Tampere University of Applied Sciences

Home Oxygen Therapy for Children

Interventions

Rawaa Al-Khalidi

Marta Gaspar del Rosal

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ABSTRACT

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AL-KHALIDI RAWAA & GASPAR DEL ROSAL MARTA
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This thesis delves into the challenges, interventions, and outcomes of pediatric home oxygen therapy (HOT), to provide a comprehensive literature review for healthcare professionals and families. The significance of HOT for children is emphasized, and a robust framework for nurses and caregivers is outlined.

The methodology utilized is a descriptive literature review, aided by using the PICO framework and conducting searches in databases like CINAHL, PUBMED, Medline, and Google Scholar. The collected articles were compared and analyzed.

As a result, the four studies revealed key points about pediatric home oxygen therapy, including the challenges faced by parents and caregivers, and emphasized the importance of effective coordination among healthcare providers, the need for respite care and educational support, and considering both parents and children's perspectives. Additionally, the studies explored how long-term oxygen therapy affects children's quality of life, influenced by disease severity, extrapulmonary manifestations, and nutritional support.

In conclusion, this comprehensive literature review deepened our understanding of pediatric home oxygen therapy and emphasized the need for further research and practical measures to improve care and support for children on home oxygen therapy.

Keywords: home oxygen therapy, hypoxemia, hypoxia, parents, caregivers, children, nursing interventions, family nursing

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1 INTRODUCTION

Every year, a staggering number of children worldwide face treatable illnesses, with respiratory conditions emerging as a leading cause of mortality especially among those under five years old (World Health Organization, 2016). A significant proportion of these cases lead to chronic conditions, necessitating home oxygen therapy (HOT) for these young patients.

In addition, premature infants, especially those weighing less than one kilogram and diagnosed with bronchopulmonary dysplasia, a respiratory condition, may find themselves discharged from medical facilities with an oxygen therapy requirement (WHO. 2016).

This transition places a newfound responsibility on parents and caregivers for administering the treatment in a home environment.
Advancements in medical technology have expanded the possibility of children with respiratory conditions receiving ventilator support at home (Kai-Wei et al., 2016), introducing a novel domestic setting for both the children and their families.

Consequently, parents and caregivers must adapt to this altered reality.
Studies by Kai-Wei et al. (2016) have revealed that those caring for children receiving home oxygen therapy (HOT) frequently experience psychological distress, encompassing stress, frustration, and anxiety. This underscores the critical need for caregivers to possess the requisite knowledge, skills, and a sense of confidence in effectively monitoring and managing the child's condition at home (Anderson & Hillman. 2019).

It is imperative that, before children are discharged from healthcare facilities, the medical team, including nurses, equip parents with comprehensive education and instructions for managing oxygen therapy at home. Furthermore, these healthcare professionals should provide the necessary support to parents and caregivers grappling with this newfound way of life (Anderson & Hillman. 2019).

The primary objective of home oxygen therapy for hospitalized children is to facilitate their return to a familial environment. The significance of this topic arises

from the growing survival rates among children with pulmonary conditions, leading to an increased demand for oxygen therapy (Rahimi, 2019). Moreover, research has uncovered potential consequences of untreated hypoxemia, including elevated risks of secondary disorders such as neurological impairments, sleep disturbances, impaired growth, and pulmonary hypertension (Rahimi, 2019).

2 THEORETICAL STARTING POINT

The significance of this subject for us arises from the substantial number of children grappling with respiratory ailments necessitating oxygen therapy at their residences.

According to Wang, Lin, Lee, & Lee (2016), Oxygen, though non-flammable, has the potential to enhance the combustion of other substances (Cameo Chemicals. n.d.). As a result, parents and caregivers must grasp the essentiality of safe oxygen therapy. To accomplish this objective, nurses should engage in the process by providing education, guidance, and assistance to caregivers and parents of oxygen-dependent children (Wang, Lin, Lee, & Lee. 2016).

Once children are back home, the entirety of responsibility falls upon parents and caregivers, potentially leading to emotional and physical overwhelm (Wang, K.-W. K et al. 2016).

Oxygen therapy involves administering supplemental oxygen to patients with low blood oxygen levels (MedlinePlus n.d.). Hypoxemia denotes insufficient oxygen levels within the blood circulation, manifesting notably as breathlessness. Oxygen levels can be gauged through arterial blood gas sampling (Mayo Clinic. 2023). Hypoxia, on the other hand, pertains to insufficient oxygen levels in body tissues (Cleveland Clinic. 2022).

A parent signifies a child's mother or father, while a caregiver denotes an individual responsible for the well-being of another, not necessarily the biological parent. A child refers to a young human who has not yet reached adulthood (Oxford Learner’s Dictionaries n.d.).

Family nursing encompasses evaluating and addressing the physical and psychological necessities of all members within a family unit (Stones, S. 2020).

Nursing interventions encompass the actions nurses undertake to execute the patient's care plan, encompassing procedures, treatments, and educational guidance, all geared toward enhancing the patient's well-being (The Free Dictionary n.d).

Home oxygen therapy consists of various considerations, including necessary materials such as oxygen tanks, nasal cannulas, and pulse oximeters, alongside child skin care. Multiple safety risks are associated with home oxygen therapy, including oxygen toxicity, hypoxia, fire hazards, and infection. Adequate patient and caregiver education and training are imperative for the secure utilization of oxygen therapy, encompassing proper storage and handling of oxygen containers, usage of oxygen equipment, and continuous oxygen level monitoring. (Moore 2019.)

Hayes et al. (2019) elucidate that Home Oxygen Therapy (HOT) pertains to the supply of extra oxygen to patients in their domestic setting, aimed at elevating arterial blood oxygen concentration and ameliorating tissue oxygenation for those enduring chronic hypoxemia.

2.1 Home Oxygen Therapy: Clinical Indications

Home oxygen therapy (HOT) is a crucial intervention commonly employed to address chronic respiratory conditions in children afflicted with hypoxemia, a condition marked by diminished oxygen levels in the bloodstream. Hypoxemia can give rise to hypoxia, leading to disruptions in adenosine triphosphate (ATP) generation and carbohydrate metabolic processes. (Walsh & Smallwood, 2017.) As per the recommendations by the American Thoracic Society (ATS), HOT is advisable for children with a PaO2 of 55 mm Hg or lower, or an oxygen saturation of 88% or less at sea level while breathing ambient air, or 85% or less at altitudes of 1,600 meters or higher (ATS, 2013).

The guidelines established by the ATS (Hayes Jr. et al., 2018) identify various scenarios that may lead to chronic hypoxemia in children, potentially necessitating HOT. These encompass chronic lung conditions like cystic fibrosis, bronchopulmonary dysplasia, and interstitial lung disease, as well as pulmonary hypertension, sleep-related breathing disorders, and neuromuscular diseases affecting respiratory function. Children with advanced or terminal illnesses requiring palliative care might also be candidates for HOT. (Hayes Jr. et al., 2018.)

In addition to chronic lung conditions and pulmonary hypertension, there are several other situations that could warrant the prescription of home oxygen therapy (HOT) for children. For instance, children grappling with cyanotic congenital heart conditions, characterized by inadequate blood flow to the lungs, may necessitate HOT due to low oxygen saturation levels. (Mason et al., 2015.)

Furthermore, children affected by sickle cell disease, who are prone to acute chest syndrome leading to hypoxemia, might require HOT. Children with bronchiolitis obliterans, a condition marked by lung airway inflammation and scarring, may also require HOT to maintain adequate oxygen levels. Children experiencing severe asthma and chronic hypoxemia, despite optimal medical management, may also be prescribed HOT. Finally, children with neuromuscular disorders like spinal muscular atrophy or muscular dystrophy may require HOT due to respiratory muscle weakness leading to chronic hypoventilation and hypoxemia. (Mason et al., 2015.)

2.2 Equipment for HOT

Various supplies are accessible for delivering oxygen therapy, and the selection of equipment should be tailored to each patient's specific medical requirements (Hayes Jr. Et al., 2018).

Nasal cannulas are commonly preferred method for delivering oxygen to infants and neonates due to their ease of use and secure placement compared to masks; however, it's essential to ensure proper adherence to the skin for effective oxygen therapy (Pirr & Peter, 2020).

Irrespective of the equipment employed, nurses should periodically reassess the child's living circumstances. This evaluation encompasses daily activities, physical fitness, mental capacity, and the comprehension level of both the child and their caregivers. Such evaluations guarantee the appropriateness of the equip-

ment for indoor and outdoor use (Fields, Whitney, & Bell, 2022). Considering children's active nature and frequent desire to engage in play, portable oxygen becomes more suitable for these situations (Fields, Whitney, & Bell, 2022).

For patients residing in rural areas prone to frequent power outages, it's advisable for them to maintain additional oxygen tanks, as oxygen concentrators may not function during these instances (Fields et al., 2022).

2.2.1 Sources of oxygen

Oxygen can be administered through various methods: using gas cylinders or oxygen concentrators. Gas cylinders can supply up to 100% oxygen. However, a primary drawback of oxygen cylinders is their limited duration of around 75.5 hours at a rate of two litres/minute before requiring replacement with a fresh cylinder (Adde, F.V., Alvarez, A. E., Barbisan, B.N & Guimaraes, B.R. 2013).

Concentrators operate by extracting nitrogen from the air to heighten the oxygen concentration for the patient. These devices offer advantages such as not necessitating frequent replacements and occupying minimal space. Additionally, a tubing of approximately 15 meters can be connected to the concentrator, allowing the patient to move freely around their home. Some concentrators also come with battery operation, suitable for use when outside the residence. (Fields, B et al. 2022.)

It's important to note that concentrators rely on electricity, which underlines the significance of considering the family's socioeconomic circumstances. Despite this, concentrators entail 55% lower expenses compared to gas cylinders (Adde, F.V., et al. 2013).

During air travel, airlines typically provide oxygen; however, this should be arranged beforehand. The oxygen supplied is typically administered through pulse oxygen delivery, which may not be safe for young children. Alternatively, it might be possible for the patient to carry their own portable oxygen tank, provided the arrangements are made in advance with the airline. (Pirr, S & Peter, C. 2020.)

The percentages of oxygen delivered depending on the flow rate are the following (Adde, F.V et al. 2013). TABLE 1:

Flow rate	Oxygen %
≤ 2l/min	≥ 95%
3-5l/min	≥ 90%
>5l/min	< 90%

2.2.2 Nasal cannula

To guarantee the appropriate positioning of the nasal cannula in children, meticulous attention must be given to its accurate placement beneath the child's nostrils. The tubing is secured in place by employing medical tape and subsequently threaded either over or under the ears. It is of paramount importance to ensure that the tape does not induce any skin irritation. (Nationwide Children's. 2022.)

Adequate fitting of the nasal cannula necessitates that the tubing does not elicit imprints on the skin or chafe against the hairline. Additionally, consistent upkeep is vital to preserve the cleanliness and mucus-free state of the cannula. Should any mucus accumulation occur, the tubing should either be properly cleansed or replaced. Cleansing should be carried out using soap and water on a weekly or bi-weekly basis, followed by thorough drying. The recommended interval for nasal cannula replacement is every two to four weeks. (Fields, B et al. 2022.)

Manipulation or truncation of the tubing's prongs that enter the nostrils must be strictly avoided, as any such modification would render the prongs sharp, posing a risk of nostril damage. The prongs possess a naturally occurring curvature, and this should align downwards, adhering to the nasal anatomy. Incorrectly positioned prongs can similarly contribute to tissue irritation within the nasal region. (Fields, B et al. 2022.)

Concomitant humidification of the delivered oxygen is imperative to maintain nasal moisture (Nationwide Children's). This humidified oxygen serves to retain adequate moisture levels within the nasal passages. Humidification becomes requisite for flow rates surpassing one litre per minute. (American Thoracic Society, 2018.)

In pursuit of heightened comfort, the availability of foam padding can further be considered as a means of safeguarding pressure points in the regions encompassing the ears and nose (Fields, B et al. 2022).

2.3 Goals of oxygen therapy

The goals can be classified into physiological effects and clinical effects. The physiological effects are increasing PaO2 to enhance the delivery of oxygen to the tissues; correct the haematocrit levels; reduction of pulmonary artery pressure which will decrease the development of pulmonary hypertension and help to the proper performance of the right ventricle. (Adde, F.V et al. 2012.)

Clinical effects include promotion of the cognitive capacity, strengthening of the sleep quality and efficiency, increasing exercise tolerance, hospital visits reduction, promoting quality of life and optimizing survival rate (Adde, F.V et al. 2012).

2.4 Safety at home

While acknowledging the positive aspects of home oxygen therapy, it's crucial to emphasize that when providing such therapy to children, certain safety factors must be considered (American Thoracic Society, ATS. 2019).

ATS's guidelines underscore the primary safety concern of selecting the appropriate oxygen delivery device for children. These guidelines stress the importance of considering the child's age, size, health status, and preferences when choosing

an oxygen device (ATS, 2019). Selecting an incorrect device can lead to discomfort or harm. Thus, a personalized approach to device selection is essential to ensure the best outcomes for the child (ATS, 2019).
Another key safety aspect is the regular monitoring of a child's oxygen saturation levels during home oxygen therapy. This monitoring is crucial to ensure that the prescribed oxygen flow rate meets the child's needs effectively. ATS recommends continuous or intermittent monitoring using pulse oximetry, with adjustments to the oxygen flow rate as necessary. (ATS, 2019.)

Similarly, BTS (British Thoracic Society) guidelines highlight the importance of checking oxygen levels every four hours and making appropriate adjustments (Hardinge et al., 2015).

Additionally, due to the flammable nature of oxygen, it's vital to maintain a safe environment. This involves prohibiting smoking near the oxygen setup and keeping open flames at least two meters (Hardinge et al., 2015). It's also important to avoid items that could potentially cause sparks around the oxygen equipment (ATS. 2019).

It's essential to display "no smoking" notices throughout the household. Nurses should actively motivate the family members and caregivers who smoke, to cease smoking, as this will effectively lower the potential of a fire hazard (Fields, B et al. 2022).

It is important to switch off the oxygen supply when it is not being used and ensure that oxygen cylinders are stored in an upright position within a well-ventilated space ensuring they are at a safe distance of around two meters away from any heat source like a furnace. During car travel, avoid storing oxygen tanks in the trunk; instead, secure them properly to prevent movement and leave a partially open window to prevent accumulation of oxygen. Keep oxygen concentrators uncovered and position them at least 30.48 centimetres away from walls, furniture, or curtains. (Fields, B et al. 2022.)

Additional oxygen supplementation may introduce a potential risk of stumbling or falling. The tubing connected to oxygen concentrators can extend up to 15.24

meters, thus elevating the likelihood of accidents. Similarly, any insecure tanks or equipment can pose a falling risk. To enhance safety measures, caregivers should take the proactive step of informing neighbours and local authorities, including the fire department, power company, and telephone provider, about the presence of supplemental oxygen within the household (Fields, B et al. 2022.)

2.5 Skin care

The NHS (National Health Service. 2021) stresses the significance of following the prescribed oxygen therapy regimen and promptly reporting any adverse reactions to healthcare providers (NHS, 2021). Healthcare providers should routinely assess skin condition, particularly in areas prone to friction and pressure. (NHS, 2021.)

If the face mask or nasal cannula is too tight, it can cause irritation or bruising on the skin around them. Additionally, the inside of the nose might become dry, leading to nosebleeds (Shebl, E., Modi, P., & Cates, T. D. 2023). Saline sprays are beneficial for keeping the inner tissues of the nose moisturized (Fields, B et al. 2022).

Patients need to be informed that oil-based moisturizers and petroleum jelly can pose a fire hazard in the presence of oxygen. To ensure safety, it is recommended that they use water-based products on their hands, face, or inside the nose while receiving oxygen therapy. (Hardinge et al., 2015.)

Nurses should be vigilant in assessing the patient's skin and acting appropriately to prevent and treat any skin complications that may arise (Hayes et al., 2019).

Regarding (Hardinge et al., 2015; Hayes et al., 2019), which stress the importance of patient education regarding skin care during oxygen therapy, patients should be instructed to use moisturizer to prevent dry and cracked skin.

Regularly inspect oxygen delivery equipment for wear, damage, or contamination. Cleaning equipment according to manufacturer recommendations is crucial to prevent bacterial growth and maintain skin health (Fields, B et al. 2022).

2.6 Signs of breathing problems, their prevention, and associated illnesses

According to Pirr and Peter (2020), recognizing signs of breathing problems in children receiving home oxygen therapy is crucial. These signs include rapid or laboured breathing, retractions (indrawing of the chest wall with each breath), flaring of the nostrils, grunting, wheezing, and changes in skin colour (such as cyanosis, which is a bluish tint to the skin or lips).

Resuscitation skills should be provided to the family/caregivers, in case of an emergency at home (Pirr, S & Peter, C. 2020). If the oxygen delivery format used is oxygen concentrators, we should ensure especially in this case that the family has an electricity provider that is safe and reliable and ensure that the family has all the telephone numbers that could be needed in case the equipment malfunctions. (Pirr, S & Peter, C. 2020.)

Other signs that may indicate a need for home oxygen therapy in children include decreased activity level, poor feeding, and lethargy. Children who require oxygen therapy may also have a history of prematurity, lung disease, or heart disease (Hayes, D et al. 2019).

2.7 Hypoxemia

Every year children’s risk of death went up five times, and when comparing with other pulmonary conditions, hypoxemia was the leading cause (WHO. 2016).
According to the American Thoracic Society (Hayes, D et al. 2019), when children persist with low levels of oxygen (SpO2) for a period of two weeks is clinical evidence that indicates “chronic hypoxemia”. The first route of treatment is initiating oxygen therapy. This article (Hayes, D et al. 2019) also studies the values of

oxygen levels to determine desaturation in children. It indicates that low levels of oxygen events in children were reduced by age, meaning that the older the child, the less probable SpO2 levels would decrease.

In conclusion, for children younger than one-year-old, hypoxemia was defined when SpO2 levels were less or equal to 90%, and for children of one year old or older SpO2 levels would be less or equal to 93% to diagnose hypoxemia (Hayes, D et al. 2019).

If hypoxemia is not treated, it will cause acidosis in the tissues which consequently it will damage the cells and cause death (Pirr, S & Peter, C. 2020).

2.8 Monitoring oxygen delivery at home

Once a patient's need for home oxygen therapy has been assessed, continuous monitoring of their physiological response to treatment is crucial (Walsh, B.K et al. 2017). Pulse oximetry serves as the primary monitoring tool, offering a noninvasive estimate of arterial oxygen saturation, and has largely supplanted invasive arterial blood gas sampling (Walsh, B.K et al. 2017). However, it is important for healthcare providers to be cognizant of its limitations, which encompass motion artifacts, perfusion concerns, calibration assumptions, and more (Walsh, B.K et al. 2017).

Pulse oximetry is highly valuable in assessing hypoxemia but is unable to detect hyperoxia and its potential complications. If a patient experiences distress despite a reassuring SpO2 level (≥88–90%), other aspects of oxygen delivery should be considered (Walsh, B.K et al. 2017).

Moreover, caregivers and parents should be proficient in handling the equipment and should receive guidance on maintaining the cleanliness of nasal cannulas, masks, concentrator filters, and humidifying bottles to minimize the risk of infections (Fields, B et al. 2022).

Healthcare providers should also educate parents and caregivers about various factors that can potentially disrupt pulse oximetry readings, such as motion artifacts, calibration issues, irregular heart rhythms, variations in skin pigmentation, and the presence of abnormal haemoglobin levels (Walsh, B.K et al. 2017).

2.9 Follow-up

Monitoring the child's oxygen saturation levels is critical, according to the American Thoracic Society's clinical practice guideline on HOT for children, to ensure that the HOT prescription is giving appropriate oxygenation (Hayes et al., 2019).

The guideline also emphasizes the importance of educating and training families of children receiving HOT on safety measures and emergency preparedness, such as proper storage of oxygen cylinders and knowledge of what to do in case of an emergency (Hayes et al., 2019).

Regular evaluation of the child's clinical status, oxygen saturation levels, and safety measures can help prevent adverse events and hospitalizations related to HOT use (Hayes et al., 2019).

Additionally, it is important to monitor the child's growth and development while receiving HOT, as chronic hypoxemia can impact these areas (Hayes et al., 2019). The guideline recommends that the child's HOT prescription be regularly reviewed and adjusted as needed based on their clinical status and oxygen saturation levels (Hayes et al., 2019).

Moreover, it is critical to monitor the child's growth and development while getting HOT, since chronic hypoxemia might have an influence on these areas (Hayes et al., 2019).

According to the guidelines, the child's HOT prescription should be checked on a frequent basis and changed as needed based on their clinical state and oxygen saturation levels (Hayes et al., 2019).

Healthcare practitioners must also evaluate the possible emotional impact of HOT on the kid and his or her family, as well as any financial or logistical impediments to treatment adherence (Hayes et al., 2019).

A multidisciplinary team, including respiratory therapists, social workers, and dietitians, can assist address these difficulties and enhance treatment outcomes (Hayes et al., 2019).

Although HOT can be an effective treatment for children with chronic hypoxemia, it is important to note that the therapy does not treat the underlying condition and should be used in conjunction with other medical interventions as necessary (Hayes et al., 2019).

2.10 Discontinuing and weaning of HOT

Hayes et al. (2019) offer insightful recommendations for discontinuing HOT in paediatric patients. They suggest that HOT should be considered for discontinuation if the patient consistently maintains oxygen saturation levels above 92% for a minimum of three months without significant respiratory issues. This recommendation aligns with the crucial principle of ensuring the patient's underlying condition is stable and that any comorbidities are effectively managed before discontinuing HOT. (Hayes et al., 2019.)

As emphasized by Pirr and Peter (2020), it's essential to acknowledge that patients who have been on HOT for an extended duration may develop tolerance to it. Abrupt discontinuation can trigger a resurgence of hypoxemia and related complications. To mitigate these risks, gradual reduction of the flow rate and treatment duration is advisable. (Pirr and Peter., 2020.)

Weaning from HOT involves the gradual reduction of the flow rate or treatment duration, a strategy that can be particularly beneficial for patients who have improved but still require some supplemental oxygen. This weaning process should be executed under close observation, with frequent monitoring of the patient's oxygen saturation, as advised by Pirr and Peter (2020.)

Regarding the retention of oxygen equipment at home post-discontinuation, it is vital to note that they can be kept for up to two weeks after stopping HOT. However, there's no proven benefit beyond this timeframe, and retaining the equipment may result in unnecessary charges. Ideally, the equipment should be removed when healthcare professionals are confident in the child's progress. (Smith, R, Nzirawa, T, Yap, SL, Camden, A & Lock. 2022.)

In case of any unexpected need, arrangements for an emergency oxygen supply within four hours can be made. The child should not be discharged from the caseload until the equipment is removed, and this request can be made through the designated nurse. (Smith, R., et al. 2022.)

Once a child has undergone a successful weaning process and reached an adequately low flow rate, the possibility of discontinuation may be explored. It is worth noting that preterm neonates with bronchopulmonary dysplasia (BPD) have shown greater success with room air challenges and clinical stability six months after discharge if they maintained stability while receiving oxygen at rates equal to or below 20 ml/kg/min. (Hayes et al., 2019.)

A consensus panel suggests that room air challenges are suitable for clinically stable children under 1 year of age who receive less than 0.1 L/min of oxygen and for children up to preschool age who receive 0.1–0.25 L/min. Extrapolating from these recommendations, school-age and older children might consider a flow rate less than 0.25–0.5 L/min. It's crucial to note that the decision to wean or discontinue oxygen usage should be based on flow rate rather than FiO2. (Hayes et al., 2019.)

To confirm that patients are prepared for the discontinuation of nighttime hyperbaric oxygen therapy (HOT), a home-based, room air, nocturnal pulse oximetry assessment should be performed, access to pediatric equipment and adhere to the guidelines outlined in relevant documents. Healthcare professionals are advised to suggest that families retain access to home oxygen therapy (HOT) for an extended period after discontinuation, especially during the winter season when viral infections are common. This approach allows for sufficient time to assess

the timing of HOT withdrawal and the patient's ability to manage respiratory illnesses without supplemental oxygen, as per the recommendations of Hayes et al. (2019.)

It is vital to continually assess a patient's readiness for weaning from home oxygen therapy (HOT) and to monitor their responses to each adjustment. Due to the persistent nature of these respiratory conditions, modifications should be introduced gradually over an extended period, spanning weeks to months, rather than hastily. This approach helps prevent the oversight of subtle deteriorations and enables the prompt correction of suboptimal therapy. Aspects that necessitate monitoring encompass the patient's growth, development, cardiorespiratory health, and overall stability, including their ability to manage respiratory conditions and adapt to changes in altitude. (Hayes et al. 2019.)

2.11 Infection prevention

For avoiding infections to the child, parents and caregivers need to follow some hygiene practices (Nationwide Children's):
Washing their hands before feeding or touching the child.
Ask family visitors to not visit if they are ill.
Besides of the reason for risk of fire, smoking can also affect the child and cause ear infection, difficulty in breathing, congestion and even pneumonia.

2.12 Recommendations for parents and caregivers

The most important aspects can be collected into the following (Fields, B et al. 2022):
Equipment:
Get comfortable with the equipment, including the sources of oxygen (tanks or concentrators), pulse oximeter, nasal cannula or mask, tubing and humidifier. Understand the flow rate and put it into practice. Ask always in case of doubt to the healthcare provider.

Keep track of the pulse oximeter readings. Write them down to provide them if necessary to the healthcare.
Keep the same oxygen flow rate that was prescribed and don’t change it unless it has been discussed with the healthcare provider.
Keep the nasal cannula or mask clean by washing them with soap and water, rinsing and properly drying it every two to four weeks.
The tubing should be replaced if dirty and needs to be kept dry.
Change the air filters once a month or according to the manufacturer. The filters should be cleaned once a week with soap and water and dry properly.
Ensure enough oxygen in the tanks periodically. Contact the healthcare provider in case the oxygen is running out.

Safety:
A fire extinguisher and smoke detector should be present in the house.
Smoking is forbidden indoors or close to the patient using oxygen. Keep people around you informed and warned of it.
Oxygen shouldn’t be used or stored close (around two meters) to any open flame or source of heat, such as candles, furnaces, heating pads, electric heaters or gas stoves.
Electrical appliances such as curling irons, hair dryers, electric toothbrushes or razors shouldn’t be used within two meters of the source of oxygen.
If supplemental oxygen is not in use, keep it turned off.
If you use hand sanitizer before handling the oxygen source, do it at least two meters apart from it.
Only use products on the skin that are water-based or oil-based. Avoid petroleum-based products, such as Vaseline or VapoRub.
Avoid using aerosols close to the oxygen source.
Ensure the oxygen tanks are fastened upright and two meters away from heat sources. When traveling, never let the tank lose in the trunk of the car.
To promote airflow, keep the oxygen concentrator at least three meters away from the wall or curtains. Never cover the concentrator. Don’t use extension cords.
Don’t use tubing longer than 15 meters so that falls are avoided.

Contact the healthcare provider if:

You observe the child is having difficulty breathing and the flow rate is right, and the tubing and equipment are working correctly.

You observe restlessness, anxiousness, confusion, drowsiness, or the lips or fingernails are bluish (cyanosis).

The child has constant headaches.

The child is breathing shallowly or slower.

3 PURPOSE, TASKS & OBJECTIVES

The purpose of the thesis to conduct an in-depth analysis by doing a descriptive literature review of the articles that introduce us to oxygen therapy protocols in children, how and in which terms home oxygen therapy is initiated, and the parents, caregivers and nurses' feelings and experiences on at-home oxygen therapy.

The objective to provide with the best instructions for nurses on how to initiate and follow up oxygen therapy at home for children suffering a pulmonary condition, improving the children's quality of life. This thesis in intended to result beneficial for nurses and nursing students, resulting in being as well beneficial for parents and caregivers in the care of oxygen-dependent children.

The task:
What are the interventions needed when a child is discharged with home oxygen therapy?

4 METHODOLOGICAL STARTING POINT

The thesis methodology employed is a descriptive literature review (D, LN 2018).

The first step was to define the topic and identify relevant literature related to research problems and questions. For the extraction of data, we followed the PRISMA Flow Diagram (Lubbe, W et al. 2020). First, we will identify the articles that answer our research question from the databases selected. After identifying we will do the screening where we will follow the inclusion and exclusion criteria process. From the included articles we will read full articles to see if they're eligible for the thesis, and finally, after the inclusion and exclusion of articles we will finalize with the documents that will be included in our thesis from which we will extract the information (Lubbe, W et al. 2020.). In the final inclusion, we included four research articles.

While reading and understanding the connections between the sources, we identified, compared and discussed between the articles. Based on this analysis, we outlined our own literature review's structure and framework. This involved creating a coherent narrative that synthesizes the information from the selected sources to answer our research question. (Booth, A., et al., 2021.) We establish a 10-year period frame for the sources checked.

4.1 Selection criteria

The authors of this thesis based their search on the keywords and research question. Two of the main key concepts included "home oxygen therapy" and "children". To extend the result list's possibilities different words and combinations were tried.

The data collection was aided by using the PICO framework, which was applied to search relevant databases such as CINHAL, PUBMED, Medline, EBSCOhost, and Google Scholar.

To maintain the quality of the references included, the authors exercised careful judgment when choosing and attributing sources. They made a deliberate choice to focus on the most significant and pertinent information that aligns with the subject matter of the bachelor's thesis.

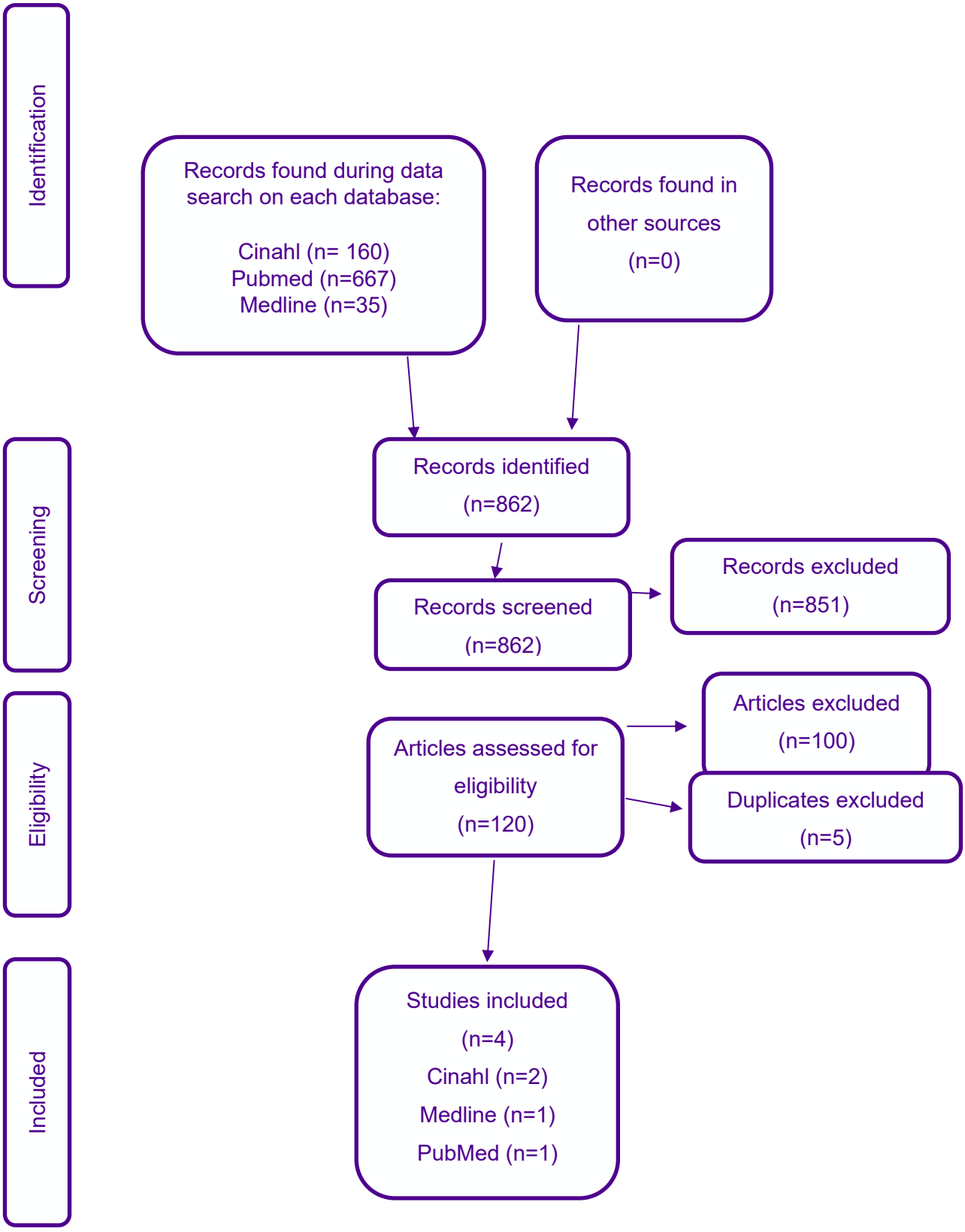

FIGURE 1. PRISMA flow diagram of searches.

5 FINDINGS

5.1 Parents' and caregivers' support

Medical advancements have made it possible for children under oxygen therapy to return home along with oxygen therapy. In this context, primary caregivers are responsible for performing both the routine child-rearing tasks and the healthcare-related duties for their child depending on oxygen. (Kai-Wei, K.-W. K et al. 2016.)

Research in the field (Kai Wei, K.-W. K et al. 2016) of caring for medically complex children at home has revealed that primary caregivers in this group often report experiencing stress across different dimensions of their lives. Research studies have also indicated that mothers of medically complex children frequently mention significant physical stress, including a decline in their overall physical well-being. (Kai Wei, K.-W. K et al. 2016.)

Another study as well supporting this (Feeley, C. A., Turner-Henson, A., Christian, B. J., Avis, K. T., Heaton, K., Lozano, D., & Su, X. 2014.) indicates that usually mothers bear the ultimate responsibility for delivering healthcare treatments, overseeing the child and their medical equipment, and providing overall physical care for the child within the home environment. Many of them felt they weren't prepared enough before discharge.

Consequently, caregiving can have far-reaching effects on the mother, affecting various aspects of her quality of life, and also impacting the entire family, which, in turn, affects the quality of care provided to the child (Feeley, C. A et al. 2014).

Although healthcare practitioners may have imparted patient education regarding medical care items and procedures, caregivers might have encountered specialized terminology and information that was either unsuitable or over-whelming, as well as disparities in support from different healthcare providers. Research findings have indicated that adequate professional assistance for families with technology-dependent children should account for the distinctiveness of their family routines. (Kai Wei, K.-W. K et al. 2016.)

This is supported by the previously mentioned study (Feeley, C. A et al. 2014.) stating that whenever feasible, the coordination of a child's care, which includes scheduling medications and breathing treatments, should be planned in a way that does not disrupt the sleep patterns of the maternal caregiver. Effective coordination among multiple healthcare providers is essential, as many of these children receive care from various medical professionals. Healthcare providers should evaluate the caregiver's daily routines at home, considering their sleep and rest needs.

Additionally, for caregivers who may not be aware of the existence of respite care, healthcare providers should engage in discussions and education regarding its availability. In alignment with prior research, this study carries forward implications for the future necessity of respite care or supportive services for these caregivers, allowing them opportunities for sleep or short naps when uninterrupted nighttime sleep is unattainable. Moreover, ensuring that the caregiver receives adequate training and education, along with the knowledge required for monitoring the child's condition, can enhance her sense of empowerment and potentially alleviate stress and the burden of caregiving. (Feeley, C. A et al. 2014.)

5.2 Long-term use of oxygen therapy and quality of life

There is little evidence mentioning quality of life during long-term oxygen therapy, but according to a study (Lauby, C., Boelle, P. Y., Taam, R. A., Bessaci, K., Brouard, J., Dalphin, M. L., ... Epaud, R. 2019.) where quality of life is evaluated in children with interstitial lung disease concludes that greater disease severity was associated with a reduced quality of life score. The adverse effects of extra pulmonary manifestations, the use of oxygen therapy, and the provision of nutritional support had comparable negative effects.

In addition, it was observed a significant level of agreement between parents and their children when evaluating their point of view towards oxygen therapy and

children’s quality of life. Nevertheless, it is noteworthy that, albeit statistically insignificant, parents tended to evaluate their children's quality of life more negatively compared to the children's self-assessment. (Lauby et al., 2019.)

This pattern aligns with findings in prior studies related to paediatric quality of life, suggesting that parents' perceptions are influenced by the disease itself and the challenges associated with treatment. It has been proposed that par-ents and children may consider different sets of information when forming their judgments, and both perspectives offer valuable insights. (Lauby et al., 2019.)

Another study (Liguoro et al., 2021) comments on the long-term effects of oxygen therapy in children with sickle cell disease and chronic hypoxemia, one of the conditions that require oxygenation. Overall, long-term oxygen therapy is a secure and well-accepted treatment choice for children experiencing sickle cell disease and chronic hypoxemia, with minimal adverse effects documented. (Liguoro et al., 2021).

6 DISCUSSION

Drawing upon the theoretical framework that guided our descriptive literature review, we have explored the multifaceted challenges and implications associated with children's home-based oxygen therapy and the critical role of primary caregivers. Our thesis sheds new light on this topic and contributes valuable insights to the existing body of knowledge in this domain.

The theoretical foundation of our thesis, rooted in the existing literature, recognizes the intricate demands placed upon caregivers of medically complex children receiving home-based oxygen therapy. Our findings, in consonance with previous research. (Kai Wei, K.-W. K et al., 2016; Feeley, C. A et al., 2014.) reaffirm the substantial stress and physical strain experienced by caregivers. However, our findings introduce a fresh perspective by revealing that these caregivers often lack the necessary preparation to fulfil their caregiving responsibilities adequately. This highlights the urgent need for tailored caregiver education and support programs that go beyond the scope of standard medical care instructions. (Kai Wei, K.-W. K et al., 2016.)

Moreover, our investigation underscores the pivotal importance of seamless coordination among healthcare providers to minimize disruptions to caregivers' sleep patterns. While previous studies have acknowledged the significance of professional assistance (Feeley, C. A et al., 2014; Kai Wei, K.-W. K et al., 2016), our thesis advances this concept by underscoring the requirement for a more comprehensive approach to care coordination. This approach should factor in the specific sleep and rest needs of caregivers, with a focus on avoiding interruptions to these essential aspects of their well-being. This newly emphasized aspect of caregiving has practical implications for healthcare providers, suggesting that holistic and personalized care strategies can be pivotal in optimizing the support and well-being of caregivers. (Feeley, C. A et al., 2014; Kai Wei, K.-W. K et al., 2016.)

With respect to the quality of life during long-term oxygen therapy, our findings corroborate existing research by confirming that the severity of a child's medical condition can negatively impact their quality of life (Lauby, C. et al., 2019). What

sets our findings apart is the recognition of a distinct trend: parents tend to assess their children's quality of life more negatively compared to the self-assessments of the children themselves (Lauby, C. et al. 2019). This divergence in perspectives, while statistically insignificant, is a noteworthy discovery. It suggests that both parental and child assessments provide unique insights into the child's well-being and highlights the importance of considering multiple perspectives when evaluating the quality of life of children undergoing extended oxygen therapy. (Lauby, C. et al., 2019.)

Furthermore, our thesis adds to the expanding body of knowledge by providing insights into the long-term effects of oxygen therapy in children with sickle cell disease and chronic hypoxemia, a specific group that necessitates oxygenation (Liguoro et al., 2021). Our findings affirm that long-term oxygen therapy is a secure and well-accepted treatment choice for children with these conditions, with minimal documented adverse effects. This finding provides valuable reassurance to healthcare providers and families grappling with these medical conditions (Liguoro et al., 2021).

7 CONCLUSION

The most critical aspects that need to be considered for implementing home oxygen therapy can be summarized as follows and serve as a guide for parents and caregivers.

Equipment:

Acquaint yourself with the equipment, which includes oxygen sources (tanks or concentrators), pulse oximeter, nasal cannula or mask, tubing, and humidifier. Understand the prescribed flow rate and apply it, and don't hesitate to seek clarification from healthcare providers if there are any uncertainties.

Keep a record of pulse oximeter readings and maintain them for potential sharing with healthcare professionals.

Adhere to the prescribed oxygen flow rate and refrain from adjusting without consulting healthcare providers.

Ensure the cleanliness of nasal cannulas or masks by washing them with soap and water, rinsing, and thoroughly drying them every two to four weeks.

Replace tubing if it becomes soiled and keep it dry.

Change air filters monthly or as per manufacturer recommendations. Clean filters weekly with soap and water, ensuring they are properly dried.

Periodically check oxygen tank levels and promptly contact healthcare providers if oxygen is running low.

Safety:

Maintain a fire extinguisher and smoke detector in the household.

Prohibit indoor or close proximity smoking for individuals using oxygen and inform those in the vicinity of this restriction.

Oxygen should not be used or stored within approximately 2 meters of any open flame or heat source, such as candles, furnaces, heating pads, electric heaters, or gas stoves.

Electrical appliances like curling irons, hair dryers, electric toothbrushes, or razors should not be operated within two meters of the oxygen source.

When supplemental oxygen is not in use, ensure it is turned off.

If hand sanitizer is applied before handling the oxygen source, do so at a distance of at least two meters from it.

Only utilize water-based or oil-based skin products and avoid petroleum-based items such as Vaseline or VapoRub.
Refrain from using aerosols in close proximity to the oxygen source.
Secure oxygen tanks in an upright position and keep them at least 2 meters away from heat sources. While traveling, ensure the tank is properly secured in the car's trunk.
To allow proper airflow, maintain a minimum distance of 3 meters between the oxygen concentrator and walls or curtains. Never cover the concentrator and avoid using extension cords.
Use tubing that is no longer than 15 meters to prevent falls.

Contact the healthcare provider if:
You notice the child is having trouble breathing despite the correct flow rate and proper functioning of the equipment and tubing.
You observe restlessness, anxiety, confusion, drowsiness, or bluish discoloration of the lips or fingernails (cyanosis).
The child complains of constant headaches.
The child exhibits shallow or slow breathing.

Overall, the topic chosen provided us with a strong theoretical background, as many guidelines have been stablished. In regards of research, there isn’t enough studies regarding home oxygen therapy in children, including, among others, play, activities, school, and sleep.

8 ETHICS AND RELIABILITY

The thesis adhered to TAMK's research ethics principles, ensuring an honest, thorough, and precise approach in gathering, presenting, and assessing the results. The researchers demonstrated a commitment to ethical conduct by responsibly referencing and citing the works of other authors, showing due respect for their contributions (TENK, 2012).
Comparison were made between different protocols/guidelines to see differences and similarities we needed to consider (Lubbe, W., Ham-Baloyi, W.T & Smit, K. 2020).

The cornerstone of effective research and sound decision-making in evidence-based practice is the reliability of the data used. In situations where data cannot be vouched for, making informed judgments becomes a complicated challenge. The trustworthiness of data hinges on the quality of the instruments or tests employed for its collection. (Boswell, C. & Cannon, S. 2020, 380.)

Given this imperative, the authors conducted a systematic literature search. Articles selected for inclusion in this literature review were sourced from reputable databases, subjected to peer review, and were published between 2013 and 2023.

To provide transparency regarding the data search process, we intend to employ the Prisma flow chart, illustrating the systematic steps undertaken during our quest for relevant literature. Furthermore, it's important to acknowledge that the authorization to undertake this thesis was granted by TAMK after the authors' research plan was rigorously checked through and approved. This institutional approval underscores the academic rigor and ethical compliance of our work effort.

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APPENDICES

Appendix 1. TABLE 1. Description of eligible studies

Authors	Year	Title of the Article	Purpose	Results
Feeley, C. A., Turner-Henson, A., Christian, B. J., Avis, K. T., Heaton, K., Lozano, D. & Su, X.	2014	Sleep Quality, Stress, Caregiver Burden, and Quality of Life in Maternal Caregivers of Young Children with Bronchopulmonary Dysplasia (cinahl)	Evaluation of different stressors on mothers caring for children with bronchopulmonary dysplasia	In this examination involving maternal caregivers of young children with BPD, the quality of sleep and the presence of depressive symptoms emerged as noteworthy predictors.
Kai-Wei, K.-W. K., Hung-Ching, L., Chin-Ting, L., & Kuo-Sheng, L.	2016	Primary caregivers of in-home oxygen-dependent children: predictors of stress based on characteristics, needs, and social support (3) (Pubmed+Cinahl+Medline)	To ascertain the factors predicting stress experienced by primary caregivers tending to oxygen-dependent children within a home setting, the study explores the correlation between stress levels, caregiver requirements, and the extent of social support	The caregivers exhibited elevated levels of stress overall, with the greatest emphasis placed on information requirements. Emotional support emerged as the primary form of assistance accessible from family and friends. Health professionals

				provided informational support, while both instrumental and emotional support held substantial significance.
Lauby, C., Boelle, P. Y., Abou Taam, R., Bessaci, K., Brouard, J., Dalphin, M. L., Delacourt, C., Delestrain, C., Deschildre, A., Dubus, J. C., Fayon, M., Giovannini-Chami, L., Houdouin, V., Houzel, A., Marguet, C., Pin, I., Reix, P., Renoux, M. C., Schweitzer, C., Tatopoulos, A., Thumerelle, C., Troussier, F., Wanin, S., Weiss, L., Clement, A., Epaud, R., & Nathan, N.	2019	Health-related quality of life in infants and children with interstitial lung disease (pubmed + medline)	To study the quality of life among children with interstitial lung disease submitted to oxygen therapy. Perspectives by parents and their children	The quality of life related to health is noticeably diminished in children with interstitial lung disease in comparison to a healthy population. It is relatively straightforward to identify the factors that influence the quality-of-life score, which can aid in the identification of children at an increased risk of having a lower quality of life.

Liguoro, I., Arigliani, M., Singh, B., Rees, D., Inusa, B. P. D., & Gupta, A.	2021	Long-term oxygen therapy in children with sickle cell disease and hypoxemia (pubmed	To assess the level of acceptance and safety characteristics of extended nocturnal oxygen therapy in pediatric patients with sickle cell disease and persistent hypoxemia	Long-term use of oxygen therapy is a secure and viable treatment choice for pediatric patients with sickle cell disease and persistent hypoxemia.