Chapter 18
Emergent First-Time Leadership in Patient Advocacy Organizations

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ABSTRACT

Leadership in effecting change and transformation of the healthcare landscape on behalf of patients resides chiefly in patient advocacy organizations. The purpose of this chapter is to focus on leadership among not-for-profit patient advocacy organizations both in the U.S. and Europe by examining case studies of first-time leaders emerging in recent decades. Characteristics of these selected individuals are analyzed in the context of established leadership theories. Because of the necessity of securing funds to fulfill an organization's mission, transparency is of growing importance as an on-going and future challenge. Social entrepreneurism is introduced at the chapter's conclusion for its possible relevance to tomorrow's leaders emerging in patient advocacy organizations. Such thinking opens the door to future research to identify essential elements of success in the examination of first-time leadership in patient advocacy and to determine how it is best nurtured, mentored, and applauded.

INTRODUCTION

The purpose of this chapter is to focus on leadership as it emerges in not-for-profit patient advocacy organizations in both the U.S. and Europe by examining case studies of first-time leaders among them in recent decades. This chapter resists the argument, especially in the era of patient-centered care, that patient/client advocacy belongs under the auspices of the professional nurse, or clinicians in general. Instead, it presents a novel perspective, grounded in case studies offered as examples and supported by established leadership theories, that leadership in effecting change and transformation of the health care landscape on behalf of patients today resides chiefly in patient advocacy organizations in the not-for-profit sector headed by a variety of leader types, or categories. The ethical challenges to secure mission-driven funding confronting the leader in not-for-profit are also raised, as full disclosure of sources and

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appropriate transparency are safeguards against potential loss of credibility and the public trust. Since the chapter concludes with social entrepreneurism as a new pathway for not-for-profit leadership, it also suggests entirely new initiatives and possibilities given the sustainable value as a model that it contributes, whether at the local community or global, societal level. The chapter, therefore, opens the door for a rich array of new graduate research and study.

Objectives for Student Learning

- To articulate the variety of characteristics, by category, of leadership that can emerge in patient advocacy organizations
- To understand through case examples the challenges that a leader confronts and overcomes in pursuing a vision and thus fulfilling the mission of the organization
- To identify the important role of engaging key stakeholders for support, resources and leverage
- To grasp how both transactional mobilizing and transformational organizing as concepts can maximize the engagement of others in collaboration, goal achievement and capacity-building
- To appreciate that contemporary leaders in the not-for-profit sector of patient advocacy do not exert influence over others based upon authority or title but rather because of the inspiration they generate with the passion in their voice, their energy and dedication, the consistency in their message and the respect they command by their behavior and fervor.

BACKGROUND

In nursing education, academicians long considered the counseling of patients by nurses to be a role and responsibility traditionally taught and thus expected of their graduates, once licensed, to practice in nursing. Educators considered this role essential to empowering patients to advocate for themselves (Holmes, 1991). Noteworthy is the fact that patients did not ask the nurse to counsel and thus empower them; rather, the nurse simply assumed, as taught, this was the role expected of the professional nurse (Mallik, 1997). Consequently, the professional nurse long claimed the chief role of patient/client advocacy on the basis that it is the patient's vulnerability when ill to have an advocate to speak for them (Curtin, 1979; Pellergino, 1981).

Others argue this role is justified simply because nurses know how to advocate since they understand how to navigate the health care system in which they work (Albarran, 1992; Fay, 1978; Graham, 1992; Jezewski, 1993; Jones, 1982; Kosik, 1972). Still others are of the opinion that nurses are in the best position to serve as patient advocates because of the sheer amount of time they spend with patients (Albarran, 1992; Gadow, 1989; Kosik, 1972). The literature alludes to opinions by still others that patients and nurses are natural allies because of their relative weak power compared to the dominance of physicians, at least historically (Winslow, 1984).

In the decades to follow such arguments, nothing has altered the landscape of health care more than technology and consumerism. The two drivers have changed health care delivery and patient care, in general, and thus patient advocacy, specifically (Smith, 1997; Cohen, Grote, Pietraszek, & Laflamme, 2010). Americans are increasingly using electronic health records and smart phones to make appointments, view lab results and reports and negotiate payment of their medical bills not covered by insurance. Over three-fourths of all U.S. health care systems have partially, or fully, converted to electronic