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*Published in:*  
International Journal of Nursing Practice

*DOI:*  
[10.1046/j.1440-172X.2002.00356.x](https://doi.org/10.1046/j.1440-172X.2002.00356.x)

2002

[Link to publication](#)

*Citation for published version (APA):*  
Runeson, I., Hallström, I., Elander, G., & Hermerén, G. (2002). Children's needs during hospitalization: an observational study of hospitalized boys. *International Journal of Nursing Practice*, 8(3), 158-66.  
<https://doi.org/10.1046/j.1440-172X.2002.00356.x>

*Total number of authors:*  
4

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✧ RESEARCH PAPER ✧

# *Children's needs during hospitalization: An observational study of hospitalized boys*

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*Accepted for publication October 2001*

Runeson I, Hallström I, Elander G, Hermerén G. *International Journal of Nursing Practice* 2002; 8: 158–166

## **Children's needs during hospitalization: An observational study of hospitalized boys**

Twenty-one boys (age range 5 months to 16 years) were followed during their stay at hospital. Total observation time was 120 h. Field notes were made immediately after each observation. These were then transcribed into a narrative text, which was analysed by content analysis. Six categories of needs were identified during non-threatening situations at the hospital: the need for activity, the need for new experiences, the need for information, the need for participation, the need for praise and recognition, and needs related to physical resources. Four categories of needs were found during episodes of threat, discomfort and pain: the need for control, the need for having their parents nearby, the need for what is familiar, and the need for integrity. These results indicate that those involved in the care of children should be alert to the fact that as circumstances change, different needs have to be met. During non-threatening situations efforts should be made to inform children and to allow them to continue with their everyday lives. During threatening situations the children should be assisted and supported in keeping the situation under control.

**Key words:** children, hospital, need, observation study.

## **INTRODUCTION**

During the latter part of the 20th century, attempts were made to make hospitalization as positive as possible for children by means of preparation, encouraging parents to stay with the child, and by trying to provide more indi-

vidualized care. Professionals who work in paediatric departments have special training in dealing with sick children and their needs, and the physical ward environment has been designed to meet children's needs, with playrooms and school facilities.<sup>1–3</sup>

Traditionally, it was generally believed that children lack the verbal skills, conceptual abilities, recall, and overall narrative competence to convey their experiences. Parents, caregivers and other adults were therefore the informants in research focused on children.<sup>3,4</sup>

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Children are major users of health services, but are rarely consulted as health-care consumers. Parents are used extensively as proxies for children, although their accounts may not always reflect children's perceptions.<sup>3,5</sup> It is also assumed that the staff know how children think and feel about treatment and care.

Children are in a state of constant development, both physically and psychosocially. Their ability to understand and cope with the different aspects of hospital admission is affected by their age and developmental stage, and this is what makes their needs different from those of adults. They have special requirements that should be met in specific ways.<sup>6</sup>

In the literature, needs are classified in a variety of ways.<sup>7-10</sup> According to a definition by the Finnish philosopher von Wright, one needs something which one fares badly without.<sup>11</sup> Given this definition, what do sick children need? The definition is vague but von Wright asserted that a more precise definition would lead to a false description. French distinguished between needs and wants, suggesting that needs must be satisfied but wants can be deferred.<sup>12</sup> Holmes and Warelow suggested that wants are private psychological states, needs are objective, public ascription.<sup>13</sup> However, needs are socially constructed, have an inherent normative dimension, and are difficult to distinguish from wants. In this study needs are, according to normal values, what ought to be met to enable a person's normal existence.

Scoffstall discovered that the greatest stressors perceived by children in hospital were missing their families, being afraid of surgery, pain from their illness, infection, and being touched by people they did not know.<sup>14</sup> An often-cited study by Oksala and Merenmies showed that the need for rest and leisure was the only need that was strongly emphasized during a period of intensive care.<sup>15</sup> However, observational studies on how children in hospital experience problems concerning need satisfaction are rare.

The aim of the present study was to learn, through observations, about children's needs during hospitalization as expressed by their body language and verbal expressions when interacting with their parents and staff members.

## METHODS

### Sample

The data collection was carried out during a 9-week period in 1999, at Lund University Hospital, Sweden. Ini-

tially, the sample consisted of 21 boys and two girls. The children were chosen in order to get as great variation as possible with respect to sex, age, diagnosis and type of admission, either planned or acute. However, no children with life-threatening diagnoses were included. Great efforts were made to include more girls. However, for reasons beyond the observers' control, this was not possible. Therefore, the girls were excluded from the analysis.

The boys were between five months and 16 years of age (mean = 6.1). They were hospitalized at seven different units: emergency department, infection, neurology, endocrinology, oncology, cardiology and surgery. Eight boys sought care at the emergency department. The others were planned admissions owing to chronic illness or admission from the waiting list. The boys and their parents were followed during the course of events at the hospital. Observations were made during both day care and longer hospital stays, totally 120 h.

### Research ethics

When the child and parent arrived acutely, they were informed about the study by the observer immediately after they were cared for by the staff. Information was given verbally and in writing. The child and parent were then left alone to be able to decide if they wanted to participate. When the admission was planned, an information letter was sent to the family approximately 1 week before the admission. Upon arrival, the child and parent were treated as described. Children and parents were asked for consent to participate, and children over 12 years of age were asked to sign the informed consent form along with their parents.

Participants were ensured confidentiality and were informed that participation was voluntary and could be withdrawn at any time. They were also assured that the observer would leave the room during embarrassing and private conversations, and medical examinations. The child and the parents were informed that the observer did not belong to the ward staff and that no information about individuals would be transferred to hospital staff. Staff members at all wards involved were informed about the study. The Research Ethics Committee at Lund University approved the study.

### Observations

For data collection, non-participant observation was used.<sup>16-18</sup> The observer was sitting near the door or standing in a corner of the room, observing and listening.

Children and parents were able to initiate topics of conversation themselves. Observations were performed by mobile positioning, meaning that the observer followed the child and the parent throughout a given activity or period.<sup>16</sup> The total observation time for each child lasted between 1 h and 22 h (Table 1) depending of the length of hospitalization. Seven children, who had a very limited hospital stay, were observed during the whole visit in hospital, from the arrival to the departure. These children sought care at the emergency unit or had a planned medical check-up and returned home the same day. The others had longer stays, up to 9 days, and were observed at different periods during the day and the late evening according to the observer's availability. The observer said when observations were going to be performed, that the child and the parent could accept or decline. The observer usually left the child and parent when the child was going to sleep or there were no activities going on.

The observer made field notes immediately after each observation period. If observations lasted for several hours, notes were made during short breaks. The field

notes included descriptions of people present, events and conversations. Information such as time, place, activity and dialogue were recorded as completely and objectively as possible.<sup>18</sup> The observer's actions and feelings were also indicated in order to distinguish these from the observation notes. The field notes were then transcribed into a narrative text, more than 300 pages, which were used in the analyses to make sure that different parts of the data fitted together in a coherent picture.

Two observers carried out the fieldwork in order to enhance the validity.<sup>16</sup> One of the observers (IR) followed 13 boys and the other (IH) followed eight boys. Both observers were registered paediatric nurses, experienced in observation and conducting research. They were dressed in street clothes in order to differentiate themselves from the staff.

### Analysis

The narrative text transcribed from the field notes was analysed by content analysis at both manifest and latent levels. Manifest coding means coding of visible, surface

**Table 1** Observational data

Child's age	Reason for admission	Accompanying adult	Observation time
5 months	Check-up after heart surgery	Mother	3 h 45 min
7 months	Minor operation	Mother, grandmother	3 h 20 min
1.5 years	Cytostatic treatment	Mother	4 h 40 min
2 years	Poisoning	Mother, common-law husband	1 h 45 min
2 years	Hydrocele	Mother, father, brother	3 h 45 min
3 years	Infection	Mother, father	18 h 45 min
3 years	Antibiotic treatment	Mother, brother	9 h 10 min
4 years	Infection	Father, interpreter	1 h
4 years	Surgery for heart defect	Mother, father	22 h 45 min
5 years	Minor operation	Mother	3 h 45 min
5 years	X-rays before operation	Mother, father	3 h
6 years	Anometri	Mother, father	3 h 20 min
6 years	Suspected malignancy	Mother, father	3 h 30 min
8 years	Neurological check-up	Mother, brother, assistant	1 h 15 min
8 years	Minor operation	Mother	20 h 10 min
9 years	Constipation	Mother	2 h 20 min
9 years	Feeling of dizziness	Mother, father	4 h 30 min
9 years	Bone-marrow transplantation	Mother	4 h 35 min
12 years	Planned kidney surgery	Mother	1 h 10 min
14 years	Neurological check-up	Mother, father	2 h
16 years	Cirrhosis of the liver	Mother, father	1 h 15 min

content in text. The coding system lists actions located in the text. In latent coding the underlying, implicit meaning in the context is looked for,<sup>17</sup> which means that the text is analysed in cycles, from comprehensive picture back to individual elements in the data.<sup>19</sup> The text was read through several times by the first three authors independently and all meaning units in the text relating to children's behaviour were indicated. Then the same procedure was performed by the three first authors together. Only those meaning units about which the authors agreed, which comprised 236 meaning units, were used in the further analysis. Each meaning unit was read, transformed and coded as it related to different needs. At the next level in the analysis one of the authors (IR) established categories based on similarity of content in the meaning units. Several modifications were made. Finally, 10 categories expressing needs of the observed children were identified. When inserting the needs back into the original text, it became obvious that some needs were predominant in non-threatening situations and others during threatening situations (Table 2). The other two authors validated the categories and clarifications were made. Examples are given from the text in the field notes to exemplify the established categories.

## RESULTS

Through analysis of the children's behaviour, needs emerged that could be grouped into 10 categories. All the needs were found during almost the whole observation time, but at different intensities. Six categories clearly emerged when the child was not exposed to threatening, unpleasant or painful procedures on those occasions when the child was in the examination room with his parent, waiting for the doctor, at play therapy, in the hospital corridor or in the child's hospital room when no special examinations or treatments were underway. During these periods children expressed the need for activity and for new experiences, the need to get information, the need to participate in procedures and decisions, the need for recognition and praise, and finally those needs related to physical satisfaction

On other occasions, in threatening, unpleasant or pain-filled situations such as when samples were being taken for tests, and during examinations and treatments, the children clearly demonstrated the need for control over the situation, for having their parents nearby, the need for what is familiar, and finally, the need for respect for their integrity (Table 2).

The different categories are reported on below along with examples of situations such as those described in the text.

### Needs during non-threatening situations

#### *Need for activity*

After an operation or during the course of an acute illness, the children stayed quietly in their beds, but when their physical condition permitted them to move about freely, they gave vent to their need to move around. They joked and were rowdy when they had the chance. A 3-year-old boy got very happy every time the physiotherapist came.

*'Should we do some breathing?' asks the physiotherapist. 'No,' answers the boy and jumps out of his bed and runs out in the corridor. The boy runs back and forth and jumps up and down on the bed. The physiotherapist catches the boy and fools around with him in her lap, tickles him and falls backwards on the bed with the child on top of her. The boy is overjoyed. 'You fell, you fell!' he screams, and then he laughs. (3-year-old)*

#### *Need for new experiences*

The study provided examples of inquiring children who investigated how things around them functioned. They asked their parents and the staff questions about everything.

*When the boy and his parents entered the room the boy started investigating the bed. He raised and lowered it and pushed all the buttons he came across. He jumped up and down on the bed and finally he put the bedside table in order. (9-year-old)*

#### *Need for information*

By posing questions to the staff and to their parents, the children obtained information about hospital routines and also about what were planned for them. *'How long do I have to lie here?'* (9-year-old). Another boy, a 4-year-old receiving treatment for infection, asked his father: *'Why do the nurses wash their hands all the time?'*

#### *Need for participation*

Children want to be involved in discussing issues concerning their care. They also want to make decisions. These discussions often take place with their parents and mainly concern issues regarding daily life, food, clothes and activity. But the staff are also challenged. A 4-year-old boy

**Table 2** Examples of the content analysis: meaning units (describing the children's behaviour) and categories of needs during non-threatening and threatening situations

Observed behaviour	Interpretation
Needs during non-threatening situations	
Jumps down from his father's lap and crawls around on the floor	The need for activity
Jokes and pinches everybody's nose	
Goes back and forth in his wheelchair, talking the whole time	
Raises and lowers his bed constantly	The need for new experiences
Constantly asks questions about different things	
Pushes all the buttons he can reach	
Asks what the medicine tastes like	The need for information
Wants them to read the preparation folder	
Has some of his own questions such as what he can eat	
Wants to wipe off some blood himself	The need for participation
Doesn't want to agree with what his mother says	
Helps attach the EKG cables	
Looks at the nurse to see that he is doing it right	The need for praise and recognition
Points out many times that he acted better than his mother	
Looks happy when he is praised	
Lacks concentration and is 'hyper'. His mother says he is tired.	Needs related to physical resources
Takes a swallow, asks for more	
Turns his head away, does not want any ice cream	
Needs during threatening situations	
Does not want to lie down when the EKG is going to be taken	The need for control
The nurse says she is going to prick him, he starts crying	
Hides his hands and yells, 'I don't dare'	
Stretches both arms toward his father and whimpers, 'Daddy.'	The need to have parents nearby
Suddenly feels dizzy, yells for his mother	
Hides behind his mother when he is going to be weighed	
His mother comes with his pram. He is content.	The need for what is familiar
Does not want to be here any longer, wants to go home	
Sees the blood, becomes sad and wants to go home	
Wants everyone to leave. 'You're laughing at me.'	The need for integrity
Does not feel like talking, turns toward the wall	
Puckers up his eyebrows and looks down when anyone comes too close	

wanted to have some input when an EMLA patch (an ointment containing a local anaesthetic) was going to be applied.

*At first he did not want to be involved at all, and then he allowed the nurse to apply the patch but he wanted to decide where she was going to put it. Finally he announced that he did not want to have a bandage over the patch, which he then did not have to have. (4-year-old)*

#### *Need for praise and recognition*

The children also showed that they needed to be acknowledged. They wanted praise when they managed a task successfully. After every means of persuasion had been used, an 8-year-old boy had allowed the nurse to take a blood sample.

*He pointed out many times that he hadn't screamed and that he 'sure was braver than Mum. She wasn't quiet at all when she had a blood*

*test. She talked all the time. She didn't act her age!' The boy was highly praised. The nurse gave him a medal for bravery.*

#### *Needs related to physical resources*

When the children were hungry or thirsty they asked their parents for help. However, sometimes the children asked the nurse directly.

Other needs, such as, the need for rest, could be shown very plainly by the child but were not always detected by the staff.

*A 4-year-old child who was undergoing a programme of information and examination became totally exhausted. The programme lasted for several hours and included visits to the operating theatre, play therapy, the laboratory and so on. Finally, the child showed total disinterest and did not look at the nurse at all. Suddenly he said, 'I'm tired.' He could not handle a whole day of information and instruction. The boy's mother pointed out that it would have been good if she could have taken part in planning the day.*

### **Needs during threatening situations**

#### *Need for control*

The children showed a need to have control over the situation in which they found themselves. If the parents or staff showed that they had control over the course of events, this made things easier for the children, who then had to concentrate only on having control over their own behaviour.

*A 7-year-old boy was going to get an intravenous injection. He definitely wanted to see the syringe and decide how slowly the nurse should inject the fluid. 'No, wait a minute, I don't want you to give it so fast', he said firmly. He did not trust the nurse and got no support from his mother, who sat on a chair some distance away and did not get involved.*

Another boy, aged 6 years, received help and support from his parents. They were with him, they put their arms around him, they explained what was going to happen and showed no hesitation as to what was the best thing to do. The boy was going to have a cyst on his arm punctured.

*He was bright red in the face and he whined. The father sits next to him with his arms around him. The mother explains what is going to happen. The doctor punctures the cyst. The boy yells but holds his arm still and does not try to free himself.*

#### *Need to have their parents nearby*

The children showed in different ways that it was important to them to have their parents nearby. They called them, stretched their arms out towards them, climbed up in their laps, or had eye contact with them.

*An 8-year-old boy was going to be operated on for hypospadias. He had been frank and open throughout the entire period of preparation. When it was time for him to be taken into the operating theatre he still did not look anxious. On the other hand he looks for his mother the whole time and wants to have eye contact with her. She tries to walk so that he can see her the whole time. When the operation is over and he starts to wake up after anaesthesia, he is very careful to lie with his face toward his mother the whole time. As soon as she moves, he follows what she does very carefully.*

#### *Need for what is familiar*

Many children said they wanted to go home. 'When he had vomited for the third time, he cried that he was tired and wanted to go home' (2-year-old). This was interpreted to mean that the children did not feel comfortable in the hospital environment and that they were expressing a longing for their familiar, safe, home environment.

A 3-year-old boy woke up after minor surgery.

*He looked around, confused and disoriented, and started crying. He did not calm down until his mother brought his own pram.*

#### *Need for integrity*

Although most children expressed a need to have their parents nearby, there were situations when the children asked their parents to leave them alone.

*A 9-year-old boy felt ashamed in front of his parents and the staff because of his behaviour when blood was going to be drawn. He had screamed and kicked and thrown utensils on the floor. All the adults present had tried to be kind. The boy felt everyone was laughing at him. He wanted everyone to leave the room. 'You're all laughing at me,' he said and looked down at the floor.*

Some children became hesitant when unknown persons got too close, and they did not want to be questioned about their friends, school and interests.

### **DISCUSSION**

Observation is a method that gives specific knowledge that no other method can offer. One is, for instance, given

immediate and first-hand access to what is actually happening in the field. Moreover, the method provides the possibility of viewing interactions between various actors and gives an overview over the whole picture.

The method is specifically useful in relation with children as these patients' verbal ability is limited. In addition, children, and also sometimes their parents, convey a different type of information to an observer who is not involved in the care than to representatives of care.<sup>20</sup>

The method, however, is time-consuming, a conceivable reason why these types of studies are rare. Another disadvantage is that what is happening is recorded without a knowledge of what is behind the actions. A preferable alternative would be a combination of methods to receive the optimal understanding of situations.

Great efforts were made to make the collection of data as objective as possible, as a common criticism of observational studies is that observers, because of their background, only see what they want to see. By inserting a 'meaning unit' back into the original text and interpreting the described behaviour based on its context, and by having three different persons do the same analysis in parallel, the risk for incorrect interpretation was decreased.

As the boys represented different ages, had a variety of diagnoses, and were hospitalized for different periods of time at different wards, the sample should be sufficiently varied to indicate important needs of sick boys who are at hospitals. It is conceivable that a study consisting only of girls would have led to different results, as girls and boys are raised and treated differently. Further research is therefore essential in order to investigate girls' needs.

Studying the needs of sick children involves significant difficulties. Some children are quiet and shy, while others are noisy and demanding. Children come to the hospital having had different experiences in the past. This means that a situation experienced as threatening and frightening by one child can be experienced as an everyday happening by another. For example, a child who has been restrained and coerced when an intravenous cannula was inserted enters a similar, new situation with different needs than a child who has had a cannula inserted without pain or unpleasantness following preparation and application of EMLA local anaesthetic ointment. The child's age and maturity also play a role with respect to what needs arise and how these are communicated. An older child is more experienced, and has easier to understand how and why a procedure has to be performed than a younger child. A younger child communicates his needs different to a teen-

ager. If he needs his parents near by he cries until they arrive, but the teenager who also needs his parents, phones them and asks them to come.

Similar behaviour can be interpreted as indicating many different needs and can be interpreted in many different ways. This is also complicated by the fact that the different needs are related to one another and influence one another in different ways. Children who want and are allowed to be close to their parents, who receive adequate information when they want it, and who are allowed to be involved in issues concerning their own care, probably experience increased security and self-control. These children dare to make demands on those around them; that is, to ask questions when they wonder about something, to ask for what they want, and to demand to be involved in decisions and procedures. In contrast, insecure children do not dare to ask questions or to make demands. If they do not demand information, there is a great risk that they will not get any information and that there will therefore be no possibility for involvement.

Thus needs can differ in different children in similar situations during hospitalization. Some needs emerge more clearly than others in special situations. Just as children have needs for food, drink, rest, play, activity, and other developmental and stimulating activities during everyday life at home,<sup>21</sup> the children in this study clearly demonstrated these needs during the calm, non-threatening hours of hospitalization. The child was often with one of his parents while in hospital. For example, the time between examinations and treatments was often spent in the child's room, in the hospital school or at play therapy. The children behaved as if they more or less had control over their situation and felt secure. They wanted to know what was going to happen, how things worked, and they wanted to participate in procedures and decision-making processes. These were often situations the children recognized, and they knew the rules of the game in relation to their parents. They questioned routines and the staff's actions. They showed a pronounced need for activity, new experiences and social togetherness. They did not seem to worry about whether or not their parents were physically nearby. What was of main importance was that they could call them, and that they came when the child wanted. The children's physical needs were usually satisfied, but when they felt hungry or thirsty, for example, they expressed the wish to have their needs met.

The children tried to live a normal life to as great an extent as possible. However, when the staff approached,

the child's activity stopped and he put himself at their disposal. As soon as the staff left the room the child returned to his usual role in interaction with his parents and his activity. This was also described by Højlund Pedersen.<sup>22</sup> Her study showed that children did not view themselves as patients just because they were within the four walls of the hospital. As far as they were concerned, it was important for it to be fun and exciting at the hospital.

When the staff's presence meant that something painful, unpleasant or threatening was going to be done, the children showed in different ways that they tried to maintain or take back control over their situation. They cried for their parents and wanted them nearby, or they sought their protection. They protested in different ways when the staff got too close. They wanted to flee from what was threatening and expressed their desire to go home to what was familiar and safe.

In threatening situations, the children did not express any clear need for play or new experiences, to experiment or explore, or to participate in decision-making processes and procedures. This could be considered natural, as they were fully occupied with maintaining control over their situation. According to Højlund Pedersen, they usually do not have sufficient knowledge to be able to participate. The child's possibility of maintaining control increased if the child knew what was going to happen, if the surroundings were familiar, and if the child had confidence in the persons around him.<sup>6,23</sup>

Many children cried, screamed and kicked in threatening, painful situations. This was interpreted as meaning that the child felt he was losing or had lost control over the situation as well as his self-control; that is, control over his own behaviour. It has been found that anxious parents may cause their child to become anxious, and that calm, secure parents help their child by having control over the course of events.<sup>24</sup> A nurse or doctor in whom the child has confidence can also help the child by conveying to the child that they have control over what is happening. A child who feels he has control over his behaviour can very well cry, but does not do so in panic. Instead, the child feels that crying is allowed.

## CONCLUSIONS

The task of health-care professionals is to meet the needs of the individual child. This study shows that children have different needs in threatening and non-threatening situations. If care is to be optimal in order to meet children's needs in non-threatening situations, a home-like, familiar

environment with possibilities for everyday activities and stimulation should be offered. It is also during this time that the child could be informed about and prepared for what is going to happen a little later, as it is now that the child shows some curiosity, wants information, and wants to participate in discussions and decisions. When children are informed and well-prepared, and allowed to participate in decisions regarding the own care, the chances for them to maintain control increase, even during painful, unpleasant, threatening situations. They should be surrounded by familiar people in whom they have confidence. They ought to feel familiar with the environment in which the unpleasant or painful procedures are carried out. The routine at some paediatric wards is to move the child from a familiar environment to a special treatment room when, for example, an intravenous cannula is going to be inserted. In addition, a nurse with whom the child is unfamiliar is sometimes called to do this procedure. By being in an unfamiliar room surrounded by unfamiliar people, the child's ability to maintain control decreases. Calm, secure, well-informed parents and professional staff in whom the child has confidence, and who take responsibility for what is happening, must be with the child, if the care is to be optimal. This increases the child's possibility to maintain control over the whole situation or at least over his/her own behaviour. This is important not only for adults, but also for children.

To identify the needs of each individual child requires special knowledge about children and how children communicate their needs. As most research in this area has been based on the views of adults, studies are needed that obtain data from the children themselves. Studies are needed concerning how children express their needs, as well as studies that show the extent to which the interpretation of children's statements and behaviour are in agreement with the children's actual needs. More research is also needed to find out what kind of interventions children expect in different areas of needs.

## ACKNOWLEDGEMENTS

We wish to thank the children and parents who participated in the study, and the medical and nursing staff who allowed us to be present at the various wards. The research was supported by grants from Kalmar University College, Department of Health Sciences and Behavioural Sciences, and the Ethics in Health Care Programme supported by the Vårdal Foundation, the Swedish Research Council, the Swedish Children Cancer

Foundation and the Heart and Lung Foundation, all of which are gratefully acknowledged.

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