


Community based Primary Care for Adolescents and Young Adults Transitioning From Pediatric Specialty Care: Results from a Scoping Review

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Abstract

Background: Ongoing primary care during adolescence is recommended by best practice guidelines for adolescents and young adults (AYAs; ages 12-25) with chronic conditions. A synthesis of the evidence on the roles of Primary Care Physicians (PCPs) and benefits of primary care is needed to support existing guidelines. **Methods:** We used Arksey and O'Malley's scoping review framework, and searched databases (MEDLINE, EMBASE, PsychINFO, CINAHL) for studies that (i) were published in English between 2004 and 2019, (ii) focused on AYAs with a chronic condition(s) who had received specialist pediatric services, and (iii) included relevant findings about PCPs. An extraction tool was developed to organize data items across studies (eg, study design, participant demographics, outcomes). **Results:** Findings from 58 studies were synthesized; 29 (50%) studies focused exclusively on AYAs with chronic health conditions (eg, diabetes, cancer), while 19 (33%) focused exclusively on AYAs with mental health conditions. Roles of PCPs included managing medications, “non-complex” mental health conditions, referrals, and care coordination, etc. Frequency of PCP involvement varied by AYAs; however, female, non-Black, and older AYAs, and those with severe/complex conditions appeared more likely to visit a PCP. Positive outcomes were reported for shared-care models targeting various conditions (eg, cancer, concussion, mental health). **Conclusion:** Our findings drew attention to the importance of effective collaboration among multi-disciplinary specialists, PCPs, and AYAs for overcoming multiple barriers to optimal transitional care. Highlighting the need for further study of the implementation of shared care models to design strategies for care delivery during transitions to adult care.

Keywords

primary care, community health, pediatrics, access to care, health outcomes

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Introduction

The transition from pediatric to adult care, recommended to start at age 12 and continue until 25, is a challenging process for adolescents and young adults (AYAs) with chronic physical health (eg, diabetes, cystic fibrosis) and/or mental health (eg, depression, schizophrenia)¹⁻³ conditions. Without continuous care during this period, AYAs may disengage from needed healthcare services or experience a worsening of symptoms leading to hospitalization or emergency department utilization.⁴⁻⁶ Prior to transfer (typically at age 1),^{2,3} it is recommended that AYAs are connected to a primary care physician (PCP), most

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commonly a family physician in Canada, or equivalent PCP, such as a general practitioner in the United Kingdom.^{7,8}

A systematic review designed to support AYAs exiting pediatric services and enhance their long-term outcomes revealed only 3 studies with a primary care component⁹; none evaluated the effectiveness of primary care specifically. It is largely unknown what proportion of AYAs with chronic conditions transition to a PCP from pediatric specialist(s), or how PCPs are involved during the transition process. A broader understanding of PCP involvement for AYAs with various chronic conditions, including models of primary-specialty collaborative care, is critical to informing how PCPs can optimally assist during transition.

The purpose of this scoping review was to summarize how PCPs support AYA (ie, 12-25 years old) during the transition period. Sub-questions included: (1) How many AYAs visit a PCP before and after transfer? (2) What are the potential benefits or challenges of PCP involvement during transition? and (3) What models of collaborative primary-specialty care models exist for transition care? This work will inform the development of a primary care intervention to optimize care transitions for AYAs.

Methods

The protocol for this study has been published¹⁰ and registered within the Open Science Framework database (registration DOI: 10.17605/OSF.IO/6X4MQ). This review is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extended for scoping reviews checklist¹¹ (Supplemental Material). A six-step scoping review framework, originally developed by Arksey and O'Malley,¹² and refined by Levac et al¹³ and Peters et al^{14,15} was utilized. A librarian guided the search of multidisciplinary online databases (Figure 1). To identify additional studies of relevance, we applied snowball methods¹⁶ to the reference lists of articles found by the initial search.

Data Analysis

Inclusion/exclusion criteria for eligible studies are summarized in Supplemental Table S1. Briefly, eligible studies were published in English between 2004 and 2019, presented primary research with no limitations on study design, and focused on AYAs with chronic physical health and/or mental health condition(s) who had received care by a specialist physician (eg, psychiatrist, pediatric oncologist). Study screening was completed in triplicate (KS, BA, AF) and occurred at 2 levels: (i) title/abstract and (ii) full-text. Discrepancies about study relevance were resolved via group discussion. A data extraction tool¹⁰ was developed through an iterative process including pilot testing and team consultation. Microsoft Excel and NVivo software¹⁷ were used to track, organize, and extract data. Extracted data included characteristics relevant to: study (eg, year, design), population (eg, AYA mean age, diagnoses),

context (eg, country, clinical setting), and concept (eg, relevant findings/outcomes). Where appropriate, we used qualitative description^{18,19} and summative content analysis,²⁰ to synthesize data.^{21,22} We maximized validity and rigor through independent and team analysis of the extracted data, re-reading articles, reviewing supplementary data, and comparing interpretations within our multidisciplinary team.²²

Ethical Approval

Ethical approval was not needed nor sought for this study.

Results

Study Characteristics

From a total of 3176 (nonduplicate) abstracts, 239 full-text articles were screened for eligibility (Figure 1). The final analysis included 58 studies, of which most were conducted in North America and published in or after 2015. Half of the studies (n=29) focused on AYAs with chronic physical health conditions (eg, type 1 diabetes, sickle cell disease); of these studies, 12 focused on AYA cancer survivors. Nineteen studies focused on AYAs with a primary mental health issue (eg, depression, anxiety). The remaining 10 studies focused on AYA with both physical and mental health conditions (Table 1).

Evidence Summary for Transitioning AYAs and Primary Care

PCP roles and responsibilities: Perceived roles of PCPs for AYAs with chronic conditions who had received (or were receiving) specialist care were described in 18 studies (7 quantitative^{23,35,47,50,59,60,79}; 11 qualitative),^{55,61,64,66-71,73} which included the perspectives of AYAs and/or their caregivers (n=6),^{37,68-70,73,75} specialist providers (n=4),^{63,67,68,70} and family physicians (FPs) themselves (n=14).^{37,52,61,64-68,70-72,74-76} Common responsibilities of PCPs included: medication management (specifically prescribing and counseling),^{35,52,61,64,67,70,71} making referrals to specialists and/or community resources,^{35,64,70,71,73} managing mental health problems until more specialized services were needed or became available,^{35,61,70,71} serving as care coordinator when multiple services/providers were involved,^{64,71} and addressing “primary health care issues” (eg, immunizations; discussing lab results; managing flu-like symptoms, acute injury).^{23,35,73,75} Often PCPs were comfortable with caring for AYAs until their symptoms reached a threshold wherein more expertise was desired/needed.^{61,67,70,71}

Frequency of PCP Visits

In a population survey of caregivers of AYAs with special healthcare needs, 39% of AYAs reported receiving care from a “lifespan-oriented” provider (eg, PCP).⁴⁸ In 2 population-based cohort studies,^{40,41} 34% of AYAs with diabetes⁴¹ and

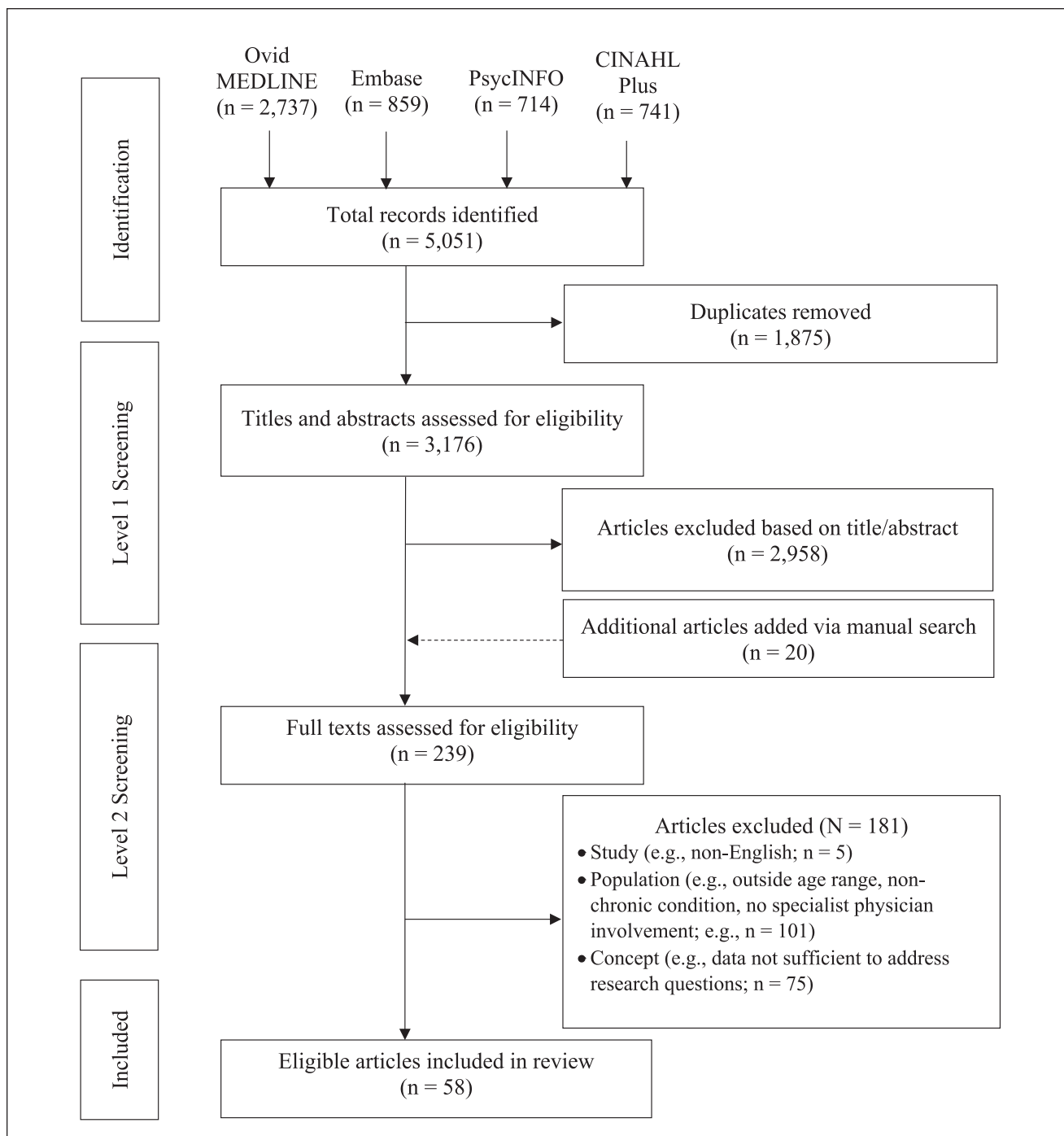


Figure 1. Study inclusion flowchart.

27% of those with severe mental illness⁴⁰ saw a different physician during the “transition ages” (ages 17-18) compared to “pre-transition” (ages 12-16), that is, discontinuous primary care. In both studies, AYA with discontinuous or no primary care during transition experienced worse outcomes in young adulthood (ages 19-26).

Six studies reported annual PCP visit rates by AYAs with chronic conditions (cancer survivors^{23,24}; congenital

heart disease⁴⁴; severe mental illness⁴⁰; diabetes⁴¹; complex chronic conditions)⁴²; 4 additional studies also reported PCP visit frequency within the last year based on AYA/caregiver self-report.^{48,51,54,55} Frequency of PCP visits per year varied within and across studies. For example, AYAs with either muscular dystrophy or complex chronic conditions were observed to have a median of 3 to 4 PCP visits/year,³³ while AYA cancer survivors appeared to have

Table 1. Study Characteristics and Relevant Findings of Included Studies (N = 58 studies).

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Heins et al ²³	Canada	Case-control	Population-based cancer registry	AYAs (N = 774); M = NR, ages 15-19 (39%), 20-24 (62%) SD = NR, R = 15-24	Cancer	Frequency of PCP contact: 96% of AYAs visited a FP in first year after diagnosis (M = 10 visits); significantly greater than controls in this age group (79%, M = 6 visits). Percentage of AYAs with a FP visit declined during the first 5 years after diagnosis to 84% (7 visits/year), but still higher than controls. Roles of PCP: "neoplasms," "signs and symptoms" (eg, general symptoms, skin), discussing results of lab tests, prenatal care, disorders of menstruation, respiratory problems Frequency of PCP contact: 97% AYAs had ≥ 1 FP in 3-year period; compared with 50% of controls. AYAs 2x likely to see FPs ≥ 10 times and 28% more visits to FPs than controls.
McBride et al ²⁴	Canada	Case-control	Population-based cancer registry	AYAs (N = 1157); M = NR, ages 10-14 (19%), 15-19 (27%) SD = NR, R = NR	Cancer	Unique characteristics of AYAs followed by PCP: Female and older AYAs more likely ≥ 10 FP visits. AYAs with relapses and CNS tumors had significantly more visits to all types of physicians (including FPs). SES, residence, treatment or disease-related factors did not affect likelihood of FP visits. Benefits of collaboration: Proportion of AYAs involved in follow-up by their PCP (83% vs 18%) and the proportion of AYAs involved in follow-up according to a shared-care follow-up care strategy (83% vs 2.8%) were higher in the intervention cohort (shared care follow-up) than in the control group. Lack of any follow-up was lower in the intervention cohort than controls (7.5% vs 25%); 100% of AYAs in intervention were provided with a survivorship care plan compared to only 52.8% of controls. Unique characteristics of AYAs followed by PCP: No demographics/clinical differences between those who received intervention vs controls; 12 AYAs in intervention arm, followed by specialists for severe long-term effects (neurological or neuropsychological deficiency, blindness, endocrinological deficiency), refused the shared care follow-up model and were followed up only by the pediatric oncology unit.
Ducassou et al ⁵	France	Case-control	Specialized cancer care center in a pediatric oncology department of a university hospital; Model of Care ²⁵ . Shared care follow-up model with PCPs and cancer center	AYAs (N = 204); Median = 16.2, SD = 28.5, R = NR	Cancer	

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Table 1. (continued)

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Feyissa et al ²⁶	US	Case-control	Pediatric subspecialists (ie, neurology, sports medicine) at suburban medical center partnership with pediatricians Model of care ^b : Co-management collaborative care	AYAs (n = 148), M = 12.9, SD = 5.9, R = NR; Pediatricians (n = 6), Nurse Practitioners/ PAs (n = 3);	Concussion	Benefits of specialist collaboration: co-management of concussion patients (where GPs use a toolkit and care is planned, delivered, and evaluated by 2 or more providers) with GPs and specialists shown to improve care, and access to care Facilitators to specialist collaboration: training for GPs in co-delivering care for concussion patients (ie, toolkit with visit templates, informational handouts, continuing medical education video) % transferred from CYMH care to PCP: 0%; None transferred to community primary care.
Berens and Peacock ²⁷	US	Cohort	Specialized Transition Clinic based in an academic affiliated hospital. Model of care ^b : "Transition Medical Clinic"	AYAs (N = 292); M = 22.6, SD = 7.3, R = 14-54	Cerebral palsy, Spina bifida, Down syndrome, Genetic conditions, ASD	% transferred from CYMH care to PCP: 28% transferred to primary care pediatrician; (for ADHD, 49%; anxiety, 27.9%; depression, 5.9%); 72% followed in pediatric mental health.
Aupont et al ²⁸	US	Cohort	Program served 22 primary care practices Model of care ^b : Collaborative consultation psychiatric model: "Targeted Child Psychiatric Services"	AYAs (N = 329); M = 12.3, SD = 4.0, R = NR	Mental health issues	% transferred from CYMH care to PCP: 22% transferred to PCP; 2% to PCP with consultation to psychiatrist; 45% referred to specialized adult mental health services; 2% chose no follow-up; 27% dropped out or lost to follow-up; 1% died; 1% long-term facility. Unique characteristics of AYAs followed by PCP: stable (ie, no hospital admissions or emergency services in the last year of treatment), not receiving case management services, only receiving maintenance pharmacotherapy or no pharmacotherapy. AYAs followed by FPs had the lowest levels of symptoms and highest levels of social functioning.
Addington and Addington ²⁹	Canada	Cohort	Tertiary care subspecialty multi-disciplinary service: specialized Early Psychosis Program	AYAs (N = 292); M = 24.5, SD = 8.2, R = NR	Schizophrenia and related disorders	% transferred pediatric care to PCP: 20% to PCP; 38% to specialized outpatient units; 41% to adult diabetes center
Neu et al ³⁰	Germany	Cohort	Outpatient department at I pediatric center	AYAs (N = 99); M = 21.8, SD = 2.8, R = NR (at time of transition)	Type I Diabetes	
Grossen et al ³¹	US	Cohort	Population-based cohort of a program for low-income children with chronic disease	AYAs (N = 5263); M = NR, ages 13-21 (50%), SD = NR, R = 0-21	Type I Diabetes	Benefits of PCP involvement: AYAs with DKA were more likely than those without to have had preventive and non-preventive primary care visits in 6 months prior, and less likely to have visited pediatric specialist. Non-preventative or acute care PHC visits might signal increased likelihood of DKA.

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Table 1. (continued)

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Costell ³²	US	Cohort	Pediatric hospital-based survivorship clinic and primary care practice Model of care*: Shared care transition visit between AYA, PCP, and survivorship team (via telemedicine)	AYAs (N = 19); M = 26.5, SD = NR, R = 2 1-4	Cancer	Benefits of specialist collaboration: enhanced ability to take care of AYA (PCP); improved knowledge about AYA care (PCP); easier to communicate with PCP about cancer history (AYA); liked ability to talk to both PCP and survivorship team simultaneously. Barriers to specialist collaboration: difficulties with telemedicine equipment (eg, installation, use, etc.)
Ozturk et al ³³	US	Cohort	Population-based cohort of individuals diagnosed with muscular dystrophy	AYAs (N = 1012); M = 19, SD = NR, R = 15-24	Muscular Dystrophy	Frequency of PCP contact: about 3 PCP visits per year; age 15-18 (M = 3.39 visits); 19-24 (M = 2.28 visits). Barriers to PCP involvement: Black AYAs have less primary care involvement compared with all other races.
Richardson et al ³⁴	US	Cohort	Telephone survey to AYAs insured with a group health cooperative	AYAs (N = 767); M = 13.9-14.6, SD = 1.6-2.1, R = 11-17	Asthma	Unique characteristics of AYAs followed by PCP: AYAs with asthma and a mental health comorbidity (ie, anxiety, depression) had significantly more PCP visits for mental health and other reasons, and more specialty outpatient mental health visits, but less asthma specialty visits, than those without mental health comorbidity.
Kinahan et al ³⁵	US	Cohort	Comprehensive cancer center within a large tertiary care medical center Model of care*: Shared care follow-up model with PCPs and oncologists	Nurse Practitioners/ PAs (n = 34) and Oncologists (n = 27)	Cancer	Roles of PCP: Ensure AYA physical and emotional health needs addressed; assume responsibility of chronic care that are feasible in primary care setting; refer for problems and assessments; consult. Benefits of specialist collaboration: Pre-intervention, 47% of AYAs had a PCP; post-intervention this increased to 55%. Majority of providers felt shared-care model was a desirable model of care. Barrier to PCP involvement: Interestingly, high percentage (10%) of AYAs initially listed their pediatric oncologist as their PCP pre-intervention: education on PCP role possibly required.
Chua et al ³⁶	US	Cohort	Population-based cohort of individuals diagnosed with asthma	AYAs (N = 3469); M = NR, age 14-17 (54%), age 19-25 (46%) SD = NR, R = 14-25	Asthma	Unique characteristics of AYAs followed by PCP: Older AYAs (aged 19-25) less likely to have ≥ 1 primary care visit in last 12 months, but more likely to have ≥ 1 ER visit, than younger AYAs (aged 14-17). Barrier to PCP involvement: Discontinuing school during transition period associated with decreased use of primary and preventative care; no significant association changes in adult presence in home (ie, transitioning to continuous independent living) or insurance changes (eg, losing continuous insurance) and use of primary and preventative care.

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Table 1. (continued)

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Kaal et al ³⁷	Netherlands	Cohort	Subspecialty clinic within a university affiliated hospital	Caregivers (n = 15) and Family physicians/GPs (n = 9)	Cancer	<p><i>Benefits of specialist collaboration:</i> collaboration with palliative specialist services supports GPs' ability to manage AYA with terminal illness in primary care</p> <p><i>Barriers to specialist collaboration:</i> GPs reported feeling out of the loop when specialists become involved. Communication problems with specialist team regarding role and accessibility of GP in cancer care; lack of collaboration and communication amongst primary and specialty care due to system issues/silos</p> <p>% transferred pediatric care to PCP: 90% of AYAs were followed up by GPs. However, none of the AYAs had undergone the recommended assessments for Turner Syndrome in primary care. Two-thirds of AYAs said PCP aware of their Turner Syndrome diagnosis.</p> <p><i>Benefits to specialist collaboration:</i> consultations helped PCPs meet the needs of AYAs, and improved their skills in mental health care; improved access to child and adolescent psychiatry.</p>
Gawlik et al ³⁸	Poland	Cohort	Subspecialty clinic within a university-affiliated hospital	AYAs (N = 22); M = 23.0, SD = 2.8, R = 18.6-28.0	Turner syndrome	<p>% transferred from CYMH care to PCP: to PCP 57%; required long term psychiatric care outside of the model, 10%; in the process of consultation, 12%; did not attend their scheduled follow-up appointment</p> <p><i>Frequency of PCP contact:</i> At baseline (ages 12-16), most AYAs (87%) seen by a FP, during transition (17-19), 74% FP, 5% no primary care.</p> <p><i>Unique characteristics of AYAs followed by PCP:</i> AYAs with schizophrenia had the least continuity during transition (27% received care from a different FP, 8.5% no primary care).</p>
Fallucco et al ³⁹	US	Cohort	Specialized outpatient child psychiatric consultation for 3 primary care practices Model of care*: "Child Psychiatry Consultation Model"	Pediatricians (n = 19) and Nurse Practitioners/PAs (n = 3)	Depression, anxiety, ADHD	<p><i>Benefits of PCP involvement:</i> AYAs with discontinuous primary care during transition had higher rates of MH-related admission in young adulthood compared with those with continuous primary care. AYAs with no primary care during transition had higher rates of MH-related admissions.</p>
Toulany et al ⁴⁰	Canada	Cohort	Population-based cohort of individuals diagnosed with severe mental illness	AYAs (N = 8409); M = 14.8, SD = 1.2, R = 12-16	Severe mental illness (ie, mood disorder, schizophrenia, eating disorder with prior 72-h admission)	<p><i>Benefits of PCP involvement:</i> AYAs with discontinuous primary care during transition had higher rates of MH-related admission in young adulthood compared with those with continuous primary care. AYAs with no primary care during transition had higher rates of MH-related admissions.</p>

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Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Shulman et al ⁴¹	Canada	Cohort	Population-based cohort of individuals diagnosed with Type 1 Diabetes	AYAs (N = 2525); M = NR SD = NR R = 15-26	Type 1 Diabetes	Frequency of PCP contact: 10% of AYAs had no primary care visits during transition age (ages 17-18). Of those whose physician for pre-transition primary care was a family physician, 25% had a different physician for primary care during transition age. 34% had at least one visit with a physician for primary care during transition age, but none with the physician who provided pre-transition primary care. Benefits of PCP involvement: FP visits during transition was associated with an increased risk of ketoacidosis or death in early adulthood (ages 19-26). Frequency of PCP contact: Across all groups, visits to an adult specialist increased in the 2 years after transfer, whereas both primary care and subspecialty visits to pediatricians decreased. Visits to a family physician increased slightly after transfer only among youth with CCCs (78.3% vs 82.7%, $P < .001$). The proportion of youth with at least 1 annual primary preventative care visit in the 2 years after transfer decreased across all 3 clinical groups. Overall (across groups) 10 primary care visits (6-17) between 10 and 16 years old (baseline) Model of care: (1) PCP only (n = 932); (2) specialist-only (ie, pediatricians, endocrinologists, internists) (n = 1598); or (3) shared care involving both specialists and PCP (n = 2622). Benefits to specialist collaboration: Proportion at goal (optimal or good diabetes adherence) were lowest in GP-only group and highest in the specialist-only and shared-care groups. A shared model of care between GPs and specialists provides the same level of adherence to guidelines as care provided by specialists only.
Cohen et al ⁴²	Canada	Cohort	Population-based cohort of individuals with chronic conditions	AYAs (N = 104,497); M = NR, SD = NR, R = 16-20	"Complex chronic" conditions (CCC); "non-complex chronic" conditions, "chronic mental health" conditions	
Amed et al ⁴³	Canada	Cohort	Population-based cohort of individuals diagnosed with Type 1 Diabetes	AYAs (N = 1472); M = 11.8 years, SD = NR, R = 1-24	Type 1 Diabetes	Frequency of PCP contact: 87% of 18-22 year olds seen by a PCP, compared to only 39% seen in an outpatient cardiology setting; gap between outpatient PCP encounters vs cardiologist visits widened with increasing AYA age. Compared with school-age children, AYAs were more likely to be seen by a PCP than by cardiologists.
Mackie et al ⁴⁴	Canada	Cohort	Pediatric- and adult-oriented outpatient cardiology care, and primary care province-wide. All universal and government funded services	AYAs (N = 643); M = NR, SD = NR, R = 6-22	Congenital Heart Disease	

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Table 1. (continued)

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Davis et al ⁴⁵	US	Cross-sectional survey	Survey sent to pediatricians' part of American Academy of Pediatrics chapter in city	Pediatricians (N=70)	Mental health issues	<p><i>Barriers to specialist collaboration:</i> lack of access to psychiatrist and/or mental health counselors for consultation and referral</p> <p><i>Facilitators to specialist collaboration:</i> strong preference for consultation model (88%) (ie, MH services provided in primary care setting in consultation with MH specialists) vs co-location model (77%) (ie, MH clinicians available "on-site" in primary care office), vs integrated model (67%) (ie, MH clinician hired to treat patients collaboratively)</p> <p><i>Facilitators to specialist collaboration:</i> Shared medical records and faxed written notes were most preferred communication modalities with MH specialists. Psychological evaluations, progress summaries, and MH treatment plans were the most helpful types of shared information. Pediatricians who were more comfortable treating MH reported frequent communication.</p> <p><i>Barriers to specialist collaboration:</i> communication with MH specialists never happens (24%); dissatisfaction with collaborative communication due to: for example, MH specialists not consistent or timely, unwillingness to communicate.</p> <p><i>Roles:</i> prompt referrals to secondary care, not: diagnosis and management.</p> <p><i>Facilitators to PCP involvement:</i> if AYA first: assessed by specialist services, years of clinical experience</p> <p><i>Barriers to PCP involvement:</i> lack of confidence by PCP for management</p>
Campbell et al ⁴⁶	US	Cross-sectional survey	Survey sent to pediatric primary care providers across 41 states	Pediatricians (N=123)	Mental health issues	
Buhagiar and Cassar ⁴⁷	Malta	Cross-sectional survey	Survey sent to all GPs in country registered with Family Practitioners Register	FPs/GPs (N=157)	Mental health issues	
Nishikawa et al ⁴⁸	US	Cross-sectional survey	Survey sent to physicians working in primary care, internal medicine, and pediatrics nationwide	Caregivers (N=18,198)	Special health care needs	<p><i>Frequency of PCP contact:</i> 39% AYAs received care from a "lifespan-oriented provider"; 61% from child-only providers.</p> <p><i>Benefits of PCP involvement:</i> AYAs with lifespan-oriented providers had significantly higher odds of having discussed adult health needs and adult health insurance. Life course approach may be critical components to improve transition and overall health for these adolescents.</p>

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Table 1. (continued)

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Nathan et al ⁴⁹	US and Canada	Cross-sectional survey	Survey sent to FPs/GPs from the American Academy of Family Physicians' membership directory of physicians	FPs/GPs (N = 1124)	Cancer	<i>Facilitators of PCP involvement:</i> access to clinical care guidelines; receipt of a patient-specific letter from specialists with surveillance recommendations; continuing medical educational activities; shared-care (involvement of specialist); PCPs who had seen at least one survivor in past 5 years were significantly more comfortable caring for all AYA survivors; majority (85%) of PCPs stated they would be willing to care for survivors if they would be able to consult with a cancer center-based physician or survivorship program <i>Barriers to specialist collaboration:</i> 48% reported they never or almost never received a treatment summary prior to the AYAs first visit
Agrawal et al ⁵⁰	US	Cross-sectional survey	Survey sent to pediatricians in one state	Pediatricians (N = 376)	Special health care needs	<i>Roles:</i> coordinate care among subspecialists, prescribe physical/occupational/speech therapies, write letters of medical necessity, conduct developmental screenings, order home health supplies; >50% felt prepared to perform these tasks; only 44% felt somewhat or very prepared to help with transitioning from adolescent to adult care <i>Barriers:</i> insufficient time to care for needs, insufficient reimbursement for time, lack of support services such as case management and social work, lack of knowledge about services available, lack of understanding of coding/billing, providing care to children requiring dialysis <i>Unique characteristics of AYAs followed by PCP:</i> Increased pain severity, but not presence of recurrent musculoskeletal pain, was significantly associated with having visited the GP. <i>Frequency of contact:</i> 47% of AYAs had visited their PCP the year before study participation <i>Benefits of specialist collaboration:</i> increases GPs' understanding of using and monitoring psychotropic medications; GPs have high confidence in managing mental health problems following telehealth consultations with mental health specialists; improved patient care for AYA with mental illness
Ramstad et al ⁵¹	Norway	Cross-sectional survey	Survey sent to AYAs involved with specialist health centers in a region	AYAs (N = 74); M = 16.5, SD = 0.6, R = NR	Cerebral palsy	<i>Facilitators to specialist collaboration:</i> use of telepsychiatry for consultations with behavioral health consultants, child/adolescent psychiatry
Malas et al ⁵²	US	Cross-sectional survey	Survey sent to primary care providers using a telepsychiatry service. Model of care ⁵³ : Michigan Child Collaborative Care Program	Nurse practitioners/PAs and Other PCPs (n = 159)	Mental health issues	<i>Facilitators to specialist collaboration:</i> use of telepsychiatry for consultations with behavioral health consultants, child/adolescent psychiatry

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Table 1. (continued)

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
McLaughlin et al ⁵³	US	Cross-sectional survey	Survey sent to internists and FPs working in adult-oriented primary care within the state	FPs/GPs and General internists (N = 404)	Special health care needs	<i>Facilitators to PCP involvement:</i> Factors associated with willingness to accept AYA: female provider, fewer years in practice, presence of AYA in current practice, practice accepting new patients, provision of a medical summary, availability of time-limited care coordinator, reimbursement for time. <i>Barriers to PCP involvement:</i> 44% of PCPs rated themselves "willing" or "enthusiastic" to accept AYAs.
Meehan et al ⁵⁴	AUS	Cross-sectional survey	Survey sent to caregivers from a state-wide Cerebral Palsy register	Caregivers (N = 350)	Cerebral Palsy	<i>Frequency of PCP contact:</i> 83% of parents reported their child had 31 GP visit in prior 12 months; 58% saw 2-5 different pediatric medical specialists. Severity/complexity associated with having been seen by medical specialist but not a GP. Family characteristics were not associated with service use.
Gisela et al ⁵⁵	Switzer-land	Cross-sectional survey	Survey sent to professional associations across country	FPs/GPs (n = 122), Oncologists (n = 40), and Pediatricians (n = 21)	Cancer	<i>Frequency of PCP contact:</i> 39% of GPs reported being involved in AYA follow-up care. <i>Roles of PCP:</i> Content of follow-up care different significantly between specialists and GPs. More specialists reported examining AYAs for relapse, second tumors, late somatic effects, and informed them about their former disease and possible late effects; both providers provided counseling and examined psychological effects. <i>Barriers to PCP involvement:</i> 58% of GPs noted not being aware of AYAs needing follow-up care; 40% assumed pediatric/medical oncologist takes care of AYA survivors as reason for not engaging in follow-up. <i>Facilitators to PCP involvement:</i> standardized protocols and guidelines, need for specific training, financial resources, support from treating oncologist (including referral report).
Yoon et al ⁵⁶	US	Cross-sectional survey	Survey sent to cardiologists and nephrologists providing outpatient care	Cardiologists (n = 220) and Nephrologists (n = 179)	Hypertension	<i>Barriers to PCP involvement:</i> only 50%-56% of specialists reported that PCPs were somewhat or very comfortable with AYA hypertension diagnosis and management.
Pidano et al ⁵⁷	US	Cross-sectional survey	Survey sent to pediatricians working in primary and specialty care settings across state Model of Care*	Pediatricians (n = 65) and Nurse Practitioners/PAs (n = 7)	Mental health issues	<i>Benefits of specialist collaboration:</i> significantly greater availability of ongoing communication and consultation with psychiatric providers regarding medication issues. <i>Facilitators of PCP involvement:</i> formal consultative relationship with a MH provider; having a MH provider on-site

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Table 1. (continued)

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Marcer et al ⁵⁸	UK	Cross-sectional survey	Survey sent to community pediatricians providing consultation across select health regions of the UK from a membership database	Pediatricians (n = 78)	ADHD	AYA criteria for transfer to PCP: almost a quarter of respondents felt at least 40% of their patients would require ongoing services; specific criteria not specified. Barriers to GP involvement: Pediatricians perceived GP as inappropriate to manage young people with ADHD because "GPs won't prescribe methylphenidate to adults because not licensed." "GPs do not have the skills or the interest" Facilitators of GP involvement: availability of shared care with adult specialists Barriers to specialist collaboration: lack of adequate reimbursement, 38% of pediatricians and 51% internists agreed to statement, "It would be easy for AYAs with a childhood-onset chronic disease to find a general internist who would be willing to care for their primary care needs"; other barriers, such as lack of training, not associated with perceived quality of chronic illness delivery. Facilitators to specialist collaboration: 57% of the general pediatricians reported that it was easy to communicate with an adult provider to transition their young adult patients to adult-based care, and 62% of internists reported that it was easy to communicate with a pediatric provider about transitioning; having an office structure that is effective in care coordination had the greatest positive association on the perceived quality of care; for pediatricians, subspecialty support was significantly associated with higher perception of quality of care delivery. For general internists, effective communication between subspecialists was associated with higher perceptions of the quality of chronic care delivery. Roles of PCP: Internists and pediatricians were both comfortable being the PCP for AYAs with SCD, but less comfortable for AYAs with CF and congenital heart disease. Internists more comfortable treating AYAs with hypertension, diabetes, depression and chronic pain. About half of pediatricians reported that a pediatrician (generalist or specialist) should be delegated primary care responsibility for an 18-year-old AYA with CF or SCD; over 80%-90% of internists thought an adult-focused provider (generalist or specialist) should take responsibility for the primary care needs. Barriers to involvement: Internists more likely than pediatricians to report insufficient training limited their ability to provide care. Pediatricians more likely than internists to report barriers due to insufficient time during office visits, insufficient mental healthcare support and social work support. Facilitators to involvement: Higher treatment comfort; experience/training with CF and SCD treatment in practice
Okumura et al ^{59,60}	US	Cross-sectional survey	Survey sent to internists and pediatricians working in internal medicine or general pediatrics nationwide	Pediatricians (n = 751) and General internists (n = 537)	Special health care needs	

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Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Lempp et al ⁶¹	Germany	Delphi	Survey sent to pediatricians and GPs providing office-based state-funded primary care	Pediatricians (n = 241) and Family physicians/GPs (n = 194)	Mental health issues	<p>Roles of PCP: managing mental health problems (medications, talk therapy. GPs manage mental health problems until "threshold reached" and more expertise needed)</p> <p>Barriers to PCP involvement: perceived lack of knowledge, training and education on managing mental health problems</p> <p>Facilitators to specialist collaboration: collaboration with child/adolescent psychiatry perceived as "good" by GPs, and quality of collaboration</p> <p>Facilitators to specialist collaboration: inter-agency collaboration (standardized referral/information sharing) deemed important in identifying and treating youth mental health in primary care; guidelines for GPs on how to interact with specialty mental health care recommended to increase information sharing and improve care transitions; establishing clear referral pathways between primary and specialist mental health care deemed important</p> <p>Barriers to PCP involvement: perceived lack of knowledge, training and education on managing chronic conditions (ie, late effects of cancer/treatment)</p> <p>Facilitators to specialist collaboration: education of specialists in how to "hand off" to primary care; communication between primary and specialty care; collaborative care model (ie, having GP assume responsibility for cancer survivor's care, but have specialists available for consultation and remunerated accordingly for preventative care and early identification of needs); written guide for managing after-effects, ongoing needs and risks of cancer survivors requested by GPs from oncologists</p> <p>Barriers to specialist collaboration: lack of communication between primary and specialty care; GPs have difficulty obtaining access to medical information for cancer diagnosis/treatment</p>
Schaffa-litzky ⁶²	Ireland	Delphi	Policy experts/key stakeholders identified by the research team for relevancy to research aim	Family physicians/GPs, Nurse practitioners/PAs, Psychologists/Psychiatrists, and Other key stakeholders (N = 17)	Mental health issues	
Mertens et al ⁶³	US	Delphi	Policy experts/key stakeholders identified by the research team for relevancy to research aim, representing national cancer advocacy organizations, national cancer institutes, medical directors of health maintenance organizations, and health policy experts.	Other key stakeholders (N = 18)	Cancer	

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Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Junge ⁶⁴	Germany	Mixed methods	Surveys sent to general pediatricians who delivered pediatric palliative care in region	Pediatricians (N=293)	Palliative needs	<p>Roles of PCP: "central coordinator in the care of children and adolescents with a life-limiting disease"; providing palliative care; assisting with connecting with resources like homecare, psychological supports for AYA with terminal illness; performing home visits; prescribing narcotics</p> <p>Benefits of PCP: "trusted key person" who accompanies AYA and families over many years; longstanding clinical relationship</p> <p>Barriers to PCP involvement: lack of time/adequate reimbursement for palliative care</p> <p>Benefits of specialist collaboration: collaboration with palliative specialist services supports GPs' ability to manage AYA with terminal illness in primary care</p> <p>Barriers to specialist collaboration: GPs unaware of all available palliative care specialist services</p>
Salt et al ⁶⁵	UK	Mixed methods	Survey sent to all GPs in a primary care trust	Family physicians/GPs (N=106)	ADHD	<p>Barriers to PCP involvement: perceived lack of knowledge, GPs lack education on managing chronic conditions;</p> <p>Barriers to specialist collaboration: lack of collaboration and communication amongst primary and specialty care due to system issues/silos; "uncomplicated" cases of ADHD handed back from specialists to GPs for management with no collaboration</p> <p>Facilitators to specialist collaboration: clear roles (ie, specialist to diagnose ADHD, initiate medications and provide ongoing management, while GP does repeat prescriptions); recommendation that more structured communication protocols be put in place for specialists and PCPs</p>
Holge-Hazelton ⁶⁶	Denmark	Qualitative	Research unit for general practice	Family physicians/GPs (N=10)	Cancer	<p>Roles of PCP: GPs play vital role in palliation; assist with connecting with resources like homecare, psychological supports for AYA with terminal cancer</p> <p>Frequency/timing of PCP contact: GPs feel out of the loop (ie, when patients admitted to hospital); AYA with chronic conditions "disappear" once specialists become involved</p> <p>Barriers to PCP involvement: perceived lack of knowledge, training and education on managing chronic conditions;</p> <p>"When I look at my medical education, I feel that I am very very badly equipped to manage the really heavy cases."</p>

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Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Murphy et al ⁶⁷	Canada	Qualitative	Physicians licensed to practice who had prescribed antipsychotics in the last 2 years	Family physicians/ GPs (n=7) and Psychologists/ Psychiatrists (n=4)	Mental health issues	<p>Roles of PCP: medication management when adequate training provided</p> <p>Frequency/timing of PCP contact: GPs prescribe medications to “tie them over until they can see a psychiatrist or neurologist”</p> <p>Benefits of PCP involvement: clinical decision-making positively impacted by long-standing relationships with AYA and family; “GPs stressed the importance of making judgments based on knowing youth and their families for “years” or over “decades” with the needed “collateral” history. This was advantageous and an asset in making clinical decisions, knowing when to refer, and offering potentially viable options for antipsychotic treatments based on family members’ responses to medications.”</p> <p>Barriers to PCP involvement: perceived lack of knowledge, training and education on managing mental health problems</p> <p>Benefits of specialist collaboration: pharmacists provide useful information about medication interactions; GPs confident in managing medications when specialists available for consultation</p> <p>Barriers to specialist collaboration: Psychiatrists question whether GPs overstepping scope in prescribing anti-psychotics</p> <p>Roles of PCP: GP does not address complex cases in primary care</p> <p>Barriers to PCP involvement: perceived lack of knowledge, training and education on managing complex conditions</p> <p>Barriers to specialist collaboration: lack of collaboration and communication amongst primary and specialty care due to system issues/silos</p> <p>Roles of PCP: providing transition-related support; GP does not address complex cases in primary care</p> <p>Barriers to PCP involvement: perceived lack of knowledge, training and education on managing complex conditions (spina bifida)</p>
da Nobrega ⁶⁸	Brazil	Qualitative	Health Care Network of people with chronic diseases, which aims provide continuous comprehensive care across network regions	Nurse practitioner/PAs, Other primary care physicians, and Other key stakeholders (n=20), and Caregivers (n= 12)	Special health care needs	<p>Roles of PCP: GP does not address complex cases in primary care</p> <p>Barriers to PCP involvement: perceived lack of knowledge, training and education on managing complex conditions</p> <p>Barriers to specialist collaboration: lack of collaboration and communication amongst primary and specialty care due to system issues/silos</p> <p>Roles of PCP: providing transition-related support; GP does not address complex cases in primary care</p> <p>Barriers to PCP involvement: perceived lack of knowledge, training and education on managing complex conditions (spina bifida)</p>
Lindsay et al ⁶⁹	Canada	Qualitative	Pediatric rehabilitation hospital (outpatient clinic) partnered with an adult community health center (transition clinic) Model of care ^b : Transition clinic	AYAs (n=21), Caregivers (n= 11); M=NR, ages 14-21 (43%), ages 19-25 (57%) SD=NR, R= 14-25	Spina bifida	<p>Roles of PCP: providing transition-related support; GP does not address complex cases in primary care</p> <p>Barriers to PCP involvement: perceived lack of knowledge, training and education on managing complex conditions (spina bifida)</p>

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Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Schraeder et al ⁷⁰	Canada	Qualitative	Publicly-funded community children's mental health agencies	AYAs (n = 10), M = 13.1, SD = NR, R = 12-15; Caregivers (n = 10), Psychologists/ Psychiatrists (n = 10), and PCPs (n = 3)	Mental health issues	<p><i>Roles of PCP:</i> medication management (prescribing, counseling); managing mental health problems; supportive counseling; providing referrals to specialists; ongoing mental health screening</p> <p><i>Barriers to PCP involvement:</i> perceived focus on physical issues as opposed to mental health; "band-aid" approach to managing mental health in primary care; limited time in appointments; lack of knowledge, training and education about mental health management</p> <p><i>Frequency/timing of PCP contact:</i> monitoring following specialist mental health services; GPs feel out of the loop when specialists become involved; GPs manage mental health problems until "threshold reached" and more expertise needed</p> <p><i>Benefits of PCP involvement:</i> clinical decision-making positively impacted by long-standing relationships with AYA and family; "trusted key person" who accompanies AYA and families over many years</p> <p><i>Barriers to specialist collaboration:</i> GPs feel like "receivers" of information but are not engaged in mental health management when specialists involved; lack of collaboration</p>

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Table 1. (continued)

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Richardson et al ⁷¹	US	Qualitative	Community-based pediatric practices, solo and group practice types	Pediatricians (n = 32), and Nurse Practitioners/PAs (n = 3)	Depression	<p><i>Roles of PCP:</i> “Coordinator of care”: supportive counseling visits, directing patients to counseling community resources, rarely prescribing medications; “First step in treatment”—starting antidepressants and informal counseling, refer to specialists only when necessary; “Stop-gap measure” for treating depression when long wait times for mental health specialty care exist; GPs feel obligated to diagnose, but not necessarily treat depression; medication management when adequate training provided; specific strategies used to monitor and track prescriptions refills for depressed patients (uniquely colored refill forms, lists of patients)</p> <p><i>Benefits of PCP involvement:</i> clinical decision-making positively impacted by long-standing relationships with AYA and family; GPs who have known AYA since childhood more likely to treat depression</p> <p><i>Frequency/timing of PCP contact:</i> GPs manage mental health problems until “threshold reached” and more expertise needed</p> <p><i>Barriers to PCP involvement:</i> limited time in appointments for addressing mental health; screening for depression not done consistently because it would overwhelm the practice’s limited staff and resources; lack of adequate mental health supports in rural communities; lack of time/adequate reimbursement for managing complex mental health concerns; black-box labels on anti-depressant medications make GPs hesitant to prescribe medications without collaboration with a psychiatrist; when prescribed follow-up schedule unreasonable in primary care</p> <p><i>Barriers to specialist collaboration:</i> lack of collaboration and communication amongst primary and specialty care due to system issues/silos; GPs desire collaboration with psychologists for follow-up of depressed youth, but lack of communication made this strategy for coordinating care questionable; lack of information from mental health specialists regarding treatment termination/progress results in GPs having difficulty assessing treatment & perceptions of poor effectiveness of therapy</p>

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Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Gadomski et al ⁷²	US	Qualitative	Funded, state-level training program focusing on mental health and primary care integration Model of care ^b : "Project Training and Education for the Advancement of Children's Health" (TEACH)	Pediatricians (n = 34), Other primary care physicians (n = 6)	Mental health issues	<p><i>Barriers to PCP involvement:</i> limited time in appointments for addressing mental health</p> <p><i>Facilitators to PCP involvement:</i> training program led by child and adolescent psychiatrists increased GPs' feelings of self-efficacy in diagnosing and treating mental health problems in primary care by educating about systematically assessing mental health issues</p> <p><i>Facilitators to specialist collaboration:</i> training GPs in collaborating with child/adolescent psychiatrists (via advice on referrals, teleconsultations, face-to-face evaluations of patients by specialists) increased GPs' comfort level in prescribing psychotropic medications significantly based on survey data; "free Web site access to screening tools, medication guidelines and patient education materials were seen as increasing efficiency, providing diagnostic direction and facilitating communication with mental health specialists"; training, reference materials, ongoing consultation and referral support appeared to work synergistically in changing practice among trained GPs; established relationships with specialists; having training facilitators as the same specialists available for future consultation increased credibility for GPs and decreased hesitancy in seeking support; ability of GPs to consult with child/adolescent psychiatrists over the phone or face-to-face in managing patients with mental health concerns</p> <p><i>Benefits of specialist collaboration:</i> "Participation in Project TEACH seemed to have taken some PCPs a step toward working in a more integrated manner with the MH system. Some reported assuming the "prescriber" role as part of a treatment team alongside a nonprescribing MH specialist. Better knowledge of MH treatment, especially nonpharmacologic treatments with which they had not been familiar, enabled trained PCPs to make better use of existing services."</p>

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Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Han et al ⁷³	Canada	Qualitative	Inpatient units and subspecialty clinics at a tertiary care pediatric hospital	Caregivers (n = 109) and AYAs (n = 29); M = 16.4, SD = NR, R = 14-18; 16-17 (49%)	Special health care needs	<p><i>Roles of PCP:</i> providing referrals to specialists; AYA with chronic conditions & disabilities/caregivers access GP for primary health issues such as immunizations, cold/flu-like symptoms, injury, referrals, completion of forms; AYAs seek information about condition, mental health and sexual health from both specialist and GP</p> <p><i>Benefits of PCP involvement:</i> presence of GP improves overall health by providing continuity of care; majority of AYA report more comfort with GP than specialists, view GP as medical home; AYA with chronic conditions & disabilities/caregivers report positive communication and trust in GP due to longstanding relationships and sharing the same GP</p> <p><i>Barriers to PCP involvement:</i> perceived lack of knowledge, training and education on managing chronic conditions; AYA/caregivers perceive GPs that for complex patients, health concerns are "above and beyond our family doctor's capabilities"; AYA/caregivers have poor understanding of GP role in coordinating care; AYAs report GP not readily available, difficult to access, so families use walk-in clinics if issue is outside of medical condition</p> <p><i>Facilitators to specialist collaboration:</i> AYA/caregivers perceive good communication between specialist and GP (ie, necessary documents received)</p>
Hassink-Franke et al ⁷⁴	Netherlands	Qualitative	Collaboration between specialists and GPs in management of ADHD Model of care ^b : Collaborative ADHD program	PCPs (N = 15)	ADHD	<p><i>Benefits of PCP involvement:</i> clinical decision-making positively impacted by long-standing relationships with AYA and family; trusted key person who accompanies families over many years knowledge of family helps in identifying which AYA need to be referred to specialists for ADHD diagnostic testing; less stigmatizing to see GP than psychiatrist; GP closer to home than specialists</p> <p><i>Barriers to PCP involvement:</i> perceived lack of knowledge, training and education on managing chronic conditions; lack of time for psychoeducation regarding ADHD in primary care; lack of comfort in diagnosing mental health problems due to limited knowledge</p> <p><i>Benefits of specialist collaboration:</i> ability of GPs to consult with psychiatrists regarding the management of uncomplicated ADHD (ie, doses, side effects of medications or switching to new medications) very beneficial</p> <p><i>Facilitators to specialist collaboration:</i> clear roles (ie, psychiatrists diagnose ADHD and provide psychoeducation, GP does medication management in primary care)</p>

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Table 1. (continued)

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Duffey-Lind et al ⁷⁵	US	Qualitative	Primary and community care setting	AYAs (n = 18), Caregivers (n = 7), and Pediatricians (n = 3); Median = 24.5, SD = NR, R = 16-54; 16-17 (22%), 20-54 (78%)	Cancer	Roles of GP/FP: AYA seek GP support for "simple things and mild symptoms"; post-cancer treatment but see specialists for "serious problems" Barriers to PCP involvement: perceived lack of knowledge, training and education on managing chronic conditions; lack of time/adequate reimbursement to treat after-effects of cancer in thorough manner Benefits of specialist collaboration: collaboration with palliative specialist services supports GPs' ability to manage AYA with cancer in primary care Facilitators to specialist collaboration: hospital discharge summaries, written document and clinic notes from hospital/oncologist helpful in managing post-cancer patients in primary care; written guide for managing after-effects, ongoing needs and risks of cancer survivors requested by GPs from oncologists Barriers to specialist collaboration: no summary of cancer treatment available to GPs from oncologist; difficult for GPs to access specific information regarding cancer status/treatment options from specialist (therefore, the AYA has to act as their own "conduit")
Vaz et al ⁷⁶	Brazil	Qualitative	Family health units	Other key stakeholders (n = 11), Nurse Practitioners/PAs (n = 11), and Pediatricians (n = 4)	Special health care needs	Barriers to PCP involvement: perceived lack of knowledge, training and education on managing chronic conditions Barriers to specialist collaboration: lack of specialists to manage youth with special health care needs; lack of clarity surrounding GP role in management (ie, specific counter-referral from specialist back to GP is needed to articulate what the specialist has done to avoid repeat procedures, but this is often missing); lack of electronic reporting system so that all team members have access to same information; difficult to access information about GP management of youth with special health care needs following care by specialist
Asarnow et al ⁷⁷ ; Rapp et al ⁷⁸	US	RCT	5 healthcare organizations including public sector, managed care, and academic health programs. Model of care ^b : "Youth Partners in Care"	AYAs (N = 418); M = 17.2, SD = 2.1, R = 13-21	Depression	Benefits of specialist collaboration: Increase in AYA treatment engagement, clinically significant improvement in depression symptoms; greater AYA satisfaction with MH care

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Table 1. (continued)

Authors	Country	Type of study	Clinical setting/context	Target population ^a	Primary diagnosis	Relevant study findings
Patterson et al ⁷⁹	AUS	Survey study	Continuous national survey	Family physicians/GPs (N = 9721)	Cancer	<p>% transferred pediatric care to PCP: 29% “new” to PCP</p> <p>Unique characteristics of AYAs followed by PCP: AYAs aged 25-29 years significantly higher cancer management rate by PCP than younger AYAs (10-24 years).</p> <p>Roles of PCP: using nonpharmacological treatments (30.7% of AYA cancers managed at GP encounters)—mainly counseling, advice, or education about the cancer and its treatment, and excisions for biopsy; making referrals to specialists (29.7%; eg, gynecologists, dermatologists, oncologists); prescribing medications (only 16.0% of visits)</p>

Abbreviations: ADHD, attention deficit-hyperactivity disorder; ASD, autism spectrum disorder; AUS, Australia; M, mean; PCPs, primary care physicians; R, range; RCT, randomized controlled trial; SD, standard deviation; UK, United Kingdom; US, United States.

Family physicians/GPs included “family physicians,” “general practitioners,” “general practitioners with additional psychiatric training,” and “family medicine practitioners.” Pediatricians also included “consultant community pediatricians,” “general and hospital-based pediatricians,” “primary care pediatricians,” “pediatric primary care physicians,” “Nurse Practitioners and Physician Assistants (PAs) also included “advanced practice providers,” “family nurse practitioners,” “nurses,” “pediatric nurse practitioners.” Other PCPs included “general internists” and “doctors of osteopathy.” Other key stakeholders included “diabetes educators,” “health district managers/directors,” “health managers,” “medical directors of health maintenance organizations,” “directors of state or national cancer advocacy organization,” “representatives from the National Cancer Institute,” “representatives from the National Cancer Policy Board,” “national congress members,” “health policy experts,” “occupational therapists,” “social workers,” “community youth workers,” “CEO of community project,” and “youth mental health advocate.”

Caregivers also included parents and other family members. Psychologists/psychiatrists also included “mental health providers,” “psychotherapists,” and “family therapists.”

^aAYA mean age in years at enrollment, if applicable.

*Models of care are defined in detail in Table 4.

higher PCP visit rates (ie, 7-10 visits/year).^{23,24} Most studies reported AYAs visiting a PCP at least once a year; however, observation windows varied across studies and none reported annual visit rates during the entire transition period (ages 12-25). The longest observation window (16 years) was reported in 1 longitudinal study⁴⁴ of children with congenital heart disease, followed from age 6 to 22; these children were more likely to visit their PCP than their cardiologist over time and their frequency of specialist visits decreased as they became older. Finally, characteristics of AYAs more likely to be seen by a PCP during the transition period included: being female,²⁴ non-Black,³³ older,^{24,79} and greater disease severity/complexity (eg, greater number of cancer relapses,²⁴ increased pain severity,⁵¹ mental health comorbidity).³⁴

Transfer or discharge from pediatric services: Five intervention studies^{28-30,38,39} reported rate of transfer to a PCP among AYAs discharged from pediatric services. Most of these studies examined transfer from a specialized pediatric mental health service (eg, early psychosis program²⁹; collaborative child psychiatric consultation model).^{28,39} The rate of transfer to a PCP in these studies varied based on diagnosis: 24% of those in an early psychosis program,²⁹ 49% with ADHD, 28% with anxiety, and 6% with depression.²⁸ If AYAs were not discharged to a PCP, they either remained in pediatric services or were transferred to specialized adult mental health services.^{28,29} Only 1 study²⁹ outlined specific criteria for AYAs most appropriate for follow-up in primary care: stable (ie, no hospital admissions or emergency services in the last year of treatment), not receiving case management services, and only receiving maintenance (or no) pharmacotherapy. Two studies examined rates of transfer to a PCP from a chronic physical health condition program (Turner syndrome³⁸; diabetes).³⁰ In the diabetes cohort, 20% transferred to a PCP, 38% to a specialized outpatient unit, and 41% to an adult diabetes center.³⁰ About 90% of AYAs in the Turner syndrome cohort reported having seen their PCP in follow-up; however, one third indicated their PCP was not aware of their Turner syndrome diagnosis.³⁸ One study uniquely described a Transition Medical Clinic (TMC)²⁷ designed specifically to support AYAs with special healthcare needs transitioning to adult care, including primary care. The authors noted the complex nature of AYAs accepted into the clinic made it “impossible to find adult community providers who had the necessary time, training, and resources” (p. 5).³³ As such, the TMC stood as the most suitable “medical home” for patients (up to age 54) who continued to receive care from pediatric providers.²⁷

Benefits and Challenges to PCP Involvement and Care Collaboration During Transition

The most commonly cited benefit of PCP involvement during the transition period was the positive impact of

long-standing relationships between PCPs and AYAs (and family members) on clinical decision-making.^{64,67,70,71,73,74} This finding was evident across qualitative and mixed methods studies exploring the perspectives of AYAs/caregivers, specialists, and PCPs using interviews, focus groups, and surveys. One study,⁶⁷ described the advantages PCPs have in understanding a young person’s needs and the “*collateral history*” based on their in-depth knowledge of the family. This relationship was reported by psychiatrists and PCPs themselves as advantageous in making decisions about when to refer an AYA for mental health services and which medications to prescribe based on other family members’ responses to medications.⁶⁷ PCPs were often described as trusted members of the health care team^{64,70,74}; 1 study highlighted that PCPs felt they were less stigmatizing for AYAs to see than specialists (ie, psychiatrists).⁷⁴ Another found AYAs with lifespan-oriented providers (eg, FPs) were more likely to have discussions about adult health needs and adult health insurance compared to AYAs followed solely by child-only providers.⁴⁸

The most common barriers associated with PCP involvement for AYAs with chronic conditions included a perceived lack of knowledge by PCPs about chronic conditions and complex mental health conditions, and a lack of training and education in managing AYAs with complex and chronic conditions, which was identified in 12 articles spanning the perspectives of AYAs/caregivers, specialists, and PCPs themselves.^{61,63,65-70,73-76} Another barrier to PCP involvement for this group was the lack of time to address complex mental health issues during appointments,^{70-72,74} and inadequate reimbursement for time-intensive responsibilities like providing palliative care or managing complex mental health diagnoses.^{70,71,75}

Thirty studies reported on perceived benefits and/or challenges of primary-specialty care collaboration and are summarized in Table 2. Ten qualitative studies, summarized in Table 3, reported on perceived barriers in the management of AYAs with chronic conditions.

Shared Care Models of Primary and Specialist Care

Thirteen studies^{25-28,32,35,39,52,57,69,72,74,77,78} evaluated a shared care model involving some form of collaboration between PCPs and specialists for certain conditions; model summaries are provided in Table 4. Overall, there was a strong preference among PCPs for consultation or shared-care models.^{35,45,49} Participating PCPs reported this improved their ability to support AYAs with chronic conditions in primary care settings.³⁷ In 2 studies involving AYA cancer survivors,^{25,35} a shared-care model substantially increased the number of AYAs followed by a PCP post-intervention compared to a control group receiving usual care. For shared-care models specifically targeting AYAs with mental health issues, participating PCPs reported consultations

Table 2. Studies (N=30; 13 Quantitative and 17 Qualitative or Multi-Methods) Reporting on Perceived Benefits and/or Challenges of Primary-Specialty Care Collaboration for Transition-Age AYAs.

Benefits of collaboration	Article(s)
Improved capacity of PCPs to provide palliative care to terminal AYA	Jünger et al, ⁶⁴ Duffey-Lind et al, ⁷⁵ Kaal et al ³⁷
Improved quality of and access to care	Hassink-Franke et al, ⁷⁴ Malas et al, ⁵² Feyissa et al ²⁶
Better knowledge of mental health treatment (including medication options) amongst PCPs	Murphy et al, ⁶⁷ Gadomski et al, ⁷² Malas et al ⁵²
Better integration between primary care and specialist mental health services	Gadomski et al, ⁷² Malas et al ⁵²
Facilitators to collaboration	
Training/guidelines for PCPs on managing complex patients in primary care and communicating with specialists	Duffey-Lind et al, ⁷⁵ Mertens et al, ⁶³ Gadomski et al, ⁷² Feyissa et al, ²⁶ Schaffalitzky et al ⁶²
Good communication channels (eg, shared medical records, faxed written notes) in place for the exchange of written/verbal information about patients	Han et al, ⁷³ Duffey-Lind et al, ⁷⁵ Salt et al ⁶⁵
Establishment of clear roles for PCPs and specialists in the management of patients (ie, psychiatrists diagnose ADHD and provide psychoeducation, PCP does medication management in primary care)	Hassink-Franke et al, ⁷⁴ Salt et al ⁶⁵
Use of telehealth/telepsychiatry for consultations between GPs and specialists	Malas et al ⁵²

Table 3. Studies (N= 10, All Qualitative) Reporting on Perceived Barriers to in the Management of AYA With Chronic Conditions.

Barriers to collaboration	Article(s)
Lack of collaboration/communication due to system-level issues and “silos” (eg, no summary of treatment available to PCPs following oncologist involvement; no procedure for communication about the needs of depressed youth being followed by psychologist and PCP; lack of counter-referral information from specialist back to PCP to avoid repeat procedures)	Schraeder et al, ⁷⁰ Nóbrega et al, ⁶⁸ Richardson et al, ⁷¹ Kaal et al, ³⁷ Mertens et al, ⁶³ Salt et al ⁶⁵
PCPs experiencing difficulties accessing medical information/reports for patients being cared for by specialists	Richardson et al, ⁷¹ Duffey-Lind et al, ⁷⁵ Mertens et al, ⁶³ Vaz et al, ⁷⁶ Nathan et al ⁴⁹
Lack of clarity surrounding PCP role and scope in the management of complex patients	Murphy et al, ⁶⁷ Vaz et al ⁷⁶
Lack of an integrated electronic reporting system for all providers involved in a patient’s care	Vaz et al ⁷⁶
Lack of remuneration or adequate reimbursement	Okumura et al, ⁵⁹ Okumura et al ⁶⁰
Dissatisfaction among PCPs with communication with mental health specialists and lack of access to psychiatrists for referrals and/or consultation was common	Davis et al, ⁴⁵ Campbell et al ⁴⁶
PCPs were generally described as “out of the loop” once specialists became involved in the management of AYA with complex conditions was identified in three studies	Hølge-Hazelton and Christensen, ⁶⁶ Schraeder et al, ⁷⁰ Kaal et al ³⁷

with mental health specialists helped them to better meet the mental health needs of AYAs and improved their skills in mental health care.³⁹

Conclusion

This scoping review sought to identify and synthesize available evidence about the involvement of PCPs during transitional care, the potential outcomes of continuous primary care, and the benefits and/or barriers of PCP involvement for AYAs with chronic conditions involved with specialist

services. The roles identified to be the shared or sole responsibility of PCPs were managing medications, attending to mild to moderate mental health issues, making referrals to specialists, care coordination, and general health concerns. PCPs involvement was typically reported at diagnosis, or at discharge from specialty services. Frequency of PCP involvement was more often reported through quantitative studies, and varied greatly by condition; however, PCP involvement did appear more likely for female, non-Black, older AYAs, and those with greater disease severity/complexity.

Table 4. Descriptions of Shared Models of Care Presented in Included Studies (n= 14).

Authors	Type of model of care	Detailed description of model
Berens and Peacock ²⁷	Specialized Transition Clinic	A continuous and well-coordinated medical home in the adult-oriented healthcare (equivalent to specialized pediatric clinic) for complex patients (eg, high ER users, low transition readiness, complex/on-going conditions, technology dependence, intellectually disabled) unable to use or graduate to community-based care/services. Service providers included internal medicine residents, physician trained in internal medicine and pediatrics, social workers, and nurses.
Aupont et al ²⁸	Targeted Child Psychiatric Services	Primary care providers (ie, primary care physicians and nurse practitioners) and psychiatrists and child psychiatric nurse practitioner were connected through telephone consultation, referral/access to specialist services for evaluation and written treatment plans, and then transition back into primary care for management/long-term care. Consultation was same day and lasted up to 2h.
Costell ³²	Shared care cancer survivorship telemedicine model (telemedicine shared transition visit)	AYAs who were at least 18years old and 10 or more years post-cancer treatment were asked to schedule an office visit with their PCP. Collaborative partnership developed between AYA's survivorship team (eg, pediatric oncology team), the PCP, and the survivor, using telemedicine. A one-time "transition visit" involved PCP completing a standard history and physical and a virtual portion (via telemedicine) conducted by a provider from the survivorship team. This involved a review of the individual's treatment summary, oncology treatment details, potential late effects of treatment, screening, and surveillance recommendations.
Lindsay et al ⁶⁹	Inter-agency spina bifida transition clinic	Collaborative partnership developed between a pediatric rehabilitation hospital and an adult community health center to provide continuous, client-centered care to AYAs with spina bifida (14-25 years). At the pediatric rehabilitation hospital, transition team members including an adolescent medicine specialist, transition-focused nurse practitioner, transition-focused life skills coach were integrated into the spina bifida outpatient clinic. Transition supports included health education, checklist, readiness assessments, promoting independence, self-care, life-skills and self-advocacy. Supports continues from 18years till 25 years.
Malas et al ⁵²	Collaborative Care Program	Multi-level telepsychiatry consultation service connecting primary care providers (ie, nurse practitioners, physician assistants, MDs, doctors of osteopathic medicine) with mental health specialists for support. Behavioral Health Consultants (BHC) could provide referrals, brief in-person consultation, evaluation, and non-pharmacological treatment; child and adolescent psychiatrists (CAP) could phone consult; video consultation for patients and their caregivers was available; group consults involving many primary care providers seeking help facilitated/ lead by BHC or CAP; some in-person or embedded CAP consultation; and partnership with community resources and organizations for any additional unmet needs.
Kinahan et al ³⁵	Shared care follow-up model	Primary care providers (eg, GP) and oncologists communicated with electronic medical records and up-to-date clinical notes. Oncologists were responsible for cancer treatment, informing primary care physician, making plan and recommendations for long-term cancer survivorship care, transition support to primary care, being available for consults or referrals. Primary care providers roles were to manage physical and mental health post-cancer treatment, treat/manage some aspects of chronic condition within primary care knowledge and resources, refer and consult when aspects of chronic condition are out of primary care scope.

(continued)

Table 4. (continued)

Authors	Type of model of care	Detailed description of model
Asarnow et al ⁷⁷ ; Rapp et al ⁷⁸	Collaborative integrated care model	Mental health specialists (ie, psychotherapists, social workers, persons with masters or PhD degrees in mental health field) delivered treatment and assisted primary care providers in patient evaluation, education, treatment initiation, follow-up care, and referral during 6-month intervention period.
Gadomski et al ⁷²	Project Training and Education for the Advancement of Children's Health (TEACH)	State program promoting PCP-mental health integration. Child and adolescent psychiatrists provided: 3 h evening or weekend long courses to train PCPs on mental health, telephone consultation about specific cases (either twice monthly for 6 months or every weekday within a 90 min window), advice on referrals and face-to-face evaluations when no other mental health resources available to PCPs.
Hassink-Franke et al ⁷⁴	Collaborative ADHD program	Care roles were divided between specialists and GPs. ADHD was diagnosed by specialists in secondary or tertiary care, while GPs prescribed medications and monitored symptoms following a 1-h ADHD training course. For uncomplicated ADHD, collaboration was no on-going post-diagnosis and referral back to GP.
Ducassou et al ²⁵	Shared-care follow-up model	GPs received personalized survivorship care plan and a written medical history report from pediatric oncology/cancer centers.
Fallucco et al ³⁹	Child Psychiatry Consultation Model	PCPs had access to psychiatrists during reserved consultative time slots, triage forms, a referral coordinator, and specialized mental health training/workshops. PCPs and psychiatrists communicated via phone and mail/email.
Pidano et al ⁵⁷	Partnered practices	Partnership between pediatric primary care and mental health services to ensure availability of ongoing communication and consultation between providers for mental health issues.
Feyissa et al ²⁶	Co-management care model for concussion	Subspecialists (ie, psychiatrists, nephrologists, endocrinologists) and pediatric primary care providers used toolkits including patient screening and assessment, and caregiver education, and provider communication materials, designed by both provider type, for more common and lower-acuity conditions (eg, concussion, migraines) were used by primary care providers.

Early PCP involvement among AYAs may facilitate improved uptake of adult-oriented services, increased knowledge and education for the PCP regarding childhood-onset conditions, and ensure continuous care during transition, a period often marked by changes or “hand-offs” between providers and services. In some cases, AYAs with mild to moderate chronic conditions (eg, asthma) may receive all their care within primary care or the “medical home”⁸⁰⁻⁸²; yet, research shows PCPs often refer to specialist care for AYAs with chronic conditions.⁸³ Another study reported that physicians prefer co-management of referred AYAs in more than 2 out of 3 cases.⁸⁴ Our review found benefits to shared care models, such as improving the ability of PCPs to provide support to AYAs and increasing retention and follow-up; therefore, facilitating integrated or shared care models may be 1 target of further research or a solution to overcoming multiple barriers to providing optimal transitional care.

Resources including time, money, and access were also reported as barriers. Strategies for overcoming these

barriers will be context- and health jurisdiction-specific, requiring the cooperation of clinicians and policy makers. Lack of adequate reimbursement or financial incentives for the extra time required to provide care coordination with multiple services is a modifiable barrier, and reform can be informed by examples of integration of chronic disease diagnostic/billing codes in adult care. Access to care can be improved further by embracing virtual technologies, including smartphone-delivered interventions⁸⁵ and e-mental health service delivery,⁸⁶ both of which have been found to be acceptable, feasible, and safe by AYA. Adoption of these approaches also serves to promote more accessible digital communication, favored by youth in transition.

Limitations

We excluded articles that did not focus on AYAs (ages 12-25), which may have limited our understanding of beneficial PCP practices for follow-up and management during early childhood or adulthood. We excluded studies

which examined the impact of specialized training for PCPs, as the focus of this review was to understand current practices. Studies examining the effectiveness of curricula for integrated care practices warrants further investigation, especially how this training influences practice.⁸⁷⁻⁸⁹ Of note, we did not identify any studies focused on AYAs with HIV or sexually transmitted diseases that met inclusion criteria for this review. These groups warrant further investigation for transitional care and supports given their age of onset often overlaps with the transition period. While we reported on the country and clinical context of the studies included in this review, we recognize that transitional interventions in lower income countries must be considered within these contexts. Few of the included studies offered exhaustive sociodemographic information about AYA race/ethnicity, income, sexual orientation, and/or gender identity, thus potentially impacting the generalizability of our findings to some groups such as LGBTQ2S+ AYA.

Conclusions

We summarized the evidence on PCP involvement for AYAs transitioning from pediatric to adult care. PCP roles included medication management, non-complex mental health referrals, care coordination, and general health care. Frequency of PCP involvement varied greatly across chronic conditions. Long-term, trusting relationships with AYAs and families was an important facilitator of PCP involvement, and this aspect can be strengthened with early engagement of PCPs in AYAs' care, and continued collaboration with specialists when medical management becomes more complex.

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Author Contributions

Dr. Schraeder and Ms. Allemang contributed substantially to study conception and design, data acquisition, data analysis, data interpretation, drafting and revising the manuscript. Ms. Felske contributed substantially to data acquisition, data analysis, data interpretation, drafting and revising the manuscript. Drs. Scott, McBrien, Dimitropoulos, and Samuel contributed substantially to study conception and design, data acquisition, supported/supervised data interpretation and substantially contributed to manuscript revisions. All authors approved the final manuscript and agreed to act as guarantor of the work.

Data Sharing Statement

All data presented in this scoping review was obtained from available published articles.

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Supplemental Material

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