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Patient- and Family-Centered Care as an approach to reducing disparities in asthma outcomes in urban African American children: A review of the literature

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Abstract

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¹Care that involves patients and their families has been described with a number of terms (e.g., family centered care, patient centered care). In this paper, the term “patient and family centered care” is used.

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Background—Patient- and family-centered care (PFCC) has the potential to address disparities in access and quality of healthcare for African American pediatric asthma patients by accommodating and responding to the individual needs of patients and families.

Study Objectives—To identify and evaluate research on the impact of family–provider interventions that reflect elements of PFCC on reducing disparities in the provision, access, quality, and use of healthcare services for African American pediatric asthma patients.

Methods—Electronic searches were conducted using PubMed, CINAHL, and PsycInfo databases. Inclusion criteria were peer-reviewed, English-language articles on family–provider interventions that (a) reflected one or more elements of PFCC and (b) addressed healthcare disparities in urban African American pediatric asthma patients (≥ 18years).

Results—Thirteen interventions or programs were identified and reviewed. Designs included randomized clinical trials, controlled clinical trials, pre-and post-interventions, and program evaluations.

Conclusions—Few interventions were identified as explicitly providing PFCC in a pediatric asthma context, possibly because of a lack of consensus on what constitutes PFCC in practice. Some studies have demonstrated that PFCC improves satisfaction and communication during clinical interactions. More empirical research is needed to understand whether PFCC interventions reduce care disparities and improve the provision, access, and quality of asthma healthcare for urban African American children.

Electronic databases used—PubMed, CINAHL, and PsycInfo

Keywords

patient and family centered care; asthma; healthcare disparities; African American

Recommendations from the Institute of Medicine (IOM)¹ Committee on the Consequences of Uninsurance, Health insurance is a family matter and other national organizations^{2,3} strongly advocate for children in the United States to have equal and consistent access to quality healthcare. An IOM 2001 report⁴ further mandates that healthcare in the 21st Century “should not vary in quality because of [patients'] personal characteristics.” However, minority children are at greater risk for poor oral and medical health, have less access to care, and have less utilization of medical and dental services, underscoring the existing racial and ethnic disparities in “access, use, and patient experience of care”⁵ in our current pediatric healthcare system.⁶

Patient- and Family-Centered Care

A patient and family centered care (PFCC)¹ approach has been widely endorsed as an optimal framework to improve the quality of current healthcare in the United States.^{4,7–9} The IOM's 2001 report, “Crossing the Quality Chasm,” included patient-centeredness as one of six key principles to guide reform of the current healthcare system. Broadly defined, PFCC is an approach to the “planning, delivery, and evaluation of healthcare,”¹⁰ which recognizes the pivotal and equal role of patients and families in healthcare partnerships.¹¹ An integral part of this process is being responsive to the individual preferences, needs,

values, and cultural traditions of patients and their families.^{4,7} This individualized approach is theorized to equalize the amount, type, and quality of healthcare provided; ensure equal access and opportunity for quality care; and increase patients' use of available services through the development of “mutually beneficial partnerships.”^{4,10}

To date, studies have examined how using a PFCC approach with patients and families influences perceptions of the care during the clinical interaction (e.g., trust, satisfaction with provider, patient–provider communication).^{12–14,15,16} However, the existing literature is limited in that changing patients' perception of the quality of care *alone* does not offer sufficient evidence that PFCC changes disparities in care. It is not clear how—or if—using PFCC influences the quality of care, access to care, or use of services. In short, it is possible that PFCC *could* ensure equal and consistent access to quality healthcare for all patients; however, there is no empirical evidence to date that PFCC *does* accomplish this goal. Thus, there is clearly a need to better understand the extent to which using PFCC practices in family-provider interactions might reduce healthcare disparities in the amount, type, and quality of care provided; the access to care; and the use of care services.

Asthma

Asthma is an exemplar for examining the influence of PFCC practices on health outcomes in children. While asthma affects children of all races and ethnicities, poor urban children and African American children share a disproportionate burden of this illness.^{17,18,19,20,21,22,23,24,25–28,29} Asthma is the most common chronic condition among children under age 18, affecting 7.1 million children in the United States.³⁰ In the last decade alone, the prevalence of asthma has increased 42% with the average death rate increasing by 40%.³¹ African American children not only have a higher prevalence of asthma relative to whites³² but also have higher rates of ED visits and hospitalizations, are less likely to have an asthma management plan, and are more likely to have the severity of their asthma underestimated by a physician.^{18,33,34,35–38,39,40–42,43,44}

The disparities in access, care, and use of services between African American and white pediatric asthma patients suggest the need for interventions focused on reducing disparities in care.⁶ Life-course theories of illness suggest that intervening to reduce and manage childhood illness has the potential to reduce disparities and improve health outcomes across every future life stage.^{45,46,47,48} From a public health perspective the potential of improving the health of African Americans across the lifespan is a strong incentive to develop interventions that fulfill the IOM's mandate of providing equal and consistent access to quality healthcare for all children regardless of race or ethnicity.^{1–3}

The strong advocacy for PFCC as a means to improve the quality of healthcare in this country^{4,7–9} suggests pairing a PFCC approach with an intervention to reduce healthcare disparities in pediatric asthma. In theory, interventions based on building partnerships with parents, open communication and collaboration, shared and informed decision-making, and active participation should effect the amount, type, and quality of care provided; the accessibility and type of care available; and the uptake and use of available healthcare

services.^{4,10} Thus, interventions using a PFCC approach may be one avenue to reduce disparities in care.

The purpose of this literature review is to identify and evaluate existing empirical research on the impact of family-provider interventions or programs using PFCC practices on reducing disparities in the “access, use, and patient experience”⁵ of asthma care for urban African American children.

Methods

Search Strategy

Our review was guided by the PRISMA statement.⁴⁹ We conducted our review of existing literature using PubMed (1966–2011), CINAHL (1981–2011), and PsycInfo (1987–2011). Primary search terms included controlled vocabulary and key word searches for (*asthma*) paired with terms to identify (*patient and family centered care*), (*healthcare disparities*), and (*African American*) populations. Variations in search terms were determined by the specific indexing requirements of each database. The search strategy for each database is in Appendix 1.

Study Selection

Inclusion Criteria

Patient- and Family-Centered Care—Our *first inclusion criterion* was that studies needed to clearly reflect core elements of PFCC. Attempts to operationalize *PFCC* in order to identify studies showed how widely definitions of this concept varied. For the purposes of this study, we drew on definitions from national organizations^{4,50,51,52,53,54–56,57,58,59} and research review articles^{60,61} to create an *operationalization* of PFCC (see Table 2).

An initial search of the literature found no interventions or programs that (a) were explicitly identified as based on PFCC principles *and* (b) had the goal of reducing disparities in pediatric asthma care. As a result, we modified this first inclusion criterion to include any family-focused intervention that incorporated one or more PFCC elements, which we broadly defined as “family involvement in the planning, delivery, or management of care.”

Intervention Studies—Our *second inclusion criterion* was studies testing the effects of interventions or programs that used PFCC elements to reduce healthcare disparities in pediatric asthma care. Initially, this review sought to identify only those interventions with randomized clinical trials (RCT) or controlled clinical trial (CCT) designs as they are considered the “gold standard” of empirical research designs. However, our review identified several other study designs (i.e., program evaluations, surveys), which we elected to include in the review because of their potential contribution as empirical studies.

PFCC Outcomes—Our *third inclusion criterion* was studies needed to have at least one clinical care outcome. We looked to the existing literature on PFCC to operationalize what outcomes would be used to assess the impact of PFCC practices on quality of care. Many outcomes have been proposed^{58,62,63,64} (see Table 3). While families' perceptions of the

clinical interaction (e.g., trust, satisfaction with provider) are an important measure of PFCC,^{12–14,15,16} (and likely related to clinical outcomes), changes in the clinical interaction or features of the interaction *alone* do not offer sufficient evidence that PFCC reduces disparities in care. Therefore, this review did not include studies that used “parent satisfaction with care” (or similar outcomes related to the clinical interaction) as their only outcome measure.

Other inclusion criteria were: (a) published in an English language peer-reviewed journal; (b) conducted in the United States; (c) focused on children with asthma 18 years old; and (d) sample included at least 25% African American children. Studies excluded were: (a) unpublished dissertation or thesis work; and (b) studies conducted in countries other than the United States.

As shown in Table 1, a total of 233 studies were identified, which after de-duplication, yielded 231 unique articles. To identify additional studies that might meet inclusion criteria, we also searched the bibliographies of included articles. All identified articles were imported into and organized using EndNote X6⁶⁵ software. The first author (FKH) screened the titles and abstracts of all identified articles to determine inclusion. Questions about inclusion were discussed and resolved in discussions with two other authors (TLA, SE).

Results

Thirteen studies met the inclusion criteria and are included in this review. The following data were extracted from each study: sample characteristics, type of study design, purpose of study, PFCC principles used, and key findings (see Table 4). Seven studies were randomized controlled trial designs (RCT), one was a controlled clinical trial (CCT), three evaluated the effects of pre- and post-interventions, and two studies were program evaluations. The number of PFCC elements reflected in each intervention or program ranged from 3–6 (out of a possible 7) elements.

Of the 13 studies, eight evaluated interventions or programs to improve the asthmatic child's home environment. Morgan et al.⁶⁶ conducted an RCT in a sample of 937 children (approximately 60% low income, 40% AA, 44% Hispanic) recruited from 7 cities in the United States: The 1-year intervention was an individualized, home-based educational program designed to reduce children's exposure to allergens and environmental (i.e., secondhand) tobacco smoke (ETS) within the family. The intervention was delivered in 6 content modules by research staff during 5 home visits with families. Results showed intervention children had fewer symptom days and greater declines in levels of home allergens than control children. An RCT of a similar educational intervention by Wilson and colleagues⁶⁷ also showed decreases in acute service rates; intervention children were less likely than control children to have multiple asthma-related ED visits. Lower urine cotinine levels and more home smoking restrictions were also noted in intervention children but the difference was not statistically significant.

A multi-site RCT by Evans et al.⁶⁸ evaluated an individualized family-based intervention, which was designed to reduce asthma symptoms, in a sample of 1033 children with

moderate or severe asthma (approximately 75% AA, 67% low-income). The number and length of contacts with families was tailored to the family's baseline asthma risk profile (i.e., higher risk = more contacts). Intervention content focused on asthma education (e.g., physiology, triggers, ETS), asthma management strategies, and family-provider communication. Parents attended two asthma education groups and had individual sessions with a trained asthma counselor. Families were also given referrals to resources as needed (e.g., smoking cessation, psychological and social issues). Results showed intervention children had fewer symptom days and hospitalizations than control children, and even more encouraging, maintained these gains for a second year without active intervention.

Walders and colleagues⁶⁹ conducted an RCT of an interdisciplinary team intervention consisting of a treatment plan, asthma education, 24-hour access to a nurse, and problem-solving therapy. The study sample, recruited from an urban pediatric hospital, was 175 families of children with uncontrolled asthma (85% AA). Although groups showed no differences in asthma symptoms post-intervention, intervention families used significantly fewer healthcare services for acute asthma episodes than control families (28% v 41%, respectively). Both intervention and control families received a written treatment plan and basic asthma education, which may account for a symptom reduction in both groups. However, intervention families also received a cognitive-behavioral problem-solving session, which may have yielded more effective responses to acute episodes, thereby reducing the number of ED visits relative to control families.

A prospective RCT by Teach et al.⁷⁰ tested the effectiveness of an urban ED follow-up clinic, which provided individualized treatment plans and education to asthmatic children (N=488) and their families (86% AA, 9% Hispanic). At 6-month follow-up, compared to control children, intervention children had significantly fewer unscheduled visits to acute care facilities (including the ED), higher levels of medication adherence, and more positive quality of life outcomes.

Stout et al.⁷¹ conducted an evaluation of a family-based, coordinated-care program in which a community-based lay person worked with families and a team of providers (physicians, pharmacists, nurses) to implement asthma treatment plans. The intervention, which emphasized working within each family's unique social environment, included home visits and clinic visits. The program was piloted with 23 urban, low-income children with moderate to severe asthma. Medical data abstracted from charts showed children had fewer hospitalizations, ED visits, and unscheduled visits and more scheduled ("well") clinic visits after participating in the program. Parents who participated in the program also reported greater knowledge of asthma (e.g., triggers, symptoms, environmental factors) and greater perceived control in caring for their child.

Using chart reviews, Navaie-Waliser et al.⁷² evaluated the impact of a home-health nurse program on asthma outcomes in approximately 1000 urban-dwelling children (25% AA). The program consisted of home-based educational and clinical care components. At entry into the program, the majority of parents had "inadequate" knowledge about asthma physiology, asthma-related symptoms, triggering factors, correct use of medication, and strategies to manage their children's asthma (e.g., nebulizers, inhalers). Although the number

of parents with “adequate” knowledge increased after participation in the program, almost 25% of parents were considered to have “inadequate” knowledge. Further, 75% of children were discharged from the program without any further follow-up, suggesting that gaps in care persisted even with the program.

Of the 13 studies included in the review, four studies evaluated the economic impact of PFCC pediatric asthma programs. Greineder and colleagues⁷³ evaluated an outreach program in a sample of 57 children (60% AA, 12% Hispanic, 4% Asian). Intervention children had fewer ED visits, fewer hospitalizations, and fewer out-of-plan care visits than control children, which represented a cost savings of \$11.67 for every dollar of an intervention nurse's salary. In a CCT, Szelc et al.⁷⁴ evaluated the financial impact of a comprehensive asthma intervention (parent education, tertiary clinic care, asthma outreach nurse) in a sample of 78 children (94% AA) with Medicaid. Children were alternately assigned into control or intervention groups. On average, intervention children had fewer ED visits (1.7 versus 2.4 visits) and hospitalizations (0.2 versus 0.5 admissions per year) than control children. Intervention children also had greater reductions in average care costs per year (\$721 versus \$178) compared to children in the control group.

A study conducted at an urban children's hospital in the Midwest⁷⁵ evaluated a family-based inpatient asthma service, which was designed to address the medical and social needs of families and coordinate referrals for follow-up care and family education. Findings showed that, relative to previous years, the service decreased the length of hospital stays (i.e., 0.5 days per admission) and reduced annual costs by \$300,000 for the hospital. Additional benefits were improved family understanding and care coordination. Although conducted almost 10 years ago, and likely there have been advances in asthma education and prevention since that time, even a portion of these cost savings would translate into a significant financial benefit in the current economy.

Finally, Sullivan et al.⁷⁶ conducted a multi-site RCT⁶⁸ to evaluate the cost-effectiveness of a pediatric asthma intervention (environmental control and educational program). Results showed similar cost benefits to Szelc et al.⁷⁴ with intervention children having fewer symptoms days than control children. The program cost for each symptom-free day per child was \$9.20. Considering the inpatient and/or outpatients costs of treating a child with an asthma exacerbation, a cost of approximately \$10 per child per day represents a substantial costs savings. Evaluating the economic impact and cost savings of pediatric interventions and programs is an understudied but nevertheless key outcome. Interventions that are costly and/or fail to reduce service utilization have little promise of providing practical benefit or application in underserved areas.

Discussion

Summary of Evidence

The studies in this review featured programs that focused on one (or all) of three elements: asthma education, asthma management, and coordination of care (e.g., referrals, family-provider communication, and continuity in care): Some programs were home-based and designed to reduce children's exposure to allergens and ETS, while others focused on

modifying elements of inpatient or ED visits. Positive outcomes of programs included fewer symptom days, unscheduled visits, and ED admissions, and cost savings as a result of reduced service use. Increased parent knowledge about asthma and asthma management strategies and reduced child exposure to environmental asthma triggers were also positive outcomes. Support was found for interventions, including written treatment plans, monthly phone calls to families, and content tailored to a child's individual risk profile and/or family circumstances. In particular, behavioral or cognitive-behavioral approaches, which emphasize teaching strategies and problem-solving skills to parents, seemed beneficial in preventing escalation of symptoms, thereby reducing utilization of acute care services. Also beneficial were asthma “counselors” who worked with families to coordinate care, facilitate family-provider communication, and provide referrals (e.g., smoking cessation, mental health).

As a whole, the studies in this review had a number of methodological strengths, including multi-site data collection, large sample sizes, intention-to-treat analyses, and follow-up assessments over time. The majority used RCT or CCT designs,^{66,67,68,69,70,73,74,76} which provide the most stringent test of intervention effects, and therefore, yield the strongest empirical support. At the same time, some studies had methodological weaknesses, including small sample sizes, high rates of missing data, lack of baseline data for comparison, lack of comparison group, and limited or no statistical analyses. However, perhaps the biggest weakness in these studies and the broader body of existing research is a lack of consensus about how to conceptualize and measure a PFCC approach to care. With rare exception, there were few explicit references to PFCC. Of those studies that mentioned using a PFCC approach, there was no consistency in how PFCC was defined or what practices were included. A comparison of definitions of PFCC used by national organizations that advocate for a PFCC approach to healthcare^{58,62,63} generated a list of almost 30 different core elements used to define and operationalize PFCC.^{4,50,51,52,53,54–56,57,58,77} Thus, while research on PFCC over the past 10 years has evolved, confusion persists about how to operationalize PFCC.^{60,61} There is little consensus on how to define PFCC as an approach and an equal amount of confusion about how to select and/or define appropriate outcomes to test the effectiveness of a PFCC approach.

More critically, this review highlights the relative paucity of empirical research on the effect of PFCC interventions on reducing disparities in healthcare outcomes in urban African American children with asthma. Despite broadening inclusion criteria to studies using at least one PFCC practice, only 13 empirical studies outcomes were identified. Several studies have addressed the question of when healthcare providers use PFCC and with which patients, and others have demonstrated the impact of PFCC on satisfaction and communication during clinical interactions.^{15,16,78,79} For example, a mixed method study by Wissow et al.¹⁵ found that a provider's use of “patient-centered” communication with children in the ED elicited a 5-fold increase in “talk” with children, more parent communication, and higher parent ratings of information exchange and partnership with providers. However, studies such as these do not address whether PFCC influences outcomes beyond the clinical interaction. Thus, it remains unclear how—or if—using PFCC influences, for example, access to or use of services.

Conclusions

Recommendations from the Institute of Medicine¹ Committee on the Consequences of Uninsurance, and other national organizations^{2,3} strongly advocate for all children in the United States to have equal access to consistent quality healthcare. Sadly, the divide between the ideal and current levels of access to quality healthcare for children in this country remains vast. Data from national surveys show low-income families and families of ethnic/racial minorities are less likely than white families to have an established source of healthcare.^{80,81} A lack of consistent care is especially problematic for asthma patients as routine care and prevention is the key to successful management of the condition.³⁹

PFCC is theorized to equalize access to care by responding to the individual needs of patients and families and developing “mutually beneficial partnerships,”⁷⁷ thereby reducing disparities in the amount, type, and quality of care provided; the access to care; and the uptake and use of available healthcare services.^{4,10} Yet the benefit of a PFCC approach to pediatric asthma care remains speculative given the lack of empirical evidence that a PFCC approach reduces disparities in healthcare. Although there have been major strides in including families in care decisions in the past 10 years, it is unclear whether these partnerships are focused more on streamlining the care process or whether parents are equal shareholders in the planning, decision making, and treatment of their child.

Thus, the existing research in this area fails to shed light on the most relevant question: *Does PFCC reduce disparities in the quality of care, access to care, or service utilization in African American children with asthma?* In short, while it is possible that a PFCC approach to care *could* ensure equal and consistent access to quality healthcare, there is no empirical evidence to date that PFCC *does* in fact accomplish this goal.

This review suggests more empirical research is needed to understand whether PFCC interventions reduce disparities and improve the provision, access, and quality of asthma healthcare for urban African American children. To this end, first, we need a clear and concise definition of what constitutes PFCC. Second, we need studies that examine the effect of PFCC practices on clinical outcomes (e.g., symptom-free days, inpatient admissions and acute care visits) over and above the effect on clinical interactions. Third, we need studies that provide evidence of the economic benefit and cost savings of using a PFCC approach. Although understudied, the effect on service utilization is nevertheless a key consideration in evaluating intervention effectiveness. Empirical studies that address these critical questions about the value of PFCC as an approach to reducing healthcare disparities will be a significant contribution to the pediatric asthma literature.

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Appendix 1 - Search Strategy for Each Database

PubMed (Search dates 1966 to August 9, 2011)²

1. (((“Asthma”[Mesh]) OR
 “Asthma, Aspirin-Induced”[Mesh]) OR
 “Asthma, Exercise-Induced”[Mesh]) OR “Status Asthmaticus”[Mesh]
2. (“African Continental Ancestry Group” [Mesh]) OR
 “African Americans”[Mesh] OR
 blacks OR
 African
3. 1 and 2
4. (“Family Nursing” [Mesh]) OR
 “Patient-Centered Care”[Mesh] OR
 “family centered” OR
 “patient and family centered”
5. National Library of Medicine Topic Specific Query: Healthcare disparities and
 Minority Health ((delivery of healthcare[MeSH:NoExp] OR
 health behavior [MH] OR
 health knowledge, attitudes, practice [MH] OR
 health services accessibility [MH] OR
 health services, indigenous [MH] OR
 mass screening [MH] OR
 mass screening [TIAB] OR
 mass screenings [TIAB] OR
 health inequality [TIAB] OR
 health inequalities [TIAB] OR
 health inequities [TIAB] OR
 health inequity [TIAB] OR
 health services needs and demand [MH] OR
 patient acceptance of healthcare [MH] OR

²In PubMed [TIAB] means search for that term in the title and abstract. Most terms were searched both as a MeSH (medical subject heading, indicated by MH) term and with the [TIAB] designation. As this was a Topic Specific Query developed by the National Library of Medicine, the single and plural versions of many of the terms were spelled out.

patient selection [MH] OR
quality of healthcare [MAJR:NoExp] OR
quality of life [MH] OR
quality of life [TIAB] OR
social disparities [TIAB] OR
social disparity [TIAB] OR
social inequities [TIAB] OR
social inequity [TIAB] OR
Socioeconomic Factors [MAJR] OR
socioeconomic factor [TIAB] OR
socioeconomic factors [TIAB])
AND
(African American [TIAB] OR
African Americans [TIAB] OR
African ancestry [TIAB] OR
African Continental Ancestry Group [MH] OR
AIAN [TIAB] OR
American Native Continental Ancestry Group [MH] OR
Asian continental ancestry group [MH] OR
Asian [TIAB] OR
Asians [TIAB] OR
black [TIAB] OR
blacks [TIAB] OR
Caucasian [TIAB] OR
Caucasians [TIAB] OR
diverse population [TIAB] OR
diverse populations [TIAB] OR
environmental justice [TIAB] OR
ethnic group [TIAB] OR
ethnic groups [MH] OR
ethnic groups [TIAB] OR
ethnic population [TIAB] OR

ethnic populations [TIAB] OR
ghetto [TIAB] OR
ghettos [TIAB] OR
Hispanic [TIAB] OR
Hispanics [TIAB] OR
Indian [TIAB] OR
Indians [TIAB] OR
Latino [TIAB] OR
Latinos [TIAB] OR
Latina [TIAB] OR
Latinas [TIAB] OR
medically underserved area [MH] OR
minority group [TIAB] OR
minority groups [MH] OR
minority groups [TIAB] OR
minority population [TIAB] OR
minority populations [TIAB] OR
Native American [TIAB] OR
Native Americans [TIAB] OR
Oceanic Ancestry Group [MH] OR
pacific islander [TIAB] OR
pacific islanders [TIAB] OR
people of color [TIAB] OR
poverty area [MH] OR
poverty area [TIAB] OR
poverty areas [TIAB] OR
rural health [MH] OR
rural health [TIAB] OR
rural health services [MH] OR
rural population [MH] OR
rural population [TIAB] OR
rural populations [TIAB] OR

slum [TIAB] OR
 slums [TIAB] OR
 urban health [MH] OR
 urban health services[MH] OR
 urban population [MH] OR
 urban population [TIAB] OR
 urban populations [TIAB] OR
 vulnerable populations [MH] OR
 vulnerable population [TIAB] OR
 vulnerable populations [TIAB] OR
 white [TIAB] OR
 whites [TIAB])
 OR
 (ethnic disparities [TIAB] OR
 ethnic disparity [TIAB] OR
 healthcare disparities [TIAB] OR
 healthcare disparity [TIAB] OR
 health disparities [TIAB] OR
 health disparity [TIAB] OR
 health status disparities [MH] OR
 healthcare disparities [MH] OR
 healthcare disparities [TIAB] OR
 healthcare disparity [TIAB] OR
 minority health [MH] OR
 minority health [TIAB] OR
 racial disparities [TIAB] OR
 racial disparity [TIAB] OR
 racial equality [TIAB] OR
 racial equity [TIAB] OR
 racial inequities [TIAB] OR
 racial inequity [TIAB]))

6. 1 and 5

7. 6 and 2

Limits to 7: English, All Child: 0–18 years

CINAHL (Search dates 1981 to August 9, 2011)³

1. ((MH “Asthma”) OR (MH “Asthma, Exercise-Induced”) OR (MH “Status Asthmaticus”)) OR asthma*
 2. (MH “Blacks”)
 3. “african american” OR african OR “people of color”
 4. slum OR urban OR vulnerable OR ethnic OR minority OR poverty OR ghetto
 5. disparit* OR “minority health” OR inequit* OR equit* OR equalit*
 6. 2, 3, or 4
 7. 1, 5, and 6
 8. (MH “Social Justice”) OR (MH “Health Care Delivery”) OR (MH “Quality of Health Care”) OR (MH “Health Services Accessibility”) OR (MH “Direct Access”) OR (MH “Gatekeeping”) OR (MH “Health Services Needs and Demand”) OR (MH “Medically Underserved Area”) OR (MH “Health Behavior”) OR (MH “Health Knowledge”) OR (MH “Attitude to Health”) OR (MH “Attitude to Illness”) OR (MH “Health Services, Indigenous”) OR (MH “Health Services for the Indigent”) OR (MH “Health Screening”) OR (MH “Patient Selection”) OR (MM “Socioeconomic Factors+”) OR (MH “Quality of Life”)
 9. 1, 6, and 8
 10. 7 or 9
 11. Limits to 10: English Language; Age Groups: Fetus, Conception to Birth, Infant, Newborn: birth-1 month, Infant: 1–23 months, Child, Preschool: 2–5 years, Child: 6–12 years, Adolescent: 13–18
 12. MH family centered care OR MH patient centered care OR MH family nursing OR “family centered” OR “patient centered” OR (“family and patient centered”)
 13. 11 and 12
 14. 10 and 12
 15. 1, 6, and 12
- 13, 14, or 15

³In CINAHL and PsycInfo, the MH designation indicates a medical heading, which in some cases is slightly different than in PubMed. The PubMed terms and search strategy were followed as closely as possible. Further, CINAHL and PsycInfo use an asterisk (*) to truncate a term such that it searches all variations of the word. An * it indicates that both the singular and plural of the term was searched.

PsycINFO (Search dates 1987 to August 9, 2011)³

1. ((MH "Asthma") OR (MH "Asthma, Exercise-Induced") OR (MH "Status Asthmaticus")) OR asthma*
2. "african american" OR african OR "people of color" OR black*
3. slum OR urban OR vulnerable OR ethnic OR minority OR poverty OR ghetto OR "medically underserved" OR diverse
4. disparit* OR "minority health" OR inequit* OR equit* OR equalit* OR discrimination
5. "Social Justice" OR "Health Care Delivery" OR "Quality of Health Care" OR "Health Services Accessibility" OR "Direct Access" OR "Gatekeeping" OR "Health Services Needs and Demand" OR "Medically Underserved Area" OR "Health Behavior" OR "Health Knowledge" OR "Attitude to Health" OR "Attitude to Illness" OR "Health Services, Indigenous" OR "Health Services for the Indigent" OR "Health Screening" OR "Patient Selection" OR "Socioeconomic Factors" OR "Quality of Life"
6. "family centered care" OR "patient centered care" OR "family nursing" OR "family centered" OR "patient centered" OR "family and patient centered"
7. 2, 3 or 4
8. 1, 6, and 7
9. 1 and 6

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Abbreviations

AA	African American
CCT	Controlled clinical trial
ED	Emergency Department
ETS	Environmental tobacco smoke
FCC	Family Centered Care
PFCC	Patient and Family Centered Care
RCT	Randomized, controlled trial

Table 1
Search Results According to Database

Database	Total No. of Citations
PubMed	182
CINAHL	14
PsycINFO	37
Total before de-duplication	233
Total after de-duplication	231

Table 2
Definitions Used in the Review

Patient and Family Centered Care (PFCC) Practices

- Recognizes the family as central to and/or the constant in the child's life and as the primary source of strength and support for the child
- Acknowledges the uniqueness and diversity of children and families;
- Acknowledges the expertise that parents bring to the process of care-giving level
- Encourages open communication, co-operation, and collaboration between families and health-care providers
- Facilitates family-to-family support and provides families with the physical and emotional support needed to meet their needs
- Actively involves families in decisions about their child's care and provides families with information to enable informed decision making
- Encourages and negotiates parents' participation and role in the physical aspects of care for their child

Patient and Family Centered Care (PFCC) Outcomes

- *Clinical care process*: features directly related to the patient-physician clinical encounter (e.g., patient-provider communication, amount of information provided)
- *Clinical care outcomes*: results or effects of clinical care process (e.g., change in service utilization and cost of care)

Health care Disparities

Differences in the “access, use, and patient experience of care by racial, ethnic, socioeconomic, and geographic groups”

Table 3
Outcomes of PFCC⁵⁸⁶²⁶³⁶⁴

General Area	Outcomes
Health care utilization	Length of open claims
	Number of admissions
	Number of hospitals days
	Emergency department visits
	Use of pain medication
	Rate of hospice/home care use
	Medication adherence
Health care costs	Infection rates
	Medication errors
	Adherence to medications
	Litigation/settlements
	Cost to patients
	Days lost from work/school
Patient and Family Experience	Patient/family satisfaction
	Likelihood of recommending hospital to others
	Patient-reported symptoms
	Patient functional ability
	Overall rating and perceptions of care
	Quality of patient and family communication with healthcare providers
	Degree to which patients felt informed by medical staff
	Use of appropriate language
Patient and Family Knowledge	Appropriate support received to meet needs
	Understanding of condition and treatment options
Staff	Health literacy (understanding and recall of information)
	Attitudes, perceptions, and beliefs regarding PFCC
	Self-efficacy in providing care
	Knowledge and understanding of PFCC principles
	Respect for parent decisions
	Providing cultural sensitive care

Table 4
Interventions to Address Disparities in Pediatric Asthma Health care

Authors	Participants	Ethnic/racial composition	Study Design	Purpose	PFCC elements	Outcomes
Ebbinghaus & Bahrainwala ⁷⁵	Inner city hospital; 1500 inpatient children/year	~95% AA	Program evaluation	Inpatient asthma service	1, 5, 7	Decreased length of hospitalization by 12 hours/admission; \$300K/year cost savings for hospital; improved family understanding and coordination of care
Evans et al. ⁸²	1033 children	~ 75% AA	RCT	Family-based tailored intervention	1, 2, 4, 5, 7	Intervention group had fewer symptom days, fewer hospitalizations; gains maintained during 2 nd year even without active intervention
Greineder et al. ⁸³	53 urban children	70% AA	Pre-and post-intervention	Asthma outreach program	1, 2, 4, 7	ED admissions reduced by 79%; hospital admissions by 85%; annualized cost of outreach nurse (~\$11K) yielded savings of \$87K
Greineder et al. ⁷³	57 children	60% AA 12% Hispanic 4% Asian	RCT	Pediatric asthma outreach program	1, 2, 5, 7	Intervention had fewer emergency department visits, hospitalizations, out-of-plan care; estimated savings up to \$11.67 per \$ of intervention nurse salary
Morgan et al. ⁶⁶	937 children (urban)	40% AA 40% Hispanic	RCT	Family-focused educational intervention to improve child's environment	1, 2, 7	Intervention had fewer symptom days, greater decline in home allergens than controls; fewer cockroach/dust-mite allergens = less asthma symptoms
Navaie-Waliser et al. ⁷²	1007 children	25% AA 37% Latino; 48% Medicaid; 20% no insurance	Program evaluation	In-home care program	1, 2, 7	Program improved parent/caregiver knowledge about asthma symptoms,

Authors	Participants	Ethnic/racial composition	Study Design	Purpose	PFCC elements	Outcomes
Rich et al. ^{84,85}	20 children, urban	50% AA; 15% biracial	Video intervention	Visual intervention to develop patient narratives	1, 2, 3, 4, 7	Narratives showed substantial exposure to environmental risks and inappropriate medication use not documented in medical record
Stout et al. ⁷¹	23 children (low-income, urban)	87% AA	Pre-and post-test	Coordinated care model	1, 2, 4, 5, 7	Fewer emergency department visits, hospitalizations, unscheduled clinic visits; increase in scheduled follow-up visits
Sullivan et al. ⁷⁶	1033 families	75% AA	RCT	Comprehensive care program	1, 3, 4, 5, 7	Intervention reduced symptoms, additional cost was \$9.20 per symptom free day; intervention more effective for children with severe asthma
Szelc et al. ⁷⁴	78 children	94% AA	CCT	Comprehensive care program	1, 2, 5, 7	Intervention group had fewer ER visits and hospitalizations; average asthma healthcare costs decreased more than in controls
Teach ⁷⁰	488 children	86% AA 9% Hispanic	RCT	Family education, tailored treatment plan in emergency department	1, 2, 4, 5, 7	At follow-up, intervention associated with declines in unscheduled visits, increases in medication adherence; no limitations in quality of life
Walders et al. ⁶⁹	175 children	85% AA	RCT	Family-based intervention	1, 2, 3, 4, 5, 7	Intervention associated with less use of acute care services; no differences in asthma symptoms
Wilson et al. ⁶⁷	87 families	44% Hispanic 38% AA	RCT	Family-focused behavioral intervention	1, 2, 7	Intervention reduced healthcare utilization

Authors	Participants	Ethnic/racial composition	Study Design	Purpose	PFCC elements	Outcomes
<hr/>						
¹ Note: AA—African American. CCT—controlled clinical trial. RCT—randomized, controlled trial. PFCC elements						
² Recognizing the primary role of parents in children's lives						
³ Acknowledging the diversity and uniqueness of each family						
⁴ Acknowledging the expertise of parents						
⁵ Encouraging open communication, cooperation, and collaboration between parents and health-care providers						
⁶ Providing families with physical and emotional support to meet their needs						
⁷ Actively involving families in decision-making about their child's care						
Encouraging parents' participation and negotiation of their role in physical care of their child						

but not urine cotinine levels or smoking restrictions at home