

**Distress and resilience narratives within pain memories of adolescents and young adults
with complex regional pain syndrome : A multi-method study**

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Abstract

A comprehensive understanding of pain memories requires consideration of risk and resilience factors across biopsychosocial domains. Previous research has typically focused on pain-related outcomes, largely ignoring the nature and context of pain memories. Using a multiple-method approach, this study explores the content and context of pain memories in adolescents and young adults with complex regional pain syndrome (CRPS).

Recruited via social media and pain-related organizations, participants completed an autobiographical pain memory task. Two-step cluster analysis was conducted on the pain memory narratives of adolescents and young adults with CRPS (n=50) using a modified version of the Pain Narrative Coding Scheme. Narrative profiles generated from the cluster analysis subsequently guided a deductive thematic analysis.

Cluster analysis identified two narrative profiles of Distress and Resilience, with the role of coping and positive affect emerging as important profile predictors across pain memories. Subsequent deductive thematic analysis, utilizing Distress and Resilience codes, demonstrated the complex interplay between affect, social, and coping domains.

Findings highlight the importance of applying a biopsychosocial framework to pain memory research, accounting for both risk and resilience perspectives and encourage the use of multiple method approaches to improve understanding of autobiographic pain memories. Clinical implications of reframing and recontextualizing pain memories and narratives are discussed, and the importance of exploring the origins of pain and possible application to developing resilience-based, preventative interventions is highlighted.

Perspective

Using multiple methods, this paper presents a comprehensive account of pain memories in adolescents and young adults with CRPS. Study findings promote the importance of adopting a biopsychosocial approach to examining both risk and resilience factors in understanding autobiographical pain memories in the context of pediatric pain.

Distress and resilience narratives within pain memories of adolescents and young adults with complex regional pain syndrome (CRPS): A multi-method study

Complex regional pain syndrome (CRPS) is a persistent, localized chronic pain condition that typically affects the extremities (57). Prevalence of CRPS in pediatric populations is estimated at 1.16/1000, with higher rates in females and peak onset during adolescence (1). As a primary pain condition, young people with CRPS report significantly elevated levels of pain compared to young people with other conditions including chronic back or abdominal pain (32). Previous literature has focused on examining pain-related disability and functioning in chronic pain more broadly (48) and also in relation to CRPS (50,52), while recent research has also begun to illustrate the protective role of resilience factors, highlighting the importance of optimism and benefit finding pediatric chronic pain (13,53). Furthermore, it is widely acknowledged that pain must be viewed within a biopsychological perspective to address physical, psychological and social factors (30,31). Thus, a comprehensive understanding of the experience and impact of living with CRPS requires the careful consideration of risk and resilience factors, rooted within a biopsychosocial framework.

Pain memories are considered to be an influential cognitive factor in the development and maintenance of chronic pain (20). For instance, various child and parental behaviors, such as pain catastrophizing and parent-child reminiscing, have been found to influence pain memory development through both risk and resilience perspectives (13,40,53). Furthermore, detailed understandings of pain memory development require consideration of not only sensory factors, but also affective and contextual factors, such as social networks and coping strategies (38,40,44). Previous studies exploring the development of pain memories in

adolescents and young adults have typically focused on acute rather than chronic pain (e.g., 39,41,42) and have broadly adopted nomothetic approaches, quantifying generalities in groups of individuals to study the impact of pain memories on functioning (38,41). Consequently, such studies have been limited in their data collection approaches through often sole use of single-item pain scales and computer-based tasks, largely ignoring the importance of social and other contextual factors (see 39).

In contrast, qualitative methods adopt an idiographic approach, providing an understanding of how experiences are constructed and understood (34), facilitating researchers to explore the underlying nature of the pain memory itself. Narratives provide important means to understand an individual's beliefs and perceptions (8) and can be studied via both nomothetic and idiographic approaches (3,35). Recent studies exploring parent pain narratives have applied an innovative coding scheme to narratives collected during pain-related interventions administered to their children (12,37). The latter study identified two narrative profiles of Distress and Resilience, characterized by risk and resilience factors respectively. Both studies, however, only explored parent narratives and thus there remains scope to explore the content and context of pain narratives of adolescents and young adults with chronic pain.

The current study therefore sought to apply a three phase, multiple methods approach to autobiographic pain narratives in adolescents and young adults with CRPS. Specifically, a modified version of Noel and colleagues' coding scheme (37) was applied to pain memory narratives, followed by a deductive reflexive thematic analysis on the same narratives. It was hypothesized that: (1) adolescents and young adults would express both risk- and resilience-based elements in their narratives, and (2) based on these elements, two distinct narrative profiles reflecting "Distress" and "Resilience" would be identified. Furthermore, to extend

findings and further explore the context of affective and contextual factors of distress and resilience in pain memory narratives, we developed three research questions:

- (1) How do pain memories of adolescents and young adults with CRPS reflect emotional experiences of distress and resilience?
- (2) How do pain memories of adolescents and young adults with CRPS reflect social experiences of distress and resilience?
- (3) How do pain memories of adolescents and young adults with CRPS reflect the role of coping strategies in distress and resilience?

2. Method

For the current study, we used data collected as part of a larger project exploring future perceptions in adolescents and young adults with CRPS. The data used in the current study was unique and distinct from previous publications in its focus on the pain memory task, as opposed to future-orientated story completion tasks (25,36). Please see the registered protocol for details of the larger study: <https://osf.io/r2wsc/>. The original study received ethical approval from the Psychology Research Ethics Committee at the University of Bath (18-111).

Participants

Participants were required to be aged 14-25 years, reflecting calls for a broader age range for adolescence and young adulthood to acknowledge delayed socio-developmental milestones and brain changes (49). A minimum age of 14 years was chosen due to feedback from participants involved in the pilot development of the story completion task concerning the

cognitive demands of the task (25). All participants were required to self-report having received a formal diagnosis of CRPS, as well as reporting an absence of severe mental health conditions (e.g., psychosis), be able to provide informed consent, speak fluent English and have access to the internet. Participants were excluded from the study if they did not meet these inclusion criteria or did not provide a written pain memory (see Procedure).

Participants were recruited through purposive sampling due to the current study's focus on adolescents and young adults with CRPS. The study achieved its aim of recruiting 50 participants (see Table 1), in accordance with published sample size recommendations within the context of the larger project's qualitative survey story completion approach (6). Sample size was also congruent with published guidelines for both chosen analyses methods, with between 20-30 participants per subgroup for the cluster analysis (14) and between 10-50 participants for the deductive thematic analysis (10).

The average age of the final sample of adolescents and young adults was 19.75 years (SD=3.68), which included 45 females and 5 males, with 1 participant preferring not to state their gender (see Table 1).

[Insert Table 1 here]

Procedure

Participants were recruited for the wider study via social media platforms, pain-related charities, online forums, and newsletters. Interested participants were invited to email the research team to determine eligibility. Participants aged 16 years and above were emailed a direct online link (47) to the survey. Participants aged 15 years or below were asked to

provide their parent/caregiver's email address, generating an online link to the information sheet and consent form being emailed to their parent/caregiver. Once informed consent was provided by the parent, the adolescent was automatically emailed the survey link, which included a young person consent form.

First, participants completed demographic items including age, gender, education, and employment status. All participants were requested to provide the duration of their diagnosis of CRPS in months. Participants were subsequently asked to complete two story completion tasks (11), followed by a short pain memory task. Following the completion of the study, participants were provided with a debrief form comprising useful links to sources of support and a £15 UK shopping voucher to thank them for their time.

Pain Memory Task

Following the instructions below, participants were asked to write about a time when the participant had experienced pain (see Supplementary Files for full task instructions). The memory task was specified as follows:

“For this task, we would like you to think about a time when you have experienced pain. Try to remember what this time was like and write down below as much detail as you can about this particular time when you were experiencing pain”.

Participants were provided with prompts to offer some suggestions regarding content that they may wish to include in their response. Possible prompts included cause of pain, length of pain, when the pain occurred, who was present at that time, actions taken to alleviate the pain and how the participant felt during the incident. A minimum length of 10 lines was required

in the participants' response to ensure sufficiently rich data for both the story completion task type (11).

A three phase, multi-method approach

Narrative Coding Scheme

The first study method phase involved a narrative coding scheme that was applied to pain memory narratives. A modified version of the Parent Pain Narrative Coding Scheme (37) was developed and applied to the pain memory task. This extended previous work by modifying the original coding scheme in several ways. Firstly, the codes of Humor/Laughter and Anger were removed due to the short, written nature of the task (note: the original coding scheme was applied to audio-recorded narratives). Secondly, the coding scheme was extended to include a broader range of factors and behaviors that have been implicated in the development of pain memories in adolescents and young adults (9) Therefore, minor amendments were made to operational definitions to better capture the reflective nature of the pain memory task. Additionally, two novel codes of Coping and Social were piloted and applied to pain memory narratives to account for the inclusion of adolescents and young adults experiences (43,45) All operational definitions of included codes were included in the coding manual (see Tables 2 and 3). See also Noel et al., 2016 (37) for detailed justification of included codes from the original coding scheme.

Original Codes: Affect and Content Codes

The following Affect Codes were used: Intensity of Positive Affect, Frequency of Positive Affect, Intensity of Negative Affect and Frequency of Negative Affect. Each code was rated on a 5-point Likert Scale, ranging from (1) "Not at All" to (5) "Very Often". In addition to

the four affect codes, four of the original content codes were included, similarly using the same 5-point Likert Scale: Threat/Anxiety, Benefit Finding/Growth and Pessimism/Optimism.

Novel Codes: Content and Social Codes

A novel Content code of Coping was added to the coding scheme following research evidence implicating the impact of coping strategies on pediatric chronic pain (10). Participants were rated as either using Attention or Non-attention focused coping strategies. Attention-focused coping included strategies that involved directly attending to the pain, such as discussing pain, rubbing the painful area or taking medicine for the pain (15). Non-attention focused coping included strategies that involved not attending to the pain, such as distraction or relaxation techniques (55,56). Current terminology was chosen to capture coping behaviors and strategies that involved directly attending or not attending to the pain by the individual, as opposed to other terms frequently used in the literature that may fail to capture to this deliberate allocation of attention to the pain (e.g., active vs. passive coping).

Finally, the current study added a novel Social Content code of Type of Observer to account for the wide range of reported social observers in young person and parental chronic pain literature, and both the positive and negative influence observers can have on pain and functioning (17,22,27). For the purposes of this study, Type of Observer was coded as Loved One (including family member, partner, or friends), Strangers or Alone.

[Insert Tables 2 and 3 here]

Implementation and Reliability of the Coding Scheme

Two coders were involved in applying the coding scheme (EN, and a research assistant (MC)). Both coders coded all narratives. Pilot testing of the coding scheme was completed by EN, who was primary coder. Pilot testing on a small sample was also performed by MC, and any disagreements or concerns were solved by mutual agreement. Interclass correlations were conducted on a random subset (20%) of coded narratives from each group to assess observer agreement, in line with published recommendations (2). The average intraclass correlation across the nine narrative codes was .84, indicating a high rate of agreement.

Two-step cluster analysis

The second study method phase involved conducting a two-step cluster analysis on codes generated from the narrative coding scheme. Descriptive analyses were conducted on narrative codes to characterize pain memory narratives. Preliminary construct validity of the coding scheme was analyzed by computing bivariate correlations between codes, to ensure that codes that reflect positive affect and content were positively correlated with each other, and not with negative affect and content codes. A two-step cluster analysis was then conducted to characterize narrative profiles, chosen over alternative clustering methods due to the current data having both continuous and categorical codes (16). Sample size was appropriate, adhering to published recommendations of a minimum of twice the number of participants per code (16). Following cluster analysis, independent samples t-tests were conducted on continuous variables between clusters, and a chi-square test was for conducted on categorical variables to compare codes between narrative profiles.

Deductive reflexive thematic analysis

The third and final study method phase involved conducting a deductive thematic analysis, based on profiles generated by the two-step cluster analysis. Thus, informed by the results of

the cluster analysis, we conducted a deductive qualitative thematic analysis (19) on the same pain memory narratives, using Distress and Resilience as the two over-arching codes. This approach was taken to complement and extend quantitative findings and provide a more detailed exploration of the nature and context of pain memories across social, emotional, and coping domains (reflected in affect, type of observer and content codes respectively). Following the cluster analysis, we identified two deductive codes of Distress and Resilience, and applied these to pain memory narratives. Specifically, this involved applying these two overarching codes to each narrative independently, as opposed to pre-categorizing each narrative as solely a distress or resilience narrative.

The current study sought to adhere to the highest standard of qualitative rigor and quality, in line with best practice guidelines across research design and analysis, as well as conclusions and reporting of results (24,60). Guided by a robust and empirically supported research-framework (37), the qualitative pain memory data was analyzed using a deductive reflexive thematic analytical approach (7,19). Reflexive thematic analysis is a widely used and theoretically flexible qualitative approach that seeks to “identify, analyze and report patterns within the data” (5). Deductive thematic analysis uses theory or research to develop a conceptual framework which guides data analysis (19). In this study, the domains used in the quantitative element of the study (informed by Noel and colleagues, (37) were used to inform the deductive thematic analyses. For the qualitative element of this study, we adopted a realist approach, whereby we sought to report the experiences and realities of participants (5).

We adopted a pre-defined, research-driven framework to guide our analyses. To achieve this, we used a ‘template approach’, whereby a code manual was developed to organize the data for subsequent interpretation (7). This approach has previously been recommended for

researchers conducting a deductive thematic analysis with a realist approach (43) and has been previously used in previous pediatric pain literature (48). Based on the original study (23) and our initial quantitative findings, the code manual comprised two codes: distress and resilience. Following published recommendations, codes were identified by the code label, the definition, and a description of how to know when the theme occurs (19) (see Table 4).

Following the work of EN as the primary coder, a subset of coded narratives (20%) were double coded and checked by AJ. After reading through the data several times, each narrative was coded under the two deductive codes and further guided by the research questions outlined above to identify the emotional, social, and cognitive components of distress and resilience. Across all data, eligible codes could be full or partial statements, however each code had to represent a distinct and clear point.

Quality of the qualitative analyses was addressed in multiple ways. First, credibility was established by including a range of quotations across the participant groups in the results section demonstrating how analyses are grounded in the data and reflective of the wider sample. Credibility was also established through detailed ongoing discussions of developing codes and themes between the first author and supervisors across the duration of the analytical process (51). Second, a clear detailed description above of the analytical process undertaken provides evidence of dependability (24). Third, the active role of the researchers in the process of collecting and analyzing the qualitative data is acknowledged, demonstrating reflexivity (5). A key element of reflexivity concerns researchers clearly describing their position in relation to both the participants and data itself (4). In this study, online data was collected by Research Assistants supervised by AJ, none of whom were involved in the analytical process. Data was analyzed by the first author (supervised by AJ

and LC). Consequently, prior to undertaking the initial analyses of the data, the first author did not have any existing relationship with the participants or data itself. As a group, all researchers have a background in psychology, identify as women, have no prior experience of chronic pain and with the exception of the first author, and have multiple years' experience of studying pediatric pain, with two members being qualified to practice clinically in the area. Contrastingly, the first author was new to the topic of chronic pain when undertaking this study as part of their Masters degree under the supervision of the last author, thus having no prior knowledge of the field.

[Insert Table 4 here]

3. Results

i. Two-step cluster analysis

Descriptive statistics for adolescent and young adults pain memory narratives are presented in Table 5, with adolescents and young adults exhibiting a wide range of affect, content and social codes. Largest variances were identified concerning frequency and intensity of negative affect, and a notable majority reported the presence of loved ones (90.2%).

[Insert Table 5 here]

Bivariate correlations were conducted between positive and negative codes to establish whether they were correlated in the expected directions (Table 6). As expected, the codes related to positive affect and content were positively associated with each other, and negatively associated with negative affect and content codes. For most codes related to

negative affect, the expected positive association with negative content codes and negative association with positive affect and content codes was similarly found.

[Insert Table 6]

A two-step cluster analysis was conducted to test whether narrative codes could be reduced into two distinct narrative profiles. No assumption tests were run due to the analysis being robust to violations. The number of clusters to be yielded was set at two to replicate and test for the presence of Distress and Resilience narratives in adolescents and young adults' pain memory narratives (23).

Two-step cluster analysis confirmed the presence of both Distress and Resilience profiles in adolescent and young adults' pain memories, characterized by risk and resilience aspects of their pain memories. A significant two-profile solution was yielded with an adequate estimation (average silhouette score =.20). A silhouette score of 0.1 indicates minimal distinction between clusters, and 1 indicates maximum distinction (47). The ratio of largest cluster to smallest cluster was 1.32, which falls under the satisfactory cut-off of <3.00 (58).

Predictor importance of the narratives codes for these profiles were as follows (from the most important/contributory to the least important/contributory): Coping (1.00), Intensity of Positive Affect (0.31), Frequency of Positive Affect (0.29), Frequency of Negative Affect (0.10), Intensity of Negative Affect (0.05), Type of Observer (0.02), Threat/Anxiety (0.01), Optimism/Pessimism (0.01) and Benefit Finding/Growth (0.01). The first cluster comprised 29 adolescents and young adults (56.9%) and the second cluster comprised 22 adolescents

and young adults (43.1%) (see Figures 1, 2 and 3 for means and percentages of narrative codes in each cluster).

Compared to adolescents and young adults in the second cluster, those in the first cluster provided pain memory narratives that were characterized by higher frequencies of non-attention focused coping strategies (81.8% of the cluster, $X^2(1) = 36.67$, $p=0.000$), a lower frequency of positive affect ($t(49) = 3.33$, $p=.002$) and a lower intensity of positive affect ($t(49) = 3.14$, $p=.003$). Intensity and frequency of negative affect, benefit finding, optimism/pessimism, anxiety, and the presence of a loved one were not found to be statistically significant. This cluster was characterized by more negative affect and content, reflecting the “Distress Narratives”.

Insert Figure 1 here

In contrast, adolescents and young adults who were grouped in the second cluster reported higher frequencies of attending coping strategies, and a higher frequency and intensity of positive affect. This second cluster was characterized by more positive affect and content, and by the presence of a loved one, reflecting the “Resilience Narrative”.

Insert Figures 2 and 3 here

i.i. Deductive reflexive thematic analysis

Further idiographic research questions were generated from the results of the quantitative analysis to guide a richer in-depth qualitative analysis of pain memories. Specifically, we wished to provide a more detailed exploration of the factors that emerged as most the

important predictors of narrative profile, such as positive affect and coping strategies. Despite the social code not emerging in our quantitative analyses as a significant predictor, it is possible that the quantitative nature of the coding scheme failed to fully capture the context of social factors. The following section will report on the qualitative analysis of pain memory narratives generated by adolescents and young adults. Each section will be presented according to each of the three research questions: (1) emotional experiences, (2) social experiences and (3) coping strategies, and in relation to its over-arching deductive code. Analytical points are supported by anonymized extracts from the qualitative pain memory narrative data. It is important here to note that across all narratives, participants reflected on pain memories associated with their chronic pain, as opposed to other instances of pain. This occurred without being prompted to do so (see *Pain Memory Task*).

Emotional Experiences

Distress

A sense of perceiving distress at the time of the recalled painful event was a dominant experience of adolescents and young adults. The experience of pain typically invoked a sense of being incapacitated by pain, resulting in feelings of anger and frustration. One participant articulated this in terms of feeling “*extremely useless and disappointed (AYA15)*”. Such distress in the presence of pain was often accompanied by a keen sense of loss. Loss took numerous forms, dependent on whether loss was due to loss of control, hope or ability to separate oneself from the pain. For some, the dominance of the pain and associated distress robbed them of their humanity: “*pain made me feel like I wasn’t human anymore. I lost all my hope, I never thought I would see a light at the end of the tunnel*” (AYA35). For this participant, the recalled pain memory was a seminal life moment, where severe pain and distress lead to a sense of de-humanization and hopelessness.

For others, this inability to separate themselves from their experience of pain was extended beyond a distinct timepoint in the past to consideration of the present day. One participant noted that their current *“experiences are of pain and torment and trying to make it through a day and I hate that this is now my focus over enjoying life but, with this [condition], I cannot have both”* (AYA22). Pain here is depicted to be all-consuming, invoking a sense of loss in the form of both enjoyment and hope. This long-term distress was so acute for other adolescents and young adults that it led to them seeking *“counselling due the fact it [experience of pain] has affected me so much”* (AYA10). This example illustrates how more temporally bound distress associated with the incident of pain extends to developing a deleterious and longstanding impact on their mental health.

Resilience

Participants also reflected upon their emotional experiences of resilience. For some, these salient pain memories acted as an anchor, reminding them of their lowest points and causing them to *“think of how to pull myself out of it, so I do not have to go through that again”* (AYA25). Over time, their initially distressing pain memories adopted an important function, beginning to act as positive reminder of adaptive strategies that can be employed to minimize the impact of living with chronic pain. This encouraging shift highlighted how adolescents and young adults were able to reflect on their pain memories positively over time rather than as triggers for future pain and distress. For example, one participant described that it was the distressing nature of their pain that caused them to decide *“to change the way I used to heal myself.... I accepted the fact I had pain...and it’s working for me. I’ve made huge progress since that time”* (AYA38). This contextualizing of pain is important, enabling them to simultaneously acknowledge their distress and demonstrate resilience, knowing that *“the sun*

will rise again” (AYA34). This positive sentiment emphasizes the important role of optimism and hope, in stark contrast to the pessimism and hopelessness reflected on in emotional experiences of distress.

Social Experiences

Distress

A sense of isolation from peers was commonly featured in pain memories, with descriptions of perceptions of loneliness and frustration in relation to altered friendships. Consequences of this peer-related isolation were keenly felt, with participants reflecting how the “...*saying out of sight out of mind truly does apply here, they [friends] moved on and found another friend to fill my spot*” (AYA35). The use of the possessive regarding their place in their social group suggests a loss of their social identity and sense of insignificance at their ability to be replaced. Many other participants similarly experienced peer-isolation and altered friendships as leading cause of distress. One young person stated that she was often driven to “*tears of worthlessness as I couldn’t do the same things every other 15-year-old was doing and telling me about it all at school*” (AYA9), highlighting the disparity between her abilities and those of her peers who didn’t have chronic pain.

This sense of isolation from peers was magnified by a wider perceived lack of peer understanding of their pain, with one participant reporting peers calling them terms such as “*liar*” and a “*faker*” (AYA9). Such experiences served to further isolate the young person further, both in terms of isolation imposed by friends and the broader idea of experiencing chronic pain is an isolating experience in and of itself.

Resilience

The social nature of the pain experience was reflected in resilience pain memories around the protective role adopted by others during their reported memory, namely mothers. Participants typically perceived maternal support to exceed expectations of parental support and hence, this support was regarded with great reverence. For example, one participant described how her mother was *“an angel”* (AYA9). Another attributed her recovery from the pain experience solely to her mother, stating that *“my mum was around the whole time, and I’m so grateful. She is so strong and was there I needed a cuddle, a gossip or just someone to cry on. She was the one who was there from start to end that got me back from being a sick girl in bed to going to school full time. She got my life back”* (AYA35). Key to these social experiences is a sense of support provided by others facilitating a source of resilience for adolescents and young adults during painful moments, reminding them that *“they are still human and still the person they were before their illness/pain”* (AYA35). Counterbalancing the previous dehumanizing effects of pain, social support reduced this sense of dehumanization.

Coping Strategies

Distress

Whilst the pain experience itself was distressing, several pain memories were characterized by typically ineffective attempts to manage the pain that consequently resulted in distress. Several participants reflected on the futility of distraction techniques, such as watching TV or talking to a family member, feeling that they quickly learnt there was *“nothing [we] can do let it run its course...it’s just an absolutely helpless situation.”* (AYA18). Such strategies were broadly reported as ineffective in terms of relieving pain, resulting in a sense of hopelessness. Hence, many adolescents and young adults felt that nothing could be done, and it was a case of *“just waiting for it to go away and hoping that it would dissipate quickly”* (AYA47).

For other participants, a lack of effective medications to manage pain evoked distress. One participant noted how they were “*trialing different medications with not having much luck and feeling depressed after about 6 months and feeling like I’d never get rid of the pain*” (AYA44). Additionally, the side effects of these medications often gave rise to significant challenges including “*anxiety to the point where I was suffering multiple panic attacks a day*” (AYA41). Thus, it appears that while medication in certain instances was found to be futile in alleviating pain, side effects of pharmacological treatments had a significant impact on level of functioning, with a universal theme across strategies of fundamentally invoking a sense of defeat and helplessness.

Resilience

Pain management strategies that characterized resilience pain memories were varied. Interestingly, numerous non-pharmacological techniques that involved directly attending to pain were described as effective in terms of boosting management of their pain. For example, cooling techniques were described to be helpful in reducing pain to manageable levels, engendering a self-management to pain management. This is exemplified by one participant who described how cooling agents enabled them “*to try and calm myself*” (AYA26), emphasizing a personal responsibility for managing pain.

In a minority of pain narratives, distraction techniques, such as playing video games or listening to music, were found to promote resilience. Instead of directly addressing pain itself, the reported utility of these strategies focused on managing associated consequences of pain such as distress, frustration, or anger. Distraction enabled the individual to manage their anxiety as distraction “*myself put me in a better place mentally to cope with the pain*”

(AYA46). Resilient coping strategies therefore emphasized a broad pain management focus, targeting both reduction in pain and improvements in associated functioning.

Discussion

The current study adopted a multiple method, biopsychological approach to studying pain memories in adolescents and young adults with CRPS, using risk and resilience factors to characterize pain memory narrative profiles. Narratives exhibited both risk- and resilience-based aspects that could be used to characterize Distress and Resilience pain memories. Overall, findings highlighted the need to carefully consider both risk and resilience factors in approaches to chronic pain, in addition to the need to prioritize different factors across adolescent- and parent-centered approaches. The current study expands limited previous assessment of pain memories and demonstrates the utility of embracing multiple methods to investigate autobiographical pain memories.

Evidence for two distinct narrative profiles of Distress and Resilience was found in adolescents and young adults with CRPS, reflective of risk and resilience-based factors. Such findings were congruent with previous classifications illness narratives in health and chronic pain research (21,62). These narrative profiles also emerged from pain memories universally associated with CRPS, further suggesting that these profiles may play a specific and significant role in experiences of paediatric chronic pain. Notably, distribution between distress and resilience clusters was equal for adolescent and young adult narratives, highlighting the importance of including both risk and resilience-based perspectives in understandings of pediatric chronic pain. Furthermore, considering that study findings suggest that resilience factors were almost equally as important as risk factors, it is therefore

of the utmost importance that resilience-based approaches are promoted and applied to future research and clinical considerations.

Coping strategies and positive affect were found to be most important in characterizing adolescent and young adult pain narratives, a finding that is congruent with research that posits emotion as an influential factor in the development and recall of memories (28,54). While the role of affect and emotion has been well documented in pediatric chronic pain literature (10,33), little attention has been paid to their role in pain memories specifically, despite the acknowledgement that comprehensive understandings of pain memories need to incorporate sensory, contextual and affective factors (e.g., 38). Current findings provide novel insights into the influence of affect on pain memories (e.g., negative impact of social isolation on emotional distress) and provide unique contributions regarding the role of positive affect for adolescents and young adults with chronic pain. This finding also has encouraging implications for resilience research, supporting a shift towards promoting more positive factors and away from negative factors (13).

Non-attention coping strategies characterized distress narratives, while attention-focused strategies characterized resilience narratives. Such findings are congruent with research that suggests that non-attention coping strategies encourage a maladaptive, avoidance approach to managing pain, while attention-focused strategies encourage an engaging and adaptive response to pain (45). However, our qualitative findings suggest a more nuanced picture, whereby use pain management approaches that involved attending directly to the pain, such as medication, was sometimes observed to cause significant distress and impaired functioning, while several adolescents and young adults commented on the positive impact of non-attention focused approaches, such as distraction techniques. It is possible that an attending vs. not attending to pain dichotomy may not fully account for the impact of coping

strategies and that the context here is integral in our understandings. These findings highlight the complex multi-faceted nature of management strategies in pediatric pain and the importance of implementing targeted coping strategies that best meet the specific and often diverse needs associated with the individual's experience of pain

While social factors were not shown to be statistically significant in the quantitative analysis, qualitative exploration highlighted the importance of social experiences of both distress and resilience. A keen sense of loneliness was a salient experience for both adolescents and young adults, who perceived isolation as something enforced on them due to constraints associated with living with CRPS invoking emotional distress and cascading socio-emotional complexities. Interestingly, many narratives noted that peers were the cause of social isolation and distress, while parents were often the source of emotion support, a finding at odds with typical development during adolescence where there is an increased need for peer support and decreased need for parental support. These insights are congruent with previous studies maintaining that young people with chronic pain face unique development trajectories to their peers not in pain, These insights are congruent with previous studies, maintaining that adolescents and young adults with chronic pain face unique development trajectories marked by social and emotional challenges (26). The importance of social factors highlighted by the qualitative analyses also highlights the importance of conducting multiple methods research studies, allowing for comprehensive understandings of phenomena and the insights into subtle nuances across biopsychosocial factors.

There are several strengths of the current study. By adopting a multi-method approach to analyzing pain narratives, findings provide novel understandings of the nature of pain memories in adolescents and young adults' with CRPS. By exploring pain memory

narratives, the current study complements narrative research, generating further understandings of how narratives are established and perceived (8). We hope that current study findings will encourage novel and more sophisticated approaches to researching pain memories that extend beyond single interviews or questionnaires. Secondly, the current study was the first study to examine pain memories in adolescents and young adults with chronic pain, extending existing work with adolescents and young adults experiencing acute pain. Additionally, this study highlights the benefits of adopting a novel narrative approach (46,59) rooted in the perspectives of the individuals and their families, to complex topics such as pediatric chronic pain.

The current study is not without limitations. Participant characteristics revealed a female bias in the adolescent and young adult sample, mirroring the high prevalence of CRPS in females (2). Race and ethnicity demographics were not collected, limiting interpretations regarding the representativeness of the sample and highlighting the importance of adhering to recent calls advocating the importance of collecting and reporting sociodemographic data in line with an anti-racism framework (29). Participants themselves self-reported their diagnosis of CRPS and thus it is important to acknowledge that not all participants with a self-reported diagnosis of CRPS may also meet the requirements for a medically confirmed CRPS diagnosis. There were also several limitations regarding the design of the study. The cross-sectional nature of the current study limits our ability to draw causal inference on identified factors or on how the influence of these factors may change over time. Gender and age differences were not calculated between groups, a consideration worthy of future investigation to explore possible gender or developmental nuances in narratives. Additionally, while careful consideration was made modifying the coding scheme to current study aims, future studies should work towards developing coding schemes specific to

adolescent and young adult's experiences of chronic pain. It should also be noted that, while a strength of the study is its focus on CRPS as an under-researched condition, CRPS is a unique condition with condition-specific challenges, and no attempt should be made to generalize study findings to other pediatric chronic pain conditions.

The current findings suggest exciting avenues for future research including exploration of the wider context of friends, peers and family in terms of pain memories. In comparison to their peers without pain, adolescents and young adults with chronic pain have been shown to display differences across physical, social and psychological domains (see 10). Thus, it is likely that there will also be differences in factors contributing to the development, understanding and recollection of pain memories for adolescents and young adults with chronic pain, and future studies could explore possible differences in pain memory trajectories within a biopsychosocial approach. Future research could also seek to include narratives of the adolescent or young adults' broader social context, such as those of their parents or their siblings. By including whole-family perspectives, future research could start to compare possible similarities and differences around how pain memory narratives are formed surrounding the adolescents' or young adult's pain and what impact this may have on the individual. Finally, while careful consideration was made modifying the coding scheme to current study aims, future studies should work towards developing coding schemes specific to adolescent and young people's unique experiences of chronic pain. For example, a more robust social behavioral coding scheme could be developed, accounting for the unique importance and trajectories of social factors and development during adolescent and young adulthood.

Current findings may have important clinical implications, suggesting some promising targets for future treatments. Where possible, future treatments should be individualized to meet the specific needs of the adolescent or young adult, facilitating the implementation of individually relevant strategies for managing pain and associated functioning. While current approaches to pediatric chronic pain management, such as CBT, contain elements of cognitive restructuring, our current findings highlight the importance of reframing and recontextualizing pain memories. This could have possible clinical implications through eliciting and reframing these autobiographical pain memories. Alternatively, narrative therapy is a well-recognized therapy that primarily targets narratives in an effort to support the understanding and reframing experiences (46,59), which could intuitively be applied to pain memories. Such nuanced attention-focused strategy applied within narrative therapy not only provides clinicians with a rich source of information regarding how the adolescent or young adult has made sense of their pain experiences, but also offers a promising target for challenging and changing the pain experience, allowing the adolescent or young adult to reinterpret their pain. This line of therapy would also be supported by results from the cluster analysis, highlighting the importance of using strategies that attend to and engage with the pain in promoting resilience. Furthermore, by exploring on autobiographical pain memories the current study focused on possible origins of chronic pain as opposed to outcomes, thus highlighting possible avenues for more preventative approaches. For example, study findings suggest that positive affect was one of the most important factors implicated in determining whether adolescents and young adults displayed Distress or Resilience narratives. This is an encouraging finding and contributes to the less understood role of positive affect in pediatric chronic pain (18). This would suggest that early interventions may benefit from focusing on promoting positive affect and is in line with a shift towards a more strengths and resilience-based approaches (e.g., 61).

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Figure Legends

Figure 1. Mean narrative codes across Adolescent Pain Narrative Profiles. These figures depicts the mean value of each continuous narrative code* across Distress and Resilience adolescent narrative profiles.

***Int PA:** Intensity of Positive Affect ($p = .003$); **Freq PA:** Frequency of Positive Affect ($p = .002$); **Int NA:** Intensity of Negative Affect; **Freq NA:** Frequency of Negative Affect; **Anxiety:** Threat/Anxiety; **BF:** Benefit Finding/Growth; **Opt/Pess:** Optimism/Pessimism.

Figure 2. Coping Strategy across Adolescent Pain Narrative Profile. The above figures depict the percentage of adolescents characterized as either Attention or Non-attention focused ($p=.000$) across Distress and Resilience narrative profiles.

Figure 3. Observer Type across Adolescent Pain Narrative Profile. The above figures depict the percentage of adolescents characterized as either being in the presence of a Loved One, Stranger or Alone across Distress and Resilience narrative profiles

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