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Children’s experiences of hospitalization over time: An evaluation of using poetry and creative writing by children to assess their experiences of hospitalization

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Abstract
This article explores children’s experiences of hospital admissions through their poetry and creative writing and assesses the validity of this medium compared to other methods of evaluation. Pediatric patient experiences of hospital and their effects on children have been studied in various ways and there have been stepwise changes throughout the past century, matching the overall changes of medical care from paternalistic to patient centered. 17 poems were analyzed from children aged 6-13 years old (median 10) for recurrent themes whilst admitted to a large tertiary hospital in the north of England. Children frequently wrote about attacks on their senses, missing friends and family as well as their interactions with hospital staff. Other aspects described by the children included invasive procedures, difficulty with sleep, and their opinions of hospital food. Not all things were described in a negative way, with positivity surrounding play areas, meeting new peers and the availability of play therapists. Children’s voices are often lost in the hospital setting and it is of vital importance that they are heard so that their care can be optimized and lessen any damaging effects that traumatic experiences have on them. The results of this article match those of previous investigations and show creative writing can be used as a patient experience analysis tool.

Keywords
Patient experience, pediatrics, holistic, patient-centred care, family-centered care

Introduction

Historical context
Medical opinion surrounding the emotional effects of illness on children has changed over the years, as have the ways researchers assess it. In 1934 David Forsyth wrote about the psychological effects of bodily illness in children and claimed to be the first person to formally assess it.¹ His work didn’t involve direct discussion with children, rather, was based on his experiences. He believed children attributed illness to previous sin and that they were unable to conceptualize causative agents of disease.³ Forsyth’s work laid the foundations for those who followed and promoted the idea that hospitals were stressful places and could be psychologically damaging for children. He believed that children should be well informed and that illness and its resultant separation from peers was greatly damaging and could lead to stigmatization.¹

In the decades that followed Forsyth’s work, the approach of researchers changed and began to listen to the voices of children. The Platt Report in 1959 for the UK Ministry of Health was instrumental in changing the perceptions of how children should be treated in hospital.² This report was triggered by the vital work of Bowlby in describing attachment theory and was later followed by the 1953 short film by Robertson following the journey of a distressed two year old as they were admitted to hospital and separated from their mother.²-⁵ Before this time, hospitals were starkly different to how we see them today, notably that parents were only allowed limited access to visit their children and that there were seldom play areas; although, there have been echoes of these restrictions throughout the Covid pandemic. Over time, hospitals have evolved to better accommodate children and to try and normalize life for those admitted, as set out in the UK Department of Health’s national service framework for children, young people and maternity services 2004.⁶

Effects of hospitalization on children
Developmental studies have confirmed that young children who spend long periods of time in hospital and are separated from family and unable to play, fall behind their age matched peers and are more prone to developing psychiatric disorders.⁷-¹¹ Interest from nursing and psychology groups has driven an evolution within the study of children’s perceptions: from presumptions to developmental studies, and the creation of in-depth questionnaires.¹⁰,¹²-¹⁵ Several research papers have utilized the Barton Hospital Picture Test, including Wilson et al., a test that asks children to tell a story by describing various pictures of children in different situations in hospital.¹⁶ Other studies have moved away from generalist reviews, instead focusing on specific aspects of pediatric
admissions such as intensive care with a view to combat the emerging phenomenon of post-traumatic stress disorder in the sickest of children. There have also been studies reviewing children’s arts and craft work throughout their admissions and how this could mirror their feelings and show their changing emotions throughout their illness journey. This wide-ranging spread of data collection methods have yielded similar results and shown that children’s priorities in hospital focus on comfort, family contact, spaces to play and building trusting relationships with staff.

The interest in finding what aspects of care matter most to children has been matched by the interest in finding out how much involvement children want in planning their care. Studies have highlighted the importance of caregivers and parents/guardians remembering that children have limited autonomy. As such, it is vital that adults try to understand and employ the child’s perspective when it comes to planning their care. A systematic review in 2020 showed that only half of child hospital experience studies included the child’s voice as well as the parents’, and that those that did, showed a difference in reported outcomes between the two groups. Observational and interview based investigations in Ireland and Sweden showed that children were generally happy for adults to decide the major aspects of their care, but that they valued being informed about the decision making process highly and in particularly how treatments would be administered.

This study reviews children’s poetry which was written whilst they were patients in hospital, using it as a medium for assessing their fears, their ideas and the things that they like about hospital. To date, there are few reports using poetry as a medium of analysis; however, creative work has been shown to be both therapeutic and beneficial for supplementing more formal questionnaire-based studies and for providing a window onto the less tangible, holistic views of treatment success.

**Methods**

Poems were written by pediatric inpatients in a UK teaching hospital when attending the hospital school and children were encouraged to write about their experiences of hospital life. The project was approved by the local ethics committee and both the children and their parents/guardians were aware that the project was taking place and gave verbal consent. A series of 30-minute lessons were run over a four-week period, and children were able to work on their creative writing outside of lesson time. Sessions were guided by teachers and lessons tailored to aid those new to poetry by showing them examples of poems and practicing writing in different styles. Different styles of poetry were taught to the children including acrostic, haiku, kenning and freeform. These poetry classes were incorporated into the curriculum of the school and intended to be of minimal disruption to the other subjects taught. The teachers giving the lessons were fully trained educationalists with experience of working in the hospital setting and had previously taught classes on poetry including the styles of poetry used for this analysis. The completed works were shared with their classmates and made into a wall display. The children were aware of each other’s writing, but their thoughts on other children’s work was not recorded and neither were the parents'/guardians’ feelings about the results.

There were no constraints on inclusion criteria, and all the poetry that was collected was reviewed. No set percentage of each type of poetry was requested, and all children that the teachers felt were able to participate were approached by the school staff; none refused.

The poems were analyzed for recurring themes surrounding children’s views and feelings on hospital life and on the staff that they encountered. The analysis was performed by a pediatric doctor with previous experience in education and language teaching. Analysis was performed manually by first reading the pieces as a whole for their general themes and then by picking out key words and phrases and recording these. These key words were then grouped with similar or related words into categories. Increased frequency of a category was interpreted as being more important to the children. Where there were spelling errors a best guess was made as to the intended word. Although creative writing can have hidden meanings intended by the writer, this aspect was not explored as the children were not interviewed about their works and what they had written.

Bias was minimized by word processing the poetry after it was completed, and it was analyzed in anonymized form without any demographic information available. The poetry was later matched with demographic information for further review. The analyzer did not meet the children and they were free to stop their involvement if they wished. The children were reminded throughout that there were no right or wrong answers and although parents/guardians were allowed to help the children, they were requested to ensure the work was that of the child.

**Forms of poetry used**

There were three different types of poem analyzed which had unique structural rules; children were also allowed to write freeform poems in whatever structure they wished. Children were encouraged by the teaching staff to choose the type or types of poetry they wanted to write. Although the lessons given within the hospital school are matched to national curricula there is an ethos of fun and flexibility within this teaching environment. The implications of setting rules on the forms of poetry could be argued to restrict the creative output of some; however, others
would argue that restricting the way that a poem must be formed causes an individual to find more dynamic solutions to portray their message. This dynamic use of language is not just present in adults but is part of the natural language development of children as they explore how to convey messages to those around them and be understood.

The different types of poetry used were as follows. An acrostic poem has a subject word written down the left margin of a page and the first word of each line starts with the corresponding letter from the subject word. This simple form of poem writing helps frame an idea and generate creativity to fit within the constraints of its rules. A kenning originates from an Old Norse style of writing. Each line of the poem consists only of two words which are a figurative descriptor for a noun, often used in a metaphorical way. For example, a young child could be called a thumb-sucker. A haiku is formed of three lines, restricted to five, seven and five syllables respectively.

To help foster a fun and creative experience, these rules were described to the children as being more like games and a chance to play with words rather than being a list of things that they could or could not do. This approach was used to try and minimize any feelings of constraint and to help them to enjoy the process and generate creativity.

Results

Seventeen poems from different children were analyzed with a median age of 10 years, range 6-13; 4 children were 10 years old, and 6 were 13 years old. There were 8 acrostic poems, 4 freeform, 3 kennings and 2 haikus. The combined word count of the works was 825. The children were inpatients in the hospital at the time of writing their poems, and they were being treated for a variety of medical and surgical problems. The majority of them, 12, had been admitted to the hospital on multiple occasions whereas 5 were admitted for the first time. The children were from a variety of different social backgrounds and ethnicities, but this was not recorded or analyzed. All the children approached participated and none dropped out.

The poetry covered a variety of subjects yet revealed a series of recurring themes detailed below and summarized in Table 1, including: attacks on the senses; hospital staff; missing family and friends; food and beds; invasive procedures; spaces to play; and medical treatments.

Attacks on the senses

Sensory experiences were the most commonly noted theme, occurring 23 times. Children mentioned the sights, smells and sounds they encountered throughout many of the poems. They mentioned strong smells that weren’t common at home, such as ‘smelly sterile gloves’ and ‘antibacterial wipes’. The taste of an oxygen mask ‘like

being forced to eat metal’ and ‘hearing babies crying like a knife scraping a plate’. Other sensory experiences included the ‘unbearable hot heating’, and ‘smelling sick shooting from someone’s mouth’.

Hospital staff

Hospital staff were mentioned 14 times. Most children wrote of hospital staff in a positive way, with the only negative lines being reserved for ‘frowning doctors’. Whereas nurses were said to be ‘smiling’, and ‘rushing around like magic mice’. Non-clinical staff were referenced too with quotes including, ‘play workers provide lots of fun’ and ‘cleaners shrivel their cloths and clean the beds.’

Friends and family

There were 13 references to friends, family and social interaction. Several poems made reference to being homesick and looking forward to going home. Children wrote about how they looked forward to having visitors and were sad when the visitors had to leave. However, one child mentioned that ‘in the hospital I meet a lot of interesting people’.

Food and sleep

Food and sleeping conditions were mentioned 13 times. Food was mostly regarded negatively, one child said they would ‘turn into one’ if they ate any more potatoes. Others described the food as ‘horrid’ and ‘nasty’, but another said they enjoyed the smell of toast in the morning. One child seemed to enjoy hospital beds, describing them as, ‘weird but cool because they can move up and down’, whereas another wrote about the ‘rough bed sheets’ and, ‘squeaky beds’.

Invasive procedures

Invasive procedures were mentioned on 12 occasions. This included the mention of, ‘sharp needles’ and, ‘gory blood’. One child wrote a longer freeform poem that frequently described procedures, ‘I’ve had catheters and epidurals and drains galore’. Another child commented on other children and said that ‘some children get upset about the spike needles’.

Spaces to play

Play was mentioned 10 times within the poems. One child was excited about going to the playroom as ‘there is lots of things to do’, whereas another said theirs was a ‘big disappointment’. Another simply said ‘fun, fun, fun’.

Treatments

The medical treatments that the children received were referenced 7 times throughout the poems. There were positive comments such as, ‘medicine eases the pain’ and one child mentioned how after struggling with intravenous access she had been given a permanent intravenous line and wrote, ‘now I’ve got a portacath – it’s the best thing I’ve had in years’. One child described prednisolone as...
Table 1. Recurring Themes

<table>
<thead>
<tr>
<th>Subject</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attacks on the senses (23)</td>
<td>Smells – ‘smelly sterile gloves’, ‘antibacterial wipes’, ‘sick shooting from someone’s mouth’</td>
</tr>
<tr>
<td></td>
<td>Sounds – ‘babies crying like a knife scraping a plate’, ‘nebulizers whooshing’</td>
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<td></td>
<td>Taste – an oxygen mask ‘like being forced to eat metal’</td>
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<tr>
<td></td>
<td>Temperature – ‘unbearable hot heating’, ‘none of the windows open’</td>
</tr>
<tr>
<td>Hospital staff (14)</td>
<td>Nurses – ‘smiling’, ‘rushing around like magic mice’, ‘special every day’, ‘are like machines’</td>
</tr>
<tr>
<td></td>
<td>Doctors – ‘frowning’, ‘friendly surgeons’</td>
</tr>
<tr>
<td></td>
<td>Other – ‘cleaners shrivel their cloths and clean the beds’, ‘play workers provide lots of fun stuff’</td>
</tr>
<tr>
<td>Friends, family and social interaction (13)</td>
<td>Positive comments – ‘lots of people want to see me’, ‘a visitor like Richard makes me happy’, ‘I meet a lot of interesting people’, ‘there’s people like me’</td>
</tr>
<tr>
<td></td>
<td>Negative comments – ‘I feel sad when my visitors leave’, ‘I miss my mum’, ‘I miss my house’</td>
</tr>
<tr>
<td>Food and sleep (13)</td>
<td>Positive comments – ‘toast makes your belly rumble’, ‘perfect pavlova’, one child described the beds as ‘weird but cool because they can move up and down’, ‘some children get upset about the spikey needles’</td>
</tr>
<tr>
<td></td>
<td>Negative comments – one child said they would ‘turn into one’ if they ate any more potatoes, the food was ‘nasty’ and ‘horrific’, ‘a loathsome plate of food’, ‘rough bed sheets’, ‘squeaky beds’</td>
</tr>
<tr>
<td>Invasive procedures (12)</td>
<td>‘Sharp needles’, ‘gory blood’, ‘I’ve had catheters and epidurals galore’, ‘some children get upset about the spikey needles’</td>
</tr>
<tr>
<td>Spaces to play (10)</td>
<td>Positive comments – ‘lots of things to do’, ‘cracking fabulous fun’, ‘fun, fun, fun’</td>
</tr>
<tr>
<td></td>
<td>Negative comments – the playroom was a ‘big disappointment’</td>
</tr>
<tr>
<td>Treatments (7)</td>
<td>Positive comments – ‘Medicine eases the pain’, ‘now I’ve got a portacath – it’s the best thing I’ve had in years’</td>
</tr>
<tr>
<td></td>
<td>Negative comments – ‘Despicable prednisolone’, ‘tablets taste terrible’</td>
</tr>
</tbody>
</table>

‘despicable’ and another said generally that, ‘tablets taste terrible’.

**Discussion**

The analysis of the poetry yielded qualitative data which was open to interpretation. As described in the methods section, the poetry was reviewed for recurring themes and not for any hidden meaning which could have been contained. Although subtext or concealed meaning will have been missed, this approach minimized interpreter bias by only allowing the literal meaning of words to be used. The sample size was quite small with there being only 17 poems containing a cumulative total of 825 words which could have resulted in some skewing of results. There was only one person interpreting the works, so any future research would benefit from multiple analysists comparing and combining their interpretations. Although there are computerized methods for analyzing a corpus of writing for themes and recurring words, such as the Latent Dirichlet Allocation, this small body of work made manual analysis possible and helped allow for incorrectly spelled words to be included.\(^{30,31}\)

The ages of the children were varied, with the youngest being 6 years old; however, the majority were over 10. There were no set age ranges for inclusion criteria, and, as such, the poetry collected was from children with variable language abilities. Although children’s capability to express complex emotions and to describe challenging events improves with advancing age, it is vital to highlight the voices of all children, no matter how young.\(^{32}\) The children had different medical conditions and prior experiences of hospital which will have effected what they decided to write about. The children were also allowed to be supported through the writing process by their parents/guardians, but the words written were believed to be those of the children. A challenge of this method of data collection was in the children’s understanding of the task of writing poetry about a specific topic, but this was negated as best as possible by the teachers running lessons on what poetry is and how to write it.
An additional benefit of collecting data through a creative medium such as poetry and narrative writing is the therapeutic benefit that some children may have experienced. The children were not questioned on how the writing of poetry helped any anxiety or depression they may have had, but previous research has shown that writing about hospital experiences can reduce levels of depression and anxiety.\textsuperscript{26,33,34} Assessing this added effect was outside of the scope of this research, but could be investigated as part of future work.

Making hospitals child-friendly is of the utmost importance for allowing a minimally traumatic experience for children, with the least impact on development and mental health.\textsuperscript{9–11} The most commonly described themes in the poems were the attacks on the senses noted by the children. The word choices used evoked strongly negative imagery and created a sense that the hospital they were experiencing was, at times, not a comfortable place. Every sense was being bombarded, especially the sounds and smells they experienced. It is clear from these poems that for these children hospital was not a home away from home or place of calm recuperation.

Ever since Forsyth (1934), separation from family and friends has been highlighted as one of the main negative effects on children’s development whilst being in hospital.\textsuperscript{1} There were several mentions of children missing family and wanting to have visitors during their time in hospital. However, one child mentioned that ‘in the hospital I meet a lot of interesting people’, and this is an aspect of hospital life that can be protective for the developing child. Meeting new people and finding peers with similar medical conditions can give children with health conditions a way to address psychosocial problems and help them form robust coping mechanisms, something that could be beneficial for some.\textsuperscript{39}

It is clear that for the children who wrote these poems the staff were a major part of hospital life. Nurses, healthcare assistants and play therapists spend longer building relationships with patients than doctors and were more commonly described in positive ways. Board (2005) found that children who had been in paediatric intensive care retained recollections of how staff treated them after their stays in hospital had finished, highlighting the importance of building thoughtful, caring relationships with paediatric patients.\textsuperscript{17} It is also important to note that non-clinical staff such as cleaners and play workers were mentioned in the poems. This highlights how observant the children were who recorded these poems and that they were not wholly focused on themselves but others too. The outward looking nature of these children was further shown by the child who wrote of other children being scared, and another child who commented on how busy the nurses were. Previous research has shown how hospital staff, especially nurses, need to work together with children to build trust and by doing so can lessen children’s fears and anxieties, leading to better patient experience.\textsuperscript{22,32,36}

Children need spaces to play and to try and gain some normality from their time in hospital, especially those who spend long periods of time as inpatients. It has been written about previously by Coyne and Conlon about the importance of ensuring children have places to play to lessen the risk of developmental arrest and distress whilst in hospital.\textsuperscript{10,11} The children who wrote about the playrooms had them on their minds and possibly saw them as a place to escape the things they feared on the wards; but above all else, the children wanted to have fun and act how they would away from the hospital.

The general population often regards hospital food as being of a poor quality.\textsuperscript{37} Children’s nutrition is of paramount importance, especially when unwell and hospitals should strive to listen to children’s comments on food available to them and to minimize any issues with unfamiliarity that can further worsen their enteral intake.\textsuperscript{38} Sleep, like food, is important for recouperation and is often disrupted when in hospital, be that by the aforementioned smells and sounds, the beds, or sleeping in a ‘Nightingale’ style ward with multiple people in the same room.\textsuperscript{39} By listening to children’s concerns and comments on issues surrounding sleep and food, improvements can be made on these two important areas.

Invasive procedures are something that people of all ages may be fearful of and children are no different.\textsuperscript{40} Despite the work of play specialists and various pharmacological and non-pharmacological interventions, some children remain scared.\textsuperscript{41} Each child’s poetic focus will be based on their own personal experiences of what has happened to them or those around them. It is likely therefore that those children who wrote about invasive procedures have had traumatic experiences of them or have witnessed others in distress. It is vital therefore that efforts continue to be made to make these experiences as minimally traumatic as possible to lessen any psychological impact they may have.

The journey that healthcare research has taken to realize the importance of patient experience and to appreciate the voices of children has been long. But in recent years the aims of meeting The United Nations convention on the rights of the child have come closer to being met.\textsuperscript{42} Söderbäck et al. described how the child’s voice is often lost and that their sense of a lack of self-determination is one of the most psychologically damaging aspects of hospitalization.\textsuperscript{43} For adults and healthcare workers it is challenging to view a child’s best interests without skewing their perspectives through their own lenses.\textsuperscript{44} The continual improvement in child centered care matches the gradual shifting of medical treatment away from its previously long-held paternalistic style of delivery, towards a more patient-led approach which is greatly helped by listening to children’s voices.\textsuperscript{44}
Assessing children’s experiences of hospitalization through poetry, Wood

The topics raised by the children within their poetry matched those of previous studies. Although there were no new areas of interest raised, it does validate the use of poetry and creative writing as a way to evaluate what children feel is important to them in the healthcare environment. The small size of the study and simple method allows for further research to be made and for improved data analysis methods to build upon this body of work. The poetry collected shows that children’s voices can be heard and interpreted through their creative output and that many of the things they have highlighted can be controlled and improved with the added benefit of possible therapeutic effects from writing. It should be ensured at all times that hospitals are child friendly and child centered to lessen the negative impact that hospitals can have on children’s development and their future engagement with healthcare services. This work opens the door to further creative writing-based studies being used as a method for assessing what matters to children and how they rate their experiences of hospital.

References


