Scottish Parliament Region: Highlands and Islands

Case 200700519: Highland NHS Board

Summary of Investigation

Category

Health: Renal Medicine; consent

Overview

The complainant (Mr C) raised a number of concerns about the care and treatment provided to his wife (Mrs C) in the weeks leading up to her death in June 2006.

Specific complaints and conclusions

The complaints which have been investigated are that Highland NHS Board (the Board) failed to:

(a) obtain properly informed consent for an operation (*upheld*);

(a) manage a 'Do Not Attempt Resuscitation' order properly (*upheld*); and

(b) provide reasonable care and treatment to Mrs C from 2004 onwards (*not upheld*).

Redress and recommendations

The Ombudsman recommends that the Board:

(i) undertake an audit of operative consent and reflect if further action is needed in light of the results of the audit; and

(ii) undertake an audit of the use of 'Do Not Attempt Resuscitation' orders and reflect if further action is needed in light of the results of the audit.

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

Main Investigation Report

Introduction

1. On 21 May 2007 the Ombudsman received a complaint from Mr C about the care and treatment of his late wife (Mrs C) primarily relating to the weeks before her death on 7 June 2006. Mr C had complained to Highland NHS Board (the Board) who had provided an external review of Mrs C's care. The external review identified some concerns but the medical staff within the Board did not accept all of these. Mr C remained concerned that a comprehensive review of his wife's care was needed to ascertain the truth and brought his complaint to this office.

1. The complaints from Mr C which I have investigated are that the Board failed to:

(a) obtain properly informed consent for an operation;
(b) manage a 'Do Not Attempt Resuscitation' (DNAR) order properly; and
(c) provide reasonable care and treatment to Mrs C from 2004 onwards.

2. Following my initial consideration of his complaint, I advised Mr C that I would not be formally investigating a number of the issues of concern which he raised, as the clinical advisers to the Ombudsman (the advisers) were satisfied that, based on their review of the clinical records and other complaint documentation, the overall care and treatment of Mrs C was reasonable. I provided Mr C with a detailed breakdown of the advisers' views on the matters not being investigated. I would note that Mr C does not agree with this overall conclusion. He considers that much of the care his wife received was good but that she had suffered from a number of misdiagnoses caused by a lack of investigation and differential diagnosis.

Investigation

3. Investigation of this complaint involved obtaining and reviewing Mrs C's clinical record relevant to the events of the complaint, as well as the Board's complaint file and all the papers supplied by Mr C. The Board's complaint file includes the report (the Report) of the independent reviewer (the Reviewer) asked to assess Mrs C's care by the Board. I have obtained the views of an internal renal specialist adviser to the Ombudsman (Adviser 1), an internal surgical (cardiac specialist) adviser to the Ombudsman (Adviser 2) and an external transplant surgeon adviser to the Ombudsman (Adviser 3).

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

Medical Background

5. Mrs C developed end stage chronic kidney failure in 1990 and had a kidney transplant in 1993. The transplant failed and Mrs C commenced peritoneal dialysis (PD) in late 1995. This continued until 2004 when Mrs C developed peritonitis associated with PD and was transferred to haemodialysis rather than PD. In October 2004 following an abdominal x-ray showing calcification of bowel loops, Mrs C was diagnosed as having sclerosing peritonitis which was causing colicky pain and vomiting. Mrs C was readmitted in June 2005 with similar symptoms and again on 25 April 2006. Mrs C was discharged the same day as the pain resolved itself but readmitted on 29 April 2006 with a recurrence of the pain and vomiting. She was discharged again the same day as nothing was noted on an abdominal x-ray but readmitted once more on 30 April 2006 with continuing pain and other symptoms. Following a CT scan it was suspected Mrs C was suffering from a closed loop bowel obstruction and it was decided to perform a laparotomy to investigate further and treat. The laparotomy revealed that Mrs C did not have closed loop bowel obstruction but had encapsulating sclerosing peritonitis. Small bowel resection was performed causing bowel perforation which was immediately treated. Mrs C's overall condition began to cause concern and on 14 May 2006 a suspicion of bowel leak was raised and antibiotics were commenced. This was confirmed on 16 May 2006. Mrs C continued to deteriorate with multiple problems, including management of her routine dialysis which was proving increasingly difficult to achieve. She was considered too ill to transfer to the Intensive Care Unit for ventilation. A DNAR notice was placed on her record on 29 May 2006. Mrs C's condition continued to change but without improvement and she died during dialysis on 7 June 2006.

(a) The Board failed to obtain properly informed consent for an operation

6. Adviser 2 told me that Mrs C had a pre-existing rare abdominal condition (sclerosing peritonitis) which was itself a recognised complication of previous treatment of PD for chronic renal failure. Adviser 2 noted that the Report from the Reviewer was critical of the surgical decision to operate, bearing in mind Mrs C's abdominal condition. The surgeon who made the decision to operate (the Surgeon) responded to this criticism by defending his decision, stating that

he felt operation was the best option on the balance of risks involved. Adviser 1 told me that in his view both the Reviewer and the Surgeon are correct. He noted that it was very likely that abdominal surgery in a patient with sclerosing peritonitis would be complicated by perforation of the bowel. The Surgeon, however, felt that the risk of surgery was justified as he felt there was a high chance that Mrs C had a fatal intestinal complication (closed loop obstruction) which could only be confirmed and treated by surgery. Adviser 1 was concerned, however, that the key issue was whether or not these different risks (that of not operating versus that of operating) were fully explained to Mrs C before she consented to the operation. Adviser 1 noted that it was clear from Mr C's statements that he did not consider that Mrs C had been advised of the risks of the operation and noted that there was very little information available in the clinical record to demonstrate that Mrs C had been advised on the issues.

7. The relevant standards for consent in Scotland pertinent at the time of the operation were those set out in the General Medical Council Booklet *'Seeking patients' consent: - the ethical considerations'* published in 1998. This contains the following advice 'You must use the patient's case notes and / or a consent form to detail the key elements of the discussion with the patient, including the nature of the information provided, specific requests by the patient, details of the scope of the consent given.' The Scottish Executive[1] *'Good practice guide on consent for health professionals in NHS Scotland'* was published on 16 June 2006, after Mrs C's operation. This guidance contains the following 'it is important that you and your patient both understand what has been agreed. It is also important to document within the patient's health record the information provided verbally and outcome'.

8. There is a signed consent form in the hospital case notes. There is no record of what information was relayed to Mrs C by the surgical team either in the case file or on the consent form. The Surgeon, who made the decision to operate, stated that in his judgement at that time, Mrs C's best interests were best served by laparotomy rather than continued conservative treatment.

9. Adviser 2 told me that he would expect there to be some record of what discussion had taken place with the patient in a difficult case such as this,

[1] On 3 September 2007 Scottish Ministers formally adopted the title Scottish Government to replace the term Scottish Executive. The latter term is used in this report as it applied at the time of the events to which the report relates.

where the decision was not taken lightly, but that he could not see evidence that informed consent was taken in this case. Clearly, the Surgeon was aware that there were risks to the surgery and felt that these were outweighed by the risks of continued conservative treatment, but there is no record that these points were relayed to Mrs C. Neither is there any evidence that she was then given the opportunity to decide which course of action was best for herself.

(a) Conclusion

10. The clinical advice I have received is that the decision by the Surgeon, that the laparotomy was in Mrs C's best interests, was a reasonable one in the circumstances and that the operation itself was carried out with reasonable skill. The difficulty that has arisen is in the apparent lack of information conveyed to Mrs C or Mr C about the benefits and risks of the operation itself. This lack of information has given rise to a considerable number of Mr C's concerns which understandably reflect in substantial part, his wife's concerns in the month before her death. There is adequate written evidence of consent being obtained but insufficient evidence of informed consent being obtained. For this reason, I uphold this aspect of the complaint.

(a) Recommendation

11. The Ombudsman notes with considerable regret the distress caused to Mrs C prior to her death and the prolonged distress caused to Mr C by the lack of information surrounding the decision to proceed with a laparotomy. The process for obtaining informed consent is adequate but in this instance, the practice did not follow the process. The Ombudsman, therefore, recommends that the Board undertake an audit of operative consent and reflect if further action is needed in light of the results of the audit.

(b) The Board failed to manage a DNAR order properly

12. There is a detailed entry in the case notes at 23:15 on 27 May 2006 by a junior doctor. This entry records the fact that Mr and Mrs C were told that Mrs C was likely to deteriorate and ultimately die. This same doctor completed a DNAR order which was filed at the front of the medical record. The form itself is incomplete with the sections marked for review timescales being unfilled. It was counter-signed by the consultant responsible for Mrs C's care (the Consultant) on 28 May 2006. Adviser 2 told me that there is no entry in the handwritten case file of the justification behind this DNAR order. The Consultant wrote in the case file on two separate occasions on 29 May 2006 but did not mention the DNAR order in either entry. The DNAR order was never reviewed prior to

Mrs C's death on 7 June 2006 although Adviser 2 noted that her clinical condition fluctuated over this time.

13. Adviser 2 did state that there is no evidence that Mrs C's treatment was materially affected by the DNAR order as she continued to receive very active treatment up until the time of her death. This treatment included parenteral nutrition, dialysis, antibiotic therapy (which was altered according to microbiology results post the DNAR order) and blood transfusion. Mrs C's blood pressure (BP) fluctuated on a daily basis. The first record in the clinical record that attempts to improve and / or treat her condition were fruitless was on the day of her death, when a renal consultant wrote that 'her BP is falling and … she is failing despite all our efforts'.

14. Adviser 2 told me that, in his opinion, the failure to record the decision making behind this DNAR order, the failure to record the communication with Mr and Mrs C over this issue and the failure to review the DNAR order, are all unreasonable and in contravention of the Guidance Notes typed on the back of the DNAR form used at that time, although the DNAR order and subsequent treatment itself were not unreasonable.

(b) Conclusion

15. I have reviewed the DNAR process of the Board in light of the guidance issued by the British Medical Association (most recent version October 2007) on *'Decisions relating to cardiopulmonary resuscitation'.* While the process accords with this guidance, once again it is practice that does not reflect the process. In so far as the DNAR form is incomplete and does not indicate an appropriate level of discussion or review, I uphold this aspect of the complaint.

16. Based on the clinical advice I have received I conclude that there was a failure to properly administer the DNAR process as the necessary paper work was not completed and the process for review was not followed. There is also insufficient evidence of discussions with Mr and Mrs C.

(b) Recommendation

17. The Ombudsman notes that again the process for obtaining a DNAR order is adequate but that once more, in this instance, the practice did not follow the process. The Ombudsman, therefore, recommends that the Board undertake an audit of the use of DNAR orders and reflect if further action is needed in light of the results of the audit.

(c) The Board failed to provide reasonable care and treatment to Mrs C from 2004 onwards

18. I advised Mr C that I would not be formally investigating and reporting on a number of the issues of concern which he raised as the advisers were satisfied that the overall care and treatment of Mrs C was reasonable. I provided Mr C with a detailed breakdown of the advisers' views on the matters not being investigated. Mr C remains unhappy with this decision as he considers that there were a number of actions which might have been taken to avoid Mrs C's untimely death.

19. The advisers did note that they were concerned about two specific issues in Mrs C's care and treatment beyond those raised in (a) and (b). The two issues of concern are the decision to remove three litres of fluid during dialysis on the day Mrs C died and the failure to give Mrs C prophylactic treatment with tamoxifen when sclerosing peritonitis was raised as an issue in 2004. The advisers noted though that these concerns were within the range of reasonable practice and that while they would wish to draw attention to them in this report they did not consider the actions concerned to be of sufficient concern to warrant upholding a complaint about Mrs C's care and treatment overall. The advisers also noted that both issues had previously been identified and raised by the Reviewer and that medical staff were already aware of the issues.

20. On the first issue, removal of fluid during dialysis, Adviser 1 felt that it would have been the more prudent course to remove less fluid and to remove fluid more conservatively in view of Mrs C's already unstable condition, but that he could not say it was unreasonable to do so but would wish his concern to be noted and considered in any future similar situation by other clinicians.

21. On the question of tamoxifen Adviser 1 noted that in 2004 there was already some evidence of the possible benefits of this drug in the treatment of sclerosing peritonitis and that by 2006 there was evidence of its prophylactic use being of possible benefit as a preventative measure for those with milder forms of disease. Again, Adviser 1 did not consider it was unreasonable not to have used this possible treatment but wished his concern that it may have been of benefit in this case to be noted for future considerations.

(c) Conclusion

22. Based on the views of the advisers I am satisfied that the care and treatment provided to Mrs C was reasonable and do not uphold this aspect of the complaint, but note the advisers' concerns about specific aspects of Mrs C's treatment.

(c) Recommendation

23. Based on this conclusion the Ombudsman has no recommendation to make.

24. The Board have accepted the recommendations and will act on them accordingly. The Board have advised me that a review of consent processes has already commenced and a detailed action plan is in place to address deficiencies identified with regular monitoring of this by Clinical Governance teams. The Board will also shortly be reviewing their consent policy in light of Informed Consent Guidance issued by the General Medical Council. The Clinical Effectiveness Department is also scoping a proposal for the audit of DNAR processes as contained in the Ombudsman's recommendations. The Ombudsman asks that the Board continue to notify her of progress towards the recommendations being implemented.

Annex 1

Explanation of abbreviations used

Mr C	The complainant
Mrs C	The wife of Mr C, the aggrieved
The Board	Highland NHS Board
DNAR	Do Not Attempt Resuscitation
The advisers	The clinical advisers to the Ombudsman
The Report	The report of the independent reviewer asked to assess Mrs C's care by the Board
The Reviewer	The independent reviewer asked to assess Mrs C's care by the Board
Adviser 1	An internal renal specialist adviser to the Ombudsman
Adviser 2	An internal surgical (cardiac specialist) adviser to the Ombudsman
Adviser 3	An external transplant surgeon adviser to the Ombudsman
PD	Peritoneal dialysis
The Surgeon	The surgeon who made the decision to operate
The Consultant	The consultant responsible for Mrs C's care during her final admission and who counter-signed the DNAR order

BP	Blood pressure

Annex 2

Glossary of terms

Parenteral nutrition	Feeding a person intravenously, bypassing the usual process of eating and digestion
Peritoneal dialysis (PD)	A treatment for kidney failure
Sclerosing peritonitis	Rare but serious complication of peritoneal dialysis
Tamoxifen	Hormone drug therapy