

2018 Doctoral thesis (Abstract)

Surrogate decision-making concerning terminal practice for residents
of long-term care welfare facilities for older adults

Interactions between the families and nurses of older adults with dementia

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Chapter I. Introduction

1. Preface

Currently, many families find themselves forced to make decisions regarding the terminal medical care of older adults with dementia. Studies conducted in Europe and the United States have shown that in surrogate decision-making regarding treatment, families experience a negative emotional burden,¹⁾ and that such families find making the decision to withhold treatment to be more difficult than making the decision to provide treatment.²⁾ As will be shown in this thesis, a similar situation exists in Japan, where it can be said that support for families who make decisions regarding terminal medical care for older adults with advanced dementia is a significant issue.

In 2018, with the simultaneous revision of medical services and long-term care fees,³⁻⁴⁾ the capabilities of long-term care welfare facilities for older adults to provide end-stage care was enhanced, and it is expected that such facilities will encounter an increasing demand to provide such services for older adults with dementia in the future. However, in such long-term care welfare facilities, a doctor's presence is not mandatory and, consequently, nurses must play an important role in supporting families' decision-making concerning the provision of terminal medical care to older relatives.

2. Research trends and future research subjects in Japan

In 2017, Makino et al. conducted a literature review focusing on terminal medical care for older adults, with the aim of clarifying research trends regarding surrogate decision-making by families in Japan, as well as future research topics.⁵⁾ According to this literature review, the following five research topics have been suggested in existing studies as requiring investigation in the future: (1) improved intervention research, (2) verification of families' evaluations of nursing support, (3) the psychological process of families' who have decided not to administer life-prolonging treatment, such as gastrostomy, and elucidation of the characteristics of nursing support, (4) expansion of target subjects to family members other than cohabitants such as children and spouses, and (5) the accumulation of knowledge regarding older adults with dementia.

Chapter II. Aim and significance of this study

In this study, we define "terminal practice" as both medical care for persons in the end-stage of their lives and the general care provided to such persons. Specifically, this relates to medical care that can be administered in long-term care welfare facilities for older adults, or care that involves residents of such facilities being transported to hospital to receive life-prolonging treatment, such as artificial hydration and nutrition.

In this study, in order to evaluate the support nurses provide to families who are

engaging in surrogate decision-making regarding the terminal practice of older adults with dementia who are residents of long-term care welfare facilities, two issues were focused on. The first was to clarify the interactions between the family members and the nurses during the surrogate decision-making process, primarily through the conducting of a qualitative survey of the family members, and the second was to clarify the factors related to the feelings of satisfaction and regret experienced by bereaved families who have performed surrogate decision-making regarding terminal practice, which involved the conducting of a questionnaire survey.

This study is significant in regard to two aspects. First, this is the qualitative-survey-based study of pairs of families and nurses with the aim of examining the support nurses provide to families of residents of long-term care welfare facilities for older adults in regard to surrogate decision-making. Second, this study is a questionnaire survey aiming to clarify the factors that influence bereaved families' feelings of satisfaction or regret regarding their decisions concerning the terminal practice of such residents. As far as the author searched Japanese and English literature, these studies were not found.

The practical significance of this study is that its findings can be presented to nurses who work in long-term care welfare facilities for older adults and can be used to support the development of assistance measures that lead to the reduction of the mental burden on families delegated to perform decision-making regarding such matters. By understanding the feelings, thoughts, and needs of such families and considering nursing support based on these, it is possible for nurses who support the families to reduce associated dilemmas and difficulties, and it also facilitates the development of a surrogate-decision-making support system that allows family members to make decisions without experiencing regret.

Chapter III. Study 1: “Families’ surrogate decision-making processes regarding terminal practice and the terminal care process in facilities for older adults with dementia: Focusing on the interaction between families and nurses”

This chapter describes a qualitative study. The aim of this study was to clarify the interactions between families and nurses in long-term care welfare facilities for older adults regarding 1) the families’ surrogate decision-making processes concerning the provision of terminal practice and 2) the terminal care processes for older relatives with dementia. The subjects of the study comprised 16 pairs: families who made a surrogate decision regarding the provision of terminal practice for an older adult with dementia and the nurses who primarily supported the families. These pairs were recruited from three long-term care welfare facilities for older adults. These facilities were formally announced as ones which provided terminal care. Informed consent was obtained from all participants,

and individual semi-structured interviews were conducted from April 2015 to January 2016. In order to understand the contents of the support the nurses provided and to interview the families regarding their opinions of this support, the interviews were conducted in the order of nurse, then family. In the first phase of the analysis, the modified grounded theory approach was applied, which revealed the families' decision-making processes regarding terminal practice and the terminal care process, along with the contents of the nurses' support in this regard. In the second phase, we focused on concepts related to the families' satisfaction regarding their surrogate decision-making and terminal care. The interactions between the families and nurses were analyzed by contrasting them with nurses' concepts regarding related topics, such as support for older adults and their families, which were explored through a survey of nurses.

Through entering their older relatives into long-term care welfare facilities for older adults, families tasked with surrogate decision-making gradually begin to "realize and accept that senescence is difficult to cure," and they also view their older relatives with dementia and feel a sense of "relief that they appear to be living peacefully." When an older adult's condition worsens, the family "recognizes that their older relative is entering his/her terminal stage," and develop the internal opinion that "hospitalization treatment will be unnecessary" or a "desire to prolong life." Families that "made a surrogate decision to allow their relative to die, based on their trust in and expectations of the facility" expressed "100% satisfaction with their relative's death at the facility." These families can be considered to have conducted "surrogate decision-making without heavy responsibility"; families who "make decisions based on the will of the older adult," and who "make decisions based on the consensus of all family members involved" can also be considered to have enjoyed such decision-making. The following two factors were determined to be associated with their high satisfaction: (1) they felt "relief that the older adult appeared to be dying peacefully," and (2) they had a "positive feeling regarding the terminal care provided in the older adult's 'second home.'"

For 14 families who performed "satisfactory surrogate decision-making without regret," two points at the time of the surrogate decision-making were determined to be related to their positive experiences: (1) They belonged to the group "surrogate decision-making without heavy responsibility," and (2) they "made a surrogate decision to allow their relative to die, based on their trust in and expectations of the facility," and this decision was also based on a sense of satisfaction and security. Further, for the period from their surrogate decision-making to the provision of terminal care, these families reported "100% satisfaction with their relative's death at the facility."

The following section clarifies the interactions between the families and nurses at each stage of the families' experiences in the facilities; the underlined passages indicate quotes

from the nurses, which were based on their concepts, while those from the families are not underlined.

A: Period from entering the older adult into the facility until the surrogate decision-making

1) During the families' regular visits, the nurses provided "easy-to-understand explanations that helped the families understand and accept the nature of senility." The families felt that this was to help them "realize and accept that senescence is difficult to cure."

B: Time of the surrogate decision-making

2) Regarding the families' desire to "make decisions based on the will of the older adult," none of the families mentioned influence from nurses in this regard. However, nurses mentioned "attempting to trigger memories of the older adults that would help intuit their will." feeling that this would help families who the nurses determined to be "concerned about whether they select terminal care at the facility during their older relative's end-stage"; concerned because they did not know what the older adult would want, or families who were "hesitant [to make a decision regarding terminal practice] because they had conflicting emotions." These actions on the part of the nurses supported the families' desire to "make decisions based on the will of the older adult."

3) For families who the nurses determined to be "concerned about whether they select terminal care at the facility during their older relative's end-stage," and families who "did not know the opinions of the older adult's other relatives" regarding whether to select terminal care in the facility, nurses adopted the approach of "performing groundwork in order to assist relatives' decision-making." This support helped the families "make decisions based on the consensus of all family members involved." Families who recognized this behavior on the part of the nurse mentioned that it was beneficial.

4) "Visualization of the comprehensive roles of medical care staff." and "the presence of Kuroko [a person behind the scenes] who helps older adults live more comfortably," which are evident from the time the older adult enters the facility, were determined to impact the families' decisions regarding the administering of terminal care at the facilities, allowing them to "make a surrogate decision to allow their older relative to die, based on their trust in and expectations of the facility."

C: Period from surrogate decision-making to terminal care

5) As nurses "supported families' decisions and explained the care guarantee," the families were able to discern the approach of the facility's staff, and developed a sense of "relief that care was being provided by trustworthy medical care staff"; this

constituted a form of mental support for families' in the post-surrogate-decision-making period.

- 6) The nurses' approach of "providing assistance through simulating the process of dying at home" was evaluated by families as a helpful form of nursing support, with families positively assessing the terminal care provided as a "realization of the simulated end-stage home care." In addition, families mentioned that they did not feel a heavy care burden, even during the end-stage period, and that they felt a sense of "appreciation for the terminal care, as it exceeded expectations."

This study showed that, although the families experienced a mental burden, the related factors that helped the families perform satisfactory surrogate decision-making were present not only at the time the decision was made, but also during the preceding and succeeding periods. It also clarified that nursing support, which was important for family members to perform "satisfactory surrogate decision-making without regret," commences when the older adult is in stable physical health. Furthermore, through investigating pairs comprising families and the nurses who primarily supported them, the elements of nursing support that families typically do not recognize and which contribute to families' satisfaction regarding surrogate decision-making were clearly revealed, including their specific contents. In long-term care welfare facilities for older adults, which are expected to provide an increasing amount of end-period care for older adults with dementia in the future, nurses are expected to continue to play an important role in supporting family members' surrogate decisions regarding terminal practice. This study summarized the practical knowledge that the experienced nurses provided, and it is now possible to provide it to nurses who will perform such tasks in the future.

Chapter IV. Study 2: "Factors related to the feelings of satisfaction and regret experienced by bereaved families who made a surrogate decision regarding terminal practice for older adults with dementia"

The aim of Study 2 is to clarify the factors related to the feelings of satisfaction and regret experienced by bereaved families who have performed surrogate decision-making regarding terminal practice, especially considering the support they received from nurses. For this study, the 33 long-term care welfare facilities for older adults in the Chubu region of Japan that implement terminal care were approached and asked to distribute, on the researchers' behalf, questionnaire surveys to members of bereaved families who had made a decision regarding the provision of terminal practice to an older adult with dementia; informed consent was obtained. Family members who were willing to participate returned the completed questionnaires directly to the researchers by mail. The distribution and

collection of the questionnaires occurred from January to March, 2017. In total, 226 questionnaires were distributed, and 120 responses were obtained (recovery rate: 53.1%). The measurement items of the survey form concerned (1) whether respondents felt satisfaction or regret regarding their surrogate decision-making, (2) whether respondents were satisfied with the process of their older relative's death at the facility, (3) respondents' recognition of the implementation of nursing support, (4) respondents' opinions on whether surrogate decision-making and terminal care are positive, and (5) basic information concerning the bereaved family members and older adults in question (gender, age, relationship with the older adult, time since bereavement, age of the older adult at the time of the surrogate decision-making, the level of care required, physical condition).

To analyze the results, first, covariance structure analysis was conducted using the statistical analysis software IBM Amos 24. Second, binomial logistic regression analysis (forced entry method) was performed using the statistical analysis software IBM SPSS Statistics 24. Among the four classifications of satisfaction and regret, "1: high satisfaction and low regret" (set as the reference) "2: high satisfaction and high regret" (model 1), "3: low satisfaction and low regret" (model 2) and "4: low satisfaction and high regret" (model 3), each were analyzed as subordinate variables. In each model, the independent variables were four items (satisfaction with the process of their older relative's death at the facility, recognition of the implementation of nursing support, positive evaluation of surrogate decision-making and terminal care, and time since bereavement). The statistical significance level was set at less than 5%.

The correlation between "satisfaction" and "regret" for surrogate decision-making was $r = -.247$, and the covariance structure analysis model's fitness was $CFI = 0.902$, $RMSEA = 0.072$. The bereaved family members' "satisfaction regarding surrogate decision-making" was most influenced by "satisfaction with the process of their older relative's death at the facility." On the other hand, "recognition of the implementation of nursing support" was not a factor that directly affected "satisfaction regarding surrogate decision-making." "Recognition of the implementation of nursing support" had an indirect effect through "satisfaction with the process of their older relative's death at the facility" and "positive evaluation of surrogate decision-making and terminal care." For bereaved family members who showed "regret regarding surrogate decision-making," "recognition of the implementation of nursing support" not only directly, but also indirectly affected this through "positive evaluation of surrogate decision-making and terminal care" and "satisfaction with the process of their older relative's death at the facility."

Through binomial logistic regression analysis, model 1 was found not to guarantee the significance of the model equation ($p \geq .05$). For models 2 and 3, however, the model chi-square test was significant, the Hosmer-Lemeshow test showed good compatibility, and

the percentage of correct classifications was high. Model 2 (comparison of the “high satisfaction and low regret” group and the “low satisfaction and low regret” group), and Model 3 (comparison between the “high satisfaction and low regret” group and the “low satisfaction and high regret” group) were significantly different from the “satisfaction with the process of their older relative’s death at the facility” ($p < .01$). The odds ratios were 0.816 and 0.778, and the lower the “satisfaction with the process of their older relative’s death at the facility” was, the more likely the evaluation of the surrogate decision-making was to be “low satisfaction and low regret” or “low satisfaction and high regret.”

In this study, there was no strong correlation identified between bereaved family members’ “regret regarding surrogate decision-making” and “satisfaction regarding surrogate decision-making,” and it became clear that each related factor could differ. This new finding suggests that if the factors that enhance satisfaction and those that reduce regret are not simultaneously supported, the simultaneous realization of “highly satisfactory decisions” or “decisions with little regret” will be unachievable.

In terms of factors relating to the support provided by nurses, both “satisfaction” and “regret” regarding surrogate decision-making were indirectly influenced by “recognition of the implementation of nursing support” through “positive evaluation of surrogate decision-making and terminal care” and “satisfaction with the process of their older relative’s death at the facility.” The finding that “positive evaluation” affects “satisfaction with the process of their older relative’s death at the facility” and that “satisfaction with the process of their older relative’s death at the facility” influences “satisfaction” and “regret” regarding surrogate decision-making was also present in Study 1, and it was statistically confirmed in Study 2 that “recognition of the implementation of nursing support” has an influence on these. Through logistic regression analysis, compared with the group that reported “high satisfaction and low regret” regarding surrogate decision-making, the “low satisfaction and low regret” group and the “low satisfaction and high regret” group both had significantly lower “satisfaction with the process of their older relative’s death at the facility.” In addition to the fact that “satisfaction with the process of their older relative’s death at the facility” was determined through the covariance structure analysis to be the factor that most significantly affected “satisfaction regarding surrogate decision-making,” “satisfaction with the process of their older relative’s death at the facility” is likely to be a regulating factor for “satisfaction regarding surrogate decision-making.” On the other hand, the difference between “satisfaction” and “regret” concerning surrogate decision-making depended on the presence or absence of a direct influence of “recognition of the implementation of nursing support.” Recognition of the implementation status of nursing support has a direct impact on “regret,” but it was found to have no direct impact on “satisfaction.”

Chapter V. General discussion

Based on the findings of Study 1 (qualitative research) and Study 2 (quantitative research), this overall discussion considers the viewpoint of families performing surrogate decision-making; specifically, we would like to consider the constituent subjects effectiveness of nursing support for surrogate decision-making regarding terminal practice for older adults with dementia who are residing in long-term care welfare facilities for older adults.

1. Effectiveness of and practical subjects concerning nursing support for families' performing surrogate decision-making for residents of long-term care welfare facilities for older adults.

1) Effectiveness of nursing support

In the quantitative research of Study 2, it was shown that "recognition of the implementation of nursing support" has a direct or indirect influence on "satisfaction" and "regret" regarding surrogate decision-making. Moreover, in the qualitative research of Study 1, it was revealed that nurses had direct and indirect involvement in the decision-making processes of families who reported "satisfactory surrogate decision-making without regret" at each point in the surrogate decision-making process. This suggests that if nurses can provide surrogate decision-making support of an appropriate quality and quantity, there is a possibility that the receiving family can perform satisfactory surrogate decision-making without regret.

2) Practical subjects concerning nursing support

There are two constituent subjects regarding nursing support for surrogate decision-making. The first is confirmation of the will of the older adult. In the quality research of Study 1, surrogate decision-makers reported being burdened by making a decision without knowing the will of their older relative. In one instance, several months after their bereavement, a family who had doubts regarding surrogate decision-making mentioned that they "regretted not confirming the will [of their older relative]." Meanwhile, the nurses reported "verifying contents of decision making by families based on the wishes of older adults which they presumed". Since it is important to understand the will of older adults in order to make a decision regarding terminal practice that is as consistent as possible with the hopes and intentions of the older adults, future research should examine means of determining, supporting, and manifesting older adults' wishes.

The second subject is active involvement in the creation of an appropriate care organization. The narrative provided by the nurses in Study 1 comprised the following: (1) repeatedly holding discussions with other professionals over several years, until nurses have confirmed older adults' intentions regarding terminal practice and have practiced

terminal care, and (2) nurses are actively involved in providing educational mental support for care staff who administer terminal care and nighttime practice, and participate in various conferences (including death-related conferences), etc. At long-term care welfare facilities that do not yet have the capacity to support decision-making regarding terminal practice and/or to provide terminal care, it is necessary to increase the knowledge and skills of each nurse, cultivate the ability to perform assessments and reflections, create an organizational structure that involves sharing facility policies and targets regarding terminal care, and foster cooperative collaboration with related professionals.

2. Study limitations and future direction

The first limitation of this study is that clarifying the factors concerning families' satisfaction with the surrogate decision-making process was limited to examinations of the interactions between families and nurses. In Study 2, the analytical model was intentionally limited to factors related to nursing support, and covariance structure analysis returned a small regression coefficient for "regret regarding surrogate decision-making." Previous studies have reported "family belief in ceasing treatment" and "a sense of despair because there was no other option" as factors influencing families' regrets concerning surrogate decision-making, and the effect of not confirming the will of the older adult, as mentioned by the families in Study 1, was speculated.⁶⁾ In this way, it is fully conceivable that factors other than nursing support can influence family members' evaluation of surrogate decision-making.

Second, the interviews with the facility staff in Study 1 were limited to nurses, and the nurses were only interviewed in regard to support they provided for families. This means that information concerning the cooperative collaboration between professionals in the facilities was limited. In order to clarify the collaborative efforts of facility staff and to help them facilitate satisfactory surrogate decision-making for families, it is necessary to develop a research framework that incorporates the relationship between nurses and other professionals.

Finally, in terms of future research, this study constitutes a research project that comprises a first step towards determining the support long-term care welfare facilities for older adults provide for surrogate decision-makers. The first point to build upon is the identity of the "surrogate decision-maker." In this study, we set surrogate decision-makers as family members of older adults residing in such facilities, but it is expected that the number of single households will increase in the future. This means that there will be an increase in the number of cases in which a person other than a family member will be a surrogate decision-maker, and research that expands on this subject is necessary. The second point concerns support for cases in which the will of the older adult and the desires

of their family differ. In Study 1, all families who were aware of the will of their older relatives accepted and implemented their relatives' desires. Research on support for surrogate decision-making in cases where the intentions of the older adults and family members conflict, ⁷⁻⁸⁾ which is one of the most difficult situations for nurses, is necessary. The third point concerns intervention research. Both studies 1 and 2 were cross-sectional and were conducted after the families' older relatives had passed away. Although intervention research has been conducted in general wards,⁹⁾ no study has focused on the surrogate decision-making process in long-term care welfare facilities for older adults, clarified intervention procedures practiced, and evaluated them. If standardized steps to support decision-making regarding terminal practice can be determined and publicized, this will represent an effective and meaningful way of improving the quality of support nurses can provide.

【References】

- 1) Wendler D, Rid A : Systematic review: The effect on surrogates of making treatment decisions for others, *Annals of Internal Medicine*, 154 (5), 336-346, 2011.
- 2) Rabins PV, Hicks KL, Black BS : Medical decisions made by surrogates for persons with advanced dementia within weeks or months of death, *American Journal of Bioethics Primary Research*, 2(4), 61-65, 2011.
- 3) Ministry of Health, Labour and Welfare : Outline of FY 2018 Revision of Medical fee. (<http://www.mhlw.go.jp/file/06-Seisakujouhou-12400000-Hokenkyoku/0000197979.pdf>, 2018.8.27)
- 4) Ministry of Health, Labour and Welfare : Regarding the revision of each long-term care service in FY 2018: Revision of long-term care fees. (<http://www.mhlw.go.jp/file/06-Seisakujouhou-12300000-Roukenkyoku/0000196994.pdf>, 2018.8.27)
- 5) Makino K, Sugisawa H, Shirayanagi S, et al. : Surrogate decision-making regarding terminal care for elderly by family members: A literature review, *Journal of Japan Academy of Gerontological Nursing*, 23(1), 65-74, 2018.
- 6) Shiozaki M : Determinants of bereaved families' regrets regarding decision-making concerning older adults' hospitalization in hospice and palliative care units. (https://www.hospat.org/assets/templates/hospat/pdf/j-hope/J-HOPE_3_3.pdf, 2018.8.27)
- 7) Mori K, Sugimoto T : Actual state of and challenges in decision-making support for the terminal care of elderly cancer patients, *Journal of the Faculty of Nursing, Iwate Prefectural University*, 14, 21-32, 2012.
- 8) Ueda R, Shono S : Support by nurses at special nursing homes on the family's substituted judgment for terminal patients unable to express their will, *Journal of Japanese Society for the Study of Nursing and Social Work*, 21(2), 183-195, 2016.
- 9) Saida A, Koizumi M : Nursing care of elderly terminal ill patients who are unable to communicate their intentions: Effect of introducing end-of-life nursing care protocol for taking account of personality in nursing care by discussing with families, *Journal of Japan Academy of Gerontological Nursing*, 14(1), 42-50, 2010.