

Women's experiences of information, psychological distress and worry after treatment for gynaecological cancer

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Abstract

Sensitive, appropriate patient information is considered to be an important element in the psychological support of patients. Specialist nurses are seen to have a key responsibility for this work. With regard to gynaecological cancer, evidence suggests that women do not get optimum psychological care. This study set out to explore women's experiences of information, psychological distress and worry after treatment for gynaecological cancer. The study was a survey (not an RCT) and 70 patients from two specialist gynaecological oncology centres were interviewed at the time of diagnosis/initial treatment and again at 6 months. The semi-structured schedule included recognised instruments to assess; sources of information, concerns, and psychological distress. Both initially and at 6 months there was evidence of a considerable burden of worry; over half the women had four or more significant concerns related to their illness experience. However, women who had initial support from a clinical nurse specialist at the time of diagnosis experienced a clinically significant reduction in their level of psychological distress 6 months from diagnosis. Hospital linked professional sources of information were well used at the time of diagnosis, but by 6 months many patients were using non-professional sources such as television, magazines and newspapers. This study suggests that support from a clinical nurse specialist may be able to assist psychological recovery. However, to be effective in this area nurses should be skilled and willing to assess the individual's need for help with information, and managing their worry.

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1. Introduction

In England and Wales, cancer of the ovary, endometrium and cervix are amongst the most common sites of cancer in women after breast, lung and bowel cancer (Table 1) [1]. Consequently, the management of patients with gynaecological cancers is an important facet of the current thrust to improve cancer care. Evidence suggests that once women are in the health care system much more needs to be done to help them deal with the wider impact of their diagnosis and treatments. It is known for instance that women treated for gynaecological cancer can experience a wide range of physical, and psychosocial problems up to a year after diagnosis, and that frequently they do not get the opportunity to discuss their worries or obtain access to appropriate information and

support [2–5]. Sexual and relationship problems can cause particular difficulties which health care professions can be reluctant to address [6–8]. In addition, emotional difficulties such as depression, anxiety and a fear of dying have been found to be especially prevalent around the diagnosis and treatment phase [9].

This is in line with the incidence of psychological problems in all groups of cancer patients, with reports that up to a third develop a depressive illness and/or anxiety disorder [10–12]. Links have been demonstrated between unresolved concerns and emotional distress, with patients having four or more significant concerns being more likely to develop psychological illness. Patient's concerns cannot be predicted by disease type, age or gender and must be actively sought out if patients are to be helped [13,14].

The psychosocial aspects of care are reflected in current cancer care policy in the United Kingdom. There is a clear emphasis on the importance of information provision not least to facilitate patients' involvement in decision-making,

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Table 1
Range of diagnoses

Disease site	<i>n</i> = 70 (%)	Proportion (%) of gynaecological cancer in England
Cervix	32 (45.7)	21.5
Endometrium	24 (34.3)	28.5
Ovary	6 (8.6)	42.0
Vulva	7 (10.0)	6.4
Vagina	1 (1.4)	1.6

Improving outcomes in gynaecological cancers (NHS Executive, 1999).

for instance, *women with cancer should always be given sufficient information to enable them to contribute to decision-making if they wish to do so* [1].

Putting this policy into practice may cause some difficulty. There is evidence that access to sources of professional information can vary over time for women with breast cancer and there is a wide variation in the amount of preferred involvement in making decisions [15,16]. In gynaecological cancers, specific sexual information and advice can often be overlooked by professionals or mistimed [6–8].

Nurses or nurse specialists may be well placed in the new cancer services to contribute to care in these areas [17]. Reviews by Wilson-Barnett [18,19] suggest that innovative roles in nursing can lead to patient benefit and that specialist nurses can successfully undertake extended functions. In addition, it seems likely that specially trained, and supported nurses can make meaningful differences to cancer patients' lives and wellbeing [20,21]. This is an issue of current importance in the United Kingdom because specialist gynaecological oncology nursing services are being developed in many cancer centres and units. Evidence about how these new nursing services might best be developed to help patients with gynaecological cancer is therefore urgent and necessary.

A prospective study of patients with gynaecological cancers was conducted to explore:

- number and content of patients' concerns;
- psychological distress; and
- use of sources of information.

2. Method

The location for this study was a specialist gynaecological oncology service in the North West of England incorporating Hospital 1, a major teaching hospital, which received referrals from Family Practitioners in the local area and also from oncology units in the wider region. Hospital 2 was an oncology centre where patients attended mainly for chemotherapy and radiotherapy treatments. The relevant Research Ethics Committees gave permission for the study.

Women over the age of 18 years with a first time diagnosis of a gynaecological cancer were eligible to take part in

the study. There was no upper age limit. Exclusion criteria included a previous diagnosis of cancer, physical or psychological impairment that would render interview inappropriate and an inability to read and understand spoken English. Women who fitted the referral criteria and gave consent were interviewed by trained researchers as near as feasible after the diagnosis has been given, and followed up at 6 months after diagnosis. The time surrounding diagnosis/initial treatment was chosen because it was then that a specialist nurse was likely to be most available and women in most immediate need. Six months later, it was assumed that most women would have finished treatment. Patients were interviewed in hospital, or at their home, whichever was more convenient.

The semi-structured interview schedule included a questionnaire used successfully with women with breast cancer to establish sources of information [22,23]. Women were asked to consider a list of potential information sources that included professional, lay and media sources of information. Womens' concerns were assessed using the checklist by Harrison et al. [13], which consists of a number of subject areas found to be important to people with cancer. Individuals are asked to say if the areas have relevance for them. The items cover subjects such as current illness, physical symptoms, treatment, inability to do things, future, relationships and support. This allows the interviewer to identify all significant concerns under these headings (with an "other" category where necessary). A summary of major concerns can then be generated and checked out with the patient.

A card sort procedure designed to establish decision-making preferences [23] was utilised. Finally, there was a screening tool utilised to assess psychological distress the Hospital Anxiety and Depression Scale (HADS) which is a 14-item self-rated questionnaire incorporating two sub-scales for anxiety and depression [24]. This is considered quick to administer, acceptable to patients, has a known provenance within the field and will permit comparisons with related patient groups [25]. Data analysis was carried out using the statistical software package SPSS. The decision-making data from this study is being reported in a separate paper.

3. Results

3.1. Sample

Seventy patients were recruited to the survey and interviewed at the time of diagnosis/initial treatment and again at 6 months (*n* = 61). Forty-three (61.4%) women were recruited from Hospital 1, and 27 (38.6%) from Hospital 2. Nine women were lost to study (two had died, two refused and five were uncontactable). The average time from diagnosis to first interview was 8 weeks, but there was a wide variation (1–21 weeks). This was a due to some difficulties of patient identification, particularly patients attending Hospital 2 who were referred from several hospitals in the re-

gion, increasing the referral time from diagnosis. The time from diagnosis to second interview ranged from 25 to 41 weeks, with an average of 31 weeks. The majority of women in the study ($n = 66$) were white British. Two of the women were Eastern European, one was Afro-Caribbean, and one Ugandan-Asian. The age range of women recruited into the study was 24–83 years, with an average age of 52 years.

This was a therefore heterogeneous sample of patients with gynaecological cancer who were attending specialist centres (see Table 1). The under-representation of women with ovarian cancer was due to pre-existing studies limiting our access to this group. Twenty-eight patients (40%) had surgery as the primary treatment, and six (8.6%) had radiotherapy alone. The remainder had combination treatment, the most common being surgery followed by adjuvant radiotherapy. Two women had chemotherapy and radiotherapy. Four women had surgery followed by chemotherapy, and only one patient in the study had all three modes of treatment.

Clinical nurse specialists (one in each hospital) operated as an integral part of their hospital team, giving the majority of their patient support around the time of diagnosis and initial treatment. Both nurse specialists were experienced clinical practitioners but, there were differences in their roles. In Hospital 1, the main emphasis of the role was patient information and support. In Hospital 2, the nurse specialist also carried out physical examination of patients. Both nurse specialists placed a high priority on meeting the information needs of patients, discussing decisions and providing psychological support. Neither routinely used assessment tools to identify individual information needs or to assess psychological function. Both provided written information in addition to verbal explanation of treatments and both gave patients a contact number to be used if they had additional information or support needs. In Hospital 1, the consultation was in addition to the medical consultation providing additional information and emotional support. At the time of the study, it was the policy that all patients receiving treatment for gynaecological cancer at this hospital be offered a nurse consultation and all our study patients accepted. In Hospital 2, the consultation with the nurse specialist took the place of consultation with a junior member of the medical team and for the most part patients saw either a junior member of the medical team or the nurse specialist but not both. Not all gynaecological patients therefore were offered a nurse consultation at Hospital 2; in fact 16 of the patients in the study had no opportunity to access this service. There was no policy that the nurse saw those patients thought to have more or fewer problems than those seen by the junior doctor. At both hospitals, consultation with the nurse specialist was in addition to the services of other health care professionals such as social worker, dietician or physiotherapist.

3.2. Patients' concerns

We found that at both time points more than half our sample had four or more concerns which is important in the

Table 2
Burden of worry

Concerns	Time 1 ($n = 61$)	Time 2 ($n = 61$)
Total number ^a	365	280
Median (25th, 75th percentiles)	5 (2.5, 9.0)	4 (2.0, 6.0)
Zero to three concerns	22 (36.1%)	27 (44.3%)
Four or more concerns	39 (63.9%)	34 (55.7%)

^a There was a significant decrease in the total number of concerns per patient at time 2 (Wilcoxon $P = 0.009$, $z = -2.607$).

light of evidence that undisclosed worries of four or more is clinically significant [13,14] (see Table 2).

In terms of what exactly about their situation was concerning to the women, we found that at first interview (baseline), the top three categories of concern were the current illness, the future, and treatment related issues. At the 6 months interview, there were many similarities in the main categories of women's concerns, but there seemed to be more emphasis on physical symptoms and being unable to do things (see Fig. 1). Relationships with partners and sexually related matters did not score very highly as major concerns during these initial stages of the patient journey.

We found that patients at the initial interview who had contact with a clinical nurse specialist were significantly less likely to have four or more significant worries relating to their illness (see Table 3).

A possible explanation for this finding is that the availability of a specialist nurse increased patients' opportunities

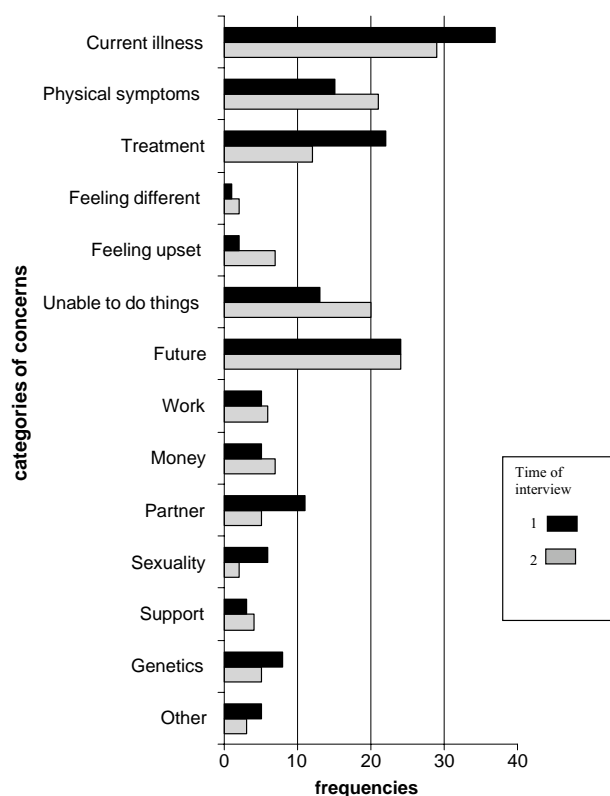


Fig. 1. Three main concerns: change over time ($n = 61$).

Table 3
Worry and clinical nurse specialist

Number of concerns at time 1	CNS at time 1 (n = 45)	No CNS at time 1 (n = 16)
Median (25th, 75th percentiles)	5 (2.0, 9.0)	7 (4.25, 9.0)
Zero to three concerns	20 (44.4%)	2 (12.5%)
Four or more concerns ^a	25 (55.6%)	14 (87.5%)

^a Significant difference between groups at time 1 (Fishers' exact $P = 0.033$).

for talking about and resolving worries. If this is so, it has implications for patients' psychological recovery.

3.3. Anxiety and depression scores

Further, likely impact of initial clinical nurse specialist contact on the psychological aspects of patients' experience is illustrated by the HADS scores in Fig. 2.

We found that for the group overall median scores decrease over time. However, the situation was not as favourable for those 16 patients without the support of a clinical nurse specialist at the time of diagnosis/initial treatment. The impact can perhaps be best illustrated by considering changes in individuals' scores over time. It will be seen that women mostly improved on both the anxiety and depression sub-scales, change being more marked where there was initial clinical nurse specialist contact. Without this, contact patients did not improve, on the contrary, the data show indications that the depression scores tended to become worse (see Table 4).

3.4. Sources of Information

We found information sources at time of diagnosis/initial treatment were mainly hospital linked professional sources such as the consultant, specialist hospital nurses and written information from the hospital (Fig. 3). The sources at 6 months from diagnosis show that as contact with the hospitals decreased there was a significant reduction in the use of all hospital linked professional sources of information. In contrast, there was a significant increase in the use of television and radio and a trend towards increasing use of magazines and newspapers.

Table 4
Changes in HADS scores: time 1 – time 2

	Median change (25th, 75th percentiles)		
	HADS anxiety	HADS depression	HADS total
All cases Test used: Wilcoxon	1.0 (–1.0, 3.7) $P = 0.020$	1.0 (–1.0, 2.5) $P = 0.021$	2.5 (–1.0, 5.7) $P = 0.005$
CNS at time 1 Test used: Wilcoxon	2.0 (0.0, 4.0) $P = 0.004$	2.0 (0.0, 3.5) $P = 0.001$	3.5 (1.0, 7.0) $P < 0.001$
No CNS at time 1 Test used: Wilcoxon (exact)	0.0 (–2.0, 0.7) $P = 0.448$	–0.5 (–2.75, 0.0) $P = 0.082$	–1.0 (–3.0, 0.7) $P = 0.187$

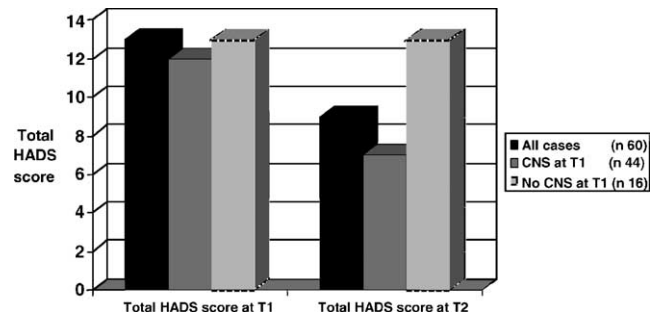


Fig. 2. Median HADS total scores at interview 1 and 2.

There were exceptions to this general picture. Twenty-two of the 59 women completing the checklist at both points were known to have maintained contact with their clinical nurse specialist. We did find there was a slight decrease in the use of the specialist nurse for information by this group but the decrease were not statistically significant, suggesting that active contact with a patient will facilitate the use of a professional as a source of information. Of the 22 women who mentioned that they had clinical nurse specialist contact at both time points; 21 (95.5%) identified the CNS as a source of information at time 1 and 17 (77.3%) identified the CNS as a source of information again at time 2 (McNemar test $P = 0.125$).

3.5. The clinical nurse specialist

Because the study was not designed to test for the effect of a clinical nurse specialist, the question of her possible impact arose from the data set itself. A post-hoc analysis brings a number of inherent limitations:

- The sample was not a random sample but a series of consecutive patients from two hospitals.
- The study was designed as a survey; it was not designed to test an intervention.
- Some patients dropped out of the study.
- It follows from the design that there was no random allocation to clinical nurse specialist, and the clinical nurse specialist groups and non clinical nurse specialist groups were unequal in size.

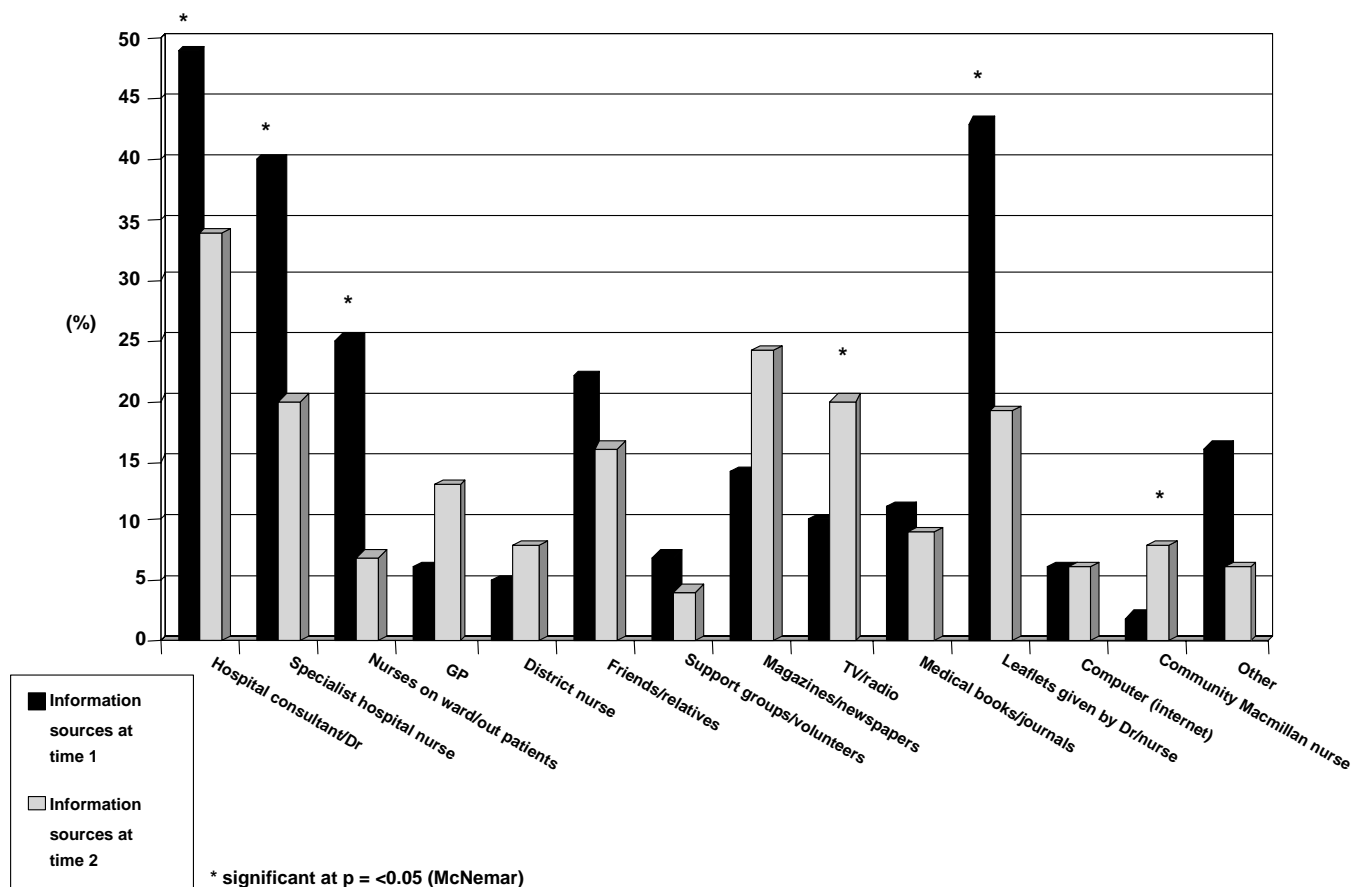


Fig. 3. Information sources at interview 1 and 2.

- The groups were not equally distributed between the hospitals indeed all the patients without clinical nurse specialist input were from Hospital 2.

It has to be accepted that this was not a randomised controlled trial, such a design would have been difficult if not impossible to conduct when the clinical nurse specialists were an embedded part of the service at both hospitals. However, we have done our best to examine the issues arising from our data. Firstly, there was no reason to believe that the sample was not representative of the patients who attend the two hospitals. When we looked for significant difference in total HADS scores at baseline between women who left the study and those who remained, there was no significant difference between those that dropped out and those that had a second interview with regard to hospital recruited from, or with regard to contact with a specialist nurse. Then, as far as our data would permit, we examined the possibility that apparent specialist nurse differences were caused by either patient differences, or hospital differences. In light of the fact that all the patients without specialist nurse input came from Hospital 2, differences between those with and those without the specialist contact at that hospital were very important.

In the overall sample, we found no significant differences in HADS scores at baseline either between the patients at Hospital 1 and Hospital 2, or between the group of patients with specialist nurse input and those without. In addition, we found no significant differences in terms of patient age and time from diagnosis between the group of patients with specialist nurse input and those without. The key analysis of the 24 patients at Hospital 2 who had two interviews is shown in Table 5. Here, again there was no significant difference between those who received the specialist nursing service and those who did not, but it must be pointed out that in this part of the analysis the numbers in each category were becoming small and the standard deviations were large.

Table 5
Hospital 2 patients

CNS group (n = 8) vs. non-CNS group (n = 16)	Significance and test
Age	ns p.278 <i>t</i> -test
Time from diagnosis to first interview	ns p.595 <i>t</i> -test
HADS anxiety at baseline	ns p.596 Mann–Whitney exact
HADS depression at baseline	ns p.107 Mann–Whitney exact
HADS total at baseline	ns p.229 Mann–Whitney exact

We believe this demonstrates that the findings follow a consistent pattern, but that we need to be cautious as to how far we can extrapolate our findings.

4. Discussion

Policy in cancer care recognises that women with gynaecological cancer can experience a wide range of emotional and relationship difficulty. The women in this study reported a wide range in the number and nature of their illness related concerns. Many were carrying a high burden of worry which is consistent with other work about patients with gynaecological cancers [3,5,8]. In our sample at 6 months, the average patient was still managing four significant concerns relating to her illness and treatment. There was a great deal of individual variation, but concerns to do with the illness, treatment and outcome were of major importance. Relationships with partners and sexually related matters did not score particularly highly as major concerns during these initial stages of the patient journey. Clearly, this might change later on as patients may become more confident about their future. Providing opportunities to identify and explore patients' individual concerns (whatever they are) is potentially important in terms of patient care because of the increased likelihood of anxiety and/or depression [13,14].

This is a vulnerable group of patients who are likely to welcome help, and this highlights the importance of good communication and information provision. While et al. [26] indicated that health professionals are seen by many cancer patients as being very helpful with regard to the worries and anxieties associated with their illness. The concerns checklist utilised in this study seems to be a useful framework for communicating about patients' concerns. It provides an acceptable way to focus on the nature and impact of particular worries and has been found to be reliable in other cancer patient groups [13,27]. In the While study, the hospital doctor was the person most frequently identified as addressing these problems, but few of those patients had access to a specialist nurse. In this study, it was very interesting to find that in the group where a specialist nurse was available to the patient, fewer worries were reported at 6 months.

The availability of skilled assessment may also underlie another key study finding. Patients with cancer are generally considered to have an increased relative risk of times three the prevalence of affective disorder in the general population. There is agreement that patients suffering in this way should be identified and offered prompt and appropriate management [10–12]. Cancer nurse specialists have been shown to be very helpful in this process. Much of the original evidence originates from breast cancer where clinical nurse specialists were first established.

A randomised controlled trial [28] sought to determine whether counselling by a breast cancer clinical nurse specialist prevented the psychiatric morbidity associated with mastectomy and breast cancer. Counselling failed to reduce

significantly initial distress. However, the nurse's regular monitoring of the women's progress led her to recognise and refer 76% of those who needed psychiatric help. Only 15% of the control group whose condition warranted help were recognised and referred. Consequently, 12–18 months after mastectomy there was much less psychiatric morbidity in the counselled group (12%) than the control group (39%). A further trial [29] randomised 40 newly diagnosed patients to receive routine care or routine care plus counselling by a specialist breast care nurse. Although both groups continued to adjust throughout the year following surgery, this adjustment occurred more rapidly if the specialist nurse had supported patients. A study in 1996 [30] undertook a comparison of the effects of professional support on psychological morbidity in 273 women undergoing surgery for breast cancer. Once again in the patient sample as a whole, prevalence of psychological morbidity decreased over time, but scores were consistently lower in the patients offered routine ward care plus support from the breast cancer clinical nurse specialist. It is worth noting that informed consent for studies such as these may become increasingly difficult in the future. This is because many patients and service providers now consider access to the information and support provided by clinical nurse specialists integral to good practice.

In our study, therefore, we have found the data presents a picture supported by findings from the randomised studies in breast care. Many patients had high HADS scores, and although there were considerable improvements with time, the exceptions were more likely to be those who never had contact with the specialist nurse. It must be pointed out that the results of this study represent associations, rather than the results of a randomised trial of specialist nursing intervention. In addition, it was the case that all the patients without clinical nurse specialist input came from Hospital 2. Nevertheless, our analysis shows a change in HADS scores which does not seem to stem from differences at baseline between the group of patients with the specialist nurse's service and those without. That the difference may be attributable to her impact is therefore plausible.

Access to information about the disease, its treatment and consequences for patients with gynaecological cancer is clearly important [6,8,9]. However, it is likely that many clinicians underestimate patients' desire for information and discussion [31] whilst overestimating patients' desire to make decisions [32]. Fallowfield [33] argues powerfully that benefits found when there is patient involvement in decision-making, may relate mostly to the therapeutic benefits of increased communication and information sharing. Opportunities to discuss the situation and access appropriate information seem therefore to be the key to effective practice whether or not patients want actively to be involved in making treatment decisions [34–36]. In this respect, it was encouraging to note that health professionals were well used as a source of information for patients with gynaecological cancer. We found however that this declined in the follow-up period when there was less contact with the

treatment centre, the patients moving towards the use of lay sources such as magazine articles and television. This is congruent with other reports [16]. The finding from this study that the trend was less apparent in those who maintained specialist nurse contact, supports our other findings that a specialist nurse intervention seems associated with patient benefit. There is agreement that such nursing work is considered appropriate and necessary by patients and professionals. Information and support by specialist nurses is highlighted as important to cancer patients in the UK Commission for Health Improvement *Listening to patients' views and experiences* [37].

5. Conclusions and practice implications

5.1. Conclusions

This study has shown that patients' concerns, access to information and psychological distress were amenable to the skills and attention available from the two specialist nurses at the study hospitals. These were experienced, credible, highly trained and well regarded in their respective institutions. They both functioned as part of the specialist team, and had access to further support and help for their patients where this was necessary. We consider it is important that these issues of team working and support within the organisation are fully considered if specialist nursing interventions are being planned.

5.2. Practice implications

Overall what the findings from this survey of patients undergoing initial treatment for gynaecological cancer would suggest is that there may be specific areas of the patient's psychological management which can be assisted by skilled nursing. The study shows that although this group are likely to be experiencing a great deal of worry even 6 months after diagnosis; health care professionals can help. The clinical nurse specialists were a well utilised source of information, a situation more likely to be maintained if the specialist nurse keeps in touch. In addition, we have highlighted the necessity for careful communication concerning information and listening to patient's concerns. We consider these are all areas where specialist nurses working with this patient group can usefully target their efforts, making partnerships with real potential to help patients better manage their difficult and often distressing situation.

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