Evaluation of timeliness and models of transporting critically ill children for intensive care: the DEPICT mixed-methods study

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Scientific summary

DEPICT mixed-methods study

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Scientific summary

Background

Intensive care services for children were centralised in the NHS over two decades ago. Each year in England and Wales, nearly 5000 critically ill children and young people (CYP) require transport to receive care in an appropriate setting, such as a paediatric intensive care unit (PICU). The majority of these transfers are performed by nine specialist paediatric critical care transport teams (PCCTs). National clinical audit data from the Paediatric Intensive Care Audit Network (PICANet) reveals wide variation in how quickly PCCTs reach patients, how quickly patients are transported to the PICU, who leads the transport and how frequently critical incidents occur. However, it is not clear whether or not these differences affect clinical outcomes and patient experience for critically ill CYP and their families. It is also not clear how cost-effective PCCTs are and whether or not alternative service models might further improve clinical outcomes while remaining cost-effective.

Objectives

The main aim of the DEPICT (Differences in access to Emergency Paediatric Intensive Care and care during Transport) study was to understand if and how clinical outcomes and experiences of transported critically ill CYP are affected by national variation in the timeliness of access to paediatric intensive care (PIC) and care provided by PCCTs.

The study objectives were to:

1. perform a quantitative analysis using linked national clinical audit data to study the association between timeliness of access to PIC and clinical outcomes
2. perform a quantitative analysis using linked national clinical audit data to study the association between care delivered by PCCTs and clinical outcomes
3. explore, using qualitative methods (i.e. individual interviews and workshops) and questionnaires, the experiences and perspectives of a purposively sampled national cohort of parents of transported critically ill CYP, and, if and where feasible, to use innovative methods to explore the experiences of transported critically ill CYP
4. explore, using qualitative methods (i.e. individual interviews and workshops), the experiences and perspectives of a purposively sampled national cohort of clinicians and service managers
5. perform cost-effectiveness analyses of PCCT provision for critically ill CYP, comparing different service models currently in use
6. use mathematical modelling and location–allocation optimisation methods to explore whether or not alternative cost-effective models of service delivery for PCCTs can improve clinical outcomes
7. synthesise study findings to inform the development of evidence-based national standards of care and information resources for families and clinicians.

Methods

The study followed a mixed-methods study design with four workstreams: a retrospective analysis of linked data from routine national clinical audit and administrative sources (workstream A), a prospective observational study involving administration of questionnaires to parents of transported children, as well as parent, patient and staff interviews (workstream B), health economic evaluation (workstream C) and mathematical modelling (workstream D). Stakeholder workshops were planned to synthesise findings from the four workstreams.

Workstream A

Data sources

A study data set for England and Wales was created by linking record-level data from PICANet, comprising case mix, resource use and outcome information on children transported to PICUs between 1 January 2014 and 31 December 2016, with (1) Intensive Care National Audit & Research Centre case mix programme data on CYP admitted to adult critical care units prior to paediatric transport, (2) Hospital Episode Statistics, comprising administrative and clinical data on acute hospital attendance and admissions from English hospitals (and similar data from Digital Health and Care Wales), and (3) Office for National Statistics mortality data.

Study population

Inclusion

All critically ill CYP (before their 16th birthday) who were transported to a PICU in England and Wales from 1 January 2014 to 31 December 2016.

Exclusion

Critically ill CYP transported by neonatal or local/non-specialist teams and critically ill CYP transported by PCCTs that could not be matched to a corresponding PICU admission.

Outcomes

The primary outcome was mortality within 30 days following PICU admission. Planned secondary outcomes were (1) mortality at PICU discharge, 90 days and 1 year following PICU admission, (2) number of PICU admissions during study period and time to readmission (if applicable), (3) length of stay in PICU, (4) resource use in PICU (i.e. number of days of invasive ventilation, vasoactive agent therapy, renal replacement therapy and extracorporeal life support), (5) length of hospital stay linked to the index PICU admission, (6) number of emergency department (ED) attendances in the 12 months following discharge from PICU and (7) hospital resource use in the 12 months following PICU discharge.

Analysis

Two main statistical models were used for the primary analysis to investigate the impact of (1) timeliness of access to intensive care (i.e. time taken for the PCCT to reach the patient's bedside and time taken for the child to reach the PICU from acceptance of the transport) on 30-day mortality and (2) the care delivered by the PCCT during transport (i.e. seniority of team leader, prolonged vs. short stabilisation approaches and occurrence of critical incidents) on 30-day mortality.

Workstream B

Study population

Parents/guardians of CYP transported to 24 PICUs in England and Wales from January 2018 to January 2019 were approached for consent to participate in the study (including completion of a questionnaire relating to the transport, potential contact 3–6 months later for participation in an interview, contact 12 months later for completion of follow-up questionnaires and linkage of PICANet data on their child's transport to the questionnaire data). Study procedures were developed to encourage participation of bereaved families and of parents whose first language was not English.

Questionnaires

Participants were asked to complete a study questionnaire to collect parents' responses to specific questions regarding their experience before, during and after their child's transport to PICU (relating to arrival of the PCCT, information provided about the transport process, expectations about the transport team and whether or not these were met, and whether or not the family were able to accompany the child in the transport). Paper and electronic versions of the study questionnaire were available in English and five other languages, and there was a 'speak-aloud' version for families with low literacy levels.

Interviews

A purposive sample of parents and health-care staff (i.e. clinicians and managers) were interviewed. Using a sampling matrix to ensure diversity in terms of child's age, diagnosis, distance from referring hospital to PICU, previous use of PCCTs and whether or not parents travelled with the child in the ambulance, we conducted face-to-face or telephone interviews with eligible parents 3–6 months after PICU admission, focusing on what went well, what worked less well and what an optimum retrieval service would look like. Similarly, a stratified sample of clinicians and managers from general hospitals, PCCTs and PICUs were interviewed. Participants were asked to describe a transfer that went well and a transfer that went less well, to discuss the wider impact of the PCCT on the care of other children and services and to describe what they felt an optimal service would look like.

Analysis

Questionnaire data were analysed to study the association between timeliness of access and aspects of care provided by the PCCT with a composite transport satisfaction score. Interview transcripts were entered verbatim into NVivo (QSR International, Warrington, UK) and a framework approach was used to enable thematic analysis of described experiences. Data were compared within cases (i.e. people and PCCTs) and across cases.

Workstream C

Workstream C utilised data from workstreams A and B, supplemented with NHS cost data. The primary outcome measure was number of lives saved in each strategy. The secondary outcome was quality-adjusted life-years (QALYs). For costs, an NHS and Personal Social Services perspective was adopted in the base case, and a societal perspective was adopted in sensitivity analysis. Costs and outcomes were evaluated using several time horizons (i.e. up to 30 days and 1 year following PICU admission, and lifetime). A detailed cost analysis of transport by the PCCT was carried out using travel time, team composition, interventions performed and management of critical incidents, based on workstream A data. Mortality up to 1 year was measured directly in the study (workstream A). Quality of life was assessed at 12 months, measured via proxy assessment by the parent (workstream B), using Health Utilities Index Mark 2, and combined with data on survival to compute QALYs. We produced a patient-level data set of costs and outcomes for every patient in workstream A and used this to analyse the costs and outcomes associated with different PCCT models using regression analysis.

Workstream D

Mathematical modelling and location–allocation optimisation were used to explore the potential impact on efficiency of alternative service models, such as more PCCT locations nationally, more teams at each PCCT location and seasonal allocation of teams to manage winter demand.

Integration of workstream findings

A convergent triangulation study design was used to integrate findings from workstream B with findings from workstream A to generate complementary views of paediatric retrieval with respect to the main research questions. Further integration of study findings from the health economic evaluation and mathematical modelling were attempted at the workshop stage (although this was not completed because of the COVID-19 pandemic).

Results

The study findings are presented in themes, rather than by individual workstreams.

Timeliness of access to a retrieval team (time to bedside)

Transports of 9116 children were included in the analysis. PCCTs reached the patient bedside within 3 hours in > 85% of transports, with very few children waiting for > 4 hours. After adjustment for confounders (i.e. patient age, severity of illness score, diagnosis, whether or not receiving critical care

at referral, size of referring unit and ventilation status at referral), there was no association between time to bedside and 30-day mortality or other secondary outcomes. Questionnaire and interview data showed that, although timeliness mattered to parents, the perception of timeliness (rather than actual time) was associated with higher satisfaction, for example parents were less satisfied when they were not communicated a time frame for the arrival of the team.

Models of care

In adjusted analyses of our linked data sets, the probabilities of 30-day mortality for transports led by junior doctors and advanced nurse practitioners were similar. Consultants had a slightly higher adjusted probability of mortality, although we believe that there was an element of residual confounding, as consultants may be informally triaged for the sickest children. Similarly, although prolonged stabilisation (i.e. more than one major intervention performed by the PCCT) was associated with a slightly higher 30-day mortality, compared with short stabilisation, we believe that remaining differences were also due to residual confounding. The occurrence of a critical incident during transport was not associated with 30-day mortality, but the occurrence of a patient-related critical incident was (adjusted odds ratio 3.07, 95% confidence interval 1.48 to 6.35). Team confidence, more so than a specific team leader grade, was associated with parental satisfaction in workstream B. Effective working relationships between the PCCTs and referring hospitals was identified as a key factor highlighted by parents and staff.

Parental presence in the ambulance

Findings from the questionnaires and interviews showed that the ability of parents to travel in the ambulance was associated with greater satisfaction, especially if both parents were able to travel together. It was also clear that offering the parents the choice, regardless of the choice they actually made, was of greater importance.

Cost-effectiveness of retrieval teams

There was no association between team composition (i.e. team leader grade and grade of most senior nurse) and various cost and outcome measures (i.e. total interventions by the transport team, primary care costs, outpatient and ED costs, family costs, health-related quality of life). We found that some costs were higher and some outcomes were worse when the team leader was a consultant, which may suggest that there was residual confounding that could not be measured by the severity of illness score used in the regression model to account for the patient's acuity.

Mathematical modelling

As there was no evidence of a survival benefit from reduced time to bedside from workstream A, the modelling workstream shifted its focus to study whether or not different team allocations across the current 11 PCCT locations (or a subset) could improve the proportion of children reached within 3 hours. In non-winter periods, a range of different configurations (in terms of numbers of teams/numbers of locations) have very similar performance, although tweaking the allocation of the current 16 teams would lead to some improvements in performance. The annual winter surge in demand could be mitigated by adding three teams across the current 11 PCCT locations (for a total of 19 teams nationally). For a given number of overall teams, reducing the locations to eight tended to give better performance.

Conclusions

We found that variation between retrieval teams in factors such as time to bedside, team composition and stabilisation approach did not affect patient outcomes or experience, whereas patient-related critical incidents and the ability of parents to travel in the ambulance did constitute key areas for service improvement. Team composition has little impact on health-care costs and outcomes. Although commissioned on a regional basis, paediatric retrieval should be considered a national resource and planned as such to maximise the cost-effective delivery of high-quality services, particularly at times of high demand.

Implications for health care

The evidence generated from this study should be used to inform future national standards and quality metrics for PCCTs, particularly related to the time-to-bedside target, parental presence in the ambulance during transport and collection of standardised data on patient/family experience. PCCTs should have a system in place to regularly evaluate patient-related critical incidents to ensure lessons are learnt to minimise a repeat event. Initiatives focusing on improving communication with parents regarding team availability and arrival, staff training to improve confidence of transport team members and building better outreach links with referring hospitals should be supported. Winter surge planning should be done at supraregional level, as well as at a regional level, to improve the efficiency of use of limited transport resources.

Recommendations for research

Future research should consider:

- enhancements to the PICANet transport data set (including exact team composition and patient status at initial referral)
- regular automatic data linkage between PICANet referral, transport and admission events to provide rich clinical data on the critically ill child pathway
- development and/or refinement of risk-adjustment tools for use in PIC and transport research
- development and validation of a taxonomy of critical incidents during transport that can be used to collect standardised data for international benchmarking exercises
- validation of the short patient/parent experience questionnaire developed in this study to facilitate a single standardised patient-reported experience measure for paediatric critical care transport
- factors that inhibit and promote effective communication and points in the transport process where effective communication is most important
- how best to involve critically ill children in future research.

Trial registration

This trial is registered as ClinicalTrials.gov NCT03520192.

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