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ORIGINAL ARTICLE

Information Sharing for Collaborative Care of Older Patients with Heart Failure; Perspectives of Nurses in Hospitals, Home-visiting, and Long-term Care Insurance Facilities

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ABSTRACT

This study aimed to clarify the information required by hospital nurses (HN), home-visiting nurses (HVN), and long-term care insurance facility nurses (LFN) for continuous home care support for community-dwelling older patients with heart failure (HF).

Semi-structured interviews with HN, HVN, and LFN involved in HF nursing were used to collect empirical data during August 2019–March 2020. The interview data were organized as narratives about the information necessary for continuing home-care support for older patients with HF, and categories were generated by content analysis.

A total of 13 categories were discovered. Among these, 6 were in common for HN, HVN, and LFN: disease management, medication management, activities, diet, family/supporters, and cognitive function. The other 7 categories included 1 in common for HN and HVN, hopes of the patient/family; 1 in common for HVN and LFN, anxiety/stress; 1 for HN, social resources; 1 for HVN, cooperation status of medical institutions; and 3 for LFN, sleep, defecation, and difficult behaviors.

This study found that HN, HVN, and LFN had common information items determined necessary for continuous home care support for community-dwelling patients with HF, and each type of nurse also had different informational item requirements.

Key-words: Older patients, heart failure, information needs, nurse to nurse, transitional care

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I. Introduction

Heart failure (HF) is a progressive heart disease, with steadily increasing morbidity and deaths worldwide, estimated to reach 1.3 million in Japan by 2030.¹⁾ Furthermore, the readmission rate after 1 year due to exacerbation of HF symptoms in patients with chronic HF in Japan is as high as 35%²⁾; hospitalization for HF requires longer hospital stays than other illnesses, putting pressure on the medical economy and social burdens.

Efforts to reduce readmission for HF have been reported, such as the effectiveness of multidisciplinary team disease management programs and home-visiting nursing.³⁻⁶⁾ However, these efforts were interventions centered on education for hospitalized patients with HF and an average age in the 70s. The largest increase in patients with HF will be for those aged 85 years and older,¹⁾ and the readmission rate in 2 years will reach 45% for patients aged 80 years and older.⁷⁾ Many of these older adults with HF in Japan are often admitted to a long-term care insurance facility or treated at home while receiving home-visit nursing care, and the number of these patients is estimated to increase in the future. Therefore, to prevent readmission and enable patients to continue their daily lives with peace of mind, appropriate care is required not only in hospitals but also in long-term care facilities and at home. To accomplish this, nurses involved in HF nursing should obtain appropriate information and seamlessly cooperate and collaborate with nurses across facilities; this arrangement is indispensable.

Nurses involved in HF nursing mainly include hospital nurses (HN), home-visiting nurses (HVN), and long-term care insurance facility nurses (LFN). HN work in hospital wards and primarily care for patients from the acute phase to discharge, whereas HVN are based in home-visiting nursing stations in the community and visit patients in their homes to provide nursing care, including post-discharge care. LFN practice in long-term care insurance facilities and provide nursing care with a focus on assistance with daily living. These categories of nurses mainly belong to different organizations, which hinders effective sharing of detailed information about patients. In addition, they handle different patients with varied care needs and thus require different information about the patient.

In previous studies and case reports, continuous nursing between wards and the outpatient department in the same hospital and cooperation between outpatient nursing and home-visit nursing were reported.⁸⁾ However there have been few reports on collaboration with nurses from long-term care insurance facilities. Moreover, HVN decri difficulties in caring for patients with HF, such as difficulty in sharing information and lack of confidence in knowledge about disease management.^{9, 10)} In addition, there is a report about information sharing between hospital and nursing home staff, but contents of the information have not been scrutinized.¹¹⁾ Therefore, it is necessary to first clarify what information is required by HN, HVN, and LFN and consider measures to facilitate information sharing among nurses in order for nurses involved in HF nursing to cooperate and practice.

The purpose of this study was to clarify the information required by HN, HVN, and LFN for continuous home care support for community-dwelling older patients with HF.

II. Methods

1. Study design and participants

This qualitative descriptive study used semi-structured interviews. Study participants were nurses involved in HF nursing who worked in a hospital (heart center of a special functioning hospital), home-visit nursing station, or long-term care insurance facilities. Their clinical experience in the field of HF nursing was 5 years or longer. We explained the study to the facility director or the person in charge of the department and asked them to select the participants. Interviews were conducted after explanation to the participants, and their consent was obtained.

2. Data collection procedures

Interviews were conducted from August 2019 to March 2020 and followed an interview guideline. Participants were asked: "What care do you provide for older patients with HF?"; "What information do you require to care for older patients with HF?"; and "What type of collaboration is needed between nurses to care for older patients with HF?" The interviews were recorded on a digital voice recorder with consent from the participants. In addition, data were collected on basic attributes of the participants: gender, age, years of clinical experience, years of clinical experience in HF nursing, number of patients with HF in charge.

3. Analysis

All interviews were transcribed, and a content analysis¹²⁻¹³⁾ was performed. As an initial step, interview data were organized as narrative records, which were carefully read and divided into minimum paragraphs with semantic contents as units for analysis. These units were encoded, focusing on the information necessary for care of older patients with HF. Then, while repeating similarity from code contents, the degree of abstraction was increased, and subcategories and categories were generated. To enhance their validity, repeated discussions were held between the authors. This analysis process was performed with interview data of HN, HVN, and LFN.

4. Ethical Considerations

The procedures of the study were conducted according to the Declaration of Helsinki and approved by the Ethical Committee of Department of Medicine, Saga University (approval number R1-10), Saga, Japan. All the participants provided written informed consent before participating in this study.

III. Results

1. Participant characteristics

A total of 18 nurses participated in this study. As shown in Table 1, there were 5 HN, 9 HVN, and 4 LFN; 16 females and 2 males; average age (\pm standard deviation), 47.4 ± 10.2 years; clinical experience of 21.3 ± 9.6 years; experience in HF nursing field, 14.5 ± 7.4 years; and number of patients with HF in charge of per month, 46.1 ± 60.2 . Each interview lasted 48.1 ± 8.0 minutes. HN belonged to 1 facility, HVN belonged to 7 facilities, and LFN belonged to 1 facility.

<Table 1> Participant characteristics

Workplace	No.	Gender	Age (years)	Years of clinical experience (years)	Monthly number of patients with heart failure	Interview length (min)
HN (nurses working in hospitals)	1	Female	33	10	10	51
	2	Female	33	9	10	54
	3	Female	49	26	10	67
	4	Male	30	8	15	52
	5	Male	45	13	15	47
HVN (nurses working in home-visiting nursing station)	6	Female	56	25	5	38
	7	Female	49	25	172	47
	8	Female	49	23	24	50
	9	Female	55	30	200	42
	10	Female	40	20	16	51
	11	Female	57	34	15	37
	12	Female	60	35	10	50
	13	Female	56	22	23	51
	14	Female	30	6	4	56
LFN (nurses working in long-term care insurance facility)	15	Female	52	17	30	51
	16	Female	52	31	100	50
	17	Female	61	35	120	33
	18	Female	46	15	50	39
Mean \pm standard deviation			47.4 ± 10.2	21.3 ± 9.6	46.1 ± 60.2	48.1 ± 8.0

2. Information nurses require to continue home care for older patients with HF

Regarding information necessary for care of older patients with HF, a total of 198 codes and 38 subcategories were extracted, and 13 categories were generated. Table 2 presents the categories and subcategories for each nurse type.

There were 6 common categories generated: disease management, medication management, activities, diet, family and supporters, and cognitive function. In addition, 2 categories for HN: hope of the patient / family, and social resources; 3 categories for HVN: hope of the patient / family, anxiety / stress, and cooperation status of medical institutions; and 4 categories for LFN: anxiety / stress, sleep, defecation and difficult behaviors were generated.

1) Information required for HN

Regarding information required by HN, 59 codes were extracted, and 22 subcategories and 8 categories were generated. The categories and subcategories are presented in Table 2.

< Table 2 > Information nurses require to continue home care for older patients with HF

Type of nurse	Categories	Subcategories				
HN	Disease management	Symptoms of HF	Target value for HF management	Vital signs		
	Medication management	How to medication	Self-management of medication	Person who manages medicine		
	Activities	Activity status	Activity restrictions			
	Diet	Dietary intake status	Salt restriction status			
	Family / supporter	Family structure and key persons	Relationship with family/supporters	Support contents of family / supporters	Family / supporter visit status	
		Support status for families				
	Cognitive function	Degree of cognitive function	Understanding of disease			
	Hope of the patient / family	Living conditions desired by patient	Meaning of life	Living conditions desired by family		
Social resources	Reasons for getting long-term care insurance	Usage of social resources				
HVN	Disease management	Symptoms of HF	Target value for disease management	Vital signs	HF exacerbation factor	
		Severity of HF	Causes of HF	Course of HF		
	Medication management	How to medication	Self-management of medication	Contents of medication	Person who manages medicine	
	Activities	Activity status	Activity restrictions			
	Diet	Dietary intake status	Salt restriction status			
	Family / supporter	Family structure and key persons	Relationship with family/supporters	Support contents of family / supporters	Family situation	
		Support status for families				
	Cognitive function	Degree of cognitive function	Understanding of disease			
	Hope of the patient / family	Decisions related to ACP	Acceptance for death			
	Anxiety / stress	Situation of Anxiety / stress				
Cooperation status of medical institutions	Cooperation status of medical institutions					
LFN	Disease management	Symptoms of HF	Target value for HF management	Vital signs	HF exacerbation factor	
		Education content for HF				
	Medication management	How to medication	Contents of medication			
	Activities	Activity status	Activity restrictions			
	Diet	Salt restriction status				
	Family / supporter	Family structure and key persons				
		Support status for families				
	Cognitive function	Degree of cognitive function				
	Anxiety / stress	Situation of Anxiety / stress				
	Sleep	Sleep status	Use situation of sleeping drug			
	Defecation	Defecation control status				
Difficult behaviors	Difficult behaviors during admission		Behaviors of refusal to care			

HN: hospital nurse, HVN: home-visit nurse, LFN: long-term care insurance facility nurse, HF: heart failure, ACP: advance care planning

(1) Disease management

In this category, 3 subcategories were summarized. The following is a typical narrative of the participants:

“Points to observe every day, like physical condition, no edema now, how many times a day they urinate, can walk without HF symptoms, etc. Current patient weight and weight to be managed; the target weight. About patient's blood pressure and pulse rates”

(2) Medication management

In this category, 3 subcategories were summarized. The following is a typical narrative of the participants:

“If they know about taking medicine, I want that information. Did he/she take it properly? Management status of the patient, and family management status. Whether the patient can manage medicine by himself/herself or family manages it. Whether they use a calendar or not. If someone is not watching him/her, he/she may forget.”

(3) Activities

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“How they spend their daytime or nighttime. I think it's important to know what kind of activities they are doing and how their time is spent. The level of activity intensity. I think it's difficult to understand at Mets. So specifically, what patients can do for a level of exercise.”

(4) Diet

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“I would like them to tell me the contents and amount of food they eat. Such as meals and salt.”

(5) Family / supporter

In this category, 5 subcategories were summarized. The following is a typical narrative of the participants:

“How is the family involved with the patient, whether it be supplying food, medicine, or whatever? Is the situation completely no-touch, or estranged, what family relationships are included, is someone visiting them every day? For example, the family lives in patient's neighborhood, only meals are brought by the neighbor's daughter etc. About visiting hours and how involved the family is. I want the patient to let me know if they have any support from family.”

(6) Cognitive function

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“I think because they are elderly I want information about their cognitive function. We want to know they are able to take their medications or not. Some people's cognitive function declines after hospitalization, so we need to know how much they understand about their disease.”

(7) Hope of the patient / family

In this category, 3 subcategories were summarized. The following is a typical narrative of the participants:

“I want them to clearly indicate what they want to do at this point. Example, I want to go home and continue working, etc. I try to confirm how they feel about themselves, what they look forward to, what they want to do with their lives, and how they want to live their lives. If the patient and family are heading in the same direction, it will go smoothly, so I want to know what the patient and family want.”

(8) Social resources

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“I need information, a reason for getting long-term care insurance. When they are leaving hospital to go home, I want to know what kind of social resources they are using now.”

2) Information required for HVN

Regarding information items required by HVN, 87 codes were extracted, and 25 subcategories and 9 categories were generated. The categories and subcategories are presented in Table 2.

(1) Disease management

In this category, 7 subcategories were summarized. The following is a typical narrative of the participants:

“It would be helpful if they could tell us the patient's target weight, approximate daily water intake, weight, edema status, etc., before they leave the hospital. Vital signs range, shortness of breath, etc. In fact, HF caused by valvular disease is a cause, so if we know that, we'll pay attention to that. The severity level, such as how bad HF is. I most commonly use NYHA classification.”

(2) Medication management

In this category, 4 subcategories were summarized. The following is a typical narrative of the participants:

“What medications, how is the patient taking them, and are they taken properly or not? Can the patient take medications? Include swallowing function. And who manages the medications?”

(3) Activities

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“I would like to know about patient living conditions. They are old, so I would like to know how much they can move now and how much we can move them.”

(4) Diet

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“Dietary status, content, and quantity. If they are on a restricted diet, such as low-sodium, how many grams, etc.”

(5) Family / supporter

In this category, 4 subcategories were summarized. The following is a typical narrative of the participants:

“Knowing about the family is important information. Key person. Even if the patient herself/himself doesn't realize something, if family can say something is wrong, we can take care of it immediately. Family relationships; for example, like you're not allowed to contact the daughter. For example, if there is a person with a mental illness in the home, I would like that information.”

(6) Cognitive function

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“I want the results of the cognitive function tests. I can make comparisons in a few months or years. First of all, I need the most information about whether the patient understands her/his disease. The symptoms are totally different between those who think they need to take medicine and those who think they don't need medicine.”

(7) Hope of the patient / family

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“If they have decided about ACP, we would love to know what they know about that. I would like to know how they feel about death, how much they know about it, and how much they accept it.”

(8) Anxiety/Stress

This category had 1 subcategory. The following is a typical narrative of the participants:
“I think that it will not be good for the heart if stress is applied too much, so I would like to know the stress factors.”

(9) Cooperation status of medical institutions

This category had 1 subcategory. The following is a typical narrative of the participants:
“Emergency response and coordination. Like when the patient is admitted, is there appropriate cooperation between the home doctor and hospital doctor?”

3) Information required for LFN

Regarding information items required by HVN, 52 codes were extracted, and 18 subcategories and 10 categories were generated. Categories and subcategories are presented in Table 2.

(1) Disease management

In this category, 5 subcategories were summarized. The following is a typical narrative of the participants:

“I want to know about their physical condition, such as wheezing due to exertion, because I would be confused if there were any abnormalities in the patient’s condition. I want to know if there are any special restrictions, like weight control, fluids. How much is good?” I’d like to have information on how they were provided guidance on heart failure.”

(2) Medication management

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“All medicines are managed by nurses and given to residents, but some can just take them, and some can't. In such cases, do I have to put them in their mouths, can they take it if it is a tablet, or can they not take it without crushing it? I need such information. I’d like to know the contents of the medicines.”

(3) Activities

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“Activity status. How much they can move? I don't think they have restrictions on rest levels, but if they need restrictions, I want to know.”

(4) Diet

This category had 1 subcategory. The following is a typical narrative of the participants:
“I want to know if they need a low-salt diet.”

(5) Family / supporter

This category had 1 subcategory. The following is a typical narrative of the participants:
“Who is the primary key person? I try to make it clear who to contact if something happens.”

(6) Cognitive function

This category had a subcategory. The following is a typical narrative of the participants:
“I also ask about cognitive function and their MMSE scores.”

(7) Anxiety / stress

This category had 1 subcategory. The following is a typical narrative of the participants:
“Details of anxiety; I try to ask what kind of situations make them anxious.”

(8) Sleep

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“I would like to know about insomnia; like the status of falling asleep and use of sleeping pills.”

(9) Defecation

This category had 1 subcategory. The following is a typical narrative of the participants:
“Residents with HF must not exert effort due to constipation, so defecation is controlled. I want to know that information.”

(10) Difficult behaviors

In this category, 2 subcategories were summarized. The following is a typical narrative of the participants:

“Even if it was written that a patient shouted in a strange voice while in a hospital, it may be different when he/she comes here, so I want various information to some extent. I want to have information such as refusal of excretion assistance, or if they had.”

IV. Discussion

In this study, we conducted a survey of HN, VHN, and LFN to identify subjectively the information that nurses felt that they needed for continuous home care support for community-dwelling older patients with HF. The 6 common information needs of nurses working in each of the 3 nursing settings were disease management, medication management, activities, diet, family and supporters, and cognitive function. These 6 categories were commonly extracted as basic information necessary for patient support. The 5 categories other than cognitive function are content normally provided in

management and nursing care for patients with chronic HF.¹⁴⁻¹⁵⁾ Another key issue for older patients with HF is cognitive impairment, which has an estimated incidence between 3.1% and 90.0% (average 41.4%) in patients with HF.¹⁶⁻¹⁸⁾ It is widely known that patients with HF are vulnerable to cognitive impairment with serious consequences in healthcare and outcomes due to the interplay of poor self-care, incapacity of adhering to treatment regimens, and weakening daily living due to decreased attentions, memory, and execution abilities;¹⁹⁾ thus, taking care of these patients becomes complex and requires individual ingenuity.^{20, 21)} Cognitive function was extracted as one of the common concerns among nurses in this study and is consistent with findings of previous studies.

Among the categories common to all the 3 types of nurses, there were different subcategories in disease management and family and supporters. In the category of disease management, HN required only the 3 subcategories: symptoms of HF, target value for HF management, and vital signs, whereas HVN required 4 more subcategories: HF exacerbation factor, severity of HF, causes of HF, and course of HF, and LFN required 1 more subcategory: education content for HF, including information such as how the patient is educated about the disease. Previous studies have reported that HVN find it difficult to obtain necessary information about the patients' illnesses.¹⁰⁾ Another related study has reported the need for LFN and long-term care facility administrative staff to share patient information, especially among multiple facilities.¹¹⁾ The present study also found a lack of opportunities to obtain such information on patients' illnesses. Our survey findings revealed that HVN resorted to detecting disease progression by themselves from changes in the patient's appearance rather than from laboratory data²²⁾ and lacked more detailed information compared to the HN.

The common category extracted for HN and HVN was the hopes of the person/family. To provide support for home care, HN required information on the personal hopes of the patient/family, such as desired living conditions, the meaning of life, and living conditions desired by the family. In contrast, HVN wanted information related to end-of-life care decisions, such as advance care planning (ACP) and acceptance of death. In Japan, the overwhelming majority of patients still receive end-of-life care in hospitals,²³⁾ although with progress being made in establishing a regional comprehensive medical care system, the number of patients with HF receiving end-of-life care at home is increasing. Our survey showed that HVN were actively involved in ACP, consistent with previous findings,²⁴⁾ and primary care physicians recognized that collaboration with HVN was important to promote ACP. HN and HVN also required information on social resources and cooperation status of medical institutions, and it can be considered that this information was extracted because it is necessary to promote cooperation between facilities for continuation of patients' home care.

The only categories extracted for LFN were sleep, defecation, and difficult behaviors. Patients who reside in long-term care facilities have a high complication rate of ADL decline and dementia, and behavioral and psychological symptoms of dementia prevalence

is as high as 64-100%.²⁵⁾ As a result, nurses will be required to provide more living support, and will be required to handle symptoms associated with dementia. To provide this kind of support, LFN in our survey reported the need for information concerning sleep, such as sleeping status and use situation of sleeping drugs; information about defecation, such as defecation control status; and information about difficult behaviors, such as those noted during admission.

The limitations and issues of this study are that the participating nurses belonged to 1 hospital and 1 long-term care insurance facility. Therefore, future studies are warranted to replicate this survey in a larger number of participants.

In conclusion, this study showed that HN, HVN, and LFN shared some common information items deemed necessary to support continuing home care, and each category of nurses had own information needs. As home care nursing develops, there is increasing need for individualized care, which consequently raises complex information needs. The findings in the present study suggest that sharing information among HN, HVN, and LFN could effectively improve the health of geriatric patients transitioning from institutional to home care.

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VOL.24 APRIL 2023
CONTENTS

ORIGINAL ARTICLES

- A Critical Discourse Analysis of Feminism in Katherine Mansfield's *Bliss*
Israa Burhanuddin Abdurrahman, et al. p.1
- A Japan-Korea Comparative Study on Welfare Professional Training;
Focusing on Grit and Self-esteem Scores
Kazutoshi FURUKAWA, et al. p.21
- Relationship of “Tooth Condition” with Mobility and Cognitive Function of
Residents in Special Elderly Nursing Homes Practicing Functional
Recovery Care;
Case-control Study
Yuko FUJIO, et al. p.33
- Explaining Peers with Autism Spectrum Disorder to Others and Coping with
Others’ and Siblings’ Negative Attitudes
Mayu KIRIHARA, et al. p.46
- Information Sharing for Collaborative Care of Older Patients with Heart Failure;
Perspectives of Nurses in Hospitals, Home-visiting, and Long-term Care
Insurance Facilities
Chie FURUSHIMA, et al. p.61
- A Study on Awareness of Young Peer Supporters in a Japanese Secondary
School Through Thematic Analysis
Hideo KATO p.75
- Effectiveness of a Short Program to Improve Emotional Management of Nurse
Managers in Japan
Hiroko SHIRAI, et al. p.97

SHORT PAPERS

- Association between Autistic Traits and Maladaptive Behaviors in Preschool
Children Using the Child Development Support Center in Japan
Kai NAGASE, et al. p.115
- Questionnaire Survey on the Prevalence of and Support for Selective Mutism
at High School in Akita Prefecture
Toru SUZUKI, et al. p.126