

*Case report*

# When the patient says “no”

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## Case report

This is a report about S.K., a woman who suffered from cancer during the last 8 years of her life, but continued to exercise her free will, and to participate actively in her medical management until she died. This was only possible through an empowering and transparent patient–doctor relationship.

Doctors and patients are often faced with the dilemma of undergoing management options which are medically indicated, but do not fit the patient’s lifestyle or goals. The doctors’ duty is to furnish all available options, but more importantly to respect the patient’s choices, including how they want to die.

S.K. was a 55-year-old woman who presented in November 1999 with clinical evidence of mechanical intestinal obstruction which had insidiously progressed from partial to complete. She had a previous history of left radical nephrectomy with left adrenalectomy 1.5 years prior to hospitalization, followed by radiation therapy to the kidney area as treatment for hypernephroma.

Besides having proximal bowel obstruction, she was found to have a large, 8 cm diameter right adrenal tumour. No evidence of any other tumour deposits was found. I explained to her and her family the situation, the advantages and risks of the operation and the possible complications. She consented to the surgical intervention. I operated on her with the preoperative di-

agnosis of complete proximal small bowel obstruction and right adrenal tumour. I performed exploratory coeliotomy, lysis of adhesions, side-to-side enteroenterostomy bypassing the grossly abnormal irradiated bowel, and right adrenalectomy.

During the first week postoperatively, the patient continued to produce large amounts of gastrointestinal fluid through the nasogastric tube and continued to vomit. I explained the situation to her and her family. The family had a number of inquiries and worries. She overruled them, and said to me, “Do what you think is appropriate.”

She was re-explored, found to have an obstruction at the anastomosis site, and stenosis of the whole segment of the bowel used for the anastomosis. Therefore, resection of the entire grossly abnormal small bowel was performed with duodeno–jejunal anastomosis in the 4th portion of the duodenum. This time, the postoperative course was smooth. S.K. was discharged in the second postoperative week with oral corticosteroids replacement. She was followed up in the general surgery clinic until her wounds healed and she had normal gastrointestinal function. Then she was discharged, to be followed up in the endocrinology and the medical oncology clinics.

During the following few years, S.K. agreed to continue corticosteroid hormone replacement only after it was explained to her that her body does not produce this hormone any more because we had removed the glands that secrete it. Moreover, I em-

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phasized the importance of the medication in order to continue living and functioning as close to normal as possible. The patient agreed only on condition that I was present with her whenever she saw the endocrinologist, and for me to approve the therapy.

The same scenario developed with adjuvant cancer therapy, but her decision then was not to undergo any further treatment. She continued to demand follow-up from me on various issues, sometimes by personal visits and other times by phone or through a member of her family.

Four years later S.K. presented with a painful lump in the right clavicle, which clinically was highly suspicious of a tumour deposit. A battery of tests was performed and she was found to have metastases in various organs in her body, but none in the brain.

She was informed of this and of the predicted natural history of her disease to the best of my knowledge at that time. She elected only to undergo brief symptomatic treatment by radiotherapy to the painful clavicle and nothing else.

After this, I moved to another medical institution.

S.K. continued to live an independent functional life as a homemaker. When her bone pain escalated, she resorted to opiates and non-steroidal anti-inflammatory medications to control the pain, and continued functioning as an independent human being. I learnt later that she had sustained a pathological fracture of the right humerus but refused to have any form of treatment. This was shortly before she became bedridden.

In the final 2 weeks of her life, S.K. asked to see me 3 times and the only thing I was able to offer was moral support for her and her family. She wanted to be respected [1] while dying the same way she was respected while living. For her this meant "no" to any further medical intervention. On

the last day of her life, in April 2007, despite her clouded consciousness, she knew my full name, and knew what I was doing at her bedside. S.K.'s wish was granted. She was allowed to die in her bed, among her family, 2 hours after I had visited her, respected.

## Discussion

In the midst of the numerous discussions and deliberations about human rights, patients' rights, quality improvement, evidence based medicine, medico-legal litigation and patient-focused medical management, a crucial issue often appears to be overlooked: the patient-doctor bond.

The patient's basic human right to consent to medical intervention was put on paper when it was established as case law in the United States of America in 1957 [2]. Thereafter, the issues of written consent, emergency consent, implied consent and refusal to consent arose. As it is the patient's right to know their disease and treatment options, it is their duty and their right to give consent or to refuse consent. On the other hand, as it is the duty of the health care provider to explain the disease to the patient as best as possible, it is their right and their duty to get consent or refusal to consent. The consenting process is not a paper to sign, in fact, it is a cooperative process, which is only fulfilled, when the patient-doctor bond is acknowledged, and strengthened.

It may be said that cancer patients seldom choose a treatment. Instead, they choose a physician and then rely entirely on their chosen physician's advice. Most cancer patients are so emotionally upset by the discovery that they have cancer, or that a previously treated cancer has recurred and requires further therapy, that they are incapable of making objective and rational

decisions. Family members or friends are not much help in this regard, either, since they are also emotionally involved [3].

S.K. did the opposite. She fully assumed her role as a patient, and fully claimed and received her rights as a human being. She was illiterate, non-academic unsophisticated, and “oncologist-naive” [4], according to the modern concept of these terms. But she knew exactly what she wanted.

Her power over herself, including her body, and in receiving what she wanted from the medical services was guaranteed by respecting her wishes [5], her informed decisions, and her ethical standards. The patient–doctor bond that was strengthened from both sides over the years proved its merits.

The London declaration of patients for patients’ safety only emphasizes what patients already know [6]. We as doctors sometimes think that we know more than

our patients do. This is true concerning medical details, but definitely not as far as fitting therapy to the individual patient’s life, family and lifestyle [7].

The law may limit the freedom of doctors in medical management [8]. An empowered patient–doctor bond liberates doctors as well as patients. Understanding this bond and the fact that death is not an event but a process, may alleviate the pressure on patients and doctors, strengthen patient autonomy [9] and decision-making, limit litigation and diffuse out the whole idea of physician-assisted suicide [10, 11].

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