小児慢性特定疾患児の在宅ケアに関する文献検索

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【目的】 小児慢性児在宅ケアに関するこれまでの研究動向およびその成果を明らかにする目的で主に海外文献を中心に収集した。

【方法】 MEDLINE(MEDLARS onLINE)を利用して1985年から1991年9月まで発表された英文文献を検索した。検索に用いたKey WordはChild, Home Care, Home Oxygen Therapy, Home Ventilation Care, Neoplasma, Peritoneal Dialysis, Continuous Ambulatory, Muscular Dystropy等である。

【結果】 Medlineにより49件の文献が検索できた。これらの文献をⅠ. 在宅呼吸管理、在宅腹膜灌流、Ⅱ. 小児がん在宅管理、Ⅲ. 小児筋ディストロフィー在宅管理の項目に分類し文献リスト（抄録付き）を作成した。

【まとめ】 小児在宅ケアに関する文献４９件を収集し項目別に文献リストを作成した。

【文献リスト】

Ⅰ. 在宅呼吸管理、在宅腹膜灌流

1) Kazzi NJ, Brans YW, Poland RL.: Dexamethasone effects on the hospital course of infants with bronchopulmonary dysplasia who are dependent on artificial ventilation. Pediatrics 1990 86:722-727

A randomized double-blind placebo-controlled trial was conducted to evaluate the effects of enterally administered dexamethasone on the hospital course of infants with bronchopulmonary dysplasia. A total of 23 infants with a birth weight less than 1500 g who were dependent on artificial ventilation 3 to 4 weeks of age received dexamethasone (n = 12) or saline placebo (n = 11). Dexamethasone (0.5 mg/kg per day) was given in tapering doses for 7 days followed by hydrocortisone (8 mg/kg per day) which was progressively reduced for a total of 17 days of therapy. Infants who received dexamethasone required less oxygen on days 8 and 17 (P less than .05) and were more likely to extubate 8 days after therapy than infants in the control group (respectively 8/12 vs 3/11 infants, P less than .05; P = .12 after Yates correction). The use of dexamethasone significantly shortened median duration of mechanical ventilation (4 vs 22 days, P less than .05) but had no effect on length of oxygen therapy, hospitalization, home oxygen therapy, occurrence and severity of retinopathy of prematurity, rate of growth, and mortality. No significant complications resulted from dexamethasone therapy. Measurements of plasma dexamethasone levels confirmed the absorption of drug from the gastrointestinal tract (23.7 ng/mL in dexamethasone vs 4.6 ng/mL in the control group, P less than .05). Dexamethasone administration resulted in short-term improvements in pulmonary function but did not ameliorate the hospital course of infants with bronchopulmonary dysplasia.

2) Kanemoto N, Yamaguchi H, Shiina Y, Goto Y.: Reversibility of primary pulmonary hypertension with vasodilator, anticoagulant and nocturnal oxygen therapy. Jpn Heart J 1989 30:929-934

Successful vasodilator therapy of a 19 year old woman with primary pulmonary hypertension is described. Long-term home oxygen therapy during sleep (2 l/min, 8 hours) in combination with vasodilator drugs (prazosin 2 mg and long-acting ISDN 20 mg bid) and an anticoagulant (ticlopidine 100 mg bid) brought significant reduction of pulmonary artery pressure and a rise of cardiac output 3 years later. This combination therapy may be effective in selected patients with primary pulmonary hypertension.

3) Fiascone JM, Rhodes TT, Grandgeorge SR, Knapp MA.: Bronchopulmonary dysplasia: a review for the pediatrician. Curr Probl Pediatr 1989 19:169-227

In this review we have attempted to introduce bronchopulmonary dysplasia as a new chronic lung disease of infancy and childhood. The major risk factors for this illness are preterm birth and the respiratory distress syndrome. The precise etiology of BPD is not understood but trauma from mechanical ventilation and toxicity from exposure to supplemental oxygen are thought to be important. Problems in diagnosis and diagnostic criteria have been discussed as have the details of the unfavorable pulmonary mechanics. We have mentioned some of our own practices in regard to a large and successful home oxygen therapy program. Suggestions have been made for establishing readiness for discharge and for follow-up of these children. Medical management of these patients presently suffers from a lack of prospective and controlled studies. Medical care draws heavily from experience with pediatric asthma. What is known about the long-term outcome of these children has been reviewed with an attempt to highlight controversies between published reports and underscore the need for further investigation. The greatest future success in this area would be the prevention of premature birth. Prior to this, we must await the completion of future controlled and prospective studies. (136 Refs.)

4) Sauve RS, McMillan DD, Mitchell I, Creighton D, Hindle NW, Young L. : Home oxygen therapy. Outcome of infants discharged from NICU on continuous treatment. Clin Pediatr 1989 28:113-118

Forty-four oxygen-dependent infants were discharged home in oxygen from an NICU during an 8-year period. Survivors were followed for 3 years. The infants' discharge diagnoses were bronchopulmonary dysplasia (BPD) (39), sleep apnea (2), and congenital cardiac defects (3). The five infants who had diagnoses other than BPD all died, but 34 of 39 infants with BPD survived. Supplemental oxygen was discontinued at a mean age of 13.4 months. The infants with BPD experienced health, growth, nutritional, neurodevelopmental and sensory problems that necessitated frequent rehospitalizations and utilization of a variety of medical and support services.

5) Hudak BB, Allen MC, Hudak ML, Loughlin GM.: Home oxygen therapy for chronic lung disease in extremely low-birth-weight infants. Am J Dis Child 1989 143:357-360

Chronic lung disease that requires prolonged oxygen therapy commonly complicates the recovery of extremely low-birth-weight infants (less than 1000 g). We report follow-up data through 18.5 +/- 0.9 (mean +/- SEM) months of age in 30 extremely low-birth-weight infants (birth weight, 783 +/- 24 g; gestational age, 26.0 +/- 0.3 weeks) who were discharged home receiving supplemental oxygen. Oxygen was prescribed to maintain arterial oxygen saturation at 95% or greater. At discharge, postconceptional age was 40.5 +/- 0.6 weeks, and weight was 2220 +/- 50 g. Duration of home oxygen therapy was 4.5 +/- 0.5 months. The mean weight percentile increased from less than 5 to 23 between discharge and the last follow-up. All infants survived; only 6 required hospitalization for acute medical illnesses. We conclude that carefully supervised home oxygen therapy permits the safe early discharge of selected extremely low-birth-weight infants with chronic lung disease.

6) Lifschitz MH, Seilheimer DK, Wilson GS, Williamson WD, Thurber SA, Desmond MM.: Neurodevelopmental status of low birth weight infants with bronchopulmonary dysplasia requiring prolonged oxygen supplementation. J Perinatol 1987 7:127-132

Fifty infants weighing 1,500 g or less at birth with a diagnosis of bronchopulmonary dysplasia (BPD) were followed to a mean age of 25 months to determine their clinical course and short-term neurodevelopmental outcome after discharge from the Neonatal Intensive Care Unit, and to identify possible predictive factors for outcome. Because study participation was voluntary, the subjects may not have represented the total population of BPD survivors. Occurrences of abnormalities were high: 11 hearing impaired, 10 legally blind, 14 cerebral palsy, and 23 abnormal development scores. Twenty-one subjects had feeding problems and weight was below the fifth percentile in 26. Home-oxygen therapy was required by 50 per cent of the subjects. Although severity of illness, duration of oxygen therapy and feeding problems were greater among those sent home on oxygen, their neurodevelopmental status did not differ from that of infants breathing room air by discharge. Factors associated with neurodevelopmental outcome were intracranial hemorrhage, pulmonary air leak, and length of hospital stay.

7) Abman SH, Ogle JW, Butler-Simon N, Rumack CM, Accurso FJ.: Role of respiratory syncytial virus in early hospitalizations for respiratory distress of young infants with cystic fibrosis. J Pediatr 1988 113:826-830

To determine the frequency of respiratory syncytial virus (RSV) as the cause of hospitalization for acute pulmonary exacerbations in young infants with cystic fibrosis (CF), and to assess the clinical effects of RSV infections, we prospectively followed 48 children with a diagnosis of CF after identification by newborn screening. At a mean follow-up age of 28.8 months (range 5 to 59), 18 infants (38%) had been hospitalized a total of 30 times for acute respiratory distress. At the time of admission, 18 infants (60%) were less than 12 months, 8 (27%) between 12 and 24 months, and 4 more than 2 years of age. The RSV was identified in seven hospitalized infants, as determined by fluorescent antibody, immunoassay, or culture. Before admission with RSV infection, one of the seven infants had chronic respiratory signs, none had Brasfield chest x-ray scores below 20, and a previous throat culture was positive for Staphylococcus aureus in one infant. Hospitalizations were prolonged (mean duration 22 days), and were characterized by significant morbidity, with three infants (43%) requiring mechanical ventilation and five infants (71%) requiring home oxygen therapy for persistent hypoxemia at discharge. At a mean follow-up age of 26 months, these infants more frequently have chronic respiratory signs (p less than 0.01) and lower chest radiograph scores (p less than 0.05) than other CF infants. These findings demonstrate that RSV is an important cause of early acute respiratory tract morbidity in young infants with CF, and suggest the need for studying new strategies to implement early and aggressive antiviral therapy in young infants with CF.

8) Brissette S, Zinman R, Reidy M.: Disclosure of psychosocial concerns of young adults with advanced cystic fibrosis (CF) by a nurse home visiting program. Int J Nurs Stud 1988 25:67-72

Twelve patients with advanced cystic fibrosis were enrolled over a 36 month interval in a trial to assess the effect of nocturnal home oxygen therapy. As part of this study, there were repeated home visits by the nurse. Immediately following a visit, the nurse encoded all spontaneous expressions of concern into three general categories: CF management, growth and development and family relations. During the first 6 months, the concerns focused on CF management and over the subsequent year were followed by concerns related to growth and development and, finally to family interactions. This pattern suggests a sequence to the types of interventions accepted by this population.

9) Groothuis JR, Rosenberg AA.: Home oxygen promotes weight gain in infants with bronchopulmonary dysplasia. Am J Dis Child 1987 141: 992-995

To study the effect of oxygen therapy on weight gain in bronchopulmonary dysplasia (BPD), the growth of 22 infants with BPD enrolled in a premature follow-up clinic and home oxygen program was examined retrospectively. Mean gestational age was 28 weeks (range, 26 to 33 weeks) and mean birth weight was 1110 g (range, 680 to 2000 g). After discharge, infants were monitored monthly to maintain transcutaneous oxygen tension over 55 mm Hg and/or pulse oximeter oxygen saturation over 92%. With appropriate home oxygen, all 22 infants grew as well as healthy, full-term infants (mean, 40th percentile; range, tenth to 80th percentile) when ages were corrected for prematurity. Parents discontinued oxygen therapy inappropriately in seven infants, and all seven experienced significant deceleration in weight gain. When home oxygen therapy was resumed, their weight gain improved, but the infants never regained their original percentiles during the study period. The 15 infants who continued home oxygen therapy maintained their original weight percentiles throughout the study period. These data support an important role for home nasal cannula oxygen in promoting weight gain in selected infants with BPD.

10) Thilo EH, Comito J, McCulliss D.: Home oxygen therapy in the newborn. Costs and parental acceptance. Am J Dis Child 1987 141: 766-768

To assess the cost of and parental response to home oxygen therapy in the newborn, a telephone survey was conducted of 34 families of infants discharged from our intensive care nursery along with supplemental oxygen therapy. Mean birth weight was 1988 g and gestational age was 33 weeks. The mean length of time oxygen was required at home was 74 days. Savings were estimated for each infant and were found to average $33,370. The typical problems encountered by these families are described. Despite the inconveniences involved, 94% of these families stated they would again take a baby home while oxygen dependent if necessary.

11) Givan DC, Wylie P.: Home oxygen therapy for infants and childlen. Indiana Med 1986 79:849-853

12) Marcotte JE, Canny GJ, Grisdale R, Desmond K, Corey M, Zinman R, Levison H, Coates AL.: Effects of nutritional status on exercise performance in advanced cystic fibrosis. Chest 1986 90:375-379

Initial evaluation of 22 patients with cystic fibrosis (CF) on entry into a trial of home oxygen therapy was used to elucidate the possible effects of poor nutritional status on exercise performance in CF. The patients had advanced lung disease (mean FEV1, 36 percent predicted) and all had a stable resting PaO2 less than or equal to 65 mm Hg. Nutritional status was determined by calculating weight as a percentage of ideal for height (Wt/Ht) for each subject. Exercise testing consisted of a progressive exercise test on a cycle ergometer to measure maximum work capacity (Wmax), and a steady state test at 50 percent of baseline Wmax. During the steady state test, cardiac output (Q) and stroke volume (SV) were computed by the indirect Fick (CO2) method. Wmax, SV, Q and lung function results are expressed as percent predicted. Mean (+/- SD) Wmax was 58 +/- 15 percent predicted. Wmax correlated with both FEV1 and Wt/Ht, but FEV1 and Wt/Ht were not related. During steady state exercise, 12 of 22 patients had a SV less than 80 percent predicted. SV correlated with Wt/Ht, but not with lung function. Thirteen of the 22 patients had a Wt/Ht less than or equal to 90 percent and were considered malnourished. When compared with the well-nourished patients (Wt/Ht greater than 90%), these malnourished subjects had significantly lower mean values for Wmax%, SV% and Q% predicted, but not for lung function parameters. We conclude that: in patients with CF and advanced lung disease, nutritional status plays a significant role in determining exercise capacity; lower exercise tolerance of malnourished patients is an independent effect, as nutritional status and lung function were not related; and malnourished patients with CF have an altered cardiac performance on exercise testing which is due to a reduced SV rather than an impaired heart rate response.

13) Berman W Jr, Katz R, Yabek SM, Dillon T, Fripp RR, Papile LA.: Long-term follow-up of bronchopulmonary dysplasia. J Pediatr 1986 109:45-50

We observed 10 children with bronchopulmonary dysplasia, evaluated initially by cardiac catheterization (mean age 18 months), for an average of 4.4 years. Age at last evaluation averaged 5.8 years; subjects reside in and around Albuquerque, N.M. (altitude 5000 ft). At initial cardiac catheterization, mean pulmonary artery pressure was 40 mm Hg, pulmonary vascular resistance index 8.9 units, and intrapulmonary shunt fraction was high; pulmonary wedge angiograms were normal. Over the period of follow-up the group has done poorly. Four of the 10 continue to receive home oxygen therapy, but none requires inotropic or diuretic therapy; four children have marked developmental or motor delays. Nine of 10 patients have abnormalities of respiratory function on spirometric testing. Four patients underwent recatheterization because of clinical indications; two had large atrial level left-to-right shunts not found on initial study. Reductions in pulmonary artery pressure (55 to 37 mm Hg) and pulmonary vascular resistance (11.9 to 7.8 units) occurred between the two studies in these four patients (average study interval 4.0 years); the still elevated levels of pressure and resistance fell further in response to 40% O2 administration. Pulmonary wedge angiograms were abnormal in each restudied patient. Although not uniformly bleak, the long-term outlook for children with severe bronchopulmonary dysplasia is diverse and guarded.

14) Abman SH, Wolfe RR, Accurso FJ, Koops BL, Bowman CM, Wiggins JW Jr. : Pulmonary vascular respons to oxygen in infants with severe bronchopulmonary dysplasia. Pediatrics 1985 75:80-84

The cardiac catheterization data of six infants with bronchopulmonary dysplasia (BPD) were reviewed to examine the responsiveness of their pulmonary vascular beds to changes in oxygen tension. The infants were studied because of slow recovery from their oxygen requirements and clinical evidence of persistent pulmonary hypertension. All were receiving home oxygen therapy and had abnormal chest radiographs and right ventricular hypertrophy by ECG at the time of catheterization (mean age, 25 months). All infants had mean pulmonary artery pressure greater than 25 mm Hg in room air, with a mean of 48 mm Hg. All decreased mean pulmonary artery pressure by at least 10 mm Hg when placed in high levels of inspired oxygen (FiO2 greater than 80), with a mean pulmonary artery pressure of 25 mm Hg. This represented a significant decrease in mean pulmonary artery pressure from room air pressures (P less than .005). Mean pulmonary artery pressure was also measured in three infants who were breathing supplemental oxygen by nasal cannula at flow rates similar to levels used for outpatient therapy. Most of the reduction in mean pulmonary artery pressure that occurred at high FiO2 occurred at these lower flow rates of supplemental oxygen. It is concluded that infants with bronchopulmonary dysplasia who have pulmonary hypertension generally have reactive pulmonary vascular beds, responsive to supplemental oxygen. Continuous oxygen therapy by nasal cannula may be useful in the treatment of pulmonary hypertension associated with bronchopulmonary dysplasia.

15) Parsons CL.:Manual and home oxygen therapy for infants: a discharge planning guide. Crit Care Nurse 1984 4:84-85

16) Rubin J, Case G, Bower J.: Comparison of rehabilitation in patients undergoing home dialysis. Continuous ambulatory or cyclic peritoneal dialysis vs home hemodialysis. Arch Intern Med 1990 150: 1429-1431

Rehabilitation was assessed in 70 patients undergoing continuous ambulatory (CAPD; n = 67) or cyclic (CCPD; n = 3) peritoneal dialysis and 76 patients undergoing home hemodialysis (HHD). In the CAPD/CCPD group, there were more blacks (83% vs 53%) and diabetics (24% vs 8%). If patients too infirm to work were excluded, no statistically significant differences were found between those working for gain and in school (19% for CAPD/CCPD vs 32% for HHD); homemakers (16% for CAPD/CCPD vs 28% for HHD); and those not working (66% for CAPD/CCPD vs 41% for HHD). Although the CAPD/CCPD group had less formal education (8.9 +/- 3.7 years vs 10.9 +/- 2.2 years for HHD), illiteracy rates were similar (CAPD/CCPD, 16%; HHD, 7%). If unemployable (elderly and debilitated) patients were excluded, full rehabilitation was excellent in both groups (57% for CAPD/CCPD vs 65% for HHD), despite the greater number of blacks and diabetics in the CAPD group.

Ⅱ. 小児がん在宅管理

17) Chen YC, Chao YM.: Promoting hearlth care for children with cancer in Taiwan. Int Nurs Rev 1991 38:22-25

In Taiwan cancer has become the second leading cause of death of children, subjecting healthcare professionals to new challenges in carrying out their duties. Not only is the treatment long, but relapses often occur, requiring expensive, repeated hospitalization and appropriate care. To help families cope with the financial burden of long treatments, nurse researchers involved in a study of the cost pressures of such treatment literally went to the streets--including a TV programme on the plight of these children and their families--and collected financial contributions from both the public and medical professions. Thanks to their efforts a Childhood Cancer Foundation is now aiding these children and their families both financially and morally. Below, a report on how the nursing profession took action to involve the community and government in a collective effort.

18) Wong DL.: Transition from hospital to home for childen with complex medical care. J Pediatr Oncol Nurs 1991 8:3-9

Home care has become a well-accepted option for children with chronic illnesses, such as cancer, who require continued technological care for survival. Components of successful home care include assessment of the child and family for this option, assessment of the community's ability to provide the services the family needs, development of a comprehensive care plan, education of care givers, and ongoing evaluation of the plan. Nurses play a major role in the discharge planning for home care by educating care givers to perform the necessary care, by providing opportunities for care givers to demonstrate competence before assuming total responsibility, and by ensuring that the care givers and the home environment are ready for the child's discharge. Throughout this process, the principles of normalization are applied to provide the child with an optimun home environment. Establishing parent-professional partnerships is crucial to providing family support that empowers family members, especially parents, to assume the responsibilities of caring for their child.

19) Birenbaum LK, Robinson MA.: Family relationships in two types of terminal care. Soc Sci Med 1991 32:95-102

This study investigated parent's perception of family relationships in 87 parents from 48 families during the terminal illness and first year following a child's death from cancer. Using the Family Relationships Index, parents' perception of family relationships were compared: (a) to normative data and (b) between home and hospital terminal care. Data collection occurred before death during the terminal phase, and two weeks, four months, and one year post death. The results of data analyses by confidence intervals and t-tests generally indicated that (a) parents' perceived family relationships to differ from "normal" families and (b) hospital based terminal care families presented evidence of better family relationships than home care based terminal care families.

20) Hockenberry-Eaton M, Benner A.: Patterns of nausea and vomiting in childen: nursing assessment and intervention. Oncol Nurs Forum 1990 17:575-584

Although aggressive treatments for childhood cancer have resulted in an increased cure rate, increased incidence of treatment-related side effects also has occurred. Nausea and vomiting are two common side effects of cancer treatment in children. This clinical review discusses nursing issues related to the treatment of nausea and vomiting in children. Focus is placed on assessment, incidence and etiology of nausea and vomiting, patterns of nausea and vomiting, developmental influences on nursing intervention, innovative nursing strategies, behavioral interventions, specific antiemetic therapy, and home care. A need for further study of nausea and vomiting associated with childhood cancer treatment is identified. (114 Refs.)

21) McGuire P, Moore K.: Recent advances in childhood cancer. Nurs Clin North Am 1990 25:447-460

Major advances during the past 25 years in the treatment of childhood cancer have resulted in a dramatic improvement in disease-free survival for more than 60% of diagnosed patients. Advances in both laboratory and clinical research have demanded a concomitant expansion of nursing skill and practice to keep pace in this area. This article strives to provide an overview of recent advances in pediatric oncology in both the scientific and clinical arenas and to highlight some of the contributions made by pediatric oncology nurses. (97 Refs.)

22) Dufour DF.: Home or hospital care for the child with end-stage cancer: effects on the family. Issues Comper Pediatr Nurs 1989 12: 371-383

Despite the fact that many children are cured from cancer, this illness remains the leading cause of death among children due to disease. When the likelihood of death is confronted, decisions regarding how best to provide care must be made. Research regarding what factors influence this choice and the effects that different modalities of care may have on the family system are discussed. This discussion and review of the literature will assist the pediatric nurse in guiding the family to an appropriate choice for the care of their child. Pediatric nurses must be aware of the many technical, economic, and theoretical issues which confront a family prior to making this very difficult decision. (23 Refs.)

23) Richard's story. Nurs Times 1990 86:74-76

24) Beardsmore S.: Symptom care of the child with cancer. Nurs Times 1990 86:72-74

25) Rogers AG.: Home intravenous opioid therapy in a toddler with advanced cancer. J Pain Symptom Manage 1989 4:230-231

26) Pasut B.: Home administration of medications in pediatric oncology patients: use of the Travenol infusor. J Pediatr Oncol Nurs 1989 6: 139-142

Administration of chemotherapy and other medications with an infusor can facilitate home care of the pediatric oncology patient. An infusor that is reliable, lightweight, disposable, and delivers an infusion at a constant rate is described in two case studies. Use of this device has allowed children to receive most of their chemotherapy as outpatients thus decreasing the cost of care and facilitating the child's return to more normal daily activities.

27) Campbell JB, Morgan DW, Pearman K.: Experience with the home-care of tracheotomised paediatric patients. Arch Otorhinolaryngol 1989 246:345-348

Many infants with tracheotomies remain cannulated for prolonged periods while the underlying cause of airway obstruction is either treated or natural resolution is awaited (usually by growth). To enable these children to enjoy a relatively normal family environment despite a tracheotomy, it is desirable that they should be managed at home for at least part of the time. For the past 8 years we have routinely used soft polyvinyl chloride paediatric tracheotomy tubes (Shiley) in our patients. These tubes have proved to be relatively resistant to obstruction with secretions and are changed at 1- to 2-week intervals. They can be modified by making a series of three to four 2-mm through-and-through fenestrations around the shoulder in order to improve speech production and facilitate decannulation. Parents are tutored in tracheotomy care, which includes tube changing, humidification and suction. They are then permitted to take their child home from hospital when they are considered to be competent. Twenty-eight children (13 boys, 15 girls) with a mean age of 14.5 weeks (range 1-525 weeks) at the time of tracheotomy have been managed at home using this system. The median period of hospitalisation was 12 weeks (range 5-75 weeks), and the median duration of home management was 94 weeks (range 13-394 weeks). Sixteen patients have been successfully decannulated, 11 remain cannulated and 1 died at home from sudden infant death syndrome. Despite supportive measures, the majority of the children developed intermittent chest infections.(ABSTRACT TRUNCATED AT 250 WORDS)

28) Bendorf K, Meehan J.: Home parenteral nutrition for the child with cancer. Issues Compr Pediatr Nurs 1989 12:171-186

Compliance with treatment is greatly increased when the caregiver(s) understand the treatment, the need for the treatment, and the need for strict adherence to sterile technique. When the caregiver is not ready to handle home care of the child, compliance is less than optimal and may be a threat to the child. Parenteral nutrition support can be both safe and effective in children with cancer when the family and health-care team work together. Nutrition support facilitates treatment of the whole child and can help improve his or her quality of life. (35 Refs.)

29) Chambers EJ, Oakhill A, Cornish JM, Curnick S.: Terminal care at home for children with cancer. BMJ 1989 298:937-940

30) Lange BJ, Burroughs B, Meadows AT, Burkey E.: Home care involving methotrexate infusions for children with acute lymphoblastic leukemia. J Pediatr 1988 112:492-495

31) Becton DL, Kletzel M, Golladay ES, Hathaway G, Berry DH.: An experience with an implanted port system in 66 children with cancer. Cancer 1988 61:376-378

Totally implanted port catheter systems have a lower incidence of infection and are more easily used in home care that external catheters in adult cancer patients. Experience with this method in children has been limited. During the past 2 years, we have implanted 71 ports in 66 children with cancer. Our experience demonstrates an infection rate (0.15 episodes of bacteremia per 100 patient days) slightly lower than that reported for children with Broviac or Hickman catheters, but not as low as that seen in adults with implanted systems. Patients and families have been extremely satisfied with the devices. Our experience supports further use of implanted systems in children with cancer.

32) Powers JS, Burger MC.: Terminal care preferences: hospice placement and severity of disease. Public Health Rep 1987 102:444-449

National Hospice Study data for 1981-82 were used to predict the location of care for terminal cancer patients. Sites of care were conventional care in hospitals, hospital-based hospice care, and hospice care in the home. Subjects were terminal cancer patients with a prognosis of less than 6 months of life who were attended by a primary concerned person. There were 1,732 patients 18-99 years old-293 conventional care, 612 hospital-based hospice care, and 827 hospice home care patients. Data sources were the patient, the primary concerned person, the family, and the medical record. Data were obtained at initial interview for the study, 1-week followup, reassessment every 2 weeks, and bereavement interviews. Information was grouped in the following categories: patient functional status, patient psychological outlook, symptomatology, medical condition, and characteristics of the primary concerned person and family. Conclusions were reached by univariate and multivariate analysis. First, a progression of functional disability was found to exist among care sites, from hospice home care for the least disabled to hospital-based hospice care to conventional care for patients with the greatest disabilities. The location of care was best explained by the patient's functional capacity. Second, the location of care was found to be poorly explained by extent of organ involvement or specific symptoms. Third, the primary concerned persons of patients under hospice home care experienced more stress but reacted no differently when compared with primary concerned persons at other care sites. Fourth, patients under hospice home care survived the longest and reported greater family closeness than other care groups.

33) Morris M.: Traveller health care: stopped in their tracks. Community Outlook 1987:16-19

34) Vargas JH, Ament ME, Berquist WE.: Long-term home parenteral nutrition in pediatrics: ten years of experience in 102 patients. J Pediatr Gastroenterol Nutr 1987 6:24-32

One hundred two pediatric patients received all or part of their nutritional needs parenterally at home during the past decade. All received total parenteral nutrition (TPN) at night during an 8- to 12-h infusion. Patients with short bowel syndrome (33%), inflammatory bowel disease (23%), chronic intractable diarrhea (15%), chronic idiopathic intestinal pseudo-obstruction syndrome (10%), and malignancy (10%) made up the largest groups. The mean duration of parenteral support was 735 days (range, 90-3650 days); the mean number of catheters per patient was 2.1 (range, 1-8). Twenty-one patients continue to receive full or partial home TPN: four for more than 10 years and seven for more than 5 years. Fifty-one no longer require it and have had healing of mucosa or bowel adaptation. Complications related to administration of fluid and electrolytes were quite rare. Biotin deficiency was recognized once. Thirty-one have died, but only 13 deaths were related to TPN. Sepsis in nine and liver failure in two were the most common causes of death in the TPN-related group. Three of 21 still on home TPN have graduated either from high school or college. All but one of the school age children attend regular school; one attends a school for the medically disabled, another attends a school for the mentally gifted.

35) Norman R, Bennett M.: Care of the dying child at home: a unique cooperative relationship. Aust J Adv Nurs 1986 3:3-16

36) Howard L, Heaphey LL, Timchalk M.: A review of the current national status of home parenteral and enteral nutrition from the provider and consumer perspective. JPEN J Parenter Enteral Nutr 1986 10:416-424

Home parenteral and enteral nutrition (HPEN) has grown rapidly in the past decade. By examining data from physician reports, patient surveys, and the infusion industry, this review attempts to delineate the diagnostic indications, age range, mortality, medical complications and rehabilitation potential of HPEN patients. A clear trend exists towards greater use of this expensive therapy in bowel obstructed cancer patients and in pediatric and geriatric age groups. Complications in parenterally fed patients appear to result in a readmission to the hospital, on average, once every 2 yr. Life expectancy depends heavily on the underlying diagnosis: whereas 50% of the patients with a malignancy survive only 6 months, 50% without a malignancy survive beyond 3 yr. Fifty to 60% of HPEN patients are able to work full time or part time, 15 to 20% are retired or of preschool age, and 20 to 30% are unable to work. The home care service options considered most important by patients are the pharmacy premixing of intravenous solutions, home delivery of supplies by the home service carrier, reimbursement management by the home care service and the availability of a nurse for an initial home visit and 24-hr emergency backup. In regard to fiscal concerns one of the difficult issues that should be addressed is the separation of medical coverage from disability status; another is that enteral feedings can sometimes be a less expensive alternative to parenteral feedings but little information exists about the complications and outcome with this modality and its fiscal reimbursement is much less assured. (28 Refs.)

37) Gemlo B, Rayner AA, Lewis B, Wong A, Viele CS, Ungaretti JR, Delorimier AA, Hohn DC.: Home support of patients with end-stage malignant bowel obstruction using hydration and venting gastrostomy Am J Surg 1986 152:100-104

Palliative terminal care of patients with malignant bowel obstruction is a major clinical and ethical challenge. These patients are often mentally alert and ambulatory, but are kept in the hospital for hydration, nasogastric suction, and pain control. Parenteral nutrition requires frequent metabolic monitoring, is expensive, and is ethically questionable. We have used an alternative method of home management for 27 patients who met the following criteria: inoperable bowel obstruction due to untreatable cancer, an estimated life expectancy of between 2 weeks and 3 months, and understanding of the goals and limits of therapy. Hydration was provided by 10 percent dextrose and electrolyte solutions administered as overnight infusions through long-term central venous catheters. Thirteen patients with complete bowel obstruction required a venting gastrostomy which, when connected to passive drainage, relieved nausea and vomiting. The mean duration of survival was 64 days (range 9 to 223 days). Acceptance by patients and families was excellent, although most acknowledged increased costs due to limited insurance coverage for outpatient care. Seven patients returned to the hospital for terminal care (average stay 3.2 days), and 20 chose to die at home. The mean daily expense for fluids and supplies was +73.50, with an overall cost decrease of $900,000 compared with inpatient care. Home support with fluids and gastric venting is a humane, cost-effective alternative to in-hospital care for selected patients.

38) Lauer ME, Mulhern RK, Hoffmann RG, Camitta BM.: Utilization of hospice/home care in pediatric oncology. A national survey. Cancer Nurs 1986 9:102-107

39) Monaco GP.: Resources available to the family of the child with cancer. Cancer 1986 58:516-521

Progressive and continuing advances in the care of the child with cancer have resulted in potential cure of over 50% of our children. However, no matter how encouraging these statistics, nearly one half of our children now die from their disease. To bring the family through the cancer experience, we must meet the challenge of attending to their practical, spiritual, emotional and experiential requirement from diagnosis, treatment through possible relapse, death, hoped for cure, and survival as an adult with the stigmata of a history of cancer as an obstacle to jobs, insurance, and productive lives, and the further shadow of a possible late second cancer caused by their curative treatment. Families require access to a firm, unfragmented foundation of support, incorporating a multidisciplinary network of resources, involving the combined efforts of the primary health care team and the family's community. Medical and emotional counseling, peer support, spiritual guidance, and special community services contribute to the optimal care of both patient and family. In addition, legal advisory assistance and help with financial planning are important ingredients in assisting families.

40) Shah NR.: The community physician's involvement in clinical trials and home treatment. Cancer 1986 58:504-507

The advances in outcome of children with cancer in the last four decades have been remarkable. The improvement, however, has not been uniform. It has recently been shown that the outcome of children with medulloblastoma treated at nonuniversity cancer centers has been less successful than those who were treated at the university cancer centers. Protocol treatment and location of treatment has been correlated with outcome in children with acute lymphocytic leukemia. Cooperative group protocols, used in the clinical setting of pediatric oncologists, with extensive resources and major referral center backup, have improved the prognosis of childhood ALL. Therefore, to improve outcome of pediatric cancer patients a multidisciplinary team at a center with partnership of community physician (CP) would be helpful. The CP can assume an extremely important role in shared management of children with cancer. Major involvement can be anticipated in areas including: chemotherapeutic treatment, immunization, infection surveillance and treatment, detection of disease recurrence, and late effects of cancer treatment. A CP could decrease the financial burden, and help alleviate the anxieties and emotional stresses placed upon the patients and parents. More importantly, the CP can facilitate home terminal care when necessary. These CP-referral center arrangements are of value to the CP, as well, through their educational and psychological benefits.

41) Martinson IM, Moldow DG, Armstrong GD, Henry WF, Nesbit ME, Kersey JH.: Home care for children dying of cancer. Res Nurs Health 1986 9:11-16

The feasibility of home care as an alternative to hospitalization for children dying of cancer was studied. The home care system was defined as nurse-directed with a consultant physician and did not entail extensive participation by other health professionals. Of 58 children cared for at home during the 2-year project, 79% died at home and 21% died in the hospital or en route to it. The findings, as shown by interview data, suggest that home care at the end stage of life is a viable alternative for children dying of cancer and for their families.

42) Rayburn W, Wolk R, Mercer N, Roberts J.: Parenteral nutrition in obstetrics and gynecology. Obstet Gynecol Surv 1986 41:200-214

Parenteral nutrition is required to maintain and restore an anabolic state when oral or enteral routes are not feasible. Despite 16 years of parenteral nutrition availability, reports about parenteral therapy in gynecologic patients or during pregnancy have not been published until relatively recently. Most information is anecdotal but suggests that this mode of therapy is safe, effective, and occasionally life-saving. Parenteral nutrition is used most commonly in women with gynecologic malignancies who are unable to obtain adequate nourishment either during or after surgery, radiation, or chemotherapy. Parenteral alimentation during pregnancy has been used mostly to provide adequate nutrition for those who suffer from prolonged hyperemesis or when there is difficulty in absorption of adequate nutrients. The proper selection and administration of dextrose, fat, protein, vitamins, trace elements, and electrolytes for pregnant women has been associated with apparent favorable perinatal outcomes. Preterm deliveries and intrauterine fetal growth retardation are relatively common and relate to the preexisting or a coexisting medical or obstetric complication. Nutritional assessment before therapy should include a detailed diet history and establishment of baseline clinical and laboratory parameters. Oral or enteral feedings should be attempted beforehand if possible to conserve high costs and potential complications. Parenteral requirements are extrapolated from recommended daily allowances for oral intake, allowing for adjustments in variable absorption. Standardized formulations and fat emulsions are available at pharmacies in many hospitals, making ordering of complex solutions easier, more efficient, and cost effective. Metabolic and septic complications occur infrequently with close monitoring. Few women require intravenous therapy for very long, and home parenteral nutrition is rarely necessary. (60 Refs.)

43) Hadlock DC.: The hospice: intensive care of a different kind. Semin Oncol 1985 12:357-367

44) Rees GJ.: Cost-effectiveness in oncology. Lancet 1985 2:1405-1408

45) Carr-Gregg MR, White L.: The child with cancer: a psychological overview. Med J Aust 1985 143:503-508

46) Edwardson SR.: Physician acceptance of home care for terminally ill children. Health Serv Res 1985 20:83-101

The study reported here explored the factors associated with the implementation of Martinson's model of home care and treatment for children in the terminal stages of illness with cancer. The model is described as an example of a health care strategy that was dramatically different from the prevalent model of care and may have conflicted with existing values. Data for the study were gathered from the hospital records of the children and from a survey of their oncologists. The findings suggest that physicians viewed the model of care as desirable and made their referral decisions on the basis of their judgment about whether the family in question was technically and emotionally capable of providing the care.

47) Fergusson J, Hobbie W.: Home visits for the child with cancer. Nurs Clin North Am 1985 20:109-115

Home visits for children with cancer has yet to become widely understood and accepted. However, health care planners and policy makers must be convinced of the numerous advantages and benefits of home visits for the child, his family, and the community.

Ⅲ. 小児筋ディストロフィー在宅管理

48) Baydur A, Gilgoff I, Prentice W, Carlson M, Fischer DA.: Decline in respiratory function and experience with long-term assisted ventilation in advanced Duchenne's muscular dystrophy. Chest 1990 97:884-889

We present 17 patients with advanced DMD who required long-term assisted ventilation. Eleven patients used part-time assisted ventilation. Five of the patients received BV and/or M-IPPV or N-IPPV between two and nine years before requiring full-time T-IPPV, while six others initially used part-time T-IPPV. One patient used all three modes before requiring full-time T-IPPV. Mean (+/- SD) FVC and rebreathe PCO2 at the outset of assisted ventilation were 0.62 +/- 0.20 L and 47.4 +/- 7.5 mm Hg, respectively. Clinical features were divided between symptoms suggesting respiratory muscle fatigue and sleep-related disordered breathing. We found that, while useful in early respiratory insufficiency, BV is associated with recurrent aspiration. In our experience, N-IPPV offers the safest and most convenient form of noninvasive ventilation. When the VC has decreased to about 300 ml, most patients will require full-time ventilation; T-IPPV is advised to provide airway access to suction secretions.

49) Matsuoka Y, Sakai M, Iida M, Takahashi A.: Advance of disability and prognosis in Duchenne muscular dystrophy--a comparison between institutionalized care and home care. Rinsho Shinkeigaku 1989 29: 1000-1003

Rate of advance of disability and age at death were studied in patients with Duchenne muscular dystrophy (DMD). A comparison was made between DMD patients under care in their own homes and those hospitalized in National Suzuka Hospital. In 45 patients with home care, rate of advance of disability was considerably high in their age of 6 to 12 years, the average being 0.83 stage per year after the N.Y. University-Ueda's rating stage of disability. In the age of 12 to 17 years, however, the disease progression was much slower, the average being 0.14 stage per year. Beyond 18 years old, the average stage of disability was constantly 7.7, meaning almost bedridden stage. On the contrary, in 56 patients with institutionalized care, the average rate of advance was lower, being 0.5 stage per year in the age of 7 to 15 years and 0.13 stage per year from 15 to 23 years of age. The result of statistical analysis indicated that the stage of disability was significantly higher in the patients under the home care than those with institutionalized care at the age of 12-16, 18 and 19 years. The age when the patients became unable to walk was 9.7 +/- 1.8 years (mean +/- SD) in those with home care and 10.9 +/- 2.3 years in those with institutionalized care. The difference was statistically significant (p less than 0.01). The age at death was 18.3 +/- 3.8 years in 19 DMD patients with home care and 20.4 +/- 3.6 years in 33 patients with institutionalized care. The difference was also statistically significant (p less than 0.05).(ABSTRACT TRUNCATED AT 250 WORDS)

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【目的】小児慢性児在宅ケアに関するこれまでの研究動向およびその成果を明らかにする目的で主に海外文献を中心に収集した。