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"I felt shamed and blamed": an exploration of the parental lived experience of school distress

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Introduction: School Distress refers to a child or young person's (CYP) difficulty attending school due to the extreme emotional distress associated with school attendance. Limited research exists on the impact of School Distress on the parents/carers supporting these CYP.

Methods: Using a case-control, concurrent embedded mixed-method design, we explored this lived experience. 947 parents of CYP with School Distress completed a bespoke online questionnaire, alongside two control parent groups (n=149, n=25) and one professional group (n=19).

Results: Findings revealed a devastating impact on the mental health of parents, with parents displaying significantly heightened daily anxiety and significantly lower mood during, but not before, their children's school attendance difficulties. In addition, parents with children experiencing School Distress reported significantly higher negative emotion states and significantly lower positive emotion states. Parents also reported overwhelmingly negative treatment from professionals, including being disbelieved or blamed for their child's difficulties, threatened with fines and court action, and disempowered by the actions of professionals surrounding their child. Significant, deleterious impacts were also evident across all aspects of their lives, including their careers, finances, and other children. Perhaps unsurprisingly, half of these parents reported developing a new mental health condition since their child's difficulties began, with the experience itself rated as the second most threatening potential life event, superseded only by the death of a first-degree relative (including a child or spouse). On the other hand, professionals working with CYP with School Distress did not experience these deleterious mental health or wider life consequences. Despite understanding how threatening the experience is for parents, they were often quick to blame parents for their children's difficulties. Professionals, like parents, expressed frustration with the lack of help available for these CYP and their families.

Discussion: This study highlights a bleak, adversarial, and lonely picture for parents of CYP struggling to attend school. More specifically, the findings depict a system rife with parental blame; a system that appears to isolate parents through hostile, threatening, and punitive actions. A wider lack of societal understanding of the experience of School Distress further compounds this dearth of support for parents, placing parental mental health in further peril.

KEYWORDS

school attendance problems, school distress, school refusal, emotionally based school avoidance, parent mental health, parental blame, neurodiversity, autism

1 Introduction

1.1 School distress in UK school children

In 2022, England's Children's Commissioner's attendance audit estimated that, in the 2021 Autumn term, 1.7 million pupils in England missed over 10% of school sessions, and 124,000 pupils missed over 50% (1). Updated Department for Education figures show 150,000 pupils (i.e., 1 in every 50 pupils) missed over 50% of school in 2022-23; a figure which is 150% higher than in 2018-19. School absences in Scotland are even higher, with March 2024 figures revealing that 41% of secondary school and 32% of primary school pupils missed over 50% of school in 2022-23 (2). Similarly, in the US, a review of state policy and practice in the school year 2021-22 concluded that chronic absenteeism has blossomed into a full-scale crisis (3). Of additional concern are the findings of the Centre for Social Justice's termly analysis of official data relating to school absences from English schools, which reported that in the 2023 Autumn term, 1.97% of the school population (i.e., 142,487 pupils) were absent from school more often than they were present (i.e., severely absent); the highest number during an Autumn term on record and 137% higher than before the Covid-19 pandemic (4).

Whilst the underpinnings of these persistent school absences are likely multifaceted, the largest academic study of school attendance difficulties in UK school children to date (5) found that in 94.3% of the cases surveyed, school attendance problems were underpinned by significant emotional distress - with often harrowing accounts of this distress provided by parents. This study also reported that, in most of these cases, the children's School Distress began within their formative years and was enduring in nature. Of note too was the finding that in the group of children and young people (CYP) currently struggling to attend school ($n=738$), 92.1% were neurodivergent - with each CYP having, on average, 3.7 identified neurodivergences. Autism was the most prevalent neurodivergence identified, with 83.4% of the CYP currently experiencing School Distress either diagnosed or identified as autistic, and in these CYP, the onset of their School Distress occurred significantly earlier (average age of onset: autistic CYP = 7.94 years; non-autistic CYP = 8.78 years), and was significantly more enduring (duration: autistic CYP = 3.94 years; non-autistic CYP = 2.95 years) relative to non-autistic CYP with School Distress.

In addition, as this study (5) used a case-control research design, including age-matched CYP who do not experience School Distress ($n=149$), important statistical comparisons could be made. One of the most striking of these was the odds ratio of diagnosed autistic CYP experiencing School Distress, relative to their non-autistic peers, which was 46.61. Multi-modal sensory processing difficulties (evident in 56.9% of the CYP with School Distress), ADHD (55.3%), dyslexia (25.4%), dyspraxia (24.7%) and Auditory Processing Disorder (18.2%), amongst other neurodivergences, were also significantly more prevalent in CYP with School Distress than in those without.

Comparable findings have been reported elsewhere in the literature, albeit in smaller samples (e.g., 6, 7). In addition, a recent survey of parents living in Hackney, London ($n=55$),

conducted by Hackney Independent Parent-Carers (8), closely replicated the findings of Connolly et al. (5), with 83% of CYP in this smaller Hackney cohort diagnosed autistic, and 71% of these autistic CYP having more than one diagnosis. This is an important replication as the cohort in (8), although relatively small, closely matched the consensus data from the area with respect to ethnicity (57% White British/Other respondents) and household income (with 47% of respondents in receipt of free school meals), whereas Connolly et al.'s (5) sample (although large) was skewed in favour of White British families living in areas with relatively low rates of socio-economic deprivation.

In addition to neurodivergent profiles, anxiety was highly prevalent in both of these cohorts. For instance, in Connolly et al. (5), 92.5% of the CYP currently experiencing School Distress exhibited clinically significant anxiety symptomology, and elevated demand avoidance was pervasive (9), whilst 46% of CYP in the Hackney cohort (8) had an official diagnosis of anxiety. Importantly, Connolly et al. (5) also found that mental health difficulties in the absence of a neurodivergent profile were relatively rare - accounting for only 6.17% of cases of CYP currently experiencing School Distress - thus highlighting the ubiquity of neurodiversity in the experience of School Distress. In addition, higher anxiety scores in Connolly et al. (5) correlated with a longer School Distress duration, lower school attendance in the current and previous academic years, and how parents rated the impact that school attendance had on their child's mental health (with higher anxiety associated with a more severe, negative impact). Hence, school attendance for many neurodivergent CYP appears deeply problematic, with many children enduring protracted and significant unmet needs at school - leading to severe emotional distress and likely imperilling their longer-term wellbeing, academic outcomes, and overall quality of life.

1.2 Parental lived experience of school distress

In a typical year, English school students are expected to attend school on ~190 days and, under Section 444 Education Act 1996, their parent(s) have a legal obligation to ensure their attendance, with failure of parents to ensure regular school attendance punishable by a fine of up to £2,500 and a prison sentence of up to 3 months (10). Within the context of School Distress, this inevitably places a significant emotional burden on these parents and there is a concerning dearth of empirical research investigating the parental experience of School Distress. This is likely due to the longstanding discourse in the literature around the topic of School "Refusal", which posits that persistent school absences are typically due to neglectful, deficient, or failing parenting (e.g., 11, 12) (see also 13, 14).

Such narratives persist, with a recent study of 201 teachers in England indicating that teachers, when asked to describe the causal underpinnings of School Distress, attributed a high level of importance to home (and peer) related factors and least importance to school-related environmental factors (15). This

appears to be equally true even in the case of neurodivergence. For instance, using a mixed-method study to explore the school experiences of demand avoidant autistic children via parental report ($n=211$), Truman and colleagues (16) reported that parents often felt misunderstood by professionals and blamed for their child's school attendance difficulties, up to and including being treated "like a criminal and a liar by the school and the education system" (AUT-EDA)" (16 p. 68) and prosecuted "School number 4 decided to prosecute me instead of helping us (AUT-EDA)" (16 p. 68). Moreover, a survey by Autistic UK (17), that included completed responses from 25 autistic individuals and 224 parent/carers of autistic individuals, again described a high instance of parents being blamed by professionals with reasons such as 'non-compliance', 'overprotective parenting' and 'poor parenting' emerging. They also reported that their respondents' understanding of the contributing underpinnings of School Distress, such as sensory processing differences, anxiety, and trauma, were often unacknowledged/unrecognised by professionals.

Relatedly, in a thematic analysis of email-based interviews with 40 parents of CYP with school attendance problems who were seeking support for their children, Bodycote (2022) formulated the concept of the 'Parents Journeys' (13). This described an overview of common parental experiences, whereby the tension between parental understanding of School Distress and the understanding of school staff and other professionals was front and centre. This tension often led to school staff dismissing parental reports of their children's difficulties within the school environment, and a tendency for school staff to interpret these difficulties as stemming from deficient parenting abilities and/or problems in the home. Similarly, 62% of parents in the Hackney cohort (8) reported feeling judged by school staff. Moreover, 60% felt ignored and 59% reported feeling blamed, whilst only 32% reported feeling listened to.

The catastrophic consequences of this narrative on parents was amplified by the findings of a survey conducted by Not Fine In School (NFIS) in 2020 (18), which found that 63% of the 714 parents who took part had been blamed for their child's difficulties, 38% had been reported to social services (with 50 children being put on a Child In Need Plan and 12 children being put on a Child Protection Plan), and 23% (153 respondents) had been accused of Fabricated or Induced Illness (FII) – a form of child abuse whereby a parent or carer exaggerates or deliberately causes symptoms of illness in their child (19) (although in <2% of these cases were parents found guilty, with another 3 cases awaiting a verdict). In addition, parents in this survey frequently reported having been threatened with fines due to schools recording their child's absence as unauthorised (38%), and a small number were prosecuted for their child's non-attendance. Again, the children themselves were also often blamed, with 69% of parents reporting that their child was criticised. These testimonies are consistent with the "pervasive view [amongst scholars] that the responsibility of school refusal lies with the individual students and their families" (14 p. 41).

Evidence of the negative impact of school attendance problems on parents has also been highlighted recently by the Local Government and Social Care Ombudsman (LGSCO) (20). Specifically, within one of the case studies presented, the LGSCO

described the significant anxiety and distress experienced by parents of a child with school attendance difficulties, which included threats of prosecution when they asked for help. In addition to the above, missed time from work, legal and financial difficulties (21), endangered careers, increased conflict between parents, and parental separations (22) have all been documented in the literature as potential consequences of School Distress on parents. This latter study also highlighted the impact of School Distress on the whole family unit, due to the necessary reorganisation of daily life.

1.3 Current study

Despite the above, the weight of the clinical and academic evidence has focused on parental deficiencies as drivers of school attendance difficulties, with limited research in the psychological literature exploring the impact that having a child who experiences School Distress has on parents. This research sought to address this. By comparing the lived experiences of parents of CYP who have experienced School Distress with both parents of CYP who attend school without distress and parents of CYP who have never attended a school setting, we aimed to qualitatively explore the parental lived experience of School Distress and to quantitatively assess the impact on their lives. The questions posed can be considered under five related categories: 1, the direct impact of parenting a child or young person experiencing School Distress on the parent themselves; 2, the interactions that parents have with others, including the professionals/services surrounding the child and family, and how these impact parental lived experiences and mental health; 3, action(s) taken against parents to enforce school attendance and the impact of these actions; 4, key causal factors underpinning School Distress; and 5, key sources of support available to participants supporting CYP with School Distress.

We also recruited a separate group of educational professionals and other professionals who support CYP with School Distress to enable a comparison of the parental experiences and understanding of School Distress with that of professionals in each of the above five categories.

2 Method

2.1 Participants

2.1.1 Parents

Participants were required to live in the United Kingdom and be parents/carers of school aged CYP. 1,121 participants were recruited in total, consisting of 738 parents of children currently experiencing School Distress (Current SD), 209 parents of children who have previously experienced School Distress (Past SD), 149 parents of children who have never experienced School Distress (No SD), and 25 parents of children who have never attended a school setting (Lifelong EHE). 97.03% were mothers. The mean completion of the questionnaire was 77.35%, with 62.5% of participants completing 100%. A detailed description of the methods and the CYP's profiles is available elsewhere (5) (see also Table 1).

TABLE 1 Demographic characteristics of the sample.

Characteristic	Current SD	Past SD	No SD	Lifelong EHE	Professionals
Number of Participants	738	209	149	25	19
Mean IMD Decile (StDev)	6.16 (2.8)	5.51 (3.1)	6.17 (2.9)	5.50 (2.6)	–
Country of Residence					
England	88.0%	89.7%	86.6%	96.0%	93.3%
Scotland	9.3%	6.4%	8.7%	0%	0%
Wales	1.9%	2.5%	1.3%	4.0%	0%
Northern Ireland	0.8%	1.5%	3.4%	0%	6.7%
Respondent who are...					
Parents	100%	100%	100%	100%	80%
Mothers	96.6%	98.0%	97.3%	100%	66.7%
Fathers	1.9%	0.5%	2.0%	0%	13.3%
Other	1.5%	1.5%	0.7%	0%	–
Parent/Professional Neurodivergence:					
Yes	21.3%	24.6%	6.7%	21.7%	0%
Maybe	48.0%	37.7%	15.4%	43.5%	7.14%
No	30.7%	37.7%	77.9%	34.8%	92.86%
Child Demographics:					
Age: Years (StDev)	11.8 (3.1)	11.8 (3.6)	11.1 (3.5)	8.7 (3)	–
School Attendance Problems	100%	100%	0%	–	10.5%
Neurodivergent	92.1%	83.6%	22.2%	88.0%	–
Autistic	83.4%	66.2%	16.8%	52.0%	–
Sensory Processing Difficulties	56.9%	43.3%	6.7%	52.0%	–
ADHD	55.3%	43.3%	8.7%	48.0%	–
Mean number of ND (StDev)	3.7 (2.5)	3 (2.5)	0.72 (1.7)	2.5 (2.0)	–
Main Language: English	99.2%	100%	99.2%	100%	–
Ethnicity: White	93.5%	95.8%	90.6%	94.1%	–
Ethnicity: Mixed/Multiple Ethnic Groups	4.9%	3.4%	7.7%	0%	–
Ethnicity: Asian/Asian British	0.6%	0.8%	0.9%	5.9%	–
Ethnicity: Black/African/Caribbean/Black	0.4%	0%	0.9%	0%	–
Ethnicity: British Other	0.6%	0%	0%	0%	–

SD, School Distress; EHE, Elective Home Education; IMD, Index of Multiple Deprivation; StDev, Standard Deviation; ADHD, Attention Deficit Hyperactivity Disorder; ND, Neurodivergence.

2.1.2 Professionals

Professionals due to attend a conference on school anxiety in the North of England were invited to participate. 19 professionals participated (mean completion = 82.84%, with 78.95% completing 100%). Their roles were varied but the majority were school staff (Supplementary Note 1). Most participants were parents, mainly mothers (Table 1). One participant identified as neurodivergent and four were parents of neurodivergent CYP. Participants had a range of experience working with CYP accessing education in different educational provisions and/or

without educational provision for a variety of reasons (Supplementary Table S1) and ranged in confidence when supporting CYP with school attendance problems and/or autistic CYP (Supplementary Table S2).

2.2 Research ethics and language

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University’s Research

Ethics Committee. Where possible, we use identity-first language (e.g., autistic CYP) within this paper (23). We defined neurodivergence (ND) for parents as “a term for when someone’s brain processes, learns and behaves differently from what is considered ‘typical’. Autism is an example of a neurodivergence.” We use the term ‘neurotypical’ (NT) to refer to CYP whose parent identified them as not being neurodivergent. When designing and conducting this study, we used the term ‘school-refusal’ to refer to CYP unable to attend school due to the emotional distress experienced at school. During the data analysis, it became evident that this was not an appropriate terminology, at which point we coined the term School Distress to describe this experience more appropriately and to ensure the CYP’s experience is front and centre stage of discussion (5).

2.3 Design

The study employed a case-control, concurrent embedded mixed-methods design, within which qualitative data was collected to supplement quantitative data. This was chosen due to the exploratory nature of this study, and because the limited literature base prevented us from providing fully comprehensive lists of response options to some questions. To collect qualitative data, free text boxes were presented within some questions for parents to provide additional comments.

2.4 Materials

Whilst the full questionnaire used here is described elsewhere (5), questions relating to the parent/professional lived experience of School Distress are described here. These are considered under five related categories: (1) the direct impact of supporting a child or young person experiencing School Distress on the parent/professional themselves, (2) the interactions that parents and professionals have with others, including the professionals/services surrounding the child and family, and wider family, friends, and acquaintances, (3) perspectives with respect to underlying drivers of school attendance problems, (4) the key sources of support available to parents of CYP experiencing School Distress, and (5) action(s) taken against parents to enforce school attendance and the impact of these actions.

2.4.1 Direct impact of supporting a child with school distress

2.4.1.1 Impact on mental health

2.4.1.1.1 Mood and anxiety levels

All participants were asked to quantify their typical daily mood (0=very negative to 10=very positive) and the level of daily anxiety they currently experience (0=none to 10=high). Parents of CYP currently experiencing School Distress were also asked to rate their typical daily mood and anxiety prior to the onset of their child’s school attendance problems. Parents who rated their children’s school attendance problems as historical (Past SD) were asked to

quantify their typical daily mood and anxiety both before and during their child’s School Distress, as well as currently.

2.4.1.1.2 Discrete Emotions Questionnaire

To comprehensively describe the emotional lived experience of supporting a CYP with School Distress, all participants were also asked to complete the Discrete Emotions Questionnaire (24). This self-report scale consists of 32 items, aiming to measure eight distinct state emotions, with 4 emotions per emotion state (see Figure 1A). Individuals respond along a 7-point Likert scale (1=not at all, 7=an extreme amount), stating the extent to which they experience each of the 32 items. Total scores are then calculated by summing participant’s responses to each subscale. This scale has excellent internal consistency ($\alpha > 0.82$ for each subscale).

School Distress parents responded based on their emotions when their child was experiencing School Distress. Parents of Lifelong EHE CYP and participants in the professional group responded with respect to a period of time of at least a few months over the last year (excluding Covid-19 lockdowns), and parents of children who do not experience School Distress (No SD) were asked to think about an equivalent period of time over the last year where their child was attending school.

2.4.1.1.3 New Mental Health Condition

Finally, participants who had parented a child with School Distress (Current or Past) were also asked whether they had developed a new mental health condition since the onset of their child’s school attendance difficulties.

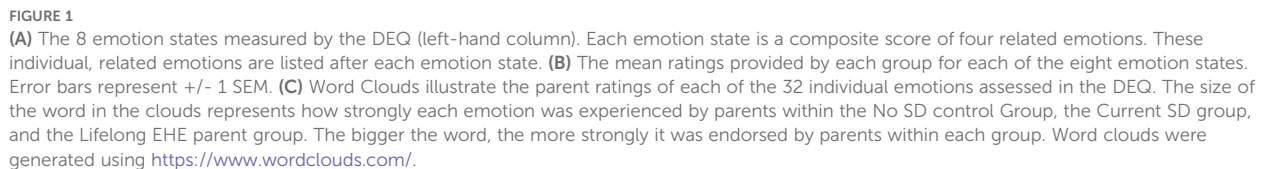
2.4.1.2 Wider impact of school attendance problems

Using a Likert scale, parents in the two School Distress groups (Current and Past SD) rated the impact that supporting a CYP with School Distress has/had on their own physical health, relationships, career, and financial situation, as well as the impact on their other children, wider family, and family friends (0=no impact, 5=some negative impact, 10=considerable negative impact). Professionals who reported having direct experience working with a child or children with school attendance difficulties also completed this section – with the question being whether the experience of working with children with school attendance difficulties, and the associated events, had negatively impacted their own physical health, their relationships, their career, their financial situation, their other children, their wider family, and their family friends.

All participants were provided the opportunity to discuss ‘Other’ impacts.

2.4.1.3 School distress as a threatening life event

To understand how the experience of parenting a child with School Distress compares to other stressful or threatening life events, we utilised the List of Threatening Life Experiences (LTE) (25). This is a list of twelve life event categories with considerable long-term contextual threat, including ‘serious illness or injury to self’, ‘death of a first-degree relative, including spouse or child’, and ‘major financial



For scoring and analysis purposes, the most threatening life event selected by each participant was given a score of '10', with the second most threatening scored '9'. This proceeded until the item ranked lowest within the selected 10 life events was scored '1', after which all life events not selected within the top 10 were scored as '0'. These scores were used to compute an average score for each of the 18 items for each of the five groups respectively.

Parents were asked whether they have ever felt like they have not been believed when they have raised concerns about their child's difficulties [response options: 'No', 'Yes, by school staff', 'Yes, by health care professionals', and 'Yes, by others (please specify)']. Professionals were asked whether they have ever felt like they have not been believed when they have tried to raise

concerns about a child's difficulties [response options: 'No', 'Yes, by the CYP's parents', 'Yes, by school staff', 'Yes, by health care professionals', and 'Yes, by others (please specify)'].

2.4.2.3 Experience of professional gaslighting

All parents were asked if they have ever experienced professional gaslighting (defined as an interaction "where a professional makes you question your own reality"). Three response options were provided: 'No, never', 'Yes, occasionally', and 'Yes, frequently'. Professionals were not asked this question.

2.4.2.4 Feeling threatened or vulnerable

All parents were asked whether, as a parent/carer, they have ever felt threatened or vulnerable as a result of an interaction with a member of school staff (response options: 'No', 'Unsure', and 'Yes, definitely'). As with above, the professional group was not asked this question.

2.4.3 Action taken against parents to enforce attendance

Parents in the Current SD and Past SD groups were asked whether they have ever had any action taken against them to enforce their child's school attendance [response options: 'No', 'Yes, a fine (sometimes known as a 'penalty notice')', 'Yes, a Parenting Order', 'Yes, an Education Supervision Order', 'Yes, a School Attendance Order', 'Yes, I was prosecuted and given a Community Order', 'Yes, I was prosecuted and given a jail sentence', 'Yes, a Fabricated or induced illness (FII) accusation', 'Yes, Child Protection Procedures', and 'Other (please provide details below)']. Parents were asked to select all options that applied to their situation.

Professionals were also asked whether they (or a colleague working with them on a case) had ever taken any of the above actions against a parent(s) to enforce school attendance. They were also asked whether they had ever punished or rewarded a CYP personally because of their school attendance record.

2.4.4 Causal factors

Following a comprehensive, collaborative review of the literature, encompassing a multitude of factors which have been suggested to underpin school attendance problems, we compiled a list of 98 potentially causal factors of School Distress. This included an 'other' item with a free text box. For clarity of presentation here, these 98 items have been classified into 12 broad categories i.e., 'Mental Health' (containing 6 items), 'Physical Health' (3 items), 'Worries/Negative Emotions' (11 items), 'School-Related Factors' (22 items), 'Academic Factors' (3 items), 'Neurodivergence/SEN-Related factors' (16 items), 'Peer Relations' (9 items), 'Pupil Behaviour' (3 items), 'Teacher Related Factors' (6 items), 'Reward/Punishment by School Staff' (4 items), 'Parent/Family Related Factors' (9 items), and 'Other' (6 items). For complete list, see [Supplementary Notes 4-6](#).

School Distress parents were asked to identify the reasons underlying their child's difficulties attending school from this list. Control parents and professionals were asked to select factors which they believed may be the reasons that children experience school attendance difficulties. Once School Distress parents and

participants in the Professional group had identified what they believe to be causal factors, they were then asked to identify the most important factor(s). Participants were instructed to limit this selection to a maximum of 3 factors (which we subsequently referred to as 'key' reasons). Note: due to the fact the two control parent groups will likely have less direct experience of school attendance difficulties, these two groups were not asked to refine their initial selection of potential underlying reasons in this manner.

The rationale for including responses to this question within this paper is that it permitted a statistical exploration of differences in opinion with respect to the most important drivers of School Distress from a parental lived-experience perspective relative to the professional perspective. In addition, the inclusion of the opinions of the control parent groups enables a wider appreciation of lay understanding of why CYP may struggle to attend school.

2.4.5 Sources of support for parents and professionals

Finally, using a free text box, all parents were asked: "As a parent, what has been your most important source(s) of support?", whereas professionals were asked "As a professional working with CYP with school attendance difficulties, what has been your most important source(s) of support?". Professionals were also asked "In your experience, how do you believe professional support could and/or should be improved, and how would this have benefitted you personally, and the CYP you were supporting?". Professionals were also asked whether they would like a) more support and b) more training 'When supporting CYP with School Attendance Problems' and 'When supporting Autistic CYP'.

2.5 Procedure

Data was collected using Qualtrics. The parent survey link was shared widely on social media, and the additional control participants recruited via [prolific.org](#) were directed to the Qualtrics link. Participants in the professional group were attendees at a conference on school anxiety and were invited to participate via email from the conference organisers prior to attending the conference. After reading the information sheet, participants provided written consent before commencing. Participants were informed that they could skip any questions and stop/start at any time. Qualtrics' display-logic function ensured respondents were only asked questions which were relevant to them. Upon completion, participants were presented with a debrief form, including a comprehensive list of support services. The parent study ran for 14 days (22/02/2022–08/03/2022) and the professional study was conducted in January 2023.

2.6 Data analysis

Quantitative data analyses were run using IBM SPSS Statistics V26. Descriptive statistics were calculated to summarise participants' responses to each question. Further statistical

analyses were then conducted to examine relationships between variables. Before performing statistical analyses, Normality was assessed by plotting results in histograms and conducting Shapiro-Wilk and Kolmogorov-Smirnov tests. When results were not normally distributed, non-parametric methods were used (e.g., Kruskal-Wallis tests with Mann-Whitney U *post-hoc* analyses examined differences in anxiety and mood scores between School Distress groups). Chi-squared tests were used to determine whether there was a statistically significant difference between the expected frequencies and the observed frequencies in one or more categories. A significance level of $\alpha=0.05$ was adopted for all analyses, except during *post-hoc* tests where Bonferroni adjustment was applied.

Qualitative analysis was used to analyse additional comments provided by parents in response to some survey questions. In the interest of space, a thematic analysis of just one question is reported here i.e., free text comments in response to the question “Have you ever had any action taken against you to enforce school attendance?”. This question was chosen as, in this instance, the ‘Other’ option was the second most endorsed option (after ‘No’), with 106 parents providing a free text comment. The volume of responses indicated value in formally analysing these free-text comments.

Qualitative data analysis followed the six phases of thematic analysis recommended by Braun and Clarke (2006), aiming to identify key themes within the data to help answer our research question. During analysis, an inductive approach was taken, such that codes and themes were developed from the content of the dataset itself, rather than any prior theoretical commitments. Given the current lack of in-depth research into the experience of School Distress, this enabled us to identify new, valuable information. An essentialist/realist position was taken, assuming a unidirectional

relationship between the participants’ experiences and their language used.

3 Results

3.1 Direct impact of supporting a child with school distress

3.1.1 Impact on mental health

3.1.1.1 Mood and anxiety levels

Current parental mood differed significantly between groups (Kruskal-Wallis test: $p<.001$), with *post-hoc* Mann-Whitney U tests indicating that parental mood levels were significantly lower in parents in the Current SD group compared to all of the other four groups (i.e., the Past SD group, No SD group, Lifelong EHE group and Professional group) (see Figure 2A). Current anxiety levels also differed between groups ($p<.001$), with parents of children currently experiencing School Distress reporting significantly greater levels of daily anxiety than parents in the other three parent groups (i.e., the Past SD, No SD, and Lifelong EHE groups) and the Professional group (see Figures 2B, C for full details).

In addition to providing estimates of current mood and anxiety, parents in the Current SD group also provided retrospective estimates of their mood and daily anxiety levels before their child’s School Distress began. Parents reported significantly higher mood and significantly lower daily anxiety before their child’s School Distress commenced (see Figure 3A).

Similarly, parents whose child’s School Distress was historical (i.e., parents in the Past SD group) also retrospectively estimated their mood and daily anxiety levels before their child’s School Distress

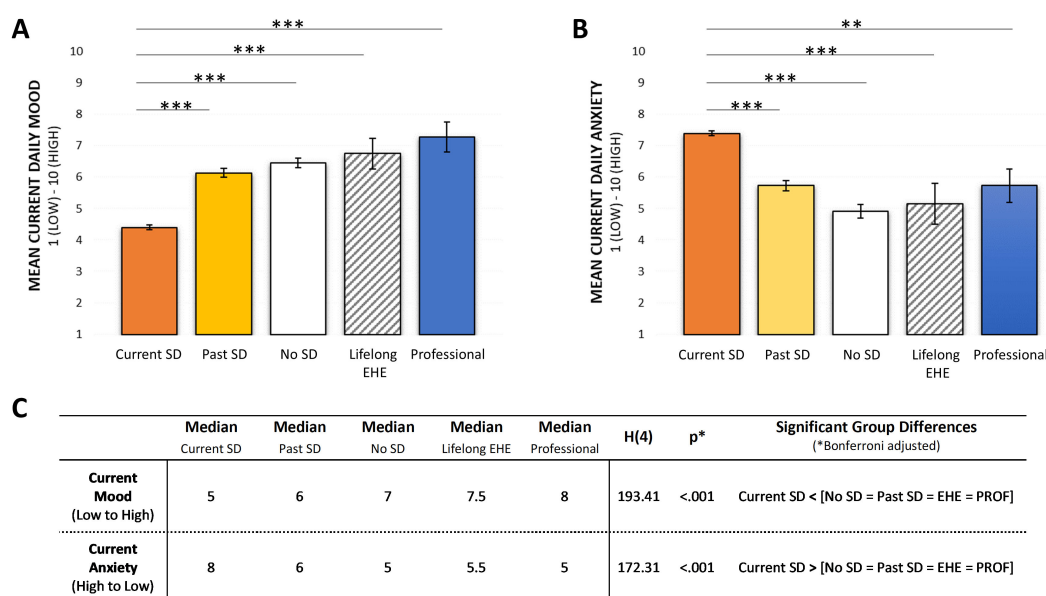
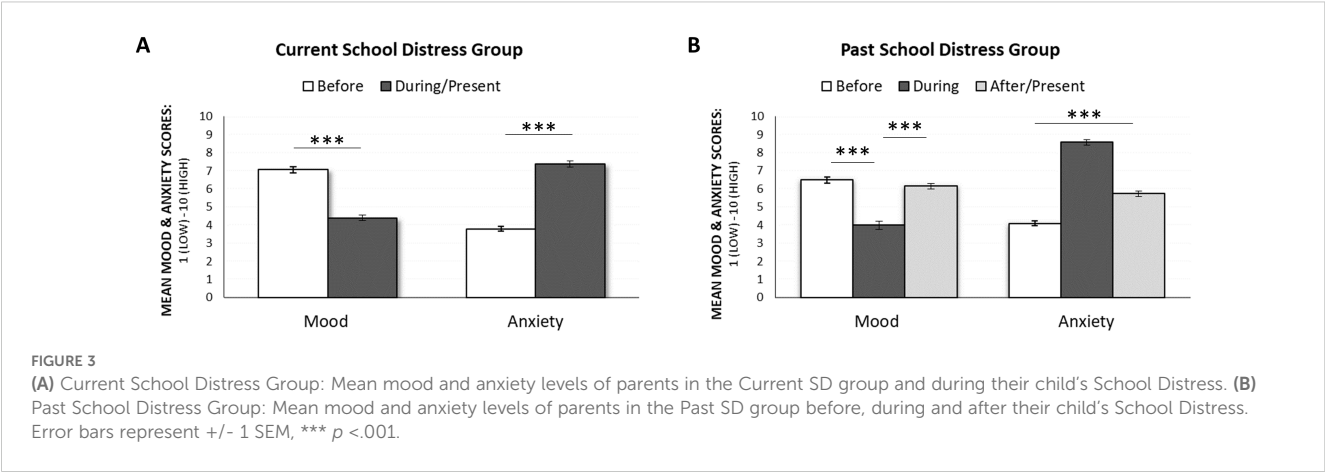


FIGURE 2

(A) Mean mood ratings currently experienced by respondents in each of the five groups. (B) Mean anxiety ratings currently experienced by respondents in each of the five groups. (C) Results of the between-group Kruskal-Wallis analyses and subsequent post-hoc Mann-Whitney U tests. Error bars represent ± 1 SEM, ** $p < .01$, *** $p < .001$.



began, in addition to providing retrospective estimates of their mood and daily anxiety levels during their child’s School Distress. Importantly, the change in parental mood and anxiety pre-School Distress relative to during-School Distress in the Past SD group mirrored that reported in the Current SD group (see Figure 3B). Reassuringly, the Past SD group also showed a relative recovery of their mood and daily anxiety levels once their children’s School Distress resolved (often via parents removing their children from a school setting and educating them at home themselves), although parental anxiety levels post-School Distress did remain significantly higher than pre-School Distress (Figure 3B).

3.1.1.2 Discrete Emotions Questionnaire (DEQ)

A score for each of the eight distinct emotion states (i.e., anger, disgust, fear, anxiety, sadness, happiness, relaxation, and desire) was computed from the 32 individual emotions sampled in the DEQ. Significant between-group differences were evident in each (see Figure 1B). Mann-Whitney U post-hoc tests revealed that during their child’s School Distress, parents in the Current and Past SD groups experienced significantly lower levels of positive emotion states (relaxation and happiness) and significantly higher levels of all negative emotion states (anger, anxiety, sadness, disgust, and fear) relative to the parents in the No SD and Lifelong EHE groups, and to the professionals (see Table 2).

Parental responses to each of the 32 individual emotions in the DEQ are represented at the group level qualitatively in Figure 1C. The larger the word in these word clouds, the more strongly this emotion was endorsed by the parents in the respective groups (i.e., No SD group, Current SD group, Lifelong EHE group).

3.1.1.3 Development of new mental health condition

51.7% of parents in the Current SD group, and 42% of parents in the Past SD group, reported having developed a new mental health condition (diagnosed or suspected) since their child’s School Distress began.

3.1.2 Wider impact

One-sample t-tests (where no impact = 0) found that School Distress had a significant, negative impact on every aspect of the

parents’ lives measured - on parental physical health, their careers, their financial situation, their other children, their wider family unit and family friends, and on their relationships with their partners (see Figure 4 and Supplementary Note 3). Both the Current and Past SD groups reported the most negative impact as being on their own careers, followed closely by their other children, their financial situation, and their relationship with their partner. When parents reported ‘Other’ negative impacts, free text comments indicated that this most frequently referred to the deleterious impact on their own mental health (see Discussion for further descriptions). No significant negative impact on professionals’ lives was found (all p’s > .05) (see Figure 4).

3.1.3 School “refusal” as a threatening life event

Parents in the No SD (control) group perceived the experience of a ‘Child School Refusing’ as the 10th most threatening life event, relative to the 9 other events that they selected to be most threatening (see Table 3). Parents whose children have never attended school (Lifelong EHE) also placed the experience of having a ‘Child School Refusing’ low with respect to other

TABLE 2 Significant group differences in DEQ scores – Kruskal Wallis H test with Mann-Whitney U post-hoc tests (Bonferroni adjusted).

Emotion State	H (4)	p*	Significant Group Differences (*Bonferroni adjusted)
Happiness	244.65	<.001	Current SD/Past SD < No SD/EHE/PROF
Relaxation	235.89	<.001	Current SD/Past SD < No SD/EHE/PROF
Anxiety	254.35	<.001	Current SD/Past SD > No SD/EHE/PROF
Sadness	281.26	<.001	Current SD > Past SD/EHE > No SD Current SD > PROF
Anger	169.84	<.001	Current SD/Past SD > No SD Current SD > EHE
Fear	189.34	<.001	Current SD > No SD/EHE/PROF Current SD > Past SD
Desire	76.64	<.001	Current SD > Past SD > No SD
Disgust	85.30	<.001	Current SD/Past SD > No SD

SD, School Distress; EHE, Lifelong Electively Home-Educated; PROF, Professionals.

threatening life events, with it not appearing at all within their selection of the top 10 most threatening life events. Instead, this experience fell in joint 12th place with the experience of 'having moderate financial difficulties'.

In contrast, parents of CYP currently experiencing School Distress collectively rated a 'Child School Refusing' as the 2nd most threatening life event, only superseded by the 'Death of a 1st degree relative including child or spouse'. Parents with historical School Distress experience (Past SD) collectively rated this experience as the 5th most threatening life event category, superseded by 'Death of a 1st degree relative including child or spouse', 'Serious Illness or Injury to Self', 'Death of close family friend or 2nd degree relative' and 'Major financial crisis'.

The Professional group rated the experience of a 'Child School Refusing' as the 4th most threatening life event, superseded by 'Death of a 1st degree relative including child or spouse', 'Serious Illness or Injury to Self', and 'Death of close family friend or 2nd degree relative'. Thus, qualitatively, this group showed an understanding more in keeping with parents with direct experience of school attendance problems than parents without.

A Kruskal-Wallis test was performed on the scores of the five groups (see Figure 5). With respect to scores for a child "school refusing", the differences between the rank were significant, $H(4, n=841) = 170.57, p < .001$. *Post hoc* comparisons conducted using Mann-Whitney U Tests (with a Bonferroni adjusted alpha level)

revealed that parents in both the Current and Past SD groups rated the experience of a child "school refusing" significantly more threatening than control parents (i.e., the No SD and Lifelong EHE groups; p 's $< .001$, adjusted sig.). Similarly, the professional group rated the experience of a child "school refusing" as significantly more threatening than control parents (i.e., the No SD and Lifelong EHE groups; p 's $< .05$, adjusted sig.); with no significant differences between SD parent groups and the professional group (p 's = 1.0, adjusted sig.). Finally, parents in the Current SD group rated the experience of a child "school refusing" as significantly more threatening than the Past SD group ($p < .05$, adjusted sig.).

3.2 Interactions with individuals surrounding child and family

3.2.1 Tone of communication

When asked to identify adjectives that best describe the tone of communication used by professionals when communicating with them, parents of children with experience of School Distress most frequently selected negative adjectives, such as 'dismissive', 'critical', 'unsupportive', and 'uninformed'. Some positive adjectives were selected, but less frequently than the above negative adjectives (see Table 4). This was consistent in both the Current SD and Past SD groups, and contrasted

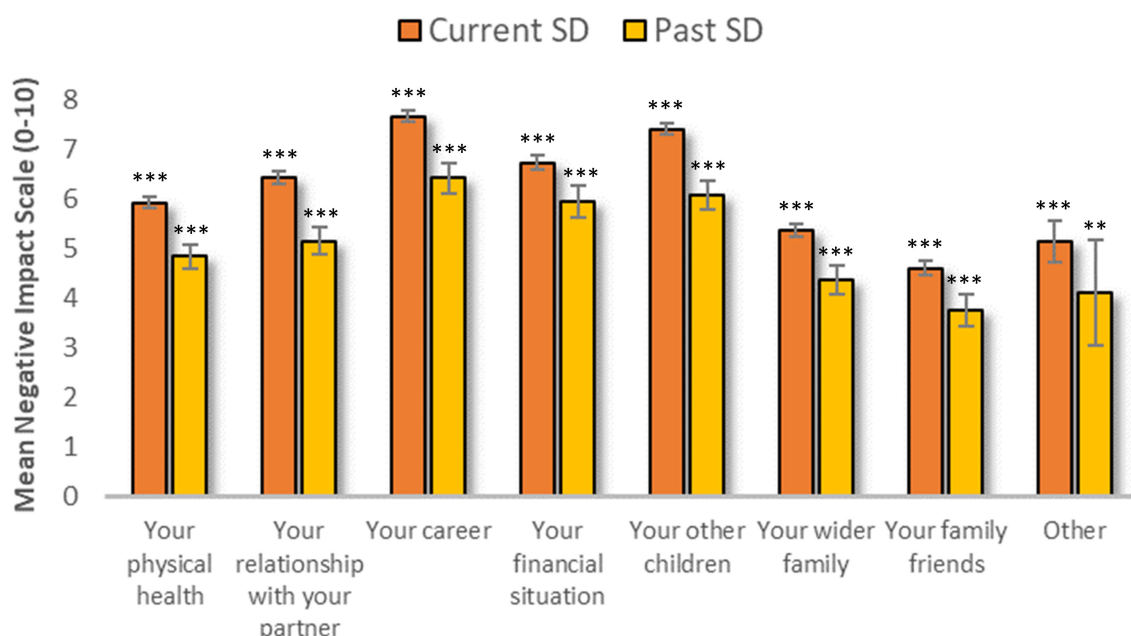


FIGURE 4

The mean extent to which school distress has a wider negative impact on the respondent's life. Note: Responses were rated on a scale of 0-10, where 0 indicates no negative effect and 10 indicates a very large negative effect. One-sample t-tests revealed that the mean scores for each variable were significantly greater than 0: i.e., there was a significant negative impact of School Distress on parents' (1) physical health [Current SD: $t(526) = 49.15, p < .001$; Past SD: $t(127) = 19.22, p < .001$], (2) their relationships with their partners [Current SD: $t(460) = 49.01, p < .001$; Past SD: $t(119) = 18.28, p < .001$], (3) their careers [Current SD: $t(509) = 67.94, p < .001$; Past SD: $t(121) = 21.67, p < .001$] (4), their financial situation [Current SD: $t(476) = 48.58, p < .001$; Past SD: $t(121) = 18.43, p < .001$], (5) their other children [Current SD: $t(466) = 66.66, p < .001$; Past SD: $t(102) = 20.55, p < .001$], (6) their wider family unit [Current SD: $t(476) = 42.34, p < .001$; Past SD: $t(114) = 14.66, p < .001$] (7), their family friends [Current SD: $t(413) = 29.87, p < .001$; Past SD: $t(97) = 11.66, p < .001$], and on (8) 'other' [Current SD: $t(97) = 12.26, p < .001$; Past SD: $t(18) = 3.85, p < .01$]. Error bars represent ± 1 SEM. ** $p < .01$, *** $p < .001$.

TABLE 3 Most to least threatening life events, as reported by participants in each of the five groups.

Most to Least Threatening	Current SD	Past SD	No SD	Lifelong EHE	Professionals
1st	Death of a 1st degree relative including child or spouse	Death of a 1st degree relative including child or spouse	Death of a 1st degree relative including child or spouse	Death of a 1st degree relative including child or spouse	Death of a 1st degree relative including child or spouse
2nd	Child “School Refusing”	Serious Illness or Injury to Self; Death of close family friend or 2nd degree relative	Serious Illness or Injury to Close Relative	Serious Illness or Injury to Self	Serious Illness or Injury to Self
3rd	Serious Illness or Injury to Self	Major financial crisis	Serious Illness or Injury to Self	Serious Illness or Injury to Close Relative	Death of close family friend or 2nd degree relative
4th	Serious Illness or Injury to Close Relative	Child “School Refusing”	Death of close family friend or 2nd degree relative	Major financial crisis	Child “School-Refusing”
5th	Death of close family friend or 2nd degree relative	Serious Illness or Injury to Close Relative	Major financial crisis	Death of close family friend or 2nd degree relative	Separation due to marital difficulties
6th	Major financial crisis	Separation due to marital difficulties	Separation due to marital difficulties	Separation due to marital difficulties	Major financial crisis
7th	Separation due to marital difficulties	Problems with police/court appearance	Sacked from job	Serious problem with close friend, neighbour or relative; Sacked from job	Serious Illness or Injury to Close Relative
8th	Problems with police/court appearance	Sacked from job	Problems with police/court appearance	Had a baby	Problems with police/court appearance
9th	Sacked from job	Had a baby	Child “School-Refusing”	Problems with police/court appearance	Sacked from job
10th	Serious problem with close friend, neighbour or relative	Serious problem with close friend, neighbour or relative; Unemployed seeking work for more than 1 month	Unemployed seeking work for more than 1 month	Unemployed seeking work for more than 1 month	Had a baby

Events are ordered based upon the mean position they were placed by participants. Events separated by a ‘;’ were chosen as equally threatening. For ease of understanding, the option ‘Child “School Refusing”’ has been highlighted with bold.

with the parents of children who have never experienced School Distress (i.e., the No SD group), who most frequently selected positive adjectives such as ‘friendly’, ‘calm’, ‘caring’ and ‘helpful’.

Parents were also able to add additional adjectives into a free text box. Parents with experience of School Distress included adjectives such as ‘arrogant’, ‘apologetic’, ‘cold’, ‘condescending’, ‘confusing’, ‘deceitful/lying’, ‘derogatory’, ‘disbelieving’, ‘disempowering’, ‘duplicitous’, ‘friendly’, ‘gaslit’, ‘helpful’, ‘ignorant’, ‘inconsistent’, ‘irritated’, ‘negative’, ‘nice’, ‘respectful’, ‘underhand’, ‘unprofessional’, ‘unsure’, ‘pacify’, ‘patronising’, ‘sarcasm’, ‘scary’, ‘sceptical’, ‘trivialising’, ‘voiceless’, and ‘wrong’. Of the additional adjectives, ‘patronising’, ‘deceitful/lying’, ‘condescending’ and ‘sarcasm’ were reported most frequently.

3.2.2 Not feeling believed

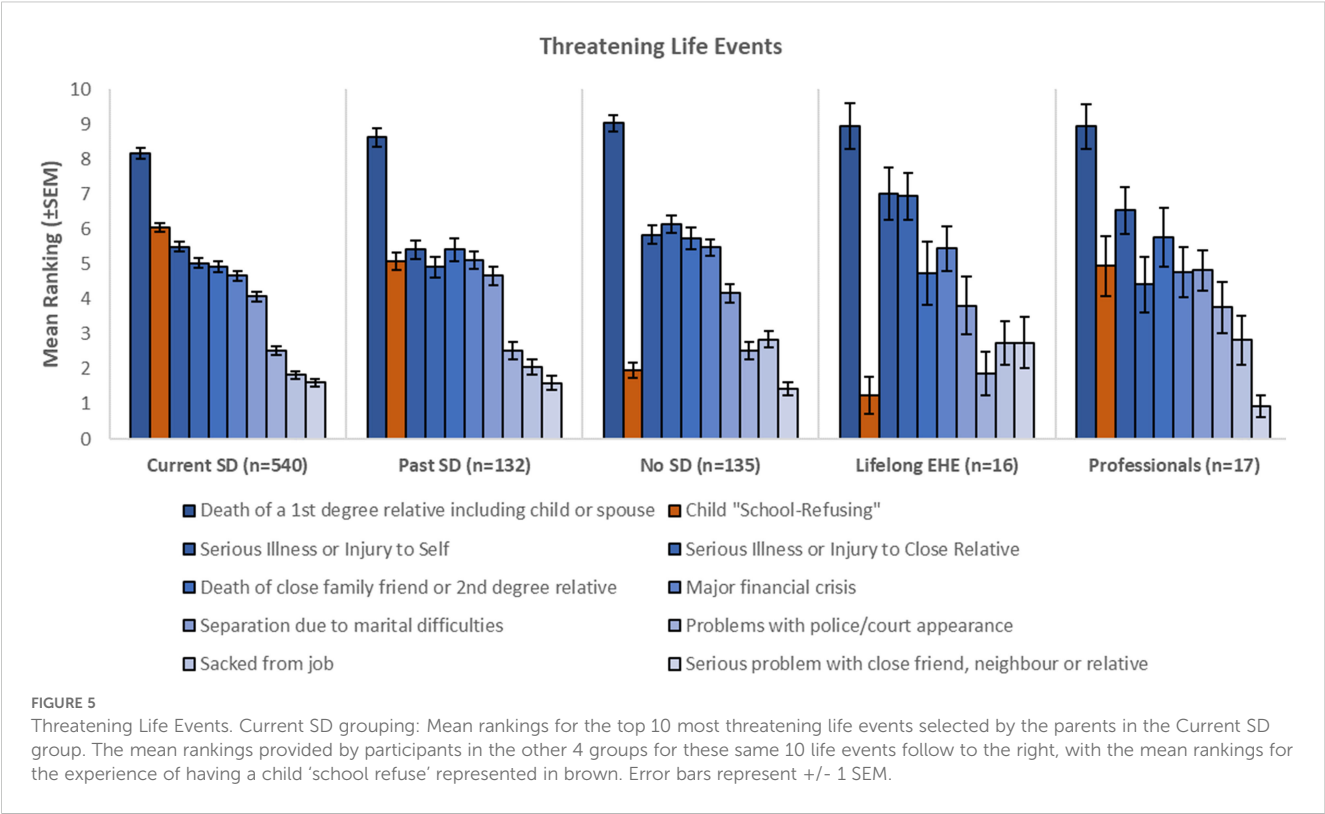
3.2.2.1 Not feeling believed by school staff/parents

When directly asked if they had ever felt like they have not been believed when they have raised concerns about their child’s difficulties, 78.7% of parents in the Current SD group and 75.7% of parents in the

Past SD group reported feeling like they have not been believed by school staff when raising concerns about their child, compared to just 17.8% of parents in the No SD group (see Figure 6A). A chi-square test was performed to examine the relationship between feeling believed by school staff and being a parent with or without experience of School Distress (Current SD/Past SD versus No SD). School Distress parents were significantly more likely to report not being believed by school staff than control (No SD) parents ($X^2(1, N = 658) = 160.34, p < .001$). In addition, 28.6% of participants in the Professional group also reported not feeling believed by school staff when raising concerns about a child’s difficulties. This percentage included a SENCO, a senior psychological wellbeing practitioner, a pastoral manager, and an attendance inclusion officer. However, only 10.5% of participants in the Professional group reported not being believed by the CYP’s parents when raising concerns with them about a child’s difficulties.

3.2.2.2 Not feeling believed by health care professionals

38.7% of parents in the Current SD group and 26.2% of parents in the Past SD group reported having felt disbelieved by health care



professionals when they have tried to raise concerns about their child's difficulties, relative to only 10.2% of parents in the No SD group and 5.3% of professionals. As with school staff, parents with experience of School Distress were significantly more likely to report not being believed by health care professionals when raising concerns about their child's difficulties [$X^2(1, N = 658) = 30.58, p < .001$].

Notably, 52.9% of parents in the Lifelong EHE group reported that they have felt disbelieved by health care professionals previously. This was significantly higher than in the No SD control group [$X^2(1, N = 135) = 20.69, p < .001$] and Past SD group [$X^2(1, N = 120) = 4.64, p < .05$], but did not differ significantly relative to the Current SD group ($X^2(1, N = 454) = 1.39, p = .237$).

3.2.2.3 Not feeling believed by others

In addition, many parents indicated that they felt that they have not been believed about their child's difficulties 'by others', with the majority of these parents falling into the School Distress (Current and Past) or Lifelong EHE groups. A total of 84 parents provided free text comments with respect to who they were referring to. Responses are represented in Figure 6B. Children's Social Services (x18), family (x14), friends (x11) and Local Authorities (x10) were the most frequently mentioned by parents (although different descriptors were used for Children's Social Services: 5 x Social Workers, 4 x Social Care, 3 x Social Services, 3 x Early Help, 1 x Disability Social Worker, 2 x Family Support Worker). In addition, partners, ex-partners, and ex-husbands were mentioned by several

TABLE 4 Adjectives selected most frequently by parents to describe the tone of communication used by professionals when communicating with them.

Position (Most to Least Commonly Used)	Current SD	Past SD	No SD	Lifelong EHE
1st	Dismissive	Dismissive	Friendly	Caring/ Friendly
2nd	Critical/ Unsupportive	Unsupportive	Calm	Helpful
3rd	Uninformed	Uninformed	Helpful	Calm
4th	Calm	Critical/Caring	Respectful	Compassionate/Respectful
5th	Caring	Compassionate/ Friendly	Caring	Kind/Uninformed

For parents in both the Current SD and Past SD groups, this referred to communications specifically during their child's School Distress.

parents, as well as other parents, work colleagues, and the parent's own parents. More specialist mental health services, such as CAMHS, educational psychology, and an ASD-team were also mentioned.

3.2.3 Experience of professional gaslighting

77.6% of parents of children currently experiencing School Distress, and 69.9% of parents of children who have experienced School Distress in the past, reported either occasionally or frequently experiencing professional gaslighting (see Figure 6C), which is where individuals are manipulated “into doubting his or her perceptions, experiences, or understanding of events” (American Psychological Association, n.d.). A Kruskal-Wallis H test with Mann-Whitney U *post-hoc* analyses revealed that significantly more parents in the Current and Past SD groups reported either occasionally or frequently experiencing gaslighting compared to parents in the No SD group ([Current SD = Past SD] > No SD; Current SD > Lifelong EHE).

3.2.4 Feeling threatened or vulnerable

Furthermore, 47.7% of parents in the Current SD group, and 52% of those in the Past SD group, reported that they have felt threatened or vulnerable due to an interaction with a member of school staff (see Figure 6D). A Kruskal-Wallis H test with Mann-Whitney U *post-hoc* analyses revealed that significantly more parents in the Current and Past SD groups have felt threatened or

vulnerable compared to parents in the No SD and Lifelong EHE groups ([Current SD = Past SD] > [No SD = Lifelong EHE]).

3.3 Action taken against parents to enforce attendance

When asked about action taken against parents to enforce school attendance, 42.1% of the professional group who responded to this question stated that they (or a colleague working with them on a case) had action taken against a parent/parents to enforce school attendance that had resulted in a fine (sometimes known as a ‘penalty notice’), 21.1% had taken action that resulted in a ‘Child in Need’ assessment being conducted, 10.5% reported having taken action that resulted in ‘Child Protection’ procedures, with a similar percentage reported to have taken action that had resulted in a Parenting Order being issued, and 5.3% of the professional group reported having taken action that resulted in a School Attendance Order and a Community Order. Separately (but relatedly), 18.7% of the professional group reported having punished (or given sanctions) directly to a CYP because of their school attendance record, and 63.2% had rewarded CYP for 100% school attendance (hence indirectly penalising students with attendance difficulties).

Considering parent responses to specific actions taken against them because of their child's school attendance, most of the School Distress parent participants in our cohort reported that ‘no action’

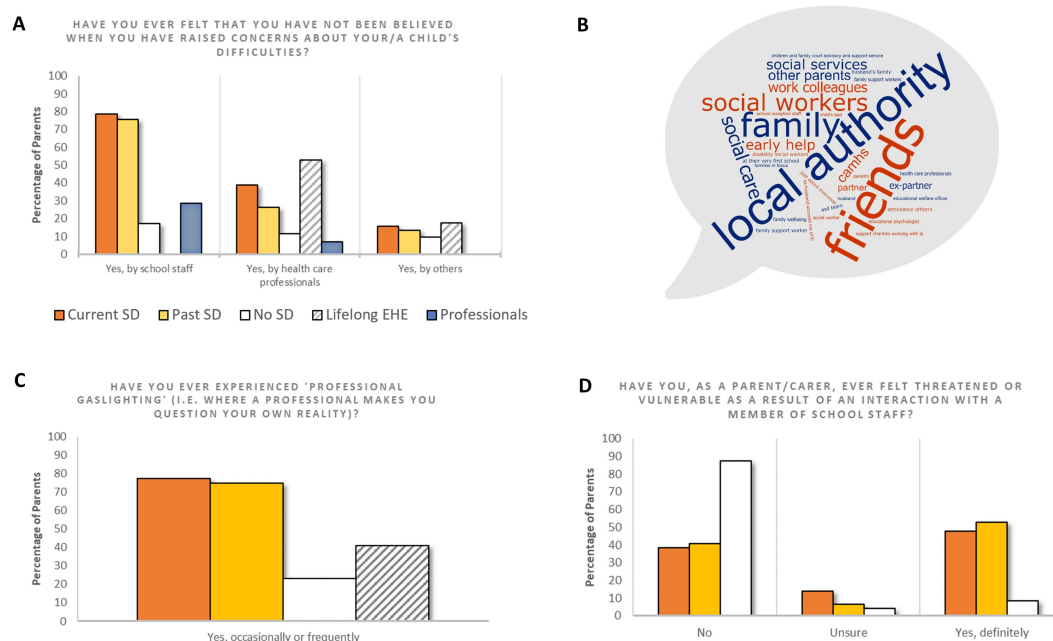


FIGURE 6

(A) Percentage of participants who have ever felt as if they have not been believed by School Staff, Health Care Professionals, or ‘Others’, when they have raised concerns about their/a child's difficulties. (B) A word cloud of the free text responses provided by School Distress parents to the question of who else (i.e. the ‘Others’ in Panel A) did not believe them when they raised concerns about their child's difficulties. The bigger the word, the more frequently this option was disclosed by parents. (C) Percentage of parents who reported ‘never’, ‘occasionally’, and ‘frequently’ experiencing professional gaslighting i.e., where a professional made them question their own reality. (D) Percentage of parents who have ever felt threatened or vulnerable as a result of an interaction with a member of school staff.

had been taken against them by professionals. However, a small percentage of parents reported being fined, having a School Attendance Order issued against them, being accused of Fabricated or Induced Illness (Fii), and/or involvement from Child Protection Services (for full details see Table 5).

3.3.1 Thematic analysis (parental experiences)

Outside of the response options that we provided to parents and professionals, 106 SD parents provided additional comments in response to this question. Given the breadth of information provided here, a thematic analysis was conducted, with four themes (‘Dread, Fear and Vulnerability’, ‘Hostile Action(s)’, ‘Protection’, ‘Dereliction of Duty’) and eight subthemes identified. Figure 7 displays the thematic map that highlights the links between the themes and subthemes. Additional example quotes from each theme/subtheme are presented in Table 6.

The first theme, ‘Dread, Fear and Vulnerability’ encapsulates the feelings of dread and fear that parents feel because of threats they receive, mainly from school staff, about being fined or prosecuted for their child’s non-attendance at school or being referred to external agencies such as School Attendance Officers and/or Children’s Social Services. It also encompasses parental vulnerability; specifically, their vulnerability to being blamed for their child’s school attendance difficulties and/or accused of child abuse. Within this theme, four interlinked subthemes were identified:

TABLE 5 Percentage of parents who have had different types of action taken against them to enforce school attendance.

Action	Current SD	Past SD
No Action	77.96	83.54
Fine	2.00	0.63
Parenting Order	0.17	0
Education Supervision Order	0.17	0
School Attendance Order	3.51	0.63
Prosecuted (Community Order)	0	0
Prosecuted (Jail)	0	0
Fabricated or Induced Illness Accusation	3.51	3.16
Child Protection Services	4.34	1.27
Other (Additional Comments)	15.03	9.49

- “Living in Fear” - Despite no action having been taken yet, parents often reported being concerned about punitive actions that may be taken against them in the future. The words “not yet” appeared frequently in these descriptions e.g., “Not yet. I have been threatened with court action for non-attendance, she is on a CIN [Child in Need] plan with social services”. The extract “no action taken, however I am living in fear of this” further underlined the dread of

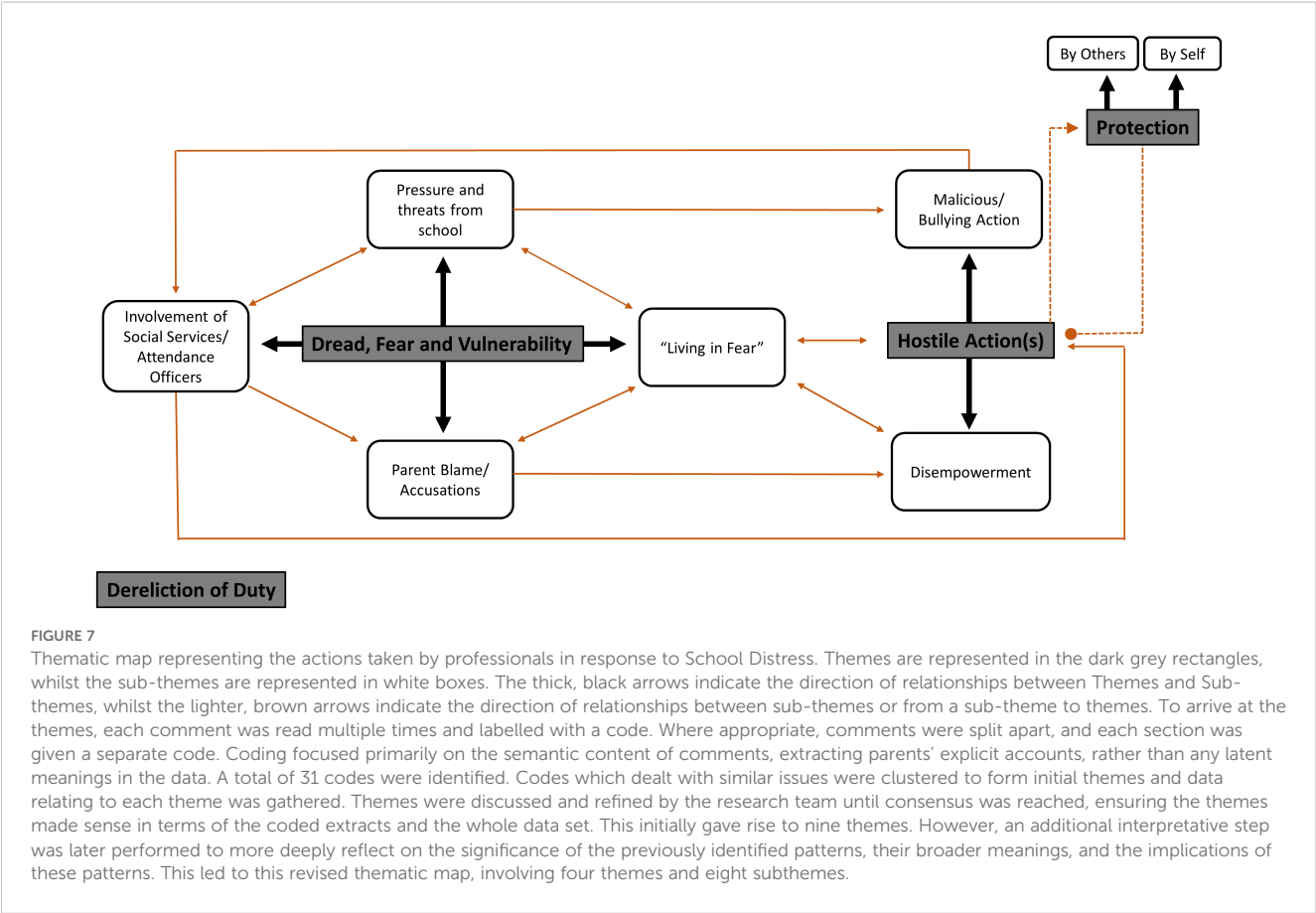


TABLE 6 Example quotations from parent participants who have experienced School Distress, and which support the themes identified via thematic analysis.

Theme 1: 'Dread, Fear and Vulnerability'			
Subtheme 1: 'Living in fear'	Subtheme 2: 'Pressure and Threat from School'	Subtheme 3: 'Involvement of Social Services/ Attendance Officers'	Subtheme 4: 'Parental Blame/Accusations'
"Not yet. I have been threatened with court action for non-attendance, she is on a CIN plan with social services"	"Threats to call social services if I didn't stop trying to get child support/telling them he was struggling"	"We've had to have attendance meetings with EWO and head which made us feel under even more pressure although they were trying to understand"	"All through primary I felt shamed and blamed"
"Not yet but have been asked to provide proof of illness"	"Not given but threatened with prosecution on many occasions"	"I received a letter from the EWO that threatened court action"	"Implying it's my mental health"
"I was told prosecution proceedings would be commencing shortly, but they did not start due to the pandemic and then we were offered specialist school place"	"Threatened with school attendance officer involvement"	"I was threatened with fines/court orders and received the initial letter. Once the EIO got in contact they were happy that I was doing everything within my power to support my child so it was not taken any further"	"Told my anxiety causes child's anxiety ie FII"
"not yet, but it's coming"	"Letters threatening fines and court action"		
"not yet but it worries me that I will in the future"	"Threatened/reported to childrens services by school"	"They reported me to social services who thankfully said it was an inappropriate referral"	"made out to be incompetent"
"no action taken, however I am living in fear of this"	"Threatened with fine and threatened with social services"		
Theme 2: 'Hostile Action(s)'			
Subtheme 1: Disempowerment		Subtheme 2: Malicious/Bullying Behaviour	
"I had son removed as SS did not believe that I was trying to get him into school"		"Malicious safeguarding referral"	
"Threatening emails, parent blame, teachers showing up at my door to 'take control'"		"Primary school Head teacher used bullying tactics on us as parents and on my child"	
"No formal supervision order but punitive regime of daily phone calls to justify absence imposed by Ed Welfare Officer and attempts to impose home school behaviour contracts"			
"I was called into a meeting and made to feel very small, lectured a lot. They then called my daughter in & went through it all again & upset her"			
"Attendance team visit to house ... Didn't have a problem with using physical force on a disabled child to get them to attend school"			
Theme 3: 'Protection'			
Subtheme 1: 'By Others'		Subtheme 2: 'By Self'	
"having a GP and therapist backing me was absolutely crucial as they diagnosed my grandson with PTSD, insomnia, anxiety and OCD"		"Prosecution started, but dropped when I contested it"	
"Had to provide a GP letter about child's severe mental health crisis before they backed off"		"They tried the attendance order approach, but we managed to stop it"	
"court action threatened but protected by headteacher"		"only no problems as [I am a] doctor and fought our corner"	
"I got taken to court for my sons attendance but eventually they dropped the charges after lots of fighting with the help of a solicitor"		"after so much school refusal we HE to save us from prosecution due to poor attendance"	
"Investigation by local council attendance team but held off fining as they could see we were trying"		"I was beginning to get threatening letters before I decided to home educate"	
		"Was on a fast track to prosecution before I de registered"	

(Continued)

TABLE 6 Continued

Theme 4: 'Dereliction of Duty'
"this does not apply at private school, they just don't care less you are not there, as long as you keep paying fees!"
"I was told that the EWO would be contacting me and that it would be easier if I offrolled my child"
"They threatened to take him off register"
"School did everything they could to get rid of my child"

CIN, Child in Need; De register, agree to remove a child from their school setting to home educate them; EWO, Education Welfare Officer; EIO, Early Intervention Officer; FII, Fabricated or Induced Illness; GP, General Practitioner/Family Doctor; HE, Home Educate; OCD, obsessive compulsive disorder; PTSD, Post Traumatic Stress Disorder; SS, Children's Social Services.

impending action and the fear that this inserts into parents' daily lives.

- In 'Pressure and Threat from School', parents frequently reported being placed under pressure to enforce attendance (e.g., "constant pressure from school", "Just continuous letters from school"). In addition, the word "threatened" was pervasive (i.e., it was mentioned 40 times within the 106 individual responses). These threats took the form of threats of fines, threats of prosecution, or threats of being reported to external agencies such as School Attendance Officers and/or Children's Social Services (presumably for investigation and/or prosecution).
- A closely related subtheme was labelled 'Involvement of Social Services/Attendance Officers'. This related to actual referrals of the families to external agencies by school (e.g., "School contacted MASH [Multi-Agency Safeguarding Hub] for Child in Need assessment"). In some instances, this led to additional threats and pressure. Other quotes indicated that although the threat of referral had been carried out by school staff, the outcome was non-threatening.
- Finally, within this theme, the subtheme 'Parental Blame/Accusations' encompassed parental vulnerability to accusations and/or blame as a result of their child's school attendance difficulties e.g., "All through primary I felt shamed and blamed" and "Told my anxiety causes child's anxiety ie FII [Fabricated or Induced Illness]". Such allocation of blame and/or accusations were reported from multiple sources (e.g. head teachers, family doctor).

The second theme, 'Hostile Action(s)', encompasses the instances where the situation progressed beyond threats and accusation to action against parents. Considering the level of severe emotional distress, clinically significant anxiety symptomology, and the disability-related barriers to school attendance evident within this cohort of CYP (see (5) for full description), punitive actions against their parents within this context can be perceived as hostile. Example quotes include "I have been told I have to attend a formal interview under caution" and "I got taken to court for my sons attendance". Reflecting further on parental descriptions of actions taken, we arrived at two subthemes within this broader theme:

- The subtheme 'Disempowerment' arose as some descriptions reflected a loss of parental autonomy as a consequence of the

actions taken by professionals to enforce school attendance. Example quotes include "Threatening emails, parent blame, teachers showing up at my door to 'take control'". In addition to disempowering parents, some of the actions described were likely to have caused significant trauma to the parent(s) and child, for example "Attendance team visit to house ... Didn't have a problem with using physical force on a disabled child to get them to attend school".

- 'Malicious/Bullying Behaviour' arose from descriptions that were distinct from other actions described, in that the motivation for the described action taken against parents was perceived by the parents as stemming from a place of ill intent, e.g., "Malicious safeguarding referral".

Running alongside the above, a third theme was identified, labelled as 'Protection'. This highlighted instances where action was taken to protect parents from punitive action, disempowerment and/or prosecution. Within this, there were two distinct subthemes:

- Protective actions taken 'By Others' (i.e., by a specific professional surrounding the family). For one parent this was a member of school staff ("court action threatened but protected by headteacher"), whilst the others referred to external professionals, including doctors and solicitors.
- The other subtheme that emerged (labelled 'By Self') highlighted instances where parents successfully defended themselves against such actions. Example quotes included "Prosecution started, but dropped when I contested it". Interestingly, in some cases, self-protection required parents to remove their child entirely from the State education system (i.e., by agreeing to home-educate their child).

Whilst the above themes and subthemes appeared interconnected, the final theme labelled 'Dereliction of Duty' appeared independent. This described instances where parents reported that their child's school were either uninterested in the child's lack of school attendance (e.g., "No this does not apply at private school, they just don't care less you are not there, as long as you keep paying fees!"), or where schools tried to ensure that the child left the school (e.g., "I was told that the EWO would be contacting me and that it would be easier if I offrolled my child", "They threatened to take him off register", and "School did everything they could to get rid of my child").

3.4 Causal factors

Notable similarities and differences emerged when each group reflected on the causal factors underpinning school attendance difficulties. More specifically, whilst all five groups most frequently endorsed 'Anxiety' as a major driver of School Distress (see [Figures 8, 9](#) and [Supplementary Notes 4, 5](#)), understanding of the drivers of this anxiety and the wider experience of School Distress itself, diverged considerably between groups. Moreover, when considering the initial stage of this question i.e., when participants were asked to identify all factors contributing to their/a child's school attendance difficulties, parents with experience of School Distress were significantly more likely to endorse school-related factors (i.e., the child not feeling safe at school, the length of the school day, the impact of an increasingly standardised education system, staff:student ratio; [Figure 8A](#)), neurodivergence/SEN-related factors (i.e., neurodivergence, sensory processing difficulties, exhaustion from masking neurodivergence, burnout relating to neurodivergence, the child not feeling their difficulties are believed at school; [Figure 8B](#)), unpredictable behaviour of peers/classmates, not feeling listened to, being afraid of getting into trouble, and teacher-related factors (i.e., teaching behaviour such as shouting, a lack of teacher understanding, a lack of teacher training in SEN/neurodivergence, a lack of trust in teachers) relative to the Professional group. The Professional group, on the other hand, were significantly more likely than School Distress parents to endorse illness, child concerns about Covid-19, a lack of structure in the school day, difficulties with unstructured period of time, pupil behaviour (i.e., non-compliance and conduct disorders), peer-related factors such as cyber bullying, sexual harassment/violence, peer/gang intimidation and/or exploitation at school, gang violence at school, mental health factors (i.e., separation difficulties and non-school related trauma; [Figure 8C](#)), and most notable, parent/family-related factors (i.e., parental mental health, poor parenting/lack of discipline, over-protective parenting, over-dependency within the family, difficulties at home/within the family, child neglect, detachment within the family, and to gain attention from the parent(s); [Figure 8D](#)) (for *p*-values see [Supplementary Note 4](#)).

Interestingly, parents of CYP who attend school without difficulty, believed that factors such as bullying (both in-person and cyber), a lack of friendships, difficulties with friends/peers, and academic pressure were more likely to drive children's difficulties than parents of children with School Distress, whilst Lifelong EHE parents appeared to be more alert to the possibility of neurodivergence/SEN-related factors and factors relating to unmet needs at school as relevant (See [Supplementary Note 5](#)).

Following on from this initial question, participants in the School Distress Parent groups and the Professional group were asked to refine their selection of causal factors to just the key causal factors. The 13 most frequently selected of these key causal factors is shown in [Figures 9A, B](#). Statistical analyses of these responses showed that professionals continued to be significantly more likely to select 'parent-related' factors (i.e., parental mental health,

poor parenting/lack of discipline, over-dependency within the family, overprotective parenting, difficulties at home/within the family), and child factors such as non-compliance and separation difficulties, than School Distress parents ([Figure 9B](#)), whilst the rate of endorsement of neurodivergence/SEN-related factors was notably higher in the School Distress parent group than the Professional group, with exhaustion from masking neurodivergence ranked 2nd, neurodivergence ranked 3rd, demand avoidance, 4th, ineffective SEN support, 5th, sensory processing difficulties, 6th, and SEN, 7th ([Figure 9A](#)) (see [Supplementary Note 6](#) for full details).

3.5 Sources of support

In response to the question "As a parent, what has been your most important source(s) of support?", 39.25% of School Distress parents referred to other parents with similar experiences/parent support groups (e.g., Facebook communities), 15.96% referred to their own family/husband/partner/their CYP's other parent, and 11.75% referred to their friends. Additional responses from a smaller number of parents included teachers, SENCOs, support workers, SENDIASS, GPs, clinical/educational/private psychologists and private therapists, as well as the internet/their own research. Concerningly, several parents also highlighted having received no support, or having to support themselves.

Professionals were also asked to identify their most important source(s) of support and how this support could be improved (see [Table 7](#) for professional quotations). Many professionals reflected back the same lack of support that the parents frequently referred to. They also described barriers to accessing what available support there is, including lengthy referral processes, long waiting times, and external support that typically comes too late (e.g., "*they do not engage sometimes not until crisis point*"). Whilst some professionals referred to the parents/families as an important source of support, and working alongside families and external agencies as helpful, this was, however, contingent on them having the time to do this and/or access to external agencies in the first instance. CAMHS, Early Help, Pastoral staff, educational therapy, networks, and school counselling teams were all referenced.

Almost half (46.7%) of the Professional group indicated that they would like more support to help CYP with school attendance problems, whilst 60% indicated that they would like more training. A similar proportion of the Professional group (60%) indicated that they would also like more training to support autistic CYP (see [Supplementary Table S2](#)).

4 Discussion

This study shines a valuable light on the experiences of parents of CYP experiencing School Distress in the UK, including the treatment of parents by professionals, action taken against parents due to their child's School Distress, beneficial sources of support,

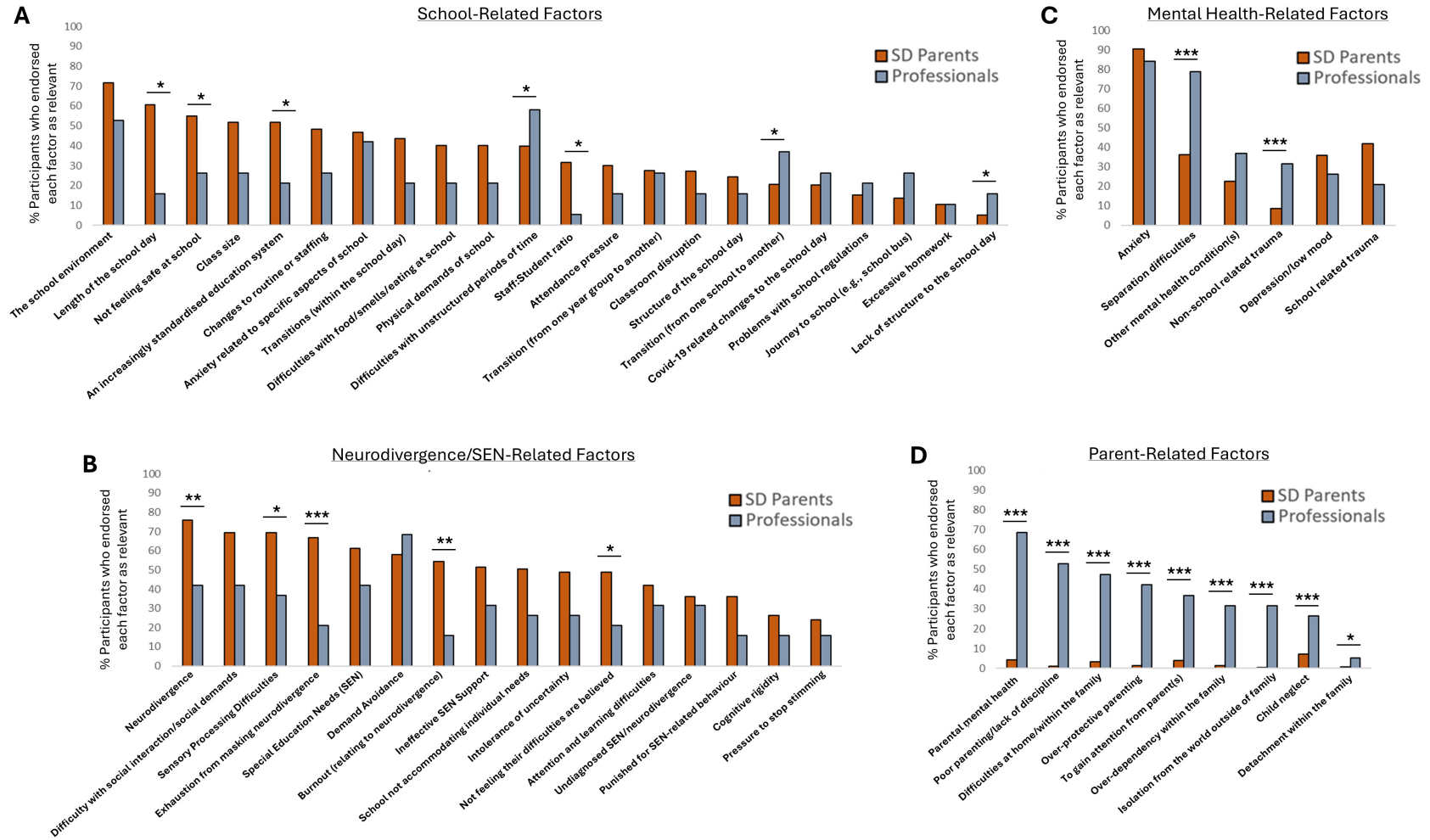


FIGURE 8

(A) The percentage of School Distress parents who endorsed each school-related item as a likely reason underlying their child's school attendance difficulties, relative to the percentage of professionals who endorsed each of these school-related items as a reason underlying CYP's difficulties more generally. (B) The percentage of School Distress parents who endorsed each neurodivergence/SEN-related item as a likely reason underlying their child's school attendance difficulties, relative to the percentage of professionals who endorsed each of these items more generally. (C) The percentage of School Distress parents who endorsed each mental health-related item as a likely reason underlying their child's school attendance difficulties, relative to the percentage of professionals who endorsed each of these items more generally. (D) The percentage of School Distress parents who endorsed each parent/family-related item as a likely reason underlying their child's school attendance difficulties, relative to the percentage of professionals who endorsed each of these items more generally. Significant between-group differences are shown: * $p < .05$, ** $p < .01$, *** $p < .001$.

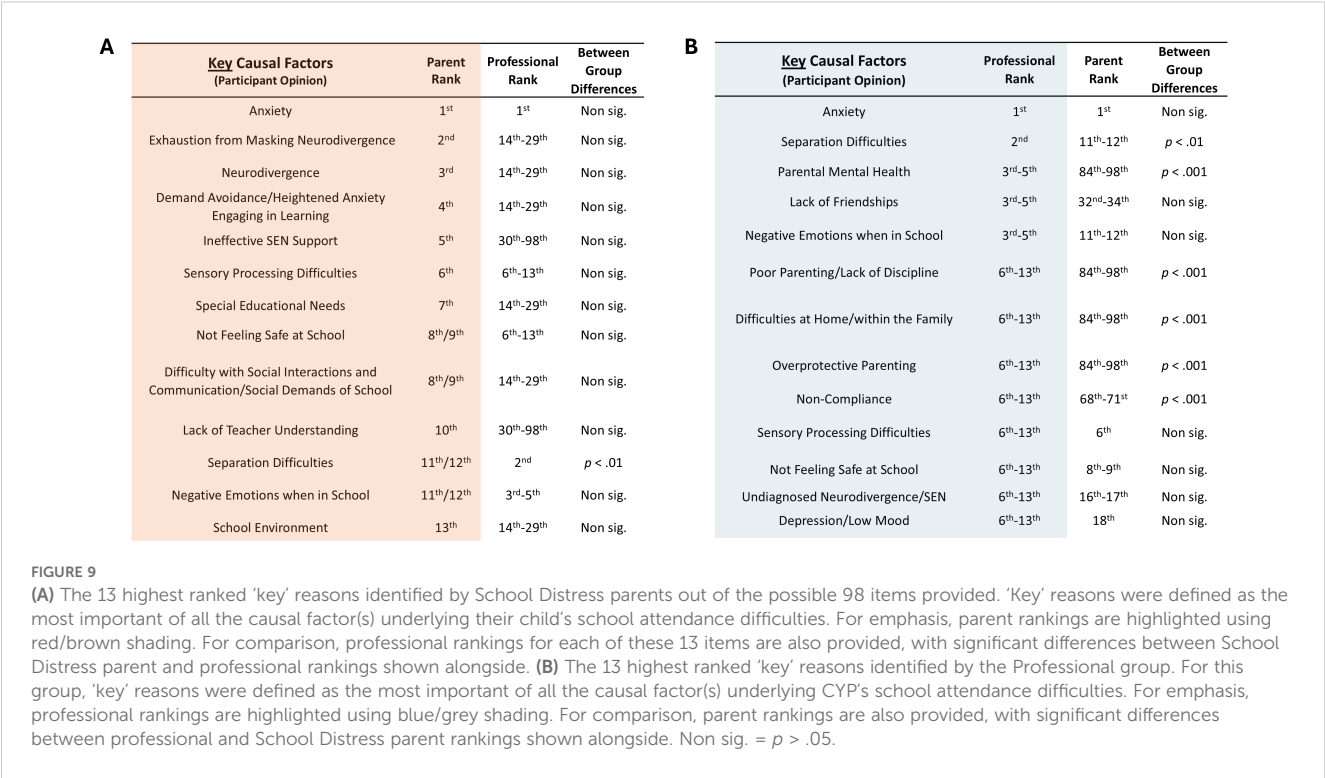


FIGURE 9

(A) The 13 highest ranked ‘key’ reasons identified by School Distress parents out of the possible 98 items provided. ‘Key’ reasons were defined as the most important of all the causal factor(s) underlying their child’s school attendance difficulties. For emphasis, parent rankings are highlighted using red/brown shading. For comparison, professional rankings for each of these 13 items are also provided, with significant differences between School Distress parent and professional rankings shown alongside. (B) The 13 highest ranked ‘key’ reasons identified by the Professional group. For this group, ‘key’ reasons were defined as the most important of all the causal factor(s) underlying CYP’s school attendance difficulties. For emphasis, professional rankings are highlighted using blue/grey shading. For comparison, parent rankings are also provided, with significant differences between professional and School Distress parent rankings shown alongside. Non sig. = $p > .05$.

and the impact of the experience on the parents themselves and their wider family. Valuable input was also provided by a separate group of professionals with experience of working with CYP with school attendance difficulties, enabling a comparison of parental lived-experiences and understanding of School Distress with the lived-experiences and understanding of professionals.

Findings revealed the significant deleterious impact that School Distress can have on multiple aspects of parents' lives, including on their mental and physical health, their careers, their financial situation, their other children, and their relationships with their partner, their family, and their friends. Only one parent (out of 947 parents with experience of School Distress) noted a positive impact on their life of School Distress, and that was being at home more now.

Analysis of responses in the Professional group did not find any areas where professionals were significantly and deleteriously impacted because of working with CYP experiencing school attendance difficulties.

TABLE 7 Professionals’ reflections on help and support available to them and the CYP and families they are supporting.

Lack of Support:					
“There is little to no support”	“Other than LA fines, no support from higher level. School leadership have to play good cop/bad cop”	“There is little or no support for schools in tackling attendance difficulties. Local authority intervention has been reduced even further this year ... Schools are operating alone”	“It is often a box ticking exercise. Real help isn’t easy to access”	“We simply need more of them- it is worrying when parents look to me for support and provision of services and they are placed on a waiting list”	
Barriers to Support:					
“external services need to have a swift referral process rather than it be lengthy as professionals have limited capacity to fill in forms to acquire the help necessary”	“All services need to work together and it cannot just be left to mental health services or schools by themselves to support CYP to get back in to school”	“on several occasions [external services] have not picked up families and it has taken the police to force them even though trained professionals have referred in with concerns which are ignored or sign posted to agencies that are not appropriate”	“Time to work with families and children”	“Early intervention could prevent poor attendance habits from becoming established early for the CYP”	“Knowing fully what’s available and what to do if everything has been tried”
Positive Experiences:					
“Meetings with parents/carers so we can both come up with a solution”			“Working alongside family and CAMHS”		

4.1 Impact on parental mental health

Strikingly, over half of parents in the Current SD group reported that they developed a new mental health condition since the onset of their child's School Distress and parents' narrative descriptions of impact focused heavily on this aspect. Harm to mental health was often described as being driven by a loss of confidence in their parenting abilities and a loss of confidence in themselves, including attenuated self-esteem and self-belief. In addition, parents described the loss of leisure time, friendships (both personal friendships and their child's friendships), sexual relationships, self-care time to support their own mental health needs, and their ability to carry out normal daily activities. Parents also noted a negative impact on their partner's mental health and career, and multiple parents referred to breakdowns in their relationship with their child who is experiencing School Distress. Moreover, parents often described a profound loss of trust in the system and in the professionals working within this system; a loss previously documented by parents of disabled children in discussions surrounding their interactions with children's social services e.g., "Parents have lost trust and so have I" (28 p. 32). Here we extend this finding to include the breakdown of trust that parents have for education, health, and social care systems.

In addition, and relative to parents whose children are not currently experiencing School Distress (i.e., parents in the No SD control group, the Lifelong EHE group, and the Past SD group), parents in the Current SD group reported significantly poorer current mood and significantly higher current anxiety levels. Analyses exploring changes in mood and anxiety ratings at different points in time (i.e., Current School Distress Group: Before and During School Distress; Past School Distress Group: Before, During and After School Distress) revealed that parents' mood declined significantly during their children's School Distress and anxiety levels increased significantly. Whilst it is important to note that some of these ratings were provided retrospectively, and that retrospective reporting may have led to inaccuracies (29), the strikingly similar pattern observed across the Past and Current SD groups is notable given the differing temporal perspectives of these two groups of parents. One possible factor of relevance here is the high rate of neurodivergence in the parents of CYP in both School Distress groups, as there are strong links between neurodivergence (ND) and mental health difficulties such as anxiety and depression (30–32). However, whilst parental ND may be relevant, it cannot explain the specific pattern of mood and anxiety results reported here, which deteriorated specifically during active periods of School Distress. Similarly, whilst there were comparable rates of neurodivergence in parents in the Current SD, Past SD and Lifelong EHE groups, it was only the parents in the Current SD group who demonstrated the striking elevation of *current* anxiety and the significant attenuation of *current* mood.

4.2 Poor parental mental health: cause or consequence of school distress?

Poor mental health in parents of CYP with school attendance difficulties has been reported elsewhere in the literature (e.g., 33),

however such observations have typically been used to infer that poor parental mental health plays a causal role in a CYP's School Distress. The temporal pattern of decline in parental wellbeing observed here challenges this inference, and instead suggests that poor parental mental health may not (at the group level) precede the experience of School Distress, but instead occur specifically during active periods of School Distress in their children. Hence, heightened anxiety and low mood may be a consequence of the parental experience of School Distress, as opposed to a precipitating factor of the child's School Distress in the first instance. Future research should further explore the directionality of this effect, ideally using longitudinal assessment of parental mental health across multiple time points. Such research should also consider parental neurotype, as the significantly elevated rate of neurodivergence amongst School Distress parents may help explain the higher rates of parental mental health difficulties (34) previously noted in the School Distress literature (33).

4.3 School distress as a threatening life event

To gain further traction over the parental lived experience of School Distress, we asked parents to rate this experience with respect to other life events containing considerable long-term contextual threat. The result of this comparison was striking, with parents currently supporting children with School Distress rating this life experience as the second most threatening life event, superseded only by experience of a 'Death of a 1st Degree Relative, including spouse or child', and more threatening than events such as 'Death of a close family friend', 'Serious Illness or Injury to Self', and 'Serious Illness or Injury to Close Relative'. Both School Distress Parent groups and the Professional group rated the experience of a child "school refusing" as significantly more threatening than parents in the two control groups who had no direct lived experience of School Distress (i.e., the No SD and Lifelong EHE groups). This mismatch is in keeping with the wider lack of societal understanding of School Distress.

Reinforcing this level of threat was the finding that parents supporting CYP with School Distress experience had significantly higher levels of all negative emotion states measured by the Discrete Emotions Questionnaire (24) (i.e., fear, sadness, anxiety, anger, and disgust) and significantly lower levels of positive emotion states (i.e., relaxation and happiness), relative to control parents and professionals. The fear and vulnerability experienced by parents supporting CYP with School Distress was also evident in our thematic analysis which is discussed further below, and in the finding that parents in both the Current and Past SD groups reported feeling threatened or vulnerable due to an interaction with a member of school staff significantly more frequently than control parents.

4.4 Not believed by school staff and professionals

The two School Distress parent groups were also significantly more likely to report not being believed by school staff, health professionals

and other professionals (including Local Authority staff and Children's Social Services) when raising concerns about their child's difficulties, and to experience professional gaslighting, relative to parents without experience of School Distress. This was supported by free text comments provided by parents, for example *"Dismissed and told they are fine in school"*, *"...they minimise my concerns"* and *"As my child masks in school I often get a look from the teachers and told he doesn't do that in school he's playing you up"*. These quotes echo the Hackney cohort of parents who overwhelmingly reported feeling judged, ignored, and blamed by school staff for their child's school attendance difficulties (8), as well as the parents whose voices were documented by Bodycote (13). Notably, such parents reported a dismissal of their concerns about the impact of the school environment on their children by school staff, with school staff instead tending to blame the child's difficulties within the school environment on deficient parenting abilities and/or problems at home.

Concerningly, over a quarter (28.6%) of participants in our Professional group also reported not being believed by school staff when raising concerns about a CYP's difficulties. Research is needed to better understand why some teachers appear reluctant to accept parent or professional opinions with respect to potential difficulties being experienced by their pupils. The pervasive view that School Distress stems from parental, family and/or child behavioural issues (14) is likely highly relevant here, and highlights the urgency of disseminating research into the complex drivers of School Distress [which often include child disability-related factors and unmet need (5)] amongst school staff, especially when one considers that access to supports/interventions for children and families experiencing School Distress is typically gatekept by professionals (35).

4.5 Causal factors

Further reinforcing the ubiquity of neurodivergence and related factors in the experience of School Distress was the finding that the top ten most frequently identified key causal factors of School Distress (identified by participants who have parented a child with School Distress) were "Anxiety" (1st), "Exhaustion from masking neurodivergence" (2nd), "Neurodivergence" (3rd), "Demand avoidance/heightened anxiety engaging in learning and/or adult-directed tasks" (4th), "Ineffective SEN support" (5th), "Sensory processing difficulties/Sensory sensitivity" (6th), "SEN" (7th), "Not feeling safe at school" (8th/9th), "Difficulty with social interactions and communication/social demands of school" (8th/9th), and "Lack of teacher understanding (e.g. about the child or their neurodivergent diagnosis)" (10th). Hence, for most CYP in the Current and Past SD groups, their persistent school attendance difficulties were not driven by neglectful, deficient, or failing parenting, further calling into question the pervasive belief that School Distress stems from parental issues (11, 12).

4.6 Parent blame

Notably, however, within this study, factors such as 'overprotective parenting', 'poor parenting/lack of discipline', and

'to gain attention from a parent/caregiver' emerged amongst the most frequently selected causal factors of School Distress by participants in the Professional group - factors which were amongst the least frequently selected by parents (see Figures 8, 9 and Supplementary Notes 4, 6).

Statistically, professionals were significantly more likely to select 'parent-related' factors such as 'parental mental health', 'overdependency within the family', 'overprotective parenting', 'difficulties at home/within the family', and 'poor parenting/lack of discipline' to be key drivers of a CYP's School Distress relative to School Distress parents (see Supplementary Note 6), with one participant in the Professional group stating:

"We are seeing more attendance difficulties with students in year 7, 8 and 9 students particularly. Parents/carers with their own anxieties tend project onto their children. I feel that even after every reasonable adjustment it is never enough for these parents" (SENCO).

Such findings corroborate previous research in which parents have described feeling unjustly blamed for their children's school attendance difficulties (8, 13, 16–18).

However, it is important to note that one participant in our professional group (a senior mental health lead for a service working with young people who are experiencing School Distress and are unable to attend school) actively advocated against professionals orientating towards parental blame explanations, stating: *"The parents are under enormous stress- we must avoid blaming parents"*.

4.7 Child blame and limited autism understanding

Professionals were also significantly more likely to highlight child behaviour factors such as 'non-compliance' than School Distress parents, therefore situating the problem within the child themselves (14). This again, is consistent with previous parental and child reports (17, 18). Parents, on the other hand, were significantly more likely than professionals to identify school-, teacher, and Neurodivergence/SEN-related drivers of their children's school attendance difficulties. The finding that disability related factors were more strongly endorsed by parents, relative to professionals, is consistent with previous studies conducted with parents and young people which have highlighted factors such as anxiety, the sensory environment of school, and fear of teacher behaviour as causing or contributing to School Distress (36–40).

Poor understanding of autism can also explain why 'separation difficulties' was selected significantly more frequently by professionals than by parents, as 'separation difficulties' in neurotypical children often occur as a consequence of atypical early life attachment, whereas in autistic children, they appear to relate to sensory hyperactivity (41, 42). As teachers and other professionals often have a good educational grounding in attachment theory in neurotypical children, but not of

autism (43, 44), they are thus primed by their training to misattribute autistic children's distress at being separated from their safe adult at the school gate to attachment difficulties with their care-giver, and hence more likely to generate parental blame explanations of such presentations. Indeed, the majority of participants in our Professional group indicated that they personally would like more training to support autistic CYP.

4.8 Problematic communication with school staff

The tone of conversations between parents of children with School Distress and school staff also warrants further research investigation and likely the provision of additional training for school staff as this was described with strikingly different terms (e.g., 'dismissive', 'critical', 'unsupportive', 'uninformed', 'patronising', 'deceitful', 'condescending' ...etc.) by parents of CYP with School Distress, relative to control parents (who described these conversations as 'friendly', 'calm', 'caring' and 'helpful'). The fact that it is overwhelmingly parents of disabled children who are reporting these negative tones from their children's school staff is of extra concern, and aligns with previous research that reported that when seeking an initial educational placement for their child, parents of autistic children often feel intimidated by school staff and not believed regarding their child's difficulties (45).

4.9 Parental neurodivergence

Of potential relevance too is the finding that participants in our School Distress parent group (and Lifelong EHE group) were significantly more likely to be neurodivergent than control parents. For neurotypical teachers, interactions with autistic parents are likely experienced as unusual (46) and rapidly perceived as less favourable than interactions with neurotypical parents (47). These cross-neurotype differences in communication styles may appear to professionals working parents of children experiencing School Distress as markers of "family dysfunction" (48) when perceived through a neurotypical lens, hence leading to more negative responses from professionals. Research exploring relationships between parent-teacher pairs that share the same neurotype versus those that have different neurotypes would likely be helpful here.

Potentially relevant too are the findings of a comparative study of autistic and non-autistic women's experiences of motherhood (34). This study found that autistic mothers were also more likely to report feeling misunderstood by professionals and reported experiencing higher levels of anxiety and selective mutism when interacting with professionals. They also had concerns with respect to not knowing which details were appropriate to share with professionals. Increased recognition and understanding of parental neurodivergence, including the strong bonds and intense connection and love that autistic mother's report sharing with their

children (49), may also help prevent unnecessary safe-guarding referrals of School Distress families to children's social services.

4.10 Power imbalance

The fear and vulnerability of parents supporting CYP with School Distress mentioned above was also evident in our thematic analysis within the core theme of 'Dread, Fear and Vulnerability'. Parental awareness of the power that professionals have to initiate punitive actions against parents of children with poor school attendance (which can range from fines to imprisonment) often drove this dread, fear and vulnerability, as too did the threat of having one's parenting capacity questioned by others, including children's social services. Similar findings have been reported in research regarding children's social services, for example "*there was a tendency to use the social work assessment as an opportunity to judge parenting capacity through a child protection lens rather than through a lens of social care need. This has long been a complaint of families caring for disabled children*" (50 p. 13) (see also 28).

4.11 Abuse of power

The related theme of 'Hostile Action(s)' and subtheme 'Malicious/Bullying Behaviour' extended the above, with some parents describing the use of what they perceived to be retaliatory practice by school staff, such as being reported to children's social services when they have challenged school practices. Again, such behaviour has been reported elsewhere for example "*a growing number [of parents] are finding that they are being investigated for fabricated and induced illness as a result of challenging the practice*" (28 p. 33), requesting support for their disabled child, or raising a complaint about a lack of support (51).

Within this second theme of 'Hostile Action(s)' was the subtheme 'Disempowerment'. This encompassed scenarios where parents described a loss of parental autonomy because of the actions taken against them by professionals to enforce school attendance. This may help explain the high levels of new mental health conditions (1 in every 2 parents supporting a child with School Distress) reported by parents in the Current School Distress group, as disempowerment is an essential feature of psychological trauma (52–54).

4.12 Off-rolling/'coercive' home-education

Moreover, although there were no quotes linking the decision to de-register a child from school into Home Education directly with the sub-theme of parental disempowerment, many quotes indicated that there was a connection between the themes of 'Hostile action(s)' and 'Dread, Fear and Vulnerability' and parents deciding to remove their children from their school roll to home educate them. Future research is urgently required to establish whether the threat of punitive action(s), disempowerment and/or malicious/bullying behaviour is knowingly

being used by educational professionals to ‘off-roll’ CYP perceived as ‘problematic’ from the school, and if so, to establish how widespread this practice is. Off-rolling (i.e., excluding children from school for non-disciplinary reasons) is unlawful in the UK, although respective UK governments are aware that this unlawful practice does occur (55–57). Such links may explain why, alongside compelling evidence of increasing School Distress amongst UK school children, there is a simultaneous increasing rate of home-education in the UK (58, 59). Recent data collected by the home education charity Education Otherwise is revealing in this regard – with over half (54%) of parents who had begun home education in 2023 reporting ‘schools not meeting their child’s needs’ as their primary reason for deciding to home educate their child (60), an increase from just under one-third of parents (32%) who cited this as their primary reason previously (61). Our previous finding that School Distress is predominately driven by neurodivergence and unmet needs in school settings (5), alongside the almost doubling of home educating families in some areas since the Covid-19 pandemic (59), combine to create a very concerning picture.

4.13 Privilege

However, not all families have the option to home educate their child when their child’s needs are not being met at school due to the significant cost that this incurs, for example due to the required re-adjustment of family life and parental careers – something which would be prohibitive for many families. In such circumstances, parents may experience an even greater sense of disempowerment due to limited options to alleviate their and their child’s distress, and hence may be at even greater risk of experiencing mental and/or physical health difficulties than parents who are in the more privileged position of being able to “choose” to home educate.

Furthermore, whilst it was reassuring to find that a small number of parents reported being protected against punitive actions by others (such as Head Teachers and GPs) within our third theme of ‘Protection’, it is notable that when protective actions were reported they were more commonly described within the context of the parent having to protect themselves, perhaps via societal privilege (e.g., a respected professional occupation). This, again, indicates that it is likely the most vulnerable parents who are most at risk of the most deleterious impacts of supporting a child through the experience of School Distress.

4.14 Invalidation and wider isolation

Returning to the findings that parents of CYP who have experienced School Distress reported feeling dismissed, not believed and gaslighted by school staff significantly more frequently than parents of CYP without School Distress, it is important to consider the consequences of these specific experiences on parental mental health. As the cohort reported here consisted primarily of mothers (97%), the wider literature on the impact of professional gaslighting on women is particularly relevant. A recent systematic review evaluating the experiences of

medical gaslighting in women, which in this paper was defined as “*the dismissive, invalidating, and biased experiences of people within the healthcare system*”, found that such experiences lead to feelings of frustration, distress, isolation, extreme anxiety, and trauma, often resulting in patients turning away from their doctors and seeking support from online communities instead (62). Similar consequences of sustained gaslighting of women in other contexts have been reported elsewhere (e.g., 63). Our findings echo these consequences, with online support groups being the most consistent source of support identified by School Distress parents.

However, our parents did not just report being dismissed and invalidated by school staff, they also reported not being believed by family, friends, local authorities, social workers, psychologists, partners, ex-partners, other parents, work colleagues, and even by their own parents. Interestingly, when contrasting the actual reasons underpinning their children’s school attendance difficulties with both professional and lay opinions as to why children experience school attendance difficulties, we found striking differences between ‘actual’ and ‘assumed’ underlying drivers, with control parents (alongside professionals) tending to assume parental/family issues to be causal factors (for complete data see [Supplementary Note 6](#)). Moreover, control parents whose children attend school without distress tended to over-estimate the role played by factors such as bullying (which was actually endorsed by less than one-quarter of parents with School Distress experience), whilst simultaneously underestimating the role of factors such as the school environment itself, sensory processing difficulties, exhaustion from neurodivergent masking, a lack of teacher understanding of neurodivergent pupils, an increasingly standardised educational curriculum, and schools not accommodating individual needs. Interestingly, these latter factors were widely appreciated within the Lifelong EHE Parent group, who, like the SD Parent groups, also had a preponderance of neurodivergent neurotypes (for further discussion see [Supplementary Note 6](#)). Hence, people who have not experienced parenting neurodivergent children may be less able to appreciate the more foundational difficulties neurodivergent CYP experience at school. This likely makes it hard for them to fully appreciate the experiences of parents whose neurodivergent children are experiencing School Distress. In the words of one School Distress parent, they were not believed about their child’s difficulties by “*just about everyone*” in their life. Alongside disempowerment, the other essential feature of psychological trauma is isolation (52–54).

4.15 Strengths, limitations, and future research

One limitation of the present study is that most participants were mothers, meaning that our findings regarding the parental experience of School Distress may not be representative of the experience of fathers. Future research should therefore explore the experiences of fathers, as any differences may have implications for the support offered to parents of children experiencing School Distress (64). However, it may also be telling that most

respondents were mothers, as some mothers commented on how differently their child's father was treated by professionals, and others called for further research on the topic to explore whether the treatment that mothers experience in this context may be underpinned by systemic misogyny. This study was not however designed to explore these issues.

In addition, this study was limited to the United Kingdom, further reducing generalisability of findings. Given that education systems vary internationally, the experiences of parents may differ between countries, providing an additional avenue for future research.

Finally, it is important to acknowledge the relatively small number of professionals ($n=19$) relative to parents with experience of School Distress within our study's sample. Moreover, it is notable that the individuals in our Professional group were recruited prior to attending a local conference on school anxiety, therefore indicating that they will already have had an interest in the topic which may have impacted upon their beliefs. Further research involving a larger number of professionals will likely be beneficial. In addition, it is also worth noting that two of the professional participants were also parents of children who have experienced School Distress. Hence, a minority of the participants in the Professional group will likely have shared similar lived experiences with the parents in the Past SD group.

Despite these limitations, this study also had several strengths, including the large number of participants included in both School Distress groups. This was much greater than in previous School Distress research, enabling stronger conclusions to be made. Furthermore, the inclusion of the control parent and professional groups within this study enabled us to make several important comparisons.

5 Conclusions

To our knowledge, this is the first study of this scale to explore the familial experience of School Distress. Findings revealed that supporting a child experiencing School Distress is an overwhelmingly negative experience for parents. Deleterious impacts were evident across all aspects of parents' lives, including on their mental and physical health, their careers, their financial situation, and their wider family, including their other children. Parental blame was also found to be rife, with hostile and punitive treatment by professionals surrounding the family compounding this experience and leading to parental disempowerment. A profound loss of trust in school staff and in systems more broadly were common. The responses in this study also revealed that those experiencing School Distress from the perspective of a parent perceive this experience as being one of the most threatening possible life events, superseding even a serious illness or injury to themselves. One in every two parents currently supporting a child with School Distress reported developing a new mental health difficulty since the onset of their child's difficulties.

Despite recognising the threatening nature of this experience for parents, professionals were significantly more likely to select parent/family-related factors as drivers of children's school attendance difficulties and rated many Neurodivergence/SEN-related factors as less relevant than School Distress parents, confirming parental reports of feeling blamed and shamed for their child's difficulties. This likely relates to the dominant narrative in the older School Refusal literature that typically overlooked child neurodivergence as a key causal factor of school attendance difficulties, alongside an under-appreciation of the high rates of neurodivergence amongst the parents of CYP with School Distress. Urgent recognition of the most common antecedent of School Distress (i.e., unmet neurodivergent need at school (5)), alongside recognition of the daily stressors and serious threats facing the parents of CYP experiencing School Distress, is required by educational, health and social care professionals so that supportive and non-threatening relationships can be fostered with parents.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

SLM: Conceptualization, Data curation, Formal analysis, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing. SEC: Formal analysis, Methodology, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpsy.2025.1489316/full#supplementary-material>

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