

The Attorney As the Newest Member of the Cancer Treatment Team

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INTRODUCTION

In a recent survey of cancer patients conducted by the Lance Armstrong Foundation (Austin, TX),¹ nearly half of the individuals surveyed said that nonmedical issues relating to their cancer were unmet by their oncologists, including 35% who said nonmedical issues were wholly unaddressed and another 14% who said they believed their oncologists wanted to assist with nonmedical issues but did not have enough information or experience to do so.

More is being done to integrate basic symptom management into routine cancer treatment, including early intervention for pain, fatigue, adverse effects of treatment, and adjustment to life in anticipation of cancer survivorship.² Until now, little has been done to integrate legal advocacy services into the cancer treatment matrix, especially for patients who are medically underserved and from hard to reach communities. Legal problems for patients with cancer are a significant nonmedical need that must be addressed to maintain quality of life during and after cancer treatment and to promote continued access to care.

As the number of cancer survivors steadily increases,³ many patients still face extended survivorship or progressive illness, often creating complicated end-of-life decisions for the patients and their families and treatment staff. These decisions are often made without the involvement or advice of legal counsel. Traditionally, an historical and outdated tension between physicians and attorneys over contentious malpractice litigation discouraged their collaboration. With the advent of multidisciplinary care, the input of interested attorneys benefits patients and their families, oncology professionals, and the offices and cancer centers where the professionals practice. Other barriers to proactive attorney involvement include the prioritization of the tasks of treatment over personal issues until they impede care, a lack of immediate and easy access to legal counsel, and a lack of knowledge base within the cancer treat-

ment team, delaying intervention until it is too late and the patient is in crisis.

ADDRESSING ADVOCACY NEEDS

Other vulnerable patient populations have had a more progressive approach to accessing legal services. Geriatric patient groups have long embraced the input of legal teams in estate planning as well as in conservatorship and guardianship issues.⁴ Such collaborations are again being formalized, as evidenced by the recent trend in pediatric practices to incorporate medical-legal teams that are often housed on-site in pediatric ambulatory centers.⁵ Recent training in both pediatric and psychiatric residency programs has included legal advocacy in the core competencies.⁵

Most striking was the influx of advocacy efforts and resources in the early 1980s directed at the HIV/AIDS community. From the beginning of the HIV crisis, it was recognized that a person with HIV/AIDS needed legal assistance to cope with the myriad of life changes brought on by the disease and its treatment. It is becoming clearer that the legal issues facing patients with cancer mirror those found in the HIV/AIDS population, yet similar resources are not available to cancer patients. Although hundreds of legal service offices were opened nationally that were tailored to the special needs of those with HIV/AIDS, such services have not been duplicated for the 9 million cancer patients and survivors alive today.⁶

At this stage, it is unlikely that such services for people with cancer will be duplicated on the scale of the HIV/AIDS model without a targeted federal funding stream similar to that provided by Ryan White legislation. Yet even with limited funding, advocacy programs can and should be developed. As recent experiences in pediatrics have shown, placing such services within ambulatory cancer centers offers the best chance of integration and collaboration between the two disciplines and a way for oncology specialists to assist with some of

their patients' unmet nonmedical needs that indirectly impact adherence to treatment.

THE LEGALHEALTH MODEL: A MEDICAL AND LEGAL COLLABORATION SERVING PEOPLE WITH CANCER

LegalHealth (New York, NY) is the first fully staffed free legal services program that has sought to make legal intervention a component of cancer care. LegalHealth, which is a project of a larger nonprofit law office, provides free legal services to individuals with chronic illness and trains health care professionals on the legal issues affecting their patients. The program has promoted the health care setting as one of the primary entry points to implement legal interventions with poor/chronically ill cancer patients. LegalHealth helps patients and families alike who may otherwise not have access to legal services. Access to other supportive services by cancer patients at community-based settings sometimes becomes difficult as a result of the complexities of ambulatory care superimposed on life's difficult circumstances, such as illness, poverty, and other related stressors. Such ease of access and immediacy of intervention in the LegalHealth model is an added service that is not an additional burden for the already encumbered cancer patient. Bringing services to hospitals or other ambulatory cancer centers also limits the burden and stigma of seeking help.⁷ In addition, as a result of the immediacy of the intervention, LegalHealth is often able to intercede preventively with effective advocacy strategies. To date, LegalHealth had provided legal services to more than 500 individuals with cancer.

Cancer specialists are often in the best position to identify legal issues impacting their patients. Oncology specialists, physicians, and nurses become acquainted with families and care partners throughout the trajectory of care. Frequent contact with the oncology team from the early stages of an illness results in extended or intimate trusting relationships among providers, patients, and families. This affords the physician or nurse the opportunity to observe the patient's and family's well-being over time.⁸ For patients with quickly progressive cancer, the treatment relationship is likewise intense, fostering significant trust in an abbreviated time.

Oncologists and oncology nurses routinely access data that screen for legal issues (although they may not realize it), starting when the patient is first diagnosed with cancer and continuing throughout the course of treatment. On initial diagnosis, patients often have insurance, employment, and financial concerns. If the disease progresses, there may be debt management and disability benefits issues. At the end of life, advanced planning becomes necessary, such as drafting wills, health care proxies, and permanency planning documents for parents with minor children. Expanding the spectrum of services available to a cancer patient to include legal assistance has the potential to substantially improve patient health and family stability over time.

Although many cancer specialists know that their patients' unmet nonmedical needs are having a deleterious impact on their patients' health, they don't have the knowledge or experience to advocate for them.⁷ LegalHealth trains physicians to recognize significant issues that may negatively impact medical outcomes but have a legal remedy, such as employment problems that can threaten a cancer patient/survivor's ability to retain health insur-

ance, the lack of homecare when a patient is discharged from the hospital, or poor housing conditions, which can further weaken an already compromised patient.

The LegalHealth model recognizes the substantial time pressures faced by the clinical staff and, therefore, simplifies advocacy intervention so it can be woven seamlessly into the clinical consultation.⁸ Although substantive legal information is taught in periodic training sessions for physicians, it is behavior change that is the ultimate goal of these trainings. The LegalHealth model encourages physicians and advanced practice nurses to listen to the pertinent personal information from the patient during the examination in a new light. Rather than discourage the discovery of nonmedical information, the physician and nurse are trained to actively triage to the attorney. Physicians are taught to ask a few basic questions that will elicit the information needed to assess whether a legal intervention is necessary. Once it is determined that legal intervention is needed, the physician's role is clearly defined so as not to add unwarranted responsibilities. Sometimes, the referral to LegalHealth is the extent of the intervention; in other situations, the physician might play a more active role in the advocacy effort, such as filling out necessary forms for disability benefits or writing a letter for a patient who needs a reasonable accommodation in their workplace.

In the LegalHealth model, lawyers are stationed in the same clinical area where cancer treatment is provided. Through routine physician-patient interaction, patients are prescreened by the physician, nurse, or oncology social worker, and a legal appointment is set up for a time in the future. In some cases, where there is a time-sensitive issue, patients are literally walked over by their physician to the lawyer. LegalHealth lawyers are generalists and, therefore, able to handle the myriad issues the physician has uncovered. To date, LegalHealth is on site at five New York City hospital-based cancer centers and one community cancer center.

In a pilot survey conducted by LegalHealth, 20 of its clients with cancer were asked a variety of questions about the impact legal interventions had on the quality of their lives. The questions sought to determine how legal services impacted their ability to keep medical appointments and maintain treatment regimens and how they affected their emotional health and family stability. The survey found that 75% of patients interviewed said the legal services reduced stress, 50% said receipt of legal services had a positive effect on their family or loved ones, 45% indicated the services had a positive effect on their financial situation, 30% said the services helped them maintain their treatment regimen, and 25% said the services helped them keep medical appointments (LegalHealth Study conducted by Fordham University School of Law [New York, NY] students enrolled in a public interest lawyering seminar in conjunction with the school's Stein scholars Program, internal communication, 2005).

The incorporation of lawyers creates a truly formidable team. This integration can bridge gaps in information and resources and provide valuable on-site advocacy and support.

BENEFITS OF THE COLLABORATION

The collaboration between LegalHealth and oncology health care providers benefits individual patients and their families, care partners, providers, and health care institutions.

Benefits to Patients, Families, and Care Partners

Legal problems that present simultaneous or result from cancer illness add to the patient's and family's burden at a time when their reserves are already stretched. Seeking free legal help outside of the treatment setting is often fraught with bureaucratic obstacles even if one can access the services. LegalHealth attorneys are sensitive to the problems and special needs of the cancer treatment population. Such a marriage of services improves the patient's general quality of life and makes it easier for the patient to adhere to treatment. Integration of such services in cancer centers reinforces the principle that comprehensive cancer treatment embraces the realities of patients' daily lives.

Benefits to Providers

An increased recognition of noncancer obstacles to care can impact a health care provider's treatment plan. Patients with job, housing, financial, or insurance-related concerns may be less able to adhere to rigorous treatment plans. These nonmedical factors negatively affect a patient's ability to seek care at all or keep scheduled appointments for treatment or follow-up. Such interruptions in treatment can reduce its effectiveness because both chemotherapy and radiation therapy rely on optimal treatment administered sequentially over time.³ Certainly, distress over such issues reduces a patient's quality of life, and these burdens become another source of stress beyond the cancer and its treatment. Legal interventions broaden the array of services oncology specialists can offer to patients and families and enrich their own repertoire of skills and training opportunities.

The attorneys themselves benefit from the collaboration by translating their skills to a new environment, accessing more clients before crises occur, and being welcomed into the health care team. Inclusion on the treatment team enhances the appreciation of an attorney's advocacy role and helps overcome an adversarial stereotype.

Benefits to the Health Care Institution

Patients' legal difficulties lead to missed appointments and treatment interruptions that can be costly when chemotherapy or radiation therapy need to be administered or when a patient does not show for a prescheduled surgical procedure. By assessing and intervening in patients' legal obstacles to care early on, such losses are contained. Additional savings are realized when legal intervention results in unraveling insurance and entitlements to pay for care that may otherwise go unreimbursed. Cancer centers that provide such legal help for their patients sharpen their competitive edge by enriching the array of services available on-site and at no cost to their patients.

CASE EXAMPLES

Case 1: End-of-Life Issues

Monica S., who is now deceased, sought LegalHealth's services in 2003 after being diagnosed with leukemia. She was a 45-year-old single mother of a 12-year-old girl. She had entered the United States as a tourist and overstayed her visa. Although she had continued to work as a hair stylist, in late 2003, she stopped working. She had difficulty getting short-term disability payments. She had no will, health care proxy, or power of attorney. Monica had no family members in New York, and although the father paid child support, he had no interest in raising his daughter. Monica was concerned how she would live and what she would do if her employer stopped paying for her health insurance. LegalHealth's first step was to

work with her physician to make sure she got her short-term disability. LegalHealth then prepared Monica's will, health care proxy, and power of attorney and made standby guardianship plans. LegalHealth also researched whether any other disability benefits were available to her and what her long-term insurance options would be. Ten months after Monica's death, LegalHealth represented the standby guardians in court to get letters of guardianship. As a result of the services provided to Monica by LegalHealth, she was able to get practical help related to her financial and estate planning concerns from her attorneys, allowing her to focus solely on her daughter and maintaining her strength during her treatment. LegalHealth was also instrumental in Monica's referral to hospice for end-of-life care, which brought much comfort and quality of life into her home.

It is clear from this case example that Monica had many legal issues that needed to be prioritized and addressed. Her greatest concern was ensuring that she had a permanency plan for her daughter. The term permanency planning in relation to individuals with a chronic or serious illness describes the options available to parents to plan for the future care and custody of their children if something should happen to them. Standby guardianship laws, which were enacted in response to the AIDS crisis, are now being used by parents with cancer and other serious illnesses (LegalHealth Study conducted by Fordham law students enrolled in a public interest lawyering seminar in conjunction with the law school's Stein Scholars Program, internal communication, 2005). They allow a parent to put into place, while they are able, guardianship plans that become effective on a later triggering event, which is often the parent's death or incapacity. Because permanency planning demands involvement of parents, children, and caregivers/guardians, it is an extraordinary challenge for lawyers, social workers, and doctors to help families with what many say is the hardest decision of their lives.

Case 2: Financial Issues

Rosa A., a 38-year-old woman suffering from fibrosarcoma was referred to LegalHealth by her hospital social worker and oncologist; they were concerned about the stress she was experiencing as a result of her financial situation. Although her cancer is under control, she is in a great deal of pain and being monitored closely by the pain clinic at the hospital. Before her illness, Rosa A. worked. Now, her family lives on the money she receives from Social Security Disability and her children's Social Security Survivor benefits from their deceased father. The original reason for the referral was a denial of food stamps, which LegalHealth was able to rectify. Help with the food stamps revealed that she owed thousands of dollars of credit card debt from before she became ill. Because she is no longer working, she rapidly fell behind in the payments. She attempted to pay her debts through a credit consolidating agency but could not keep up with the payments. She mentioned that calls from her creditors were coming in regularly and were extremely upsetting, both from her own guilt that she was in debt and from the harassment from bill collectors. She said she couldn't sleep at night because of her worries about the bills and trying to pay them when she simply had too little money to even afford food. LegalHealth wrote to all the creditors requesting that they cease and desist their collection efforts because Rosa has no income to pay them and is considered judgment proof and requesting that any further collection efforts be referred to LegalHealth.

This case example is typical of what individuals with cancer experience when they are no longer able to continue working and

must live off entitlements or disability. Before the onset of illness, people like Rosa are able to live pay check to pay check and pay the minimum amount on their debts to keep creditors at bay. With a cancer diagnosis, a person's financial situation often deteriorates, and many people end up either like Rosa or needing to file for bankruptcy. In a recent study conducted by Harvard, it was found that medical problems contribute to approximately half of all bankruptcies filed in the United States.⁹ Rosa is only one example of how patients are concerned with their financial situation. When faced with cancer, patients must think not only about the need to pay for their health care and treatments but also about out of pocket expenses that can lead to bankruptcy. Examples of such expenses include "the need for services such as meal preparation, housekeeping, and home health care, child-care, transportation and the unavailability of family caregivers because of their need to work."¹⁰ Financial problems and the stress they cause can be mitigated by legal involvement, allowing individuals such as Rosa to concentrate on her health.

Case 3: Workplace Issues

David Z., a 51-year-old man with colon cancer, was employed as a designer at a clothing manufacturer. Although work gave him an important diversion from his cancer, the continued income and insurance coverage for him and his family also played a big role in his decision to keep working. When David met with LegalHealth, he had many questions regarding his rights in the workplace, insurance coverage, and the amount of time he could take off from work. LegalHealth counseled him extensively on the Family and Medical Leave Act, long-term disability, and COBRA coverage. With this knowledge, David was able to make a more informed decision as to when to stop working.

Because many patients with cancer depend on their jobs for insurance coverage as well as income, maintaining employment is often a key concern. The effect of this job lock, or inability to leave a position for fear of losing insurance coverage, causes great psychological and emotional stress in addition to having a significant impact on the family's overall financial status.¹⁰ In addition to these concerns, many patients/survivors battle stigmas about cancer in the workplace, which can result in employer's concerns about an employee's productivity, missed promotions, undesirable transfers, or even terminations.¹¹

Madeline L., a 32-year-old woman with ovarian cancer, worked in an administrative job. She continued her employment throughout her chemotherapy, but she found the length of the day overly demanding. Her employer was uncomfortable allowing her to work a flexible schedule. LegalHealth worked with her treating physician to prepare a letter that supported her need to reduce her hours as a reasonable accommodation under the Americans with Disabilities Act, and Madeline's employer adjusted her schedule accordingly.

Often, cancer survivors need a reasonable accommodation in the workplace. To obtain an accommodation, an individual must inform their employer about their work limitations, and the decision to disclose a disability is often a difficult one. Realistic input from their treatment team in conjunction with their lawyer about their ability to

work and/or the accommodations needed helps a survivor realistically assess their employment situation.

CONCLUSION

Although LegalHealth is a worthwhile model, it is one prototype of collaborative care. Hospital staff, public interest, and pro bono attorneys and patient advocates can adapt these basic principles to the community or academic treatment setting, taking into account available resources and the willingness to collaborate in innovative ways. Such joint efforts are satisfying to all involved, including patients, families, oncology treatment team members, and attorneys. The potential cost savings by reducing missed appointments for chemotherapy or radiation therapy are apparent and measurable. The practice or hospital's revenue stream is better protected when patients' care is reimbursed by insurance or entitlements, as a result, in large part, of lawyers' involvement after they are brought to the forefront by the oncology team. The LegalHealth collaboration provides a win/win/win situation for everyone involved, including the patients and their families, the oncology teams and their institutions, and the attorneys.

As oncology care is evermore provided in an ambulatory setting, oncology treatment teams are forced to confront family and financial issues that may expedite or impede patient treatment. An on-site, specialized attorney can intervene to address these issues before a crisis develops that interferes with cancer treatment.

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