FAMILY CENTERED CARE: A LITERATURE REVIEW

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ABSTRACT

Collaborative action between families and health professionals, in this case nurses, doctors, nutritionists, pharmacies in forming harmonious support is the philosophy of family centered nursing care which aims to involve families as the main focus in care. The aim of this literature review is to identify family-centered family member care: a literatu review. This language method uses literature reviews which are summaries of 10 articles in the publication years of 2020-2021 on search 4 databased electronic searches containing namely Scopus, ProQuest, Pubmed, and Scient Direct. This review used prisms. The eligibility of these studies were from its title, abstract, research methodology, results and discussion. The results of the review were presented in narrative form. The results of a review of 10 articles found that the form family centered care Conclusion: The family is considered a partner in the care of other family members. The concept of family centered care is a philosophy in nursing where the role of the family is very important in caring for family members who are sick.

Keyword: family centered care

INTRODUCTION

Background

The family is the smallest unit of society consisting of the head of the family and several family members who gather and live in a place in a state of dependence on one another (1). The daily life of family members cannot be separated from the healthy range of illness which is a dynamic condition (2). Conditions can occur when there is an imbalance between the host (human) and the environment (environment) around (3). The role of the family in the care of family members in the hospital can affect the lives of other family members both physically, psychologically and socially (4). Families are considered partners in the care of other family members (5). The concept of family centered care is a philosophy in nursing that recognizes the very important role of the family in caring for family members who are sick(6) .

Aim of the study

Describes family-centered care of family members

Research question

What is family-centered care for members of the family?

METHODS

A comprehensive summary in the form of a literature review on family-centered care of family members. Protocol and evaluation from literature review used the PRISMA checklish to determine the selection of studies that were identified and tailored to the objectives of the literature review.

Literature review which is a comprehensive summary of several studies, research that is determined based on a specific theme. The search for literature was carried out in March 2021. The data used in the study were secondary data obtained, not from direct observation but obtained from the results of research that had been conducted by previous researchers. The secondary data source obtained is in the form of reputable journal articles both nationally and internationally within the last 3 years with a predetermined theme. The rivew literature search in this case used five databases with high and medium quality criteria, namely Scopus, ProQuest, Pubmed, and Scient Direct.

Searching for articles or journals uses keywords and boolean operators (AND OR NOR or AND NOT) which are used to expand or specify a search, making it easier to determine which articles or journals are used. Key words in the review literature are adjusted accordingly Medical Subject Heading (MeSH) and consists of the following:

Table2.1. Keywords: family centered care review

Family	**Center**	**Care**
Relatives	Core	Manage
OR	OR	OR
Kindred	midst	Take care of

Based on the results of literature searches through publications in five databases and using keywords that have been adjusted to MeSH, the researchers obtained 200 articles that match these keywords. The search results that have been obtained are then checked for duplication, it is determined that there are 60 similar articles so they were excluded and the remaining 140 articles. The author then conducted a screening based on the title (n = 140), abstract (n = 40) and full text (n = 25) which was adjusted to the theme of the literature review. An assessment that was carried out is based on the eligibility of the inclusion and exclusion criteria obtained as many as 25 articles that can be used in the literature review.

RESULTS

Reviews contained in 10 journals regarding family center care from the inclusion criteria of quantitative and caulitative research designs from 4 databased electronic searches contain namely Scopus, ProQuest, Spingerlink, and Scient Direct, obtain the following results:

1. Article title: "Anticipating the Future of the Child and Family in Pediatric Palliative Care: A Qualitative Study Into the Perspectives of Parents and Healthcare Professionals".

This article started at background preparing to future scenarios in pediatric palliative care is perceived as complex and challenging by both families and healthcare professionals. This interpretative qualitative study using thematic analysis aims to explore how parent and healthcare professionals anticipate the future of the child and family in pediatric palliative care. Single and repeated interviews were undertaken with 42 parents and 35 healthcare professionals of 24 children, receiving palliative care. Anticipating the future was seen in three forms: gold detected conversation, anticipated care and guidance on the job. Goal directed conversations were initiated by either parents or healthcare professionals to ensure others could align with their perspective regarding the future. Anticipated care meant healthcare professionals or parents organized practical care arrangements for future careers with or without informing each other. Guidance on the job was a form of short-term anticipation, whereby healthcare professionals guide parents ad hoc though difficult situations(7).

2. Article title: "Development ang Psychometric Validation of the Family-Centered Multidimensional Outcome Measure for Pediatric Palliative Care Targeted to Children with Severe Neurological Impairmentis-A Multicenter Prospective Study".

This article started at background comprehensive outcome measurement in pediatric palliative care focusing on the entire of care, that is affected child and its family is crucial to depict treatment effects. Despite its increasing relevance no appropriate multidimensional outcome measures exist for the largest patient group in this field, namely children with severe neurological impairments. The aim of this study was to develop and validate a family centered multidimensional outcome measure for pediatric palliative care patients with severe neurological impairment that encompasses the entire unit of care. Based on the results of a qualitative study of employing ang comfirmatory factor analyzes as well as reliability and item analysis. A total of 11 pediatric palliative care teams across aided in the recruitment of study participants. Quesionares were answered by 149 parents of chidren with severe neurological impairment and 157 professional caregivers. The exploratory factors analysis of parent data revealed a 6 factor structure of the questionnaire representing: symptoms, the child's social participation, normalcy, social support, coping with disease and caregiver's competencies. This structure was verified by a confirmatory factor analysis of professional caregiver data. Five separate items regarding sibling, patners and further symptoms not applicable for all patients were added to ensure full multidimensionality normalcy, social support, coping with disease and caregiver's competencies. This structure was verified by a confirmatory factor analysis of professional caregiver data. Five separate items regarding sibling, patners and further symptoms not applicable for all patients were added to ensure full multidimensionality normalcy, social support, coping with disease and caregiver's competencies. This structure was verified by a confirmatory factor analysis of professional caregiver data. Five separate items regarding sibling, patners and further symptoms not applicable for all patients were added to ensure full multidimensionality(8).

3. Article title: "Dignity of Informal Caregivers of Migrant Patients in the Last Phase of Life: a Qualitative Study".

This article started at background palliative care is to improve the quality of life patients and their families. To help ensure quality of life for the families of patients with migrant, this study sought insight into the dignity of informal caregivers in migrant communities. This could improve understanding of family centered care for migrant patients. Method: twenty semi structures interviews with informal caregivers of Turkish, Morocca or Surinamese background living in the Netherlands were analyzed thematically. The dignity of the patient and that of their informal caregivers were found to be strongly interrelated. Most important for the dignity of caregivers was ensuring good care for their patients and preserving the patient's wishes. For many informal caregivers it also included delivering care to the patient by themselves or together with only family members despite having to give up part of their own lives. Providing care themselves was part of maintaining a good relationship with the patient, the care was to cater to the patient's preferences and help preserve the patient's dignity, and it cloud be accompanied by valuable aspects such as time for good conversations. Positive interaction between an informal caregiver and a patient positively influenced the informal caregiver's dignity. Informal caregiver and patient dignity were often compromised simultaneously, when informal caregiver felt healthcare professionals were undermining a patient's dignity, their own dignity suffered. According to informal caregivers,(9).

4. Article title: "Impact of Patient-Centered and Family -Centred Care Meeting on Intensive Care and Resource Utilization in Patients with Terminal Illness: a Single-Center Retrospective Observational Study in Taiwan".

This article started at background shared decision making is essential for patients and their families when Facing serious and life-threatening diseases. This study aimed to evaluate the impact of patient centered and family centered care meeting (FPCCM) on intensive measures and resource ulitisation during end of life (EOL) hospitalization among terminally III patients. Design: a retrospective cross sectional study using electronic medical records was conducted in a tertiary referral medical center in Taiwan. The participants we identified 6843 deceased patients with terminal illness who either received or did not receive PFCCM during EOL hospitalization between January 2013 and December 2015. Premary and secondary outcome measures patients who were transferred to the intensive care unit (ICU). Those who underwent invasive or non invasive mechanical ventilation, tracheostomy, haemodialysis and surgical intervention during the final hospitalization were derermined by the use of intensive care measures, secondary measures were individual total and daily medical expenditures. A generalized estimating equation (GEE) model was used to compare the differences between the two groups. Or and beta coefficients (β) with 95% CI were estimated. This study identify 459 patients (6.7%) who received PFCCM during EOL hospitalization. Multivariate analyzes showed that patients who received PFCCM were less likely to have ICU admissions (OR 0.44; 95% CI 0.34 to 0.57) undergoing surgical interventions (OR 0.74; 95% CI 0.58 to 0.95) and invasive mechanical ventilation (OR 0.50; 95%. CI 0.38 to 0.66) during the final hospitalization, after adjusting to patient demographic clinical conditions and year of admission. Additionally, a significant decrease in daily medical expenditures was observed in PFCM patients (β-0.18; 95% CI-0.25 to -0.12) than in non PFCCM patients(10).

5. Article title: "Experts of General Practices of Children with Complex and Palliative Care Needs and their Families: a Qualitative Study".

This article started at background to investigate the views and experiences of general practice of children with life limiting and life threatening conditions and their family members, through secondary analysis of a qualitative serial interview study. Thematic analysis was conducted on all interview data relating to experiences of primary care. A total of 31 participants (10 children with life limiting and life threatening conditions and 21 family members) from 14 families. Secondary thematic analysis of qualitative interview data from a study carried out in the West Midlands UK. Method: 41 serial interviews with 31 participants from 14 families (10 children aged 5-18 years with life limiting and life threatening conditions and 21 of their family members. Three key themes emerged: poor experiences of general practice cause children and families to fell isolated, children and families value support from general practice, there are practical ways through which general practice has the potential to provide important aspects of care. Children and families reported benefits from fostering their relationship with their general practice in order to access important aspects of care including the assessment and management od acute illness, chronic disease and mediction reviews and holistic support(11).

6. Article title: "Family Experiences with Palliative Care for Children at Home: a Systematic Literature Review".

This article started at background the main goal of pediatric palliative care (PPC) is to improve or maintain the best possible quality of life (Qol) for the child and their family. PCC can be provided in community health centers, within the specialist health care service and or in the child's home. Home is often the preferred place for families and recommendations state that, whenwever possible, the family home should be the center of care for the child. The study is to systematically review the experiences and need of families with children receiving palliative care at home. Methods: conducted a systematic review and searched the peer reviewed databased CINAHL, Embased, Pcyclnfo and MEDLINE for articles published between January 2000 and October 2019. We included 23 studies emphasising the experience of family members when their child (0-18 years) received palliative care at home. We used a thematic analysis to identify relevant themes in the literature and synthesis the findings from the different studies. The review represents the experiences of the families of almost 300 children with life limiting (LL) and life threatening (LT) conditions receiving applicable care at home. In general the children mothers are interviewed and seldom the sick children themselves or their siblings. Most families preferred staying at home since it made it easier to maintain a normal family life, was less stressful for the sick child and meant that siblings could still attend school and be with friends. Families experienced a range of calls due to the coordination of care, including a lack of support and adequately skilled staff with appropriate experience. Respite care was needed in order to cope with everyday life. Some studies were not specific concerning the place of care and some relevant papers may have been omitte(12).

7. Article title: "Support for Familes at Home during Childhood Cancer Treatment: a Pilot Study with Mr. V Spaceman, a Family-Based Activities Tol".

This article started at background it is important to support families in dealing with the distress that comes along with the diagnosis and treatment of childhood cancer. Therefore we developed a playful tool that families can use at home to support their family functioning and safeguard their normal family life.

We pilot tested this new tool called Mr. V and desribe how families used and evaluated the tool and how it could be further improved. Method: MrV is an interactive dispenser that looks like a spaceman and proposes family activities. These activities are suggested by family members themselves and dispensed by the machine at unexpected moments. MrV producted data on how it was used and questionnaire and semi structured interview were used to evaluate the experiences of families and the potential of this tool. Results: ten families with a child with cancer between 5 and 9 years old (Mage = 6.7 years) who were in active treatment (mixed diagnoses) participated (n = 47; npatients = 10, nsibling = 9, nparent = 16). All families used Mr. V for multiple days and were very satisfied with the tool regarding its acceptability, feasibility and potential effectiveness. The also had suggestions on how the tool could be further improved(13).

8. Article title: "the Effect of a Family Centered Pcychosocial Based Nutrition Intervention in Patients with Advanced Cancer: the PiCNIC2 Pilot Randomized Controlled Trial"

This article started at background malnutrition in advanced cancer patients is common but limited and inconclusive data exists on the effectiveness of nutrition interventions. Feasibility and acceptability of a novel family based nutritional psychosocial intervention were established recently. The aims of this present study outcome measures and to explore preliminary outcomes. Method: pilot randomized controlled trial recruiting advanced cancer patients and family caregivers in Australia and Hongkong. Participants were randomized and assigned to one of two groups, either a family centered nutritional intervention or the control group receiving usual care only. The intervention provided 2-3 hour of direct dietitian contact time with patients and family members over a 4-6 week period. During the intervention issues with nutrition impact symptoms and food or eating related communication between the dyads and setting nutritional goals. Feasibility assessment included recruitment, consent rate, retention rate and acceptability of assessment tools. Validated nutritional and quality of life self reported measures were used to collect patient and caregiver outcome data, including the 3 day food diary, the patient generates subjective global assessment short form, the functional assessment anorexia or cachexia scale, eating related distress or enjoyment and measures of self efficacy, carers distress, anxiety and depression. Results: seventy four patient and 54 family caregivers participanted in the study. Recruitment was challeging and for every patient agreeing to participate, 14-31 patients had to be screened. The concent rate was 44% in patients and 55% in caregivers. Only half the participant completed the trial's final assessment. The data showed promise for some patient outcomes in the intervention group, particulary with improvements in eating related distress (p = 0.024 Hongkong data) and quality of life (p = 0.045 Australian data). Energy and protein intake also increased in a clinically meaningful way. Caregiver data on eating related distress, anxiety, depression and caregiving burden however showed little or no change. Energy and protein intake also increased in a clinically meaningful way. Caregiver data on eating related distress, anxiety, depression and caregiving burden however showed little or no change. Energy and protein intake also increased in a clinically meaningful way. Caregiver data on eating related distress, anxiety, depression and caregiving burden however showed little or no change.

9. Article title: "Families Control Preference for Participation in Patient Care in Adult Intensive Care".

This article started at background understand families preferences and observed participantion in patient care in an adult ICU. Method: the mixed methods design used survey and naturalistic observation to collect data from a convenience sample of 30 family members of critically ill patients. Setting of two public hospital intensive care units in Australia. Main outcomes measures: (1) families prefences for participation in decision making and physical patient care activities in the adult intensive care unit, measured using a modified control preference scale (2) the type and frequency of family participant in patient care activities in the intensive care unit. Result: almost half (47%) reported a preference to share in decision making about care for their relative with health care professionals, 17% reported a preference for active participation in decision making. Alternatively most families preferred a passive (60%) role in the physical care of their relative 33% preffered shared participation with staff and very few (3%) preffered active participation with little involvement of staff. Of the 193 activities observed family participation in physical care was the least frequent.

10. Article title: "What Matter to Patients and their Families during and after Critical Illness: a Qualitative Study".

This article started at background despite increase emphasis on providing higher quality patient and family centered care in the intensive care unit (ICU), thera are no widely accepted definitions of such in the ICU. To determine aspects of care that patients and families valued during their ICU encounter, out comes that patients and families prioritized after hospital discharge and outcome perceived as aquivalent to or worse than death. Method: semistructured interviews (n = 49) of former patients of an urban, academic medical ICU and their family members. Two investigators reviewed all transcripts line by line to identify key consepts. Codes were created and defined in a codebook with decision rules for their application and were analyzed using qualitative content analysis. Result: salient theme were identified and grouped into 2 major categories (1) processes of care within the icu communication, patient comfort and a sense that the medical team was doing everything (providing exhaustive medical care), (2) patient and surrogate outcomes after the ICU survival, quality of life, psychological function and cognitive function. Several outcomes were deemed worse than death, severe cognitive / physical disability, dependence on medical machinery or equipment and severe or constant pain(14).

DISCUSSION

Families are considered partners in the care of other family members (5). The concept of family centered care is a philosophy in nursing that recognizes the very important role of the family in caring for family members who are sick(15). Hospitalization is a process that requires a sick child or family member to stay and be hospitalized(7). Hospitalization is carried out by undergoing therapy and treatment until the condition is healthy as before or conditions that require support in cases of palliative care, for example in cancer latrines both to family members being treated and to the family itself.(16). Cultural adaptation of sick family members during hospitaliation also requires adjustments to the culture in the hospital or treatment procedures(17). The role of the family as a partner for nurses to determine the fulfillment of children's needs(8). Needs oriented towards the needs of family members with terminal illnesses in the form of family-centered nursing care(9). Family centered care is the most important thing in the hospitalization process(10). The hospitalization process is based on collaboration between sick family members, families, other health professionals in clinical care based on planning, providing nursing care.(11). Family centered care is based on a partnership approach to health care related decision making(18). Based on several studies, family centered care is building collaboration between nurses and parents in improving the health and development of each child or family member who is sick(19). Families also play a role in improving clinical decision making, creating and developing follow-up collaborative care plans(6). The family is suggested to increase understanding of the strengths of the family, the use of health care resources and the time of professionals more efficiently and effectively(12). Family members who are hospitalized require adequate nutritional intake for the healing process(4). Competitive marketing competition, increased professional satisfaction, increased satisfaction of children or family members who are sick with the health services received (20). Increasing professional satisfaction to customers requires effective communication between the family and the health team (21).

CONCLUSION

Caring for a sick or chronically ill family member can affect family life (22). Support systems from health workers are needed by families during the care of children or family members who are sick(13). Support systems are needed, especially for families who have family members with terminal illnesses (23). Survival between sick family members and caring families and caring health workers is very important in relation to the recovery of the client who is cared for (24). Family centered nursing is a collaboration between health workers and the patient's family (25).

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