

1 **Title:** Beliefs about worry and pain amongst adolescents with and without chronic pain.

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25

26

Abstract

27 Objective: to explore beliefs about worries, beliefs about pain and worries about pain held by adolescents
28 with and without chronic pain.

29 Methods: Adolescents with and without chronic pain aged 14-19 completed an online survey with free
30 text questions about pain and worry. We collected demographics and used the Penn State Worry
31 Questionnaire and Pain Catastrophising Scale for Children to contextualize the qualitative data, which
32 was analyzed with reflexive thematic analysis.

33 Results: Eighty-one participants completed the survey, 36 with chronic pain, and 45 without (mean
34 age:16.73). Compared to adolescents without chronic pain, adolescents living with chronic pain reported
35 significantly higher general worry and pain catastrophizing. Thematic analysis generated two themes,
36 “Worry changes perceptions of selfhood”, and “Pain changes perceptions of selfhood”. Each theme
37 comprised two sub-themes showing how current and future identity trajectories were distorted by worry
38 and pain. The theme “Pain changes perceptions of selfhood” also included a third sub-theme: “Pain
39 impedes future working choices”. Worry content as well as process was problematic in all adolescents.
40 Adolescents experiencing chronic pain had specific, additional worries that pain reduces future career
41 progression. These worries appeared highly salient and challenging

42 Conclusions: Adolescents may need greater support in recognizing worry as part of normative
43 development. Adolescents in pain may benefit from specific support identifying and reducing how pain-
44 related worries interact with their futures and careers, and from school-based and vocational interventions
45 to reduce the realistic risks they face negotiating modern labour markets.

46 **Introduction**

47 Chronic pain, defined as lasting or recurring more than 3-6 months (Merskey & Bogduk, 1994;
48 Treede et al., 2015) is now classified within ICD-11, recognizing its impact (Mills et al., 2019; World Health
49 Organisation, 2018). It is reported by approximately 25% of adolescents (King et al., 2011); 8% of children
50 and adolescents state it is disabling (Huguet & Miro, 2008). Youth with chronic pain show impaired
51 physical, social (Palermo et al., 2008) and emotional functioning (Vinall et al., 2016). Specifically, children
52 with chronic pain report elevated pain-related anxiety, associated with increased pain severity (Cohen et
53 al., 2010), frequency (Simons et al., 2012), and disability (Simons & Kaczynski, 2012). However, most

54 measures that assess pain-related anxiety in children have taken a ‘top-down approach’; adapting adult
55 measures via developmentally appropriate language. This is particularly true of the Pain Catastrophizing
56 Scale for Children (PCS-C), a common pain anxiety measure (Fisher et al., 2018). It has also been argued
57 that the concept of catastrophizing could be better described as worry in children and adults (Crombez
58 et al., 2020; Eccleston et al., 2012).

59 Worry is an iterative cognitive process; the possible negative effects of a potential threat are
60 considered, leading to negative emotions and automatic processes, prolonging the worry. During
61 adolescence, improved cognitive ability allows youth to worry for extended periods, develop more
62 abstract thought, and think about worries beyond their own experiences (Weems & Costa, 2005).
63 Consequently, as rates of chronic pain increase in early adolescence (King et al., 2011), worries also
64 become more elaborate and increase in duration. Worry has therefore been deemed imperative in the
65 attempt to understand the process of chronic pain in youth (Fisher et al., 2016). It is proposed that worry
66 functions to aid vigilance and problem-solving to unresolved threats (Davey, 1994). In the absence of
67 effective solutions for chronic pain, worry intensity, uncontrollability, and interruption becomes
68 problematic (Eccleston & Crombez, 2007). Furthermore, beliefs about pain are significant in the
69 subjective aspects of reporting pain such as pain intensity and distress, reducing treatment compliance
70 (Williams & Thorn, 1989). Beliefs about worry and pain are important in understanding maintenance of
71 these phenomena, and thus may be important in the processes that link them.

72 Worry is common among adolescents experiencing high pain levels (Simons et al., 2012). While
73 quantitative studies provide important contributions to the literature, they are nomothetic, hence unable
74 to explore the more idiographic nature of adolescents’ experiences of co-occurring worry and chronic
75 pain. Two studies have adopted a more idiographic approach. Fisher, Keogh, and Eccleston (2017) used
76 a diary method to investigate worries in adolescents with and without chronic pain in a community sample.
77 This study focused on the content, intensity, or interference of worry and found no differences between
78 those adolescents experiencing and not experiencing chronic pain. Heffernan et al. (2020) interviewed

79 twelve adolescents with chronic pain attending a pain clinic. Participants described different experiences
80 of worry and pain, with worry rippling from an initial thought which took hold and became overwhelming,
81 whereas pain was unpredictable. This study illuminates experiences of worry in young people with chronic
82 pain, but does not allow any comparison with worry and pain experiences of young people who do not
83 experience chronic pain. To date, the literature lacks qualitative explorations of the experience and
84 process of worry in a community sample of adolescents with chronic pain.

85 Given the role that beliefs play in the maintenance of worry and pain and the incongruent findings
86 from studies comparing worry in adolescents with and without chronic pain, it is important to further
87 explore differences in worry between these two groups. We conducted an online survey, asking
88 participants to provide free text response to questions about pain and worry, and we also collected
89 demographics and general worry and pain-related scores using standardized measures. We
90 hypothesized that adolescents with chronic pain will have higher general worry and pain-specific worries
91 compared to adolescents without chronic pain. However, these measures are to contextualize the
92 qualitative data. . As we have little detailed understanding of worry within chronic pain in adolescence
93 from the adolescents' perspective, here we focus adopting a more idiographic approach to qualitatively
94 studying an open-the nature of beliefs about worries, beliefs about pain and worries about pain held by
95 adolescents with and without chronic pain.. Whilst the fear avoidance model (Crombez et al, 2012)
96 provides an important contribution to our understanding about pain and worry in individuals, is important
97 to illuminate adolescents' subjective experiences. This should contribute to our understanding of how
98 beliefs about worry and pain may maintain pain intensity and distress and enable future theory and model
99 development of worry within chronic pain in youth which is grounded in their lived experience.

100

Methods

101

Study Design

102

We developed an online survey to explore differences in worry between adolescents with and
103 without chronic pain. The main part of the survey was qualitative, asking participants to provide free text

104 responses to questions about their experiences of pain and worry. The remainder of the survey consisted
105 of some descriptive data collection, and two quantitative measures, the Penn State Worry Questionnaire
106 (PSWQ-C, Chorpita et al 1997) to investigate between group differences between generalized worry and
107 the PCS-C (Crombez et al, 2003) for pain-specific worry. The purpose of the quantitative data was to
108 contextualize the qualitative data; whether or not there were between-group differences between the
109 PSWQ-C and PCS-C, we aimed to gain insight into reasons behind such observations through analysis
110 of adolescents' lived experience.

111 We primarily used a qualitative online survey as we wanted to focus on the nuanced, considered
112 understanding of issues qualitative data offer whilst remaining mindful of key issues of adolescence that
113 may hinder engagement or honest responding (Toepoel, 2017; Vehovar & Manfreda, 2017). We
114 anticipated that use of a survey in our context could enable young people to respond freely with what is
115 important to them, accessing their own language and terminology in a detailed way that was also not too
116 burdensome (Braun et al., 2020; Toepoel, 2017). This is particularly important during a developmental
117 period where individuation from parents is crucial; something that can be impaired by the experience of
118 chronic conditions including pain (Akre & Suris, 2014; Liakopoulou, 1999). Qualitative interviews offer
119 opportunities for insight and exploration but qualitative surveys can provide depth, even if individual
120 responses are short, when the whole dataset is considered (Braun et al., 2020). Furthermore, qualitative
121 surveys offer something unique within qualitative data collection methods; a 'wide-angle' lens on the topic
122 (Toerien & Wilkinson, 2004) that also enables capturing a diversity of experiences (Braun et al., 2017).
123 A survey that could be completed in adolescents' own time and space would also allow a wider range of
124 participants to take part as they would not be dependent on parents to facilitate an interview.

125 We used a critical realist framework, which distinguishes between a real world, i.e. one that is
126 unobservable and independent of human theory and construction of meaning, and an observable world,
127 which is what we know and understand from our experiences and perspectives (Denzin and Lincoln,
128 2011). This framework allowed us to examine participants' own beliefs of worry and pain while also being

129 attentive to the significance and influence of the material contexts within which they operate. Inductive
130 reflexive thematic analysis principles guided our question development and analysis, i.e. we were data
131 driven when generating our themes, and reflexive thematic analysis refers to a particular way of coding
132 which requires researchers to be highly analytic and reflexive in generating themes from codes (Braun &
133 Clarke, 2006; 2019a; 2021). We have detailed this process below. Several strategies were employed to
134 ensure credibility and quality of the whole research process (Shenton, 2004). We achieved research
135 transparency via regular meetings and debrief sessions to allow appraisal of sample size, data collection
136 and analyses, including research reflexivity (Spencer et al., 2003; Yardley, 2000). This means we ensured
137 that we reflected on the possible impact of how we structured our data collection which could arise from
138 our backgrounds and experiences in pediatric and adolescent pain (authors AJ, EF), pediatric clinical
139 psychology (CW), placement within a clinical psychology child service (DM) occupational health
140 psychology (EW), and working within schools (HM). For example, the mini pilot described below enabled
141 us to be reflexive about our own and others' perceptions in shaping the final study questions.

142 ***Participants***

143 We aimed to recruit adolescents who self-identified as living with chronic pain and those who
144 self-identified as living without it, aged 14-19, since this is the period when pain is most prevalent during
145 childhood and adolescence (King et al., 2011). In line with our use of reflexive thematic analysis (Braun
146 & Clarke, 2006; Braun & Clarke 2019a) we did not use the contested concept of saturation to guide
147 sample size (Malterud et al., 2016; Saunders et al., 2018). Rather, we followed Braun & Clarke (2019b),
148 acknowledging that meaning is generated through data interpretation not excavation, so deciding when
149 to stop data collection is subjective and cannot be decided fully a priori. We generated a provisional
150 sample size of 70 that could generate sufficient data to enable a rich account of our phenomena of
151 interest, considering our method (Braun et al, 2020, discuss a lower end of 20-49, mid-range of 60-99 for
152 qualitative online surveys), aim, and population (Sim et al., 2018). We did not proscribe a priori that our
153 sample should comprise half adolescents self-identifying as living with chronic pain and half not, since in

154 line with our thematic analysis framework, we planned to analyze data across the whole dataset, rather
155 than by pain status. Therefore, we recruited adolescents with convenience sampling, collecting and
156 analyzing data iteratively. In sum, we used data type and iterative analyses and collective author
157 judgement about when to stop coding and move to thematic generation (Braun & Clarke, 2019b) to guide
158 us towards a sample size likely to achieve our study aims (Vasileiou et al., 2018).

159 We recruited adolescents through schools and charities across England and Ireland. Consistent
160 with good practice (Lindsay, 2019), we recruited samples from these countries through similar strategies,
161 comprising a combination of online recruitment through pain and parenting websites, and contacting
162 schools and sports organizations to offer study information packs or presentations.

163 **Ethics**

164 Adolescents interested in taking part received study information packs and the opportunity to
165 contact researchers with any questions. Parents/caregivers of under 18s received their own study pack
166 and contacts. Once questions from adolescents and caregivers had been answered, all adolescent
167 participants gave informed consent, as did their adult caregivers if they were under 18. This included
168 permission to publish anonymized quotations. Adolescents were sent a link to an online survey using
169 Google Forms software (Ireland) and Online Surveys (England). A safeguarding protocol stated
170 information was confidential unless it suggested the participant or someone they wrote about was at risk,
171 in which case appropriate agencies would be informed. Ethical approval for the study was granted by all
172 researchers' institutions: Bath Spa University reference 200219AS; Trinity College Dublin University
173 reference SPREC112018-04; University of Bath reference PREC 17:201.

174 **Measures**

175 **Qualitative survey questions:** Free text questions were used to elicit adolescents' positive
176 and negative beliefs about worry, as well the content of their worries following a qualitative open-ended
177 survey design, which enables personal responses to challenging issues (Clarke & Smith, 2015; Jordan
178 et al., 2018; Toerien & Wilkinson, 2004). The questions were designed to explore general and pain-

179 related worries and were based on successful use in a previous study about worry in a developmental,
180 but not pain, context (Wilson & Hughes, 2011). See Appendix 1 for questions. We piloted the qualitative
181 questions, as it was important to check the survey would be accessible to the target age range, likely to
182 encourage rich and relevant answers, and not burdensome (Braun et al., 2020). No substantive changes
183 were recommended, but we did reword some qualitative questions to improve clarity based on feedback.
184 All adolescents were asked to complete all free text questions irrespective of whether they had identified
185 as living with chronic pain or not so differences between groups could be considered.

186 **Demographics:** Participants self-reported their age, sex, nationality or race.

187 **Pain characteristics,** Participants were asked to report if they had chronic pain by responding
188 to: “do you experience ongoing pain? By ongoing pain we mean pain that you experience anywhere in
189 your body, for three months or longer”. We went on to clarify that pain may fluctuate and not have to be
190 experienced every day to qualify. This follows the definition of chronic pain by the International
191 Association for the Study of Pain definition (Treede et al., 2015). Only participants who reported they had
192 chronic pain were asked to report pain intensity (Birnie et al., 2019), pain interference and pain
193 bothersomeness using a 0-11 Numerical Rating Scale (NRS).

194 **General worry:** Adolescents completed the Penn State Worry Questionnaire for Children
195 PSWQ-C (Chorpita et al 1997)). The PSWQ-C is a 14-item inventory where participants rate each
196 statement on a 4-point Likert scale (0 = Never True, to 3 = Always True). After reversing three items,
197 responses are summed for a total score of 42 (range 3-42). Acceptable internal reliability was found for
198 this study, $\alpha = 0.794$. Whilst clinical cutoffs are not available for this measure, norms for children and
199 adolescents without clinical diagnoses of anxiety report a mean of 18 on the measure and those with a
200 clinical diagnosis of generalized anxiety disorder reported a mean of 27 (Chorpita et al 1997).

201 **Pain-related worry:** The Pain Catastrophising Scale for Children (PCS-C, Crombez et al, 2003)
202 is a widely used measurement consisting of 13 items which are designed to assess pain catastrophizing
203 in young people through combining subscales of helplessness, magnification, and rumination.

204 Participants respond to 13 statements on a 5-point scale (1= Not at all, 5 = Extremely). Responses are
205 summed for a total of 65 (range 1-65). Pielech et al (2014) suggest clinical reference points low (0-14),
206 moderate (15-25) and high (26 and greater) catastrophizing. Excellent internal consistency was observed
207 for the study at hand $\alpha = 0.96$.

208 **Data analytic plans**

209 We calculated participants' mean age, summarized demographic information and used a one-
210 way ANOVA to analyze generalized worry and pain-related worry between groups. For free text data
211 reflexive thematic analysis was used, adopting an inductive approach so codes and themes were created
212 from the data rather than a pre-conceived coding scheme (Braun & Clarke, 2006; Braun & Clarke, 2019a).
213 We followed Braun and Clarke's (2006) 6 main stages. In all stages, we could not be naïve to our
214 knowledge of developmental experiences of pain and worry but remained consciously open to all new
215 perceptions and ideas. EW kept reflexive notes at each meeting about how our backgrounds may impact
216 on our analysis which we brought forward into each subsequent stage to discuss. In all stages we paid
217 special attention to the emergence of any exceptions within the datasets which might test our emerging
218 themes. This is important to enable a credible account of the data (Green and Thorogood, 2009).
219 However, these were not in evidence. For example, it was striking that all adolescents with pain wrote
220 about concerns that pain would negatively affect their future choices, not just their current selves.

221 In stage one, we all familiarized ourselves with the data through repeated readings. In stage two,
222 authors EW and HM generated initial codes, or labels of meaningful patterns in the data, using Word and
223 Excel. We created initial codes to organize the data into meaningful segments. We conducted this initial
224 step without looking at whether data segments arose from adolescents living with pain or those not living
225 with pain. The survey responses were downloaded then presented for analysis without identifying
226 information such as pain status. We did this to try to reduce researcher bias of expecting adolescents
227 with chronic pain to have a particular set of worries distinct from those not in pain. However, adolescents'
228 pain status was sometime clear from a data excerpt so we could not eliminate bias although we were

229 reflexive and debated analyses in detail. In stage three, EW and HM considered how our codes combined
230 to form broader themes. EW and HM completed stages two and three independently before meeting
231 together and then with AJ who also contributed codes and themes; as a trio, we reviewed and refined
232 these stages. We repeated this process for stage four, so EW and HM independently checked if the
233 themes worked for what had been coded and also across the whole dataset. EW and HM discussed
234 together before meeting with AJ to generate an initial thematic map which we took to the whole team. In
235 stage 5, all authors met and discussed the coding, themes and map. There were no substantial title
236 changes, but we negotiated code salience, based on intensity with which relevant data were expressed
237 and ensured we paid particular attention to any seemingly contradictory data. We debated differences
238 until our situated, reflexive interpretation enabled us to define, name and exemplify themes (Braun &
239 Clarke, 2019b). In stage 6, we wrote the analytic account (EW with significant input from all authors).

240 **Results**

241 ***Demographic characteristics of participants:*** Ninety-one adolescents expressed interest in
242 participating; 5 withdrew without giving a reason before providing consent, and 4 withdrew after providing
243 consent, without giving reasons. The remaining 82 adolescents completed the survey. One participant
244 was excluded following survey completion as it was clear from their answers that despite the specific
245 inclusion criteria, they had finished school some time ago, so the final sample included 81 participants
246 (62 female, 19 male). Participants reported a mean age of 16.73 years (SD 1.27). Of these participants,
247 36 reported they lived with chronic pain, and 45 adolescents reported they did not live with chronic pain.
248 There were no differences in outcomes measures between female and male participants and no
249 relationships between age, nationality, race, and outcomes measures, and so these were not controlled
250 for in further analyses.

251 ***Quantitative data analysis:*** Adolescents with chronic pain reported moderate levels of pain
252 intensity, bothersomeness, and interference from pain. Compared to adolescents without chronic pain,
253 adolescents with chronic pain had significantly higher general worry ($F(1,78) = 6.10, p = 0.016$), pain

254 catastrophizing (total score); $F(1,75) = 21.37, p < 0.001$), rumination ($F(1,74) = 11.61, p = 0.001$),
255 magnification ($F(1,69) = 7.62, p = 0.007$), and helplessness ($F(1,70) = 23.16, p < 0.001$). Pain
256 catastrophizing scores in both groups were moderate (Pielech et al., 2014), general worry for the chronic
257 pain group was more similar to clinical samples (Chorpita et al., 1997; Pasarelu et al., 2017) and
258 adolescents without chronic pain more similar to adolescents without clinical anxiety in the original child
259 study (Chorpita et al., 1997). See Table 1. [insert table here].

260 **Qualitative data analysis:** In the qualitative data, twelve participants omitted to complete one
261 or two questions (and these were always the follow-up questions, see Appendix 1 for the question
262 schedule). Twenty-six responses out of a total of 567 (81 participants x 7 questions) were between one
263 and two words long. All other responses were rich in content, allowing for in-depth analyses performed
264 by experienced qualitative researchers.

265 When coding the qualitative data, we generated two overarching themes; *worry changes*
266 *perceptions of selfhood*, and *pain changes perceptions of selfhood*. Each theme had two sub-themes
267 about how current and future identity trajectories were distorted by worry. *Pain changes perceptions of*
268 *selfhood* also had a third sub-theme *pain impedes future working choices*. See Figure 1. The themes
269 reflect how adolescents in pain and not in pain are affected by what may appear to be normal
270 developmental worries but to a concerning degree; additionally, adolescents in pain have a specific,
271 additional set of worries regarding the impact of pain on future career progression. Verbatim quotations,
272 with identifying features redacted, exemplify the findings. Carefully chosen pseudonyms support
273 idiographic exploration of experience (Braun & Clarke, 2013; Lahman et al., 2015). [insert Figure 1 about
274 here].

275 **Theme 1: Worry Changes Perceptions of Selfhood**

276 Adolescents described, how their actions and affect change, in response to their worries across
277 a range of social situations. More crucially however, these changes distort how adolescents see
278 themselves in their present lives and alter projections of their future selves. Worries about what people

279 think of them change what adolescents feel they should do in the next few months and years. This
280 combination of worry changing both present and future self-identities combines so that worry can change
281 views of selfhood.

282 ***Theme 1, Subtheme 1: Worry Changes Perceptions of Current Identity***

283 Adolescents reported that worry can be strong enough to cause undesirable behavior change,
284 exemplified by Darius: *“Worry is bad because you might act on impulse if your worry is involved with*
285 *something like jealousy”*. (Darius, 16-year-old male, with chronic pain). Here, worry is linked to a
286 negatively perceived phenomenon, jealousy, leading to lack of control over actions.

287 However, even when worry is linked to something potentially more positive, such as making
288 friendships, it can lead to unhelpful behavior change: *“Worry is also unhelpful in social situations. If you’re*
289 *a naturally shy person then you’ll worry about making friends, keeping friends, worrying about maintaining*
290 *conversations. Worrying about being interesting, worrying can cause you to try to over-please”*. (Nala,
291 16-year-old female, without chronic pain). Adolescents experience that worry can impede a broad
292 category of “social situations”. It may be developmentally normal to worry about social situations, yet the
293 focus on worry being negative, and on a causal mechanism of worry changing behavior, suggest
294 adolescents are uncomfortable with the effect of worry on their actions.

295 Furthermore, when worry interferes with affect, this can extend into altering participants’ views
296 of themselves. Kim expresses: *“It [worry] can cause you to feel sad and not yourself”*. (Kim, 15-year-old
297 female, without chronic pain). Feeling sad is not aligned to how Kim sees herself, showing that
298 adolescents’ sense of self can be distorted by worry. This distortion is emphasized when worry is
299 constant: *“It [worry] can destroy or weaken relations as if you are constantly worried you will not act like*
300 *yourself and so may act differently towards your friends and family”*. (Jade, 17-year-old female, without
301 chronic pain).

302 These data suggest that worry can fundamentally make adolescents feel they are not acting
303 authentically and that this presentation of the self will harm relationships. It is noticeable that all the

304 examples given concern how worry can cause behavior likely to weaken relations with others. Further, it
305 is striking that all data bar one quotation coded to the sub-theme *worry changes perceptions of current*
306 *identity* came from adolescents who are not living with chronic pain.

307 **Theme 1, Subtheme 2: Worry Changes Notions of Future Selves**

308 Adolescents experience different ways in which worry affects their projected future selves.
309 Adolescents are worried about their own abilities to achieve a desired future. They also report worries
310 that they are being funneled into things they do not want to do or cannot succeed at in order to fulfil
311 others' expectations. For example, Zara reported: *"I don't want to go to uni [university] but feel as I should*
312 *and am expected too in order to seem 'smarter' and of a 'higher level'".* (Zara, 16-year-old female, without
313 chronic pain). Zara does not specify who is doing the "expecting" but experiences concern she feels
314 compelled to do something in her near future which is alien to her wishes. Furthermore, this act (*"go to*
315 *uni"*) appears required so Zara can present herself and be perceived in a particular way.

316 A different way in which worry challenges the perceived future self is when adolescents worry
317 they will simply be unable to achieve their desired future goals. This is exemplified by Nala: *"I worry that*
318 *I won't pass my exams so I worry that I won't get into university then I worry that my parents will be*
319 *disappointed then I worry that I'll live at home forever because I won't be employed then I worry that when*
320 *I'm older I'll regret my entire life".* (Nala, 16-year-old female, without chronic pain). It is striking how each
321 worry leads on to the next in an almost stream of consciousness expansion of worry from one particular
322 event (failing exams) right up to regretting one's entire life. These data reflect many participants' global
323 set of worries in the dataset.

324 Adolescents feel that if someone worries too much, they are in some way abnormal and there is
325 a sense of worrying limiting their enjoyment almost constantly, now and for the foreseeable future until
326 they can control their worries: *"A lot of the time people who worry can't really enjoy themselves like*
327 *everyone else because they're never living in the moment".* (Conor, 18-year-old male, with chronic pain).

328 Overall, analysis in this sub-theme suggests that worry about others' requirements of
329 adolescents to act a certain way, and also about failure at personally desired goals, are linked by an
330 underlying worry about what others think of them. This suggests that there is an unhelpful mirroring in
331 which adolescents worry about their personal trajectory changing and also more fundamentally, worry
332 can negatively affect adolescents' future projections of themselves. It is notable that most data about
333 worry changing notions of future selves were from adolescents who were not living with chronic pain, with
334 the exception of those from Conor only.

335 **Theme 2: Pain Changes Perceptions of Selfhood**

336 This theme mirrors the *worry changes selfhood* theme, since it shows that pain-specific worries
337 can distort how adolescents with pain currently see themselves and also alter projections of their future
338 selves. Perhaps unsurprisingly, all data pertaining to this theme and its sub-themes arose from
339 adolescents living with chronic pain.

340 **Theme 2, Subtheme 1: Pain Reduces Current Possibilities**

341 Pain leads to adolescents' perceptions that they cannot socialize with their peers: "*The worse*
342 *part for me (about pain) is feeling like you can't do things with your friends or miss out on going to social*
343 *events*". (Eoin, 15-year-old male, with chronic pain). Adolescence is an important period for peer
344 interaction and Eoin's comment exemplifies the feeling of missing out. Furthermore, adolescents in pain
345 may experience that pain proscribes not only their behavior but their identity: "*I wish I wasn't in it [pain]*
346 *constantly, and I don't want to burden people that I'm in pain so I don't really tend to discuss it with my*
347 *family. My mother is also very ill so I feel like I can't be in pain because she is*". (Daisy, 18-year-old
348 female, with chronic pain). Here, analyses suggest that whilst Daisy is in constant pain, she feels unable
349 to either discuss this or even be herself as someone in pain. This simultaneous experience of constant
350 pain whilst simultaneously having to deny it is challenging.

351 A key part of adolescents' pain-related worries center around schoolwork as there was a sense
352 that achieving in this domain is developmentally critical. Adolescents in pain are clear that consequences

353 of living with it include worries about struggling with their current school lives: *"I worry that my art will be*
354 *hindered as I find it hard to draw when I'm in pain and I worry that in an art exam, that could be a problem*
355 *for me"*. (Mia, 17-year-old female, with chronic pain). Adolescents clearly felt ownership over their
356 academic work and want to do well at it. Here, Mia's use of the possessive in "my art" suggests art means
357 a lot to her. Her worries about things that may or may not occur (*"could be a problem"*) are based in fact
358 (*"I find it hard to draw when I'm in pain"*).

359 Furthermore, adolescents experiencing pain report how pain impairs how they would otherwise
360 be in their present lives, a chief aim of which is to do well at school: *"I worry about pain, because it's*
361 *uncomfortable, I hate it and it feels handi-capping. I worry a lot about school work and how much pressure*
362 *I put on myself to do well"*. (Aisling, 16-year-old female, with chronic pain). Here, all four parts of the
363 sentence focus on the worry, indeed the 'hate' that Aisling feels about her pain as it is not only causing
364 her discomfort but making her feel disadvantaged. The attention paid to pain, the feeling it is "handi-
365 capping", concomitant worry about social activities and school work, and fundamental concerns it
366 interferes with identity, combine to make adolescents feel very pressurized and that there are reduced
367 possibilities for their current selves.

368 ***Theme 2, Subtheme 2: Pain Distorts Perceptions of Identity Development Trajectories***

369 Adolescents living with chronic pain have worries about their pain that affect not only their present
370 but their much longer-term future selves. Asha states: *"I am never free from it. It is running my life"*. (Asha,
371 15-year-old female, with chronic pain). This continuous emphasis, *"it is running"*, combined with the
372 definitive *"never free"* suggests pain is always in charge and will always be so. What it might mean to
373 have a life "run" by pain is explored by Rebecca, when she elaborates: *"It is hard not to feel that my*
374 *opportunities next year have been effected by how restricting pain and worry can be. I haven't had to*
375 *capacity to apply myself. In the long run I worry about the long-term effects"*. (Rebecca, 18-year-old
376 female, with chronic pain). Here, pain is robbing Rebecca of potential. She states that capacity is reduced
377 in the present, sandwiched between two references to the future which project the struggle she endures

378 trying “not to feel” that opportunities have been restricted. Her other future possible self is peering out but
379 being squashed by the limitations pain imposes: *“Sometimes it feels like the pain takes over and it won't*
380 *end. That I won't be able to do anything else but be in pain”*. (Rebecca, 18-year-old female, with chronic
381 pain). The mix of the present continuous and future tenses emphasizes the ongoing impact of worries
382 about pain reducing one's self now but also in the future. The sense of uncontrollability is critical here.

383 **Theme 2, Subtheme 3: Pain Impedes Future Working Choices**

384 We have seen that pain impedes current and future selves. Adolescence is a critical time for
385 thinking about school work and futures beyond that. A mix of uncertainty, possible “catastrophizing” but
386 also possible realism, combined with the developmental focus on the future which is normal in this age
387 range, lead adolescents in pain to specific concerns that pain may impeded future career opportunities
388 and ability to work. This is simply but powerfully stated by Hannah: *“I miss out on a lot of school [due to*
389 *pain] and it affects my results for later life”*. (Hannah, 18-year-old female, with chronic pain). Hannah's
390 use of the word “results” could imply forthcoming exams but “later life” is broad and shows she has worries
391 beyond the immediate. Adolescents also explicitly worry that pain in its currently experienced or possible
392 future forms will reduce what jobs they can do: *“The main worry is ‘is this [pain] going to get worse in the*
393 *next few years’ and is this going to affect my ability to get certain jobs?”* (Jazmine, 18-year-old female,
394 with chronic pain). Adolescents express even more fundamental concerns, that not only pain may impede
395 getting “certain jobs” but just any job at all: *“I'm scared that I won't be able to get a job when I'm older*
396 *because of the pain, it hurt [sic] and I want it to stop”*. (Ella, 15-year-old female, with chronic pain). This
397 combines fear of pain reducing future working choices, with a simple, powerful wish for the pain to stop.

398 Other data unpack how currently experienced risk factors interact with concerns about future
399 work, imparting a sense of concern grounded in realism: *“I also worry that due to me having neck pain*
400 *and the limited mobility that comes with that (e.g. can't use my right arm, can't carry anything) I worry it*
401 *will affect me in my workplace or future workplaces”*. (Megan, 17-year-old female, with chronic pain).

427 Thus when considering the pain-related worries, the quantitative and qualitative data have a different
428 thrust. The PCS-C results suggest we may be moderately concerned for both groups, although the
429 adolescents with pain more so. Yet the qualitative analyses suggest we should be highly concerned to
430 ameliorate the intense, grinding worries that ongoing pain engendered about present and future selves
431 for those young people who identified as living with chronic pain. A bleak picture emerges of youth with
432 and without chronic pain struggling with worry content and processes, so both groups may need support
433 with managing generalized worry. However, the group with pain have worries which need additional and
434 more targeted support to enable management of present and future pain-related worries and worries
435 relating to their future working selves.

436 When considering how worry changes perceptions of current identity, adolescents do not always
437 experience worry as part of the natural process of identity formation, rather our analysis shows
438 adolescents are aware they are doing things with which they are uncomfortable but feel unable to
439 discontinue. Regarding how worry changes perceptions of future identity, adolescents appear to
440 experience being on an unstoppable trajectory. Initial worries about passing exams develop into larger
441 worries about regretting one's entire life. For both groups of adolescents, it is not just worry content but
442 worry processes that appear problematic.

443 For the adolescents with chronic pain, pain limits their options, presenting them with an
444 increasingly narrowed funnel of opportunities. It could be that pain is being incorporated into normative
445 identity developmental processes, but the incorporation is, in itself, difficult for the adolescents. The range
446 of issues that pain affected was extensive, ranging from relationships with friends and family to current
447 academic success. It is to be expected that the age range we studied will be concerned with their
448 immediate futures (Violato & Holden, 1988). However, the effect of pain runs deep as ideal futures are
449 jettisoned due to projections of what adolescents consider they will and will not be able to do. This was
450 particularly so when adolescents thought about work.

451 Regarding the relationship to background literature, many adolescents with chronic pain report
452 impaired physical and social functioning, and quality of life (Gold et al., 2009; Grasaas et al., 2020; Vinall
453 et al., 2016). Our study's findings provide detailed qualitative evidence of the multi-faceted burden that
454 living with pain brings, reducing adolescents' social interaction and functioning. School functioning and
455 performance is also significantly affected in older adolescents with chronic pain (Logan et al., 2012). This
456 was highlighted in the present study's findings whereby adolescents struggled with studies due to pain
457 affecting mood, concentration, and functioning.

458 In the current study there is also a striking focus on the future. For all participants, worries are
459 projected into their future lives and selves. These were negative cognitions about the future held by
460 adolescents with and without chronic pain, consistent with previous findings from at-risk adolescents
461 (Esters, 2003; Esters et al., 2007). Notably, adolescents with chronic pain expressed worries that their
462 pain would persist, affecting physical and social functioning (consistent with previous studies, Heffernan
463 et al., 2020; Caes et al., 2015), and future working choices. The latter appears more novel
464 phenomenologically; there is related evidence from a story completion study that adolescents with
465 Complex Regional Pain Syndrome focused on centrality of loss, and also adjusting to loss, in respect of
466 future identities (Jones et al., 2020). Additionally, an American nationally representative study found that
467 adolescent chronic pain is subsequently associated with poor vocational functioning (Murray et al 2020),
468 so it appears that the adolescents in this study, who have such clear worries about future work, are
469 displaying realistic concerns.

470 One key finding from the present study is that when salience of concerns are considered, worries
471 about pain are crucial in understanding identity disruption for adolescents who experience chronic pain
472 whereas it appears that worries in general disrupt this process in adolescents without chronic pain. The
473 present study, like Heffernan et al. (2020) finds that worries change behavior and a single worry can set
474 off a chain of worries. It also highlights the importance of uncertainty in the pain experience. However,
475 the current research can compare those adolescents with and without chronic pain and while worry in

476 general is important to both, it is worry about pain that is most important to those who experience chronic
477 pain.

478 Worry is common amongst adolescents experiencing high levels of pain (Simons et al., 2012).
479 Our analysis suggests that the worry-pain cycle is challenging for adolescents since pain fuels worry,
480 especially future worry. There is an inevitability about worrying about who you are as part of the
481 developmental process (Finkenaur et al., 2012). When chronic pain is experienced, this disrupts
482 potentially normal identity development processes even more, consistent with previous findings (Jordan
483 et al., 2018b).

484 We found that worry is experienced as changing perceptions of self in ways adolescents do not
485 like. Regarding clinical implications, worry can be part of a normal developmental process, but
486 adolescents may need more support in recognizing this. This may enable them to feel more comfortable
487 in the challenging developmental stage that includes worries about change, and recognition that change
488 is likely, but also that there are often choices about how we change and about how we manage related
489 emotions. This may reduce the unpleasant sense of uncontrollability that adolescents experienced.
490 Adolescents in pain reported concerns about family relationships: whilst we know much about how
491 adolescent chronic pain can affect parent-child interactions, we need to redress the maternally centric
492 focus of existing literature to include other caregivers, use more longitudinal methods to investigate the
493 effect of rapid changes in youth in the context of parenting a young person in pain, and optimize
494 technology to capture dyadic pain interactions in real time (Jordan & Jaaniste, 2019). Furthermore, we
495 know that those who catastrophize about pain persisting and worsening over time can benefit from
496 cognitive restructuring training (Thorn et al., 2002). The participants in the current study were recruited
497 from the community; however, the intensity of their worries and the impact these had on their lives was
498 clinically significant. Therefore, interventions could be useful in different contexts including primary care
499 and schools.

500 Given the distress felt by adolescents in pain around work, we should consider how best to
501 support their thoughts about career aspirations, whether this is via targeted CBT intervention or by helping
502 teachers and schools to support an adolescent in pain more effectively (Caes & Logan, 2019). For all
503 adolescents, an increasingly complicated labor market means that authentic careers guidance is needed
504 (Mann & Huddleston, 2017): this is crucial for adolescents negotiating transitions to work whilst also
505 managing the functional and psycho-social challenges of living with ongoing pain (Calnan & Douglass,
506 2019). This transition also raises serious issues about inequality of working lives; workplace and policy
507 stakeholders could shape working practices to enable sustainable working lives for people across the
508 lifespan (Wainwright and Eccleston, 2019).

509 Considering strengths and weaknesses of the study, given the high worry scores, there may
510 have been recruitment bias as the study was advertised as being about pain and worry. Arguments have
511 been presented that qualitative surveys are unsuitable for small-scale qualitative research (Terry and
512 Braun, 2017). However, participants here produced rich data so we support Terry and Braun's (2017)
513 and Braun et al.'s (2020) view that qualitative online surveys can enable complex accounts of lived
514 experience.. We recognize that the qualitative survey encompasses a particular kind of data collection
515 hence analyses:only young people with internet access could participate in this study, though there is
516 some evidence that such anonymity, relative to other forms of qualitative data collection, can enable
517 enhanced freedom for participants to say what they want to (Terry & Braun, 2017). Our study is not
518 generalizable through a positivistic lens as we are not trying to find out how widely our findings would be
519 applicable using statistical probabilistic generalizability but this would not be an appropriate aim for this
520 kind of qualitative research (Smith, 2018). Rather, we aimed to generate richer understanding of our
521 phenomena of interest (Green & Thorogood, 2009) with a reflexive, multi-analyst analytic procedure to
522 enhance the credibility of the findings.

523 In conclusion, adolescents without chronic pain experienced worry as a salient phenomenon
524 impacting identity development. However, for adolescents with chronic pain, pain itself and worries about

525 pain may be the most salient. Experiencing chronic pain appears particularly troubling when pain-related
526 worries are added to normative age-related worries about the future. For those supporting adolescents,
527 it may help adolescents to recognize that worries are embedded in the adolescent's developing sense of
528 self, albeit in an unwanted way, and that supporting adolescents is not about removing the worry, but
529 contextualizing it for them, and supporting them to make choices. Adolescents with chronic pain may
530 benefit from specific support with identifying and reducing how pain-related worries interact with their
531 futures, notably their career plans.

532

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729 **Appendix 1: Free text survey questions**

- 730 1. Sometimes worry is good and friendly. Can you write a little bit about why worry is good?
- 731 2. Sometimes worry is bad and unfriendly. Can you write a little bit about why worry is bad?
- 732 3. Have you got any worries about being in pain? If so, can you write a little bit about this?
- 733 4. Is there anything else you would like to write about being in pain?
- 734 5. Have you got any other worries? If so, can you write a little bit about these worries?
- 735 6. Is there anything else you would like to write about worry?
- 736 7. Have you got any worries about the future that you can write a little bit about?