Development of a Theory to Support Patients with Cerebral Vascular Disease and their Families in Solving Post-discharge Difficulties in Daily Living Activities.

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―― 原 著 ――

Development of a Theory to Support Patients with Cerebral Vascular Disease and their Families in Solving Post-discharge Difficulties in Daily Living Activities

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Summary

The purposes of this study are to develop a conceptual framework of difficulties cerebral vascular patients and their family caregivers face in their daily life after discharge from the hospital and to provide a theoretical proposition to be verified with the Case Study Research (Yin, 1994) approach. The subjects were 10 caregivers of the cerebral vascular patients (7 females and 3 males), the average age of whom was 59.0 (SD=9.8). The interviews were given with semi constitutive questionnaires. The questions were organized around difficulties in home care and data was collected and analyzed qualitatively. The seven concepts thus extracted were: difficulties for the patients; difficulties for the caregivers; caregiver's coping strategies; shift of awareness; information; environmental factors; and change in patients and caregivers' difficulties. The framework was structured with these concepts and the difficulties were estimated to reduce or expand depending on the three coping strategies of the caregivers. The theoretical proposition to be verified was: If caregivers use coping strategy 1 (observation-plan-trial-confirmation), the difficulties may be reduced.

Key words
cerebral vascular disease patients, family caregivers, activities of daily living, difficulties, theory development, case study research

Introduction

Cerebral vascular disease is one of the diseases most seriously affecting the daily life of the patients[1)]. The cerebral vascular disorders produce different levels of functional impairment depending on the lesion, affecting recovery differently. The patients are usually discharged from the hospital after acute treatment and rehabilitation. The patients and the family caregivers then suffer from confusion and conflicts in their daily life[2)-4)]. Care of the patients with higher level of brain dysfunctions is often left in the hands of the caregivers who cannot but make trials and errors [5)-6)].

It is necessary to design a system of support, which can flexibly take care of many changes in the care situation as well as disease conditions. Such a support system is indispensable in assisting patients and families to reorganize their daily lives. Designing such systems requires identification of confusion specific to cerebral vascular diseases and difficulties patients and families face, as well as development of intervention adequate for each care situation. Wallhagen reports that personal demands are perceived as more difficult than task demands and are associated to a greater extent with caregiver life satisfaction and depression[7)]. Caregivers for patients with higher brain disorders felt a sever psychological burden, in communication in a care setting[8)].

Interest in care provision was increased in the 1990's and various factors influencing caregivers

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were identified. In the field of home care, a large database concerning needs and problems of the clients was constructed. Verification of the database, however, has rarely been done and there is a limitation in generalizing service effectiveness measures. It is also found that there is little theoretical background in this field[9)-13)]. The author reached the conclusion that a conceptual framework applicable to complicated home care conditions and theoretical proposition is needed to verify the effectiveness of intervention.

Research Design

It is very important to design how to measure difficulties patients and caregivers face at home after discharge from hospitals. It is also necessary to take the followings into consideration: a) There is a limit in supporting cerebral vascular disease patients alone, since their disabilities require support of both patients and caregivers; b) There is no clear definition of difficulties, which are critical variables in the process of care and c) Difficulties change as disease states change and it is critical to take change of care and disease states into consideration in designing the study.

In this study, Case Study Research proposed by Yin (1994)[14)] is considered appropriate as the research strategy, because the researcher can barely control the subjects' behaviors and should focus on present events rather than historical events. Home care is too complicated an environment to take survey strategy or to conduct an experimental study. The research strategy the author took was to describe the real context of interventions which explains causative relationships.

Figure 1 shows the structure of Case Study Research. The first step is theory development. In the process of design and data collection, it is important to select cases and to define specific measures. Theoretical proposition should be proposed based on the previous findings. Then, it should be verified. These two steps can modify the existing theory into a new one.

In this study, the author reports how the conceptual framework was developed and the theoretical proposition could be proposed, since there had been no effective theoretical frameworks available for home care. The overall structure including theory verification was designed using Case Study Research.

Research Purpose

The conceptual framework of difficulties cerebral vascular disease patients and their family caregivers face in their daily life after discharge was to be developed and the theoretical proposition to be verified with the Case Study Research (Yin, 1994) approach was to be proposed.

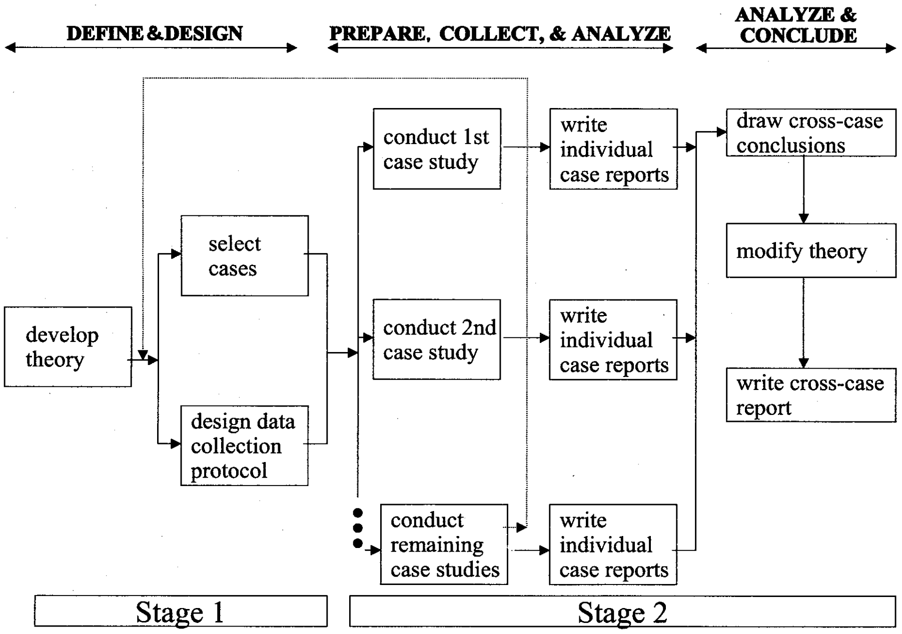

Figure 1 Case Study Method

Method

To design a conceptual framework of difficulties, those in daily life were identified through interviews with emphasis upon activities of daily living of both patients and their caregivers.

a) Case selection

Family caregivers had been caring at home for patients diagnosed as having been damaged by their first cerebral vascular attack .

b) Data collection

Data was collected by interviews. Most of the interviews were conducted in the researcher's office because many family members preferred the office to their own homes. Each interview lasted between one and two hours and was tape recorded. The broad data-gathering question was used to start the open-ended interview; "Tell me what it has been like living with the patient, what has been your burden in taking care of him/her, what has changed your mind and what helps you with your task?"

The researcher informed the patients and their family caregivers of the purpose to receive consent in participation. The patients and the family caregivers were assured of their right to abstain without prejudice from offering information if they so wished. It was also confirmed that full anonymity was maintained to protect their privacy.

c) Data analysis

Data was analyzed qualitatively. Open coding was used for initial analysis of the transcribed data and initial categories were adjusted based on subsequent interviews. The analysis resulted in selecting subsequent informants. Data was then refined by merging data into smaller sets of higher level concepts fitting the emerging theory. Concurrent coding and analysis was continued until unique categories no longer appeared in the data.

The process of analysis described above was reviewed by three researchers of home care nursing and was supervised by the researcher of qualitative study to improve the study reliability.

Results

Seven female and three male caregivers participated in the study. Their average age was 59.0 (SD=9.8) and the average duration of care-giving was 6.7 years (3-9, SD=4.5).

Findings suggested that the core process can be described as: difficulties through trials and errors of living with a stroke patient. Seven categories were extracted and used to build the theoretical framework: difficulties for the patients; difficulties for the caregivers; caregiver's coping strategies; shift of awareness; information; environmental

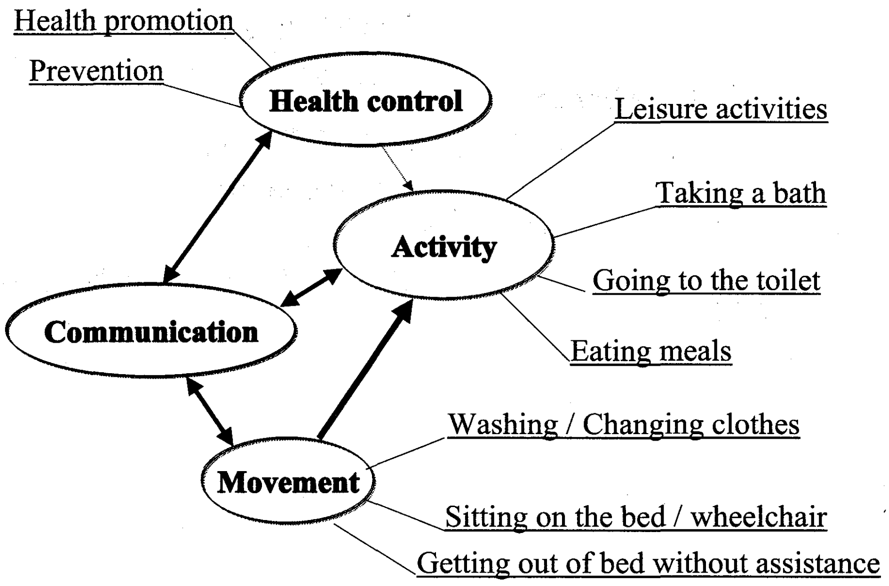

Figure 2　Difficulties in daily lives for patients

factors; and change in difficulties patients and caregivers face.

a) Difficulties in daily life for patients

Difficulties in daily life for patients can be structured as those caused by sensory impairment, motor impairment and cognitive impairment. Difficulties in daily living were classified based upon the verbal description of the caregivers. Nine items were identified; “getting out of bed without assistance”, “sitting on the bed /wheelchair”, “washing/changing clothes”,“eating meals”,“going to the toilet”, “taking a bath”, “leisure activities”, “health promotion” and “prevention” (Figure 2).

“The patient can not turn in the bed; he/she insists that they sit straight even when leaning or bending,” are the phrases we often hear from the caregivers. Though the patient could sit, it was difficult for the person to keep postural balance (Case 5). When the patient has agnosia of the left side of the body, “the person cannot recognize that the left side is not functioning and he says I am in his way.” Attention problems in addition to indifference to the left side of the body made the person put his left arm in the back when making turns or unaware that his left arm was pressed against his back when lying on the bed (Case 3). Cognitive impairment made it difficult for the patient to wash his/her face and to change clothes even if he/she had no paralysis(Case 8). Common activities such as “getting out of bed without assistance”, “sitting on the bed/wheelchair” “washing/ changing clothes” were grouped as “Movement”.

Frontal lobe symptoms caused by subarachnoid hemorrhage and such, left hemispheric paralyses such as aphasia, apraxia paralysis and ataxia, caused difficulty for the patients in“eating meals”. “They cannot recognize how much and how fast they eat and they just continue eating”. Quantitative and speed balance of eating was not functioning properly (Cases 1 and 8). Excretion is another important activity in maintaining life. It requires a combination of different actions. Many patients presented dysfunction in elimination. When a patient had additional cognitive impairment, he might wander in the yard, saying “I am going to the toilet”. He remembered that the toilet was outside the house when he was a child.“taking a bath” and “leisure activities” strongly reflect the patients' intention, will, wish and expectation. These behaviors require acquisition of the aforementioned activities of “getting out of bed unaided”, “sitting on the bed/wheelchair” and “washing/changing clothes”. The behaviors affected by the acquisition of “Movement” were grouped as “Activities”.

Problems in “communication” were more promi-

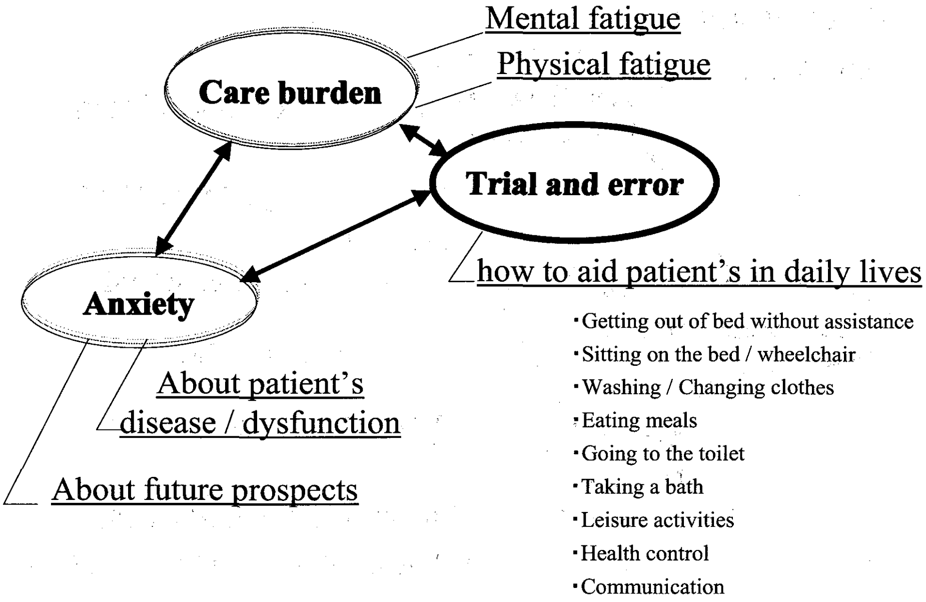

Figure 3　Difficulties in daily lives for caregivers

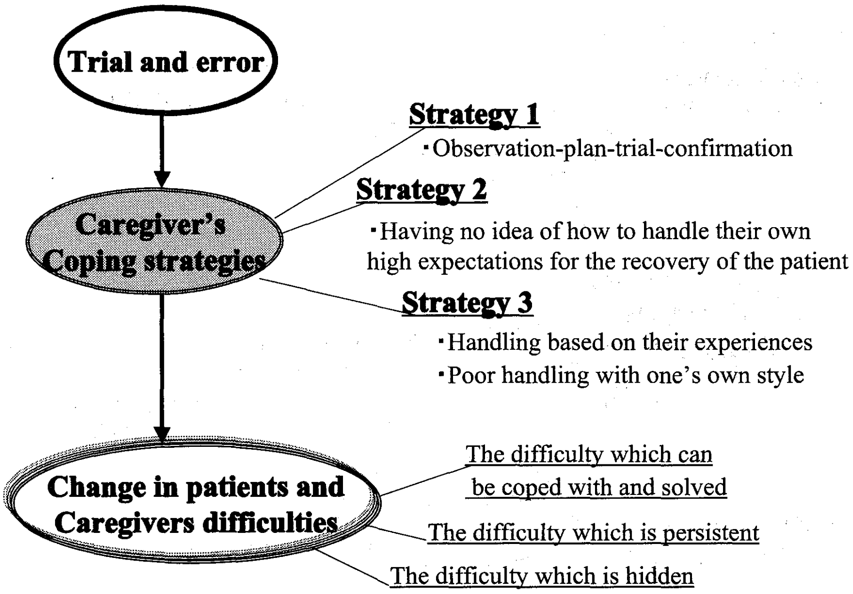

Figure 4　Caregiver's coping strategies

nent among the patients with cognitive impairment. "When I said I would like to go to the post office, the patient could not understand what a post office was"(Cases 1, 5 and 7). The patients could not communicate their will and/or emotions. Lack of understanding of their own disorders made it difficult for them to protect their health and to avoid accidents. Functional impairment attributable to specific cerebral vascular lesions was another cause of difficulty. Difficulties in daily life for patients were interactions among "Activities" directly affected by "Movement", "Communication" and "Health control".

b) Difficulties in daily life for caregivers

Caregivers' difficulties lie in aiding patients in their daily life. Caregivers are especially confused when the patients are discharged from the hospitals and when they have no ideas how to take care of them. They start giving care to patients through "trials and errors". At the same time, caregivers are always concerned about "relapse" (Case 7) and worry about some accidents (Case 9). Their anxieties centered on "patients' disease/dysfunction" and "future prospects" (Case 2). Most of the caregivers had to spend almost all day taking care of the patients with such "Anxieties". "It was the most awful for me that I had to take care of the patient all day" (Case 2), and "I felt tired when I was with the patient" (Case 1) are common comments made by family caregivers. "Care burden" composed of "mental fatigue", "physical fatigue" and "Anxiety" were interacting with daily "Trial and error" efforts (Figure 3).

c) Caregiver's coping strategy and change in patient's and caregiver's difficulties.

There are three major coping strategies of the caregivers in the process of trials and errors (Figure 4).

1. Observation-plan-trial-confirmation
2. Having no idea of how to handle their own high expectation for the recovery of the patient
3. Handling based on experiences and poor handling with one's own style

To develop 'Observation-plan-trial-confirmation' strategy from "Trials and errors", it was essential to have specific information of the functional level of the patient and practical information useful in daily life. When a caregiver acquires this coping strategy, the caregiver could evaluate and confirm the effectiveness of his/her own care and became more flexible. Examples of "difficulty in coping and solving" contained many specific methods of care. For instance, in order to maintain postural stability of the patient, "it is necessary for you to look at the patient (posture) critically. Put his feet front, hands far back and his head low. You have to

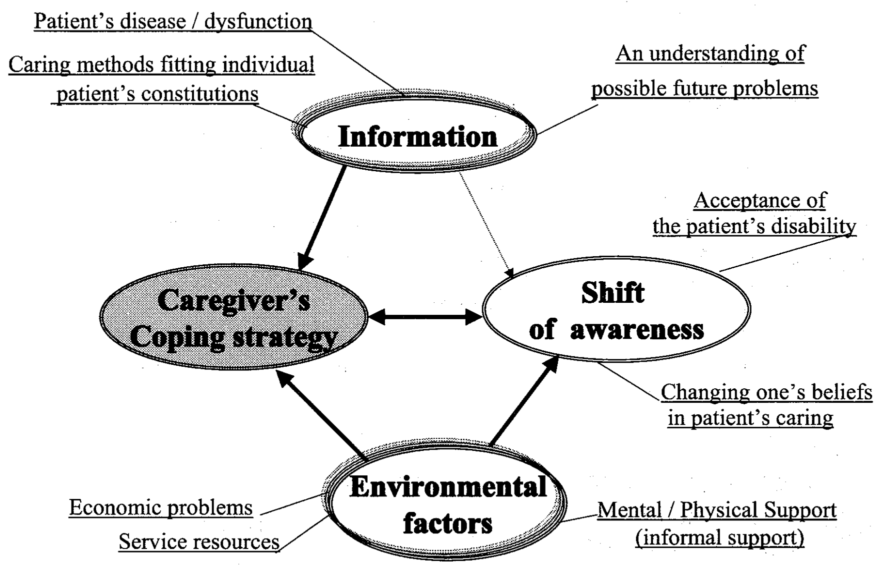

Figure 5 Shift of awareness, information, environmental factors

try it yourself"(Case 2).The caregivers then became confident in their care. Change in the caregiver's attitudes coincided with the patient's reacquisition of activities of daily living. "persistent difficulty" reflects a vicious cycle that the more care inappropriate to the functional level of the patient and to the ability of the caregiver was given, the greater the difficulty became both for the patient and the caregiver. "hidden difficulty" was when the caregiver established the practice of care only satisfactory to him/her, he/she tended to force the patient to do excessive exercise, leading to damage of healthy side and making latent difficulties bigger. "difficulty in coping and solving", "persistent difficulty" and "hidden difficulty" were grouped as "Change in difficulties for patients and caregivers".

d) Shift of awareness

Subordinate items of "Shift of awareness" are "acceptance of patients' disability" and "change in one's belief in patient care". The process in which a caregiver develops individualized and effective strategies of care through trials and errors is the process in which he/she accepts the functional state of the patient. In this process, the caregivers learned to accept even very minor changes in the level of the patients' functions. Such subtle changes will help a caregiver solve difficulties and find meaning in care giving. Shift of awareness affects the positive attitudes toward care. The ways caregivers receive information and select coping strategies affect if the difficulties reduce or expand. Conversely, the difficulties reduce or expand the abilities of caregivers in receiving information and selecting coping strategies. "Shift of awareness" promotes caregivers effort in problem solving. "Environmental factors" influence the care process (Figure 5).

e) Information and environmental factors

Subordinate items of "Information" are "care methods fitting individual patient's constitutions", "patient's disease/dysfunction", and "anticipating future problems". Information on "patient's disease /dysfunction" is often limited to the description of functional impairment, leaving caregivers uncertain how to cope with the problems in daily life. Information fitting individual patient's constitutions is effective and guides caregivers in finding coping strategies. What caregivers need most are the pieces of information to find prospects for the future life of both the caregiver and the patient.

Subordinate items of "Environmental factors" are "economic problems", "service resources" and" mental/physical support (informal support)". Economic environmental factors directly affect "Caregiver's coping strategy" and "Shift of awareness". "economic problems" and collaboration with medical institutions, which is one of the "service resources," are especially important. Whether

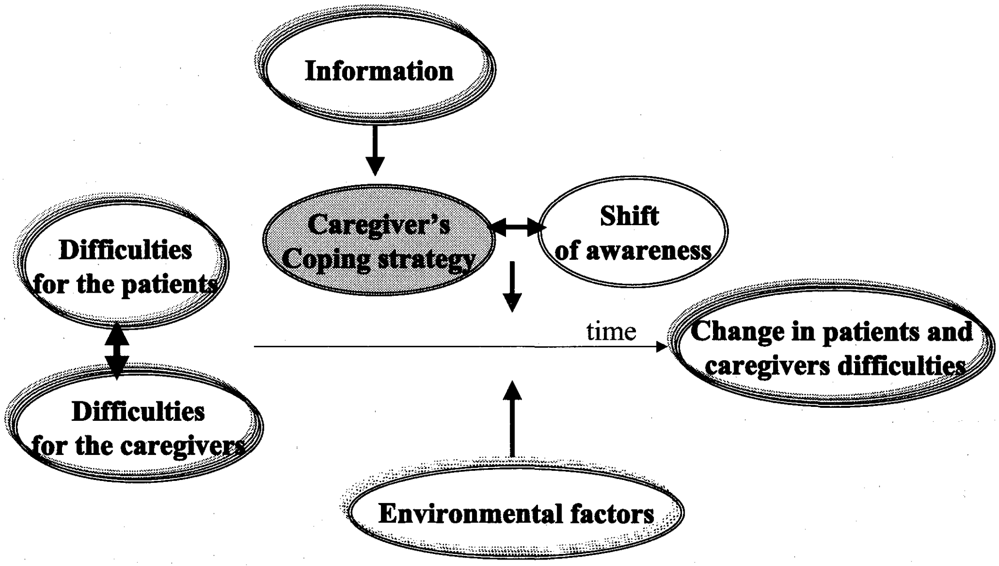

Figure 6　Conceptual framework

patients can live successfully at home or not depends on the above environmental factors.

Many patients with cerebral vascular diseases live at home with functional impairments, which are the major causes of difficulties in daily living. Such difficulties change as time passes and develop into solved and unsolved difficulties. Many factors including information induce these changes. There are three major coping strategies of the caregivers. The ways caregivers receive information and select coping strategies affect if the difficulties reduce or grow. As the caregivers learn more effective methods of care, they come to accept the disability and impairment of the patients. This process is called "Awareness shift"; it promotes caregivers' efforts for problem solving (Figure 6).

Three theoretical propositions were derived from the data and analyses of stage 1:

1. If caregivers use coping strategy 1 (observation-plan-trial-confirmation), the difficulties may be reduced.
2. If caregivers' expectations are higher than the ability of the patients, the difficulties may expand (strategy 2), and
3. If caregivers continue to use coping strategy 3 (handling based on the experiences, and poor handling with one's own style), the difficulties may grow.

Discussion

a) Difficulties for patients/caregivers in daily life and caregivers' coping strategies

Difficulties for patients in daily life include "getting out of bed without assistance", "sitting on the bed/wheelchair", "washing/changing clothes, "eating meals", "going to the toilet", "taking a bath", "leisure activities", "health promotion" and "prevention". The higher concepts, "Movement", "Activity", "Health control" and "Communication" interact creating difficulties for patients in their daily life. Observation of patients' behaviors in daily living helped the author to identify difficulties the caregivers face. Difficulties for caregivers in daily life may reduce or expand depending on their coping strategies starting with "Trials and errors".

One of the problems in developing effective home nursing intervention for patients and caregivers is to identify who is to be targeted. Who needs support most or who is most benefited by the support should be identified[11]. It is difficult to verify the effectiveness of the intervention without identifying who is the subject. In the previous theory where both patients and caregivers are targeted, a concept dealing with their interaction is required. Evans et al.[15] focused on the family function for family interaction and showed it was necessary that problem solving should effectively support families taking care of patients. Another study on elderly people and their caregivers reported that subjective sense of burden and quality of care by caregivers change in the process of interaction between caregivers and patients[16].

There are three subordinate strategies under "Trials and errors", which may affect difficulties of both patients and caregivers. The factors affecting "Caregiver's coping strategy" include concepts of "Information", "Environmental factors" and "Shift of awareness". In this study, the author observed coping strategies for difficulties of caregivers so that difficulties are handled as a concept changing over the time. Many report anxiety and care burden as predictors[17]. Difficulties can be understood not only as the negative components of anxiety, care burden and depression which are often used as outcome measure of the caregivers' adaptation but also as something that caregivers can cope with and solve. When difficulty is reduced, caregivers can accept their role in a positive way. Since difficulties can be explained with subjective satisfaction and depression of caregivers, difficulty is balanced between positive and negative aspects on the time axis. As a coping strategy selected by a caregiver may reduce or expand difficulties, we can design and develop nursing support to reduce the difficulty a caregiver is facing. It is important that the timing and content of risk management should match the disability and impairment of the patient, and that a psycho-educational support system be utilized[4]. Provision of knowledge and information on impairment and disability caused by cerebrovascular diseases is necessary so that caregivers can understand the significance of their care and cope positively, and provision of knowledge about the disorder and disability so that caregivers can understand their role objectively and have a future outlook[18)-20].

b) Theoretical framework and proposition

Difficulties for patients/caregivers can be analyzed with activities of daily living and be handled as indices of change in difficulties by coping strategies. This process helps clearly define difficulties as observable indices.

Difficulties of the patients and their family caregivers after being discharged from the hospital may reduce or expand depending on the coping strategies of the caregivers at home. The most frequently observed coping strategy at home was "observation-plan-trial-confirmation". The second most frequently observed coping strategy is blockage of information due to caregiver's excessive expectation of the patient's ability. The third strategy is the lack of effective utilization of information by the caregivers, leading to continued difficulties. In this study, difficulties were narrowly defined as difficulties in daily activities which were observed to reduce or expand depending on the caregiver's coping strategy. The difficulties here are not identical to disabilities or unsolvable problems.

What are components of a theory? First, theories comprise a set of concepts[21]. In this theory seven categories were extracted and used to build the theoretical framework: difficulties for the patients; difficulties for the caregivers; caregiver's coping strategies; shift of awareness; information; environmental factors; and change in difficulties patients and caregivers face. Second, theories comprise a set of statements or propositions, each of which indicates a relationship among the concepts[21]. Difficulties for the patients and their caregivers change as time passes and develop into solved and unsolved difficulties. The ways caregivers receive information and select coping strategies affect if the difficulties reduce or grow. Third, the propositions must form a logically interrelated deductive system. This means that the theory must provide a mechanism for logically arriving at new statements from the original propositions[21]. In this theory patients and their caregivers' difficulties change as time passes, reducing or expanding. One of the factors causing change in the care process is information. Information affects the caregiver's selection of care behaviors. In the process of developing an evidence-based effective care method, the caregivers also acquire basic understandings and methods of care appropriate to the patient. It is important for the caregivers to earn the coping strategy of "observation-plan-trial-confirmation" (strategy 1) for difficulties they face in their daily lives so that the process of care is established. Incorporation of information and selection of coping strategy by the caregivers affect reduction or escalation of difficulties of both patients and caregivers.

The task for theoretical verification

For theoretical verification, the next step of Case

Study Research, cases should be selected in a controlled manner. The conditions in selecting functional level of patients, the scope of care capacity of the families as well as such environmental factors as collaboration with health care institutions, service functions, economic problems and acceptance of disability by the caregivers should be controlled.

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——和文抄録——

脳血管障害者と家族介護者を対象とした退院後の生活行為場面の困難を解決するための理論開発

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（東京都立保健科学大学）

本研究の目的は、脳血管障害者と家族介護者が退院後の生活行為場面で直面する困難の概念枠組みを作成し，困難を解決するための理論命題を提出することである。方法は，Yinのケース・スタディ・リサーチを用いた。対象は，在宅脳血管障害者の家族介護者（女7名，男3名），平均年齢59.0歳(SD=9.8)であり，データ収集は，在宅介護でなにが大変であったかを中心に半構成的質問紙による面接調査を実施し質的に分析した。結果として，7つの概念：「障害者の困難」「介護者の困難」「介護者の対処方法」「意識の転換」「情報」「環境」「障害者/介護者の困難の変化」から枠組みが構造化された。この枠組みにおいて，障害者/介護者の困難は介護者の3つの対処方法により減少，あるいは増加する。理論命題として，「介護者が対処方法1（観察する－工夫する－試す－確認する）をとると障害者/介護者の困難は減少する」が提出された。

キーワード
脳血管障害者，家族介護者，生活行為，困難，理論開発，ケース・スタディ・リサーチ