

Navigating an unfamiliar world: how parents of young people who self-harm experience support and treatment.

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Background: Self-harm in young people is a common reason for contact with clinical services. However, there is little research focusing on parents' perspectives of care following self-harm. The aim of this study was to explore parents' experiences of treatment and support for the young person and for themselves. **Methods:** A qualitative design was used to explore parents' perspectives. Semi-structured narrative interviews were conducted across the UK with 37 parents of young people who had self-harmed. Thematic analysis was undertaken to identify themes relating to how parents experienced the help and treatment received. **Results:** Parents reported differing reactions to contact with helping services. Many found these helpful, particularly in keeping the young person safe, developing a trusting relationship with the young person, encouraging skills in managing self-harm and giving them an opportunity to talk about and find solutions to their difficulties. They spoke about the importance of practical help including prompt access to care, the right intensity of care, practical strategies and information and support. Some aspects of services were perceived as unhelpful, particularly a judgmental approach by professionals, lack of early access to treatment, inadequate support, or failure to listen to the perspective of parents. **Conclusions:** Parents' views highlight the need for clinicians to consider carefully the perspective of parents, involving them wherever possible and providing practical help and support, including written information. The need for training of clinicians in communicating with young people and parents following self-harm is also highlighted.

Key Practitioner Message:

- Parents feel ill-prepared and unconfident in managing their child who has self-harmed
- Intensive early intervention can increase confidence in parents
- Services should emphasise the important role of parents in helping and supporting their child
- Parents can benefit from practical strategies and written information
- Attitudes towards people who self-harm can make a considerable difference to engagement and motivation.

Introduction

Findings from community-based studies indicate that at least 10% of adolescents, most commonly females, reported having self-harmed (De Leo & Heller, 2004; Hawton et al.,

2002; Madge et al., 2008). The impacts on their families can be devastating. Parents describe emotional distress, shame, and helplessness (Byrne et al., 2008; Ferrey et al., 2016), strong and long-lasting emotional reactions (Oldershaw et al., 2008), confusion and a sense of being trapped (McDonald, O'Brien & Jackson, 2007; Lindgrem, Astrom & Granheim, 2010; Hughes et al., 2015). Parents also report lack of knowledge about self-harm, uncertainty about what to do and the need for solutions and understanding (McDonald et al., 2007).

Some young people reporting self-harm receive help from health or education services. However, there is relatively little research indicating the most effective interventions (Hawton et al., 2015). A review of randomized controlled trials of interventions for suicidal adolescents indicated that a focus on family interaction, mobilisation of parental and non-familial support, intensive early treatment and adequate length of treatment were all important factors in reducing suicidal ideation or self-harm (Brent et al., 2013).

Very little research has explored young people and families' perceptions on treatment offered. Berger and colleagues (2013) asked adolescents for their views on how parents and teachers could help those who are self-harming. Participants emphasised a non-judgmental approach, establishing helpful relationships with adults and referral for professional help. Studies of parental reactions to self-harm and treatment have found that parents usually experience treatment as beneficial (Oldershaw et al., 2008) and stress the importance of a trusting relationship, honesty and genuine caring (Rissanen, Kylma & Laukkanen, 2009).

In this study, we explored how parents of young people who had self-harmed experienced support and treatment, both for their child and for themselves. We aimed to gather views from parents with a wide range of experiences of services and our intention was to generate information that could be helpful for parents and for clinicians helping families navigate through this experience.

Methods

Sample and recruitment

This study is part of a wider qualitative investigation exploring parental views on self-harm, including how parents make sense of self-harm and the impact of self-harm on parents and family life (Hughes et al., 2015; Ferry et al., 2016). Self-harm is defined as self-injury or self-poisoning, regardless of method. Semi-structured narrative interviews were conducted with 37 parents of 35 young people aged up to 25 years who had self-harmed at any point in the past. Where both parents agreed to take part (two pairs of parents) they were interviewed separately. Participants were recruited through clinicians, mental health charities, support groups, advertisements, social media and personal contacts. People expressing an interest were sent an introductory letter, a participant information sheet and a form to return if they wished to take part. They were contacted by researchers to answer any questions and arrange an interview, held at their choice of location.

We conducted maximum variation purposive sampling to capture a range of experiences. We aimed for variation in demographic characteristics, including gender, ethnicity and geographical location (See Table 1), although acknowledging the difficulties in recruiting participants with a balance of gender and ethnic diversity (Hussain-Gambles, Atkin & Leese, 2004). Participants came from a range of socio-economic backgrounds across England, Scotland and Wales (with a planned focus on Oxfordshire and Buckinghamshire for recruitment via clinicians). The majority were mothers. Only one was non-white. The majority of the young people were daughters, and over two-thirds were less than sixteen years old when they began to self-harm (See Table 1). Most self-harm incidents involved cutting but participants also described other methods such as overdoses, burning and strangulation. Our aim was to focus on parental reactions rather than collecting detailed information about the young person's characteristics.

Table 1 here

Participants gave written informed consent prior to their interviews. Pseudonyms were assigned to all participants to ensure confidentiality. The study was approved for national recruitment by Berkshire NHS Research Ethics Committee (09/H0505/66)

Data generation and analysis

Interviews were conducted by two experienced interviewers (NH, SS) between August 2012 and October 2013. Interviews were either video- or audio-recorded and lasted on average 84 minutes. The interviews consisted of an initial open-ended section in which the person was asked to describe their experiences of caring for a child who had self-harmed. This was followed by prompts in specific areas based on prior research findings and suggestions from the project's advisory panel (which included parents, researchers and clinicians). The research interviewers had no clinical contact with the participants.

Interviews were professionally transcribed. Transcripts were checked by the researchers and sent to participants, who could remove any part of the interview before giving written consent for the material to be used in research and other publications. Final transcripts were uploaded to qualitative software (NVivo9) for coding. A coding framework of anticipated and emergent themes was developed using the technique of constant comparison. Coding reports were generated and used for an initial broad thematic analysis. We adopted a modified grounded theory approach to thematic analysis as described in Ziebland and McPherson (2006), using both inductive and deductive methods. Themes were derived from a combination of previous literature and clinical experience of the research team and advisory panel (anticipated), and by paying detailed attention to the parents' accounts (emergent). Two researchers (NH and SS) carried out the initial analysis of the complete set of interviews independently and identified key themes. Any discrepancies or differences in interpretation were resolved through discussion. AS conducted further detailed inductive analysis to identify more focused themes relating to parents' experiences of support and treatment. Reflexive discussion regarding these themes occurred in the research group.

Results

Participants described a range of reactions to treatment and support for the young person and themselves. We identified three main themes: attitudes of clinicians towards the young person (this included general practitioners, emergency department doctors, paediatricians and mental health professionals); practical aspects of help; and the need for parents to be involved in treatment.

Attitudes towards the young person

Approach to the young person

Many parents talked about the importance of professionals' attitude towards their child. A general practitioner (GP) is often the first professional involved. Parents often found their GP very helpful and described them as 'lovely' or 'fantastic'. However, others thought their GP was judgmental towards their child, which was unhelpful and distressing. Nancy thought that the doctor judged her daughter as being attention seeking and Sian felt that the GP told her daughter off:

...the GP turned round and said to her, "I can't believe that you've done this. It's about time you grew up. You're immature, you know. You're supposed to be a mature girl. You've got a good parent, you know. Talk to your parent and just stop attention seeking. Nancy

But her response with my daughter was just to tell her off. She just said, "Oh, you mustn't do that. You mustn't cut yourself. You know, you're going to leave scars and when you get older, how do you think you'll feel about that? And I know Caitlin was absolutely furious.

Sian

Parents also described interactions with other clinicians. Some were very pleased with the professionals' response. Shannon told us that respondents at NHS Direct (a national helpline) were "very, very nice. They weren't judgemental at all. They explained everything very clearly". Several parents commented positively about hospital staff:

They were really caring at the hospital. The triage nurse, all the nurses that she saw were extremely caring and asked her if she felt she needed to be admitted... She said, "No." They were very non-judgmental, very caring towards her and I really appreciated that... Jennifer.

When young people had self-harmed more than once, some parents detected less positive attitudes. Janet thought that staff found it difficult when young people presented repeatedly, becoming "switched off and negative" about those who self-harm. She felt that "attitudes must change" and that the person who self-harms should be seen as a person rather than "an annoying case".

Parents frequently perceived the services as very pressed; they reported on how distressing it can be when this is conveyed to the young person and their parents. Nadine said staff were often so busy that they saw the young person as a 'waste of time' but thought that 'there's a nicer way of treating these patients than being so dismissive'.

Being assessed

Adolescents generally receive a standardised assessment to ascertain their level of risk. However, this could come across as an interrogation or an alienating "tick box" exercise:

"Do you still think that you might kill yourself?" And just a succession of these sorts of questions and it was tick-box stuff. So Melanie, obviously, to the question, "Are you still thinking of killing yourself?" sits there and shakes her head, so the box gets ticked and (he) says, "Well, that's fine. I can let you back out into the community because you're not an immediate risk to yourself. Jacqueline

She sat down. She just stared at my daughter....And just, no kind of attempt to try and get any kind of background, or anything of that sort, and just went through the check-list of questions again, and my daughter just wouldn't speak to her. Janet

Being taken seriously

Some parents believed self-harm was not taken seriously. Alana thought that professionals did not understand her son:

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.

Other parents felt that the self-harm and safety of the young person were taken seriously, with the right level of support given, which was a considerable relief. Evelyn was reassured that the crisis team rang frequently to check that her daughter was safe.

Making a relationship

Parents reported that if their child could easily relate to the clinician this made all the difference to engagement. Barbara commented that 'there has to be a trusting relationship' and Joy emphasised the qualities of being able to be supportive and firm:

The CPN is very, very honest with her and... she won't buy into what she's saying. She will challenge her. Sometimes it doesn't go down very well, as you can imagine. Sometimes she's very angry with her [CPN] but, on the whole, they have a trusting good relationship and that's really important.It's quite important for my peace of mind as well as hers. Joy

Practical aspects of help

Parents reported on practical aspects of treatment, including access to care and the location, frequency, intensity and continuity of care. They discussed whether it was helpful or unhelpful and the need for information about self-harm.

Prompt access to care

Prompt access to care was reported as important but didn't always happen. Many parents described delays in referral to Child & Adolescent Mental Health Services (CAMHS). Sian said that her daughter's GP "refused to refer her to CAMHS". Amy had great difficulty in accessing treatment because her daughter was aged over 16:

So I phoned CAMHS again and they said, "Well, she is too old." And I said, "So what are we all doing here? While you're battling referrals back and forth, I've got a child who is cutting herself, becoming more isolated and withdrawn and is obviously in some sort of emotional distress that I don't understand and who's going to help us with that? Does it actually take for her to try and kill herself?" And they said, "Well, we don't really know what to suggest."

Access to the right context of care

Several parents talked about the difference between adult and children's wards in the general hospital. Isla told us, 'I'd say my child had a very good experience when she was fifteen, in that she was seen very quickly and nurses' response to her was warm and caring and friendly, which was in stark contrast to when she was over fifteen.' Amber's daughter

was on a surgical ward with older patients: 'It wasn't very pleasant, but the staff were very caring.' Louise was unhappy her daughter was not in a ward for young people but found it difficult to be assertive about this:

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.

Frequency of care

Parents reported the importance of intensive support early on when they were feeling uncertain about how to manage. Joan thought that they were 'embraced by the home treatment team.....who came to see her every day'. She described them as 'fantastic, even offering to come out and see her on Christmas day'. Amber felt the crisis team made a huge difference:

I can hand on heart say, that team turned our lives around. They visited my daughter every day for a month but also it was all so joined up...They were incredible people. They would come at whatever time was suitable to us. They would come in the morning. They would come in the evening. Sometimes, they came twice a day.

Others reported not being seen as intensively as needed. Jacqueline found appointments were difficult to arrange and restricted appointment times did not help engagement:

And it was just so pointless and then a list of small print stuff, "You do understand, don't you, that we are only here during office hours, so if you if you need any help we're here between nine and five." "I don't work on Fridays so it's nine to five Monday to Thursday. I can be contacted by e-mail but, obviously, I'm a very busy person so don't expect me to reply straight away..... If you do need any help outside those hours, go to A& E.

Having the intensive support of a crisis team early on was helpful. However, once the crisis team left, support could be less satisfactory:

My criticism is that once you're discharged from the crisis team, you then go back to your three monthly or your six monthly appointments ... What's in the middle? And the answer is very little. Amber.

Receiving treatment

The main psychological treatments mentioned were cognitive behaviour therapy (CBT) and dialectical behaviour therapy (DBT). Evelyn thought DBT was 'absolutely amazing.' It taught her daughter techniques she still uses for coping with thoughts and emotions. CBT 'really helped' Roberta's daughter and 'she hasn't harmed herself for over a year':

She said it (CBT) was mainly about dealing with negative thought processes and, obviously, negative thought processes tend to compound each other and negative thoughts tend to lead to particular sorts of behaviours and one of those behaviours would be cutting or burning and the need to hurt yourself, feel some sort of pain.

Some parents reported on the use of medication. Janet felt that medication had put her daughter 'on an even keel' and reduced her stress. Christopher's son thought his increased dose of antidepressants was helpful. Janet said that when her daughter was on her medication 'She's lively, she's bubbly, she's just normal.' Others reported that medication had not helped. Amy felt medication made her daughter worse. She said that 'the medication had a lot to do with her behaviours at that particular episode'. Joan noticed that her daughter's behaviour was becoming more 'erratic' after her GP reduced the dose. Georgia's daughter was put on some medication which affected her badly: 'She was going stir crazy... and she just felt like she was going to explode'.

Need for practical strategies

Provision of practical support from the start, such as specific guidance on what to do and how to access information, including web resources, organisations and leaflets, was seen as helpful and supportive:

...she's got the number for CAMHS. They've left it for her to be able to ring. She's got lots of information where she can get help. They've given her booklets. They've given her absolutely everything. The literature for her has been incredible really. It's been really, really

good, written in a way to understand, they've given strategies, talking and writing it down, buy her a book, everything has been really brilliant. Louise

Parents also wanted feedback on how they were responding to their young person and ideas about what to do differently. Jacqueline thought she needed more direct guidance on what to do: 'when you're that lost, you need a map in front of you'.

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

When practical strategies were suggested this was perceived as very helpful.

Involving parents

Many parents talked about the importance of families being involved in order to support the young person effectively and provide information for clinicians.

Support for parents

Support to manage the situation was seen as crucial by many parents who reported feeling uncertain what to do and wanting clinical support:

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

Nancy felt there wasn't enough help for parents. She cited 'the lack of support, the lack of services, everything for a parent', although she 'couldn't fault' what they provided for her daughter.

Many parents recommended parent groups, where they could share ideas with others and receive mutual support:

We have a parent support group at the unit for all the parents of the young people that are there, no matter what they're going through, and that's very helpful just to be able to express to someone else who knows what it's like to have a child away from home who's in need. Shannon

Specific help for parents

Parents talked about needing a clinician to talk to, particularly in the early stages. This was not always available but when it was, it was much appreciated. Nadine thought that the space for her and her husband to talk really helped them to cope and 'probably kept my marriage together'.

Self-harm in a young person can take its toll on parents' mental health (Morgan et al., 2013; Ferrey et al., 2016) and therefore specific help for parents' physical and mental health was valued as reported by Theresa.

I think also, looking after yourself, looking after your own sort of mental and physical health is really, really important and I sought help [um] myself and had some had some counselling support. and I think I was very, very fortunate with that actually to get that help. Theresa

Listening to parents and involving them in treatment

It was crucial for many parents that they found someone who listened to them and involved them in treatment. Nadine and Jocelyn said that clinicians needed to listen to the parents in order to understand the young person:

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

Clinicians, listen to the parents, please, please, please. Nobody has spoken to us enough. We're the ones that know about our children and we're the ones that can help you to help our children so please talk to us more because sometimes our children won't talk to you but we can tell you a lot more, especially about their background. Jocelyn

Jacqueline thought it was a 'huge, huge issue' not knowing what was said to her child.

Parents understood the dilemmas of confidentiality but found it hard being kept separate:

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.

Regular updates from professionals were seen as essential but communication was not always adequate:

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 self-harmed. Denise

However, others had good experiences of communication with staff. Shannon could phone at any time to talk to a team member and they updated her regularly. Sally was reassured by the communication between professionals as well as with her:

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.

Discussion

In this qualitative study we explored parents' perspectives on the treatment their children received and the support provided for them. Parents felt unprepared for the process of caring for a young person following self-harm and appreciated support to help them navigate this unfamiliar world. A major theme was the need for professionals to have the right attitude, including being non-judgmental, taking the self-harm seriously, engaging with the young person, conveying that they are important and assessing risk without the young person feeling it was a "tick-box" exercise. When these characteristics were missing, the young person found it hard to engage and open up. The results are consistent with those of a systematic review by Taylor and colleagues (2009) on attitudes to clinical services among people who self-harm, in which a common theme was poor communication between patients and staff.

It can be difficult for clinicians to balance assessing risk and developing a therapeutic relationship; national guidance recommends against an over-reliance on risk assessment tools (NICE, 2011). The process of the risk assessment, not just the content, is crucial in engaging the young person and hence managing the risk. There has been interest recently in introducing a therapeutic approach to the initial psychosocial assessment. Ougrin and colleagues (2011) have developed a therapeutic assessment for self-harm (to follow a standard psychosocial assessment) which focusses on motivation for change as well as identifying solutions and alternatives to self-harm. This was found to significantly increase attendance for subsequent treatment (Ougrin et al., 2011; Ougrin et al., 2013).

Parents also talked about practical aspects of treatment and support. Common themes were the need for prompt and easy access to intensive help, particularly early on and practical strategies for managing self-harm. Some parents were frustrated by difficulties in obtaining specialist referral. Practical support was just as important as psychological treatment. The parents' views on intensive early help are consistent with previous research. Taylor et al (2009) found that patients wanted prompt referral for after-care and information and resources following self-harm. Repeated self-harm or suicidal attempts are most common within 1-4 weeks following admission to emergency department or psychiatric hospital (Ho, 2003; Vitiello et al., 2009), so improved care during this period may reduce the risk of further suicidal behaviour (While et al., 2012).

The third major theme was the need to be involved and listened to. Brent and colleagues' (2013) review of randomised controlled trials found that a focus on family interactions was important in reducing self-harm. Parents can help clinicians understand their child's self-harm as well as being an important resource for the young person. Many parents talked about the need to care for themselves in order to be able to focus on the young person. Parent forums can be a useful way of facilitating support and understanding for the parent; there is preliminary evidence of the benefit of these (Power et al., 2009). Many parents reported how helpful it is to have written information and access to websites and organisations, particularly early on. This is consistent with other studies emphasising the importance of psycho-education following self-harm (Ougrin et al., 2013).

Strengths of this study include the involvement of a sample of parents at different stages in the process of managing self-harm (initial discovery and managing repeated self-harm), the relatively large sample size and the inclusion of both mothers and fathers (although there were only five fathers). Participants came from a variety of backgrounds across the UK, although a substantial proportion came from Oxfordshire and Buckinghamshire due to the location of the research. Limitations include a lack of ethnic diversity, with only one participant being from a non-white ethnic background, and a preponderance of mothers. The difficulty in acknowledging and talking about self-harm in some cultures may have contributed to the lack of ethnic diversity in participants; this is a general finding in mental health research (Yancey, Ortega & Kumanyika, 2006). A more diverse sample may have produced different perspectives. The exclusive focus on parents was another limitation; future research should include the perspective of young people.

Attitudes towards young people who self-harm can make a considerable difference to engagement and motivation. Given the evidence that training can improve communication (De Ridder, Theunissen & van Dulmen, 2007) and that training about self-harm can increase staff knowledge and change attitudes (Saunders et al., 2012), clinicians dealing with self-harm, including emergency department staff, paediatric doctors, psychiatrists, therapists and medical students, should have relevant training.

Although self-harm is now much more widely recognised, parents can feel very isolated and unconfident in managing it and may benefit from prompt intervention, intensive early support and provision of written or online resources. Parents frequently spoke about wanting to talk to clinicians and to meet other parents. The important role of parents in helping and supporting their child should be emphasised and strengthened by clinicians. Interventions should include individual time as well as possible opportunity to meet other parents in a facilitated group (Power et al., 2009).

Public health services and advocates for young people should consider making appropriate information regarding self-harm more widely available, for instance through leaflets, websites and booklets, but avoiding providing details of self-harm methods to minimise the risk of contagion (Pirkis & Nordentoft, 2011).

In conclusion, the perspectives of parents add a significant contribution to how we understand and manage young people who self-harm. There is scope for further qualitative research with parents and siblings in order to enhance our understanding of the strategies that are likely to help, as well as research exploring young people's perspectives on support and treatment.

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Table 1: Demographic characteristics of the parents and carers and of the young people who self-harmed

Parents	N
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Relationship to young person			
	Mother	32 (1 adoptive)	
	Father	5	
Ethnicity			
	White	36	
	Black British	1	
Geographical location			
	Southeast England	5	Southwest England 3
	Northern England	2	Scotland 2
	Oxfordshire and Bucks	14	Wales 2
	Midlands of England	6	London 2
	East of England	1	

Young people who self-harmed	Females N = 29	Males N = 6
Average age started self-harm	13.8 years	16.3 years
Range	9 – 20 years	9 – 21 years
Average age at time of interview	18.7 years	22.8 years
Range	14 – 24 years	17 – 28 years
