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A Narrative Synthesis of the Components of and Evidence for Patient- and Family-Centered Care

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Abstract

A narrative synthesis was conducted to determine typical patient- and family-centered care (PFCC) components and their link to outcomes in pediatric populations. 68 studies with PFCC interventions and experimental designs were included. Study features were synthesized based on five core PFCC components (i.e., education from the provider to the patient and/or family, information sharing from the family to the provider, social-emotional support, adapting care to match family background, and/or shared decision-making) and four outcome categories (health status; the experience, knowledge, and attitudes of the patient/family; patient/family behavior; or provider behavior). The most common PFCC component was education; the least common was adapting care to family background. The presence of social-emotional support alone, as well as educational interventions augmented with shared decision making, social-emotional support, or adaptations of care based on family background, predicted improvements in families' knowledge, attitudes, and experience. Interventions that targeted the family were associated with positive outcomes.

Keywords

Patient- and family-centered care; Shared decision-making

Introduction

Since the landmark report from the Institute of Medicine on Crossing the Quality Chasm,¹ attention to patient- and family-centered care (PFCC), with the goal of increasing partnerships among providers, families, and patients, has been prioritized as a core component of quality health care. Prior to that report, the Institute of Patient- and Family-Centered Care was founded as a nonprofit organization in 1992 (previously the Institute for Family-Centered Care), introducing more widely the concept of patient- and family-centered care (PFCC).²⁻⁴ A recent policy statement in *Pediatrics*⁵ outlined six core principles of

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patient- and family-centered care: (1) listening to and respecting the child and family while honoring and incorporating family background into health care planning and delivery; (2) ensuring sufficient flexibility on organizational, procedural, and provider levels to tailor services to families' needs, beliefs, and values; (3) open and ongoing information-sharing from provider to family; (4) formal and informal support for the patient and family; (5) collaboration between providers, patients, and families at all levels of health care; and (6) building on patients' and families' strengths to empower them to participate in decision-making. A major goal of PFCC in pediatric health care and mental health care settings is to change the family's role in their child's health care—to being crucial and equal participants in their child's health care. Despite this overarching goal, the best methods to implement PFCC remain elusive, in part due to the dearth of evidence supporting its efficacy in pediatric health.^{6, 7}

Calls for PFCC are also occurring outside of pediatric health care. In one prominent example, the Institute of Medicine (IOM) described the six dimensions of quality in health care as safety, efficiency, effectiveness, equity, timeliness and patient-centeredness (with patient-centered defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions”).¹ The goals of PFCC are also in line with the “Triple Aim” framework created by Donald Berwick and colleagues at the Institute for Healthcare Improvement (IHI): that new initiatives should improve the individual experience of health care (including quality and satisfaction), improve the health of populations, and decrease the per capita cost of care.⁸ The first tenet of the Triple Aim, improving the individual experience of health care, is in line with the principles of PFCC in health care settings.

Despite calls for increased presence of PFCC in pediatric health care settings,⁵ challenges remain—challenges that can often be attributed to a tendency for providers to focus on diagnosing and managing diseases. By involving families in making decisions, supporting their needs, and adapting care to fit their backgrounds, providers can ensure that families are more effective participants in their children's care. However, the concept of PFCC remains broad, and different stakeholders have emphasized different aspects of PFCC. Without a clear understanding of which components of PFCC are most effective, establishing clear standards of care is elusive. A better understanding of which components of PFCC lead to positive outcomes can allow for more targeted development of effective interventions.

Recent adult studies demonstrated that including PFCC components positively affected patients' and families' experience of care; in addition to patients' subjective experience of their care, PFCC has been linked to various types of outcomes related to patient behavior (e.g., clinical adherence⁹⁻¹¹ and decreased readmissions^{12, 13}) as well as health status, such as reduced rates of mortality.¹⁴ A Cochrane review of PFCC trainings for providers who conduct clinical consultations found that PFCC trainings were effective in supporting providers to share control of topics and decisions with patients, with mixed findings on resulting levels of patient satisfaction, general health, and health behaviors.¹⁵ In the pediatric literature, two recent Cochrane reviews of family-centered care for hospitalized children found zero⁷ and one⁶ acceptable study, respectively, that met rigorous inclusion criteria, underscoring the lack of high-quality quantitative research on PFCC. Some evidence for the

benefit of PFCC in pediatric setting was found, especially on clinical care, parental satisfaction and costs, but the authors cautioned about the preliminary nature of these conclusions given the small sample size.⁶ A Cochrane Review of qualitative studies in the pediatric literature found that negotiation (a concept which is similar to shared decision-making) between pediatric patients and/or parents and providers was associated with more successful interactions during a child's hospitalization.¹⁶

In recent years, growing evidence of the importance of including family members in a child's health care experience has led to an increased focus on PFCC in pediatric health care settings. The goal of this paper is to review the current state of the evidence in the pediatric literature on PFCC. Our objectives were to review all studies that assessed the impact of PFCC interventions across pediatric health conditions, to identify core components of this broadly defined concept across these studies, and to examine which components of PFCC are associated with specific outcomes.

Methods

Study Eligibility Criteria

Given the relative dearth of eligible studies of PFCC in pediatric populations found in the recent Cochrane reviews,^{6, 7} we utilized a narrative synthesis approach to review and synthesize the findings from multiple studies, focusing on qualitative descriptions of outcomes and methods. We reviewed the literature to identify specific components of PFCC that have been used in experimental studies through a comprehensive review of the previous decade and a half of literature (from 1998-2013). We first developed a taxonomy to classify the core PFCC components specific to pediatric populations; we focused on studies that primarily included patients age 0-12 in our review because of the shift in both child and parental roles in adolescents' care. To qualify as a PFCC intervention for this review, an intervention must have been identified by the authors as being patient-centered, family-centered or involving shared decision making, considered a hallmark of patient-centered care (Dwamena et al., 2012) (Table 1). We excluded several studies that described PFCC as simply allowing a parent to be present during a child's procedure, or making structural improvements to a family waiting area, because they did not sufficiently meet the criteria of more current definitions of PFCC in the literature. While PFCC can occur at different levels,¹⁷ this paper focuses on the direct care (i.e., patient and provider) level.

Only studies with experimental designs were included. (See Figure 1 for the article selection process; search terms are listed in Table 1.) The PubMed search, which focused on studies published between 1998 and 2013, resulted in the identification of 1,792 studies. All abstracts were reviewed by the lead author (KG) to select articles that merited a full-text review; 135 met criteria for a full-text review. Criteria for full-text review were: (1) experimental design; (2) at least one outcome category reported; (3) at least one category of PFCC included (i.e., education from the provider to the patient and/or family (Edu), information sharing from the family to the provider (InfoShare), social-emotional support (SocEm), adapting care to match the family background, (Adapt), and/or shared decision-making (SDM). To ensure the comprehensiveness of our study, we further cross-referenced our selected articles with the Cochrane Reviews by Shields et al. (2007 and 2012) and

reviewed additional relevant studies referenced in the 135 articles selected, bringing the total number of abstracts to 139. Two independent coders (KG, LH) reviewed the full-text articles to determine if each article met final inclusion criteria. In the event of a discrepancy, or if inclusion was unclear, coders conferred with each other and the senior author (SO) to make a final determination. From the 139 papers reviewed, 81 articles comprising 68 distinct studies met final inclusion criteria. Studies that examined the same study population were linked in our analyses. See Table 3 for information about included studies' design, setting, and population.

PFCC Core Components and Coding Process—Following an initial review of the existing definitions of PFCC and the studies included in this review, three study authors independently generated components of PFCC. Through an iterative process and by consensus, we distilled descriptions of PFCC interventions into five distinct components: (1) education from the provider to the patient and/or family (Edu), (2) information sharing from the family to the provider (InfoShare), (3) social-emotional support (SocEm), (4) adapting care to match the family background, (Adapt), and/or (5) shared decision-making (SDM) (see Table 2 for components and explanations). Further, we focused on four categories of commonly examined outcomes, namely, the experience, knowledge, and attitudes of the patient or family; patient or family behavior; provider behavior; or health status.

Once article selection was finalized, each article was coded according to the above set of variables. In addition, we also examined the effects of targeting different participants in children's health care (i.e., provider only, patient and/or family only, or both). Most studies examined impact of PFCC on more than one outcome or used multiple metrics within each outcome. Because studies are not consistent in identifying primary versus secondary outcomes, and we did not attempt to distinguish these in our exploratory study. Rather, we took a blunt approach to examine the effects of the intervention on each outcome category, assigning each intervention's impact on each outcome category as positive/improved, negative/worsened, or no change/neutral. Where multiple metrics were used under each outcome category, we assigned impact based on the majority of findings related to that outcome category. A primary coder was assigned to each article, and a secondary coder check coded 20% of the primary coder's work ($\kappa = .833$, $p < .001$). Disagreements were resolved through discussion among all the authors.

To explore potential links between PFCC components and outcomes, descriptive statistics (Chi-square) were utilized to examine whether PFCC components (number and specific components) or the intended target of the care component were associated with outcomes. We utilized regression analyses to determine whether the target of a study's intervention (i.e., the provider, the patient and/or family, or both) had an effect on the percentage of positive outcomes. (Reported means and standard deviations are for the percentage of positive results).

See table 4 for comprehensive ratings from each study. As these are exploratory analyses, we did not correct for multiple tests.

Results

Study characteristics

Figure 1 presents information about study selection; 68 studies were included in this review. Table 3 displays information about included studies' design, setting, and sample characteristics. 26 of the studies were randomized controlled trials (RCTs). For this review, a study was determined to be an RCT if random allocation to intervention and control groups occurred at the individual participant level at baseline. As mentioned earlier, a Cochrane review of PFCC found only one RCT conducted stringently enough for their inclusion criteria. However, unlike this review, the Cochrane review excluded premature neonates.⁶ 14 of the RCTs in the current review took place on Neonatal Intensive Care Units (NICUs,) including 8 NIDCAP (Newborn Individualized Developmental Care and Assessment Program) studies. 42 of the included studies had pre-post or other quasi-experimental designs. 42 studies took place in inpatient pediatric settings and 26 studies took place in outpatient pediatric settings. PFCC interventions were applied to a wide range of pediatric populations. The most common populations for inpatient studies were related to parents and infants in the Neonatal Intensive Care Unit (NICU) or Pediatric Intensive Care Unit (PICU; $n=29$), with general pediatric inpatient settings ($n=4$) being the next most common, and post-surgical care and asthma studies occurring twice each.

Frequency of PFCC Components

The modal number of PFCC components per study was 2 (with 45.6% of studies having 2 PFCC components), and the mean number of PFCC components per study was 2.31 ($SD=1.04$). 3 studies (4.4%) had 5 PFCC components, 6 studies (8.8%) had 4 FCC components, 14 studies (20.6%) had 3 PFCC components, 31 studies (45.6%) had 2 FCC components, and 14 studies (20.6%) had 1 PFCC component.

Education from the provider to the patient and/or family (Edu) was the most commonly occurring PFCC component ($n=64$; 94.1%). The remaining components, in order of frequency, were InfoShare ($n=38$; 55.9%); SocEm ($n=22$; 32.4%); SDM ($n=12$; 17.6%); and Adapt ($n=8$; 11.8%). Percentages do not add up to 100% because many studies (45.6%) included more than one component.

Individual(s) Targeted by the Intervention(s)

The patient and/or family were most common targets for the intervention(s) ($n=33$; 48.5%). 23 studies (33.8%) had both the provider and the patient and/or family as targets, while 12 studies (17.6%) targeted the provider alone.

Outcomes measured

Among the included studies, the most frequently occurring type of outcome measured was the experience, knowledge, and/or attitudes of the patient or family ($n=43$; 63.2%). 41 studies (60.3%) measured health status; 22 studies (32.4%) measured patient and/or family behavior, and 14 studies (20.6%) measured provider behavior. Percentages do not add up to 100% because the majority of studies (98.5%) measured more than one type of outcome.

PFCC components and outcomes—Studies examined the positive impact of PFCC components on the following outcomes: patient and/or family behavior (63% of studies that included this indicator showed a positive impact); experience, knowledge, and attitudes of patients/family (61%); provider behavior (58%); and health status (46%).

Chi-square analysis did not show a significant relationship between the number of PFCC components included in a study and overall positive impact on outcomes. However, when individual PFCC components were examined (i.e., Edu, SocEm, InfoShare, Adapt, or SEM) in relation to outcomes, the presence of social-emotional support to the patient or family was found to be associated with positive changes in patient/family knowledge, attitudes, and/or experience; $\chi^2 (1, N=43) = 5.59, p=.02$. No other associations between individual PFCC components and outcomes were significant.

Given the finding that education by the provider to the patient/family (Edu) was almost a universal component across all PFCC interventions (94%), we examined the additive value of the other PFCC components. InfoShare was the next most common PFCC component (in 55.9% of studies). This component focused on straightforward information from family to provider. We examined whether the presence of augmenting Edu with *only* information sharing from the family to the provider (i.e., Edu + InfoShare = 48.8% of studies) affected the knowledge, attitudes, and/or experience of the patient or family, as compared to the addition of SDM, Adapt, and/or SocEm (i.e., Edu + one or more of SDM, Adapt, or SocEm = 51.2% of studies). Chi-square analyses revealed improved knowledge, attitudes, and experience of the patient/family when the intervention was also augmented by SDM, Adapt, and/or SocEm as compared to when information sharing and education were the only PFCC components present: $\chi^2 (1, N=43) = 6.78, p=.01$. No differences in other outcomes were found.

PFCC and to whom the intervention was targeted—Based on regression analyses, targeting the patient or family alone with a PFCC intervention significantly predicted better overall positive results ($M=66.33\%$; $SD=34.81$) than targeting the provider alone ($M=47.09\%$; $SD=30.75$) or a combination of both the provider and the patient/family ($M=43.18\%$; $SD=31.25$) [$F(2, 65) = 3.77, p = 0.028$].

We further examined the relationship between the individual(s) targeted by the intervention and each outcome. No significant difference between results for outcomes was found by target for health status, provider behavior, or patient and family behavior. However, the percentage of positive results did significantly differ by target of the intervention for the component of experience, knowledge, and attitudes of the patient and family [$F(2, 40) = 5.739, p=.006$]. Specifically, those interventions that targeted only the family ($M=74.8\%$; $SD=33.47\%$) were significantly more effective than those that targeted both the provider and family ($M=60.82\%$; $SD=44.47\%$) and those that targeted the provider only ($M=24.78\%$; $SD=38.80\%$).

Discussion

With increasing calls for the use of PFCC in pediatric health care settings, determining the most effective components of PFCC, and the most effective ways to promote and deliver such care, is essential to improving knowledge about ways to infuse PFCC in a sustained way into health care systems. In this paper, we reviewed the current state of the evidence in the pediatric literature to develop a taxonomy of PFCC components. Our review identified five common core components of PFCC interventions (listed in order of frequency of inclusion): education by the provider to the patient and/or family, information sharing from the family to the provider, social-emotional support, shared decision-making, and adapting care to match the family background.

Studies varied widely in their use of PFCC benchmarks and outcomes, with little overlap in reported outcomes. Aside from education by the provider, studies included a variety of the remaining four PFCC components and tracked a wide range of outcomes. No single outcome was consistently included across studies that examined impact of PFCC. The most frequently examined outcomes of a PFCC intervention were patient or family experience ($n=43$; 63.2%) and health status ($n=41$; 60.3%). While education by the provider was an almost universal component of PFCC in all studies reviewed, the components that required the most individualization to patient care were the least commonly included in these interventions. Yet, our findings suggest that these more individualized components, or what has come to be known as *personalized medicine*, may be key to quality measures of care, particularly those related to family experience in pediatrics. The outcomes on which we report may be used as accountability metrics as health care evolves toward the use of benchmarks for quality.

As in the adult literature,¹⁸ multi-component interventions appear to be more beneficial than single-component interventions. PFCC interventions that contained only information-sharing back and forth between families and providers were less effective in improving family care experiences than those that also contained more personalized PFCC components, such as shared decision-making, adapting care to the family's background, or social-emotional support. Our findings correspond with existing evidence that patient education alone is not effective at improving patient behavior or health status; the importance of adapting care and supporting patients' confidence and skills in handling health conditions, as opposed to simply providing knowledge of the condition, has been highlighted in previous studies.¹⁹

Consistent with the literature on the impact of PFCC, descriptive statistics from the present study show overall improvements in three of the four outcomes (i.e., patient and/or family behavior, patient experience, and provider behavior). The impact on health status remains more elusive, with fewer than half of the studies showing a benefit to health status (where measured). We found evidence for specific PFCC components predicting one type of outcome (i.e., patient experience). The lack of findings for other outcomes may be due to study methodology—the majority of the studies examined acute outcomes and measured them concurrently, but patient/family experience, knowledge and/or attitudes likely precede changes in health status, patient behavior, and even provider behavior. This hypothesis is consistent with the growing literature and evidence on the impact of patient activation on

health outcomes.²⁰ Addressing patient knowledge and attitudes are key processes in patient activation as they become more actively engaged in their own health care. Thus, changes in patient experience represent an important precursor to other health-related outcomes.

Our analyses revealed that it may be more effective to target the patient and/or family alone as compared to the provider alone, or even as compared to a combination of the provider and family concurrently, particularly for outcomes related to patient/family experience. For change to be most effective or enduring, a focus on the patient and/or family is likely to be necessary. Interventions directed at patients and families are more effective at changing their experience, while interventions targeted at providers to foster change in family experience are less effective. When the provider is the target of PFCC intervention, the impact of the intervention on families may be diminished due to variability in provider delivery of PFCC. This finding is consonant with one of the key components of the Chronic Care Model, developing self-management skills.¹⁹ Patients are involved in their own health care for their entire lives. It therefore seems more effective for patients to steer their own health care choices, as opposed to the provider, who is only involved for a limited time, and may be one of many professionals involved in a patient's care. However, it may be that a difference in the interventions themselves, rather than differences in outcomes among target groups, was the cause of the differences in outcomes between target groups.

Limitations

Our review focused on five common PFCC components and four outcomes commonly examined in PFCC papers; while parsimonious, these components are not exhaustive. However, given the lack of consensus around what constitutes PFCC and which aspects of care it is purported to influence, such an approach is reasonable as a preliminary effort to capture the state of the evidence on PFCC. Additionally, included studies varied significantly in quality. Despite our attempt at an exhaustive literature review, we may have inadvertently missed studies meeting inclusion criteria. Further, cumulative evidence may be affected by the selective reporting of findings within studies. Most studies do not report fidelity to the interventions; thus it is unclear the extent to which findings, or lack thereof, may be related to how well various PFCC components are implemented. Given the limitations of the field and existing literature, our findings should be regarded as preliminary. Further rigorous studies of the five components of PFCC are needed. Finally, the prevalence of studies performed on a NICU or ICU studies may limit generalization to other settings.

Conclusion

To date, there has been a lack of attention paid to specific competencies needed by patients, providers and the health care system to optimize patient and family centered care initiatives. Calls to focus on PFCC have not been accompanied by a well-established body of work to guide care delivery. The proposed PFCC taxonomy based on our review, in consort with the existing evidence for PFCC in the literature, may provide the necessary groundwork for establishing a stronger science base for PFCC, by creating a common platform for examining key PFCC components and outcomes by which to benchmark the effectiveness of PFCC. This preliminary evidence suggests the utility of patient- and family-centered care in

pediatric settings, especially when patients and families are the targets of interventions and when the provision of information is augmented with individualized components.

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Figure 1. Study Selection Process

Table 1**Search methods**

Search Field	Search Terms
SET 1: Topic	
Abstract/Title	“patient centered” OR
	“patient centred” OR
	“patient-centeredness” OR
	“patient-centredness” OR
	“family centered” OR
	“family centred” OR
	“family-centeredness” OR
	“family-centredness” OR
	“shared decision-making”
SET 2: Population	
Abstract/Title	child* OR
	adolescent* OR
	family OR
	pediatric* OR
	paediatric*
SET 3: Methods	
All Text	treatment OR
	intervention OR
	“randomized controlled trial” OR
	“randomised controlled trial” OR
	RCT

The PubMed database was searched with Set 1 AND Set 2 AND Set 3 of search terms.

Additional Filters: Journal Articles, Published 1998-2013, English Language

Table 2
Components of Patient- and Family-Centered Care

Component	Abbreviation	Explanation
Education from the provider to the patient and/or family	Edu	Information given by the provider to the patient and/or family about any relevant topic (e.g., causes of the disease, treatment options, possible health status).
Information sharing from family to provider	InfoShare	Factual exchanges of information by the patient and/or family to the provider that do not involve negotiation and decision-making.
Social-emotional support	SocEm	Formal and informal emotional support ⁵ given directly or indirectly (e.g., through support groups or networking opportunities with other families) by the provider to the patient or family to support self-efficacy, increase confidence, reduce anxiety, etc.
Adapting care to match the family background	Adapt	Eliciting of patient and/or family preferences and needs so that care can be adapted to be consistent with and respectful of them (including but not limited to racial, ethnic, cultural, and socioeconomic background, and patient and family experiences).
Shared decision-making	SDM	A collaborative process which allows patients and families access to the information needed to help them participate in care (possibly requiring that information be presented in a range of cultural and linguistic formats); this information includes all care options and their potential benefits and risks/harms. SDM involves a negotiation or discussion between family and provider about care that takes into account best available scientific evidence and family/patient preferences and values. ²¹

Table 3
Included studies and study characteristics

Study #	Authors	Setting	Population
1	(1) Als et al., 2003; (2) McAnulty et al., 2009	Inpatient	NICU
2	McAnulty et al., 2010	Inpatient	NICU
3	Als et al., 2004	Inpatient	NICU
4	Arauz Boudreau et al., 2013	Outpatient	Obesity
5	Barkin et al., 2012	Outpatient	Obesity
6	Blauw-Hospers et al., 2011	Outpatient	Infants at high risk of developmental disorders
7	Brinkman et al., 2013	Outpatient	ADHD
8	Chan et al., 2002	Inpatient	Post-Anesthesia Care Unit
9	Cooper et al., 2007	Inpatient	NICU
10	Goldbeck et al., 2001	Outpatient	Cystic fibrosis
11	Ireys et al., 2001	Outpatient	Chronic illness
12	Junnla et al., 2012	Outpatient	Mildly overweight children
13	Kamerling et al., 2008	Inpatient	Post-Anesthesia Care Unit
14	Kleberg et al., 2000	Inpatient	NICU
15	Kressin et al., 2009	Outpatient	Risk of tooth decay
16	Kuo et al., 2012	Inpatient	General pediatric inpatient
17	(1)Maguire et al., 2009; (2)Maguire et al., 2009	Inpatient	NICU
18	McCann et al., 2008	Inpatient	Medical and surgical wards
19	McKean et al., 2012	Outpatient	Speech disorders
20	Mello et al., 2004	Inpatient	PICU
21	Melnyk et al., 2006	Inpatient	NICU
22	Melnyk et al., 2004	Inpatient	PICU
23	Melnyk et al., 2001	Inpatient	NICU
24	Morey et al., 2012	Inpatient	NICU
25	O'Brien et al., 2013	Inpatient	NICU
26	Penticuff et al., 2005	Inpatient	NICU
27	Porter et al., 2006	Inpatient	Asthma or other respiratory complaint
28	Preyde et al., 2003	Inpatient	NICU
29	Samadi et al., 2013	Outpatient	Autism
30	(1)Skuladottir et al., 2003 (2)Thome et al., 2005	Inpatient	Sleep problems
31	Tzeng et al., 2010	Outpatient	Asthma
32	(1)van der Pal et al., 2007; (2)van der Pal et al., 2007 (3)van der Pal et al., 2008	Inpatient	NICU
33	Voos et al., 2011	Inpatient	NICU
34	Wade et al., 2006	Outpatient	Traumatic Brain Injury
35	Weis et al., 2013	Inpatient	NICU
36	Westermann et al., 2013	Outpatient	Mental health

Study #	Authors	Setting	Population
37	(1)Westrup et al., 2000; (2)Kleberg et al., 2002; (3)Westrup et al., 2002; (4)Westrup et al., 2004; (5)Kleberg et al., 2007	Inpatient	NICU
38	(1)Wielenga et al, 2006.; (2)Wielenga et al., 2007; (3)Wielenga et al., 2009	Inpatient	NICU
39	Won, 2006	Inpatient	Procedures requiring intravenous procedures
40	Woods et al., 2012	Outpatient	Acquired Brain Injury
41	Wright et al., 2013	Outpatient	Obesity risk
42	Borhani et al., 2011	Outpatient	Thalassemia
43	Bouvé et al., 1999	Inpatient	PICU
44	Brady et al., 2013	Inpatient	Acute osteomyelitis
45	Clark et al., 2000	Outpatient	Asthma
46	Davison et al., 2013	Outpatient	Obesity
47	Dudas et al., 2010	Inpatient	General pediatric inpatient
48	Byers et al., 2006	Inpatient	NICU
49	Felder-Puig et al., 2003	Inpatient	Ear, nose, and throat surgery
50	Gray et al., 2000	Inpatient	NICU
51	Hughes et al., 2008	Outpatient	Overweight
52	Stewart et al., 2006	Outpatient	Special needs
53	(1)Kain et al., 2007; (2)Fortier et al., 2011	Inpatient	Elective surgery
54	Lammi & Law, 2003	Outpatient	Cerebral palsy
55	Peters et al., 2009	Inpatient	NICU
56	Hart et al., 2006	Outpatient	General ambulatory care
57	Kuntaros et al., 2003	Inpatient	PICU
58	Monzavi et al., 2006	Outpatient	Overweight
59	Clark et al., 1998	Outpatient	Asthma
60	van Dulmen & Holl, 2000	Outpatient	Unspecified
61	Porter et al., 2005	Inpatient	Asthma
62	Porter et al., 2008	Inpatient	Emergency room
63	Cho et al., 2012	Outpatient	Preterm infants
64	Welch et al., 2013	Inpatient	NICU
65	(1)Als et al., 2011; (2)McAnulty et al., 2013	Inpatient	NICU
66	Als et al., 2012	Inpatient	NICU
67	Kleberg et al., 2008	Inpatient	NICU
68	Ullenhag et al., 2009	Inpatient	NICU

Table 4

PFCC components and outcomes by study.

Study #	PFCC Component					Target of the Intervention			Outcomes			Health status	Patient/Family Experience, Knowledge, Attitudes
	Info Share	SocEm	Adapt	SDM	Edu	Provider	Patient/Family	Provider Behavior	Patient/Family Behavior	Health status	Patient/Family Experience, Knowledge, Attitudes		
1	X				X	X	X				●	●	●
2	X				X	X	X				●	●	●
3	X				X	X	X				●	●	●
4			X		X		X		●		●	●	●
5		X			X		X				●	●	●
6					X		X				●	●	●
7	X			X	X	X	X				●	●	●
8					X		X				●	●	●
9		X		X	X	X	X		●		●	●	●
10					X		X		○ and ●		○	○	○
11		X			X		X				●	●	●
12	X	X					X			○ and ●	○ and ●	○ and ●	○ and ●
13							X		●				
14	X					X	X		●		●	●	●
15	X					X		●			●	●	●
16	X					X		●			●	●	●
17	X					X	X				●	●	●
18				X		X		●	●		●	●	●
19	X		X	X	X	X					●	●	●
20	X				X	X			○		○	○	○
21					X		X		●		●	●	●
22					X		X		●		●	●	●
23					X		X				●	●	●
24					X		X				●	●	●
25		X			X	X	X		●		●	●	●

	PFCC Component					Target of the Intervention		Outcomes			
Study #	Info Share	SocEm	Adapt	SDM	Edu	Provider	Patient/Family	Provider Behavior	Patient/ Family Behavior	Health status	Patient/ Family Experience, Knowledge, Attitudes
26	X			X	X	X			●		●
27	X					X		● and			● and ○
28		X					X			●	●
29		X			X		X		●		●
30	X				X		X			●	●
31	X				X		X		●	●	
32	X				X	X	X			●	●
33	X				X	X		●			●
34	X		X		X		X			●	●
35	X				X	X	X	●			●
36	X			X	X	X	X	●	●		●
37	X				X	X	X			●	●
38	X				X	X	X			●	●
39					X		X		●		● and ●
40		X			X		X				●
41		X	X		X		X		●	● and ●	
42		X			X		X				●
43					X		X				●
44				X	X	X		●		●	
45	X	X	X	X	X	X	X	●	●	●	●
46		X	X		X		X		● and ●	● and ●	●
47					X		X				●
48			X		X	X	X			●	
49					X		X				●
50	X	X			X		X		●	●	●
51	X	X		X	X		X		●	●	●
52	X				X		X				● and ●
53		X			X		X			●	●

	PFCC Component					Target of the Intervention		Outcomes			
Study #	Info Share	SocEm	Adapt	SDM	Edu	Provider	Patient/Family	Provider Behavior	Patient/ Family Behavior	Health status	Patient/ Family Experience, Knowledge, Attitudes
54	X	X		X	X	X	X			●	
55	X				X	X	X			◐	
56	X	X			X	X		◐			●
57	X	X		X	X		X				●
58					X		X			●	
59	X	X	X	X	X	X		●		●	◐
60	X	X			X	X		◐			
61	X						X		●		
62	X				X	X	X	◐			
63		X			X	X	X		◐	◐	◐
64		X			X		X			◐	
65	X				X	X	X			◐	
66	X				X	X	X			●	
67	X				X	X	X	●		◐	
68	X				X	X	X			●	

Note: "X" denotes a primarily positive impact; "●" denotes a primarily negative/adverse impact; "○" denotes a neutral or no impact