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Introduction: Ethics Committees and Failure to Thrive

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This Special Issue of *HEC Forum* asks "Are Healthcare Ethics Programs Failing to Thrive?" In pediatric medicine, 'failure to thrive' is a clinical observation associated with "growth and development less than expected, with evidence of one or more problems to be diagnosed and addressed before they lead to severe dysfunction (or death)." The term has been applied to ethics programs since the early 1990s (Fletcher and Spencer, 2005, pp. 301-302). As the authors of our contributions consider 'failure to thrive' they suggest various reasons why some ethics committees are troubled by their health, as well as making various recommendations to improve it. Ellison Conrad's case study that opens this issue poignantly traces the devolution of a successful ethics program—one that had captured the imagination and good will of the institution and the community it served but became increasingly irrelevant, both to the institution and to the community.

Ethics committees or their equivalent have been required as a condition of accreditation since 1992. In the two decades since they became common in U.S. hospitals, the institutions in which they operate have endured many vicissitudes as the healthcare system as a whole undergoes cataclysmic changes. As the context in which the ethics committee functions changes around it, individual committees struggle to accommodate, with varying degrees of success. Walter Davis' essay emphasizes the importance of attention to the specific environment in which a committee operates, and suggests that inflexibility can contribute to failure to thrive.

Committees may fail to thrive for many reasons, including invisibility within their institution, vagueness about their mission, or lack of support by the parent institution. Failure to thrive is particularly difficult to diagnose unless one takes into consideration the perspective of the evaluator and the criteria which are being applied. A committee in high demand for consults

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may be viewed as 'thriving' by its members, who relish the activity level, but viewed as failing in its educational role by Medical Staff evaluators who wonder why so many consults are called for the same issues. An administration wrestling with complex decisions may implicitly or explicitly constrain or reduce the range of issues for which ethics consults are deemed appropriate, conveying a message that some issues (or individuals) are 'out of bounds'. In organizations, in transition in a changing healthcare system, a pattern of function that was very successful for a committee at one point in its history may become less useful as its context changes.

Few will argue with the fact that health care in the U.S (and Canada) is changing rapidly, with many new and untested ideas concerning the direction of health care in the future. The shifting emphasis of the Joint Commission on the Accreditation of Hospitals focuses time and attention on administrators, managers and clinical staff and may divert organizational attention from activities sponsored by the ethics program. Recent Institute of Medicine reports have looked closely at the healthcare system, asking whether this system is effective and efficient and what can be done to improve it (Kohn, Corrigan & Donaldson, 2000; Institute of Medicine, 2001). Many of the newer ideas concerning these issues come directly from the recommendations of the Institute of Medicine. In this volume, for instance, Elizabeth Nilson and Joseph Fins take notice of recent Institute of Medicine initiatives, and argue that the Institute of Medicine's quality initiatives in health care should be applied to ethics activities. Thorough systematic evaluation of the programs data could be generated to determine what counts as thriving and what as failing. The federal and state governments are paying much more attention to health care as more of the tax monies they collect are allocated to health care for various populations. This has led to specific mandates requiring attention and time in each healthcare organization. Healthcare organizations themselves are attempting innovations aimed at decreasing costs and increasing efficiency, which change the climate within the organization, often without full consideration of the all the ramifications of the instituted changes. All of these changes force healthcare administrators and managers to evaluate how needed, how effective, and how efficient each of the institution's programs really are. "Soft" programs such as ethics programs may receive less attention and thus fail to thrive, as many programs are doing.

The three functions of any committee, education, policy development and consultation on individual cases, remain, but different committees may have shifted their priorities or distribution of labor as some of those functions are supplemented or supplanted by other institutional structures. A given committee may be valued for its consultation activities, but expected only to

rubber-stamp policies developed by other hospital units or committees. Different institutions provide varying support for the educational activities of their committees, as well as varying degrees of support for education for their committee members, often a low priority in financially stressed institutions.

Consultation

What are the signs and symptoms of failure to thrive that we see in many of today's healthcare ethics programs? Of the three canonical functions of ethics committees, consultation in troubling clinical cases remains the most visible. Thus, the most obvious problems, although not necessarily the most important, are associated with ethics consultation. Ethics consultation in a number of the institutions with which we are familiar has significantly decreased in number while increasing in complexity. Although controversial at first, when many thought the ethics consultants would act as the final arbiter in very difficult emotion laden questions (end of life decisions, decision making capacity, refusal of treatment, reproductive issues, etc.), when the non-directive, clarifying, consensus building aspects of the ethics consultation became recognized, acceptance by clinical staff members, administration, and affected patients and families in many institutions came quickly.

Previously, most ethics consultation cases surrounded issues well defined by state and federal case law and legislative actions, by professional ethics codes or guidelines, and by institutional policies and guidelines so that the ethics consultant(s) could offer a real service by helping to define the parameters that could be applied to the particular case without necessarily determining the "answer" to the problem. However, in a well functioning ethics program with an active educational component, the parameters for making these decisions can quickly disseminate throughout the institution and the need for more than occasional reassurance in occasional cases markedly decrease. This reduction in the volume of consults has been disconcerting to many ethics programs that have taken consultation as their primary task. Today ethics consultations frequently involve issues that are unique and not well defined, and therefore do not lend themselves to being "solved" by anybody. Consider, for instance, the diabetic patient who insists on contacting "food services" to order meals that inevitably put him in a coma, and who, when confronted by his doctor, contacts the institution's patient representative, who then is required to "write up" the complaint. Help in these cases does not depend on knowing which parameters apply so ethics consultants are no better equipped than others to determine what the "best"

or "most ethical" course is. Ethics consultants may be able to help in these cases by setting up meetings among the principals or by discussing similar cases, but beyond this their work may be limited.

Education

The education function of an ethics program is one of the most neglected in many institutions. Education has two faces—education of the committee, and education by the committee. Few committees require (or reward) specific ethics education for their members, who are typically busy clinicians for whom committee work is an additional burden in an already heavy schedule. If an institution is committed to the education of committee members, the paper in this volume by Pape and Manning offers an inspiring model. They give a comprehensive look at how education of committees might be undertaken and evaluated in an organization that supports committee education. Unfortunately, few organizations are supported to do so as thoroughly as the one they describe.

Education by the committee can be similarly under-supported. Familiar war-horse topics of clinical ethics can gather little interest and a degree of stagnation in the educational presentations sponsored by the ethics program has been noted. The paper by DeRenzo and colleagues describes how 'rounding' can serve as a site for reinvigorating the committee's education of the hospital membership, but institution-wide Grand Rounds on ethics topics often do not present an inspiring picture of the ethics committee's centrality. Specific topics for discussion tend to be repeated by the same educators or at least by educators who have similar ideas. Other required education in the institution (compliance, HIPAA, practice guidelines, etc.) takes up more and more of the time of the clinical staff once allotted to ethics education. While such topics have an important normative component, it may be difficult for a committee to take the initiative to contribute appropriately. In some institutions, risk management or compliance education seems to have completely supplanted ethics education.

Policy and Organization Ethics

The areas of greatest concern for the editors are policy development and review, and organization ethics. Although policy consideration and development have never been a primary focus for the average ethics program, these important aspects of institutional decision making have, since the advent of the clinical ethics movement in the latter decades of the 20th century, been considered an area which should concern the ethics program.

Ethics program attention is important particularly in reference to decisions concerning the level of treatment for very sick and/or dying patients and questions of who has the authority to make decisions for these patients. The case study by Collier and colleagues suggests that some committees are taking the initiative in suggesting possible policies, as well as reviewing policies submitted to them.

A process for "organization ethics" in healthcare organizations has been mandated by the Joint Commission on the Accreditation of Health Care Organizations (JCAHO) in 1995 and was recommended by the American Hospital Association at about the same time (JCAHO, 1995; AHA, 1997). The implementation of this recommendation has not been standardized. Many ethics committees have evolved from considering only patient rights issues to considering issues related to the institution as a whole and some act as a bridge between the parent institution and the community the institution serves. But how far should this go? Should the ethics committee of today look at issues related to the ethical climate of the entire organization and how this climate is maintained, or should it maintain its patient rights perspective?

Most ethics committees at present have not yet decided whether or not they *should* address management and operational decisions, although, as most will admit, such decisions have important ethical implications and dramatically affect ethical patient care. When these issues are not looked at in relation to the values of the institution, standards of right and wrong may be ignored or overridden without much discussion or thought.

But who is best able to provide this ethical oversight–and how should it be accomplished? Ethics committees are a part of the organization's structure but as they are now constituted they may not be adequately equipped to deal with these new, rapidly changing situations, and would certainly require a specific mandate from their organization in order to do so. And if they are to be reconstituted, how should that occur? The roles of those involved will change as well, but what will they change to? What issues should be addressed, and how?

Several of the papers in this issue address these questions explicitly. Patrick McCruden and Mark Kuczewski argue that clinical ethicists do not have the expertise needed to take on tasks associated with "organization ethics." They argue that these tasks are important and should be done, but they suggest that a role like that found in many Catholic hospitals and systems should be implemented – the role of mission leadership. They argue that clinical ethics activities should best be viewed as a resource for mission leadership, informing and informed by mission leadership.

Papers by Carol Bayley and Earl White speak to 'failure to thrive' from

positions of mission leadership. White describes a comprehensive approach to ethics activities within a large system of hospitals, and describes what he believes to be the most serious challenge facing today's ethicists. He believes that because of time and resources constraints, ethicists will have a difficult time recruiting and training for the future. Carol Bailey's paper, "Ethics Committee Dx: Failure to Thrive," looks at ethics programs in individual hospitals, and asks why they fail to thrive. She suggests various strategies to address it. Both these papers come from persons running successful ethics programs in large healthcare systems, and suggest through their insights the importance of institutional support of the sort that a 'mission leader' of a system can provide.

If we assume that patient care is not just a commodity, then in health care, any decision, any process, any policy, any role change, has ethical implications because it affects either directly or indirectly individual patient care or the community that is served by the healthcare organization. So an ethics committee may wish to assume responsibility for challenging decisions with ethical implications not related to direct patient care. Of course, this is not as easy as it sounds. It requires forethought, it requires the assent of at least some institutional leaders, it requires representatives from ethics committees educating themselves on issues they may not have hitherto considered relevant to their roles, it may require some restructuring of the committee and planning as to the most appropriate way of bringing these issues to the attention of leadership. But perhaps most important, it requires an examination of and a commitment to the organization's positive ethical climate and the development of effective mechanisms to support and enhance the values upon which it is based.

A number of ethics programs have attempted to expand their area of focus to include the ethical climate of the organization and to develop mechanisms to assure that the organization itself is functioning in an ethical manner. Although a few healthcare organizations have instituted organization ethics committees or groups, most would agree that this movement has not lived up to its potential and that today the ethical climate of the organization is seldom addressed or considered by major decision makers in most healthcare organizations. Thus, we believe the time is ripe to ask those participating in ethics activities in their institutions to reflect on their activities and ask whether or not their activities are failing to thrive, what they can do about it, what they can't do about it, and what they see as major challenges in the future.

We end with Jonathan Moreno's essay, "Ethics Committees: Beyond Benign Neglect." Jonathan offers a bleak assessment of the activities of most healthcare ethics programs. He suggests that a comprehensive approach that

takes into account the moral climate of an institution is needed for ethics programs to be successful but he suggests that given the low esteem in which most ethics programs are held such an approach, to be implemented, must be mandated by regulatory authorities.

The essays in this special edition are drawn from practitioners and academics. They represent a range of viewpoints, and are presented in a variety of voices. Some of the papers are written from an academic perspective, some are written from the perspective of someone "on the ground," and some are reflective pieces on what has gone on in a specific institutional setting. Although we do not begin to address all the issues associated with failure to thrive, we picked each essay for publication because we believe that the essay, whether or not we agree with the author(s), brings a unique perspective to the failure to thrive syndrome.

To our readers who are attempting to diagnose the health of their committees, or are seeking ways to improve it, we offer the following first-aid kit:

1) Evaluate present status and decide how the ethics program can realistically enhance the parent organization
    a. Involve administration, clinical staff, and other affected entities.
    b. Decide where the program should go, what steps are necessary to get there, and develop a timetable for change, asking for help when needed
    c. Check with other healthcare organizations and see how they are responding
2) Hire a consultant – Evaluation and advice from a knowledgeable and experienced person can be invaluable and, if major changes are likely, necessary. The consultant's work need not be overly expensive or time consuming.
3) Reinvigorate ethics committee members with educational programs and recruit new members eager for challenge
4) Involve administration and Board members in the planning
5) Obtain institutional buy-in at all affected levels.
6) Monitor the committee's function at regular intervals to check for signs of incipient malnutrition

None of these activities are easy – especially when those involved with ethics programs are feeling marginalized. Perhaps the most difficult is evaluating the present status of a program. It is never easy to critically evaluate an activity that one feels passionately about. But for us, at least, it seems the first step in trying to reinvigorate an ethics program, and a necessary barometer of continuing success.

We started this project in the hope that this issue will ignite concern about

ethics programs and their place in today's healthcare organization. We end with that hope because no matter how vigorous the ethics program seems today, the environment within which the institution functions continues to change, and what is true today may not be true tomorrow.

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