

The Effect of Ostomy on Pediatric Patient and Family in Nursing

A Systematic Review

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Aim: This study aimed to examine the studies on children with stoma/ostomy in the field of nursing in terms of nursing science.

Method: This was a qualitative research based on a document analysis of the studies, and it was designed as a systematic review. It was carried out in accordance with the Centre for Reviews and Dissemination guide. The databases of EBSCOhost, PubMed, Science Direct, Google Scholar, and Web of Science were searched between January 2010 and October 2020, and the studies on ostomy in pediatric patients were examined. The search was conducted by using the English keywords including "ostomy/stoma, children, nursing care." Inclusion and exclusion criteria to select studies were determined based on the PICOS method (P = populations, I = interventions, C = comparison, O = outcomes, and S = study type). Data were extracted by two researchers independently. All studies were examined in full text, and it was decided which studies to include in the systematic review.

Results: In this study, 9,857 studies were found by entering the keywords in the first search. Among these, 87 studies were selected when their titles, abstracts, and keywords were examined. By the inclusion criteria, 20 studies from the EBSCOhost, PubMed, Scopus, Google Scholar, and Science Direct databases were included in the study.

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Conclusion: It was observed that the most common studies were the ones that were investigating the problems experienced by the children with an ostomy and their parents and its effects on them. It has been suggested that this systematic review will form a base for the experimental or randomized controlled studies that are needed in the field of ostomy and make a contribution to the literature.

KEY WORDS: children, nursing care, ostomy, pediatric nursing, stoma

INTRODUCTION

Stoma/ostomy is a surgical practice with a follow-up and care that is often performed in pediatric intensive care units, neonatal intensive care units, and surgery clinics in our country and all over the world to save lives and enhance the quality of life (Beitz et al., 2010; Colwell & Beitz, 2007; Kyle & Carman, 2013; Pittman et al., 2008). There are many reasons to open an ostomy in children. Imperforate anus, necrotizing enterocolitis, Hirschsprung disease, bladder exstrophy, inflammatory bowel disease, meconium ileus, intestinal tumors, and abdominal traumas can be shown as examples (Jordan & Burns, 2013; Slatter, 2011). An ostomy may be a major source of fear, anxiety, and stress by adversely affecting the quality of life of the child and his or her family. Therefore, the child and the family may experience difficulty in adapting to an ostomy. Parents generally consider this situation as a failure, lack of normality, and loss of hope (Yildiz, 2015). In ostomy surgery, it is aimed to eliminate pathology, prolong life, and improve quality of life. However, the idea of opening an ostomy to the child causes him or her and the family to experience problems in psychological and social aspects and to worry from the first moment (Celik et al., 2015). The causes of anxiety are generally the size and care of ostomy, body image problems, disease process, complications, daily care needs, stigma, psychosocial barriers, and uncertainties (Nicholas et al., 2007).

Deterioration in skin integrity and physical appearance because of ostomy has a psychological effect that may cause the child to stay away from his or her friends and even from the family. These difficulties associated with an ostomy are the factors reducing the quality of life of the child and the family (Bonita, 2008).

The task of a pediatric health nurse is to help the child and the family, who need assistance in adapting to a new life, to evaluate them in physical, psychological, and social aspects; to determine in which areas their quality of life is affected; and to plan and perform nursing interventions for the areas affected. Pediatric nurses can provide support to children with stoma and their families, especially with their roles of providing care and information, counseling, emotional support and advocacy (Uzsen et al., 2018). This systematic review aimed to examine nursing studies on children with an ostomy in the field of nursing.

Study Questions

Below are the guide questions used for this study:

1. What are the common complications and their causes in pediatric patients with an ostomy?
2. What kind of initiatives has been carried out to improve the knowledge levels and skills of the parents and nurses who provide care to the children with an ostomy?
3. What are the physiological, psychological, and psychosocial experiences of the child with an ostomy and the families?

METHOD

The study protocol was generated for the examination of nursing studies regarding ostomy in pediatric patients, and the PRISMA statement was used in writing (Moher et al., 2009).

Research Strategy

This was a qualitative study based on a document analysis of the other studies and had a systematic review design. The aim of a systematic review is to collect, analyze, and report on the documents. This study was carried out in accordance with the Centre for Reviews and Dissemination guide (CRD), which was developed by the National Health Research Institute in the University of York and provides information about the basic principles and methods of systematic reviews (CRD, 2008). This literature review was conducted by searching the EBSCOhost, PubMed, Scopus, Google Scholar, and Science Direct databases between January 2010 and October 2020 to examine nursing studies on ostomy in pediatric patients. The search was made by using the English keywords including “ostomy/stoma, children, nursing care.”

Selection of Studies

The EBSCOhost, PubMed, Scopus, Google Scholar, and Science Direct databases were searched for qualitative and quantitative nursing studies that were published between 2010 and 2020 regarding nursing care of the child with an ostomy by using the keywords of “child with a stoma, the child with an ostomy” to define health condition of interest and “nursing care” to search for the intervention evaluated. The search appears in Figures 1 and 2, which are included in the supplemental material (see Figure 1, available at <http://links.lww.com/JPSN/A32> and Figure 2, available at <http://links.lww.com/JPSN/A33>). The data extraction procedure was carried out by two researchers independently. Selected articles were compared by both researchers and provided consensus on articles with different opinions. Full texts of all studies, which were considered as appropriate depending on their titles and abstracts, were retrieved, and agreement was made on the final inclusion and exclusion criteria. Studies were reviewed in full text to ascertain which studies would be included in the systematic review. In this literature review, a meta-analysis could not be performed because the characteristics of the participants, interventions used, and measurement methods were not the same.

In the selection of studies, inclusion and exclusion criteria were based on the PICOS method. PICOS consists of participants (P), interventions (I), comparators (C), outcomes (O), and study design (S).

Inclusion Criteria

Below are the inclusion criteria for this study:

- P: Children with an ostomy who were aged 18 years or younger and adults caring for their children with an ostomy (nurses, nursing students, parents)
- I: Care of children with an ostomy
- C: Different study methods, any intervention, or a combination of interventions
- O: Any clinical outcome, determination of problems related to ostomy, the effect of ostomy care, the effect of ostomy education, care strategies, and nonpharmacological methods used
- S: Qualitative or quantitative research methods in the field of nursing (written in the English language)

Exclusion Criteria

Below are the exclusion criteria for this study:

1. Other health areas
2. Language other than English
3. Reviews and letters to the editor

Ethical Aspect of the Study

There was no financial/moral risk of harm during the literature review.

RESULTS

During the first search in the study, the numbers of articles reached via databases was found to be 828 in EBSCOhost, 155 in PubMed, 144 in Science Direct, 11 in Scopus, nine in WOS, and 8,710 in Google Scholar. After the examination of titles, abstracts, and keywords of the articles, 87 articles were included in the systematic review. In the other steps, 20 studies that met the inclusion criteria were found after the search. Data summarizing the 20 studies are included in Table 1 in the supplemental material (available at <http://links.lww.com/JPSN/A31>). Among these studies, 50% were qualitative, 25% were quasiexperimental, and 10% were descriptive.

DISCUSSION

In this systematic review, studies on children with an ostomy in the field of nursing were evaluated. According to the results, it was determined that qualitative studies were more common, and randomized controlled or experimental/quasi-experimental studies were less common. In the previous studies, it was found that children with ostomy experienced skin-associated complications often a week after the surgery and more severe complications such as dislocation and skin erosion after 3 months. The reasons for complications have been indicated as inadequate care and late closure of colostomy. Families had to buy a colostomy pouch because of the late closure of colostomy, and this brought a financial burden to the family. Families with a poor socioeconomic status used cotton instead of a colostomy pouch. The use of cotton increased the risk of peristomal skin complications especially among the children with diarrhea. Peristomal skin complications are followed by fungal infections. Cutaneous fungal infection is seen more often (Abd-Elhay et al., 2019). In the study by Li et al. evaluating nursing care given to the pediatric patients with enterostomy in 483 cases during the last 5 years, it was determined that 30 newborns had peristomal skin lesions, 15 cases had allergic dermatitis, 13 cases showed fecal dermatitis, and two cases were presented with avulsion injury. These complications were thought to be derived from inadequate nursing education and lack of knowledge and care skills among the caregivers at home (Li et al., 2019). In another study, Shauq (2015) reported skin lesions and enterocolitis as the most common colostomy complications. The families were assessed based on the Zarit Care Burden Scale in this study, and it was found that colostomy brought a severe burden in social, psychological, and economic aspects. However, it was

also determined that family relationships and parents living together increased endurance power and decreased care burden among the mothers (Shauq, 2015).

In the study by Kerr (2015), an artificial ostomy was created on volunteer nursing students based on their choice (urinary or fecal ostomy). Then, they were asked to write their experiences during 1 day. It was found that their experiences were negative, they experienced problems during dressing and the appearance of ostomy through the clothes, they could not find an appropriate position to sleep at night, and they had difficulties in sports activities and about draining, drying, and preserving the ostomy after showering. They also stated that there were a rash, itching, and wetness of the skin where the ostomy was placed and they felt discomfort and anger against this condition. It was determined that they felt different regarding body image, they were ashamed, and they dressed differently than the fashion because of their choice of clothes. The students also declared that individuals having an ostomy should be definitely trained in adapting and coping with an ostomy and they should be informed about how the ostomy site would affect their lives based on their daily experiences (Kerr, 2015).

In the study by Yang et al., parents were given verbal education and practical training about ostomy care in the clinic, and this training was repeated before discharge. A consulting service was continued with the parents who were providing ostomy care at home via WeChat. Skin lesions and allergic dermatitis complications were frequently observed. On the basis of the study results, it was found that the quality of life of the parents and patients was enhanced, the incidence of complications was reduced, and the job satisfaction of the nurses increased because of the WeChat intervention (Yang et al., 2015). In the randomized controlled study of Goudarzi et al. (2016), which was conducted with the mothers of babies in the neonatal intensive care whose infants would undergo colostomy, routine care was applied to the control group. The experimental group was given a mother empowerment education within three-step colostomy care, and the education was repeated for the mothers as often as needed. The study results showed that the stress and depression levels of the mothers in the experimental group were significantly decreased (Goudarzi et al., 2016). In the quasi-experimental study of Dabas et al. (2016), including 30 mothers, the education given to the mothers regarding colostomy care on video increased their knowledge and care skills (Dabas et al., 2016). In the thesis study of Dhanalakshmi (2016), the author assessed the level of knowledge regarding colostomy care and the effectiveness of an instructional

package on colostomy care among caregivers. It was also reported that colostomy training given to the mothers enhanced their knowledge and care skills (Dhanalakshmi, 2016). Moreover, in the study by Hashem and Abusaad (2016), a training program was prepared on ileostomy care and clinic nurses were educated. The results of this study showed that the knowledge and care skills of the nurses were greater after training (Hashem & Abusaad, 2016).

Caregivers may face many complications during colostomy and ileostomy care. Besides, this may be accompanied by physical, psychological, and psychosocial problems. It has been considered that training on ostomy care given to the families and children will enhance their care skills, decrease complication risk, and facilitate adaptation to ostomy by reducing anxiety and stress on the family and children (Aite et al., 2006; Sheikh et al., 2006).

Children with an ostomy should be allowed to express their fear and anxiety. Their concerns about body image should be shared, and they should be given consultation on how they can behave (Stiekema, 2021). Knowledge levels of the children and families should be evaluated, and information about basic anatomy, physiology, and operation site should be given with developmentally appropriate language. Hands-on care training should be provided on technical skills. A consultation about activity, nutrition, pain, and complications should be provided. In a qualitative study where children, adolescents, and parents shared their experiences before permanent ostomy surgery (Bray et al., 2012), individuals suggested that their information needs are not being met in relation to the day-to-day and longer-term implications of surgery. The preparation process was described as being positively influenced by contact with a nurse specialist and being given time to make the decision and access different sources of information. Children, adolescents, and parents emphasized that the most important point was the organization of training by the nurses in the most proper and understandable language following their individual qualities. Some individuals declared that they were given sufficient time to decide during the preparation period, whereas some others stated that they were not given sufficient time to think about the course of life with a permanent ostomy and that they were operated on very quickly (Bray et al., 2012). Considering that this process will affect the whole life trajectory of the individual in physiological, psychological, and psychosocial terms, it is considered important to provide an individualized consultation to each child; to plan training at a level that can be understood by the child; to continue consulting also on education, social life,

complications, and care during the period after preparation; and to introduce children and adolescents with other individuals having an ostomy to benefit from their experiences. In a qualitative study conducted with mothers of babies with ostomies in the neonatal intensive care unit (Cruz & Angelo, 2012), it was reported that their maternal-infant bonds were affected because mothers saw their children for limited time periods. Furthermore, it was reported that mothers want to spend more time with their children. Parents stated that they were anxious because they did not know the healthcare professionals working in a neonatal intensive care environment and they were scared of the ostomy on their babies because of the multiplicity and complexity of the equipment. Moreover, some parents indicated that they thought their children would experience pain because of ostomy and, thus, they were worried, whereas some other parents declared that they saw the presence of ostomy as a chance of life for their child and they tried to adapt to their new lives. They also emphasized that communication with pediatric surgical clinic nurses was very important and they should be given education on the subjects appropriate for the condition of their babies (Cruz & Angelo, 2012). Nurses are recommended to plan interventions within the framework of family-centered care according to the beliefs, feelings, and needs of children, adolescents, and parents (Leite et al., 2016; Melo et al., 2020).

CONCLUSION

In this systematic review, it is apparent that there are more qualitative and descriptive studies evaluating the problems experienced by the children with an ostomy and their families and the ostomies' effects on them. It is recommended that experimental or randomized controlled studies be conducted that will enhance the quality of life of children with an ostomy and their parents, enhance the quality of care, and make a significant contribution to the literature in this field.

Children with an ostomy and their families have special care needs. Ostomy care should be provided by the nurses specializing in this field, and primary caregivers of the children who need home care should be included in regular and continuous verbal and practical educational programs. The training program should be initiated before ostomy surgery and should be continued as long as the ostomy is present. It is also thought that preoperative consulting, appropriate training, and providing psychosocial support to the children and families will increase knowledge on ostomy care, decrease complications, and facilitate the adaptation process of the individuals.

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