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## How to support parents and healthcare professionals in the decision-making process of tube feeding in children?

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## ABSTRACT

**Background:** Tube feeding in children has a severe psychosocial impact on children and their families. Parents also feel that they have limited communication with healthcare professionals (HCPs) about decision-making and the implications of tube feeding.

**Objective:** This study focussed on the parents' experiences and expectations about tube feeding of children and a solution to improve the management and communication of it.

**Methods:** We applied a design thinking method in two parts. First, focus groups and individual interviews were conducted with parents of children aged 0–10 years who are or had been tube fed and HCPs. Thereafter, two sounding boards with HCPs and parents were convened to discuss improvements in the management of tube feeding.

**Results:** In total, 17 parents participated in the study. Two main topics derived from the focus groups and interviews: psychosocial impact and communication with HCPs. The sounding boards (five HCPs and two parents) divided the challenges of tube feeding into three stages: the moment tube feeding is considered, the insertion of the tube in the hospital, and transfer to the domestic environment and follow-up. Interview topics were used to develop a communication sheet to support the decision process of tube feeding.

**Conclusions:** The empowerment of parents in the process of tube feeding is important. More attention should be paid to alternatives, consequences, and planning for the long term. The developed communication sheet offers suggestions for issues to discuss and could support communication between parents and HCPs about tube feeding.

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## Introduction

Children may need to be tube fed if medical, nutritional, feeding skill, and/or psychosocial dysfunction makes oral feeding unsafe, inadequate, and/or inefficient to complete or provide adequate nutritional intake.<sup>1</sup> Benefits of tube feeding include improving a child's nutrition and constipation and easing medication administration and feeding for the caregiver.<sup>2</sup> In the Netherlands, 83 to 92 children per 100,000 a year are tube fed, most frequently in the first year of life.<sup>3</sup> A significant number of children who need tube

feeding have complex physical, developmental, and functional challenges where communication, feeding, or other dimensions of daily function are compromised. Interventions, such as tube feeding, may be needed to compensate and adapt, allowing for better function and participation in everyday life.<sup>2</sup> While tube feeding is often inevitable, side effects range from physical and behavioral symptoms of the child to psychosocial effects for the family.<sup>4,5</sup> Tube feeding is considered a disability, according to the International Classification of Function, Disability, and Health (ICF), and has an impact on the activities, participation, and environmental factors.<sup>6</sup> At the level of body function, tube feeding decreases the risk of aspiration, pneumonia, and undernutrition. Tube placement also can lead to long-term difficulties, e.g., in the transition to normal oral feeding.<sup>7,8</sup> The durability and long-term

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outcomes of tube feeding are difficult to calculate and are dependent on many variables related to medical conditions, the child, and environmental factors.<sup>4</sup>

Whereas the guideline of the European Society for Clinical Nutrition and Metabolism (ESPEN) on home enteral nutrition concentrates mainly on the indication, kind of tube, and medical issues, no information is provided about the practical issues at home, such as feeding schedules, weaning from tube feeding, caregiver effects, or patients' involvement in decision-making. It may be difficult for parents to make decisions about this complex kind of intervention.<sup>9</sup> It is generally accepted that critical life decisions about children should be made in a process involving physicians, parents, and the child.<sup>10</sup> Therefore, it is important how HCPs guide them in this process.<sup>11,12</sup> By including the perspectives of parents, child, and healthcare professionals (HCPs), the current paper acknowledges this challenging process and strives to elucidate several important aspects of tube feeding such as medical, nutritional, and psychosocial.

Studies have presented three sources of decisional conflicts related to tube feeding: (1) context: the unique circumstances of each child and family; (2) values: parents' values, attitudes, and beliefs about oral feeding; and (3) care processes: information sharing and support for families.<sup>2,13,14</sup> These studies have emphasized the need to consider and respect both parents' wishes around the decision to insert a tube and the child's clinical status and social contexts.<sup>2,13–16</sup> However, it is unclear how parents of children with tube feeding experience their involvement in the process and the application of the recommendations about context, values, and care processes regarding tube feeding in children by HCPs in the Netherlands. Therefore, this study has two aims: (1) to evaluate parents' experiences and expectations about tube feeding, and (2) to explore HCPs' suggestions for improving the management of tube feeding in children.

## Methods

### Design

We applied a design thinking method based on four principles: observe and notice; frame and reframe; imagine and design; and make and experiment.<sup>17</sup> Two focus group discussions and individual interviews with parents and HCPs were arranged to gain insight into the psychosocial impact of tube feeding on the child, the parents, and the family.

In addition, a sounding board was set up that met twice to develop a tool based on these experiences that can be used in the decision-making process.

### National program

The study was a part of a subsidy project 'Psychosocial consequences in major somatic disorders' as a part of 'Transparency about the quality of care' of Zorginstituut Nederland (ZIN), the National Health Care Institute.

### Participants

For the focus group discussions and individual interviews, eligible participants were parents of children aged 0–10 years with (complete or partial) tube feeding (nasogastric or gastrostomy) during the last two years. Exclusion criteria were insufficient ability to speak Dutch and applying the intervention in a foreign hospital. Participants were recruited by convenience sampling via social media, by a post on a closed Dutch Facebook group for tube feeding, and at an informal meeting of an association of parents whose

children have feeding difficulties in the Netherlands (*Nee-eten, about 130 parents and 45 professional members*). If parents were willing to participate, they had to email the researchers for detailed information and informed consent.

For the sounding board meetings, parents and HCPs with expertise in interventions for tube-fed children from the *Nee-eten* network (further mentioned as 'expert group') were invited. The HCPs represented a professional group of dietitians, pediatricians, speech-language therapists, psychologists, nurses, and they consulted their colleagues for input. Two experienced researchers of an independent research bureau to increase the quality of healthcare (VP and CK) organized all meetings. All activities of this study were held in 2019 and 2020. Parents and HCPs were only compensated for travel costs and lunch but not for their time for interviews or meetings.

### Data collection

The interview guidelines were developed inductively by the authors and previously tested to structure the focus groups and interviews. The guidelines covered the following topics:

Experiences of parents of a child who is or has been tube fed, the influence of tube feeding on the (later) life of the child and family; expectations of tube feeding, the need for information or support to prevent psychosocial consequences as a result of tube feeding; current information of HCPs; experience on communication with HCP's regarding tube feeding. The interviews were semi-structured and held along with these topics.

All interviews and focus groups were tape-recorded to allow verbatim transcription. All participants received a summary of the interview to verify data and interpretations. The interviews lasted about 60–45 min and the focus group about 90–120 min. The focus group discussions were conducted by two experienced researchers of the research bureau (VP and CK) in a city near the parents' homes. Individual interviews were conducted by two speech-language therapy students and supervised by the researchers. These interviews took place in an online, face-to-face connection due to the COVID-19 lockdown.

Next, we conducted two sounding board meetings with the expert group. The purpose was to reflect on the outcomes of the interviews and focus groups for recognition and more examples. The two researchers of the research bureau guided and structured the meetings. The first meeting concerned the issues parents mentioned about their experiences and expectations on tube feeding and the view of the HCPs. This meeting covered the stage of 'frame and reframe'. The second meeting focussed on suggestions for improving the management of tube feeding and the preliminary design of a tool. The meetings lasted about two hours. Afterward, a summary of the discussions was sent to all participants for a member check and eventual additions.

### Data analysis

The explorative design led us to take an inductive approach to the analyses. The interviews were analyzed using the steps of Braun & Clarke (2006).<sup>18</sup> The open coding process was started by the interviewer as the primary coder. Notes were made in the first readings of the texts to shape and define concepts. The first coder marked meaningful text blocks in the transcripts, and they were checked by a second coder and discussed them in-depth to reach consensus about the codes and code groups. Thereafter, the coders identified themes in the data, working through the transcripts with colors and highlights in Word files. The meaningful text blocks were arranged and clustered in a table. The coders searched for positive and negative deviant quotes to provide a thorough

description of the variety in the data. All themes were discussed by the researchers. The sounding board meetings were only summarized as the notes were additional to the interviews to frame and reframe and focus on the design of improvement.

### Trustworthiness

The study met any criteria for acceptability according to Nowell et al. (2017).<sup>19</sup> The study was set up systematically and clearly documented. Demographic data about the participants and children were described in detail to enable readers to evaluate the transferability of our findings to their situation. For ensuring credibility, a member check was conducted to check the right intentions of the participants. Data triangulation was realized by including various participants and methods of data collection. The interviewers coded all interviews, and those codes were controlled by all researchers for investigator triangulation. The quotes and communication sheet were expertly translated from Dutch to English in the final version of this manuscript.

### Ethical issues

This study was reviewed and approved by the Medical Research Ethics Committee at HAN University of Applied Sciences in the Netherlands (ECO 266.04/21), and it was conducted in line with the guidelines in the Declaration of Helsinki. The researchers provided written and verbal information to the participants. Informed consent was orally obtained before the interview and audio recorded, due to COVID-19 restrictions.

## Results

Nineteen parents responded positively to the invitation to participate in a focus group or individual interview. Two parents were not included: one due to the older age of their child and one not responding to the invitation. The characteristics of the seventeen participants are summarized in Table 1. Parents were primarily invited to a focus-group meeting, but due to limited availability, nine were individually interviewed. Five HCP were included: dietician, pediatrician, speech-language therapist, psychologist, and nurse. They were included in the sounding board with two parents.

Two main themes were distracted from the focus groups and interviews: (1) psychosocial impact and (2) communication with HCP. The psychosocial impact concerns issues from the parents, family, and children, as well related to tube feeding, mostly in everyday life. The themes were derived from the code groups and subthemes and visualized in Fig. 1.

**Table 1**  
Characteristics of participating parents and their children.

Group (n)	Gender of parent n (%)	Gender of child n (%)	Mean age of child years (range)	Kind of tube n (%)	Diagnosis of child (n)	Mean duration/ (range)
Focus group n = 8	6 female (75%)	5 female (63%)	5.5 years (10 months–10 years)	NT n = 3 (38%) GT n = 3 (38%) No tube n = 2 (25%)	Heart diseases (2) Gastroesophageal reflux/gastric problems (2) Prematurity (1) No specific diagnosis (3)	4.5 years/1–10 years
Interviews n = 9	8 female (89%)	7 female (78%)	2.5 years (11 months–6 years)	NT n = 5 (55%) GT n = 4 (45%)	Neurodevelopmental disorder (4) Gastroesophageal reflux/gastric problems (2) Syndrome (2) No specific diagnosis (1)	1.8 year 0.5–7 years

NT: nasotube.

GT; gastrostomy tube.

After a child is discharged from the hospital with a tube, parents report a lack of information about the consequences of tube feeding in everyday life. "Because one cannot imagine the impact of such a nasogastric tube from a doctor's chair. No matter how much you [doctor] talk about it with parents about the impact, if you don't deal with it day in and day out, you can't imagine." One mother said: "He came home with the tube and with some sort of protocol of four feeding times a day. And it started with vomiting and we knew that all too well. On the day I got home, so when we were mopping up again, I said, Okay, we're going to do things differently". One mother said: "The vomiting has a big impact. For example, when she vomits in the supermarket, everyone is staring and feels sorry for her: "Oh, poor girl". But she is not a "poor girl"." (Focus group (FG) 2, mother of a 2-year-old girl).

One HCP concluded on the psychosocial impact: "If it has been decided that tube feeding is necessary for a child, it is almost unavoidable that this is a traumatic experience for both the child and the parents, due to the invasive method. The child cannot control this process itself leading to a traumatizing effect. Moreover, the trauma can be reinforced, because the tube feeding goes against the needs of the child. the development of the mouth and throat and against the fact that swallowing should be a pleasant experience. Tube feeding reinforces the negative experience of the child by withholding the pleasure of swallowing."

Child tube feeding has an impact on social life. For example, not being invited for family parties due to the vomiting of the child, not being able to go out, because no babysitter dares to take care of a child with tube feeding.

It is not always clear who is responsible for tube feeding. After being discharged from the hospital, parents report a lack of clarity about tube feeding issues: will and should it continue, who is responsible for problems, or who can help after the initial stage. *At first, things went smoothly. But at a certain age, the child gets strong-willed. Then she didn't want tube feeding anymore. It became a battle. When our battle started, we didn't know where to go for help. Also, the sense that things were not heading in the right direction and that we would depend on tube feeding for a while longer made me think we needed a less impactful solution. But I didn't know where or to whom to go.*" (FG 1, mother of a 6-year-old girl)

In most cases, the technical side of tube placement was straightforward and planned: a home-care nurse took charge of regularly changing the nasogastric tube, and in an acute situation with a displaced tube, parents could contact the hospital to replace a tube. However, personnel changes, unfamiliar nurses, or unknown preferences of the child can often cause frustration, and parents often felt forced to change the tube themselves. One father explained why he decided to insert the tube himself: "It was because we saw the mismanagement in the home care that we decided to insert the tube ourselves. One crucial moment was on Boxing Day

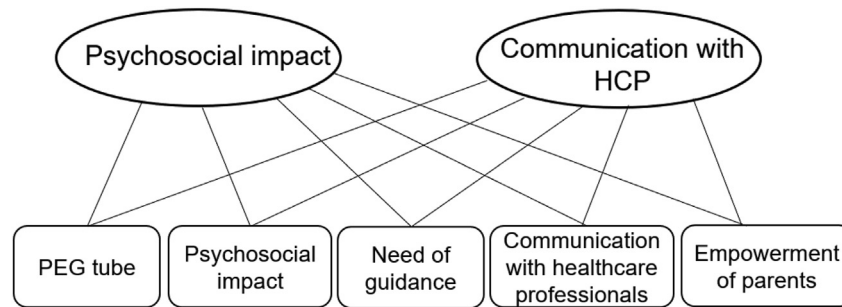


Fig. 1. Themes and subthemes derived from the group and individual interviews.

when the home care didn't want to come at all due to winter weather conditions. They told us to go to the hospital. That's the moment when I said: "I've seen how it's done so many times that I might as well do it myself". Since then, I've always replaced the tube myself." (FG1, father of a 9-year-old girl).

## 2) Communication with HCP "You had to be assertive to ask critical questions to the HCP"

Unfortunately, most parents had limited information about the choice of tube feeding, although they needed it because of unfamiliarity with enteral feeding. In a few cases, parents perceived that they had adequate information about the necessity and the decision to start tube feeding. But some parents were not informed about the start of tube feeding during in-patient care. "She was tube fed for the first time on the fourth day of hospitalisation. We were not really informed about this. In the beginning, it was constant tube feeding ..... But I always ask about how much she is getting and why. Actually, they didn't tell me much about it. I had to ask." (Interview (1) 1, mother of an 8-month-old girl) Another mother had a similar experience: "I don't think it was even communicated; they just put the nasal tube in. They didn't say she was going to get a tube." (I9, mother of a 6-year-old girl).

Although the start of tube feeding has a significant impact on parents, it is also important that they have information about the subsequent process, the duration, and the consequences of partial oral feeding. A mother explained: "The paediatrician told us: "The tube can stay in place for six weeks." So, in my mind, you might understand, it was only for six weeks. At least, I thought, it will only be for a brief time ..... It was also the intention that she would eat during the day and then be supplemented with tube feeding in the evenings ... but they didn't tell us that when a child is tube fed, they almost entirely stop eating. The little bit that she still drank or ate, she also stopped. And I didn't know that; they should have told me. I also didn't know about the excessive vomiting in the beginning and still today. They certainly should have told us that she could vomit three times a day ..... It's just a shame, the information was just bad." (I 5, mother of a 23-month-old girl).

A pediatrician added: "If a child is very ill in the ICU and receives tube feeding, it is usually not (yet) the right time to talk to parents about the consequences of tube feeding. The parents are then mainly focused on the survival of their child. As soon as the life-threatening situation is over or if the child goes home and continues tube feeding, it is a good time to inform the parents about the consequences of tube feeding."

While parents felt that they knew their child best and had a basic instinct for what was good or not for their child, they felt that HCPs sometimes maintained their protocols and barely listened to them or paid attention to the individual child's needs. "The healthcare workers just followed the schedule, while we saw that she

was reacting very badly to it. She vomited a lot. When I said, "Stop now, because she's only vomiting", they looked at me like, "Yes, but the schedule indicates something different. She must be fed now. Why are you meddling with that?" (I6, mother of a two-and-a-half-year-old girl).

Parents who had more healthcare knowledge (mostly because of their profession) were able to be more assertive and dared to ask critical questions to the HCPs. Still, it did not seem that all professionals act from the same perspective and that there is clear communication between professionals and hospitals. "There was also very little communication between hospital staff. A dietician might come by and have no idea what had been agreed to with the paediatrician. The healthcare staff would just blindly do what was ordered. And if we made plans to change something with the healthcare professionals, that information didn't get to the paediatrician." (I6, mother of a two-and-a-half-year-old girl).

The expert group recognized the issues parents mentioned and discussed the broad range of differences in child and parent characteristics. They agreed that parents should be more involved in decisions about tube feeding and thus needed clear information and enough time to decide at several stages. HCPs should be aware of alternatives and adaptations that best suit an individual child and environment. The expert group clustered the information from the interviews into three stages of tube feeding: (1) first considering tube feeding, (2) inserting the tube in the clinical setting, and (3) transferring to the domestic environment and following up. At each stage, parents should receive information and alternatives, and attention should be paid to parental skills and desires. One expert stated: "All healthcare professionals should be in agreement ... Everyone is equal, everyone is aligned. Only then will you get open communication, and that is in the patient's or client's interest .... It's good that protocols exist, but you must dare to deviate from them. If you do so, you are working in the interest of your patient. And if you don't, you're not working in the interest of your patient or the hospital or institution where you work."

In the second sounding board meeting, the idea to develop a communication sheet (see appendix) emerged. We developed an overview of important topics to discuss tube feeding with parents at the three stages. The topics are meant to support HCPs and parents in the decisions of the tube feeding process.

## Discussion

This study aimed to improve the management of tube feeding and narrow the gap between parents' needs and the provided care. Therefore, we conducted a design thinking method with the focus on two topics to explore (1) parents' experiences and expectations about tube feeding of their child and (2) HCPs' experiences and suggestions for improving the management of tube feeding in children. The results of the focus group and individual interviews



highlighted the psychosocial impact of tube feeding on a child and family and the lack of sufficient and tailored communication from HCPs to parents on the decision-making and the psycho-social impact. The expert group recognized the topics of the parents and designed a communication sheet to help in the communication in the three stages of tube feeding.

Parents gave examples of incomplete and missing information about the necessity of tube feeding. In particular, there was little information about its prognosis and consequences in the short and long term. Several parents mentioned limited communication with HCPs and no agreement on shared decision-making. When parents are faced with this weighty decision, information processing takes time, and the emotional process likely requires more than one consult or one source. In the initial stage, parents should receive information about the benefits of tube feeding, as well as its risks, the possibility of alternative interventions, and the prognosis of its duration. HCPs should also listen to parents' wishes and consider the characteristics of the individual child.

This study confirmed that tube feeding has a major psychosocial impact on children and their parents. These results were previously found in other studies of Missouri<sup>15</sup> and Australia.<sup>20</sup> While HCPs base the decision about tube feeding on rational facts about nutritional intake, parents focus on the emotional issues and characteristics of their child. Time spent feeding their child by mouth is an expression of love, a time for close contact, and an expression of parent-child interaction.<sup>2</sup> Moreover, our data confirmed that parents who had to tube feed their child perceive a lack of understanding and support from their environment.<sup>16</sup>

In the initial stage in the hospital environment, parents can share their concerns and sorrow with HCPs and other parents in similar situations. It is different at home, where parents have to deal with comments and attention from passers-by and solve practical problems themselves. Parents mentioned a difference in the perception of the HCPs who look at the child's general health and food intake and the reality of daily care (24 h a day) by parents, which is characterized by frequent vomiting, a lack of acceptance in regular child day-care centers, and the development of behavioral issues due to tube feeding. These findings are similar to those by Garro and colleagues (2005), who stated that feeding difficulties contribute to parental stress, anxiety, and depression, as well as fear of social stigmatization due to unconventional feeding practices.<sup>21</sup>

During decision-making, HCPs should exchange information with families. HCPs can inform parents, and if possible, also the child about the benefits, risks, and impacts of treatment options, while parents can provide information and insight about personal values and preferences. Attention should be paid to child, parent, and family topics. Clinicians should tailor their approaches accordingly.<sup>2</sup> Insufficient time is a major factor that hampers decision-making.<sup>22</sup> Families of children who require long-term or permanent tube feeding may experience less stress if they better understand the reasons for the tube placement and the overall management of tube feeding.<sup>23</sup> The Dutch guideline for malnutrition stresses the importance of parental involvement in decision-making, and this should be part of the personalized care solution.<sup>24</sup> In this process, the child should be given space and voice in the decision-making process too. The communication sheet provides practical help for the implementation of the guideline.

In our interviews, parents often reported and felt that the care for tube feeding seemed to end at hospital discharge. Parents seemed unaware of whom they could address practical issues, such as improving oral feeding and changing formula or systems. Studies confirmed that clinicians could underestimate the impact of tube feeding on medical, financial, cultural, and emotional factors.<sup>14,15</sup>

Professionals should suggest peer support through patients' organizations and offer professional support since parents would like to talk to a professional about their situation.<sup>16</sup>

Tube removal planning was not a topic in the interviews but is also essential to prevent tube dependency in children with the potential for oral feeding.<sup>25</sup> Parents expected care to be coordinated and multidisciplinary to ensure the right care at the right time. An inventory of improvements derived from the interviews showed that better coordination of (interdisciplinary) care is an important priority. This follows the recommendations of Edwards et al. (2016) and is imported into the communication sheet.

The communication sheet was developed to address issues about the decision to tube feed. This interactive PDF with links to in-depth issues (also available in print) is a tool for parents and HCPs to use to open and ease the discussion when a child is initially tube fed at the hospital and later at home. It includes questions like: What is the purpose of tube feeding; How will we monitor this, and who is responsible for tube feeding in and outside the hospital. The communication sheet should help parents and HCPs with decision-making at different stages. The issues and questions of the communication sheet were in line with the aspects of Nelson et al. (2015), who sorted out into child, parents, and family topics for G-tube placement. The communication sheet should enable the empowerment of the parents.

#### *Strengths and limitations and future research*

For ensuring different perspectives, the study included parents and HCPs. Although we cannot be certain that the information gathered is representative of the entire target group, the issues emerging from individual and group interviews were clear and consistent, and therefore, indicative and inductive for the target group. They are also in line with the literature and the indications of the HCPs in the sounding boards. Therefore, we assume that the results of this study provide a good overview of many issues related to this important topic. Many researchers were involved in the data collection and analysis, which optimize the independence and the use of various perspectives.

This study also has some limitations. It is a small study that only involved 17 parents, in which selection bias is an issue. As we recruited participants via a social media platform or the association group *Nee-eten*, not all parents of children with tube feeding are affiliated with these groups. It is well known that parents with a moderate to high educational level or parents with particular meanings and experiences will react to those calls-up. Furthermore, only a few fathers participated. We did not collect data on sociodemographic indicators of parents, which could impact their health literacy and self-advocacy. It might also have been less than ideal for including children of different ages, medical diagnoses, and different tube feeding durations because the impact could be different in very young and complex medical conditions or time had elapsed since the decision to insert the tube and perceptions may have evolved. The communication sheet is suitable for a general population and written at a moderate language level. A version for low literacy families and a version for children should be developed.

In this paper, we have described the development of a communication sheet to use in various stages of decisions in tube feeding. We will explore the experiences in using the communication sheet on the psychosocial impact of tube feeding on parents. Moreover, the effect on the HCPs in their attention on the individual issues on participation, personal and environmental factors. More attention has to be paid to an adapted/simplified version of the communication sheet for people with low health literacy.

## Conclusion

Tube feeding has a large psychosocial impact on children and their families. The empowerment of parents in the process of tube feeding is important. More attention should be paid to the alternatives, consequences, and planning for the long-term process of tube feeding, and different stages can be identified in which a choice has to be made. The communication sheet is developed to improve mutual communication between parents, children, and HCP during these different stages.

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## Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

## Declaration of competing interest

The authors declare that they have no conflict of interest. All authors were responsible for proposal development, study design, data collection, preliminary data analysis, and writing the paper.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.dhjo.2021.101261>.

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