

Medical XPress

Young people suffering chronic pain battle isolation and stigma as they struggle to forge their identities

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Picture by 'Hannah', a young person with chronic pain. *Credit: Abbie Jordan, Author provided*

Adolescence can be a difficult but exciting time, when young people make discoveries and decisions about their futures, and develop a sense of who they are and their place in the world. But for young people with chronic pain – that is, pain that lasts for three months or longer – this period can be especially challenging.

Rates of chronic pain are high among children and adolescents. A recent review of 42 studies found that between 11% and 38% of children and adolescents report experiencing chronic pain. Rates of chronic pain are higher in girls than boys, and rates of chronic pain typically increase in early adolescence.

There are lots of reasons why young people might experience chronic pain. It could arise as part of a long-term health condition such as arthritis, or a pain-specific condition such as Complex Regional Pain Syndrome. Sometimes chronic pain occurs after an injury, or simply without any explanation at all.

Studies have found that for many young people, pain is an "invisible enemy": though it can't be seen by others, it's a "malign invader" which has a damaging effect on many aspects of their lives and isolates them from their friends and family.

Research from across the world has consistently shown that young people who experience chronic pain report higher levels of anxiety, depression, isolation and friendship challenges compared with their pain-free friends.

Pain also has a significant cost for society – one study from the US shows that the financial costs associated with treating chronic pain in adolescents are greater than those for treating asthma in the same age group.

A recent study that I carried out with colleagues in the UK and Canada built on existing research to see how young people with chronic pain tackle these challenges on their journey to adulthood. We conducted in-depth interviews with ten young people, aged 12 to 17 years, about their experiences of growing up with chronic pain.

Finding yourself

We found that developing a sense of identity was really challenging for young people who experience chronic pain. Sophie, aged 17, explained that this was difficult because friends, family and healthcare professionals saw her pain condition and its impact on her life, rather than her as an individual. She said: "It's difficult to establish an identity when you've already been given one you don't really want."

Our participants also talked about pain "robbing" them of opportunities and things that other young people take for granted, such as going to see a sports match or playing a musical instrument.

These are not only activities that people enjoy – they also help to define who they are and what they're passionate about.

Some young people – such as Alice, aged 15 – found ways to hold onto an important part of who they are, in spite of their pain.

For Alice, this was her love of dance, which she practised at home, even when her pain was unbearable. "The one thing they couldn't take away is dancing, it was like something I had on my own, without my mum, without anyone, it was something I achieved."

Living with chronic pain also disrupted young people's lives and singled them out as different from friends. One of our participants – Emily, aged 15 – had to resit a school year due to pain, while her friends moved onto the next year. As well as having to make new friends, Emily described a sense of feeling left behind and different from her former classmates.

Forging a way forward

Clearly, pain is disruptive for young people and can hinder their ability to develop a sense of who they are. That's why treatments should support young people as they try to

establish a sense of identity despite their pain, while taking into consideration how this may affect how they see their future into adulthood and beyond.

This is something researchers are working on at the moment. But an even bigger challenge is to change the perceptions of those around the young person. Like other young people in our study, Jack (aged 15), described how he wanted others to view him as separate from his pain condition. "It's hard because a lot of people don't understand the situation you are in, so you sort of get stereotyped and pushed to one side as a cripple or somebody like that, and it's hard to sort of pick yourself back up again once you've been called those names, because it's not like you're just living with the pain, it's living with the consequences of the pain and the people, how do people react around you like your friends and teachers."

Teenage years can be challenging for everyone, but young people with chronic pain report feeling stigmatised by teachers, friends and even families. A useful remedy could be to provide education about chronic pain and its effects, in schools where there are young people with chronic pain in attendance. There is already some evidence to show this approach works to reduce the stigma around mental health, surely it's time to do the same, for young people who experience chronic pain.