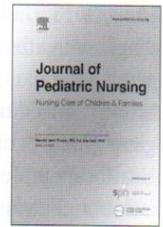




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The experiences of children, adolescents and their parents in isolation in a Danish paediatric unit: A qualitative study

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ABSTRACT

Background: Previous studies on adult patients in hospital isolation show that it can be highly stressful, with some patients affected by depression and anxiety. This study aimed to explore how children, adolescents, and their parents perceive isolation and how it affects them physically, psychologically, and socially.

Methods: A qualitative approach was used comprising semi-structured interviews, participant observations, and field notes.

Findings: Two adolescents and 13 parents were selected to participate in the interviews, while three children and their parents participated in participant observation. Besides the participant observation one of the adolescents and one parent also participated in interviews. The children and adolescents were isolated at the hospital due to bacterial or viral infections or were carriers of an antibiotic resistant bacteria. After performing a thematic analysis to identify patterns in the data, four themes emerged: 1. Differing information provided about bacteria, virus, hygiene precautions, and isolation, 2. Dependence on healthcare professionals, 3. Impact of the environment, and 4. Coping and psychological reactions on isolation.

Discussion: The participants conveyed positive and negative experiences and emotions during isolation in relation to daily activities, psychological well-being, and social life. Adolescents and their parents requested clear comprehensible and consistent information on isolation from healthcare professionals.

Application to practice: To improve hospital isolation for children, adolescents, and their parents, well-written information on isolation and hygiene precautions is crucial, as are evolving strategies to minimise social exclusion and the emotional impact of isolation.

Introduction

Hospitalisation is distressing for children because it disrupts their everyday routine and activities, separates them from family and friends, and puts them in an unfamiliar environment (Boztepe et al., 2017; Pelander & Leino-Kilpi, 2010; Silva et al., 2017). Studies have shown that children report missing various aspects of home life (Alvarez et al., 2020; Coyne, 2006). Medical examinations and treatment resulted led in experiencing a loss of self-determination due to a restriction in activities, but also a lack of control over personal needs, sleeping and waking times, food and mealtimes and the timing of procedures (Alvarez et al., 2020; Coyne, 2006).

Carrier status or infection with multi-resistant bacteria is escalating in Danish hospitals (Statens Serum Institut, D, 2019), including paediatric wards, where especially infection rates with carbapenems-producing organisms are on the rise (Statens Serum Institut, D. N. F. I., Technical University of Denmark, 2021). Furthermore, the global pandemic after the outbreak of SARS-CoV-2 (COVID-19) led to the increased use of isolation worldwide, which is essential in healthcare settings and the gold standard for reducing and preventing the spread of bacterial and viral infections with serious adverse outcomes (Committee on Infectious, D., and Committee on Hospital, C, 1998; Gammon & Hunt, 2018; Siegel et al., 2007). Studies in adults have reported the negative effects of isolation in recent decades (Abad et al., 2010; Gammon &

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Hunt, 2018; Guilley-Lerondeau et al., 2017; Martin et al., 2018). Being diagnosed with multidrug-resistant bacterial microorganisms alone can cause adult patients in isolation to experience emotional and social reactions, in addition to receiving a lack of information, and poorer hygiene (Abad et al., 2010; Gammon & Hunt, 2018; Heckel et al., 2020). Healthcare professionals are less likely to enter the rooms of patients in isolation (Barratt et al., 2011; Evans et al., 2003; Kirkland & Weinstein, 1999). Research also shows that precautions related to isolation have negative psychological effects, leading to anxiety, which affects quality of life and compromise patient satisfaction among adult patients (Abad et al., 2010; Barratt et al., 2011; Gammon & Hunt, 2018; Guilley-Lerondeau et al., 2017; Heckel et al., 2020; Martin et al., 2018). There is a lack of research on the paediatric population on how children, adolescents, and their parents' experience isolation and how hospital isolation affects them.

Qualitative studies on children and hospitalisation do not address the knowledge gap on how children and adolescents are affected when in hospital isolation. The distress children who are hospitalised experienced (Boztepe et al., 2017; Pelander & Leino-Kilpi, 2010; Silva et al., 2017) is likely to exacerbate in isolation, which also prevents children from using the playroom and interacting with other children (Committee on Infectious, D., and Committee on Hospital, C, 1998). Critical illness is a life-changing event for children, adolescent, and their families. Studies show that the majority of children who survive critical illness will be at risk of developing post intensive care syndrome, which has commonly occurring symptoms such as cognitive, physical and mental health impairments after discharge from the intensive care unit (Manning et al., 2018; Watson et al., 2018). However, there is limited evidence in how children, adolescents, and their parents perceive the overall state of hospital isolation, which is why improved knowledge on, is crucial to meeting the needs of children and adolescents who experience distress during hospitalisation. As a result, the aim of this study was to explore how children, adolescents, and their parents experience isolation due to infection and examine how hospital isolation affected them physically, psychologically, and socially.

Methods

Setting

This qualitative study took place in Denmark, at the Paediatric Semi-Intensive Care Unit at Copenhagen University Hospital, which treats children and adolescents 0–18 years of age. The children and adolescents in our study were hospitalised due to either chronic disease or acute illness. We applied a qualitative approach using an ethnographic method to gain insight into how children react to hospital isolation (DeWalt, 2011; Spradley, 1980). We used semi-structured interviews to collect detailed information and obtain insights into hospital isolation. Of note, treatment and care at the hospital is based on a family-centered care perspective in which the family was the child's primary source of strength and support ("Patient- and Family-Centered Care and the Pediatrician's Role", 2012).

Participants

Inclusion criteria for children, adolescents, and parents were 1) isolation due to bacterial or viral infection or carrier status, 2) 0–18 years old (inclusive newborns), and 3) able to understand and speak Danish. Participants were purposely selected to ensure information-rich cases within the group based on purposeful maximum variation sampling strategy (Patton, 1990) taking variations in age, time, and cause of isolation into account. Fourteen families met the inclusion criteria, 11 of which enrolled in the study. Two adolescents and 13 parents were selected to participate in the interviews, while three children and their parents participated in participant observation. Two families were excluded due to the language barrier.

Recruitment

One researcher identified potential families for the study and checked that they met the inclusion criteria's while nurses on the unit handed out written information on the project to eligible families. The definition of adolescents is young people from the age of 12 years in the Danish Healthcare system, therefore adolescents from the age of 12, and parents could choose to participate in both participant observation and interviews, or one or the other. When the consent was given, the researcher planned the participant observation and/or interview with the family. The researcher checked on a daily basis to see if any potential participants had been hospitalised. If the researcher was not present ward nurses noted that a potential participant had been admitted and then sent the researcher an email.

Data collection

Data were collected between December 2020 and August 2021.

Observations

Participant observations, which were primarily done during isolation at the unit, provided the opportunity to observe the children, adolescents, their parents, and healthcare professionals in various situations during hospitalisation (DeWalt, 2011; Spradley, 1980). One researcher conducted the participant observations, most of which took place in the patient's room, though some were conducted at their homes during or after the interview. Fieldnotes, which were taken during observations and subsequently transcribed, included descriptions of who was present, conversations, activities, and experiences during their stay. During the observations, casual conversations took place between the researcher and those being observed. Information such as time, setting of activity, and dialogue was recorded as completely and objectively as possible.

Interviews

Two researchers conducted interviews with the adolescents and their parents, some were performed at the hospital and others at home after discharge. The interviews focused on perceptions and experiences in relation to isolation due to bacterial or viral infection or carrier status and how hospital isolation affected the family physically, psychologically, and socially. Interviews were based on a semi-structured interview guide drawn up by two of the authors that was based on inspiration from the existing literature examining the impact of isolation (Heckel et al., 2020; Martin et al., 2016; Martin et al., 2018) but also qualitatively assessed by an expert panel of nurses and doctors who worked daily with the patient categories under study. A semi-structured interview guide reflecting the aim of the study was used to manage the interviews. Each interview began with the same question: Would you like to tell me about your experiences during hospital isolation? Furthermore, adolescent and parents were asked open-end questions on following topics: information, isolation in relation to treatment, and the impact of isolation. During the interview questions were asked to clarify or explore their answers in detail. Sony IC Recorder was used to audio record the interviews, which were then converted to an MP3 file that the researcher transcribed verbatim using Express Scribe Transcription Software. No software was used to manage the transcribed data.

Analysis

Two of the authors performed a thematic analysis to identify, analyse, and report patterns and themes across the transcribed interviews and observation texts. Each data set was coded separately before comparisons were made across all interviews and consensus was achieved. The process Braun and Clarke's (Braun & Clarke, 2006) six phases of thematic analysis. In phase one two authors familiarised themselves

with the interviews and fieldnotes by reading and re-reading them while noting any initial ideas. In phase two they generated an initial set of codes by assigning codes to interesting features across the data. In the next phase the codes were organized into potential themes, with relevant data collected into each potential theme. Then, in phase four, they reviewed the themes by checking whether they were suitable in relation to the coded extracts by reading all the extracts for each theme to determine whether they appeared to form a consistent pattern. Two authors checked whether the themes worked in relation to the entire set of texts. Afterwards, in phase five, they defined and named the themes and subthemes in an ongoing analysis to refine the specifics of each theme and subtheme, which resulted in generating clear definitions and titles for each theme and subtheme. Finally, phase six involved selecting vivid, compelling extracts in the final analysis and relating the themes and subthemes to the research aim and literature before writing this article. All the authors reached consensus on the final themes, their definitions, and what to call them.

Presuppositions

One author employed as a project nurse, was the primary investigator, while two authors being, a clinical nursing specialist, and a pediatrician, drew up the project description. Another author who is a head nurse on the paediatric ward, helped to jointly conceptualise the project with the research team. The research group comprised of experienced researchers with expertise in a variety of fields, including quantitative research in infectious diseases, qualitative and quantitative nursing research in hospital-based home care services for children and adolescent with long-term illness, and research in infectious diseases in children and adolescents.

Research ethics

Participants received oral and written information about the study. Children, adolescents, and their parents were informed that participation was voluntary and that they could withdraw at any time. Parents

gave written consent, and if the child were > 12 years, they were also invited to provide written consent. Children <12 years were asked to give oral consent to participate. The Danish Data Protection Agency (Journal number: P-2020-417) and the Danish National Center for Ethics were notified about the project. The study were carried out in accordance with the principles of The Helsinki Declaration ("World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects", 2013). Participants were ensured of confidentiality.

Results

Two adolescents and 13 parents were selected to participate in the interviews, while three children and their parents participated in participant observation. Besides the participant observation one of the adolescents and one parent also participated in interviews. Table 1 presents demographic data, time of isolation, cause of isolation and time of interview and participant observation (Fig. 1).

Data

The range and median are presented in hour: minutes: seconds. The range of the interviews (00:16:02–02:18:23) with a median of (01:05:27). The range of participant observation (01:04:00–01:32:00) with a median of (01:17:09).

Themes

The current study aimed to explore children, adolescents, and parents' experiences in hospital isolation and examine how it affected them, resulted in the identification of four themes and 10 subthemes (Table 2) based on the data. The following sections summarize the key findings illustrated by quotes from the semi-structured interviews.

Table 1

Demographic and isolation characteristics of the children and adolescents. Time of interview and participant observation is calculated as hour: minutes: seconds.

ID	Age of the child	Gender of the patient	Days in isolation	Precautions at home	Cause of isolation	Interviewed	Time of interview/ participant observation
Interview 1	14 years	Female	31 days	No	COVID-19 ¹	Patient	00:16:02
Interview 2	15 years	Female	1 day	Yes	CPO ²	Patient	00:37:59
Interview 3	3 years	Female	13 days	Yes	Pseudomonas	Mother	01:34:54
Interview 4	1 year	Female	14 days	Yes	VTEC ³	Mother	01:22:14
Interview 5	<1 year	Female	3 days	No	MRSA ⁴	Mother & Father	00:56:27
Interview 6	<1 year	Female	22 days	–	VRE ⁵ + CMV ⁶	Mother & Father	01:32:25
Interview 7	3 years	Male	7 days	Yes	VTEC ³	Mother & Father	02:18:23
Interview 8	17 years	Male	7 days	No	COVID-19 ¹	Mother	01:29:54
Interview 9	14 years	Female	31 days	No	COVID-19 ¹	Father	00:48:23
Interview 10	7 years	Female	14 days	Yes	Pseudomonas	Mother	01:14:28
Interview 11	15 years	Female	1 day	Yes	CPO ²	Mother	00:39:52
Interview 12	7 years	Male	54 days	No	CPO ²	Mother	00:37:47
Fieldnote 1	<1 year	Female	3 days	No	COVID-19 ¹	–	01:03:00
Fieldnote 2	7 years	Female	6 days	No	COVID-19 ¹	–	01:32:00
Fieldnote 3	7 years	Female	6 days	No	COVID-19 ¹	–	01:48:00
Fieldnote 4	14 years	Female	31 days	No	COVID-19 ¹	–	01:04:00

¹ COVID-19: SARS-CoV-2.

² CPO: Carbapenems-producing organisms.

³ VTEC: Verotoxin-producing Escherichia Coli.

⁴ MRSA: Methicillin-resistant Staphylococcus aureus.

⁵ VRE: Vancomycin-resistant enterococci.

⁶ CMV: Cytomegalovirus.

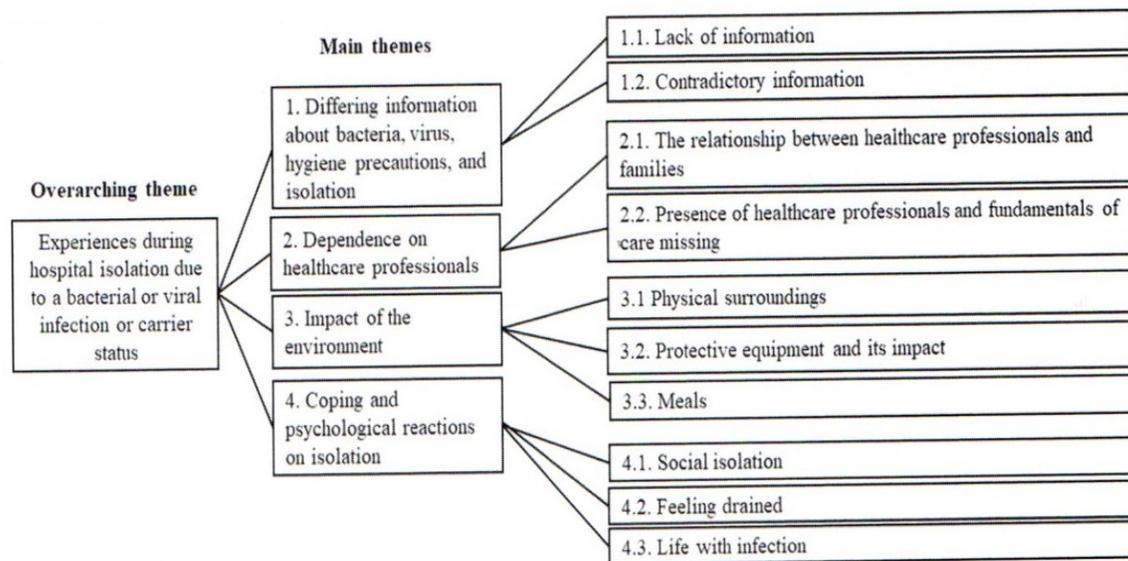


Fig. 1. Results.

Table 2
Themes with associated subthemes.

Theme	Subtheme
Differing information provided about bacteria, virus, hygiene precautions, and isolation	Lack of information
	Contradictory information
Dependence on healthcare professionals	Relationship between healthcare professionals and families
	Presence of healthcare professionals and fundamentals of care missing
Impact of the environment	Physical surroundings
	Protective equipment and its impact
	Meals
Coping and psychological reactions to isolation	Social isolation
	Feeling drained
	Life with infection

Differing information provided about bacteria, virus, hygiene precautions, and isolation

Lack of information

Adolescents and parents experienced a lack of information. They reported that the information they received about bacteria, virus, and isolation was inadequate and provided too late. In several cases parents mentioned that the information the healthcare professionals gave them was inconsistent and that there was a lack of information about hygiene precautions, leading to an increased risk of insecurity, mistakes, and frustrations among the participants. Parents also reported that there was a lack of information about the treatment, its consequences, and precautions.

“I have especially missed information about all these hygiene precautions.” (Interview 6).

The information parents received about bacteria, virus, and isolation was provided orally and not in writing. Many parents said it was challenging for them to remember information provided orally due to the stressfulness of the situation and the large quantity of complicated information they received. Parents expressed a need to have information repeated and said that clear and consistent written information would have helped them remember and prevent mistakes and misunderstandings.

“I do not think it was given to me, but I just think, maybe they said it to my mother. Maybe she got some papers, but I did not get anything.” (Interview 2).

Age-appropriate information for children and adolescents was lacking. Some parents shared information with and involved their child,

which they believed made their child feel more secure. Parents requested that healthcare professionals ask families how they prefer to be informed.

Contradictory information

Parents reported that they received conflicting information on hygiene precautions and that what they were told varied depending on which healthcare professionals they spoke with, just as they lacked clear guidelines on hygiene precautions. This affected the families and made them feel insecure, leaving them with the impression that the healthcare professionals were incompetent.

“Consistent information! What I mean is, everyone should provide the same information. If you give people six different options, they’ll choose the one that’s most convenient to them...” (Interview 12).

Some parents said they found themselves searching for solutions by seeking a reliable source of information and questioned the hygiene precautions they had received. Some reported that they were not taken seriously and that the healthcare professionals often tended to choose the easy way out and thus chose a solution that the parents felt was not safe.

Dependence on healthcare professionals

Relationship between healthcare professionals and families

Parents reported they were dependent on the healthcare professionals because they required help to get any items they needed since they were not allowed to leave their room. Parents described how they tried to maintain a good relationship with the healthcare professionals by restricting themselves and their needs, or by being less critical toward the healthcare professionals because they were worried about the quality of their child’s care and treatment.

“If they get mad at me, then they won’t take care of her properly.” (Interview 9).

Moreover, they reported that the relationship was downgraded during isolation due to having fewer conversation with the healthcare professionals however, they did feel that the close relationship returned once isolation ended.

Presence of healthcare professionals and fundamentals of care missing

Some parents and adolescents reported that the healthcare professionals were less present in their rooms during isolation, and that they only preformed what was most necessary.

"They were in the room less. But they came when we called, of course, but no one just came by and said: 'Hello!' or 'How are you?' – these little details were skipped though." (Interview 9).

Furthermore, parents experienced a lack of focus from healthcare professionals in relation to the fundamentals of care, pointing out that the isolation may cause a decreased focus on treatments. For instance, there was a lack of focus on personal hygiene, such as changing clothes, showering, and hair and hand washing. Likewise, they reported that the healthcare professionals showed a lack of focus in terms of preventing hospital-related complications regarding the skin and mucous membranes, including prevention of decubitus, urinary tract infections in patients with a urinary catheter, and infection from peripherally inserted central catheters.

Impact of the environment

Physical surroundings

Adolescents and parents reported that the physical surroundings in the room played an essential role during hospital isolation, e.g., a television with internet access, a toilet with bath, a refrigerator, closets for their things, and clothing hooks. Especially the availability of a refrigerator provided increased flexibility and made it possible to keep familiar foods in the room, helping their child to eat more. Furthermore, parents wanted to be able to let fresh air in the room and to be able to directly walk outside.

Parents reported that the cleaning staff did not clean their room adequately and that the rooms were not cleaned satisfactorily between patients.

"The worst part is that I know it's not clean. There were, in the cupboard in the bathroom, there were used toothpicks and stuff like that from the previous patient. [...] Minor items, like the protective paper from panty liners and stuff like that..." (Interview 10).

Some parents said they never once saw the cleaning staff in their room, while others said that commenting on the inadequacy of the cleaning to the cleaning staff had no effect, so they did the cleaning themselves.

Protective equipment and its impact

The parents reported that the enforcement of isolation and hygiene precautions differed and that the protective equipment in the patient's rooms and was deficient or used improperly. Moreover, they reported that the healthcare professionals lacked knowledge and were at times indifferent.

One mother, whose child was three years old, commented on how her child's behaviour changed when the healthcare professionals were wearing protective equipment, for example she withdrew more into herself, fled, or tried to hide when they entered the room. The mother mentioned that there was another look in her daughter's eyes and that her daughter reacted to the protective equipment by trying to hit it. One adolescent reported that the protective equipment made her feel poisonous.

"I hardly feel clean because they're so careful. When they touch me, they always must wear so many things. I understand, I don't want to infect anyone else, but I feel really bad about it." (Interview 10).

One father had a similar experience and reported that the protective equipment affected his relationship to the healthcare professionals because decoding his child's condition based on their facial expressions was more difficult. The parents reported that the protective equipment was a barrier that created distance between them. The physical appearance of the healthcare professionals when wearing protective equipment had a significant effect and clearly demonstrated how much people rely on decoding facial expressions when communicating.

"When you're in our situation, facial expressions mean a lot because, well, she smiles at your child, then it goes well. Does she have a serious facial

expression right now, no..." (Interview 9).

One mother also described how her child had difficulty recognising the healthcare professionals because they all looked the same when wearing protective equipment. Despite the challenges, some parents described how they became accustomed to being in isolation and reached a point where they managed to accept being in the isolation and that the healthcare professionals had to use protective equipment.

Meals

Many parents reported feeling frustrated about meals and snacks, due to lack of information and because they were not always readily available.

"Just a menu would do wonders." (Interview 10).

Parents and adolescents expressed a desire to see the food being served or pictures instead of listening to or reading the menu. Parents wished there were tools or a system for relaying what was on the menu and availability, not to mention way for the healthcare professionals to remember more easily what the family ordered.

"These are really minor issues but sometimes I can't see what food will be served, and my mom just chooses something that I like but I want to be involved in deciding things, like if I was going to watch a movie. If I could go out and see which food I could choose. I just like to have some control." (Interview 2).

Sometimes the healthcare professionals forgot to bring food to the families and the parents ended up not getting anything because they did not want to ask for it. Some parents reported that they felt like they had to beg the healthcare professionals to bring them food. Furthermore, some parents reported that their child lost weight during isolation due to limited access to food and the selection of food that was available. Finally, it was not always easy to meet the child's need for a specific food.

Coping and psychological reactions to isolation

Social isolation

Parents found that hospital isolation was demanding and mentally draining for their children and adolescents because they were bored, had limited freedom and were socially isolated. Adolescents reported that social isolation was the worst issue because there was too much time to think about their situation and some of them felt lonely. One young female adolescent said that the presence of the nurses helped her during the isolation:

"There's not much joy in being like that, all alone here. I'm just here with my mom...I want to be with a lot of people, meet new people but it helps me a little bit that there are so many nurses, every day they come in and talk to me." (Interview 2).

Children and adolescents reacted with restless and feeling claustrophobic, lonely, or frustrated, while others acted out and were irritated. Some children tried to go out the door. Especially prolonged isolation was mentally hard. Parents found that activating their child was difficult and mentioned how important it was to have access to toys and other activities, and that bringing familiar items from home provided comfort.

Parents expressed feelings of loneliness during the hospitalisation since they did not call friends and family members while their child was asleep out of fear of waking their child up. The feeling of loneliness was amplified when only one parent was co-admitted. The parent who was co-admitted reported that they felt lonely, with no adult to talk to. One mother talked about how she planned walks with friends and family members in the evening while her child was asleep in the pram, having made an unconscious decision to prevent the feeling of loneliness while alone with her sick child. Some parents described hospital isolation as a state of emergency, where their own needs fell by the wayside and the entire focus was on their child.

"I couldn't do anything. Other than be there for my boy. Well... just try to

go and get some food...” (Interview 7).

Parents described the time as standing still, one mother reporting feeling burnt out because she had no time to herself, she was with her child day and night. She described feeling stressed due to a lack of sleep and the disruption in their daily routine. She read articles verifying her experience of anger and frustration, which she believed lack of sleep caused. She was aware that depression was a risk due to loneliness, which she felt combined with feeling trapped.

The parents most commonly reported mood changes due to the limitations associated with being in isolation, describing themselves as more irritable. One mother spoke of how difficult it was to meet the need for physical activity. Some parents tried to be aware of their own mental health and practiced selfcare by taking breaks from the isolation, e.g., by going for walks outside, exercising, and taking long hot showers.

Parents reported that they felt limited because they could not see or spend time with friends and family due to visitor restrictions, but also because they could not freely choose what to eat from the kitchen and they were not able to move around freely. One father described his experience of isolation as limiting his sense of liberty and that the healthcare professionals were like a lock on the door. Many parents described the experience of being in isolation as being trapped or like being in jail.

The parents tried to distract their child and used humour to help cope with isolation. They noted that live music in the hallway was beneficial due to its calming effect and ability to move their attention away from infection and isolation.

“Music was playing out in the hallway. That was the most wonderful thing. It’s a bright spot in this whole process with the music because it is calm and soothing.” (Interview 7).

Parents described how their children coped with the hospital isolation. Some of them tried to keep contact with families and friends outside the hospital with phone and video calls. Parents cherished creating a nice atmosphere in the room and around their child, making sure that the day offered some fun and good moments.

Feeling drained

Parents overwhelmingly reported experiencing a lack of psychosocial support, leading to an increasing sense of frustration and worry during isolation. They reported that they felt a tremendous need to take breaks during isolation to regain and renew their energy. One mother compared doing so to the safety videos shown before takeoff, where adults are encouraged to put their own oxygen mask on before doing the same for their child. Some parents reported that they received psychological help to process the hospitalisation after discharge, while others were planning to see a psychologist subsequently.

The parents experienced a variety of reactions after hospitalisation, including fatigue, lack of energy, and mood changes. Minor challenges and tasks seemed complicated and insurmountable the parents reporting feeling paralysed. One mother described lying-in bed, trying to pull herself together just to open her eyes but that she was so exhausted that she could hardly get out of bed. Her husband experienced episodes where he felt that his brain was short-circuiting, and that simple everyday activities were arduous.

“You can’t think clearly or what you can say...” (Interview 7).

Life with infection

Parents reported that they had changed their behaviour due to the infection, paying increased attention to potential sources of infection and bacteria during hospitalisation but also after discharge. One mother reported that they were question themselves if they could bring their child to the yard, where there would be other children from the building. Furthermore, she was thinking about if other parents would judge them when they came pick up their second child from kinder garden. She reported that they were afraid of infect others, therefore they made rules

for themselves and others.

“We made the rule that others could not touch her. And we didn’t invite guests to our home... We did what felt right for us and we didn’t want to take any risk.” (Interview 4).

Some children and adolescents also changed their behaviour toward potential sources of infection and bacteria. Parents reported that they were aware of the changes in their behaviour but refused to let potential worries affect their lives or generate unnecessary unhealthy concerns. Adolescents and parents described the highly uncomfortable feeling of being dirty and dangerous to others because of the risk of spreading the infection. This resulted in feelings of loneliness that decreased their quality of life.

In addition, isolation and hospitalisation have affected the relationship between the child’s parents. Many parents reported assigning their relationship lower priority, putting it on standby to focus all the attention on their child. Parents spent less time together, which affected their relationship. Furthermore, tension between the parents often occurred due to the frustration of being isolated, challenging the supportive relationship that is essential during hospitalisation. Many reported that they had different roles during hospitalisation. Both couples and single parents requested psychosocial support such as therapy or tools to manage the effects of being in isolation and the cause of their child’s illness. Single parents in particular are in an exposed position if they do not have a strong social network during prolonged admission.

Discussion

Main findings

The findings from this study offer novel insights into how isolation affects children, adolescents, and their parents during hospital isolation by providing knowledge on what families experience and how hospital precautions are transferred to the home after discharge, but also how the isolation affects their lives and mental well-being. Although precautions during isolation depend on the cause of isolation, families with more restrictive precautions share many of the same experiences in this study.

Gaining access to clear and consistent information on the bacteria or virus and the hygiene precautions regarding the infection is an immense challenge since it is not available in writing. Families lack information about the expected duration of their isolation and how they should relate to the infection in- and outside the hospital setting. Studies on the experiences of adult patients’ concerning the effects of multidrug-resistant bacterial microorganisms show that similar deficiencies exist (Gammon & Hunt, 2018; Guilley-Lerondeau et al., 2017; Heckel et al., 2020) in end-of-life geriatric care and have an emotional and social impact, as do hygiene precautions and simply being diagnosed with multidrug-resistant bacterial microorganisms (Heckel et al., 2020). Coyne (2006), who also studied children’s experiences of hospitalisation identified the need for information on hospitalisation and adequate information tailored to the age and needs of the child.

Although patient isolation is an established and important aspect of infection control, it may also negatively affect patient care and fundamentals of care (Abad et al., 2010; Guilley-Lerondeau et al., 2017; Heckel et al., 2020), which align with the results in our study. Studies show that isolation may negatively impact patient care and contribute to adverse events in terms of cleaning, fundamentals of care, and the patient experience of quality of life (Abad et al., 2010; Guilley-Lerondeau et al., 2017; Heckel et al., 2020), even though there are conflicting results. One study had fewer adverse events (Cohen et al., 2008) but their results were based on the first two days of admission, which is why this study is limited in terms of assessing the long-term effects of isolation. Our findings contribute to existing knowledge showing that healthcare professionals who do not have the time to talk to or see patients negatively affect the patient experience of care, the fundamentals of care, and ultimately patient safety, recovery, and well-being (Feo & Kitson, 2011; Kitson & Soerensen, 2017).

A lack of social contact with friends and family and the awareness of putting them in a risk of infection were also major themes in our study. One study revealed that isolated patients experience that their social life was affected, and they reported feeling upset because of their limited participation in social life, which made them feel lonely. Furthermore, the patients also found that their own behaviour toward their families changed (Heckel et al., 2020). These results are comparable with results from our study, where adolescents and parents reported that they missed their social life, though some tried to prevent the feelings of loneliness by planning walks outside the hospital with friends and family. The COVID-19 pandemic and related restrictions may have affected our results since they made it difficult for inpatient families to receive visits from friends and family. This project was carried out during the pandemic, and the parents reported that their perception of precautions had changed because they had been living with precautions since the first lockdown in Denmark in March 2020.

Our study revealed that many families in isolation have thoughts revolving around food and meals because they are dependent on the healthcare professionals. They are not allowed to leave their room and not knowing what kind of food is available is frustrating, as not being able to choose the food. Developing of digital solutions that allow the families to choose the food themselves could help give them a sense of independence from healthcare professionals, especially if it were possible to order everyday things like towels, diapers, and bedding. This approach could contribute to making it easier for healthcare professionals to remember what the families lack. One study described electronics devices as a helpful method for communicating visually with parents and caregivers at the hospital when others were unable to be present. The devices included monitors in the child's room, walkie talkies, and tablets for video chatting (LaFond et al., 2022). The development of digital solutions or making technology a natural part of the environment can positively affect the children, adolescents, parents, and healthcare professionals.

Hospitalisation is a stressful event for children (Coyne, 2006), and critical illness is a life-changing event that not only affects the children and adolescents due to new and persistent impairments, it affects the entire family (Watson et al., 2018). Children experience physical, psychosocial, cognitive, and social function impairments after critical illness. Studies on post intensive care syndrome in paediatric intensive care units are limited (Manning et al., 2018; Watson et al., 2018), but do report impairments comparable to the results from this present study. As a result, it is important that healthcare professionals are aware of how children experience and are affected by hospitalisation, and that they understand that critical illness in children and adolescents is a life-changing event, also for their families. LaFond et al. (2022), who studied children in isolation due to I-Metaloidebenzylguanidine therapy, found that the nurses played a highly important role in supporting children and parents during isolation and that they have an opportunity to further integrate coping strategies into their care to help children and their parents (LaFond et al., 2022). Increased awareness among healthcare professionals and in education about the needs of families in isolation could be beneficial for healthcare professionals concerning how to take care of and support children, adolescents, and their parents during hospital isolation. Moreover, another essential way to support the entire family is to increase awareness of providing families with clear and consistent written information and of individually gauging what their needs are. This is in line with what previous literature describes (Manning et al., 2018; Watson et al., 2018), indicating that parents and the families are affected by their child's critical illness after discharge. The well-being of the parents is also important for the well-being of the child since post-traumatic symptoms in children after hospitalisation are associated with symptoms in parents (Manning et al., 2018; Watson et al., 2018), which underpins our results, which show that parents are affected by their children's reactions to their illness.

Limitations and strengths

Fewer children, adolescents, and parents were admitted and isolated due to infection with resistant bacteria, virus or carrier status than expected during the study period, likely due to general restrictions during the COVID-19 pandemic. The study sample was also relatively small for this reason. Although a bigger sample may have contributed an even greater wealth of details about isolation, it was still possible to achieve data saturation with our small sample size and to describe their experiences of isolation in detail. There is a preponderance of mothers represented, which means the inclusion of the perspective of more fathers may have affected the data differently.

The present study has some notable limitations, including the low number of adolescents who were available and willing to participate. Relying primarily on data collected from parents on their experiences mainly provides a picture of their perceptions of isolation, which was not the chief aim of this study, which also intended to include the points of view of children and adolescents to greater degree. This was not possible, however, since more parents participated than children and adolescents. The experiences of the children and adolescents were nonetheless communicated through their parents' points of view and corroborated by participant observation of children and their parents in their rooms or observations during the interview. This represents a strength as observations aims to capture the children's experiences through their actions and moods. Another weakness is that comorbidities were not included in the study design, and the data were not specifically matched with chronic diseases. Comorbidities may influence patient anxiety during their hospital stay, regardless of infectious status and isolation precautions.

The semi-structured interviews conducted during isolation minimised the risk of adolescents and their parents being unable to recall their experiences. Another strength of the study was the use of triangulation combined with participant observation and interviews. Besides performing the analysis two authors did the coding separately, then third author jointly discussed the codes, and ultimately reached consensus on the final themes, their definitions, and what they were called with the entire research team.

Overall, more research is necessary to identify ways to remedy the problems that children, adolescents, and their parents experience during isolation, just as the potential of interventions and tools designed to match their needs must be explored further.

Implication to practice

Well-written information on isolation and hygiene precautions is crucial to improve the experience of hospital isolation for children, adolescents, and their parents. Healthcare professionals must be aware of their communication with families in hospital isolation and be clear and consistent when informing families about isolation and hygiene precautions. Furthermore, strategies to minimise social exclusion and the emotional impact of isolation must be involved.

Conclusion

The experiences of children, adolescents, and parents during hospital isolation indicate that they may benefit from written information on isolation and hygiene precautions that is clearer and more consistent. Improving communication by enabling and facilitating regular communication between adolescents and parents with healthcare professionals will address one of the main unmet needs that patients and their parents identified. Most importantly healthcare professionals must be more aware of the influence isolation may have on the psychological well-being of children, adolescents, and their parents.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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