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## A developmental perspective on the impact of chronic pain in late adolescence and early adulthood: Implications for assessment and intervention

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### 1. Introduction

The prevalence and severity of chronic pain is well defined in children and adults. Epidemiological studies estimate that 11–38% of children [25] and 35–51% of adults [17] have chronic pain; for 5–8% of children [21] and 10–13% of adults [36] the pain is severe and disabling. Although progress has been made in assessment and treatment of chronic pain, there remain significant disparities. We highlight here an age disparity. Most chronic pain research has been conducted on the “average” pediatric (i.e., older child or adolescent) or adult (i.e., middle-age adult) individual. This has left gaps in knowledge for the subpopulation in the period of late adolescence and early adulthood where important developmental milestones may not be reached leading to lifelong individual and societal consequences. Surprisingly little research attention is directed toward understanding clinically meaningful outcomes, strategies for tailoring pain therapies, and strategies to reduce disparities in access or utilization of care in the adolescent and young adult population.

While there is limited data on the course of pain during late adolescence and early adulthood, likely a subset experience a continuation of chronic pain from childhood [22;23]. Unique vulnerabilities may also increase likelihood of new onset chronic pain during late adolescence and early adulthood. Although not conclusive, specific point prevalence rates of chronic pain in older adolescents and young adults indicate rates between 7.6 and 14.3% worldwide [15;24;29]. Consistent with child and adult literature, females report higher rates of pain than males [4;41;44;50]. Reflecting potential age disparities, adolescents and young

adults report greater interference from their pain than people with pain over the age of 35 years [4] and may have greater healthcare needs [29].

However, limited data exist on what constitutes clinically meaningful outcomes of chronic pain treatment in early adulthood. Given the differing context related to functioning and productivity, this may include unique domains from childhood or later adulthood. Vulnerabilities that emerge in late adolescence and early adulthood related to health risk behaviors and poor access to healthcare have significant implications for chronic pain management [2;3;5;10;11;47;48] but have not been fully characterized. Further, chronic pain treatments have not been tailored for this subpopulation.

A relevant starting point for progress in chronic pain research in late adolescence and young adulthood is to better understand the impact of chronic pain during this developmental period. Therefore, the objective of this review is to: (1) highlight chronic pain impact in older adolescents and young adults, specifically within developmentally relevant areas of functioning and productivity, and (2) present ideas for informing optimal assessment and intervention approaches in adolescents and young adults with chronic pain.

## 2. The Period of Late Adolescence and Early Adulthood

The developmental period of late adolescence and early adulthood is typically defined as occurring between 16 and 29 years [11], and is marked by the occurrence of neurobiological, psychological and behavioral changes, attainment of societal milestones, and adjustment to contextual life changes [2;11]. Neurobiological changes including further brain maturation of response inhibition and planning [6;40] may impact self-control and regulatory tasks important to pain management. Psychological and behavioral changes during this period place older adolescents and young adults at risk for an increase in psychiatric symptoms [7–9]. Health risk behaviors, including smoking and substance use as well as difficulties with adherence to medical regimens, declines in physical activity, and increased obesity [20;30;43] also emerge during this period. All of these changes have potential to influence chronic pain management.

Older adolescents and young adults often experience difficulty accessing healthcare, which places them at risk for disparities in care. This is likely due to a combination of factors including transition from pediatric to adult care, loss of insurance coverage under their parents in some countries with private insurance systems (e.g., USA) [35], and organizational, provider, and patient barriers and preferences, resulting in older adolescents and young adults being less likely to seek care from a pain clinic [48].

## 3. The impact of chronic pain among older adolescents and young adults

Across developmental stages, a wide range of domains may be affected by chronic pain including mood, physical functioning, sleep, school or work, and social interactions and activities [18;49]. Considerable literature has been published on outcome measures and domains relevant to assess in clinical trials of chronic pain treatments [13;31;34;51;52]. An underlying principle of patient-reported outcomes is that they reflect areas of personal relevance. Here we highlight three areas of chronic pain impact relevant to the late

adolescent and early adult period: education and vocation, independence from family, and peer and romantic relationships.

### 3.1. Education and Vocation

The negative effects of chronic pain on adolescents' school functioning has been a major focus of research [53]. Adolescents with chronic pain miss more days of school than their peers [12;28;45;48], impacting their academic achievement [28]. When at school, adolescents with chronic pain find it difficult to concentrate, comprehend, and retain information [19], with greater pain intensity associated with poorer school progress [53]. Adolescents with chronic pain perceive their development to be behind peers [14], with impact most prominent in school progress and employment [14;48].

Negative consequences of chronic pain on school achievement during childhood may impact success in achieving further educational and vocational goals during adolescence and early adulthood. In one of the few longitudinal studies on this topic, adolescents with juvenile-onset fibromyalgia were less likely to achieve higher education or gain full-time employment as young adults compared to their pain-free peers [22]. Further research is needed on older adolescent and young adult's education and vocational outcomes given that the negative consequences of chronic pain on educational attainment have lifelong impact on socioeconomic status and achievement of financial independence.

### 3.2. Independence from Family

Chronic pain may significantly impact transition to independence from parents/family during late adolescence and early adulthood due to lack of personal or financial resources, disability, low levels of autonomy, or not progressing to higher education. Amongst adolescents and young adults with chronic pain, greater pain intensity is associated with lower levels of independence [14;48]. Pain behaviors may solicit attention from parents, which reinforces continued parental involvement [16;39], further challenging the adolescent and young adult's ability to build autonomy. The importance of family and parent factors on the physical and psychosocial functioning of children and adolescents with chronic pain has been emphasized [27;37]. For example, higher levels of parent-adolescent conflict, poorer family functioning and lower levels of autonomy are associated with greater pain-related functional impairment and depressive symptoms in adolescents with recurrent headache [26;38]. Limited promotion of independence in adolescents with juvenile fibromyalgia predicts poorer emotional outcomes in young adulthood [46]. As a domain of chronic pain impact, further research is needed to understand how to assess the level of independence attained by adolescents and young adults with chronic pain.

### 3.3. Peer and Romantic Relationships

Peer and romantic relationships increase in importance during adolescence and early adulthood. Chronic pain may impact peer and romantic relationships due to effects of pain on attachment styles and social participation. For example, having secure attachments with caregivers and peers early in life allows for the development of healthy relationships with others in adulthood [42]. Models of attachment in pain propose that attachment influences help-seeking and use of coping strategies [32], which may impact relationships with peers

and romantic partners [33]. Research has shown that adolescents with chronic pain spend less time with same age peers and romantic partners than peers without pain [33] and have more negative experiences with romantic relationships [42].

Lower levels of social participation continue to young adulthood, especially in adolescents with higher levels of pain intensity [54]. However, the impact of low social participation on adult relationships is equivocal; some studies find that young adults with chronic pain marry earlier and have children sooner than their age-matched peers [22], while others find that pain may prevent the development of intimate sexual relations with a partner, limiting advancement of romantic relationships [14;48]. More research is needed to understand the impact of chronic pain on early adulthood social participation and romantic relationships and how best to measure this domain.

#### **4. Integrating a developmental perspective in assessment and treatment of older adolescents and young adults with chronic pain**

Understanding developmentally relevant areas of chronic pain impact may inform optimal assessment and treatment approaches in the older adolescents and young adults including measurement of clinically meaningful outcomes (e.g., education, vocation) and use of developmentally informed strategies to tailor chronic pain treatments.

In addition to standard assessments of chronic pain severity and disability, our review highlights developmentally specific areas of relevance to older adolescents and young adults including education and vocation, independence from family, and romantic relationships. Several types of research may be needed to expand and validate measures appropriate for older adolescents and young adults. First, researchers should examine the psychometric properties of existing measures of disability and pain impact specifically in adolescents and young adults to understand whether they perform similarly in this subpopulation as compared to middle-age adult samples often used in original measure validation. Second, researchers may consider whether development of new measures including developmentally-specific domains is needed by reviewing and testing the developmental relevance of existing measures of pain-related disability and impact in adolescents and young adults. For example, adult measures of disability rarely capture the impact of pain on education or the emergence of new romantic relationships. Further, identifying impairment in vocation may require more nuanced items that capture the interference of chronic pain on gaining full-time employment in a field of interest and that allows for financial independence. Qualitative methodology to acquire adolescent and young adult perspectives on these domains may be useful to inform developmentally appropriate items on new measures.

As described, developmental changes occurring during late adolescence and early adulthood may be important to consider in tailoring chronic pain interventions. For example, strategies to achieve independence and build meaningful peer and romantic relationships are potential areas to developmentally tailor chronic pain interventions. To date, there has been limited development and testing of treatments specifically targeting adolescents and young adults with chronic pain. One exception is a recent pilot study of a peer mentorship program for young adults with chronic pain [1]. This program provides modeling and reinforcement by

peers (trained young adults with chronic pain) to enhance independence around self-management of chronic pain in young adults. Further work is needed to understand how to adapt chronic pain interventions to target specific adolescent and young adult needs.

A related issue is that age group differences in existing chronic pain interventions are unknown. At present, most of the evidence for a range of chronic pain interventions (e.g., psychological, physical therapy, CAM) has been produced in samples comprised of middle-aged adults. Studies do not often present subgroup analyses on participants aged 16–29 years to test age group differences in treatment effects. As a result it is not clear whether existing chronic pain treatments are effective for adolescents and young adults and whether they are able to foster critical developmental outcomes such as autonomy and independence. Therefore, future treatment studies should target recruitment of larger sample sizes of older adolescents and young adults, and conduct subgroup analyses to evaluate late adolescent and early adult treatment outcomes.

Research is also needed on health system factors that may influence chronic pain treatment in older adolescents and young adults including access, availability, and utilization of different treatments. Finally, research is needed to better understand and address provider and adolescent and young adult patient barriers (e.g., stigma) to engagement in effective treatments.

## 5. Conclusions

Older adolescents and young adults fall into a unique developmental stage marked by neurobiological, psychological, behavioral, and social changes. Developmentally specific areas of chronic pain impact on adolescents and young adults are important to understand in order to optimize assessment and treatment approaches with this population.

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