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The Impact of Hospitalisation of Children on Parental Dietary Habits: A Qualitative Study

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Abstract

Objective: To explore how prolonged hospitalisation of a child with a neurological condition influences the dietary habits of parents, taking account of their attitudes and perceptions of this experience.

Design: Qualitative study using semi-structured interviews and inductive thematic analysis.

Subjects: Fifteen parents of children (aged 2 – 16 years) with a neurological condition resulting in prolonged periods of hospitalisation were recruited.

Results: Mothers (n=13) and fathers (n=2) that were interviewed experienced frequent hospital visits brought about by their child's condition, or associated medical complications. Dietary habits of parents were affected throughout their time in hospital. Three key themes were identified relating to how hospitalisation influenced this (1) access to food, (2) emotional and physical wellbeing and (3) impact on eating patterns and food choice.

Conclusions: Findings from this study suggest that parents in these circumstances need to be better supported within the hospital setting as a number of barriers exist when it comes to accessing food in hospital and making healthy food choices. Additionally, having a child in hospital has a considerable effect on a parent's emotional wellbeing which further impacts on their dietary habits. The longer term physical and mental health implications of this may influence their ability to care for the sick child.

Introduction

Caring for a child with a chronic condition can have a substantial impact on parents' health due to the burden of care[1]. In particular, heightened stress has been reported in parents of children with developmental and intellectual disabilities[2]. Balancing the healthcare needs of their child with those of other family members and work commitments has been shown to contribute to feelings of depression, anxiety and social isolation[2-4].

Although research in this population group is limited, more generally, the relationship between stress and anxiety on nutritional intake has been reported. It is well understood that stress can cause either under- or over-eating depending on the severity, where chronic stress more often leads to an increased intake in energy-dense foods, namely those higher in sugar and fat[5,6]. Inevitably, this type of diet will be associated with an increased risk of obesity and other non-communicable diseases.

It is estimated that eight percent of the child population in the UK will have a level of disability[7], with the vast majority being neurological in origin. A number of these chronic neurological conditions can result in recurrent hospital admissions due to the challenges of treatment, progression of the disease and requirements of follow-up therapy. Although there are studies which have looked at specific neurological disorders and supporting parental care needs[4,8], research in the wider area is lacking. More specifically, how hospital admission influences the health and wellbeing of the parent of a child with a neurological disorder is unknown. This study uses a qualitative approach to explore how prolonged periods of hospitalisation of a child with a neurological condition influences the dietary habits of parents. We were

particularly interested in understanding more about parents' experiences and perceptions of their dietary habits while attending the hospital.

Methods

Participants and Recruitment

Participants were included if they were the parent of a child (aged 16 years or younger) with a neurological condition which had resulted in hospital admission of at least seven consecutive days in the last two years. The study was promoted through Cerebra, a UK based charity, using social media (Facebook). As compensation for their time commitment, participants were offered a £25 shopping voucher upon completion of the interview.

The purposive sampling framework considered parent's gender, age, marital status and neurological condition of their child. This approach was adopted to ensure we interviewed parents with varied backgrounds. This information, along with an estimated height and weight, used to establish body mass index (BMI), was obtained through self-reporting by parents.

Data Collection

One to one semi-structured interviews were conducted in person or over the telephone with one of the researchers (KC). All interviews were completed between April 2017 and July 2017. The semi-structured interview guide was developed through discussions within the research team. It was structured around three key questions that enabled participants to openly describe their food habits on a typical day when their child was at home, moving on to discuss their diet on a day when

their child was at hospital. Participants were prompted in order to encourage a deeper discussion and reflection of their feelings and experiences. They were also asked to consider reasons why their eating habits differed under these two circumstances. Interviews ceased when it was considered that topics being covered were already present in the dataset. Informed consent was recorded at the beginning of each interview.

Analysis

Data analysis was conducted concurrently with data collection. Data were analysed using an inductive thematic approach[9]. Audio recorded interviews were transcribed verbatim, generating just over 27,750 words of text. All identifiable information was removed in order to maintain the anonymity of the participants. To familiarise the researcher with the data the transcripts were imported into Nvivo[10] read and reread. The initial codes that were generated from the data consisted of an extract from the text that represented an area of interest relevant to and reflecting the participants' experiences of their dietary habits. Mind-maps were used to further explore the data assembling and combining the relevant data-coded extracts into three themes. Discussion by two of the research team (KC and VH) led to further refinement and structuring of the analysis where sub-themes were identified and theme headings agreed.

Ethics Approval

The study was granted ethical approval by the University of Sheffield, School of Health and Related Research, Ethics Committee (Reference number 013380).

Results

Fifteen interviews were conducted, 14 of which were by telephone and one interview in person. Interviews lasted between 20 and 60 minutes. Participant's demographic details, as well as the neurological conditions of the children, are outlined in Table 1. The participants' age ranged from 24 to 55 years, with the average age being 38 years. The majority of participants were mothers (n = 13) and were married (n = 12). Two of the parents interviewed had more than one child with a chronic neurological condition.

All parents who were interviewed experienced frequent hospital visits brought about by the condition itself, or associated medical complications. Collectively, participants attended 12 different NHS hospitals in the UK. Ten of these were specialist children's hospitals and two were large general hospitals with a paediatric department. Four participants reported that their child received ongoing care from two different units. The frequency of visits ranged from twice a year to three visits within a six-month period with varied lengths. Some parents reported spending more time at hospital than at home within a year's span.

[Insert Table 1]

Two major themes which emerged from the interviews were (1) access to food and (2) emotional and physical wellbeing. Encompassing these two themes was an overarching theme (3) 'Impact on parents' eating patterns and food choice'. The thematic analysis is summarised below. Sub-themes have been included to help structure our findings with quotes from the data adding depth to the understanding of the narrative.

Theme 1: Access to Food

Hospital catering provision and facilities

Experiences of the hospital facilities were mixed and varied between hospitals. For some, parents' rooms and accommodation provided amenities which allowed them to bring in food and store it.

> *"If I'm lucky enough to get a room in the parent's accommodation then it will be better because I can use the facilities there to manage myself better because they give you a shelf in a fridge and a shelf in a freezer and a cupboard."* (Mother)

Opening hours of catering facilities was a common issue, with limited food available later in the day and weekends. In these circumstances some parents accessed food from a vending machine.

> *"..... it is manageable on weekdays but on weekends, absolutely everything is shut. There's no shops, there's no food canteen..... So, unless you leave the hospital you literally are limited to a packet of crisps out of the machine."*
>
> (Mother)

A few parents were able to have food from the hospital restaurant or takeaway food delivered to their room. For others, accessing the catering facilities in the hospital was not an issue.

Financial considerations

The expense of eating out at hospital was a recurring finding. Due to multiple hospital visits, some parents left their job to care for their child or received unpaid leave. Others were dependent on their partner's salary

> "*To be honest you also can't afford to keep going down to the canteen either and buying meals you know snacks do work out cheaper.*" (Mother)

Caring responsibilities

In a number or cases, participants described caring for their child in hospital meant that they did not have enough time to leave the ward to get food. Others felt guilty or fearful if they did. In most cases, parents were only willing to leave their child once they were asleep or if family or friends were available to look after them.

> "*When I came back he was sobbing…… he does need a lot of your time and that's why I can only really get food when somebody else can sit with him*."
>
> (Mother)

Self-provision of food

Parents that reported not being able to leave their child for any amount of time explained how they would prepare food at home to bring into hospital. Although they felt that this was sufficient for short stays, it was not a viable option for parents who stayed for more than a few days at a time.

"*So, for the admission last week …..I went with a bag full of fruit and porridge bars and stuff, to make sure because I knew I wouldn't be leaving the room until I left.*"

(Father)

Theme 2: Emotional and physical wellbeing

The impact on parents' health included a range of physical and psychological symptoms such as anxiety and exhaustion. Although responses varied, emotions appeared to heavily influence how and what a parent ate at hospital.

Sleep deprivation

All parents in this study stayed with their child over the course of their hospital stay. The majority reported a lack of sleep due to the environment such as having to sleep on chairs or cots that were too small. Parents described how they felt exhausted, often due to a combination of lack of sleep, stress and worry about being at the hospital.

"*So you pull this bed out at 9 o'clock at night and you sleep next to him but at the same time you have nurses coming in and doing blood sugars, waking him up, moving around you….. and you just don't get any [sleep] you know you're completely sleep-deprived…..*" (Mother)

Stress

The majority of parents explained how they felt stressed at hospital being away from their family, seeing their child in pain and not being in control of administering their child's medication or feed. Parents described how these feelings affected their appetite, leading to over- or under-eating.

> *"I think when you're riding a level of stress then the temptation to go and get a coffee and a Mars bar is really high*." (Father)

Boredom

Due to the confinements of staying next to their child's side most of the parents expressed feelings of boredom. For some, their time was filled by eating high calorie snack foods.

> *"All you've got to do is just sit next to your child's cot or bed all day and you're just watching over them and you just eat out of boredom."* (Mother)

Changes to weight

A minority of parents reported being unable to eat because they were too worried, stressed, preoccupied by their child to think about food, or they had no appetite.

> *"I pretty much always lose weight whenever I go into hospital….anything from up to like half a stone [3Kg] because I'm just not eating…"* (Mother)

As most parents' response to being in hospital was to over-eat, weight gain was a concern.

"It's quite a massive thing that we, both my husband and myself, have put on a lot of weight last year because we spent so much time just sitting in hospital and eating just rubbish." (Mother)

In these cases parents described feeling frustrated with themselves as well as worrying about their health due to gaining weight in such a short space of time.

Theme 3: Impact on eating pattern and food choice

For the majority of parents, there was a stark contrast in response when describing what and how they ate at home and at hospital.

Irregular eating pattern

Parents highlighted a number of scenarios that resulted in irregular eating patterns. Whilst some wanted to wait until their child was sleeping, for others, meal times were dictated by doctor's rounds.

"I suppose the harder thing about popping out is making sure you don't miss the doctors …….. So you can kind of get there at 9 and think, "Well I won't get any breakfast until I've seen the doctors." And then you're still sitting there at 1 o'clock and they still haven't been around." (Mother)

Excessive Snacking

As parents were aware of the likelihood of irregular eating patterns at hospital, many said that they would either come to the hospital with multiple snacks or they would

buy their food in bulk in the morning. These snacks primarily consisted of crisps, chocolate and biscuits.

> *"Um crisps, biscuits, chocolates - anything that you can just grab hold of from the canteen or the vending machine. It's just stuff that I know won't go off….."*
>
> (Mother)

Impact on family meals

After spending time in the hospital with their child, parents expressed they would often reach home feeling exhausted or upset. This in turn would affect the family's diet as most parents who were the carers were also responsible for cooking for their families when they were home.

> "*.....the impact on the diet is not limited just to the parents of the child but the whole of the family as well because I don't have time to get home and cook proper meals for my other children.*" (Mother)

Discussion

This is the first study to investigate the effects of hospitalisation of children on parental dietary habits. The interviews provided a rich source of information on parents' access to food, their emotional and physical wellbeing and how it impacted on their eating patterns and food choice. It is particularly valuable considering the dearth of literature on how hospitalisation of children affects their parents, specifically from a nutritional stance. Whilst personal factors such as income and access to food, as drivers of food choice, are not new concepts[11], this study begins to uncover some of the barriers and facilitators to parents having healthy eating habits during periods of child hospitalisation.

In relation to the physical environment, our study suggests that life was made easier for parents in healthcare settings where food was delivered to the ward from the hospital restaurant, or where they were able to make a meal at their hospital accommodation or in a parent room. Vending machines, although often not ideal in terms of providing healthy options, were also seen as a valuable option. In some cases the organisational structure, such as limited opening hours of hospital catering facilities, was a hindrance. Overall, inconsistency in the facilities available in childrens' services in UK hospitals led to varied experiences. Finally, our findings concur with previous work[12], recognising the financial strain of caring for sick children in relation to parents accessing food in hospital.

Additional barriers to healthy eating habits in this hospital visitor context appear to relate to parents' perceived role in caring for their child in hospital. Previous work by Avis and Reardon[13] describes how a breakdown in the negotiation of family-centred care between nurses and parents has the potential for parents to feel unable to leave their child's bedside. What is of particular interest in our study, and to our knowledge is unreported elsewhere, is how the parents' perceived burden of care within the hospital environment impacted on their behaviour in terms of when, and for how long, they felt able to leave their child to get food and eat. The times that they felt able to leave the ward were often dictated by the availability of someone else to stay with their child, waiting for them to be asleep or not wanting to miss the opportunity to speak to the doctor on their rounds. Overall, high levels of parental stress, worry, anxiety and upset found were consistent with previous literature where parents' mental health suffered through their caregiving duties[1,12,14,15].

In our study snacks, ready-meals, and takeaways were chosen as they were convenient and could be eaten quickly, minimising the time away from their child. In some cases these food choices were also made on the basis of emotional stress and boredom. Previous research highlights a relationship exists between stress and eating patterns that contribute to obesity[5,6]. Furthermore, people under chronic life stress are more likely to have a greater preference for foods that are high in sugar and fat[5,6]. The potential long term implications of this on the physical and mental health of parents of sick children requires further investigation.

Whilst our findings provide new insights into a previously under-studied area, limitations should be acknowledged. In the UK, recruiting participants from the National Health Service requires ethical approval from the Health Research Authority and from each healthcare organisation involved in the study. Due to the intention to gain the experiences of families from as many NHS hospitals as possible, alongside the relatively short timescale of the project, the decision was made to use social media to disseminate the details of the project. This meant that recruitment was a challenge as face to face contact with families within a clinical environment was not possible. Taking into account parents' busy and stressful lives, participating in research may not have been a priority, leading to under-representation of some carers in our sample. For example, only two fathers took part in the study and therefore their views were under-represented. Having both a mother's and a father's perspective on caring for a child in hospital could provide a more rounded perspective on the impact on dietary habits and food intake of the whole family. Finally, although the analysis provided an account of how parents' perceived their

eating habits were affected, due to the nature and timing of the study, it was not possible to gain participant verification of the findings.

This study identifies the need to develop and test interventions aimed at supporting parents to make healthy eating choices during periods of hospitalisation of their child. Catering services that delivered food to the ward and use of family rooms were highlighted as good examples of practice. Development of an intervention that encompasses these aspects of support may have the potential to positively influence parents' food choice and dietary habits during this stressful period. Importantly, the healthcare team, including hospital managers, have an opportunity to play a significant role in improving the lives of parents caring for their child in hospital. Given that these children, and therefore their carers, are frequent users of hospital services, exploring ways to ensure that parents are physically and emotionally supported during their stay is paramount. In the UK, reasonable adjustments should be made prior to admission to accommodate the specific needs of this group of patients. The potential for the dietary needs and sleeping arrangements of carers to be considered as part of this practice, needs to be explored.

Conclusion

This study has improved our understanding related to how parents' eating habits are affected when caring for a child that is in hospital. Findings suggest that parents in these circumstances need to be better supported within the hospital setting as a number of barriers exist when it comes to accessing healthy food in hospital. Furthermore, being in hospital has a considerable effect on a parent's emotional wellbeing which in turn impacts on their eating pattern and food choice. Importantly, this study provides insight into how and why parents of children with neurological conditions eat the way they do while at hospital. Further research is needed to

develop and test interventions which may be able to positively change parents' eating behaviour and improve their wellbeing. Indeed, changing hospital practices in this way has the potential to be relevant for all families caring for a child that has prolonged periods of hospitalisation.

What is already known on this topic:

- Hospitalisation of children leads to heightened stress, depression, and anxiety in parents due to balancing the healthcare needs of their child with daily commitments.
- Parents of a child with a disability have an increased risk of poor health and a lack of wellbeing, mostly due to psychological strain.
- Individuals suffering from chronic stress tend to report an increased intake in energy- and nutrient-dense foods.

What this study adds:

- Access to food, finances and caring responsibilities drive parents' food choice while at hospital, leading to a change in dietary habits.
- Having a child in hospital negatively impacts on a parent's emotional and physical wellbeing, influencing their eating pattern and food choice.
- Ensuring that catering facilities are available in hospitals may support parents to make healthy food choices, which in turn may improve their wellbeing.

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Table 1. Demographic data of parents and their children

Participant characteristics	**N**
Mother	13
Father	2
Mean Age (years)	38
Range of Age (years)	24 – 55
Marital Status	
Married	12
Single	2
Divorced/ Separated	1
Self-reported BMI of the parent kg/m^2	
Normal (18.5 – 25)	5
Overweight (25 – 30)	3
Moderately obese (30 – 35)	4
Severely obese (35 – 40)	3
Geographical region	
England	
North	5
South	6
Northern Ireland	1
Scotland	
North	1
South	2
Neurological Conditions of the Children	
Cerebral Palsy	1
Complex epilepsy	3
Fucosidosis	1
Herpes simplex encephalitis	1
Hydrocephalus	3
Hypoxic-Ischemic Encephalopathy	2
Leukodystrophy	1
Microlissencephaly	1
Undiagnosed multiple disabilities	2