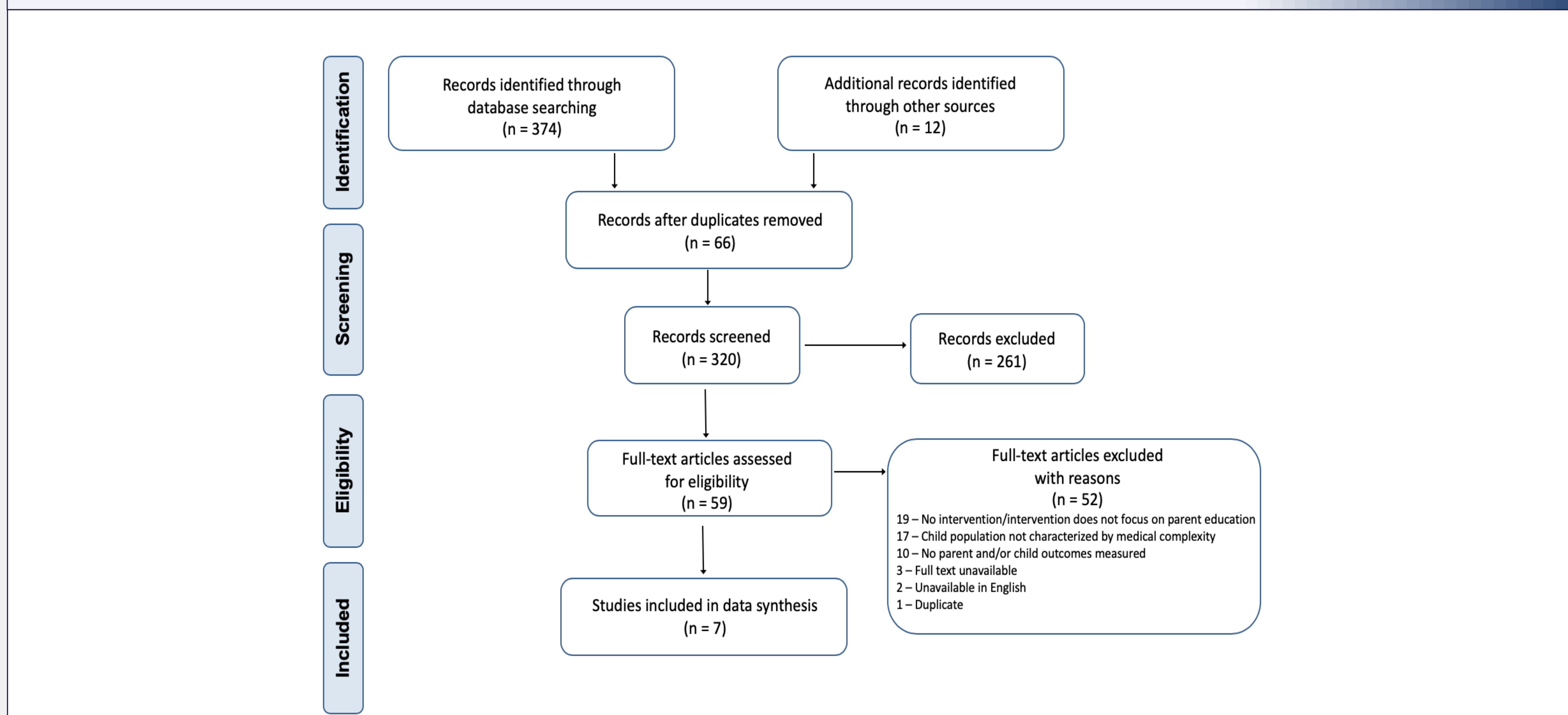


Background

- Children with medical complexity (CMC) are a high needs subgroup of children with special health care needs, characterized by:
 - Family-identified service needs** (e.g. medical care, specialized therapy, education)
 - Chronic condition(s)** associated with medical fragility (e.g. spinal muscular atrophy, congenital heart disease, epilepsy, chronic lung disease)
 - Functional limitations** (e.g. ambulation, breathing, or feeding impairments), and
 - High health care utilization** (e.g. frequent or prolonged hospitalizations, multiple subspecialist providers)
- CMC represent an estimated 0.4% of children in the United States and account for 1/3 of pediatric health care spending
- Parenting CMC is associated with unique demands and challenges:
 - Greater caregiver and economic burden
 - Increased worry, anxiety, social disruption, conflict with home care providers, and parental role conflict
- Benefits of parent education programs for children and youth with special health care needs have been established; however, no systematic reviews have examined how parent education programs can benefit the subgroup of CMC

Search and Retrieval Process



Results

Author/Year Design	Parent and Child Characteristics	Study Characteristics			
		Duration	Theory	Intervention Components	Interventionist
Coller et al. (2018) <i>Randomized Controlled Trial</i>	147 primary caregivers of children with medical complexity	18 months	None identified	Plans for Action and Care Transitions (PACT) • Patient-specific action plans • Post-discharge coaching	Medical home physician or nurse practitioner and nonclinical transition coach
DeMaso et al. (2000) <i>Quasi-experimental one group post-test only</i>	Phase 2: 40 mothers of children hospitalized for cardiac disease	Not specified	Derived from preventative intervention, medical crisis counseling, and narrative therapy	The Experience Journal • Computer-based application to deliver psychoeducation	Experience Journal software
Haney and Tufts (2012) <i>Quasi-experimental pre- post-test design</i>	19 parents of medically fragile and technology dependent children cared for at home	12 weeks	Margaret Newman's Theory of Health as Expanding Consciousness	Electronic communication intervention • Weekly education focused on parenting or specific healthcare topic • Open communication between parents and nurse	Nurse
McCusker et al. (2009) <i>Non-randomized controlled trial</i>	70 mothers & 56 fathers of infants admitted to a cardiology unit, born with congenital heart disease who required surgical or catheter interventions	Not specified	Transactional Stress and Coping Model	Congenital Heart Disease Intervention Programme (CHIP) • Six sessions focused on meaning and grief, mother-infant transactions, and problem-solving strategies • Program manual with resources	Pediatric clinical psychologist and pediatric cardiology nurse specialist
McCusker et al. (2012) <i>Randomized Controlled Trial</i>	68 mothers of children with congenital heart disease entering school who had undergone at least one invasive procedure for a major heart defect	1-4 weeks	Transactional Stress and Coping Model	Congenital Heart Disease Intervention Programme (CHIP)-School • One day workshop • Bicycle exercise stress test • Individualized follow-up family session • Program manual with resources	Pediatric: clinical psychologist, cardiologist, or cardiology nurse specialist
Toly & Zauszniewski (2014) <i>Randomized Controlled Trial</i>	22 mothers caring for technology-dependent children recruited from pulmonology and gastroenterology clinics	6 weeks	Zauszniewski's Resourcefulness Theory	Resourcefulness training intervention • In-person education resourcefulness skills • Wallet-sized card and magnet • Daily journaling for reinforcement	Nurse
Orne, Branson, and Cazzell (2018) <i>Quasi-experimental pre- post-test design</i>	34 primary caregivers of children with medically complex conditions and newly placed tracheostomies	Not specified	None identified	Predischarge "Boot Camp" Training Program for Caregivers • Nine structured sessions • Caregivers must progress in order	Nurse

Purpose

To systematically examine components of parent education programs for CMC and synthesize evidence about these programs' effectiveness on parent and/or child outcomes

Methods

- Design**
- Whittemore and Knaf's (2005) integrative review methodology
- Study Selection**
- Inclusion Criteria
 - Described an intervention focused on providing education to parent and/or family caregivers
 - Included children between 0-18 years of age
 - Child population is documented as medically complex or can be characterized this way
 - Measured a parent and/or child outcome
 - Exclusion Criteria
 - Full-text was unavailable electronically or in English
- Search Method**
- Databases: Cumulative Index of Nursing and Allied Health Literature, PubMed, Scopus, and PsycINFO
 - MH: "Child, medically fragile" AND "Education" AND "Parent"
 - Keywords: "children with medical complexity" AND "caregiver" AND "training"
- Data Extraction and Synthesis**
- Study variables extracted in data collection tools developed by investigators
 - Papers reviewed and findings synthesized

Results, cont.

Author (Date)	Study Outcomes	
	Outcomes	Findings
Coller et al. (2018)	Hospitalization	Lower for PACT group (p=0.04) ^a
	30-day readmission	Lower for PACT group (p=0.05) ^a
	Total charges	Lower for PACT group (p=0.02) ^a
DeMaso et al. (2000)	Mortality	0 deaths in PACT group, 4 deaths in control group
	Satisfaction and Safety	High overall satisfaction with EJ (M= 5.7, SD=1.8) ^b
	Coping Response	Mixed results, positive survey comments
Haney and Tufts (2012)	Attitude Change	Moderate increases in mother's understanding of their own feelings (M=5.0, SD=1.8) ^b
	Overall well-being	No statistically significant difference (p< .227))
	Parent well-being	No statistically significant difference (p< .314)
McCusker et al. (2009)	Family well-being	No statistically significant difference (p< .178)
	Parent satisfaction	No statistically significant difference (p< .528)
	Infant development	No statistically significant difference (p=0.63)
McCusker et al. (2012)	• Psychomotor	Improved infant mental development (p=0.02)
	• Mental	
	• Infant feeding	
Toly and Zauszniewski (2014)	• Time	No statistically significant difference (p=0.85)
	• Breastfeeding	Increased incorporation of breastfeeding (p=0.03)
	• Perceived competence	Increased perceived competence (p=0.027)
Orne, Branson, and Cazzell (2018)	Maternal coping & adjustment	Decrease in maternal state anxiety scores (p=0.04)
	Child Adjustment	
	• Problem Behavior	No statistically significant difference (p> .1)
Toly and Zauszniewski (2014)	Family Functioning	
	• Personal Strain	CHIP-School group with lower personal strain (p=0.01)
	• Family Strain	CHIP-School group with lower family strain (p=0.02)
Orne, Branson, and Cazzell (2018)	Negative emotions	Intervention had medium effect size (d=0.052)
	Depressive cognitions	Intervention had small effect size (d=0.22)
	Acceptability of study procedures (journaling)	Positive exit interview comments
Orne, Branson, and Cazzell (2018)	Patient length of stay	Lower for bootcamp group (92 vs 60 days; p=0.02)
	Discharge training time	Lower for bootcamp group (60 vs 16 days; p<0.001)
	Caregiver stress	Lower for bootcamp group (49 vs 45; p<0.001)
Orne, Branson, and Cazzell (2018)	Caregiver satisfaction	Positive survey responses to open-ended questions

^a Adjusted analyses
^b Ratings determined by using a 7 point scale



Photo courtesy of Almost Home Kids

Conclusions

- Inconsistencies in describing this population of children exist in the literature
- Few parent education programs directly target parents of CMC and among those that do, the focus is on providing adequate caregiver education to support safe home care
- Parent education programs for families of children and youth with special health care needs demonstrate a positive impact on parent-child relationships, coping skills, and family functioning
- There is a need for continued development of evidence-based parenting education programs to meet the unique needs of parents of CMC