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The supporting process of visiting nurses in Japan for facilitating the independence of family caregivers in caring for medical technology-dependent relatives

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Abstract

The purpose of the present study was to clarify the supporting process used by visiting nurses in order to facilitate the independence of family caregivers who are caring for medical technology-dependent relatives. The study was performed on 14 Japanese visiting nurses using semi-structured interviews and the Modified Grounded Theory Approach. The visiting nurses judged the caregivers' ability to perform care independently according to 3 concepts: uncertainty, conditional certainty, and certainty. These judgments changed over time and the visiting nurses provided support based on their judgments. Family caregivers were considered to have achieved independence once they possessed caregiving knowledge and skills and adapting to a caregiver role. When a caregiver's ability was judged to be uncertain, the visiting nurse acted to facilitate the family caregiver's understanding of real situations and assessed how to help the family caregiver gain independence. Conditional certainty was a midway stage between uncertainty and certainty. This stage included substantial adjustment of service and emotional support and required caregivers to possess a positive attitude for the next step. The independence of family caregivers was judged to be certain when visiting nurses provided support in consideration of the stabilization of patients' condition and the ability of caregivers to provide continuing care at home in collaboration with supporting home-helpers. This support successfully facilitated the independence of caregivers, suggesting that the individual support at each stage was important for establishing independence. The present study showed that visiting nurses played an important role in continuing home medical care for medical technology-dependent patients and their caregivers.

Keywords

Caregiver, Independence, Medical technology-dependent, Visiting nurse

Introduction

With hospital stays being further shortened, there are increasing numbers of home care patients in Japan who are dependent on medical technology^{1, 2)}. The United States is ahead of Japan in providing high-tech medical care at home, and many reports have shown that family caregivers are faced with a large burden of care³⁻⁷⁾ and often suffer serious health problems^{8, 9)}. Smith et al.^{10, 11)} studied the role of adaptation among family caregivers for home care patients who were

dependent on ventilators and total parenteral nutrition. They reported that family caregivers felt competent and successful regarding their roles as caregivers. Furthermore, findings regarding the 'Caregiving Effectiveness Model' indicated that knowledge was related to caregivers' motivation-to-help and mutual interactions^{12, 13)}. Providing good care is important to family caregivers; therefore, developing caregiving competency, knowledge, and skill is a central concern for those in the process of becoming a caregiver¹⁴⁾.

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Discharge planning and education reduce caregivers' stress, maintain their health and satisfaction^{3, 15)}, and promote their role adaptation¹⁶⁾ and acquisition of caregiving skills^{15, 17, 18)}.

Home care nursing was not introduced in nursing education in Japan until 1997; therefore, many nurses working at hospitals and visiting nursing stations have not received basic education in home care nursing. Consequently, visiting nurses are learning how to support home care patients who are dependent on medical technology, by voluntarily attending lectures. Though it is important for family caregivers to begin to prepare for providing independent care during hospitalization, the outcome of such preparation is not adequately transferred from hospital nurses to visiting nurses^{19, 20)}. The first author examined the post-discharge stabilization of life for medical technology-dependent patients receiving home care. Stabilization was found to be greatly affected by not only medical conditions and other factors related to individual patients, but also by the ability of caregivers to act independently; that is, whether caregivers could appropriately assess situations or take initiative in performing care tasks²¹⁾. We considered that caregivers might acquire their independence through interaction with the people around them. For family caregivers providing care for medical technology-dependent relatives at home, visiting nurses are a source of knowledge, skills, and education for the caregivers and their patients. Therefore, clarifying the process through which visiting nurses support family caregivers in attaining independence is an important factor in helping patients and caregivers to achieve a stable life with home care. As the number of medical technology-dependent patients is expected to increase further in the future, clarifying this process will also provide useful and practical suggestions for supporting these patients and their caregivers. However, despite some reports on the relationship between nurses and the family carers of frail elders²²⁻²⁵⁾, few studies have examined the interaction between visiting nurses and the caregivers of medical technology-dependent relatives in the process of attaining independence.

The purpose of this study was to clarify the process through which visiting nurses support the family

caregivers of medical technology-dependent relatives in attaining independence.

Methods

Data collection and analysis were conducted using the Modified Grounded Theory Approach (M-GTA)²⁶⁾ that is useful in uncovering the process in this particular area. We considered that this method was suitable for clarifying difficulties faced by visiting nurses in developing and providing support in accordance with the changing level of independence of family caregivers.

Definition of terms

Home care patients dependent on medical technology were determined to be the persons who require management and assistance for medical procedures at home, including mechanical ventilations, daily central intravenous catheter infusion, or multiple catheters. Support from visiting nurses that facilitated the independence of family caregivers was defined as assistance that allows family caregivers to provide adequate care based on their own knowledge and skills, and helps the patient and family caregiver to continue home medical care.

Participants

The participants in this study, in addition to being experienced clinical nurses, were also experienced visiting nurses who had 3 or more years experience in supporting the independence of family caregivers of medical technology-dependent patients. Letters were sent to the managers of 11 visiting nursing stations in A and B Prefectures requesting the introduction of nurses who met the above-mentioned experience conditions. A total of 15 visiting nurses from 10 stations were introduced. On a later date, a researcher explained the purpose and ethical considerations of the study to those 15 nurses, and 14 of them agreed to participate in the study with written consent. Participants were nine nurses from visiting nursing stations managed by two prefectural nursing associations and five nurses from privately owned visiting nursing stations. In addition, eight individuals attended a training course hosted by a nursing association that trains visiting nurses. The nursing policy at each station comprised the following goals: to collaborate with attending physicians and other

care service agencies; to provide services that meet the needs of each user; and to support patients and their families so that they can recuperate with peace of mind. All participants were women and had a mean age of 41.3 years (29-55 years). The mean years of experience was 4.8 (3-7) as a visiting nurse and 10.5 (4-25) as a clinical nurse.

Data collection

Between November 2003 and February 2004, a 60- to 90- minute semi-structured interview was conducted with each participant. In consideration of the participants' privacy, the first author met and conducted the interview with each participant in a location selected by the participant. Interviews were conducted while the author and participant were alone in a room in order to maintain the confidentiality of cases that were discussed. During the interviews, the participants were asked about cases in which the home care of medical technology-dependent patients stabilized as well as cases in which the care did not easily stabilize. Participants were also asked about the relationship between the nurse and the family caregiver in each case. To determine suitable support for facilitating the independence of family caregivers, participants were also asked questions such as, "at what time did you feel that the caregiver had attained independence?" and "what was the evidence for the attainment of independence?" The interviews were recorded and transcribed with the participants' consent. Data gathering and analysis were carried out simultaneously.

Data analyses

The M-GTA was proposed by Kinoshita based on the Grounded Theory Approach devised by Glaser and Strauss²⁷⁾. In the analysis, a new proposal was made that data should not be segmented in order to avoid losing the solid context of social interactions, perception, and behavior. First, approximately 1 page of data was read with a focus on items that appeared to be related to the theme of "supporting the independence of caregivers." The items of focus were compared with participants' behaviors and perceptions, and were then analyzed and defined. Subsequently, names were given to the concepts. To avoid arbitrariness of the interpretation, a continuous comparative analysis was conducted to

confirm whether there were similar or antithetical examples. Concepts generated following this method are the smallest unit of analysis in the M-GTA. Next, categories were formed and multiple concepts were merged based on the relationships between the generated concepts. Third, we examined the "supporting process by visiting nurses for the independence of family caregivers," based on these concepts and categories.

The following is an example of the process through which one concept was generated. In one interview, a participant stated that "the family caregiver seemed to feel that it was easier having the visiting nurse take over when care was provided, and talked continuously about her friend when I was giving the patient a sponge bath. When I changed the patient's position he sometimes choked. The family wanted a nurse to come every day, and I am still visiting every day." This was interpreted as a situation in which the family caregiver depended on the visiting nurse and the visiting nurse complied. This was defined as follows "To provide relief care, the caregiver relied more on the formal care service by the visiting nurse who was a medical professional. The visiting nurse complied with those needs." This was called "becoming a mainstay."

To ensure the credibility of this qualitative study²⁸⁾ university faculty members who were specialists in community health nursing were asked to examine the results of the analysis. In addition, the results were mailed to the subjects for their confirmation that the analysis results were correct.

Informed consent and ethical procedures

The request sent to visiting nursing station managers for the introduction of nurses as participant included a written summary of the purpose of the study and ethical considerations together with a consent form for participation in the study. The ethical considerations listed in the letter were as follows. 1) Participation in the study is completely voluntary and only those persons who provide consent will be enrolled as study participants. 2) The data obtained in the study will be used solely for study by the researchers. 3) Strict anonymity will be maintained when the study is published, and no individual including cases referred to by the participants, will be

identified in order to protect privacy. 4) Participants can end their participation in the study at any time, and refusal to participate will not affect their job evaluation or job security. 5) The researcher will respond to all questions regarding the study. The ethical considerations also included a comment that participants would be requested to sign a consent form to confirm that they understood the purpose of the study. Before conducting the study, the research protocol was examined and approved by the ethical committee of C University School of Medicine.

provided by visiting nurses in order to facilitate the independence of caregivers was the visiting nurses' judgments of the level of independence of the caregivers. Those judgments were used to establish the category of caregivers' independence. Caregivers' ability could be classified into 3 stages in terms of the independence in providing care. These stages were labeled uncertainty, conditional certainty, and certainty. Support from the visiting nurses was used to develop the independence support category, and consisted of 10 concepts (Table 1). Differences in support were seen in association with the movement through the 3 stages of independence.

Findings

The main factor found to affect the support

Table1 The generated concepts and categories

Categories	Definitions
Caregivers' independence	
1 . Uncertainty	The process of confirming whether each caregiver had attained independence or not
2 . Conditional certainty	The process of making judgments regarding methods for facilitating the independence of family caregivers after observing the course of home care
3 . Certainty	The process of being confident that family caregivers could attain independence as well as continue to provide home care
Independence support	
1 . Becoming a mainstay	Complying with caregivers' needs
2 . Providing caregiving in daily life	Support through which caregivers could recognize the family's care becoming a part of daily life
3 . Combining care experience with knowledge	Providing appropriate information about concerns raised by family caregivers or about the anxiety felt while performing care tasks
4 . Sharing the problem-solving process	Collaborating on difficult problems that occurred when the family caregiver was concerned about finding a solution to changes in the care or condition of the patient
5 . Maintaining safety	Checking caregivers' performance of care tasks such as aspiration and handling of disinfectants
6 . Becoming a mediator	Making contact with other service providers and adjusting care when problems occurred with the patients and their families
7 . Reducing care load	Forming a care strategy to reduce the family's care load when visiting nurses were not present
8 . Eliciting positive feelings	Providing care that might increase the quality of life of the patient and elicit positive feelings in the family caregiver toward providing care
9 . Adapting to the family's caregiving	Adjusting the method of caregiving to each family
10. Introducing a supporter to continue providing care at home	Using not only visiting nurses but also home-helpers to aid family caregivers in continuing to provide stable care to ill relatives

Uncertainty

The independence of a family caregiver was considered to be uncertain during the process of confirming whether each caregiver had attained independence or not. It was identified at the start of home care immediately after the patient was discharged from the hospital. The nurses said, "the process was started by trying to determine how much the family could do", and "since the instruction on the techniques had been received in the hospital and a certain level of proficiency had been achieved, the process was started by determining whether the family could properly manage skills related to aspiration and catheters". Thus, the nurses felt the need to ascertain the family's level of ability to continue to provide care for the patient at home in the future. The support for independence by the visiting nurses involved 5 concepts: becoming a mainstay, providing caregiving in daily life, combining care experience with knowledge, sharing the problem-solving process, and maintaining safety. When performing medical tasks as daily care for medical technology-dependent patients, family caregivers tended to depend on visiting nurses for reasons such as inexperience in using techniques and lack of accurate knowledge about caring for the patient's condition. The visiting nurses also acted to facilitate family caregivers' understanding of the actual situation.

Becoming a mainstay was described in the Data analyses section. **Providing caregiving in daily life** was defined as support through which caregivers could recognize the family's care becoming a part of daily life. The visiting nurses fostered confidence in the family caregivers to provide care to ill relatives through day-to-day caregiving practices. One nurse said that family caregivers "learned by watching by my side when I performed a procedure. After that, I provided care together with the family caregiver, and the next time I visited, I created a situation in which the family caregiver could perform the procedure." Combining care experience with knowledge was defined as providing appropriate information about concerns raised by family caregivers or about the anxiety felt while performing care tasks, in order to develop family caregivers' ability to make judgments and to provide necessary care. One nurse said during

the initial period of home care, "in addition to my daily visit, the family called me many times every day. I explained the reasons for all aspects of home care and what was important or not." She said that in this situation, the family caregiver understood the meaning of the alarm on a mechanical ventilator and could deal with care tasks such as aspiration of phlegm. **Sharing the problem-solving process** was defined as collaborating on difficult problems that occurred when the family caregiver was concerned about finding a solution to changes in the care condition of the patient. The visiting nurses provided support with the recognition that many caregivers were anxious about caring for the patient, as evident in the following statement: "The caregiver told me that the patient developed a fever, but I did not know the cause of it, either. If the urine withdrawal was not cloudy, even advice such as 'let's cool the patient and see what happens' could be useful to the caregiver." **Maintaining safety** was defined as checking caregivers' performance of care tasks such as aspiration and handling of disinfectants, and then clarifying the points of minimum adherence and teaching them in order to prevent complications. One nurse said, "in the beginning, caregivers were instructed at the hospital so that they could perform the tasks as required, but later they started to change the procedures to suit themselves. Such changes had to be identified during the visits and corrected."

Conditional certainty

The independence of a family caregiver was considered to be conditionally certain when visiting nurses could make judgments regarding methods facilitating the independence of family caregivers after observing the course of home care. At this point, caregivers could provide routine care and attain independence if provided with some help. One nurse said, "it is important to give a laxative (to a patient with constipation), but sometimes family caregivers don't give it even after we have explained to them that they should. After repeating the instruction on several visits they finally said things like 'I got it' or 'it worked.' I cannot generalize and say that family caregivers have no care ability even if they didn't do exactly as I said. I think the situation will be fine as long as family caregivers gradually com-

be able to do the tasks.” Conditional certainty was a midway stage between uncertainty and certainty, and visiting nurses’ support for independence may have overlapped both uncertainty and certainty. This stage was composed of the following 4 concepts: becoming a mediator, reducing care load, eliciting positive feelings, and adapting to the family’s caregiving. In addition, this stage included substantial adjustment of service and emotional support in preparation for independence.

Becoming a mediator was defined as making contact with other service providers and adjusting care when problems occurred with the patients and their families. A nurse stated, “there were some people who hesitated to contact the doctor for trivial things, so I let them first contact the visiting nurse” , or “I found out what kind of instruction had been given to the family in the hospital, so I could give them the same instruction in order to avoid confusing them.”

Reducing care load was defined as forming a care strategy to reduce the family’s care load when visiting nurses were not present. One example was, “we carefully expelled phlegm through hand percussion or other means during an evening visit so that aspiration would not have to be performed repeatedly during the night and the family caregiver did not have to get up many times.” **Eliciting positive feelings** was defined as providing care that might increase the quality of life of the patient and elicit positive feelings in the family caregiver toward providing care. “The patient had a more tranquil expression than she did in the hospital. When her hair was washed, she was happy and said that she felt good. The patient’s happiness made the family caregiver glad that the patient was able to come home.” **Adapting to the family’s caregiving** was defined as adjusting the method of caregiving to each family. Adapting to the family’s care was the basic approach used by visiting nurses. The visiting nurses understood the spatial and social idiosyncrasies of the family and did not impose clinical practice or had excessive expectations regarding the family’s role. The nurses expressed opinions such as, “for actions that have a limited effect on a patient’s condition, such as assistance with daily life activities, I compromise and try to adapt to the family’s way of providing care” ; “I try to help them become accustomed to providing care

as a part of their daily lives. It is not good if the way the family provides care adds to the caregiver burden. Therefore, I do not tell them they have to do things a certain way, but try to support them so that we can continue together” ; and “families are free to do as they want at home. Even if the patient has several tubes inserted into his or her body, they may still keep a cat indoors, for example.”

Certainty

The independence of a family caregiver was considered to be certain when visiting nurses were confident that family caregivers could attain independence as well as continue to provide home care while making good use of various home care services. The nurses said, “when the family becomes accustomed to providing care, they are able to make decisions such as waiting until the next morning to assess the condition of a patient who has developed a certain level of fever,” and “at first, I ask the family to do things in a certain way and explain what the visiting nurse service does, and make suggestions to them. After a while, the family would say ‘We can do this, but we’d like you to do that,’ and communicate their desires for service to the visiting nurse.” These were situations in which visiting nurses observed an increase in care ability among family caregivers, and they judged that the family had the ability to decide and act in order to provide the required care at home. Certainty is based on the judgment of the visiting nurse; therefore, the support provided by the visiting nurses changes in order to promote a shift from dependence to independence. **Introducing a supporter to continue providing care at home** was defined by taking the stabilization of the patient’s condition and the care ability of the caregivers into consideration. The factor proposed using not only visiting nurses but also home-helpers to aid family caregivers in continuing to provide stable care to ill relatives. The emphasis of the home care service was shifted from the medical care provided by visiting nurses to the welfare services provided by home-helpers. One nurse said, “a visiting nurse was required to provide care every day following the patient’s discharge from hospital, but as the patient’s condition stabilized it might be a good idea to bring in a home helper. Doing so allowed the family caregiver

to make time for himself.” At that point, the caregiver was almost able to make full use of services, and was in a position to instruct a home-helper, who was a new service provider. This gave the caregiver an opportunity to use the respite care service. ⁴

Supporting process for the independence of family caregivers

At the beginning of home care, when visiting nurses were uncertain of the family caregiver's ability to perform care tasks independently, the visiting nurses' main approach was to remain with the family caregiver during the procedures. The visiting nurse showed how the care tasks should be performed. Subsequently, the caregiver became conditionally certain of the family caregivers' ability to independently perform the care tasks. Then, by promoting independence from a supporting role, the visiting nurse developed a caregiving environment that facilitated the independence of the family caregiver. This was achieved using the 4 concepts of becoming a mediator, reducing care load, eliciting positive feelings, and adapting to the family's caregiving. When the visiting nurse judged that the caregiver had become independent, she could transfer a part of her supporting role to the welfare service providers. As Japanese law prevents home-helpers and other welfare service providers from performing medical tasks, they cannot provide services related to medical judgment or medical tasks in the manner

that visiting nurses can. Therefore, before placing the emphasis in home care service on a home helper, the patient's physical condition must be stable, the family caregiver must be able to make judgments regarding the patient's physical condition, and the family must be able to perform the medical tasks required to maintain the patient's life, such as aspiration of phlegm or management of daily central intravenous catheter infusion.

All family caregivers for medical technology-dependent patients who used the visiting nursing service did not necessarily achieve independence so smoothly. Some caregivers remained dependent on the visiting nurses at all times. One nurse said, “the caregiver could not manage enteral tubes well and finish visiting nursing.” Because of the caregiver's inability to perform care tasks independently, the visiting nurse could not reduce her support for the caregiver and introduce the home-helper for support. The visiting nurse could not determine which form of support was suitable for the caregiver. In addition, some visiting nurses succeeded in making the caregiver independent after alternating between uncertainty and conditional certainty. Moreover, as the numbers of aged caregivers without the ability to act independently increases, visiting nurses discovered that care and social resources are required for such caregivers (Figure 1).

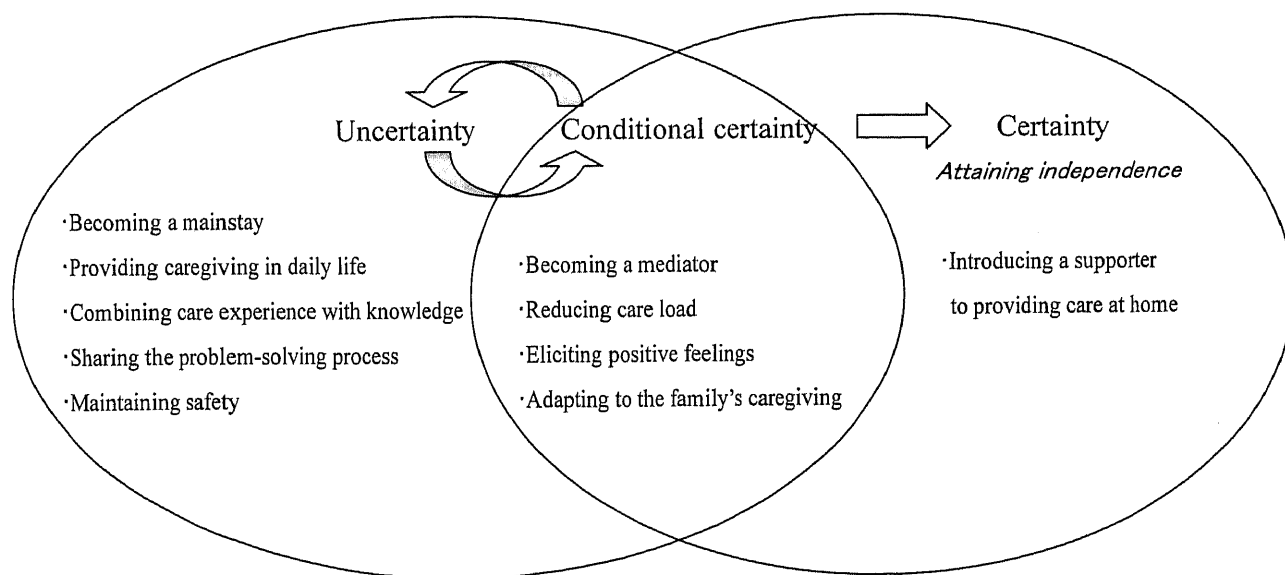


Figure1 Supporting process by visiting nurses for the independence of family caregivers

Discussion

In the present research, we focused on the process through which visiting nurses were able to support the independence of caregivers for medical technology-dependent relatives. The findings of this study emphasize that the level of independence of caregivers was categorized by visiting nurses as uncertainty, conditional certainty, or certainty. Furthermore, 10 aspects of support for the independence of family caregivers providing care for medical technology-dependent patients were conceptualized, and visiting nurses supported their care based on the 3 possible stages of independence.

As the foundation of home care is self-care, patients and their caregivers should determine the required level of assistance and the methods for managing daily care²⁹). The role of visiting nurses is to perform some care-related duties and to support home care. Therefore, family caregivers providing care for medical technology-dependent patients must be able to make decisions about home care independently. The results of the present study clarified the manner in which visiting nurses supported caregivers on a daily basis and ascertained the independence of caregivers for highly dependent patients. Visiting nurses intentionally and unintentionally facilitated caregivers' independence. Visiting nurses indicated that caregivers become independent when they "acquired the necessary knowledge and skills and actually applied them in home care" and when they "became able to utilize available social resources to smoothly carry out home care". These two factors were directly related to the abilities of patients and their families to care for themselves²⁹⁻³⁰). As a result, visiting nurses provided proper support to family caregivers providing care for medical technology-dependent patients.

Furthermore, support for caregivers' independence was divided into the following three concepts: uncertainty, conditional certainty, and certainty. These were the assessments of caregivers' ability in each family. Assessment of caregivers' behavior by a professional may inadvertently take on judgmental quality based on inadequate appreciation of caregiver's perspective. Of note is the fact, however, that family caregivers often sought visiting

nurses' assessment of their care and expected the nurses to help them developing caregiving skills. Especially for visiting nurses supporting the independence of caregivers, it is important to find out conditional certainty in this study. For family caregivers responsible for medical technology dependent patients, knowledge and skill acquisition were closely correlated with their adaptation to the role of caregiver¹²⁻¹⁴). The support in conditional certainty led from dependence to independence of the caregiver. This support successfully facilitated the independence of caregivers, suggesting that the individual support at each stage was important for establishing independence. Hence, the three concepts of caregivers' independence based on the judgment of visiting nurses and independence support based on these concepts should greatly contribute to future nursing practices.

As indicated above, basic education in home care nursing has just begun in Japan. Therefore, many hospital nurses have limited knowledge regarding home medical care. Especially for medical technology dependent patients, various medical procedures and treatments must be continuously performed after discharge; thus, educating family members while patients are still in the hospital is important for the quality of care provided by caregivers. In order for medical technology dependent patients to be able to recuperate at home in a stable manner, collaboration between hospitals and home-care services is required. To this end, visiting nurses must not only act as mediators between families and hospitals, but also actively contact hospital nurses in order to deepen their understanding of home medical care.

To ensure the credibility of this qualitative study, results of the analysis were examined by experts and confirmed by the enrolled participants. All participants agreed upon the general process of supporting caregivers to facilitate independence, which they experienced daily as visiting nurses, and with the analysis results. This process may reinforce the credibility of our results.

In the present research, the independence of caregivers was judged by visiting nurses, and aspects of the support were described from the perspective of the visiting nurses. Therefore, judgments of

independence may have been different from those of the family caregivers. In addition, there may be a discrepancy between the nurses and family caregivers in terms of awareness of the contents of the support provided. Future research using an action research method is thus required in order to examine the attainment of independence by caregivers in collaborative work between family caregivers and multiple home care service providers. This may be beneficial to developing the empowerment of caregivers.

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医療依存度の高い療養者の介護者の主体性獲得を支える訪問看護師の支援プロセス

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要 旨

本研究は、医療依存度の高い療養者の介護者の主体性獲得を支える訪問看護師の支援プロセスを分析し記述することを目的とする。対象者は訪問看護ステーションに勤務する14名の訪問看護師である。データ収集方法は半構成的面接で、グラウンデッド・セオリー・アプローチによる分析を行った。その結果、訪問看護師の支援プロセスには、看護師による介護者の主体性獲得に関する介護能力の判断として、懐疑、条件付確信、確信の3段階が認められた。判断には変化があり、訪問看護師はこれらの判断に応じた支援を提供していた。介護者が知識、技術を身につけ介護に適応したと判断されたときが、介護者の主体性が身についたときである。懐疑では、訪問看護師は介護者が現状を理解できるような支援を提供していた。その後、こうすれば介護者の主体性が獲得できるという判断を行っていた。条件付確信とは、懐疑から確信への移行の段階であり、訪問看護師は実質的なサービスの調整と次のステップに向けての介護者への情緒的支援を行っていた。確信は介護者の主体性が獲得できた状態であり、訪問看護師は療養者の病状の安定化と介護者の介護能力を勘案した上で、あらたな在宅療養継続支援者であるホームヘルパーの導入をすすめていた。これらの支援は介護者を依存から自立へと導くものであり、これらを段階的に行使することにより介護者の主体性獲得を促進することが示唆された。訪問看護師は医療依存度の高い療養者と介護者の在宅療養継続に重要な役割を担っていることが示された。