



# Understanding the impact of children's and young people's self-harm on parental well-being: a systematic literature review of qualitative and quantitative findings

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**Background:** Self-harm in children and young people is increasing. Parents are vital in supporting young people; however, parents may experience distress linked to the self-harm. Previous reviews have highlighted the emotional impact and need for information and support, however, have not elucidated the relationships between these themes, nor examined the quantitative data examining parents' well-being. **Methods:** We conducted a mixed methods review, with qualitative meta-synthesis focusing on links between themes and quantitative synthesis of parental well-being findings, including pooled means. PsycInfo, Medline, EMBASE, AMED, CINHAL and Web of Science were searched to identify relevant records. References of included studies were also searched. Every abstract was screened by two authors. Data were extracted by one author and checked by another. **Results:** We identified 39 reports of 32 studies: 16 with qualitative data and 17 with quantitative data (one had both). Qualitative findings showed how parents' emotions were associated to their knowledge and beliefs about self-harm. Parents' emotions often evidenced the need to self-care, but emotions of guilt reduced engagement in self-care. How parents supported their young person was linked to their knowledge, and the management of their own emotions, and influenced if they could engage in self-care. Quantitative findings were mixed, however suggested poor general mental health amongst these parents. **Conclusions:** Further good quality quantitative studies are needed, with measurement of psychological mechanisms that may underpin parental distress. Current evidence supports peer-support and interventions that go beyond information provision to address the connected factors of knowledge, emotion, self-care, and parenting behaviours.

## Key Practitioner Message

- Parents (meaning any adult in the parent/ main carer role) are known to describe significant distress in relation to their child or young person's self-harm
- This review adds an understanding of the links between parents' emotions, parents' knowledge and interpretations of self-harm; parents' own self-care; and parenting behaviours in response to the self-harm
- This review is the first to synthesise quantitative evidence of parents' psychological well-being in relation to child or young person's self-harm, showing some evidence for poor mental health in parents
- Clinicians should be aware of the potential distress experienced by parents and their need for information and support to care for themselves in the face of high levels of self-blame, shame and guilt

**Keywords:** Systematic review; parents; self-harm; self injury; children; young people

## Introduction

Self-harm amongst children and young people (CYP) is increasing globally (Griffin et al., 2018). In the UK 15% of 13–14 year olds and 24% of 16–17 year olds report having self-harmed in the last 12 months (Patalay &

Fitzsimons, 2020). Self-harm refers to intentional injury to oneself without the intention of causing death (Mughal et al., 2022). It is linked to high levels of distress for the CYP and represents increased risk of suicidal behaviour and death by suicide (Grandclerc, De Labrouhe, Spodenkiewicz, Lachal, & Moro, 2016). Although

not all CYP disclose self-harm to their parents (Geulayov et al., 2022), parents are often aware and may act as a major support to their CYP being a key factor in a CYP accessing mental health services (Ferrey et al., 2016a, 2016b).

Support from family is important in helping CYP reduce self-harm (Carter et al., 2016). However, parents may be stressed, distressed, and uncertain how to support their CYP (Baetens et al., 2014; Ferrey et al., 2016a, 2016b; Whitlock et al., 2018). Parents may take the role of the primary adult supporting their CYP, owing to obstacles including lack of access to appropriate support mental health services, or not being able or willing to seek input. This role is significant and can create stress (Ferrey et al., 2016a, 2016b). Supporting parents can be key to ensure they are best placed to support their CYP (Townsend, Miller, Matthews, & Grenyer, 2021). Moreover, the parent themselves may have their own needs arising from the distress of their CYPs self-harm (Ferrey et al., 2016a, 2016b).

Previous reviews have explored issues around the experiences of and support for parents of CYP who self-harm. Most recently, Mughal et al. (2022) systematically reviewed the qualitative literature covering experiences and needs of people supporting CYP who self-harm and reported experiences of distress, guilt and self-blame, with a need for peer-support and other intervention. Their review provided a systematic approach and updated the field following previous studies by Simes, Shochet, Murray, and Sands (2022), Curtis et al. (2018), and Arbuthnott and Lewis (2015). The description of needs and experiences is now well established.

There are two areas for research to develop. First, an in-depth exploration of experiences specifically of parents is needed to advance the field, including detailed consideration of how elements of parent experiences interlink. Simes et al. (2022) suggested in their review a vicious circle may occur: parents needs to manage their emotions (shame, failure, guilt and isolation) lead to isolation, uncertainty and loss of confidence in parenting, increasing overwhelming emotions. Further work is needed to offer greater evidence and specificity around these associated factors. Meta-synthesis focusing on associations between themes can then directly inform intervention design to support parents (Egan, Wade, Fitzallen, O'Brien, & Shafran, 2022).

Second, there is a need to consider the quantitative evidence that attempts to understand the impact on parents, may address the number of parents reaching cut-off points for high levels of distress, or potentially could quantitatively explore links between different concepts. To date, no quantitative synthesis of the evidence has been conducted.

This review aimed to

- 1 synthesise qualitative data to elucidate the relationships between different elements of distress, responses to that distress, and how that leads to outcomes for parents in terms of their own well-being,
- 2 provide the first synthesis of quantitative data relating to address the question of what evidence if there of the levels of parents' well-being and satisfaction, where they are parenting a CYP who self-harms.

## Methods

The protocol was registered on PROSPERO [CRD420221126]. Deviations were made from the protocol:

- 1 A review of interventions and their effectiveness was separated into another paper, focusing here only on literature relating to the impact on parents.
- 2 Web of Science was added as recommended by expert librarian.
- 3 CYP age range was restricted to up to 25 years, in line with the other work (Patel, Flisher, Hetrick, & McGorry, 2007) and policy relating to CYP's mental health services (Chitsabesan & Dubicka, 2021).
- 4 The registered protocol specified outcomes relating to parents' well-being. We operationalised this to include a broad range of psychological well-being outcomes, including symptoms of anxiety, depression, stress, grief, burden/strain, as well parenting satisfaction and family functioning, as linked to parents' well-being. Health utility was also considered, as an overall measure of health status.
- 5 Quality appraisal and risk of bias (ROB) assessment tools added to strengthen our methods.

This review was reported in line with systematic reviewing reporting guidelines (PRISMA 2020) (Page et al., 2021), guidelines for the reporting synthesis of qualitative data (Tong, Fleming, McInnes, Oliver, & Craig, 2012), and guidelines for synthesis without meta-analysis were used (Campbell et al., 2020).

### Eligibility criteria

Eligible studies must include participants who are parents (any adult in a parenting role, including biological parent, step-, adoptive-, or foster-parent) with exposure to parenting a CYP (no lower age limit, up to age 25) who had self-harmed (current or historical) on the parents. Self-harm is intentional, non-lethal injury (De Leo et al., 2021), without the intention to die (Mughal et al., 2022), and can include cutting, burning, hitting, and poisoning. Restricted eating or substance misuse were excluded. Any design, approach or analysis method was eligible. There must be primary data from parents relating to the phenomenon of interest – i.e. experiences, reactions, needs or other impacts their well-being. For quantitative studies, any design was included. Parents' scores on relevant outcomes must be reported, in isolation (e.g. baseline scores prior to intervention, cross-sectional findings), or in comparison to established norms or control group (e.g. parents of CYP with no mental health difficulties). Relevant outcomes should relate to the aspects of parental well-being (below).

### Search: Sources and strategy

PsycInfo, Medline, EMBASE, AMED, CINHALL and Web of Science (Core Collection) were searched, with no limiters applied. The search covered all available records on 26th March 2023. We considered PICOS and SPIDER (Cooke, Smith, & Booth, 2012). Three blocks of search terms were designed to identify studies focusing on (1) parents and carers, (2) children and young people and (3) self-harm. As this search was used to identify qualitative and quantitative papers, in addition to also being used to identify intervention studies, no further terms relating to design, comparator, evaluation, outcomes, research type nor setting were included. Full search strategies are provided in Appendix S1. References for included papers were also inspected.

### Inclusion/exclusion criteria and the selection strategy

At least two authors reviewed every abstract for inclusion, with disputes resolved by a third reviewer. Full-texts were

reviewed by at least two (FM, TO and SvE). Records were managed in EndNote and Excel. No automation tools were used.

Studies must focus on the parents' experiences, impacts, needs or outcomes relating to CYP (under 25 years) self-harm. Self-harm could include a broad range of behaviours, including cutting, burning, hitting etc. However, studies focusing on parents of CYP with suicidal intent were excluded, as we focused on non-lethal self-harm. For quantitative studies, included measures must cover parental stress, anxiety, depression, psychological well-being including grief, parenting burden or strain, parenting satisfaction, health utility, or family functioning. Only validated measures were included.

Parents of CYP with intellectual disabilities or specific developmental conditions e.g. autism spectrum disorders were excluded, as were CYP with eating disorders. This is owing to the different treatment pathways and challenges.

### Data collection items and process

Data extraction for the qualitative meta-synthesis was conducted by FM: reading all studies in full; extracting information about study design, sample etc into a Word table; and extracting information from findings/results section, which was managed in NVivo (release 1.7).

Quantitative data were extracted in Excel by SvE or FM, checked by FM or TO. Study details, (setting, design, participants, measures used), and key findings were extracted. All relevant outcomes data were extracted. Where the study was an intervention, baseline scores of relevant variables were extracted.

### Quality appraisal and the risk of bias analysis

For qualitative studies, the CASP qualitative checklist was completed by FM and checked by TO, to appraise their methodological quality (Critical Appraisal Skills Programme, 2018). For quantitative studies, ROB was assessed (FM), based on Cochrane criteria for non-randomised studies (Sterne, Higgins, & Reeves, 2014). This was selected to provide ROB dimensions that covered all included study designs, although this review does not concern intervention outcomes. ROB was conducted at study level, managed in Excel. A summary rating was assigned based on domains of bias: confounding, selection, exposure (to CYP self-harm), outcome measurement, missing data and reporting. No study was excluded from the review based on quality.

### Effect measures

The quantitative analysis is a synthesis of scores on each measure. Descriptive data (means, % of sample) were extracted. Where possible, these were related to norms/cut-offs. 95% confidence interval (CI) of means were calculated. Comparisons with 'control' samples (parents not exposed to CYP self-harm), were reported with original findings (e.g., mean difference) and effect size for differences between means (Cohen's *d*) calculated where necessary.

### Synthesis methods: qualitative

First, a logic map of the problem was created, known as a PRECEDE model (Bartholomew, Parcel, Kok, & Gottlieb, 2006). This lists the reported personal determinants, behavioural factors, and environmental factors that were described in the literature, together with the reported health outcomes. For meta-synthesis, to focus on connections between data that are often missed (Sandelowski, Docherty, & Emden, 1997), we first developed core themes and then coded data for links between themes, with these third level findings addressing how experiences for parents arise and are maintained (Nye, Melendez-Torres, & Bonell, 2016). FM and TO led the meta-synthesis. Core themes were established following reading and re-reading. Next, coding focused on associations or links between those core themes (Sandelowski & Barroso, 2006). This was informed

by concept mapping, to develop reciprocal translation (Melendez-Torres, Grant, & Bonell, 2015). To remain rooted in interpretations of participants data, analysis returned frequently to participants' quotes. All authors commented on a draft synthesis, leading to refinements.

### Synthesis methods: quantitative

Narrative synthesis was conducted based on each extracted variable. The data were grouped into measured variable for synthesis: general mental health, depression, parenting strain/burden/stress, family functioning, and parenting satisfaction. Where multiple studies reported the same measure, pooled means and pooled standard deviations were calculated to summarise, appropriate as we are seeking to establish the level of e.g., parenting satisfaction in the target group of parents, rather than analyse the impact of an intervention.

## Results

A total of 39 reports, representing 32 studies, were included in the analysis. A total of 16 reported qualitative data. Totally there were 17 reported quantitative data (one had both). Flow of records through the review is shown in Figure 1.

### Qualitative studies

Across 23 reports, 16 qualitative studies were included, detailed in Table S1. Half included data from Europe (8: 4 from UK and one each from Ireland, Portugal, Malta, and Finland); 4 with data from Australia, 3 – China, and 2 – USA (one covered the USA and Australia). No studies were included from Africa, South- or Central America. Studies mostly recruited via children's mental health services, with some media recruitment and community groups. Where design was specified, the majority were phenomenological (De Miranda Trinco, Santos, & Barbosa, 2017; Galea & Galea, 2018; McDonald, O'Brien, & Jackson, 2007; Raphael, Clarke, & Kumar, 2006; Rose, Cohen, & Kinney, 2011; Russell, 2018; Wang, Huang, Huang, & Zhao, 2022), with one study each described as descriptive (Rissanen, Kylmä, & Laukkanen, 2008, 2009, one study with two reports), sequential mixed methods (Townsend, Matthews, Miller, & Grenyer, 2022; Townsend et al., 2021, one study with two reports) and collective case study (Tuls, 2011). A range of analysis methods were used: thematic analysis, various phenomenological analysis approaches, grounded theory and content analysis.

Methodological quality was high. Details are provided in Table S2. With the exception of the abstract only report (Galea & Galea, 2018), all of the studies had a clear statement of research aims and used appropriate methodology and design. Recruitment strategy was appropriate to reach the target population. Quality issues observed related to lack of full description of data collection setting, or detailed consideration of ethical issues, or limitations in reporting of analysis methods. The relationship between researcher and participants was frequently not considered in detail, which is a limitation owing to the highly stigmatised nature of the topic of study. No studies were excluded or given less/greater weight based on quality.

The PRECEDE logic model of factors linked to the parents' outcomes is shown in Figure 2.

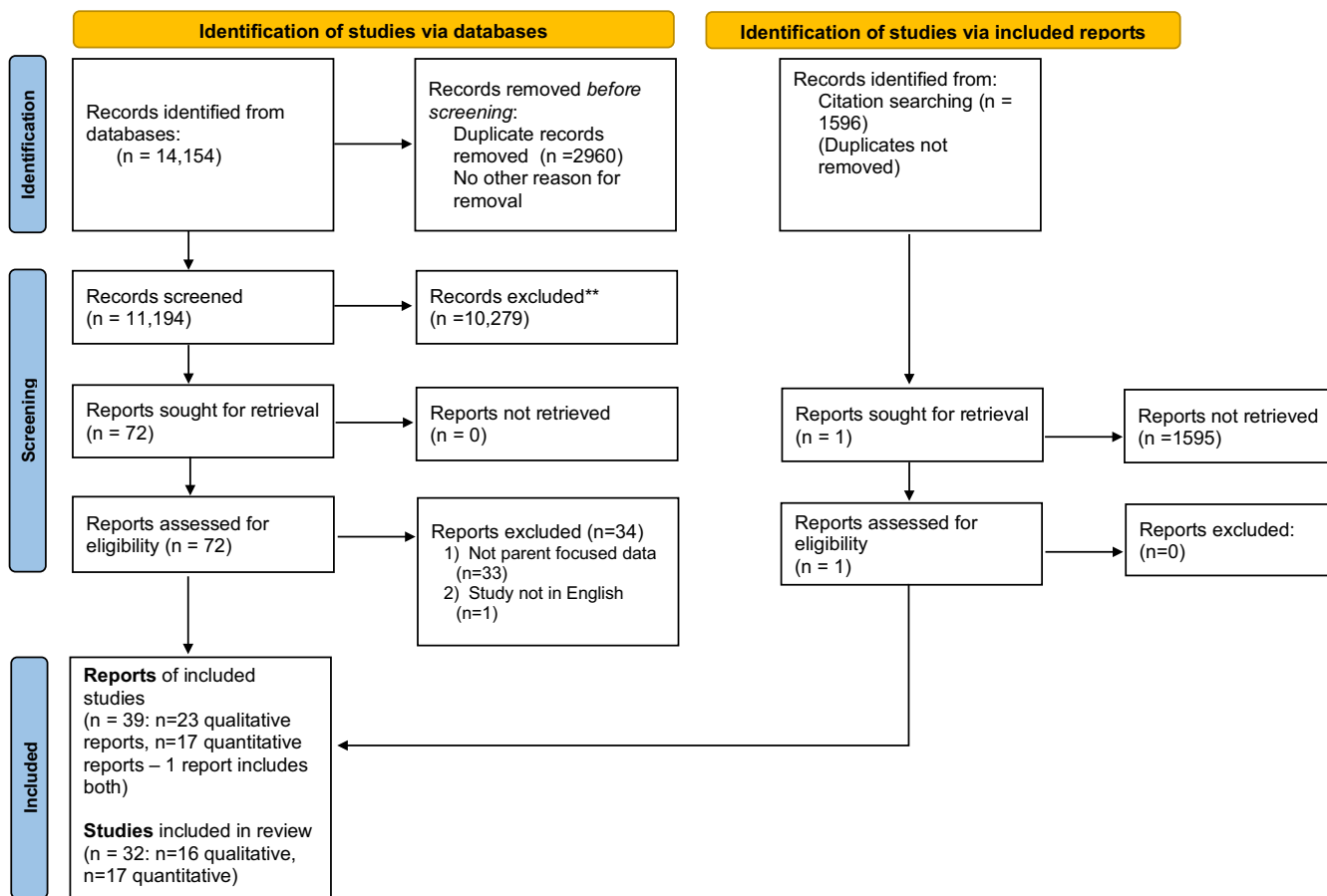


Figure 1. PRISMA flowchart.

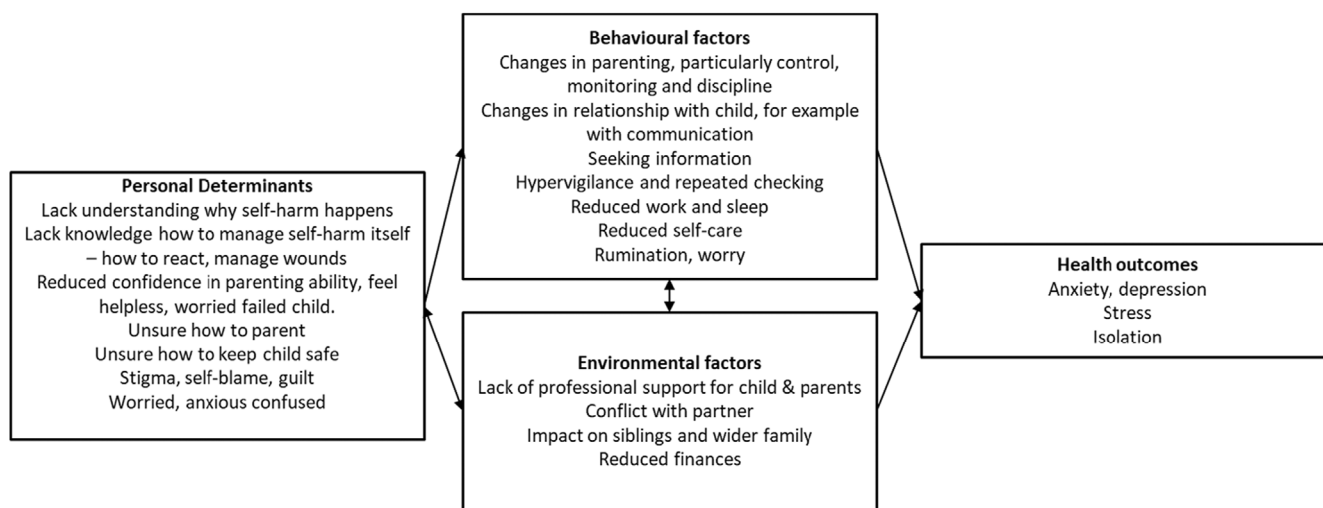


Figure 2. Logic model of factors associated with parents' health outcomes.

**Core themes.** We identified four core themes, which are briefly outlined, prior to the discussion of links between them.

**Parents' emotions.** As identified in previous reviews, parents' experience intense emotional reactions to their CYP's self-harm. Box 1 provides a list of the emotion words commonly seen.

Emotions were commonly strongly felt: '...cried hysterically for an hour' and 'inside my heart broke'

(Townsend et al., 2021). Feeling extreme guilt was common and specifically described by one participant 'I feel so guilty, what have I done, how have I let her down' (McDonald et al., 2007).

**Knowledge beliefs and interpretation of self-harm.** For many parents, knowledge about self-harm was lacking, with a desire for more: 'I can't do anything about changing her mind, but I wish I could be her to understand her better' (Ye, Hu, Xue, Liang, & Lu, 2021, p. 3). For some



**Box 1.** Descriptions of parents' emotions seen in qualitative papers

Guilt, concern, shame/embarrassment, stigma, fear, frightened, loss trust, surprise, shock, hurt, numb, denial, self-blame, fear something awful will happen, sense failed their child, confusion, panic, apathy, hopelessness, helplessness, felt not listened to, frustrated, rejection, horrified, worried, impatient, annoyed, angry, depressed, anxious, sleepless, hypervigilant, ruminating, overwhelmed, isolated, afraid, ashamed, uncomfortable.

parents, self-harm was something they could do nothing about (Raphael et al., 2006). In a study in China, it was seen as shameful, that only 'idiots' would do (Fu et al., 2020).

*Parenting behaviours.* Parents described a shift in their parenting behaviours (Ferrey et al., 2016a, 2016b; Kelada, Whitlock, Hasking, & Melvin, 2016). This was often towards 'walking on eggshells' or lots of checking: 'I was knocking on her door every 5 minutes, "You alright Gabi" (Mrs M)' (Oldershaw, Richards, Simic, & Schmidt, 2008, p. 142).

*Parents' self-care and life role.* The importance of self-care was highlighted by some parents, typically operationalised as small moments of time for themselves: 'go sit with a cup of tea out the front of the house, out the door, on your own for five minutes, ...and breathe' (Krysinska et al., 2020, p. 8). Self-care was frequently diminished, owing to stress and practical demands of supporting their CYP. Life roles shifted for many. In one study, mothers often reduced work and other roles at home (McDonald et al., 2007).

*Linking themes.* Figure 3 illustrates the core themes and their links, as outlined below in the following sections.

*Interplay between parents' emotions and the knowledge/interpretation of self-harm.* Understandable anxiety about how to keep their CYP safe at home drove parents to seek information (Tuls, 2011), highlighting the significant ask made of parents to look after their CYP with minimal support. For some, information was seen as risky: 'I think I would have really scared myself at that point if I'd looked too deeply into the information on self-harming' (Hughes et al., 2017).

Data clearly showed the link between parents' emotions, and their knowledge/understandings. Whilst essential, knowledge alone did not reduce parents' emotions: self-harm in one's child is self-evidently distressing. Overwhelmingly the studies provided evidence of parents' lack of knowledge about self-harm; however one participant, importantly noted 'I've worked with children who self-harm, but when it's on your own doorstep it's a whole different kettle of fish and it's how you deal with it, and how it affects you and how you're going to handle it' (Oldershaw et al., 2008, p. 141). Intense emotions were deepened by a lack of knowledge, creating uncertainty

and helplessness. One parent talked about being 'at a loss as to why she's done it', with study authors noting rumination as an attempt to understand, often with an underlying assumption that the parent is in part responsible (Hughes et al., 2017). This uncertainty then has a path directly to guilt.

The intense emotions, linked to uncertainty and helplessness (De Miranda Trinco, Santos, & Barbosa, 2017; Raphael et al., 2006; Rose et al., 2011), led parents to seek further knowledge. Information may provide a sense of power over the situation, but can inadvertently increase guilt and blame. Parents talked about how they 'should have seen all the signs' and would 'have stopped it' (Rose et al., 2011), revealing a strong sense of blame twinned with a perception they could control the situation. One mother, Jayne, described blaming herself as she conceptualised family relationship changes as her fault and the cause of her daughter's distress and self-harm, leading to 'this huge, really strong sense of blame' (McDonald et al., 2007). One mother examined every interaction: 'From the very beginning, when I was pregnant with her, what did I do wrong? Did I eat the wrong things? Did I get too stress? When [she] was young, did I feed her properly? Did I interact with her? When she was older, did I praise her enough? Did I criticise her too much?' (Hughes et al., 2017). Seeking an explanation was common, to make sense of what has happened. This comes in tandem with responsibility, and perceived control.

Guilt and shame were ubiquitous. Seeking to understand self-harm was intertwined with anger and self-blame for one mother 'You just think, what did I do wrong? Why? What didn't I do for you? You know? Like why wasn't I enough' (Parent 4) (Krysinska et al., 2020). A UK mother, Susanne, described embarrassment: 'I'm embarrassed by it, you know, because you think you've failed because if they were normal, well-balanced children they wouldn't be doing these things' (Ferrey et al., 2016a, 2016b). An interpretation of failure was also seen: 'There was no reason for her not to be able to come to me; therefore I failed miserably really' (Raphael et al., 2006).

*Parenting behaviours driven by knowledge and emotions.* A profound shift was seen in parenting behaviours as parents sought to support their CYP and manage their own emotions (Ferrey et al., 2016a, 2016b; Krysinska et al., 2020). The natural fear of harm to their child was intense, leading to checking, controlling parenting, and rumination: 'It's always the fear, is she going to go in her room? Is she going to do it? Have I upset her that much that she's going to keep doing it sort of thing' (Krysinska et al., 2020). Parents' behavioural responses were linked to their interpretation of self-harm as controllable. This helped manage the parents' emotions: 'Because it's something I can manage then and I don't have to be as afraid, if I'm in control' (Krysinska et al., 2020). A way to manage powerlessness was to exert control (Ferrey et al., 2016a, 2016b).

The interpretation of self-harm is key to parenting behaviour. A study in China found that some parents felt that ignoring to it would be useful: 'I am afraid that if I pay too much attention to her self-injury, she will think she is more abnormal' (Fu et al., 2020, p. 15). Others interpreted self-harm as a manipulation: 'C, wondered if

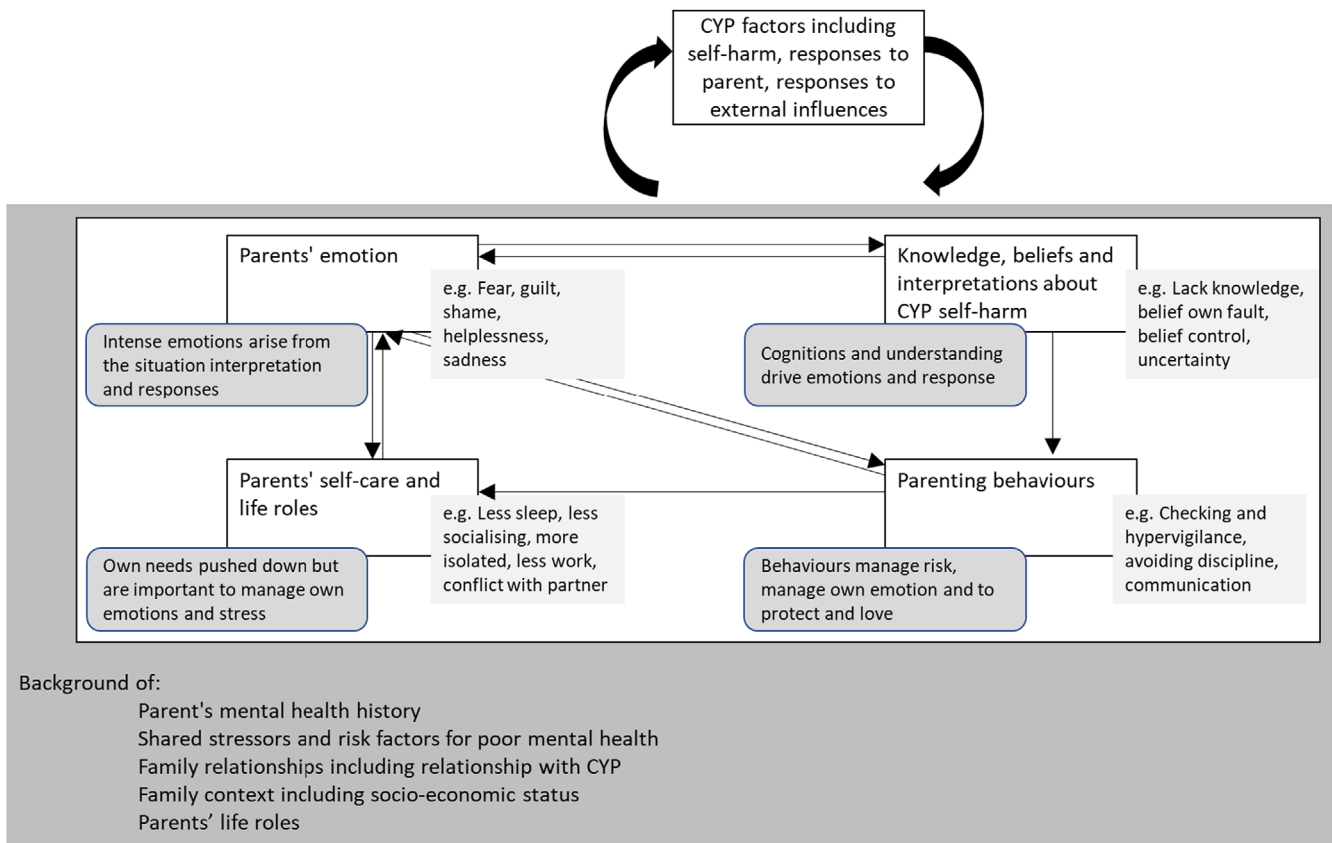


Figure 3. Basic schematic of links between core themes.

her son might be using the threat of self-harm to get his own way' (Hughes et al., 2017). For others, an understanding that this is 'something he does when he's upset' led that parent to 'just make a point of reminding him to keep the knife clean' (Hughes et al., 2017).

Parenting behaviour was also linked to emotions, for example as parents were 'nervous of triggering an episode of self-harm' (Oldershaw et al., 2008). 'Living in fear something awful will happen, the child will seriously hurt themselves, also linked to hypervigilance and worry, with checking the child and means for harm' (Russell, 2018). There is a maintaining cycle of feeling worried, increasing checking and vigilance, increasing belief that checking is necessary, and feeling worried. Guilt also drove vigilance: checking diaries, journals, emails, listening to conversations, and supervising activities were underpinned by a belief that they had previously not been caring enough and that these things would help control risk (McDonald et al., 2007). This in turn fed-back from parenting behaviour to their emotions. The vigilance led to guilt, as it meant intruding on privacy 'I used to go into her drawers, which is something I swore I would never do' (McDonald et al., 2007). Conflict was a consequence of parenting behaviours: 'because I was trying, um, [to] implement strategies and it didn't work, it would just cause conflict' (Linda) (Townsend et al., 2022). When strategies did not work, parents became more distressed and withdrew: 'I tried to ignore it at first... felt very powerless to effectively help him ... tried to pretend it wasn't happening because I had no idea who to deal with it (JDB)' (Townsend et al., 2022). Others talked of blaming their CYP: 'We blamed him

because we were scared that he would commit [sic] suicide in the future' (Fu et al., 2020, p. 5). For some, this changed over time, becoming gentler, as emotions were more controlled and understanding shifted: 'When I speak to her now, my voice is a little lower and softer. I will deliberately pay attention to the content and my way of talking to her' (Fu et al., 2020).

Continuing to feel scared and worried for their CYP meant some parents felt uncertain about their parenting. Parents were acting in a state of high emotional arousal, with a vicious cycle: feeling scared, not developing parenting strategies to cope due to feeling too concerned, feeling powerless and uninformed about what to do, leading to continued sense of fear. This was evidenced in particular by one mother describing talking to her daughter: 'I didn't know when to approach her to talk... It was really hard, so that didn't go very well, and then when we did, we always picked the wrong time it seemed like or the wrong way... it was a burden to talk to her' (Kelada, Whitlock, et al., 2016).

*Parents' self-care and roles altered by parenting Behaviours.* The increased checking, hypervigilance, avoidance of discipline and shifts in communication at times altered parents' self-care and other life roles. Being available for their CYP became an essential parenting behaviour, meaning loss of other roles: 'If it comes between my job and Alison then Alison obviously comes first and what I do will be go temping and then if she needs me, I am available' (Raphael et al., 2006). Checking, providing support to their CYP, and working to keep their CYP safe meant lack of sleep, physical exhaustion,

panic and anxiety, and reduced time with friends (Ferrey et al., 2016a, 2016b; Fu et al., 2020). Reduced paid work, travel to visit children in in-patient hospitals far from home or increased costs of private therapy could further reduce self-care owing to financial worries and less means for self-care (Ferrey et al., 2016a, 2016b), at a time when this is needed owing to high stress.

Parents cautioned that they may hide their needs: 'Even if parents say they are "ok" or "good", they probably are not. They may be suppressing their own needs and feelings because they are trying to attend to their child's needs' (Townsend et al., 2022). Oldershaw et al. (2008) echoed this 'Many parents feel that they had to deny their own needs and make changes to or limit their lifestyle as a direct results of the self-harm'.

*Parents' emotions interlocked with parent self-care.* Self-blame led to isolation, but also parents felt guilt about looking after their own needs: 'for some participants, learning self-care "has been a struggle"' (Krysinska et al., 2020, p. 8). Parents described reduced self-care, pushing down their own needs. However, given high levels of distressing emotions, self-care was needed, and particularly important as parents typically felt unsupported (Kelada, Whitlock, et al., 2016; Raphael et al., 2006; Rissanen, Kylma, & Laukkanen, 2009; Stewart et al., 2018; Townsend et al., 2022). Although many did not seek help, parents felt it was important to take care of themselves to be able to look after their CYP (Ferrey et al., 2016a, 2016b).

Engaging with health-care professionals can be important for parents' self-care, providing information and support. Parents described feeling confused, distressed and guilt, meaning that they felt unable to seek or take up support: 'Had it been on the day [the offer of family therapy] I would have definitely felt that it would have been intrusive I would have wanted time and space to accept what had happened' (Raphael et al., 2006, p. 17). Others felt excluded from services, with knowledge held or withheld by professionals, with no support for parents: 'Oh this is a service for Amy and it's nothing to do with you... I just felt that I was being kicked out all the time' (Rose et al., 2011).

The stigma of mental illness had an impact on help-seeking (Fu et al., 2020). Stigma, shame and guilt encouraged isolation: '[she] would not have spoken not to family or friends at the time about her daughter's self-harm' (McDonald et al., 2007). Reduced sharing of events in life was described, owing to the pressure of having a family that is not 'Instagram-able' as 'life can be a bit shit in between the Instagram pictures' (Krysinska et al., 2020). A 'profound sense of isolation' was evidenced: 'It can be very lonely, you can tell everybody but people will then cross the road to avoid talking to you' (Ferrey et al., 2016a, 2016b).

Parents described a need for peer support (e.g. Russell, 2018). It is unclear what changed for parents to be able to reach out for or receive peer support. When it was possible, this led to a strong connection with people 'on the same wavelength' (Krysinska et al., 2020), 'tips for them in how they cope and so they know they are not alone in this experience' (Townsend et al., 2022) and a realisation that other parents '[are] just like me, they are all good and normal and ordinary' (Byrne et al., 2008),

creating a reduction in self-stigma and other self-evaluations.

### Quantitative studies

The details of the quantitative studies are given in Table S3. All studies took place in high-income countries: 5 in USA, 4 in Ireland, 2 in UK/England, 2 in Australia, 2 in Germany and 1 each in Switzerland (one study recruited from Switzerland and Germany), Finland and Sweden. Most studies recruited via CYP mental health teams or emergency rooms. 10/17 of the studies were interventional with uncontrolled pre-post (repeated measures) studies ( $n = 6$ ), and randomised-control trials ( $n = 4$ ). The remainder of studies were four case-control designs, three cross-sectional, and one longitudinal. ROB analyses are reported, then data are analysed in relation to each the variables measured: general mental health/well-being, depression and anxiety, other general mental health/well-being, parenting strain, family functioning, and parenting satisfaction.

*Risk of bias.* Table 1 provides a summary of studies, including results of ROB analysis. The majority of studies have moderate ROB in relation to this review, because many were interventions studies with samples potentially representing either the more severe levels of distress (as parents are seeking intervention), or a lower level of distress (as parents are able to consider taking part in research). Appropriate selection, exposure, validated measures, low attrition and clear reporting were seen, however. Full ROB analysis is provided in Table S4.

*General mental health/well-being. GHQ-12.* This measure of non-specific mental health difficulties (Hankins, 2008) was used in five studies (Cottrell et al., 2018; Morgan et al., 2013; Power et al., 2009; Tubeuf et al., 2019). Four studies provided mean and standard deviations; however different scoring systems were used. Three studies used 0–12 scoring (Morgan et al., 2013; Power et al., 2009; Tubeuf et al., 2019). The pooled mean ( $n = 928$ ) was 6.0 (pooled standard deviation 4.03, 95% CI = 5.74–6.26). This is above the cut-off of 4 indicating probable mental health difficulties (Morris, Earl, & Neave, 2017). The final study used a scoring range 0–36, (each item rated 0–3) (Cottrell et al., 2018), where a score greater than 15 indicates probable mental health difficulties (Anjara, Bonetto, Van Bortel, & Brayne, 2020). They reported a mean 18.2 ( $n = 829$ ,  $SD 7.16$ , 95% CI = 17.7–18.7).

Where reported, the percentage of participants scoring in 'caseness' was high – 'over 80%' and 86% (Boylan et al., 2013; Morgan et al., 2013). In addition, Morgan et al. (2013) also conducted further analysis using the GHQ-12 scores, showing worse parental well-being was correlated with greater reported child difficulties in a sample of parents seeking support for their CYP self-harm (Kendall's Tau .174,  $p = .007$ ). Worse parental well-being was also linked to lower parenting satisfaction ( $-.404$ ,  $p = -.000$ ) and worse family communication (.142,  $p = .030$ ), however there was no relationship between parental well-being and perceived social support. These correlations were significant, but small.

**Table 1.** Summary of quantitative results

	ROB summary	Variables measured					
		General health/well-being	mental	Depression and anxiety	Parenting strain/burden/stress	Family functioning	Parenting satisfaction
Asarnow, Berk, Hughes, and Anderson (2015)	Moderate			X			
Asarnow, Babeva, Sugar, and Hughes (2017)	Moderate			X			
Asarnow et al. (2021)	Moderate	X					
Berk et al. (2020)	Moderate			X	X		
Boylan et al. (2013) = ABSTRACT ONLY	Moderate	X					
Cottrell et al. (2018)	Moderate	X				X	
Flynn, Gillespie, Joyce, and Spillane (2020)	Moderate				X		X
Kandsperger et al. (2022)	Moderate				X		
Kelada, Hasking, and Melvin (2016)	Low					X	
Morgan et al. (2013)	Moderate	X				X	X
Pitkänen, Remes, Aaltonen, and Martikainen (2023)	Low	X					
Power et al. (2009)	Moderate	X					X
Townsend et al. (2021)	Moderate			X	X		
Tschan, Schmid, and In-Albon (2015)	Low			X	X		
Tubeuf, Saloniki, and Cottrell (2019)	Moderate	X					
Whitlock et al. (2018)	Low				X		
Wijana, Enebrink, Liljedahl, and Ghaderi (2018)	Moderate			X	X		

For low ROB, all domains had to be rated as low. Moderate ROB was assigned where studies had no serious or critical issues but at least one moderate rating. Serious ROB was given where serious bias seen in at least one domain; and critical ROB rating where critical in at least one domain.

**Depression and anxiety.** Depression was measured in six studies (Asarnow et al., 2015, 2017; Berk et al., 2020; Townsend et al., 2021; Tschan et al., 2015; Wijana et al., 2018). Three used Center for Epidemiological Studies-Depression measures (CES-D and revised scale CESD-R). There was a lack of complete reporting of the data. All reported baseline scores from intervention studies. Asarnow et al. (2015) reported mean scores 20.26 (*SD* 13.34, *n* = 45, 95% *CI* = 16.4–24.2), while Asarnow et al. (2017) reported only that clinically elevated depressive symptoms were observed in 52.4% of the parents. Berk et al. (2020) used the updated measure (CESD-R) with a sample of nine parents, observing median score 13, with a large inter-quartile range of 6–52. Asarnow et al.'s (2015) mean score is above the clinical cut-off of 16 (Radloff, 1977), indicating probable clinical depression, whilst the Berk median is below this.

Using the Mental Health Inventory, 66.7% of parents were found to score in the range of likely clinical difficulties with anxiety and/or depression (Townsend et al., 2021). Importantly, this study also found higher involuntary engagement coping (e.g., rumination) linked to worse mental health when compared to those who engaged in secondary control coping (e.g., acceptance), with a large effect size (Cohen's *d* = 3.16).

Tschan et al. (2015) used the Depression Anxiety Stress Scale-21 (DASS-21) (Lovibond & Lovibond, 1995) to measure depression, anxiety and stress. All scores were in the normal range, except for stress for fathers of CYP who self-harm. Comparisons to parents without

CYP who self-harm revealed mothers of self-harm group report significantly more depression, anxiety and stress than mothers in the group with no mental health history, however there were no differences between self-harm and clinical control groups.

The Hospital-Anxiety Depression Scale (HADS) has a clinical cut-off score of 8 (Bjelland, Dahl, Haug, & Neckelmann, 2002). Wijana et al. (2018) reported anxiety and depression means above 8 however 95% *CI*s were above 8 for anxiety scores only for mothers (95% *CI* anxiety = 11.1–12.3, depression = 7.6–8.8) and fathers (95% *CI* anxiety = 9.4–10.3, depression = 6.6–8.3).

**Other general mental health/well-being results.** Six studies used other measures relating to general mental health related issues (Joan Rosenbaum Asarnow et al., 2021; Flynn et al., 2020; Morgan et al., 2013; Pitkänen et al., 2023; Tubeuf et al., 2019; Wijana et al., 2018). The Brief Symptom Inventory, Global Severity Index measures the severity overall distress in the last week (Derogatis & Melisaratos, 1983). It was used in two groups of parents taking part in an intervention (Asarnow et al., 2021). Baseline mean scores were reported by each of the study's two intervention groups: 0.62 and 0.59 (95% *CI*s = 0.50–0.74 and 0.47–0.71), both below levels seen in clinical populations (Derogatis & Melisaratos, 1983).

Generalised stress was measured using the Swedish version of the Perceived Stress Scale-10 (Cohen, Kamarck, & Mermelstein, 1983), finding mean scores of



23.98 (95% CI = 22.29–25.67) and 19.55 (95% CI = 17.49–21.61) in mothers and fathers respectively (Wijana et al., 2018). A large-scale study of the measures properties reported mean of 14.56 and 13.20 in women and men, with higher scores indicating higher stress and norms in general Swedish adult population being mean 13.96, *SD* 6.34 (Nordin & Nordin, 2013). Observed 95% CIs are within one standard deviation of the mean, suggesting they are not extreme.

Grief was measured in one study, reporting mean 49.46 (*SD* 12.64) (Flynn et al., 2020) using the Grief Assessment Scale (Struening et al., 1995). This maximum score is 60, however there are no published norms and no comparison group was used in the study.

The Multidimensional Scale of Perceived Social Support (Zimet, Powell, Parley, Werkman, & Berkoff, 1990) has a cut-off where a score of 65 or less indicated poor support. Morgan et al. (2013) found a mean score of 58.6, with 61% falling into the range for poor support.

Receipt (dichotomous outcome) of any sort of psychiatric treatment was examined following CYP self-harm, indicating 52% of mothers and 33% fathers had psychiatric treatment following CYP self-harm (Pitkänen et al., 2023). Overall, parents with less education were more likely to have treatment, however immediately after the self-harm rates of support were higher for those with high levels of education and in employment.

Finally, health state utility (HUI2) mean score of 0.71 (*SD* 0.28,  $n = 754$ , 95% CI = 0.69–0.73) was reported for parents at baseline (Tubeuf et al., 2019), which is below suggested normed mean of 95% CI 0.869–0.891 (HUI, 2009).

*Parenting strain/burden/stress.* Versions of the Caregiver Strain Questionnaire (CGSQ) (Brannan, Heflinger, & Bickman, 1997) were used in two studies. First, Berk et al. (2020) used the short-form version with  $n = 10$ , reporting median total strain of 26.5 (objective 14, subjective 13). Second, Whitlock et al. (2018) found significantly higher strain in parents of children who self-harm compared to parents of children who have not self-harmed, using the original full measure. They explored predictors of caregiver strain using multiple regression models. They found that non-judgement of self and child, having told others about the self-harm, lower number of mental health challenges for the CYP, feeling responsible, having sought therapy for CYP, and CYP having had therapy all predicted lower objective caregiver strain. Although there were missing data, longer duration of self-harm was linked to higher objective strain. Subjective external strain was linked to non-judgement and number of mental health challenges for CYP. Subjective internal strain was linked to feeling responsible, not feeling socially supported, having child in therapy and being in therapy themselves.

Burden was assessed in one study (Flynn et al., 2020), using the Burden Assessment Scale (scale range 19–76) (Reinhard, Gubman, Horwitz, & Minsky, 1994), reporting total mean score of 45.55. No reported norms, comparison nor cut-off were available.

Stress was measured using two different scales. One study (Kandsperger et al., 2022) used the German version of the Parental Stress Index (Tröster, 2011), which does not have cut-offs established for the individual domains (Buechel et al., 2022). The mean scores were

31.42 for parent domain, 22.83 for child domain and 18.67 for interaction domain, however it is not possible to interpret these scores as high/low.

Two studies used the Parent Stress Scale (Berry & Jones, 1995), with scores ranging from 18 to 90 (higher being worse). There were no reported norms or cut-offs available. One study reported mean scores of 41.92 (*SD* 11.49) (Flynn et al., 2020). However, another used a case-control design compared scores between parents with and without CYP who self-harm, finding higher stress in mothers where there is self-harm, but not fathers (Tschan et al., 2015).

Finally, response to stress (Connor-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000) was found to be most commonly in the form of rumination and emotional arousal, with acceptance and cognitive restructuring being second most common (Townsend et al., 2021), although there are no norms or control group scores to assist interpretation.

*Family functioning.* Four studies assessed family functioning (Cottrell et al., 2018; Kelada, Hasking, & Melvin, 2016; Morgan et al., 2013; Tubeuf et al., 2019), using the McMaster Family Assessment Device (FAD) or its sub-scales (Epstein, Baldwin, & Bishop, 1983). Scores of 2.20 or more on the communication sub-scale and of 2.0 or more on the 'general' score indicate difficulties with family functioning (Mansfield, Keitner, & Archambault, 2018). Morgan et al. (2013) observed communication sub-scale means of 14.95 (*s.d.* 2.95, 95% CI 14.4–15.5), which converts to a scale score of 1.66 (95% CI = 1.60–1.72) (Epstein et al., 1983). This is below the cut-off. Cottrell et al. (2018) reported FAD 2.2 (*SD* 0.36), above cut-off point, with all sub-scales in the 'unhealthy' range. Tubeuf et al. (2019) observed general FAD of 2.20 (*SD* 0.37, 95% CI = 2.17–2.23), with 95% CI range straddling the cut-off. Kelada, Hasking, et al. (2016) and Kelada, Whitlock, et al. (2016) reported 1.99 (*SD* 0.51, 95% CI = 1.9–2.08) general score in parents of CYP who were aware of their child's self-harm, below the cut off, also noting however significantly higher scores in that group compared to parents who were unaware of the self-harm or parents of CYP who did not self-harm.

*Parenting satisfaction.* The Kansas Parenting Satisfaction (KPS) measure was used in two studies (Morgan et al., 2013; Power et al., 2009), conducted by the same team in relation to their intervention known as 'SPACE'. KPS has a score range of 7 to 21, with higher scores indicating higher satisfaction (James et al., 1985). Using different samples they reported baseline mean KPS of 10.40 (*SD* 3.83), from 130 parents (Morgan et al., 2013) and 12.13 (*SD* 3.21, achieved  $n = 45$ ) (Power et al., 2009), leading to a pooled mean of 10.8 (pooled *SD* 3.70). There are no established norms or cut-off points with this measure, however the mean scores are around 3–5 points above the scale minimum, suggesting low satisfaction.

## Discussion

This study reviewed 32 studies in 39 reports, providing qualitative and/or quantitative data relating to parents' well-being, needs or impacts on them linked to CYP self-

harm. Overall, it is challenging to draw conclusions as to the levels of parents' well-being, however qualitative findings indicate a significant impact on parents. The literature itself is limited. The majority of studies were conducted in USA or European countries. Attitudes towards mental health and self-harm in particular vary cross-culturally, with high levels of shame and stigma as well as different conceptualisations of the causes and meanings of self-harm (Quarshie, Waterman, & House, 2020; Rojas-Velasquez, Pluhar, Burns, & Burton, 2021). This lack of studies from middle-low income countries or cultures outside of the Global North constrains any transferability or generalisability of findings.

### Discussion of qualitative findings

The extent of the emotional impact on parents is clear: CYP self-harm has a non-trivial impact for many parents. Need for further information and support remain, together with the stigma around self-harm. The logic model of the problem (Figure 2) illustrated the range of factors that are described in the qualitative findings as potentially important to parents' well-being. Logic models are frequently used in intervention development (Bartholomew et al., 2006). It provides an overview of relevant factors to be targeted and factors that may impede or promote the success of interventions. For example, parenting interventions that seek to train parents to use control differently may need to consider the significant driver of not just lack of knowledge but also intense emotions driving parenting behaviour, or attempts to improve parental self-care may need to consider the impact of reduced financial security.

The core themes identified are similar to other reviews (Arbuthnott & Lewis, 2015; Curtis et al., 2018; Mughal et al., 2022; Simes, Shochet, Murray, & Sands, 2022): emotional and practical impacts on the parents; a need to seek information; a need for support and a shift in themselves as they seek to manage the self-harm. Our analysis of links between themes extends existing reviews. For example, Mughal noted the high level of shame and feeling isolated amongst parents (Mughal et al., 2022). The link between guilt and/or shame and the reluctance of parents to seek their own support was noted in the review by Curtis et al. (2018). Our findings support these links and provide further details (Figure 3). We detailed the impact of emotions such as shame on parenting behaviours, and how knowledge and information also interact with emotions. This provides further understanding of processes of distress that can inform which constructs to target within an intervention. Parents' lack of knowledge about self-harm appears to deepen their emotional distress, however there is a complex relationship between knowledge that leads to perceptions that CYP self-harm can be controlled, experiences of self-blame, and controlling parenting as a way to manage. Information then clearly has a role; however it is vital to consider the impacts of information. No data were found that linked knowledge/beliefs about self-harm to parents' self-care. Future qualitative research that seeks to better understand the drivers for parents' self-care could explore this.

### Discussion of quantitative findings

Poor general mental health, measured using the GHQ12, is the only finding that was consistently

reported across multiple studies. Conversely, the BSI measure, which also exams general mental health, found scores below clinical cut-off. Depression scores showed an inconsistent pattern, typically showing only mothers had higher depression. Importantly, there may be no greater depression in mothers of CYP who self-harm compared to mothers of CYP with other mental health conditions, but both are more depressed than non-clinical controls (Tschan et al., 2015), suggesting it is also important to explore parents' well-being in relation to other CYP mental health difficulties. The lack of large-scale surveillance data of parental well-being in relation to CYP mental health should be addressed.

Stress, grief and parenting satisfaction are challenging to interpret as measures had no norms and no control group was used. Social support indicated around 61% with poor support. Burden was also higher compared to a control group. Family functioning was largely below the cut-off for clinical concern. There therefore is a lack of certainty around most areas of distress and stress in parents of CYP who self-harm. There were just three case-controlled studies, with only two that used normed measures (Kelada, Hasking, & Melvin, 2016; Tschan et al., 2015). They evidenced worse family functioning and maternal mental health when compared to families with no CYP self-harm/mental health difficulties. Levels of psychiatric treatment were found to be up to 52% in mothers following self-harm, suggesting high levels of family distress, however without comparison to a control group (Pitkänen et al., 2023). Overall conclusions are limited.

Studies do not provide a detailed examination of parental characteristics linking to greater or lesser parental distress, satisfaction or family functioning. Whitlock et al. (2018) highlighted the impact of therapy for parent and CYP, parent factors around judgement and feeling responsible, parental peer support, and the duration and number of mental health challenges for the child as relevant to parenting strain. However, these findings have not been further explored and factors around parental mental health history, age, socioeconomic status, work status and pre-existing social support have not been explored in depth. Some studies investigated differences between mothers/fathers, however there is insufficient data to draw conclusions. Furthermore, it remains unclear to what extent a parent's distress dissipates if/when the CYP 'recovers': a key question to understanding the need for parent support.

Methodological issues affect the conclusions that can be drawn from the quantitative data. The interventions studies present ROB, for example parents with higher levels of distress may be more likely to be attracted to participate in an intervention. Although measures were validated, many measures had no established norms/cut-off scores making interpretation difficult. The case-control studies provide a more informative picture; however they are scant and cover over family functioning, depression and parent burden. Large-scale, representative studies are required to establish the well-being of parents of CYP who self-harm. This may use existing datasets, with a control group and normed measures.

### Linking qualitative and quantitative findings

Few quantitative studies explored variables linked to parents' distress. There are complex bi-directional links

between parental and CYP mental health, and parents with mental health difficulties may be more likely to have CYP with mental health difficulties (Wilkinson et al., 2021). Little is understood about the mechanisms of distress and well-being within parents. The qualitative themes have not yet been translated into quantitative hypothesis testing, designed to understand the importance of different variables. The qualitative findings clearly show that having a CYP who self-harms affects parents. There is a core role for uncertainty arising from lack of information; that guilt and self-blame may partly drive parenting behaviours and distress; and that rumination, partly due to uncertainty, creates further distress. A lack of self-care may be an outcome and further cause of this distress. Quantitative research has not yet addressed these variables in detail and is now needed to understand the extent of any effects, which parents are most affected, and through which mechanisms. This will aid intervention design and targeting. One study did examine the role of psychological processes, finding parents who ruminated, for example had worse mental health than those engaging in acceptance (Townsend et al., 2021). Further studies of this nature are required to construct a psychological model of distress in our population.

### *Implications for practice*

The need for peer support and community based interventions for parents has been acknowledged (Arbuthnott & Lewis, 2015; Curtis et al., 2018; Mughal et al., 2022). Our review also supports this, as peer support may reduce isolation, address social norms around self-care, and shift beliefs about self-blame. Interventions may also be needed that are aimed at modifying self-blame and shame, for example using self-compassion or acceptance based ideas (Luoma & Platt, 2015). This may allow parents to engage in self-care, reducing the impact of negative emotions. This may improve parents' well-being, which is a goal in itself and may also indirectly improve the CYP's well-being (Mughal et al., 2022).

The interpretation of self-harm due to parents' actions was evidenced. Implicit within this is an assumption that the parent could have done something to prevent the self-harm, that they have the power to do this. Shifting these core attitude may require more than simple information provision. Information alone may not be enough to reduce distress, anxiety or low mood in all parents. For example, patients with cancer have been found to require more than information to address the anxiety and depression that can accompany this distressing situation (Leykin et al., 2012). Here, this may be due to deeply held cultural beliefs that it is a parents' role to protect their child from harm and the belief behind the stigma that self-harm is somehow wrong. These beliefs present resistant and robust pieces of 'information' within parents. Whilst information may help shift a narrative around self-blame, it may not be sufficient to battle against these attitudes and beliefs. Further, these beliefs that lead to self-blame, for example, may have a function for the parent – to help them make sense of what is happening and feel there is a way to control and move forward in the presence of this perceived threat to their child's well-being (Tennen, Affleck, & Gershman, 1986). Again, information alone may not be enough to shift this process away from causing

emotional distress. Cognitive-behavioural therapy (CBT) based approaches may instead be required, as distress is frequently maintained by the way in which information is processed and the fundamental interpretation of the 'threat' situation (Kaczurkin & Foa, 2015).

The findings suggest not only potential content for interventions to better support parents with their distress, but also approaches that may help prevent distress in parents of CYP who self-harm. Reliable online information may address likely self-blame and provide practical advice on parenting, to reduce uncertainty. Training for staff in CAMHS, emergency departments and primary care, could improve communication, address difficulties about information sharing, and lead to better recognition and validation of parents' understandable worry.

### *Limitations of the review*

This review is limited by focusing only on studies published in English. The results are limited to information from high-income countries, with the majority of participants being middle-class females. The studies typical have low ethnic diversity. Grey literature was not included. The analysis of the quantitative studies is descriptive and narrative, limiting conclusions. For some variables, pooled means and standard deviations were calculated, however this was not always possible owing to availability of reported data. Within the three case-control studies, the only overlap was two measuring parenting strain/stress. Meta-analysis of two studies, using different measures, and from different populations (a broad sample, and only parents of young-people who were inpatients in psychiatric care), was unlikely to provide useful insight. More case-control designed studies are required to address questions around the extent of distress in our population of interest, compared to a general parent population.

## **Conclusions**

Our review illustrates the significant impact of self-harm on parents, with interwoven cognitive, behavioural and emotional factors. There is a clear need for interventions to support parents of CYP who self-harm. Further quantitative research is required to better understand the mechanisms underpinning parents' needs, and to identify parent and CYP characteristics linked to greater need for support for parents.

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## **Conflict of interest**

The authors have declared that they have no competing or potential conflicts of interest.

## **Author contribution**

FM conceived of and was involved in all elements of the study. All authors were involved in ratings records for inclusion/exclusion in the review and interpretation of findings. FM and SE completed the data extraction. TO



provided expert qualitative input. All authors have contributed to the final version of the manuscript.

## Ethical information

This study is a systematic review and no ethical approvals were required.

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## Supporting information

Additional Supporting Information may be found in the online version of this article:

**Appendix S1.** Search strategies: PsycInfo, Medline, EMBASE, AMED, CINHAI and Web of Science.

**Table S1.** Details of the qualitative studies of impacts and needs.

**Table S2.** Quality appraisal ratings for Qualitative studies (using Critical Appraisal Skills Program “CASP” tool).

**Table S3.** Summary of Quantitative studies of impacts and needs.

**Table S4.** Risk of bias ratings for quantitative studies.

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