


BMJ Open Lived experiences of parents providing care to young people who self-harm: a protocol for a meta-aggregative synthesis of qualitative studies

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ABSTRACT

Introduction The self-harm of young people can cause tremendous distress to their parents/carers and impair parents' ability to provide care. At the same time, parents play an essential role in supporting their child during the management and treatment of self-harm. The synthesis of evidence about parental experiences and needs can inform mental health practice and the development of interventions to provide better care to young people who self-harm and their parents.

Methods and analysis A comprehensive search will be conducted across several information sources, including multiple electronic databases (eg, PubMed, Embase, CINAHL, PsycINFO, ProQuest, CNKI, Wanfang, VIP and SinoMed), grey literature, the websites of specific organisations and hand-searched reference lists of all the relevant studies. Qualitative studies published in English or Chinese and focusing on the lived experiences of parents whose child self-harms will be included. Two reviewers will independently screen all the retrieved articles according to the flow diagram proposed by PRISMA (the Preferred Reporting Items for Systematic Reviews and Meta-Analyses). Two independent reviewers will then appraise the methodological quality of all the included articles using the JBI (Joanna Briggs Institute) critical appraisal checklist for qualitative research. The meta-aggregation approach will be used to synthesise the findings of the included qualitative studies, and the level of confidence in the synthesised findings will be assessed using the Confidence in the Qualitative synthesised finding approach.

Ethics and dissemination No additional ethical clearance is required since this review is a secondary analysis of published primary studies. The findings will be disseminated through publication in a peer-reviewed journal and conference presentations.

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INTRODUCTION

Self-harm refers to any intentional act of self-poisoning or self-injury carried out by an individual, irrespective of the type of motivation or the extent of suicidal intent.^{1–3} Over 33 terms have been adopted to describe this phenomenon,⁴ such as self-injurious behaviours (SIB), self-harm (SH), deliberate self-harm (DSH),

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ To our knowledge, this is the first meta-synthesis of qualitative evidence regarding parental experiences of providing care to a self-harming young person.
- ⇒ Our search strategy will be developed following the Joanna Briggs Institute search guidelines and validated with the Peer Review of Electronic Search Strategies checklist by an information specialist to ensure its comprehensiveness and accuracy.
- ⇒ Confidence in synthesised findings will be assessed using the Confidence in the Qualitative synthesised finding approach.
- ⇒ Caution should be exercised when generalising our findings to other cultures in that only studies published in English or Chinese will be included in this review.

self-injury (SI), self-mutilation, self-inflicted violence, self-cutting, non-suicidal self-injury (NSSI), etc, among which SH, DSH and NSSI are the most commonly used expressions. The term DSH has been used predominantly in Europe and Australia and is a more encompassing term for SIB, both with and without suicidal intent.⁵ Recently, removing the term 'deliberate' has been proposed because those who harm themselves during a dissociative state often describe diminished or absent awareness of their actions.² The term NSSI, compared with SH, is used more commonly in Canada and the USA. NSSI, by the definition of the International Society for the Study of Self-Injury (ISSS),⁶ is the deliberate, self-inflicted damage of body tissue without suicidal intent and for purposes not socially or culturally sanctioned. Although this definition of NSSI allows it to be recognised from other types of SI, such as suicide attempts (SAs), the inclusion of NSSI as an independent diagnostic category in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders has also sparked ongoing



scholarly enquiry and discussion among researchers and clinicians.^{7–9} The debate mainly revolved around the validation of dichotomising self-harming behaviour as NSSI or SA due to the dynamic changes of suicidal intent and the strong association between these two subtypes. Given that previous research concerning SH has been largely divided into two subcategories: NSSIs and SAs.¹⁰ The more general and comprehensive terminology, SH or SI, was therefore chosen to encompass any self-harming behaviours regardless of suicidal intent in this review.

SH has been identified as a major public health concern among young people worldwide.¹¹ Internationally, it is estimated that 16%–18% of people will SH at some point in their lives,^{5 12} and recent findings indicate a significant association between the age of onset and the severity of SH behaviours and suicide risk.¹³ With adolescence being the typical period of onset for SH behaviours,^{14 15} family remains an integral part and a crucial factor in the management of the SH behaviours of young people. Considerable research has shown that caring for a young person who engages in SIB can be overwhelming and emotionally traumatic for parents and can affect the wider family system.^{16–22}

To date, many qualitative studies have explored parents' experiences of caring for a child who SHs in a range of contexts, such as A&E (Accident and Emergency) departments, psychiatric wards and the communities.^{17–28} The findings reveal that youth SH takes a tremendous toll on the physical and mental well-being of parents, whose abilities to support their child, in turn, may be affected.¹⁶ In addition, research has consistently shown that young people tend to seek help from informal sources such as friends and family first.^{29–33} Although friends are ranked ahead of parents as the most preferred source of help by teens who SH, according to Berger and colleagues,³¹ friends who are approached for help do not just 'talk and listen'; instead, they typically suggest that their self-injuring peers disclose their mental health issues to parents and family, who can give advice and support or help seek professional services on their behalf. For children and adolescents, parents are arguably the primary decision-makers regarding whether or what professional help should be accessed. Although young adults have increased maturity and autonomy and may be able to access mental health services on their own, they still rely heavily on their parents for connecting with professionals and for assuming the cost of mental health services.^{34 35} Therefore, parents play a critical role in facilitating professional assistance for young people, and their beliefs and attitudes towards self-harming behaviours undoubtedly influence their decisions regarding whether to initiate the professional help-seeking process. The thought that self-harming might resolve of its own accord could impede parents from getting timely professional help for their child,²⁰ an essential factor to decrease the risk of future suicidal ideations or behaviours.²⁹ In another study, young people who present to an emergency department following an episode of SH acknowledged that their parents had a significant impact on their

compliance with the follow-up treatment.³⁶ Therefore, many evidence-based interventions targeting youth SH have involved parents in the therapeutic process.^{37–40} The National Institute for Health and Care Excellence also states in its current clinical practice guideline regarding SH that the involvement of the family, carers or significant others should be encouraged in the treatment of SH behaviours.¹ Therefore, it is essential to gain an overall understanding of parents' experiences, thoughts, perspectives and needs when they are providing care to their self-harming child.

A synthesis of multiple qualitative studies can create a new or heightened understanding of a phenomenon and identify gaps and areas of ambiguity in the existing literature, thereby revealing directions for future research and informing decision-making by policymakers and healthcare practitioners.⁴¹ For example, a recent qualitative systematic review, from the perspectives of those who engaged in NSSI, has shed light on our understanding of the important role of interpersonal processes in the occurrence of NSSI, which further highlights the potential benefits of relational therapies for clinicians.⁴² Among the previously published systematic reviews of qualitative literature concerning parents whose child SHs,^{16 43 44} one has mainly focused on parent-related factors for SH (eg, poor parent–child communication, lack of parental support, parental loss or separation/divorce), the role of parents in help-seeking and the impact of youth SH on parents' well-being and parenting, yet it does not have a specific focus on parents' overall experiences and perceptions.¹⁶ Another review⁴⁴ examined the experiences and perspectives of both young people and parents; it took the form of a narrative synthesis and failed to employ the method of systematic review, subjecting the findings to limited inclusiveness and comprehensiveness. A third, more recent review also took a broad approach, including both young people and their caregivers affected by suicidal and SH behaviours, yet focused more specifically on their experiences of and needs towards professional help.⁴³ In light of this, a synthesis of qualitative studies exploring the lived experiences of parents whose child SHs is lacking.

Therefore, this synthesis aims to address this gap. Through identifying, examining and synthesising the qualitative evidence on parents' experiences of providing care to self-harming young people, we seek to (1) identify the existing evidence base; (2) identify parents' experiences and needs when providing care to self-harming young people under different settings, that is, communities, hospitals and emergency departments; (3) explore their experiences and views about the support received from formal (mental health professionals) and informal sources (friends, family members and social peer groups); (4) identify ways in which support could be improved; and (5) identify gaps in the evidence base and directions for future research and clinical practice.

The results of this synthesis can help mental health professionals raise their awareness of taking family

dynamics and contextual factors into consideration. The findings will also enhance their competence in engaging parents in the treatment of youth who SH by providing parents with the education and training they need to support their child embarking on the journey towards recovery in various settings.

METHODS

Review registration and reporting

This systematic review has been registered within the International Prospective Register of Systematic Reviews (PROSPERO) database.

This protocol is being reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Protocols statement (checklist included in online supplemental file 1).⁴⁵ The final review will be reported according to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement.⁴⁶ The PRISMA 2020 statement⁴⁷ will also be used to guide the process of conducting and reporting this proposed review.

Study eligibility criteria

In this review, the PICO framework for primary qualitative studies will be used to identify the elements of our review question. The inclusion and exclusion criteria will then be established in line with each element of the PICO mnemonics (Population, phenomena of Interest and Context).

Population

Primary studies will be deemed eligible for this review that present data directly obtained from parents or caregivers of young people who SH. The participants can be fathers, mothers or both parents or other immediate family members who take on the primary responsibility of carers such as grandparents. Foster carers such as adoptive parents or other forms of non-blood relatives, as long as they were primary carers, will also be included. With regard to the demarcation standard of young people, there is no agreed definition at present. Because the occurrence of SH can start as early as 5 years of age and extend until young adulthood,^{14 15} carers of a child, an adolescent or young adult will all be included in this review to capture a wide range of experiences of carers. According to the demarcation made by Medical Subject Headings (MeSH) that are used in the PubMed search system, a child is defined as a person between 6 and 12 years of age, an adolescent between 13 and 18 years of age and a young adult between 19 and 24 years of age. Consequently, qualitative studies involving carers of young people under the age of 25 will be included.

Phenomena of interest

The phenomena of interest for this review include the following: (1) How parents make sense of the self-harming behaviours in young people, that is, how they perceive

the motives and reasons behind their child's self-harming behaviours. (2) The lived experiences of parents discovering and caring for a child who SHs. More specifically, how they discovered their child's self-harming, how they feel (eg, guilty, ashamed, embarrassed, confused or angry) and how they react to and cope with the situation (eg, responsive and supportive or dismissive and avoidant). (3) The information needs of the parents dealing with self-injuring youth, which include the content (eg, topic), mode of delivery (eg, electronic, paper-based, verbal, audio or video) and amount of information that parents desire to receive about managing their child's SIB. (4) The views and perspectives of parents on the support they received (either formal or informal), their experiences and preferences and their thoughts about how support can be improved. Any qualitative data fulfilling one or more of these criteria will be deemed eligible for inclusion.

Context

This review will consider any setting where parents are taking care of their self-harming child, such as an A&E department, psychiatric ward or community setting.

Study types

Any study that focuses on qualitative data, including but not limited to, designs such as grounded theory, action research, phenomenology, ethnography or feminist research, will be included. Mixed-methods studies with a qualitative component will also be included, with only the qualitative data extracted for this review.

Study exclusion criteria

This review will exclude any studies published not in English or Chinese, conference abstracts, books, reviews, commentaries or letters to editors. Studies reporting only quantitative data (eg, cross-sectional, case-control, cohort studies and clinical trials) will also be excluded.

Information sources

To generate a comprehensive list of primary studies, several sources of literature, both published and unpublished, will be approached. The primary source of literature will be multiple health-related electronic databases, including English-language databases such as PubMed, Embase, CINAHL and PsycINFO and Chinese-language databases such as CNKI, Wanfang Database, VIP database and SinoMed. Each database will be searched from its inception to the present. Prior to conducting a literature search for primary studies, the CDSR (Cochrane Database of Systematic Reviews), Joanna Briggs Institute (JBI) EBP (Evidence-Based Practice) Database and PROSPERO have been searched to ascertain that there are no systematic reviews with a similar topic, either published or underway. The secondary source of potentially relevant materials will be a search of the grey or difficult-to-locate literature using the Google Scholar, GreyNet International and ProQuest Dissertations and Theses database. These searches will be further supplemented

**Box 1 Search strategy for PubMed**

#1. (parent* OR father* OR mother* OR carer* OR caregiver* OR "care giver*" OR grandparent* grand-parent* OR grandfather* OR grandmother* OR guardian* OR famil* OR home* OR household* OR household*).ti,ab.
 #2. (parents OR fathers OR mothers OR family OR caregivers OR "legal guardians" OR "family relations" OR "parent-child relations" OR "father-child relations" OR "mother-child relations" OR parenting).mh.
 #3. #1 OR #2.
 #4. ("young adult*" OR "young people" OR "young person*" OR youngster* OR youth* OR juvenile* OR teen* OR preteen* OR child* OR minor* OR adolescen* OR pubescen* OR student* OR underage* OR "under age*").ti,ab.
 #5. (child OR adolescent OR young adult OR "psychology, child" OR "adolescent development" OR "psychology, adolescent" OR "adolescent psychiatry" OR "adolescent behavior").mh.
 #6. #4 OR #5.
 #7. ("suicide ideation" OR "suicidal ideation" OR "suicide attempt" OR "suicidal attempt" OR parasuicid* OR para-suicid* OR nonsuicid* OR non-suicid* OR overdos* OR "over dose*" OR "self harm*" OR "self hurt*" OR "self mutilat*" OR "self injur*" OR "self damag*" OR "self inflit*" OR "self destruct*" OR "self violen*" OR "self directed violen*" OR "self immolat*" OR "self poison*" OR "auto mutilat*" OR automutilat* OR "self cut*" OR "self burn*" OR "self bit*" OR "self abus*" OR "self hit*" OR "head bang*" OR headbang* OR "self wound*").ti,ab.
 #8. ("self-Injurious behavior" OR "drug overdose").mh.
 #9. #7 OR #8.
 #10. (qualitative OR interview OR interviews).ti,ab. OR (experience OR experiences).tw.
 #11. "qualitative research"[mh] OR interviews[mh] OR interviews(mh:noexp).
 #12. #10 OR #11.
 #13. #3 AND #6 AND #9 AND #12.
 #14. Limit to English and Chinese.

with hand-searching the reference lists, such that the titles of all articles cited within eligible studies will be checked. Websites of specific organisations, such as the ISSS, will also be searched for potentially eligible studies. Efforts will also be made to contact authors of completed, ongoing or in-press studies for information regarding additional studies or relevant materials.

Search strategy

The search strategy for the primary database (PubMed) was developed in collaboration with an experienced librarian from our institute. It has been peer reviewed using the Peer Review of Electronic Search Strategies (PRESS) checklist.⁴⁸ To develop an appropriate and expansive list of search terms, an initial search of PubMed was undertaken, followed by an analysis of the text words contained in the title and abstract and of the MeSH terms used to describe the articles, which, in turn, informed the development of the final search strategy for PubMed (see [box 1](#)) and will be tailored for the remaining information sources. The detailed search strategies for various information sources can be found in online supplemental file 2 (see Appendices 1–10). No data limits will be applied to the searches, and only studies published in the English

or Chinese language will be included due to practical concerns and resource constraints.

Data management

The search results will be managed with the assistance of EndNote reference management software. Once the number of records identified from each database search has been clearly documented, all search results will be imported and merged into one EndNote group. Then, automatic duplicate checking will be initiated first, followed by a manual check to ensure that all potential duplicates have been eliminated. After duplicates are removed, a final list of the search results will be generated, and the following screening process will also be performed using EndNote.

Screening and selection of studies

The final list of the search results will be shared between the two reviewers (YZ and QZ) and independently screened by title and abstract against the eligibility criteria. The studies that the two reviewers agreed on will then undergo a full-text reading by the same independent reviewers. Records from Google Scholar search will be cross-checked with the citations from database search at the full-text screening stage. Any discrepancies, along with the screening process, will be resolved through discussion or adjudication by a third reviewer (WZ) until consensus is achieved. The reasons for exclusion will be presented at the full-text review. If multiple papers describing the same research are found, the paper that describes the most comprehensive findings will be included. The final list of eligible papers will receive unanimous approval from the review team. A flow diagram depicting the screening and selection process and results, following PRISMA guidelines, will be produced.

Evaluation of methodological quality of included studies

Two authors (YZ and QZ) who have received training on evidence synthesis will appraise the methodological quality of all included studies independently using the standard JBI critical appraisal instrument for qualitative research.⁴⁹ The JBI qualitative appraisal checklist contains 10 criteria that are scored as being 'met', 'not met' or 'unclear' and, in some instances, as 'not applicable'. Before conducting the critical appraisal, the reviewers will first meet to clarify precise definitions, come to an agreement on the mutual understanding of the criteria and then embark on their independent evaluation processes. Any discrepancies between them will be resolved through discussion or arbitration from a third reviewer (WZ). Following the critical appraisal results, all studies will be scored, with higher scores indicating a greater proportion of the quality criteria having been met. However, our review team decided not to set a quality threshold so as not to exclude any article but rather to focus broadly on topical relevance. Meanwhile, once the findings are synthesised, a dependability score, assessed against five questions of the same checklist (Items 2–4 and 6–7), will be assigned

to each study to determine the overall confidence in the resultant synthesised findings of the qualitative evidence synthesis.

Data extraction

General characteristics of included studies will be extracted using a predesigned Microsoft Excel form, which, before formal data extraction commences, will be pilot tested on two articles to make any necessary revision or adjustment. Information on author(s), year of publication, locale of study, research aims, study methodology, number and characteristics of participants, method of data collection, method of data analysis and main findings will be extracted to gain a better understanding of the literature. These descriptive data about study characteristics will be presented in a tabular form included in the final report.

To facilitate data synthesis, all the text labelled by authors of primary qualitative studies as results/findings, discussion/interpretation and conclusions will be extracted verbatim from study reports and entered into NVivo V.12 software (QSR International). Findings will be extracted from the included papers with a supporting illustrative quotation attached. Each finding will then be assigned a level of plausibility (unequivocal, equivocal or unsupported) based on the congruency between the author's conclusion and the participant's voice.⁴⁹

With regard to the data extraction process, the principal reviewer (YZ) will extract these data from all included studies according to the prespecified guidelines. A second reviewer (QZ) will cross-check the accuracy of the extracted data against the original study reports. Any disagreements will be discussed until consensus, and consultations will be sought from a third reviewer (WZ) if necessary.

Data synthesis

This review will use a meta-aggregative approach recommended by JBI collaboration⁴⁹ to synthesise the findings of the included qualitative studies. The meta-aggregation method is philosophically grounded in pragmatism and Husserlian transcendental phenomenology.^{49 50} The alignment of this method with the philosophy of pragmatism is reflected in its aim to produce synthesised statements in the form of 'lines of action' to inform decision-making at the clinical or policy level. As a result, it avoids reinterpretation of original study findings and moves beyond the generation of theory, which, in contrast, is central to meta-ethnography, realist synthesis and critical interpretive synthesis. The roots within transcendental phenomenology are embodied in its purpose to develop knowledge in an unbiased, unprejudiced way, not influenced by self or outside factors.⁵¹ Primary empirical studies operating under different philosophical paradigms, either postpositivism or social constructivism, will all be included in the meta-aggregation, with only qualitative elements extracted and synthesised. All findings or themes will be presented in the way they were in

the original studies, without reinterpretation. Categories and synthesised findings will be allowed to emerge from the extracted themes without preconceived categories or theories imposed on them.

Two reviewers will read and re-read each included study to ensure the utmost familiarity with the data. Then, a three-step process will be undertaken to synthesise qualitative evidence. First, all the concluding findings from every included paper will be extracted with an accompanying illustration and allocated with a level of credibility. Second, these findings will be assembled, compared and categorised on the basis of similarity in meaning, with at least two findings per category. Third, these categories will then be subjected to a meta-synthesis to produce a single comprehensive set of synthesised findings that can be used as a basis for EBP.

During the synthesis process, only unequivocal and equivocal findings will be included in the aggregation. Not-supported findings will not be included in the meta-aggregation and will be presented separately. The aggregation and descriptions of categories and synthesised findings will be created by a consensus process among review group members. We will also use the Confidence in the Qualitative synthesised finding approach to assess our level of confidence in the main findings from the meta-synthesis by creating a table with a summary of the qualitative findings.⁵²

Patient and public involvement

This review aims to synthesise published research studies and involves no patients or members of the public. The primary studies concerning participants have obtained their consent.

DISCUSSION

Parental involvement in their child's treatment is recognised as a crucial factor in improving a child's prognosis.¹⁰ Therefore, it is urgent to examine parents' experiences of caring for a self-harming child and identify their needs when providing support to their child through ongoing treatment. However, a comprehensive synthesis of such knowledge is lacking in the current literature. Our proposed review will focus on the experiences and first-hand accounts of parents responsible for the care and management of the self-harming behaviours of young people. We anticipate that this review will deepen our understanding of the experiences and needs of parents whose child SHs. The results will inform mental health professionals and policymakers to better provide education and training to those parents and, together with the engagement of these parents, develop more tailored and individualised interventions to improve the treatment outcomes of young people who SH.

Correction notice This article has been corrected since it first published. Article title has been updated.

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Contributors YZ conceived the idea for this review, wrote the first draft of the protocol and will act as the first reviewer of this synthesis. QZ will act as the second reviewer and WZ will be the third reviewer. All authors (YZ, RDDR, QZ, WZ, HX, RW, LM) read, offered feedback and agreed on the final manuscript of this protocol and will be responsible for the refinement of the search strategy, study screening, quality appraisal, data extraction and synthesis process.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

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