In the Matter of
Aaron Maxwell

A Resident of Rome Developmental Center

**A Report by the New York State
Commission on Quality of Care
for the Mentally Disabled
and
The Mental Hygiene
Medical Review Board**

CLARENCE J. SUNDRAM
CHAIRMAN

November, 1980

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COMMISSIONERS

PREFACE

This investigation into the circumstances surrounding the death of Aaron Maxwell*, a resident at Rome Developmental Center, was undertaken by the Commission and its panel of physicians, the Mental Hygiene Medical Review Board, as part of the Commission's and Board's ongoing responsibility to review all deaths of mentally disabled persons.

Findings, conclusions and recommendations set forth in the report represent the unanimous opinion of the members of the Commission and the Mental Hygiene Medical Review Board.

The contents of this report have been shared with the Commissioner of the State Office of Mental Retardation and Developmental Disabilities, the Associate Commissioner for the Northern County Service Group, the Director of Rome Developmental Center, and the Board of Visitors of the Developmental Center. Statements of actions taken by Rome Developmental Center and the Office of Mental Retardation and Developmental Disabilities, in response to Commission recommendations, have been incorporated into the report following each of the recommendations.

Clarence J. Sundram
Chairman

Mildred B. Shapiro
Commissioner

I. Joseph Harris
Commissioner

*A pseudonym for the name of the deceased

PURPOSE OF INVESTIGATION

To determine the circumstances surrounding the death of Aaron Maxwell* in order to assess the medical care afforded this client and whether such care was adequate and appropriate.

PRELIMINARY STATEMENT

Aaron Maxwell, a 57-year old, long-institutionalized client at Rome Developmental Center (RDC), died in early 1979 in the Rome Hospital. He had been transferred there two weeks prior to undergo surgery (bilateral vagotomy and hemigastrectomy -- cutting of the vagus nerve and removal of half of the stomach) for a gastric ulcer. The diagnosis of this ulcer stemmed from a three-month earlier GI Series (October 24, 1978) which suggested the possibility of an ulcer.

BACKGROUND

Mr. Maxwell, a severely retarded client had, over the years, exhibited episodes of depression, and low activity fluctuating with hyperactivity and euphoria. He was apparently noted to be in a depressed or withdrawn state in September 1978. Records also indicate he had experienced a gradual weight loss. On July 1, 1977, this 5'1" client weighed 115 pounds; by September 24, 1978, some 14 months later, he was down to 99 1/2 pounds.

Mr. Maxwell was given Ensure, a nutritional supplement, three times a day. He also was on a soft diet, with Presamine (for depression), Gelusil, Akineton and multivitamins. He exhibited no signs of anemia, hemorrhage or pain associated with food intake. He did, however, have a bladder infection in November 1978 for which he was treated with Septic tablets for ten days and then with Macrodantin for ten days.

According to the RDC Mortality Committee records, the weight loss prompted the ward physician to order a GI Series on October 4,

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* A pseudonym for the deceased.

1978, which showed: "suggestive evidences of a small sliding diaphragmatic hernia of the stomach." However, the distal portion of the stomach was not well shown and a repeat x-ray was suggested. On October 24, 1978, a repeat GI Series report noted: "suspicious evidences of a small irregular extrusion on the less curvative side of the gastric antrum, and this may well be representative of a gastric ulcer in this area. Suggest follow-up exam after 4-6 weeks of rigid medication therapy."

The unit physician ordered a surgical consultation on October 27, 1978, three days after the GI Series which noted there "may well be" an ulcer. On the RDC Surgical Consultation Request Form, the physician wrote the following: "weight loss, GI Series revealed gastric ulcer. Thank you." (emphasis supplied) When the consulting surgeon saw Mr. Maxwell on November 9, 1978, he dictated a note for inclusion on the consultation record.

> "...has been refusing his meals and medication. An upper GI Series last month revealed presence of a gastric ulcer lesser of the stomach. Since this patient has been refusing his meals and medications, conservative treatment would not be possible. A program of management which usually starts with gastroscopy with biopsy and a period of conservative treatment could not work in this patient because of lack of cooperation."

The consultant recommended "elective surgical repair as he was refusing conservative treatment."

The ward physician also requested a psychiatric consultation on November 17, 1978, due to the depression and decreased talking and appetite. However, the Chief of Psychiatric Services, responded on December 5, 1978 and noted that the Presamine Mr. Maxwell had been placed on was apparently working: "the staff reported that since then the patient has improved." He further noted Mr. Maxwell was "suffering with gastric ulcer" and said "it is the undersigned's opinion that before a surgical procedure, patient should be brought to a better physical condition with medical treatment of the ulcer."

Prior to his transfer to Rome Hospital for surgery, Mr. Maxwell was sent to the medical unit at RDC as a routine preparatory measure. At that time, five days before the surgery, a physician on the medical unit recorded that Mr. Maxwell was "in his usual state of health" and questioned the risk of general anesthesia. Nurses' notes in the days prior to his January 8, 1979 transfer to Rome Hospital for surgery indicate his appetite was good, no complaints of discomfort and that Ensure was taken well. Notes and interviews concerning this period indicate that the possibility of a perforation of the ulcer in this client appeared to warrant taking the surgical risk.

On January 9, 1979, Mr. Maxwell underwent a bilateral vagotomy and hemigastrectomy. The Rome Hospital admission note, written by the surgeon, noted progressive weight loss since September 1978.

Mr. Maxwell did well for several days following surgery, but soon developed a small bowel obstruction and a dehiscence (opening at the lower end of the incision). He was returned to surgery where the obstruction was released. Postoperatively he developed respiratory distress and x-ray indicated aspiration pneumonia. Several days later, he developed septicemic shock and bilateral pneumonitis and died. Cause of death was listed as acute peritonitis, secondary to posterior abscess, post surgery one day.

Both the operative pathological reports and the subsequent autopsy report failed to substantiate any ulcer in this client.

FINDINGS

(1) THE RECORDS FAIL TO DOCUMENT THE DEFINITIVE DIAGNOSIS OF A GASTRIC ULCER AND THE SUBSEQUENT NEED FOR THE SURGERY WHICH WAS PERFORMED.

(a) The October 24, 1978 GI Series only indicated a possibility of an ulcer, but did not confirm this diagnosis.

However, notations by physicians in the client's records refer to the ulcer as a definite finding, thus transforming a diagnostic possibility into a pathologic certainty.

(b) The consulting surgeon who recommended surgery on November 11, 1978 rested his recommendation upon three findings:

(i) A positive x-ray -- which was never obtained.

(ii) That the patient had been refusing meals and medication, concluding that he would be uncooperative to medical treatment, thus warranting surgery. The patient's records indicate little substantiation of any frequent or persistent uncooperativeness by Mr. Maxwell. His medications were most often recorded as being taken; his recent appetite was usually recorded as good and there was no indication he was a severe behavior or management problem.

(iii) That a program of management which usually starts with gastroscopy with biopsy and a period of conservative treatment could not work in this patient because of a presumption by the surgeon that there would be lack of cooperation.

Gastrectomies are performed in recent years most often for cancer or, in the case of ulcers, for those patients who exhibit severe gastric bleeding or hemorrhage, and/or have intractable pain for which intensive medical invention has been unsuccessful. Mr. Maxwell did not exhibit any such symptomatology. When interviewed, physicians at RDC stated that the decision to do surgery rests solely with the surgeon and the unit physician stated he had no discussion about the case with the surgeon.

The autopsy and pathology reports did not confirm the presence of a gastric ulcer in this patient.

(2) THERE WAS NO ATTEMPT AT CONSERVATIVE MEDICAL TREATMENT OR USUAL DIAGNOSTIC PROCEDURES. SURGERY WAS PERFORMED WITHOUT A STANDARD DIAGNOSTIC WORKUP OF GASTROSCOPY DUE TO THE SURGEON'S STATED OPINION THAT THE PATIENT WOULD NOT BE COOPERATIVE.

Conservative medical treatment was simply not attempted. It appears that occasional uncooperativeness in this man, who exhibited cyclic depression in the past, was not addressed as possibly a manifestation of some psychotic or depressive process.

(3) THE NOTATIONS ON THE CONSULTATION SHEET, WHICH OFTEN SERVES AS THE PRIMARY INFORMATIONAL TOOL FOR CONSULTANTS, WERE BRIEF AND INCORRECT.

According to RDC Administrators, a client, when referred to the consultant, is often accompanied to the appropriate clinic by an escort therapy aide who has little or no knowledge of the client's day-to-day functioning. Available records accompanying the client are either not read by the consultant or they are incomplete. In this case, the consultation sheet stated the ulcer as a fact rather than a possibility.

(4) THE PSYCHIATRIST AT RDC DOCUMENTED HIS OPPOSITION TO SURGERY ON NOVEMBER 17, 1978, BUT THIS WAS NEVER ADDRESSED BY THE MEDICAL STAFF IN THE RECORD.

The psychiatrist further stated that Mr. Maxwell's depression was lessening, but already-made plans for surgery were not reevaluated despite this documentation. Medical specialists state they leave the psychiatric care to the psychiatrists, and medical care to the medical and surgical specialists. The unit physician appropriately referred Mr. Maxwell for two specialty consultations: surgical and psychiatric, but there is no indication that the psychiatric evaluation findings were transmitted to the surgeon, or that planned surgery was reevaluated in light of the psychiatrist's report.

(5) POST-SURGICAL COMPLICATIONS ULTIMATELY LED TO THE PATIENT'S DEATH.

Mr. Maxwell developed a small bowel obstruction and dehiscence after surgery. These complications led to a need for further surgery which ultimately led to peritonitis, pneumonitis, aspiration pneumonia and his death.

CONCLUSIONS

There was an inadequate basis for concluding that Mr. Maxwell had a gastric ulcer and that surgery was indicated. The reading of the patient record from a "possibility" to a definitive diagnosis of ulcer poses questions of professional judgment and communication in this case.

Standard diagnostic procedures, e.g. gastroscopy, should have been performed prior to surgery. The fact that a client is mentally retarded should not effect usual procedures or medical intervention.

The ward physician failed to reconcile conflicting recommendations by bringing the physicians together and the physicians did not communicate with each other. Each physician proceeded independently of the others and, once the decision was made for surgery, there was no reevaluation or consideration given to input from other physicians.

The decision to perform surgery was made over two months prior to surgery, and the patient or his need for the surgery was never reevaluated just prior to the procedure.

RECOMMENDATIONS

(1) RDC physicians should meet with the consulting surgeon in any case involving elective surgery. Such a meeting should document that there has been input from the RDC physicians concerning the

special needs of MR/DD clients. It should also substantiate agreement by the medical specialists as to the need for surgery.

(In response to the Commission recommendation, the Commissioner of the State Office of Mental Retardation and Developmental Disabilities indicates that Rome Developmental Center has instituted revised procedures on elective surgery to include special meetings, reviews and documentation. In addition, the Commissioner stated the Office of Mental Retardation and Developmental Disabilities has reviewed and is currently revising their overall policy on elective surgery. The Commission will review these revisions when they are completed.)

(2) In cases where the client is also being treated by a psychiatrist for some disturbance or psychosis, the psychiatrist also should be a part of the meeting prior to any elective surgery. The impact of a mental condition on physical symptomatology should not be overlooked due to professional jurisdictional disputes.

(In response to this Commission recommendation, the newly revised procedures on elective surgery at Rome Developmental Center contain provision for a special meeting, convened by the chief of the medical clinic one week prior to the scheduled surgery, of <u>all</u> facility physicians involved in the case.)

(3) In cases of elective surgery, a second surgical opinion should be sought.

(In response to this recommendation, the director of Rome Developmental Center indicates that the newly revised procedures at Rome on elective surgery include a provision that such second surgical opinions be rendered by the chief of the medical clinic.)

(4) RDC physicians should be aware of their responsibility to act as professional advocates for clients, assuring clients of their right to prevailing medical practice.

(5) Recommendations by outside consultants should be based upon a thorough review of appropriate records and an assessment of the patient beyond that of a single visit.

(6) Surgery recommended by an outside consultant should be done in a timely manner. If a significant period of time elapses before the surgery is actually performed, the need for such surgery should be reassessed.