Growing pains: understanding the needs of emerging adults with chronic pain

British Journal of Pain
2017, Vol 11(3) 108–118
© The British Pain Society 2017
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/2049463717709641
journals.sagepub.com/home/bjp

Hannah Twiddy¹, Julie Hanna² and Louise Haynes³

Abstract

Background: Emerging adulthood (18–30 years), in the Western world, is often a time of identity development and exploration, focusing on areas of work, relationships and education. Individuals with chronic illnesses, such as chronic pain, may be more vulnerable to facing challenges during this time. This study aims to investigate the needs of young adults (YAs) attending a tertiary level National Health Service (NHS) Pain Management Programme (PMP) Service in the United Kingdom; exploring how these needs may translate on to clinical assessment and the delivery of rehabilitation interventions.

Method: This is a descriptive qualitative study influenced by phenomenological approaches. YA with a diagnosis of chronic pain were recruited and assigned to one of four focus groups facilitated by a clinical psychologist and occupational therapist. A semi-structured interview guide was used to help facilitate the group discussion.

Results: Qualitative analysis identified four key themes in understanding the needs of YAs with chronic pain: (1) thwarted opportunities, (2) peer separation, (3) perceived illness validity in the context of age and (4) dependency/parental enmeshment.

Conclusions: The emerging adulthood literature provides a valuable framework for examining a normal developmental trajectory and highlights the relevance of age-related processes in YAs with chronic pain. The *idealisation* of opportunity and the role of *perception* in this developmental phase both appear relevant. It is significant that emotional stability is not yet established in emerging adulthood and links to unhelpful management strategies that may be differentiated from older populations are identified.

Keywords

Emerging adults, emotional regulation, chronic pain, self-identity, pain management

Introduction

Chronic pain is a common condition causing significant distress and disability.¹ However, there is currently an absence of qualitative research in to the specific impact of chronic pain in young adults (YAs). Potentially, this patient group represents a unique population that requires specific areas of focus in pain management interventions.

Emerging adulthood

Emerging adulthood (EA), in the Western world, is often a time of identity development and exploration,

focusing on areas of work, relationships and education. Literature suggests that individuals who fall in the age

¹Pain Management Programme, The Walton Centre NHS Foundation Trust, Liverpool, UK

²University of Liverpool, Liverpool, UK

³The Walton Centre NHS Foundation Trust, Liverpool, UK

Corresponding author:

Hannah Twiddy, Pain Management Programme, The Walton Centre NHS Foundation Trust, 1st Floor, Sid Watkins Building, Fazakerley, Liverpool L9 7LJ, UK.
Email: Hannah.twiddy@thewaltoncentre.nhs.uk

range of 18–30 years have specific developmental needs.² The apparent indecisiveness and lack of direction within the emerging adult phase has been suggested to illustrate a normative phase of selection and optimisation eventually leading to adaptation to adulthood (Baltes and Carstensen, 1996). In addition, there are a series of psychological changes, including the stabilisation of emotional regulation in the emerging phase (Schulenberg et al., 2004).⁴⁴ The role of social context and peer relationships is integral in this phase of development.³ It is missed opportunities and reduced positive peer interactions that are related to poorer psychological well-being in this age group.

The development of identity can play a notable role in the management of illness in respect to coping styles and adjustment. It has been suggested that promotion of optimal self-management strategies in young adulthood is particularly vital as techniques of disease management are typically less than optimal. Optimising self-management can often impact both the efficacy of treatments and overall quality of life. There is suggestion that developmental needs should be noted and taken into consideration in the delivery of psychologically based interventions.⁴

Chronic pain and YAs

EA may present additional vulnerabilities to individuals with persistent pain due to both physical challenges and the potential stigma living with a chronic illness can bring.⁵ In a study investigating identity formation in emerging adults with type 1 diabetes, it was described that developing a strong sense of identity helped individuals with diabetes to refrain from using dysfunctional strategies, including withdrawal in coping with their illness and integrating the illness into their self-definition.⁶ Stinson et al.⁷ completed the first study to explore the information and service needs of YAs with chronic pain through the use of three YA Focus Groups to help in the development of a web-based self-management programme. We intend to continue to build on this emerging area of research by working to identify the service needs of YAs within a tertiary level NHS pain clinic.

The aim of this article is to qualitatively explore key themes of relevance in a population of YAs in the United Kingdom with chronic pain. It appears that this has not been explored previously.⁸ It is also hoped that the findings will contribute to an emerging body of knowledge and can be extrapolated to help inform the wider delivery of services for YAs with chronic pain.

This study was ethically approved by the National Research Ethics Service Committee, London, Fulham (IRAS no. 157379; REC Ref. 14/LO/1116).

Method

This is a descriptive qualitative study influenced by phenomenological approaches.

Participants, sampling and recruitment

A non-probability purposive sample of participants was recruited from YAs who were currently being assessed and/or receiving treatment for a chronic pain condition in an NHS Pain Management Clinic. Participants were included in the study who were aged between 18 and 30 years (3 males and 15 females) with a diagnosis of chronic pain, able to provide consent for themselves and could engage in a verbal discussion in English.

Participants were recruited during their attendance at the Pain Management Clinic. A poster was displayed in the clinic waiting room with information about the study and qualified chronic pain clinicians approached potential participants during their scheduled appointments. YAs who expressed an interest in participating were then given written information about the study and 2 weeks to consider whether they were willing to participate with the opportunity to talk with family members and to raise any questions with clinicians at the clinic. Participants at the start of each focus group gave their written informed consent to both participate and be audio recorded. Participants could withdraw at any time from the study.

Data collection

The authors have adopted an interpretivist orientation to research. This is a constructionist position based on ontological assumptions that there are diverse and subjective interpretations of reality (Bunniss and Kelly, 2010).⁴⁶ A method of data collection that would facilitate an increased understanding of the lived experience of YAs with chronic pain was adopted. There was a focus on the narrative experience of illness and vulnerability, recognising that illness can be a stimulus for story telling.⁹

Focus groups were selected as the method of data collection for this exploratory study. This method allowed for the possible option of carrying out more in depth research in the future based on, for example, individual narrative interviews to confirm and explore the study findings further. The focus group method gives voice to both personal and collective experiences.¹⁰ They provide an opportunity to gather rich and meaningful data about the participants' shared and common experience¹¹ of living with chronic pain.

The current research was guided by the literature that discusses optimal planning and organisation of

focus groups,^{12–17} suggesting ideal numbers in these groups to facilitate discussion while creating an environment that is comfortable for participants to share their experiences.

Four focus groups were conducted over a 4-month period held in the NHS Pain Clinic. Each group met once with the sessions varying in length, ranging from 50 to 90 minutes. A total of 18 YAs attended the focus groups, with an average age of 24.33 years, and a range of 18–30 years. A semi-structured interview guide (illustrated in Table 1) was used to help facilitate the group discussion. The questions were developed to facilitate the YAs in exploring their experiences of chronic pain. Questions intended to gain more of an insight into the YA's experience of pain management services within the NHS and how delivery might be tailored more to meet their specific needs.

All the focus groups were facilitated by a Clinical Psychologist and Occupational Therapist. An assistant psychologist was also in attendance at each group to take notes to supplement the audio recordings. The facilitators had significant experience of working with the target population in a variety of group settings, and their knowledge and skills helped to mitigate against the potential for a variable quality in the data as a result of group dynamics.¹¹ There were some minor challenges as a result of differences in communication styles between the young participants and facilitators which were overcome in carrying out the focus groups and then later during analysis. These differences arose at least in part because of the age difference between the facilitators and YA participants. The participants tended at times to use a more informal language style. During the analysis, there were occasions when an extract from a transcript had to be re-read/listened to several times to for the researchers to agree meaning. Differences in communication styles have been identified as a possible difficulty when working with younger groups.¹⁸

The tapes and transcripts don't suggest that an easy flow of conversation was impeded.

The facilitators were able to be flexible in the way the interview guide was followed in order to encourage greater participation. YAs and marginalised groups can feel empowered by being in a group and are perhaps more forthcoming than in an individual interview.^{19,20} The facilitators were aware also that there might be issues of inequality of power between the health professional facilitators and the young participants.²¹ An informal and conversational approach was chosen to help engage the YAs.

Data analysis

It is essential that methodological rigour is demonstrable in qualitative research to ensure trustworthiness.²²

A clinical psychologist and occupational therapist from the research team, who had both facilitated the focus groups, carried out analysis of the data. In addition, an academic from the School of Health Sciences at a University contributed to the thematic analysis of the data. This researcher had no experience of working in chronic pain services and had not been involved in the gathering of data. This researcher brought experience of analysing qualitative and focus group data and their participation in the research at the analysis stage as an external researcher enhanced the rigour of the study by offering an external and alternative perspective.²³

As a fundamental part of the analysis, the focus groups were transcribed so that the researchers had access to both the audio recordings and written transcriptions of the data. Adopting a reflexive approach in qualitative research helps in understanding the impact of the researcher and their position in relation to the data.²² The three researchers, throughout the analysis, challenged and corroborated each other's understandings of the data.

We adhered to a process of constant comparison analysis.²⁴ Data were initially chunked into small units (open coding), then into categories (axial coding) and finally themes were developed. This method was appropriately applied to focus group analysis.²⁵

A major aim during analysis is to identify areas of agreement and controversy to increase understanding of the subjective experience of participants.²⁶ Focus groups can be seen as producing complex and messy data¹¹ and difficult to analyse.²⁷ Therefore, in order for the three researchers to immerse themselves in the data, the analysis took time and was carried out over a period of several months. Individuals carried out allocated work in between meetings which was then fed back into the process of constant comparison carried out by the group. This method of emergent-systematic focus group design²⁸ led to data from each focus group being compared. This method of data analysis encompasses two phases: the emergent phase where each focus group is seen as producing emerging or exploratory data and the systematic phase where each subsequent focus group verifies data from the previous group. The researchers' experience was that this process was not linear and that as analysis progressed there was a fluidity to the process. The data were gradually perceived as one data set however with traceable origins back to the four focus groups. Literature suggests that three or four focus groups should aid theoretical saturation (Flick, 2009),⁵⁰ which reflected the experience of the researchers in this study.

Useful examples of how data were grouped and subsequently informed the final four themes are presented in Table 2.

Table 1. Focus group questions schedule.

1	What has living with a chronic pain condition been like for you?
2	What are the main ways living with chronic pain has impacted you?
3	How do you understand your pain?
4	How do you explain chronic pain to friends and family?
5	What would help you learn to cope with your pain condition?
6	Has living with a chronic pain condition changed how you see yourself?
7	Has living with a chronic pain condition changed how you see your future?
8	Do you think as a young person living with pain there are any specific issues that impact on you when compared with someone older who is living with chronic pain?
9	How do your family/friends help to support you?

Distinct themes emerged encompassing focus group participants' perceptions of their past, present and anticipated future. These are now described in the results and discussion sections of this article.

Results

Qualitative data

Qualitative analysis identified four key themes in understanding the needs of YAs with chronic pain: (1) thwarted opportunities, (2) peer separation, (3) illness validity in the context of age and (4) dependency/parental enmeshment. Direct quotes from participants are utilised throughout this section to illustrate these identified themes, to demonstrate to the reader the journey from the narratives to the generation of themes.

Theme 1: thwarted opportunities. All the participants in this study described a sense of loss and sadness about reduced opportunities to explore various avenues in respect to work, relationships and education because of their pain. Capturing this narrative a 21-year-old female described,

and also you haven't achieved half of the things, and it's kind of like, you know what, I didn't do this and it's alright if I didn't do that, but when you're young it's like well I haven't even done that!

The quote encapsulates the sense of never being able to participate; a grief for loss of opportunity as opposed to loss of past lifestyle. The following contributions from two participants illustrate this story of thwarted opportunities in respect to career development being hampered by pain:

I was an apprentice engineer for Shell, and I was four weeks into it and I could never go back. And then everyone who was in my group worked on the Formula One team and they travelled the world and I haven't done that. I missed out on that. It's been life changing, because I was properly diagnosed at 18, so for me I had everything in my life, and like, from that I've lost my career, my bike, things like that.

The EA literature informs us that the opportunity to explore across a variety of life domains and options is vital in identity formation in early adulthood.²⁹ In the absence of relevant external factors, possibilities at this time (emerging phase) are endless and many futures should remain open and a real possibility to YAs. The participants in this study repeatedly noted that as well as their past and current opportunities their future opportunities also felt thwarted because of their pain. Two female participants contributed the following narratives of future loss: 'I've got 30 years ahead of me at work which is completely beyond the limit of what I can do'.

I'd love to start a family and my partner's worried about how I'm going to be, am I going to be more in a wheelchair. But, I've always wanted kids, I still want kids, but I'm not able to ...

All of the YAs in this study perceived that the opportunity to pursue any or all avenues of interest to them is in some way thwarted or disrupted. A female participant summarised this point in her contribution: 'you're reaching for things and you're like that could've been incredible'.

It is important to consider the impact that this perceived lack of positive opportunities has on YAs with chronic pain and their development of sense of self-identity in adulthood, one contributor spoke about feeling that 'it [pain] defines who you are, changes who you are'. Several participants noted that their current lifestyle and self-perception is not where or how they thought it would be and the participants all gave a sense of 'what could have been'. An example provided by one young female participant: 'I probably wouldn't be the person I am, I would be off doing the job I wanted, I'd be off doing everything I wouldn't be living at home'. A female participant was saddened to report 'I'm actually jealous of my brother, he has got his dream job, he's got his own place ... he's not reliant on anyone else, he's got everything and ... that's what I wanted'. This latter statement captures this individual's sense of a life never to be achieved.

An additional example provided by a 21-year-old female participant illustrates the potential relationship between these perceived thwarted opportunities and psychological distress: 'You know, I have a kind of guilt as well if you're not doing things and you feel awful for

Table 2. Examples of data analysis leading to the development of themes.

Stage 1: Open coding (small chunks)	Stage 2: Axial coding (categories)	Stage 3: Selective coding (themes)
<p><i>Example One</i></p> <p>Endings 'I went from being really active . . . to nothing' (1) (a)</p> <p>Struggle 'I ended up missing my 2nd year of Uni ... making it this competition between myself and the pain' (2) (b)</p> <p>Current loss '... it's just come to a standstill in a horrific kind've ... like a car crash' (1) (c)</p> <p>'... you can't push past barriers [pain]' (3) (d)</p> <p>Past loss 'It's (pain) stopped me ...' (1) (e)</p>	<p>Conceptualising my pain: The following metaphors were identified in the open coded data that helped in developing and understanding this category. Pain is like – nothing (a) a competition (b) a car crash (c) a barrier (d) something that stops me (e)</p> <p>Following further analysis primary data relating to the impact of pain on the young adult participants from the category, 'conceptualising pain', contributed to the development of the theme of Thwarted Opportunities.</p>	<p>Thwarted opportunities (a,b,c,d,e)</p>
<p><i>Example Two</i></p> <p>Difference 'and the whole kind of thing that sticks with me is that I am not the same as anyone else my own age' (1) (a)</p> <p>Age perceptions/believed 'everybody sort of expects as you get old your body starts to give in and you require a bit more help and that's a progression of life so if you were older and requiring more help it would be slightly easier I think. I don't mean to devalue what anybody else is going through just because it's more socially expected rather than accepted it would be easier to accept yourself "Ok yeah I can do that and that." When you're young in particular when it's not something that's not obvious that you don't walk with crutches, they look at me instantly and assume I'm perfect for work' (2) (b)</p> <p>Age perceptions/believed 'Yeah, "cause you're younger you'll get over it". (3) (c)</p>	<p>Age-related beliefs There were many examples in all the Focus groups of narratives that were age related. This led to the development of 'Age related beliefs' as a category. With further analysis data was divided and contributed to the development of different themes according to its content. In this example primary data links to two themes of a. Peer separation and b. Perceived illness validity in the context of age</p>	<p>Peer separation (a) Perceived illness validity in the context of age (b, c)</p>
<p><i>Example Three</i></p> <p>Disconnected "well you can't come and walk the dog and you can't do this" well what is left to do? So I think it [pain] has totally changed my relationship with others'. (1) (a)</p> <p>Dependence/Independence 'Cause the similarity to that to people who are our age in general [inaudible] not having the free roam to go at it yourself does your head in, but that's what the pain thing, that's an age thing, and that's a situation thing, being back at home with your parents and the with the pain on top of that that's the bit where it gets to that level' (4) (b)</p>	<p>Acceptance In the second stage of analysis a category of acceptance (lack of acceptance) was developed. With further analysis differences in the data emerged. In some instances one extract of data contributed to the development of more than one theme; for example Peer separation and Dependence/ Parental enmeshment (b).</p>	<p>Peer separation (a) Peer Separation and Dependence/ Parental enmeshment (b)</p>

1,2,3,4, bracketed refer to Focus groups in order that they were carried out.

not doing what everyone else is doing, why am I letting myself down?'

Further comments demonstrated the impact of others and the experience of thwarted opportunities on the *idealisation* of a life without pain,

I always get my dad saying your illness doesn't define who you are. You can still go and do what you want to do. But it's so hard to keep feeling like that when other people kind of make you feel like well actually you can't you know ... I've been in that kind of situation where I could sit there and everyone else is thinking the world is my oyster.

The YAs repeatedly made reference to a life without pain being *without* problems or loss of any opportunity.

Theme 2: peer separation. The theme of peer separation encapsulates the feelings of separation or isolation from peers and societal expectations, which most attribute to their pain. A female participant comments about her ability to engage in peer related activity: 'Well yeah like quite a lot of my mates still go to town ... at the weekends ... I can't really do stuff like that and they just stop asking you'. Other examples appear to highlight feeling psychologically disconnected, for example 'and the whole kind of thing that sticks with me is that I am not the same as anyone else my own age'. The contributions suggest that this separation represents a disruption to the normal trajectory of events on these age-related pathways, in other words that they are unable to fulfil the activities and pursuits commonly followed by peers of the same age. A male participant explained 'I feel as if I live separately from the world that is around outside me, like I can't do them things'. Adding to this discussion another participant added,

whereas now it's what do you want to do 'well you can't come and walk the dog and you can't do this' well what is left to do? So I think it [pain] has totally changed my relationship with others.

A chronic condition can bring difficulties in this time of life; particularly in respect to the pressure to conform and fit in with peers and age-related ideals.³⁰ A 20-year-old female participant laments,

you want that acceptance from people, you want people to understand, but you know in the nicest possible way everyone is selfish at that age, think a lot of themselves and if you are not there you kind of get put to the wayside.

This description is relevant as the loss of peer connectedness within the emerging phase is associated with reduced psychological well-being.³¹

Theme 3: illness validity in the context of age. Illness validity in the context of age appears directly linked with YAs perception of more general societal expectations of the physical health of a YA. YAs in the current study described feeling invalidated in their chronic pain conditions because of their age; dismissed as being 'too young' to experience any type of debilitating pain condition. YAs described feeling disbelieved by peers, parents and health-care providers alike. Contribution by a 21-year-old female participant and 23-year-old male, respectively, exemplify this theme: 'So when you're quite young it's like well you can't have chronic

pain because you're young. It will be growing pains. Growing pains was a crap diagnosis'.

People who are older ... think your pain threshold is lower than someone who is like older ... It's like I had that from professionals 'oh you are just being a bit of a hypochondriac and you can't handle pain very well.

These quotes illustrate the perceived views that they are either poor copers or exaggerating pain. An 18-year-old female participant explained. 'I've had it before where I've had a fall and I couldn't move my left leg so they took me to A and E and the doctor was like "your parents aren't looking you can move it" and I was like if I could move my leg I wouldn't be sat here'.

Within the narratives there was evidence of feeling disconnected with the norms of an older chronic pain population. Focus group participants gave many examples of scenarios where they felt there was a disparity in the care received by older relatives:

... I mean I get told you're not getting out of bed because you're lazy, but they look at my nan and they go, oh yeah she must really be unwell.

I know somebody who was diagnosed when she was in her 80's..Social services sorted everything out for her, where I was ...fighting to get a second stair rail ...

A 22-year-old male participant commented that following transition to adult care he experienced a lack of acknowledgement for the seriousness of his chronic pain due to his age: 'you're not an adult when it started so it's like what do we do with you? We'll just wait a couple of years and we can deal with you then, it will be more serious then'. Within the same discussion another female participant reported, '... you feel like you are drowning in a big pool and shouting "will someone listen to me"'.

Theme 4: dependence/parental enmeshment. YAs within the current study identified a notable experience of *dependence* upon others, including parents and health-care providers most notably. One male participant explained the relationships he developed with the professionals involved in his care and contrasted with his peer relationships: 'you know you end up being friendlier with the nurses you go and see rather than the kids you went to school with'. Further discussions highlight relationships of perceived dependence with health-care professionals:

With anyone else it's like you don't really want to talk to people about it, and I think that is an age thing, like you start to depend on your consultant. I don't know anyone who looks forward to going into hospital, but you just,

like, looking for something that helps, so kind of like I'm looking forward to going to see if I'm going to get help. It's like you are dependent on the consultant, and I think that's like a young thing, when you are developing a relationship you can trust.

The authors of the current study suggest that emerging adults discuss feeling dependent in the context of never having felt able to learn the skills of being independent. This aspect is stated by a male participant of the groups: '... not having the free roam to go at it yourself does your head in, being at home with your parents with pain on top of that, that is the bit where it gets to that level'. A female contributor explained the dependency within her parental relationship,

... My mum doesn't let me do anything. So it's like if I'm in the house she won't let me do any washing up she won't let me look after myself essentially, that's infuriating particularly when you are ok. On the days you feel 'yes I can do a little bit today' and then she comes in and flips a lid because I cleaned up for her I've tried to give a little something back. The tiniest thing but that makes her more upset because she thinks that it's going to make me worse and then the guilt comes in and I don't know what to do for better or worse despite trying to help.

The authors noted many examples where dependency was discussed in the context of parents.

Conflict and struggle were identified as subthemes, highlighting the movement between YAs desire for independence and the context of dependency that chronic pain can create. Participants acknowledged the need for some parental support and the recognition of parents' good intentions juxtaposed with their repeated reports of the desire for independence. The contributions of two focus group participants exemplify this point:

As much as I say I don't want it, there are days I appreciate the fact that my mum knows I don't have any energy left.

It robs you of your independence particularly if you are a teenager and searching for your identity. As a young adult to [then] be mollycoddled and you're fighting against it and you're causing all these arguments and it makes the atmosphere in the house far worse, then you realise they are only doing it because they love you.

Conflict in families also appears linked to the lack of understanding regarding the variability of chronic pain and the translation that this can have on needs around independent living:

you constantly have to tell people it's too much, I can't do that, can you just[help] and you don't want to have to do that ... [but]sometimes you can actually push through it, ... I asked my sister would she mind carrying my water

Figure 1. Conceptual model of themes and processes: associated targets for clinical interventions in an acceptance based framework.

bottle ... and she said you seemed to be fine yesterday... you can't pick and choose when you want help ... I was just trying to have some independence and she made me feel bad for it.

Discussion

The recognition of the social and emotional developmental trajectory differentiates YAs with pain from older populations. The latter is exemplified by the relevance of both the development of self-identity and emotional regulation in this phase. Four key themes are identified within the study, and Figure 1 highlights both the reciprocal relationships and the context of thematic processes.

It has been described in the literature that emerging adults are in a time of their lives when they are clarifying a sense of their identity, of where they fit in to the world and what they want out of life.²⁹ This is described as a time where emotional stability is not yet established.³² The identified future goals of adolescents and YAs with chronic musculoskeletal pain when compared with those without pain showed little difference despite the identification of greater levels of goal frustration (Stommen et al., 2015).⁴⁷ The latter is possibly connected with a perception of being unable to engage in normative developmental tasks. We propose that the identified theme of *thwarted opportunities* is reflective of this previously identified higher level of goal frustration.

We suggest that the overarching thematic processes to consider in this age range, irrespective of the presence

of chronic illness, are *idealisation* and *perception*, and these are discussed in relation to the 4 themes. *Idealisation* is conceptualised as

an age of high hopes and great expectations ... all their hopes seem possible, because for most people the range of their choices for how to live is greater than it has ever been before and greater than it will ever be.²⁹

In a normal developmental trajectory *idealisation* is managed through opportunity for broad and varied exploration of goals and life experiences. It is the value of feeling *able* to pursue any idealised avenue that is noteworthy when considering YAs with chronic pain. Hence, the value of being able to pursue goals represents the perceived loss of idealised goals as well as realistic opportunities. While instability and uncertainty appear to be part of a normal developmental trajectory for emerging adults we also know that chronic pain, irrespective of age, can exacerbate a sense of uncertainty for the future and instability in planning.³³ As a consequence, we suggest that both the *perception* of thwarted *idealised* opportunities and the reality of thwarted past, present and future opportunities reduce the ability of YAs with pain to engage and function in normal developmental activities. It is suggested that YAs with chronic pain are vulnerable to poorer behavioural and psychological functioning as their opportunities for goal exploration is thwarted. The potential consequences of this are expressed in negative ramifications for both skill development and independent living. It is also proposed that their ability to identify future goals with personal meaning (value-led)³⁴ may be harder to both identify and achieve.

A viewpoint gathering interest in the emotional regulation literature is the importance of differentiating between negative emotions, where each emotion serves a differing adaptive function (Saarni et al., 2006).⁵² Specifically, anger is defined by the appraisal that a goal of personal significance has been blocked and sadness is understood to represent the loss of a goal of personal significance. Generally, emerging adults have been shown to be characterised by high dysregulation of anger when compared with other age groups.³² A sense of thwarted opportunities may increase the likelihood of individuals experiencing both anger and sadness due to goal blocking and loss. YAs in this study state a *perception* of inequality and misunderstanding from health professionals, family and friends. This is categorised as *illness perception in the context of age*. The clinical relevance of discourses of justice and injustice in relation to the intensity of the pain experience has previously been discussed (Scott et al., 2016).^{35,54} Anger has been noted as the predominant response to perceived injustice in individuals with chronic pain;^{36,37} an emotion already

cited as particularly problematic in its regulation in emerging adults. It is suggested that perceived injustice is relevant to the identified *idealisation* of possible life opportunities without the context of chronic pain ('without pain I could've been anything, achieved anything'). In other words, in the absence of pain, all opportunities would be maximised and achieved, perhaps as perceived, peers 'unfairly' and 'always' achieve. The authors propose that perceptions of injustice may indeed be elevated in this YA population due to the magnification of age-related expectations of life and opportunities. There may be further relevance in the specific beliefs cited that 'young people don't suffer with pain' thus creating an unhelpful reciprocal relationship between YAs beliefs that they are disbelieved and treated inequitably and the potential expectations of some health-care professionals that YAs should *cope better* or *just get on with life*.

Social support has repeatedly been related to psychological well-being (Cohen, 2004).⁴⁸ Peer support is noted as a significant variable in the developmental trajectory of self-esteem in early to middle adolescence (Diehl et al., 1998).⁵³ Moreover, a decrease in social support during the emerging adult phase is linked with increased depressive symptoms.³ The onset of chronic pain in childhood, adolescence or the EA phase of emotional development is relevant as there is direct impact upon an individual's ability to access peer relationships and support networks. Galambos et al.³ demonstrated that decreases in social support were related to increases in depression in an EA group. Social networks tend to reduce in size with age. Importantly, the emotional tone of social support networks and peer relationships is directly related to daily emotional experiences.³⁸ Access to a positive social support network is clearly beneficial to all individuals with and without chronic pain, across the lifespan.³¹ The authors suggest, however, that separation and disconnection from peers in the EA phase is particularly detrimental for the development of emotional regulatory strategies in to adulthood. YAs reporting small social networks and negative interactions with peers are more likely to experience poorer emotional functioning which has detrimental future negative implications for behavioural choices and quality of life. It is both quality and quantity of peer relationships that are relevant in this EA group. In a normative process 'network pruning', the act of reducing social relationships, happens naturally over time to support the optimisation of social and emotional functioning in adulthood (Carstensen et al., 2011).⁴⁹ We posit that difficulties in engaging with 'network pruning' due to limited social contacts has negative consequences for this social optimisation and decreases the opportunity for experiencing positive emotions in YAs with pain.³⁹ We further hypothesise that *perceiving* being unable to engage in normative

activities due to thwarted opportunities magnifies a feeling of separation and disconnection from peers.

Individuals with chronic pain (across the age span) often identify feeling dependent upon others, along with a perceived burdensomeness.⁴⁰ In adopting a developmental perspective, the relevance and role of caregivers has been repeatedly highlighted as significant in the regulation of emotions in infants and childhood, with the role of carers being a precursor to the development of independent regulation of emotions. Arnett (2002)⁴⁵ describes that having the opportunity for a period of self-focus allows individuals in EA to develop skills of independent living. In taking a closer look at the theme of *dependency*, three factors identified as important milestones in reaching adulthood are as follows: reaching financial independence, making independent decisions and accepting responsibility for oneself (Nelson and Luster, 2014).^{29,43} YAs with chronic pain have described finding it difficult to reach these milestones as they struggle to ever even enter the employment market. It is noteworthy that studies in broader non-chronic pain EA samples show that leaving the parental home can reduce anxiety and improve parental relationships (Wood et al., 2004).^{41,51}

Implications for clinical practice

If we are gathering a picture that there are distinct themes of relevance in YAs with chronic pain then potentially interventions should be guided by this finding. Both perceived and real loss of opportunities may have spanned, for some YAs, from early childhood. We have highlighted the value of noting the situational context (thwarted opportunities, peer separation, dependency and validation of illness) of the EA phase and its relevance in understanding coping and management of chronic pain. Moreover, the context of age may also mean that there has been less opportunity to explore a range of behavioural responses across a variety of situations. It may be of value to consider the development and maintenance of social relationships when supporting YAs with chronic pain. The role of negative peer evaluations may also be relevant to emotional distress and coping.

The framework of thwarted opportunities and dependence suggests that the provision of more detailed information regarding employment and education with greater reference to perceived barriers to future opportunities may be useful. There may be value in involving significant others, particularly parents, in the delivery and content of pain management treatments. The stories of struggle from the YAs indicate the importance of a careful balance between supporting care needs and

developing parental/caregiver confidence in facilitating growing independence. Dependency and solicitous care giving is discussed widely in the broader pain literature.⁴² In this study, for some YAs, independent milestones were described as never having been achieved as opposed to those lost to the development of a pain condition. Therefore, there may be utility in YAs being provided with additional support in this area.

Limitations of the current study

It is acknowledged that the current study is limited by the number of YAs involved in the focus groups. This study may indeed be the experiences of a minority of YAs with chronic pain. Moreover, the narratives were limited to a selective group being cared for within a tertiary level pain team and it may be that YAs managed in the community or primary care describe differing experiences, although the authors note that the identified themes do appear to resonate with findings in the literature investigating the impact of chronic illnesses on YAs.

Conclusions

This exploratory and qualitative study presents a preliminary narrative of the experience of chronic pain in YA life. The emerging adult literature provides a valuable framework for examining a normal developmental trajectory and highlights the relevance of age-related processes. The *idealisation* of opportunity and the role of the *perception* of experiences in this developmental phase appear relevant. The numerous biological and social alterations that occur during adolescence and EA present many opportunities for experiencing and managing emotions. It is relevant that emotional stability is not yet established in EA as we begin to understand how the connection with unhelpful management strategies may be differentiated from older populations with chronic pain. It is imperative that further research is conducted in this area to allow the translation of these specific needs in this patient population to be addressed and managed. We suggest further avenues of immediate interest may involve the examination of anger, perception of inequality and dysregulation of emotion, as well as neuroimaging studies to identify neurobiological processes associated with emotional regulation development in this population.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

References

- Williams AC, Eccleston C and Morley S. Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Db Syst Rev* 2012; 11: CD007407.
- Arnett JJ. Emerging adulthood: a theory of development from the late teens through the twenties. *Am Psychol* 2000; 55(5): 469–480.
- Galambos N, Leadbeater B and Barker E. Gender differences in and risk factors for depression in adolescence: a 4-year longitudinal study. *Int J Behav Dev* 2004; 28(1): 16–25.
- Casey BJ, Getz S and Galvan A. The adolescent brain. *Dev Rev* 2008; 28(1): 62–77.
- Maslow GR, Haydon A, McRee AL, et al. Growing up with a chronic illness: social success, educational/vocational distress. *J Adolescent Health* 2011; 49(2): 206–212.
- Luyckx K, Seiffge-Krenke I, Schwartz SJ, et al. Identity development, coping, and adjustment in emerging adults with a chronic illness: the sample case of type 1 diabetes. *J Adolescent Health* 2008; 43: 451–458.
- 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. *Clin J Pain* 2013; 29(7): 600–612.
- Toye F, Seers K, Allcock N, et al. A meta-ethnography of patients' experience of chronic non-malignant musculoskeletal pain. *Health Serv Deliv Res* 2013; 1(12).
- Frank A. *The wounded story teller: body, illness and ethics*. Chicago, IL: University of Chicago Press, 1995.
- Pini B. Focus groups, feminist research and farm women: opportunities for empowerment in rural social research. *J Rural Stud* 2002; 18(3): 339–351.
- Kidd P and Parshall M. Getting the focus and the group: enhancing analytical rigor in focus group research. *Qual Health Res* 2000; 10(3): 293–308.
- Baumgartner TA, Strong CH and Hensley LD. *Conducting and reading research in health and human performance*. 3rd edn. New York: McGraw-Hill, 2002.
- Bernard HR. *Research methods in anthropology: qualitative and quantitative approaches*. Walnut Creek, CA: AltaMira Press, 1995.
- Johnson RB and Christensen LB. 2004; *Educational research: quantitative, qualitative and mixed approaches*. Boston, MA: Allyn & Bacon.
- Krueger RA. *Focus groups: a practical guide for applied research*. 2nd edn. Thousand Oaks, CA: SAGE, 2000.
- Morgan DL. *Focus groups as qualitative research*. 2nd edn. Thousand Oaks, CA: SAGE, 1997.
- Onwuegbuzie AJ, Jiao QG and Bostick SL. 2004; *Library anxiety: theory, research and applications*. Lanham, MD: Scarecrow Press.
- Curtin C. Eliciting children's voices in qualitative research. *Am J Occup Ther* 2001; 55(3): 295–302.
- Chiu L. Transformational potential of focus group practice in participatory action research. *Action Res* 2003; 1(2): 165–183.
- Skop E. The methodological potential of focus groups in population geography. *Popul Space Place* 2006; 12(2): 113–124.
- Alex L and Hammerstorm A. Shift in power during an interview situation: methodological reflections inspired by Foucault and Bourdieu. *Nurs Inq* 2008; 15(2): 169–176.
- Finlay L. 'Rigour', 'Ethical Integrity' or 'Artistry'? Reflexively reviewing criteria for evaluating qualitative research. *Brit J Occup Ther* 2006; 69(7): 319–326.
- Stanley M and Shoba N. Methodological rigour: ensuring quality in occupational therapy qualitative research. *New Zeal J Occup Ther* 2014; 61(1): 6–12.
- Strauss A and Corbin J. *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks, CA: SAGE, 1998.
- Leech NL and Onwuegbuzie AJ. Qualitative data analysis: a compendium of techniques for school of psychology research and beyond. *School Psychol Quart* 2008; 23(4): 587–604.
- Carey M and Smith M. Capturing the group effect in focus groups: a special concern in analysis. *Qual Health Res* 1994; 4(1): 123–127.
- Bagnoli A and Clark A. Focus groups with young people: a participatory approach to research planning. *J Youth Stud* 2010; 13(1): 101–119.
- Onwuegbuzie AJ, Dickinson WB, Leech NL, et al. A qualitative framework for collecting and analyzing data in focus group research. *Int J Qual Meth* 2009; 8(3): 1–21.
- Arnett JJ. *Emerging adulthood: the winding road from the late teens through the twenties*. 2nd edn. New York: Oxford University Press, 2015.
- Balfe M. The body projects of university students with type 1 diabetes. *Qual Health Res* 2009; 19(1): 128–139.
- Galambos NL, Barker ET and Krahn HJ. Depression, self-esteem, and anger in emerging adulthood: seven-year trajectories. *Dev Psychol* 2006; 42(2): 350–365.
- Zimmermann P and Iwanski A. Emotion regulation from early adolescence to emerging adulthood and middle adulthood: age differences, gender differences, and emotion-specific developmental variations. *Int J Behav Dev* 2014; 38(2): 182–194.
- Bunzli S, Watkins R, Smith A, et al. Lives on hold: a qualitative synthesis exploring the experience of chronic low-back pain. *Clin J Pain* 2013; 29(10): 907–916.
- Wilson KG and Murrell AR. 2004; Values work in acceptance and commitment therapy: setting a course for behavioral treatment. In: Hayes SC, Follette VM and Linehan M (eds) *Mindfulness and acceptance: expanding the cognitive-behavioral tradition*. New York: Guilford Press, pp. 120–151.
- McParland JL and Eccleston C. It's not fair: social justice appraisals in the context of chronic pain. *Current Dir Psychol Sci* 2013; 22(6): 484–489.

36. Mikula G, Scherer KR and Athenstaedt U. The role of injustice in the elicitation of differential emotional reactions. *Pers Soc Psychol B* 1998; 24(7): 769–783.
37. Trost Z, Vangronsveld K, Linton SJ, et al. Cognitive dimensions of anger in chronic pain. *Pain* 2012; 153(3): 515–517.
38. English T and Carstensen LL. Selective narrowing of social networks across adulthood is associated with improved emotional experience in daily life. *Int J Behav Dev* 2014; 38(2): 195–202.
39. Baltes MM and Carstensen LL. The process of successful ageing. *Ageing Soc* 1996; 16(4): 397–422.
40. Kowal J, Wilson KG, McWilliams LA, et al. Self-perceived burden in chronic pain: relevance, prevalence, and predictors. *Pain* 2012; 153(8): 1735–1741.
41. Smetana JG, Campione-Barr N and Daddis C. Longitudinal development of family decision making: defining healthy behavioral autonomy for middle-class African American adolescents. *Child Dev* 2004; 75(5): 1418–1434.
42. Bailey KM, Holmberg D, McWilliams L, et al. Wanting and providing solicitous pain-related support: the roles of both relationship partners' attachment styles. *Canadian J Beh Sci/Revue canadienne des sciences du comportement* 2015; 47(4): 272–281.
43. Nelson LJ and Luster S. *Oxford handbook of emerging adulthood*. New York: Oxford University Press, 2014.
44. Schulenberg JE, Sameroff AJ and Cicchetti D. The transition to adulthood as a critical juncture in the course of psychopathology and mental health. *Dev and Psychopath* 2004; 16(4): 799–806.
45. Arnett JJ. The psychology of globalization. *Am Psychol* 2002; 57(10): 774–783.
46. Bunniss S and Kelly DR. Research paradigms in medical education research. *Medi Edu* 2010; 44(4): 358–366.
47. Stommen NC, Verbunt JA and Goossens ME. Future goals of adolescents and young adults with chronic musculoskeletal pain. *Eur J Pain* 2015; 20(4): 564–572.
48. Cohen S. Social relationships and health. *Am Psychol* 2004; 59(8): 676.
49. Carstensen LL, Turan B, Scheibe S, et al. Emotional experience improves with age: evidence based on over 10 years of experience sampling. *Psychol and Aging* 2011; 26(1): 21.
50. Flick U. *An introduction to qualitative research*. London: SAGE, 2009.
51. Wood MD, Read JP, Mitchell RE and Brand NH. Do parents still matter? Parent and peer influences on alcohol involvement among recent high school graduates. *Psychol Addi Behav* 2004; 18(1): 19.
52. Saarni C, Campos J, Camras LA, et al. Emotional development. In: Damon W and Lerner R (eds) *Handbook of child psychology*, 6th edn. New York: Wiley, 2006.
53. Diehl DS, Lemerise EA, Caverly SL, et al. Peer relations and school adjustment in ungraded primary children. *J Edu Psychol* 1998; 90: 506–515.
54. Scott W, McEvoy A, Garland R, et al. Sources of injustice among individuals with persistent pain following musculoskeletal injury. *Psychol Injury and Law* 2016; 9.