

## **Where should critically ill adolescents receive care?**

### **A qualitative interview-based study of perspectives of staff working in Adult and Paediatric Intensive Care Units**

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**ACKNOWLEDGEMENTS:** The authors would particularly like to thank Dr Deborah Easby and Dr Rebecca Appelboam for their support of the study

**FUNDING:** This work was supported by the Great Ormond Street Hospital Children's Charity (Clinical Research Starter Grant V0015). The funders were not involved in data collection, interpretation or reporting.

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#### **ABSTRACT**

**Purpose:** In the UK, critically ill adolescents are treated in either adult or paediatric intensive care units (AICUs or PICUs). This study explores staff perspectives on where and how best to care for this distinct group.

**Materials and Methods:** Semi-structured interviews were conducted with 12 members of staff (3 medical, 6 nursing and 3 allied-health professionals) working in 4 ICUs; 2 general hospital AICUs and 2 tertiary centre-based PICUs in England. Interviews were audio-recorded, transcribed and analysed using Framework Analysis.

**Findings:** One overarching theme was identified, reflecting staff understanding of the term “adolescent”, and this was linked to two further themes, each of which had several subthemes. “Needs of the critically ill adolescent” included medical needs, dignity and privacy; issues around consent; and the impact of intensive care admission.

“Implications for staff” included managing parental presence, and lack of familiarity with, and emotional impact of, dealing with this patient group. Some of these factors are currently better accommodated in adult settings.

**Conclusions:** Decision-making about place of care should take into account the individual circumstances of the patient (e.g. nature of their medical condition and previous experiences, maturity, family preference) and not be based only on age at admission. We should work across disciplines to ensure we can discover, and consistently deliver, best practice to meet the needs of critically ill adolescents.

#### **KEY WORDS:**

critical care; adolescent; staff; qualitative; intensive care units, pediatric

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#### **INTRODUCTION**

In the UK, since the publication of “Framework for the Future” in 1997, Paediatric Intensive Care Unit (PICU) services have been centralised with a recommended minimum age for admission to an Adult Intensive Care Unit (AICU) of 16 years[1]. The aim of centralisation was to achieve better medical outcomes for critically ill children generally, the vast majority of whom are infants and small children. However, data on the effect of centralisation of critically ill adolescents were not analysed separately and we cannot assume that adolescents, who make up a small proportion of the PICU population, benefit from this policy in the same way.

In other healthcare settings, efforts are being made to improve healthcare delivery to adolescents, recognising that they have distinct needs that differ from those of both adults and younger children[2]. There are strong arguments in favour of dedicated adolescent units for young people who require hospitalisation; adolescents feel out of place in both adult and paediatric settings[3]. Outside of critical care, adolescents may receive care in specialist adolescent units and/or from specialists in adolescent medicine, particularly if they have a chronic condition. However, dedicated adolescent wards are not practical in intensive care as a low-volume, high-acuity speciality. Even where guidelines and recommendations for the provision of health services to adolescents have been developed[4], particularly for some specific conditions such as cancer, there is huge variation in how and where services are provided. To date, the focus has been on transition from paediatric to adult services and views of stakeholders, including staff, have primarily been reported in relation to elements of the transition

process rather than on their perceptions of where adolescents should receive inpatient care.

4500 adolescents (aged 12-19 years) are admitted to adult or paediatric intensive care units in the UK every year[5]. Although there have been attempts to improve care for adolescents in PICUs[6], we do not know how best to meet their needs and those of their families. In addition, the views of staff, adolescents and their parents can give us insight into what high quality care looks like[7-12]. A particular challenge to involving critically ill adolescents in decisions related to their care is that they may be too ill to take in information and be party to decision-making[13].

Adolescence covers an age range during which a young person develops from a child into an adult; it is not clear whether a single age cut-off can be used to decide which adolescents might be more appropriately treated in an AICU, particularly where PICU admission might require inter-hospital transport over significant distances. Treatment of appropriate adolescents in an AICU environment would both avoid moving the young person and their family away from local services and support networks and provide more flexibility for PICU networks in times of high demand.

In order to meet the needs of these young people, however, staff on AICU would need to be willing and able to develop specific skill sets appropriate to this adolescent population (for example, scaling medication doses according to patient size, taking account of differing legal, including consent, and safeguarding considerations).

In this study, our objective was to explore staff perspectives regarding both the optimal environment (AICU or PICU) in which to care for critically ill adolescents, and the implications for staff providing care to this distinct group of patients.

## **MATERIALS AND METHODS**

We undertook a qualitative study underpinned by an interpretivist framework, which placed emphasis on exploring and understanding the care of critically ill adolescents from multiple perspectives. Reported here are the views of a range of healthcare professionals with expert knowledge and experience of what it is like to care for adolescents in adult or paediatric intensive care units.

### **Settings and Participants**

A purposive sampling frame, ensuring a mixed representative sample, was used to recruit medical, nursing and allied-health professionals working in 4 ICUs; 2 General Hospital AICUs and 2 PICUs in England.

Sites were chosen which firstly had at least 12 emergency admissions of adolescents in the previous 12 months and secondly to represent different geographical regions. Both PICUs represented treat a mixed caseload of cardiac and general intensive care patients. One is a large split unit with a total of 1800 admissions annually, the other a combined unit with 800 admissions annually. Each adult ICU was in the area served by one of the PICUs (so were in different geographical regions of England); they have 20 and 10 intensive care beds respectively. ~~Use of different sites and participants from different staff groups allowed triangulation of data to improve credibility.~~

Lead clinicians were sent study information to share with their teams and participants then contacted the research team directly to take part if they were interested. Ethical approval was granted from the South West – Central Bristol ethics committee (Ref 14/SW/1131). Written informed consent was obtained.

## Data Collection and Analysis

Interviews were performed by a single researcher (a female social scientist with experience of interviewing ICU patients/families). Each lasted 30-60 minutes and took place in quiet rooms across the hospital or by telephone using topic guides (Appendix 1) developed by consensus among the study team, all of whom were experienced researchers and/or intensive care clinicians.

Interviews were recorded and transcribed verbatim (identifiable data were removed). Qualitative data were analysed using the Framework approach[14], which provides a systematic model for mapping and managing the data and is particularly suited to analysis of interview data involving multiple researchers. The Framework approach enables data to be compared and contrasted by themes across multiple cases but also retains the connections to other aspects of a participant's account. It also emphasises the importance of both *a priori* issues as well as themes from the emergent data in the development of the analytic framework. The process involves five stages:

familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation[15]. During analysis a series of "frameworks" or grids were constructed, into which the summarised qualitative data were entered under descriptive headings.

~~These headings were independently generated and agreed by three members of the research team after careful reading of the transcripts, allowing investigator triangulation and ensuring confirmability.~~ Data from each transcript were individually entered into the framework, key themes were extracted from the completed frameworks and the relationships between the themes explored. SG undertook the primary data analysis and themes were checked and validated by JW, any disagreement was resolved by discussion. ~~Records of all stages of the analysis process, including meeting notes and documentation about decision-making, were kept throughout the study.~~ An extract from one of the charts is provided in Table 1.

## **Trustworthiness and Rigour**

We used a purposive sampling frame to ensure a mixed representative sample within a relatively small study. Use of different sites and participants from different staff groups allowed triangulation of data to improve credibility.

While a single researcher performed all interviews, both development of interview topic guides and the analysis of transcripts involved several members of the research team.

Interviews were transcribed verbatim from recordings, minimising bias from this source. The descriptive headings used in analysis were independently generated and agreed by three members of the research team after careful reading of the transcripts, allowing investigator triangulation.

Records of all stages of the analysis process, including meeting notes and documentation about decision-making, were kept throughout the study to allow confirmability.

## **FINDINGS**

### **Participants**

12 members of staff participated in the study: 6 worked in AICUs (4 in one unit, 2 in the other unit); 6 worked in PICUs (3 in each unit); at least two participants had experience of working in both settings. 6 nurses, 3 consultants and 3 allied health professionals were interviewed. Time working in ICU ranged from 3-20 years with a median of 12 years; all but 3 of the staff were in 'senior' roles (medical consultant, senior allied health professional, charge nurse). To ensure confidentiality, direct quotes were attributed to Staff Participant (S) working in AICU (A) or PICU (P).



One over-arching theme was identified, which reflected staff understanding of the term ‘adolescent’ (‘What are adolescents like?’) (Figure 1) and this was linked to two further themes, each of which had a number of subthemes:

- ‘The needs of critically ill adolescents’ with four subthemes: medical needs, dignity and privacy, issues around consent and minimising the impact of ICU
- ‘Implications for staff’ with three subthemes: parental presence, lack of familiarity and emotional impact.

### **What are adolescents like?**

Staff views on what they understood by the terms “adolescent” or “teenager” were varied and subjective, often reflecting their own experiences, including whether they worked in AICU or PICU settings. Some staff drew upon their own experience of having children:

*“When I was twelve, thirteen, there’s no way I was as mature as my [child]” (S2P).*

Many staff discussed the variation between adolescents of the same age:

*“Some fourteen year olds are a lot more mature than other fourteen year olds but it varies massively” (S7P).*

Some participants noted the effect of being ill on young people’s behaviour:

*“in some ways they fluctuate from being children and adults, and when they are needy, in a difficult position, they tend to go into being children more” (S3P).*

### **The needs of critically ill adolescents**

#### ***Medical Needs***

We identified that the medical needs and the ability to deliver appropriate clinical care were the principal factors in deciding the most appropriate location of care for

adolescents. Staff identified a number of circumstances in which either AICU or PICU may be more appropriate.

For adolescents with complex, on-going needs, or those who require prolonged critical care, it may be more suitable for them to be in the PICU:

*"The only difficulty arises when they've got a progressive disease or they have something where they are critically ill, where they might need prolonged critical care treatment. In that situation, they're probably better in an environment which is used to looking after the long-term critical care of children" (S10A);*

*"There's another group of children who would be better off here [PICU]...if they've got complex [conditions, they might be] better looked after by [a] children's neurologist or if they've got congenital heart disease...so there are other circumstances, which would be better coming here" (S6P).*

Adolescents expected to have short, one-off admissions could receive care in AICU:

*"...it would be wrong to start putting a sixteen, seventeen year old DKA in an ambulance and sending them 100 miles or stopping our [scoliosis] service, when they come here overnight, go back to the ward and are never ventilated. If they are ventilated, we get them off the next day" (S10A);*

*"...if you've got appendicitis or if you've had a skull fracture...then you could be looked after [outside a PICU]..." (S6P)*

If a patient's condition deteriorates then transfer to a PICU from an AICU was considered necessary by one participant:

*"When they get more than one system failure it makes sense to move them onto a PICU because that's what their expertise is in" (S4A).*

Overall, there was consensus that the duration of the admission and complexity of the adolescent's medical needs were key considerations in determining place of care, with

those likely to have prolonged admissions or those with complex medical needs more appropriately cared for in a PICU whilst adolescents with shorter or isolated admissions could be cared for in an AICU.

Most participants felt that decisions on where care is delivered should be assessed on an “individual basis”. Two participants summarised the importance of ensuring appropriate care above any concern over *where* care is delivered:

*“[a guideline] just needs to say, make a plan and if the upshot of that plan is that they're in the wrong place but then we can discuss that afterwards but sort out the child first”* (S6P);  
*“If people are loving and caring and providing safe care...”* (S4A).

### ***Dignity and Privacy***

Dignity and privacy issues were primarily discussed in relation to staffing decisions; where possible assigning a male nurse to a male patient, as well as considering whether parents should be present for certain procedures. Some staff considered their role as that of patient advocate; when patients are awake and can express whether they would like their parents there, and also when they unable to do so. One participant discussed this role:

*“Many of our nursing staff will actually ask them [the parents] to leave the room now, because I think they're aware that obviously, ordinarily, a young person wouldn't ask for their mum to be in the bathroom when they're in having something done”* (S2P).

### ***Issues around consent***

The issue of consent was discussed by a small number of participants working in both AICU and PICU. Some staff in the PICU discussed that their ‘family-centred’ approach may mean that they are too aligned with what parents tell them and want for their child,

of particular relevance to the critical care setting, where patients may be sedated and unable to express their views:

*"...going on to wonder whether, where the rights of the child lie in there and whether, obviously you can't wake them up and ask them..." (S6P).*

One participant talked about their concerns:

*"... paediatricians aren't geared up to treating them as integral beings in a sense, with their own rights, their own views and their own thoughts. I think I've seen that on the unit, when you have a seventeen-year-old who's unwell, quite often the parents want something and we tend to, in this hospital align with what the parents want...it worries me that sometimes we don't align to what the teenager wants" (S3P).*

In contrast, one participant working in AICU stated:

*"ultimately, if they're able to voice a view, then we'll respect their view rather than the parents' view" (S10A).*

### ***Minimising the psychological impact of ICU***

Both AICU and PICU staff spoke about advantages their setting might have for this patient group. Some participants spoke about staff needing a heightened awareness of what is going on around them, to enable them to act as an advocate for their patient:

*"You don't want to make it a more stressful experience by what they're witnessing during their stay" (S11A).*

Participants working in PICUs considered noise levels and sleep as the biggest issues for adolescents. Some of the staff who worked in PICU perceived AICU as a more "daunting" and harder environment for young people, whereas the PICU *"has a friendly atmosphere about it" (S5P)*, perhaps protecting young people more than an AICU. One participant considered that adolescents may be able to relate more to a

paediatric environment: *"they see dolls and teddy bears...but they can remember that...It's [AICU] like no reference point to them; it's not even their parents, it's their grandparents"* (S3P).

Some staff working in AICU felt that it may be a quieter environment, and less overwhelming than PICU where it could be *"quite distressing to see babies that poorly"* (S11A).

One participant working in AICU considered that adolescents may be too sick to be worried about their environment when critically ill, and that as their awareness increases this may be more of an issue.

## **Implications for staff**

### ***Parental Presence***

Staff working in paediatric services believed that support provided for families was holistic in nature, benefiting parental coping and consequently a young person's abilities to cope. Furthermore, the majority of staff working in paediatric settings thought that children's services were better established and equipped to support families than adult services:

*"We're [Paediatric] more family-centred, whereas...they're individual-centred care. So they're looking at the patient, we look at the family"* (S2P).

Several participants used the example of visiting hours to demonstrate the perceived difference between services:

*"I certainly know that on adult wards, they're a lot stricter than on our wards and ... if it means that your family and parents can be with you more than I think it's [PICU] a better environment"* (S7P).

When staff working in AICU talked about their role in supporting families in the AICU, it was evident that parental presence was not typical for their usual patient population:

*"...many nurses are not used to having family, parents there all the time so that's a different concept for them to get used to" (S4A).*

Participants shared different perspectives on parental presence – some staff reported that it was beneficial for communication; others considered that it could negatively affect how much an adolescent engages with treatment and procedures. One participant discussed the role of parents and staff:

*"we tend to do the, sort of, medical management of them, and then the parents are there, really, to do the entertainment and reassurance side as well" (S11A).*

Most staff discussed the importance of facilitating the presence of parents: *"[for] parents – you're anxious whatever age your child is... we have to be a lot more supportive of the teenagers' families...because it's a very anxious time for them" (S8A).*

One participant felt that supporting parents in AICU was an area that could be improved:

*"For some people it is easier if relatives aren't there because it is more hassle and they are obviously questioning what is done reasonably enough...if they don't make it too comfortable then they may not want to stay..." (S12A).*

In terms of visiting hours, most participants working in adult services discussed the flexibility afforded to parents of young people: *"probably about the age of eighteen, when they technically become an adult, then we tend to say, 'Right you have to stick to the*

*visiting hours.' Under eighteen, then, obviously we allow parents in more freely... it depends on why the child's here and what the child's like (S11A)".*

### ***Lack of familiarity***

All staff participants reported that adolescents make up a small proportion of their workload. Participants who worked in AICU reflected that admissions after elective surgery were more common with far fewer emergency admissions and they all specifically mentioned the post-operative care of scoliosis patients. Staff working in PICUs reported that it can be more time consuming to care for adolescents as they require more explanation and may be more demanding than younger children: *"I think from the nursing workload...it [caring for adolescents] definitely has an impact. Everything takes longer. They need more of everything (S7P)".*

Due to their physical size, they may be more difficult to move and drug doses are calculated differently. Staff working in AICUs considered little difference between caring for adolescents and adults in terms of drug doses and size, and were less anxious about caring for adolescents than for smaller children:

*"As soon as staff see somebody in the room [used for caring for children and young people] everybody's blood pressure goes up a bit and then you realise, oh it's a big child, oh that's alright" (S4A).*

### ***Emotional Impact of caring for adolescents on an ICU***

Some staff discussed the emotional impact of caring for critically ill adolescents. Some Paediatric staff felt that it could be more upsetting caring for adolescents as they are able to voice their worries and concerns in a way that younger children are not:

*"it is the questions like when they start waking up and they say to the nursing staff, 'I don't want to do this, I want to die'" (S3P).*

Some staff working in AICUs found caring for adolescents more emotive. One participant described the effect it can have on the unit:

*“we’re so used to adults and not children...There’s always a very different atmosphere on the unit when there’s a child in, everybody’s more subdued” (S9A).*

When an adolescent dies on an adult unit it can be very difficult for staff. Conversely, one participant reflected how caring for adolescents can be positive as they often have greater potential for recovery:

*“it might be worthwhile treating them, rather than your general adult population where you think, ‘Why are we doing this?’” (S10A).*



## **DISCUSSION**

This report of how intensive care staff view caring for critically ill adolescents was part of a larger study which also looked at the views of adolescents and their parents[7]. The main determinant of where staff thought adolescents should be looked after was the setting's ability to deliver appropriate, safe medical care, depending on individual medical and psychosocial needs, and not only on age. Staff from both AICU and PICU identified advantages that their own settings provided for critically ill adolescents, although both described ways in which they had to adapt their usual practice to cater for these patients.

Adolescents are a distinct group, developmentally, psychologically and medically distinct from both children and adults [16]. Staff had differing views about what adolescents are like, invariably reflecting their personal experiences of adolescents, as identified previously[17]. Throughout the interviews the importance of assessing each adolescent as an individual was evident and this related to the themes of both the needs of critically ill adolescents and the implications for staff of caring for them. It also reflects existing guidance on caring for adolescents and for critically ill children[18].

Staff described adolescents' medical and physical needs, which also included dignity and privacy, as well as their psychological needs related to the impact of the environment and how these might be addressed in either the paediatric or adult setting. Previous literature on staff perspectives on caring for hospitalised adolescents is limited, but some similar themes (need for supportive staff, importance of the environment) emerged from a study of staff caring for adolescent patients with cancer[19].

Participants also highlighted the issue of consent. In the UK, there is a legal distinction between incapacitated adolescents aged under 18 (where those with parental

responsibility may consent on their behalf) and those over this age, for whom decisions are made by the healthcare team (usually with input from close relatives, including parents)[20]. Staff in PICUs expressed concerns that there can be a tendency to align with parental wishes; that some paediatric health care professionals are not used to thinking about older teenagers as autonomous individuals with potential capacity to consent, whereas those working in adult settings are more likely to expect adolescents to provide their own consent where feasible.

Although a few previous studies on adolescent care – generally in oncology or mental health - have included staff perspectives, these have mainly been limited to staff opinions on what is important to adolescents rather than the implications for the staff themselves[19, 21-22]. The impact on staff, both in practical and emotional terms, was a prominent theme in our study despite featuring minimally in our interview topic guide (Appendix A). The reasons for this difference are not clear but may reflect methodology rather than real differences in the emotional impact of working in these different clinical areas.

There are some limitations to this study. Firstly, whilst the findings are based on the views of English hospital staff from a range of professional backgrounds, most of whom had considerable experience of working in intensive care settings, it may not reflect the views of less experienced staff. Although differing staff experience was one of the criteria in our sampling matrix, we were unable to recruit any staff who were less experienced whilst ensuring sufficient inclusion of staff from different professional backgrounds and units. Secondly, participants were self-selecting and therefore more highly motivated staff, or those who have a particular interest in this age group, may be overrepresented in the sample; those with less interest in treating this age group may have had markedly different views. Furthermore, the qualitative nature of this small

study, together with the limitations identified with respect to the participants, limits the generalisability of the findings to a wider population of critically ill adolescents, particularly those cared for in differing health-care systems. Whilst some of the results we describe reflect the views of a single participant, we recognise that all of the professionals had expert knowledge that contributed to our overall understanding of where adolescents should be cared for. There are no comparative data on physical morbidity or mortality outcomes between adolescents admitted to PICU or AICU, or on parents' and ex-patients' perspectives on which type of unit better meets their needs, so we are unable to triangulate or sense-check against these data.

## **Conclusions**

It appears that neither the adult nor paediatric clinical environments are entirely appropriate for adolescents. However, even in this relatively small study, staff were able to provide information both on challenges critically ill adolescents pose and ways in which their settings best meet the needs of this patient group. Decision-making about place of treatment should take into account the individual circumstances of the patient (including the longitudinal nature of their condition), the expected duration of critical care and consideration of the needs of the adolescent for specific expertise. In almost any healthcare system, adolescents will continue to be admitted to both AICU and PICU. In addition to the contribution of patients and families, staff views, such as those elicited in this study, are crucial to optimise intensive care for critically ill adolescents.

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## **FIGURES**

Fig 1: Thematic framework derived from staff interviews

# TABLES

Table 1: An extract from one of the charts (Admissions) showing the framework and summarised data from one participant

Participant	Number/frequency	Type of admission	Where should they go?	Age
S111(A)	Don't get big proportion partly because of demographics of the area (P2L9)	Mostly scoliosis children who have come in for routine surgery (P2L11)	15-18 year olds probably better in adult environment than paed's (p6L15); Sticking point is the middle age 12 -15 year olds more difficult because some are younger and more child-like and some are as big as adults.	Quite a big difference between 13, 14 year old and a 15, 16 year old; all different at that age – can get very mature teenagers, some very immature so should be guided by each individual ideally



## **APPENDIX A. Topic guide for staff interviews**

1. What proportion of your time is spent looking after adolescents?
2. In what circumstances would an adolescent come to ICU (adult or child) for care? – are there any specific circumstances?
3. Are there specific policies relating to care of adolescents on the ward? – e.g. visiting times
4. Does your role change when you are looking after an adolescent? How? Are there differences in the how care is given to an adolescent compared to an adult/child?
5. In caring for adolescents on ICU, what aspects of working with them and their families work well? Or not so well? What are the main barriers to supporting adolescents and their families on the ward?
6. What are the needs of adolescent patients and their families? How does this compare to adults/ children on the ward?
7. Do you think there are any benefits to the patient in caring for an adolescent on an adult ICU/ Child ICU? Or their family?
8. Do you think there are any negative consequences for them? Or their family?
9. Thinking back on your most recent experience of caring for an adolescent in ICU, can you describe your experiences in working with the patients, parents and family? [what were the needs of the family, how did you meet these needs] Did you feel that that was the right place for them?
10. Can you describe the impact of having adolescent patients on critical care on staff, other patients in the hospital? Families? Are there cost implications?
11. What is your view on adolescent being cared for in a Paediatric vs adult ICU? What are the issues associated- are there any?