

学位論文題名

Families' Acceptance of Near Death:  
A Qualitative Study of the Process for  
Introducing End-of-Life Care

(高齢者終末期状態に対する家族の受容プロセスに関する質的研究)

学位論文内容の要旨

(Background and Objectives) Because of rapidly aging population, providing effective end-of-life (EOL) care for the elderly is an important social and medical problem in Japan. According to the profiles of Medicare patients in the U.S., more than half of older people at the EOL stage are not identified as or are not assumed to be near death. As a result, health care providers do not recognize them as near a terminal stage and do not engage their families effectively. Japan faces the same situation because there is little consensus regarding the definition of the "terminal stage" in older people with severe brain damage, such as advanced cerebral vascular disease or dementia. Even if health care providers consider that older people with severe brain damage should be treated as terminal based on their experience, they might well find out that it would be too hard for patients' families to accept the patient's condition as near death. As a result, they could not appropriately introduce any EOL services. The purpose of our study is to develop a comprehensive understanding of the process by which families accept the elderly with severe brain damage as near death.

(Methods) A qualitative methodology employing focus groups and semi-structured interviews was conducted to establish theoretical triangulation. Twenty-three participants in two-male and two-female focus groups (convenience samples) were interviewed in a semi-structured format. Ten participants (five males and five females) who made important medical decisions (theoretical sampling) were then interviewed separately. Interviews were conducted by a public health nurse and a nurse who specialized in EOL care. Both were experienced facilitators in qualitative studies. Interviews were directed on the basis of case scenarios and interview guides to allow participants to express personal and sensitive problems. Semi-structured interviews for the participants were developed to reflect the themes derived from the focus group interviews. Interviews continued until the same themes were reported and no new themes emerged, i.e. saturation. All interviews were tape-recorded and transcribed. The recording of the interviews were implemented by two researchers (MW, MMA). The verbatim transcripts were first analyzed independently by them. A second and third author (HK, MMu) independently read the interview transcripts and then the results of the analyses in order to validate the preliminary results. All four authors contributed to discussion, interpretation, and agreement of the final results for emerged themes and codes, and broader categories were created by the codes in agreement with a constant comparison method. A conceptual

model was molded by the extracted categories. “Trustworthiness” of the analysis was determined by (1) peer debriefing, (2) member-checking and (3) reviewing the earlier literature on EOL care for correlation with our interpretation.

(Results) Analysis of the interview transcripts yielded 11 categories: (1) *family affection with wishes for continued survival*; (2) *vacillation of desire for death with dignity*; (3) *family members' hierarchy*; (4) *awareness that others may make different decisions*; (5) *family members' discussion overcoming discordance*; (6) *satisfaction with the physicians' explanations*; (7) *impressions of life-sustaining measures*; (8) *entrusting important decisions to hospital physicians*; (9) *significance of family members' previous experiences*; (10) *patient's age*; and (11) *duration of medical treatment*. Considering connections between categories, a conceptual model was developed. The model groups 11 categories into four themes: (1) *individuals*; (2) *families and relatives*; (3) *relation to medical services*; and (4) *experience*. Our conceptual model starts from the point when family members face the situation in which their elderly loved ones suffer from severe brain damage. They are informed of the condition by attending physicians or other family members. Having some own ideas as *individuals*, they exchange opinions with one another as *families*. They may have several chances to ask physicians some questions *relating to medical services*. While their elderly loved ones receive treatment, they have many *experiences* involving life-sustaining measures. During this period, they may have meetings with *families and relatives* to overcome discordance. Through this process families' acceptance of death with dignity is formed gradually.

(Discussion) Introducing EOL care to families caring for invalids is crucial to accomplish “good death”. The concept of “good death” has been investigated from the patients' and families' perspectives, which consist of “(1) pain and symptom management, (2) clear decision making, (3) preparation for death, (4) contributing to others, and (5) affirmation of the whole person”. Teno JM, et al. have advocated “Patient-focused, Family-centered end-of-life medical care”, emphasizing “attending to the needs of the family for information, increasing their confidence in helping with patient care, and providing emotional support prior to and after the patient death”.

Patients also desire to have family members involved in EOL decisions. Rosenfield et al. explained that “patients' desires may be achieved best by a model of collaborative surrogate decision making by families and physicians. Families can represent patients' interest by defining acceptable outcomes and delineating goals of care based on their understanding of patients' values”.

Effective discussion with families is required to introduce EOL care particularly in families caring for the elderly with severe brain damage. It is useful for explaining patients' medical information and sharing in the decision-making process what expectations they have, with medical staff, that may lead to the caregiver's satisfaction, which is said to be an essential factor enabling home death of elderly patients. Therefore this study was designed to develop a comprehensive understanding of the process by which families accept the elderly with severe brain damage as near death.

There are some limitations in this study. Firstly, this is a qualitative study performed in one area of Okinawa where the first author has practiced as a family physician. An in-depth understanding was the aim rather than the study's generalizability. Secondly, as the scenario was presented with mainly physical aspects of the patient, the statements of participants may lean toward biomedical topics. Further studies with a presented scenario of a patient with psychosocial issues, such as, among others, physical, mental and financial burdens, are required in different areas involving other cultural and ethnic backgrounds. Finally, from the researchers' standpoints, all of the researchers are doctors, which may have influenced this study; however, member-checking modified biased views.

(Conclusion) We identified 11 categories and four themes. These were identified in the language of

participants as family members with elderly loved ones. This conceptual model is useful for evaluating which categories and themes they consider, as well as introducing them to EOL care in a timely manner.

# 学位論文審査の要旨

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## Families' Acceptance of Near Death: A Qualitative Study of the Process for Introducing End-of-Life Care

(高齢者終末期状態に対する家族の受容プロセスに関する質的研究)

本研究は超高齢時代における高齢者への適切な終末期医療のあり方に関するものである。終末期の重度脳障害を有する高齢者を抱える家族がどのようなプロセスで死を受容していくかを質的に分析し、臨床の場での応用方法を明らかにすることを目的とした。

申請者は、方法論的トライアングレーションとして、フォーカスグループインタビュー及び半構造化面接を用い、得られたデータを逐語化したスクリプトの形にし、グラウンデッドセオリーアプローチの手法を用いて分析した。真実性(trustworthiness)の確保として、ピアデブリーフィング、メンバーチェック、先行研究との整合性の確認の各手法が用いられた。結果として、家族が高齢者の死について受容するプロセスが、11のカテゴリー、4つのテーマを元に、ストーリーライン・概念モデルという形で明らかにできた。

11個のカテゴリーは①その高齢者が生き続けることを望むという家族愛、②高齢者の尊厳死を尊重することへの迷い、③高齢者に対する家族間の意思決定についてのヒエラルヒー、④家族間の意思の違いに対する気づき、⑤家族同士での意思の違いを乗り越える議論プロセス、⑥高齢者の状態についての医師の説明に対する家族の満足感、⑦高齢者の生命維持の方法についてその家族が受けてしまう印象、⑧主治医に重要な判断を任せてそれを信じること、⑨高齢者の家族が以前に経験したことの重み、⑩患者の年齢、⑪患者が受けている医療サービスの時間の長さ、に分類された。

4つのテーマに分類された。(A)高齢者の家族に内在する感情[カテゴリー①②]、(B)高齢者の家族間の関係[カテゴリー③④⑤]、(C)高齢者が受ける医療サービスに関すること[カテゴリー⑥⑦⑧]、(D)高齢者の家族が経験したこと[カテゴリー⑨⑩⑪]。

著者の概念モデルは、家族が重度脳障害の高齢者が直面して苦しんでいる状況に対峙することに始まり、家族は、主治医や周囲の人達からその状況を告げられる。高齢者の家族に内在する感情を、家族間の葛藤を踏まえつつ家族間で意見交換し、主治医にも、生命維持治療も含めた医療サービスに関することを助言・援助してもらう機会(C)を持ち、家族として様々なことを経験(D)していき、家族間の意思の違いや置かれている状況の困難さを克服し、乗り越えていく。この流れこそが、高齢者の死に対する尊厳について家族

が受容していくプロセスである。これらのカテゴリーを理解することは適切な終末期ケアを導入するための有効な一助となると考えられた。

質疑応答では副査の生駒教授から対象の理論的サンプリングや結果の解釈に関する質問があった。ついで副査の前沢教授からこの理論が今後臨床の場で活用できる可能性、他県と沖縄における住民医療文化の差異に関する質問があった。主査の寺沢から、尊厳死等の言葉の定義に関する問題、特に本研究が抱える倫理的課題についての質問があった。さらに審査者以外から本研究の手法的側面および実際の医療現場からの経験的側面に関する追加発言があった。

申請者は対象の理論的サンプリングはWHOの手法でも指摘されている通りに合目的に行ったものであるが、それを考慮しても研究者の立場や研究の置かれている状況によって、結果の解釈が変わり得るものであることを示した。また、著者が家庭医として医療を実践している沖縄の一地域で行われたことであり一般化可能性の問題はあるものの、現象の深い(in-depth)理解を目指した研究であり、さらなるインタビューによって研究が深めていける可能性があるとは回答した。沖縄では地域住民の結び付きが強い特性を生かしながら地域の保健師・看護師とも協力しつつ高齢者の家族への適切な終末期医療についての可能性を回答した。尊厳死の言葉の定義に関する解釈についても、申請者は概念図のスライドを提示しながら結果解釈が変化する可能性について説明した。本研究で得られた概念図上のストーリーラインに沿った右下から左上へのベクトルの重要性を強調した。

いずれの質問に対しても、申請者は、質的研究手法の基礎知識に関わる重要な文献、並びに、自身の共著論文・学位論文の内容を引用して適切に回答した。

この論文は、*Geriatrics and Gerontology International* 誌で高く評価され、終末期医療に関する先駆的研究として、今後この方面でのさらなる研究への影響が期待される。

審査員一同は、これらの成果を高く評価し、大学院課程における研鑽や取得単位なども併せ申請者が博士(医学)の学位を受けるのに十分な資格を有するものと判定した。