The purpose of our study, "Home Care for the Child with Cancer", was to examine the feasibility and desirability of a home care alternative to hospitalization for children dying of cancer. Home care was defined as "the delivery of services, nurse-directed with physicians and other health care professionals as consultants, to enable parents to give comfort and care as required by a child at the end stage of life."

A pilot study was done from 1972 to 1975 in which home care was offered to eight families. In five families, the child did die at home. Based on this nonfunded pilot study, a federal grant proposal was submitted to the National Cancer Institute, Department of Health, Education and Welfare, and the project was funded in 1976. There were two research phases during the four years of the study. For the first two years, the grant provided staff who directed the nursing care of children with cancer at the end stage of life. During this time, collaborative arrangements were being developed with public health nursing and three hospital/clinic-based institutions. The grant staff organized and provided the actual care, and collected data on this care. During the third year, the coordination of the care, both directly and indirectly, was essentially turned over to three already existing health care organizations and to the public health nurses utilized by these institutions. In the fourth year, the grant staff then devoted their full attention to the question of the desirability of home care, and to the observation of what was happening in the three institutions. This was done to

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help answer questions regarding the feasibility of the institutionalization of this home care alternative.

The criteria for referral of terminal cancer patients to the study included the following: (1) the patient was 17 years of age or younger; (2) the patient had some form of cancer and was expected to die fairly soon as a consequence; and, (3) no procedures requiring inpatient hospitalization were planned. Whether the child met both the second and the third criteria were determined by the child's pediatric oncologist.

The services available for the family were as follows:

1. The nurse would be on call 24 hours a day, seven days a week.

2. The nurse would be available to help the family members, who were the primary care givers dealing with problems that might arise.

3. The nurse was available to make home visits whenever and wherever the family desired such contact.

4. The option of the child returning to the hospital was always open.

5. The child's physician could be called at any time.

During the first two years, 64 children were referred to the project: of those, 58 died. Sources of referrals for these 58 children were as follows: More than 50% were from the University of Minnesota; St. Louis Park Medical Center in Suburban Minneapolis provided the next largest number; and 15 children were referred from eight other hospitals. A total of 23 physicians were involved: Fourteen from the University of Minnesota, two from pediatric oncologists at St. Louis Park Medical Center, and, seven other physicians representing eight other hospitals.

The places of death for the 58 children were as follows: Forty-six (79%) at home, twelve (21%) in the hospital, with one of these children dying in a hospital in Mexico, and one child dying in an ambulance while returning to the hospital.

The range of ages of the children who died at home was one month to 17 years, with the largest number (13) being in the age range of 15 to 17. The ages of children with cancer who died in the hospital ranged from 3 to 17 years. The data suggests that the age of the child is not a significant factor in determining the feasibility of home care.