

The economic burden experienced by carers of children who had a critical deterioration at a tertiary children's hospital in the United Kingdom (the DETECT study): an online survey

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Abstract

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Background

Unplanned critical care admissions following in-hospital deterioration in children are expected to impose a significant burden for carers across a number of dimensions. One dimension relates to the financial and economic impact associated with the admission, from both direct out-of-pocket expenditures, as well as indirect costs, reflecting productivity losses. A robust assessment of these costs is key to understand the wider impact of interventions aiming to reduce in-patient deterioration. This work aims to determine the economic burden imposed on carers caring for hospitalised children that experience critical deterioration events.

Methods

Descriptive study with quantitative approach. Carers responded to an online survey between July 2020 and April 2021. The survey was developed by the research team and piloted before use. The sample comprised 71 carers of children admitted to a critical care unit following in-patient deterioration, at a tertiary children's hospital in the UK. The survey provides a characterisation of the carer's household and estimates of direct non-medical costs grouped in five different expenditure categories. Productivity losses can also be estimated based on the reported information.

Results

Two-thirds of working carers had missed at least one workday in the week prior to the survey completion. Moreover, eight in ten carers reported having had to travel from home to the hospital at least once a week. Most carers reported expenditures associated to the child's admission in the week preceding the survey completion. These expenditures, on average, amount to £166 per week, grouped in five categories (38% each to travelling costs and to food and drink costs, with accommodation, childcare, and parking representing 12%, 7% and 5%, respectively). Additionally, weekly productivity losses for working carers are estimated at £195.

Conclusion

Unplanned critical care admissions for children impose a substantial financial burden for carers. Moreover, productivity losses imply a subsequent cost to society. Even though subsidised hospital parking and on-site accommodation at the hospital contribute to minimising such expenditure, the overall impact for carers remains high. Interventions aiming at reducing emergency critical care admissions, or their length, can be crucial to further contribute to the reduction of this burden.

Keywords: Economic burden, productivity loss, critical deterioration events, paediatric, children, critical care

Trial Registration: Current Controlled Trials ISRCTN61279068, date of registration 03.06.19, retrospectively registered.

Background

The hospitalisation of a child creates an emotional burden for carers (Rokach et al, 2016). Clinical deterioration requiring emergency escalation of care is likely to increase that psychological burden substantially. These effects are likely to be more profound, for children and parents whose transfer to high dependency or paediatric intensive care units was unplanned, compared to planned transfers e.g. following major elective surgery. Surrounded by uncertainty, carers of these children can experience anxiety and depression (Shah et al, 2018; Alzawad et al, 2020; Didisen et al, 2020).

Despite the emotional burden faced by carers, typically, their regular presence and caregiving skills at their child's bedside are well received by health professionals (Bijttebier et al, 2001). Their presence in the hospital setting can contribute to enhancing the recovery of their children (Rennick et al, 2019).

To be able to spend time with their child in the hospital, carers need to modify their lifestyle (Wasserfallen et al, 2006; Wakefield et al, 2014). This has implications regarding their working status and their daily routine, particularly for carers of children with a long-term condition (Limburg et al, 2008; Hjelmstedt et al, 2021). For instance, a study in the UK suggests that over one third of mothers gave up all paid work following their child's cancer diagnosis (Eiser et al, 2007). Even in the short term, a child's hospitalisation can financially impact carers, and also imposes a productivity loss for society (Pagano et al, 2014).

Moreover, changes to the daily routine generated by the child's hospitalisation are likely to expose carers to additional out-of-pocket direct expenditures (DiFazio and Vessey, 2013). Even in a publicly financed healthcare system, such as the UK NHS, users are faced with expenses due to transportation, accommodation, food, among others. These costs are magnified when a child is admitted to a specialised paediatric facility situated far from their home. A recent study in Ireland suggests that travel, parking, accommodation, food and childcare costs are among the main expenditures paid directly by families - direct out-of-pocket payments (Children in Hospital Ireland, 2020). Literature suggests considerable time and financial resources expended by families caring for hospitalised children (Mumford et al, 2018). For children with cancer, the literature suggests also high economic burden faced by carers (Rativa et al, 2018). Moreover, this burden increases with treatment complexity and among families with younger children (Pagano et al, 2014). The literature on the economic burden for children admitted in critical care units is scarcer. Still, existing estimates suggest considerable out-of-pocket expenditures faced by carers (Wasserfallen et al, 2006) and additional work productivity impact (Clark et al, 2019).

Overall, emergency critical care admissions following in-hospital deterioration in children are expected to increase the hospital costs for care delivered. These events also impose a significant burden for carers, which is poorly acknowledged in the literature.

The Dynamic Electronic Tracking and Escalation to reduce critical Care Transfers (DETECT) study (Sefton et al, 2019), implemented a proactive SMART technology end-to-end deterioration solution (the DETECT surveillance system) across a tertiary children's hospital. The DETECT surveillance system aims to proactively screen paediatric patients for early signs of serious deterioration or sepsis, thereby reducing complications and emergency transfers to critical care following deterioration in hospital. Part of the analysis plan is to evaluate the cost-effectiveness of the technology at reducing critical deterioration. During the Patient and Public involvement

(PPI) process contributing to this research proposal, parents were very vocal that the cost-effectiveness component of the study should report wider than the direct hospital costs associated with in-patient deterioration and should also incorporate the impact on families. Therefore, the aim of this paper is to provide an assessment of the economic burden imposed on carers of hospitalised children that experience critical deterioration events, specifically the direct out-of-pocket expenditures, as well as indirect productivity losses for carers of children admitted to critical care units.

Methods

Design and administration of the survey

The health economic evaluation of the DETECT technology used in the study balanced the cost of the technology against the cost and productivity gains for the hospital. However, a relevant dimension relates to measuring the cost to carers whose child has a critical deterioration. In this study, these carers are primarily the children's parents.

An online survey² was conducted with the goal of assessing the carers' personal situation. This was an essential tool to estimate both the expenditures and the productivity losses incurred by carers due to children's hospitalisations. The survey included 18 questions to provide a characterisation of the carer household and costs. Different indicators were also collected to estimate the burden associated with these hospitalisations and productivity losses. Identifiers were used to link to the hospital case number for each critical deterioration. This allowed for demographic data including postcode to be recorded. Details on the survey questions can be found in appendix 1.

Ethics approval was given for the study, by the regional ethics committee, REC 17/NW/0533, and the Health Research Authority permission to proceed was issued, IRAS ID 215339. After agreement on the final version was reached, a pre-final final version was piloted with carers advisors. Following feedback received, amendments were made, and it was released. The survey was developed on Qualtrics platform, allowing surveys to be completed on computers or mobile devices.

Dedicated DETECT study research nurses underwent training before the dissemination of the survey. Recruitment occurred between July 2020 and April 2021 at Alder Hey Children's Hospital, a tertiary setting in Liverpool in the UK. Carers of children who experienced critical deterioration events during their hospitalisation were invited by the DETECT research nurses to participate in the survey. Carers were provided information about the purposes of the survey and were asked to sign a consent form. The data were uploaded to the secure Qualtrics platform at Lancaster University. The survey data were downloaded from the Qualtrics platform and analysed using Excel and Stata 13.1.

² The survey was developed by Céu Mateus, Enitan Carrol, Gerri Sefton, Bernie Carter and carers and approved by the Study Management Group as part of the DETECT project. For more details please refer to Sefton et al, (2019)

Estimating direct out-of-pocket expenditures

Out-of-pocket expenditures are costs paid directly by the carers incurred due to their children's hospitalisation. Costs were assessed for five different categories and stated in British Pounds (£). Individuals were asked to report average costs for five different categories (travelling, parking, accommodation, food & drink, and childcare). Carers were asked to report costs experienced during the week preceding the survey completion. Overall, there was very few missing data. Adjustments and inference were required to provide a more accurate estimate on the costs faced by carers.

Travelling costs were either reported directly by the carer or estimated based on the distance reported between home and hospital, and the number of days of travel reported. Quantification of miles costs performed based on Mileage Allowance Payments established by the UK Government³ (45p – rate per business mile for Cars and Vans, first 10,000 miles).

Based on self-reported information, average weekly expenditures were estimated for all carers answering the survey. Moreover, because not all carers are exposed to all costs, average weekly expenditures were also computed for each subset of carers who reported costs greater than zero in each cost category.

Moreover, three heterogeneity analysis were considered for different subsamples. First, we looked at carers with on-site accommodation versus carers who slept at home. Information was available for most participants regarding whether they slept at the hospital (either at bedside or at other hospital-provided facilities), or at home. Information on housing arrangements was missing for only five carers, who were excluded from this specific analysis.

Second, we compared average weekly expenditures for single parent families, and households with both parents. The survey did not include a specific question regarding this. Instead, classification into "single parent" or "both parents" was based on the reported information regarding the number of household members and the number of children in the household. The difference between those two variables was interpreted as a proxy of the number of parents in the household, which should be interpreted with caution. Households where the difference between those two variables was equal to one were classified as "single parent", while households with a difference equal to two were classified as "both parents". All remaining households were excluded from this specific analysis (five observations).

Third, we compared carers living in most and least deprived neighbourhoods. Deprivation information was collected from the 2019 English Index of Multiple Deprivation, provided by the Ministry of Housing, Communities & Local Government. This index is an overall relative measure of deprivation, combining seven different deprivation domains for each Lower Super Output Area code (LSOA). Carers answering the survey reported their post-code information. Post-code data was merged with each LSOA code to identify the index of multiple deprivation associated with each carer's region. Carers living in districts belonging to the first five deciles of the index were considered to be in the "most deprived" group. Carers living in districts belonging to the last five deciles are assigned to the "least deprived" group. Information on post-codes and on

³ <https://www.gov.uk/expenses-and-benefits-business-travel-mileage/rules-for-tax>

the index of multiple deprivation was missing for only six carers, who were excluded from this specific analysis.

Estimating productivity losses

Productivity losses were estimated using aggregate wage statistics. For each carer, the median wage was assigned based on the carer gender and age group. Seven different age groups were available, based on Office for National Statistics. Information was collected for the median weekly earnings for full-time employees in the United Kingdom in 2020⁴.

Productivity losses were estimated for three sets of carers. The first group included all answers to the survey. The second group included the subset of working carers, either with a full-time or a part-time job. The third group included the subset of working carers with at least one missing workday (in the previous week).

Results

Descriptive survey results

In total, 71 surveys were completed. Table 1 describes the survey main descriptive statistics. Mean age of carers was 34 years old, with a mean household size of four members. Apart from the child in the hospital, carers had on average one additional child. In the week preceding the completion in the survey, carers reported missing an average of two days of work because of their child's hospitalisation. Moreover, they travelled on average four days in that week between home and the hospital, and vice-versa.

Table 1: Key descriptive statistics for the survey main variables

Variable	Observations	Mean	Standard Deviation	Minimum	Maximum
Age (years)	71	34.3	7.6	16.0	53.0
Household (number of individuals)	71	4.0	1.6	2.0	9.0
Other children (number)	71	1.3	1.5	0.0	8.0
Distance Home-Hospital (miles)	70	26.1	24.1	0.5	131.0
Off work (days)	65	2.2	2.6	0.0	7.0
Travelling home-hospital (days)*	70	4.3	3.7	0.0	24.0

*in the last week

Table 2 details the characteristics of the carers who answered the survey. Eighty two percent of carers were mothers, and 73% households had no more than four members. Thirty four percent of carers had only one child who, at the time of survey completion, was hospitalised and 35% of carers had another child besides the one staying at the hospital.

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<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/earningsandworkinghours/datasets/agegroupshetable6>

The majority of carers were employed, either in full time (52%) or in part time (11%); 37% were not in paid work. Employment status seemed to reflect the carer's gender: 41% of mothers reported not being in paid work, compared to 15% of fathers.

Most of carers (54%) reported no missing work days in the week preceding survey completion. However, this estimate included a set of carers who reported no employment status. Considering the subset of carers employed (n=45, 63%), the proportion reporting zero missing days dropped to 34%.

Eight in ten carers reported travelling between home and the hospital at least once in the past week, and almost one third reported travelling between home and hospital daily in the past week. Still, as described below, some carers were able to stay on-site, which contributed to minimise their travelling expenditures.

Table 2: Characterisation of carers (survey responses; N=71)

	Frequency	Percent	Cumulative
<i>My relationship to my child who is in Alder Hey is</i>			
Father	13	18%	18%
Mother	58	82%	100%
<i>How many people live in your household?</i>			
2	7	10%	10%
3	25	35%	45%
4	20	28%	73%
5	8	11%	85%
6	4	6%	90%
7	3	4%	94%
8	3	4%	99%
9	1	1%	100%
<i>Apart from your child in hospital, how many other children do you have?</i>			
0	24	34%	34%
1	25	35%	69%
2	10	14%	83%
3	5	7%	90%
4	4	6%	96%
5	2	3%	99%
8	1	1%	100%
<i>Are you currently</i>			
Employed (full time)	37	52%	52%
Employed (part time)	8	11%	63%
Not in paid work	26	37%	100%
<i>How many days have you had to take off work?*</i>			
0	35	54%	54%
2	3	5%	58%
3	2	3%	62%
4	3	5%	66%
5	15	23%	89%
6	2	3%	92%
7	5	8%	100%

<i>How many days have you had to travel between home and the hospital?*</i>			
0	13	20%	20%
1	5	8%	28%
2	9	14%	42%
3	5	8%	49%
4	4	6%	55%
5	9	14%	69%
7	20	31%	100%

* in the last week; 65 valid observations

Direct out-of-pocket expenditures

Most carers reported expenditures due to their child's hospitalisation in the week preceding survey completion. Most carers reported food and drink costs (90%), as well as travelling costs (75%). Almost one third of carers reported parking expenditure (35%). Some carers (17%) reported childcare expenditures or accommodation costs (10%).

Table 3 presents average weekly expenditures reported by all carers in the survey. On average, carers reported weekly expenditures of £166, of which, 38% were due to travelling costs, and food and drink costs each, and accommodation, childcare and parking represented 12%, 7% and 5%, respectively.

Because not all carers are exposed to all costs, analysis has been undertaken of the subset of carers who reported costs greater than zero (see table 3). For instance, a carer living in hospital with their child will not have any accommodation costs or substantial travelling expenditures, although some residential carers may also travel home to see the child's siblings. Looking to the subset of individuals who report costs greater than zero, average weekly travelling expenditures increase from £63 to £84, while food and drink costs increase from £64 to £71. Parking expenditures also increase from £8 to £24. The largest increases occur in childcare costs which increase from an average of £11 to £67, and accommodation expenditures which increase from £20 to £203.

On-site accommodation can be a way to protect carers from facing high costs. Additionally, on-site accommodation allows carers to be closer to their child, should the child deteriorate, and they need to return to the ward. Information was available for most participants regarding whether they used accommodation at the hospital (either at bedside or at other hospital-provided facilities), or slept at home (see Table 3). Most carers (58%) were able to stay in the hospital. The average weekly cost for these carers was substantially lower than the cost faced by carers sleeping at home (£139 versus £214). Carers sleeping at home reported considerably higher travelling, parking, and accommodation expenditures. Conversely, they also reported lower expenditure related to childcare, and food and drinks.

Table 3: Out-of-pocket expenses for carers by type of cost (£)

Cost category (mean, SD)	All carers (N=71)		Carers reporting costs greater than zero (N=64 ⁵)		Carers with hospital accommodation (N=38)		Carers without hospital accommodation (N=28)	
	Cost (£)	SD	Cost (£)	SD	Cost (£)	SD	Cost (£)	SD
Travelling	63	88	84	93	33	41	104	120
Parking	8	18	24	23	5	10	13	25
Accommodation	20	67	203	93	6	32	43	96
Food and Drink	64	57	71	56	79	67	51	38
Child Care	11	35	67	61	16	45	4	13
Total weekly cost (mean)	166		448		139		214	

Table 4 provides some heterogeneity analysis on the previous results by looking to two particular subsets of carers. On one hand, we decompose the sample between households with a single parent and households with both parents. Households were classified as “single parents” or “both parents” according to the reported information on the number of household members and the number of children. On average, single parents report weekly expenditures of £209 above the expenditures reported by two-parents’ households (£149). Single parents’ expenditures, relative to two-parents’ households, are mostly driven by higher accommodation, travelling and food and drink costs.

On the other hand, the sample was divided between carers living in most and least deprived neighbourhoods. Carers living in districts belonging to the first five deciles of the index of multiple deprivation were considered to be in the “most deprived” group. Carers living in districts belonging to the last five deciles were assigned to the “least deprived” group. According to this classification, carers living in the most deprived regions report 12% lower weekly costs than carers living in the least deprived regions (£162 versus £183). Such decrease is driven by lower travelling and accommodation costs.

Table 4: Out-of-pocket expenses for carers according to household and deprivation (£)

Cost category	Single parents (N = 19)		Both parents (N = 47)		Most deprived (N = 46)		Least deprived (N = 19)	
	Cost (£)	SD	Cost (£)	SD	Cost (£)	SD	Cost (£)	SD
Travelling	84	143	57	57	59	100	87	71
Parking	13	28	9	14	12	22	4	10
Accommodation	45	109	17	57	27	73	33	92
Food and Drink	87	73	65	49	69	55	69	65
Child Care	8	16	16	44	11	32	10	25
Total weekly cost (mean)	209	209	149	99	162	135	183	165

⁵ The number of carers reporting costs (greater than £0) changes depending on the cost category. The number of observations refers to the category with the largest number of carers reporting costs.

Productivity losses

Productivity losses include work absenteeism for the carers of children who had an in-hospital deterioration. From a societal perspective, there is a significant opportunity cost associated with the days those carers take off work. This opportunity cost was estimated based on average weekly UK wages adjusted by gender and age, since the survey did not include specific questions on wage or income.

Productivity losses do not represent actual financial losses for carers, even though they can be interpreted as a proxy. Losses were computed based on median gross values. This does not consider taxation or social security contributions. To some extent, carers are expected to have some level of protection regarding their absence from work. Still, as gross wages should reflect the marginal productivity of each worker, these estimates should be seen as a proxy for the impact on society of having that worker absent from work.

On average, the weekly productivity loss amounts to £124 per carer. This estimate was performed considering all answers to the survey. However, as described above, 37% reported not being in paid work. The remaining carers reported having either full-time or a part-time employment. Focusing on this subset of working carers (n=45, 63%), the average weekly lost wage increases to £195. Within this subgroup, some carers reported missing work for some days, while others did not report any missing day. In fact, 66% of working carers had missed at least one workday in the previous week. For this subset (n=29, 41%), the average weekly lost wage increases to £303.

Discussion

Unplanned critical care admission for children following critical deterioration imposes a substantial burden on carers. The impact of such admission is more than psychological, representing substantial out-of-pocket expenses. Moreover, productivity losses imply a subsequent loss to society. In this study, we provide an assessment on both direct out-of-pocket expenditures and indirect productivity losses. This financial burden is estimated based on 71 carers whose children, following a CDE, were admitted to a critical care unit in a tertiary children's hospital in the UK. Estimates suggest weekly average direct out-of-pocket expenditures of £166 and a weekly productivity loss for working carers of £195. The magnitude of these estimates is considerable, particularly when considering public policy related with childcare. For instance, the "Universal Credit" policy, established by the UK government to support carers with childcare costs, caps monthly payments to £646 per child, which corresponds to a weekly £162 subsidy. This is closely aligned with the direct out-of-pocket payments estimated for carers of children hospitalised in critical care units.

This paper reinforces previous findings of substantial costs for carers caring for hospitalised children (Mumford et al, 2018; Rativa et al, 2018; Pagano et al, 2014; Children in Hospital Ireland, 2020). The emergency and unplanned nature of these admissions to critical care means that carers have less time to plan family and friend support. This can in turn accentuate the carer's financial burden. Results are aligned with the results found by Wasserfallen et al (2006) in Switzerland, in which carers insured by the country's social security system, were found to experience significant non-medical costs during their child's admission to a paediatric intensive care unit. In our study, undertaken in the UK health system, we provide similar evidence of

increasing costs for carers of children admitted to critical care units following in-hospital deterioration. The main sources of expenditure for carers in our study were travel and food and drink, as are seen in Wasserfallen et al (2006).

The scope of this study is focused on the assessment of out-of-pocket expenditures and productivity losses experienced during the child's unexpected hospitalisation in a critical care unit. We do not document any potential long-run costs after the critical care hospitalisation. However, the literature suggests that these losses may continue following critical care hospitalisation. For instance, children often miss school in the weeks following hospital discharge, while carers also miss work (Carlton et al, 2021). Hence, the estimates of this paper should be interpreted as a lower-bound of the true impact, or as short-run estimates.

In this study setting the hospital provides subsidised hospital parking and on-site accommodation for some carers with the aim of minimising some direct out-of-pockets expenses. Accommodation is prioritised for carers who live furthest from the hospital or for children who are seriously ill. Nonetheless, the overall impact for carers remains high. Moreover, our estimates should be interpreted as a lower bound when comparing with hospitals without such schemes. These results stress the importance of specific policies to address the financial burden imposed on carers. These policies should be flexible to prevent substantial bureaucratic and time-consuming processes experienced by carers (Children in Hospital Ireland, 2020).

Results suggest that the relative importance of out-of-pocket payments is different depending on whether carers are able to stay at the hospital or not. Policies aiming at reducing this burden should be adapted depending on the housing arrangements. For carers having to return home, travelling, parking and accommodation expenditures are relatively more important compared with carers staying at the hospital. Nonetheless, even for carers with on-site accommodation, there are periodic costs for returning home to see other family and collect supplies. Interestingly, accommodation expenditures are higher for carers without hospital accommodation, which may reflect that some carers stayed temporarily in accommodations closer to the hospital.

Moreover, results indicate that the financial burden is higher for carers who are single parents, relative to carers that live in two-parent households. Out-of-pocket average weekly expenditures for single parents are 40% higher relative to expenditures reported by two-parent households. This disproportional burden may reflect the struggle faced by single parents when managing simultaneously their hospitalised child with their other arrangements, which may include additional children.

Finally, we found no evidence that carers living in deprived neighbours experience higher out-of-pocket costs than carers living in less deprived regions. In fact, carers living in the most deprived regions report 12% lower weekly costs. This reduction can be explained by different factors. First, we may have different underlying needs and traveling arrangements between both groups. Secondly, specific support provided by charities, social security, and other institutions to deprived carers may be in place, which can help minimising their expenditures. Finally, the lack of disposable income may prevent higher expenditures, crowding-out out-of-pocket expenditures beyond their desired level. However, the assignment of carers to more or least deprived neighbourhoods was made solely based on self-reported post-code information. No

information specific to each individual socio-economic condition was collected, which may be different from the average deprivation of the neighbourhood.

This study has some limitations, given the setting and context in which the survey was implemented. First, a retrospective questionnaire was implemented to investigate carers' expenditures when a child was admitted to the hospital. However, this type of tool is subject to recall errors and selection bias. Secondly, the study is specific in the context of the UK NHS, and a specific hospital. Thirdly, the number of carers included in the study was limited. Additionally, cost information was collected based on self-reported information within cost categories. These do not include other expenditures and are restricted to a specific time frame – the week preceding survey completion. Finally, productivity losses were estimated based on national wage statistics and do not capture specific socio-economic characteristics of the carers or regions where they are located.

Moreover, estimates can be affected considering that the study took place during the COVID-19 pandemic, which can introduce some bias in the analysis. In fact, the COVID-19 crisis shifted the usual pattern for carers, given changes in hospital policy for visitors. For instance, visiting periods were restricted during lockdowns, with carer attendance limited to one person per child. Also, hospital parking costs were waived temporarily during the pandemic. Changes to the carers working status during the pandemic, such as wage losses and remote working, may also have affected carers' out-of-pocket expenditures.

In the UK, the overall number of bed days in paediatric intensive care units was 143,533 in 2019 (PICANet, 2020). Our study estimates a weekly direct out-of-pocket cost per carer of £166, as well as an average productivity loss of £124. These estimates may not be directly comparable with the national context, given the specificities and limitations discussed above. Nonetheless, if one abstracts from those limitations, such financial burden estimate would be translated into a yearly £3.4 million direct out-of-pocket payments paid by carers of children hospitalised in critical care units. Moreover, the national productivity loss associated with those carers would amount to £2.5 million.

Overall, few studies exist regarding the economic burden associated with children's hospitalisation and even fewer focus on admission to critical care. The present study, despite its limitations, provides evidence that the burden is considerable. Policies and innovations that can reduce the likelihood of critical deterioration events can prevent some of these costs, by reducing or avoiding admissions to critical care units.

Further studies should be developed to inform policy makers on the economic burden faced by carers. These can be crucial to help the design and implementation of policies to support carers during their children's admission to critical care units.

Conclusion

This study provides a snapshot of the impact on 71 carers of their child's stay in a critical care unit in a children's hospital. Direct out-of-pocket costs for carers are substantial (£166 per week), mostly driven by travelling and food and drink expenditure. Sizeable differences are identified when comparing costs for carers that can stay at the hospital, with carers who had to travel to and from their homes. Moreover, weekly productivity losses for working carers are estimated

at £195. The direct out-of-pocket payments, coupled with the indirect productivity losses impose a sizeable economic burden associated with the admission of such children to critical care units.

These results support the development and implementation of policies aiming at reducing the financial burden faced by carers. It also suggests the importance of looking to the economic burden when studying innovations likely to reduce the length of stay in these critical care units.

List of abbreviations

CDE – Critical Deterioration Event

DETECT - Dynamic Electronic Tracking and Escalation to reduce critical Care Transfers

LSOA - Lower Super Output Area code

NHS – National Health Service

PPI - Patient and Public involvement

Ethics approval and consent to participate

Ethics approval was given for the study, by the regional ethics committee, REC 17/NW/0533, and the Health Research Authority (HRA) permission to proceed was issued, IRAS ID 215339. Consent was collected for the families of children who are transferred to critical care following deterioration, so that additional data can be captured to ascertain the indirect financial cost to families associated with critical deterioration. The consent process incorporates statements about the use of anonymised data for publication.

Consent for publication

Consent for publication is incorporated within the consent form used to document consent for participants, and their families. This explicitly states that no patient identifiable data will be published.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

This study/project is funded by the NIHR i4i programme [II-LA-0216-20002]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Acknowledgements

We wish to acknowledge the support of the NIHR Clinical Research Network, North West Coast. We also wish to acknowledge the children, parents and health professionals who participated in the survey and the research nurses who supported the collection of data during the COVID-19 lockdowns.

Authors' contributions

EC; Contributed to conducting the statistical and health economics analysis and drafting the manuscript. Lead author for the manuscript. Corresponding author: costa.eduardo@novasbe.pt. CM; Contributed to designing the study, providing feedback on the statistical and health economics analysis, drafting, and reviewing the manuscript. Corresponding author: c.mateus@lancaster.ac.uk. BH; Contributed to designing the study, securing funding , providing feedback on the statistical and health economics analysis, drafting, and reviewing the manuscript. EDC; DETECT study co-Chief Investigator, contributed to designing the study, securing funding and reviewing the manuscript. GS; DETECT study co-Chief Investigator , contributed to designing the study, securing funding, drafting, and reviewing the manuscript. All remaining authors; Contributed to designing the study and reviewing the manuscript. All authors read and approved the final manuscript.

Disclaimer

This report is independent research funded by the National Institute for Health Research (Dynamic Electronic Tracking and Escalation to reduce Critical Care Transfers (The DETECT Study), I4I Challenge award ref II-LA-0216-20002). The views expressed in the publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health and Social Care Research, or the Department of Health and Social Care.

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Appendix 1: Survey flow

Q1 I understand that if i tick YES, I am agreeing to take part in this survey. If I don't want to take part I know I can just hand the tablet back to the researcher. *Yes / No*

Q2 Please enter your study number in the box below. This is the number the nurse/ researcher gave you and it will look like xxxxxxxx.

Q3 My relationship to my child who is in Alder Hey is: *Mother/Carer / Father/Carer /Other (please explain)*

Q4 What year were you born in? (This information helps us with our analysis)

Q5 How many people live in your household?

Q6 Apart from your child in hospital, how many other children do you have?

Q7 How far from the hospital do you live (please state in miles)

Q8 Are you currently: *employed (full time) / employed (part time) / not in paid work / retired*

Q9 How many days has your child been in hospital during this admission?

Q10 How many days have you had to take off work? In the last week (Please tell us to the nearest half day)

Q11 How many days have you had to come to and from home to the hospital? In the last week.

Q12 How much money have you spent on travel to and from the hospital per day?

Q13 If you can't remember how much you've spent, how many miles have you travelled per day (approximately)? In the last week.

Q14 How much have you spent on parking at the hospital per day? In the last week.

Q15 If you had to pay for accommodation, how much have you had to pay? In the last week.

Q16 How much have you spent on food and drink at the hospital per day on average? In the last week.

Q17 How much more are you spending on child care costs for your other children each day? (If your costs haven't increased or you have no other children just say no extra costs). In the last week.

Q18 And finally, if you have any other comments about costs you would like to share, please do tell us, we'd love to hear about them.