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Finding voices: a survey of young people's experiences of the ED

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Finding Voices: a survey of young people's experiences of the ED

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ABSTRACT

Background Mental health presentations in young people are increasing. Recurrence of self-harm (SH) presentations is common and of great concern since self-harm is known to be a risk factor for suicide. Previous reports suggest that the ED experience for this group is poor. A study was carried out at the Royal Berkshire NHS Foundation Trust. The objective was to pilot new and existing measures to capture the perceived needs and expectations of young people attending ED following SH compared with those attending with suspected fractures (SFs).

Methods Young people were approached to complete a questionnaire as they arrived in ED and again before they left. Questionnaires were a combination of pre-existing tools as well as piloting novel questions specific to the ED where no suitable tool previously existed. Satisfaction with the ED treatment was measured along with reattendance up to one year later.

Results The survey was started in 2019 and suspended in March 2020 at the outset of the COVID-19 pandemic and subsequently closed, having screened 917 and recruited 104 adolescents. All the measures showed satisfactory psychometric properties with internal consistencies (alpha) of over 0.75. The two patient groups differed at baseline: it was found that the SH group had lower mood on the Short Mood and Feelings Questionnaire ($p<0.001$) and scored more highly on the Borderline Personality Features Scale for Children than the SF group ($p<0.001$) but the expectations of care across both groups was similar. Using the experience measures, the SH group was less satisfied with treatment than the SF group ($p=0.0263$).

Conclusion Our findings underline the similarities between the two groups in terms of their expectations of care. Terminating the study early at the outset of the COVID-19 pandemic has precluded any further firm conclusions to be drawn. Further research is needed.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Adolescents with self-harm (SH) commonly present to the ED.
⇒ Recurrence is a significant issue and there is a clear association with a risk of suicide.
⇒ The ED experience of this group of patients is reported as poor.

WHAT THIS STUDY ADDS

⇒ It is possible to engage young people presenting with SH and undertake research in the ED setting.
⇒ The expectations of care and how they describe their experience is similar between the two groups.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ While limited by sample size, this study demonstrates that it is possible to conduct research with adolescents with SH in the ED.
⇒ Improving care for patients with mental health presentation to the ED is a JLA (James Lind Alliance) priority.
⇒ Further research is needed to better understand how to improve the care of this population.

INTRODUCTION

Mental health presentations in children and young people continue to rise. A 2020 report from NHS Digital found that one in six (16.0%) children aged 5–16 years were identified as having a probable mental health disorder, increasing from one in nine (10.8%) in 2017.[1] In addition, there is evidence that the prevalence of self-harm (SH) in young people continues to rise with a recent review stating that one in five 16–24 year olds reported an episode of SH.[2]

The Royal College of Emergency Medicine in collaboration with the James Lind Alliance (JLA) Priority Setting Partnership identified the need to optimise the care for patients with mental health in the ED as one of the top 10 research priorities for the specialty: focusing on both staff training and patient experience.[3] SH among adolescents is a major concern because it gives rise to considerable distress and disruption in young people's lives. SH commonly recurs and is associated with increased risk of completed suicide.[4 5] Reduction of recurrence is a major priority with studies reporting no single effective treatment or intervention over a period of time following initial presentation.[4 6]

In 2018, the Care Quality Commission (CQC) undertook a comprehensive, independent review of children and young people's mental health services in England.[7] While they found a number of examples of good practice, they also found the system to be complex and disjointed. They describe a system under pressure, from schools to the voluntary sector, to acute trust to specialist Child and Adolescent Mental Health Services (CAMHS)—and all regulated by different agencies. The unintended consequences of fragmented care drives demand in EDs as children, young people, their families and carers find they have to reach crisis point before they are able to get help. The experience of care in the ED is repeatedly described as negative.[7 8]

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Previous studies have concluded that contact with social services, CAMHS and the ED are the least helpful for young people presenting with SH.[8] Of note, within the 2020 CQC survey on Urgent and Emergency Care, younger people, females, people who reported a mental health condition and people whose attendance lasted more than 4 hours consistently reported poorer experiences of ED.[9]

This raises the question of whether such negative experiences may add to risk of repetition of SH, and conversely whether better ED experiences may be protective.[7 10] There are no previous controlled studies comparing the experience of any young person presenting to the ED to the experience of those presenting with a mental health problem. Research on both ED and ambulance staff attitudes to children and young people presenting with SH have found staff to be willing to help.[11] However, it is often cited that there has been a lack of training for frontline teams to deal with mental health issues.[12 13]

The aim of the study was to compare levels of needs and expectations and subsequent patient satisfaction between two groups of adolescent patients in the ED. We hypothesised that adolescents who attended ED with SH would have lower expectations of care from ED staff than adolescents attending ED for other reasons, which may then relate to their satisfaction. Adolescents attending with a suspected fracture (SF) were chosen as the control group because this is a common reason for ED presentation, in the same age group, with a straightforward care pathway.

The objectives were as follows:

1. To pilot new and existing measures to establish a range of perceived needs, expectations and satisfaction among adolescent patients attending ED following SH compared with those attending with SFs.
2. To report on the reattendance rates at up to 1 year.

METHODS

This was a case-control study that was carried out in the ED of a busy district general hospital from July 2019–March 2020, which terminated early due to the onset of the COVID-19 pandemic. Follow-up was completed 12 months after the initial attendance. The annual attendances to the ED were approximately 110 000 with about one-quarter under 16 years of age. The paediatric ED was managed and staffed by the same team as the adult ED, including dual accredited Paediatric Emergency Medicine consultants. Both doctors and advanced clinical practitioners worked in paediatric ED seeing both injury and illness presentations.

Data collection took place when research staff were present in the department. A service evaluation undertaken in 2017 allowed the research team to profile the times when children and young people presented with SH. This evaluation found that two-thirds of presentations were outside of office hours. We used this information to roster the team of trained researchers across 7 days a week, including evenings until 22:00 and weekends.

All research staff approaching patients were postgraduate psychology students with previous experience working with young people, often those with mental health needs. All researchers were trained in the conduct of the study, had Good Clinical Practice training and had training sessions on how to approach participants before being allowed to recruit.

Study inclusion criteria were patients aged 12–18 years old attending ED with either SH or SF. The children and young people excluded from the study were those with insufficient English to understand the study, intoxication, an acute psychosis, a possible self-inflicted fracture or in need of urgent medical treatment. Those previously included, too distressed to take part or those unable to consent were also excluded.

Adolescent patients attending with either SH or an SF were identified from the electronic patient record (EPR) by researchers, who then requested permission from the clinical staff to approach the patient about the study. Informed consent from patients over the age of 16 to participate in the study was completed with the researcher on duty. Those under the age of 16 gave their assent to participate in the study, with consent provided by their parents. Baseline demographics were then captured by the researcher. Questionnaire 1 (Q1) about perceived needs and expectations of ED was started by the patient within 30 min of arrival to the ED, and questionnaire 2 (Q2) was undertaken after at least 2 hours, just before discharge from the ED, about their experience in ED. Each participant had the opportunity to complete the questionnaire in private. They were asked to score statements on Likert scales.

Both questionnaires had several sections, as outlined in table 1, with relevant additional questions for the SH group. The questionnaires are included in online supplemental appendix 1. We used a combination of pre-existing tools as well as piloting novel questions, specific to the ED, where no suitable tool previously existed.

At 12 months, the EPR was reviewed for all patients, searching for reattendance(s) to ED and the reason for any reattendance was recorded.

Data entry

Questionnaires were completed on paper and subsequently transcribed into a secure database by the researchers.

Patient and public involvement

Children and young people were involved in the study design through local focus groups that included looked-after young people. The prevalence of SH is higher in looked-after young people and they are more likely to present to ED for its management.[8] Young people who had previously presented to the ED with SH were involved in pretesting all questionnaires and their feedback was incorporated into the design.

Sample size

For prediction of experience of patient care to experience of staff care, the sample size of 150 will have 80% power to detect a correlation of 0.23 at alpha=0.05, and similar power for multiple linear regression with up to three covariates. For comparison of means between the SH and SF groups, there will be 80% power to detect a standardised difference in means of 0.32 at alpha=0.05.

Missing data

A small number of missing data points were imputed using the median of the group for the item involved. The criteria for using imputation were that data had to be missing from only one or two items within a section. In total, 15 data points were imputed (2% of the missing data).

Statistical analysis

All analysis was performed using the R statistical program.[14]

The internal consistency of each section of the questionnaires was checked with Cronbach's alpha using the 'psy' package in R.[15] An alpha larger than 0.75 was considered as acceptable.

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Table 1 Description of questionnaires 1 and 2

Section	Title and abbreviation	Overview	Origin	Number and style of questions	Analysis method
Questionnaire 1 (Q1)					
Section 1	Royal Berkshire Emergency Department Patient Needs and Expectations Questionnaire **RBED PNEQ**	What is important to you while you are in the ED?	Devised for the study to enquire what adolescents feel they need and expect from their ED attendance.	Self-harm: 11 Suspected fracture: 8 10-point numerical Likert scale for each question.	Analysed item by item
Section 2	Expectations of Staff Care Instrument **ESCI**	What are you expecting from staff in the ED?	Seven items were adapted from the 25 in the Parental Bonding Instrument,[17] which is a widely used, valid, reliable measure used with adults to assess recalled care from parents during childhood. Items were adapted to refer to staff rather than parents, and selected to reflect expectations of care.	Both groups: 7 items 5-point Likert scale: not at all/a little/quite/ definitely/very	Summed to a total score (range 7–35)
Section 3	Short Mood and Feelings Questionnaire[18 19] **SMFQ**	How have you been feeling over the past 2 weeks?	Validated measure assessing Diagnostic and Statistical Manual Mental Disorders (DSM) symptoms of depression over the prior 2 weeks.[20] The measure has been widely used in general population studies.[21 22]	Both groups: 13 items 3-point Likert scale: not true/ sometimes/true	Summed to a total score
Section 4	Borderline Personality Features Scale for Children[23 24] **BPFSC**	What are you usually like?	Validated measure, includes reliable self-report measure of adolescent borderline symptoms.	Both groups: 11 items 5-point Likert scale: not at all true/hardly ever/sometimes/ often/always true	Summed to a total score
Questionnaire 2 (Q2)					
Section 1	Royal Berkshire Emergency Department Patient Experience Questionnaire **RBED PEQ**	What was your experience in the ED?	Matched to section 1 of Q1 (**RBED PNEQ**) to ask about experience rather than expectations.	Both groups: 8 items 10-point numerical Likert scale for each question	Analysed item by item
Section 2	Experiences of Staff Care Instrument **ESCI**	My experience of staff in the ED.	Matched to section 2 of Q1 (**ESCI**) to ask about experience rather than expectations.	Both groups: 7 items 5-point Likert scale: not at all/a little/quite/definitely/very	Summed to a total score
Section 3	Client Satisfaction Scale[25 26] **CSS**	How satisfied are you with your treatment in the ED?	Validated measure in an adult in-patient psychiatric setting with substitution of 'our programme' by 'the Emergency Department' (ED). The Client Satisfaction Scale has been shown to have excellent internal consistency when used in a hospital setting.[27]	Self-harm: 8 Suspected fracture: 7 4-point Likert scale Higher scores reflect more dissatisfaction	Summed to a total score

Differences in patient characteristics between the two groups (SH and SF) were examined using statistical techniques that were appropriate to the distribution of the data. χ^2 tests (with Yates' continuity correction, where cell values were small) were used to examine associations between count variables. Differences were considered significant if $p<0.05$ and were then assessed for inclusion as potential confounders in subsequent statistical models.

Several outcome variables from questionnaire 1 were derived from the sum of the items in their section: 'What are you expecting from staff?' (Expectations of Staff Care Instrument, ESCI); 'How have you been feeling?' (Short Mood and Feelings Questionnaire, SMFQ); and 'What are you usually like?' (Borderline Personality Features Scale for Children, BPFSC). Similarly, some outcome variables from questionnaire 2 were also summed for further analysis: 'What is your experience of staff?'; 'How satisfied are you with treatment?' (Client Satisfaction Scale, CSS).

Several statistical models were built involving the summed outcome variables and explanatory variables of each patient group (SH and SF) and appropriate covariates to adjust for differences in group patient characteristics. Model assumptions were checked using standard diagnostics (eg, normality of residuals) and linear regression was deemed the most appropriate analysis technique.

Where the outcome variable was ordinal in nature (Likert data), ordinal regression models were constructed using explanatory variables of patient group (SH and SF) and appropriate covariates to adjust for differences in group patient characteristics using the 'polr' function in the 'MASS' R package.[16]

RESULTS

At the outset of the COVID-19 pandemic in March 2020, the Finding Voices survey was suspended and subsequently closed having screened 917 and recruited 104 adolescents (see patient recruitment overview in figure 1). Thirteen patients (six from SH group, seven from SF group) agreed to take part in the survey but did not complete either of the two questionnaires and were excluded from further analysis (see online supplemental table 1 for their characteristics). For the remaining 91 patients, there were 849 missing data points from a potential 5632 items (15% missing data overall) for the sections being reported in this paper. An overview of the number of patients that were analysed for each section of each questionnaire is given in online supplemental table 2. The results of the test for internal consistency

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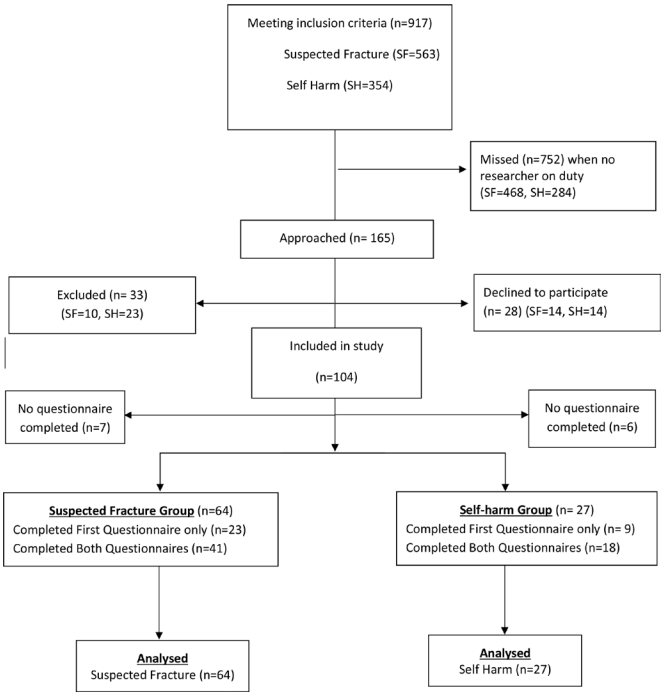

Figure 1 Finding Voices patient recruitment overview. SF, suspected fracture; SH, self-harm.

(using Cronbach's alpha) for each questionnaire section is also given in online supplemental table 2 and was within the range of 0.76–0.94, which is deemed appropriate.

Patient characteristics are described in table 2. As reported in previous literature, there was a difference in the gender balance between the two groups. The SH group were older and had a longer length of stay (LOS) in the ED.

Table 3 shows that both groups had similar expectations of staff and identified the same priorities: that staff should explain what they were doing and that staff should know how to deal with their medical problem. Statistical models were used to analyse the differences between the groups for each outcome. As highlighted in table 2, age and gender differ between the groups so they were added to the models as covariates to adjust the analysis for potential confounding. Table 3 also shows that the SH group had a lower mood (SMFQ) and scored more highly on the BPFSC than the group who presented with an SF ($p<0.001$).

Table 2 Patient characteristics

	Self-harm	Suspected fracture	P value
n (%)	27 (30%)	64 (70%)	
Age in years (mean (SD))	15.0 (1.8)	14.1 (1.5)	0.014
Index of Multiple Deprivation decile (median)	7	8	0.410
Length of stay in ED (mean (SD)) (min)	237 (108)	131 (57)	<0.001
Previous visits (median)	2	2	0.080
Previous visits for same (median)	0	1	0.828
Gender			
Male (n (%))	7 (26%)	37 (58%)	0.011
Female (n (%))	20 (74%)	27 (42%)	
Ethnicity			
White (n (%))	19 (83%)	45 (78%)	0.843
Non-white (n (%))	4 (17%)	13 (22%)	

Following on from their reportedly similar expectations in ED, both groups describe a similar experience (Q2), see table 4. The highest ranking statements were the same across both groups: acknowledging that staff were respectful towards them, explained what was being done and were caring. There was no significant difference between how they described the experience of the care received by ED staff. However, after correction for the difference in age, gender and ED LOS, those presenting with an SF were more satisfied with their experience ($p=0.026$).

Patients in the SH group (19/27=70%) were significantly more likely to return to the ED in the subsequent 12 months than those in the SF group (20/64=31%), and also more likely to return more often (SH group 110 times, SF group 27 times in subsequent 12 months). Of note, a small number of patients reattended on multiple occasions (table 5).

DISCUSSION

Conducting research in this population and setting has been one of the JLA priorities. We have shown that it is possible to conduct research with this population, in a busy ED environment, including out-of-hours recruitment. We were encouraged by the positive reception to the research by both patients and staff. The initial COVID-19 risk assessment highlighted the risks to research staff recruiting in the department and so the decision to halt the study was upheld. Although the sample size is smaller than planned, initial review of the data suggested that the findings were of sufficient interest to inform future work in this important area, currently under-represented in the literature.

Interestingly, the results show that young people presenting to ED with both SH and an SF have similar expectations of their experiences and of staff in ED (ESCI section) and both groups had the same priorities (RBED PNEQ section): that staff explained what they were doing and that staff knew how to deal with their medical problem. However, Q1 highlighted differences between the two groups at baseline: the SH group had a lower mood (SMFQ) and scored more highly on the BPFSC (eg, likely to have more unstable opinions of themselves and of interactions with others) than the group who presented with an SF, although these findings are limited by the sample size. These features may be important to consider when looking at ED processes and interactions with staff.

There were fewer responses to Q2 than to Q1, perhaps related to the LOS in ED. In Q2, both groups describe a similar experience. The highest ranking statements were the same across both groups: acknowledging that staff were respectful towards them, explained what was being done and that staff were caring. There was no significant difference between how they described the experience of the care received by ED staff, although this may be an effect of small sample size. However, those presenting with an SF were statistically more satisfied with their experience. This finding persists after correction for the difference in ED LOS between the groups. We do not know if the difference in reported satisfaction with care between the SH and SF groups may reflect differing interpretations of experience by the two groups or to other unidentified factors. These findings are again limited by the sample size.

In keeping with previous literature, the patients in the SH group were more likely to return to the ED with the same problem, although further conclusions here are limited by the small number of patients within our dataset.

Previous literature has concluded that the experience of attending the ED after SH is negative and the least helpful of the services available.[8 9] While ED staff report feeling unprepared to

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Table 3 Responses to questionnaire 1 for each patient group (summarised as the median score)

Questionnaire 1 components	Self-harm (median score)	Suspected fracture (median score)	P value*
'What is important to you?' (RBED PNEQ)			
For staff to explain who they are	8	7	0.800
For staff to explain what they will be doing	10	10	0.407
To be seen quickly	7	8	0.850
For you to feel that the ED team know how to deal with your medical problem	10	10	0.922
For ED staff to understand how you are feeling	9	8	0.047
That staff are respectful	9	9	0.419
That staff show you matter to them	8	8	0.702
That staff are caring towards you	9	9	0.947
'What are you expecting from staff?' (ESCI)			
(Total score†)	28.5	28.5	0.475
'How have you been feeling?' (SMFQ)			
Short mood and feelings questionnaire (total score†)	34	16	<0.001
'What are you usually like?' (BPFSC)			
Borderline personality features scale (total score†)	38	22	<0.001

All analyses carried out with appropriate statistical test as necessitated by the type and distribution of the data and model residuals.
*P value for difference in self-harm versus fracture group adjusted for age and gender.
†The sum of the scores for that particular questionnaire.
BPFSC, Borderline Personality Features Scale for Children; ESCI, Expectations of Staff Care Instrument ; RBED PNEQ, Royal Berkshire Emergency Department Patient Needs and Expectations Questionnaire; SMFQ, Short Mood and Feelings Questionnaire.

manage this group, there is some evidence that the attitude of staff towards the patients may be characterised as positive.[11 12] However, our study confirms that the experience of both ED and staff by both groups was described in a similarly positive way. Similarly, their priorities and expectations were also noted to be similar. One noticeable difference is that the SH group was less satisfied with the experience than the group presenting with an SF although this finding is limited by the sample size. A patient with an injury usually has a one stop visit to receive a diagnosis and treatment for the problem, whereas SH presentations are

Table 4 Responses to questionnaire 2 for each patient group (summarised as the median score)

Questionnaire 2 components	Self-harm (median score)	Suspected fracture (median score)	P value*
'What has been your experience of ED?'			
For staff to explain who they are	9	8	0.481
For staff to explain what they will be doing	9	9	0.652
To be seen quickly	5	6	0.817
For you to feel that the ED team know how to deal with your medical problem	8	9	0.853
For ED staff to understand how you are feeling	7	8	0.631
That staff are respectful	10	9	0.050
That staff show you matter to them	8	8	0.712
That staff are caring towards you	9	9	0.478
'What is your experience of staff?'			
(Total score)†	28	30	0.921
'How satisfied are you with treatment?' (CSS)			
(Total score)†	13	9	0.026

*P value for difference in self-harm versus fracture group adjusted for age, gender and length of stay in ED. All analyses carried out with appropriate statistical test as necessitated by the type and distribution of the data and model residuals.
†The sum of the scores for that particular questionnaire.
CSS, Client Satisfaction Scale.

Table 5 Reasons for returning to ED in subsequent 12 months (self-harm vs suspected fracture)

	Self-harm	Suspected fracture	P value
Original cohort	27	64	
Returned to ED?			
Did not return to ED	8 (30%)	44 (69%)	<0.001
Did return	19 (70%)	20 (31%)	
Returned to ED due to:			
Self-harm injury/issue	10	0	
Soft tissue/fracture injury	3	8	
Other	14	12	
Returned to ED ONCE due to:			
Self-harm injury/issue	5	0	
Soft tissue/fracture injury	2	6	
Other	9	10	
Returned to ED>ONCE due to:			
Self-harm injury/issue	5	0	
Soft tissue/fracture injury	1	2	
Other	5	2	
Number of times returned to ED			
Total returns to ED (any reason)	110	27	
Total returns to ED (self-harm)	71 (65% of total returns)	0 (0% of total returns)	<0.001
Total returns to ED (suspected fracture)	6 (5%)	10 (37%)	
Total returns to ED (other)	33 (30%)	17 (63%)	

Data are frequency (% of group (column percentage)), unless stated otherwise. P value indicates the likelihood of a difference in self-harm versus fracture groups using the appropriate statistical test.

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not 'fixed' in the same way in a single visit. There is often a less well-defined pathway to receive help for the underlying mental health problem, often involving other healthcare providers, leaving the individual more likely to need to attend again as the problem has not been 'fixed'. While it is important to ensure LOS in ED is optimised for all patients, the LOS difference may reflect the pressures under which CAMHS teams are working given the increase in mental health attendances.

Limitations

The study was terminated early at the onset of the pandemic and so the numbers are smaller than anticipated, limiting the strength of the conclusions. It was conducted in a single ED and findings may not be generalisable to other ED settings. We have only compared two defined presentations of adolescent patients and findings may not be generalisable to adolescents with other reasons for attending ED. We excluded those thought to be too distressed to take part which may have limited how representative our group is and therefore biased our results. The survey was carried out when a researcher was present in the department therefore represents a convenience sample and so this may have impacted on our sampling. Some young people declined to participate so there is an element of self-selection. The questionnaires used in this study represent a mixture of novel, adapted and validated questionnaires to capture the breadth of data that was not covered by an existing tool. Participants only had the option to self-report gender as male or female, and we would amend this in any future study to allow other responses. It is possible that the study failed to capture the differences between the two groups either due to small numbers of participants or due to limitations of the questionnaires themselves in this environment and population. Of note, there were fewer responses to Q2 which limits the conclusions that can be drawn. It is also possible that the Likert scale may not be the most appropriate means to capture information in this area. The ED LOS was greater in the group presenting with SH and may affect reported experience of ED care, although attempts were made to correct for this statistically.

Strengths

The strengths of this study are that the researchers had all previously worked with children and young people. The hours covered by the research team reflected the times that young people attend with SH. We have successfully used novel questionnaires where none previously existed and have shown good internal consistency for these questionnaires. Missing data have been recognised in the analysis and a small number of data points were imputed. Of note, as expected, the group presenting with SH were statistically more likely to reattend as previously reported which may reflect that we captured the opinions of those with whom we were keen to engage.

CONCLUSION

This study was terminated early at the onset of the COVID-19 pandemic so its conclusions are limited by smaller numbers than anticipated. However, we have demonstrated that it is possible to undertake research in young people presenting to the ED with SH. Both groups of young people described their expectations and experiences of care in a positive light. Further work is needed to ascertain how care for patients presenting with SH to the ED can be improved.

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Contributors LK and JH conceived the project and JH constructed the questionnaires. JD undertook the statistical analysis. LK and SW wrote the paper. All authors contributed to the content of the paper. LK is acting as guarantor for this project.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval The South Central-Berkshire Research Ethics Committee gave approval for the study (19/SC/0159). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data are available on reasonable request.

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