

routine follow up care (Pennery and Mallet 2000) reported that 54% of women questioned would prefer their follow up care to be provided by the nurse specialist as they were more 'supportive' and had the necessary 'time, skills and knowledge'. In addition, the majority of patients (79%) reported feeling uncomfortable raising psychological and emotional concerns at their clinic appointment as they were conscious of taking up too much time. Nurse led follow up provides an opportunity for patients to discuss emotional and psychological concerns (Cox et al. 2006b), and for nurses to utilise their specialist skills in providing holistic care.

Routine follow up appointments for ovarian cancer are discussion based and therefore perfectly suited to being conducted over the telephone. A review of nurse led services and telephone interventions (Cox and Wilson 2003) concluded that the telephone 'enables a large number of patients to be accessed, is convenient, and allows for immediate responses and for the length of time to be controlled' (p59).

This pilot study aimed to evaluate a nurse led telephone intervention which encouraged a proactive approach to ovarian cancer management, with a holistic attitude to patient wellbeing that covered both the detection of recurrent disease and the identification and management of physical and psychological morbidity. This paper outlines the intervention and using data from the nurse's assessment and feedback from the patient satisfaction questionnaire considers the following questions:

- Which areas of psychosocial wellbeing did women with ovarian cancer discuss with the nurse during telephone follow up?
- How satisfied were these women with telephone follow up?
- What are the benefits of telephone follow up from a patient perspective?

## **Methods**

### *Patients*

Seventy-seven women post treatment for ovarian cancer who were eligible for follow up care were invited to receive nurse led telephone follow up, 21 women were unable to or refused to participate and 56 women were recruited.

### *Procedure*

Women received a follow up telephone call every 3 months (or at time intervals determined by their treatment trajectory) during the 10 month intervention period. Patients received a clinic appointment letter in the same way as usual, identifying a date and time for their telephone appointment. The appointment letter included a blood test form to be used at the patient's local medical practice. Prior to the telephone clinic the patient notes were identified and collected in the normal way and the nurse contacted the appropriate centres to obtain the CA125 results for the patients in that telephone clinic. Each telephone appointment was allotted 20 minutes, if more time was needed the nurse arranged a time to call the patient back. Patients were given the contact details for the nurse and encouraged to telephone in between follow up appointments if they needed to discuss anything further. Following the telephone consultation, the nurse dictated a letter to the patient's GP in the usual manner. A letter was sent to the patient that included details of their next

appointment, with a telephone number for them to call in case this time was unsuitable and they would like to reschedule. The nurse entered details regarding each telephone consultation/assessment onto a study database, this included a summary of discussions between the nurse and the patient in each domain of the intervention. At the end of the intervention period, patients were sent a copy of a satisfaction and experience with follow-up questionnaire.

### *The intervention*

The follow up telephone call initially focused on the detection of recurrent disease. The nurse gave the patient their recent blood test results and discussed any implications of this result. An assessment of current symptoms followed, protocols for care algorithms were consulted for any reported symptoms, with an immediate referral back into medical care if necessary. The intervention then focused on providing tailored information, practical advice and coping strategies in physical, psychological and social domains. The discussion points were informed by the literature and the experience of the clinical nurse specialist. Within the psychological domain, discussion points included the patient's current level of anxiety and/or depression, fear of recurrence, and concerns surrounding the predisposition of their children to cancer. Within the social domain, discussions included sexual intimacy issues, the patient's family, work and finances, and spirituality. In addition to information, advice, and coping strategies, the patient was given details of support networks in their area, and any necessary specialist referrals. Figure 1 highlights the key aspects of the intervention. This paper will consider the psychosocial elements of the intervention only.

### *Measures*

Satisfaction and experience with follow-up questionnaire.

The satisfaction and experience of care questionnaire has four domains; the organisation of care, information and advice, personal experience of care, and satisfaction with care. The last section asks patients about their 'general views' on the care they experienced. Within this section, patients were asked to rate the support they had received during telephone follow up and identify what has been particularly good about their follow up care, and which approach they preferred. The experience of care questionnaire has been used in a number of other cancer studies (Avis et al. 1995; Thomas et al. 1996; Faithfull et al. 2001).

### *Analysis*

Discussions between the nurse and the patients, and open responses from the 'general views' section of the satisfaction and experience of care questionnaire were subjected to content analysis. Responses were independently split into agreed categories by two researchers.

## **Results**

Fifty-two women received telephone follow up. The mean age of patients participating in the intervention was 62 years (SD 10.89). This position aligns with the literature on the likely age of patients contracting ovarian cancer (Ries et al. 2007). Of this sample 49% had ovarian cancer at stage I/II and 51% at stage III/IV.

### *Psychosocial discussions with the nurse*

During the telephone follow up call, all women were offered the opportunity to discuss their psychosocial wellbeing. Details of which women had discussed certain topic areas were taken from the nurse's database of telephone consultations. Thirty-three women were recorded as having discussed issues within the psychological domain. Forty two percent (14/33) of these women were recorded as having discussed anxiety/depression, 33% (11/33) as having discussed the recurrence of disease, and 6% (2/33) of women as having discussed familial risk (see table 1).

Thirty-nine women were recorded as having discussed issues within the social domain with the nurse. Fifty six percent (22/39) of women were recorded as having discussed their family (husband, children etc), 51% (20/39) as having discussed work and/or finances, 41% (16/39) as having discussed sexual intimacy, and 8% (3/39) as having discussed spirituality (see table 1). There was no significant difference in the mean age of women who did discuss sexual intimacy (mean age = 61.4, SD 2.3) and those who did not (mean age = 60.7, SD 2.5), ( $t(37) = 0.18$ ;  $P > 0.05$ ).

### *Patient satisfaction with telephone follow up*

Forty-six patients returned the satisfaction and experience with follow-up questionnaire following the intervention. In the 'general views' section of the questionnaire, patients were asked to rate the support they had received during telephone follow up. On a scale from 1 'dreadful' to 10 'excellent', the mean rating score was 8.24 (SD 2.0), the distribution of ratings is given in figure 2. Of the 44 women who answered the question on preference for method of follow up, 73% (32/44) preferred telephone appointments, 18% (8/44) indicated that they preferred doctor/ consultant appointments and 9% (4/44) were 'not sure'.

### *Benefits of telephone follow up*

In an open question within the same section of the questionnaire, patients were asked 'what has been particularly good about your follow up care?'. Thirty-five women completed this question, some women offered more than one advantage so a total of 43 advantages were cited in total. Figure 3 summarises the patients' perspective of the advantages of telephone follow up.

The two main advantages cited were a) the relationship and discussions between the patient and the nurse, and b) the convenience of having follow up appointments over the phone instead of having to attend clinic. Examples of patient feedback in these areas are given below.

### *Relationship/discussions with the nurse*

Thirty-nine percent of advantages cited related to relationship/discussions with the nurse. Women valued the fact that they were 'able to establish a very close relationship with the nurse over the telephone' (Patient 17) and felt the advantage of 'knowing the nurse and feeling that she really understands' (Patient 13). Women reported that they felt 'able to discuss problems in more depth' (Patient 21) and were more comfortable discussing subjects of a sensitive nature, e.g. 'I choose to talk openly on sexual issues and the

*oncology nurse is not embarrassed' (Patient 19).*

### *Convenience*

Thirty-three percent of advantages cited by women related to the convenience of telephone follow up. Patients felt that telephone follow up was more convenient in terms of travel time, e.g. *'Not having to drive forty miles to attend clinic for my follow-up care' (Patient 37)*, *'not having to make the two hour journey to hospital' (Patient 41)*, and waiting time *'Not having to wait around to see the doctor at the hospital' (Patient 33)*, *'Not having to go to the clinic and wait a long time' (Patient 26)*. Telephone follow up was particularly appreciated by women who were still employed *'It has been at my convenience and I have not had to take time off work' (Patient 48)*.

### **Discussion**

Almost half of the women in this study who discussed psychological issues referred to anxiety or depression, and a third of women discussed fear of recurrence. As treatments develop and improve we are able to consider survivorship within ovarian cancer, initial studies in this area indicate that anxiety and fear of recurrence continue to be a concern for women who have had treatment for ovarian cancer (Wenzel et al. 2002). This emphasises the need for psychological concerns to be addressed throughout the patient pathway.

Previous research cites the genetic association of their disease as a concern for women with ovarian cancer (Ferrell et al. 2003; Howell et al. 2003), which is heightened by the lack of a reliable screening method. The small minority of women who were recorded as having discussed familial risk within this study is therefore surprising and requires further investigation in future studies. Eliciting patient concerns for their daughters and alleviating their anxiety should be incorporated as a routine aspect of follow up care.

Concerns regarding sexual issues are frequently cited by women with ovarian cancer (Wenzel et al. 2002; Carmack Taylor et al. 2004) but sexual well being is a neglected area of discussion between health care professionals and women with gynaecological cancers (Corney et al. 1992; Corney et al. 1993; Cull et al. 1993; Stead et al. 2001; Stead et al. 2003). Lack of time, lack of privacy and lack of resources have been cited as reasons for not discussing sexual issues with patients (Stead et al. 2003). The results of this study highlight that sexual intimacy is an important concern for women with ovarian cancer, regardless of their age. All women who have had treatment which could affect sexual activity should be informed that advice is available on reducing adverse affects on their sexual relationships (NHSExecutive 1999).

The findings of this study supports the previous body of evidence that indicates patients with cancer are satisfied with telephone follow up (James et al. 1994; Sardell et al. 2000; Moore et al. 2002; Booker et al. 2004). The main advantages of nurse led telephone follow up were reported as the relationship and discussions between the patient and the nurse, and the convenience of having follow up appointments over the telephone instead of attending clinic. Convenience has been cited by previous studies which investigate patient benefits of telephone follow up (James et al. 1994; Booker et al. 2004). Patient

acknowledgement of their relationship with the nurse and the areas of discussion this allowed highlights the specialist skills of nurses in providing psychosocial support.

There is a paucity of data examining patient perceptions of current follow up practice and their preferences for future care following treatment for ovarian cancer. Without medical evidence to support the value of follow up clinics in terms of detecting recurrence of gynaecological cancers (Nordin 2006), there should be greater focus on the enhancement of patient quality of life and psychosocial wellbeing. A meta-analysis of psychosocial intervention components (Graves 2003) reports that interventions for improving quality of life in cancer patients include; providing information; assessing affective reactions; and teaching coping strategies. These components should be included in future follow up practice. Patients need holistic follow up care and deserve a practitioner who is skilled in addressing both physical and psychosocial concerns.

There is a need to explore alternative approaches of follow up which ensure an equivalent quality of surveillance whilst addressing the psychosocial concerns of women with ovarian cancer. The results from this pilot study have directed the design of a randomised controlled trial which will compare a telephone follow up intervention which encourages a proactive approach to cancer management incorporating a holistic attitude to patient wellbeing with traditional clinic based follow up care. Recommendations which are based on patient outcomes are urgently needed for the future follow up of women with ovarian cancer.

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