

Self-harm: assessment, management and preventing recurrence

[D] Evidence review for Involving family and carers in the management of people who have self-harmed

NICE guideline number tbc

Evidence reviews underpinning recommendations 1.4.1-1.4.5 and 1.10.2 in the NICE guideline

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Draft for consultation

These evidence reviews were developed by the National Guideline Alliance which is a part of the Royal College of Obstetricians and Gynaecologists

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1 Involving family and carers in the 2 management of people who have self- 3 harmed

4 Review question

5 What are the views and preferences of people who have self-harmed, their families and
6 carers, and staff working with people who have self-harmed about the best ways of involving
7 family and carers in the management of people who have self-harmed?

8 Introduction

9 People with sufficient mental capacity who have self-harmed have the right to autonomy
10 regarding decision-making and consent in the management of their care. Family members
11 and carers can provide support and information to people who have self-harmed.
12 Establishing an open and collaborative approach between people who have self-harmed,
13 their family, carers and professionals is of key importance in the management of self-harm to
14 prevent or minimise recurrence. It is important to consider if involving family members and
15 carers may cause harm as well as benefit. The aim of this review is to identify the most
16 effective ways of involving family and carers in the management of people who have self-
17 harmed.

18 Summary of the protocol

19 See Table 1 for a summary of the Population, Phenomenon of interest and Context (PPC)
20 characteristics of this review.

1 **Table 1: Summary of the protocol (PPC table)**

<p>Population</p>	<p>Inclusion:</p> <ul style="list-style-type: none"> • All carers or family members of people who have self-harmed, including child and adult family members, and carers/ family members of people who have self-harmed and have a mental health problem, neurodevelopmental disorder or a learning disability. • All people who have self-harmed, including those with a mental health problem, neurodevelopmental disorder or a learning disability. • All health care staff working in settings where people who have self-harmed present, are assessed or are treated • Staff working in educational setting, prison settings and social care with people who have self-harmed • Staff working in third sector and other sectors involved in the delivery in the clinical support of people who have self-harmed <p>Exclusion:</p> <ul style="list-style-type: none"> • Carers or family members of people displaying repetitive stereotypical self-injurious behaviour, for example head-banging in people with a significant learning disability • People displaying repetitive stereotypical self-injurious behaviour, for example head-banging in people with a significant learning disability
<p>Phenomenon of interest</p>	<p>Views and preferences about involving family and carers in the management of people who have self-harmed that are regarded as useful/ not useful or important/ not important by the population</p>
<p>Context</p>	<p>Settings - Inclusion: All inpatient, outpatient and community settings in which management of people who have self-harmed is provided, including:</p> <ul style="list-style-type: none"> • Primary, secondary and tertiary healthcare settings (including pre-hospital care, accident and emergency departments, community pharmacies, inpatient care, and transitions between departments and services) • Home, residential and community settings, such as supported accommodation • Supported care settings • Education and childcare settings • Criminal justice system • Immigration removal centres. • Community mental health services • Inpatient mental health services

1 For further details see the review protocol in appendix A.

2 **Methods and process**

3 This evidence review was developed using the methods and process described in
4 [Developing NICE guidelines: the manual](#). Methods specific to this review question are
5 described in the review protocol in appendix A and the methods document (supplementary
6 document 1).

7 Declarations of interest were recorded according to [NICE's conflicts of interest policy](#).

8 **Qualitative evidence**

9 **Included studies**

10 The qualitative aspects of 2 mixed-methods studies (Hom 2020, Kelada 2016 (study 1)) and
11 24 qualitative studies published in 28 articles were included in this review (Bouwman 2018,
12 Byrne 2008, Chew-Graham 2002, Dempsey 2019, Dransart 2017, Ferrey 2015, Ferrey
13 2016a, Ferrey 2016b, Grandclerc 2019, Hom 2020, Idenfors 2015, Jennings 2020, Kelada
14 2016 (study 2), Kennard 2020, Krysinska 2020, Lindgren 2010, McLaughlin 2016, Nadeem
15 2016, Oldershaw 2008, Raphael 2006, Rissanen 2009a, Rissanen 2009b, Rissanen 2012,
16 Sellin 2018, Spillane 2019, Stewart 2018, Wand 2019a, Wand 2019b, Wester 2018). One
17 article (Kelada 2016) reported results from 2 different studies, 4 articles (Ferrey 2015, Ferrey
18 2016a, Ferrey 2016b, Stewart 2018) reported results from the same study, and 2 articles
19 (Wand 2019a, Wand 2019b) reported results from the same study.

20 The included studies are summarised in Table 2.

21 The studies were carried out in the following countries: UK (Chew-Graham 2002, Ferrey
22 2015, Ferrey 2016a, Ferrey 2016b, Jennings 2020, McLaughlin 2016, Oldershaw 2008,
23 Raphael 2006, Stewart 2018), Australia (Dempsey 2019, Kelada 2016 (study 1), Krysinska
24 2020, Wand 2019a, Wand 2019b), Finland (Rissanen 2009a, Rissanen 2009b, Rissanen
25 2012), France (Grandclerc 2019), Ireland (Byrne 2008, Spillane 2019), The Netherlands
26 (Bouwman 2018), Sweden (Idenfors 2015, Lindgren 2010, Sellin 2018), Switzerland
27 (Dransart 2017), and the USA (Hom 2020, Kelada 2016 (study 2), Kennard 2020, Nadeem
28 2016, Wester 2018).

29 Sixteen studies from 19 articles included family or carers of people who had self-harmed. Of
30 these studies, the participants were adult carers or family members of adults who have self-
31 harmed (Dransart 2017, Lindgren 2010, Wand 2019a, Wand 2019b), adult carers or family
32 members of children who have self-harmed (Byrne 2008, Jennings 2020, Kelada 2017
33 (studies 1 and 2), Oldershaw 2008, Rissanen 2009b, Wester 2018), or adult carers or family
34 members of adults or children who have self-harmed (Ferrey 2015, Ferrey 2016a, Ferrey
35 2016b, Krysinska 2020, Raphael 2006, Stewart 2018). One study did not report information
36 about the ages of the participants or of those who had self-harmed (Bouwman 2018), and 3
37 studies only reported the ages of the participants (adults) but not those who had self-harmed
38 (Dempsey 2019, McLaughlin 2016, Spillane 2019). There were no studies that included
39 participants who were either child family members of adults who have self-harmed or child
40 family members of children who have self-harmed.

41 Six studies reported in 7 articles included people who had self-harmed. Of these studies,
42 people who had self-harmed in the following age groups were included: adults (age 18
43 years+: Hom 2020, Wand 2019a, Wand 2019b); adolescents and adults (age 17 to 24 years:
44 Idenfors 2015; age 17-50 years: Chew-Graham 2002; age 12 to 21 years: Grandclerc 2019,
45 Rissanen 2009a). There were no studies that exclusively included participants who were
46 under the age of 18.

1 Seven studies included staff who worked in settings where they interacted with or provided
2 care for people who had self-harmed. Of these studies, the following settings were
3 represented: health care (tertiary mental health service: Dempsey 2019); community
4 (Kennard 2020, Sellin 2018); educational (secondary school: Nadeem 2016, Wester 2018).
5 Two studies represented mixed settings (primary care, outpatient and school: Rissanen
6 2012; community, inpatient and primary care: Bouwman 2018).

7 See the literature search strategy in appendix B and study selection flow chart in appendix C.

8 Excluded studies

9 Studies not included in this review are listed, and reasons for their exclusion are provided in
10 appendix J.

11 Summary of included studies

12 Summaries of the studies that were included in this review are presented in Table 2.

13 **Table 2: Summary of included studies**

Study and aim of the study	Population	Methods	Author themes
<p>Bouwman 2018</p> <p>Aim of the study To “examine whether and how patients and families are involved in the analysis of, and formal reporting on a sentinel event including suicide (attempts).”</p> <p>Country The Netherlands</p>	<p>N=31 participants: n=24 healthcare staff; n=7 family members of people who had sentinel events</p> <p>Mean age (SD): Not reported.</p> <p>Sex (female/male): Not reported.</p> <p>For family members or carers:</p> <p>Relationship to person who has self-harmed: Not reported</p> <p>For staff members:</p> <p>Role:</p> <ul style="list-style-type: none"> • Patient counsellors: 2 • Family counsellors: 5 • Members of family committee: 4 • Psychiatrist: 4 • Medical director: 1 • Director: 3 • Inspector: 5 <p>Setting: Not reported</p> <p>Years in post/experience: Not reported</p>	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Semi-structured interviews were analysed inductively using iterative grounded-theory techniques</p>	<ul style="list-style-type: none"> • Involvement during treatment • Limited involvement in sentinel event analysis in practice • Reasons against involving patients and families in sentinel event analyses • Reasons in favor of involvement during sentinel event analyses

Study and aim of the study	Population	Methods	Author themes
	Client group (adults, children/CYP): Not reported		
<p>Byrne 2008</p> <p>Aim of the study To “describe parents’ and carers’ experiences of self-harm in their child in order to identify their support needs.”</p> <p>Country Ireland</p>	<p>N=25 parents/ carers of young people who had self-harmed/ expressed suicidal ideation</p> <p>Mean age (SD): Not reported.</p> <p>Sex (female/male): Not reported.</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Parent: 15 • Carer: 10 	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Focus group meeting, analysed using an inductive approach</p>	<ul style="list-style-type: none"> • Information and education • Parenting
<p>Chew-Graham 2002</p> <p>Aim of the study To “generate a range of perspectives of attempted suicide and self-harm”, in order to “encourage Asian women to share their perceptions of experiences of mental distress, attempted suicide and self-harm, and to comment on barriers preventing access to service provision”.</p> <p>Country UK</p>	<p>N=31 South Asian women who had attempted suicide and/or self-harm and women from South Asian women’s groups</p> <p>Age range: 17-50 years</p> <p>Sex (female/male): 31/0</p> <p>Co-morbidity: Not reported</p> <p>Duration of self-harm: Not reported</p> <p>Number of suicide attempts: Not reported</p>	<p>Recruitment period: January 2011</p> <p>Data collection and analysis methods: Focus group meetings, analysed according to the principles of framework analysis</p>	<ul style="list-style-type: none"> • Access to mainstream service provision
<p>Dempsey 2019</p> <p>Aim of the study To “explore clinician and caregiver perspectives on service provision for family members of young people (15–25 years) attending a specialist clinic for moderate–severe mood disorder.”</p> <p>Country Australia</p>	<p>N=16 participants: n=8 parent caregivers; n=8 clinicians</p> <p>Mean age (SD):</p> <ul style="list-style-type: none"> • Parent caregivers: 52.50 (3.78) • Specialist YMC treating clinicians: 36.33 (8.82) <p>Sex (female/male):</p> <ul style="list-style-type: none"> • Parent caregivers: 7/1; 	<p>Recruitment period: Not reported,</p> <p>Data collection and analysis methods: Semi-structured interviews, analysed using thematic analysis</p>	<ul style="list-style-type: none"> • Information • Crisis needs: Support • Initial needs: Information

Study and aim of the study	Population	Methods	Author themes
	<ul style="list-style-type: none"> Specialist YMC treating clinicians: 7/1 <p>For family members or carers:</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> Parent: 8 <p>For staff members:</p> <p>Role:</p> <ul style="list-style-type: none"> Clinical psychologists: 7 Occupational therapist: 1 <p>Setting: Tertiary mental health service</p> <p>Years in post/ experience: Range 2–29 years (M = 9.5 years, SD = 10.23)</p> <p>Client group (adults, children/ CYP): Young people aged 15-25 years old</p>		
<p>Dransart 2017</p> <p>Aim of the study To identify “how taking care or supporting a suicidal person or suicide attempter impacted on the life of informal carers and on how they sought help”, and to describe “the process these people underwent in their attempt to find help for their loved ones; the type of actions taken, the institutions or persons contacted, and the outcomes.”</p> <p>Country Switzerland</p>	<p>N=18 significant others of adult suicidal persons</p> <p>Mean age (range): 44 (23-61) years</p> <p>Sex (female/male): 16/2</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> Spouse/partner: 5 Child: 3 Mother: 3 Sister: 3 Ex-spouse: 2 Friend: 2 	<p>Recruitment period: February 2007 – January 2008</p> <p>Data collection and analysis methods: Semi-structured interviews, analysed using a mixed approach</p>	<ul style="list-style-type: none"> Help-seeking process to support the suicidal person/suicide attempter Significant others’ perception of patient/client care for the suicidal person/suicide attempter Significant others’ perception of their collaboration with professionals
<p>Ferrey 2015</p> <p>Aim of the study (See Stewart 2018)</p>	<p>(See Stewart 2018)</p>	<p>Recruitment period: August 2012 – October 2013</p>	<ul style="list-style-type: none"> Ongoing impact on parents’ emotional state and mental health

Study and aim of the study	Population	Methods	Author themes
Country UK		Data collection and analysis methods: (See Stewart 2018)	
Ferrey 2016a Aim of the study (See Stewart 2018) Country UK	(See Stewart 2018)	Recruitment period: August 2012 – October 2013 Data collection and analysis methods: (See Stewart 2018)	<ul style="list-style-type: none"> Experiences with clinical services
Ferrey 2016b Aim of the study (See Stewart 2018) Country UK	(See Stewart 2018)	Recruitment period: August 2012 – October 2013 Data collection and analysis methods: (See Stewart 2018)	<ul style="list-style-type: none"> Changes in parenting Longer-term effects on parenting Suggestions for other parents
Grandclerc 2019 Aim of the study “To describe the subjective experience of adolescent girls and young women who present NSSI and/or suicidal behaviors and to determine the common aspects and the specificities of each experience.” Country France	N=18 young people who had self-harmed Mean age (SD): 16.5 (1.86) Sex (female/male): 18/0 Co-morbidity: Not reported Duration of self-harm: Not reported Number of suicide attempts: <ul style="list-style-type: none"> Participants reported one or more suicide attempts: 12 	Recruitment period: August 2015 – December 2017 Data collection and analysis methods: Semi-structured interviews, analysed using interpretive phenomenological analysis	<ul style="list-style-type: none"> The act as a test of the separation process in adolescence
Hom 2020 Aim of the study “To examine attempt survivors’ experiences interfacing with mental health care services.” Country USA	N=96 suicide attempt survivors Mean age (SD): 35.05 (11.43) Sex (female/male/gender non-conforming): 64/31/1 Co-morbidity: Not reported Duration of self-harm: Not reported Number of suicide attempts: Not reported. All 96	Recruitment period: Not reported. Data collection and analysis methods: Unstructured interviews, coded and analysed thematically	<ul style="list-style-type: none"> Positive support from family and friends regarding mental health service use Provider not open to input; did not trust individual’s own expertise

Study and aim of the study	Population	Methods	Author themes
	participants had attempted suicide in the previous one year		
<p>Idenfors 2015</p> <p>Aim of the study To “explore young people’s views of professional care before first contact for DSH, and factors that influenced the establishing of contact.”</p> <p>Country Sweden</p>	<p>N=10 people who had self-harmed</p> <p>Mean age (range): 20 (17-24) years</p> <p>Sex (female/male): 6/4</p> <p>Co-morbidity: Not reported</p> <p>Duration of self-harm: Not reported</p> <p>Number of suicide attempts: Not reported</p>	<p>Recruitment period: 2009 - 2011</p> <p>Data collection and analysis methods: Semi-structured interviews, analysed using an inductive thematic approach</p>	<ul style="list-style-type: none"> • One should not communicate distress • The importance of family and friends when overwhelmed by emotional storms
<p>Jennings 2020</p> <p>Aim of the study To “explore inter-professional relationships between social care and healthcare professionals, utilising self-harm prevention and management as a site for study.”</p> <p>Country UK (Wales)</p>	<p>N=30 carers of children and adolescents with experience of caring for children who had self-harmed</p> <p>Mean age (SD): Not reported.</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Foster carers: 15 • Residential carers: 15 	<p>Recruitment period: November 2015 – May 2016</p> <p>Data collection and analysis methods: Focus groups and semi-structured interviews, analysed using a grounded theory approach</p>	<ul style="list-style-type: none"> • Contestations in expertise: the duality of propositional and experiential knowledge • Preclusion of professional identity: inadequate professionalisation processes and the labour of legitimacy
<p>Kelada 2016</p> <p>Aim of the study “Two studies aimed to understand adolescent NSSI from the parent perspective by assessing the impact NSSI has had on parent health, parent responses to their adolescent following discovery of NSSI, interactions with professional help, and whether they believe their responses to NSSI to be appropriate or detrimental.”</p> <p>Country Study 1: Australia</p>	<p>Study 1: N=16 parents of people who had self-harmed</p> <p>Study 2: N=22 parents of people who had self-harmed</p> <p>Mean age (SD):</p> <ul style="list-style-type: none"> • Study 1: Parents: 45.44 (4.88) / Adolescents: 15.38 (1.89) • Study 2: Not reported <p>Sex (female/male):</p> <ul style="list-style-type: none"> • Study 1: 10/6 • Study 2: Not reported 	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Study 1: Open-ended questionnaire, coded and thematically analysed</p> <p>Study 2: Semi-structured interviews, coded and thematically analysed</p>	<ul style="list-style-type: none"> • Lack of empathy • Lack of support • Negative experiences with mental-health professionals

Study and aim of the study	Population	Methods	Author themes
Study 2: USA	Relationship to person who has self-harmed: <ul style="list-style-type: none"> Study 1: Mother n=15; Father n=1 Study 2: Mother n=18; Father n=4 		
Kennard 2020 Aim of the study “To better understand the sociocultural and logistical treatment needs and barriers of lowincome Latinx suicidal youth; and to solicit feedback and identify best practices to adapt and implement a suicide treatment program for this population in a community mental health clinic.” Country USA	N=8 clinicians and clinic staff Mean age (SD): Not reported. Sex (female/male): 6/2 Role: <ul style="list-style-type: none"> Licensed Professional Counsellors: 3 Qualified Mental Health Professionals: 2 Clinical managers: 2 Operations manager: 1 Setting: 3 community clinics within a large network of community mental health service providers Years in post/experience: 8.56 (SD =14.09, Range 1.5–43)/ 11.13 (SD=14.41, Range 0–45) Client group (adults, children/ CYP): Not stated	Recruitment period: Not reported. Data collection and analysis methods: Interviews, analysed thematically using a codebook	<ul style="list-style-type: none"> Cultural transitions Negative experiences with mental-health Professionals Strategies to engage families
Krysinska 2020 Aim of the study To explore “the experience and needs of parents who are supporting a young person who self-harms.” Country Australia	N=19 parents of young people who had self-harmed Mean age (SD): Not reported. Sex (female/male): 16/3 Relationship to person who has self-harmed: <ul style="list-style-type: none"> Mothers: 16 Fathers: 3 	Recruitment period: March – August 2018 Data collection and analysis methods: Semi-structured individual and group interviews, thematically analysed using a combined inductive and deductive approach	<ul style="list-style-type: none"> Discovering self-harm: “there’s life before and after self-harm” Need for psychoeducational resources: “I wish I had something like this [booklet] when I was going through it [self-harm]” Parents’ emotional reactions: “you

Study and aim of the study	Population	Methods	Author themes
			<p>might have strong emotions yourself”</p> <ul style="list-style-type: none"> • Self-Care and help seeking: “you’ve got to help yourself before you can help your child”
<p>Lindgren 2010</p> <p>Aim of the study “To discover and describe lived experiences of professional care and caregivers among parents of adults who self-harm.”</p> <p>Country Sweden</p>	<p>N=6 parents of adult children who had self-harmed</p> <p>Age range: 45-55 years</p> <p>Sex (female/male): 5/1</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Mother: 5 • Father: 1 	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Narrative interviews, analysed using a phenomenological hermeneutic approach</p>	<ul style="list-style-type: none"> • Being ‘broken • Being confused • Feeling accused • Feeling hoodwinked • Feeling invisible • Feeling released • Losing confidence in the healthcare system • Negotiating and bridging gaps
<p>McLaughlin 2016</p> <p>Aim of the study “To explore the support needs of family members of suicidal people.”</p> <p>Country UK (Northern Ireland)</p>	<p>N=18 carers for suicidal family members</p> <p>Age range: 25-78 years</p> <p>Sex (female/male): Not reported</p> <p>Relationship to person who has self-harmed: Not reported</p>	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Semi-structured interviews, analysed thematically</p>	<ul style="list-style-type: none"> • Consistency of support • Feeling acknowledged and included
<p>Nadeem 2016</p> <p>Aim of the study “To explore school personnel perspectives on working with parents in a school-based suicide prevention program serving primarily low income and ethnic minority students— Youth Suicide Prevention Program (YSPP).”</p> <p>Country USA</p>	<p>N=45 school staff</p> <p>Mean age (SD): Not reported.</p> <p>Sex (female/male): 26/19</p> <p>Role:</p> <ul style="list-style-type: none"> • Counselors or mental health staff: 7 • Nurses: 2 • Teachers: 26 • Administrators: 10 <p>Setting: School</p> <p>Years in post/experience: 6.4 (SD=5.5) / 14 (SD=11.32)</p>	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Semi-structured focus groups and interviews, coded and thematically analysed</p>	<ul style="list-style-type: none"> • Parent involvement during the crisis phase • Parent involvement postcrisis • Strategies for enhancing parent engagement and involvement

Study and aim of the study	Population	Methods	Author themes
	Client group (adults, children/ CYP): Children		
<p>Oldershaw 2008</p> <p>Aim of the study “To gain perspective of parents of adolescents who self-harm on: (a) history of self-harm and health service provision; (b) their understanding and ability to make sense of self-harm behaviour; (c) emotional and personal impact; and (d) parent skills as carer and hope for the future.”</p> <p>Country UK</p>	<p>N=12 carers of children referred to CAMHS</p> <p>Mean age (SD): Not reported.</p> <p>Sex (female/male): 10/2</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Mother: 9 • Father: 2 • Grandmother: 1 	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Semi-structured interview, analysed using an interpretive phenomenological approach</p>	<ul style="list-style-type: none"> • Influence of outside agencies on the psychological impact • The process of discovery
<p>Raphael 2006</p> <p>Aim of the study “To understand parents’ concerns, expectations and experiences following an episode of deliberate self-harm in young people in order to identify their support needs.”</p> <p>Country UK</p>	<p>N=9 parents of young people who had self-harmed</p> <p>Mean age (SD): Not reported.</p> <p>Sex (female/male): 5/4</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Mother: 5 • Father: 4 	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Unstructured interviews, analysed using a phenomenological approach</p>	<ul style="list-style-type: none"> • Emotional responses • Health professionals
<p>Rissanen 2009a</p> <p>Aim of the study “To provide adolescents who self-mutilate a possibility to describe help and helping factors from their viewpoint and in their own words.”</p> <p>Country Finland</p>	<p>N=72 adolescents who had self-harmed</p> <p>Age range:</p> <ul style="list-style-type: none"> • Written descriptions: 12-21 years • Interviews: 15-19 years <p>Sex (female/male):</p> <ul style="list-style-type: none"> • Written descriptions: Not reported • Interviews: 10/0 <p>Co-morbidity: Not reported</p>	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Emailed written descriptions and open-ended interviews, analysed using inductive content analysis</p>	<ul style="list-style-type: none"> • Any person who knows about their self-mutilation can be a helper • Factors enabling help-seeking • Help-hindering factors

Study and aim of the study	Population	Methods	Author themes
	<p>Duration of self-harm: Not reported</p> <p>Number of suicide attempts: Not reported</p>		
<p>Rissanen 2009b</p> <p>Aim of the study “To examine parental views on how to help adolescents who self-mutilate.”</p> <p>Country Finland</p>	<p>N=4 parents of adolescents who had self-harmed</p> <p>Mean age (SD): Not reported.</p> <p>Sex (female/male): 3/1</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Mother: 3 • Father: 1 	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Open-ended interviews, analysed using inductive content analysis</p>	<ul style="list-style-type: none"> • Adolescent self-help • Adult siblings as helpers • Helping the parents and the family • Parents as helpers
<p>Rissanen 2012</p> <p>Aim of the study “To describe Finnish nurses’ conceptions and experiences of helping adolescents who self-mutilate.”</p> <p>Country Finland</p>	<p>N=9 nurses</p> <p>Mean age (SD): Not reported.</p> <p>Sex (female/male): Not reported</p> <p>Role:</p> <ul style="list-style-type: none"> • Registered Nurses: 5 • Practical Nurses: 4 <p>Setting: Participants included nurses who had worked on wards and in the out-patient department and one nurse who worked in a school.</p> <p>Years in post/experience: Not stated / All of the participants had worked for more than five years in health care.</p> <p>Client group (adults, children/ CYP): Not stated</p>	<p>Recruitment period: April – May 2005</p> <p>Data collection and analysis methods: Written descriptions, open-ended focus groups and open-ended individual interviews, coded and grouped into categories</p>	<ul style="list-style-type: none"> • Parents as helpers
<p>Sellin 2018</p> <p>Aim of the study “To describe what characterizes a recovery-oriented</p>	<p>N=16 healthcare staff and researchers</p> <p>Mean age (SD): Not reported.</p>	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Focus groups,</p>	<ul style="list-style-type: none"> • Acknowledging relationships and contexts with others

Study and aim of the study	Population	Methods	Author themes
<p>caring approach, and how this can be expressed through caring acts involving suicidal patients and their relatives.”</p> <p>Country Sweden</p>	<p>Sex (female/male): Not reported</p> <p>Role:</p> <ul style="list-style-type: none"> • Representatives from a suicide prevention organisation: 5 • Registered nurses: 6 • Researchers: 5 <p>Setting: Swedish organisation which works with suicide prevention and support to relatives who have lost a close one to suicide; County Council in Sweden; researchers with special knowledge about suicide prevention</p> <p>Years in post/experience: Not stated.</p> <p>Client group (adults, children/ CYP): Not stated.</p>	<p>analysed using the Delphi method involving qualitative thematic analysis</p>	
<p>Spillane 2019</p> <p>Aim of the study “To explore the overall impact of a family member’s high-risk selfharm, in terms of psychological, physical and psychosomatic consequences”.</p> <p>Country Ireland</p>	<p>N=9 family members of people who had self-harmed</p> <p>Mean age (range): 44 (33-61) years</p> <p>Sex (female/male): 6/3</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Spouse: 3 • Sibling: 3 • Parent: 2 • Close friend (listed by patient as next-of-kin): 1 	<p>Recruitment period: July 2014 – August 2016</p> <p>Data collection and analysis methods: Semi-structured interviews, analysed using interpretive phenomenological analysis</p>	<ul style="list-style-type: none"> • Care for self • Caring for self to care for others • Formal aftercare following self-harm • Gaining control of the uncontrollable

Study and aim of the study	Population	Methods	Author themes
<p>Stewart 2018</p> <p>Aim of the study To explore “how parents of young people who had self-harmed experienced support and treatment, both for their child and for themselves” and “to generate information that could be helpful for parents and for clinicians helping families navigate through this experience.”</p> <p>Country UK</p>	<p>N=37 parents of young people who had self-harmed</p> <p>Mean age (SD): Not reported.</p> <p>Sex (female/male): 32/5</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Mother: 32 (including 1 adoptive) • Father: 5 	<p>Recruitment period: August 2012 – October 2013</p> <p>Data collection and analysis methods: Semi-structured interviews, analysed using a modified grounded theory approach</p>	<ul style="list-style-type: none"> • Access to the right context of care • Being taken seriously • Listening to parents and involving them in treatment • Need for practical strategies • Support for parents
<p>Wand 2019a</p> <p>Aim of the study “To follow-up a cohort of older people who self-harmed, their carer, and general practitioner (GP) and examine their reflections on the self-harm, care experiences, and outcomes.”</p> <p>Country Australia</p>	<p>N=48 participants: n=19 people who had self-harmed (30 were recruited, 11 were not available for follow-up); n=29 family members/ carers of people who had self-harmed (32 were recruited, 3 were not available for follow-up)</p> <p>Mean age (range):</p> <ul style="list-style-type: none"> • People who had self-harmed: 86.2 (81-94) years • Family/ carers: Not reported. <p>Sex (female/male):</p> <ul style="list-style-type: none"> • People who had self-harmed: 12/7 • Family/ carers: 15/14 <p>For people who had self-harmed:</p> <p>Co-morbidity:</p> <ul style="list-style-type: none"> • Dementia: 17/26* • Major depression: 3/22* <p>Duration of self-harm:</p> <ul style="list-style-type: none"> • Repeat self-harm: 5/30* 	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Structured interviews, analysed thematically</p>	<ul style="list-style-type: none"> • Abandonment by clinicians • Being heard • Relief and satisfaction with care

Study and aim of the study	Population	Methods	Author themes
	<p>Number of suicide attempts: Not reported</p> <p>*30 people who had self-harmed were originally recruited for this study but 11 were not available for follow-up. Denominator varied according to availability of information.</p> <p>For family members or carers:</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Child: 22 • Child-in-law: 2 • Spouse: 2 • Grandchild: 1 • Friend: 1 • Nephew: 1 		
<p>Wand 2019b</p> <p>Aim of the study (See Wand 2019a)</p> <p>Country Australia</p>	<p>(See Wand 2019a)</p>	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: (See Wand 2019a)</p>	<ul style="list-style-type: none"> • Clinicians dismissing the carer • Improving communication • 'It made us ill' • Suicide and secrets
<p>Wester 2018</p> <p>Aim of the study "To explore what community and family support systems think, feel, and do when supporting adolescents' termination of NSSI."</p> <p>Country USA</p>	<p>N=9 participants: n=7 family members of people who had self-harmed; n=2 healthcare/ school staff</p> <p>Mean age (SD): Not reported.</p> <p>Sex (female/male):</p> <ul style="list-style-type: none"> • Family carers: 7/0 • Staff members: 1/1 <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Parent: 2 • Sister: 1 • Aunt: 1 • Friend: 3 <p>For staff members:</p>	<p>Recruitment period: Not reported.</p> <p>Data collection and analysis methods: Semi-structured interviews, analysed using grounded theory analysis</p>	<ul style="list-style-type: none"> • Accepting some questions will remain unanswered • Accepting there are some things you can't control • Evaluating needs • Feeling it's a time-consuming responsibility • Identifying a Conflicted Relationship Between a Support and the Adolescent • Seeing involving others as steps toward recovery and protection

Study and aim of the study	Population	Methods	Author themes
	<p>Role:</p> <ul style="list-style-type: none"> • Therapist: 1 • School counselor: 1 <p>Setting: Community</p> <p>Years in post/ experience: Not stated</p> <p>Client group (adults, children/ CYP): Not stated.</p>		

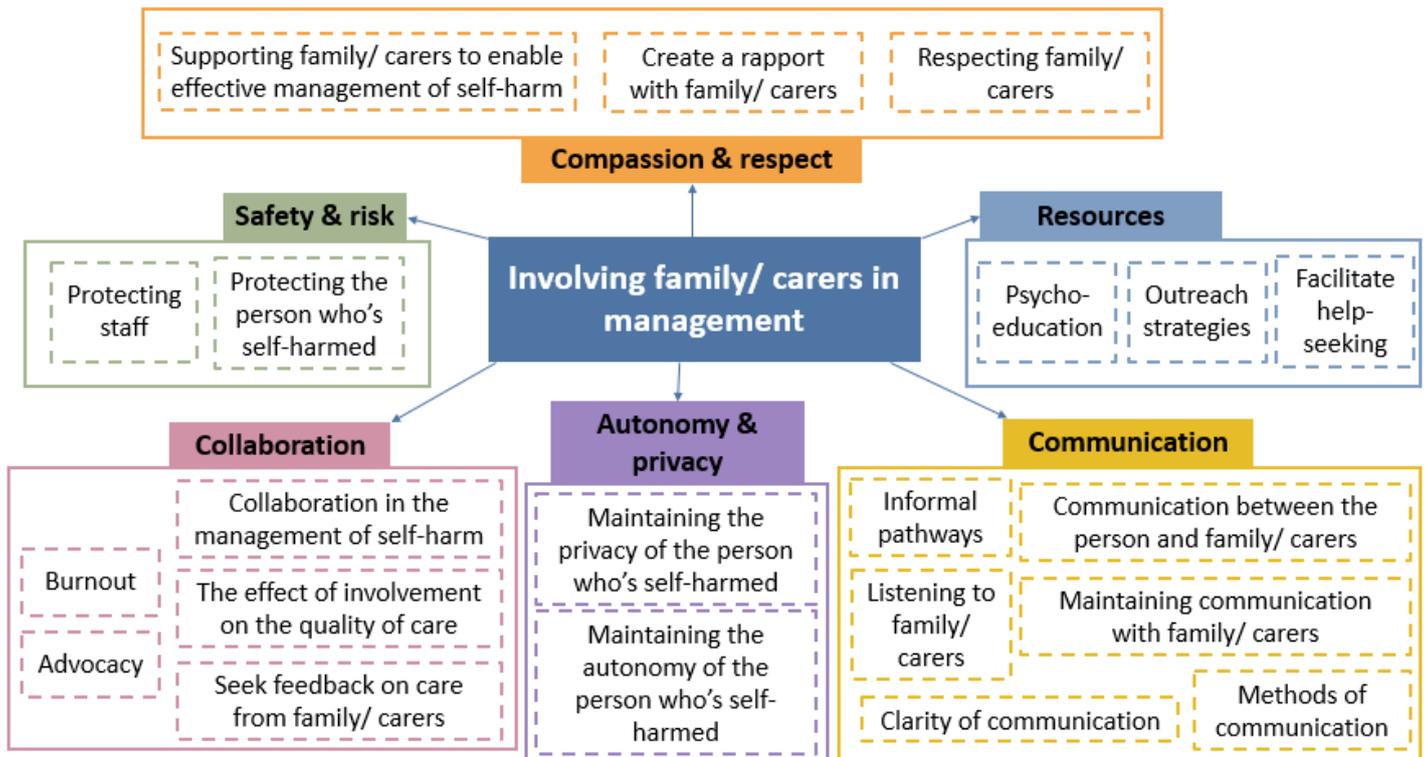
1 CYP – Children and Young People; DSH – Deliberate Self-Harm; GP – General Practitioner; NSSI – Non-Suicidal
 2 Self-Injury; SD – Standard Deviation; YSPP – Youth Suicide Prevention Program; YMC – Youth Mood Clinic

3 See the full evidence tables in appendix D.

4 Summary of the evidence

5 The information and support needs and preferences identified in the included studies fell
 6 under 6 main themes – communication, collaboration, compassion and respect, resources,
 7 autonomy and privacy, and safety and risk. A total of 21 subthemes were associated with the
 8 6 main themes, and these are all illustrated in Figure 1 and summarised in Table 3. The
 9 following subgroups were represented in the evidence: family or carers of people who had
 10 self-harmed (adult carers or family members of adults who have self-harmed, adult carers or
 11 family members of children who have self-harmed), people who have self-harmed (adults,
 12 children), and staff who worked in settings where they interacted with or provided care for
 13 people who had self-harmed (healthcare, education, community, mixed). The following
 14 subgroups were not represented in the evidence: child family members of adults who have
 15 self-harmed; child family members of children who have self-harmed; staff working in prison
 16 settings.

1 **Figure 1: Involving family or carers in management thematic map**



1 Table 3: Summary of themes and subthemes

Themes and subthemes		Quality	No. of studies	Study populations, including those specified as sub-groups in the protocol (number of studies)
1. Communication				
	1.1 Listening to family/ carers	Moderate	8	<p>Family/ carers of people who have self-harmed (5): adult carers/family members of adults who have self-harmed (2); adult carers/family members of children who have self-harmed (2); adult carers/ family members of adults or children who have self-harmed (1); adult carers/ family members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (3): family/ carers of people who have self-harmed, ages of participants not reported and staff from mixed settings (1); adult carers/ family members, age of person who has self-harmed not reported and staff from healthcare settings (1); adult carers/family members of adults who have self-harmed and adults who have self-harmed (1)</p>
	1.2 Maintaining communication with family/ carers	Moderate	10	<p>Family/ carers of people who have self-harmed (6): adult carers/family members of adults who have self-harmed (1); adult carers/family members of children who have self-harmed (1); adult carers/ family members of adults or children who have self-harmed (2); adult carers/ family members, age of person who has self-harmed not reported (2); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (2): healthcare (0); education (1); community (1); mixed (0)</p> <p>Mixed populations (2): adult carers/family members of adults who have self-harmed and adults who have self-harmed (1); adult carers/family members of children who have self-harmed and staff from education settings (1)</p>
	1.3 Methods of communication	Low	1	<p>Family/ carers of people who have self-harmed (0): adult carers/family members of adults who have self-harmed (0); adult</p>

Themes and subthemes		Quality	No. of studies	Study populations, including those specified as sub-groups in the protocol (number of studies)
				<p>carers/family members of children who have self-harmed (0); adult carers/ family members of adults or children who have self-harmed (0); adult carers/ family members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (1): healthcare (0); education (0); community (1); mixed (0)</p> <p>Mixed populations (0)</p>
	1.4 Clarity of communication	Moderate	1	<p>Family/ carers of people who have self-harmed (1): adult carers/family members of adults who have self-harmed (1); adult carers/family members of children who have self-harmed (0); adult carers/ family members of adults or children who have self-harmed (0); adult carers/ family members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (0)</p>
	1.5 Informal pathways	Moderate	4	<p>Family/ carers of people who have self-harmed (2): adult carers/family members of adults who have self-harmed (0); adult carers/family members of children who have self-harmed (1); adult carers/ family members of adults or children who have self-harmed (0); adult carers/ family members, age of person who has self-harmed not reported (1); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (1): healthcare (0); education (1); community (0); mixed (0)</p> <p>Mixed populations (1): family/ carers of people who have self-harmed, ages of participants not reported and staff from mixed settings (1)</p>

Themes and subthemes		Quality	No. of studies	Study populations, including those specified as sub-groups in the protocol (number of studies)
	1.6 Communication between the person and their family/ carer	Moderate	6	<p>Family/ carers of people who have self-harmed (3): adult carers/family members of adults who have self-harmed (0); adult carers/family members of children who have self-harmed (2); adult carers/ family members of adults or children who have self-harmed (1); adult carers/ family members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (1): adults (0); adults and adolescents (1)</p> <p>Staff members (1): healthcare (0); education (0); community (0); mixed (1)</p> <p>Mixed populations (1): adult carers/family members of children who have self-harmed and staff from education settings (1)</p>
2. Collaboration				
	2.1 Collaboration in the management of self-harm	Moderate	13	<p>Family/ carers of people who have self-harmed (7): adult carers/family members of adults who have self-harmed (2); adult carers/family members of children who have self-harmed (2); adult carers/ family members of adults or children who have self-harmed (2); adult carers/ family members, age of person who has self-harmed not reported (1); ages of participants not reported (0)</p> <p>People who have self-harmed (3): adults (1); adults and adolescents (2)</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (3): family/ carers of people who have self-harmed, ages of participants not reported and staff from mixed settings (1); adult carers/ family members, age of person who has self-harmed not reported and staff from healthcare settings (1); adult carers/family members of adults who have self-harmed and adults who have self-harmed (1)</p>
	2.2 Seek feedback on care from family/ carers	Low	3	<p>Family/ carers of people who have self-harmed (1): adult carers/family members of adults who have self-harmed (1); adult carers/family members of children who have self-harmed (0); adult carers/ family members of adults or children who have self-harmed (0); adult carers/ family</p>

Themes and subthemes		Quality	No. of studies	Study populations, including those specified as sub-groups in the protocol (number of studies)
				<p>members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (2): family/ carers of people who have self-harmed, ages of participants not reported and staff from mixed settings (1); adult carers/ family members, age of person who has self-harmed not reported and staff from healthcare settings (1)</p>
	2.3 The effect of involvement on the quality of care	High	10	<p>Family/ carers of people who have self-harmed (5): adult carers/family members of adults who have self-harmed (2); adult carers/family members of children who have self-harmed (1); adult carers/ family members of adults or children who have self-harmed (1); adult carers/ family members, age of person who has self-harmed not reported (1); ages of participants not reported (0)</p> <p>People who have self-harmed (3): adults (1); adults and adolescents (2);</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (2): adult carers/family members of adults who have self-harmed and adults who have self-harmed (1); adult carers/family members of children who have self-harmed and staff from education settings (1)</p>
	2.4 Advocacy	Moderate	3	<p>Family/ carers of people who have self-harmed (3): adult carers/family members of adults who have self-harmed (1); adult carers/family members of children who have self-harmed (1); adult carers/ family members of adults or children who have self-harmed (1); adult carers/ family members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p>

Themes and subthemes		Quality	No. of studies	Study populations, including those specified as sub-groups in the protocol (number of studies)
				<p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (0)</p>
	2.5 Burnout	Moderate	9	<p>Family/ carers of people who have self-harmed (6): adult carers/family members of adults who have self-harmed (2); adult carers/family members of children who have self-harmed (1); adult carers/ family members of adults or children who have self-harmed (2); adult carers/ family members, age of person who has self-harmed not reported (1); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (3): adult carers/ family members, age of person who has self-harmed not reported and staff from healthcare settings (1); adult carers/family members of adults who have self-harmed and adults who have self-harmed (1); adult carers/family members of children who have self-harmed and staff from education settings (1)</p>
3. Compassion and respect				
	3.1 Respecting family/ carers	High	6	<p>Family/ carers of people who have self-harmed (5): adult carers/family members of adults who have self-harmed (1); adult carers/family members of children who have self-harmed (3); adult carers/ family members of adults or children who have self-harmed (1); adult carers/ family members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (1): adult carers/family members of children who have self-harmed and staff from education settings (1)</p>
	3.2 Supporting family/ carers to enable	High	5	<p>Family/ carers of people who have self-harmed (4): adult carers/family members</p>

Themes and subthemes		Quality	No. of studies	Study populations, including those specified as sub-groups in the protocol (number of studies)
	effective management of self-harm			<p>of adults who have self-harmed (1); adult carers/family members of children who have self-harmed (1); adult carers/ family members of adults or children who have self-harmed (1); adult carers/ family members, age of person who has self-harmed not reported (1); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (1): family/ carers of people who have self-harmed, ages of participants not reported and staff from mixed settings (1)</p>
	3.3 Create a rapport with family/ carers	Low	5	<p>Family/ carers of people who have self-harmed (3): adult carers/family members of adults who have self-harmed (1); adult carers/family members of children who have self-harmed (1); adult carers/ family members of adults or children who have self-harmed (0); adult carers/ family members, age of person who has self-harmed not reported (1); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (2): healthcare (0); education (0); community (2); mixed (0)</p> <p>Mixed populations (0)</p>
4. Resources				
	4.1 Psychoeducation	Moderate	10	<p>Family/ carers of people who have self-harmed (7): adult carers/family members of adults who have self-harmed (2); adult carers/family members of children who have self-harmed (2); adult carers/ family members of adults or children who have self-harmed (2); adult carers/ family members, age of person who has self-harmed not reported (1); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (2): healthcare (0); education (1); community (1); mixed (0)</p>

Themes and subthemes		Quality	No. of studies	Study populations, including those specified as sub-groups in the protocol (number of studies)
				Mixed populations (1): adult carers/ family members, age of person who has self-harmed not reported and staff from healthcare settings (1)
	4.2 Outreach strategies	Moderate	3	<p>Family/ carers of people who have self-harmed (1): adult carers/family members of adults who have self-harmed (0); adult carers/family members of children who have self-harmed (1); adult carers/ family members of adults or children who have self-harmed (0); adult carers/ family members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (1): healthcare (0); education (1); community (0); mixed (0)</p> <p>Mixed populations (1): adult carers/family members of children who have self-harmed and staff from education settings (1)</p>
	4.3 Facilitate help-seeking	Moderate	4	<p>Family/ carers of people who have self-harmed (4): adult carers/family members of adults who have self-harmed (0); adult carers/family members of children who have self-harmed (3); adult carers/ family members of adults or children who have self-harmed (1); adult carers/ family members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (0)</p>
5. Autonomy and privacy				
	5.1 Maintaining the privacy of the person who's self-harmed	Moderate	6	Family/ carers of people who have self-harmed (2): adult carers/family members of adults who have self-harmed (1); adult carers/family members of children who have self-harmed (0); adult carers/ family members of adults or children who have self-harmed (1); adult carers/ family members, age of person who has self-

Themes and subthemes		Quality	No. of studies	Study populations, including those specified as sub-groups in the protocol (number of studies)
				<p>harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (1): adults (0); adults and adolescents (1)</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p> <p>Mixed populations (3): family/ carers of people who have self-harmed, ages of participants not reported and staff from mixed settings (1); adult carers/ family members, age of person who has self-harmed not reported and staff from healthcare settings (1); adult carers/family members of children who have self-harmed and staff from education settings (1)</p>
	5.2 Maintaining the autonomy of the person who's self-harmed	Moderate	7	<p>Family/ carers of people who have self-harmed (3): adult carers/family members of adults who have self-harmed (1); adult carers/family members of children who have self-harmed (0); adult carers/ family members of adults or children who have self-harmed (1); adult carers/ family members, age of person who has self-harmed not reported (1); ages of participants not reported (0)</p> <p>People who have self-harmed (2): adults (1); adults and adolescents (1)</p> <p>Staff members (2): healthcare (0); education (1); community (1); mixed (0)</p> <p>Mixed populations (0)</p>
6. Safety and risk				
	6.1 Protecting staff	Very low	1	<p>Family/ carers of people who have self-harmed (0): adult carers/family members of adults who have self-harmed (0); adult carers/family members of children who have self-harmed (0); adult carers/ family members of adults or children who have self-harmed (0); adult carers/ family members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (0): adults (0); adults and adolescents (0)</p> <p>Staff members (0): healthcare (0); education (0); community (0); mixed (0)</p>

Themes and subthemes		Quality	No. of studies	Study populations, including those specified as sub-groups in the protocol (number of studies)
				Mixed populations (1): family/ carers of people who have self-harmed, ages of participants not reported and staff from mixed settings (1)
	6.2 Protecting the person who's self-harmed	Moderate	5	<p>Family/ carers of people who have self-harmed (2): adult carers/family members of adults who have self-harmed (1); adult carers/family members of children who have self-harmed (1); adult carers/ family members of adults or children who have self-harmed (0); adult carers/ family members, age of person who has self-harmed not reported (0); ages of participants not reported (0)</p> <p>People who have self-harmed (1): adults (0); adults and adolescents (1)</p> <p>Staff members (1): healthcare (0); education (0); community (0); mixed (1)</p> <p>Mixed populations (1): adult carers/family members of children who have self-harmed and staff from education settings (1)</p>

1

2 Economic evidence

3 Included studies

4 A single economic search was undertaken for all topics included in the scope of this
5 guideline but no economic studies were identified which were applicable to this review
6 question. See the literature search strategy in appendix B and economic study selection flow
7 chart in appendix G.

8 Excluded studies

9 Economic studies not included in the guideline economic literature review are listed, and
10 reasons for their exclusion are provided in appendix J.

11 Economic model

12 No economic modelling was undertaken for this review because the committee agreed that
13 other topics were higher priorities for economic evaluation.

14 Evidence statements

15 Economic

16 No economic studies were identified which were applicable to this review question.

1 The committee's discussion and interpretation of the evidence

2 The outcomes that matter most

3 The aim of this review question was to determine which ways were considered the most
4 effective for involving family and carers in the management of people who have self-harmed.
5 The committee wanted to consider a broad range of views including those involved in the
6 care of people who had self-harmed and therefore considered the views of family, carers and
7 staff in multiple settings who provide support for people who have self-harmed, as well as
8 people who had self-harmed, of equal importance for this question. The committee
9 suggested potential themes which may have arisen from the evidence such as Autonomy
10 and Advocacy but did not want to constrain the question; therefore, any views and
11 preferences about involving family and carers in the management of people who have self-
12 harmed that were regarded as useful/ not useful or important/ not important by the population
13 were included.

14 The quality of the evidence

15 When assessed using GRADE CERQual methodology the evidence was found to range in
16 quality from very low to high quality. Despite the range of quality of evidence, the committee
17 agreed that most themes identified were representative of their own knowledge and
18 experience, including those of low or very low quality. For this reason, the committee
19 considered all evidence when drafting the recommendations, supplementing any poor quality
20 data with their own expertise when necessary.

21 In some cases the evidence was downgraded due to poor applicability where the themes
22 were not based on any research from a UK context, had only been identified in studies of
23 populations which included the friends of people who had self-harmed but not necessarily
24 their carers, had only been identified in studies of populations which included people
25 expressing suicidal ideation who had not necessarily self-harmed and/ or staff working with
26 them or their family or carers, and/ or had only been identified in studies of populations which
27 included people who had lost a family member to suicide. Some downgrading for adequacy
28 occurred when the richness or quantity of the data was low. Other issues resulting in
29 downgrading were in the event of methodological problems that may have had an impact on
30 the findings, and/or for incoherence within the findings.

31 Where there was incoherence in themes due to conflicting opinions within or between
32 different populations, the committee considered why the conflict might exist to ensure that
33 recommendations were based on consensus rather than potentially minority populations. The
34 committee also tried to make recommendations that could apply a wide range of scenarios,
35 or which were dependant on variables being met, in order for care to be appropriate to each
36 individual depending on their wants and needs.

37 Benefits and harms

38 There was conflicting evidence from sub-themes identified under the theme 'Autonomy &
39 privacy'; some family members felt they had a right to private information and an input on the
40 care of the person who had self-harmed regardless of the person's wishes, while other family
41 members felt it was important that the person's privacy was maintained. People who had
42 self-harmed were wary of information being shared against their will and felt it was important
43 that they retained autonomy regarding their own care options, which some healthcare staff
44 agreed with, while school staff and other healthcare staff considered the withholding of
45 information for privacy reasons to be a barrier to family involvement, or against protocols.
46 The committee agreed with the opinions of some of the healthcare workers expressed in the
47 evidence that the person who had self-harmed should be asked if and how their family
48 members/ carer should be involved in their care, and that the involvement of family members
49 should not inappropriately override the consent of the person. The committee felt this

1 balanced the desire for family members and carers to be involved with care with the person's
2 right to maintain autonomy and privacy. The committee also reviewed the moderate quality
3 evidence which showed that there were benefits to including family members and carers in
4 the management of self-harm and agreed that it was important to encourage family members
5 to be involved in care if the person who had self-harmed had consented, as this could have a
6 positive benefit on the person's care at home.

7 The recommendations about considering the involvement of family members and carers
8 were based on the evidence mentioned above that respect for the privacy and autonomy of
9 the person who had self-harmed should be balanced with the family members' or carer's
10 desire to be involved and the potential benefits and harms of their involvement. There was
11 also evidence from the sub-theme 'Protecting the person who has self-harmed' that some
12 people who had self-harmed and their family/ carers did not want other family members to be
13 involved in the care of the person in order to protect them from harmful interactions.
14 However, this evidence contradicted other evidence that family members felt their
15 involvement was important because they could protect the person from being mistreated in
16 care. The committee agreed that there were potential risks when involving families, for
17 example where the person had not consented to their involvement, or where the sharing of
18 information could lead to safeguarding concerns or a breach of trust. They agreed that this
19 was important for adults, children and young people, because adults could also be
20 vulnerable to safeguarding issues. They also considered the evidence from the sub-theme
21 'Advocacy' that family members could advocate on behalf of the person who had self-
22 harmed, and discussed the potential benefits of family involvement if the person did not have
23 capacity. Additionally, the committee discussed whether there should be different
24 considerations for people who had self-harmed who were under the age of 18 but agreed
25 there should not be a blanket recommendation to share information about children or young
26 people of a certain age, as it may not be appropriate or could create safeguarding concerns.
27 Instead, the committee felt it was important that the decision to involve or not involve family
28 members and carers should be made in the best interests of the person who had self-
29 harmed, regardless of their age. Overall, the committee agreed that a number of factors
30 should be considered and thresholds should be met before involving family/ carers in the
31 management of self-harm.

32 There was evidence from the sub-theme 'Collaboration in the management of self-harm' that
33 family members and carers, some healthcare staff and some people who had self-harmed
34 considered a collaborative care approach that included family/ carers to be important.
35 However, there was also evidence that some people who had self-harmed and some
36 healthcare workers did not think family/ carers should be involved in care management. The
37 committee discussed this conflict of evidence in conjunction with the moderate quality
38 evidence from the sub-theme 'The effect of involvement on the quality of care' that the
39 involvement of family members and carers could have a positive effect on the person who
40 had self-harmed, and agreed that if consent for family or carer involvement had been given,
41 a collaborative approach to management of self-harm throughout the care pathway should
42 be sought. The committee agreed that this could provide a positive effect on the care of the
43 person, would meet a duty of care to the family member or carer, and would help family
44 members and carers feel validated. Family members, school staff and healthcare staff also
45 felt it was important that communication was maintained with family members and carers, as
46 evidenced in the sub-theme 'Maintaining communication with family/ carers'. The committee
47 agreed that there should be ongoing communication between family members/ carers and
48 healthcare staff involved in the care of the person. The committee also agreed, based on
49 their knowledge that consent is not static and may change at any time, that there should be
50 regular reviews of whether the person who has self-harmed still wants their family or carers
51 to be involved. They agreed regular reviews would bring awareness to any changes in the
52 person's preferences, and allow caregivers to make changes to their care as appropriate.

53 The recommendation that family members and carers could provide information on the
54 person who had self-harmed regardless of their involvement in care was based on evidence

1 from the sub-theme 'Listening to family/ carers', which showed that family members, carers
2 and healthcare staff believed that family members and carers often had access to important
3 information that could be paramount to creating the most appropriate care pathway for the
4 person who had self-harmed, and that family members could advocate on behalf of the
5 person who had self-harmed. Based on the evidence, the committee felt that a lack of
6 consent should not prevent family members and carers from sharing information that could
7 be vital to the person's wellbeing. The committee also agreed that listening to family
8 members and carers could be a validating experience and should be recommended to
9 maintain their engagement even when the person has not consented to their involvement in
10 care.

11 In the sub-theme 'Communication between the person and family/ carers', people who had
12 self-harmed and their family members and carers expressed that having the ability to
13 communicate with each other about self-harm helped to manage it, including through
14 nonverbal means such as by text or letter. The committee discussed ways in which people
15 who had self-harmed could be encouraged to communicate their needs to family members to
16 enhance care at home, and agreed based on their experience that alternative methods of
17 communication were beneficial and therefore should be recommended.

18 There was additional evidence which the committee used to inform other recommendations
19 in this guideline regarding the information and support needs of family members and carers
20 (see evidence report B). The sub-themes which explored the support needs of family
21 members and carers were: 'Burnout'; 'Supporting family/ carers to enable effective
22 management of self-harm'; 'Respecting family/ carers'; 'Create a rapport with family/ carers'.
23 The sub-themes which explored the information needs of family members and carers were:
24 'Psycho-education'; 'Outreach strategies'; 'Facilitate help-seeking'; 'Clarity of
25 communication'. The sub-theme 'Seek feedback on care from family/ carers' was also used
26 to inform the recommendation that staff training should be informed by input from people who
27 have self-harmed and their family members and carers (see Evidence Reports P and R).

28 The quality of the evidence from the sub-themes 'Methods of communication', 'Informal
29 pathways' and 'Protecting staff' was very low and there was other sufficient moderate or high
30 quality evidence to support the drafting of recommendations, so the committee only
31 discussed these sub-themes briefly, as supplementary to the others.

32 **Cost effectiveness and resource use**

33 The committee noted that no relevant published economic evaluations had been identified
34 and no additional economic analysis had been undertaken in this area. They drafted
35 recommendations to promote changes in service delivery and to incorporate potentially more
36 effective ways of involving families and carers.

37 The committee noted that providers may need to change how they involve carers in the
38 support and treatment of people who have self-harmed, but the costs will be minimal and are
39 expected to result in a higher quality of care for people who have self-harmed.

40 **Recommendations supported by this evidence review**

41 This evidence review supports recommendations 1.4.1-1.4.5 and 1.10.2.

1 References – included studies

2 Qualitative

Study
Bouwman, R., de Graaff, B., de Beurs, D. et al. (2018) Involving patients and families in the analysis of suicides, suicide attempts, and other sentinel events in mental healthcare: A qualitative study in The Netherlands. <i>International Journal of Environmental Research and Public Health</i> 15 (6)
Byrne, S., Morgan, S., Fitzpatrick, C. et al. (2008) Deliberate self-harm in children and adolescents: A qualitative study exploring the needs of parents and carers. <i>Clinical Child Psychology and Psychiatry</i> 13: 493-504
Chew-Graham, C., Bashir, C., Chantier, K. et al. (2002) South Asian women, psychological distress and self-harm: Lessons for primary care trusts. <i>Health and Social Care in the Community</i> 10: 339-347
Dempsey, Sarah-Jane A., Halperin, Steve, Smith, Karen et al. (2019) "Some guidance and somewhere safe": Caregiver and clinician perspectives on service provision for families of young people experiencing serious suicide ideation and attempt. <i>Clinical Psychologist</i> 23: 103-111
Dransart, D. A. C. and Guerry, S. (2017) Help-seeking in suicidal situations: Paramount and yet challenging. Interactions between significant others of suicidal persons and health care providers. <i>Journal of Clinical Medicine</i> 6 (2)
Ferrey, A. E., Hughes, N. D., Simkin, S. et al. (2016) Changes in parenting strategies after a young person's self-harm: A qualitative study. <i>Child and Adolescent Psychiatry and Mental Health</i> 10 (1)
Ferrey, A. E., Hughes, N. D., Simkin, S. et al. (2016) The impact of self-harm by young people on parents and families: A qualitative study. <i>BMJ Open</i> 6 (1)
Ferrey, Anne E., Hawton, Keith, Simkin, Sue et al. (2015) "As a parent, there is no rulebook": A new resource for parents and carers of young people who self-harm. <i>The Lancet Psychiatry</i> 2: 577-579
Grandclerc, S., Spiers, S., Spodenkiewicz, M. et al. (2019) The quest for meaning around self-injurious and suicidal acts: A qualitative study among adolescent girls. <i>Frontiers in Psychiatry</i> 10 (APR)
Hom, Melanie A., Albury, Evan A., Gomez, Marielle M. et al. (2020) Suicide attempt survivors' experiences with mental health care services: A mixed methods study. <i>Professional Psychology: Research and Practice</i> 51: 172-183
Idenfors, Hans; Kullgren, Gunnar; Salander Renberg, Ellinor (2015) Professional care as an option prior to self-harm: A qualitative study exploring young people's experiences. <i>Crisis: The Journal of Crisis Intervention and Suicide Prevention</i> 36: 179-186
Jennings, S. and Evans, R. (2020) Inter-professional practice in the prevention and management of child and adolescent self-harm: foster carers' and residential carers' negotiation of expertise and professional identity. <i>Sociology of health & illness</i> 42: 1024-1040

Study
Kelada, Lauren, Whitlock, Janis, Hasking, Penelope et al. (2016) Parents' experiences of nonsuicidal self-injury among adolescents and young adults. <i>Journal of Child and Family Studies</i> 25: 3403-3416
Kennard, B., Moorehead, A., Stewart, S. et al. (2020) Adaptation of Group-Based Suicide Intervention for Latinx Youth in a Community Mental Health Center. <i>Journal of Child and Family Studies</i>
Krysinska, K., Curtis, S., Lamblin, M. et al. (2020) Parents' experience and psychoeducation needs when supporting a young person who self-harms. <i>International Journal of Environmental Research and Public Health</i> 17 (10)
Lindgren, Britt-Marie; Astrom, Sture; Graneheim, Ulla Hallgren (2010) Held to ransom: Parents of self-harming adults describe their lived experience of professional care and caregivers. <i>International Journal of Qualitative Studies on Health and Well-being</i> 5: 1-10
McLaughlin, C., McGowan, I., Kernohan, G. et al. (2016) The unmet support needs of family members caring for a suicidal person. <i>Journal of Mental Health</i> 25: 212-216
Nadeem, E., Santiago, C. D., Kataoka, S. H. et al. (2016) School Personnel Experiences in Notifying Parents About Their Child's Risk for Suicide: Lessons Learned. <i>The Journal of school health</i> 86: 3-10
Oldershaw, A., Richards, C., Simic, M. et al. (2008) Parents' perspectives on adolescent self-harm: Qualitative study. <i>British Journal of Psychiatry</i> 193: 140-144
Raphael, H.; Clarke, G.; Kumar, S. (2006) Exploring parents' responses to their child's deliberate self-harm. <i>Health Education</i> 106: 9-20
Rissanen, M. L.; Kylma, J.; Laukkanen, E. (2009) Descriptions of help by Finnish adolescents who self-mutilate. <i>Journal of child and adolescent psychiatric nursing : official publication of the Association of Child and Adolescent Psychiatric Nurses, Inc</i> 22: 7-15
Rissanen, M. L.; Kylma, J.; Laukkanen, E. (2009) Helping adolescents who self-mutilate: parental descriptions. <i>Journal of clinical nursing</i> 18: 1711-1721
Rissanen, M. L.; Kylma, J.; Laukkanen, E. (2012) Helping self-mutilating adolescents: Descriptions of Finnish nurses. <i>Issues in Mental Health Nursing</i> 33: 251-262
Sellin, L., Kumlin, T., Wallsten, T. et al. (2018) Caring for the suicidal person: A Delphi study of what characterizes a recovery-oriented caring approach. <i>International journal of mental health nursing</i> 27: 1756-1766
Spillane, A., Matvienko-Sikar, K., Larkin, C. et al. (2019) How do people experience a family member's high-risk self-harm? An interpretative phenomenological analysis. <i>Archives of suicide research : official journal of the International Academy for Suicide Research</i> : 1-23

Study
Stewart, A., Hughes, N. D., Simkin, S. et al. (2018) Navigating an unfamiliar world: how parents of young people who self-harm experience support and treatment. <i>Child and Adolescent Mental Health</i> 23: 78-84
Wand, A. P. F., Draper, B., Brodaty, H. et al. (2019) Self-harm in the very old one year later: Has anything changed?. <i>International Psychogeriatrics</i> 31: 1559-1568
Wand, A. P. F., Peisah, C., Draper, B. et al. (2019) Carer insights into self-harm in the very old: A qualitative study. <i>International Journal of Geriatric Psychiatry</i> 34: 594-600
Wester, Sheri Lea (2018) Community and family support systems' process of supporting adolescents' termination of nonsuicidal self-injury: A grounded theory study. <i>Dissertation Abstracts International: Section B: The Sciences and Engineering</i> 79: No-Specified

1 Economic

2 No studies were identified that met the inclusion criteria.

3

1 Appendices

2 Appendix A Review protocols

3 Review protocol for review question: What are the views and preferences of people who have self-harmed, their families 4 and carers, and staff working with people who have self-harmed about the best ways of involving family and carers in the 5 management of people who have self-harmed?

6 Table 4: Review protocol

Field	Content
PROSPERO registration number	CRD42020206261
Review title	Involving family and carers in the management of people who have self-harmed
Review question	What are the views and preferences of people who have self-harmed, their families and carers, and staff working with people who have self-harmed about the best ways of involving family and carers in the management of people who have self-harmed?
Objective	To identify the most effective ways of involving family and carers in the management of people who have self-harmed.
Searches	<p>The following databases will be searched:</p> <ul style="list-style-type: none"> • Applied Social Sciences Index and Abstracts (ASSIA) • Cochrane Central Register of Controlled Trials (CENTRAL) • Cochrane Database of Systematic Reviews (CDSR) • Database of Abstracts of Reviews of Effects (DARE) • Embase • Emcare • International Health Technology Assessment (IHTA) database • MEDLINE & MEDLINE In-Process • PsycINFO • Social Sciences Citation Index (SSCI) • Web of Science (WoS) <p>Searches will be restricted by:</p> <ul style="list-style-type: none"> • Qualitative/patient issues study filter • English language studies • Human studies • Date: 2000 onwards <p>Other searches:</p>

Field	Content
	<ul style="list-style-type: none"> Inclusion lists of systematic reviews Forward and backward citation searches of key studies <p>The full search strategies will be published in the final review.</p>
Condition or domain being Studied	<p>All people who have self-harmed, including those with a mental health problem, neurodevelopmental disorder or a learning disability.</p> <p>'Self-harm' is defined as intentional self-poisoning or injury irrespective of the apparent purpose of the act. This does not include any mental health problem or substance use disorder that may be associated with self-harm, nor does it include repetitive stereotypical self-injurious behaviour, for example head-banging in people with a significant learning disability.</p>
Population	<p>Inclusion:</p> <ul style="list-style-type: none"> All carers or family members of people who have self-harmed, including child and adult family members, and carers/ family members of people who have self-harmed and have a mental health problem, neurodevelopmental disorder or a learning disability. All people who have self-harmed, including those with a mental health problem, neurodevelopmental disorder or a learning disability. All health care staff working in settings where people who have self-harmed present, are assessed or are treated Staff working in educational setting, prison settings and social care with people who have self-harmed Staff working in third sector and other sectors involved in the delivery in the clinical support of people who have self-harmed <p>Exclusion:</p> <ul style="list-style-type: none"> Carers or family members of people displaying repetitive stereotypical self-injurious behaviour, for example head-banging in people with a significant learning disability People displaying repetitive stereotypical self-injurious behaviour, for example head-banging in people with a significant learning disability
Phenomenon of interest	<p>Views and preferences about involving family and carers in the management of people who have self-harmed that are regarded as useful/ not useful or important/ not important by the population</p> <p>Themes will be identified from the literature, but may include:</p> <ul style="list-style-type: none"> Information content/psychoeducation Collaborative decision making Communication Autonomy Compassionate and respectful treatment Help-seeking Advocacy Safety and risk Validation
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	<ul style="list-style-type: none"> Systematic reviews of qualitative studies

Field	Content
	<ul style="list-style-type: none"> Qualitative studies (for example, semi-structured and structured interviews, focus groups, observations, and surveys with free text questions)
Other exclusion criteria	<p>Studies will not be included for the following reasons:</p> <p>Study design:</p> <ul style="list-style-type: none"> Purely quantitative studies (including surveys with only descriptive quantitative data) <p>Country:</p> <ul style="list-style-type: none"> The committee wished to prioritise evidence from settings which most closely reflect the UK practice context. They therefore agreed to include studies from high income European countries according to the World Bank (https://datahelpdesk.worldbank.org/knowledgebase/articles/906519; i.e., Andorra, Austria, Belgium, Channel Islands, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Faroe Islands, Finland, France, Germany, Gibraltar, Greece, Greenland, Hungary, Iceland, Ireland, Isle of Man, Italy, Latvia, Lichtenstein, Lithuania, Luxembourg, Monaco, Netherlands, Norway, Poland, Portugal, San Marino, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, and UK), Canada, US, Australia and New Zealand, which would be sufficiently transferable. Priority will be given to UK studies, however data from studies conducted in other high-income countries will be added if new themes arise that are not captured in the UK evidence. <p>Language:</p> <ul style="list-style-type: none"> Non-English <p>Publication status:</p> <ul style="list-style-type: none"> Abstract only
Context	<p>Settings - Inclusion:</p> <p>All inpatient, outpatient and community settings in which management of people who have self-harmed is provided, including:</p> <ul style="list-style-type: none"> Primary, secondary and tertiary healthcare settings (including pre-hospital care, accident and emergency departments, community pharmacies, inpatient care, and transitions between departments and services) Home, residential and community settings, such as supported accommodation Supported care settings Education and childcare settings Criminal justice system Immigration removal centres. Community mental health services Inpatient mental health services
Primary outcomes (critical outcomes)	Please see potential themes under Phenomenon of interest
Secondary outcomes (important outcomes)	Please see potential themes under Phenomenon of interest
Data extraction (selection and	All references identified by the searches and from other sources will be uploaded into EPPI and de-duplicated.

Field	Content
coding)	<p>Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol.</p> <p>Dual sifting will be performed on 10% of records; 90% agreement is required. Disagreements will be resolved via discussion between the two reviewers, and consultation with senior staff if necessary.</p> <p>Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion.</p> <p>A standardised form will be used to extract data from studies. The following data will be extracted: study details (reference, country where study was carried out, type and dates), participant characteristics, details of research questions and methods (including analytical and data collection technique), relevant key themes/ findings, risk of bias and source of funding. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.</p>
Risk of bias (quality) assessment	<p>Risk of bias of systematic reviews of qualitative studies will be assessed using the scale by Flemming (2012) (https://www.sbu.se/contentassets/14570b8112c5464cbb2c256c11674025/methodological_limitations_qualitative_evidence_synthes_is.pdf) and risk of bias of original qualitative studies will be assessed using the CASP qualitative checklist as described in Developing NICE guidelines: the manual.</p>
Strategy for data synthesis	<p>EPPI-Reviewer software will be used for generating bibliographies/citations, study sifting and data extraction.</p> <p>Studies will be reviewed chronologically from most recent first to oldest.</p> <p>Thematic analysis of the data will be conducted and findings presented.</p> <p>The quality of the evidence will be assessed using GRADE-CERQual for each theme.</p>
Analysis of sub-groups	<p>Formal subgroup analyses are not appropriate for this question due to qualitative data, but the evidence from the following groups will be considered separately if there is inconsistency or incoherence in the results for a given theme:</p> <ul style="list-style-type: none"> • Family members/carers (Adult carers/family member of adults who have self-harmed, adult carers/family member of children who have self-harmed, child family member of adults who have self-harmed, child family member of children who have self-harmed); • People who have self-harmed (adults, children); • Staff working in the following settings with people who have self-harmed: Healthcare, education, prisons, and in the third sector and other sectors involved in the delivery in the clinical support of people who have self-harmed
Type and method of review	Qualitative
Language	English
Country	England
Anticipated or actual start date	17/08/2020
Anticipated completion date	26/01/2022

Field	Content																					
Stage of review at time of this submission	<table border="1"> <thead> <tr> <th>Review stage</th> <th>Started</th> <th>Completed</th> </tr> </thead> <tbody> <tr> <td>Preliminary searches</td> <td><input type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> <tr> <td>Piloting of the study selection process</td> <td><input type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> <tr> <td>Formal screening of search results against eligibility criteria</td> <td><input type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> <tr> <td>Data extraction</td> <td><input type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> <tr> <td>Risk of bias (quality) assessment</td> <td><input type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> <tr> <td>Data analysis</td> <td><input type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> </tbody> </table>	Review stage	Started	Completed	Preliminary searches	<input type="checkbox"/>	<input checked="" type="checkbox"/>	Piloting of the study selection process	<input type="checkbox"/>	<input checked="" type="checkbox"/>	Formal screening of search results against eligibility criteria	<input type="checkbox"/>	<input checked="" type="checkbox"/>	Data extraction	<input type="checkbox"/>	<input checked="" type="checkbox"/>	Risk of bias (quality) assessment	<input type="checkbox"/>	<input checked="" type="checkbox"/>	Data analysis	<input type="checkbox"/>	<input checked="" type="checkbox"/>
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Data analysis	<input type="checkbox"/>	<input checked="" type="checkbox"/>																				
Named contact	<p>5a. Named contact: National Guideline Alliance</p> <p>5b Named contact e-mail: selfharm@nice.org.uk</p> <p>5e Organisational affiliation of the review: National Institute for Health and Care Excellence (NICE) and National Guideline Alliance</p>																					
Review team members	National Guideline Alliance																					
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance which receives funding from NICE.																					
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.																					
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10105																					
Other registration details	None																					
URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=206261																					

Field	Content
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: <ul style="list-style-type: none"> • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.
Keywords	Self-harm, assessment, management, prevention, support needs, health care
Details of existing review of same topic by same authors	None
Current review status	Ongoing
Additional information	Not applicable
Details of final publication	www.nice.org.uk

- 1 *CASP: Critical Appraisal Skills Programme; CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; CERQual: Confidence in the Evidence*
- 2 *from Reviews of Qualitative Research; GRADE: Grading of Recommendations Assessment, Development and Evaluation; NGA: National Guideline Alliance; NICE: National Institute for Health and*
- 3 *Care Excellence*

1 Appendix B Literature search strategies

2 Literature search strategies for review question: What are the views and
3 preferences of people who have self-harmed, their families and carers, and
4 staff working with people who have self-harmed about the best ways of
5 involving family and carers in the management of people who have self-
6 harmed?

7 Clinical

8

9 Database(s): MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-
10 Indexed Citations and Daily – OVID interface

11 Date of last search: 4th September 2020

12

#	Searches
1	exp self-injurious behavior/ or self mutilation/ or suicide/ or suicidal ideation/ or suicide, attempted/ or suicide, completed/
2	(automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*).ti,ab.
3	or/1-2
4	caregiver*.sh. or exp family/
5	(brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*).ti,ab.
6	or/4-5
7	(autonomy* or advocacy).hw. or exp *caregivers/ed, og, px or exp *communication/ or exp *decision making/ or *decision making, shared/ or empathy/ or exp *families/ed, og, px or help seeking behavior/ or information seeking behavior/ or exp *interpersonal relations/ or exp parent child relations/ or professional family relations/
8	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*) adj5 (autonom* or choice* or cohesion or communicat* or consensus or decision* or dissent* or disput* or empower* or engag* or expertise or inclusion or information* or involv* or intervention* or manag* or negotiat* or network* or participat* or phamplet* or plan* or program* or psychoed* or psycho ed* or strateg* or support*) adj5 (adolescent* or adult* or boy* or child* or girl* or harmer* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*).ti,ab.
9	((camhs or clinician* or counsel?or* or cpn*1 or crisis resolution team* or doctor* or gp or lecturer* or (mental health adj (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist*

#	Searches
	or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*) and (educat* or learn* or teach* or train*) and ((autonom* or choice* or cohesion or communicat* or consensus or decision* or dissent* or disput* or empower* or engag* or expertise or inclusion or information* or involv* or manag* or negotiat* or network* or participat* or phamplet* or plan* or program* or psychoed* or psycho ed* or strateg* or support*) adj5 (carer* or caregiv* or care giv* or famil* or parent*))) .ti,ab.
10	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) adj10 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) adj10 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or self harmer* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*))) .ti.
11	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) adj5 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) adj5 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or self harmer* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*))) .ti,ab.
12	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) adj5 (intervention* or program* or strateg*)) and (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*)) .ti,ab.
13	((carer* or caregiv* or care giv* or famil* or parent*) and (early adj2 intervention*)) .ti,ab.
14	((carer* or caregiv* or care giv* or famil* or parent*) adj7 (educat* or intervention* or learn* or program* or skill* or strateg* or teach* or technique*) adj7 confiden*) .ti,ab.
15	((carer* or caregiv* or care giv* or famil* or parent*) and information) .ti. or (((carer* or caregiv* or care giv* or famil* or parent*) adj group*) or ((carer* or caregiv* or care giv* or famil* or parent*) adj7 information) or ((carer* or caregiv* or care giv* or famil* or parent*) and (phamplet* or (written adj2 information)))) or ((carer* or caregiv* or care giv* or famil* or parent*) adj5 (communicat* or decision* or information or interact* or involv* or manag* or speak* or talk*) adj5 (camhs or clinician* or counsel?or* or cpn*1 or crisis resolution team* or doctor* or gp or lecturer* or (mental health adj (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or

#	Searches
	professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*))).ti,ab.
16	((((carer* or caregiv* or care giv* or family or family focused or home or home based or parent*) adj3 (helping service* or intervention* or psychoed* or psycho ed* or psychosocial or service level intervention* or system* or support network* or therap*)) or (help adj3 (carer* or caregiv* or care giv* or famil* or parent*) adj3 recover*) or ((carer* or caregiv* or care giv* or family or family focused or home or home based or parent*) adj7 experience* adj7 (support* or treatment*)) or (((information* or skill*) adj5 (manag* or support) adj5 (automutilat* or auto mutilat* or cutt* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*)) and (carer* or caregiv* or care giv* or famil* or parent*)) or ((carer* or caregiv* or care giv* or famil* or parent*) adj3 (help* or support*))).ti,ab.
17	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*) and (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) and (focus group* or (qualitative* or interview* or focus group* or questionnaire* or narrative* or narration* or survey*) or (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*) or (hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*) or (metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*) or (critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)) or (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*))).ti.
18	((family or parent) adj (based or led)).ti,ab.
19	((carer* or caregiv* or care giv* or famil* or parent*) adj2 support*).ti,ab.
20	((carer* or caregiv* or care giv* or famil* or parent*) adj3 (((intra* or inter*) adj2 professional*) or interprofessional* or intraprofessional*))).ti,ab.
21	((carer* or caregiv* or care giv* or family or family focused or home or home based or parent*) adj3 involve* adj5 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*))).ti,ab.
22	((carer* or caregiv* or care giv* or famil* or parent*) adj5 (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or interaction* or know* or needs or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view* or help seek or helpseek* or (seek* adj2 help)) adj5 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or

#	Searches
	men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or self harmer* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*).ti,ab.
23	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) adj5 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) adj5 (focus group* or (qualitative* or interview* or focus group* or questionnaire* or narrative* or narration* or survey*) or (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*) or (hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*) or (metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*) or (critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)) or (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*))).ti,ab.
24	or/7-23
25	anthropology, cultural/ or cluster analysis/ or focus groups/ or grounded theory/ or health care surveys/ or interview.pt. or "interviews as topic"/ or narration/ or nursing methodology research/ or observation/ or "personal narratives as topic"/ or narrative/ or qualitative research/ or "surveys and questionnaires"/ or sampling studies/ or tape recording/ or videodisc recording/
26	focus group*.ti,ab.
27	(qualitative* or interview* or focus group* or questionnaire* or narrative* or narration* or survey*).ti,ab.
28	(ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*).tw.
29	(hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).tw.
30	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw.
31	(critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)).tw.
32	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife* or adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or selfharmer* or self harmer* or self harmed or self harmed or service

#	Searches
	user* or teen* or woman or women or youngster* or youth* or camhs or clinician* or counsel?or* or cpn*1 or crisis resolution team* or doctor* or gp or lecturer* or (mental health adj (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*) adj6 (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*).ti,ab.
33	or/25-32
34	letter/ or editorial/ or news/ or exp historical article/ or anecdotes as topic/ or comment/ or case report/ or (letter or comment*).ti. or (animals not humans).sh. or exp animals, laboratory/ or exp animal experimentation/ or exp models, animal/ or exp rodentia/ or (rat or rats or mouse or mice).ti.
35	(3 and 6 and 24 and 33) not 34
36	35
37	limit 36 to (english language and yr="2000 -Current")

1

2 **Database(s): Embase and Emcare – OVID interface**

3 Date of last search: 4th September 2020

4

#	Searches
1	automutilation/ or exp suicidal behavior/
2	(automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*).ti,ab.
3	or/1-2
4	caregiver*.sh. or exp family/
5	(brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*).ti,ab.
6	or/4-5
7	patient autonomy/ or advocacy.hw. or exp child parent relation/ or human relation/ or exp *interpersonal communication/ or exp *decision making/ or empathy/ or help seeking behavior/ or exp human relation/ or exp information seeking/ or ((*caregiver/ or exp *family/) and (education* or organi?ation or planning).hw.)
8	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*) adj5 (autonom* or choice* or cohesion or communicat* or consensus or decision* or dissent* or disput* or empower* or engag* or expertise or inclusion or information* or involv* or intervention* or manag* or negotiat* or network* or participat* or phamplet* or plan*

#	Searches
	or program* or psychoed* or psycho ed* or strateg* or support*) adj5 (adolescent* or adult* or boy* or child* or girl* or harmer* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*).ti,ab.
9	((camhs or clinician* or counsel?or* or cpn*1 or crisis resolution team* or doctor* or gp or lecturer* or (mental health adj (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*) and (educat* or learn* or teach* or train*) and ((autonom* or choice* or cohesion or communicat* or consensus or decision* or dissent* or disput* or empower* or engag* or expertise or inclusion or information* or involv* or manag* or negotiat* or network* or participat* or phamplet* or plan* or program* or psychoed* or psycho ed* or strateg* or support*) adj5 (carer* or caregiv* or care giv* or famil* or parent*))).ti,ab.
10	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) adj10 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) adj10 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or self harmer* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*).ti.
11	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) adj5 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) adj5 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or self harmer* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*).ti,ab.
12	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) adj5 (intervention* or program* or strateg*)) and (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*).ti,ab.
13	((carer* or caregiv* or care giv* or famil* or parent*) and (early adj2 intervention*).ti,ab.
14	((carer* or caregiv* or care giv* or famil* or parent*) adj7 (educat* or intervention* or learn* or program* or skill* or strateg* or teach* or technique*) adj7 confiden*).ti,ab.

#	Searches
15	((carer* or caregiv* or care giv* or famil* or parent*) and information).ti. or (((carer* or caregiv* or care giv* or famil* or parent*) adj group*) or ((carer* or caregiv* or care giv* or famil* or parent*) adj7 information) or ((carer* or caregiv* or care giv* or famil* or parent*) and (phamplet* or (written adj2 information))) or ((carer* or caregiv* or care giv* or famil* or parent*) adj5 (communicat* or decision* or information or interact* or involv* or manag* or speak* or talk*) adj5 (camhs or clinician* or counsel?or* or cpn*1 or crisis resolution team* or doctor* or gp or lecturer* or (mental health adj (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*))).ti,ab.
16	(((carer* or caregiv* or care giv* or family or family focused or home or home based or parent*) adj3 (helping service* or intervention* or psychoed* or psycho ed* or psychosocial or service level intervention* or system* or support network* or therap*)) or (help adj3 (carer* or caregiv* or care giv* or famil* or parent*) adj3 recover*) or ((carer* or caregiv* or care giv* or family or family focused or home or home based or parent*) adj7 experience* adj7 (support* or treatment*)) or (((information* or skill*) adj5 (manag* or support) adj5 (automutilat* or auto mutilat* or cutt* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*)) and (carer* or caregiv* or care giv* or famil* or parent*)) or ((carer* or caregiv* or care giv* or famil* or parent*) adj3 (help* or support*))).ti,ab.
17	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*) and (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) and (focus group* or (qualitative* or interview* or focus group* or questionnaire* or narrative* or narration* or survey*) or (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*) or (hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*) or (metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*) or (critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)) or (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*))).ti.
18	((family or parent) adj (based or led)).ti,ab.
19	((carer* or caregiv* or care giv* or famil* or parent*) adj2 support*).ti,ab.
20	((carer* or caregiv* or care giv* or famil* or parent*) adj3 (((intra* or inter*) adj2 professional*) or interprofessional* or intraprofessional*)).ti,ab.
21	((carer* or caregiv* or care giv* or family or family focused or home or home based or parent*) adj3 involve* adj5 (automutilat* or auto mutilat* or (self adj2 cut*) or

#	Searches
	selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*).ti,ab.
22	((carer* or caregiv* or care giv* or famil* or parent*) adj5 (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or interaction* or know* or needs or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view* or help seek or helpseek* or (seek* adj2 help)) adj5 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or self harmer* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*).ti,ab.
23	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*) adj5 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) adj5 (focus group* or (qualitative* or interview* or focus group* or questionnaire* or narrative* or narration* or survey*) or (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*) or (hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*) or (metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*) or (critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)) or (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*).ti,ab.
24	or/7-23
25	cultural anthropology/ or cluster analysis/ or grounded theory/ or health care survey/ or information processing/ or interview/ or narrative/ or nursing methodology research/ or observation/ or qualitative research/ or questionnaire/ or recording/ or verbal communication/ or videorecording/
26	focus group*.ti,ab.
27	(qualitative* or interview* or focus group* or questionnaire* or narrative* or narration* or survey*).ti,ab.
28	(ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*).tw.
29	(hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).tw.
30	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw.

#	Searches
31	(critical interpretive syntheses* or (realist adj (review* or syntheses*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj syntheses*)).tw.
32	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive* or adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or selfharmer* or self harmer* or self harmed or self harmed or service user* or teen* or woman or women or youngster* or youth* or camhs or clinician* or counsel?or* or cpn*1 or crisis resolution team* or doctor* or gp or lecturer* or (mental health adj (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*) adj6 (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*)).ti,ab.
33	or/25-32
34	(animal/ not human/) or exp Animal Experiment/ or animal model/ or exp Experimental Animal/ or nonhuman/ or exp Rodent/ or (rat or rats or mouse or mice).ti.
35	(3 and 6 and 24 and 33) not 34
36	35
37	limit 36 to (english language and yr="2000 -Current")

- 1
- 2 **Database(s): PsycINFO – OVID interface**
- 3 Date of last search: 4th September 2020
- 4

#	Searches
1	self-injurious behavior/ or self-destructive behavior/ or self-inflicted wounds/ or self-mutilation/ or self-poisoning/ or exp suicide/ or suicidal ideation/
2	(automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*).ti,ab.
3	or/1-2
4	Caregivers/ or exp family/
5	(brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*).ti,ab.
6	or/4-5

#	Searches
7	autonomy/ or (*caregivers/ and (education.hw. or management planning.sh.)) or *communication/ or exp *decision making/ or empathy/ or (exp *family/ and (education.hw. or management planning.sh.)) or help seeking behavior/ or health care seeking behavior/ or *interpersonal relationships/ or parent child relations/
8	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) adj5 (autonom* or choice* or cohesion or communicat* or consensus or decision* or dissent* or disput* or empower* or engag* or expertise or inclusion or information* or involv* or intervention* or manag* or negotiat* or network* or participat* or phamplet* or plan* or program* or psychoed* or psycho ed* or strateg* or support*) adj5 (adolescent* or adult* or boy* or child* or girl* or harmer* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*)).ti,ab.
9	((camhs or clinician* or counsel?or* or cpn*1 or crisis resolution team* or doctor* or gp or lecturer* or (mental health adj (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*) and (educat* or learn* or teach* or train*) and ((autonom* or choice* or cohesion or communicat* or consensus or decision* or dissent* or disput* or empower* or engag* or expertise or inclusion or information* or involv* or manag* or negotiat* or network* or participat* or phamplet* or plan* or program* or psychoed* or psycho ed* or strateg* or support*) adj5 (carer* or caregiv* or care giv* or famil* or parent*))).ti,ab.
10	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) adj10 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) adj10 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or self harmer* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*)).ti.
11	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) adj5 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) adj5 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or self harmer* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*)).ti,ab.

#	Searches
12	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*) adj5 (intervention* or program* or strateg*)) and (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*).ti,ab.
13	((carer* or caregiv* or care giv* or famil* or parent*) and (early adj2 intervention*).ti,ab.
14	((carer* or caregiv* or care giv* or famil* or parent*) adj7 (educat* or intervention* or learn* or program* or skill* or strateg* or teach* or technique*) adj7 confiden*).ti,ab.
15	((carer* or caregiv* or care giv* or famil* or parent*) and information).ti. or (((carer* or caregiv* or care giv* or famil* or parent*) adj group*) or ((carer* or caregiv* or care giv* or famil* or parent*) adj7 information) or ((carer* or caregiv* or care giv* or famil* or parent*) and (phamplet* or (written adj2 information))) or ((carer* or caregiv* or care giv* or famil* or parent*) adj5 (communicat* or decision* or information or interact* or involv* or manag* or speak* or talk*) adj5 (camhs or clinician* or counsel?or* or cpn*1 or crisis resolution team* or doctor* or gp or lecturer* or (mental health adj (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*))).ti,ab.
16	((carer* or caregiv* or care giv* or family or family focused or home or home based or parent*) adj3 (helping service* or intervention* or psychoed* or psycho ed* or psychosocial or service level intervention* or system* or support network* or therap*)) or (help adj3 (carer* or caregiv* or care giv* or famil* or parent*) adj3 recover*) or ((carer* or caregiv* or care giv* or family or family focused or home or home based or parent*) adj7 experience* adj7 (support* or treatment*)) or (((information* or skill*) adj5 (manag* or support) adj5 (automutilat* or auto mutilat* or cutt* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*)) and (carer* or caregiv* or care giv* or famil* or parent*)) or ((carer* or caregiv* or care giv* or famil* or parent*) adj3 (help* or support*))).ti,ab.
17	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*) and (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) and (focus group* or (qualitative* or interview* or focus group* or questionnaire* or narrative* or narration* or survey*) or (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*) or (hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*) or (metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*) or (critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or

#	Searches
	framework) adj synthes*) or (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*))).ti.
18	((family or parent) adj (based or led)).ti,ab.
19	((carer* or caregiv* or care giv* or famil* or parent*) adj2 support*).ti,ab.
20	((carer* or caregiv* or care giv* or famil* or parent*) adj3 (((intra* or inter*) adj2 professional*) or interprofessional* or intraprofessional*))).ti,ab.
21	((carer* or caregiv* or care giv* or family or family focused or home or home based or parent*) adj3 involve* adj5 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*))).ti,ab.
22	((carer* or caregiv* or care giv* or famil* or parent*) adj5 (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or interaction* or know* or needs or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view* or help seek or helpseek* or (seek* adj2 help)) adj5 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or self harmer* or selfharmer* or service user* or teen* or woman or women or youngster* or youth*))).ti,ab.
23	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wive*) adj5 (automutilat* or auto mutilat* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*) adj5 (focus group* or (qualitative* or interview* or focus group* or questionnaire* or narrative* or narration* or survey*) or (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*) or (hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*) or (metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*) or (critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)) or (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*))).ti,ab.
24	or/7-23
25	cluster analysis/ or focus group/ or grounded theory/ or surveys/ or intervies/ or narratives/ or qualitative methods/ or questionnaires/ or tape recorders/
26	focus group*.ti,ab.

#	Searches
27	(qualitative* or interview* or focus group* or questionnaire* or narrative* or narration* or survey*).ti,ab.
28	(ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*).tw.
29	(hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).tw.
30	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw.
31	(critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)).tw.
32	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife* or adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or selfharmer* or self harmer* or self harmed or self harmed or service user* or teen* or woman or women or youngster* or youth* or camhs or clinician* or counsel?or* or cpn*1 or crisis resolution team* or doctor* or gp or lecturer* or (mental health adj (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*) adj6 (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*)).ti,ab.
33	or/25-32
34	(3 and 6 and 24 and 33)
35	limit 34 to (english language and yr="2000 -Current")

1

2 **Database(s): Cochrane Library - Wiley interface**

3 Cochrane Database of Systematic Reviews, Issue 9 of 12, September 2020;

4 Cochrane Central Register of Controlled Trials, Issue 9 of 12, September 2020

5 Date of last search: 4th September 2020

6

#	Searches
1	MeSH descriptor: [poisoning] this term only
2	MeSH descriptor: [self-injurious behavior] explode all trees
3	MeSH descriptor: [self mutilation] this term only
4	MeSH descriptor: [suicide] this term only
5	MeSH descriptor: [suicidal ideation] this term only

#	Searches
6	MeSH descriptor: [suicide, attempted] this term only
7	MeSH descriptor: [suicide, completed] this term only
8	(automutilat* or "auto mutilat*" or cutt* or (self near/2 cut*) or selfdestruct* or "self destruct*" or selfharm* or "self harm*" or selfimmolat* or "self immolat*" or selfinflict* or "self inflict*" or selfinjur* or "self injur*" or selfmutilat* or "self mutilat*" or selfpoison* or "self poison*" or selfwound* or "self wound*" or suicid*):ti,ab.
9	{or #1-#8}
10	caregiver*.kw.
11	MeSH descriptor: [family] explode all trees
12	(brother* or carer* or caregiv* or "care giv*" or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or "significant other*" or sister* or spous* or mother* or parent* or wife* or wive*):ti,ab.
13	{OR #10-#12}
14	(autonomy* or advocacy):kw.
15	MeSH descriptor: [caregivers] this term only and with qualifier(s) [education - ED, organization & administration - OG, psychology - PX]
16	MeSH descriptor: [communication] explode all trees
17	MeSH descriptor: [decision making] explode all trees
18	MeSH descriptor: [decision making, shared] this term only
19	MeSH descriptor: [empathy] this term only
20	MeSH descriptor: [families] this term only and with qualifier(s) [education - ED, organization & administration - OG, psychology - PX]
21	MeSH descriptor: [help seeking behavior] this term only
22	MeSH descriptor: [information seeking behavior] this term only
23	MeSH descriptor: [interpersonal relations] explode all trees
24	MeSH descriptor: [parent child relations] explode all trees
25	MeSH descriptor: [professional family relations] this term only
26	((brother* or carer* or caregiv* or "care giv*" or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or "significant other*" or sister* or spous* or mother* or parent* or wife* or wive*) near/5 (autonom* or choice* or cohesion or communicat* or consensus or decision* or dissent* or disput* or empower* or engag* or expertise or inclusion or information* or involv* or intervention* or manag* or negotiat* or network* or participat* or phamplet* or plan* or program* or psychoed* or "psycho ed*" or strateg* or support*) near/5 (adolescent* or adult* or boy* or child* or girl* or harmer* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or selfharmer* or "service user*" or teen* or woman or women or youngster* or youth*)):ti,ab.

#	Searches
27	((camhs or clinician* or counsel?or* or cpn* or “crisis resolution team*” or doctor* or gp or lecturer* or (“mental health” next (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*) and (educat* or learn* or teach* or train*) and ((autonom* or choice* or cohesion or communicat* or consensus or decision* or dissent* or disput* or empower* or engag* or expertise or inclusion or information* or involv* or manag* or negotiat* or network* or participat* or phamplet* or plan* or program* or psychoed* or “psycho ed*” or strateg* or support*) near/5 (carer* or caregiv* or care giv* or famil* or parent*)):ti,ab.
28	((brother* or carer* or caregiv* or “care giv*” or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) near/10 (automutilat* or “auto mutilat*” or (self near/2 cut*) or selfdestruct* or “self destruct*” or selfharm* or “self harm*” or selfimmolat* or “self immolat*” or selfinflict* or “self inflict*” or selfinjur* or “self injur*” or selfmutilat* or “self mutilat*” or selfpoison* or “self poison*” or selfwound* or “self wound*” or suicid*) near/10 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or “self harmer*” or selfharmer* or “service user*” or teen* or woman or women or youngster* or youth*)):ti.
29	((brother* or carer* or caregiv* or “care giv*” or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or significant other* or sister* or spous* or mother* or parent* or wife* or wife*) near/5 (automutilat* or “auto mutilat*” or (self near/2 cut*) or selfdestruct* or “self destruct*” or selfharm* or “self harm*” or selfimmolat* or “self immolat*” or selfinflict* or “self inflict*” or selfinjur* or “self injur*” or selfmutilat* or “self mutilat*” or selfpoison* or “self poison*” or selfwound* or “self wound*” or suicid*) near/5 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or “self harmer*” or selfharmer* or “service user*” or teen* or woman or women or youngster* or youth*)):ti,ab.
30	((brother* or carer* or caregiv* or care giv* or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or “significant other*” or sister* or spous* or mother* or parent* or wife* or wife*) near/5 (intervention* or program* or strateg*)) and (automutilat* or “auto mutilat*” or (self near/2 cut*) or selfdestruct* or “self destruct*” or selfharm* or “self harm*” or selfimmolat* or “self immolat*” or selfinflict* or “self inflict*” or selfinjur* or “self injur*” or selfmutilat* or “self mutilat*” or selfpoison* or “self poison*” or selfwound* or “self wound*” or suicid*)):ti,ab.
31	((carer* or caregiv* or “care giv*” or famil* or parent*) and (early near/2 intervention*)):ti,ab.
32	((carer* or caregiv* or “care giv*” or famil* or parent*) near/7 (educat* or intervention* or learn* or program* or skill* or strateg* or teach* or technique*) near/7 confiden*)):ti,ab.
33	((carer* or caregiv* or “care giv*” or famil* or parent*) next group*) or ((carer* or caregiv* or “care giv*” or famil* or parent*) near/7 information) or ((carer* or caregiv* or “care giv*” or famil* or parent*) and (phamplet* or (written near/2 information))) or

#	Searches
	((carer* or caregiv* or "care giv*" or famil* or parent*) near/5 (communicat* or decision* or information or interact* or involv* or manag* or speak* or talk*) near/5 (camhs or clinician* or counsel?or* or cpn* or "crisis resolution team*" or doctor* or gp or lecturer* or ("mental health" next (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*)):ti,ab.
34	((((carer* or caregiv* or "care giv*" or family or "family focused" or home or "home based" or parent*) near/3 ("helping service*" or intervention* or psychoed* or "psycho ed*" or psychosocial or "service level intervention*" or system* or support network* or therap*)) or (help near/3 (carer* or caregiv* or care giv* or famil* or parent*) near/3 recover*) or ((carer* or caregiv* or "care giv*" or family or family focused or home or "home based" or parent*) near/7 experience* near/7 (support* or treatment*)) or (((information* or skill*) near/5 (manag* or support) near/5 (automutilat* or "auto mutilat*" or cutt* or (self near/2 cut*) or selfdestruct* or "self destruct*" or selfharm* or "self harm*" or selfimmolat* or "self immolat*" or selfinfect* or "self infect*" or selfinjur* or "self injur*" or selfmutilat* or "self mutilat*" or selfpoison* or "self poison*" or selfwound* or "self wound*" or suicid*)) and (carer* or caregiv* or "care giv*" or famil* or parent*)) or ((carer* or caregiv* or "care giv*" or famil* or parent*) near/3 (help* or support*)):ti,ab.
35	((((carer* or caregiv* or "care giv*" or famil* or parent*) and information) or ((brother* or carer* or caregiv* or "care giv*" or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or "significant other*" or sister* or spous* or mother* or parent* or wife* or wive*) and (automutilat* or "auto mutilat*" or (self near/2 cut*) or selfdestruct* or "self destruct*" or selfharm* or "self harm*" or selfimmolat* or "self immolat*" or selfinfect* or "self infect*" or selfinjur* or "self injur*" or selfmutilat* or "self mutilate*" or selfpoison* or "self poison*" or selfwound* or "self wound*" or suicid*)) and ("focus group*" or (qualitative* or interview* or "focus group*" or questionnaire* or narrative* or narration* or survey*) or (ethno* or emic or etic or phenomenolog* or "grounded theory" or "constant compar*" or (thematic near/4 analys*) or "theoretical sampl*" or "purposive sampl*") or (hermeneutic* or heidegger* or husser* or colaizzi* or "van kaam*" or "van manen*" or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*) or (metasynthes* or "meta-synthes*" or metasummar* or "meta-summar*" or metastud* or "meta-stud*" or metathem* or "meta-them*") or ("critical interpretive synthes*" or (realist next (review* or synthes*)) or (noblit and hare) or (meta next (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) next synthes*)) or (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*)):ti
36	((family or parent) next (based or led)):ti,ab.
37	((carer* or caregiv* or "care giv*" or famil* or parent*) near/2 support*):ti,ab.
38	((carer* or caregiv* or "care giv*" or famil* or parent*) near/3 (((intra* or inter*) near/2 professional*) or interprofessional* or intraprofessional*)):ti,ab.
39	((carer* or caregiv* or "care giv*" or family or "family focused" or home or "home based" or parent*) near/3 involve* near/5 (automutilat* or "auto mutilat*" or (self near/2 cut*) or selfdestruct* or "self destruct*" or selfharm* or "self harm*" or selfimmolat* or "self immolat*" or selfinfect* or "self infect*" or selfinjur* or "self injur*")

#	Searches
	or selfmutilat* or "self mutilat*" or selfpoison* or "self poison*" or selfwound* or "self wound*" or suicid*)):ti,ab.
40	((carer* or caregiv* or "care giv*" or famil* or parent*) near/5 (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or interaction* or know* or needs or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view* or "help seek" or helpseek* or (seek* near/2 help)) near/5 (adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or "self harmer*" or selfharmer* or "service user*" or teen* or woman or women or youngster* or youth*)):ti,ab.
41	((brother* or carer* or caregiv* or "care giv*" or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or "significant other*" or sister* or spous* or mother* or parent* or wife* or wive*) near/5 (automutilat* or "auto mutilat*" or (self near/2 cut*) or selfdestruct* or "self destruct*" or selfharm* or "self harm*" or selfimmolat* or "self immolat*" or selfinflict* or "self inflict*" or selfinjur* or "self injur*" or selfmutilat* or "self mutilat*" or selfpoison* or "self poison*" or selfwound* or "self wound*" or suicid*) near/5 ("focus group*" or (qualitative* or interview* or "focus group*" or questionnaire* or narrative* or narration* or survey*) or (ethno* or emic or etic or phenomenolog* or "grounded theory" or "constant compar*" or (thematic near/4 analys*) or "theoretical sampl*" or "purposive sampl*") or (hermeneutic* or heidegger* or husser* or colaizzi* or "van kaam*" or "van manen*" or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*) or (metasynthes* or "meta-synthes*" or metasummar* or "meta-summar*" or metastud* or "meta-stud*" or metathem* or "meta-them*") or ("critical interpretive synthes*" or (realist next (review* or synthes*)) or (noblit and hare) or (meta next (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) next synthes*)) or (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*)):ti,ab.
42	{OR #14-#41}
43	MeSH descriptor: [anthropology, cultural] this term only
44	MeSH descriptor: [cluster analysis] this term only
45	MeSH descriptor: [focus groups] this term only
46	MeSH descriptor: [grounded theory] this term only
47	MeSH descriptor: [health care surveys] this term only
48	(interview):pt.
49	MeSH descriptor: [interviews as topic] this term only
50	MeSH descriptor: [narration] this term only
51	MeSH descriptor: [nursing methodology research] this term only
52	MeSH descriptor: [observation] this term only
53	MeSH descriptor: [personal narratives as topic

#	Searches
54	MeSH descriptor: [narrative] this term only
55	MeSH descriptor: [qualitative research] this term only
56	MeSH descriptor: [surveys and questionnaires] this term only
57	MeSH descriptor: [sampling studies] this term only
58	MeSH descriptor: [tape recording] this term only
59	MeSH descriptor: [videodisc recording] this term only
60	"focus group*":ti,ab.
61	(qualitative* or interview* or focus group* or questionnaire* or narrative* or narration* or survey*):ti,ab.
62	(ethno* or emic or etic or phenomenolog* or "grounded theory" or "constant compar*" or (thematic near/4 analys*) or "theoretical sampl*" or "purposive sampl*"):ti,ab.
63	(hermeneutic* or heidegger* or husser* or colaizzi* or "van kaam*" or "van manen*" or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*):ti,ab.
64	(metasynthes* or "meta-synthes*" or metasummar* or "meta-summar*" or metastud* or "meta-stud*" or metathem* or "meta-them*"):ti,ab.
65	("critical interpretive synthes*" or (realist next (review* or synthes*)) or (noblit and hare) or (meta next (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) next synthes*)):ti,ab.
66	((brother* or carer* or caregiv* or "care giv*" or famil* or father* or husband* or mother* or parent* or partner* or relative* or sibling* or "significant other*" or sister* or spous* or mother* or parent* or wife* or wive* or adolescent* or adult* or boy* or child* or girl* or inpatient* or kindergarten* or juvenile* or man or men or minor* or patient* or paediatric* or pediatric* or people or person* or population* or preschool* or school* or selfharmer* or "self harmer*" or "self harmed" or "service user*" or teen* or woman or women or youngster* or youth* or camhs or clinician* or counsel?or* or cpn* or "crisis resolution team*" or doctor* or gp or lecturer* or (mental health next (service* or team*)) or neuropsychiatrist* or neuropsychologist* or neurospecialist* or nurs* or paramedic* or pharmacist* or police* or practitioner* or professional* or provider* or psychiatrist* or psychologist* or psychotherapist* or specialist* or staff or teacher* or therapist* or warden* or worker*) near/6 (anx* or attitud* or aware* or belief* or concern* or emotion* or experience* or fear* or feeling* or felt* or know* or opinion* or perception* or perspective* or preference* or satisfact* or stress* or thought* or uncertain* or understand* or unsure or view*)):ti,ab.
67	{OR #43-#66}
68	(#9 and #13 and #42 and #67) with Cochrane Library publication date Between Jan 2000 and Sep 2020

- 1
- 2 **Database(s): CDSR and HTA – CRD interface**
- 3 Date of last search: 4th September 2020
- 4

#	Searches
1	MeSH descriptor: poisoning IN CDSR, HTA
2	MeSH descriptor: self-injurious behavior EXPLODE ALL TREES IN CDSR, HTA
3	MeSH descriptor: self mutilation IN CDSR, HTA
4	MeSH descriptor: suicide IN CDSR, HTA
5	MeSH descriptor: suicidal ideation IN CDSR, HTA
6	MeSH descriptor: suicide, attempted IN CDSR, HTA
7	MeSH descriptor: suicide, completed IN CDSR, HTA
8	(automutilat* or "auto mutilat*" or cutt* or (self near2 cut*) or selfdestruct* or "self destruct*" or selfharm* or "self harm*" or selfimmolat* or "self immolat*" or selfinflict* or "self inflict*" or selfinjur* or "self injur*" or selfmutilat* or "self mutilat*" or selfpoison* or "self poison*" or selfwound* or "self wound*" or suicid*) IN CDSR, HTA
9	(#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8) from 2000 to 2020

1

2 **Database(s): ASSIA - Proquest interface**

3 Date of last search: 4th September 2020

4

#	Searches
S5	(s1 and s2 and s3 and s4) with limits
S4	(MAINSUBJECT.EXACT("Cluster analysis") or MAINSUBJECT.EXACT("Focus groups") or MAINSUBJECT.EXACT("Grounded theory") or MAINSUBJECT.EXACT("Narration") or MAINSUBJECT.EXACT("Personal narratives") or MAINSUBJECT.EXACT("Qualitative research") or MAINSUBJECT.EXACT("Social surveys") or MAINSUBJECT.EXACT("Surveys") or MAINSUBJECT.EXACT("Tape recordings") or MAINSUBJECT.EXACT("Videotape recording")) OR noft("focus group*" or qualitative* or interview* or focus or questionnaire* or narrative* or narration* or survey* or ethno* or emic or etic or phenomenolog* or "grounded theory" or "constant compar*" or (thematic near/4 analys*) or "theoretical sampl*" or "purposive sampl*" or hermeneutic* or heidegger* or husser* or colaizzi* or "van kaam*" or "van manen*" or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau* or metasynthes* or "meta-synthes*" or metasummar* or "meta-summar*" or metastud* or "meta-stud*" or metathem* or "meta-them*" "critical interpretive synthes*" or "realist synthes*" or "thematic framework" or "thematic synthes*")
S3	su((attitude* or perspective* or view*) OR noft((attitude* or experience* or opinion* or perspective* or view*) near/7 (selfharm* or "self harm*" or suicid*)))
S2	su(engag* or involv* or participat* or interact*) OR noft(engag* or involv* or participat* or interact*)
S1	(MAINSUBJECT.EXACT("Poisoning") or MAINSUBJECT.EXACT("Selfdestructive behaviour") or MAINSUBJECT.EXACT("Suicide") or MAINSUBJECT.EXACT("Violent suicide")) OR noft((selfharm* or "self harm*" or suicid*))

5

6 **Database(s): SSCI - Clarivate interface**

7 Date of last search: 4th September 2020

8 *[forward citation searches conducted for selected references found in the systematic database search, above]*

10

1 **Economic**

2 A global, population based search was undertaken to find for economic evidence covering all
3 parts of the guideline.

4

5 **Database(s): Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-
6 Indexed Citations and Daily – OVID interface**

7 Date of last search: 12th August 2021

8

#	Searches
1	poisoning/ or exp self-injurious behavior/ or self mutilation/ or suicide/ or suicidal ideation/ or suicide, attempted/ or suicide, completed/
2	(automutilat* or auto mutilat* or cutt* or (self adj2 cut*) or selfdestruct* or self destruct* or selfharm* or self harm* or selfimmolat* or self immolat* or selfinflict* or self inflict* or selfinjur* or self injur* or selfmutilat* or self mutilat* or selfpoison* or self poison* or selfwound* or self wound* or suicid*).ti,ab.
3	or/1-2
4	Economics/
5	Value of life/
6	exp "Costs and Cost Analysis"/
7	exp Economics, Hospital/
8	exp Economics, Medical/
9	Economics, Nursing/
10	Economics, Pharmaceutical/
11	exp "Fees and Charges"/
12	exp Budgets/
13	budget*.ti,ab.
14	cost*.ti.
15	(economic* or pharmaco?economic*).ti.
16	(price* or pricing*).ti,ab.
17	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
18	(financ* or fee or fees).ti,ab.
19	(value adj2 (money or monetary)).ti,ab.
20	Quality-Adjusted Life Years/
21	Or/4-20
22	3 and 21
23	limit 22 to yr="2000 -current"

9

10 **Database(s): Embase and Emcare – OVID interface**

11 Date of last search: 12th August 2021

12

#	searches
1	automutilation/ or exp suicidal behavior/
2	(auto mutilat* or automutilat* or self cut* or selfcut* or self destruct* or selfdestruct* or self harm* or selfharm* or self immolat* or selfimmolat* or self inflict* or selfinflict* or self injur* or selfinjur* or self mutilat* or selfmutilat* or self poison* or selfpoison* or suicid*).ti,ab.
3	or/1-2

#	searches
4	health economics/
5	exp economic evaluation/
6	exp health care cost/
7	exp fee/
8	budget/
9	funding/
10	budget*.ti,ab.
11	cost*.ti.
12	(economic* or pharmaco?economic*).ti.
13	(price* or pricing*).ti,ab.
14	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
15	(financ* or fee or fees).ti,ab.
16	(value adj2 (money or monetary)).ti,ab.
17	Quality-Adjusted Life Year/
18	Or/4-17
19	3 and 18
20	limit 19 to yr="2000 -current"

- 1
- 2 **Database(s): Cochrane Library - Wiley interface**
- 3 Cochrane Central Register of Controlled Trials, Issue 8 of 12, August 2021
- 4 Date of last search: 12th August 2021
- 5

#	Searches
1	MeSH descriptor: [poisoning] this term only
2	MeSH descriptor: [self-injurious behavior] explode all trees
3	MeSH descriptor: [self mutilation] this term only
4	MeSH descriptor: [suicide] this term only
5	MeSH descriptor: [suicidal ideation] this term only
6	MeSH descriptor: [suicide, attempted] this term only
7	MeSH descriptor: [suicide, completed] this term only
8	(automutilat* or "auto mutilat*" or cutt* or (self near/2 cut*) or selfdestruct* or "self destruct*" or selfharm* or "self harm*" or selfimmolat* or "self immolat*" or selfinflict* or "self inflict*" or selfinjur* or "self injur*" or selfmutilat* or "self mutilat*" or selfpoison* or "self poison*" or selfwound* or "self wound*" or suicid*):ti,ab.
9	{or #1-#8}
10	MeSH descriptor: [Economics] this term only

#	Searches
11	MeSH descriptor: [Value of life] this term only
12	MeSH descriptor: [Costs and Cost Analysis] explode all trees
13	MeSH descriptor: [Economics, Hospital] explode all trees
14	MeSH descriptor: [Economics, Medical] explode all trees
15	MeSH descriptor: [Economics, Nursing] this term only
16	MeSH descriptor: [Economics, Pharmaceutical] this term only
17	MeSH descriptor: [Fees and Charges"]
18	MeSH descriptor: [Budgets] this term only
19	budget*:ti,ab.
20	cost*.ti.
21	(economic* or pharmaco?economic*):ti.
22	(price* or pricing*):ti,ab.
23	(cost* near/2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)):ab.
24	(financ* or fee or fees):ti,ab.
25	(value near/2 (money or monetary)):ti,ab.
26	MeSH descriptor: [Quality-Adjusted Life Years] this term only
27	{OR #10-#26}
28	(#9 and #27) with Cochrane Library publication date Between Jan 2000 and Aug 2021

1

2 **Database(s): NHS EED and HTA – CRD interface**

3 Date of last search: 12th August 2021

4

#	Searches
1	MeSH descriptor: poisoning IN NHSEED, HTA
2	MeSH descriptor: self-injurious behavior EXPLODE ALL TREES IN NHSEED, HTA
3	MeSH descriptor: self mutilation IN NHSEED, HTA
4	MeSH descriptor: suicide IN NHSEED, HTA
5	MeSH descriptor: suicidal ideation IN NHSEED, HTA
6	MeSH descriptor: suicide, attempted IN NHSEED, HTA
7	MeSH descriptor: suicide, completed IN NHSEED, HTA
8	(automutilat* or "auto mutilat*" or cutt* or (self near2 cut*) or selfdestruct* or "self destruct*" or selfharm* or "self harm*" or selfimmolat* or "self immolat*" or selfinflict* or "self inflict*" or selfinjur* or "self injur*" or selfmutilat* or "self mutilat*" or selfpoison* or "self poison*" or selfwound* or "self wound*" or suicid*) IN NHSEED, HTA
9	(#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8) from 2000 to 2021

5

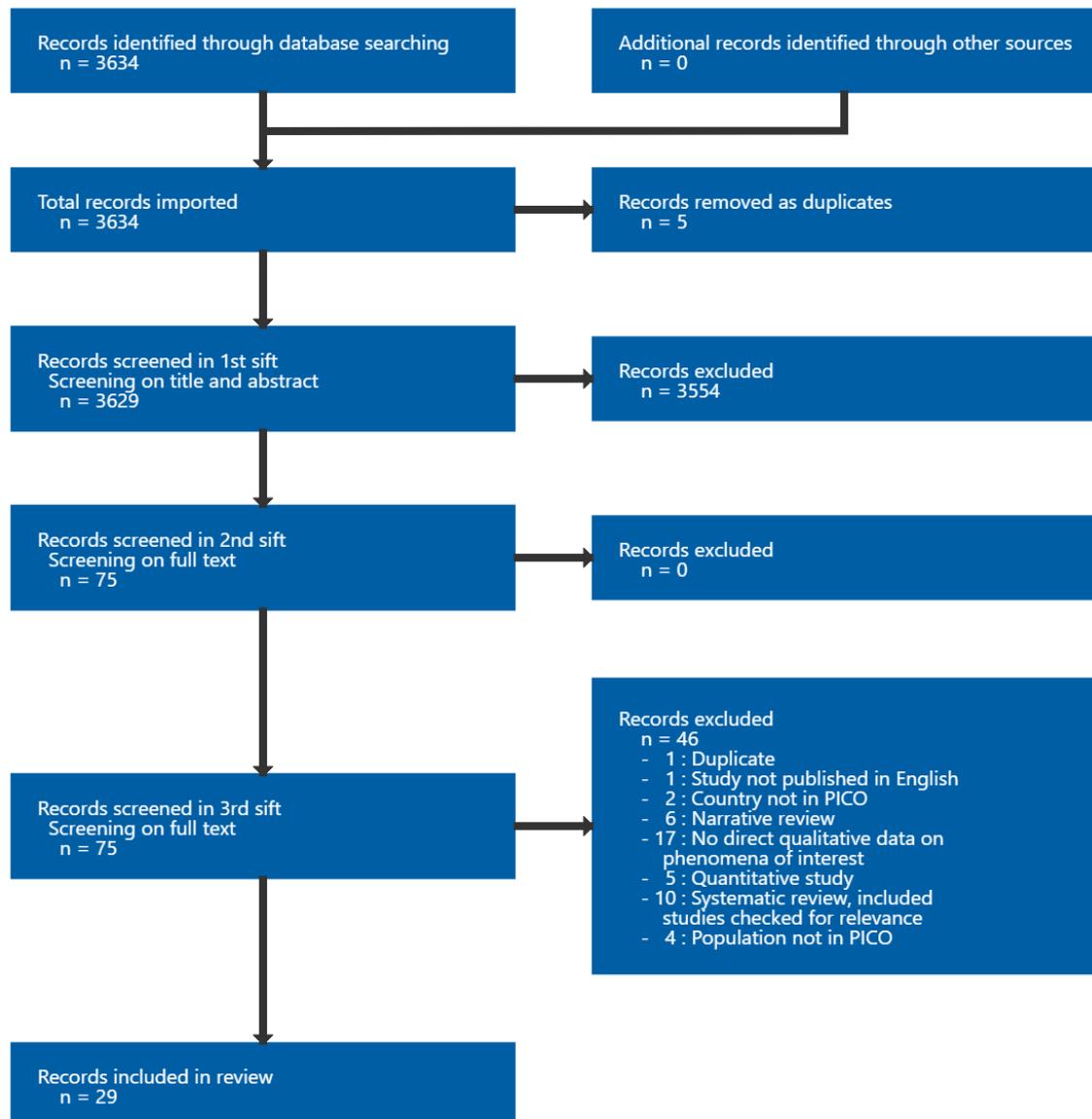
6

7

1 Appendix C Qualitative evidence study selection

2 Study selection for review question: What are the views and preferences of
3 people who have self-harmed, their families and carers, and staff working with
4 people who have self-harmed about the best ways of involving family and
5 carers in the management of people who have self-harmed?

6 Figure 2: Study selection flow chart



7

8

9

1 Appendix D Evidence tables

2 Evidence tables for review question: What are the views and preferences of people who have self-harmed, their families and 3 carers, and staff working with people who have self-harmed about the best ways of involving family and carers in the 4 management of people who have self-harmed?

5 Table 5: Evidence tables

Bouwman, 2018

6

Bibliographic Reference Bouwman, R.; de Graaff, B.; de Beurs, D.; van de Bovenkamp, H.; Leistikow, I.; Friele, R.; Involving patients and families in the analysis of suicides, suicide attempts, and other sentinel events in mental healthcare: A qualitative study in The Netherlands; International Journal of Environmental Research and Public Health; 2018; vol. 15 (no. 6)

7

8

9 Study Characteristics

Country/ies where study was carried out	The Netherlands
Study type	Grounded theory
Study dates	Not stated.
Sources of funding	This study was funded by ZonMw, the Netherlands Organization for Health Research and Development.
Recruitment strategy	Large medical healthcare institutions (n=28) were approached by letter asking them to send their family and sentinel events policies. Interviews were conducted with different groups of stakeholders involved with sentinel events. Stakeholders were approached through professional organizations, interest groups, and patient organizations using a snowball method. Additional effort was made to recruit patients via the Inspectorate, patient organizations, and by approaching former patients.

Inclusion criteria	Not stated.
Exclusion criteria	Not stated.
Setting	Mental healthcare organisations. Stakeholders contacted through professional organizations, interest groups, and patient organizations using a snowball method.
Sample size	n=24 healthcare staff n=7 family members of people who had sentinel events Data were also available for patient participants but not extracted as no relevant qualitative data were available from these participants.
Participant characteristics	<p>Mean age (SD): Not reported.</p> <p>Sex (female/male): Not reported.</p> <p>Role:</p> <ul style="list-style-type: none"> • Family: 7 • Patient counsellors: 2 • Family counsellors: 5 • Members of family committee: 4 • Psychiatrist: 4 • Medical director: 1 • Director: 3 • Inspector: 5 <p>Relationship to person who has self-harmed: Not reported</p> <p>For staff members:</p> <p>Setting: Not reported</p>

	<p>Years in post/experience: Not reported</p> <p>Client group (adults, children/CYP): Not reported</p>
<p>Data collection and analysis</p>	<p>A content analysis was performed on the policy documents to assess the degree of the involvement of patients and family members. Semi-structured interviews using a topic list which included topics on the role of patients and families in sentinel events, what the considerations are in whether or not to involve them, and the benefits, drawbacks, and best practices when involving them. The transcripts made during the interviews were analysed inductively by the four authors following iterative grounded-theory techniques.</p>
<p>Results</p>	<p>Author theme: Involvement during Treatment</p> <p><i>Example quote: “So she had compulsive thoughts. I noticed that straight away in her non-verbal communication. Actually in all sorts of small things. Then they upped her medication and valium. I said, ‘This isn’t going to help her enough. (...) I say, ‘you can keep her here, I’m not taking her home anymore, I’m no longer taking responsibility’. Then she got a psychosis on the spot.” (Mother of a patient)</i></p> <p>Author theme: Limited Involvement in Sentinel Event Analysis in Practice</p> <p><i>Example quote: “Then we draft the improvement measures, but at that point the family is no longer involved. At least everything (the event analysis) is done. No, the points for improvement are just outlines. If more points turn up, they’ll be in the report. And then worked out in detail. That’s without the family, but they can say what they think of the broader outlines.” (Care institution director)</i></p> <p><i>“So that’s what we do. But what we’ve recently discussed, the feedback for example on what has come from the analysis to the family, well, we don’t yet report that to them. And that’s the question, whether it might be useful to report it back to the family. Sometimes when the family really insist on it, but we don’t report that to them as a matter of course (...) And I think that’s the next step, that we also involve the family or patient in the evaluation and that we also give them the feedback, what came out of it (the evaluation), also to family and friends.” (Director)</i></p> <p>Author theme: Reasons against Involving Patients and Families in Sentinel Event Analyses</p> <p><i>Example quote: “So the inspectorate only wants to know if the patient is the victim. Whereas in ninety-nine out of a hundred cases, the staff member is the victim.” (Medical director)</i></p> <p><i>[...] our study shows that the contribution of family or patients quickly becomes devalued and questioned by healthcare providers or inspectors. When this happens patients and families are considered for example to be ‘overwhelmed by emotions’ (medical director).</i></p> <p>Author theme: Reasons in Favor of Involvement during Sentinel Event Analyses</p>

Example quote: "It's better to share the real story with each other than to follow formal pathways. That's pretty much our approach." (Family counselor)

"It's also a kind of duty for the care organization, to provide aftercare to the family. (...) To give them the opportunity to tell their story again, or to hear how everything happened. So that they can learn to cope with what has happened. Yes, in that sense it's an extra reason for paying attention to the family and relatives." (Inspector)

"(...) you need that family for the biography and the history. (...) The family is (therefore) indispensable for a proper analysis of the event, otherwise you're only looking at the care provided and that's the major problem, for the crisis services too. (. . .). Otherwise you're taking snapshots and not seeing the movie." (Inspector)

"It's also a kind of duty for the care organization, to provide aftercare to the family. (...) To give them the opportunity to tell their story again, or to hear how everything happened. So that they can learn to cope with what has happened. Yes, in that sense it's an extra reason for paying attention to the family and relatives." (Inspector)

1

2

3 Critical appraisal

4

Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Can't tell <i>(Authors used a grounded theory approach but did not justify their reasoning.)</i>
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Can't tell <i>(Authors recruited stakeholders through various methods but do not discuss inclusion/exclusion criteria or why the participants were appropriate to the aims of the study.)</i>

Section	Question	Answer
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Methods chosen were not justified and saturation of data not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Researchers did not state whether they critically examined their own role during data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Can't tell <i>(Approval sought from an ethics committee and informed consent was sought from participants, however insufficient information given regarding how the research was explained to participants or issues raised by the study.)</i>
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Insufficient information/ justification given regarding recruitment, data collection and ethical considerations.)</i>
	Relevance	Partially relevant <i>(Study looks at qualitative evidence relating to sentinel events, including suicide attempts, however does not specify if participants are family members of/ healthcare staff for people who have self-harmed. Additionally, study not conducted in the UK.)</i>

1

Byrne, 2008

2

Bibliographic Reference

Byrne, S.; Morgan, S.; Fitzpatrick, C.; Boylan, C.; Crowley, S.; Gahan, H.; Howley, J.; Staunton, D.; Guerin, S.; Deliberate self-harm in children and adolescents: A qualitative study exploring the needs of parents and carers; *Clinical Child Psychology and Psychiatry*; 2008; vol. 13; 493-504

1

2

3 Study Characteristics

Country/ies where study was carried out	Ireland
Study type	General qualitative inquiry
Study dates	Not reported.
Sources of funding	This study was funded by the Fundraising Department of Children's University Hospital and the Health Promotion Department, Health Service Executive Northern Area
Recruitment strategy	Participants were recruited from those who had presented to the A&E department of the Temple Street Children's University Hospital (TSCUH) with self-harm or suicidal behaviour. Participants were also recruited from Child and Adolescent Mental Health Teams and Family Support Services in Dublin.
Inclusion criteria	Participants had to: <ul style="list-style-type: none"> • Be parents or carers of young people who were aged 16 years or younger and had self-harmed or expressed suicidal ideation
Exclusion criteria	Not reported.
Setting	The Child Psychiatry Department of TSCUH.
Sample size	N=25 parents/ carers of young people who had self-harmed/ expressed suicidal ideation
Participant characteristics	<p>Mean age (SD): Not reported.</p> <p>Sex (female/ male): Not reported.</p>

	<p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Parent: 15 • Carer: 10
Data collection and analysis	A focus group meeting was held. Participants divided into subgroups and were asked open-ended questions, with discussions lasting 45 minutes. A stenographer recorded the discussion verbatim, and data were analysed conceptively using an inductive approach.
Results	<p>Author theme: Information and education</p> <p><i>Example quote: If you have the knowledge and background you feel more confident in dealing with it.</i></p> <p>Author theme: Parenting</p> <p><i>Example quote: ' . . . How to help us to open up and to get in touch with the anger, but express it'.</i></p>

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Can't tell (<i>Aim not clearly stated but can be deduced.</i>)
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes

Section	Question	Answer
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Focus groups can limit discussion of a sensitive topic, and saturation of data was not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Participants were recruited from the DSH Team in the Children's University Hospital (TSCUH), where the authors work. It is unclear whether they were involved in the care of the participants, and researchers did not state whether they critically examined their own role during data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	No <i>(Authors provided details of how the research was explained to participants however there is no further consideration for ethical issues, and no details of approval having been sought from an ethics committee.)</i>
Data analysis	Was the data analysis sufficiently rigorous?	Can't tell <i>(Unclear justification for conceptual analysis as analytical technique chosen)</i>
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Serious concerns <i>(Insufficient information given for data collection and analysis; serious concerns around ethical considerations and the relationship between the researchers and participants)</i>
	Relevance	Relevant <i>(Authors included parents/ carers of young people who had expressed suicidal ideation but had not necessarily self-harmed. The number of these participants is not reported. Additionally, the study was not conducted in UK.)</i>

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Chew-Graham, 2002

1

Bibliographic Reference Chew-Graham, C.; Bashir, C.; Chantier, K.; Burman, E.; Batsleer, J.; South Asian women, psychological distress and self-harm: Lessons for primary care trusts; Health and Social Care in the Community; 2002; vol. 10; 339-347

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4 **Study Characteristics**

Country/ies where study was carried out	UK
Study type	General qualitative inquiry
Study dates	January 2011
Sources of funding	Not stated.
Recruitment strategy	An information sheet was drafted resembling an informal research contract was sent to 12 existing women's groups to convene specific meetings for separate discussion on the topic of 'distress.
Inclusion criteria	Not stated.
Exclusion criteria	Not stated.
Setting	Four existing women's groups (Saheli, an Asian women's refuge residents group; 42nd Street, a young women's group; Women Working Together, a Salford community health project; Bangladeshi Women's Project).
Sample size	N = 31 women
Participant characteristics	Mean age (SD): Not reported. Age range 17-50 years. Sex (male/female): 0 / 31

	<p>Co-morbidity: Not reported</p> <p>Duration of self-harm: Not reported</p> <p>Number of suicide attempts: Not reported</p>
Data collection and analysis	Focus group discussions using an interview guide to elicit the views and beliefs of participants. Analysis of the focus group notes defined themes and emergence of framework was carried out by three researchers. The data were analysed according to the principles of framework analysis, a content analysis method.
Results	<p>Author theme: Access to mainstream service provision</p> <p><i>Example quote: You get called all sorts by your husband and in-laws, and when you get treated badly and if you tell someone, they judge you like you're spoiling izzat, or get called stupid or a slapper, or they go and tell someone else. It's not just them. When I left home and went to the police, they actually told them where I'd gone. They're all the same, like, we're Asian and women and we don't matter. How can you trust anyone when you've gone through that? It's like all I wanted was someone to listen or talk to ... (26-year-old)</i></p>

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes

Section	Question	Answer
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Can't tell <i>(Authors recruited participants through existing women's groups but do not discuss inclusion/exclusion criteria or provide sufficient information as to why the women's groups were appropriate for the specific aims of the study.)</i>
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Authors used focus groups but justified their reasoning as to why this was more appropriate than individual interviews in order to collect the most data. However, a language interpreter was used to collect data from one of the groups, which could lead to bias in the data collection. Additionally, saturation of data was not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes
Ethical Issues	Have ethical issues been taken into consideration?	Yes <i>(Ethics approval was not sought because it was not needed due to the method in which the participants were recruited.)</i>
Data analysis	Was the data analysis sufficiently rigorous?	No <i>(Very little information given about the analysis process, relatively little data given to support findings, the authors did not discuss their role or potential bias during analysis.)</i>
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Serious concerns <i>(Serious concerns over the lack of information regarding data analysis and authors did not specify what steps, if any, they took to check credibility of findings.)</i>
	Relevance	Partially relevant <i>(The aims of the research and collected data imply that women who had self-harmed were recruited,</i>

Section	Question	Answer
		<i>but due to the lack of information regarding recruitment and included participants, authors do not explicitly state whether participants are specifically people who have self-harmed.)</i>

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Dempsey, 2019

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Bibliographic Reference	Dempsey, Sarah-Jane A.; Halperin, Steve; Smith, Karen; Davey, Christopher G.; McKechnie, Ben; Edwards, Jane; Rice, Simon M.; "Some guidance and somewhere safe": Caregiver and clinician perspectives on service provision for families of young people experiencing serious suicide ideation and attempt; <i>Clinical Psychologist</i> ; 2019; vol. 23; 103-111
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5 Study Characteristics

Country/ies where study was carried out	Australia
Study type	General qualitative inquiry
Study dates	Not stated.
Sources of funding	None
Recruitment strategy	Caregivers were identified by Youth Mood Clinic (YMC) clinicians, and the relative young person was notified regarding consent to contact them. Clinician participants were sourced from within YMC. Informed consent was obtained.
Inclusion criteria	Caregivers who had a young person in their care who had a minimum three months' involvement with YMC.
Exclusion criteria	Not stated.

Setting	Youth Mood Clinic (YMC) a tertiary mental health service
Sample size	Parent caregivers N = 8 Specialist YMC treating clinicians N = 8
Participant characteristics	<p>Mean age (SD):</p> <ul style="list-style-type: none"> Parent caregivers: 52.50 (3.78) Specialist YMC treating clinicians: 36.33 (8.82) <p>Sex (female/male):</p> <ul style="list-style-type: none"> Parent caregivers: 7 / 1; Specialist YMC treating clinicians: 7 / 1 <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> Parent: 8 <p>For staff members:</p> <p>Role:</p> <ul style="list-style-type: none"> Clinical psychologists: 7 Occupational therapist: 1 <p>Setting: Tertiary mental health service</p> <p>Years in post/ experience: Range 2–29 years (M = 9.5 years, SD = 10.23)</p> <p>Client group (adults, children/ CYP):</p> <p>Young people aged 15-25 years old</p>
Data collection and analysis	Semi-structured interviews. Thematic analysis was used to interpret qualitative findings.

Results	<p>Author theme: Crisis needs: Information</p> <p><i>Example quote: "The trouble is that I do not know how much the therapists know from what he is saying and whether they cotton onto things that I think are happening because I see him every day. I am still waiting though for them to talk to me." (Caregiver)</i></p> <p><i>"So the focus with seeing the family towards the end of treatment is around discharge planning and referring out and skilling up the family in being able to notice early warning signs." (Clinician)</i></p> <p><i>"The trouble is that I do not know how much the therapists know from what he is saying and whether they cotton onto things that I think are happening because I see him every day. I am still waiting though for them to talk to me." (Caregiver)</i></p>
	<p>Author theme: Crisis needs: Support</p> <p><i>Example quote: "Where there's been a pattern of kind of high-risk or challenging behaviours going on for an extended period of time, the family might start to feel quite burnt-out in terms of what they have been able to manage...Invariably, families are doing the very best they can with the resources they have, but then can be feeling very stretched." (Clinician)</i></p>
	<p>Author theme: Initial needs: Information</p> <p><i>Example quote: "I see the relationship between families and clinicians, particularly in the early stages, as collaborative. I think they need to have an opportunity to share their experiences, their perspectives, their thoughts and ideas about what's going on for the young person." (Clinician)</i></p> <p><i>"I think information is the thing they most need at first; and then emotional support, would be the thing that they need second most." (Clinician)</i></p>

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
	Relevance	Relevant <i>(Study included participants experiencing suicidal ideation but did not specify whether they had self-harmed. Additionally, study not conducted in the UK.)</i>

1

Dransart, 2017

2

Bibliographic Reference Dransart, D. A. C.; Guerry, S.; Help-seeking in suicidal situations: Paramount and yet challenging. Interactions between significant others of suicidal persons and health care providers; Journal of Clinical Medicine; 2017; vol. 6 (no. 2)

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5 Study Characteristics

Country/ies where study was carried out	Switzerland
Study type	General qualitative inquiry
Study dates	February 2007 - January 2008
Sources of funding	Not reported.
Recruitment strategy	Participants were recruited through several professional mental health institutions/ associations and advertisements.
Inclusion criteria	Participants had to:

	<ul style="list-style-type: none"> • Be a significant other of a suicidal person/ suicide attempter over the age of 18 years who had displayed suicidal behaviour within 5 years of the study taking place and was still alive at the time of interview • Be living in Fribourg or Valais • Have subjective affective closeness to the suicidal person • Have witnessed or been involved with help-seeking for the suicidal person
Exclusion criteria	<p>Potential participants were excluded if:</p> <ul style="list-style-type: none"> • They only had occasional contact with the suicidal person • They had witnessed their significant other's suicidality over 5 years before the interview
Setting	In the community.
Sample size	N = 18 significant others of adult suicidal persons
Participant characteristics	<p>Mean age (range): 44 (23-61) years</p> <p>Sex (female/male): 16/ 2</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Spouse/ partner: 5 • Child: 3 • Mother: 3 • Sister: 3 • Ex-spouse: 2 • Friend: 2
Data collection and analysis	Semi-structured interviews took place in the participants' preferred location and lasted between 1.5 - 2.5 hours. Interviews were audio-taped, transcribed verbatim. Authors used a mixed approach to analyse the content of the interviews.
Results	<p>Author theme: Help-Seeking Process to Support the Suicidal Person/Suicide Attempter</p> <p><i>Example quote: ION: "I tried very hard to find help during this time and after a while, because we can't find it, well, we just give up."</i></p>

EAR: "The real disappointment for me was when her suicide attempt led her to the hospital, but after three days, they just released her and that was it. Yet I told them 'but listen, she is not ready to get out, we've been dealing with this for ten years, you can be sure that she will try again'."

LEY: "The doctor told me 'your husband is a grown-up man', and then that it wasn't my role to intervene, and then, that they don't have to take into account what the family has to say."

Author theme: Significant Others' Perception of Patient/Client Care for the Suicidal Person/Suicide Attempter

Example quote: SAM: "And in the evening, at 19h15, the psychiatrist calls me and then she tells me 'you know, I have contacted your husband's GP, and we have decided to give up half of another drug'. I found this fantastic!"

SAM: "After, there is nothing, after those 6 weeks in hospital. Then, nobody had told us he needed to see a psychiatrist so at that point we felt we had more or less been dumped."

Author theme: Significant Others' Perception of Their Collaboration with Professionals

Example quote: SAM: "Because with the psychiatrist, it goes like this: I go there with my husband, we have a little chat, and then I leave, and they talk together."

UTT: "Which solution? How to react? This is how I feel that relatives, they need help in these situations."

AUM: "On the day following his suicide attempt, I told myself 'I really have to find a psychologist or someone', well, I tried calling some and I was told everywhere 'there is a 6-month waiting list'."

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Can't tell <i>(Authors used a mixed approach but did not justify their reasoning.)</i>
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Saturation of data was not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes

Section	Question	Answer
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Minor concerns <i>(Lack of justification for research design and no discussion of data saturation.)</i>
	Relevance	Partially relevant <i>(Authors included family members/ carers of young people who had expressed suicidal ideation but had not necessarily self-harmed. The number of these participants is not reported. Additionally, the study included 2 friends of people who had self-harmed/ expressed suicidal ideation (11%) but did not clarify whether they were their carers. The study was not conducted in the UK.)</i>

1

Ferrey, 2016a

2

Bibliographic Reference Ferrey, A. E.; Hughes, N. D.; Simkin, S.; Locock, L.; Stewart, A.; Kapur, N.; Gunnell, D.; Hawton, K.; Changes in parenting strategies after a young person's self-harm: A qualitative study; Child and Adolescent Psychiatry and Mental Health; 2016; vol. 10 (no. 1)

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5 **Study Characteristics**

Country/ies where study was carried out	UK
Study type	Grounded theory
Study dates	August 2012 - October 2013
Sources of funding	(See Stewart 2018)
Recruitment strategy	(See Stewart 2018)
Inclusion criteria	(See Stewart 2018)
Exclusion criteria	(See Stewart 2018)
Setting	(See Stewart 2018)
Sample size	(See Stewart 2018)
Participant characteristics	(See Stewart 2018)
Data collection and analysis	(See Stewart 2018)
Results	<p>Author theme: Experiences with clinical services</p> <p>Example quote: <i>“My criticism is that once you’re discharged from the crisis team, you then go back to your 3 monthly or your 6 monthly appointments with your psychiatrist. What’s in the middle? And the answer is, very little.”</i></p> <p><i>“I felt I was included as much as I needed to be and I thought it was good...for my daughter to have an opportunity to talk to someone where she felt she could say what she liked and it wouldn’t come back to me”.</i></p>

"[It's helpful] having this outlet where my husband and I can go and meet with the psychiatrist individually. We find it's really helpful, for us, I think we find it easier to support [our daughter]."

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Authors explained their methods for data collection but did not justify their choices or discuss data saturation. Additionally, one set of parents was interviewed together, which may limit discussion of a sensitive topic.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors specified they had no clinical contact with the participants, however recruitment methods involved recruiting via personal contacts, and researchers did not state whether they critically examined their own role during data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes

Section	Question	Answer
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Lack of justification for data collection; no discussion of data saturation; some concerns around potential influence of the researchers on review findings)</i>
	Relevance	Highly relevant

1

Ferrey, 2016b

2

Bibliographic Reference Ferrey, A. E.; Hughes, N. D.; Simkin, S.; Locock, L.; Stewart, A.; Kapur, N.; Gunnell, D.; Hawton, K.; The impact of self-harm by young people on parents and families: A qualitative study; *BMJ Open*; 2016; vol. 6 (no. 1)

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5 **Study Characteristics**

Country/ies where study was carried out	UK
Study type	Grounded theory
Study dates	August 2012 - October 2013

Sources of funding	(See Stewart 2018)
Recruitment strategy	(See Stewart 2018)
Inclusion criteria	(See Stewart 2018)
Exclusion criteria	(See Stewart 2018)
Setting	(See Stewart 2018)
Sample size	(See Stewart 2018)
Participant characteristics	(See Stewart 2018)
Data collection and analysis	(See Stewart 2018)
Results	<p>Author theme: Changes in parenting</p> <p><i>Example quote: Sally said that giving her daughter extra cuddles had been “quite therapeutic for her... and... also [reduced] the thoughts [about self-harm] and carrying them out because she knows I’m there for her.”</i></p> <p>Author theme: Longer-term effects on parenting</p> <p><i>Example quote: “initially, I was horrified and very distressed and now I just feel very sad really and sometimes impatient.”</i></p> <p>Author theme: Suggestions for other parents</p> <p><i>Example quote: “When somebody is feeling so miserable that they can’t even talk about it, rather than reaching for something to harm themselves with, to reach for their phone.”</i></p>

“Inform yourself from absolutely every source you can find. From other parents, from books, from the internet, from research papers, so that... you know what you’re dealing with and that way you will be able to talk to professionals on their own terms and be able to make intelligent decisions about your child’s treatment.”

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Authors explained their methods for data collection but did not justify their choices or discuss data saturation. Additionally, one set of parents was interviewed together, which may limit discussion of a sensitive topic.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors specified they had no clinical contact with the participants, however recruitment methods involved recruiting via personal contacts, and researchers did not state whether they critically examined their own role during data collection.)</i>

Section	Question	Answer
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Lack of justification for data collection; no discussion of data saturation; some concerns around potential influence of the researchers on review findings)</i>
	Relevance	Highly relevant

1

Ferrey, 2015

2

Bibliographic Reference Ferrey, Anne E.; Hawton, Keith; Simkin, Sue; Hughes, Nicholas; Stewart, Anne; Locoock, Louise; "As a parent, there is no rulebook": A new resource for parents and carers of young people who self-harm; The Lancet Psychiatry; 2015; vol. 2; 577-579

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5 Study Characteristics

Country/ies where study was carried out

UK

Study type	Grounded theory
Study dates	August 2012 - October 2013
Sources of funding	(See Stewart 2018)
Recruitment strategy	(See Stewart 2018)
Inclusion criteria	(See Stewart 2018)
Exclusion criteria	(See Stewart 2018)
Setting	(See Stewart 2018)
Sample size	(See Stewart 2018)
Participant characteristics	(See Stewart 2018)
Data collection and analysis	(See Stewart 2018)
Results	<p>Author theme: Ongoing impact on parents' emotional state and mental health</p> <p><i>Example quote: I'm tired. Emotionally, I'm so tired and I want it to stop and, whilst I would never commit suicide, the thoughts are there at times, you know. I have actually pre-planned what I would do and how I'd do it. So it does have a knock-on effect... And the depression it leaves with you is very hard because you're almost constantly living a lie. (Flora)</i></p>

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- 3 Critical appraisal
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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Authors explained their methods for data collection but did not justify their choices or discuss data saturation. Additionally, one set of parents was interviewed together, which may limit discussion of a sensitive topic.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors specified they had no clinical contact with the participants, however recruitment methods involved recruiting via personal contacts, and researchers did not state whether they critically examined their own role during data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Lack of justification for data collection; no discussion of data saturation; some concerns around potential influence of the researchers on review findings)</i>

Section	Question	Answer
	Relevance	Highly relevant

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Grandclerc, 2019

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Bibliographic Reference Grandclerc, S.; Spiers, S.; Spodenkiewicz, M.; Moro, M. R.; Lachal, J.; The quest for meaning around self-injurious and suicidal acts: A qualitative study among adolescent girls; *Frontiers in Psychiatry*; 2019; vol. 10 (no. APR)

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5 Study Characteristics

Country/ies where study was carried out	France
Study type	Phenomenological
Study dates	August 2015 - December 2017.
Sources of funding	Not stated.
Recruitment strategy	Girls and young women were purposively sampled so the subjects selected were representative of typical cases of acts of both suicidal and nonsuicidal self-injury (NSSI).
Inclusion criteria	Participants had to: <ul style="list-style-type: none"> • Be aged 12–21 years old during the study period. • Have at least once intentionally committed an act of aggression against themselves (NSSI or attempted suicide).

Exclusion criteria	An acute delusional state was an exclusion criterion.
Setting	The girls and young women were recruited within the Maison de Solenn (Hospital Cochin, AP-HP, Paris, France) and in the department of child and adolescent psychiatry of the Caen Normandy UHC (Caen, France).
Sample size	N = 18 young people who had self-harmed
Participant characteristics	<p>Mean age (SD): 16.5 (1.86)</p> <p>Sex (female/ male): 18 / 0</p> <p>Co-morbidity: Not stated.</p> <p>Duration of self-harm: Not stated.</p> <p>Number of suicide attempts:</p> <ul style="list-style-type: none"> Participants reported one or more suicide attempts: 12
Data collection and analysis	Semi-structured interviews analysed by applying the method of Interpretative Phenomenological Analysis (IPA). The methodological criteria were retrospectively verified according to the COREQ (COnsolidated criteria for Reporting Qualitative research) checklist.
Results	<p>Author theme: The act as a test of the separation process in adolescence</p> <p><i>Example quote: Girl 18: "I think that it's not [my parents'] role in fact, to . . . try to prevent me from cutting myself. I think it's the therapist's role... So I think that they know it, well yes, they know it, but I mean that they shouldn't get involved after, I think . . . I think that's not their business in fact. . ."</i></p>

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Saturation of data not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors did not state whether they critically examined their own role during data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Minor concerns <i>(Authors did not state whether they critically examined their own role during data collection.)</i>
	Relevance	Relevant <i>(Study not conducted in the UK.)</i>

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Hom, 2020

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Bibliographic Reference Hom, Melanie A.; Albury, Evan A.; Gomez, Marielle M.; Christensen, Kirsten; Stanley, Ian H.; Stage, Dese'Rae L.; Joiner, Thomas E.; Suicide attempt survivors' experiences with mental health care services: A mixed methods study; Professional Psychology: Research and Practice; 2020; vol. 51; 172-183

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4 **Study Characteristics**

Country/ies where study was carried out	USA
Study type	General qualitative inquiry
Study dates	Not stated.
Sources of funding	This study was funded by the Military Suicide Research Consortium.
Recruitment strategy	Collaboration with a suicide prevention activist, participants were self-selected to take part from the Live Through This project.
Inclusion criteria	<p>Participants had to be:</p> <ul style="list-style-type: none"> • Aged 18 years or older; • Willing to use their full name and likeness, sign a model release, and have their voice recorded; • Personally identify as a suicide attempt survivor, with at least 1 year having elapsed since their most recent attempt.
Exclusion criteria	Not stated.
Setting	Tertiary mental health service.
Sample size	N = 96 suicide attempt survivors

Participant characteristics	<p>Mean age (SD): 35.05 (11.43)</p> <p>Sex (female/ male/ gender nonconforming): 64/ 31/ 1</p> <p>Co-morbidity: Not stated</p> <p>Duration of self-harm: Not stated</p> <p>Number of suicide attempts: Not stated. All 96 participants had attempted suicide in the previous one year.</p>
Data collection and analysis	<p>All participants completed an unstructured interview. During the interview, participants were first asked to provide demographic information (for example, name, age, location). They were then provided with an opening prompt of, “Tell me your story as you see fit to tell it.” Follow-up questions were asked throughout the interview to encourage participants to elaborate on specific aspects of their story and to elicit additional information. Coding and thematic analyses were conducted on the interview narratives.</p>
Results	<p>Author theme: Positive support from family and friends regarding mental health service use</p> <p><i>Example quote: “My mother was instrumental in getting me the help that I needed early on—the therapy and whatever medications I needed and whatever doctors I needed to see—and she’s done her best to help me since then.”</i></p> <p>Author theme: Provider not open to input; did not trust individual’s own expertise</p> <p><i>Example quote: “. . . it would have been nice to be treated like I actually knew what I was talking about. A lot of times I was just brushed off and they would talk to my mom instead of me . . .”</i></p>

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes

Section	Question	Answer
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	No <i>(Authors used data collected for the purposes of a separate advocacy project (the Live Through This project) and believed the participants selected to be potentially inappropriate to provide the desired information. The authors acknowledged that participants had to consent to being identifiable for the project which may have discouraged individuals with more negative experiences from participating.)</i>
Data collection	Was the data collected in a way that addressed the research issue?	No <i>(Authors used data collected for the purposes of the Live Through This project and assessed that the chosen method of unstructured interviews was inappropriate to capture data effectively. Additionally, data saturation not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors did not state whether the researcher critically examined their own role during data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	No <i>(No information is given regarding ethics issues, including whether approval was sought from an ethics committee. Additionally, participants were identifiable from the study with no discussion around confidentiality or informed consent.)</i>
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Serious concerns <i>(Serious concerns about bias arising through the recruitment, data collection and ethics processes due to data being collected for a separate advocacy project.)</i>

Section	Question	Answer
	Relevance	Relevant (Study not conducted in the UK.)

1

Idenfors, 2015

2

Bibliographic Reference Idenfors, Hans; Kullgren, Gunnar; Salander Renberg, Ellinor; Professional care as an option prior to self-harm: A qualitative study exploring young people's experiences; Crisis: The Journal of Crisis Intervention and Suicide Prevention; 2015; vol. 36; 179-186

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5 Study Characteristics

Country/ies where study was carried out	Sweden
Study type	General qualitative inquiry
Study dates	2009 - 2011
Sources of funding	Not reported.
Recruitment strategy	Interviewees were recruited from the emergency department, psychiatric emergency services, the child and adolescent psychiatry clinic, or a psychiatric ward.
Inclusion criteria	Participants had to be: <ul style="list-style-type: none"> Aged 16 to 24 years with ICD-10 criteria for intentional self-harm X60-X84 (codes include all forms of self-harm but exclude suicidal intent)

Exclusion criteria	Not reported.
Setting	Emergency (no previous contact with emergency department, or psychiatric emergency services - initial contact for self-harm)
Sample size	N=10 people who self-harmed
Participant characteristics	<p>Mean age (range): 20 (17-24) years</p> <p>Sex (female/male): 6/ 4</p> <p>Co-morbidity: Not reported</p> <p>Duration of self-harm: Not reported</p> <p>Suicide attempts: Not reported</p>
Data collection and analysis	1-2-1 semi-structured interviews were conducted according to a script. Questions were asked in an open-ended manner to encourage the participants to speak freely about the subject. Interviews were recorded. 9 interviews ranged from 27 to 50 minutes, while 1 interview was 14 minutes long. Interviews were transcribed in Swedish. Data were analysed using an inductive thematic approach.
Results	<p>Author theme: One Should Not Communicate Distress</p> <p><i>Example quote: There may be people who feel worse than I do. Their problems may be a little different than mine. It didn't feel like my problems were anything compared with theirs. It just felt weird to seek help because you just... well... (Participant 1)</i></p> <p><i>If you seek help for some psychiatric reason, it may affect you if you look for a job or something else, I don't know. (Participant 10)</i></p> <p>Author theme: The Importance of Family and Friends When Overwhelmed by Emotional Storms</p> <p><i>Example quote: She's the one who called and reserved everything. Because I haven't had the strength to do anything then so this was really nice. (Participant 2)</i></p>

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1 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(1-2-1 semi-structured interviews with open-ended questions. Data saturation discussed (10 to 12 interviews planned but stopped after 10 as material was considered rich enough to reach saturation))</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Comment that researcher had no access to participant medical records and all information was retrieved from participants)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Can't tell <i>(Ethical approval granted. Participants were consented prior to taking part in the study but detail not provided)</i>
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Minor concerns <i>(Insufficient information provided on ethical considerations)</i>

Section	Question	Answer
	Relevance	Relevant (<i>Study not conducted in the UK.</i>)

1

Jennings, 2020

2

Bibliographic Reference Jennings, S.; Evans, R.; Inter-professional practice in the prevention and management of child and adolescent self-harm: foster carers' and residential carers' negotiation of expertise and professional identity; *Sociology of health & illness*; 2020; vol. 42; 1024-1040

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5 Study Characteristics

Country/ies where study was carried out	UK (Wales)
Study type	Grounded theory
Study dates	November 2015 to May 2016.
Sources of funding	Funded by the National Institute for Social Care and Health Research (NISCHR) in Wales, the British Heart Foundation, Cancer Research UK, the Economic and Social Research Council, the Medical Research Council, the Welsh Government and the Wellcome Trust, under the auspices of the UK Clinical Research Collaboration.
Recruitment strategy	Participants were purposively recruited through a private foster care association, a national foster carer network, and a private residential care association comprising of a large number of group homes. Each of these associations disseminated information about the study to members via email or a meeting. The information invited members to participate in a focus group on a pre-specified date or to contact the lead researcher to arrange an interview. Participants were provided with information about the study in advance of data collection, documenting confidentiality, anonymity and the process of informed consent.
Inclusion criteria	Participants had to be:

	<ul style="list-style-type: none"> Carers across Wales who have a statutory responsibility for children and adolescents aged 18 years or younger.
Exclusion criteria	Not stated.
Setting	Foster care and residential care.
Sample size	N = 30 carers (9 participated in interviews; 21 participated in focus groups)
Participant characteristics	<p>Mean age (SD): Not stated.</p> <p>Sex (female/ male): 23 / 7</p> <p>Relationship to person who has self-harmed: Not stated.</p> <ul style="list-style-type: none"> Foster carers: 15 Residential carers: 15
Data collection and analysis	<p>Focus groups and semi-structured interviews were undertaken with participants. Nine participants took part in interviews. Three were undertaken in person and six via telephone. Focus groups were conducted with 21 carers. Transcripts analysed with the grounded theory approach by coding the text. A coding framework was developed and refined as coding progressed. Axial coding was then conducted in accordance with the four constituent elements. First, codes were categorised according to the phenomenon under consideration (for example, inter-professional relationships). Second, codes were examined for those explaining the conditions that give rise to the phenomenon (such as expertise). Third, categories of codes were developed to explain the practices and experiences related to the management of the phenomenon (such as inter-professional communication). Fourth, categories explored the consequences of these actions (for example, experiences of marginalisation within inter-professional interactions). The process of analysis involved the continual revisiting of the data in order to re-contextualise and further develop themes from the four categories.</p>
Results	<p>Author theme: Contestations in expertise: the duality of propositional and experiential knowledge</p> <p><i>Example quote: Because I wasn't able to put a name on what I think it [self-harm] could have been or you know, suggest what it may have been and push a little bit further, I felt quite overpowered by these big psychologists and doctors, that it was kind of a bit, like no, it's nothing really. (IDRC10: Residential Carer)</i></p>

Author theme: Preclusion of professional identity: inadequate professionalisation processes and the labour of legitimacy

Example quote: The other thing is the way the statutory agencies don't involve, I mean we are the amateurs, really aren't we? That's what they see. They don't actually kind of seem to realise the level of expertise. So, where they have the multi-agency meetings, they will have multi-agency meetings about our children but not invite us because we are not a statutory agency. And often we're providing, we will provide a report and they won't read it because we're not a statutory agency. (IDRC03: Residential Carer)

When we've had a young person from [Local Authority] who has gone to [Local Authority] CAMHS the service has been just unreal. I cannot fault them. They've been superb with us, with the young person, with the whole thing. I cannot fault them. And we worked really well with CAMHS and they listen to us and we listen to them. And I think we've built an extremely good relationship with them to the point that they think [CAMHS Nurse] is the best thing since sliced bread. (IDRC13: Residential Carer)

As they've sat in on meetings that we have been in with other care professionals on this young man, they've sort of changed and they have realised that actually [laughs] we are fellow professionals, not childminders and we have even been able to pass on leaflets and pamphlets and things to help them with the care of the young person we've got, which is good to be able to help them. We now have an excellent rapport with them. (IDFC01: Foster Carer)

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes

Section	Question	Answer
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors did not state whether the researcher critically examined their own role during formulation of the research questions.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
	Relevance	Relevant <i>(1 participant (3%) did not have experience caring for a person who had self-harmed.)</i>

1

Kelada, 2016

2

Bibliographic Reference

Kelada, Lauren; Whitlock, Janis; Hasking, Penelope; Melvin, Glenn; Parents' experiences of nonsuicidal self-injury among adolescents and young adults; *Journal of Child and Family Studies*; 2016; vol. 25; 3403-3416

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3 Study Characteristics

Country/ies where study was carried out	Study 1: Australia Study 2: USA
Study type	General qualitative inquiry
Study dates	Not stated.
Sources of funding	Not stated.
Recruitment strategy	Study 1: Participants were recruited through high schools in Victoria, Australia. Parents of students were invited to participate in the study and were mailed a questionnaire. Study 2: Participants were recruited for interviews in New York State via flyers, online advertisements, and emails as part of a larger study on recovery from NSSI.
Inclusion criteria	Study 1: Australian parents of a community-based sample of adolescents with a history of NSSI. Participants had to have answered 'yes' to the following question in order to take part: "To the best of your knowledge, has your adolescent ever self-injured". Study 2: American parents of young adults with a history of NSSI. At least 1 parent of the young person had to be aware of the NSSI, and the parents and child were required to be willing to complete a pre-assessment survey and a follow-up interview.
Exclusion criteria	Study 1: Not stated. Study 2: Not stated.
Setting	Community.
Sample size	Study 1: N = 16 parents of people who had self-harmed Study 2: N = 22 parents of people who had self-harmed

<p>Participant characteristics</p>	<p>Mean age (SD):</p> <ul style="list-style-type: none"> • Study 1: Parents: 45.44 (4.88) / Adolescents: 15.38 (1.89) • Study 2: Not reported <p>Sex (female/ male):</p> <ul style="list-style-type: none"> • Study 1: 10 female/ 6 male • Study 2: Not reported <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Study 1: Mother = 15, Father = 1 • Study 2: Mother = 18, Father = 4
<p>Data collection and analysis</p>	<p>Study 1: Parents of students return mailed the open-ended questionnaire. Participants' responses to the open-ended questions ranged from 1 word to 146 words. Responses were coded to detect patterns within the areas of interest. These codes were then categorized into overarching themes for each area of interest.</p> <p>Study 2: Semi-structured interviews were held face-to-face or remotely (over the phone or via Skype), audio-recorded and transcribed verbatim. The results were thematically analysed in accordance with study 1.</p>
<p>Results</p>	<p>Author theme: Lack of empathy</p> <p><i>Example quote: She [psychologist] was manipulative and vengeful. Threatened and wasted valuable resources from real need. [P2, mother]</i></p>

Author theme: Lack of support

Example quote: She had weekly/fortnightly sessions for 10 months with psychologist but I didn't know if she was improving. Didn't feel supported as a parent by the psychologist. [P1, mother]

Author theme: Negative Experiences with Mental-Health Professionals

Example quote: I pretty much right away tried to get her into a counsellor but...I got lost, like I was completely on my own trying to- to figure out who I should get her into...I didn't feel like there was a good resource and then once you did find who you wanted to go too- I mean I remember calling like five, six therapists one day and not getting any of them to answer me. [P7, mother]

I don't know how successful therapy was in general, I mean, honestly, the deeper he would dive, the more she would resist...I think that it was just ineffective to try and dig in there...I think that was not a very useful approach on her. Just if he had looked at the case, and saw that it wasn't working, I think it was probably time to maybe try something else that maybe she was a little more receptive to. [P4, father]

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes

Section	Question	Answer
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Study 1: Authors provided information about the way the questionnaire was set out but did not justify their reasoning for using a questionnaire. Data saturation not discussed. Study 2: Insufficient information provided about the interview method. Data saturation not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors did not state in either study whether the researcher critically examined their own role during data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Can't tell <i>(Authors did not state in either study whether the researcher critically examined their own role during data analysis. Additionally, study 1 provides minimal data for each theme.)</i>
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Authors did not state in either study whether the researcher critically examined their own role during data collection or analysis, and data saturation was not mentioned.)</i>
	Relevance	Relevant <i>(Studies not conducted in the UK.)</i>

1

Kennard, 2020

2

Bibliographic Reference Kennard, B.; Moorehead, A.; Stewart, S.; El-Behadli, A.; Mbroh, H.; Goga, K.; Wildman, R.; Michaels, M.; Higashi, R. T.; Adaptation of Group-Based Suicide Intervention for Latinx Youth in a Community Mental Health Center; Journal of Child and Family Studies; 2020

1

2

3 Study Characteristics

Country/ies where study was carried out	USA
Study type	General qualitative inquiry
Study dates	Not stated.
Sources of funding	Funded by the University of Texas Southwestern Medical Center Community-Based Pilot Research Grants.
Recruitment strategy	Staff participants were recruited by email from three community clinics and asked to participate in a web-based survey and in person, semi-structured interview. Adolescent and parent participants were identified by staff participants who solicited their assent for inclusion.
Inclusion criteria	Not stated.
Exclusion criteria	Not stated.
Setting	Community clinics within a large network of community mental health service providers that primarily serves patients of low socioeconomic status in an urban area.
Sample size	N = 8 clinicians and clinic staff
Participant characteristics	<p>Mean age (SD): Not stated</p> <p>Sex (female/ male): 6 / 2</p> <p>Role:</p> <ul style="list-style-type: none"> Licensed Professional counsellors: 3

	<ul style="list-style-type: none"> • Qualified Mental Health Professionals: 2 • Clinical managers: 2 • Operations manager: 1 <p>Setting : 3 community clinics within a large network of community mental health service providers</p> <p>Years in post/ experience: 8.56 (SD =14.09, Range 1.5–43)/ 11.13 (SD=14.41, Range 0–45)</p> <p>Client group (adults, children/ CYP): Not stated</p>
Data collection and analysis	<p>Interviews were audio-recorded, transcribed, and analysed thematically using a deductively-driven codebook corresponding to interview domains.</p>
Results	<p>Author theme: Cultural transitions</p> <p><i>Example quote: So that bond of knowing culturally you may have had a similar experience, I've noticed it makes them more comfortable and even with the parents, the parents are a little bit more comfortable being more real with you and telling you things they might not tell someone else.—clinician</i></p> <p><i>Another thing is often with more among the Latino population that, that I see in the summer they will go to Mexico for the summer or other places and so they'll be gone for a month or two months or and it's not always planned. So, sometimes it's like we'll have an appointment scheduled, I'll see them one week, we'll have an appointment scheduled the next week, suddenly they don't show up and I call and it's like oh yeah they're in Mexico for two months. And it's like well it would have been good for us to go over a plan of how to handle things while they're there.—clinician</i></p> <p>Author theme: Negative Experiences with Mental-Health Professionals</p> <p><i>Example quote: My number one thing would be to ask [the mental health professional] if they are familiar with selfinjury and if they treated other children that have dealt with that issue. And maybe even ask them if they can provide some resources for, ya know, the parents to study to educate themselves on, ya know- to become better qualified to deal with it. [P19, father]</i></p>

Author theme: Strategies to engage families

Example quote: [I use] metaphors and parables...once they understand and start explaining it, then get them to identify how it works clinically...[One] illustration is high blood pressure. High blood pressure—you take the pills but with the pills you also must eat healthy and you have to exercise. A pill alone won't fix it, but with exercise and eating healthy...—clinician

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors did not state whether they critically examined their own role during data collection.)</i>

Section	Question	Answer
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Can't tell <i>(One author had conflicts of interest and financial disclosures due to receiving research support from the National Institute of Mental Health and royalties from Guilford Press, as well as serving on the Board of Trustees of the Jerry M. Lewis, M.D. Research Foundation. This author led the data analysis, however it is explained that this was due to language barriers for the other researchers involved in analysis. The authors argue that coder continuity and the coding of both English and Spanish transcripts using the same codebook increased reliability.)</i>
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Minor concerns <i>(Authors did not state whether they critically examined their own role during data collection.)</i>
	Relevance	Relevant <i>(Study included adolescents who were identified as having suicidal thoughts and behaviours but had not necessarily self-harmed, their parents, and their clinicians. The study was not conducted in the UK.)</i>

1

Krysinska, 2020

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Bibliographic Reference

Krysinska, K.; Curtis, S.; Lamblin, M.; Stefanac, N.; Gibson, K.; Byrne, S.; Thorn, P.; Rice, S. M.; McRoberts, A.; Ferrey, A.; Perry, Y.; Lin, A.; Hetrick, S.; Hawton, K.; Robinson, J.; Parents' experience and psychoeducation needs when supporting a young person who self-harms; International Journal of Environmental Research and Public Health; 2020; vol. 17 (no. 10)

3

4

1 Study Characteristics

Country/ies where study was carried out	Australia
Study type	General qualitative inquiry
Study dates	March - August 2018
Sources of funding	Funding from the Western Australia Primary Health Alliance (WAPHA) as part of the National Suicide Prevention Trial, Future Generation Global, and The William Buckland Foundation, National Health and Medical Research Council Career Development Fellowships, The Giorgetta Charity Fund.
Recruitment strategy	Parents were recruited in a number of ways, including: through a local council, headspace centres and a parent and carer support group; a combination of posters/advertisements and social media posts on Twitter; referral by clinicians at participating sites.
Inclusion criteria	Parents with experience of supporting a young person (age range 12–25 years) who had engaged in self-harm (either currently or recently).
Exclusion criteria	Not stated.
Setting	Community based.
Sample size	N = 19 parents of young people who had self-harmed
Participant characteristics	<p>Mean age (SD): Not stated.</p> <p>Sex (female/ male): 16 / 3</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Mothers: 16 • Fathers: 3
Data collection and analysis	Semi-structured individual and group interviews with parents of young people who self-harm. The interview schedule aimed to elicit participants' views regarding the original UK version of "Coping with Self-Harm" resource, which they were given in advance of the interview. Participants also provided suggestions for the Australian adaptation. These questions prompted further discussion about the experience of having a young person who self-harms, and parents' needs around this. Data were analysed using generic thematic analysis involving a combined inductive and deductive approach.

Results

Author theme: Discovering Self-Harm: “There’s Life before and after Self-Harm”

Example quote: “if you could just get a little baggy of stuff - they just go, here, look, here’s some information. You’re probably not going to look at it right now because you’re still in that crisis mode, but it’s just sitting there” (Parent 4).

Author theme: Need for Psychoeducational Resources: “I Wish I Had Something Like This [Booklet] When I Was Going Through It [Self-Harm]”

Example quote: “There needs to be a discussion with the child that’s actually self-harming about why it needs to be discussed and why it needs to be discussed with certain people. (: :) It should be a joint decision on who - say, for myself and my son, who those people were going to be” (Parent 3)

Author theme: Parents’ Emotional Reactions: “You Might Have Strong Emotions Yourself”

Example quote: “there are a lot of myths around, bad parenting equals ADHD [Attention-deficit/hyperactivity disorder] or equals self-harm”, Parent 11

Author theme: Self-Care and Help Seeking: “You’ve Got to Help Yourself before You Can Help Your Child”

Example quote: “If the parent is stressed, the main caregiver is stressed then how does that impact around other siblings? The child that you’re trying to support, who’s self-harming, are they looking at it like they’re not coping because I’m.. It kind of-yeah, dominoes” (Parent 3).

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- 3 Critical appraisal
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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Can't tell <i>(Authors conducted a general qualitative inquiry but did not justify their reasoning.)</i>
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
	Relevance	Relevant <i>(Study not conducted in the UK.)</i>

1

Lindgren, 2010

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Bibliographic Reference

Lindgren, Britt-Marie; Astrom, Sture; Graneheim, Ulla Hallgren; Held to ransom: Parents of self-harming adults describe their lived experience of professional care and caregivers; International Journal of Qualitative Studies on Health and Well-being; 2010; vol. 5; 1-10

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4 **Study Characteristics**

Country/ies where study was carried out	Sweden
Study type	Phenomenological
Study dates	Not reported.
Sources of funding	This study received no funding.
Recruitment strategy	Participants were recruited through advertisement and recommendations by the participants.
Inclusion criteria	Participants had to: <ul style="list-style-type: none">• Be the parent of an adult person who self-harmed.
Exclusion criteria	Not reported.
Setting	In the community.
Sample size	N = 6 parents of adult children who self-harm
Participant characteristics	Age range: 45-55 years Sex (female/male): 5/ 1

	<p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none">• Mother: 5• Father: 1
Data collection and analysis	<p>Narrative interviews lasted between 30-85 minutes and were tape-recorded and transcribed verbatim. Transcripts were analysed using a phenomenological hermeneutic approach.</p>
Results	<p>Author theme: Being 'broken'</p> <p><i>Example quote: 'After that they decided to crack me; it was their goal. They said to my daughter, "Your mother doesn't want you to receive care, she's destroying everything", and so on'.</i></p> <p>Author theme: Being confused</p> <p><i>Example quote: I asked at the care meeting whether someone could visit Tina if necessary? There was nobody [who could visit] was the answer I got. Now I've got the information that there was someone who could have come. There were personnel from the community who were available if needed.</i></p> <p>Author theme: Feeling accused</p> <p><i>Example quote: It was a shock being blamed; I felt that the first time my daughter was in mental health care. Feelings of guilt and shame, but most of all it felt like a failure. In the end I felt I was of no use as a parent.</i></p> <p>Author theme: Feeling hoodwinked</p> <p><i>Example quote: Then they [the caregivers] had discovered that a child who has passed 16 years of age can change the place of domicile to the other parent // So, they took my daughter to a place where she could do just that, without my knowledge. I had sole custody and they went behind my back!</i></p>

If only I'd been more persistent and said 'She's not just an ordinary girl, something is wrong with her'. She's lost so many years unnecessarily. 'Please, listen to what we're saying, something about her isn't right and we need help'.

Author theme: Feeling invisible

Example quote: 'We weren't asked about what we thought, how we thought things should be solved. On the other hand, we are the one affected by their decisions'.

I needed help to know how to behave. I am a parent, not a carer. We don't have the professional education to be a therapist. I just wanted some kind of tools instead of being helpless.

It scares me that they forget the most important people in my daughter's life. They need to see the significant others. We're the ones who are the main caregivers and we have to keep it together around the person who is ill.

Author theme: Feeling released

*Example quote: 'Caregivers with their own experience of suffering*maybe they had a tough and shady life behind them, and then they educated themselves*they were the ones who were the best in meeting us as parents'.*

Author theme: Losing confidence in the healthcare system

Example quote: 'I was her therapist instead of just being her mother. To get rid of the anxiety we would talk for hours; she should have had that help from the care providers instead'.

'What am I going to do with my kid? I can't watch her fall apart in pieces; I can't handle that'.

Author theme: Negotiating and bridging gaps

Example quote: You really have to think twice before saying anything. How should I express myself so that this person doesn't think that I'm barging in on their territory, only making a suggestion, like maybe it can be done in this way?

'It's difficult to satisfy her need to be with her little sister and at the same time consider the rules for visiting the ward'.

'One of these caregivers was rather rough towards Tina, but I didn't take it so hard because she was rather cocky herself'.

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3 Critical appraisal

4

Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Can't tell <i>(Authors used a phenomenological hermeneutic approach, but did not justify their reasoning.)</i>
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes

Section	Question	Answer
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Saturation of data was not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Minor concerns <i>(Lack of justification for data collection and no discussion of data saturation.)</i>
	Relevance	Relevant <i>(Study not conducted in UK.)</i>

1

McLaughlin, 2016

2

Bibliographic Reference

McLaughlin, C.; McGowan, I.; Kernohan, G.; O'Neill, S.; The unmet support needs of family members caring for a suicidal person; Journal of Mental Health; 2016; vol. 25; 212-216

3

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5 Study Characteristics

Country/ies where study was carried out	UK (Northern Ireland)
Study type	General qualitative inquiry
Study dates	Not stated.
Sources of funding	Not stated.
Recruitment strategy	Recruitment was undertaken through a media call. Participants made initial contact with the lead researcher via a secure publicised telephone number. Then the study was explained. Once eligibility was determined, an appointment was made for the research interview. Interview locations were chosen by the participant and included the participant's home, the rooms of a voluntary counselling facility, or a university office.
Inclusion criteria	Participants who identified themselves as currently living with and caring for, or had lived with and cared for, a suicidal family member.
Exclusion criteria	Not stated.
Setting	In the community.
Sample size	N = 18 carers for suicidal family members
Participant characteristics	Mean age (SD): Not stated. Age range between 25 and 78 years.
	Sex (female/ male): Not stated.
	Relationship to person who has self-harmed: Not stated.
Data collection and analysis	Data was gathered by in-depth semi-structured interview. Questions focussed on the participant's experiences of discovering and living with a suicidal person. Additional probes were used, when required, to explore the experiences of any support they received. Each interview was recorded, transcribed verbatim and analysed using thematic analysis.
Results	Author theme: Consistency of support <i>Example quote: we were lucky to have a good psychiatric team, there was continuity of care, the same consultant that looked after him in the community, (also) looked after him in the hospital.</i>

Author theme: Feeling acknowledged and included

Example quote: "staff were nice to my sister but they were not helpful to me. I was not allowed to be given any information about her treatment. They said it was up to my sister to tell me. My sister didn't really want to be there, I was worried about her, I cared about her and so did her children and they wouldn't give us any help or information. There is no support for carers. We need to be able to ring up the services to find out how she is. The services tell you nothing. That is no good as we are expected to help. How can we help if we don't know and are kept in the dark? Services need to talk to family members about their relatives."

The medical side of affairs will not, and I stress this point, will not discuss anything with us and I think that for people to be asked to look after somebody who is in this state of mind without telling them how they can actually help or when should they step in to help, is totally wrong.

Staff need to make an effort to approach people, even if it seems like a betrayal of a person's feelings. In my case keeping the secret did not help and only created problems for me. Mental Health Services need to contact family and children and involve them and inform them.

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes

Section	Question	Answer
Research Design	Was the research design appropriate to address the aims of the research?	Can't tell <i>(Authors conducted a general qualitative inquiry, but did not justify their reasoning.)</i>
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Can't tell <i>(Insufficient information provided regarding the recruitment strategy.)</i>
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Saturation of data not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors did not state whether they critically examined their own role during data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Can't tell <i>(Insufficient information provided regarding the analysis process, however rich data presented to support the themes.)</i>
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research has some value <i>(Authors acknowledge the inability to transfer findings to other populations. Additionally, although they acknowledge the need for further research, the authors do not identify areas where research is necessary.)</i>
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Insufficient information provided regarding recruitment and data collection and analysis.)</i>
	Relevance	Partially relevant <i>(Participants included family members of people who were suicidal but had not necessarily self-harmed, as well as 7 participants (39%) who had lost a family member to suicide.)</i>

Nadeem, 2016

1

Bibliographic Reference Nadeem, E.; Santiago, C. D.; Kataoka, S. H.; Chang, V. Y.; Stein, B. D.; School Personnel Experiences in Notifying Parents About Their Child's Risk for Suicide: Lessons Learned; The Journal of school health; 2016; vol. 86; 3-10

2

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4 Study Characteristics

Country/ies where study was carried out	USA
Study type	General qualitative inquiry
Study dates	Not stated.
Sources of funding	Not stated.
Recruitment strategy	6 schools were randomly chosen to participate from a group of schools who had high or low levels of implementation of a Youth Suicide Prevention Program (3 schools with high levels and 3 schools with low levels). From the 5 schools which agreed to participate, participants were identified via referral from a school point person (school social worker or administrator), or through flyers in faculty mailboxes and faculty meeting announcements.
Inclusion criteria	Not stated.
Exclusion criteria	Not stated.
Setting	School
Sample size	N = 45 school staff (35 focus group participants, 10 interview participants)

<p>Participant characteristics</p>	<p>Mean age (SD): Not stated</p> <p>Sex (female/ male): 26 / 19</p> <p>Role:</p> <ul style="list-style-type: none"> • Counselors or mental health staff: 7 • Nurses: 2 • Teachers: 26 • Administrators: 10 <p>Setting: School</p> <p>Years in post/ experience: 6.4 (SD=5.5) / 14 (SD=11.32)</p> <p>Client group (adults, children/ CYP): Children</p>
<p>Data collection and analysis</p>	<p>Semi-structured focus groups and interviews asking staff about their experiences with suicide-prevention strategy implementation, crisis intervention follow-up, improving the Youth Suicide Prevention Program specific to middle school needs, and parents' role in the crisis intervention phase. Interviews and focus groups were coded and analysed using thematic analysis.</p>
<p>Results</p>	<p>Author theme: Parent Involvement During the Crisis Phase</p> <p><i>Example quote: "You always call the parent. Even if the child says, I'm not, I'm not, I'm not."</i></p> <p>Author theme: Parent Involvement Postcrisis</p> <p><i>Example quote: "Every two weeks we'll [review] the students who have been referred. There will be a follow-up as to whether or not the parents followed through with the intakes, if the child's attending, or if the parent indicated that they didn't want the services."</i></p> <p>Author theme: Strategies for Enhancing Parent Engagement and Involvement</p>

Example quote: “Even problems that are not necessarily school-related, [parents] will come to the school and ask for help. It is more family issues. I’ve gone out with the principal to homes, you know, when crises have happened, just to help connect them with services because they look at the school like the safe place for them to go.”

“When it comes to emotional problems, we can only do so much in the classroom. Having a Healthy Start program in school, they can channel it better than we could.”

“How should we address parents, how can we make them aware without scaring them, aside from providing facts and statistics. Everyone thinks it’s not ever going to happen to them. We have to continuously keep them aware. I think that’s what we’re lacking.”

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Can't tell <i>(Authors conducted a general qualitative inquiry, but did not justify their reasoning.)</i>
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Authors did not provide a justification for why the majority of data were collected)</i>

Section	Question	Answer
		<i>through focus groups, which can limit discussion of a sensitive topic. Additionally, saturation of data not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors did not state whether they critically examined their own role during data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Can't tell <i>(Approval was sought from an ethics committee but insufficient information provided regarding ethical considerations.)</i>
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Insufficient information provided regarding ethical considerations and data collection.)</i>
	Relevance	Relevant <i>(Study not conducted in the UK.)</i>

1

Oldershaw, 2008

2

Bibliographic Reference

Oldershaw, A.; Richards, C.; Simic, M.; Schmidt, U.; Parents' perspectives on adolescent self-harm: Qualitative study; British Journal of Psychiatry; 2008; vol. 193; 140-144

3

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5 Study Characteristics

Country/ies where study was carried out	UK
Study type	Phenomenological
Study dates	Not reported.
Sources of funding	This study was funded by the Psychiatry Research Trust, and South London and Maudsley Research and Development funds.
Recruitment strategy	Participants were recruited through Child and Adolescent Mental Health Services (CAMHS).
Inclusion criteria	Participants had to: <ul style="list-style-type: none"> • Be a main carer living with a person aged 13-18 years who had been referred to a CAMHS for treatment of self-harm.
Exclusion criteria	Potential participants were excluded if: <ul style="list-style-type: none"> • They were unaware of their child's self-harm • Their child who had been referred to a CAMHS had a serious comorbid illness
Setting	In the CAMHS centre.
Sample size	N=12 carers of children referred to CAMHS
Participant characteristics	<p>Mean age (SD): Not reported.</p> <p>Sex (female/male): 10/ 2</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Mother: 9 • Father: 2 • Grandmother: 1

Data collection and analysis	Semi-structured interviews lasted approximately 1 hour and were transcribed verbatim. Transcripts were analysed using an interpretive phenomenological approach.
Results	<p>Author theme: Influence of outside agencies on the psychological impact</p> <p><i>Example quote: 'The health professionals have got to deal with the patient haven't they, but I must say I have felt, I'm feeling, as though I'm trying to deal with this 24 hours a day and I don't know what to do for the best, so I don't know if what I'm doing and how I'm dealing with her is helping or if I might be making her worse! For all I know it might be totally the wrong, the wrong way of dealing with it. You feel like it's been taken out of your hands really without being given any kind of instruction.'</i> (Mrs K)</p> <p>Author theme: The process of discovery</p> <p><i>Example quote: 'The teacher at the school actually was really quite good. She actually gave me a lot of the background for self-harm, why girls self-harm . . . she seemed to be quite clued up and in fact it was her that, she was the one that explained to me, a lot of it to me, because I had no idea what it [self-harm] was, what it meant . . . I didn't feel as though I was floundering as much as I think I would have if I hadn't had her advice.'</i> (Mrs S)</p> <p><i>'The doctor put her off actually because I think we may have got further, but the doctor was more interested in how old she was, whether she was having sex and if she was using contraceptives and Kate came out very disillusioned.'</i> (Mrs E).</p> <p><i>'[We] decided that our best course of action was not to make a big dramatic fuss and just let it unfold and just see if this evaporated. Erm, we realised that there was a sort of element of risk in that, but we weren't sure whether this was something that was deeply rooted, and erm ingrained as it were, or if this was something that was pretty temporary and would pass.'</i> (Mr J)</p> <p><i>'We kind of brushed that under the carpet . . . We try to ignore it really, to try and get on with life and hopefully she will stop doing it.'</i> (Mrs P)</p>

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Can't tell <i>(Aim not clearly stated but can be deduced.)</i>
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
	Relevance	Highly relevant

1

Raphael, 2006

2

Bibliographic Reference

Raphael, H.; Clarke, G.; Kumar, S.; Exploring parents' responses to their child's deliberate self-harm; Health Education; 2006; vol. 106; 9-20

1

2

3 Study Characteristics

Country/ies where study was carried out	UK
Study type	Phenomenological
Study dates	Not reported.
Sources of funding	Not reported.
Recruitment strategy	Participants were recruited through the medical staff of the emergency medical unit of a local hospital, who identified the children of potential participants for the study and approached them for consent for their parents to be contacted. Further participants were also recruited opportunistically and through advertisements.
Inclusion criteria	Participants had to: <ul style="list-style-type: none"> • Be an adult with a parental role for a young person who had self-harmed
Exclusion criteria	Potential participants were excluded if: <ul style="list-style-type: none"> • Their child who had self-harmed suffered from a psychotic mental disorder or significant cognitive impairment • Their child who had self-harmed was not between the ages of 16-24
Setting	In the community and the local hospital.
Sample size	N=9 parents of young people who had self-harmed
Participant characteristics	Mean age (SD): Not reported. Sex (female/male): 5/ 4

	<p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Mother: 5 • Father: 4
Data collection and analysis	Unstructured interviews lasted between 1-1.5 hours and were audio recorded and transcribed verbatim. For some participants, a second interview was conducted. Thematic analysis was conducted by three researchers using a phenomenological approach.
Results	<p>Author theme: Emotional responses</p> <p><i>Example quote: Actually we phoned the hospital first and the staff nurse said that he had just come in and I was a little bit taken aback . . . she said I will go and ask his permission for you to come in and I was thinking but this is his parents you can't do that and we still did not know what was wrong this was the thing we had no idea what had happened . . . Then she came back and said yes, it is alright . . . but I was angry how dare she say ask his permission, and I think it would have been worse if he [son] had said no</i></p> <p>Author theme: Health professionals</p> <p><i>Example quote: . . . had it been brought up in conversation, yes I would probably have made a few references to the fact . . . I probably would have in the end but I certainly wouldn't go out and announce 'it to the world.</i></p>

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes

Section	Question	Answer
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Can't tell <i>(Participants were recruited in part on an emergency medical unit by the medical staff, which may have allowed for bias in the recruitment strategy.)</i>
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Two sets of parents were interviewed together, which may limit discussion and therefore not provide the necessary richness to address the research question. Additionally, saturation of data was not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	No <i>(Limited consideration given to minimising bias during data collection. In addition, 'non verbal observations' were made of participants during data collection which were entirely derived from the author's perspective.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Can't tell <i>(Authors give an in-depth description and justification of their analysis process and provide sufficient data to support their analyses. However, authors used their personal interpretation of 'non verbal observations' of participants to inform their analyses, sometimes contrary to responses given by participants.)</i>
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Serious concerns <i>(Some concerns around bias in the data analysis, recruitment strategy, and the relationship between the researchers and participants; no discussion of data saturation)</i>
	Relevance	Highly relevant

1

Rissanen, 2009a

2

Bibliographic Reference Rissanen, M. L.; Kylma, J.; Laukkanen, E.; Descriptions of help by Finnish adolescents who self-mutilate; Journal of child and adolescent psychiatric nursing : official publication of the Association of Child and Adolescent Psychiatric Nurses, Inc; 2009; vol. 22; 7-15

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5 Study Characteristics

Country/ies where study was carried out	Finland
Study type	General qualitative inquiry
Study dates	Not reported
Sources of funding	Not reported
Recruitment strategy	Written descriptions: Advertised in 4 magazines targeted at adolescents, on magazine websites, and on the principal researcher's own website. Interviews: Participants selected for interview from a population sample of 13- to 17-year-old adolescents who lived in eastern Finland and who had reported past or current self-mutilation in a structured questionnaire Recruitment period: Not reported
Inclusion criteria	Adolescents who had self-mutilated or were currently self-mutilating
Exclusion criteria	Not reported
Setting	Not reported

Sample size	N=72 adolescents who had self-harmed (Written descriptions: N=62, Interviews: N=10)
Participant characteristics	<p>Age range:</p> <ul style="list-style-type: none"> • Written descriptions: (12 to 21 years) • Interviews: (15 to 19 years) <p>Sex (female/male)</p> <ul style="list-style-type: none"> • Written descriptions: not reported • Interviews: 10/0 <p>Co-morbidity: Not reported</p> <p>Duration of self-harm: Not reported</p> <p>Suicide attempts: Not reported</p>
Data collection and analysis	<p><u>Written descriptions:</u> Submission of written descriptions were invited via email. All adolescents who had self-mutilated would have a possibility to talk about that they wanted concerning help for self-mutilation (including age and gender information).</p> <p><u>Interviews:</u> 1-2-1 open-ended interviews invited the interviewee to talk about self-mutilation. The interviews lasted 45 to 75 minutes and were audiotaped.</p> <p>The analysis began by combining written descriptions and audio-taped interviews transcribed verbatim. Data were analysed using inductive content analysis.</p>
Results	<p>Author theme: Any Person Who Knows About Their Self-Mutilation Can Be a Helper</p> <p><i>Example quote: "It was helpful when I went to psychiatrists and talked there more with my mother, too."</i></p> <p><i>"My parents got worried and helped me to get professional help."</i></p>

<p>Author theme: Factors enabling help-seeking</p> <p><i>Example quote: "Although my mother did not understand how bad I felt, chatting with her was enough to keep me from self-mutilating that night."</i></p> <p><i>"Sometimes it is better not to tell parents because it can cause more difficulties for the self-mutilating adolescent."</i></p> <p><i>"Although my mother did not understand how bad I felt, chatting with her was enough to keep me from self-mutilating that night."</i></p> <p>Author theme: Help-hindering factors</p> <p><i>Example quote: "My mother dressed me down."</i></p>

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes

Section	Question	Answer
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Can't tell <i>(Limited information provided particularly around the submission of written descriptions)</i>
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Data collection description provided - written descriptions and individual open-ended interviews; written descriptions were emailed and demographic information were not always provided; no limit on number of written submissions; no discussion of data saturation)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(No information reported)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Method of data collection has limitations; no discussion of data saturation; insufficient information on the potential influence of the researcher or of the relationship between researchers and participants on results)</i>
	Relevance	Relevant <i>(Study not conducted in the UK.)</i>

1

Rissanen, 2009b

2

Bibliographic Reference Rissanen, M. L.; Kylma, J.; Laukkanen, E.; Helping adolescents who self-mutilate: parental descriptions; Journal of clinical nursing; 2009; vol. 18; 1711-1721

1

2

3 Study Characteristics

Country/ies where study was carried out	Finland
Study type	General qualitative inquiry
Study dates	Not reported.
Sources of funding	Not reported.
Recruitment strategy	Participants were recruited through adolescents who were taking part in another study on self-cutting (Rissanen 2006).
Inclusion criteria	Participants had to: <ul style="list-style-type: none"> • Be the parent of an adolescent taking part in a study on self-cutting (Rissanen 2006) • Be aware of their child's self-harm
Exclusion criteria	Not reported.
Setting	In the community.
Sample size	N=4 parents of adolescents who had self-harmed
Participant characteristics	Mean age (SD): Not reported. Sex (female/male): 3/ 1

	<p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none">• Mother: 3• Father: 1
Data collection and analysis	<p>Open-ended interviews lasted between 45-75 minutes and were audiotaped and transcribed. Transcripts were interpreted using inductive content analysis.</p>
Results	<p>Author theme: Adolescent self-help</p> <p><i>Example quote: Parent 4: She asked me to come along to the doctors' to make sure that everything of importance would be said. She just said that she won't leave the ward. She said that she is in need of hospital care.</i></p> <p>Author theme: Adult siblings as helpers</p> <p><i>Example quote: We drove her to her adult sister because she was the one with whom she could discuss self-mutilation and all the things associated with it. Their conversations were long ones.</i></p> <p>Author theme: Helping the parents and the family</p> <p><i>Example quote: We (parents) were shocked when we found out about her selfmutilation. I personally felt that I was too close to her to provide help. I felt that I had no means to help her, too. We once had a possibility to say something about our feelings when she was an inpatient, but it was not enough.</i></p> <p>Author theme: Parents as helpers</p> <p><i>Example quote: 'If the child implicitly asks for help, you as a parent must respond and try to find out what is going on'.</i></p>

There was a school doctor, a school nurse, me as the mother and my daughter together and we talked and tried to find a suitable way to help her. She was afraid of having to go to the hospital or somewhere away from home. But then, we agreed that the school nurse would make appointments with her weekly and she could call her as the need arises.

'Discussing with the adolescent, for example about self-mutilation, in her own terms, and all things associated with it'.

'At parents' meetings it (self-mutilation) should be discussed, so that parents could get information about it and where help can be obtained'.

Parent 4: On the ward they (healthcare staff) always took selfmutilation very seriously. It was like an alarm signal to nurses.

'Some of the doctors who have cared for my daughter have had brilliant professional skills'.

'At parents' meetings it (self-mutilation) should be discussed, so that parents could get information about it and where help can be obtained'.

'When someone's self-mutilation is discovered at school, the contact with home should be made in the name of helping, not blaming'.

Reproaching and denouncing the parents of adolescents who selfmutilate for the self-mutilation does not help the adolescents or their parents at all. I have tried to be as direct as possible in discussing my daughter's self-mutilating behaviour, but I have experienced that they (healthcare staff) do not believe me, like I have tried to cheat or whitewash something.

1

2

1 Critical appraisal

2

Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Saturation of data was not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Can't tell <i>(The data analysis process is insufficiently described to deduce the framework for thematic analysis.)</i>
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research has some value <i>(There is some consideration of the contribution this research makes to the existing literature, but no discussion of the implication of the researchers' findings on current practice.)</i>

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns <i>(Insufficient information given for data analysis and no discussion of data saturation.)</i>
	Relevance	Relevant <i>(Study not conducted in the UK.)</i>

1

Rissanen, 2012

2

Bibliographic Reference Rissanen, M. L.; Kylma, J.; Laukkanen, E.; Helping self-mutilating adolescents: Descriptions of Finnish nurses; Issues in Mental Health Nursing; 2012; vol. 33; 251-262

3

4

5 Study Characteristics

Country/ies where study was carried out	Finland
Study type	General qualitative inquiry
Study dates	April - May 2005
Sources of funding	Not stated.
Recruitment strategy	Nurses were invited to participate in focus group interviews. The head nurses of four wards were informed about this study and were sent advertisements about the study with a request to give a copy of it to each nurse on their wards. The research project, including purpose, was presented in the advertisement. The study was advertised in three magazines targeted at health care professionals.

	Health care professionals were asked to send their descriptions of help for adolescents who self-mutilate anonymously by mail or by e-mail to the researcher to protect their privacy.
Inclusion criteria	<p>Participants had to be:</p> <ul style="list-style-type: none"> • A qualified nurse (Registered Nurse or Practical Nurse), and having experience caring for self mutilating adolescents.
Exclusion criteria	Not stated.
Setting	University Hospitals (wards and in the out-patient department) and one nurse who worked in a school.
Sample size	N = 9 nurses
Participant characteristics	<p>Mean age (SD): Not stated</p> <p>Sex (female/ male): Not stated</p> <p>Role:</p> <ul style="list-style-type: none"> • Registered Nurses: 5 • Practical Nurses: 4 <p>Setting: Participants included nurses who had worked on wards and in the out-patient department and one nurse who worked in a school.</p> <p>Years in post/ experience: Not stated / All of the participants had worked for more than five years in health care.</p> <p>Client group (adults, children/ CYP):</p> <p>Not stated</p>
Data collection and analysis	Five nurses participated in two focus group interviews, two nurses were individually interviewed, and two nurses provided written descriptions. All the interviews were open-ended and began by asking the interviewees to talk about their experiences and conceptions of helping self-mutilating adolescents. The interviews lasted from 45 to 75 minutes. Data were coded and grouped into categories (for

	example, “content of caring”) and subcategories (for example, “aims of care”) based on their similarities and differences, and the categories were given names according to their content.
Results	<p>Author theme: Parents as helpers</p> <p><i>Example quote: “Although the interaction between an adolescent and the parents may have previously been functional, it might be that they have not been used to discussing matters that they have experienced as difficult.”</i></p>

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(The authors did not justify their use of focus groups or written descriptions, which can limit discussion of a sensitive topic. Additionally, saturation of data was not discussed.)</i>

Section	Question	Answer
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(The authors discussed the interviewer's response to one participant disagreeing to audio-taping and the use of note-taking instead, then allowing the participant to check the notes. However, researchers did not state whether they critically examined their own role in the research.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research has some value <i>(The authors do not discuss the findings in relation to current practice, or ways in which the research can be used.)</i>
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Authors did not justify their methods of data collection, and did not discuss saturation of data. Authors did not state they critically examined their own role during data collection.)</i>
	Relevance	Relevant <i>(Study not conducted in the UK.)</i>

1

Sellin, 2018

2

Bibliographic Reference

Sellin, L.; Kumlin, T.; Wallsten, T.; Wiklund Gustin, L.; Caring for the suicidal person: A Delphi study of what characterizes a recovery-oriented caring approach; International journal of mental health nursing; 2018; vol. 27; 1756-1766

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4

1 Study Characteristics

Country/ies where study was carried out	Sweden
Study type	General qualitative inquiry
Study dates	Not stated.
Sources of funding	Not stated.
Recruitment strategy	Participants were recruited through representatives from a Swedish organisation which works with suicide prevention and support to relatives who have lost a close one to suicide; registered nurses at a County Council in Sweden; and researchers with special knowledge about suicide prevention. Participants were invited to a focus group interview with participants with expertise in the same area of experience.
Inclusion criteria	<p>Participants had to:</p> <ul style="list-style-type: none"> • be seen as experts in relation to the care of suicidal persons based on their personal and/or professional experiences; • be at least 18 years old; • be able to understand and speak Swedish.
Exclusion criteria	Not stated.
Setting	Participants from a Swedish organisation which works with suicide prevention and support to relatives who have lost a close one to suicide; (ii) registered nurses at a County Council in Sweden; and (iii) researchers with special knowledge about suicide prevention.
Sample size	N = 16 healthcare staff and researchers
Participant characteristics	<p>Mean age (SD): Not stated.</p> <p>Sex (female/ male): Not stated.</p> <p>Role:</p> <ul style="list-style-type: none"> • Representatives from a suicide prevention organisation: 5 • Registered nurses: 6

	<ul style="list-style-type: none"> • Researchers: 5 <p>Setting:</p> <p>Swedish organisation which works with suicide prevention and support to relatives who have lost a close one to suicide; County Council in Sweden; researchers with special knowledge about suicide prevention</p> <p>Years in post/ experience: Not stated.</p> <p>Client group (adults, children/ CYP): Not stated.</p>
Data collection and analysis	Focus group interviews with the participants were carried out as reflections around four themes 'Enable the suicidal person to express and to be him/ herself in the struggle with life and death', 'Making it possible to be in a vital rhythm in everyday life', 'Allowing relatives to contribute with their perspectives', and 'Contributing to a nurturing connectedness with the persons concerned'. Interview data was analysed using the Delphi method involving qualitative thematic analysis.
Results	<p>Author theme: Acknowledging relationships and contexts with others</p> <p><i>Example quote: 'My experience is that there is often shame and guilt that contribute to obstacles for involving relatives in acute care. And that nurses sometimes need to work more actively to involve relatives'.</i></p> <p><i>'My experience is that there is often shame and guilt that contribute to obstacles for involving relatives in acute care. And that nurses sometimes need to work more actively to involve relatives'.</i></p>

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes

Section	Question	Answer
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(The authors used focus groups to collect evidence but justified their reasoning for doing so. However, data saturation was not discussed.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Can't tell <i>(Little data provided to support the analysis.)</i>
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Little data provided to support analysis and data saturation not discussed.)</i>
	Relevance	Relevant <i>(Study not conducted in the UK, participants were people with expertise in the care of suicidal persons but did not clarify whether this included self-harming behavior.)</i>

1

Spillane, 2019

1

Bibliographic Reference Spillane, A.; Matvienko-Sikar, K.; Larkin, C.; Arensman, E.; How do people experience a family member's high-risk self-harm? An interpretative phenomenological analysis; Archives of suicide research : official journal of the International Academy for Suicide Research; 2019; 1-23

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4 Study Characteristics

Country/ies where study was carried out	Ireland
Study type	Phenomenological
Study dates	July 2014 - August 2016
Sources of funding	This study received funding as part of the SPHeRE Programme; grant number SPHeRE/2013/1. It also received funding from the Health Research Board (grant number HRA-2013- PHR-438), and the National Office for Suicide Prevention.
Recruitment strategy	Participants were drawn from a previous case-control study (the SSIS-ACE study), which recruited participants following hospital presentation for high-risk self-harm.
Inclusion criteria	Participants had to: <ul style="list-style-type: none"> • Be a family member of a person who had presented at hospital for self-harm • Have their family member's self-harm act either be high-risk, or with a clinical impression of high suicide intent • Have witnessed their family member's high-risk self-harm • Have participated in the SSIS-ACE study and consented for further follow-up
Exclusion criteria	Not reported.
Setting	In the community.
Sample size	N=9 family members of people who had self-harmed

<p>Participant characteristics</p>	<p>Mean age (range): 44 (33-61) years</p> <p>Sex (female/male): 6/ 3</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Spouse: 3 • Sibling: 3 • Parent: 2 • Close friend (listed by patient as next-of-kin): 1
<p>Data collection and analysis</p>	<p>Semi-structured collateral interviews took place in the participants' preferred location and lasted between 48-144 minutes (average: 94). After each interview field notes were taken and interviews were transcribed, data were coded by two authors and analysed using interpretive phenomenological analysis.</p>
<p>Results</p>	<p>Author theme: Care for self</p> <p><i>Example quote: There might be some things that I don't want to do, like the housework, I'm not in the form for it ... it's only since he went into the hospital.... I was getting phone calls from the hospital, I was getting calls from his social worker.... There was often times I could be sitting down having my dinner and the calls would come through ... and then I would have to leave my dinner and talk to them on the phone so my health was going down for a while. (P1, sister)</i></p> <p>Author theme: Caring for self to care for others</p> <p><i>Example quote: It's not just about me. Like okay if I had a mental breakdown fine, no problem, but that's grand if I have no dependents. But I do have dependents. Like so I just can't. So I have to look after my own mental health. I've got the high blood pressure. I need to do my best for the kids and yeah this needs to be part of it, like you know. (P8, partner)</i></p> <p>Author theme: Formal aftercare following self-harm</p> <p><i>Example quote: Particularly, participants found it distressing that there was no one to explain what self-harm was or explain to them what was happening with their family member as "doctors would never talk to us, never call us out." Being cut out of the interaction</i></p>

between the hospital staff and their family member left some feeling like they were “to blame” because they were perceived as “bad parents.”

Family members wanted the hospital staff to “look at the patient, not as another suicide attempt” and “see he was part of a family unit, he wasn’t living out on his own, his mam and dad were there ... they need to be involved.”

They described how no one “followed up” with them after their family member was discharged from hospital and one participant felt that someone from the hospital should “call in” and check on them as “it’s very easy to lie down [over] the phone” regarding their progress and mental health.

Author theme: Gaining control of the uncontrollable

Example quote: For a long time, every time he went out on a Saturday night ... I’d be very worried. If he’s not home by a certain time, it doesn’t matter if I’m in a coma, I’ll wake up and I’ll be awake until he gets home ... kind of like a teenager, “oh it’s 3:30am, he should be home soon.” And then I’ll send a text “all OK?” (P9, partner)

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes

Section	Question	Answer
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Authors explained their methods for data collection but did not justify their choices or discuss data saturation.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Researchers did not state whether they critically examined their own role in the research.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Minor concerns <i>(Lack of justification for data collection and no discussion of data saturation.)</i>
	Relevance	Relevant <i>(Study not conducted in UK. 1 friend was included in the study, however they were listed as the person who had self-harmed's next-of-kin, and therefore classified as family according to the study's inclusion criteria.)</i>

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Stewart, 2018

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Bibliographic Reference Stewart, A.; Hughes, N. D.; Simkin, S.; Locock, L.; Ferrey, A.; Kapur, N.; Gunnell, D.; Hawton, K.; Navigating an unfamiliar world: how parents of young people who self-harm experience support and treatment; Child and Adolescent Mental Health; 2018; vol. 23; 78-84

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4 Study Characteristics

Country/ies where study was carried out	UK
Study type	Grounded theory
Study dates	August 2012 - October 2013
Sources of funding	This study received funding from the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme; grant number RP-PG-0610-10026.
Recruitment strategy	Participants were recruited via a number of different channels: through healthcare professionals; mental health charities; support groups; advertisements; social media; personal contacts.
Inclusion criteria	Participants had to: <ul style="list-style-type: none"> • Be a parent of a young person aged up to 25 years who had self-harmed at any point in the past.
Exclusion criteria	Not reported.
Setting	In the community.
Sample size	N=37 parents of 35 young people who had self-harmed, including 2 sets of parents
Participant characteristics	Mean age (SD): Not reported. Sex (female/male): 32/ 5

	<p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Mother: 32 (including 1 adoptive) • Father: 5
<p>Data collection and analysis</p>	<p>Semi-structured narrative interviews lasted on average 84 minutes, and were either video- or audio-recorded and transcribed verbatim. Transcripts were coded and thematically analysed using a modified grounded theory approach.</p>
<p>Results</p>	<p>Author theme: Access to the right context of care</p> <p><i>Example quote: I felt that we were in the wrong place then. I couldn't understand why we weren't on a ward for young people. It wasn't entirely made clear to me what was happening. I had to keep asking what was happening and I felt I was being a pest.</i></p> <p>Author theme: Being taken seriously</p> <p><i>Example quote: Well, it was difficult to get anyone to actually really take him seriously. I do remember saying the appearance he's giving to you isn't actually what he is feeling because I'm seeing a different side of him. But when they spoke to him, he had a humour in his voice so that was mistook for him having a lighter mood.</i></p> <p>Author theme: Listening to parents and involving them in treatment</p> <p><i>Example quote: Clinicians, please talk to carers. Don't exclude us. We're part of the solution. We may be part of the problem. I think often clinicians' perception, certainly in my experience, can be that you're part of the problem. Well, I maybe but actually, if you help me out I can maybe be part of the solution too. Nadine</i></p> <p><i>We wasn't told. We had a ward round every week. . . . They always forgot to phone. I'd have to go in on the Tuesday and say, "What happened on the ward round?" When she came home on weekend leave, we got a great diary that we had to fill in. . . . But yet, she was in hospital all week and I never got any of that. I never got told whether she'd eaten. Whether she got out of bed. Whether she went to the school. Whether she selfharmmed. Denise</i></p> <p><i>They would report to me at the end of the day or the end of the week to let me know she's had a good week. So at least there was</i></p>

some communication and some dialogue going, because I think in cases where children are self-harming that has to happen so that all parties are aware and they are on full alert because the young people are so vulnerable.

I find it very frustrating that I can't discuss a lot of things with CAMHS. I understand why, she needs to know that it's confidential, that the things she discusses with them are not going to be discussed with me. And that's fair enough. But it's very frustrating So I wish that I could have been involved more, but I can see why it is the way that it is. Christopher.

Author theme: Need for practical strategies

Example quote: And then the other sort of issue was the decision about what you say to people about what had happened and you're very fragile, very vulnerable, you're not thinking straight, you don't. . . . know what to do. We needed somebody to sit down and talk to myself, my husband, my oldest daughter and say, "Right, this is what you've got to do." Don't give us any choices, just say, "Right, our experience tells us that this is what you should do, one, two-three." Jacqueline

Author theme: Support for parents

Example quote: I think what I would have liked is more parental support. It's very difficult, when you're in that situation, you don't exactly want to go and talk to other people because you're so focussed on yourself . . . There are still very, very hard evenings, very hard nights, when she gets very upset and slightly unsafe . . . At those times, it would be really nice to be able to pick up the phone and talk to somebody who knows what you're talking about. Evelyn

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Can't tell <i>(Authors explained their methods for data collection but did not justify their choices or discuss data saturation. Additionally, one set of parents was interviewed together, which may limit discussion and therefore not provide the necessary richness to address the research question.)</i>
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(Authors specified they had no clinical contact with the participants, however recruitment methods involved recruiting via personal contacts, and researchers did not state whether they critically examined their own role in the research.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Moderate concerns <i>(Lack of justification for data collection; no discussion of data saturation; some concerns around potential influence of the researchers on review findings)</i>
	Relevance	Highly relevant

1

Wand, 2019a

2

Bibliographic Reference Wand, A. P. F.; Draper, B.; Brodaty, H.; Peisah, C.; Self-harm in the very old one year later: Has anything changed?; International Psychogeriatrics; 2019; vol. 31; 1559-1568

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5 Study Characteristics

Country/ies where study was carried out	Australia
Study type	General qualitative inquiry
Study dates	Not reported.
Sources of funding	Not reported.
Recruitment strategy	Participants were recruited from two tertiary general hospitals and associated community centres, within a month of self-harm.
Inclusion criteria	Participants had to: <ul style="list-style-type: none"> • Be a person aged 80 or older who had self-harmed within the past month

	<ul style="list-style-type: none"> OR be a nominated carer of one of the above participants who had self-harmed <p>GPs were also recruited but there was no relevant qualitative evidence from these participants so data were not extracted.</p>
Exclusion criteria	Not reported.
Setting	Two tertiary general hospitals and affiliated community centres.
Sample size	<p>Of those who were available for follow-up:</p> <p>People aged 80 or older who had self-harmed: N=19 (30 were recruited, 11 were not available for follow-up)</p> <p>Family/ carers: N=29 (32 were recruited, 3 were not available for follow-up)</p> <p>Data were also available for GP participants but not extracted as no relevant qualitative data were available from these participants.</p>
Participant characteristics	<p>Mean age (range):</p> <ul style="list-style-type: none"> People who had self-harmed: 86.2 (81-94) years Family/ carers: Not reported. <p>Sex (female/ male):</p> <ul style="list-style-type: none"> People who had self-harmed: 12/7 Family/ carers: 15/14 <p>For people who had self-harmed:</p> <p>Co-morbidity:</p> <ul style="list-style-type: none"> Dementia: 17/26* Major depression: 3/22* <p>Duration of self-harm:</p> <ul style="list-style-type: none"> Repeat self-harm: 5/30*

	<p>Number of suicide attempts: Not reported</p> <p>*30 people who had self-harmed were originally recruited for this study but 11 were not available for follow-up. Denominator varied according to availability of information.</p> <p>For family/ carers:</p> <p>Relationship to person who has self-harmed:</p> <ul style="list-style-type: none"> • Child: 22 • Child-in-law: 2 • Spouse: 2 • Grandchild: 1 • Friend: 1 • Nephew: 1
<p>Data collection and analysis</p>	<p>Carer and patient participants were interviewed separately. Face-to-face structured interviews lasted between 7-46 minutes (mean 18.5), and were audio-recorded and transcribed verbatim. Transcripts were thematically analysed by two of the authors.</p>
<p>Results</p>	<p>Author theme: Abandonment by clinicians</p> <p><i>Example quote: “She had people talk to her, but we don’t know what she said or how she came across. I think maybe if we had of been spoken to more maybe we could have given it a better holistic look : : : ” Daughter</i></p> <p><i>“The nursing home staff [and the family] had voiced their concerns about Dad’s possibility of self-harm and it was being ignored [by mental health] as well.” Son-in-law</i></p> <p><i>“Everyone dropped off as soon as she was released [from hospital].” Daughter-in-law</i></p>

Author theme: Being heard

Example quote: "I was very happy that I could stay at my daughter's house : : : They are helping me quite a bit." 86F [patient]

Author theme: Relief and satisfaction with care

Example quote: "But for me and my sister it is a great weight lifted off us, because to see her and to see that she is cared for, knowing that she participates and she even sings and does all sorts : : : " Daughter

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Can't tell <i>(Authors thematically analysed data in a qualitative data management program, but did not justify their reasoning.)</i>
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes

Section	Question	Answer
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(2 of the authors were involved in the care of 12 patient participants, however the authors implemented a reflexive approach to enable consideration of this relationship and enhance methodological rigor. One researcher additionally interviewed their relative/ friend. The authors argue the breadth of responses indicates these considerations did not impact data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Can't tell <i>(Authors sought ethical approval and informed consent and considered the impact of the study on participants during the study, however no information was given about maintaining confidentiality, how research was explained to participants, or consideration for participants after the study.)</i>
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Minor concerns <i>(Lack of justification for research design; more information needed regarding ethical considerations.)</i>
	Relevance	Relevant <i>(The study included 1 friend of a person who had self-harmed (3%) but did not clarify whether they were their carer. Study not conducted in the UK.)</i>

1

Wand, 2019b

2

Bibliographic Reference

Wand, A. P. F.; Peisah, C.; Draper, B.; Brodaty, H.; Carer insights into self-harm in the very old: A qualitative study; International Journal of Geriatric Psychiatry; 2019; vol. 34; 594-600

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2 Study Characteristics

Country/ies where study was carried out	Australia
Study type	General qualitative inquiry
Study dates	Not reported.
Sources of funding	(See Wand 2019a)
Recruitment strategy	(See Wand 2019a)
Inclusion criteria	(See Wand 2019a)
Exclusion criteria	(See Wand 2019a)
Setting	(See Wand 2019a)
Sample size	(See Wand 2019a)
Participant characteristics	(See Wand 2019a)
Data collection and analysis	(See Wand 2019a)
Results	<p>Author theme: Clinicians dismissing the carer</p> <p><i>Example quote: "I did call the Emergency they says 'oh, he's OK', you know that he will go home. And I say 'wait a minute. This person is depressed, he wants to hurt himself.'" [brother]</i></p>

“One doctor I spoke to ... he was really dismissive ... dismissing with a wave of the hand the observation of someone who'd known him [patient] for a long time.” [friend]

Author theme: Improving communication

Example quote: “So I think it would be a good idea [that] the GP can coordinate into this and keep contact with the family member. ... So if some issue happening I can reach him at least.” [daughter]

Author theme: 'It made us ill'

Example quote: “It is having a big impact for my family especially.... Every single time I try to bring the positive energy to sort of change him ... but the thing is you can only do so much, talking, talking. After a while he goes back to the same square one. Oh my God! You feel depressed.” [daughter]

Author theme: Suicide and secrets

Example quote: “When the nurse from [the hospital], psychiatrist or whatever, went to see him before he told them “I really don't want to kill myself I want to get a better service.” But he told our relatives, basically, “I don't want to live”. [daughter]

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3 Critical appraisal

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Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes

Section	Question	Answer
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Can't tell <i>(Authors thematically analysed data in a qualitative data management program, but did not justify their reasoning.)</i>
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Can't tell <i>(2 of the authors were involved in the care of 12 patient participants, however the authors implemented a reflexive approach to enable consideration of this relationship and enhance methodological rigor. One researcher additionally interviewed their relative/ friend. The authors argue the breadth of responses indicates these considerations did not impact data collection.)</i>
Ethical Issues	Have ethical issues been taken into consideration?	Can't tell <i>(Authors sought ethical approval and informed consent and considered the impact of the study on participants during the study, however no information was given about maintaining confidentiality, how research was explained to participants, or consideration for participants after the study.)</i>
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	Minor concerns <i>(Lack of justification for research design; more information needed regarding ethical considerations.)</i>

Section	Question	Answer
	Relevance	Relevant <i>(The study included 1 friend of a person who had self-harmed (3%) but did not clarify whether they were their carer. Study not conducted in the UK.)</i>

1

Wester, 2018

2

Bibliographic Reference Wester, Sheri Lea; Community and family support systems' process of supporting adolescents' termination of nonsuicidal self-injury: A grounded theory study; Dissertation Abstracts International: Section B: The Sciences and Engineering; 2018; vol. 79; No-Specified

3

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5 Study Characteristics

Country/ies where study was carried out	USA
Study type	Grounded theory
Study dates	Not stated.
Sources of funding	Not stated.
Recruitment strategy	Participants were selected from a population of adults who responded to direct advertising, which included flyers posted on public bulletin boards in convenience stores, laundromats, and coffee shops as well as on bulletin boards on a community college campus.
Inclusion criteria	Participants to be: <ul style="list-style-type: none"> mentally healthy adults who had not engaged in NSSI themselves, who agreed to participate in the study, and who had, at some time provided practical or emotional support to an adolescent who was seeking to terminate NSSI behaviours.

	<ul style="list-style-type: none"> For family support system participants, the adolescent the participants' supported were now themselves adults and did not live with the participant.
Exclusion criteria	Not stated.
Setting	In the community.
Sample size	N=7 family members of people who had self-harmed N=2 healthcare/ school staff
Participant characteristics	<p>Mean age (SD): Not stated</p> <p>Sex (female/ male):</p> <p>Family/carers: 7/0</p> <p>Staff members: 1/1</p> <p>Relationship to person who has self-harmed:</p> <p>Parent: 2</p> <p>Sister: 1</p> <p>Aunt: 1</p> <p>Friend: 3</p> <p>For staff members:</p> <p>Role:</p> <p>Therapist: 1</p>

	<p>School counselor: 1</p> <p>Setting: Community</p> <p>Years in post/ experience: Not stated</p> <p>Client group (adults, children/ CYP): Not stated.</p>
<p>Data collection and analysis</p>	<p>Semi-structured face-to-face interviews. Data analysed using grounded theory qualitative analysis.</p>
<p>Results</p>	<p>Author theme: Accepting some questions will remain unanswered</p> <p><i>Example quote: "I never asked my son what he and the counselor talked about. I let the counseling just be his. He saw the counselor four or five times, then let me know that he and the counselor had agreed that he had done what he needed to and didn't need to go anymore..."</i></p> <p>Author theme: Accepting there are some things you can't control</p> <p><i>Example quote: "I think it's very challenging when parents don't seek treatment for their child and the child continues to self-harm. When I get the second or third report that they've harmed themselves and I feel like the child really needs more help than they're getting, I feel like I have to push the parents a bit to take that step. That's a challenge because even though I think they need to get treatment for their child it's their child. They get to make those decisions."</i></p> <p>Author theme: Evaluating needs</p> <p><i>Example quote: "It was more how can we help Jessica? What does Jessica need? What is she not able to express? She can express everything else so what is it that we're missing and how do I get her to tell me what's really going on?"</i></p> <p>Author theme: Feeling it's a time-consuming responsibility</p>

Example quote: "I just couldn't handle them as well as me. You know, I couldn't take them both on."

Author theme: Identifying a Conflicted Relationship Between a Support and the Adolescent

Example quote: "I didn't inform my ex-husband either. I think because I knew he would over-react, which wouldn't be helpful. He lived in a different town and I didn't think yelling at my son over the phone would help my son to deal with it in a healthy way."

"But, we got her into therapist. Which, I'll be honest, I didn't like her at all because almost immediately she seemed to tell Katie that everything was my fault, our fault. That we had taken away her sense of person, that we were stifling her creativity."

Author theme: Seeing involving others as steps toward recovery and protection

Example quote: "I talk with all of those parents about counseling as an option to help the student learn other ways to manage stress or emotions that are safer than self-harm."

"He knew that I wasn't asking him to see a counselor to torture him. He knew that I was sincere in my desire to help him find other things to do to deal with stress."

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Critical appraisal

Section	Question	Answer
Aims of the research	Was there a clear statement of the aims of the research?	Yes

Section	Question	Answer
Appropriateness of methodology	Is a qualitative methodology appropriate?	Yes
Research Design	Was the research design appropriate to address the aims of the research?	Yes
Recruitment Strategy	Was the recruitment strategy appropriate to the aims of the research?	Yes
Data collection	Was the data collected in a way that addressed the research issue?	Yes
Researcher and participant relationship	Has the relationship between researcher and participants been adequately considered?	Yes
Ethical Issues	Have ethical issues been taken into consideration?	Yes
Data analysis	Was the data analysis sufficiently rigorous?	Yes
Findings	Is there a clear statement of findings?	Yes
Research value	How valuable is the research?	The research is valuable
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns
	Relevance	Relevant (Study not conducted in the UK.)

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1 **Appendix E Forest plots**

2 **Forest plots for review question: What are the views and preferences of people who have self-harmed, their families and**
3 **carers, and staff working with people who have self-harmed about the best ways of involving family and carers in the**
4 **management of people who have self-harmed?**

5 No meta-analysis was conducted for this review question and so there are no forest plots.

6

1 Appendix F GRADE-CERQual tables

2 GRADE-CERQual tables for review question: What are the views and preferences of people who have self-harmed, their families and carers, and staff working with people who have self-harmed about the best ways of involving family and carers in the management of people who have self-harmed?

5 Table 6: Summary of evidence (GRADE CERQual): 1 Communication

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 1.1: Listening to family/ carers					
8 (Bouwman 2018, Dempsey 2019, Dransart 2017, Jennings 2020, Kelada 2016 (study 2), Lindgren 2010, Stewart 2018, Wand 2019a/ Wand 2019b)	5 studies using semi-structured interviews; 1 study using narrative interviews; 1 study using structured interviews; 1 study using focus groups and semi-structured interviews	<p>Family/ carers and healthcare professionals expressed that family members should be listened to as part of a duty of care. Family members expressed that being listened to by healthcare staff was a validating experience. Additionally, they often spend the most time with the person who's self-harmed and therefore usually know them well enough to provide additional useful information, such as: being able to tell when someone's behaviour at home indicates self-harm or an increased risk of self-harm; knowing what interventions do or don't work; important background information that professionals might not otherwise know.</p> <p>Family members wanted to be taken seriously and considered it a barrier to help-seeking when they weren't listened to. They felt that the person who had self-harmed often suffered unnecessarily as a result of being ignored.</p> <p>"(...) you need that family for the biography and the history. (...) The family is (therefore) indispensable for a proper analysis of the event, otherwise you're only looking at the care provided and that's the major problem, for the crisis services too. (...) Otherwise you're taking snapshots and not seeing the movie." (Inspector) (Bouwman 2018)</p> <p>"If only I'd been more persistent and said 'She's not just an ordinary girl, something is wrong with her'. She's lost so many years unnecessarily. 'Please, listen to what we're saying, something about her isn't right and we need help'." (Lindgren 2010)</p>	<p>Methodological limitations</p> <p>Relevance</p>	<p>Minor concerns about methodological limitations as per CASP qualitative checklist</p> <p>Moderate concerns: most evidence is from a substantially different context to the review question (6 studies not conducted in the UK; 1 study looked at responses to sentinel events including self-harm; studies included people with suicidal ideation who had not necessarily self-harmed and/ or their family/</p>	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				<i>carers, friends of people who were not necessarily their carers, and/ or 1 staff member without experience caring for a person who had self-harmed)</i>	
			Coherence	No or very minor concerns	
			Adequacy	No or very minor concerns	
Sub-theme 1.2: Maintaining communication with family/ carers					
10 (Dransart 2017, Ferrey 2015/ Stewart 2018, Kelada 2016 (study 1), Kennard 2020, McLaughlin 2016, Nadeem 2016, Raphael 2006, Spillane 2019, Wand 2019a/ Wand 2019b, Wester 2018)	5 studies using semi-structured interviews; 1 study using unstructured interviews; 1 study using structured interviews; 1 study using interviews; 1 study using semi-structured focus groups and interviews; 1 study using open-ended questionnaires	<p>Family members, school staff and healthcare staff felt it was important that communication was maintained with family throughout all stages of help-seeking, including during and after treatment.</p> <p>Family members and healthcare staff both expressed frustration when the other party did not communicate while treatment was ongoing for the person who had self-harmed. Clinicians, for example, wanted family plans to be communicated so as not to interfere with a treatment schedule, while family members wanted updates on how treatment was progressing. Family members also reported wanting further follow-up after treatment or hospital discharge, as well as communication between appointments. Some mentioned that they found it difficult to get in contact with healthcare staff and that this was made it difficult to manage care for the person. Those who received regular updates or who could easily contact health professionals valued this experience.</p> <p>School staff said that they regularly reviewed students' referrals and maintained communication to ensure that parents did engage with services as advised. Healthcare staff also said they occasionally had to follow up with family members to ensure they had sought further help for the person who had self-harmed.</p>	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	Moderate concerns: most evidence is from a substantially different context to the review question (<i>7 studies not conducted in the UK; studies included people with suicidal ideation who had not necessarily self-harmed and/ or</i>	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
		<p>“We wasn’t told. We had a ward round every week. . . .They always forgot to phone. I’d have to go in on the Tuesday and say, “What happened on the ward round?” When she came home on weekend leave, we got a great diary that we had to fill in. . . .But yet, she was in hospital all week and I never got any of that. I never got told whether she’d eaten. Whether she got out of bed. Whether she went to the school. Whether she selfharmed.” Denise (Stewart, 2018)</p> <p>“Another thing is often with more among the Latino population that, that I see in the summer they will go to Mexico for the summer or other places and so they’ll be gone for a month or two months or and it’s not always planned. So, sometimes it’s like we’ll have an appointment scheduled, I’ll see them one week, we’ll have an appointment scheduled the next week, suddenly they don’t show up and I call and it’s like oh yeah they’re in Mexico for two months. And it’s like well it would have been good for us to go over a plan of how to handle things while they’re there.”—clinician (Kennard 2020)</p> <p>“Every two weeks we’ll [review] the students who have been referred. There will be a follow-up as to whether or not the parents followed through with the intakes, if the child’s attending, or if the parent indicated that they didn’t want the services.” (Nadeem 2016)</p>		<p><i>their family/ carers, people who had lost family members to suicide, and/ or a small number of friends of people who had self-harmed who were not necessarily their carers)</i></p>	
			Coherence	No or very minor concerns	
			Adequacy	No or very minor concerns	
Sub-theme 1.3: Methods of communication					
1 (Kennard 2020)	1 study using interviews	<p>Healthcare staff felt that multiple methods of communication should be used to help engage people in the care of their family members. They felt this was especially important when communicating with family members who came from backgrounds/ cultures where self-harm may be less understood as a phenomenon.</p> <p>“[I use] metaphors and parables...once they understand and start explaining it, then get them to identify how it works clinically...[One] illustration is high blood pressure. High blood pressure—you take the pills but with the pills you also must eat healthy and you have to exercise. A pill alone won’t fix it, but with exercise and eating healthy...”—clinician (Kennard 2020)</p>	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	Very low
			Relevance	Serious concerns: all evidence is from a substantially different context to the review question (<i>study not conducted in the UK; study included clinicians who</i>	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				<i>had cared for people with suicidal thoughts and behaviours but had not necessarily self-harmed)</i>	
			Coherence	No or very minor concerns	
			Adequacy	Moderate concerns: Although findings were based on one study only with a small sample size, there were moderately rich data relating to this theme	
Sub-theme 1.4: Clarity of communication					
1 (Lindgren 2010)	1 study using narrative interviews	Family members said that they could not effectively help-seek or manage care for the person who had self-harmed when they received contradictory or confusing information about care. “I asked at the care meeting whether someone could visit Tina if necessary? There was nobody [who could visit] was the answer I got. Now I’ve got the information that there was someone who could have come. There were personnel from the community who were available if needed.” (Lindgren 2010)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	Moderate concerns: all evidence is from a different context to the review question (<i>study not conducted in the UK</i>)	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
			Coherence	No or very minor concerns	
			Adequacy	Moderate concerns: Although findings were based on one study only with a small sample size, there was good descriptive detail relating to this theme.	
Sub-theme 1.5: Informal pathways					
4 (Bouwman 2018; Nadeem 2016; Rissanen 2009b; Spillane 2019)	2 studies using semi-structured interviews; 1 study using open-ended interviews; 1 study using semi-structured focus groups and interviews	<p>Healthcare and school staff expressed that candid information sharing and informal conversations were more useful than formal pathways for engaging family members and carers.</p> <p>Some family/ carers agreed that clinical, detached approaches were received negatively. However, other family members said they appreciated when healthcare staff approached them in a formal, professional manner as it indicated that they took the situation seriously.</p> <p>“It’s better to share the real story with each other than to follow formal pathways. That’s pretty much our approach.” (Family counselor)’ (Bouwman 2018)</p> <p>‘All but one of the participants spoke negatively about their experiences in the hospital setting. Many referred to the detached and “clinical” approach taken by the health professionals in the hospital.’ (Spillane 2019)</p> <p>“Some of the doctors who have cared for my daughter have had brilliant professional skills”. (Rissanen 2009b)</p>	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Very low
			Relevance	Serious concerns: all evidence is from a substantially different context to the review question (<i>4 studies not conducted in the UK; 1 study looked at responses to sentinel events including self-harm</i>)	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
			Coherence	Minor concerns: some evidence is contradictory without a credible explanation for difference	
			Adequacy	No or very minor concerns	
Sub-theme 1.6: Communication between the person and their family/ carer					
6 (Byrne 2008, Ferrey 2016a, Rissanen 2009a, Rissanen 2009b, Rissanen 2012, Wester 2018)	2 studies using semi-structured interviews; 1 study using open-ended interviews; 1 study using written descriptions and open-ended interviews; 1 study using written descriptions and open-ended focus groups and interviews; 1 study using focus groups	<p>People who had self-harmed considered being able to talk to family members a source of relief, or a way to help manage self-harm. Awareness of self-harm by itself could change family dynamics and encourage a supportive environment with open communication. People who had self-harmed expressed that family members should talk to them, help solve problems and provide advice to them.</p> <p>Family members felt they needed to be able to ask and listen to what the person who had self-harmed needed in order to help them. They felt that communication was important, including through nonverbal means such as through text or letters, and expressed that problems in communication hindered their ability to manage self-harm.</p> <p>Nurses also believed that family members were ineffective as helpers when they did not communicate with the person who had self-harmed about sensitive topics such as self-harm.</p> <p>“Although my mother did not understand how bad I felt, chatting with her was enough to keep me from self-mutilating that night.” (Rissanen 2009a)</p> <p>“It was more how can we help Jessica? What does Jessica need? What is she not able to express? She can express everything else so what is it that we’re missing and how do I get her to tell me what’s really going on?” (Wester 2018)</p>	Methodological limitations	Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns: most evidence is from a different context to the review question (<i>5 studies not conducted in the UK; study included family members/ carers of people with suicidal ideation who had not necessarily self-harmed</i>)	
			Coherence	No or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
		“Although the interaction between an adolescent and the parents may have previously been functional, it might be that they have not been used to discussing matters that they have experienced as difficult.” (Rissanen 2012)	Adequacy	No or very minor concerns	

1 Table 7: Summary of evidence (GRADE CERQual): 2 Collaboration

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 2.1: Collaboration in the management of self-harm					
13 (Bouwman 2018, Dempsey 2019, Dransart 2017, Hom 2020, Idenfors 2015, Jennings 2020, Krysinska 2020, Lindgren 2010, Rissanen 2009a, Rissanen 2009b, Spillane 2019, Stewart 2018, Wand 2019a)	6 studies using semi-structured interviews; 1 study using semi-structured individual and group interviews; 1 study using open-ended interviews; 1 study using narrative interviews; 2 studies using structured interviews; 1 study using focus groups and semi-structured interviews; 1 study using written	<p>People who had self-harmed, their families/ carers, and healthcare staff had mixed opinions about whether making decisions and evaluating care pathways should be a collaborative effort between the person who's self-harmed, family members and healthcare staff.</p> <p>Family members appreciated being informed and included in the care of the person who'd self-harmed, as well as having their perspectives and ideas acknowledged because they considered this validating and encouraging. Some family members considered it an important responsibility to be involved. Family/ carers also felt they were often the ones who felt the impact of clinical decisions and were therefore frustrated when decisions regarding care were made without their knowledge or consent.</p> <p>Some people who had self-harmed agreed that adult family members should be involved in care or seek help for the person, and that it was an indication of a lack of care if they did not intervene. However, other people who had self-harmed contradicted this and felt that, even if family members knew about the self-harm, they should not be involved and that self-harm management should be solely down to the healthcare staff. Some people were wary of healthcare providers deferring to the opinions of family members over their own if family were involved. Others felt that self-harm was purely a personal responsibility that should not involve family or health professionals, and felt they would be a burden if they were to seek help. It is</p>	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	Moderate concerns: most evidence is from a substantially different context to the review question (<i>studies not conducted in the UK; 1 study looked at responses to sentinel events including self-harm; studies included people with suicidal</i>)	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
	descriptions and open-ended interviews	<p>to be expected that there would be variation in views on this theme from people who had self harmed, especially due to the differences between study populations (1 study looked specifically at suicide attempt survivors while the others included people who had self-harmed of varying ages, including children, adolescents, and young people).</p> <p>Some clinicians felt that self-harm management should be a collaborative process with family/ carers, others felt that family should not be directly involved with care or care planning and instead should have their involvement limited to a feedback capacity. The differences between clinician perspectives seems largely due to the difference in study settings (1 study looked at parental involvement in sentinel events specifically, while another looked at their involvement in care more generally).</p> <p>“Clinicians, please talk to carers. Don’t exclude us. We’re part of the solution. We may be part of the problem. I think often clinicians’ perception, certainly in my experience, can be that you’re part of the problem. Well, I maybe but actually, if you help me out I can maybe be part of the solution too.” Nadine’ (Stewart 2018)</p> <p>“It was helpful when I went to psychiatrists and talked there more with my mother, too.” (Rissanen 2009a)</p> <p>“... it would have been nice to be treated like I actually knew what I was talking about. A lot of times I was just brushed off and they would talk to my mom instead of me...” (Hom 2020)</p> <p>“There may be people who feel worse than I do. Their problems may be a little different than mine. It didn’t feel like my problems were anything compared with theirs. It just felt weird to seek help because you just... well...” (Participant 1)’ (Idenfors 2015)</p> <p>“I see the relationship between families and clinicians, particularly in the early stages, as collaborative. I think they need to have an opportunity to share their experiences, their perspectives, their thoughts and ideas about what’s going on for the young person.” (Clinician)’ (Dempsey 2019)</p>		<p><i>ideation who had not necessarily self-harmed and/ or their family/ carers, friends of people who had self-harmed who were not necessarily their carers, and/ or 1 staff member without experience caring for a person who had self-harmed)</i></p>	
			Coherence	Minor concerns: Some evidence is contradictory without a credible explanation for differences, however most differences are explained by the fact that they are reported by different population groups	
			Adequacy	No or very minor concerns	
Sub-theme 2.2: Seek feedback on care from family/ carers					

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
3 (Bouwman 2018; Dempsey 2019; Lindgren 2010)	2 studies using semi-structured interviews; 1 study using narrative interviews	<p>Family members sought to provide feedback (for example on the quality of care or why sentinel events happened), however some expressed that when they had tried to do this they had been unfairly accused of sabotaging the care of the person who had self-harmed.</p> <p>Some clinicians felt that seeking feedback from family/ carers could improve lessons learned in healthcare settings such as inpatient wards, and some felt this was the only way that family members should be involved in the management of self-harm.</p> <p>“After that they decided to crack me; it was their goal. They said to my daughter, “Your mother doesn’t want you to receive care, she’s destroying everything”, and so on”. (Lindgren 2010)</p> <p>“So that’s what we do. But what we’ve recently discussed, the feedback for example on what has come from the analysis to the family, well, we don’t yet report that to them. And that’s the question, whether it might be useful to report it back to the family. Sometimes when the family really insist on it, but we don’t report that to them as a matter of course (...) And I think that’s the next step, that we also involve the family or patient in the evaluation and that we also give them the feedback, what came out of it (the evaluation), also to family and friends.” (Director)’ (Bouwman 2018)</p>	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	Low
			Relevance	Serious concerns: all evidence is from a substantially different context to the review question (3 studies not conducted in the UK; 1 study looked at responses to sentinel events including self-harm; study included people with suicidal ideation who had not necessarily self-harmed)	
			Coherence	No or very minor concerns	
			Adequacy	No or very minor concerns	
Sub-theme 2.3: The effect of involvement on the quality of care					
10 (Dransart 2017, Ferrey 2016a, Hom 2020, Idenfors 2015, Lindgren	5 studies using semi-structured interviews; 1 study using open-ended	People who self-harmed stated involvement of family in the management of self-harm positively influenced their mental wellbeing because they wanted to be able to seek necessary support and information from family members	Methodological limitations	Minor concerns about methodological limitations as per CASP	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
2010, Rissanen 2009a, Rissanen 2009b, Spillane 2019, Wand 2019a, Wester 2018)	interviews; 1 study using structured interviews; 1 study using unstructured interviews; 1 study using narrative interviews; 1 study using written descriptions and open-ended interviews	<p>outside of a healthcare setting. Some even said that their family member's care had prevented them from self-harming.</p> <p>Family members said they were often approached by the person who had self-harmed for support, and felt they could positively impact the person's care by encouraging positive activities, influencing home life, limiting unhealthy interactions and activities, and taking precautions. Some family members wanted their care abilities to be acknowledged by health professionals.</p> <p>Additionally, people who had self-harmed and their family/ carers said that informing family members of self-harm (either by the person themselves, or by school staff for example) can facilitate or initiate help-seeking.</p> <p>"My mother was instrumental in getting me the help that I needed early on—the therapy and whatever medications I needed and whatever doctors I needed to see—and she's done her best to help me since then." (Hom 2020)</p> <p>"Sally said that giving her daughter extra cuddles had been "quite therapeutic for her... and... also [reduced] the thoughts [about self-harm] and carrying them out because she knows I'm there for her." (Ferrey 2016a)</p>	Relevance	qualitative checklist Moderate concerns: most evidence is from a substantially different context to the review question (8 studies not conducted in the UK; studies included family/ carers of people with suicidal ideation who had not necessarily self-harmed, and/ or friends of people who had self-harmed who were not necessarily their carers)	
			Coherence	No or very minor concerns	
			Adequacy	No or very minor concerns	
Sub-theme 2.4: Advocacy					
3 (Lindgren 2010, Rissanen 2009b, Stewart 2018)	1 study using semi-structured interviews; 1 study using open-ended interviews; 1 study using	Family/ carers felt they had to advocate on behalf of the person who had self-harmed when that person was unable to, which meant negotiating with healthcare staff. Family members felt like they had to be cautious when talking to healthcare staff in order not to overstep a perceived boundary while still standing up for the person's rights.	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
	narrative interviews	'Parent 4: "She asked me to come along to the doctors' to make sure that everything of importance would be said. She just said that she won't leave the ward. She said that she is in need of hospital care.'" (Rissanen 2009b)	Relevance	Minor concerns: most evidence is from a different context to the review question (2 studies not conducted in the UK)	
			Coherence	No or very minor concerns	
			Adequacy	Minor concerns: findings were based on moderately rich data from 3 studies, but understanding of the theme would benefit from richer data	
Sub-theme 2.5: Burnout					
9 (Dempsey 2019, Dransart 2017, Ferrey 2016a/ Ferrey 2016b, Krysinska 2020, Lindgren 2010, Oldershaw 2008, Spillane 2019, Wand 2019a/ Wand 2019b, Wester 2018)	6 studies using semi-structured interviews; 1 study using semi-structured individual and group interviews; 1 study using structured interviews; 1 study using narrative interviews	<p>Clinicians and family/ carers expressed that family members being involved in the management of self-harm could result in them feeling overwhelmed and 'burnt-out', and therefore unable to help. Sometimes this was due to the family member's proximity to the person and the willingness to make sacrifices to care for them. Family members also felt burnt-out when they had sought help for a person who had self-harmed for a long time without success or when they felt they had to compensate for inferior healthcare, and considered this a barrier to help-seeking. Family/ carers expressed that some of this feeling was alleviated when the person who had self-harmed was receiving good care or treatment, or when they were given advice by healthcare staff (for example, CAMHS staff).</p> <p>"Where there's been a pattern of kind of high-risk or challenging behaviours going on for an extended period of time, the family might start to feel quite burnt-out in terms of what they have been able to manage... Invariably, families are doing the very best they can with the resources they have, but then can be feeling very stretched." (Clinician) (Dempsey 2019)</p>	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	Moderate concerns: most evidence is from a substantially different context to the review question (7 studies not conducted in the UK; studies included people	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
		<p>“If the parent is stressed, the main caregiver is stressed then how does that impact around other siblings? The child that you’re trying to support, who’s self-harming, are they looking at it like they’re not coping because I’m.. It kind of-yeah, dominoes” (Parent 3). (Krysinska 2020)</p>		<i>with suicidal ideation who had not necessarily self-harmed or their family/ carers, and/ or; friends of people who had self-harmed but did not state if they were their carers)</i>	
			Coherence	No or very minor concerns	
			Adequacy	No or very minor concerns	

1 Table 8: Summary of evidence (GRADE CERQual): 3 Compassion and respect

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 3.1: Respecting family/ carers					
6 (Jennings 2020, Kelada 2016 (study 1), Krysinska 2020, Lindgren 2010, Rissanen 2009b, Wester 2018)	1 study using semi-structured interviews; 1 study using open-ended interviews; 1 study using narrative interviews; 1 study using semi-structured individual and group interviews; 1 study using focus groups	<p>Family/ carers reported negative experiences in situations where medical professionals were perceived as dominant or overbearing, or treated family members punitively when accompanying people who had self-harmed to hospital. Additionally, they found that some psychoeducational materials, healthcare staff and school staff unfairly assigned blame for the self-harm to family or doubted the honesty of their experiences. In some situations, participants expressed they were discouraged from seeking professional help for the person who had self-harmed after these negative experiences.</p> <p>“Reproaching and denouncing the parents of adolescents who selfmutilate for the self-mutilation does not help the adolescents or their parents at all. I have tried to be as direct as possible in discussing my daughter’s self-mutilating behaviour, but I have experienced that they (healthcare staff) do not believe me, like I have tried to cheat or whitewash something.” (Rissanen 2009b)</p>	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	High
			Relevance	Minor concerns: most evidence is from a different context to the review question (5 studies not conducted in the UK; study included 1 staff	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
	and semi-structured interviews; 1 study using open-ended questionnaires			<i>member without experience caring for a person who had self-harmed)</i>	
			Coherence	No or very minor concerns	
			Adequacy	No or very minor concerns	
Sub-theme 3.2: Supporting family/ carers to enable effective management of self-harm					
5 (Bouwman 2018, Ferrey 2015/ Stewart 2018, Lindgren 2010, Rissanen 2009b, Spillane 2019)	3 studies using semi-structured interviews; 1 study using open-ended interviews; 1 study using narrative interviews	<p>Healthcare staff and family/ carers reported that family members needed to be physically and mentally well themselves in order to provide support to the person who had self-harmed in turn. Some family members said that being supported by healthcare professionals enabled them to provide support, and that when they didn't receive this support, they often felt overwhelmed.</p> <p>"It's also a kind of duty for the care organization, to provide aftercare to the family. (...) To give them the opportunity to tell their story again, or to hear how everything happened. So that they can learn to cope with what has happened. Yes, in that sense it's an extra reason for paying attention to the family and relatives." (Inspector) (Bouwman 2018)</p> <p>"[It's helpful] having this outlet where my husband and I can go and meet with the psychiatrist individually. We find it's really helpful, for us, I think we find it easier to support [our daughter]." (Ferrey 2015)</p>	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	Moderate concerns: most evidence is from a substantially different context to the review question (<i>4 studies not conducted in the UK; 1 study looked at responses to sentinel events including self-harm</i>)	
			Coherence	No or very minor concerns	
			Adequacy	No or very minor concerns	
Sub-theme 3.3: Create a rapport with family/ carers					

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
5 (Jennings 2020, Kennard 2020, Lindgren 2010, McLaughlin 2016, Sellin 2018)	1 study using semi-structured interviews; 1 study using narrative interviews; 1 study using interviews; 1 study using focus groups and semi-structured interviews; 1 study using focus groups	<p>Clinicians reported family members engage better with healthcare staff when staff attempt to create a bond with them, for example through acknowledging the individual needs of family members, continuity of care by the same person/ group of people, a shared culture, or other connection.</p> <p>Family members agreed that professional caregivers were most understanding when they had insight into different types of suffering and were compassionate as a result.</p> <p>“So that bond of knowing culturally you may have had a similar experience, I’ve noticed it makes them more comfortable and even with the parents, the parents are a little bit more comfortable being more real with you and telling you things they might not tell someone else.”—clinician (Kennard 2020)</p> <p>“Caregivers with their own experience of suffering - maybe they had a tough and shady life behind them, and then they educated themselves - they were the ones who were the best in meeting us as parents.” (Lindgren 2010)</p>	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	Low
			Relevance	Serious concerns: all evidence is from a substantially different context to the review question (3 studies not conducted in the UK; studies included people with suicidal ideation who had not necessarily self-harmed, their clinicians, and/ or their family/ carers, or people who had lost family members to suicide)	
			Coherence	No or very minor concerns	
			Adequacy	No or very minor concerns	

1 **Table 9: Summary of evidence (GRADE CERQual): 4 Resources**

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 4.1: Psychoeducation					
10 (Byrne 2008, Dempsey 2019, Dransart 2017, Ferrey 2016a/ Stewart 2018, Kennard 2020, Krysinska 2020, Lindgren 2010, McLaughlin 2016, Nadeem 2016, Rissanen 2009b)	4 studies using semi-structured interviews; 1 study using open-ended interviews; 1 study using narrative interviews; 1 study using interviews; 1 study using semi-structured individual and group interviews; 1 study using semi-structured focus groups and interviews; 1 study using focus groups	Family/ carers felt that they needed psychoeducation to better engage with management of their child's self-harm, such as information on safety planning, early warning signs, and coping skills. Family members felt that it was unfair to be expected to help manage self-harm without this type of education and that they needed feedback and strategies in order to be able to help at all. They also noted that being informed about self-harm allowed them to interact with health professionals better and make more informed decisions about the care of the person who had self-harmed.	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Moderate
		School and healthcare staff agreed that it was important for parents to be educated about self-harm and mental health, and that training should be ongoing to keep them aware.	Relevance	Moderate concerns: most evidence is from a substantially different context to the review question (8 studies not conducted in the UK; studies included people with suicidal ideation who had not necessarily self-harmed, their clinicians, or their family/ carers, people who had lost family members to suicide, and/ or friends of people who had self-harmed who were not necessarily their carers)	
		“My number one thing would be to ask [the mental health professional] if they are familiar with selfinjury and if they treated other children that have dealt with that issue. And maybe even ask them if they can provide some resources for, ya know, the parents to study to educate themselves on, ya know- to become better qualified to deal with it.” [P19, father] (Kennard 2020)	Coherence	No or very minor concerns	
		“How should we address parents, how can we make them aware without scaring them, aside from providing facts and statistics. Everyone thinks it's not ever going to happen to them. We have to continuously keep them aware. I think that's what we're lacking.” (Nadeem 2016)			
		“So the focus with seeing the family towards the end of treatment is around discharge planning and referring out and skilling up the family in being able to notice early warning signs.” (Clinician) (Dempsey 2019)			

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
			Adequacy	No or very minor concerns	
Sub-theme 4.2: Outreach strategies					
3 (Nadeem 2016, Rissanen 2009b, Wester 2018)	1 study using semi-structured interviews; 1 study using semi-structured focus groups and interviews; 1 study using open-ended interviews	<p>School staff and parents thought it was important for family members to be reached out to regarding self-harm even before self-harm occurred, in order to more effectively train and educate family members, and facilitate their involvement in care. They felt this was important so family/ carers could recognise self-harm and know what to do in the event of self-harm.</p> <p>“When it comes to emotional problems, we can only do so much in the classroom. Having a Healthy Start program in school, they can channel it better than we could.” (Nadeem 2016)</p>	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	Moderate concerns: all evidence is from a different context to the review question (3 studies not conducted in the UK)	
			Coherence	No or very minor concerns	
			Adequacy	Minor concerns: Although findings were based on 3 studies with a moderate sample size, there were poor quoted data relating to this theme, and understanding of the theme would benefit from richer data	
Sub-theme 4.3: Facilitate help-seeking					

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
4 (Kelada 2016 (study 2), Oldershaw 2008, Raphael 2006, Rissanen 2009b)	2 studies using semi-structured interviews; 1 study using open-ended interviews; 1 study using unstructured interviews	<p>Family/ carers wanted resources that could point them to the right services in order to get help for the person who had self-harmed. They expressed that healthcare professionals could encourage or discourage help-seeking for the person who had self-harmed based on how good or poor initial care for the person was.</p> <p>“At parents’ meetings it (self-mutilation) should be discussed, so that parents could get information about it and where help can be obtained.” (Rissanen 2009b)</p>	<p>Methodological limitations</p> <p>Relevance</p> <p>Coherence</p> <p>Adequacy</p>	<p>Moderate concerns about methodological limitations as per CASP qualitative checklist</p> <p>No or very minor concerns</p> <p>No or very minor concerns</p> <p>Minor concerns: Although findings were based on 4 studies, they had a small sample size and poor quoted data relating to this theme, and understanding of the theme would benefit from richer data</p>	Moderate

1 Table 10: Summary of evidence (GRADE CERQual): 5 Autonomy and privacy

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 5.1: Maintaining the privacy of the person who has self-harmed					
6 (Bouwman 2018, Chew-Graham 2002, Dempsey 2019, Ferrey 2015/	4 studies using semi-structured interviews; 1 study using narrative	Some people who had self-harmed were wary of family members being given information about their self-harm, and saw the sharing of this information against their wishes as a breach of their privacy and their trust.	Methodological limitations	Minor concerns about methodological limitations as per CASP	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Stewart 2018, Lindgren 2010, Wester 2018)	interviews; 1 study using focus groups	<p>Family members also expressed that they felt it was important for the person who had self-harmed to have an ability to talk to a professional privately without the family member knowing everything that had been said, and wanted the person's treatment to be their own. Some family members therefore did not ask questions or want specific updates from healthcare staff, and were embarrassed and concerned when healthcare staff did not respect the person's confidentiality. However, other family members felt frustrated when information was withheld from them and wanted to be more involved. Some family members felt excluded unnecessarily when this was information was withheld even when the person who had self-harmed had consented to share it.</p> <p>Some clinicians felt that the privacy of the person who had self-harmed hampered the involvement of family/ carers. Others assumed that if people did not explicitly consent to the sharing of information with family members, they should not be given it. Some said that collaborating with/ providing clarity to patients around what information would be shared with others allowed for information sharing without affecting patient concerns about confidentiality.</p> <p>"You get called all sorts by your husband and in-laws, and when you get treated badly and if you tell someone, they judge you like you're spoiling izzat, or get called stupid or a slapper, or they go and tell someone else. It's not just them. When I left home and went to the police, they actually told them where I'd gone. They're all the same, like, we're Asian and women and we don't matter. How can you trust anyone when you've gone through that? It's like all I wanted was someone to listen or talk to ..." (26-year-old) (Chew-Graham 2002)</p> <p>"I felt I was included as much as I needed to be and I thought it was good...for my daughter to have an opportunity to talk to someone where she felt she could say what she liked and it wouldn't come back to me". (Ferrey 2015)</p> <p>"I find it very frustrating that I can't discuss a lot of things with CAMHS. I understand why, she needs to know that it's confidential, that the things she discusses with them are not going to be discussed with me. And that's fair enough. But it's very frustrating... So I wish that I could have been involved more, but I can see why it is the way that it is." Christopher.' (Stewart 2018)</p>	Relevance	<p>qualitative checklist</p> <p>Moderate concerns: most evidence is from a substantially different context to the review question (4 studies not conducted in the UK; 1 study looked at responses to sentinel events including self-harm; studies included people with suicidal ideation who had not necessarily self-harmed or who had ambiguity around whether they had self-harmed)</p>	
		Coherence	<p>Minor concerns: Some evidence is contradictory without a credible explanation for differences, however most differences are explained by the fact that they are reported by different</p>		

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
		'The privacy of the patient and professionals might hamper family involvement. Because of this, organizations do not always share information about the sentinel event with the family. Sometimes the patient explicitly stated that they did not give permission for information to be shared with family. In other cases, it was assumed that a patient has not given permission to share information with family.' (Bouwman 2018)	Adequacy	population groups No or very minor concerns	
Sub-theme 5.2: Maintaining the autonomy of the person who has self-harmed					
7 (Dransart 2017, Grandclerc 2019, Hom 2020, McLaughlin 2016, Nadeem 2016, Raphael 2006, Sellin 2018)	3 studies using semi-structured interviews; 2 studies using unstructured interviews; 1 study using semi-structured focus groups and interviews; 1 study using focus groups	<p>People who had self-harmed wanted to maintain a feeling of responsibility for themselves and their actions, and therefore wanted to preserve their autonomy with regards to their own care. They felt that the opinions of family members should not override the opinions of those who have self-harmed when involving family members in the management of self-harm.</p> <p>Healthcare staff felt that they should discuss with people who have self-harmed whether they wanted family/ carers to be actively involved in the management of their care, as well as the extent to which and in what ways family should be involved. They felt that stigma was a barrier preventing people who had self-harmed from wanting to involve family/ carers.</p> <p>Some family members disagreed and believed they should have a say in the care of people who had self-harmed who were ≥18 years old, regardless of the wishes of the person who had self-harmed.</p> <p>School staff also expressed that they would always inform family members as a matter of protocol, due to liability issues if the parents weren't informed.</p> <p>Girl 18: "I think that it's not [my parents'] role in fact, to . . . try to prevent me from cutting myself. I think it's the therapist's role... So I think that they know it, well yes, they know it, but I mean that they shouldn't get involved after, I think I think that's not their business in fact. . . ." (Grandclerc 2019)</p> <p>"My experience is that there is often shame and guilt that contribute to obstacles for involving relatives in acute care. And that nurses sometimes need to work more actively to involve relatives." (Sellin 2018)</p> <p>"Staff need to make an effort to approach people, even if it seems like a betrayal of a person's feelings. In my case keeping the secret did not help</p>	Methodological limitations Relevance	Moderate concerns about methodological limitations as per CASP qualitative checklist Moderate concerns: most evidence is from a substantially different context to the review question (5 studies not conducted in the UK; studies included clinicians or family/ carers of people with suicidal ideation who had not necessarily self-harmed, people who had lost family members to suicide, and/ or friends of people who had self-harmed who were not	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
		and only created problems for me. Mental Health Services need to contact family and children and involve them and inform them.” (McLaughlin 2016) “You always call the parent. Even if the child says, I’m not, I’m not, I’m not.” (Nadeem 2016)	Coherence	<i>necessarily their carers)</i> Minor concerns: Some evidence is contradictory without a credible explanation for differences, however most differences are explained by the fact that they are reported by different population groups	
			Adequacy	No or very minor concerns	

1 Table 11: Summary of evidence (GRADE CERQual): 6 Safety and risk

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 6.1: Protecting staff					
1 (Bouwman 2018)	1 study using semi-structured interviews	When involving families in the analysis of sentinel events, healthcare professionals were often wary of sharing information for fear of negative responses, and wanted to be able to learn from mistakes without being blamed. “So the inspectorate only wants to know if the patient is the victim. Whereas in ninety-nine out of a hundred cases, the staff member is the victim.” (Medical director) (Bouwman 2018)	Methodological limitations	Moderate concerns about methodological limitations as per CASP qualitative checklist	Very low
			Relevance	Serious concerns: all evidence is from a substantially different context to the review	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				question (<i>study not conducted in the UK; study looked at responses to sentinel events including self-harm</i>)	
			Coherence	Moderate concerns: Most evidence is ambiguous	
			Adequacy	Serious concerns: Findings were based on 1 study with a small sample size and poor quoted data relating to this theme, and understanding of the theme would benefit from richer data	
Sub-theme 6.2: Protecting the person who's self-harmed					
5 (Idenfors 2015, Lindgren 2010, Oldershaw 2008, Rissanen 2009a, Wester 2018)	3 studies using semi-structured interviews; 1 studies using narrative interviews; 1 study using written descriptions and open-ended interviews	Some people who had self-harmed and their family/ carers did not always want other family members to be involved in the care of the person who had self-harmed because they felt they would react negatively, potentially leading to unhelpful or even harmful interactions. Additionally, some family/ carers admitted they had dismissed concerns or delayed help-seeking after becoming aware of self-harm. Some people who had self-harmed were also worried about the negative consequences of disclosure to family members resulting in the information spreading to others. For example, some feared this would affect career opportunities.	Methodological limitations	Minor concerns about methodological limitations as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns: most evidence is from a different context to the review question	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
		<p>On the other hand, other family/ carers said that their involvement meant that they could be informed by the person who had self-harmed if they were being mistreated in care - although some family members tried to justify this mistreatment.</p> <p>“Sometimes it is better not to tell parents because it can cause more difficulties for the self-mutilating adolescent.” (Rissanen 2009a)</p> <p>“I didn’t inform my ex-husband either. I think because I knew he would over-react, which wouldn’t be helpful. He lived in a different town and I didn’t think yelling at my son over the phone would help my son to deal with it in a healthy way.” (Wester 2018)</p> <p>“One of these caregivers was rather rough towards Tina, but I didn’t take it so hard because she was rather cocky herself.” (Lindgren 2010)</p>	Coherence	<p>(4 studies not conducted in the UK)</p> <p>Moderate concerns: most evidence is contradictory without a credible explanation for differences</p>	
			Adequacy	No or very minor concerns	

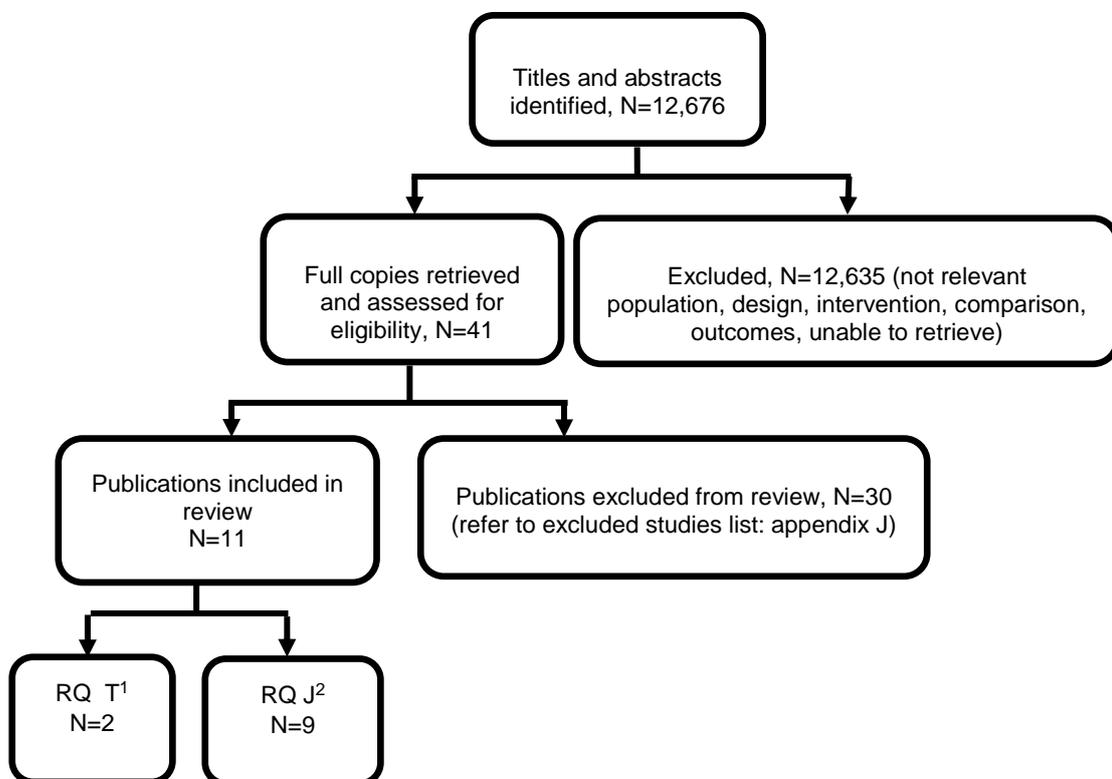
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1 Appendix G Economic evidence study selection

2 **Study selection for review question: What are the views and preferences of**
3 **people who have self-harmed, their families and carers, and staff working with**
4 **people who have self-harmed about the best ways of involving family and**
5 **carers in the management of people who have self-harmed?**

6 A global health economics search was undertaken for all areas covered in the guideline.
7 Figure 3 shows the flow diagram of the selection process for economic evaluations of
8 interventions and strategies associated with the care of people who have self-harmed.

9 **Figure 3: Flow diagram of economic article selection for global health economic**
10 **search**



11
12 Abbreviations: RQ: Research question

13 Notes:

14 1 What are the most effective models of care for people who have self-harmed?

15 2 What psychological and psychosocial interventions (including safety plans and electronic health-based
16 interventions) are effective for people who have self-harmed?

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1 **Appendix H Economic evidence tables**

2 **Economic evidence tables for review question: What are the views and**
3 **preferences of people who have self-harmed, their families and carers, and**
4 **staff working with people who have self-harmed about the best ways of**
5 **involving family and carers in the management of people who have self-**
6 **harmed?**

7 No evidence was identified which was applicable to this review question.

8

9

1 **Appendix I Economic model**

2 **Economic model for review question: What are the views and preferences of**
3 **people who have self-harmed, their families and carers, and staff working with**
4 **people who have self-harmed about the best ways of involving family and**
5 **carers in the management of people who have self-harmed?**

6 No economic analysis was conducted for this review question.

7

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1 Appendix J Excluded studies

2 Excluded studies for review question: What are the views and preferences of
3 people who have self-harmed, their families and carers, and staff working with
4 people who have self-harmed about the best ways of involving family and
5 carers in the management of people who have self-harmed?

6 Excluded qualitative studies

7 Table 12: Excluded studies and reasons for their exclusion

Study	Code [Reason]
(2012) Understanding self-harm. The Lancet 380: 1532	- No direct qualitative data on phenomena of interest
Allbaugh, L. J., Mack, S. A., Culmone, H. D. et al. (2018) Relational factors critical in the link between childhood emotional abuse and suicidal ideation. Psychological services 15: 298-304	- Quantitative study
Amoss, Sarah; Lynch, Monica; Bratley, Mary (2016) Bringing forth stories of blame and shame in dialogues with families affected by adolescent self-harm. Journal of Family Therapy 38: 189-205	- No direct qualitative data on phenomena of interest
Arbuthnott, A. E. and Lewis, S. P. (2015) Parents of youth who self-injure: A review of the literature and implications for mental health professionals. Child and Adolescent Psychiatry and Mental Health 9 (1)	- Systematic review, included studies checked for relevance
Berger, E.; Hasking, P.; Martin, G. (2013) 'Listen to them': Adolescents' views on helping young people who self-injure. Journal of Adolescence 36: 935-945	- Population not in PICO <i>Only 10% (N=263) of participants had self-harmed</i>
Broadbent, E. (2011) Working with people who self-harm: What does the service user need?. Wounds UK 7: 78-84	- Narrative review
Brown, Rhonda and Martin, Graham (2002) Self harm and suicide risk for same-sex attracted young people: A family perspective. AeJAMH (Australian e-Journal for the Advancement of Mental Health) 1: 1-11	- Narrative review

Study	Code [Reason]
Brown, T. B. and Kimball, T. (2013) Cutting to Live: A Phenomenology of Self-Harm. <i>Journal of Marital and Family Therapy</i> 39: 195-208	- No direct qualitative data on phenomena of interest
Buckmaster, R.; McNulty, M.; Guerin, S. (2019) Family factors associated with self-harm in adults: a systematic review. <i>Journal of Family Therapy</i> 41: 537-558	- Systematic review, included studies checked for relevance
Clarke, Adam R., Schnieden, Vivienne, Hamilton, Blake A. et al. (2004) Factors Associated with Treatment Compliance in Young People Following an Emergency Department Presentation for Deliberate Self-Harm. <i>Archives of Suicide Research</i> 8: 147-152	- No direct qualitative data on phenomena of interest
Cruz, Diana; Narciso, Isabel; Sampaio, Daniel (2016) Adolescents' maps about well-being, distress and self-destructive trajectories: What's in their voices?. <i>Psychologica</i> 59: 95-115	- Population not in PICO <i>Participants were adolescents, self-harm is not mentioned as inclusion criteria</i>
Curtis, S., Thorn, P., McRoberts, A. et al. (2018) Caring for young people who self-harm: A review of perspectives from families and young people. <i>International Journal of Environmental Research and Public Health</i> 15 (5)	- Systematic review, included studies checked for relevance
Drysdale, Emma E.; Jahoda, Andrew; Campbell, Elizabeth (2009) Investigating spontaneous attributions in mothers of individuals with intellectual disabilities and self-injurious behaviour. <i>British Journal of Learning Disabilities</i> 37: 197-206	- Population not in PICO <i>Participants were parents of individuals who engaged in repetitive stereotypical self-injurious behaviour, including head banging and skin pinching</i>
Duperouzel, Helen and Fish, Rebecca (2010) Hurting no-one else's body but your own: People with intellectual disability who self injure in a forensic service. <i>Journal of Applied Research in Intellectual Disabilities</i> 23: 606-615	- No direct qualitative data on phenomena of interest
Durand, S. C. and McGuinness, T. M. (2016) Adolescents Who Self-Injure. <i>Journal of psychosocial nursing and mental health services</i> 54: 26-29	- Narrative review
Emery, A. A.; Heath, N. L.; Rogers, M. (2017) Parents' role in early adolescent self-injury: An application of self-determination theory. <i>School</i>	- Quantitative study

Study	Code [Reason]
psychology quarterly : the official journal of the Division of School Psychology, American Psychological Association 32: 199-211	
Fodstad, J. C., Kirsch, A., Faidley, M. et al. (2018) Demonstration of Parent Training to Address Early Self-Injury in Young Children with Intellectual and Developmental Delays. Journal of Autism and Developmental Disorders 48: 3846-3857	- Population not in PICO <i>Participants were parents of individuals who engaged in repetitive stereotypical self-injurious behaviour, including head banging and skin pinching</i>
Grant, Cynthia; Ballard, Elizabeth D.; Olson-Madden, Jennifer H. (2015) An empowerment approach to family caregiver involvement in suicide prevention: Implications for practice. The Family Journal 23: 295-304	- Narrative review
Grimmond, J., Kornhaber, R., Visentin, D. et al. (2019) A qualitative systematic review of experiences and perceptions of youth suicide. PLoS ONE 14 (6)	- Systematic review, included studies checked for relevance
Han, J., Batterham, P. J., Cleave, A. L. et al. (2018) Factors Influencing Professional Help-Seeking for Suicidality. Crisis 39: 175-196	- Systematic review, included studies checked for relevance
Holland, J., Sayal, K., Berry, A. et al. (2020) What do young people who self-harm find helpful? A comparative study of young people with and without experience of being looked after in care. Child and Adolescent Mental Health 25: 157-164	- No direct qualitative data on phenomena of interest
Jackman, K., Edgar, B., Ling, A. et al. (2018) Experiences of transmasculine spectrum people who report nonsuicidal self-injury: A qualitative investigation. Journal of counseling psychology 65: 586-597	- No direct qualitative data on phenomena of interest
Kelada, Lauren; Hasking, Penelope; Melvin, Glenn (2016) The relationship between nonsuicidal self-injury and family functioning: Adolescent and parent perspectives. Journal of Marital and Family Therapy 42: 536-549	- Quantitative study
Lachal, J., Orri, M., Sibeoni, J. et al. (2015) Metasynthesis of youth suicidal behaviours: Perspectives of youth, parents, and health care professionals. PLoS ONE 10 (5)	- Systematic review, included studies checked for relevance

Study	Code [Reason]
Lindgren, B. M.; Svedin, C. G.; Werko, S. (2018) A Systematic Literature Review of Experiences of Professional Care and Support Among People Who Self-Harm. Archives of suicide research : official journal of the International Academy for Suicide Research 22: 173-192	- Systematic review, included studies checked for relevance
McAndrew, S. and Warne, T. (2010) Coming out to talk about suicide: Gay men and suicidality. International Journal of Mental Health Nursing 19: 92-101	- No direct qualitative data on phenomena of interest
McClatchey, K., Murray, J., Chouliara, Z. et al. (2019) Protective Factors of Suicide and Suicidal Behavior Relevant to Emergency Healthcare Settings: A Systematic Review and Narrative Synthesis of Post-2007 Reviews. Archives of suicide research : official journal of the International Academy for Suicide Research 23: 411-427	- Systematic review, included studies checked for relevance
Michaud, L., Stiefel, F., Moreau, D. et al. (2019) Completed Suicides in Psychiatric Patients: Identifying Health Care-Related Factors through Clinical Practice Reviews. Archives of suicide research : official journal of the International Academy for Suicide Research: 1-15	- No direct qualitative data on phenomena of interest
Morris, M. (2015) Clinical care of the suicidal college student: When and how to involve parents. Psychiatric Times 32	- Narrative review
Prabhu, S. L., Molinari, V., Bowers, T. et al. (2010) Role of the family in suicide prevention: An attachment and family systems perspective. Bulletin of the Menninger Clinic 74: 301-327	- Narrative review
Rissanen, M. L.; Kylm, A. J. P. O.; Laukkanen, E. R. (2008) Parental conceptions of self-mutilation among Finnish adolescents. Journal of Psychiatric and Mental Health Nursing 15: 212-218	- No direct qualitative data on phenomena of interest
Sellin, L., Asp, M., Wallsten, T. et al. (2017) Reconnecting with oneself while struggling between life and death: The phenomenon of recovery as experienced by persons at risk of suicide. International journal of mental health nursing 26: 200-207	- No direct qualitative data on phenomena of interest

Study	Code [Reason]
Sharaf, A. Y.; Thompson, E. A.; Walsh, E. (2009) Protective effects of self-esteem and family support on suicide risk behaviors among at-risk adolescent. <i>Journal of Child and Adolescent Psychiatric Nursing</i> 22: 160-168	- Duplicate
Sharaf, A. Y.; Thompson, E. A.; Walsh, E. (2009) Protective effects of self-esteem and family support on suicide risk behaviors among at-risk adolescents. <i>Journal of child and adolescent psychiatric nursing : official publication of the Association of Child and Adolescent Psychiatric Nurses, Inc</i> 22: 160-168	- Quantitative study
Shilubane, Hilda N., Ruiters, Robert A. C., Bos, Arjan E. R. et al. (2012) Psychosocial determinants of suicide attempts among Black South African adolescents: A qualitative analysis. <i>Journal of Youth Studies</i> 15: 177-189	- Country not in PICO
Spiers, S., Grandclerc, S., Guenole, F. et al. (2020) Adolescents-parents relationships around deliberate self-harm behaviours: A qualitative exploration. <i>Neuropsychiatrie de l'Enfance et de l'Adolescence</i> 68: 46-54	- Study not published in English
Steggals, P.; Lawler, S.; Graham, R. (2020) 'I couldn't say the words': communicative bodies and spaces in parents' encounters with nonsuicidal self-injury. <i>Social Theory and Health</i>	- No direct qualitative data on phenomena of interest
Sun, Rachel C. F. and Hui, Eadaoin K. P. (2007) Building social support for adolescents with suicidal ideation: Implications for school guidance and counselling. <i>British Journal of Guidance & Counselling</i> 35: 299-316	- Country not in PICO
Thompson, M. P., Kaslow, N. J., Short, L. M. et al. (2002) The mediating roles of perceived social support and resources in the self-efficacy-suicide attempts relation among African American abused women. <i>Journal of Consulting and Clinical Psychology</i> 70: 942-949	- Quantitative study
Torok, M., Cleave, A. L., Smart, A. et al. (2019) Preventing adolescent suicide: A systematic review of the effectiveness and change mechanisms of suicide prevention gatekeeping training programs for teachers and parents. <i>Journal of Adolescence</i> 73: 100-112	- Systematic review, included studies checked for relevance

Study	Code [Reason]
Wadman, R., Armstrong, M., Clarke, D. et al. (2018) Experience of Self-Harm and Its Treatment in Looked-After Young People: An Interpretative Phenomenological Analysis. Archives of suicide research : official journal of the International Academy for Suicide Research 22: 365-379	- No direct qualitative data on phenomena of interest
Wadman, R., Clarke, D., Sayal, K. et al. (2017) An interpretative phenomenological analysis of the experience of self-harm repetition and recovery in young adults. Journal of health psychology 22: 1631-1641	- No direct qualitative data on phenomena of interest
Wadman, R., Vostanis, P., Sayal, K. et al. (2018) An interpretative phenomenological analysis of young people's self-harm in the context of interpersonal stressors and supports: Parents, peers, and clinical services. Social Science and Medicine 212: 120-128	- No direct qualitative data on phenomena of interest
Wand, A. P. F., Peisah, C., Draper, B. et al. (2018) Why Do the Very Old Self-Harm? A Qualitative Study. American Journal of Geriatric Psychiatry 26: 862-871	- No direct qualitative data on phenomena of interest
Winter, David, Bradshaw, Siobhan, Bunn, Frances et al. (2014) A systematic review of the literature on counselling and psychotherapy for the prevention of suicide: 2. Qualitative studies. Counselling & Psychotherapy Research 14: 64-79	- Systematic review, included studies checked for relevance
Yamaguchi, T., Fujii, C., Nemoto, T. et al. (2015) Differences between subjective experiences and observed behaviors in near-fatal suicide attempters with untreated schizophrenia: A qualitative pilot study. Annals of General Psychiatry 14 (1)	- No direct qualitative data on phenomena of interest

1 Excluded economic studies

2 Table 13: Excluded studies from the guideline economic review

Study	Reason for Exclusion
Adrian, M., Lyon, A. R., Nicodimos, S., Pullmann, M. D., McCauley, E., Enhanced "Train and Hope" for Scalable, Cost-Effective Professional Development in Youth Suicide Prevention, Crisis, 39, 235-246, 2018	Not relevant to any of the review questions in the guideline - this study examined the impact of an educational training ongoing intervention, and the effect of the post-training reminder system, on mental health practitioners' knowledge, attitudes, and behaviour surrounding suicide

Study	Reason for Exclusion
	assessment and intervention. As well, this study was not a full health economic evaluation
Borschmann R, Barrett B, Hellier JM, et al. Joint crisis plans for people with borderline personality disorder: feasibility and outcomes in a randomised controlled trial. <i>Br J Psychiatry</i> . 2013;202(5):357-364.	Not relevant to any of the review questions in the guideline - this study examined the feasibility of recruiting and retaining adults with borderline personality disorder to a pilot randomised controlled trial investigating the potential efficacy and cost-effectiveness of using a joint crisis plan
Bustamante Madsen, L., Eddleston, M., Schultz Hansen, K., Konradsen, F., Quality Assessment of Economic Evaluations of Suicide and Self-Harm Interventions, <i>Crisis</i> , 39, 82-95, 2018	Study design - this review of health economics studies has been excluded for this guideline, but its references have been hand-searched for any relevant health economic study
Byford, S., Barrett, B., Aglan, A., Harrington, V., Burroughs, H., Kerfoot, M., Harrington, R. C., Lifetime and current costs of supporting young adults who deliberately poisoned themselves in childhood and adolescence, <i>Journal of Mental Health</i> , 18, 297-306, 2009	Study design – no comparative cost analysis
Byford, S., Leese, M., Knapp, M., Seivewright, H., Cameron, S., Jones, V., Davidson, K., Tyrer, P., Comparison of alternative methods of collection of service use data for the economic evaluation health care interventions, <i>Health Economics</i> , 16, 531-536, 2007	Study design – no comparative cost analysis
Byford, Sarah, Barber, Julie A., Harrington, Richard, Barber, Baruch, Beautrais Blough Brent Brodie Byford Carlson Chernoff Collett Fergusson Garland Goldberg Harman Harrington Hawton Huber Kazdin Kerfoot Knapp Lindsey McCullagh Miller Netten Reynolds Sadowski Shaffer Simms Wu, Factors that influence the cost of deliberate self-poisoning in children and adolescents, <i>Journal of Mental Health Policy and Economics</i> , 4, 113-121, 2001	Study design – no comparative cost analysis
Denchev, P., Pearson, J. L., Allen, M. H., Claassen, C. A., Currier, G. W., Zatzick, D. F., Schoenbaum, M., Modeling the cost-effectiveness of interventions to reduce suicide risk among hospital emergency department patients, <i>Psychiatric Services</i> , 69, 23-31, 2018	Not relevant to any of the review questions in the guideline - this study estimated the cost-effectiveness of outpatient interventions (Postcards, Telephone outreach, Cognitive Behaviour Therapy) to reduce suicide risk among patients presenting to general hospital emergency departments
Dunlap, L. J., Orme, S., Zarkin, G. A., Arias, S. A., Miller, I. W., Camargo, C. A., Sullivan, A. F., Allen, M. H., Goldstein, A. B., Manton, A. P., Clark, R., Boudreaux, E. D., Screening and Intervention for Suicide Prevention: A Cost-Effectiveness Analysis of the ED-SAFE Interventions, <i>Psychiatric services (Washington, D.C.)</i> , appips201800445, 2019	Not relevant to any of the review questions in the guideline - this study estimated the cost-effectiveness of suicide screening followed by an intervention to identify suicidal individuals and prevent recurring self-harm
Fernando, S. M., Reardon, P. M., Ball, I. M., van Katwyk, S., Thavorn, K., Tanuseputro, P., Rosenberg, E., Kyeremanteng, K., Outcomes and Costs of Patients Admitted to the Intensive Care Unit Due to Accidental or Intentional Poisoning, <i>Journal of Intensive Care Medicine</i> , 35, 386-393, 2020	Study design – no comparative cost analysis

Study	Reason for Exclusion
Flood, C., Bowers, L., Parkin, D., Estimating the costs of conflict and containment on adult acute inpatient psychiatric wards, <i>Nursing economic</i> , 26, 325-330, 324, 2008	Study design – no comparative cost analysis
Fortune, Z., Barrett, B., Armstrong, D., Coid, J., Crawford, M., Mudd, D., Rose, D., Slade, M., Spence, R., Tyrer, P., Moran, P., Clinical and economic outcomes from the UK pilot psychiatric services for personality-disordered offenders, <i>International Review of Psychiatry</i> , 23, 61-9, 2011	Not relevant to any of the review questions in the guideline
George, S., Javed, M., Hemington-Gorse, S., Wilson-Jones, N., Epidemiology and financial implications of self-inflicted burns, <i>Burns</i> , 42, 196-201, 2016	Study design – no comparative cost analysis
Gunnell, D., Shepherd, M., Evans, M., Are recent increases in deliberate self-harm associated with changes in socio-economic conditions? An ecological analysis of patterns of deliberate self-harm in Bristol 1972-3 and 1995-6, <i>Psychological medicine</i> , 30, 1197-1203, 2000	Study design - cost-of-illness study
Kapur, N., House, A., Dodgson, K., Chris, M., Marshall, S., Tomenson, B., Creed, F., Management and costs of deliberate self-poisoning in the general hospital: A multi-centre study, <i>Journal of Mental Health</i> , 11, 223-230, 2002	Study design – no comparative cost analysis
Kapur, N., House, A., May, C., Creed, F., Service provision and outcome for deliberate self-poisoning in adults - Results from a six centre descriptive study, <i>Social Psychiatry and Psychiatric Epidemiology</i> , 38, 390-395, 2003	Study design – no comparative cost analysis
Kinchin, I., Russell, A. M. T., Byrnes, J., McCalman, J., Doran, C. M., Hunter, E., The cost of hospitalisation for youth self-harm: differences across age groups, sex, Indigenous and non-Indigenous populations, <i>Social Psychiatry and Psychiatric Epidemiology</i> , 55, 425-434, 2020	Study design – no comparative cost analysis
O'Leary, F. M., Lo, M. C. I., Schreuder, F. B., "Cuts are costly": A review of deliberate self-harm admissions to a district general hospital plastic surgery department over a 12-month period, <i>Journal of Plastic, Reconstructive and Aesthetic Surgery</i> , 67, e109-e110, 2014	Study design – no comparative cost analysis
Olfson, M., Gameroff, M. J., Marcus, S. C., Greenberg, T., Shaffer, D., National trends in hospitalization of youth with intentional self-inflicted injuries, <i>American Journal of Psychiatry</i> , 162, 1328-1335, 2005	Study design – no comparative cost analysis
Ostertag, L., Golay, P., Dorogi, Y., Brovelli, S., Cromec, I., Edan, A., Barbe, R., Saillant, S., Michaud, L., Self-harm in French-speaking Switzerland: A socio-economic analysis (7316),	Conference abstract

Study	Reason for Exclusion
Swiss Archives of Neurology, Psychiatry and Psychotherapy, 70 (Supplement 8), 48S, 2019	
Ougrin, D., Corrigan, R., Poole, J., Zundel, T., Sarhane, M., Slater, V., Stahl, D., Reavey, P., Byford, S., Heslin, M., Ivens, J., Crommelin, M., Abdulla, Z., Hayes, D., Middleton, K., Nnadi, B., Taylor, E., Comparison of effectiveness and cost-effectiveness of an intensive community supported discharge service versus treatment as usual for adolescents with psychiatric emergencies: a randomised controlled trial, <i>The Lancet Psychiatry</i> , 5, 477-485, 2018	Not self-harm. In addition, the interventions evaluated in this economic analysis (a supported discharge service provided by an intensive community treatment team compared to usual care) were not relevant to any review questions
Palmer, S., Davidson, K., Tyrer, P., Gumley, A., Tata, P., Norrie, J., Murray, H., Seivewright, H., The cost-effectiveness of cognitive behavior therapy for borderline personality disorder: results from the BOScot trial, <i>Journal of Personality Disorders</i> , 20, 466-481, 2006	Not self-harm
Quinlivan L, Steeg S, Elvidge J, et al. Risk assessment scales to predict risk of hospital treated repeat self-harm: A cost-effectiveness modelling analysis. <i>J Affect Disord</i> . 2019;249:208-215.	Not relevant to any of the review questions in the guideline - this study estimated the cost-effectiveness of risk assessment scales versus clinical assessment for adults attending an emergency department following self-harm
Richardson JS, Mark TL, McKeon R. The return on investment of postdischarge follow-up calls for suicidal ideation or deliberate self-harm. <i>Psychiatr Serv</i> . 2014;65(8):1012-1019.	Not enough data reporting on cost-effectiveness findings
Smits, M. L., Feenstra, D. J., Eeren, H. V., Bales, D. L., Laurensen, E. M. P., Blankers, M., Soons, M. B. J., Dekker, J. J. M., Lucas, Z., Verheul, R., Luyten, P., Day hospital versus intensive out-patient mentalisation-based treatment for borderline personality disorder: Multicentre randomised clinical trial, <i>British Journal of Psychiatry</i> , 216, 79-84, 2020	Not self-harm
Tsiachristas, A., Geulayov, G., Casey, D., Ness, J., Waters, K., Clements, C., Kapur, N., McDaid, D., Brand, F., Hawton, K., Incidence and general hospital costs of self-harm across England: estimates based on the multicentre study of self-harm, <i>Epidemiology & Psychiatric Science</i> , 29, e108, 2020	Study design – no comparative cost analysis
Tsiachristas, A., McDaid, D., Casey, D., Brand, F., Leal, J., Park, A. L., Geulayov, G., Hawton, K., General hospital costs in England of medical and psychiatric care for patients who self-harm: a retrospective analysis, <i>The Lancet Psychiatry</i> , 4, 759-767, 2017	Study design – no comparative cost analysis
Tubeuf, S., Saloniki, E. C., Cottrell, D., Parental Health Spillover in Cost-Effectiveness Analysis: Evidence from Self-Harming Adolescents in England, <i>PharmacoEconomics</i> , 37, 513-530, 2019	This study is not a separate study from one already included in the guideline for topic 5.2 (Cottrell 2018). This secondary analysis presents alternative parental health spillover quantification methods in the context of a randomised controlled trial comparing family therapy with treatment as usual as an intervention for self-harming adolescents of

Study	Reason for Exclusion
	(Cottrel 2018), and discusses the practical limitations of those methods
Tyrer, P., Thompson, S., Schmidt, U., Jones, V., Knapp, M., Davidson, K., Catalan, J., Airlie, J., Baxter, S., Byford, S., Byrne, G., Cameron, S., Caplan, R., Cooper, S., Ferguson, B., Freeman, C., Frost, S., Godley, J., Greenshields, J., Henderson, J., Holden, N., Keech, P., Kim, L., Logan, K., Manley, C., MacLeod, A., Murphy, R., Patience, L., Ramsay, L., De Munroz, S., Scott, J., Seivewright, H., Sivakumar, K., Tata, P., Thornton, S., Ukoumunne, O. C., Wessely, S., Randomized controlled trial of brief cognitive behaviour therapy versus treatment as usual in recurrent deliberate self-harm: The POPMACT study, <i>Psychological medicine</i> , 33, 969-976, 2003	Study design - no economic evaluation
Van Roijen, L. H., Sinnaeve, R., Bouwmans, C., Van Den Bosch, L., Cost-effectiveness and Cost-utility of Shortterm Inpatient Dialectical Behavior Therapy for Chronically Parasuicidal BPD (Young) Adults, <i>Journal of Mental Health Policy and Economics</i> , 18, S19-S20, 2015	Conference abstract
van Spijker, B. A., Majo, M. C., Smit, F., van Straten, A., Kerkhof, A. J., Reducing suicidal ideation: cost-effectiveness analysis of a randomized controlled trial of unguided web-based self-help, <i>Journal of medical Internet research</i> , 14, e141, 2012	Not self-harm

1

1 **Appendix K Research recommendations – full details**

2 **Research recommendations for review question: What are the views and**
3 **preferences of people who have self-harmed, their families and carers, and**
4 **staff working with people who have self-harmed about the best ways of**
5 **involving family and carers in the management of people who have self-**
6 **harmed?**

7 No research recommendations were made for this review question.

8

1 Appendix L Qualitative quotes

2 Qualitative quotes for review question: What are the views and preferences of 3 people who have self-harmed, their families and carers, and staff working with 4 people who have self-harmed about the best ways of involving family and 5 carers in the management of people who have self-harmed?

6 Table 14: Theme 1. Communication

Study	Evidence
Sub-theme 1.1: Listening to family/ carers	
Bouwman 2018	"I said, 'This isn't going to help her enough (...) I say, 'you can keep her here, I'm not taking her home anymore, I'm no longer taking responsibility'. Then she got a psychosis on the spot.'" (Mother of a patient)
Bouwman 2018	"It's also a kind of duty for the care organization, to provide aftercare to the family (...) To give them the opportunity to tell their story again, or to hear how everything happened. So that they can learn to cope with what has happened. Yes, in that sense it's an extra reason for paying attention to the family and relatives." (Inspector)
Bouwman 2018	"you need that family for the biography and the history. (...) The family is (therefore) indispensable for a proper analysis of the event, otherwise you're only looking at the care provided and that's the major problem, for the crisis services too" (Inspector)
Dempsey 2019	"The trouble is that I do not know how much the therapists know from what he is saying and whether they cotton onto things that I think are happening because I see him every day. I am still waiting though for them to talk to me." (Caregiver)
Dransart 2017	"The real disappointment for me was when her suicide attempt led her to the hospital, but after three days, they just released her and that was it. Yet I told them 'but listen, she is not ready to get out, we've been dealing with this for ten years, you can be sure that she will try again'."
Jennings 2020	"they have realised that actually [laughs] we are fellow professionals, not childminders and we have even been able to pass on leaflets and pamphlets and things to help them with the care of the young person we've got, which is good to be able to help them. We now have an excellent rapport with them. (foster carer)
Kelada 2016	"I don't know how successful therapy was in general, I mean, honestly, the deeper he would dive, the more she would resist...I think that it was just ineffective to try and dig in there...I think that was not a very useful approach on her. Just if he had looked at the case, and saw that it wasn't working, I think it was probably time to maybe try something else that maybe she was a little more receptive to." (father)
Lindgren 2010	"If only I'd been more persistent and said 'She's not just an ordinary girl, something is wrong with her'. She's lost so many years unnecessarily. 'Please, listen to what we're saying, something about her isn't right and we need help'"
Stewart 2018	"I do remember saying the appearance he's giving to you isn't actually what he is feeling because I'm seeing a different side of him. But when they spoke to him, he had a humour in his voice so that was mistook for him having a lighter mood."
Wand 2019a	"The nursing home staff [and the family] had voiced their concerns about Dad's possibility of self-harm and it was being ignored [by mental health] as well." Son-in-law'
Wand 2019b	"I did call the Emergency they says 'oh, he's OK', you know that he will go home. And I say 'wait a minute. This person is depressed, he wants to hurt himself'" [brother]'

Study	Evidence
Wand 2019b	“One doctor I spoke to ... he was really dismissive ... dismissing with a wave of the hand the observation of someone who'd known him [patient] for a long time.” [friend]
Wand 2019b	“When the nurse from [the hospital], psychiatrist or whatever, went to see him before he told them “I really don't want to kill myself I want to get a better service.” But he told our relatives, basically, “I don't want to live”. [daughter]
Sub-theme 1.2: Maintaining communication with family/ carers	
Dransart 2017	“And in the evening, at 19h15, the psychiatrist calls me and then she tells me ‘you know, I have contacted your husband’s GP, and we have decided to give up half of another drug’. I found this fantastic!”
Dransart 2017	“After, there is nothing, after those 6 weeks in hospital. Then, nobody had told us he needed to see a psychiatrist so at that point we felt we had more or less been dumped.”
Ferrey 2015	“My criticism is that once you’re discharged from the crisis team, you then go back to your 3 monthly or your 6 monthly appointments with your psychiatrist. What’s in the middle? And the answer is, very little.”
Kelada 2016	“She had weekly/fortnightly sessions for 10 months with psychologist but I didn’t know if she was improving. Didn’t feel supported as a parent by the psychologist.” [P1, mother]
Kennard 2020	“So, sometimes it’s like we’ll have an appointment scheduled, I’ll see them one week, we’ll have an appointment scheduled the next week, suddenly they don’t show up and I call and it’s like oh yeah they’re in Mexico for two months. And it’s like well it would have been good for us to go over a plan of how to handle things while they’re there.”—clinician
McLaughlin 2016	"There is no support for carers. We need to be able to ring up the services to find out how she is. The services tell you nothing. That is no good as we are expected to help. How can we help if we don't know and are kept in the dark? Services need to talk to family members about their relatives."
Nadeem 2016	“Every two weeks we’ll [review] the students who have been referred. There will be a follow-up as to whether or not the parents followed through with the intakes, if the child’s attending, or if the parent indicated that they didn’t want the services.”
Raphael 2006	‘Parents expressed the need for the reassurance and the lack of any follow up appointment left the parents felt insecure and uncertain about their own ability to cope or prevent any future incidents.’
Spillane 2019	‘They described how no one “followed up” with them after their family member was discharged from hospital and one participant felt that someone from the hospital should “call in” and check on them as “it’s very easy to lie down [over] the phone” regarding their progress and mental health.’
Stewart 2018	“They would report to me at the end of the day or the end of the week to let me know she’s had a good week. So at least there was some communication and some dialogue going, because I think in cases where children are self-harming that has to happen so that all parties are aware and they are on full alert because the young people are so vulnerable.”
Wand 2019a	“Everyone dropped off as soon as she was released [from hospital].” Daughter-in-law
Wand 2019b	“So I think it would be a good idea [that] the GP can coordinate into this and keep contact with the family member. ... So if some issue happening I can reach him at least.” [daughter]
Wester 2018	“I think it’s very challenging when parents don’t seek treatment for their child and the child continues to self-harm. When I get the second or third report that they’ve harmed themselves and I feel like the child really needs more help than they’re getting, I feel like I have to push the parents a bit to take that step. That’s

Study	Evidence
	a challenge because even though I think they need to get treatment for their child it's their child. They get to make those decisions."
Sub-theme 1.3: Methods of communication	
Kennard 2020	"[I use] metaphors and parables...once they understand and start explaining it, then get them to identify how it works clinically...[One] illustration is high blood pressure. High blood pressure—you take the pills but with the pills you also must eat healthy and you have to exercise. A pill alone won't fix it, but with exercise and eating healthy..."—clinician'
Sub-theme 1.4: Clarity of communication	
Lindgren 2010	"I asked at the care meeting whether someone could visit Tina if necessary? There was nobody [who could visit] was the answer I got. Now I've got the information that there was someone who could have come. There were personnel from the community who were available if needed."
Sub-theme 1.5: Informal pathways	
Bouwman 2018	"It's better to share the real story with each other than to follow formal pathways. That's pretty much our approach." (Family counselor)'
Nadeem 2016	"Even problems that are not necessarily school-related, [parents] will come to the school and ask for help. It is more family issues. I've gone out with the principal to homes, you know, when crises have happened, just to help connect them with services because they look at the school like the safe place for them to go."
Rissanen 2009b	'Parent 4: "On the ward they (healthcare staff) always took selfmutilation very seriously. It was like an alarm signal to nurses."'
Rissanen 2009b	"Some of the doctors who have cared for my daughter have had brilliant professional skills".
Spillane 2019	Family members wanted the hospital staff to "look at the patient, not as another suicide attempt" and "see he was part of a family unit, he wasn't living out on his own, his mam and dad were there ... they need to be involved."
Sub-theme 1.6: Communication between the person and their family/ carer	
Byrne 2008	". . . How to help us to open up and to get in touch with the anger, but express it."
Ferrey 2016a	"When somebody is feeling so miserable that they can't even talk about it, rather than reaching for something to harm themselves with, to reach for their phone."
Rissanen 2009a	"Although my mother did not understand how bad I felt, chatting with her was enough to keep me from self-mutilating that night."
Rissanen 2009b	'Discussing with the adolescent, for example about self-mutilation, in her own terms, and all things associated with it'.
Rissanen 2012	"Although the interaction between an adolescent and the parents may have previously been functional, it might be that they have not been used to discussing matters that they have experienced as difficult."
Wester 2018	"It was more how can we help Jessica? What does Jessica need? What is she not able to express? She can express everything else so what is it that we're missing and how do I get her to tell me what's really going on?"

1 Table 15: Theme 2. Collaboration

Study	Evidence
Sub-theme 2.1: Collaboration in the management of self-harm	
Bouwman 2018	"Then we draft the improvement measures, but at that point the family is no longer involved. At least everything (the event analysis) is done. No, the points for improvement are just outlines. If more points turn up, they'll be in the report. And then worked out in detail. That's without the family, but they can say what they think of the broader outlines." (Care institution director)'

Study	Evidence
Dempsey 2019	"I see the relationship between families and clinicians, particularly in the early stages, as collaborative. I think they need to have an opportunity to share their experiences, their perspectives, their thoughts and ideas about what's going on for the young person." (Clinician)'
Dransart 2017	'SAM: "Because with the psychiatrist, it goes like this: I go there with my husband, we have a little chat, and then I leave, and they talk together."'
Hom 2020	". . . it would have been nice to be treated like I actually knew what I was talking about. A lot of times I was just brushed off and they would talk to my mom instead of me . . ."
Idenfors 2015	"There may be people who feel worse than I do. Their problems may be a little different than mine. It didn't feel like my problems were anything compared with theirs. It just felt weird to seek help because you just... well..." (Participant 1)'
Jennings 2020	"The other thing is the way the statutory agencies don't involve, I mean we are the amateurs, really aren't we? That's what they see. They don't actually kind of seem to realise the level of expertise. So, where they have the multi-agency meetings, they will have multi-agency meetings about our children but not invite us because we are not a statutory agency. And often we're providing, we will provide a report and they won't read it because we're not a statutory agency." (IDRC03: Residential Carer)'
Krysinska 2020	"There needs to be a discussion with the child that's actually self-harming about why it needs to be discussed and why it needs to be discussed with certain people. (...) It should be a joint decision on who - say, for myself and my son, who those people were going to be" (Parent 3)'
Lindgren 2010	"Then they [the caregivers] had discovered that a child who has passed 16 years of age can change the place of domicile to the other parent // So, they took my daughter to a place where she could do just that, without my knowledge. I had sole custody and they went behind my back!"
Lindgren 2010	"We weren't asked about what we thought, how we thought things should be solved. On the other hand, we are the one affected by their decisions".
Rissanen 2009a	"It was helpful when I went to psychiatrists and talked there more with my mother, too."
Rissanen 2009b	"If the child implicitly asks for help, you as a parent must respond and try to find out what is going on."
Rissanen 2009b	"There was a school doctor, a school nurse, me as the mother and my daughter together and we talked and tried to find a suitable way to help her. She was afraid of having to go to the hospital or somewhere away from home. But then, we agreed that the school nurse would make appointments with her weekly and she could call her as the need arises."
Spillane 2019	Particularly, participants found it distressing that there was no one to explain what self-harm was or explain to them what was happening with their family member as "doctors would never talk to us, never call us out." Being cut out of the interaction between the hospital staff and their family member left some feeling like they were "to blame" because they were perceived as "bad parents."
Stewart 2018	"Clinicians, please talk to carers. Don't exclude us. We're part of the solution. We may be part of the problem. I think often clinicians' perception, certainly in my experience, can be that you're part of the problem. Well, I maybe but actually, if you help me out I can maybe be part of the solution too."
Wand 2019a	"She had people talk to her, but we don't know what she said or how she came across. I think maybe if we had of been spoken to more maybe we could have given it a better holistic look " Daughter'
Sub-theme 2.2: Seek feedback on care from family/ carers	
Bouwman 2018	"So that's what we do. But what we've recently discussed, the feedback for example on what has come from the analysis to the family, well, we don't yet report that to them. And that's the question, whether it might be useful to report it

Study	Evidence
	back to the family. Sometimes when the family really insist on it, but we don't report that to them as a matter of course (...) And I think that's the next step, that we also involve the family or patient in the evaluation and that we also give them the feedback, what came out of it (the evaluation), also to family and friends." (Director)'
Dempsey 2019	"The trouble is that I do not know how much the therapists know from what he is saying and whether they cotton onto things that I think are happening because I see him every day. I am still waiting though for them to talk to me." (Caregiver)'
Lindgren 2010	"After that they decided to crack me; it was their goal. They said to my daughter, 'Your mother doesn't want you to receive care, she's destroying everything', and so on".
Sub-theme 2.3: The effect of involvement on the quality of care	
Dransart 2017	"On the day following his suicide attempt, I told myself 'I really have to find a psychologist or someone', well, I tried calling some and I was told everywhere 'there is a 6-month waiting list."
Ferrey 2016a	'Sally said that giving her daughter extra cuddles had been "quite therapeutic for her... and... also [reduced] the thoughts [about self-harm] and carrying them out because she knows I'm there for her."
Hom 2020	"My mother was instrumental in getting me the help that I needed early on—the therapy and whatever medications I needed and whatever doctors I needed to see—and she's done her best to help me since then."
Idenfors 2015	"She's the one who called and reserved everything. Because I haven't had the strength to do anything then so this was really nice." (Participant 2)'
Lindgren 2010	'They believed that their daughters still needed their help and support, but they were made to believe that visiting hours were regarded as bad for their daughters and caregivers kept asking them, 'Why do you run here so often?'
Rissanen 2009a	"My parents got worried and helped me to get professional help."
Rissanen 2009a	"Although my mother did not understand how bad I felt, chatting with her was enough to keep me from self-mutilating that night."
Rissanen 2009b	"We drove her to her adult sister because she was the one with whom she could discuss self-mutilation and all the things associated with it. Their conversations were long ones."
Spillane 2019	"For a long time, every time he went out on a Saturday night ... I'd be very worried. If he's not home by a certain time, it doesn't matter if I'm in a coma, I'll wake up and I'll be awake until he gets home ... kind of like a teenager, "oh it's 3:30am, he should be home soon." And then I'll send a text "all OK?" (P9, partner)'
Wand 2019a	"I was very happy that I could stay at my daughter's house ... They are helping me quite a bit." 86F [patient]'
Wester 2018	"He knew that I wasn't asking him to see a counselor to torture him. He knew that I was sincere in my desire to help him find other things to do to deal with stress."
Sub-theme 2.4: Advocacy	
Lindgren 2010	"You really have to think twice before saying anything. How should I express myself so that this person doesn't think that I'm barging in on their territory, only making a suggestion, like maybe it can be done in this way?"
Rissanen 2009b	"She asked me to come along to the doctors' to make sure that everything of importance would be said. She just said that she won't leave the ward. She said that she is in need of hospital care."
Stewart 2018	"I felt that we were in the wrong place then. I couldn't understand why we weren't on a ward for young people. It wasn't entirely made clear to me what was happening. I had to keep asking what was happening and I felt I was being a pest."

Study	Evidence
Sub-theme 2.5: Burnout	
Dempsey 2019	“Where there’s been a pattern of kind of high-risk or challenging behaviours going on for an extended period of time, the family might start to feel quite burnt-out in terms of what they have been able to manage...Invariably, families are doing the very best they can with the resources they have, but then can be feeling very stretched.” (Clinician)’
Dransart 2017	“I tried very hard to find help during this time and after a while, because we can’t find it, well, we just give up.”
Ferrey 2016a	“initially, I was horrified and very distressed and now I just feel very sad really and sometimes impatient.”
Ferrey 2016b	“I’m tired. Emotionally, I’m so tired and I want it to stop and, whilst I would never commit suicide, the thoughts are there at times, you know. I have actually pre-planned what I would do and how I’d do it. So it does have a knock-on effect... And the depression it leaves with you is very hard because you’re almost constantly living a lie.”
Krysinska 2020	“If the parent is stressed, the main caregiver is stressed then how does that impact around other siblings? The child that you’re trying to support, who’s self-harming, are they looking at it like they’re not coping because I’m.. It kind of-yeah, dominoes” (Parent 3).’
Lindgren 2010	“I was her therapist instead of just being her mother. To get rid of the anxiety we would talk for hours; she should have had that help from the care providers instead.”
Oldershaw 2008	“The health professionals have got to deal with the patient haven’t they, but I must say I have felt, I’m feeling, as though I’m trying to deal with this 24 hours a day and I don’t know what to do for the best, so I don’t know if what I’m doing and how I’m dealing with her is helping or if I might be making her worse! For all I know it might be totally the wrong, the wrong way of dealing with it”
Spillane 2019	“There might be some things that I don’t want to do, like the housework, I’m not in the form for it (...) There was often times I could be sitting down having my dinner and the calls would come through ... and then I would have to leave my dinner and talk to them on the phone so my health was going down for a while.” (sister)’
Wand 2019a	“But for me and my sister it is a great weight lifted off us, because to see her and to see that she is cared for, knowing that she participates and she even sings and does all sorts” (daughter)’
Wand 2019b	“It is having a big impact for my family especially.... Every single time I try to bring the positive energy to sort of change him ... but the thing is you can only do so much, talking, talking. After a while he goes back to the same square one. Oh my God! You feel depressed.” [daughter]’
Wester 2018	“I just couldn’t handle them as well as me. You know, I couldn’t take them both on.”

1 Table 16: Theme 3. Compassion and respect

Study	Evidence
Sub-theme 3.1: Respecting family/ carers	
Jennings 2020	“Because I wasn’t able to put a name on what I think it [self-harm] could have been or you know, suggest what it may have been and push a little bit further, I felt quite overpowered by these big psychologists and doctors, that it was kind of a bit, like no, it’s nothing really.” (IDRC10: Residential Carer)’
Kelada 2016	“She [psychologist] was manipulative and vengeful. Threatened and wasted valuable resources from real need.” [P2, mother]’
Krysinska 2020	“there are a lot of myths around, bad parenting equals ADHD [Attention-deficit/hyperactivity disorder] or equals self-harm”, Parent 11’

Study	Evidence
Lindgren 2010	"It was a shock being blamed; I felt that the first time my daughter was in mental health care. Feelings of guilt and shame, but most of all it felt like a failure. In the end I felt I was of no use as a parent."
Rissanen 2009b	"When someone's self-mutilation is discovered at school, the contact with home should be made in the name of helping, not blaming"
Rissanen 2009b	"Reproaching and denouncing the parents of adolescents who selfmutilate for the self-mutilation does not help the adolescents or their parents at all. I have tried to be as direct as possible in discussing my daughter's self-mutilating behaviour, but I have experienced that they (healthcare staff) do not believe me, like I have tried to cheat or whitewash something."
Wester 2018	"But, we got her into therapist. Which, I'll be honest, I didn't like her at all because almost immediately she seemed to tell Katie that everything was my fault, our fault. That we had taken away her sense of person, that we were stifling her creativity."
Sub-theme 3.2 Supporting family/ carers to enable effective management of self-harm	
Bouwman 2018	"It's also a kind of duty for the care organization, to provide aftercare to the family. (...) To give them the opportunity to tell their story again, or to hear how everything happened. So that they can learn to cope with what has happened. Yes, in that sense it's an extra reason for paying attention to the family and relatives." (Inspector)
Ferrey 2015	"[It's helpful] having this outlet where my husband and I can go and meet with the psychiatrist individually. We find it's really helpful, for us, I think we find it easier to support [our daughter]."
Lindgren 2010	"It scares me that they forget the most important people in my daughter's life. They need to see the significant others. We're the ones who are the main caregivers and we have to keep it together around the person who is ill."
Lindgren 2010	"What am I going to do with my kid? I can't watch her fall apart in pieces; I can't handle that."
Rissanen 2009b	"We (parents) were shocked when we found out about her selfmutilation. I personally felt that I was too close to her to provide help. I felt that I had no means to help her, too. We once had a possibility to say something about our feelings when she was an inpatient, but it was not enough."
Spillane 2019	"It's not just about me. Like okay if I had a mental breakdown fine, no problem, but that's grand if I have no dependents. But I do have dependents. Like so I just can't. So I have to look after my own mental health. I've got the high blood pressure. I need to do my best for the kids and yeah this needs to be part of it, like you know." (partner)
Stewart 2018	"I think what I would have liked is more parental support. It's very difficult, when you're in that situation, you don't exactly want to go and talk to other people because you're so focussed on yourself ... There are still very, very hard evenings, very hard nights, when she gets very upset and slightly unsafe ... At those times, it would be really nice to be able to pick up the phone and talk to somebody who knows what you're talking about."
Sub-theme 3.3 Create a rapport with family/ carers	
Jennings 2020	"When we've had a young person from [Local Authority] who has gone to [Local Authority] CAMHS the service has been just unreal. I cannot fault them. They've been superb with us, with the young person, with the whole thing. I cannot fault them. And we worked really well with CAMHS and they listen to us and we listen to them. And I think we've built an extremely good relationship with them to the point that they think [CAMHS Nurse] is the best thing since sliced bread." (carer)
Kennard 2020	"So that bond of knowing culturally you may have had a similar experience, I've noticed it makes them more comfortable and even with the parents, the parents are a little bit more comfortable being more real with you and telling you things they might not tell someone else." (clinician)

Study	Evidence
Lindgren 2010	“Caregivers with their own experience of suffering*maybe they had a tough and shady life behind them, and then they educated themselves*they were the ones who were the best in meeting us as parents”
McLaughlin 2016	“we were lucky to have a good psychiatric team, there was continuity of care, the same consultant that looked after him in the community, (also) looked after him in the hospital.”
Sellin 2018	“My experience is that there is often shame and guilt that contribute to obstacles for involving relatives in acute care. And that nurses sometimes need to work more actively to involve relatives.”

1 Table 17: Theme 4. Resources

Study	Evidence
Sub-theme 4.1 Psychoeducation	
Kennard 2020	“My number one thing would be to ask [the mental health professional] if they are familiar with selfinjury and if they treated other children that have dealt with that issue. And maybe even ask them if they can provide some resources for, ya know, the parents to study to educate themselves on, ya know- to become better qualified to deal with it.” (father)’
Krynska 2020	“if you could just get a little baggy of stuff - they just go, here, look, here’s some information. You’re probably not going to look at it right now because you’re still in that crisis mode, but it’s just sitting there” (Parent 4).’
Lindgren 2010	“I needed help to know how to behave. I am a parent, not a carer. We don’t have the professional education to be a therapist. I just wanted some kind of tools instead of being helpless.”
McLaughlin 2016	“The medical side of affairs will not, and I stress this point, will not discuss anything with us and I think that for people to be asked to look after somebody who is in this state of mind without telling them how they can actually help or when should they step in to help, is totally wrong.”
Nadeem 2016	“How should we address parents, how can we make them aware without scaring them, aside from providing facts and statistics. Everyone thinks it’s not ever going to happen to them. We have to continuously keep them aware. I think that’s what we’re lacking.”
Rissanen 2009b	“At parents’ meetings it (self-mutilation) should be discussed, so that parents could get information about it and where help can be obtained.”
Stewart 2018	“And then the other sort of issue was the decision about what you say to people about what had happened and you’re very fragile, very vulnerable, you’re not thinking straight, you don’t. . . .know what to do. We needed somebody to sit down and talk to myself, my husband, my oldest daughter and say, “Right, this is what you’ve got to do.” Don’t give us any choices, just say, “Right, our experience tells us that this is what you should do, one, two-three.”
Sub-theme 4.2 Outreach strategies	
Nadeem 2016	“When it comes to emotional problems, we can only do so much in the classroom. Having a Healthy Start program in school, they can channel it better than we could.”
Wester 2018	“I talk with all of those parents about counseling as an option to help the student learn other ways to manage stress or emotions that are safer than self-harm.”
Sub-theme 4.3 Facilitate help-seeking	
Oldershaw 2008	“The teacher at the school actually was really quite good. She actually gave me a lot of the background for self-harm, why girls self-harm . . . she seemed to be quite clued up and in fact it was her that, she was the one that explained to me, a lot of it to me, because I had no idea what it [self-harm] was, what it

Study	Evidence
	meant . . . I didn't feel as though I was floundering as much as I think I would have if I hadn't had her advice."
Raphael 2006	". . . had it been brought up in conversation, yes I would probably have made a few references to the fact . . . I probably would have in the end but I certainly wouldn't go out and announce 'it to the world."
Rissanen 2009b	"At parents' meetings it (self-mutilation) should be discussed, so that parents could get information about it and where help can be obtained."

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2 Table 18: Theme 5. Autonomy and privacy

Study	Evidence
Sub-theme 5.1 Maintaining the privacy of the person who's self-harmed	
Bouwman 2018	'The privacy of the patient and professionals might hamper family involvement. Because of this, organizations do not always share information about the sentinel event with the family. Sometimes the patient explicitly stated that they did not give permission for information to be shared with family. In other cases, it was assumed that a patient has not given permission to share information with family.'
Chew-Graham 2002	"When I left home and went to the police, they actually told them where I'd gone. They're all the same, like, we're Asian and women and we don't matter. How can you trust anyone when you've gone through that? It's like all I wanted was someone to listen or talk to . . ."
Dempsey 2019	'Setting prior clear boundaries with a young person about what would, and would not, be discussed between clinicians and caregivers was seen as a way to facilitate a shared understanding without compromising confidentiality.'
Ferrey 2015	"I felt I was included as much as I needed to be and I thought it was good . . . for my daughter to have an opportunity to talk to someone where she felt she could say what she liked and it wouldn't come back to me".
Lindgren 2010	"Am I not her parent anymore? What is my part in all this? What insights do I have?"
Stewart 2018	"I find it very frustrating that I can't discuss a lot of things with CAMHS. I understand why, she needs to know that it's confidential, that the things she discusses with them are not going to be discussed with me. And that's fair enough. But it's very frustrating . . . So I wish that I could have been involved more, but I can see why it is the way that it is."
Wester 2018	"I never asked my son what he and the counselor talked about. I let the counseling just be his. He saw the counselor four or five times, then let me know that he and the counselor had agreed that he had done what he needed to and didn't need to go anymore . . ."
Sub-theme 5.2 Maintaining the autonomy of the person who's self-harmed	
Dransart 2017	"The doctor told me 'your husband is a grown-up man', and then that it wasn't my role to intervene, and then, that they don't have to take into account what the family has to say."
Grandclerc 2019	"I think that it's not [my parents'] role in fact, to . . . try to prevent me from cutting myself. I think it's the therapist's role . . . So I think that they know it, well yes, they know it, but I mean that they shouldn't get involved after, I think . . . I think that's not their business in fact. . ."
Hom 2020	". . . it would have been nice to be treated like I actually knew what I was talking about. A lot of times I was just brushed off and they would talk to my mom instead of me . . ."
McLaughlin 2016	"Staff need to make an effort to approach people, even if it seems like a betrayal of a person's feelings. In my case keeping the secret did not help and

Study	Evidence
	only created problems for me. Mental Health Services need to contact family and children and involve them and inform them.”
Nadeem 2016	“You always call the parent. Even if the child says, I’m not, I’m not, I’m not.”
Raphael 2006	“Actually we phoned the hospital first and the staff nurse said that he had just come in and I was a little bit taken aback . . . she said I will go and ask his permission for you to come in and I was thinking but this is his parents you can’t do that and we still did not know what was wrong this was the thing we had no idea what had happened . . . Then she came back and said yes, it is alright . . . but I was angry how dare she say ask his permission, and I think it would have been worse if he [son] had said no”
Sellin 2018	“My experience is that there is often shame and guilt that contribute to obstacles for involving relatives in acute care. And that nurses sometimes need to work more actively to involve relatives.”

1 Table 19: Theme 6. Safety and risk

Study	Evidence
Sub-theme 6.1 Protecting staff	
Bouwman 2018	“So the inspectorate only wants to know if the patient is the victim. Whereas in ninety-nine out of a hundred cases, the staff member is the victim.” (Medical director)
Sub-theme 6.2 Protecting the person who’s self-harmed	
Idenfors 2015	“If you seek help for some psychiatric reason, it may affect you if you look for a job or something else, I don’t know.”
Lindgren 2010	“One of these caregivers was rather rough towards Tina, but I didn’t take it so hard because she was rather cocky herself.”
Oldershaw 2008	“[We] decided that our best course of action was not to make a big dramatic fuss and just let it unfold and just see if this evaporated. Erm, we realised that there was a sort of element of risk in that, but we weren’t sure whether this was something that was deeply rooted, and erm ingrained as it were, or if this was something that was pretty temporary and would pass.” (Mr J)’
Oldershaw 2008	“We kind of brushed that under the carpet . . . We try to ignore it really, to try and get on with life and hopefully she will stop doing it.” (Mrs P)’
Rissanen 2009a	“Sometimes it is better not to tell parents because it can cause more difficulties for the self-mutilating adolescent.”
Rissanen 2009a	“My mother dressed me down.”
Wester 2018	“I didn’t inform my ex-husband either. I think because I knew he would over-react, which wouldn’t be helpful. He lived in a different town and I didn’t think yelling at my son over the phone would help my son to deal with it in a healthy way.”

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