

CHAPTER 13

Deaths from malignancy

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Deaths from cancer: key recommendations

These recommendations are also generally applicable for the management of pregnant women with other severe medical conditions.

Service provision

All maternity trusts should develop a protocol for the provision of multidisciplinary care should the need arise.

Pregnant women who are seriously ill from conditions not immediately related to pregnancy require exceptional care and routine referral patterns are not good enough for them.

The importance of planned multidisciplinary care for women with cancer and other serious problems cannot be over-stressed. Obstetricians, midwives, general practitioners, oncologists, surgeons, Macmillan nurses and palliative care services need to be involved, in conjunction with the woman and her partner, in planning a course of antenatal care that respects the wishes of the woman yet should optimise the outcome for the fetus.

Individual practitioners

Previous Reports have repeatedly stressed, and this Report does so again, that pregnancy is not a contraindication for radiological investigations for women with severe and unremitting pain or vomiting, including back, chest or epigastric pain, particularly if the pain is so severe that it requires management by major or epidural analgesia or prevents the woman from walking.

A clear medical and family history should be taken at booking to lower the threshold for the index of suspicion in women who complain of other symptoms during their pregnancy.

Clear, relevant and complete information must be passed from the general practitioner to the antenatal care team, at booking, accurately detailing any past medical history including previous malignancies, abnormal cervical smears, operations and any relevant family history.

When a woman says that she is or has been treated by an oncologist or any other consultant, such as a respiratory or cardiac physician, for an ongoing condition, these consultants should be contacted and up-to-date records made available. It

should not be left to the woman to give her complete medical history or act as a go-between.

Pregnant women undergoing intercurrent treatment or investigation for medical or surgical conditions should be reviewed by a consultant obstetrician even though they may appear to be obstetrically well.

Women planning pregnancies after treatment for cancer, particularly breast or cervical cancer, should be counselled by an obstetrician or a clinician with specialist knowledge of obstetrics.

Pregnant (and all other) women should be encouraged to report breast lumps if they find them by chance.

Delivery needs to be planned with care and, if possible, performed at an optimum time with consultants in attendance. An anaesthetist should be involved at an early stage in the pregnancy. A written and agreed care plan should be in the woman's notes to pass this information on to colleagues who may have to attend for an emergency delivery.

If preterm delivery is planned to allow more radical therapy for the mother, a paediatrician should be involved antenatally, not only to optimise the care of the baby but also to discuss with the parents what may happen afterwards in regard to neonatal care.

Cancer in pregnancy

The incidence of cancer in pregnancy is around one in 6000 live births. This is about 50% lower than the incidence in the nonpregnant population of a similar age. There are several possible reasons for this. A woman who already has cancer diagnosed may avoid pregnancy. A pregnant woman with occult cancer may have the diagnosis delayed because routine screening is not carried out or because symptoms are not investigated promptly (being attributed to the pregnancy) or because investigation is less thorough.

It is often thought that pregnancy accelerates the growth of cancer, particularly if the cancer is hormone-dependent, such as arising from the breast or cervix. For many types of cancer, the numbers of cases occurring in pregnancy are too small for reliable epidemiological studies to be carried out, but it appears that for most types, pregnancy does not alter the incidence or prognosis compared with cancer diagnosed at a similar stage in the nonpregnant patient. However, the Royal College of Obstetricians and Gynaecologists' 2000 Study Group on cancer in pregnancy¹ identified certain types of cancer that may be aggravated by pregnancy, as shown in Table 13.1, and deaths from these are classified as *Indirect* or *Late Indirect*. Further discussion of this can be found in the last Report² or the report of the RCOG Study Group.¹

Although 14 of the 28 cases in this chapter are defined as *Indirect* or *Late Indirect*, in that the course of the disease was modified by the pregnancy or pregnancy masked its effects, the classification used by the UK CEMD does not accord with the International Disease Classification of Maternal Deaths (ICD10). The inclusion of these extra cases in

Table 13.1 Classification of causes of deaths from tumours or malignancy and type of death; United Kingdom 2000–02

Cause	<i>Indirect</i>	<i>Late Indirect</i>	<i>Coincidental</i>	<i>Late Coincidental</i>	Total
Central nervous system:					
Astrocytoma			1*		1
Glioma	2	2	1*		5
Cancer of the breast	2	3			5
Cancer of the lung			2	2	4
Cancer of the cervix	1	1			2
Hepatic cancer				2	2
Lymphoma or leukaemia		2			2
Cancer of unknown origin			1	1	2
Neurofibrosarcoma			1		1
Cancer of the oesophagus			1		1
Osteosarcoma				1	1
Pathathyriod adenoma			1		1
Cancer of the vulva		1			1
Total	5	9	8	6	28

* Known prior to pregnancy and therefore unaffected by pregnancy.

the overall maternal mortality figures helps to artificially inflate the UK *Indirect* maternal death rate when compared with *Indirect* and overall maternal mortality rates from other countries. An adjusted calculation for the UK maternal mortality rate, for comparative purposes, is given in Chapter 1.

Introduction

This chapter was introduced in the last Report because, in the past, the lessons from deaths from malignancy were difficult to draw together, as they were scattered throughout the Report and discussed in several different chapters. The chapter to which they were assigned depended upon the timing of the death and whether or not the assessors considered the course, diagnosis or treatment of the disease was modified by the pregnancy itself. As such, key recommendations may have been missed. However a death is categorised, it is the diagnosis and management, or lack of it that forms the most important part of case assessment. This chapter therefore aims to draw together all these deaths, irrespective of classification, to strengthen the impact and recommendations that can be drawn from them. It also provides an overview of both the key remediable factors as well as examples of outstanding care.

The overall number of cases reported to the Enquiry was 28, as shown in Table 13.1, with an age range of 15–41 years. As discussed in Chapter 15 *Late* deaths, a significant number of women who died of cancer some months after delivery were not reported to the Enquiry as they were no longer in touch with midwifery services.

Discussion

In general, a high and in some cases outstanding level of care was provided for women, babies and families once the diagnosis had been made. However, as has been discussed

in several previous Reports, in many cases there were significant opportunities to have made the diagnosis earlier. While this may not have affected the eventual outcome, it would have enabled an appropriate degree of symptom relief to be provided to alleviate suffering as well as enabling earlier access to further medical care and the support services required. The messages and lessons to be learnt are summarised here.

Prepregnancy counselling

A few women who had previous episodes of cancer sought prepregnancy counselling. Women planning pregnancies after such a diagnosis, particularly of breast or cervical cancer, should be counselled by an obstetrician with a special interest in oncology or an oncologist with specialist knowledge of obstetrics. The latest guidance from the Royal College of Obstetricians and Gynaecologists recommends that pregnancy should be deferred for at least 2 years after treatment for breast cancer, as this timescale helps to differentiate those women with a better chance of long-term survival from those with more aggressive disease.³ It further recommends that and that women with stage-IV disease (with a 5-year survival of less than 15%) should be advised not to have further pregnancies and women with stage-III disease should consider deferring pregnancy for 5 years.

Women not known to be pregnant

Two women who died of disseminated carcinomatosis late in pregnancy were unknown to the obstetric services. Both had concealed their pregnancies, perhaps from a misguided fear of being advised to consider a termination of pregnancy. One was an inpatient in the care of an oncology team.

Cases where poor communications between professionals led to a delay in diagnosis and treatment

As has been noted in past Reports, and in other chapters throughout this one, in some cases general practitioners failed to mention key aspects of the woman's past medical history to the obstetric team. In others, the obstetric or midwifery team did not communicate with other specialists providing her care and missed vital opportunities to alter her management plan. The following vignette provides an example:

A woman with a history of cervical intraepithelial neoplasia grade 3 (CIN3) and lymphadenectomy was given an inadequate referral letter to the booking clinic by her GP which mis-stated the severity of her past disease (said to be CIN1) and omitted the fact she had had a cone biopsy and pelvic lymphadenectomy for presumed squamous cell cervical cancer. She herself was a poor historian but did mention to her antenatal care provider that she was still under the care of the oncology team; however, this was not followed up. The fact she had had cervical cancer was not highlighted anywhere in her notes and the operation for pelvic lymphadenectomy was only discovered when she was being prepared for an emergency caesarean section. She subsequently died.

Breast examination in pregnancy

As in previous Reports, cases of breast cancer continue to be detected late in pregnancy, usually in an advanced state. The practice of professional examination of the breasts as part of the routine antenatal care has been discontinued but women should be encouraged to examine their own breasts regularly.

Cases where a lack of investigation in pregnancy may have delayed the diagnosis

As has also been seen and repeatedly highlighted in previous Reports, there were a worrying number of cases where women were not investigated for severe sustained pain, vomiting, weight loss or other abnormal symptoms during pregnancy. Although earlier diagnosis would not have altered the course of the disease, appropriate pain relief and referral to the oncologists and support services could have been provided earlier.

A number of women made multiple presentations to hospital with chronic chest, abdominal and/or back pain. In several cases this necessitated several admissions for bed rest and analgesia, although no investigations were undertaken despite severe pain being recorded in the notes. Although the course of the disease could not have been altered by earlier diagnosis, more appropriate management would have enabled a better quality of these women's remaining life.

Women, whether they smoke or not, and who present with severe shortness of breath, chest pain and coughs, especially of the severity to necessitate one or more hospital admissions, require chest X-rays as part of the diagnostic investigation to help exclude embolism or lung cancer as a differential diagnosis. This was not undertaken in several cases, one in particular in the presence of a strong familial history of a genetically linked cancer. Even when the respiratory physicians are involved, as in a case of suspected embolism which failed to respond to treatment and which eventually was found to be due to non-Hodgkin's lymphoma, investigations were limited for several months and no contact was made with the obstetric team already caring for the woman.

Some women who required repeated antenatal admissions for chronic abdominal pain and vomiting were investigated for pre-eclampsia and fatty liver without imaging. When these conditions had been excluded there was little attempt to elucidate the underlying pathology, which only became apparent after delivery. Although the outcome may not have been different, an earlier diagnosis would have enabled an appropriate management and support plan to be implemented and would also have afforded the women symptomatic relief.

Severe back pain, sciatica and urinary incontinence continue to be under-investigated. A number of women in this triennium again had pain and symptoms so severe that they repeatedly attended accident and emergency departments or were admitted to hospital on a number of occasions. They often required complete bed rest and analgesia in hospital or at home, were unable to walk unaided and a few suffered urinary incontinence.

Previous Reports have repeatedly stressed, and this Report does so again, that pregnancy is not a contraindication for radiological investigations for women with severe and unremitting pain or vomiting, including back, chest or epigastric pain, particularly

if the pain is so severe it requires management by major or epidural analgesia or prevents the woman from walking.

Cases where 'social labelling' may have affected the diagnosis and management

Women with severe social problems, including drug dependency, can be challenging to care for, and sometimes their clinical symptoms may be dismissed as attention seeking, as demonstrated by the following case:

A severely excluded drug-dependent woman, with a past history of abnormal cervical cytology, was admitted several times in pregnancy with severe abdominal and lower back pain. This was not investigated until after delivery, despite her past history and being noted to be in acute pain when visited at home during the antenatal period and also while in hospital. It was considered that she may have been attention seeking or wanting unnecessary pharmacological relief. A magnetic resonance imaging scan after delivery revealed a disseminated carcinoma, most likely to be cervical in origin, and thereafter she received excellent palliative care.

The importance of planned multidisciplinary care

When a woman with a malignancy is known prior to pregnancy, or as soon as it is diagnosed, planned multidisciplinary care is essential. It is heartening to note that this was the case for the majority of women in this Report, who, in the main, received excellent care. The multidisciplinary teams involved in their care comprised obstetricians, midwives, oncologists, radiologists, anaesthetists, paediatricians, Macmillan nurses, social services and others, as required. It is gratifying that it appears that the lessons from earlier Reports have been learned. Nevertheless, it is recommended that all maternity Trusts devise a formal protocol for the provision of such care should the need arise. The role of the midwife in such cases was summarised in the last Report and is reproduced here in Box 13.1.

Box 13.1 The midwife's role in supporting women suffering from malignancy or other serious medical conditions

- Acting as her advocate.
- Arranging familiarisation visits to the special care baby unit.
- Acting as the focal point for liaison with other health care teams.
- Providing information for her and her family.
- Ensuring time for rest and privacy.
- Ensuring the complex set of hand held-notes were transferred to all the professionals involved in her care.
- Teaching her partner parenting skills.
- Being involved with the first course of post-delivery treatment, if appropriate.

Cases of well-provided, thoughtful care, which supported the woman's dignity, wishes and beliefs

The majority of women received good multidisciplinary care once the diagnosis was made, but there were further instances of exceptional individualised care, which required an unconventional approach. These cases provide an excellent example of how sensitive but unconventional midwifery, obstetric and paediatric care can be the best option in the face of overwhelming illness and patient choice. Two short vignettes are given to demonstrate some of the variety of approaches that were adopted for such women and their families:

A woman with an advanced malignancy actively sought alternative therapy during her pregnancy. She wanted no involvement from NHS professional services and wished to have a home birth under the care of an independent midwife. This request was supported and the midwife, in turn, liaised with and was supported by the supervisor of midwives. A number of family and professional meetings were held to discuss the prognosis and options with the staff respecting her choice to reject their care. She was helped to prepare a 'living will'. Eventually her condition required an early delivery, to which she agreed. The anaesthetist, while recommending a general anaesthetic for the necessary caesarean section, in view of her deteriorating condition opted for a slow-onset spinal block to provide a supportive environment with no aggressive interventions. Plans were made for her early discharge home but her condition rapidly deteriorated and she died peacefully with her family and friends in a specially prepared room at the hospital.

All the staff who were involved in this case commented that she taught them the true meaning of maternal choice. She was cared for in an exemplary manner throughout and died with dignity. Her wishes were respected at all times.

A woman with known cancer developed secondary deposits in pregnancy. She was given appropriate highly specialised care but still required an early caesarean section. After a few weeks, and with the help of skilled multidisciplinary working, including the neonatal outreach team, she was able to help care for her premature baby at home until she died.

The neonatal team offered constant support and trained the family in neonatal resuscitation. All involved in her and her baby's care learned how to overcome routine obstacles such as transport and liability insurance, which, while put in place to support and protect patients and the organisation, can hinder optimum care in unforeseen circumstances. In the event, sensible decision making and the element of considered risk taking, such as enabling the baby to go home in an incubator, enabled the family to stay together as long as possible and to generate memories which should strengthen the father's ability to care for the child in the years to come.

References

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