

Summary of Doctoral Dissertation

Purpose

This study aims to build a cognitive model for parents' perceived shared decision making (SDM) for medical treatment of their children who had severe motor and intellectual disabilities (SMID). The model explained the influence of SDM on: 1) the choice that facilitated improvement of children's health and parents' burden of caring for their children and 2) parents' satisfaction with decision for medical treatment.

Methods

Valid responses were received from 262 parents with children under the age of 18 with SMID who received respirator support, tracheotomy or tube-feeding in the past 5 years. Instruments were: 1) The Parents' SDM for Medical Treatment of their Children with Severe Motor and Intellectual Disabilities Scale (SDM-CSMID Scale); 2) Parents' burden of caring for their children (VAS); 3) Parents' cognition of children's health and 4) Satisfaction with decision scale (Japanese version). Structural Equation Modeling examined Parents' perceived SDM model. St. Luke's College of Nursing's ethic review committee approved the study(10-078).

Results

The 22-item SDM-CSMID Scale has six factors regarding parents: "consideration about medical treatment from children's perspective"; "circumstance facilitating participation in decision making"; "respectful attitude of medical staff for feelings and opinions"; "sharing values with each other"; "support in understanding professional opinion and information" and "support to be proactive about physical changes of children". The total Cronbach's α was 0.946. Optimum goodness of fit of the Parents' Perceived SDM Model was: GFI=0.810, AGFI=0.782, CFI=0.904, RMSEA=0.062. SDM had direct influence on improvement of children's health and parents' satisfaction with decision, and indirect influence on improvement of parents' burden of caring for their children.

Conclusion

SDM should be promoted among all who care for children with SMID.