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SUPPORTING FAMILIES WITH CHILDREN AFFECTED BY CANCER

EDUCATIONAL VIDEO FOR
INTERNATIONAL FAMILIES

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ABSTRACT

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This thesis project aimed to develop educational video material tailored to the international families with a child diagnosed with cancer in Finland, addressing the need for comprehensive support and information. The decision to focus on this topic was influenced by the realization of the importance of providing supporting materials for caregivers and family members, particularly considering the average annual mortality of 26 individuals under 20, as reported by the Finnish Cancer Registry from 2012 to 2021. We recognized that there were enough support materials available in Finnish, which could be challenging for international families living in Finland, especially considering language barriers, cultural differences, and access to resources. Therefore, the aimed video resource was in English language.

The project followed an agile project management approach, drawing upon diverse sources to create evidence-based content covering various aspects of childhood cancer care, such as nutrition, hygiene, social support, medication, and vaccination. Through deep research, planning, execution, and evaluation, the project sought to empower families, enhance coping strategies, and foster a sense of community among caregivers. The video material, designed to complement clinical care, aimed to promote informed decision-making, and improve the overall well-being of families coping with childhood cancer. The project was made possible through collaboration with Sylvania and HUS.

Additionally, the project thesis revealed the importance of tailored support services and educational initiatives for international families affected by paediatric oncology. Future research endeavours were proposed to further evaluate the effectiveness of such interventions and inform the development of evidence-based support services in the field of paediatric oncology.

Keywords: childhood cancer, pediatric oncology, international families, educational video material, comprehensive support, evidence-based care

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ABBREVIATIONS

WHO - World Health Organization

HUS - Helsingin yliopistollinen sairaala

CNS - Central Nervous System

PDCA - Plan, do, check, act

SAMK- Satakunnan ammattikorkeakoulu

TENK - Tutkimuseettinen neuvottelukunta

1 INTRODUCTION

Cancer is a large group of diseases which could occur in any organ or tissue of the body because of abnormal and uncontrollable cell growth. The cells spread and invade the adjoining body parts resulting to complications. It is widely known that cancer is among the major reason of death in the world. (WHO International Agency for Research on Cancer). However, it's heartening to note that advancements in cancer care and interventions have significantly improved prognosis. With innovative treatments and dedicated medical teams, many individuals are experiencing more positive outcomes in their battle against cancer. (Shams, et al., 2023.)

Cancer as a disease in childhood is rare and the types vary compared to adults. According to the World Health Organisation, the worldwide estimate of cancer development in children is approximately 400,000. The common types include blood related cancer, brain cancer, lymphatic cancers, and solid tumours, like neuro-blastoma and Wilms tumours, also called nephroblastoma (WHO International Agency for Research on Cancer). According to the data of cancer society of Finland, the nationwide diagnosis count of childhood cancer is approximately 150. The breakdown of the total is about 80 male and 70 female children. There is a significant improvement in the relative five-year survival rates since 1970s. The recent data shows that four out of five children diagnosed with cancer survive for at least five years (Website of Cancer Society of Finland). About 7 000 people in Finland have a history of cancer under the age of 25 years. Majority of childhood cancer survivors become victims of complicated physical or psychosocial issues in life later. (Cancer Society of Finland). The above data and statistics show the importance of this topic in the sector of modern health science.

When a child has cancer, the effect does not just remain within themselves. It affects the whole family. Parents, brothers, sisters, and even other family members feel the emotional stress and face new problems. Things like getting to appointments, managing work and school, and just daily life become harder. Everyone has to adapt to these changes together. (Childhood Cancers - NCI. n.d.) In paediatric oncology, "family" encompasses not just biological relatives but also caregivers, close friends, and other support networks crucial for the child's well-being and resilience throughout treatment. These families play an important role from providing emotional support to advocating for their needs, assisting with medical care, and managing day-to-day activities, their involvement significantly contributes to the well-being and overall quality of life of the child throughout the cancer treatment journey. (Kästel & Enskär, 2014.)

The purpose of the project thesis is to create supporting video material for international families with children battling cancers. The project's goal is to provide information and guidance through video on paediatric cancer to those families whose child has a severe diagnose to support their daily living. The material will be published in English language as it targets to international families living in Finland and considering the fact that English language ensures the global accessibility.

Our cooperation partner of this thesis is Sylva ry and Helsingin yliopistollinen sairaala (HUS). Sylva ry is a daily companion, guardian, and supporter of paediatric cancer patients. They offer a community of peers, events, and professional support. When a child, teenager or young adult gets cancer, both the patient and their loved ones need practical information and support at different stages of the treatment path. Sylva ry offers support and activities to families of children and adolescents with cancer. (Sylva ry, n.d.) Similarly, Helsingin yliopistollinen sairaala (HUS) plays a vital role as Finland's largest healthcare provider. HUS specializes in arranging specialized medical treatments within the Uusimaa region and manages care for numerous rare and complex diseases nationwide, including paediatric cancers. Collaborating with organizations like Sylva ry and HUS ensures that children with cancer receive comprehensive and expert care tailored to their unique needs,

providing hope and support for families facing these challenging circumstances. (HUS Comprehensive Cancer Centre, Annual Report 2018.)

2 THEORETICAL BACKGROUND

2.1 Children diagnosed with cancer

Childhood or pediatric cancer refers to the contingency of cancer in children and adolescents, encompassing various types of malignancies. The age range for “paediatric” vary slightly depending on the country. American cancer society defines the occurrence of cancer from birth to 19 years as paediatric cancer. Same age range will be taken into consideration in the thesis. Paediatric cancer remains a significant health concern worldwide, but advancements in diagnosis, treatment, and supportive care have improved outcomes over time. (Website of American Cancer Society.)

Childhood cancer encompasses a range of malignancies that affect children and adolescents, typically under the age of 18. Among the most prevalent types are leukaemia's, which involve unusual growth of non-typical leukocytes in the blood stream and bone marrow. Brain and Central Nervous System (CNS) tumours, whether benign or malignant, can develop in various areas of the brain or spinal cord, impacting neurological functions. Neuroblastoma is another childhood cancer, often originating in the adrenal glands and potentially spreading to nerve tissues. Wilms tumour, a kidney cancer predominantly found in young children, typically emerges in preschool-aged individuals. Lymphomas, including Hodgkin lymphoma and non-Hodgkin lymphoma, affect the lymphatic system. Sarcomas, such as Ewing sarcoma and rhabdomyosarcoma, manifest in bone and soft tissues like muscles and tendons. (Website of American Cancer Society.)

On average, 233 people of the age below 20 are diagnosed with cancer in Finland. The following table shows the average record of childhood cancer diagnosed in Finland from the year 2012-2021. The most common among them are leukemias with an average of 54, lymphomas with an average 39 and brain and central nervous system tumors with an average of 51 cases diagnosed each year.

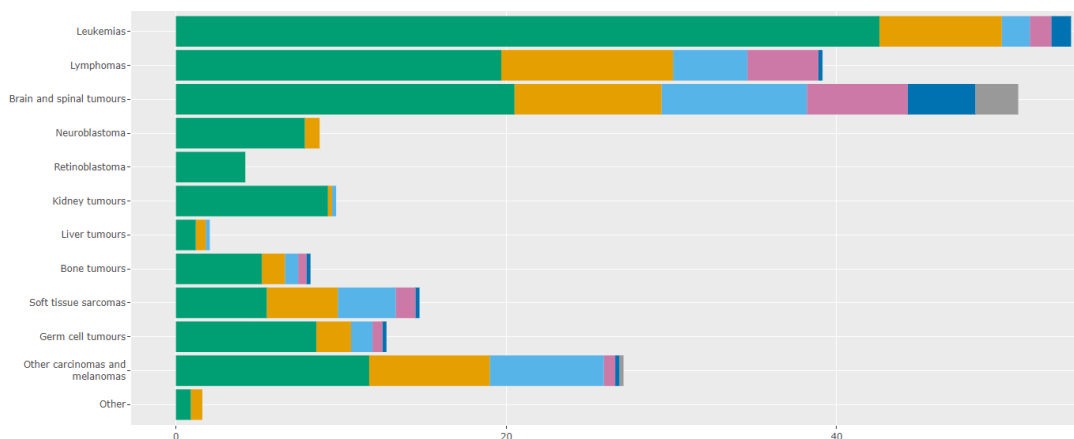


Figure 1: Common Childhood cancers in Finland (2012-2021) (Source: Finnish Cancer Registry)

The causes of childhood cancer are often complex and multifactorial. In many cases, the exact cause is unknown, and cancer is assumed to occur from a combination of various factor such as gene and environment. Some genetic conditions may predispose children to cancer, while exposure to certain chemicals, ionizing radiation and infections are potential environmental factors. (Zahnreich & Schmidberger, 2021.)

There are diverse cancer treatment modalities available. The specific interventions administered to a paediatric patient are contingent upon the type and stage of cancer. Common therapeutic approaches encompass surgery, chemical therapy, radiotherapy, immunotherapy, and stem cell transplantation. The selection of a particular treatment is determined by the unique characteristics and progression of the cancer in the child. (Zahnreich & Schmidberger, 2021.)

2.2 International Families Living in Finland

Family is a fundamental social unit that typically includes parents and their children, united by emotional bonds, mutual support, and shared values (Parsons, 1955). It serves as a primary context for socialization, where a person learns social morals, roles, and behaviours (Bronfenbrenner, 1979). Family is responsible for providing emotional support and love. These feelings and a sense of belonging contribute to the well-being and development of the family members (Conger et al., 2010). They play a significant role in mounting individuals' identities, relationships, and overall life experiences (Fiese et al., 2002). The term “family” in our thesis will refer mostly to parents of the cancer affected child. In the absence of parents, the term refers to the closest guardian of the child.

In Finland, the societal landscape is enriched by the presence of international families, often termed expatriate, whose numbers have steadily increased in recent years (Migration Institute of Finland, 2022). These families face unique challenges in adapting to a new culture, language, and societal norms, particularly during critical life events like dealing with health issues such as childhood cancer.

The Finnish Immigration Service provides crucial resources aimed at assisting international families in integrating into Finnish society (Finnish Immigration Service, n.d.). However, studies conducted by the University of Helsinki's Institute of Behavioural Sciences indicate that navigating Finland's healthcare system remains challenging for international families, primarily due to language barriers and differences in healthcare practices (Mustajoki et.al., 2020).

For families with a child battling cancer, the Finnish Childhood Cancer Association offers valuable support and guidance, catering to the needs of both Finnish and international families (Finnish Childhood Cancer Association, n.d.). Yet, providing educational material specifically targeting international families living with a child diagnosed with cancer may require tailored

approaches considering language barriers, cultural beliefs, and access to personalized information. Understanding the distinct needs and challenges faced by international families in Finland, especially in the context of healthcare and support systems for a child with cancer, necessitates a holistic approach. This approach should encompass considerations for cultural diversity, language accessibility, and the provision of tailored resources to ensure equitable support within the Finnish healthcare framework.

The number of international families living in Finland is growing steadily. As of 2022, over one hundred thousand families live in Finland, who use the language other than Finnish, Swedish or Sami at home (Tilastokeskus, n.d).

Families 31.12. by Year. FOREIGN LANGUAGES, TOTAL, Families.

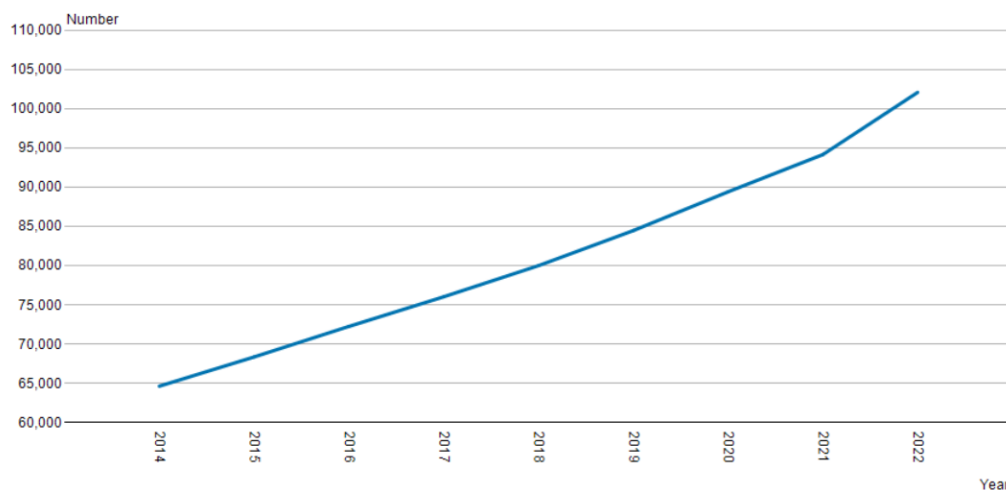


Figure 2: International Families in Finland (2014-2022) (Source: Tilastokeskus)

2.3 The Impact of Childhood Cancer on Families

The typical activity and schedule of entire family could be affected after the diagnosis of paediatric cancer. Immediate stress is likely to be seen in the diagnosed child and other family members. Though some families could be more emotionally attached in the tough situation, in a long run, emotional distress, anxiety, post-traumatic stress could occur. Problems could arise in cohesion and conflict may occur. There could be adaptability and

communication issues. Support system and overall family functioning may get deviated (van Schoors et al., 2015).

Families dealing with childhood cancer often face emotional and psychological challenges. The diagnosis, treatment, and uncertainties can take a toll on parents, siblings, and extended family members. (Bindsbergen et al., 2021.)

The financial implications of paediatric cancer for parents can be considerable. The costs associated with childhood cancer treatment, including medical bills and travelling will come as additional expense for the families. This strain could result in psychosocial consequences. In attempting to manage the financial burden, parents may engage in risky financial practices which could worsen the overall family situation and generate negative outcomes. (Santacroce et al., 2018.) Paediatric cancer significantly impacts school attendance, learning, gaining experience, and also the educational results, which impacts the life even after the treatment. It is needed to clarify the specific barriers and should be communicated with the education facilitators and after cancer treatment. Analysis and evaluations of the successful intervention is necessary. (Bryan et al., 2021.)

In the modern world with improved treatment possibilities, approximately four out of five children with cancer survive after five years. There exists a chance of severe somatic late effects. Other difficulties the family may need to go through are the socioeconomic difficulties when the child reaches adulthood. Competing with a healthy individual could be very challenging for the individual who has grown up with serious cancer related complications. There could be a contrast in personal qualifications and available opportunities. (Erdmann et al., 2021.)

2.4 Home Care for Paediatric Cancer

Caring a cancer patient at home is a challenge for parents and other family members. When it comes to child, it could be more stressful. Physical and emotional changes due to the existing sickness and medications could worsen the situation (Website of Cancer Council, n.d.). Nutrition, along with hygiene, social life, and medication/vaccination, forms an integral part of home care for paediatric cancer patients. According to oxford dictionary, "Nutrition is the process of providing or obtaining the food necessary for health and growth. (Oxford Dictionary.)" It is a three-part step process from consumption to break down and fuelling of the body. Consumption of food and drinks consisting of essential nutrients in a required amount is necessary for proper nutrition. (Website of American Cancer Society, n.d.)

Regardless of the deviation in appetite, nutritional needs of cancer affected children could be higher than the needs normal children. Nutrients like protein, vitamins, minerals, and healthy fats are needed for growth and repair, healing from therapies, and maintain the energy level and immunity of the body. Keeping the child hydrated is extremely necessary to avoid dehydration as the body could lose water through different means like vomiting and diarrhoea. (Website of Numerous Kids Health.)

Similarly, hygiene refers to the action or practice of cleanliness for avoiding diseases and maintaining good health (Oxford dictionary). Improved hygienic practices are necessary while caring cancer patients. Keeping up with a good hygienic habit in the family reduces infection risks to the children with reduced immunity. Proper cleanliness practices from both care giver and care receiver are vital during cancer care. Cleanliness of skin, hair, oral areas, and nails are the most important aspects. Hand hygiene of caregiver while assisting the patient is crucial. (Website of Leukaemia & Lymphoma Society.)

Social life plays a fundamental role in shaping the quality of life. Social interaction and connection fulfil essential psychological needs, including the need for belonging, companionship, and support. Studies in psychology and

sociology have always highlighted the positive role of social relationships on mental and emotional health. Strong social ties often contribute for lower rates of depression, anxiety, and loneliness. (Holt-Lunstad et al., 2010.) Maintenance of meaningful relationships supports in making distraction from worries and fear caused by cancer. A good social life catalyses the feeling of positivity and helps to develop the sense of normalcy. (Stanton et al., 2007.)

Medication and vaccination are critical elements of childcare. Proper medication and vaccines protect children from diseases, manage illnesses, and promoting their overall well-being and support physical and mental growth and development. (Sung et al., 2001.) Immune system is likely to be suppressed during cancer treatment. Vaccinations are usually kept on hold during chemotherapy. Killed vaccines may not be danger to the children but live viral and bacterial vaccines are suggested to be deferred until the immune system comes back to normal. It may take up to three months from the completion of therapy. (Sung et.al., 2001.)

3 PURPOSE AND OBJECTIVE OF THE PROJECT

The purpose is to create video material for international families whose child is diagnosed with cancer. The project goal is to provide information and support families who have children diagnosed with cancer at home.

4 PROJECT PLAN AND IMPLEMENTATION

The project is designed to address the need for educational resources for families in English language on paediatric cancer care in Finland. Through our research, it became evident that there is a significant gap in accessible guidance for family caregivers of paediatric cancer children's, particularly for

those who primarily understand English. In Finland, a majority of patient instructions and educational materials are available only in Finnish, leaving English-speaking caregivers with limited support.

4.1 Methodology

A project method encompasses a collection of principles, tools, and techniques designed for the planning, execution, and management of projects. It supports project managers in guiding team members and overseeing tasks, all while promoting team collaboration. (Westland, 2021.) Agile method implementing PDCA (Plan, do, check, act) development tool is followed in the project. Agile project management is a dynamic and cooperative approach for team self-organization. In the agile methodology, project planning and work management are flexible and evolve over the course time, aiming for early delivery and remaining open to changes that enhance processes. This method is both rapid and adaptable. (Website of Tech Target Network). The PDCA cycle is better viewed as an ongoing loop rather than a process with a defined start and end point. Each improvement made to a product or process sets a new baseline, emphasizing the importance of continuous improvement as the core principle of this methodology. (Website of Lean Enterprise Institute, n.d.).

Agile methodology and the PDCA cycle are chosen in the thesis project because this offers a flexible and target-centric approach, allowing the scholars to adapt to evolving needs and prioritize feedback from international families coping with childhood cancer. Agile's iterative development aligns well with the project's goals, and the PDCA cycle ensures continuous quality improvement. Additionally, Agile promotes efficient risk management and stakeholder involvement, making it an ideal choice to create impactful educational material in this sensitive and dynamic context. (Application Of Plan-Do-Check-Act Cycle for Quality and Productivity Improvement - A Review, 2017.)

4.2 The stages and timetable of the project

The project has been split into five main parts called stages. A special goal is reached in each step to reach. The stages were research, planning, executing, finalizing, and handing it over. The project is initiated with research. All the required information for the project has been gathered and a systematically listed schedule was set. This helped the authors to create a plan with a mind map of necessary actions. The execution stage went through process of making script, video, editing and finalizing. The draft thesis work was done in parallel. As the video was approved by the supervising teacher, the thesis was written and finalised. After self-review, it was submitted following the thesis instructions provided by SAMK. To keep everything on track and on time, PDCA model is used. It has the four steps, Plan, Do, Check, and Act. The five stages of the thesis were blended into 4 steps of PDCA model as shown in Table 1. The following target timetable was set which deviated due to the unforeseen situations during the project execution.

Table 1. PDCA table of this project thesis

PDCA	Stage	Date	Action
PLAN	Kick-offs Stage	01.09.2023- 01.12.2023	Meetings involved with thesis supervisors and other parties involved directly and indirectly
	Project Plan	01.09.2023- 01.12.2023	Preparation of documented thesis plan and proposal SWOT analyses
DO	Research Stage	01.09.2023- 30.09.2023	Launch research, Search database, select articles, Review
	Project Planning	01.10.2023 -2.1.2024	Collect theories and information, Prepare content for video,
	Execution	02.1.2024 - 15.2.2024	Shoot video, design, and edit, create draft video, own internal analysis,

			implement necessary correction, prepare draft thesis
CHECK	Finalizing	15.2.2024- 30.3.2024	Create final version of the video, Complete thesis report and submit final draft of thesis.
	Evaluation	30.3.2024- 29.05.2024	Present video, Self-evaluation, and review. Peer, thesis supervisor and SYLVA comments Refinements based on the feedback and comments
ACT	Handover	05.06.2024	Submit Thesis and Publish video. Improve self-competence, disclose areas for improvement and further studies.

4.3 Resource and Risk management

Resources in a project or research refers to various assets, materials, and means that are required or utilized to conduct the study or complete the project. Resources can be classified into different categories. Among them, most common resources are economic resources, manpower, information resources, materials and physical resources, and institutional resources. (Watt et al., 2014.)

As information resources, the project thesis has collected information available in different freely available literatures and articles from various databases, e.g. Google scholar, Finna, PubMed and Science direct. The literature review and retrieval methodology involved a comprehensive search across multiple databases, as outlined in Appendix 1, which catalogues the keywords utilized and the corresponding databases searched to ensure a thorough selection of

relevant literature. Information from web pages of genuine cancer related organisations is also taken into consideration. Financial resources are not considered in the project as the arrangement of physical resources are organised by the thesis authors. The used physical resources were electronic devices, laptops with software for video editing, mobile phones, cameras, and accessories for filming. The authors fulfilled the requirement of human resources used for making the video material.

Project risk management involves proactively identifying, assessing, prioritizing, and addressing potential events or circumstances that could negatively impact a project. The objective of risks management is to protect and create value by understanding and managing risks related to strategic decision-making, project execution, and change. This is done through various tools and techniques to anticipate and monitor risks throughout the project lifecycle, ultimately optimizing outcomes. (Watt et al., 2014.)

One of the common methods used to manage risks and analyse the project lifecycle is SWOT analysis. SWOT analysis is a methodological planning tool used to assess an individual, institution, or a project in the basis of the strength, weaknesses, opportunities, and threats. It is typically conducted by identifying and evaluating each of these four factors and analysing how they interact with each other. The goal is to gain insights into the subject's current situation, pointing out the improvement possibilities, and make analytical decisions about future strategies and actions (Website of TechTarget). The SWOT analysis performed for this project thesis work is tabulated in

Table 2.

Table 2. SWOT Analysis of this Project thesis

<u>Strengths</u>	<u>Weakness</u>
<ul style="list-style-type: none"> Diverse perspectives as students have seen healthcare system outside Finland. 	<ul style="list-style-type: none"> Finnish Language No previous experience acting in video. Lack of video editing skills

<ul style="list-style-type: none"> • Good communication skills, proactive approach, and active thinking abilities <p>Actions: Utilizing the strengths perfectly for better outcomes and working to add more strengths skills</p>	<p>Action: Planned to practice speaking in video beforehand and ask help from colleague who has video editing skills. In the place where fluent Finnish is required, planned to ask support from supervisor teacher.</p>
<p><u>Opportunities</u></p> <ul style="list-style-type: none"> • Networking opportunities via SAMK, Sylvania, HUS • Availability of enough data resources for research purpose <p>Actions: Utilizing the opportunities to contact and discuss on possible resources from Sylvania and HUS who are supposed to use the created video materials</p>	<p><u>Threats</u></p> <ul style="list-style-type: none"> • Meeting the created timeline • Holiday may affect the fluency in contacting several persons. <p>Actions: Frequent timeline review to check where all actions are performed within deadlines, marking the calendar beforehand and keeping less actions in December and January where many people are on vacation.</p>

4.4 Previous Research & Studies

Literature search was conducted to find out the previous thesis works performed in the similar topic by scholars of similar level. of education. Theseus database is used to find out the thesis written by AMK students in Finland. Some keywords were used to search the title of the thesis work performed on similar topic. The most relevant ones were selected. Table 3 consists of the results of the literature retrieval.

Table 3. Previous studies and research

Database	Title Keywords	Found	chosen
Theseus	Paediatric cancer	1	1
Theseus	cancer in adolescents	2	2

Theseus	families; paediatric; oncology	1	1
Theseus	cancer in children	2	None (Irrelevant)

The following topics were identified as studies done on the similar topic as this thesis.

Rguibi and Mäkinens (2023) thesis aimed to explore the methods employed by the healthcare providers in offering psychological and social support to paediatric cancer patients and the challenges they face in doing so. The thesis revealed that healthcare providers utilize various approaches, including screening tools, educational sessions, recreational activities, animal-assisted therapy, and social events to deliver comprehensive support. However, challenges arise in terms of time management, resource allocation, and understanding the unique circumstances of younger patients. Each method demonstrates a proactive approach that enhances the quality of life and fosters positive relationships between caregivers and the patient. The use of above-mentioned various approaches has a positive impact on paediatric cancer patients' psychosocial care, and healthcare providers are actively striving to provide these methods using diverse resources. These findings hold significant implications for future research in the area of paediatric psychosocial care. (Rguibi & Mäkinen, 2023.)

Kahugu and Mbuh (2015) thesis is focused on social developmental challenges faced by adolescents with cancer. The key challenges identified were in the areas of relationships for example, family and peer, personal development (identity formation, confidence, and career path), and the course of life. Cancer impacts the relationships of adolescents, leading to social isolation. It disrupts the process of identity development, hindering the formation of a unique sense of self. Cancer treatments often result in changes in body image, leading to a loss of confidence and fear of intimate relationships. Additionally, young cancer survivors may have lower vocational aspirations and reduced expectations for their future. Comprehensive support

programs are necessary to address these challenges and improve the well-being of adolescent cancer patients. (Mbuh & Kahugu, 2015.)

Teku (2019) thesis aimed to explore the psychological difficulties of cancer in adolescents and young people aged 18-24 years. Cancer presents significant challenges for individuals, including emotional, psychological, and social burdens. Adolescents diagnosed with cancer face various psychological challenges, such as anxiety, social isolation, and negative body image, impacting their coping abilities and overall well-being. Nursing interventions, including cognitive-behavioural therapy, interpersonal psychotherapy, and coping skills therapy, aim to address these challenges by improving social skills, problem-solving abilities, and coping mechanisms. These interventions provide essential social support and aim to enhance resilience, reduce psychopathology, and improve mental and physical health outcomes. Implementing effective nursing interventions is crucial in supporting adolescents with cancer and mitigating the psychological challenges they face. (Teku, 2019.)

Hopia and Heino-Tolonen (2019) thesis identifies three domains where critical incidents occur in paediatric oncology nursing: families' capability and resources, parents' behaviour, and emotional labour. Nurses in this field encounter stressful situations and ethical dilemmas when interacting with patients' parents, which can burden them emotionally. The findings emphasize the importance of supporting families by helping them identify their resources and empowering them to adapt to their new circumstances. The results have implications for education and management as well. It highlights the need for management support in nurses' work with families and the development of educational interventions to enhance nurses' ability to navigate challenging situations. Overall, the study underscores the significance of addressing the multifaceted challenges faced by nurses in providing family-centred care in paediatric oncology. (Hopia & Heino, 2019.)

Regardless of these thesis studies, there appears a big room for further research in Finland in universities of applied sciences level.

4.5 Target group

The project is targeted to immigrant families in Finland living with cancer affected child. Immigrant families often experience trouble understanding the information about healthcare in Finland as most of the materials are available only in Finnish. The project video is intended for families with sufficient skills of English Language. According to recent statistics from Statistics Finland, Finland's total population was 5,563,970 by the end of 2022, with an increase of 15,729 people during the year. Interestingly, the number of native Finnish, Swedish, or Sami speakers decreased by 22,221 individuals, while the number of people speaking other languages grew by 37,950, marking the highest increase in at least 40 years. It's important to note that these statistics don't include Ukrainians who have received residence permits under the Temporary Protection Directive. Additionally, it's observed that many individuals who don't speak Finnish primarily communicate using English in their day-to-day activities. (Statistics Finland, 2022.)

4.6 Video material

Oxford dictionary definition of video is, “the process of recording, reproducing, broadcasting, or distributing moving visual images on magnetic tape or (in later use) in a digital format.” Video material can be created using different recording devices, including cameras, smartphones, and professional video equipment (Oxford dictionary). Video material is chosen instead of e-material or f2f lectures as the purpose is to educate the international families. Professionals believe that, in the modern digital world, attention spans are short and a lot of knowledge at once is not efficient for educating. An attractive video can engage and connect emotionally with audiences. (R. Shinde, 2023.)

Educational video material is a video designed with a purpose of educating people on a specific context. They are used as a tool to teach or aware people using various platforms such as classrooms, web-based courses or any other teaching-learning environment (Savelyeva et al., 2014). In comparison to

printed materials, videos and applications have become more effective in teaching the people. These materials improve the level of health education of care givers in a family and raises the confidence to deal with the challenges which come up during treatment and care of cancer affected child. (Silva et al., 2023.)

5 VIDEO EXECUTION

The authors collaborated on a manuscript grounded in a theoretical framework, which they subsequently divided amongst themselves for presentation. For a comprehensive transcript of the video material, please consult Appendix 2. This section encompasses the entire script, providing a detailed reference for the content delivered in the video presentation.

Several days were dedicated to rehearsal to ensure fluency in language delivery. Once the authors had developed confidence in their delivery, the video recording was scheduled. All necessary materials were prepared for recording, including a mobile phone camera, tripod, and lighting equipment. Care was taken to create an aesthetically pleasing screen frame. Given the target audience of families, efforts were made to maintain a homely environment throughout the video. Consequently, one of the author's living rooms was selected as the shooting location, where they were seated on a sofa to enhance the homely ambiance.

Recording commenced once all preparations were finalized. Each author delivered their respective sections of the script while facing the camera. To mitigate monotony, speakers alternated frequently, with each delivering brief segments before passing the spotlight to the next speaker. Multiple retakes were conducted, with authors engaging in self-analysis to enhance the quality and appeal of the video. Clips deemed unattractive were promptly discarded.

Following the recording session, the raw video footage underwent editing using professional video editing software. Subtitles and text boxes were incorporated, and the final version was prepared for submission to the supervisor for review. The completed video presentation was shared with Sylva Ry, and adjustments were made based on their valuable feedback and comments. Their input ensured that the final version of the video met the desired standards and effectively conveyed the intended message.

6 EVALUATION

6.1 Evaluation of the Video Material

To assess the effectiveness and relevance of the video material developed for international family members of children with cancer, a comprehensive evaluation process was undertaken. This evaluation aimed to gather in-sights into the perceived usefulness, usability, and impact of the video material on its target audience.

The video was first self-evaluated and forwarded to the supervising teacher. After receiving comments, updates on the video were made accordingly. Thereafter, the video was sent to representatives of the client, Sylva Ry. Comments were received, and minor updates were made. The final version was approved after resubmission. Following the evaluation process, all feedback gathered was meticulously reviewed and analysed to ensure that the video material could effectively address the needs and concerns of international family members of children with cancer. This involved synthesizing the insights gained to identify areas of improvement and refinement. Suggestions and critiques were carefully incorporated into the development process, with particular attention paid to enhancing the clarity, relevance, and accessibility of the content.

The video has extracted important information from multiple sources and bind them in one video material. The target group will therefore not necessarily need to search through different sources for learning on how to care their ill child at home. The video is like a guide that holds the important things together which intends to make the cancer treatment journey easier for the affected families.

6.2 Learning and Professional growth

This thesis project has been pivotal in our professional growth, offering hands-on experience in project management, video production, and stakeholder engagement. Through Agile methodology and the PDCA cycle, we've learned to plan, execute, and evaluate projects effectively, enhancing our skills in time management and adaptability. Creating educational video materials has bolstered our proficiency in multimedia content creation, encompassing scripting, filming, and editing. This experience has not only developed our technical skills but also strengthened our ability to communicate complex information visually.

Engaging with diverse stakeholders has broadened our network and taught us the importance of inclusive decision-making and ethical conduct. By adhering to ethical guidelines and prioritizing integrity throughout the project, we've deepened our commitment to responsible research and professional practice. Overall, this thesis project has equipped us with a comprehensive skill set and valuable insights that will undoubtedly shape our future career endeavours. From project management to multimedia production and ethical leadership, the lessons learned have laid a solid foundation for our continued growth and development in the field, particularly in our understanding of paediatric cancers.

6.3 Ethical considerations

The ethical principles outlined in our thesis plans were adhered, with a framework prioritizing integrity and sensitivity throughout all stages of our research and educational video production. Guidance was sought from reputable sources such as the Finnish advisory board on research integrity (Finnish National Board on Research Integrity TENK. n.d.) and the research integrity advisor at SAMK, ensuring that the project maintained the highest standards of ethical conduct by continuously referring to these advisory guidelines and minimizing the risk of any unforeseen breaches of research integrity.

Furthermore, specific measures were implemented to uphold the privacy and confidentiality of individuals involved in the research, with a commitment to complying with general data protection regulations and the data protection act. This entailed obtaining necessary consent and safeguarding the anonymity of participants in feedback sessions conducted during the preparation of educational video materials. Additionally, a precious approach to plagiarism prevention was adopted, ensuring that all reporting materials were sourced from authorized sources and appropriately cited to avoid instances of academic dishonesty. Efforts have been made to ensure that no copyright violation has occurred in the work.

In the development of the educational video for families dealing with paediatric cancer, dedication to ethical considerations remained crucial. The content was characterized by sensitivity and empathy, avoiding language or imagery that could potentially cause distress to viewers. Accuracy and credibility were prioritized through consultation with experts and the use of reliable sources, providing families with trustworthy information and support. Moreover, commitment to cultural sensitivity ensured inclusivity and respect for diverse backgrounds and beliefs. By maintaining a balanced perspective that acknowledged both the challenges and sources of hope for paediatric cancer families, the ethical integrity of the educational endeavour was upheld, with its

primary objective focused on providing valuable education and support, rather than exploiting the experiences of those affected by paediatric cancer.

6.4 Reliability

The prepared educational video material is a reliable resource that has been meticulously crafted with careful consideration of ethical standards, drawing from a variety of reputable Finnish and international sources as listed in references. The information presented in the video is thoroughly researched, ensuring accuracy and credibility. Prior to publication, the material underwent rigorous fact-checking procedures to verify the validity of the information provided. Therefore, viewers can trust the reliability and authenticity of the content, which has been prepared with the utmost dedication to providing valuable support and guidance to families facing the challenges of caring for children with cancer. (D Gajjar Education, 2013.)

In order to enhance the clarity and correctness of the language used in this thesis report and video script, an advanced language model named ChatGPT developed by OpenAI was used for grammar correction and language refinement. This tool helped to identify and rectify grammatical errors. This helped to improve structure of sentences and ensure overall coherence. While AI has contributed to the linguistic quality of the report, all technical content, research findings, and analyses remain the original work of the authors which are cited as per the SAMK's AI guidelines.

6.5 Impact and Implications

The prepared educational video material holds significant potential for positively impacting the well-being and coping strategies of families with a child undergoing cancer treatment. By providing accessible and comprehensive information, the video aims to empower families, alleviate stress, and enhance their ability to navigate through the hardships associated with caring a child with cancer.

One of the primary impacts of the video material is its potential to improve the knowledge and understanding of families regarding childhood cancer. By addressing common concerns, providing practical tips, and offering guidance on various aspects of care, the video equips families with the necessary tools to make informed decisions and effectively manage the care of their child at home. This increased knowledge can lead to greater confidence and reduced anxiety among caregivers, enabling them to provide better support to their child throughout the treatment process.

Furthermore, the development of educational video materials opens avenues for future research in the field of paediatric oncology support services. By evaluating the effectiveness of such interventions, researchers can gain valuable insights into the needs and preferences of families, as well as the impact of educational resources on clinical outcomes and quality of life. This knowledge can inform the design of more targeted and evidence-based interventions, ultimately leading to improved support services for families affected by childhood cancer.

6.6 Conclusion

In conclusion, this project thesis has aimed to address a critical need for educational support among families with a child diagnosed with cancer. Through the creation of accessible and informative video material, the project strives to empower families, enhance their coping strategies, and improve their overall well-being. By leveraging the power of technology and collaboration with healthcare organizations like HUS and Sylva Ry, the project contributes to the broader goal of providing patient-centred care for children with cancer and their families.

Moving forward, it is essential to continue building upon this work, refining educational resources, and conducting further research to better understand

the needs of families and optimize support services in the field of paediatric oncology. By working together with healthcare providers, policymakers, and researchers, we can continue to make meaningful strides towards improving outcomes and enhancing the quality of life for families affected by childhood cancer.

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APPENDIX 1: LITERATURE RETRIEVAL

Database	Keywords	Results	Chosen
Science Direct	Educational Video Materials Filter range: year 2019-2024 Article type: Clinical Species: Humans	1009	5
Google scholar	Paediatric cancer Filter-Year range 2014-2024, Medical journals, Includes Citation	360	1
Google scholar	Childhood cancer and impact on family Filter-Year range 2014-2024, Medical journals	85	1
Google scholar	Childhood cancer financial strain family Filter-Year range 2014-2024,	26	1
Science Direct	Causes of childhood cancer Results by year: 2014-2024 Books and documents	75	1
PubMed	Impact of Cancer Filter-Year range 2020-2024, Medical journals, Includes Citation	976	2
Science Direct	Types of cancer Filter-Year range 2014-2024, Medical journals, Includes Citation	6875	2
Science Direct	Educational challenges on families living with cancer. Filter-Year range 2014-2024, Medical journals, Includes Citation	71	1
Science Direct	Child with cancer Filter range: year 2019-2024 Article type: Clinical	4375	2

	Species: Humans		
Google scholar	Types of child cancer Filter-Year range 2019-2024, Medical journals, Includes Citation	126	1
PubMed	Family management of pediatric cancer Filter-Year range 2019-2024, Medical journals, Includes Citation	136	1
Google scholar	Assessing family psychosocial risks in pediatric cancer Filter range: year 2019-2024 Article type: Clinical Species: Humans	53	2
PubMed	Comparison of video-assisted education and traditional classroom education in pediatric Filter-Year range 2014-2024, Medical journals, Includes Citation	14	1
Google scholar	Media and memory: the efficacy of video and print materials for promoting patient education. Filter-Year range 2014-2024, Medical journals, Includes Citation	78	1
PubMed	Role of communication for pediatric cancer patients and their family Filter-Year range 2019-2024, Medical journals, Includes Citation	6	1
Google scholar	Pediatric cancer patients Filter range: year 2019-2024 Article type: Clinical Species: Humans	198	2

APPENDIX 2: VIDEO MANUSCRIPT

The below script provides a written reference for the video materials prepared in this project thesis.

NUTRITION

A balanced diet with healthy foods is very important for children, but treatments can affect their appetite, often causing sensations like nausea.

Despite these challenges, maintaining the diet is key. It helps children stay strong, supports their immune system, manages side effects, and aids in healing.

The health care team is there to help and support you to create a personalized nutrition plan and keep an eye on your child's weight and health during treatment.

Setting regular mealtimes and having the family sit together during meals is essential. Family meals provide support and encouragement.

Serving foods your child enjoys can make mealtime more appealing. And a beautifully set table with nice dishes can create a positive environment.

When serving, place one food item on the plate at a time, offering small portions. This helps manage appetite fluctuations.

Allowing your child to eat at their own pace according to their appetite is important. It respects their needs during treatment.

Additionally, if your child faces constipation, various exercises, including gentle gymnastics, and fluids like sweetened juices, soup, tea, and water, can be beneficial.

HYGIENE

Taking care of cleanliness, like washing hands, is vital for staying healthy.

Hygiene is crucial in everyday life, especially during treatments when a child's immune system is lowered, making them more prone to illness.

Let's remember the key times when handwashing is important:

Before, during, and after making food.

Before eating.

After using the bathroom.

After changing diapers or assisting a child in the bathroom.

After sneezing or coughing.

After touching or cleaning pets.

After handling trash.

Before or after dealing with wounds, catheters, ports, or access devices.

Encourage everyone, friends, and family included, to follow these practices.

It's a simple yet caring way to protect your child and yourselves from getting sick. Other than hand hygiene, assisting the child to follow proper hygienic practice is necessary. Make sure the child stays neat and clean. Support the child to avoid contaminated from disease carrying germs.

SOCIAL LIFE

Despite the difficult situation of your family, maintaining social life is very important. Remember to take personal time and stay connected with friends and family.

It's important to prioritize self-care, seek help when needed, and try to find joy also in the small moments. Healthy and supportive parents positively impact the well-being of the child.

If there are other children in the family, involve them in the treatment process. Playing and expressing feelings through art can play important role on your child's well-being. Schooling, even in a hospital setting helps the child feel normal despite the illness.

Encourage exercise for mood improvement and appetite, and if there are any concerns, consult with a doctor or physiotherapist.

Your ethical and caring approach significantly impacts your child's journey.

Now, let's discuss how you can get support from Kela.

If one parent needs to stay out of work, you can apply for a D-certificate (D-todistus).

This certificate, also known as special care allowance, compensates for income loss when a parent caring for a sick or disabled child under 16 can't work due to participating in the child's treatment or rehabilitation.

You'll need the D-certificate from the child's doctor to apply for the special care allowance from Kela.

For single parents, discussing financial and support options is essential. A social worker can assist in this process.

HOME MEDICATION AND VACCINATION

Each child has an individualized medication plan that may include regular medications and those which can be used if needed. Regular medications are important to take according to the doctor's prescriptions. If you have any medication related questions, you should contact the unit which is responsible for your child's care.

Additionally, it is important to notice, that Children's normal vaccination program is interrupted during cancer treatments because the treatment itself worsens the effectiveness of the vaccinations.

Try to be mentally strong and maintain positivity within you. Keep the faith on better tomorrow and never lose the hope. Difficult times do not last forever.