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## Research Article

# Partnership Between Families of Children with Muscular Dystrophy and Health-care Professionals: From Parents' Perspective

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## ABSTRACT

**Purpose:** At present, there is still controversy between parents of children with muscular dystrophy (MD) and health-care professionals on care issues. Partnerships can connect the affected children and their families to appropriate health-care services, to jointly face the care environment together and thereby improve the quality of life of children with MD. Therefore, the objective of this study is to explore partnerships between families and health-care professionals from the perspectives of parents of children with MD.

**Methods:** Husserl's phenomenological research was applied to explore the basic structures of parents' descriptions of MD. Through purposive sampling, we conducted in-depth interviews with parents, and analyzed the data according to the theory of Giorgi. Nineteen parents (10 mothers, 9 fathers) participated in this study. The precision of the research results was tested by applying the four standards of Lincoln and Guba.

**Results:** This study identified five constituents: feasible resources and detailed care information; the provision of an integrated medical care across systems; family and home as key elements in critical care; respect and care for family care demands; and finally, feedback and support from families.

**Conclusion:** This study demonstrated that partnerships were established by health-care professionals, enhancing the care capacity of the families, developing the preventive medicine of MD, and enhancing children's potential for self-care within the families. Hospital policies should include the promotion of family partnership care. The findings can help health-care professionals recognize the life experiences of children with MD when providing medical care.

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## Q4 Introduction

There are many types of muscular dystrophy (MD) diseases, among which spinal muscular atrophy (SMA) and Duchenne muscular dystrophy (DMD) are the most common. The incidence of SMA is 1/10000 to 1/25000 while that of DMD, which is the most common pediatric sex-linked recessive genetic muscular disorder, is 1/3500 live boys. Every year in Taiwan, SMA is diagnosed in approximately 25 infants and DMD in about 30 infants [1]. Wang

et al [2] established the standard care for MD. Considering the complexity of MD, families bear a heavy load in providing care. In Taiwan, such families require coordinated care plans to navigate the health-care system; they need respect and empathy during their children's treatment because they feel that the health-care system does not recognize their children's conditions [3,4].

The so-called partnership care provided by health-care professionals refers to continuous communication, information sharing, and family participation in decision-making [5]. Wu and Lin [6] indicated that by the process of partnership care, families are able to cope with their situations and thus have a better quality of life. Therefore, partnership between parents of children with MD and health-care professionals refers to the continuous communication, information sharing, and joint decision-making to assist families in integrating resources from health-care

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professionals of different specialties, such as pulmonology, orthopedics, rehabilitation, and nursing. This will allow families to obtain information to delay the rate of muscle deterioration in their children, take appropriate measures when their children experience acute breathing difficulties, assist their children in self-care and social development, and search for their own meaning of care.

For the development of partnerships, Olds [7] proposed the nurse–family partnership program, in which nurses make house visits to promote pregnant women's health, help women build supportive relationships with their families, and link women and their families with required health services. Davis et al [8] developed the Family Partnership Model (FPM), which is characterized by cooperation, power sharing in decision-making, agreement regarding goals, complementary specialties, mutual respect, communication, and negotiation. Although nurse–family partnership program and FPM have complete theoretical frameworks, Olds [7] suggested improving the programs over time through continuous improvement strategies. Using FPM, Fowler et al [9] trained health-care personnel to cooperate with parents taking care of high-risk children and found that due to care complexity, the parents had to rely on nurses for professional care knowledge and skills. Thus, it is necessary to explore partnerships from the perspectives of families concerning complicated care issues and assess the challenges in practice. In the care of children with MD, the lack of care information and experienced health-care professionals results in problems with the partnership and care intervention. Therefore, this study, based on the FPM model, explored the complex care of families of children with MD and professional partnership of the phenomenon in greater depth.

Current studies on children with MD mostly probe into the stress and care experiences of their families [10–12], while the interactions between families and health-care professionals are seldom discussed. However, Yang et al [4] recently demonstrated that children with MD and their families expect professional care decision-making based on the family care experience, to enhance their children's security of life.

Pomey et al [13] found that families were not invited to health-care meetings concerning their cases and that the decision-making process for medical care and services was very slow. Kingsnorth et al [14] explored the partnership interactions among families caring for children with complicated health-care demands and suggested that professional collaboration and integration of communication are essential factors to integrate care plans for families. Hence, the families of children with complicated diseases suggest that partnerships should involve participation, sharing care plans and the expected conditions of the children, and integration of professional care organizations.

To sum up, although previous literature provides the theory and tools of partnership, most of them discuss the effectiveness of care. In the face of progressively deteriorating diseases and lack of medical resources, treatment and care cannot prevent progressive failure in patients with MD. Besides the effect of health care, we can further discuss the meaning and essence of establishing partnerships between health-care providers and families during the life-span of the patients and their family members. Thus, the study aimed to explore the meaning of partnerships between the families of children with MD and health-care providers, as seen from the perspectives of parents caring for children with MD, in order to realize family-based health care.

The theory of phenomenology is based on the back to things themselves, sharing as subjects, and the development of knowledge through life experience. This study aimed to discuss the partnership between health-care providers and parents and probe

into the meaning and essence of the phenomenon. Based on the phenomenological study, we could identify the parents' experiences to trace the nature of the phenomenon and find common constituents that emerge in the process of recognizing partnerships, in order to establish the structure.

## Method

### Study design

This study explores the partnerships between families and health-care professionals using the Husserl phenomenological method as it does not deny the existing beliefs in partnership. This method helps to recover and reflect on intersubjectivity under the contemporary context of families of children with MD. Partnership is a relationship of intersubjectivity, and phenomenology uncovers the visible and invisible phenomena in the shared world of intersubjectivity [15], thereby revealing the whole picture of the interactive relationships. Interviews were held with the parents.

### Setting and sample

Through phenomenological research from the parents' perspectives, this study explores the basic structure of partnerships between families and health professionals caring for their children with MD. We applied purposive sampling to the case transfers from doctors at two medical centers in Northern Taiwan. The participants are parents of children with SMA or DMD. The children range in age from 7 to 13 years. Nineteen parents (10 mothers, 9 fathers) of 10 children participated in this study.

Phenomenology emphasizes control of the truth of things, as well as the intention to describe the “phenomena”. In the broadest sense, things are thoroughly presented by themselves, meaning they demonstrate themselves through human consciousness and experience. The research situations selected were those in which the participants perceived convenience and comfort, felt undisturbed, and could freely express themselves. Therefore, the researcher conducted the interviews in locations selected by the participants and was open to all ways for them to describe their experiences. All the participants were interviewed in their homes.

### Ethical consideration

The study was approved by the Institutional Review Board of the participating hospital, IRB: 100-3606B. We explained the research objectives and procedures to the participants; safety of the participants was provided by us, including confidentiality and use of pseudonyms to protect participant identities and awareness of any emotional risks that might result from participating in this study.

### Data collection

Through in-depth interviews and retrospection, the researchers guided participants by “intentionality” to trace their experiences and to use language to describe their families and the life experiences of their partnerships with the health professionals caring for their children with MD. The health-care professionals are nurse, doctors, and physical therapists. Interviews were conducted by the first author.

The interviews served to indicate the “properties” of life experience regarding the partnerships and to help the participants develop “intentionality” regarding the significance of their “life experience in the partnership”. Participants were asked to indicate the experiential phenomena of their families and their experiences

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