Caring for Colleagues

RICHARD T. PENSON, MICHAEL V. SEIDEN, BRUCE A. CHABNER, THOMAS J. LYNCH, JR.

Department of Medicine, Division of Hematology/Oncology, Massachusetts General Hospital, Boston, Massachusetts, USA

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ABSTRACT

Shortly before his death in 1995, Kenneth B. Schwartz, a cancer patient at Massachusetts General Hospital (MGH), founded the Kenneth B. Schwartz Center. The Schwartz Center is a non-profit organization dedicated to supporting and advancing compassionate health care delivery, which provides hope to the patient, support to caregivers, and sustenance to the healing process. The center sponsors the Schwartz Center Rounds, a monthly multidisciplinary forum where caregivers reflect on important psychosocial issues faced by patients, their families, and their caregivers, and gain insight and support from fellow staff members.

Caring for colleagues who develop cancer is a privilege woven with an extra dimension—caregiver-patient issues. As well as stretching the usual need for a supportive relationship, when one of the health care team develops cancer it particularly provokes concerns about our own mortality. The case is presented of a well-known physician who developed a second cancer and has been cared for at the MGH Cancer Center. Staff discuss her care as it has been effected by her status as a colleague. They perceived unique barriers to optimal care such as assumptions about the patient’s level of medical knowledge, and technical, informational, emotional, and hierarchical issues that may obstruct the development of a trusting relationship between caregivers and the physician/patient. Emotional stress may prevent the sharing of an accurate prognosis. In the case under consideration, the patient had a frank and open attitude to her cancer yet her caregivers were concerned about continual breeches of patient confidentiality. Despite the many potential problems inherent when the caregiver becomes the patient, this case discussion was a poignant reminder of the unique challenges of every experience with cancer and the weighty privilege of being involved with patient care.

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PRESENTATION

This patient is a well-known physician. She has a complex history, which well illustrates some of the challenges inherent in taking care of a physician/patient.

Dr. B presented 7 years prior to this time at age 35 with a short history of difficult and painful swallowing. A 2-3 cm lesion was seen in the distal esophagus. Biopsy revealed poorly differentiated invasive squamous cell carcinoma. There was no clinical evidence of metastases. She was treated with 5-fluorouracil (5-FU) and cisplatin followed by Ivor Lewis esophagectomy and pyloromyotomy. The cancer was metastatic to one of the five lesser curvature lymph nodes, and she received two further cycles of 5-FU and cisplatin.

She was well until recently developing a fever and cough. A work-up revealed a left pleural effusion positive for adenocarcinoma. There was initially some concern that possibly her esophageal cancer had returned. However, a computerized tomography (CT) scan revealed a pelvic mass and left hydronephrosis. CA-125 was 1,903. At exploratory laparotomy she had a complex mass densely adherent to the

Correspondence: Richard T. Penson, MRCP, Instructor in Medicine, Hematology-Oncology, Cox 809, 100 Blossom Street, Boston, Massachusetts 02114-2617, USA. Telephone: 617-726-5867; Fax: 617-724-3166; e-mail: rpenson@partners.org

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cul-de-sac, scant ascitic fluid and diffuse peritoneal studding measuring up to 5 mm. She underwent total abdominal hysterectomy, bilateral salpingo-oophorectomy, left pelvic side wall dissection, node biopsy and appendectomy. Pathology revealed grade II/III serous cystadenocarcinoma.

She is married and has a 3-year-old son. She has a full-time hospital-based practice. So, despite what everyone would consider a very healthy lifestyle, she has developed two serious malignancies in 7 years and is already a cancer veteran, a cancer survivor. Some things are a little different now. Her first cancer, of course, was terrifying for her but came before she had a child and now this second cancer comes at a time when she has a 3-year old and is in the middle of building a successful practice. Subsequently she was given a number of different choices of chemotherapy but wanted the most aggressive approach possible. She enrolled on a high-dose chemotherapy protocol with peripheral stem cell support, despite advice that there was no clinical evidence to favor such an approach.

Following two cycles of standard chemotherapy and with a fall in her CA 125, she received further chemotherapy for peripheral blood stem cell mobilization. CT of the abdomen showed no evidence of disease, and she was then treated with high-dose cyclophosphamide, carboplatin, and Paclitaxel with autologous peripheral blood stem cell support. She had a very good but not complete response, with a persistently elevated CA-125.

I’d like to bring up three particular issues. The first is that it’s been challenging to give this person accurate information. The reason for that is that she has a very savvy grasp of the vocabulary and already knows quite a bit. You are never exactly sure where to start your discussions. In the initial consultations I would normally spend an hour or two walking somebody through, “you have cancer,” “you have ovarian cancer,” “what it means to have ovarian cancer,” “these are the types of things you’ll have to deal with.” This sort of health care provider’s first question is, “Hi, I hear you are here to talk about angiostatin.” You skip the first five introductory chapters because you think the patient is completely up to date. It is easy to forget that the patient is not a gynecologic oncologist or medical oncologist until you subsequently discover that there are definite information gaps; that you’ve done her a disservice. This “fast-forward” relationship also prevents making the usual emotional attachment. Normally patients are scared to death and as you work with them, step by step, explaining what it means to have advanced stage ovarian cancer, there is a time to become emotionally connected. Physicians come in and say, “Well, the pathology came back, this is Stage IV ovarian cancer. OK, I know what that means.” You then skip that whole process of, “let’s work through what this means to you” and they, being physicians, say, “I’m tough, don’t worry about it, I know what this means. Let’s get on talking about angiostatin.” Somehow it’s hard to emotionally connect with this person who is just as terrified as any other patient. Sometimes she can barely cover her terror, which is really very palpable yet it is still hard to connect. You do wonder if you should have done things differently. I think that in retrospect I would approach the initial first couple of chapters a little differently as far as opening the relationship.

Secondly, you also have to be careful not to do a medical disservice as far as your evaluation. Physicians tend to examine themselves and be their own primary care physician so that when you say, “How are you doing?” they will say, “Oh, I’m doing fine. My lungs sound great. I listened to myself today.” You might say, “It’s time for your pelvic exam” and they will say, “Oh, I don’t need a pelvic exam, I don’t have any pelvic pain.” Whereas with a patient you might say, “OK, but a pelvic exam is an important part of my assessment,” you’re tempted, with another physician, to defer and say, “OK, you’re right.”

The last thing I wanted to comment on is patient confidentiality, and this applies to physicians and nurses, but also other VIPs in general. On occasion, we take care of people who are relatively well known and it’s not uncommon to get a half dozen questions each week on, “how is Dr. B doing?” or “how is Dr. So-and-So doing” because people know you are taking care of this person. How should we as a group respond to those questions?

**Dialogue**

**Facilitator:** I think the whole point of the Schwartz Rounds is to focus on the unique bond between caregiver and patient. We’ve always defined caregiver very broadly to include physicians, nurses, social worker, nursing assistants, secretaries, and chaplains. In fact, it includes everyone who works at the hospital and everyone who is involved in this enterprise of caring for patients. Many of the issues raised in caring for a colleague illuminate the very special bond between caregiver and patient.
EMOTIONAL CONNECTION

Oncology Nurse: I first met Dr. B when she came in for her mobilization chemotherapy prior to having her stem cell transplant. We were told that she was a prominent physician. So we thought, “OK, this woman definitely knows what’s going on.” The transplant team had changed the chemotherapy orders and there was a conflict between what her doctor had told her and the written orders. So I said, “Well this is what you will be receiving.” She said, “No, I am not getting that, I am not taking that, that is not what my doctor told me I was receiving.” I said, “Well, you are now on the bone marrow transplant team and your doctor has stepped back.” “No,” she said, “you get him on the phone right now.” I said, “Ok, fine!” So I got him on the phone and I got the orders and I gave her the orders and I told her she could look at the orders and she said, “OK, I’m sorry. I was a b****.” Her fear was just as great as any other patient, which can be easily forgotten. You think “clinician to clinician” and not “human to human.” She has already survived cancer and now she has it again and she has a three-year-old and a developing practice. She has so much to live for. That part of it was overwhelming.

Oncology Nurse: On the protocol she was to receive 96 hours continuous chemotherapy and on the last day chemo did not come up. Pharmacokinetic samples were to be drawn to a very specific schedule but the pharmacy wouldn’t bring up the chemotherapy. I was frantic: we’ve got two hours, we’ve got one hour, we’ve got 45 minutes. It ended up that she had a two-hour delay for that one chemotherapy. It only happens to the VIPs! I said to her, “You know what, it’s better that you receive the right chemotherapy and it be a little bit delayed.” Yet, she knows, more than a regular patient, what and the consequences. She was a trooper. It’s been interesting. It’s very different taking care of a clinician or a co-worker in oncology. There’s no privacy.

Nurse: No, actually she did. I have this book on how to help children cope with a parent’s serious illness. I gave her that book and she brought it with her on every single admission. She would say, “Did you see this chapter; this is so perfect as to where I’m at and what we want to explain to our son.” That part was great. I had that bond with her in the fact that I was the one that had started the project. I really got into feelings with her. I think as a primary nurse, you do that because you are with them for a 12-hour shift and you have the time to spend with them. She was very anxious. Another important aspect was that her sister was a physician as well. Her sister would call up and start “grilling us.” The two of them would be going at you and you would think, “OK, I’ve got my armor on” and it was very intimidating. When I went to a course, I asked another nurse from our floor to take over. I later asked what her experience was like with this patient and she said, “I just treated her like she was a patient” and I said to her “You weren’t scared that she is a physician and has all that knowledge?” and she said, “No.” Maybe this has something to do with 15 rather than 4 years experience as a nurse. The senior nurse didn’t even think about it. Yet, I was talking to somebody who had taken care of her when she had esophageal cancer who had also felt intimidated.

Oncologist: She was very quick to ask, “What’s my white count, what’s my platelet count?” and much less time was spent on feelings.

Nurse: To think of how much she’s gone through, it’s unbelievable. I think the bottom line is that you always have to remember that they are human. You think about patients coming in and you tell them their diagnosis. Usually, they stop listening right there because it’s like “Oh my God.” It’s important to have a second pair of ears to be able to hear the follow-up. That’s true for physicians as well. I think that for me I learned a lot from taking care of her.

Oncologist: I had difficulty dealing with this patient and understanding her emotional state. I would ask her, “How are you doing up here?” and she would continually break into tears and then say, “I’m OK.” I think, as they say, physicians make difficult patients. She was not very receptive. When you continued to explore this, she would clearly get very emotional, very upset. She could both crumble and get tougher all at the same time. She would break into tears and say, “I pity the son-of-a-bitch who comes between me and my 3-year-old son.” She clearly was very angry and very terrified. When you would say
things like “Are you going to talk to me about this disease?” “Have you thought about getting into a group?” or “Would you be willing to talk to one of the social workers?” She would say, “No, no, no, I will be OK.”

**Physician:** How affected were you by the fact that she was a resident when you and I were interns and she is close to us in terms of age and life situations? You have young children, she has young children. How much did that play a role?

**Oncologist:** I think she is probably the first colleague that I’ve taken care of and it is different. If you push her and she looks like she’s crumbling a little bit and you reach out to offer support, her reflexes sort of snap back. When she starts crying, which is at almost every office visit, she spends at least as much time apologizing. She will say, “You don’t need another crying patient in your office” or “Your day is tough enough, I’m not going to be patient #7 crying.”

**Oncologist:** Some of the “intellectually” or “financially” or “socially” prominent patients—family of Dr.’s, Dr.’s, sons and daughters of Dr.’s, Ph.D.’s, feel like they are supposed to be in a special support group although the best I can tell, their emotional needs are no different than anyone else’s. They have so much overlay of how they are different that they probably actually need more support. They feel as if “support groups” are for the “average” person who is really upset and has trouble handling their emotions and “I’m spectacularly successful and I don’t need this help.”

**Oncologist:** Because of her training she is very black or white. She’ll say “Do you think angiostatin is a good drug?” I’ll say, “Well, I hope angiostatin is a good drug.” and she’ll exclaim, “Oh well that’s it. I’m doomed.” I’ve actually never told her she was doomed. She was already so convinced she was doomed before she met me that I’ve spent most of my time trying to convince her that she isn’t.

**VIP Care**

**Physician:** Do you find that if you want to use a certain kind of protocol, she would ask you to modify it or change it in any way?

**Oncologist:** Well-educated, aggressive physicians walk a fine line between getting truly spectacular health care and the worse health care you’ve ever seen. What happens is they concoct their own protocols in their own head and while it is relatively easy to derail somebody that doesn’t have a medical education, the better educated patients are, the more they can push you into a corner. Of course, the more you have already bonded with them to be their advocate, the harder it can be to say no. In fact, right now we are in a major discussion about the use of Thalidomide. There will be no protocol. We haven’t really reached a conclusion. Negotiations are not over, but you’re right, this is very difficult, particularly when she is a very well-informed consumer. She did ask to add something on the protocol that wasn’t there. She asked for, I think, 16 extra weeks of Taxol® and I told her no.

**Physician:** When I’ve taken care of physicians and nurses with institutional ties, I’ve had a fairly explicit policy of treating them just the same way I would anyone else.

**Oncologist:** Can you ignore the fact that you’ve known them for 10-15 years in this institution? You can say, “Look, you’re just a patient like everybody else and I’m going to treat you exactly the way I would treat any other patient.” But isn’t that equally artificial? You have known them in a different setting and there is a totally different history between you and that person.

**Oncologist:** There are definitely differences in communication. The way a physician presents a question to you is so much different than the way a “non-medical” person presents the same question.

**Oncologist:** They tend to be extraordinarily respectful of your time. They know how busy you are so they tend to call and say, “I need 2 seconds of your time to answer one question.” It is not normal communication.

**Confidentiality**

**Physician:** What do you do when you have somebody that is well known by people and even though “confidentiality”
is stressed, you are asked by somebody “How is ____ doing”?

**Oncologist:** Conversely, if you pass a colleague in the corridor and you know that they’re here for treatment and you are one of the caregivers who isn’t theoretically supposed to even know what the person’s diagnosis is, should you just look past them?

**Physician:** One of the interesting things about that is that sometimes one of the things that builds a patient’s trust in the concept of a team is that we all talk about a patient’s care and we communicate. That builds a sense of trust. The team is actually working together. However, it brings up the issue of confidentiality of “how large that circle should be” and “who knows about it.” How do you respond when somebody who isn’t a fellow oncologist and doesn’t really have any reason to know, asks about Dr. B’s care? You are trying to draw a line wide enough to create an effective team to care for the patient, and narrow enough to protect the privacy that this person is trying to maintain. It is clearly challenging.

**Oncologist:** This is unfortunately a disease that can be a semi-chronic disease, not forever but for many years and there are a lot of transitions that people have to go through. Young people with young children need a fairly big safety net, a lot of support from their colleagues. You don’t want to shut them out.

**Hierarchy**

**Physician:** A patient I took care of approximately 3-4 years ago was a nursing professor. One of the things that I was struck by was how many of the younger nurses were extremely hesitant to even enter her room and felt very, very uncomfortable because they felt that their own abilities would not measure up in her eyes. All she really wanted was a nurse to “be a nurse” and not to treat her any differently.

**Physician:** Confidence in our own capabilities is an issue. I think when you feel extraordinarily capable in your own knowledge base you’re safe, but even then deep down there is probably always a little bit of doubt.

**Vulnerability**

**Physician:** Can you say what’s helped you to deal with your feelings of vulnerability? Maybe just not around the power issue but also around your anxiety or sadness?

**Nurse:** You need each other in these situations; the wisdom of other people who’ve dealt with these issues and the solidarity of the team.

**Physician:** I’ve been struck by how often, when people talk about their own experiences, they tend to involuntarily protect themselves. If we see another person taking charge by pushing us away, the natural inclination is to withdraw. We’re not likely to make ourselves even more vulnerable by disagreeing with the patient and saying, “Oh no, I don’t think we should do it this way.” I think it is good to be prepared for that circumstance. We can help to anticipate how our colleagues might respond and to think about a constructive, gentle yet firm way in which to challenge them.

**Physician:** I think the feeling that a lot of people have, because of the unique nature of this individual, is that perhaps physicians are not the best people to participate in support groups. Yet that is an erroneous conclusion, and I know of many examples where professionals, nurses and physicians did very well as members of support groups.

**Physician:** One of the things that makes caring for a colleague so difficult is that it brings out in yourself your own personal vulnerability.

**Social Worker:** We recently ran the “role-play” *Life of a Group*. Members of the cancer center had the experience of playing the role of patients. Without being professional actors, staff were profoundly tuned in to what patients were really experiencing at a deep level. They looked and thought just like cancer patients themselves. It was a great education for both those involved and those watching. To me it was an incredible demonstration of how astutely
and deeply caregivers really observe, empathize and identify with patients whether they want to or not. Here, talking about colleagues as patients, we have that same experience of a closer brush with reality.

**Social Worker:** The difficulty of referring someone to a group has to do with your own experiences in a group. It can be a scary notion if you haven’t done it and had the positive experience of it.

**DISCUSSION**

People are uncomfortable with their mortality. Physicians are no different. When they become sick, their prior experience rarely seems to prepare them for a uniquely difficult situation when their sense of immortality is shaken. The average car driver will have an accident every ten years, one in twenty of which will be fatal. However, nobody considers themselves an average driver. Epidemiological data show that male doctors have a significantly higher mortality from hepatoma, and female doctors have a higher incidence of carcinoma of the pancreas [1]. However, compared with the general population, doctors have a significantly lower mortality ratio except for deaths from specific causes such as suicide, injury and poisoning and it is easy to dismiss the actuarial <5% risk of death before retirement. However, with a one in three chance of developing cancer, and one in five chance of dying from cancer, most physicians know of a colleague who has developed cancer or have experienced it themselves. Our dialogue raised a series of difficult issues regarding the physician/patient and his or her care. A review of the literature raises additional issues relevant to the subject.

**The Arrogant Physician: Good or Bad Thing?**

*Franz Ingelfinger,* an eminent gastroenterologist, delivered a fascinating lecture, “Arrogance,” as the George W. Gay lecture at the Harvard Medical School, May 5, 1977 shortly before he retired as editor of the New England Journal of Medicine [2]. He gave a very personal insight to his own experience developing adenocarcinoma of the gastroesophageal junction. The article starts with a vigorous defense of a physician’s primary function: to make a patient feel better. He observed that a certain “authoritarianism, paternalism, and dominance” may be necessary for a physician to be effective and reported that his own experience had strongly reinforced his belief that the physician must take, to some degree, an authoritarian stance. He presented with limited stage disease and underwent successful surgery. Following this he was promptly presented with the dilemma of whether he should have adjuvant chemotherapy or radiotherapy. He was clearly uncomfortable with the data 25 years before McDonald et al., presented INT-0116 at the plenary session of the American Society of Clinical Oncology [3]. This study demonstrated a 44% improvement in relapse-free survival and 28% improvement in overall survival for postoperative combined radiation and chemotherapy for just this disease.

At this point, Dr. Ingelfinger describes himself as “barraged by well-intentioned but contradictory advice” with himself, his wife, his son and daughter in-law (both doctors), and other family members becoming increasingly confused and emotionally distraught. Finally, when the pangs of indecision had become nearly intolerable, one wise physician friend said, “What you need is a doctor.” He was advised by this friend to forget the information he already had and the information coming at him from every quarter and to seek a person who would, in a paternalistic manner, assume responsibility for his care. When this “excellent” advice was followed, there was an immediate and immense sense of relief.

A subsequent letter, prompted by the article criticized Ingelfinger’s false dichotomy between the arrogant authoritarian physician and the diffident physician who takes no responsibility for the patient’s progress or decline [4]. The letter writers suggested that the role of the physician was to offer authoritative (not authoritarian) counsel, emotional support, realistic hope, and firm recommendations that leave the patient free to refuse. However, it is clear that neither of these doctors had cared for Dr. Ingelfinger. In this case, and in many others, patients may respond to the reassurance of an authority figure. However, what works for one patient may not work for another.

**On Being a Physician/Patient**

*Dr. Ingelfinger* suggests, tongue in cheek, that only those who had been hospitalized during their adolescence or adult years be allowed to attend medical school. For many who have experienced serious illness the experience enriches their appreciation of the patient’s perspective.

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**One of the things that makes caring for a colleague so difficult is that it brings out in yourself your own personal vulnerability.**
He quoted Robert Loeb, who told generations of students at Columbia, “listen to your patients, they’re trying to tell you something” [5]. Davidoff’s series presents helpful “real life” experiences of physicians who become patients. One physician who underwent bone marrow transplant for chronic lymphatic leukemia confessed his lack of both knowledge and insight and how this state of ignorance heightened his sense of isolation in making a decision about transplantation [6]. He was puzzled by his inability to share his terror with anyone and hypothesized that he was trying to retain the role of a dispassionate physician; someone who trusted in the science of his therapy and feared that admitting to his terror would make his experience still harder. He describes his sense of extreme helplessness and loss of dignity after an episode of fecal incontinence. He contrasts these feelings with the importance of his trust in his caregivers, which provided a safe haven from this fear and helplessness and were an essential component to his recovery.

Patients need a doctor who provides expertise and both effective communication and emotional support. A medical student tells of her harrowing experience of an acute asthma attack during rounds and the invasion of her anonymity and then her privacy with all of her “medical details, social habits and sexual preferences” available to her peers [7]. This experience clearly transformed her academic pursuit of medicine to a personal one and like many others she judged her caretakers not only by their knowledge, but also by how they justified the trust that she placed in them and how they acknowledged her dependence and vulnerability. A seasoned skeptic describes needing not only to have elements in a medical decision articulated intelligibly but also the essential issues driven home convincingly so that he could make an informed decision [8]. These and others make helpful reading for caregivers and perhaps provide greater understanding than the hackneyed reports of patients being callously treated like pathology specimens [9].

**Uncertainty**

Confronting uncertainty is a very large part of the emotional toll of having cancer. Despite Ingelfinger’s advice to find a paternalistic physician, the truth is that any realistic physician/patient will know that the outcome can only be measured in probabilities that no physician, no matter how skilled, can alter and that time alone will address the fear. A particularly revealing vignette eloquently records the experience of a breast cancer survivor [10]. Dr. McKinley describes the lurching transitions between bravery and fear, joy and abandonment, during adjuvant treatment as the “rocky experience of cancer survivorship” begins. She describes a “cancer ghost” who would not let her forget where she had been or allow her to freely choose where she might be going. How she relished touching and playing with her children, how she listens to their breathing at night, and how she seeks friends with whom she can laugh until late in the evening. She describes uncertainty as a “slippery foe.” She encourages physicians to talk to their cancer survivors about the unique struggle of survivorship and the loss that they experience when active treatment is over and they leave the very intensive environment of the cancer center. These experiences help us understand the fear and uncertainty. While in a professional role the doctor accepts the uncertainty and explores the probability; as a patient, they naturally will attempt to reduce the uncertainty and eliminate the unimaginable.

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**Sorrow, Anger, and Compassion**

Rarely is a physician/patient adequately prepared to deal with the sorrow and anger of a serious illness. While some physicians may dismiss these responses as aberrant, labile and inconsistent behavior, it is important to recognize them and provide ongoing opportunities for them to be expressed and addressed. Illness and accidents change our lives forever. Cries for help, poorly formulated and difficult to recognize but nonetheless important, require a response. As cancer specialists, we see this in our patients every day, and hesitate to break through its surface. It demands our time, our understanding, and our compassion [11]. In an interesting editorial Samuel Vaisrub reminded health care workers that although we hear a great deal about compassionate physicians, many patients are tremendously compassionate [12]. A fellow physician may more completely understand the joys and anxieties of medicine, the successes and failures of therapy, and respond to a physician’s need for appreciation, gratitude, and approval. There is an obvious inherent risk that a compassionate patient may be too eager to please and not to disappoint his or her colleagues. This may well contribute to concealing or minimizing symptoms or concerns.
Confidentiality
Doctors gossip. Few in the medical profession will not have experienced instances in which colleagues have disregarded their duty of confidentiality in the doctor-patient relationship. When a patient is a mutual friend and colleague, the temptation to share information becomes constant and intense. Such gossip may be based on the belief that medical culture, with its blunted conscience, accepts the breach of confidentiality as insatiable curiosity. Being a doctor’s doctor is a privilege, but also anxiety provoking, and physicians may feel a need to share, and thereby reduce, their personal burden of responsibility. The causes are likely to be multiple, but every disclosure, unless it is done with the intent of improving care and with the patient’s consent, becomes a serious breach of professional conduct [13]. Since the time of the Hippocratic oath, clinical privacy has been held as something that the medical profession should strongly affirm. However the oath’s commitment to “not spread abroad all that may come to my knowledge in the exercise of my profession…” is often compromised. The American Medical Association code of ethics permits physicians to disclose confidential information only when required to do so by law, yet it leaves decisions about clinical discretion, conflict of interest, and a myriad of other responsibilities to clinical judgment. Maintaining a commitment to the highest standards of confidentiality fuels the sort of trust that is a foundation to the best doctor-patient relationship.

CONCLUSION
To care for fellow caregivers is a tremendous privilege. Though potentially vexed with false assumptions, collusion, conflict, and breaches of confidentiality, it can be particularly rewarding and provide profound insight on the essential human aspect of medical care.

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