

## Patient Centered Care



### Introduction

Dental decay (caries) is the most prevalent chronic disease of childhood. It is so widespread in the pediatric population that the U.S. Surgeon General described it as a “silent epidemic”.<sup>1,2</sup>

*Although dental caries has been declining for most age groups, according to the CDC, the prevalence of dental caries for pre-school children is increasing, despite being largely preventable with estimates of untreated decay ranging from 14% to 31%.<sup>3,4</sup>*

Untreated caries can cause pain and infection, which can result in poor nutrition, interfere with sleeping and affect a child's ability to speak, learn and socialize. Poor oral health also increases a child's risk of other disorders which can affect overall health and increase the possibility of fatal infections.<sup>5</sup>

There are many reasons why our current health care system struggles to deliver oral health care effectively to all children who need it. However, a major factor has been the lack of integration of oral health into the overall health system. Young children visit physicians earlier and more often than they visit dentists, especially during the all-important first years of life. In contrast, older children will often visit a dentist more often than their physician.<sup>5</sup> Yet, attempts to coordinate care through medical and dental homes have been isolated and have had many limitations.<sup>6</sup>

The task of providing adequate access to care will only become more difficult as the provisions of the Affordable Care Act are enacted in coming years. It is estimated that 8.7 million children will be added to the number of insured and many will have dental benefits for the first time.<sup>7</sup> Given the limited resources available and the looming potential increase in the patients seeking care, now more than ever, is the time to examine approaches to health care that foster increased integration and coordination while addressing evolving patient needs and expectations. The model of caries initiation proposed by Fisher-Owens et al (Pediatrics) suggested that inroads in the childhood caries epidemic will come from non-biologic as well as biologic interventions with closer attention to the roles of family and the community.<sup>8</sup> Patient- and family-centered care is a concept that may improve the oral health of children.

# The Principles of Patient- and Family-Centered Care (PAFCC)

The term patient-centered care came into use in the late 1960s to discuss how practitioners should interact with their patients and signaled a shift from the traditional clinician- or disease-centered models. As the values of patient-centered care evolved and moved beyond the hospital setting where they originated, they were adapted to different areas of health care delivery and the term was renamed and appropriated in various ways. Today, patient-centered care is generally defined as “care that is respectful and responsive to individual patient preferences, needs, and values”<sup>9</sup> but there is no consensus about its meaning. This article uses Walker and Avants’s method of concept analysis as a framework to analyze PCC. A literature search was completed and data were collected using several search engines (CINAHL, Medline, PubMed, and Cochrane Review). However, the term is somewhat limiting in recognizing the role of the family in child and young-adult care. The term “patient- and family-centered care” grew out of the patient-centered care concept along with the desire to create a model that is more focused on the child and the family. The American Academy of Pediatrics (AAP) has adopted the term “patient- and family-centered care” to better describe the role of the family in pediatric patient-centered care and emphasize the importance of their support and perspective in the health care decision-making process.<sup>10</sup>

Patient- and family-centered care (PAFCC) seeks an approach grounded in collaborative decision-making among patients, families, dentists, physicians, nurses, and other health care providers for the planning, delivery, and evaluation of health care.<sup>11</sup> This approach acknowledges that care should be planned not only around the individual child, but also around and in partnership with the family.<sup>10</sup> In order to meet the physical, psychosocial, and developmental needs of the child, the values, strengths, culture, traditions, expertise, and goals of the family need to be understood and respected by health care professionals.<sup>12</sup> Viewing care in the context of this framework, patients, families, and practitioners can engage in a partnership approach to care that honors the following principles.

## 1. Respect and Cultural Competence

- *Cultural sensitivity towards the family*, which includes, but is not limited to, socioeconomic status, race, religion, ethnicity, and perception of care.<sup>10,13</sup>
- *Respectfully considering the family’s needs and preferences* in making decisions to ensure flexibility in practices.<sup>10,13</sup>
- *Advocating services with the purpose of building on the family’s strengths* and tailored to the needs, beliefs and cultural values of the family.<sup>13,14,15,16</sup>

## 2. Integration and Coordination of Care

- *Multidisciplinary teams working together to deliver care*. These include families, health care providers, case managers, educators, insurers, policy makers, and community support systems.
- *Successfully facilitating care among these multidisciplinary teams to improve collaborative efforts and access to care*. This can be achieved with improved case management (see Pediatric Oral Health Research and Policy Center brief: Case Management, 2013).<sup>13,14,16</sup>

## 3. Communication and Information Sharing

- *Maintaining open communication among the health care team and between the team and family* to ensure transparency, continuity of care, and broad input into the treatment planning process.<sup>10,13</sup> This can be fostered through enhanced communication skills and the use of improved health information technology.
- *Enhancing health literacy* by providing families with access to educational materials and support programs in order to understand and achieve treatment objectives and outcomes.<sup>10,13,16</sup>

## 4. Quality of care

- *Providing high quality, evidence-based health care to patients and their families*.<sup>13,14,16</sup>
- *Gaining feedback from families and the health care team* and collecting objective data which can be used to improve health care delivery and outcomes.<sup>14,16</sup>

## 5. Whole-Person and Comprehensive Care

- *Ensuring the patient’s physical and mental health care needs are met* by providing a medical and dental home for families.<sup>14,16</sup>
- *Placing an emphasis on health promotion*, which includes preventive care and education, to reduce risk factors and improve quality of life.<sup>10,14</sup>

Although these five individual core principles have been identified, many elements of these principles will, and should, overlap and intersect for a patient- and family-centered approach to be effective. An overarching theme is the need to care for the entire patient (and in the case of pediatric care, the entire family) not just a particular disease or condition. When functioning together these principles allow the health care team to collaborate across the spectrum of health management and provide a continuity of care over the lifespan with a particular emphasis on health promotion and disease prevention. Some of these principles are demonstrated in the medical home concept which has increasingly become the standard for provision of high-quality comprehensive care. The 2007 National Survey of Children’s Health found that children

who received care in medical homes were less likely to have unmet medical and dental needs and more likely to have annual preventive visits<sup>17</sup>. The concept of the medical home is centered around the idea that the practitioner be very familiar with the child and the family. This type of relationship fosters care that is accessible, coordinated and compassionate while encouraging mutual responsibility and trust<sup>16</sup>. The medical home concept has been embraced by the pediatric dental community as well in the form of the dental home, “As in medicine, the dental home should embrace prevention at the earliest time possible”<sup>18</sup>. The ideal characteristics and practical advantages of a dental home are that it be accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent<sup>18</sup>. Patient- and family-centered care would envision a seamless integration between the medical and dental home. A recent report suggests that both pediatric dentists and general dentists already incorporate elements of the dental home (Hammersmith et al, JADA, 2013).<sup>19</sup>

## **The Potential Benefits of Patient- and Family-Centered Care**

The potential benefits for patient- and family-centered care include improved patient and family health outcomes, increased patient and family satisfaction, increased professional satisfaction, decreased health care costs, and more effective use of health care resources.<sup>11</sup> Realizing these potential benefits depends greatly on how the principles of PAFCC are put into practice, as well as the settings in which they are carried out.<sup>13</sup> For example, changes in traditional family structures, such as single parent families and families with foster children, may influence the way PAFCC is implemented. Current models of care may no longer be sufficient in meeting the needs of the

diverse family types that compose our society. As for health expenditures, the continual rise of health care costs has resulted in models of care that are increasingly unsustainable and place care at a cost too great for many families to bear.<sup>20</sup> At this writing, the so-called mandate for pediatric oral health care in the Affordable Care Act may be in jeopardy because of large deductibles, out-of-pocket expenses, and competing health insurance. Many health care reforms currently being explored focus on reducing costs while maintaining quality. These types of social and fiscal factors have resulted in the need to explore the potential benefits of approaches that might better meet the health care needs of children and families.

After a thorough review of the literature, limited health outcomes-based research was found involving patient- and family-centered care. There were few studies pertaining to pediatrics and even fewer in dentistry. More specifically, there was little evidence to support PAFCC in pediatric oral health. However, a small number of studies examined pediatric medical homes and family-centered care, although the majority of these were based on surveys completed by parents. Several of these survey-based studies found that children with a medical home have increased preventive visits, increased dental visits, and decreased emergency visits when compared to children without a medical or dental home.<sup>20,21</sup> Furthermore, parents expressed increased satisfaction in a medical home as compared to those without a medical home.<sup>20</sup> Federally Qualified Health Centers (FQHC), which often house medical and dental providers, as well as other types of health and social services, are another example of sites with the potential to engage in integration and coordination to improve access to dental care. Access to an FQHC has been shown to reduce disparities in oral health care and increase patient satisfaction.<sup>22</sup>



## Case Studies

Of the limited outcomes-based studies available, five have been selected as Case Studies and discussed below along with the Core Principles they illustrate.

### Case Study #1: Care-by-Parent Unit

A systematic review of family-centered hospital care interventions undertaken by The Cochrane Collaboration found only one study that met the criteria for inclusion according to the reviewers' established model of family-centered care. The study compared post-tonsillectomy pediatric patients who had received standard inpatient postoperative care with those who received treatment in the Care-by-Parent Unit (CBPU). The CBPU followed a more holistic model of care where parents and children, as appropriate, were encouraged to take part in decision-making about care and participate, as much as possible, in providing care. The study found children receiving care in the CBPU reported less nausea and vomiting, better pain control, more prompt medical attention, better on-time discharge, and less unplanned medical consultations compared with children in the standard care unit. The CBPU approach also had high parental satisfaction and lowered the cost of care.<sup>23</sup>

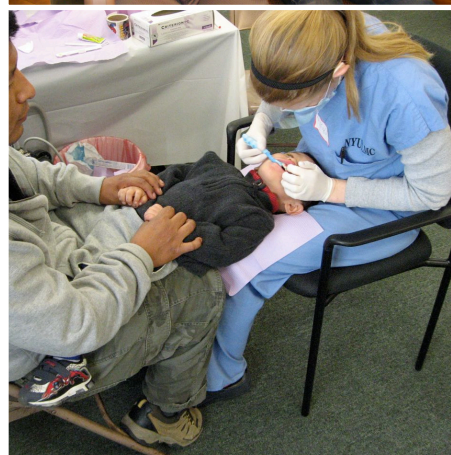
Core Principles: Whole-Person and Comprehensive Care, Communication, Quality of Care



### Case Study #2: Family-Centered Rounds

Family-centered rounds (FCR) are defined as rounds conducted with the family at the bedside. The approach includes obtaining family consent to round at the bedside, introducing team members, family members participating in discussions of the patient's care, the patient's nurse being present during rounds and the family being invited to ask questions at the end of rounds. A cohort study found that active family participation in treatment management during bedside rounds resulted in families being more likely to report consistent medical information, an increased likelihood of discussing a care plan with providers, and doctors listening more carefully and respectfully to family concerns and questions. Patient families also reported feeling a stronger sense of partnership with physicians and higher rates of understandable language being used by health personnel, though use of simplified medical terminology was not a part of FCR training. Improvement of family experiences and participation was deemed a worthwhile benefit of FCR, even though there were no differences found between FCR and non-FCR patients regarding time of discharge or medications used.<sup>24</sup>

Core Principles: Respect and Cultural Competence, Communication





### Case Study #3: Motivational Interviewing

Motivational interviewing is a communication tool used to assist patients in self-examination by raising awareness of their health complaints, identifying their oral health-related goals, and increasing their understanding of how their behavior may be inconsistent with their health goals. This approach is patient-centered in that it uses reflective listening and open-ended questioning to personalize patient counseling. In dentistry, motivational interviewing can be used to emphasize the importance of oral health, preventative behaviors, compliance with treatment plans, and increase utilization of community resources for patients and families<sup>25</sup> “container-title: J Consult Clin Psychol, page: 843-61, volume: 71, archive\_location: 14516234, abstract: A meta-analysis was conducted on controlled clinical trials investigating adaptations of motivational interviewing (AMIs)”. Motivational interviewing has been shown to correlate with positive oral health outcomes. For example, patients participating in a motivational interviewing program received more fluoride varnish treatments and had 46% fewer cavities than those that did not. Additionally, when used in conjunction with other preventive and restorative services, motivational interviewing was found to correlate with a reduction in dental caries and a substantial cost savings.<sup>26</sup>

Core Principles: Respect and Cultural Competence, Communication

### Case Study #4: Dental Case Management Program

A Dental Case Management Program (DCMP) was piloted in Tompkins County, NY, to increase dental access for children under 6 years old enrolled in Medicaid. This program utilized a dedicated case manager to alleviate administrative burdens on health care providers and maintain a communication portal for families. The case manager provided a variety of services including resolving billing and payment problems, educating patients, and assisting with patient transportation to appointments. The DCMP program showed an increase in access to dental care for Medicaid-enrolled families from 9% to 41%. This program also resulted in an increase in the number of dentists accepting Medicaid patients in the county. The case manager was also able to increase oral health literacy and treatment compliance among patients.<sup>27</sup>

Principles: Integration and Coordination of Care, Communication





### Case Study #5: Access to Baby and Child Dentistry

The Access to Baby and Child Dentistry (ABCD) program in Washington State is an example of patient- and family-centered care being put to use in pediatric oral health care. Established in 1995, the goal of this program was to increase access to dental care among children ages 6 and younger enrolled in Medicaid. The program incorporates many of the principles of patient- and family-centered care and enlists the participation of families, dentists, physicians, care coordinators and the Medicaid program. Training was provided to physicians in oral health promotion, oral health assessment and appropriate referral using tools such as the Smiles for Life curriculum.<sup>28</sup>

Participating physicians were reimbursed for their oral health services and financial incentives were provided to participating dentists, in the form of enhanced Medicaid fees. Since its establishment, the ABCD program has trained hundreds of dentists, physicians and students. The program showed a marked increase in the number of young children receiving dental care, in particular children under two years of age.<sup>29,30,31</sup>

Beyond simply showing an increase in utilization, this program has also demonstrated that children in the ABCD program had improved oral health, with fewer decayed or filled teeth and more sound teeth than those not in the program.<sup>29</sup> However, a cost analysis of the program also found an increase in mean dental costs for children in the ABCD program as compared to a control group.<sup>29</sup> This short-term increase in cost (\$8.17 per user) could be offset in the long-term by improved oral health and reduced future costs, factors not measured in the study.

More information about the ABCD program can be found on their website: [abcd-dental.org](http://abcd-dental.org)

Principles: Integration and Coordination of Care, Quality of Care, Comprehensive Care

The Case Studies discussed above are representative of the evidence supporting the conclusion that patient- and family-centered care can result in increased access to, and utilization of, health services as well as increased patient and parent satisfaction. It is important to note, however, that an increase in utilization alone does not assure an improvement in health or a reduction in costs. There is consensus in the literature that more research is needed to measure health care outcomes and potential cost savings in patient- and family-centered care models.

*The pictorial representations presented here are for illustration purposes only and the individuals represented are not affiliated with the institutions or programs presented as case studies.*

## Health Information Technology

An important aspect of patient- and family-centered care involves the use of health information technology (HIT)<sup>14,15</sup>. The electronic health record (EHR) provides a tool to improve communication among the extensive team of people involved in patient- and family-centered care<sup>14,34</sup>. Increased access to patient information, improved efficiency of reimbursement, and reduced paperwork are just a few examples of the improvements enhanced HIT is expected to bring to PAFCC<sup>15</sup>. In addition, patient education and health promotion can be further enhanced<sup>14</sup>.

In 2005, The RAND Corporation published a report on the potential savings and benefits of HIT in the United States. The report estimated efficiency savings of \$77 billion per year in addition to increased safety and improved health benefits<sup>32</sup>. In a recent article published seven years after the initial RAND report, annual U.S. health care expenditures were reported to have actually grown \$800 billion<sup>33</sup>. Many believe the lack of savings from HIT is in large part due to slow adoption of this technology into the health care system and lack of interoperability of systems<sup>33</sup>. Improved standardization and patient access of HIT systems must be achieved in order to reap the benefits of HIT in a patient- and family-centered care health system<sup>33</sup>.

For HIT to be a benefit to patient- and family-centered care, coordination of data and systems is critical. Having the ability to access a patient's medical and dental history from an EHR can provide tremendous information for the health care provider especially when addressing the many systemic disorders that have oral manifestations. By having access to integrated medical and dental EHRs, clinicians could better determine a patient's risk for disease and even identify associations among medical and dental conditions that may have gone unnoticed<sup>34</sup>.

In an effort to increase adoption, coordination and standardization, the U.S. Department of Health and Human Services' Agency for Healthcare and Research Quality (AHRQ) and Centers for Medicare & Medicaid Services (CMS) have undertaken several initiatives. Working closely with the American Academy of Pediatrics and the American Academy of Family Physicians, they have developed a children's EHR format<sup>35</sup>. This EHR format is customized to the health care needs of the child and will permit exchange of data within health care facilities in a safe and effective manner. Also, in 2009 Congress passed the Health Information Technology for Economic and Clinical Health (HITECH) Act, part of the Recovery Act. This legislation designated funds for programs that would promote and expand the adoption of HIT. In one such program, designed to promote greater use of EHR and improve accuracy and access of health information, CMS developed a set of "Meaningful Use" standards that determine guidelines for the use of EHR and set eligibility for providers and health care facilities to earn financial incentives for its adoption<sup>36</sup>.

Although technology will play a key role in the future of health care, it is still only a tool that should be used to reinforce the core principles of PAFCC.

## Obstacles and Limitations

There are a number of obstacles that may limit the feasibility of the patient- and family-centered approach<sup>14</sup>.

- **Time-** Providing PAFCC may require a larger investment of time on the part of providers. This additional time may be spent interacting with patients, families, other providers or using HIT. In a system where most providers already feel they do not have sufficient time this may be a significant obstacle.
- **Cost-** There is little evidence to demonstrate a cost-savings with the implementation of PAFCC. In fact, indications are that costs, at least in the short-term, would increase. For example, incorporating HIT and adding care coordination are essential elements that would add substantially to the cost of care<sup>14,33</sup>. Also, offering incentives to health care providers has been shown to result in better health outcomes and improve the transition toward PAFCC<sup>27,29,37</sup>. The sources of funding for these incentives are limited and have mainly been used to facilitate new pilot projects<sup>13,14,27</sup>.
- **Lack of research on health outcomes-** There are few studies to support long-term improvement of health in the PAFCC approach. This may limit the willingness of providers or health care facilities to adopt this approach. Also, it is often difficult to translate the predominantly hospital-based patient- and family-centered care strategies to outpatient settings. It may be even more difficult to extend these strategies to most pediatric dental settings.
- **New roles for families-** Families may not be able<sup>38</sup> or willing to take on more responsibility in health care decisions. Some may be more comfortable relying on health care providers<sup>13</sup>.
- **New roles for health care providers-** Health care providers would have to make a conscious effort to incorporate the core principles into their practice. For many, this would entail a radical change in the culture of the profession. It would affect almost every facet of their practice, and in some cases, contradict many of the principles they learned during their training. There is also the risk that some providers may misinterpret the aim of PAFCC to be simply improving patient and family satisfaction rather than improved health outcomes<sup>13,14</sup>.



## Federal Programs to Promote Patient- and Family-Centered Care

The passage of the Patient Protection and Affordable Care Act (ACA) in 2010 was an effort to address some of the obstacles to broad implementation of PAFCC. The act promoted a shift in emphasis from the traditional primary care model toward an approach focused on the medical and dental home. To promote this reform Congress funded demonstration projects to develop training programs and promote care coordination. Also, participating health care providers who meet certain criteria and guidelines pertaining to patient- and family-centered care could receive incentives for their work<sup>39</sup>.

The integration of oral health into primary care has been identified by the Health Resources and Services Administration (HRSA) as one of its **top strategic priorities** and also as a goal of the 2010-2015 Department of Health and Human Services (HHS) Strategic Plan.<sup>40</sup>

Integration of care is a critical element of patient- and family-centered care and the recognition by HRSA and HHS of its importance in oral health is a strong endorsement of the importance of cooperation between primary care providers, such as pediatricians, and pediatric dentists.

To address the lack of research pertaining to patient PAFCC, Congress established the Patient-Centered Outcomes Research Institute (PCORI). The mission of the PCORI is to “help people make informed health care decisions, and improve health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community”. This program is funded by the Patient-Centered Outcomes Research Trust Fund which is expected to receive

more than \$3 billion through 2019 to invest in research to evaluate patient- and family-centered care in practice.<sup>44,41</sup> A current project is aimed at incorporating parent preferences in policy and clinical decisions in the administration of childhood vaccines. This is just one of many projects currently funded by the PCORI to gain a greater understanding of patient- and family-centered care and improving health outcomes. More information about the PCORI can be found at [www.pcori.org](http://www.pcori.org).

Promotion of Accountable Care Organizations (ACOs) is a central provision in the ACA. An ACO, a group of coordinated health care providers accountable for quality and cost,<sup>42</sup> is just one example of an approach, already common in medicine, that relies on robust integration, coordination and outcome assessment—all core principles of PAFCC. ACOs lend themselves to the patient and family-centered care approach in that care is more coordinated and integrated across the hospital and related organizations. They include, for example, care coordinators, pharmacy support for medication management and increased support staff to improve efficiency. An ACO has a broader scope than most medical homes in that they coordinate care across the entire spectrum of health care from hospitals to a variety of clinicians.<sup>42</sup>

## Conclusion

Existing models for the medical and dental home already incorporate many of the principles of PAFCC. What is missing, however, is the integration of oral and systemic health. There is a need to create a professional environment that fosters coordination of care between pediatric dentists and other primary care providers. The core principles of PAFCC, if applied effectively, could serve as a guide to achieving this type of coordination while engaging patients and families more completely in the health care process.



## Policy Recommendations For Patient- And Family-Centered Care

- Pediatric dentists should examine their system of care, from individual interactions with patients and families to the coordination of care with other providers, to see where opportunities for patient- and family-centered care exist.
- Third party payers should consider offering incentives to health care providers to adopt a PAFCC model.
- Enhance HIT standardization, through adoption of the children's EHR format, and increase accessibility of health information across all health care systems, including pediatric dental practices.<sup>43</sup>
- Support programs that implement the HRSA strategic plan priority of integrating oral health into primary care. This type of integration is central to the core principles of PAFCC.<sup>40</sup>
- Educate primary care and other health providers in oral health care and the establishment of a dental home<sup>43,44,45</sup>
- Provide students in the health professions with training in PAFCC including cultural competence and interprofessional collaboration.<sup>46</sup>
- Promote research on the PAFCC model in practice.
  - Evidence-based measurement and evaluation tools for PAFCC should be developed.
  - Studies need to go beyond patient satisfaction and examine long-term health outcomes and the impact of PAFCC models on time burden, workforce and costs.

## Patient- and Family-Centered Care vs. Convenient and Free Care

Missions of Mercy was launched in 1994 to provide medical and dental care in mobile and temporary clinics to underserved populations. It now provides more than 25,000 free patient visits each year across the country.<sup>45</sup> Central Appalachia Health Wagon was established in 2009. It conducts a total of 157 medical and dental clinics providing over 3000 patient encounters and over 200 telemedicine specialty consultations at no cost to their patients<sup>47</sup> and link to Health Wagon website.

These types of services are growing due to economic pressures, unemployment, the high cost of medical insurance and an inadequate Medicaid system. Many families feel this model of care to be patient-centered because it meets their immediate needs. Even those who have other ways to access care may choose this model instead because it is convenient and there are no out of pocket expenses. This model of care may also appear more comprehensive than the care many patients currently have available to them because these temporary clinics often include vision, dental, medical, and other health services all in one setting.

It is important to bear in mind that patient- and family-centered care was not intended to take this form. Although these programs fill a void in our health care system, they lack continuity of care, true comprehensiveness, coordination of care and sustainability. Nevertheless, many patients are quite satisfied with this type of care. Therein lies the dilemma inherent to the concept of patient- and family-centered care. How to satisfy the perceived needs of the patient and family while still delivering high quality care?

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The Pediatric Oral Health Research and Policy Center (POHRPC) exists to inform and advance research and policy development that will promote optimal children's oral health and care. To fulfill this mission, the POHRPC conducts and reports oral health policy research that advances children's oral health issues and supports AAPD public policy and public relations initiatives at the national, state, local, and international levels with legislatures, government agencies, professional associations, and other non-governmental organizations.

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