Parenting an adolescent with complex regional pain syndrome: A dyadic qualitative investigation of resilience

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Objectives. Adolescent chronic pain exists within a social context, affecting the lives of adolescents, parents, peers, and wider family members. Typically, parental research has focussed on the negative impact on parents associated with parenting an adolescent with chronic pain. However, a small number of studies have identified positive parental outcomes and functioning, with a focus on parental resilience. This study sought to extend existing knowledge by providing a detailed and contextualized understanding of how parental dyads experience and demonstrate resilience in response to parenting an adolescent with Complex Regional Pain Syndrome (CRPS) and the meaning that parents ascribe to these shared experiences.

Design. An Interpretative Phenomenological Analysis (IPA) was used to conduct an in-depth qualitative interview study of parents of an adolescent with CRPS.

Methods. Semi-structured interviews were conducted via Skype with eight mother–father parental dyads of an adolescent aged 11–25 years with CRPS.

Results. A single prominent theme ‘masking reality in the face of pain’ dominated the parental discourse and experience of resilience. Resilience was experienced as an incongruence between private distress and the perceived obligation to display socially desirable resilience behaviours to protect their child from their own distress.

Conclusions. Study findings highlight the benefits of strength-based interventions to enhance parental resilience. This is particularly important since parental behaviours have been shown to influence child pain outcomes. Future research should seek to explore resilience in different populations such as lone parents, siblings, and those parenting an adolescent with pain conditions other than CRPS.
Statement of contribution

What is already known on this subject?
- Chronic pain can have an all-encompassing negative impact on the lives of the adolescent, parents and wider family.
- Parental resilience is central to the well-being and development of parents and children with long-term pain.
- Most parental studies in the context of paediatric pain have focussed solely on the maternal impact.

What does this study add?
- This is the first qualitative study exploring resilience in parental dyads of an adolescent with CRPS.
- Resilience was experienced as an incongruence between private distress and an outward display of resilience.
- Displaying resilience served several functions for parents but created a perceived sense of social isolation.

Background

Pain is a common and often unremarkable experience in childhood and adolescence for many, with a small yet sizable number of young people going on to develop chronic pain and associated disability (Forgeron & Stinson, 2014; Huguet & Miro, 2008). Chronic pain is commonly defined as pain that persists beyond the typical course of an acute disease or reasonable time for an injury to heal, which is typically more than 3 months (Nicholas et al., 2019). A systematic review of community-based epidemiological studies identified that 11–38% of children and adolescents experience chronic pain, with 5% of these reporting significant pain-related dysfunction (King et al., 2011). Chronic pain may be related to a disease or injury or can be idiopathic in aetiology (Jordan & Caes, 2020). Complex Regional Pain Syndrome (CRPS) is a chronic condition characterized by intense localized pain which affects children, adolescents and adults (Goh, Chidambaram, & Ma, 2017; Weissmann & Uziel, 2016). Paediatric CRPS is more prevalent in adolescent girls (de Mos et al., 2007; Low, Ward, & Wines, 2007) and young people with CRPS report greater pain intensity and functional disability in comparison to young people with other chronic pain conditions (Logan et al., 2013). The impact of living with chronic pain in adolescence can be substantial, negatively impacting on physical and emotional functioning, peer relationships, school engagement, and attainment (Haraldstad, Sørøm, Eide, Karin, & Helseth, 2011; Simons, Sieberg, & Clar, 2012).

Chronic pain exists within a social context (Williams & Craig, 2016), with the impact of adolescent chronic pain extending beyond the individual to family and peers (Forgeron et al., 2010; Jaaniste, Phupps, Lang, & Champion, 2013; Jordan, Eccleston, & Osborn, 2007). Individuals who parent an adolescent with chronic pain report low levels of health-related quality of life (Mano, Khan, Ladwig, & Weisman, 2011), restrictions in their social life and feelings of helplessness (Skarstein, Bergem, & Helseth, 2020), sleep disruption, (Meltzer & Moore, 2008) and elevated levels of stress, anxiety, and depression (Eccleston, Crombez, Scotford, Clinch, & Connell, 2004). Additionally, parents report feelings of helplessness regarding their inability to relieve their child’s pain (Jordan et al., 2007), fear, lack of control, and believe their parenting skills are impaired (Baert et al., 2020). Parental behaviours play a critical role in their child’s adaptation to chronic pain and associated functioning (Harrison et al., 2020). Parental responses may be a risk factor for child pain and associated disability, and in turn, child pain and disability may impact parental responses (Palermo & Chambers, 2005).
Typically, research has framed the impact of child pain on their parents in a negative way. However, a smaller body of evidence has identified positive outcomes and functioning for parents. For example, one qualitative study identified that some fathers of adolescents with chronic pain reported a sense of enhanced relational closeness with their adolescent after the onset of pain due to a sense of shared adversity (Jordan, Crabtree, & Eccleston, 2016). A further qualitative study identified that parents of young people engaged with chronic pain treatment reported a sense of empowerment concerning their attempts to adapt their parenting style and its observed positive impact on their child’s functioning (Gaughan, Logan, Sethna, & Mott, 2014). Such findings suggest the importance of better equipping parents with the skills to manage adverse experiences, both in terms of their own functioning and that of their adolescent. One promising area is that of resilience.

The construct of resilience has been the focus of growing research attention within the field of chronic pain (Goubert & Trompetter, 2017; Sturgeon & Zautra, 2010; West, Stewart, Foster, & Usher, 2011). In this context, resilience is typically defined as a process, rather than a trait, whereby individuals adapt and lead successful lives despite exposure to adversity. Parental resilience has been defined as the ability of parents to deliver quality parenting in the face of adverse circumstances (Gavidia-Payne, Denny, Davis, Francis, & Jackson, 2015). Parental resilience is displayed through parents’ use of their skills, personal assets, knowledge, and previous experience to adaptively respond and cope with problems that may hinder the delivery of quality parenting (Gavidia-Payne et al., 2015). The demonstration of parental resilience is central to the well-being and development of both parents and their child. Managing stress and functioning well in the face of adversity enhances parental well-being and self-efficacy which enables parents to provide high-quality parenting. This fosters prospective resilience in children and mediates future coping responses to adversities (Gavidia-Payne et al., 2015; Weisner, 2013). Promoting resilience in parents of an adolescent with chronic pain supports parents to approach their child’s pain differently and decreases parental pain-catastrophizing and stress (Gauntlett-Gilbert, Clinch, Connell, & Rogers, 2015). An understanding of how parents experience and demonstrate resilience could act as an evidence base to inform and develop paediatric chronic pain management by offering an additional clinical focus that focuses on the family, not just the child with pain.

Research in this emerging field must be cognisant of current gaps within the parenting literature. Most studies have focussed on the maternal impact of parenting an adolescent with chronic pain, ignoring the paternal impact despite the unique role that fathers play in their child’s development (Flouri & Buchanan, 2003). Including fathers in research may identify any differences in how mothers and fathers make sense of and respond to their child’s pain (Brody & Simmons, 2007) and whether such perceived differences influence how mothers and fathers perceive and demonstrate resilience in the face of managing their child’s pain. Also missing from the literature is a consideration of how parental and paternal responses to their child’s pain may work in conjunction with each other to consider the parental unit as a single dyad. A dyadic approach would facilitate exploration of how parental responses and interactions impact broader family functioning and parental adaptation in the face of their child’s pain. A dearth of existing studies around parental resilience has adopted a nomothetic approach (Gavidia-Payne et al., 2015), preventing an idiographic detailed understanding of how parents experience and demonstrate resilience. Parents’ verbal accounts of resilience offer a novel and potentially fruitful opportunity to understand this complex experience. This idiographic study aims...
to meet these knowledge gaps by exploring how parental dyads experience and demonstrate resilience in response to parenting an adolescent with CRPS.

**Method**

**Design**
Dyadic semi-structured interviews were conducted with eight parental dyads for the purpose of generating rich qualitative data.

**Participants**

*Inclusion and exclusion criteria*
Eligible participants were two parental figures living in the same household who were parenting an adolescent daughter or son aged 11–25 and reported their child had been medically diagnosed with CRPS. 'Parent' refers to those who carry out significant parenting duties. Caregivers and step-parents were included, regardless of gender or marital status. Both parents were required to be able to converse in English and to be living together and with the adolescent with CRPS on a full-time basis. The latter requirement was important in this study to enable us to explore the unique shared experiences of both parents in the context of them both living with the adolescent. Both parents were required to complete an online survey to collect basic demographic data before being contacted by the first author to take part in the interview.

*Sampling*
A purposive homogenous sampling strategy was adopted. Interpretative Phenomenological Analysis (IPA) studies are conducted on small sample sizes because the primary concern is the use of an idiographic approach to provide a detailed account of individual’s experiences (Smith, Flowers, & Larkin, 2009). Eight mother and father parental dyads (16 participants) were recruited which is an ideal sample size for an in-depth IPA analysis (Smith et al., 2009).

*Recruitment*
Participants were recruited to the study via social media posts, email communication, and blog posts from the study authors and pain specific charities and organizations. Further details of the participant recruitment process can be found in the procedure section, with details of numbers of participants recruited to the study shown in Figure 1. A total of 8 parents were ineligible to participate because they were lone parents. In Figure 1, ‘participant’ refers to each individual parent, for example 16 participants refer to 8 parental dyads.

*Development of the interview schedule*
A semi-structured interview schedule was developed by the first author (DC) with feedback provided by the second (JP) and third authors (AJ). The full interview schedule can be found in Appendix 1. The interview schedule was developed following a review of the existing literature on parenting an adolescent with chronic pain and, more broadly,
parental resilience. An open-ended questioning route was adopted. The schedule comprised 13 interview questions which followed a specific structure. Opening questions queried the child’s pain condition, family life prior to their child’s diagnosis, and the present impact of their child’s CRPS. Key questions investigated coping mechanisms, resilience, sources of support, and lessons learned from parenting an adolescent with CRPS. Closing questions involved checking accuracy of information and whether there was anything the participants wanted to add.

Procedure

All study procedures were approved by the relevant university’s departmental research ethics committee. All interested participants were directed to an online survey (Qualtrics, Provo, UT) which comprised an information sheet and demographic questions to determine study eligibility. Interested participants were asked to provide informed consent, complete demographic questions, and provide their personal contact details. Each member of the parental dyad was required to complete the survey before the first author (DC) emailed them both to schedule the interview and requested their Skype username. Participants were interviewed by the first author (DC).

Interviews were conducted with both members of the parental couple together. The interviews were conducted remotely through the internet-based video calling software Skype which offers both audio and visual communication between participants and
interviewer. All participants elected to conduct the interviews whilst in their homes. At the start of the interview, participants were reminded about the purpose of the study and asked to verbally consent to being interviewed and for the interview to be audio-recorded using MP3 Skype Recorder. Interviews lasted between 31 and 81 min, with a mean duration of 51 min (SD, 17 min). Participants were thanked for taking part and informed that they would be emailed the debrief sheet and electronic £15 Amazon voucher. The debrief sheet provided clear contact details for the researcher in addition to specific contact details for sources of support such as Samaritans and CRPS UK. Interviews were recorded and transcribed verbatim by the first author. All personal identifying information was changed to ensure anonymity of quotations.

**Data analysis**

The audio-recorded data were transcribed verbatim by the lead author; all spoken words and semantic sounds (e.g., mm-hm) were transcribed promptly after the interview and transcripts were checked twice by the first author by listening to the audio-recording whilst reading the transcript to ensure they matched. Data were analysed using IPA (Smith, 1996). With a dedicated focus on idiographic exploration of participant accounts of phenomena, IPA was selected as the most suitable methodological framework for the design and analysis of the data. IPA has three theoretical underpinnings; phenomenology, idiography, and hermeneutics. Phenomenology aims to capture rich, in-depth statements and the interpretative component seeks to understand the meaning of such statements. The idiographic approach is concerned with a focus on the lived experiences of individuals rather than generalizing to groups of individuals. IPA examines how participants understand and make sense of their lived experiences, through exploring the meaning(s) that participants ascribe to experiences that are important to them (Smith et al., 2009). A key epistemological assumption of IPA is that understanding the participant’s experiences is a process produced by the participant and the researcher, referred to as a ‘double hermeneutic’ as the researcher tries to make sense of how the participant understands their own experiences (Smith, 2004). The exploratory approach of IPA suits the nature of this study which aimed to explore a research question that is both novel and under-studied (Smith, 2004). IPA has been successfully employed to study the phenomenon of chronic pain (Smith & Osborn, 2007; Snelgrove & Liossi, 2009), and in particular, the individuals’ experiences of parenting an adolescent with chronic pain (Jordan et al., 2007).

With regard to analytical processes, the authors followed specific IPA guidelines developed by Smith et al. (2009). The first author familiarized themselves with the data, analysed the language used and how it reflected the meaning that the participants gave to their thoughts and experiences and generated initial codes and themes for each transcript. Transcripts were then compared to identify any shared patterns and the second and third authors provided input into reviewing, redefining and creating the final theme via email.

**Trustworthiness and rigour**

To establish credibility of analyses, interpretation of the transcripts was discussed during frequent meetings with co-authors to ensure a coherent, compelling and grounded analyses based on the existing data. Dependability and confirmability were addressed through clear reporting of the study processes in the study protocol which was pre-registered on the Open Science Framework (weblink: https://osf.io/wjh3d/) and
inclusion of interview schedules in this manuscript for the purposes of ensuring transparency of the research process. Careful documentation of analytical decisions by the main researcher using a reflective journal as part of an audit trail also addresses the issues of dependability and confirmability.

**Reflexivity**

IPA’s phenomenological and interpretative standpoint requires the researcher to engage in a reflexive process (Smith et al., 2009). The first author (DC) who conducted the interviews and led the analysis kept a reflective journal throughout the research process. This provided the opportunity to record perceptions before and after conducting each interview and reflect on the researcher’s own position and relation to the research topic. Collectively, the authors considered their own position in relation to the research topic as women pain researchers with no personal experience of pain who have worked in the field for over 20 years.

**Results**

**Participant characteristics**

Table 1 shows that the dyads were similar in age, with an age range of 41–53 years. Most parents were employed on a full-time basis. Parents reported their adolescents to be aged 11–18 years and to have lived with CRPS for 1–3 years.

**Overview of findings**

A single key theme ‘masking reality in the face of pain’ dominated the parental discourse and experience of resilience. This theme identified an incongruence between the shared

| Dyad | Parents | Adolescents |
|------|---------|-------------|
|      | Pseudonym | Age (years) | Employment status | Age (years) | CRPS duration (years) |
| 1    | David (father) | 53 | Full-time | UK | 14 | 3 |
|      | Helen (mother) | 44 | Unemployed |     |     |     |
| 2    | Paul (father) | 42 | Full-time | UK | 12 | 3 |
|      | Sally (mother) | 43 | Unemployed |     |     |     |
| 3    | Tom (father) | 48 | Full-time | UK | 11 | 2 |
|      | Kate (mother) | 44 | Part-time |     |     |     |
| 4    | Mark (father) | 51 | Full-time | USA | 18 | 4 |
|      | Emily (mother) | 51 | Full-time |     |     |     |
| 5    | Craig (father) | 50 | Full-time | UK | 15 | 1 |
|      | Carol (mother) | 53 | Part-time |     |     |     |
| 6    | John (father) | 52 | Full-time | USA | 16 | 1 |
|      | Mary (mother) | 51 | Part-time |     |     |     |
| 7    | Chris (father) | 48 | Full-time | USA | 15 | 2 |
|      | Diana (mother) | 42 | Part-time |     |     |     |
| 8    | Mike (father) | 55 | Full-time | UK | 14 | 2 |
|      | Claire (mother) | 55 | Part-time |     |     |     |
private distress experienced by the parents and the perceived need for an outward display of resilience behaviours in the face of their child’s pain. Whilst the display of parental resilience was perceived to fulfil multiple functions, the most important functions concerned protecting the child and one’s own identity as a ‘good’ parent in relation to demonstrating socially desirable behaviours in the face of this adversity. However, to achieve this outward display of resilience, parents needed to mask their shared suffering and distress in multiple ways. Displaying resilience enabled parents to find ways to manage their child’s pain and to protect their child from their own distress, yet it also created a sense of isolation from others who perceived the parents to be managing their child’s pain effectively without the need for additional support.

**Masking reality in the face of pain**

An important aspect of resilience for the parents concerned the feeling that they needed to isolate themselves from other people, except for their partner. Parents often shared a feeling of helplessness in managing their child’s condition, but typically only expressed these feelings to their partner and chose not to seek support from family and friends. This is reflected in the quotation below.

> The majority of the people just don’t get it... we rely on each other because I think we understand what it is, and it is difficult to try to explain and share our feelings outside of our family (Emily, dyad 4, mother of daughter aged 18).

Emily explained how she and her husband were solely dependent on each other for emotional and practical support which was driven by their shared understanding of their daughter’s condition and needs. As their parenting experience was unique to them, this dyad found it easier to distance themselves from others who lacked the understanding of the emotional strain attached to parenting a child with CRPS. This observation that the parents found strength in each other may have been different had the parents been interviewed separately where perhaps there may be less pressure or expectation to appear cohesive and dependent on each other. The display of resilience was presented publicly by putting on a ‘brave face’, not asking for any help or advice and reassuring friends and family that everything is okay. This is indicated in the quotation below through attempts to present and achieve normality.

> Some of the wider family have found it harder to understand than others um it’s very difficult to explain this illness to people as one day they [daughter with CRPS] could be in bed and the next day they could be walking so people find it really difficult and it’s difficult for us to explain it again and again so we do try to act like everything is normal, yeah, as normal as possible (Kate, dyad 3, mother of daughter aged 11).

This public display of resilience functioned to protect others, create a sense of calmness, and avoid having to explain their daughter’s condition which was often met with confusion and misunderstanding. This was beneficial as it motivated parents to avoid behaviours associated with ruminating on the situation and allowed them to find ways to try to adapt to their child’s pain. Perhaps the parents found it hard to express their experiences during the interview as they were used to experiencing difficulty when explaining it to others. Additionally, they had no prior knowledge as to whether the interviewer had any personal experience of chronic pain and thus that shared
understanding, but could make the assumption they had a level of knowledge of chronic pain. The majority of parents did ask the interviewer at the end of the interview about their background and relationship to chronic pain.

Despite these benefits of appearing resilient, the outward display of resilience in the face of inward personal distress was also disadvantageous. Parents’ inability to honestly display their feelings resulted in a sense of social isolation from those outside the family unit. Many parents described how they felt that it was important and necessary to alter their appearance to present themselves as being resilient and coping even though this did not represent their true feelings. This was often portrayed and explained by the parents through the use of metaphors to describe their faked facial expressions and new clothing.

There’s no point crying and moaning about it. For the most part, it works, there are days that I do get upset about it [her child’s experience of pain], but I just try, like I say, just to carry on, paint a smile on my face and keep going (Helen, dyad 1, mother of daughter aged 14).

This outward smile is incongruent with the perceived sense of helplessness and frustration that Helen experienced on particularly challenging days. Her smile was painted on to achieve the desired effect of illustrating that she is happy to others and perhaps to herself when she looks in the mirror. Nonetheless, her feelings of frustration helped support Helen to bounce back, push forwards and ‘keep going’; therefore, facilitating her expression of resilience.

Although the parents frequently presented a public display of resilience, in rare circumstances they were able to share their distress with others and the sense of relief associated with this was palpable. This is highlighted below by Carol when attending a treatment centre for her daughter.

It’s the hardest thing um (pause) ever because you have to put on this shirt and you know this brave face and you have everybody saying “Oh gosh, you’re so positive” when really on the inside it is just (pause) terrible (cries) but in [name of treatment centre] it was really good because Olivia (child) would go off and I was in the waiting room with the people with CRPS you know similar things, and um I just cried like for 4 days and then they said “It’s fine, don’t worry about it” you know because they understand and it’s hard to understand (Carol, dyad 5, mother of daughter aged 15).

Here, Carol continued the metaphor of the use of clothing and a ‘brave face’ to mask her true self, something that was difficult and emotive through Carol’s tears when describing this. She also highlights the support she received when she allowed herself to show her true feelings to other families living with CRPS who did have a shared understanding of her experiences. The disparity between the strength of the parents’ feelings of helplessness and the desire to not share their feelings with others outside of the family unit who do not share this experience suggests that perceived social pressures may provide a partial explanation for this incongruence between how parents feel and how they behave. Specifically, the parents may have chosen to avoid displaying their feelings of powerlessness or vulnerability to others due to the sense of a wider perceived societal pressure to exhibit behaviours indicative of resilience and coping effectively when facing adversity. Such pressure to display resilience was perceived in their relationship with other significant individuals in the lives such as their family, friends, colleagues, and, importantly, their daughter with CRPS. Maintaining a resilient appearance to the individuals that the parents are closest to and see every day requires substantial effort and
energy. It also questions the authenticity of these relationships if they feel scared to ‘crack’ and share their distress with those individuals who form their social and support network.

The parental display of resilience was not only driven by perceived social pressure but also by a strong desire to protect and care for their child. For example, under the pressure to be a ‘good’ parent to her child, Mary describes how she ‘did what had to be done’ and was willing to do anything and go the extra mile to ‘fight’ for her daughter to ensure that her daughter’s needs were being met to give her daughter the resilience that she also needs. This is indicated in the excerpt below from dyad 6.

She said to me anyway, she said that um, I’m getting emotional, that she (pause) she found her strength from (crying) (Mary, dyad 6)

From what? (John, dyad 6, father of daughter aged 11)

(Crying) she got her strength from watching me fight for her (pause) and I mean I just (pause) obviously that’s her version of it. I took you know, I did what had to be done and be the strength and resilience is her and it’s in her now, we’re still fighting through it (Mary, dyad 6, mother of daughter aged 11).

In the quotation above Mary demonstrates strength, yet her tears and heightened emotions expose her vulnerability in making an effort to protect her daughter from her maternal distress and give her daughter the opportunity to see her mother displaying strength and resilience. In discussing such ‘resilient’ behaviours she describes her ‘fight’ function to both show herself as a strong individual to others and importantly, as a strong ‘advocate’ for her daughter. Related to this, the parents also felt the need to be brave specifically for their child, as indicated below by Craig.

Probably with me just keeping a brave face (Craig, dyad 5, father of daughter aged 15)

For Craig, being ‘brave’ was an ongoing process. Maintaining a ‘brave’ face was key to convincing his daughter with CRPS, that the challenges of living with CRPS were manageable. This served to create a sense of calm and control over the situation for the whole family. Craig’s need to convince his daughter that he was resilient was salient to his identity as both a father and a man, as gender social norms teach and expect men to refrain from showing emotional vulnerability or weakness and instead show a ‘brave face’ (Chaplin, 2015).

Parents also strived to protect their daughters by creating a family environment that did not revolve around their child’s pain as a mechanism to create a ‘normal’ family environment. All parents described how they conducted themselves ‘normally’, with this ‘normative’ behaviour being actively encouraged by health care professionals and treatment providers. Specifically, health care professionals encouraged many of the parents to try to normalize CRPS by not focussing on it day to day and instead create a sense of normality that is not defined and controlled by pain. This attempt to maintain normality may have affected their public presentation of resilience to others as the parents could have interpreted that they should also withhold difficulty conversations from family and friends, impacting their support systems. Avoiding talking about CRPS with their daughter was difficult for the parents as highlighted by Sally who said that herself and her husband Paul felt that they both couldn’t share their feelings of ‘frustration’ with her.
You’ve got to nurture her and almost you can’t talk about CRPS, you’re not supposed to focus on it, but you have all these feelings of frustration and you can’t share them with her (Sally, dyad 2, mother of daughter aged 12).

Whilst Sally concealed her true emotions of distress from her daughter, her use of the word ‘nurture’ suggests that she wanted to care for and protect her daughter; an important parental role. In this instance, not only is Sally striving to put her daughter first, but caring and ‘nurturing’ her daughter could also be a way of enabling her daughter to develop resilience as she continues to grow. This contrasts the parental sense of obligation to ‘fake’ resilience. Consequently, the behaviour of the parents in this study was directly oppositional to the behaviour that they encouraged their adolescents to adopt. The parents strived to build their child’s own resilience by encouraging them to adapt to their condition rather than allow it to stop them from taking part in activities and socializing. Additionally, they often discussed how their child was resilient in the face of their condition. The perceived need to display resilience was tied to the participants’ sense of their parental identity and the desired characteristics of a ‘good’ parent that puts their child first and protects them from distress. Emily described her shared experience of ‘our resilience’ with her husband as an obligation that comes with parenthood, rather than a choice:

Our resilience is I think is good, I mean we just have no choice as parents, it’s not an option (laughs). It’s not an option, you have to, what else can you do? You have to keep going (Emily, dyad 4, mother of daughter aged 18).

By implication, Emily suggests that it is advantageous to display resilient behaviour, inferring that the absence of such behaviours is associated with ‘bad’, or less desirable parenting. This is particularly interesting given the clear difficulties that Carol and Craig below highlight in relation to the pressures of displaying behaviours that show them as strong, happy, and resilient individuals when such behaviour directly conflicts with their inward feelings of distress. Despite the outward appearance of ‘strength’, this resilience is misleading. Carol and Craig acknowledge a sense of fragility and resilience as an obligation when there are no other options.

I think to keep you know to maintain that resilience um if we crack (Carol)

Yeah (Craig)

Then she’s gonna see us being upset, so the amount of times you know in the middle of the night we’ve woken up in tears um, to my friends you know I’ve been in tears, but for Olivia (daughter) it’s always been “You’re okay Olivia, we’ll get through this” so appearing resilient to her but on the inside not being resilient at all (Carol, dyad 5, mother of daughter aged 15).

Yeah (Craig, dyad 5, father of daughter aged 15)

This sense of fragility is shared only between parents, with their daughter explicitly protected from witnessing the possible ‘cracking’ of her parents’ external resilient appearance. Carol and Craig were afraid that their resilient appearance would ‘crack’ and break and that this would have negative implications on their daughter. Whilst the parents felt this pressure to appear resilient to their child, all of the parents described their daughter as already being the definition of resilience, as indicated in the quotation below.
I’d say um she is the definition of it uh I mean resilience. I’d say it’s the ability to um you know in her case like dig deep inside and find whatever it is to um be that strength that pulls her through and then allows you um to continue, the resilience is in her (Mary, dyad 6, mother of daughter aged 16).

What is evident here is that Mary does not perceive herself to be resilient, but instead focusses the discussion on her ‘resilient’ daughter. Congruent with other parents, Mary perceived pressure to display a resilient exterior for their child and others too. This may be in order to protect her child and identity as a ‘good’ parent. The irony, for all parents, is that pretending to be resilient may add pressure and make it difficult to become resilient in an already difficult and challenging situation. Whilst the parents naturally felt obliged to practically adapt their day to day lives to their child’s pain, this experience was not without difficulty and the true inner turmoil faced by the parents in managing this and their external display to others was emotionally exhausting but viewed as a necessity to protect themselves and their child and ultimately to put their child first.

Discussion
This study provided an in-depth and detailed examination of the meaning that parental dyads ascribed to their shared experience and demonstration of resilience, in the context of parenting an adolescent with CRPS. One dominant theme, ‘masking reality in the face of pain’, was generated. The theme highlights the incongruence between the private distress experienced by the parents and their perceived need for an outward display of resilience behaviours. This was experienced in relation to their perceived role, duty and identity as parents. Additionally, it was guided by their perception of what constitutes as ‘good’ and socially desirable parenting behaviour which conveys a favourable image of positive parental behaviours including parental warmth, support, and adaptive coping in response to adversities (Bornstein et al., 2014). Parenting an adolescent with chronic pain was often very distressing as parents typically felt helpless due to not being able to alleviate their child’s pain, which was a violation of the parenting role (Skarstein et al., 2020). Such parental distress is a normal response to a challenging situation, highlighting the importance of future pain research focussing on normalization of both adolescent and parental responses to pain and associated disability (Eccleston, 2011). The additional context of parenting an adolescent with a chronic condition may have further shaped how they viewed their duties as parents and how they should conduct themselves. These perceived duties have been previously explored, for example, in parents of children with cancer and also reveals that parents feel obliged to be a ‘good’ parent by putting their child’s needs first, being the advocate for their child when making decisions about their care and remaining at their side in the face of difficult situations and circumstances (Feudtner et al., 2015; Hinds et al., 2009).

The importance of the role of the family environment in young people’s resilience and adaptation to chronic pain is reflected in the ecological resilience-risk model of paediatric pain (Cousins, Kalapurakkel, Cohen, & Simons, 2015). The model outlines the interactions between resilience mechanisms and risk factors with a bidirectional relationship between the individual and the family. One prominent finding in our study that relates to this relationship is the parental motivation to appear ‘brave’ and externalize resilience which they believed helped to promote resilience and coping in their child. This finding highlights not only the importance of the resources that families have but also how they use and present this to others. The impact of the tension between what an
individual displays externally versus what they experience internally will be an important consideration in future research.

Of particular interest in this study was how parents made sense of and enacted resilience. Our findings identified that parents understood resilience in the context of adapting to their child’s pain to maintain a lifestyle that was as close to ‘normal’ as possible. For many parents, these adaptations were difficult and they made the decision to ‘suffer in silence’ and put on a ‘brave face’, rather than drawing upon help and support from family and friends which would have facilitated their own resilience (Rosenberg & Yi-Frazier, 2016). Accommodating their child’s pain through trying to live a ‘normal’ life is resonant with the broader resilience literature which has demonstrated the importance of carrying on with life in those previously or currently living with a long-term condition. For example, in an interview study, Edwards, Welsh, and Chater (2009) identified that adults in remission for a mental illness described resilience as the ability to move forwards in life, perceiving value in how this ‘moving forwards’ could enable them to adapt to future circumstances and events. Additionally, West et al. (2011) found that achieving normality and stability was associated with resilience in adults with chronic pain.

Findings from our study highlighted how parents tried to hide their distress from their child with the aim of protecting their child and creating a calm and safe environment. Suppressing their own emotions seemed to be the optimal way to achieve this. These findings highlight the importance of further extending the parental remit of paediatric chronic pain research to focus on better understanding parental emotional and behavioural response to child pain, for the purposes of improving both child and parental functioning. Understanding the adolescent’s response and experience of living in a household in which the parents display resilience with reduced focus on the pain may lead to adolescents perceiving their experience of pain to be invalidated by parents, subsequently influencing adolescents’ responses to their pain and selected management strategies. This is an area worthy of further research. It is important to acknowledge the critical role that parents play in their child’s adaptation to chronic pain (Palermo, Valrie, & Karlson, 2014) and the association between parental psychological distress and functional impairment in young people with chronic pain (Harrison et al., 2020). Furthermore, parental resilience may buffer the association between parental symptoms of depression and child pain intensity which highlights the important interaction between resilience and risk factors (Khu, Soltani, Neville, Schulte, & Noel, 2018).

The finding that parents chose to hide their distress and struggles by ‘painting a smile on my face and keep going’ is of importance in relation to a recent research study identifying that even when mothers try to mask and hide feelings of stress, they can still pass these feelings on to their child (Waters, Karmilowicz, West, & Mendes, 2020), highlighting the importance of the parental response. This effect did not apply to fathers in the study, perhaps due to gender differences in responses to stress. In fact, previous research has revealed differences between the maternal and paternal experience of parenting a child with a long-term condition (Swallow, Lambert, Santacroce, & Macfayden, 2011). In comparison to the wider literature, our study deliberately did not seek to compare maternal and paternal responses as its aim was to capture the parental couple’s shared experiences of resilience. Exploration of such gender differences in relation to different aspects of the relationship between parent and adolescent and between parents would be a fruitful area for future study.

In two-partner households, parenthood, even if not equally balanced between mothers and fathers, is a shared responsibility and experience. In our study, the parents discussed their experiences of resilience as a parental unit rather than as individuals.
Congruent with previous research, our findings highlighted they placed importance on working as a team and valued the support that they received from their partner who had a shared understanding of the difficulties and challenges they faced (West et al., 2011). These consistent findings highlight a gap in the literature for future research to explore resilience in lone parents who do not have support from a partner and therefore may require more tailored clinical support. Similarly, future research could helpfully focus on studying other configurations of parental relationships that move beyond the traditional biological mother–father dyadic relationships.

**Strengths, limitations, and implications**

A strength of the current study is that the parents were directly asked what the term resilience meant to them, rather than being presented with an existing empirically or theoretically informed definition (Rosenberg, Starks, & Jones, 2014). Exploring and clarifying the meaning of resilience in this way is particularly beneficial for IPA research. A shared understanding of the term is an important part of interpreting how the parents made sense of their lived experiences. Thus, future resilience research should also aim to clarify what the term resilience means to their participants in terms of how they understand and embody it.

It is important to highlight that, conforming to the requirements of IPA, the sample comprised a homogenous sample of eight couples parenting an adolescent with CRPS. Parents of adolescents with other chronic pain conditions may have different experiences of resilience, particularly considering that paediatric CRPS is often more severe than other pain conditions (Logan et al., 2013). Nonetheless, the aim of the present study was to understand the experiences of a specific sample in a specific context, rather than to represent the experiences of all parents of an adolescent with chronic pain.

Most parental research focuses on the experience of the mother. This study provided a novel methodological approach by interviewing both mothers and fathers together to explore their shared experience of resilience. It could have been beneficial to additionally interview each parent separately to explore potential differences in disclosure and consider gender differences in reported parenting experiences. This is worthy of investigation in future research.

There were differences between the parent dyads. Whilst all parents were White, five out of the eight couples lived in the UK, whilst three couples lived in the USA. There were geographical differences in terms of accessing health care, finance, and insurance related to medical treatment and in the treatment available. It would be interesting for future research to further explore the experiences of parents living specifically in the USA with a detailed focus on the relationship between finances, other resources and resilience.

The sample also consisted solely of parents of an adolescent daughter with CRPS. Whilst unintentional, this was not wholly unsurprising given that paediatric CRPS is more prevalent in adolescent girls (de Mos et al., 2007; Low et al., 2007). It would be interesting for future research to actively recruit parents of a son with CRPS to explore any differences in biases or parenting behaviour in response to parenting a son or daughter with CRPS. Current research in populations without chronic pain has found differences in parental ratings of pain between sons and daughters undertaking a cold pressor pain task whereby fathers gave their sons higher pain ratings than fathers of a daughter despite comparable facial expressions of pain (Moon et al., 2008). In this study, no differences were found for mothers’ ratings of pain between child genders. This may suggest that fathers may expect
sons to display less pain than they are experiencing to conform with societies ideal masculinized stereotypes of males responding less to pain.

With regard to clinical implications, how parents understood resilience is key to consider here. Specifically, when parents were asked what resilience meant to them, they described it not only in relation to their own experiences, but their experiences as a family. A strength-based approach to clinical interventions and treatment could help to support the whole family. Promoting and sustaining further positive development for families in which a member experiences chronic pain has been proposed to be more effective than interventions which focus on the shared difficulties faced by the family (Foster, 2010; Usher, Jackson, & O’Brien, 2005). A family resilience strength-based approach would enable health care professionals to identify and focus on the strengths of the family, rather than focussing on their problems. Since our research has found that parents tend to shield their distress from others including their child, health care professionals should be encouraged to incorporate parent-only sessions as an integral part of paediatric chronic pain treatment where parents can be encouraged to identify and share any challenging feelings regarding a perceived need to display externalized resilience in a safe and open environment. Additionally, helping the family to recognize their strengths and enhance their resilience could help them to use their skills to confront future crises from a positive perspective (Walsh, 2006). A strength-based approach should not only be limited to families who are not coping well, but should also be used to support families who are coping well, as a preventative measure for responses to future crises (Zautra, Johnson, & Davis, 2005).

Conclusion
This study adds to the growing literature on the parental experiences of parenting an adolescent with chronic pain and adds a novel insight into how parents experience resilience in the context of parenting an adolescent with CRPS, particularly by focussing on the shared experiences of both mothers and fathers. The findings highlight the benefit of promoting parental resilience through strength-based approaches. This may help to promote positive functioning within the whole family and help the adolescent to manage their pain, improve their pain outcomes, and reduce parental distress.

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Conflicts of interest
All authors declare no conflict of interest.

Data availability statement
Research data are not shared as consent to do so was not gained when the data were collected.
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Appendix 1: Interview Schedule

Introduction and confirmation of consent

First of all, I would like to thank you both for taking the time to talk to me today. As you know, I am interested in hearing about your experiences of parenting a child or young person with CRPS. During the interview, I will ask you a number of questions about your experiences and it would be great to hear from both of you whenever possible.

With your permission, I will record the interview so that I am able to transcribe all that was said during the interview. If you want to stop the interview or recording at any time, you are free to do so. Once the interview is transcribed, all names and identifying information will be removed to ensure anonymity.

Are you happy to consent to take part in the study and for the interview to be recorded?

Before we begin do you have any final questions about the study?

Ice breaker/background

- Could you please tell me about your child’s pain condition?
- Prompt: When did it start?
- Prompt: How does CRPS affect your child?

Life prior to CRPS

- I would like to firstly focus on what things were like before [child’s name] developed CRPS.
- Can you tell me a little about what family life was like before [child’s name] diagnosis of CRPS?
- Prompt: What were relationships like between family members?
- Prompt: What was life like for you?

Present effects of CRPS

I would now like to focus on what things are like now in terms of your child having CRPS.

- How have your daily lives been affected by your child’s pain condition?
- Prompt: How does it affect your a) personal lives, b) family life and c) relationships?
- Prompt: How have roles and responsibilities changed?
- Can you describe your feelings about raising a child with CRPS?
Exploring coping mechanisms and resilience

- Can you tell me a little about a particular time when things were particularly difficult with managing your child’s pain?
- **Prompt:** How did this affect the family?
- **Prompt:** How did you as a family deal with this?
- **Prompt:** How did you feel in this situation?
- **Prompt:** Can you tell me what you learned from this experience? How have experiences like this influenced how you respond?

Some people talk about the term resilience. I am interested in your thoughts on this term.

- What does the term ‘resilience’ mean to you?
- **Prompt:** How would you describe a person who is resilient?
- **Prompt:** Can you describe to me an example of when you demonstrated resilience in the face of your child’s pain experience?

Some parents have talked about finding some positives in life even though their child has CRPS.

- Can you describe to me any positives you and your family have experienced as a result of living with a child who has been diagnosed with CRPS?
- Can you describe to me what helps each of you to cope with your child’s condition?
- **Prompt:** This could be personal attributes, support from family or friends etc.
- **Prompt:** Can you tell me about any strengths each of you draw on to help you cope?
- Can you describe to me how you support each other?

External sources of support

- Can you tell me about your own well-being in relation to parenting a child with CRPS?
- Can you tell me what you do to support and manage your own well-being?
- **Prompt:** Can you describe to me any hobbies or activities that you take part in?
- **Prompt:** How these hobbies or activities help you?
- **Prompt:** When you need support how do you gain it from family or friends?
- **Prompt:** Are you satisfied with the support that you receive? Why/why not?

Lessons learned

- What have you both learnt about parenting a child with CRPS that might help other families?

Anything else

- Is there anything else that you think we should know about how you support yourselves individually and as a family that you have not already told us about?
Close
Brilliant. I would like to thank you both very much for taking the time to take part in this interview today. Your comments have been really helpful, and I appreciate your participation. A debrief sheet will be emailed to you shortly, providing information about this study and relevant organizations to contact if necessary. (Also mention about payment).