Conference Paper

Chronic Disease Management Strategies of Early Childhood Caries: Support from the Medical and Dental Literature

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Abstract: *An Institute of Medicine report places chronic disease management (CDM) as an intervention on a treatment spectrum between prevention and acute care. CDM commonly focuses on conditions in which patient self-care efforts are significant. Framing early childhood caries (ECC) as such a chronic condition invites dentistry to reconsider its approach to caries management and shift gears from a strictly surgical approach to one that also incorporates a medical approach. This paper's purpose was to explore the definition of and concepts inherent in CDM. An explanatory model is introduced to describe the multiple factors that influence ECC-CDM strategies. Reviewed literature suggests that early evidence from ECC-CDM interventions, along with results of pediatric asthma and diabetes CDM, supports CDM of ECC as a valid approach that is independent of both prevention and repair. Early results of ECC-CDM endeavors have demonstrated a reduction in rates of new cavitation, dental pain, and referral to the operating room compared to baseline rates. ECC-CDM strategies hold strong promise to curtail caries activity while complementing dental repair when needed, thereby reducing disease progression and cavity recurrence. Institutionalizing ECC-CDM will both require and benefit from evolving health care delivery and financing systems that reward positive health outcomes.* *(Pediatr Dent 2015;37(3):281-7) Received January 26, 2015 | Last Revision April 3, 2015 | Accepted April 3, 2015*

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Review of literature

Chronic disease management. Dentistry, with historic roots in a surgical tradition, commonly approaches dental caries as an acute surgical problem requiring restoration and rehabilitation rather than as a chronic disease process requiring individually tailored management of etiologic factors. This mindset may be rapidly changing, as reflected in the American Academy of Pediatric Dentistry (**AAPD**) guidelines on caries management,[1] the Caries Management by Risk Assessment (**CAMBRA**) movement,[2] our profession's partnership with primary care medicine in delivering caries risk assessment and counseling, and a substantive body of federally sponsored research currently underway.

While other contributions to this conference explore etiological factors in early childhood caries (**ECC**) initiation and progression, the purpose of this paper was to closely examine the definition of, and concepts inherent in, chronic disease management (**CDM**) in order to explore how these concepts may be utilized to manage and arrest the disease process that ultimately manifests as cavities.

A whitepaper prepared for the Institute of Medicine's 2009 Summit on Integrative Medicine places CDM as a distinct category of intervention on a spectrum of health care services located midway between prevention and acute care.[3] In so doing, it defines CDM as separate in concept and practice from both prevention and therapeutic management of acute signs and symptoms. By implication, it calls on dentistry to recognize that prevention is no longer clinically relevant once a patient evinces active disease, even if that disease has not yet expressed itself as a clinical lesion. This framing invites dentistry to explore a third option in caring for children impacted by ECC: neither prevention nor repair but treatment of the underlying disease processes that result in cavities. Importantly, CDM is as much treatment as is dental repair and can be regarded as an adjunct to, and complementary with, dental repair.

CDM focuses on patient self-management using evidence-based protocols developed by health professionals. CDM is actualized when informed and activated patients and prepared and proactive practitioner teams contribute care equally through productive interactions within the contexts of health systems and community characteristics. All of these components, which are key elements of Wagner's chronic care model, are necessary for CDM to succeed.[4] An example of this approach is well described by the Childhood Asthma Leadership Coalition, which states:

> "Treating, managing, and reducing the burden of childhood asthma requires coordinated interventions that integrate community-based approaches into patient care and take the management of asthma beyond the doctor's office. While patients receive initial instruction in clinical settings, evidence-based guidelines call for repeated education in homes and community settings to reinforce treatment recommendations. These community-focused interventions help children and their caregivers proactively mitigate asthma triggers and manage asthma symptoms throughout their daily routine."[5]

Simply substituting ECC for asthma in this description allows our profession to envision a more holistic approach to caries management in young children. CDM is often implemented in collaboration with helping professionals such as nutritionists, social workers, health educators, psychologists, and behaviorists. For example, endocrinologists who specialize in diabetes created a unique provider to complement their

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professional care, the certified diabetes educator (**CDE**). The CDE promotes self-management to achieve individualized behavioral and treatment goals that optimize health outcomes[6] by guiding families through the day-to-day management of diet, exercise, and insulin administration. In doing so, affected children and their families take primary responsibility for controlling the disease. Similarly, family engagement has been vigorously applied to obesity management, asthma management, and immunization promotion but less so to ECC.

As medical personnel have engaged in CDM, they have come to recognize the many biological, social, behavioral, educational, environmental, and health systems factors that influence health attainment and maintenance for both individuals and populations. They have developed theories to explain and strategies to control factors that promote ill health while enhancing factors that promote improved health. They have increasingly called upon the helping professions, case managers, and community health workers to provide support and guidance to families and populations. The work of such teams reflects the social-ecological model[7] that the Centers for Disease Control and Prevention has adapted for conditions ranging from obesity to colorectal cancer. It recognizes the impacts of relationships, communities, and society on individual health. This causality chain has meshed CDM with public health in a field now called population health. An example of this evolution is the branding of an organization dedicated to advancing disease management implementation. Originally called the Disease Management Association of America, it rebranded as the Care Continuum Alliance and is now known as the Population Health Initiative. Common to each stage of this insurance industry group's maturation is a commitment to improve health while lowering health care costs through innovative care delivery models that address risk factors and target health determinants rather than exclusively ameliorate extant disease.

In 2009, the *International Journal of Integrated Care's* editor reviewed definitions of CDM and concluded that a full definition should include eight elements: "(1) a focus on a target group (2) of persons with chronic diseases (3) with the goal to improve clinical outcome and quality and (4) cost-effectiveness of care (5) by means of a systematic approach (6) with preventive and curative interventions (7) in which self-management by patients is important (8) provided by a multidisciplinary professional team."[8]

For purposes of this paper, we rely on this definition of CDM that is based on the following principles: "Chronic disease prevention and management consists of a group of coherent interventions, designed to prevent or manage one or more chronic conditions using a community wide, systematic, and structured multidisciplinary approach potentially employing multiple treatment modalities. The goal of chronic disease… management is to identify persons with one or more chronic conditions, to promote self-management by patients, and to address the illness or conditions according to disease severity and patient needs and based on the best available evidence, maximizing clinical effectiveness and efficiency regardless of treatment setting(s) or typical reimbursement patterns."[8]

Tinanoff and Douglass anticipated many of these CDM principles for ECC management and reflected the Wagner chronic care model when describing clinical decision-making for caries management in children, stating that "current evidence regarding the caries process and caries risk assessment allows the practitioner to go beyond traditional surgical management of dental caries." They called for patient-specific approaches, that reflect both an individual child's level of disease activity and a practitioner's knowledge of the caries process.[9]

In a 2010 working paper for the Institute of Medicine entitled "Lessons from Medicine: Opportunities and Constraints for Oral Disease Management," Edelstein reported that "Lacking in refinement (in dentistry) are evidence-based and protocol-driven risk assessments, individualized counseling, pharmacobehavioral modifications of risk factors, and longitudinal case management supported by health information technologies." He claimed that this deficit is consequential at many levels, as it leads to oral diseases in individuals that are not controlled, disease burdens in populations that are excessive, reparative treatments that frequently fail, and missed opportunities to achieve better health outcomes at lower costs.[10]

Common to all descriptions of CDM is its focus on conditions in which patient self-care efforts are significant.[11] Framing ECC as such a condition, analogous to pediatric asthma and diabetes, further invites dentistry to reconsider its approach to caries management and shift gears from a strictly surgical to a medical approach. Unlike asthma and diabetes, which can be effectively managed via pharmacologic approaches in conjunction with lifestyle/behavioral changes, dental caries usually requires surgical treatment once cavitated lesions have manifested. A paradigm shift is called for, whereby CDM efforts are incorporated into clinical dental practice, with the focus on improving quality of care and patient outcomes. As part of a protocol to achieve individualized behavioral and treatment goals, patients would also receive procedures—such as sealants, interim therapeutic restorations, and fluoride varnish applications—in conjunction with traditional restorative treatment, as required.

At every possible clinical encounter, caries risk factors are revisited, and patients/parents receive engagement and coaching on self-management care by members of the care team. Within a dental practice, coaching activities may be delegated to various well-trained support staff on the care team; however, the entire team should be well versed in the CDM protocols. At the same time, dentistry can also engage a variety of professions in leveraging CDM approaches that partner counselors with patients, families, and populations to reduce or eliminate risk factors, initiators, and contributors to ECC.

Recent years have witnessed a shift toward incorporation of CDM in dentistry for young children and an evolving distinction of CDM from prevention. The AAPD's caries management guidelines now call for risk-banded care paths.[1] DentaQuest Institute's ECC Collaborative, detailed in this paper, now engages over 30 sites across the United States in testing changes, collecting data, and working with nationally recognized clinical and quality improvement experts to implement the practices and protocols of disease management for early childhood caries.[12] The Federal Center for Medicare and Medicaid Innovation has promoted ECC management with the States as they develop health innovation programs; it currently supports a demonstration of family-level, peer-counseled, and technology-assisted behavioral risk reduction strategies among children with early signs of ECC.[13]

Similarly, NIDCR's multidisciplinary centers that are focused on oral health disparities have explored a range of ECC interventions that involve psychologists, anthropologists, pediatricians, social workers, nutritionists, lay health workers, epidemiologists, basic scientists, and health economists.[14] CAMBRA has grown in acceptance and visibility, as evidenced

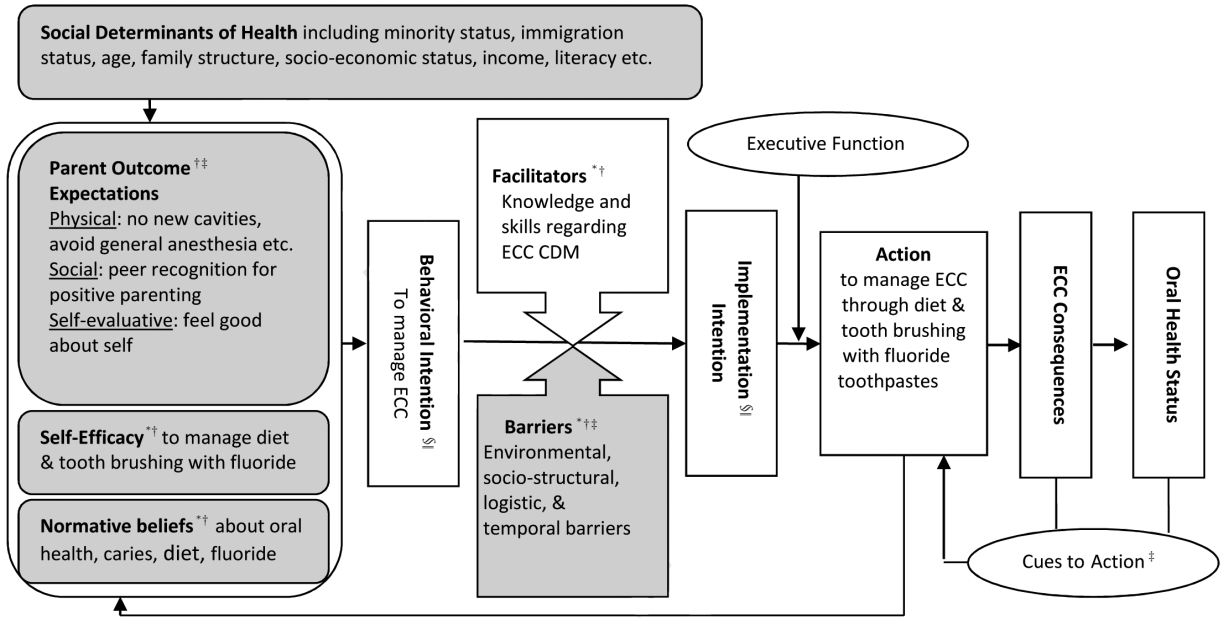
by its inclusion in multiple publications (including one focused on ECC[15]), an online course, and continuing education courses, emerging industry product development by companies including Elevate Oral Care and CariFree, and endorsement by dental associations. Additionally, Berg and Slayton's text, *Early Childhood Oral Health*, includes a chapter called "Managing caries: Obtaining Arrest."[16] Each of these endeavors, and many others, seek to elucidate strategies to manage and control disease that results in dental cavities among young children by arresting the caries process.

Modeling CDM for ECC. Fisher-Owens et al. illustrated and validated the multilevel determinants of children's oral health outcomes in an oft-cited conceptual model that nests oral health within increasingly larger contexts of child-level, family-level, and community-level influences bounded by time and the environment.[17] This model holds strong value for understanding CDM's potential for ECC management, as it includes 22 domains, the majority of which were subsequently validated as significantly impacting young American children's oral health status.[18]

Multiple health behavioral theories have been advanced to assess the mechanisms by which such multilevel domains influence health outcomes.[19,20] Relying on these theories, an interdisciplinary group of ECC researchers at Columbia University developed an explanatory model that seeks to describe how CDM can leverage multiple domains to influence caries outcomes in young children (Figure). The model begins with social determinants of health that directly influence parental expectations, self-efficacy, and normative beliefs. These, in turn, influence parents' intention to adopt salutary behaviors or limit harmful behaviors. Without such behavioral intention, CDM—which always involves self-care efforts—cannot be implemented. However, behavioral intention alone is not sufficient, as even our best of intentions are filtered through perceived and real facilitators and barriers before they are transformed into implementation intentions. Once parents have committed to implement ECC disease management strategies, their abilities to take action are influenced by their executive function which governs the capacity to plan, organize, manage, and strategize. When parents succeed in taking action (e.g., improving the diet or utilizing appropriate fluoride strategies), they experience a sense of personal reward (e.g., observing that the child is less distressed when eating or sleeping) that further enhances behavioral intention. Successful action also leads to reductions in ECC activity (e.g., signs of caries arrest), which similarly provides cues to parents that their actions are meaningful. As ever greater engagement occurs, psychosocial feedback loops continuously reinforce parental accomplishment, and their child's oral health status improves.

The multiple cultural, social, psychological, and logistic variables inherent in the explanatory model illustrate why parents are often challenged in their efforts to follow dentists' instructions regarding feeding practices, diet, and fluorides. Rather than denigrate a parent as having a low dental IQ, a CDM approach utilizes techniques—such as motivational interviewing, coaching, role modeling, peer engagement, positive

Figure. Explanatory model of factors influencing early childhood caries (ECC) chronic disease management (CDM) strategies by parents.



* Social cognitive theory. † Theory of planned behavior. ‡ Health belief model.
§ Analysis of implementation intentions. ‖ Readiness to change.

Developed by Contento I, Wolf R, Koch P, Custodio-Lumsden C, Levine J, Edelstein BL. A testable conceptual model of early childhood caries behavioral determinants. Columbia University Teachers College and College of Dental Medicine, 2012.

reinforcement, and social reward—to engage parents and collaboratively solve individual impediments to action. CDM also calls for delivery system redesign, which is useful to facilitate reliable adoption of such techniques and evidence-based clinical protocols and evaluate patient outcomes. Partnering with helping professionals, peer counselors, and community health workers holds strong potential for dentistry to address the fundamental determinants of health behaviors and thereby engage families in successfully managing ECC risks.

Strategies for ECC-CDM management. Many articles have been published describing the application of chemotherapeutics as the primary ECC management intervention (often blended with various levels of patient instruction and counseling), including: silver diamine fluoride and sliver nitrate to arrest carious lesions without excavation[21-24]; topical iodine to suppress the microbial flora[25-27]; and emerging nonfluoride remineralizing products, such as casein phosphopeptide and calcium phosphate products[28,29] (used alone or in combination with topical fluoride to prevent and manage ECC) and xylitol (a sugar substitute, that can reduce plaque formation, bacterial adherence, and inhibit enamel demineralization).[25] One clinical phamacobehavioral protocol involved patients returning to dental providers for applications of silver nitrate and fluoride varnish over multiple visits, during which dietary and preventive home care recommendations were also addressed. This protocol reported that it had achieved complete arrest of active caries in almost all the teeth for which it was used.[30] While these various chemotherapeutic approaches have shown promise to improve patient outcomes, they do not meet the definition of CDM because they are not focused on supporting patients to adopt self-management strategies, nor are they focused on system redesign to support reliable and evidence-based processes in the care delivery system.

Family level and self-care strategies to manage, control, and suppress ECC overlap with strategies to prevent its occurrence but differ in intensity and in specific tailoring to individual families. Presently, very little available evidence has been published demonstrating the effectiveness of such CDM for ECC. Among the most promising in addressing self-management and care delivery reforms are the: ECC Quality Improvement Collaborative[31,32]; community-based pediatric oral health program at UCLA[33]; Australian studies on home visits and telephone contacts[34]; and MySmileBuddy research at Columbia University.[35,36]

Home and community-based endeavors seek to engage families, often in the contexts of their community groups, to enhance awareness of ECC and increase compliance with clinical recommendations. Ramos-Gomez proposed a population health model for community-based pediatric oral health, inclusive of CDM, that partners with a range of community-based organizations (e.g., a health and wellness center, pediatric medical resource, and WIC and Head Start programs) to deliver culturally and linguistically appropriate, family centered, health behavior interventions through nontraditional providers in nontraditional settings.[33] In an ECC prevention study with promising application to CDM, home visits by Australian oral health therapists and telephone contacts conducted every six months, starting at birth, to coach mothers on oral health behaviors were found to be effective in reducing ECC prevalence at 24 months compared to a control group of children (ECC developed in 1.5 percent of home-visited families, 6.8 percent of telephoned families, and 22.5 percent of nonintervention families).[34]

A pilot report of family visits by community health workers (**CHWs**), who use tablet technology to explain cariogenesis and help parents develop family centric CDM action plans, suggests high levels of acceptance by parents and usability and usefulness by CHWs.[35] Focus groups conducted with CHWs revealed the value for CDM of their awareness of local community resources, ambient attitudes regarding oral health and dental care, and their cultural/linguistic compatibility with families. They also highlighted the importance of power sharing among health professionals, CHWs, and families in creating ECC interventions that are both engaging and readily accepted in the community. Because ECC is essentially a dietary disease, the MySmileBuddy tablet platform includes a diet widget through which CHWs, in partnership with parents, can assess the cariogenicity of a child's diet and develop actionable options to reduce dietary risk.[36]

The dental office-based ECC Quality Improvement (**QI**) Collaborative that promotes family level disease management has demonstrated that CDM can be implemented into dental practice and has the potential to improve care delivery and clinical outcomes[31,32] while also reducing health care costs.[37] In the Collaborative, following the chronic care model, quality improvement strategies are used to aid in the redesign of the oral health care delivery systems and processes to support CDM. All six essential elements of the model are addressed in the redesign: (1) community resources and policies; (2) health care organization; (3) self-management support; (4) delivery system design; (5) decision support; and (6) clinical information systems. The QI collaborative is focused on practices providing chronic care of ECC in reliable and evidence-based processes and systems (e.g., providers reliably and consistently assessing caries risk and providing self-management support; patient returning for follow-up consistently based on their risk of caries). Provider interactions with patients include systematic assessments (caries risk assessment, oral examinations), attention to treatment guidelines (following evidence-based clinical protocols), and behavioral support of self-management care. These interactions are linked in time by clinically relevant information systems (patient registry) and continued follow-up by providers (return visits based on caries risk).

Results of phase one of the ECC Collaborative in two sites found that, after 30 months, ECC children in the intervention group experienced lower rates of new cavitated lesions, pain, and referral for restorative care in the operating room compared to baseline historical controls with ECC. [32] Phase two, involving five additional sites across the United States, replicated these results after 18 months of intervention. The Collaborative teams found that QI strategies facilitated adoption of CDM and resulted in improved care to patients and better patient outcomes overall.[31] A cost effectiveness analysis of phase one concluded that the CDM program was cost effective from the health care system, Medicaid, and societal perspectives.[37] ECC patients were found to have had significantly more preventive visits, significantly fewer restorative and surgical visits, and lower overall costs compared to baseline historical controls.

Evidence for childhood CDM from medical studies. Evidence supporting the basic elements of CDM in health care has been accumulating for many years.[38] Significant improvements in quality of care and health outcomes as a result of CDM can be found for several disease categories for adults, including diabetes, heart failure, arthritis, and depression.[39]

Approaches using the chronic care model have been reported to lead to improved care and health outcomes in patients with diabetes[40,41] and pediatric asthma.[42-47] However, the impact on health care costs and revenues remains uncertain overall and may vary by condition.[48] There is evidence that CDM approaches may be cost effective for some conditions, including diabetes[49] and pediatric asthma.[50] However, the combined effort required by busy practices, unsupported reimbursement, and an uncertain impact on health care costs and revenues are believed to be important factors limiting widespread implementation of chronic disease management, including the use of the chronic care model.[48]

Systematic reviews and meta-analyses of pediatric asthma related to patient/family asthma education and self-management found improvements in patient outcomes, including lung function, self-efficacy, absenteeism from school, number of restricted days from activity, and visits to emergency departments.[42,43] A systematic review of QI strategies for children with asthma by Bravata et al.[46] found that various types of QI interventions improved outcomes and processes of care for children with asthma, although the magnitude of improvement was often modest. A notable finding was that the greater number of QI strategies used, the more likely a study was to report statistically significant improvements in clinical outcomes. A recent intervention in adolescents with asthma using the chronic care model found improved clinical outcomes and process measures.[47] Results include an increase from: 10 to 30 percent of patients with optimally well-controlled asthma; 38 to nearly 100 percent for evidence-based care (consisting of an asthma action plan and controller medications prescribed); and zero to 90 percent of patients receiving a self-management bundle.

Two controlled trials reported on the engagement of CHWs resulting in improved outcomes for asthmatic children. In a randomized control trial of 309 three- to 13-year-olds with asthma living in low-income households, 24 additional symptom-free days per year and a small increase in caretaker quality of life were observed among children who received in-home asthma self-management support by CHWs versus children who received standard asthma education from clinic-based nurses.[51] In another CHW trial, hospitalizations and emergency department visits decreased by more than 50 percent after 12 months in the 472 families who had enrolled in the program between 2006 and 2010. At the same time, caregiver confidence in controlling their child's asthma was increased to nearly 100 percent.[52]

The diabetes search did not identify any published reports on pediatric diabetes and use of QI strategies or the chronic care model. One meta-analysis[53] that included 15 studies of children younger than 19 years old with type one diabetes compared the results of glycemic control in controls versus strategies that promote adherence or self-management promotion. Only a modest improvement was found in the intervention groups compared to the controls, although there was variability in the effects. Multicomponent interventions that targeted emotional, social, or family processes, and which facilitated diabetes self-management, were found to be more potent than interventions that just targeted a direct, behavioral process (e.g., increase in blood glucose monitoring frequency).

Conclusions

There exists a tension between the biomedical research community—with its longstanding reliance on randomized controlled clinical trials (**RCTs**)—versus the quality improvement (**QI**) community, with its adoption of continuous QI strategies and learning organization approach.[54,55] The chronic disease management (**CDM**) model for ECC, despite being grounded in a scientific understanding of caries pathogenesis and recognition that disease control must meaningfully engage children in the contexts of family and community, is similarly subject to criticism for lack of evidence from RCTs. This critique may be unwarranted, as RCTs may not be the most appropriate investigational approach to establishing optimal health care practices in complex environments.[56] In fact, clinical decisions are made every day by practitioners seeking to provide the best possible care and by public and private policymakers aiming to establish and support delivery and financing systems that are effective and efficient for individuals and populations.

This review suggests that early evidence from CDM interventions for ECC, coupled with results of CDM demonstrations for asthma and diabetes, supports the concept that CDM is a valid approach to ECC that is independent of both prevention and repair. Its rapid adoption holds strong promise to curtail caries activity while complementing dental repair, as necessary, thereby markedly reducing disease progression and cavity recurrence.

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