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The Structure of Pulmonary Hypertension Health Care Delivery: Translating Ethical Considerations into Practice

Michael McGoon

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The ethical imperative to provide optimal care to patients applies not only to individual caregivers, but also to the medical community as a whole. Best care frequently requires a team approach. This is the obvious basis for the common practice of referring a patient from one physician to another for all or part of the patient's management. The incremental benefit may occur by providing specialized knowledge to the medical issue at hand; by contributing a broad second perspective to an incompletely defined clinical problem; by applying particular technical skills; or by facilitating access to an infrastructure of management not otherwise available. Other less obvious advantages may result from referrals, such as reducing for the referring caregiver the intensity of labor involved in managing a complex patient and enhancing the breadth and depth of experience of the referred-to caregiver. This in turn may allow economies of scale to improve efficiency of clinical care, promote knowledge acquisition by observation of multiple cases, and facilitate opportunities for formal clinical research. Many of these issues are particularly relevant for diseases that occur relatively infrequently, especially if management is capable of influencing outcome. Pulmonary arterial hypertension

is an example of this category of disease. Are there principles that can be articulated to guide collaboration among caregivers to promote the best possible outcome in the most patients?

The starting point for determining the means of providing optimal care must be a clear understanding of what patients with pulmonary hypertension (PH) need and what the goals of successful treatment are. The needs of patients are: confidence in the accuracy of the diagnosis, achieved in a thorough and expeditious manner, recognition of the level of severity and prognosis of disease, clear and comprehensive explanation of treatment options, recommendations for the most appropriate treatment based on data that apply to their specific situation, access to conscientious follow-up, and continued attention to global health issues. The goals of treatment (in general terms) are: improved survival, reduced symptoms, improved functional and exercise tolerance, improved hemodynamic status, and maintenance of general health. Intermediary goals are those that serve as measurements of the degree to which the general goals are being met. These include: evaluation of quality of life, appropriately conducted and interpreted standardized functional or exercise tests, accurate assessment of right ventricular function, and integration of data into an evidence-based assessment of severity, prognosis, and degree to which therapeutic targets have been adequately achieved.

The multiple facets of evaluation and management imply that a clinical environment equipped to oversee care from multiple perspectives is desirable. On the one hand, specialized attention to the complicated evaluation and treatment of PH is required; on the other, accessible and knowledgeable care for general medical problems (whether directly related to PH or not) must continue to be available. The provision of both of these vital aspects of care may not (and in most cases, definitely will not) be centered in one location. Consequently, a system of collaborative care must be considered. The 2 fundamental components of such a system are a specialized center devoted to the pulmonary vascular disease and a primary caregiver attentive to the multiple medical demands of a patient with a life-threatening illness who is treated with complicated and frequently toxic medications.

SPECIALIZED CENTERS

The rationale for availability of specialized PH centers is compelling. A regulated system of a limited number of centers to which patients are reliably referred is already in place in a number of countries in which there is strong centralized health care allocation. Independent of political or cultural mandates, however, persuasive clinical and scientific justification for a nationwide organization of specialized centers can be articulated. The central argument is that consolidation of management of a low prevalence disease into focused centers allows for the development of an infrastructure by which to best achieve the “3 E's” of treatment: Efficacy, Efficiency, and Economy.

Efficacy

Although there has been no formal examination of outcome in patients managed in different types of practice, several lines of evidence exist to suggest that optimal treatment approaches and outcomes may be more likely in highly experienced centers compared to less experienced practices, including those in which patients are managed as part of a mix of patients with general medical issues, or even in general pulmonary or cardiology practices. Occasionally, when patients are referred late in the course of disease, it is apparent, in retrospect, that earlier diagnostic accuracy or therapeutic choices may not have been ideal.

Consultative phone calls from primary physicians to referral centers sometimes suggest that crucial procedures or decision making is occurring without important background information or technical knowledge. Pharmaceutical representatives sporadically report that they have seen debatable approaches undertaken in some of the practices they visit. While all of these “data-acquisition” methods are fraught with potential bias, the possibility is raised as to whether directing the patient to a referral center earlier may not have been beneficial.

Though most often the pattern is one of under-diagnosis and arguably under-aggressive treatment, the reverse scenario also occurs. Patients may be treated with expensive medications laden with potential adverse effects based on dubious or incomplete evidence that an appropriate indication for therapy exists.

In the absence of a specialized center, the ability to provide concentrated follow-up is certainly compromised. Follow-up to assess whether treatment targets have been achieved is increasingly recognized as a vital determinant of outcome, and therefore is central to the efficacy of any treatment plan. Follow-up entails not only appropriately timed office visits, but also interim contacts by telephone and rapid responsiveness to new or unexpected clinical developments. This type of follow-up, if undertaken with appropriate intensity, would generally lie outside the capacity of a busy practitioner dealing with a range of other patients and clinical situations. It would also be outside the scope of practice and expertise of allied health colleagues in a general practice.

A specialized center, on the other hand, would be expected to have expert physician and nursing resources with robust training and experience who practice in an intensively focused data-driven manner, and who are readily accessible to the patient, their primary caregivers, and to others (such as emergency room staff) who may become involved with the patient at any time. This type of ongoing assessment of a treated patient is vital for making adjustments in therapy on a continuing basis, if necessary, in order to best achieve treatment targets as early as possible.

Efficiency

Consistent levels of patient demand and development of a dedicated infrastructure at a busy referral center promote efficiencies of operation that would be difficult to replicate in a general medical, cardiology, or pulmonology practice. Practice algorithms, clearly delineated responsibilities of personnel, access to related areas of expertise, and procedural standards create an environment conducive to expedient evaluation and delivery of therapy. Although there may be variability between centers, a patient referred to the Pulmonary Hypertension Center at Mayo Clinic for suspected PH generally would have a complete noninvasive and invasive evaluation and prescription for therapy within 48 hours of presentation. This includes referral to relevant related areas of expertise (such as rheumatology, adult congenital heart disease specialists, interventional radiology, medical genetics, surgery, and transplant services if appropriate) and to specialized imaging areas (CT or MR scanning), as well as comprehensive physician- and nurse-administered education and support for the patients and their families. The center is staffed by both pulmonologists and cardiologists who see 25 patients per week. In addition, a pulmonology or cardiology fellow and/or medical resident is usually in attendance.

Efficiency is an important aspect for a specialized center referral practice since patients will often have traveled out of their locality in order to be seen.

Economy

Pulmonary hypertension is expensive. Medical therapies are among the most costly for any disease, even more so when considering expected duration of treatment. From a societal standpoint, it is incumbent on the practitioner to manage costs whenever and wherever possible. The ability of specialized centers to provide efficient workups and tailor therapy to the appropriate indications contributes to economical care. From an institutional perspective, efficient care (mainly in the outpatient environment) reduces costs and diminishes risks of complications that would incur further expense. For example, at our institution we routinely initiate intravenous prostacyclin analogues in the outpatient clinic since facilities and personnel have been developed to provide adequate oversight without the need for potentially costly inpatient stays.

COLLABORATION

Despite the advantages that a specialized center can provide, it remains abundantly clear that the specialized center should not, and indeed cannot, assume primary care for the patient. This is in part necessitated by geographical separation between the patient's locale and the referral center. More importantly, the efficiencies and economies-of-scale provided by the specialized nature of the center would be thwarted by dealing with daily comorbid health issues, many of which are not directly related to the presence of PH. Most importantly, however, is that the expertise that the specialized caregivers provide for management of PH is countered by the relative paucity of expertise they have for other medical problems. The primary physician is uniquely qualified to address these issues and remains therefore indispensable for optimal patient management.

The key to collaboration is bidirectional communication. Ideally, correspondence between the referring physician or local caregiver and the referral center should transparently address the roles of each: that the referral center will continue to follow up and play a leading role in management decisions pertaining to PH whereas the primary caregiver will continue to assume overall care. It is important that lines of communication remain open so that clinical decisions can benefit from all key perspectives. If, for example, a patient requires orthopedic surgery, what are the considerations? Where and by whom should this be performed? Is there adequate surgical and anesthesiology expertise to handle such a high-risk patient locally? Is it clear what needs to be monitored and in what setting? What adjustments may need to be made to best guarantee patient safety?

How can a collaborative atmosphere best be ensured? Timely correspondence is an important first step. Adjuncts to this may include clinical and educational outreach from the referral center to the communities from which patients have been referred, mechanisms for linking referring physicians to electronic records of his/her patients at the referral center, or priority phone lines for referring physicians (and their patients) to access PH specialist physicians, nurses, or the scheduling office. Although various institutions may need to “solve” individually the specific issue of how best to collaborate with referring physicians, the common denominator must be overt recognition that the referrer and the referral center constitute a team of equals who contribute pivotally to overall management of the patient.

CENTERS OF EXCELLENCE

The discussion thus far has posited that a specialized center does indeed provide a

substantial increment of benefit to the assessment and management of a given patient with PH. But how can this be assured? There are certainly a number of institutions in the United States and internationally that see many patients, have participated in clinical studies, and conduct basic research in the area of pulmonary vascular disease. It is not unreasonable to suppose that these centers represent a high level of quality in caring for patients with PH. Nevertheless, at present there is no definition of what constitutes an “excellent” or even above-average specialized PH center, nor is there any method for credentialing, ranking, or otherwise recognizing such centers. Although the idea of defining centers of excellence or credentialing has been raised, such discussions have never been extended. Obstacles to doing so have been appropriately identified: who would do the defining or credentialing; what criteria would be used; what would the implications be; how would the process be administered? The fact that formal discussions have not yet occurred should not pose a barrier to considering here how such an endeavor might be pursued.

Should Centers of Excellence be Credentialed?

The answer to this question (and the related one about whether individual physicians should be licensed as “PH specialists”) requires resolution between 2 opposing perspectives. On the one side is the opinion that high quality specialized centers have much to offer for optimal patient care (as discussed above) and that there should be some way to identify to both referring practitioners and patients those centers which might be expected to provide them with superior care. On the other side is the concern that any method of assessing programs will not perfectly capture all the parameters that define quality, such that some programs will be erroneously included, and (perhaps more unjustly) some would be wrongly excluded from being credentialed. Additional concern is that this would simply add further regulatory hurdles to a profession that already seems burdened by excessive red tape.

Both perspectives are supported by persuasive arguments. The opinion of this author is that although the criteria may be difficult to define, there exist in theory qualities that are characteristic of centers and individuals most likely to provide efficient, accurate, effective, and innovative progress-oriented care. Though easier said than done, the medical community would be providing a service to itself, and to patients, in describing and cataloging qualities by which institutions and practitioners could be compared. At this juncture of health-delivery evolution in the US, it seems likely that increasing emphasis will be placed on the value of care delivered as a means of determining reimbursement; thus, disciplines prepared to address this will be at an advantage. Whether the appellation of “excellence” or another form of identification is less important than the fact that some distinction is used to inform the public about the quality of PH management that is being reimbursed.

Who Should Establish Criteria and Do Credentialing?

While it may be possible to agree that there are hypothetical criteria that define excellence, or at least adequacy, it is more challenging to contemplate who might be in a position to establish these criteria and then adjudicate among centers and practitioners. It seems appropriate that relevant professional associations would take on this responsibility. In the field of PH, representation from the Pulmonary Hypertension Association, American Thoracic Society, American College of Chest Physicians, American College of Cardiology, and American Heart Association might provide broad input and credibility. Of course, individual participants may bring to this effort biases which could be perceived as promoting their own interests, but this could be ameliorated to some degree by selecting individuals with diverse

perspectives as well as respected clinicians, scientists, and administrators who are knowledgeable but do not have direct self-interests within the field of PH. Though arduous, such a process should not be impossible; it has already been accomplished in other subspecialty disciplines. As a first step, the process by which other clinical fields (such as interventional cardiology or electrophysiology) have achieved meaningful accreditation standards should be examined in order to replicate the results. The difficulty of this task should not be an impenetrable barrier to proceeding with this initiative.

What Criteria Should be Utilized?

If, as suggested previously, a broad-based committee (board) were to be charged with developing a process for accreditation, it would be premature and presumptuous to suggest at this juncture what the criteria should be. Nevertheless, the discussion must start somewhere and it is not unreasonable to propose the dimensions that should be considered.

At an institutional level, reasonable parameters of quality should include volume of cases, staffing levels (physician and allied health), availability of related disciplines and clinical laboratories, quality control, research involvement, and outcomes. At an individual level, parameters might include personal case volume, medical and subspecialty board certification, continuing medical education, and formal knowledge assessment (eg, “board examinations”).

Specific criteria and thresholds of acceptability would be the responsibility of the board.

THE ETHICS OF PH HEALTH CARE DELIVERY

The overarching ethical principle in this discussion is the obligation of the medical community to provide the best possible care to the patient with PH. Dilution of specialized care to a relatively sparse patient population risks inadequate and unmonitored clinical methodology and injudicious application of expensive resources. The foregoing discussions and the tentative general proposals are intended as a starting point for further consideration and conversation. The advantages of such a realistic examination of PH would seem to outweigh any purported difficulties; ultimately, such abstract ethical principles must be translated into tangible and transparent practices.

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