Digital Literacy, Mutuality, and Self-care in Patients with Heart Failure and their Caregivers
: A Dyadic Approach

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: A Dyadic Approach

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ABSTRACT

Digital Literacy, Mutuality, and Self-care in Patients with Heart Failure and their Caregivers
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Introduction: The rising prevalence of heart failure (HF) and the growing emphasis on HF self-care have led to the widespread adoption of digital health-based strategies. However, the aging population of HF patients has limited the application of the advanced involving digital devices. Recently, the role of caregivers in supporting self-care for HF patients has gained growing importance. Thus, understanding the digital literacy level and the mutuality dynamics within the patient-caregiver dyads may be the first step toward implementing digital self-care for HF patients. This study aimed to examine the relationship dynamics of digital literacy, mutuality, and HF self-care in dyads of patients with HF and their caregivers, and to determine the influence and differences within dyads using the Actor-Partner Interdependent Model (APIM).

Methods: This cross-sectional study recruited 102 patient-caregiver dyads with HF at the outpatient department in a tertiary hospital located in a medium-sized city with surrounding rural area of South Korea. Digital literacy, mutuality, and HF self-care and the caregiver's contribution to HF self-care with three dimensions (maintenance, symptom perception, and management) were surveyed. Statistical analyses were performed using the APIM on SPSS version 26.0 and AMOS version 26.0.

Results: The majority of caregivers of patients with HF were adult children (65.7%, age: 58.97±13.07). The patients (age: 78.90±9.01, digital literacy level: 31.93±20.95, and mutuality 2.84±0.74) were older and had lower education level, economic status, digital literacy compared to caregivers (digital literacy: 77.75±30.75 and mutuality:2.65±0.87). Patients' self-care and caregivers' contributions to HF self-care were below adequate levels (<70 points). In the APIM dyadic approach, primarily actor effects were observed, revealing distinct dynamic patterns within patient-caregiver dyads; caregiver's digital literacy (maintenance: B=0.146, p=.029; symptom perception: B=0.259, p<.001; management: B=0.148, p=.037) and mutuality (maintenance: B=8.358, p<.001; symptom perception: B=9.423, p<.001; management: B=8.577, p<.001) demonstrated significant actor effects across all dimensions of caregiver contribution to HF self-care. The patient's digital literacy had significant actor effects in symptom perception and management (symptom perception: B=0.219, p=.012; management: B=0.199, p=.021), while mutuality only had significant actor effects in symptom perception (B=5.910, p=.034). However, a notable partner effect only emerged between caregiver mutuality and HF self-care maintenance (B=3.083, p=.049), with no other partner effects observed.

Conclusion: This study highlights the significant impact of caregivers' digital literacy and mutuality on their contribution to HF self-care. Notably, lower levels of caregiver mutuality emerge as a potential risk factor for self-care of patients with HF. Therefore, when developing digital healthcare intervention for the self-care of HF patients, it is crucial to take into account both the digital literacy level and the mutuality dynamics between patients and caregivers.

Key words: digital literacy, mutuality, heart failure, self-care, patient, caregiver, dyadic approach, actor-partner interdependent model

I. INTRODUCTION

1.1. Background

Heart Failure (HF) is a severe cardiovascular syndrome prevalent in older adults resulting from age-related changes in cardiovascular structure and function or prior heart diseases (Bui et al., 2011). In South Korea, the incidence of HF had tripled over a 15-year period from 0.4 million in 2002 to 1.16 million in 2018 (Park & Choi, 2020; Park et al., 2021), estimated to be increased up to 1.7 million by 2040 (Lee et al., 2016). In an aging population, HF with preserved ejection fraction (HFpEF) has become the predominant form of HF (Cho & Yoo, 2021; Nair, 2020). Patients with HFpEF, despite having a preserved with an left ventricular ejection fraction (LVEF) of ≥50%, experience fluctuating HF symptoms such as worsening dyspnea and edema, leading to hospitalization (Dharmarajan & Rich, 2017; Roger, 2021; Toth & Gauthier, 2021). Previous studies have shown that implementing HF self-care reduces readmissions and mortality, improves the quality of life in HF patients (Aghajanloo et al., 2021; Moser et al., 2012; Ponikowski et al., 2016; Ruppar et al., 2016). Therefore, to avoid deteriorating disease and permanently damaging heart function, performing self-care, such as recognizing changes in HF symptoms, adjusting prescriptions on timely manner with medical professionals, treatment compliance, and maintaining a low-sodium diet and regular exercise in daily life (Aghajanloo et al., 2021; Ponikowski et al., 2016; Ruppar et al., 2016) is essential for patients with HF. However, most HF patients with the age of >70 experience cognitive decline or decrease ability to perform activities of daily living (Zavertnik, 2014). As like the HF population ages, the caregivers' role becomes crucial in promoting self-care in patients with HF (Deek et al., 2017).

Recently, various interventions have been introduced for HF self-care, including emotional support, symptom monitoring, delivery of self-care information, and behavioral support through internet-based mobile application (Bezerra Giordan et al., 2022; Mortara et al., 2020; Singhal & Cowie, 2021). However, the efficacy of digital health-based approaches in the self-care of patient with HF had been reported to depend on their level of acceptance and literacy with technology and their demographic characteristics (Baik et al., 2023; Choukou et al., 2022; Zisis et al., 2021). Prior to implementing digital health, understanding digital literacy of both patient and caregivers and its influence on self-care is essential. Digital literacy refers to individuals' capacity to understand, utilize, and problem-solve using mobile devices. Studies conducted on the general population have shown variations in digital literacy, influenced by factors such as age, education level, and economic status (Oh et al., 2021). Higher digital literacy has been associated with increased adherence to digital health-based interventions, promoting HF self-care (Mortara et al., 2020). Hence, it is necessary to determine the level of digital literacy among HF patients to establish effective strategies for implementing digital health self-care interventions (Rodríguez Parrado & Achury Saldaña, 2022).

As the role and function of the caregivers of patients with HF become increasingly important in the age of digital health (Baik et al., 2023; Vellone et al., 2020; Wali et al., 2020), it’s time to reconsider how we study the caregivers. Research on caregivers has been fragmented, with most efforts focused on enhancing their knowledge of HF self-care (Bidwell et al., 2018), or developing caregiver-specific coaching programs (Piamjariyakul et al., 2015; Riegel et al., 2019). However, given that caregivers and patients interact with each other the most (Uchmanowicz et al., 2022), determining the mechanisms of self-care and their influence on patients’ behavior from a single perspective is challenging. Thus, a patient-caregiver dyadic approach has recently emerged to analyze the dynamic role and impact of caregiver, considering both perspectives simultaneously (Son, 2021). The dyadic approach uses the Actor-Partner Interdependent Model (APIM) to examine the interdependence dynamics within patient-caregiver relationships or other factors (Buck et al., 2018).

Mutuality, the concept that determines the positive quality of dyadic relationships (Archbold et al., 1990; Park & Schumacher, 2014), is a pivotal in HF self-care practice. Enhanced relationships were associated with lower mortality, improved health status of HF patients, reduced caregiving burden, and lastly lower stress, and depression in both patients and caregivers (Hooker et al., 2015; Vellone et al., 2018). As study investigating the dynamics of mutuality and self-care between HF patients and their caregivers found that mutuality influences caregiving and self-care adherence, which are mediated by the caregiving burden (Hooker et al., 2018). The mutuality of HF patients and caregivers exhibited an actor effect on patients' maintenance of HF self-care, as well as the patients' and caregivers' confidence in self-care. Conversely, in caregivers, mutuality had a partner effect on management to HF self-care (Vellone et al., 2018).

The dynamics of relationship between patients with HF and their caregivers varies across cultures and regions (Steinberg et al., 2022; Vellone et al., 2019). Previous studies have primarily focused on spouse-main caregiver relationships in the U.S. and Europe (Hooker et al., 2018; Trivedi et al., 2012). In contrast, in Korea and East Asia, adult children often take on the primary caregiver role, and the dynamics of this relationship are not well understood (Chen et al., 2017; Lee & Lee, 2020; Wang et al., 2023). Importantly, there is a lack of Korean dyadic, APIM-based studies of the mutual influence between patients with HF and their caregivers in HF self-care are lacking (Son, 2021; Uchmanowicz et al., 2022).

Therefore, by employing the dyadic approach and the APIM, we investigated the relationship between digital literacy, mutuality, and self-care of patients with HF and caregivers' contribution to HF self-care in Korea. To establish more sophisticated interventions tailored to the characteristics of patients with HF and their caregivers in South Korea, it is necessary to obtain baseline data.

1.2. Purpose

This study aimed to determine the relationship dynamics between digital literacy, mutuality, and HF self-care in dyads of patients with HF and their caregivers, and to determine the influence and differences between them via the following specific purposes:

１) To assess the level of digital literacy, mutuality, and HF self-care (contribution to HF self-care) in patients with HF and their caregivers.

２) To examine the correlation between digital literacy, mutuality, and HF self-care (contribution to HF self-care) in patients with HF and in their caregivers, respectively.

３) To determine the impact and dynamics of digital literacy and mutuality on HF self-care (contribution to HF self-care) within the dyads of patients with HF and their caregivers, respectively, using APIM.

<u>The study is based on the following specific hypotheses:</u>

Hypothesis 1: Digital literacy, mutuality, and HF self-care (contribution to HF self-care) in patients with HF and their caregivers correlate significantly.

Hypothesis 2: The impact of digital literacy and mutuality on HF self-care (contribution to HF self-care) within dyads of patients with HF and their caregivers have bi-directional dynamics.

  2.1. The digital literacy of HF patients has an actor effect on HF self-care and a partner effect on the caregiver’s contribution to HF self-care.

  2.2. The digital literacy of caregivers has an actor effect on caregivers’ contribution to self-care and a partner effect on HF self-care.

  2.3. The mutuality of patients with HF has an actor effect on HF self-care and a partner effect on the caregiver’s contribution to HF self-care.

  2.4. The mutuality of caregivers has an actor effect on the caregivers’ contribution to self-care and a partner effect on HF self-care.

1.3. Definitions

1.3.1. HF self-care

１) Theoretical definition: A set of activities through which patients with HF follow a complex therapeutic regimen, monitor HF symptoms, respond to changes, and adjust their diet and living environment (Aghajanloo et al., 2021). Based on the context-specific theory of HF self-care, the dimensions of care include the maintenance of disease management, perception of current symptoms, and implementation of future self-management (Riegel et al., 2016).

２) Operational definition: Self-care of patients with HF is defined as measured using the self-care of HF index v 7.2 (Riegel et al., 2019). The SCHFI contains 29 items in the domains of self-care maintenance, symptom perception, and self-care management. Based on standardized scale, higher scores in each domain indicate better self-care.

1.3.2. Digital literacy

１) Theoretical definition: The ability to collect, analyze, and utilize the information needed for problem-solving using various digital devices (Kim et al., 2021).

２) Operational definition: In this study, digital literacy is assessed using a 22-item Everyday Digital Literacy Questionnaire (EDLQ) developed in Korean to measure digital literacy, with higher total scores indicating higher digital literacy

(Choi et al., 2023; Oh et al., 2021).

1.3.3. Mutuality

１) Theoretical definition: The quality of being connected. In this context, it refers to the quality of the patient-caregiver relationship and is characterized by love and affection, sharing of enjoyable activities, and shared values and empathy (Archbold et al., 1990; Hooker et al., 2018).

２) Operational definition: Mutuality is measured using the Mutuality Scale of the Family Caregiving Inventory (Archbold et al., 1990), which assesses the quantity and quality of relationships in a dyad of patient with HF and their caregiver. The scale contains 15 items that assess emotional commitment and mutual support, with higher scores indicating better mutuality.

1.3.4. Caregiver

１) Theoretical definition: Most commonly refers to informal caregivers, who provide care to patients without monetary compensation. The name for caregiver varies across countries and cultures, including the concept that collectively means patients' protector in Korea (Chung, 2020)

２) Operational definition: An adult who has a blood or family relationship with a patient with HF, does not necessarily live with the patient, and helps the patient with self-care without financial compensation.

II. LITERATURE REVIEW

2.1. HF patient self-care and caregivers' contribution to HF self-care

The self-care of patients with HF includes recognizing daily symptoms changes, adhering to medications, seeking timely treatment, and adjusting one's lifestyle, e.g., by following a low-sodium diet to maintain current heart function, avoid symptom exacerbations, and manage HF (Aghajanloo et al., 2021). Strategies to promote self-care in patients with HF effectively improve patient outcomes, including by reducing readmission and mortality rate (Zavertnik, 2014). Facilitating self-care in patients with HF including symptom management, is an effective way of shifting the focus from intensive treatment of symptom exacerbation to preventive and palliative measures, thereby reducing the societal healthcare burden caused by HF (Savarese et al., 2019).

For the implementation mechanisms and promotion strategies of self-care in patients with HF, Riegel and Dickson developed (Riegel & Dickson, 2008), revised a self-care theory that can be specifically applied to patients with HF in context-specific theory (Riegel et al., 2016). This theory describes the process of self-care in patients with HF as three-dimensional. The first dimension is the maintenance of self-care behavior, which includes therapeutic behaviors like medication compliance and dietary adjustments. The second dimension refers to the importance of symptom perception and posits that self-care behavior consists of observing and recognizing symptom changes. The third dimension is the overall self-care operation, which is based on the ability to solve problems in future situations through past and present self-care behavior (Vellone, De Maria, et al., 2020).

Caregivers, who are typically close to patients and are often spouses or children, significantly influence the daily management of patients with chronic conditions (Lyons & Lee, 2018). With the increasing age of the HF population, the role of the caregiver is key to promoting self-care in patients with HF (Deek et al., 2017). Several recent HF studies have also included caregivers (Buck et al., 2018; Trivedi et al., 2016). Given the key role of caregivers in the self-care of patients with HF, in 2018, Riegel and Vellone developed a theory to explain caregiver contributions to HF self-care by borrowing same concepts and structure from existing theories (Vellone et al., 2019). Furthermore, factors that influence the overall contribution process include the patient, the caregiver, and their relationship. Patient factors influencing contribution to HF self-care were education level, disease and symptom severity, and HF duration; caregiver's factors were knowledge, skill, perceived control, confidence, support from others, education, and anxiety level; and finally, mutuality was as a factor in the positive quality of the patient-caregiver relationship. Riegel and Vellone suggest that the three dimensions simultaneously influence the stepwise self-care of patients with HF, resulting in positive personal growth, self-esteem, satisfaction, and reward to caregivers. However, this may also have negative consequences, which can be manifested as care burden. Cultural background, which is the basic premise of shaping the beliefs, values, and disciplines of patients and caregivers, was highlighted as a key moderating factor in the three dimensions. Both HF self-care specific theory and theory of caregivers' contribution to HF self-care have the same structure and provide a parallel theoretical basis for the self-care of patients with HF from the perspectives of patients and caregivers (Vellone, Barbaranelli, et al., 2020).

The main factors affecting self-care in patients with HF include mental and physical health, and the patient's family and social support system (Heo et al., 2023; Jaarsma et al., 2017; Riegel et al., 2019). Additional caregiver contributions to HF self-care include mutuality, cultural factors, and the burden of caregiving (Vellone et al., 2019). Depression, which is prevalent among patients with HF and their caregivers, is reported to decrease self-care levels in patients with HF (Bidwell et al., 2021; Buck et al., 2015; Freedland et al., 2021). There are conflicting reports about the impact of patients' health on self-care (Kalogirou et al., 2020; Ruppar et al., 2019). The caregivers' physical health has also been shown to be influence contribution to HF self-care in a previous study (Lee et al., 2015). Another previous study has found that caregivers with more comorbidities and poorer health tend to experience a greater caregiving burden, which decrease contribution to self-care, thereby decreasing self-care in patients with HF (Heo et al., 2022; Lee et al., 2015). In addition, studies have reported variations in family relationships and attachments across countries, regions, ethnicities, and cultures (Steinberg et al., 2022). Differences in caregiving behavior, particularly in patients' perspectives on caregiving, and variations in self-care behaviors have also been reported (Gould, 2020; Graven et al., 2021).

2.2. Effect of digital literacy on self-care in patients with HF and caregiver contribution to HF self-care

Recent telecommunication advances have improved remote monitoring technologies and led to the development of new digital health devices, thereby shifting therapeutic interventions towards patient self-monitoring, and symptom management outside hospital settings (Portz et al., 2018). Because the prolonged COVID-19 pandemic severely restricted hospital visits, various new digital health approaches were tried in clinical practice for HF management (Charman et al., 2021). The use of wearable devices that monitor symptoms in patients with HF has been shown to improve the early detection of symptom changes, particularly in at-home self-care (Singhal & Cowie, 2021). However, there are varying opinions about the effectiveness of digital health in recognizing HF symptoms and promoting self-care in older patients (Foster et al., 2022; Krishnaswami et al., 2020). The implementation of digital health in HF self-care in older adults necessitates simpler, more user-friendly strategies (Wali et al., 2020).

A systematic review of the use of digital technologies in social connections by people with chronic diseases found that digital healthcare improves social connections and support in the form of emotional and informational support, and improves overall health (Wright et al., 2023). In Korea, it is estimated that 20% of older people live alone and that this proportion is growing. Because as people age they have fewer opportunities to interact with other (Kim, 2017), using digital devices to communicate has become an alternative

(Lind & Karlsson, 2014). However, there are many concerns about the efficacy of digital health applications among older people (Choukou et al., 2022; Masterson Creber et al., 2023).

With the recent increase in digital health-based interventions, including HF self-care, age, digital literacy, and education have been identified as influencing digital health intervention (Singhal & Cowie, 2021). The main factor that affects digital literacy is age, with older age being associated with lower levels of digital literacy and higher education level being associated with higher digital literacy level (McBeath et al., 2022; Rodríguez Parrado & Achury Saldaña, 2022). Therefore, it is necessary to examine digital literacy, which is defined as the basic understanding and ability to use digital devices. With rapid changes in science and information technology, the concept of digital literacy, which was initially identified as literacy in internet-based environments, now encompasses the ability to utilize various digital devices, including mobile and wearable devices. A study on digital literacy among older adults (age: > 55 years), found that although 53% of the participants had access to digital devices, including internet access, only 49% exhibited high levels of digital literacy (Arcury et al., 2020). A study on patients with HF (average age: 61 years) found moderate levels of digital literacy (Spindler et al., 2022). However, studies on digital literacy in patients with HF aged ≥ 70 years are lacking. In Korea, digital literacy is reported to be low among healthy older adults, and even lower among older adults with cancer (Kang et al., 2023). In the U.S., digital literacy among people with HF is reported to be low to moderate, with high inter-individual variability (Oh et al., 2021). The education level of older individuals is key factor in digital literacy, and the high cost of installing and equipping digital devices also contributes to the digital literacy gap (Chesser et al., 2016).

2.3. The Effect of mutuality on self-care in patients with HF and caregiver contribution to HF self-care

Recent dyadic studies have increasingly focused on and identified the quantity and quality of relationships within dyads from various perspectives. In studies that defined caregivers as spouses, the quality of relationship was often measured through marital satisfaction (Litzelman et al., 2018; Trivedi et al., 2012), while in others, it was assessed through the quality of communication between members in the dyad (Bouldin et al., 2019). When the dyad was defined as a family member, the quality of relationship was identified through the concept of family relationship satisfaction (Lee & Lee, 2020). The mutuality was derived from family relationship research and identified as an interplay of communication, shared experiences, and emotional connection (Archbold et al., 1990) and has been actively used and discussed in patient-caregiver dyadic studies (Chen et al., 2022b; Hooker et al., 2018; Park & Schumacher, 2014).

The quality of the relationship between patients with HF and their caregivers was influenced by their respective health status, social support, and depressive symptoms, which, in turn, influenced HF and self-care. As an indicator of relationship quality, couple satisfaction influenced the caregiver’s perceived care burden, which reciprocally influenced disease management (conceptualized as self-care) and disease outcomes, including patient mortality and readmission rates (Trivedi et al., 2012). A study on mutuality and self-care in HF revealed that patients and caregivers with better mutuality were more confident in the patient's self-care. Mutuality in patient-caregiver dyads is also associated with patient self-care and caregiver burden and may be an important intervention for improving self-care and reducing hospitalization (Hooker et al., 2018). The study identified mutuality between HF patients and caregivers as a key factor in boosting caregivers' confidence in self-care and their contribution to actual care outcomes (Chen et al., 2022a). Low mutuality in dyads was also a significant predictor of inadequate HF self-care (Hooker et al., 2018). However, it is difficult to generalize the causal effects of various aspects of mutuality in HF patient-caregiver dyads on self-care and other patient outcomes because of differences in study population characteristics.

The general characteristics of the caregivers of patients with HF vary by region and culture. In the US, most caregivers are spouses (Chung, 2020), with an average age of 41.4 years (Graven et al., 2021). In China, the average caregiver age is 48.7 years, with 42.9% of caregivers being spouses and ≥ 45% being adult children (Hou et al., 2020). Unlike in Western societies, where spouses are the most common caregivers, in East Asia, adult children serve as primary caregivers in equal or even more cases than spouses. Hence, it is necessary to determine the type and quality characteristics of the relationship based on cultural factors.

2.4. Dyadic approach for patient with HF and their caregivers

As the role of caregivers becomes as important as the role of patients in the self-care of chronic diseases, including HF, there is a growing focus on the mutual impact between patients and caregivers. As the dyadic approach, introduced for the study of family function and interrelationships in social sciences, has been applied to caregiver studies on chronic disease management with caregivers, the perspective of the research subject was expanded from the individual caregiver to the patient-caregiver dyad (Buck et al., 2018). In addition, various finding revealed on how different aspects of the relationship affect actual disease management performance (Son, 2021). A dyad refers to two individuals or members of a group in a sociologically meaningful relationship and can extend from a two-person dynamic to a multi-person dynamic. In a dyadic approach, the type of dyads can be divided into cases where members of the dyad are distinguishable, such as patients and caregivers, and the other cases where members are not distinguishable, such as two friends. Most research in healthcare, including nursing, involves distinguishable dyads (Rayens & Svavarsdottir, 2003). The interdependence between the patient and the caregiver needs to be considered when analyzing data on dyads. The Actor-Partner Interdependent Model (APIM) is the most optimal statistical method for analyzing data on HF self-care dyads (Uchmanowicz et al., 2022).

In 1999, Kenny introduced the APIM (Kenny & Cook, 1999)(Figure 1) as a new way of examining relationships and influences within dyads. This model provides a detailed look into how two subjects, paired as a unit, interact with each other about the same concept with actor and partner effects. In a dyad with the same independent and dependent variables, the actor effect refers to the effect of one’s own independent variable on the dependent variable, while the partner effect refers to the effect of the other's independent variable on one’s dependent variable, or vice versa (Figure 2). By statistically analyzing the interrelationships between members of a dyad using a hierarchical linear model to evaluate the size of the effect between two members, one can identify and quantitatively evaluate the most influential factors in the hierarchy. In addition, the relationship and influence of the members of the dyad, which are inferred empirically, can be statistically analyzed to secure a scientific basis to accurately define the dynamics of dyad members and assess changes in dynamics over time. This analytical approach has been used to identify dynamics in one-on-one relationships, such as between couples in a family, parents and children, and mentors and mentees. Examining the influence and direction of relationships between patients with HF and their caregivers as a unit using APIM can identify the actual flow of dynamics between the dyad and determine which individuals are more effective (Campbell & Kashy, 2002).

Studies that have utilized APIM to analyze the dynamics of the HF patient-caregiver dyad have found that the emotional status of caregivers, such as depressive symptoms, negatively impact the patient's quality of life and self-care within the dyad. Additionally, a high quality of life in the caregiver has been linked to improved treatment adherence in the HF patient. The interrelationships within the dyad were validated using APIM to confirm their significance and mutual influence, and physical health was also an important validating factor in this analytical approach (Uchmanowicz et al., 2022).

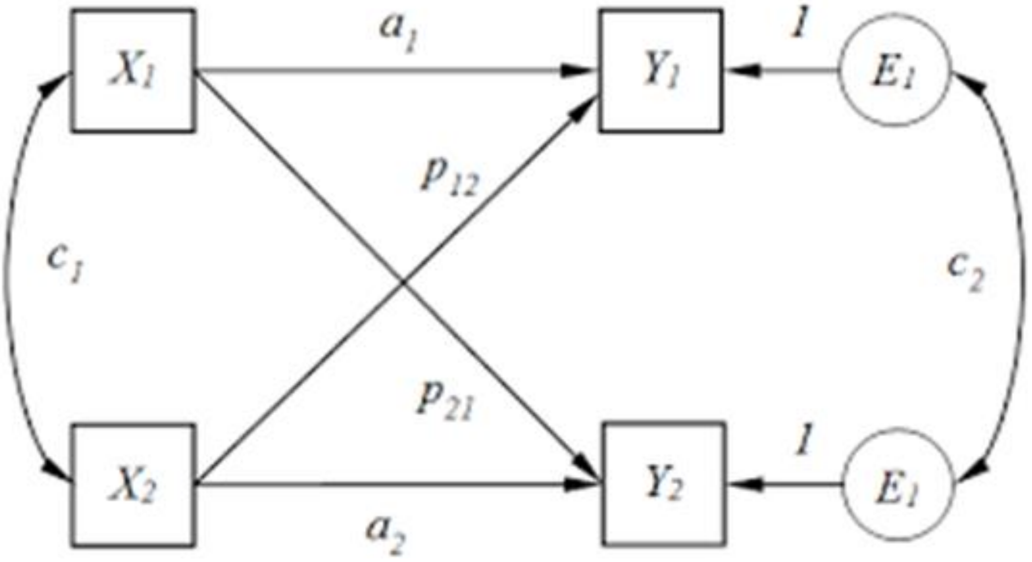


Figure 1. The basic Actor-Partner Interdependent Model (APIM) (Kenny & Cook, 1999)

III. CONCEPTUAL FRAMEWORK

3.1. HF Patient and Spouse Interrelatedness and Stress Model

Trivedi et al. developed the HF Patient and Spouse Interactivity and Stress Model by identifying the relationship flow between mutuality (identified through relationship satisfaction) and spousal stress (identified through caregiving burden) in dyads of patients with HF and their spouses (Trivedi et al., 2012). In this model, as in previous studies, physical health, social support, and depressive symptoms interacted with each other to influence relationship satisfaction between patients with HF and their spouses (Figure 2). Better physical health, social support, and lower depressive symptoms in both HF patients and their spouses were associated with better relationship satisfaction. The interrelationships in relationship satisfaction influenced the spouses' perceived caregiving burden, which, in turn, influenced disease management and patient outcomes. In this theoretical model, physical health was assessed using questionnaires and medical record reviews of the patients' past disease progress, current dyspnea, and cardiac function measures. The spouses' physical health information was collected through questionnaires on current health status and social support, and it was assessed on the basis and degree of social support perceived by the patient and spouse. HF management was assessed based on the patients' execution of daily activities, medication adherence, and self-care. The final patient outcome was determined based on readmission and mortality rates. This theoretical model goes beyond determining the impact of patient- and caregiver-specific factors on disease management, care burden, and disease outcomes by recognizing the importance of relationships within the dyad. This provides a theoretical framework for examining the impact of mutuality on overall self-care and disease outcomes in patients with HF through relationship satisfaction.

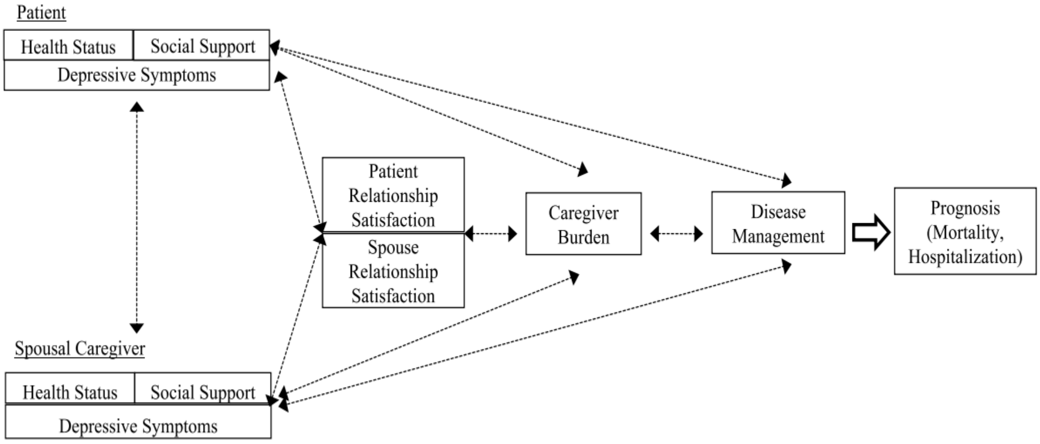


Figure 2. The theoretical model of The Interrelatedness of Patient and Spousal Stress in Heart Failure (Trivedi et al., 2012)

3.2. Conceptual framework of this study

This study’s conceptual framework was developed by incorporating digital literacy and mutuality, respectively, into the interconnectedness of concepts in the interrelatedness model of stress in patients with HF and their spouses (Trivedi et al., 2012). The methodology used was the APIM (Kenny & Cook, 1999). Through a literature review, this study identified the digital literacy and mutuality of HF patients and caregivers as the key factors affecting HF self-care (caregivers’ contribution to HF self-care). The study’s conceptual framework was organized as a flow, in which the digital literacy and mutuality of patients with HF and caregivers affect HF self-care (caregiver contribution to HF self-care), respectively, and statistical significance was evaluated in APIM (Figure 3).

Depression in patients with HF and their caregivers is associated with decreased self-care (Freedland et al., 2021). However, to focus more on the effects of digital literacy and mutuality, depression was excluded from this study’s conceptual framework and controlled for as a confounding variable in the statistical analyses. Furthermore, the conceptual framework also excludes the variable, caring burden, which is a significant mediating factor (Hooker et al., 2018; Trivedi et al., 2012). This exclusion was done to utilize APIM analysis, which examines the same variable bilaterally (Figure 3).

Based on the situation-specific theory of HF self-care (Riegel & Dickson, 2008; Riegel et al., 2016) and situation-specific theory of caregiver contribution to HF self-care (Vellone et al., 2019; Vellone et al., 2013), which analyzes and explains HF self-care and caregiver contribution to HF self-care with a parallel structure(Vellone et al., 2019) disease management in patients with HF is considered to have three HF self-care dimensions; maintenance, symptom perception, and management.

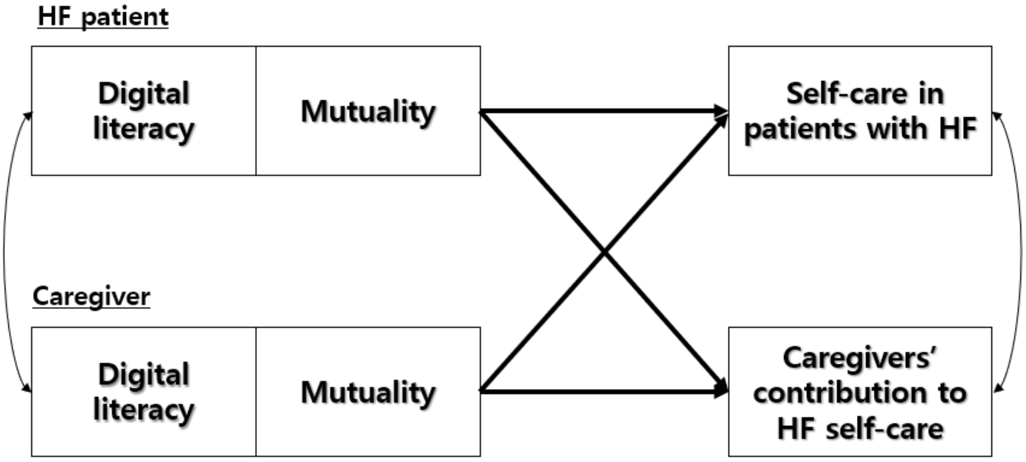


Figure 3. The Conceptual framework in this study

IV. METHODS

4.1. Study design

This descriptive cross-sectional study examined the association between digital literacy, mutuality, HF self-care, and caregiver contribution to HF self-care, and determined the dyadic dynamics between patients with HF and their caregivers.

4.2. Study participants

The study's participants are dyads of patients with HF and their caregivers. Its target population was adult patients diagnosed with HF, who visited the outpatient department of cardiology for treatment and management of HF at a S tertiary hospital in Wonju, South Korea, and their caregivers. Participants were recruited based on convenience sampling and the specific inclusion and exclusion criteria are shown in Table 1. The sample size needed determine the association between variables was calculated using the G*Power (version.3.1.9) program. The minimum sample size based on the structural equation was approximately 200 participants, at a significance level of 0.05, a power of 0.95, a medium effect size of 0.15, and 10 predictor variables. Considering a 10% dropout rate, the study aimed to include 110 dyads (220 participants).

Table 1. The study's inclusion and exclusion criteria

Participants	Inclusion criteria	Exclusion criteria
HF patients	- Patients diagnosed with HF - Patients receiving HF medication and symptom management at an outpatient department. - Patients aged > 19 years	- Patients with heart transplant or left ventricular assisted device - Patients with cognitive impairment (dementia diagnosis) - Patients without caregivers
Their caregivers	- Person who has a familial relationship with patient - A caregiver who primarily helps HF self-care - Person aged > 19 years	- Paid caregiver - Person with cognitive impairment (dementia diagnosis)

§ Cohabitation between patients with HF and their caregivers: a caregiver does not necessarily have to live with patient with HF

4.3. Measurements

This study used a structured questionnaire and electronic medical record (EMR) reviews. The questionnaires were administered via an online survey. Permission to use the instrument for digital literacy, mutuality, and care burden was obtained from the original and Korean adaptation authors, while the instruments for HF self-care and caregiver contribution to HF self-care were open access. The survey took 15-20 minutes to complete. The disease progression status and the outcomes of patients with HF were verified in bulk through EMR data collection separately with online survey.

4.3.1. HF self-care and caregiver contribution to HF self-care

Self-care in patients with HF was measured using the self-care of heart failure index v 7.2 (SCHFI v7.2), which was developed in 2008 and revised in 2016 by Riegel et al (Riegel & Dickson, 2008; Riegel et al., 2016), and adapted into Korean by Jin-Sil Kim (Kim et al., 2018). It contains the following three dimensions: 1) self-care maintenance (11 items), 2) symptom perception (10 items), and 3) self-management (eight items). SCHFI v7.2, which has 29 items, uses a five-point scale to measures HF self-care in each dimension by converting the sum of each domain into a standard score. For all dimension, higher scores indicate better HF self-care. The tool has been applied to patients with HF in various countries and it has high validity and reliability, with the original tool and its Korean version exhibiting reliabilities of .70 and .71 - .96, respectively.

The Caregiver Contribution to Self-care of Heart Failure Index v 2.0 was developed as a parallel construct to the SCHFI (Vellone et al., 2013) and was recently revised into Korean by Jin Sil Kim (Heo et al., 2022). The Caregiver Contribution to Self-care of Heart Failure Index v2 is a parallel instrument to the SCHFI, with the same three dimensions and 29 items, and assesses the caregiver contribution to HF self-care on a five-point scale, which is converted to a standardized score. For each dimension, higher scores indicate a higher contribution to HF self-care. The original tool exhibits high validity in diverse populations, with a reliability of .90 (Vellone, Barbaranelli, et al., 2020). In this study, its reliability was .72 for HF self-care maintenance, .85 for symptom perception, and .76 for self-care management.

4.3.2. Digital literacy

To measure digital literacy, we used the EDLQ, which was developed for older adults in South Korea (Choi et al., 2023). The EDLQ is a 22-item, five-point scale that leverages mobile devices to assess information and communication, content creation and management, and safety and security. A higher total score indicates a higher digital literacy. In the original study, EDLQ had a reliability of .98 (Choi et al., 2023), whereas in this study, its reliability was .96.

4.3.3. Mutuality

Mutuality between patients with HF and their caregivers was assessed using the Mutuality Scale of the Family Caregiving Inventory (Archbold et al., 1990; Han, 2012). This 15-item instrument measures the four domains of love, shared values, sharing of enjoyable activities, and reciprocity on a five-point scale (range from 0 to 4), with higher scores indicating better mutuality. The original instrument exhibited high validity in the measurement of caregiver interactions with patients with various diseases, and it has shown high reliability and validity in older individuals. A recent study of patients with HF and their caregivers showed that the instrument has a reliability of .91 - to .94 . (Hooker et al., 2018). In a study involving Korean Pando patients with stroke and their caregivers, the reliability of the Mutuality Scale of the Family Caregiving Inventory was found to be .96 (Han, 2012), whereas in this study, it was .95.

4.3.4. Demographic and caring characteristics 1) General characteristics

4.3.4.1. Demographic characteristics

The following demographic items were analyzed: gender, date of birth, relationship between patients with HF and their caregivers, marital status, level of education, employment, economic status, and cohabitation of the patients with HF and their caregivers.

4.3.4.2. Depression

The Patient Health Questionnaire (PHQ) (Spitzer et al., 1999), which was adapted into Korean by Han et al. (Han et al., 2008), was used to assess depression. The nine-item PHQ, has a four-point scale, with higher scores indicating higher depression. In the Korean version, a score of five or higher indicates the presence of depression. In addition to psychiatric clinical use, the PHQ exhibited high validity and reliability (.80) in a secondary analysis of raw data from the 6th National Health and Nutrition Examination Survey (2014), which screen the general population for depression (Park, 2017). In this study, the reliability of the depression scale was .86.

4.3.4.3. Characteristics of care

Open-ended questions were asked about the number of hours per week that a caregiver spend caring for a patient with HF and the length of time since they started caring for patients with HF.

4.3.4.4. Caregiving burden

The Zarit Burden inventory (Zarit et al., 1980) was revised to include 22 items in 2000 (Hébert et al., 2000). The Zarit Burden inventory, which was adapted into Korean by in 2005 (Yoon & Robinson, 2005), is a five-point scale with scores ranging from 0 to 88, with higher total scores indicating higher caregiving burden. The reliability of the instrument at the time of its development in Korea was high (.94), which was confirmed in this study.

4.3.4.5. Physical health status

The perceived health status of caregivers was assessed using the second question of the World Health Organization Quality of Life Brief Version (WHOQOL BREF) survey, i.e., “How satisfied are you with your health status?”. This question is based on a five-point Likert scale, with higher scores indicating greater satisfaction, and its measurement of health status satisfaction is independent of existing instruments that have reported high validity and reliability in Korean adult populations (Min et al., 2002).

4.3.5. Clinical characteristics

4.3.5.1. HF patients’ outcomes

In this study, the EMRs of the patients with HF were reviewed to determine the presence, number, and duration of readmission or emergency department visits for HF before the survey data was collected (outpatient visits).

4.3.5.2. HF patients' physical health status

In this study, the clinical characteristics of patients with HF were identified by a reviewing of patients' EMRs. For patients with HF, data on comorbidities like cardiovascular disease including myocardial infarction, dementia, hemiplegia, liver disease, respiratory disease, peripheral vessel disease, hypertension, diabetes, and renal failure, based on the Charlson comorbidity index (CCI), were reviewed (Charlson et al., 1994). HF diagnosis year determined by the HF diagnosis code in EMRs, and current HF medication prescribed and taken were retrieved. Data on LVEF, an echocardiogram-based measure of heart function, were also reviewed. The New York Heart Association (NYHA) classification recorded during the most recent outpatient visit was used to determine the patient's current HF symptoms.

4.4. Participants recruitment, data collection, and ethics

Ethical approval for the study was granted by the Institutional Review Board (IRB) of Hospital S (approval no. 4-2022-1622). Participants were recruited immediately after outpatient cardiology visits at S tertiary university hospital located in Wonju (2021 population: 361,056) (Statistics, 2022), Gangwon-do, South Korea. At the end of the outpatient visit of the patients with HF, survey data were collected from the patients and their caregivers via an online survey, respectively, form after they provided informed consent. If, at the time, the caregiver was not with the patient, data were collected later by sending the caregiver a link to the online survey. The questionnaire was organized in an online survey format. Where possible, the patient and caregiver questionnaires were collected simultaneously. Hence, at least two researchers were present at the same time. After the patients had completed the questionnaire and consented, they were each given a gift worth USD 10 as a reward for participating in the study. Researchers requested and collected necessary information about the patients' HF and echocardiogram data from the institutional EMRs. From March 28, 2023, to September 19, 2023, 102 patients with HF and their caregivers were recruited to complete their data collection, resulting in 102 dyads.

4.5. Data analysis

Data analyzes were done on SPSS version 26.0 and AMOS version 26.0 (IBM Corporation, Armonk, NY, USA).

4.5.1. Data distribution and structure

Descriptive statistics, including frequencies, percentages, means, and standard deviations were used to present data on demographics, disease, and caring-related characteristics, digital literacy, mutuality, HF self-care, and caregiver contribution to HF self-care. Homogeneity was assessed through a paired t-test and chi-square test. Pearson's correlation coefficients were used to determine and assess the correlation between key variables about the patients and caregivers.

4.5.2. Analysis of dyadic data using APIM

Hypotheses testing using the dyadic approach was carried out using structural equation modeling with APIM to identify, test, and verify the actor and partner effects of digital literacy and mutuality on HF self-care (caregiver contribution to HF self-care) in the dyads while controlling for covariates like age adjusted Charlson Comorbidity Index (aged CCI), perceived economic status of patients with HF, the type of relationship between the patients with HF and their caregivers (as a reference of patients with HF and their spouses), and the residential area of patients with HF (as a reference of the rural area). After standardizing the collected data using the overall mean and variance of patients with HF and their caregivers, the patient and caregiver data, respectively, were reorganized, followed by the calculation of the respective unstandardized and standardized regression values of the actor-partner effects within the structural model to determine statistical significance at the .05 level of significance.

V. RESULTS

5.1. Characteristics of patients with HF and their caregivers

The mean age of patients with HF (female: 53.9%) was 79.44 years (SD=9.05), whereas the mean age of the caregivers (female: 65.7%) was 58.97 years (SD=13.07). The patients with HF were significantly older than the caregivers (t=14.297, *p*< .001). Most caregivers (62.7%) were adult children (including direct sons, daughters, daughters-in-law, and sons-in-law), whereas spouses accounted for 32.4% of the caregivers. Both patients with HF (57.8%) and caregivers (85.3%) were most likely to be currently married. Almost half (48.0%) of the patients lived with caregivers, while 25.5% and 26.5% of the patients lived alone, or with other family members (not the dyad's caregivers), respectively. Exact half of the patients lived in rural areas. While 65.7% of patients with HF had less than an elementary school education, caregivers were more educated than the patients, with 81.4% having a middle school education or higher. The difference in level of education between the patients and caregivers was statistically significant (X2=69.835, *p*< .001). Most patients with HF (71.6%) did not have a job and their average monthly family income was KRW 1,202,800 (SD=126.54), and most (63.7%) perceived their economic status as low. Most caregivers (61.8%) were employed, with an average monthly household income of KRW 3,365,500 (SD=244.85), and most perceived their economic status as moderate (54.9%), with 15.7% of the caregivers perceiving their income as high or above. Depression levels were low in both the patients (score=5.74, SD=4.08) and their caregivers (score=3.59, SD=4.63). With a depression score of less than five indicating not depressed, 45.1% of the patients and 71.6% of the caregivers were identified as not depressed. The difference in depression levels between the patients and caregivers was statistically significant, with patients having higher depression levels than their caregivers (t=3.755, *p*=.001, Table 2).

The caregiver burden was found to be 27.48 (SD=17.62), with low moderate levels. The caregivers' average caring time per week was 47.78 (SD=63.58), whereas their average total caring period was 86.27 months (SD=89.74). Based on health, 38.2%, 35.3%, and 26.4% of the caregivers perceived their health status to be bad, moderate, and good, respectively, with 58.8% of caregivers having comorbidities, including hypertension in 35.3% (Table 2).

Most patients had HF for more than one year, and 33.3% and 32.4% had been diagnosed with HF in the previous 5-9 and 1-4 years, respectively. The most recent LVEF data indicated that on average, the patients had a heart function of 52.25% (SD=12.18), with 17.6% having HFrEF (LVEF: < 40%), 28.4% having a mid-range LVEF (LVEF: 40%-50%), and 53.9% having HFpEF (LVEF: ≥ 50%). Based on the NYHA classification of HF symptoms, 36.3% and 51% of the patients were in class I and II, indicating that most patients had mild-moderate HF symptoms. The average number of medications taken by the patients was 5.25 (SD=1.65). In the period between the initial HF diagnosis and the most recent outpatient visit, 77.1% of patients had been hospitalized or visited emergency department because of HF exacerbation, whereas 23.8% had hospitalization or visited the emergency department for readmission because of HF in the previous six months. On average, the patients' CCI and adjusted CCI scores were 3.04 (SD=1.98) and 6.35 (SD=2.16), respectively, and 77.5% of the patients had at least one comorbidity (Table 3).

Table 2. Demographic, psychological, and caring characteristics of HF patients and caregivers

Characteristics	Categories	HF patients (N=102)				HF caregivers (N=102)				X^2/t	P value
		N	%	M	SD	N	%	M	SD		
Gender	Males	47	(46.1%)			35	(34.3%)			2.936	.087
	Females	55	(53.9%)			67	(65.7%)				
Age (years)				79.44	(9.05)			58.97	(13.07)	14.297**	<.001
Type of Relationship	Spouse					33	(32.4%)				
	Adult child					63	(61.7%)				
	Etc.					6	(5.9%)				
Marital status	Marriage	59	(57.8%)			87	(85.3%)			50.050**	<.001
	Single	1	(1.0%)			12	(11.8%)				
	Bereaved	40	(39.2%)			2	(2.0%)				
	Divorced	2	(2.0%)			1	(1.0%)				
Living together status	Living alone	26	(25.5%)								
	Living with caregivers	49	(48.0%)								
	Living with other family members	27	(26.5%)								

Table 2. Demographic, psychological, and caring characteristics of HF patients and caregivers (Continuous)

Characteristics	Categories	HF patients (N=102)				HF caregivers (N=102)				X^2/t	p-value
		N	(%)	M	(SD)	N	(%)	M	(SD)		
Residential region	Urban	51	(50.0%)								
	Rural	51	(50.0%)								
Education level	Below elementary school	67	(65.7%)			19	(18.6%)			69.835**	<.001
	Middle to high school	30	(29.4%)			48	(47.1%)				
	Above college	5	(4.9%)			35	(34.3%)				
Employment	Yes	29	(28.4%)			63	(61.8%)			22.887**	<.001
	No	73	(71.6%)			39	(38.2%)				
Monthly income (10,000 won)				120.28	(126.54)			336.55	(244.85)	-8.242**	<.001
Perceived economic status	Low	65	(63.7%)			30	(29.4%)			29.635**	<.001
	Moderate	33	(32.4%)			56	(54.9%)				
	High	4	(3.9%)			16	(15.7%)				
Depression	Total score			5.74	(4.08)			3.59	(4.63)	3.755**	<.001
	None	46	(45.1%)			73	(71.6%)			22.220**	<.001
	With depression symptom	56	(54.9%)			29	(28.4%)				

Table 2. Demographic, psychological, and caring characteristics of HF patients and caregivers (Continuous)

Characteristics	Categories	HF patients (N=102)				HF caregivers (N=102)				X^2/t	p-value
		N	(%)	M	(SD)	N	(%)	M	(SD)		
Care burden								27.48	(17.62)		
Care time (hours/week)								47.78	(63.58)		
Care period (months)								86.27	(89.74)		
Caregiver perceived health status	Bad					39	(38.2%)				
	Moderate					36	(35.3%)				
	Good					27	(26.4%)				
Caregiver comorbidity	Yes					60	(58.8%)				
	No					42	(41.2%)				

Table 3. Clinical characteristics of the patients with HF

Variables		N	%	M	SD	min	max
HF Diagnosis (year)				6.05	6.18	0	30
	< 1 year	17	(16.7%)				
	1-4 years	33	(32.4%)				
	5-9 years	34	(33.3%)				
	≥10 years	18	(17.6%)				
Recent LVEF (%)				52.25	12.18	23	73
	< 40% (HFrEF)	18	(17.6%)				
	40%-50% (HFmEF)	29	(28.4%)				
	≥ 50% (HFpEF)	55	(53.9%)				
NYHA class	I	37	(36.3%)				
	II	52	(51.0%)				
	III	13	(12.7%)				
Readmission or ER visit	Yes	81	(77.1%)				
	No	24	(22.9%)				
PO medication per day				5.25	1.65	2	10
Comorbidity	CCI			3.04	1.98	1	9
	Aged CCI			6.35	2.16	2	12
	None	23	(22.5%)				
	With comorbidity	79	(77.5%)				

Note. M=Mean; SD=Standard distribution; HF=Heart Failure; LVEF=Left ventricular ejection fraction; HFrEF=HF with reduced EF; HFmEF=HF with middle range EF; HFpEF=HF with preserved EF; NYHA=New York heart association; ER=Emergency Room; CCI=Charlson comorbidity index

5.2. Digital literacy and mutuality in patients with HF and their caregivers

The average digital literacy score of the patients with HF was very low (31.93, SD=20.59), while caregivers had a moderate score (77.75, SD=30.75). Moreover, the caregivers' digital literacy levels were significantly higher than those of the patients (t=-12.604, *p*<.001, Table 4). Patients' digital literacy correlated negatively with the patients' age (r=-.615, *p*<.001) and depression symptoms (r=-.276, *p*<.001), and positively with the relationship with the caregivers (reference. adult children, r=.275, *p*<.001), patients' education level (r=.579, *p*<.001), patients perceived economic status (r=.359, *p*<.001), and caregivers perceived economic status (r=215, *p*=.030). Similarly, the caregivers' digital literacy correlated negatively with caregivers' age (r=-.656, *p*<.001), relationship with the patient (ref. adult children, r=.576, *p*<.001), and care burden (r=-.276, *p*=.005), and positively with the caregivers' education level (r=.719, *p*<.001), caregivers' perceived economic status (r=.414, *p*<.001), caregivers' perceived health (r=.399, *p*<.001), and patients' LVEF (r=.216, p=.029, Table 5).

The mutuality (based on a five-point scale, range:0-4) of patients with HF and their caregivers had mean values of 2.84 (SD=0.74) and 2.65 (SD=0.87), respectively, indicating moderate mutuality. The total mutuality score was significantly higher in patients than in caregivers (t=2.996, *p*=.003). On the mutuality subscale, patients' total scores were higher than those of the caregivers' in all domains. Love between the patients and the caregivers was not significant (t=.289, p=.773), but the remaining subscale, shared value (t=4.345, *p*<.001), shared pleasure activities (t=2.118, *p*=.037), and reciprocity (t=2.784, *p*=.006) between the patients and the caregivers were significantly differences in the group mean comparison analyses (Table 4). There was a negative correlation between patients' mutuality and caregivers' care burden (r=-.244, *p*=.031), patients' depression symptoms (r=-.287, *p*<.001, Table 5).

Table 4. Digital literacy, mutuality, and HF self-care between HF patients and their caregivers

Variables		HF patient (N=102)		HF caregiver (N=102)		t	p
		M	SD	M	SD		
Digital literacy	Total	31.93	20.59	77.75	30.75	-12.604**	<.001
	Safety & security	13.53	9.50	33.27	12.89	-12.426**	<.001
	Information & communication	12.97	8.10	31.91	12.60	-12.982**	<.001
	Contents creation & management	5.43	3.27	12.56	6.10	-10.508**	<.001
Mutuality	Total	2.84	0.74	2.65	0.87	2.996**	.003
	Love	2.95	0.71	2.93	0.92	.289	.773
	Reciprocity	2.88	0.74	2.69	0.88	2.784**	.006
	Shared pleasure activities	2.76	0.90	2.59	1.02	2.118*	.037
	Shared value	2.65	0.86	2.19	1.13	4.345**	<.001
Self-care	Maintenance	62.60	10.23	59.04	17.41	2.045*	.043
	Symptom perception	46.93	16.64	52.45	19.70	-2.659**	.009
	Management	62.13	16.08	64.98	18.12	-1.388	.168

Note. M=Mean; SD=Standard distribution

Table 5. Pearson’s correlation between digital literacy, mutuality, demographics, HF and caregiver characteristics

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1.Pt Age	1																		
2.CG Age	0.184	1																	
3.Relationship	-.392**	.611**	1																
4.Pt education	-.380**	.209*	.488**	1															
5.CG education	0.106	-.477**	-.527**	-.225*	1														
6.Pt depression	0.153	-0.056	-0.177	-.291**	0.053	1													
7.CG depression	0.041	0.070	0.094	0.063	-0.102	0.125	1												
8.Pt ECON	-0.094	0.043	.207*	.304**	0.088	-.255**	-0.092	1											
9.CG ECON	-0.177	-.203*	-0.109	0.080	.421**	-0.180	-0.128	.386**	1										
10.NYHA	.269**	0.170	0.043	-0.007	-0.124	0.110	0.014	-0.039	-.200*	1									
11.LVEF	0.182	-0.167	-.251*	-.386**	0.176	-0.128	0.075	0.035	0.096	-0.054	1								
12.Pt CCI	0.010	0.074	0.188	0.062	-0.180	0.023	0.149	.235*	-0.106	0.135	-0.177	1							
13.HF prevalence	0.047	0.038	-0.023	-0.049	0.057	-0.082	-0.088	0.160	0.057	-0.098	0.137	0.044	1						
14.CG HEALTH	-0.036	-0.193	-0.154	-0.034	.211*	-0.015	-.501**	0.035	.201*	0.105	0.016	-0.157	0.136	1					
15.Care burden	0.024	.253*	.250*	0.054	-.305**	0.111	.367**	-0.040	-0.091	0.078	-0.018	0.153	-.222*	-.366**	1				
16.Pt digital literacy	-.615**	-0.057	.275**	.579**	0.008	-.276**	0.067	.359**	.215*	-0.184	-0.141	0.024	0.054	0.096	-0.100	1			
17.CG digital literacy	-0.008	-.656**	-.576**	-0.186	.719**	0.084	-0.173	0.066	.414**	-0.093	.216*	-0.155	0.077	.399**	-.276**	0.017	1		
18.Pt mutuality	0.092	-0.020	-0.080	0.006	0.102	-.287**	-0.114	0.132	-0.026	0.024	0.114	0.012	0.167	-0.001	-.244*	0.036	0.171	1	
19.CG mutuality	0.146	0.041	0.005	-0.002	0.070	-.245*	-0.038	0.149	0.064	-0.003	0.116	-0.041	0.087	0.105	-0.156	0.140	0.162	.695**	1

§ PT: patient; CG: caregiver; ECON: perceived economic status; NYHA: New York Heart Associations; LVEF: left ventricular ejection fraction; HEALTH: perceived health status

5.3. HF self-care and caregiver contribution to HF self-care

HF self-care has the following three dimensions: HF self-care maintenance, HF symptom perception, and HF self-care management. Patients with HF scored 62.60 (SD=10.23) for HF self-care maintenance, 46.93 (SD=16.64) for HF symptom perception, and 62.13 (SD=16.08) for HF self-care management. Caregiver contributions to HF self-care were similar to those of HF patients, with scores of 59.04 (SD=17.41) for HF self-care maintenance, 52.45 (SD=19.70) for HF symptom perception, and 64.98 (SD=18.12) for HF self-care management. Symptoms perception was the lowest dimension in the patients and caregivers, whereas the patients' symptom perception score was significantly lower than that of the caregivers contribution to symptom perception (t=-2.659, *p*=.009). The patients' score for maintenance of HF self-care was significantly higher than that of the caregiver contribution to the maintenance of HF self-care (t=-2.045, *p*=.043). The scores for the other dimensions were not significantly different (t=-1.388, *p*=.168) (Table 4).

HF self-care symptom perception correlated positively with the patients' education level (r= .295, *p*=.003), and negatively with patients' depression level (r= -.212, *p*=.032) and NYHA class (r = -.247, *p*=.012). The caregivers contribution to HF self-care maintenance correlated positively with the caregivers' age (r = .265, *p*=.004), caregivers' relationship with the patient (ref. parents, r = .256, *p*=.005), patients' perceived economic status (r = .217, *p*=.014) and care burden (r = .195, *p* = .024). The caregivers contribution to HF self-care symptom perception correlated positively with the patients' perceived economic status (r = .256, *p* = .009) and negatively with the patients' depression (r = -.259, *p* = .009). Finally, the management dimension of the caregivers contribution to HF self-care correlated positively with the patients’ perceived economic status (r = .262, *p* = .004) (Appendix 1).

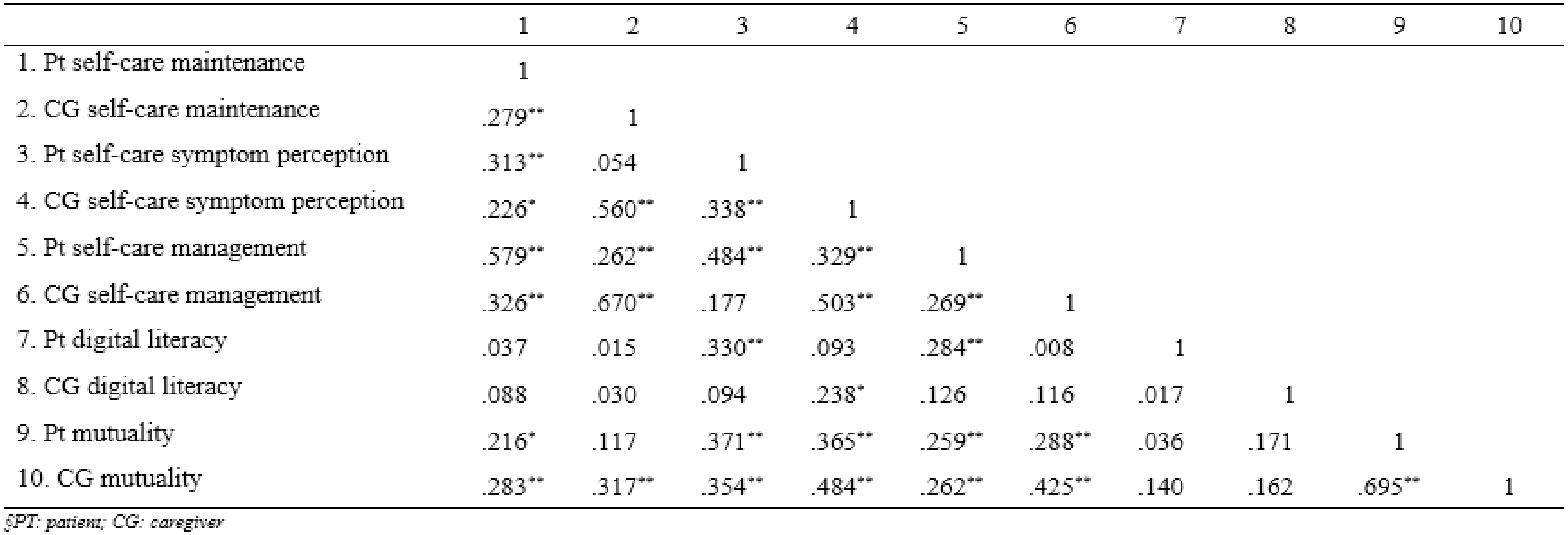
5.4. Correlation between digital literacy, mutuality, and HF self-care

The HF patients' digital literacy correlated positively with HF self-care symptom perception (r = .330, *p* = .001) and HF self-care management (r = .284, *p* = .004). The caregivers' digital literacy correlated positively with symptom perception dimension of the caregivers contribution to HF self-care (r = .238, *p* = .016).

The mutuality of the patients with HF and caregivers had a highly positive correlation (r = .695, *p* < .001). Patient mutuality had significant positive correlation with HF self-care maintenance (r = .216, *p* = .029), symptom perception (r = .371, *p* < .001), and management (r = .259, *p* < .001) dimension of HF self-care, as well as symptom perception (r = .365, *p* < .001) and management (r = .288, *p* < .003) dimension of caregiver contribution to HF self-care. The caregivers' mutuality correlated positively with maintenance (r = .283, *p* = .004), symptom perception (r = .354, *p* < .001), management (r = .262, *p* = .008) dimension of HF self-care, also, maintenance (r = .317, *p* = .001), symptom perception (r = .484, *p* < .001) dimension of caregivers contribution to HF self-care (r = .425, *p* < .001).

HF self-care and the caregivers contribution to HF self-care correlated positively except for HF self-care symptom perception and the caregivers contribution to HF self-care maintenance and management dimension (Table 6)

Table 6. Pearson's correlation between digital literacy, mutuality, HF self-care, and caregiver contribution to HF self-care



	1	2	3	4	5	6	7	8	9	10
1. Pt self-care maintenance	1									
2. CG self-care maintenance	.279**	1								
3. Pt self-care symptom perception	.313**	.054	1							
4. CG self-care symptom perception	.226*	.560**	.338**	1						
5. Pt self-care management	.579**	.262**	.484**	.329**	1					
6. CG self-care management	.326**	.670**	.177	.503**	.269**	1				
7. Pt digital literacy	.037	.015	.330**	.093	.284**	.008	1			
8. CG digital literacy	.088	.030	.094	.238*	.126	.116	.017	1		
9. Pt mutuality	.216*	.117	.371**	.365**	.259**	.288**	.036	.171	1	
10. CG mutuality	.283**	.317**	.354**	.484**	.262**	.425**	.140	.162	.695**	1

§PT: patient; CG: caregiver

5.5. The effect of digital literacy, mutuality on HF self-care, and caregiver contribution to HF self-care within dyads based on APIM

5.5.1. The effect of digital literacy on HF self- care and caregiver contribution to HF self-care within dyad based on APIM

APIM analysis in this study revealed a significant actor effect of a patient's digital literacy on HF self-care symptom perception (B = .219, *p* = .012) and management (B = .199, *p*=.021) with controlling for patients perceived economic status, patients' aged CCI, patient-caregiver relationship, and the patients' residential region as covariates. Additionally, APIM analysis in this study showed an actor effect of caregivers' digital literacy on all dimensions of caregivers contribution to HF self-care; maintenance (B = .146, *p* = .029), symptom perception (B = .259, *p* < .001), management (B = .148, *p* = .037) with controlling for patients' perceived economic status, patients' aged CCI, patient-caregiver relationship, and the patients' residential region as covariates(Table 7). Dyadic analysis between digital literacy and HF self-care using APIM did not reveal a significant partner effect (Figure 4).

Table 7. APIM analysis of digital literacy and mutuality in dyads of patients with HF and caregivers.

Parameter	Actor - Partner effect		Self-care maintenance			Self-care symptom perception			Self-care management		
			Estimate	β	*p*-value	Estimate	β	*p*-value	Estimate	β	*p*-value
Digital literacy	Patient	Actor	0.022	.053	.704	0.219	.413	.012	0.199	.404	.021
		Partner	-0.136	-.329	.134	-0.094	-.178	.350	-0.101	-.205	.291
	Caregiver	Actor	0.146	.355	.029	0.259	.489	<.001	0.148	.300	.037
		Partner	0.050	.122	.233	0.052	.098	.422	0.083	.168	.193
Mutuality	Patient	Actor	0.580	.033	.775	5.910	.260	.034	3.554	.168	.218
		Partner	-4.107	-.231	.165	1.800	.079	.568	-0.550	-.026	.855
	Caregiver	Actor	8.358	.471	<.001	9.423	.414	<.001	8.577	.404	<.001
		Partner	3.083	.174	.049	3.032	.133	.199	2.641	.125	.278

§ Controlling covariates: patients perceived economic status, patient-caregiver relationship (ref. adult children as caregiver), patients' aged Charlson comorbidity index, patients' residential area (ref. rural)

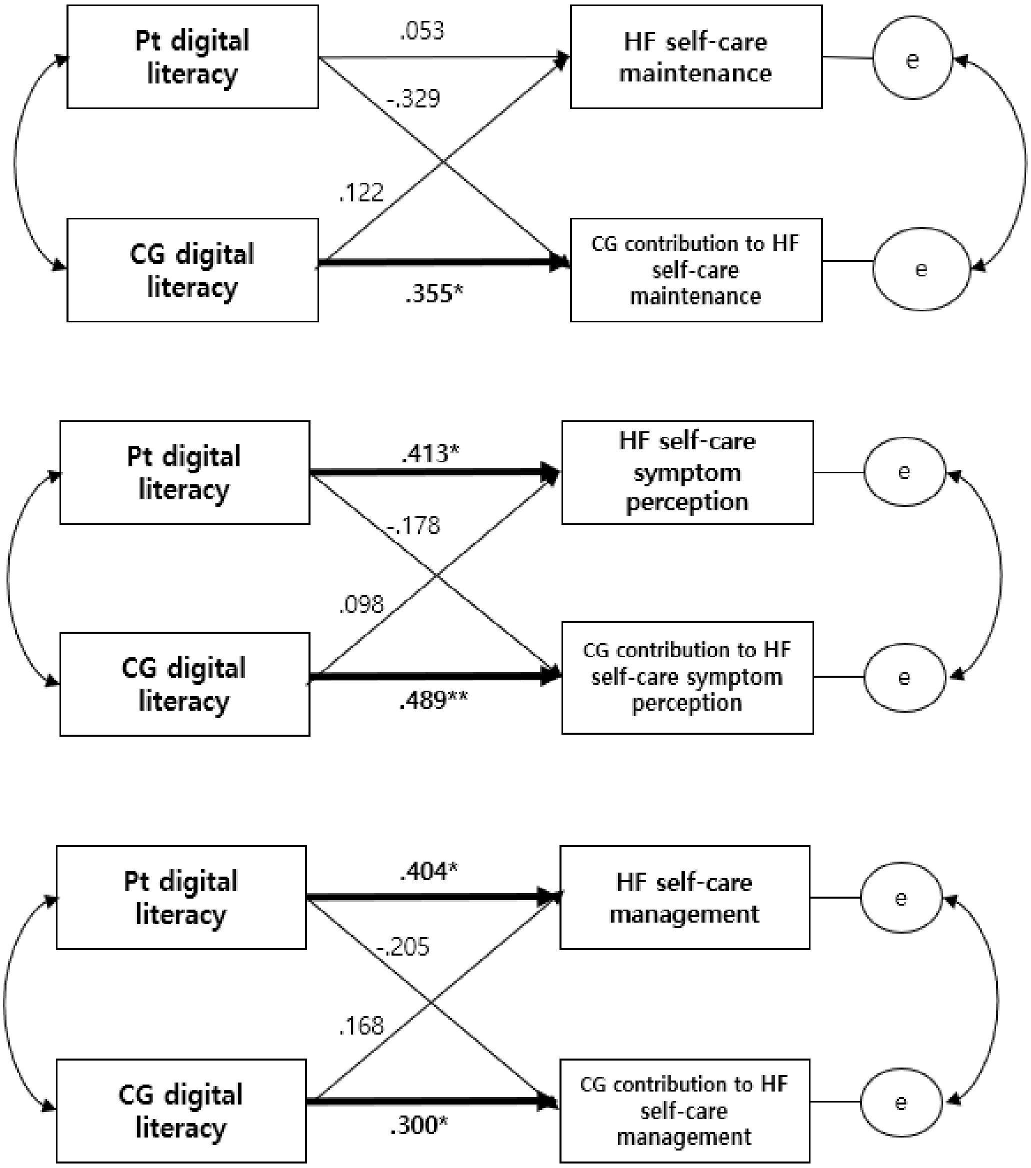


Figure 4. The digital literacy to HF self-care in dyads using APIM after controlling for covariates (patients' aged CCI, residential area, perceived economic status, and patient-caregiver relationship.

5.5.2. The effect of the mutuality on HF self- care and caregiver′s contribution to HF self-care within dyad using APIM

The mutuality of HF patients had actor effect on only HF self-care symptom perception in the APIM analysis after controlling for patient's perceived economic status, patient's advanced CCI, patient-caregiver relationship, and patient's region of residence as covariates (B = 5.910, *p* = .034). And there was no statistically significant partner effect in the relationship between the mutuality of HF patients on caregivers' contribution to HF self-care. While the mutuality of caregivers indicated an actor effect on all dimensions of caregiver’s contribution to HF self-care; maintenance (B = .8.358, *p* < .001), symptom perception (B = 9.423, *p* < .001), management (B = 8.557, *p* < .001) with controlling patient perceived economic status, patient’s aged CCI, relation between patient and caregiver, patient’ living region as covariate. In this study using the APIM, the only significant partner effect on HF self-care was the impact of the caregiver's mutuality on the maintenance of HF self-care (B = 3.083, *p* = .049) (Table 7, Figure 5)

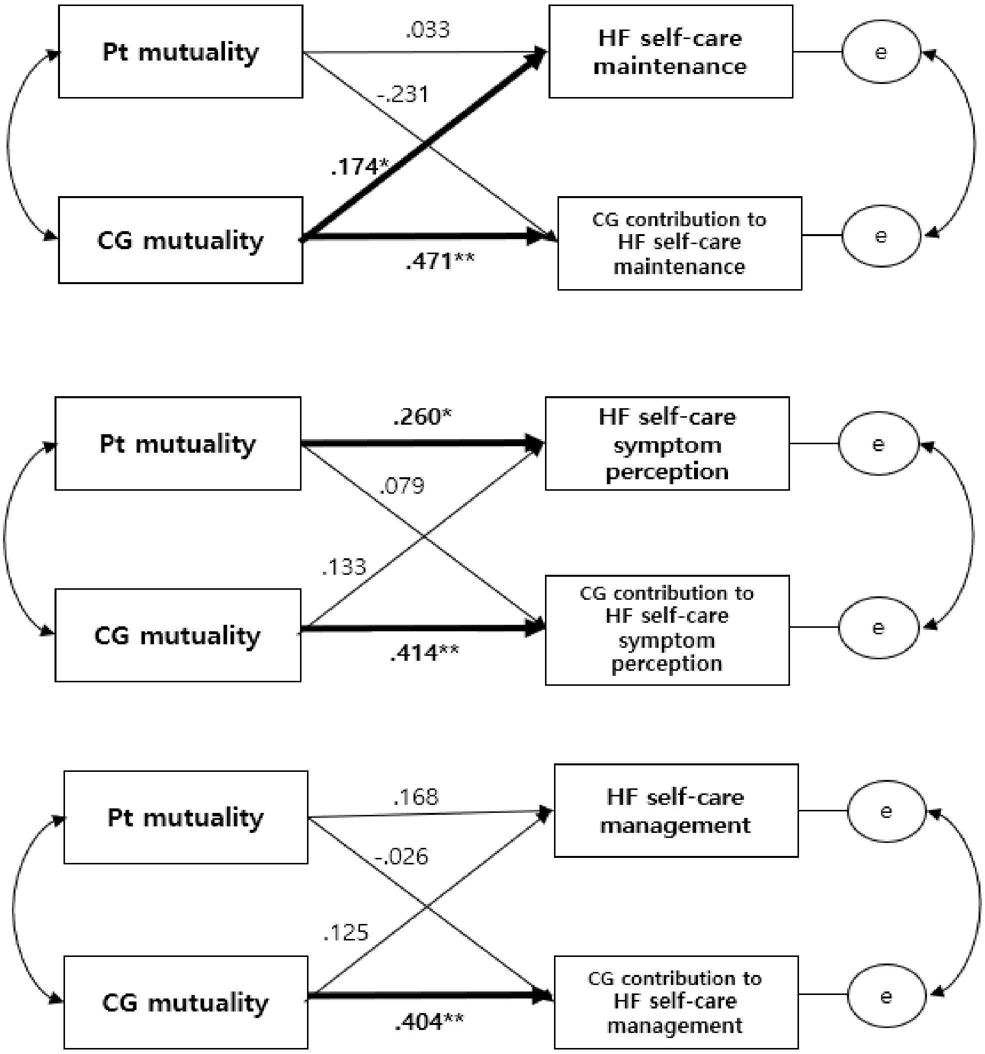


Figure 5. The mutuality to HF self-care in dyads using APIM after controlling for covariates (patients' aged CCI, residential area, perceived economic status, and patient-caregiver relationship)

VI. DISCUSSION

Employing APIM on 102 dyads consisting of Korean HF patients and their caregivers, we conducted the first examination of the influence of digital literacy and mutuality on HF patient self-care (as well as parallel caregiver contribution to HF self-care) within the dyad. Our findings revealed that significant actor effects of digital literacy on both patients and caregivers, with no partner effect. Additionally, the mutuality had a clear actor effect on caregiver contribution to HF self-care, while a partner effect observed only in the maintenance of HF self-care. Patient mutuality demonstrated an actor effect solely in HF self-care symptom perception.

6.1. Digital literacy of HF patients and caregivers and its impact on HF self-care

Contrary to the initial hypothesis, this study found no partner effect on digital literacy to HF self-care (and parallel caregiver contribution to HF self-care) within the dyads of HF patients and their caregivers. The digital literacy of HF patients was not associated with caregivers contribution to HF self-care, and the digital literacy of caregivers was not related to HF self-care. Notably, these results contradict previous studies that have identified caregivers' knowledge level or social support as key factors in promoting patients' self-care (Cavalcante et al., 2023). The observed differences may be attributed to the significant gap in digital literacy levels between HF patients and caregivers, particularly considering the advanced gap of the patients, averaging nearly 80 years old. The low digital literacy among HF patients in this contrasts with previous studies showing moderate to high levels of digital literacy in similar concepts (Arcury et al., 2020; Choukou et al., 2022; Rodríguez Parrado & Achury Saldaña, 2022). The predominance of adult children as caregivers in this study, over 60%, may also contribute to the current results. Previous studies have shown that partner effects in APIM analyses tend to be low unless the caregiver is highly interactive such as a spouse (Hooker et al., 2018; Uchmanowicz et al., 2022).

The actor effect was evident in the digital literacy to HF self-care and caregivers contribution to HF self-care. Higher levels of patient digital literacy were linked to improved symptom perception and management in HF self-care. Symptom perception, a dimension of HF self-care, is improved by knowledge and understanding of the mechanisms and causes of HF symptoms (Ryou et al., 2021). This dimension is mainly affected by education level and access to information. It can be inferred that the most noticeable influence comes from the direct impact of digital literacy, reflecting the patient's educational background and knowledge level (Wali et al., 2020). Moreover, previous studies highlight that the dimension most influenced by knowledge-based support, education, and other forms of social support was management of HF self-care (Riegel et al., 2016; Son et al., 2020). The limited impact on the maintenance dimension may be attributed to controlling for the actual severity of HF disease and its management (Riegel et al., 2016), resulting in no actor effects. This suggests that healthcare professionals need to recognize the direct impact of digital literacy on each patient's self-care, considering the dimension of HF self-care (Son et al., 2020), especially when designing digital health-based intervention strategies for older patients. Additionally, higher levels of digital literacy among caregivers were associated with increased contribution to all dimensions of HF self-care, termed the actor effect. Caregivers in this study demonstrated moderate to high levels of digital literacy, notably higher than findings in other studies (Baik et al., 2023; Mortara et al., 2020). This suggests that digital health strategies for the older population should consider the unique characteristics of each dimension of HF self-care.

Age, education, and economic status were identified as significant factors influencing digital literacy in the elderly (Evans et al., 2016; Smith & Magnani, 2019). Therefore, the efficacy and validity of enhancing HF self-care through the promotion of digital literacy in patients with HF require careful consideration. Identifying the most optional approach necessitates a clearer validation of relevant factors. This aligns with other studies on digital health-based interventions, where older participants often struggle with understanding the operation and process of digital devices, acquiring skills, and performing interventions (Bezerra Giordan et al., 2022; Masterson Creber et al., 2023). The substantial difference in digital literacy levels within dyads suggests that future digital health-based intervention should first identify the level of digital literacy and understand the demographic and geographic characteristics of the target population for effective intervention candidacy assessment. These results also emphasize the necessity of improving digital literacy in both patients and caregivers to enhance self-care for HF and caregivers contributions to HF self-care, respectively.

Furthermore, enhancing the digital literacy of caregivers alone does not seem to be directly linked to improved HF self-care. This supports previous research in the field of digital health that high levels of digital literacy among both patients and caregivers are key factors but emphasizes the importance of education to simultaneously improve within the dyad rather than taking an independent approach (Baik et al., 2023; Cavalcante et al., 2023; Lind & Karlsson, 2014). The findings of this study also provide valuable insights into effectively addressing dyads with significant differences in digital literacy.

6.2. Mutuality of HF patients and caregivers and its impact on HF self-care

Utilizing the APIM to assess the influence of mutuality between HF patients and caregivers on HF self-care, a significant partner effect was observed only in the maintenance dimension of HF self-care, specifically for caregiver mutuality. This implies that when caregivers of HF patients experience a positive relationship with the patient, the patient is more likely to engage in effective self-care practices, such as adhering to a low-sodium diet, exercising, and adhering to medication, with active support of the caregiver (Vellone et al., 2018). However, no other partner effects were found for symptoms perception in HF self-care or future self-care ability; only actor effects were evident. This suggests that the perceived quality of the relationship between an individual and their partner directly affects their own self-care performance. Specifically, elevated levels of patient mutuality were associated with higher levels of HF self-care, particularly in the symptom perception dimension, while increased levels of caregiver mutuality were linked to greater caregiver contributions to HF self-care across all dimensions.

The dynamics observed in mutuality and HF self-care differed slightly from findings in other studies. Among adult child caregivers of Korean HF patients, mutuality exhibited distinct characteristics compared to spouses as caregivers in Western cultures. In this study, the caregivers, who were adult child, did not necessarily live together with the patients. Thus, the characteristics of mutuality was emerged, which reflects a recent unique form of parenting care in South Korea, where the caregivers do not live with HF patients but actively participates in disease management through frequent in-person visits and phone calls. The distinction between perceiving the caregiving relationship positively and negatively, responding only to the burdens and obligations of caregiving patients has been associated with variations in the caregivers' genuine interest in and contribution to the HF self-care (Cooney et al., 2021; Dellafiore et al., 2022; Steinberg et al., 2022). This may reflect East Asian cultures' view of caregiving as a shared duty within the family rooted in filial piety, necessitating exploration and tailored approaches (Huang et al., 2023; Liu et al., 2021).

The mutuality levels of both HF patients and their caregivers in this study were lower than the results reported in the U.S. (Hooker et al., 2018) and Italy (Vellone et al., 2018). This discrepancy may be indicative of difference in relationship styles and characteristics within dyads influenced by the cultural backgrounds. In studies with predominantly spousal caregivers, “the direct expressions of love” and “sharing pleasure activities” were significantly higher among the mutuality domains, resulting in the overall higher total score (Dellafiore et al., 2022; Hooker et al., 2018; Vellone et al., 2018). Conversely, in studies with predominantly adult child caregivers (including daughters-in-law and sons-in-law), “shared values” ranked the lowest among the mutuality domains, contributing to an overall lower level of mutuality. This underscores the importance of considering the nature of the relationship, including type, quality, and generational gap, and suggests the need for different approaches for diverse relationships within dyads in the future.

6.3. HF patients and their caregivers in South Korea

This study identified the characteristics of HF patients and their caregivers in South Korea. Notably, over 60% of the caregivers were identified as adult children, aligning with similar research on caregivers for chronic illnesses, including HF, in China and other East Asian regions (Fang et al., 2023; Wang et al., 2023). In East Asia, where caregiving is more family-centered, the proportion of spouses and adult children was comparable, with the majority of caregivers being adult children (Wang et al., 2023). When comparing caregiving by a spouse of similar age to caregiving by an adult child with significant age difference of more than 20 years, various distinctions in the dynamics and effectiveness of mutuality and communication in each dyad were observed. Moreover, significant differences were noted in education, economic status, and health status. Given the influence of family and caregiving cultures rooted in Confucian values in East Asia, distinct approaches are necessary to comprehend the relationship patterns between HF patients and their caregivers (Huang et al., 2023). Identifying factors contributing to these variations is essential for optimizing intervention. Thus, a shift away from spouse-centered caregiver strategies prevalent in Western societies is recognized, emphasizing the need for customized strategies reflecting the characteristics of adult children and family-wide caregiver relationship in East Asia, particularly in South Korea (Hooker et al., 2018; Uchmanowicz et al., 2022).

In this study, only 25.5% of caregivers cohabited with the HF patients, contrasting with the 55.10% reported in previous studies where spouses were predominant caregivers in the U.S. and Western countries (Uchmanowicz et al., 2022; Vellone et al., 2018). According to the 2010 Korean Population and Housing Census, 20% of the elderly population lived alone, 35% lived in elderly couples, and the proportion of elderly people living with adult children was decreasing (Kim, 2017). This demographic shift may explain the study’s findings, particularly given that 50% of the HF patients resided in rural areas. The living situation of HF patients should be considered in the development of future health systems for HF. Additionally, caregiving burden in this study was reported as relatively low, with a mean score of 27.48 (SD = 17.62) out of 88 points. This burden level was found to be lower than that reported for caregivers of HF patients in both Korea and abroad (Graven et al., 2021; K. A. Kim et al., 2022). This finding could be attributed to the milder severity of the disease in this study and the lower rate of cohabitation with HF patients compared to other studies. Further investigation is required to provide more detailed explanations in future studies.

Furthermore, this study was able to elucidate the characteristics of HF patients and their caregivers living in a region with a high proportion of the elderly population- a small and medium-sized rural complex city with a total population of 300,000 in South Korea (Statistics, 2022). Currently, severe patients are concentrated in large hospitals in Seoul, and this study focused on HF patients dwelling in a small and medium-sized city including rural areas, providing insights into the characteristics of mild patients with HFpEF. HF patients in this study showed insufficient self-care levels with a self-care standard score of 70 or lower, similar to the results from previous studies (Aghajanloo et al., 2021; J. Kim et al., 2022). These findings underscore the challenges in promoting patient-centered self-care and emphasize the need for active intervention and involvement of caregivers.

6.4. Limitations

This study has several limitations. First, the recruitment of 102 dyads of HF patients and their caregivers from a single institution raise concern about the generalizability of the findings to all HF patients and their caregivers in South Korea. Second, the study does not explore the effects of social support and intimacy beyond the family unit. Given the evolving nature of Korean society into an aging society, where care for chronic diseases is transitioning from intra-family care to social care facilitated by infrastructure like daily care centers, home health aides, and nursing caregivers, the impact of this societal shift warrants future investigation. Third, the relationship between HF patients and caregivers in South Korea often involves role sharing among various family members rather than a single caregiver within the family dynamic. Therefore, expanding the dyads to include all family members and conducting analysis within a dyad with multiple members can offer a more comprehensive understanding of the role dynamics of HF patients and their caregivers. Forth, it is necessary to expand the study to collect all individual variables in the basic APIM to identify the impact of variables such as care burden. Additional modeling incorporating mediating or moderating variables could extend the results of this study, providing more detailed predictors. Finally, considering the low levels of digital literacy in the elderly population, further discussion on the application of qualitative research methods, including interviews, is needed to explore aspects that may not be captured by quantitative survey. Based on this study, we concluded that addressing digital literacy in the elderly population is a significant and multifaceted issue that requires ongoing attention.

6.5. Suggestion for future study

To address the limitations of this study, future research should consider several aspects. First, the next study should involve a larger, multicenter sample, including big cities and other regions, to better reflect the overall characteristics of HF patients and their caregivers. Second, even though there was no clear partner effect in this study, the findings may provide ideas for further research to identify other forms of relationships. Previous studies have highlighted caregiver knowledge level and digital literacy itself as significant facilitators or mediators of HF self-care (Masterson Creber et al., 2023; Wali et al., 2020). Additional relationships and impacts should be explored using an extended APIM that can determine whether key variables act as mediators or moderators. Third, given the recent expansion of the boundaries of care, further research is needed to identify and enhance the influence of extended social support and networks. Additionally, the conceptual framework will require expansion and refinement to address this issue. Finally, it is worthwhile to conduct a sub-analysis by spouse and adult child relationships with caregivers to identify the clear impact of caregiver type on relationships.

6.5. Implications

The significance of this study is that it is the first study in Korea, particularly in a small to medium-scale rural complex city, to explore the effects of digital literacy and mutuality on HF self-care in dyads of HF patients and caregivers using the APIM, despite the partner effect was not clearly significant in all relationships. Identifying the characteristics of elderly HF patients and their caregivers, especially in rural areas with a high prevalence of HFpEF, adds value to understanding the necessity of self-care in such context. Moreover, determining the digital literacy levels among older HF patients and their caregivers will provide foundational data for future digital health-based HF research, contributing to the development of sophisticated HF self-care strategies.

In the context of nursing research, this study reaffirms the significance of dyadic approach, emphasizing the role of human support and resources around the patient. It sets the stage for future analyses of caregiver functions and roles in various diseases, including HF. The study's comprehensive understanding of the multidimensional structure of HF self-care provides guidance for future research designs. In the context of the Fourth Industrial Revolution, where digital health baseline studies are prevalent, this study sheds the light on leveraging caregivers in the study of HF patients using digital devices.

In nursing practice, the promotion of self-care for older patients remains a substantial challenge. This study provides practical evidence on caregiver role assignments and key strategies for promoting self-care in chronic serious illnesses, including HF. It also marks the beginning of a shift towards a patient-caregiver mutuality level and type-specific approach, demonstrating that mutuality is not solely the private domain of the individual but can be actively identified by healthcare providers, including nurses, to design the most effective intervention strategies.

VII. Conclusion

The purpose of this study was to explore the impact of digital literacy and mutuality on HF self-care within a dyad of HF patients and caregivers by applying the APIM. In the present study, high levels of self-digital literacy were found to be associated with increased levels of all dimensions of HF self-care, except for the patient's HF self-care maintenance (actor effect between digital literacy and HF self-care). The mutuality of caregivers increased their contribution to all dimensions of HF self-care (actor effect), as well as the patients' maintenance of HF self-care (partner effect). Patient mutuality only had an effect on the patient's perception of HF symptoms (actor effect) and did not have any significant effects on the other dimensions.

This study provides valuable insights into effective strategies for promoting self-care, considering the digital literacy of HF patients with unique aging characteristics in the context of the rising prevalence of digital health-based HF self-care. Additionally, the findings underscore the crucial role of caregivers in HF self-care, offering a rationale for strategic caregiver role placement and intervention approaches.

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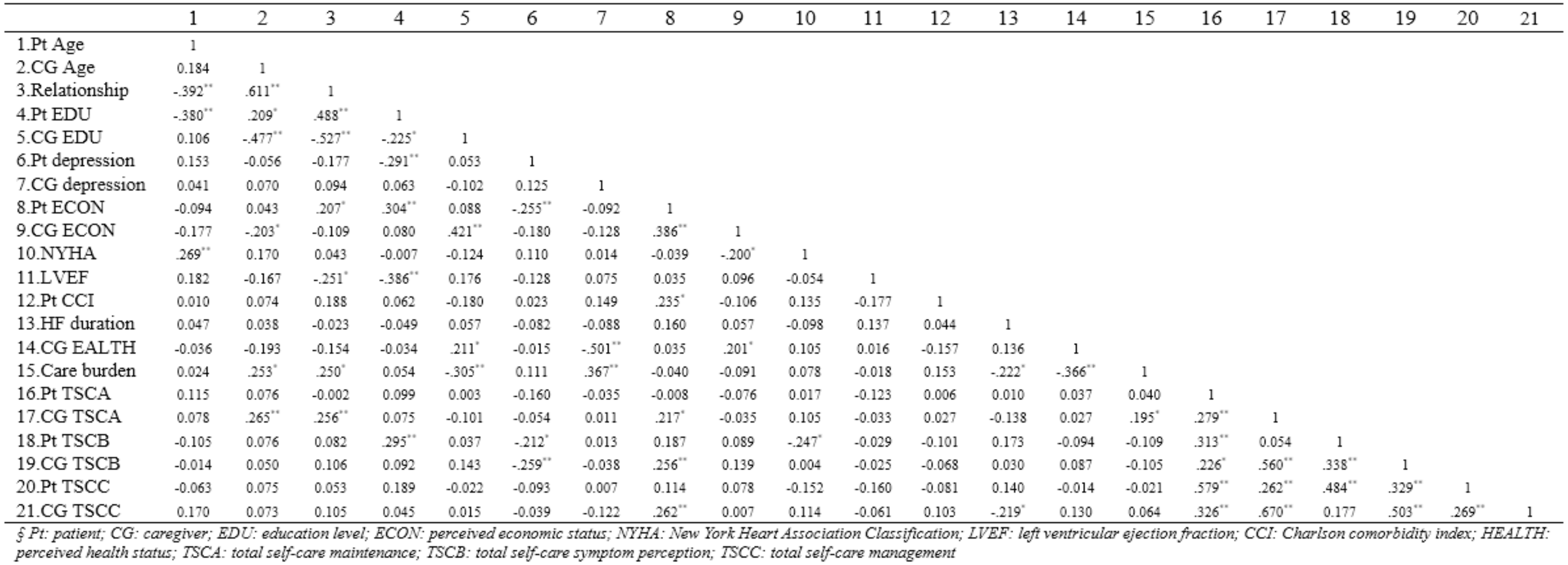
APPENDICES

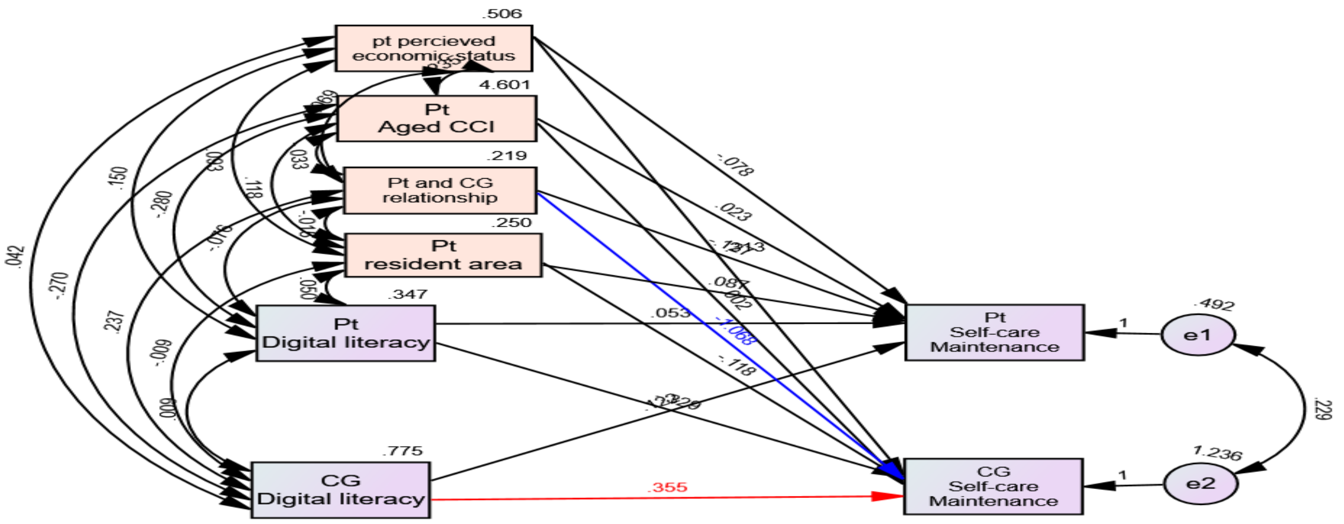
Appendix 1. Pearson’s correlation between HF self-care, caregiver contribution to HF self-care, and demographics



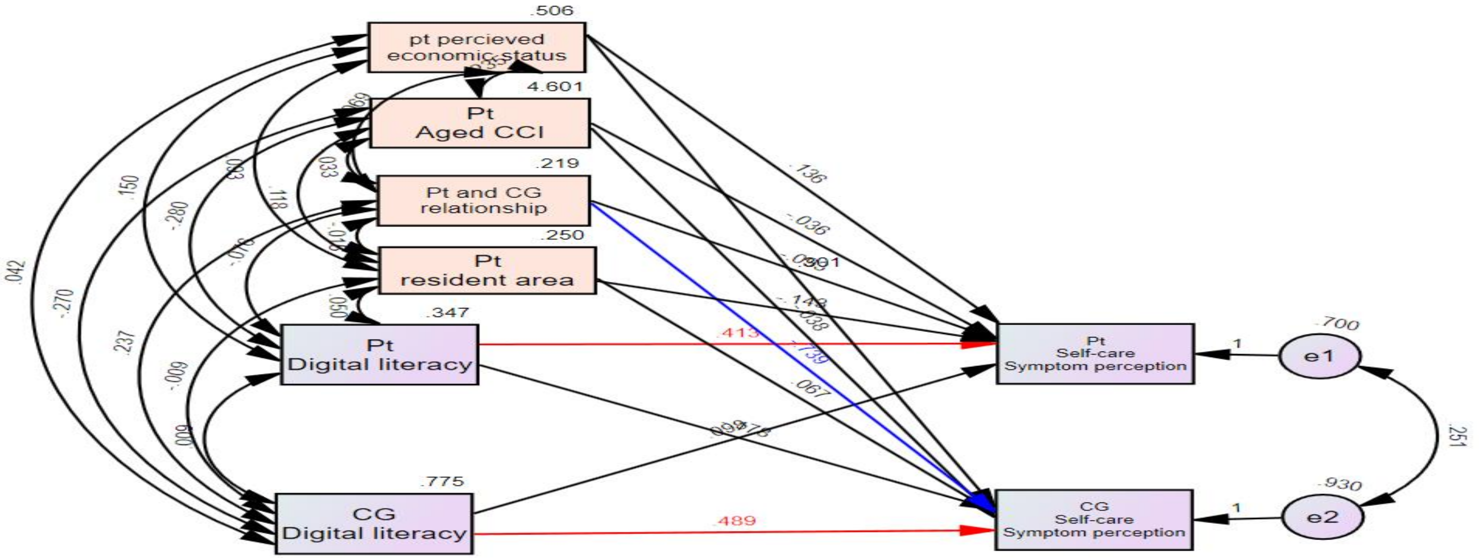
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
1.Pt Age	1																				
2.CG Age	0.184	1																			
3.Relationship	-.392**	.611**	1																		
4.Pt EDU	-.380**	.209*	.488**	1																	
5.CG EDU	0.106	-.477**	-.527**	-.225*	1																
6.Pt depression	0.153	-0.056	-0.177	-.291**	0.053	1															
7.CG depression	0.041	0.070	0.094	0.063	-0.102	0.125	1														
8.Pt ECON	-0.094	0.043	.207*	.304**	0.088	-.255**	-0.092	1													
9.CG ECON	-0.177	-.203*	-0.109	0.080	.421**	-0.180	-0.128	.386**	1												
10.NYHA	.269**	0.170	0.043	-0.007	-0.124	0.110	0.014	-0.039	-.200*	1											
11.LVEF	0.182	-0.167	-.251*	-.386**	0.176	-0.128	0.075	0.035	0.096	-0.054	1										
12.Pt CCI	0.010	0.074	0.188	0.062	-0.180	0.023	0.149	.235*	-0.106	0.135	-0.177	1									
13.HF duration	0.047	0.038	-0.023	-0.049	0.057	-0.082	-0.088	0.160	0.057	-0.098	0.137	0.044	1								
14.CG EALTH	-0.036	-0.193	-0.154	-0.034	.211*	-0.015	-.501**	0.035	.201*	0.105	0.016	-0.157	0.136	1							
15.Care burden	0.024	.253*	.250*	0.054	-.305**	0.111	.367**	-0.040	-0.091	0.078	-0.018	0.153	-.222*	-.366**	1						
16.Pt TSCA	0.115	0.076	-0.002	0.099	0.003	-0.160	-0.035	-0.008	-0.076	0.017	-0.123	0.006	0.010	0.037	0.040	1					
17.CG TSCA	0.078	.265**	.256**	0.075	-0.101	-0.054	0.011	.217*	-0.035	0.105	-0.033	0.027	-0.138	0.027	.195*	.279**	1				
18.Pt TSCB	-0.105	0.076	0.082	.295**	0.037	-.212*	0.013	0.187	0.089	-.247*	-0.029	-0.101	0.173	-0.094	-0.109	.313**	0.054	1			
19.CG TSCB	-0.014	0.050	0.106	0.092	0.143	-.259**	-0.038	.256**	0.139	0.004	-0.025	-0.068	0.030	0.087	-0.105	.226*	.560**	.338**	1		
20.Pt TSCC	-0.063	0.075	0.053	0.189	-0.022	-0.093	0.007	0.114	0.078	-0.152	-0.160	-0.081	0.140	-0.014	-0.021	.579**	.262**	.484**	.329**	1	
21.CG TSCC	0.170	0.073	0.105	0.045	0.015	-0.039	-0.122	.262**	0.007	0.114	-0.061	0.103	-.219*	0.130	0.064	.326**	.670**	0.177	.503**	.269**	1

§ Pt: patient; CG: caregiver; EDU: education level; ECON: perceived economic status; NYHA: New York Heart Association Classification; LVEF: left ventricular ejection fraction; CCI: Charlson comorbidity index; HEALTH: perceived health status; TSCA: total self-care maintenance; TSCB: total self-care symptom perception; TSCC: total self-care management

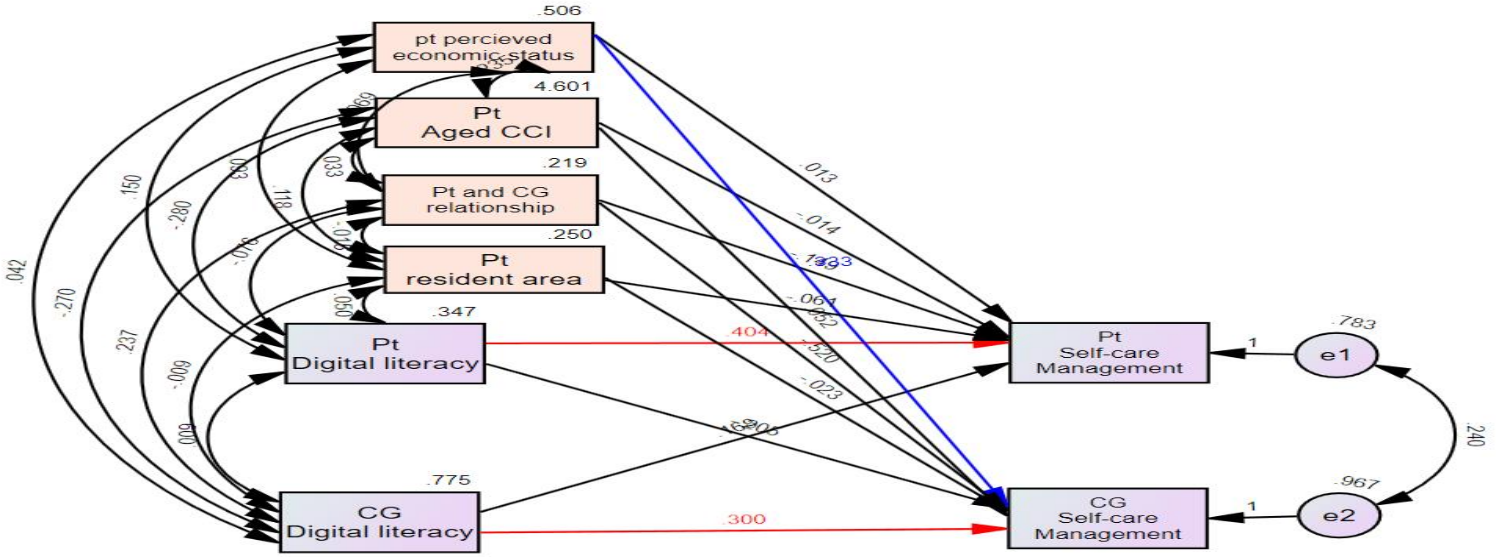
Appendix 2. Effects of digital literacy on maintenance in HF self-care and caregiver's contribution to HF self-care within dyads after controlling covariates (patient's aged CCI, resident area, perceived economic status, and relationship between HF patients and caregivers



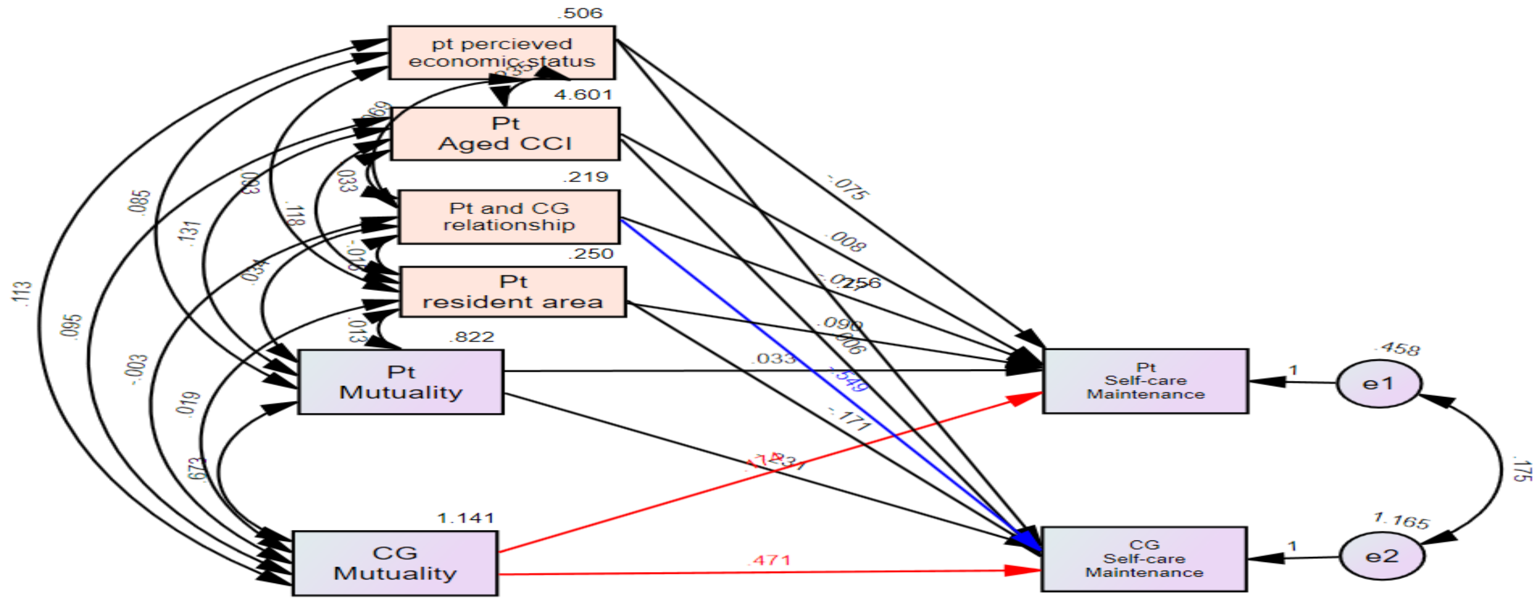
Appendix 3. Effects of digital literacy on symptom perception in HF self-care and caregiver's contribution to HF self-care within dyads after controlling covariates (patient's aged CCI, resident area, perceived economic status, and relationship between HF patient



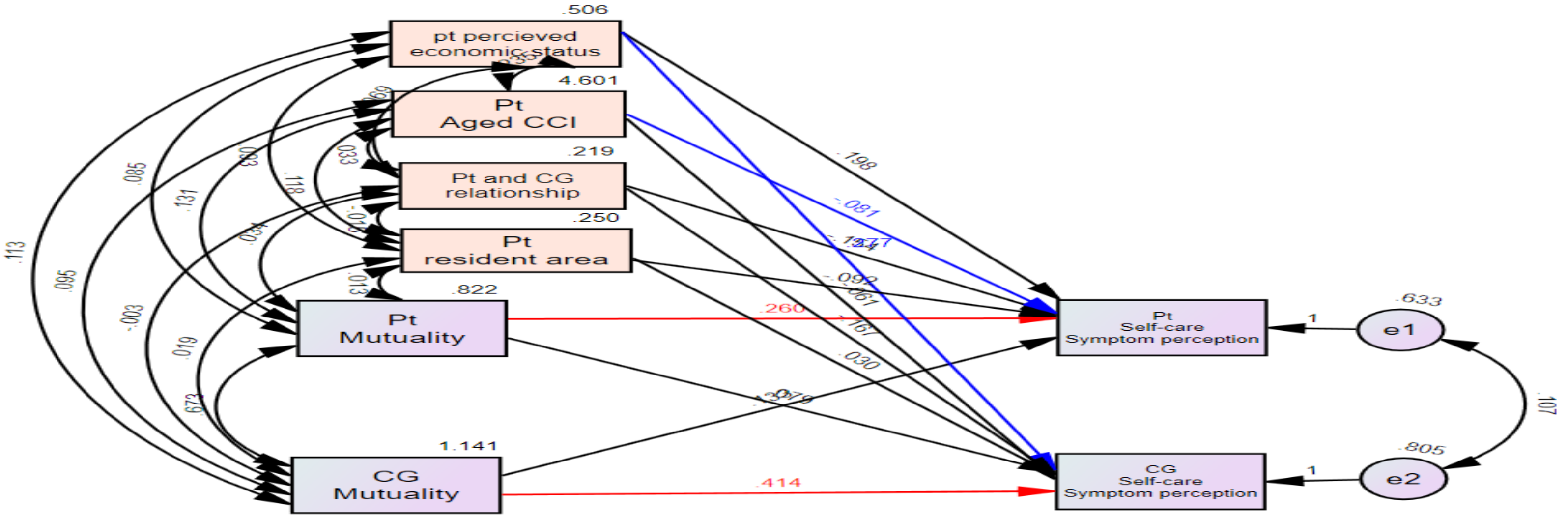
Appendix 4. Effects of digital literacy on management in HF self-care and caregiver's contribution to HF self-care within dyads after controlling covariates (patient's aged CCI, resident area, perceived economic status, and relationship between HF patients.



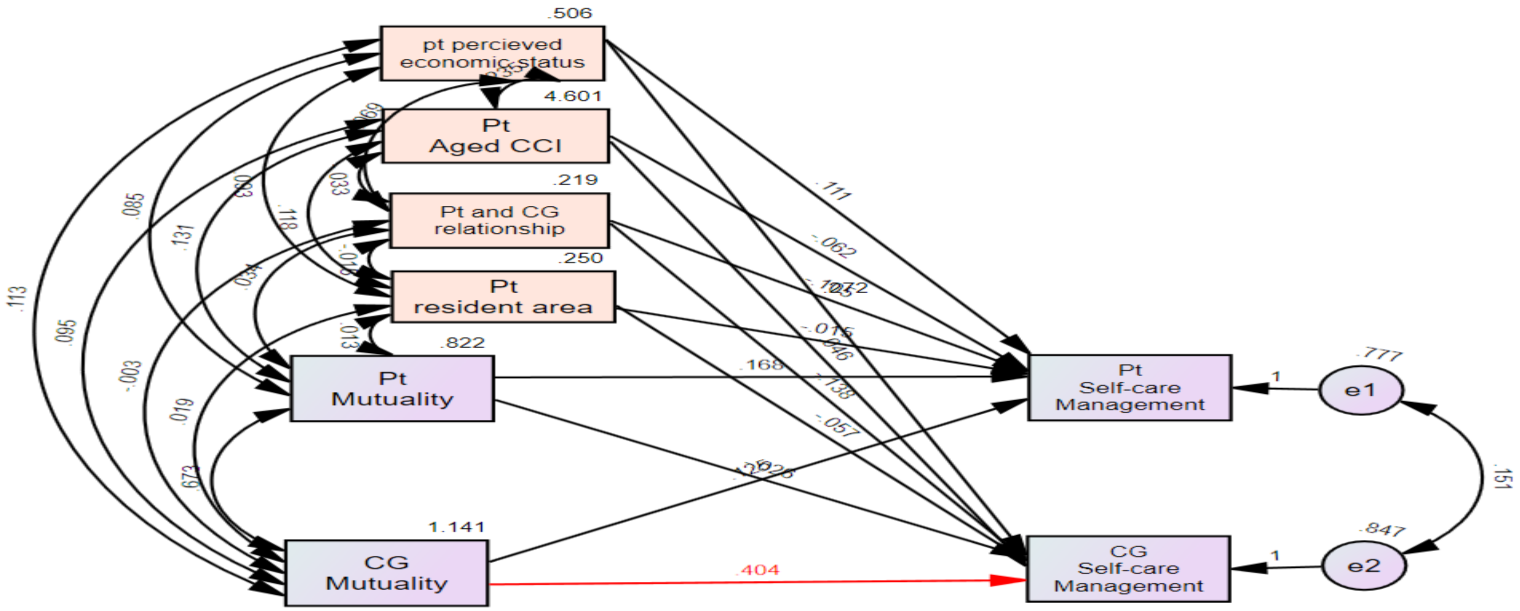
Appendix 5. Effects of mutuality on maintenance in HF self-care and caregiver's contribution to HF self-care within dyads after controlling covariates (patient's aged CCI, resident area, perceived economic status, and relationship between HF patient



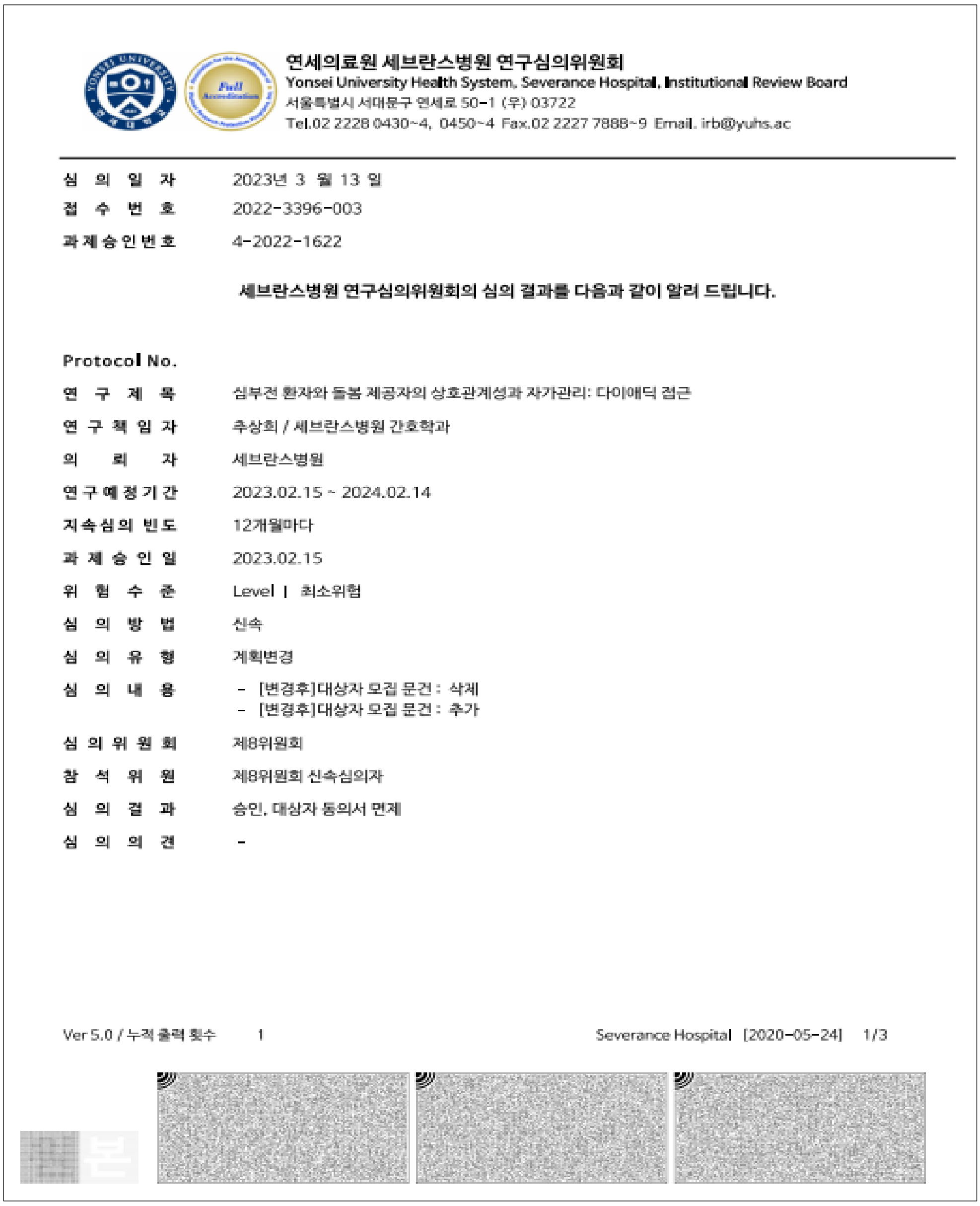
Appendix 6. Effects of mutuality on symptom perception in HF self-care and caregiver's contribution to HF self-care within dyads after controlling covariates (patient's aged CCI, resident area, perceived economic status, and relationship between HF patients



Appendix 7. Effects of mutuality on management in HF self-care and caregiver's contribution to HF self-care within dyads after controlling covariates (patient's aged CCI, resident area, perceived economic status, and relationship between HF patient



Appendix 8. Approval from the institutional review board



연세의료원 세브란스병원 연구심의위원회
Yonsei University Health System, Severance Hospital, Institutional Review Board
서울특별시 서대문구 연세로 50-1 (우) 03722
Tel.02 2228 0430~4, 0450~4 Fax.02 2227 7888~9 Email. irb@yuhs.ac

심의일자	2023년 3 월 13 일
접수번호	2022-3396-003
과제승인번호	4-2022-1622

세브란스병원 연구심의위원회의 심의 결과를 다음과 같이 알려 드립니다.

Protocol No.	
연구제목	심부전 환자와 돌봄 제공자의 상호관계성과 자가관리: 다이애딕 접근
연구책임자	추상희 / 세브란스병원 간호학과
의뢰자	세브란스병원
연구예정기간	2023.02.15 ~ 2024.02.14
지속심의 빈도	12개월마다
과제승인일	2023.02.15
위험수준	Level Ⅰ 최소위험
심의방법	신속
심의유형	계획변경
심의내용	- [변경후]대상자 모집 문건 : 삭제 - [변경후]대상자 모집 문건 : 추가
심의위원회	제8위원회
참석위원	제8위원회 신속심의자
심의결과	승인, 대상자 동의서 면제
심의의견	-

Ver 5.0 / 누적 출력 횟수 1 Severance Hospital [2020-05-24] 1/3

Appendix 8. Approval from the institutional review board (continued)

※ 본 통보서에 기재된 사항은 세브란스병원 연구심의위원회의 기록된 내용과 일치함을 증명합니다.
※ 세브란스병원 연구심의위원회는 국제 임상시험 통일안(ICH-GCP), 임상시험 관리기준(KGCP), 생명윤리 및 안전에 관한 법률을 준수합니다.
※ 연구책임자 및 연구담당자가 IRB위원인 경우, 해당 위원은 위 연구의 심의과정에 참여하지 않았습니다.

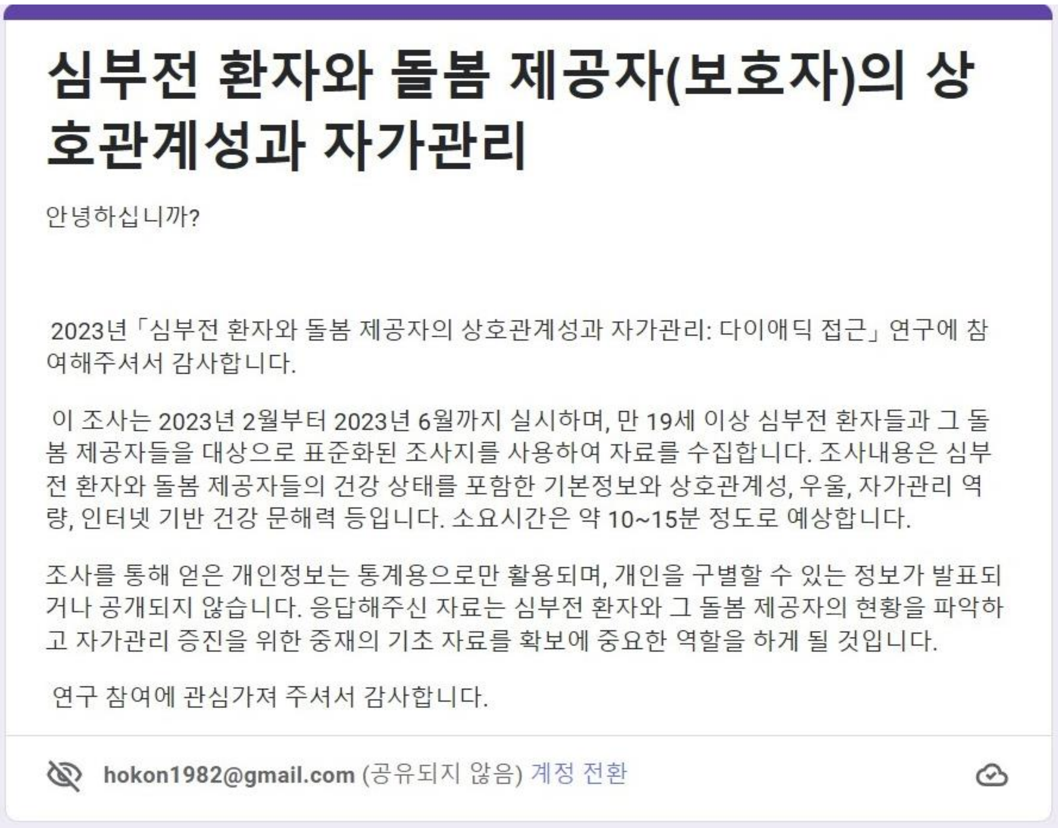
연세의료원 세브란스병원

연구심의위원회 위원장

Ver 5.0 / 누적 출력 횟수 1

Severance Hospital [2020-05-24] 2/3

Appendix 9. Survey questionnaire



심부전 환자와 돌봄 제공자(보호자)의 상호관계성과 자가관리

안녕하십니까?

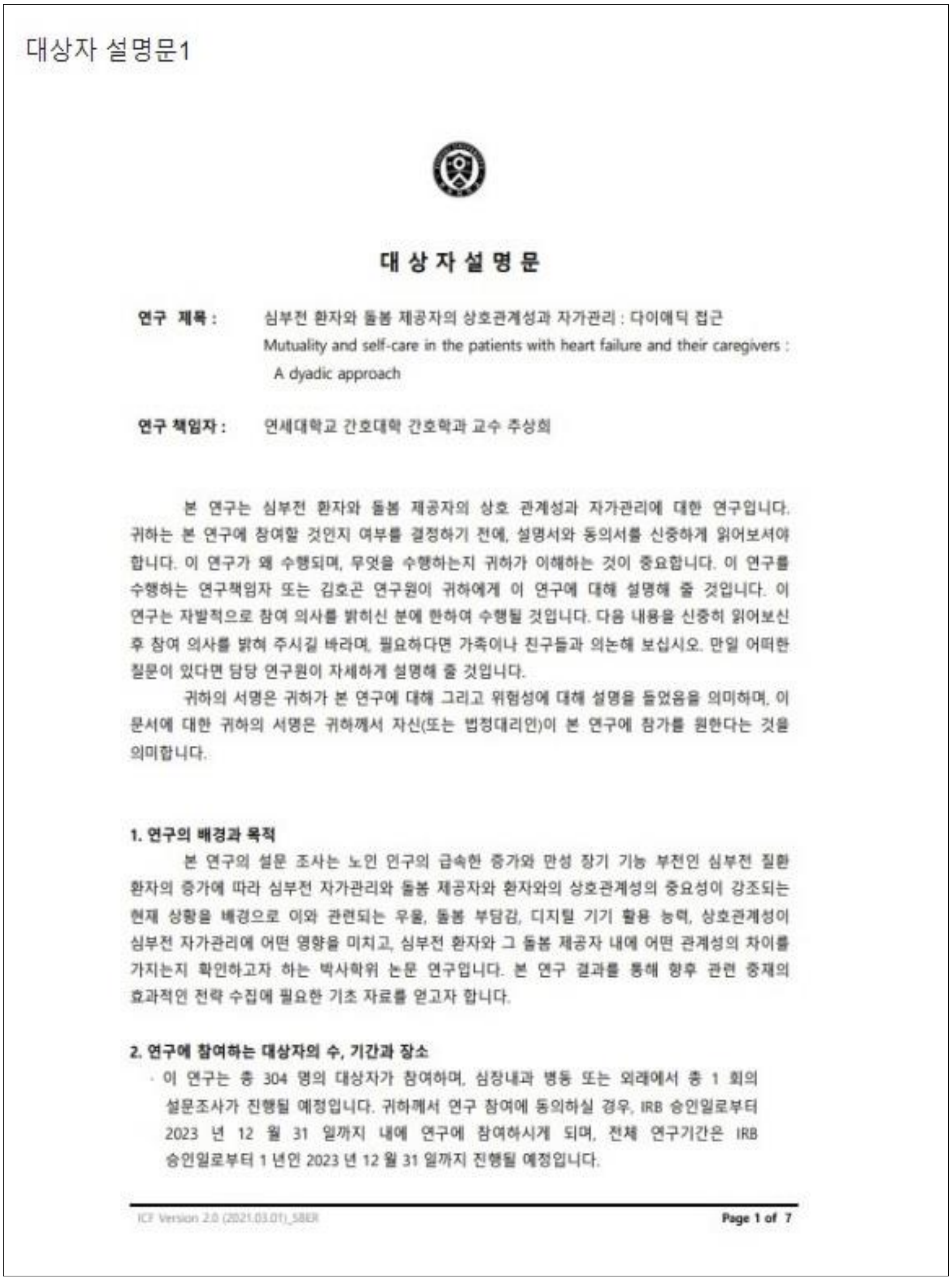
2023년「심부전 환자와 돌봄 제공자의 상호관계성과 자가관리: 다이애딕 접근」연구에 참여해주셔서 감사합니다.

이 조사는 2023년 2월부터 2023년 6월까지 실시하며, 만 19세 이상 심부전 환자들과 그 돌봄 제공자들을 대상으로 표준화된 조사지를 사용하여 자료를 수집합니다. 조사내용은 심부전 환자와 돌봄 제공자들의 건강 상태를 포함한 기본정보와 상호관계성, 우울, 자가관리 역량, 인터넷 기반 건강 문해력 등입니다. 소요시간은 약 10~15분 정도로 예상합니다.

조사를 통해 얻은 개인정보는 통계용으로만 활용되며, 개인을 구별할 수 있는 정보가 발표되거나 공개되지 않습니다. 응답해주신 자료는 심부전 환자와 그 돌봄 제공자의 현황을 파악하고 자가관리 증진을 위한 중재의 기초 자료를 확보에 중요한 역할을 하게 될 것입니다.

연구 참여에 관심가져 주셔서 감사합니다.

Appendix 9. Survey questionnaire (continued)



대상자 설명문1

대상자설명문

연구 제목 : 심부전 환자와 돌봄 제공자의 상호관계성과 자가관리 : 다이애딕 접근
Mutuality and self-care in the patients with heart failure and their caregivers : A dyadic approach

연구 책임자 : 연세대학교 간호대학 간호학과 교수 추상희

본 연구는 심부전 환자와 돌봄 제공자의 상호 관계성과 자가관리에 대한 연구입니다. 귀하는 본 연구에 참여할 것인지 여부를 결정하기 전에, 설명서와 동의서를 신중하게 읽어보셔야 합니다. 이 연구가 왜 수행되며, 무엇을 수행하는지 귀하가 이해하는 것이 중요합니다. 이 연구를 수행하는 연구책임자 또는 김호곤 연구원이 귀하에게 이 연구에 대해 설명해 줄 것입니다. 이 연구는 자발적으로 참여 의사를 밝히신 분에 한하여 수행될 것입니다. 다음 내용을 신중히 읽어보신 후 참여 의사를 밝혀 주시길 바라며, 필요하다면 가족이나 친구들과 의논해 보십시오. 만일 어떠한 질문이 있다면 담당 연구원이 자세하게 설명해 줄 것입니다.

귀하의 서명은 귀하가 본 연구에 대해 그리고 위험성에 대해 설명을 들었음을 의미하며, 이 문서에 대한 귀하의 서명은 귀하께서 자신(또는 법정대리인)이 본 연구에 참가를 원한다는 것을 의미합니다.

1. 연구의 배경과 목적

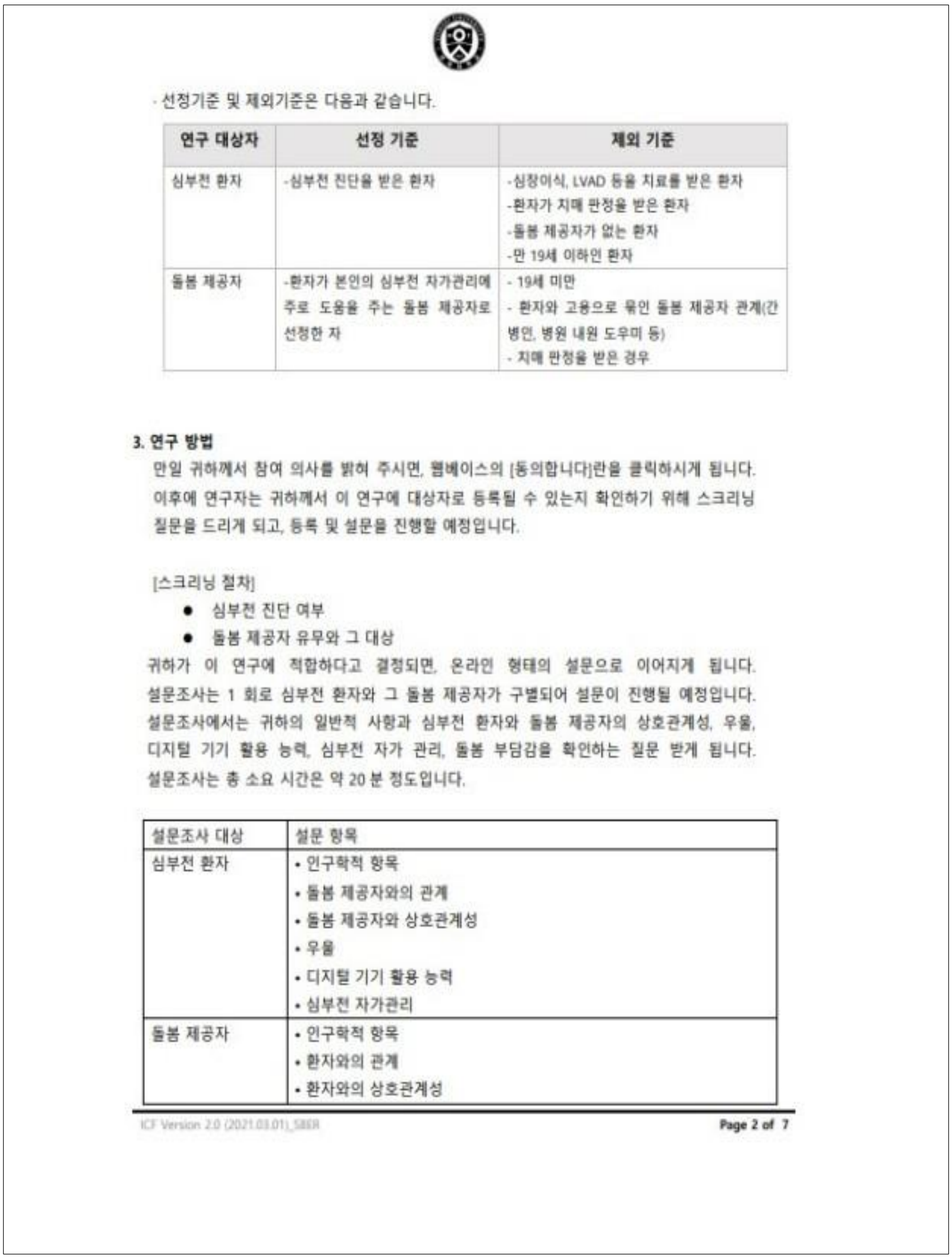
본 연구의 설문 조사는 노인 인구의 급속한 증가와 만성 장기 기능 부전인 심부전 질환 환자의 증가에 따라 심부전 자가관리와 돌봄 제공자와 환자와의 상호관계성의 중요성이 강조되는 현재 상황을 배경으로 이와 관련되는 우울, 돌봄 부담감, 디지털 기기 활용 능력, 상호관계성이 심부전 자가관리에 어떤 영향을 미치고, 심부전 환자와 그 돌봄 제공자 내에 어떤 관계성의 차이를 가지는지 확인하고자 하는 박사학위 논문 연구입니다. 본 연구 결과를 통해 향후 관련 중재의 효과적인 전략 수집에 필요한 기초 자료를 얻고자 합니다.

2. 연구에 참여하는 대상자의 수, 기간과 장소

- 이 연구는 총 304 명의 대상자가 참여하며, 심장내과 병동 또는 외래에서 총 1 회의 설문조사가 진행될 예정입니다. 귀하께서 연구 참여에 동의하실 경우, IRB 승인일로부터 2023 년 12 월 31 일까지 내에 연구에 참여하시게 되며, 전체 연구기간은 IRB 승인일로부터 1 년인 2023 년 12 월 31 일까지 진행될 예정입니다.

ICF Version 2.0 (2021.03.01)_SBER **Page 1 of 7**

Appendix 9. Survey questionnaire (continued)



· 선정기준 및 제외기준은 다음과 같습니다.

연구 대상자	선정 기준	제외 기준
심부전 환자	-심부전 진단을 받은 환자	-심장이식, LVAD 등을 치료를 받은 환자 -환자가 치매 판정을 받은 환자 -돌봄 제공자가 없는 환자 -만 19세 이하인 환자
돌봄 제공자	-환자가 본인의 심부전 자가관리에 주로 도움을 주는 돌봄 제공자로 선정한 자	- 19세 미만 - 환자와 고용으로 묶인 돌봄 제공자 관계(간병인, 병원 내원 도우미 등) - 치매 판정을 받은 경우

3. 연구 방법

만일 귀하께서 참여 의사를 밝혀 주시면, 웹베이스의 [동의합니다]란을 클릭하시게 됩니다. 이후에 연구자는 귀하께서 이 연구에 대상자로 등록될 수 있는지 확인하기 위해 스크리닝 질문을 드리게 되고, 등록 및 설문을 진행할 예정입니다.

[스크리닝 절차]

- 심부전 진단 여부
- 돌봄 제공자 유무와 그 대상

귀하가 이 연구에 적합하다고 결정되면, 온라인 형태의 설문으로 이어지게 됩니다. 설문조사는 1 회로 심부전 환자와 그 돌봄 제공자가 구별되어 설문이 진행될 예정입니다. 설문조사에서는 귀하의 일반적 사항과 심부전 환자와 돌봄 제공자의 상호관계성, 우울, 디지털 기기 활용 능력, 심부전 자가 관리, 돌봄 부담감을 확인하는 질문 받게 됩니다. 설문조사는 총 소요 시간은 약 20 분 정도입니다.

설문조사 대상	설문 항목
심부전 환자	• 인구학적 항목 • 돌봄 제공자와의 관계 • 돌봄 제공자와 상호관계성 • 우울 • 디지털 기기 활용 능력 • 심부전 자가관리
돌봄 제공자	• 인구학적 항목 • 환자와의 관계 • 환자와의 상호관계성

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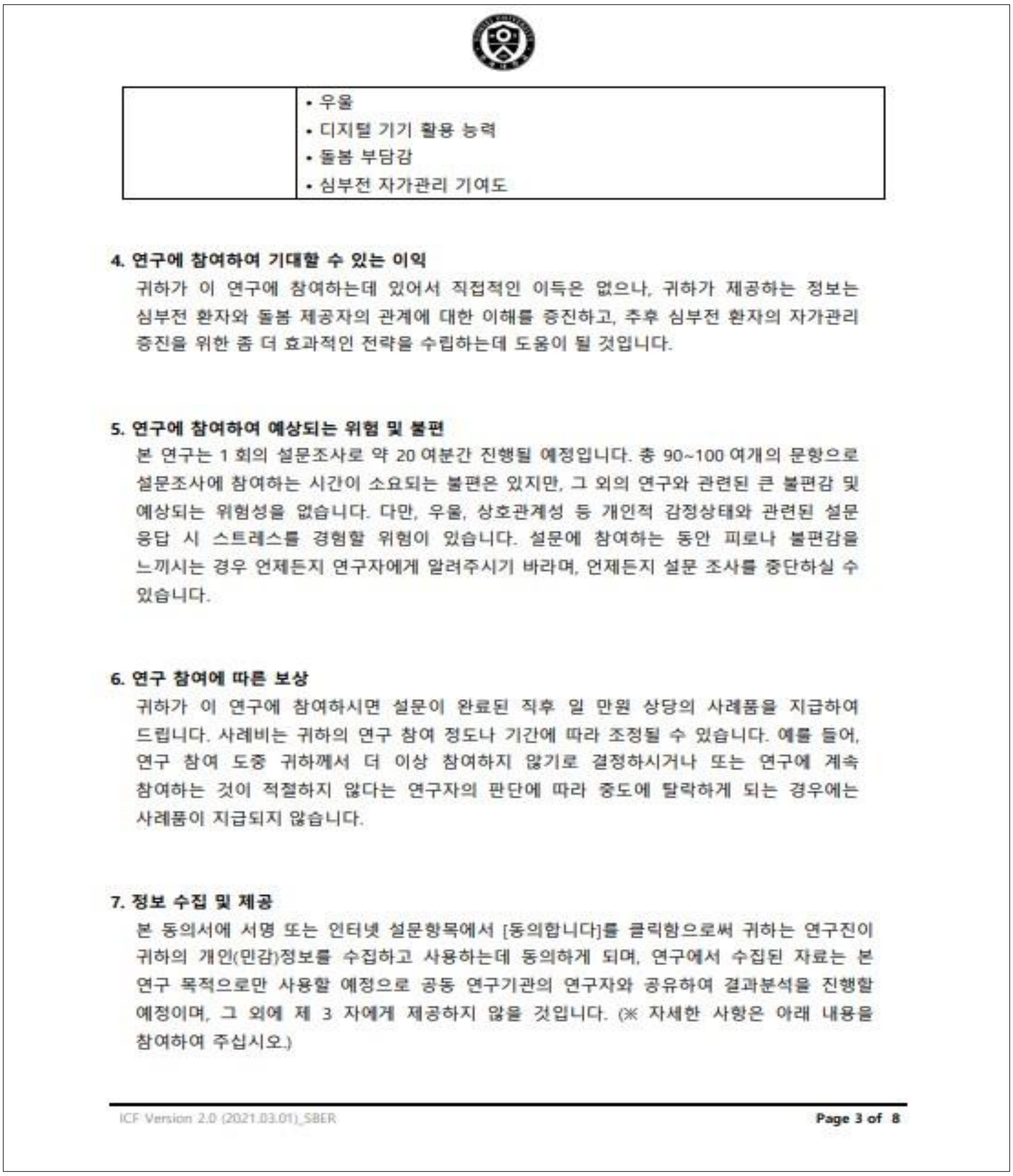
Appendix 9. Survey questionnaire (continued)



	• 우울 • 디지털 기기 활용 능력 • 돌봄 부담감 • 심부전 자가관리 기여도

4. 연구에 참여하여 기대할 수 있는 이익

귀하가 이 연구에 참여하는데 있어서 직접적인 이득은 없으나, 귀하가 제공하는 정보는 심부전 환자와 돌봄 제공자의 관계에 대한 이해를 증진하고, 추후 심부전 환자의 자가관리 증진을 위한 좀 더 효과적인 전략을 수립하는데 도움이 될 것입니다.

5. 연구에 참여하여 예상되는 위험 및 불편

본 연구는 1 회의 설문조사로 약 20 여분간 진행될 예정입니다. 총 90~100 여개의 문항으로 설문조사에 참여하는 시간이 소요되는 불편은 있지만, 그 외의 연구와 관련된 큰 불편감 및 예상되는 위험성을 없습니다. 다만, 우울, 상호관계성 등 개인적 감정상태와 관련된 설문 응답 시 스트레스를 경험할 위험이 있습니다. 설문에 참여하는 동안 피로나 불편감을 느끼시는 경우 언제든지 연구자에게 알려주시기 바라며, 언제든지 설문 조사를 중단하실 수 있습니다.

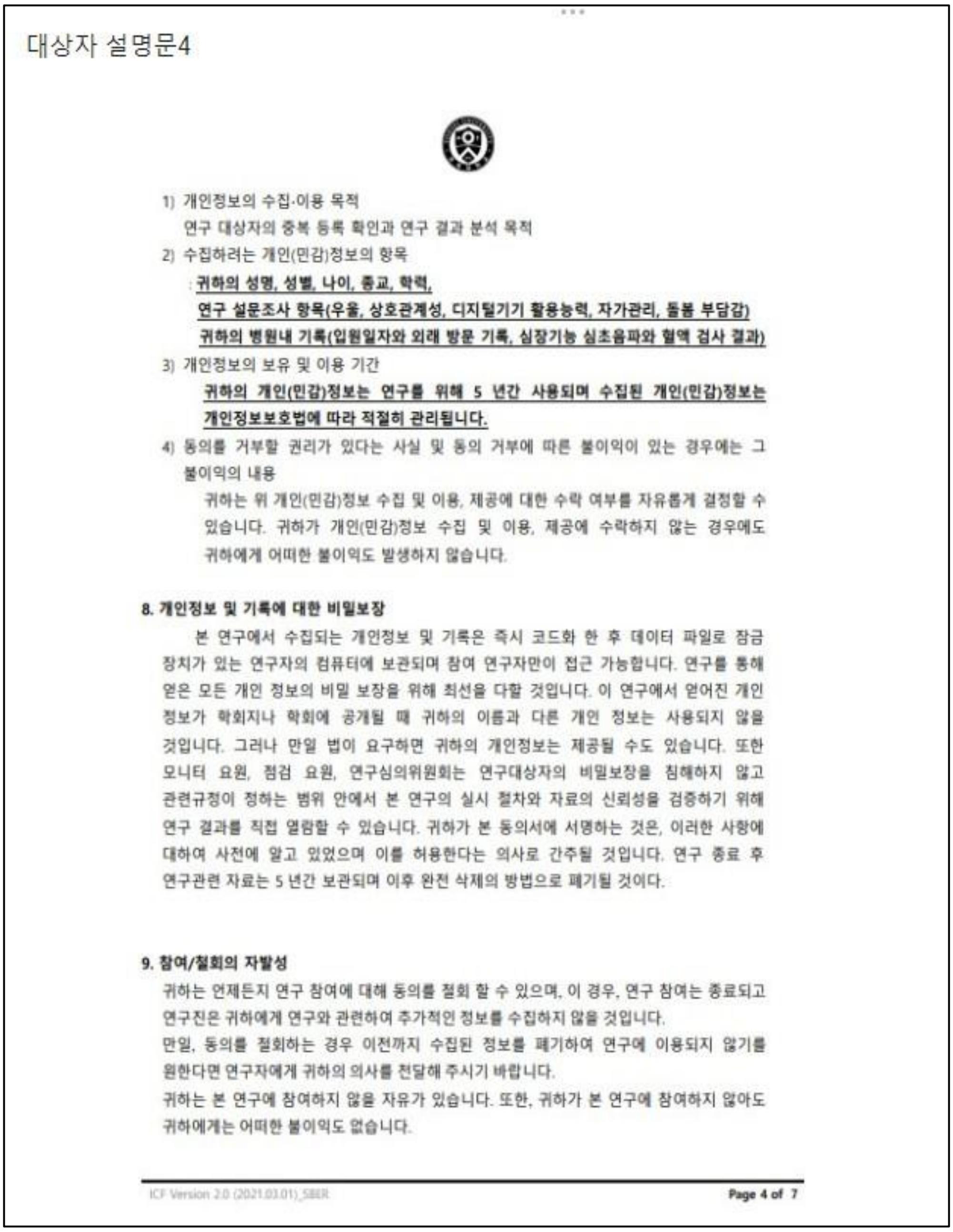
6. 연구 참여에 따른 보상

귀하가 이 연구에 참여하시면 설문이 완료된 직후 일 만원 상당의 사례품을 지급하여 드립니다. 사례비는 귀하의 연구 참여 정도나 기간에 따라 조정될 수 있습니다. 예를 들어, 연구 참여 도중 귀하께서 더 이상 참여하지 않기로 결정하시거나 또는 연구에 계속 참여하는 것이 적절하지 않다는 연구자의 판단에 따라 중도에 탈락하게 되는 경우에는 사례품이 지급되지 않습니다.

7. 정보 수집 및 제공

본 동의서에 서명 또는 인터넷 설문항목에서 [동의합니다]를 클릭함으로써 귀하는 연구진이 귀하의 개인(민감)정보를 수집하고 사용하는데 동의하게 되며, 연구에서 수집된 자료는 본 연구 목적으로만 사용할 예정으로 공동 연구기관의 연구자와 공유하여 결과분석을 진행할 예정이며, 그 외에 제 3 자에게 제공하지 않을 것입니다. (※ 자세한 사항은 아래 내용을 참여하여 주십시오.)

Appendix 9. Survey questionnaire (continued)



대상자 설명문4

1) 개인정보의 수집·이용 목적
   연구 대상자의 중복 등록 확인과 연구 결과 분석 목적
2) 수집하려는 개인(민감)정보의 항목
   : **귀하의 성명, 성별, 나이, 종교, 학력,**
   연구 설문조사 항목(우울, 상호관계성, 디지털기기 활용능력, 자가관리, 돌봄 부담감)
   귀하의 병원내 기록(입원일자와 외래 방문 기록, 심장기능 심초음파와 혈액 검사 결과)
3) 개인정보의 보유 및 이용 기간
   귀하의 개인(민감)정보는 연구를 위해 5 년간 사용되며 수집된 개인(민감)정보는 개인정보보호법에 따라 적절히 관리됩니다.
4) 동의를 거부할 권리가 있다는 사실 및 동의 거부에 따른 불이익이 있는 경우에는 그 불이익의 내용
   귀하는 위 개인(민감)정보 수집 및 이용, 제공에 대한 수락 여부를 자유롭게 결정할 수 있습니다. 귀하가 개인(민감)정보 수집 및 이용, 제공에 수락하지 않는 경우에도 귀하에게 어떠한 불이익도 발생하지 않습니다.

8. 개인정보 및 기록에 대한 비밀보장

본 연구에서 수집되는 개인정보 및 기록은 즉시 코드화 한 후 데이터 파일로 잠금 장치가 있는 연구자의 컴퓨터에 보관되며 참여 연구자만이 접근 가능합니다. 연구를 통해 얻은 모든 개인 정보의 비밀 보장을 위해 최선을 다할 것입니다. 이 연구에서 얻어진 개인 정보가 학회지나 학회에 공개될 때 귀하의 이름과 다른 개인 정보는 사용되지 않을 것입니다. 그러나 만일 법이 요구하면 귀하의 개인정보는 제공될 수도 있습니다. 또한 모니터 요원, 점검 요원, 연구심의위원회는 연구대상자의 비밀보장을 침해하지 않고 관련규정이 정하는 범위 안에서 본 연구의 실시 절차와 자료의 신뢰성을 검증하기 위해 연구 결과를 직접 열람할 수 있습니다. 귀하가 본 동의서에 서명하는 것은, 이러한 사항에 대하여 사전에 알고 있었으며 이를 허용한다는 의사로 간주될 것입니다. 연구 종료 후 연구관련 자료는 5 년간 보관되며 이후 완전 삭제의 방법으로 폐기될 것이다.

9. 참여/철회의 자발성

귀하는 언제든지 연구 참여에 대해 동의를 철회 할 수 있으며, 이 경우, 연구 참여는 종료되고 연구진은 귀하에게 연구와 관련하여 추가적인 정보를 수집하지 않을 것입니다.

만일, 동의를 철회하는 경우 이전까지 수집된 정보를 폐기하여 연구에 이용되지 않기를 원한다면 연구자에게 귀하의 의사를 전달해 주시기 바랍니다.

귀하는 본 연구에 참여하지 않을 자유가 있습니다. 또한, 귀하가 본 연구에 참여하지 않아도 귀하에게는 어떠한 불이익도 없습니다.

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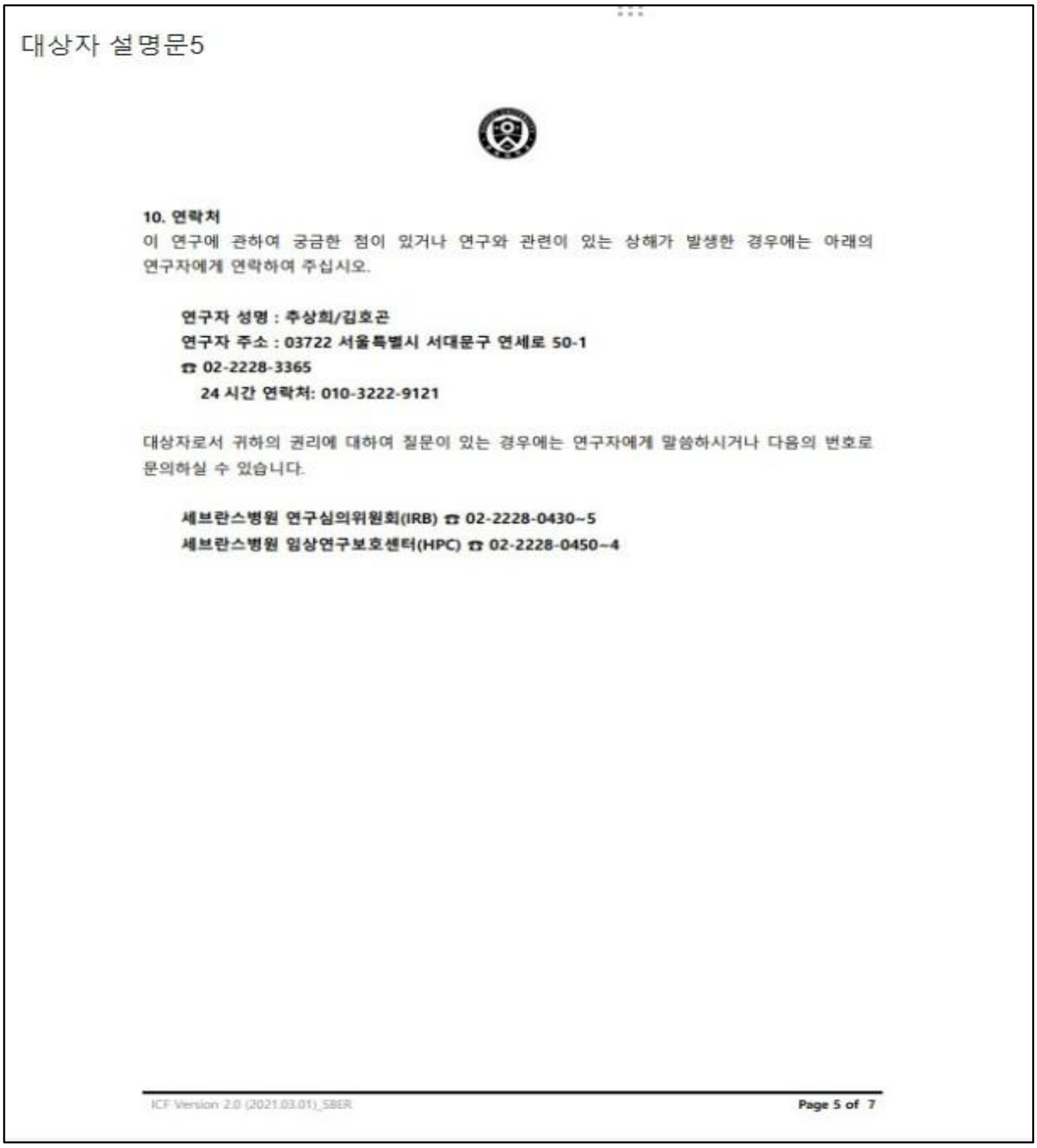
Appendix 9. Survey questionnaire (continued)



대상자 설명문5

10. 연락처

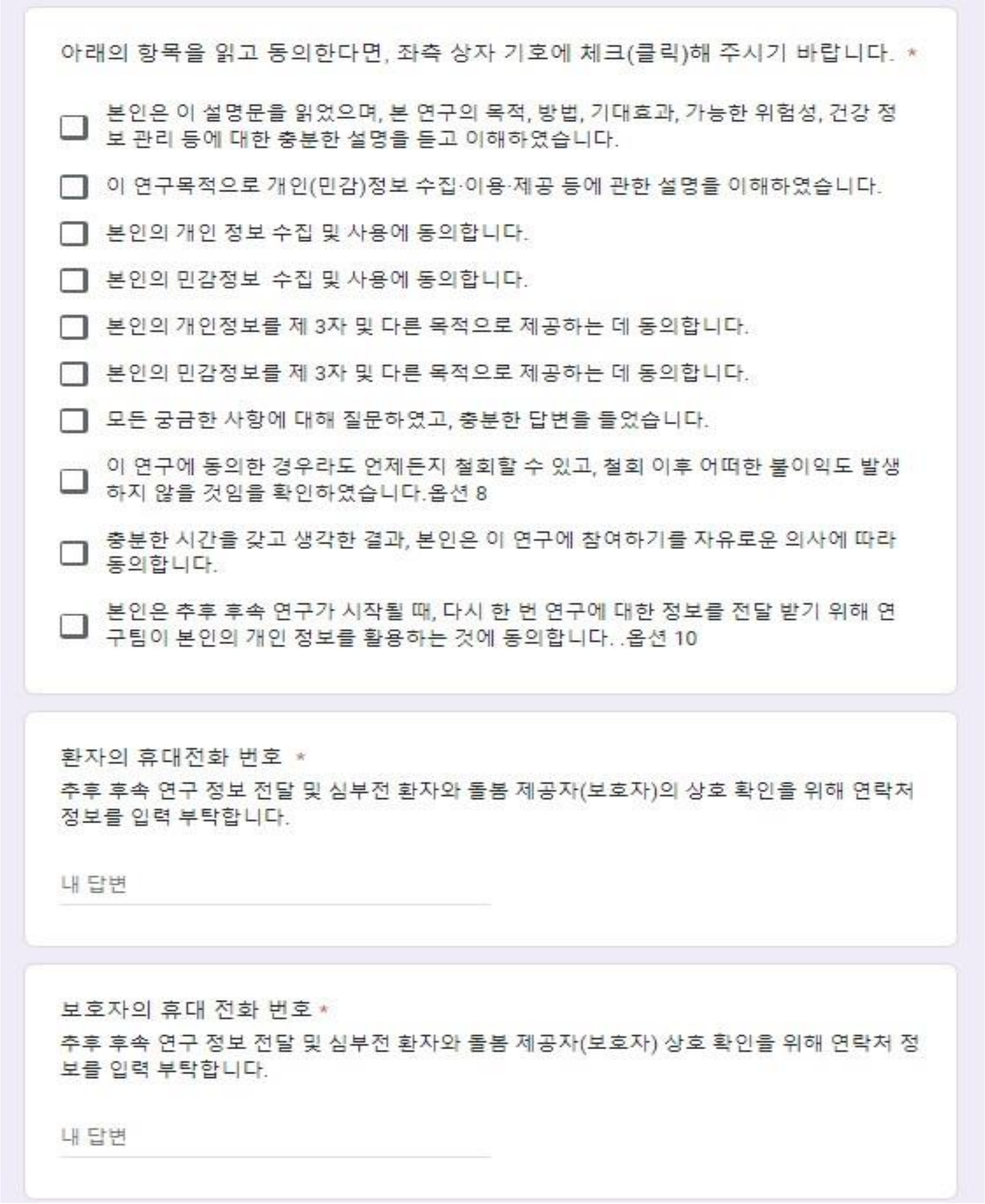
이 연구에 관하여 궁금한 점이 있거나 연구와 관련이 있는 상해가 발생한 경우에는 아래의 연구자에게 연락하여 주십시오.

연구자 성명 : 추상희/김호곤
연구자 주소 : 03722 서울특별시 서대문구 연세로 50-1
☎ 02-2228-3365
24 시간 연락처: 010-3222-9121

대상자로서 귀하의 권리에 대하여 질문이 있는 경우에는 연구자에게 말씀하시거나 다음의 번호로 문의하실 수 있습니다.

세브란스병원 연구심의위원회(IRB) ☎ 02-2228-0430~5
세브란스병원 임상연구보호센터(HPC) ☎ 02-2228-0450~4

Appendix 9. Survey questionnaire (continued)



아래의 항목을 읽고 동의한다면, 좌측 상자 기호에 체크(클릭)해 주시기 바랍니다. *

☐ 본인은 이 설명문을 읽었으며, 본 연구의 목적, 방법, 기대효과, 가능한 위험성, 건강 정보 관리 등에 대한 충분한 설명을 듣고 이해하였습니다.

☐ 이 연구목적으로 개인(민감)정보 수집·이용·제공 등에 관한 설명을 이해하였습니다.

☐ 본인의 개인 정보 수집 및 사용에 동의합니다.

☐ 본인의 민감정보 수집 및 사용에 동의합니다.

☐ 본인의 개인정보를 제 3자 및 다른 목적으로 제공하는 데 동의합니다.

☐ 본인의 민감정보를 제 3자 및 다른 목적으로 제공하는 데 동의합니다.

☐ 모든 궁금한 사항에 대해 질문하였고, 충분한 답변을 들었습니다.

☐ 이 연구에 동의한 경우라도 언제든지 철회할 수 있고, 철회 이후 어떠한 불이익도 발생하지 않을 것임을 확인하였습니다.옵션 8

☐ 충분한 시간을 갖고 생각한 결과, 본인은 이 연구에 참여하기를 자유로운 의사에 따라 동의합니다.

☐ 본인은 추후 후속 연구가 시작될 때, 다시 한 번 연구에 대한 정보를 전달 받기 위해 연구팀이 본인의 개인 정보를 활용하는 것에 동의합니다. .옵션 10

환자의 휴대전화 번호 *

추후 후속 연구 정보 전달 및 심부전 환자와 돌봄 제공자(보호자)의 상호 확인을 위해 연락처 정보를 입력 부탁합니다.

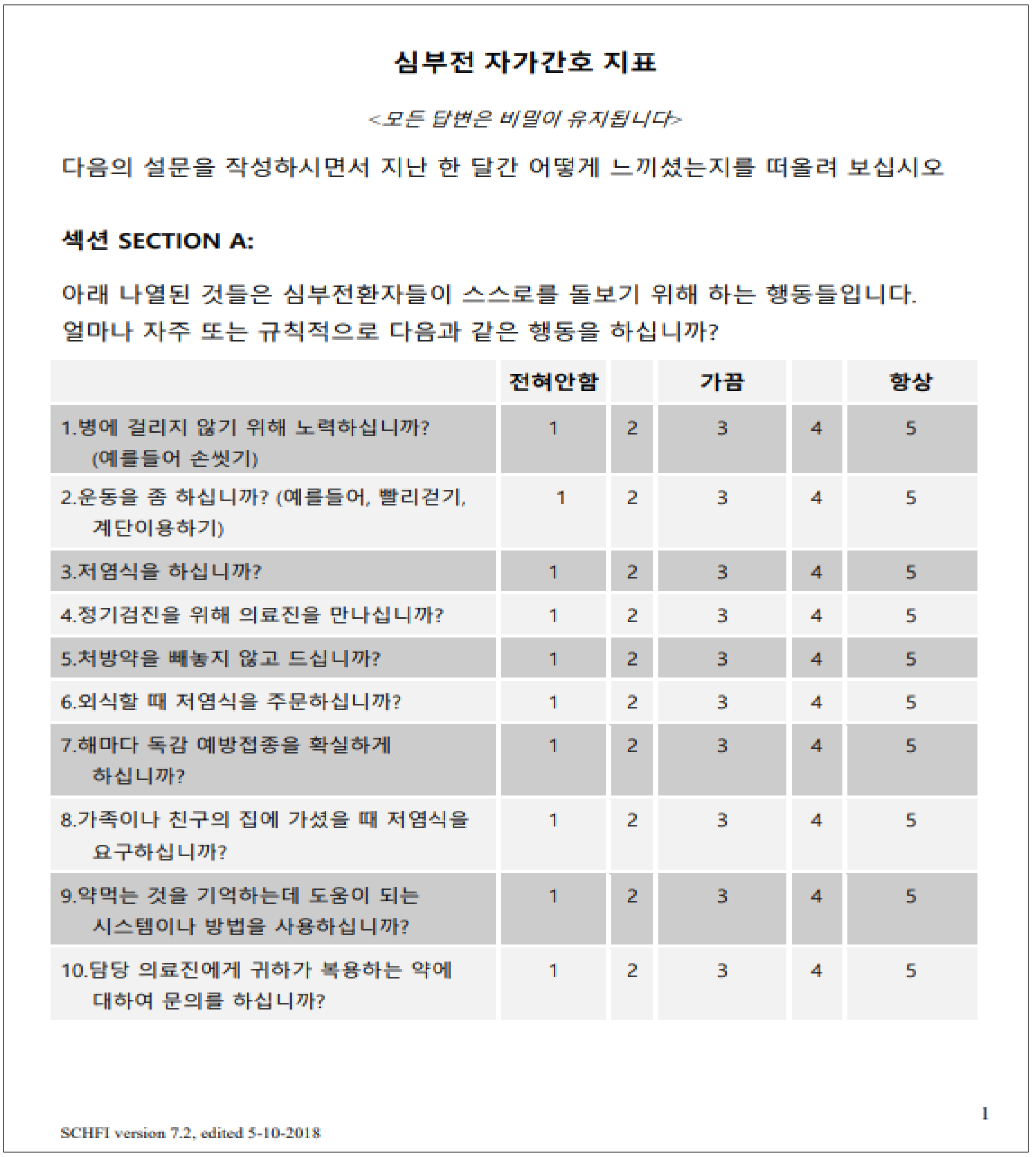
내 답변

보호자의 휴대 전화 번호 *

추후 후속 연구 정보 전달 및 심부전 환자와 돌봄 제공자(보호자) 상호 확인을 위해 연락처 정보를 입력 부탁합니다.

내 답변

Appendix 9. Survey questionnaire (continued)



심부전 자가간호 지표

<모든 답변은 비밀이 유지됩니다>

다음의 설문을 작성하시면서 지난 한 달간 어떻게 느끼셨는지를 떠올려 보십시오

섹션 SECTION A:

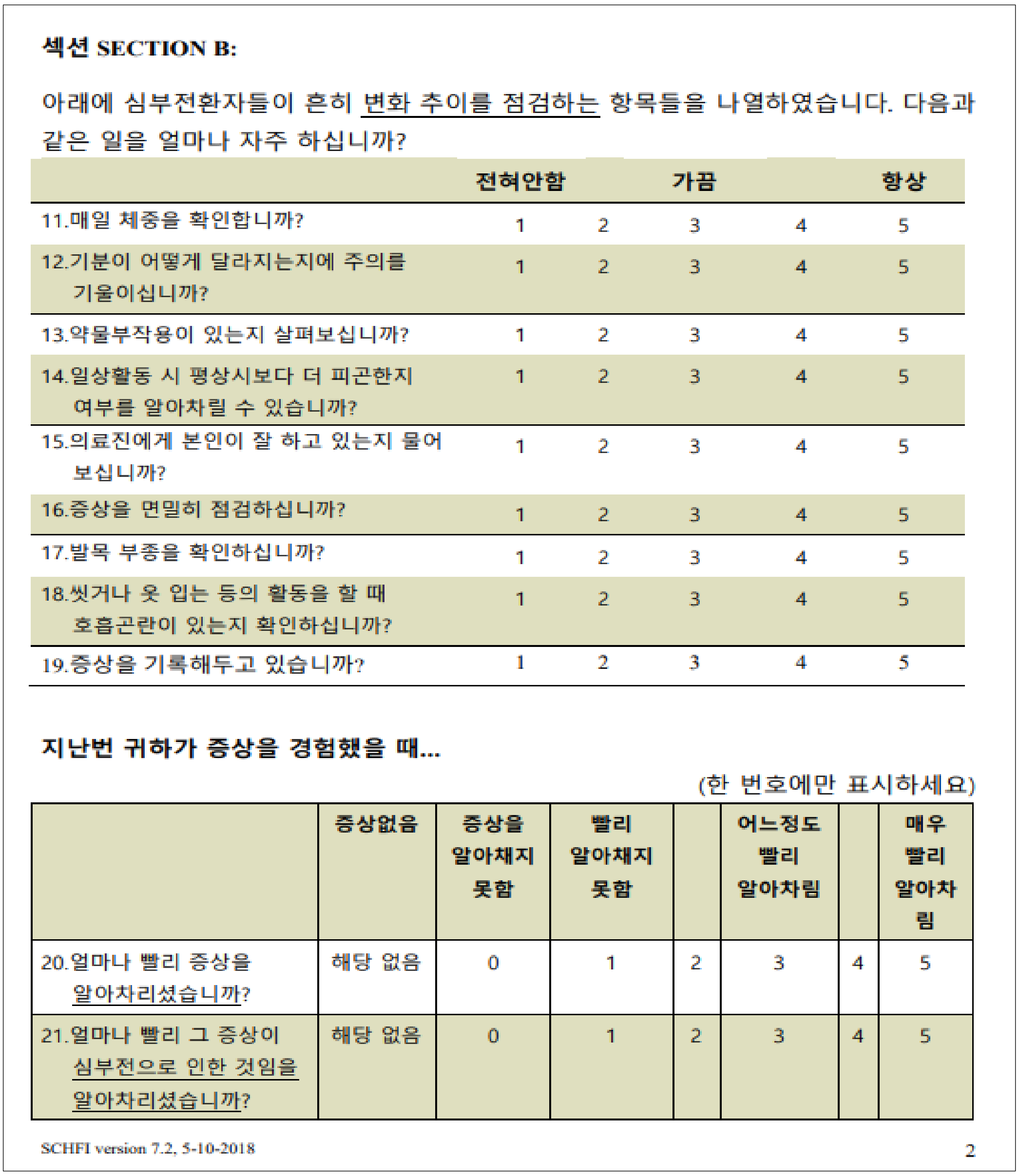
아래 나열된 것들은 심부전환자들이 스스로를 돌보기 위해 하는 행동들입니다.
얼마나 자주 또는 규칙적으로 다음과 같은 행동을 하십니까?

	전혀안함		가끔		항상
1.병에 걸리지 않기 위해 노력하십니까? (예를들어 손씻기)	1	2	3	4	5
2.운동을 좀 하십니까? (예를들어, 빨리걷기, 계단이용하기)	1	2	3	4	5
3.저염식을 하십니까?	1	2	3	4	5
4.정기검진을 위해 의료진을 만나십니까?	1	2	3	4	5
5.처방약을 빼놓지 않고 드십니까?	1	2	3	4	5
6.외식할 때 저염식을 주문하십니까?	1	2	3	4	5
7.해마다 독감 예방접종을 확실하게 하십니까?	1	2	3	4	5
8.가족이나 친구의 집에 가셨을 때 저염식을 요구하십니까?	1	2	3	4	5
9.약먹는 것을 기억하는데 도움이 되는 시스템이나 방법을 사용하십니까?	1	2	3	4	5
10.담당 의료진에게 귀하가 복용하는 약에 대하여 문의를 하십니까?	1	2	3	4	5

1

SCHFI version 7.2, edited 5-10-2018

Appendix 9. Survey questionnaire (continued)



섹션 SECTION B:

아래에 심부전환자들이 흔히 변화 추이를 점검하는 항목들을 나열하였습니다. 다음과 같은 일을 얼마나 자주 하십니까?

	전혀안함		가끔		항상
11.매일 체중을 확인합니까?	1	2	3	4	5
12.기분이 어떻게 달라지는지에 주의를 기울이십니까?	1	2	3	4	5
13.약물부작용이 있는지 살펴보십니까?	1	2	3	4	5
14.일상활동 시 평상시보다 더 피곤한지 여부를 알아차릴 수 있습니까?	1	2	3	4	5
15.의료진에게 본인이 잘 하고 있는지 물어 보십니까?	1	2	3	4	5
16.증상을 면밀히 점검하십니까?	1	2	3	4	5
17.발목 부종을 확인하십니까?	1	2	3	4	5
18.씻거나 옷 입는 등의 활동을 할 때 호흡곤란이 있는지 확인하십니까?	1	2	3	4	5
19.증상을 기록해두고 있습니까?	1	2	3	4	5

지난번 귀하가 증상을 경험했을 때...

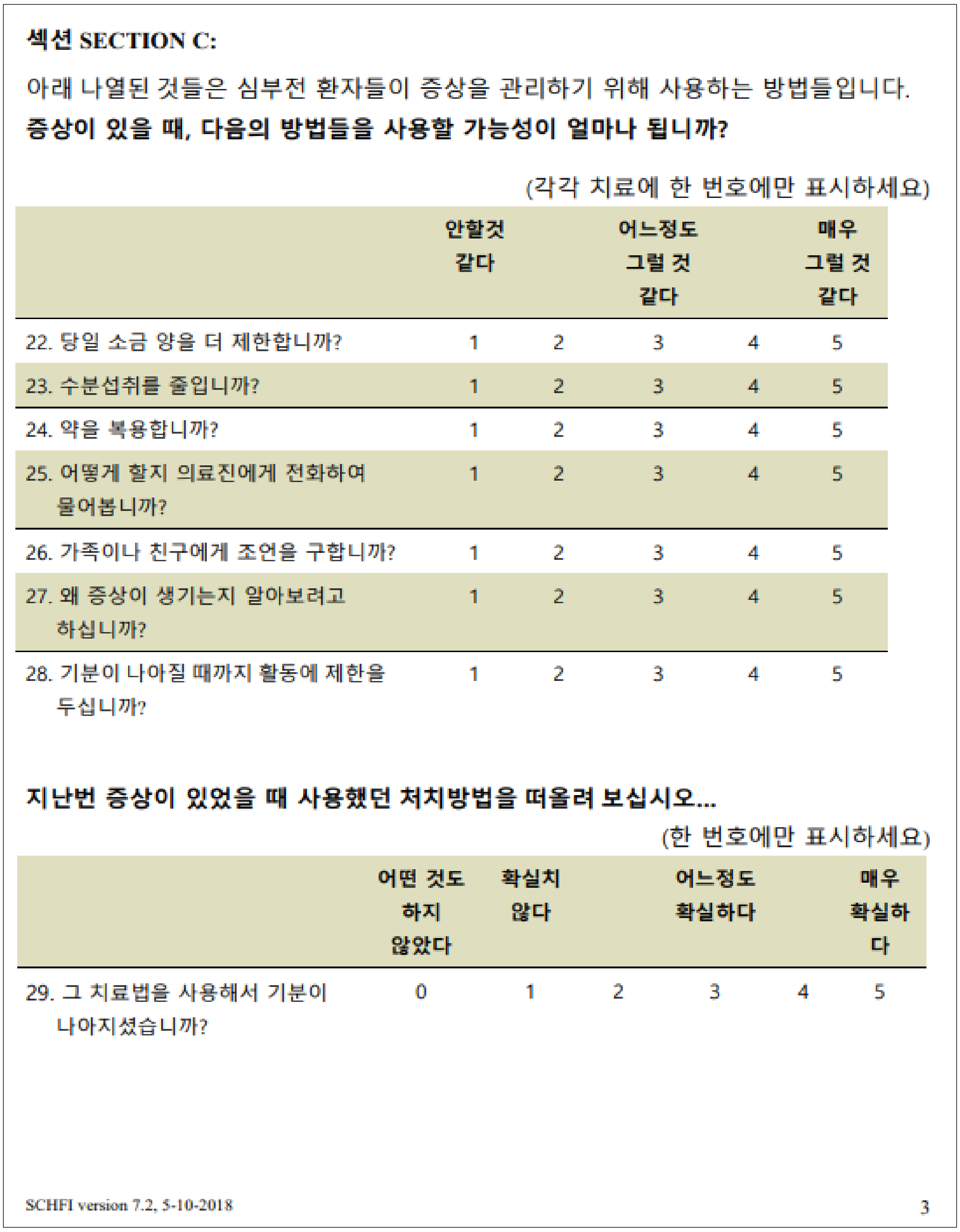
(한 번호에만 표시하세요)

	증상없음	증상을 알아채지 못함	빨리 알아채지 못함		어느정도 빨리 알아차림		매우 빨리 알아차림
20.얼마나 빨리 증상을 알아차리셨습니까?	해당 없음	0	1	2	3	4	5
21.얼마나 빨리 그 증상이 심부전으로 인한 것임을 알아차리셨습니까?	해당 없음	0	1	2	3	4	5

SCHFI version 7.2, 5-10-2018

2

Appendix 9. Survey questionnaire (continued)



섹션 SECTION C:

아래 나열된 것들은 심부전 환자들이 증상을 관리하기 위해 사용하는 방법들입니다.

증상이 있을 때, 다음의 방법들을 사용할 가능성이 얼마나 됩니까?

(각각 치료에 한 번호에만 표시하세요)

	안할것 갈다		어느정도 그럴 것 같다		매우 그럴 것 같다
22. 당일 소금 양을 더 제한합니까?	1	2	3	4	5
23. 수분섭취를 줄입니까?	1	2	3	4	5
24. 약을 복용합니까?	1	2	3	4	5
25. 어떻게 할지 의료진에게 전화하여 물어봅니까?	1	2	3	4	5
26. 가족이나 친구에게 조언을 구합니까?	1	2	3	4	5
27. 왜 증상이 생기는지 알아보려고 하십니까?	1	2	3	4	5
28. 기분이 나아질 때까지 활동에 제한을 두십니까?	1	2	3	4	5

지난번 증상이 있었을 때 사용했던 처치방법을 떠올려 보십시오...

(한 번호에만 표시하세요)

	어떤 것도 하지 않았다	확실치 않다		어느정도 확실하다		매우 확실하다
29. 그 치료법을 사용해서 기분이 나아지셨습니까?	0	1	2	3	4	5

SCHFI version 7.2, 5-10-2018

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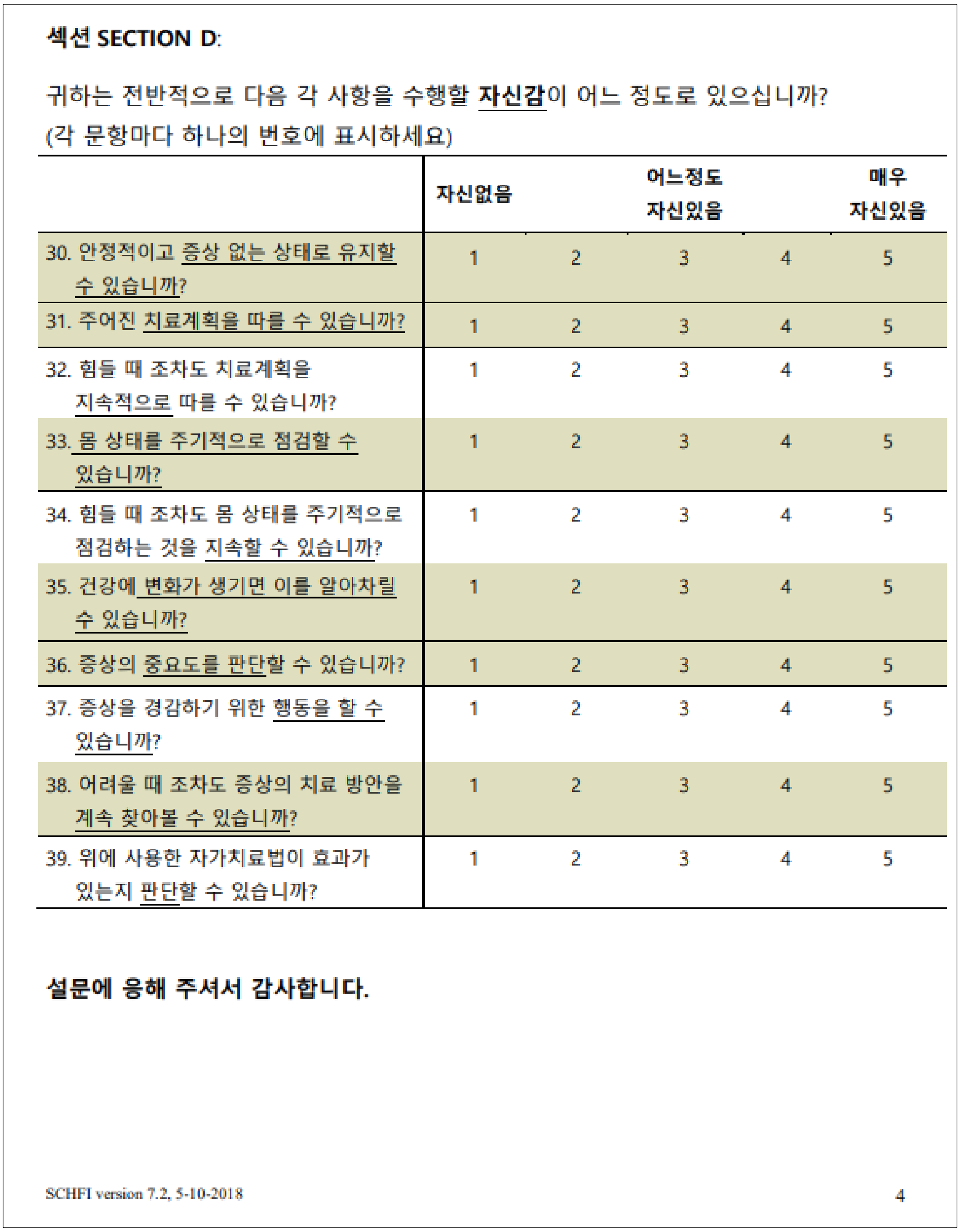
Appendix 9. Survey questionnaire (continued)



섹션 SECTION D:

귀하는 전반적으로 다음 각 사항을 수행할 **자신감**이 어느 정도로 있으십니까?
(각 문항마다 하나의 번호에 표시하세요)

	자신없음		어느정도 자신있음		매우 자신있음
30. 안정적이고 증상 없는 상태로 유지할 수 있습니까?	1	2	3	4	5
31. 주어진 치료계획을 따를 수 있습니까?	1	2	3	4	5
32. 힘들 때 조차도 치료계획을 지속적으로 따를 수 있습니까?	1	2	3	4	5
33. 몸 상태를 주기적으로 점검할 수 있습니까?	1	2	3	4	5
34. 힘들 때 조차도 몸 상태를 주기적으로 점검하는 것을 지속할 수 있습니까?	1	2	3	4	5
35. 건강에 변화가 생기면 이를 알아차릴 수 있습니까?	1	2	3	4	5
36. 증상의 중요도를 판단할 수 있습니까?	1	2	3	4	5
37. 증상을 경감하기 위한 행동을 할 수 있습니까?	1	2	3	4	5
38. 어려울 때 조차도 증상의 치료 방안을 계속 찾아볼 수 있습니까?	1	2	3	4	5
39. 위에 사용한 자가치료법이 효과가 있는지 판단할 수 있습니까?	1	2	3	4	5

설문에 응해 주셔서 감사합니다.

Appendix 9. Survey questionnaire (continued)

심부전 자가간호지표에 대한 보호자의 기여(v.2)

<모든 답변은 비밀이 유지됩니다>

귀하가 심부전 환자를 위해 하셨던 것이 무엇인지 알 수 있도록, 다음 질문에 대하여 답변해 주시기를 부탁드립니다. 정답이나 오답은 없습니다.

섹션 A:

귀하께서 돌보시는 심부전 환자에게 이러한 것들을 얼마나 자주 권유하셨습니까?
(또는, 돌보시는 심부전 환자가 아래 일을 할 수 없을 경우, 귀하는 얼마나 자주 이 일들을 하셨습니까).

	전혀 안함		가끔 함		항상 함
1. 아프지 않도록 노력하십니까? (예: 손씻기)	1	2	3	4	5
2. 운동을 좀 하십니까? (예: 활기차게 걷기, 계단이용하기)	1	2	3	4	5
3. 저염식으로 먹습니까?	1	2	3	4	5
4. 정기검진을 위해 의료진을 만나십니까?	1	2	3	4	5
5. 처방약을 빼놓지 않고 드십니까?	1	2	3	4	5
6. 외식할 때 저염식을 주문하십니까?	1	2	3	4	5
7. 매년 독감 예방접종을 했는지 확인 하십니까?	1	2	3	4	5
8. 가족이나 친구를 방문할 때 저염식을 요청하십니까?	1	2	3	4	5
9. 약먹는 것을 기억하는데 도움이 되는 시스템이나 방법을 사용하십니까?	1	2	3	4	5
10. 담당 의료진에게 환자가 복용하는 약에 대하여 문의하십니까?	1	2	3	4	5

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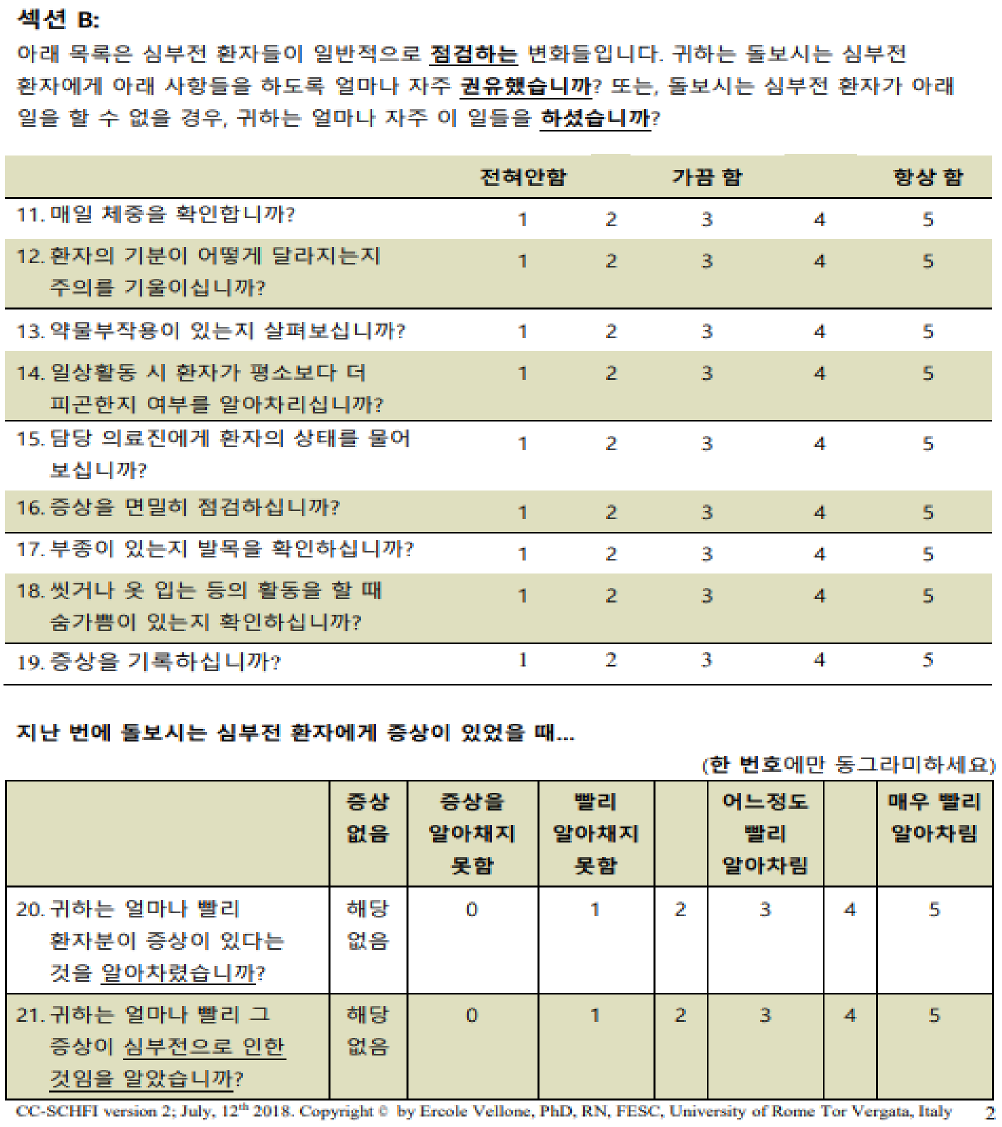
Appendix 9. Survey questionnaire (continued)



섹션 B:

아래 목록은 심부전 환자들이 일반적으로 **점검하는** 변화들입니다. 귀하는 돌보시는 심부전 환자에게 아래 사항들을 하도록 얼마나 자주 **권유했습니까**? 또는, 돌보시는 심부전 환자가 아래 일을 할 수 없을 경우, 귀하는 얼마나 자주 이 일들을 **하셨습니까**?

	전혀안함		가끔 함		항상 함
11. 매일 체중을 확인합니까?	1	2	3	4	5
12. 환자의 기분이 어떻게 달라지는지 주의를 기울이십니까?	1	2	3	4	5
13. 약물부작용이 있는지 살펴보십니까?	1	2	3	4	5
14. 일상활동 시 환자가 평소보다 더 피곤한지 여부를 알아차리십니까?	1	2	3	4	5
15. 담당 의료진에게 환자의 상태를 물어 보십니까?	1	2	3	4	5
16. 증상을 면밀히 점검하십니까?	1	2	3	4	5
17. 부종이 있는지 발목을 확인하십니까?	1	2	3	4	5
18. 씻거나 옷 입는 등의 활동을 할 때 숨가쁨이 있는지 확인하십니까?	1	2	3	4	5
19. 증상을 기록하십니까?	1	2	3	4	5

지난 번에 돌보시는 심부전 환자에게 증상이 있었을 때...

(**한 번호**에만 동그라미하세요)

	증상 없음	증상을 알아채지 못함	빨리 알아채지 못함		어느정도 빨리 알아차림		매우 빨리 알아차림
20. 귀하는 얼마나 빨리 환자분이 증상이 있다는 것을 알아차렸습니까?	해당 없음	0	1	2	3	4	5
21. 귀하는 얼마나 빨리 그 증상이 심부전으로 인한 것임을 알았습니까?	해당 없음	0	1	2	3	4	5

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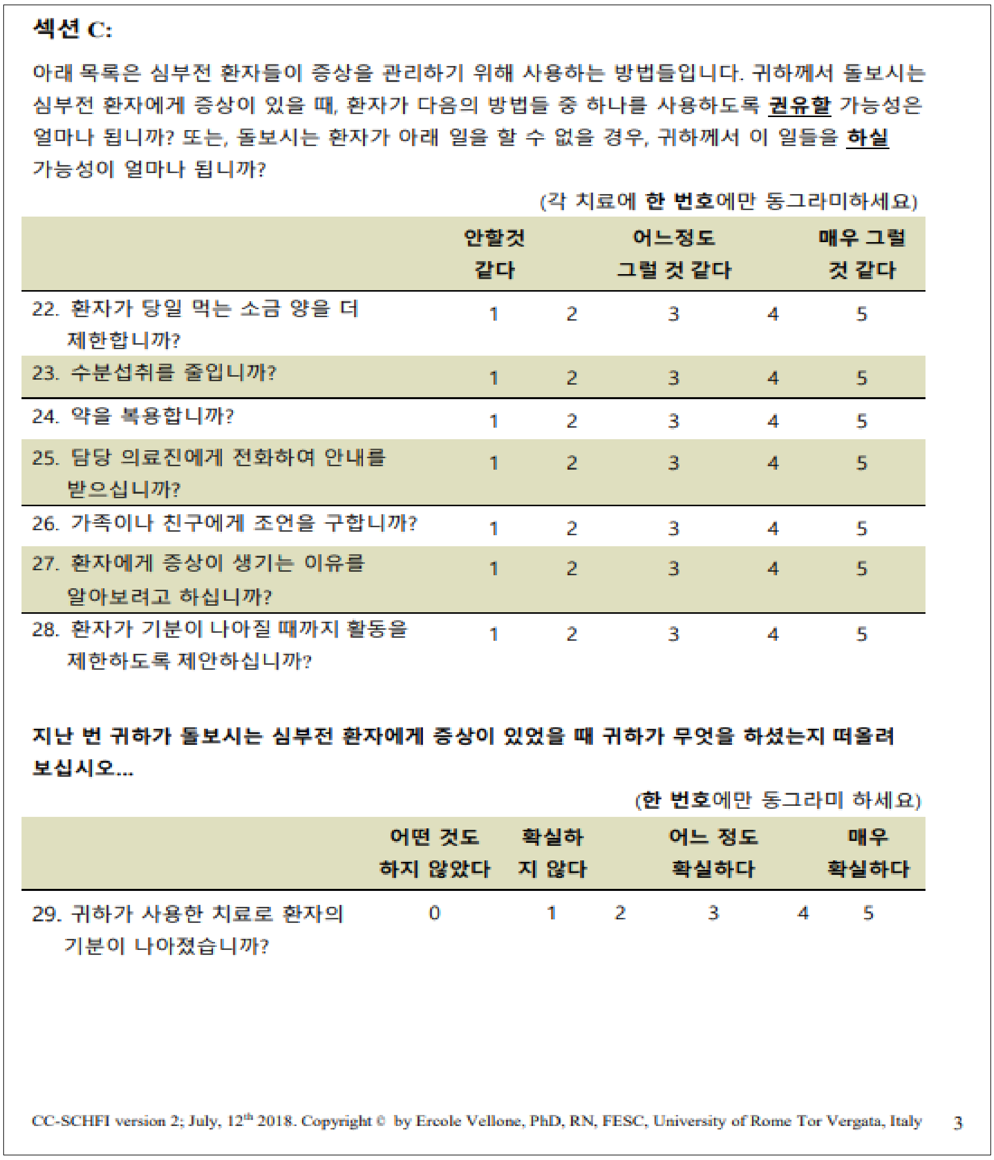
Appendix 9. Survey questionnaire (continued)



섹션 C:

아래 목록은 심부전 환자들이 증상을 관리하기 위해 사용하는 방법들입니다. 귀하께서 돌보시는 심부전 환자에게 증상이 있을 때, 환자가 다음의 방법들 중 하나를 사용하도록 **권유할** 가능성은 얼마나 됩니까? 또는, 돌보시는 환자가 아래 일을 할 수 없을 경우, 귀하께서 이 일들을 **하실** 가능성이 얼마나 됩니까?

(각 치료에 **한 번호**에만 동그라미하세요)

	안할것 같다		어느정도 그럴 것 같다		매우 그럴 것 같다
22. 환자가 당일 먹는 소금 양을 더 제한합니까?	1	2	3	4	5
23. 수분섭취를 줄입니까?	1	2	3	4	5
24. 약을 복용합니까?	1	2	3	4	5
25. 담당 의료진에게 전화하여 안내를 받으십니까?	1	2	3	4	5
26. 가족이나 친구에게 조언을 구합니까?	1	2	3	4	5
27. 환자에게 증상이 생기는 이유를 알아보려고 하십니까?	1	2	3	4	5
28. 환자가 기분이 나아질 때까지 활동을 제한하도록 제안하십니까?	1	2	3	4	5

지난 번 귀하가 돌보시는 심부전 환자에게 증상이 있었을 때 귀하가 무엇을 하셨는지 떠올려 보십시오...

(**한 번호**에만 동그라미 하세요)

	어떤 것도 하지 않았다	확실하지 않다		어느 정도 확실하다		매우 확실하다
29. 귀하가 사용한 치료로 환자의 기분이 나아졌습니까?	0	1	2	3	4	5

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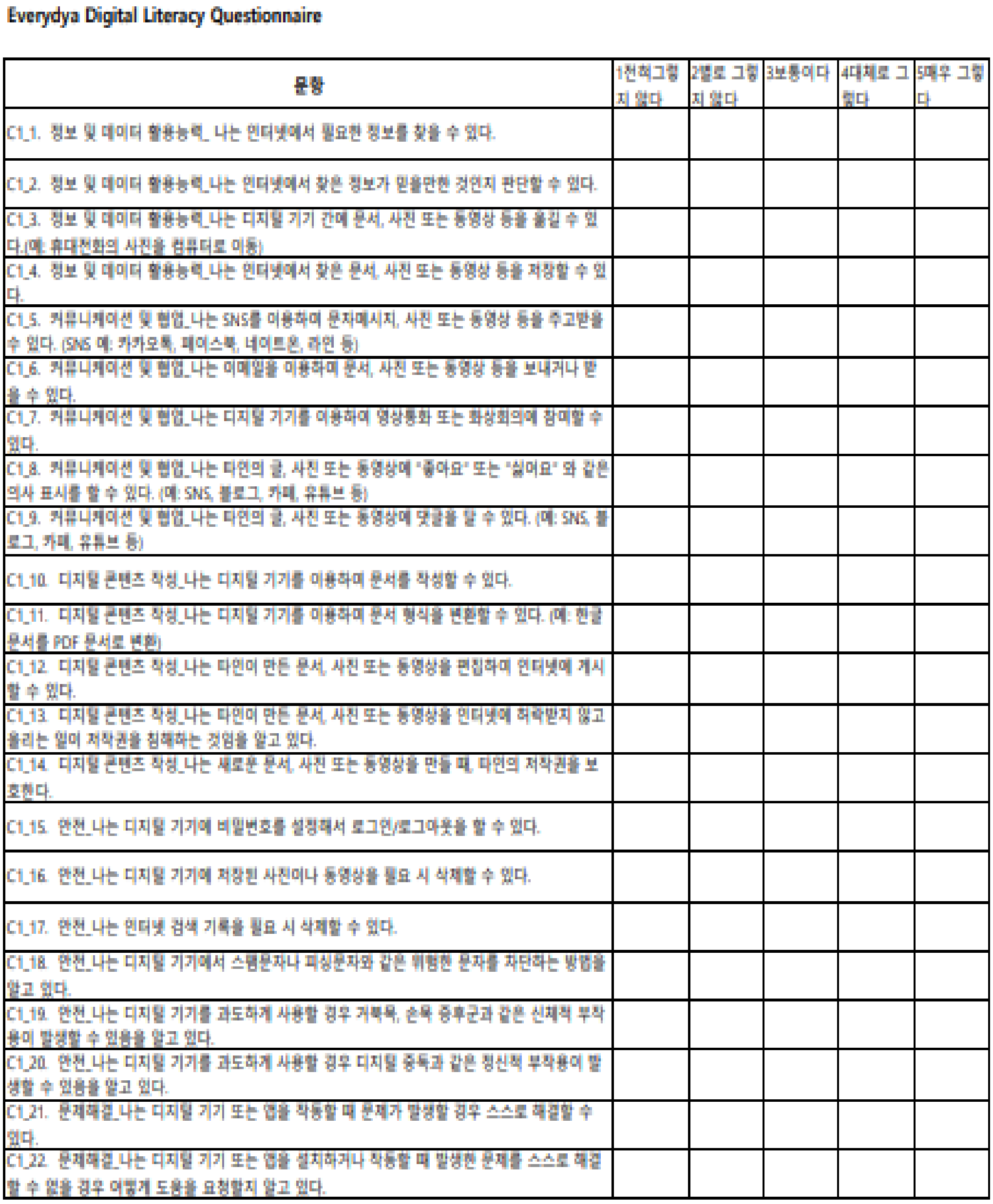
Appendix 9. Survey questionnaire (continued)



Everydya Digital Literacy Questionnaire

문항	1전혀그렇지 않다	2별로 그렇지 않다	3보통이다	4대체로 그렇다	5매우 그렇다
C1_1. 정보 및 데이터 활용능력_ 나는 인터넷에서 필요한 정보를 찾을 수 있다.					
C1_2. 정보 및 데이터 활용능력_나는 인터넷에서 찾은 정보가 믿을만한 것인지 판단할 수 있다.					
C1_3. 정보 및 데이터 활용능력_나는 디지털 기기 간에 문서, 사진 또는 동영상 등을 옮길 수 있다.(예: 휴대전화의 사진을 컴퓨터로 이동)					
C1_4. 정보 및 데이터 활용능력_나는 인터넷에서 찾은 문서, 사진 또는 동영상 등을 저장할 수 있다.					
C1_5. 커뮤니케이션 및 협업_나는 SNS를 이용하여 문자메시지, 사진 또는 동영상 등을 주고받을 수 있다. (SNS 예: 카카오톡, 페이스북, 네이트온, 라인 등)					
C1_6. 커뮤니케이션 및 협업_나는 이메일을 이용하여 문서, 사진 또는 동영상 등을 보내거나 받을 수 있다.					
C1_7. 커뮤니케이션 및 협업_나는 디지털 기기를 이용하여 영상통화 또는 화상회의에 참여할 수 있다.					
C1_8. 커뮤니케이션 및 협업_나는 타인의 글, 사진 또는 동영상에 "좋아요" 또는 "싫어요" 와 같은 의사 표시를 할 수 있다. (예: SNS, 블로그, 카페, 유튜브 등)					
C1_9. 커뮤니케이션 및 협업_나는 타인의 글, 사진 또는 동영상에 댓글을 달 수 있다. (예: SNS, 블로그, 카페, 유튜브 등)					
C1_10. 디지털 콘텐츠 작성_나는 디지털 기기를 이용하여 문서를 작성할 수 있다.					
C1_11. 디지털 콘텐츠 작성_나는 디지털 기기를 이용하여 문서 형식을 변환할 수 있다. (예: 한글 문서를 PDF 문서로 변환)					
C1_12. 디지털 콘텐츠 작성_나는 타인이 만든 문서, 사진 또는 동영상을 편집하여 인터넷에 게시할 수 있다.					
C1_13. 디지털 콘텐츠 작성_나는 타인이 만든 문서, 사진 또는 동영상을 인터넷에 허락받지 않고 올리는 일이 저작권을 침해하는 것임을 알고 있다.					
C1_14. 디지털 콘텐츠 작성_나는 새로운 문서, 사진 또는 동영상을 만들 때, 타인의 저작권을 보호한다.					
C1_15. 안전_나는 디지털 기기에 비밀번호를 설정해서 로그인/로그아웃을 할 수 있다.					
C1_16. 안전_나는 디지털 기기에 저장된 사진이나 동영상을 필요 시 삭제할 수 있다.					
C1_17. 안전_나는 인터넷 검색 기록을 필요 시 삭제할 수 있다.					
C1_18. 안전_나는 디지털 기기에서 스팸문자나 피싱문자와 같은 위험한 문자를 차단하는 방법을 알고 있다.					
C1_19. 안전_나는 디지털 기기를 과도하게 사용할 경우 거북목, 손목 증후군과 같은 신체적 부작용이 발생할 수 있음을 알고 있다.					
C1_20. 안전_나는 디지털 기기를 과도하게 사용할 경우 디지털 중독과 같은 정신적 부작용이 발생할 수 있음을 알고 있다.					
C1_21. 문제해결_나는 디지털 기기 또는 앱을 작동할 때 문제가 발생할 경우 스스로 해결할 수 있다.					
C1_22. 문제해결_나는 디지털 기기 또는 앱을 설치하거나 작동할 때 발생한 문제를 스스로 해결할 수 없을 경우 어떻게 도움을 요청할지 알고 있다.					

Appendix 9. Survey questionnaire (continued)

Korean version of The Mutuality Scale of the Family Caregiving Inventory

번호	문항	답변				
		1. 전혀 그렇지 않다	2. 약간 그렇다	3. 어느 정도 그러하다	4. 꽤 그러하다	5. 매우 그러하다
1	우리는 서로 의견이 일치한다.					
2	우리는 서로 가깝게 느낀다					
3	우리는 함께 지내온 일들을 이야기하는 것이 즐겁다.					
4	우리는 상대방이 해준일에 대해 고마움을 표현한다					
5	우리는 서로에게 애착이 있다					
6	우리는 서로를 도와준다.					
7	우리는 함께 앉아서 이야기하는 것을 좋아한다					
8	우리는 서로를 사랑한다.					
9	우리는 서로 동일한 가치관을 공유한다.					
10	필요할 때, 우리는 서로에게 위안이 되어 준다.					
11	우리는 함께 웃을 때가 많다.					
12	우리는 서로에게 속마음을 털어놓는다.					
13	우리는 마음으로 서로를 응원해 준다.					
14	우리는 서로 함께 하는 시간을 즐거워한다.					
15	우리는 서로에게 따뜻하게 대해준다.					

KOREAN ABSTRACT

심부전 환자와 돌봄제공자의 디지털 문해력, 상호관계성과 자가관리: 다이애딕 접근

김호곤

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인구의 급속한 고령화로 전세계적으로 심부전의 유병률은 빠르게 증가하고 있다. 아울러, 심부전 환자의 고령화와 디지털 헬스 기반 자가관리 적용이 광범위하게 확대되면서 심부전 환자의 자가관리 수행이 저하되고 있다. 이에 따라 심부전 환자의 자가 관리를 지원하는 돌봄 제공자의 역할과 환자와 돌봄 제공자의 상호 관계성이 중요해지고, 환자와 돌봄 제공자의 디지털 문해력 및 상호관계성을 이해하는 데 중점을 두는 연구가 주목받고 있습니다. 하지만, 환자와 돌봄 제공자의 관계 특성이 서구권과는 차이가 나는 동아시아, 한국을 배경으로 아직 이에 대한 관심과 이해가 부족하다. 따라서, 이 연구는 심부전 환자와 돌봄 제공자의 디지털 문해력, 상호 관계성, 심부전 자가

관리의 관계 역학을 파악하고, 행위자-파트너 상호의존 모델(Actor-Partner Interdependent Model, APIM)을 사용하여 환자와 돌봄 제공자의 영향력과 차이점을 파악하고자 한다.

본 서술적 횡단 연구는 한국 도서산간 지방에 위치한 3차 병원에서 심부전 환자와 돌봄 제공자를 한 쌍의 다이애드로 연결하여 연구를 수행했다. 본 연구에는 102쌍의 심부전 환자와 그 돌봄 제공자 다이애드가 참여했으며, 디지털 문해력, 상호관계성, 심부전 자가 관리, 돌봄 제공자의 심부전 자가 관리에 대한 기여도, 환자와 돌봄 제공자의 관계 유형, 각 대상자의 나이, 성별, 학력, 경제 수준, 고용 상태 등 인구통계학적 정보를 포함한 자료를 수집 후 분석했다. 통계 분석은 SPSS 버전 26.0과 AMOS 버전 26.0의 APIM을 사용하여 실행되었다.

심부전 환자(여성: 53.9%)의 평균 연령은 78.90세(SD =9.01)였고, 돌봄 제공자(여성: 65.7%)의 평균 연령은 58.97세(SD= 13.07)였다. 환자와 돌봄 제공자 관계형태는 돌봄 제공자로 성인 자녀가 63%로 가장 많았고, 배우자(32.4%)가 그 뒤를 이었다. 심부전 환자와 돌봄 제공자의 디지털 문해력 수준은 각각 31.93 (SD=20.95), 77.75 (SD=30.75) 였다. 상호관계성 수준은 심부전 환자의 경우 2.84 (SD=0.74), 돌봄 제공자의 경우 2.65 (SD=0.87) 였다. 심부전 환자의 자기 관리와 돌봄 제공자의 심부전 자기관리에 대한 기여도는 부적절한 수준(70점 미만)인 것으로 나타났다.

다이애딕 내에서 디지털 문해력은 행위자 효과(Actor effect)로만 심부전 자기 관리와 돌봄제공자의 심부전 자기관리에 대한 기여도에 영향을 미쳤다. 돌봄제공자의 상호관계성은 행위자 효과로서 돌봄 제공자의 심부전 자가 관리에 대한 기여도에 영향을 미쳤으며, 파트너 효과(Partner effect)로서 심부전 자가 관리 유지에 영향을 미쳤다. 반면에 심부전 환자의 상호관계성은 오직 행위자 효과로만 심부전 자기 관리의 증상 지각에만 영향을 미쳤다.

본 연구는 디지털 건강 기반 심부전 자가 관리가 점점 더 널리 보급됨에 따라 뚜렷한 고령화특성을 가진 심부전 환자의 디지털 문해력을 확인하여 심부전 환자의 자가 관리를 가장 잘 촉진하는 방법에 대한 귀중한 통찰력을 제공한다. 또한, 본 연구 결과는 심부전 자가 관리에서 돌봄제공자의 중요성을 드러내고 효과적인 돌봄제공자 역할 배치 및 개입 접근법에 대한 근거를 제공한다.

핵심되는 말: 디지털 문해력, 상호관계성, 자가관리, 심부전, 돌봄제공자, 환자, 다이대딕 접근, 자기-상대방 상호의존 모형