

Introduction

POLICY FORUM: *Patient Advocacy in North Carolina*

Advocating on behalf of sick, vulnerable, or dying patients is an age-old value of our society. Family, friends, and formal organizations take on this responsibility to help those who cannot help themselves or who need assistance. As the health care system becomes more complex, this role has become more apparent to the point where we see patient advocacy as an almost necessary element in our “non-system.” That necessity is compounded by the need to understand not just what is needed, but also how to gain access to the right kind of care at the right time, the right place, and at the right cost.

Our public programs Medicaid and Medicare have important patient advocacy elements and fund these activities in certain instances. This type of patient advocacy for the sick and disabled is gaining recognition as a permanent component of medical care. However, we are more familiar with programs that deal with specific types of people or special needs. Organizations such as the Red Cross advocate for victims of disasters while Planned Parenthood advocates for women’s reproductive health.

The ultimate goal of patient advocacy is to improve the quality, safety, and effectiveness of health care. This is primarily done through improved patient/provider communication. Traditionally the doctor has been the sole or dominant advocate for patients but we are changing the role of the patient and we are expanding the professions and developing teams that include lay-people. What does this changing paradigm mean for those who provide and receive health care?

Patient advocacy can, at times, come close to the boundaries of issue and policy advocacy as advocacy for patients whose needs are not well understood or recognized must press for attention not only for the individual but also to their class of disease or the problem they face. The overlap of these types of advocacy occasionally creates resistance from established institutions and professions who see threats to their power or their economic position. In the context of patient advocacy we have to recognize that there are emerging problems and conditions that, when better understood, deserve our attention and support and the services and resources of our professions.

The type of patient advocacy that this issue of the *North Carolina Medical Journal* focuses on is firmly planted in past traditions of advocacy for those who need the support of society. The scope of patient advocacy, as discussed here, is clearly focused on the patient and his or her family. But it also reexamines the entire medical model and attempts to shifting the focus toward the patient—her wants and her experiences. That approach is to provide health care that is patient-centered.

In the issue brief it is clear that there are many ways to practice patient advocacy. In the pages that follow we explore everything from the patient/provider interaction, to access to health care and health insurance. We learn from the experience of others that one can be an advocate for oneself or a family member, or that we can advocate by speaking out on behalf of countless others by using the law or the media. Anything that empowers the patient to make well-informed decisions and helps the patient to understand her options and to know her rights—this is what the scope of patient advocacy encompasses.

The growing attention to patient advocacy has profited, in part, from a health care system that gives currency to the term ‘byzantine.’ From multiple and conflicting professionals with different theories of care and cure to co-pays to deductibles to self-directed plans to diagnoses to prescriptions that turn into polypharmacy—there is simply too much for a reasonable citizen to understand. The aim of patient advocacy is to help guide the patient and her family through the maze and to ease the confusion and discomfort at every turn.

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