

Doctoral Thesis in 2018 (Abstract)

Study on Empathy in Surrogate Decision-Making by Families
for Elderly with Dementia

Graduate School of International Studies
International Humanities and Social Sciences
J. F. Oberlin University

Michiyo Bando

Abstract

In the present study, to enable utmost respect of the intentions of elderly with dementia, we believe that support to improve empathy among the family members should be urgently examined. Focusing on empathy in surrogate decision-making by family members, we will examine support strategies with which to improve empathy among the family members toward elderly with dementia.

Study 1: Study background : Furthermore, in making a medical care determination, problems are organized into surrogate decision-making by the family, decision-making of the elderly with dementia, and decision-making support for elderly with dementia. From this point of view, nurses are required to provide support to increase family empathy toward the wishes of elderly with dementia, and to enable surrogate decision-making.

Study 2: Study purpose, significance and design : The purpose of the present study is to find support strategies aimed at improving empathy in the event of surrogate decision-making by family members of an elderly with dementia residing in a long-term health care facility. Furthermore, we will summarize the significance and design of the present study, as well as the definitions of terminology.

Study 3: Examination of empathy in the process of surrogate decision-making by the family [study 1] : In this Study, we structured the ‘surrogate decision-making process experienced by families’, and examined family empathy toward elderly with dementia. In deciding upon medical care for elderly with dementia, the emotions of family members in surrogate decision-making became essential content for empathy toward the elderly with dementia, while holding empathy for the wishes of the elderly with dementia, because the wishes of the family member are also included in the agreement and decision.

Study 4: Examination of the decision-making process of elderly with dementia [study 2] : In this Study, we structuralized the decision-making process of elderly with dementia in deciding on medical acts, and examined related problems. As a result, the decision-making process of elderly with dementia consisted of two cases, ‘vague decision-making’, and ‘clear decision-making’. Therefore, the task for families does not lie in accepting the content heard before, but in gradually confirming their intentions together with the elderly with dementia.

Study 5: A comparison of decision-making between elderly with dementia and their family members [study 3] : In the present study, we examined the differences in the desires of the elderly with dementia and of the family in decisions regarding medical care, and examined family empathy toward the wishes of elderly with dementia. It was suggested that to be able to reflect the wishes of elderly with dementia, information should be fully shared between the family and health/welfare workers to be able to reach an agreement, and consider measures to take.

Study 6: An examination of empathy in the surrogate decision-making process of family perceived by nurses [study 4] [study 5] : In this Study, we obtained an outline of the surrogate decision-making process of the family regarding medical care for elderly with dementia perceived by nurses. Empathetic support for elderly with dementia requires the creation and provision of a space where discussions can be held regarding decisions about medical care, and it was suggested that it is important to have ample time for the elderly with dementia, their family, and nurse to discuss, surmise, and confirm by each of the three parties how the individual concerned ‘sees, feels, and thinks’ about the medical care.

Study 7: The development and examination of an assessment scale of family empathy in surrogate decision-making [study 6] [study 7] : In this Study, we examined family empathy toward elderly with dementia in deciding whether elderly with dementia receive medical care. As a result, we created the ‘family empathy scale’ to determine the extent to which the family infers the wishes of the elderly with dementia, and were able to examine a model to identify empathy towards the wishes of the elderly with dementia. The characteristics of the ‘family empathy scale’ can be used to determine empathy toward elderly with dementia when performing surrogate decision-making regarding medical care for the elderly with dementia.

Study 8: Trials of support to improve empathy of families in surrogate decision-making [study 8] : In this Study, we examined the development of support to perform intervention to acquire knowledge of medical care for elderly with dementia, and to improve awareness regarding the importance of discussions with family members. As a result, family members were able to envision the content of medical care in detail through several examples, which provided the opportunity to consider what they would do if it was their own family. Furthermore, it was suggested that holding discussions upon understanding medical care could improve participants’ empathy toward elderly with dementia.

Study 9: General discussion : The purpose of the present study is to find supporting measures to help families perform surrogate decision-making based on empathy toward elderly with dementia in deciding whether elderly with dementia residing in a long-term health care facility will receive medical care. In the surrogate decision-making process of family for elderly with dementia, the family makes decisions representing the wishes of the elderly with dementia, and therefore we were able to confirm a position of empathy toward the elderly with dementia. Nurses are obliged to respect the wishes of elderly with dementia. Therefore, we developed a family empathy scale to understand the current state of family empathy toward elderly with dementia, which would lead to support. The family empathy scale was confirmed to have a four-factor structure (ability to envision medical care choices, psychological understanding of elderly with dementia’, ‘empathetic consideration toward elderly with dementia’, and ‘distress in surrogate decision-making’). In the

present study, while discussing medical care options was considered important, families rarely discussed this; thus, with regard to making decisions about medical care, creating support to facilitate discussions was needed. As empathy support in the present study, examples of decisions made regarding medical care were included, and therefore, we believe that opportunities might have been created to enable discussions with family members. Furthermore, discussions based on examples where family members of elderly with dementia performed surrogate decision-making helped to envision the feelings of family members when selecting medical care, and discussion among all participants helped to envision and confirm the feelings of fellow participants. Moreover, with regard to the decision as to whether or not elderly with dementia will receive medical care, opportunities to talk need to be created with a space where discussions can be held daily. Therefore, from high school and university students, it can be said that this can also serve to encourage families to discuss whether or not to receive medical care.

The researchers felt throughout the present study that there was little encouragement created for families to engage in discussion, and few opportunities to create a space where families could do the same. Support to improve empathy toward elderly with dementia requires the creation and provision of a space where people can talk over decisions regarding medical care, and sufficient time to hold discussions among elderly with dementia, family, and medical welfare workers. Therefore, we hope to dig deeper in our investigation of support to improve empathy in surrogate decision-making by family members, so that the wishes of elderly with dementia will be respected.