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Integrated Study Master's Thesis

Empowering Patients and Their Families - Support for Self-Management and Personalized Care in Community Settings

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List of Abbreviations

AYA – Adolescent and Young Adult

CALD – Culturally and Linguistically Diverse

DHI – Digital Health Interventions

EAPC – European Association of Palliative Care

EHRs – Electronic Health Records

ePROs – Electronic Patient-Reported Outcomes

HCP – Healthcare Professional

PPC – Pediatric Palliative Care

WHO – World Health Organization

Summary

Pediatric cancer is still the leading cause of disease-related mortality in European children and adolescents. Even though survival rates are improving, children and their families still experience chronic physical, psychological, and emotional consequences of the disease. Pediatric palliative care (PPC) plays an essential role in improving the quality of life of the affected children with life-threatening or life-limiting illnesses. Pediatric palliative care is not only focused on pain and symptom control. Important aspects are also emotional support, communication, and spiritual well-being.

Historically, palliative care was provided only at the end of life when all curative treatments had failed. Today, PPC is a holistic approach with many facets. It can begin at diagnosis and continue throughout the disease, while curative therapies are also provided. The role of patient and family empowerment in pediatric palliative care, especially in community settings, is the subject of this thesis.

A systematic review of recent literature and qualitative interviews with the affected families were conducted. Results show that empowered families felt more informed, confident, and engaged in care. These families are also better able to manage care at home and act on behalf of their child's needs. Providing access to information, shared decision-making, and training in practical skills are also important components of empowerment.

The reviewed research shows the importance of effective communication and recognition of the child's voice in decision-making as besides other important aspects. Empowerment not only improves psychosocial results but has also shown to reduce hospital visits and improve treatment adherence, and caregiver distress. The families value compassionate care, tailored information, and the ability to stay actively involved in their child’s care and decision-making.

In general, the findings are that empowerment is an important variable in maximizing the experience and outcome of pediatric palliative care. Health systems can better meet the needs of children and families with cancer by focusing on personalized, community- and family-centered strategies.

Key Words

Pediatric Palliative Care, Patient and Family Empowerment, Self-Management, Community-Based Care

1. Introduction

Cancer remains the most common cause of disease-related death in children and adolescents (1). According to the European Commission, it is estimated that in Europe, 14.000 children and adolescents (0-14 years old) received a cancer diagnosis in 2022 (1). More than 81% of those affected manage to survive the illness, still the long-term physical and psychological burdens on the patients and their families persist (1).

In this context, pediatric palliative care comes in as a vital component of cancer treatment.

It has evolved from historically being limited to end-of-life scenarios to a comprehensive approach that goes beyond meeting the physical needs of the sick child.

The World Health Organization (WHO) recommends the early initiation of PPC as a means of addressing symptoms effectively and optimizing well-being at all stages of the disease (2).

Modern PPC combines pain and symptom control with psychosocial, emotional, and spiritual support.

However, access to and understanding of PPC still varies widely across Europe. Many families face structural, educational, and emotional barriers in managing their sick child's care. Misconceptions about PPC, limited empowerment resources as well as language and cultural barriers often hinder families from engaging confidently in care decisions.

Empowerment is defined as the process of enabling patients and caregivers to gain knowledge, confidence, and autonomy in the management of their disease. This concept is closely linked to PPC and has been increasingly recognized as a key element in improving patient outcomes.

As future health systems face growing demands and limited resources, research on supporting families in becoming caregivers at home becomes increasingly important.

My research was guided by four objectives:

- Explore existing measures of Pediatric palliative care and empowerment
- Assess the experiences and needs of families receiving Pediatric palliative care
- Identify current barriers
- Develop practical recommendations

A systematic literature review was conducted alongside qualitative interviews with parents of children who received PPC in Germany. These perspectives offer insight into how informed decision-making, practical training, and emotional support influence the outcomes of care.

The thesis aims to evaluate how patient and family empowerment can improve care outcomes for children with cancer. It aims to provide practical knowledge and recommendations that can enable families to gain knowledge, skills, and confidence needed to be equal partners in the care of their child.

2. Description of the Method of Searching the Scientific Literature

A systematic electronic literature search was conducted to identify relevant scientific studies on empowerment in Pediatric Palliative Care. PubMed, Google Scholar, and UpToDate were the databases selected to research relevant content for the literature review.

Search was limited to articles with free full text availability provided by the previously mentioned databases.

Search terms were collected based on the research focus and included a combination of free-text keywords and subject headings such as “pediatric palliative care”, “empowerment”, “family-centered care”, “decision making”, “communication”, and “parental involvement”.

Some inclusion and exclusion criteria needed to be defined in order to refine search results on the topic and ensure topicality and relevance.

Inclusion criteria were defined as: Studies published between 2014 and 2024, peer-reviewed articles, focus on children and adolescents (0 - 18 years of age), exploration of empowerment strategies or related themes (e.g. communication or shared-decision making), articles published in the English language.

Exclusion criteria were editorials, and published studies that were not related to palliative care in pediatrics or patient empowerment. Articles that were published before 2014 or were not published in English language**.**

Full texts of potentially eligible studies were retrieved and assessed according to my criteria. Reference lists of found publications were also screened to identify additional studies that were not captured in the initial database search. A total of 34 articles were included in the final review.

3. Palliative care in pediatric cancer

3.1 Definition of Pediatric Palliative Care

Pediatric palliative care is a specialized medical field that addresses the needs of children with life-threatening or life-limiting conditions. The word palliative is derived from the Latin term "to cloak" or "cover,". It emphasizes providing an additional layer of support and care for patients facing critical illnesses. Its purpose is not solely to treat physical symptoms but to address all aspects of the well-being of a patient (3).

The American Academy of Pediatrics (AAP) also defines pediatric palliative care as a comprehensive approach. It includes the management of physical symptoms such as pain, nausea, dyspnea, and many others, as well as addressing the psychosocial issues and needs of the children and their families (4).

Central to palliative care is the principle of compassion, another term rooted in the Latin words com (together/with) and pati (to suffer) (5). Suffering is the primary concern in palliative care. People experience suffering in many ways while navigating the course of a critical illness. It may include, for example, pain, fear, sadness, loneliness, anxiety, hopelessness, uncertainty, or loss. According to a famous palliative care philosopher Eric Cassel in “Diagnosing Suffering: A Perspective.” 1999: “Suffering is a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted. It lasts until the threat is gone or integrity is restored.” (6). This definition highlights that components of suffering can be multifactorial, and include physical, emotional, psychological, and spiritual dimensions.

Not one single specialist can cover all these components on their own. That is why a multidisciplinary, team-based approach is crucial in pediatric palliative care to address needs holistically.

As commonly misconceived, palliative care is not just end-of-life care and can not only be introduced at the final stage of a disease (7). Palliative care focuses on improving the quality of life for individuals with serious or chronic illnesses (7). Regardless of which stage of the disease the patient is in or the prognosis of his or her disease. It can be provided alongside curative treatments (7). PPC is designed to address physical symptoms, emotional and psychological well-being, and spiritual needs throughout the course of the illness (7).

For children, pediatric palliative care may begin at the time of diagnosis, which can even mean before the child is born, when conditions such as anencephaly or severe genetic or metabolic disorders are diagnosed prenatally (8). It may continue throughout recovery or during long-term management of chronic conditions (8).

Pediatric palliative care includes a variety of interventions. These interventions, of course, include symptom management, such as pain relief and control of nausea or fatigue to ensure physical comfort. Emotional and psychological support is provided through counseling, music, and play therapy, as well as other techniques (7). Newer techniques include legacy interventions or animal-assisted interventions (7).

Spiritual care, tailored to the family’s beliefs, addresses existential or spiritual concerns.

The coordination of all these services also plays a major role in palliative care that should not be underestimated. The children's clinical pictures are often so complex that they must make use of many of the mentioned services. To ensure smooth transitions between different services and settings of care, they need to be coordinated (7). This process is also part of palliative care that cannot be underestimated (7).

3.2 Key concepts of pediatric palliative care

As palliative care comes in at a very vulnerable stage in the life of a patient and their family, some key concepts are necessary for healthcare providers in order to follow the meaning of optimal palliative care.

Communication (Involving/Engaging the child/patient)

Communication is critical and is a cornerstone to being a good clinician in any field of medicine. A famous quote by Dr. Eric Cassell, a palliative care philosopher, states: “Similar to scalpels for surgeons, words are the palliative clinicians’ greatest tools. Surgeons learn how to use their tools with extreme precision because any error can be devastating. So too, should clinicians who rely on words.” (9). It highlights the importance of communication in palliative care. Even though no patient or family ever wishes to receive a cancer diagnosis, some may find relief by learning the cause of their Child’s symptoms. A clear diagnosis and a defined treatment plan from a trusted healthcare provider can help patients and families (10). It can make them feel empowered to engage in treatment and care and prepare for the journey (10).

The goal of good communication is to take away insecurities and help children not feel alone (10). It is important to take questions and concerns seriously even though there may not be an immediate answer (10).

Communication should be culturally appropriate, honest, child-centered, developmentally appropriate, timely, and linked to concrete experience (7). Effective communication is associated with improved quality of life and is essential for promoting and facilitating shared decision-making between healthcare providers, patients, and families (7).

Compassion/ Therapeutic Alliance

Compassion is also an important aspect of pediatric palliative care. It includes shared therapeutic goals and meaningful personal relationship among the healthcare provider, family, and child (7). Developing a therapeutic alliance is extremely important, as it sets the foundation for helping to guide families through the trajectory of an illness (8). This alliance must be built on professionalism and trust for all team members. The families bring unique knowledge about their child's preferences and needs. A strong therapeutic alliance is associated with better treatment satisfaction, illness coping, quality of life, and improved adherence to treatment (7). Non-adherence to treatment has been reported to be a major issue, especially in adolescent and young adult (AYA) patients (11). Rates of nonadherence in AYAs with cancer have been reported to be up to 60% and are associated with poor clinical outcomes (11).

The clinician's role is to provide education to ensure families fully understand the child´s diagnosis. It's important to explain treatment options while also empathizing with the family's worries and frustrations (7). Regular interdisciplinary team meetings are a good way to address all components of the child's care and strategize ways to improve it (8). Clinicians need to support pediatric patients' autonomy needs and help them to take responsibility for proper areas of care. As a result, studies have supported reduced decisional regret and improved psychosocial outcomes in families (7).

Decision-Making – Goals of Care

Another essential aspect is establishing and understanding the goals of care. Collaborative goal setting ensures that the treatments are in line with the values and priorities of the patient and the family. Without setting clear goals, there is a risk that clinicians perform interventions, that while medically possible and reasonable, do not serve the patient's best interest (7). Open discussions about uncomfortable topics such as: resuscitation orders, preferred location of death, or experimental treatments are crucial (8). Research supports that having end-of-life discussions with AYA patients and their families leads to greater congruity between what the patient needed and what the families thought they would need (12). A study indicated that half of end-of-life conversations occurred in the final 30 days prior to the death of the patient, leaving very little time for preparation and modification (12). Half of the patients included in this study died at the hospital despite findings that the patient would have liked to have died at home (12). Therefore, it is essential to engage in these conversations regularly and evolve with the changing situation and mental state of the child. Clinicians must offer constant support for decision-making to help families sift through difficult and painful choices (7).

Navigating Hope

Hope is an integral part of pediatric palliative care. It can serve as an emotional coping mechanism as well as a source of strength (13). Hope provides purpose, fosters connection, and enhances quality of life (13).

A 2022 study revealed that clinicians that supported hope, empowered parents which may be associated with longer-term outcomes including increased quality of care and lower rates of treatment abandonment (13).

Maintaining a balance between hope and realism is necessary. Clear communication that is adjusted to the cultural and spiritual needs of the family is essential (13). It must be ensured that families feel supported without creating false expectations.

End-of-Life Care/Opportunities for Legacy

End-of-life care in pediatric palliative practice involves creating opportunities for legacy-building and meaningful reflection. Legacy-making interventions focus on actions to be remembered (7). They can help seriously ill children and their families cope with illness and end-of-life. Children facing terminal illnesses often worry about being forgotten and leaving loved ones behind (7). They may engage in activities like writing letters, drawing, or communicating important messages to address unfinished business (7).

It is important to help children, and their families make lasting memories, whether through fulfilling last wishes, such as traveling or creating different kinds of art, or spending quality time with loved ones (10). Clinicians also play a crucial role in addressing mutual pretense, a common coping mechanism, where parents and children may avoid discussing the reality of death to protect one another (10). Facilitating open and honest conversations allows for deeper connections and provides emotional relief (10).

Regret (Anticipatory Guidance)

There is a need to prepare families for the possibility of incurable illness, disease progression, or death to avoid regret (14). It is the clinician’s responsibility to help families make informed decisions. It is necessary in order to prevent feelings of regret about treatment decisions, location of the child’s death, or missed opportunities for farewell (14). According to research, parental regret can heighten stress levels, increase anxiety, reduce quality of life, and even heighten mortality rates in bereaved parents (14). Clear guidance and emotional support can help to minimize these long-term consequences (14).

Grief and Bereavement

Finally, pediatric palliative care recognizes the importance of grief and bereavement support. End-of-life physiology can be highly distressing and hard to understand. Expected end-of-life symptoms (grimacing, agonal breathing, decreased level of responsiveness) must be explained (10). A good symptom management plan is crucial for the highest level of comfort. Often parents express fears of abandonment by Healthcare providers when the goals of care shift from cure to comfort (10). Healthcare providers should make an effort to assuage these fears. Factors such as timing and manner of death affect parental grief (10). Families coping with the loss of a child face a profound and enduring sense of loss, described as living with “a hole in their heart” (15). Research has shown that the quality of relationships and communication between healthcare providers and families significantly can have a significant impact the process of grieving (15). Positive experiences with care teams can provide comfort and healing. At the same time, negative interactions may exacerbate grief. Institutions also play a significant part in supporting grieving families. Through sharing resources and ongoing connections, professionals help navigate their journey of grief (15).

In conclusion, pediatric palliative care is an empathetic, multidimensional approach to care. It seeks to provide comfort and alleviate suffering while honoring the individuality of each child and family. Through good communication, collaborative decision-making, relationship-based care, and ongoing support, it aims to reduce suffering even in the most challenging circumstances (9,10).

3.3 Current challenges in Pediatric palliative care

Despite the many established benefits, many children and adolescents with cancer still do not have access to palliative care. This may be due to geographic, financial, organizational, or individual constrains.

Difference in Palliative care in pediatrics versus adult care

As recognized by the WHO, pediatric palliative care is different to adult palliative care in many aspects. The number of children requiring this care is relatively small. Many conditions are rare and specific to childhood (16). Unlike in adults, children's illnesses may require palliative care for varying durations ranging from days to years and can affect multiple children within a family due to genetic factors (16). The care focuses not only on the child but also on supporting the entire family, as parents often take on complex caregiving roles, especially for technology-dependent children (16). Additionally, children continue to develop physically, emotionally, and cognitively despite their illness (16). This makes age-appropriate communication, education, and play critical, with education remaining a legal right in many countries (16). Special training for healthcare providers is therefore needed to address these needs specific to children.

Limited availability of services

One major barrier is the limited availability of these services. Pediatric palliative care is a relatively new and growing field, but specialized programs are not always sufficiently distributed (17).

Research supports that in many countries, children's care needs are not sufficiently addressed and families do not receive the support needed. (17). Especially in pediatric cancer, clinical pictures and needs for care are very unique. Therefore, the type of palliative care needs to be tailored to the individual situation. Various types of services offer distinct types of support in different settings.

The Atlas on Palliative Care in Europe published by the European Association of Palliative Care (EAPC) provides a map showing the distribution of different types of PPC services in Europe (17).

There are three categories of services: hospice inpatient services, home care and hospital-based services.

21 European countries reported having inpatient hospices, 27 had hospital PPC programs and 29 home care programs. Germany, United Kingdom, and Netherlands show robust representation across each of the categories. Poland stands out for having a high number of home care services. The opposite holds for Eastern and Southeastern European countries like Romania as well as Bulgaria whose profiles are being dominated by hospital care with little or no home care services.

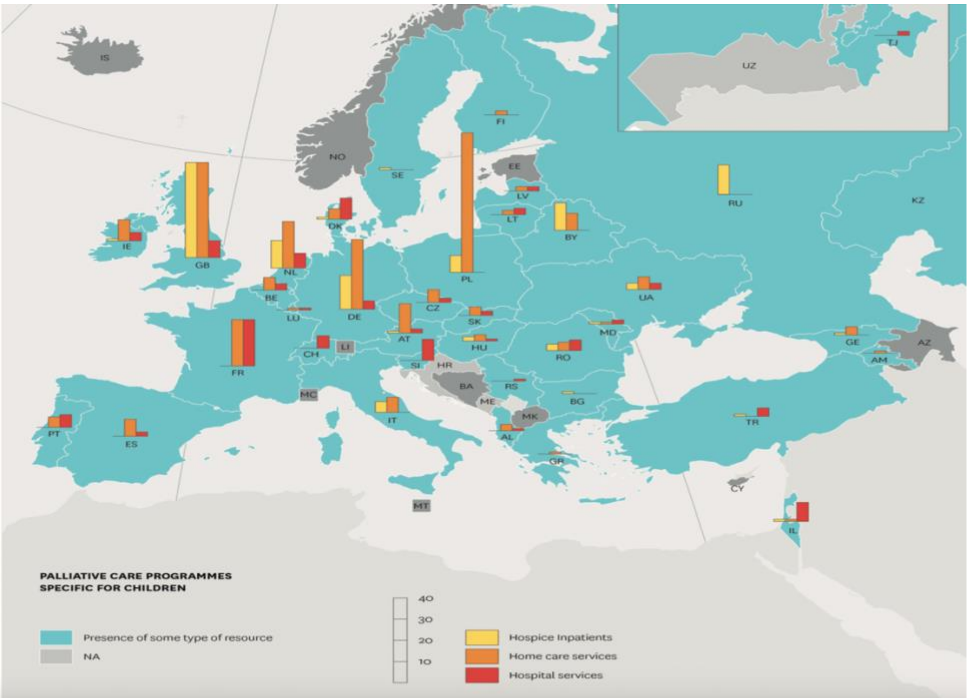

Figure 1. Distribution of PPC services in Europe (17).

Many healthcare providers are not trained specifically in pediatric care. The Atlas on Palliative Care in Europe published by the European Association of Palliative Care (EAPC) published in 2019 has shown that training in the specialty is available for doctors in fourteen countries in Europe (17). For nurses it is available in sixteen European countries (17). It shows that there still are major gaps in the WHO Europe region where pediatric palliative care is not available.

In addition to this, the population of children with life-limiting or life-threatening conditions is changing. Children with life-limiting conditions living longer is a great achievement (18). It must be noted that, as these children live longer, they have increasing needs for healthcare e.g. medical technologies such as long-term home ventilation and gastrostomy tubes. The increase in survival may result in an increased need for palliative care services. Identifying and assessing what resources will be needed in the future requires extensive research, solid data and careful analysis (17).

Financial Barriers to Pediatric Palliative Care in Europe

Access to pediatric palliative care in Europe is influenced by multiple different factors. Financial constrains are a significant challenge for many families. Many European countries provide well-structured healthcare systems that cover essential medical services. Still gaps in founding often exclude supportive care elements that are often crucial for the well-being of children with life-limiting conditions (18).

A 2020 study titled "Advances and Challenges in European Paediatric Palliative Care" highlights the financial challenges faced by families seeking PPC. It indicates that despite medical treatments being covered, supportive services such as psychotherapy, respite care, and bereavement counseling may not be covered by standard healthcare coverage. Families therefore have to pay for these services out their own pocket (16). It can only be possible if they are financially able. Children from families that are not able to pay for themselves are deprived of these services. This pressure creates another source of stress during an already challenging time (16). Besides that, families are frequently burdened with more indirect costs. These include travel expenses for accessing specialized palliative care facilities, accommodation costs when care is provided far from home, and the need for specialized medical equipment which also may not be covered by national healthcare programs. Again, limiting the access to pediatric palliative care for low-income families.

In 2021, a study examined PPC delivery in Romania and revealed the broader financial disparities within Europe (19). It reported that an estimated 139.000 children in Europe fail to receive adequate palliative care due to funding gaps and a shortage of resources. This statistic suggests the urgent need for improved financial support systems in Europe to ensure that families are not placed at a financial disadvantage to obtain necessary care (19).

Experts recommend expanding healthcare financing to make available more financial support programs in the future and, if possible, include essential supportive services that are needed. The goal would be to provide access to all children with life-limiting conditions to the comprehensive and compassionate care they need (19).

Misconception and Lack of Awareness

Another significant challenge is the misconception and lack of awareness about what pediatric palliative care incorporates. Many families and even healthcare providers mistakenly think of it solely as end-of-life care. This creates hesitancy in seeking or recommending these services early in a child's illness. Parents may hesitate to engage in open discussions about end-of-life care with a fear that these conversations about the timeline reflect abandoned hope for a cure (7). They may be in denial and afraid to admit to the possibility of their child's death. By suppressing the conversations, well-meaning parents hope to avoid fear and depression in their children (7). More educational work is necessary to dispel these prejudices.

Language and cultural challenges

Due to globalization and various political situations worldwide, the diversity of cultural backgrounds among patients continues to grow. As this diversity is encountered by healthcare professionals and patients on a daily basis, it is very important to address cultural competence in patient care.

Patients and caregivers from Culturally and Linguistically Diverse (CALD) backgrounds often face significant language and cultural challenges (20). CALDS individuals may have different cultural expectations e.g. in how they comprehend and accept disease, death, and care. This can conflict with the Western biomedical approach, which is based on patient autonomy and full disclosure (20).

Terms like “palliative” or “cancer” might be avoided in some cultures due to association with death or taboo. This can significantly complicate clear communication about diagnosis and prognosis (20).

Language barriers exacerbate these issues. If available, translators can be called in to provide accurate translations. But they can only help with the linguistic part of the conversation as they are not familiar with the patient´s background or the situation in detail. Some patients prefer family members as interpreters, which will inevitably introduce some sort of bias or misunderstanding (20).

Due to a lack of time, it is almost impossible for the healthcare team to explore and honor all differences (7). Providing bilingual services as much as possible is an important initiative for allowing clear and compassionate communication. Recognizing the challenges and improving healthcare professionals' cultural competency can help healthcare providers to better support CALD patients.

4. The role of Empowerment in Patient and family care

4.1 Definition of Patient Empowerment

According to the European Patients' Forum, patient empowerment is defined as a “process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important.” (21).
It involves patients as well as caregivers, both actively participating in the care. Making informed decisions and taking responsibility for managing the disease together are key aspects. The focus of the relationship between the patient and healthcare provider is for it to be equal and cooperative (22).

Pediatric empowerment goes beyond medical outcomes. It is about teaching children and their families to advocate for themselves in healthcare and life. By involving pediatric patients in decision-making early on, they develop skills like communication, critical thinking, and resilience.

Patient empowerment combines self-management with professional support through the course of the disease. When empowered, patients and families are experts in their own conditions (23). They possess invaluable experience about their situation that no one else has. When recognized and nurtured, this expertise becomes a powerful resource for improving care and outcomes (23). The EMPATHIE study was the first initiative founded by the European-Commission to map patient empowerment. It brought out three key areas of empowerment: information/education (health literacy), self-management, and shared decision-making (23).

Access to high-quality information is essential for empowerment. Health literacy is defined as: “The degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.” (24). Providing patients and families with necessary information in a culturally and cognitively appropriate way is the healthcare professional’s duty. Actively trying to understand and familiarize with their condition is the patients’ and family’s duty. Informed patients can seek earlier diagnoses, resulting in more timely and effective treatment (21).

Self-management is built upon partnership between patients, families, and healthcare professionals (HCPs). It involves patients living with their condition while receiving ongoing support. The goal is to help patients feel confident about their abilities and to motivate and empower them to manage their health problems.

Shared decision-making emphasizes an equal partnership between patients and HCPs. Empowerment is not a one-sided process. Patients must also actively inform themselves and participate. But it is equally important for HCPs to be willing to acquire the skills and mindset to collaborate and guide patients. Various tools, such as informational flyers and videos, can help set an informational base for these joint decisions (21).

Additional aspects of empowerment include self-awareness, coping skills, and confidence. According to the EMPATHIE study an empowered patient is defined as one that: “has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes, and self-awareness to adjust their behavior and to work in partnership with others where necessary, to achieve optimal well-being.” (23).

The healthcare professional acts as the important bridge between the patient and the system, helping to make collaboration possible. When patients are empowered according to their unique circumstances and capabilities, they can contribute to the sustainability of healthcare systems by also reducing dependency and improving care efficiency (18).

Especially since cancer is usually a very complex condition, empowering patients and their families is vital for effective pediatric palliative care.

The more families are involved in the decision-making, the more likely they are to understand the treatment process. It leads them to be more willing to adhere to medical advice and engage constructively with healthcare providers (25).

Empowerment also involves strengthening the family's ability to advocate for their child's needs within the healthcare system. When they become more and more familiar with their child's condition, parents will be better able to communicate more effectively. It becomes easier to voice their wishes, concerns, and plans to the healthcare team. Requesting alterations in care plans that are more aligned with the values and preferences of the family can improve the overall quality of care and patient satisfaction (25).

It is important to state that patient empowerment is not only about transferring knowledge. It is about creating an environment where families feel valued and respected. Empowered families are more likely to view healthcare providers as partners rather than authoritative figures. This makes the relationship more collaborative and trusting and therefore allows for better holistic care that addresses the physical as well as emotional needs of both the patient and the family (26).

The increased survival rates of children with life-limiting and life-threatening diseases are both a success and a challenge for healthcare systems. Many systems are unable to deal well with the complex needs of these patients. This can result in families feeling as though they must "fight the system" to receive the care they need (21). Chronic underfunding and a shortage of healthcare professionals are well-known issues in most European countries and exacerbate these issues. However, empowered families - those who can effectively manage health challenges within their communities - are less dependent on external support. They reduce the strain on healthcare resources (18).

4.2 Impact of Empowerment and Community-Based Pediatric Palliative Care on Health Outcomes

Throughout the past years, several studies have shown a significant impact of empowerment-based interventions on both children and parents in pediatric oncology settings (27).

A study published in 2018 examined the effects of community-based pediatric palliative care programs on health-related quality of life (HRQoL), hospital utilization, and the associated costs (27). The findings indicated improved health-related quality of life in pediatric patients. Both the overall healthcare cost and hospital admissions were significantly decreased. These findings show that community-based PPC can lead to more efficient use of resources as well as better health of patients.

Additional studies confirm these findings. A study has shown that home-based PPC services not only improve the quality of life of the patients but also alleviate the burden on the caregiver (26). The care being provided in familiar environments contributes to better overall experiences for patients and families (26).

Parents play a highly engaged role in managing their child's cancer symptoms. Many parents feel overwhelmed with this task. They lack the necessary knowledge and skill to perform care effectively. This can lead to inadequate care, which shows the importance of structured empowerment interventions performed by healthcare professionals even more (27).

Several empowerment programs have been set in place in different countries, designed for the carers of critically ill children. These programs have demonstrated great improvements in parents' knowledge and skills. A study from 2019 reported a significant reduction of gastrointestinal complications in children whose carers underwent training in specialized care programs. Additionally, a study by Krishna et al. found that these interventions also decreased the stress levels of parents as well as improved their ability to provide care and their emotional status (27). These results show the value of empowerment programs by achieving better results for both pediatric patients and their families.

Additionally, studies have proven improved adherence to treatment plans in empowered families. They are more likely to follow medical advice in general as they better understand the ideas and reasons behind it (28).

Moreover, empowerment can allow patients and families to acquire coping skills for different situations. For patients and families, it can become easier to manage the emotional and psychological aspects of cancer through education and skill acquisition. Coping skills can be stress management, problem-solving capacity, or even the ability to seek social or medical help when needed (28).

Family empowerment can also lead to more individualized and patient-centered care. Once they are familiar with the unique needs of their child, families can stand up for them and ensure that healthcare providers implement interventions in a manner that addresses these needs. Personalization can be of valuable utility, particularly in pediatric palliative care.

Since every child's situation and condition are unique, a one-size-fits-all strategy is not effective. Therefore, empowerment is crucial to providing high-quality, customized care for every child.

5. Support for Self-Management in Palliative Care

5.1 Education and Training for Families

Understanding the disease and the treatment options available are the first and also most important components of self-management in pediatric palliative care. Education on these topics should be tailored to the individual needs of each family. Their unique circumstances, challenges, and resources need to be taken into account. Providing clear and accessible information is crucial. It simplifies and demystifies complex medical concepts. This, then can reduce anxiety and set up a collaborative approach between healthcare teams and families (10).

Teaching parents on effective symptom management or emergencies at home is an important way to build confidence and competence in caring for the sick child. This includes training in managing pain, nausea, fatigue, and other symptoms that are prevalent in pediatric cancer patients (7).

Families equipped with these beneficial practical skills can respond promptly to the needs of their child and may reduce the need for hospital visits and thereby improve quality of life (29).

It is widely recognized that the role of healthcare professionals goes beyond delivering medical treatments. To empower families it involves training, regular communication, and follow-up appointments to ensure that families can understand and carry out the care plans effectively. Continuous support and feedback loops help families feel more secure in their role as caregivers (30). The importance of consistency of care must be emphasized. Healthcare professionals need to offer guidance on how to adapt care as the child's condition will evolve and encourage parents to seek help when needed (27).

Integrating educational initiatives into routine care can make learning a part of the caregiving process instead of making it an additional burden. On one hand, learning sessions can be incorporated into regular appointments to not disrupt their daily lives. On the other hand, workshops, informational sessions, and hands-on training outside the routine appointments can not only have an educational but also a social aspect by meeting individuals facing similar challenges (27).

It is obvious that family members often play a crucial role in providing palliative care. Yet public knowledge about the topic is very limited to those who have not experienced this type of care around them. There are some programs in Europe addressing this issue. One of them is called "Last Aid Course". It is designed to inform citizens about end-of-life care in a concise, accessible format (31). It covers themes such as care at the end of life, advance care planning, symptom management, and cultural aspects of death and bereavement.

The course emphasizes the importance of equipping citizens with practical skills and knowledge in a brief but impactful way (31). Besides gaining valuable information, participants also become more engaged in conversations about end-of-life care, promoting death literacy and encouraging social action (31).

The initiative has shown promising results across various countries. Participants reported increased knowledge and feeling more prepared to discuss death, dying, and palliative care with their families and in other social environments (31).

The course was honored in 2015 as it received a prize from German Chancellor Angela Merkel for being one of the best social projects in Germany (31). The success of the course shows the potential to empower communities and improve palliative care at home (31). Since resources for specialized palliative care are often limited, public education initiatives like the Last Aid Course are vital in strengthening community-based support systems.

5.2 Tools and Resources for Self-Management

There are many different tools and resources available for families with different wishes and preferences for care.

Community Services/ Resources

Support groups and other community resources are obvious but invaluable components of self-management. They offer emotional as well as practical assistance to families. By connecting to others who are facing similar situations, families can open up, share insights and solutions, spread encouragement, and learn from each other. This creates a sense of community and solidarity (28).

But these groups can not only serve as emotional support but also as platforms for exchanging information about e.g. local resources, financial assistance programs, and respite care services (28).

The availability of community resources can make a great difference in the possibility for families to manage a sick child's care at home. Where available, local healthcare facilities, non-profit organizations, or groups in community centers can offer a wide variety of services. These could include home visits, trainings, or workshops on stress management and coping strategies (28).

By providing a network of support out of these combined resources, isolation and insecurities often felt by families during difficult times can be reduced (28).

Digital Health Technologies

Digital health technologies are a relatively new field that is constantly evolving and has become more widespread. While Electronic Health Records (EHRs) are already part of standard healthcare in most European countries there are newer technologies currently emerging (32). Virtual assistants and artificial intelligence are finding new uses in healthcare as they become more common and affordable (32). The Covid-19 pandemic has also promoted this development.

Digital health interventions (DHIs) offer promising opportunities for managing cancer symptoms and offer innovative solutions that address systemic gaps to enhance family empowerment (33).

Interactive applications, wearable devices, and educational platforms are gaining more and more attention for their potential to improve patient outcomes (33). They can offer autonomy, especially for children, while also ensuring safety and support. They offer the possibility of patients and families being able to learn about their conditions and even directly communicate with healthcare providers.

These tools not only allow for ongoing monitoring and therefore earlier interventions but are also especially important in community contexts or settings where direct medical supervision may not always be conveniently available (34).

There is a wide variety of services available that provide valuable insights, such as real-time information on symptom management, medication schedules, or emergency protocols.

The use of electronic patient-reported outcomes (ePROs) allows for real-time data collection, which provides a deep insight into the current status of the disease and also enables an improved management of adverse effects and symptoms (34). This ability to self-manage symptoms through digital tools has been shown to reduce distress and improve overall well-being (33).

Digital apps, such as the Pain Squad+ offer the possibility to complete a digital pain journal. Results help HCPs understand the location and nature of pain and identify which medications are helping, and to what extent. Research supports that the app has reduced pain intensity and improved symptom management among adolescents (33).

When used, these tools transform children from passive care recipients into active partners. Evaluation of results can enable customizable alert thresholds for concerning symptoms and provide visual data trends that can be a solid base for discussions about adjustments of care (35).

However, the integration of digital health into the daily pediatric palliative care does come with challenges. One of the biggest obstacles is ensuring the tools are understandable, user-friendly, and accessible for families with different levels of technological proficiency (30). Specific education and training for both families and healthcare professionals are necessary to ensure the benefits of these digital solutions. Additionally, there are concerns about data privacy and patient confidentiality.

These questions and concerns must be addressed to build trust and ensure the willingness to use these applications (30).

Despite all challenges, the proven benefits of digital health solutions have made them valuable tools in pediatric palliative care.

Compassionate communities

Compassionate communities are another public health approach to palliative care. It encourages local groups, neighborhoods, and institutions to actively engage in caring for those facing death, loss, or bereavement. The concept emphasizes that “end-of-life care is everyone’s responsibility” (30). Through social awareness, education, and collective action, these communities build supportive networks for people in need. They foster a shared responsibility and therefore empower citizens to provide care and improve the lives of individuals that are facing terminal illnesses (31).

6. Interview Reports

To explore how pediatric palliative care is lived by families and how empowerment is conceived in practice, qualitative interviews with affected parents were conducted. The interviews were semi-structured, which allowed for flexibility in exploring the different perspectives while also maintaining comparability of responses. Due to the sensitive and personal nature of the topic, recruiting participants was challenging. Only a limited number of 3 parents agreed to participate.

The interviews were conducted in the German language as it was the native language of the participants. For the purpose of this thesis, the statements were translated into English. The original meaning is preserved as closely as possible. The interviews have been conducted via telephone. Two have been recorded. One interview could not be recorded. Its content is based on detailed notes taken during and immediately after the conversation. For the purpose of data protection the names of the participating parents are not mentioned.

This study seeks to identify key areas for improvement in pediatric palliative care by analyzing these qualitative findings. There is a particular focus on the topics of communication, family support, and home-based care approaches.

Findings: Perspectives of Parents in Pediatric Palliative Care

The following sections present the findings under four major themes

- Communication and Delivery of Diagnosis
- Understanding of Palliative Care
- Role of Parents and Children in Decision-Making
- Home-Based Care and Hospital Experience

Communication and Delivery of Diagnosis

All parents described considerable dissatisfaction in communication with the healthcare team in some situations. In one case, the initial diagnosis and in another, prognostic information were described as delivered poorly and with not enough empathy. In one case, the news of the terminal phase of the child's disease was delivered shortly before the child's death. Parents expressed a desire for more empathy and clearer, earlier conversations with trusted medical staff. One father described the delivery of the diagnosis as emotionally cold and lacking compassion. One mother strongly emphasized that the conversation about the terminal prognosis came too late. She described that she missed out on opportunities for emotional preparation and time for farewell.

These findings strongly align with literature, highlighting that, clear, empathetic communication is essential. It also reinforces the need for dedicated, trained staff, who has the necessary communication-skills to handle such sensitive conversations.

Understanding of Palliative Care

All parents also indicated that they did not understand the meaning of palliative care at the time of their child's diagnosis. They associated the term only with end-of-life care when all curative treatments have failed. They were unaware that palliative and curative treatments could coexist or that palliative care could be integrated early in the illness trajectory. One father explained that the new, altered meaning of palliative care was never explained to him. After clarifying he admitted: "To be honest I still perceived it that way until today".

There were different treatments and therapies offered on the wards (e.g., art therapy, music therapy, relaxation treatments) that are associated with palliative care. The parents, due to a lack of knowledge, did not identify them as such. All children have received strong pain medication before their deaths, which parents identified as palliative care. This limited understanding may have contributed to confusion or delays in emotional adaptation.

While families were given extensive written information about hygiene, emergency procedures, and medical routines, the amount of materials was perceived as overwhelming. The information about palliative care was perceived as rather small. While all this information was provided in a bulk and during a very emotionally turbulent time, the parents did not pay much attention to the flyers for palliative care services. One father admitted to suppressing the information as he did not want to think about the possibility of his child's death.

Role of Parents and Children in Decision-making

All parents reported feeling actively involved in their child’s care and the medical decisions that were made. They were regularly informed about the process and included in medical discussions. In one case, the mother was a trained pediatric nurse. She was able to take a significant caregiving role. At home, by administering infusions and medications through the child’s chemotherapy port. She reported that her knowledge and skills allowed for frequent, early discharges and therefore an improved quality of life for the family. She explained that on the ward, there were courses available for parents on how to use different types of medical equipment needed to care for children at home. One father who did not work in the medical field and did not have any experience at the time described the task of understanding the disease and making decisions as challenging.

Regarding medical decisions such as chemotherapy options, he trusted the doctors' expertise and refrained from intervening. For decisions involving home care arrangements and additional therapies for their child’s well-being, he was able to include their own wishes and ideas. He appreciated the benefits of care in the hospital in terms of having aspects of daily care and additional therapeutic activities, such as art therapy combined.

In all cases, the parents explained that their children were actively involved in the decision-making about their treatment and daily routines. All children had the freedom to shape their daily routines both in the clinic and at home e.g. decide what additional therapies or activities they would like to participate in.

One father highlighted that his daughter became very familiar with hospital routines, including the order in which her medications were administered. In one notable incident, while receiving chemotherapy, a nurse attempted to administer a medication out of sequence. The daughter stopped the nurse and explained that a prior medication had not yet been given. The nurse acknowledged the mistake and corrected the error. This shows how even young children profit from empowerment and can even be protected from fateful situations. The father stated that to him it was “indispensable” to be involved in his child’s care to be able to watch over and critically analyze the child’s care to avoid harmful mistakes.

Another child explicitly stated the preference for early discharge whenever possible. The parents emphasized that the child’s wish to be home as much as possible was taken seriously by the healthcare team. They felt as if they worked together as a team on achieving this goal. This empowerment had a positive effect on the child’s autonomy and emotional well-being.

Home-based care and care in hospital settings

Parents generally reflected very positively on the periods of home-based care. These phases were described as important for maintaining family cohesion and providing emotional comfort. In one family, the father and mother stayed alternately at the hospital with their daughter and appreciated being allowed to share the caregiving activities. In another family, it was noted that the mother’s medical knowledge enabled a smooth transition to home care and, therefore, increased quality of life. They pointed out that this experience might not be possible for families without this background.

All families described moments of being overwhelmed in clinical settings. One example mentioned by two parents was the large number of professionals from different specialties present during medical rounds (up to 15 in one case). “The room was suddenly full of people” one mother stated. She felt “beaten” by the huge number of people in the room and often did not know who they were. Therefore, she felt unable to ask questions.

The speed at which complex information was delivered in these situations, contributed to feelings of emotional overload. All parents reported they would have wished for calmer and more personal communication. The need for more empathy and time for conversations was expressed clearly.

Reflections on Interview Findings

One of the strongest messages across the interviews was communication. In two cases, the initial diagnosis and then the subsequent prognosis were delivered in a manner that made the families feel overwhelmed or unsupported. The parents expressed a very strong desire for increased empathy and honesty by doctors, especially when delivering bad news. There was also a very strong desire for earlier discussion of the prognosis of the child, to allow additional time to process, adjust, and say goodbye.

All parents also spoke of the importance of being part of caregiving. They needed to do everything in their power for their child. When equipped with the tools and information, they felt empowered and more connected to their child. One mother was a nurse herself and was able to take over medical tasks at home. This allowed the family to spend more time together and contributed to a better quality of life. The second family also appreciated feeling trusted and being part of the decision-making process. For both, this sense of mutual responsibility made the experience feel more human.

The children themselves played an important role as well. The parents explained how their children were asked to be engaged in decisions and understood their routines. These moments exemplified how even very sick children can be resilient, competent, and capable of managing their condition for themselves if they are empowered.

The hospital experience had both positive and negative aspects to it. The family valued the care and support provided to them. However, simultaneously, they voiced their experiences when they were under immense stress, especially with ward rounds and a full room. It was challenging to have questions asked or receive the entire information necessary. The parents required more private, quiet moments where they could process the information and ask questions.

Finally, the families explained how much information they received at times, all at once. They understood the need for this but said that it was overwhelming at such an emotional moment. One parent, who was a medical professional, handled it fine. But others felt lost or confused. They suggested a better method of providing important information, spaced out over time and in simple terms.

7. Discussion

This study shows the growing emphasis on empowerment within pediatric palliative care. While PPC has traditionally focused on end-of-life care and symptom control, current practice integrates emotional, spiritual, and psychosocial interventions from diagnosis onwards. Empowerment adds an additional dimension to this framework. Empowerment facilitates the active involvement of children and families in planning care, managing symptoms, and interacting with professionals.

The findings of the literature review and interviews substantially show that empowered families have a more positive experience and greater emotional coping. They feel more involved and better equipped to manage the difficulties of living with a child's illness. This confirms prior research that has shown greater adherence to treatment and improved quality of life when empowered and trained families are engaged.

However, the study also uncovered some barriers. Many families do not have any perception of what palliative care incorporates. They associate it with the end of a patient’s life only and therefore sometimes hesitate to come forward for assistance. Medical professionals also, at times, don't communicate effectively or in a timely manner. During the interviews, parents had said that they had been told about terminal diagnoses insensitively or at a moment when there was not sufficient emotional capacity, which created emotional consequences.

Another important observation was the emotional strain that families felt in clinical environments. Overwhelming amounts of professionals, disorganized communication, and overwhelming amounts of information led to stress and confusion. Families expressed a clear need for more open, timely, and personalized communication styles.

Children themselves, when actively included in the process of their care, showed resilience and competence. They were familiar with their treatment plans and took part in decision-making about their care. Empowering children at appropriate levels of development strengthens their autonomy and sense of control. This was especially the case when families and healthcare teams felt they worked together as a team.

Community-based care and technology were also crucial factors. Families could appreciate the potential to offer home care. Remote communication and technology platforms for death literacy and tracking symptoms, as well as for education, contributed to more productive care continuity. Public health measures like the Last Aid Course supported increasing awareness and death literacy.

The study demonstrates that empowerment is neither a secondary benefit but rather an integral aspect of effective pediatric palliative care. To achieve enhanced outcomes, health systems must prioritize education, effective communication, training, and integration of the children as well as their families.

8. Conclusion

This thesis examined the role of empowerment in pediatric palliative care, focusing on families of children with cancer. The research was guided by four objectives: To explore the existing measures of pediatric palliative care and empowerment, to assess family experiences, to identify existing obstacles, and to formulate recommendations on how to improve care.

Firstly, communication was noted as being among the most vital and frequently badly managed aspects of PPC. Parents reported that they were being presented with complex or emotional information in blunt, perplexing or insensitive manner. Timing of discussion, especially for prognosis and end-of-life treatment was too late and did not allow families to prepare emotionally or logistically. This resulted in long-term regret and emotional distress.

A clear message throughout the interview was that families require clear, honest information and time to process information and ask questions

Families that indicated they were empowered indicated improved confidence in being able to manage medical systems, enhanced emotional resilience and enhanced ability to care at home. Interviews confirmed that empowerment enabled parents to gain a sense of control during an uncertain time.

Home-based care allows families to care for their children at home, as long as they receive the right training and support. Families in this study described these periods as some of the most rewarding. Tools like pain-tracking apps, online training, and support groups help make home care more effective and less stressful.

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Participation of the child in decisions about their care according to their age and developmental level, was shown to have marked impacts. Children who understood and guided parts of their routine were resilient and even corrected medical mistakes. Empowerment also has to include the voice of the child, rather than just that of the parent.

There are still many challenges. Prejudices, lack of information, and organizational obstacles such as limited budgets and poor training must be addressed. Professional training and education for the public are crucial for improving access and awareness of pediatric palliative care.

In the years ahead, health systems will have to integrate empowerment as a core element of pediatric palliative care. This means investing in caregiver training, digital health technology, and patient-centered care planning. Empowered families are not just more resilient, they are also essential partners in constructing high-quality, compassionate care.

9. Practical recommendations

This thesis investigated the ways empowerment can improve the management of children with cancer and their families in community-based pediatric palliative care. The following recommendations are based on the outcomes of the literature review and interviews.

Pediatric palliative care has shown several benefits in the care of pediatric oncology patients that have been outlined in this thesis. Education on these practices should therefore be integrated more and earlier into clinical practice. Hospitals could establish early referral protocols that automatically involve palliative care at diagnosis. This way families would not have to actively opt for palliative care but still have the opportunity to decline the offer. The automatic involvement could help normalize PPC and allow more families to benefit from it sooner.

Families should be provided with structured, detailed information and education at an early point in the disease course. The fact that the field of palliative care does not only resemble end-of-life care should be clarified in every case as the study has shown that information about the shift in PPC is not yet widespread. Discussions on this topic should be sought several times, as parents may not be able to process all information right away. Parents may suppress the fact that their child is critically ill and, in a situation, where palliative care is necessary. Support must be customized to their needs, language, and educational backgrounds. A lack of time and empathy of doctors in conversations has been clearly identified and criticized by parents. Involving specialized personnel, such as psycho-oncology professionals, is essential. They are not only specifically trained to handle emotionally sensitive discussions, but have more time to hold these conversations, ensuring that families feel heard and supported.

Resources like flyers or short videos can help to allow parents to revise information multiple times and when it is convenient for them.

There remain wide inequalities in access to palliative care across Europe. Low-income and rural households are more affected. More funding for home care, training programs, and outreach is required. While this would mean more expenses for the healthcare systems in short-term, this approach could save costs long-term as multiple studies have shown how family empowerment and home-based care has reduced hospital admissions and reduced cost (29).

Patient and family empowerment has shown several benefits that have been outlined in this thesis. Empowerment strategies should therefore be integrated even more into everyday clinical practice.

My study has shown that generally, families appreciate being able to leave the hospital and take care of their child at home. Therefore, empowerment plays an essential role. Empowerment must be understood not as a secondary benefit but as a clinical goal and should be addressed early. Topics of discussion should cover emotional readiness, decision-making capacity, and confidence in care tasks. This would help tailor support over time and shift empowerment from an abstract idea to a measurable outcome.

To reach the goal of empowerment families need to be trained and educated. More workshops provided in every hospital that offers care for critically ill children must be available, so parents are actively confronted with the possibility of participating instead of having to look for courses themselves.

To evaluate how empowered a family feels over time, short questionnaires could track their abilities. If gaps are identified, support can be provided in a timely manner before critical situations appear.

Electronic Patient-Reported Outcomes such as pain-tracking applications have shown success in the past and should be incorporated to reach this goal (34). As there are still some barriers and concerns about these technologies funding and more research should be conducted to improve these technologies.

Telehealth follow-ups can play a good role in reviewing care skills, answering questions and adjust care plans. Instead of replacing in-person care they can strengthen continuity between hospital and home.

Public education courses like the “Last Aid Course” have shown to help raise awareness and allay fear around palliative care. These education initiatives should be expanded.

The practical recommendations aim to show that targeted changes can make a meaningful difference in pediatric palliative care. They reflect what families themselves have identified as missing or needed. Empowerment must become a standard component of care. Constant improvement supported by technology and education is vital to delivering every child and family care that is compassionate, coordinated, and focused on their needs. By putting high-quality communication, accessible education and family empowerment strategies at the top of health systems agendas, children can receive the care they need in their most vulnerable times.

10. Literature

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