The illness of withholding information

At the time of consultation for a pelvic mass, the family of S.Y. asks the gynecological surgeon to withhold the diagnosis from S.Y. if she proves to have cancer. S.Y. is a 46-year-old woman from a very traditional family, as is her surgeon. Their families share a long-held belief that if a patient is diagnosed with a terminal illness, the doctor should inform the family members but not the patient herself, as a kindness to the patient. The surgeon listens to S.Y.’s family’s request and responds, “Let’s wait and see how the surgery goes first.”

Surgery reveals that S.Y. has stage II epithelial ovarian cancer. The surgeon informs her family of the diagnosis and of the need for further treatment. The family repeats their request to withhold the information from S.Y. Thus, the doctor informs S.Y. that the surgery has gone well but that further treatment will be required to prevent recurrence of the mass. S.Y. asks no further questions. Her doctor prescribes oral chemotherapy, which he refers to as “medication” and which her family calls “health supplements.”

Soon, severe medication-related nausea and vomiting limits S.Y.’s ability to conduct her daily duties for several days following each administration. S.Y. refuses to continue taking the drugs. In response to incessant pressure from family members to “take her health supplements,” she moves to another small town, where she dies of cancer within 8 months.

Questions for discussion

1. What are the medical issues in this case? Specifically:
   a. What is the appropriate treatment for stage II ovarian cancer?
   b. What are the health consequences of the interruption of postoperative chemotherapy for stage II ovarian cancer?

2. Using the Integrating Human Rights and Health Checklist, identify the human rights that were infringed in this case.

3. What are the health consequences of failing to fully inform the patient of her condition and treatment?

4. What hospital policies and laws in your state/province/country protect patients’ rights to health information?

5. How would you respond to the strong cultural pressures to comply with the family’s wishes and meet the ethical obligation to support the patient’s right to information about her diagnosis, prognosis, and treatment?

6. What measures need to be put in place to avoid similar situations occurring in the future?