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Discharged from Paediatric Intensive Care Unit: A mixed methods study of teenager's anxiety levels and experiences after PICU discharge.

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This study was granted ethical approval by the London City and East NHS Research Ethics Committee. Consent was provided by parent/guardians if the child was <16years, if >16years Children signed their own consent. Assent was provided by all children whose parents signed consent.

Abstract

Background

Teenagers represent a small proportion of patients on Paediatric Intensive Care Units (PICU) in the United Kingdom. During a time when their development is rapidly changing, an admission to PICU causes additional disruption. The impact of critical illness on psychological health after discharge has not been widely reported within this population.

Aim

To measure anxiety that teenagers report 48-96 hours and 4 weeks after discharge from PICU. To explore teenagers' experiences of being admitted onto PICU.

Study design

Two phase mixed methods, explanatory sequential design.

Methods

This single site study was conducted between February to July 2018. An NHS Ethics committee approved the study. Teenagers were screened if they were aged 13-18 years old and had an elective or emergency admission to PICU for longer than 24 hours.

Hospital Anxiety and Depression Scale, Anxiety subscale (HADS-A) was administered on paper and completed with the researcher present. Semi-structured interviews were conducted in-person and over the telephone, audio-recorded and transcribed verbatim. Data were analysed using inductive thematic analysis.

Results

Nine of eighteen participants (50%) obtained scores indicating levels of anxiety which were mild (n=3;17%), moderate (n=2;11%) or severe (n=4;22%) 48-96 hours after PICU discharge. Four weeks later all participants scored below the clinically significant cut-off level for the HADS-A-1 Teenagers described their experiences on PICU within three themes:

1. Memories of treatments, side effects and the PICU environment
2. Losing a sense of self
3. Feeling cared for

Conclusions

Measured levels of anxiety had resolved in this small sample, four weeks after PICU discharge. This finding was not consistent with qualitative data that indicated that many experiences shared by participants were anxiety provoking.

Relevance to clinical practice

Support for teenagers after PICU discharge should be available to meet individual needs; screening teenagers to identify support needs would be beneficial.

Background

Worldwide the number of children and teenagers requiring Paediatric Intensive Care Unit (PICU) admission has increased significantly over the past decade (Boeschoten et al. 2020). In England and Wales there are 32 specialist PICU's which provide high acuity care for critically ill children and teenagers (Paediatric Intensive Care Unit Audit Network 2019). Teenagers have been defined as young people aged between 13-18 years old (Vaghi and Emmott 2018). The term 'teenager' is used based on patient and public involvement work from University College London, where the term 'teenagers' was preferred by this age group (Vaghi and Emmott 2018). Data collected in the UK and Republic of Ireland between 2017-2019 indicates that there were 60,424 PICU admissions of teenagers aged 13-16 years old (Paediatric Intensive Care unit Audit Network 2020). Advances in care mean that 96.5% of children and teenagers are now discharged from PICU alive (Paediatric Intensive Care Unit Audit Network 2019). Despite increasing survival rates there has been an increase in new and associated morbidity (Lopes-Júnior et al. 2018).

Being on PICU can be a difficult time for teenagers and their families, dealing with the possibility of mortality, disability, and potential risk to long term health (Aylott 2010, Kudchadkar et al. 2020). Between 10-13% may experience impairments which alter their normal function more than two years after PICU discharge (Ong et al. 2016). A study in America found new onset morbidity of 4.8% among PICU survivors (Pollack et al. 2014). Teenagers are exposed to pain, invasive procedures, delirium, and drug withdrawal whilst being in an unfamiliar environment (Rennick et al. 2014, Rodríguez-Rubio et al. 2020). While physical health needs are met after discharge from PICU, impact of critical illness on psychological health after discharge is not well documented (Manning et al. 2020, Ong et al. 2016). Teenagers are in a unique phase of development and their experience of a PICU admission could arguably be very different from that of an adult or child (Manning et al. 2017). Teenagers have been reported to experience more complex and long-lasting distress after discharge from PICU (Sansom-Daly et al. 2012), hence a need for more teenager-focused research studies (Tuckwell et al. 2017).

In the general population one in five teenagers will suffer from mental health problems, the most common being anxiety and depression. Over 50% of mental illness starts by the age of 14 and 75% develops by age 18 (Murphy and Fonagy 2012). Anxiety is a normal reaction to life stressors and uncertainties (Wiener 2015). The concern occurs when anxiety is not transitory. Persistent anxiety can lead to anxiety disorders (Voltas et al. 2017, Wang 2017). Prolonged feelings and symptoms of

anxiety can affect a teenagers ability to thrive (Dias et al. 2016). Anxiety can also have detrimental effects on quality of life and day to day functioning and can have adverse consequences for educational achievement, social skills and confidence (Burkholder et al. 2016, Miller 2017). Anxiety as a characteristic of illness recovery is largely underreported in research (McDonnell et al. 2015, Stuber et al. 2006). Examining the aetiology of anxiety is valued in reducing long-term psychological problems (Christian-Brandt et al. 2019).

Considering trauma associated with critical illness and the prevalence of mental illness in teenagers highlights a greater risk for teenagers of developing a mental health problem after an admission to PICU (Delamater et al. 2017, Jackson and Goossens 2020, Manning et al. 2018a).

In a systematic review of articles relating to post intensive care anxiety in the adult population it was found that one third of intensive care survivors experienced anxiety symptoms that were persistent during their first year of recovery (Nikayin et al. 2016). Another study highlighted the presence of anxiety among young people aged 12-20 years old with heart disease and identified the lack of services to recognise their anxiety and support young people (Wang et al. 2012).

In recognition of the multifactorial effect a PICU admission can have on long term physical, cognitive, emotional and social aspects of health and well-being the Post Intensive Care Syndrome – Paediatrics (PICS-p) theoretical framework has been developed (Manning et al. 2018b, Watson et al. 2018). This framework incorporates the child and their family and recognises the interdependence of these, consistent with the family centered care philosophy within PICU (Hill et al. 2019). A systematic review of PICS-p included nine studies which measured psychological morbidity, but the focus was on Post-Traumatic Stress Disorder (PTSD) rather than anxiety as an outcome (Herrup et al. 2017). In a review of cohort studies looking at psychological outcomes after PICU by Lopes-Júnior et al. (2018) only one included study used a validated tool to assess anxiety and no difference in anxiety levels was found between children admitted to PICU or those admitted to ward areas (Rees et al. 2004). However, this small, single center study focused on children rather than teenagers. Understanding the extent, duration and aetiology of anxiety in this specific age group will provide a more informed insight into holistic care needs for this population.

Aims and objectives.

The aim was to explore anxiety that teenagers experience after discharge from PICU.

The objectives were to:

- Measure levels of anxiety that teenagers experience 48-96 hours and 4 weeks (+/-10 days) after PICU discharge.
- Explore experiences of teenagers who were admitted to PICU 4 weeks (+/-10 days) after discharge.

Design and methods

A mixed methods study incorporating an explanatory sequential design was used to determine anxiety levels and experiences of teenagers after PICU discharge (Creswell 2015). The researchers recognise their ontological standpoint as pragmatic; appreciating the qualitative nature of human experience and placing this in context of life events and experiences. In social and health sciences research a pragmatic paradigm is a common choice of philosophical system to apply to mixed methods research (Mitchell 2018). Use of this design enabled an insight into prevalence and extent of anxiety symptoms with explanations from teenagers about their experiences on PICU. This method enabled a broader view of the outcome within a specific population, which was most appropriate considering limited data (Creswell 2015, Jacobsen 2020). Due to lack of available time and funding and the small possible population size, a practical approach to sampling dictated that a consecutive sampling strategy be used for phase one. This included all participants who met the inclusion criteria and is classified as a non-probability sampling technique (Daniel 2012). Quantitative data were used to purposefully select participants who had high or low anxiety scores for the qualitative phase. Greater emphasis was placed on the qualitative phase. A sample size of 20 teenagers for HADS-A-1 data collection was considered sufficient to observe anxiety symptoms in a small sample and provide an initial understanding of their experiences in relation to symptom severity as well as providing sufficient participants from which to select 8-12 for qualitative interviews. This number of interviews was considered likely to enable data saturation to be reached (Fusch and Ness 2015).

The research was based at one specialist children's hospital in England and teenagers were recruited during their stay in PICU between February 2018 and July 2018 using pre-specified inclusion and exclusion criteria (Table 1). Nurses checked to see if teenagers would be willing to discuss the study in more detail before referring them to the investigator (EB). They were then provided with participant information sheets, given an opportunity to ask questions and decline or give their consent/assent. Consent for both phases of the study was taken by the primary author who worked only in a student researcher capacity during the time of recruitment and did not provide care for those recruited. Teenagers >16 years old who were deemed competent provided

sole consent. Competence and capacity were ascertained by asking the teenager to explain the study to assess their understanding of their involvement in the research. If they were not deemed competent or were <16 years old, the parent/guardian provided consent and the teenager provided assent (Nuffield Council of Bioethics 2015).

Demographic data including age, gender, length of stay, admission reason, and severity of illness (The Paediatric Index of Mortality (PIM3) score) were collated for all participants. The PIM3 score was based on physiological signs within the first 24 hours of PICU admission and is an international standard for risk adjusted mortality used in PICU research (Straney et al. 2013) with documented reliability (Wolfler et al. 2016).

The first phase of the study included a measurement of anxiety levels using the Hospital Anxiety and Depression Scale – Anxiety (HADS-A) (Zigmond and Snaith 1983). The HADS comprises 14 questions, 7 of which measure anxiety and 7 measure depression; only questions relating to anxiety were asked in this study. The HADS-A scale is the most frequently used instrument to measure anxiety in adult ICU patients (Nikayin et al. 2016). In a community sample of teenagers, the HADS-A demonstrated satisfactory psychometric properties. The coefficient values of Cronbach's alpha for the anxiety subscale was 0.80, which was deemed an acceptable level of internal consistency (Chan et al. 2010). In addition to demonstrated internal consistency within this population, the HADS-A was used because of its brevity resulting in low participant burden. Participants were asked to score the relevance of seven statements in relation to how they had felt during the previous 7 days. The total score ranges from 0-21, with scores of 8–10 indicating mild levels of anxiety, 11-14 moderate and 15-21 severe. The HADS-A was provided as a paper copy and was completed in the presence of the researcher. The questionnaire was self-reported but in situations where teenagers were unable to write their responses these were recorded on paper by the researcher. HADS-A was administered at two time points: 48-96 hours after PICU discharge (HADS-A-1) and 4 weeks after PICU discharge (HADS-A-2) but prior to interview. If the participant had been discharged home or to another hospital the HADS-A-2 was emailed and returned to the researcher prior to interview.

The second phase of the study consisted of semi-structured interviews with participants who had completed HADS-A at both time points. Interviews took place four weeks after PICU discharge, either by telephone or face-to-face during an outpatient appointment. Participants had an option to be interviewed alone or with their parents, and if parents were present, they were informed that any information they provided would not be included in the analysis. It was made clear to all participants that the interview could be stopped at any time. There was a topic guide to structure the interview, however the interview style was informal. Questions were open ended to encourage

participants to share more detail about their experiences and emotions related to their PICU stay, but did not refer directly to their HADS-A score; this decision was made to minimise distress caused to participants and ensure they discussed their experiences in their own words, rather than being led by mention of anxiety. If distress was experienced by the participants during interview, psychological support services within the hospital were available and the teenager could be referred for further follow-up if they wanted to.

Safeguarding teenagers was of paramount importance when conducting our research. The United Nations Convention on the Rights of the Child (1989) express children's right to be actively involved in matters which affect their lives (The United Nations 1989). This includes their rights to participate, freedom to express their opinions and be involved in decision making (Bailey et al. 2015, Twycross and Smith 2017). Appreciating the importance of hearing the teenager's voice, it is important to acknowledge the undeniable inherent hierarchy of adult and teenager and researcher and participant within this study (Holland et al. 2010). The desirable notion of symmetrical reciprocity as discussed by Benhabib (1992) means that there is equality of role and power in these interactions. Having met all the teenage participants previously in a friendly interaction without pressure, together with reassurance about the confidentiality of what they shared, recognition of their expertise in this situation and encouragement to share only what they felt comfortable to share helped to make these interviews as relaxed as possible and to reduce any power imbalance. Despite the researcher (EB) directing the interview by asking questions, teenagers had the power to stop the interview or move on from questions they felt uncomfortable with. The interview guide is available in Figure 2.

Analysis

Descriptive statistics were used to characterise the sample, The Wilcoxon Signed Rank test was used to compare the two dependent samples (HADS-A-1+2 scores) to assess for significant differences. For qualitative data, interview transcripts were thematically analysed by the lead author (EB) using an inductive and reflexive approach detailed by (Braun et al. 2019). Data were first coded by EB, then reviewed and discussed as a team. A coding framework was developed; codes and themes were refined jointly with a university supervisor. Theme development was led by EB but discussed and refined with university supervisors who had experience with qualitative data analysis.

Ethical and research approvals

This study was granted approval by the London City and East NHS Research Ethics Committee (18/LO/0064).

Results

Of 44 teenagers who met inclusion criteria, 19 (43%) consented to participate although one did not complete the HADS-A-1 in the allocated timeframe, resulting in 18 teenagers participating in phase one (Figure 1). Demographics and anxiety scores are shown in Table 2.

The HADS-A-1 was completed by 18 teenagers 48-96 hours after PICU discharge and 9 teenagers four weeks after PICU discharge. At 48 – 96 hours after PICU discharge nine teenagers had no anxiety symptoms, 3 had mild, 2 had moderate and 4 had severe anxiety symptoms. Two of the four who had severe symptoms of anxiety had previous admissions to PICU. All 9 teenagers who provided data four weeks after PICU discharge indicated no anxiety symptoms. Of nine teenagers who only completed HADS-A-1 at 48-96 hours after PICU discharge, 5 had no anxiety symptoms, 1 had mild, 1 had moderate and 2 had severe symptoms.

Qualitative Findings

Nine teenagers were interviewed, and demographic data is available in Table Two. Three were interviewed by telephone and six face to face. All teenagers had some memories of their time on PICU, some more detailed than others. From these memories three themes were identified, and quotes for each are provided in Table 3.

Memories of treatments, side effects and the PICU environment.

Experiences of teenagers were narrated around their experiences of 'waking up' and being a patient on PICU. This experience was contextualised by the high technology environment and was interpreted as negatively influencing their feelings of anxiety.

Elective patients all had some preparation for surgery and knew that they would wake up on PICU, although none made a visit to see this environment before admission. Expectations of this environment were often worse than reality. In contrast, teenagers who were admitted as an emergency reported the PICU environment frightening, with the sound of people talking around them, alarms and noises of machines experienced as confronting. Regarding the high technology PICU environment, participants made frequent reference to their experience of being attached to tubes and wires. Whilst these were understood as a vital part of recovery, they were the cause of serious discomfort, irritation, and a feeling of being restricted. Teenagers described some procedures and invasive equipment using extreme similes such as "stabbing" (describing line insertions) "being electrocuted in the heart" (pacing) and "suffocating" (being awake with an endotracheal tube), highlighting the traumatic nature of these experiences.

All participants learnt retrospectively that they received some form of sedative and pain relief before waking up on PICU. Upon 'waking', participants remembered being able to hear and make sense of what was being said before they were able to verbalise or communicate their needs. Being able to understand but not action a response led to teenagers feeling "trapped in their own body" and highly "vulnerable". Sometimes conversations were overheard by teenagers relating to other patients or events on PICU, which were experienced as distressing. While medicines for pain and sedation were understood to help the teenager feel calm and more able to cope with their situation, these same medications were also understood to be a cause of highly distressing delirium and hallucinations. These memories led participants to question which experiences were real and which were formed through hallucinations. Emotions related to these hallucinations caused obvious distress for two participants during their interviews despite their scores on the HADS-A-2 being below the clinical cut-off at this time.

Loss of a sense of self

Most participants described feeling as if they were back to their "usual selves" by four weeks after their PICU admission. This sense of self can be understood as having been disrupted in the unfamiliar and hostile environment of PICU. This disruption of sense of self occurred in three main ways.

First, participants experienced a loss of independence during their PICU stay leading to intense feelings of vulnerability. These feelings were especially apparent for those teenagers who had elective surgery: they transitioned from what they described as being independent or "normal" to feeling unable to manage or "needy" after their operation.

Secondly, teenagers found a lack of privacy in the PICU environment difficult to come to terms with. Participants found it difficult to accept help with personal care and felt embarrassed during these intimate routines. Due to one-to-one nursing on PICU, privacy from nursing staff was detailed as impossible at times. In contrast, teenagers were reassured by a nurse's presence.

Finally, participants in this study described pain they experienced as adding to their feelings of vulnerability and loss of independence. While pain was recognised as an anticipated part of their illness, with one teenager pointing out that: "there is no way you can have open heart surgery without expecting a bit of pain", the actual experience of pain led to their body feeling "so different" and dislocated from what they felt was normal. Changes in their levels of pain were also experienced as a cause for concern. Participants explained that they were unsure if this pain was "normal" or if it represented something being wrong further adding to feelings of "worry".

Feeling cared for

All teenagers interviewed also had support during their stay from family members. Recognising difficulties discussed above, it is unsurprising that care provided to teenagers by staff and their family was invaluable for mitigating some of these traumatic effects. All teenagers found their proximity to a nurse on PICU reassuring. One-to-one nursing lent itself to questions and problems being quickly addressed, which participants found especially important when they were in pain or felt worried. Nursing staff were described as “nice, kind and intuitive”. The informal communication style of staff was appreciated by teenagers, to facilitate their understanding of what was happening to them, mitigating some distress described previously.

In addition to formal forms of staff support, teenagers valued the presence of their parents, family, and friends, providing reassurance and comfort during their stay. The ability for family to visit as much as they wanted was praised by participants as a supportive mechanism. In turn, having social and familial support helped to reaffirm the sense of self that had been disrupted. All participants spoke about their families filling in memory gaps about their PICU trajectory, with one teenager’s parent keeping a diary of events and most parents taking photos. Families helped participants to orientate themselves to time and place and parents helped them to understand more difficult aspects of their PICU journey including hallucinations, emergency surgeries, cardiac arrests and complications associated with their illness. This information helped teenagers to “piece things together” which was a term to describe filling in memory gaps or understanding their illness course. This was valued as an important part of recovery and more important after leaving hospital when life returned to normal.

Discussion

Anxiety symptoms among teenagers after a PICU discharge have been poorly studied and available research is dated. We found that half of the teenagers in this study reported some anxiety on the HADS-A-1. However, at four weeks no participants had symptoms of anxiety which were above the specified cut off on the HADS-A-2. Interestingly, narrative shared during interviews often referred to memories or experiences which were distressing and potentially anxiety provoking. Teenagers did not use the term ‘anxiety’ but described similar feelings such as nerves, fear or worry. This further confounds the complexity of these feelings, how teenagers described them and how other terms used fit into the clinical term anxiety. Recall of their experiences after discharge caused visible distress for some teenagers.

Themes identified from narrative reconstruction of critical illness in our study had similarities to findings with adults in intensive care (Egerod et al. 2015). The three themes: memories of treatments, side effects and the PICU environment; loss of a sense of self; and feeling cared for

illustrate the complex nature of experiencing a critical illness and how the environment and people involved contextualise this experience. The state of being unconscious denies intensive care patients their temporality leading to confusion and lack of clarity about what happened to them which can cause considerable distress (Tembo 2017). The term biographical disruption has been used to explain how critical illness can stop life progression and negatively impact a person's hopes for their future. This is an especially turbulent time for teenagers; they are navigating their psychological development whilst piecing back together their journey through critical illness and recovery. Acknowledging the loss of sense of self identified from participants' narratives may help professionals to recognise that teenagers need support navigating this during recovery.

It is unsurprising that anxiety exists within this population; vulnerability, pain, procedures, treatments, hallucinations, emotions and facing the risk of poor quality of life or death have been defined as medical trauma (Marsac et al. 2014). Other qualitative studies have identified similar findings where teenagers recalled experiences they described as anxiety provoking (Colville et al. 2008). Around 25% of children and teenagers have been reported to demonstrate psychological and behavioral difficulties and their emotional wellbeing was negatively affected in the first year after their discharge from a PICU (Davydow et al. 2010, Rennick and Rashotte 2009). Regardless of the reason for admission to PICU, the nature of this environment, and the care required by critically ill patients is serious. Some teenagers described their PICU journey by making jokes and flippant remarks about how difficult it may have been or complications they experienced. Minimising is often a way that people cope with difficult situations (Patallo and Wadsworth 2019).

Teenagers shared their experiences and perspectives to enable healthcare workers to gain a better insight into the overall outcome. This represents rich data that would have not been available from just collecting quantitative data. A high or low anxiety score may give information to a clinician about a teenager's anxiety but may not reflect how a teenager experienced their critical illness and recovery (Khangura et al. 2015). Understanding how teenagers make sense of the impact of critical illness within a social context is vital (Meisel and Karlawish 2011).

Although more research is emerging about the psychological outcomes of children and teenagers leaving PICU after a critical illness or major surgery (Herrup et al. 2017, Manning et al. 2014, Manning et al. 2018a) the provision of care and follow up after PICU discharge is poor (Aspesberro et al. 2015, Manning et al. 2020). With the development of a theoretical framework focusing on Post Intensive Care Syndrome in paediatrics (PICS-p) (Manning et al. 2018b) there is increased interest and awareness about psychological health and focusing on this as a priority for future research

(Manning et al. 2020). The adult field of research on Post Intensive Care Syndrome research is more developed and much more is required to better understand this phenomenon in the paediatric and teenage population (Fink and Watson 2018).

Limitations

Small sample size and single centre recruitment limited the ability to generalise these results to a wider population. A larger sample size would have provided enough power to explore the relationship between key demographic characteristics and anxiety scores.

After providing study information to teenagers and families it was a challenge to ensure they didn't exceed 48-96hrs after PICU discharge. As a lone researcher it was not possible to be present on the hospital site each day. It was also a challenge to find the right time to approach families about research if they were receiving personal cares, in pain or having contact with other members of the MDT. This may explain the high rate of breaching time scales before recruitment, something which could be mitigated with a larger research team.

Of note, the attrition rate in the study was 36% which is not dissimilar from other studies with teenagers who reported about 30% (Farris et al. 2020). Contributory factors are likely to include our geographically dispersed population and loss of some participants when they were discharged to local hospitals. External access to medical records was outside of our ethical permissions so follow up relied upon parental or teenager contact. Four teenagers who had symptoms of anxiety at time point one did not complete the HADS-A-2. It is not known if these symptoms of anxiety reduced over time or if they persisted. Some teenagers lost contact; others withdrew explaining that they wanted to put their PICU experience behind them.

Seventy-seven patients were screened for eligibility; of those who were not eligible, many with a learning disability could have contributed to the interview component but would not have been able to score their anxiety using the HADS-A. Some parents of teenagers felt that yes/no answers would have been manageable but questions asking about the degree of a feeling were complex concepts. Lack of funding meant that no translations of the scales or the ability to undertake the interview in a language other than English were limitations.

Another limitation is the absence of a baseline anxiety score; this would have been impossible for emergency patients but may be useful for future research observing state/trait anxiety in the elective PICU admissions cohorts.

Implications and recommendations for Practice

The findings highlight that anxiety is an issue for teenagers and signposting them to services for psychological support after discharge is essential. This study has also reiterated the importance of narrative in research, as validated scales do not capture the full story.

Conclusion

Our mixed methods study provides some evidence that anxiety symptoms exist amongst teenagers after a PICU discharge. Limited evidence suggests that these symptoms resolved without intervention four weeks after PICU discharge. Teenagers explained feelings of nervousness, worry and fear in relation to their PICU experience and recall of this time. Considering how they described their anxiety and their visible distress during interviews, this area warrants further investigation on long term outcomes and to ascertain if the development of a Post PICU specific follow up programme would be beneficial.

Acknowledgments

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What is known about the subject?

- Development during the teenage years is complex and rapidly changing which may mean that teenagers' experiences of receiving intensive care treatment and during critical illness are different to those of children or adults.
- There is recognition that some adults experience Post Intensive Care Syndrome (PICS) and there is growing recognition that we need to understand the similarities and differences of PICS in the paediatric intensive care patient population.

What this paper contributes.

- Anxiety symptoms did exist among this small sample of teenagers after a PICU discharge yet these symptoms resolved without intervention four weeks after PICU discharge.
- Teenagers explained feelings of nervousness, worry and fear in relation to their PICU experience and recall of this time. Qualitative data collected for this study suggests that research observing longitudinal outcomes would be beneficial.

Table 1 – Inclusion and exclusion criteria

<u>Inclusion criteria</u>	• Aged 13-18 years • Elective or Emergency admission to PICU • >24-hour admission to PICU • Conscious and orientated to time and place (time and place of consent)
<u>Exclusion criteria</u>	• Any cognitive abilities which may prevent them being able to fully articulate feeling and emotions and the ability to self-report on the HADS. • • Disagreement relating to study participation between the young person and their parent/guardian • Young person on any palliative care pathway

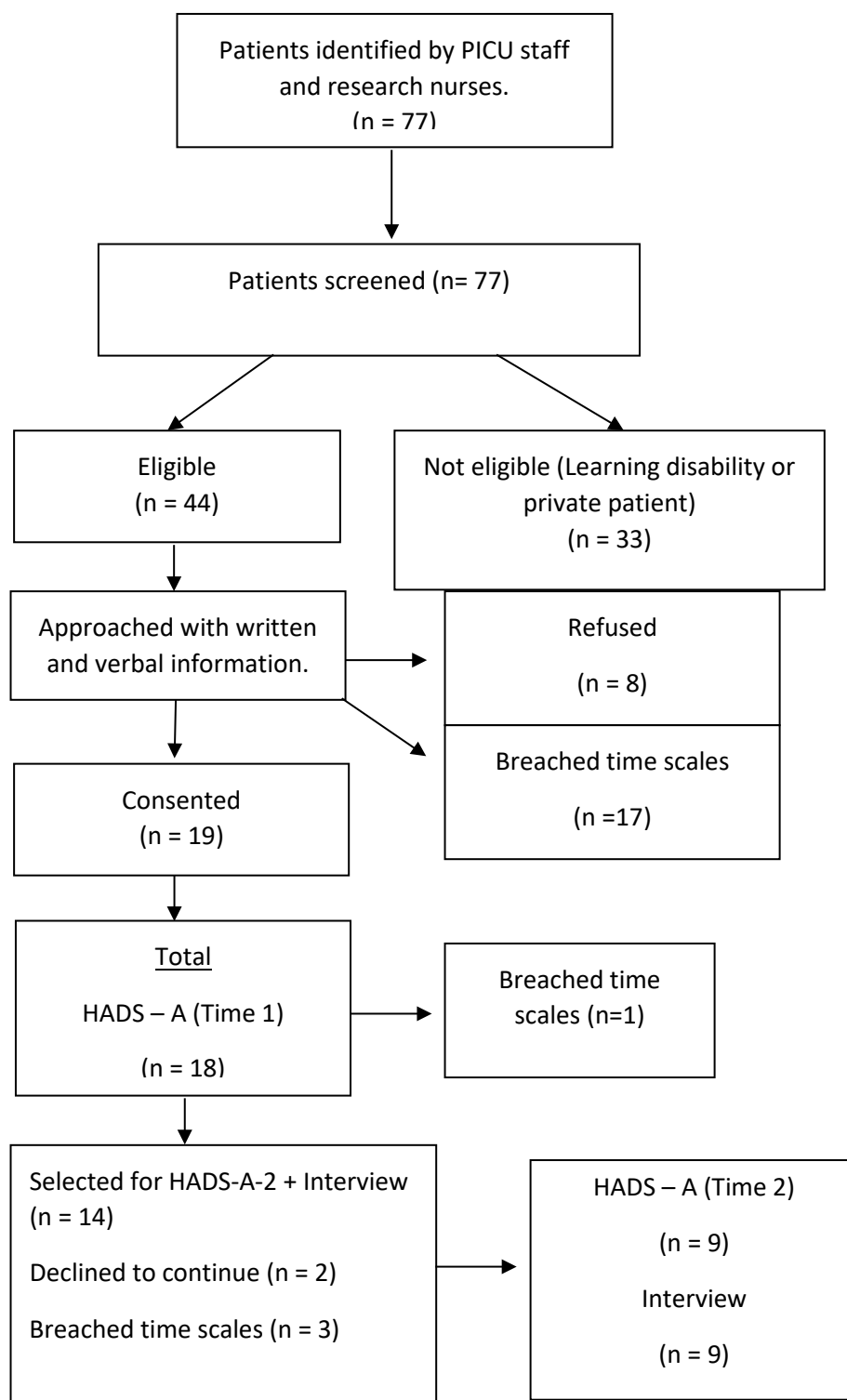


Figure 1 - Study recruitment flow chart

Table 2 – Demographic details and anxiety scores of participants

Time Point 1 (48-96 hrs after PICU discharge)			
		Anxiety Score	P value
Gender	n= (%)		
Male	12 (64)	M=4/Range 2-17	
Female	6 (36)	M=9/Range 5-17	0.57
Age (years)	Median/Range		
	M=16/13-18 years		
Ethnicity			
White British	13 (72)		
Any other White background	1 (6)		
Black British	1 (6)		
Asian Bangladeshi	1 (6)		
Asian Pakistani	1 (6)		
Asian British	1 (6)		
Diagnostic Group			
Cardiovascular	10 (55)		
Respiratory	2 (11)		
Neurological	1 (6)		
Musculoskeletal	3 (17)		
Oncology	1 (6)		
Blood/Lymphatic	1 (6)		
Previous PICU admission	n= (%)		
Yes	6 (21)	M=8/Range 4-17	
No	12 (43)	M=6/Range 2-16	0.047
Admission Category	n = (%)		
Elective	6 (33)	M=6/Range 2-17	
Emergency	12 (67)	M=8/Range 4-16	0.71
Length of stay (Days)	Median/Range		
	16/1-30		
PIM3	n= (%)		
<1%	10 (55)	M=7.0/Range 2-17	
1-5%	6 (33)	M=8.0/Range 5-11	
5-15%	1 (6)	16	
15-30%	1 (6)	4	
HADS-A – 1	n= (%)		
<7 Non case	9 (50)	M=4.0/Range 2-7	
8-10 Mild	3 (17)	M=8.0/Range 8-10	

11-14 Moderate	2 (11)	M=11.5/Range 11-12	
15-21 Severe	4 (22)	M=16.0/Range 5-17	
Time Point 2 (4 weeks after PICU discharge)		Anxiety Score	P Value
Gender	n= (%)		
Male	6 (67)	M= 6/Range 3-7	
Female	3 (33)	M=5/Range 5-7	
Age (Years)	Median/Range		
	14/13-18		
Ethnicity			
White British	6 (67)		
Asian Bangladeshi	1 (11)		
Asian Pakistani	1 (11)		
Asian British	1 (11)		
Diagnostic Group			
Cardiovascular	6(67)		
Neurological	1 (11)		
Musculoskeletal	2 (22)		
Blood/Lymphatic	1 (6)		
Previous PICU admission	n= (%)		
Yes	4(44)	M=6/Range 5-7	
No	5(56)	M=5/Range 3-5	
Admission Category	n= (%)		
Elective	5(56)	M=6/Range 5-7	
Emergency	4(44)	M=6/Range 3-7	
Length of Stay (Days)	Median/Range		
	5/1-25		
PIM3	n= (%)		
<1%	2(22)	Range 5-7	
1-5%	5(56)	M=6/Range 5-7	
5-15%	1(11)	Anxiety Score = 6	
15-30%	1(11)	3	
HADS-A 2	n= (%)		
<7 Non case	9 (100)	M=5.0/Range 3-7	0.03

Pediatric Index of Mortality 3 – PIM3; Hospital Anxiety and Depression Scale (Anxiety scale only) 48-96 hours after PICU discharge – HADS-A-1; Hospital Anxiety and Depression Scale (Anxiety scale only) four weeks after PICU discharge – HADS-A-2; M=Median

Interview questions and guidance

Could you tell me about your experiences of being admitted on to the PICU?

Can you tell me about what happened before you came to PICU?

Could you tell me about your experiences of staying on the PICU?

- What were your first impressions of PICU?
- What memories stick in your mind?
- What's your first memory after waking up?
- How did you feel waking up?

Could you tell me about the best and worst aspects of being on PICU? – can you give any examples?

What were your experiences of the care provided by staff on the unit?

Are there any members of staff that you remember?

Why were they memorable?

If you could help a young person who is planning a stay on PICU what would you say to them?

What has it been like since leaving PICU?

If you ever had to go to PICU again, what would you like to be different?

Figure 2 – Interview guide

Table 3 – Quotes from teenagers supporting theme development.

Memories of treatments, side effects and the PICU environment.	Uncomfortable memories	<i>"I was just trying to speak but when I figured out that wasn't going to be that easy, I did just resort to physical sign language." Amir</i> <i>"They were talking about a patient who had died, not what you want to hear when you are lying there" Jonathon.</i> <i>"You don't forget everything; you still remember you just get over it." Elizabeth</i>
	Experiencing dreams/nightmares	<i>"I don't like it when my dreams go somewhere where I don't want them to go." Maria</i> <i>"I do remember before when I was on the drugs, I started to not tell the difference between my dreams and reality" Amir</i> <i>"I won't talk about the nightmares because they're gonna make me cry" Fatima</i>
	PICU environment	<i>"ICU was creepy, it felt scary" Florence.</i> <i>"I would describe being there [in PICU] as the hospital equivalent of culture shock" Marcus.</i>
Loss of a sense of self	Putting your life into the hands of others	<i>"I was worried that I might not made it, or something would go wrong." Carlos</i> <i>"I couldn't hear beeping but I saw everyone like crowding around my bed and then the doctor was pumping some oxygen in my lungs because my saturations went down, I was so nervous." Maria</i>
	The importance of privacy and dignity	<i>"I mean, the lack of showers and being washed by the nurses wasn't fun" Jonathon</i> <i>"If something happened, I don't think I'd really want privacy, so yeah I mean I kind of needed them (the nurses)." Amir</i>

	Gravity of pain	<i>"It does get better. It doesn't feel like it at first it feels like you're in pain forever" Laura.</i> <i>"The pain made me feel quite nervous, because I didn't exactly know what it was" Marcus</i>
	Perceptions of lack of choice	<i>"It's got to happen if I want to live." Amir</i> <i>"That's just the way it is, I couldn't see how it could be different" Aiden.</i> <i>"They had a look at my heart and they said "it's actually really bad you will probably die before we can do that (clear the infection)" so I had no choice (about the operation)" Elizabeth</i>
Feeling cared for	Formal support	<i>"I guess the people looking after me made me feel relaxed because I thought, they know exactly what they're doing" Aiden</i> <i>"Having someone near me that I could trust and to have someone that was like there to help or answer any questions I had made me feel quite calm really." Maya</i>
	The importance of communication	<i>"Everyone treated me as if like, I was an adult." Jonathon</i> <i>"But they were kind of just more forward and open and made it like less of a stressful situation" Amir</i>
	Informal support	<i>"Yeah, apparently I was just lying there with my chest open, they did the operation again like on the bed, like dad went to sleep he came back, and they said we are doing another operation and they just did it there and then." Marcus</i> <i>"They've taken photos from since when I was at the other hospital to today, my dad is just been taking pictures since." Carlos</i>

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