Practicing Western Oncology in Shanghai, China: One Group's Experience

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In October 2011, we—David H. Garfield, MD, medical oncologist, United States; Harold Jacob Brenner, MD, FRCR, radiation oncologist, Israel; and Lucy Lu, oncology nurse, Shanghai, China—were part of a group that opened the first of planned multiple outpatient cancer centers in China, offering radiation therapy, chemotherapy, and imaging, including magnetic resonance imaging (MRI), computed tomography (CT), ultrasound, and mammography. Although we had previously researched oncology in China, we were still in for a great many surprises.

The Chinese and Their Doctors

Mainland Chinese attitudes are different from what we are accustomed to in the West. There is a lack of trust between patients/families and physicians, related in part to there being few urban general practitioners, resulting in no long-standing, physician-patient relationships. There is a feeling that care is being provided for personal gain, much more so than in the West. When individuals are ill, or think they may be, they go directly to hospitals, including traditional Chinese medicine hospitals, rather seeing a non–hospital-based practitioner. Care is received almost entirely in hospital; this is the main way physician-patient relationships develop.

If patients receive chemotherapy once per week, or radiation therapy 5 days per week, patients happily remain in hospital full time, which is especially appealing when they are bedded on VIP floors or during monsoon seasons. This may last longer than 1 month, during which time they are housed and fed.

Chinese Oncology

As an example of unintended consequences, the government has made it inexpensive to see physicians. This has led to a general complaint about medical care in Shanghai: the limited time physicians spend per patient. We know an excellent surgical specialist who sees up 40 patients within 2 hours, meaning approximately 3 minutes are spent with each, at a cost of approximately $40 per patient. For $3.50 each, 80 to 100 patients are seen during 4 hours by that same physician on another day. During those few minutes, rarely is a physical examination performed. Several questions are asked and answered, with a brief look at images and laboratory tests, tumor markers, and so on; that is it.

Lucy Lu: A woman with estrogen receptor–positive breast cancer, whose mother died as a result of breast cancer and possible treatment-related heart disease, stopped taking tamoxifen after 2 weeks for fear of the adverse effects about which she had read. Our Western oncologist convinced her, after much discussion, to continue tamoxifen by telling her the most important thing was to be alive for her 4-year-old daughter. She called back later and said she really appreciated what we did for her because her Chinese physician had just given her the pills, not caring whether she risked her life by not taking them.

Drs Brenner and Garfield provide physical examinations at nearly every patient visit. They get medical information and communicate with the patient. For example, a woman who underwent surgery for breast cancer had, unknown to her surgeons, recent hyperthyroidism, noted only by Dr Garfield, who felt this could have made the cancer grow faster.

Patients, Physicians, and the Party

Chinese patients, thinking they have or are diagnosed with cancer, will demand that certain tests be performed. Physicians, rather than argue necessity, will acquiesce instead of having these patients complain to hospital administrators, when they must then defend their case. In this regard, it must be pointed out that hospitals have two administrators: first, a conventional one, as in the West, and second, a Communist party member. A physician must take care. A bad outcome is felt to put physicians, particularly surgeons, at risk for administrative admonishment, lawsuits, or, worse, bodily harm.

Lucy Lu: Chinese physicians order many kinds of blood tests for patients, often treating numbers instead of diseases. The increase or decrease of tumor markers frustrates both physicians and patients. Our Western oncologists, however, pay more attention to how the patient feels, physical examination, and/or imaging, instead of tumor makers.

Respect for Lives

Lucy Lu: Our Western physicians take difficult cases as challenges, whereas Chinese physicians first assess risk to themselves and hesitate in helping patients. We saw a 55-year-old patient with lung cancer who was refused treatment for severe hemoptysis by radiation physicians at another hospital because, they said, the bleeding was too severe. However, in reality, they did not want to take responsibility for a bad outcome. After seeing the patient, we had no hesitation in starting radiation therapy immediately and on a Saturday. The Chinese physicians would not let him leave their ward until the family provided written consent, saying that the hospital was not responsible if the pa-

tient died on the way to our center. Two days later, after bleeding was controlled, his hospital demanded that it take over radiation. This is not unique. There was an patient with advanced lung cancer whom we suspected had appendicitis but who soon died because the Chinese surgeon would not operate on him for fear of a bad outcome.

Consultations Versus Opinions

Patients will invariably seek opinions from a number of physicians, often leading to patient/family confusion. The patient or family thus become the physician. The advice of friends, friends of friends, or physician friends, none of whom have much knowledge of the case, commonly is more trusted and more often heeded than that of the formally consulted physicians. Indeed, having a physician for a friend is considered wise. After receiving so many opinions and then ours, we are then asked to compare and contrast ours with the others.

Studies and Tests

Commonly, only the families arrive seeking consultation, bringing records, including, in their opinion, the important tumor markers, along with CT, positron emission tomography (PET)/CT, and MRI results. Under their social security, the PET/CT scans are relatively costly, at $1,200; however, if patients want and can afford them, physicians will order them, warranted or not. Then follow long discussions with patients and families concerning which findings are or are not significant.

Lucy Lu: Patients are overtested before they come to us for consultation, bringing CT, MRI, and PET/CT scans, often demanded by patients of their local physicians. Rarely does a chest evaluation start with a simple x-ray. Our Western oncologists told me we should take an x-ray first and only later resort to CT, MRI, and so on. So Chinese physicians are losing their physical examination abilities by relying more and more on scanning machines. They feel they cannot make a diagnosis without them.

Disclosure

There is a lack of full disclosure. During the initial history taking, important facts are deliberately left out. For example, patients may be receiving concurrent chemotherapy or may have had recent PET/CT scans, but they might not tell us, perhaps from lack of trust or fear of offending their Chinese cotherapists or because, in the past, disclosing too much may have led to trouble.

Patients are often felt by their families to be unaware of the diagnosis or prognosis, and we are warned not to disclose them, although most seem to know already. Patients themselves rarely ask for a prognosis, although family members will do so.

Hospitals are reluctant to have patients die on their premises. Lack of hospices for dying patients is problem. Patients who do die in hospital are removed from the ward in closed metal cylinders.

Treatment: Who Pays and How Much?

In our center, a private enterprise, with radiation therapy, chemotherapy, and imaging capabilities on site, costs and charges are higher than in public hospitals. Initially surprising, in the spirit of the new Chinese free-enterprise system, everything is negotiable, even the complete blood count price. It is now our policy that patients must pay before each visit and procedure, including daily radiation treatments. Otherwise, if patients become unhappy, they will simply not pay and walk out, never to return. It is not at all unusual that after a lengthy discussion concerning therapy, be it chemotherapy or irradiation, patients will not arrive for the initial therapy appointment. When we inquire, we are told that the patient is tired and will reschedule. What that really means is that the patient does not plan to return. Never are we told directly why. They just do not reappear.

Patients have stopped radiotherapy before completion because they feel better, and chemotherapy can be and is administered by any physician, most often by surgeons, for the financial rewards. Thus, some of our treatments have been stopped midstream.

Lucy Lu: Dr Garfield says that a treatment guideline is only a guideline, not a rule or law. Our Western oncologists use guidelines as references when making regimen decisions, whereas Chinese physicians usually do not even look at guidelines.

Another difference is the use of dexamethasone for reducing edema around a spinal cord or brain lesion. In the West, dexamethasone has been used for many years, but in China, the drug of choice is mannitol, used sometimes even on a daily basis, for fear of the reported adverse effects of dexamethasone. Also, use of adriamycin seems limited in patients with lymphoma, presumably because of excess fear of heart damage.

The difference in criteria for transfusions between our Western oncologists and Chinese physicians is clear. The Chinese physicians cannot give blood unless a patient's hemoglobin is < 6.0 g, no matter the patient's age or symptoms.

Many otherwise simple outpatient procedures performed by Western physicians are made complicated in China. We had a patient with ovarian cancer with severe ascites, so much so that she could not lie down and had trouble eating. Because of our clinic limitations at that time, we tried sending her to local hospitals, but all refused, citing the dangers of infection, leakage, and shock. Finally, we performed drainage with her as a hospital outpatient; she slept well, ate well, and continued her life without the complications about which Chinese physicians worried, to their surprise. We are not sure they had ever performed a paracentesis.

Another difference of treatment differences is concurrent chemotherapy and radiation therapy for locally advanced lung cancer in China, even though it is being done in many other East Asian countries. We are told that Chinese patients cannot tolerate it. Again, their main concern is adverse effects, even though it is provides a survival advantage. In part, this is because in China, one radiation machine will treat as many as 200

patients per day, so technicians do not have time for quality control or communication with chemotherapists.

Communication and Translation

Although our nurses are fluent in English, they cannot always accurately translate what patients or families say. Thus, we hear nurses' interpretations. Patients/families and nurses frequently have long conversations, which are then translated as "the patient says okay" or "yes" or "no." Physician-patient conversations are difficult to limit, control, and direct, as in the West. However, our Western expatriot patients here are compliant, trusting, and fully open to our therapeutic suggestions.

Lucy Lu: Usually, foreign physicians cooperate with one another when treating the same patient. Chemotherapists share information with radiotherapists. However, in Shanghai, physicians hesitate to cooperate. They feel threatened and offended when their patients' other physicians check with them about treatments or test details.

Diagnosis

We have seen patients whose chests CTs suggest only lung cancer. Rather than confirming the diagnosis, they ask us, because we are the so-called experts, if it is cancer and, if so, can they not just have one of the "knives" (see below).

Lucy Lu: Our two Western oncologists almost always demand that patients have a biopsy before they give treatment advice or administer therapy. They almost never treat patients without a definite diagnosis. However, we have seen many Chinese patients who have been treated without biopsy confirmation.

A recent patient coughed for 2 weeks, and chest CT showed a lung shadow. Two bronchoscopies were negative. After 2 weeks of antibiotics, the lesion got smaller. Even so, he then underwent gamma knife treatment. Physicians in another hospital later tried to determine the diagnosis by endobronchial ultrasound but failed after the gamma knife treatment. So the diagnosis remains unknown.

"Who's in Charge Here?"

There is no culture of "the captain of the ship." Thus, we cannot control what other treatments patients are simultaneously receiving. One patient presented with metastatic retro-orbital maxillary adenoid cystic carcinoma, with proptosis and vision loss. After our targeted therapy, there was resolution of signs and symptoms and MRI improvement, and she spoke of a so-called miracle. Nine months later, during another illness, she stopped our therapy. She returned to the clinic 3 months later with the original problems. When asked why she had stopped, she had no answer. Additionally, for other intracranial lesions, she was being treated by cyberknife, a heavily advertised treatment, costly and not covered by national insurance. When asked which lesions were treated, she was reluctant to ask because she felt that the physician might be offended. When patients have received prior conventional radiation therapy, they are reluctant to obtain their records, and requests to the offices that provided it are usually not honored, although they are never directly denied.

Patient Cases We Are Seeing

The patient drawing area for Shanghai includes approximately 200 million people, with many patients coming to Shanghai with complicated cases of cancer. If not satisfied with Shanghai tertiary hospitals, they seek our opinion. These cases are often rare, difficult, complicated, and heavily pretreated. Additionally, even patients with common cancers present in uncommon ways. Thus, we spend time on PubMed, looking at reviews, case reports, or National Comprehensive Cancer Network guidelines. Some patients have synchronous, seemingly unrelated cancers, such as renal cell and breast cancers. This phenomenon, although rare in the West, must always be considered here, rather than assuming that one lesion is a metastasis from another. Chinese physicians, however, invariably assume this situation to represent one cancer, largely because of lack of general oncology training. Thus, some patients with two curable cancers are managed as having one incurable, metastatic cancer.

Chinese Oncologists

There are approximately 8,000 registered Chinese medical oncologists, but we have yet to meet a general medical oncologist. This means that when a problem arises outside of their subspecialty, such as breast or lung cancer, they are unprepared. Those with specialties in radiation, medical, and surgical oncology invariably see one another as competitors rather than peers. Who treats a patient with cancer depends on which specialist sees the patient first. Surgeons and radiation oncologists administer chemotherapy. Pulmonologists and medical oncologists do not consider local therapy often enough. Patients with superior vena cava obstruction, brain or spinal cord metastases, and impending pathologic fractions merely have their chemotherapy regimens changed. Patients with metastatic or stage IV breast cancer are treated with two- and three-drug combinations as if they had early-stage disease, with little consideration given to antiestrogen therapy. Additionally, all too often, pathology or imaging reports are only read, without subsequent discussion with the pathologists or radiologists. The understanding and use of general oncologic concepts seem to be absent.

Lucy Lu: Oncology is a complicated subject, so an oncologist should be a general physician as well. I feel that a patient with cancer should be considered as a human being instead of several body parts. But nowadays in Shanghai, local hospitals are separated into different departments that treat only one kind of disease. Physicians just treat their special diseases but do not know what to do when a patient's condition gets complicated.

Patient Confidentiality and Privacy

Patient confidentiality and privacy seem nonexistent. Indeed, when speaking with one patient, another patient or family will listen in, interrupt, comment, and even disagree. In one large

hospital outpatient clinic we attend, in addition to medical staff, the room contains three groups: a patient, never alone, waiting to be seen; another group being seen; and a third group previously seen. In addition, there also may be a representative from the next group, peeking in to see how things are moving. The commotion is indescribable.

Treatment Quality Control and Drug Costs and Availability

One issue is the quality of radiation therapy and anticancer drugs. Patients will usually buy the least expensive drugs (eg, capecitabine), but the quality of drugs produced in China or India is questionable, and there seems to be little quality assurance. Anticancer drugs, even for patients treated in public hospitals, are costly. Thus, many of the new monoclonal antibodies and tyrosine kinase inhibitors, although available, are out of reach for all but the wealthy. Other agents, including lapatinib, amrubicin, eribulin, and everolimus, can only be obtained from nearby countries or Hong Kong. Radiation therapy quality control, with machines in use from early morning until late evening treating 100 to 140 patients daily, is poor if attempted at all.

Compliance and Trust

Because there is little trust of physicians, when our therapy proves ineffective, patients, rather than reporting this, will transfer to another facility, not knowing or even caring that we could try a different therapy. It is thought we have failed and thus cannot be trusted with another attempt at disease control. Most patients we see have far-advanced and heavily pretreated cancers. Thus, our chance of finding an initial effective salvage regimen is not high.

Discussion

In conclusion, this has been a challenging experience for us. It was not possible to anticipate beforehand what to expect or how to manage what we were about to experience, except by trial and error. It can be done, although likely never efficiently. Respect for and knowledge of Chinese culture and an attempt, as difficult at that may be, not to be judgmental are required. Patience, which the Chinese have in abundance, is also needed, as is an awareness of the importance placed on so-called "face." We feel that we have introduced a different cancer care viewpoint and have, with satisfaction, seen even our Chinese colleagues change their approach to this all-too-common disease.

Lucy Lu: Shanghai is a city of 24 million people. With the opening up of government policies, new medical technologies and fantastic scanning machines have come here as wonderful gifts from advanced science and technology. However, we are attempting to serve a huge population with limited resources, and the system to protect Chinese physicians remains a big issue. If there are bad results, the physicians are guilty unless they can prove themselves to be right. The speed of advancement of the whole country is so fast that we may have missed something that is important, and we need to think about it. We need to learn more from the West than just importing these fabulous machines.

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