Research

**Assessing the experiences of care of children and young people in mental distress in acute care settings: a service evaluation**

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**Abstract**

**Background/Aims** Current literature may not be fully representative of the views of all children and young people experiencing mental ill health concerning their experience of attending an acute care setting with mental distress. Research highlights opinions of children and young people known to community mental health services; however, it is estimated that 65–75% of children and young people experience mental health problems are undiagnosed and untreated (Care Quality Commission, [2018](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\6)). The aim of this study was to compare experiences of patients presenting to emergency settings both known (Group 1) and unknown (Group 2) to community mental health services.

**Methods** A service evaluation was distributed to children and young people experiencing mental distress. Survey responses were categorised into two patient groups: participants known to community children and adolescent mental health services and accessing support (group 1) and those not currently known or receiving support from any children and adolescent mental health services (group 2). Responses were categorised into ‘environment rating’, ‘nurse rating’ and overall ‘acute care rating’.

**Results** Disparities were identified between groups 1 and 2. Group 1 had negative acute care ratings, mainly resulting from environmental factors. Both groups reported negatively when nurses spoke to parents or carers instead of the young person themselves.

**Conclusions** Further research is needed into experiences of the children and young people not meeting criteria for community mental health support, as there is a data gap. Paediatric nurses must directly communicate with children and young people experiencing mental distress, rather than speaking to parents or carers.

**Key words**

Acute care setting, Children and adolescent mental health services, Emergency care, Mental health crisis, Paediatric nurse, Patient experience

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**Background**

During the last 20 years, the NHS has launched significant reforms in service provision for children and young people who are experiencing mental disorders. There has also been considerable growth in mental health charities supporting vulnerable children and young people. Subsequently, how children and young people feel about the services provided to them has been explored through research, taskforce groups, Care Quality Commission (CQC) assessments and Parliamentary inquiries.

The CQC (2017a; 2017b) has reported children’s concerns around the skills and training of the staff caring for them, echoing the findings of an earlier House of Commons inquiry (House of Commons Health Committee, 2014). More recently, a review concluded that nurses were not confident in their ability to care for patients with mental distress in non-psychiatric hospital settings and were unsure of their role (Grieve, 2019). This has been classed as an ‘ongoing powerlessness loop of care’ (Vallières-Noël et al, 2016). Vallières-Noël et al (2016) stressed that, for mentally unwell patients in general hospital settings, patients’ physical needs are mistakenly prioritised over emotional needs, and emphasised the necessity for further nurse training. This paper called for greater definition of the paediatric nurse’s role with regards to mental health, especially as paediatric nurses are commonly the initial contact for children and young people experiencing acute mental distress (Vallières-Noël et al, 2016; Grieve, 2019).

Children and young people are commonly placed on paediatric medical wards while they await mental health assessment or mental health beds, which is reported to worsen their mental state (Healthy Living Partnership, 2016). Children and young people have also reported experiences of hospital nurses who are not friendly or welcoming, and have testified to feeling judged by nurses, which makes it difficult to share their feelings (Department of Health and Social Care (DHSC), [2015](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\7); Public Health England (PHE), 2015; CQC, [2018](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\6)). However, current research is primarily based on the opinions of 25–35% of children and young people who are known to mental health services (PHE, 2015; Mental Health Taskforce, [2016](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\21)). Therefore, findings may not be representative of the 65–75% of children and young people with diagnosable mental health conditions who remain undiagnosed and are not accessing services (Green et al, [2005](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\13); Mental Health Taskforce, [2016](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\21); CQC, [2018](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\6)). Charity reports are insightful; however, these, again, use feedback from children and young people who have sought help for their mental health issues. It must also be considered that charities primarily rely on fundraising efforts and, therefore, may display a tendency to negative reporting as a means of rallying support bias. This is because the more that the public are convinced of severity of mental health problems, the more they are likely to offer financial support.

**Introduction**

Children and young people often present to acute care settings, such as emergency departments, during the peak of mental health crisis. The majority do not have formal diagnoses and/or do not meet the criteria for a community child and adolescent mental health services (CAMHS) referral. Due to their heightened levels of distress, they can be unwilling to engage with practitioners, meaning that their encounters with mental health professionals and services can be chaotic, sporadic and/or isolated events that are primarily focused on crisis management, as opposed to the ongoing improvement of their mental wellbeing. There is no national feedback mechanism or outcome measurement to benchmark service provision for all children and young people experiencing mental illness presenting in acute healthcare settings and being cared for by general paediatric nurses.

This study aimed to capture feedback from children and young people presenting with mental distress that were either known or not known to CAMHS, to explore and compare their acute care experiences. To inform our understanding of mental illness and how this develops from childhood into adulthood, it is imperative to understand how children and young people feel about their experience of mental crisis and crisis care. It is also vital to offer those patients that are only accessing support during the height of a mental crisis the opportunity to input into the service they access. Therefore, this study aims to answer the following questions:

* What is the experience of children and young people who present with mental distress in an acute care setting?
* Is there a difference in opinion between those known to community CAMHS (group 1) and those not known to community CAMHS (group 2)?

**Methods**

The project was implemented as a service evaluation. A narrative review explored the existing literature summarising feedback from children and young people experiencing mental health conditions. The review identified five fundamentals of care, which formed the foundation of the questions for the service evaluation:

1. Feeling safe, comfortable and welcome in the care environment
2. Staff that are friendly, welcoming and caring
3. Not feeling judged
4. Feeling involved in decisions about their care/feeling listened to
5. Confidence in ability/training of staff caring for them.

Ethical approval

Ethical approval was granted by the University of Southampton faculty ethics committee (reference: ERGO II 42785) and approval obtained from the care settings who distributed the surveys, including the inpatient CAMHS team. CAMHS practitioners gained informed verbal consent from eligible patients and gave them a survey, self-sealing envelope and briefing card.

*Participants*

Eligible patients were:

* Those with mental distress as the presenting complaint in acute care settings
* Aged 8–18 years
* Literate in English
* Referred to the inpatient CAMHS team for assessment of their mental health.

Children and young people excluded from taking part were those considered by CAMHS to be unsuitable/unable due to:

* Their level of mental distress (those deemed not to have capacity or who exhibited aggressive behaviour)
* Being medically unfit to carry out the survey
* Having the researcher as their named nurse.

*Setting*

The study was conducted in Southampton Children’s Hospital, University Hospital Southampton NHS Foundation Trust, Southampton, UK. The Trust was one of the first to have a dedicated inpatient CAMHS nurse in the paediatric emergency department.

Southampton is representative of a large UK city, with a population of approximately 25 2796 people, placing it within the UK’s 50 largest cities (Office for National Statistics (ONS), [2020](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\25)). In 2019, approximately 61962 children and young people (24% of the total population) aged ≤19 years were living in the city (ONS, [2020](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\25)). Southampton is ethnically diverse; 39% of school-aged children and young people have an ethnic minority background, compared to 32% across England as a whole (GOV UK, 2020). Southampton is also relatively deprived. According to the 2015 National Index of Multiple Deprivation (IMD), it ranked 67th of 326 socioeconomically disadvantaged local authorities in England (Southampton City Council, [2015](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\29)). One of the IMD’s seven areas of assessment is the health deprivation and disability domain, which includes mental health; Southampton demonstrated the largest deterioration in this category between 2010–2015 (Southampton City Council, [2015](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\29); Ministry of Housing, Community and Local Government, [2019](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\22)).

Survey

Information was provided in simple language, with a bullet point structure. Bright colours were used to highlight specific points to ensure information was clear, accessible and appropriate for children and young people. The patient completed the survey, inserted it into the sealed envelope and returned it to the CAMHS practitioner. The CAMHS practitioner then provided anonymised demographic details on the front of the envelope and placed it into a locked box for collection by the researcher.

*Data management*

Each survey and its envelope, which included demographic data, were given corresponding identifiers. Survey responses were categorised into two patient groups: participants known to community CAMHS and accessing support (group 1) and those not currently known or receiving CAMHS support (group 2). Data regarding patient gender, age, presenting complaint and time spent in the department were also collected.

Participant responses to the closed questions were categorised into positive and negative factors. A rating system was created across three key areas:

1. Care environment (ie environment rating)
2. Nursing care (ie nurse rating)
3. Amalgamation of environment rating and nurse rating (ie overall acute care rating).

A positive/negative point allocation was given for each response recorded. The results were split into quartiles for the three areas, so that ratings could be standardised across them:

* Quartile 1: very negative
* Quartile 2: negative
* Quartile 3: positive
* Quartile 4: very positive

Free-text answers were thematically categorised. For example, when respondents were asked why they felt the way they did about the hospital environment, most responses fell within the categories of ‘internal factors’ and ‘external factors’.

Cross-case analysis was conducted on the quantitative data, comparing the responses of group 1 and group 2.

**Table 1. Group 1 and 2 by environment, nurse and acute care ratings**

AQ: are the % response rates? If so, please provide numbers

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Environment rating** | | | | **Nurse rating** | | | | **Acute care rating** | | | |
| **Very negative** | **Negative** | **Positive** | **Very positive** | **Very negative** | **Negative** | **Positive** | **Very positive** | **Very negative** | **Negative** | **Positive** | **Very positive** |
| **Group 1\*** | 6% | 30% | 56% | 6% | 13% | 13% | 19% | 56% | 6% | 13% | 44% | 38% |
| **Group 2†** | 7% | 21% | 21% | 50% | 0% | 7% | 14% | 79% | 0% | 14% | 14% | 71% |

Group 1: known to CAMHS **†**Group 2: not known to CAMHS. *Percentages may not total 100 due to rounding*.

Results

Surveys were offered to 30 patients and 0 declined, giving a 100% response rate. The male to female ratio of participants was 2:3, with ages ranging from 9–17 years; the mean age was 14. The most common presenting complaints were ‘overdose’ and ‘low mood/depression’, jointly accounting for 40% (*n*=12) of each. This was followed by 20% (*n*=6) presenting with ‘deliberate self-harm’. The less common presentations were ‘behavioural difficulties’ (10%, *n*=3), ‘anxiety’ (7%, *n*=2), ‘suicidal ideation/intent’ (7%, *n*=2), or ‘emotional dysregulation’ (3%, *n*=1). Percentages do not total 100%, as some participants had more than one presenting complaint, such as ‘low mood’ and ‘anxiety’.

Females were more positive in their overall acute care rating than males in the 14–17 years age group. There was no significant correlation between the length of time that respondents stayed in the department and their overall acute care rating.

Some 53% (*n*=16) of respondents were categorised as Group 1 and 47% as Group 2 (*n*=14). Only 33% (*n*=10) of all respondents reported negatively or very negatively regarding the hospital environment. Of this percentage, 60% (*n*=6) of the negative reporters belonged to Group 1.

In Group 2, 79% (*n*=11) answered ‘very positively’ about nursing care, in comparison with only 56% (*n*=9) in Group 1 (*Table 1).*

Some 17% (*n*=5) of all respondents answered negatively about their nursing care; of those with negative nurse ratings, 80% (*n*=4) were in Group 1. These negative perceptions were mostly caused by the feeling that their nurse spoke primarily to their parent/carer, rather than including them in decisions; or the belief that their nurse was only partially competent (40%, *n*=2) or did not know how to look after them (20%, *n*=1).

The acute care ratings demonstrated that patients in Group 1 were more negative about their acute care experience as a whole than those in Group 2. The lowest acute care rating (-6) was given by a Group 1 participant, whereas the two most positive acute care ratings (13) were from Group 2. Participants in Group 2 had a median acute care rating of 10.5 compared to those in Group 1, who had a median acute care rating of 7.

Only 13% (*n*=4) of all respondents made suggestions for improvement in their care in the free-text questions. Of these, 50% suggested environmental improvements, such as games consoles, and 50% suggested procedural improvements, such as ‘find me a bed faster’. Neither of these would necessarily be within the nurse’s ability to change. No respondents made suggestions regarding actions a nurse could directly take to help them feel better.

**Discussion**

Patients generally responded positively about their experience of acute care, which was mainly regarding nursing care as opposed to the care environment itself. Some 67% (*n*=20) had a ‘very positive’ nurse rating; only 27% (*n*=8) gave a ‘very positive’ environment rating. This indicates that the hospital environment was a key negative factor in the respondents’ overall experience of acute care, which supports the literature (Healthy Living Partnership, 2016). Some 37% (*n*=7) of respondents who reported positively about the environment justified their environment rating through favourable comments about the nurses looking after them. This suggests that these participants’ satisfactory experiences of nursing care was behind their positive perception of the environment. This challenges existing literature, which highlights lack of competence and the negative impact that paediatric nurses have on patients experiencing mental distress in acute care (PHE, 2015; CQC, 2017a; CQC, [2018](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\6); Healthwatch England, 2018).

Group 1 had a more negative acute care rating overall. This supports assertions in the current literature that the hospital environment is inappropriate for children and young people struggling with mental distress (DOH, [2015](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\7); PHE, 2015; Faulconbridge et al, [2016](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\9); Healthy Living Partnership, 2016; CQC, 2017a). However, Group 2 regarded hospital and nursing care more positively. Positive regard for the hospital setting is not reflected in existing reports; however, in the current study, 79% (*n*=11) of children and young people in Group 2 described the hospital setting as ‘safe’, compared to only 38% (*n*=6) of Group 1. This disparity is pertinent, as current feedback mechanisms for those experiencing mental distress draws from the opinions of those who are known to community mental health services (Group 1) and are accessing support. This could explain why current literature reports a negative perception of the hospital environment and nursing care from those in mental distress.

Although over three-quarters (79%) of patients not yet known to CAMHS had considerable mental health difficulties, causing them to seek medical attention in an acute/emergency care setting, they did not proceed to meet the criteria for further assessment by community CAMHS. It is this group whose patient experience would not routinely be captured by existing feedback mechanisms; therefore, their voices are not represented in the existing literature. It is vital to capture information from children and young people who have a lower number of sporadic presentations to acute care throughout childhood, to improve our understanding of paediatric mental health as a whole. It is also likely that this patient group form part of the 65–75% of children who, although meeting the criteria for mental health conditions, are undiagnosed and are, therefore, unable to access support (Mental Health Taskforce, [2016](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\21)). Undiagnosed and unsupported mental health conditions throughout childhood contribute to poorer prognosis into adulthood (Hughes et al, [2016](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\19)), thereby adding to the existing strain on adult mental health services. Unfortunately, the NHS has ‘limited sight on what happens’ to these children and young people (House of Commons Committee of Public Accounts, 2018).

There are multiple factors that could have contributed to the variance in the opinions between Groups 1 and 2. For example, Group 1 patients may have higher levels of understanding and insight into the type/level of care that they require. As it is the severely unwell cases who are eligible for community CAMHS support, their more negative acute care ratings could have been because they had a higher level of mental need, which surpassed the nurses’ competence, linked to basic levels of training. Group 1 may also have higher expectations of nursing care, because of the support they already receive from specialist mental health nurses in the community. However, these considerations must be taken alongside the fact that 69% (*n*=11) of Group 1 had no suggestions for how the paediatric nurses could have improved their care.

However, the current study did support one finding of the existing literature across both patient groups: children and young people desire to be heard and spoken to directly by nurses, as opposed to via their parent/carer. This was the key negative aspect of their patient experience. Children and young people want to be involved in decisions about their care, and the service evaluation demonstrated that nurses did not always do this for either group.

*Limitations of research*

One limitation of the service evaluation is the relatively small sample size of participants (*n*=30); however, the 100% response rate somewhat offsets this. A collection of 100 completed surveys was originally planned, which would have required 40% of mental health presentations to the acute care settings being offered a survey (according to internal trust figures between 2016–2017). However, only ≈12% of eligible presentations were offered the survey, which limited the results. There was also the time limitation of a 3-month data collection period. Given a longer time period, more data could have been collected that may have strengthened the findings.

The service evaluation was also only implemented in one NHS trust, which is a large regional centre with a dedicated inpatient CAMHS nurse. Therefore, the participants’ experiences may not be representative of children and young people who present at, for example, a district general hospital in a small town. Their experiences could also be location- and demographic-specific. These factors may impact this study’s findings and limit the usefulness of the information gathered.

*Recommendations*

It would be useful to repeat the service evaluation in different settings, such as in trusts of several sizes and geographical locations and with a mix of deprivation indices, to ascertain the level of variation across regional centres and district generals. It would also be of interest to repeat the study in hospitals with and without an inpatient CAMHS team onsite. This would further enhance understanding of children and young people’s experience of acute care when experiencing mental distress; consequently, quality of patient care could be improved.

As 79% (*n*=11) of Group 2 presentations did not meet the criteria for community CAMHS referral, this service evaluation supports the potential for future service development of an alternative model of care/care pathway for the lower risk patients requiring acute care for mental distress. In addition, the fact that environment ratings were considerably lower than nurse ratings means that improving the environment could vastly enhance the patient experience.

Some 90% (*n*=27) of respondents reported that they felt that their nurse knew how to look after them, despite existing reports stating that nurses do not have adequate mental health knowledge (HCHC, 2014; CQC, 2017a, 2017b). The current study should encourage paediatric nurses with the possibility that, although they may not be adequately trained in specific mental health nursing, it is sufficient to be kind, caring, compassionate and non-judgmental towards children and young people experiencing mental distress in order to gain patient satisfaction. These are basic competences that every nurse requires to maintain their professional registration (Nursing and Midwifery Council, [2018](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\24)). Feedback demonstrated that relatively small actions made a big difference to patients. For example, being given a bowl of cereal was significant enough for one participant to report.

The main reason for nursing care to be scored negatively was due to patients feeling that their nurse spoke more to their parent/carer as opposed to them directly. This is a message which should be disseminated to paediatric nurses to improve patient experience for children and young people experiencing mental distress. Educating nurses in best practice when caring for this patient population would embolden and empower nurses in their advocacy for all children and young people, but especially those with presentations of mental distress.

Children and young people experiencing mental distress who were not known to community CAMHS and not accessing support had a markedly different experience of acute care. There was a distinctly more positive view of acute care in this patient group for both the hospital environment and nurses—for example, not feeling judged and believing that nurses were welcoming and friendly and the hospital environment was safe. The lack of reference to this in existing literature indicates a gap in current feedback mechanisms, an issue highlighted by other studies that claim that children and young people experiencing mental distress are an under-researched clinical population (Scott-Brown and Wright, [2001](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\28); Fisher, 2015).

It is crucial that this gap in data collection is rectified through further exploration of this population. Childhood experiences profoundly impact upon a person’s mental wellbeing as an adult (Bowlby, [1988](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\2); Boyes et al, [2016](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\3); Gerhardt, [2015](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\11); Mental Health Foundation, [2015](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\20); Hughes et al, [2016](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\19)). Studies show that 75% of mental health conditions will present before adulthood (Alink et al, [2012](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\1); Parkin et al, [2017](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\26)), and over 50% will present before the age of 14 years (Earle, [2016](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\8); NHS Providers, [2016](file:///\\chenassoft\SmartEdit\WatchFolder\NormalProcess\Normalization\IN\INPROCESS\23)). Therefore, there is a strong case for children’s experiences being key to comprehending adult mental health conditions. Greater understanding and consequential advancements in the support of children and young people’s mental distress offers the potential of an improvement of adult mental health and overall wellbeing, which has enormous economic and social benefits. If treated effectively in childhood and adolescence, the severity of mental health conditions could be reduced, resulting in better prognosis for children and young people (Grieve, 2019) and future adult generations.

**Conclusions**

The current study results support assertions made in existing literature for children and young people known to community CAMHS experiencing a crisis in their mental health. It concurs with the suggestion that the acute care environment can have a negative impact on this patient group and that their experience of general paediatric nursing care can be negative in some ways. Furthermore, this study found agreement with reports highlighting that nurses speaking to a patient’s parents/carers, rather than the patient themselves, can engender a negative experience. This resonated across both patient groups.

However, existing reports are not fully representative of all children and young people who experience considerable mental distress, as there are limited feedback mechanisms in place. Further appraisal of all children and young people experiencing mental health problems, with a diagnosis or otherwise, could have multiple benefits by facilitating:

* Further understanding and knowledge about how mental health conditions develop into adulthood
* The focus and dissemination of resources
* More effective prevention of, and treatment for, children’s mental health problems, reducing the level of need for adult mental health services later in life.

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Conflicts of interest

The authors have declared that they have no competing or potential conflicts of interest.

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**Key points**

* There is a dearth of literature relating to the perspectives of children with mental health difficulties previously not known to child and adolescent mental health services (CAHMS) in acute settings.
* Patients who were known to CAHMS were markedly more negative about their experience, while those not known to CAHMS reported more positive experiences. This refutes the current literature, which focuses on opinions of patients known to community mental health services and/or accessing support from local charities, and where reported experiences are negative. Further research is required.
* Paediatric nurses should be encouraged by the possibility that, although they may not be adequately trained in mental health nursing, it is sufficient to be kind, caring, compassionate and non-judgmental towards children and young people experiencing mental distress.

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