LEGAL SERVICES: A NECESSARY COMPONENT OF PATIENT NAVIGATION

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OBJECTIVES: Access to legal advocacy is an essential tool to help cancer patients and survivors through the continuum of care. This article examines delivery models that can seamlessly integrate into patient navigation programs.

DATA SOURCES: Technical reports, books, journal articles, and Web sites.

CONCLUSION: Psychosocial obstacles are common barriers of low-income individuals facing a cancer diagnosis. Legal solutions can help to minimize these obstacles, yet patients rarely have access to these services. Training patient navigators to appropriately screen for legal issues and collaborate with attorneys can be used to help prevent, rather than just react to, legal issues by addressing them as a part of a treatment plan.

IMPLICATIONS FOR NURSING PRACTICE: Attorneys working with patient navigators, particularly nurse navigators, can impact oncology nursing practice by providing an innovative collaboration that is consistent with emerging trends in patient-centered treatment.

KEY WORDS: Legal assistance, medical-legal partnership, quality of life, collaborative care, multidisciplinary team, psychosocial needs, barriers to care, legal advocacy, health disparities, continuum of care, non-medical needs

PATIENT navigation is a process by which patients, families, and caregivers are guided through the health care continuum. Patient navigators provide assistance to overcome health care system barriers and facilitate timely access to quality medical and psychosocial care. The goal of patient navigation is the elimination of financial,
communication, psychological, and logistical barriers to patients and improve access to care, especially for low-income patients. Incorporating legal services into the patient navigation model for cancer and other serious illnesses will further this goal by eliminating a substantial barrier to care, assist with unresolved legal issues, and enable patients to fully focus on treatment and survivorship.

**BACKGROUND**

The estimated incidence of cancer is currently at approximately 1,596,670 in the United States, and is expected to increase as the population ages. Most people with cancer need help to cope with the complexity, inefficiency, and cost of the current American health care system. People with new diagnoses are often too ill, too tired, and too overwhelmed by decisions they are required to make, tasks they need to perform, and problems they must solve to overcome barriers to care. In addition to the health care system, they must navigate many other systems such as Social Security, public and private payers, workplaces, and more, which often lead to problems that have legal remedies residing in laws, regulations, or policies. These individuals need someone to advocate with and for them, identify interrelated legal issues that must be addressed, and make appropriate referrals. Patient navigators have an important role in this process.

The origins of the patient navigation process are attributed to Dr Harold P. Freeman, who has long recognized the importance of incorporating free legal services into the patient navigation model as a means of overcoming health disparities. The Harold Freeman Patient Navigation Institute is one of the only training models in the country that regularly includes in its curriculum, a module on the importance of utilizing legal services in patient navigation. To date, over 350 navigators have been trained on this topic, and the clinic that Dr Freeman founded at the Ralph Lauren Center for Cancer and Prevention guarantees free legal assistance available to its patients through LegalHealth, a division of the New York Legal Assistance Group. Since 2001, LegalHealth has provided free legal assistance to low-income New Yorkers with serious health problems within hospitals and community-based health organizations throughout the five boroughs. LegalHealth complements health care with legal care, bringing together legal and medical professionals to improve the lives of these clients and their families where and when they need it most. In addition to onsite free legal clinics, LegalHealth trains health care professionals to recognize legal issues that may negatively affect medical outcomes.

Due in large part to the growth of patient navigation programs, the American College of Surgeons Commission on Cancer (ACS CoC) a consortium of professional medical organizations that collaborate to advance the survival and quality of life for cancer patients through regulation, research, and education revised program standards to include the patient navigation process as a means to improve cancer care. Hospitals seek accreditation from the ACS CoC to acknowledge high-quality, systematic care to cancer patients served by that institution.

The ACS CoC review of facilities seeking accreditation will assess health disparities, barriers to care for each specific population served, and the effectiveness of patient navigation processes in addressing identified barriers. As health care facilities develop navigation programs and models, it is essential that a legal services component be included if health disparities and barriers to care are to be overcome and improved quality of life for patients throughout the continuum of care achieved.

**RECOGNIZING AND ADDRESSING LEGAL ISSUES**

Identification of common legal issues and being aware of appropriate sources of legal information can help patient navigators assist seriously ill patients. Before recent medical advances, legal services for people with cancer were generally limited to assistance at the end of life, with a focus on drafting wills and advanced planning. As patient survival rates increased over time, so has the complexity of legal needs of this population. In addition to wills, health care proxies, powers of attorney and permanency planning, patients’ legal needs include issues relating to insurance benefits and denials, workplace accommodations, protection from debt harassment, Family Medical Leave Act, housing, immigration issues, and a host of other concerns. Psychosocial factors, which negatively affect a patient’s quality of life or ability to seek and maintain medical treatment, can often be improved by legal remedies.

There is a wide and consistent spectrum of legal issues often related to or intensified by a serious medical diagnosis. A 2007 empirical focus group...
study identified approximately 30 medically related legal needs that affect people diagnosed with cancer. Medically related legal needs were identified in a focus group setting. These needs were subsequently sorted and rated by a sample of 50 mixed-site cancer patients (22 men and 28 women; mean age, 52 years) and subjected to multidimensional scaling and cluster analyses. Study participants rated legal needs as having a significant impact on quality of life and reported that these needs were not met by current medical or supportive care. A review of 180 matters referred from patient navigators to LegalHealth from the Ralph Lauren Center for Cancer and Prevention revealed, in descending order, the top referred legal matters as housing, public benefits, advance planning and consumer issues.

When patient navigators guide people with serious illness through a treatment process, it is advantageous for navigators to be mindful of legal needs that can affect quality of life and ability to maintain treatment. These legal issues can be incorrectly perceived as purely social problems. Many patients are unaware or misinformed about their legal rights. Misperceptions in regards to legal rights can be exacerbated by poverty, education levels, language, cultural, and social differences. Increased recognition of common legal obstacles to care can directly influence the efficacy of a health care provider’s treatment plan by, for example, helping patients who have job, housing, financial, or insurance-related concerns adhere to rigorous treatment plans.

When legal issues are not properly addressed, they can inhibit patients from fully benefiting from current medical breakthroughs: continuous care from screening through diagnosis and treatment often ensures best quality outcomes. Because of the complexity of legal issues, medical providers may be ill equipped to help patients address legal needs. As a result, patients may miss appointments or delay potentially lifesaving care. For example, a patient with a housing matter in landlord-tenant court may be forced to miss chemotherapy appointments to keep court appearances. Interruptions in cancer treatment can reduce its effectiveness because optimal outcomes of chemotherapy and radiation therapy rely on sequential and timely protocol administration.

Despite recognition that legal issues can affect outcomes in patient treatment, there are substantial barriers to proactive attorney involvement. Barriers include prioritization of the tasks of treatment over personal issues until they impede care, lack of immediate and easy access to legal counsel, and lack of knowledge within the treatment team that results in intervention delays until patients are in crisis. Some of these barriers have been overcome by the rise of a new model of legal service delivery: the Medical-Legal Partnership (MLP), which can provide direction for patient navigators.

### Medical–Legal Partnership

The medical–legal partnership (MLP) is a health care and legal services delivery model that aims to improve health and well-being of vulnerable communities by integrating legal assistance in medical settings. The MLP exists in a collaborative setting with the treatment team so that potential legal problems are recognized, addressed, and resolved early, through less stressful administrative and negotiated solutions and, where possible, before legal issues reach crisis mode. The MLP establishes a new arm in the interdisciplinary medical team: a legal branch.

A report by the Robert Wood Johnson Foundation Commission to Build a Healthier America cites MLPs as an action step through which health care providers can address social disparities. The report indicates that health care providers, in partnership with programs and agencies that offer legal or social services counseling and advocacy, can help patients address social causes of health disparities. The report further states that “clinicians are in a unique position to identify vulnerable patients” and that “examples of programs that connect patients with services and resources in the greater community are the Medical-Legal Partnership.”

The MLP model recognizes that the outcome of an illness is not purely the result of medical factors and that vulnerable populations often face legal barriers that adversely affect quality of life and management of serious illness. Therefore, if legal problems are not addressed and resolved, patients are less likely to benefit from medical resources. Attorneys working in collaboration with a treatment team can play important roles in alleviating stress that accompanies patients’ illnesses and reduce anxieties associated with medical-related legal issues. Collaborations with MLPs add to the arsenal of resources that patient navigators can tap to manage psychosocial needs of their patients.
MLPs acknowledge the substantial time pressures faced by clinical staff and, therefore, simplify advocacy intervention so it can be seamlessly integrated into initial clinical consultations. Health care providers, including navigators and nurses, can be taught to triage for certain legal issues. If legal intervention is needed, the provider’s role is clearly defined and does not add unwarranted responsibilities. In the MLP model, lawyers are situated in the same location as the medical treatment team. Ready availability of a knowledgeable attorney facilitates speedy resolution of legal issues that interfere with medical treatment. The following case example from LegalHealth exemplifies the inherent benefits of such collaboration in a cancer care setting.

Gloria is a 35-year-old woman with stage IV metastatic breast cancer. A patient navigator from a local hospital referred Gloria to LegalHealth after she received a letter stating that she no longer qualified for Medicaid because her income exceeded the eligibility limit. Termination of her Medicaid would prevent her from receiving life-prolonging treatment. LegalHealth requested a fair hearing and sent copies of Gloria’s monthly medical bills to Medicaid to validate that her medical costs qualified her for coverage, and her coverage was reinstated. At the same time, Gloria had received a letter stating that her food stamp benefits were terminated because of her failure to re-certify. LegalHealth represented her at an administrative fair hearing and succeeded in having her food stamp benefits reinstated retroactively. During the 5-month period that she received no food stamps, Gloria depleted her cash to purchase food, and consequently had insufficient funds to pay rent. LegalHealth, working in partnership with the patient navigator, secured a 1-month rental assistance grant from a local charity. LegalHealth’s timely intervention prevented an eviction. Because she is back on food stamps and Medicaid, Gloria can pay her rent and can focus on her treatment.

Gloria’s story is just one example of how legal collaboration with a health care provider can create positive results for patients. Legal collaboration with medical providers benefit patients across a variety of treatment settings by, among other things, increasing access to health care and improving the patient’s and family’s sense of well-being. In a self-evaluative survey completed by LegalHealth on 51 cancer clients, 83% of those interviewed said legal services reduced stress, 33% said use of legal services positively impacted family or loved ones, 51% indicated that legal services had a positive effect on financial situations, 23% said services helped them adhere to treatment regimens, and 22% stated that legal assistance helped them keep medical appointments.

**Patient Navigation and Legal Partnerships in the HIV/AIDS Context**

While the innovation of the MLP originated in pediatrics, MLPs now encompass many clinical disciplines, including geriatrics, primary care, oncology, and other chronic illness. The powerful role that MLPs have in improving comprehensive patient care makes MLPs a promising addition to the patient navigation model for any chronic disease. MLP collaborations that include patient navigators have occurred in the HIV/AIDS context and they are excellent sources of information, and experience, for new patient navigation programs in oncology settings.

Callen-Lorde Community Health Center provides sensitive, quality health care and related services primarily to New York City’s lesbian, gay, bisexual, and transgender communities regardless of ability to pay. In 2011, Callen-Lorde served over 15,500 patients; 23% were HIV-positive. In 2010, the Callen-Lorde Intensive Care Coordination team, which provides field-based case management services and health promotion to HIV-positive patients, developed a medical–legal partnership with Legal Services-NYC, now called “Healthcare Legal Partnership” (HeLP) with patient navigators as the key health care partner. The model incorporates regular training programs for patient navigators on significant legal issues, on-site intake of new legal cases by attorneys, creation of educational materials for patients, and development of strategies to address systemic legal issues impacting the health of the HIV community.

In this model, following a referral by the primary care provider, the HeLP team, including a patient navigator, conducts a comprehensive assessment of all medical and psychosocial needs. These needs may include health insurance, housing, home health care, entitlements, transportation, adherence, and child care. Additionally, the assessment screens for issues that may require legal intervention by collecting information regarding patients’ current housing status, source of income, insurance status, immigration status, and household composition, among other things.
The case of a person who has fallen behind in rent highlights the need for an attorney and patient navigator. In the best case scenario, the patient informs their patient navigator about the event causing the inability to make a rent payment before a missed payment: for instance, loss of income from employment or government benefits. At this stage, the patient navigator can work independently of the attorney. If the patient has become unemployed, the patient navigator can help the patient apply for unemployment insurance or public assistance, provide referrals for job placement programs, and determine the reason for job loss. The attorney can meet with the patient and discuss the case with the patient navigator and the steps they have taken up to that point. As the attorney develops a patient's case, a patient navigator is relied on to assist the patient in gathering relevant information. Optimally, the team will correct the issue, and rental arrears are paid before the landlord moves to evict the patient. This demonstrates the value of training patient navigators to identify issues before they escalate.

It is often the case that patients present with court evictions already in progress. In this scenario, patient navigators are trained to refer patients to the attorneys. Patient navigators guide patients through information collection before attorney meetings. In short time, an attorney assumes responsibility for the case and performs research, writes pleadings and makes appearances necessary for patients’ defense. Attorneys often rely on patient navigators to assist with a welfare agency that may be able to provide rental arrears and assistance, help patients gather necessary documents, escort patients to court proceedings, and re-explain processes and plans to patients as needed. In the end, the team’s regular communications amongst each other ensures the best possible results for patients.

The HeLP model has proven beneficial to the attorney, the patient navigator, and the patient. For the attorney, patient navigators ensure that patients follow through with requests from attorneys, and often most importantly, help create an environment of trust between the attorney and the patient. For the patient navigator, the trainings offered by the attorneys develop their understanding of the law and provide clear direction to address patients’ other needs and assist the attorney working on a patient’s case.

For patients, the model provides resources and support without the run-around usually associated with accessing legal services (assuming their health permits them to try in the first place). Patient navigators are extremely valuable to ensure that patients, despite bouts of illness and other obstacles, are able to follow through on their responsibilities in their case.

This HeLP model is easily transposed to other chronic disease settings, particularly oncology. Patient navigators are often frustrated by their perceived lack of power and limited understanding of the sometimes complex legal issues encountered by their patients. The HeLP model allows patient navigators to learn more about patients’ issues and achieve successful results in an efficient way; with the support of a skilled and expert team of attorneys to assist or take the lead when necessary.

**Patient Navigators and Legal Partnership in the Cancer Context**

Creative integration of legal services into oncology patient navigation programs is slowly beginning to appear throughout the United States. The Cancer Pro Bono Legal Project model was developed at George Washington University Cancer Institute and George Washington University Law School. This Medical–Legal Partnership is a model that connects law students seeking pro bono hours (under the supervision of licensed attorneys) with cancer patients and survivors. The program at George Washington provides patients with assistance on matters related to advance directives, insurance denials, simple wills, Social Security Disability initial filings, and employment related issues. The Duke Cancer Institute and The University of North Carolina Lineberger Cancer Institute have adopted a similar model. This program offers limited direct service through assistance with creating powers of attorney and advance directive documents, and includes a series of “Know Your Rights” presentations covering advance care planning, employment rights, insurance rights under the changes of the Affordable Care Act, and Social Security Disability.

Patient navigators are the front line for this program model. When the program began at GW Cancer Institute, the navigators were aware of some of the legal issues faced by their patients, but felt ill-equipped to identify or manage them appropriately. All three university programs provide training to the health care provider teams, including patient navigators, oncology nurses and social workers, as well as physicians, on common
legal issues faced by patients to recognize when a patient might benefit from a referral to the program. Clinical teams are given materials and resources for their patients about the Cancer Pro Bono Legal Project. Law students participating in the program must also attend rigorous training sessions to ensure competency with the areas of law, as well as sensitivity training on dealing with seriously ill patients and their caregivers.

Once a patient elects to enroll in the program, students are assigned and paired with a licensed attorney to help meet the needs of the patient. Patients with complex cases are referred by the Project to local attorneys specializing in the area needed, often checking the National Cancer Legal Services Network (NCLSN) database. The NCLSN promotes access to health care and seeks to increase the availability of legal services for people living with cancer, their families, and caregivers. Through direct work, educational efforts, and advocacy, this multidisciplinary coalition helps to alleviate the legal and economic consequences of cancer so that those affected may focus on their medical care and quality of life. The NCLSN supports the efforts of individuals and organizations focused on meeting the legal needs of the cancer-affected community. It augments the voice of disparate services, creates a forum for established and nascent legal advocacy groups, and facilitates the development of similar programs.

Among the positive aspects of the Callen Lorde’s H eLP Program and George Washington Cancer Pro Bono Legal Project is the ability to adjust programs to fit patient’s needs. These models integrate legal services with patient navigation processes, using tools and services that most effectively assist their distinctive populations. This flexibility and easy integration into different treatment situations will better assist the diverse array of patients presenting to developing and unique patient navigation programs.

CONCLUSION

Legal services are an important piece in managing acute and chronic illness. Legal services have a place in all aspects of patient navigation, from screening, active care, remission and relapse. Navigators are on the front line with patients coordinating and assessing medical and psychosocial consequences of illness. It is essential that patient navigators learn to recognize when psychosocial consequences are legal in nature and partner with legal counsel to address them.

This is a pivotal moment for navigation program leaders to look within their communities to find available legal resources, including existing legal aid programs, bar associations, and cancer advocacy groups. There are not enough free legal resources for people with cancer, but incorporating the need for such services as navigation standards are being implemented is a start. “As we plan for the future, we must recognize that if patient navigation programs are to overcome barriers to care for all people, particularly low-income people, there must be a full panoply of services, including legal assistance.” (H. Freeman, personal communication, November 2012).

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REFERENCES


12. LegalHealth case referral list.


