Scottish Parliament Region: Glasgow

Case 200503196: Greater Glasgow and Clyde NHS Board

Summary of Investigation

Category

Health: Hospital; Oncology and Palliative Care

Overview

The complainant (Mrs C) raised a number of concerns about the care and treatment of her husband (Mr C) at a number of hospitals in Greater Glasgow between June 2004 and his death from mesothelioma in September 2004. Mrs C complained that Mr C was not given information about his prognosis and delays occurred which prevented his being given any useful treatment.

Specific complaint and conclusion

The complaint which has been investigated is that Greater Glasgow and Clyde NHS Board (the Board) failed to provide Mr C with timely and appropriate care and treatment between June and September 2004 (*partially upheld*).

Redress and recommendations

The Ombudsman recommends that the Board:

(i) apologise to Mrs C for communication failures;

(ii) consider using the events of this complaint to inform practise in communicating with patients affected by cancer; particularly when a number of different specialists are involved in care; and

(iii) gives consideration to improving written recording of discussions with patients and their elatives especially in situations where there are a number of clinicians involved in delivering care.

The Board have accepted the recommendations and will act on them accordingly.

Main Investigation Report

Introduction

1. On 17 February 2006, the Ombudsman received a complaint from Mrs C that the NHS Greater Glasgow and Clyde (the Board) had failed in their care and treatment of her husband (Mr C) at a number of hospitals in Greater Glasgow between June 2004 and his death from mesothelioma in September 2004. Mrs C complained that Mr C was not given adequate information about his prognosis and delays occurred which prevented his being given any useful treatment. Mrs C also complained that there had been a lack of support available to Mr C throughout his illness which meant he had suffered considerable distress and pain in his last months of life. Mrs C complained to the Board on 7 January 2005 and received a detailed response on 31 March 2005 and a further response on 5 August 2005. Mrs C remained unhappy with the response and complained to the Ombudsman's office.

2. The complaint from Mrs C which I have investigated is that the Board failed to provide Mr C with timely and appropriate care and treatment between June and September 2004.

Investigation

3. Investigation of this case involved obtaining and reviewing copies of Mr C's clinical records. I have also sought the views of a medical adviser (the Adviser) to the Ombudsman and made written enquires of the Board. I have discussed particular issues of this case with Mrs C.

4. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked. Mrs C and the Board were given an opportunity to comment on a draft of this report.

Medical Background

5. The Adviser provided the following information by way of medical background to the issues of this complaint. Mr C died from mesothelioma. Over 90% of this type of cancer is caused by previous asbestos exposure. There is no cure for mesothelioma and treatment for relief of symptoms is of limited effect. Most patients die within two years of diagnosis and in some cases (as with Mr C) the tumour is more cellular and there can be very rapid advancement of the illness. As the tumour advances it encases the lung and worsens breathlessness. The most common symptoms are chest pain and

breathlessness due to pleural effusion. The main purpose in management of the condition is to provide relief of the pain and breathlessness and will include analgesia and radiotherapy. It is often very difficult to get adequate pain relief. Relief of the breathlessness is obtained by draining the pleural fluid and/or pleurodesis (a procedure to prevent recurrent fluid accumulation). Mesothelioma is diagnosed by finding malignant cells in the pleural fluid or by biopsy of the tumour. The main alternative diagnosis is adenocarcinoma and it can be difficult to distinguish between these two types of cancer.

6. A particular problem of mesothelioma (and to a lesser extent adenocarcinoma) is the spread of tumour cells through wounds in the chest wall when for example a drain is inserted or a pleural biopsy performed. Because of this it is now standard practice to give a dose of radiotherapy to the puncture site to try and prevent tumour growth. It is important to minimise the number of invasive procedures.

Complaint: The Board failed to provide Mr C with timely and appropriate care and treatment between June and September 2004

7. Mr C took ill while in Thailand and had a significant pleural effusion drained which was found to contain malignant cells which were then thought likely to be an adenocarcinoma. Mr C returned to the UK and was admitted to the Victoria Infirmary, Glasgow (Hospital 1) on 8 June 2004 under the care of Consultant 1. The drain was removed and a sample of the fluid was collected. A previous minor contact with asbestos was noted. A bronchoscopy was performed and a normal result was recorded. At this time it was thought that adenocarcinoma was the likely diagnosis. The medical plan was to wait and see if more fluid accumulated (which was likely) and use this fluid to perform a definitive diagnostic biopsy procedure. Mr C was discharged on 11 June 2004 with an appointment to be reviewed in three weeks at the out-patient clinic. Mr C was seen on 7 July 2004 at which time he was breathless again and had chest pain especially around the drain site. It was suspected that the tumour had spread through the scar to the chest wall. This was an indication that the tumour was growing very rapidly. At this point the management plan was for a VATS procedure (a keyhole insertion of a telescope/ thoracoscopy combined with a biopsy) and drainage of fluid. This was planned for 26 July 2004.

8. Mr C was admitted to the Glasgow Royal Infirmary (Hospital 2) on 16 July 2004 with breathlessness and a chest x-ray showed a further accumulation of fluid. On 22 July 2004 the fluid was drained with the VATS

being performed on 26 July 2004. The VATS biopsy showed the lung to be completely encased in tumour and the skin lesion (from the previous drain site) was excised. The initial biopsy result was inconclusive but a further report indicated it was mesothelioma. Mr C had local radiotherapy to the chest wall where the lesion had been removed. The chest drain was removed on 30 July 2004 and Mr C was discharged. Records indicate that the Palliative care team were notified.

9. Mr C was then transferred to the care of Consultant 2, a clinical oncologist, (an oncologist trained in a wide range of cancer therapies but primarily responsible for radiotherapy) and Consultant 3, a medical oncologist (specialist role to prescribe appropriate drug related treatments, including chemotherapy). Mr C commenced Chemotherapy on 10 August 2004. A second course was planned but in the event Mr C was too ill to receive further treatment and was readmitted to Hospital 1 on 26 August 2004 with breathlessness, abdominal swelling and other symptoms. Mrs C was advised on 1 September 2004 that nothing more could be done for Mr C and he was given a prognosis of two weeks. Mr C returned home by taxi on 3 September 2004 as the ambulance booked did not arrive (Mrs C received an apology for this error later and an assurance that the service had been reviewed in light of the problems identified). Mr C's condition deteriorated and he died at home on 7 September 2004.

10. The Adviser told me that the initial medical plan to await further fluid accumulation and then to perform VATS was reasonable since fluid examination had not been successful in determining the type of malignancy and further drainage would be needed for relief of Mr C's breathlessness. As the initial tests were more suggestive of adenocarcinoma it was reasonable not to consider it necessary to treat the drain site with radiotherapy. The Adviser noted that there was no initial medical urgency to do anything more since which ever malignancy was diagnosed only palliative treatment (relief of the pain and breathlessness) could be given and for both types of tumour this treatment is not especially successful in providing relief from symptoms.

11. The Adviser told me that it may have been possible to avoid the biopsy in July 2004 and leave definitive diagnosis until post-mortem although it was not unreasonable to proceed with the VATS as planned. The Adviser noted that during local resolution the Board had commented that the biopsy was mandatory for compensation but in his view this was not correct. The Board

also commented that it was their experience that families were reluctant to agree to a post-mortem. The Adviser told me that again in his opinion this was not the case where there was a question of mesthelioma diagnosis.

12. The issue of diagnosis is an important one as this is usually needed to support any legal claim for compensation for mesothelioma sufferers. In Scotland all deaths where mesothelioma is suspected must be reported (as was Mr C's) to the Procurator Fiscal who has the authority to order a post-mortem if he considers this necessary. Mrs C told me that no mention of the need for diagnosis or indeed the Mesothelioma Compensation Scheme was made to her or Mr C. Mrs C told me that it was only after Mr C's death when she approached a mesothelioma charity to make a donation that she was advised by them that she may have a claim against her husband's former employers. Mrs C also advised me that she was never asked whether or not she would consent to a post-mortem.

13. The Adviser noted that there were no entries in the medical record he reviewed of the meeting with Mr and Mrs C by Consultant 2 in August 2004 or of any discussion of the merits of chemotherapy. He also noted that there was confusion between Consultant 2 and Consultant 3 about the exact drug regime being used and that it was not clear from the records why both consultants were actively involved in Mr C's care. The records indicate that Mr and Mrs C were not happy about the mixed messages they were receiving in late August 2004 and in particular Mrs C was not happy that the chemotherapy was not to be continued and felt this was because it had not been offered sooner.

14. The Adviser told me that overall there is very little evidence of communication between doctors and Mr and Mrs C. With a disease like mesothelioma discussion of possible treatments and their limited purposes is very important. There is clear disagreement between the Board and Mrs C as to what was discussed and without evidence in the medical records it is not possible to resolve this disagreement.

15. The General Medical Council (GMC) issues guidance to doctors on communications with patients. The most recent version of this, 'Good Medical Practice, November 2006', (published after the events of this case but replacing previous similar guidance) sets out the principles for good practice. The relevant section can be found in full at Annex 3 but includes:

'Good communication

To communicate effectively you must:
(a) listen to patients, ask for and respect their views about their health, and respond to their concerns and preferences
(b) share with patients, in a way they can understand, the information they want or need to know about their condition, its likely progression, and the treatment options available to them, including associated risks and uncertainties
(c) respond to patients' questions and keep them informed about the progress of their care'

16. The Board have advised me that since the events of this complaint there have been some changes to the referral system for Oncology from Hospital 1 and Hospital 2, and referrals will now only happen after a multi-disciplinary team review. The Adviser noted that the improved co-ordination of care this should bring would help avoid the difficulties caused in Mr C's case by having multiple consultants involved in planning his treatment and care.

17. Following sight of the draft of this report Mrs C told me that she still feels there was a lack of care and humanity given to Mr C throughout his illness. Mrs C remained very critical even of the most basic nursing care. Mrs C told me that she wanted people to realise Mr C mattered as man and not just another statistic.

Conclusion

18. On the basis of the medical evidence I have received I am satisfied that the clinical management of Mr C was reasonable. Mr C's disease proved to be a very aggressive form of an aggressive cancer and Mr C's decline was more rapid that would have been anticipated by the medical staff managing his care.

19. The lack of evidence of discussions in the medical record is a concern and is inadequate. The record-keeping does not demonstrate compliance with the GMC guidance. However, of greater concern is the failure to provide information to Mr and Mrs C which meets the standard set out in the guidance. Either Mr and Mrs C were not provided with the information and/or it was not provided in a way which enabled them to properly consider the implications of Mr C's illness and the options for managing this illness. The decision to carry out the biopsy appears to have been taken without any discussion with Mr and Mrs C about the need for it or about the possible implications of any diagnosis. Nor was there any mention of the compensation scheme.

20. At the heart of Mrs C's complaint is her concern that had they been advised of the poor prognosis at the outset then both she and Mr C would have wished to be able to make the most of his final months rather than be given false hope and endure unnecessary medical treatment. While I accept that it would not have been possible to give an exact prognosis, I conclude that the nature of Mr C's illness was not adequately communicated to allow Mr and Mrs C to make informed decisions. I acknowledge Mrs C's views of Mr C's care and note that the consequence of poor communication in this case was very real suffering on the part of Mr and Mrs C.

21. The evidence I have considered is that the medical treatment was reasonable but that the communication was significantly deficient. I partially uphold this complaint.

(a) Recommendation

22. The Ombudsman recommends that the Board apologise to Mrs C for the failure to effectively communicate with her and Mr C. The Ombudsman further recommends that the Board consider using the events of this complaint to inform practise in communicating with patients affected by cancer, particularly when a number of different specialists are involved in care. This consideration should include recording such communication.

20 June 2007

Annex 1

Explanation of abbreviations used

Mrs C	The Complainant
The Board	NHS Greater Glasgow and Clyde
Mr C	The complainant's husband (the aggrieved)
The Adviser	A medical adviser to the Ombudsman
Hospital 1	Victoria Infirmary, Glasgow
Consultant 1	A consultant at Victoria Infirmary, Glasgow
Hospital 2	Glasgow Royal Infirmary
Consultant 2	A clinical oncology consultant at Glasgow Royal Infirmary
Consultant 3	A medical oncology consultant at Glasgow Royal Infirmary
GMC	General Medical Council

Annex 2

Glossary of terms

Adenocarcinoma	A malignant tumour originating in the glands
Bronchoscopy	The visual inspection of the trachea and airways using a rigid or flexible scope through the nose or mouth
Mesothelioma (Compensations Scheme)	Cancer associated with exposure to asbestos The compensation scheme was established by Damages (Scotland) Act 1976 (subsequently ammended in March 2007)
Pleurodesis	A procedure to prevent recurrent fluid accumulation in the lungs
Thoracoscopy	The insertion of an instrument through the chest wall, with which the lining of the lung(pleura) can be visualised
VATS	Keyhole insertion of thorascope combined with biopsy

Annex 3

List of legislation and policies considered

Good Medical Practice, GMC November 2006

Good communication
22 To communicate effectively you must:
(a) listen to patients, ask for and respect their views about their health, and respond to their concerns and preferences
(b) share with patients, in a way they can understand, the information they want or need to know about their condition, its likely progression, and the treatment options available to them, including associated risks and uncertainties
(c) respond to patients' questions and keep them informed about the progress of their care
(d) make sure that patients are informed about how information is shared within teams and among those who will be providing their care.