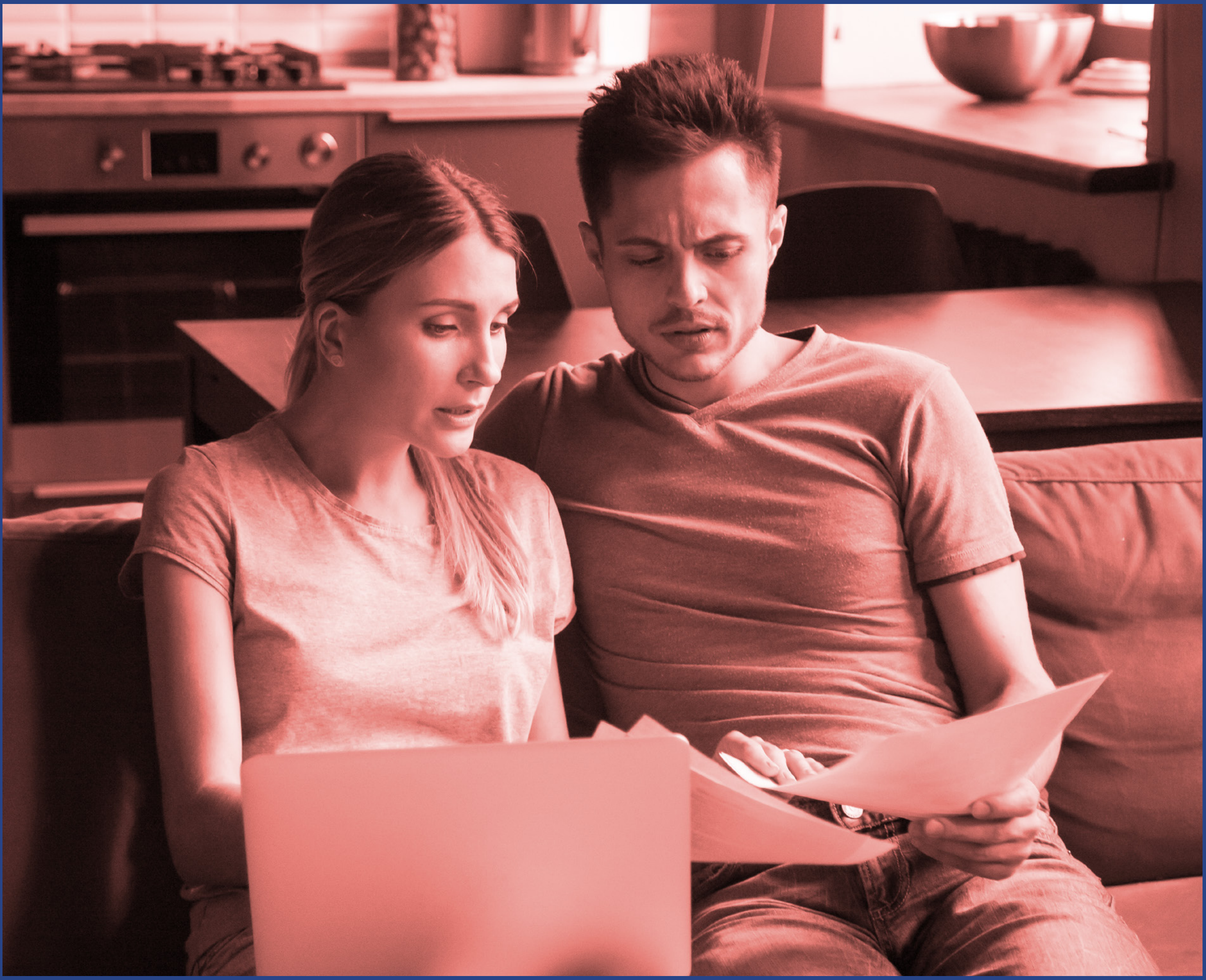
Report: April 2023

NI Children's Health Coalition

Ulster University

The Hidden Costs of Having a Child in Hospital in Northern Ireland



Version two: Costs of Travel (p10) updated November 2024

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Further we would like to recognise the contribution made by **Ben Parr** and **Chantel Odesanya**.

Executive Summary

This report aimed to address four aims:

a) Ascertain the financial costs associated with having a child who has received inpatient hospital care in Northern Ireland.

b) Understand if caregivers think their physical and mental health is impacted by having a child experience inpatient care.

c) Understand how caregivers psychologically cope with having a child experience inpatient care.

d) Identify what caregivers would like to see change to support them and their children.

In total, 269 caregivers who had a child (<18 years-old) who had experienced inpatient care in the previous 18 months responded to the survey. Caregivers reported substantial financial burdens associated with inpatient care of their child, including transport and food costs and loss of earnings for their family. Caregivers also indicated that there were substantial negative impacts on their physical and mental health. Overall, caregivers reported relying on positive coping strategies to deal with the stress and strain of having a child who experienced inpatient care. However, caregivers provided many suggestions for improvement for their family's experience. These suggestions included the provision of free car parking, access to basic equipment to make food and beverages, access to showering facilities, ensuring that equipment in hospital wards was suitable for children with complex needs and increasing provision for comfortable and safe sleeping for caregivers. In addition, caregivers highlighted the need for timely financial and psychological support, not just for themselves, but also for their children.

Introduction

In Northern Ireland, 9.9% of hospital admissions are defined as being under "Maternal and Child Health Programme of Care" (Dunbar et al., 2021). There is large variation in the reasons for children receiving inpatient care, from common ailments such as fractures and viral infections to premature birth, childhood cancer/leukaemia, neurological disorders, or heart conditions. Some children who are admitted for hospital care may require readmittance over the course of their life due to underlying complex medical health problems (Children in Hospital Ireland, 2020). Admittances in Northern Ireland are under the provision of the National Health Service (NHS) and have *no direct* associated costs for families.

International research has established that there are clear hidden costs associated with "free" health care for children and their caregivers. In the United States of America, over 90% of children have medical insurance, but additional cost burdens for families have been identified and described as "medical out-of-pocket" (OOPs) expenses that are non-reimbursable. These expenses may include additional insurance costs, medical equipment, or therapies (DiFazio et al., 2011). In addition, "nonmedical OOPs" (NOOPs) have also been identified. These expenses are nonreimbursable by health insurance companies but are integral in maintaining family functioning, such as travel, food, childcare for other dependents, incidental expenses or loss of caregiver earnings (DiFazio et al., 2011). Without recognition of these OOPs the overall financial burden of having a child in hospital is vastly underestimated. These additional costs may lead to significant family financial stress and may inadvertently impact on health outcomes of all family members, including the child in hospital (Banthin et al., 2008).

Although the financial costs of admittances in Ireland are covered by the Health Service Executive (HSE), research has indicated significant additional financial implications for families of children that receive inpatient care. A recent report by Children in Hospital Ireland (CiHI, 2020) suggests that families may face significant costs- especially if their child must have a prolonged inpatient stay.

The findings of the CiHI survey, conducted with 318 caregivers of children who had received inpatient care, indicated increased financial burdens associated with hospital stays including:

(a) Family car transport due to children being immunocompromised and therefore being unable to use public transport.
(b) High-cost car parking.
(c) The cost burden of necessity of overnight accommodation for family members. In addition, many caregivers reported long journeys to and from hospital that were emotionally and physically draining.

Many parents who responded to the CiHI survey reported the welcome introduction of on-site accommodation that reduced their need to leave their children alone in hospital. However, many of these facilities charged a nominal fee. Access to accommodation for free was dependent on the nature of the illness that their child was experiencing as many services were offered by specialist charities. This research investigated caregivers experience across the island of Ireland. However, to date no research has specifically investigated the experiences and hidden cost burdens for families who specifically live in Northern Ireland.

In addition to the hidden financial costs of having a child who has experienced inpatient care, many caregivers also report associated psychological distress, even when children were hospitalised short periods of times with mild acute diseases (Commodari, 2010). Caregivers have reported high levels of anxiety and depression whilst their child was an inpatient. These outcomes were mediated by sleep patterns and sleep location (Stremler et al., 2017). Anxiety has been reported to be associated with interventions that may be necessary for their child's treatment, such as operative care and anaesthesia, but also worry about being in a hospital environment in general (Shirley et al., 2002). Elevated levels of anxiety have also been reported to be sustained even up to three months post-discharge (Wray et al., 2011), but may be attenuated by activities offered to children in hospital such as access to schooling (Commodari, 2010). A substantial minority of caregivers report having sought specialist mental health support to deal with their stress. For example, 21% of caregivers in the CiHI (2020) survey attempted to gain access to mental health services to deal with their psychological distress. Of those caregivers who did not seek support, 23.1% of families reported that the barrier to accessing support was lack of affordable services (CiHI, 2020).

The current study

To date, we do not understand the additional non-medical financial impacts, or NOOPs, of having a child or children who experience inpatient care in Northern Ireland. In addition, many families anecdotally report that having a child who experiences inpatient care can be very stressful. However, we do not currently have any quantitative data to indicate the extent of this issue, nor what strategies caregivers use to cope with psychological distress. Therefore, the proposed study aims to replicate and extend the CiHI (2020) survey in Northern Ireland.

Aims

The present study aims to:

a) Ascertain the financial costs associated with having a child who has received inpatient hospital care in Northern Ireland.

b) Understand if caregivers think their physical and mental health is impacted by having a child experience inpatient care.

c) Understand how caregivers psychologically cope with having a child experience inpatient care.

d) Identify what caregivers would like to see change to support them and their children.

Methodology

Ethical governance

Ethical governance for this research was provided by the School of Psychology, Ulster University Research Ethics Committee. Participants were assured that their responses were fully anonymous and that they could opt to either not complete specific questions if they wished or submit the survey without full completion. Participants provided informed written consent before completing the survey.

Design and recruitment

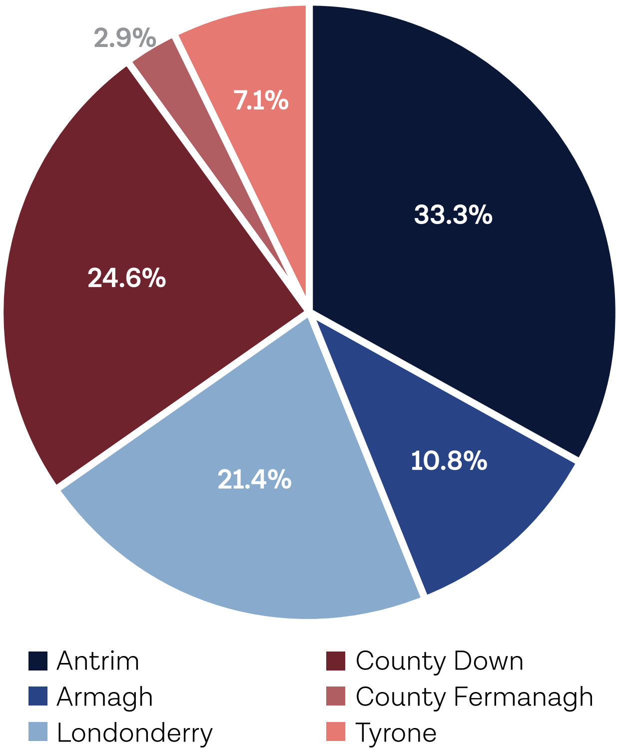
Opportunistic sampling was used for recruitment with the Children's Health Coalition distributing the link for the online survey to partner organisations for distribution through their own mail servers to caregivers.

Participants

The participants were all adults (18+) who were caregivers of a child (defined as a dependent up to the age of 18 years-old) who has experienced inpatient health care in Northern Ireland. 398 participants responded to the survey, with 269 (68%) having a child who had been treated as an inpatient in the last year. Most respondents were female (95%), were aged between 25-44 years-old (82.6%) and reported being White British (68.6%) or White Irish (28.4%). A small proportion of participants reported being from other White backgrounds (1.3%) or Mixed or Multiple ethnic groups (1.7%).

Most respondents had lived in Northern Ireland for over 3 years (96.7%). Respondents were geographically spread from across Northern Ireland (Figure 1; Antrim: 33.3%, Armagh: 10.8%, Derry/Londonderry: 21.3%, Down: 24.6%, Fermanagh: 2.9%, Tyrone: 7.1%).

Figure 1: Geographical spread of respondents



Most respondents described the place they lived as a town (42.7%), followed by a city (23.4%), rural area (18.8%) or village (15.1%). Most respondents were classified as homeowners with a mortgage/ loan (53.6%), followed by private renters (16.5%) and social renters (9.7%). 15.2% of respondents were owner occupiers. A small proportion of respondents stayed with their family (3.4%), had no fixed address (0.4%) or lived in emergency accommodation (0.4%).

Respondents reported their current working status. These data are summarised in Table 1. Approximate annual household income was reported by 233 respondents and is summarised in Table 2.

Table 1: Respondents working status

Working status	N	%
Looking after the home/family full-time	37	30.6
On carer's leave	7	5.8
Full-time employee	36	29.8
Part-time employee	25	20.7
Self-employed full-time	6	5.0
Self-employed part-time	4	3.3
Unable to work due to sickness or disability	5	4.1
Part-time education	1	0.8

Table 2: Annual household income

Income level	N	%
Below £15k	26	11.2
£15k-£30k	74	31.8
£31k-£40k	35	15.0
£41k-£60k	44	18.9
£61k-£99k	30	12.9
£100k or more	5	2.2
Prefer not to say	19	8.2

Measures and procedure

The survey was administered in March 2022 and was open for 6 weeks. Three reminder emails were sent to potential participants to prompt responses. Once participants had indicated their informed consent, they completed a brief 20-minute survey. Participants completed a single online survey via Qualtrics that assessed the financial implications of having a child in inpatient care in Northern Ireland. These questions were adapted from those included in the Children in Hospital (2020) survey. Respondents were asked to state reasons for their child's inpatient care, lengths of stay, document a range of expenses associated with inpatient care and any associated loss of earnings. In addition, parents/guardians were asked to complete the Coping Orientation to Problems Experienced (COPE) scale that assesses coping responses to a broad range of health-related issues. The scale consists of 14 subscales, each with two items and is responded to using a 4-point likert scale. The COPE scale has high levels of internal consistency (range Cronbach's Alpha= .8 to .91) and has high levels of test-retest reliability (Chesney et al., 2006).

Results

Demographics of children experiencing inpatient care

Most respondents had children who were under 12 months old experiencing inpatient care (Table 3). 41.2% of respondents' children had been attending hospital for less than 18 months due to their illness, 14.2% had been attending between 18 months to 3 years and 44.6% had been attending for over 3 years.

Table 3: Age of child experiencing inpatient care

Age	N	%
Under 12 months old	85	31.6
12-36 months old	43	16.0
3-8 years-old	77	28.6
9-12 years-old	29	10.7
13-16 years-old	28	10.4
17-18 years-old	7	2.6

Respondents gave a diverse set of reasons for their child to require inpatient stay, including complex co-morbidities. Table 4 specifies the main reason for the child experiencing inpatient care as reported by the caregiver.

Table 4: Main reason for child experiencing inpatient care

Classification	Number of responses	Percentage of responses
Developmental Anomaly	54	26.0%
Disease of nervous system	39	18.8%
Conditions originating in perinatal period, including prematurity	31	14.9%
Neoplasm/Cancer	24	11.5%
Disease of circulatory system	20	9.6%
Mental, behavioural or neurodevelopmental disorder	9	4.3%
Disease of respiratory system	8	3.9%
Disease of digestive system	7	3.4%
Injury	4	1.9%
Unclassified	3	1.4%
Disease of genitourinary system	2	1.0%
Disease of musculoskeletal system or connective tissue	2	1.0%
Endocrine, nutritional or metabolic disease	2	1.0%
Disease of blood or blood-forming organs	1	0.5%
Disease of immune system	1	0.5%
Disease of visual system	1	0.5%

35% of children had required one inpatient stay over the last 18 months (Figure 2), with the modal length of time of their most recent stay being 2-3 nights (30.4%, Figure 3).

Figure 2: Number of inpatient stays over the last 18 months

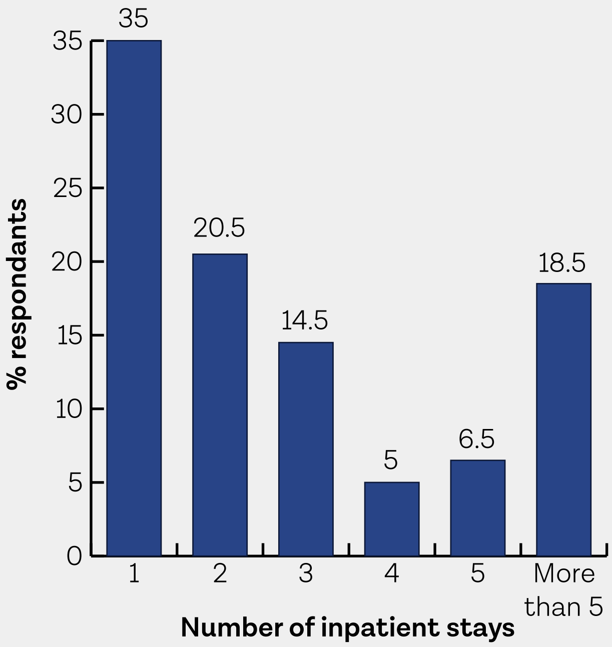
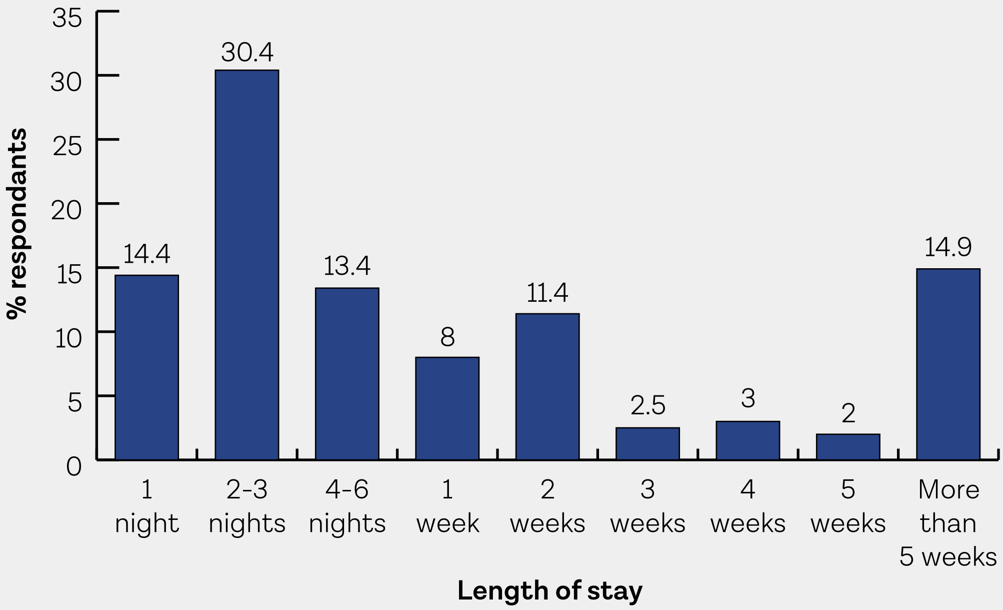


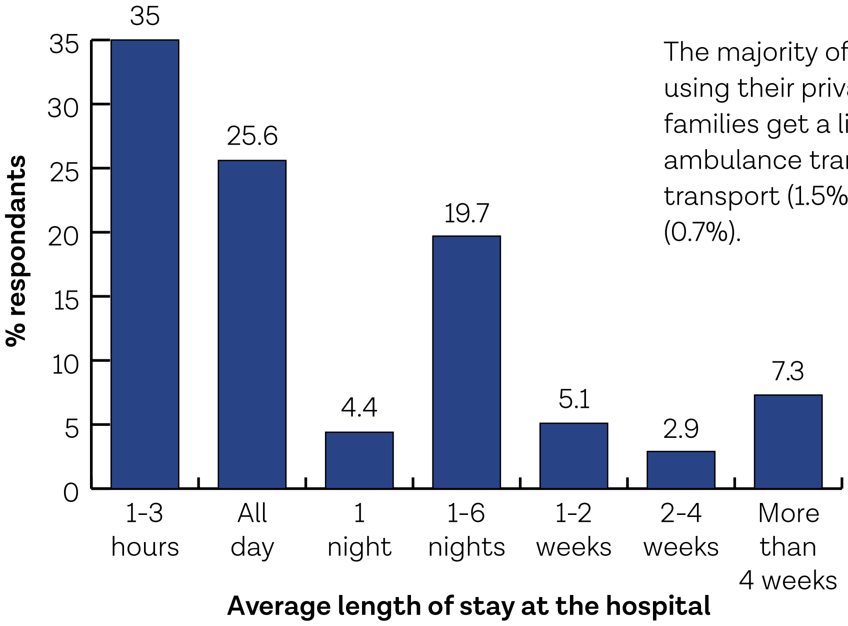
Figure 3: Length of time of most recent stay in hospital



Travel to and from hospital

On average, families live 40.1 miles (range: 1 mile – 471 miles) from the hospital in which their child receives most of their care. Most children receive their care in Northern Ireland (90.1%), with 0.7% receiving care in the Republic of Ireland and 8.7% receiving their care in Great Britain. 63% of respondents travel to and from the hospital once a week or less, 10.1% a few times a week, 13.8% once per day and 13.0% more than once per day. The average length of time of each stay is summarised in Figure 4.

Figure 4: Average length of stay at the hospital



The majority of families travel to the hospital using their private car (87.6%). Small proportions of families get a lift from family or friends (3.7%), get ambulance transport (2.2%), fly (2.2%), use public transport (1.5%), use a taxi service (0.7%) or walk (0.7%).

Costs of travel

Not all respondents responded with transport costs to and from hospital on a typical day, but for those who did, these data are summarised in Table 5.

Table 5: Average transport costs per trip

Transport item (N who reported cost)	Public transport (N=3)	Taxi (N=9)	Petrol for private car (N=108)
Average cost (£)	37.11*	20.66	14.61
Minimum reported cost (£)	3.33	1.43	1.43
Maximum reported cost (£)	100	50	60

* Average cost excluding one respondent who reported £100 public transport cost= £5.67; Three respondents petrol costs and one respondents taxi costs, were excluded as they could not be effectively assigned per typical day values.

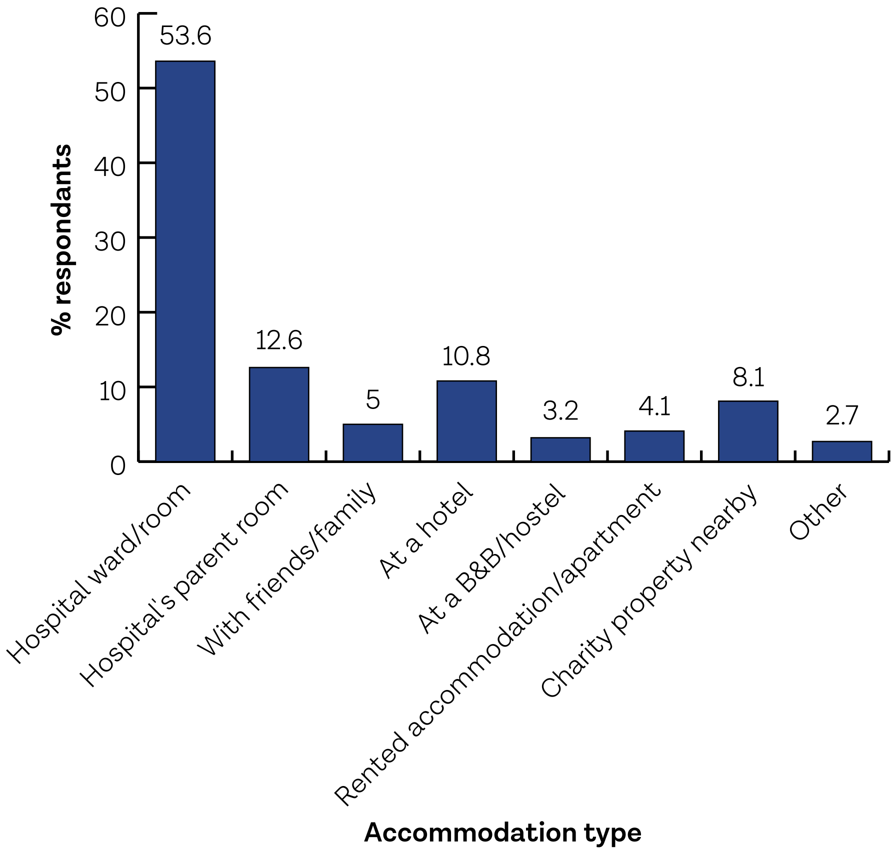
Some respondents reported additional costs associated with transport. Two respondents reported toll costs, with an average per typical day cost of £1.17 (range= £1.14 to £1.19). Seventy-two** respondents reported parking charges, with an average per typical day cost of £6.07 (range £0.65 to £25.00).

** Two respondents parking costs were excluded as they could not be effectively assigned per typical day values.

Overnight stays

46.0% of respondents stated that they and/or their partner had stayed overnight to be with, or close to, their child in hospital. 2.9% of respondents reported that their partner had stayed overnight to be close or near to their child in hospital. Overnight stays were spent in a variety of accommodation and these data are summarised in Figure 5. If caregivers had to pay for overnight accommodation this cost, on average, £61 per night.

Figure 5: Accommodation type for overnight stays



Daily living costs

Additional costs associated with hospital stays were mainly associated with food and beverages (Table 6). In total, caregivers spent £38 per day on food and beverages.

Table 6: Average daily food and beverage costs

Food and drink	£
Breakfast	£5
Lunch	£7
Dinner	£13
Hot drinks	£7
Snacks	£6
Total	**£38**

49.2% of respondents reported requiring additional childcare for other children in their family who were not in hospital. This childcare was mainly provided by another parent or partner (27.2%), relatives (13.7%) or friends (6.8%). 13.6% of respondents reported needing support from a childminder or babysitter or additional time from afterschools/crèche (7.8%). If respondents reported associated costs per day for additional childcare due to having a child in hospital, on average the cost per day was £35.39. Respondents also noted additional incidental costs including:

- Treats/toys for children (both in and out of hospital)
- Trips for children
- Reading materials
- Data for mobile phone
- Laundry
- Clothing

Loss of earnings

7.7% of respondents were not in paid employment prior to their child being in hospital. Strikingly, only 1.6% of caregivers reported that having a child in hospital had not impacted their ability to work. The impacts of having a child in hospital on caregivers job/career are summarised in Table 7. (Overleaf)

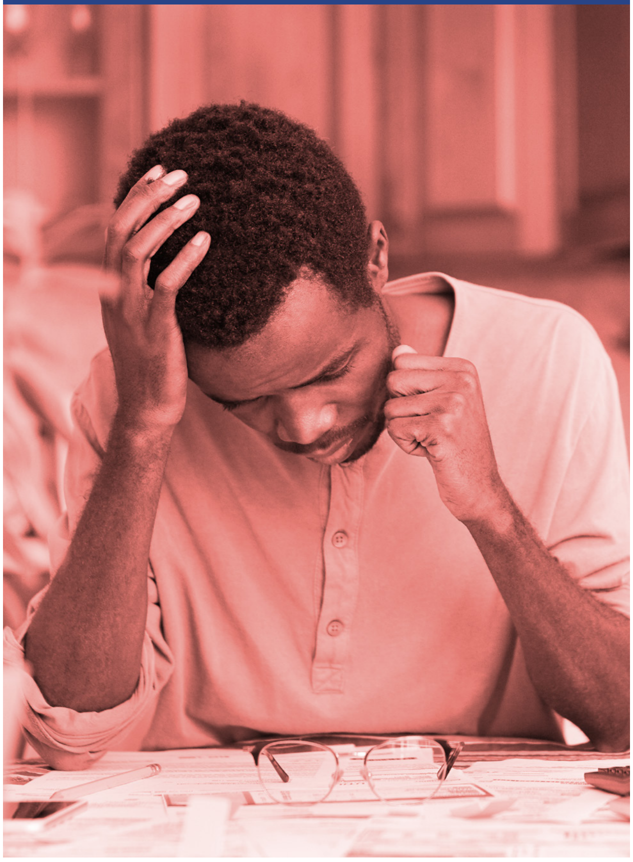
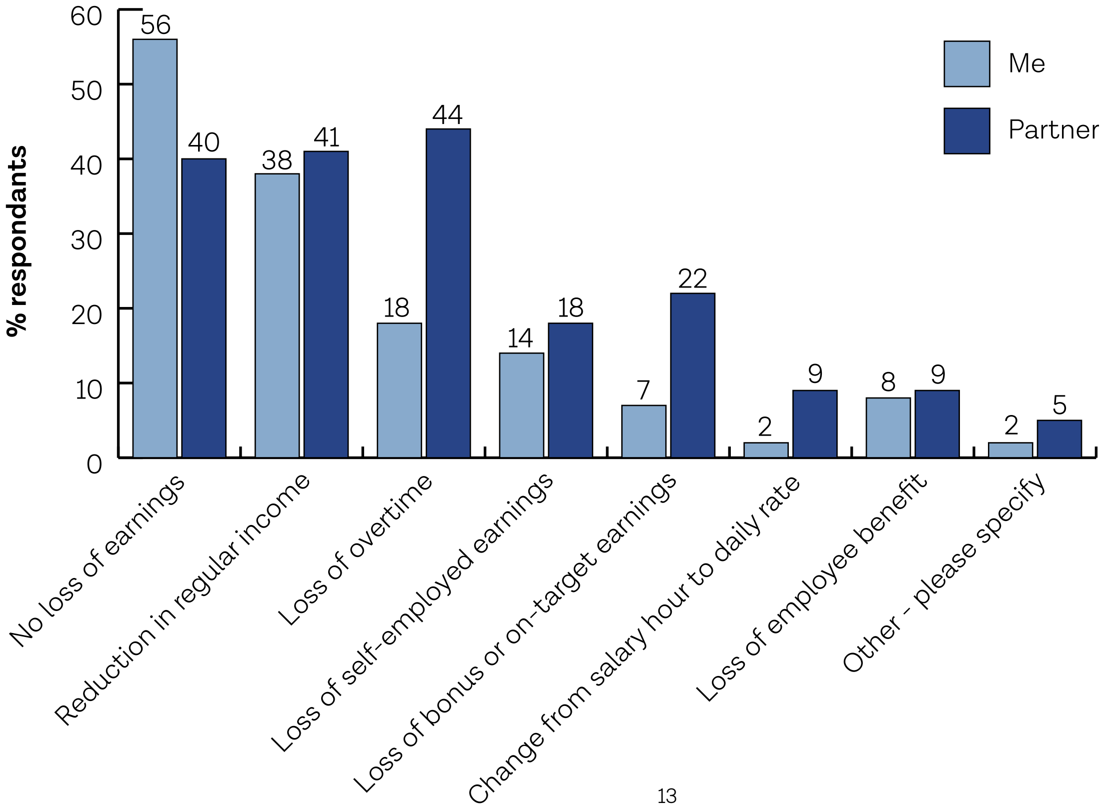


Table 7: Impacts of having a child in hospital on caregivers job/career

Impact on job/career	N	%
I have given up my work to look after my child in hospital	33	17.1
I have reduced my hours	28	14.5
I took a temporary leave of absence from my job	31	16.1
I have missed out on promotions, raise, or other opportunities	17	8.8
I have used much/all of my annual leave	28	14.5
I have use much/all of the force majeure leave	3	1.6
I have taken a role with a lower wage or missed out on promotion	7	3.6
I work the same hours but my job is negatively impacted by caring (e.g. tiredness, lateness, stress)	15	7.8
There has been no impact on my work	3	1.6
I was not in paid employment prior to my child being in hospital	15	7.8
Not impacted as was on maternity leave	11	5.7
Other	2	1.0

If an impact on loss of earnings was reported on average there was a weekly loss of earnings of £265.41 for the respondent and £282.45 for the respondents partner. Broader impacts on income are summarised in Figure 6 for both the respondent and their partner.

Figure 6: Impact on earnings



Respondents reported whether they had heard of, received in the past or currently receive financial support in several forms. These responses are summarised in Table 8. Currently, most financial support is being provided through the mechanisms of DLA and Carers Allowance. Additional support was also provided though meal vouchers (13.3%), parking vouchers (23.8%) and accommodation support (17.5%).

Table 8: Financial support mechanisms

Support	Heard of	Currently receive	Received in the past
Carers Allowance	49.1%	42.6%	8.3%
Direct Payment	36.1%	21.3%	0%
DLA	32.4%	63.0%	4.6%
PIP	50.0%	9.3%	0%
Universal Credit	46.2%	17.6%	2.8%
Other	1.9%	6.5%	0%

28.3% of respondents reported that they had received one-off financial support from a charity, 3.5% of respondents reported ongoing financial support from a charity. In addition, respondents reported broader financial implications and sources of finance due to having a child in hospital, including borrowing money from friends and family (22.6%), using general savings (31.7%) and incurring debt (15.6%, Table 9).

Table 9: Further sources of financial support

Support	N	%
Borrow money from family/friends	45	22.6
Fundraise money	12	6.0
Borrow money from a bank/credit union	14	7.0
Incur debt	31	15.6
Remortgage home	1	0.5
Use general savings	63	31.7
Use retirement savings	4	2.0
Use pay day loans	2	1.0
I have not had to do any of the above	27	13.6

Broader impacts of having a child in hospital

75% of respondents reported that having a child in hospital had either a strong or extreme negative impact on their mental health (Figure 7). In addition, 50% of respondents reported that having a child in hospital had either a strong or extreme negative impact on their physical health (Figure 8).

Figure 7: Impact of having a child in hospital on mental health of caregiver

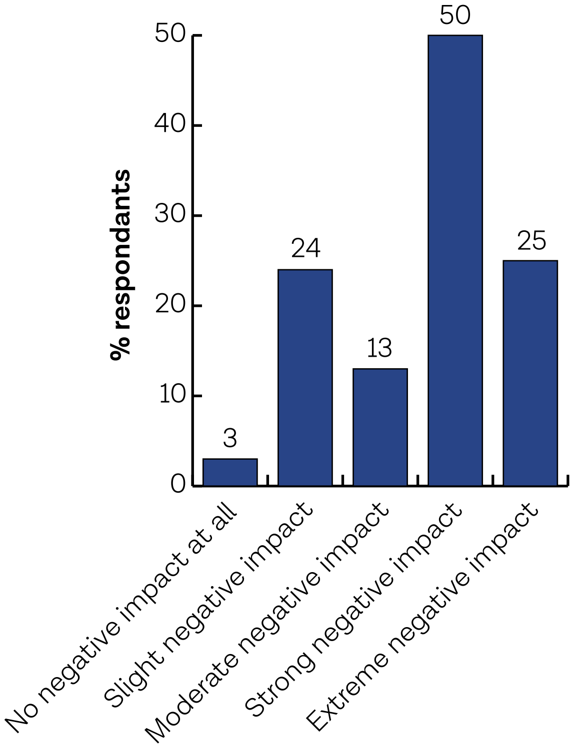
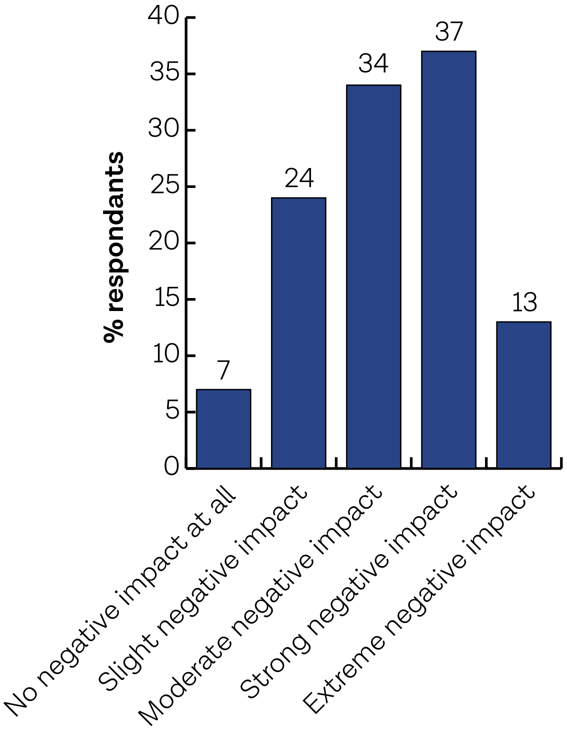


Figure 8: Impact of having a child in hospital on physical health of caregiver



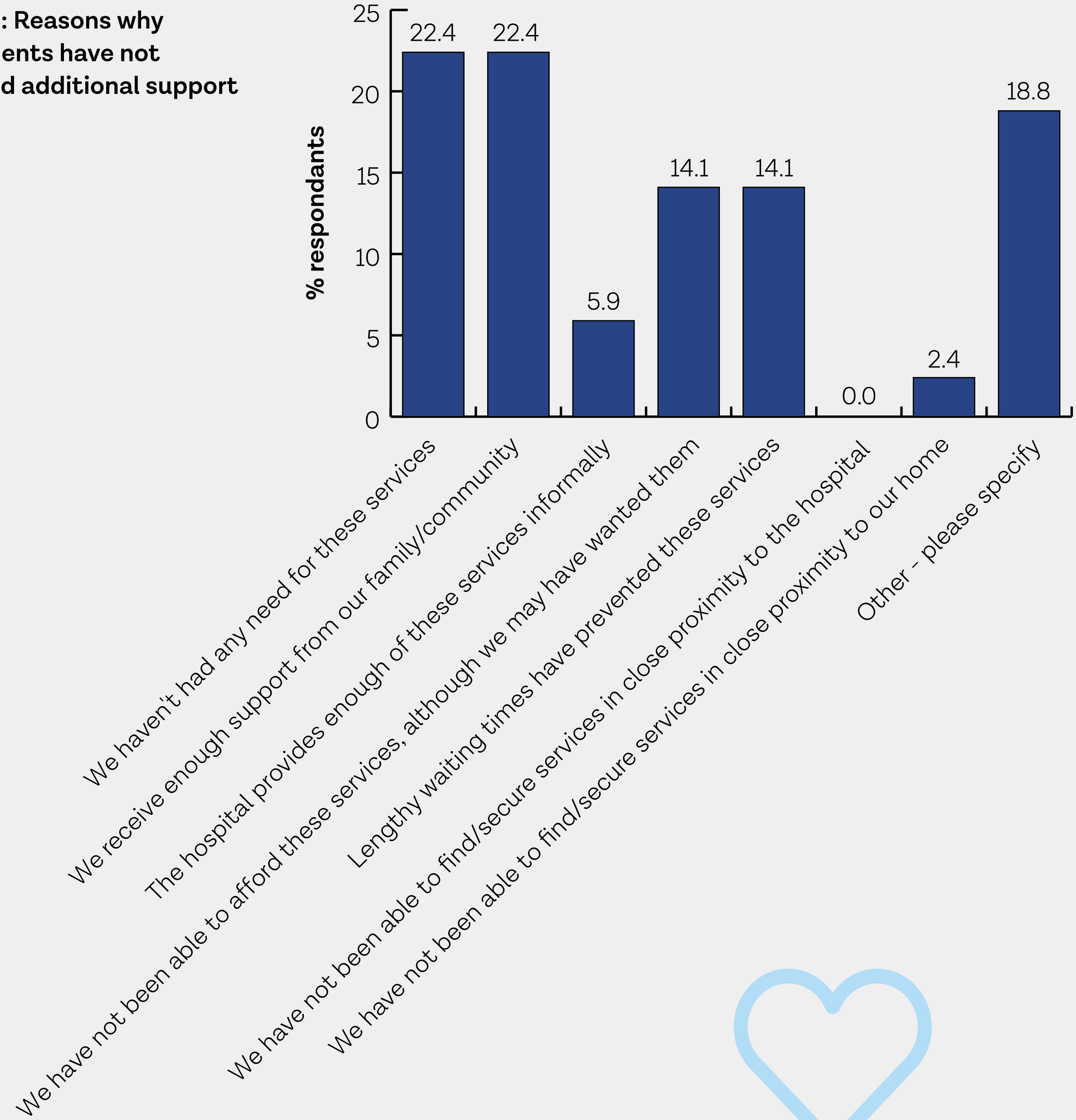
Overall, respondents reported accessing a number of additional services for physical and mental health support for themselves, their partner and their children at home (Table 10). Approximately one third of respondents had not accessed additional services.

Service	Me	My Partner	Children at home
Physiotherapy	63.0%	14.8%	22.2%
Visits to the GP	53.9%	25.3%	20.9%
Counselling/psychology	53.6%	19.1%	27.4%
None	31.6%	39.0%	29.5%

Table 10: Additional services accessed for support

For those respondents who had not accessed services there were numerous reasons why they had not engaged in this process (Figure 9). 22.4% of respondents did not see the need for additional support, with 22.4% reporting they received enough support from family/community and 5.9% saying the support from the hospital was sufficient.

Figure 9: Reasons why respondents have not accessed additional support



Psychological coping strategies

Respondents reported a variety of different ways that they psychologically coped with having a child in hospital. These coping styles are defined as the following, and group level scores are summarised in Table 11:

- Problem-focused coping (active coping, using of information and positive reframing): High scores indicate the use of coping strategies to change the situation and reflect positive coping strategies and are predictive of positive outcomes.
- Emotion-focused coping (use of emotional support, venting, religion and humour): High scores indicate coping strategies to regulate emotions. Low or high scores are not predictive of positive or negative psychological outcomes.
- Avoidant coping (use of self-distraction, substance use or disengagement): Low scores indicate adaptive coping, high scores indicate disengagement with the situation.

Definitions taken from: https://novopsych.com.au/assessments/formulation/brief-cope/

Coping strategy type	Mean (SD)	Range (min to max)
Problem-focused coping	19.5 (5.1)	8-29
Emotion-focused coping	26.1 (4.8)	14-42
Avoidant coping	14.2 (4.4)	8-31

Acceptance

Most respondents reported that they were learning to accept the reality of their child and family's situation, with the following endorsement rates of these statements:

68% "I've been learning to live with it"

62% "I've been accepting the reality of the fact that it has happened"

75% "I've not been making fun of the situation"

Problem solving

Over half of the respondents positively endorsed statements around taking proactive and positive action to solve the problems that their family may face:

58% "I've been thinking hard about what steps to take"

52% "I've been taking action to try to make the situation better."

Using positive supports

Most respondents were not relying on drugs or alcohol to face their stressors:

77% "I've not been using alcohol or other drugs to make myself feel better"

However, relatively low endorsements were provided around psychological support from family and friends:

40% "I've been getting emotional support from others"

43% "I've been trying to get advice or help from other people about what to do"

Results

Respondents were given free text space to suggest changes to services and support that may help improve their, and their families', experiences. First, some parents remarked on the therapeutic nature of simply being asked about their experience and opinions of having a child in hospital:

"Completing this survey was somewhat cathartic. Thank you for taking the time to do this research."

It is also important to note that many caregivers reported high standards of care from all nursing and medical staff. Caregivers did highlight the need for improved communications between busy staff and families, with some caregivers reporting that they felt they were "*being kept in the dark*" over some elements of their child's care.

Overall, there were four key themes identified from caregivers qualitative statements:

- **The COVID-19 response**
- **Finance**
- **Access to amenities**
- **Access to psychological support**

The COVID-19 response

Caregivers recognised the extreme pressures that COVID-19 placed on the health service and its staff. However, parents wished for the health care providers to recognise the special needs of children in hospital in any future health care crisis. Compassionate care of families was requested by caregivers as well as the recognition of the importance of connection with loved-ones for sick children:

"Especially during covid it was so difficult. I saw my baby for about 30s after I regained consciousness from my section. My partner was told to leave the hospital afterwards. My family couldn't visit me most of the time while I was an inpatient in hospital as we lived an hour away and visiting times booked quickly and time slots were terrible."

The need for flexibility of visitors when caring for sick children was also emphasised, especially when young families may have more than one child and childcare may be extremely difficult:

"If we had also been allowed a couple of other relatives into the ward this could have allowed the other parent to stay at home and also provide practical help (such as meals or to get out of hospital for an hour) to the parent in hospital."

Caregivers reported the difficulties in balancing their caregiving duties between their child in hospital and their siblings. The exclusion of siblings from visiting hours led to significant stress: for example, one mother reported that "… *they (sic: the other siblings) got to see their brother three times in five months".*

Caregivers also discussed the support that was provided to them through other parents who had experienced similar situations. This was particularly pertinent during COVID-19 restrictions. These parents acted as guides to navigate the health care or social security system. Caregivers were keen to encourage the facilitation of these relationships to ensure that parents felt connected to one another and provide support:

"We also would have benefitted from emotional support from other parents going through a similar experience with a child with cancer. We had little to no contact with other parents due to covid… Even a WhatsApp group or some form of contact with others would be beneficial."

Finance

Caregivers reported significant financial ramifications of having a child who experienced inpatient care. Additional costs for food and drinks have already been summarised within the report, but the qualitative comments specifically focused on parking charges and the prohibitive expense if both caregivers had to park their vehicles. Issues with the timeliness of access to Disability Living Allowance and Carers Allowance were highlighted. Caregivers reported having to go on sick leave with "stress" as there was no other alternative to taking extended time off work to look after their vulnerable child. This was particularly problematic when one or both caregivers were self-employed.

Access to amenities

Caregivers reported the absolute importance of access to basic amenities when caring for a child in hospital. By having access to simple cooking (such as a kettle, fridge or microwave) and washing facilities, caregivers feel more equipped to deal with the stressors of having a sick child. In turn, these facilities ensure that parents can maintain a healthy diet:

"*The canteen also randomly just doesn't open some evenings so parents have to order takeaways which isn't always very convenient if you don't know where to order from or how to organise this. The last time I stayed I had a packet of crisps from a vending machine for my dinner as the canteen was closed. Also shower facilities should be available to parents who stay. Food and hygiene are basic needs that can cause unnecessary stress if not met."*

Caregivers also discussed the poor nutritional value of food provided for their children adding to concern about their child's health and their own physical and mental wellbeing.

Overall, caregivers discussed the poor standards of accommodation for overnight stays- this was particularly emphasised by parents whose children had experienced care across different hospital settings with variable quality of sleeping arrangements for parents. Caregivers reported the need for appropriate chairs or cot beds as the knock-on impact of lack of these facilities was additional costs for physiotherapy. One parent reported their *"hips screaming with pain"* from the sleeping requirements in hospital. Another reported that *"the camp bed destroyed my back."*

Caregivers highlighted the lack of suitable, safe beds for children with complex needs and disability. This would mean that parents felt unable to leave their children to get food or to go the bathroom due to safety concerns:

"We would often go hungry rather than leave the child."

Caregivers highlighted that even *"a little break to get food"* would make a considerable difference. Caregivers of children with complex needs also reported the problematic lack of hoists to enable personal care (especially showering) meaning that parents needed to lift their children independently, with potential health and safety ramifications. In addition, the lack of play therapy or educational support for children with special educational needs was highlighted as a need, especially considering days in hospital may be particularly difficult to entertain children with complex needs.

Psychological support

Respondents used words such as loneliness, helplessness, and isolation to describe their psychological state whilst their child was experiencing inpatient care. One caregiver described hospital settings as *"emotionally and mentally stressful"*. Caregivers reported psychological distress in response to having a child in hospital. This was faced both on an individual level and couple level:

"Marriage support as relationships can be strained."

Caregivers recognised the need for psychological support in their circumstances:

"I would certainly value a follow up emotional/ counselling service."

However, caregivers reported the intermittent offering of psychological services:

"Psychology services were offered to me once during a prolonged admission because I was very tearful one day on the ward but beyond that never mentioned/alternative supports available."

Once engagement with these services was established, the experience and response was positive:

"The best help during all of our emergency and scary diagnoses has been the introduction of psychology last year. My child has PTSD now from Medical Intervention, the introduction of psychology has been such a difference in the care my daughter has received on the ward which has made things so much easier."

Caregivers indicated the need for ongoing support, especially after a period had passed through which they were able to begin to process their traumatic experiences.

Conclusion

This report highlights the unseen costs, both financial and psychological, that are associated with having a child who has experienced inpatient care. The report indicates that the financial implications for families can be large and that this, combined with the stress of having a child who is ill, is associated with negative impacts on caregivers physical and mental health.

Caregivers have highlighted numerous approaches that may alleviate some of these stressors, from provision and increased access to basic facilities, better provision for caregivers when overnight stays are required, more information and access to financial support and the prioritisation of psychological services for families who have experienced significant, potentially life-changing, health-related events.

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NI Chidren's Health Coalition
The Northern Ireland Children's Health Coalition is a collective of leading charities working in Northern Ireland.

The aim of the coalition is to improve the quality of health services and holistic support for children and young people in Northern Ireland and their families.

The coalition commissioned this report.

NI Children's Health Coalition

Ulster University