Individualized Plans of Care to Improve Outcomes Among Children and Adults With Chronic Illness: A Systematic Review

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Background: Adults and children with chronic illness often require services from multiple providers. Individualized plans of care (IPCs) are sometimes developed to improve care coordination. However, their association with improved outcomes is unknown.

Methods: We searched literature published between January 2001 and October 2011, using Medline, CINAHL, EMBASE, PsychINFO, and bibliographic review. Eligible studies involved an IPC with input from the patient and/or family of individuals with chronic illness, evaluated outcomes, and were conducted in the United States. We assessed evidence quality using Oxford Centre for Evidence-Based Medicine criteria.

Results: 15 studies met inclusion criteria. Studies were heterogeneous regarding populations and outcomes examined and were generally low quality. Most described IPC use within a multifaceted care coordination intervention. The strongest evidence links IPC use and symptom improvement in depressed adults; the weakest evidence exists for outcomes in children. Vague descriptions of the IPCs' limited analysis.

Conclusions: Current evidence supporting an association between IPC use and improved outcomes, particularly among children, is sparse. Well-designed evaluations of clearly described IPCs are needed to examine who should be involved in their development, what they should include, and how often they should be updated to improve outcomes of care for this vulnerable population.

Keywords: patient care planning; patient-centered care; case management; disease management

Comprehensive, well-coordinated care improves patient and family experiences with care (Farmer, Clark, Drewel, Swenson, & Ge, 2011; Farmer, Clark, Sherman, Marien, & Selva, 2005; Palfrey et al., 2004), patient health outcomes (Counsell et al., 2007; Farmer et al., 2011; Farmer et al., 2005; Rocco, Scher, Basberg, Yalamanchi, & Baker-Genaw, 2011), and decreases hospitalizations and cost (Casey et al., 2011; Counsell et al., 2007; Dorr, Wilcox, Brunker, Burdon, & Donnelly, 2008; Gordon et al., 2007; Palfrey et al., 2004). However, care coordination requires substantial investment of personnel and infrastructure, and it is unknown which aspects are most likely to benefit patients. Medical providers and health care systems face challenges prioritizing which groups of patients with chronic illness should receive care coordination services. In addition, systems and payers must decide which components of care coordination to use as metrics for evaluating the quality of care provided to individuals with chronic illness.

The American Academy of Pediatrics (AAP) recommends individualized plans of care (IPCs) as a key element of the medical home and comprehensive care coordination; other professional bodies, including the American Academy of Family Physicians, advocate similar principles (AAP, 2002; American College of Physicians, 2010; Association of American Medical Colleges, 2008; Homer et al., 2008; McAllister, Presler, & Cooley, 2007). Yet there are no definitive reviews of the evidence that IPCs improve care coordination or other outcomes for adults or children with chronic illness. We undertook this

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review to better understand the relationship between IPCs and outcomes of importance to patients, families, providers, and systems. We also sought to identify evidence regarding who should participate in IPC development, what elements should be included, how often they should be updated, and which populations are most likely to benefit from them. Establishing such standards can inform the development of care coordination quality measures for people with chronic illness.

METHODS

Inclusion Criteria

We included peer-reviewed literature published between January 2001 and October 2011 that examined short- or long-term outcomes associated with IPC use. Given the lack of a standard definition or terminology around IPCs, we used the AAP concept of a written "plan of care [that] is developed by the physician, child or youth, and family and is shared with other providers, agencies, and organizations involved with the care of the patient" (AAP, 2002). We also included IPCs developed by the patient or family with a nurse or care coordinator. We examined both the adult and pediatric literature. All studies concern patients with at least one chronic condition. Where relevant, we distinguish between individuals with complex and noncomplex chronic illness. We defined complex chronic illness as chronic illness that affects multiple organ systems. As we conducted this review to inform development of quality measures for use within the U.S. healthcare system, we included only U.S.-based studies.

Search Strategy

We searched PubMed, PsycINFO, CINAHL, and Embase for relevant articles. Prespecified search strategies were developed for each database (see Appendix). The search returned 1,201 articles from PubMed, 1,450 from PsycINFO, 2,523 from CINAHL, and 2,387 from Embase, totalling 7,561 articles (see Figure 1). Titles were screened for relevance and abstracts were reviewed for further details. References from relevant articles were screened, adding an additional 36 articles. There were 59 full-text articles evaluated, of which 15 are included in this review. The most common reasons for exclusion were failure to specifically mention IPC use, failure to evaluate outcomes, and being conducted outside of the United States. For two studies (Cady, Finkelstein, & Kelly, 2009; Casey et al., 2011), more detailed descriptions of the intervention's

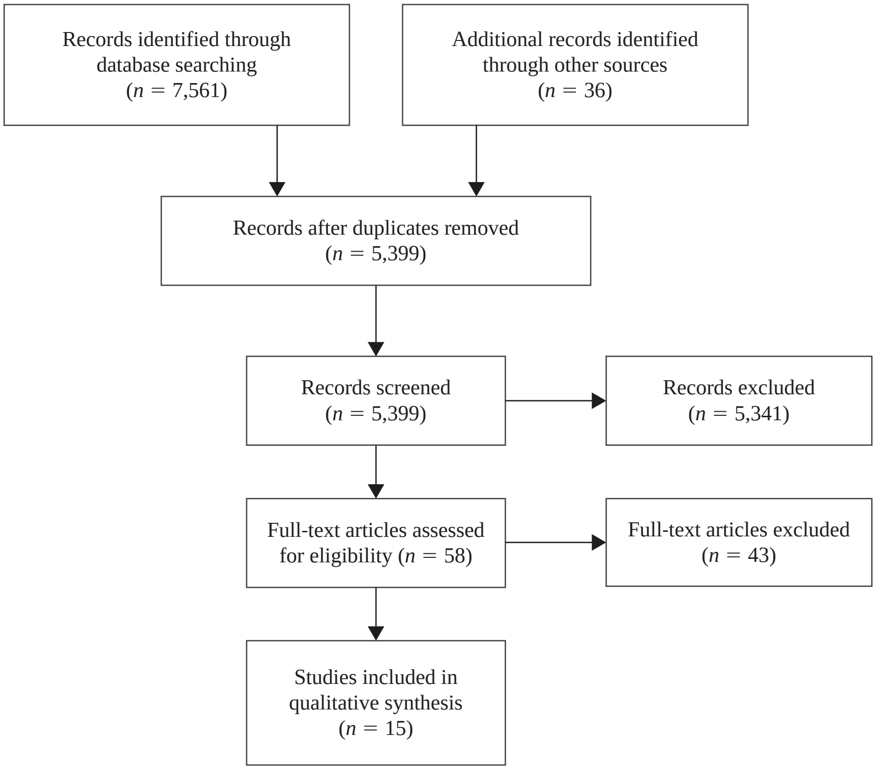

Figure 1. PRISMA Diagram of study identification and selection. From "*P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalysis: The PRISMA Group," by D. Moher, A. Liberati, J. Tetzlaff, and D. G. Altman, 2009, *PLoS Medicine*, *6*(6), e100097. http://dx.doi.org/10.1371/journal.pmed1000097. Copyright 2009 by The PRISMA Group. Adapted with permission.

IPCs were identified in separate publications (Kelly, Kratz, Bielski, & Rinehart, 2002; Tanios, Lyle, & Casey, 2009); these descriptions were used for our analysis. We did not contact authors for additional information. Evidence quality for each study was formally evaluated using the University of Oxford's Centre for Evidence-Based Medicine (OCEBM) levels of evidence, in which Level 1 represents the highest quality evidence and Level 5 represents expert consensus (OCEBM Levels of Evidence Working Group [Jeremy Howick et al., 2011]).

RESULTS

Evidence Quality

The IPC literature is generally sparse and of low quality. Although we did identify some high-quality studies (Counsell et al., 2007; Katon et al., 2010; Katon et al., 2001; Lozano et al., 2004), these were generally most relevant to adults with chronic illness, with those of lower quality being more relevant to children. Findings from the literature are summarized in the following text; and study information, IPC descriptions and outcomes are detailed in Tables 1 and 2.

Outcomes Associated With IPC Interventions by Intervention Type

Most identified studies evaluated outcomes associated with IPC use in the context of larger care coordination or disease-specific management interventions. We consider outcomes associated with IPC use first by intervention type, then by IPC attributes and targeted populations.

IPC as the Intervention. We identified a single study describing the impact of an IPC alone on outcomes. The small trial ($n = 20$) evaluated the effect of an IPC with multidisciplinary input for adult primary care patients considered "frequent attenders" (Adam, Brandenburg, Bremer, & Nordstrom, 2010). Compared to controls, IPC patients had greater satisfaction, fewer clinic visits, and improved referral to mental health and pharmacy services. However, they also had more cancelled clinic visits and increased emergency department (ED) use. No statistical testing was reported.

IPC Within a Care Coordination Intervention. We identified 10 articles describing the impact of broad care coordination interventions that featured IPCs, 4 among adult populations and 6 in children. These studies evaluated multiple outcomes from various interventions.

We identified two care coordination randomized controlled trials (RCTs) in adults, both using protocol-based IPCs and demonstrating some positive findings (Aiken et al., 2006; Counsell et al., 2007). Counsell et al.'s (2007) study enrolled low-income seniors and demonstrated significantly better outcomes for four of eight patient-reported measures of health and well-being. Intervention patients in the preidentified subset at high risk for hospitalization had fewer ED visits and hospitalizations. There were no significant differences in activities of daily living, overall hospitalization rate, or mortality between groups. Aiken et al.'s (2006) RCT enrolled ill adults with cardiac or pulmonary disease. Intervention patients reported improvements in knowledge, self-management, and distress, but ED use was similar between groups. There was substantial attrition (62% by 9 months) because of higher than anticipated mortality and disqualifying insurance changes.

The two cohort studies among adults also achieved positive outcomes in some domains. In Dorr's prospective matched cohort study of seniors with chronic illness, patients and care managers developed a protocol-based IPC focused on managing chronic issues (Dorr et al., 2008). Intervention group mortality was lower during Year 1, but not Year 2. Intervention patients' ED use was higher in the second year, whereas hospitalization rates remained similar between groups. For patients with diabetes, mortality and hospitalizations were lower during both years.

The second cohort study retrospectively evaluated an IPC tool within a medical home, compared to patients in another clinic without the IPC or the medical home (Rocco et al., 2011). Primary care providers (PCPs) and patients used the tool to list diagnoses, specific goals, and specific actions with a time frame for completion. Intervention patients demonstrated small but significant improvements compared to controls in measurements of hemoglobin A1C and low-density lipoprotein (LDL) cholesterol. However, because only the intervention clinic used a medical home model, it is difficult to differentiate the impact of the IPC from that of the medical home.

The only pediatric RCT evaluated care coordination for 100 Medicaid-enrolled children with chronic illness (Farmer et al., 2011). The intervention IPC, described as a "written health plan" addressing specific goals, was developed by the family and a care coordinator, with PCP input. Compared to controls, intervention families reported greater satisfaction with some aspects of care and less unmet need for information. Following crossover to intervention, parents reported improvements in child health, caregiver strain, and satisfaction. There were no differences in days of work or school missed. Study follow-up was low, with 12-month retention of 61%. Families of children with more diagnoses were more likely to remain enrolled.

Five studies conducted uncontrolled pre–post care coordination interventions in children with chronic illness, with sample sizes from 43 to 245 (Cady et al., 2009; Casey et al., 2011; Farmer et al., 2005; Gordon et al., 2007; Palfrey et al., 2004). All involved the family in IPC development, with a range of other participants, including care coordinators (Farmer et al., 2005), nurse practitioners (Cady et al., 2009; Palfrey et al., 2004), clinic physicians (Gordon et al., 2007), or multidisciplinary teams (Casey et al., 2011). The studies examined various outcomes, some of which showed consistent improvements over baseline following intervention (cost [Casey et al., 2011; Gordon et al., 2007] and hospitalizations [Cady et al., 2009; Gordon et al., 2007; Palfrey et al., 2004]) and some

TABLE 1. Summary of Reviewed Studies Providing Evidence for Outcomes Associated With Written Individualized Plans of Care

Source and Study Design	Population	Intervention	Level of Evidence^{a}	ED Use	Hospitalization^{b}	OP Visits	Cost of Care	Adherence	Work Loss	School Absence	Clinical Measures	Function	Quality of Life	Satisfaction^{c}	Mortality	Knowledge
Adam et al., 2010 Nonrandomized controlled trial	20 adult "frequent attenders" to clinic with multiple chronic illnesses (12 intervention, 8 control)	A team of 4 doctors (including the PCP), a psychologist, a pharmacist, and a nurse discussed the patient and developed a tentative IPC; the IPC was discussed with the patient, their feedback was incorporated, and then the plan was implemented.	4	↑^{d}	nc	↓^{d}					↑^{d}			↑^{d}		
Aiken et al., 2006 RCT	192 adults with COPD or CHF and estimated 2-year life expectancy; (101 intervention, 91 control)	A nurse case manager—supported by a medical director, social worker, and pastor—provided in-home and telephone support, education, and care coordination, guided by an IPC. The IPC was shared with the PCP and other service providers.	1	nc									↑^{e}			↑
Cady et al., 2009 Uncontrolled pre-post cohort	43 children with complex chronic illness	Nurse practitioners (NP) provided phone-based care coordination between the family, PCP, and specialists, and helped develop an IPC for recurrent acute illnesses (intervention details from Kelly et al. (2002).	4		↓											
Casey et al., 2011 Uncontrolled pre-post cohort	225 children with complex chronic illness	Multidisciplinary clinic (MD, RN, nutrition, social work) worked with the family to develop an IPC, which included a medical summary, medications list, and therapeutic plans of care. They also helped to coordinate care between providers and services.	4	↓	↓	↑	↓									

Counsell et al., 2007 Cluster RCT	951 low-income seniors with chronic illness (474 intervention, 477 control)	2 years of home-based care management by a NP and social worker, collaborating with the PCP and an interdisciplinary team to develop and implement a protocol-based IPC with annual reassessment.	1	↓	↓[f]					nc	↑		nc
Dorr et al., 2008 Matched prospective cohort	3,432 adults with chronic illness aged >64 years (1,144 intervention, 2,288)	Patients from intervention clinics were referred by their PCPs to the intervention, which consisted of a nurse care manager using structured protocols to develop an IPC. Intervention patients were matched to 2 patients from control clinics on age, comorbid score, sex, specific diseases, recent hospitalizations, and hospice; these patients received usual care.	2	↑	↓[g]								↓[g,h]
Farmer et al., 2011 RCT with crossover to intervention	100 children with complex and noncomplex chronic illness (50 randomized to each arm, 36 intervention and 25 controls completed)	6-month intervention supporting 32 PCP offices, in which the care coordinator worked with the family to develop a written IPC for the child, provide access to services, coordination with doctors and home visit/telephone support.	2					nc	nc	↑		↑	
Farmer et al., 2005 Uncontrolled pre–post cohort	51 children with complex chronic illness	NP-led care coordination involving a home visit, assessment, referral to resources, and an individualized written plan with specific goals. The NP serves as a consultant to the PCPs.	4			↓		↓	↓	↑		↑	
Gordon et al., 2007 Uncontrolled pre–post cohort	227 children with complex chronic illness	Depending on complexity and number of involved providers, patients were assigned to an NP only or to an NP and MD, who developed an IPC with the family, interfaced with the PCP along with other providers and services, and provided support.	4	↑[i]	↓	↑	↓						

(continued)

TABLE 1. **(*continued*)**

Source and Study Design	Population	Intervention	Level of Evidence[a]	ED Use	Hospitalization[b]	OP Visits	Cost of Care	Adherence	Work Loss	School Absence	Clinical Measures	Function	Quality of Life	Satisfaction[c]	Mortality	Knowledge
Katon et al., 2010 RCT	214 adults with poorly controlled diabetes mellitus (DM), coronary heart disease(CHD), or both and depression (106 intervention, 108 control)	12-month intervention in which a nurse care coordinator—supervised by a psychiatrist, the PCP, and a psychologist—worked with patients to develop and implement an individualized treatment plan.	1								↑		↑	↑		
Katon et al., 2001 RCT	386 adults with major depression, currently controlled (194 intervention, 192 control)	Intervention included 2 visits with a depression specialist in which a written relapse prevention IPC was devised and then shared with the PCP, 3 follow-up phone calls, and medication refill monitoring.	1					↑			↑/nc[j]					
Lozano et al., 2004 Multisite cluster RCT	678 children with mild to moderate persistent asthma (199 control, 213 intervention)	Asthma nurses conducted assessment, developed IPC with family, provided self-management support and phone follow-up. There was a concurrent MD peer leader to champion office-wide change.	1					↑			↑	↑[c]				
Palfrey et al., 2004 Uncontrolled pre–post cohort	117 children with complex and noncomplex chronic illness in 6 practices	An NP serving as care coordinator within a medical home model provided home visits (including sick visits), family support, and services coordination as well as working with the family to develop an IPC.	4	nc	↓				↓	nc				↑		

Rocco et al., 2011 Controlled retrospective cohort	1,110 adults with chronic disease (at least one of the following: DM, CHD, hypertension, heart failure); (593 intervention, 517 control)	IPC intervention, in which PCP and patient collaborate to develop individual problems, goals, and actions to be taken, within a medical home model clinic; controls were drawn from a nonmedical home model clinic without the plan of care tool.	4		↑			
Unützer et al., 2002 RCT	1,801 adults >59 years old with major depression or dysthymic disorder (906 intervention, 895 control)	Intervention included 12 months of depression care management by a care manager, under the supervision of an internist and a psychiatrist, beginning with assessment and development of a protocol-guided IPC.	1	↑	↑	↑	↑	↑

Note. ED = emergency department; OP = outpatient; PCP = primary care provider; IPC = individualized plan of care; ↑ = increase in any outcome measure within column domain (bold indicates statistically significant); nc = no change; ↓ = decrease in any outcome measure within column domain (bold indicates statistically significant); RCT = randomized controlled trial; COPD = chronic obstructive pulmonary disease; CHF = congestive heart failure; RN = registered nurse.

[a] Level of Evidence Codes:
1: RCT
2: Controlled cohort studies
3: Case-control studies
4: Case-series or uncontrolled cohort
5: Consensus, opinions or "first principles" research

[b] This category includes number of hospital days, number of hospitalizations, and number of unplanned hospitalizations; see review text for details.

[c] Multiple different measures were used within and between studies; see Table 2 for details. A positive indicator in this column reflects improvement in any measure.

[d] No statistical testing performed.

[e] As measured by symptom-related distress.

[f] In the patient subgroup classified prior to intervention as being at high risk for hospitalization.

[g] In the patient subgroup with diabetes mellitus.

[h] At the end of Year 1 (but not Year 2) for the overall study population.

[i] In the more complex subgroup assigned to the NP/MD team.

[j] Intervention patients reported fewer depressive symptoms but had depression relapse rates that did not significantly differ from those of controls.

Table 2. Details of Outcomes Associated With Written Individualized Plans of Care

Source and Study Design	Population	Outcomes Assessed and Summary of Results
Adam et al., 2010 Controlled intervention, nonrandomized	20 adult "frequent attenders" to clinic with multiple chronic illnesses (12 intervention, 8 control)	ED use: Median ED visits increased by 0.5 in intervention group, whereas unchanged in control group. Hospitalizations: None in either group. OP visits: Median decreased by 3 visits over 6 months in intervention group (compared to +1.5 in controls) but also more cancelled clinic visits in intervention patients (+1.5 vs. −2.0 in controls over 6 months). Satisfaction with care: Increased in intervention group from 75% to 92%; 100% in control group at both time points. Clinical measures: Improved referral to mental health and pharmacy services. Note: No statistical testing was reported.
Aiken et al., 2006 RCT	192 adults with COPD or CHF and estimated 2-year life expectancy (101 intervention, 91 control)	ED use: No difference. Quality of life: Better symptom-related distress in intervention patients (0.73–0.95 higher on 4-point scale, $p < .05$). Knowledge: Intervention patients reported better self-management (0.39 higher on 4-point scale, $p < .05$), knowledge of community resources (0.44–0.55 higher on 4-point scale, $p < .05$), and were more likely to have a will (71% vs. 65%, $p < .05$). Note: There was substantial attrition (at 9 months, 38% of participants remained) because of higher than anticipated mortality and disqualifying insurance changes. Rates of leaving this study were similar between groups for medical reasons, but control patients left more often for other reasons.
Cady et al., 2009 Uncontrolled pre–post cohort	43 children with complex chronic illness	Hospitalization: Unplanned hospitalizations decreased from 74 to 35 ($p < .007$).
Casey et al., 2011 Uncontrolled pre–post cohort	225 children with complex chronic illness	ED use: Decreased from 0.18 to 0.16 per patient per month, comparing the year before the intervention to the year after ($p < .001$). Hospitalization: Adjusted number of hospitalizations decreased from 0.15 to 0.11 per patient per month ($p < .001$); mean length of stay decreased from 14.5 to 10.0 days ($p < .001$). OP visits: Increased outpatient claims from 9.4 to 10.3 per patient per month ($p < .001$). Costs of care: Medicaid cost decreased by $1,179 per patient per month in the year following intervention ($p < .001$).
Counsell et al., 2007 Cluster RCT	951 low-income seniors with chronic illness (474 intervention, 477 control)	ED use: Fewer ED visits over 2 years, among intervention patients overall (1,445 vs. 1,748 per 1,000, $p = .03$) and among the pre identified subset at high risk for hospitalization (848 vs. 1,314 per 1,000, $p = .03$). Hospitalization: No difference overall, but fewer hospitalizations among intervention patients in the pre identified subset at high risk for hospitalization (396 vs. 705 per 1,000, $p = .03$). Function: No difference in activities of daily living. Quality of life: Intervention group demonstrated significantly better outcomes for 4 out of 8 survey measures (general health, vitality, social functioning, and mental health, $p < .05$ for each). Mortality: No difference between groups.

Table 2. (*continued*)

Source and Study Design	Population	Outcomes Assessed and Summary of Results
Dorr et al., 2008 Controlled prospective cohort	3,432 adults with chronic illness aged >64 years (1,144 intervention, 2,288)	ED use: Intervention patients' ED use was higher than control patients in the second year ($OR = 1.28$, $p = .02$). Hospitalization: Overall hospitalization rates were similar between groups. Among patients with diabetes, hospitalizations were lower for intervention patients in Years 1 and 2 ($OR = 0.65$, $p = .04$; $OR = 0.56$, $p = .01$). Mortality: Intervention group mortality was lower during Year 1 ($OR = 0.68$, $p = .01$) but not Year 2 ($OR = 0.77$, $p = .07$). For patients with diabetes, intervention group mortality was lower during Years 1 and 2 ($OR = 0.56$, $p = .01$; $OR = 0.66$, $p = .03$).
Farmer et al., 2011 RCT with crossover to intervention	100 children with complex and noncomplex chronic illness (50 randomized to each arm, 36 intervention and 25 controls completed)	Work loss: No difference between groups. School absence: No difference between groups. Function: Following crossover to intervention, parents reported improvements in family functioning ($p < .001$), perceived burden ($p = .008$), caregiver strain ($p = .004$), and overall child health ($p = .02$). Satisfaction: Compared to controls, intervention families reported greater satisfaction with some aspects of care ($p < .05$) and less unmet need for information ($p = .04$). Following crossover to intervention, parents reported improvements in satisfaction in multiple domains ($p < .05$). Note: Study follow-up was low, with 12-month retention of 61%. The authors note that families of children with more diagnoses were more likely to complete the study ($p = .02$).
Farmer et al., 2005 Uncontrolled pre–post cohort	51 children with complex chronic illness	OP visits: Comparing the year before intervention to the year after, parents reported a mean of 0.62 fewer PCP visits ($p = .001$) and 0.52 fewer outpatient specialty visits ($p = .003$). Work loss: Proportion of mothers reporting loss of 10 or more days of work decreased from 38% to 22% ($p = .03$). School absence: Decreased by 0.72 on a 7-point scale (from 1 = no days missed to 7 = >20 days missed, $p = .02$). Function: Family functioning improved across multiple domains ($p < .05$). Satisfaction: Improved parent-reported satisfaction with primary care ($p = .02$) and care coordination ($p = .007$); no difference for ED, inpatient, specialty, or mental health services. Note: Families of children with more severe or complex disease were more likely to report benefit.
Gordon et al., 2007 Uncontrolled pre–post cohort	227 children with complex chronic illness	ED use: Increased ED use in more complex patients, from 0.001 to 0.002 median visits per patient per day ($p = .01$). Hospitalization: Median hospital days per patient per day decreased from 0.17 to 0.03 among the more complex group ($p < .001$) and from 0.02 to 0.007 among the less complex group ($p < .001$). OP visits: Median clinic visits per patient per day increased from 0.04 to 0.07 among the more complex group ($p < .001$) and from 0.02 to 0.05 among the less complex group ($p < .001$). Cost: Annual hospital payments decreased $10.4 million following intervention ($p < .001$).

(continued)

Table 2. (*continued*)

Source and Study Design	Population	Outcomes Assessed and Summary of Results
Katon et al., 2010 RCT	214 adults with poorly controlled diabetes mellitus (DM), coronary heart disease (CHD), or both and depression (106 intervention, 108 control)	Clinical measures: Compared to controls, intervention patients demonstrated greater improvement in depression scores (effect size 0.67, $p < .001$) and greater reductions in hemoglobin A1C, LDL cholesterol, and systolic blood pressure (3-disease composite $p < .001$). Quality of life: Intervention patients reported better quality of life at 12 months (mean 6.0 vs. 5.2 out of 10, $p < .001$). Satisfaction: Intervention patients more satisfied with depression care (90% vs. 55%, $p < .001$) and with diabetes and/or heart disease care (86% vs. 70%, $p < .001$) at 12 months than controls.
Katon et al., 2001 RCT	386 adults with major depression, currently controlled (194 intervention, 192 control)	Adherence: Compared to controls, intervention patients were more likely to refill antidepressant prescription ($OR = 1.91$, $p < .001$) and to receive an adequate antidepressant dosage ($OR = 2.08$, $p < .001$). Clinical measures: Intervention patients had lower depression symptom scores over time (difference 0.08 points, $p = .04$) but no difference in relapse frequency.
Lozano et al., 2004 Multisite cluster RCT	678 children with mild to moderate persistent asthma (199 control, 213 intervention)	Adherence: Greater parent-reported controller medication adherence among intervention patients (rate ratio 1.05, 95% CI 1.00–1.09). Clinical measures: Intervention patients had 13.3 fewer symptom days ($p = .02$) and 39% decreased oral steroid burst rate per year (95% CI 11%–58%) compared to controls. Function: Intervention patients had improved asthma-specific functional status in 2 out of 5 domains (physical health +3.68 [0.06, 7.30]; child emotional +6.42 [0.80, 12.04]).
Palfrey et al., 2004 Uncontrolled pre–post cohort	117 children with complex and noncomplex chronic illness in 6 practices	ED use: No change in ED visits following intervention. Hospitalization: Parent-reported hospitalizations decreased from 57.7% to 43.2% ($p < .01$). Work loss: Parents reporting >20 days of work missed decreased from 26.3% to 14.1% following intervention ($p = .02$). School absence: No difference in missed school days was detected. Satisfaction: Parents reported improvements in the ease of care access across multiple domains; however, no baseline data or statistical testing were presented. Note: Families of children with more severe or complex disease were more likely to report benefit.
Rocco et al., 2011 Controlled retrospective cohort	1,110 adults with chronic disease (at least one of: DM, CHD, hypertension, heart failure); (593 intervention, 517 control)	Clinical measures: Intervention patients demonstrated improvements compared to controls in measurements of hemoglobin A1C (mean change −0.3 vs. 0.0, $p = .005$) and LDL cholesterol (mean change −9.0 vs. −3.5, $p = .03$). Patients with more fully completed IPCs were more likely to have a decrease in hemoglobin A1C. Note: Intervention and control clinics were not comparable because intervention clinics already had a well-developed medical home model operating.

Table 2. ***(continued)***

Source and Study Design	Population	Outcomes Assessed and Summary of Results
Unützer et al., 2002 RCT	1,801 adults >59 years old with major depression or dysthymic disorder (906 intervention, 895 control)	Adherence: Compared to controls, intervention patients had greater odds of having used recommended antidepressants ($OR = 2.03$, $p < .001$) or psychotherapy ($OR = 4.13$, $p < .001$) at 12 months. Clinical measures: Compared to controls at 12 months, intervention patients had lower depression scores (difference -0.4, $p < .001$), greater odds of treatment response ($OR = 3.45$, $p < .001$), and greater odds of complete remission ($OR = 3.72$, $p < .001$). Function: Intervention patients had less functional impairment at 12 months than controls (difference -0.94, $p < .001$). Quality of life: Intervention patients had better quality of life than controls at 12 months (difference $+0.56$, $p < .001$). Satisfaction: Intervention patients had 3.38-fold greater odds of reporting satisfaction with depression care at 12 months ($p < .001$).

Note. ED = emergency department; OP = outpatient; RCT = randomized controlled trial; COPD = chronic obstructive pulmonary disease; CHF = congestive heart failure; OR = odds ratio; PCP = primary care provider; LDL = low-density lipoprotein; CI = confidence interval; IPC= individualized plan of care.

of which showed variable responses (ED use [Gordon et al., 2007; Palfrey et al., 2004], outpatient appointments [Casey et al., 2011; Farmer et al., 2005; Gordon et al., 2007], missed work and school [Farmer et al., 2005; Palfrey et al., 2004], and satisfaction [Farmer et al., 2005; Palfrey et al., 2004]). Two studies noted that families of children with more severe or complex disease were more likely to report benefit (Farmer et al., 2005; Palfrey et al., 2004).

IPC Within a Disease-Specific Management Intervention. We identified four studies featuring IPC use within a disease-specific case management intervention. These included some services beyond having an IPC, but they involved less comprehensive care coordination and more narrowly defined patient populations than the studies mentioned earlier. We identified three studies in adults and one in children.

The three adult RCTs examined IPC-based interventions for depressed adults. All featured an IPC that was protocol driven and focused on goal-setting and achieved improvements in clinical measures of depression (Katon et al., 2010; Katon et al., 2001; Unützer et al., 2002). Two also reported improvements in quality of life and satisfaction with care (Katon et al., 2010; Unützer et al., 2002) and one reported improvements in clinical measures of comorbid diabetes and coronary artery disease (Katon et al., 2010).

Lozano et al.'s (2004) pediatric cluster-RCT evaluated the impact of an IPC-based asthma care intervention. The IPC was developed by an asthma nurse and the family; it included a current medical summary then used protocols to assist management plan development. Intervention patients had fewer symptom days, lower oral steroid use, and improved controller medication adherence compared to controls.

Important Components and Participants in IPCs

Participants in IPC Development. No studies explicitly evaluated outcomes associated with the mix of individuals involved in the development of the IPC. By design, all studies we included involved input from the patient and/or family and at least one provider or care coordinator. Other participants varied and sometimes included mental health professionals (Katon et al., 2010; Unützer et al., 2002) or multidisciplinary teams (Adam et al., 2010; Aiken et al., 2006; Casey et al., 2011; Counsell et al., 2007). The outcomes observed and strength of associations does not clearly favor one participant mix over others.

Components of the IPC. Of the studies reviewed, most did not provide a detailed description of the IPC components. In many cases, it was unclear what was included and whether particular elements of the broader intervention (e.g., goal setting) were part of the IPC or not. A summary of the elements included in the published IPC descriptions is given in Table 3. The interventions with protocol-based IPCs provided the strongest evidence for improved outcomes (clinical symptoms [Katon et al., 2010; Katon et al., 2001; Lozano et al., 2004; Unützer et al., 2002], functional status [Aiken et al., 2006; Counsell et al., 2007], hospitalizations [Counsell et al., 2007; Dorr et al., 2008], and mortality [Dorr et al., 2008]), but, by necessity, they all targeted conditions with evidence-based treatment approaches. We did

TABLE 3. Individualized Plan of Care Attributes Described in Pediatric and Adult Patient Populations

IPC Attribute	Pediatric Studies (*n*)	Adult Studies (*n*)	References
Clinical summary or diagnosis list	3	2	Casey et al., 2011; Dorr et al., 2008; Lozano et al., 2004; Palfrey et al., 2004; Rocco et al., 2011
Medication list	2	0	Casey et al., 2011; Lozano et al., 2004
Anticipated acute medical management plans	1	1	Aiken et al., 2006; Cady et al., 2009
Medical management plan for chronic or general problems	1	6	Adam et al., 2010; Casey et al., 2011; Counsell et al., 2007; Dorr et al., 2008; Katon et al., 2010; Katon et al., 2001; Unützer et al., 2002
Protocol-based medical management plans	1	6	Aiken et al., 2006; Counsell et al., 2007; Dorr et al., 2008; Katon et al., 2010; Katon et al., 2001; Lozano et al., 2004; Unützer et al., 2002
Goal-setting	2	4	Aiken et al., 2006; Farmer et al., 2005; Farmer et al., 2011; Katon et al., 2010; Katon et al., 2001; Rocco et al., 2011
List of community services	3	0	Casey et al., 2011; Farmer et al., 2005; Gordon et al., 2007
Self-monitoring plans	1	1	Katon et al., 2001; Lozano et al., 2004

Note. IPC = individualized plan of care.

not identify other variations in outcomes or effect size by IPC components.

Responsibility for IPC Implementation. Few articles mentioned the assignment of responsibility for implementing the IPC, although all had someone responsible for IPC development. Rocco et al.'s (2011) IPC assigned specific tasks to the patient and PCP, with time frames for completion. The intervention achieved clinically small but statistically significant decreases in LDL cholesterol and hemoglobin A1C (Rocco et al., 2011). The AAP suggests the IPC should include "clear articulation" of the roles of primary and subspecialty medical providers but gives no further details (AAP, 2002).

Review and Updating of IPCs. One article mentioned specific time frames for reevaluating and updating IPCs, and none compared outcomes based on different parameters. Counsell et al.'s (2007) RCT required annual IPC reassessment and demonstrated significant improvements in health and vitality and lower ED visit rates among seniors. No study mentioned patient or family involvement in the update process.

Targeted Populations

Populations targeted fell into three main categories: patients with chronic disease impacting multiple organ systems, considered complex (Adam et al., 2010; Aiken et al., 2006; Cady et al., 2009; Casey et al., 2011; Farmer et al., 2005; Gordon et al., 2007; Kelly et al., 2002); patients with chronic disease impacting primarily a single organ system, considered noncomplex (Katon et al., 2001; Lozano et al., 2004; Rocco et al., 2011; Unützer et al., 2002); and a mixture of the two preceding groups (Counsell et al., 2007; Dorr et al., 2008; Farmer et al., 2011; Katon et al., 2010; Palfrey et al., 2004). Studies in all three categories reported significant associations with a range of outcomes, although the strongest study designs, and therefore the strongest evidence for improved outcomes, were conducted among adults with mixed levels of complexity (Counsell et al., 2007; Katon et al., 2010) and adults or children with a single chronic illness (Katon et al., 2001; Lozano, et al., 2004; Unützer et al., 2002). However, three studies, including one RCT, noted in subgroup analyses that patients with more severe or complex disease benefitted most from multifaceted interventions that included IPC use (Counsell et al., 2007; Farmer et al., 2005; Palfrey et al., 2004).

DISCUSSION

The evidence demonstrating an association between the use of an IPC alone and improved outcomes is sparse. Studies examining who should participate in developing an IPC or which components are most effective for improving outcomes are also lacking, although most IPCs described in the literature included a clinical summary or medical management plan, and many from the adult literature tailored standardized protocols to individuals' needs. Nonetheless, IPC use is a common and often prominent part of multifaceted interventions that have resulted in improved mortality, hospitalization, disease management, and family satisfaction, among other outcomes. The evidence is particularly compelling for improved symptoms and

The evidence is particularly compelling for improved symptoms and disease management in adults with depression.

disease management in adults with depression. The evidence for IPC use in children with chronic illness is of lower quality but still shows consistent associations with improved experiences with care, use, and cost. Although several studies reported increased ED use following intervention, this finding may reflect more appropriate accessing of the ED based on information in the IPC or contact with a care coordinator, rather than worsened health status or poor access, because the increased ED use was coupled with decreased hospitalization (Dorr et al., 2008; Gordon et al., 2007) and increased outpatient visits (Gordon et al., 2007). In interventions enrolling patients with varying complexity, those with more complex illness benefitted the most. Despite the lack of clear and consistent evidence, strong consensus from professional organizations (AAP, 2002; American College of Physicians, 2010; Association of American Medical Colleges, 2008) recommends IPC use as an important element of high-quality care for patients with chronic illness.

A previous nonsystematic review of care coordination interventions for adults with chronic systemic disease found similar results (Chen, Brown, Archibald, Aliotta, & Fox, 2000). The authors reviewed 24 programs with demonstrated impacts on cost or hospitalization via published articles, reports, and interviews with program staff. They also evaluated five programs with "typical" components of successful programs (e.g., a thorough initial assessment and regular conversations between the care manager and PCP) but without any impact on outcomes. They reported that a written, practical, goal-oriented IPC that the patient, PCP, and care coordinator had all agreed on was integral to successful programs. Programs with typical components but no impact used less comprehensive, less specific, or less goal-oriented IPCs. These results complement our findings and help to shed light on specific elements that are likely to be important, but rigorous testing of these concepts is still needed.

This review represents the first synthesis of evidence for associations between improved outcomes and IPC use and so may be helpful for providers, health care system leaders, and program developers interested in improving care coordination for patients with chronic illness. We considered the topic of IPC use broadly, including a wide range of intervention types and populations, resulting in a fairly comprehensive view of the contexts in which IPC use has and has not been shown to improve patient and family outcomes. However, given the small number of studies eligible for inclusion, our review includes some of low quality, limiting the strength of the conclusions we can draw. Our focus on U.S.-based studies also limits the generalizability of our conclusions to the U.S. health care system. In addition, most of the included studies evaluated IPC use as part of multifaceted and sometimes very intensive care coordination programs; the effect of the IPC alone cannot be isolated. Moreover, so little information was provided about the IPCs themselves that rigorous comparison between studies based on IPC attributes was not possible. Finally, given the challenges involved in determining when an IPC had been used as part of an intervention, we may have missed some relevant studies; however, studies in which IPC use was not emphasized as important to the intervention are unlikely to have substantially impacted our findings.

Several gaps in the literature exist. We found a single small study evaluating the impact of an IPC alone, and we identified no studies that compared alternate versions of IPCs or evaluated the incremental benefit of the IPC in the context of a multifaceted intervention. Multifaceted interventions are more likely to be effective than those with only a single component (Hulscher, Wensing, van Der Weijden, & Grol, 2001), so attempts to isolate the impact of the IPC may not be possible or helpful. However, the current literature does not offer compelling guidance about what an effective IPC should look like, even within a multifaceted intervention. Future studies involving IPCs should include a clear description of what components were included, how the IPC was used and how often it was updated. Although several studies commented that the patients with complex chronic illness benefitted the most, few studies evaluated that finding quantitatively. Further research explicitly assessing the effect of interventions by illness complexity is needed to efficiently target the right services to the right populations.

IPC use shows promise in improving outcomes in adults with depression as well as in more heterogeneous pediatric and adult populations as part of multifaceted care coordination interventions. IPCs are associated with improvements in satisfaction, functional status, symptom management, ED use, hospitalization, and mortality in various study contexts and patient populations. The evidence for effectiveness in children with complex chronic disease

IPC use shows promise in improving outcomes in adults with depression, as well as in more heterogeneous pediatric and adult populations as part of multifaceted care coordination interventions.

is less compelling. Further research is required to better understand which IPC components and participants are most likely to improve health outcomes. Such future work will allow care providers to prioritize those elements most likely to have a positive impact.

REFERENCES

Adam, P., Brandenburg, D. L., Bremer, K. L., & Nordstrom, D. L. (2010). Effects of team care of frequent attenders on patients and physicians. *Families, Systems & Health*, *28*(3), 247–257. http://dx.doi.org/10.1037/a0020944

Aiken, L. S., Butner, J., Lockhart, C. A., Volk-Craft, B. E., Hamilton, G., & Williams, F. G. (2006). Outcome evaluation of a randomized trial of the PhoenixCare intervention: Program of case management and coordinated care for the seriously chronically ill. *Journal of Palliative Medicine*, *9*(1), 111–126.

American Academy of Pediatrics. (2002). The medical home. *Pediatrics*, *110*(1, Pt. 1), 184–186.

American College of Physicians. (2010). The patient-centered medical home neighbor: The interface of the patient-centered medical home with specialty/subspecialty practices *Policy paper*. Philadelphia, PA: Author.

Association of American Medical Colleges. (2008). *The medical home: AAMC position statement*. Retrieved from https://members.aamc.org/eweb/upload/The%20Medical%20Home.pdf

Cady, R., Finkelstein, S., & Kelly, A. (2009). A telehealth nursing intervention reduces hospitalizations in children with complex health conditions. *Journal of Telemedicine and Telecare*, *15*(6), 317–320. http://dx.doi.org/10.1258/jtt.2009.090105

Casey, P. H., Lyle, R. E., Bird, T. M., Robbins, J. M., Kuo, D. Z., Brown, C., . . . Burns, K. (2011). Effect of hospital-based comprehensive care clinic on health costs for Medicaid-insured medically complex children. *Archives of Pediatrics & Adolescent Medicine*, *165*(5), 392–398. http://dx.doi.org/10.1001/archpediatrics.2011.5

Chen, A., Brown, R., Archibald, N., Aliotta, S., & Fox, P. D. (2000). *Best practices in care coordination*. Baltimore, MD: Health Care Financing Administration, Division of Demonstration Programs, Center for Health Plans and Providers.

Counsell, S. R., Callahan, C. M., Clark, D. O., Tu, W., Buttar, A. B., Stump, T. E., & Ricketts, G. D. (2007). Geriatric care management for low-income seniors: A randomized controlled trial. *Journal of American Medical Association*, *298*(22), 2623–2633. http://dx.doi.org/10.1001/jama.298.22.2623

Dorr, D. A., Wilcox, A. B., Brunker, C. P., Burdon, R. E., & Donnelly, S. M. (2008). The effect of technology-supported, multidisease care management on the mortality and hospitalization of seniors. *Journal of the American Geriatrics Society*, *56*(12), 2195–2202. http://dx.doi.org/10.1111/j.1532-5415.2008.02005.x

Farmer, J. E., Clark, M. J., Drewel, E. H., Swenson, T. M., & Ge, B. (2011). Consultative care coordination through the medical home for CSHCN: A randomized controlled trial. *Maternal and Child Health Journal*, *15*(7), 1110–1118. http://dx.doi.org/10.1007/s10995-010-0658-8

Farmer, J. E., Clark, M. J., Sherman, A., Marien, W. E., & Selva, T. J. (2005). Comprehensive primary care for children with special health care needs in rural areas. *Pediatrics*, *116*(3), 649–656. http://dx.doi.org/10.1542/peds.2004-0647

Gordon, J. B., Colby, H. H., Bartelt, T., Jablonski, D., Krauthoefer, M. L., & Havens, P. (2007). A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, *161*(10), 937–944. http://dx.doi.org/10.1001/archpedi.161.10.937

Homer, C. J., Klatka, K., Romm, D., Kuhlthau, K., Bloom, S., Newacheck, P., . . . Perrin, J. M. (2008). A review of the evidence for the medical home for children with special health care needs. *Pediatrics*, *122*(4), e922–e937. http://dx.doi.org/10.1542/peds.2007-3762

Hulscher, M. E., Wensing, M., van Der Weijden, T., & Grol, R. (2001). Interventions to implement prevention in primary care. *The Cochrane Database of System Review*, (1), CD000362. http://dx.doi.org/10.1002/14651858.cd000362

Jeremy Howick, I. C., Glasziou, P., Greenhalgh, T., Heneghan, C., Liberati, A., Moschetti, I., . . . Hodgkinson, M. (2011). *The Oxford 2011 Levels of Evidence Oxford Centre for Evidence-Based Medicine*. Retrieved from http://www.cebm.net/index.aspx?o=5653

Katon, W. J., Lin, E. H. B., Von Korff, M., Ciechanowski, P., Ludman, E., Young, B., . . . McCulloch, D. (2010). Collaborative care for patients with depression and chronic illnesses. *The New England Journal of Medicine*, *363*(27), 2611–2620. http://dx.doi.org/10.1056/NEJMoa1003955

Katon, W., Rutter, C., Ludman, E. J., Von Korff, M., Lin, E., Simon, G., . . . Unützer, J. (2001). A randomized trial of relapse prevention of depression in primary care. *Archives of General Psychiatry*, *58*(3), 241–247.

Kelly, A. M., Kratz, B., Bielski, M., & Rinehart, P. M. (2002). Implementing transitions for youth with complex chronic conditions using the medical home model. *Pediatrics*, *110*(6, Pt. 2), 1322–1327.

Lozano, P., Finkelstein, J. A., Carey, V. J., Wagner, E. H., Inui, T. S., Fuhlbrigge, A. L., . . . Weiss, K. B. (2004). A multisite randomized trial of the effects of physician education and organizational change in chronic-asthma care: Health outcomes of the Pediatric Asthma Care Patient Outcomes Research Team II Study. *Archives of Pediatrics & Adolescent Medicine*, *158*(9), 875–883. http://dx.doi.org/10.1001/archpedi.158.9.875

McAllister, J. W., Presler, E., & Cooley, W. C. (2007). Practice-based care coordination: A medical home essential. *Pediatrics*, *120*(3), e723–e733. http://dx.doi.org/10.1542/peds.2006-1684

Palfrey, J. S., Sofis, L. A., Davidson, E. J., Liu, J., Freeman, L., & Ganz, M. L. (2004). The pediatric alliance for coordinated care: Evaluation of a medical home model. *Pediatrics*, *113*(Suppl. 5), 1507–1516.

Rocco, N., Scher, K., Basberg, B., Yalamanchi, S., & Baker-Genaw, K. (2011). Patient-centered plan-of-care tool for improving clinical outcomes. *Quality Management in Health Care*, *20*(2), 89–97. http://dx.doi.org/10.1097/QMH.0b013e318213e728

Tanios, A. T., Lyle, R. E., & Casey, P. H. (2009). CH medical home program for special needs children. A new medical era. *The Journal of the Arkansas Medical Society*, *105*(7), 163–165.

Unützer, J., Katon, W., Callahan, C. M., Williams, J. W., Jr., Hunkeler, E., Harpole, L., . . . Langston, C. (2002). Collaborative care management of late-life depression in the primary care setting: A randomized controlled trial. *The Journal of the American Medical Association*, *288*(22), 2836–2845.

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APPENDIX

MEDLINE SEARCH STRATEGY

Special need* OR "medically complex" OR "medical complexity" OR "complex health" OR "complex medical" OR (complex* AND [chronic condition* OR "chronically ill" OR chronic illness* OR chronic medical condition*])

AND

"Patient Care Management" [Mesh] OR "patient participation" OR outcome assessment OR cooperat* OR co-operat* OR decision* OR share OR shared OR sharing OR "care management" OR "care plan" OR "care plans"