

A Cluster Nursing Strategy in the Management of Congenital Constriction Ring Syndrome

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Abstract

Purpose: To investigate the effect of cluster nursing strategy in the management of patients with congenital constriction ring syndrome.

Methods: A total of 57 post-surgical patients with congenital constriction ring syndrome (CCRS) were included in this retrospective study from December 2013 to January 2020 (control group, 25 cases; cluster group, 32 cases). Incision infection and flap necrosis, and the time required for lymphedema to subside in perioperative period was compared. Vancouver Scar scale was used to evaluate the scar formation. The Pediatric Quality of Life Inventory (PedsQL) questionnaire was used to evaluate the activity of daily living of patients and Face Questionnaire was used to evaluate the parents' satisfaction with the entire treatment and nursing interventions.

Results: Compared with the control, less post-surgical incision infection (0% vs. 32%) and flap necrosis (0% vs. 12%) was found in the cluster group. The mean time required for lymphedema to subside was shorter in the cluster group (2 months vs. 3.5 months). Average Vancouver Scar Scale score in the cluster group was lower than the control group (1.6 vs. 2.4). Function evaluation by PedsQL Questionnaire was higher in the cluster group than the control group (85 vs. 70 assessed by parents). After surgery, all parents in the cluster group were satisfied with the nursing strategy.

Conclusion: Cluster nursing interventions could be an effective strategy to ensure satisfactory function and appearance outcomes for the surgical patients with congenital constriction ring syndrome.

Keywords: Congenital constriction ring syndrome; nursing; function; appearance; amniotic band

Level of Evidence: Therapeutic II

Introduction

Congenital constriction ring syndrome (CCRS) is characterized by a complete or incomplete annular narrowing of the extremities and fingers [1,2]. The clinical manifestations of congenital constriction ring syndrome include distal syndactyly, brachydactyly, ectrodactyly, and local swelling or finger/toe lymphedema distal to the constriction band [3,4]. The most commonly used intervention for CCRS is surgical treatment, such as multistage Z- and W-plasty, followed by subsequent functional training [5]. Reliable pre- and post-surgical nursing management could assure successful recovery and satisfactory outcomes.

Surgery is definitely the core treatment, but we must manage congenital deformity, especially of pubertal children, as a disease with constant physiological and psychological effects. Traditional nursing management for the CCRS mainly focus on the post-operational care, such as blood supply observation, anti-infection, incision healing and fluid infusion [2]. We need to explore a more integrated and effective approach that can simultaneously take into account diagnostic assessment, perioperative management, psychological intervention, scar management, home care, and functional follow-up.

Cluster nursing strategy refers to a series of evidence-based treatment and nursing measures to manage a certain disease [6]. This strategy, targeting a specific or type of disease, was considered effective to provide patients with the most appropriate medical care services and outcomes as much as possible [7]. It converts evidence from research, guidelines or consensus into specific clinical practice [7].

This method is widely used in the nursing of internal medical diseases which are characterized by a relatively clear pathogenic mechanism and a relatively fixed treatment plan or process [6]. Such cluster nursing interventions can usually be researched, formulated and successfully implemented by a professional nursing team with knowledge and skills in a certain discipline. For congenital limb deformities as CCRS, it is not feasible to implement cluster interventions by a single specialty nursing team. To achieve a more integrated and effective approach, participation of a multidisciplinary nursing team is required.

Few reports were found to investigate how to perform cluster nursing interventions for children with congenital limb deformities. This study aimed to design a standardized cluster nursing strategy and evaluated its effect on the management of surgery patients with congenital constriction ring syndrome.

Material and Methods

Participants

This study used a case control design. From December 2013 to December 2016, twenty-five CCRS patients (13 males and 12 females; average age 3.5 ± 1.6 yr) with traditional nursing were enrolled in the control group. From January 2017 to January 2020, thirty-two CCRS patients (20 males and 12 females; average age 3.2 ± 1.3 yr) with cluster nursing interventions were enrolled in the cluster group. There was no statistical difference in the basic data of the patients (Table 1).

Cluster Nursing Interventions for Congenital Constriction Ring Syndrome

The designed strategy, cluster nursing interventions, is a combination of multidisciplinary nursing measures committed to reduce the physical and psychological burden of young patients. The interventions improve the compliance of diagnosis and treatment, reduce the occurrence of complications, and significantly improve the long-term quality of life. Some measures could be implemented immediately after birth, throughout the entire treatment process or even long after treatment, some need to be coordinated by different professional nursing teams (Figure 1).

Psychological Nursing

Physical deformities in young children often bring anxiety to parents and make children feel inferior, and the surgery itself can create fear. Aim of the psychological nursing was to eliminate negative emotions of young patients and their parents in order to promote a healthy psychological state and self-confidence in children. We mainly carried out the following approaches: (1) Conduct effective communications with parents. We educated the parents about the knowledge of CCRS to make them understand the entire

medical process which included the sequence of the cluster nursing interventions, precautions and response measures during treatments. (2) Pay close attention to young patients. We would establish good relationship with patients once they entered into the hospital and gain the trust via greeting, companionship, games, storytelling and gifts. Good psychological interventions can effectively promote the clinical treatment, which is also a reliable support for good outcomes.

Clinical Assessment Integration

The clinical assessment of CCRS requires the coordination of different departments including plastic and construction surgery, hand surgery, orthopedics, radiology and rehabilitation⁸. For physical examination, we would evaluate the development of the skeleton, muscle, nerve and blood vessels of young patients. In consideration of a situation that requires MRI, ultrasound, and CT/CTA evaluation, it could make this process seamless and time-saving by pre-arranging the necessary nursing procedures such as disinfection, injection and mental preparation. For patients who need genetic examination, nurses with a professional background should cooperate with clinicians to carry out the collection of tissue samples. For some rare cases, further family analysis is needed to obtain the clinical and laboratory data. Experienced nursing staff should work together with physicians to complete tissue sample collection, transportation and preservation.

Pre-surgical Nursing Interventions

Nursing team should give relevant health education on the characteristics of CCRS in different position of the limb. (1) We would instruct our young patients and their families to correctly understand that the purpose of treatment is to improve limb function, limb appearance, and the quality of life (Figure 2). (2) The surgical indications, surgical procedures, anesthesia methods and possible outcomes after surgery would be introduced, as well as the measures to prevent cross-infection, fever and diarrhea which are common in pediatric patients. Special attention should be paid to prevent accidents such as falling injuries and crush injuries. (3) Evidence-based skin care should be carried out before surgery, including cleaning the affected limb, trimming the nails, especially the thorough removal of

the stains in the nail crevices or the deep stains in the skin folds of complex upper extremity deformities. For young patients with CCRS, we would clean the amniotic membrane band early to improve the blood supply of the fingers and clean the fetal fat accumulated in the syndactyl gap. If necessary, soak hands in warm water three days before the operation, in the morning and evening, to remove dead skin and ensure proper disinfection during the operation, which will greatly reduce the chance of postoperative incision infection (Figure 3 A, D).

Post-Surgical Nursing Interventions

Post-surgical nursing interventions mainly focused on the blood supply of distal limbs, pain, infection and immobilization. (1) We would closely observe the color, temperature, and capillary filling of the fingertips. If there is a problem with blood circulation, we will notify the doctors timely to seek treatment. (2) Sometimes, younger children are unable to accurately describe their pain feelings, we will evaluate the pain level from their facial expression, breathing, irritability, and crying. We would inform the attending physician to treat the pain and distract the patient by telling stories or playing games to relieve pain. (3) Additionally, young patients are very active which could cause the dressing to fall off or be wetted by body fluids resulting in infection. We would change dressings promptly. (4) Immobilization of the affected limb is often required after limb deformity correction, however children often have poor self-control and swing the affected limb at will. Therefore, it is necessary to guide the patient's family members to monitor the compliance of corresponding limb immobilization measures (such as plaster or protective support) to prevent hand injury. If necessary, the doctor should be notified to replace the fixed device in time to ensure the treatment effect.

Rehabilitation, Massage and Immobilization

Effective rehabilitation leads to a satisfactory functional recovery and is considered a necessary intervention after discharge. We would emphasize to family members the importance of persevering in rehabilitation training. (1) Passive movement. Considering that children have poor self-control and cannot take the initiative to comply, the training needs the cooperation of their parents. A professional

nursing team would help the parents be aware of the entire arrangement and the physical therapist would teach them the basic methods of rehabilitation including the passive motion of finger extension/flexion and abduction/adduction. Special attention should be paid to the passive movement of the metacarpophalangeal joint and interphalangeal joint of the thumb. The frequency and intensity of the therapy should be based on the tolerance of young patients. (2) Massage therapy. To prevent lymphedema and mitigate symptoms, massage therapy was recommended to promote lymphatic angiogenesis and recanalization for the patients with congenital constriction ring syndrome and the patients who underwent banding resection or fascial valvuloplasty. (3) Immobilization. Some patients needed to wear braces to fix the affected limbs and we would make active follow-ups to adjust the position of the braces.

Scar Management

To inhibit post-surgical scar formation, measures in this cluster nursing strategy aimed to reduce the inflammatory response and to avoid hypertonicity of surgical incisions. (1) Firstly, we would regularly remove the exudate, sebum and blood scab after operation, keep the incision clean and dry, and avoid infection to ensure that the incision heals well. (2) Secondly, we would instruct family members to regularly inspect the operating area and take measures to maintain appropriate immobilization of the affected hand (limb) to reduce incision tension. (3) Lastly, anti-scar measures, such as massage and silicone gel, were also recommended from 2 weeks to 6 months after surgery. If possible, a tension reducer would be recommended to inhibit post-surgical scar hyperplasia for 3 months.

Measurements

Post-treatment assessment of appearance and function was performed regularly by the nursing team, including the degree of scar formation by Vancouver Scar Scale and the time needed for lymphedema to subside (defined as <10 percent difference in the circumferences of the extremity with lymphedema and the noninvolved extremity)⁸. The Pediatric Quality of Life Inventory (PedsQL) questionnaire for parents and children was collected to evaluate the activity of daily living. Face Questionnaire was used to evaluate the parents' satisfaction with the entire treatment and nurs-

ing interventions (5 points: love it; 4 points: very much; 3 points: pretty much; 2 points: somewhat; 1 point: not at all). The results of two groups were compared and shown as a percentage, where applicable.

Data Collection

In this study, clinical evaluations of all patients were performed independently by the same nurse. The basic information of patients, including gender, age, sites, Patterson classification and grade of lymphedema was collected before surgery. Post-surgical observations including infection and flap necrosis were recorded while in hospital. All the patients were followed up routinely in the clinic after surgery and the evaluation indexes such as Vancouver Scar Scale score, Time needed for lymphedema to subside, PedsQL score and Faces Questionnaire were collected.

Ethical Considerations

All procedures performed in studies involving human participants were in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The parents/guardians of all the patients included in the study signed informed consent forms before surgery and the study was approved by the ethics committee.

Data Analysis

Data analysis was performed using the SPSS 26.0 software. Data were presented as mean (range). Significance between the two groups was determined by the chi-square test (or Fisher's exact test) regarding the incidence of infection, flap necrosis and patients' satisfaction. Vancouver Scar Scale score and time needed for lymphedema to subside between the two groups was analyzed using paired t tests. $p < 0.05$ was considered significantly different.

Results

Infection and Flap Necrosis

No incision infection was found in the cluster group, while 8 patients in the control group experienced incision infection after surgery (8/25 vs. 0/32, $p < 0.001$). No flap necrosis was found in the cluster group, while it oc-

curred in three patients in the control group with a higher rate (3/25 vs. 0/32, $p=0.0441$) (Table 2, Figure 3C, E).

Scar and Lymphedema

In the cluster group, no patients suffered from hypertrophic scarring and the mean Vancouver Scar Scale score was 1.6 (range 1-2.5). In the control group, the mean Vancouver Scar Scale score was 2.4 (range 1.5-6), which was significantly higher than the cluster group ($p<0.05$). Average time needed for lymphedema to subside in the cluster group was 2 months (range 1.5-3.5), which was significantly decreased compared with the control group (average 3.5, range 3-13) (Table 2, Figure 4, Supplementary Figure).

Quality of Life and Satisfactory Evaluation

The PedsQL Questionnaire, completed by patients and parents respectively, was utilized to evaluate the activity of daily living of patients [9]. The PedsQL score of cluster group was higher than that of the control group, whether it was finished by patients (85 vs 70,) or their parents (92 vs 73). Overall, the satisfactory rate (*love it* and *very much*) of the cluster group was significantly higher than the control group ($p=0.0019$). Cluster group had much more '*love it*' patients than the control group (87.5% vs 28%, $p<0.001$) (Table 2).

Discussion

The causes of congenital limb malformations are diverse, including genetics, somatic activating mutations, and changes in intrauterine factors. This leads to a complex and diverse clinical presentation and the medical care model based on single surgery is insufficient to meet the requirements of precision treatment [10]. In recent years, a multidisciplinary combined model has been used to intervene such diseases to achieve targeted and precise treatment, providing a very ideal diagnosis and treatment model [11-13]. Likewise, nursing strategy for congenital limb deformity requires multidisciplinary interventions [6].

In this study, we proposed a cluster nursing strategy in the management of patients with CCRS and the retrospective study demonstrated its feasibility and effectiveness. Good clinical outcomes and patients' satisfaction resulted

from specific nursing interventions and multidisciplinary cooperation, which was involved in the whole process of the treatment including full-course psychiatric care, thorough physical and radiological examinations, pre-surgical preparation, post-surgical cares, rehabilitation and long-term follow-up. Such a cluster strategy challenges the old perception that nursing is a mere supplement to surgery treatment, it is actually a key function that connects separate clinical interventions together and optimizes the whole treatment process. Based on multidisciplinary collaboration, the nursing intervention can be penetrated to the favorable timing of the diagnosis and treatment of congenital limb deformity. It can significantly improve the final outcomes, either at birth (amniotic band syndrome) [4] or during the long-term follow-up of a patient after surgery (such as rehabilitation training).

A few important points that are easily overlooked should be mentioned. Before surgeries, nurses need to focus on performing comprehensive examinations. As mentioned earlier, CCRS patients are generally young and have various deformed lesions in multiple parts and organs of the whole body, which will greatly increase the risk of surgery. During the health education process, the nurses inform the patients of the steps they will go through during the entire treatment process and reasonable expectations for functional improvement. Before surgery, nurses should try the best to remove the vernix caseosa to avoid incision infection. Nurses need to pay close attention to patients' main complaints and clinical manifestations.

This study has a limitations. This was a retrospective study and the patients included in this study were enrolled in two separated periods. Although we had verified the consistency between the control group and cluster group, it was possible that the bias of objects may influence the results of the study. Thus, a high-quality prospective study is needed to verified the clinical effect of the cluster nursing strategy we proposed.

Conclusion

To conclude, cluster nursing is a novel and effective strategy for patients with CCRS. Based on patients' characteristics and surgery-related adverse effects, the cluster

nursing provides a feasible model. The cluster nursing helps maximize the benefits of surgeries. Moreover, it can also provide novel perspectives of nursing for patients with other congenital limb malformations.

Conflict of Interest

The authors declare that they have no conflict of interest.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research commit-

tee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent

Informed consent was obtained from all individual participants included in the study.

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