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SYSTEMATIC REVIEW

A Systematic Review of Qualitative Research of the Experiences of Young People and their Caregivers Affected by Suicidality and Self-harm: Implications for Family-Based Treatment

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Abstract

Despite the greatest onset and increased frequency of suicidal or self-harm behavior occurring in adolescence, most youth affected do not receive professional care. Family-based intervention offers a promising treatment for this population, however, there is much to learn about the barriers and facilitators to effective care and the tailoring of treatment necessary to meet youth and family needs. Such insights can be sourced from a growing qualitative literature reporting the views of young people and their caregivers affected by suicidality and self-harm. This systematic review analyzes qualitative research to synthesize the perspectives of these youth and their caregivers about their needs for and experiences of professional help. Following a search of 4 databases, 35 studies were analyzed using Consensual Qualitative Research methods. Barriers to effective care were identified at individual, family, and systems levels. Young people and their caregivers experienced fractured relationships and overwhelming emotions that impeded engagement, increased young people's distress and suicidality, and reduced parenting efficacy. Systemic barriers to care included insufficient, fragmented, and inaccessible services, and stigmatizing or dismissive responses from healthcare providers. In contrast, effective professional care was timely, non-judgmental, collaborative, and included separate and joint sessions for youth and caregivers to address their individual needs and foster relationship repair. This review's findings support the value of family-based treatment that pro-actively addresses stigma and highlight the need for increased services that are structured to facilitate therapeutic engagement from crisis through recovery.

Keywords Youth · Family · Suicide · Self-harm · Family therapy · Mental health · Psychotherapy · Qualitative · Lived experience

Introduction

Despite decades of prevention programs, rates of youth suicide and self-harm remain alarmingly high (Curtin, 2020), and most young people affected by suicidal behavior do not receive professional care (Rowe et al., 2014). Clinical trials show family-based treatment to be a promising intervention for youth suicidal behavior (Glenn et al., 2019; Iyengar et al., 2018) however, to increase treatment engagement and improve the tailoring of professional care, it is crucial to develop a greater understanding of the experiences and views of youth and their caregivers affected by suicidal or self-harm behavior. The present study addresses this research gap by systematically reviewing the qualitative literature to synthesize the perspectives of this population on professional care needed or experienced.

Youth self-harm and suicide rates are at concerning levels despite prevention efforts (Curtin, 2020). Suicide is the

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second leading cause of death for youth in the USA (Center for Disease Control, 2020; Ivey-Stephenson et al., 2020) and internationally (World Health Organization, 2019). As the greatest onset and increased frequency of self-harm and suicidal behavior occur in adolescence, prevention and treatment at this developmental stage are crucial (Valencia-Agudo et al., 2018). Across different samples and contexts, between 10.5% (Kokkevi et al., 2012) and 17% (Liu et al., 2018) of adolescents report having attempted suicide, and self-reported youth self-harm ranges from 17% (Swannell et al., 2014) to 31.3% (Aggarwal et al., 2017), thus representing a significant proportion of young people. Among high school youth surveyed in the USA, 7.4% said they had attempted suicide at least once during the previous 12 months, and up to 26.1% had made a suicide plan (Kann et al., 2018). Health intervention for young people affected by self-harm or suicidal behavior is imperative to relieve associated health, social, and educational burdens (Glenn et al., 2019), and because these youth are at the most significant risk of subsequent suicide death (Liu et al., 2018; Olfson et al., 2018).

However, most youth affected by suicidal behavior do not receive mental health treatment (Michelmore & Hindley, 2012; Rowe et al., 2014). Youth self-report studies found only 30% to 45% of those who had attempted suicide subsequently accessed professional support (Slovak & Singer, 2012; Wu et al., 2010). Youth with mental health problems generally have low help-seeking rates (Velasco et al., 2020), and young people with more severe suicidal symptoms are less likely to seek help than those with milder mental health concerns (Armiento et al., 2014; Berger et al., 2013). Among suicidal or self-harming youth who do access treatment, up to half drop out prematurely (Brent et al., 2013; Glenn et al., 2015). Therefore, increasing engagement and treatment retention are essential priorities for the prevention of youth suicide and self-harm (Ougrin et al., 2015).

Family-based treatment is a promising intervention for youth affected by suicidal behavior. Although clinical trials of treatments for suicidal adolescents are mostly small-scale and with a single site (Glenn et al., 2019; Zalsman et al., 2016), systematic reviews of such trials identify several characteristics common to promising treatments. These characteristics include mandated family or caregiver involvement in treatment (Calear et al., 2016; Iyengar et al., 2018), a focus on enhancing the coping skills of youth and caregivers (Glenn et al., 2019), strengthening youth-caregiver relationships (Brent et al., 2013; Glenn et al., 2015), the delivery of treatment over several weeks or more (Glenn et al., 2019), and having higher intensity treatment at the start of care (Brent et al., 2013). Of promising treatments, only adapted Dialectical Behavior Therapy-Adolescent (DBT-A), incorporating strong family systems elements and the aforementioned characteristics, has been independently replicated (Glenn et al., 2019; Iyengar et al., 2018). Notably, some interventions were only effective for reducing suicidal or self-harm behavior when family or parent components were added (Calear et al., 2016; Glenn et al., 2015), and family-based treatment appears to be associated with higher levels of treatment engagement (Curtis et al., 2018; Iyengar et al., 2018).

Extensive research into the role of family relationships and attachment with caregivers in youth suicidality provides theoretical support for family-based treatment (Ewing et al., 2015). Supportive connections with caregivers and family contribute to resilience, and improvements in this attachment relationship have been associated with sustained reductions in suicidal behavior (Czyz et al., 2012). Family dynamics that are predictive of suicidal events include family conflict (Wagner & Wagner, 2012), low cohesion and family stress (Ewing et al., 2015), poor parent–child connection (Cruz et al., 2014), and family-related loneliness (Giletta et al., 2012). Given the empirical and theoretical support for family-based treatment, it is important to examine the professional care needed and experienced through a family systems lens, considering both youth and caregiver perspectives.

There is a growing qualitative literature reporting the views of young people and their caregivers affected by suicidal behavior, including rich data about their emotional experience, the caregiver-youth relationship, access to effective care, and their perspectives on professional help. This literature presents an opportunity to address the gaps in knowledge about treatment approaches that engage young people and their families affected by suicidal behavior or self-harm (Ougrin et al., 2015). Previous systematic reviews of the qualitative literature concerning young people affected by suicidal or self-harm behavior have highlighted the significance of family influences for suicidality and recovery (Grimmond et al., 2019; Lachal et al., 2015), that some youth describe their self-harm relationally, as attempting to communicate or connect (Stänicke et al. 2018), the need for more research on youth experiences of professional care (Lindgren et al., 2018), the impact of shame as a barrier to accessing help (Curtis et al., 2018; Grimmond et al., 2019), and potential benefits of intervention to improve caregiver-youth communication and support (Curtis et al., 2018). However, there is a gap in the research with a lack of studies focusing specifically on family-based treatment experienced or wanted or examining the qualitative literature from a family intervention lens.

Current Study

It is crucial to listen to the voices of young people and their caregivers affected by suicidal or self-harm behavior to better understand their needs and drive appropriate professional

care however, systematic reviews to date have not examined the available qualitative literature from a family intervention perspective, despite the promising support for family-based treatment. The present study addresses this gap by systematically reviewing and synthesizing qualitative research reporting the views of young people and their caregivers affected by suicidal or self-harm behavior from a family systems lens to inform how to increase engagement and improve the tailoring of treatment to meet their individual and family needs. To this end, the study considers how young people and their caregivers describe their experience of suicidality and self-harm, the challenges they faced individually and within the context of family relationships, their views on professional help needed, barriers and facilitators to accessing effective help, and helpful or unhelpful aspects of intervention experienced.

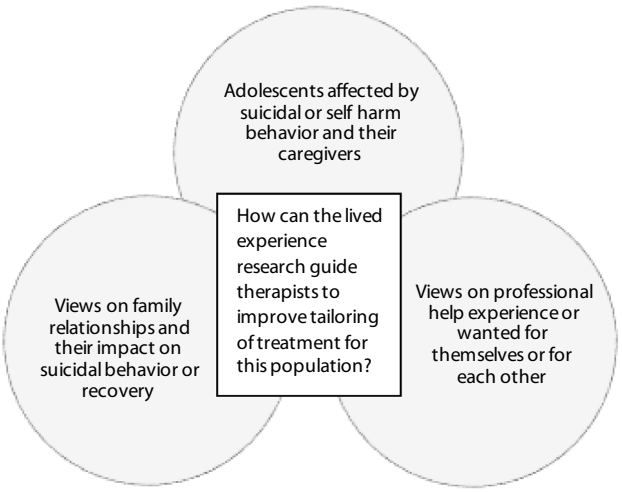

Fig. 1 Selection criteria for the systematic review

Method

The procedure for searching, selecting, appraising the quality, and synthesizing the findings was based on the ENTREQ statement's steps (Tong et al., 2012) and the Consensual Qualitative Research (CQR) approach (Hill, 2012). CQR involves multiple researchers in all research stages and analysis, with the data being discussed together until a consensus is reached about the findings. Transparency between the raw data and the conclusions drawn is facilitated by extracting direct quotes and describing each theme's prominence in the presentation of the data.

Selection Criteria

Following a preliminary literature review, the selection criteria were refined through an iterative process. An initial literature search for qualitative research with a primary focus on family-based treatment experiences for adolescents (12–18 years) affected by suicidal or self-harm behavior found no studies. Selection criteria were subsequently broadened as follows:

1. age extended to include youth (12–25 years) or their parents/caregivers;
2. studies with comments on needs or help wanted (in addition to professional help experienced); and,
3. studies with participants' views on the impact of family relationships on a young person's suicidality or recovery.

The intersection of these selection criteria is shown in Fig. 1. Implications for policy and family-based treatment for this group are identified from the data drawn from these broadened criteria.

Search and Selection Strategy

An exhaustive search strategy was pursued to yield a large sample of studies for review. Published research from Jan 1, 1994, to Apr 20, 2020, was searched across Medline, PsycINFO, CINAHL, and Embase. Primary search terms were combined using Boolean operators AND OR. Terms included adolescent (youth; child; young person) AND suicide (suicide attempt; self-harm; suicidal ideation; suicidal behavior) AND treatment (counseling; family therapy; family treatment; psychotherapy; risk assessment; intervention) AND qualitative experience (lived experience; perspectives; views). A complete set of search terms is contained in Supplementary Table S2.

The selection process is shown in Fig. 2. A total of 4,320 items was retrieved from the initial database search. Following removal of duplicates and screening by title, 320 articles remained. A further 18 articles were added from hand searching other reviews and the reference lists of articles, resulting in 338 articles for abstract review. Ninety-six articles were included for full-text review, and of these, 35 met the selection criteria. One author (DS) conducted the screening of articles by title and abstract. Two authors (DS and IGS) independently screened articles by full text, resolving any disagreements regarding selection through discussion. Articles were excluded based on participant characteristics (e.g., age, community, or professionals' surveys), methodology (e.g., not qualitative), the nature of publication (e.g., not written in English) and focus (e.g., lacking any comment about family relationships or help wanted or experienced).

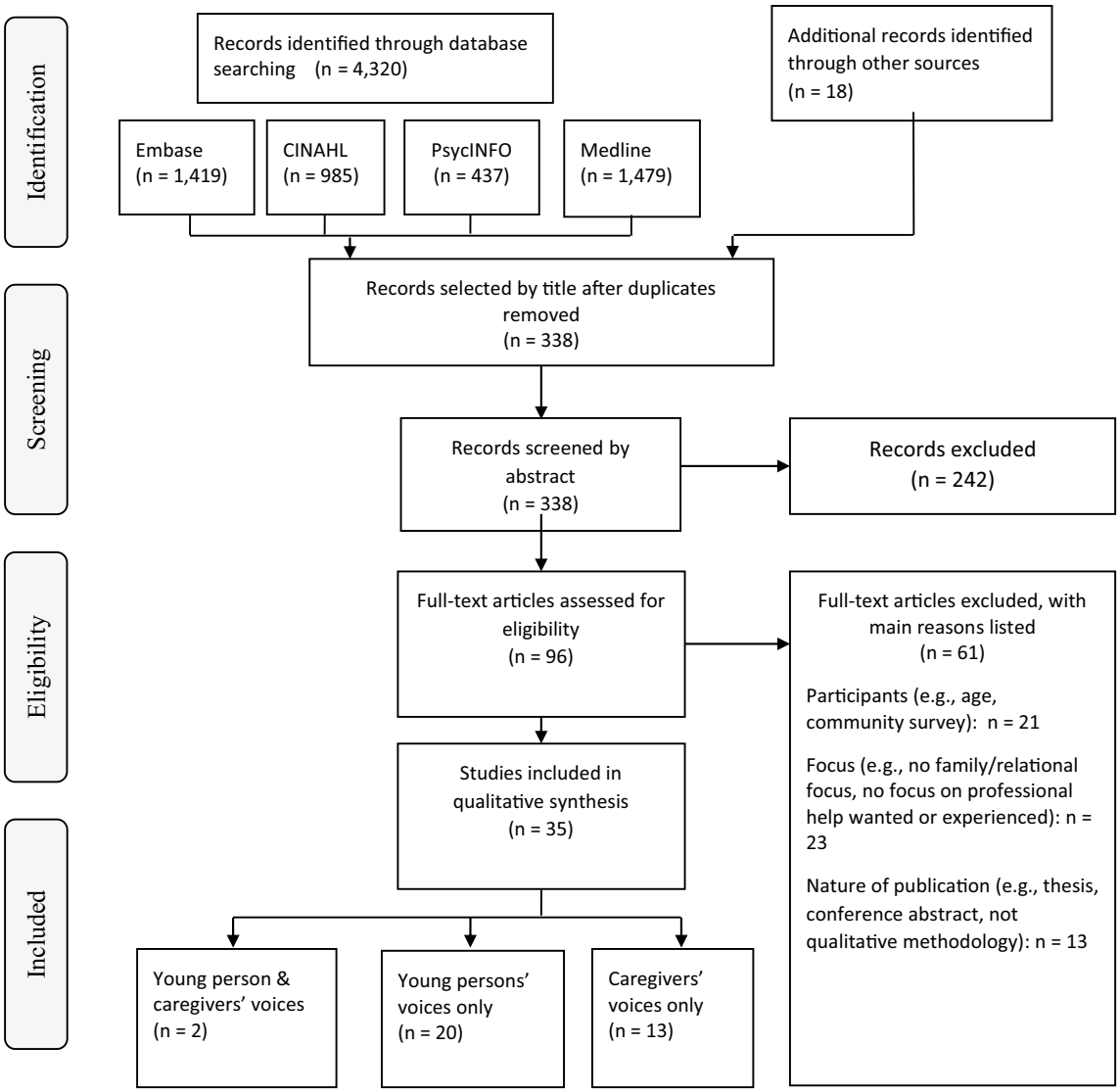

Fig. 2 PRISMA Flowchart

Quality Appraisal

The quality of studies was evaluated by two authors (DS and KM) using the Critical Appraisal Skills Program (CASP, 2019). The Cochrane collaboration recommends the CASP measure (Noyes et al., 2021), and it is used widely in systematic qualitative reviews (Lachal et al., 2017). No study was excluded based on its CASP ratings.

Data Analysis and Synthesis

CQR informed the analysis of qualitative studies. Two authors (DS and IGS) independently analyzed the 35 included articles, reading each in full, summarizing key themes, and recording extensive direct quotes from participants in relation to each theme. These authors then compared their initial data analysis and jointly developed a single list of themes and sub-themes with exemplar quotes. The list of themes was further refined in consultation with other authors (IS and KM), and the final themes and sub-themes are shown in Tables 2, 3, 4. The prominence of each theme is indicated using the terms recommended by the CQR method, with "General" indicating that a theme was unanimously or near-unanimously referenced; "Typical" indicating that the theme was present in the majority; and "Variant" indicating a theme with some, but less than majority agreement (Hill et al., 2005). All authors jointly conducted a higher-level analysis of the data, categorized themes into overarching domains, and discussed key findings and their implications.

Results

No articles with a primary focus on the lived experience of family-based treatment were retrieved during the literature search. Thirty-five articles met the expanded selection criteria and are shown in Table 1, incorporating the views of 342 young people and 183 caregivers across 11 countries. Studies varied in sample size (from 3 to 68 with a median of 12) and location (with 44% of studies conducted in Europe, 36% in North America, 6% in both Asia and Australia, and 3% each from Africa and Central America). The gender of participants, where specified, was overwhelmingly female (85% of youth and 86% of caregivers), as shown in Table 5 in Appendix. While many studies did not identify the participants' racial, cultural or linguistic background, when stated, most participants were of Caucasian background, 11% of studies had Hispanic or Latina participants, 9% had participants of Asian backgrounds, and 3% (1) had Native American participants. Most studies (80%) used one-on-one interviews, while 9% used focus groups, and a further 9% used both surveys and interviews.

Overall, the studies were of good quality. All had clear aim statements, clear findings, were appropriate for qualitative methodology, and constituted valuable research. Almost all studies had research designs appropriate to their aims (97%), appropriate recruitment (89%), and appropriate data collection strategies (94%). However, only a minority of studies (29%) demonstrated consideration of the relationship between the researcher and the participants (i.e., reflexivity). The CASP ratings for each study are shown in Supplementary Table S3.

Participants' descriptions were categorized into two major domains. The first, "Fractured Relationships", focused on the quality of family relationships and the lived experience of suicidality or self-harm within the family systems context. Themes within this domain included reports from young people and their caregivers of overwhelming emotions and a sense of disconnection or conflict and how this contributed to the young person's suicidality and reduced parenting efficacy. The second domain, "Professional help wanted or experienced", focused on healthcare experiences and aspects of treatment identified as critical to engagement and recovery, or conversely, unhelpful to engagement and recovery. This domain included participants' descriptions of professional help they had wanted or experienced, barriers to accessing support, helpful and unhelpful aspects of professional care, and family-based treatment experiences. Changes in family relationships perceived as helpful and the role of professional help in facilitating such change, if applicable, were also described. The themes in each domain and their inter-relationships are represented in Figs. 3 and 4. The themes, along with example quotes, are shown in Tables 2, 3 and 4.

Fractured Relationships

A general theme for youth was the experience of overwhelming emotions such as hopelessness and shame, accompanied by an acute sense of isolation and disconnection. Young people typically spoke of concealing their distress and suicidal or self-harm behavior, which further intensified their isolation. Together with a fear of adverse reactions or judgment, shame and hopelessness often impeded young people from sharing their thoughts of suicide or self-harm and asking others for help.

When discussing family relationships before treatment, young people generally felt unable or unwilling to communicate their distress or ask caregivers for support. Reasons for doing so included shame, concern about their parents' reactions, a lack of hope that parents could or would help, and a prevailing sense of disconnection in the relationship, e.g., "Our relationship is a boat and it's got holes in it and we're both trying to haul out the water," (Tingey et al., 2014, p. 1522). In addition, many young people also described a longing for support and for their distress to be acknowledged by their caregivers. They typically reported making indirect cries for help that were not heard and left them feeling misunderstood or not cared about. Some also described their suicidal behavior as attempting to resolve a relationship impasse, or seeking affirmation that others cared about them, e.g., "I wanted to try killing myself. I wanted to know if anyone would be sorry if I died or if anyone wanted me" (Sukhawaha et al., 2016, p. 337).

A variant to typical theme referenced in youth studies was young people's experience of caregivers' adverse responses when their suicidality or self-harm was eventually disclosed. These negative responses included being dismissed and ignored, e.g., "any time I displayed any signs of it in my home it was wrote off or I was told I was being foolish" (Bostik & Everall, 2006, p. 281), or experiencing angry, punitive, or abusive reactions. Family relationship problems were described as typically directly triggering or worsening the young person's suicidality. Family conflict, rejection, criticism, abuse, or feeling unloved were among the reasons listed for self-harm or suicide attempts.

Overwhelming and wide-ranging emotions in response to discovering their child's suicidality or self-harm were general themes in caregiver studies. The most cited emotions parents and caregivers reported were shame, guilt, and powerlessness, and they also described feeling shock, denial, confusion, anger, grief, and fear. These feelings, and the idea that self-harm could only happen in a sick family, made it harder for caregivers to access support from either professional or informal sources. Adverse reactions from others

Table 1 Summary of the 35 articles included in the systematic review of qualitative research

Author(s) and Year	Country	Participants	Methods[a,b]
Dual focus: Young peoples' and caregivers' perspectives			
Humensky et al. (2017)	USA	31 Latinas (11–19 years) who had been suicidal and 8 of their mothers were asked about their needs and their experience of a community youth mental health treatment program	FG; GT
Sukhawaha et al. (2016)	Thailand	12 young people (9 female, 3 male) aged 15–18 years who had attempted suicide and six parents or close family members described their experience and views on reasons for suicidal behavior	SSI; CCI
Young people's perspectives			
Beekrum et al. (2011)	South Africa	10 female adolescents (14–17 years) of Indian origin who had been hospitalized following a suicide attempt were interviewed about influences on their suicidality	SSI
Bostik and Everall (2006)	Canada	50 formerly suicidal youth (41 female, 9 male) aged 13 to 26 were interviewed about their suicidality and attachment relationships	SSI; GT
Bostik and Everall (2007)	Canada	50 formerly suicidal youth (41 female, 9 male) aged 13 to 26 were interviewed about their attachment relationships and recovery	SSI; GT
Everall et al. (2006)	Canada	50 formerly suicidal youth (41 female, 9 male) aged 13 to 26 were interviewed about their emotional experience of suicidality and self-harm	SSI; GT
Gulbas et al. (2019)	USA	17 Latinas (14–18 years) were interviewed 6 and 12 months after attempting suicide about their experience, ongoing risk, resilience, and trajectory	SSI; TA
Herrera et al. (2006)	Nicaragua	8 female youth, aged 12–19 years, who had been hospitalized after a suicide attempt were asked about their suicidal feelings and their suicide attempt	SSI; GT
Holliday and Vandermause (2015)	USA	6 youth (5 female) aged 15–19 years who had previously attended the emergency department for a suicide attempt were asked about their experiences	UI; IPA
Hausmann-Stabile et al. 2018)	USA	68 female Latina adolescents aged 11–19 years were asked about their experience of treatment following a suicide attempt	SSI; TA, CA
Keyvanara and Haghshenas (2011)	Iran	25 young people aged 14–17 years (16 female, 9 male) were interviewed after having attempted suicide through self-burning or poisoning	UI; TA
McAndrew and Warne (2014)	UK	7 female youth (13–17 years) with a history of self-harm or suicidal behavior were interviewed about their self-harm and experience	SSI; IPA
Mitten et al. (2016)	Canada	12 young people (10 female, 1 male; 1 other) aged 15–19 years who had self-harmed more than once were asked about their experience of treatment received and perceived attitudes of staff	SSI; CCA
Murray and Wright (2006)	Canada	3 young people (1 female, 2 males) aged 14–18 years with suicidal thoughts and behaviors were asked about their experience of assessment and intervention	SSI; TA
Orri et al. (2014)	Italy	16 youth (8 female) aged 17–25 years who had suicidal thoughts and behavior as adolescents were asked about their experience	SSI; IPA
Owens et al. (2016)	UK	The online forum contributions of 31 young people (30 female) aged 16–25 years were examined regarding their descriptions of care experienced in the emergency department following self-harm	Online forum; TA
Rissanen et al. (2009a)	Finland	10 young women aged 15–22 years, drawn from a survey of 62 young women who had self-harmed, were asked about what helped or did not help them	SSI (10) Survey (62); ICA
Storey et al. (2005)	UK	38 young people aged 16–22 years with a history of self-harm were asked about their experiences of support in the emergency department following self-inflicted injury	SSI; NS

Table 1 (continued)

Author(s) and Year	Country	Participants	Methods[a,b]
Tingey et al. (2014)	USA	22 Native American youth aged 13–19 years were asked about the individual, family, and community circumstances before, during, and after their suicide attempt	SS1; CA
Wadman et al. (2018)	UK	24 young people (20 female, 4 male) aged 14–21 years who had lived in out of home care were asked about their experiences of self-harm and of support received	SSI; IPA
Wadman et al. (2018)	UK	14 female youth aged 13–18 years were asked about their experiences and perceptions of self-harm and support received	SSI; IPA
Zayas et al. (2010)	USA	27 Latinas (11–19 years) who had attempted suicide within the last six months were asked about the experience of the suicide attempt, perceived stressors, relationship with family and peers, and their needs	SQ, SSI; TA
Parent/caregiver's perspective			
Buus et al. (2014)	Denmark	14 parents (9 mothers, 5 fathers) whose young person had attempted suicide were interviewed about their emotional response and the relational impact on them and their family, and their needs	FG; TA
Byrne et al. (2008)	Ireland	25 parents and caregivers of youth who had self-harmed were asked about their support needs	FG; TA
Daly (2005)	Canada	6 mothers of adolescents affected by suicidal behavior and who had contact with community mental health care were interviewed about their treatment experience	UI; P
Dempsey et al. (2019)	Australia	8 parents (7 mothers, 1 father) of young people with ongoing suicidal ideation or behaviors were asked about their challenges, experiences, needs, and experiences of support (the study also included clinicians)	SSI; TA
Ferrey et al. (2016a)	UK	37 parents (32 mother, 5 fathers) were asked about how caring for a young person who self-harmed affected their parenting strategies	SSI; TA
Ferrey et al. (2016b)	UK	37 parents (32 mothers, 5 fathers) were asked about their experience caring for a young person who self-harmed	SSI; TA
Hughes et al. (2017)	UK	41 caregivers (34 mothers, 5 father, 2 others) were asked about the narrative of their young person's self-harm and the impact on their lives	NI; TA
Kelada et al. (2016)	Australia and USA	16 Australian parents (15 mothers, 1 father) of adolescents and 22 American parents (18 mothers, 4 fathers) of young adults were asked about their experience of their offspring's self-harm, effects on family relationships, and professional care	SQ (Aust); SSI (USA); TA (both)
McDonald et al. (2007)	Republic of Ireland	6 mothers of adolescents who had self-harmed were interviewed about the impact on self and family relationships	UI; P
Oldershaw et al. (2008)	UK	12 caregivers (9 mothers, 2 fathers, 1 grandmother) of adolescents referred to treatment for self-harm were asked about their experience and perception of self-harm and their hopes for the future	SSI; IPA
Raphael et al. (2006)	UK	6 parents (3 mothers, 3 fathers) of adolescents and young adults were interviewed about the meaning and experience for them of their son/daughter's self-harm and their needs	UI; P
Rissanen et al. (2009b)	Finland	4 parents (3 female) of adolescents who self-harmed were asked about their views on help needed	UI; ICA
Stewart et al. (2018)	UK	37 parents (32 mothers, 5 fathers) were interviewed about their experience of caring for a young person who self-harmed	SSI; modified GT

[a]Data collection abbreviations—FG: focus group, UI: unstructured interview, LH: life history, SSI: semi-structured interview, NI: narrative interview, SQ: survey/questionnaire

[b]Data analysis abbreviations—CA: content analysis, CCA: conventional content analysis, ICA: inductive content analysis, TA: thematic analysis, CQM: consensual qualitative method, GT: grounded theory, IPA: interpretative phenomenological analysis, IQI: interpretative qualitative inquiry, P: phenomenological, NS: not specified

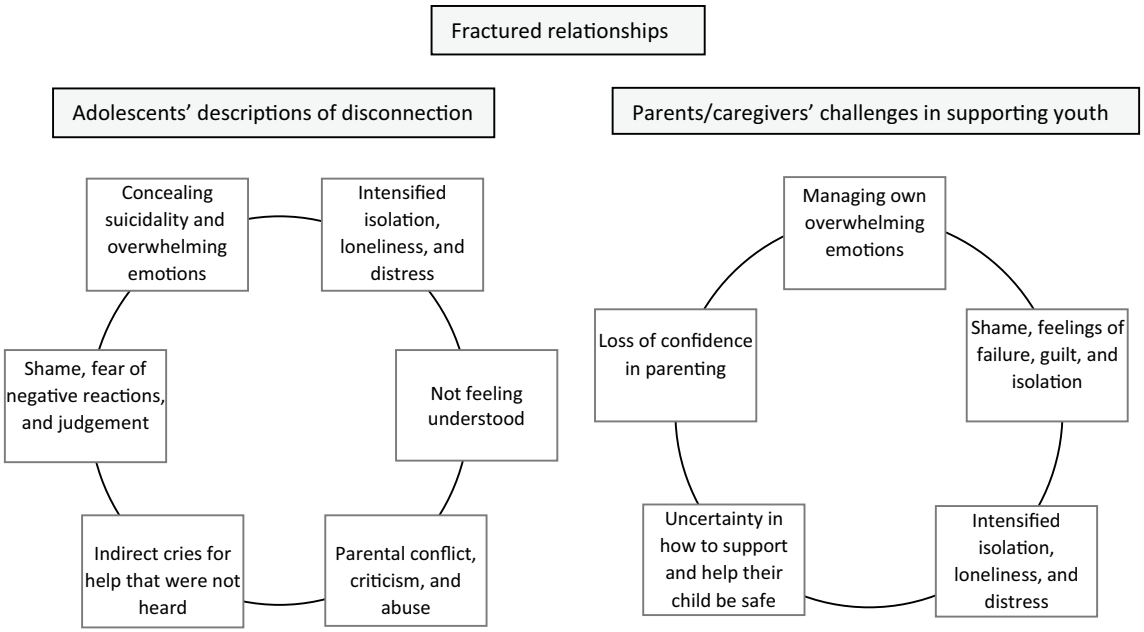

Fig. 3 Domain one: Fractured relationships

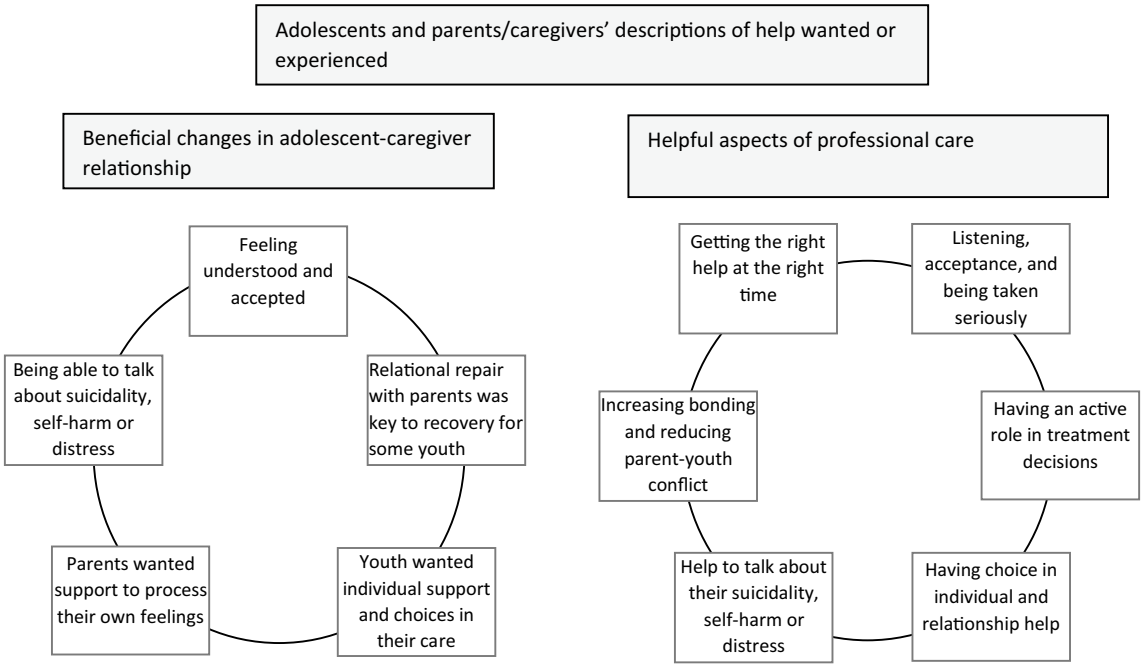

Fig. 4 Domain two: Professional help wanted or experienced

intensified their sense of isolation, e.g., one parent reported, "It can be very lonely… you can tell everybody, but people will then cross the road to avoid talking to you" (Ferrey et al., 2016b, p. 4). Panic, fear, and pervasive worry about the risk of future suicidal behavior were typical experiences for caregivers, impacting them personally and affecting family relationships. The young person's suicidal behavior was typically experienced as a relationship rupture. Many caregivers expressed grief and sadness about changes in the relationship, while variant themes described by caregivers included a sense of rejection, betrayal, anger, or rage towards their child.

Table 2 Youth descriptions of fractured relationships: themes and illustrative quotes

Theme	Exemplar	Prominence[a]
Young people's descriptions of disconnection and isolation		
Managing overwhelming emotions in isolation	"And you look around and go, 'No one else feels this way'… You don't' see anyone else around you feeling that depressed, so you think you're a bit of an outcast. And those same thoughts make you feel even more alone." (Holliday & Vandermause, 2015, p. 171)	General
Concealing self-harm and suicidal behavior	"I used to feel very bad after it (cutting) and get all the antiseptic lotions out and cleanse everything and do it in my room and hide everything so nobody would see it." (Storey et al., 2005, p. 72)	Typical
Reasons for concealing distress, suicidality and self-harm:		
Shame	"the shame hinders you in seeking help. It is an overwhelming feeling." (Rissanen et al. 2009a, p. 13) "I didn't want people to know I was suicidal. I was just really ashamed and worried that people would find out and look down on me." (Everall et al., 2006, p. 379)	General
Fear of negative reactions	"(I) keep things to myself and think it's better off that way 'cos that way no one else can get upset about it." (Wadman, Vostanis, et al., 2018, p. 124)	General
Hopelessness	"I felt I have lost my dreams…It seemed I had lost my future and my life. I felt everything in my life is finished." (Keyvanara & Haghshenas, 2011, p. 531)	General
Feeling worthless	"You're just to the point where… you feel totally worthless… It feels like you're being spit on by a thousand people." (Holliday & Vandermause, 2015, p. 171)	General
Stigma	"I wanted to go back to school (after hospital) … but I started hearing stories around, saying that I was a crazy person." (Tingey et al., 2014, p. 1523)	Typical
Feeling no one cares	"I was so sad. I thought nobody loved me, so it was better to just die". (Sukhawaha et al., 2016, p. 336)	Typical
Absence of secure attachment	"I've never had somebody in my life who I know I can actually rely on … I've never felt I can actually trust somebody to reach out, so I don't." (Wadman, Armstrong, et al., 2018, p. 371)	Typical
Worry about the effect on others	"I didn't want my mum to find out because she had a lot of stress going on as well." (Wadman, Vostanis, et al., 2018, p. 124)	Variant
Young people's descriptions of fractured relationships/communication		
Lack of communication or connection	"Our relationship is a boat, and it's got holes in it, and we're both trying to haul out the water. The only time we talk is when I'm going to tell her where I am going and who I am going with, and that's it." (Tingey et al., 2014, p. 1522)	General
Seeking connection or validation through suicidal behavior	"I wanted to try killing myself. I wanted to know if anyone would be sorry if I died or if anyone wanted me." (Sukhawaha et al., 2016, p. 337) "I hoped it would get my mom and I to bond. And I hope that my boyfriend hears about it and comes back to me." (Beekrum et al., 2011, p. 66)	Typical
Indirect communication: "cries for help"	"it was not just for attention…I wanted someone to know my feelings, how I felt, and why I did it." (Beekrum et al., 2011, p. 66) "the open diary (with an account of self-harm) was left open for me to read." (parent) (Rissanen et al., 2009b, p. 1714)	Typical
Rejection /abandonment	"And if nobody cared, why bother trying to live? In my mind I was alone. There was nobody" (Bostik & Everall, 2006, p. 277)	Typical

Table 2 (continued)

Theme	Exemplar	Prominence[a]
Uncaring responses from caregivers	"When I did it (attempted suicide), my mom wasn't even there; like my family doesn't really care about me" (Tingey et al., 2014, p. 1522)	Typical
Not feeling heard	"you feel betrayed cause no one is helping you. No one's seeing the little signs." (Holliday & Vandermause, 2015, p. 170)	Typical
Not feeling valued in the family	"I felt sad and like nobody needed me around" (Tingey et al., 2014, p. 1522)	Typical
Criticism or abuse	"My mother when she gets angry tells me, 'I don't want to see you, I hate you, I hate you, I don't love you, get lost" (Zayas et al., 2010, p. 177)	Typical
Angry responses from caregivers	"they were really full of hatred…and every time I did it (attempted suicide) … they were increasingly irritated." (Orri et al., 2014, p. 6)	Variant
Feeling a burden to their family	"Last night, when I realized my father had no money to buy food … I thought by taking my own life my family's difficulties would be eased" (Keyvanara & Haghshenas, 2011, p. 533)	Variant
Not feeling supported within family	"(I) argue with my younger brother, my parents take his side…I intend to kill myself because this situation is really intolerable." (Keyvanara & Haghshenas, 2011, p. 532)	Variant

[a]Prominence ratings within CQR – General (present in all or nearly all of youth or caregiver studies); Typical (present in majority); Variant (present in two or more but less than 50%)

Reduced parenting efficacy was a general theme. The discovery of their child's suicidality or self-harm shattered caregivers' confidence in parenting, and they felt unsure about how to help their son or daughter. A loss of trust and ease in the relationship was fueled by pervasive worry about future suicidal behavior. Parents typically felt they were "walking on eggshells" and being hypervigilant to maintain safety and supervision (Oldershaw et al., 2008, p. 142). Caregivers also discussed problems navigating normal adolescent-parent conflict and setting limits. Fear about possible future self-harm led some to oscillate between being overly lenient or restrictive.

Parents' psychological, family, or socio-economic struggles intensified their sense of powerlessness, e.g., one mother reported, "I can't do anything to save her in the role of a mom because of I am powerlessness, alcoholic, and poor mom" (Sukhawaha et al., 2016, p. 338), while others spoke of their dismay or despair when their attempts to support their youth seemed to have no positive impact. Another general theme for caregivers was problems in communication with their young person. They found it hard to initiate conversation and felt unsure about what to say and how to give the young person space while maintaining the active supervision and support necessary to be confident that their child was safe. Parents' own emotional reactions, particularly anxiety, hurt, or anger, typically made it harder to keep the focus on supporting their child, e.g., one parent spoke of "yelling and screaming at her to stop (self-harming)" (Kelada et al., 2016, p. 3407), while other parents spoke about minimizing communication with their young person to avoid emotional or frustrated communication.

Descriptions of Help Wanted or Experienced

There were three main sub-themes explored within participants' descriptions of the professional help they received or reported wanting to have received. These included the barriers they experienced in accessing effective care, what they described as being effective in the care they received, and the distinct needs of youth and caregivers.

Barriers to Effective Care

Young people and their caregivers typically had problems accessing professional help. Systemic barriers to care included a lack of services or information about how to access services, stigma concerning youth suicidal or self-harm behavior, and the impact of healthcare providers' stigmatizing responses. Many caregivers and youth said they did not know where and how to get help. A general lack of information about suicidal or self-harm behavior and that it was a problem that could be helped, contributed to this. One parent said, "I got lost, like I was completely on my own trying to

Table 3 Caregiver descriptions of fractured relationships: themes and illustrative quotes

Theme	Exemplar	Prominence[a]
Parents' descriptions managing overwhelming emotion		
Wide-ranging emotions	"initially, I was horrified and very distressed and now I just feel very sad really and sometimes impatient." (Ferrey et al., 2016a, p. 5) "It's confusing. I felt angry. I felt sad. I didn't know what to do. Mums and dads are supposed to know everything aren't they, but we don't….we didn't know why she was doing this to herself." (Hughes et al., 2017, p. 218)	General
Shame and isolation	"I don't want (other mums) to know because I feel ashamed of what she's done and I feel responsible for it." (Ferrey et al., 2016b, p. 3)	General
Guilt	"From the very beginning, when I was pregnant with her, what did I do wrong? Did I eat the wrong things?… did I praise her enough? Did I criticize her too much? … that was very, very difficult, the blame, the guilt" (Hughes et al., 2017, p. 218)	General
Anxiety /Stress	"The worry was all consuming me. I could not function normally being on high alert for months. Stress levels affected the whole family and our existence." (Kelada et al., 2016, p. 3407)	General
Failure	"the first thing you do as a parent is blame yourself", "where did I fail?" (Byrne et al., 2008, p. 498)	Typical
Fear	"The biggest thing is the isolation, terror and fear…it's a very harsh journey" (Byrne et al., 2008, p. 498)	Typical
Frustration	"something you love most in your whole life…I've been lying there, when I couldn't sleep and (I think)… 'Well do it then for Christ's sake'. 'We might as well get it over with, mightn't we?'… 'Why the hell should I spend ten years of my life trying to save you, if you can't?" (Buus et al., 2014, p. 828)	Variant
Anger	"her self-harming makes me … angry and upset but mostly it makes me cross. It makes me cross that she does that to herself." (Ferrey et al., 2016a, p. 5)	Variant
Secondary guilt	"(I'm) thinking what kind of mother am I? I hate my child, so I must be the worst mother." (Daly, 2005, p. 26)	Variant
Parents' descriptions of fractured relationships		
Communication problems	"I tried to approach her, but she rejected me. It was very difficult to communicate with her….I did not know how to handle it." (Rissanen et al., 2009b, p. 1715) "You just had to be so careful…you wanted to… be able to talk to her but if you made her mad or she felt like she was a failure, she would go and cut." (Kelada et al., 2016, p. 3411)	General
Loss of trust and ease in relationship	"It means that you are constantly aware, watching them for any signs…which is terrible. You feel like you are sneaking around all the time," (McDonald et al., 2007, p. 305)	General
Grief– loss of relationship	"It's like *erm* a bereavement really because that person's not there anymore." (Oldershaw et al., 2008, p. 143)	Typical
Rejection /hurt	"So, I sat (her down) and, (said) "Oh my God, explain." And she was really dismissive … completely gave me the cold shoulder." (Hughes et al., 2017, p. 219) "Is dying more attractive than living with your mother?" (Daly, 2005, p. 26)	Typical
Difficulty in parenting and supporting their young person		
Loss of confidence in parenting arising from incomprehension	"I don't know what to feel because I'm at a loss as to why she's done it … so it (was) really total bewilderment as to why the hell she's done it because it didn't make any sense, really, to me." (Hughes et al., 2017, p. 218)	General

Table 3 (continued)

Theme	Exemplar	Prominence[a]
Risk of harm hovers over interaction	"those conflicts you have in all other families. There's just the unique difference that the consequences can be fatal, if you make a wrong decision" (Buus et al., 2014, p. 829)	Typical-General
Powerlessness	"as a parent you're programmed to make it all alright and this is something that you can't make alright." (Ferrey et al. 2016a, p. 3)	Typical-General
Embarrassment; self-blame	"How could it have gotten this bad without me knowing? I felt like I had been a really bad parent." (McDonald et al., 2007, p. 303)	Typical
Increased vigilance	"Let me describe a typical day. I tiptoe in her room and watch the clothes, looking at the blankets to see if they are moving up and down…." (Daly, 2005, p. 27) "It was red alert 24 hours a day. I slept outside her door." (Buus et al., 2014, p. 827)	Typical
Difficulty setting limits	"where is the mental illness and where is simply bad behavior?" (Ferrey et al., 2016a, p. 4)	Typical
Difficulty holding limits/Inverted parental-child hierarchy	"you begin to be a pleaser, because you are frightened out of your wits that if … I face hard with hard, then it will be my fault if they kill themselves. So suddenly it slowly turns into a sort of downward spiral, where the one who threatens us who has sort of taken over and who decides what the rest of us may think and do and use in the upbringing. Because we carry a guilty conscience the whole time…" (Buus et al., 2014, p. 828)	Typical
Miscued communication	"She argued with me, so I scolded her, "… go somewhere to die"… she (took) bathroom cleaner. She…thought that I didn't love her. She didn't get it that I had only scolded out of concern." (Sukhawaha et al., 2016, p. 338)	Variant
Regression in the relationship	"It was like looking after a baby again... I was hiding the knives, I was hiding any pills... I was knocking on her door every 5 minutes." (Oldershaw et al., 2008, p. 142)	Variant

[a]Prominence ratings within CQR – General (present in all or nearly all); Typical (present in majority); Variant (present in two or more but less than 50%)

figure out who I should get her into…I didn't feel like there was a good resource" (Kelada et al., 2016, p. 3412).

The impact of shame and fear of judgment was typically experienced as a barrier to professional help. One young person described feeling exposed and vulnerable at the point of help-seeking, "It was really scary... you feel like everybody knows what you're being there for... it's like sitting in the waiting room of a doctor's office and they didn't give you a gown... just like a total walk of shame." (Murray & Wright, 2006, p. 159). Adverse or dismissive reactions from health professionals were variant to typical themes. Some youth felt looked down on or judged by some healthcare staff, particularly when seeking help in hospital emergency departments, e.g., "(the clinicians) just look at you with utter disgust like you're some monster" (Owens et al., 2016, p. 288). They felt staff ignored their needs and treated them as attention-seekers who diverted resources from other patients with more "legitimate" emergency healthcare needs, and they did not feel listened to or understood. Caregivers similarly reported not being included in professional care and feeling judged or blamed by healthcare staff.

Not getting enough help, having to wait for treatment, or receiving fragmented care were typical themes in unhelpful care experienced by youth and caregivers. Some spoke of waiting weeks or months after the suicidal crisis before being offered services. Others commented on not having enough help due to infrequent appointments and a lack of support outside of scheduled sessions.

Fragmentation in the provision of care was another barrier to effective treatment. A typical theme in youth studies was that care involved seeing many different clinicians rather than having the chance to engage with a consistent treating team. This was exemplified in the experience of one young person who felt they had "seen, over the past three years, "about 20 different" counselors, psychiatric nurses, and doctors" (Storey et al., 2005, p. 73). Similarly, young people and caregivers noted problems with coordination between acute and ongoing treatment and falling between the gaps in the referral criteria of available services, leading to them

Table 4 Young people and parents' descriptions of help wanted or experienced

Theme	Exemplar	Prominence
Accessing help		
Not knowing how to get help	"I've got a child who is cutting … in some sort of emotional distress that I don't understand and who's going to help us with that?" (Stewart et al., 2018, p. 81)	Typical—General
Not feeling able to seek help	"I know I need help, but I am unable to seek help." (Rissanen et al., 2009a, p. 13)	
Not getting help soon enough	"She waited for the first appointment without any care for two months at home." (Rissanen et al., 2009b, p. 1715)	Typical
Not getting enough help	"Once I left that hour of therapy I had nothing …. no background support." (Byrne et al., 2008, p. 498) "We are there for an hour. She comes home. She spends the next 150 hours with us (without support)." (Dempsey et al., 2019, p. 107)	Typical
Fragmented professional systems	"We are in dire need of some sort of self-injury headquarters… for people to have a single place to go a single 1–800 number to call or a website… (to get) a specialist in my area." (Kelada et al., 2016, p. 3411)	
Quality of relationship with health professionals—Unhelpful aspects		
Lack of transparency Feeling excluded from treatment	"Clinicians, please talk to carers. Don't exclude us … I think often clinicians' perception…can be that you're part of the problem. Well, I may be but actually, if you help me out I can maybe be part of the solution too." (Stewart et al., 2018, p. 82)	Typical
Fragmented care, lack of continuity	"See someone, then it stops. See another person. You need to see someone continuously or it's not going to work." (Storey et al., 2005, p. 73)	Typical
Stigmatized; denied care	"(they) look at you with utter disgust", "they refused to treat me!! … basically 'cos it's self-harm." (Owens et al., 2016, p. 288) "Their (healthcare staff) attitude was somehow skeptical, like I did not want to do all I could to help my daughter." (Rissanen et al., 2009b, p. 1719)	Typical
Feeling dismissed	"they kinda made me feel like my problems weren't like, valid." (Mitten et al., 2016, p. 8)	Variant
Not having enough say Coercive treatment	"When you say things that you really don't mean, you end up in a place that you don't wanna be in… locked up." (Hausmann-Stabile et al., 2018, p. 169)	Variant
Quality of relationships with health professionals -Valued aspects		
Importance of therapeutic relationships	"the only one that I could like share my feeling with, was my therapist at the time." (Gulbas et al., 2019, p. 1770)	Typical
Professionals being transparent	"they were more like informative, they were saying ok this is what is going to happen, and stuff, so it kinda relaxed me a bit." (Mitten et al., 2016, p. 13)	Typical
Help attuned to level of need	"They visited my daughter every day for a month…. They would come at whatever time was suitable for us." (Stewart et al., 2018, p. 81)	Variant
Feeling listened to; understood	"The counsellors are very calm…(and) understanding. They don't try to jump to conclusions." (McAndrew & Warne, 2014, p. 574)	Variant
Comments on family therapy		
More supportive family relationship	"My family… started being very supportive and very positive with me …instead of focusing on all the things that are wrong with me." (Bostik & Everall, 2007, p. 88)	Typical
Help with communication (in session)	"I have never felt comfortable talking to my parents... It felt therapeutic talking to my mom in the (counselling) office... some sort of mediation." (Murray & Wright, 2006, p. 160)	Typical

Table 4 (continued)

Theme	Exemplar	Prominence
Help communicating about suicidality and self-harm	"my therapist …. helped me to tell (my father… what had happened)." (Hausmann-Stabile et al., 2018, p. 169)	Typical
Reduced conflict	"My mother and I can sit for a little longer and talk without fighting. Things have cooled down." (Beekrum et al., 2011, p. 67)	Variant-Typical
Having a say in treatment focus and pacing		
Readiness for family sessions	"Had it been on the day (the offer of family therapy) I would have definitely felt that it would have been intrusive I … wanted time and space to accept what had happened." (Raphael et al., 2006, p. 17)	Typical
Choices about family sessions	"I know I haven't given it a try, but it felt so hard, I hated it… I just didn't want to be any more exposed." (Storey et al., 2005, p. 74)	Variant
Understanding, connection and attachment		
Improving mutual understanding	"They help me understand my mom better." (Humensky et al., 2017, p. 430) "Even though I hated it and couldn't condone it, with my… understanding of it…I supported her and helped her to (hold her emotions)." (Hughes et al., 2017, p. 220)	General
Parental understanding increased confidence	"If you have the knowledge and background, you feel more confident in dealing with it." (Byrne et al., 2008, p. 499)	General
Need for specific parenting advice	"Well, I think I still feel like I—a little bit "all at sea" (managing suicide risk) … I'm not really sure I would know what to do, to be honest." (Dempsey et al., 2019, p. 107)	General
Fostering closeness; emotional support	"Me and my mom became really, really close. Whenever I was really depressed, and I wanted somebody to talk to…to cry to, it would just be my mom. We grew a lot from each other." (Bostik & Everall, 2007, p. 85)	Typical
Attachment repair; feeling cared for	"I realized … that she had done so much for me … to help me, but I didn't realize." (Orri et al., 2014, p. 6)	Variant

receiving insufficient or fragmented care. One mother stated, "So what are we all doing here? While you're batting referrals back and forth, I've got a child who is cutting herself, becoming more isolated and withdrawn" (Stewart et al., 2018, p. 81).

A lack of transparency from health professionals and being excluded from treatment decisions were typical to general themes. Some youth reported a lack of openness from health professionals, particularly about diagnoses and treatment planning, while a variant youth theme concerned not having enough say about inpatient care, psychotherapy, or pharmacotherapy. Caregivers also described being excluded from treatment planning and intervention even when they had actively instigated it. Despite being given little or no information by treating health professionals about their child's difficulties, caregivers were expected to be responsible for monitoring the young person's wellbeing and safety.

Effective Professional Care

When discussed, effective care was typically described as timely and flexible. Helpful, professional support was available as frequently as needed, with clear avenues for crisis support outside scheduled sessions. The crucial nature of relationships with health professionals in facilitating engagement and helpful care was a general theme. Youth and caregivers typically highlighted the importance of open, trusting, and collaborative relationships with health professionals. Being listened to and feeling accepted by clinicians who took time and care to get to know them and understand their concerns was a similarly recurrent theme. As one young person reported, "It (therapy) was beneficial because it was somebody I could come and talk to, and somebody I got familiar with, and somebody I felt comfortable with for the first time." (Murray & Wright, 2006, p. 161). The benefits of having a say in treatment planning and reviewing progress were also typical themes in both youth and caregiver studies.

Youth and Caregiver Needs

Helpful, professional care was comprehensive and focused on the distinct youth, caregiver, and family-related needs. Young people and caregivers typically wanted individual

sessions for themselves, and some interventions focused on joint or relationship work. Caregivers spoke of the need for space and support to manage their own emotions before they felt ready for family therapy. Separate sessions for caregivers were also important for specific advice and guidance on supporting their child and responding to their distress in an emotionally attuned yet containing manner. Interestingly, some young people expressly wanted their caregivers to have individual treatment and felt relieved when this occurred, e.g., one young person noted, "I think that it changed my mom quite a bit; I think my mom started doing different measures of releasing her stress, or even her depression, instead of bottling it up. I think she (the clinician) helped her to do something in a different way, I don't know but I think she (the clinician) helped our family quite a bit" (Murray & Wright, 2006, p. 160). Youth studies also typically highlighted the importance for young people of having individual sessions, with space to reflect with a clinician who they experienced as caring about them, e.g., "I really had that sense that she honestly did care about me and how I was doing, and she genuinely did want to help me and didn't mind listening to me when I did talk and if I was blabbing on about something she just sat there and listened" (Bostik & Everall, 2007, p. 88).

Improving the relationship between young people and their parents was identified as a critical aspect of the intervention and a general theme across youth and caregiver studies. For some youth, improved connection with caregivers was identified as the most critical factor in their recovery, e.g., one young woman said, "I realized after I hit rock bottom. I'm not in it alone. I have my mom. My mom loves me" (Holliday & Vandermause, 2015, p. 172). Therapy that fostered dialogue and helped young people talk to their parents about their feelings and support needs, or discuss issues with less conflict, was beneficial and a typical youth theme. Preparation before joint sessions and having choices about these appointments' focus and timing were also important for young people. While some wanted health professionals to speak to their caregivers on their behalf, others said they wanted their therapist to help them speak to their parents and expressed relief in having joint sessions with a supportive therapist actively involved in these conversations. However, in contrast, two young people reported feeling coerced into family sessions where they felt exposed to family members and burdened by hearing about their parents' concerns (variant theme).

Discussion

There is a growing qualitative literature reporting on the views of young people and their caregivers affected by suicidal behavior, though past systematic reviews have not specifically examined this through the lens of family therapy intervention, a promising treatment approach. It is vitally important to understand more about the experience of these youth and their caregivers as adolescence is a time of increased onset and frequency of suicidal and self-harm behavior, and most youth do not receive professional care. This systematic review examined the available qualitative literature and identified a range of individual, family, and systemic barriers to treatment, including overwhelming emotions, in particular shame, and disconnection experienced by young people and their caregivers that contributed to their isolation and made it harder to seek help. Systemic barriers included a lack of available services, professional care experienced as fragmented and poorly coordinated, inadequate information about how to access care, and stigmatizing or dismissive responses from healthcare providers. This review supports family-based interventions and highlights the importance of carefully tailoring treatment to the varied and dynamic needs of youth and their caregivers within direct therapeutic processes and at broader policy and systems levels to improve engagement in effective care and outcomes for youth suicidal behavior.

Family Relationships

The core themes identified in this review underscore the importance of attending to family relationships to reduce the risk of suicidal or self-harm behavior and promote recovery. Young people's descriptions highlighted the role of poor family relationships in contributing to suicidal behavior (e.g., Gulbas et al., 2019) and the positive potential of relationship repair and supportive relationships with caregivers (e.g., Hausmann-Stabile et al., 2018). This is consistent with previous qualitative reviews (Curtis et al., 2018; Grimmond et al., 2019) and research identifying poor attachment/family relationships as risk factors for suicidal behavior and, conversely, supportive relationships as related to resilience and recovery (Ewing et al., 2015). Before recovery, most young people felt unable or unwilling to seek support from their caregivers about their distress or suicidality, feeling disconnected, isolated (Holliday & Vandermause, 2015), rejected, or abused (Zayas et al., 2010). Despite this, a prominent theme in youth accounts was the importance of improved connection with caregivers (e.g., Bostik & Everall, 2007; Wadman, Vostanis, et al., 2018). These findings are consistent with, and strengthen support for, family-based treatments involving relationship repair and enhancing the protective potential of caregiver-youth relationships (Brent et al., 2013; Glenn et al., 2019).

Improving Engagement in Effective Care

Improving engagement in professional care is a critical suicide prevention priority, given that most young people with suicidal ideation or self-harm behavior do not access or complete professional treatment (Rowe et al., 2014). The experience of youth and their caregivers described in this article highlighted barriers to engagement at individual, family, and systems levels. At individual and family levels, overwhelming emotions, shame, isolation, and fractures in family relationships impeded help-seeking. This is consistent with previous research that identified worthlessness, self-loathing, and shame as hindering youth help-seeking (Grimmond et al., 2019), and shame and guilt as impeding help-seeking by caregivers (Curtis et al., 2018).

Also consistent with previous research (Lindgren et al., 2018), a lack of knowledge about self-harm or suicidal behavior, and confusion about the availability or usefulness of professional help, curtailed access to both informal support and professional treatment. Many caregivers reported that they were previously unaware of self-harm and did not know how to get help (Kelada et al., 2016). Young people noted that, while there are "posters all around school (for smoking) …there are actually more people who self-harm than smoke or drink. Have an assembly about self-harming" (McAndrew & Warne, 2014, p. 575). This lends support for increased public education about self-harm and suicidal behavior, as has also been suggested in previous research (Grimmond et al., 2019; Lindgren et al., 2018).

Society-based stigma about self-harm (Mitten et al., 2016), coupled with dismissive or stigmatizing healthcare providers' responses, were systems-level barriers to professional care. Young people who had self-harmed or were suicidal and their caregivers reported feeling dismissed or judged across healthcare settings (Hausmann-Stabile et al., 2018, Kelada et al., 2016), particularly in hospital emergency departments (Owens et al., 2016). These themes are similar to the negative professional care experiences of adults who self-harm (Lindgren et al., 2018) and highlight the critical importance of the quality of relationships with health professionals in facilitating engagement in effective care.

Finally, consistent with previous research, a fundamental systemic barrier to effective care engagement was the lack of available services (Grimmond et al., 2019; Lachal et al., 2015). Waitlists (Rissanen et al., 2009a), being turned away from services (Stewart et al., 2018), and insufficient or fragmented care were all identified as issues (Keladaet al., 2016; Wadman, Vostanis, et al., 2018). Problems in getting help after a crisis, difficulties in transitions between services, and the lack of consistent care providers also contributed to fragmented care experiences (Stewart et al., 201; Storey et al., 2005). This is consistent with research into the implementation of youth suicide prevention programs that found that services could be difficult to navigate, poorly coordinated, and sometimes have duplicated and overlapping elements alongside significant gaps in service (Arnautovska et al., 2013).

These findings provide essential direction regarding policy, the structuring of services, and the skills needed at the level of intervention and practice. Fundamentally, the need for increased specialized, integrated, accessible services is highlighted. Such services should provide timely (Brent et al., 2013), sustained (Glenn et al., 2019), and tailored treatment to meet individual and family needs. Youth and caregivers valued developing a trusting and collaborative relationship with a therapist or therapeutic team rather than seeing multiple clinicians from different services (e.g., Gulbas et al., 2019). Continuity and cohesive planning in the delivery of treatment and structuring of youth mental health services is therefore recommended. Services should have cohesive linkages with crisis or inpatient mental health services and hospital emergency departments to improve continuity of care and engagement in community treatment after emergency presentations and should foster transitions of care between settings that are mindful of building trust and therapeutic engagement (Storey et al., 2005).

Psychoeducation and stigma reduction programs are essential to improve access to professional care. Broader strategies to improve mental health literacy and raise awareness about suicidality and self-harm are crucial for reducing stigma and improving treatment access. Promising results from school-based programs that aimed to increase young people's willingness to seek help for depression (Velasco et al., 2020) strengthen the case for similar programs focused on suicidal or self-harm behavior. Likewise, it is critical that health professionals actively consider and address the sense of stigma, shame, and fear of judgment that young people and their caregivers experience so as to facilitate engagement in treatment. Staff at initial engagement points within the health system may not be mental health therapists and may therefore lack pertinent sophistication in response skills to the hidden shame of young people and caregivers. As emergency department care can have a pivotal role in facilitating treatment engagement for this population, training for these clinicians about self-harm and the shame and stigma young people and families experience is signposted by client experience and warrants urgent attention (Hodgson, 2016; Owens et al., 2016). Given caregivers' role in instigating and accessing help for their young person (Curtis et al., 2018), and the importance of family-based treatment for recovery (Glenn et al., 2019), it is important that such potential service engagement points do not convey judgment or stigma towards these caregivers.

Tailoring of Treatment

This qualitative synthesis highlights the importance of carefully tailoring treatment to meet the distinct needs of youth and caregivers affected by self-harm and suicidal behavior, from their initial self-harm experiences through to recovery. Contact with professional care often begins in the context of a suicidal or self-harm crisis, such as a suicide attempt, or with the disclosure of suicidal ideation or behavior to a third party, and represents a personal and relationship crisis for both the young person and their caregivers. At that time, the young person is dealing with their suicidal thoughts and feelings, and any physical aftermath of the self-harm, in addition to grappling with the fact that their self-harm and suicidal struggle are now visible to others, with the accompanying sense of shame and attendant anxiety that this may entail (Beekrum et al., 2011; Orri et al., 2014). Before treatment, most youth were reluctant to reveal their distress or suicidality to their caregivers. Consequently, at the outset of professional intervention, youth may be unwilling or strongly ambivalent about having caregivers involved, despite struggling to manage their suicidal feelings independently and wanting to be accepted and supported by their family (Holliday & Vandermause, 2015; Wadman, Vostanis, et al., 2018).

It is essential to recognize that discovering the young person's suicidal or self-harm behavior is also a crisis for caregivers. This systematic review showed that caregivers experienced wide-ranging and overwhelming emotions and all had various struggles in coming to terms with their child's self-harm (e.g., Byrne et al., 2008; Ferrey et al., 2016a) consistent with previous qualitative research (Curtis et al., 2018; Lachal et al., 2015). These struggles may contribute to some caregivers responding in emotionally uncontained or conversely dismissive or avoidant ways to their young person, neither of which were experienced as helpful by youth (Curtis et al., 2018). Therefore, the context of the initial discovery of self-harm or suicidal event calls for sensitive and nuanced professional care to meet the immediate needs of youth and caregivers and set a foundation for ongoing treatment.

Getting help when it was most needed, access to intensive treatment, and crisis support were identified as necessary for youth and parents alike (e.g., Wadman, Vostanis, et al., 2018), and this aligns with clinical findings supporting front-loaded treatment (Brent et al., 2013). Young people and their caregivers also valued transparency and collaboration in treatment planning. Given that both youth and caregivers may be in crisis at the start of treatment, such care planning must extend beyond a surface-level list of treatment goals to address the complex and conflicting emotions experienced by young people and their caregivers and be revised over time according to their changing needs. These distinct and dynamic needs also have important implications for the role of individual or joint sessions for youth and caregivers.

Individual and Joint Sessions

The qualitative synthesis showed that both youth and caregivers needed significant individual support and that the majority wanted assistance from therapists to improve youth-caregiver communication. Both spoke about the value of independent preparatory work before conjoint sessions (e.g., Humensky et al., 2017) and the importance of therapists' role as mediators in family sessions (e.g., Hausmann-Stabile et al., 2018). Impacting on the timing of conjoint work was the essential role for therapists in deconstructing indirect or miscued communication, e.g., young people seeking parental connection through self-harm (Beekrum et al., 2011) or parents seeking to express love for their child through "scolding" and criticism (Sukhawaha et al., 2016). Therapists must take an active role in facilitating relationship repair, consistent with the clinical treatment trials that showed benefits of relationship-focused work in which therapists scaffold and support such attachment repair (Diamond et al., 2016).

Individual sessions for caregivers were important to process their emotional reactions to regroup and remain regulated and prioritize their child's support needs (Raphael et al., 2006). Caregivers also wanted specific and concrete psychoeducation, support, and direction. Such caregiver support may need to be quite detailed to help them problem-solve new and challenging parenting dilemmas, such as how to respond to their child's suicidal ideation or self-harm in the moment (Dempsey et al., 2019), when and how to access emergency care, and how to maintain parenting limits and monitor the young person's safety while fostering warmth and trust in the relationship (Byrne et al., 2008; Hughes et al., 2017). In addition, caregivers will likely benefit from individual professional support and psychoeducation focused on emotion coaching because responding to their young person's distress and self-harm in an emotionally attuned way, showing genuine care and concern without "overreacting", appears to be experienced as helpful for most youth (Curtis et al., 2018; Wadman, Vostanis, et al., 2018).

While highlighting the crucial role of family-based treatment, the qualitative accounts synthesized here show that a model embracing relationship repair in joint sessions should not be rigidly imposed. A couple of young people described feeling coerced into family sessions where they felt exposed and criticized (Storey et al., 2005), while other youth highlighted the importance of having choices about their care and joint sessions with parents. Therapists should not force young people to participate in family therapy. However, it is important therapists explore the young person's doubts, fears, and expressed and unexpressed attachment wishes and

actively incorporate practical support to empower young people to have more positive connections with their caregivers should they so wish. Thus, careful and collaborative planning of individual and joint sessions is essential for both youth and caregivers.

Strengths-Based Framework

The findings lend support for a strengths-based focus in work with both caregivers and young people. Young people spoke of the adverse effects of feeling judged and the need for acceptance and validation from mental health professionals to foster their sense of agency and self-worth. At the same time, parents reported that their feelings of failure, shame, and loss of parenting efficacy were exacerbated when they felt dismissed or judged by healthcare providers. Importantly, even when youth identified critical, abusive, or other negative caregiver behaviors, many still identified relationship repair and bonding with caregivers as vital to their recovery. This is highly salient for practice delivery. Therapists need to address the caregiver's problematic behavior, affirming the young person's need for safety and support. However, this needs to be located within a strengths-based framework and contribute to building upon any available points of positive caregiving. Treatments should focus on helping parents to understand their young person's self-harm within a therapeutic framework that seeks to rebuild parental presence, confidence, and connection (Asarnow et al., 2015; Diamond et al., 2010), and build on parenting strengths (Pineda & Dadds, 2013).

Implications for Policy and Practice

Several critical considerations have emerged from this review. First, the findings lend strong support to the implementation of family-based treatments for this population. However, this evidence is tempered by adjacent evidence that people in this relationally fragile context need to receive responses characterized by considerable finesse. Practice responses need to be tailored and multi-modal, incorporating individual support and active therapeutic intervention to scaffold communication and relationship repair in joint sessions. Second, this review's results cast an illuminating light on the need for treatments to be strengths-focused and, in particular, to encompass a sophisticated and nuanced appreciation of the operations of stigma and shame. Within a range of overwhelming emotions, shame was cited most frequently by both parents and young people, contributing to their isolation and distress, and was sometimes exacerbated by problems accessing treatment or stigmatizing responses from health professionals. Although both young people and their caregivers may engage in unhelpful behaviors, these must be addressed within a non-judgmental strengths-focused framework. Third, this review highlights the importance of attachment across the developmental life span. Despite adolescence being a time of increased independence, secure attachment and relationship repair with caregivers were important for the youth affected by suicidal behavior in reducing their isolation and shame, increasing their coping, and ultimately decreasing their suicidality.

At a policy level, prevention and intervention programs that include both youth and caregivers and address stigma as barriers to accessing help are highlighted. To this end, policies should improve mental health literacy and training for mental health professionals and other professionals who may be gatekeepers to treatment. Importantly, increased funding of comprehensive youth mental health services that provide multi-modal individual and family treatment with young people and caregivers is strongly indicated. Lack of appropriate services, long waitlists, and fragmented care were identified as unhelpful professional care experiences. These problems can only be addressed by the increased provision of integrated and affordable services that prioritize fostering therapeutic relationships with youth and their caregivers.

Limitations

Several limitations in this systematic review and synthesis should be noted. Most importantly, none of the studies had a primary focus on family treatment experience, and research explicitly examining this is needed. In addition, the participants included in the studies are not representative of all youth affected by suicidality and self-harm or their caregivers. For example, the perspectives of young people who died by suicide or those who declined to participate in qualitative studies are not represented, while those who disengaged from treatment are under-represented. Although the analysis incorporates both young people and parents/caregivers, no study paired their responses or included therapist experiences to provide a triangulated perspective about the same treatment. Male participants were under-represented, both for youth and caregivers. As shown in Table 1, the studies were mainly from Western nations, although several studies had participants from minority groups. Most studies did not report the LGBTQI + identity of participants. Also, studies with a specific adolescent focus were so few that the selection criteria were broadened to include young people aged 12 to 25 years. Therefore, further research is required to explore family-based treatment experiences, the unique needs of youth and their caregivers across different developmental periods and subgroups, and to develop a deeper understanding of the pathways into the fractured relationships and the repairing of those relationships.

Conclusion

Most youth and their caregivers affected by suicidality or self-harm do not access professional care. This systematic qualitative review identified that access to effective professional care was hampered by the psychological and relationship impact of the young person's suicidality and self-harm, the operation of shame and stigma, a lack of awareness about professional help, and insufficient, fragmented, and poorly coordinated services. In contrast, effective professional care was facilitated by a timely, strengths-focused treatment that engaged both young people and their caregivers and fostered open, collaborative, and trusting therapeutic relationships. The review's findings lend strong support for family-based intervention incorporating individual and joint sessions and emphasize that professional care should be tailored to meet youth and their caregivers' distinct and dynamic needs from the initial disclosure of suicidal or self-harm behavior through recovery. Barriers to effective care must be addressed through increased youth mental health services that provide timely and integrated care from crisis intervention through community treatment and a concerted effort to promote public education about youth suicidal and self-harm behavior to reduce stigma, particularly for staff at potential engagement points. As the quality of therapeutic relationships was crucial to youth and their caregivers for engagement and effective intervention, this lived experience should inform direct clinical practice and the design and delivery of suicide prevention and treatment programs.

Appendix

See Table 5 in Appendix.

Table 5 Participant details

Study author(s) & Year published	Youth 12–25			Parents/caregivers		
	Total	Female	Male	Total	Female	Male
Beekrum et al. (2011)	10	10	0			
Bostik and Everall (2006)	50	41	9			
Bostik and Everall (2007)						
Everall et al. (2006)						
Buus and et al. (2014)				19	9	5
Byrne et al. (2008)				25		
Daly (2005)				6	6	0
Dempsey et al. (2019)				8	7	1
Ferrey et al. (2016a)				41	34	5
Hughes et al. (2017)						
Stewart et al. (2018)						
Ferrey et al. (2016b)						
Herrera et al. (2006)	8	8	0			
Holliday and Vandermause (2015)	6	5	1			
Humensky et al. (2017)	68	68	0	8	8	0
Gulbas et al. (2019)						
Hausmann-Stabile et al. (2018)						
Zayas et al. (2010)						
Kelada et al. 2016				38	33	5
Keyvanara and Haghshenas (2011)	25	16	9			
McAndrew and Warne (2014)	7	7	0			
McDonald and et al. (2007)				7	6	1
Mitten and et al. (2016)	12	10	2			
Murray and Wright (2006)	3					
Oldershaw et al. (2008)				12	9	2
Orri et al. (2014)	16	8	8			
Owens et al. (2016)	31	30	1			
Raphael et al. (2006)				9		
Rissanen et al. (2009a)	10	10	0			
Rissanen et al. (2009b)				4	3	1
Storey et al. (2005)	38					
Sukhawaha et al. (2016)	12			6		
Tingey et al. (2014)	22					
Wadman, Armstrong, et al. (2018)	24	15	9			
Wadman, Vostanis, et al. (2018)						
Total	342	228+	39+	183	115+	20+

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Declarations

Conflict of interest The authors declare that they have no conflict of interest.

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*References included in the systematic review are marked with an asterisk

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