Transition of Care Readiness Among Adolescents with Chronic Pain Between 2021-2022 in a Nationally Representative Sample

Daron Vandeleur

A thesis

submitted in partial fulfillment of the

requirements for the degree of

Master of Science

University of Washington

2024

Committee:

Stephen Schwartz

Tonya Palermo

Program Authorized to Offer Degree:

Epidemiology

University of Washington

Abstract

Transition of Care Readiness Among Adolescents with Chronic Pain Between 2021-2022 in a Nationally Representative Sample

Daron Vandeleur

Chair of the Supervisory Committee:

Stephen Schwartz

Department of Epidemiology

Chronic pain impacts 11-33% of children and will continue into adulthood for over half of them. Transition of pain management to adult care is crucial given high risk of interruption of care which is associated with subsequent poor medical, social, and vocational outcomes. Yet the transition experience for these youth is poorly characterized. We aimed to determine the prevalence of transition readiness among adolescents with chronic pain in the U.S. and estimate the association of readiness with biopsychosocial-cultural and health system characteristics. 2,584 adolescents age 14-17 with chronic pain were identified by parent report in the 2021 and 2022 National Survey of Children's Health. Poisson regression was used to identify characteristics associated with readiness. 23.9% of adolescents met criteria for transition readiness. Those more likely to meet criteria were older (PR 1.8 95%CI: 1.3, 2.6), female (PR 1.6 95% CI: 1.2, 2.2), White (Asian PR 0.4, 95% CI: 0.2, 0.9, Multi-racial PR 0.6 95% CI: 0.4, 0.9), and experienced shared decision making (aPR 1.7 95% CI: 1.1, 2.8). Fewer than half met criteria for medical home, effective care coordination, and adequate insurance. This study is an important first step in demonstrating low transition readiness among adolescents with chronic pain and identifying healthcare continuity concerns. Future research should incorporate adolescents and provider perspectives and investigate pain specific factors relevant to transition readiness and investigate how readiness relates to transition outcomes.

Introduction

Chronic pain (pain lasting >3 months) is a significant pediatric health issue that impacts 1 in 5 youth[1] and costs $19.5 billion annually in the United States.[2] Pain may be due to a primary pain condition (e.g. chronic abdominal pain, chronic headache, chronic regional pain syndrome) or secondary to a chronic illness (e.g. juvenile idiopathic arthritis (JIA), sickle cell disease, cerebral palsy). Childhood pain can have consequences into adulthood, including ongoing pain for up to half of these youth.[1,3] Inadequate pain management during adolescence can disrupt crucial decisions and have lasting medical and social impacts into adulthood.[3,4] Beyond pain itself, the impact of pain in young adulthood can be disruptive to important decisions and changes (such as to pursue higher education or full-time work) and impact subsequent quality of life, vocation, and financial independence.[5] Pain management is often interrupted during this critical time due to aging out of pediatric care, relocation, and lack of clear transition pathway.[1,5–13] Chronic pain in young adulthood is often managed by primary care or specialty providers (e.g. rheumatologists), though management may be hindered by lack of formal chronic pain training for most clinicians who are not pain specialists and difficulty of coordinating multidisciplinary care.[1,5] Transition to adult pain clinics is often not preferred by young adults (as such settings may not provide developmentally appropriate care), an option (given limited access), or necessary (if the pain is of low complexity and not requiring interventions).[6] However, while transition to adult services has been identified as a priority by adolescents with chronic pain,[1,5–8,10,11,14] providers,[10,15,16] and the research community,[1,3,5,6,9–13,15–17] scant research and guidance exists, leaving these youth vulnerable to lapses in care.

Transition from pediatric to adult care is an important task of adolescence for which most youth are unprepared. Transition readiness describes preparedness to shift from pediatric to adult health provider(s) and manage one's own health needs.[18,19] Despite recommendation for universal screening for transition readiness by a 2002 joint consensus of pediatric, family medicine, and internal medicine societies,[20] readiness remains low, increasing from 14% in 2016 to 19% in 2020.[18] Nationally, transition to adult care remains consistently higher among all youth with special health care needs (defined as those

who have (or are at increased risk of "chronic physical, developmental, behavioral, or emotional conditions")[21] as well as within specific illness populations (e.g. diabetes[22], juvenile arthritis[23,24], sickle cell disease[25,26]) as compared to youth without special healthcare needs. However, no studies to date have quantified transition readiness among youth with chronic pain. Lack of transition readiness is associated with lapses in care, adverse health outcomes, lower quality of life and higher symptom severity.[27–29] Higher readiness has also been observed among youth who are: older[18,23,30–36], female [31,33,35,36], White[30,31,35], without a developmental condition[37], and who have higher family income.[23,30,31,33] Positive interaction with health systems has also emerged as important, with higher rates of readiness for those who report better communication and relationships with providers, comprehensive and available primary care, and adequate insurance.[32,33] There have been no studies to date quantifying and examining disparities in transition readiness among youth with chronic pain. Qualitative studies of transition experience in youth with chronic pain echo concerns in other illness populations including provider relationships, support during transition, and increased autonomy and self-efficacy. Concerns more unique to the pain experience expressed by patients include pain-acceptance, fluctuating nature of pain symptoms, invalidation of pain symptoms, and provider stigma.[1,5–8,10–12,14]

Promisingly, implementation of structured transition interventions increases readiness and positive transition outcomes in other chronic illness populations (e.g. juvenile arthritis, diabetes, irritable bowel syndrome, sickle cell disease).[1,38,39] Interventions may include education (e.g. self-care, disease management, developing skills), care coordination (e.g. scheduling assistance, linkage to community resources, assigned transition nurse), planning for and assistance with transfer (e.g. care plan, transition clinic), and integration into adult care (e.g. welcome/orientation process).[22,23,28,29,38–40] Some interventions employ general assessments and interventions (e.g. Transition Readiness Assessment Questionnaire (TRAQ), Six Core Elements of Health Care Transition™, Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART)) and others have used condition specific adaptations.[9,16,41,42] No interventions have been implemented among or evaluated in youth with chronic pain and those used in other pediatric populations may not apply to this population given their unique needs. Murray et al proposed a conceptual model for transition of care specific to youth with chronic pain that

identified pertinent biopsychosocial-cultural factors impacting readiness as well as pain-specific concerns, but elements of the model have not been studied.[5] Characterization of transition readiness and salient contextual factors (biopsychosocial-cultural and health systems characteristics) is an important first step in informing and evaluating transition frameworks for youth with chronic pain.

The specific aims of this study were to 1) determine the prevalence of transition (of care) readiness among adolescents with chronic pain in a nationally representative sample, and 2) estimate the association between individual/family biopsychosocial-cultural and health care system characteristics with adequate transition readiness.

Methods

This was a cross-sectional study measuring transition of care readiness among adolescents with chronic pain using data captured in the 2021-2022 National Survey of Children's Health (NSCH), available at https://www.childhealthdata.org. The NSCH is funded by the Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB) and is fielded by the US Census Bureau. NSCH is designed to provide national level data on the health and wellness of children 0-17 years of age in the US. All 50 states and the District of Columbia are represented, with each contributing between 1.5-4.0% of survey participants. Parents of children selected for inclusion were the primary survey respondents; however, results are weighted to reflect the US population of children 0-17 years of age. Children 0-5 years of age and those with special health care needs were oversampled. Minoritized groups were not oversampled. All participants provided consent. Data are available to the public for free. The Institutional Review Board at the University of Washington deemed this study exempt from review. The Strengthening the Report of Observational Studies in Epidemiology (STROBE) reporting guidelines for cross-sectional analyses were followed.[43]

Subjects included youth who are represented through parent responses in the 2021 and 2022 NSCH surveys. The final sample of the 2021-2022 NSCH contained 104,995 participants, however we only included adolescents (14-17 years of age) with chronic pain (defined as described below). We excluded adolescents who are likely to transition to adult specialty care for another medical condition (n=279).

Excluded adolescents had to have comorbid conditions of at least moderate severity and included autoimmune disease (type 1 diabetes, celiac, and juvenile idiopathic arthritis), blood disorders (sickle cell disease, thalassemia, or hemophilia), epilepsy or seizure disorder, cerebral palsy, heart conditions, and cystic fibrosis. After survey weighting, our sample is nationally representative of adolescents 14-17 years of age with chronic pain (and without excluded comorbid conditions) living in the US as per NSCH's design.

To identify respondents whose child suffered from chronic pain the following NSCH data item was used: "During the past 12 months, has this child had frequent or chronic difficulty with repeated or chronic physical pain, including headache or other back or body pain?" Children were classified as having chronic pain whose parents responded "Yes". This measure of pediatric chronic pain has been used in several previous NSCH studies.[44,45]

The outcome, (adequate) transition readiness, describes the extent to which a child with chronic pain is prepared to transition to adult care. This was measured as a dichotomous composite transition readiness variable (methodologically equivalent with the HRSA MCHB Title V national performance measure). Adolescents were classified as having adequate transition readiness if they meet all three criteria (by parent report): 1) If a discussion regarding transfer to an adult provider was needed it occurred, 2) their provider worked with the adolescent to take responsibility for their own health care needs and/or understand adult health care needs, and 3) the adolescent had time alone with their provider (Table 1).[32]

Covariate selection was informed by our conceptual model for transition for adolescents with chronic pain which was developed from existing transition frameworks (Figure 1).[5,38,40] Covariates fell into two categories: biopsychosocial-cultural characteristics (demographic features, health status, and psychological health) and health system characteristics (insurance status, shared decision making, and medical home).

Demographic characteristics included age (measured in years), sex (male or female), family socioeconomic status (SES, calculated as a ratio of total family income and the federal poverty threshold

(<100%, 100–199%, 200–399% or ≥400%)), race (American Indian or Alaskan Native alone (AIAN), Asian alone, Black or African American alone (Black), Native Hawaiian and other Pacific Islander alone (NHPI), White alone, or two or more races), Hispanic ethnicity (yes or no), and household language (English, Spanish, or other). Health status was assessed by parent report of adolescents' overall health (excellent, very good, good, fair, or poor) and frequency and impact of functional impairment (if any). Individual characteristics reflecting the adolescents' psychological health were divided into: mental health (presence of depression and/or anxiety), developmental condition (presence of developmental delay, autism spectrum disorder, Down syndrome, and/or intellectual disability), and individual flourishing[46] (dichotomized composite measure of curiosity about learning, self-regulation, and resilience). Insurance status was dichotomized reflecting whether or not the family's insurance met the adolescent's needs. We applied the NSCH definition of both having continuous insurance over the past 12 months and having current insurance adequate for the adolescent's needs (benefits usually or always met needs and insurance usually or always allowed them to see needed providers, and out-of-pocket costs were either usually or always reasonable (or non-existent)). Shared decision making integrates a child and family's values, goals, and concerns with available evidence about medical decisions and is associated with improved care.[47] We created a dichotomized composite measure to reflect shared decision making.[48] Shared decision making was considered present when parents indicate providers always/usually (as opposed to sometimes/never): discussed a range of options, made it easy to raise concerns or disagree, and worked with families to make decisions. The medical home is a concept proposed by the American Academy of Pediatrics as the availability of comprehensive primary care and is a Federal Title V performance measure. This was measured using established methods to generate a dichotomized composite variable consisting of five components (usual source of care, personal provider, obtaining referrals, family centered care, and effective care coordination) which was considered achieved if all pertinent components were met.[31] Pertinent to all children was having a usual source of care when sick (yes or no) and a personal doctor or nurse (always/usually versus sometimes/never). Obtaining referrals pertained to those needing referrals in the past 12 months and was met if parents indicated obtaining these was not a problem (versus a small or big problem). Family centered care pertained to children who had a visit in the past 12 months and met if parents indicated that their child's provider spends enough

time with them, listens carefully, is sensitive to family's culture/values, provides enough information, and makes the family feel like partners. Effective care coordination pertains to families reporting needing more than two health-related medical, educational, or social services in the past 12 months and is met if parents respond "always" or "usually" (versus "sometimes" or "never") receive sufficient help with care coordination, being very satisfied (versus somewhat or not satisfied) with communication among providers and between providers and other programs.

Statistical analyses were conducted with R Studio version 2022.12.0+353. Survey weights were applied according to the NSCH guidelines. The biopsychosocial-cultural and health systems composition of the sample population were characterized using weighted percentages and 95% confidence intervals (CI). To address the primary aim, prevalence estimates and 95% CI of transition readiness in the sample were calculated using survey weighting by dividing the number of adolescents with chronic pain meeting adequate transition readiness by the total number of adolescents with chronic pain. Prevalence estimates and 95% CI were also calculated for all four transition subcomponents. To address the secondary aim, separate multivariable Poisson regression models were fit to estimate the adjusted and unadjusted prevalence ratios (aPR and PR) and corresponding 95% CIs for each biopsychosocial-cultural and health systems characteristic comparing those with adequate transition readiness to those without. These models were fit with the overall transition composite measure as the outcome, as well as with each of the four transition subcomponents as the outcome. To select confounders for inclusion in the models, variables plausibly associated with both the exposure of interest and outcome (transition readiness) were identified based on existing research. Each exposure of interest is listed with *a priori* adjustment factors in parenthesis: family SES (race, ethnicity, language), health status (family SES, language, insurance, medical home), mental health (health status), individual flourishing (age, sex, race, ethnicity), insurance (family SES), shared decision making (health status, developmental condition), and medical home (family SES, language, health status, developmental condition, insurance). [5,13,17,19,31,46,49–52] Models estimating the association of the outcomes with age, sex, race, ethnicity, language, and developmental condition were not adjusted for confounders.

We also performed a *post-hoc* sensitivity analysis after our primary analysis showed that readiness did not increase with each year of age as previous research has demonstrated. We observed that among older adolescents the proportion of “don’t know” responses increased slightly for the two transition subcomponents with this as an option (provider discussed changing health care needs and provider discussed positive health choices). Thus, we decided to conduct a sensitivity analysis where we coded “don’t’ know” responses as meeting criteria for the subcomponent. We examined the overall prevalence of transition readiness as well as prevalence ratios and 95% CI for all biopsychosocial-cultural and health systems characteristics for overall transition readiness as well as the two individual transition components with “don’t know” response options.

Results

This sample included 2,584 adolescents 14 to 17 years of age with chronic pain. Biopsychosocial-cultural and health systems characteristics of the sample are presented in Table 2. Most adolescents were female, White, not of Hispanic or Latino origin, and spoke English as a primary language at home. Parents reported 41.2% of adolescents experienced depression, 31.5% experienced anxiety, and fewer than half met criteria for flourishing. Only 39.1% of adolescents met criteria for adequate insurance. About one third met all five criteria for a medical home, though most met criteria for all subcomponents except effective care coordination (33.4 %). Most experienced adequate shared decision making (78.5%).

Overall transition readiness

Overall, 23.9% (95% CI 20.3, 28.0) of adolescents with chronic pain met all criteria for the outcome measure of adequate transition readiness (Table 3). The prevalence of overall transition readiness varied by several demographic and biopsychosocial-cultural characteristics of age, sex, race, presence of a developmental condition (Table 4). Shared decision making was the only health system characteristic associated with transition readiness (Table 5).

Generally, older adolescents attained transition readiness more often than younger adolescents. Those age 15-17 years of age met criteria 1.8 times as often as compared to those aged 14 (95%CI: 1.3, 2.6). Prevalence of transition readiness did not, however, increase with each year of age, such that compared to those 14 years of age, prevalence was 1.8 times as high among those 15 and 16 years of age but only 1.6 times as high among those 17 years of age (Table 4). Sensitivity analyses demonstrated comparatively increased readiness among those age 17 (PR=2.1 95% CI: 1.4, 3.2) and similar comparatively increased readiness prevalence among those 14-16 years of age. Readiness was 1.6 times as high among females as males (95% CI: 1.2, 2.2) (Table 4). Compared to White adolescents, prevalence of readiness was lower among all other races, and particularly among Asian (PR=0.4, 95% CI: 0.2, 0.9) and multi-racial adolescents (PR=0.6, 95% CI: 0.4, 0.9). Adolescents who experienced shared decision making met criteria for readiness 1.7 times as often as those who did not (95% CI: 1.1, 2.8) (Table 5).

Overall transition readiness did not otherwise vary by SES, ethnicity, language, health status, mental health, insurance status, overall medical home measure (or any of the five subcomponents).

Transition subcomponents

If a discussion regarding transition was needed, it occurred for only around a quarter of adolescents in the sample (Table 3). Having a discussion varied by biopsychosocial-cultural but not by health systems characteristics (Tables 4 and 5). These discussions occurred most often for adolescents who were 16 years of age and with higher family SES (200-399% FPL and >=400% FPL). As compared to White adolescents, discussion occurred only about half as frequently among Black and multi-racial adolescents and a minority of the time among AIAN adolescents (Table 4).

About two thirds of adolescents had time alone with their provider (Table 3). Prevalence did not vary meaningfully by biopsychosocial-cultural or health systems characteristics (Tables 4 and 5).

About two-third of parents reported a provider worked with their adolescent to make positive health choices (Table 3). Prevalence was slightly higher among those who met criteria for several medical home subcomponents: usual place for sick care, had a regular provider, and experienced family centered care) (Table 5).

About a third of parents reported that providers discussed changing healthcare needs with their adolescent (Table 3). Discussion of changing healthcare needs occurred more often among Black (PR= 1.6 95% CI: 1.2, 2.2), Asian (PR=1.7 05% CI: 1.1, 2.9) and AIAN adolescents (PR: 1.6 95% CI: 0.9, 2.8) as compared to White adolescents. Prevalence was slightly increased among those whose adolescents met criteria for flourishing (Table 4).

Discussion

This is the first study to our knowledge to estimate quantitatively transition readiness among adolescents with chronic pain. Using parental responses to the 2021-2022 NSCH we identified 2,584 adolescents with chronic pain, 23.9% of whom met criteria for adequate transition readiness. Adolescents who were older, female, and experienced shared decision making were more likely to meet criteria for readiness. Asian or multiracial adolescents and those with one or more disabilities were less likely to meet criteria for readiness. We also identified high prevalence of personal and health systems vulnerabilities including poor mental health and inadequate healthcare access that were not associated with our outcome of interest (transition readiness) but may impact other aspects of the transition of care continuum (Figure 1) beyond the scope of this study (e.g. transition outcomes).

Prevalence of readiness among adolescents with chronic pain is low and comparable to that of other chronic illness populations (17-40%).[18,19,23,26,30–32,37,40,53] Direct comparison of our estimates to those from prior studies is difficult given shifting definitions of readiness and age ranges examined (from 12-18 years of age).[53–55] The extant literature among other chronic illness populations consistently reports that

readiness increases with age but differs regarding how readiness varies by biopsychosocial-cultural and health systems characteristics.

Consistent with most previous work, adolescents who were older or female were more likely to be described by their parents as ready for transition to adult care. Interestingly, readiness did not increase with each year of age in our sample. It is unclear if this finding is novel as previous work has reported age groups without disaggregating age by year.[30,33,37,56]Click or tap here to enter text.. That decreasing parental involvement in later adolescence contributed to uncertainty regarding details of the discussions between adolescents and their provider is supported by our sensitivity analyses. It is also possible that COVID-related care disruption impacted transition readiness among the oldest adolescents. The COVID-19 pandemic disrupted routine and urgent medical care both in adolescents with and without special healthcare needs.[57,58] However, the impact of COVID-19 on transition readiness has not been examined specifically among any adolescent population. Additionally, transition readiness may be impacted by developmental stage (which could not be measured in this study) rather than age alone.[16] Like most studies, we found higher readiness among female as compared to male adolescents. [31,33,35,36] This is an area that should be further explored as healthcare use diverges in young adulthood by sex such that males receive significantly less overall and preventative care than females.[59]

Our work adds to a growing body of evidence demonstrating racial disparities in transition readiness. We found transition readiness was higher among White adolescents compared to all other races, particular among Asian and multi-racial adolescents. While data published from the 2016 NSCH showed no difference in readiness by race,[30] a growing body of evidence indicates non-Hispanic White youth meet criteria for readiness more often than other groups.[18,31,35,37] Similar to previous work we also found disparities in the individual subcomponents of readiness such that White youth had a discussion regarding shifting to an adult provider more often (than Black, AIAN, and multi-racial adolescents) but discussed changing healthcare less often than Black, AIAN, and Asian adolescents.[30] Explanation(s) for these findings are unclear and should be explored (e.g. understanding the role of provider perceptions and beliefs and parental involvement). Most previous work reports aggregate racial categories and often

combines race and ethnicity making direct comparison of results difficult. As a first step, future work should prioritize disaggregation to permit understanding of disparities.[60] Understanding these disparities will require studies designed and interpreted using rigorous health disparities frameworks.[61–63]

Our study adds to the evidence that adolescents with developmental conditions are less likely to meet criteria for adequate transition readiness[37]. Future work should first investigate causes of decreased readiness (e.g. increased caregiver involvement, provider knowledge, unique needs) and if needed tailor interventions accordingly. Mental health did not appear related to transition readiness, though it may impact ability to carry out the actions needed for a successful transition.[5,37] Our findings highlighted the high burden of comorbid mental health issues among children with chronic pain. Consistent with previous studies, [4,64,65] prevalence of anxiety and/or depression was common, impacting nearly half of adolescents with chronic pain. Fewer than half of adolescents with pain met criteria for flourishing which continues the downward trend observed since 2019.[66]

Shared decision making was the only health system characteristic associated with overall transition readiness among adolescents with chronic pain. Those who experienced shared decision making met criteria for both overall readiness and each individual subcomponent more often than those who did not. This has been previously observed in adolescents with special health care needs (but not those without).[32,33] This finding suggests that shared decision making may be an important foundational component to successful transition preparation.

The medical home has been identified as a potential practice-based implementation system for all stages of the transition process, beginning in early adolescence[36]. Fewer than a third of adolescents with chronic pain met criteria for having a medical home, which is less than the general pediatric population (50%) and other chronic illness populations (~45%).[32] Despite most parents reporting no difficulty with obtaining referrals, fewer than half of those who needed care coordination reported it was effective, similar to previously reported findings. [32,67] This is particularly concerning given the multidisciplinary nature of pain care. Care coordination may be impacted by systems issues (e.g. lack of access to specialized pain care,

inadequate time, insufficient support services) and provider factors (e.g. poor communication). Consistent with previous work among youth without special healthcare needs, [32] we found that meeting criteria for a medical home did not impact transition readiness. Among adolescents with chronic pain, having a medical home was associated with only one subcomponent of the transition measure (provider discussing making healthy choices with the youth). Having a medical home may provide a good foundation to apply a transition framework and intervention but does not appear sufficient to prepare adolescents to transition.

Adequate and continuous insurance is important for healthcare continuity. Concerningly, fewer than half of adolescents with pain met criteria for adequate insurance in our study. However, we did not find an association between adequate insurance and transition readiness. Previous work has found that insurance was associated with transition among youth with special health care needs (but not among those without).[32] For adolescents with chronic pain, though insurance status may not be associated with transition readiness, it may be associated with transition outcomes.[21]

Our study had several strengths. This is the first study to our knowledge to describe transition readiness among adolescents with chronic pain at a national level and demonstrate the scope of the issue in this population. Additionally, this is the first study to characterize availability of a medical home among adolescents with chronic pain. We also observed personal and health systems vulnerabilities for this population including low prevalence of flourishing, adequate and continuous insurance, effective care coordination and high prevalence of anxiety and depression. An additional strength is application of a framework for assessing potential influences on transition of care specific to this population. Unlike previous studies we also chose to disaggregate race and ethnicity data.

Our study has several limitations including those intrinsic to cross-sectional and survey design. Selection and non-response bias are potential limitations of all survey-based studies. However, NSCH evaluates survey data for potential non-response bias and did not find strong or consistent evidence of nonresponse bias after survey weighting procedures.[68] Due to the cross-sectional design, it is not possible to infer a

causal relationship between biopsychosocial-cultural and health systems characteristics and transition readiness. NSCH collects data from parents and caregivers, which may affect the accuracy of chronic pain prevalence without the use of specific criteria to diagnose chronic pain conditions. However, this definition has been used in previous studies.[2,44,64] Parental report of transition readiness does not necessarily reflect the adolescent's perspective on the transition process. Parents may be unaware of transition-relevant discussions during time alone with the provider that would impact the accuracy of their survey answers, consistent with our sensitivity analysis. However, previous nationally representative transition research has relied on parental response. [18,26,30–33,53] Our study could not capture if or what kind of pain care the adolescents was receiving, and if the transition questions are capturing future pain care (versus other types of care). This study was also unable to measure relevant pain-specific processes relevant to transition: such as pain interference, acceptance, severity, self-efficacy, caregiver protectiveness, and perceived provider stigma.[1,3,5,6,9,11–14,16,17]

More generally it is not clear how transition readiness relates to transition outcomes (or a consensus about how to define and measure either). However, implementation of transition programs has consistently demonstrated improved readiness (as measured by knowledge, confidence, and self-management skills) and outcomes (improved condition outcomes, cost and utilization, mental health, lapses in care, satisfaction with care and life, and stress) indicating an important area for future work.[22,23,28,29,38–40]

Conclusions

This study represents an important first step in demonstrating low transition readiness among adolescents with chronic pain at a national level. Readiness was lower among adolescents who were male, Asian or multiracial, with a developmental condition, and who did not experience shared decision making. Healthcare continuity may be a concern for adolescents with chronic pain as few met criteria for a medical home (mostly driven by lack of effective care coordination) and less than half had adequate insurance.

Future research should incorporate adolescents and provider perspectives and investigate pain specific factors relevant to transition readiness, include measures of pain-specific care, and investigate how readiness relates to transition outcomes.

Table 1. Survey items used to measure transition of care readiness in the 2021-2022 National Survey of Children's Health

Transition subcomponents	NSCH survey item	NSCH response options
Q1) If a discussion regarding transfer to an adult provider was needed it occurred	Do any of this child's doctors or other health care providers treat only children? • If yes, have they talked with you about when this child will need to see doctors or other health care providers who treat adults?	Yes No (skip to Q2) Yes No
Q2) The adolescent's provider worked with them to take responsibility for their own health care needs AND/OR understand adult health care needs	Has this child's doctor or other health care provider actively worked with this child to: Understand the changes in health care that happen at age 18. For example, by understanding changes in privacy, consent, access to information, or decision-making? Has this child's doctor or other health care provider actively worked with this child to: Gain skills to manage their health and health care. For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications they may need?	Yes No Don't know Yes No Don't know
Q3) The adolescent had time alone with their provider at their last preventative visit	At their LAST medical care visit, did this child have a chance to speak with a doctor or other health care provider privately, without you or another caregiver in the room? (Note: Youth without preventive check-up in the past 12 months are coded as No.)	Yes No

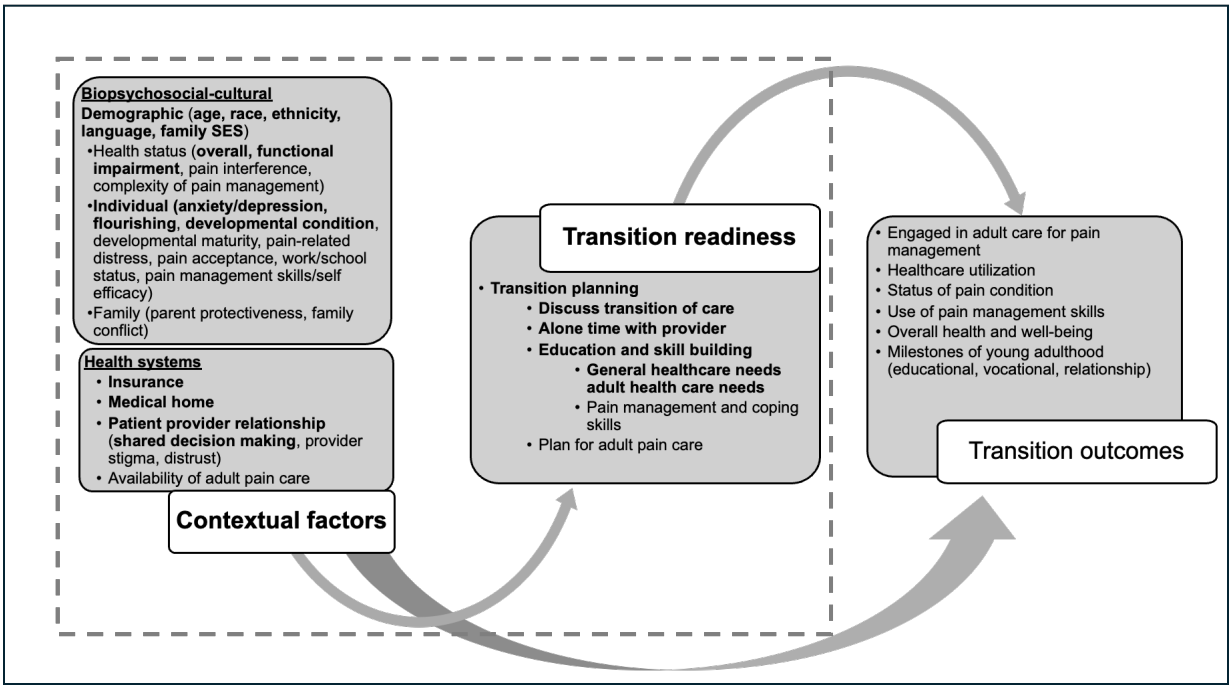

Figure 1. Conceptual model of transition of care continuum for adolescents with chronic pain. This study examined the portion of the model contained within the dashed box and assessed associations with the bolded biopsychosocial-cultural and health systems elements.

Table 2. Biopsychosocial-cultural and health systems characteristics of adolescents (age 14-17 years) with chronic pain in the United States, National Survey of Children's Health, 2021-2022

Biopsychosocial-cultural characteristics	n (total=2584)	Weighted prevalence (%)
Demographics		
Age (years)		
14	522	23.3
15	612	26.3
16	725	25.8
17	725	24.6
Sex		
Female	1613	64.4
Male	971	35.6
Family SES**		
<100%	431	21.6
100-199%	512	25.6
200-399%	744	24.8
>=400%	897	24.1
Race		
AIAN	40	2.3
Asian	96	3.3
Black	189	14.5
NHPI	24	1.6
Two or more races	234	6.7
White	2001	71.7
Ethnicity		
Hispanic	435	32.7
Not Hispanic	2149	67.4
Language		
English	2390	78.8
Spanish	121	18.3
Other	58	2.9
Health status		
Overall health		
Excellent	682	25.1
Very good	1003	38.6
Good	693	28.7
Fair	181	6.9
Poor	22	0.7
Frequency of functional impairment		
No health conditions	653	30.6
Never	530	23.5
Sometimes	1086	37
Usually	205	5.2
Always	101	3.7
Severity of functional impairment		
Very little	671	47.3
Somewhat	736	41.9
A great deal	211	10.7
Psychological health		
Mental health		
Either anxiety or depression	1405	47.5
Neither anxiety nor depression	1162	52.5
Developmental condition±		
None	2180	86
One or more	380	14

Individual flourishing		
No	1462	57.6
Yes	1086	42.4
Health systems characteristic		
Adequate insurance		
No	1101	60.9
Yes	872	39.1
Shared decision making		
No	283	21.5
Yes	1160	78.5
Medical home		
No	1594	67.4
Yes	983	32.6
Subcomponents		
Usual place for sick care	2223	78.9
Regular provider	2015	70.7
Family centered care[+] (n=2334)	1836	75.4
Referral[+] (n=1125)	785	74.4
Effective care coordination[+] n=1474)	674	43.4

**Ratio of total family income and federal poverty threshold

[±]Developmental delay, autism spectrum disorder, Down syndrome, and/or intellectual disability

[+] Only applied to those for whom it was pertinent

Table 3. Weighted prevalence of transition readiness by biopsychosocial-cultural and health systems characteristics among adolescents (age 14-17 years) with chronic pain, National Survey of Children's health, 2021-2022

		Transition readiness subcomponents			
Characteristic	Overall adequate transition readiness	Transition to adult care discussed	Alone with provider	Discussed positive health choices	Discussed changing healthcare needs
	Weighted prevalence % (95% CI)				
Entire sample	23.9 (20.3, 28.0)	23.4 (19.0, 27.9)	65.4 (61.3, 69.5)	68.8 (64.2, 73.3)	31.7 (27.9, 35.5)
Biopsychosocial-cultural characteristics					
Demographics					
Age (years)					
14	15.2 (10.2, 20.2)	11.8 (6.0, 17.7)	58.7 (50.3, 67.0)	67.3 (59.8, 75.0)	26.5 (19.0, 34.0)
15	27.7 (17.8, 37.6)	22.8 (11.6, 34.0)	63.8 (55.3, 72.2)	76.2 (68.6, 83.9)	31.0 (23.1, 38.9)
16	26.9 (19.9, 34.0)	36.6 (27.3, 45.9)	65.8 (58.7, 72.9)	68.6 (59.0, 78.2)	36.5 (28.7, 44.2)
17	24.9 (19.1, 30.7)	24.1 (17.5, 30.8)	72.9 (65.7, 81.2)	62.3 (52.2, 72.4)	32.3 (24.6, 39.7)
Sex					
Male	17 (13.0, 21.0)	19.9 (14.3, 25.5)	57.4 (51.0, 63.8)	66.2 (60.3, 72.1)	30.3 (24.5, 36.0)
Female	27.7 (22.3, 33.0)	25.6 (19.3, 31.9)	69.6 (64.5, 74.6)	70.2 (63.9, 76.5)	32.5 (27.4, 37.5)
Family SES**					
<100%	22.0 (12.6)	12.3 (5.5, 19.2)	57.8 (47.4, 68.2)	63.2 (51.4, 75.0)	38.3 (28.3, 48.2)
100-199%	20.0 (12.9, 27.1)	13.9 (7.9, 19.9)	64.4 (54.7, 74.1)	65.8 (55.0, 76.5)	32.9 (24.1, 41.8)
200-399%	27.4 (19.6, 35.3)	30.7 (20.1, 41.4)	68.5 (61.4, 75.6)	69.6 (62.4, 76.8)	38.5 (22.7, 36.3)
>=400%	25.3 (20.8, 29.8)	29.8 (23.3, 36.4)	68.4 (62.7, 74.1)	76 (70.8, 81.1)	27.3 (22.1, 32.6)
Race					
White	25.8 (21.1, 30.6)	28.2 (22.4, 34.0)	67.3 (62.6, 72.0)	68.7 (63.1, 74.3)	28.1 (23.9, 32.4)
Black	22.7 (13.4, 32.1)	14.9 (7.0, 22.8)	58.0 (46.1, 70.0)	67.3 (55.9, 78.8)	45.4 (33.9, 56.9)
AIAN	21.0 (0.6, 41.4)	2.9 (0.0, 7.2)	63.7 (34.9, 92.5)	82.1 (68.7, 95.4)	43.9 (19.4, 68.4)
Asian	10.4 (1.8, 18.9)	12.4 (1.8, 23.1)	59.3 (35.5, 83.1)	77.2 (58.9, 95.4)	48.7 (25.4, 72.0)
NHPI	8.0 (0, 21.7)	N/A	50.2 (7.4, 93.0)	46.6 (12.3, 81.0)	17.4 (0.3, 34.5)
Multi-racial	16.3 (10.1, 22.5)	12.2 (6.3, 18.2)	67.2 (55.8, 78.6)	69.4 (57.0, 81.7)	31.6 (19.6, 43.7)
Ethnicity					
Not Hispanic	25.1 (21.7, 28.4)	23.1 (18.9, 27.3)	63.7 (59.5, 67.8)	71.8 (68.0, 75.6)	33.5 (29.6, 37.6)
Hispanic	21.5 (12.4, 30.6)	24.2 (12.9, 35.5)	69.5 (60.1, 78.9)	62.7 (51.7, 73.8)	27.8 (19.9, 35.8)
Language					
English	25.4 (22.1, 28.7)	22.6 (18.6, 26.6)	65.7 (61.8, 69.7)	71.5 (68.0, 75.1)	33.7 (29.9, 37.5)
Spanish	17.2 (2.9, 31.6)	26 (8.0, 43.9)	65.7 (49.5, 81.8)	56.7 (63.1, 74.4)	21 (1.4, 31.6)
Other	28.7 (2.7, 53.6)	39.1 (5.6, 72.5)	56.7 (30.5, 82.8)	53.2 (45.7, 92.4)	40.5 (16.7, 64.3)
Health status					
Overall health					
Excellent	24.8 (16.5, 33.1)	27.8 (16.4, 39.2)	64.8 (57.0, 72.6)	70.8 (63.7, 77.9)	31.1 (23.9, 38.3)
Very good	24.2 (19.2, 29.4)	23.1 (17.0, 29.2)	63.8 (57.8, 70.0)	71.6 (66.0, 77.2)	33.8 (28.1, 39.4)
Good	22.6 (14.5, 30.1)	20.5 (13.0, 28.0)	66.9 (58.1, 75.7)	62.8 (51.4, 74.3)	30.5 (22.1, 38.9)
Fair	24.6 (13.4, 35.7)	19.6 (8.3, 30.8)	69.7 (55.9, 89.4)	69.6 (56.3, 83.0)	29.6 (17.5, 41.6)
Poor	14.0 (0, 30.8)	32.3 (0.0, 68.0)	64.0 (28.4, 99.7)	77.0 (49.6, 100.0)	8.0 (0.0, 17.9)
Frequency of functional impairment					
No health conditions	17.5 (12.2, 22.7)	20 (12.9, 27.1)	63.8 (56.2, 71.4)	63 (54.1, 72.0)	35.0 (27.2, 42.8)
Never	30.6 (19.9, 41.3)	33.8 (20.9, 46.8)	64.3 (54.9, 73.6)	65.3 (56.2, 74.3)	29.5 (21.7, 37.4)
Sometimes	25.4 (20.3, 30.5)	20.3 (14.8, 25.8)	68.2 (61.9, 74.5)	75.6 (68.0, 83.1)	30.2 (24.5, 35.9)
Usually	25.6 (14.7, 36.5)	20.5 (11.4, 29.6)	73.2 (64.0, 82.4)	74.9 (64.3, 85.4)	30.5 (18.9, 42.0)

Always	15.3 (3.9, 26.7)	24.6 (2.9, 46.2)	42.1 (21.8, 62.3)	62.7 (43.6, 81.8)	34.4 (12.4, 56.3)
Impact of functional impairment					
Very little	25.0 (17.2, 32.8)	21 (14.0, 28.0)	68.2 (60.2, 76.4)	71.2 (61.1, 81.3)	29.4 (22.1, 36.6)
Somewhat	29.9 (32.2, 36.6)	24.5 (16.7, 32.3)	67.7 (60.1, 75.2)	72.1 (64.5, 79.6)	32.9 (25.9, 40.0)
A great deal	16.0 (8.4, 23.6)	18.7 (9.7, 27.8)	24.7 (39.8, 69.6)	74.3 (64.4, 84.2)	29.8 (15.3, 44.2)
Psychological health					
Mental health (anxiety or depression)					
Neither	23.7 (17.5, 29.9)	25.8 (18.4, 33.2)	59.3 (53.1, 65.4)	64.6 (58.0, 71.2)	28.4 (23.2, 33.7)
Either	24.3 (20.2, 28.5)	21.3 (16.5, 26.2)	70.7 (65.1, 76.2)	73.9 (67.8, 80.1)	34.6 (29.2, 40.0)
Developmental condition[±]					
None	25.3 (21.09, 29.7)	23.8 (18.9, 28.9)	68.3 (64.0, 72.6)	68.1 (63.0, 73.3)	32.4 (28.2, 36.7)
1+	17.0 (11.7, 22.3)	22.2 (12.3, 32.0)	49.6 (39.4, 59.8)	70.2 (61.1, 79.2)	25.9 (16.7, 35.1)
Individual flourishing					
No	23.0 (18.0, 28.1)	21.6 (16.3, 26.9)	66.0 (60.4, 71.6)	67.3 (60.7, 73.8)	28.3 (23.2, 33.3)
Yes	25.4 (19.7, 31.2)	27.0 (19.3, 34.8)	64.9 (58.9, 71.0)	71.5 (65.5, 77.4)	35.9 (30.1, 41.7)
Health systems characteristics					
Adequate insurance					
No	23.3 (18.6, 28.1)	25.3 (17.0, 33.6)	69.5 (63.1, 75.9)	61.1 (53.0, 69.2)	28.5 (22.4, 34.6)
Yes	25.4 (19.6, 31.1)	26.6 (19.6, 33.5)	66.2 (59.9, 72.6)	73.4 (67.0, 79.8)	30.2 (24.0, 36.4)
Shared decision making					
No	18.8 (8.8, 28.9)	24.9 (13.4, 36.4)	58.7 (46.1, 71.3)	68.6 (58.6, 78.6)	19.3 (10.4, 28.3)
Yes	31.1 (28.8, 37.2)	28.6 (22.2, 35.0)	67.9 (62.2, 73.5)	82.1 (77.4, 86.8)	33.0 (27.3, 38.7)
Medical home					
No	24.3 (19.1, 29.4)	24.5 (18.2, 30.8)	67.3 (62.0, 72.6)	64.0 (57.9, 790.1)	32.6 (27.5, 37.8)
Yes	23.0 (8.6, 27.5)	21.6 (16.0, 27.1)	61.5 (55.4, 67.5)	78.5 (73.4, 83.6)	29.8 (24.5, 35.0)
Subcomponents					
Usual place for sick care					
No	22.5 (12.1, 32.9)	23.4 (12.6, 34.1)	69.6 (57.7, 81.4)	54.1 (41.7, 66.5)	35.3 (24.9, 45.7)
Yes	24.2 (20.3, 28.2)	23.5 (18.6, 28.4)	64.5 (60.3, 68.8)	72.7 (68.2, 77.2)	30.8 (26.7, 34.8)
Regular provider					
No	23.1 (13.4, 32.7)	24.5 (11.1, 37.8)	67.5 (58.3, 76.7)	56.5 (46.3, 66.7)	30.5 (22.4, 38.6)
Yes	24.2 (20.7, 27.8)	23.2 (19.0, 27.4)	64.6 (60.1, 69.2)	74.0 (69.2, 78.8)	32.3 (28.0, 36.5)
Family centered care[+]					
No	27.5 (16.0, 39.0)	26.7 (13.3, 40.0)	66.2 (57.3, 75.0)	63.9 (55.1, 72.8)	20.9 (14.1, 27.6)
Yes	26.8 (22.9, 30.6)	23.2 (18.7, 27.7)	65.1 (60.5, 69.7)	79.1 (74.1, 84.1)	37.6 (32.9, 42.3)
Referral[+]					
No	28.2 (18.6, 37.8)	19.7 (11.0, 28.4)	72.0 (61.8, 82.2)	74.7 (66.0, 83.3)	27.6 (18.7, 36.5)
Yes	31.7 (24.0, 39.3)	28.2 (20.8, 35.5)	68.0 (61.2, 74.9)	80.8 (75.4, 86.2)	34.3 (27.6, 41.1)
Effective care coordination[+]					
No	27.6 (20.6, 34.7)	22.2 (15.3, 29.1)	65.6 (58.5, 72.7)	76.2 (70.2, 82.3)	37.3 (30.0, 44.7)
Yes	29.2 (22.3, 36.1)	29.0 (21.4, 36.6)	67.2 (59.4, 75.0)	79.9 (68.4, 91.0)	38.7 (30.4, 47.0)

**Ratio of total family income and federal poverty threshold

[±]Developmental delay, autism spectrum disorder, Down syndrome, and/or intellectual disability

[+] Only applied to those for whom it was pertinent

NA indicates the outcome did not pertain to the adolescent in the specified category

Table 4. Prevalence ratios of transition readiness by biopsychosocial-cultural characteristics among adolescents (age 14-17) years with chronic pain, National Survey of Children's health, 2021-2022

Characteristics	Overall adequate transition readiness	Transition readiness subcomponents			
		Transition to adult care discussed	Alone with provider	Discussed positive health choices	Discussed changing healthcare needs
Demographics	Prevalence ratio (95% CI)				
Age (years)					
14	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
15	1.8 (1.1, 3.0)	1.9 (1.0, 3.9)	1.1 (0.9, 1.3)	1.1 (1.0, 1.3)	1.2 (0.8, 1.7)
16	1.8 (1.2, 2.7)	3.1 (1.8, 5.4)	1.1 (0.9, 1.3)	1.0 (0.9, 1.2)	1.4 (1.0, 2.0)
17	1.6 (1.1, 2.5)	2.0 (1.2, 3.6)	1.2(1.0, 1.5)	0.9 (0.8, 1.1)	1.2 (0.8, 1.8)
Sex					
Male	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Female	1.6 (1.2, 2.2)	1.3 (0.9, 1.9)	1.2 (1.0, 1.4)	1.1 (0.9, 1.2)	1.1 (0.8, 1.4)
Family SES**, ∩, Σ, θ					
<100%	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
100-199%	0.9 (0.5, 1.2)	1.0 (0.5, 2.1)	1.1 (0.9, 1.4)	1.0 (0.8, 1.4)	0.9 (0.6, 1.2)
200-399%	1.2 (0.7, 2.0)	2.2 (1.2, 4.2)	1.2 (0.9, 1.4)	1.1 (0.9, 1.4)	0.8 (0.6, 1.1)
>=400%	1.1 (0.7, 1.8)	2.1 (1.2, 3.7)	1.1 (0.9, 1.4)	1.2 (1.0, 1.5)	0.8 (0.6, 1.1)
Race					
White	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Black	0.9 (0.6, 1.4)	0.5 (0.3, 0.9)	0.9 (0.7, 1.1)	1.0 (0.8, 1.2)	1.6 (1.2, 2.2)
AIAN	0.8 (0.3,2.2)	0.1 (0.0, 0.5)	0.9 (0.6, 1.5)	1.2 (1.0, 1.5)	1.6 (0.9, 2.8)
Asian	0.4 (0.2, 0.9)	0.4 (0.2, 1.1)	0.9 (0.6, 1.3)	1.2 (0.9, 1.4)	1.7 (1.1, 2.9)
NHPI	0.3 (0.1, 1.8)	N/A	0.7 (0.3, 1.8)	0.7 (0.3, 1.4)	0.6 (0.2, 1.7)
Two or more races	0.6 (0.4, 0.9)	0.4 (0.3, 0.7)	1.0 (0.8, 1.2)	1.0 (0.8, 1.2)	1.1 (0.8, 1.7)
Ethnicity					
Not Hispanic	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Hispanic	0.9 (0.6, 1.3)	1.0 (0.3, 1.7)	1.1 (0.9, 1.2)	0.9 (0.7, 1.1)	0.8 (0.6, 1.1)
Language					
English	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Spanish	0.7 (0.3, 1.6)	1.1 (0.6, 2.4)	1.0 (0.8, 1.3)	0.8 (0.6, 1.1)	0.6 (0.4, 1.0)
Other	1.1 (0.5, 2.8)	1.7 (0.7, 4.2)	0.9 (0.5, 1.4)	1.0 (0.7, 1.4)	1.2 (0.7, 2.2)
Health status⊗,Σ,♦,∇					
Overall health					
Excellent	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Very good	0.9 (0.6, 1.7)	0.7 (0.5, 1.1)	1.0 (0.9, 1.6)	1.1 (0.9, 1.3)	1.0 (0.7, 1.4)
Good	0.9 (0.5, 1.5)	0.7 (0.5, 1.2)	1.0 (0.8, 1.2)	1.0 (0.8, 1.2)	0.9 (0.6, 1.4)
Fair	0.5 (0.3, 1.1)	0.5 (0.2, 1.1)	0.9 (0.6, 1.2)	1.1 (0.8, 1.5)	0.7 (0.4, 1.3)
Poor	0.4 (0.1, 1.8)	1.2 (0.5, 3.2)	1.0 (0.5, 2.0)	1.1 (0.8, 1.7)	0.1 (0.0, 0.4)
Frequency of functional impairment					
No health conditions					
Never	1.5 (0.8, 2.6)	1.5 (0.9, 2.6)	1.0 (0.8, 1.2)	1.1 (0.8, 1.4)	0.8 (0.5, 1.2)
Sometimes	1.4 (0.9, 2.1)	1.0 (0.6, 1.6)	1.1 (1.0, 1.3)	1.2 (1.0, 1.5)	0.8 (0.6, 1.1)
Usually	(0.6, 1.9)	0.9 (0.5, 1.8)	1.2 (1.0, 1.5)	1.2 (0.9, 1.6)	0.7 (0.4, 1.2)
Always	0.8 (0.3, 1.9)	1.2 (0.5, 2.6)	1.0 (0.7, 1.5)	1.0 (0.6, 1.6)	0.5 (0.2, 1.2)
Impact of functional impairment					
Very little	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Somewhat	1.3 (0.7, 1.6)	1.1 (0.7, 1.7)	1.0 (0.8, 1.2)	1.0 (0.8, 1.2)	1.0 (0.7, 1.6)
A great deal	0.6 (0.3, 1.1)	0.8 (0.4, 1.5)	0.9 (0.7, 1.2)	0.9 (0.7, 1.2)	0.6 (0.3, 1.1)
Psychological health					
Mental health (anxiety of depression)Ω					

Neither	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Either	1.1 (0.8, 1.4)	0.9 (0.6, 1.2)	1.2 (1.0, 1.4)	1.2 (1.0, 1.4)	1.2 (1.0, 1.6)
Developmental condition[±]					
None	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
1+	0.7 (0.5, 0.9)	0.9 (0.6, 1.5)	0.7 (0.6, 0.9)	1.0 (0.9, 1.2)	0.8 (0.6, 1.2)
Individual flourishing [+,∘,∩,θ]					
No	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Yes	1.1 (0.8, 1.4)	1.2 (0.8, 1.6)	1.0 (0.9, 1.1)	1.1 (0.9, 1.2)	1.3 (1.0, 1.6)

**Ratio of total family income and federal poverty threshold

[±]Developmental delay, autism spectrum disorder, Down syndrome, and/or intellectual disability

Adjusted for: [+]age, [∘]sex, [⊗]family SES, [∩]race, [θ]ethnicity, [Σ]language, [Ω]health status, [♦]insurance, [▽]medical home

NA indicates no adolescents in this row required a discussion regarding transition (i.e. were already seeing a provider who saw adults)

Table 5. Adjusted prevalence ratios of transition readiness by health systems characteristics among adolescents (age 14-17) years with chronic pain, National Survey of Children's Health, 2021-2022

Characteristics	Overall adequate transition readiness	Transition subcomponents			
		Transition to adult care discussed	Alone with provider	Discussed positive health choices	Discussed changing healthcare needs
	Adjusted prevalence ratio (95% CI)				
Adequate insurance[⊗]					
No	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Yes	1.0 (0.7, 1.4)	0.9 (0.6, 1.4)	0.9 (0.8, 1.1)	1.1 (1.0, 1.3)	1.1 (0.8, 1.4)
Shared decision making[Ω,ω]					
No	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Yes	1.7 (1.0, 3.0)	1.1 (0.7, 1.8)	1.2 (0.9, 1.5)	1.2 (1.0, 1.4)	1.7 (1.1, 2.8)
Medical home[⊗, Σ, Ω,ω,♦]					
No	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Yes	1.0 (0.7, 1.3)	0.8 (0.6, 1.2)	0.9 (0.8, 1.1)	1.2 (1.1, 1.3)	0.9 (0.7, 1.2)
Subcomponents					
Usual place for sick care					
No	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Yes	0.9 (0.5, 1.6)	0.7 (0.5, 1.2)	0.8 (0.7, 1.0)	1.4 (1.0, 1.9)	0.9 (0.6, 1.4)
Regular provider					
No	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Yes	1.0 (0.7, 1.5)	1.0 (0.6, 1.6)	1.0 (0.8, 1.1)	1.4 (1.1, 1.8)	1.0 (0.7, 1.5)
Family centered care					
No	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Yes	1.0 (0.7, 1.5)	0.8 (0.6, 1.2)	1.1 (0.9, 1.3)	1.3 (1.1, 1.6)	1.7 (1.1, 2.6)
Referral					
No	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Yes	1.2 (0.8, 2.1)	1.3 (0.8, 2.3)	1.0 (0.8, 1.2)	1.1 (0.9, 1.3)	1.1(0.7, 1.8)
Effective care coordination					
No	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)	1.0 (ref)
Yes	1.0 (0.7, 1.5)	1.1 (0.7, 1.6)	1.0 (0.9, 1.2)	1.1 (0.9, 1.3)	1.2 (0.8, 1.8)

Adjusted for: [⊗]family SES, [Σ]language, [Ω]health status [ω] developmental condition, [♦]insurance

References

1. Huckerby L, McDonagh JE, Lee RR. Growing up with chronic pain: a systematic review of the evidence in transitional care for young people with chronic pain. *Rheumatol Adv Pract*. 2023;7(Suppl 1):i19-i25. doi:10.1093/RAP/RKAD006
2. Groenewald CB, Palermo TM. The price of pain: the economics of chronic adolescent pain. *Pain Manag*. 2015;5(2):61. doi:10.2217/PMT.14.52
3. Champion J, Crawford M, Jaaniste T. Predicting the need for rransition from pediatric to adult pain services: A retrospective, longitudinal study sssing the electronic persistent pain outcome collaboration (ePPOC) Databases. *Children (Basel)*. 2023;10(2). doi:10.3390/CHILDREN10020357
4. Murray CB, De La Vega R, Murphy LK, Kashikar-Zuck S, Palermo TM. The prevalence of chronic pain in young adults: A systematic review and meta-analysis. *Pain*. 2022;163(9):E972-E984. doi:10.1097/J.PAIN.0000000000002541
5. Murray CB, Murphy LK, Jordan A, Owens MT, McLeod D, Palermo TM. Healthcare transition among young adults with childhood-onset chronic pain: A mixed methods study and proposed framework. *J Pain*. 2022;23(8):1358-1370. doi:10.1016/J.JPAIN.2022.02.010
6. Twiddy H, Hanna J, Haynes L. Growing pains: understanding the needs of emerging adults with chronic pain. *Br J Pain*. 2017;11(3):108. doi:10.1177/2049463717709641
7. Dewar A, White M, Posade ST, Dillon W. Using nominal group technique to assess chronic pain, patients' perceived challenges and needs in a community health region. *Health Expect*. 2003;6(1):44. doi:10.1046/J.1369-6513.2003.00208.X
8. Stinson JN, Lalloo C, Harris L, et al. iCanCope with Pain™: User-centred design of a web- and mobile-based self-management program for youth with chronic pain based on identified health care needs. *Pain Research & Management : The Journal of the Canadian Pain Society*. 2014;19(5):257. doi:10.1155/2014/935278
9. Lynch Milder MK, Ward S, Bazier A, Stumpff J, Tsai Owens M, Williams AE. The health care transition needs of adolescents and emerging adults with chronic pain: A narrative review. *J Clin Psychol Med Settings*. Published online June 26, 2023:1-11. doi:10.1007/S10880-023-09966-0/TABLES/1
10. Stinson J, White M, Isaac L, et al. Understanding the information and service needs of young adults with chronic pain: Perspectives of young adults and their providers. *Clinical Journal of Pain*. 2013;29(7):600-612. doi:10.1097/AJP.0B013E31826DCE65
11. Oreper J, Khalid A, Sheffe S, Mustafa N, Vader K, Bosma R. Defining success in transitions from pediatric to adult chronic pain care: A descriptive qualitative study of perspectives of young adults living with chronic pain. *Pain Medicine*. 2022;23(7):1217-1224. doi:10.1093/PM/PNAC058
12. Higginson A, Forgeron P, Harrison D, Finley GA, Dick BD. Moving on: Transition experiences of young adults with chronic pain. *Canadian Journal of Pain*. 2019;3(1):85. doi:10.1080/24740527.2019.1587707
13. Kashikar-Zuck S. Transition of care for adolescents with chronic pain. *Lancet Child Adolesc Health*. 2021;5(1):9-11. doi:10.1016/S2352-4642(20)30317-5
14. Forgeron PA, McGrath PJ. Self-identified needs of youth with chronic pain. *Journal of Pain Management* . Published online 2008:163-172.
15. Higginson A, Forgeron P, Dick B, Harrison D. Moving on: A survey of Canadian nurses' self-reported transition practices for young people with chronic pain. *Canadian Journal of Pain*. 2018;2(1):169. doi:10.1080/24740527.2018.1484663
16. Kudrina I, Bartlett G, Pagé MG, et al. Transitional pain care in Quebec: Did we forget our youths? A brief research report. *Frontiers in Pain Research*. 2022;3:885570. doi:10.3389/FPAIN.2022.885570/BIBTEX
17. Forgeron P, Higginson A, Truskoski C. Departure from pediatric care: Transitioning of adolescents with chronic pain to adult care. *Pain Management Nursing*. 2017;18(5):273-277. doi:10.1016/J.PMN.2017.05.001
18. Mulkey M, Baggett AB, Tumin D. Readiness for transition to adult health care among US adolescents, 2016–2020. *Child*. 2023;49(2):321. doi:10.1111/CCH.13047
19. Eaton CK, Davis MF, Gutierrez-Colina AM, LaMotte J, Blount RL, Suveg C. Different demands, same goal: Promoting transition readiness in adolescents and young adults with and without

medical conditions. *Journal of Adolescent Health*. 2017;60(6):727-733. doi:10.1016/J.JADOHEALTH.2017.01.002
20. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110(6):1304-1306.
21. Okumura MJ, Kuo DZ, Ware AN, Cyr MH, White PH. Improving health care transitions for children and youth with special health care needs. *Acad Pediatr*. 2022;22(2S):S7-S13. doi:10.1016/J.ACAP.2021.03.014
22. Findley MK, Cha ES, Wong E, Faulkner MS. A systematic review of transitional care for emerging adults with diabetes. *J Pediatr Nurs*. 2015;30(5):e47-e62. doi:10.1016/J.PEDN.2015.05.019
23. Scal P, Horvath K, Garwick A. Preparing for adulthood: Health care transition counseling for youth with arthritis. *Arthritis Care Res (Hoboken)*. 2009;61(1):52-57. doi:10.1002/ART.24088
24. Rheumatology E, El Miedany Y, Hassan Abu-Zaid M, et al. Consensus evidence-based recommendations for transition of care for adolescents with juvenile idiopathic arthritis: meeting patients', parents', and rheumatologists' perspectives. *Egyptian Rheumatology and Rehabilitation 2023 50:1*. 2023;50(1):1-12. doi:10.1186/S43166-023-00195-9
25. Calhoun C, Luo L, Baumann AA, et al. Transition for adolescents and young adults with sickle cell disease in a US midwest urban center: A multi-level perspective on barriers, facilitators, and future directions. *J Pediatr Hematol Oncol*. 2022;44(5):e872. doi:10.1097/MPH.0000000000002322
26. Telfair J, Ehiri JE, Loosier PS, Baskin ML. Transition to adult care for adolescents with sickle cell disease: Results of a national survey. *Int J Adolesc Med Health*. 2004;16(1):47-64. doi:10.1515/IJAMH.2004.16.1.47/MACHINEREADABLECITATION/RIS
27. Fenton N, Ferris M, Ko Z, Javalkar K, Hooper SR. The relationship of health care transition readiness to disease-related characteristics, psychosocial factors, and health care outcomes: Preliminary findings in adolescents with chronic kidney disease. *J Pediatr Rehabil Med*. 2015;8(1):13-22. doi:10.3233/PRM-150314
28. Rosen D, Annunziato R, Colombel JF, Dubinsky M, Benkov K. Transition of inflammatory bowel disease care: Assessment of transition readiness factors and disease outcomes in a young adult population. *Inflamm Bowel Dis*. 2016;22(3):702-708. doi:10.1097/MIB.0000000000000633
29. Fredericks EM, Dore-Stites D, Well A, et al. Assessment of transition readiness skills and adherence in pediatric liver transplant recipients. *Pediatr Transplant*. 2010;14(8):944-953. doi:10.1111/J.1399-3046.2010.01349.X
30. Lebrun-Harris LA, McManus MA, Ilango SM, et al. Transition planning among US youth with and without special health care needs. *Pediatrics*. 2018;142(4). doi:10.1542/PEDS.2018-0194/37417
31. Richmond N, Tran T, Berry S. Receipt of transition services within a medical home: Do racial and geographic disparities exist? *Matern Child Health J*. 2011;15(6):742-752. doi:10.1007/S10995-010-0635-2/TABLES/8
32. Ilango SM, Lebrun-Harris LA, Jones JR, et al. Associations between health care transition preparation among youth in the U.S. and other components of a well-functioning system of services. *Journal of Adolescent Health*. 2021;69(3):414-423. doi:10.1016/J.JADOHEALTH.2021.01.006
33. McKenzie RB, Sanders L, Bhattacharya J, Kate Bundorf M. Health care system factors associated with transition preparation in youth with special health care needs. *Popul Health Manag*. 2019;22(1):63. doi:10.1089/POP.2018.0027
34. Morton B, Damato EG, Ciccarelli MR, Currie J. Care coordination for children with special healthcare needs anticipating transition: A program evaluation. *J Pediatr Nurs*. 2021;61:7-14. doi:10.1016/J.PEDN.2021.02.024
35. Javalkar K, Johnson M, Kshirsagar A V., Ocegueda S, Detwiler RK, Ferris M. Ecological factors predict transition readiness/self-management in youth with chronic conditions. *Journal of Adolescent Health*. 2016;58(1):40-46. doi:10.1016/J.JADOHEALTH.2015.09.013
36. Cooley WC, Sagerman PJ, Barr MS, et al. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182-200. doi:10.1542/PEDS.2011-0969
37. Leeb RT, Danielson ML, Bitsko RH, et al. Support for transition from adolescent to adult health care among adolescents with and without mental, behavioral, and developmental disorders - United States, 2016-2017. *MMWR Morb Mortal Wkly Rep*. 2020;69(34):1156-1160. doi:10.15585/MMWR.MM6934A2

38. Schmidt A, Ilango SM, McManus MA, Rogers KK, White PH. Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *J Pediatr Nurs*. 2020;51:92-107. doi:10.1016/J.PEDN.2020.01.002
39. Gabriel P, McManus M, Rogers K, White P. Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *J Pediatr*. 2017;188:263-269.e15. doi:10.1016/J.JPEDS.2017.05.066
40. Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between paediatric and adult healthcare: a systematic review. *Arch Dis Child*. 2011;96(6):548-553. doi:10.1136/ADC.2010.202473
41. Jensen PT, Paul G V., LaCount S, et al. Assessment of transition readiness in adolescents and young adults with chronic health conditions. *Pediatric Rheumatology*. 2017;15(1):1-7. doi:10.1186/S12969-017-0197-6/FIGURES/1
42. Takeuchi J, Yanagimoto Y, Sato Y, et al. Efficacious interventions for improving the transition readiness of adolescents and young adult patients with chronic illness: A narrative review of randomized control trials assessed with the transition readiness assessment questionnaire. *Front Pediatr*. 2022;10. doi:10.3389/FPED.2022.983367
43. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *J Clin Epidemiol*. 2008;61(4):344-349. doi:10.1016/J.JCLINEPI.2007.11.008
44. Groenewald CB, Murray CB, Palermo TM. Adverse childhood experiences and chronic pain among children and adolescents in the United States. *Pain Rep*. 2020;5(5). doi:10.1097/PR9.0000000000000839
45. Tumin D, Drees D, Miller R, et al. Health care utilization and costs associated with pediatric chronic pain. *J Pain*. 2018;19(9):973-982. doi:10.1016/J.JPAIN.2018.03.012
46. Ignacio DA, Emick-Seibert J, Serpas DG, Fernandez YS, Bargotra S, Bush J. Individual, family, and social correlates of flourishing outcomes among youth: Findings from the 2016–2017 National Survey of Children's Health. *Child Abuse Negl*. 2022;127:105560. doi:10.1016/J.CHIABU.2022.105560
47. Cochrane Library Cochrane Database of Systematic Reviews Interventions for promoting participation in shared decision-making for children and adolescents with cystic fibrosis (Review) Interventions for promoting participation in shared decision-making for children and adolescents with cystic fibrosis (Review). Published online 2019. doi:10.1002/14651858.CD012578.pub2
48. Chiam M, Rojas E, Bergey MR, Mackie TI. The effect of medical home on shared decision-making for caregivers of children with emotional, developmental, or behavioral health conditions. *Matern Child Health J*. 2021;25(8):1285-1295. doi:10.1007/S10995-021-03148-W/TABLES/2
49. McKenzie RB, Sanders L, Bhattacharya J, Kate Bundorf M. Health care system factors associated with transition preparation in youth with special health care needs. *Popul Health Manag*. 2019;22(1):63-73. doi:10.1089/POP.2018.0027
50. Lynch Milder MK, Ward S, Bazier A, Stumpff J, Tsai Owens M, Williams AE. The health care transition needs of adolescents and emerging adults with chronic pain: A narrative review. *J Clin Psychol Med Settings*. Published online June 26, 2023:1-11. doi:10.1007/S10880-023-09966-0/TABLES/1
51. Hart ER, Troller-Renfree S V., Sperber JF, Noble KG. Relations among socioeconomic status, perceived stress, and the home language environment. *J Child Lang*. 2023;87(3):1-18. doi:10.1017/S0305000923000156
52. Fiks AG, Localio AR, Alessandrini EA, Asch DA, Guevara JP. Shared decision-making in pediatrics: A national perspective. *Pediatrics*. 2010;126(2):306-314. doi:10.1542/PEDS.2010-0526
53. Cheak-Zamora N, Betz C, Mandy T. Measuring health care transition: Across time and into the future. *J Pediatr Nurs*. 2022;64:91-101. doi:10.1016/J.PEDN.2022.02.018
54. Betz CL, Coyne I, Hudson SM. Health care transition: The struggle to define itself. *Compr Child Adolesc Nurs*. 2023;46(3):162-176. doi:10.1080/24694193.2021.1933264
55. Straus EJ. Challenges in measuring healthcare transition readiness: Taking stock and looking forward. *J Pediatr Nurs*. 2019;46:109-117. doi:10.1016/J.PEDN.2019.03.016
56. Mulkey M, Baggett AB, Tumin D. Readiness for transition to adult health care among US adolescents, 2016–2020. *Child*. 2023;49(2):321. doi:10.1111/CCH.13047

57. Gigli KH, Graaf G. Changes in use and access to care for children and youth with special health care needs during the COVID-19 pandemic. *Journal of Pediatric Health Care*. 2023;37(2):185-192. doi:10.1016/J.PEDHC.2022.09.008
58. Lebrun-Harris LA, Sappenfield OR, Warren MD. Missed and delayed preventive health care visits among US children due to the COVID-19 pandemic. *https://doi.org/101177/00333549211061322*. 2021;137(2):336-343. doi:10.1177/00333549211061322
59. Callahan ST, Cooper WO. Changes in ambulatory health care use during the transition to young adulthood. *Journal of Adolescent Health*. 2010;46(5):407-413. doi:10.1016/J.JADOHEALTH.2009.09.010
60. Kauh TJ, Read JG, Scheitler AJ. The critical role of racial/ethnic data disaggregation for health equity. *Popul Res Policy Rev*. 2021;40(1):1. doi:10.1007/S11113-020-09631-6
61. Bauer GR. Incorporating intersectionality theory into population health research methodology: challenges and the potential to advance health equity. *Soc Sci Med*. 2014;110:10-17. doi:10.1016/J.SOCSCIMED.2014.03.022
62. Roux AVD. Complex systems thinking and current impasses in health disparities Research. *Am J Public Health*. 2011;101(9):1627. doi:10.2105/AJPH.2011.300149
63. Dean LT, Thorpe RJ. What structural racism is (or is not) and how to measure it: clarity for public health and medical researchers. *Am J Epidemiol*. 2022;191(9):1521-1526. doi:10.1093/AJE/KWAC112
64. Kapos FP, Vandeleur DM, Tham SW, Palermo TM, Groenewald CB. Comparing the prevalence of chronic pain in school-aged children in the United States from 2019 to 2020: a nationally representative study examining differences associated with the COVID-19 pandemic. *Pain*. Published online August 8, 2023. doi:10.1097/J.PAIN.0000000000003020
65. Vinall J, Pavlova M, Asmundson GJG, Rasic N, Noel M. Mental health comorbidities in pediatric chronic pain: A narrative review of epidemiology, models, neurobiological mechanisms and treatment. *Children*. 2016;3(4). doi:10.3390/CHILDREN3040040
66. Kapos FP, Vandeleur DM, Tham SW, Palermo TM, Groenewald CB. Comparing the prevalence of chronic pain in school-aged children in the United States from 2019 to 2020: a nationally representative study examining differences associated with the COVID-19 pandemic. *Pain*. 2024;165(1):233-242. doi:10.1097/J.PAIN.0000000000003020
67. Lichstein JC, Ghandour RM, Mann MY. Access to the medical home among children with and without special health care needs. *Pediatrics*. 2018;142(6). doi:10.1542/PEDS.2018-1795
68. *2021 National Survey of Children's Health Nonresponse Bias Analysis*. 2023.