

From innocence to audit: Transatlantic lessons on the routinization of hospice

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Recently a British colleague called my attention to an article entitled, "The routinization of hospice: Charisma and bureaucratization," in the journal, *Social Science and Medicine*.¹ This well-researched paper by Nicky James and David Field represents a valuable contribution to hospice systems analysis and an asset to hospice programmatic and discipline-wide planning. The article reviews the history of hospice in Britain and surveys recent trends. The authors apply the organizational theories of seminal German sociologist-economist Max Weber (1864-1920) to this history. A predictable progression common to successful social movements is revealed; from hospice's origins as an idealistic reaction to intolerable prevailing conditions and toward routinization and bureaucratization. Looking ahead, Weber's theories provide insight into the forces currently acting upon hospice and the direction of coming change.

The article's style is scholarly. The details of history provided, the studies cited, and the density of analysis will be of interest primarily to academicians and hospice trivia buffs. Those involved in hospice systems planning will find their efforts rewarded by a heightened ability to discern trends and remain proactive as hospice encounters forces of quality assurance, audit, and health care reform.

The article's perspective is decidedly British. However, the implications arising from the analysis send a compelling message to hospice in America.

History

The seeds of hospice in Britain were sown in the social context of the 1950s, 1960s and 1970s. It was a time of relative peace and prosperity. Medicine was changing rapidly and acquiring ever greater power and esteem. Disease and its cure became the nearly exclusive focus of medical practice and medical research. Infectious diseases appeared to be on the verge of being eliminated as significant causes

of death. Heart disease, respiratory disease and cancer commanded greater attention. Indeed, it seemed that even cancer, the most dreaded of modern ailments, might soon yield to an aggressive research campaign.

During this period, dying in a hospital became the norm. Yet studies have found that prior to entering a phase of active dying, the chronically ill and the debilitated elderly tended to spend a large portion of their waning months at home, alone. The symptomatic care of patients with progressive illness, such as cancer, was often woefully inadequate. There were some long-term care facilities for those who failed at home. Many cancer patients and frail elderly lived in lamentable conditions which included public facilities that one quoted study called "human warehouses." The suffering experienced within was known, but rarely spoken of.

Hospice sprouted and took root in response to these conditions. Of anecdotal interest, the authors note that the British Voluntary Euthanasia Movement also enjoyed a flourish of public support during this time.

Application of Weber's theories

The history of British hospice conforms well to Weber's notion of important social movement originating through charisma and inevitably becoming routinized through bureaucracy. In Weber's view charismatic movements can give rise to valuable challenges to prevailing social beliefs and values. Such movements are commonly the stimulus for radical, important institutional innovations.

Charisma, in Weber's view, commonly arises from a personal response to intolerable situations or experiences. By their nature charismatic movements are inherently unstable, initially lacking an organized support structure. Early financial support takes the form of donations, grants, and endowments, all "uncontrollable, irregular sources of income." Authors James and Field identify specific features of the hospice movement that reflect its initial charismatic nature. These include:

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- The role of a highly visible leader;
- The spiritual motivation that led many to hospice work;
- The narrowness of focus on terminal care of cancer patients;
- An oppositional stance to the prevailing social context (in this case, established medicine of the period).

Charisma and organizational innocence

While a few hospices had existed in England and Ireland in the early 1950s, the inception of modern hospice movement is rightly attributed to the efforts and person of Cicely Saunders. Calling attention to social need and developing specialized expertise distinct from mainstream practice carries with it implicit criticism of the *status quo*.

The authors point out that Cicely Saunders' early efforts conform to Weber's view of charismatic leaders as being "creative and disruptive." Her enormous personal energy, absolute commitment and unique clarity of vision, had influence far beyond those in her immediate presence and was to change health care forever. Yet, for Dame Cicely, what was to become the "hospice movement" started at the bedside, by bringing the best of mind and heart to the care for her patients in their dying.

In order for the best of mind and heart to be available at many bedsides, organization on local and national levels would ultimately be required. The first priority and primary focus for hospice was symptom management. What was known about the effective management of pain, dyspnea and other sources of distress had to be uncovered, collected, put into practice—and taught to others. More potent, less burdensome modalities were needed and, thus, research was essential. Comprehensive care for the dying patients and their loved ones clearly required the clinical teamwork of trained personnel from a variety of disciplines. Dissemination and acceptance of the ideals that hospice embodied and the clinical approach hospice employed ultimately would require the efforts of many inspired volunteers and the support of the general public. Combined fund raising-public education campaigns of community programs and national associations were to prove an integral component of the movement's success.

The number of British hospices increased from under 15 in 1965 to more than 430 in 1991. In the United Kingdom today, hospice has entered the mainstream of

medicine. Through contracts with health district authorities hospice programs have begun receiving considerable financial support from the National Health Service. In 1987, palliative medicine was officially recognized as a medical sub-specialty by the Royal College of Physicians. Hospice concepts of care are part of the routine curriculum for district (public health) nurses and can be found in general physician training. Specially trained Macmillan nurses are available in many communities, where they serve as consultants to the district nurses and to the general practitioners on matters of terminal care. Hospice in Britain has gained the status of a "proper" career choice for nurses, physical therapists, social workers, chaplains, administrators and even physicians.

Routinization: Bureaucracy and audit

It is axiomatic that those movements that succeed—which is to say those which provide effective strategies and gain wide support—become established. Routinization is part and parcel of a social movement's success; with it comes stability, confidence, and bureaucracy.

For Weber, bureaucracy is the hallmark of routinization. The authors explore the emergence of bureaucracy in British hospice. They point to key features of bureaucracy that are reflected in the more recent history and current trends in hospice. These include:

- *The division of roles and responsibilities into spheres of authority determined by rules and regulations.* This has occurred within local hospice programs as a consequence of the established standards and guidelines of professional organizations and the regulation of law and bureaucracy.
- *A hierarchy of position, division of labor and channel of communication.* A conscious de-emphasis on hierarchy and blurring of job definition marked early hospice organizations. Recently there has been a trend toward professional role clarification within the interdisciplinary team. There has been an emergence of the role of the physician in terminal care. Additionally, specialized palliative care training and certification is now available to nurses and physicians in Britain who wish both the knowledge and recognition.
- *The work requires formal training.* Completion of a six week basic and eight week advanced palliative care nursing module are near requisites for hospice nursing staff positions and Macmillan

nurse practice respectively. One or more year programs leading to a diploma in palliative nursing are now offered at a few teaching centers. Even physicians can now enter postgraduate training, receive a specialty diploma and be granted consultant status in palliative medicine.

- *There is a separation of official activities and personal affairs.* From the article: "The early hospice workers worked long hours, both through commitment and lack of choice since there was no-one to cover if they were not there. While there has always been recognition that people have and need their own lives outside 'their hospice,' hours of work and 'cover' are increasingly regularized as hospices and health authorities recognize sources of stress arising from overly long hours."
- *Rules are applied to the performance of job responsibilities.* Early hospice leaders defied unwritten (and unspoken) rules of practice. As hospice has evolved and matured, clinical protocols have become commonplace. Clinical guidelines and formally developed standards of professional conduct effectively constitute rules for patient care.

Lessons for American hospice

While the history of hospice in America is unique, there are similarities to the history of hospice in England. On both sides of the Atlantic similar stages of development—and modern trends—can be discerned. The early development of hospice in North America was also charismatic, with a considerable portion of charisma flowing from Cicely Saunders as well as other prominent British clinicians such as Robert Twycross, Eric Wilkes, Derek Doyle, Geoffrey Hanks, Colin Murray Parkes, Richard Lamerton and many others. In North America, the work, writings, and public presentations of Elisabeth Kubler-Ross, Balfour Mount, Josephina Magno and others ignited a movement. American hospice was conceived later than its cousins in England and Eire and from inception manifested a distinct style (variety of styles) and temperament.

As is so often the case in comparing things British to things American, the history of hospice in the states appears hurried and compressed. The same progressive phases of development—from impassioned personal response, to charismatic movement, to public acceptance, establishment and bureaucratization—all seem to crowd in

and overlap one another. It is a familiar, if uncomfortable, modern experience: Future shock is a feature of our time.

As has been true for so many young growing up in the America of the 70s and 80s, there has been pressure for hospice to grow up fast. Responsibility and accountability were imposed very early. For American hospice and hospice programs, the period of guileless acceptance by the public and unabashed dependence on volunteerism and the generosity of the community seems now already over, before having been fully realized. Like our British counterparts, American hospice programs have changed from primarily informal and idealistic, to progressively more structured, rule-bound and regulated.

As a consequence of the compressed, overlapping phases of our brief history, many organizational aspects of hospice in America have become routine without hospice care having become routinely available. In fact the type of palliative care that hospice represents is frequently unavailable, especially to the poor, those of color, and those who do not speak English. Also, ironically, while the process of routinization is now well under way, much of the American public still does not know what the word "hospice" means.

The principle lesson to be taken from the article by James and Field is that change toward greater bureaucratization of hospice care is inevitable; that it is, in fact, inherent in the success of the hospice movement. It is a consequence of the growing acceptance of hospice concepts and ideals that we have worked so hard to achieve.

While bureaucracy may be part and parcel of any social movement's success, it comes with a new set of serious problems. Inevitably, bureaucratization will challenge the hospice's ability to remain true to its core values and goals. There is no need to *posit malintent*; this challenge to the movement's mission is a predictable effect of the interface of society and hospice organizations and component programs.

The increased attention on evaluation and audit, for instance, is a legitimate, responsible activity of bureaucracy and a mark of the maturation of hospice. While providing a welcome review of the quality of care, the authors' point to some of the problems that the process of audit will bring to hospice:

"The difficulties of defining and measuring the quality of inputs such as 'effective communication' and 'empathy' and outcomes such as 'feelings,' 'satisfaction' and 'well-being' are immense. Yet it is these inputs and outcomes which lie at the

center of hospice ideals. Will the pressure of audit lead to a diversion of interest away from such 'soft' factors towards the more easily defined and measured 'harder' indicators of treatment and 'output' such as drugs used, physical interventions made and bed throughput?"

Pertinent issues arise: What are the core values, goals and guiding principles of hospice? Have we adequately defined them? Is there a way to "etch them in stone?" How do we ensure that the core of hospice is preserved while the business of hospice moves forward? These questions will need to be asked again and again in the next few years.

A decade or two hence different questions may be posed. One of the problems associated with bureaucracy is the tendency for it to assume an independent existence. While social movements arise in response to intolerable conditions, bureaucracy tends to establish a new orthodoxy.

As hospice has matured, clinical as well as operational protocols have evolved. This is good—providing consistency, stability. But might these protocols and our organizational policies give rise to a clinical dogma? Will there soon be "the hospice approach" which does not tolerate criticisms or recognize clinical innovations that may hold value for our patients?

Orthodoxy diminishes the responsiveness of organizations comprising established "movements." Innovation is inhibited. Without the capacity for ongoing change, original intent can be thwarted. Laurence J. Peter, the late author (*The Peter Principle: Why Things Go Wrong*) and management pundit, said, "Bureaucracy defends the *status quo* long past the time when the *quo* has lost its status."

How can hospice proactively respond to these predictable challenges?

At a minimum, renewed emphasis must be accorded to the formal mission statements of each incorporated hospice organization and to the official, professional standards of relevant national associations. The National Hospice Organization's recently revised *Standards of Professional Practice*² represents an important contribution. It merits careful inspection and should become a valuable hospice management tool. Similar efforts are warranted by other national hospice organizations.

Collectively, formal statements of this nature represent the foundations of hospice in America. They function to anchor clinical practice and professional conduct to core concepts and ideals. While not immutable, they provide important documentation of original vision and intent. A

touchstone question for those who contribute to future practice standards and mission statements might be, "Have we accurately articulated the core of our work?" Mission statements and standards of practice which reflect our deepest goals are the most important investments we can make to the long-term health of our programs and, collectively, our discipline.

Operationally, on a day-to-day basis, attention to the hiring, training and support of staff is essential if an individual hospice program is to meet these standards and realize its mission. All staff, including business office and clerical personnel, deserve a thorough orientation to hospice as well as ongoing in-service education. We are not making widgets. We are meeting and striving to provide comprehensive care for patients and families who are in the midst of a complex, physically and emotionally stressful, and often chaotic, time in their lives. Clinical and nonclinical employees contribute their special talents and energies to this effort and deserve to share in the pride of working in hospice.

There is some reason for optimism. The current wave of Total Quality Management (TQM) and Continual Quality Improvement (CQI) which is sweeping through business management in America is impressive. TQM/CQI has the potential of fundamentally changing the nature of bureaucracy. It is possible that Max Weber's theories might no longer apply to such a changed organizational dynamic. Bureaucratic encrustation might just be prevented—or at least substantially delayed.

For we Americans, change is not only inevitable, the rate of change seems continually to increase. Events not only streak past us, at times they race toward us with threatening force. Discernible trends in where we have been and where we may be heading are most welcome.

Success for American hospice will require finesse in navigating among the obstacles and within the constraints of the emerging health care-economic environment. Success will also depend on the ability of hospice programs and professional associations to exemplify the discipline's founding ideals. Achieving both will require careful forethought and preparation. There is no time to waste. As we say in America, "The future is now." □

References

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