Some Personal Reflections on Comprehensiveness of Care

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During the past several months I have had occasion to personally encounter the health care system as a patient. This experience has led to some reflections on comprehensiveness of care that may be of general interest. After discovery of a testicular mass on self-examination last summer, I immediately became a "cancer patient," and the next four months were filled with four hospitalizations for two surgical procedures and two cycles of chemotherapy with cisplatinum, vinblastine, and bleomycin.

All of my care was rendered in a first-line university medical center where, when viewed from a tertiary care standpoint, the quality of medical and nursing care is excellent. My particular cancer, embryonal carcinoma, remains a rare one, representing only 1 in 800 of all male cancers. Nevertheless, the urologist was fully familiar with the detailed alternatives of surgical care, and the medical oncologist was well versed in the experience around the country with various chemotherapy regimens for this tumor. He was and still is even participating directly in one of the few centers involved with a prospective study of the currently preferred and very effective Einhorn regimen.

My hospital care was on traditional surgical and medical teaching services. As a physician, however, I no doubt served as my own advocate in certain instances and also had the advantages of the advice of visting family physician colleagues.

My subspecialist care was expert and concerned in all details of surgical and drug therapy, but despite this excellence of care, some major problems arose in total patient managment that required a broader yet specific approach.

Three examples involving the comparatively mundane yet important items of sleep, exercise, and diet will serve to make this point. Cisplatinum is given as an intravenous infusion preceded by saline hydration and an antiemetic "cocktail," including large amounts of dexamethasone, and followed by mannitol. The entire infusion lasts at least ten hours each day and is usually administered at night, thereby preventing all but two or three hours of sleep as well as disturbing the sleep rhythm. As a result of this treatment, disturbed sleep patterns continued after discharge. After two weeks of sleep deprivation with less than three hours of sleep per night, despite the use of various sedatives, a fresh approach was required. A brief talk with a member of the Psychiatric Liaison Service led to the use of doxepin (Sinequan), which promptly re-established nocturnal sleep patterns. A search of the literature revealed that 100 mg of dexamethasone in just five days does in fact suppress adrenal function and, further, that sleep deprivation per se also decreases adrenal cortical secretions. The second cycle of chemotherapy, therefore, went much better because of two changes in the "standard" hospital chemotherapy protocol—daytime infusions of cisplatinum and tapered corticosteroids for the first two weeks after discharge.

With regard to activity level after chemotherapy, the only advice given was, "Do what you feel like." After the first chemotherapy admission, fatigue and myalgia were prostrating for a full three weeks. By then it was difficult to know how much of the fatigue was due to prolonged bed rest and could have been prevented by an active exercise program. Yet the only physician of the many involved who recommended a specific program for active exercise was a family physician colleague with a special interest in sports medicine. As soon as such a program, involving isometric and stretching exercises of specific muscle groups and daily walking to tolerance, was started, my general improvement accelerated promptly.

Concerning diet, all chemotherapy patients lose

appetite and weight as well as change their usual taste patterns. Yet no specific advice was offered on diet, and another family physician colleague fortunately put me in touch with a dietitian and a specific cookbook designed for patients on chemotherapy.

These examples simply make the point that much excellent *general* medical care is often left to chance and is not addressed, despite its importance in patient care. After two weeks of sleep deprivation, disordered sleep was my principal medical problem, yet this is often of little interest to physicians. The average patient, of course, is not a physician, is totally vulnerable to these problems, and thus requires an available and knowledgeable advocate in traversing the system.

Family practice has much to offer in this regard. The family physician knows the patient and his or her family better than any of the consulting physicians. He can and should be expert in *all* areas of general medical care, particularly those areas usually de-emphasized in the secondary and tertiary care system. One need not have a special interest in sports medicine, for example, to be able and willing to provide an individualized exercise program for all patients encountering major illness and bed rest. Through daily rounds, clinical problem solving, care of concurrent medical problems, and brief contacts with other health professionals as needed, the family physician can actively serve the patient's needs even when under the direct care of subspecialists for unusual medical or surgical problems.

My own recent experience is not unique; surely it is repeated many thousands of times each day across the country, usually aggravated for the average patient not familiar with the health care system. It may be tempting for many family physicians to assume that good general medical care will be provided for their patients with unusual problems referred to excellent consultants. This assumption cannot be made. Team care by family physicians and their consultants before, during, and after hospitalizations for major illnesses should be the rule, not the exception or haphazard occurrence.