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Pain and discomfort in children with gastrostomy tubes – In the context of hematopoietic stem cell transplantation

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ABSTRACT

Background: In children with malignant and severe non-malignant disorders undergoing hematopoietic stem cell transplantation (HSCT), treatment related pain and discomfort are common. Food consumption may become troublesome, making the use of a gastrostomy tube (G-tube) necessary and resulting in complications, why the purpose was to explore pain and discomfort during the transplantation and post-transplantation time.
Methods: This was a mixed methods study where data were collected along the child's total health-care process between 2018 and 2021. Questions with fixed answer options were used, simultaneously, semi-structured interviews were performed. In total, sixteen families participated. Descriptive statistics and content analysis were used to describe analysed data.
Findings: Intense pain was common during the post-surgery phase, especially in conjunction with G-tube care, which is why the children needed support to manage the situation. After the post-surgery phase when the skin has healed, most of the children experienced minor to no pain or bodily discomfort, why the G-tube became a well-functioning and supportive tool in daily life.
Conclusions: This study describes variations in and experiences of pain and bodily discomfort in conjunction with G-tube insertion in a unique sample of children who had undergone HSCT. In conclusion, the children's comfort in daily life after the post-surgery phase seemed to be only marginally affected by G-tube insertion. Children with severe non-malignant disorders seemed to experience a higher frequency and intensity of pain and bodily discomfort due to the G-tube than children with malignant disorders.
Practice implications: The paediatric care team need competence in assessing G-tube related pain and awareness that experiences may differ depending on the child's disorder.

Background

Suffering from a malignant or severe non-malignant disorder may constitute a threat to the life of a child (Choudhry, 2017; Filbin & Monje, 2019; Haddad & Hoenig, 2019; Hulbert & Shenoy, 2018; Lam et al., 2019; Parini et al., 2017; Young, 2018). However, hematopoietic stem cell transplantation (HSCT) can be used as a treatment in both leukaemia, brain tumours and other malignant tumours, as well as in non-malignant disorders such as thalassemia, aplastic anaemia, sickle cell anaemia, severe combined immunodeficiency (SCID) and mucopolysaccharidosis type 1, and others (Ljungman et al., 2010; Sureda et al., 2015). Most children experience significant side effects from the treatment such as pain and discomfort (Sampaio et al., 2019), but also oral mucositis (Donohoe et al., 2018; Kamsvåg-Magnusson et al., 2014), changed taste (Loves, Plenert, et al., 2019; Loves, Tomlinson, et al., 2019), and an altered appetite (Tomlinson et al., 2020), which may cause feeding difficulties and troublesome food consumption (Kamsvåg-Magnusson et al., 2014; Tomlinson et al., 2020). Pain and discomfort during mealtimes may also contribute to further negative consequences, such as fear of feeding and malnutrition (Damasco-Ávila et al., 2019). Thus, enteral nutrition (EN) (McGrath & Hardikar, 2019; McMillen et al., 2020; Trehan et al., 2020) via a nasogastric tube (NG-tube) or a gastrostomy tube (G-tube) may be necessary to maintain an adequate nutritional intake (McGrath & Hardikar, 2019; Trehan et al., 2020). The two separate experiences of pain and

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discomfort, which are closely related to each other (Eccleston et al., 2021), need to be described in children who have undergone a HSCT and received a G-tube to improve nutritional intake and mealtime comfort.

In 2020, the definition of pain was revised, requiring a new holistic approach to assessment and interpretation (Raja et al., 2020; Stevens, 2021). This emphasize and enable a broader understanding of children's varying pain expressions, but also highlight the importance to consider multiple pain perspectives, e.g., in disabled and non-verbal children (Stevens, 2021). Granulation tissue, leakage, infections, and inflammations are common complications associated with a G-tube, contributing to pain and discomfort (Evans et al., 2021; McGrath & Hardikar, 2019). The description of pain highlights its complexity as an individual experience, influenced by the senses and emotional factors as well as biological, psychological, and social aspects (Eccleston et al., 2021; Raja et al., 2020; Stevens, 2021).

The development during childhood affect the child's comprehension of pain (Jaaniste et al., 2016), also their prerequistes to perceive and express pain (World Health Organization WHO, 2020). Thus, infants, children and adolescents may experience pain differently compared to adults (Eccleston et al., 2021; World Health Organization WHO, 2020). Culture, norms and contextual aspects have a great impact at the child's ability to express and respond to pain (Eccleston et al., 2021; World Health Organization WHO, 2020). Infants may cry, appear to be restless and annoyed as a response to the pain. Children up to five years can exhibit these behaviours, and they can also scream and pushing. Older children up to 12 years can do attempts to escape from the pain, while adolescents instead may negate the experience (Duffy et al., 2019).

The presence of pain is disagreeable and adverse – it affects comfort to a high degree (Eccleston et al., 2021; Raja et al., 2020) – but in children, it also risks going unnoticed or undertreated (Eccleston et al., 2021; Friedrichsdorf & Goubert, 2020). A holistic approach with a biopsychosocial perspective is therefore necessary to manage the condition and facilitate the goal of symptom relief (Eccleston et al., 2021; Raja et al., 2020).

In contrast to pain, discomfort can be seen as a state or a subjective feeling. The individual experiences of being and daily life are then perceived as unpleasant (Stanghellini, 2001; Vink & Hallbeck, 2012). Discomfort consequently involves several symptoms that are not experienced as pain (Stanghellini, 2001). Pain is a common experience in paediatric care. Pain may occur due to illness, treatment and procedures (Eccleston et al., 2021; Friedrichsdorf & Goubert, 2020), while oncology treatments may contribute to discomfort, such as sleep disturbances (Daniel et al., 2020; Ward et al., 2020) and G-tube complications (Evans et al., 2021; McGrath & Hardikar, 2019).

For those children who need a feeding tube, an NG-tube insertion may be quick and easy but entails complications, such as vomiting and dislodgement (McGrath & Hardikar, 2019). Unfortunately, the paediatric care team, as well as the parents, might use NG-tubes as a threat to force the child to eat (Fleming et al., 2015; Trehan et al., 2020), leading them to be frightened of the unknown process (Bicakli et al., 2019). Moreover, an NG-tube may cause feelings of discomfort due to its visibility, causing an altered appearance (Bicakli et al., 2019; McGrath & Hardikar, 2019). Although a G-tube marginally affects the child's appearance and body image, it may still be an advantageous choice (McGrath & Hardikar, 2019; Trehan et al., 2020), as G-tube insertions have been shown to impact positively on the child's nutritional status (Evans et al., 2021; McGrath & Hardikar, 2019). Nevertheless, bodily changes, such as scars, may be an additional aspect for the child to manage later in life (Darcy et al., 2019; Lee et al., 2012) and the insertion of a G-tube can be associated with complications affecting the majority of children who have undergone this intervention at some point (Evans et al., 2021; McGrath & Hardikar, 2019). A high proportion of children who undergo a HSCT have been reported to develop complications and seem to be especially at risk of G-tube related infections (Evans et al., 2021). Therefore, the choice to insert a G-tube may be complex (Evans et al., 2019; Evans et al., 2021). Pain and discomfort in conjunction to a G-tube have been identified as a serious problem in children and have previously not been highlighted. These children are referred to and dependent of health care during a long-term period, which can be seen as a complex issue, were cultural and institutional barriers complicate the situation further. To our knowledge, there are no reports on how children undergoing a HSCT experience pain and discomfort associated with a G-tube along a total health-care process.

Purpose

The purpose of the present study was to explore pain and discomfort in this vulnerable group of children with malignant and severe non-malignant disorders during the transplantation and post-transplantation time until the G-tube was removed.

Methods

Study design

This was a mixed methods study (Creswell & Plano Clark, 2017), where both qualitative and quantitative data were collected simultaneously and repeatedly along the child's total health-care process to describe variations in their and their parents' experiences regarding pain and discomfort when the child had received a G-tube. A child-centred care approach (CCC) focusing on the child's perspective but also the parents' complementary child perspective (Nilsson et al., 2015; Söderbäck et al., 2011) has been used. The intention was to conduct semi-structured interviews and questions with fixed answer options (once a week for a month on each occasion) with children and their parents three times a year, until the G-tube was removed.

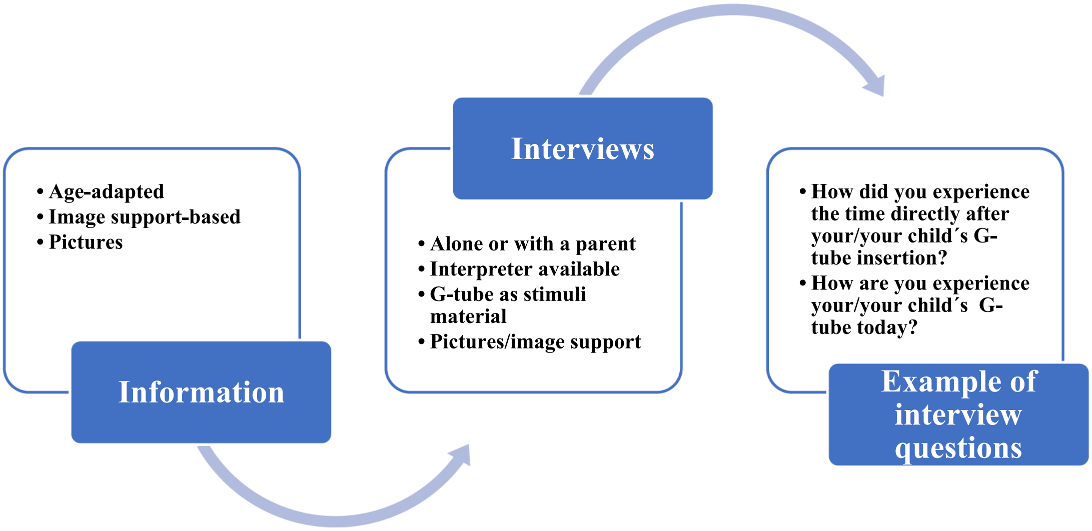
Participants were invited to engage in semi-structured interviews and provide responses to questions with fixed answer options, all performed in parallel, face-to-face or via telephone, individually and repeatedly during the study period between 2018 and 2021. See Fig. 1.

All the information about the study given to the children was age-adapted and supported by pictures. The semi-structured interviews gave the participants opportunity to share a broader point of view of their experiences regarding pain and discomfort, while the questions involved predetermined questions with fixed answer options. The data collection was performed with the children and their parents along the total health-care process during the child's treatment or until the G-tube was removed (see Supplementary file).

Setting and sample

Recruitment took place at one of the Childhood Cancer Centres in Sweden where the insertion of a G-tube prior to HSCT has been part of the clinical routine for many years. All children, irrespective of origin, culture and language, aged 1–18 years and scheduled for a HSCT for a malignant or severe non-malignant disorder between January 2018 and April 2020 were considered for the study ($n = 40$ children) (see Fig. 2). Of those 40 children, some were excluded because they did not receive a G-tube and some for other reasons. Thus, a total of 28 children were available for inclusion. Of these, nine did not participate due to particularly serious medical conditions (assessed by health care professionals (HCP's) on the ward) and three families declined to participate. Consequently, the total number of children and their parents consenting to be included in this study was 16 (see Fig. 2).

Of the included children, ten were followed during the process of HSCT until the G-tube was removed, which was approximately six months after the HSCT (see Fig. 2). In all the children the G-tube was inserted before HSCT (median 48.5 days, range 9–113 days), and changed to a gastrostomy button (G-button) at three months after HSCT. Two children died during the study period, while four families chose to end participation (see Fig. 2). This left four families. In two of



- How did you experience the time directly after your/your child´s G-tube insertion?
- How are you experience your/your child´s G-tube today?

Fig. 1. The interview process.

these families, each participant responded once, while in the other two families´ participants answered twice and three times respectively (See Supplementary file). The included children underwent HSCT due to brain tumour ($n = 1$), leukaemia ($n = 5$), Wilms' tumour ($n = 1$), thalassemia ($n = 3$), aplastic anaemia ($n = 2$), sickle cell anaemia ($n = 2$), SCID ($n = 1$) or Hurler syndrome ($n = 1$). The children were born between 2003 and 2017, with an average age of 8.9 years at HSCT (See Table 11).

Sixteen children were assessed regarding pain and discomfort associated with the G-tube (see Table 1). Of the included children, five children younger than five years were excluded, which is why the parents in these families performed semi-structured by-proxy interviews instead and answered questions with fixed answer options. Another three children decided not to participate in the study (due to demanding treatment or not feeling well enough) (see Fig. 2).

In total, eight children (two boys and six girls) answered questions with fixed answer options by themselves while their parents simultaneously performed complementary structured interviews. The remaining eight included children were represented by their parents' by-proxy answers. In summary, eight children and a total of 21 parents (11 fathers and 10 mothers) answered questions with fixed answer options. A total of 117 occasions for questions with fixed answer options were conducted with the 16 included families, whereof 23 with the children and 94 with their parents. The children were interviewed a median of 2.5 times each (range 1–7 times) and parents a median of 4.0 times each (range 1–10 times) (see Supplementary file). The first collection of quantitative data with the children was performed at a median of seven weeks (range 17 weeks) after the HSCT, while the first collection of quantitative data with the parents were performed at a median of one week (range 17 weeks) after the child's HSCT (see Supplementary file I). Collection of all quantitative data with the children completed at a median of 7 weeks after the HSCT (mean 10 weeks), while all collection of quantitative data with the parents was completed at a median of six weeks after the child's HSCT (mean 10 weeks).

Of the 16 included children and their families, semi-structured interviews were performed with 14 families. This was because two families chose not to participate in this part of the study. Seven children performed semi-structured interviews by themselves, while their parents simultaneously gave their complementary point of view. The remaining seven children were represented by their parents in semi-structured by-proxy interviews (see Fig. 2). In summary, seven children and 19 parents performed semi-structured interviews. A total of 50 semi-structured interviews were performed, 13 of which were with the children and the remaining 37 with their parents (see Supplementary file I). Parent interviews dominated as a result but were seen as important and complementary to get a broad view of the children's descriptions and experiences. The first semi-structured interview with the children was performed a median of one week after their undergoing HSCT, whereas parents performed their first interviews a median of two weeks after the child's HSCT. For the children, each semi-structured interview lasted between 15 and 35 min (median 24 min) and for the parents, between 16 and 69 min (median 32 min). Six children were interviewed twice, and one child once during the study period. Five parents were interviewed three times, nine parents twice, and five parents once during the study period (see Supplementary file I).

The plan was to conduct semi-structured interviews and ask questions with fixed answer options three times a year until the G-tube was removed. Of the eight children who participated in the semi-structured interviews and answered questions with fixed answer options, all could be followed until the removal of the G-tube. For the five children younger than five at HSCT, participation ended either due to removal of the G-tube or death (see Fig. 2).

The data collection was performed both in hospital care and in the families' homes. All semi-structured interviews were audio recorded and the interview guide was based on the M-FAMM and its seven aspects, i.e., the room, the meeting, the product, the management control system, the atmosphere, bodily discomfort and time of change and acceptance (Mårtensson, Cederlund, et al., 2021; Mårtensson, Jenholt Nolbris, et al., 2021), see supplementary file II. However, in this study, data concerning pain and discomfort, here linked to the aspect bodily discomfort (Mårtensson, Cederlund, et al., 2021; Mårtensson, Jenholt Nolbris, et al., 2021) was in focus, see Fig. 1.

Interpreters were available and translated during interviews when the participants did not master Swedish or English in speech and writing. Thus, a number of families with different origins and cultures became represented in the study. The children had the choice of being interviewed on their own or having a parent present. Pictorial aids were available to assist with the interviews. In the spring of 2020, the COVID-19 pandemic resulted in restrictions that required social distancing in research, thus changing the method of data collection to a digital format (e.g. face-time, skype, zoom and video links) with the purpose of continuing to gather data (Morgan & Hoffman, 2020).

Study measurement

An expert group consisting of the first author (U.M.), the second author (S.N.), the third author (M.J.N.), and the last author (K.M.) selected

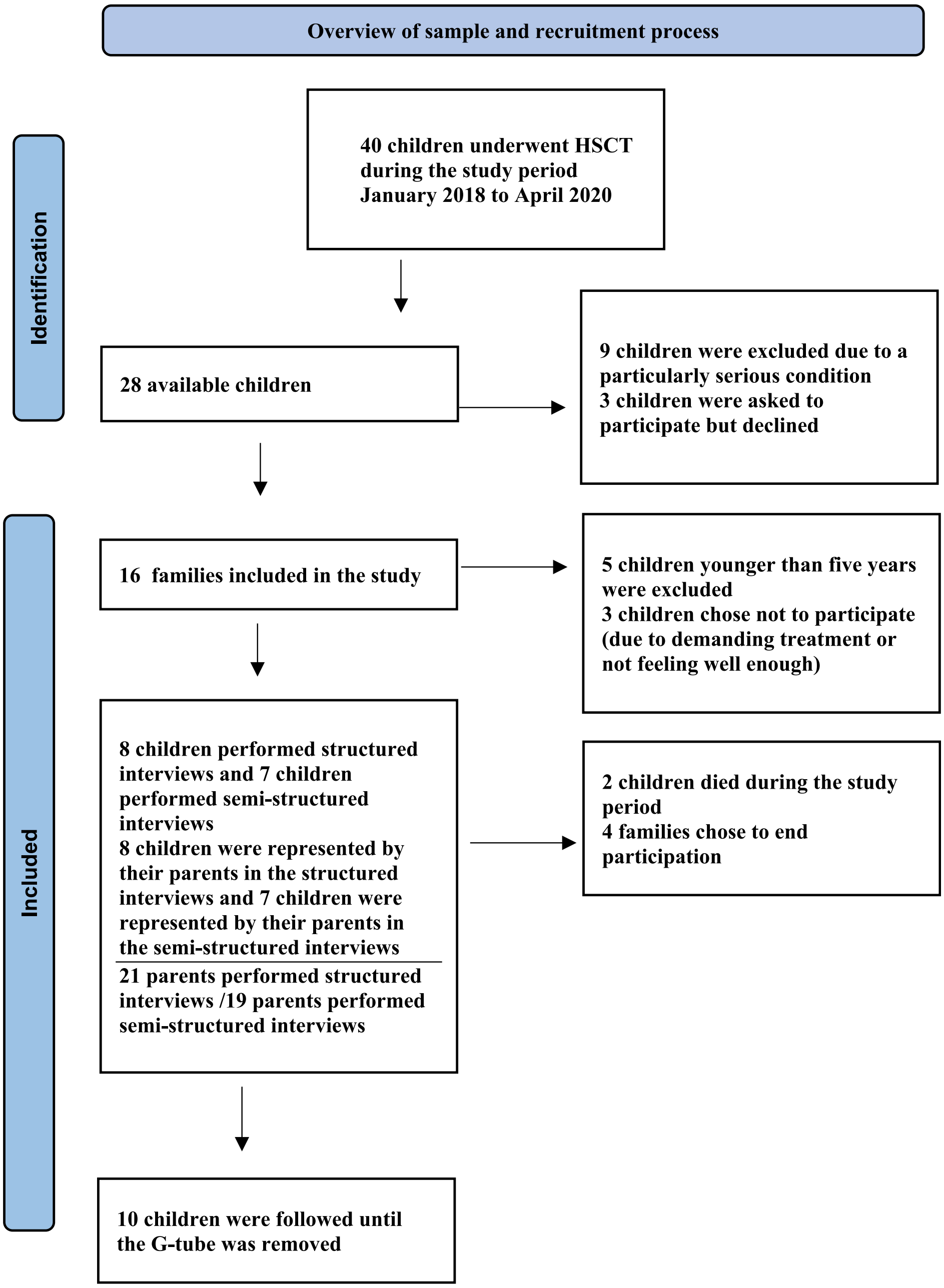


Fig. 2. Overview of sample and recruitment process.

study-specific questions with the purpose of mapping pain and discomfort (see supplementary file III). The chosen questions originated in a questionnaire developed to evaluate meal situations in children with a G-tube (Nolbris et al., 2019), but could also be related to already established approaches within clinical paediatric care (Birnie et al., 2019; Zieliński et al., 2020) as well as the aspect of bodily discomfort in the M-FAMM (Mårtensson, Cederlund, et al., 2021; Mårtensson, Jenholt Nolbris, et al., 2021). Pain intensity was reported with an 11-step numeric rating scale (NRS) (0–10) (Birnie et al., 2019; Zieliński et al., 2020). Pictures that visualized verbal questions were also used, as it is important to use alternative, child-centred research methods to facilitate the child's ability to share experiences (Carter & Ford, 2013).

Several factors can influence a child's experience of pain. For example, families in a crisis due to their child's life-threatening disease probably affect their child's experience of pain. Another situation that has impact on the child's pain is a G-tube insertion. Consequently, this study will focus on pain and discomfort in conjunction to the child's G-tube.

Procedures

The study was approved by the regional ethics committee (ref 2019-05671; 937-17). Information about the study was given to the children and their parents both verbally and in writing. All the parents gave written consent for themselves and their children (in agreement with the child) to participate in the study.

Data analysis

Qualitative and quantitative data were analysed separately but collated to give a broader description of the children's and parents' various experiences of pain and discomfort in conjunction with HSCT and G-tubes. In this study, data concerning pain and discomfort were analysed

Table 1
Sample characteristics.

Diagnosis	Children	Sex	Age at inclusion	Treatment	Days between G-tube insertion and HSCT
Non-malignant disorders					
Aplastic anaemia	2	Girl	9	HSCT, allogeneic	30
		Girl	9		43/79 (HSCT no. 1/no. 2)
Hurler syndrome	1	Boy	1	HSCT, allogeneic	57
SCID	1	Girl	2	HSCT, allogeneic	47
Sickle cell anaemia	2	Girl	10	HSCT, allogeneic	50
		Girl	13		35
Thalassemia	3	Girl	10	HSCT, allogeneic	34
		Boy	15		50
		Boy	10		70
Malignant disorders					
Brain tumour	1	Girl	4	HSCT, autologous	17/62 (HSCT no. 1/no. 2)
Leukaemia	5	Boy	7	HSCT, allogeneic	91
		Boy	6		60
		Boy	4		113
		Girl	2		9
		Boy	13		62
Wilms' tumour	1	Girl	7	HSCT, autologous	109

separately from data focusing on meals and mealtime experiences, which were analysed and reported in another study (Mårtensson, Jenholt, et al., 2021). During the analysis process, data from the structured and semi-structured interviews were connected and integrated to each other (Fetters et al., 2013) by the first author (U.M.), and reviewed by the co-authors. This in order to strengthen the quality and results (Fetters et al., 2013), but also with the purpose to improve the trustworthiness of the study.

Qualitative analysis

Qualitative data was analysed using content analysis with an inductive approach, thus enabling the researcher to prepare, organize, and report the findings of the collated data (Elo & Kyngäs, 2008). As a supportive tool, aiming to maintain a high degree of trustworthiness, a checklist developed by Elo et al. (2014) was used (Elo et al., 2014). The author started to read the text repeatedly aiming to organize gathered data (Elo & Kyngäs, 2008). By carefully reading and re-reading the text, by moving from details to the whole, the essence of the data was successively identified and later on sorted into significant units (Elo & Kyngäs, 2008). An open coding process was used (Elo & Kyngäs, 2008). This enabled the first author (U.M.) to proceed the analysis further, why the units later on were coded, grouped and categorized before abstraction concluded with presentation of the data (Elo & Kyngäs, 2008), see Table 2. The data was discussed with and reviewed by the co-authors during the analysis process in order to ensure the quality of the study.

Quantitative analysis

The data program SPSS version 25 was used to chart variations in pain and discomfort within the groups of children, which was later described with descriptive statistics (Polit & Beck, 2016).

Table 2
Overview of the analysis process.

Main categories	Generic categories
Time of uncertainty	Negative emotions Overwhelming feelings
Need of support	Negatively experiences Unpleasant feelings/unexpected reactions
Side-effects as a challenge	Additional complications Aspects to manage
A supportive solution	Helpful tool Facilitating

Results

Integration of data from the structured and semi-structured interviews were carried out through “narrative” and a “contiguous approach”, why the results are presented in two separately parts (Fetters et al., 2013), qualitative and quantitative findings, in order to give a broader description of the children's and parents' various experiences of pain when the child is living with a G-tube.

Qualitative findings

The inductive content analysis (Elo & Kyngäs, 2008) resulted in four main categories: time of uncertainty, need for support, side-effects as a challenge, and a supportive solution. See Fig. 3.

Time of uncertainty

In children, the G-tube insertion was a source of bother and concern, mostly due to lack of information or not having comprehended it in regard to the procedure. This contributed to feelings of discomfort, thoughts and fantasies before the surgery: “*I cried before…because I felt it would be dangerous…*” (a six-year-old boy). The children experienced uncertainty, which lead to feelings of insecurity because they did not understand the process. Despite the paediatric care team's preparatory efforts, the children experienced negative emotions, but also fear of pain in conjunction with G-tube insertion: *“I know it was the*

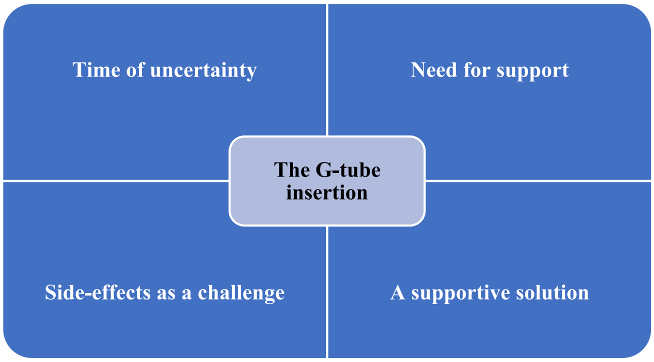


Fig. 3. Overview of main categories.

day of the surgery, but then…I felt a little nervous because I was a little afraid it would hurt…" (a nine-year-old girl). A lack of necessary information and preparation regarding the procedure and its aftereffects resulted in the children feeling overwhelmed. Some experienced intense pain directly after the surgery, and this became an aggravating aspect to manage: *"Yes, I pretty much had pain…for a while…"* (a thirteen-year- old girl). Some parents emphasized that they had not been prepared for their children's experience of pain afterwards, which created a feeling of powerlessness and inability to help: "*…Maybe she was in a little more pain the first night than they (the staff) had said she should be. So maybe they didn't do pain relief very well…she was quite sad that night…"* (mother of a four-year-old girl). The children's reactions after the surgery contributed to some parents feeling a need for action in order to regain control and manage the situation: "*He was in such a lot of pain, and we called the surgeon down as well. And he simply thought x was getting too little morphine afterwards. So he was in so much pain, especially the first day…"* (father of a seven-year-old boy). Although some of the children initially experienced intense pain, this period was seen as limited and transient, as a process of recovery: *"When x got used to it and it had healed a little better, then it didn't hurt so much and then it worked quite well…"* (mother of an eight-year-old girl).

Need for support

Daily care of the G-tube in connection with insertion was initially associated with intense pain and discomfort in some children. The surgery they had undergone resulted in both tenderness and a sensitivity in the skin around the G-tube, contributing to unpleasant experiences in conjunction with care: "*The first time you twisted it…it was tender, it hurt…"* (a nine-year-old girl). Caring for the G-tube had to be done on a daily basis and in some cases became associated with a painful and negative experience: *"When you clean and wash it and touch it, it hurts…"* (a ten-year-old girl). The children who perceived pain tried to find coping strategies but sometimes experienced that the paediatric care team did not listen to them or fulfil their need for support in a painful and vulnerable situation: *"Sometimes they (the staff) were a bit fast…and then they didn't listen to me when I said ouch, because they don't really know how I want it to be…"* (a ten-year-old girl). The child's intense pain could also give rise to unexpected feelings and emotional reactions in the parents, which in turn led to their needing support as the situation could sometimes feel unmanageable: *"They (the staff) have probably not understood how difficult my husband and I think it is…it is, of course, very hard to see that she is in so much pain…"* (mother of a two-year-old girl). Nevertheless, the intense pain seemed to be mostly associated with the G-tube surgery, which is why time to recover and accept the situation was required to reach improvement. Most of the children were aware of this: *It hurt quite a bit, but if it helps me…you know, it is almost like medicine, everything goes better and better. But even if it hurts, so it's best for you sometimes…"* (a ten-year-old girl). Generally, the pain successively decreased as the child's recovery process continued: *"It hurt…but we had to clean…over time it became less painful and easier to handle. Now it is going great…"* (father of a fifteen-year-old boy).

Side effects as a challenge

For most of the children, the pain and discomfort associated with G-tube care stabilized and disappeared quite soon after the surgery: "*… we are happy with it…no problems…"* (mother of a four-year-old boy). However, some children experienced minor complications, which added to the challenges of managing daily life: *"I had a little pain around (the G-tube) and then it became a little red…"* (a ten-year-old girl). Cleaning and properly caring for the G-tube was a challenge, giving rise to parents reflecting on possible causes for the complications: "*… maybe that was why it was infected previously, because it had such large wings that everything was gathered there. Even if you washed every day and we had pads…"* (mother of a one-year-old boy). Granuloma tissue was another mild complication that affected some of the children. Despite treatment, the granuloma tissue had a tendency to return quite soon, making it an ongoing challenge, but in most cases it was not a painful problem: *"It is granuloma…the physician prescribes cortisone ointment or eye drops, so it usually works well for a few weeks and then it comes back again…"* (mother of a five-year-old girl).

A supportive solution

Although the G-tube surgery and subsequent recovery process could involve intense pain and discomfort, for most children it immediately or successively became a helpful tool in an already severe situation: "*She had no pain and no complications (after the surgery). It went very well, and we felt calm and relieved…"* (mother of a five-year-old girl). In most cases, the G-tube was seen as a well-functioning and supportive solution in the children's already bothersome situation: "*…it has worked incredibly well…there have been no problems..*" (mother of a nine-year-old girl). With support from the paediatric care team and parents the children tried to cope with an additional challenge in their daily lives: *"Then he is magical, from day two he has twisted the G-tube himself…from day two…so that has worked well…"* (father of a six-year-old boy). Most children experienced the G-tube as an intervention to facilitate mealtimes during a demanding period of treatment. The G-button replacement further facilitated daily life and improved the process: *"You don't need to twist it (the G-button) and then there won't be so many crusts…"* (a seven-year-old girl). Care was enhanced as the G-button involved fewer procedures associated with pain and discomfort: *"The button still works better…you don't have to tape the stomach, which means you don't have to fight every day…"* (father of a two-year-old girl).

Quantitative results

All the data from the structured interviews are related to the time point when the child or the parents answered the questions.

Pain

Pain around the G-tube

Five families reported that their children experienced no pain around the G-tube, while eleven families reported that at some point during data collection their children (born 2003–2016) experienced pain in the skin around the G-tube (see supplementary file IV and V). Most children experienced occasional, low-intensity pain, which is why several painless episodes were recorded. Three children (born 2008–2016) with a severe non-malignant disorder reported a higher frequency and intensity of pain around the G-tube compared to the other participants.

Four parents assessed the pain differently to their children (born 2008–2010). Two of the parents reported their child had pain more frequently than the children (born 2008–2009) reported themselves. In two families, the children (born 2009–2010) assessed their pain as non-existent, whereas their parents assessed the child's pain as five out of ten on NRS-11.

Stomach pain

Eleven children experienced no pain due to the hose or balloon (associated with the G-tube) inside the stomach. The five children (born 2008–2016) who experienced pain (one with a malignant disorder, born 2016) and four with a non-malignant disorder (born 2008–2016) reported low intensity pain on a few isolated occasions. Stomach pain (due to the G-tube) with a higher frequency and intensity was present in one child (born 2016) with a non-malignant disorder.

Three parents assessed the pain differently to their children (born 2009–2010). Two of the parents assessed their child had pain more frequently than the children reported themselves. In one family, the child (born 2009) assessed no existing pain, whereas the parent assessed it as three on the NRS-11.

Discomfort

Pressing or squeezing

Six children experienced no pain, while ten children (born 2003–2017) experienced pain due to pressing or squeezing from the G-tube. Four of the children who experienced pain had a malignant disorder; the other six had a non-malignant disorder. The pain that occurred was reported once or occasionally several times, which is why several painless periods also occurred.

One child with a non-malignant disorder (born 2016) was reported to experience a higher frequency of pain compared to the other children. Four parents assessed the pain differently to their children (born 2009–2012). In one family, the child (born 2012) reported pain more often than the parent. Three parents stated that their children (born 2009–2010) had pain more frequently than the children reported themselves.

As shown in supplementary file IV and V, pain was more frequently reported early after HSCT and only one parent reported pain late after HSCT. When interviewed early after HSCT, the parents of two children reported that pain was always present, but at later time points the same parents reported that pain was intermittent.

Sleep disturbance

Nine of the children (born 2006–2016) had no sleep disturbance, meaning these children slept well despite the G-tube. Six children (born 2003–2012) had mostly unaffected sleep, meaning their sleep was as good as it was before the G-tube insertion. One child (born 2016) with a severe non-malignant disorder was reported to experience sleep disturbances due to the G-tube.

Two parents assessed their children's ability to sleep differently to the children (born 2009–2012) themselves. For the majority of the time, these children assessed themselves as sometimes having trouble sleeping while the parents assessed them as always sleeping well at night.

Discomfort related to the G-tube

Six children (born 2007–2016) experienced no bodily discomfort due to the G-tube insertion. No infections or major complications were reported. Redness around the G-tube was present in nine children (born 2003–2017), two of whom had a malignant disorder and seven a non-malignant disorder. However, the skin seemed to recover in between evaluations. Granuloma tissue was present in two children (born 2015–2017), one of whom had a malignant disorder (born 2015) while the other (born 2017) had a non-malignant disorder. In the child with a non-malignant disorder (born 2017), both granuloma tissue and redness were reported to be present. The bodily discomfort reported was mild and rare and did not seem to affect the children significantly.

Two parents assessed bodily discomfort differently to their children (born 2006–2010). In one case, the child (born 2010) reported no bodily discomfort, while the parent reported redness around the G-tube. In the other family, the child (born 2006) reported redness around the G-tube, while the parent assessed no bodily discomfort.

Interpretation and integration of qualitative and quantitative results

The mixed analysis confirmed differences in the two types of data, here related to the time after the G-tube insertion. Consequently, time became an expanded aspect, which contributed to supplementary and further dimensions of the results (Fetters et al., 2013). In the post-surgery phase most children experienced pain, especially during the G-tube care, and needed support to manage their pain. After the post-surgery phase when the skin has healed, most children reported no pain or minor pain of low intensity due to the G-tube. Complications due to the G-tube such as redness around the tube, infections and granuloma tissue occur for some children and was perceived as an unappealing circumstance. The G-tube did not seem to affect the child's ability to sleep. Overall, after the recovery process, most families reported that the G-tube was a well-functioning and supportive tool in daily life. See Fig. 4.

Discussion

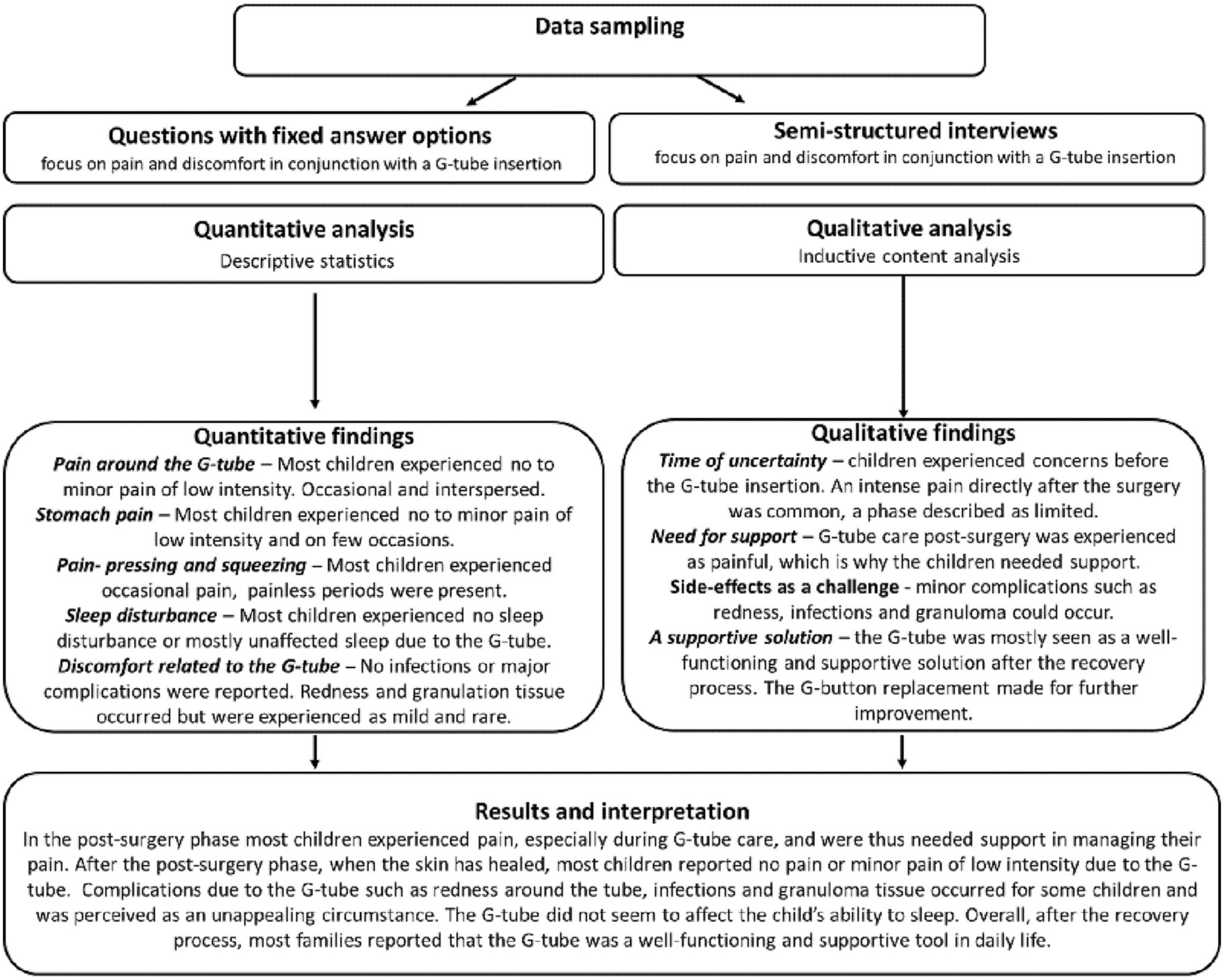
The overall conclusion of the study is that children need to be well prepared before a G-tube insertion. Inserting a G-tube can be associated with several complications, especially in the context of oncology (Evans et al., 2021; McGrath & Hardikar, 2019), and aspects of pain and discomfort may affect the child negatively. A G-tube insertion implies an invasive procedure that may cause pain and bodily discomfort in children (Evans et al., 2021; McGrath & Hardikar, 2019), which correlated with the experiences shared by the children and their parents in this study. During the post-surgery phase the children and parents described experiences of intense pain which were challenging to manage, especially in conjunction with G-tube care. This is why the children need support from the paediatric care team. Although this phase of intense pain was seen as limited and transient, adequate pain relief, support and an emphatic approach from the paediatric care team was considered essential to cope with the pain.

After the post-surgery phase when the skin has healed, most children experienced no pain or minor pain of low intensity due to the G-tube, even if minor pain or bodily discomfort could occur at some point (see supplementary file IV and V). Most of the children in this study were not visibly bothered by pain or bodily discomfort due to the G-tube, although a few experienced stomach pain, pressing/squeezing or sleep disturbances related to the G-tube. In cases where pain or bodily discomfort occurred, these were reported as being minor and of low intensity, mostly occasional and interspersed with several painless periods.

It is also well known that minor complications are common in conjunction with G-tube insertion (Evans et al., 2021; McGrath & Hardikar, 2019). Nine children in this study were at some point bothered by bodily discomfort such as redness around the G-tube, while two experienced granuloma tissue. One of these children experienced a combination of redness and granuloma tissue. It has been emphasized that minor complications such as infection and inflammation are common in children who have undergone oncology treatments and HSCT (Evans et al., 2021). Aspects such as the age of the child (Fernandez-Pineda et al., 2016; McGrath & Hardikar, 2019), as well as choice and type of G-tube insertion method seem to affect the frequency and degree of complications (Baker et al., 2015; Fernandez-Pineda et al., 2016; McGrath & Hardikar, 2019). In this study, complications such as redness and granuloma tissue were experienced as a challenging and unappealing circumstance which caused the child discomfort, mainly in conjunction with care and tube feeding, and became another aspect to manage in daily life.

Experiences of pain are common among children in paediatric care (Friedrichsdorf & Goubert, 2020), especially in those who undergo oncology care and treatments (Linder & Hooke, 2019; Tutelman et al., 2018). Some of the children in this study also experienced a higher frequency and intensity of pain and bodily discomfort after the post-surgery phase. For example, one child with a non-malignant disorder experienced pain and bodily discomfort throughout all procedures and phases. This child also had negatively affected sleep, which corresponds with earlier research suggesting that oncology treatments, hospital stays (Daniel et al., 2020; Hooke & Linder, 2019) as well as pain (Hooke & Linder, 2019) might be a reason for sleep disturbances (Daniel et al., 2020; Hooke & Linder, 2019) and consequently affect the child's ability to recover and attain health (Daniel et al., 2020).

In the current study, the children with non-malignant disorders seemed to experience a higher frequency and intensity of pain and



Pain around the G-tube – Most children experienced no to minor pain of low intensity. Occasional and interspersed.
Stomach pain – Most children experienced no to minor pain of low intensity and on few occasions.
Pain- pressing and squeezing – Most children experienced occasional pain, painless periods were present.
Sleep disturbance – Most children experienced no sleep disturbance or mostly unaffected sleep due to the G-tube.
Discomfort related to the G-tube – No infections or major complications were reported. Redness and granulation tissue occurred but were experienced as mild and rare.

Time of uncertainty – children experienced concerns before the G-tube insertion. An intense pain directly after the surgery was common, a phase described as limited.
Need for support – G-tube care post-surgery was experienced as painful, which is why the children needed support.
Side-effects as a challenge - minor complications such as redness, infections and granuloma could occur.
A supportive solution – the G-tube was mostly seen as a well-functioning and supportive solution after the recovery process. The G-button replacement made for further improvement.

In the post-surgery phase most children experienced pain, especially during G-tube care, and were thus needed support in managing their pain. After the post-surgery phase, when the skin has healed, most children reported no pain or minor pain of low intensity due to the G-tube. Complications due to the G-tube such as redness around the tube, infections and granuloma tissue occurred for some children and was perceived as an unappealing circumstance. The G-tube did not seem to affect the child's ability to sleep. Overall, after the recovery process, most families reported that the G-tube was a well-functioning and supportive tool in daily life.

Fig. 4. Interpretation and integration of qualitative and quantitative results.

bodily discomfort than children with a malignant disorder. We can only speculate that this difference might be related to the family's level of preparation, as children with malignant disorders often undergo surgical interventions prior to the HSCT. Some of the parents in our study reported unexpected feelings and emotional reactions due to the child's intense pain. This highlights how important it is to inform the entire family about post-surgery pain and to offer support to the parents too.

It is worth noting that only eight children in this study (three with a malignant disorder and five with a severe non-malignant disorder) self-reported pain and bodily discomfort, whereas the parents of four children with a malignant disorder and four children with a severe non-malignant assessed their child as having pain and bodily discomfort. Thus the results indicate some discrepancies in pain evaluation between the children and their parents, with a tendency for the children to report less pain and bodily discomfort than their parents. Such differences in reporting between parents and children need not be seen as errors of judgment; rather as a complementary perspective, giving a broader view of the experiences (Eccleston et al., 2021). Consequently, considering both the child's and the parents' by-proxy perspective during measurements and assessments of pain seems to be advantageous (Duffy et al., 2019; Eccleston et al., 2021; Stevens, 2021).

This study emphasize the importance of including a CCC approach (Nilsson et al., 2015; Söderbäck et al., 2011) in the health care. The HCP's need to listen and take the children's point of view in consideration (Söderbäck et al., 2011). The results of this study show that children receiving a G-tube prior to HSCT experience a painful post-surgery period, indicating they need support to manage the situation. After the post-surgery phase, when the skin has recovered, no major experiences of pain, bodily discomfort or major complications occur, which is why a G-tube appears to be a supportive intervention for children undergoing HSCT.

Application to practice

Our findings suggest that during an HSCT process, most children experience intense pain post-surgery, so it seems necessary to emphasize the child's need for support and adequate pain relief to facilitate nursing care. Thus, it is of the greatest importance to assess pain and offer all children adequate pain relief after a surgery, as these measures may result in enhanced well-being (Zieliński et al., 2020). Comic stories used for educational purposes have been shown to reduce children's anxiety and stress before a surgery (Hamza Taha & Hassan El-Sayed, 2021) and might be useful in preparing younger children for insertion of a G-tube. This study showed that the parents could experience unexpected feelings and emotional reactions could due to the child's intense pain. Consequently, parents of children in paediatric oncology care who experience pain may need more psychological support than is currently offered to manage their situation (Uhl et al., 2020). Offering parents psychological support may contribute to better emotional health and thus help them manage situations in which their child may be suffering, for example, while living with cancer or pain (Law et al., 2019).

After the post-surgery phase, when the skin has recovered, minor to no pain or bodily discomfort due to the G-tube insertion seems to be present. Children with severe non-malignant disorders seem to experience a higher frequency and intensity of pain and bodily discomfort due to the G-tube than children with a malignant disorder, and we speculate that this can be related to the level of preparation that the families have received prior to the intervention. Moreover, parents seem to assess pain differently to their children. It is important that the paediatric care team are competent in assessing pain in conjunction with G-tube insertion and are aware that experiences of pain may be different, depending on the child's disorder. The paediatric care team need to be aware of and take the child's development and ability to communicate into account, as this might affect expressions of pain (Duffy et al., 2019). However, they can also use tools adapted for children in the assessment of pain (Birnie et al., 2019; Zieliński et al., 2020). The paediatric care team need to inform children and their parents about common side effects, such as pain and bodily discomfort, that may occur in conjunction with G-tube insertion. Thus, the ability to interact and create a trustful relationship with the family is important when assessing pain within paediatric oncology care (Duffy et al., 2019). By inviting the children to share any experiences they may have, pain and bodily discomfort can be more easily highlighted and prevented at an early stage.

Research implications

A small number of children undergoes HSCT yearly in Sweden, why the result of this study needs to be further explored. Additional studies are needed in order to improve knowledge of pain and bodily discomfort in children who have undergone HSCT and received a G-tube, and especially to clarify causes of and differences in pain frequency and intensity. Future research is needed to explore and identify appropriate strategies to reduce pain and discomfort in children with malignant and severe non-malignant disorders. Research is also needed as to how aspects such as the child's disease, age, culture, and environment affect the experience of pain and bodily discomfort.

Strength and limitations

The total population of children undergoing HSCT in Sweden is small. This group is also vulnerable and consequently extremely susceptible to infections. The children in this study had life-threatening diagnoses with many side effects, meaning their current condition determined whether or not they were able to answer the questions or participate in interviews, and this contributed to limited data collection. Severe side effects also affected the children's daily condition negatively. Moreover, such life-threatening disorders may also pass into a palliative phase, which is why some of the children in this study did not survive. These are all aspects that might hinder a child's participation in research, no matter how willing they were to participate in the first place. These aspects have thus sometimes negatively affected and prevented the collection of data as planned.

Nevertheless, one strength of the study was the extensive data collection, with both qualitative and quantitative data gathered throughout a complete health care process, ensuring the capture of many measurement points.

A CCC approach, which involved both the child's perspective and the parents´ complementary child perspective (Nilsson et al., 2015; Söderbäck et al., 2011) was used. This was combined with pictures and age-adapted information in conjunction to the interviews, which all can be seen as a strength. Semi-structured interviews were performed with children who lived with different severe long-term conditions, but also with their parents, during an extensive period. This can be seen as aspects that strengthened the trustworthiness of the qualitative results (Elo et al., 2014). The long-term process gave also the first author (U.M.) possibility to regularly perform member-checks (Elo et al., 2014), which can be seen as an additional strength. The transparency, both in text, figures and tables, strengthened the trustworthiness of the study further (Elo et al., 2014). However, a limitation of qualitative research and analysis is the risk of inaccurate interpretation of data (Elo et al., 2014). To prevent this risk, the first author (U.M.) invited the co-authors to take part of, check and follow up the analysis (Elo et al., 2014) included codes, subcategories, generic categories and main categories.

The first author (U.M.) had performed previous research in paediatric oncology care, which can be seen as a strength, as it meant there was familiarity with the area and experience of performing interviews with children of different ages. One additional strength is that several of the authors in the research group have extensive experience of paediatric oncology care.

To integrate quantitative data from structured interviews and qualitative data from semi-structured interviews may entail in benefits (Fetters et al., 2013). In this mixed-methods study, the first author (U.M.) used “narrative” and a “contiguous approach” to integrate gathered data (Fetters et al., 2013). The results indicated an expansion (Fetters et al., 2013), since it became clear that time was an important aspect that affected the children's experiences of pain, which gave an added dimension into the results. The results confirmed each other since both quantitative and qualitative data indicated minor to no experiences of pain after the post-surgery phase. Thus, time seems to be a decisive aspect.

Conclusions

This study describes variations in and experiences of pain and bodily discomfort in conjunction with G-tube insertion in a unique sample of children who had undergone HSCT. Intense pain was common during the post-surgery phase, especially in conjunction with G-tube care, which is why the children needed support to manage the situation. After the post-surgery phase when the skin has healed, most of the children experienced minor to no pain or bodily discomfort in this regard. We observed that children in this group with severe non-malignant disorders seemed to experience a higher frequency and intensity of pain and bodily discomfort due to the G-tube than children with malignant disorders. In conclusion, the children's comfort in daily life after the post-surgery phase seemed to be only marginally affected by G-tube insertion.

Author contributions

All the authors were involved in the design of the study. The first author performed the data collection. The first, second and last author were involved in the data analysis. The first author wrote the drafts while all authors were involved in the review and editing of the manuscript. The final version of the article has been approved by all the authors.

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Declaration of Competing Interest

The authors declare that they have no competing interests.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pedn.2023.02.005.

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