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Parental perspectives on the transfer process for critically ill children

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BRIEF ORIGINAL RESEARCH

Parental perspectives on the transfer process for critically ill children

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Abstract

Objective To understand parental stressors and identify potential stress-mitigators during interfacility transfer of critically ill children.

Methods Descriptive qualitative multi-case study using semi-structured interviews. This study involved caregivers of patients admitted to the Paediatric Critical Care Unit at Children's Hospital, London Health Sciences Centre transported from outlying hospitals. Study participants were recruited through purposeful sampling. Interviews were recorded, transcribed verbatim and manually de-identified. Coding was performed by two independent coders using a standard method of content analysis to identify common themes.

Results Themes were identified and reached saturation after twelve interviews were completed. Children were admitted primarily from Northwestern and Southwestern Ontario, at distances ranging from 36 to 1146 km. Sixty-seven percent were transported by ground and 33% were transported by air ambulance. We identified stressors (patient pain and discomfort on transport, separation anxiety, feeling of being uninvolved, general anxiety about transport, cost and logistics of return trip home, lack of support systems/loneliness and leaving other family members behind) and stress-mitigators (parental accompaniment, immediate access to the child at accepting facility, parental involvement in care/comfort, support systems – other families in hospital, support systems – staff, communication with the parents/caregivers and trust toward the transport team) associated with the transport process.

Conclusions The current study identified important parent perspectives regarding the transfer of critically ill children. We recommend that stakeholders at referral centres, transport services and accepting facilities examine their current standards regarding transport processes to ensure relevant mitigators are incorporated into their programs to improve the transport experience for critically ill children and their families.

Keywords Paediatric · Transportation of patients · Parental accompaniment · Parental stress · Mitigators

Résumé

Objectif Comprendre les facteurs de stress des parents et identifier les facteurs de stress potentiels pendant le transfert inter-hospitalier d'enfants gravement malades.

Méthodes Étude qualitative multi-cas descriptive à l'aide d'entretiens semi-structurés. Cette étude a porté sur les aidants de patients admis dans l'unité de soins intensifs pédiatriques de l'hôpital pour enfants du London Health Sciences Centre et transportés depuis des hôpitaux périphériques. Les participants à l'étude ont été recrutés au moyen d'un échantillonnage ciblé. Les entretiens ont été enregistrés, transcrits mot à mot et dépersonnalisés manuellement. Le codage a été effectué par deux codeurs indépendants utilisant une méthode standard d'analyse de contenu pour identifier les thèmes communs.

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Résultats Des thèmes ont été identifiés et ont atteint la saturation après la réalisation de douze entretiens. Les enfants ont été admis principalement du Nord-Ouest et du Sud-Ouest de l'Ontario, à des distances allant de 36 à 1 146 kilomètres. Soixante-sept pour cent ont été transportés par voie terrestre et 33 % par ambulance aérienne. Nous avons identifié les facteurs de stress (douleur et inconfort du patient pendant le transport, anxiété de la séparation, sentiment de ne pas être impliqué, anxiété générale concernant le transport, coût et logistique du retour à la maison, manque de systèmes de soutien, solitude et abandon d'autres membres de la famille) et les facteurs d'atténuation du stress (accompagnement parental, accès immédiat à l'enfant dans l'établissement d'accueil, implication des parents dans les soins/le confort, systèmes de soutien – autres familles à l'hôpital, systèmes de soutien – personnel, communication avec les parents/aidants et confiance envers l'équipe de transport) associés au processus de transport.

Conclusions La présente étude a identifié d'importants points de vue des parents concernant le transfert d'enfants gravement malades. Nous recommandons aux parties prenantes des centres d'aiguillage, des services de transport et des établissements d'accueil d'examiner leurs normes actuelles concernant les processus de transport afin de s'assurer que des mesures d'atténuation pertinentes sont intégrées dans leurs programmes pour améliorer l'expérience de transport des enfants gravement malades et de leurs familles.

Clinician's capsule

What is known about the topic?

Despite known advantages, parental accompaniment during critical care paediatric interfacility transfer continues to be debated by healthcare and transport providers.

What did this study ask?

What are parents' perspectives regarding the entirety of the critical care interfacility transfer process, from referral centre to accepting facility?

What did this study find?

This study identified parental stressors experienced throughout the transfer process, and potential stress mitigators that could improve the experience.

Why does this study matter to clinicians?

Identifying parental stressors and stress-mitigators relating to paediatric interfacility transfer processes could improve the experience for children and their families.

Introduction

Due to the centralization of paediatric critical care, the interfacility transfer of critically ill children is a necessity. A recent survey determined that children, parents, and healthcare professionals thought it was important that parents have the opportunity to accompany their child on transport (84, 100, and 79% respectively) [1]. Generally, parents choose to accompany their children (71%). Parental presence may be advantageous for emotional comfort, anxiety reduction for patient and parent, parent satisfaction and improved cooperation from the child [2–7]. Despite this, some transport providers are reluctant to have parents aboard. In instances where parents were not allowed to accompany their child on transport, 26% reported feeling unwelcome by the transport team [4].

There is a paucity of literature describing patient and family perspectives regarding the transfer process, from referral to arrival at a paediatric critical care unit. We conducted a prospective, qualitative study to understand parental perspectives on all aspects of the transfer process to identify parental stressors and potential stress-mitigators.

Methods

This was a descriptive, qualitative multi-case study that used semi-structured interviews. The interview guide was developed by the study team and was reviewed by a study parent advisor. To ensure consistency, all interviews were conducted by the same investigator. This study was approved by the Western University Research Ethics Board and conducted in accordance with Canadian standards of Good Clinical Practice.

Study setting

Participants were caregivers of patients admitted to the Paediatric Critical Care Unit at Children's Hospital, London Health Sciences Centre (CH-LHSC) transported by either a hospital-based transport team (paediatric critical care trained registered nurse/respiratory therapist) or a regional critical care team with paramedic providers.

Study design

Purposeful sampling was utilized to achieve maximal variation in patient demographics, including varied ages, geographies, transport lengths and modes. Families were approached regarding study participation during their inpatient stay once nursing staff felt it was appropriate; at least one caregiver per family was included.

Written informed consent was obtained from participants by the Research Coordinator prior to study participation.

Interviews were conducted either at patient beside or a private location within the hospital according to family preference once they felt emotionally prepared. Interviews were recorded using digital recording software on a tablet device. The research team performed verbatim transcription of the interviews, which were manually de-identified. NVivo 12 Pro was used to code the qualitative data. Coding was performed by the investigators independently using content analysis to identify and quantify themes until saturation was achieved.

Results

Themes were identified and reached saturation after twelve interviews. The children of the parents who were interviewed ranged in age from 0 to 16 years. Fifty percent of the children were male. None of the children died during hospitalization. The diagnoses of the children were respiratory (67%), neurological (17%), overdose (8%), and gastrointestinal (8%). Children were admitted from distances ranging from 36 to 1146 km. Sixty-seven percent were transported by ground, and 33% were transported by air ambulance. Three interviews were conducted with a mother and father, and the rest were only mothers (only one parent available).

Seven (58%) participants accompanied their child on transport (all mothers). Two participants chose not to accompany their child, two were unable to due to space restrictions in the transport vehicle and one was not provided the option. Parents who chose not to accompany their child stated that they wanted time to go home and pack or to take care of issues (e.g., pet-care).

Overwhelmingly, parents were relieved to have their child transported to a hospital with a higher level of care, indicating that their main priority was ensuring their child received appropriate care and that they get better. Eleven parents indicated that inadequate expertise or resources at the referral site was the primary reason for their child's transport. Two parents cited that there were geographically closer Paediatric Critical Care Units that could not accommodate them due to census. Three parents of children with chronic medical conditions regretted they were not accommodated at a hospital where their child is regularly a patient due to staff familiarity and pre-existing support systems.

Parents of children with complex medical conditions, with previous transport experience, emphasized the importance of a specialized paediatric critical care transport team. They also noted that their previous transports impacted their most recent transport experience. One parent recalled a previous transport where they felt unwelcome by the transport team, which increased their apprehension prior to the recent transport.

While parents reported generally positive transport experiences, stress was a universally shared experience. We classified the sources of stress as related to the transport itself or related to the admission of their child to the Paediatric Critical Care Unit (Table 1, Online Resource). Parents also identified several ways they felt their stress could be mitigated (Table 1, Online Resource).

Table 1 Stressors and stress-mitigators identified by families throughout the transport process

Stressors
Transport related stressors
Patient pain and discomfort on transport
Separation anxiety
Parental feeling of being uninvolved
General anxiety about transport
Cost and logistics of return trip home
Admission related stressors
Lack of Support Systems/Loneliness
Leaving other family members behind
Mitigators
Parental accompaniment
Immediate access to child at accepting facility
Parental involvement in care/comfort
Facilitate communication with family
Support systems—other families in hospital
Support systems—staff
Communication
Trust toward transport team

Discussion

Interpretation of findings

This study provides an overview of parental perspectives regarding the entirety of the interfacility, paediatric critical care transfer process. Of particular interest to all paediatric healthcare providers, is the novel identification of parental stress-mitigators, relevant to referral centres, transport services, and accepting facilities, respectively.

Positive communication needs to begin at the referral centre [8], including expressed confidence in the transport team and accepting facility. Anticipatory guidance about the transfer may mitigate parental stress. This study supported previous findings that parent's perception of competence and technical proficiency of the transport team can affect parental perception of care, stress, and anxiety [8]. Involving parents in the transport process may also mitigate parental stress. Parents may be asked how their child indicates discomfort (e.g., specific behaviours/signs)

and be given a simple task. When a parent is unable to accompany the child, the transport team should identify a means of communicating with the family on route and situations where communication cannot be facilitated. Transport team members should determine if parents have had any previous experience with medical transport and any lingering concerns should be addressed.

Upon arrival to the Paediatric Critical Care Unit, parents can be overwhelmed and distressed, especially if they must wait to see their child or if they arrive before their child [7]. We suggest that families are made aware of support resources, repatriation programs, available parking, and housing options.

Previous studies

While many parents expressed their desire to accompany their child, as previously documented in the literature [4, 6, 9], the predominant priority was the safe and efficient transfer of their child to a centre that specialized in paediatric critical care and, thus, was better equipped with personnel and resources to provide optimal care than their local community hospital. Supporting previous work, our study identified stressors experienced by families concerning the transport of their child to a tertiary care facility. We also uncovered stress-mitigators that families identified to improve the transport process.

Strengths and limitations

This study provides a detailed overview on the parental perspective regarding the entirety of the transport process and enhances the existing literature. There are limitations to this study. This is a single centre study, which may limit generalizability. The purpose of this study was to compile a rich composite of parental perspectives from varied interfacility transfer experiences and was not designed to facilitate comparative analysis of experiences between patient groups. It is possible that parents experienced recall bias; however, we were interested in parents' residual perspectives rather than the accuracy of their event recollection. Non-accompanying parents were invited to participate, but their participation varied. Their presence or absence, respectively, may have affected parental narratives, and for families with only one parent available, we inquired of the other parent's experience to attempt inclusivity.

Clinical implications

Awareness of these stressors and stress-mitigators may help healthcare providers better relate to the family experience and motivate innovations in resources, policies and processes that enhance patient care.

Research implications

Future work will evaluate interventions designed to positively affect parental and patient experience during the interfacility transfer of critically ill children and that aims to streamline policies and procedures regarding family-experience during patient transfer at the regional and national level.

Conclusion

Our study identified important parent perspectives regarding the transfer of critically ill children. We recommend that stakeholders at referral centres, transport services and accepting facilities examine their current standards regarding transport processes to ensure relevant mitigators are incorporated into their programs to improve the transport experience for critically ill children and their families.

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Data availability The authors declare that this manuscript is an honest, accurate and transparent account of the study and that no important aspects of the study have been omitted.

Code availability Not applicable.

Declarations

Conflict of interest The authors declare that they have no conflict of interest.

Consent to participate Informed consent was obtained from all individual participants included in the study.

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