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Empowering patients and supporting self-management in paediatric asthma: A qualitative approach on health care professionals' needs, expectations and experiences

Master´s thesis

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PhD

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TALLINNA TEHNIKAÜLIKOOL
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Pediaatrilise astma patsientide võimestamine ja enesehoolde toetamine: tervishoiutöötajate vajadused, ootused ja kogemused

Magistritöö

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Author’s declaration of originality

I hereby certify that I am the sole author of this thesis. All the used materials, references to the literature and the work of others have been referred to. This thesis has not been presented for examination anywhere else.

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Abstract

Background: There are estimated 262 million people who have asthma worldwide and it is the most common chronic disease among children. For children, it is one of the leading causes of missed school days. Self-management, patient engagement and patient empowerment have shown a great effect in keeping the disease under control and preventing major asthma attacks from appearing in the future. The responsibility of managing the disease primarily falls on parents and other caregivers who have to communicate with healthcare professionals to support a child. **The aim of the study** is to explore the needs, expectations, and experiences of healthcare professionals (HCPs) in relation to communication and information sources and tools including the potential of digital solutions to support children and their parents in childhood asthma self-management. **Methods:** A qualitative study was conducted in which 7 semi-structured interviews were performed with the healthcare professionals of Tallinn Children´s Hospital during February and March 2023. A combination of deductive and inductive methods was used to analyse the data in this study. The **results** revealed three main categories, encompassing the regular consultation of pediatric asthma patients; outlining the differences in understanding the meaning of expected patient empowerment and self-management; and emphasizing the significance of self-management among pediatric asthma patients. Additionally, the study explored the experiences and expectations of clinicians in Tallinn Children's Hospital, in regards to digital health technologies outlining the lack of suitable solutions despite the readiness to use those. **Conclusions**: HCPs emphasise that to be successful, patient empowerment and self-management are essential. While patient empowerment has no standard definition, this may lead to confusion regarding concrete activities among healthcare providers. Therefore making a shared understanding of this concept necessary. Digital health technologies can support healthcare providers, but collaboration between clinical staff and technology representatives is necessary to address existing problems.

This thesis is written in English and is 65 pages long, including 7 chapters, 6 figures.

Annotatsioon

Pediaatrilise astma patsientide võimestamine ja enesehoolde toetamine: tervishoiutöötajate vajadused, ootused ja kogemused

Taust: Hinnanguliselt põeb astmat maailmas 262 miljonit inimest ja see on kõige sagedasem lastel esinev krooniline haigus. Seetõttu on astma üks peamisi põhjuseid, miks lapsed koolist puuduvad. Enesejuhtimine, patsiendi kaasamine ja patsiendi võimestamine on näidanud positiivset mõju haiguse kontrolli all hoidmisel ning tulevikus astma ägenemiste ennetamisel. Haiguse juhtimise vastutus, mis hõlmab suhtlemist tervishoiutöötajatega, langeb peamiselt lapsevanematele või teistele hooldajatele. Uurimistöö **eesmärk** on selgitada välja tervishoiutöötajate vajadusi, ootusi ja kogemusi seoses suhtlus- ja teabeallikatega ning sealhulgas digitaalsete lahenduste potentsiaali, et toetada lapsi ja nende vanemaid lapseea astmaga toimetulekul. **Metoodika**: kvalitatiivse uuringu käigus viidi läbi 7 poolstruktrueeritud intervjuud SA Tallinna Lastehaigla tervishoiutöötajatega, kes vastasid uuringusse kaasamise kriteeriumitele. Andmete analüüsimiseks kasutati deduktiivse ja induktiivse kombineeritud meetodit. **Tulemused** tõid välja kolm põhilist teemakategooriat, sh pediaatriliste astmaatikute regulaarse konsultatsiooni ja nõustamise viisid, patsientide võimestamise ja enesejuhtimise mõistetest erinevad arusaamad ning enesejuhtimise olulisuse pediaatriliste astmaatikute hulgas. Lisaks uuriti SA Tallinna Lastehaiglas töötavate klinitsistide kogemusi ja ootusi digitaalsete tervisetehnoloogiate osas. **Järeldus**: Tervishoiutöötajate arvates on patsiendi võimestamine ja enesejuhtimine eduka ravi saavutamiseks olulised. Kuna patsiendi võimestamine ei ole ühtselt defineeritud, siis võib see nii tervishoiutöötajate kui patsientide seas segadust tekitada, mistõttu on kontseptsiooni üheselt mõistmine vajalik. Digitaalsed tervisetehnoloogiad võivad tervishoiutöötajaid toetada, kuid parem koostöö klinitsistide ja tehnoloogia valdkonna esindajate vahel on vajalik olemasolevate probleemide lahendamiseks.

Lõputöö on kirjutatud inglise keeles ning sisaldab teksti 65 leheküljel, 7 peatükki ja 6 joonist.

List of abbreviations and term

EARIP	European Asthma Research and Innovation Partnership
EMD	Electronic monitoring device
eHealth	The use of digital information and telecommunication technologies which include computers, the Internet, mobile devices, and applications to provide healthcare services and to support health development
GINA	Global Initiative for Asthma: Global Strategy for asthma management and prevention
HCP	Health care provider
SG	Serious games
RSV	Respiratory syncytial virus

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1 Introduction

Introduction

Paediatric asthma is a common chronic condition that has far-reaching implications for the health of children, families, and the healthcare system [1]. According to the World Health Organization, 262 million people were affected by asthma in 2019, and 461 000 ended with death. In Europe, almost 10 million people below 45 years of age were diagnosed with asthma which made the prevalence of asthma 8,2% in adults and 9,4% in children [1]. Although the prevalence of asthma in 2019 was the highest in European Union in Sweden and Portugal, Estonia was showing the lowest prevalence [2]. Despite general prevalence, asthma in children is still rising [3]. While the diagnosis may be relatively straightforward, if the child displays characteristic symptoms, triggers, and responds to therapy, there are other less common presentations that can complicate the diagnosis. It can be difficult to diagnose asthma in a toddler with recurrent wheezing [4]. A step-by-step approach to asthma treatment usually reduces symptom frequency and improves asthma control [5].

Managing asthma can be challenging and cause poor disease outcomes if inadequate precautions are taken [6]. Developing partnerships between healthcare providers, patients, and their parents is one of the recommended ways to improve asthma management [7]. It is unknown, however, whether young children are aware of asthma symptoms and their management, or how health professionals approach children and parents during clinical consultations [8]. Despite this, there are several barriers that prevent an ideal consultation from taking place. The main requirements for a successful asthma consultation are adequate time and effective communication [9]. Awareness of the symptoms, management of the child's well-being good communication regarding education, and consultation between healthcare providers and families are the key components of the positive treatment path [7].

In order to utilize limited time effectively, patients can be provided with more information before consultations. Communicating with health professionals is the primary responsibility of parents and other caregivers [10]. Some parents may express difficulty identifying asthma triggers and symptoms [11]. Additionally, they may lack knowledge regarding how to prevent and manage asthma symptoms.

By providing patients with the necessary tools and skills, e-health interventions may enhance their ability to manage their health conditions effectively [12]. Healthcare professionals may find e-health valuable for assisting patients interactively, facilitating contact and information exchange, and interventions during consultations [5]. E-health disease self-management tools are growing in popularity, however, there is still a need for conducting trials in order to develop strategies promoting e-health solutions into daily practice [12]. In terms of providing advanced and targeted asthma care for children, e-Health solutions have a great deal of potential however, unresolved issues must be considered before they can be properly utilized in clinical practice, therefore healthcare professionals will be essential in the development of these solutions [13].

The aim of the thesis is to explore the needs, expectations, and experiences of healthcare professionals (HCPs) in relation to communication and information sources and tools including the potential of digital solutions to support children and/or their parents in childhood asthma self-management.

The thesis consists of seven chapters. The first chapter introduces the topic of this thesis. The second chapter gives an overview of the theoretical framework of the study. Chapter three introduces the aims and objectives of the study. The fourth chapter gives an overview of the methodology and methods used in the study and chapter five presents the results. A discussion is presented in the sixth chapter, and a summary is provided in the seventh chapter.

2 Theoretical framework

This chapter presents a literature review and establishes the theoretical framework for the study.

2.1 Overview of paediatric asthma

Asthma is a chronic inflammatory disease of the airways, marked by recurrent episodes of obstruction of airflow as a result of oedema, bronchospasm, and increased production of mucus [14]. There are a number of respiratory symptoms that may be experienced by asthma patients, including wheezing, shortness of breath, coughing, and chest tightness [14]. Asthma symptoms can vary in severity and frequency, but uncontrolled asthma and acute exacerbations can result in respiratory failure and death [15].

2.1.1 Types of paediatric asthma

There are several types of asthma: virus-induced, exercise-induced, allergen-induced and "unresolved" asthma challenging the diagnosis and treatment of asthma even further [16]. Virus-induced asthma, also known as viral-induced wheezing or asthma exacerbation, this type of asthma is triggered by respiratory viral infections such as the common cold, flu, or respiratory syncytial virus (RSV) [5]. It is more common in young children and may present with symptoms such as wheezing, coughing, and difficulty breathing [5][17].

As evident from the name, exercise-induced asthma is triggered by physical activity or exercise. It is more common in children who already have asthma, but it can also occur in children without a history of asthma [5][18]. Symptoms may include coughing, wheezing, chest tightness, and shortness of breath during or after exercise [5].

Allergen-induced asthma, also known as allergic asthma or extrinsic asthma is triggered by exposure to allergens such as pollen, dust mites, mould, and pet dander [5]. The immune system overreacts to these allergens, causing inflammation and narrowing of the airways[5][15]. Symptoms may include coughing, wheezing, chest tightness, and shortness of breath [5].

"Unresolved asthma" is not typically considered a distinct type of pediatric asthma, however, healthcare providers may use the term to describe asthma that is difficult to control or asthma that continues to cause symptoms despite appropriate treatment [16][5].

As a result of increased immune system sensitivity, certain triggers cause swelling and mucus production in the lungs and airways [19]. There is a possibility of a delayed reaction to a trigger, making the identification of the trigger more difficult. Understanding and avoiding asthma triggers is an important aspect of asthma management [19]. Different asthma triggers are shown on Figure 1.

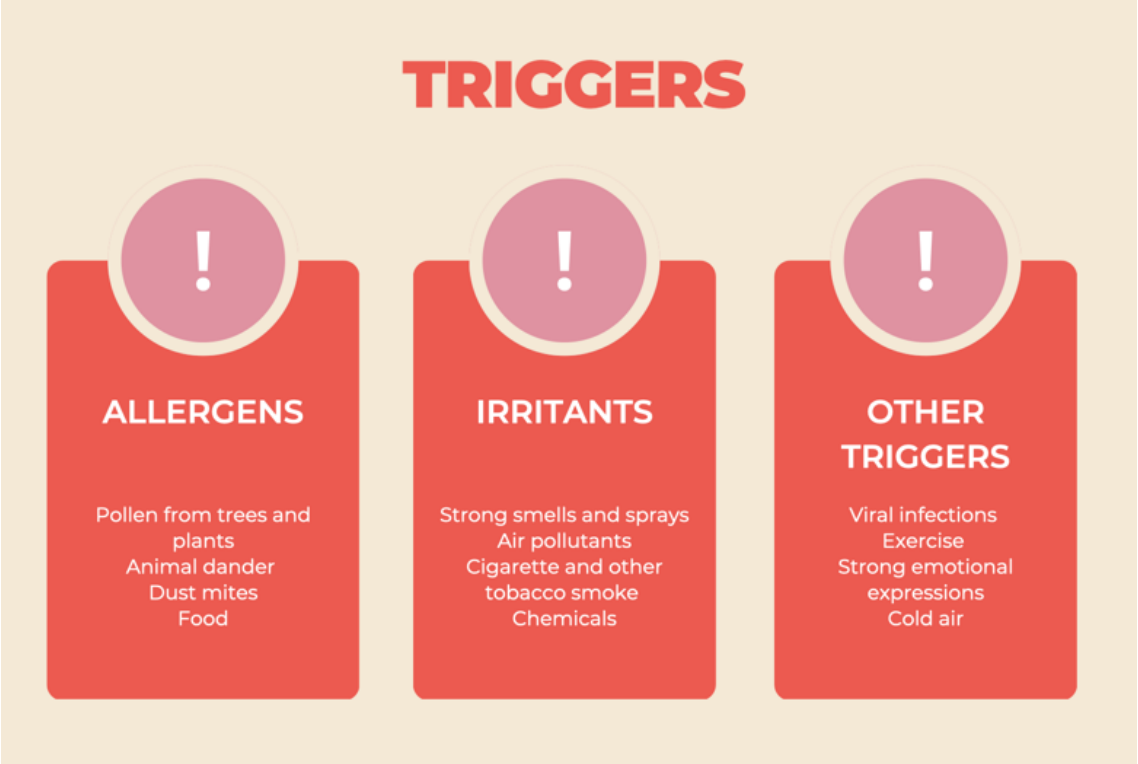

Figure 1. Asthma triggers (modified by author) [19]

As seen from figure 1, triggers vary a lot by their nature but also among individuals and can be influenced by environmental, genetic, and lifestyle factors [19] and in some cases, asthma symptoms can occur with no apparent cause [19].

2.1.2 Levels of paediatric asthma control and disease management

Levels of control are used by healthcare providers to assess the severity of a child's asthma and to guide treatment decisions [5]. It is important for children with asthma to achieve

and maintain good asthma control, as this can reduce the frequency and severity of asthma attacks, improve lung function, and improve quality of life [8]. Figure 2 outlines the common understanding according to GINA guideline regarding asthma control.

Characteristic	Controlled	Partly controlled (any measure present in any week)	Uncontrolled (3 or more features of partly controlled present in any week)
Daytime symptoms	None	> Twice a week (typically for short periods of the order of minutes and rapidly relieved by use of a bronchodilator)	> Twice a week (typically lasts minutes or hours or recur. Partially or fully relieved by bronchodilator)
Limitations of activities	None	Any (cough, wheeze or difficulty breathing during exercise, play or laughing)	Any (cough, wheeze or difficulty breathing during exercise, play or laughing)
Nocturnal symptoms or awakening	None	Any (coughs during sleep or wakes with cough, wheezing and/or difficulty breathing)	Any (coughs during sleep or wakes with cough, wheezing and/or difficulty breathing)
Need for reliever/rescue	In 2 or less days in a week	More then 2 days per week	More then 2 days per week

Figure 2. Levels of paediatric asthma control (modified by author) [5]

As seen from figure 2, when asthma is controlled, the symptoms are well-managed and occur infrequently, with no more than two asthma attacks per week, and no interference with daily activities or sleep. The child's lung function is normal or near-normal, and they have minimal or no need for rescue medication (such as albuterol)[20][5]. When asthma is controlled partly, the symptoms occur more frequently than with controlled asthma, with three or more asthma attacks per week, and some interference with daily activities or sleep[16]. The child may have some limitations in lung function, and may require rescue medication more frequently (but less than daily)[3]. With uncontrolled asthma, symptoms are poorly managed, with frequent asthma attacks (more than three per week) and significant interference with daily activities or sleep [5]. The child may have reduced

lung function and may require frequent use of rescue medication (more than twice per week) [15].

In 2009, the Estonian Society of Immunologists and Allergists developed a treatment guideline adapted to Estonia, the purpose of which is to assist both family doctors working at the primary care level, as well as paediatricians, pulmonologists and allergists working on an outpatient basis and in a hospital, in harmonizing treatment tactics, taking into account the characteristics of children of different ages [16]. The treatment requires close collaboration between the patient and his or her family members, as well as the doctor and the entire medical team [16]. Comprehensive pediatric asthma treatment is of paramount importance given the chronic and potentially debilitating nature of this condition [16]. A comprehensive approach to pediatric asthma treatment involves several essential components as provided in figure 3.

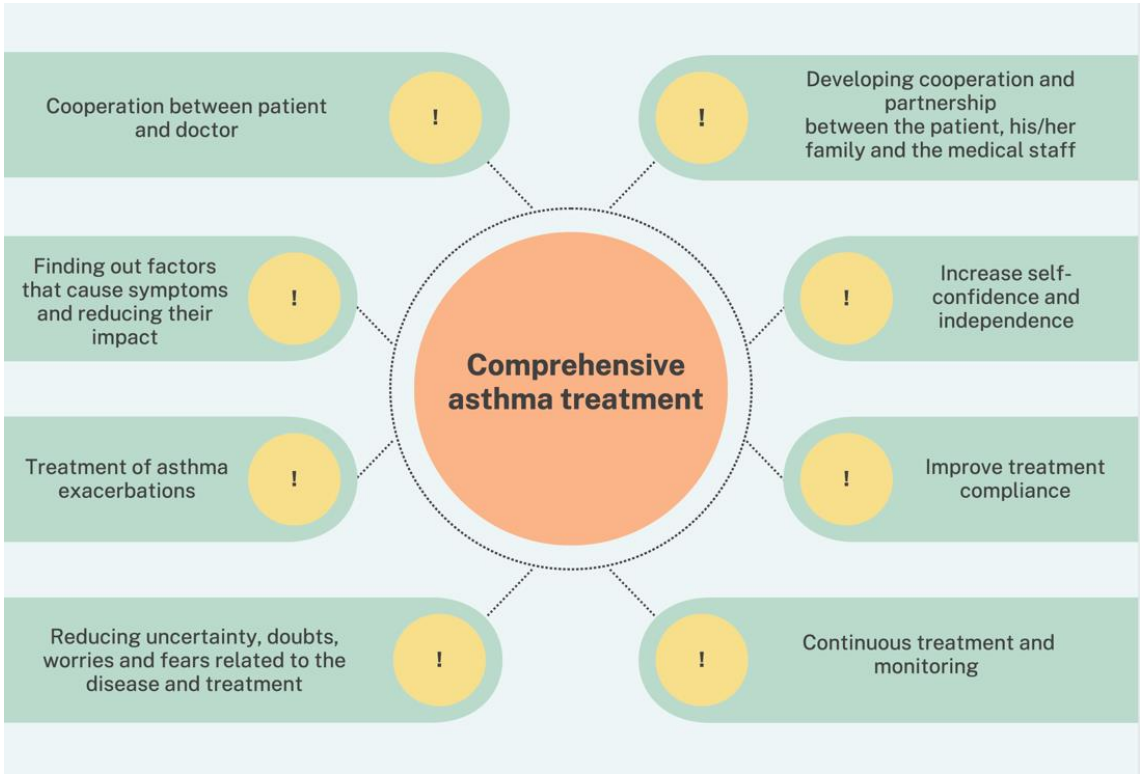

Figure 3. Comprehensive asthma treatment (modified by author) [16]

As seen from figure 3, several components (e.g., cooperation between different stakeholders, increasing confidence, reducing emotional concerns such as fear and uncertainty etc.) that contribute to the provision of comprehensive asthma treatment are

related to patient empowerment and support to self-manage the illness. An asthma treatment's objective is to keep disease symptoms under control over the long term in order to allow children to live a normal life, engage in unrestricted physical activity, and maintain near-normal lung function [16]. Asthma control is attempted to be maintained with the least possible treatment and thus with the least risk of side effects [16]. Pediatric asthma can be well-controlled with the appropriate medication and management plan [5]. However, the effectiveness of the medication can vary from child to child, and it may take some time to find the right medication and dosage that works best for each individual child [5].

2.2 The impact of paediatric asthma

The burden of asthma can be significant both for patients and for society as a whole [5], [8]. For patients, asthma can have a significant impact on their quality of life and from a societal perspective, asthma is a significant public health issue that imposes a substantial economic burden [8]. The following section will elaborate on those impacts in more detail.

2.2.1 The impact on physical and mental health

Pediatric asthma can have a significant impact on a child's physical health, including frequent respiratory symptoms such as coughing, wheezing, and shortness of breath [21]. These symptoms can interfere with daily activities, such as exercise, and can disrupt the sleep [5]. Severe asthma attacks can be life-threatening and may require emergency medical treatment [18]. Severe asthma symptoms are defined as current asthma symptoms in combination with four or more attacks of wheeze per week, waking up at night with asthma symptoms one or more times per week, and/or episodic wheeze severe enough to limit one's ability to speak [20]. According to the findings of the study which was led by the Global Asthma Network, up to one-third of children, adolescents, and adults with asthma symptoms experience severe symptoms that interfere with their daily activities [22], [23].

In addition to direct physical impact, children with asthma are at increased risk of developing anxiety and depression due to the chronic and unpredictable nature of the disease, as well as the limitations it can place on their daily activities [24]. It can impact a child's quality of life by limiting their physical activity, disrupting their sleep, and

affecting their social interactions (e.g., missing school or activities) as well as can have an impact on the family unit, as parents may feel stressed and anxious about their child's condition, and siblings may feel neglected due to the attention given to the child with asthma [25]. Some children with asthma may experience stigma from their peers due to their condition, which can impact their social and emotional well-being [24].

2.2.2 Economic impact and costs

Over the last 40 years, there has been a significant increase in the prevalence, morbidity, and mortality associated with childhood asthma among children worldwide [26]. The prevalence of asthma in European children varies widely, ranging from less than 2% in some eastern European countries to more than 20% in some western European countries [3]. In terms of disability-adjusted life years among children, asthma ranks among the top 20 chronic diseases worldwide [27]. Over the past several decades, the prevalence and incidence of asthma have increased throughout the world, largely due to a variety of environmental and lifestyle risk factors [28].

According to a 2019 report by the European Asthma Research and Innovation Partnership (EARIP), the total cost of asthma in Europe is estimated to be over €19 billion per year [29]. This includes direct costs such as healthcare expenses and indirect costs such as lost productivity and absenteeism from work and school [29].

The direct costs of pediatric asthma include medical treatments such as doctor visits, hospitalization, medications, and emergency care [28]. These costs can be substantial, especially for families without health insurance or with limited financial resources [28].

Indirect costs include lost productivity and absenteeism from work and school. For example, parents may need to take time off work to care for their child during asthma attacks or to attend medical appointments [28]. Children with asthma may miss school days due to illness, which can impact their academic performance and long-term educational outcomes [30] [28].

Overall, the economic impact of pediatric asthma in Europe is substantial and underscores the need for effective prevention and management strategies to reduce the burden on families and healthcare systems [3].

2.3 The concept of a successful treatment path: patient engagement and self-management

Despite the availability of effective treatments, asthma remains a major public health concern, with a significant burden on healthcare systems and families (see section 2.2). To improve health outcomes that matter to patients, it is essential to engage them in health care, however, it is unfortunate that modern health care might seem complex to some patients, and many patients are unable to obtain, process, communicate, or understand information and services regarding their health [31]. One approach to improving asthma outcomes is through patient engagement and self-management, which involves empowering patients to take an active role in their care.

2.3.1 The complex definition of patient engagement

As healthcare evolves from a disease-centred approach to a patient-centred approach, patient engagement has become an increasingly important [32]. Patient engagement and self-management are important components of paediatric asthma care, and have been shown to improve outcomes. Therefore understanding patients' information needs and information-seeking behaviour, clinicians will be able to effectively satisfy patients' expectations, which will promote informed clinical decision-making and increase the quality of patient care [33].

Patient engagement refers to the active involvement of patients and their families in decision-making regarding their care. In the context of paediatric asthma, this involves providing education and resources to help patients and families understand the disease, its management, and how to recognise and respond to exacerbations [34]. Patient engagement has been shown to improve asthma outcomes by increasing adherence to treatment regimens, reducing the risk of exacerbations, and improving quality of life [35]. Engaging parents in their child's asthma management can lead to significant improvements in lung function, symptom control, and quality of life [36].

The definition of patient engagement varies according to different studies [37]. It has been defined as follows: *"a set of behaviours by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations with the desired*

goals of patient and family engagement include improving the quality and safety of health care" [38]. Some scholars define patient engagement in terms of the level of "activation," by referring to an engaged patient as *"an active agent in the management of his/her own health"* [39]. Taking into account several definitions, patient engagement can be viewed as a complex and multi-faceted experience which cannot be reduced to merely considering the patient's ability to adhere to medical instructions [37].

2.3.2 The importance of self-management in paediatric asthma care

Self-management is the ability of patients to manage their own health effectively [40]. In the context of paediatric asthma, self-management involves the active participation of both the child and their caregivers in the management of the condition [41]. An effectice self-management has been shown to reduce asthma-related emergency department visits and hospitalizations, and improve quality of life as well as significant improvements in asthma control, peak flow rates, and medication adherence [42].

Self-management has been shown to improve asthma outcomes significantly. Studies have demonstrated that children who receive self-management education have better asthma control, fewer symptoms, and reduced asthma-related hospitalizations [41]. Children who are actively involved in their asthma management have been found to have fewer missed school days and improved quality of life. [41] Additionally, self-management education has been associated with improved medication adherence, which is crucial in the management of paediatric asthma [35].

Asthma-related education is a crucial aspect of paediatric asthma care as it empowers children and their families to take control of their condition and improve their quality of life [35]. Self-management education provides knowledge about the condition, its triggers, and appropriate management strategies [5][35]. This knowledge empowers children and their families to recognise early signs of asthma exacerbations and take appropriate action promptly [35].

Education to support self-management includes several components. The first component involves the identification of asthma triggers, which is essential in the prevention of exacerbations [35]. The second component is the recognition of early symptoms, which can allow prompt treatment and prevent exacerbations [35]. The third component is the

proper use of asthma medication, which is critical in maintaining asthma control [40]. The fourth component is the development of an asthma action plan, which outlines the steps to take in case of an asthma exacerbation and the fifth component is the regular monitoring of asthma symptoms, which is necessary for optimal asthma control [35].

In terms of the economic impact, effective self-management in paediatric asthma can reduce healthcare costs associated with the disease [34]. Children with well-managed asthma require fewer doctor visits, emergency room visits, and hospitalizations, which can save healthcare systems and families money [21]. Additionally, effective self-management can reduce the indirect costs associated with asthma, such as missed school days and lost work productivity for parents [8].

In relation to mental and emotional adaptation to asthma in children, research indicates that many children with asthma may suffer from anxiety, depression, and other psychological and behavioral problems [43]. These problems can be related to the severity of asthma symptoms, the frequency of hospitalizations, and the use of medication [44]. It is not uncommon for children with asthma to experience social isolation and difficulty participating in physical activities, which can lead to feelings of frustration and low self-esteem [43]. Children with asthma who receive education and support from healthcare professionals and family members are better able to cope with their illness and have better mental and emotional outcomes [43]. Therefore the importance of providing children with asthma with education, support, and psychological interventions is essential for their mental and emotional well-being [43].

2.4 The use of digital health technologies in paediatric asthma care

The following subchapter introduces a wide definition of digital health technologies and how it is used in asthma care.

Digital health technologies have increasingly become important for managing pediatric asthma [8]. These technologies can range from mobile applications, wearable devices, telehealth services, electronic health records (EHRs), and other health-related online platforms. In pediatric asthma care, digital health technologies have been used to improve symptom monitoring, medication adherence, patient education, and communication between healthcare providers and patients [45]–[47].

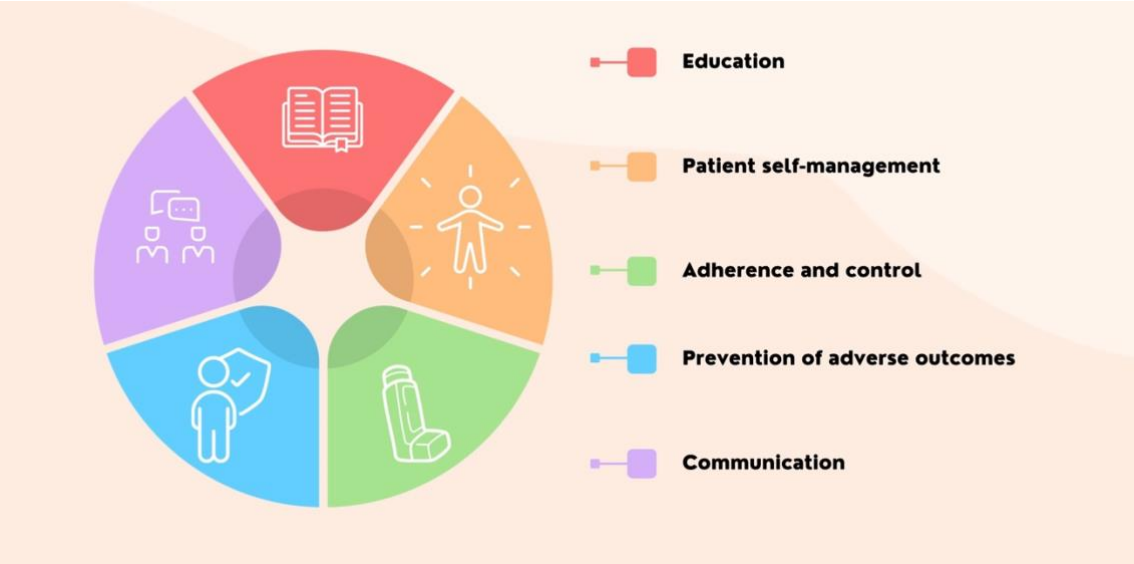

Figure 4. Goals of digital health interventions in paediatric asthma (modified by author) [46]

E-health technologies have been found to be an effective resource for encouraging the active involvement of patients in their healthcare beyond improving health outcomes [48]. By facilitating symptom monitoring, medication adherence, patient education, and communication between healthcare providers and patients, these technologies have the potential to improve asthma outcomes and enhance the quality of life for pediatric asthma patients [13].

2.4.1 Serious games

The term 'serious games' (SG), which are games without a primary focus on entertainment, enjoyment, or fun, has emerged as a new generation of videogames that provide an opportunity for constructive learning and training [45]. SGs differ from traditional video games in that they incorporate interactive backgrounds similar to those encountered in real-life scenarios in order to convey meaningful information [46]. A serious game designed specifically for paediatric asthma management typically includes several elements that make it an effective tool for the education and engagement of children with asthma [49]. Asthma simulations may include realistic simulations of asthma symptoms and their triggers, which are combined with interactive educational content that teaches children about asthma, how it develops, and how to manage it [46]. Children may also be motivated to adhere to their treatment plans by implementing reward systems incorporated into some games [46]. It can be concluded that SG´s are an effective and engaging means of educating and motivating children with asthma to become active participants in managing their condition [46]. The use of digital games in

the teaching of asthma to children offers healthcare professionals the possibility of improving treatment outcomes and enabling children to lead a healthier and more active lifestyle [49].

2.4.2 Digital health tools to monitor adherence

It is possible to monitor the date and time of drug actuation with electronic monitoring devices (EMDs), but they do not provide feedback regarding the inhaler's technique[46]. Commercially available smart-inhalers are capable of detecting and storing the date and time of each dose taken, providing information regarding dumping of doses before a clinical appointment [46]. Inhalers of this type are considered the gold standard among commercially available products [50]. A study conducted in 2010 including 26 children and monitoring their medical adherence via EMD concluded that SmartInhalers did increase the adherence of the medicine but regarding asthma control and lung function, no significant difference was found compared to a target group who did not use SmartInhalers [51]. This was because SmartInhalers had no capability or function to teach inhalation techniques [51].

2.4.3 Digital health tools to remind medication intake and monitor symptoms

The use of digital health tools in managing pediatric asthma is on the rise to improve medication intake [49]. A variety of tools are available that can assist children and their parents in remembering when it is time to take their medication [46]. These tools include smartphone apps, electronic reminder systems, and wearable devices [46].

An example of a digital health tool used in asthma management is AsthmaMD, an app that allows children and their parents to monitor asthma symptoms, medication use, and triggers [52]. Users can set medication reminders in the app so that they are reminded every time they need to take a medication [52]. In addition, the application provides personalized feedback on medication adherence, asthma control, and symptom trends, based on the data entered by the user [52].

A further example is the Propeller Health platform [53]. This is a digital health tool that consists of a sensor attached to the inhaler and a smartphone app that provides reminders, feedback, and support for medication adherence [53]. The sensor detects when the inhaler is used, and the app reminds when a dose is missed [54]. Additionally, the app provides

personalized feedback on medication use, asthma control, and symptom trends, and alerts healthcare providers if symptoms worsen or frequent exacerbations occur [54].

Wearable devices have also been used in pediatric asthma care to monitor symptoms and medication adherence [12]. These devices can provide real-time data to healthcare providers and patients, allowing for more timely interventions [45]. One such device is the VitalFlo Sensor, which monitors wheezing, coughing, and shortness of breath, and transmits data to a smartphone app for tracking and analysis [12].

2.4.4 The role of telemedicine in paediatric asthma care

Telehealth services, which allow healthcare providers to remotely diagnose and treat patients, have successfully been utilized in the pediatric asthma care [56]. Telehealth services can provide convenient access to healthcare providers and reduce the need for in-person visits [13]. This can be especially useful for patients who live in rural or remote areas, or who have difficulty travelling to appointments [33]. A study regarding the use of telemedicine in paediatric asthma care found that telehealth services for pediatric asthma care can lead to improvements in symptom control and medication adherence [56]. As well as providing patient education and self-management tools, telemedicine can also provide video demonstrations of inhaler techniques, educational resources, and reminders to adhere to medication regimens [56].

2.4.5 Potential obstacles in the use of digital health technologies in paediatric asthma care

The implementation of digital health interventions in the management of pediatric asthma has been shown to be a promising strategy for improving patient outcomes. However, healthcare professionals' support is critical in the successful implementation of these interventions [57]. Healthcare providers may be concerned about the reliability and accuracy of digital health technologies, which may lead to hesitancy in recommending them to patients [47]. Privacy and security concerns are also major obstacles to the use of digital health technologies [58]. HPS´s must ensure that patient information is kept confidential and secure, which can be challenging when using technology that is not specifically designed for healthcare purposes [59]. HPS´s may also be concerned about the potential for technology-related errors or system failures that could compromise the patient care [59].

Healthcare providers may be reluctant to adopt digital health technologies due to the perceived burden on their workflow [60]. Implementing and managing these technologies can require additional time and resources, which may already be limited in a busy clinical setting [45]. Providers may also be concerned about the additional workload involved in managing patient data and communicating with patients remotely [59]. Even though HCPs might be actively involved in the education, information, and intervention of asthmatic patients, medication and therapeutic adherence have also shown to remain low in the paediatric population, with estimates suggesting that adherence rates are below 50% [46].

In addition to the barriers HCPS have, it is necessary to consider lay-people barriers as otherwise, the approach to patient engagement may fail [61].A recent study by the World Health Organization (WHO) and Public Health Wales has revealed that digital health technologies are not equally accessible to all communities across Europe, raising concerns over the equitable use of digital tools for health [62]. The study, which summarizes evidence from 2016 to 2022 on inequity in access, use, and engagement with digital health technologies, highlights that people with poor health are among the most affected by the lack of access to these tools [62]. Digital health technologies, such as wearable devices, artificial intelligence, and software, have the potential to improve health outcomes by supporting health workers and improving diagnosis, treatment, and quality of care [62]. However, the study emphasizes the need for a better understanding of why these inequities persist and how to improve access for everyone, to ensure that digital health technologies can be leveraged to develop a more equitable future for health care [62].

3 Aims and Objectives

Based on the theoretical background, the **research problem** is that digital health technologies have the potential to support healthcare professionals and patients in the management of chronic conditions/asthma [35] but the limitations and barriers in terms of clinical implementation among Estonian healthcare professionals of paediatric asthma are not known.

The research aims to explore the needs, expectations, and experiences of healthcare professionals (HCPs) in relation to communication and information sources and tools including the potential of digital solutions to support children and/or their parents in childhood asthma self-management.

The objectives of the research are:

1. To identify the key components of a successful treatment path and the factors that impact the success of the treatment path for paediatric asthma patients.
2. To identify the definition and importance of patient empowerment and self-management among HCPs, and to identify the tools and strategies utilized by HCPs to support and promote patient empowerment and self-management.
3. To identify the potential benefits and limitations of technological interventions among HCPs and the ways to optimize their use for better patient outcomes.

Research questions:

1. How a successful treatment path of peadiatric asthma is described and what factors might hinder it?
2. How do healthcare professionals define patient empowerment in the context of paediatric asthma, and what tools and strategies do they use to support and promote these concepts among their patients?
3. What are healthcare professionals' experiences and needs regarding communication and education tools to support patients and their parents in self-management?

4 Methodology

The methodology of the study is presented in this section of the paper, including the design of the study, sampling, data collection, and analysis, as well as ethical considerations and data protection. The period of the study was from January 2023 until May 2023. The collection of the data was conducted in February 2023.

4.1 Study design

This study has been conducted as qualitative research. Qualitative research aims to collect and process information that is impossible to be done numerically or has no direct relevant purpose [63]. Research using qualitative methods aims to obtain a deeper understanding of social phenomena through exploration, interpretation, or analysis. It enables researchers to explore phenomena from a variety of perspectives and ask different research questions [64]. To study interviewees' perceptions, opinions, and issues, a semi-structured interview was chosen [65]. Qualitative research can be applied to healthcare settings to determine what matters most to healthcare professionals and how their experiences can be improved. A particular strength of the current approach is the richness of the data as well as the descriptions and depth of exploration it provides [63]. Data were gathered through individual semi-structured in-depth interviews to explore particular themes or further discussion.

The first contact with Tallinn Children´s Hospital regarding the interest in the study was made in December 2022. All requested documents were submitted to Tallinn Children´s Hospital in January 2023 including a study invitation, a short introduction of the study, a semi-structured interview plan and informed consent (Appendix 3). Potential participants received the study invitation shared via personal work e-mail (Appendix 2). The individual interviews were conducted face-to-face at the facilities of Tallinn Children´s Hospital. After a participant showed interest of the study, digitally signed informed consent (Appendix 3) by the author of the study was forwarded to the participant.

4.2 Sampling

The target group for the study was doctors and nurses who were working at the given moment in Tallinn Children´s Hospital. A total of 7 participants were selected for the study based on inclusion criteria (Table 1).

A convenient sampling method combined with a purposive sampling method was used to select the participants. The convenience sampling (also known as Haphazard Sampling or Accidental Sampling) refers to a nonprobability sampling technique whereby members of the target population are included in the study if they meet certain practical requirements, such as easy accessibility, geographical proximity, availability at a given time, or willingness to participate [66]. A purposive sampling technique, sometimes referred to as judgment sampling, involves deliberately choosing participants based on their characteristics. Essentially, the researcher decides what information needs to be acquired and sets out to identify those who are able and willing to provide that information through their knowledge and experience [67].

The study's inclusion criteria were carefully selected to ensure that participants possess the requisite qualifications and expertise necessary to contribute meaningfully to the research. Specifically, eligible participants had to be either doctors or nurses who were fluent in Estonian and are currently working in the department of allergology and pulmonology at Tallinn Children's Hospital. Additionally, participants had to be actively involved in counselling paediatric asthma patients, which requires specialized knowledge and experience. These criteria were chosen to ensure that participants have the necessary language proficiency and professional background to effectively contribute to the study's objectives, as well as the specific expertise required.

Based on the purpose of the research, the interviews are divided into unstructured, semi-structured and structured interviews [68]. In order to receive the needed information regarding personal thoughts and experiences, a semi-structured interview was chosen in this particular study as it provided the ability for data gathering via probing and open-ended questions.

4.3 Data collection and analysis

In qualitative research, data is often collected through interviews, as this creates an opportunity for direct and deeper information transfer by the subject [68]. Therefore, interviews were conducted face to face in the facilities of Tallinn Children´s Hospital during February 2023. An option to perform an interview via Microsoft Teams was included in the study invitation in case some participants were unable to meet face-to-face. It was explained to the participants what the study was seeking to achieve, how the data would be used, and how the recordings would be made before recording for the interviews began.

After receiving the consent of the participants, the data for the study was collected through semi-structured interviews. The interview plan (Appendix 4) consisted of 15 questions and according to the necessity the extended questions were included during the interview. The interview plan was categorized into three main topics. Firstly, the participants were asked about their experiences and opinions regarding the treatment path of children with asthma. The sources of information and communication tools situated with patient empowerment and patient engagement were chosen as a topic after. And for the final part of the interviews, the participants were asked about the support of technological solutions related to the treatment of paediatric asthma. All interviews lasted from 19 minutes to 1 hour and 17 minutes.

Recorded audio files were transcribed using a web-based speech recognition programme [69] and perfected by re-listening and adding missing text parts of the text. All recorded files were stored in TalTech One Drive Cloud.

During data analysis using the NVivo programme, the names of the people participating in the study were not published, all the interviewees were coded according to the number of the interview sequence and according to their professional abbreviation “N” as a nurse and “D” as a doctor.

In this study, transcripts of the interviews were coded based on themes using the NVivo software shown in Figure 4.

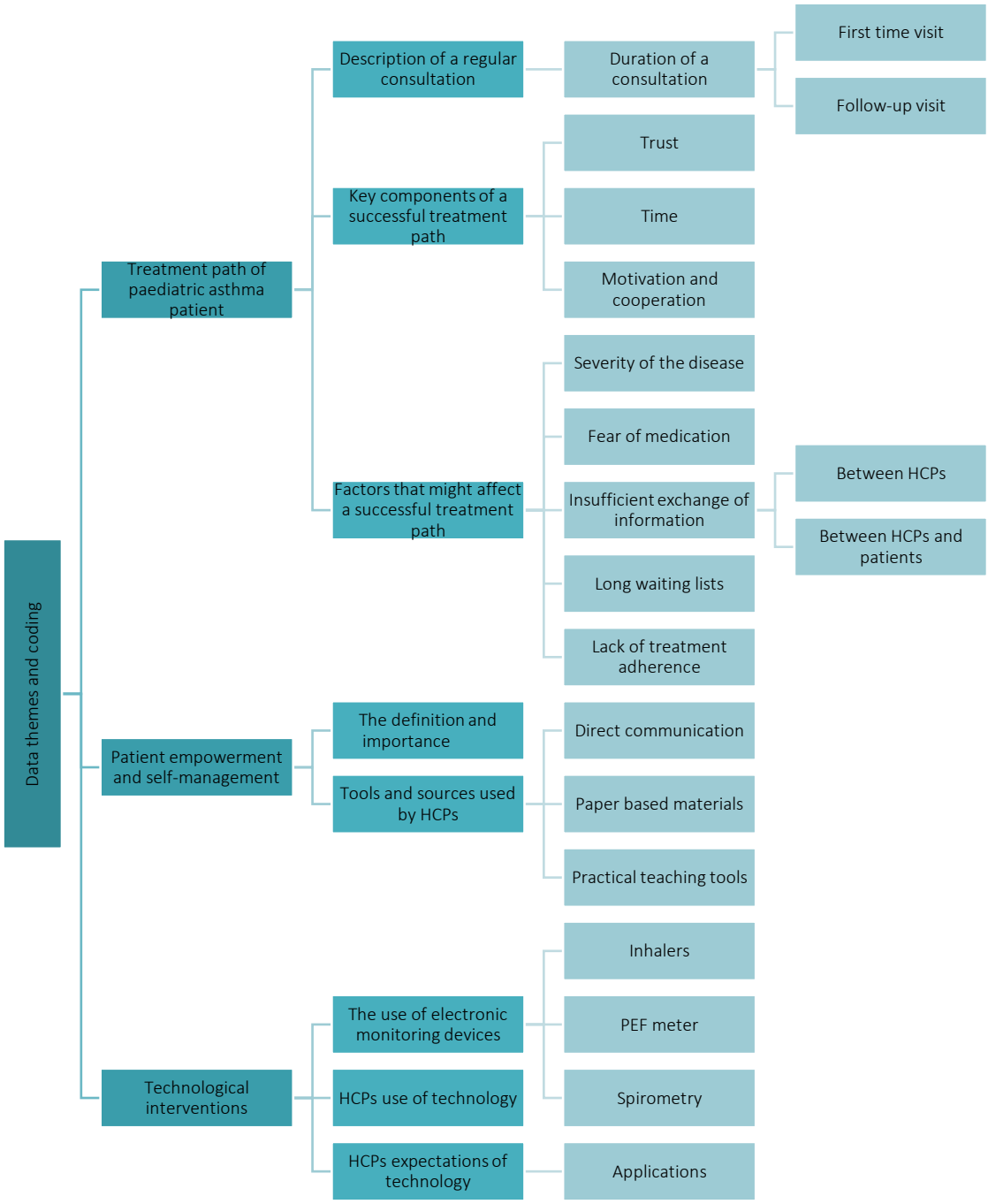

Figure 6. Data themes and coding

The qualitative content analysis uses the deductive approach if there are theories and/or previous studies about the phenomenon under investigation, that can be verified or developed further in a particular empirical setting while an inductive approach provides the ability to understand the world of research participants and explore their

interpretations and meaning systems [70]. Therefore the combination of deductive and inductive methods was used to analyse the data in this study.

4.4 Ethical considerations and data protection

As the aim of the study was to identify the opinion and experiences regarding different aspects of their consultations of the specialists who work with paediatric asthma patients, ethical committee approval was not required.

The purpose of the study was explained to each participant prior to the interview. The informed consent form (Appendix 3), was previously signed by the author of the study and was also signed by everyone who agreed to participate and have the interview recorded. Prior to the interviews, participants were reminded data protection aspects of the study as well as the aim of the study. During the interviews, data was recorded via personal device of the student in charge using the "voice memo" program. Voice recordings did not contain information of the interviewees such as name, age or occupation. In appreciation for their participation, the participants received a gift from the student in charge after the interview. Voice recordings from the interviews were transcribed using TalTech speech-recognition programme [69]. Transcripts were forwarded the author of the study´s TalTech e-mail account.

All required information regarding data was collected through the interviews. Information about the participant's profession and employer was collected in order to validate if the participant met the inclusion criteria of the study. The full name of the participant was shown only on informed consent and not used in other purposes. The data collected from study participants was securely stored in a password-protected OneDrive cloud server managed by TalTech. The study's author and supervisor were the only individuals granted access to this information. Subsequent to data collection, the digitally signed consent forms were eliminated, while audio recordings were disposed of following transcription. It should be noted that the transcribed interview texts were not presented in their entirety. The findings derived from the data will be presented in a generalized manner both in the master's thesis and in other publications. It is important to emphasize that the collected data will not be disclosed to third parties nor will it be uploaded to any databases. Sharing of data analysis files will only be considered if it is deemed necessary for the publication process.

5 Results

An overview of the results of the interviews is presented in this chapter.

5.1 Treatment path of paediatric asthma patient

The following chapter describes the regular consultation and/or visitation of the paediatric asthma patient. As well as what are the key components of a successful treatment path and the obstacles and problems that HCP´s come into contact with.

5.1.1 Regular consultation of a patient with paediatric asthma

The presented results describe the job responsibilities and tasks of nurses and doctors in the context of paediatric asthma consultations. The findings indicate that nurses play a crucial role in empowering and engaging patients and supporting their self-management during the visit. As one participant explained:
"First, we discuss what asthma is, what medications are available, what illness it is, and what medications are used with what regimen, and then we will also go through it technically and practically /.../" (1-N)

Nurses provide practical guidance and support to patients and their families by explaining the disease, demonstrating daily management techniques, and advising parents who continue to work with their children at home which contributes to the self-management abilities and patient engagement.

/.../I will demonstrate and go through it with the child - what they will start doing at home. And from this, I can see what they are not doing well, and what is not working well for them. Then, the idea is still that I will advise the parent who goes home and starts working with their child themselves." (1-N)

On the other hand, doctors conduct thorough assessments, accurate diagnoses, and personalized treatment plans to improve patient outcomes. As one participant refered, *"For children over five years old, we also do a spirography test to assess lung function. If necessary, we will also do allergy tests*." (3-D) Doctors also order additional tests to identify specific allergies or breathing issues if needed.

The consultation times for both doctors and nurses vary and depend on several factors, such as whether the patient is a first-time or a patient who has a follow-up visit, the nature of the patient's behaviour, and the child's age and condition during the visit. As one nurse explained, *"Usually 20-25 minutes, it depends. For patients who are not in a consultation for the very first time, it goes faster with them."* (3-N) However, consultation times among both doctors and nurses vary greatly and depend on various factors. As one doctor noted, "*It might take ten to fifteen minutes for a returning patient who doesn't have any particular problems, who comes for a check-up to make sure everything is fine and he's doing well. For the patient who visits first time, it can take half an hour to forty minutes with the tests he or she goes to do in the meantime, an hour, or even more."* (1-D)

"That depends on the issues now, and it really depends on the parent and the child. You may have children of very different ages...That we can't say that the first visit is maybe longer and the second shorter because some things are still that you talk at one visit and then you talk at the second visit and it also depends on that." (1-N)

Collaboration between healthcare professionals and patients and their families is essential to achieve optimal asthma control. In addition, factors such as the child being sleepy, or tired, or how much the parent who has already been to the consultation remembers the previous information, can also affect the consultation.

5.1.2 The key components of a successful treatment path

According to the research findings, the majority of the participants highlighted the importance of trust and effective communication in achieving successful treatment outcomes. They emphasized the significance of patients feeling comfortable and confident in discussing all their concerns and being able to establish mutual understanding with healthcare professionals. As one participant explained,
"/.../ The better we, the child and parent, understand things in the same way, the better. And the more likely the result will be better." (4-D).
Moreover, the participants acknowledged the importance of individualized treatment plans and counselling, irrespective of the particular diagnosis. In this regard, pulmonology was deemed as a field where personalized attention is particularly essential.

Effective communication was also found to be critical in successful self-management. Participants highlighted the need for continued patient engagement and follow-up, with regular consultations that provide sufficient information on the disease, its dangers, and the appropriate course of action.

"First of all, so there would be enough information about what has happened. And certainly, the description by the parents is very very important. Different people describe things differently /.../. So that the exchange of information is sufficient and adequate /.../. (4-D) In this context, the information provided by patients about their disease history and experiences was considered vital for healthcare professionals to provide personalized treatment plans. Furthermore, participants noted the significance of avoiding distractions during consultations and focusing on the information provided.

Another important factor that emerged from the findings was the need for adequate time resources during consultations. Participants expressed the need for doctors to have sufficient time to engage with patients and for patients to feel that the consultation time is dedicated solely to them. The absence of enough time and resources was seen as a potential barrier to establishing trust and effective communication between patients and healthcare professionals. As one participant stated, "One *thing that is very important, time. That the doctor has time, that the patient feels that this is the time for him/her and that I myself do not rush."* (1-D) It highlights the importance of trust, effective communication, individualized attention, and adequate time resources in achieving successful treatment outcomes for children. In the absence of sufficient time and resources, neither party should be forced to rush.

Cooperation between the patient and healthcare professional (HCP) is essential for the success of treatment, especially in cases where the patient is required to take medication at home. According to one participant, good cooperation relies on the patient's ability to follow instructions provided by the HCP. The participant states, *"/.../ how the patient still follows the instructions given to him/her at home /.../ it still depends on both the parent and the child, how it would be done and how correctly it would be done"* (1-D). This highlights the importance of the patient's and caregiver's commitment to the treatment plan.

Another important factor in treatment success is the patient's motivation to follow the treatment plan. As one participant states, *"/.../ it's the most important thing in my opinion.*

They need to be motivated and they still need to understand that for eg permanent treatment will help, that he can live a normal life, that he doesn't have to sit at home /.../" (3-N).

Effective communication is also crucial in ensuring cooperation between the patient and the HCP. Participants highlight the importance of openness and honesty in their interactions. As another participant states, "*It's definitely a constant cooperation, that we still meet on a regular basis /.../ It's also that we're open and honest with each other. /.../ That the patient also is comfortable talking about his/her own fears and difficulties in following the treatment plan"* (3-D). On the opinion of HCPs, patients need to feel comfortable discussing their concerns with their clinician, especially when they are struggling to follow the treatment plan.

Furthermore, it is important to ask the right questions and to monitor the patient's response. As one participant explains, *"The questions that you ask are important, what is the mother's answer to that /.../Mother must be interested in it herself. /.../ The better a parent, caregiver, or whoever, the better they understand why something is being done, the easier it seems to be. They must receive individual counselling"* (1-N). This emphasizes the need for individualized care and attention to ensure that patients and caregivers understand the treatment plan and are committed to following it.

In conclusion, looking from the HCPs side, effective cooperation between the patient and HCP is crucial in ensuring the success of treatment. This requires patients to follow instructions and be motivated to participate actively in their treatment, however, it is the task of HCPs to help patients to reach to that point and ensure that it has happened. Communication is essential, and patients need to feel comfortable discussing their concerns with their HCP. Additionally, individualized care and attention are necessary to ensure patients and caregivers understand the treatment plan and are committed to following it.

5.1.3 Factors that affect a successful treatment path

There are also obstacles in the treatment journey that might affect its effectiveness. The following statement confirms that, in addition to the nature of the patient, the effectiveness of the treatment journey also depends on how serious the disease is at the

moment. If the patient does not show symptoms and feels good, they are not motivated to follow the regular treatment plan.

"/.../Also, how severe the disease is, because the more severe the disease, the worse it is, the better the treatment is actually done" (1-D)

Any small piece of information can contribute to making a child's treatment successful.

"/…/*Let's say from the very beginning, was the child born premature or at an age? Has the child had any breathing problems? Has the child had any skin or other problems? Suffering from severe respiratory viruses in the first year of life? Are there any other malformations such as oesophagal atresia or any other problems? /.../ Any small piece of information can contribute to making this child's treatment as successful as possible. That it was made exactly for the child and based on a good base of information"* (4-D).

As the quotation indicates, there is a lot of background information that has to be collected for making right decision which might explain the lack of time to contribute to pateints' self-management abilities and engagament to the process.

Additional burden may come from successful treatment journey as patients who are doing well on their medication may start to slip after some time, leading to the reemergence of asthma symptoms.

"/.../Because asthma is so well controlled with medication, if they're doing really well and they're well on their medications, at some point they start to slip /.../" (1-N).

This quote indicates that support and communication are constant needs in that process and HCPs have to consider those potential fallbacks in advance.

In addition, parents who have personal problems may leave their child alone with the treatment, and the control of medication adherence may get out of hand. *"/.../Another thing is the technical implementation, whether it is done correctly or not. In reality, they do not see how the child is doing it, and in reality, they do not check whether the child does it or not. That you can agree with the treatment, but at the same time, you are not interested in it either. That this control is getting out of hand/.../"* (1-N).

These findings highlight the challenges that can impact the effectiveness of asthma treatment, including the potential risks associated with patients failing to adhere to their treatment plans. Therefore, it is crucial for healthcare professionals to provide accurate and comprehensive patient information and support to enable patients to manage their illnesses effectively.

5.2 Patient empowerment and self-management

The following chapter covers the topics of the importance of patient empowerment and self-management from health care providers' perspective and introduces the information and communication tools that they use to support it.

5.2.1 The meaning and importance of patient empowerment and self-management

The participants were asked about the meaning and importance of patient empowerment and self-management in the treatment of asthma patients.

It can be seen that healthcare professionals consider patient empowerment and self-management to be extremely important components of the treatment journey, but they define these terms differently.

"I think it's important to understand what we mean by patient empowerment, because there are probably many different interpretations of it." (4-D)

Most often, patient empowerment was defined as motivating and involving the patient on the treatment journey.

"/.../ I think if that means that it's patient involvement, motivation /.../." (1-D)

Another participant added *"More like motivating and engaging. /.../".* (2-N)

As the findings outlined, motivating to engagae and empower patients may mean equipping patients with knowledge and skills to manage their condition on their own. As one participant explained:

"It's still when I share information with a patient about their illness, I pass on information on how to deal with that disease, and I also try to get an idea of what the problems are if they don't cope well. So that the patient could find a resource in him/herself and remain motivated /.../". (3-D)

On the other hand, there are those who view patient empowerment as encouraging the patient to take an active role in their treatment as referred *"Rather, it's still like empowerment or like encouragement /.../".* (1-N)

It can be seen that healthcare professionals consider patient empowerment and self-management to be extremely important components of the treatment journey, but they define these terms differently.

5.2.2 Information and communication tools used by HCP´s to support patient empowerment and self-management

Physicians and nurses use various informational materials to support patient or parental knowledge during consultations. As one participant outlined,

"Well, as for the written materials, they will definitely get them at the beginning/.../. Allergy magazine which is published in Estonian language /.../. I also recommend using the pollen calendar that is on the webpage of the Estonian Allergy Association" (1-D).

This quote indicate the expectation towards high level of agency of individual actions to work through all materials they are given or guided to which might pose one of the obstacles of low self-management abilities or level of patient engagaement.

In addition to materials, also personal guidance was outlined:

"In the case of asthma, they get trained by an asthma nurse. Where, on the one hand, is the teaching of inhalation aids, and the video is also shown in relation to what asthma is. For my part, I have provided information about allergens on paper. There is currently no such collection about asthma, but allergialiit.ee is a website that I like /.../" (3-D).

The quotation outlined the role of nurses in supporting treatment self-management and "*also training EpiPen´s as well as inhalers with the whistle which is perfect for the child to practice the medication inhalation at home /.../"* (3-N). But in addition to practical education, also *" we use informational materials on paper, some of them I have designed myself /.../.*(3-N).

However, some specialists believe that the existing paper-based materials are outdated and instead provide all necessary information verbally during the consultation. One

physician stated, *"We have leaflets, but they are also quite old. /.../ But regarding what asthma is, I have not suggested that they would have to read by themselves. Actually, I still talk more by myself"* (2-D).

As those quotations indicate, the role of HCPs in talking and education based on given materials or simulation tools is seen as important.

To help patients adhere to medication schedules, HCPs may recommend using alarm clocks on phones to remind them to take their medication on time.

"*Now, if we're talking about technological things, what I recommend is to put a reminder on the phone so that the phone gives a reminder every day to take medicine"* (1-D).

Although some online resources are recommended by HCPs, direct communication is still preferred and considered indispensable over other materials. One participant highlighted, that "*nothing replaces direct communication.''*(4-D).

Additionally, it was outlined that *''another thing is that an anxious person remembers 20% of what you just said, so all kinds of written information material, we still try to share it here. We currently have it on paper, once we have more time and opportunity, we will organize the online form as well. That with foreign web pages it is the case that some are easy to use, but not quite all /.../" (4-D).*

As seen, the lack of time is having an impact also on collecting and providing materials online in Estonian however, due to the limited time available during consultations, specialists may provide recommendations for videos available online as "*there are videos on the Internet, I also have them saved. I don't show much here, but it is available there"* (3-N).

The participants also highlighted the issue of scattered information sources, with each healthcare advisor using materials that are suitable for them, resulting in varying information being provided to patients.

"In this sense, we do not have such an organization or system that does 'substantial work'. The information we share with patients is not gathered in one place. Each counselling asthma nurse uses the materials that he likes or suits or that he or she considers useful /.../". (1-N)

Overall, both nurses and doctors primarily use paper-based materials as information sources. However, there is variation in preferences for information sources among specialists. While some consider it important to provide information to patients on paper,

others prefer to provide verbal information during consultations to ensure that patients understand the specifics of their disease and have the opportunity to discuss it with patients directly. Nevertheless, it is acknowledged that providing a lot of information during consultations can be challenging, and there is uncertainty about whether patients are able to fully remember the information they receive.

5.3 Technological solutions

The following subchapter concentrates mainly about technological interventions in regards of supporting the patients.

5.3.1 The use of electronic monitoring devices

Electronic monitoring devices might be useful in managing paediatric asthma by providing real-time information about a child's lung function and symptoms, as well as reminders to take medication. Therefore participants in this study were asked about their experience and opinion regarding those devices.

As reported by the participants, both physicians and nurses confirmed that they only use devices for collecting electronic health data in the form of spirometry. One participant stated, *"Well, spirometry for sure. But some children definitely have a watch that counts steps"* (1-D). However, using smartwatches to monitor physical activity was not a common practice among healthcare providers.

Still, it was stated that *"to be honest, I actually have never heard about any options regarding asthma treatment"* (3-N).

Although devices such as PEF meters for at-home testing exist, they are not commonly implemented in practice. As another participant stated, *"I know that there is an opportunity to do spirometry from home, but here we do not"* (2-N). Overall, while some participants were aware of the existence of certain devices, such as inhalers that count doses or spirometry tests that can be performed at home, these devices were not commonly used in practice. Another participant recommended using an alarm clock as a reminder to take medication, stating, "*If there are forgettings, then the easiest way is to put, for example, an alarm that reminds you when you need to take the medication"* (3-D).

The most commonly used electronic health monitoring devices among healthcare providers were those that performed spirometry tests to check lung function, with the data being stored and compared over time.

5.3.2 Healthcare professionals use and expectations of technological interventions to support paediatric asthma patients

In addition, the aim was to explore the perspectives of healthcare professionals regarding the use of technological interventions to support patient empowerment in paediatric asthma management. The participants were asked about their experiences with the current technological support available to clinicians, what they believe is missing, and what their expectations are for the future.

One common theme that emerged from the participant's responses was the lack of adequate technical support for asthma management. Many healthcare professionals expressed a need for an asthma app that is specifically adapted to the Estonian language and healthcare system.
"*Actually, the support does not exist. /.../ there could be some kind of asthma app in the Estonian language /.../ should be adapted to Estonia in some way, and it should definitely be different for different ages /.../."* (1-D)

On the other hand, some participants felt that the existing technological support works well. For example, one participant stated that "*the tests at Children's Hospital are so easy to look at, such as the results of spirometry in dynamics for eg /... /, I can also watch it together with the patients to motivate them /.../".* (3-D)

While some participants saw applications as a potential solution to the current lack of technical support, others felt that nothing could replace the human factor in asthma management. One participant stated that "*depending on the generation, nothing can replace a person. Currently, for both digital referrals and e-consultations, for eg the anamnesis must be filled (online form), but how it is filled, still depends on the person filling it. That no matter what digital functions you set there, it still depends on the performer".* (4-D)

These findings suggest that healthcare professionals have different expectations and experiences with technological interventions for paediatric asthma management. While some see potential in the use of applications, others feel that nothing can replace the human factor in healthcare. Nevertheless, it is clear that there is a need for more tailored and organized technological support in asthma management, with a focus on providing consistent and evidence-based information to patients.

5.3.3 Technology´s potential for improvement

In the subsequent chapter, participants were asked about the technological solution that could support their consultations with paediatric asthma patients, and how these interventions could be helpful.
Some participants suggested that an application that helps patients with medication adherence and provides answers to frequently asked basic questions during consultations could be beneficial.

"*If there was any kind of technological solution that would improve the patient's adherence of treatment, I think that would be the most important /.../. Because of the correct use of this treatment by chronic patients, the percentages are extremely small, it is somewhere between twenty and thirty per cent that people are taking their medications correctly and sufficiently /.../."* (1-D).

Additionally, some participants expressed the need for visual tutorials for patients, stating that *"In real life, we lack visual tutorials for the patient/.../."* (1-N). These varying suggestions indicate that healthcare professionals have specific requests and ideas as to how technology can assist them in their consultations.

When asked why these technological tools are not in everyday practice, some participants suggested a lack of awareness of their necessity among those involved in their creation, a lack of competence among medical personnel to create them, and a shortage of IT professionals who may not prioritize the medical field in that area.
"Perhaps they are not aware that it is necessary, the people who are involved in its creation because its (application or device) *creators cannot be medical personnel directly; well, we simply do not have that competence /.../."* (1-D).

As indicated, the level of digital competences is important in modernizing the consultation and thus, there might be the need to address the digital competences of healthcare professionals more thoroughly.
nother participant expressed uncertainty, stating that "*I don't know, maybe because there is no such person who would do it? Or who would come across it? There is no right person."* (3-N).

These results suggests that healthcare professionals have specific technological needs and desires to support their work with paediatric asthma patients. However, the development and implementation of these tools may require greater collaboration between medical and IT professionals but there also might be the need to reconsider the education and continuous education of healthcare professionals in terms of digital literacy and digital competences.

6 Discussion

A comparison of the findings from this study with those of previous studies and theories will be presented in this chapter of the study.

6.1 Treatment path of paediatric asthma patient: the key components of a successful treatment path, factors and obstacles that affect treatment outcomes

The treatment of pediatric asthma is a complex process that requires a comprehensive approach involving the collaboration of healthcare professionals from different specialities [71]. The key components of a successful treatment path include accurate diagnosis, development of an individualized treatment plan, regular monitoring and follow-up, and education of the patient or caregiver[5], confirmed both by the guideline of GINA and participants of the study. Healthcare professionals need to have a good understanding of the pathophysiology of asthma, the different treatment options available, and the factors that can affect treatment outcomes. Effective communication and trust between patients and healthcare professionals are essential for successful treatment. Studies have found that HCPs who used a collaborative approach with patients and their families had better treatment outcomes[72]. All participants of the current study agreed that effective communication and trust between patients and healthcare professionals are essential for the successful treatment of asthma.

It was also found that individual approaches were considered important regardless of whether the asthma was allergy-related or not. In addition, the importance of communication and understanding between patients and healthcare professionals was emphasized. It was particularly important to thoroughly explain the disease, its dangers, and the treatment. To achieve better results, health professionals felt that parents and children understand the same thing in the same way as HCPs. Guidelines support and confirm the importance of a asthma related education for the patients and the direct effect of it [5], [16].

Furthermore, effective communication between patients and healthcare professionals allows patients to keep returning for follow-up consultations, preventing them from

disappearing and abandoning their treatment. Therefore, the availability of time-related resources is essential in the treatment of asthma. In order for healthcare professionals to provide patients with undivided attention, they must have sufficient time to consult with them. When either party feels rushed, it may result in misunderstandings and misinterpretations.

Healthcare professionals who treat pediatric asthma patients have different job responsibilities and consultation durations vary significantly. GINA confirms that good cooperation, individual approach, and trust are an important part of a successful treatment journey, but according to the guidelines, if these criteria are met, consultation times should not be longer and are rather criteria for shortening the time spent [5]. However, based on current research, it appears that the predetermined time for consultations is not enough and has been considered as an obstacle in order to fulfil those criterias. The length of a consultation varies based on the patient's condition, the type of tests they require, and whether they are first-time or follow-up patients.

Additionally, patients' motivation and good cooperation with healthcare professionals are essential [17]. Due to the fact that most of the treatment is performed at home, patients must be motivated to follow instructions [40]. Despite the fact that healthcare professionals should provide adequate instructions and prescriptions, the patient and their parents are ultimately responsible for carrying out the plan[5], [16]. According to the participants of the study, in order for patients to follow the treatment plan as prescribed, they must be motivated and understand the need for treatment. Clinical guidelines for HCPs are mainly similar, but patients' individual characteristics and needs can vary. It is precisely patients' nature and personalized needs that may not be possible to address uniformly.

In conclusion, trust, time, and cooperation between patients and healthcare professionals are essential to the success of asthma treatment. In order to ensure better treatment results, patients must feel heard and receive a personalized approach [73]. In order to ensure that patients receive undivided attention, adequate time resources must be available to healthcare professionals in order that they may consult effectively. As a result of motivation and cooperative behaviour between patients and healthcare professionals, patients are more likely to adhere to the treatment plan, resulting in better health outcomes. The treatment guideline adapted to Estonia, which is specialized for pediatric

asthmatic patients, confirms all the points mentioned above by the participants, which are important for ensuring a successful treatment journey [16].

6.2 The role of patient empowerment and self-management: the importance and the use of information and communication tools

Patient empowerment and self-management are important components of paediatric asthma treatment [73]. Patient education in asthma self-management improves patients' management skills and adherence to the treatment [5]. Healthcare providers (HCPs) of this study acknowledged the importance of patient empowerment and self-management. In general, patient empowerment refers to motivating and engaging patients throughout the treatment process. In the opinion of healthcare professionals, it is essential that patients participate in the decision-making process and understand why certain treatments or procedures are necessary. Furthermore, healthcare professionals emphasize the importance of self-management, in which patients assume an active role in managing their health conditions. It may involve managing symptoms, monitoring their health, and adhering to treatment plans. However, it is evident from the study that healthcare professionals define patient empowerment and self-management differently. In the opinion of some HCPs, patient empowerment refers to encouraging patients, while in the opinion of others, it refers to motivating and engaging patients. There is no standard definition of the term, which may cause confusion among patients and healthcare providers. Due to the lack of a unified understanding regarding the meaning and actions associated with the concept, patient empowerment is currently being implemented according to individuals' own interpretations, which may not ensure the desired outcomes.

The use of information and communication tools, such as mobile applications and telemedicine, can also improve patient self-management and treatment outcomes. However, the level of adherence to guidelines for primary care management of paediatric asthma remains unclear [74]. A variety of informational materials are used by health care professionals to support patient empowerment and self-management, including written materials, videos, and websites. In most cases in current study, HCPs use written materials in the form of paper which is also recommended by guidline adapted for Estonian paediatric patients [16]. Nevertheless, some websites are recommended by

healthcare professionals, while others develop their own informational materials. To teach patients how to use medication properly, healthcare professionals use practical tools, such as inhalers with whistles.

Despite the fact that physicians and other health care professionals agree that information and communication technology are essential, some still believe that direct communication is preferable and indispensable. In their view, direct communication is necessary to ensure that patients understand the specifics of their disease. To supplement direct communication, HCPs may recommend videos available online as consultation times are limited.

Ultimately, patient empowerment and self-management are vital components of effective healthcare. In order to support patient empowerment and self-management, health care professionals make use of a variety of information and communication tools. However, the lack of a standard definition of patient empowerment may cause confusion among patients as well as health care providers. Adherence to treatment guidelines and maintenance therapies remains a challenge that needs to be addressed to achieve successful treatment outcomes.

6.3 The role of technological interventions: health care professionals' experiences and expectations

The following subchapter focuses on the use of electronic monitoring devices in the context of pediatric asthma treatment.

Digital health technologies refer to a range of tools, including mobile applications, wearable devices, telehealth services, electronic health records (EHRs), and other health-related online platforms, which have become increasingly important in the management of pediatric asthma. These technologies have been used to improve symptom monitoring, medication adherence, patient education, and communication between healthcare providers and patients [50]. The use of technology in pediatric asthma treatment has the potential to improve patient outcomes, but there are also obstacles to its implementation which the results of the current study also confirms. Electronic monitoring devices, such as spirometry tests and smartwatches, are commonly used to collect electronic health data

in some practices[43]. The current study confirms that spirometry tests were the most commonly used electronic device among healthcare professionals to collect electronic health data on-site. Some specialists recommended using smartwatches to monitor physical activity in overweight children but devices were not widely used in everyday practice.

The lack of implementation of these home monitoring devices may be due to various factors, including the limited availability of such particular technology in Estonia, concerns about the accuracy of the test results, and challenges in ensuring proper use by patients at home. As some participants noted, there is an opportunity to do spirometry from home, but there is no control over the technique used by patients at home. As home-based data may not be accurate, there might occur a need for healthcare providers to perform on-site testing. However, this might not be anticipated beforehand and only becomes evident after the tests have been conducted and the results have been verified. Moreover, in such a situation, the patient would require additional education, which would be time-consuming and held during consultation. Therefore, the question arises as to whether it is reasonable to perform these tests with a healthcare provider at the first place and to ensure proper technique or to what extent performing these tests at home with the aforementioned risks still aids the daily work of healthcare providers.

In addition to the use of electronic monitoring devices, healthcare professionals were asked about their expectations and opinions on technological interventions to support pediatric asthma patients. Most of the participants reported a lack of technical support, which they considered a "painful topic." They felt that there was no unified system for providing asthma-related information to patients and that each advisor used materials that suited them. They recommended the development of a new asthma app that could centralize information and be adapted to different age groups. However, some participants also highlighted the importance of the human factor in asthma treatment, noting that nothing can replace a person's expertise and guidance. The existing system for digital referrals and e-consultations relies on the person filling out the online form, which can affect the quality and accuracy of the information gathered. Therefore, it can be concluded that it may not be possible to create unified applications or solutions that work for everyone. It might be necessary to take into account the characteristics of the users, both patients and healthcare providers.

Overall, the study suggests that there is a need for more technical support and a unified system for providing information to pediatric asthma patients. The development of new asthma apps and the implementation of electronic monitoring devices could potentially improve patient outcomes, but it is important to address concerns about accuracy and proper use. The human factor remains crucial in asthma treatment, and any technological interventions should complement rather than replace the expertise of healthcare professionals.

6.4 Main contribution

The study contributes by offering a more comprehensive overview of HCPs needs, experiences and expectations regarding patient empowerment and the potential of digital health solutions to support them. While digital solutions have the potential to assist healthcare workers[75][46][47], HCPs still feel that the current level of support is inadequate. However, they do recognize the potential for digital solutions to be useful in their work.

In this study, the needs of healthcare workers were assessed to identify potential solutions that could directly address these needs. By doing so, the study provides a comprehensive overview of the challenges faced by healthcare workers in this context, and highlights the potential for digital solutions to be part of the solution.

It is important to note that the need for improved support for healthcare workers is critical, given the significant impact they have on the health outcomes of pediatric patients with asthma. By recognizing the challenges that healthcare workers face and exploring the potential for digital solutions to address these challenges, this study offers important insights that can inform the development of effective support services in this area. Since there are no unified definitions, the necessary authorities should take it into account when planning and managing processes and activities.

6.5 Limitations

In interpreting the findings of the study, however, several limitations should be considered.

Taking into account that the study surveyed HCPs working in a single children's hospital, it is limited in its scope. In primary care and private practice, patients with pediatric asthma may have different needs and expectations as well as HCPs than those seen in the study. Accordingly, the study's findings may not reflect the experiences and perceptions of HCPs in those settings.

There were only Estonian-speaking healthcare providers (HCPs) included in this study. The findings of this study may not be generalizable to other healthcare settings where different languages are spoken. Depending on the cultural background, language, and training of the health care provider, the experiences and perceptions of the health care provider may differ.

It is also possible that the study is limited by the fact that the children's hospital where the research was conducted is only located in one region (Harju county). The results of this study may not be applicable to other regions within Estonia or to countries with different healthcare systems, structures, and cultural backgrounds. Depending on the region or country in which HCPs practice, their experiences and perceptions may differ.

Despite the limitations of this study, which focuses on subjective experiences and does not lead to objective conclusions that can be generalized, the author considers the research to be valuable in providing insights into patient empowerment and self-management and believes that it can contribute to improving the experiences of healthcare providers and patients in this area.

6.6 Future research

The following chapter provides suggestions and directions for future research.

1. **Combining qualitative and quantitative methods** which can provide a more comprehensive understanding of the issues and a deeper analysis of what the HCPs experience and perceive.
2. **A larger sample size** would improve the generalizability of the study, as the current study had a sample size of seven participants. It is also possible to provide a broader perspective on the experiences and perceptions of HCPs who consult

with pediatric asthma patients by conducting multi-centre studies involving several hospitals and healthcare settings.

3. **Including healthcare professionals from diverse languages** which can gain a deeper understanding of HCPs who work with pediatric asthma patients who speak different languages as well as come from different cultural backgrounds, as well as their experiences and perceptions.
4. **Including HCPs from different healthcare settings**, such as primary care or private practice, and studying HCPs' experiences and perceptions over a **longer period**.

6.7 Final conclusions

The conclusions that can be drawn from the findings of the present study are as follows:

- Despite the distinct roles of nurses and physicians, both are involved in empowering patients. Clinicians emphasise that to be successful, patient empowerment and self-management are essential. While patient empowerment has no standard definition, this may lead to confusion among healthcare providers. Therefore making a shared understanding of this concept necessary.

- The study concludes that effective communication, trust, individual approaches, and sufficient time resources are essential to the successful treatment of pediatric asthma by clinicians in Tallinn Childrens Hospital. However, healthcare providers feel that meeting the mentioned criterias requires more time resources than currently allocated.

- Digital solutions have the potential to simplify and support the work of healthcare providers, but in order for this to work and for existing problems to be solved, better collaboration between clinical and technology representatives is needed.

- HCPs who are providing asthma related educational trainings use diferent educational methods and materials. As this has been identified as an obstacle,there is a need for a unified system for providing information to patients. The need for more technical support and the development of new asthma apps and centralized information solution adapted to Estonia.

- HCPs note that human factor remains essential in asthma treatment and that any technological interventions should complement the expertise of healthcare professionals.

7 Summary

The aim of the thesis was to explore the needs, expectations, and experiences of healthcare professionals (HCPs) in relation to communication and information sources and tools used to support children and/or their parents in childhood asthma self-management. The author of the study used semi-structured interviews in order to identify the tools and information sources used in HCPs everyday practice to support asthma patients on their disease management, obstacles that hinder and digital health tehnologies that support this process.

Firstly, the findings showed that collaboration, effective communication, individualized attention, and adequate time resources between healthcare professionals and patients and their families is essential to achieve optimal asthma control and successful treatment outcomes for children. This requires the availability of sufficient time resources but what so far has been limited.

Secondly, healthcare providers recognize the importance of patient empowerment and self-management, but there is no standard definition of the term. Healthcare professionals define patient empowerment and self-management differently, which can cause confusion among patients and providers. As a result, patient empowerment is currently being implemented according to individuals' own interpretations, which may not ensure the desired outcomes.

Thirdly, guidance, as well as paper-based materials, are commonly used by healthcare professionals to support patient self-management. Direct communication is still considered indispensable, and the use of online resources is limited due to the lack of time available during consultations.

Fourth, healthcare professionals expressed the need for an asthma app that is specifically adapted to the Estonian language and healthcare system, providing consistent and evidence-based information to patients.

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Appendix 2 – Study Invitation

Hello!
I am Liina Harjus-Soostar, a second-year student in e-Health curriculum at the Faculty of Information Technology, Tallinn University of Technology.

I invite you to participate in my research related to my master's thesis, which focuses on supporting children with asthma and their parents in self-management during the treatment journey, and which describes the healthcare provider's perspective on technological aids.
The aim of the research is to identify the preferred information and communication tools used by healthcare providers, as well as their previous experience with these tools, including electronic and technological aids.

You are welcome to participate in the research if you:

• Are a doctor or nurse and are an employee of the Tallinn Children's Hospital Foundation
• And you are part of counseling children diagnosed with asthma and their representatives

The research will be conducted through individual interviews. Participation in the interview will take place at a time and in an environment of your choice (Microsoft Teams) during February 2023.

Participation in the research is voluntary. The results will be published in a generalized format, and confidentiality will be ensured. Individuals not involved in the research will not have access to the information and data provided by the participants in the research.

If you have any additional questions about the research, please feel free to contact me by email.

Liina Harjus-Soostar, lharju@ttu.ee

Appendix 3 - Informed Consent Form for the Participants

Dear participant,

Thank you for deciding to participate in the research aimed at analyzing the experiences of healthcare professionals working at Tallinn Children's Hospital in using various information and communication tools preferred by healthcare professionals to support and empower patients in self-care.
Your opinion and experiences as a healthcare professional are of great value in conducting this research. The research will result in a master's thesis in e-health at Tallinn University of Technology in 2023.

Participation in the research will take place as individual interview at a time convenient for you during February 2023. The interviews are planned to be conducted in a location or environment of your choice (Microsoft Teams), and its duration is approximately 30-45 minutes depending on the volume of your responses. Personal data that can directly identify you will not be collected.

Participation in the research is voluntary, and you can withdraw your consent at any time, but data collected up until the point of withdrawal will be used in pseudonymized form for further analysis of the study.

The interviews will be recorded and transcribed as soon as possible. After transcription, all audio and video files will be deleted. The data collected in the research will be stored on Tallinn University of Technology's OneDrive server, which is password protected and accessible only by the author of the study and supervisor, Kadi Lubi.

The research findings will be published in a generalized form, and the confidentiality of research participants will be ensured. After the defense of the master's thesis, the collected pseudonymized data will be permanently deleted, and the raw analysis data will be kept for up to 5 years after the defense of the thesis (June 2028) to enable further answering of any additional questions, if necessary.

I, ..., have been informed of the purpose and methodology of the research mentioned above. I confirm my consent to participate in the research and to the processing of my responses and data provided with my digital signature.

I am aware that if any questions arise during the research, I can obtain necessary additional information from the researcher:

Appendix 4 – Interview plan

Theme	Question	Extension	Time
Treatment path and communication	What is your profession?	Which medical specialty are you specialized in?	20 min
	How would you describe your typical interaction with asthmatic children and their parents?	To what extent do you encounter them in your work? At what stage of treatment does the patient have contact with you? In what context does that happen?	
	When you think of a typical consultation with an asthmatic child patient, how would you describe it?	How much time does such a visit typically take? (for a newly diagnosed patient and a family with a longer illness experience)	
	When you think of your typical encounters, what do you consider to be the key factors in a successful treatment journey?	What are the stages or parts of the treatment journey that make it successful in your opinion? Why do you consider these?	

		What is the role of the doctor/nurse and the parent in this? What patient and parent-related factors influence the success of the treatment journey?	
	How important do you consider the communication between healthcare workers and the patient and/or parent?	What factors, in your opinion, support communication? What factors, in your opinion, can limit communication?	
Sources of information and communication tools: patient empowerment and self-management	How would you define "patient empowerment"?	How important do you consider the patient-empowerment and self-management of the child and/or the parents in the treatment process?	20 min
	In your opinion, in your daily prantice, what are the activities that support and empower patients and their parents?	What sources of information do you use for this purpose? How would you rate the user-friendliness of the aforementioned sources of information?	
	What communication tools do you prefer to use when communicating with patients?	How do you evaluate the usability and time requirements of the communication tools currently in use?	

		What are the limitations of these tools? What obstacles prevent successful communication when using these tools?	
Technology	What is your experience with applications or devices that collect electronic health data?	What is your overall opinion and experience regarding the mentioned applications/devices?	15 min
	Have you had any experience with applications or devices that support self-care related to asthma?	Please describe the mentioned solution. Please describe your experience with the aforementioned applications. Would using such an application/device provide you with any opportunities in your daily work, and if so, what would they be? What are the concerns you have regarding these applications, if any? Whose responsibility, in your opinion, is it to address these obstacles/concerns and solve these problems?	
	In terms of empowering and involving patients in their treatment journey, to what extent do	Which parts of the solution would be supportive, and which parts could potentially cause additional problems? What are these potential problems, and whose responsibility is it to address them?	

	technological solutions currently support the everyday work of healthcare professionals?		
	If you could create an ideal technological solution, what would it be?	What would be the functions of the mentioned solution? What problems would the mentioned application be able to solve? Why, in your opinion, is the mentioned application not yet in use?	