



# The Health Care Transition Needs of Adolescents and Emerging Adults with Chronic Pain: A Narrative Review

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## Abstract

The aim of this narrative review was to provide an overview of what is known about the health care transition process in pediatric chronic pain, barriers to successful transition of care, and the roles that pediatric psychologists and other health care providers can play in the transition process. Searches were run in Ovid, PsycINFO, Academic Search Complete, and PubMed. Eight relevant articles were identified. There are no published protocols, guidelines, or assessment measures specific to the health care transition in pediatric chronic pain. Patients report many barriers to the transition process, including difficulty attaining reliable medical information, establishing care with new providers, financial concerns, and adapting to the increased personal responsibility for their medical care. Additional research is needed to develop and test protocols to facilitate transition of care. Protocols should emphasize structured, face-to-face interactions and include high levels of coordination between pediatric and adult care teams.

**Keywords** Pediatric · Chronic pain · Health care transition · Transition of care

## Introduction

Pediatric chronic pain, or persistent pain lasting longer than 3 months, is a widely prevalent condition (King et al., 2011). Conservative population prevalence estimates range from 5 to 37% in the U.S. (Tumin et al., 2018). The incidence of chronic pain peaks in adolescence (Eccleston & Malleon, 2003) and a significant proportion of youth continue to experience chronic pain well into adulthood (i.e., 33 to 64% (Kashikar-Zuck, 2021; Walker et al., 2010), suggesting many youth with chronic pain do not “grow out” of their symptoms and will require ongoing care for pain into adulthood.

Adolescence and emerging adulthood are periods of time characterized by important developmental milestones,

increased personal responsibility, and movement toward independence (Alderman & Breuner, 2019; Arnett, 2014). Adolescents with chronic pain have been found to be at risk of declines in overall health outcomes into early adulthood (Prior et al., 2014). Furthermore, adolescents with chronic pain differ substantially from their healthy peers as high intensity and frequent pain has been associated with overall a poor self-reported quality of life, poor health status, greater stress and sleep disturbances, anxiety, depression, and poor social functioning (Merlijn et al., 2006).

Particularly relevant to those with chronic pain, youth must transition from the pediatric to the adult health care system and advance their self-management skills. The concept of transitioning care to the adult health care system is not new—indeed, pediatric and adult hospitals have been successfully managing the transition of their young adult patients for several decades. According to the American Academy of Pediatrics, American Academy of Family Medicine, and American College of Physicians—American Society of Internal Medicine, best practice for health care transition includes six core elements: an established clinic policy/guide, identification of transition age youth, assessment of transition readiness, transition planning, transfer of care, and successful establishment of ongoing care with adult providers (American Academy of Pediatrics et al.,

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2002; Cooley et al., 2011). This is a multi-stage process beginning in early adolescence that involves collaboration between patient, parents, and providers (Blum et al., 1993; McManus et al., 2015). Further, careful consideration should be given to the developmental level of the adolescent, their disease specific needs, adherence to health recommendations, communication between patient and provider(s), and patient self-advocacy skills for successful transition of care (Gray et al., 2015).

The Social–ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) is a validated theoretical model for addressing important aspects to transition of health care (Schwartz et al., 2011, 2013). While it has not yet been studied in pediatric chronic pain conditions, it provides a structure that is relevant to this population. The SMART theoretical model includes multiple stakeholders (patients, parents, and providers) and both objective and subjective factors that influence readiness and success for transition. Objective factors include things such as access to care, insurance coverage, and medical status. Subjective factors include health care literacy, self-management skills, and perceptions of self-efficacy. This theoretical model helps provide initial conceptual factors that may influence the transition of care process for youth with chronic pain. Unfortunately, across chronic illness populations, pediatric patients often do not receive adequate guidance or support during the transition process, leaving them unprepared and vulnerable to lapses in care (Gabriel et al., 2017; Hilliard et al., 2014; Michaud et al., 2018). Without a coordinated and informed transition, the quality of care is impacted and the patient is at increased risk for negative physical and psychosocial outcomes (Zhou et al., 2016).

Adolescents' and emerging adults' ability to establish care, independently manage their medical needs, and adhere to treatment recommendations is often less than optimal which negatively impacts their health and quality of life (Okumura et al., 2015; Simons et al., 2010; Stinson et al., 2013). The barriers to achieving an effective transition are significantly heightened among those who develop chronic pain in adolescence, in part due to the limited amount of time these individuals have to acquire independent self-management skills needed for transition readiness (Rosenbloom et al., 2017; Walker et al., 2010). Moreover, given the widespread impact of chronic pain in youth, the presence of chronic pain has been found to disrupt attainment of developmental milestones in emerging adulthood and beyond (Murray et al., 2020). A diagnosed chronic pain syndrome in adolescence has been associated with long term risk of socioeconomic and social disparities in adulthood due to prolonged disability accompanied by symptoms and treatment regimens (Scascighini et al., 2008).

Treatment regimens for chronic pain are comprehensive in nature. It often consists of cognitive–behavioral

approaches, physiological response/relaxation education, and pain management through medication or other medical approaches. Given the complex and multidisciplinary treatment approach for chronic pain accompanied by long-term economic costs for treatment, the significance of pain specific transition care is further highlighted.

Because of the inherent challenges associated with transitioning to the adult health care system, pediatric psychologists play an integral role in supporting these patients. For example, psychologists are knowledgeable in developmental issues related to transition of care, help promote patients' autonomy, teach self-advocacy skills, and are actively involved in health regulations pertaining to the planning and execution of the transition (Gray et al., 2015). Psychologists can also serve as a liaison between these patients and available resources within the adult setting to provide adequate resources to meet the needs of the patient while attempting to maintain continuity (Bonanno et al., 2019). Research is limited on the transition needs, barriers to care, and protocols for supporting transition age youth with chronic pain. The purpose of this narrative review is to provide an overview of what is known about the health care transition process in pediatric chronic pain, barriers to successful transition of care, and the roles that pediatric psychologists and other health care providers can play in the transition process. Psychologists and other mental health professionals often work within multidisciplinary teams treating chronic pain. As such, they are in a unique position to help prepare youth for the transition to an adult-oriented health care setting.

## Methods

Database searches were conducted on July 14, 2021. 120 Citations were retrieved in MEDLINE (Ovid), and 161 citations were retrieved in EMBASE (Ovid). The following subject headings and keywords were used to identify relevant articles: Chronic Pain, Young Adult, Adolescent Psychiatry, Adolescent Health Services, Adolescent, Adolescent Health, Adolescent Medicine, Transition to Adult Care, "Continuity of Patient Care", Self-Management, (chronic adj3 pain), ((transition\* or health) adj3 (care or management or service or process\*)), and adolescen\*.tw. Additionally, PsycINFO, Academic Search Complete, and PubMed were searched using the following terms: Transitional Care, Chronic Pain, Continuum of Care, Adolescent Health, transition\*, adolescen\*, adult, pediatric, pain, persistent pain, long term pain, and long-term pain. Only one unique article was found when searching PsycINFO, Academic Search Complete, and PubMed for a total of 182 articles. Only articles available in English were retained. Grey literature was searched on April 22, 2023 and one additional citation was identified (Tsai

Owens, 2018). However chronic pain conditions were not discussed in this dissertation.

Titles and abstracts were reviewed by two authors (MKLM and SW) to identify relevant articles and any disagreements were discussed. Only articles specifically related to pediatric chronic pain (e.g., pain lasting 3 or more months) were retained. Articles focused on conditions that include chronic pain as a symptom were assessed on an individual basis to determine applicability to the review objectives. Articles that reported focusing on adolescents, young adults, or emerging adults were included; specific age ranges were not required for inclusion. The participants for studies were wide ranging and could include patients, parents, and medical professionals. Commentaries were excluded. Articles that discussed communication preferences of adolescents and young adults with chronic pain but not health care transition were excluded.

Studies focused on the health care transition process in sickle cell disease and juvenile arthritis diagnoses were not retained for this review given the unique medical needs of these patients. These were the only diagnoses present in the articles focused on pediatric chronic pain that warranted exclusion for this review. Sickle cell disease is associated with the potential for cognitive decline, most notably following both overt strokes and silent cerebral infarcts (Prussien et al., 2019). This must be taken into consideration when developing transition programs (Saulsberry-Abate et al., 2021). Policy statements and position papers by national and international organizations have established guidelines for the transition of care of pediatric patients with sickle cell disease (Bryant et al., 2015; Sobota & Uwaezuoke, 2022). Juvenile arthritis conditions have treatment options not available in most chronic pain conditions, including disease-modifying antirheumatic drugs and biologics, which aim to achieve disease remission (Vanoni et al., 2017). Internationally, standards of care and consensus guidelines regarding transition of medical care have been published supporting best practices for pediatric patients with arthritis treated in rheumatology clinics (Foster et al., 2017).

Of the initial 182 articles found in databases, 14 were deemed relevant. Reference lists from relevant articles were searched for additional articles, adding an additional 5 articles. Finally, forward citation searching in Google Scholar was conducted on relevant articles in order to identify articles that had cited them. This yielded 11 articles.

The full text of thirty articles was retrieved, and those articles were screened in detail, extracting information on the study objectives, methods, patient population (age, gender, diagnosis), and results. Four articles were removed as they did not discuss chronic pain, 4 were not included as they were commentaries, 3 were removed as they focused on communication preferences of adolescent patients but did not talk about the transition process, and 2 additional articles

were removed as they focused solely on juvenile idiopathic arthritis. Finally, 9 articles were removed as they discussed the experiences of adolescents and emerging adults with chronic pain but did not talk about the transition process. See Fig. 1 for flow diagram of article identification, screening, and inclusion.

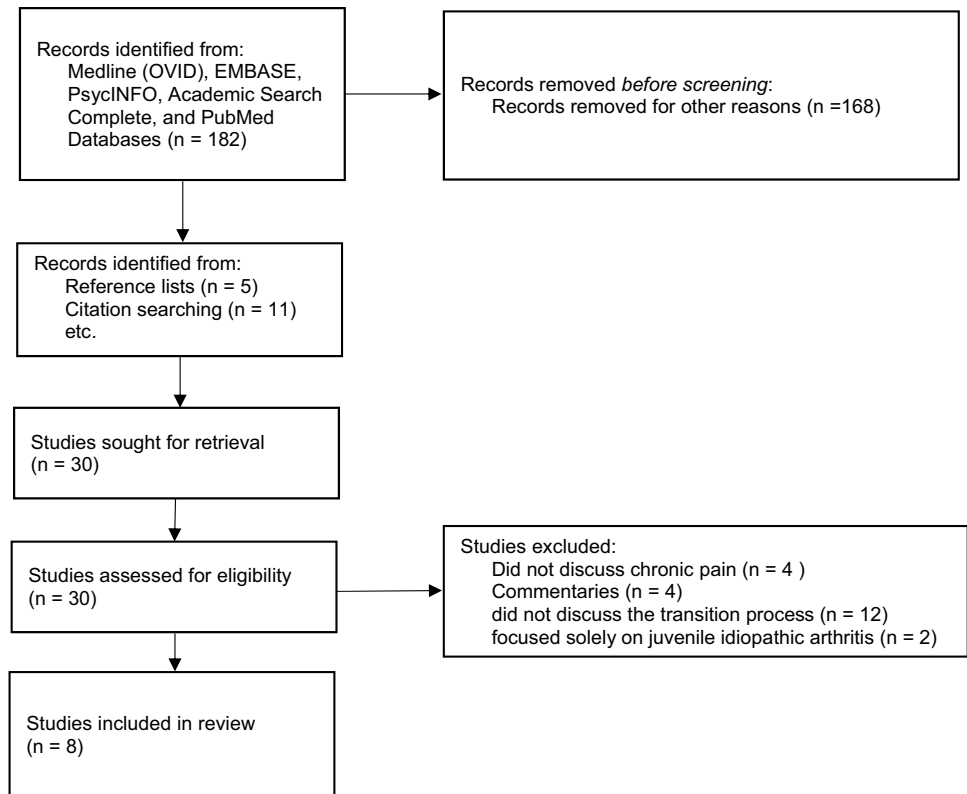
## Results

Eight articles provided relevant information on the transition needs of adolescents and emerging adults with chronic pain. See Table 1 for author, year, manuscript title, type of project, participant information, and location. These articles were primarily qualitative studies ( $N=7$ ) and many were conducted in Canada ( $N=6$ ). Studies reflected the perspectives of pediatric and young adult patients as well as medical providers (nurses, physicians). Due to the limited research specifically published on the health care transition process in pediatric chronic pain, a narrative review was conducted instead of a systematic review. Relevant themes are discussed below, focusing on general knowledge on the transition process in pediatric chronic pain and barriers to successful transition of care. None of the articles provided specific findings related to the role of psychologists or other health care professionals in the transition of health care for adolescents and emerging adults with chronic pain. Patient experiences with regards to their interactions with various medical professionals have been woven into the other sections as appropriate.

### Transition Programs in Chronic Pain

To date, there have been no published guidelines or clinical protocols specific to the health care transition process in pediatric chronic pain. A 2018 survey of nurses in Canadian pain clinics highlighted informal approaches taken by individual providers (Higginson et al., 2018). Pediatric nurses reported informally assessing the patient's knowledge of chronic pain and readiness to transition to adult care, but neither a consistent reproducible process nor psychometrically valid tools were used (Higginson et al., 2018). Most providers reported that literature or informative materials were not given to families in preparation for the transition process (Higginson et al., 2018).

When asked about the transition process, pediatric patients with chronic pain noted concerns and unanswered questions about adult pain clinics (Stinson et al., 2014a). Specifically, there were worries that they wouldn't receive the same level of flexible, personalized care (Stinson et al., 2014b). Setting realistic expectations on the type of care they would receive and addressing the lack of knowledge about the differences between pediatric and adult care may help

**Fig. 1** Flow diagram of articles searched

adolescent and young adult patients feel more prepared for the adult pain clinic setting. Unfortunately, adult pain nurses felt unable to support the needs of newly established young adult patients (Higginson et al., 2018) so this preparation likely falls on the pediatric providers. Adolescent patients with chronic pain have also expressed concern about the physical environment of adult clinics, noting that pediatric clinics are typically warm and colorful while adult clinics are generally all white, which they perceived as “void of caring” (Forgeron & McGrath, 2008).

Patients described feeling stressed about having to get to know new providers and share their story and history again (Forgeron & McGrath, 2008). Structured communication between pediatric and adult providers varied, but generally consisted of a letter and a follow-up phone call with only a small minority reporting a formalized collaboration between clinics (Higginson et al., 2018). Patients of clinics with high collaboration between pediatric and adult pain providers reported having a positive, smooth transition process (Higginson et al., 2019). Unfortunately, patients without strong collaboration between clinics often experienced trouble coordinating their own care, delays in receiving services, and worsening pain and quality of life (Higginson et al., 2019).

## Barriers to Care

### Attainment of Information and Establishing Care

Adolescent and young adult patients have described a wide range of concerns and barriers to chronic pain care and the transition to adult care. Several of these barriers begin when the patient is first diagnosed. In a qualitative study of young adults’ perspectives of their chronic pain experience, many reported that they did not fully understand the chronic, long-term nature of their condition (Daffin et al., 2021). They described being unaware of the multifaceted presentation of symptoms associated with their pain condition such as a fatigue, brain fog, and mental health concerns. This led to confusion when they were referred to psychological care as they perceived chronic pain to be primarily a physical concern. There was also difficulty obtaining information regarding their condition, both from providers and in independent searches (Daffin et al., 2021; Dewar et al., 2003). The limited information available and a lack of understanding of their pain condition may lead to difficulties making appropriate treatment decisions during the transition from pediatric to adult health care.

Several studies have also reported negative experiences with the health care system and health care providers as important barriers. In particular, patients discussed a lack of available providers who have specialized knowledge

**Table 1** Summary of published articles addressing the health care transition experiences of youth with chronic pain

First author	Year	Type of project	Participants	Demographics	Type of chronic pain	Study purpose	Location
Daffin, M	2021	Qualitative study	<i>N</i> = 13; 26–34 years of age with chronic pain	14% female; 85.7% White, 14.3% Black; 92.9% Non-Hispanic/Latinx; 50% Married	Juvenile-onset Fibromyalgia	To identify themes of young adults' perspectives about risk and resilience after juvenile fibromyalgia diagnosis in adolescence	Ohio, USA
Dewar, A	2003	Qualitative study	<i>N</i> = 53; 18 years of age and older; 10 focus groups	13 Males, 40 females; 69% reported chronic pain for 2+ years	No specific diagnoses listed	To understand the experience of those who have suffered from chronic pain to inform educational interventions	Canada
Forgeron, P	2008	Qualitative study	<i>N</i> = 6; 12–18 years old with chronic pain	1 Male, 5 females; 100% Caucasian	No specific diagnoses listed	Understanding the self-identified needs of youth with chronic pain	Maritime Provinces, Canada
Higginson, A	2018	Cross-sectional descriptive online survey	<i>N</i> = 22; registered nurses who work in chronic pain clinics	45.5% Worked in a pediatric setting, 54.4% worked in an adult healthcare setting	n/a	To summarize current nursing methods utilized in pediatric and adult healthcare in Canada to facilitate the transition of young people with chronic pain	Canada
Higginson, A	2019	Qualitative study	<i>N</i> = 9; 18–23 years of age with chronic pain	8 Females, 1 male; 8 receiving care in an adult setting, 1 no longer receiving care but still experiencing chronic pain	Concussion, complex regional pain syndrome, musculoskeletal pain on lower limbs, sickle cell anemia, endometriosis and soft tissue damage, juvenile rheumatoid arthritis, avascular necrosis, daily headaches	To examine how young adults with chronic pain in Canada transitioned from receiving medical treatment as children to receiving medical care as adults	Canada
Stinson, J	2013	Qualitative study	<i>N</i> = 17; 18–29 years of age with chronic pain	88% Female, 12% male; average duration of pain: <i>M</i> = 68.65 months	Headache, abdominal, widespread, lower back, neuropathic, pelvic, facial	To inform the creation of a web-based chronic pain self-management program	Ontario, Canada
Stinson, J	2014	Qualitative study	<i>N</i> = 23; 14–18 years of age with chronic pain; 3 focus groups	73.9% female, 21.7% male; 39.1% Grade 12, 17.4% Grade 11, 21.7% Grade 10, 13% Grade 9; Duration of pain: <i>M</i> = 49.5 months	Headache, abdominal, widespread, lower back, neuropathic, pelvic, facial	Conduct a needs assessment in order to guide the creation of iCanCope with Pain™, an online program for teenage chronic pain self-management	Canada

Table 1 (continued)

First author	Year	Type of project	Participants	Demographics	Type of chronic pain	Study purpose	Location
Twiddy, H	2017	Qualitative study	N = 18; 18–30 years of age with chronic pain; 4 focus groups	3 Males, 15 females	No specific diagnoses listed	To examine the requirements of young adults enrolled in a National Health Service Pain Management Program Service at the tertiary level in the UK, as well as how these needs may affect clinical evaluation and the provision of rehabilitative therapies	United Kingdom

in chronic pain care (Daffin et al., 2021; Stinson et al., 2013). Because of this, many patients were referred to multiple providers leaving them feeling frustrated and unable to establish quality care. They also reported that adult chronic pain programs seemed to be more tailored to older adults, disconnected from the life experiences of young adults (Twiddy et al., 2017). Because of this, patients felt that their pain was not validated or taken as seriously as older adults which negatively impacted their treatment experiences (Twiddy et al., 2017).

### Stigma and Inadequate Support

Another barrier frequently reported by young adults was inadequate support and stigma from the public due to the invisible nature of chronic pain (Daffin et al., 2021; Stinson et al., 2013). Young adults perceived invalidation from others such as experiences with people in their social networks seeing chronic pain as an attempt to get attention (Dewar et al., 2003). Furthermore, they perceived negative attitudes from providers resulting in experienced stigma and invalidation (Dewar et al., 2003). There was a lack of perceived illness validity due to patients' young age (Twiddy et al., 2017). Participants reported the perception that as young adults the societal expectation was that they are healthy. Because of this, they reported feeling a lack of empathy and understanding from providers and believed their pain experiences were being dismissed because they were "too young" to experience debilitating chronic pain (Twiddy et al., 2017). These negative experiences early on in chronic pain care led to frustration and served as a barrier to future care.

### Feeling "In-Between"

Patients experience a wide range of worries related to the transition to adult health care. Some patients reported that they did not "feel adult enough" for adult care, but also felt too old for pediatric care (Forgeron & McGrath, 2008). Support groups are a component of some adult pain settings, however adolescent and young adult patients have expressed concern about the appropriateness of these groups for young adult needs. Expressed concerns cited that often support groups were focused on the experiences and needs of older adults leaving young adults feeling like they don't belong (Stinson et al., 2014b) and triggering feelings of despair about their future with chronic pain (Higginson et al., 2019). This feeling of being "in-between" pediatric and adult care, reflects young adults' desire for pain care that is more tailored to needs unique to their developmental stage which



unfortunately is not widely available in the adult health care system.

### Increased Personal Responsibility

Participants of one study described the difficult process of adjusting to their chronic pain diagnosis during adolescence, which they stated often took years before they reached acceptance and understanding about what the diagnosis would mean for them long-term (Daffin et al., 2021). This prolonged period of adjustment and acceptance may delay the process of seeking effective treatments. In addition to adjusting to a new diagnosis during a complex developmental period, adolescents and young adults soon face the challenge of managing the transition to adult care and the increased independence associated with this transition.

When asked about the transition process adolescents with chronic pain were aware and willing to acknowledge that the transition to adult care would require them to take on more responsibility and ownership for their health care, and would require new skills such as self-advocacy (Stinson et al., 2014a). However, another sample of youth with chronic pain described feeling so dependent on pediatric providers and their parents for their care that they never developed the appropriate skills to be more independent (Twiddy et al., 2017). Therefore, it seems that while adolescents and young adults are aware of the need to be more independent in the adult health care system, they have concerns about their ability to take on this responsibility so quickly during the health care transition.

### Financial Limitations

One study of individuals in the community with chronic pain found that financial issues were a concern for those living with chronic pain (Dewar et al., 2003). Patients reported that the cost of their medication, treatment, necessary medical equipment, and alternative and complementary treatments were a significant burden. Additionally, some patients mentioned that pain limited their ability to be employed and impacted their work, further adding to the financial burden. These participants noted that financial support for individuals with chronic pain would be beneficial (Dewar et al., 2003).

### Discussion

While general guidelines have been published on the health care transition process (American Academy of Pediatrics et al., 2002; Cooley et al., 2011), there are no published protocols or guidelines specific to chronic pain. In this narrative review, only articles specifically including adolescents

and young adults with primary chronic pain conditions were included. Among the studies pulled, only articles focused on sickle cell disease and juvenile arthritis were excluded due to the unique aspects of these conditions that may not apply to the general chronic pain population. Overall, pediatric patients with chronic pain receive either informal guidance or none at all (Higginson et al., 2018). The communication between pediatric and adult clinics varies widely with direct implications on the ease with which patients are able to establish care as adults (Higginson et al., 2018, 2019).

Furthermore, per our literature review and Parfeniuk et al. (2020)'s systematic review of transition readiness measures, there are no transition readiness measures specifically designed for youth with primary chronic pain conditions, and there are no general transition readiness measures validated in the pediatric chronic pain population. This makes it even harder to consistently assess and gather data on patients' level of preparation for adult care. While generic transition readiness measures may be used, specific pain management skills such as use of nonpharmacological coping strategies, use of activity pacing, and incorporation of safe physical activity are not captured. There are often skill deficits, knowledge gaps, and unclear expectations for adult care that should be directly identified and addressed prior to the transition process. This has been accomplished in other chronic illness populations such as spina bifida (Johnson et al., 2019), liver transplant (Annunziato et al., 2018), sickle cell disease (Treadwell et al., 2016), and rheumatic conditions (Spiegel et al., 2021). The SMART theoretical model could be applied as a structure to develop a diagnosis specific measure and intervention in pediatric chronic pain, similar to its use in sickle cell disease (Mulchan et al., 2016).

Patients themselves report a wide range of barriers to the transition process, including difficulty attaining reliable information on their diagnosis and challenges in finding providers with experience and knowledge relevant to their pain condition. As pediatric patients transition to adult care, their relatively young age compared to most patients in the adult pain clinic may become a concern, leaving them feeling like their pain isn't taken seriously and the treatment approach doesn't match their stage in life. Invalidation felt in the medical setting may be further compounded by stigma from peers. Stigma in pediatric chronic pain is an under-researched domain, however the current pain-related stigma model suggests that pain-related stigma has a negative impact on pediatric health outcomes (Wakefield et al., 2018).

Finally, transitioning to adult health care requires a large increase in personal responsibility. This comes at a time when patients are also making other life decisions and transitions with increased independence. While aware of the expectation to be independent with their health care, young adult patients may be unprepared due to past reliance on

their parents and the pediatric medical team. Additionally, there are likely aspects to their care that patients haven't independently covered before such as the cost of medical care, medication refills, and advocating for themselves (Le et al., 2019). Interventions have been developed and implemented to support parents of youth with chronic pain, often focused on psychoeducation (e.g., neuroscience of pain, miscarried helping), communication strategies, problem solving, and coping skills to manage parents' own distress (Guite et al., 2018). These programs could be expanded to include strategies to help parents prepare their child for the transition to adult care.

### Role of Psychologists and Other Health Care Professionals

Given the concerns and challenges young adult patients with chronic illnesses report regarding the transition to adult care, pediatric psychologists may play an important role in aiding in the transition process. Pediatric psychologists can play a role in assessing patient readiness for transition through evaluation of factors including knowledge of their illness and its treatment, motivation and goals for transition, disease self-management, and communication between patient, family, and provider (Devine et al., 2017). Goals and targets for treatment can be made based on areas of need pertaining to the transition to adult care and can be integrated as a standard part of treatment for adolescents and young adults approaching this transition. For example, pediatric psychologists may help patients prepare for what to expect in adult care, and work with patients on gaining independence regarding management of their illness and communicating with medical providers. Additionally, given a lack of research regarding interventions for aiding in the transition process and long-term effectiveness of healthcare transition programs, pediatric psychologists are well positioned to engage in research in this area as well as aid in program development and quality improvement projects that emphasize improving this transitional period. Patient advocacy is an important part of pediatric psychology, thus, pediatric psychologists working with the adolescent and young adult population should work to advocate for the needs of this unique population by increasing communication and partnerships with adult provider systems (Devine et al., 2017).

Gray et al. (2015) invited psychologists to complete a survey regarding their roles in transition programming for emerging adults. Almost all (92.2%) of participants reported involvement on pediatric to adult transition teams with most reporting transition work as part of their clinical care and occurring in their work as part of a multidisciplinary team. Participants also reported barriers in their roles as part of transition teams including lack of consensus within the field regarding transition best practices. Another study assessing

pediatric psychologists' role within the transition process discussed how assessment, support, education, and liaison efforts can be an important part of supporting youth in the transition to adult care (Bonanno et al., 2019). Regarding education and liaison, psychologists in this study emphasized the importance of providing education and awareness regarding the psychosocial issues related to chronic illnesses to families and treatment teams. Additionally, participants emphasized the psychologist's role in serving as a liaison with adult health care centers and collaborating with medical providers from both the pediatric and adult health care centers to ease the burden of this transition (Bonanno et al., 2019).

### Pediatric Rheumatology as Model

Given the absence of health care transition guidelines for young people with chronic pain, it may be helpful to consider transition guidelines and practices implemented in other pediatric-onset chronic medical conditions as an example that could be adapted to the needs of this population. Like young people with chronic pain, young people with chronic rheumatic and musculoskeletal diseases (RMDs) have conditions that place them at increased risk of significant functional disability and that may require care from multidisciplinary teams including medical subspecialists, nursing, physical and occupational therapists, and mental health providers. A review (Clemente et al., 2016) of eight transition programs for young people with chronic RMDs identified several common components: (1) written transition policies supported by the pediatric and adult rheumatology teams; (2) education provided to young people and their families about their condition and treatments, general health and social/developmental issues, and pediatric and adult health services; (3) development of young people's skills related to disease self-management, participation in health care services and decision making, problem-solving, and communication; (4) a transition coordinator who provides individualized transition planning services; (5) a period of shared care during which young people meet with members from both the pediatric and adult rheumatology teams in the pediatric clinic, the adult clinic, or a specialized transition clinic; and (6) transfer of care (and records) at a specific age or when transition readiness criteria were met. Outcomes were reported for two of the programs and indicated program participants experienced improved physical, psychosocial, and rheumatic-specific health status as well as parental promotion of patient's autonomy and independence (Hilderson et al., 2016); improved health-related quality of life (Hilderson et al., 2016; McDonagh et al., 2007); disease knowledge, satisfaction with rheumatologic care, and vocational readiness (McDonagh et al., 2007). A study of



another rheumatology transition program not included in the Clemente review indicated higher rates of successful transition to adult rheumatology care (defined as attendance of more than one clinic appointment) among individuals who had participated in transition programming prior to transfer compared to those who did not (Jensen et al., 2015).

Several generic transition readiness measures have been used in rheumatology transition programs (Stinson et al., 2014b) and one condition-specific measure, the Readiness for Adult Care in Rheumatology (RACER), has been developed demonstrating adequate reliability and construct validity and preliminary evidence of responsiveness to intervention (Spiegel et al., 2021). While many of these transition practices in rheumatology (which generally correspond to the aforementioned six core elements) would likely be beneficial for young people with chronic pain, additional research is needed to adapt to the specific needs of pediatric patients with chronic pain.

### Limitations

This article focused on transition needs of adolescents with chronic pain receiving care from dedicated pain clinics. A resulting limitation of this paper is the low generalizability to other populations. Specifically, papers including adolescents with medical conditions that have pain as a prominent symptom but are more medically complex such as sickle cell disease and juvenile arthritis were not included in this review. We chose to exclude these conditions for two reasons, first they are often followed for medical care within sub-specialty clinics (e.g., hematology or rheumatology) rather than pain clinics. Second, the differing medical complexity of these conditions introduces transition considerations that may be less relevant to patients seen in chronic pain clinics such as neuropsychiatric and other disease specific functional impairments. Future work should consider unique transition needs for a broader scope of conditions that include pain as a symptom rather than as the primary disorder.

### Future Directions

Given the sparse literature on the transition process for adolescents with chronic pain, future work by psychologists is needed to delineate specific needs of this population and develop and test protocols to facilitate transition of care while minimizing barriers to participation in the transition process. Adolescents, young adults, and their parents or caregivers should be included in the development of transition protocols to provide their input regarding what types of support would be most beneficial and accessible to a diverse patient population (Jacquez et al., 2013).

Protocols for transition planning should emphasize structured, face-to-face interactions with adolescents and young adults during the transition process and should include high levels of coordination between pediatric and adult care teams. Where possible, multidisciplinary pediatric and adult pain programs (or adult primary care providers) should work closely during the transition process including having appointments with providers from both clinics present to facilitate transition. Additionally, validation and/or adaptation of existing assessment measures, or creation of a pain specific measure, for transition readiness in pediatric chronic pain is an important area for future work (Stinson et al., 2014a).

In addition to clinic-based transition readiness models, transition planning efforts may benefit from development of more flexible approaches to dissemination of transition readiness protocols. For example, researchers may consider developing or testing single session transition workshops, transition groups, or e-health interventions for adolescents with chronic pain. These types of interventions may be more practical and cost-effective for widespread dissemination, while also reducing barriers associated with attending clinic visits (which are often during work hours and in clinics that are frequently geographically sparse).

Finally, research should aim to develop methods to identify children and adolescents with chronic pain who are at risk for pain persistence into adulthood so that transition efforts can be effectively targeted to patients at greatest need. Similarly, developing assessment methods to identify the ideal adult health care environment (e.g., intensive interdisciplinary pain treatment, outpatient multidisciplinary pain rehabilitation clinic, or primary care provider) for each adolescent patient based on anticipated future health care needs would be beneficial.

### Conclusion

Guidelines to help youth with chronic pain transition to adult care have not been established. This leaves providers to employ unstandardized processes and measures that have not been validated for this population. Patients are provided with less-than-optimal care during the transition process and are at risk of adverse outcomes. Researchers, clinicians, patients, and families must collaborate to develop evidence-based transition guidelines for youth with chronic pain.

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**Data Availability** Not applicable.

**Code Availability** Not applicable.

## Declarations

**Conflict of interest** Mary K. Lynch Milder, Sydney Ward, Ashley Bazier, Julia Stumpf, Michele Tsai Owens, and Amy E. Williams declare that they have no conflicts of interest to disclose.

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**Informed Consent** Not applicable.

**Consent for Publication** Not applicable.

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