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Using family focused-care solutions to improve child's quality of life

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Using family focused-care solutions to improve child's quality of life

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NURS 4500: Nursing Research and Senior Thesis

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Table of Contents

Abstract	3
Acknowledgements	4
Introduction	5
Problem Statement	6
Research Questions	7
Literature Review	7
Introduction	7
Family Struggles that are associated with child illnesses	8
Nursing Solutions to help improve quality of life for families struggling with	10
Literature Review Summary	14
Purpose of Research and relation to Literature Review	15
Theoretical Framework	16
Research Proposal	17
Conclusion	22
References	23
Appendix	24

Abstract

Chronic illness in children impacts not only themselves but their families too. Everyone in the family supports each other and provides each other with pretty much all our physiological needs including our emotional needs. Parents/caregivers are the role models for their young children and really shape the person they become because basic values and their early relationships are formed. A family provides that consistent balance in our life that is the center of our life at a young age. When children are diagnosed with a chronic illness, parents may feel responsible, ashamed, guilty, or angry. Families may turn on each other and that consistent balance is lost which causes a huge change for the family. Each family member reacts differently to their child's illness. Every family member is important so it is very important as nurses to provide our full support to each individual family member. As nurses it is our job to provide any education they may need, be a person they can talk to and provide the necessary resources they may need to help them cope. This thesis will provide a review of the recent research literature and offer a study proposal for further investigation of this important topic.

Acknowledgments

I would like to thank Dr. Patricia Harris for her support and guidance throughout my entire Senior Thesis Paper. I would also like to thank all of my family and friends, my girlfriend, my ading, and grand for supporting me. I appreciate all your motivation and for being my biggest fans.

Introduction

Family-focused care is very important when a family's child has a chronic illness. It connects the healthcare professionals, patients, and families so that everyone is on the same page and are aiming for the same goals. Family-focused care makes sure that the families are part of the planning and any interventions that are needed to be taken upon for the child. While the healthcare professionals plan and implement, they make sure that the parents are present and respect their views/opinions or any culture/traditions they may have. Family Strengths Oriented Therapeutic Conversation (FAM-SOTC) is an intervention that encourages discussion of the illness experience, asks therapeutic questions, provides active listening, cognitive and emotional support, evidence-based information, offering recommendations, and identifying family strengths. (Journal of Family Nursing, 2020). The purpose of this literature review is to identify how FAM-SOTC provides support to families, better understanding of their child's illness, and how it improves the quality of life for the child and their family. This literature review will show how different illnesses impact a family and how different factors and interventions can help or hinder a family. Family Strengths-Oriented Therapeutic Conversations (FAM-SOTC) guides families in the right way from supporting their decisions to respecting their choices, and increasing the well-being of the family and quality of life. Following the literature review, a proposal for further research to examine how FAM-SOTC may affect the quality of life of a child diagnosed with cancer as well as the child's family.

Problem Statement

With chronic illness impacting not only the child but also the entire family, it causes some disruption. With families not unified, it creates a toxic environment for the child. Due to the toxic environment and early adversity, it can affect normal brain development of a child. All this stress for a young child hurts them in the long run because their brains will not be able to handle stress as well as others. Therefore, protecting a child's normal development starts with the parents/families. A study that evaluated nearly 1000 mothers and 182 fathers, found that more than 55 percent of the children's primary caregivers were anxious and felt isolated and stressed by such challenges as obtaining insurance when a child has a pre-existing condition and the financial strain of co-payments for doctors' visits and medication (Center on the Developing Child 2007). Parents and families do not receive the necessary support they should be receiving to be able to fully understand their child's illness and to cope in a healthy way. Parents end up struggling and burning out with taking care of their child, so family focused-care solutions are needed to support these families. Interventions that can help these families are providing education for them on their child's disease so they can understand and properly care for their child, providing education on how to cope and manage their stress, activities that promote relaxation or distraction, and providing them with resources that can provide them with additional support.

Research Questions

- What are the family struggles associated with a child diagnosed with a life-threatening illness, such as cancer?

- Do family focused care solutions improve the quality of life for the child living with cancer ?

Literature Review Introduction

According to the (Harvey A. Andruss Library) from Bloomsburg University of Pennsylvania “ a literature review is a comprehensive summary of previous research on a topic. The literature review surveys scholarly articles, books, and other sources relevant to a particular area of research”. A literature review helps you justify your research and it shows the gaps that are missing/have not been researched within the existing literature which also shows why you are furthering your research with your certain topic.

The main database used for the research was Dominican University of California database Iceberg. The terms used to search articles related to the research question were: “pediatrics”, “family focused care”, “stress”, “cancer”, “youth”, and “ quality of life”. The author used these terms in various different combinations to find useful articles. There were many results when these terms were used but there were not too many articles that related to the author's research questions. The author chose six articles to be included in the literature review. The articles were organized into two categories: Family struggles that are associated with child illnesses and nursing solutions that can help improve the quality of life for families that struggle with their child's illness. Please see the appendix for a Literature Review Table with a summary of each article.

Family Struggles that are associated with child illnesses

Parenting Stress Among Caregivers of Children

Cousino, Melissa K, and Rebecca A Hazen (2013) aimed to critically review, analyze, and synthesize the literature on parenting stress among caregivers of children with asthma,

cancer, cystic fibrosis, diabetes, epilepsy, juvenile rheumatoid arthritis, and/or sickle cell disease. This meta-analysis study had a sample size of 13 meta-analysis studies and 96 qualitative analysis studies that were conducted. These articles were found/taken from Psychinfo, MEDLINE, and Cumulative Index to Nursing and Allied Health Literature were searched according to inclusion criteria. The search was limited to articles published in a peer-reviewed journal from January 1980 to June 2012 to allow for the inclusion of as many studies as possible, while also limiting the review to studies relevant to current medical practice. Predetermined search terms were used to identify articles meeting the inclusion criteria.

Researchers found that findings suggested that generic aspects of the caregiving experience, not specific to the child's chronic illness, bring about greater stress for parents of children with pediatric chronic illnesses. To continue, the researchers found that in addition to experiencing greater general parenting stress, caregivers of children with chronic illness are also likely to experience illness-related parenting stress. Parents finding out that their child has a chronic illness can be devastating. The stress and responsibility that is thrown on the parent is huge and it is the job of the nurse to really provide support in that unknown for the parent because it can be really scary.

This study was meta-analysis so there is a high level of evidence. Study was evidenced based on statistics and articles that were chosen from top reliable nursing databases. A limitation for the study is that there may be some publication bias within the different articles that were founded; not 100% trustful; maybe misleading conclusions.

Family factors and health-related quality of life

al Ghriwati, N., Stevens, E., Velázquez-Martin, B., Hocking, M. C., Schwartz, L. A., & Barakat, L. P. (2021) aimed to evaluate associations between cancer and treatment-related

variables, family factors (family functioning, caregiver health-related quality of life and caregiver distress), and patient HRQOL after treatment completion. This quantitative study had a large sample size of 154 caregivers (of patients' ages 0-18 years) and 52 youth (ages 7-18 years). Researchers assessed the indirect effects of neurocognitive difficulties on youth HRQL through family factors. The caregivers completed questionnaires which assessed family factors, neurocognitive difficulties, and HRQL for patients within 6 months following treatment completion. Electronic health records were reviewed for cancer and treatment-related information. Bootstrapping analyses assessed whether neurocognitive function had indirect effects on HRQOL through family factors.

Researchers found that family factors were associated with self and caregiver reports of children's HRQL. Researchers controlled for demographic, cancer, and treatment covariates. Researchers found that caregiver reports of their child's neurocognitive difficulties had an indirect effect on their reports of child physical HRQL through family functioning. They also found that caregivers' reports of their child's neurocognitive difficulties indirectly related to caregiver reports of child psychosocial HRQL through family functioning and caregiver HRQL. Lastly, researchers saw indirect effects for self-reported neurocognitive difficulties and HRQL were not supported.

This large sample size was a strength of the study. In addition, the researchers had different types of questions to assess the caregivers. A limitation of this study was that the sample represented predominantly white children with biological mothers serving as primary caregivers. Given that race was associated with HRQL, health disparities exist, and family beliefs and attitudes regarding illness management patterns may differ across cultural backgrounds, the findings require replication with a larger, more diverse sample.

Nursing Solutions to help improve quality of life for families struggling with a child's illness

The Effect of the Family-Centered Empowerment Model

Shoghi M, Shahbazi B, Seyedfatemi N. (2019) aimed to determine the effect of the Family-Centered Empowerment Model (FCEM) on the care burden of the parents of children, diagnosed with cancer. This Quasi-experimental study had a sample size of 78 parents that had children with cancer. The two groups were similar in terms of demographic variables and level of burden of care. The FCEM was implemented in the **intervention group** in four stages which were; namely perceived a threat, self efficacy, educational participation and evaluation during four sessions of 20-40 minutes. The **control group** only received the basic usual care. Then the burden of care of the intervention and the control groups were measured one month after filling out the initial questionnaire, and one month after the end of the intervention, respectively.

Researchers found that the study showed that informed participation and motivating parents to gain caring skills is effective in reducing their care burden. This is important because this simple intervention can help parents reduce their care burden which can lead to better quality of life for their child. Researchers also found that a caregiver's participation in an empowerment program would significantly increase their competence in caring for the children with cancer.

This was an innovative study that is examining an important problem/issue. A strength of the study was that there were different stages that the FCEM was used for and each family had different scenarios such as single parent families or two-parent families. Some limitations of the study were the difference in mental and psychological characteristics, difference in interpersonal interactions with patients, and difference in motives and personalities of the subjects. These are

factors that could not be controlled by the researchers, but many affect the learning, sense of self-efficacy, self-esteem, and self-control, and subsequently the empowerment.

The Impact of Family Strengths Oriented Therapeutic Conversations

Svavarsdottir, Erla K, et al (2020) aimed to evaluate the benefits of two sessions of a Family Strengths Oriented Therapeutic Conversation intervention, offered by advanced practice nurses to mothers of children and adolescents in Iceland with newly diagnosed chronic illnesses/disorders. This Quasi-Experimental study had a sample size of 31 mothers where they were all primary caregivers of children or adolescents with T1DM, JIA, epilepsy, or sleeping disorder with ADHD. The study consisted of establishing a therapeutic relationship with the parent of the ill child, drawing a family genogram, exploring the quality of the family relationships, encouraging the telling of the family illness story, asking therapeutic questions, identifying strengths, resilience, and resources, offering evidence-based information and recommendations, and identifying failing or helpful illness beliefs and or challenging constraining or hindering illness beliefs.

Researchers found that the two sessions of Family Strengths Oriented Therapeutic Conversation were beneficial for mothers, who were primary caregivers of children and adolescents. Participants reported significantly higher quality of life (total score) for their family after the two sessions of FAM-SOTC intervention compared to baseline. This is important because this intervention was beneficial to all the mothers who had children with different medical illnesses. All the mothers took only 2 sessions which led to great results. If the mothers took more FAM-SOTC sessions, it would benefit them tremendously. FAM-SOTC covers a lot that goes through a parents' mind while establishing a therapeutic relationship.

Having mothers of children or adolescents with T1DM, JIA, epilepsy, or sleeping disorder with ADHD shows the wide range of illnesses that children can develop at a young age. These are some serious illnesses and are hard for a parent to hear when they hear that their child has been diagnosed with this illness. With using FAM-SOTC to help these parents out it shows how it can benefit families no matter what type of chronic illness it is. A limitation was that the study only included mothers and it was a fairly small sample size.

Family centered care, caregiving burden, and adaptation in parents of children with cancer

Crespo, C., Santos, S., Tavares, A., & Salvador, Á. (2016) aimed to identify the direct and indirect associations, through caregiving burden, between parents' family centered care and quality of life and life satisfaction. This correlated study had a sample of 204 parents and other relatives involved in taking care of children diagnosed with cancer. For the study, the parent was the child's primary informal caregiver for health issues and the child was at least 3 months **post diagnosis**, and the child had been receiving treatment for newly diagnosed/relapsed **cancer** or had finished antineoplastic treatments within the last 5 years. A researcher approached parents at the inpatient and outpatient treatment settings of both hospitals. With the study, all parents except one agreed to participate and provide informed consent for the study after being briefed about its goals and procedures. Also, participants filled out questionnaires for care burdens at the hospital while waiting for their children's clinical appointments in the presence of a researcher.

Researchers found that older parents and parents of older children reported higher levels of family centered care and lower caregiving burden. They found that being an older parent was also associated with higher life satisfaction. Another big thing the researchers found was the caregiving burden was correlated with worse quality of life and lower life satisfaction. This

shows how much cancer can have on a younger child with younger parents. This means that as nurses, providing that support/information for younger families is very essential so they can learn how to cope and have better quality of life and life satisfaction within their family. Cancer is a big blow to any family so making sure that the family centered care is strong and supportive will help the family a lot.

This innovative study had a large sample size and it showed how important family centered care is and how it benefits families and a child's quality of care. Some limitations of this study were the ways in which the two hospital sites operationalised Family Centered Care which are important factors that were not covered in this study. Also, the cross-sectional nature of the data, which precluded the verification of causality among the variables in the mediation model.

FOCUS Program

Hui Ling Chen, Tsui-Sui Annie Kao, Reuille, K. M., & Northouse, L. (2021) aimed to evaluate the feasibility and preliminary efficacy of the nurse-guided, psychoeducational, family-based FOCUS program intervention at a local oncology outpatient clinic. This evidence-based pilot study had a sample size of 30 patient-caregiver dyads that were recruited from a local oncology clinic. Researchers used intervention delivery that occurred using home visits and telephone calls. Participants did self-administered questionnaires that were used to assess participants' self-efficacy, quality of life, and coping pre-and-post intervention, and intervention satisfaction post intervention. Researchers also had three tailored psychosocial education sessions that were held during a 6-to-9 week period.

Researchers found that significant changes in outcomes were found, including increased self-efficacy in both patients and caregivers, higher quality of life in caregivers, and decreased use of substances for coping in patients. Researchers found that there was a trend for patient's

emotional well-being to improve over time. Other aspects of quality of life showed little change and there were no significant changes in caregiver's coping. This shows that nurses can do more for the FOCUS program so we can work on how the caregiver copes which can lead to better quality of life for the family.

This study had volunteers that were willing to participate and 6 months of life were excluded because of the extreme stress which was strong about the study. A limitation was this study had a limited sample size which was only 30 people.

Literature Review Summary

The research review demonstrates that families need support when a child is diagnosed with a severe illness. There is a need for family focused care solutions due to the fact that a child's diagnosis not only affects the child but affects the entire family. A lot of families are not well informed or equipped to take on this new responsibility and the situation can be overwhelming to family members. Providing different family focused care solutions such as Family Strengths Oriented Therapeutic Conversation may help families tremendously so making sure all families have access to these resources is essential.

Purpose of Research and relation to Literature Review

When families find out their child is diagnosed with a serious illness or even the smallest disease it can be heartbreaking. Families who are not familiar with the medical field may feel lost or overwhelmed. By providing a family focused care solution such as family strengths-oriented therapeutic conversation, nurses can help ill children and their families by guiding them in a positive direction from supporting their decisions to respecting their choices, and improving their well-being and quality of life. Cancer can develop in kids and it is life changing for a child and their family. Every family member is affected and as nurses, we have to

provide as many resources as we can for these families. If not, families could be torn apart and children will not have that positive family environment they need at a young age to promote healthy development .

The study that is going to be proposed will arise from my literature review because the research showed how child illnesses affect families. One article talked about the parenting stress among caregivers of children with asthma, cancer, cystic fibrosis, diabetes, epilepsy, and other diseases. These serious illnesses in children, often diagnosed at a young age are devastating for families and cause great stress. Another article talked about how family factors were associated with self and caregiver reports of children's health related quality of life. It shows how if the family factors were mostly negative it could negatively impact the child's quality of life. With Family Strength-Oriented Therapeutic Conversation and other family focused care solutions, we can help provide more support, comfort, and education for these families so they are not overwhelmed, lost, or burnt out which will benefit both family and the child.

Theoretical Framework

My theory to support his proposed research is Katharine Kolcaba's theory of comfort. (Kolcaba, 1990). This theory was developed in the 1990s and emphasizes how comfort is an immediate desirable outcome of nursing care. According to Kolcaba's theory of comfort, it considers patients, families, institutions, or communities in need of health care and the four contexts in which patient comfort can occur are: physical, psychospiritual, environmental, and sociocultural. The nursing theory model says that the environment is any aspect of the patient, family, or institutional surroundings that can be manipulated by a nurse or loved one in order to enhance comfort. The model also considers health as the optimal functioning in the patient, as defined by the patient, group, family, or community. In the model, nursing is described as the

process of assessing the patient's comfort needs, developing, and implementing appropriate nursing care plans, and evaluating the patient's comfort after the care plan has been carried out. The model also describes nursing as including the intentional assessment of comfort needs, the design of comfort measures to address those needs, and the reassessment of comfort levels after implementation.

This theory goes well with the proposed research study because the goal of the study is to show the importance of family focused care solutions and how providing that support and comfort for the family can be very beneficial for the child. The purpose is to show how providing support and comfort for the family is just as important as providing support/care for the child. With providing a solid family focused care solution, nurses can improve that environment within the family for the child to improve their quality of life. The proposed research study will aim to address the problem of families not being well informed about their child's illness and being overwhelmed with the responsibility of this new change within their family. By providing a Family-Strength Oriented Therapeutic Conversation, the researcher plans to evaluate how it affects a family and how this intervention may lead to better outcomes for their child (or not).

Research Proposal

After doing the literature review, the researcher found that when families have a child diagnosed with a life-threatening illness or living with a serious disease it affects them in different ways. Parenting stress arises when the responsibility of caring for an ill child is placed upon them due to different factors which include; single parenting, low health literacy, feeling overwhelmed, or not receiving the right kind of support or resources. Families finding out their child has an illness such as cancer can be devastating and cause huge stress throughout the

family. According to (Cousino & Hazen, 2013,) “researchers found that in addition to experiencing greater general parenting stress, caregivers of children with chronic illness are also likely to experience illness-related parenting stress.” To continue, with the family being overwhelmed and burnt out, it is hard for them to provide a nurturing and supportive environment for the child. Within the literature review, it is found that family factors affect the quality of life of a child. If the family was not functioning well together, it affected the child negatively including the child's health and quality of life.

The purpose of this thesis is to examine how Family Strength-Oriented Therapeutic Conversation (FAM-SOTC) affects the quality of life of a child with cancer. The purpose, in addition, is to determine if the Family Strength-Oriented Therapeutic Conversation provides support and guidance for the family members. Since the research in the literature review on FAM-SOTC showed a positive impact on families through only two sessions, the researcher hypothesizes that this research will have a positive impact on the ill children and their families. Implementing more sessions and doing interviews after six months and one year will allow us to see more in depth how FAM-SOTC positively impacts a family (or not) and more specifically, how it affects each family member including the child with cancer. This topic is important because caring for the whole family is a huge nursing role. Not only does the nursing role include taking care of the patient but also providing that support and comfort for the family as well since the family is a huge part of the child's life. Also, as talked about earlier in the research, families play a large role in the early development of a young child.

Research Questions

- Does using Family Strengths-Oriented Therapeutic Conversation (FAM-SOTC) improve quality of life for the child living with cancer ?

- Does Family Strengths-Oriented Therapeutic Conversation (FAM-SOTC) provide support and guidance for family members?

Research Aims

- To determine the positive effect of Family-Strength Oriented Therapeutic Conversation on the quality of life of a child with cancer.
- To assess how parents feel after having a session of Family-Strength Oriented Therapeutic Conversation after six months and one year.

Research Design

The study will be a longitudinal, qualitative research study. It will be a one year study, in which the progress of families who receive FAM-SOTC will be checked up on at one month, three, six, and nine months and then after a year. The check in/follow up of the families will be to assess how the FAM-SOTC is affecting each family member.

Methodology

Each FAM-SOTC session will consist of providing any needed education or support the family members may need, showing the families the available resources that are available to them, teaching them different ways to cope and manage their stress, and establishing a therapeutic relationship with the family to assist with any of their needs or concerns. Each one-hour long FAM-SOTC session will be recorded and will take place once a month. The sessions will occur at the families' convenience, such as when they come into the hospital for a follow up for their child's cancer condition, in a private conference room at the hospital. Notes will be taken by the researchers to document the FAM-SOTC sessions.

At the start of the study, after three, six and nine months and after one year the parents and child will be interviewed together for an additional one hour to see how the FAM-SOTC sessions are benefiting them (or not). If additional siblings are present, they may be included in the interview hour. The interviews will be audio recorded.

In certain circumstances, if a child with cancer gets progressively worse during the study or dies, the nurse will also provide some grief counseling for the family to help provide support and comfort for that particular family. This grief counseling will be included in the FAM-SOTC sessions for the family who will be given the option to continue the sessions if the child passes away.

To conduct the study, a research team of three registered nurses (RN) or nursing students, including the primary researcher will be convened to make up the study team. The primary researcher is familiar with the process for conducting the FAM-SOTC Sessions and will be responsible for conducting all sessions to help ensure consistency. The other two researchers will be RNs who are familiar with the FAM-SOTC and are well-versed in therapeutic communication. They will conduct the follow-up interviews after the first session and last session, and at three, six, and nine months.

Population and Sampling

The population for this research would be focused on two pediatric hospitals, Lucile Packard Children's Hospital Stanford and UCSF Benioff Children's Hospital Oakland. The sample includes families with children within the age range of three to 19 years who have been diagnosed or living with cancer. The proposed sample size would be 10 families who are having a hard time adjusting to their child's illness or just need a little guidance or support with this serious illness. Recruitment for this study would involve putting flyers up at doctor's offices at

Lucile Packard and Benioff Children's Hospital and the study would begin after 10 families have agreed to be part of the study. The recruitment flier will include a brief description of the study, purpose and aims, and will include the research's contact information for family members who are interested in participating to contact the researcher.

Data Analysis

We will use a content analysis based upon my research design. All the audio recorded interviews will be transcribed in writing. After each family's interview, the transcript of the interviews will be read thoroughly and explored by the three researchers who are all knowledgeable about therapeutic communication. We will meet regularly and read the transcripts of the interviews together to find common words and phrases between the different family members. We will organize the common phrases and words into categories. Then from the categories, we will derive common themes from the categories of similar words and phrases each month. The nurse researchers will note/document any changes from each FAM-SOTC session to see if the sessions are positively benefiting the families (or not). Collecting this data this way will be an efficient way to study the changes throughout the months and year and also it is an effective way to organize all the different data that is collected and gathered throughout the study.

Ethical Considerations

One main ethical issue that arises in this research study is the patients' age. Children are a vulnerable population. The sample age range that will be studied is from three to 19 years. Parental consent for the child is necessary to obtain for the patients who are 17 years old or younger. If the adolescent is 18 or 19 they are able to provide their own consent. For all those who are under the age of 18 (including any siblings who are present at the hospital and included

in the FAM-SOTC sessions, and thus become part of the study), assent will be required. Assent consists of explaining the study to the children and obtaining his/her/their permission to include the child in the study. If the child can read and write, a written assent can be provided in which the study is explained to the child and he/she/they can give their signature. If the child is too young to know how to read or write, the nurse will obtain assent by explaining to the child what the study consists of and what will happen to him/her/them and getting their approval to participate verbally. The verbal assent will be documented by the researcher.

The parents will also have to sign a consent form. Prior to obtaining consent, the study purpose, aims and procedure will be thoroughly explained and parents will have the opportunity to ask questions. In addition, consent will need to be obtained for audio recordings of the interviews.

Prior to enrolling participants, the internal review boards (IRBs) of Lucile Packard Children's Hospital Stanford and UCSF Benioff Children's Hospital Oakland will need to review the study for ethical considerations and provide their approval.

Conclusions

With the proposed research design the researcher hopes to show how effective family focused care solutions are. Family focused care solutions benefit everyone in the family which correlates to higher quality of life for the child. Providing a nurturing and solid environment for that child is very important at a young age. Also, parents are rarely given the respect and appreciation they rightfully deserve because they do so much for their child and family. Taking care of a child with cancer or a serious disease is not easy at all, so nurses need to give them that support and guidance which can help parents in a huge way. The author hopes that Family Strength- Oriented Therapeutic Conversation will be adopted in the nursing field because

FAM-SOTC provides a better quality of life for the child because it provides the support and resources the family may need while listening to their concerns and creating a strong therapeutic relationship.

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Hui Ling Chen, Tsui-Sui Annie Kao, Reuille, K. M., & Northouse, L. (2021). FOCUS Program: Treating patients with cancer and family caregivers as a unit of care. *Clinical Journal of Oncology Nursing*, 25(3), E17–E25. <https://doi.org/10.1188/21.CJON.E17-E25>

<p>Shoghi M, Shahbazi B, Seyedfatemi N. The Effect of the Family-Centered Empowerment Model (FCEM) on the Care Burden of the Parents of Children Diagnosed with Cancer. Asian Pac J Cancer Prev. 2019 Jun 1;20(6):1757-1764. doi: 10.31557/APJCP.2019.20.6.1757. PMID: 31244297; PMCID: PMC7021596.</p>	<p>This study aims to determine the effect of the Family-Centered Empowerment Model (FCEM) on the care burden of the parents of children, diagnosed with cancer.</p>	<p>78 parents, having children with cancer. The two groups were similar in terms of demographic variables and level of burden of care.</p>	<p>Quasi-experimental</p>	<p>The FCEM was implemented in the intervention group in four stages, namely perceived a threat, self-efficacy, educational participation, and evaluation during four sessions of 20-40 minutes. The control group only received the usual care. The burden of care of the control and intervention groups were measured one month after filling out the initial questionnaire, and one month after the end of the intervention, respectively.</p>	<p>Study showed that the informed participation and motivating parents to gain caring skills is effective in reducing their care burden. According to the results, the level of caregiver burden for the intervention group, decreased after the implementation of the FCEM. • Caregiver's participation in an empowerment program would significantly increase their competence in caring for children with cancer, undergoing chemotherapy.</p>	<p>there were different stages and different scenarios (single parent families, two-parent families) the study Innovative study that is examining an important problem/issue .</p>	<p>There were some limitations in this study. The difference in mental and psychological characteristics , difference in interpersonal interactions with patients, and difference in motives and personalities of the subjects, are factors that could not be controlled by the researchers, but may affect the learning, sense of self-efficacy, self-esteem, and self-control, and subsequently the empowerment .</p>
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<p>Svavarsdottir, Erla K, et al. <i>The Impact of Family Strengths Oriented Therapeutic Conversations on Parents of Children with a New Chronic Illness Diagnosis</i>, 29 July 2020, pp. 1–24.</p>	<p>The aim of the study was to evaluate the benefits of two sessions of a Family Strengths Oriented Therapeutic Conversation (FAM-SOTC) intervention, offered by advanced practice nurses to mothers of children and adolescents in Iceland with newly diagnosed chronic illnesses/disorders.</p>	<p>Sample size was 31 mothers. Participants in this study were 31 primary caregivers all of whom were the mothers of children or adolescents with T1DM, JIA, epilepsy, or sleeping disorder with ADHD.</p>	<p>Quasi-Experimental with pre- and post-test comparison of the main study variables.</p>	<p>Consisted of establishing a therapeutic relationship with the parent of the ill child, drawing a family genogram, exploring the quality of the family relationships, encouraging the telling of the family illness story, asking therapeutic questions, identifying strengths, resilience, and resources, offering evidence based information and recommendations, and identifying facilitating or helpful illness beliefs and or challenging constraining or hindering illness beliefs</p>	<p>The two session FAM-SOTC intervention was beneficial for the mothers, who were primary caregivers of children and adolescents. Participants reported significantly higher quality of life (total score) for their family after the two session of the FAM-SOTC intervention compared to baseline. also reported significantly higher scores on the subscales of the quality of life scale including physical functioning (T2: <i>M</i> and were significantly less worried</p>	<p>-Participants in this study were 31 primary caregivers all of whom were the mothers of children or adolescents with T1DM, JIA, epilepsy, or sleeping disorder with ADHD . These are all different types of chronic illnesses and shows how this study can really benefit families.</p>	<p>-Only the mothers were part of the study - small sample size</p>
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<p>Cousino, Melissa K, and Rebecca A Hazen. "Parenting Stress Among Caregivers of Children With Chronic Illness: A Systematic Review." <i>Journal of Pediatric Psychology, Volume 38, Issue 8</i>, vol. 38, no. 8, 13 July 2013, pp. 809–823., https://doi.org/https://doi.org/10.1093/jpepsy/jst049.</p>	<p>To critically review, analyze, and synthesize the literature on parenting stress among caregivers of children with asthma, cancer, cystic fibrosis, diabetes, epilepsy, juvenile rheumatoid arthritis, and/or sickle cell disease</p>	<p>Meta-analysis of 13 studies and qualitative analysis of 96 studies was conducted -PsycInfo, MEDLINE, and Cumulative Index to Nursing and Allied Health Literature were searched according to inclusion criteria</p>	<p>Quantitative Review (Meta-Analysis)</p>	<p>The following databases were searched: PsychInfo, MEDLINE, and Cumulative Index to Nursing and Allied Health Literature (excluding MEDLINE results). The search was limited to articles published in a peer-reviewed journal from January 1980 to June 2012 to allow for the inclusion of as many studies as possible, while also limiting the review to studies relevant to current medical practice. Predetermined search terms were used to identify articles meeting the inclusion criteria.</p>	<p>Findings suggest that generic aspects of the caregiving experience, not specific to the child's chronic illness, bring about greater stress for parents of children with pediatric chronic illnesses. In addition to experiencing greater general parenting stress, caregivers of children with chronic illness are also likely to experience illness-related parenting stress (e.g., frequent clinic appointments, demanding treatment regimens).</p>	<p>-Meta-analysis = high level of evidence Study was evidenced based on statistics and articles were chosen from top reliable nursing data bases. -Shows what is a future concern/problem for the general population of parents.</p>	<p>-There may be some publication bias within the different articles that were founded; not 100% trustful; maybe misleading conclusions</p>
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<p>Crespo, C., Santos, S., Tavares, A., & Salvador, Á. (2016). "Care that matters": Family-centered care, caregiving burden, and adaptation in parents of children with cancer. <i>Families, Systems, & Health</i>, 34(1), 31–40. https://doi-org.dominican.idm.oclc.org/10.1037/fsh0000166</p>	<p>Purpose: to identify the direct and indirect associations, through caregiving burden, between parents' Family centered care and quality of life (QoL) and life satisfaction.</p>	<p>204 parents and other relatives involved in taking care of children diagnosed with cancer</p>	<p>Quantitative-Correlated Study</p>	<p>The parent was the child's primary informal caregiver for health issues, the child was at least 3 months postdiagnosis, and the child had been receiving treatment for newly diagnosed/relapsed cancer or had finished antineoplastic treatments within the last 5 years. A researcher approached parents at the inpatient and outpatient treatment settings of both hospitals. All parents except one agreed to participate and provided informed consent for the study after being briefed about its goals and procedures. Participants filled out the questionnaires for care burden at the hospital while waiting for their children's clinical appointments in the presence of a researcher.</p>	<p>-older parents and parents of older children reported higher levels of FCC and lower caregiving burden. Being an older parent was also associated with higher life satisfaction. - caregiving burden was correlated with worse Quality of life and lower life satisfaction.</p>	<p>-large sample size -Innovative, shows how important family centered care is and how it benefits families and a Childs quality of care.</p>	<p>The ways in which the two hospital sites operationalized FCC are important factors that were not covered in this study. - the cross-sectional nature of the data, which precluded the verification of causality among the variables in the mediation model.</p>
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<p>Hui Ling Chen, Tsui-Sui Annie Kao, Reuille, K. M., & Northouse, L. (2021). FOCUS Program: Treating patients with cancer and family caregivers as a unit of care. <i>Clinical Journal of Oncology Nursing</i>, 25(3), E17–E25. https://doi.org/10.1188/21.CJON.E17-E25</p>	<p>This evidence-based pilot study evaluated the feasibility and preliminary efficacy of the nurse-guided, psychoeducational, family-based FOCUS program intervention at a local oncology outpatient clinic.</p>	<p>30 patient-caregiver dyads were recruited from a local oncology clinic.</p>	<p>Qualitative Study</p>	<p>Intervention delivery occurred using home visits and telephone calls. Self-administered questionnaires were used to assess participants' self-efficacy, quality of life (QOL), and coping pre- and postintervention, and intervention satisfaction postintervention. Three tailored psychosocial education sessions were held during a 6- to 9-week period.</p>	<p>Significant changes in outcomes were found, including increased self-efficacy in both patients and caregivers, higher QOL in caregivers, and decreased use of substances for coping in patients. There was a trend for patients' emotional well-being to improve over time; other aspects of QOL showed little change. There were no significant changes in caregivers' coping.</p>	<p>Volunteers were willing to participate 6 months of life were excluded because of the extreme stress</p>	<p>-Limited amount of people in the study -30 is a small sample size.</p>
<p>al Ghriwati, N., Stevens, E., Velázquez-Martin, B., Hocking, M. C., Schwartz, L. A., & Barakat, L. P. (2021). Family factors and health-related quality of life within 6 months of completion of childhood cancer treatment. <i>Psycho-Oncology</i>, 30(3), 408–416. https://doi.org/10.1002/pon.5592</p>	<p>The transition from active cancer treatment to survivorship represents a period of uncertainty for youth and their families, but factors associated with adaptation during this</p>	<p>154 caregivers (of patients' ages 0–18 years) and 52 youth (ages 7–18 years)</p>	<p>Quantitative Study</p>	<p>completed questionnaires assessing family factors, neurocognitive difficulties, and HRQL for patients within 6 months following treatment completion. Electronic health records were reviewed for cancer and treatment-related information. Bootstrapping analyses assessed</p>	<p>Family factors were associated with self- and caregiver reports of children's HRQL. Controlling for demographic, cancer, and treatment covariates, caregiver reports of their child's neurocognitive difficulties had an indirect effect</p>	<p>-Large sample size - Different types of questions that assessed the caregivers</p>	<p>- The sample represented predominantly White children with biological mothers serving as primary caregivers. Given that race was associated with HRQL, health disparities exist, and family beliefs and attitudes regarding illness</p>

	<p>period are understudied.</p> <p>Purpose was to evaluate associations between cancer and treatment-related variables, family factors (family functioning, caregiver health-related quality of life [HRQL], and caregiver distress), and patient HRQL after treatment completion. We assessed the indirect effects of neurocognitive difficulties on youth HRQL through family factors.</p>			<p>whether neurocognitive function had indirect effects on HRQL through family factors.</p>	<p>on their reports of child physical HRQL through family functioning. Caregiver reports of their child's neurocognitive difficulties indirectly related to caregiver reports of child psychosocial HRQL through family functioning and caregiver HRQL. Indirect effects for self-reported neurocognitive difficulties and HRQL were not supported.</p>		<p>management patterns may differ across cultural backgrounds, 36 our findings require replication with a larger, more diverse sample. -left minorities</p>
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