
Qualitative Research

Strategies for improving primary care for adolescents and young adults transitioning from pediatric services: perspectives of Canadian primary health care professionals

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Abstract

Background: Family physicians and other members of the primary health care (PHC) team may be ideally positioned to provide transition care to adolescents and young adults (AYAs; aged 12–25 years) exiting pediatric specialty services. Potential solutions to well-known challenges associated with integrating PHC and specialty care need to be explored.

Objective: To identify strategies to transition care by PHC professionals for AYAs with chronic conditions transitioning from pediatric to adult-oriented care.

Methods: Participants were recruited from six Primary Care Networks in Calgary, Alberta. A total of 18 semi-structured individual interviews were completed, and transcribed verbatim. Data were analyzed using a qualitative description approach, involving thematic analysis.

Results: Participants offered a range of strategies for supporting AYAs with chronic conditions. Our analysis resulted in three overarching themes: (i) educating AYAs, families, and providers about the critical role of primary care; (ii) adapting existing primary care supports for AYAs and (iii) designing new tools or primary care practices for transition care.

Conclusions: Ongoing and continuous primary care is important for AYAs involved with specialty pediatric services. Participants highlighted a need to educate AYAs, families and providers about the critical role of PHC. Solutions to improve collaboration between PHC and pediatric specialist providers would benefit from additional perspectives from providers, AYAs and families. These findings will inform the development of a primary care-based intervention to improve transitional care.

Key words: Adolescent, chronic disease, family physicians, pediatrics, primary health care, transition to adult care

Introduction

Transitioning to adult care is the planned and purposeful process of preparing adolescents and young adults (AYAs; ages 12–25) for adult-oriented care (1,2). This process involves a transfer in care, or

the eventual ‘hand-off’, from pediatric to adult-oriented providers at age 18 (the age of transfer though this varies across jurisdictions). During transition, an adolescent’s care may be transferred to a family physician (FP) and/or adult specialist. Published transition guidelines

Key Messages

- Primary health care (PHC) may support youth exiting pediatric specialty care.
- Perspectives from PHC on how to improve transition care for youth is lacking.
- Educating youth about PHC and the need for continuous care is recommended.
- Adapting existing PHC supports (e.g. flexible appointments) for youth is suggested.
- PHC may benefit from health summaries from pediatric specialists at transfer.
- Input from youth is needed to inform PHC component of transition interventions.

for specific diseases (3–5), and across countries (including Canada (6), United States (7–9), United Kingdom (10) and Australia (11)), recommend starting this process well before age 18 (e.g. 12 years old) (6). In Canada, some pediatric hospitals offer ‘transition planning’ documents to support AYAs, families, and clinicians (12,13), though evidence on uptake and effectiveness of these resources is lacking. Ideally, transition planning addresses AYAs’ physical, developmental, educational, and psychosocial needs (e.g. self-management skills, vocational needs) and is developed in collaboration with AYAs and their caregivers, specialists and FP (1,6,14). However, research suggests AYAs and caregivers view their FP as ‘*out of the loop*’, or not regularly involved in their specialist care (15,16).

Recent evidence suggests AYAs’ continuous involvement with the same FP (pre post-transfer) is associated with better outcomes in young adulthood (i.e. fewer emergency department visits and hospitalizations) (17,18); however, the proportion of AYAs seen by FPs before exiting pediatric care varies across studies (39–97%) (18–22). FPs frequently report poor communication with pediatric specialists and mental health (MH) professionals, and inadequate remuneration for supporting AYAs with complex issues in primary care (23–25). Few transition interventions include a primary care component (26–29), despite potential benefits of involving FPs during transition (25,30). Practical strategies for effectively including FPs during the transition process, or bringing them *into the loop*, need to be further explored. To the best of our knowledge, no studies have conducted interviews with FPs about the topic of transitioning adolescents from pediatric services. Thus, the purpose of our study was to gain perspectives from FPs and other PHC team members about solutions to common challenges associated with transitional care.

Methods

Study design and setting

We used a qualitative description design as it focuses on describing and exploring a topic of interest (31,32). Participants were recruited within Calgary, Alberta (Canada) where nearly all primary care is delivered by FPs in Primary Care Networks (PCNs) (33,34). There are 42 PCNs in Alberta, with ~3,800 FPs and 1000 other healthcare professionals (e.g. social workers, nurses), who are typically employed by a single PCN and rotate among physician practices to provide services (35). PCNs enable the ‘medical home’ vision, providing patients with a central place to access continuous, coordinated, comprehensive and family-centered primary care; details about the ‘medical home’ and Alberta’s model are described online (34) and by the College of Family Physicians of Canada (33). This study was approved by the University of Calgary’s Conjoint Health Research Ethics Board (REB17-2397) and followed the Consolidated Criteria for Reporting Qualitative Studies (see [Supplementary material](#)).

Data collection and analyses

Eligible participants were English-speaking PHC providers with experience caring for AYAs with chronic conditions (Table 1) (25).

Purposeful sampling was used, and snowball sampling techniques (36) allowed for additional recruitment of PHC professionals (e.g. colleagues of participants) with relevant experiences, diverse training backgrounds and practice locations. Interested participants emailed the research team, or were introduced by other participants, and signed a consent form prior to their interview.

Semi-structured interviews were conducted in-person or by telephone with participants (by KS). Interviews were audio-recorded, transcribed verbatim, and identifying participant information was removed. Data collection and analysis occurred simultaneously and iteratively; analytic details are published elsewhere (25). Authors read transcripts separately and together. Two authors (KS and BA) developed an initial coding template, which was modified and refined based on regular discussions within the research team. Our team met regularly to discuss the data from our diverse professional lenses (i.e. pediatrics, MH, social work and PHC). Data collection was discontinued when it was agreed within our team that the data obtained from participants was sufficient to answer our research question (37).

Rigor and validity were maximized in several ways. Our interview guide (available as [Supplementary material](#)) incorporated feedback from content experts in pediatric transition research and PHC, and from key stakeholders (e.g. Alberta’s Primary Health Care Integration Network). We sampled participants in various PHC roles to gain a comprehensive understanding of potential solutions to improve transitional care. Our analysis was enhanced by triangulation techniques (38), such as comparing interpretations between experts in our team and presenting initial findings to stakeholder groups to verify the accuracy of interpretations.

Findings

About 18 participants were interviewed, 10 FPs and 8 PHC team members [nurse (n) = 3, social worker (SW) = 3, mental health (MH) clinician = 1, dietician (D) = 1]. Of 32 individuals who expressed interest in participating, two were not PHC providers (not eligible) and 12 did not respond or could not be scheduled. Participants represented six PCNs; most FPs were remunerated by a fee-for-service model (Tables 1 and 2). Participants’ ideas for improving transitional care for AYAs are summarized under three themes as given below (Figure 1) and additional quotes provided in Table 3.

Theme 1: Educating AYAs, families, and providers about the role of PHC

Participants expressed that AYAs and families need to know who their FP is before they exit pediatric services and the important role FPs play in their healthcare team. Participants noted families receiving pediatric services often view their pediatric specialist as the primary ‘*doctor*’: ‘My [AYA] patients think their specialist is “the doctor”. [They say] I have a doctor, and it’s my rheumatologist’ (FP11). Participants believed families could be better informed about the importance of continuous primary care. The benefits of

Table 1. Characteristics of sample of primary health care professionals (N = 18) from data collected between June and October 2018

Characteristics	% (n)
Sex	
Female	83.3% (n = 15)
Age	
<30–39	55.6% (n = 10)
40–49	16.7% (n = 3)
>49	27.8% (n = 5)
Professional role	
FP	55.6% (n = 10)
Nurse/Nurse practitioner	16.7% (n = 3)
Social worker	16.7% (n = 3)
Dietician	5.6% (n = 1)
MH clinician	5.6% (n = 1)
PCN affiliation	
Mosaic	22.2% (n = 4)
South Calgary	22.2% (n = 4)
Calgary West Central	22.2% (n = 4)
Calgary Foothills	16.7% (n = 3)
Rural and Highland	16.7% (n = 3)
Years of professional experience	
<5	22.2% (n = 4)
5 to <10	27.8% (n = 5)
>10	50.0% (n = 9)
Participants' primary patient population	
Adults (>18)	22.2% (n = 4)
Children/adolescents (<18)	16.7% (n = 3)
Both	61.1% (n = 11)
Number of AYAs seen with chronic conditions in practice	
<10	27.8% (n = 5)
10–15	16.7% (n = 3)
>15	55.6% (n = 10)
Method of AYA entrance into participants' care ^a	
Transferred/referred from pediatric specialist(s)	50.0% (n = 9)
Transferred/referred from adult specialist(s)	22.2% (n = 4)
Patient self-referred	27.8% (n = 5)
Since birth or childhood	33.3% (n = 6)
Transferred from other FP	22.2% (n = 4)
Practice location	
Suburban	55.6% (n = 10)
Inner city	27.8% (n = 5)
Rural	16.7% (n = 3)

^aParticipants indicated receiving AYAs from multiple referral sources, so percentage of cases for method of entrance into care, sum to be >100%.

maintaining 'the relationship' between FPs and AYAs, not just for 'the routine stuff' (e.g. immunizations, physical exams), was emphasized: 'I say to mother, "it's really important we stay in touch... [AYA]'s not gonna be with pediatric endocrinologist forever. It's important because the relationship [AYA] has with me is really important. If we leave it for 5 years, re-connecting at age 16–17 is a lot harder"' (FP11). If AYAs are transferring to a new FP, participants urged 'a bit of lead time' to develop a relationship with AYAs and educate families about the roles of FPs for AYAs with chronic conditions. PHC team members echoed the need for FP involvement to facilitate referrals and monitor symptoms: 'If I need to refer to specialized services, [AYAs] need a family doc to make that referral... It's for safety, continuity of care, and making sure they're able to be monitored long-term' (SW14).

Advertising within clinics (e.g. newsletters, websites) about available resources was also perceived as potentially beneficial for

families: 'Patients need to know about our programs... Advertising on social media, [or] physician's offices... why aren't we just blitzing this?' (SW12). Other strategies to educate AYAs and families about the role of PHC were perceived as not feasible given current funding structures, but still important. For example, some participants believed 'shared visits' (with FPs, AYAs, and specialists) could facilitate uptake of PHC: 'Then [AYAs] know [I'm] a trusted, safe person. It would give me a chance to show them...I'm here, I'm ready to care for you. I bet that would increase the rate of [AYAs] who actually show up to their [PHC] appointments' (N15).

Finally, educating about PHC roles and resources applied to FPs themselves. Some FPs believed formal education (e.g. residency placements, continuing education credits) or 'some exposure' to AYAs with common chronic conditions during their training would be beneficial. One participant offered the solution of 'mentor-mentee relationships', or identifying PHC 'champions' with AYA expertise to mentor FPs on supporting this population in their practice. Many FPs were not clear about PHC professionals or services available in their network to support AYAs with chronic conditions, and some were reluctant to refer to services unknown to them:

If a resource is there and we don't know what it is, what they provide, and how they do it, [then] we're not going to access it (FP21).

SW and N participants shared FPs' view that a better understanding of their scope of practice could facilitate appropriate referrals:

Physicians' understanding [of] what a SW does is still an uphill battle. Every [PCN physician] can refer to me... [But], Monday Tuesday, Saturday, I have no patients, not one. So, what's going on? What's the gap? (SW12).

To increase FPs' awareness of available supports and professionals in their network, some participants also suggested holding 'meet-and-greets' with AYA-focused providers in PCNs. In summary, educating AYAs, families and providers about the roles of FPs and local services available was viewed as an opportunity for enhancing the visibility and value of PHC for supporting AYAs.

Theme 2: Adapting existing primary care supports for AYAs

Participants generally felt PHC supports were designed for older adults with chronic conditions, and not for younger people:

In my opinion, [PHC] is set up to care for the elderly, rather than [for] teenagers... The perception then is "this is for old people", not for my age group. If [FPs] can understand teenagers, and make them feel comfortable, I think that would go a long way in improving their care (FP21).

All participants expressed concerns about the appropriateness of existing primary care-based-MH services for AYAs, described as 'all on adult side' and 'very time-limited' (4–6 sessions). One of the SW participant noted the constraints of 'brief' counselling models for establishing a therapeutic relationship with AYAs, but noted

it's not that [a brief] model never works for families or adolescents—it's not that black-and-white (SW20).

Participants offered strategies to adapt PHC for this AYAs: providing 'convenient' appointment times (e.g. outside of school hours), longer appointments (e.g. to build rapport, assess complex issues) and involving family members as appropriate. Participants recommended existing supports be 'flexible' to address the unique clinical

and developmental needs of AYAs and families. Rather than ‘*trying to reinvent the wheel*’, or create new services for AYAs in primary care, participants suggested ‘*liaising with [community] programs that already exist*’. Leveraging existing resources to improve PHC for AYAs was deemed feasible depending on the services available within communities.

Some participants described working in PHC settings tailored specifically to AYAs with chronic conditions, where all PHC team

members worked ‘*under one roof*’ and services (e.g. MH counseling, pharmacy) were co-located. These participants perceived a co-location model as ideal for AYAs with chronic conditions because it facilitates a team-based approach to transitional care, and ‘*makes it a lot easier in terms of appointment attendance and cohesiveness*’ (D1). Some participants described ‘*specialty [PHC] clinics*’ in their community (e.g. maternal health), and wondered if specialized ‘*transition clinics*’ could ‘*serve as hubs to centralize and mobilize [chronic care] services*’ for AYAs. Others expressed concerns about relying on these models, which may ‘*come and go...may not be reliable, because PCNs are based on government funding*’ (FP2). Overall, participants expressed a need for consistent government funding to support flexible practice models for AYAs.

Table 2. Unique characteristics of participant sample ($n = 18$) from interview data collected between June and October 2018^a

Unique characteristics	% (n)
Remuneration model	
Fee-for-service	8 (44.4%)
Salary	10 (55.6%) ^b
Leadership or management position (e.g. medical team lead)	3 (16.7%)
Expertise working with marginalized AYA populations	
Mental health	15 (83.3%)
Problematic substance use	4 (22.2%)
Homelessness	1 (5.6%)
Belongs to more than one PCN, or works in multiple clinics	5 (27.8%)
Employed in a “unique role” for AYA (e.g. pediatric case manager)	4 (22.2%)
Offers after-school-hours (for appointments, phone calls, etc.)	5 (27.8%)
Co-manages care with pediatricians	7 (38.9%)
Works in clinic with umbrella model/offers multiple services	9 (50%)

^aInformation was spontaneously provided by participants during interviews.

^bAll of the eight primary health care team members (e.g. nurses and social workers) were in salaried positions; this included two FPs in salaried positions.

Theme 3: Developing new tools or practices to improve transition care coordination

Participants described a lack of information-sharing between FPs and specialists during transition, leading to ‘*problems with the hand-over process*’. At transfer, participants expressed needing a ‘*very solid discharge plan*’ from specialists:

We need some direction as to what [specialists] want us to monitor. Once we have that, we’re happy to manage, no matter how complex or challenging the mental health or physical need is (FP21).

One idea to improve care coordination at transfer was to develop a ‘*transition summary*’, with a clear PHC component, and include: (i) a brief summary of specialist pediatric involvement (what AYAs received), and (ii) specific recommendations for FPs to manage AYAs within PHC (what AYAs still need). Participants expressed needing direction on medication management and referrals, particularly for adult MH services: ‘*If [pediatric provider] can make the referral to the appropriate resources or adult psychiatrist, that would make it a lot easier*’ (FP7). This point, however, was in contrast to others who believed FPs should be responsible for making all referrals. Participants felt a transition summary should be ‘*comprehensive*’

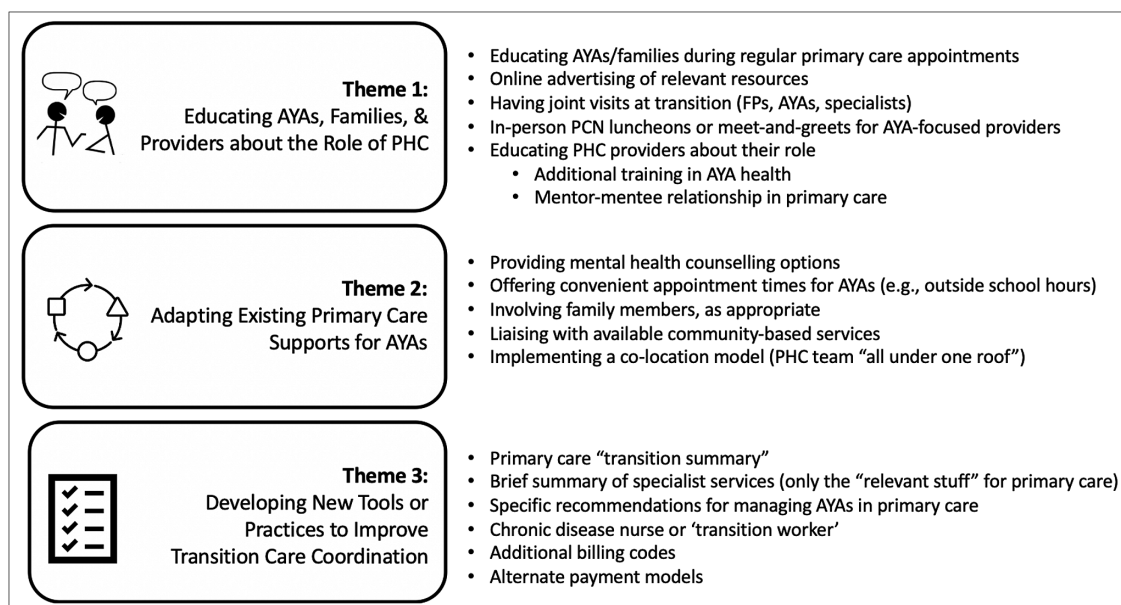


Figure 1. Strategies for improving primary care for AYAs offered by participants and categorized by themes.

Table 3. Additional exemplar participant quotes categorized by key themes from data collected between June and October 2018

Theme	Strategies	Additional supporting participant quotes
Theme 1: Educating AYAs, families, and providers about the role of PHC	<p>Strategies</p> <ul style="list-style-type: none"> Educating AYAs and families about the importance of continuous primary care (e.g. during primary care appointments and sub-specialty appointments) Shared visits between FPs, AYAs, and pediatric specialists Time to build relationship with FP, and educate about their role Educating FPs about resources available in the 'medical home' 	<p>'It's okay to have a family doctor and not see them for a few years, but have somebody. Especially anybody with a chronic condition, they in particular need a family doctor' (FP11).</p> <p>'You have to explain why... I say to mother, "it's really important we stay in touch, ideally bring [AYA] here for routine stuff. She's not gonna be with pediatric endocrinologist forever... it's really important because the relationship [patient] has with me is really important. If we just leave it for 5 years, re-connecting at age 16, 17... is a lot harder"' (FP11)</p> <p>'In an ideal system... you always [cared for] them. When you know them, everything is easier. Conversations are quicker, trust is there, the load is lighter' (FP19).</p> <p>'Ideally that every [AYA] would have a family doctor who they've stayed with for a long, long, long time and so you have continuity' (FP19)</p> <p>'You may actually need to do more than saying to the patient, "By the way you need a family doctor. Here's the list. Find one and then go follow-up with them." It's unlikely to happen. Whereas if you say, "This is why it's important, this is part of your care." (FP11)</p> <p>'Their family physician is supposed to be the hub. The one who has the most information. So, even though it might be the pediatrician and the pediatric endocrinologist versus the adult endocrinologist, the commonality should be the family practice physician.' (N8)</p> <p>'I think it would be great if we could do a face-to-face meeting... so we double-book the session so I'm able to come in, say hi to them... So they know this is a trusting person, a good person, a safe person. It would give me a chance to show them... I'm here, I'm ready to care for you.... I would bet that would really increase the rate of [AYAs] who actually show up to their [PCP] appointments' (NP15)</p> <p>Another participant expressed a need for 'shared visits' between FP and previous providers to 'develop relationship with patient so they know you're on their side' and so</p> <p>'[AYA] would trust you, they don't have to explain it all over again, at a time when maybe they don't feel like talking' (FP2).</p> <p>'The pediatricians could say, "Well ok if we have a family doctor very involved, what will happen when that child is 16 still in the pediatric age range and they're thinking about birth control, who should be giving the birth control advice? Me or you?" I would tend to argue the family doctor, but I'd also say you know what, doesn't matter to me. Let's just make sure to keep talking to each other.' (FP11)</p> <p>'If you're going to start seeing them [in primary care] when they're 18, then you need to kinda start getting familiar with them when they're 15 or 16 at least' (FP6).</p> <p>Another participant echoed this: I think it should start probably 2 years before [transfer]. If you leave it too late, the challenge to prepare everybody... often patients feel they're being abandoned... Some form of 2-year warning before the transition, I think that would be useful' (FP21).</p> <p>'Often times we don't even know them [PHC team members]. We don't know what they do.' (FP21)</p> <p>'Physicians understanding what a social worker does is still an uphill battle. Every physician in [PCN] can refer to me. I'm the only one that exists... [but] Monday Tuesday, Saturday I have no patients, not one. So what's going on? What's the gap? It's got better, now there's [a] couple physicians that always refer... They know, and they're referring like crazy... (SW12)... "What does she do? What could she do to help? [it's] unfortunate because [PCPs] say, 'we need more social workers'. But, I'm not busy enough...'" (SW12)</p> <p>PCN team members recommended more 'face time with physicians' and 'being in same physical space': 'there's lots [of physicians] who refer that I've never met and I don't know who they are' (SW12)</p>

Table 3. Continued

Theme	Strategies	Additional supporting participant quotes
	<ul style="list-style-type: none"> • Additional training on adolescent health/MH for FP • Mentor-mentee relationship between FPs and AYA providers in PCNs • Adapting primary care Strategies • Practice models for AYAs (e.g. co-location model) • Adapting MH services for AYAs in primary care 	<p>'[Additional training] is always helpful, but for complex AYAs, that could be an entire residency... as long as the [AYA training] is not in the absence of other things' (FP19)</p> <p>'I've gotten better at it with experience but I wouldn't say by any means I'm super comfortable. I think [AYAs] respond to [pharmacological] treatment a bit differently. Or they might use other substances in conjunction with their medications without telling you' (FP16)</p> <p>'I need more education because it's not a clientele I see regularly. Like, I see them into young adulthood when they're in crisis or a really little kid and the occasional adolescent. I just don't have a lot of training in how to do that, like [my] schooling certainly didn't prepare me for it... so it's a lot of flying by the seat of my pants.' (NP15)</p> <p>'It bothers me there's a movement in my College to have another designated sub-specialist [like obstetrics, geriatrics, women's health]... All these things are part of integral family medicine. There's a thing about having a program for adolescent health which I'm really opposed to because it suggests you need training to learn how to relate to adolescents. That's not true. There's some unique things in the same way there are unique things for women between age 45 to 55. What's the difference?' (FP11)</p> <p>'I think it'd be helpful to identify a few people in the [Primary Care Network] organization that have a passion for adolescent mental health... then [FP] develops mentor-mentee relationship and they can be the go-to person in the [PCN]' (N15)</p> <p>'You know right now we don't really do rounds, like I said, or like case studies or you know discuss patients as a group, and I think especially with kids with chronic conditions, I think that would be really really important' (D1)</p> <p>'In the ideal world you would have their designated health care team all under one roof... it would make it a lot easier in terms of appointment attendance and cohesiveness' (D1)</p> <p>'All PCNs should have complex care clinics [for AYAs with chronic conditions] because they are 'cheaper in the long-run' (FP5).</p> <p>'PCNs have specialty clinics [for women's health, prenatal care], so potentially they could have a transition clinic...[to] serve as a hub to centralize and mobilize those services' (FP6)</p> <p>Participants described MH supports in PCN as 'short term solutions' (FP16) and 'time-limited' ranging between 4-6 sessions (FP2). 'Behavioural health consultants tend to be limited in terms of number of sessions' (FP16).</p> <p>'You know [AYAs] need ongoing support, and it's hard when they can only connect in a 6-session model...'. '[limited sessions] is a definite issue with chronic [mental health] problems... I feel my hands are tied in these 6 sessions. It's really hard to feel like you can effectively help that person... You're just trying to move them forward' (SW20)</p> <p>'More social workers. We have social workers for adults in PCN, not adolescents' (FP16)</p> <p>'I'm skeptical whether the care [from local mental health hotline] is ideal [for AYAs]' (FP21)</p> <p>'Psychologist [in PCN] won't see anyone under age 16.' (FP3)</p> <p>'We can't accept [AYAs] that have really severe trauma. We're not going to open up [trauma] in 5 sessions... If they have to wait 7 months [for a trauma program outside PCN], that's a huge barrier of getting them care in a timely manner' (SW20)</p> <p>'Even just having pediatrician copy some relevant files to bring to the first appointment instead of relying on us to gather it all... Here's the relevant stuff that's been happening over the past few years... that would be huge! A summary letter would be fantastic... so the parent has a copy, and then they bring it to us and we have a copy. These are the things that are ongoing, these are the specialists that they've transferred to in adult world, and these are areas that need resolution or something.' (FP7)</p>
Developing new tools or practices to improve transition	<ul style="list-style-type: none"> • FP's receive short summary letter from specialists or pediatrician before transfer 	

Table 3. Continued

Theme	Strategies	Additional supporting participant quotes
	Care coordination	<p>Many suggested having a clear written summary ('something in writing') or letter from specialists: 'here's what I've been doing and what I think they need' (FP2), possibly to 'lay out a plan' for both PCP and AYAs/family, 'so that when you take on a patient you have a global picture of how they are functioning... not just what diagnoses they've been given, but really a functional review (FP5)</p> <p>Other participants echoed the need for a letter from pediatrician: 'when the child gets to a particular age, a letter from pediatrician to family doctor and says "This is my recommendation for ongoing care" and maybe at 6 months check on whether plan has been put into place... to make sure patient doesn't fall through the cracks' (FP21)</p> <p>'[Some information] about how the [counseling] sessions were going... Not every visit has to be shared, but maybe some of them? 'Ok they're stable, here's what I've been doing and what I think they need.' (FP2)</p> <p>'The [summary] report we get from the developmental clinic has these little sub-sections: speech therapy, OT... Maybe there should be primary care! Then it's seen as important by the team and formalized in a kind of way, otherwise parents don't pick up on it.' (FP11)</p> <p>'A big thing that I would like to see changed is if they are seeing like a mental health specialist then that person doesn't just send them back to me, but send them to a colleague that, like a psychiatrist in the adult world to take over care - someone they know and trust.' (FP2)</p> <p>'If the pediatric, GI and pediatric respiratory would be willing to approve a generic, just a one-pager they could put in the EMR that gets attached at the time the kid is 17, that says, "Time is approaching, the kid needs to transition. We'd appreciate you seeing them in follow-up, to make sure this transition is as fluid as possible." Perhaps address issues of confidentiality. Just make it clear which information they are willing to have passed on, check in about anxiety, whatever. We recommend you see them at 3 months, whatever it might be. I think it would really help the jobs of the family doctors, and it will make it standard, like there's nothing standard!' (FP13)</p> <p>'Say the patient is aged out of the [pediatric] system but the pediatric endocrinologist for example says, "You know what they're stable, you can manage this", but then to have something in writing to us that says, "If things don't, if things get complicated or you need more support with this patient, these are the resources available", or "This is who I'd refer them to", or "These are the things you can try", like if they could lay out something of a plan for us, if we're going to be taking over, that would be super helpful.' (FP3)</p> <p>'I would say also a commitment to be available by phone for 6 months for quick phone consults, if the family physician doesn't know what the heck is going on or has a question or doesn't know what to do.' (FP5)</p>
	<ul style="list-style-type: none"> • Having a one-pager or outline on how to manage certain chronic conditions 	
	<ul style="list-style-type: none"> • Consultation between FPs and specialists 	
	<ul style="list-style-type: none"> • Having a chronic disease nurse or 'transition worker' for AYAs in primary care 	<p>'Every clinic needs maybe just one champion, like a nurse manager, to say 'we need to make sure all our kids move to a family doctor' (FP11)</p> <p>'Have a person to make sure everything's coordinated' (FP7) Chronic disease nurses exist 'for elderly' in primary care clinic populations (e.g. diabetes, hypertension and epilepsy) but not AYAs (FP7, FP3, FP6).</p> <p>'I think there [should be] a nursing role... for [AYAs] with any kind of chronic disease. I think the role will be getting them connected to different resources' (N1)</p> <p>Another participant echoed need for the transition coordinator to be a 'discrete role' (D1): 'if there were a coordinator who can [perform] case management, [that's] what we need in our program' (D1). This participant also viewed this as a nursing role.</p> <p>A social worker participant expressed need for a 'youth transition worker': 'I would say [we need] a youth transition worker because, bless the family doctors, [but] we're expecting them to be specialists in all these areas and they're not. We're expecting them to have all this information, and they don't. If anything happens, who's the first person we go to? Our family doctor... If we had someone [in PCN] that can say 'we're doing this transition'...' (SW14)</p>

Table 3. Continued

Theme	Strategies	Additional supporting participant quotes
<ul style="list-style-type: none"> Alternative payment models and additional billing codes 		<p>'If somehow there was a nurse or a something like that that was within the clinic that would then work with that transition team to connect that web up.' (N8)</p> <p>'If you don't have a funding system that supports taking more time with patients, then this is what you get [poor transition experiences]...' (FP3)</p> <p>'If a physician had a practice of complex patients, would they be able to even make a go of it? Like keep their practice from going bankrupt? The answer would probably be no' (FP19)</p> <p>Participants expressed concern about keeping 'head above water' and keeping family practice 'financially stable': 'Complex patients can very, very quickly become a big stress to your practice in terms of tremendous amount of extra work that you are doing completely for free, in your evening time' (FP19). This participant described experiences working in a capitated model (salaried): 'I would say it was no better in terms of incentivizing [or] making it easier to care for complex patients' (FP19).</p> <p>'There's a billing code for complex care patients for adult patients... Not for adolescents. None whatsoever' (FP21)</p> <p>Some participants felt 'payment models are huge': 'de factor funding model is fee-for-service which in my opinion does not support the care of complex patients' (FP3). Some described having 'supported time' in their academic teaching clinic to care of complex AYAs: 'no pressure to see 30 patients in a day to make more money' (FP3).</p>

and provide a 'functional review' (e.g. diagnoses, global functioning). For AYAs with MH issues, a short, solution-focused summary was desired:

Just a summary - "patient attended this DBT group. We set these 3 goals". You know, short. Cause a lot of these community [reports] are like 10 pages...we don't have time to read those (FP16)

In addition to a summary, one participant suggested a 'one-pager' for FPs on managing common conditions (e.g. transition topics, discussing confidentiality) could be helpful; for example, 'a top 10 tips for managing Crohn's with a FP'(FP13).

Another strategy to improve transition coordination was establishing a 'discrete role' in PHC for assisting AYAs and families during this period:

It would be useful to have a chronic care nurse. Someone to talk to families... a resource person who calls [AYAs] after their transition [from pediatrics] to get [information] (FP21).

Other participants considered the possibility of 'youth transition workers' in PHC; details about this role were limited and varied: '[We need] a youth transition worker. We're expecting FPs to be specialists in all these areas and they're not. If anything happens, who's the first person we go to? Our FP. And they don't have all the answers' (SW14). Some participants noted chronic disease nurses were available in their practice, but only for adult patients. Two SWs described being hired to provide 'navigation support' for AYAs in PHC practices: 'I think there should be one of me in every clinic [laughs]. Having extra people like me to help coordinate [is needed]... it's really not a medical need, more of a social need' (SW18).

Another system-level strategy to address care coordination difficulties involved changing payment models. As stated by one FP:

the de-facto funding model of fee-for-service, in my opinion, does not support the care of complex [AYAs] (FP3).

Some participants perceived fee-for-service models as a barrier to supporting AYAs with chronic conditions because they did not account for the 'tremendous amount' of indirect time required by physicians to coordinate care. Participants in academic teaching clinics with 'supported time' viewed this as beneficial for supporting AYAs. There were mixed views among participants about whether alternate payment models were 'the' solution. Some felt additional billing codes within fee-for-service models were feasible:

We function on codes. If there was a billing code to facilitate some of this extra work to care for complex AYAs-that would probably go a long way to fixing the problem (FP19).

Discussion

Our study revealed three themes about supporting FPs' roles in transition: (i) educating AYAs, families, and providers about the role of PHC; (ii) adapting existing PHC supports for AYAs and (iii) developing new tools or practices to improve transitional care coordination. We discuss below, how the strategies we heard, fit with available evidence, and considerations for research on transition interventions.

As recommended by national transition guidelines and indicated by our participants, all AYAs exiting pediatric services should be 'attached' to a PHC professional (6). It may seem beneficial for families to receive their entire child's care from pediatric specialists, this can lead to additional provider transitions when AYAs 'age-out' of the pediatric system (25). AYAs receiving their PHC from pediatric

specialists, walk-in clinics, or multiple providers are at risk of experiencing poor continuity of care post-transition (39,40). Participants believed FPs need to play a *continuous* role in AYAs' care, ideally from the outset of treatment/diagnosis, which is supported by studies on continuity of PHC for young people with chronic conditions (17,41). Some guidelines recommend pediatric specialists hold 'transition appointments' to prepare AYAs for adult care (7); such appointments could be used to educate about the roles of FPs and available multidisciplinary supports. As noted by participants, PHC team members with pediatric expertise may be unknown to FPs, unless providers are working 'under one roof' (e.g. co-location model). Since co-location PHC models are uncommon (33,35), research on strategies to enhance PHC team-based care is essential, especially when it relates to care of pediatric populations (42,43).

AYAs historically have had the lowest rate of PHC use among any age group in North America (44), which may reflect a need to adapt PHC for this population. A growing body of literature on 'adolescent-friendly healthcare services', coined by the World Health Organization (45), recognizes the unique barriers faced by AYAs accessing PHC and a need to develop acceptable, appropriate, equitable, and effective healthcare services for this age group (46). In our study, offering convenient appointment times, confidential appointments, and liaising with existing community-based supports were some suggestions to adapt care. Evidence to support the effective matching of 'brief' counselling models for AYAs is still needed. Participants identified major challenges with care coordination for AYAs during transition. Healthcare transition summaries were recommended and consistent with published guidelines (6,7,47). Yet, our findings highlight a need to assess barriers to sharing health summaries with FPs, and their uptake by AYAs and PHC teams. Patient 'navigators' or care coordinators are a promising intervention for chronic disease populations and could facilitate sharing of information and transition readiness (e.g. communication and health literacy skills, assisting with system/service navigation and addressing social determinants of health) (48,49). However, research on the core components of cost-effective navigators for AYAs is needed. Finally, evidence comparing remuneration models for FPs is lacking. The most common model in Canada is fee-for-service (72% of all payments), but some FPs receive payments through a salaried model (50). Little is known about how alternate payment structures impact AYA care (51) and this is an important direction for future research.

Strengths and limitations

An important strength was our inclusion of multidisciplinary PHC professionals in addition to FPs, which allowed us to obtain a deeper understanding of what occurs in practice during the transition to adult care. Based on our data, team-based PHC may be well-suited for AYAs with chronic conditions who may benefit from multidisciplinary supports (e.g. individual/family counselling). Our sample represented professionals across PCNs; however, the majority were female and from urban practices. A larger, diverse sample including perspectives from professionals in geographical regions serving different communities will improve generalizability of the results. In particular, additional perspectives from MH professionals on transition care are needed (52–54). Engagement of AYAs and families is critical to build consensus about strategies (e.g. 'adolescent-friendly' services, healthcare summaries) for transition interventions incorporating PHC professionals (55).

Conclusions

Our study, which examined PHC perspectives about strategies to support AYAs with chronic conditions, provides new insights to optimize transition. Clarifying FP roles during this process is a critical first step. PHC services also need to be tailored for younger individuals and additional supports may be needed for care coordination. If PHC is to be viewed as a suitable and effective 'medical home' (56) for AYAs, feasible evidence-based strategies need to be designed and tested with input from AYAs and families.

Supplementary material

Supplementary material is available at *Family Practice* online.

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