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Validity of substituted judgment in terminal care: a literature review

Wei-Hsi Chen^{1,2*}, Chieh-I Chen³

¹ Department of Neurology, Kaohsiung Chang Gung Memorial Hospital, Kaohsiung City, Taiwan

² The Chinese Arbitration Association (Taipei), International arbitrator

³ The National Kaohsiung University of Science and Technology, Graduate Institute of Science and Technology Law

Abstract

Objective: The protection of patient autonomy is an important parameter of healthcare quality. Substituted judgment by patients' family members may violate patient autonomy, cause hesitation and conflict, and result in incorrect decisions regarding inappropriate medical procedures.

Methods: This study reviewed the literature on the differences between medical decisions made by terminally ill patients and their family members between January 2009 and June 2019 and compared the legal policies on medical decision-making and dispute resolution strategies between the states of New York and California in the United States and Taiwan.

Results: Approximately 30% of patients changed their decisions during their course of disease. Most patients expected their spouses and children to make decisions together. Spouses and children were equally often chosen as sole decision makers. The families frequently modified patient decisions, and their accuracy rate in predicting patient decisions was only 56.7%. Unlike that in the United States, Taiwan's legislature does not address substituted judgment by family, legal guardianship, or the right of refusal of futile or substandard medical care.

Conclusions: Medical decisions are dynamic. Substituted judgment by family poorly predicts terminal patient decisions. To solve disputes arising from substituted judgement, the relevant rights and duties of family and judiciary and medical institutions require adjustment.

Keywords: Hospice, Living will, Family, Futile medical care, Physician–patient relationship