Quality improvement science permeates the culture of health care. Infrastructure and systematic changes have been instituted with the ultimate goal of improved care delivery at reduced expenditures. Unfortunately, the scope and status of pediatric heart failure quality improvement cannot be accurately assessed as there is a paucity of publications in the literature. Nonetheless, there are models in health care that exist as is evidenced by the American College of Cardiology and the American Heart Association approved process measures for quality improvement in heart failure in the adult population. Despite these efforts, defining appropriate process measures is challenging as the ultimate goal is to positively affect the outcome. Linking process measures to outcome measures may be fraught with difficulties. However, the paradigm of process improvement has been associated with institutional adherence to guidelines and ultimately improved overall outcome. In pediatrics, our field has limited comprehensive, universal registries and trials. Similarly, heart failure in pediatrics exemplifies a heterogeneous population with many comorbid conditions. These challenges incite the need for strong advocacy for this process which will be constantly evolving. Organization and infrastructure to augment quality improvement across centers will be vital to ultimate success. Finally, via leveraging existing pediatric databases, international collaboration of committees, and the development of a comprehensive registry, guidelines for quality improvement in pediatric heart failure may be developed.

1. Introduction

W. Edwards Deming created the intellectual foundation for quality improvement science. Applications of his concepts have been applied to industry and entrepreneurial endeavors with success. Translating this science to health care has led organizations to create infrastructure to assure quality improvement permeates the culture of hospital systems. However, even though the Center for Medicare and Medicaid Services and the United Network for Organ Sharing has very strong metrics for quality improvement for pediatric heart transplant programs, at present, there is no governing body or health advocacy organization that has set quality improvement standards for pediatric heart failure care. In adult cardiology models, there are published standards for heart failure quality improvement. Via an understanding of adult health care models and analysis of the current state of pediatric heart failure care delivery and infrastructure, an initial discussion of quality improvement science commences in our field.

2. Text

The actual status of pediatric heart failure quality improvement science cannot accurately be assessed as there are no published data detailing endeavors. Nonetheless, in pediatric medicine, institutional level initiatives are ever growing. Similarly, pediatric cardiac care has led to multiple avenues for collaboration across centers including national quality assurance partnerships, registries, or research networks. This prototype has been extremely beneficial for a better understanding of rare diseases and the development of practice models. The challenge for the pediatric heart failure community is that there is no universal multicenter database at this time. Several entities do exist that have been prolific in publications and advancing the field including the Pediatric Heart Network, Pediatric Cardiomyopathy Registry, and the Pediatric Heart Transplant Study group to name a few. Unfortunately however, development of a universal database is still elusive although it is sure to become a reality in the near future through the founding work of the International Society of Heart and Lung Transplant. With this current dynamic, opportunity exists to write our own story detailing the uniqueness of pediatric heart failure quality improvement in a simultaneous fashion with forging a contemporary, multicenter, comprehensive database.

The timing for setting benchmarks is impeccable as many health care systems are demanding value and certainly suggesting that “pay for performance” models will become a standard for pediatrics. The word “value” is difficult to construe for each patient population but Porter in 2010 placed it in context by stating that value is defined as outcomes relative to costs thus it encompasses efficiency [1]. He further stated that value should determine the framework for performance improvement in health care. In turn, by measuring value, the reimbursement system may be reformed to provide bundled payments for a full
care cycle covering periods of a year or more. In other words, by aligning reimbursement with value, it rewards institutions for efficiency and assures accountability for substandard care [1]. Additionally, there are reports in the literature that show that "pay for performance" models outperform public reporting in obtaining the desired, specific care for a particular condition [2]. Utilizing these concepts as groundwork, conceptualizing quality in our field should assure the best outcomes which will ultimately translate into efficiency and value.

In the adult cardiology world, guidelines have been published for clinical performance measures in heart failure and endorsed by the American College of Cardiology and the American Heart Association [3]. These endeavors, in most cases, may be adapted and altered for a pediatric population, however it is likely worthwhile to mirror the concepts but not simply transform adult guidelines to those for children (Table 1) [3]. Performance measures directly measure quality of care by a health care provider or group and encompass important characteristics including being reliable, reproducible, and practically assessed [3]. Performance measures ultimately should lead to system redesign to assure beneficial care is universally provided to all patients [4]. Each performance measure would have its own interventions based on the particular hospital system. What works in one organization may not work in another and thus innovation is paramount within a system. Nonetheless, the use of well-defined process measures across institutions, whatever the intervention to obtain the goal, should lead to universal, guideline based therapies provided to appropriate patients. This paradigm should lead then to better outcomes.

Table 1
Adult heart failure quality improvement metrics (2011) [3].

1) Left ventricular ejection fraction (LVEF) assessment: Percentage of patients with heart failure in whom quantitative or qualitative results of a recent or prior (any time in the past) LVEF assessment is documented within a 12 month period
2) Left ventricular ejection fraction assessment: Percentage of patients with a principal discharge diagnosis of heart failure with documentation in the hospital record of the results of an LVEF assessment performed either before arrival or during hospitalization, or documentation in the hospital record that LVEF assessment is planned after discharge
3) Symptom and activity assessment: Percentage of patient visits for those patients with heart failure with quantitative results of an evaluation of both current level of activity and clinical symptoms documented
4) Symptom management: Percentage of patient visits for those patients with a diagnosis of heart failure and with quantitative results of an evaluation of both level of activity and clinical symptoms documented in which patient symptoms have improved or remained consistent with treatment goals since last assessment or patient symptoms have demonstrated clinically important deterioration since last assessment with a documented plan of care
5) Patient self-care education: Percentage of patients with a diagnosis of heart failure who were provided with self-care education on ≥3 elements of education during ≥1 visit within a 12 month period
6) Beta-blocker therapy for left ventricular systolic dysfunction: Percentage of patients with a diagnosis of heart failure with a current or prior LVEF of ≤40% who were prescribed beta-blocker therapy with bisoprolol, carvedilol, or sustained-release metoprolol succinate either within a 12 month period when seen in the outpatient setting or at hospital discharge
7) Angiotensin-converting enzyme inhibitor (ACE) or angiotensin II receptor blocker (ARB) therapy for left ventricular systolic dysfunction: Percentage of patients with a diagnosis of heart failure with a current or prior LVEF of ≤40% who were prescribed ACE inhibitor or ARB therapy either within a 12 month period when seen in the outpatient setting or at hospital discharge
8) Counseling about implantable cardioverter-defibrillator (ICD) implantation for patients with left ventricular systolic dysfunction receiving combination medical therapy: Percentage of patients with a diagnosis of heart failure with current LVEF ≤35% despite ACE inhibitor/ARB and beta-blocker therapy for at least 3 months who were counseled about ICD implantation as a treatment option for the prophylaxis of sudden death
9) Post-discharge appointment: Percentage of patients discharged from an inpatient facility to ambulatory care or home health care with a principal discharge diagnosis of heart failure for whom a follow-up appointment was scheduled and documented, including location, date, and time for a follow-up office visit or home healthcare visit

Key adaptation for organizations centers on managed care, accreditation, patient empowerment, and risk management. Quality improvement science incorporates all of these factors and provides a framework for continuous adaptive strategies ever changing based on data. The Institute for Healthcare Improvement developed the Triple Aim which encompasses a model to improve the health of a population while reducing costs. This paradigm includes simultaneously improving population health, improving the patient experience of care, and reducing per capita cost [5]. Although this is a lofty goal as pediatric heart failure quality improvement is in its infancy, it is a reasonable prototypic model to adapt. In pediatric heart failure, our field struggles to absolutely know the scope of the problem especially as we deal with a markedly heterogeneous population. Simply trying to define and quantitate the patient population has been difficult. Rossano and colleagues published a retrospective analysis of the Healthcare Cost and Utilization Project Kids’ Inpatient Database for patients less than 18 years of age for heart failure [6]. The authors found that heart failure related hospitalizations occur in 11,000 to 14,000 children annually in the United States, with an overall mortality of 7% [6]. It is clear that heart failure, with all of the comorbid conditions, constitutes a very large percentage of health care system utilization in pediatrics. Despite this very comprehensive analysis representing the largest population based study of heart failure in children, the study exemplified the limitations of a large database restricted to ICD-9 codes with no gold standard for the diagnosis of heart failure. Additionally, only hospital data were able to be reviewed and thus outcome was unable to be obtained long term [6]. The lack of granularity of such a database limits strong understanding and exact determination of the scope of the problem. Pasquali et al. have described the leverage of multi-center databases in pediatric cardiovascular research [7]. In other words, linking databases with differing qualities and informational infrastructure may capitalize on the strengths of each dataset while mitigating the weaknesses of each. This strategy may also allow for longitudinal evaluation of some disease processes instead of describing isolated outcomes restricted to the individual dataset [7].

In the adult medicine arena, OPTIMIZE-HF is a registry and performance improvement initiative [8]. This registry enrolled hospitalized patients with heart failure and collected data via a web-based case report form system on in-hospital and post-discharge heart failure management and patient characteristics. Five original process measures endorsed by the American College of Cardiology and the American Heart Association were subsequently analyzed using this patient population. In short, prescription of an angiotensin-converting enzyme inhibitor or angiotensin receptor blocker at discharge was related to 60- to 90-day post-discharge mortality or re-hospitalization [8]. Similarly, beta-blockade at the time of hospital discharge was strongly associated with reduced risk of mortality and re-hospitalization during follow-up [8]. The other measures had no impact on mortality or re-hospitalization [8]. This analysis points out that identifying and validating performance measures is extremely important if the ultimate goal is to affect outcomes. However, OPTIMIZE-HF is the largest national hospital-based program dedicated to quality improvement in heart failure care. Hospitals that participated in OPTIMIZE-HF did demonstrate increased adherence to guidelines over time and had improved hospital mortality rates overall [9]. In pediatrics, we are plagued by limited data. The field lacks registries and clinical trials with adequate subject numbers thus yielding expert opinion guidelines for monitoring and managing our patients. This certainly poses the risk that initial quality improvement performance measures defined for pediatric heart failure may not be associated with outcomes, value, or efficiency. Nonetheless, advocacy for this process must be strong and constantly evolving. Organization and infrastructure to augment this process across centers will be vital to ultimate success.

Outcome measures, which may encompass mortality, health resource utilization, and quality of life, are the ultimate goals of quality improvement processes. However, as discussed, the tact in adult medicine has been to define performance measures that are attainable,
reproducible, and are evidence based to ultimately affect the outcome. It is reasonable to speculate that in pediatrics, the same paradigm will be followed, however with all the aforementioned concerns including smaller, heterogeneous patient populations, lack of registries and trials lending to a lack of strong evidence based medicine, the dilemma of actually defining the correct performance measures is enhanced. Nonetheless, this is not the only issue with attempting to affect the end result, as outcome measures themselves have limitations [10]. For example, with mortality, it is very difficult to discern death due to heart failure or other causes as there are many confounding variables. Similarly, assessing health resource utilization, especially readmissions, is fraught with inaccuracies. Readmissions must be defined as whether it is heart failure related or for another cause. Also, it is extremely challenging to track patients when they may be readmitted to other centers or seen in other emergency departments [10]. These few examples compound the already complex interplay of quality improvement science and relatively rare diseases in pediatrics.

3. Conclusion

Quality improvement tools, education, and culture sculpt the framework for continuous change and adaptation of organizations and health care delivery systems. The paradigm of optimizing collaboration of international pediatric heart failure committees with strong health care organizational endorsement and the simultaneous development of a universal, contemporary, and dynamic registry may lead to the development of practice models. Linking phenotype and genotype data and evaluating targeted therapeutics for pediatric heart failure will further enhance the care of this patient population and potentially lead to stronger evidenced based guideline directed therapy. All of these endeavors will ultimately fuel the evolution of pediatric heart failure performance measures that will impact outcomes and optimize care.

Conflict of Interest

There are no conflicts of interest to note.

References