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ABSTRACT
Youth in the U.S. foster care system are prescribed risky psychotropic medications at high rates. In response, state child welfare agencies have developed policies, yet there is little research to inform patient-centered care (PCC) approaches. To fill this gap, we aimed to identify (1) the perspectives of youth in or formerly in foster care and their caregivers and providers regarding how psychiatric care aligns or does not align with PCC, and (2) effectiveness of interventions aiming to improve PCC within this context. We conducted a systematic review of the literature based on PRISMA-P guidelines, searching four databases and gray literature. Eleven studies met inclusion criteria and quality appraisal benchmarks, none of which were interventions. We applied narrative synthesis techniques to six studies that described youth/former youth perspectives. They described a pervasive lack of knowledge, perceived little voice in decision-making, and described imbalanced power between patients and providers and weak therapeutic relationships, whereas feeling understood by providers and being provided autonomy in decisions were helpful. Systemic barriers also contributed to many concerns. We make a limited number of recommendations to leaders and policy-makers based on our synthesis, however, many critical research steps are needed.

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KEYWORDS
Foster care; psychotropic medications; psychiatry; patient-centered care

Use of psychotropic medications among youth in foster care

An estimated 13–40% of children and youth (hereby referred to as youth) in foster care receive at least one psychotropic medication (Kutz, 2011; Leslie, Raghavan, Zhang, & Aarons, 2010; Raghavan & McMillen, 2008; Raghavan et al., 2005). These rates are 2–4.5 times higher than the rate of other youth enrolled in Medicaid (6–9%), who share some social determinants associated with poor mental health, such as poverty, but who are not in foster care (Kutz, 2011; Raghavan, Brown, Allaire, Garfield, & Ross, 2014). Furthermore, these rates are 2–6.5 times higher than the general U.S. youth population
Because youth in foster care have higher mental health needs than other youth – largely due to the maltreatment and adversity they have experienced – it is not surprising that they receive more psychotropics. Some estimate that around half of youth in foster care have significant mental health concerns (McMillen et al., 2005). However, youth in foster care are also subjected to more risky practices such as polypharmacy (i.e., > 2 psychotropic medications), doses exceeding the maximum age recommendations, off-label use, and use in very young children (Kutz, 2011; Vanderwerker et al., 2014).

Psychotropic medications are an important component of mental health treatment; they can help youth function in their homes, schools, and communities. Nevertheless, potentially significant side effects require extensive coordination and monitoring (e.g., Zuddas, Zanni, & Usala, 2011). There is remarkably low adherence to recommended side effect monitoring (e.g., body mass index, blood pressure, blood laboratory tests) for the general U. S. youth population, especially with respect to monitoring for atypical antipsychotics (Crystal et al., 2016; McLaren, Brunette, McHugo, Drake, & Daviss, 2017). Medication monitoring is further complicated for youth in foster care due to youth’s involvement in multiple systems and frequent changes in caregivers and providers.

**Federal and state responses**

In response to the potential over-reliance on psychotropic medications among youth in foster care, federal legislation has mandated that state child welfare agencies, in coordination with state Medicaid programs, create plans to improve the coordination and oversight of psychotropic medications (Child and Family Services Improvement and Innovation Act, 2011; Fostering Connections to Success and Increasing Adoptions Act, 2008). The U.S. Department of Health and Human Services’ Administration for Children and Families then issued an Information Memorandum in 2012 specific to the use of psychotropics for youth in foster care. This Memorandum called for, among other things, improvements to patient-centered care within this context (U.S. Department of Health and Human Services, 2012). All state child welfare agencies have since developed a policy, in collaboration with Medicaid. In a recent review of these policies, Mackie, Hyde, Palinkas, Niemi, and Leslie (2017) revealed that state policies most frequently employed top-down oversight strategies such as database reviews (67% of states employed this strategy) and prior authorizations (49% of states). Clearly, these top down strategies are important in reducing risky medication scenarios; however, they do not promote care that is centered around individual patients, as called for by the federal Memorandum. Although Mackie et al. (2017) found that 31% of states reported direct care team reviews of psychotropic medications, there were no
details regarding the extent of youth and parent involvement in these team reviews or whether or how these review processes promoted patient-centered care.

**Patient-centered care (PCC)**

For youth, a focus on the family and family systems are paramount to high-quality care, and the term family-centered care is appropriate. However, in an effort to align our language with that of the dominant literature, we will use the term patient-centered care (PCC). PCC promotes a focus on the person with the illness and/or the family rather than the diagnosis or illness (Mezzich et al., 2016). PCC also promotes the patient as empowered to manage her or his own health through informed and values- or preference-based decisions (Harding, Wait, & Scrutton, 2015; Mead & Bower, 2000). In their seminal paper, Mead and Bower (2000) describe PCC across five conceptual dimensions: using a biopsychosocial perspective; embracing a “patient-as-person” approach; doctors and patients sharing power and responsibility; doctors and patients developing a therapeutic alliance; and embracing a “doctor-as-person” philosophy.

Numerous health care, policy, and advocacy organizations have advocated for PCC within broad health care services, as well as mental health. In 2006, the Institute of Medicine (2006) Quality Chasm report called for PCC to improve mental health services. This sentiment was paralleled by the 2008 Substance Abuse and Mental Health Services Administration (SAMHSA) children’s mental health report (2008) and more recent policies relevant to child and adolescent mental health services more broadly (Gondek et al., 2016). Beyond the moral imperative behind PCC, the research literature is also starting to support its usefulness, particularly to improve patient satisfaction and self-management of diseases or conditions (Rathert, Wyrwich, & Boren, 2013). Yet examinations of PCC within the mental health sector, and youth mental health sector, lag behind. In their recent review of the facilitators and barriers to PCC within broad mental health services for all children, Gondek et al. (2016) describe the current state of affairs as one in which there is a clear precedent and need for PCC within youth mental health services, yet few examples of such care and numerous barriers. Recent efforts within children’s mental health services have highlighted the potential for Systems of Care and wrap-around approaches to mental health outcomes for youth (Bruns, Pullmann, Sather, Brinson, & Ramey, 2015; Suter & Bruns, 2009). PCC is a driving philosophy behind these approaches. However, no studies or initiatives that we know of, within the Systems of Care movement, focus specifically on promoting patient-centered psychiatric care, specifically, with youth in foster care. One recent study did examine the effects of a
wraparound program (not specifically driving PCC within psychiatric visits) on polypharmacy among youth with severe emotional disturbance, but found no effect on the rates of polypharmacy (Wu et al., 2018).

**PCC for youth in foster care**

For youth in foster care, PCC is especially complex. As is true for nearly all youth, they do not have legal capacity to consent to their own treatment, they may have several parents/caregivers with similar or different views from each other and from the youth. Younger or delayed youth, while they should be involved, do not always have the capacity to make primary decisions about treatment (Heath, Charles, Crow, & Wiles, 2007). Further, the person with consenting authority may not accompany the child to the psychiatric visit. Then, depending on the state and the circumstances for youth in foster care, any number of people may be able to consent to psychiatric care and psychotropics, including child welfare staff or agencies or birth parents, and in fewer circumstances, judges or foster parents. Further, no matter who has legal authority to consent, ultimately, the child welfare agency, along with foster parents, are responsible for the safety and well-being of the youth.

Youth in foster care also can have complicated emotional and behavioral difficulties stemming from histories of trauma, abuse, or neglect (Griffin et al., 2011). Youth often experience frequent changes in caregivers and providers, multiple placements, and they may be involved with multiple systems (Burns et al., 2004; Leslie, Mackie, et al., 2010; Stahmer et al., 2005; Worthington, 2011). These circumstances create gaps in their social, family, medical, and mental health histories, and a potential vacuum in treatment oversight and child advocacy (Camp, 2011; Rubin, Feudtner, Localio, & Mandell, 2009; Strayhorn, 2006). Moreover, foster parents, and foster youth may feel disempowered in psychiatric care decisions. This disempowerment ranges from feelings of being left out of decisions to perceived coercion to take the medications (Barnett, Boucher, Neubacher, & Carpenter-Song, 2016; Moses, 2011). Of course, there are also times when youth may truly benefit from medications yet refuse them.

Finally, these social circumstances occur within a larger context of paternalistic mental health care (Cooper et al., 2008; Grim, Rosenberg, Svedberg, & Schon, 2016; Hansson, Jormfeldt, Svedberg, & Svensson, 2013; Mistler & Drake, 2008). Paternalism occurs when providers frame treatment discussions such that they know best and provide little room for patient autonomy or patient-provider shared decisions regarding treatment (Hamann et al., 2008). Indeed, numerous studies have now found evidence of high levels of paternalism in mental health care (Hamann et al., 2012; Hansson et al., 2013; Mistler & Drake, 2008).
In sum, applying Mead and Bower’s five dimensions of PCC is quite complex for youth in general, and even more so for youth in foster care: Who is the patient? How and with whom is power and responsibility shared and therapeutic alliance built? The youth who cannot consent and who carries extra layers of disempowerment? The consenting authority who may not be present during the office visit? How does one employ a biopsychosocial approach when there are gaps in the family, social, and medical history?

**Purpose of the current paper**

The purpose of our systematic and critical review was twofold. We aimed to identify the perspectives of youth currently or formerly in foster care, caregivers, and direct service providers regarding how the psychiatric care of youth in foster care aligns or does not align with PCC. Second, we aimed to identify and review the effectiveness of interventions aiming to improve PCC within the psychiatric care of youth in foster care. For intervention studies, any type of comparison group or setting would be allowed, provided that it included the eligible population. Outcomes had to be related to at least one element of PCC as identified by Mead and Bower (2000). Through our systematic search of the literature and critical synthesis of findings, we aimed to propose areas where additional research is needed and, if enough evidence was available, to provide guidance to leaders and policy makers in their efforts to promote patient-centered psychiatric care for this vulnerable population.

**Methods**

We conducted our systematic review in accordance with recommendations from the Preferred Reporting Items for Systematic review and Meta-Analysis Protocols (PRISMA-P) 2015 checklist for systematic review protocols (Shamseer et al., 2015).

**Search strategy**

We systematically searched Ovid-Medline, PsycINFO, CENTRAL, and Google Scholar for articles published from 1990 to February 2017. We chose 1990 because that is when the use of psychotropics with children began to dramatically increase, mostly accounted for by stimulants and antidepressants early on (Parks-Thomas, Conrad, Casler, & Goodman, 2006; Zito et al., 2003). Our search involved the use of MeSH terms (Medical Subject Headings; U.S. National Library of Medicine, 2018). Our search terms described the populations of interest (e.g., caregiver, parent, youth, clinician), health topic (e.g., psychotropic, psychiatry), and multiple facets of patient-centered care (e.g.,...
shared decision-making, engagement) and text-words. We supplemented the systematic search with a scoping gray literature search using Google search engine with nine various combinations of search terms, as well as a search of dissertation abstracts and abstracts from two national conferences for which this topic is relevant. The search terms appear in Appendix A.

**Initial eligibility criteria**

Studies were included if they met the following criteria: (1) published during or after 1990; (2) published in the English language; (3) not a review, policy brief, commentary, or opinion paper (any other type of study design was accepted); (4) populations/samples drawn from youth currently or formerly in foster care/state’s custody or guardianship, parents and caregivers, or people providing direct services to the youth; (5) the aims of the study aligned with one or both aims of our review: to identify perspectives of how psychiatric care aligns with PCC, or to examine the effectiveness of interventions aiming to improve PCC in this context. After meeting these initial criteria, studies were excluded if the quality appraisal rating applied to the study did not demonstrate sufficient research quality (see Critical Review and Quality Appraisals).

**Initial paper selection**

**Peer-reviewed journal articles**

We imported identified records into reference management software. Next, three authors (ERB, MTCZ, YZI) piloted the selection process by reviewing together the first (in alphabetic order) 30 abstracts from the list of 268 references retrieved. The remaining references were divided into two equal groups \((n = 119)\) and reviewed independently by two authors (ERB reviewed both groups). Reviewers categorized papers as included, excluded, or unsure. For one group of 119 references, no disagreements between include or exclude occurred. For the second group of 119 references, the researchers disagreed on whether 1 abstract should be included vs. excluded. For this paper, and for all papers for which at least one reviewer was unsure, all three reviewers came to an agreement through discussion. In cases of unavailable full-text, we used interlibrary loan service or contacted the authors. Reviewers were not blind to journal titles, study authors, or institutions.

**Gray literature**

The lead author reviewed all 48 abstracts retrieved through the gray literature search. In four papers for which she was unsure, two additional authors (MTCZ, YZI) were asked to review the papers and the reviewers came to a consensus through discussion.
**Data extraction**

The authors decided which variables would be extracted from the papers and created a database to log these variables. Each of the three authors performed the extraction on one-third of the papers. Extraction variables included: authors, title, year, country, type of publication (e.g., peer-reviewed journal), study design (e.g., qualitative, case study, observational, controlled trial), aims of the study, respondent/target population, sample size, sample gender/age/race, study setting, if an intervention, if comparison group used, measurement tools, primary outcomes, and secondary outcomes.

**Critical review and quality appraisals**

We used the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, 2017) and the Center for Evidence-Based Management (Center for Evidence Based Management, 2017) quality appraisal programs and accompanying checklists to review the quality of each study, as applicable. We chose to only include studies that were rated at or above the half-way mark (i.e., rated 5 or higher out of 10 on the CASP; 6 or higher of 12 on the CEBM). We also assessed, as a team, the potential for any meta-biases.

**Data analyses/syntheses**

Based on previous literature (Gondek et al., 2016), we expected most of the included studies to be qualitative. We planned to employ textual narrative synthesis techniques to our synthesis. This type of synthesis is only applicable if there are a sufficient number of studies within a group or domain to synthesize, and we planned to separately synthesize results from different groups (i.e., youth, caregivers, providers) given the potential for very disparate perspectives. Although textual narrative synthesis has its roots in qualitative studies, it can be used to synthesize qualitative and quantitative studies, wherein findings are grouped into homogeneous groups using similar standards, and similarities and differences can be made across studies (Lucas, Arai, Baird, Law, & Roberts, 2007).

**Results**

**Paper selection**

Our initial database search retrieved 268 references. After exclusion of 14 duplicates, 8 papers retrieved from the database search met the eligibility criteria. See Figure 1 for the flow diagram. The gray literature search yielded 48 articles. Two papers duplicated those found in the database selection process. Seven papers identified from the gray literature search met the
eligibility criteria; however, one publication could not be accessed in full text after two emails to the authors. In total, then, quality appraisals were applied to 14 papers (8 database, 6 gray literature) See Figure 1.

**Quality appraisals**

Three authors (ERB, MTCZ, and YZI) critically reviewed the 14 selected papers. The authors discussed the overall value of each paper and applied the CASP (rating of 0–10) or CEBM (rating of 0–12) quality appraisal checklists to each paper. Three of the 14 papers were excluded from the primary review due to low quality appraisals (i.e., rated below half the total possible score), leaving a final count of 11 papers. See Table 1 for the quality rating score applied to each of the remaining 11 papers. During the meta-bias review process, the authors found no evidence of bias; there appeared to be no influence from industry or pharmaceutical funding.

**Description of included papers**

Of the 11 papers, 6 focused solely on perspectives from adolescent youth or young adults currently or formerly in foster care regarding how their psychiatric care did or did not align with PCC. Three papers focused on social worker/
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<th>Authors, Year, Country, (Type of public.)</th>
<th>Aims</th>
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<tr>
<td><strong>Youth/Former Youth Samples (n = 6)</strong></td>
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<td>Aldape, 2015, US (Master’s thesis)</td>
<td>Explore young adult's self-reported experiences, opinions on mental health services</td>
<td>Young adults ages 18–24 yrs at community agency serving foster youth; 62% M; 42% Cauc, n = 13</td>
<td>Qualitative study, semi-structured interview guides, thematic analyses</td>
<td>Main themes: 1. Value of autonomy (having a choice as empowering, resistance through noncompliance, mandated services as oppressive). 2. Value of a caring relationship. 3. Value of being heard and understood. 4. Mental health stigma, including negative views on medication. 5. Mental health mystification.</td>
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<td>Lee et al., 2006, US (peer-review journal)</td>
<td>Identify and describe characteristics that youths value in relationships with mental health professionals and services</td>
<td>Youth in MO foster care, 56% F, all age 17 yrs, 51% Af-Am, n = 406</td>
<td>Qualitative study, semi-structured interview guides, thematic analyses</td>
<td>37% described a positive experience with a mental health professional. These experiences were classified into two broad categories: benefits of mental health services and relationship with a mental health professional (including listening, engagement, and empathy). 4% of positive experiences described related to psychotropics. 26% described negative experiences. These were divided into treatment concerns, relationship to provider, and unprofessional provider behavior. The most common theme within “treatment concerns” was medication and included perceptions of being overmedicated, uncertainty if meds were working, beliefs that meds are prescribed too quickly, and side effects.</td>
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<td>Moses, 2011, US (peer review journal)</td>
<td>Examine medication commitment and the subjective medication experiences among system-involved adolescents, 54% in out of home care</td>
<td>Adolescents receiving wraparound treatment and prescribed psychotropics, ages 12–18 yrs, n = 50</td>
<td>Mixed methods - Qualitative study, semi-structured interview guides and quantitative survey, thematic analyses and mean ratings</td>
<td>62% not committed to taking medications if external pressures removed – 78% of these had proactive plans to stop meds when able/when 18. Those who were committed perceived having a choice in decision (among other themes); those uncommitted perceived being coerced into taking medications and did not trust providers (among other themes). Overall, 44% perceived being coerced into taking meds, including threats of punishment and withdrawal of privileges, and a few described physical force. Youth who were uncommitted wanted control, wanted to test whether/which meds helpful</td>
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<tr>
<td>Narendorf, Munson, Floersch, 2015, US (peer review journal)</td>
<td>Explore perspective of young adults with mental illness transitioned out of public systems toward psychotropics</td>
<td>Young adults formerly involved with public systems and taking psychotropic meds; 71% F, 68% &quot;of color,&quot; n = 52</td>
<td>Qualitative study, semistructured interview guides, thematic analyses</td>
<td>Main Themes: 1. what medications do to me? (a) body, (b) feelings/mood, (c) thinking/cognitive functions, and (d) relationships and/or daily functioning. 2. Getting medication treatment-the process: (a) interactions with psychiatrists, (b) the trial-and-error process of finding the right medication and the right dosage of a medication, and (c) the quality of the treatment</td>
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<td>Polvere, 2009, US (dissertation)</td>
<td>Highlight critical youth perspectives on the mental health system</td>
<td>NY youth forum participants and youth movement leaders ages 16–24 yrs ($n = 16$)</td>
<td>Qualitative study, semi-structured interview guides, thematic analyses</td>
<td>Themes: lack of knowledge/education and opportunities to discuss meds with providers; use of meds for control, coercive practices (take meds or be restrained), psychiatrists did not listen, wanted therapy and help preparing for life rather than meds</td>
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<td>Pope, 2015, US (peer review journal)</td>
<td>Understand how female adolescents in residential understand their diagnoses and psychiatric care as related to their sense of self</td>
<td>~ 100 female youth age 11–20 years in residential treatment facility. 38% in foster care. 63% African American, 27% Latina</td>
<td>Qualitative – 11 month Ethnography, interviews and observations</td>
<td>Themes: Youth attempt to distance themselves from psychiatry, at times uninformed about diagnoses and medications, and yet are lived experts. Youth try to navigate their sense of “normal” selves versus medicalized and medicated selves. Having a diagnosis or psych med allowed for youth to not take accountability for their behaviors, and also, for others to not give them credibility in their own care</td>
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<td>Parent/Caregiver, Direct Care Provider Samples ($n = 2$ foster parents, $n = 3$ social workers/advocates, $n = 2$ prescribing clinicians, $n = 2$ therapists)*</td>
<td>Explore foster parent knowledge, attitudes, recommendations regarding psychotropic meds for foster children</td>
<td>Foster parents in one state, 92% F, 46% 41–50 yrs, 100% Cauc, $n = 13$</td>
<td>Qualitative study, semi-structured interview guides, thematic analyses</td>
<td>Lack of information about meds and monitoring; Mixed values and attitudes towards psych meds; internal and external pressures around child using meds; uncertainty of med effects, side effects; unsatisfactory decision-making process/recommend team decisions</td>
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<tr>
<td>Barnett et al., 2016, US (peer review journal)</td>
<td>Characterize activities of oversight and coordination related to psych meds for youth in foster care in four groups in direct contact with these youth</td>
<td>209 foster/adoptive parents, 169 child welfare staff, 84 therapists, 33 clinical prescribers</td>
<td>Quantitative survey</td>
<td>40% of parents reported not receiving info about purpose or side effects of psych meds; disagreement among them of who was primarily responsible for oversight; poor communication and info sharing among provider groups.</td>
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<td>McMillen et al., 2007, US (peer review journal)</td>
<td>Examine child welfare and mental health professionals’ views of the quality of psychiatric services received by consumers of the child welfare system</td>
<td>68% of sample child welfare staff, 22% therapists, &lt; 10 each of child psychiatrists, court profess., administrators, child advocates. Overall 75% F, 55% Cauc, n = 130</td>
<td>Qualitative study, semistructured interview guides, thematic analyses</td>
<td>Overall themes: concerns about overmedication/sedation, brief evaluations; short inpatient stays; discontinuity of care. Themes related to perceived root causes of quality problems: prescriber productivity model, brief inpatient stays, Medicaid reimbursement policies, stakeholders push for meds, lack of clinical feedback; liability concerns. Related to theme of prescribers not receiving clinical feedback – child welfare staff described being hesitant to give opinions/feedback if they disagree – due to 1) lack of expertise – child welfare professionals do not feel expert enough to authorize meds, although legally often that it is their role, and 2) fears of offending prescribers when they are in high demand and need them to serve this population.</td>
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<td>Moses, 2008, US (peer review journal)</td>
<td>Identify differences in perceived psych med processes and outcomes according to social workers who work with system involved children vs. not system involved</td>
<td>395 social workers, 90 of whom worked with youth in child welfare/juvenile justice</td>
<td>Quantitative survey comparing perceptions of those working with system-involved children versus not system-involved</td>
<td>Responses from social workers helping children involved with systems indicated perceptions of medication processes (e.g., perceptions of client receptivity to meds, shared decisions) and outcomes (e.g., effectiveness, effect on sense of self, self-efficacy) as more negative than those not working with system involved children. Differences were accounted for by children’s level of functional impairment and behavior problems.</td>
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<td>Oldani, 2009, Canada (peer review journal)</td>
<td>Characterize the “prescribing logic” of high prescribers and the intersection of culture (colonization) and psychiatry</td>
<td>Child and adolescent psychiatrists (n = 3) treating Aboriginal children in foster care in Manitoba Canada</td>
<td>Qualitative – Ethnography</td>
<td>Themes of racialized prescribing, providing the same combination of medications to all Aboriginal children without proper evaluation; believing psych meds were the only hope; characterizing refusal/hesitance of parents to put children on psych meds as noncompliance</td>
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Note. CASP = Critical Appraisal Skills Programme. The CASP rating was used for qualitative papers and is based on the sum of a 10-item checklist (0–10). CEBM = Center for Evidence-Based Medicine. The CEBM rating was used for observational survey studies and is based on the sum of a 12-item checklist (0–12). *not mutually exclusive, some studies captured more than one perspective.
child welfare worker perspectives, two papers focused on foster parent perspectives, two on mental health therapists, and two on clinical prescribers. (Some papers included more than one group in their study; groups were not mutually exclusive.) See Table 1. Nine of the 11 papers were drawn from peer-reviewed publications, one was a dissertation, and one was a master’s thesis (see Table 1). Publication years ranged from 2006 to 2016 and 10 of the 11 samples were drawn from the United States (1 from Canada). Eight of the 11 studies were solely qualitative in nature, 2 of which were ethnographies. Two studies were quantitative surveys, and one was mixed methods. Sample sizes ranged from 8 to 389. However, for two studies, youth in foster care made up only a proportion of the samples (i.e. 33% in Polvere, 2009; 38% in Pope, 2015). We were not able to disaggregate the responses; however, because the other participants were similarly vulnerable based on their placement in a restrictive care settings, we chose to include the papers. None of the 11 studies examined outcomes associated with an intervention aiming to improve PCC in this population. Further, despite the PCC driving philosophy behind Systems of Care and wraparound initiatives within the youth mental health sector, our systematic search did not retrieve any such studies within the context of psychiatric visits among our target population of youth in foster care.

**Capacity for synthesis**

The domains assessed in these various target groups (e.g., youth, parents, providers) were too disparate to warrant a combined synthesis and we therefore chose to apply narrative synthesis techniques to each target group separately. The only stakeholder group that we felt had enough studies to warrant a synthesis was that of youth/former youth perspectives \( (n = 6) \). Therefore, although we present the main findings from other groups in Table 1, we only synthesize perspectives from youth/former youth below.

**Youth/former youth perspectives on how their psychiatric care aligned with PCC**

Four themes were pervasive across the six studies examining perspectives of youth currently or formerly in care related to how their psychiatric care aligned with PCC. See Table 1 for information on study aims, population, methods, and outcomes. These themes included: (1) a lack of knowledge about medications and subsequent uncertainty whether medications were working; (2) feelings of disempowerment and coercion by various caregivers and providers; (3) perceptions of being invisible and overmedicated to control behavior; and (4) weak therapeutic relationships with providers. Youth who *did* perceive their psychiatric care as patient-centered described
providers who listened, understood, and gave them autonomy in the deci-
sion-making process.

**Lack of knowledge about medications and effectiveness**
The most prevalent theme across these six studies was youth lack of knowl-
edge. Many youth described being unaware of the names of their medications
and what symptoms they were targeting. For example, one young person
stated “I don’t know what I was taking. For depression I think.” (Aldape,
2015, pg 37). Because they were on multiple medications, they could not tell
which one(s) worked:

> You can only treat so much with medication….I was on tons of medication. And I
couldn’t really tell you which ones worked and didn’t work because I was never on
just one medication. I was always on five or six” (Polvere, 2009, pg 158).

Some youth even described being uninformed about their diagnoses, and to
some, medications and diagnoses meant the same thing, as if they were
interchangeable and represented each other. Some youth conveyed frustra-
tion over their lack of knowledge, and others held the attitude of disregard,
which seemed to stem from a sense of helplessness and disempowerment.
Youth did assert that their lived experience with mental health and medica-
tions was as important if not more important than the technical knowledge
of their providers.

**Feelings of disempowerment and coercion**
Most of the youth described being excluded from decisions regarding the use
of psychotropics, and they were upset by the lack of opportunities to discuss
their medications with providers. Some described feeling coerced or pres-
sured to take medications, usually through threats of punishment or removal
of privileges by caregivers or residential staff. As one youth put it, “It was not
good because I wasn’t involved in the decision. At any age you should be
asked, unless you can’t talk…I felt like I was being forced to do things I
didn’t want to do…I guess I didn’t have a choice. (Aldape, 2015, pg 31). One
study (Moses, 2011) found that nearly half of the 50 youth felt coerced into
taking the medication, and most would have stopped taking it if they felt they
could decide for themselves or would not have consequences.

In several studies set within residential facilities, youth stated that their
reason for taking the medications was not to improve their mental health and
functioning, but to comply with authorities so they could earn privileges, or,
if in residential, leave the facility. When asked why she took her medications,
one youth reported: “Because I have to. If I don’t take it I’m not never leaving
here. I’m not going nowhere. I have to take it. I have Bipolar, alright?” (Pope,
2015, pg 518). Youth also described how at times, their mental illness was
used as a way of discrediting their desires and preferences and thereby prohibited them from sharing power and responsibility:

Because you’re diagnosed with a mental illness, you lose all your human rights, whether it’s to happiness, whether it’s anger, being sad, you’re not supposed to have them, and if you do have them we’re gonna give you a pill for it because it means you’re having an episode. And that’s just not fair. (Polvere, 2009, p. 139)

Those youth who perceived the ability to make the decision for themselves (a paradox because they should already have this right) and who wanted to continue the medication stated that being granted autonomy in the decision to take the medications, along with a strong therapeutic alliance, were crucial to their buy-in.

**Perceptions of being invisible and over-medicated**

Along with limited power, youth felt over-medicated such that medications were being used to “keep them quiet” and control behavior rather than to help them heal as individuals and learn strategies to cope with their symptoms and the demands of life:

We’d see the psychiatrist for maybe five minutes, once a month. And I would be like, I’d try to tell them, I can’t be taking 300 mg of Seroquel in the morning, and then I get in trouble because I fall asleep in group. (Polvere, 2009, pg195)

In this way, they felt invisible as persons, and instead, controlling their behavior and trying “experiments” with medications seemed the only goal of providers and caregivers:

It feels like a rat…that they test on… Because I’ve been on different medicines, different diagnoses….I kept gaining weight, losing weight, gaining weight, gaining and losing, gaining and losing. (Moses, 2011, pg 107).

Notably, in several papers, youth and former youth also described other mental health and social service providers aside from clinical prescribers as equally ineffective in teaching them strategies to cope with mental health symptoms and heal from the many adversities they had experienced in life.

**Weak therapeutic relationships**

Youth and former youth, in general, also described weak therapeutic relationships – with clinical prescribers as well as other mental health and social service providers. Youth felt unheard and had trouble trusting providers. “[He] didn’t hear what I said and told me that I would never change” (Lee et al., 2006, pg 450); and “My med doctor doesn’t listen to me. They don’t listen to what I want to do about my meds and what meds I want to be on” (Narendorf, Munson, & Floersch, 2015, pg 8). Some even perceived unprofessional behavior of providers, which deepened their mistrust. However, as noted earlier, when youth did report positive experiences with providers and
with medications, they often attributed this to a strong therapeutic relationships. Lee et al. (2006) reported that when youth described positive relationships with providers, they attributed it to strong communication skills that involved not just listening skills, but also acceptance and understanding of the youth.

Although there were not enough studies retrieved from any of the other target groups to allow for a full narrative synthesis of their perspectives, we have summarized these outcomes in Table 1. In general, themes from these stakeholder groups parallel those of youth. Most notably, themes of poor knowledge regarding medications were reported for foster parents, child welfare workers, and non-MD therapists, as well as imbalanced power in relationships with clinical prescribers. For example, McMillen, Fedoravicius, Rowe, Zima, and Ware (2007) describe how child welfare workers and therapists are hesitant to discuss concerns with medications with clinical prescribers due to a lack of their own felt expertise and fears of offending them. Clinical prescribers also mention many systemic barriers to PCC in this population in the McMillen study. For example, poor reimbursements, brief evaluations and inpatient stays, and liability concerns were raised as antithetical to PCC.

**Discussion**

We aimed to identify the perspectives of youth currently or formerly in foster care, caregivers, and direct service providers regarding how the psychiatric care for youth in foster care aligns or does not align with PCC and to examine the effectiveness of interventions aiming to improve PCC in this context. Through our systematic search of the literature and critical synthesis of findings, we aimed to propose areas where additional research is needed and, if enough evidence was available, to provide guidance to leaders and policy makers in their efforts to promote patient-centered psychiatric care for this vulnerable population.

Eleven studies met final inclusion criteria and quality standards, none of which examined outcomes with interventions aiming to improve PCC in this population. Moreover, the various target groups (youth, parents, providers) were too disparate to synthesize together, and therefore, each target group was separated. The only group with enough studies \( n = 6 \) to warrant synthesis was youth/former youth in foster care. We only, then, had enough evidence from which to draw conclusions based on youth/former youth perspectives related to how psychiatric care aligns with PCC. And we have no evidence (no studies retrieved) to make conclusions or recommendations related to interventions aiming to improve PCC in this context.

Youth/former youth perspectives revealed four main themes: (1) lack of knowledge about medications and subsequent uncertainty whether medications were working; (2) feelings of disempowerment and coercion by various
caregivers and providers; (3) feelings of being invisible, and overmedicated in an effort to control behavior rather than help and heal; and (4) weak therapeutic relationships with various mental health providers. Finally, underlying these factors were inherent systemic barriers to PCC. These themes were most directly relevant to four of the five PCC domains outlined by Mead and Bower (2000): Sharing power and responsibility, therapeutic alliance, patient-as-person, and biopsychosocial approach. Below, we describe the intersections between the themes revealed in our narrative synthesis and these PCC domains. No studies shed light on Mead and Bower’s conception of doctor-as-person.

**Lack of knowledge and uncertainty of medication effectiveness**

A lack of youth knowledge about medications, side effects, monitoring, and treatment options has been documented elsewhere. In a recent systematic review of the facilitators and barriers to patient-centered mental health care in the broader child population, participants also reported a lack of knowledge about medications and the absence of easily understood treatment information as major barriers to PCC (Gondek et al., 2016). To share power and responsibility, as outlined by Mead and Bower (2000), doctors and patients must first both understand the conditions and treatments, including risks, before they can share power and responsibility in an effective way to make decisions. Without knowledge, youth were unable to share in this responsibility.

The youth/former youth participants in the retrieved studies were vocal about feeling like they were being experimented on with various medications. Based on our findings, we recommend that clinical prescribers talk frankly about the “art” of psychopharmacology with youth and caregivers, acknowledging that it is not an exact science and that at times, trial and error approaches may be appropriate, if the youth and person with consenting authority agree to such trials. We also recommend that clinical prescribers talk more openly about side effects and necessary monitoring, not only of medication side effects, but progress towards intended symptom reduction or functioning improvements. Clinical practice guidelines recommend that clinicians use standardized tools to measure changes in targeted symptoms over time (e.g., every 1–3 months; Walkup, 2009) and to facilitate careful monitoring of side effects (Findling, Drury, & Jensen, 2011). A host of screening and assessment measures are in the public domain, as are monitoring tools (e.g., Abnormal Involuntary Movement Scale exam for antipsychotics). Administrators could institute such tracking mechanisms into electronic medical records or use other clinical reminder systems to improve the use of ongoing symptom and functioning assessments and monitoring of side effects. For example, a system that alerts clinicians of when blood laboratory tests are “due” and that provides results of labs when they are completed would be incredibly useful. In keeping with PCC’s principle of shared power and
responsibility, and based on our synthesis identifying a pervasive lack of knowledge about the purpose of medications, effects, and side effects, we encourage clinicians to then provide this feedback to youth and caregivers in a transparent manner so they are aware of the target symptoms, effectiveness, and side effects and can make decisions accordingly. Finally, we recommend, based on our synthesis of findings, that clinical prescribers spend more time learning from youth what their lived experience – another type of knowledge that is equally important – has taught them about their mental health, treatment, and medications.

**Feelings of disempowerment**

Our findings revealed that youth/former youth felt unheard, and at times, coerced, into taking the medications, reflecting a serious imbalance of power as described by Mead and Bower (2000). Many others have described the power imbalances among doctor-patient relationships, as well as the extent of patient disempowerment in mental health services, including those focused on children and families (Gondek et al., 2016). In the recent decade, we have witnessed the establishment of shared decision-making (SDM) research and practice to facilitate patient-centered care in adult mental health settings (Duncan, Best, & Hagen, 2010; Zisman-Ilani, Harik, Barnett, Pavlov, & O’Connell, 2017). Yet, SDM research among youth is in its infancy (Cheng et al., 2017; Coyne, O’Mathuna, Gibson, Shields, & Sheaf, 2013). Mental health care, including that for children, has also long been troubled by paternalism (Hamann, Leucht, & Kissling, 2003; Pelto-Piri, Engstrom, & Engstrom, 2013). Together with other powerful dynamics at play when caring for youth in foster care – who are without capable biological parents and natural supports, and who are familiar with having little to no power in their day-to-day lives - it is easy to see why this population is vulnerable to disempowerment. Yet researchers have documented that adolescents with mental health conditions (barring no major intellectual disability or major crises) are capable of making appropriate treatment decisions (Coyne & Harder, 2011; Harper, Dickson, & Bramwell, 2014). We recommend urgent clinical and research attention to the power imbalances revealed here and elsewhere. Interventions that promote shared power – such as Shared Decision-Making interventions – need tested in this population (e.g., Drake, Deegan, & Rapp, 2010).

**Feeling invisible and overmedicated**

Many youth felt that they were being over-medicated in an effort to control their behavior and keep them quiet rather than to help them heal as individuals. The over-reliance on medications and excessive polypharmacy in this population are real documented concerns and have been raised in a number of policy arenas, including General Accountability Office reports (Kutz, 2011) and state child
welfare legislation. In this context, youth also described feeling invisible, and feeling that they as a person were not understood. These themes reflect (or lack reflection of) what Mead and Bower (2000) described as patient-as-person. We recommend further research exploring novel ways to ensure holistic, PCC in this population, as well as policies that ensure proper monitoring of sedation and other side effects and that limit the use of medications to control behaviors given the pervasive lack of knowledge and empowerment among youth (and their caregivers) to advocate for proper monitoring and oversight.

Weak therapeutic relationships

In the context of their descriptions of feeling disempowered, youth described weak therapeutic relationships with various mental health providers, mapping on directly to one of the PCC domains identified by Mead and Bower (2000). An extra layer of complexity arises when working with youth in foster care, for whom poor or disrupted attachments are common. These early attachment experiences may contribute to later difficulty trusting and developing relationships, and providers need to be aware of this impact.

Underlying system-level barriers

Finally, although the studies included in this review did not ask youth explicitly about system-level barriers to PCC, many concerns were closely tied to underlying systemic problems. For example, as youth discussed feeling unheard by providers, they described frustration with having too little time to discuss their medications with prescribing clinicians and other providers and a subsequent sense of invisibility. These themes reflect a lack of a biopsychosocial approach as described by Mead and Bower (2000). To realize PCC, a full picture of the youth’s biological, social, and psychological history and current functioning are reviewed and considered before making treatment recommendations. However, a biopsychosocial approach is difficult in many payer systems that disincentivize lengthy appointments and collateral or care coordination activities. Youth also described restrictive settings that used coercive tactics such as removing privileges to get youth to do what was wanted (i.e., take psychotropics). These, and other systemic barriers have been discussed elsewhere (e.g., Camp, 2011; Alavi & Calleja, 2012; Barnett et al., 2016) and it is clear that these barriers need to be addressed to assist providers in delivering PCC.

Limitations

A number of limitations warrant mention. First, our systematic search did not retrieve a sufficient number of studies to synthesize perspectives of other stakeholders other than youth. More research is needed to better understand
the perspectives of other groups. Additional insights from clinical prescribers are especially vital to better understand the barriers and facilitators to PCC within this population, as well as to thoroughly characterize systemic influences. In addition, youth and former youth described their experiences within a mix of care settings, including foster homes, group homes, and residential treatment centers. Additional studies are needed to determine specific influences on PCC in these various settings, and how to best carry information between placements. Moreover, our systematic search did not retrieve any studies of PCC interventions focused on psychiatric care/psychotropic medications with this target population. Studies testing the effectiveness and efficacy of PCC interventions within this population are sorely needed to provide guidance to leaders and policy makers in their care for and empowerment of youth in foster care. Finally, the authors were not blind to study authors, and, the lead author has initiated research in this area and is an author on two of the studies included in the review. Although this has the potential to bias the findings and conclusions drawn from this review, the inclusion of three other authors throughout the extraction and review process minimizes the risk of any potential biases being realized.

**Implications, future directions, and conclusions**

Legislation mandating oversight of psychotropic medications and PCC for youth in foster care was enacted in 2011. Our systematic search found only five studies meeting our criteria examining perspectives of youth, caregivers, and direct care providers related to PCC prior to that legislation, three of which were drawn from youth/former youth samples. Policy makers, then, had a limited literature base from which to draw, and it is not surprising that subsequent state child welfare policies largely leave out mention of PCC. Rather, these policies focus heavily on top-down oversight strategies such as audit and feedback and prior authorizations (Mackie et al., 2017). Top down oversight strategies are a good start, but are not enough to ensure care that is centered around each patient’s and family’s needs and preferences. Since the 2011 legislation, an additional six studies meeting our eligibility criteria have been published. We hope this literature continues to grow. What is clear is that in general, youth do not perceive that the use of psychotropic medications is centered on them and their needs and preferences.

Researchers are encouraged to continue exploring perceptions of youth, caregivers, advocates, and providers as it relates to how the psychiatric care of youth in foster care can be more centered on the youth. Structuring the aims and constructs of these studies around Mead and Bower’s (2000) domains of PCC would be useful to assist future investigators in synthesizing the findings from various studies and groups. Researchers are also encouraged to develop and test interventions and strategies to support youth, caregivers, and guardians
in having meaningful, empowered relationships with providers and in having the (consumer-friendly) information they need about medications, effects, and side effect monitoring to share in oversight responsibility. Part of this approach could include workforce development strategies, such that clinical prescribers and other mental health and social service providers receive training and consultation in PCC, as well as the complexities of working with youth and families involved with the foster care system. Interventions could also institute communication mechanisms that promote team discussions and feedback loops so that input from all people on the youth’s care team could be gathered efficiently. We also need to develop and test strategies to promote equal voice for youth and caregivers/guardians during informed consent and assent processes when making decisions related to mental health treatment.

In conclusion, our systematic review of the literature identified youth perceptions of pervasive gaps in PCC as it relates to their psychiatric care. Our search did not retrieve a sufficient number of studies from other stakeholders’ perspectives to warrant a synthesis of findings, nor did our search retrieve any intervention studies aiming to improve PCC in this context. A major research opportunity exists to fill these gaps to inform service delivery and policy.

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References

*Indicates that the study was included in this review


Appendix A. Search terms for the review

Systematic review search terms:

Patient-centered care:
Patient/person-centered care
Patient centeredness
Shared decision making
Perspectives
Attitudes
Perceptions
Experiences
Decision-making
Decision support
Patient participation
Patient involvement
Collaborative relationships
Communication
Engagement
Involvement
Empowerment

Health topic:
Mental disorders
Mental Health/Mental Health Treatment
Psychiatr*
Child psychiatry
Psychotropic medication
Psychotropics

Populations of interest:
Prescribing clinician
Pediatric*
Doctor
Parent
Foster parent
Restrictive settings/Restrictive care
Residential treatment facility/center
Group home care/Congregate care
Wrap-around care
At-risk/High risk
Children
Youth
Foster care

**Gray literature search terms:**

Google search - The Google search included the following nine combinations of terms:

Foster care | psychotropic medications | perceptions
Foster care | psychotropic medications | perspectives
Foster Care | Perspective | Medication | Child
psychotropic drugs | foster care system
Residential care | child | Psychotropic | Perspectives
Foster care | Psychotropic Medication | Attitudes
Foster Care | Attitudes | Medication | Child
Child | Inpatient Care | Psychotropic | Perceptions
Child | Residential Care | Psychotropic | Perceptions

Search of Dissertation Abstracts International
Search of two conference websites:
Society for Social Work and Research 21st Annual Conference
Annual Research and Policy Conference: Child, Adolescent, and Young Adult Behavioral Health