

THE UNIVERSITY OF HULL

Deliberate Self-harm in adolescence: Parenting and Stigma

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by

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Overview

The portfolio has three parts: a systematic literature review, an empirical study and a set of Appendixes.

Part one is a systematic literature review in which empirical literature relating to the experiences of parenting a young person that engages in self-harm is reviewed and critically evaluated. It aims to present an understanding of parents' perceptions of self-harm, how it impacts themselves and others and the support available.

Part two is an empirical paper which used qualitative methodologies to explore how young people that self-harm perceive stigma, how stigma impacts on them, and how they manage it. To achieve this, young people aged 14-17 attended a semi-structured interview with the main researcher which was analysed using Interpretive Phenomenological Analysis (IPA). The emerging themes are discussed at length and linked to previous research to identify theoretical implications. The clinical implications and methodological limitations are also discussed and areas requiring further research are identified.

Part three comprises the Appendixes to support the work in the first two parts and a reflective account of the research process.

Contents

Acknowledgements.....	2
Overview.....	3
Part One: Systematic Literature Review.....	9
Synopsis.....	11
Introduction.....	12
Method.....	15
- Search strategy.....	15
- Study selection criteria.....	16
- Data extraction.....	17
- Data synthesis.....	17
- Study quality assessment.....	18
Results.....	19
- Overview of research results.....	19
- Details of included and excluded studies.....	19
- Summary of studies.....	21
- Quality assessment.....	21
- Data from the qualitative studies.....	23
- Data from the quantitative studies.....	27
- Main findings.....	31

Discussion.....	40
- Overview of research findings.....	41
- Future research methodology based on limitations of studies.....	43
- Limitations of the review.....	44
- Summary and implications.....	46
- Focus of future research.....	47
References.....	48
 Part Two: Empirical Paper.....	55
Abstract.....	57
Introduction.....	58
- Deliberate self-harm.....	58
- Stigma.....	59
- Managing stigma.....	60
- Stigma and mental illness.....	61
- Stigma and self-harm in adolescence.....	62
- Stigma, self-harm and identity in adolescence.....	64
- Rationale and research questions.....	65
Method.....	66
- Design.....	66
- Measures.....	67

- Procedures.....	67
o Ethical considerations.....	67
o Participant identification.....	68
o Data collection.....	70
- Participants.....	71
- Data analysis.....	73
Results.....	73
Discussion.....	104
- Overview of findings.....	104
- Limitations of the study.....	109
- Clinical implications and future research.....	109
References.....	113

Part Three: Appendices

Appendix A – Guidelines for authors for the systematic literature review.....	123
Appendix B – Guidelines for authors for the empirical paper.....	129
Appendix C – Search terms used for the systematic literature review.....	133
Appendix D - Rationale for the inclusion and exclusion criteria used within the Systematic literature review.....	135
Appendix E – Data extraction sheet.....	138
Appendix F – Quality checklist for qualitative studies.....	141
Appendix G – Quality checklist for quantitative studies.....	143
Appendix H - Quality assessment of qualitative studies.....	145
Appendix I – Quality assessment of quantitative studies.....	148
Appendix J – Rationale behind choosing IPA and credibility check.....	151
Appendix K – Semi-structured interview schedule.....	157
Appendix L - Demographic form.....	163
Appendix M – Ethical documentation.....	166
Appendix N - Rationale for participant Inclusion and exclusion criteria.....	187
Appendix O– Participant and parental information packs.....	189
Appendix P – Participant consent, participant assent and parental consent form.....	211

Appendix Q – Example of data analysis.....	217
Appendix R - Supporting quotes.....	221
Appendix S – Reflective statement.....	230

List of Figures and Tables

Part One: A systematic literature review into the experiences of parenting a young person that engages in self-harm.

Figure 1. Study selection process.....	20
Table 1. Data from the qualitative studies included in the review.....	23
Table 2. Data from the quantitative studies included in the review.....	27

Part Two: Deliberate Self-harm in adolescents: An exploratory study into perceptions of, responses to and impacts of stigma.

Table 1. Participant inclusion and exclusion criteria.....	69
Table 2. Participant demographics.....	72
Table 3. Super-ordinate themes with corresponding sub-ordinate themes.....	74

Part One

Systematic Literature Review

**A systematic literature review into the experiences of parenting a young person
that engages in self-harm.**

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This paper is written in the format ready for submission to the journal Parenting:
Science and Practice. Please see Appendix A for the guidelines for authors.

Synopsis

Objective: When a child falls ill, parents can play a significant role in supporting a child through recovery. The wellbeing and views of parents are therefore important in order to help ensure that they have the resources to support their child effectively. This review aims to integrate existing research on the experiences of parenting a young person that engages in self-harming behaviours. **Design:** Publications were identified using a list of selection criteria applied to the results of defined searches in several electronic data bases and manual searches of articles' reference lists. The quality of each study was evaluated and the main findings were extracted. **Results:** Twelve studies were reviewed, 8 of which employed a qualitative methodology and 4 of which employed a quantitative methodology. The main findings extracted from the studies related to making sense of and understanding self-harm, psychosocial impacts on parents, effect of self-harm on parenting style and family functioning, and support. **Conclusions:** The findings of the studies reviewed suggest that parents are keen to understand self-harm although can be ambivalent about seeking help due to the stigma around self-harm. Discovering that a child engages in self-harm can be an emotional experience and parents commonly feel unsupported. They report that support for themselves as well as for the child would be valuable.

Keywords: Self-harm, parents, experiences, adolescents

(Word count: 10, 522)

A Systematic Literature Review into the Experiences of Parenting a Young Person that Engages in Self-harm.

Self-harm has been defined as “the intentional injuring of ones own body without apparent suicidal intent” (Klonsky, Oltmanns, & Turkheimer, 2003). There are several methods of self-harm, some of the most common being self-cutting, self-burning, skin picking, hair-pulling, head banging and self-poisoning. Reported prevalence rates of self-harm among young people vary; some studies report rates as low as 2.8% (Hargus, Hawton, & Rodham, 2009) and some as high as 46.5% (Lloyd-Richardson, Perrine, Dierker, & Kelley, 2007). The inconsistency in reported prevalence rates reflects the difficult nature of determining the exact prevalence of self-harm among young people due to the secret nature of the behaviour. Self-harm typically begins in adolescence (Favazza, 2007), a stage in life which is considered particularly difficult since it involves predictable and unpredictable changes and challenges in roles, relationships and responsibilities as an individual makes the transition from adolescence to adulthood. As a result, families commonly experience anxiety, uncertainty, frustration, and ambivalent relationships during this period (Jivanjee, Kruzich, & Gordon, 2009) and these challenges are likely to be more intense for families of children with mental health difficulties (Hitchings, Natelle, & Ristow, 1999). Whereas most western families of developing adolescents follow cultural expectations that their responsibility for their children will reduce as they approach adulthood, parents of adolescents with mental health difficulties prepare to have more involved roles in their children’s lives (Jivanjee et al., 2009).

Young people describe engaging in self-harming behaviours largely to manage internal emotions by regulating affect (Klonsky, 2007) and cognition (Najmi, Wegner, & Nock, 2007), and to influence the behaviours of others (Lloyd-Richardson et al.,

2007). After reviewing research, Klonsky revealed that acute negative affect (e.g., anger, anxiety, guilt, loneliness, self-hatred and sadness) precedes self-harm, that self-harm is most often performed with the intention to reduce this negative affect, and that self-harm is mostly successful in bringing temporary emotional relief and a reduction in negative affect. More specifically Nock, (2009b) reported that people describe engaging in this behaviour with the intention of either intrapersonal-negative reinforcement (e.g., to decrease/ distract from negative thoughts/feelings), intrapersonal positive reinforcement (e.g., to generate feeling/sensation when experiencing numbness dissociation or anhedonia), interpersonal-negative reinforcement (e.g., to escape from some undesirable social situation), or interpersonal-positive reinforcement (e.g., to communicate with/seek help from others).

Research has suggested that parents and parenting style are considered to have an impact on the development and maintenance of adolescent self-harming behaviour (Newman, Harrison, Dashiff, Carol, & Davies, 2008). Research has specifically found associations between adolescent self-harm and poorer parent-adolescent communication (Tulloch, Blizzard, & Pinkus, 1997), early parent-child relationships (Bureau et al., 2010), perceived parental care and control (Diamond et al., 2005) expressed emotion (Wedig & Nock, 2007) and attachment (Irvin, 2009; Hallab & Covic, 2010). Additionally, the family environment is thought to be influential as adolescent self-harm is more likely to be present in families with lower cohesion, expressiveness, independence and organisation, and higher conflict (Jella, 2007). However, the transactional nature of families lends itself to a dynamic impact in which the act of adolescent self-harm is also considered to impact on the parents and parenting style of the adolescents.

Child psychopathology has been reported to be a major stressor for families and often impacts on parental well-being (Angold et al., 1998), parents sense of competence in managing their children's difficulties and parenting capacity (Berg-Nielson, Vikan, & Dahl, 2002). Coping with the challenges of having a child with a mental illness can lead to frustration, anxiety, grief and shame in parents (Grandón, Jenaro, & Lemos, & 2008), and the presence of a chronically ill child has been shown to negatively affect the relationship between the parent-couple (Higgins, Bailey, & Pearce, 2005; Moller-Leimkuhler, 2005). 'Family burden' has been the term used for the negative consequences that family caregivers experience when caring for an individual with mental health difficulties (Hasson-Ohayon, Levy, Kravetz, Vollanski-Narkis, & Roe, 2010). Lefley (1989) suggested that family burden is likely to be higher when families experience self-stigma, that is, when they worry that they are seen as an extension of 'the problem' or that they are responsible for the mental illness, producing feelings of shame or guilt. Due to such self-stigma, parents avoid professional help seeking for fear of embarrassment or being judged as a poor parent (Sayal et al., 2010). Liu, Lambert, and Lambert (2007) suggest that effective nursing interventions should be introduced to help the parents of a child with mental illness cope with caregiver burden and self-stigma while maintaining a functional family life.

The roles of parents and carers are changing as clinicians value more highly their experiences and expertise (Ahuja & Williams, 2010). Although mental health services recognise the importance of employing family based psychosocial interventions, in order for this to be effective, the views and experiences of parents must also be heard and valued so that they can be best supported to support their children. Over the last decade research has started to consider the experiences of parenting a young person that self-harms. The main objective of this systematic literature review

was to review the literature on parental views and experiences of having a child that self-harms. For the purpose of this review, the term ‘experience’ refers to parental perceptions of self-harm, parental coping styles and parental wellbeing.

Method

Search Strategy

A search of the literature up to and including May 2011 was conducted using electronic resources. Databases covering a range of disciplines that may conduct research on adolescent self-harm or parenting were searched for relevant articles. These databases included: PsychINFO, PsychARTICLES, MEDLINE, CINAHL, ERIC and NHS libraries (including Scopus & Web of science). A start date cut-off was not employed. Reference lists were also searched and hand searches were carried out where referenced studies were not available in electronic form. Additionally, a search was carried out for existing review papers in this area to ensure that this review would not be replicating previous work. This search did not identify any systematic literature reviews investigating the experiences of parenting young people that self-harm.

Initially the terms self-harm* AND parent* were entered into the databases as part of the scoping search. Further search terms were selected from the keywords that were stated most often by the articles generated during the scoping search. These were further refined to those terms that produced articles relevant to the question under review and which met the inclusion criteria. The final list of search terms used is shown in Appendix C.

All possible combinations of these terms were systematically entered into each database to retrieve articles that featured the terms in their title, abstract, subject or keywords. Relevant articles were identified from their titles and the selection criteria were applied to the abstract. In the case of uncertainty, full copies of potentially suitable articles were obtained so that the selection criteria could be applied fully to assess the article's eligibility. Additionally, manual searches of reference sections from articles included within the review were conducted to identify further articles of relevance. The abstracts of these articles were assessed and copies of the full text obtained in relevant cases.

Study Selection Criteria

The selection criteria were developed and refined from reading abstracts retrieved from the scoping search. The rationale for the inclusion and exclusion criteria can be found in Appendix D. Studies had to meet all inclusion and no exclusion criteria to be included in the review.

Inclusion criteria.

- Experiences of Parents/guardians of young people that engage in non fatal deliberate self-harm defined as “the intentional injuring of ones own body without apparent suicidal intent” (Klonsky, Oltmanns & Turkheimer, 2003).
- Experiences of parenting a young person that has co-morbid difficulties as long as experiences related to self-harm are distinguished.
- Parents with offspring up to the age of 25 years old.

Exclusion criteria.

- Studies that state that the offspring self-harmed with suicidal intent or committed suicide.
- Studies where the offspring have undefined mental health difficulties.
- Studies where the offspring have learning disabilities or medical conditions.
- Studies where the offspring engage in genital mutilation.
- Literature reviews or other non-empirical papers.
- Case studies.
- Studies that have not been peer reviewed.
- Studies not printed in English.

Data Extraction

Data were extracted from studies using a pro-forma designed specifically for recording data for this review (Appendix E).

Data Synthesis

Statistical methods of data synthesis were not conducted as outcome measures and methodologies of the studies were too diverse. Extracted data were collated and reported qualitatively within the review, enabling findings from the studies to be described in some detail.

Study Quality Assessment

Studies were not excluded from the review based upon quality ratings as there was not a large literature base from which studies could be drawn from to investigate the specific literature review focus whilst meeting all of the inclusion criteria. Rather than use quality as an exclusion criterion, it was decided that the quality of each paper would be rated and reported in the data synthesis tables (Tables 1 and 2). Quality ratings allowed the reviewer to make informed judgements as to how strong findings from the studies were during the analysis. Furthermore, the inclusion of studies of varying quality enabled a critique of the research literature available to be conducted and recommendations for future research to be made.

Studies identified for inclusion were assessed for quality using checklists developed by the reviewer. Due to the variation in study designs, two quality control tools were adapted; one for assessing the quality of qualitative studies (Appendix F) and one for quantitative studies (Appendix G). These were developed based on quality assessment measures by the National Institute for Health and Clinical Excellence (NICE, 2009) and Downs and Black (1998). Questions assessing the quality of general aspects of research studies were selected to form the checklists as these reflected the types of studies generated by the database searches.

A point scoring system was employed to allow comparisons across studies. Checklist items were rated as either 'Excellent', 'sound', 'poor' or 'no/unsure' for each study, and scores of either 3, 2, 1 or 0 were respectively given. Each study was given an overall quality rating, determined by summing the number of 'excellent', 'sound' and 'poor' ratings. The maximum obtainable scores were 63 on the qualitative checklist and 69 on the quantitative checklist. Appendices H and I respectively outline the quality

scoring assigned to each qualitative and quantitative study. To ensure reliability of the ratings, an independent rater, experienced in psychological research, also assessed a random sample of four of the studies. Inter-rater reliability was assessed and Cohen's Kappa found to be .67 ($p < .0001$), which is considered 'substantial agreement' by Landis and Koch (1977).

Results

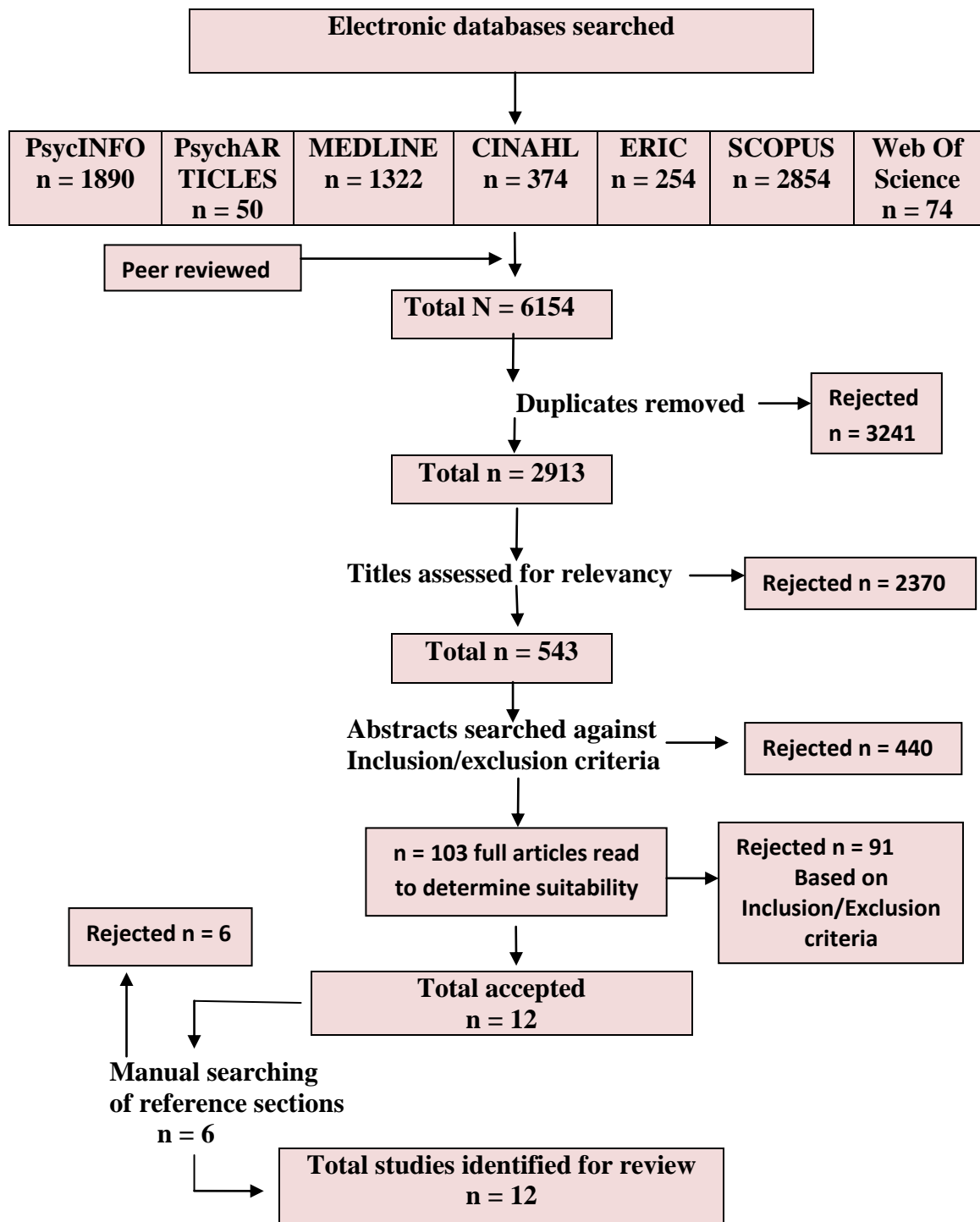
Overview of Search Results

Both quantitative and qualitative studies were included in the review due to the limited research area. Twelve studies all obtained from database searches satisfied all selection criteria and were thus included within the review. Study selection methodology is depicted in Figure 1.

Details of Included and Excluded Studies

The search strategy produced 6818 articles. These were limited to those from peer reviewed journals, leaving 6154 articles. Duplicate articles were removed (i.e. papers found in more than one database) leaving 2913 articles. 543 articles were selected through title and the abstracts read. 440 were removed according to the inclusion and exclusion criteria. The remaining 103 were obtained and full articles read. 91 were excluded on the basis of the criteria and the remaining 12 were reviewed. 6 articles were selected from manual reference searches but all were excluded upon access to the full text.

Figure 1

Study selection process

Summary of Studies

The process of study selection, shown in figure 1, led to twelve studies being included in the review, eight of which employed a qualitative methodology and four employed a quantitative methodology. The studies that used a qualitative methodology tended to directly and thoroughly explore the experiences of parenting children that self-harm. In contrast, the studies that took a quantitative approach mostly did not aim to explore the experiences of parenting a young person that self-harms but included parental input, usually in the form of measures of parental psychological wellbeing when more generally investigating youth self-harm. Subsequently, the quantitative studies tended to provide less rich, often correlational data. The studies were carried out in a number of different countries. Participants were predominantly mothers of adolescents that were recruited via a public support service or hospital. For qualitative studies, data was mainly sought by interviewing a small number of participants and findings were presented in the form of themes or categories. In contrast, the quantitative studies featured more variable designs and thus variable data collection methods, typically recruited larger samples and presented findings statistically. Tables 1 and 2 summarise the characteristics and key findings of the twelve studies.

Quality Assessment

The results of the quality assessment are presented in Appendices H and I. Quality assessment ratings for the qualitative studies ranged between 31/63 and 56/63. The qualitative studies were of a fairly consistent high quality with only one study standing out as fairly poor in quality. The main strengths of such studies were their clearly focused rationale and objectives, and their appropriate choice of qualitative

methodology. High ratings were also given for well detailed participant demographics, sampling strategies, and data collection methods. Furthermore, the majority of studies consistently documented rigorous data analysis and reported rich data in the form of relevant and coherent findings. Several of the studies performed less well at underpinning the values of their methodological approach, stating participant inclusion and exclusion criteria and reporting limitations. Furthermore, samples often consisted of parents of young people attending mental health services and therefore were not representative. Two of the studies included the same sample of participants but took different focuses, providing data on different aspects of parental experience.

Quality assessment ratings for the quantitative studies were much more variable, ranging from 18/69 to 56/69. A couple of the studies did not accurately define their design, outcome measures or data collection methods and in addition, the lowest scoring study did not report its data analysis strategy, implications or limitations. All quantitative studies reported their findings clearly and related their conclusions to the main questions.

Table 1

Data from the qualitative studies included in the review.

Reference (Country)	Study aim	Participant characteristics	Design & Analysis	Findings (Quality Rating)
Oldershaw, Richards, Simic, and Schmidt (2008) (UK)	To gain the views of parents of adolescents who self-harm on: (a) History of self-harm and health service provision. (b) Sense-making of self-harm behaviour. (c) Emotional and personal impact. (d) Parent skills and hope for future.	12 Parents/carers (9 mothers, 2 fathers, & 1 grandmother) of adolescents aged 13-18 referred to community Child and Adolescent Mental Health Services (CAMHS) in Croydon for self-harm.	Individual semi-structured interviews lasting approximately 1 hour with parents. Interpretative Phenomenological analysis (IPA).	4 key themes 1. The process of discovery 2. Making sense of self-harm 3. Psychological impact of self-harm on parents 4. Effect of self-harm on parenting and family (54/63)
Byrne et al., (2008). (Ireland)	To describe parents/carers experiences of their child's self-harm to identify parents support needs.	15 Parents and 10 carers of children (aged 16 or younger) who had engaged in self-harm and were supported by paediatric	Parents/carers focus group meeting. Conceptual analysis conducted.	7 central themes 1. Support 2. Emotions 3. Parenting 4. Family

		emergency, 24 CAMHS or 10 Family support services.	Flip chart records, debriefing notes and participant feedback forms also analysed.	5. Psycho-education 6. Managing self-harm 7. Other: beliefs, school, internet (51/63)
Raphael, Clarke, and Kumar (2006) (UK)	To explore parental response to self-harm to better understand their concerns, expectations and experiences to inform education and training to support parental needs.	9 Parents (5 mothers and 4 fathers) of 7 young people aged 16-24 who had self-harmed.	Unstructured interviews with parents (1 face to face interview within 24 hours of self-harm and 1 telephone interview 3-8 months later). Books, television documentaries, and radio interviews exhibiting family views were examined. Phenomenological approach.	3 main themes 1. Emotional responses 2. What to do next? Where to find information and support 3. Health professionals (55/63)
McDonald, O'Brien, and Jackson (2007).	To examine the experiences of mothers of self-harming adolescents and to gather insight into its impacts on their wellbeing	6 mothers (5 married & 1 single parent) of 8 children (6 daughters and 2 sons) aged 12-21 who were	One to one interviews lasting 60-90 minutes. Hermeneutic Phenomenology.	6 main themes 1. Dilemmas of guilt and shame 2. Searching for a reason 3. Echoes from other relationships

	and the family. (Australia)	presently/ previously self-harming.		4. Embarrassment 5. Becoming hyper vigilant 6. Diminished Roles (56/63)
Rissanen, Kylma, and, Laukkanen (2008). (Finland)	To describe self-mutilation from the viewpoint of parents of self-mutilating adolescents.	4 Parents (3 mothers & 1 father) of female adolescents that self-harm. 2 parents were divorced and 2 were married. All had other children. 2 were employed, one was an adult student and one was retired.	Descriptive design using one to one interviews. Transcribed data was subjected to inductive content analysis.	4 main categories emerged: 1. The phenomenon of self-mutilation 2. Factors contributing to self mutilation 3. The purposes of self-mutilation 4. The sequels of self-mutilation (43/63)
Rissanen, Kylma, and, Laukkanen (2009). (Finland)	To examine parental views on how to help adolescents who self-mutilate.	4 Parents (3 mothers & 1 father) of female adolescents that self-harm. 2 divorced and 2 married. All had other children. 2 were employed, one was an adult student and one was retired.	Descriptive approach using one to one interviews. Transcribed data was subjected to inductive content analysis	3 main categories emerged 1. A description of an adolescent that self mutilates 2. Ways to help the self-mutilating adolescent 3. Ways to help the parents and family (44/63)

Yip, Ngan, and Lam (2003) (Hong Kong)	To explore parental influence on and response to adolescent self-cutting.	3 adolescents (2 female & 1 male aged: 16, 14 & 14) who self-cut, 3 peers and 3 parents (1 father and 2 mothers). Recruited via purposive sampling.	Inductive analysis of interview transcripts.	5 Key ideas 1. Parental Response 2. Communication 3. Dealing with parent-child conflicts behind self-cutting 4. Dealing with teacher-student conflicts behind self-cutting 5. Peer problems (42/63)
Nixon, McLagan, Landell, Carter, and, Deshaw. (2004) (Canada)	To illustrate the development and initial pilot of groups for adolescents who self-injure and their parents.	Parents of 6 young females (aged 14-18) attending a youth mental health program with a history of 2-3 self-injuring behaviours in the past month.	Intervention study. Evaluation questionnaires asking respondents to identify 1. Three main things learnt in each session. 2. Most and least helpful aspects of each session. 3. Additional comments. No analysis stated.	Overall findings: - Group set up was beneficial (peer support, validation). - Importance of removing shame. - Need to foster independence in adolescents and not “smother”. - Need to decrease reactivity to self-harm and improve communication. - improved relationship following intervention. (31/63)

Table 3

Data from the quantitative studies included in the review.

Reference (Country)	Aims of the study	Participants	Design and analysis	Measures	Main findings (Quality Rating)
Power et al., (2009) (Ireland)	To develop and evaluate the effectiveness of a group programme to support parents and carers of children who have engaged in self-harm.	46 parents (31 (67%) mothers and 15 (33%) fathers) of 32 (8 male, 24 female) children and adolescents (aged 16 years and under) who were attending mental health services having engaged in or expressed thoughts of self-harm.	Repeated measures over 3 time points. Effects of attrition: 46 parents completed measures at time 1. 32 parents (70%) completed measures at time 2. 17 parents (37%) completed measures at time 3.	GHQ SDQ (Parental version). KPS Study specific challenges and goal scales measured parents' ratings of their own defined challenges and goals.	76% of parents met the criteria for psychological distress at time 1. The mean score on the GHQ reduced over time. High levels of psychological distress were associated with previous episodes of self-harm. Parents reported that children had significantly lower levels of total difficulties (SDQ) at times 2 and 3 than at time 1. Parental satisfaction increased across the 3 time periods. Parents rated their challenges significantly more highly at time 1 than at times 2 and 3. Gains were maintained 6 months after the programme. (57/69)

Mojtabai and Olfson (2008) (UK)	To investigate the rate and predictors of parental detection of youth self-harm.	7036 dyads (a young person aged between 11-16 and one parent). 3746 parent-child dyads in 1999 and 3290 dyads in 2004.	Survey across 2 time points.	- DAWBA - SDQ (child version). - One question from SDQ (parent version). - GHQ - 5 questions from the General functioning scale of the FAD.	A history of youth self-harm was reported by 463 (6.6%) of children/adolescents and 190 (2.7%) of parents. Reports were concordant for 106 dyads, thus less than 1 in 4 parents knew about their children's self-harm. Parents that reported self-harm in their child/adolescent experienced more psychological distress than parents unaware of self-harm. Parental detection of self-harming behaviour was strongly associated with help-seeking. (49/69)
Gilliland (1990) (Ireland)	To examine the extent to which young people that self-injure differ from psychiatric controls.	Experimental group: Parents of 25 young people (aged 13 to 16) admitted to hospital following an act of self-injury from February 1986 to June 1987. Control group:	Questionnaire.	Study specific questionnaire eliciting information on; Family composition, reason for overdose, school performance, peer	Experimental group perceived the most likely precipitating factors to self-injury to be; rows with friends, rows with parents and marital rows. Experimental group were less likely to be concerned about their child's mental state (32%) than the control group (67%). Significantly more of the control group parents

		Parents of 45 young people referred to a child psychiatry department.		contact and the effect of ‘troubles’ on families.	had been contacted by school (regarding concerns) than the self-injury group. (18/69)
Cassidy et al., (2009) (Ireland)	To investigate rates of repetition of self-harm in children presenting to A&E	39 parents (34 biological parents, 2 adoptive parents and 3 guardians) of 31 female and 8 male children. 10 children (under 18 years old). All children had presented to a paediatric centre between 2000 and 2005 with self-harm.	Baseline information was collected (review of case files for demographics). Follow up (duration 1-6 years after baseline) with telephone interview based on study specific questionnaire.	Study specific questionnaire: 1. Child’s satisfaction with their mental health status & quality of life 2. Parental satisfaction with child’s mental health and child’s ability to cope with stress (likert scale). 3. Level of parental concern regarding ongoing risk.	Parents who reported being least satisfied with their child’s mental health and ability to cope with stress had children who were more likely to repeat self-harm – correlational. The relationship between repeat self-harm and ongoing parental worry regarding repetition was significant. Of the 8 children that repeated self-harm, 4 parents reported ongoing worry of future self-harm incidents. Parents rated child mental health more positively if they perceived the self-harm to be impulsive or reactive to a recent stressful event. (35/69)

General health questionnaire (GHQ-12; Goldberg, 1992) measured parents psychological distress, Parent version of the strengths and difficulties questionnaire (SDQ; Goodman, 1997) measures parents views of the reduction of young people's difficulties, Kansas parenting satisfaction scale (KPS; James et al., 1985) measures parental satisfaction (with themselves as a parent, the behaviour of their children and their relationship with their children), Development and wellbeing assessment structured interview (DAWBA; Goodman, Ford, Richards, Gatward, & Meltzer, 2000) measured child reported self-harm, Child version of SDQ (Goodman, 1997) measured child reported emotional or behavioural problems, MacMaster Family activity device (FAD; Epstein, Baldwin, & Bishop, 1983) measured communication of distress in the family.

Main Findings

Tables 1 and 2 present the methodology and overall findings of the studies. The focus of the studies assembled around four key areas; making sense of and understanding self-harm, psychosocial impacts on parents, effect of self-harm on parenting/family and support.

Making sense of and understanding self-harm.

While some parents unintentionally discovered their child's self-harming behaviours (Yip et al., 2003), others reported that they had suspicions of self-harm before their child disclosed but chose the 'wait and see' approach. Parents noticed that their children concealed the wounds so that they could not see them and often experienced denial from their children when they confronted them about the self-harm (Yip et al., 2003). Confirmation of the self-harming behaviour was often achieved through outside agencies i.e. school (Oldershaw et al., 2008). In the majority of the studies (Oldershaw et al., 2008; Byrne et al., 2008; Rissanen et al., 2008; Rissanen et al., 2009; McDonald et al., 2007; Yip et al., 2003), once parents discovered that their child was engaging in self-harm, they reported attempts to understand the phenomena of self-harm and why their child was engaging in it. Parents found it difficult to understand and empathise with since children tended not to be forthcoming with explanations (Oldershaw et al., 2008) and thus parental acceptance of self-harm was reported to be a gradual process. Parents acknowledged that self-harm is undiscussed (Rissanen et al., 2008) and were keen to know more about self-harm, suggesting the development of a self-harm information leaflet for healthcare centres (Byrne et al., 2008). Parents reported that while their children appear externally well, internally they

believe they are very sensitive with low self esteem, consider themselves inferior to others and feel lonely and ashamed of their self-harm (Rissanen et al., 2009).

Causal factors/triggers.

Causal factors to self-harm were categorised into those relating to the adolescent; puberty, difficult peer relationships (Gilliland, 1990; Yip et al., 2003) & loneliness, and those relating to the family; differential sibling treatment, lack of motherliness & troubles within the family unit (Rissanen et al., 2008; Gilliland, 1990). Parents felt responsible, worried that their children's self-harm was a reaction to adverse family circumstances such as marriage breakdowns and felt that their attention to such family crises might have lead to their children feeling unimportant (McDonald et al., 2007). Furthermore, causal factors were categorised into emotional difficulties, situational difficulties and personality factors (Oldershaw et al., 2008). When parents perceived the self-harm to be impulsive or reactive to a recent stressful event they rated their child's mental health more positively (Cassidy et al., 2009).

Purpose/function of self-harm.

Parents acknowledged that self-harm serves a function in their children's lives (Oldershaw et al., 2008). Functions identified were divided into 2 categories (Rissanen et al., 2008): purposes relating to the young person, such as to cope with negative emotions or to provide control (Oldershaw et al., 2008; Byrne et al., 2008) and purposes relating to others, such as emotional expression, attention-seeking, a cry for help or protesting against or protecting the mother (Oldershaw et al., 2008; Byrne et al., 2008). Parents also saw self-harm as a contagious, addictive phase of fashion influenced by peers (Oldershaw et al., 2008; Rissanen et al., 2008) and the internet (Byrne et al., 2008).

Consequences.

Parents divided the consequences of their children engaging in self-harm into two categories (Rissanen et al., 2008). The first related to consequences for the adolescent, such as levels of emotion and potential difficulties in the future due to permanence of scarring. The second related to consequences for family/peers, such as a closer parent-child relationship and younger siblings receiving less attention at home.

Psychosocial impact on parents.

Parents that were aware of their childrens self-harming behaviours tended to experience more psychological distress than parents who were unaware of the self-harming behaviour (Mojtabai & Olfson, 2008). Despite suggestion that parents of children that self-harm are less likely to be concerned about their child's mental health than parents of children with more general mental health difficulties (Gilliland, 1990), parents predominantly reported strong and emotional reactions to their child's self-harming behaviour. Having a child that self-harmed was reported to be traumatic and distressing for parents who felt devastated, shocked and confused by it (Raphael et al., 2006). Upon discovery of self-harm, common emotions felt by parents were those of disappointment, sadness and loss for their child (Oldershaw et al., 2008; Raphael et al., 2006). Self-harm also elicited panic and apprehension in parents who were fearful of future incidents (Byrne et al., 2008) or accidental fatal consequences (Yip et al., 2003). Dissatisfaction with a child's mental health and higher levels of worry and concern regarding repetition of self-harm was experienced by parents whose children had repeatedly self-harmed in the past (Cassidy et al., 2009). Parents reported feeling anger and frustration which was at times directed at the child whose behaviour was seen to be

disrupting the family (Byrne et al., 2008) and at times directed towards healthcare professionals who were perceived as dismissive of their emotional state (Raphael et al., 2006). Parents developed somatic and psychological symptoms such as sleeplessness and depression which sometimes resulted in them being unable to work (Raphael et al., 2006). Some parents did not know how to manage their child's self-harm and felt tired and burdened with parental responsibility (Yip et al., 2003). They described feeling inadequate, helpless, lost and out of control with the situation and reported that CAMHS were powerful in alleviating or heightening their distress (Oldershaw et al., 2008).

Guilt and shame were two prominent emotions felt by parents (Byrne et al., 2008; McDonald et al., 2007). Parents were upset that their child was so unhappy and were saddened that they enacted their unhappiness in such a way (McDonald et al., 2007). Parents felt a sense of failure and blamed themselves for failing to recognise or prevent the self-harm (Raphael et al., 2006; Byrne et al., 2008). Mothers felt guilty about their denial or minimisation of their child's difficulties, not reading the warning signs and for their delay in getting treatment (McDonald et al., 2007). Mothers were aware of the stigmatising nature of self-harm and felt that they couldn't talk to anyone about their child's self-harm for fear of judgement which contributed to their shame (McDonald et al., 2007; Byrne et al., 2008; Raphael et al., 2006). They were embarrassed by the visibility of scars and their children's self-harm was often a matter of secrecy with parents making only selective disclosures to family/friends (McDonald et al., 2007).

Effect of self-harm on parenting/family.***Bond with child.***

Self-harm challenged parents' beliefs in the strength of their bond with their child (Raphael et al., 2006). Some parents questioned their relationship with their child, feeling that the trust in the relationship had been compromised (Byrne et al., 2008) and that they may have failed them (McDonald et al., 2007). Others felt that the self-harm had helped to strengthen the parent-child relationship (Oldershaw et al., 2008; Rissanen et al., 2008). Upon discovery, parents were keen to rebuild the parent-child relationship, recognising that communication is important (Nixon et al., 2004). They were keen to help their child express emotions and develop adaptive coping strategies (Byrne et al., 2008).

Confidence in parenting and parenting skills

Parents questioned their skills and competence as parents and felt a sense of failure (Raphael et al., 2006; Byrne et al., 2008; McDonald et al., 2007). They often struggled for their children's rights and were eager to receive the best care available. Parents reported that their knowledge of the self-harm influenced their behaviour as a parent and their experiences of family life (Oldershaw et al., 2008). The feeling of guilt led them to believe they hadn't been caring enough and to regress from allowing the child to become more independent to becoming more watchful (McDonald et al., 2007; Oldershaw et al., 2008; Nixon et al., 2008). Mothers reported being hyper vigilant to their child's activities having read diaries and listened to phone calls with friends but felt guilty that they were violating their child's privacy (McDonald et al., 2007). Parents attempted to reduce their child's distress and compensate for their perceived poor parenting by giving their children materialistic gifts (Yip et al., 2003). Parents felt that a

child that self-harms has a position of power within the family and subsequently parents felt disempowered by the self-harm. They felt restricted at maintaining normal discipline and boundaries as they were keen to take a gentle approach for fear of ‘doing something wrong’ and precipitating another self-harm incident (Raphael et al., 2006; Oldershaw et al., 2008; Byrne et al., 2008; Yip et al., 2003).

Impacts on the family.

Self-harm was reported to impact on the whole family, disrupting family dynamics and impeding family functioning since the self-harming behaviour became the focal point of family life and the child held a position of power within the family (Byrne et al., 2008; McDonald et al., 2007; Oldershaw et al., 2008; Raphael et al., 2006). Parenting a child that self-harms was reported to at times lead to marital discord as mothers felt unsupported by their husbands in managing the self-harming behaviour (Raphael et al., 2006) and communication between the parents regarding the self-harm was poor (Yip et al., 2003). Dealing with a child’s self-harm often took mothers away from usual roles at work and home, leading to them feeling guilty that they weren’t meeting the expectations of themselves or others (McDonald et al., 2007). They felt as though they had to deny their own needs and make changes to/limit their own lifestyle for the sake of their child that self-harms (Oldershaw et al., 2008; Raphael et al., 2006). Mothers reduced work hours or left paid employment to play more active roles in caring for their child. This caused guilt in relation to their husbands who had to assume full financial responsibility (McDonald et al., 2007) and parents felt that the extra time, energy and attention spent on the self-harming child meant they had neglected the parenting of their other children (Rissanen et al., 2008). This led to them feeling trapped in guilt that they could not care for or meet the needs of all members of their family

sufficiently, which led to increased carer burden and stress (McDonald et al., 2007; Oldershaw et al., 2008). Additionally, parents reported that siblings felt ‘devastated’ and ‘broken hearted’ by the knowledge of the self-harm (Byrne et al., 2008).

Support.

Three aspects of support were identified by Byrne et al. (2008); A parents need for support; lack of support from services; and benefits of peer support.

Healthcare system.

Parents valued healthcare staff that had knowledge about self-harm, explicitly and realistically cooperated with family and communicated between themselves (Rissanen et al., 2009). However, on the whole, parents felt that resources in healthcare are inadequate for providing appropriate and necessary care for adolescents who self-harm (Rissanen et al., 2009). Parents felt invisible when not acknowledged as significant others in their children’s lives and questioned their insight and role as parents when information was held from them (in confidentiality). Furthermore, being excluded from decision making fostered feelings of powerlessness and helplessness (Raphael et al., 2006). Parents perceived health and social care professionals to be sceptical of their helping behaviours (Rissanen et al., 2009) and felt that when they stood up for their children’s rights, the professional caregivers saw them as troublesome, difficult and hard to handle. Parents felt anger towards health professionals who did not acknowledge or were insensitive to their feelings (Raphael et al., 2006) and thought that providing support for the self-harming adolescent is not always sufficient since the whole family often need support. They suggested that

therapy for all parents who discover that their child self-harms would be helpful in order to discuss and handle the emotions evoked with raising a child that self-harms (Rissanen et al., 2009). Parents receiving such specific support found it very beneficial (Oldershaw et al., 2008). Although parental distress and anxiety was exacerbated by feelings of helplessness due to perceived lack of information and support available from health professionals and schools (Raphael et al., 2006), the opportunity for peer support was valued and believed to be important in managing the impact of self-harm (Byrne et al., 2008; Nixon et al., 2004).

Two of the studies evaluated intervention programmes for the parents of adolescents that had self-harmed (Nixon et al., 2004; Power et al., 2009). Both interventions invited parents to group sessions in which information, support, guidance on management of the self-harm and advice around family issues such as communication and parenting was provided. Power et al. (2009) assessed parental psychological distress at 3 time points; before intervention, immediately after intervention and 6 months after intervention. They found that parental distress decreased significantly from time 1 to times 2 and 3 and that parental satisfaction had increased significantly by time 3 in comparison to times 1 and 2. Additionally, findings suggested that higher levels of parental psychological distress at time 1 were associated with previous episodes of self-harm. Parents rated their child's difficulties as significantly lower after the intervention than they had been before the intervention. Such a reduction in distress following successful intervention implies that parental distress was related to their child's self-harming behaviours. Parents receiving support in the study conducted by Nixon et al. (2004) felt that the intervention had helped them to develop a

better understanding of their children and that subsequently their relationship with their child, particularly communication, had improved. They reported learning of the need to foster independence in their children and decrease reactivity to the self-harming behaviour. Parents emphasised the benefits of group work, particularly in accessing other parents in similar situations, sharing experiences and feeling validated.

Management.

Parents saw advice on how to prevent or manage future episodes of self-harm as a priority (Byrne et al., 2008). Parents identified several ways in which a child that self-harms can be helped (Rissanen et al., 2009). Firstly, they reported that adolescents can help themselves by taking part in activities that can be done alone (i.e. writing about bad feelings, swearing to relieve tension & leaving a situation that can lead to self-harm). Alternatively, they reported that adolescents can help themselves by taking part in explicit activities in relation to others (forming new relationships, discussing the self-mutilation with others, giving sharp objects to family members & asking mother to attend doctor's appointments). Additionally, parents felt that an adult sibling, peer or friend can act as a helper as they can intervene in the self-harm behaviour, show their care by listening and discussing self-harm with the child and support an adolescent in obtaining professional care. Furthermore, parents felt that school personnel could be a good source of help to a young person that self-harms since they consider it easier to notice self-mutilation at school as opposed to at home. Parents thought that teachers could help in several ways; interacting with self-mutilating adolescents, explicitly talking about self-mutilation, intervening with self-mutilation and co-operating with parents. While parents acknowledge that they are often considered the principle

helpers, they feel that they need more information about self-harm in order to understand it better and subsequently recognize and manage it.

Stigma.

Parents initially found it difficult to speak of self-harm and tended to share the child's ambivalence about seeking support with a 'brush it under the carpet' approach (Oldershaw et al., 2008; Yip et al., 2003). Although parents felt they needed to talk to professionals about their children's self-harm, they did not know who to speak to for fear of stigma associated with self-harm which left them feeling embarrassed (Yip et al., 2003). Therefore they found it difficult to engage with health services for fear of how they would respond, anticipating a negative response (Raphael et al., 2006). Parents recognised that they may have initially been unintentionally unresponsive to interventions by health care professionals (Raphael et al., 2006) since support was not usually sought until deterioration had occurred (Oldershaw et al., 2008; Yip et al., 2003). Parents reported that outside agencies i.e. schools, impacted on help seeking by either encouraging or curbing it (Oldershaw et al., 2008).

Discussion

The current paper aimed to undertake a thorough systematic literature review of studies investigating the experiences of parenting young people that self-harm. The findings identified in the majority of the twelve studies reviewed are reports of individual experiences and may not be generalisable to all parents who have children that engage in self-harming behaviours. However, four key areas surfaced from the findings that would suggest that some experiences are shared. The four key areas were

making sense of and understanding self-harm, psychosocial impacts on parents, effect of self-harm on parenting/family and support. Within each of these areas were several sub-topics. Since the aims of the studies varied widely, not all of the key areas were identified in each study.

Over View of Research Findings

The findings suggested that upon discovery that a child is engaging in self-harming behaviours, parents attempt to develop an understanding of self-harm and why their child has engaged in it (Oldershaw et al., 2008; Byrne et al., 2008; Rissanen et al., 2008; Rissanen et al., 2009; McDonald et al., 2007; Yip et al., 2003). Parents report feeling overwhelmed with emotion to the degree that there is an initial element of denial and avoidance to intervene and manage the child's self-harming behaviours (Oldershaw et al., 2008; Yip et al., 2003). This could be considered due to the stigmatising nature of self-harm, which prevents parents seeking help from services for fear of negative judgement and blame (Yip et al., 2003; Raphael et al., 2006). According to Goffman (1963), stigma experienced by family members of children with mental health difficulties is called 'courtesy stigma'. Such 'courtesy stigma' is said to develop when parents internalise feelings of shame or embarrassment as a result of rejection, avoidance or discrimination by others who blame them for their child's stigmatising attribute (Corrigan & Miller, 2004). Moses (2010) reports that 'courtesy stigma' can impact on how parents behave towards their child, reinforcing the child's sense of stigma, feelings of shame and acts of secrecy. In line with this, the findings of this review suggest that the most prominent emotions that parents experience when they have a child that self-harms is guilt and shame (Raphael et al., 2006; Byrne et al., 2008;

McDonald et al., 2007). Furthermore, parents reported feeling a sense of failure and embarrassment which can lead to them feeling isolated and afraid to seek support. Their confidence in their parenting capacity is knocked and parents feel disempowered (Raphael et al., 2006; Byrne et al., 2008; McDonald et al., 2007; Oldershaw et al., 2008). Due to fears of precipitating further incidents, parents have difficulty maintaining discipline and boundaries and as a result, their parenting style changes. Parents report that the time, energy and attention that goes into supporting a child that self-harms often results in their other roles being neglected (Rissanen et al., 2008; McDonald et al., 2007; Oldershaw et al., 2008). As the child becomes the focal point of the family, a parent's relationship with a spouse and other offspring can be impacted due to the adjustment in family dynamics and functioning. In line with existing literature on carer burden (Hasson-Ohayon et al., 2010), the parents participating in the reported studies expressed feelings of burden and stress related to caring for their self-harming child.

Parents feel that Healthcare services are inadequate at providing appropriate and necessary care and support for young people that self-harm and their families (Rissanen et al., 2009; Raphael et al., 2006). Parents can feel left out of care planning or decision making and subsequently can feel undervalued as a supportive resource for their children. This is in line with research that has suggested that healthcare professionals distance themselves from young people that self-harm and their families (Smith, 2002). Furthermore, parents feel that their own emotions often go unacknowledged and would value specific support from healthcare professionals to help them manage the difficulties of parenting a child that engages in self-harm (Rissanen et al., 2009; Oldershaw et al., 2008).

Future Research Methodology Based on Limitations of Findings

Parents and care-givers are often asked to function in a supportive role for young people with self-harming behaviours. This review highlights the shortage of studies, particularly studies utilising quantitative methodologies that have explored the effects on parents of providing such support (Barksdale, Walrath, Compton, & Goldston, 2009). Future research directly investigating the experiences of parenting a young person that engages in self-harm would therefore benefit from a quantitative approach. Studies utilising standardised measures to examine elements of parental coping or wellbeing would provide valuable information which could help shape the development of support packages and programmes for parents of self-harming children and adolescents.

Both intervention studies, although intended to be pilot studies, featured considerable limitations. The study conducted by Power et al. (2009) lacked a control group and failed to identify and quantify any additional sources of support that participants were receiving. Therefore it was not possible to distinguish with confidence how many of the benefits were a result of the intervention reported. In credit to Power et al. (2009), they comprehensively explored parental views of support needs (Byrne et al., 2008) and used them to inform the development of the programme. The second pilot intervention study (Nixon et al., 2004) reported a treatment programme that was cut short and was implemented and facilitated by individuals who did not have training in the model being used. Based on these initial pilot intervention studies, future intervention studies should incorporate control groups, control for confounding variables, dedicate time to preparation of programme material and content and continue to involve service users in their development.

Since studies used in this review tended to use the female parent as the participant, the paternal parental perspective has been largely underrepresented. It was unclear why this was so, but future research might focus on the experiences of the father and explore how these are comparable to the mother. Future studies should also be sure to state their inclusion and exclusion criteria more clearly and to more thoroughly define self-harm so that its functions and intent are more apparent. They should attempt to use more representative samples, including parents of young people that do not access support or attend services since the experiences of such parents are likely to add richer, more diverse data. Additionally, the studies reviewed were carried out in several different countries. Since parenting is a practice which is culturally influenced (Bornstein et al., 1998), there may be issues in drawing conclusions from the studies to inform UK practice.

Finally, it is possible that the guilt and shame parents feel regarding their children's self-harm may have inhibited them from expressing the true extent of their views and feelings in the studies reviewed. Such denial or reservation to discuss child self-harming behaviour is in keeping with literature investigating mother's awareness of self-harm (Sansome, Wiederman, & Jackson, 2008). Fears of judgement and being perceived as a bad parent may have left participants reticent to openly disclose their personal experiences of raising a child that self-harms. If this were so, it is possible that the findings obtained from the studies reported in this review are not truly accurate.

Limitations of the Review

Search terms used produced a large number of search results. Although this aided a thorough literature search, the vast quantities of initial articles makes accurate

replication of this review difficult. Although at first glance many of the articles appeared to explore the impacts of parenting towards the aetiology of self-harm, it was deemed important to confirm that such papers did not include parental input before rejecting them from the search. Therefore, to ensure that relevant information was not missed and therefore that the review was unbiased, it was considered necessary to read the full texts of a large quantity (103) of articles. This made literature searching a lengthy process which may be vulnerable to replication error.

Defining inclusion and exclusion criteria was difficult due to the often vague definitions and descriptions of self-harm found in studies. Literature implies core differences in the functions and intent of self-harm as defined in this review as opposed to suicide attempts (Brausch & Gutierrez, 2010). Therefore it is possible that parental experiences of these two phenomena are not the same. Considering this, the current review attempted to distinguish parents of young people that had self-harmed with suicidal intent from those that had self-harmed without suicidal intent. It was decided that studies would be excluded if they stated that self-harming behaviours were an attempt at suicide and included where self-harming behaviours had a non-suicidal intent. In order to avoid excluding appropriate data, studies that did not explicitly state the intent of the self-harming behaviour were included. Subsequently, due to the lack of clarity of intent of self-harm in the studies reviewed, it is possible that the parental experiences detailed in this review are not purely in relation to self-harm without suicidal intent but partly in relation to parenting suicidal children too. Stricter and more defined inclusion and exclusion criteria would improve this review, although likely reduce an already limited research base even further.

Two different quality assessment checklists were developed: one to rate qualitative studies and one to rate quantitative studies. Although this allowed each study to be quality assessed using a focused and relevant checklist, it made making confident comparisons between the quality of qualitative and quantitative studies less achievable.

Summary and Implications

Since parents often play a significant role in a child's life and wellbeing and tend to be one of the main support systems around a child, when a child falls ill, a parent can potentially be a great resource in that child's recovery. This review aimed to review studies that have looked into the experiences of parents who have children that engage in self-harm. The review found that upon discovery of a child's self-harm, parents are keen to seek information and understanding about self-harm and get an idea as to how they can help support the child to avoid future incidents. This could be facilitated if there were easier and quicker access to resources and support. Since parents report feeling emotionally impacted yet mostly unsupported by services, a greater consideration of the impacts on parents should be had so that parents can be effectively supported to manage their child's difficulties. Parents would benefit from time to express their concerns and feelings and advice on how they can work with services to support their child. When developing intervention programmes for parents, some degree of focus should be aimed towards facilitating better parent-child communication and interaction, acknowledging the role of parent-child relationships. It is however important that support services do not overlook the individuality of each parent and family system. Support and care should be family-focused and tailored

towards the specific needs of the parents, bearing in mind that findings suggest that parents will feel ready to access support at varying time points.

The Focus of Future Research

Further intervention studies looking at support for parents to support their children would be valuable in order to find a style of support that is effective and that parents are happy with. Such studies should be developed from the findings of the two initial pilot intervention studies (Power et al, 2009 & Nixon et al, 2004) and informed from strategies and ideas suggested in the literature (Selekman, 2010; Toumbourou & Gregg, 2002; Trepal, Webster & MacDonald, 2006). Additionally, research that looks into the impacts on siblings might also be valuable since this emerged as a parental concern and might be an area that would benefit from further exploration so that support can be put in place if necessary.

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Part Two

Empirical Research

**Deliberate self-harm in adolescence: An exploratory study into perceptions of,
responses to and impacts of stigma.**

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This paper is written in the format ready for submission to the journal of Research on
Adolescence. Please see Appendix B for the guidelines for authors.

Abstract

This qualitative study aimed to explore how young people that self-harm view stigma, how they manage it, and how it impacts on them. Six young people aged 14-17 who had recently engaged in self-harm were recruited from Child and Adolescent Mental Health Services (CAMHS). Participants took part in a semi-structured interview and the content was analysed using interpretative phenomenological Analysis (IPA). Five super-ordinate themes emerged from the data and within each were a number of sub-ordinate themes. Themes identified suggest that young people vary in the strategies used to manage stigma and the degree to which they are impacted by it. Limitations of the study, clinical implications of its findings and areas for future work are discussed.

Keywords: self-harm, stigma, adolescents

(Word Count: 15, 255)

Deliberate Self-harm in Adolescents: An Exploratory Study into Perceptions of, Responses to and Impacts of Stigma

Deliberate Self-harm

Deliberate self-harm in this study has been defined as “the deliberate, direct destruction or alteration of body tissue without conscious suicidal intent but resulting in injury severe enough for tissue damage (e.g., scarring) to occur” (Gratz, 2003, p.193). Favazza (2007) reported the life time prevalence of self-injurious behaviour to be 17% with the average age of onset being between 15 and 16 years of age. Klonsky and Olino (2008) reported that in comparison with adult populations, self-harm appears to be more common in adolescents and young adults and that approximately 14% of adolescents report a history of one or more self-injurious behaviours. This figure is considered to be increasing (Brunner et al., 2007). 64.6% of young people that self-harm do so by cutting, making this the most common method (Fortune & Hawton, 2007). Upon evaluation of relevant literature, it was reported that although approximately 25,000 adolescents present to hospitals in the United Kingdom (UK) each year following non-fatal deliberate self-harm, it is estimated that only one in ten adolescents who intentionally harm themselves attend hospital (Fortune & Hawton, 2007). This indicates the huge and under recognized prevalence rates of child and adolescent self-harm. Self-harm in young people has become an increasing concern for health services in the UK (Department of Health [DoH], 2002), particularly since repetition of self-harm in individuals aged 13-18 is high (Hawton, Kingsbury, Steinhardt, James, & Fagg, 1999; Nadkarni, Parkin, Dogra, Stretch, & Evans, 2000).

Stigma

Goffman (1963) described stigmatized attributes as those that are deeply discrediting in particular contexts and which tend to become the dominant identities by which a person is perceived. 'Public stigma' comprises reactions of the general public towards a group based on stigma about that group. Corrigan et al. (2000) developed a social-cognitive model of public stigma which consists of three components; stereotypes, prejudice and discrimination. Stereotypes are viewed as knowledge structures that are learned by most members of a social group and allow people to generate impressions and expectations of individuals who belong to a certain 'group'. Although there is a general awareness of such stereotypes, not all members of the public endorse them. Those that do endorse them and generate negative emotions as a result are considered prejudiced. Prejudice, which is a cognitive-affective response, leads to discrimination, which is the behavioural reaction. Dinos, Stevens, Serfaty, Weich, and King (2004) identified the most common consequences of feeling stigmatised as anger, depression, fear, anxiety, isolation, guilt, shame, and embarrassment. Furthermore, such consequences ultimately lead to a reduction in self esteem and self-efficacy (Berge & Ranney, 2005; Corrigan, 2004). The modified labelling theory (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989) proposes that individuals with stigmatising attributes anticipate devaluation and discrimination and in an attempt to avoid disapproval and rejection, may withdraw from social interactions. Sartorius (2002) states that stigma attached to mental illness and the negative discrimination that is usually associated with stigmatization are the most significant barriers facing the treatment of mental illness today. More specifically, literature suggests that anticipated stigma is a major obstacle to help-seeking (Corrigan, 2004; Heflinger & Hinshaw,

2010). The experience of stigma can therefore disadvantage an individual over and above that of their stigmatising attribute.

Managing Stigma

Despite traditional literature on stigma focusing on the identification of factors that contribute to the harmful impact of stigmas on the lives of stigmatised individuals, research has indicated that there can be various reactions to, and consequences of stigma, many of which are positive. Shih (2004, p. 181) state that “Many stigmatised individuals cite that they gain strength and learn valuable life lessons in confronting adversities caused by stigma”. Corrigan and Watson (2002) developed a model of personal reactions to stigma in which people may (1) remain relatively indifferent to stigma, (2) self-stigmatize and suffer a loss of self-esteem or (3) become empowered by stigma and advocate on behalf of themselves and others who are stigmatised. They propose that the reaction an individual has towards stigma is moderated by the degree to which they identify with the stigmatised group and the degree to which they perceive the stigma to be legitimate. If an individual with a stigmatising condition does not identify with the stigmatised group, they are likely to remain indifferent to stigma because they do not feel that the prejudices and discrimination refer to themselves and thus consider the stigma irrelevant to them. Those who identify with the stigmatised group apply the stigma to themselves; however, their reaction is moderated by perceived legitimacy. If they consider the stigmatising attitudes to be legitimate they will internalise the stigmatising ideas and believe that they are less valued because of their stigmatising condition. This concept is termed ‘self-stigma’ (Watson, Corrigan, Larson, & Sells, 2007). Alternatively, if they regard public stigma to be illegitimate and

unfair, they are likely to react with righteous anger, become empowered, and make attempts to remove the stigma (Bagley & King, 2005).

Shih (2004) described three processes that stigmatised individuals use to overcome harmful consequences of stigma. The first is compensation, where the individual may refine social interaction skills, becoming more assertive and paying closer attention to how they present themselves. The second is strategic interpretation of the social environment where the individual will make external attributions in order to transfer responsibility and make in group comparisons in order to protect self worth. Thirdly, individuals may adapt their identity, emphasising valued identities and deemphasising devalued identities in certain contexts. Therefore, if stigma is viewed as a chronic stressor in ones environment, Shih would argue that some individuals have the resources to develop resilience and avoid negative consequences. Furthermore, Shih defined a difference between ‘coping’ and ‘empowerment’. Coping is most commonly viewed as efforts to adapt to (secondary control coping) or reduce distress (primary control coping) during stressful events (Miller & Kaiser, 2001) and such efforts can be problem-focused or emotion-focused (Lazarus & Folkman, 1984). Shih proposed that stigmatised individuals who ‘cope’, adopt strategies to avoid negative consequences, and thus their focus is on prevention. In comparison, those that become empowered by stigma are active, seeking to overcome adversity by creating positive outcomes rather than avoiding negative ones. Following this replenishing process, individuals are left with a sense of mastery and self efficacy.

Stigma and Mental Illness

Mental illness is a concept which attracts stereotypes, prejudice and discrimination from the general public and healthcare professionals. Hayward and

Bright (1997) reviewed the literature on stigma in mental illness, finding recurring themes of people with mental illness being perceived as dangerous (Pescosolido, Fettes, Martin, Monahan, & Mcleod, 2007), unpredictable, difficult to talk to, having themselves to blame, having poor outcomes, and responding badly to treatment. Although stigma is not unique to mental illness, the general public seems to disapprove of individuals with mental illness more than other stigmatised groups such as physical illness (Corrigan et al., 2000; Pescosolido et al., 2007). This is partly considered due to the idea that the public perceive people with mental illness to be in control of their illness and thus to have a degree of responsibility for it (Corrigan et al., 2000).

Children and adolescents with mental health difficulties are not exempt from such stigma (Pescosolido, 2007; Pescosolido, Perry, Martin, McLeod, & Jenson, 2007). Young people receiving support from mental health services report feeling a sense of shame, difference from others, embarrassment and discomfort associated with obtaining treatment (Moses, 2009). In particular, children report fear of not being liked if others know about their mental health problems and subsequently wait until they know someone well before disclosing their treatment. Although the study by Moses provided an initial insight into the experiences of adolescents with stigmatizing mental health difficulties, Moses acknowledged that future work should utilize diagnostically homogenous samples in order to ascertain the effects of disorder type on youths' stigma experiences. Camp, Finlay, and Lyons (2002) also emphasise the importance of considering subjective understandings of stigma experiences.

Stigma and Self-harm in Adolescents

Anderson, Woodward and Armstrong (2004) recognise that a diagnostic criterion is applied to self-harm which places it within the realms of mental health. We

know very little about how youths that self-harm experience the stigma which potentially accompanies being labelled and treated for mental health problems in adolescence. When a child reaches adolescence there is a general underlying expectation that morally they are socially competent and can distinguish right from wrong. Therefore, when an adolescent self-harms, it can be considered an act of deviance and tends to be disapproved of. Common prejudices held by healthcare staff include beliefs that individuals who self-harm are manipulative and attention-seeking (Friedman et al., 2006) as well as hard to engage and uncooperative (Husband & Tantam, 2000). Furthermore, in a study exploring the views of healthcare students towards adolescent self-harm, Law, Rostill-Brookes, and Goodman (2009) found that the care of adolescents can be adversely affected when healthcare students believe that such adolescents are in control of and are responsible for their actions. In addition to perceived controllability, Crocker, Major, and Steele (1998) identify visibility as an influential factor of stigma. Self-cutting, the most prevalent method of self-harm amongst adolescents, leaves permanent unique scars that are easily recognisable and considered socially unacceptable (Acikel, Ergun, Ulkur, Servet, & Celikoz, 2005). Observable conditions which are easily identifiable make a person more vulnerable to social rejection and may become the primary “mark” used by others to define an individual’s identity. Macgregor (1990, p. 250) described how people with disfigurements are subjected to “stares, startled reactions, ‘double takes’, whispering, remarks, furtive looks, curiosity, personal questions, advice, manifestations of pity or aversion, laughter, ridicule or outright avoidance.” Furthermore, adolescents who self-harm have the difficulty of deciding whether to conceal their self-harm, experiencing the threat of potential discovery, or deciding who to disclose to (Pachankis, 2007). Although individuals who self-harm may choose to conceal their scars/wounds in an

attempt to avoid the impacts of stigma, Quinn and Chaudoir (2009) propose that stigma-related distress is also common with non-visible stigmatized identities. They found that the extent to which an individual anticipates devaluation if the identity is revealed, the more central and salient the identity is to the self and the extent to which the identity is considered culturally stigmatized, each independently relate to greater psychological distress among people with concealable stigmatized identities. Such anticipated stigma is often termed ‘felt’ or ‘perceived’ stigma (Alonso et al., 2009) and is considered to impact on distress levels and illness symptoms in a similar way that enacted or actual stigma does.

Stigma, Self-harm and Identity in Adolescence

Adolescence is considered a significant period in the development of identity formation and is a time that young people strive toward independence and autonomy (Erikson, 1968; Marcia, Waterman, Matteson, Archer, & Orlofsky, 1993; Waterman, 1999). Therefore, the stigma of mental illness may be particularly devastating to a young person’s self-image, sense of mastery, and sense of what is normal (Marcussen, Ritter, & Munetz, 2010). Moreover, in the 1930s and 1940s, sociologists such as Mead (1934) and Cooley (1956) argued that the self is a social construction and that we develop our sense of who and what we are from our observation and interpretation of the responses we receive from others. According to this symbolic interactionist perspective, the perception of stigma is likely to affect an adolescent’s development of sense of self. Furthermore, it implies that an adolescent may lose their sense of self as a whole person and view themselves as defined only by their diagnosis (Corrigan & Watson, 2002; Fife & Wright, 2000), which can be demoralizing and disempowering (Ridgway, 2001; Moses, 2009). In addition, Rusch, Angermeyer, and Corrigan (2005)

discuss how language can be a powerful sign and source of stigmatisation. They propose that labelling implies a separation of ‘us’ from ‘them’ and that this separation leads to the beliefs that ‘they’ are different to ‘us’, and that ‘they’ are sometimes even the thing being labelled. This is true for individuals that self-harm who are sometimes referred to as ‘self-harmers’. Research has suggested an association between adolescents that conceptualise their difficulties using self-labels, and higher ratings of self-stigma and depression (Moses, 2009). Furthermore, Crouch and Wright (2004) suggest that young people that self-harm are aware of the ‘attention seeking’ label that people that self-harm are given. In an attempt to distance themselves from this label so that their self-harm is seen as ‘genuine’, an individual will sometimes engage in more severe self-harm. Moreover, young people that self-harm can compete against each other for a ‘genuine self-harm’ status which is considered less stigmatising (Crouch & Wright, 2004). In contrary, Crabtree, Haslam, Postmes, and Haslam, (2010) propose that group identification can buffer individuals from the adverse effects of stigma since it enhances social support which increases resistance to stigma and increases self esteem.

Rationale and Research Questions

In regards to the literature into adolescent self-harm, there is a dearth of research concerning stigma and that which has been done has examined public stigma towards young people that self-harm rather than exploring the views of those exposed to stigma (Zelst, 2009). The experience of stigma from the perspective of an adolescent who self-harms has not yet been investigated. To date, theoretical and empirical work into stigma has attempted to understand it and its effects by operationalising it into a measurable construct. However, to truly understand and appreciate what stigma is and how it

affects adolescents that self-harm, it is considered important to hear from the adolescents who potentially face that stigma on a daily basis. They may best inform us from their own personal experiences and in their own words, what stigma is, what it does, and how it is conveyed (Wahl, 1999). Considering this, exploratory rather than hypotheses driven research questions are considered more appropriate for this piece of research. This study aims to explore the following research questions:

- (1) How do adolescents who self-harm perceive stigma from others?
- (2) How do adolescents who self-harm manage or react to stigma from others?
- (3) How does stigma from others impact on adolescents who self-harm?

Investigating the experience of stigma for adolescents who self-harm may alert health services to acknowledge the effect that stigma can have on such adolescents. Findings may encourage clinicians to include self-stigma reduction as a verifiable treatment goal in addition to symptom reduction (Vauth, Kleim, Wirtz, & Corrigan, 2007). Tackling the perception of stigma is important since fear of labels or anticipation of stigma is a common barrier to adolescents help seeking and mental health service utilisation.

Method

Design

This study used a qualitative methodology to explore how young people that self-harm view stigma, how they manage it and how it impacts on them. A discovery-orientated approach by means of Interpretive Phenomenological Analysis (IPA) was used to explore how participants are making sense of their personal and social world and the interpretations and meanings that particular experiences and states hold for them

(Smith, Flowers, & Larkin, 2009). IPA was chosen because its three theoretical perspectives - phenomenology, hermeneutics and idiography, sit well with the nature of this study. A more detailed rationale for the use of IPA can be found in Appendix J.

Measures

Participants were asked to take part in a semi-structured interview (Smith & Osborn, 2003). This was guided by an interview schedule (Appendix K) featuring open ended questions on the important areas to be addressed informed from the literature and designed around the research questions. Prepared prompts were used if and when required for clarification or to elicit further information so that research questions were explored. The average length of interview was 42 minutes (range: 39 to 52 minutes). The full interview schedule can be seen in Appendix K.

Before the interview, demographic information was obtained via a short paper based questionnaire (Appendix L). This was to obtain additional information so that information obtained in the interviews could be placed within a context of individual experience of self-harm. The demographic questionnaire recorded the duration, frequency and methods of self-harm, the visibility and location of scarring and involvement with mental health services.

Procedures

Ethical considerations.

Approval to conduct the study was gained from a local research and ethics committee and the research and development departments of two local NHS Trusts in the north of England (Appendix M).

All interviews took place in a private room in the CAMHS centre that the participants attended. Participants were asked to only provide information that they felt comfortable sharing and were informed that the information they provided would remain anonymous. Exceptions to confidentiality (discussed prior to consent being taken) were in regards to concerns that the participant or others may be at risk of harm. During data collection no risk was identified, none of the participants required extra support and no participant exercised their right to withdraw during the study.

The recorded interviews were stored securely on encrypted and password protected computer software and destroyed after they were transcribed. Names and distinguishing features were anonymised and pseudonyms provided. Participants were given a unique identifying number and the master list was kept separate from the data. Any written information which left the service base was anonymised.

Participant identification.

A purposive sampling approach was used where attempts were made to recruit from a number of services and organisations including charity based, council run, and NHS services. The researcher presented the study to professionals from various staff teams, informing them of the rationale and procedure of the study. Those staff that agreed to assist with recruitment were asked to use the studies inclusion and exclusion criteria (outlined in Table 1 and detailed more thoroughly in Appendix N) to identify suitable young people from their case load/service. Once eligible young people were identified, their key workers gave them an information pack (Appendix O) detailing the study. If the young person was interested in taking part, their key workers asked them to fill in the consent for contact form at the back of the information pack. This form obtained their contact details and written consent for the main researcher to contact

them. The young person either sent this initial consent for contact form directly to the researcher or returned it to the researcher via their key worker. No payments or incentives were received for participation.

Table 1

Participant Inclusion and Exclusion criteria.

Inclusion	Exclusion
Between the ages of 13 – 18 years old (inclusive).	Parental consent was unobtainable (if young person was under 16 years of age).
At least two Self-harming behaviours in the previous year.	Non English Speaking
Currently receiving services from CAMHS or being supported by a local charity/support group/counselling service.	Has a learning disability (IQ<70)
Predominate method of self-harm is one that results in wounds/markings to the exterior of the skin i.e. self-cutting or burning.	Detained under the mental Health Act, actively suicidal, or considered by staff to be too highly distressed (CGAS score of <50).
	Severe or enduring mental illness i.e. Eating disorder or psychotic presentation

Data collection.

When consent to contact a potential participant was received, the researcher contacted the young person to arrange a suitable date and time to meet. If the young person was below 16 years of age, a parent/guardian accompanied them to the meeting but left the interview room before the recorded interview commenced. During the meeting, the information pack (Appendix O) was reviewed and discussed and questions asked by potential participants or their parent were answered. Participants were reminded of the rules regarding confidentiality, anonymity and risk and that they were free to withdraw from the study at any point with no adverse impact on the care they received from their service. Participants were also informed that approximately 2 months after the interview, once the data had been analysed, they would be invited to discuss their findings with main researcher in order to validate the themes of their interview.

If at this point a young person aged 16 years or above was keen to take part in the interview, they were asked to sign a consent form indicating that they understood the purpose of the study and their involvement. If a young person was under 16 years of age and was keen to take part in the interview they were asked to sign an assent form and their parent/guardian was asked to sign a parental consent form. Consent/assent forms can be found in Appendix P.

After signing consent forms, parents were asked to leave the room and all participants completed the demographic form (Appendix L) before taking part in the interview. After the interview, participants were given the opportunity to ask questions or explore any issues raised during the interview with the researcher. Each participant's level of distress was monitored by the researcher and all participants were offered an

immediate source of support from staff at their service if they felt they needed it. None of the participants became distressed during or immediately after the interview and therefore no extra support was required.

Two months after the interview, participants were contacted and invited to a validation meeting to discuss their findings with the main researcher. Three months after the interview all participants were sent written summaries of the findings of the study.

Participants

During the data collection period, 7 young people (1 male and 6 female) consented to take part in the study. However, during an interview with one female participant it became apparent that she did not fit the inclusion/exclusion criteria and therefore her data was not included in the study. The final sample consisted of 6 participants (1 male and 5 female). The overall age range was 14-17 years ($M = 15$ years 9 months, $SD = 1.4$ years). Participants had been self-harming for between 2 months and 5 years. All 6 participants were recruited between January 2011 and May 2011 through CAMHS provided through an NHS Trust in the north east of England. Participants had been involved with CAMHS for time periods varying from 2 weeks to 6 years and were at different stages in their recovery. All participants had self-harmed on their arms/wrists and three participants had also self-harmed on other locations of their bodies. Participants generally viewed their self-harm wounds/scars as moderately to extremely visible. The demographic information is summarised in Table 2. Three participants attended a meeting with the researcher to give feedback on the themes of their interview. Four did not respond to the invitation to provide feedback.

Table 2

Participant demographics

Participant	Age	Gender	Location and visibility of self-harm	Duration and frequency of self-harm	Duration of CAMHS
Pseudonym			0= not visible 10= extremely visible		involvement
1. Ben	14	Male	Arm (6)	4-5 years. Less than once a month	6 years
2. Scarlet	16	Female	Hips, legs and arms (4)	8 months. Less than once a month	2-3 months
3. Hannah	14	Female	Arm (8.5)	2 months. More than once a week	2 weeks
4. Fran	17	Female	Wrists, legs and stomach (6)	4 years. More than once a month	6 months – 1 year
5. Laura	16	Female	Wrist (8)	2 years. Less than once a month	7 months
6. Kelly	16	Female	Arms (10)	1 year. Less than once a month	4 months

Data Analysis

All interviews were recorded by dictaphone and transcribed into text form by the researcher, facilitating immersion in the data. Transcripts were analysed one at a time in the order in which they were gathered. The data analysis procedure was consistent with the 4 stage IPA data analysis process as outlined by Smith et al. (2009). Each transcript was read several times, emerging themes were identified and those that seem connected were grouped into related clusters. Master/subordinate themes which incorporate these clusters were then identified. A cross case analysis was undertaken in order to identify common themes among the transcripts which were comprehensively integrated to identify overall subordinate themes. The significance of these themes to the research questions was then assessed. An example of data analysis using an extract from one transcript is provided in Appendix Q. To increase the validity of the interpretations, members of an IPA group as well as an academic and field supervisor were involved in the process of analysis by examining transcripts, identifying initial themes, and by reviewing the thematic structure to ensure that the interpretations were grounded in the research data. Additionally, a summary of interview themes were fed back to participants to provide participant validation. A more detailed account of the credibility checks can be found in Appendix J. The findings were written up and organised around the identified themes.

Results

Themes Drawn From the Analysis

Whilst experiences differed on some levels, certain elements were shared across participants. The analysis generated 18 themes which clustered into 5 super-ordinate

themes. A summary of the themes is provided in Table 3 and described below.

Supporting quotes for each theme are documented in Appendix R.

Table 3

Super-ordinate themes with corresponding sub-ordinates

Super-ordinate Themes	Sub-ordinates Themes
Awareness of stereotypes	Crazy
	Attention Seeking
Disclosure	Avoid disclosure; self-harm is a personal phenomena
	Selective disclosure; trust
	Forced disclosure; visibility and rumours
Responses towards self-harm	Eggshells and exceptions
	Patronised and Fuss
	Helpful level of support
Management of response	Avoidance
	Challenge, defend or explain
	Nonchalance and acceptance
	I'm not like the rest vs. Part of a group

	Dismiss judgemental people
Impacts of stigma	Anticipatory anxiety/‘perceived’ stigma
	Shame and regret
	lifestyle
	Help seeking
	Recovery and future

Super-ordinate theme one: Awareness of stereotypes.

All participants felt that there are stereotypes attached to self-harm and that they are at times judged based on such stereotypes. A common stereotype acknowledged was that people that self-harm are viewed as ‘emotionally unstable’. Participants felt that people make assumptions and judgements too quickly based on very little understanding and often no personal experience and would prefer that people got to know them before judging them. Participants make effort to present themselves incongruently to the stereotypes in an attempt to avoid the judgement that accompanies such stereotypes.

Crazy.

Participants felt that others look down on people with mental health difficulties. There was a consistent idea that people with mental illness are not understood and therefore seen as ‘freaks’ or ‘mental’ and are avoided.

“Most people just think they’re freaks, let’s face it. You hear someone’s in a mental institution or something...don’t go near them. They’re Weirdo’s.” (Scarlet, 234-236)

Participants felt that people were disgusted by self-harm and felt that self-harm repels others who are afraid of it due to lack of understanding.

“Sometimes they tell ya that you shouldn’t be doing it and others will just sort of look disgusted” (Ben, 205-207)

“I know a few like past boyfriends when they’ve found out, like when I wasn’t too well and I had a boyfriend back then and he used to, God it like frightened, well it didn’t frighten him, it just scared him, put him off me completely” (Fran, 202-205)

More specifically, Hannah suggested that fear is generated as others think people that self-harm are unpredictable and dangerous which leads to lack of trust and avoidance.

“One of my friends said, err I don’t trust you no more cuz I self-harm, ermm I had an overdose so she thinks I’m gunna come up to her and stab her or something, so she doesn’t really trust me, it’s like, why would I do that...” (333-336)

Additionally, self-harm was viewed as a weakness and an attribute that others could single out and be critical of or make fun of.

“they was like laughing, like some people was like taking the mick going oh, what you gunna do next, try and hang yourself or stuff like that,” (Kelly, 266-269).

When asked to describe themselves, participants tended to describe themselves as they are viewed by others. This was suggestive that others opinions of them are very salient to them and very powerful in their identity development. Participant's descriptions of themselves suggested that they had to some degree internalised judgements and stereotypes in relation to the self-harm. Ben (18), Fran (11) and Scarlet (38) all used the word "*different*" when describing themselves, suggesting that they felt abnormal and unlike others.

"I'm not normal, I'm very different compared to everybody else" (Scarlet, 38-39).

Laura (4) and Hannah (21) both used the word "*weird*" when describing themselves or what others thought of them and both Fran (9) and Laura (13) used the word "*strange*". Additionally, Hannah used the word "*mental*" frequently to describe what people think of her and Laura (136) stated that people think of her as "*a freak*". Whilst these words imply that they are viewed as different to others, they also imply that they are bizarre and not understood.

Fran attempted to distance herself from the 'crazy' stereotype by describing self-harm in a medical manner, frequently describing herself as not being "*too well*" (38, 47, and 203). Similarly, a few of the participants avoided using the term 'self-harm' on several occasions, referring to it as 'it'.

Attention seeking.

Participants acknowledged attention seeking as one of the most prominent explanations that people give to self-harm. Although many of the participants held the view that some individuals do self-harm to seek attention, they attempted to distance themselves from this stereotype since it was clearly viewed upon negatively.

“some of them I must admit, some of them are attention seekers, it’s like look I cut myself I’m going to die, I hate my life...I can’t deal with people like that”

(Scarlet, 344-347)

There was a notion that the degree to which one exposes their wounds and scars can determine how ‘genuine’ the self-harm is. Participants felt that self-harm is genuine when people conceal it but that when people ‘show off’ their wounds/scars then it’s less genuine and done for the purpose of gaining attention which is frowned upon.

“She was just like showing them to everyone going oh look what I did last night and it’s just like why would you do that” (Kelly, 94-96)

“you don’t do it to show everyone” (Laura, 166)

Participants acknowledged that stereotypes such as ‘attention seeking’ develop based on overgeneralisations and ignorance and that such labels wrongly become the default construct used to judge all people that self-harm. Despite viewing attention seeking negatively, sometimes participants suggested that the attention and care they received as a result of the self-harm made them feel good. They seemed to imply that receiving attention is okay if it is a bi-product of the self-harm as opposed to the main purpose.

“One of my college teachers was really supportive, she still asks me how I am all the time when I see her” (Fran, 281-282)

Furthermore, Kelly acknowledged that those that assume people self-harm to gain attention are less likely to provide that attention for fear of reinforcing the self-harming behaviour. This seemed to be acknowledged by participants who felt that people did not take their self-harm seriously until they increased the risk status, proving that it was genuine. Ironically, the process of ‘proving’ the genuineness of self-harm to get a more positive response could be viewed as positive attention or help seeking.

“my brother didn’t really understand, he thought I was like attention seeking and stuff until things got really bad,” (Fran, 34-36)

Super-ordinate theme two: Disclosure.

In an effort to avoid stereotypes, judgement and discrimination, participants described attempting to control who knew about the self-harm. They did this by either avoiding disclosure altogether or by choosing to disclose to selected individuals that they felt they could trust. However, at times, the visibility of the self-harm and the stigma attached to it made this difficult.

Avoid disclosure; self-harm is a personal phenomena.

Participants felt that self-harm is a private phenomenon which people tend to keep to themselves and view as their own business and nothing for others to get

involved with. Ben, Scarlet and Fran choose to self-harm “*discretely and privately*” (Fran, 139), somewhere secluded where nobody will see them do it. Besides fear of judgement, participants saw self-harm as “*a personal thing*” (Scarlet, 425) that even people close to the young people often don’t know about it.

“Even some of my family don’t know what I do, what I did” (Fran, 151-152).

All participants used some sort of method to conceal their wounds and scars so that people could not see them. The most common method of concealment was using clothing. Participants went to great lengths to cover their scars, even when it wasn’t appropriate to wear clothing or long sleeved clothing.

“Like I have long sleeved tops if I’m out, if it’s real hot, I always have a jacket on, so they can’t see my cuts” (Hannah. 204-205)

“if I go on holiday I’ve got quite a lot over my stomach area, I always cover it up, in front of my boyfriend I always keep like clothes like a t-shirt on or something, never get them out” (Fran, 304-307)

Ben, Fran, Kelly and Laura mentioned adopting specific body postures to prevent certain scars from being visible. Such postures were used so often that they became habitual.

“if I was at my grandmas I always used to like have my hands like this, never used to, I do it all, I got used to it now, all the time I always cover up” (Fran, 168-170)

Attempts to reduce the visibility of the scarring had been made using several methods such as planning to get tattoo’s to cover them up, using moisturisers to reduce

the rubbery texture of the scar tissue, and using fake tan as a more temporary concealer. Participants sometimes denied that the marks were caused by self-harm and used untrue explanations.

“when I was working about 2 years ago one of the girls saw it and I was like, errr it’s um it was just a little scratch from the Bairn, just lie about it.” (Fran, 182-184)

Similarly, Kelly and Laura both mentioned that they have worn bandages on their arms to disguise the self-harm as a sprained wrist. The fact that they feel that a physical injury is more socially acceptable than the self inflicted injury of self-harm suggests that they are aware of stereotypes and feel stigma associated with self-harm. Participants felt that it is important to conceal the self-harm since exposing it is viewed as attention seeking and this is a label they all attempt to avoid.

“obviously I’m not gunna walk around showing people, like some people are like oh yeah I’ll show ya, but obviously you’re not gunna start like flashing em cuz that is attention seeking,” (Kelly, 337-340)

Selective disclosure; trust.

Most participants did not want many people to know that they self-harm and were selective in who they allowed to know. It was important to participants that people have the right intentions for wanting to know.

“if they want to know and they don’t just seem like they’re being nosey or they’re actually worried I do like say to them like why” (Fran, 380-382).

Most participants felt that they had to be selective about who knew as they feared rumours being spread and misjudgements being made.

“your close friends, you know what they’re like and you know that they’re not gunna say anything but like other friends you don’t know what they’re gunna do, they could like spread it and stuff and start like saying oh she’s tapped and stuff like that and she’s a bit crazy...” (Kelly, 61-65)

Several of the young people had only considered telling family or really good friends as they felt that it is important to trust that those who know will not tell others and will not judge them.

“if it’s somebody close to me and I can trust them, I’ll tell them if I know they’re not gunna run away as soon as I tell them” (Fran, 197-199).

Such trust needs to be built up over time and earned. When describing disclosure, Laura used the word “*confide*” (52) often, which has connotations of her trusting people with a potentially shameful secret that she hopes they will keep to themselves and refrain from judging.

“I wouldn’t just, like if I thought someone was a good friend I wouldn’t tell them like straight away, id wait a long time cuz I wouldn’t see like why it was relevant but I aren’t really open about it, I wouldn’t tell like just anyone” (Laura, 404-407)

Forced disclosure; visibility and rumours.

Participants felt that they do not have full control over the disclosure of their self-harm. They are aware of the visibility of self-harm, particularly its unique mark and the part this often played in disclosure. Ben felt that people know about his self-harm because *“they’ve sort of seen the scars or heard other people talking about it”* (Ben, 354-354). Kelly (496) felt that you can *“clearly see”* that she has self-harmed and this prevents her from being able to deny it. All participants felt that the visibility of the wounds and scars attracts attention and nosiness. Furthermore, participants found that people often need to see the scars to initiate comments or questions and therefore visibility can be a powerful tool in determining the amount of attention the young people receives regarding the self-harm.

“If they don’t see it then they don’t really ask” (Laura, 431-432)

It was acknowledged that the visibility of superficial self-harm is powerful and can shock and raise concern. Fran suggested that visible forms of self-harm elicit more attention and care than non-visible forms.

“If you tell somebody oh I took an overdose by like taking Tablets and stuff like I did, people don’t affect to that like when I cut myself too much and it wouldn’t stop bleeding” (Fran, 480-483).

Several of the participants would prefer that the self-harm wasn’t visible and that the wounds/scars were not there so that they could have more control over disclosure and thus being judged.

“I’d rather them be, if I could do, them be invisible” (Fran, 358-359)... “cuz then people wouldn’t see, and wouldn’t judge” (Fran, 362-363)

In addition to visibility, participants felt that disclosure was often more widespread than anticipated due to rumours being spread.

“then somebody’s seen my arms and then asked a question about the scars, then somebody will know, then another person will probably hear and it just like dominoes really don’t it.” (Scarlet, 195-197)

Participants were aware that these rumours were spread by people that weren’t fully informed and therefore were usually based on stereotypes and likely to be far from the truth.

“I don’t want to sound like this person that goes around trying to cut myself every single day, I don’t want them to see me like that, I don’t like people, you know when they don’t know all the facts but then they tell people things and it’s like well you don’t really know so why are you saying it” (Scarlet, 138-143)

Despite this, participants suggested that forced disclosure can at times be relieving as it reduces anticipatory anxiety of disclosure and gives the young people the freedom to discuss the self-harm.

“that way I know I can go talk to them about it. Because they already know so there’s no point in trying to hide it from them” (Ben, 416-418)

Super-ordinate theme three: Responses towards self-harm.

Participants recognised that once the self-harm had been disclosed, there was not one consistent approach in the ways that others reacted to it. While some avoid mentioning the self-harm and walk on eggshells for fear of triggering another episode, others attempt to become more involved, taking a confrontational and often patronising approach. Participants found that the approach people took depended largely on how close the individual was to them. Most participants felt that their family and close friends did not particularly treat them any differently as they understood the context and thus were less judgemental and less likely to use stereotypes to understand it. In contrast, participants found that strangers were more likely to approach them with questions or comments in an attempt to make sense of it.

Eggshells and exceptions.

It was acknowledged that most people avoid talking about self-harm and thus if they see the wounds/scars they do not mention it.

“if someone sees it, which it’s very rare, they’ll just, they’ll just sort of not say anything” (Laura, 336-337)

Laura reported that some people feel so uncomfortable talking about self-harm that they will change the conversation promptly even once it has already been mentioned.

“do ya know like when you say, when you tell someone something and then they sort of try and change the subject like almost straight away” (Laura, 125-127)

Participants suggest that the reason for this might be because people don't understand it

“I think that they don't really want to get involved with stuff like that because, that don't, I think just because it's different, just because it's something that they don't genuinely understand” (Scarlet, 526-529).

A number of participants felt that people respond differently depending on how genuine they see the self-harm to be. Those that view the self-harm as genuine behave cautiously around them as they are afraid of upsetting them, suggesting that they see them as emotionally vulnerable. For instance, Scarlet explained that her parents are aware of her self-harm but choose not to mention or discuss it for fear of making her feel uncomfortable or potentially triggering another incident of self-harm.

“my mum and dad, they know that I do it, they get upset about it, but they tend not to acknowledge it as much because if they acknowledge it, it might trigger it off again to make me want to cut so I think some people just don't mention it.” (Scarlet, 379-383)

Patronized and fuss.

Several of the participants felt patronised by the approach people take to their self-harm and described how people treat them like children.

“when I first started they were just, like people used to say oh you're stupid and stuff like best not do that again “(Kelly, 224-226)

“They treat me like a little kid” (Hannah, 75)

Participants noticed that some people are overly nice to them after discovering their self-harm. Such people tend to fuss about it, becoming more involved than participants would like.

“But then people were being over nice about it, gets a bit annoying, it’s better to just keep it, you know, people know what’s going on, just keep it like that, you don’t need to like fuss about it or be nasty about it” (Fran, 595-598)

Participants explained that people are often intrigued about the scars and subsequently ask them questions or want to see them. This tends to annoy them as they view the scars as somewhat personal.

“it did my head in, like everyone just like saying stuff all the time, oh let me see your scars, or like when they was cuts, they was like oh let me see your cuts, I was like no, “ (Kelly, 328-331)

Participants found that people tend to overreact to their self-harm and can become over vigilant with protecting them and attempting to prevent further incidents. This was a source of irritation for the young people.

“I don’t really like it when people are like too involved. I’m okay with people being involved because obviously they’ve seen the states that I get in and stuff so I don’t mind them being involved as long as they’re not like watching me constantly” (Scarlet, 96-99).

Helpful level of support.

There seems to be an optimal level of support which is helpful where anything less is neglectful and anything more is intrusive. When people provide the optimal amount of support, participants feel cared for and supported. On the whole, participants described feeling well supported by those around them. Participants implied that the time and attention people give them due to the self-harm makes them feel good.

“if somebody shows like that they care and stuff, it makes you think, I’m happy, I don’t need to do this, I don’t need to make myself feel any less than perfect I know that I need to move on and stuff, it puts you in a better, I don’t know, it puts it more into perspective to know that people actually really care” (Scarlet, 759-764)

There was however, ambivalence between liking the care shown by others and also feeling shame and embarrassment when others focus on it.

“if someone cares, like if they’re saying we care, then obviously I’ll, I’ll feel happy that someone cares but then I’ll still, I’ll still feel upset by the fact that they’ve noticed em” (Kelly , 560-562)

“people do worry a tiny bit too much but I know that they’re doing it just for the greater good” (Scarlet, 752-753)

Scarlet acknowledged that self-harm not only impacts on the young person but also on those around them that care about them. She therefore acknowledged that her actions can generate concern and elicit care.

“I think it’s quite an emotional thing, not for just the person who does it but for people who genuinely care about them around them and stuff” (Scarlet, 498-500)

In contrast, a couple of participants implied that they have felt betrayed when those close to them have not shown care for them and have instead reacted negatively to their self-harm.

“if you’ve known someone for quite a while and then you tell them that, you’d think they’d be really supportive but it sort of, makes you think that it weren’t worth being a friend in the first place and it sort of makes you feel really bad because you’ve confided in someone about that, and then you don’t know whether you can trust them again,” (Laura, 68-73)

Participants felt that the way people view self-harm differs through generations due to the idea that older generations are less familiar and thus less understanding of self-harm than younger generations. Suggestions were made that self-harm is becoming more common and acceptable nowadays. Participants implied that they received more helpful support from members of their own generation as opposed to those in older generations.

“I think young people seem to accept it more than older people, probably because more people do it now” (Fran, 286-288).

Super-ordinate theme four: Management of response.

Avoidance.

Most participants described using a form of avoidance to manage comments or questions made by others about their self-harm. Avoidance was employed in the forms

of ignoring, changing the topic of conversation or literally escaping a situation to avoid further questioning.

“I’ll just pull my sleeves down again and just like walk off like they haven’t seen nought or something” (Hannah, 273-275)

Additionally, participants sometimes deny attending mental health services or self-harming so that people are unable to make further comments or judgements.

“I was like, I just said oh I don’t go, cuz I don’t want them to think I’m mental. It’s just weird, when I say, when someone asks me oh you go to CAMHS, I’m like no I don’t.” (Hannah, 39-42)

Participants suggested that they avoid conversations around the self-harm because they feel uncomfortable talking about it, implying that it is a taboo and personal subject.

“Most people don’t like getting into things like that” (Scarlet, 523). “It’s not really a subject that you really want to talk about, it’s like you wouldn’t sit down at the dinner Table and go look what I did today (laughs)” (Scarlet, 392-394?).

This is particularly so when the person asking about the self-harm is someone that they don’t know every well.

“If it’s not like one of your good friends or something and somebody starts asking you about, you’re not going to get into too much detail, it’s like why are you asking me this, I don’t know you properly” (Scarlet, 545-548).

Challenge, defend or explain.

Some participants described taking more challenging and defensive approaches to comments and questions from others. Their reaction implies that they feel people are being rude and nosey by commenting or asking questions and that this is unfair. They thus feel it necessary to protect themselves and let people know that they will not tolerate being judged or people intruding on their privacy.

“if it’s somebody like I’m not that comfortable around and they’re like that towards me, I will just put them in their place and tell them to shut up or say well you start doing it and then you’ll understand, and I know that it’s something that you shouldn’t say to somebody, but I don’t know, if somebody judges you in any way, you’ve got to put them in their place.” (Scarlet, 650-656)

Some participants talked about putting up a facade to keep others at a distance so they wouldn’t feel comfortable enough to comment or judge them.

“I can come across quite rude but I don’t mean to be, I’m alright really, get to know me” (Fran, 27-28)

Nonchalance and acceptance.

Some participants seemed to have developed an acceptance that self-harm is part of their life and have adapted to and become more accepting of the comments and questions so that they impact on them less.

“if someone brings something like that up then someone’s obviously got a comment about it which I respect...everyone’s allowed their own outlook on things”

(Scarlet, 336-339)

Some participants seemed to justify self-harm as a coping strategy in an attempt to normalise it

“I think everybody should understand what people go through, not every bodies lives are perfect, nobodies lives are perfect I know everybody has their down times, it’s just different people cope with it differently” (Fran, 246-249)

A number of young people emphasised that it was inevitable that they would self-harm. This seems to be an attempt to create an external locus of control, removing responsibility from themselves. They described how the scars have become part of their identity and are a mark of who they are.

“It’s part of me isn’t it, it’s part of what I was like then and what I’m like now which is a lot more better” (Fran, 348-349)

Participants suggested that time helps to shape how one manages the comments, suggesting that with time comes acceptance and adjustment to the self-harm, the scars and the reactions to it. With time, young people become less vigilant about concealing it and let their guard down more easily. This would explain why Hannah, who had been self-harming for the shortest amount of time, presented as the most sensitive to and impacted on by comments and questions made by others.

“at first I didn’t wanna do P.E and stuff, but I suppose, just got over it and like now ... now it doesn’t bother me cuz it was, it’s just over and done with, there’s nothing I can do about it“ (Kelly, 645-650)

I’m not like the rest vs. Part of a group.

As a protective defence, participants attempt to distance themselves from others that self-harm and thus distance themselves from the stereotypes and judgements that accompany that identity. They do this mainly by viewing themselves as self-harming less frequently and less seriously than others.

“I see myself being alright...well not ok, because obviously it’s still like an illness but it’s like I’m like a few steps below them” (Scarlet, 275-277)

In contrast, Kelly was a little more defensive of others that self-harm, almost taking an in-group approach.

“but they don’t know obviously why, w, why they do it, why we do it” (Kelly, 231-232).

When an in-group approach was taken, participants tended to put themselves in an expert position, offering friends help and support with self-harm. It is likely that the function of this is to add status and power to their identity as someone who self-harms and is likely to boost their self esteem.

“my friends who have problems like that, they come and talk to me because I just say, look I do it, it’s stupid just don’t sort of thing... “(Scarlet, 164-166)

Some participants described feelings of relief with the knowledge that they aren't the only young people that self-harm and that there are others out there who are experiencing similar experiences, making them feel more 'normal'.

"it's kind of better cuz I aren't the only one who's like got problems going on, so it makes me a little bit better." (Hannah, 638-639)

Dismiss judging people.

In an attempt to reduce the validity and power of other people's judgements so that they have less impact, the participants attributed negative qualities to the people that judged them. Fran described people that judge self-harm as "*just pathetic people*" (Fran, 604) and Kelly described them as "*stupid*" and later implied that they are nosey

"if they're gunna be stupid enough to say summit, then let em, cuz I'm not gunna like start saying stuff to them cuz then that's just, that's just being as bad as them really" (Kelly, 620-623)

Additionally, most participants minimised the importance of those that judged them and thus viewed their comments and judgements as insignificant.

"I can just sort of say, well I don't care what your opinions are, because you're nothing, you don't mean anything to me" (Ben, 616-618)

Participants attempted to explain the reasons that others judge, putting it down to their lack of experience and thus understanding, suggesting that this makes people closed minded and ignorant.

“I don’t think anybody understands it until it happens to them or they know somebody who it affects, or if they’ve been through that, which not a lot of young people have” (Fran, 99-101)

Some participants viewed judgemental thoughts and comments as another person’s ‘opinion’. By giving ownership of the judgement to those that judge, they are implying that their judgements are not fact which makes it easier for participants to dismiss them.

“at the end of the day it’s their opinion” (Ben, 448-449)

Super-ordinate theme five: Impacts of stigma.

Anticipatory anxiety.

The majority of participants suggested that they feel anxious about others finding out about their self-harm as they are afraid of being judged and of the reaction others will have. This seems to lead to selective disclosures,

“but I haven’t told a lot of my family because, ya know, I don’t wana tell them because I’m worried about what they’ll think” (Laura, 118-120)

“my grandparents haven’t seen them because they’d be like, I don’t know, some people would just act like totally out of hand, where they could have actually been a lot more calm about it and stuff, but other people are just like go a bit too far” (Scarlet, 635-639)

Some participants presented as particularly sensitive to anticipatory anxiety. For instance, Hannah described having what sounds like panic attacks when people ask her questions.

“I feel really like, I feel dizzy sometimes when people ask me questions, and I start heating up and then I start feeling really sick and I start getting all emotional and start crying” (Hannah, 476-478)... “and I start running out of breathing and I don’t know what to say and I start panicking” (Hannah 483-484)

Laura suggested that she feels on edge when meeting new people for fear that they’ll find out about her mental health difficulties. She describes looking forward to a time when she doesn’t have to worry about how/when to disclose or people finding out.

“just not having to worry about letting people know about me going for mental health like things, they being put off, I just want it, you know like, if you meet someone, just a normal chat with them without any sort of, oh by the way I’m going to see the mental health and they’re like ooooo” (Laura, 594-598)

Shame and regret.

The common response of avoidance or escape used by all participants when disclosing self-harm or facing other people’s reactions suggests that they feel shame and embarrassment by the self-harm.

“you feel really small and you feel really stupid for doing it cuz they all come up to you and go oh what happened and ask you questions and then they go oh I feel sorry for ya ...and then you just think like you’re really tiny” (Hannah, 429-432)

Many participants described feeling ashamed, self conscious and uncomfortable about the self-harm. Fran explained that she does not mention self-harm as a symptom of her depression like she does other symptoms and this implies that self-harm is not something she readily discloses, suggesting it is shameful and embarrassing. However, participants seem to feel shame only when others comment or judge them rather than shame of the act of self-harm per se. This suggests that if it were a phenomenon which could be done invisibly and thus would not need to be disclosed, young people that self-harm would not feel the negative impacts of stigma. Additionally, there was a sense that participants feel regret and self blame about self-harming due to its permanent nature.

“it’s my fault why I did it and I’m blaming myself why I did it” (Hannah, 290-291)

“at the time it makes you feel... better, but afterwards like when you actually think about it, it’s just like actually I was really stupid, I really shouldn’t have done that “ (Laura, 467-469)

A number of participants emphasised that they feel as though the scars are permanent and will be with them forever. There was a sense that the scars will be a label of mental illness for many years to come and that this label will be inescapable. For many of the participants, their regret was regarding the scars and the reactions they have elicited rather than the actual act of self-harm.

“... I’m left with scars like, forever, like the rest of my life” (Kelly, 140-141)

Fran described how it’s not only the physical marks of self-harm that leave a permanent scar, but also that the comments and reactions from others leave a long lasting emotional impact.

“the harm was already done, the things he said to me,” (Fran, 70-71)

Scarlet acknowledged that family members are aware of stereotypes and feel stigma too. If young people are aware of others shame regarding their self-harm, it is likely to increase their own sense of shame.

“Her parents don’t seem to acknowledge it because they’re like an upper class sort of family and they’re like we raised our child wrong, so they’re not acknowledging it sort of thing” (Scarlet, 445-447)

Lifestyle.

Participants generally spoke of feeling unable to do some of the activities that they used to do. Participants felt that they have to be hyper vigilant about concealing the scars and therefore; avoid activities which would expose certain areas of their body and put special consideration into their choice of clothing.

*“I don’t do a lot of like sport outside of my house like swimming and stuff”
(Laura, 494-495).*

Participants described isolating themselves and disconnecting from others and the world around them.

“I used to just sit in my room and close the blinds and the curtains and just sit in a corner and just sit there all the time and never move” (Fran, 122-124)

Laura felt that having self-harmed and having the scars/wounds not only impacts on her daily routine, but also on her confidence

“I reckon I’d just be more confident because like obviously, id probably wear, id probably in summer id look more summery and I don’t know, probably more confident with new people as well because I wouldn’t be worried about whether they’d see it” (Laura, 485-489)

Help seeking.

Participants implied that there was often some degree of hesitation before first approaching medical or mental health services due to concerns about what clinicians would think of them. Hannah was worried about going to CAMHS as she feared that she’d be the only client that self-harmed and that ultimately the staff would not understand her and would judge and think negatively of her.

“I was like, worried that people might not be like, might be different to me and there might not be that many people coming here about self-harming themselves and that lot. So I’m a little bit worried if it’s just me the only one, but some people they actually do it” (623-627)

When talking about professional help-givers, Scarlet said

“I think they’ve actually got to have more of a understanding of it because if they’re just going to sit there and go well its wrong, they’ve actually got to have something to back them up with” (Scarlet, 692-695).

She feels that professional opinions and judgements are only valid if they fully understand self-harm and preferably have experienced something similar.

Participants had preconceptions of what mental health support would be like before they became involved with CAMHS and many of these were based on stereotypes

“Errm, at first I thought it was just going to be some old man you know sat there going you’re not well” (Scarlet, 848-849)

A couple of participants feared being viewed as crazy and being sent to an inpatient unit

“I think people think you’re gunna get carted off” (Fran, 656)...”with a straight jacket on [laughs]”

Laura initially expected her doctor to be judgemental and think that she was freak

“I was sat there thinking oh god he thinks I’m a freak I really wanna get out of here. “ (Laura, 544-546).

However, the reaction she got from him was positive which made her “*feel a lot better*” (Laura, 544). She was reassured by being told that she’s not the only young person that self-harms. Although several participants implied that their fears

around help seeking were unwarranted, for some participants, initial experiences with mental health professionals were unpleasant, intrusive and patronising which put them off seeking further support.

“the first time I came here I thought it would just be like a simple interview and a few tick boxes and what have you, but this guy was just totally going into everything and was asking to see my arms, and was going like really farfetched,” (Laura, 561-564)... “but he asked me to show him my arms and he was like saying oh how deep do you do it and I was sort of thinking, it’s a bit weird, considering it’s the first time I’ve actually met ya and you’re asking me things like that, it just sort of put me off” (Laura, 573-577)

“the first woman who came to come and see me, she said you’re not having mental health counselling because you’re mental, you’re having it because you need us...it was just so patronising it made me think, what if they’re all like that I’m not going there” (Scarlet, 851-855)

Recovery and future.

Participants felt that the reactions of others towards their self-harm both encourages and discourages them to self-harm. Laura felt that the reactions she has had have been mainly supportive and that this has discouraged her from self-harming.

“it’s showing that they actually care which makes you think well why am I doing this when people care which gives like more of a reason not to do it” (Laura, 740-743)

Similarly, Kelly felt that the negative responses encourage her to resist self-harming because

“I don’t wanna do it again cuz obviously it’s just gunna make it worse and obviously I’ll, obviously I’m gunna have more, and then obviously it’s just gunna start again and more people would say stuff” (659-662)

In contrast, some participants felt that people’s negative reactions to self-harm make them want to do it more often. Others were much more ambivalent, although thought that it would be useful to reflect on the reactions they have encountered to discourage future incidents.

“sometimes if people react badly to it, it’ll make me want to do it even more. But if people like say to me, you know, don’t do it again, and like they’re worried about me, it’ll probably make me think twice about doing it, because obviously you don’t wanna let people down” (Laura, 512-516)

“it’ll just sort of make me think like to stop and think twice about it the next time I try it” (Ben, 558-559)

Hannah felt that because of the permanent nature of the scarring, she will have to conceal the scars forever, suggesting that she will never be totally care free and the impacts will continue lifelong.

“I won’t able to show like, go swimming with the kids or with my mates or go out anywhere, I’ll be wearing like jackets all the time” (Hannah, 681-683)

In terms of the future, participants seemed concerned that the scars of their self-harm might influence vulnerable others to self-harm through imitation.

“Yeah, because if some disabled people might like ask me like questions and touch them and everything, and then they might copy off me and then they might come back and say I look like you, and I don’t really want people like to copy” (Hannah, 670-673)

Participants felt that they will be able to support their children more successfully in the future since they will “*know what to look out for*” (Fran, 711) and will be “*more understanding*” (Scarlet, 592). Similarly, Laura and Kelly felt that their experiences will place them in a better position to help others in similar situations since they will understand what others are going through and will refrain from judgement.

“if you know someone and they confide in you about it and they say oh look I really don’t wanna do anything about it, it’s like you can sort of encourage them to do, ya know like do something about it and like let them know that you’re not the only one, tell them about your experiences and stuff, that sort of help for it, be supportive
“(Laura, 602-608).

Participants were aware of the stigma around mental health and self-harm and were aware that this might lead to them being discriminated against in the future

“like employees in the future will want to know so, and I was like, it sort of worried me because if they had to know like would it give me a less of a chance of getting a job or whatever” (Laura, 625-628)

*“some people like might think, like say if I went for a job somewhere, like they might not think I’m in the right state of mind to thingy, because I’ve done that”
(Kelly, 707-709)*

Discussion

Overview of Findings

The present study explores the experience of stigma for young people that self-harm. Themes emerging from the data are in line with the literature which suggests that individuals experience the stigma attached to self-harm although vary in the strategies used to manage such stigma and the degree to which they are impacted by it.

Participants acknowledged that the distinctive mark of self-harm is perceived to be a stigmatising attribute and can be discrediting (Goffman, 1963). The two most prominent stereotypes identified by participants were that people that self-harm are either 'attention seeking' or 'crazy'. Participants explained that both stereotypes are viewed upon negatively, the former creating the reaction of disregard leading to dismissal since it is suggestive that the self-harm is not genuine (Crouch & Wright, 2004) and the latter creating the reaction of fear leading to avoidance since it is suggestive that those that self-harm are emotionally fragile, impulsive and potentially dangerous (Hayward & Bright, 1997). In line with Corrigan et al. (2000), participants felt that most people cannot make sense of self-harm and therefore rely on the stereotypes 'attention seeking' and 'crazy' as knowledge structures to generate impressions and expectations of individuals in an attempt to understand the phenomena of self-harm. Participants observed a pattern to the stereotyping. They noticed that upon disclosure others initially assume that the self-harm is performed in their control as a form of attention seeking whereas when the self-harm is done more frequently or severely, their views progress onto thoughts that participants are 'crazy'. Participants felt that people's judgements of, and reactions to the self-harm were influenced by emotions invoked by these stereotypes, although often could not identify specific

examples, suggesting that they often experienced ‘felt stigma’ as opposed to ‘enacted stigma’ (Alonso et al., 2009). Participants reported that they would prefer people to attempt to understand them on an individual basis considering their personal circumstances rather than on a stereotypic group-basis. When asked to describe themselves, participants tended to do this from the perspective of others. This suggested that participants are highly sensitive to the opinions of others and that such opinions are playing a great part in the development of their identity, supporting the symbolic interactionist and social constructionist perspectives of Mead (1934) and Cooley (1956). Furthermore, many of the adjectives used to describe themselves were in relation to the self-harm suggesting that this had an overriding influence or has become the “master status” (Goffman, 1963) in defining their sense of self.

In an effort to avoid such stereotypes and prejudice, participants attempted to control disclosure about the self-harm as much as possible. For some, this involved avoiding disclosure all together while for others this involved being selective with whom they disclosed to, choosing people that they trusted would not spread rumours nor judge and potentially reject them. In response to awareness of the stigma attached to mental health, participants concealed the scarring, sometimes disguising it for a physical accidental injury which they felt carried less stigma. Despite vigilance for concealing the self-harm, participants recognised that due to its visible nature, it was difficult to have complete control over disclosure since the unique and often long lasting marks are easily recognisable (Acikel et al., 2005). In line with Crocker et al. (1998), participants identified visibility as an influential factor of stigma since it not only forces disclosure, but furthermore attracts comments, questions and discrimination. Despite concealing the wounds and scars, participants felt anticipatory anxiety of disclosure and thus judgement. Therefore, as Quinn and Chaudoir (2009) propose, concealing the

stigmatising attribute was not sufficient to eliminate felt stigma. This suggests that participants anticipated devaluation if the self-harm were to be revealed and felt that the self-harming identity was central and salient to them. Participants did however acknowledge that the reaction they received upon disclosure was usually better than they had anticipated and that they felt a sense of relief once they no longer had to 'hide' the scars.

Participants acknowledged a variety of responses from others to their self-harm. They recognised that while some people avoid discussing self-harm to avoid an uncomfortable atmosphere and potentially triggering another incident, others ask questions and make comments in an attempt to gain involvement. Participants generally preferred the former approach, finding the latter patronising and intrusive. Participants acknowledged that self-harm is a personal phenomenon and used a variety of coping strategies to manage the unwanted responses of others. Disengagement coping strategies tended to take an avoidant style and involved changing conversation topics, denying the self-harm or physically leaving the location upon mention of self-harm. In contrast, engagement coping strategies involved either primary-control coping such as becoming defensive, justifying the self-harm or challenging those making the comments, or secondary-control coping, such as acceptance (Miller & Kaiser, 2001). Additionally, in a self protective manner, participants attempted to distance themselves from the stigma by either distancing themselves from self-harm, or by dismissing those that they felt were making judgements. These self protective defences are compatible with Corrigan and Watson's (2002) model of personal reactions to stigma where the reaction an individual has towards stigma is moderated by the degree to which they identify with the stigmatised group and the degree to which they perceive the stigma to be legitimate. By distancing themselves from others that self-harm and thus the self-harming identity,

some participants were able to accept and remain indifferent to the stigma since they did not feel that it referred to them. Participants that considered themselves close to recovery tended to distance themselves from the self-harming identity to a greater degree and were less responsive and more accepting of the stigma. In contrast, those that were newly involved with CAMHS and self-harmed more frequently identified with others that self-harmed more readily. Those participants that identified with others that self-harm either internalised the stigma or regarded it as illegitimate. Those that internalised the stigma felt less valued which lead to behaviours such as avoidance and social isolation. Those that regarded the stigma as illegitimate due to demeaning the credibility of those judging them responded more in line with primary-control coping strategies (Miller & Kaiser, 2001).

Participants acknowledged that the stigma they experienced had both emotional and practical impacts. In line with established consequences of feeling stigmatised (Dinos et al., 2004), participants described feeling anger, low mood, anxiety, shame and embarrassment as a result of stigma. However, in contrast to such negative consequences, the attention and concern that the self-harm elicited also left participants feeling cared for and supported. Participants suggested that the shame and embarrassment they felt in relation to the self-harm was socially driven rather than personally driven since they reported that they would be happier if they could self-harm but it be invisible and thus not elicit a negative reaction. For some participants it seemed that the reason they wanted to conceal the self-harm wasn't because they were ashamed of the self-harm per se, but more so because they feared the stigma of being seen as an 'attention seeker'. In support of Crouch and Wright (2004), for some participants, the desire to lose the 'attention seeking' label encouraged them to compete with others that self-harm by self-harming more/less severely or more secretively so

that their self-harm would be perceived as more 'genuine'. The attention seeking label seemed to hold more shame than the actual act of self-harm. Furthermore, participants were left in a predicament of not wanting others to see the self-harm for fear of being viewed as attention seeking and wanting others to see it to elicit help and care.

Participants also felt that their lifestyles had been impacted on as anticipation of judgement and devaluation discouraged participants from social interactions and led to withdrawal. Such attempts to avoid disapproval and rejection are consistent with the modified labelling theory (Link et al., 1989). Furthermore, consistent with the literature, the stigma attached to mental illness and the negative discrimination that is usually associated with stigmatization acted as a barrier to participant help-seeking (Schomerus & Angermeyer, 2008). Participants also feared that discrimination as a result of their current mental health difficulties would impact on their future personal life and careers due to the permanent nature of both medical records and the visibility of the scars.

Despite the above mentioned negative impacts of stigma, all participants used at least one of the three processes that Shih (2004) suggested stigmatised individuals use to overcome harmful consequences of stigma. Some participants compensated for the self-harm by paying close attention to how they present themselves so as not to fit the typical stereotype of someone that self-harms. Secondly, some participants explained their self-harm using external attributions in order to transfer responsibility and compared themselves favourably to others that self-harm in order to protect self worth. Thirdly, some participants presented confidently, emphasising identities they considered valued such as their appearance, status at school and supportive qualities. The use of such processes is indicative that all participants had the resources to develop some degree of resilience against the stigma.

Limitations of the Study

There are a number of limitations to the findings presented in this study. Despite attempts to recruit from various charity, health, and social care organisations, this was not possible and all participants were recruited through one CAMHS team in the north of England. This is likely to have led to a somewhat skewed perception of stigma. Young people attending CAMHS (and thus implied to have a mental illness), may have had different experiences of stigma than those who access charity or council run support services where the focus might not necessarily have been on mental health. Furthermore, experiences of stigma are likely to be additionally different for young people who choose not to access any support at all. It could be predicted that such individuals might be more aware of stigma and impacted more greatly by it. Although IPA does not aim to make generalisations, it might have been interesting to use a more heterogeneous sample to explore other alternative experiences of stigma. Additionally, although 6 participants is considered sufficient for a study using IPA (Smith et al., 2009), and the interviews provided rich data, this study is likely to have been of better quality if more participants had been recruited.

Clinical Implications and Future Research

Over the last decade many stigma reducing campaigns, projects and programs targeting the general public have been introduced. The findings of this paper suggest that it is important that these are continued since participants felt that others judged them using stereotypes which led to prejudice and discrimination. In terms of reducing the stigma experienced by people with mental illness, it is important that the three

necessary approaches (protest, education, and contact) suggested by Corrigan and Penn (1999) are maintained. Protest is required to reduce negative attitudes about mental illness and education is required to provide information about mental illness so that people are able to make more informed opinions. Thirdly, it is important for members of the public to have contact with people with mental illness in the community so that myths and stereotypes can be stamped out with positive experiences. The idea that participants felt that others see them as “crazy”, suggests that others view self-harm as an entrenched behaviour that is manifested within a young person rather than as a result of situational factors i.e. bullying. Stigma-reducing campaigns could therefore focus on the often temporary nature of self-harm and the large influence that situational factors and thus those around young people that self-harm can have on encouraging or discouraging the behaviour. Such an approach to campaigns would have the potential to narrow the distance and reduce the perception of fundamental differences between someone that engages in self-harm and the general public. Since stigma, attitudes, and beliefs about mental illness are considered to develop during childhood and adolescence (Wahl, Hanrahan, Karl, Lasher, & Swaye, 2007), it would be advantageous to target anti-stigma programs and interventions at this age group. Reducing stigma among children and adolescents will develop a culture within which adolescents embrace discussion of mental illness and are inclusive of others with mental illness. This modification of the youth culture may ultimately increase mental health treatment seeking behaviours and compliance with treatment.

Mental health practitioners have held negative attitudes and employed pejorative practices towards self-harm in the past (McAllister, Creedy, Moyle, & Farrugia, 2002). Participants reported healthcare professionals at times taking an intrusive and patronising approach to assessment and found this unpleasant and unhelpful. With

services becoming increasingly risk-focused, such a direct and intrusive approach to assessment is likely to deter help-seeking and impede engagement with mental health services. It may therefore be beneficial for clinicians to think about ways to balance risk management with therapeutic need to make help-seeking a more comfortable experience. Furthermore, since young people seem to have concerns and fears about how mental health practitioners will view and manage their self-harm, a more transparent service may be necessary. There may be a role for services to involve service users in thinking about how to develop services to improve access and engagement for those who self-harm.

The current study raises awareness of the experiences and impacts of stigma for young people that self-harm. It is hoped that its findings will encourage doctors and clinicians to if necessary, adapt their practise so that young people feel at ease both seeking support and complying with treatment. This study supports the pre-existing idea that stigma can disadvantage an individual over and above the difficulties that they already face with mental illness. The findings suggest that both enacted and perceived/felt stigma can impact on a young person's mood and can at times play a role in maintaining the self-harming behaviour. Additionally, findings support the idea that stigma and perceived/felt stigma acts as a barrier for help-seeking. Since perceived stigma seems to be prominent in young people that self-harm, the findings of this paper suggest that attempts to reduce or eradicate public stigma is not sufficient. In addition to stigma campaigns, projects and programs, young people are likely to benefit from direct self-stigma reducing interventions (Heijnders & Van Der Meij, 2006). Such interventions could help young people appraise the self-harm and perceived stigma in more healthy and functional ways so that they are less impacted by it. By providing young people with positive helpful coping strategies, clinicians could endow young

people with resources to manage the stigma, increasing resilience and reducing the negative impact on self esteem.

Future research could focus on the cycle of change around self-harm behaviour. In particular, it would be interesting to explore the relationship between recovery and identification with the self-harming identity. More specifically, it might be interesting to explore the processes behind distancing oneself from the self-harm identity and the factors that contribute to a desire to discontinue self-harming. Additionally, research might focus on expanding the knowledge on how young people perceive and manage stigma attached to mental health so that suitable and effective interventions can be devised, implemented and evaluated. It is important that future research does not neglect the expertise of those who personally experience stigma since their insight and understanding into the concept is invaluable.

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Part 3

Appendices

Appendix A – Guidelines for authors for the systematic literature review.....	123
Appendix B – Guidelines for authors for the empirical paper.....	129
Appendix C – Search terms used for the systematic literature review.....	133
Appendix D - Rationale for the inclusion and exclusion criteria used within the Systematic literature review.....	135
Appendix E – Data extraction sheet.....	138
Appendix F – Quality checklist for qualitative studies.....	141
Appendix G – Quality checklist for quantitative studies.....	143
Appendix H - Quality assessment of qualitative studies.....	145
Appendix I – Quality assessment of quantitative studies.....	148
Appendix J – Rationale behind choosing IPA and credibility check.....	151
Appendix K – Semi-structured interview schedule.....	157
Appendix L - Demographic form.....	163
Appendix M – Ethical documentation.....	166
Appendix N - Rationale for participant Inclusion and exclusion criteria.....	187
Appendix O– Participant and parental information packs.....	189

Appendix P – Participant consent, participant assent and parental consent form.....	211
Appendix Q – Example of data analysis.....	217
Appendix R - Supporting quotes.....	221
Appendix S – Reflective statement.....	230

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- Submitted as separate files, not embedded in text files
- Included at the end of the manuscript

Color illustrations will be considered for publication; however, the author is required to bear the full cost involved in their printing and publication. The charge for the first page with color is \$900.00. The next three pages with color are \$450.00 each. A custom quote will be provided for color art totaling more than 4 journal pages. Good-quality color prints should be provided in their final size.

Proofs and Reprints

Page proofs are sent to the corresponding author using Taylor & Francis' Central Article Tracking System (CATS). They must be carefully checked and returned within 48 hours of receipt. Reprints of individual articles are available for order at the time authors review page proofs. A discount on reprints is available to authors who order before print publication

PARENTING'S OWN STYLE GUIDE

Parenting: Science and Practice Style Guide

In manuscript preparation, adhere to requirements in this Style Guide. Otherwise, follow the guidelines on format, style, and ethics provided in the Publication Manual (6th ed.) of the American Psychological Association.

The submitted manuscript should adhere to the following format...

SEPARATE TITLE PAGE: Include the title of the manuscript, the name(s) of the author(s) and affiliation(s), and the street address, telephone, fax, and electronic mail numbers of the corresponding author.

TITLE SYNOPSIS: Written in lay English, the Synopsis should follow this outline in a single paragraph with the four sections clearly labelled. Objective. Normally a one-sentence description of the motivation for the study. Design. Provides essential information on the sample (including the N of participants), what was done, and how. Results. Summarize the main findings succinctly. Conclusions. The take-home message for the reader.

INTRODUCTION: The title of the paper, but not the names of the author(s), should appear on the first page of the text.

METHODS: Participants or Sample

Procedures

RESULTS

DISCUSSION

AFFILIATION(S) AND ADDRESS(ES)

(Only in final version accepted for publication)

Corresponding author: Whole name, full mailing address, e-mail address. Names and affiliations of co-authors (if any) follow.

ACKNOWLEDGMENTS

REFERENCES

APPENDIX (if applicable)

HEADING ORGANIZATION OF THE MANUSCRIPT

Level 1: All caps...bold...centered...text following flush left.

Level 2: Caps and lowercase...Roman...flush left...text following is paragraph indent.

Level 3: Caps and lowercase...italic...paragraph indent, followed by a period, and run into the text that follows, with a regular space between the period and the text that follows.

Thus:

INTRODUCTION

Parenting Children

Parenting children is important. Parenting children is important because, if parents do not assume this responsibility, who will?

LISTS

Standardize "listings" throughout the manuscript.

- "Variety" and "series": Each mass noun takes a singular verb: a variety is, a series is.
- Spell check the manuscript.
- cf. means "compare," rather than "see."
- Verify quotations and provide page numbers. Quotations longer than 500 words must have permission so as not to violate "fair use."

- Put spaces around hyphens, statistical symbols, and so forth.

SEXISM IN LANGUAGE: Avoid sexism in language; use plural phrases as, "children and their toys" for "a child and his toy."

FOOTNOTES: Footnotes should be used sparingly. Important information should be incorporated into the text. Footnotes should be numbered consecutively in the text as superscripts, but the material to be footnoted should be double-spaced and included on separate pages at the end of the manuscript.

STATISTICS (i, r, F, and the like): Normally statistics are reported to 2 places (after the decimal point). Specify the p level to 2 or 3 places only.

- Statistics are set off from the text with commas (not parentheses).
- Statistics should specify degrees of freedom
- Correlations: $r(df) = .xx$, $p < .0x$: begin with .xx (not a leading zero, 0.xx)

For appropriate terminology, the journal follows Cohen, J. & Cohen, P. (1983) *Applied Multiple Regression/Correlation Analysis for the Behavioral Sciences* (2nd ed., p.61). Hillsdale, NJ: Lawrence Erlbaum Associates:

"Conventional magnitudes of r corresponding to small, medium and large ES [effect sizes] that have been suggested as appropriate at least for many areas of psychological investigation, are $r = .10$, $.30$, and $.50$, respectively."

- Range: like other descriptive statistics (M , SD), range should be italicized and followed by = (not a colon :).
- N for whole sample size, n for subsample sizes.
- Means should be accompanied by a measure of dispersion (SD).
- Mediator-Moderator: For a formal discussion, see Baron, R.M. & Kenny, D.A. (1986) The Moderator-Mediator Variable Distinction in Social Psychological Research: Conceptual, Strategic, and Statistical Considerations. *Journal of Personality and Social Psychology*, 51, 1173-1182

Appendix B: Guidelines for authors for the empirical paper

JOURNAL OF RESEARCH ON ADOLESCENCE

Editorial Scope

Multidisciplinary in scope, this compelling journal is designed to significantly advance knowledge about the second decade of life. Employing a diverse array of methodologies, it publishes original research that includes intensive measurement, multivariate-longitudinal, and animal comparative studies; demographic and ethnographic analyses; and laboratory experiments. Articles pertinent to the variety of developmental patterns inherent throughout adolescence are featured including cross-national and cross-cultural studies, systematic studies of psychopathology, as well as those pertinent to gender, ethnic, and racial diversity.

Audience

Clinical, social, and developmental psychologists, sociologists, social workers, and those specializing in family studies.

Manuscript Submission

Please submit manuscripts via our new online submission site at <http://www.s-r-a.org/jrasubmit>. Complete instructions may be found on this site. Please contact Detra Davis, Managing Editor via email with any questions (jra@s-r-a.org).

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th Ed.). Any manuscript not in this style will automatically be returned to the author. Type all components double-spaced, including title page, abstract, text, quotes, acknowledgements, references, Appendices, Tables, figure captions, and footnotes. The abstract should be 120 words, typed on a separate sheet of

paper. Send only copies of figures on first submission; glossy prints (numbered lightly on the back of each figure) should be submitted only with final revision of accepted manuscript. Authors must use nonsexist language in their articles. For information on this requirement, read 'Guidelines for Nonsexist Language in APA Journals,' which appeared in the June 1977 issues of the *American Psychologist* or consult the *Manual*. All manuscripts submitted will be acknowledged promptly. Authors should keep a copy of the manuscript to guard against loss. If not already described in the manuscript, a document describing the content and psychometric properties of any instruments used in the research but not well-established in the literature should be included with the manuscript at the time of submission.

Permissions

Authors are responsible for all statements made in their work and for obtaining permission from copyright owners to reprint or adapt a Table or figure or to reprint a quotation of 500 words or more. Authors should write to original author(s) and publisher to request nonexclusive world rights in all languages to use the material in the article and in future editions. Provide copies of all permissions and credit lines obtained.

Regulations

Only original manuscripts, written in English, are considered. The corresponding author for a manuscript must, in an accompanying cover letter, warrant that all co-authors are in agreement with the content of the manuscript and that the study was conducted in accordance with the ethical standards of the American Psychological Association. Authors should also state that the findings reported in the manuscript have not been published previously and that the manuscript is not being simultaneously submitted

elsewhere. Upon acceptance, the authors are required to sign a publication agreement transferring the copyright from the author to the Society for Research on Adolescence. Accepted manuscripts become the permanent property of the journal. A statement of Editorial Policy appeared in Volume 1, Number 1.

Manuscript Review

The *Journal of Research on Adolescence* has a Board of Editors that is vested with control over manuscript review and publication. Manuscripts are reviewed by the Editor and the Board of Editors and by invited reviewers with special competence in the area represented by the manuscript. Articles and reviews *must* be judged to be of substantial importance to the broad, multidisciplinary readership of the journal as well as meet a high level of scientific acceptability. A first level of review determines the importance and appropriateness of submissions to the journal readership at large in conjunction with scientific merit; on this basis, the Board of Editors decides whether the manuscript will be reviewed further.

A system of blind reviewing is used. It is the author's responsibility to remove information about the identity of the author(s) and affiliation(s) from the manuscript; such information should appear on the cover sheet. The cover sheet will not be included when a manuscript is sent out for review. The Board member responsible for a manuscript will have the discretion to integrate solicited review with the member's own opinions and recommendations into a determinative response. The Editor retains the right to reject manuscripts that do not meet established ethical standards. The Publications Officer regrets that, in case of rejection, manuscripts cannot be returned.

There is no charge for publication in the *Journal of Research on Adolescence* unless

tabular or graphic materials exceed 10% of the total number of pages. Charges are also levied for changes in proof other than correction of printer's errors. Any inquiries relating to business matters (including reprint orders) should be addressed to the publisher:

Appendix C: Search terms used for systematic literature review.

	Search terms
Self-harm	Self-harm*
	Self-harm*
	Self injur*
	Self-injur*
	Mutilat*
	Self-cutt*
Parenting	
	Self cut*
	Parasuicid*
	Suicidal behav*
	Self-poison*
	Self poison
	Parent*
	Famil*
	Maternal
	Paternal
	Carer*

	Care-giv*
	Mother*
	Father*
Youth	Adol*
	Teen*
	Child*
	Student*
	“Young pe*”
	Youth*

Appendix D: Rationale for the inclusion and exclusion criteria used within the systematic literature review.

Inclusion/ Exclusion criteria	Rationale
Experiences of Parents/guardians of young people that engage in non fatal deliberate self-harm defined as “the intentional injuring of ones own body without apparent suicidal intent” (Klonsky, Oltmanns & Turkheimer, 2003).	
Experiences of parenting a young person that has co- morbid difficulties will be included as long as experiences related to self- harm are distinguished.	<ul style="list-style-type: none"> • The experiences of parenting a child that has non-defined mental health difficulties will not be included due to potential confounding factors.
Studies will not be suitable if they state that the offspring self-harmed with suicidal intent or committed suicide.	<ul style="list-style-type: none"> • It is considered that non fatal self-harm fulfils several functions, the primary one being emotion regulation without intent to die. Therefore, parenting experiences of young people that have attempted/committed suicide will not be

	included as such parenting experiences are likely to involve extra dynamics.
No studies where the young people have learning disabilities or medical conditions will be included	<ul style="list-style-type: none"> • The function of/motivation for the self-harming behavior is potentially different in a young person who has learning disabilities or a medical illness.
The parents will parent young people up to the age of 25.	<ul style="list-style-type: none"> • Young people over the age of 25 are considered more autonomous and are less likely to still be subject to a strong parental influence. Therefore, the parental role may not be so significant in those older than 25 years old.
No genital mutilation	<ul style="list-style-type: none"> • There are thought to be other factors involved in the function of the genital mutilation.
Not printed in English.	<ul style="list-style-type: none"> • The articles could not be translated into English due to time and financial constraints.

Literature reviews, meta-analyses, case studies, dissertations and theses.	<ul style="list-style-type: none">• Literature reviews or other non-empirical papers were excluded as these would not present new evidence and the report of previous studies may be incomplete or biased.• Case-studies are likely to have limited generalisability of findings.• Time constraints to complete the literature review and the potential accessibility of dissertations and theses were considered when deciding to exclude these forms of research. <p>Additionally, unpublished works and dissertations are to be excluded since these may not have been reviewed to the same standard as published works.</p>
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Appendix E: Data Extraction sheet

Study title:

Authors:

Year of publication:

Source (i.e. Journal: Volume / Pages / Country of Origin) and reference:

Study Characteristics

Research question/aims:

Duration of study:

Quality Score:

Study design

Quantitative/Qualitative:

Participant (young person)

Characteristics

Number of young people:

Ages of young people:

Gender ratio (female:Male):

Method(s) of self-harm:

Ethnicity:

Geographical region:

Diagnoses (?):

Other information:

Participant (parent/carers)

Characteristics

Number of parent/carers:

Age of parent/carers:

Marital status:

Employment status:

Does parent/carer live with the
young person? (Y/N)

Parent/carers relationship with the
young person?

Ethnicity:

Geographical region:

Other information:

Participant Recruitment

Recruitment methods:

Inclusion criteria:

Exclusion criteria:

Participation rate:

Procedure

Details of data collected

Method of data collection:

What was measured?

Which outcome measures were used?

Number of times data collected :

Results & Analysis

Qualitative:

Analysis method:

Theoretical perspective:

Themes/ Main findings:

Quantitative:

Statistical tests?

Summary of Results (main findings and statistical significance):

Conclusions

Interpretation of results:

Limitations:

Key links to theory/literature:

Implications of findings:

Further research:

Notes/comments:

Appendix F: Quality Checklist for qualitative studies

Qualitative Research Quality Checklist				
Paper title:				
Author (s):				
Date:	Journal:			
Quality assessment questions	Quality rating			
	Excellent	Sound	Poor	No/Unsure
	3	2	1	0
Clearly focused research question/ aims/objectives				
Clearly focused rationale/ hypotheses				
Qualitative methodology most appropriate				
Underpinning values and assumptions discussed				
Participants				
<ul style="list-style-type: none"> • Participants demographics stated • Inclusion and exclusion criteria stated • Sample representativeness to the population being assessed • Participation rate/ dropout rate reported 				
Methodology				
<ul style="list-style-type: none"> • Time course of the study 				

reported	
<ul style="list-style-type: none"> • Sampling strategy reported • Data collection methods reported 	
Ethical approval reported	
Data analysis	
<ul style="list-style-type: none"> • Data analysis strategy reported • Data analysis appropriate to data collected • More than one rater • Rigorous analysis • Rich data 	
Main findings coherent/ valid/ relevant	
Main conclusions relate to main question	
Implications of study reported	
Limitations of study reported	
Total Score	(Maximum total score: 21x3 = 63)

Appendix G: Quality Checklist for quantitative studies

Quantitative Research Quality Checklist				
Paper title:				
Author (s):				
Date:		Journal:		
Quality assessment questions	Quality rating			
	Excellent	Sound	Poor	No/
	3	2	1	Unsure 0
Clearly focused research question/ aims/objectives				
Clearly focused rationale/ hypotheses				
Outcomes to be measured are clearly defined in the introduction or method section				
Design outlined				
Participants				
<ul style="list-style-type: none"> • Participants demographics stated • Inclusion and exclusion criteria stated • Sample representativeness to the population being assessed • Participation rate/ dropout rate reported 				

Methodology

- Time course of the study reported
- Sampling strategy reported
- Data collection methods reported
- Reliability and validity of measures reported
- Control group utilized and reported

Ethical approval reported

Data analysis

- Data analysis strategy reported
- Data analysis appropriate to data collected
- Confidence intervals reported
- Have actual probability factors been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?
- If any of the results of the study were based on “data dredging”, was this made clear?

Main findings clearly reported

Main conclusions relate to main question

Implications of study reported

Limitations of study reported

Total score

(Maximum total score: $23 \times 3 = 69$)

Appendix H: Quality assessment of Qualitative Studies

Quality assessment questions		Studies						
	Byrne et al., (2008)	Raphael, Clarke, & Kumar (2006)	McDonald, O'Brien, & Jackson (2007)	Rissanen, Kylma, & Laukkanen (2008)	Rissanen, Kylma, & Laukkanen (2009)	Oldershaw, Richards, Simic, & Schmidt (2008)	Yip, Ngan, & Lam (2003)	Nixon, McLagan, Landell, Carter, & Deshaw. (2004)
Author (Independent rater) scores								
Clearly focused research question/ aims/objectives	3	3 (2)	3	2 (3)	3	3	3 (3)	3
Clearly focused rationale/ hypotheses	3	3 (2)	3	3 (3)	3	2	3 (3)	3
Qualitative methodology most appropriate	3	3 (3)	3	3 (3)	3	3	3 (3)	1
Underpinning values and assumptions discussed	1	1 (1)	3	2 (2)	2	2	1 (2)	0

Participants								
• Participants demographics stated	1	3 (3)	2	3 (2)	3	3	3 (3)	1
• Inclusion and exclusion criteria stated	2	2 (2)	2	0 (1)	0	3	0 (0)	3
• Sample representative to the population	2	2 (2)	2	1 (1)	1	1	1 (1)	1
• Participation rate/ dropout rate reported	1	3 (3)	3	2 (2)	2	3	0 (0)	3
Methodology								
• Time course of the study reported	3	3 (3)	0	0 (0)	0	3	0 (0)	3
• Sampling strategy reported	3	3 (3)	3	3 (3)	3	2	2 (2)	3
• Data collection methods reported	3	3 (3)	3	2 (2)	2	3	2 (3)	2
Ethical approval reported	0	2 (2)	3	2 (2)	2	2	2 (2)	0

Data analysis								
• Data analysis strategy reported	3	3 (3)	3	3 (3)	3	3	3 (3)	0
• Data analysis appropriate to data collected	3	3 (3)	3	3 (3)	3	3	3 (3)	0
	3	3 (3)	3	0 (0)	0	3	3 (3)	0
• More than one rater	3	3 (2)	3	3 (3)	3	3	3 (3)	1
• Rigorous analysis	3	3 (2)	3	3 (2)	3	3	2 (2)	1
• Rich data								
Main findings coherent/ valid/ relevant	3	3 (3)	3	3 (3)	3	3	2 (2)	1
Main conclusions relate to main question	3	3 (3)	3	3 (3)	3	2	3 (3)	2
Implications of study reported	3	3 (3)	3	1 (0)	1	2	3 (2)	1
Limitations of study reported	2	0 (0)	2	1 (1)	1	2	0 (0)	2
Total score	51/63	55/63 (50/63)	56/63	43/63 (42/63)	44/63	54/63	42/63 (43/63)	31/63

Appendix I: Quality assessment of Quantitative studies

Quality assessment questions		Studies		
	Power, Morgan, Byrne, Boylan, Carthy, Crowley, Fitzpatrick & Guerin (2009)	Mojtabai & Olfson (2008)	Gilliland (1990)	Cassidy, McNicholas, Lennon, Tobin, Doherty, & Adamson (2009)
	Author (Independent rater) scores			
Clearly focused research question/ aims/objectives	3 (3)	2	1	2
Clearly focused rationale/ hypotheses	3 (3)	2	1	2
Outcomes to be measured are clearly defined in the introduction or method section	3 (3)	3	0	1
Design outlined	3 (3)	2	1	1
Participants				
• Participants demographics stated	2 (3)	2	1	3
• Inclusion and exclusion criteria stated	0 (0)	1	0	1
• Sample representativeness to the population				

being assessed	2 (2)	3	1	1
• Participation rate/ dropout rate reported	3 (3)	2	0	2
Methodology				
• Time course of the study reported	3 (3)	1	2	2
• Sampling strategy reported	3 (3)	3	1	2
• Data collection methods reported	3 (3)	2	1	1
• Reliability and validity of measures reported	3 (3)	0	0	0
• Control group utilized and reported?	0 (0)	3 (N/A)	2	0
Ethical approval reported	2 (1)	2	0	2
Data analysis				
• Data analysis strategy reported	3 (3)	3	0	1
• Data analysis appropriate to data collected	3 (3)	2	0	2
• Confidence intervals reported	2 (2)	3	0	0
• Have actual probability factors been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is	2 (2)	1	2	2

less than 0.001?				
• If any of the results of the study were based on “data dredging”, was this made clear?	3 (3)	2	1	3
Main findings clearly reported	3 (3)	2	2	2
Main conclusions relate to main question	3 (2)	3	2	2
Implications of study reported	2 (2)	2	0	1
Limitations of study reported	3 (3)	3	0	2
Total score	57/69 (57/69)	49/69	18/69	35/69

Appendix J: Rationale behind choosing IPA and credibility check

Ontological and Epistemological considerations

Since the way in which we experience the world impacts on the way in which we research the world, our decisions and actions as researchers are inherently impacted on by our own world views (Crotty, 2003). Therefore, consideration of the researcher's ontological and epistemological stances play an important role in selecting an appropriate methodology.

Ontology is concerned with what entities are real or can be said to exist. Realist views would assume that there is an independent social reality which can be objectively measured. Relativist views assume that there is no absolute truth but that all understanding is subjective and relative to a frame of reference, brought about by differences in perception. Epistemology refers to the basis of knowledge, how it can be acquired and how it can be communicated to others. Reflecting a realist ontology, positivist methodologies typically acquire knowledge via scientific methods, collecting quantitative, measurable data in order to test an already derived hypothesis or theory (Cohen, Manion, & Morrison, 2007). In contrast to positivist approaches, qualitative research (Smith, 2008) concentrates on understanding rather than explaining or predicting experiences, and is therefore more aligned with a relativist ontology.

The experience of stigma is likely to be shaped by one's experiences of life, relationships with others and perspectives on the world. Therefore, although experiences may be similar in some aspects, no two individuals are expected to bring the same interpretation and meaning to their experiences, reflecting a relativist ontology. The researcher views research as learning about people rather than studying them and see's

participants as active contributors rather than passive partakers. Considering this and the absence of research into the area of stigma around self-harm in adolescents, it was decided that this study would assume an exploratory approach to stigma using a qualitative methodology. The researcher felt that the area of stigma does not easily lend itself to quantification due to its complexity and such quantification would likely be reductionist.

The researcher gave serious consideration to four qualitative approaches; Grounded theory, content analysis, discourse analysis and Interpretative Phenomenological Analysis (IPA). Following consideration of each, the researcher decided that IPA would be the most appropriate methodology for the reasons described below.

Grounded theory is designed to facilitate the process of theory generation (Charmaz, 2006). Willig (2001) argues that discovering theory from data indicates that the researcher uncovers something that already exists which suggests that it is possible for a researcher to avoid imposing their own meaning onto the data. This reflects the belief that phenomena create their own representations that are directly perceived by others and thus reflects a positivist epistemology. Since the researcher did not intend to create theory but was instead keen to explore experiences, this methodology was deemed unsuitable.

Content analysis studies the content of pre-existing communication with the purpose of providing knowledge and “facts” (Krippendorff, 1980). Although it allows an unobtrusive examination of the phenomena, it can be somewhat reductionist as it reduces the complexity of phenomena into simplified categories. This method was

considered unsuitable for this research study since the data may not provide a true representation of an individual's experiences. It is likely that interpretation will be required to gain a deeper level of understanding.

Discourse analysis is concerned with language and its role in the construction of social realities (Willig 2001). On the basis that participants may feel stigmatised during the research interviews, taking language at face value may not be appropriate since some participants may feel unable to express themselves fully and thus deeper interpretation may be required which discourse analysis does not accommodate for. Additionally, this methodology does not sit comfortably with the researcher who as a trainee Clinical Psychologist, is practised at considering more than the face value of what individuals say and instead is familiar with a deeper level of interpretation considering nonverbal cues and parallel processes.

IPA is an exploratory method which does not aim to draw conclusions, make claims of generalisability or develop theory but aims to gain insight into experiences from the perspective of the beholder, paying attention to the complexities and subtleties of individual experiences (Smith, Flowers, & Larkin, 2009). Three theoretical perspectives are central to IPA; Phenomenology, hermeneutics and idiography. Firstly, IPA is phenomenological in attempting to get as close as possible to the personal experience of the participant (Spinelli, 1989). Secondly, we may not have the knowledge or vocabulary to describe all of our experiences, and furthermore, they may remain outside of our awareness. Therefore, a degree of interpretation is necessary to gain greater access to the meaning behind the words used. The researcher is said to be involved in a double hermeneutic since they attempt to make sense of the individual who is attempting to make sense of their experience. Thirdly, IPA is idiographic as it is

concerned with the particular, aiming to explore each individual's experience in detail, valuing the complexity of individual experience.

The researcher valued the 3 theoretical perspectives held by IPA and felt that they sat well with the area of stigma. Due to differences between individuals and how they perceive and relate to the world around them, each individual experience is likely to be unique. In an area as personal as the experience of stigma, each participant's views and experiences are considered important and valid and therefore an attempt to generalise the experience of stigma is deemed inappropriate. Additionally, IPA fits with the researchers' clinical training and practise which encourages a person-centred idiographic approach to ensure that each client's needs are met.

In light of the above, since this research will take a discovery-orientated approach, with the aim to explore how participants are making sense of their personal and social world and the interpretations and meanings that particular experiences of stigma, events and states hold for them, IPA (Smith et al., 1999) was considered the most appropriate method of analysis.

Credibility Check

Avis (2005) suggest that qualitative researchers depend upon 'reflexivity' and 'transparency' to provide warrantability. In light of this, the researcher kept a reflective diary in which they documented their thinking and decision making. This was helpful in providing a transparent account of the research and facilitated understanding of the context within which research was conducted. Significant reflections were discussed with the second author to further insight.

During research it is important to recognise how our characteristics, beliefs and assumptions might be influencing the information that is shared by participants and our interpretations of that information. The fact that the researcher is a fairly young female who has not long come to the end of the journey of adolescence themselves, may have impacted on how the participants related to the researcher and thus their degree of openness. It is also possible that the researcher's youth and personal experiences during adolescence have impacted on how they understood and interpreted the information that the participants shared. Although there is an inevitable degree of researcher influence, to ensure that analysis was not confined to one interpretation/perspective, multiple analyses of transcripts occurred through involvement with an IPA group organised via the host institution. This involved discussion of transcripts and potential themes with four other analysts with knowledge or experience of using IPA. Additionally, extracts of transcripts were analysed by research supervisors to further increase validity. Furthermore, participants provided member validation of the study results and were invited to comment on emergent themes in the analysis in relation to their own experiences.

References for Appendix J: Rationale behind choosing IPA

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Appendix K – Semi Structured Interview Schedule

Version 1

Date: 13/4/2010

Ref: ***



Interview Schedule and prompts

So we are about to start the interview. It should last somewhere between 30 and 90 minutes. Like it said in the information pack, if you would like to stop the interview at any point just let me know and that will be fine.

Research Question 1: How do adolescents who self harm perceive stigma from others?

Question 1: "I'm interested to know how you would describe yourself as a person?"

Prompt: Can you tell me a bit about yourself?

Prompt: Could you pick three words or adjectives that you think best describe you?

Prompt: Think about other adolescents in your age group. To what extent do you consider yourself similar or different to them?

Prompt: What do you consider to be your strengths and weaknesses?

Question 2: "What do you think other people's first impressions of you are?"

Question 3: "How close are these impressions to how you see yourself?"

Question 4: "How do you feel that other people in your life who know that you are getting treatment from CAMHS respond to you?"

Prompt: How do they treat you, what do they do or say?

Prompt: How does this make you feel?

Prompt: How would you like people to treat you? What changes are necessary in order for this to happen?

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Cottingham Road
Hull, HU6 7RX
www.hull.ac.uk

Prompts: Family? Friends? Other children in school? Teachers/ school staff? Strangers?

Prompt: Is there anyone in particular in your life that you do not want to know about your 'self-harm' or that you are receiving mental health services?

Prompt: What is the reason for (not) wanting them to know?

Prompt: What would happen if they knew?

Prompt: What do you think they would do or say if they knew?

Prompt: How would this make you feel?

Prompt: Do you have any say over whether they know or not? How can you influence this?
What makes you unable to influence this?

Question 5: "Stepping back a bit from your personal situation, what do you think other people think about adolescents who have mental health problems?"

Prompt: Would that be something that you've heard others say or is it something that you'd expect they were thinking?

Question 6: "How do you think having a mental health diagnosis affects how an individual thinks or feels about themselves?"

Some people use the term "self harm" to describe the activity by which people deliberately inflict harm to themselves without intent to end their lives. Within your own personal experience, how do you refer to it?

"So far we've considered both mental health and self harm. From now on the questions will be in relation to self harm only."

Question 7: "How do you see yourself in comparison to other adolescents who self harm?"

Prompt: What are the similarities/differences between you and others your age who also self harm?

Question 8: "We've discussed what you think other people think of adolescents with mental health difficulties. Stepping back a bit from your personal situation again, what do you think other people think of adolescents who self harm?"

Prompt: *Why* do you think other people think adolescents self harm?

Prompt: How do you think someone who doesn't self harm would describe someone who does self harm?

Prompt: What makes you think others think this?

Prompt: Do you think they're right?

Prompt: *How open* *Are* other people open about how they feel towards adolescents who self harm? Or do they keep it to themselves?

Question 9: "I'm interested whether you think people think this of you or whether they see you differently?"

Question 10: "In your experience, if people see your self-harm scars/wounds, how do they react?"

Prompt: I'm interested whether they say anything? Or whether they do anything? How do they behave?

Prompt: What do you think they are thinking?

Prompt: How does this make you feel?

Prompt: Are everyone's reactions the same or do different people have different reactions? *For example: friends, family, strangers, health care professionals, school?*

Prompt: Do people see your scars/wounds regularly? *How often do people see your wounds/scars*

Prompt: What determines whether or not people see your scars? Do you do anything to influence whether or not people see your scars?

Research Question 2: How do adolescents who self harm manage or react to stigma from others?

Question 1: "Could you tell me about how open you are with other people about your self harm?"

Prompt: Do others know about your self harm?"

Prompt: Do you do anything to influence whether other people know about your self harm?

Prompt: Do you put yourself in situations which enable you to tell others about your self harm?

Prompt: Do the wounds/scars affect how open you are about your self harm?

Prompt: Do you try to hide your self harm? What methods do you use? What's useful about these methods?

Prompts: Does your degree of openness differ in different contexts, for example at school? At home? Or in public?

Question 2: "How do you feel when you see that someone has seen your scars/wounds or knows that you self-harm?"

Prompt: What do you do, how do you behave?

(If Avoidance/confrontation is mentioned – can you tell me a bit about how you do this?)

Prompt: How do others react when they see your scars?

Prompt: How does this make you feel?

Prompt: I'm interested to know whether people ask you about your self harm? How does this make you feel? How do you deal with the situation?

Prompt: Do people make comments about your self-harm? How do these make you feel? How do you react to these?

Prompt: Why do you think others (do/don't ask questions or make comments?)

Research Question 3: How does stigma from others impact on adolescents who self harm?

Thank you for the useful information you have given me so far. We are not quite finished yet. So far we have spoken about your experiences regarding the reactions and responses of others to your self harm and how you manage these responses. If it is fine by you I would now like to ask you some questions about any impacts these responses might have on you.

Question 1: "Can you tell a bit about whether you think the way people respond to your self harm impacts on you?"

Prompt: How does the way people react or respond when they know you self harm make you feel?

Prompt: How does the way people react or respond when they know you self harm make you behave?

Prompt: Does it make you feel good about yourself? Or not so good about your self?

Prompt: Do you think that it affects your confidence?

Prompt: Do you think that it affects your self esteem?

Prompt: Is the way people respond to you helpful in any way?

Question 2: "Can you tell me a bit about whether you think you behave differently in any aspect(s) of your life to what you would if you didn't self harm?"

Prompt: How do you behave differently? Why do you think you do/don't behave differently? How, if at all, does behaving differently impact on your life?

Prompt: Do you find yourself avoiding anything? Activities? People? Wearing certain clothes?

Prompt: Do you find you actively do things differently E.g. concealing your self harm?

Question 3: "Can you tell me about the affect that other people's reactions do or don't have on your recovery"

Prompt: Does it affect the frequency of your self harm?

Prompt: Does it encourage or discourage you to stop self harming.

Prompt: How easy or difficult do you find it to seek help or support with the self harm?

Prompt: Did you have any worries or concerns about coming to CAMHS? What did you think about coming to CAMHS? Do you consider this to be at all related to your self harm?

Question 4: "What thoughts do you have about the future?"

Prompt: Do you think that the reactions of others towards your self harm will affect you in the future in any way? "

Prompt: Do you think it will have a long term impact?

Prompt: Do you think it will impact you in 1 year? How about in 5 years? How about in 10 years?

Prompt: Do you think it will impact on any future relationships? Or ambitions?

Question 5: "In relation to what you have been able to tell me today about your experiences of how others react to your self harm and how this impacts on you, is there anything you would like to add to support the information you have given me?"

Prompt: Is there anything else you would like to tell me?

Prompt: Has anything been missed that you think it would be important for me to know?

Prompt: Is this what you expected to talk about today?

Prompt: How have you found the interviewing process?

Prompt: Are there any suggestions you would like to make about improving the interviewing process?

Prompt: Did you experience any distress or have any concerns during the interview?

Prompt: Do you feel as though you would speak to someone about this distress?

That's the end of the interview. How are you feeling? Are you feeling ok to go home?

Thank You for your time and contribution

Extra prompts: Can you tell me more about that?

How did you feel about that?

Appendix L: Demographic Form

Date: 6/06/2010

Version: 2



Centre number:

Study number:

Participant Identification number for this study:

Demographic Form**Background Information Questionnaire****Demographics***This section looks at general information about you*Please tick the appropriate
box or insert an answer

1. participant gender

Male ☐ Female ☐

2. Age

3. Date of birth

4. Are you in education?

Yes ☐ No ☐

Please state whether this is school or college

University of Hull
Hull Campus
Cottingham Road
Hull, HU6 7RX
www.hull.ac.uk

Date: 6/06/2010

Version: 2

Self Harm*This section looks at details of your selfharm*

5. Approximately how long have you self harmed for? _____

6. Approximately how often do you self harm?

Once ever

☐

Less than once a month

☐

Once a month

☐

More than once a month

☐

Once a week

☐

More than once a week

☐

Once daily

☐

Several times daily

☐

Other _____

7. What methods of self harm have you used previously? Cutting/scratching

☐

Skin picking

☐

Burning

☐

Hair pulling

☐

Drug/alcohol abuse

☐

Overdose

☐

Other (s) _____

Date: 6/06/2010

Version: 2

8. Do you have any wounds/scars from self harm?

Yes

☐

No

☐

If your answer to question 8 was yes, where are the wounds/scars on your body?

If your answer to question 8 was yes, on a scale of 1-10, how visible do you consider your scars to be? (Please mark a cross on the scale at the appropriate location)

0-----10

(Not very visible)

(Very visible)

Services

This section looks at your past and current involvement with CAMHS services

9. How long have you currently been involved with CAMHS?

10. Have you been seen by anyone in CAMHS before this time?

Yes

☐

No

☐

If your answer to question 10 was yes;

How many times? _____

When? _____

For how long? _____

THANK-YOU FOR COMPLETING THIS FORM

Appendix M: Ethical Documentation

Initial Research and Ethics Committee Approval

**National Research Ethics Service****Sheffield Research Ethics Committee**

1st Floor Vickers Corridor
Northern General Hospital
Herries Road
Sheffield
S5 7AU

Telephone: 0114 271 4011
Facsimile: 0114 256 2469

17 May 2010

Miss Jade Griffiths
Trainee Clinical Psychologist
Humber Mental Health Teaching Trust
Hull University, Hertford Building
Cottingham Road
Hull
HU6 7RX

Dear Miss Griffiths

Study Title: Deliberate self harm in adolescence: An exploratory study into perceptions of, responses to and impacts of stigma.
REC reference number: 10/H1308/36
Protocol number: Protocol Ref N/A

The Research Ethics Committee reviewed the above application at the meeting held on 10 May 2010. Thank you for attending to discuss the study.

Ethical opinion

The following points were discussed and clarified at the meeting:

- Reviewing members, and the Chair, offered congratulations on the quality of the submission, it was clear that much care had been taken putting the project together.
- The Chair asked if revisiting events may awaken bad thoughts, you confirmed that this was a possibility but there would be adequate support on hand should this occur.
- Members asked what would happen if a child under 16 years gave assent to take part but the parents did not provide consent. You confirmed that in this instance they would not be asked to join the study.
- Reviewing members asked what would happen if the parent wished to be present at the interview. You stated the intention to discuss this with the parent and decide an action depending on the parent's reasons. Members said it should be very clear in the information sheet that parents will not be present at the interview.
- The Chair asked about the possible length of the interview i.e. up to two hours. You clarified that it was highly unlikely to go on this long and they anticipated most interviews to take approximately one hour.

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the National Patient Safety Agency and Research Ethics Committees in England

- The absent reviewing member had asked what would happen if the child referred to any aspects of the care or practice at CAMHS. You clarified that she would pass any such comments on to your academic Supervisor who would initiate the correct procedure.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

1. In both the participant information sheets:

- *The introductory paragraph should state that this is an educational study.*
- *It should be clear that the parents can accompany the adolescents for support but they will not be expected to be present at the interview.*
- *It should inform that reasonable travel expenses will be paid if any additional visits are required.*

2 The demographic data sheet:

- *The number sequence needs to be checked as this does not add up.*
- *Any queries should be directed to the co-ordinator in the first instance..*
- *Please ensure any modified documents are updated with appropriate versions and dates. The committee asks that no other changes, other than those specifically requested, be made at this point in time*

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
REC application		16 April 2010
Investigator CV		
Protocol	2	13 April 2010
Participant Information Sheet	1	13 April 2010
Participant Information Sheet: Children under 16	1	13 April 2010
Participant Information Sheet: Parent guardian	1	13 April 2010
Participant Consent Form	1	13 April 2010
Participant Consent Form: parental consent	1	13 April 2010
Participant Consent Form: Assent	1	13 April 2010
Referees or other scientific critique report		21 December 2009
Summary/Synopsis	1	13 April 2010
Interview Schedules/Topic Guides	1	13 April 2010
Advertisement	1	13 April 2010
Demographic form	1	13 April 2010
CV for supervisor		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

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The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1308/36	Please quote this number on all correspondence
-------------	--

With the Committee's best wishes for the success of this project

Yours sincerely

A Dagnall

PP Dr C A Moore
Chair

Email: april.dagnall@sth.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers" [SL-AR1 for CTIMPs, SL-AR2 for other studies]*

Copy to: *Stephen Walker, Humber NHS Foundation Trust*

Sheffield Research Ethics Committee

Attendance at Committee meeting on 10 May 2010

Committee Members:

Name	Profession	Present	Notes
Miss Lauren Baxter	Research Coordinator	Yes	
Dr J Burr	Lecturer in Foundations of Medicine and Ethics	Yes	
Dr Mary Cooke	Lecturer in Midwifery and Nursing	No	
Dr N D Edwards	Consultant Anaesthetist	No	
Miss Pamela Kingman		Yes	
Mr J Kirkland	Deputy Ward Manager	Yes	
Professor R M Loynes		Yes	
Ms Kay Marriott		No	
Dr C A Moore	Consultant Anaesthetist	Yes	
Mr Ian Potter	Senior Operating Department Practitioner	Yes	
Dr Basil Sharrack	Consultant Neurologist	Yes	
Dr S Song	Consultant Diabetologist	Yes	
Mr N Sykes	Lay Committee Member	Yes	
Dr S M Thomas	Senior Lecturer in Vascular Radiology	Yes	
Dr Angela Tod	Senior Research Fellow	No	
Mr Mark Wilkinson	Consultant Orthopaedic Surgeon	Yes	
Mrs Elaine Woods-Stringer	Principal Lecturer	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mrs April Dagnall	Admin Assistant
Mrs Sue Rose	Administrator
Ms Lisa Teasdale	Observer
Mr Nathaniel White	Observer

Written comments received from:

Name	Position
Dr N D Edwards	Consultant Anaesthetist
Dr Angela Tod	Senior Research Fellow

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the National Patient Safety Agency and Research Ethics Committees in England

Research and Development Approval (Humber NHS)

Humber 
 NHS Foundation Trust
 Research & Development Department
 Trust Headquarters
 Willerby Hill
 Beverley Road
 WILLERBY
 HU10 6ED

08/07/2010

Miss Jade Griffiths
 Dept of Clinical Psychology,
 Hertford Building
 University of Hull
 Cottingham Road, Hull
 HU6 7RX

Dear Miss Jade Griffiths

Re: R&D ID: 10/04/440 REC ID: 10/H1308/36
Deliberate self harm in adolescence: An exploratory study into perceptions of, responses to and impacts of stigma.

I am please to notify you formally that this study has been approved by the Humber NHS Foundation Trust.

Your research has been approved to take place at the following locations:

Hull CAMHS John Havelot House,
 CAMHS Hull, Grange Road, Bilton Grange
 East riding CAMHS Rivendell House, Driffield
 Coltman Avenue Clinic, Beverley

Please contact Mandy Dunn (Coltman) 869200 Nicky Titchener (Rivendell) 01377 208280 and Karen Warwick (Hull) 702083 to arrange detailed access.

Humber NHS Foundation Trust conducts all research in accordance with the requirements of the Research Governance Framework, and the NHS Intellectual Property Guidance. In undertaking this study you agree to comply with all reporting requirements, systems and duties of action put in place by the trust to deliver research governance, and you must comply with the Trust information management and data protection policies. In addition, you agree to accept the responsibilities associated with your role that are outlined within the Research Governance Framework as follows:

- The study follows the agreed protocol
- Participants should receive appropriate care while involved in the study
- The integrity and confidentiality of clinical, other records and data generated by the study will be maintained
- All adverse events must be reported to the Trust and other authorities specified in the protocol
- Any suspected misconduct by anyone involved in the study must be reported

You must ensure that the protocol is followed at all times. Should you need to amend the protocol, please follow the national research ethics service procedures. You should forward a copy of all amended versions of the protocol and/or documentation together with written confirmation that a favourable opinion has been given by the REC, to the R&D office at the trust.

You will be required to complete electronic progress reports and a final monitoring form on completion . As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this trust (recruitment target, actual numbers recruited). To reduce bureaucracy, progress reporting is kept to a minimum, however, if you fail to supply the information requested, the trust may withdraw approval.

I would like to wish you every success with this project

Yours sincerely

A handwritten signature in black ink, appearing to be 'Duncan Courtney', with a stylized, flowing script.

Duncan Courtney
Clinical and Research Governance Manager

Research and Development Approval (RDASH NHS)



Rotherham Doncaster and South Humber Mental Health

NHS Foundation Trust
Clinical Effectiveness Department
 Birch View, St Catherine's, Tickhill Road,
 Balby, Doncaster. DN4 8QN
 Telephone: 01302 796726
 Fax: 01302 796729
 E.mail : helen.oldknow@rdash.nhs.uk

HJO/CAE

Miss Jade Griffiths
 Flat 15
 St Vincents Court
 36 Queens Road
 Hull
 HU5 2QP

14th July 2010

Title of project: **Deliberate Self-Harm in Adolescence. An exploratory study into perception, management and impact of reactions towards self-harm**

REC reference number 10/H1308/36
Trust ID 88/10/JG
Expiry Date:

Dear Miss Griffiths

Rotherham Doncaster & South Humber Mental Health NHS Foundation Trust has reviewed your above project for Organisational approval. We can confirm that the research project meets the requirements for Research Governance and we now give you Trust approval.

However if the protocol should change you would have to re-submit your new proposal. May we remind you that you are obliged to adhere to the Research Governance Framework for Health and Social Care.

In the interest of ensuring the Trust receives maximum benefit from co-operating with research projects such as your own, the Trust places great importance on disseminating findings and conclusions. Therefore we would welcome a short summary of the findings of this project, once completed, along with any formal publications resulting from this work.

May I take this opportunity to wish you well with your project. If you have any concerns please do not hesitate to contact Helen Oldknow on 01302 796762.

Yours sincerely

P.P

Dr Riadh Abed
 Medical Director

Serving people from all walks of life

Christine Boswell - Chief Executive

Madeleine Keyworth - Chairman

Rotherham Doncaster and South Humber Mental Health



NHS Foundation Trust

Clinical Effectiveness Department
 Birch View, St Catherine's, Tickhill Road,
 Balby, Doncaster. DN4 8QN
 Telephone: 01302 796726
 Fax: 01302 796729
helen.oldknow@rdash.nhs.uk

Date: 14.7.2010

Ms Jade Griffiths
 Trainee Clinical Psychologist
 Humber Mental Health Teaching Trust
 Hull University, Hertford Building
 Cottingham Road
 Hull
 HU6 7RX

Dear Ms Jade Griffiths

Letter of access for research

This letter confirms your right of access to conduct research through Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 14th July 2010 and ends on 31st August 2011 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust, you will remain accountable to your employer Humber Mental Health Teaching Trust but you are required to follow the reasonable instructions of Mrs Gail Hebbon Assistant Director Child and Adolescent Mental Health Services and Forensic Business Division in this NHS organisation or those given on his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Serving people from all walks of life

Christine Boswell - Chief Executive

Madeleine Keyworth - Chairman

You must act in accordance with Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely



Director of Workforce, Organisational Development and Corporate Affairs
Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust

cc: R&D office at Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust
HR department of the substantive employer

Research and Ethics Committee Approval: Amendment one

**National Research Ethics Service****Sheffield Research Ethics Committee**

Yorkshire and the Humber REC Office
First Floor, Millside
Mill Pond Lane
Meanwood
Leeds
LS6 4RA

Tel: 0113 3050160

11 November 2010

Miss Jade Griffiths
Trainee Clinical Psychologist
Humber Mental Health Teaching Trust
Trainee Clinical Psychologist
Hull University, Hertford Building
Cottingham Road
Hull
HU6 7RX

Dear Miss Griffiths

Study title: Deliberate self harm in adolescence: An exploratory study into perceptions of, responses to and impacts of stigma.
REC reference: 10/H1308/36
Protocol number: N/A
Amendment date: 15 October 2010

The above amendment was reviewed at the meeting of the Sub-Committee held on 11 November 2010 by the Sub-Committee in correspondence.

Ethical opinion

The Sub Committee gave a favourable opinion to the Notice of Amendment and revised documentation

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Letter from Sponsor		15 October 2010
Participant Consent Form: Assent Form	2	13 October 2010
Participant Consent Form: Parental Consent Form	2	13 October 2010

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Participant Information Sheet	3	13 October 2010
Participant Information Sheet: Young people under 16 years of age	3	13 October 2010
Participant Information Sheet: Parent/Guardian	3	13 October 2010
Protocol	23	03 November 2010
Notice of Substantial Amendment (non-CTIMPs)		15 October 2010
Covering Letter		15 October 2010
Participant Consent Form: Consent Form	2	13 October 2010
Demographic Form	3	13 October 2010
Advertisement	2	13 October 2010
Interview Schedule and prompts	2	13 October 2010

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/H1308/36:

Please quote this number on all correspondence

Yours sincerely



Mr John Robinson
Committee Co-ordinator

E-mail: john.robinson@leedspft.nhs.uk

Enclosures:

List of names and professions of members who took part in the review

Copy to:

Stephen Walker, Humber NHS Foundation Trust, Research and Development Department, Trust Headquarters, Willerby Hill, Beverley Road, Willerby, Hull, HU10 6ED.

Sheffield Research Ethics Committee**Attendance at Sub-Committee of the REC meeting on 11 November 2010**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr Jennifer Burr	Lecturer in Foundations of Medicine and Ethics	Expert
Dr Angela Tod	Senior Research Fellow	None

Research and Ethics Committee initial feedback: Amendment two

Sheffield Research Ethics Committee

Yorkshire and the Humber REC Office
First Floor, Millside
Mill Pond Lane
Meanwood
Leeds
LS6 4RA

Tel: 0113 3050160

02 February 2011

Miss Jade Griffiths
Trainee Clinical Psychologist
Humber Mental Health Teaching Trust
Hull University, Hertford Building
Cottingham Road
Hull
HU6 7RX

Dear Miss Griffiths

Study title:	Deliberate self harm in adolescence: An exploratory study into perceptions of, responses to and impacts of stigma.
REC reference:	10/H1308/36
Protocol number:	N/A
Amendment number:	3
Amendment date:	18 January 2011

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review decided that they could not give a favourable ethical opinion of the amendment, for the following reasons:

The Sub Committee noted that consent will be sought from all parents of non-Gillick competent children. However the Sub Committee felt there was a discrepancy between the initial application where it was suggested that, "The lower age limit was chosen as adolescents under 14 years of age may be not be cognitively and emotionally mature enough to take part in the interview," and this Amendment, which seems to indicate that under fourteen year olds can participate.

The Sub Committee felt that some form of screening process to only recruit adolescents clinically deemed suitable for inclusion is needed. If the CAMHS teams are willing to be selective in whom they give study information to or if the researcher could obtain a statement from CAMHS teams to indicate that that in their opinion the researchers were incorrect in their initial statement about the ability of children under the age of fourteen to take part in this project, then the Committee would be satisfied.

The Sub Committee expressed some concern regarding the Patient Information Sheet, which they felt could be beyond the comprehension of a thirteen year old.

We regret to inform you that the amendment is therefore not approved. The study should continue in accordance with the documentation previously approved by the Committee.

Modifying the amendment

You may modify or adapt the amendment, taking into account the Committee's concerns. Modified amendments should be submitted on the standard Notice of Amendment form. The form should indicate that it is a modification of the above amendment. Please ensure that you submit all of the documents again that need to be reviewed, that is any of those listed below which are still relevant, as well as any revised or new documents.

A revised Notice of Amendment form must be submitted at least 14 days before you plan to implement the amendment. The Committee will then have 14 days from the date of receiving the notice in which to notify you that the amendment is rejected, otherwise the amendment may be implemented.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Participant Information Sheet: Non NHS Information pack for under 16s	4	14 January 2011
Participant Information Sheet: Non NHS Information Pack for parents or guardians	4	14 January 2011
Participant Information Sheet: Parent/Guardian information pack	3	14 January 2011
Participant Information Sheet: Information pack for young people under 16 years of age	3	14 January 2011
Participant Information Sheet: Participant Information pack (16 years+)	3	14 January 2011
Protocol	4	14 January 2011
Notice of Substantial Amendment (non-CTIMPs)		18 January 2011
Covering Letter		14 January 2011
Advertisement	2	14 January 2011
Advertisement	3 (Non NHS)	14 January 2011
Participant Information Sheet: Non NHS Participant Information Sheet 16+	4	14 January 2011
Letter of support from Humber FT Clinical Governance Department		18 January 2011

Membership of the Committee

The members of the Committee who took part in the review at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/H1308/36:

Please quote this number on all correspondence

Yours sincerely

Mr John Robinson
Committee Co-ordinator

E-mail: john.robinson@leedspft.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Copy to: Stephen Walker, Humber NHS Foundation Trust

Sheffield Research Ethics Committee**Attendance at Sub-Committee of the REC meeting on 28 January 2011****Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Nigel Hoggard	Consultant Neuro Radiologist	Yes	
Dr Basil Sharrack	Consultant Neurologist	Yes	
Dr Ruth Stirton	Lecturer in Law	Yes	

Supporting Information for Amendment two

10th February 2011

Improving health and wellbeing

John Robinson (co-ordinator),
First Floor
Millside
Mill Pond Lane
Leeds
LS6 4EP

Child and Adolescent Mental Health Service

Hull CAMHS
John Havelot House
Grange Road
Bilton Grange
Hull
HU9 4LQ

Tel: 01482 702083

Fax: 01482 701279

Dear Mr Robinson

We are writing in regards to the research study: **10/H1308/36**: 'Deliberate self-harm in adolescence: An exploratory study into perceptions of, responses to and impacts of stigma'.

The researcher stated that their original reason for selecting participants between 14-18 years old was because "adolescents under 14 years of age may not be cognitively and emotionally mature enough to take part in the interview". As the researcher has suggested with the use of the word "may", this will not be true for all adolescents under 14, particularly 13 year olds. Furthermore, since every child develops at a different rate, it is not possible to judge emotional and cognitive maturity purely on chronological age and thus there is no reason why there wouldn't be 13 year olds that are cognitively and emotionally mature enough to take part in this research.

Should this amendment be passed, while the staff at Hull CAMHS will be selective to ensure that all young people that receive the study information are clinically suitable, this will be particularly so in regards to young people aged 13. Since CAMHS workers are familiar with the young people that they are working with, they are deemed competent at judging whether the young people, regardless of age, are clinically suitable to participate.

Furthermore, CAMHS staff will not pass on the study information to any young person that they feel would not fully comprehend all of the information pack developed for adolescents under 16 years of age. CAMHS are reassured that the researcher will spend time discussing all aspects of the information pack with the young person and their parent before the interview and will only seek informed consent for the interview to start if it is clear that both the young person and their parent fully understand participation and what it involves.

Yours sincerely

Patricia Ross, Consultant
Clinical Psychologist
On behalf of Hull CAMHS

Karen Warwick
Clinical Nurse Co-ordinator



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Research and Ethics Committee Approval: Amendment two

**Sheffield Research Ethics Committee**

Yorkshire and the Humber REC Office
First Floor, Millside
Mill Pond Lane
Meanwood
Leeds
LS6 4RA

Tel: 0113 3050160

01 March 2011

Miss Jade Griffiths
Trainee Clinical Psychologist
Humber Mental Health Teaching Trust
Hull University, Hertford Building
Cottingham Road
Hull
HU6 7RX

Dear Miss Griffiths

Study title: Deliberate self harm in adolescence: An exploratory study into perceptions of, responses to and impacts of stigma.
REC reference: 10/H1308/36
Protocol number: N/A
Amendment number:
Amendment date: 16 February 2011

Thank you for submitting the above amendment, which was received on 18 February 2011. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 2 February 2011 refers).

The modified amendment was reviewed by the Sub-Committee in correspondence. A list of the members who took part in the review is attached.

Ethical opinion

Favourable Opinion

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved are:

Document	Version	Date
Modified Amendment		16 February 2011
Covering Letter		16 February 2011

This Research Ethics Committee is an advisory committee to the Yorkshire and The Humber Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Participant Information Sheet: Non-NHS for under 16s	5	16 February 2011
Participant Information Sheet: Non-NHS Parent/ guardian	4	14 January 2011
Participant Information Sheet: Parent/ guardian	3	14 January 2011
Participant Information Sheet: for young people under 16 years of age	4	16 February 2011
Participant Information Sheet: (16+ years)	3	14 January 2011
Protocol	4	14 January 2011
Recruitment poster	2	14 January 2011
Reply form NonNHS 16+	4	14 January 2011
Reply form NonNHS Parent/Guardian	4	14 January 2011
Reply form Parent/Guardian	3	14 January 2011
Reply form 16+	3	14 January 2011
Participant Information Sheet: Non NHS for under 16s	4	14 January 2011
Statement from Hull CAMHS		10 February 2011
Non NHS Recruitment poster	3	14 January 2011

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/H1308/36:	Please quote this number on all correspondence
--------------	--

Yours sincerely



Mr John Robinson
Committee Co-ordinator

E-mail: john.robinson7@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Stephen Walker, Humber NHS Foundation Trust*

Sheffield Research Ethics Committee**Attendance at Sub-Committee of the REC meeting on 01 March 2011**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr Basil Sharrack	Consultant Neurologist	Expert
Dr Ruth Stirton	Lecturer in Law	Lay Plus

Appendix N: Rationale for Participant Inclusion and Exclusion criteria

Inclusion	Exclusion	Rationale
Between the age of 13-18 years old (inclusive).		This study aims to explore the experiences of stigma of young people that self-harm.
At least two Self-harming behaviours in the previous year.		Young people who self-harmed over a year ago may no longer have scar's wounds or may have difficulty recalling their experiences. Young people that have engaged in one episode of self-harm may not identify themselves as 'self-harmers'.
Currently receiving services from CAMHS or being supported by a local charity/support group/counselling service.		To ensure that participants have support available should they feel distressed during or after the interview.
Predominate method of self-harm is one that results in wounds/markings to the exterior of the skin i.e. self-cutting or burning.		This study is specifically looking into the experiences of stigma due to superficial self-harm defined by Gratz, (2003)

Inclusion	Exclusion	Rationale
	Non-English Speaking	Lack of resources for interpretation.
	Has a learning disability (Intelligence Quotient < 70)	A young person would be unlikely to fully comprehend what is being asked of them and therefore unable to provide informed consent.
	Detained under the mental Health Act, actively suicidal, or considered by staff to be too highly distressed (CGAS score of <50).	Such young people may find the interview process distressing and it may place them at risk
	Severe or enduring mental illness i.e. Eating disorder or psychotic presentation.	Experience of stigma related to self-harm may not be distinguishable from stigma related to other mental illnesses.
	Parental consent was unobtainable (if young person was under 16 years of age).	Young people under the age of 16 were only able to participate if parental consent was obtained

Appendix O: Participant and Parental Information Packs

(Participants aged less than 16 years)

Version number: 4

Date: 16/02/2011



Information sheet for children under 16 years of age

Study Title: Perception, management and impact of reactions towards self-harm.

My name is Jade Griffiths and I am currently training to become a clinical Psychologist at the University of Hull and would like to invite you to take part in an educational research project. Before you decide whether or not you want to take part, we would like you to understand why the research project is being done and what we would like you to do. So please read this information pack carefully.

Once you have read this information, if you would like to hear more about the research project, or would like to take part, please give the 'information pack for parents' to one of your parents. If you both agree that you are both interested in hearing more about this research and maybe taking part, your parent should fill in their contact details at the back of their information pack and give them to the member of the CAMHS staff team that gave you this information pack.

Why is this research being done?

From research done in the past, we know that members of the public do not always know very much about mental health, and because of this, they sometimes do not know how to react around people who are experiencing mental health difficulties. People that self-harm are often thought to be experiencing mental health difficulties and the scars/wounds as a result of self harm can attract attention. Sometimes people can react to self-harm in a positive way, and sometimes they can react in a negative way. We think that it is important to be aware of how young people that self-harm understand the reactions of others, how they deal with these reactions and how the reactions make them feel. When we know this information we may be able to support young people who self harm in a more helpful way.

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www.hull.ac.uk

1

Why have I been invited to take part?

In total we would like 12 adolescents to take part in this research project so that we can get lots of different views and experiences around this topic. Since we are looking into the experiences of young people who have self harmed, we are inviting adolescents between the ages of 13 and 18 who have self harmed at least 2 times in the last year. Because you fit this description and are involved with CAMHS we have invited you to take part.

What will I be asked to do?

If you take part, you will be asked to meet with myself (the main researcher) for a meeting where I will ask you some questions about how other people have reacted to your self-harm and how you have coped with this. It's up to you how much you talk about so it could take half an hour or if you're feeling chatty it might take up to an hour and a half.

➤ Where will this meeting be?

- The meeting will take place in a private room at the CAMHS centre that you know. We will try to arrange the meeting while you are already at the centre for an appointment. If we can't do this and you need to come at another time, we will pay for you to get there.

➤ Who will be at this meeting?

- There will only be 2 people at the meeting– myself (the main researcher) and you. On the day of the meeting we will ask one of your parents to come with you. This is so they can meet me, agree for you to take part and so that they will be there if you need them. When the meeting is ready to begin, your parent will be asked to wait in the waiting room.
- To make sure that I remember everything that we talk about, our voices will be recorded.

➤ What if I start talking and then want to leave?

- If you would like to leave in the middle of the meeting before we have finished then that's okay. It is up to you how much you talk about during the meeting.

➤ Will I miss school/college?

- We will try our best to make sure the meeting is arranged so that you don't miss any school/college.

➤ When will we have the meeting?

- At a time that is good for you and your parent.

➤ After the meeting will I have to do anything else?

- About 2 months after the meeting I will get back in touch so that we can go over what was talked about to make sure I heard and understood what you said. You will be able to ask any questions that you have and this time the meeting will take no longer than an hour. You don't have to come to this second meeting if you don't want to.
- At the very end of this research project (summer 2011) I will send you a letter telling you the results of the research project.

Will anyone else know I'm doing this?

Not unless you tell them. The only people that will know you are taking part will be your parents, the research team and the CAMHS staff.

HOWEVER, during the meeting, if I get the idea that yourself or others are at risk of harm, I will have to tell one of the CAMHS team members so that they can help you. If this person is not your main CAMHS worker, then your main CAMHS worker will also have to know so that they can meet with you for extra support.

What will you do with the information I tell you?

We will keep all your information private. This means we will only tell those who have a need or right to know. We will follow rules that the law has set to make sure that your personal information is safe. We will take your name and address off any information that leaves the building so that nobody knows who you are. After the meeting all of your personal information will be kept for 5 years in a cupboard that is locked and safe. Only people in the research team will be able to open the cupboard and after 5 years your information will be destroyed. If this study is published for the public to read, your name and address will not be included.

Is this research safe?

Yes because it is checked by a group of people that are called a Research Ethics Committee. They make sure that the research is fair. This project has been checked by the Sheffield research Ethics committee who said it was okay to carry out.

Do I have to take part?

- No. It's up to you whether you take part. If after reading this information pack you do not want to take part, then that is fine.

➤ What happens if I decide to take part?

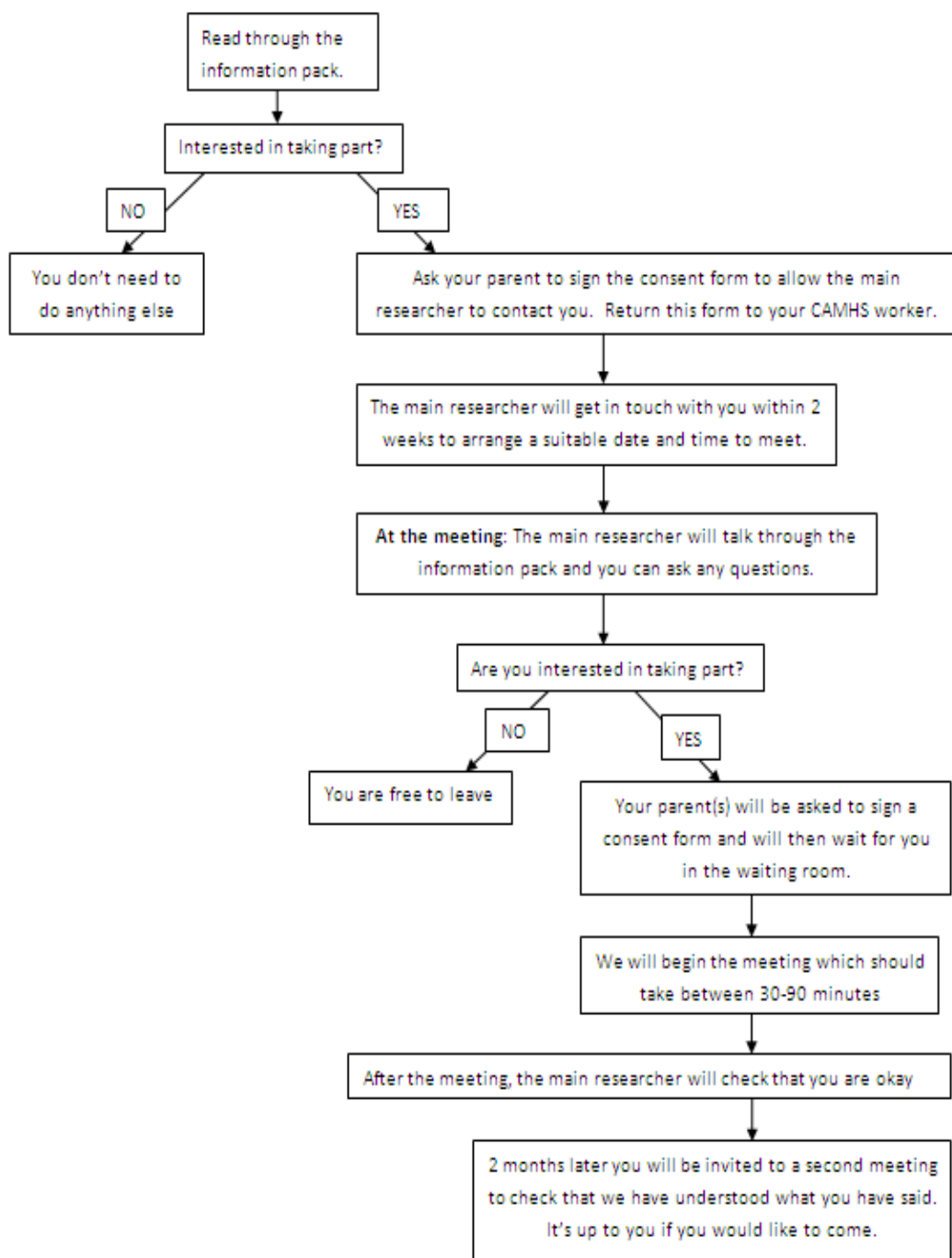
- If you *would like* to take part, or are interested in hearing more about it, we ask that you give your parents the 'Information pack for Parents'. If they are happy for you to take part they should fill in the contact form at the end of their information pack and return it back to your main CAMHS worker.
- The CAMHS staff will give your contact details to me and I will contact you within 2 weeks to invite you and your parent(s) to meet with me.
- At the start of the meeting we will talk through the information pack so that you understand the research project and what you will be doing. This will take about half an hour and you will be able to ask questions at any point. If at this point you are happy to take part, we will ask you and your parent to sign a consent form and wait in the waiting room so that we can begin the meeting. However, if you or your parent decides that you are not going to take part in this research project you will be free to leave.

If you do not want to take part in this research project then this will not affect the care you get from CAMHS.

Diagram showing the steps to taking part:

To make it clear, we have drawn a diagram showing what will happen at each step and what you will be asked to do. This can be seen on the next page.

Below is a Diagram showing the steps:



What are the possible advantages of taking part?

We cannot promise the study will help you but the information we get from this study may help to improve the treatment of young people who self harm in the future.

Is there anything to be worried about if I take part?

Talking about self-harm can sometimes be difficult or upsetting. If you feel upset at any time, we will stop talking and I will check that you're okay. To make sure that you feel better before you leave, a member of the CAMHS team will also talk to you.

What if I am not happy or have a complaint?

If you are not happy or would like to complain about any part of this research project you should speak to me (the main researcher, contact details below) and I will do my best to help you. If you are still unhappy and want to talk to somebody else about it, you can do this by contacting your local Patient Advice and Liaison Service on: 01904 623065 (Hull) or: 0800 015 4334 (Scunthorpe)

If you are still unsure whether to take part...

- If you would like advice on whether or not to take part, you may want to talk to your family or friends, to members of the research team (contact details below), or to a health care professional, such as your doctor or a member of the CAMHS team.
- If you would like to find out more about research in general you can find more information on the following website: <http://www.experiment-resources.com/what-is-research.html>.
- If you would like more information on *this* research project you can contact me, Jade Griffiths (the main researcher) using the contact details on the final page.

Thank you for reading this Information pack.

If you are interested in hearing more about the study and maybe taking part, please give the 'Information pack for parents' to one of your parents. If they agree that you should take part in this research project they should fill in the contact form in the back of their information pack and return it to your main CAMHS worker that gave you this information pack.

If you would like to me directly to ask any questions or get further information, feel free to contact me using the below contact details:

Name: Jade Griffiths (main researcher)

Telephone number: 07915156648

Email Address: j.griffiths@2008.hull.ac.uk

Address: Department of Clinical Psychology and Psychological Therapies, The Hertford building,
The University of Hull, Cottingham Road, Hull, HU6 7RX

(Participant aged 16+ years)

Version number: 3

Date: 14/01/2011



Participant Information Sheet

Study Title: Perception, management and impact of reactions towards self-harm.

My name is Jade Griffiths and I am currently completing a Doctorate in Clinical Psychology at the University of Hull and would like to invite you to take part in an educational research study. Before you decide whether or not you would like to take part, we would like you to understand why the research is being done and what it would involve for you. So please consider this information pack carefully.

Once you have read this information, if you are interested in hearing more about the study, and possibly taking part, please fill in your contact details at the back of this information pack and give them to the member of the CAMHS staff team that gave you this information pack.

Why is this research being done?

From previous research, we know that members of the public do not always know very much about mental health, and because of this, they sometimes do not know how to react around people who are experiencing mental health difficulties. People that self-harm are often thought to be experiencing mental health difficulties and the scars/wounds as a result of self harm can attract attention. Sometimes the reactions of others to people who self harm can be positive, or sometimes they can be negative. We think that it is important to recognise how young people who self harm experience the reactions of others, how they manage these reactions and how these reactions impact on them. When we know this information we may be able to support young people who self harm in a more helpful way.

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Why have I been invited to take part?

In total we would like 12 adolescents to take part in this research study so that we can obtain a range of views and experiences around this topic. Since we are researching the experiences of adolescents who have self-harmed, we are inviting adolescents between the ages of 13 and 18 who have self-harmed on at least 2 occasions in the last year. Because you fit within these criteria and are involved in the CAMHS service we have invited you to take part.

What will I be asked to do?

Participation will involve taking part in an informal interview lasting between 30 to 90 minutes. During the interview the main researcher will ask you questions about your experiences of how other people have responded to your self harm, and how you have managed this.

➤ Where will the interview be?

- This interview will take place in a confidential room at the CAMHS centre that you are familiar with. We will make every effort to conduct the interview while you are at the clinic for an existing appointment but if this is not possible and an additional visit is required, your travel expenses will be reimbursed.

➤ Who will be at the interview?

- There will only be 2 people at the interview – you and the main researcher. Although we will advise you to bring along a supportive adult, they will be asked to wait in the waiting room while the interview takes place. The interview will be audio-recorded to ensure that we do not miss important bits of information and to reduce room for error or misinterpretation of what you say.

➤ What if I start the interview and then want to leave?

- If any point you wish to leave the interview and withdraw from the research, you are free to do so with no adverse affects. Participation is completely voluntary at all times.

➤ When would I have the interview?

- We will arrange the interview at a convenient time which suits you.

➤ Will I miss school/college?

- We will do our best to arrange an interview after school hours or during school/college holidays so that you do not miss any school/college.

➤ After the interview will I have to do anything else?

- About 3 months after the interview the main researcher will contact you to invite you to a 'feedback meeting' where they will talk through the findings of your interview. The reason we invite you back for a second meeting is to check with you that we have understood what you have said correctly. This meeting should last approximately an hour and here you will have the opportunity to discuss your answers, clarify any misinterpretations and ask further questions. This meeting is voluntary and you do not have to attend.
- When the research is completed (summer 2011) you will be sent a written summary of the findings of the research as a whole.

Do I have to take part?

No! It is up to you to decide to join the study.

➤ What happens if I decide to take part?

- If after reading this information pack you think that you would like to take part, or are interested in hearing more about it, you should fill in your contact details at the back of this information pack and return this sheet to the member of staff that gave you this information pack.
- The CAMHS staff will pass your contact details over to the main researcher who will contact you within 2 weeks to invite you to an appointment at the CAMHS centre.
- During this appointment, the researcher will discuss the information sheet with you to ensure that you understand the research and what is involved. You will be given opportunity to seek further information and ask questions. The amount of time this will take will vary, but should last approximately 30 minutes.
- If at this point, you are still interested in taking part, we will then ask you to sign a consent form and we will begin the interview.

You are free to withdraw at any time, without giving a reason. Should you chose to withdraw from the research, there will be no adverse affects and the standard of care you receive will not be affected.

Will my information be kept confidential? Who will see it?

We will follow ethical and legal practice and all information about you will be handled in confidence. All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the service will have your name and address removed so that you cannot be recognised.

HOWEVER, due to the sensitive nature of the topic, there are limitations to confidentiality. If you suggest that yourself or others are at risk of harm during your interview, a clinician on the 'duty team' will be informed and it will be arranged for you to see him/her on that day. In this circumstance it would also be necessary for the researcher to contact the health care professional you are currently involved with in CAMHS. This member of staff will be fully informed regarding the risk and an appointment will be arranged for you to speak to her/him as soon as is possible.

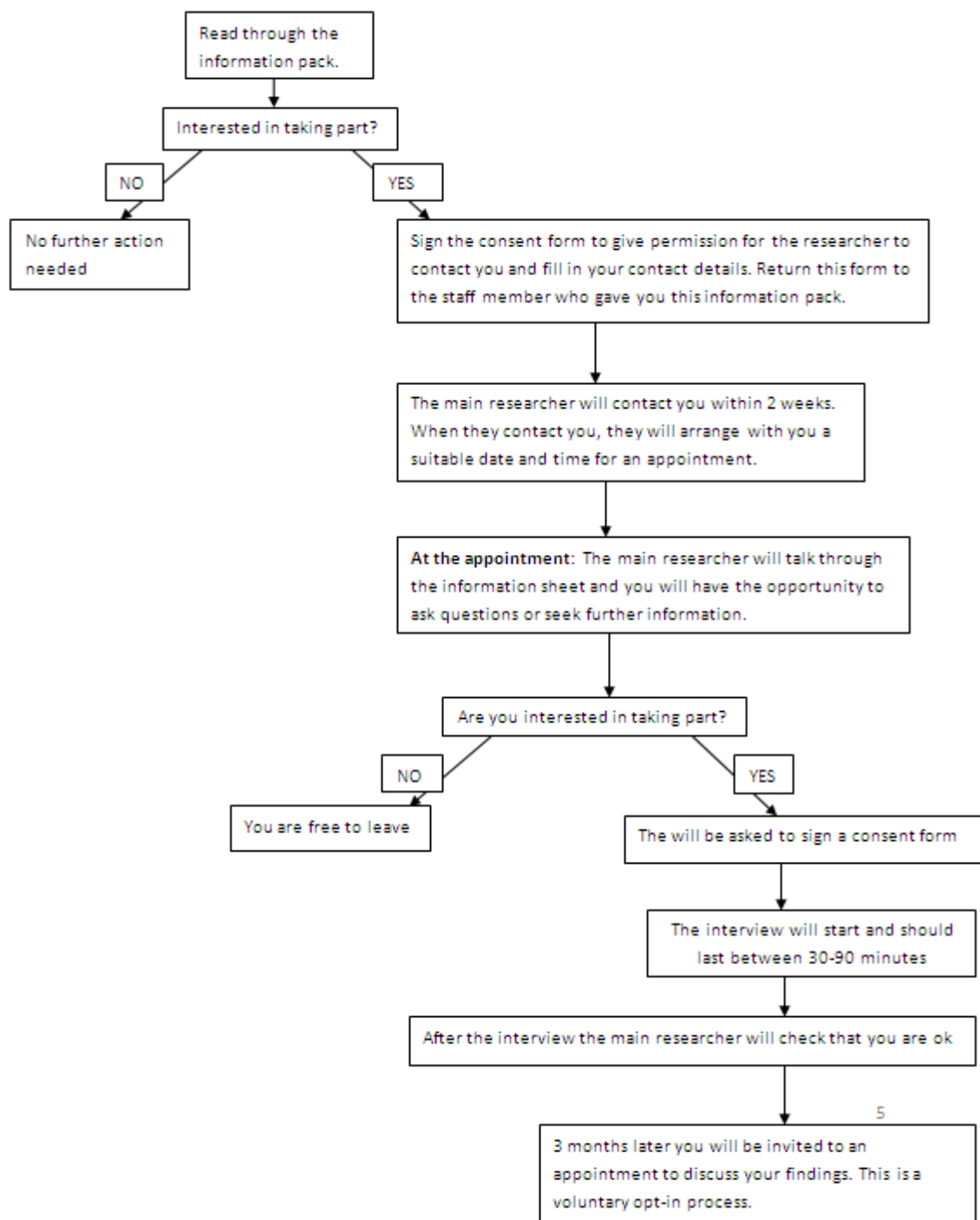
What will you do with the information I give you?

Following the interview, all data will be coded and stored anonymously. Only members of the research team will have access to your data which will be securely stored for a period of 5 years and will then be destroyed appropriately. We intend to publish the findings of this study but you will not be identifiable in any publication.

Flowchart illustrating the process:

In order to make the process clearer, we have included a diagram illustrating what will happen at each stage of the research and what you will be asked to do. This flowchart can be seen on the next page.

Below is a Flowchart illustrating the process:



What are the benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help to improve the treatment of young people who self harm in the future.

What are the risks of taking part?

Since the topic of the interview is a sensitive one, you may find some of the questions upsetting. Should you feel distress the interview will be stopped, the main researcher will debrief you and will arrange for you to speak to either a member of staff on the 'duty team', or the member of CAMHS staff that you are involved with.

Is this research safe?

Before any research goes ahead it is supposed to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been reviewed and (given a favourable opinion) by the Sheffield research Ethics committee.

What if I am not happy or have a complaint?

If you have a concern or query about any aspect of this study, you should ask to speak to the main researcher (contact details below) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting your local Patient Advice and Liaison Service on: 01904 623065 (Hull) or: 0800 015 4334 (Scunthorpe)

If you are still unsure whether to take part...

- If you would like advice on whether or not to take part, you may want to talk to your family or friends, to members of the research team (contact details below), or to a health care professional, such as your doctor or a member of the CAMHS team.
- If you would like to find out more about research in general you can find more information on the following website: <http://www.experiment-resources.com/what-is-research.html>

Version number: 3

Date: 14/01/2011

- If you would like more information on this research project you can contact the main researchers on the contact details below:

Name: Jade Griffiths

Telephone number: 07915156648

Email Address: j.griffiths@2008.hull.ac.uk

Address: Department of Clinical Psychology and Psychological Therapies, The Hertford building,
The University of Hull, Cottingham Road, Hull, HU6 7RX

You will receive a copy of this information pack, along with a signed consent form should you agree to take part.

**THANK-YOU FOR TAKING THE TIME TO READ THIS
INFORMATION BOOKLET.**

Version number: 3

Date: 14/01/2011

If you are interested in hearing more about this research study and potentially taking part, please complete the form below and give it to the member of staff from CAMHS that gave you this information pack.

I give consent for the researcher to contact me:

Please tick the appropriate box(es) and provide the contact detail(s)

- Via telephone ☐ My telephone number is _____
- Via email ☐ My email address is _____
- Via letter. ☐ My address is _____

I understand that during this contact I will be invited to request further information and ask questions about the research. If I remain interested in the research at this point, I will be invited to attend an appointment where the researcher will discuss the information pack with me to ensure I have a full understanding before I give consent and take part in the interview.

 Name of participant

 Date

 Signature

 Name of person
 Taking consent

 Date

 Signature

(Parental Information Pack)

Version number: 3

Date: 14/01/2011

**Parent/Guardian Information sheet**

Study Title: Perception, management and impact of reactions towards self-harm.

My name is Jade Griffiths and I am currently completing a Doctorate in Clinical Psychology at the University of Hull and would like to invite your son/daughter to take part in an educational research study. Before you decide whether or not you would like him/her to take part, we would like you to understand why the research is being done and what it would involve. So please consider this information pack carefully.

Once you have read this information, if you are interested in hearing more about the study, please fill in your contact details at the back of this information pack and give them to the member of the CAMHS staff team that gave you this information pack.

Why is this research being done?

From previous research, we know that members of the public do not always know very much about mental health, and because of this, they sometimes do not know how to react around people who are experiencing mental health difficulties. People that self-harm are often thought to be experiencing mental health difficulties and the scars/wounds as a result of self harm can attract attention. Sometimes the reactions of others to people who self harm can be positive, or sometimes they can be negative. We think that it is important to recognise how young people who self harm experience the reactions of others, how they manage these reactions and how these reactions impact on them. When we know this information we may be able to support young people who self harm in a more helpful way.

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Cottingham Road
Hull, HU6 7RX
www.hull.ac.uk

Why has your son/daughter been invited to take part?

In total we would like 12 adolescents to take part in this research study so that we can obtain a range of views and experiences around this topic. Since we are researching the experiences of adolescents who have self harmed, we are inviting adolescents between the ages of 13 and 18 who have self harmed on at least 2 occasions in the last year. Because your son/daughter fits within these criteria and they are involved in the CAMHS service we have invited them to take part.

What will your son/daughter have to do?

Participation will involve taking part in an interview lasting between 30 to 90 minutes. During the interview the main researcher will ask your son/daughter questions about his/her experiences of how other people have responded to their selfharm, and how they have managed this.

➤ Where will the interview be?

- This interview will take place in a confidential room at the CAMHS centre that your son/daughter is familiar with. We will make every effort to conduct the interview while your child is at the clinic for an existing appointment but if this is not possible and an additional visit is required, your travel expenses will be reimbursed.

➤ Who will be at the interview?

- There will only be 2 people at the interview – your son/daughter and the main researcher. Although you will be asked to accompany your child on the day of the interview to meet the researcher, to support your child and to provide consent, you will be asked to wait in the waiting room while the interview takes place. The interview will be audio-recorded to ensure that we do not miss important bits of information and to reduce room for error or misinterpretation of what your son/daughter says.

➤ What if your son/daughter starts the interview and then wants to leave?

- If any point your son/daughter wishes to leave the interview and withdraw from the research, they are free to do so with no adverse affects. Participation is completely voluntary at all times. Similarly, if you would like to withdraw their participation, you are free to do so at any point.

➤ When would your son/daughter have the interview?

- We will arrange the interview at a convenient time which suits you and your child.

➤ Will your son/daughter miss school/college?

- We will do our best to arrange an interview after school hours or during school/college holidays so that your son/daughter does not miss any school.

➤ After the interview will your son/daughter have to do anything else?

- About 3 months after the interview the main researcher will contact your son/daughter to invite them to a 'feedback meeting' where the researcher will talk through the findings of their interview. This meeting should last approximately an hour and here your son/daughter will have the opportunity to discuss their answers, clarify any misinterpretations and ask further questions. This meeting is voluntary and your son/daughter does not have to attend.
- When the research is completed (summer 2011) your son/daughter will be sent a written summary of the findings of the research study as a whole.

Does your son/daughter have to take part?

No! It is up to you and your son/daughter to decide whether he/she joins the study.

What happens if we decide to take part?

- If after reading this information pack you think that you would like your son/daughter to take part, or are interested in hearing more about it, you should fill in your contact details at the back of this information pack and return the sheet to the member of staff that gave you this information pack.
- The CAMHS staff will pass your contact details over to the main researcher who will contact you within 2 weeks to invite you and your son/daughter to an appointment at the CAMHS centre.
- During this appointment, the researcher will discuss the information sheet with you and your son/daughter to ensure that you both understand the research and what is involved. You will both be given opportunity to seek further information and ask questions. The amount of time this will take will vary, but should last approximately 30 minutes.
- If at this point, you are both still interested in your son/daughter taking part, we will then ask you to sign a consent form and we will ask your son/daughter to sign an assent form.

The interview will then begin. Your son/daughter can withdraw from the study at any point. You are also free to withdraw your son/daughter at any time, without giving a reason. Should you choose to withdraw your son/daughter from the research, there will be no adverse affects and the standard of care you or your son/daughter receives will not be affected.

Will my son/daughter's information be kept confidential? Who will see it?

Following legal and ethical practise, all information which is collected about your son/daughter during the course of the research will be kept strictly confidential, and any information about your son/daughter which leaves the service will have their name and address removed so that they cannot be recognised. We will follow ethical and legal practice with any personal information that you or your child gives. Following the interview, all data will be coded and stored anonymously. Only members of the research team will have access to your son/daughter's data which will be securely stored for a period of 5 years and will then be destroyed appropriately. We intend to publish the findings of this study but your son/daughter will not be identifiable in any publication.

HOWEVER, due to the sensitive nature of the topic, there are limitations to confidentiality. If your son/daughter suggests that they or others are at risk of harm during their interview, a clinician on the 'duty team' will be informed and it will be arranged for them to see him/her on that day. In this circumstance it would also be necessary for the interviewer to contact the health care professional that your son/daughter is currently involved with in CAMHS. This member of staff will be fully informed regarding the risk and an appointment will be arranged for your son/daughter to speak to her/him as soon as is possible.

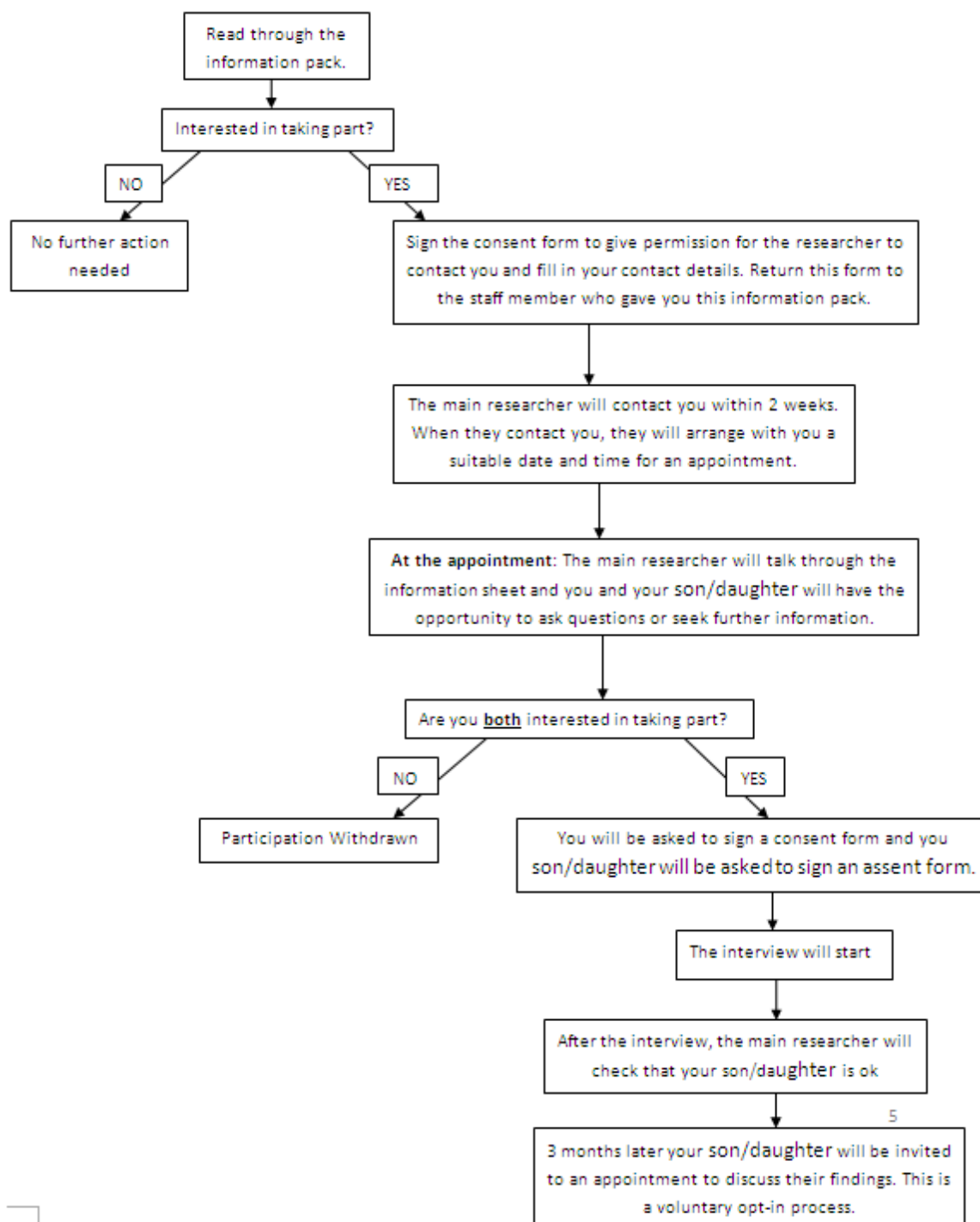
What would happen if your son/daughter chose to withdraw from the research?

Your son/daughter can withdraw from the study at any point with no adverse affects. Should they choose to withdraw, all data collected up until that point will be destroyed. Similarly, **you** have the right to withdraw your son/daughter at any point

Flowchart illustrating the process:

In order to make the process clearer, we have included a diagram illustrating what will happen at each stage of the research and what your son/daughter will be asked to do. This flowchart can be seen on the next page.

Below is a flowchart illustrating the process:



Has this research been approved and considered safe?

Before any research goes ahead it is supposed to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been reviewed and (given a favourable opinion) by the Sheffield research Ethics committee.

What are the benefits of taking part?

We cannot promise the study will help your son/daughter but the information we get from this study may help to improve the treatment of young people who self harm in the future.

What are the risks of taking part?

Since the topic of the interview is a sensitive one, your son/daughter may find some of the questions upsetting. Should your son/daughter feel distressed, the interview will be stopped, the main researcher will debrief your son/daughter and will arrange for him/her to speak to either a member of staff on the 'duty team', or the member of CAMHS staff that he/she is involved with.

What if there is a problem or I have a complaint?

If you have a concern or query about any aspect of this study, you should ask to speak to the main researcher (contact details below) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting your local Patient Advice and Liaison Service on: 01904 623065 (Hull) or: 0800 015 4334 (Scunthorpe)

If you are still unsure whether your son/daughter should take part...

- If you would like advice on whether or not your son/daughter should take part, you may want to talk to your family or friends, to members of the research team (contact details below), or to a health care professional, such as your doctor or a member of the CAMHS team.

Version number: 3

Date: 14/01/2011

- If you would like to find out more about research in general you can find more information on the following website: <http://www.experiment-resources.com/what-is-research.html>
- If you would like more information on *this* research project you can contact the main researchers on the contact details below:

Name: Jade Griffiths (main researcher)

Telephone number: 07915156648

Email Address: j.griffiths@2008.hull.ac.uk

Address: Department of Clinical Psychology and Psychological Therapies, The Hertford building, The University of Hull, Cottingham Road, Hull, HU6 7RX

THANK-YOU FOR TAKING THE TIME TO READ THIS
INFORMATION BOOKLET

Appendix P: Participant consent, participant assent and parental consent forms

(Participant Consent Form)

Date: 13/04/2010

Version Number: 1



Centre number:

Study number:

Participant Identification number for this study:

PARTICIPANT CONSENT FORM

Title of project: Perception, management and impact of reactions towards self-harm

Name of Researcher: Jade Griffiths

Please initial the box

1. I confirm that I have read and understand the information pack (version), dated, for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any medical care or legal rights being affected.
3. I understand that relevant sections of my medical notes and data collection during the study may be looked at by individuals from the NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

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Hull, HU6 7RX
www.hull.ac.uk

Date: 13/04/2010

Version Number: 1

4. I agree that should I suggest that I or others are at risk of harm, that in order for my protection, the duty team and CAMHS staff involved in my care will be informed.

☐

5. I am aware of the potential risks and benefits of taking part.

☐

6. I agree to take part in the above study.

☐

7. I give consent for the interview to be audio-recorded

☐

Name of participant

Date

Signature

Name of person
Taking consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

(Participant Assent Form)

Date: 13/04/2010

Version Number: 1



Centre number:

Study number:

Participant Identification number for this study:

PARTICIPANT ASSENT FORM**Project title:** Perception, management and impact of reactions towards self-harm**Name of Researcher:** Jade Griffiths

Please circle 'yes' or 'no'

Has somebody else explained this project to you?

Yes/No

Do you understand what this project is about?

Yes/No

Do you understand that you may find some of the questions upsetting?

Yes/No

Do you understand that if you become upset we will have to inform your
Main CAMHS worker and the duty team?

Yes/No

Have you asked all the questions you would like to ask?

Yes/No

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1

Date: 13/04/2010

Version Number: 1

Have you had your questions answered in a way that you understand? Yes/No

Do you understand that it is OK to stop taking part at any time? Yes/No

Are you happy to take part? Yes/ No

Are you happy to have the interview recorded? Yes/No

If any of your answers are 'No' or you do not wish to take part, don't sign your name!

If you do want to take part, you can write your name below.

Your Name _____ Date _____

The person who explained this research to you needs to sign too

Print name _____ Sign _____ Date _____

Thank you for your help.

(Parental Consent Form)

Date: 13/04/2010

Version Number: 1



Centre number:

Study number:

Participant Identification number for this study:

PARENTAL CONSENT FORM**Title of project:** Perception, management and impact of reactions towards self-harm**Name of Researcher:** Jade Griffiths**Please initial the box**

1. I.....,parent/guardian of
....., have been fully
informed of the research project. I have been given an information pack,
have had the opportunity to ask questions about the research, have had
them answered satisfactorily and understand what is involved.

2. I understand that his/her participation is voluntary and that I can
request he/she is withdrawn from the research at any time, without
giving any reason and without his/her care or legal rights being affected.

3. I understand that the relevant sections of his/her care record and data
collected may be looked at by individuals from the NHS trust. I give
permission for these individuals to have access to my his/her records.

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Date: 13/04/2010

Version Number: 1

4. I am aware of the potential risks and benefits of participation

☐

5. I give consent for _____ to take part in this research.

☐

6. I give consent for the interview to be audio-recorded

☐

_____	_____	_____
Name of parent/guardian	Date	Signature

Relationship to participant: _____

_____	_____	_____
Researcher	Date	Signature

When completed: 1 (original) to be kept in care record; 1 for parent; 1 for researcher site file.

Appendix Q: Example of data analysis (Laura, lines 117-177)

Emergent Themes

Exploratory comments

Unsupportive?	P5. Um, some of my friends and some of my family have	
Selective disclosures	been quite off about it, but I haven't told a lot of my	← Not as supportive as hoped?
Worry	family because, ya know, I don't wana tell them because	Self conscious, aware of others opinions
Fear of judgement	I'm worried about what they'll think, but most people	
	have been really supportive, ya know like my close	
	friends and my mum and my auntie, so yeah...	
	J. Okay, and when you say people can be off about it, can you say a bit more about that?	
Avoidance	P5. Um, well, do ya know like when you say, when you	
Uncomfortable?	tell someone something and then they sort of try and	
	change the subject like almost straight	← Haste/panic to change subject – difficult topic to talk about, people feel awkward?
	J. So people can't deal with it	
	P5. Yeah	
	J. Or get a bit sort of	Afraid of saying the wrong thing? Afraid of triggering another incident? See her as vulnerable? Emotional?
Lack of understanding	P5. It could be just they don't really know what to say, or	
	I don't know, could be a few things [laughs]	Sense making
		People don't get it - awkward
	J. Yeah...and you said a minute ago that you're	
	sometimes worried what people will say, what people	
	will think...what do you think they might be thinking?	

Different P5. That I'm a freak, cuz, that happens a lot, yeah you **Unusual, not understandable,**

Weird know like if I say to people who like ask me things and **Frequent judgement – she repels people?**

People ask questions hear from other people that they've called me a freak, so,

Rumours it's like well obviously I'm not that much of a freak **People go behind your back – betrayal can't trust others.**

because if I was I wouldn't be getting help **Help-seeking & acknowledging problem is virtuous**

J. Yeah, yeah, is there anyone in particular in your life

that you don't want to know about the self-harm? Or

about coming to CAMHS? **Secret** **Evokes emotions in others – anger/upset**

Disclosure P5. I don't want my mum to find out that I self-harm

Anticipate negative response because she'd be really, I don't know whether she'd be

Avoidance really mad or really upset, I just thought I'd stay away **Underlying shame & embarrassment? – 'Stupid' thing to do?**

Protecting mum from that...

J. Yeah...and how do you stop her finding out?

Conceal P5. Well if I do do it I just cover it up and make sure she

Visibility – forced disclosure doesn't see, so... **Easy to hide but need to be hyper vigilant to ensure it's always hidden.**

J. How do you make sure?

Avoidance P5. Pause...well I just stay away from her, so...just make

Conceal sure it's under a t-shirt, or what **Stay away = less chance of accidental disclosure?**

So no-one suspects

J. So you cover it up with clothing...

P5. Yeah,

J. any other ways of covering it up?

Happier for others to think it's a sprained wrist – less stigma with physical problem.
Less responsibility? Less perceived control?
No shock factor.

Disguise/hide
self-harm

P5. Um, sometimes like, do you know just like fabric
bandages and stuff like that

Deceit

Active attempts to conceal – has put thought into it

J. Okay, so you'll kind of keep it away from her and
you'll avoid her after, just after doing it, so she doesn't
see it

P5. Yeah

J. Is there anyone else apart from your mum that you
wouldn't like to know?

Afraid of judgement

Judgement

Attention seeking

Private/personal

Selective disclosure

P5. Um..... I think it's mainly everyone, because

Dismissive

obviously, people, mainly people look at it and think that

Visibility

it's just a cry for help or attention seeking, so it's better

that they don't see it, cuz you don't do it to show

everyone, and I think the only person that I'm like really

open about it with is my boyfriend. so...

Attention seeking is looked upon negatively – not genuine self-harm

J. Okay... so what is it about him that you feel you can be
open with him?

Trust that he won't run away? Judge? Tell others?

Intimacy

P5. I think it's because I'm closest to him than anyone

Trust

else, so.... I can trust him with absolutely anything.

Exceptional trust

J. Okay, and in general, do many people know about
yourself-harm, or is it just your boyfriend?

People ask questions P5. Um, a couple of my friends know, because they've
Supportive asked me, you know like, because they've been
Disclosure supportive they've asked me things like what go on and
I've told um...so...yeah

Needs to be asked to tell? →

Selective disclosure

Choice disclosure

← **Some people are concerned/curious/interested**

Appendix R: Supporting Quotes

Super-ordinate Themes	Sub-ordinates Themes	Supporting quotes
Awareness of stereotypes		<i>“Most people are just too quick to judge” (Scarlet, 239)</i>
		<i>“It’s better when people get to know me because they know like actually who I am” (Laura, 27-29)</i>
	Crazy	<i>“some people when I’ve been like, when I confide in them about it, they seem a bit weird about it, like cuz some people look on people with mental health problems as just awful...” (Laura, 52-55)</i> <i>“they think that I’m stupid and that I might hurt someone else, or hurt myself even more” (Hannah, 392-393)</i> <i>“she was like oh saying stuff like oh shut up you slit your wrists and stuff like that and just like calling</i>

me emo and stuff,” (Kelly, 456-458)

“Some people with mental health problems can get picked on because they’re different” (Ben, 84-85)

“people just was like crazy and stuff like that, which I wasn’t, I just wasn’t too well at the time. I prefer to say I weren’t well than I was...cuz it’s the bestest thing to say really, the bestest term to put it.” (Fran, 114-117)

Attention Seeking

“mainly people look at it and think that it’s just a cry for help or attention seeking” (Laura, 164-165)

” some people might do it to get like sympathy and stuff, like that’s, like some, and, there is people who do that I think, but it’s not all like not all are the same, so I don’t think like everyone should be judged like that” (Kelly, 188-191).

Disclosure

Avoid disclosure; self-harm is a personal phenomena

“Probably in my bedroom when no ones in it, or just around the house when no ones in the house” (Ben, 262-263)

“if there’s someone I don’t want to see it then I’ll put my sleeve down or something, so they can’t see

it” (Ben, 302-303)

“I don’t really like them on my arms, I’d rather do them like out of sight” (Scarlet, 423-424)

“I’ve tattoos everywhere now to cover them anyway” (Fran, 571-572)

“They’re fine because I use bio-oil and stuff so they’re not that bad.” (Skaret, 219-220)

“I’ve too much fake tan for you to see them” (Fran, 742-743)

“when I went to [CITY], I wore a, a bandage thing, so it looked like I had a sprained wrist” (Kelly, 478-479)

Selective disclosure; trust	<i>“and as long as I know that they won’t go telling everyone, then I’ll just like go and talk to them”</i> <i>(Ben, 420-421)</i>
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Forced disclosure; visibility and rumours	<p><i>“Quite a few people have actually asked about my cuts and stuff” (Scarlet, 484-485)</i></p> <p><i>“someone told someone on Facebook that I did overdose and now it’s spread around school”</i></p> <p><i>(Hannah, 512-513)</i></p>
Responses towards self-harm	<p><i>“Your friends can understand why because they know about ya, same with ya family. But if it’s like a teacher or a random in the street, they’ll sort of just not understand as much, because they don’t know what’s happened before hand.” (Ben, 40-244)</i></p>
Eggshells and exceptions	<p><i>“at first people thought I was attention seeking and then when they saw me do it real serious errm, they was, they got more like, they was more, they was all funny around me for ages like, d'ya know, like they wouldn’t ever say nowt to upset me, and they used to be real careful about what they said near me” (Kelly, 302-307)</i></p> <p><i>“I’ve got a pass so I can leave my class or anything whenever I want” (Scarlet, 117-118)</i></p>
Patronised and Fuss	<p><i>“if then they come round and they’re like get everything sharp away from you, I don’t like that sort of person” (Scarlet, 69-71)</i></p>

<i>“people would just come up to me and ask me loads of questions” (Hannah, 272-273)</i>		
Management of response	Helpful level of support	<i>“Well, everybody’s just been like really supportive about it. It’s like, I think everybody’s just more concerned that I get help” (Scarlet, 110-111)</i>
	Avoidance	<i>“if someone sees it, which it’s very rare, they’ll just, they’ll just sort of not say anything or some people might say what’s that on your arms, I’ll say ahhh I don’t know, just avoid it” (Laura, 336-339).</i>
	<i>“I’ll just change the conversation real quick, do that quite a lot” (Fran, 215-216)</i>	
	Challenge, defend or explain	<i>“when everyone used to just ask me about them I used to be like just shut up, cuz it did my head in, like everyone just like saying stuff all the time, oh let me see your scars, or like when they was cuts, they was like oh let me see your cuts, I was like no,” (Kelly, 327-331)....and “I’ll just tell them to shut up” (Kelly, 614)</i>
	Nonchalance and acceptance	<i>“I’m quite an open person so it doesn’t really bother me” (Scarlet, 63)</i>
		<i>“I still wear like vest tops and stuff, I don’t normally have myself covered up” (Scarlet, 209-210)</i>

“was just a part of me, it was gunna happen, one day,” (Fran, 499)

“I see it as if I’ve got over em why can’t other people...” (Kelly, 699)

I’m not like the rest

“I see these people and you can’t even see the skin on their arms and stuff” (Scarlet, 272-273)

vs. Part of a group

“I would say that I do it discretely and privately” (Fran, 139) and “I know some people that used to boast about it, I never used to” (Fran, 142-143)

Dismiss judgemental

“and it just made me think yeah like it doesn’t really matter what other people think, you just sort of gotta, you know, I’ve gotta get on with it, “ (Laura, 529-532)

people

“But to be honest I aren’t really bothered what they think” (Scarlet, 199)

“I aint got time for them” (Fran, 605)

“if it’s something that they don’t truly understand then they can’t really make an assumption on it can they” (Scarlet, 658-659)

“some of our family members didn’t understand, but because they’re older than me, and I suppose if

it didn't happen to them it won't happen to anyone else" (Fran, 283-285)

Impacts of stigma	Anticipatory anxiety/	<i>"I always think they're gunna start saying stuff like oh why the hell would you do that, that's</i>
	'perceived' stigma	<i>disgusting, so like, taking the mick and stuff, so I always get like real embarrassed in case they do say that" (Kelly, 530-533)</i>

"kind of like scared, cuz I don't want them to treat me different, I don't want them to feel sorry for me" (Hannah, 214-215).

Shame and regret	<i>"it just makes me feel a bit, well it makes me feel stupid and it makes me feel as if I've made the wrong decision. " (Laura, 367-369)</i>
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"ashamed of myself for doing it in the first place" (Fran, 260)

"if they're gunna say like bad things, then it makes me feel stupid and embarrassed about it, "(Kelly, 627-628)

"it shouldn't be acknowledged as something for people to talk about because if you talk about it then

you're just going to upset the other person that does it." (Scarlet, 402-404)

"sometimes it like upsets me because obviously I can't hide the fact that I've done it now " (Kelly, 552-553)

lifestyle

"If I didn't self-harm id be wearing like short sleeves and going out even more and going swimming more " (Hannah, 528-529)

"if your friend says oh do ya wanna go out anywhere ill just say no I don't feel very well I'll just stay in and just sit in my room..." (Laura, 391-393)

Help seeking

"well I'd been putting it off for about a year" (Laura, 527)... "when I went to the doctors I was stood outside for like half an hour like I can't do it, and I was, I was putting into my head that I really couldn't do it and there was absolutely nothing wrong with me and I could go home, but I was sat there in my doctors and I had a panic attack I was shaking and everything I was proper like, really scared," (Laura, 532-538).

"Umm, I'm not guna lie, my friend used to be in [ADOLESCENT UNIT] and I thought oh no

because they're sending me there that means I'm guna be locked up like they are (laughs) that did worry me a bit but" (Scarlet, 793-796)

"but he said, you've got nothing to worry about, you know, there's a lot of people that come in here the same as you, you know, you're not the only one, don't think that you're any different just because of any problems that you've got, so ..." (Laura, 538-542).

Recovery and future

"the thing that I was most worried about was um, in college they found out about me coming here and having appointments and stuff and they said oh you're guna have to like, they was talking me through it, like you're guna have to put it on your college like profile thingy and like employees in the future will want to know so, and I was like, it sort of worried me because if they had to know like would it give me a less of a chance of getting a job or whatever" (Laura, 621-628)

Appendix S: Reflective Statement

Reflective Statement

Throughout the research process I documented my reflections and shared and explored these with my supervisors and colleagues. This reflective statement aims to capture my research journey, focusing on the initial planning stages, experiences of recruitment and interviewing, and what I have learnt and gained from the research process.

Designing the Research Study

Choice of focus.

The first significant decision I had to make in the development of this thesis was whether to take on and develop the research interests and idea of a member of the academic team at University, or whether to research an area of my own interest, creating a research project from scratch. There seemed to be advantages and disadvantages for both options but after careful consideration I decided that for me, it was important to have a genuine passion and keen interest in the area I was to research. I felt confident that passion and interest would help maintain my motivation, focus and enthusiasm and ultimately make my research journey a more enjoyable experience. I therefore decided to focus on an area of great interest to me; stigma. In particular, I was curious about visible stigmatising attributes that can be a ‘give away’ to mental illness and how individuals manage this. Since I have a particular interest in child and adolescent mental health, I decided to focus my research around the experiences of stigma for adolescents that engage in self-harm. Initial literature searches informed me that there had been a

reasonable amount of research on how others view people that self-harm but that personal experiences of feeling or being stigmatised against had not been explored in young people that self-harm. I definitely do not regret the decision to follow my own personal research interests as although the journey was not a smooth one, as predicted, my interest and genuine curiosity maintained my motivation and focus ensuring that on the whole, developing this thesis has been an enjoyable experience.

Choice of design.

Upon embarking on the research process, I never envisaged that my empirical paper would utilise a qualitative methodology. I have always enjoyed working with numbers and statistics and inadvertently presumed that my research would take a quantitative design. As the research idea materialised, it became apparent that an explorative approach using a qualitative design would be much more appropriate. Although at first, the thought of using a research design that was unfamiliar felt daunting, I have grown fond of IPA and what it has to offer. In particular, I have valued the intimacy and insight into participant experiences that IPA has facilitated and that questionnaires could not access. Additionally, the theoretical background of IPA seems to fit nicely with the person-centred approach that I aim to achieve in my clinical practise.

Process

Recruitment.

Despite success at arriving and overcoming many of the stages of research in a timely manner, the final 6 months were a struggle. Although recruitment was planned to occur across the summer to winter of 2010, I had underestimated the challenges that recruitment would bring and was subsequently unable to recruit my first participant until February 2011. I initially planned to recruit solely through tier 3 CAMHS, and since IPA advises the use of small sample sizes, I was confident that I would meet my recruitment aims.

Upon visiting tier 3 CAMHS teams and discussing the study and participant inclusion and exclusion criteria with clinicians, it became apparent that tier 3 CAMHS did not support the young people that I was aiming to recruit. I was consistently advised by CAMHS clinicians to broaden recruitment to tier 2 CAMHS and to include council run, as well as voluntary and charity organisations. At this point I couldn't help but wonder whether staff were attempting to 'send me elsewhere' as they felt unable to take the time to recruit due to large case loads and competing demands for their resources. In response to their advice and in an attempt to reach the young people that I was hoping to recruit, I broadened my recruitment sources. To my confusion, upon contacting council run, charity based and tier 2 CAMHS services, I continued to receive the message that the young people I was seeking were not accessing such services. Feeling confident that they were out there somewhere, I began to wonder where they were? It struck me as interesting that young people that were self-harming were not seeking support services and I was curious as to whether this had a link to the stigma around self-harm.

For a significant period of time, all of my energy and resources went into recruitment. I found myself seeking out new recruitment sources, regularly emailing key individuals and when possible, making frequent visits to teams and organisations to promote my research and remind and encourage teams to support recruitment. On several occasions, and despite relentless emailing and phone calls, significant professionals who I thought might have had the ‘key’ to the door to participants, did not respond to my attempts at contact. It became clear that the demands of their job roles were such that research was not high on their list of priorities. In such instances it felt frustrating that I was unable to meet such professionals and ultimately could not set up the opportunity to ‘sell’ my research and encourage their support. I felt powerless and reliant on others, and my seeming lack of control over recruitment worried me.

Furthermore, the participants that I was aiming to recruit seemed to be not only one door away from me, but three doors away from me. Once clinicians had identified suitable participants, recruitment was far from over. The young people had to be willing and provide consent to take part and if under 16 years old, their parents also had to agree to give consent. Despite several potential participants being identified, given information packs and verbally showing an interest to take part in the research, only a fraction of these actually took part. It seemed as though this was not due to reluctance, but more to do with lack of motivation and enthusiasm to help with research which would not immediately benefit them.

Although increasing sources of recruitment seemed to make sense, in retrospect, the constraints of time due to the demands of the course did not allow me to take advantage of each potential source. I was unable to spend the amount of time with each team or organisation that was necessary to motivate them to become involved and enthusiastic about facilitating recruitment. Fortunately, my saving grace was that I was

on placement in a CAMHS team throughout the final year of my training. This provided me with almost unlimited access to the clinicians in the team and I was able to develop invaluable professional relationships and connections. Subsequently, six of my seven participants were recruited from this CAMHS team. It became apparent to me that the breadth of recruitment sources is not effective without the depth of relationships with clinicians from each.

The relief after interviewing my first participant was overwhelming. It was at this point that it dawned on me that I had absorbed myself in recruitment to such a degree that I had neglected the SLR and write up. This made the final three months of portfolio completion more stressful than planned since I found myself working outside of my usual work ethic of finishing a piece of work in a timely manner so as to avoid anxiety.

Interview process.

Interviewing participants was something that I found more difficult than I had expected. The process of interviewing participants in the role of a researcher felt foreign and uncomfortable due to its contrasting style of interaction to that of a clinical psychologist. This was further complicated by the fact that participants were to be interviewed in the CAMHS base that they attended and were familiar with. Consequently, several of the interviews were held in rooms that I carried out my clinical work in. Whereas my research role required me to listen and obtain information from participants without making any impact, my clinical training was urging me to use psychological techniques and strategies to reduce participant distress. I felt empathy and was eager to help participants, but found it frustrating that I was unable to use the

skills I had acquired to do so. At times, the process felt unethical and I felt restricted, cruel and frustrated.

Concluding Reflections

A large variety of health and social care professionals come into contact with young people that self-harm and have the potential to hold stigmatising attitudes. Additionally, such professionals also have the capacity to support the parents of these young people. I was therefore keen to submit both papers to journals that would reach a wide audience. The Journal of Research on Adolescence seemed a highly appropriate journal to submit my empirical paper to since it is multidisciplinary and international in scope, is focused on adolescence, and welcomes research that employs a diverse range of methodologies. Similarly, the Journal of Parenting: Science and Practice is also multidisciplinary and international in scope, appealing to practitioners in a variety of settings and services including: Psychology, clinical practice, social work, education and psychiatry amongst others.

The development and completion of this thesis has on the whole, been a positive experience and has encouraged me, when qualified, to make and fight for time to complete and facilitate research. Looking back on the process, I wish I knew at the start everything that I know now, which is evidence to me that the process of developing this thesis has been a valuable learning experience. I feel that I have developed a good grounding in conducting high quality research and a confidence to avoid and overcome barriers and challenges. In particular, in future research endeavours I will put great effort and attention into networking and forming relationships with those who have the means to facilitate the research process.

Although this research process is coming to an end, I feel that the seven participants that kindly took part will remain significant to me and will never be forgotten. Their openness and honesty struck me and their contributions have been invaluable. They allowed me into their worlds and for that I feel extremely privileged and grateful. I feel that they shared some of their most intimate feelings and experiences with me and there is no doubt that they have definitely left a permanent mark on me.