

# Nurses' support of hospitalized patients' self- management

Caroline E.M. Otter

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# Nurses' support of hospitalized patients' self-management

**Verpleegkundige ondersteuning van het zelfmanagement  
van patiënten tijdens opname in het ziekenhuis**

(met een samenvatting in het Nederlands)

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# General introduction

*'Sometimes I have a bit of shortness of breath, the general practitioner gave me a puffer. But now the nurse said: 'You have to use a nebulizer'. I did not want this and said ' That's not necessary, I do not use that stuff'. But she stood her ground. I pretended to use the nebulizer but put the nebulizer next to me. I brought my puffer with me, I used it a few times.'*

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(Patient, admitted for abdominal surgery, describing a situation during hospitalization, see Chapter 1).

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The patient in this example had found his way of coping with shortness of breath and wanted to continue doing so during hospitalization. The nurse seemed to pay little attention to the patient's preferences. The physician's order was more important. In the end, the patient pretended to comply with the nurse, but he stuck to his method. Here, the nurse seems to miss the opportunity to connect with the patient's experiences, discuss the patient's self-management behavior, and help the patient to achieve his own goals regarding his shortness of breath, during hospitalization and after discharge, at home.

This example shows that hospitalized patients want to be in control and want caregivers to recognize that they have specific and useful knowledge about their condition, as experts by experience. Attention to patients' self-management, to how they manage the impact of their disease(s), creates the opportunity to give the patients' own experience a place in the care provision.<sup>1</sup> This is in line with the new thinking about health as 'the ability to adapt and to self-manage in the face of social, physical, and emotional challenges' rather than the absence of disease.<sup>2</sup> In addition to efforts to cure the disease, healthcare professionals must empower patients to self-manage the consequences of their condition.<sup>2</sup>

Self-management is seen as one of the solutions to meet the growing demand for care, due to an aging population and a longer life expectancy.<sup>1,3</sup> This growing demand, coupled with the shrinking workforce and the growing shortage of healthcare personnel<sup>4,5</sup>, necessitates changes in the healthcare system. Individuals need to be involved in their care and take a more active role in protecting their health and managing the consequences of their conditions.<sup>1</sup>

Self-management is central to the Dutch education profile of nurses.<sup>6</sup> Nurses are expected to focus on supporting the self-management of their patients. What this means for the nursing care in hospitals is not clear.

In this chapter, we describe the concept of self-management, the skills needed for effective self-management, and how self-management can be strengthened. In addition, we mention the nurse's role in self-management support, and we explain why we consider self-management support during hospitalization important. Finally, the aim of this thesis is presented.

## Self-management

The most commonly used definition of self-management is "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition".<sup>3</sup> This definition indicates that self-management focuses on the impact of chronic diseases<sup>3,7</sup>, but self-management can also relate to dealing with the consequences of acute health problems or engaging in health-promoting activities.<sup>8</sup>

Self-management is usually viewed as a subset of self-care, a broader concept, referring to the individual's ability to care for oneself and to perform activities necessary to achieve, maintain, or promote optimal health.<sup>7,8</sup> Dealing with the consequences of a disease is part of one's self-care, but it is also referred to as self-management.<sup>8</sup> The difference between, and the relationship among the concepts self-care and self-management are not clear<sup>7-9</sup> and both terms are often used interchangeably.<sup>10,11</sup>

Self-care is not a new concept, it has been present in communities since the beginning of humankind.<sup>12,13</sup> People have always taken action to ensure personal safety and develop strategies to address illness and other health challenges.<sup>12,13</sup> It was not until the late 20<sup>th</sup> century that self-care became an important concept in healthcare.<sup>12</sup> Chronic diseases increased and self-care was necessary to keep healthcare affordable and to bridge the gap between the supply and demand for care.<sup>7</sup> Also various social developments, such as self-help and women's movements provided a context that promoted the development of self-care.<sup>7,12,14</sup> Dorothea Orem linked self-care with nursing practice and presented her Self-Care Deficit Theory in 1971, providing the nursing discipline with a conceptual framework to guide practice and research.<sup>13,15</sup>

There are various definitions of self-care within the literature, developed over time and across disciplines.<sup>7,8,12,13</sup> Differences between definitions concern the degree to which self-care consists of individual activities for oneself or also of activities of family and friends; whether pharmaceuticals belong to self-care or not; if self-care is about maintaining life and health in the entire population or only in persons with a health condition; and if self-care can also be a preventive measure.<sup>9</sup>

According to Lorig, one of the first uses of the term 'self-management' showed up in a book about the rehabilitation of chronically ill children, written by Thomas Creer in 1976.<sup>16</sup> Lorig said Greer suggested that self-management indicated that the patient was an active partner in treatment.<sup>16</sup> Corbin and Strauss first identified the process of self-management and mentioned three tasks of self-management; medical management, such as taking medication; behavioral management, such as adapting lifestyle; and emotional management, such as dealing with emotions that arise from having a chronic disease.<sup>17,18</sup> Self-management is more than the adherence to a treatment plan, it can be seen as an ability that individuals use to gain control of their disease, rather than being controlled by it.<sup>8,19,20</sup>

For self-management to be effective, it should "encompass the ability to monitor one's condition and to effect the cognitive, behavioral and emotional response necessary to maintain a satisfactory quality of life".<sup>3</sup> Self-management outcomes include a range of indicators, from knowledge, skills, independence and 'being yourself and not the condition', to achieving optimal physical, emotional and social health and having positive social networks, including the relationship with health professionals.<sup>20</sup> Some patients prefer not to be involved in their healthcare and prefer a passive role, due to several reasons, such as being socialized to the traditional patient role or feeling inadequate.<sup>13</sup> Various descriptions of the concept of self-management are given in the literature.<sup>1,8,9,18</sup> The differences mainly have to do with the population for which self-management is relevant, the total disease population or only for persons living with chronic disease(s); and whether self-management should be performed by the individuals themselves, or whether relevant professionals and community members can also be involved.<sup>8,9</sup> In Riegel's middle-range theory of self-care in chronic diseases, the concept of self-management covers a narrower area. This theory distinguishes between activities to improve well-being, preserve health, or maintain physical and emotional stability (self-care maintenance), activities to monitor signs and symptoms (self-care monitoring), and the evaluation of changes in signs and symptoms to determine if action is needed (self-care management).<sup>21</sup>

In this thesis, we use a definition of self-management, taken from the Dutch general nursing competency framework, based on the definition of Barlow (2002): 'Self-management is the individual's ability to prevent health problems wherever possible, and, when these still occur: to handle the symptoms, treatment, physical, psychological and social consequences of the health problems and the required lifestyle changes. This allows one to monitor and respond to their state of health in a way that contributes to a satisfying quality of life'.<sup>3,22</sup> Self-management does not mean that persons

should be self-reliant and always act independently and on their own. It also includes collaboration with family members, community, and healthcare professionals.<sup>7,8</sup> It is not important who carries out care activities, as long as it takes place within the control of the person.<sup>23</sup>

## Self-management skills

Self-management requires specific tasks from patients, such as being aware and measuring specific parameters and symptoms that indicate that action should be taken or a healthcare provider should be consulted.<sup>8,16</sup> In addition, patients sometimes have to change their lifestyle or have to deal with the emotional consequences of having a disease.<sup>16</sup> Controlling emotions such as anger, fear, frustration, and depression is also part of patients' self-management.<sup>16</sup> Five core self-management skills can be distinguished: problem-solving, including problem definition, generating possible solutions, solution implementation and evaluation of the results; decision-making in response to changes in the disease condition; finding and utilizing resources; partnering with healthcare providers; and making an action plan and carrying it out.<sup>16</sup> Patients should use all those skills and knowledge to tailor the self-management to their situation.<sup>16</sup> A central concept in self-management is self-efficacy: confidence to carry out a behavior necessary to reach a desired goal.<sup>16,24</sup> Enhanced self-efficacy is associated with positive changes in health behavior and health status.<sup>16</sup> Also an individual's health literacy is important. Patients with low health literacy, meaning having low skills to seek, understand, and utilize health information, require special attention from healthcare providers.<sup>25,26</sup>

## Self-management support

Self-management support is seen to be a strategy to enable patients to become active partners in their care<sup>1</sup> and is associated with concepts such as patient empowerment, patient-centeredness, and patient participation.<sup>27</sup> Self-management support focuses on the development of patients' skills to manage their health status<sup>28</sup> and stimulates patients to use their own skills, information, and professional services to take effective control over life.<sup>29</sup> This support can be viewed in two ways: as techniques and tools that help patients choose healthy behaviors and as a transformation of the patient-professional relationship into a collaborative partnership. It is described as

"a patient-centered collaborative approach to care that promotes patient activation, education, and empowerment".<sup>29,30</sup> Supporting self-management is an important part of the care for patients with chronic conditions, but the operationalization of this part remains underdeveloped and the integration into daily practice is difficult.<sup>31</sup> Of particular importance is the support of self-management in older patients because they often have multiple health problems, impaired hearing or vision, reduced mobility, and a lack of experience in dealing with healthcare professionals.<sup>32</sup>

Several programs have been developed to support community-dwelling patients in their self-management of chronic illness. These programs consist of a variety of interventions and are based on patient-perceived concerns and problems.<sup>11,28,33</sup> Patient education is a basic aspect of self-management support.<sup>11,28</sup> In addition, patients can be encouraged to independently monitor symptoms, to self-treatment in response to worsening symptoms or exacerbations, and to take more responsibility for medication and lifestyle choices.<sup>34</sup> Traditional verbal or written information facilitates increased understanding, but they do not ensure increased self-efficacy or behavior change. To improve self-management, patients must have self-efficacy and believe they can control their health situation.<sup>16</sup> Self-efficacy can be enhanced by skills mastery, modeling, interpretation of symptoms, and social persuasion.<sup>16</sup> Skills mastery stimulates getting people involved in behavior change, for instance by making action plans. Modeling can be done by using materials and methods that match the target group. Reinterpreting symptoms can help patients form alternative explanations as to the cause and lead to trying out new self-management behaviors. Social persuasion is one of the reasons that group education is often effective for behavior change. If members of the group are positive, other members are more likely to follow.<sup>16</sup> Behavioral change techniques, such as problem-solving, decision-making, and taking appropriate actions are also part of self-management programs.<sup>16,24,29</sup>

Programs to support patients' self-management can be general or tailored to individual patients, delivered on an individual basis and in group settings, and on varying duration, ranging from one session to programs lasting years.<sup>11</sup> These programs appear to be effective on outcomes such as quality of life, self-management behavior, clinical outcomes, and reduced healthcare costs, but there is a lack of evidence for the essential features of self-management programs and what works best for whom in which context.<sup>11,28,35</sup> An important result of self-management support is the change in culture and values of the health system towards one that supports the active involvement of individuals.<sup>29,30</sup> The effect of self-management supportive interventions was especially visible in interventions where health professionals were specifically trained to perform the intervention.<sup>36</sup>

The success of a self-management intervention should not only be measured from the patient's knowledge, clinical outcomes, and contacts with professionals but also from the patients' perspective with a focus on humanistic outcomes.<sup>34</sup> A successful self-management intervention demonstrates that patients have received information and support that is tailored and applicable to the patient.<sup>20</sup>

## Nurses' role in self-management support

Self-management support needs a multidisciplinary team approach<sup>24,30,37</sup>, but in current chronic care practice, nurses are the most important facilitators.<sup>31</sup> Because of their holistic perspective and their focus on health, nurses are the right people to play a leading role in the administration of self-management support.<sup>36</sup> Nurses find self-management support important but sometimes feel hindered in putting this concept into action.<sup>38</sup> There also seems to be a gap between their positive views of how self-management is part of their daily work and the reality of their practice.<sup>38</sup>

Providing self-management support requires a different view of the role and tasks of nurses. Nurses are traditionally trained to feel responsible *for* patients but need to shift to feel responsible *to* patients.<sup>7,39</sup> Nurses have to move away from a paternalistic role and involve patients as partners, who make their own decisions.<sup>31,39</sup> Depending on the patients' needs, nurses can take an expert role or take a more coaching role, but overall they should be facilitators and partners, not teachers or gatekeepers.<sup>7,40</sup> Nurses need to collaborate with patients and provide patients with information, expertise, and support to make the best possible decision based on the patient's priorities and goals.<sup>39</sup> The focus on patients' autonomy and own responsibility may come into conflict with nurses' values about good care. There can be tensions as to what 'good self-management' means: strictly following health advice or adapting advice to patients' own lives.<sup>20</sup> Sometimes there seems to be a lack of trust from nurses regarding patients' abilities to self-manage.<sup>10</sup>

## Self-management during hospitalization

Self-management is primarily focused on the tasks individuals must undertake to control or reduce the impact of their health condition when living at home.<sup>3,7,41</sup> However, self-management does not stop when a patient is hospitalized. It is a patient's 'daily task'.<sup>16</sup>

Hospitalization can be seen as one of the consequences of the health problem that an individual may experience and must manage. This applies to all patients, regardless of whether the reason for hospitalization is an acute or chronic illness. All patients must deal with the consequences of their disease(s). A lot of hospitalized patients have one or more chronic diseases<sup>42</sup>, which may or may not be the reason for the admission. Distinguishing between the support of patients with and without chronic diseases would be difficult and unethical.

Hospitalization can disrupt established self-management needs, expectations, and routines.<sup>18,43</sup> Therefore, it is important that inpatients' self-management is supported to maintain as much continuity in patients' self-management as possible.<sup>44,45</sup> A hospital admission is a great opportunity to give patients education in self-management skills.<sup>46</sup> Not all patients are willing to take part in an outpatient self-management program.<sup>46</sup> A program during a hospital stay is likely to reach a wider range of patients.<sup>46</sup> Ideally, patients manage their health conditions as much as possible and develop any necessary new self-management skills under the guidance of the hospital staff.<sup>45,47</sup>

This may reduce the need for home care after hospitalization. However, research showed that the hospital setting can be very disempowering, and teaching self-management skills is not part of regular hospital care.<sup>44,47</sup> Much time, effort, and resources are used to prepare a patient for discharge, but the focus is on providing information and not on ensuring patients' understanding, motivation, and skills.<sup>48</sup> Stimulating inpatients' self-management, as much and as soon as patients' health situation allows, can bridge the gap between hospital and home.<sup>44,45,49</sup>

## Aims and outline of the thesis

Self-management support should be at the heart of nursing. But what does this mean for nursing care in hospitals? How can nurses support hospitalized patients' self-management? If we cannot name this, "we cannot control it, finance it, research it, teach it, or put it into public policy" (free after Norma Lang in Clark<sup>50</sup>). The lack of clarity on this concept hinders the development of evidence-based interventions and the provision of adequate care. It also results in incomplete nursing education and a lack of healthcare policies in this area.

The general aims of this thesis are to clarify the concept of nurses' support to hospitalized patients and to investigate how nurses can support patients' self-management during hospitalization. Interventions to support inpatients' self-management are considered complex interventions, indicating that the intervention consists of several interacting components.<sup>51,52</sup> The first step in developing complex interventions is to create a deep understanding of the problem and get a clear picture of the problem as perceived by future recipients and providers.<sup>51</sup> In addition, it is important to identify the available evidence about existing interventions that address the problem.<sup>51</sup>

In the different chapters, we therefore address the following research questions:

- 1 What are older patients' perceptions concerning self-management during hospitalization?
- 2 What are nurses' perceptions of self-management and self-management support of older patients during hospitalization?
- 3 How do nurses support the self-management of hospitalized patients through verbal communication during routine nursing care?
- 4 Which interventions, presented in the current literature, can nurses use to support adult patients' abilities to self-manage during hospitalization?
- 5 What are the patients', nurses', and researchers' opinions on the appropriateness and completeness of the proposed conceptualization of nurses' support of hospitalized patients' self-management?

In the General discussion, we present the main findings of the studies and indicate what nurses can do to improve their support of patients' self-management during hospitalization, given the findings of this thesis.

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# 1

## Older patients' motives of whether or not to perform self-management during a hospital stay and influencing factors

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## Abstract

Semi-structured in-depth interviews (n=12) were held to explore older patients' motives of whether or not to perform self-management while hospitalized and to identify factors influencing self-management during hospitalization. These interviews were analyzed using the Quagol method. Self-management during hospitalization is operationalized as: collaboration with the nursing staff, having a proactive role, and having control over personal care. Three main themes, i.e., patients' abilities, expectations and opinions, as well as their perceived behavior of nurses were identified along with eight influencing factors. Results indicate that older inpatients perform self-management when they know that it impacts their recovery, when they perceive that a mistake is impending, when their own personal limits are exceeded, or when they are invited to self-manage by nurses.

This study provides several suggestions for developing interventions to support patients' self-management during hospitalization.

## Introduction

Self-management, a concept aiming at patients' active involvement in their care and own responsibility for their health<sup>1-3</sup>, is becoming increasingly important within healthcare. However, the amount of attention it is given varies between healthcare settings and patients' health problems.

Self-management has been conceptualized as a subset of self-care<sup>2,3</sup> and refers to the individual's ability to deal with the consequences of their disease in order to maintain a satisfactory quality of life.<sup>1</sup> Self-monitoring and symptom management are elements of self-management.<sup>3</sup> 'Self' must not be understood literally as it includes the collaboration with family, community, and healthcare professionals<sup>2,3</sup>. It is not important who provides the care, "but whether the care is self-managed i.e., ultimately within the control of the individual".<sup>4</sup> Self-management requires several basic skills such as problem solving, decision making, resource utilization, the formation of a patient-provider partnership, action planning, and self-tailoring.<sup>5</sup>

Different programs have been developed to support patients' abilities to manage their chronic illness.<sup>5-7</sup> These self-management programs consist of a variety of interventions such as education, advice and support for self-monitoring<sup>5-7</sup> and are based on patient perceived concerns and problems.<sup>5</sup> Age-specific programs are necessary because life contexts differ among age groups.<sup>8</sup> An important goal of self-management programs is the enhancement of self-efficacy or the belief in one's ability to achieve a desired behavior.<sup>5</sup>

Self-management support programs can be general or tailored to individual patients and are delivered in different ways such as on an individual basis and in group settings and with various durations ranging from one session lasting for ten minutes to programs with over 200 sessions or lasting for four years.<sup>6</sup> Self-management programs appear to be effective on outcomes such as quality of life, self-management behavior, clinical outcomes, and reduced healthcare costs.<sup>5,9,10</sup>

Self-management often refers to at-home management that concerns the day-to-day tasks that an individual must perform to control or reduce the impact of chronic conditions when living at home.<sup>1,2,5,8</sup> Self-management can also refer to managing the consequences of non-chronic health conditions<sup>3</sup> or managing diseases while hospitalized.

A hospital admission can be considered as one of the most disempowering situations that an individual can experience.<sup>11</sup> Hospitalized patients switch from being fully responsible for their own care into a passive consumer.<sup>11</sup> Upon discharge, they must return to being responsible and managing their own health problems.<sup>11</sup> Stimulating inpatients' self-management may bridge the gap between hospital and home, may improve patient outcomes, and may decrease unnecessary admissions to hospitals, especially for older individuals.<sup>12</sup> Examples of self-management in the hospital setting are patient's self-medication while hospitalized<sup>13</sup> and strategies that older patients use to prevent functional decline during hospitalization.<sup>14</sup> Limited research has been conducted on programs supporting self-management in hospitalized patients. It is unclear what patients need to manage their illness while admitted to a hospital. The first step to answer this question is to map older patients' perceptions concerning self-management during their hospital stay. Therefore, the aim of this study is to explore older patients' motives regarding whether or not to perform self-management while hospitalized and to identify the factors influencing patients' self-management.

# Methods

## Design

An exploratory qualitative design was conducted using semi-structured in-depth interviews and a content analysis in order to obtain insight into hospitalized patients' motives regarding self-management and influencing factors. In-depth interviews are well suited for identifying individual experiences about a specific topic<sup>15</sup>, and qualitative content analysis is an appropriate method for analysing personal viewpoints<sup>16</sup>, especially when existing theory or research literature on a phenomenon is limited<sup>17</sup>, as is the case in self-management within acute care.

## Sample

The sample consisted of 12 patients who had recently been discharged from a general teaching hospital in the Netherlands. The eligibility criteria included: living autonomously in the community prior to being hospitalized; being admitted to a surgical or a medical ward; age  $\geq 70$  years; able to understand and speak Dutch; a minimum hospital stay of three days and returning home after admission. Terminally ill patients, those suffering from dementia, and patients with intellectual disabilities, based on nurses' clinical judgement, were excluded. A purposive sampling approach was used to create diversity within the respondents on the following characteristics: ward, gender, and type of admission (acute or planned). Thirty-two patients who met the inclusion criteria were approached by staff nurses and informed about the study. Twenty patients declined to participate because they found themselves too ill or considered themselves unable to discuss the subject. These patients often declared that they were satisfied with the received nursing care and, therefore, had no information for the researcher.

## Data collection

Within several days after discharge, semi structured in-depth interviews were conducted. To create a safe environment, the interviews took place at the patients' homes. All interviews were conducted by the first author who was not involved in the patients' treatment.

There is no generally accepted description on how patients' self-management during hospitalization becomes visible and, for older persons in the Netherlands, the concept of self-management is not so common. Therefore, to prevent bias from different interpretations, the research team operationalized self-management during hospitalization as: to collaborate with the nursing staff, having a proactive role (perform own-initiative activities focusing on managing health conditions and taking care of oneself), and having control over personal care (giving direction for personal care based on own opinions about managing health conditions and taking care of oneself).

Interviews began with an open question about the patient's recent experience with nursing care and their collaboration with the nursing staff. The next questions focused on patients' experiences with and their appreciation of self-management during the hospital stay. Also, their perspective on nurses stimulating self-management was discussed. See Table 1 for the interview guide. Instead of the word 'self-management', the above-mentioned operationalization was used during the interviews. Interviews were audio recorded and transcribed verbatim while maintaining anonymity.

Prior to these interviews, two pilot interviews were held with people who share the same characteristics as the actual respondents. These pilot interviews did not result in changes in the interview guide. After each interview, the researcher reflected on her interview techniques.

After written informed consent was obtained, socio-demographic information (age) and information regarding the length of their hospital stay were obtained from patients' medical records. Data was collected from December 2015 until June 2016.

## Ethical considerations

The Regional Review Committee Patient-Related Research, Leeuwarden (ref RTPO 958a), and the hospitals' Medical Ethics Committee (nr. 2015-107) approved the study. Participants received written and oral information about it. All of the patients gave written informed consent.

Topic	Questions
Recent hospital admission/ experiences in nursing care	Ask for general appreciation nursing care. Continue talking about: collaboration with nurses; having control; active involvement; receiving information; possibility to ask questions; personal attention.
Personal experiences self-management	Ask for situations in which patient felt actively involved and in which patient felt not involved. Detailed questions: What happened exactly?; What does this mean to you?; What effect does it have?; How did the nurse respond?
Personal appreciation self-management	Ask for opinion and expectations on: having control over personal care; collaboration; active involvement; getting informed. Ask opinion about nurses' expectations with regards to self-management
Personal opinion self-management support	Ask what the nurse can do to stimulate self-management. Detailed questions: Why?; What can be the effect?; How does it work?; What is furthermore important?

TABLE 1 INTERVIEW GUIDE

**Key concepts**

- Degree of illness
- Knowledge
- Previous experiences in hospital
- Patient's preference/ personality
- Image of 'having control'
- Being part of a group
- Initiative of nurse
- Subject of 'having control'
- Setting
- Attitude of nurse
- Being equal /being dependent
- Workload nurse

TABLE 2 NONHIERARCHICAL LIST OF DATA- GENERATED SENSITIZING CONCEPTS

## Data analysis

A qualitative content analysis was conducted using the Qualitative Analysis Guide of Leuven (QUAGOL)<sup>18</sup>, which offers a comprehensive method to guide the process of qualitative data analysis and is inspired by the constant comparative method of the Grounded Theory Approach.<sup>19</sup> The process of content analysis using the QUAGOL method consist of two parts: (1) a thorough preparation of the coding process and (2) the actual coding process.<sup>18</sup> Atlas-ti (version 7.5 15) was used to support this process.

## Preparation of the coding process

Thorough preparation began with developing a framework for the actual coding process based on the interviews using only 'paper and pencil'.<sup>18</sup> Each interview was individually (re)read by members of the research team (CO, JH, EH, JK), and essential characteristics that contributed to a better understanding of inpatients self-management were listed in a brief abstract and abstracted afterwards to a more conceptual level, i.e., the key concepts. The appropriateness of the key concepts was verified and further developed by the researcher (CO) in two ways: (1) by rereading the interviews with the corresponding concepts in mind (a forward-backward movement) and (2) by comprising the brief abstracts and key concepts of the other interviews (a forward-backward movement between within-case and across-case analysis).<sup>18</sup>

## The coding process

In the second part of the Quagol method, the identified key concepts were discussed by the research team (CO, JH, EH, JK) in a consensus discussion and presented in a nonhierarchical list of 12 data-generated sensitizing concepts (Table 2).<sup>18</sup>

These concepts were used as preliminary codes in the actual coding process in the software program. All of the interviews were coded and analyzed by two researchers (CO en EH). The preliminary codes were critically examined, further developed, refined, supplemented, or merged into a broader concept. In this way, the preliminary codes were developed into a first draft of factors influencing inpatients' self-management. These influencing factor were verified by reading all of the interviews again. After Interview 9, no new information was ascertained. Finally, the research group discussed the

results and determined the final version of factors influencing inpatients' self-management. Patients' motives concerning whether or not to perform self-management were distilled from the influencing factors and placed in a model.

Trustworthiness was ensured by using a purposive sampling method and by continuing data collection until the data were saturated<sup>20,21</sup>; conducting a content analysis using Quago<sup>21,18</sup>; peer debriefing with discussions by the research team<sup>18,20,21</sup>; and providing a comprehensive description of the research process.<sup>20,21</sup>

## Results

The mean age (SD) of the patients was 78.7 years (8.8). The interviews were held 6-21 (median 7) days after discharge and lasted 17-50 (median 26) minutes. Patient characteristics are shown in Table 3.

Patient no	Gender	Ward	Admission sort	Length of hospital stay
1	m	medical	acute	3 days
2	m	medical	acute	7 days
3	f	surgical	planned	5 days
4	f	surgical	acute	5 days
5	f	medical	acute	4 days
6	m	surgical	planned	4 days
7	f	surgical	planned	12 days
8	f	surgical	planned	8 days
9	m	medical	acute	5 days
10	m	medical	acute	7 days
11	m	surgical	planned	4 days
12	m	medical	acute	10 days

**TABLE 3** PATIENTS CHARACTERISTICS

Based on the content analyses process, 12 data-generated sensitizing concepts that were identified as preliminary codes in the coding process resulted in three themes and eight influencing factors of inpatients' self-management (See Table 4). The patients often declared that they did not influence nursing care, however, various situations were mentioned in which patients were proactive and clearly indicated what they thought was necessary or desirable.

The results are shown below in two ways:

- A description of the identified themes and influencing factors;
- An explanation of the model (Figure 1) that shows inpatients' motives.

Themes	Influencing factors
Patients' abilities	Knowledge Physical and mental condition Personality
Patients' expectations and opinions	Opinions on self-management Expectations on nursing care Opinions of how to behave in a hospital
Perceived behavior of nurses	Being encouraged and invited Being heard, seen and support

**TABLE 4** INFLUENCING FACTORS AND THEMES FOUND

## Identified themes and influencing factors

Three primary themes were identified: patients' abilities; patients' expectations; and their perceived behavior of nurses (See also Table 4). In general, patients stated that they did not want to influence nursing care because they were satisfied with the care they received. Also they indicated that they had experienced little or no collaboration with the nursing staff. Sometimes patients acted pro-actively, mainly focused on their own mobility.

### Theme 1 | Patients' abilities

The question whether or not a patient performs self-management while hospitalized begins with a patient's abilities to self-manage. The following factors can be distinguished within this theme: patient's knowledge, condition, and personality.

#### Knowledge

Most patients indicated that they did not manage their own care because they did not have the necessary knowledge to do so. They had no knowledge about their treatment or the hospital procedures. Therefore, they did not consider themselves as collaborating partners in care. Patients declared that it is better to trust nurses, because they know what is going on and are the experts.

*'..... because you're always in a subordinate position. You are not the expert. And they are the professionals and I resign myself to this situation. I think 'what they say will be good.' (patient 6)*

Patients took an active role and performed some type of self-management when they knew the activity impacted their recovery. They were aware that staying active would be beneficial, therefore, they began mobilizing and performed their personal care whenever they could.

*'If I walked over the hallway the nurses said 'Are you walking again?' And I said 'Yes I'm walking, that has to be done! It will keep the bowels moving!' (patient 7)*

Only one patient stated that she always had control over her personal care, but she also allowed nurses to decide what should be done and when unless it was not going well. Several patients stated that they would intervene when a mistake could possibly happen. Patients mentioned that previous hospital admissions and knowing the hospital procedures can ensure that you know what is normal and when to intervene.

*(after being served the wrong diet) 'If I had known I was on a liquid diet, I would have told the lady so this morning.' (patient 4)*

#### Physical and mental condition

Patients stated that having a good physical and mental condition is a prerequisite for self-management during the hospital stay. They indicated that when you feel good and do not need much assistance, you can decide most things yourself. When your condition is poor, you will have less energy, and you will not quickly acquire knowledge yourself. Patients often mentioned that they were too sick for self-management as was illustrated in the following quote:

*'Also, you're not in an optimal condition. So, therefore, you don't have much need to be engaged in a serious debate with the nurses, such as 'Isn't this better?' or 'Shouldn't that be done otherwise?' (patient 6)*

#### Personality

Patients mentioned that their personality could also be an influencing factor. Some individuals are assertive and more pro-active in taking initiatives. Others are waiting for things to occur and do not take control over their personal care.

*'It's also caused by the people themselves, how they are, how you are. That's what I think.' (patient 3)*

However, patients indicated that there are limits to this 'wait and see policy'. If they really wanted things to change, they would act pro-actively. Patients intervened or declared they would intervene when personal limits were exceeded.

*'Well, I insisted on removing the infusion as soon as possible. Yes, I said, I find it terrible being so bound and having to ask everyone.' (patient 6)*

## Theme 2 | Patients expectations and opinions

The second theme was 'patients expectation and opinions'. Patient's self-management behavior seemed to be related to individuals' expectations and opinions regarding this behavior. The following factors can be distinguished: opinions on self-management, expectations on nursing care, and opinions on how to behave in a hospital.

### Patient's opinions regarding self-management

Most of the patients regarded self-management, operationalized as 'having control over personal care', as not necessary or as something that should not be necessary. They did not expect to collaborate with nurses or to exert influence over their personal care. Self-management was often considered as interfering with someone else's work as was illustrated by the following quote:

*'Often I'm looking at the infusion, thinking 'It's almost finished', and then I call for a nurse. That's not how it's supposed to be.'* (patient 4)

Some patients mentioned it was inappropriate to make demands or to be in control as a patient. Being pro-active and standing up for yourself were appreciated negatively.

*'He (another patient) commented on everything, really very assertive. Like 'I am the patient and I pay for this, and...'. I found it unpleasant. I don't want to be that way.'* (patient 6)

### Expectations of nursing care

Patients indicated that, overall, they received nursing care as expected, and stated that this was the reason why they did not exert influence over their personal care.

*'It happens naturally. They (the nurses) drop by, and you'll be dressed, and you'll get your meals, and then they go to the next. So the day passes.'* (patient 8)

In general, patients expected and experienced little or no collaboration with nurses. Patients found it difficult to visualize collaboration with nurses. It did not match their expectations regarding hospital admission.

*'In this regard, I find the word 'collaboration' difficult. You are a patient, you need to be taken care of, you need to recover. So, you're not in an equal position necessary for collaboration.'; 'I do not need it either.'* (patient 6)

In some circumstances, when patients noticed omissions or mistakes in care, such as receiving the wrong medication or a wrong diet, they intervened.

*'Food was brought, and there were mashed potatoes, though I had to be on a liquid diet. So, when I got mashed potatoes. I thought, 'This is not correct,' and I told the man, look, mashed potatoes, I cannot eat that.'* (patient 11)

### Opinions on how to behave in a hospital

While hospitalized, patients considered themselves as guests and adjusted themselves to the hospital procedures. They indicated that there cannot be self-control because the physician and the nurse are in control. Some patients mentioned they felt dependent and not in a position to indicate wishes and preferences. Patients also mentioned they had to wait for their turn to receive a nurse's attention. They did not want to be too critical and did not want to put their own needs above the needs of others. Also, other patients need care and nurses' attention as was addressed by the following patient.

*'I had to adapt myself to hospital rules. I was able to do it, but at home I'm in control'; 'I adapt myself because other people need more help than me.'* (patient 2)

## Theme 3 | Perceived behavior of nurses

Finally, the perceived behavior of nurses plays a role. Patients described nurses' behavior as a facilitator and as a barrier for their self-management. Nurses can stimulate inpatients' self-management by encouraging patients to do so. When patients were invited by nurses, they participated and took responsibility. Patients also mentioned situations in which they attempted to influence nursing care and wanted to make their own decisions, however, nurses did not respond in a way that met their needs. Nurses did not always recognize and understand these attempts to perform self-management. Hence, two factors were identified: 'being encouraged and invited' and 'being heard and seen'.

### Being encouraged and invited

Patients felt appreciated and were willing to be actively involved when they were encouraged and invited to do so by nurses. Sometimes, the nurse supported the patient by jointly preparing a planned conversation with the physician. In other situations, a nurse's approach to involve a patient was part of an existing method, such as allowing the patient choose his own menu or jointly deciding on homecare facilities, as was illustrated by the following quote.

*'She (the nurse) talked to me and said, 'You can go home, but you have to arrange homecare.' So, she came up with a list of helpers, and we chose (name organization).'* (patient 2)

### Being heard and seen

Some patients discussed their wishes, needs, and possibilities in relationship to nursing care. Patients used different ways to exert influence both direct and indirect, for example, by asking questions or expressing their preferences. Patients' attempts to achieve influence were not always recognized by nurses.

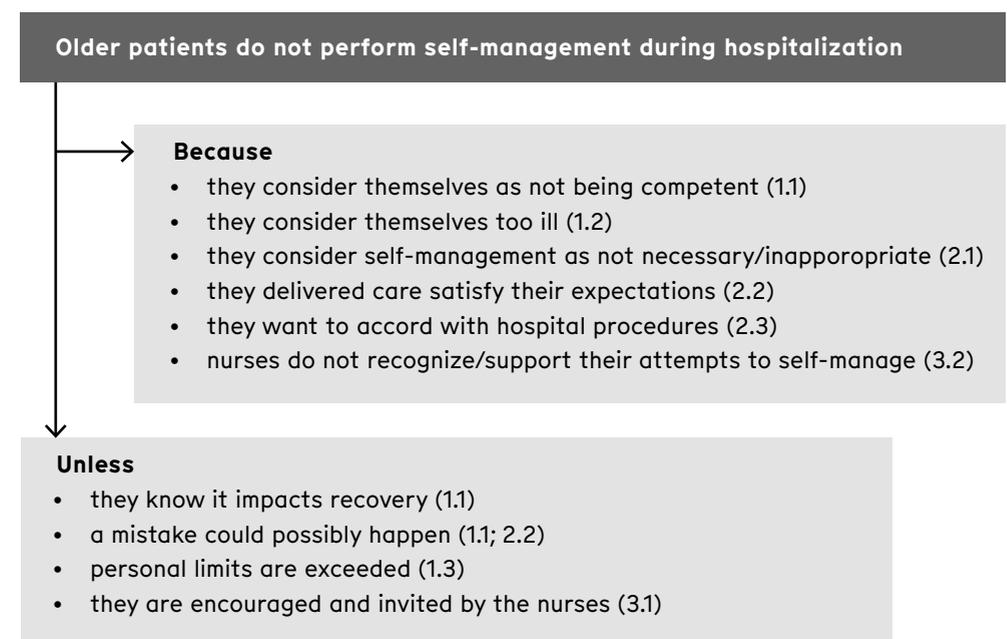
*'Sometimes, I have a bit of shortness of breath, the general practitioner gave me a puff-er.; 'But now the nurse said: 'You have to use a nebulizer.; 'I did not want this and said ' That's not necessary, I do not use that stuff.'; 'But she stood her ground.; 'I pretended to use the nebulizer but put the nebulizer next to me.; 'But I brought my own puff-er with me, I used it a few times.'* (patient 9)

Sometimes, personal care was adjusted at a patient's request, as was illustrated by the following quote.

*'So, in the end, I mentioned 'I want to take a shower'. She (the nurse) said, 'But you have wounds'. And I said, yes, but you're already washing the wounds out, you can do it while I'm showering. So, that's what happened.'* (patient 9)

## Patients' motives placed in a model

Older patients' perceptions regarding performing self-management while hospitalized were distilled from the influencing factors and were divided into motives and barriers for doing so. This resulted in a model presented in Figure 1. The numbers in this model correspond to the numbers of the themes and influencing factors.



**FIGURE 1** OLDER PATIENTS' MOTIVES OF WHETHER OR NOT TO SELF-MANAGE WHILE HOSPITALIZED

**Motives for performing self-management are:**

- Being aware that it stimulates recovery (Theme 1-1: Patients' abilities: Knowledge).
- When a mistake threatens to happen (Theme 1-1: Patients' abilities: Knowledge; Theme 2.2. Patients expectations and opinions: expectations of nursing care).
- When a patient's personal limits are exceeded (Theme 1-3: Patients' abilities: Personality).
- When patients are encouraged and invited by the nurses (Theme 3.1: Perceived behavior of nurses: Being encouraged and invited).

**Barriers for performing self-management:**

- Older patients consider themselves as not being competent (Theme 1-1: Patients' abilities: Knowledge).
- Older patients consider themselves too ill (Theme 1-2: Patients' abilities: Physical and mental condition).
- Older patients consider self-management as not necessary/not correct (Theme 2-1: Patients expectations and opinions: Opinions regarding self-management).
- Older patients are satisfied with the nursing care that is provided (Theme 2-2: Patients expectations and opinions: Expectations of nursing care).
- Older patients want to accord with hospital procedures (theme 2.3: Patients expectations and opinions: Opinions of how to behave in a hospital).
- When nurses do not recognize/support older patients attempts to self-manage (Theme 3-2: Perceived behavior of nurses: Being heard and seen).

## Discussion

By using a qualitative design, we were able to gain insight into patients' motives of whether or not to perform self-management while hospitalized. The most important motives we found for performing self-management are 1) improving recovery; 2) avoiding a mistake that is impending; 3) crossing personal limits; and 4) being encouraged and invited to self-manage by nurses.

Several barriers for performing self-management seem to be related to the nursing care given and to patients' perceptions and expectations of the nursing care. Nurses appear to be less focused on inpatients' self-management and often do not recognize patients' attempts to self-manage. Patients desire to adhere to what they perceive as hospital rules and consider self-management as not necessary. Patients were satisfied and unquestioningly complied with the care provided. This is part of the so called 'sick-role behavior' in which hospitalized patients believe they are exempt from normal responsibilities and rely on health care professionals to cater to their needs.<sup>23</sup> In addition, the patients choose not to self-manage due to their feelings of incompetence. This is consistent with the theory that patients' self-efficacy (or belief in one's ability to accomplish specific activities) is an antecedent for self-management.<sup>3</sup> Lastly, patients' physical and mental condition can be a barrier for performing self-management.

Three themes with influencing factors emerges from our study: patients' abilities; patients' expectations and the perceived behavior of nurses. These findings are consistent with the results of a qualitative study of factors affecting the at home self-management of adults with a chronic illness<sup>24</sup>. In addition, factors such as financial resources, psychosocial support, and environmental characteristics are mentioned to influence at home self-management.<sup>24</sup>

## Supporting inpatients' self-management

The results of this study and, more specifically, the model of older inpatients' motives for determining whether or not they perform self-management (Figure 1) can provide direction for nursing interventions in supporting patients' self-management. The model shows that nurses can support inpatients self-management by 1) encouraging and inviting patients to participate in their own care; 2) by strengthening patients' motives to self-manage, for example, by offering information about activities that impacts recovery and educate patients about ways to prevent hospital complications; and 3) by discussing mutual expectations regarding the hospital stay in general and being more specific about patients' involvement in their own care.

Findings shows that nurses not always recognize and support inpatients' attempts to self- manage. This is consistent with recent research which suggested that overall older inpatients perceived respect by nurses, but improvement is necessary in the area of listening and encouraging patients.<sup>25</sup> Nurses can realize this by acknowledging older patients and their views positively and supporting their individual capacities.<sup>25</sup> Although older patients are the expert when it comes to personal care and health, they consider themselves as not being competent. The awareness of this competence and the enhancement of patients' self-efficacy are considered to be key elements of inpatients' self-management programs.<sup>5</sup>

Overall, the findings of this study suggest that inpatients' self-management requires a change of roles for both patients and nurses. Nurses must relinquish some power and have to recognize patients as equal partners in care, who have control and responsibility for their own health.<sup>26</sup> And after the first period of a hospital admission, when patients' illness subsides, patients can take more responsibility for their health condition and for preparing themselves for hospital discharge.

Hospitals aim at quickly and effectively treating illness. In everyday clinical practices, the focus often lies on 'getting the job done' and on medical and/or clinical outcomes. But acute intervention options must not be privileged over equally important fundamentals of care, such as bathing and dressing, communication, mobility and nutrition<sup>14,27</sup>; over gerontologically sensitive interventions, such as the recognition, prevention and treatment of functional decline<sup>28</sup> or over supporting self-management. Supporting self-management and promoting independence may help older patients survive the hospitalization with fewer deficits and less difficulty adjusting to return home.<sup>29</sup>

## Strengths and limitations

We used purposive sampling to include acute or planned admitted patients of both gender from different wards . This means that the sample consisted of patients with various experiences which provided a broad idea of the motives and influencing factors.<sup>30</sup> The study was conducted in a single hospital, and the sample consisted of older Dutch patients with the same cultural background, which limits the transferability of the findings. Another limitation of this study is the fact that we did not perform a member check to request feedback from the respondents. We decided not to do so in order not to burden the older patients.

Self-management proved to be a difficult concept to explain. A number of patients who met the inclusion criteria did not want to participate because they were satisfied with the care. It appeared as though they only wanted to participate when they could criticize nursing care. Even after further explanation of the study subject, they persevered with their decision. It is unclear if this influenced the results because all of the participating patients also indicated that they were satisfied with the nursing care they had received.

Much research has been done on at home self-management<sup>5-8</sup>, but less is known about what this concept means in the hospital setting. Therefore we made our own operationalization of self-management based on 1) the underlying philosophy that individuals are primarily responsible for their own health<sup>3</sup> and, therefore, must take action; 2) the explanation of the concept 'self' within self-management; individuals do not have to provide the care themselves, however the care must be within the control of the individual<sup>2,4</sup>; 3) a visible basic skill of self-management while hospitalized, specifically, the formation of a patient-provider partnership.<sup>5</sup>

## Conclusion

The results of this study give insight in older patients' motives regarding whether or not to perform self-management while hospitalized and provide several suggestions for developing interventions to facilitate older inpatients' self-management. The findings indicate that often older patients do not consider self-management while hospitalized as relevant. It is nurses' job to discuss this subject with patients and to stimulate and support inpatients' self-management in order to improve patient outcome and to bridge the gap between hospital and home.

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# 2

## Nurses' perceptions of self-management and self- management support of older patients during hospitalization

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## Abstract

Four focus group interviews were held with nurses, recruited from eight wards of two general hospitals, to explore nurses' perceptions of self-management and self-management support of older patients during hospitalization. A thematic analyze of the interview transcripts was conducted. Regarding nurses understanding of self-management two perceptions emerged namely 'being self-reliant' and 'being in control'. In terms of their understanding self-management support three perceptions emerged: encouraging patients to perform activities of daily living (ADL); stimulating patient participation; and increasing patients' awareness. We also found seven themes relating to nurses' beliefs regarding older patients' self-management and self-management support during hospitalization. Results indicate that nurses have a limited understanding of self-management and do not fully understand what is expected from them with regards to inpatients' self-management. It is feasible to argue that addressing nurses' beliefs can influence nurses intention and behavior regarding supporting older inpatients' self-management.

## Introduction

Self-management, the individual's ability to deal with the consequences of their disease(s) in order to maintain a satisfactory quality of life<sup>1</sup> is part of a shift towards more participatory health care.<sup>2</sup> Self-management often refers to managing the impact of a chronic condition<sup>1,3</sup>, but can also apply to managing the consequences of other health problems or to health promotion activities.<sup>4</sup> Self-management does not necessarily mean that individuals always act on their own, as it also includes collaboration with family members, community, and healthcare professionals.<sup>3,4</sup>

Self-management is primarily focused on the tasks an individual must undertake to control or reduce the impact of their disease(s) when living at home.<sup>5</sup> However, self-management is also important during hospital stay because a hospital admission can be one of the most disempowering experiences for an individual.<sup>6</sup> Hospitalized patients switch from being fully responsible for their life to being passive consumers. Here the environment is predominantly organized to deal with acute illness, using high-tech interventions to treat patients.<sup>7</sup> But when the crisis is over a different approach, aimed at maintaining independent physical, social and cognitive functioning, is required.<sup>7</sup> Supporting inpatients' self-management, as far as patients' condition allows, may improve patient outcomes and bridge the gap between hospital and home.<sup>8</sup>

Nurses play an important role in supporting self-management.<sup>9</sup> This requires that nurses move away from the traditional style of providing advice, information and education towards developing collaborative relationships and partnership with patients<sup>10</sup> using a more coaching style that focuses on patients' individual needs.<sup>9</sup> In order to self-manage patients require several basic skills such as problem solving, decision making, resource utilization, the formation of a patient-provider partnership, action planning, and self-tailoring.<sup>11</sup> Various programs have been developed to support patients' abilities to manage their chronic illness at home<sup>11-13</sup>. These programs appear to be effective on self-management behavior, quality of live, clinical outcomes and reduced health-care costs.<sup>11,14</sup> Less research has been done on supporting patients' self-management while hospitalized. It is unclear how nurses view inpatients' self-management and what they do to support this. To optimize nurses' support of self-management in hospitalized patients, we need to understand nurses' current behavior towards supporting inpatients' self-management.

Support of self-management in older patients is particularly important because it can be hard for them to participate actively in their own care when hospitalized, and they may feel worthless, fearful or not in control of what happens during hospitalization.<sup>15</sup> In addition they often have multiple health problems, impaired hearing or vision, reduced mobility and a lack of experience in dealing with healthcare professionals.<sup>16</sup> They are worried that hospitalization might herald a change in their ability to be autonomous on returning home.<sup>17</sup>

The aim of our study is therefore to explore nurses' perceptions of self-management and self-management support of older patients during hospital admission.

# Methods

## Design

To be able to explore nurses' perceptions thoroughly we performed a qualitative descriptive study. We chose to use focus group interviews as it takes into account the interrelationship between nurses during daily care.<sup>18</sup>

## Participants

Nurses were recruited from eight wards of two general hospitals in the Netherlands. Inclusion criteria were: being a registered nurse, working at least twenty-four hours a week, having a minimum of one year work experience with older inpatients and working all shifts.

All nurses (n=94) received written information about the study. Afterwards their nurse unit managers invited nurses to participate. A purposive sampling technique was used to create diversity within the sample and to allow identification of a wide variety of opinions and experiences. Purposive sampling criteria were: nurse's education level and number of years of experience. Nurses participated based on voluntariness and availability on the date of the focus group interviews. The recruitment for participants was stopped when eight nurses for each of the four focus group interviews recruited.

## Data collection

In total four focus group interviews were held between June and October 2016, two at each of the two hospitals. Of these two interviews per hospital, one was conducted with nurses that work on surgical wards and one with nurses that work on medical wards. This group composition was aimed at creating homogeneity in the participants in terms of shared experiences in the discussion topics thereby fostering an open and productive discussion.<sup>18</sup> The interviews took place in a meeting room outside of the ward and were led by an experienced discussion moderator and observed by the researcher (CO) to confirm the completeness of the topics discussed.<sup>18</sup> Both the moderator and the observer (CO) were non-practicing nurses and were employed in one of the participating hospitals (moderator as a trainer (male), observer as a researcher (female)).

All four focus group interviews were guided by a self-developed semi structured topic list based on the constructs of the Theory of Planned Behavior. This theory has shown usefulness for predicting the behavior of healthcare professionals.<sup>19</sup> According to the Theory of Planned Behavior, an important determinant of behavior is intention, which in turn is determined by three factors, namely, attitude, subjective norms, and perceived behavioral control.<sup>20</sup> These three factors are assumed to be influenced by beliefs.<sup>20</sup>

In the context of this study the focus was on 1) nurses' attitude, or in other words: nurses' positive or negative evaluation of supporting self-management of older inpatients; 2) nurses' subjective norms, or perceived social pressure to support or not support self-management of older inpatients; and 3) nurses' perceived behavioral control, or the perceived ease or difficulty to perform self-management support towards older inpatients.<sup>20</sup> In addition, the topic list contained open questions about nurses' understanding of self-management, and their perceptions of factors that may stimulate or hinder self-management.

To test the completeness and feasibility of the topic list, we conducted a pilot focus group interview before starting the data collection. The pilot interview did not lead to changes in the topic list (See Table 1).

The focus group interview started with an open question about nurses' understanding of self-management. Next the moderator gave a definition of self-management in order to ensure a shared understanding of self-management and to prevent bias from different interpretations. For the purpose of this research project and because the research was conducted in the Netherlands, the definition of self-management from the Dutch general nursing competency framework was used. It is based on the definition suggested by Barlow: "Self-management is the individual's ability to prevent health problems wherever possible, and, when these still occur: to handle the symptoms, treatment, physical, psychological and social consequences of the health problems and the required life style changes. This allows one to monitor and respond to his/her own state of health in a way that contributes to a satisfying quality of live."<sup>1,21</sup> Subsequent questions were informed by the Theory of Planned Behavior.<sup>20</sup> Finally, the nurses were asked about factors that may influence inpatients' self-management and nurses' self-management support. All the focus group interviews were audio-recorded and anonymously transcribed verbatim (in Dutch). The transcripts have been checked against the recordings for accuracy.<sup>22</sup> Immediately after each focus group interview, the researcher made a summary, based on her notes. These summaries were sent to the participating nurses for a member check. Member checking is a form of validation used in qualitative research by which some form of data or summaries are sent back to participants to check it for accuracy and if it resonates with their experience.<sup>23</sup>

Theme /topic	Question
Opening question	<ul style="list-style-type: none"> <li>• What do you mean by self-management/self-management support?</li> </ul>
Attitudes towards self-management and self-management support (behavioral beliefs)	<ul style="list-style-type: none"> <li>• Can you give examples of self-management of older hospitalized patients?</li> <li>• How do you consider stimulating self management of older hospitalized patients?</li> <li>• What is the possible (dis)advantage of self-management of older hospitalized patients?</li> </ul>
Subjective norms regarding self-management support (normative beliefs)	<ul style="list-style-type: none"> <li>• Does self-management support belong to your tasks? Is self-management support a nursing intervention?</li> <li>• Are you expected to support self-management? How do you notice this?</li> <li>• Is self-management often discussed within your team?</li> </ul>
Perceived behavioral control regarding self-management support (control beliefs)	<ul style="list-style-type: none"> <li>• Are you supporting older patients' self-management? And if so: how do you support self-management? Or: Why not?</li> <li>• Do you think you are able to support self-management? Do you think you have sufficient knowledge and skills? Or gaps in knowledge or skills?</li> <li>• Do you experience barriers? Facilitators?</li> </ul>
Influencing factors	<ul style="list-style-type: none"> <li>• What stimulates self-management/self-management support?</li> <li>• What hinders self-management/self-management support?</li> </ul>

**TABLE 1** FOCUS GROUP INTERVIEW TOPIC LIST

## Ethical considerations

This study is exempt from legal ethical approval in the Netherlands by the hospital's Medical Ethics Committee (no. 2016-027). Participation was voluntary. All respondents received written and verbal information about the study and gave written informed consent.

## Data analysis

Thematic analysis was conducted according to the six phases of Braun and Clarke.<sup>22</sup> This method supports a theoretically flexible deductive and inductive approach to qualitative data analysis.<sup>22</sup> In phase 1 (familiarizing with the data) three members of the research team (EH, JK, CO) read the transcribed material, searching for meanings and patterns. In phase 2 (generating initial codes) two researchers (EH, CO) independently coded all focus group interviews in an inductive and thorough way. Atlas-ti (version 8.2) was used to support this process. The unit of analysis was a sentence or a few sentences that reflects a particular belief or intention. The codes that both researchers (EH, CO) created separately were compared and, where necessary, renamed. Afterwards all codes were compared to each other and discussed within the research team. As a result some codes were renamed, merged or split. After consensus was reached between the researchers about the codes, they once again looked at all focus group interviews and renamed or refined codes where relevant. The result of this has been compared and merged. In phase 3 (searching for themes) the initial codes were placed in categories, partly based on the Theory of Planned Behavior (Table 2).

Category name	Definition
Understanding	how nurses see or understand self-management and self-management support
Attitudes (behavioral beliefs)	the degree to which nurses have a favorable or unfavorable evaluation or appraisal of supporting self-management
Subjective norms (normative beliefs)	the degree to which nurses perceive social pressure to perform or not to perform self-management
Perceived behavioral control (control beliefs)	nurses' perceived ease or difficulty of supporting self-management

**TABLE 2** CATEGORIES OF CODES SUPPORTING SELF-MANAGEMENT OF OLDER HOSPITALIZED PEOPLE, PARTLY BASED ON THE THEORY OF PLANNED BEHAVIOR.<sup>20</sup>

Afterwards the codes were further analyzed through a careful exploration and study of all quotations associated with the code, and grouped into potential themes within the preconceived categories based on similarities. In phase 4 (reviewing themes) the themes were reassessed for overlap and placement in the correct category. Some candidate themes were changed. The entire dataset was re-read again to ascertain whether the themes fit the data set and to code any additional data that has been missed in earlier coding stages. In phase 5 (defining and naming themes) each theme was named, translated into English and clearly defined in a few of sentences. In phase 6 (producing the report) a first draft of the results were written. Quotes to illustrate the themes were selected (CO) and translated into English. Data saturation was achieved, since the last focus group interview did not present new codes. All the aforementioned phases of the data analysis were thoroughly discussed within the research team (EH, JK, JM, JS, CO).

## Trustworthiness

A number of strategies were undertaken to ensure trustworthiness. To enhance credibility we conducted purposeful sampling based on education level, number of years of experience, hospital and wards. This contributes to a richer variation of the data.<sup>24</sup> We also did a member check on the basis of a summary of the focus group interviews.<sup>24</sup> To increase dependability two researchers independently coded the data. Researchers' decisions and results were discussed within the research team.<sup>24</sup> To facilitate transferability, we gave a clear description of the context, the selection and characteristics of the respondents, the data collection and process of analysis.<sup>22,24</sup> An expert on qualitative research (JS) was involved in the study from the data analyses phase to strengthen rigor in the process.

## Results

We organized focus group discussions with eight nurses, but not everyone was present, due to workload, to changes in the working shifts or to private matters. Attendance ranged from five to eight participants resulting in a total of 25 participants. The focus group discussions lasted on average 1:05:56 (range 59:14-1:13:53). Only 40% of the nurses responded to the member check, all confirming the content of the summary. Table 3 presents the characteristics of the focus groups.

An initial total of 210 codes were identified, and after comparing, merging, splitting and discussion within the research team, 187 initial codes remained. These 187 codes were placed in categories and further analyzed, resulting in findings regarding nurses' understanding of self-management and self-management support and seven themes, presenting nurses' attitude, social norms and perceived behavioral control regarding self-management and self-management support of older patients during hospitalization.

Focus group	Hospital	Ward	Number of nurses (n)	Nurses' education level	Years of nurses' experience (mean, (SD))
1	hospital 1	medical	6	EQ6 (n=3) <sup>1</sup> EQ4 (n=3) <sup>2</sup>	6 (5,6)
2	hospital 1	surgical	5	EQ6 (n=2) EQ4 (n=3)	21 (12,5)
3	hospital 2	medical	6	EQ6 (n=3) EQ4 (n=3)	18 (7,4)
4	hospital 2	surgical	8	EQ6 (n=2) EQ4 (n=6)	18 (10)

<sup>1</sup> EQ6=European Qualification Framework 6: bachelor's degree  
<sup>2</sup> EQ4=European Qualification Framework 4: associate's degree

**TABLE 3** CHARACTERISTICS OF THE FOCUS GROUPS

## Nurses' understanding of self-management and self-management support

The interviews reveal that nurses have an incomplete image of self-management. They often use the terms self-care and self-management interchangeable. The nurses recognize the definition of self-management which was given during the focus group interview. Some nurses had a broader understanding of self-management, not only focusing on health and health problems, but on having control over all the aspect of life.

*'Make your own choices in life. How you actually give substance to that.'* (interview 1)

We found two perceptions that describe nurses' understanding of self-management and three perceptions of self-management support. The two perceptions regarding self-management are that self-management is 'being self-reliant' and self-management is 'being in control'. Nurses mention the following examples of being self-reliant, mostly related to activities of daily living: being able to make your own decisions and plans, and being able to act by yourself, in your own pace. Examples of being in control are: living the way you want, having control over your life, based on your norms and values. Some nurses mention that a change in focus on care is needed to support patients' self-management.

*'For me it is '..the change from 'you have to' to 'I want'.. (...). Decide yourself what is good, of course with all information, but anyway, from 'you have to' from our view, to 'I want' from patients' view.'* (interview 1)

In addition three perceptions of self-management support of older inpatients are found. Firstly encouraging a patient to perform activities of daily living (ADL) is seen as an initial step in regaining inpatients self-confidence and a starting point for performing more self-management tasks. Nurses belief that it is also important to match, where possible, the hospital setting to patients' usual way of performing the activities of daily living.

*'..... match the way a patient is used to do things at home, keep that in place as much as possible and as far as possible in a hospital setting, in terms of medication, morning rituals and things like that.'* (interview 4)

The second perception is that the involvement of the patient in the provision of care, for example by presenting the patient with choices and making agreements about the care, is an important component of inpatients' self-management support.

Thirdly, nurses perceive that self-management support must focus on increasing patients' insight and awareness by providing information about the disease, the treatment, the regimen such as diet, and the hospital admission, as well as by asking questions to help the patient to reflect on her/his situation.

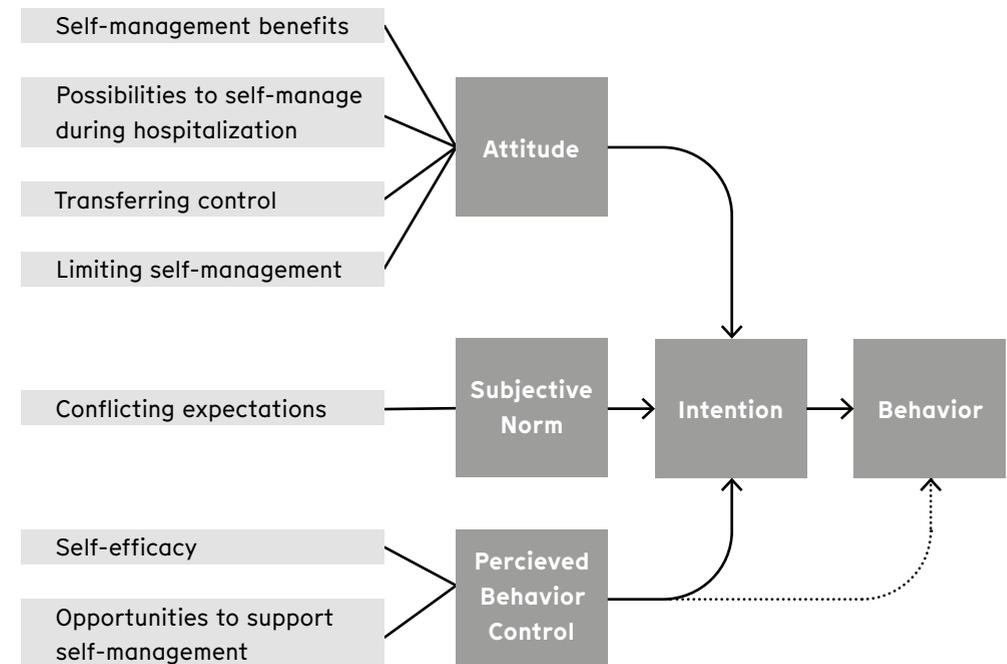
*Nurse 1: Yes, I also think that you have to think further, indeed, why the patient behaves this way, or do certain things this way, or just don't do things. And that you properly anticipate, not immediately propose a different treatment, but indeed, explain or give advice, and knowing which people you should engage/involve, who could help.*

*Nurse 2: You could also ask the patient*

*Nurse 1: Indeed, that too, find out why someone act this way, doesn't he have the right knowledge, or does he have a completely different train of thought/opinion, or is it a habit, habituation.' (interview 4)*

## Themes reflecting nurses' attitude, social norms and perceived behavioral control regarding self-management and self-management support of older patients during hospitalization

Seven themes were identified: four themes related to attitude; one theme related to subjective norms; and two themes related to perceived behavior control. These themes are presented in Figure 1.



**FIGURE 1** THEMES FOUND, PLACED WITHIN THE MODEL OF THE THEORY OF PLANNED BEHAVIOR

## Nurses' attitude towards stimulating self-management of older inpatients

Four themes relating to nurses' attitude towards self-management were identified, namely: 'Self-management benefits', 'Possibilities to self-manage during hospitalization', 'Transferring control' and 'Limiting self-management'.

### Self-management benefits

The nurses in this study have a positive view of older inpatients' self-management, because, according to them, self-management benefits both the patient and the nurse. Self-management develops patients' abilities to prevent health problems, strengthens their independence, stimulates self-esteem and promotes healing.

*'Often self-confidence is gone when hospitalized, in the sense of not knowing your own skills, and when they are stimulated, you will see more and more own initiative.'* (interview 1)

Self-management support provides an advantage for nurses because it enables them to stimulate patients' cooperation. Nurses also see self-management support as a way to show respect.

*'.. but patients, especially older people, can feel more heard and understood, when we do not mindlessly take over everything, such as 'this is how hospital works, deal with it'. (...) when you partly meet patient's wishes or habits, and what he can do himself, then you can expect more in return.'* (interview 4)

## Possibilities to self-manage during hospitalization

Interviewed nurses believe that patients are not always capable to self-manage during hospital admission. The data reveal that when nurses generally spoke about self-management as 'decide for yourself', when it came to examples from the hospital practice, self-management became a 'co-decision' and only 'when possible'. Four reasons for this limitation emerge. First, patients' physical and mental condition seem to be related to their ability to self-manage. For example, medical patients are often in a bad physical condition when admitted to a hospital and do have less power to self-manage. Nurses notice differences in patients' capability to self-management when they are physically and mentally prepared or not prepared when admitted. They also note that patients only start recognizing their own ability to self-management after the first days of hospital admission, when they begin to feel better.

*'.. I think our patient category likes this, they are so sick, and often confused, and have no idea, well, idea or need to get involved with anything at first. Only later, when they recover. You shouldn't start with that (self-management) in the beginning'* (interview 1)

Second, nurses believe that patients do not have the ability to oversee the situation and the consequences of their choices because they lack knowledge and insight in their health condition.

*'.. some people don't, you don't even have to be mentally limited, they just don't have the insights, have little disease insight'* (interview 4)

Third, patients' age is considered to be a limitation to self-manage. According to the interviewed nurses, most older patients are not accustomed to make their own health related decisions. Rather they expect the professional to decide.

*'.. older people more often report: 'if the doctor says it is all right, then it must happen.'* (interview 1)

Last, nurses suggest that hospitalized patients do not expect to self-manage and they relinquish many health related tasks and decisions to others. Nurses mention that a patient need to be personally motivated otherwise self-management and self-management support will be difficult.

*'I think the patient must support it. So, if you are only partially compliant with therapy, or you don't want to improve your health problem, then it is difficult to change the situation. So I think it is true that the patient must be willing to cooperate, otherwise it is not possible.'* (interview 3)

## Transferring control

This theme reflects nurses' feelings about performing older inpatient self-management support. Nurses indicate that they find it difficult to share or transfer control for patients' health care to the patient because they are afraid of losing their overview of the nursing care and because they are concerned that patients may not always make the best choices or take feasible decisions. Nurses also find it difficult to talk with patients about what they consider as 'poor self-management behavior'.

*'Of course, it's about patients, and you want the best for them. And that may not always be what they want'* (interview 3)

## Limiting self-management

Nurses declare that they have a tendency to take over inpatients' care activities and to make decisions on behalf of patients, more often than is necessary. They also identify themselves as the most important limiting factor for inpatients' self-management. They do this by steering patients in a certain direction, reducing the number of potential options for the patient, or by trying to convince the patient that what they suggest is necessary to do. Reasons for nurses to do this were the lack of time to choose other options or because the nurse is convinced that it is the best option for the patient, since it aligns with nurses' professional and personal norms.

*'Well, I think we very much limit peoples' self-management, because, yes, as soon as they arrive, pills are handed in and we take it over. We give medication, because, as we say, the doctor will change something and then you will not know and might take it. So we already take over this part, it starts with it.'* (interview 4)

## Nurses' subjective norms about supporting self-management of older inpatients

The social pressure that nurses experience regarding support of older inpatients' self-management is based on their beliefs about what others think and expect about this support. The various expectations that nurses experience are merged into one theme namely: 'Conflicting expectations'.

### Conflicting expectations

Nurses meet with different expectations from others regarding performing self-management support. They mention that the hospital care is changing and the duration of a hospital admission is becoming increasingly shorter, making informal care and self-management more important and expected from everyone. Also patients get knowledge about their health condition from the internet and become more empowered. But most patients do not expect to self-manage while hospitalized. Nurses note that patients often assign care responsibilities to them. Especially older inpatients seem to expect to be taken care of.

*'... because more and more the world is aging and it's increasingly coming to informal care and to taking care of yourself. So it's important that we give attention to it.'* (interview 1)

Some nurses indicate that self-management support is actually something they have always done automatically, as part of the daily nursing work, mostly to stimulate activities that help to retain physical independency. According to the nurses these activities are expected by both managers and colleagues, although self-management itself is not explicitly mentioned in hospital policy.

*'Nurse 1: So in a way it is laid down in policy, I think, it is going too far to say that is not a policy or so.*

*Nurse 2: But I don't know if it really stands as self-management. (interview 2)*

## Nurses' perceived behavior control to perform self-management support towards older inpatients

Perceived behavioral control refers to nurses' perceived ease or difficulty of supporting older inpatients' self-management. The analysis show two themes: 'Self-efficacy' and 'Opportunities to support'.

### Self-efficacy

Although nurses indicate that supporting self-management is daily nursing work, they also state that actually they do not know how to support older adults' self-management while hospitalized. On the one hand nurses find themselves competent in promoting patients' physical independency and in informing patients about health issues. But on the other hand they indicate that they need to learn more about stimulating patients' self-reliance, about the nursing care of older people and about conversational and coaching techniques. Nurses state that they have limited knowledge of transferring responsibility for care to the patient, or of stimulating older inpatients' autonomy.

*Have you ever learned how you can stimulate a senior citizen/older patient, specifically a senior citizen, to be autonomous in a hospital? I don't!' (interview 1)*

Nurses indicate that they need to become more aware of inpatients' self-management. They also need methods to support inpatients' self-management.

*'A little awareness, again I do have that, although that is not the purpose (of this interview), I do have that, so I'm trying to build in more time. Do look at my working schedule, maybe organize my work differently.' (interview 3)*

## Opportunities to support

Nurses experience limited opportunities to support inpatients' self-management. The high workload and being responsible for multiple patients make it necessary for nurses to set priorities, often at the expense of patients' self-management. In addition the heavy workload, as well as the fixed daily work schedule, leaves little possibility for activities that matches the wishes of the patients and could stimulate their self-management.

*'Well, I think you set priorities, don't you? What are the consequences of now showering you and leaving those other people behind for a long time, and for example, I cannot do checks for a long time; do not distribute the pills on time. And that is more important than giving someone a nice shower.' (interview 1)*

Also, the current working environment seem to give little possibilities for encouraging patients' self-reliance.

*'There is no cozy room where they can, just to mention a practical example, where they can eat dinner themselves. Actually, people are forced to eat while lying in bed.' (interview 4)*

## Discussion

This study provides insight into nurses' perceptions of inpatients' self-management and self-management support. Interviewed nurses have a positive view of self-management but believe that self-management for hospitalized older patients is not always possible, because of their health condition, knowledge and insights, age and motivation. Nurses indicate that it is often hard to perform self-management support. They name their own behavior as the most important limiting factor for inpatients' self-management. Also nurses are not clear about what is expected from them in this regard. They experience too little opportunities and indicate a low self-efficacy to perform self-management support.

We found that nurses' understanding of self-management consist of two perceptions: being self-reliant and being in control. Recent research among community nurses found similar results.<sup>25</sup> The perceptions of self-management support that emerge in this study are primarily focused on supporting patients in being self-reliant, not on stimulating patients to be in control. It seems that in current practice nurses mainly focus on stimulating patients' self-reliance.

Comparable with other research, nurses find it difficult to let go of their professional control and have little confidence that patients can manage their health well.<sup>26,27</sup> According to nurses this is particularly relevant for older people because they often cannot oversee the situation, they struggle to understand what is going on, and they act slowly. They are therefore less able to perform self-management while hospitalized. This attitude towards older people can lead to a universal response towards them, removing the holistic individuality of care, and can endanger older patients' independency.<sup>28</sup> The idea of older people, as a group, being less capable is common, and is caused by various factors, although lack of knowledge of the aging process and gerontology is mentioned to be the most important influencing factor.<sup>28</sup> Nurses are accustomed to play the traditional expert role, placing professional knowledge above patients' experiences and find it hard to accept that some patients make 'wrong choices'.<sup>27</sup> Dwarswaard and van de Bovenkamp (2015) mentioned this as an ethical dilemma for nurses providing self-management support. Nurses consider patients' autonomy as an indispensable part of self-management, but also want to ensure optimal medical outcomes.<sup>27</sup>

Our findings indicate nurses have a limited understanding of self-management and do not fully understand what is expected from them with regards to inpatients' self-management, which is in line with findings from existing research.<sup>25,26,29</sup> Nurses' perceptions of inpatients' self-management support that emerged in our study seem to be based more on promoting compliance with expert advice and medical regimes, and less on empowering patients to manage their health. More person-centered interventions based on patient perceived problems, on raising awareness of the disease, developing self-management behavior, and on strengthening patients' self-efficacy, are necessary to support inpatients' self-management.<sup>11</sup>

Nurses report their own behavior as the most important barrier towards inpatient self-management. In previous research, most of the barriers mentioned by nurses were considered to be beyond nurses' own sphere of influences.<sup>30</sup> Our qualitative study may have given a different result because during the focus group interviews, nurses became increasingly aware of their own role in reducing patients' choices, making decisions on behalf of patients and in steering patients in a certain direction. In line with other research<sup>30</sup> our study does show that nurses have the opinion that self-management is not possible when the patient lacks knowledge, and that, when a patient is not motivated, it makes little sense to support self-management. This is remarkable, because self-management support focuses on increasing patients' awareness and insight regarding the disease and therefore should consist on educating and motivating patients to self-manage.<sup>30</sup>

The findings reveal that nurses experienced too few opportunities to support inpatients' self-management because of heavy workload and fixed daily work schedule. Lack of time has often been described as an important barrier to self-management support<sup>30</sup>, and leads to a form of task-centered nursing where patient care is delivered in an impersonal manner and talking to the patient is seen as something that could obstruct nurses' work.<sup>31</sup> Improving nurse staffing numbers, although an unlikely prospect given the forecast of future nurse shortage<sup>32,33</sup>, may increase the opportunities for nurses to support patients' self-management, but nurses will always experience times of increased workload and patients' demands. Even when time is limited attention should be given to supporting self-management. This requires that nurses and managers recognize the importance of patients' autonomy and, realize that supporting the patients' self-management is crucial for recovery and wellbeing. One option is that nurses change their model of nursing care delivery to a one in which there are more options for redesigning the daily work schedule. The nurses that were interviewed worked in an individual patient allocation model, in which they individually perform all the tasks for a small group of patients during a shift. In team-nursing, a model in which a group of nurses care for a large group of patients<sup>34</sup>, they can redistribute tasks in a way that more opportunities for self-management support are created.

The Theory of Planned Behavior provided a theoretical foundation for this study. According to this theory, the more favorable the attitude and social norms are, and the greater the perceived behavior control is, the stronger should be the intention to perform a behavior.<sup>20</sup> So, addressing nurses' attitude, social norms and perceived behavior control may in turn impact nurses' intentions as well as their behavior regarding self-management.

Given the results of this study, nurses' intentions to perform self-management support to older patients during hospitalization could be strengthened by: 1) an improved attitude towards self-management'; knowledge of the aging process and awareness of nurses' current, often limiting role; 2) clear expectations from relevant others, laid down in policy; and 3) education and strategies to perform self-management support in daily work routines. As there is still little knowledge about methods that can support the self-management of hospitalized patients, so further research should be focused on the development of such methods. Supporting inpatients' self-management should become a nursing intervention, it should be integrated into nurses' education, as well as executed in everyday clinical practices, and become part of hospital policy.

## Limitations

This study has limitations that might have affected the trustworthiness of the findings. First, this work reflects the perceptions of a group of nurses from one country, which limit the transferability of the findings. It is likely that the results of this study are applicable for nurses in other western societies given the fact that all healthcare systems in western societies are changing as a result of an aging society, the empowerment of patients, and the changing view on health and healthcare.<sup>35</sup> Inpatients' understanding and management their own health is becoming increasingly important and, therefore, both patients and nurses must take on a different role in this regard.<sup>36</sup>

Second, using the Theory of Planned Behavior as a framework for this study may have caused bias, because this theory may not cover the full range of possible influences on human behavior. There are more models and theories focusing behavior and behavior change, it is not clear which is the most comprehensive and conceptually coherent.<sup>37</sup> To avoid bias, the topic list for the interviews also contained open questions focusing on nurses' perceptions of factors that may stimulate or hinder self-management. However, all codes found could be placed within the Theory of Planned Behavior.

Nurses often used the terms self-care and self-management interchangeably and seem to be focused on stimulating patients' self-reliance instead of patients' self-management. When interpreting the findings of this study it must be taken into account that respondents did not always refer to self-management as described in the definition of Barlow<sup>1</sup>, but rather their own perceptions of self-management, so on patients' self-reliance and being in control.

## Conclusion

Nurses have a limited understanding of self-management and do not fully understand what is expected from them with regards to inpatients' self-management. Addressing nurses attitude, social norms and perceived behavior control, by discussing their beliefs, may impact nurses' intentions as well as their behavior regarding self-management. Nurses need to become aware of the importance of patients' self-management during hospital admission and of their own, often limiting, behavior towards inpatients' self-management.

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# 3

## How nurses support self-management of hospitalized patients through verbal communication: a qualitative study

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## Abstract

**Introduction** Patients' self-management of the implications of their disease(s) is becoming increasingly important. Research shows that hospitalization disrupts established self-management routines. Nurses can play an important role in supporting patients' self-management. The aim of this study is to describe how nurses support the self-management of hospitalized patients through verbal communication during routine nursing care.

**Methods** A qualitative descriptive study, using overt, non-participant observations was conducted on three wards of a general teaching hospital in the Netherlands. A total of 215 hours of nursing work during 49 shifts was observed. Data was analyzed using thematic analysis based on the six phases of Braun and Clarke.

**Results** Our observations showed that nurses discuss patients' self-management mainly in short conversations during the care provision. Nurses ask patients about their self-management at home and stimulate patients to express their opinions and to be involved in the care process. Three themes reflect how nurses support self-management: 'Discussing patient's self-management', 'Enhancing patient's involvement in care' and 'Focusing on patient's perspective'.

**Conclusion** Hospital nurses have methods to support hospitalized patients' self-management but it does not seem to be an integral part of daily practice. Given current developments in healthcare, it is reasonable to argue that self-management should be given greater emphasis within the hospital setting, requiring a collaborative approach with patients and other healthcare professionals across the care continuum.

## Introduction

Healthcare systems in Western societies are changing from paternalistic systems toward systems that stimulate increasing active involvement of patients.<sup>1,2</sup> This is especially evident in the care for people with chronic conditions at home<sup>3,4</sup>, but also relevant for people with non-chronic diseases<sup>4</sup> because they also need to self-manage the implications of their disease(s).

Self-management is usually considered as a subset of self-care and is focused on managing the consequences of health conditions.<sup>4,5</sup> Self-management refers to the active participation of patients in their treatment<sup>3,4,6</sup> and include self-monitoring, symptom management and the management of functional, emotional, psychosocial and physical consequences of health conditions.<sup>4</sup> In this context 'self' is not understood literally as it also includes collaboration with family, community, and healthcare professionals.<sup>4,5</sup>

Self-management implies a participative collaboration with care providers.<sup>5,6</sup> Both patients and caregivers are responsible, but the ultimate responsibility rest with the patients.<sup>3,5</sup> They need to take part actively in the care process, and bear responsibility for the care process.<sup>6</sup> Health care professionals can support patients by working with patients in partnership, and by promoting patient activation, education and empowerment<sup>5,7</sup>, with the aim to encourage patients to use their own skills, information and professional services to take effective control of their life.<sup>5</sup> Interventions directed towards self-management of patients with chronic conditions are effective on clinical outcomes, self-management behavior, quality of life and reduced healthcare utilization<sup>8-10</sup>, although reported effects are sometimes inconclusive.<sup>10</sup> It is clear that interventions have to be tailored to individual patients.<sup>9</sup>

Research shows that hospitalization often disrupts established self-management routines.<sup>11</sup> Patients manage their own care at home, at hospital admission they switch to being a passive consumer and at discharge they have to resume self-management.<sup>11,12</sup> While admitted to a hospital, most patients wish to manage their illness and situation as autonomously as possible and prefer to be actively involved in the care process.<sup>11,13</sup> However, research found that patients often experience a lack of autonomy and involvement.<sup>13</sup> Patients often leave the hospital with inadequately preparation for self-management.<sup>12-14</sup> Challenges patients experience after a hospital admission are related to three areas: knowledge, resources and self-efficacy.<sup>12</sup>

It can be argued that self-management should be supported during hospital stay, in order to maintain as much continuity in patients' self-management as possible and to prepare the transition from hospital care to self-management after hospitalization.<sup>12,14</sup>

This is relevant for all patients, regardless of the reason for hospitalization. So far, most research has focused on support the self-management of community-dwelling patients with chronic diseases.<sup>3,8</sup> In a hospital setting it is not desirable to distinguish between patients' groups as it can be argued that all patients need self-management support. Making a distinction between patients with chronic and acute diseases would also be difficult, as transitions in disease states from acute to chronic occur.<sup>15</sup> Also, a lot of hospitalized patients have one or more chronic diseases<sup>16</sup>, which may be the reason for the admission or not. Thus, regardless of the reason for hospitalization, patients must manage the consequences of their health problems.

Nurses can play an important role in supporting patients' self-management.<sup>10,17</sup> It is unclear how nurses support patients' self-management while hospitalized, both with regard to maintaining continuity in patients' self-management, as well as preparing patients to perform new self-management skills at home post discharge.

Communication is a core component of nursing<sup>13,18</sup> intended to influence the patients' health status or state of wellbeing.<sup>19</sup> Research has shown that supportive communication with patients can reduce uncertainty, enhance their engagement in decision-making, improve adherence to treatment plans, increase social support and encourage effective use of health care facilities.<sup>20</sup>

## Methods

### Aim

This study aims to describe how nurses support the self-management of hospitalized patients through verbal communication during routine nursing care.

### Design

A qualitative descriptive study using overt, non-participant observation<sup>21</sup> and thematic analysis<sup>22</sup> was conducted to explore how nurses support inpatients self-management through communication. An overt non-participant observation means observing informed participants without participating in the observed activities.<sup>21</sup>

### Setting and sample

The study took place at a general teaching hospital in the Netherlands. To get a broad picture of nursing care in a hospital with regard to self-management support, we chose to observe nurses providing direct care to hospitalized patients in three wards, a Medical, Surgical, and Dialysis ward. Nurses were asked to participate by their ward manager and informed verbally and in writing. They were told that the communication between nurse and patient would be observed. The ward managers recruited a diverse group of nurses, based on age, gender, educational level and years of experience. Nurses participated voluntarily and could refuse at any time. All participating nurses gave informed consent. Patients were asked permission for the observer being present during care to observe the nurse.

### Data collection

The observations were conducted by six student nurses (last year of training for bachelor in nursing degree) who have signed up for this graduation research. The students were specifically trained in non-participant observation and qualitative research and did not work on the participating wards before. The observations took place during day- and evening shifts, for 4-6 hours at a time, between April 6, 2018 and May 17, 2018.

To minimize the impact on the normal care situation, the observers looked like other student nurses and wore a uniform.<sup>21</sup> They did not participate in the nursing care provision. Each observer individually followed one nurse at a time. Communication with severely ill, delirious and/or palliative patients (based on participants' clinical judgement) were not observed. When a patient's bed curtains were closed, for example during personal care and treatments, the observer stayed outside. The observations lasted at least four hours at a time to allow the nurse to get used to the observations. A maximum of six hours' observation time was agreed to ensure that observers remain concentrated during the observation.

## Format for making field notes

A format for making field notes was developed by the chief investigator (CO), a female non-practicing nurse, employed at the hospital as a nursing researcher, not working in one of the participating nursing wards. This format includes sections regarding: 1) ward, date, observation start and end time, observer (number) and participating nurse (number), 2) nurses' opinion about the workload during the shift (in normal or deviant), including motivation, 3) personal reflections of the observer during and after the observations (field diary), and 4) the communication, literally everything that was said, and the context (place, who is present, etc.). This format was pilot tested and discussed by the chief investigator (CO) and the observers.<sup>21</sup>

Information about the age, gender, educational level and ward of the participating nurses were recorded to evaluate diversity in the sample. Anonymity of nurses was guaranteed by giving a number to each nurse. No patients' characteristics were obtained.

## The concept of self-management

In order to ensure a shared understanding of self-management we used the definition of self-management from the Dutch general nursing competency framework, which is based on the definition suggested by Barlow: "Self-management is the individual's ability to prevent health problems wherever possible, and, when these still occur: to handle the symptoms, treatment, physical, psychological and social consequences of the health problems and the required lifestyle changes. This allows one to monitor and respond to his/her own state of health in a way that contributes to a satisfying quality of life".<sup>1,23</sup> There is no generally accepted description of how patients' self-management during hospitalization is manifested in the daily (nursing) care.

In this study, self-management during hospitalization was operationalized as: collaborating with the nursing staff and having a proactive role and control over personal care.<sup>24</sup>

## Data analysis

Thematic analysis was conducted based on the six phases of Braun and Clarke<sup>22</sup>, using Atlas-ti (version 8.0). Two members of the research team, namely CO and CR (a female transmural care consultant, MSc Sociology, working at the hospital but not in one of the participating wards), started the process by reading part of the transcribed material to obtain a broad overview of the content. In phase 2 both researchers (CO, CR) independently coded the same 12 documents inductively to generate initial codes. When searching for initial codes, the research question was kept in mind, but codes were primarily data driven. The initial codes found (n=51) were discussed to establish consensus and then placed in a codebook. All documents were subsequently analyzed independently by the researchers, using the codebook. Two new codes were added during analysis. Data saturation was achieved, since the final documents analyzed did not present any new codes. In the following phase the initial codes were further analyzed through a careful exploration and study of all citations associated with the code. Some codes were merged, other codes were broken down further, which ultimately resulted in 65 codes. Subsequently, all codes were categorized into themes. An example of the analysis process is provided in Table 1. In phase 4 themes and categories were reassessed for overlap and the entire dataset was re-read to confirm that the themes fit in the data set and to code any additional data within the themes that has been missed in earlier coding. Each theme was clearly defined in a few sentences. In the last phases each theme and the corresponding sub-themes were named and illustrated with quotes. Both names and quotes were translated into English by one member of the research group (CO). This translation was verified by all members of the research group, including a native English speaker (JS). Finally, the data analysis was thoroughly discussed within the research team to reach consensus.

Quote	Code	Subcategory	Category	Theme
<p>Nurse: 'Do you feel like eating?'</p> <p>Nurse: 'Would you like to sit on the bedside for breakfast?'</p> <p>Nurse: 'What makes you so nauseous? Was it the Naproxen?'</p> <p>Nurse: 'Do you want to see the wound?'</p>	<p>Asks wishes/opinion food/drink</p> <p>Asks wishes/opinion ADL/mobilizing</p> <p>Asks wishes/opinion medication</p> <p>Asks wishes/opinion care (involvement)</p>	Asks preferences and wishes	Asking patient's opinion	Focusing on patient's perspective
<p>Nurse: 'Do I first have to flush the infusion?'</p> <p>Nurse: 'Do you want your blood sugar tested now?' - Patient: 'It may also be done later during dialysis.' - Nurse: 'When do they normally test?'</p>	<p>Asks how action is done</p> <p>Asks for agreements made</p>	Asks knowledge of (planned) care		
<p>Nurse: 'Do you want to have the Fraxiparine in the leg or in the abdomen?'</p> <p>Nurse: 'Hello, is it okay if I help you wash yourself now?'</p> <p>Nurse: 'Today 2600cc fluid removal. What do you think of that?'</p>	<p>Offers a choice</p> <p>Offers help</p> <p>Makes a proposal</p>	Make a proposal or give a choice		
<p>Nurse: 'Hi, I want to give you the Fraxiparine.'- Patient: 'That's okay.' Nurse: 'Hi, can I flush the tube?'</p>	<p>Names what he/she will do</p> <p>Asks permission to do something</p>	Asks permission		
<p>Patient: 'I understood that I had to stop taking that one pill 7 days before the operation, but I got it this morning'. Nurse: 'How nice of you to bring this up. Thanks for thinking along'.</p> <p>Patient: 'My husband and son are coming soon, they want to take me in the wheelchair, so that I can get away for a while'. Nurse: 'Okay'.</p> <p>Patient: 'Well, I prefer it (medication) in the evening, because otherwise I get so restless.' Nurse: 'Oh, that is good to know, I'll have it changed.'</p>	<p>Express appreciation for patient's help or initiative</p> <p>Confirm patient's suggestion</p> <p>Honor patient's proposal or choice</p>	Accept patient's initiative	Acknowledge patient's initiative	

Quote	Code
Nurse: 'Today 2200cc fluid removal.' - Patient: 'Yes that's fine, more is also okay. I will note 30 minutes in advance if I get cramps.' - Nurse: 'But your blood pressure is low.' - Patient: Oh, then rather don't do it, no.'- Nurse: 'I will set it to 2200cc.' - Patient: 'That is okay.'	Offers a choice

TABLE 1 EXAMPLE OF THE ANALYSIS PROCESS REGARDING ONE THEME

### Trustworthiness

Several strategies were applied to enhance trustworthiness. To enhance credibility we used multiple data sources in time (different times of the day), space (different wards) and persons (different nurses, different observers) and investigator triangulation (two researchers to make coding, analysis and interpretations decisions (CO and CR)).<sup>25</sup> In addition, the observers were present on the wards for several weeks, to build trust and get acquainted with the context.<sup>25</sup> Furthermore, we provided information on the data analysis to illustrate how abstractions are made and gave representative quotations from the transcribed observations, which facilitates judging credibility.<sup>26</sup> To increase reliability we discussed researchers' decisions and results within the research team and described the research steps of this study.<sup>25,26</sup> The setting and the demographic characteristics of participating nurses were described to enable readers to put the findings in context and judge transferability to their own practice.<sup>25,26</sup>

Subcategory	Category	Theme
Discuss patient's initiative		

## Findings

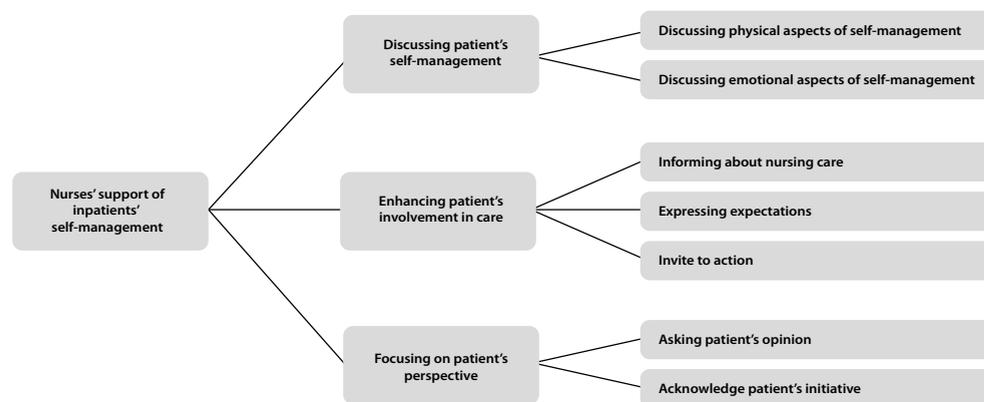
The sample consisted of 49 registered nurses, including male (n=4) and female (n=45) nurses with different educational levels (associate degree (n=32); bachelor's degree (n=17), a varying amount of work experiences (mean 15.4 years; SD 13.8); and a mean age of 39 years (SD 14.7). A total of 215 hours of nursing work during 49 shifts was observed. Some observations lasted under 4 hours, mainly because a nurse's shift ended earlier than planned. See Table 2 for an overview of the number of observations per type of ward.

Ward	Shift	Hours
Medical	6 morning	27
	6 afternoon	21
	7 evening	36
Surgical	5 morning	22
	2 afternoon	5
	5 evening	29
Dialysis	6 morning	39
	6 afternoon	18
	6 evening	18
<b>Total</b>		<b>215</b>

TABLE 2 OVERVIEW OF OBSERVATIONS, PER WARD AND PER SHIFT

According to participating nurses most of the working days were normal. Sixteen observed shifts were judged to be deviant; more quiet than normal (7), or busier than normal (9). Personal reflections of the observers were mainly about the things that stood out in relation to self-management, such as more or less conversation with patients, or about being disturbed by others during the observation. Almost all communication consisted of short talks during nursing activities, often as a one-way transfer of information from nurse to patient or as a question from nurse to patient.

The thematic analysis revealed three main themes and seven subthemes that reflect how nurses support inpatients' self-management (See Figure 1). In the following sections each of the main themes and their sub-themes are presented.



**FIGURE 1** THEMES AND SUBTHEMES REFLECTING NURSES' SUPPORT OF INPATIENTS' SELF-MANAGEMENT

## Theme 1 | Discussing patient's self-management

The data revealed that nurses pay attention to the way in which patients deal with their health problems. Two sub-themes in discussing the self-management emerged from the data, namely, discussing the management of physical consequences, and discussing the management of emotional aspects of the health condition(s) with the patients.

### Discussing physical aspects of self-management

Nurses raised the issue of patients' self-management by asking questions about the home situation and specifically about the way patients deal with health-related issues at home. This took place during some case history interview at admission and in short talks during the care provision. Questions during the case history interview were mostly aimed at screening for certain risks, such as the risk of falling or the risk of malnutrition. Questions were also asked about a prescribed diet, fluid restriction and medication use at home. Questions usually focused on factual information. Sometimes the nurse discussed the way the patient deals with self-monitoring at home, as is illustrated by this quote:

*Nurse: 'How often do you test (your blood sugar level) at home?'*  
*Patient: 'If it doesn't feel right, I'll check.'*  
*Nurse: 'With what result?'*  
*Patient: 'Good'*  
*Nurse: (Laughs)*  
*Patient: 'But sometimes it's not good, therefore I always have dextrose with me.'* (Dialysis ward)

In a few situations nurses discussed patients' self-management after discharge. For example, patients in the dialysis ward were encouraged to adhere to their regimen, such as fluid restrictions. In addition, patients were informed about medication use or were prepared for performing wound care independently at home, as one of the nurses demonstrated:

*Nurse: 'And did we mention you should rinse the wound after every bowel movement? And that a new bandage has to be put on'*  
*Patient: 'No, not yet, but that makes sense. Otherwise it's such a dirty bandage (laughs)'*  
*Nurse: 'And after 24 hours the bandage has to be removed, unless you had a bowel movement'*  
*Patient: 'Oh, yes, that is fine'*  
*Nurse: 'It's all written down in this letter, you can take it with you.'* (Surgical ward)

## Discussing emotional aspects of self-management

Nurses asked patients about feelings related to their health situation, for example regarding a planned operation, the patient's physical condition, or having to be on dialysis for years. The nurse showed understanding for the patient's situation and sometimes mentioned possible solutions or motivations, as this nurse demonstrated:

*Nurse: 'How long have you been on dialysis?' – Patient: 'For eleven years.' – Nurse: 'Ever regretted it?'- Patient: 'Regret, regret...'. – Nurse: 'If you want to carry on, you don't really have a choice, huh.'- Patient: 'No.' (Dialysis ward)*

Some patients shared their personal concerns, anxieties or fears. These concerns were generally focused on the patient's own physical situation, for instance on having to mobilize again, or about whether the right care is provided in the right way. One patient mentioned being concerned about the future, possibly ending up in a nursing home. Nurses mostly responded to patients' concern by reassuring the patient and by showing understanding. This was usually followed by providing some information, making a proposal or offering concrete help.

*Patient: '...and last night something went wrong with the blood sugars too. So I need to be checked more often.' – Nurse: 'My colleague told me, we'll keep a close eye on you today.'- Patient: 'But if I don't feel well, there must be someone.'- Nurse: 'Yes, I'm nearby.' (Medical ward)*

## Theme 2 | Enhancing patient's involvement in care

Data analysis revealed that nurses also support self-management by stimulating the patient's involvement in nursing care. This is done in three ways namely, by giving information about the nursing care, by clearly indicating expectations towards the patient, and by inviting the patient to take an active role in personal care.

### Informing about nursing care

Nurses provided information to the patient about the content and the planning of the nursing care and the motivation for these activities. Almost all nurses continuously specified what they were doing and what they plan to do next. Usually this information was general, brief, and given in combination with the performance of a nursing procedure. In some situations, nurses shared their considerations and observations with the patient, for example:

*'I've been thinking that maybe the IV/drip can be removed. You urinate well and you drink well. Only you need to eat a little better.' (Surgical ward)*

In addition, nurses gave information about the results of vital signs, medication, the dialysis, mobilizing and about aspects of daily living. These are occasionally combined with some advice. Nurses provided this information based on their own initiative or in response to patient's questions. One nurse, for example, emphasized the importance of eating when blood sugar is low.

*'You still have a sandwich for later and you did have low blood sugar, so it's wise to eat the sandwich.' (Surgical ward)*

In another example a nurse gave information to the patient about symptoms that he could monitor himself:

*Nurse: 'Do you know how to notice when you're not doing well?'- Patient: 'No.'- Nurse: 'I'll tell you. You may become dizzy, have blurred vision or you'll sweat more. Or you may experience pain or have cramps. Basically anything that is not normal.'- Patient: 'Okay, then I'll call.' (Dialysis ward)*

## Expressing expectations

Nurses also encouraged the patients to take an active role in personal care by expressing their expectations towards patients and by naming activities that the patient can perform on their own, mostly activities of daily living and using medication, as is illustrated by this quote:

*'I'll put the bag (with medication) here, so you can decide for yourself when to use it.' (Medical ward)*

Nurses regularly indicated that they expect the patient to ask for help when needed. In addition of this frequently stated general question, more specific expectations towards the patient were expressed. Nurses expected patients to report when physical complaints worsen or when particular situation or symptom occurs. Some nurses asked patients to remind them to perform planned care:

*'Oh and before you eat I have to measure your (blood) sugar, please help me remember, will you let me know?' (Dialysis ward)*

## Invite to action

In order to stimulate the patient's involvement in the care process patients were also directly invited to participate in the provision of nursing care. This mainly took place with regard to the activities of daily living, such as bathing or changing patient's physical position in bed.

On occasion nurses would ask the patient to play a role in performing a concrete nursing procedure. This was common in the dialysis ward and occurred incidentally in other nursing wards. In the dialysis ward almost all patients had a role in puncturing and removing the tubes, as demonstrated in this quote:

*'If you hold the dialysis tubes with your right hand, then you will be my assistant' (Dialysis ward)*

Sometimes the patient would be invited to self-manage medication intake. One example is this nurse discussing patients' inhaler:

*Nurse: 'Do you have your own inhaler?' – Patient: 'Yes' – Nurse: 'And you use it yourself?' – Patient: 'Yes of course.' (Surgical ward)*

## Theme 3 | Focusing on patient's perspective

This theme describes the communication in which nurses demonstrated how they took the patient's perspective into account. Two sub-themes emerged from the analysis namely, asking the patient's opinion and acknowledging the patient's initiative.

### Asking patient's opinion

Patients were encouraged to indicate their thoughts about the nursing care. Nurses did this in several ways. First, nurses asked for patients' preferences, especially regarding activities of daily living, or taking medication.

*Nurse: 'You're still in the chair. Are you okay? Or do you want to go back to bed?' (Surgical ward)*

In some situations, the patient's preference on other issues were asked, as the question below illustrates:

*Nurse: 'Do you want to see the wound?'- Patient: 'No, not yet.' (Surgical ward)*

Secondly, nurses asked patients about the agreements made about the provision of nursing care. This mainly took place in the dialysis ward. In this ward patients do have a relatively large say in determining how nursing care is provided, for example with regard to the timing of activities:

*Nurse: 'Do you want your blood sugar tested now?'- Patient: 'It may also be done later during dialysis.'- Nurse: 'When do they normally test?'- Patient: 'Usually before eating, but actually it has to be done one hour after eating and I have just eaten.' (Dialysis ward)*

Thirdly, nurses presented patients with a choice or with a concrete proposal regarding nursing care. These choices mainly related to minor decisions such as an injection in the abdomen or leg or whether an action would take place now or later. Nurses also made concrete proposals to patients, focusing on activities related to daily living or taking medication, and on a nursing procedure, such as how much fluid will be extracted during dialysis:

*Nurse: 'Today 2600cc fluid removal. What do you think of that?'- Patient: 'Yes, that should work.' (Dialysis ward)*

Last, nurses asked permission from patients to perform a nursing action. This usually involved checking vital signs or conducting certain nursing interventions. This request for consent from patients was given explicitly, but also implicitly. The nurse indicated that she would like to perform an action, to which the patient indicated that this is approved, as this nurse showed:

*Nurse: 'Hi, I want to give you the fraxiparine.'- Patient: 'That's okay.'  
(Medical ward)*

## Acknowledge patient's initiative

Nurses also focused on the patients' perspective by acknowledging initiatives taken by patients. Such initiatives include presenting specific requests, by asking questions, by giving instructions to the nurse, or simply by doing something themselves. These initiatives were aimed at activities related to daily living, the intake of medicine, the planning of care and certain nursing procedures, such as removing stitches.

Nurses responded positively to the patients' initiative in two ways. In most cases nurses accepted the patient's suggestion, agreed with the patient's proposal and indicated that they valued the patient's own initiative, as illustrated with this quote:

*Patient: 'I don't have my medication.' – Nurse: 'We have it. I see it's already written in here, and you'll get the medication at 10 AM.'-  
Patient: 'Well, I prefer it in the evening, because otherwise I get so restless.'- Nurse: 'Oh, that is good to know, I'll have it changed.'  
(Surgical ward)*

In some situations, the nurse discussed alternatives regarding patients' proposal and they decided together what to do, for example regarding fluid removal:

*Nurse: 'Today 2200cc fluid removal.'- Patient: 'Yes that's fine, more is also okay. I will note 30 minutes in advance if I get cramps.'- Nurse: 'But your blood pressure is low.'- Patient: Oh, then rather don't do it, no.'- Nurse: 'I will set it to 2200cc.'- Patient: 'That is okay.' (Dialysis ward)*

## Discussion

The analysis revealed that nurses support self-management of hospitalized patients in a direct way, through 'Discussing patient's self-management' and in indirect ways, by 'Enhancing patient's involvement in care'; and 'Focusing on patient's perspective'.

When nurses discuss patients' self-management, they seem to have little attention for the patients' self-management behavior before the hospital admission. Only a few case history interviews were observed, although the information from this interview is necessary for developing a personal nursing care plan. It is likely that interactions where information regarding behavior before admission was discussed took place in settings that were not encountered by observers and that this information may already have been included in the nurses' documentation.

Patients' self-management after discharge was not discussed with all patients. This is in line with previous studies, which indicated that teaching self-management skills is not part of hospital care.<sup>13,14,27</sup> It is important to prepare patients for self-management at home. Many patients have low health literacy and find it difficult to interpret and understand basic medical information and in translating this information into action.<sup>28,29</sup> Nurses and other health care professionals often overestimate some patients' health literacy<sup>30</sup>, therefore it may be wise to assume that all patients may have difficulty understanding information and to create an environment where all patients can improve their understanding and basic self-management skills during hospitalization.<sup>14,28</sup>

Nurses also paid attention to patients' self-management by indirect methods. We discovered two approaches: through involving the patient in the nursing care; and by paying attention to what the patient considers to be important. These approaches can be seen as strategies to stimulate individual patient participation, which can lead to greater patient empowerment and the improvement of patients' self-management.<sup>2</sup>

Self-management is daily work for the patient.<sup>3</sup> This does not stop when a patient is hospitalized. An admission is a great opportunity to give patients education in self-management skills.<sup>31</sup> It can be the start for enhancing skills needed for effective self-management, such as problem solving, decision making, self-monitoring and symptom management, and for developing a behavior change action plan.<sup>3,8</sup> In addition, patients can be prepared prior to hospitalization to perform self-management before, during and after hospitalization.<sup>32-34</sup>

As far as we know, the way in which nurses support self-management during hospitalization has not been studied before. Findings from a non-participant observation looking at the role of nurses in health promoting in the acute hospital setting showed that nurses conducted health education in a traditional way and that patient participation was limited to small personal aspects of care.<sup>35</sup> This was also the case in the current study, which shows that nurses encouraged patients to participate in their own care, mostly regarding the activities of daily living. Nurses see inpatients' involvement in these activities as a starting point for performing more self-management tasks.<sup>36</sup> However, additional action has to be taken to maintain as much continuity in patients' self-management as possible and to prepare the transition from hospital to home. During hospitalization, patients may also be involved in activities aimed at managing the impact of their condition, such as managing symptoms or preventing complications, which they also need to perform at home. This will help them to maintain self-confidence and allow them to develop new self-management skills while in the hospital<sup>12</sup>.

We looked at the content of the communication exchanges between nurses and patients, with a focus on the role of nurses in this. As reported in other studies, communication often happens while performing other tasks.<sup>19,37</sup> Nurses often communicate in a task-focused manner by focusing on physical care. Effective self-management support should also pay attention to patients' emotional and psychosocial needs regarding the consequences of their condition(s).<sup>4</sup>

Nurses did stimulate some form of partnership in the care by asking patients' view on nursing activities or asking for patients' assistance with conducting nursing care. This took place in all wards, but most often in the dialysis ward. Dialysis patients had a relatively large input in determining how nursing care is provided, probably because they are familiar with the nursing staff and the nursing procedures because they are admitted several times a week to undergo dialysis. This can be regarded as inpatients' self-management since the patient collaborated with nursing staff, was proactive and gave direction to, and had control over personal care.<sup>24</sup> In the other wards the decisions nurses handed over to the patient were limited to minor personal aspects of care. Some nurses explain the connection between vital signs and the nursing care, stimulating a patient's understanding how these parameters can be influenced and in only a few situations the patient was prepared for self-monitoring symptoms or invited to take responsibility for using medication while hospitalized. Aforementioned can be regarded as examples of strengthening patients' self-management skills during hospitalization.

Our findings indicate that nurse do have methods to support self-management of hospitalized patients, but they do not support all of the patients' possible self-management needs and these methods do not appear to be used in all relevant patients' encounters. Health care professionals seem not to be skilled to sufficiently perform self-management support.<sup>17,36</sup> Traditionally, they are trained to take responsibility for patients' acute health problems instead of engaging patients as partners in their care.<sup>17,38</sup> Nurses find it difficult to release professional control and have little confidence in patients' ability to manage their health well.<sup>17,36,39</sup> In addition, nurses experience differing expectations from patients, managers and colleagues regarding self-management support.<sup>36</sup> Most nurses working in the acute hospital care do not know what the patient needs for effective self-management and how to support the patient in this.<sup>36</sup> An unclear role definition can affect nurses' responses to patients.<sup>40</sup> Therefore, in order to improve nurses' support to hospitalized patients' self-management, nurses need knowledge, skills, a clear policy and clarity about their role. Specialized nurses are often additionally trained to provide self-management education. However, supporting inpatients' self-management requires adequate competences from all nurses and other health care providers.<sup>41</sup> Theory-driven training interventions, with time to practice, (video)feedback and follow-up seem to be the most effective to train nurses' competences in self-management support.<sup>42</sup>

In addition to training nurses' competences, self-management support programs should include patient-centered elements, such as involving patients as partners, and organizational aspects, such as having a multidisciplinary team approach.<sup>41</sup> To ensure continuity in care, programs aimed at enhancing patients' self-management are best developed across the patients' entire care pathway. This requires a joint approach in which patients, home healthcare, primary care, hospital care and long-term care work together.

Observational research contributes to our understanding of current practices. This study provides an initial, general presentation of what nurses do to support inpatients' self-management. Since there is little previous research in this area, we tried to obtain a broad overview of the practice. We have chosen to observe how nurses support the patient's self-management during hospitalization and not to map whether nurses do this in all possible and appropriate situations. To develop the findings further, additional research is needed with focused and selective observations and discussing nurses' perspectives on the meaning of what was observed, to enhance the understanding of nurses' communication in support of inpatients self-management.<sup>43</sup>

## Limitations

This study provides insight into nurses' support of inpatients' self-management in one hospital, which may limit the transferability of the findings to other settings. In addition, the use of observation as a method of data collection implies a danger that the act of observing may alter practice; the so-called 'Hawthorne effect'.<sup>21</sup> However, it is reasonable to assume that this effect was limited because participating nurses regularly supervise and train student nurses and thus are used to being observed by students while performing their duties.

Finally, observations were conducted by student nurses, which may cause bias as a result of inexperience despite the training they received. On the other hand, being a student nurse can provide an open, unbiased view.

## Conclusion

Considering current developments in health care and the changing view on health it can be argued that self-management needs to be emphasized more, also within a hospital setting. It appears that nurses pay attention to supporting hospitalized patients' self-management in several ways, but this seems to be done ad hoc and does not focus on all patient's possible self-management needs. Self-management support should be embedded in policy at organization and ward level. Interventions should be developed that support patients' ability to manage their health condition across the care continuum.

## Ethical approval

The hospital's Medical Ethics Committee assessed the study regarding local codes of conduct and approved the study (no. 2017-098). The Medical Research Ethics Committee (MREC) Leeuwarden concluded that the study does not fall under the Medical Research Involving Human Subjects Act (WMO; ref RTPO 1027a). This research has been performed in accordance with the Declaration of Helsinki. All participating nurses received written and oral information and gave written informed consent.

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# 4

## Nurses' self-management support to hospitalized patients - a scoping review

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## Abstract

**Aim** To explore the interventions that have been considered or used by nurses to support adult patients' self-management during hospitalization.

**Introduction** Nurses can play an important role in supporting patients' self-management. Currently, however, it is unclear how nurses perform this task during a patient's stay in hospital. Traditionally, nurses take the primary role in managing patients' care during hospitalization. Ideally, patients should have the opportunity to continue applying strategies to manage their health conditions as much as possible while in the hospital. This can increase patients' self-efficacy and decrease unnecessary readmissions.

**Design** Scoping review informed by the Joanna Briggs Institute methodology.

**Methods** A database search was undertaken using Pubmed, CINAHL, PsycInfo, Cochrane, Embase and grey literature sources. Data from the included studies were mapped and summarized in a narrative summary. To synthesize the information that was given about each intervention, we conducted a qualitative inductive content analysis. Results are reported in accordance with the guidelines for Reporting Items for Systematic review and Meta-Analyses extension for Scoping Review (PRISMA-ScR).

**Findings** 83 documents were included in this review. Based on the information about the interventions, three themes were identified: 'self-management support activities', 'focus of self-management support' and the 'intervention procedure'. Five self-management support activities can be distinguished: 'giving education', 'counseling and coaching', 'enhancing responsibility', 'engaging family-caregivers' and 'supporting transition from hospital to home'. The interventions focused on improving disease-related knowledge and on strengthening several self-management skills. Information about the procedure, development and the theoretical underpinning of the intervention was often limited.

**Conclusion** Most activities within the nursing interventions to support adult patients' self-management during hospitalization are part of regular nursing care. However the transfer of responsibility for care task to the patient is relatively new. Further research could focus on developing interventions addressing all aspects of self-management and that are embedded in the patient's care pathway across settings.

## Introduction

In the past, health was seen as the absence of disease. More recently a new definition is suggested, in which health is understood as 'the ability to adapt and self-manage'.<sup>1</sup> Self-management, a concept aiming at persons' abilities to live with the consequences of a health condition, has received growing attention. Efficacious self-management encompasses the ability to monitor one's condition and to effect the cognitive, behavioral and emotional response necessary to maintain a satisfactory quality of life.<sup>2,3</sup> Self-management may be viewed as a subset of self-care, a broad concept referring to individual responsibilities for healthy lifestyle behaviors required for human development and functioning, but the differences between, and the relationship among these two concepts are not clear.<sup>3-5</sup> Both terms are often used interchangeably<sup>6,7</sup>. There is no generally accepted definition for the term self-management.<sup>4,5,7</sup> For the purpose of this study, self-management is considered part of self-care, specifically aimed at managing the actual and potential impact of a disease.<sup>3,5</sup> Nurses can play an important role in supporting patients' self-management.<sup>7</sup>

In the context of long-term condition care, self-management support is described as 'a patient-centered collaborative approach to care that promotes patient activation, education and empowerment'<sup>8-10</sup>, aimed at encouraging the patient to use their own skills, information and professional services to take effective control over life.<sup>10</sup> The enhancement of self-efficacy, i.e. the confidence to carry out a behavior necessary to reach a desired goal, is considered to be a key component of self-management support.<sup>11,12</sup> Patients' self-efficacy can be enhanced by emotional and physical support during hospitalization.<sup>12</sup>

Different programs have been developed and tested to support patients' abilities to manage chronic illness at home<sup>7,11,13</sup>, but limited research has been conducted on programs that support self-management in hospitalized patients. Traditionally, nurses take the primary role in managing patients' care during the course of a hospitalization<sup>12</sup>, changing patients into passive consumers.<sup>14</sup> Ideally patients have the opportunity to manage their own health conditions and to develop necessary new self-management skills as much as possible under guidance of the hospital staff.<sup>12</sup> This may decrease unnecessary readmissions to hospitals, especially for older individuals.<sup>15</sup>

It is unclear what nurses do to support patients' self-management during hospital admission. For this reason, we conducted a scoping review to systematically map the research done in this area, to identify key components of nurses' support of patients' self-management during hospitalization and to distinguish any existing gaps in knowledge.

## Aim

The aim of this review of the literature is to explore the interventions that have been considered or are used by nurses to support adult patients' self-management during hospital admission. The findings of this review will provide a starting point for the development of programs supporting patients' self-management during hospital admission and for further investigation of this topic.

## Methods

We conducted a scoping review because it incorporates a range of study designs in both published and grey literature and generates an intellectual overview of what is known around self-management support during hospitalization.<sup>16,17</sup> Scoping reviews are particularly useful for summarizing literature about a topic area and for clarifying complex concepts.<sup>17</sup> We used a methodological framework to guide the scoping review, involving the following five stages: identifying the research question; identifying relevant documents; selecting documents to include in the review; charting of information and data within the included documents; and collating, summarizing and reporting the results.<sup>17-19</sup> The optional sixth stage, a consultation with stakeholders, was not part of the present review. For charting and analyzing the information of the interventions described in the included documents, and to obtain a broad picture of what is reported about the interventions, we employed a qualitative inductive content analysis.<sup>20,21</sup> The research team consisted of researchers with different theoretical perspectives (psychology (JK), nursing (CO, JdM, LS), research methodology(JS)) and was supported by an experienced information specialist. The guideline published by the Joanna Briggs Institute (JBI) as well as the Preferred Reporting Items for scoping reviews (PRISMA-ScR) has been followed.<sup>22,23</sup> The PCC tool (population, concept and context) was used to structure the research question, the identification of relevant documents and the inclusion criteria<sup>22,23</sup>, see Table 1.

PCC framework	Keywords
<b>Population:</b> nurses	Nurse(s) Nursing
<b>Concept:</b> interventions to support patients' abilities to self-management	Self-management Self-care
<b>Context:</b> hospital	Hospital(s) Inpatient(s) Hospitalized/Hospitalised Hospitalization/Hospitalisation

TABLE 1 PCC FRAMEWORK WITH KEYWORDS SEARCH STRING

## Step 1 | Identifying the research question

The following research question was formulated: "What interventions, presented in the current literature, do and can nurses use to support adult patients' abilities to self-manage during hospitalization".

## Step 2 | Identifying relevant documents

This stage consisted of two parts: the determination of the inclusion criteria and the search for relevant documents.

### Inclusion criteria

Documents were included in the review when they report the interventions that can be or have been used by nurses, to support adult patients' self-management during hospital admission. A nursing intervention is defined as 'any treatment, based upon clinical judgement and knowledge, that a nurse performs to enhance patient outcomes'.<sup>24</sup> Qualitative, quantitative and mixed method study designs, as well as grey literature were included.<sup>19,22,23</sup> We have chosen to limit our study to documents published between January 1, 2010 and March 1, 2020. Nursing care in hospitals is changing rapidly

due to the increasingly shorter hospital stay of patients and the higher complexity of care. How nursing care used to be more than 10 years ago is not considered relevant to answering the research question. Due to limited resources for translation, documents published in languages other than English were excluded.

## Search strategy

The electronic search strategies were developed by two researchers (CO, JK), supported by an experienced information specialist. The search for relevant documents consists of three steps, recommended in the JBI scoping reviews guidance.<sup>19</sup> First, we conducted a limited search ( $n=100$ ) in the databases Pubmed and CINAHL to check the relevance and the completeness of the chosen keywords and to test the screening method. The first search string consisted of a broad list of terms related to self-management, such as 'patient empowerment' and 'patient participation', and yielded a large number of irrelevant hits that did not match the research question. We were specifically looking for interventions that nurses planned and/or performed with the aim of supporting patients' self-management, not with the aim of supporting patient participation or empowerment. It was therefore decided to focus the final search string on the term self-management. Because of the absence of generally accepted definitions for the terms self-care and self-management, and the lack of consensus on the distinction of these two concepts<sup>3-5</sup>, we also used the term 'self-care' in the search strategy. Interventions reported to be aimed at self-care were verified to determine whether they focus on managing the actual and potential impact of a disease, in other words, whether they focus on self-management. If not, the intervention was excluded.

The final search strings were discussed and assessed by members of the research group (JdM, LS) on the basis of the Peer Review of Electronic Search Strategies (PRESS) checklist.<sup>25</sup> Basis of the search string was the PCC (population, concept, context) framework<sup>22,23</sup> (see table 1 and box 1). The final search (step two) was undertaken across the following databases of peer-reviewed and grey literature: Pubmed, CINAHL, PsycInfo, Cochrane, Embase, Google scholar, Open grey and Virginia Henderson Global Nursing, April 2020. The literature search using Google scholar was based on different combinations of keywords, the results sorted by relevance by Google, and, when relevant, limited to the first 20 pages, with the premise that relevance of retrieved articles would decrease after this point.<sup>26</sup> At last, reference lists from included documents and all reviews of literature found were hand searched for suitable, additional documents.

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(("Nursing"[Mesh] OR "Nurses"[Mesh] OR Nursing[tiab]) OR
Nurses[tiab]) OR Nurse[tiab]) AND ("Self-Management"[Mesh] OR
Self-Manage*[tiab] OR Selfmanage*[tiab] OR "Self Care"[Mesh]
OR self-care[tiab] OR selfcare[tiab]) AND ("Hospitals"[Mesh] OR
Hospitals[tiab] OR "Hospitalization"[Mesh] OR Hospitalization[tiab] OR
Hospitalizations[tiab] OR Hospitalisation[tiab] OR Hospitalisations[tiab]
OR hospitalized[tiab] OR hospitalised[tiab] OR "Inpatients"[Mesh] OR
Inpatients[tiab] OR Inpatient[tiab])) Filters: published in the last 10
years; English
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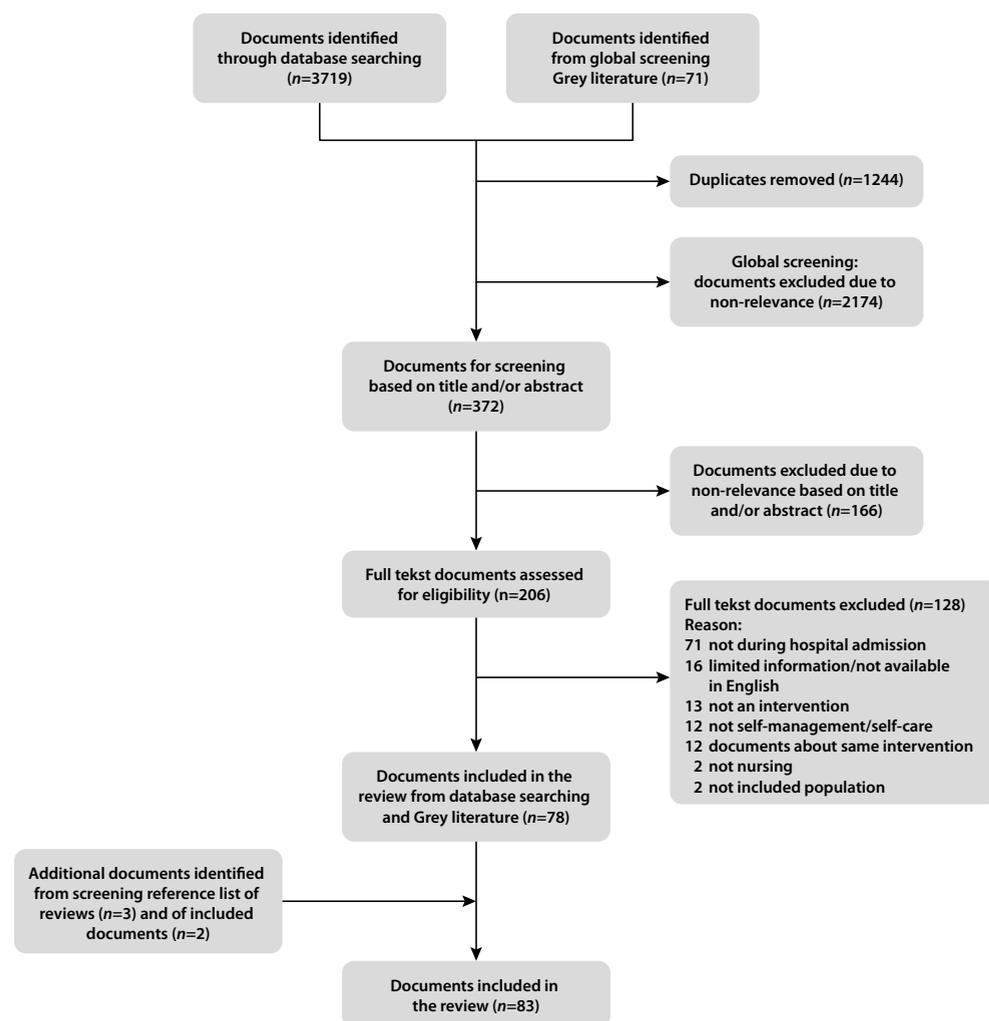
### BOX 1 SEARCH STRING PUBMED

## Step 3 | Document selection

The peer-reviewed database search (April 2020) identified 3719 potentially relevant documents (Pubmed ( $n=756$ ); CINAHL ( $n=1008$ ); PsycInfo ( $n=332$ ); Cochrane ( $n=736$ ); Embase ( $n=887$ )). All identified documents were uploaded to the systematic review web app Rayyan<sup>27</sup> and duplicates were removed ( $n=1244$ ). The main reviewer (CO) conducted an initial broad screening of all titles and abstracts for relevance on basis of the inclusion criteria and excluded 2174 documents. Global search of potentially relevant documents from Grey literature identified 71 documents, which also were uploaded in the web app Rayyan. Both reviewers (CO, JK) independently assessed the remaining 372 documents for eligibility, first on basis of title and abstract, then full text. Disagreements between the two reviewers were solved by discussing the relevant document, reaching consensus and, based on this, supplementing the criteria with the following reasons for exclusion: articles about pregnant women; psychiatric patients; patients with impaired cognition; and palliative patients. We chose not to include these patient groups on the grounds that they have specific needs. Also, the inclusion criterion 'during hospital admission' was clarified with the following criteria for exclusion: patients admitted for one day, such as dialysis patients; Emergency Room patients; or patients hospitalized in a rehabilitation center. If several documents were about the same intervention and study, then the article with the best description of the intervention was included. This step resulted in 78 documents that were included in the review. In the final stage, five additional documents were included by hand-searching the reference lists of the included documents and reviews found, resulting in a total of 83 documents included (see Figure 1: The search decision flowchart).

## Step 4 | Charting the data

A data-charting form to record characteristics of the included documents and the key information relevant to the review question was developed and discussed within the research team.<sup>19,22</sup> This tool included the following information about the document: title; author(s); year of publication; country of origin; journal of other information source; aims/purpose of the study; key concept; study design; context/setting; location; population; sample size; intervention type and comparator, duration of the intervention; outcomes; how outcomes are measured. The first reviewer/author (CO) extracted the data from the included documents registered the data in the Microsoft Excel Spreadsheet software program, and discussed the findings at several face-to-face meetings with the other reviewer (JK). During the data extraction process the data-charting form was revised to include information on the theoretical underpinning of the intervention, as this is a relevant aspect when developing complex interventions.<sup>28</sup> Consistent with the JBI approach for scoping reviews, critical appraisal of included documents was not undertaken.<sup>19</sup>



**FIGURE 1** THE SEARCH DECISION FLOWCHART

Patient population	N
Chronic heart failure	38
Oncological illness	11
Diabetes mellitus	6
Orthopedic	5
COPD	4
Having a stoma	4
Older patients	3
A liver disease	2
First-time acute stroke	2
Burns	1
Diabetes & Chronic heart failure	2
Diabetes & Obesity	1
Unspecified	4

**TABLE 2** PATIENT POPULATIONS TARGETED BY AN INCLUDED INTERVENTION

Design	N
Quantitative	
experimental	36
quasi experimental	11
pre-experimental	4
non-experimental	6
Qualitative	3
Mixed method	2
Not mentioned/relevant	21

**TABLE 3** DESIGN OF THE INCLUDED STUDIES

## Step 5 | Analyzing and synthesizing the data

The extracted data were mapped with results summarized in tabular form (See additional information) and by a narrative summary. To synthesize the information that was given about each intervention, we conducted qualitative inductive content analysis.<sup>20,21</sup> Codes were systematically applied, generated from the data instead of using a pre-existing set of codes to the data.<sup>20,21</sup> The Qualitative Data Analysis and Research software Atlas-ti (version 8) was used to support this analysis. Two reviewers/authors (CO, JK) independently coded the information regarding the interventions from the first 20 documents and met afterwards to discuss codes found and establish consensus. For multidisciplinary interventions, as well as interventions across different care settings, only the part of the intervention performed by clinical nurses was included in the analysis, if this was clearly reported in the article. Subsequently the other documents were coded by the first author, codes were grouped into categories with similar meanings and placed under themes. Finally, the mapping and summarizing of data, the qualitative analysis, and the development of themes were discussed within the research team and consensus was reached.

## Findings

### General characteristics of documents

Documents found were journal articles ( $n=59$ ), conference abstracts or trial registrations ( $n=21$ ), or theses ( $n=3$ ). A large part of the documents originated in the USA ( $n=30$ ), 17 documents in Europe and 13 documents in China. Six documents originated in Canada. The other 16 documents originated from Australia, Brazil, Egypt, Iran, Japan, Lebanon, Korea, Singapore, Taiwan or Vietnam.

About half of the interventions were directed towards specific patient populations focusing on chronic conditions (See table 2). Three interventions were directed to multimorbidity, two of them to both diabetes mellitus and cardiac conditions, and the remainder to diabetes mellitus and obesity. Samples sizes ranged from 1 patient to 3758 patients. Most of the included studies had a quantitative design (See table 3). Details about the documents are available in the Supplementary File.

## General characteristics of nurses' interventions to support patients' self-management during hospital admission

All interventions were aimed on supporting adult patients' self-management during hospitalization. The interventions reported to be aimed at self-care were also focused on managing the actual or potential impact of the patient's disease. Nevertheless distinctions can be made in the objectives of the interventions. Most of the interventions ( $n=75$ ) focused on preparing the patient for self-management after discharge, 11 of which also paid attention to patients' self-management during hospitalization. Eight interventions focused only on patients' self-management while hospitalized.

Targeted outcomes of the interventions can be classified as: (1) patients' self-management or self-care (aimed at managing the actual or potential impact of a disease); (2) outcomes that influence patient's self-management, such as self-efficacy, knowledge or attitude; (3) outcomes that can be seen as a result of patient's self-management, such as adherence, clinical and functional outcomes, quality of life, readmission rates; and (4) outcomes regarding the intervention, such as usefulness and cost-effectiveness.

Thirty-six interventions reported to be theoretically based. Most were based on theories of self-management or related concepts, such as self-care, self-efficacy, self-determination or self-regulation. Bandura's theory of self-efficacy was mentioned six times.<sup>29</sup> Four interventions were based on behavior change techniques, two of which referred to Michie's behavior change model.<sup>30</sup> Only one document reported that the intervention design was based on the Medical Research Council Framework for development of complex interventions.<sup>28</sup> The Donabedian quality assessment model<sup>31</sup>, the Green's Precede model explaining health behavior<sup>32</sup> and Bloom's taxonomy (revised) of different levels of human cognition<sup>33</sup> were also mentioned once. It is often stated that the intervention was based on previous research or guidelines.

A limited number ( $n=22$ ) of documents indicated how and by whom the intervention was developed. Involvement of a multidisciplinary team was mentioned sixteen times. Three documents reported that patients and other stakeholders participated in the development of the intervention. More than half of the interventions ( $n=51$ ) were performed within the patient's care pathway across different settings. Intervention time varied from one short session while the patient is in hospital, to several sessions and/or to a follow-up regimen up to 12 months. Details about each intervention are available in the Supplementary File. Occasionally references to individual papers are made, to exemplify the results.

## Features of nurses' interventions to support patients' self-management during hospital admission

The description of the interventions found in this scoping review is diverse and often limited. The qualitative analysis enabled us to group the relevant features of nurses' interventions to support patients' self-management during hospital admission addressed in the documents into three themes. The first theme, 'self-management support activities', describes the different activities nurses perform to support the self-management of hospitalized patients. The second theme, 'focus of self-management support' describes which aspects of patients' self-management are targeted by the interventions. The third theme, 'intervention procedure', describes the information about the intervention procedure given in the included articles.

### Self-management support activities

Nurses performed various activities in order to strengthen patients' self-management. Five activities can be distinguished: giving education; counseling and coaching; enhancing responsibility; engaging family-caregivers; and supporting transition from hospital to home. The interventions found consisted of at least one of these activities, but usually a combination of several activities.

### Giving education

Most interventions ( $n=75$ ) related to the transfer of information about the health condition and self-management and/or the acquisition of self-management skills. When this was not the case the patient education was often mentioned as part of usual care. Some teaching sessions were clearly defined and structured with tools such as checklists as well as a standardized delivery method. Others have been described only to a limited extent. Patient education was delivered at the bedside, individually, or in a group which allows participants to exchange experiences. The education varied from a session of one hour to extensive training with multiple meetings. Eleven interventions incorporated the Teach Back method, a method in which the patient is asked to repeat information just discussed to confirm the patient understands. Also, other methods for reinforcing the teaching were used.

## Coaching and counseling

In some of the interventions ( $n=36$ ), patients received personalized assistance in learning to cope with the health condition. In individual conversations, and sometimes in the presence of family members, attention was paid to patients' situation, experiences, feelings, needs and capacity to change. These conversations took place in patient's room while in hospital, or after discharge by telephone, at patient's home or in an outpatient setting. The amount of information also varies on this subject. Motivational Interviewing techniques were used in five interventions to increase patients' motivation to change and to build confidence in the ability to do so.

## Giving responsibility

In sixteen interventions, patients were actively involved in the provision of their own care and responsible for self-management activities, such as daily medication use, the administration of diabetes care, fluid input and output registration, mouth care, ileostomy care; nutrition input, diet, exercise, measuring and recording body weight or the prevention of complications while hospitalized. This transfer of responsibility is intended to teach the patients self-management skills, so that they continue these activities after discharge. Nurses' assessment of patients' suitability to self-manage while hospitalized and drafting and signing an agreement for self-management while hospitalized were part of some interventions, in particular those aimed at medication self-management. It is reported that nurses check the patient's self-administered medication list during each round of medication.

## Engaging family-caregivers

The included documents primarily described self-management support at an individual level, but in twenty-four interventions family caregivers were actively involved as well. Family members were invited to attend the educational sessions with patients about self-management knowledge; to discuss patients' support requirements and discharge plans; or to be instructed on skills like measuring blood pressure or daily weighing. In one intervention, the nurse would act as a role model for caregivers to help them adopt supportive attitudes and behaviors in their own interaction with the patient.<sup>34</sup> Family members were asked to assist the patients at home and track their adherence to the guidelines. Patients were encouraged to engage their relatives to provide social and psychological support.

## Supporting transition from hospital to home

Nineteen interventions mentioned specific activities to ensure patients were prepared for discharge and understood the post-discharge plan of care. One intervention involved a visit to the patient in hospital by nurses who had the

responsibility to oversee home care to introduce themselves as well as to arrange a suitable time to visit the patient at home.<sup>35</sup> Another intervention mentioned a Nurse Transition Coach who visits the patient prior the discharge and at home within 72 hours of discharge<sup>36</sup>. In seven interventions it was stated that the patient was given a telephone number to contact the nurse with any question. Some interventions provided information about the transfer of care to the family physician or other primary care providers.

## Focus of nurses' self-management support

The focus of the interventions varied. In almost all interventions an aim was to improve the patient's knowledge of the disease. This included information about the disease, risk factors, symptoms, and/or treatment plans. In addition the focus of the intervention was on one or more of the following aspects: (1) making lifestyle changes, such as quitting smoking, following a prescribed diet, exercise regularly, or other instructions provided, (2) medication management and adherence, (3) physical self-management activities, such as daily weighing, correct inhalation techniques, wound care, correct tooth brushing techniques and personal hygiene when receiving chemotherapy, (4) dealing with stress and strong emotions, also clarifying the sources available for psychosocial support, (5) self-monitoring and symptom management, such as recognizing the early signs of a COPD exacerbation and knowing what to do, identifying and managing complications related to stroke, or controlling side effects of chemotherapy, (6) problem-solving, by encouraging patients to discuss concerns and problems and provide them with strategies to resolve problems, (7) navigating the health system, including keeping up follow-up arrangements, access to community programs, information on patient groups and relevant websites, and (8) goalsetting and the development and the implementation of a personal self-management plan, addressing patient's priorities, including realistic short and long-term goals.

## Intervention procedure

Information about the intervention procedure was often limited and insufficient to reproduce the intervention in a different setting. We found information about who performed the intervention, where the intervention took place, how the intervention was tailored to the individual patient and about the tools used.

Most of the interventions found were only performed by nurses. Five documents indicated that a multidisciplinary team was involved. Often, the

nursing staff were given a training program to perform the intervention, to be well equipped to perform the intervention and to standardize the providing of the program. Checklists have also been developed for this purpose. Some interventions were performed by part of the nursing team or by intervention nurses or nurses with an advanced degree. One intervention also involved peers, referring to individuals who have similar conditions and can use their own experiences to provide information and help to others.<sup>37</sup>

More than half of the interventions were carried out within the patient's care pathway across different settings ( $n=51$ ). In this group, the intervention usually started during the hospital stay and was continued after discharge. Three documents described interventions that started before hospitalization to prepare the patient on performing self-management while hospitalized. The other 32 interventions only took place during hospitalization.

Most interventions were standardized in terms of contents and mode of delivery, but often the procedure and/or contents were tailored to the individual patient needs, concerns, questions and priorities. Forty-two documents specifically stated that the intervention was individualized, personalized or patient centered. This was explained more concretely by for instance indicating that the teaching was adjusted to patient's educational level and knowledge of healthcare, by developing a personal plan for self-management after discharge or through an individually tailored and agreed time and duration of a telephonic follow up.

Various tools were used within the interventions. Often the patient received written information or a textbook to take home after discharge. Sometimes training and instruction were supported by visual or audio aids. In addition, use was made of computer-aided learning, such as educational sessions on a computer performed by a virtual nurse. Virtual reality was used to induce relaxation. At home, patients were given the opportunity to online chat facilities to discuss problems with nurses. Examples of self-help materials for patients included: a pillbox; a weighing scale; a heart rate monitor; reminders; a written traffic light method for symptom management; a diary to record behavior and questions; chart for weight management or fluid intake and output. One article described a family caregiver checklist, including possible strategies to support patients without criticism<sup>34</sup>.

## Discussion

The large number of identified documents ( $n=83$ ) shows that this topic is an important area of interest. The qualitative content analysis of the information given about the interventions led to the emergence of three themes, which indicate self-management support activities, the focus of the

support, and the procedure to implement the support. The review revealed five activities nurses can undertake to support the self-management of hospitalized patients. Some activities, such as patient education or involving family care-givers, have been performed by clinical nurses for quite some time, but the aim on supporting patient's self-management is fairly new and may change the content of these activities. Making patients responsible for self-management activities during hospitalization seem to be a rather new nursing activity. Nurses are used to involve patients in Activities of Daily Living (ADL), but less so in activities aimed at managing the impact of a disease, such as fluid input and output registration or measuring body weight or preventing complications. Not all patients are able or willing to be actively involved. Patients' preferences and capacity to engage in their care while in hospital should be assessed to tailor patients' involvement to each patient's unique wishes, circumstances and condition.<sup>38</sup>

Most interventions found were aimed at improving patients' skills for self-management their chronic disease at home. There are few interventions that stimulate the patient's active self-management while in the hospital. The latter is increasingly important because hospital stays are becoming shorter, which means that more and more is expected of patients. Patients' understanding and managing their own health while hospitalized, will help them to maintain self-confidence and give them the ability to develop new self-management.<sup>12</sup> Normally patients do not perform self-management while in hospital, as they consider it inappropriate and want to adhere to, what they consider to be, hospital procedures.<sup>39</sup> Encouraging and inviting patients to have an active role and control over personal care can change this.<sup>39</sup> This calls for a different professional role for nurses. Nurses need to recognize patients as equal partners in care, responsible for their own health. Previous research showed that nurses find it difficult to share or transfer professional control and lack confidence in patients' abilities to properly self-manage.<sup>6,40</sup> Nurses are uncomfortable with the idea of being challenged by expert patients.<sup>6</sup> It is suggested that an unclear role definition of nurses and the difficulty to clearly articulate their specific expertise within a multidisciplinary team, influenced their responses to knowledgeable patients.<sup>6</sup> Describing the area of nurses' expertise and their specific role regarding self-management support, clearly assigning this task to nurses, and teaching nurses to share or transfer control to patients can enable them to accept their changing roles.

It is debatable whether every intervention that was identified can be regarded as a self-management support intervention. The core objective of self-management support is to influence the patient's health behavior and to increase the patient's skills and confidence in managing their health condition(s). However some interventions do not seem appropriate to achieve

this because they focus on only one aspect of self-management or because they are limited in duration and do not appear to be sufficient to generate a permanent change in health behavior. Self-efficacy, although considered an important part of self-management support<sup>11,12</sup>, has been mentioned only a few times as the theoretical basis for developing an intervention or as the intended outcome of the intervention. Nevertheless all activities found can be seen as a way to increase patients' knowledge and confidence in managing their own health. Previous research identified a generic set of skills to be successful for effective self-management, including problem solving, decision-making; resource utilization, forming a patient-health care provider partnership and taking actions<sup>11,41</sup>. All these skills were mentioned in this review, but not all skills are addressed in every intervention.

More than half of the interventions took place over a longer period and consisted of activities across settings. These interventions, focusing the continuity of care and designed to bridge the institutional barriers between the acute care setting and the care in the patients' community context, are good examples of self-management support interventions as they have been found to reduce readmission due to exacerbation, especially in older persons.<sup>15</sup> In view of the increasingly shorter hospital stay and thus the reduced ability to support patients' self-management while in hospital, it is important to develop self-management support programs that will be implemented in different care settings.

Only a few interventions were aimed at patients with an acute illness, such as a first-time stroke, or at patients with a planned surgical procedure. These patient groups need more attention as self-management is also important for patients with acute health problems. They also need to monitor their condition and have to deal with the cognitive, behavioral and emotional consequences of their health problem. It is striking that most interventions are aimed at dealing with the consequences of a single disease, while most of the hospitalized patients older than 65 have two or more acute and chronic diseases.<sup>42</sup> Acute conditions can complicate treatment of other conditions.<sup>42</sup> It is important for both the healthcare professional and the patient to be aware of this. Self-management support should also focus on patients with complex needs due to multimorbidity.

One of the challenges hospital nurses faced in supporting patients' self-management is the lack of time.<sup>40,43</sup> Given the prognosis of future nurses shortage<sup>44,45</sup>, the lack of time will only increase, so we need to look for interventions that respond to this. Some interventions found in this scoping review used health information technology to support patients' self-management, which reduced the time spent by nurses. These types of interventions have great potential for engaging hospitalized patients in their care.<sup>46</sup>

Scoping reviews are not intended to assess the quality of the literature scoped.<sup>18</sup> Nevertheless, several aspects were noted with regard to the quality of the information in the documents. Interventions to support patients' self-management are considered complex interventions, interventions with several interacting components that impact the length and complexity of the causal chain from intervention to outcome and the influence of the local context.<sup>28,47</sup> Best practice to design a complex intervention is to act systematically, use the best available evidence and theory<sup>28</sup>, basing the intervention on both the needs of recipients and providers and on the delivery context.<sup>48</sup> The lack of any of those elements reduce the chances of success.<sup>48</sup> Our study showed that information about the development of an intervention is often lacking or limited. This makes it difficult to understand how the intervention works, what the ingredients are and how they have an effect. The quality of most descriptions of the interventions found were also poor, making it difficult to replicate the interventions or to build on research findings.<sup>49</sup> A suggestion for further research is to use a systematic method for the development of interventions, such as the Medical Research Council Framework, and describe the intervention in sufficient detail to allow others to reproduce the intervention.<sup>49,50</sup> A recent concept analysis of self-management, identifying ten attributes delineating self-management, may provide a basis for the development of new self-management programs.<sup>41</sup>

We have performed this review of the literature systematically, using the framework of Arksey and O'Malley.<sup>18</sup> This framework suggests an optional sixth stage with stakeholders' consultations, although it is unclear when, how, and why stakeholders should be consulted, and how these data should be analyzed and integrated with the findings.<sup>17</sup> We plan to present the findings of this scoping review, along with results of previous research<sup>39,40</sup> to experts in a Delphi study with the aim of reaching consensus on the way nurses can support patients' self-management during hospital admission. This can also be seen as a first step in disseminating the research findings.

## Limitations

Despite the comprehensive database search it is possible that potentially relevant documents were missed because only English-language documents were included. Our review is further limited by the lack of detailed information about the interventions in many of the documents. Due to restricted resources, the process of data extraction was largely performed by one reviewer (CO). To limit the possibility of reviewer bias, all questions and doubts were discussed with the second reviewer (JK) and eventually within the research group.

## Conclusion

This scoping review demonstrated the interventions that nurses (can) use to support adult patients' self-management during hospitalization. Most activities within these interventions are part of regular nursing care, but the focus on patients' self-management is relatively new and may change its content. The actual involvement of patients in their care and the transfer of responsibility for care tasks to the patient is a new activity within the nursing care for hospitalized adult patients. Some interventions focus on only one aspect of self-management, usually the patient's knowledge of the disease and its treatment. More aspects of patients' self-management need to be addressed to influence patients' health behavior and to increase patients' skills and confidence in managing their health condition(s). Interventions that take place over a longer period and are carried out in different settings within the patients' care pathway, seem suitable for increasing the patients' skills and confidence in managing their health condition.

Based on our analysis we suggest that further research could focus on: (1) reviewing the literature on the effectiveness of the different activities mentioned, or, if limited research is available, conducting studies to determine the effect of the various activities on patients' self-management; (2) developing and testing interventions that focus on empowering patients to be actively involved in their own care and responsible for (parts of) their self-management during hospitalization, including methods for assessing patient's capacity to self-manage while in hospital; (3) developing and testing self-management supporting interventions embedded in the patient's care pathway across settings, targeting both chronic and acute health problems and patients with multimorbidity; (4) with specific attention to the possibilities of health information technology. We also propose to use a systematic method for the development of interventions, based on both the needs of recipients and providers, and to describe the interventions in publications in sufficient detail to allow others to reproduce. Nurses need information on how to support patient's self-management in an evidence based, structured manner and how this can be integrated into clinical practice.

## Relevance to Clinical Practice

By performing a scoping review, we did not investigate the effectiveness of the interventions found. As a result, we cannot give evidence based recommendations for practice.<sup>19</sup> The findings can be considered a first step in developing conceptual clarity regarding nurses' support of patients' self-management during hospitalization and can be used by clinical nurses to improve nursing care through developing interventions that address all aspects of self-management and make the patients as responsible as possible for self-management task while hospitalized.

## References

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## Appendix 1 | Characteristics included documents and interventions.

Author	Aim/purpose	Design	Self-management support activities (ED=providing education; GR=giving responsibility; CC=coaching and counseling; EF=engaging family-caregivers; TS=offering transition support)	Theoretical underpinning of the approach	Setting of the intervention	Targeting patients' self-management during and/or after admission	Population/sample	Outcomes
Abbasi, A. et al <sup>1</sup> (2018)	To compare the effects of self-management education using multi-method approach and multimedia on the quality of life of patients with Chronic Heart Failure.	quasi-experimental	Education usual; education with multi-method approach, education with multi-media approach and follow up (ED; EF; TS).	not stated	Hospital and after discharge	After	Patients with CHF (n=111; three groups: 36-37-38)	QOL
Abd-Almageed, A.S. <sup>2</sup> (2018)	To evaluate the effect of designed nursing instructions on knowledge and self-care behavior among patients with chemotherapy-induced neutropenia.	pre-experimental	A designed nursing instruction on knowledge and self-care behavior among patients with chemotherapy induced neutropenia, including reinforcing teaching (ED).	not stated	Only hospital	After	Patients with chemotherapy-induced neutropenia (n=60)	Knowledge; self-care behavior
Aboumatar, H. et al <sup>3</sup> (2017)	To develop and test a patient and family-centered transitional care program that helps prepare hospitalized COPD patients and their family caregivers to manage COPD at home.	experimental	The BREATHE transitional care program, three components: tailored hospital-to-home transition support, individualized COPD self-management education, teach back and support, facilitated access to community programs and health care services (ED; CC; EF; TS).	not stated	Hospital and after discharge	After	Hospitalized patients and their family-caregivers admitted to medical units with COPD-related condition (n=240; 120 in each group)	Re-hospitalization and ER visits (COPD related); health related quality of life; all cause re-hospitalizations/ ER visits; patients activation, self-efficacy; self-care behaviors.

Andrade, A et al <sup>4</sup> (2011)	To evaluate the teach back method on self-care and determine if teach back affects the number of ER visits and re-admission post discharge.	experimental	Discharge teaching and teach back method (ED).	not stated	Only hospital	After	Hospitalized HF patients (n=80)	Self-care; ER-visits; hospital admission in three months; feasibility and acceptability of adapting Teach Back method.
Austin, L.S. <sup>5</sup> (2012)	To determine if a interactive voice response system with daily self-management and clinical monitoring messages would be well accepted by patients and reduce 30 day congestive heart failure readmission.	not stated	An inpatient program with audio files(interactive voice response system) on MP3 players and an outpatient program with audio files delivered by cellphone or landline (ED; EF).	not stated	Hospital and after discharge	After	Inpatients with primary diagnosis of congestive heart failure (n=60)	Whether patients listened and understood the message; patient ability to perform self-management skills; readmission rate.
Awoke, M.S. et al <sup>6</sup> (2019)	To evaluate the impact of nurse-led heart failure patient education on knowledge, self-care behaviors and all cause 30-day hospital readmission.	quasi-experimental	A standardized HF patient education program (ED).	Theory of Culture Care & Transcultural Nursing (Leininger, M)	Hospital and after discharge	After	Patients hospitalized with HF (n=29)	Knowledge on self-care; self-care maintenance, self-care management, self-care confidence/30 days all cause readmission/nurses' ease of using teach-back method.
Ballard-Hernandez, J.M. et al <sup>7</sup>	To develop and test a NP led intervention to improve readmission rates.	not stated	Individualized education, counseling and follow up after discharge (ED; CC).	not stated	Hospital and after discharge	After	Hospitalized patients with HF	All cause readmission rates for heart failure.
Bingham, A. <sup>8</sup> (2015)	To evaluate teaching sessions that will solicit patient engagement, enhance SM skills and decrease hospitalizations.	not stated	A standard care for providing patient education, including teach back method (ED).	not stated	Hospital and after discharge	After	Patients with HF	Self-management skills: knowledge, lifestyle changes, symptom identification, confidence in managing health.

Blakely, M.D. <sup>9</sup> (2017)	To determine the effect of shifting from all nursing-provided care to a self-care approach for hospitalized heart failure patients on their self-care confidence levels.	not stated	Patient education; self-care management activities (daily weights); fluid management (record I&O) (ED; GR).	Dorothea Orem Self-Care Deficit theory/Riegel & Dickson's Situation Specific Theory of Heart Failure Self-Care	Only hospital	During and after	Adult patients being admitted to the designated unit with a HF diagnosis who anticipates returning to the community post discharge (n=54)	Patients' self-care confidence.
Bläüwer, C. et al <sup>10</sup> (2015)	Improving patient care by implementing evidence into practice and by supporting patients to manage their chronic condition. Two parts: 1) development of a nurse-led multi-professional educational program for hospitalized CHF patients; 2) explore patients' perspective in self-management at home.	mixed methods	Three educational sessions on self-management, complemented with training components, such as adjust medication/ weighing and keep a symptom diary (ED; GR; CC).	Self-regulatory model for chronic disease management (Vincenzi, C)	Only hospital	After	patients hospitalized due to cardiac decompensation (n=12)	Patients' satisfaction with the education program; usefulness of the counseling content; self-care behavior (in hospital and after discharge).
Boch, E. et al <sup>11</sup> (2016)	To improve secondary prevention after acute myocardial infarction.	not stated	Log book-information and oral advices for increasing self-management of risk factors (ED).	not stated	Only hospital	After	Patients hospitalized for an acute myocardial infarction (n=307; recurrent MI; intervention 65%)	visit to cardiologist; weight loss outcomes hospitalization; unscheduled PCI.
Chen, J. et al <sup>12</sup> (2018)	To investigate the effect of motivational interviewing on the self-care behaviors in patients with chronic heart failure.	experimental	Motivational interviewing and telephone follow up (CC).	Motivational Interviewing	Hospital and after discharge	After	Hospitalized patients diagnosed with CHF (n=92; intervention group n=29; control group n=33)	Self-care behavior.

Chen, L. et al <sup>13</sup> (2018)	To examine the effectiveness of a patient-centered self-management empowerment intervention during pre-discharge planning on stroke survivors.	experimental	Five daily sessions; one small group session, discharge instruction; four weekly telephone follow up (ED; CC; EF; TS).	Health empowerment model (Shearer, 2009)	Hospital and after discharge	After	Hospitalized patients with diagnosis of first acute stroke (n=144; 72 in each group)	Self-efficacy, activities of daily living, re-hospitalization.
Cossette, S. et al <sup>14</sup> (2016)	To assess feasibility, acceptability, and potential effectiveness of an intervention aimed to improve self-care HF patients.	experimental	Two individual education sessions and three telephone follow up (ED; CC; EF).	Self-Determination Theory (Deci and Ryan)	Hospital and after discharge	After	Hospitalized HF patients and their family care givers (n=32 dyads; 16 in each group)	Feasibility and acceptability of the intervention.
Cossette, S. et al <sup>15</sup> (2017)	To assess the feasibility and acceptability of a web-based tailored intervention (TAVIE@COEUR) designed to improve illness management in patients hospitalized for an acute coronary syndrome.	pre-experimental	A web based tailored intervention designed to improve illness management in patients hospitalized for an ACS (acute coronary syndrome): virtual nurse guide the patient through a learning process (ED).	Self-regulation theory (Leventhal); integrate motivational counseling (Miller and Rollnick) and take into account the stage of change of Prochaska	Hospital and after discharge	After	CCU patients hospitalized for an ACS (n=30)	Feasibility and acceptability of the intervention; self-care, medication adherence, anxiety management, cardiac risk factors reduction, cardiac rehabilitation enrollment.
Crawford, D. et al <sup>16</sup> (2012)	To compare two methods of ostomy care instruction and their effect on patients' knowledge, skills and confidence related to ostomy care.	experimental	Nurse instruction: one-on-one sessions and nurse guided video instruction (ED).	not stated	Only hospital	After	Adult patients with new fecal ostomies (n=68; 34 in each group)	Patients' knowledge, skills and confidence related to ostomy care.
Cui, X. et al <sup>17</sup> (2019)	To determine the effect of a structured nurse-led education program on patient self-management, symptom control, and hospital readmission.	experimental	Structured educational intervention and telephone or face-to-face consultations (ED; CC; EF; TS).	Self-management theory (Norris SL)	Hospital and after discharge	After	Patients with CHF (n=96)	Mortality; hospital admission due to cardiac problems; self-management ability for heart failure.

Cui, Y et al <sup>18</sup> (2019)	Examine the QOL, psychological and behavioral effects of a self-management program for chronic hepatitis B and C patients.	mixed methods	Two individual education sessions, after discharge telephone follow up (ED; CC).	the Health Belief Model (Becker, NH)	Hospital and after discharge	After	Patients hospitalized with chronic hepatitis B or C, receiving anti-viral therapy and able to telephone follow up after discharge (n=60; 30 in each group)	Quality of life; self-efficacy; depression symptoms; perceived cognition of illness; behavior changes.
Deane, K.H.O. et al <sup>19</sup> (2018)	To investigate if patients who self-manage their oral analgesics post-operative have better pain control than treatment as usual.	experimental	Patient-directed self-management of pain (PaDSMaP) (assess patient's competency, patient self-medication) (ED; GR).	not stated	Hospital and before admission	During	Patients undergoing total knee replacement (n=137; intervention group n= 68; control group n= 69)	pain at three days after operation or at discharge; overall pain levels; pain on mobilization; patient satisfaction with pain management; and with pain management information; quality of life; activities of daily living, time to mobilization; adverse events; quality and type of medication used whilst inpatient.

Deek, H. et al <sup>20</sup> (2017)	To evaluate the effect of involving family caregivers in the self-care of patients with heart failure on the risk of hospital readmission.	experimental	A comprehensive, culturally appropriate, educational session on self-care maintenance and symptom management along with self-care resources for patients and their family caregivers/with telephone follow up (ED, EF).	Framework for the Study of Self and Family Management (Grey, M)	Hospital and after discharge	After	Adults patients hospitalized for an exacerbation of heart failure (n=256; intervention group n=126; control group n=130)	Readmission; self-care; quality of life; health care utilization.
Dilles, A. et al <sup>21</sup> (2011)	To compare computer assisted learning with standard care.	quasi-experimental	A computer assisted learning program, reinforcing teaching (ED).	not stated	Only hospital	After	Hospitalized patients with HF (n=37 (intervention group n=21, control group n=16)	Knowledge and self-care (baseline, admission and three months after discharge); patient satisfaction with computer assisted learning.
Dinh, H. et al <sup>22</sup> (2018)	A protocol for a cluster randomized trial to test a heart failure self-management intervention.	experimental	Individual teaching, teach-back and a follow-up phone call (ED).	not stated	Hospital and after discharge	After	Inpatients diagnosed with HF (n=116; 58 in each group)	HF knowledge; HF self-care behaviors; re-hospitalization.
Domingues, F.B. et al <sup>23</sup> (2010)	To evaluate the effect of an educational nursing intervention on patients hospitalized due to decompensated heart failure.	experimental	Educational nursing intervention, reinforcing teaching, and telephone monitoring after discharge (ED; GR; EF).	not stated	Hospital and after discharge	After	HF patients with left ventricle ejection fraction ≤ 45% (n= 111; intervention group n=48; control group n=63)	Level of heart failure and self-care knowledge; frequency ER visits; re-hospitalization; deaths in three month period.
Donnelly, J. <sup>24</sup> (2016)	To examine the effects of a video game use on pain perception, pain interference perception, and perceived self-efficacy in pain management.	quasi-experimental	Video games (CC).	Bandura's self-efficacy theory	Only hospital	During	Adult inpatients progressive care and orthopedic acute care unit (n=30)	Self-efficacy; pain perceptions; factors that predict changes in pain perceptions.

Dunbar, S.B. et al <sup>25</sup> (2014)	To develop and test an integrated self-care education and counseling program for its short term effects on self-care antecedents and behaviors, and to examine the feasibility of such an intervention.	experimental	Integrated intervention involving HF-DM education and counseling/self-management support (ED; CC).	A framework to guide HF self-care studies (Dunbar, SB) and the chronic care model of self-management support (Wagner, EH)	Hospital and after discharge	After	Patients with HF and diabetes (n=71)	Knowledge about HF and DM; specific self-efficacy, standard HF and DM QOL scales; HF and DM self-care behaviors.
Elchook, A.M. <sup>26</sup>	To assess the effects of a behavior reinforcement tool.	not stated	A behavior reinforcement tool to put the patient in charge of their daily care needs and a tool for 'additional focus for today' (CC; GR).	not stated	Only hospital	During and after	Patient hospitalized in the adult bone Marrow transplant setting	Increasing self-care compliance.
Filippone, J.D. et al <sup>27</sup> (2013)	To show that testing for health literacy through nurse led educational program will enhance patients understanding of the chronic illness, enable them to understand lifestyle changes and reduce readmission.	quasi-experimental	Screening health literacy, appropriate patient education (ED).	not stated	Only hospital	After	Heart failure inpatients (n=45)	Patients understanding of the chronic illness; enable to understand lifestyle changes, reduce readmission.
Flanagan, D. et al <sup>28</sup> (2018)	Guidelines to improve inpatients experiences and safety for people with diabetes through effective self-management.	not relevant	Patient information, circumstances required, care plans, elements needed for self-management, teach back (ED; GR)	not stated	Hospital and before admission	During	Patients with diabetes	not relevant
Fox, C. <sup>29</sup> (2014)	To implement education for patients undergoing total hip and knee replacement/to provide patients with tools and knowledge to self-manage their post-operative pain.	not stated	Daily educational sessions and telephone follow up (ED).	Theory of Symptom Self-management (Hoffman, AJ)	Hospital and after discharge	After	Patients undergoing total hip or total knee replacement (n=11)	Improve self-efficacy; decrease pain.

Frame, A. et al. <sup>30</sup> (2015)	To evaluate written heart failure inpatient education materials and revise them.	not stated	Written inpatient education (ED)	not stated	Only hospital	After	not stated	not relevant
Fu, M.M.M. <sup>31</sup> (2017)	To determine of a rescue pack (assessment and education) would decrease readmission and the length of hospital stay.	not stated	A rescue pack: assessment and education including inhaler technique, lifestyle modifications, breathing techniques, smoking cessation (ED; CC; GR).	not stated	Only hospital	After	Hospitalized patients with COPD (n=63; intervention group n=33; control group n=30)	Readmission rates; length of hospitalization
Goldman, L.E. <sup>32</sup> (2014)	To examine whether a nurse-led intervention decrease emergency department visits or readmission.	experiment	Individual self-management education and coaching/after hospital care plan/telephone follow up (ED; CC; TS)	not stated	Hospital and after discharge	After	Patient admitted to mentioned wards/not planned hospitalization (n=700; 347 intervention group n=347; control group n=353)	ED visits and readmission.
Granger, B.B. <sup>33</sup> (2015)	To evaluate the efficacy of an intervention to improve medication adherence.	experimental	Assessment, education (medication adherence) and follow up/behavior change intervention (ED; CC; EF; TS)	not stated	Hospital and after discharge	After	Patient admitted to hospital with primary diagnose of HF and with poor adherence (n=86; intervention group n= 44; control group n=42)	Medication adherence; HF specific medication; patient reported beliefs; symptom frequency.
Green, C.L.A. <sup>34</sup> (2018)	To incorporate evidence based innovations into the discharge process to safely transition inpatient-outpatient, improve documentation and increase outpatient education participation.	qualitative	Discharge program interventions (assess knowledge, education, telephone call back) (ED; EF).	not stated	Hospital and after discharge	After	Adult patients with DM admitted at MMMC (n=50; 25 in each group)	Nursing diabetes education and outpatient education participation.

Haight, K. <sup>35</sup> et al (2019)	Does re-hospitalization differ by HF class attendance.	non-experimental	An inpatient group education.	not stated	Only hospital	After	Patients with HF (n=3758).	All cause 30-day (and 90 day) re-hospitalization.
Halpin, D.M.G. et al <sup>36</sup> (2012)	To evaluate the effect of discharge bundles COPD and phone follow up.	not mentioned	Bundle of discharge items and telephone follow-up (ED).	not stated	Hospital and after discharge	After	Patients hospitalized with COPD (n=324)	Outcomes, including readmission rates.
Hardiman, K.M. et al <sup>37</sup> (2016)	To evaluate the effect of the checklist to compare trends in readmission.	non-experimental	A checklist for patients to ensure that prior for discharge the patients understood the education and were able to perform task necessary to caring for their ileostomy (GR; TS).	not stated	Only hospital	During and after	New ileostomy patients, hospitalized (n= 430, 255 standard care; 175 with checklist)	Predictors of readmission; trends in readmission between both groups.
Hoover, C. et al <sup>38</sup> (2017)	To evaluate the effectiveness of a care transition quality improvement intervention on self-management and readmission rates in older patients with heart failure.	quasi-experimental	A care transition intervention, multidisciplinary activities: e.g. a nurse coach visit and follow up (RN Transition Coach), standard HF order set, pharmacy medication education (ED; CC; EF; TS).	Donabedian's quality assessment model and the Medical outcomes study framework (Kelly et al)	Hospital and after discharge	After	Older hospitalized patients with an admitting diagnosis HF (n=66; intervention group n=30; control group n=36)	Self-care; readmission.
Howie-Esquivel, J. et al <sup>39</sup>	To determine if hospitalized older patients can learn and retain self-care educated with teach back method.	not stated	Self-care topics education using the teach-back method' (ED).	not stated	Only hospital	After	Older hospitalized HF patients =276)	Knowledge on self-care.
Huang, T.T. et al <sup>40</sup> (2017)	To measure effectiveness of an educational empowerment program.	experimental	An education empowerment program (assessment condition and knowledge, instruction, support and counseling) (ED; CC; TS).	Based on 6 empowerment components by Kuo and Wang, five-step empowerment strategy by Chen and Wang, modified from Freire's three stage methodology.	Hospital and after discharge	During and after	Adults, 50 years or older, admitted for 1st total hip replacement surgery (n=108)	Self-efficacy; self-care competence; ADL, mobility, depressive mood, quality of live.

Jahn, P. et al. <sup>41</sup> (2014)	The evaluation of a nursing-administrated program to reduce patient's barriers and improve pain management and pain-related discharge management (the Self Care Improvement through Oncology nursing: SCION-PAIN).	experi-mental	Counseling program (SCION-PAIN), consisting 3 modules and a teaching booklet, a pain diary, discharge preparation checklist for patients, compact disk with muscle relaxation exercises (ED; CC; TS).	PRECEDE model explaining health behavior (Green, LW)	Hospital and after discharge	During and after	Patients hospitalized for anticancer therapy (n=263; 135 standard care; 128 intervention)	Patients' barriers to the management of cancer pain; intensity of pain; impact of pain and interference of pain with patients' life; coping with pain; adherence to pain medication; HRQoL.
Jiang, W. et al <sup>42</sup> (2020)	To examine the effects of a nurse-led individualized self-management program on health behaviors, control of cardiac risk factors, health related quality of life among patients with acute myocardial infarction undergoing percutaneous coronary intervention.	quasi-experi-mental	Group bases education sessions, a face to face consultation and 12 month telephone follow up (ED; CC; EF).	Developed based on the UK Medical Research Council framework for the development of complex interventions (Craig, P)	Hospital and after discharge	After	Patients with acute myocardial infarction undergoing percutaneous coronary intervention (n=112; 56 in each group)	Health behaviors; control of cardiac risk factors; health related quality of life.
Kato, N.P. et al <sup>43</sup> (2016)	To develop and evaluate the impact of a HF self-care program on HF self-care behavior, HF knowledge and time to hospitalization for worsening HF.	experi-mental	A multidisciplinary HF management program; face to face education and counseling (ED; CC).	The health belief model (Janz, NK)	Only hospital	After	Patients hospitalized with a primary diagnosis of systolic or diastolic HF (n=38; intervention group n=14; control group n=15)	HF self-care behavior; HF knowledge and time to the first HF hospitalization/ death

Kinugasa, Y et al <sup>44</sup> (2014)	To evaluate whether intensive inpatient education improved outcomes of hospitalized HF patients.	not stated	Multidisciplinary HF management program: optimal medical treatment, cardiac rehabilitation, patient education, pre-discharge assessment, discharge care plan (ED; EF).	not stated	Hospital and after discharge	After	Patients hospitalized with a primary diagnosis of HF (n=277; intervention group n=144; control group n=133)	Composite endpoints of HF hospitalization; all-cause mortality.
Klainin-Yobas, P. et al <sup>45</sup> (2014)	To report a study protocol of a RTC examining the efficacy of a symptom self-management program to help inpatients with acute myocardial infarction (AMI) to recognize and self-manage their physical and psychological symptoms.	experimental	A symptom self-management program consisting 1) Virtual Reality (VR) education, 2) (VR) relaxation, 3) homework assignment (ED).	Symptom management model (Humphreys et al 2008)	Hospital and after discharge	After	Inpatients with AMI (n=90; 30 in each group)	Physical variables (chest pain); psychological variables (stress, anxiety, depression, perceived relaxation, cardiac self-efficacy); economic related variables (length of hospital stay, numbers of rehabilitation, healthcare cost).
Koller, A. et al <sup>46</sup> (2018)	To test the effect of the ANtiPain intervention on pain intensity, functional related outcome, self-efficacy and patient related barriers to pain management.	experimental	ANtiPain intervention: three key strategies: information, skill building and nurse coaching (ED; CC; GR; EF).	Behavior change techniques (Mitchie, S)	Hospital and after discharge	After	Inpatient oncology with pain scores of 3 or higher (n=41; intervention group n= 21; control group n=20)	Pain intensity, functional related outcome, self-efficacy, patient related barriers to pain management.

Kommuri, N.V.A. <sup>47</sup> (2012)	To examine the changes in performance on heart failure knowledge assessment administered before and after discharge education.	not stated	An one to one teaching session (ED).	not stated	Only hospital	After	Patients admitted to the hospital with a diagnosis of heart failure and documented left ventricular systolic dysfunction (n=113)	Heart failure knowledge.
Korytkowski, M.T. et al <sup>48</sup> (2014)	To evaluate the ability of a formal inpatient Diabetes Education Program to improve glycemic control and patient satisfaction.	not stated	Education 1): diabetes knowledge assessment; 2) individualized education plan) (ED)	not stated	Only hospital	During and after	Not-critical ill patients with diagnose diabetes (n= 21; 12 usual care; 9 intervention)	Glycemic measures; patient satisfaction.
Künzler-Heule, P. et al <sup>49</sup> (2017)	To compare the structure and the content of the nurse-led consultation services of two hospitals	non-experimental	A nurse led consultation service (ED; CC).	not stated	Only hospital	After	Patients receiving liver transplant (n=33)	Number and content consultations.
Leppla, L. et al <sup>50</sup> (2015)	To compare an oral care self-management support protocol (OrCaSS) to usual pre-aHSCTcare.	experimental	An oral care self-management protocol consisting: OM assessment; self-assessment; brushing techniques; frequencies of rinses; written materials (ED; GR).	Behavior change techniques (Mitchie, S)	Hospital and before admission	During and after	Patients with ALM, awaiting aHSCT (n=18)	Incidence, severity, and duration of OM; patient adherence.

Lin, S. <sup>51</sup> (2020)	To determine the effectiveness of nurse-led health coaching for stroke survivors and primary care-givers in hospital to home transition care.	experimental	A nurse-led health coaching program (coaching sessions and after discharge telephone follow-up and face to face meetings) (ED; CC; EF).	Self-efficacy theory (Bandura, A)	Hospital and after discharge	After	Patients hospitalized with first time stroke (n=140 (70 patients, 70 family care givers)	Self-efficacy; quality of life; functional ability; stroke related health knowledge; number of deaths, adverse events and unplanned hospital admissions. By caregivers: self-efficacy; caregiver related burden.
Lindhardt, T. et al <sup>52</sup> (2019)	To test and compare the effect of a systematic discharge assessment with targeted advice and a motivational interview followed by a home visit.	experimental	A systematic self-management assessment with targeted advice and a motivational interview followed by a home visit (ED; CC; TS).	Motivational theory in relation to self-efficacy theory.	Hospital and after discharge	After	Patients hospitalized in department of medicine aged 65 or older (n=300)	Numbers of readmissions 3- and 6 months; number of days to first readmission; handgrip strength, 30 second chair to stand test, health related quality of life, depression, mortality, call on municipality services
Liu, X-L. et al <sup>53</sup> (2018)	To examine the impact of health education delivered during the acute admission of patients presenting with ACS and T2DM.	non-experimental	Education delivered as part of normal work; face to face teaching. After discharge telephone based education and Wechat (an online chat facility).	not stated	Hospital and after discharge	After	Patients admitted to cardiovascular units as an acute admission related to ACS who also had a diagnosis of T2DM (n=160).	Diabetes knowledge; attitudes of ACS symptom management; diabetes management self-efficacy; clinical outcomes (such as blood glucose level).

Lyse Harden, K. et al <sup>54</sup> (2015)	Discharge essential program: discharge video's to prepare for self-care after transplant.	not stated	Discharge video's/ discussion groups (ED; EF;TS).	Bloom's taxonomy (revised)	Only hospital	During and after	Stam cell transplant patients (n=57)	Attendance to the BMT support group; Overall Discharge Index
Macido, A. <sup>55</sup> (2019)	To utilize an evidence-based nurse-led DSMES program to improve patient knowledge on Diabetes Mellitus (DM) and improve patient adherence to treatment strategies.	pre-experimental	A nurse-led one to one non-structured education (ED).	not stated	Only hospital	After	Patients with DM (n=10)	Patient knowledge of DM; medication adherence.
Manning, S. <sup>56</sup> (2011)	To develop a bedside screening tool to assist medical-surgical nurses in quick identification and referral of high-risk HF patients to a HF nurse educator.	not relevant	A bedside screening tool to assist medical-surgical nurses in quick identification and referral of high-risk HF patients to a HF nurse educator who deliver self-care management and individualized discharge plan (ED).	not stated	Hospital and after discharge	After	HF patients with left ventrikel ejection fraction $\leq 45\%$	not relevant
Martorella, G. et al <sup>57</sup> (2012)	To assess the preliminary effects of SOULANGE-TAVIE on pain intensity, pain interference with daily postoperative activities, patients' pain barriers, tendency to catastrophize in face of pain, and analgesia consumption.	experimental	The soulage-tavie intervention: tool for screening patients' pain barriers and tendency to catastrophize pain; tailored computer animated educational session about pain management (ED; GR; EF).	Communication strategies for behavior change and the elaboration likelihood model (Petty, RE)	Only hospital	During admission	Patients after first-intention cardiac surgery (n=52)	Pain intensity; pain interference with daily postoperative activities; pain barriers and catastrophizing; analgesic consumption.
Merandy, K. et al <sup>58</sup> (2017)	To explore the feasibility and acceptability of a hospital-based, supplemental multimethod education intervention aimed at improving self-efficacy and self-care in patients with a new urinary diversion.	experimental	A multimethod educational intervention (ED).	Bandura's four sources of self-efficacy.	Only hospital	After	Patients with bladder cancer status post-RC with a UD (n=8)	Self-efficacy; self-care skills.

Mohaddes Ardebili, F. et al <sup>59</sup> (2017)	The effect of multimedia self-care education on the quality of life burn patients.	experimental	Multimedia self-care education and in person briefing session (ED; CC).	not stated	Only hospital	After	Patients with burns (10%-45%) (n=100; 50 in each group)	Quality of live.
Negarandeh, R. <sup>60</sup> (2011)	To evaluate the impact of discharge plan on satisfaction with nursing care, ability to self-care and incidence of re-admission.	quasi-experimental	A discharge plan (education, reinforcing teaching and counseling and transition support and follow up) (ED; CC; EF; TS)	not stated	Hospital and after discharge	During	Patient undergoing a Coronary Artery Bypass Graft (n=83; intervention group n=42 ; 41 control group n=41)	Satisfaction with nursing care, ability to self-care and incidence of re-admission.
Nowaskowski-Grier, L.A. <sup>61</sup> (2018)	To implement a diabetes inpatient nurse mentor program and assess its impact on 30-day readmission.	on-experimental	Diabetes education (ED).	AADE7 model of diabetes care and education.	Hospital and after discharge	After	Inpatients with diagnosis diabetes on pilot unit (n=74; intervention group n=34;control group n=40)	Readmission rate 30 day.
Price, K.A. <sup>62</sup> (2015)	To determine if there is a difference between patients experiencing Teach Back and patients who did not, in their self-reported understanding of how they manage their health after discharge.	pre-experimental	Teach back method (ED).	Orem's self-care deficit theory and Coleman's care transition model.	Only hospital	After	Inpatients of a rural Western US hospital (n=832)	Patients' self-reported understanding of how to manage their health after discharge.
Protopapas, A et al <sup>63</sup>	To determine the effectiveness of three different interventions: education only; education and telephone follow-up; telephone follow-up only.	experimental	Three different interventions: education only; education and telephone follow-up; telephone follow-up only (ED).	not stated	Hospital and after discharge	After	Patients hospitalized with HF (n=334)	HF knowledge and HF self-care

Rodrigues, C. et al <sup>64</sup> (2018)	To verify if a nursing care program centered on basic self-care and predefined physical activity, improve functional outcomes in older hospitalized patients.	experimental	A nursing care program including twice daily walking training, trips to toilet by walking, meals seated of the bed (CC).	not stated	Only hospital	During	Older patients admitted into medical wards (n=182, 91 in each group)	Change in the number of independent activities of daily living.
Schmidt, H. et al <sup>65</sup> (2016)	To evaluate the effectiveness of an interdisciplinary care program to enhance self-management in patients with hematopoietic stem cell transplantation.	quasi-experimental	The SCION-HSCT intervention to counteract three problems after HSCT: muscle weakness, oral mucositis, malnutrition (ED; CC; GR).	not stated	Only hospital	During and after	Patients receiving allogeneic or autologous HSCT as part of their cancer treatment (n=79, intervention group n=40; control group n=54)	Global health-related quality of life at discharge; physical activation and relaxation, prevention of OM, minimize complications, reduce malnutrition.
Song, H.Y. et al <sup>66</sup> (2014)	To assess the effects of a brief self-care support interventions to promote health related quality of life and self-care adherence among elderly patients with COPD.	experimental	Education, practicing exercise, motivational interviewing and follow up (ED; CC).	Motivational interviewing (Miller, W.)	Hospital and after discharge	After	Elderly hospitalized patients with COPD (n=40; 20 in each group)	Exercise capacity (6-minutes walking distance; PEFr/spirometry, SaO <sub>2</sub> ; knowledge; self-care adherence: degree of medication and exercise compliance (self-assessment); exercise compliance.
Stawnychy, M. <sup>67</sup> (2014)	To describe a 4 session brief motivational interviewing approach.	qualitative	Motivational interviewing (CC).	Motivational interviewing	Hospital and after discharge	After	One patient (n=1)	Behavior change.
Stotts Krall, J. et al <sup>68</sup> (2016)	To develop and evaluate the Nurse Education and Transition (NEAT) inpatient DM education model.	qualitative	NEAT protocol (assessment, video's, tools, appointment after discharge, teach back) (ED; TS)	not stated	Only hospital	After	Bedside nurses of three hospitals (n=26)	Feasibility NEAT protocol.

Sun, J. et al (2019) <sup>69</sup>	To investigate the application of self-care based on full-course individualized health education (FCIHE) and its influencing factors in patients with chronic heart failure.	experimental	An individualized health education program: education, participation in self-care, develop self-care plan, internet-based medical platform (ED; CC; GR; EF;TS).	not stated	Hospital and after discharge	During and after	Hospitalized patients with chronic heart failure (n=100; 50 in each group)	Self-care behavior; 6-min walking distance; health survey; influencing factors of self-care.
Thompson-Hutchison, F. et al <sup>70</sup> (2017)	To support patients to continue self-management of their diabetes while in hospital.	not stated	Tools for prescribers to identified those suitable for self-management; a patient agreement; a personal blood glucose meter; a diabetes self-management record; online module for education staff (GR).	not stated	Only hospital	During	not mentioned	Patient satisfaction, conveniences and accuracy in insulin dosing; decreased hypoglycemia and timely delivery of insulin doses.
Van Spall, H.G.C. et al <sup>71</sup> (2019)	To test the effect of the Patient-Centered Care Transition intervention in patients hospitalized with heart failure.	experimental	Needs assessment, education, discharge summary with action plan, follow up arrangements (ED; CC; EF; TS).	not stated	Hospital and after discharge	After	Adults hospitalized for HF (n=2494; intervention group n= 1104; control group n=1390)	Readmission; ED visit; death at three months; B-prepared score for discharge; care transition measure score; quality adjusted live-years.
Vander Weg, M.W. <sup>72</sup> (2017)	To examine the impact of a nurse-led tobacco cessation intervention focused on providing guideline-recommended care to hospitalized smokers.	quasi-experimental	A tobacco cessation intervention (training sessions for nurses, assessment patient recorded in electronic medical record, patient self-management support, organizational support and feedback for nurses) (ED; CC; GR).	Chronic Care Model (Wagner, EH)	Only hospital	During and after	Daily smokers admitted to a general medical inpatient unit (n=898; intervention group n=395; control group n=503)	Self-reported 7 days point prevalence abstinence at six month follow-up; self-reported abstinence at three-months, 30 day point prevalence abstinence, repeated point prevalence abstinence.

Vanwesemael, T.A et al <sup>73</sup> (2018)	Develop and validate a procedure for self-management of medication whilst in hospital (SelfMED). In particular inter-rater reliability of the nurses' assessment is tested.	on-experimental	Self-MED; phase 1: nurses' assessment patients' eligibility; phase 2: patients' self-assessment; phase 3: physician assessment/final decision; than self-management medication starts, monitored by the nurse (ED; GR).	not stated	Only hospital	During	Patients admitted to the cardiology/heart failure; cardiac revalidation; or post interventional care ward (n=158)	Interrater reliability.
Wang, S.p. et al <sup>74</sup> (2011)	To determine the effect of a heart failure self-care (HFSC) program.	quasi-experimental	Education, family meeting and follow-up post discharge (ED; CC; EF; TS).	not stated	Hospital and after discharge	After	Patient hospitalized, diagnosed with heart failure (n=27; intervention group n=14; control group n=13)	Distress symptoms; better functional status; improved quality of life and reduces hospital and ER readmission rates.
Wei, D. et al <sup>75</sup> (2016)	To explore the effect of humanistic care to the self-care ability of postoperative patients with breast cancer.	not stated	Humanistic care: professionals work with the patient to make a rehabilitation plan after surgery/patients were initiated to share their own experiences (CC).	not stated	Only hospital	After	Hospitalized post-operative patients with breast cancer (n=120, 60 in each group)	Self-care abilities; incidence of complications.
Wen, S.L. et al <sup>76</sup> (2019)	To determine the effects of a transtheoretical model-based intervention on patients' ostomy self-management.	experimental	Four sessions, based on characteristics of behavior change, one at baseline, one two days before discharge, one month and three months after discharge, including reinforcing teaching (ED; CC).	Transtheoretical model (Prochaska, JO)	Hospital and after discharge	After	Patients received surgical treatment with a permanent ostomy for the first time (n=94; 47 in each group)	Patients' stages of change; processes of change; decision balance and self-efficacy.

White, S.M. et al <sup>77</sup> (2014)	To discuss factors that may contribute to process improvement for patients with HF, introduce a multicomponent process of care for the institution, and explore process implementation.	not stated	An evidence based order set and clinical pathway to follow during acute hospital stay, including education, teach back and follow-up phone call (ED; EF; TS).	not stated	Hospital and after discharge	After	Patients with HF (n=59)	Self-care behavior; decreasing length of stay; readmission rates.
Whitehouse, C.R. et al <sup>78</sup> (2018)	To compare outcomes for older adults with type 2 diabetes mellitus and obesity following participation in a transitional care intervention that includes diabetes self-management education and homecare.	not mentioned	Inpatient DSME (diabetes self-management education) and homecare (ED; TS).	AADE7 model of diabetes care and education	Hospital and after discharge	After	Older adults with T2DM and obesity (n=180)	Re-hospitalization rates; glycemic control.
Wu CJ, et al <sup>79</sup> (2011)	To develop and test a cardiac-diabetes self-management program utilizing peer support for improving self-management for patients with both diabetes and cardiac conditions.	experimental	Cardiac-Diabetes Self-Management Program: three face to face education sessions, peer telephone and text-messages follow-up (ED).	Self-efficacy theory (Bandura, A)	Hospital and after discharge	After	Patients with diabetes type 2 and have been admitted to the CCU with a critical cardiac event (n=30; 15 in each group)	Self-manage practice; self-efficacy; knowledge; readmission rates.
Wu CJ, et al <sup>80</sup> (2017)	To evaluate the effectiveness of a Cardiac-Diabetes intervention on 6 month readmission rate.	experimental	A cardiac-diabetes transcare intervention (assessment knowledge, education with video, follow-up counseling) (ED; CC).	Self-efficacy theory (Bandura, A)	Hospital and after discharge	After	Patients diagnosed with acute coronary syndrome and type 2 diabetes (n=423)	Readmission rate (6 months); health status; health-related quality of life; self-efficacy; cost effectiveness.
Yingai Cui <sup>81</sup> (2016)	To evaluate efficacy of a self-management education program for patients with chronic hepatitis B and C.	experimental	Self-management education and after discharge telephone calls once a month (ED).	not stated	Hospital and after discharge	After	Hospitalized patients with hepatitis B or C (n=60)	Knowledge; clinical indicators; psychological indicators; self-management behaviors.

Zamanzadeh, V. <sup>82</sup> (2018)	To examine the effect of supportive educative interventions on self-care behaviors and readmission rates of patients with heart failure.	experimental	Patient education while hospitalized, telephone follow up after discharge (ED; EF).	not stated	Hospital and after discharge	After	Patients hospitalized because of congestive heart failure	Readmission; self-care behavior; cost of treatment, visit of physician.
Zhang, M. et al <sup>83</sup> (2014)	To test the effects of a nurse-led self-efficacy-enhancing intervention for patients with colorectal cancer.	experimental	A self-efficacy-enhancing intervention (education, handbook, video with relaxation techniques, telephone follow-up) (ED; CC).	Self-efficacy theory (Bandura, A)	Hospital and after discharge	After	Hospitalized adult patients with a diagnose of colorectal cancer (n=152, 76 in each group)	Self-efficacy; symptom distress; anxiety; depression; quality of life.

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# 5

## Towards a conceptualization of nurses' support of hospitalized patients' self-management, a Modified Delphi Study

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Submitted

## Abstract

**Aim** To determine patients', nurses' and researchers' opinions on the appropriateness and completeness of the proposed conceptualization of nurses' support of hospitalized patients' self-management.

**Design** A modified Delphi study.

**Methods** Between August and December 2022, we conducted a two-round Delphi survey. The panel group consisted of patients, nurses and researchers. The conceptualization of nurses' support of hospitalized patients' self-management presented in the first Delphi round was based on previous research, including a scoping review of the literature. Data was analyzed between both rounds and after the second round.

**Results** In the first round all activities of the proposed conceptualization were considered appropriate to support the patients' self-management. Panel members' comments led to the textual adjustment of 19 activities, the development of 15 new activities, and three statements about self-management support during hospitalization. In the second round the modified and the newly added activities were also deemed appropriate. The clarification statements raised in the first Delphi round were accepted, although questions remained about the wording of the activities and about what is and what is not self-management support.

**Conclusion** After textual adjustments and the addition of some activities, the proposed conceptualization of nurses' support in patients' self-management while hospitalized have been considered appropriate and complete. Nevertheless, questions about the scope of this concept still remains. The results provide a starting point for further discussion and the development of self-management programs aimed at the hospitalized patient.

## Introduction

Over the last few decades, healthcare models in Western societies have shifted from paternalistic models that place the patient in a passive role, towards models in which the patient is more actively involved.<sup>1,2</sup> An important notion in this development is self-management, a concept that focuses on how individuals deal with the consequences of their health condition(s) in order to maintain a satisfactory quality of life.<sup>1,3</sup> Self-management includes self-monitoring, symptom management and the management of functional, emotional, psychosocial and physical consequences of health conditions.<sup>4</sup> It requires specific tasks from patients, such as measuring parameters and symptoms that indicate that action should be taken or a healthcare provider should be consulted.<sup>3,4</sup> Patients sometimes have to change their lifestyle or have to deal with emotions such as anger, fear, frustration and depression.<sup>3</sup> Nurses can play a supporting role regarding patients' self-management.<sup>5</sup> Many self-management interventions are developed to increase self-management capacity in patients with a chronic disease living at home<sup>3,4</sup>, but self-management support seems understudied in the context of hospitalization.

## Background

Self-management support is described as "a patient-centered collaborative approach to care that promotes patient activation, education and empowerment".<sup>6,7</sup> It stimulates patients to use their own skills, information and professional services to take effective control over life.<sup>6</sup> Patient education is a basic aspect of self-management support.<sup>8,9</sup> In addition, patients can be encouraged to independently monitor symptoms, to self-treatment in response to choices.<sup>10</sup> To improve self-management, patients must have self-efficacy and believe they can control their health situation.<sup>3</sup> Self-management support does not appear to be part of daily practice in the hospital nursing care<sup>11-13</sup>. Hospital nurses have a limited knowledge of self-management and are uncertain about what is expected from them with regards to supporting patients' self-management.<sup>14</sup> The lack of clarity on this concept undermines the development of evidence-based interventions, resulting in inadequate care delivery, incomplete nursing training and a lack of healthcare policies in this area.

# Method

## Aim

The aim of this study is to determine patients', nurses' and researchers' opinions on the appropriateness and completeness of the proposed conceptualization of nurses' support of hospitalized patients' self-management.

## Design

A Modified Delphi study was performed to organize group communication and obtain an opinion on the appropriateness and completeness of the proposed conceptualization.<sup>15-17</sup> The main characteristics of a Delphi study are: a group of experts are questioned about the issue of interest; the process is anonymous in order to avoid social pressure; it is iterative, comprising several rounds of enquiry; and the subsequent rounds are informed by a summary of the group response of previous rounds<sup>17-19</sup>. The study is considered as 'modified', as the first round was based on previous studies and not, as is usual in a classic Delphi approach, on open-ended questions.<sup>17,19</sup> In this way, the available scientific evidence is combined with expert judgement to form an opinion about the activities that can be performed to support inpatients' self-management.<sup>18,20</sup> The RAND/UCLA Appropriateness Method (RAM) classification procedure was used to classify the appropriateness of each nursing activity mentioned in the proposed conceptualization.<sup>20</sup>

## Participants

The Delphi panel consisted of three groups of participants: hospital nurses who are experienced in providing care to hospitalized patients; researchers with scientific expertise in self-management; and patients who have experienced a hospital admission and are familiar with self-management. The RAM indicates a range of 7 to 15 participants<sup>20</sup>, therefore 8-12 participants from each group of panelists was considered suitable. The participants were recruited using non-probability sampling.<sup>19,21</sup>

Patients were recruited from three wards (medical, surgical and cardiologic) of two hospitals in the Netherlands. We planned to include two patients from each ward. Inclusion criteria were: able to speak and understand Dutch, have knowledge of, and/or experiences with self-management and able to reflect on issues related to self-management. The ward nurse approached suitable patients and gave them oral and written information about the study. When they agreed to participate, the researcher contacted them by phone after discharge from the hospital to discuss the study.

Two nurses from each of the six participating wards were recruited by their ward manager. Inclusion criteria were: being a registered nurse and have at least 1 year of work experience in a hospital. Researchers from different universities or colleges in different countries were recruited by the researcher using the researchers' networks, by searching the internet, and by means of the snowball method. Researchers' inclusion criteria were: being a (registered or non-practicing) nurse, and have published in a peer-reviewed journal about self-care or self-management. The researchers were informed about the study and asked if they were willing to participate by e-mail. We planned to recruit six researchers from the Netherlands and six researchers from other European countries and the USA.

All participants were informed about the importance, purpose, procedure and timeframe of the study. If desired, a phone call was scheduled to provide additional information and to increase the chance of lasting involvement of participants.<sup>16</sup> In total, 9 patients, 12 nurses and 9 researchers (n=30) agreed to participate in the Delphi study. See Table 1 for the panelists' characteristics.

<b>Patients</b>	n=9
Age (median, range)	66/56-80
Chronic disease	none: n=1 yes: n=8 (diabetes (n=2); cardiac disease (n=3); rheumatic disease (n=2); COPD (n=3)) <sup>1</sup>
Hospital	A: n=4; B: n=5
Ward	medical: n=4; surgical: n=2; cardiologic: n=3
<b>Nurses</b>	n=12
Age (median, range)	44/29-55
Hospital	A: n=6; B: n=6
Ward	medical: n=4; surgical: n=3; cardiologic: n=4
<b>Researchers</b>	n=19
Country	The Netherlands (n=4) USA (n=2) Germany (n=1) Sweden (n=1) Italy (n=1)

<sup>1</sup> the number of chronic diseases adds up to more than 9 because some patients have more than one chronic disease

**TABLE 1** PANELISTS' CHARACTERISTICS

## Data collection and analysis

The study took place between August and December 2022. The number of rounds were pre-defined on two. This number prevents a reduction in the response rate due to response fatigue of panelists.<sup>15,16</sup>

Nurses and researchers received the questionnaires by e-mail. Due to privacy legislation this was not possible for patients, so the patients received the questionnaires via regular post, along with a pre-paid return envelope.

## First Delphi round

Based on previous research of our research group, including a scoping review of the literature, we developed a draft conceptualization of nurses' support of hospitalized patients' self-management.<sup>14,22-24</sup> This conceptualization consisted of 43 nursing activities, clustered in 6 sets, reflecting the 6 aspects that make up the proposed conceptualization of nurses' support to hospitalized patients (See Box 1 and Appendix 1). In the first Delphi round, the participants were invited to provide their opinion on the proposed conceptualization of nurses' support of hospitalized patients' self-management. For this study, self-management was described as 'the way in which the patient deals with the disease and the consequences of the disease'.

- 1 Recognize and support the patient's current self-management
- 2 Increase the patient's insight and awareness of his health situation
- 3 Help the patient in coping with the disease and its consequences
- 4 Increase the patient's involvement and responsibility for his care
- 5 Involve family and/or informal caregivers in the patient's care
- 6 Support transition from hospital to home

**BOX 1** ASPECTS THAT TOGETHER FORM THE PROPOSED CONCEPTUALIZATION OF NURSES' SUPPORT TO HOSPITALIZED PATIENTS

The panelists were asked to rate the appropriateness of each activity on a nine point Likert scale, where 1 is 'completely inappropriate' and 9 is 'completely appropriate'.<sup>20</sup> The midpoint 5 means 'uncertain'. Prior to implementation, the questionnaire was pilot tested in all three groups of panelists to identify formulation problems.<sup>15,16</sup> This led to some textual improvements.

The panelists were also asked to indicate additional activities and to indicate why these activities are important. Furthermore, they were given the opportunity to comment on each set of nursing activities and at the end of the questionnaire. The panelists were asked to complete the questionnaire within two weeks. Data collection was partially anonymous. The individual responses were unknown to other participants but were known to the researcher.<sup>16</sup> After two weeks, the non-responders were reminded to complete the questionnaire.

## Data analysis first Delphi round

The Likert scale data were exported to a Microsoft Excel spreadsheet and the comments and additional activities of the panelists were placed in a Microsoft Word file. In accordance with the RAM method an activity is classified as 'appropriate', 'uncertain', or 'inappropriate' based on the median panel rating and the degree of agreement between the participants.<sup>20</sup>

Disagreement means that the dispersion of the panel ratings is great. This is measured with a disagreement index (DI): the ratio between the interpercentile range (IPR: 0.3-0.7) and the IPR adjusted for symmetry (IPRAS).<sup>20</sup> An IPR lower than the IPRAS indicates agreement, so a  $DI < 1$  indicates agreement.<sup>20</sup>

An activity is considered appropriate when the panel median is 7-9, with agreement; 'uncertain' when the panel median is 4-6 or any median with disagreement; and 'inappropriate' when the panel median of 1-3, with agreement.<sup>20</sup> Scores were analyzed using 'R'.<sup>25</sup> The median and the DI were determined for the panel as a whole and for the three separate panelist groups, i.e. patients, nurses and researchers. Median ratings that fall between the 3-point boundaries (medians of 3.5 and 6.5) were included in the higher appropriateness category.<sup>20</sup>

The panelists' additional activities and other comments were assessed, clustered by theme and developed into newly added activities, adjustments for existing activities, and relevant themes to consider, by one researcher (CO). Then two researchers (CO, JdM) discussed the comments and decided about the modifications needed for the second Delphi round.

## Second Delphi round

The second Delphi round started with a number of statements, based on the comments that were made in the first round, of which the participants were asked to what extent they agree on a nine point Likert scale, where 1 is 'strongly disagree' and 9 is 'strongly agree'. Subsequently, the results of the first round were indicated for each activity and the modifications and/or additions that have been proposed in response to the panelists' comments. Each participant received their own results as well as the combined panel results. The activities that scored 'appropriate' were accepted and not presented as a question in the second round, except when changes were advised by the participants. Otherwise, the procedure was identical to the first round.

## Data analysis second Delphi round

The scores on the statements and the activities were analyzed according to the RAM method, using 'R'.<sup>25</sup> Participants' comments were read and clustered by one researcher (CO). Two researchers (CO, JdM) discussed the comments and reached consensus on the results and on the adjustment for the final version of the conceptualization of nurses' support to patients' self-management.

## Trustworthiness

To enhance transparency and quality, we used and described the following eight evaluation points of Delphi studies: systematic identification of the problem area; selection of panel members based on objective and predefined criteria; anonymity of participants and responses; controlled feedback; iterative rounds; consensus criteria; analysis of consensus; and closing criteria defined a priori.<sup>17</sup> A ninth evaluation point, the stability of the results, was not implemented because the study consisted of only two rounds.<sup>17</sup> To enhance the robustness of this study, the guidance on Conducting and Reporting Delphi Studies (CREDES) was followed.<sup>18</sup>

## Ethical approval

The Medical Research Ethics Committee United (MEC-U) concluded that the study does not fall under the Medical Research Involving Human Subjects Act (WMO; refW22.025), because participants in this study were not subjected to physical or psychological procedures. The hospital's Medical Ethics Committee assessed the study regarding local codes of conduct and approved the study (no. 2022-014). All participants received written information about the study and gave written informed consent.

## Results

During the first Delphi round 96.7% (n=29, response rate 96.7%) and during the second round 90% (n=27, response rate 90%) of the questionnaires was completed. Not every panelist completed the entire questionnaire. See Appendix 1 for the median and the DI of each activity from both Delphi rounds, including the number of panelists who responded to the activity.

### First Delphi round

The panelists expressed their opinion on the appropriateness of the 43 activities of the proposed conceptualization of nurses' support to inpatients' self-management. Based on the results of the whole group of panelists, all activities were considered appropriate, with median panel ratings between 7-9, and DIs between 0.03 and 0.37 (See Appendix 1). The activities with the highest median scores were part of the set activities reflecting the aspect: 'Increase patient's involvement and responsibilities for his own care, namely: *'invite the patient to actively participate in care activities, for example by asking the patient for help in performing a nursing procedure, or by naming activities that the patient can perform on his/her own'* (median 9, DI 0.13) and *'offer the patient the opportunity to take responsibility for self-management activities related to daily living activities (ADL) during hospitalization (if possible)'* (median 9, DI 0.22).

Based on the separate results of the three panelist groups, it was found that one activity of the set reflecting the aspect 'Involving family and/or informal caregivers in patient's care' scored 'uncertain' in the group researchers, namely: *'ask family and/or informal caregivers to monitor patient adherence to the guidelines'* (median 5, DI 0.91). In addition, in the panel subgroup consisting of nurses, two activities scored between the 3-points boundaries of appropriateness, namely the activity *'ask family and/or informal caregivers to monitor patient adherence to the guidelines'* (median 6.5, DI 0.56) and the activity *'invite family and/or informal caregivers to attend self-management information sessions with the patient and/or receive instruction on self-management skills such as measuring blood pressure or weighing daily'* (median 6.5, DI 0.3). As agreed in advance, these scores mean that the activities are considered appropriate.

Seventeen panel members (2 nurses, 7 patients and 8 researchers) made comments when answering the questionnaire. Some comments were not relevant for the purpose of this study, e.g. because it consisted of compliments for the nursing care. The relevant comments led to the adjustment of 19 activities and the development of 15 new activities (See

Appendix 1). One activity, placed in the set 'Increase the patient's insight and awareness of his own situation' was moved to the set 'Help the patient in coping with the disease and its consequences', because this was a more suitable place. One activity of the set 'Support transition from hospital to home' was removed because it overlapped with an activity already mentioned in the set 'Help the patient in coping with the disease and its consequences'.

Many comments related to the wording of nurses' activities. It was indicated that some activities were formulated from the nurses' perspective, which showed less patient involvement and agreement. The sets of activities focusing on 'Increase patient's involvement and responsibility for his own care', 'Involve family and/or informal caregivers in patient's care' and 'Support transition from hospital to home' in particular have been adjusted to this feedback. Comments were also made on whether or not the activities are relevant to every patient, whether the activities support specific self-management or are general nursing care, and whether the hospital nurse should focus on the medical and physical consequences or also on the emotional and the psychosocial consequences of the health problem. This led to three statements related to self-management support during hospitalization (See Box 2).

- 
- 1 Supporting the patient in coping with hospitalization is part of supporting patient's self-management
  - 2 During hospitalization, nurses focus on supporting the patient's self-management with regard to:
    - managing the medical consequences of the patient's health problem, for example taking medication or wound care
    - managing the consequences of the health problem on the patient's daily life, for example the effect on patient's roles or on patient's sense of purpose
    - coping with the emotional consequences of the health problem, for example fear of surgery or depression
  - 3 When supporting the patient's self-management, the nurse should tailor the activities to the wishes, needs and possibilities of the patient and his/her caregivers and/or family
- 

**BOX 2** CLARIFYING STATEMENTS RELATED TO SELF-MANAGEMENT SUPPORT DURING HOSPITALIZATION

## Second Delphi round

In the second round, panelists assessed the appropriateness of the modified and the newly added nursing activities (see Appendix 1) and indicated the extent to which they agreed with the clarifying statements (see Box 2), both on a nine point Likert scale.

### Nursing activities

All 33 nursing activities were considered appropriate, with median panel ratings between 7-9, and DIs between 0 and 0.37 (See Appendix 1). The results were comparable within the three different panelist groups. One activity: *'Clearly indicate where the patient can go with questions in the home situation'* had a median of 9 (DI 0.13).

Eighteen panel members (5 nurses, 5 patients and 8 researchers) added comments. Once again some comments about the wording of nurses' activities were made. For clarification, 14 activities have been slightly modified textually and one activity was shifted to another set (see Appendix 1).

Comments were made about the aforementioned themes 'is this self-management support or general nursing care?' and about the need to tailor activities to the individual patient. In addition,

comments were made about what is meant by self-management, whether certain activities were aimed at self-care rather than self-management, or focused on patient participation rather than self-management. Since the number of rounds were predetermined on two, we were unable to ask the panelists for their views on these issues. The importance of listening carefully and believing in what the patient says, and preventing overburdening of the patient was also indicated. This is included in the set 'Increase patient's involvement and responsibility for his own care' which states that a nurse, together with the patient, determines whether the patient can and wants to take control of self-management activities during hospitalization. See Box 3 for the nursing activities after the second Delphi round.

- 
- 1 Recognize and support the patient's current self-management**
    - Discuss with the patient which self-management activities the patient carries out self-management at home and how he does this (e.g. blood sugar control, stoma care, medication intake)
    - Discuss with the patient whether the self-management activities in the hospital can be performed as in the patient's home situation
    - Discuss patient's preferences regarding nursing care
    - Offer the patient various options for providing nursing care
    - Ask the patient's opinion about the planned nursing care
    - Make agreements with the patient about the nursing care
    - Ask the patient's permission to perform a nursing action
    - Realize as much as possible what the patient finds important or wants to do
    - Use conversational tools (e.g. the Self-Management Web or the Self-Reliance Radar) to discuss the different aspects of self-management
  
  - 2 Increase the patient's insights and awareness of the health situation**
    - Ask the patient questions that allow the patient to think about the personal situation
    - Suggest keeping a diary to monitor symptoms and to gain insight into own health situation
    - Investigate whether the patient has questions about the disease, the treatment or the self-management
    - Provide information about the health condition/disease, risk factors and symptoms
    - Provide information about the treatment
    - Provide information about the regimen
    - Provide information about the hospital admission (such as procedures, expectations)
    - Provide information about and the content, planning and motivation of the nursing care
    - Provide information about patient's current health situation, such as blood pressure and body temperature
    - Provide information and instruction about activities that impacts recovery
    - Provide information and instruction about ways to prevent hospital complications such as malnutrition and falls
    - Use teach back method (in which the patient repeats in his/her own words what has been discussed) or another way to repeat/reinforce the given information
    - Offer the opportunity to get in touch with peers/others with similar condition

**3 Help the patient in coping with the disease and its consequences**

- Discuss with the patient the personal situation, experiences, feelings and needs
- Encourage the patient to discuss concerns and problems and provide ways to solve problems
- Discuss how the patient can cope with stress and strong emotions related to the health problem
- Clarify where the patient can receive (psychosocial) support, such as check-ups, access to community programs, information on patient groups and relevant websites
- Discuss important lifestyle changes for the patient, such as quitting smoking, following a prescribed diet, exercise regularly, medication adherence or other instructions provided
- Use motivational interview techniques to increase patient's motivation to change and to build confidence in the ability to do so
- Encourage the patient to set goals and create a personalized plan for self-management, with realistic short and long-term goals, focused on topics that are important to the patient
- Provide personalized information and/or instruction on how to manage the symptoms of the health problem
- Provide personalized information and/or instruction on how to respond to changes related to the health problem
- Provide personalized information and instruction about self-management and self-management skills. You can think of correct inhalation techniques, wound care, medication intake, checking blood sugar, recognizing complications and knowing what to do
- Using solution-focused approach that are aimed at utilizing the patient's strengths and resources
- Support the patient in learning and performing (new) self-management skills

**4 Increase patient's involvement and responsibility for his care**

- Discuss patient's and nurse's expectations about the hospitalization period, including expectations about patient's involvement in care
- Invite the patient to actively participate in care activities, for example by involving the patient in performing a nursing procedure, or by checking together which activities the patient can perform on his/her own
- Determine daily with the patient whether he/she can and wants take control of self-management activities during hospitalization (if necessary after training and under supervision)
  - related to daily living activities (ADL) during hospitalization
  - related to medication use (p.e. diabetes care) during hospitalization

- related to monitoring symptoms during hospitalization
- related to nutritional intake, diet, keeping track of body weight and/or the intake and output of fluid during hospitalization
- related to the prevention of complications, for example by performing certain exercises or specific oral care during hospitalization
- with regard to other self-management activities, such as wound care, catheter care, etc.

**5 Engage family and/or informal caregivers in patient's care**

- Determine together with the patient whether/to what extent informal caregiver(s) and/or family are involved during the admission period
- Support the patient in involving the caregiver(s) and/or the family in his/her self-management
- In consultation with the patient:
  - invite informal caregiver(s) and/or family to attend information meetings about self-management
  - invite informal caregiver(s) and/or family to receive instruction on self-management skills
- Determine together with the patient whether/to what extent informal caregiver(s) and/or family are involved after the admission period
- In consultation with the patient:
  - invite informal caregiver(s) and/or family to discuss the patient's request for help after discharge
  - ask informal caregiver(s) and/or family to offer the patient physical, social and psychological support at home
  - ask informal caregiver(s) and/or family to support the patient at home in complying with the guidelines/regimen

**6 Support transition from hospital to home**

- Discuss the home situation with the patient and determine the goals for discharge together
- Determine with the patient the planning of the discharge
- Verify if the patient has questions about performing self-management activities at home
- Verify that the patient knows where to go with questions in the home situation
- Contact the patient by phone after discharge to answer any questions

## The clarifying statements

We included three statements to clarify issues that arose in the first Delphi round (See Box 2). The first statement was based on comments that were made about whether certain activities specifically support the patient's self-management or are general nursing care or nurses' attitude. The activities targeted by these comments were mainly related to recognizing and supporting the patient's current self-management. This led to the statement: 'Supporting the patient in coping with hospitalization is part of supporting patient's self-management'. The respondents agreed with this statement (median: 8, DI: 0.16). Several comments have been made on this statement from panel members of the group of researchers, indicating being confused by the definition of self-management used, indicating not only patients but also their family should be included, and indicating that it depends on the outcomes the nurse aims to achieve.

In the first Delphi round, comments were posted on the focus of nursing care in the hospital. The question arose as to what the focus of nursing care in the hospital should be. Is this primarily on supporting the patient in coping with the physical and medical consequences of the health problem or also on other consequences? This resulted in three statements in which panelists were asked their view on three different aspects of self-management support, using the three tasks of self-management identified by Corbin and Strauss: medical management, such as taking medication; behavioral management, such as adapting lifestyle; and emotional management, such as dealing with emotions<sup>26,27</sup> (See Box 2). These three statements were agreed (median: between 7.5 and 8, DI from 0.16-0.23). Panelists also added comments showing they agree. One panelist questioned the meaning of 'medical' in the statement and questioned whether wound care, cited as an example, can be considered a medical consequence. In addition, the importance of a multidisciplinary team was indicated, particularly with regard to the emotional consequences of the illness, and comments have been made indicating that the options for support depend on the specific situation of the patient, including the home situation, the length of hospital stay and any necessary aftercare.

The last statement is based on comments made on the need to tailor nurses' activities to the wishes, needs and capabilities of the individual patient, and on comments made on the need to provide standard care (See Box 2). This statement was also agreed (median: 8, DI: 0.21). Some remarks have been added confirming the importance of this statement.

## Discussion

In this modified Delphi study, patients, nurses and researchers agreed on the appropriateness and completeness of a conceptualization of nurses' support of inpatients' self-management. No new sets of activities were defined during the Delphi study, but 15 new activities were added to existing sets and two sets of activities were formulated differently. Various activities were also reformulated, supplemented or moved to another set. One activity was deleted because it has already been mentioned elsewhere. The final version of this conceptualization consists of 56 nursing activities categorized into 6 sets (See Box 3).

The panelists agreed with the conceptualization, but also indicated a number of questions and points for discussion. Comments were regularly made on the formulation of nurses' activities, which seemed to address too little the patients' involvement and agreement. Nurses' activities should always be discussed with and acceptable to the patient.<sup>28</sup> To emphasize this, we have indicated in various activities that nurses should undertake these together with or in consultation with the patient.

Some panel members indicated that certain activities may not be appropriate to support the self-management of every patient and/or in every situation. The selection of nursing activities for a particular patient is part of the clinical judgement of the nurse, which is based on several factors, among which the desired patient outcomes and the acceptability to the patient.<sup>28</sup> It is not the intention that the activities mentioned in the proposed conceptualization are always fully implemented, but that nurses can determine, based on their clinical judgement and in consultation with the patients, which activities are suitable.

Also panelists suggested that the exact content of an activity should be tailored to the patient's needs, capacities and circumstances, something that is confirmed by the literature.<sup>29</sup> To emphasize this, we have added to some activities that they must be personalized.

In addition, several comments were made about what self-management support is and what not. This gave insight into possible differences in perspectives on self-management. One of the issues related to whether certain activities specifically support self-management or can be considered general nursing care, or general nurses' attitude. It is difficult to determine what the exact boundaries of general nursing care are, because there is no generally accepted description of this concept. Some proposed activities, e.g. 'discuss patient's preferences regarding the nursing care' and 'discuss patient's and nurse's expectations about the hospitalization period' can reflect a general attitude of nurses, but also encourages the patient's

self-management during hospital stay.<sup>22</sup> Many of the activities mentioned in the proposed conceptualization of self-management support during hospitalization are already part of regular nursing care<sup>24</sup> which can make it difficult to judge whether an activity is appropriate to support patient's self-management or can be considered as general nursing care. Sometimes it depends on the specific purpose and content of the activity whether or not it supports self-management. For example, information on treatment and regimen may consist of general information, not tailored to the individual patient and without regard to potential problems that may arise after discharge. For post-discharge self-management however, the patient needs not only knowledge, but also a plan and the ability and motivation to carry out that plan.<sup>30</sup>

The activities of the proposed conceptualization should not be considered in isolation, but rather as a whole from which to choose, depending on the needs, wishes and possibilities of the patient. Most of the activities are described in abstract terms and need further content aimed at supporting the self-management of specific patient populations.

Another question that arose from panelists' comments had to do with the difference between self-care and self-management. Some panelists asked whether certain activities support self-management or support self-care. Self-management can be seen as a subset of self-care, focusing on managing the actual or potential impact of disease.<sup>4,31</sup> From this point of view, self-care activities such as activities of daily living (ADL) can be seen as self-management when the disease makes it different from usual. Nurses see stimulating ADL as self-management support, as a first step to regain the patient's self-confidence and as a starting point to perform more self-management tasks.<sup>14</sup> Therefore, encouraging patient's self-responsibility for ADL tasks is seen as part of supporting the self-management of hospitalized patients.

Finally, panelists noted that some activities seem to focus on patient participation rather than self-management. Understandable, because both concepts are interrelated and fit in with the trend towards a more participatory healthcare.<sup>2</sup> Various studies have shown that patient participation has a positive effect on self-management.<sup>32</sup> Patient participation is seen as a strategy to achieve patient-centeredness and patient empowerment, which stimulates self-management.<sup>2</sup> Therefore, it can be argued that activities stimulating patient participation also support self-management.

Self-management does not stop when a patient is hospitalized. It is patient's daily task.<sup>3</sup> Self-management support is central to nursing, also within the hospital setting.

There are many conflicting definitions of self-management and self-care<sup>31</sup>, which may explain why differences in perspectives on self-management became apparent in our Delphi study. Despite these differences, the Delphi panel agreed on the appropriateness and completeness of the conceptualization of nurses' support of inpatients' self-management.

Self-management support to hospitalized patients, regardless of whether the reason for hospitalization is chronic or acute, has been understudied. Our Delphi study provides an impetus for further discussion on the topic. Next step is to develop self-management support programs for specific hospitalized patient populations, based on this conceptualization, and to assess the effectiveness of these programs on patients' self-management.

## Strengths and limitations

We chose to conduct a Delphi study because this method is an appropriate group method that does not require the panelists to meet physically. It also made it easy to involve international experts. Our study solicited information from three groups of experts with a wide range of experience to ensure that the entire spectrum of opinions was taken into account. This strengthened the likelihood that the results will hold across multiple contexts and settings.

It proved to be difficult to include patients who were able to reflect on issues related to self-management, which is why we did not reach the target number of 12 participating patients. Researchers who met the inclusion criteria and were willing to participate were also difficult to find. The RAND/UCLA Appropriateness method indicates a range of 7 to 15 participants<sup>20</sup>, therefore 9 participants from the group of patients and researchers were considered suitable.

In general, the Delphi method has been criticized with regard to reliability and validity.<sup>21</sup> There is no guarantee that the same results will be obtained in another panel of experts and the validity of the results would be debatable because the researcher has no influence in the development of the following questionnaires. Quality criteria used in qualitative research are more appropriate to evaluate a Delphi study.<sup>21</sup> We focused on trustworthiness and performed and described this study according to the evaluation points of Delphi studies by Nasa et al (2021) and the CREDES guidance.<sup>18</sup> This enhanced its trustworthiness and provides insight into the quality of the study. Another strength of study was the use of the clear rules of the RAM classification procedure to determine the appropriateness of the activities propose.<sup>20</sup> There is no standard threshold for determining consensus in a Delphi study. The RAM developed a method, based on the

classic definition for agreement within a 9-member panel (meaning that agreement exists when no more than 2 panelists rate outside the 3-point region with the median) that can be applied to any panel size.<sup>20</sup> Also the high response rate for both rounds (96.7% and 90%) is a strength of this study.

In the interpretation of the results, some limitations should be considered. First, only Dutch patients and nurses were included, which may limit the generalizability of the findings. We involved international experts to reduce this effect. Secondly, because this Delphi study was conducted with several groups of experts, including patients, we did not use a scientist definition of self-management, but gave a simple and broad description. This confused some respondent from the group of researchers, probably because they usually use a different definition. This may have led to some of the comments made about the boundaries of the concept. Third, the modifications made after the second round were not presented to the Delphi panel. These were minor textual adjustments that most likely would not have led to a different result. We also did not discuss the issues surrounding the boundaries between self-management and self-care that emerged in the second round, because the number of Delphi rounds were predetermined on two. However, the difference between, and the relationship among self-management and self-care are not clear in the literature<sup>4,31,33</sup> and both terms are often used interchangeably.<sup>8,34</sup> A third Delphi round would not have clarified this. Finally, the evidence for the effectiveness of these nursing activities on self-management has not been investigated. The existence of consensus within a Delphi study does not mean that the correct answer has been found.<sup>21</sup> Our Delphi study did not yield a right or wrong answer, but a valid opinion of experts in the field of self-management and self-management support.

## Conclusion

After textual adjustments and the addition of some activities, the proposed conceptualization of nurses' support in patients' self-management while hospitalized have been considered appropriate and complete by a Delphi panel consisting of patients, nurses and researchers. The final conceptualization consists of 56 nursing activities categorized into 6 sets (See Box 3). The Delphi study also gave us insight into some issues surrounding this concept. Different perceptions about the boundaries between self-management and self-care exists and it is not always clear how self-management support relates to general nursing care and patient participation. The results can be considered as a starting point for practice to discuss these issues, and develop, implement and research self-management programs specific for their patient population.

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	provide information about the regimen	28	8	0,13	
	provide information and instruction about self-management and self-management skills. You can think of correct inhalation techniques, wound care, medication intake, checking blood sugar, recognizing complications and knowing what to do	28	8	0,13	moved to intervention 2
	provide information about the hospital admission (such as procedures, expectations)	27	7	0,16	
	provide information about and the content, planning and motivation of the nursing care	27	8	0,16	
	provide information about patient's current health situation, such as blood pressure and body temperature	27	8	0,03	
	provide information and instruction about activities that impacts recovery	29	8	0,08	
	provide information and instruction about ways to prevent hospital complications such as malnutrition and falls	29	8	0,24	
	use teach back method (in which the patient repeats in his/her own words what has been discussed) or another way to repeat/reinforce the given information	29	8	0,24	
					offer the opportunity to get in touch with peers / fellow sufferers
<b>3 Help the patient in coping with the disease and its consequences</b>	discuss with the patient the personal situation, experiences, feelings and needs	29	8	0,22	
	encourage the patient to discuss concerns and problems and provide ways to solve problems	29	8	0,22	
	discuss ways to deal with stress and strong emotions	28	8	0,16	discuss ways to deal with stress and strong emotions related to the health problem
	clarify where/with which the patient can receive (psychosocial) support, such as check-ups, access to community programs, information on patient groups and relevant websites	29	8	0,16	

	discuss important lifestyle changes for the patient, such as quitting smoking, following a prescribed diet, exercise regularly, medication adherence or other instructions provided	28	7	0,16				
	use motivational interview techniques to increase patient's motivation to change and to build confidence in the ability to do so	28	8	0,28				
	encourage the patient to set goals and create a personalized plan for self-management, with realistic short and long-term goals, focused on topics that are important to the patient	28	8	0,29				
					provide information and instruction on how to manage the symptoms of the health problem	25	8	0,11
					provide information and instruction on how to respond to changes related to the health problem	25	8	0,16
					using solution-focused approach that are aimed at utilizing the patient's strengths and resources	25	8	0,27
					support the patient in learning new self-management skills	25	8	0,13
					let the patient practice and demonstrate the (new) self-management skills	25	8	0,11
<b>4 Increase patient's involvement and responsibility for his care</b>	discuss patient's and nurse's expectations about the hospitalization period, including expectations about patient's involvement in care	28	8	0,28				
	invite the patient to actively participate in care activities, for example by asking the patient for help in performing a nursing procedure, or by naming activities that the patient can perform on his/her own	27	9	0,13	invite the patient to actively participate in care activities, for example by involving the patient in performing a nursing procedure, or by naming activities that the patient can perform on his/her own	26	8	0
	assess the patient's abilities to take responsibility for self-management activities during hospitalization	29	8	0,29	determine together with the patient whether he/she can and wants take control of self-management activities during hospitalization (if necessary after training and under supervision)	26	8	0,21
	offer the patient the opportunity to take responsibility for self-management activities related to daily living activities (ADL) during hospitalization (if possible)	29	9	0,22	determine together with the patient whether he/she can and wants take control of self-management activities related to daily living activities (ADL) during hospitalization (if possible)	25	8	0,11

offer the patient the opportunity to take responsibility for self-management activities related to medication use and/or diabetes care during hospitalization (if possible)	29	8	0,29	determine together with the patient whether he/she can and wants take control of self-management activities related to medication use and/or diabetes care during hospitalization (if possible)	26	8	0,13
offer the patient the opportunity to take responsibility for self-management activities related to monitoring symptoms during hospitalization (if possible)	29	8	0,29	determine together with the patient whether he/she can and wants take control of self-management activities related to monitoring symptoms during hospitalization (if possible)	26	8	0,16
offer the patient the opportunity to take responsibility for self-management activities related to nutritional intake, diet, keeping track of body weight and/or the intake and output of fluid during hospitalization (if possible)	29	8	0,29	determine together with the patient whether he/she can and wants take control of self-management activities related to nutritional intake, diet, keeping track of body weight and/or the intake and output of fluid during hospitalization (if possible)	26	8	0,15
offer the patient the opportunity to take responsibility for self-management activities related to the prevention of complications, for example by performing certain exercises or specific oral care during hospitalization (if possible)	28	8	0,29	determine together with the patient whether he/she can and wants take control of self-management activities related to the prevention of complications, for example by performing certain exercises or specific oral care during hospitalization (if possible)	25	8	0,23
				determine together with the patient whether he can and wants to take control of self-management activities during hospitalization with regard to other self-management activities, such as wound care, catheter care, etc.	24	8	0,16
<b>5 Involve family and/or informal caregivers in patient's care</b>							
invite family and/or informal caregivers to attend self-management information sessions with the patient and/or receive instruction on self-management skills such as measuring blood pressure or weighing daily	28	7	0,37	determine together with the patient whether/to what extent informal caregiver(s) and/or family are involved during the admission period	25	8	0,13
invite family and/or informal caregivers to discuss the patient's request for help and the discharge plan	28	8	0,28	support the patient in involving the caregiver(s) and/or the family	25	8	0,13
				in consultation with the patient, invite informal caregiver(s) and/or family to attend information meetings about self-management	25	8	0
				in consultation with the patient, invite informal caregiver(s) and/or family to receive instruction on self-management skills	25	8	0,27
				in consultation with the patient, invite informal caregiver(s) and/or family to discuss the patient's request for help after discharge	26	8	0,16

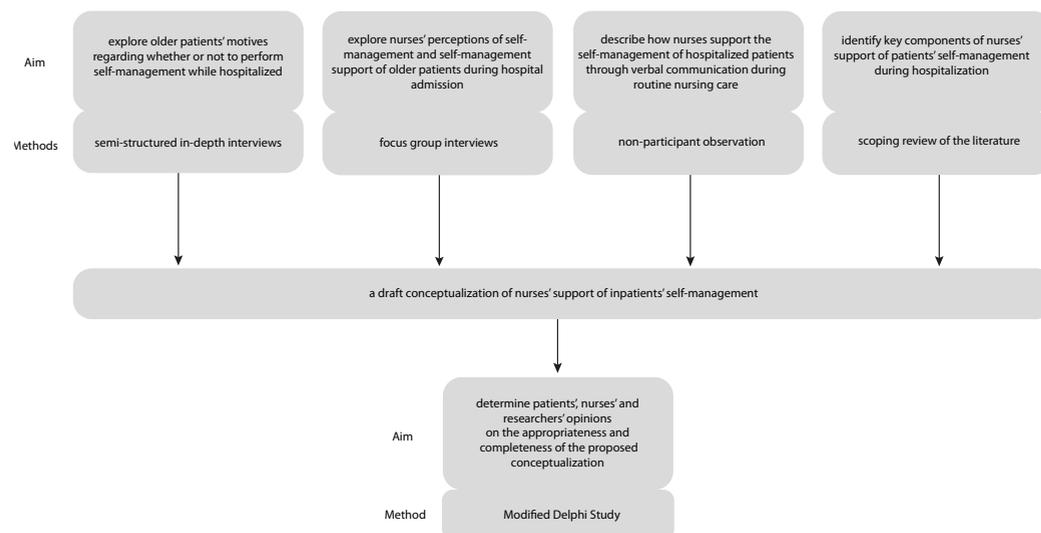
	invite family and/or informal caregivers to help them adopt a supportive attitude in their interaction with the patient	28	7	0,16		determine together with the patient whether/to what extent informal caregiver(s) and/or family are involved after the admission period	26	8	0,07
	ask family and/or informal caregivers to help the patient at home	28	7	0,35		<i>deleted, became part of another activity</i>			
	ask family and/or informal caregivers to provide the patient with social and psychological support	28	7	0,37		in consultation with the patient, ask informal caregiver(s) and/or family to offer the patient physical, social and psychological support at home	26	8	0,08
	ask family and/or informal caregivers to monitor patient adherence to the guidelines	28	7	0,36		in consultation with the patient, ask informal caregiver(s) and/or family to support the patient at home in complying with the guidelines/regimen	26	8	0,16
<hr/>									
<b>6 Support transition from hospital to home</b>	prepare the patient to return home	29	8	0,29		discuss the home situation with the patient and determine the goals for discharge together	26	8	0,07
	discuss how the patient can resume self-management at home	29	8	0,29		determine with the patient the planning of the discharge	26	8	0
	discuss any new self-management activities with the patient	29	8	0,29		discuss how the patient can perform self-management activities at home	26	8	0,13
	check that the patient understands the self-management plan after discharge and knows what to do with questions about the disease	29	8	0,29		<i>removed, already mentioned in intervention 3</i>			
						clearly indicate where the patient can go with questions in the home situation	25	9	0,13
						contact the patient by phone after discharge to answer any questions	26	8	0,16
<hr/>									

# General discussion

The general aims of this thesis are to clarify the concept of nurses' support for hospitalized patients' self-management and to investigate how nurses can support inpatients' self-management. We begin this chapter with an overview of the main findings of the studies and the most important considerations regarding the findings and the methods used. Next, we indicate what nurses can do to improve their support of patients' self-management during hospitalization, given the findings of this thesis.

## General results

Several generic qualitative descriptive studies, a scoping review of the literature, and a Delphi study were conducted. See Figure 1 for an overview of the studies.



**FIGURE 1** OVERVIEW STUDIES IN THIS THESIS

Interventions that support patients' self-management are considered complex interventions. They consist of several components that depend on and interact with each other and their complex contextual factors.<sup>1,2</sup> The number and variability of outcomes, and the number and difficulty of behaviors and attitudes required for delivering or receiving the intervention, also add to the complexity.<sup>2</sup> Designing complex interventions requires a comprehensive development process to minimize the risk of exposing patients to ineffective interventions and reduce research waste.<sup>1,3</sup> Qualitative methods, such as interviews and focus groups, as well as surveys and participant observation are suitable approaches to explore the nature of the problem and how the problem is perceived from different perspectives.<sup>1,2</sup> We explored patients' motives related to self-management during hospitalization (Chapter 1), investigated nurses' perceptions of self-management and self-management support (Chapter 2), and observed nursing communication concerning patients' self-management (Chapter 3) to create a deeper understanding of how to support patients' self-management during hospitalization.

The interviews with patients described in Chapter 1 show that nurses can support inpatients' self-management by discussing hospital stay expectations and patients' involvement in their care, and by inviting patients to participate. Patients' motives to self-manage during hospitalization can also be strengthened by providing information about what the patient can do to stimulate recovery or prevent complications.

The focus group interviews with nurses described in Chapter 2 show that nurses have a positive attitude towards self-management, but also that they find it difficult to transfer control for care tasks to patients and often take over care tasks and decisions from patients, more often than is necessary given the patient's condition. Nurses need to be more aware of this behavior and how this affects patients' self-management. It seems unclear to nurses what is expected of them in the field of self-management support and they experience few opportunities to carry out this activity.

The observations of nurses' verbal communication with patients (Chapter 3) show that while nurses have methods to support hospitalized patients' self-management, this does not appear to be an integral part of daily practice. Nurses ask patients about their self-management at home and encourage patients to express their opinions and to be involved in the care process. However, this usually happens ad hoc, in short conversations during the performance of other care tasks, and often as a one-way flow of information from nurse to patient. It can be concluded that nurses should pay more conscious attention to the patient's self-management.

To map out the current state of research concerning self-management support during hospitalization we conducted a scoping review of the literature (Chapter 4). Most activities identified by this scoping review are part of regular nursing care. Nevertheless, the focus on patients' self-management may influence their content. A relatively new self-management support activity highlighted in the review is the transfer of responsibility for certain care tasks to patients during hospitalization. Nurses sometimes transfer responsibility for some of the physical consequences of the illness, e.g. ADL tasks, but much less for other self-management tasks that the patient has to undertake after discharge.

Based on the four studies described in Chapters 1 to 4, we developed a draft conceptualization of nurses' support of inpatients' self-management. To determine patients', nurses', and researchers' opinions on the appropriateness and completeness of this draft conceptualization we conducted a modified Delphi study (Chapter 5). The draft conceptualization has been improved, supplemented, and considered appropriate. The final result consists of 56 nursing activities, divided into 6 sets (Box 1 and Chapter 5). The Delphi study also revealed some issues around the concept of self-management, including the difference between self-care and self-management.

- 
- 1 Recognize and support the patient's current self-management
  - 2 Increase the patient's insight and awareness of his health situation
  - 3 Help the patient in coping with the disease and its consequences
  - 4 increase the patient's involvement and responsibility for his care
  - 5 Involve family and/or informal caregivers in the patient's care
  - 6 Support transition from hospital to home
- 

**BOX 1** SETS OF NURSING ACTIVITIES THAT TOGETHER FORM THE PROPOSED  
CONCEPTUALIZATION OF NURSES' SUPPORT TO HOSPITALIZED PATIENTS

## Considerations regarding the findings and the methods used

### The concept of self-management

There is no conceptual clarity about self-management in scientific literature.<sup>4-6</sup> The differences and relationships between self-management and self-care are not clear and both concepts are often used synonymously.<sup>4,5</sup> This was also reflected in some of our studies. Interviewed nurses often used the terms self-care and self-management interchangeably (Chapter 2). In addition, some respondents in the Delphi study questioned whether certain activities of the conceptualization support self-management or self-care (Chapter 5).

The concepts of self-care and self-management have a lot of commonalities. They both assume the same worldview in which individuals are primarily responsible for their health and focus on the same outcomes, such as improved quality of life and lower healthcare system usage.<sup>4</sup> It is unclear exactly where the boundary lies between these two concepts.

In this thesis, we have not focused on solving the discussion around these concepts. We aimed to clarify what nurses can do to support hospitalized patients' self-management. As in the Dutch general nursing competency framework, in this thesis self-management is defined as: 'the individual's ability to prevent health problems wherever possible, and, when these still occur: to handle the symptoms, treatment, physical, psychological and social consequences of the health problems and the required lifestyle changes'.<sup>7,8</sup>

However, where relevant, we have taken into account that the differences between self-care and self-management are unclear. In the qualitative analysis of the focus group interviews, we also included sentences in which the nurses mistakenly used the word self-care instead of self-management. To avoid missing relevant information in the scoping review of the literature, we included both terms, self-care, and self-management in the search string (Chapter 4). Interventions reported to be aimed at self-care were verified to determine whether they focused on managing the actual and potential impact of a disease. If not, the intervention would be excluded. This proved unnecessary, as all interventions reported to be aimed at self-care turned out to be aimed at managing the actual or potential impact of patients' illness (Chapter 4).

## The target group and scope of the studies

The first two studies in which we examined patients' motives related to self-management during hospitalization (Chapter 1) and nurses' perceptions of self-management and self-management support (Chapter 2), were focused on older patients, as supporting patients' self-management while in the hospital can especially be useful to improve care for older people in the hospital setting.<sup>9</sup> But nurses' role in supporting inpatients' self-management is relevant for all patient groups, not only for older patients. Therefore, in the following studies, the observational study (Chapter 3) and the scoping review (Chapter 4), we focused on supporting the self-management of all adult hospitalized patients. It has not been investigated how younger adult patients experience self-management while hospitalized and what nurses' perceptions are of supporting younger adult patients' self-management. It is therefore recommended to investigate this in a subsequent study.

The first studies were also mainly focused on supporting the self-management that the patient demonstrates during hospitalization. The review reported in Chapter 4 shows that this cannot be seen separately from the patient's self-management before and after hospitalization. Therefore, the proposed conceptualization of inpatients' self-management support also addresses how nurses deal with patients' self-management before and after admission to the hospital.

We have investigated how nurses can support patients' self-management during hospitalization and developed a draft conceptualization of nurses' support of inpatients' self-management. While some respondents in the Delphi study asked questions about what self-management support is and what it is not, reflecting the unclear boundaries between both concepts, the Delphi panel agreed on the appropriateness and completeness of the conceptualization (Chapter 5).

The nursing activities described in the conceptualization, largely correspond to the components that make up programs for supporting community-dwelling patients in their self-management of chronic illness. The difference between providing self-management support in both settings lies mainly in the environment where the support is given, the patient's physical and mental condition, and the time available. Hospitalization is of limited duration and hospitalized patients sometimes feel too sick to self-manage, so there is little time to support patients in changing behavior and/or developing new self-management skills. This reinforces the importance of the development of self-management support programs across the continuum of care. However, self-management support is not only about acquiring new skills, but also about having the patient perform as many pre-existing self-management tasks as possible during the hospital stay and increasing the

patient's confidence in performing these self-management tasks. This also can be done during a short hospital stay.

Our conceptualization shows how nurses can strengthen patients' established self-management, support patients' self-management of the consequences of hospitalization, such as the prevention of (hospital) complications, and prepare the patient for self-management after discharge.

The interviews with patients show that patients often see themselves as guests in the hospital and therefore adapt to what they regard as hospital rules (Chapter 1). Hospitalized patients do not see themselves as collaborating partners or as someone who can influence personal care. This tends to be different for patients who receive nursing care at home because the patient is more in control here. Nurses should be aware of this and discuss mutual expectations about hospital care and the role of the patient with patients (Chapter 1).

The evidence for the effectiveness of the activities found to support the self-management of hospitalized patients has not been examined in our study. Most activities are part of regular nursing care and their effectiveness has probably been studied earlier. However, the focus on self-management is relatively new and most likely not included as a desired outcome in these studies. Therefore, the next step is to investigate the effectiveness of the identified activities on the patients' self-management.

## Implications for hospital nurses

Currently, healthcare systems are changing from the disease model of treating episodic illness to a focus on health and systems that reward providers for quality outcomes, with a focus on what is important to patients, and for interventions to prevent diseases.<sup>10-12</sup> Several factors drive this reform. This includes the shrinking workforce, the aging population, increased life expectancy, the growing number of people with a chronic illness, the unsustainable growth in healthcare costs, and the current healthcare infrastructure, with an emphasis on specialization, healthcare professionals working in silos, and a hierarchical structure that undermines teamwork.<sup>10,12</sup>

In the Netherlands, this led to the development of the 'Kader Passende Zorg' (Appropriate care) in which the Healthcare Institute of the Netherlands (Zorginstituut Nederland) commissioned by the Ministry of Public Health, Welfare and Sport (Ministerie van Volksgezondheid, Welzijn en Sport) describes what needs to be done to make healthcare future-proof.<sup>13</sup> Important principles are: care is value-driven; is teamwork, created together with the patient; is given in the right place; and is aimed at health instead of illness.<sup>13</sup>

For healthcare professionals, this will require a different way of acting. It leads to a shift from a provider-centric healthcare system, where the care provider knows what is good for the patient, to a patient-centered system, that engages patients by developing their health literacy and self-management.<sup>10</sup> Nurses are often close to the patient. Their position and education enable them to play a leading role in this transition.<sup>10</sup> Nurses can help prevent people's needs from being medicalized too quickly<sup>12</sup> and can support the patients in performing self-management.<sup>14</sup>

Our studies show that nurses do have methods to support the self-management of hospitalized patients, but this does not seem to be part of everyday practice. Based on our findings, nurses can take the following steps to integrate self-management in their practice: value self-management support during hospitalization; discuss the effects of self-management on nursing; and make self-management support part of policy, education and research.

## Value self-management support during hospitalization

### Emphasize the importance of inpatients' self-management

First of all, nurses must understand the importance of patient's self-management, not only patients' self-management at home but also their self-management while hospitalized. In the focus group interviews, described in Chapter 2, nurses indicate that self-management strengthens patients' independence and self-esteem and promotes recovery. According to the nurses, it also benefits the collaboration between patients and nurses. These benefits are consistent with the literature on self-management outcomes.<sup>15</sup>

In addition to these more personal interests, there also are broad social interests to stimulate patients' self-management. As indicated above, there is a need to change the current healthcare system towards a more participatory system in which self-management plays an important role.<sup>10-13</sup>

Last, it is the professional duty of nurses to promote or restore health.<sup>16</sup> In recent days, health is no longer seen as the absence of disease, but as 'the ability to adapt and to self-manage in the face of social, physical, and emotional challenges'.<sup>17</sup> So it is the professional duty of nurses to support patients in their ability to self-manage.

### Prioritize self-management support

Once the motivations for nurses to support inpatients' self-management are clear, the next step is to prioritize these activities. One of the influencing factors of nurses' behavior concerning inpatient's self-management found in

our study is the perceived lack of opportunities to provide self-management support due to a high workload (Chapter 2). Nurses cannot always provide their patients with all the necessary care, they often have to make choices about which nursing care to perform and which to omit.<sup>18-20</sup> A study across European hospitals showed that the highest priority is given to physical care, monitoring, and activities that, when omitted, have immediate negative consequences (e.g. pain management).<sup>21</sup> Activities for which the required time effort related to its added value is difficult to estimate, such as 'talk with patients' and 'educating patients and families', seem to receive the lowest priority and are more often indicated as left undone.<sup>21</sup> These activities are part of nurses' self-management support.

Missed nursing care is not only caused by a high workload or by a shortage of time but also by expectations about what needs to be done and the outcomes that are considered important in the provision of care.<sup>22</sup> The emphasis of nursing work in a hospital is largely on the support of medical treatment and less on the fundamental elements of nursing care, which consists of physical aspects, such as eating, drinking, and mobility; psychosocial aspects, such as privacy, emotional wellbeing and being involved and informed; and relation aspects, such as compassion and engaging with patients.<sup>22,23</sup> Feo (2016) argued that the central problem of patients' fundamental care needs not being met lies in the invisibility and subsequent devaluing of fundamental care, caused by the focus on the biomedical model, the consequences of managerial approaches that drive healthcare, and the devaluing of fundamental care by nurses themselves. Therefore, the first step is the valuing and prioritizing of self-management support as an important task of hospital nurses by the nurses themselves.

Nurses' priorities are influenced by factors within their professional practice environment, such as the unit culture, rules and routines, and the expectations of others.<sup>20</sup> They may view holistic care as unrealistic and develop personal norms for coping with limited healthcare resources.<sup>20</sup> This view can be influenced by, for example, education, training, and discussing the vision of care.<sup>20</sup> It is important that nurses become aware of the negative impact of not supporting patients' self-management.<sup>20</sup> Studies on missed nursing care indicate that investing in teamwork and clinical leadership can reduce missed nursing care.<sup>24-26</sup> Currently, many nurses believe that each patient should be cared for by only one nurse for the duration of a shift, but research shows that teamwork, where the team members view their work as 'ours' and not 'mine', know each other's workload and need for help, and accept team leadership roles and responsibilities, results in greater quality of care, fewer errors and more satisfied patients.<sup>27</sup>

## Discuss the effects on nursing

### Questions about 'good nursing care'

The findings from the patient interviews suggest that patients are willing to perform self-management tasks while hospitalized when encouraged and invited by nurses (Chapter 1). However, in the focus group interviews, nurses indicated that they regularly do the opposite: although they are positive about self-management, they take over care activities and decisions from patients more often than necessary (Chapter 2). Although nurses generally support the idea of empowering patients, their practice often reflects working from a paternalistic biomedical model.<sup>28</sup>

Because many of the activities mentioned in the proposed conceptualization of self-management support are already part of regular nursing care, nurses can consider that there is nothing new to self-management and that there is no need for change.<sup>29</sup> This was reflected in the Delphi study, where it was mentioned by respondents that certain activities can be considered as general nursing care, or as a general attitude, and perhaps not as self-management support (Chapter 5).

It depends on the specific content of the activity and the extent to which the nurse matches the patient's knowledge, wishes, and possibilities to make an activity supportive or not. For example, traditional patient education consists of disease-specific information and technical skills, self-management education also stimulates patients to identify their problems and provides techniques to help patients make decisions and self-management action plans.<sup>30</sup> Nurses are trained to take a holistic approach and be patient-centered,<sup>31</sup> but, as research has shown, this is usually done on an ad hoc basis, as something to fit into other tasks, not usually as a recognition of patients' needs and knowledge concerning self-management (Chapter 3).<sup>32</sup> So there is a need to change current practice. Stimulating patients' self-management means acknowledging that patients know themselves best and that patients should be actively involved in care and decision-making.

As previous research and our focus group interviews show, nurses find it difficult to let go of their professional control because they fear that patients may not always make the best choices or make executable decisions (Chapter 2).<sup>33</sup> Especially nurses who see self-management as 'compliance to the medical regimen' do not easily accept unhealthy behavior from their patients because this conflicts with their perceptions of good quality care.<sup>33</sup> In addition, there are questions about responsibilities and accountability in the case of patients' self-management while hospitalized, e.g. regarding self-management of medication.<sup>34</sup> Nurses in our studies also indicate that patients need to be motivated, otherwise, self-management will

be difficult or not possible (Chapter 2). This is remarkable because nurses' support should consist of education and motivating patients to self-manage.

The underlying question in these examples is 'What makes nursing care of good quality?'. Is this by acting according to professional standards or according to what patients consider right for their lives? And 'What is meant by good self-management?'. From nurses' view 'good' self-management may be linked to adherence to advice from health professionals while from patients' perspective, it may mean adapting advice and modifying adherence to live well.<sup>15</sup>

Issues related to self-management support rest on nurses' views about what constitutes good care provision and what is considered good self-management.<sup>33,35</sup> Currently, nurses seem to have a limited understanding of self-management and self-management support (Chapter 2).<sup>36</sup> It is important for future practice to discuss opinions about good nursing care, good self-management, and good self-management support with all members of the care team, including patients, to create a collective vision.<sup>33</sup>

### Clarity on nurses' role

As our focus group interviews revealed, nurses do not experience clear role expectations from patients or hospital policy (Chapter 2). Role ambiguity experienced by nurses providing bedside nursing care can be defined as 'a lack of information and/or clarity about responsibilities, objectives, and goals within the organization to effectively practice/perform one's role as a nurse and a feeling of unpredictability regarding consequences of one's nursing behavior'.<sup>37</sup> Role ambiguity in general can lead to increased stress, lack of organizational commitment, increased job dissatisfaction, increased burn-out, and increased intent to leave.<sup>37</sup> Nurses' perception of a lack of clear role definition regarding self-management can affect nurses' responses to patients, especially responses to expert patients.<sup>38</sup> Describing the area of nurses' expertise and their specific role regarding self-management support and assigning this task to nurses can enable them to accept the changing roles.<sup>38</sup>

The main change in nurses' roles has to do with the sharing or transfer of control. Nurses must relinquish some power and have to recognize patients as equal partners in health care, who have control and responsibility for their health (Chapter 1).<sup>39</sup> In addition, nurses need to support patients in getting used to their new roles. Patients are expected to express their perspectives, needs, and preferences, actively participate in health-related decision-making, and engage in appropriate actions and behaviors.<sup>40</sup> The results of the patient interviews, described in Chapter 1, show that patients usually do not appreciate being proactive and in control while hospitalized. They consider themselves incapable of self-management

and do not express wishes or preferences because they want to comply with what they believe to be hospital procedures. Patients are afraid of being 'difficult' if they ask too many questions. This hinders them from participating in their care.<sup>41</sup> Nurses can empower hospitalized patients by encouraging them, and inviting them to actively participate; by providing information on activities that affect recovery, by educating patients on ways to avoid hospital complications and by discussing mutual expectations about the hospital stay (Chapter 1).

### Develop self-management support programs

In our focus group interviews, nurses indicated that they need clear methods to support inpatients' self-management (Chapter 2). With the conceptualization of nurses' support (Chapter 5), nurses can develop, implement, and test self-management support programs for their patient population. This should be done systematically, for example using the Medical Research Council (MRC) Framework for developing and evaluating complex interventions.<sup>1,3</sup>

To ensure continuity, self-management support programs should be implemented across the patient's care pathway, in collaboration with the patient, the community, and the healthcare professionals involved.<sup>9,42</sup> Self-management support from different providers can target different aspects of the patient's self-management and can overlap and influence each other.<sup>43</sup> Each form of self-management support should therefore be regarded in the context of the whole.<sup>43</sup> The patients' care pathway should be the starting point for self-management programs, not the care delivered in one healthcare organization. Thanks to the growing possibilities of health technology, more and more acute hospital care can be provided at the patient's home<sup>44,45</sup>, which reinforces the need for a collaborative approach to develop self-management support programs.

Continuity of care can be achieved when discrete elements in the care pathway, such as interventions by different providers or different episodes in the patient's illness, are perceived as coherent, connected, and consistent with the patient's medical needs and personal context.<sup>46</sup> The care the patients provide themselves, i.e. the patients' self-management, should be considered as part of the patient's care pathway and nurses' support should be aimed at continuing the patients' self-management. This means that hospital nurses recognize patients' self-management before and during hospitalization; assist and empower the patients to continue their self-management tasks while hospitalized appropriate to the patient's wishes, needs, and possibilities; and prepare patients to –perhaps new or stronger- post-discharge self-management. This attention to patients' self-management can help to limit the demand for care after hospitalization.

Findings from a previous study mentioned that patients who self-manage a chronic disease at home before hospitalization face several challenges when hospital routines do not match the way they did things at home.<sup>47</sup> Therefore it is important to discuss with patients how they practice self-management tasks at home and how this can be continued as much as possible during hospitalization. During hospital admission, patients can perform various self-management tasks they also do or will do at home after discharge, such as medication use<sup>48</sup>, or fluid registration<sup>49</sup> (Chapter 4). Questions can be raised about who is liable if the patient makes mistakes in these tasks that cause harm. Therefore, the responsibilities of patients and nurses need to be incorporated into guidelines and quality standards.<sup>50</sup> Before a planned hospital admission, patients can be prepared for self-management tasks during hospitalization, e.g. oral care to reduce oral mucositis. (Chapter 4).<sup>51</sup> Last, patients can be actively involved in care, e.g. in the prevention of hospital complications (Chapter 1).

Discharge planning is part of regular nursing care. It should start at admission and continue throughout hospitalization, paving the way for successful self-management at home. Our observational study only shows a few situations in which nurses discussed patients' self-management after discharge in a short conversation, during nursing activities (Chapter 3). This did not seem to reflect a planned and structured activity. For adequate self-management after discharge, three aspects are relevant: knowledge, planning, and ability. Patients need to know what to do, need a plan for how to do it, and have to be able and willing to carry out that plan.<sup>52</sup> These aspects need to become part of the discharge planning to prepare the patient for self-management after discharge.

## Make self-management support part of policy, education and research

### Policy

In the current transformation towards a more participatory healthcare system, patients are being encouraged to take more responsibility for their health and take an active role in their care.<sup>10,12,13</sup> Self-management is central to this transformation.<sup>11</sup> One of the starting points of the abovementioned rapport 'Kader Passende Zorg' (Appropriate care) is that attention must be paid to which care tasks patients can perform themselves, possibly supported by e-health or domotics.<sup>13</sup> Therefore, hospital management and ward managers should prioritize the enhancement of patients' self-management.

As our focus group interviews with nurses show, nurses indicate that self-management is not mentioned in hospital policy (Chapter 2). Nurses can change this by encouraging hospital boards and ward managers to value self-management, make it central to the mission of the hospital, and formulate self-management support as a practice priority for nurses.<sup>53</sup> They can also ensure that their activities to support self-management are documented so that self-management support becomes visible and verifiable.<sup>29,53</sup> In this way, the provision of self-management support can become a benchmark for assessing the quality of nursing care in the hospital or ward.<sup>53</sup>

With an increasing shortage of healthcare personnel, nurses will have to make more and more choices about which nursing care they provide and which they do not.<sup>18-20</sup> The decision about this should not be left to the individual nurse but needs to be recognized as a patient safety issue and openly discussed at the policy level.<sup>20</sup>

## Education

Our studies clearly show that nurses need to be educated about how to support inpatients' self-management (Chapters 1-3). The role nurses are expected to fulfill requires new competencies, such as assessing patients' needs regarding self-management, facilitating shared decision-making, respecting patient's autonomy, and building partnerships with patients.<sup>54,55</sup> To be effective, such education should be theory-driven, reflect upon current practice, bring theory into practice, organize follow-up, and provide individual (video) feedback.<sup>56</sup> Patients differ in their ability and willingness to take an active role in their care, so nurses should be equipped to assess patients' health literacy and preferences for participation in care and tailor interventions to the individual patient.<sup>40,41</sup>

Self-management is a central aspect of the Dutch education profile of nurses.<sup>31</sup> Nursing students are prepared to provide self-management support by learning about theoretical models, developing communication skills, and reflecting on their internship.<sup>54</sup> To date, little attention has been paid to nurses' support of patient's self-management during hospitalization and it is unclear whether this topic is part of current nursing education. Student nurses should become aware of the need and possibilities to support patient's self-management during hospitalization. Therefore, it is imperative to add the findings of our research to nursing education, discuss the value of inpatients' self-management support, and give nursing students examples of how they can support the patients' self-management during a hospital stay.

## Research

The findings described in this thesis should be seen as a substantial contribution to understanding what nurses need and can do to support the patients' self-management during hospitalization. Since our first two studies focused on older patients, this understanding is limited to that patient population. This understanding of what nurses need and can do to support the patients' self-management can be further enlarged by research focusing on the care of younger adults, by exploring how younger patients perceive performing self-management while hospitalized, and what nurses' perceptions are of supporting self-management of younger adult patients.

Furthermore, to determine what needs to be done to improve nurses' support in patients' self-management during hospitalization, we need a better understanding of the motives and assumptions underlying nurses' current behavior regarding inpatients' self-management. This can be done by discussing patients' and nurses' perspectives of what has been found in the interviews and observations described in Chapters 1 through 3.<sup>57</sup>

Only when nurses can demonstrate the value that self-management support adds to patient outcomes, care experiences, or quality of life, they can invest time and energy in supporting the self-management of hospitalized patients. Therefore, it is required to focus research on the effectiveness of inpatients' self-management support programs.

## Concluding remark

Self-management support described as "a patient-centered collaborative approach to care that promotes patient activation, education and empowerment"<sup>58,59</sup> seems not to be routinely implemented in the hospital wards involved in this study. Nurses used several methods to support inpatients' self-management, but not in a conscious, visible, structured manner and not focusing on all the patients' possible self-management needs. Self-management support requires more attention and needs to be further developed within the hospital setting.

In recent years, Dutch nurses have been gaining more and more influence on hospital policy concerning nursing, nurses, and their working environment. The involvement of nurses in the policy of their healthcare organization has recently been laid down in law and must be implemented by July 1, 2023.<sup>60</sup> Now is the time for nurses to indicate the importance of self-management within hospitals, give it the highest priority and to make it part of hospital and ward policy. This will contribute to the healthcare transformation towards a more participatory care system.

As one of the panelists of the Delphi study mentioned:

*“Let a patient do as much for him or herself as possible during hospitalization with assistance and correction by the nurse so they leave with the skills and confidence to self-manage. This is more than explaining and discussing. It is a very different way of delivering care.”*

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# Summary

## Problem statement & Aims

Self-management is the individual's ability to prevent or, when necessary, handle the consequences of health problems. Supporting the patients' self-management aligns with the new thinking about health as 'the ability to adapt and to self-manage in the face of social, physical, and emotional challenges' rather than the absence of disease.

Self-management is also seen as one of the solutions to meet the growing demand for care, due to an aging population. As a result, healthcare professionals must empower patients to self-manage the consequences of their health conditions, in addition to their (traditional) role in care and cure. Self-management support creates an opportunity to incorporate the patients' own experiences into the provision of care. Nurses are well-positioned and educated to play a leading role in this task.

Self-management is primarily focused on the activities individuals undertake to handle the consequences of their health problems when living at home. However, self-management does not stop when a person is hospitalized. Stimulating inpatients' self-management, as soon as patients' health situation allows, can bridge the gap between hospital and home.

Several programs have been developed to support community-dwelling patients in their self-management of chronic illness, but little is known about how to support self-management of hospitalized patients. Interventions to support inpatients' self-management are considered complex interventions, indicating that the intervention consists of several interacting components. Developing complex interventions requires a deep understanding of the problem the intervention will address, and a clear picture of the problem as perceived by future recipients and providers. In addition, it is important to identify the available evidence about existing interventions that address the problem.

To clarify the concept of nurses' support for hospitalized patients' self-management from different viewpoints, and to investigate how nurses can support patients' self-management during hospitalization, we conducted several studies (see Figure 1).

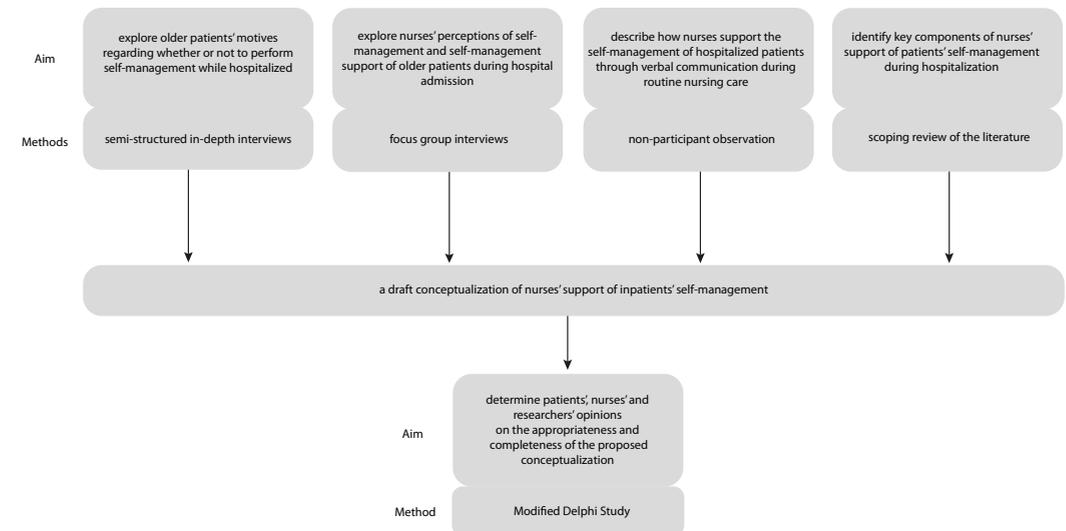


FIGURE 1 A VISUAL REPRESENTATION OF THE RESEARCH ACTIVITIES

## Performed studies & Results

### Older patients' perceptions

In **Chapter 1**, we describe the motives of older patients to perform self-management or not during hospitalization. To explore this, we conducted semi-structured interviews with 12 older patients, who had recently been discharged from a medical or surgical ward of a general hospital and performed a qualitative content analysis of the interview transcripts. Patients' self-management during hospitalization was operationalized as: to collaborate with the nursing staff, have a proactive role, and give direction for personal care based on their own opinions about managing health conditions and taking care of oneself.

The patients often stated that they did not experience collaboration with nurses and had no influence on nursing care, but they also mentioned several situations in which they were proactive and indicated what they felt was necessary. The qualitative analysis shows that patients do not perform self-management because they consider themselves as not competent or too

ill and because the care provided meets their expectations. Patients want to comply with what they believe to be hospital rules and self-management seems inappropriate in this regard. Nurses also did not always recognize or support patients' attempts to self-manage or influence personal care. However, patients did perform self-management activities when they knew it helped their recovery, when personal boundaries were being crossed, when a mistake was imminent, or when they were invited and encouraged by nurses.

So, nurses can promote patients' self-management by inviting patients to participate in their care, and by providing information about activities that influence recovery or prevent complications. Barriers to performing self-management appear to be related to patients' perceptions and expectations of nursing care. Nurses can change this by discussing mutual expectations regarding the hospital stay and the involvement of patients in their care.

## Nurses' perceptions

In **Chapter 2**, we delineate nurses' perceptions of older patients' self-management during hospitalization and nurses' support in this regard. We conducted four focus group interviews with nurses, recruited from eight wards of two general hospitals, and performed a thematic analysis of the interview transcripts. A total of 25 nurses participated.

It appears that nurses have an incomplete understanding of self-management. They viewed self-management as 'having control over your life' and being self-reliant, mostly related to activities of daily living (ADL). Nurses indicated that they supported their patients' self-management by encouraging them to independently perform ADL, involving patients in the provision of care, providing information about the disease, the treatment, and the regimen, and helping patients to reflect on their situation. Nurses' perceptions of self-management support seem to be more on promoting compliance with expert advice and less on empowering patients to manage their health.

We used the Theory of Planned Behavior to explore nurses' behavior related to self-management support. According to this theory, behavior is determined by intention, which in turn is determined by attitude, subjective norms, and perceived behavioral control.

Nurses showed a positive attitude towards self-management but believed that hospitalized patients are not always capable of self-management. Nurses find it difficult to transfer control for care tasks to patients. They indicated that they take over care tasks and decisions from patients, more often than is necessary given the patients' condition.

'Subjective norm' is about what the person thinks others value the behavior. For nurses, it is unclear what others think of self-management support and what is expected of them in this area. They experience unclear and sometimes contradictory expectations.

'Perceived behavior control' is the extent to which the person believes the behavior is easy to perform. Nurses indicated that they can promote patients' physical independence and educate them about health issues, but they do not know how to transfer responsibility for care to patients. Finally, nurses experienced few opportunities to support the self-management of inpatients due to the high workload, fixed daily schedule, and the hospital environment.

Paying attention to nurses' attitudes, social norms, and perceived behavior control, by discussing their beliefs, setting clear expectations, and teaching them how to provide self-management support can influence nurses' intentions and behavior toward self-management support.

## Nurses' support of inpatients' self-management

In **Chapter 3**, we describe a qualitative study, in which we explored how nurses support the self-management of hospitalized patients through verbal communication during routine nursing care.

This has been explored through overt, non-participant observations of nurses working in morning, afternoon, and evening shifts on three nursing wards, a medical, a surgical, and a dialysis ward. Everything that was said between the nurse and the patient was noted by the observers. A total of 215 hours of nursing work of 49 nurses was observed. We performed a thematic analysis of the transcripts of these observations.

The findings show that nurses support inpatients' self-management in a direct way, by discussing patients' self-management, and in an indirect way, by enhancing patients' involvement in care and by focusing on the patients' perspectives. Almost all verbal communication consisted of short conversations during the performance of other care tasks, often as a one-way flow of information from nurse to patient or as a question from nurse to patient.

Nurses ask patients about their self-management at home and feelings associated with their health situation. They involve patients in care by informing them about the content and the planning of nursing care. They encourage patients to express their views on nursing care and stimulate participation, especially when it comes to ADL tasks or taking medication.

It can be concluded that hospital nurses do have methods to support their patients' self-management but that it seems to be an ad hoc activity,

it does not appear to be an integral part of daily practice. Also, it seems that nurses do not support all possible self-management needs of patients, because little or no attention was paid to self-management skills such as self-monitoring or symptom management. In addition, patients were mainly involved in nursing care related to ADL tasks and taking medicines, not in other possible (future) self-management tasks.

## Nursing interventions to support self-management

We reviewed the current literature to explore the interventions nurses have considered or used to support adult patients' self-management during hospitalization. **Chapter 4** describes the results of this scoping review of the literature, performed according to the Joanna Briggs Institute methodology. A database search was undertaken using Pubmed, CINAHL, PsycINFO, Cochrane, Embase, and grey literature sources, resulting in 3719 potentially relevant documents. After removing duplicates, reviewing the remaining documents for eligibility, and hand-searching the reference list of eligible documents, a total of 83 documents were included. We performed a qualitative analysis of the description of the interventions in the documents found.

The results consist of three themes: the various activities that nurses (can) perform to support the self-management of hospitalized patients; the aspects of self-management that these activities focus on; and information about the intervention procedure. The following self-management support activities were found: giving education; counseling and coaching; enhancing responsibility; engaging family caregivers and supporting the transition from hospital to home. Almost all interventions aimed to improve the patients' knowledge of their health problem(s). In addition, the focus was on one or more of the skills, required to perform self-management. Some interventions had a very narrow focus, which raises the question of whether they influence the self-management of patients. Nevertheless, all activities can be seen as a way to increase patients' knowledge and confidence in managing their health. Information about the intervention procedure was often limited and insufficient to reproduce the intervention in another hospital. More than half of the interventions were performed within the patient's care pathway across different settings, starting during hospitalization and continuing after discharge.

The scoping review of the literature demonstrated the interventions that nurses can use to support adult patients' self-management during hospitalization. Most activities within these interventions are part of regular nursing care, but the focus on supporting patients' self-management may change their content. A relatively new activity is the transfer of responsibility for care tasks to the patient. Nurses can improve their self-management support by developing the above interventions with a focus on self-management for their patient population. It is important to pay attention to all necessary self-management skills and to give the patient as much responsibility for self-management tasks as possible while hospitalized.

## Experts opinion

Based on the above-mentioned studies, we developed a draft conceptualization of nurses' support of hospitalized patients' self-management. In **Chapter 5**, we describe the Delphi study we conducted to determine the appropriateness and completeness of this conceptualization. We asked the experts' opinions in a two-round Delphi survey. The expert panel consisted of three groups of participants: patients with recent hospitalization recruited from three wards (medical, surgical, cardiologic) of two general hospitals (n=9); ward nurses who have experience in supporting self-management, working in the previously mentioned wards (n=12); and researchers with scientific expertise in this area from the Netherlands, Germany, Sweden, Italy and the USA (n=9). The RAND/UCLA Appropriateness Method (RAM) classification procedure was used to classify the appropriateness of each nursing activity mentioned in the draft conceptualization.

The draft conceptualization consisted of 43 nursing activities, clustered in 6 sets, reflecting the 6 aspects that make up nurses' support to hospitalized patients (See Box 1). No new aspects of self-management support were defined during the Delphi rounds. However, 15 new activities were added to existing sets and several textual adjustments were made. Activities were merged, added to, or moved to another set. One activity was deleted because it had already been mentioned elsewhere. The final version of the conceptualization consists of 56 nursing activities categorized into 6 sets.

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- 1 Recognize and support the patient's current self-management
  - 2 Increase the patient's insight and awareness of his health situation
  - 3 Help the patient in coping with the disease and its consequences
  - 4 Increase the patient's involvement and responsibility for his care
  - 5 Involve family and/or informal caregivers in the patient's care
  - 6 Support transition from hospital to home
- 

**BOX 1** ASPECTS THAT TOGETHER FORM THE CONCEPTUALIZATION OF NURSES' SUPPORT TO HOSPITALIZED PATIENTS

The expert panel agreed on the appropriateness and completeness of the conceptualization (with median panel ratings between 7-9, and DIs between 0.0 and 0.37) and also identified some issues related to the activities mentioned and the scope of this concept. Panel members emphasized the importance of involving patients in these nursing activities and tailoring activities to the patient's needs, capacities, and circumstances. Several comments were made on whether certain activities support self-management or can be considered general nursing care; whether certain activities support self-care rather than self-management; and whether some activities focus on patient participation instead of self-management. This reflects the different views and opinions on the concept of self-management.

The activities of the conceptualization should not be considered in isolation, but rather as a coherent whole from which to choose, depending on the needs, wishes, and possibilities of the patient. Most of the activities are described in abstract terms and need further content aimed at supporting the self-management of a specific patient population.

## Discussion & Implications for hospital nurses

In **Chapter 6** we give an overview of the main findings of the studies and the main considerations regarding the findings and the methods used. The first studies (**Chapter 1 and Chapter 2**) are focused on older patients and on supporting the self-management of patients during hospitalization. In the following studies (**Chapters 3-5**) we focused on all adult patients and also on the way nurses ensure continuity in the patient's self-management, for example by linking up with the patient's self-management before hospitalization and by preparing the patient for self-management after hospitalization.

In scientific literature, there is no conceptual clarity about self-management, and the concepts of self-care and self-management are often used synonymously. In this thesis, where relevant, we have taken into account that the difference between these concepts is unclear. For example, in the qualitative analysis of the focus group interviews, we also included the text in which the nurses mistakenly used the word self-care instead of self-management.

In the Netherlands, the growing demand for care has led to the development of the report 'Kader Passende Zorg' (Appropriate care) in which the Healthcare Institute of the Netherlands (Zorginstituut Nederland) describes what needs to be done to make healthcare future-proof. Focusing on health instead of disease and involving patients in care are important starting points of this national program. Supporting the patients' self-management is therefore essential for future healthcare.

Our research shows that self-management support does not seem to be an integral part of the daily practice of nurses in hospital wards. To change this, nurses can take several actions. It is essential that nurses themselves understand the importance of patients' self-management during hospitalization, and recognize self-management support as their professional duty and prioritize it in their daily work. Due to a high workload, nurses often have to make choices about which nursing care they will provide. These choices are made, among other things, based on which care outcomes are considered important. Thus, self-management should be regarded as an important nursing outcome to be considered as an essential element of the nurse's daily practice.

Nursing prioritization is also influenced by the unit culture and the expectations of others. When nurses are assigned the task of supporting self-management they can integrate this into daily practice.

Issues related to self-management support, such as dealing with changing roles and responsibilities, rest on nurses' views about what constitutes good care provision and what is considered good self-management. From nurses' view good self-management can be seen as following the advice of health professionals while from a patient's perspective, it may mean adjusting the advice to live well. Nurses should discuss these topics within the care team and also with patients.

Nurses can develop self-management support programs that align with the patient care pathway through various healthcare organizations. The care the patients provide themselves, i.e. the patients' self-management, should be considered as part of the patient's care pathway and nurses' support should be aimed at continuing this. For nursing care during hospital admission, this means that nurses acknowledge the patient's self-management; enable the patient to continue self-management tasks during the hospitalization period insofar as this suits the patient's wishes, needs, and possibilities; and that the patient is prepared for self-management after discharge.

Self-management is central to what needs to be done to make healthcare future-proof. Therefore, supporting self-management should be part of a hospital's policy and part of nurses' education. In addition, research is needed to investigate the effectiveness of the aforementioned interventions on patients' self-management.

# Samenvatting

## Probleemstelling & Doelen

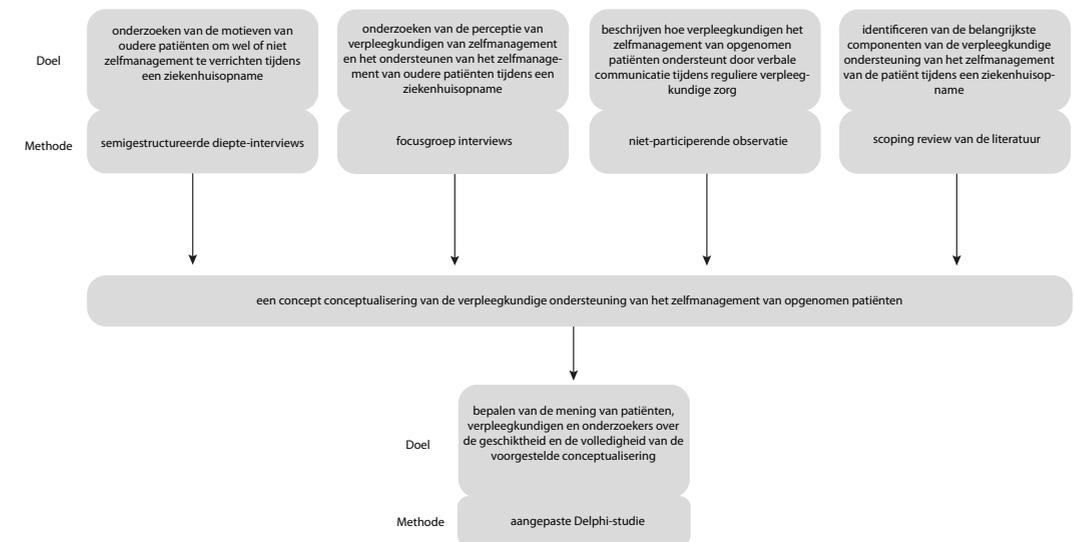
Zelfmanagement is het vermogen van het individu om gezondheidsproblemen te voorkomen of, als deze toch ontstaan, met de gevolgen hiervan om te gaan. Het ondersteunen van zelfmanagement sluit aan bij het nieuwe denken over gezondheid. Hierin wordt gezondheid niet gezien als de afwezigheid van ziekte maar als 'het vermogen om zich aan te passen en om zichzelf te managen in het licht van sociale, fysieke en emotionele uitdagingen'.

Zelfmanagement wordt ook gezien als één van de oplossingen om te voldoen aan de groeiende zorgvraag die wordt veroorzaakt door toename van het aandeel ouderen in de samenleving. Naast inspanningen om de ziekte te genezen, moeten zorgprofessionals patiënten in staat stellen zelf de gevolgen van hun gezondheidsproblemen te managen. Zelfmanagementondersteuning creëert de mogelijkheid om de eigen ervaring van de patiënt te integreren in de zorgverlening. Verpleegkundigen hebben de juiste positie en opleiding om hierin een leidende rol te spelen.

Zelfmanagement is primair gericht op de activiteiten die individuen ondernemen om de gevolgen van hun gezondheidsproblemen te managen in de thuissituatie. Zelfmanagement houdt echter niet op bij een opname in het ziekenhuis. Het stimuleren van zelfmanagement tijdens een ziekenhuisopname, zodra de gezondheidssituatie van de patiënt dit toelaat, kan de kloof tussen ziekenhuis en thuis overbruggen.

Er zijn verschillende programma's ontwikkeld om thuiswonende patiënten te ondersteunen bij het zelfmanagement van chronische aandoeningen, maar er is weinig bekend over wat kan worden gedaan om zelfmanagement van patiënten tijdens een ziekenhuisopname te ondersteunen.

Interventies ter ondersteuning van zelfmanagement worden beschouwd als complexe interventies omdat de interventie bestaat uit verschillende op elkaar inwerkende componenten. Het ontwikkelen van complexe interventies vereist een diepgaand begrip van het probleem waar de interventie zich op richt en een duidelijk beeld van het probleem gezien vanuit toekomstige ontvangers en aanbieders. Verder is het belangrijk om het al beschikbare bewijs over bestaande interventies in kaart te brengen. Om de verpleegkundige ondersteuning van zelfmanagement van opgenomen patiënten vanuit verschillende gezichtspunten te verduidelijken en te onderzoeken hoe een verpleegkundige het zelfmanagement van een opgenomen patiënt kan ondersteunen hebben we diverse onderzoeken uitgevoerd (zie figuur 1).



FIGUUR 1 EEN VISUELE WEERGAVE VAN DE ONDERZOEKSACTIVITEITEN

## Uitgevoerde studies & Resultaten

### Percepties van oudere patiënten

In **hoofdstuk 1** beschrijven we de motieven van oudere patiënten om al dan niet aan zelfmanagement te doen tijdens een ziekenhuisopname. Om dit te onderzoeken, hebben we semigestructureerde interviews gehouden met 12 oudere patiënten die vlak daarvoor waren ontslagen van een interne of chirurgische verpleegafdeling van een algemeen ziekenhuis. We hebben een kwalitatieve inhoudsanalyse van de interviewtranscripties uitgevoerd. In dit onderzoek werd het zelfmanagement van patiënten tijdens een opname in het ziekenhuis geoperationaliseerd als: samenwerken met het verplegend personeel, een proactieve rol spelen en richting geven aan de persoonlijke zorg op basis van eigen opvattingen over het omgaan met gezondheidsproblemen en zorgen voor jezelf.

Patiënten gaven vaak aan dat ze geen samenwerking met verpleegkundigen hadden ervaren en dat ze geen invloed hadden op de verpleegkundige zorg, maar ze noemden ook verschillende situaties waarin ze wel proactief waren en duidelijk aangaven wat volgens hen nodig was.

Uit de kwalitatieve analyse blijkt dat patiënten geen zelfmanagement laten zien omdat ze zichzelf niet competent vinden of te ziek vinden en omdat de verleende zorg aan hun verwachtingen voldoet. Patiënten willen zich houden aan wat zij beschouwen als de regels van het ziekenhuis en zelfmanagement lijkt in dit opzicht ongepast. Daarnaast herkenden en ondersteunden verpleegkundigen niet altijd de pogingen van patiënten om hun persoonlijke zorg zelf te regelen of te beïnvloeden. Patiënten lieten echter wel zelfmanagementactiviteiten zien als ze wisten dat het hun herstel ten goede kwam, als persoonlijke grenzen werden overschreden, als er een fout dreigde of als ze werden uitgenodigd en aangemoedigd door verpleegkundigen.

Verpleegkundigen kunnen zelfmanagement van patiënten tijdens een ziekenhuisopname dus bevorderen door patiënten uit te nodigen om te participeren in de zorgverlening en door voorlichting te geven over activiteiten die het herstel beïnvloeden of complicaties voorkomen.

Belemmeringen voor het uitvoeren van zelfmanagement lijken verband te houden met de percepties en verwachtingen van patiënten over de verpleegkundige zorg. Verpleegkundigen kunnen dit veranderen door wederzijdse verwachtingen te bespreken over het verblijf in het ziekenhuis en de betrokkenheid van patiënten bij hun eigen zorg.

## Percepties van verpleegkundigen

In **hoofdstuk 2** schetsen we de percepties van verpleegkundigen van zelfmanagement van oudere patiënten tijdens een ziekenhuisopname en van de verpleegkundige ondersteuning hiervan. Om dit te onderzoeken hebben we vier focusgroep interviews gehouden met verpleegkundigen en een thematische analyse van de interviewtranscripties uitgevoerd. De deelnemende verpleegkundigen waren werkzaam op acht verschillende verpleegafdelingen van twee algemene ziekenhuizen. In totaal hebben 25 verpleegkundigen deelgenomen.

Het blijkt dat verpleegkundigen een onvolledig beeld hebben van wat zelfmanagement is. Zij zien zelfmanagement als 'controle hebben over je leven' en als zelfredzaamheid, meestal gerelateerd aan activiteiten van het dagelijks leven (ADL). Verpleegkundigen gaven aan dat zij het zelfmanagement van hun patiënten ondersteunen door hen te stimuleren zelfstandig ADL uit te voeren, door hen te betrekken bij de zorgverlening,

door voorlichting te geven over de ziekte, de behandeling en de leefregels en door hen te helpen reflecteren op hun situatie. De perceptie van verpleegkundigen van zelfmanagementondersteuning lijkt meer gericht te zijn op het bevorderen van het naleven van het advies van deskundigen en minder op het in staat stellen van patiënten om hun gezondheid te managen.

We gebruikten de Theory of Planned Behavior om het gedrag van verpleegkundigen gerelateerd aan het ondersteunen van zelfmanagement te onderzoeken. Volgens deze theorie wordt gedrag bepaald door de intentie, die op haar beurt wordt bepaald door de attitude, subjectieve normen en waargenomen gedragscontrole.

'Attitude' gaat over de houding van een persoon ten opzichte van het gedrag. Verpleegkundigen lieten een positieve houding ten opzichte van zelfmanagement zien, maar waren van mening dat opgenomen patiënten niet altijd in staat zijn tot zelfmanagement. Verpleegkundigen vinden het moeilijk om de regie over zorgtaken over te dragen aan de patiënt. Ze gaven aan dat ze regelmatig zorgtaken en beslissingen van de patiënt overnemen, vaker dan nodig gezien de conditie van de patiënt.

'Subjectieve norm' gaat over datgene wat de persoon denkt dat anderen vinden van het gedrag. Het is voor verpleegkundigen onduidelijk wat anderen vinden van zelfmanagementondersteuning en wat er van hen wordt verwacht op dit gebied. Ze ervaren onduidelijke en soms tegenstrijdige verwachtingen.

'Waargenomen gedragscontrole' is de mate waarin de persoon gelooft dat het gedrag eenvoudig is uit te voeren. Verpleegkundigen geven aan dat ze de fysieke onafhankelijkheid van patiënten kunnen bevorderen en voorlichten kunnen geven over gezondheidsproblemen, maar dat ze niet weten hoe ze verantwoordelijkheid voor de zorg kunnen overdragen aan patiënten. Tot slot ervaren verpleegkundigen weinig mogelijkheden om zelfmanagement van opgenomen patiënten te ondersteunen vanwege de hoge werkdruk, het vaste dagschema en de ziekenhuisomgeving.

Aandacht geven aan de attitude, sociale normen en waargenomen gedragscontrole van verpleegkundigen, door hun overtuigingen te bespreken, duidelijke verwachtingen te stellen en hen te leren hoe ze zelfmanagementondersteuning kunnen bieden, kan de intentie en het gedrag van verpleegkundigen met betrekking tot zelfmanagement beïnvloeden.

## Verpleegkundige ondersteuning van zelfmanagement van opgenomen patiënten

In **hoofdstuk 3** beschrijven we een kwalitatief onderzoek, waarin we onderzochten hoe verpleegkundigen zelfmanagement van opgenomen patiënten ondersteunen met verbale communicatie tijdens de verpleegkundige zorg. Dit is onderzocht door middel van openlijke, niet-participerende observaties van verpleegkundigen tijdens hun werkzaamheden in de ochtend-, middag- en avonddienst op drie verpleegafdelingen, een interne, een chirurgische en een cardiologische verpleegafdeling. Letterlijk alles wat tussen de verpleegkundige en de patiënt werd gezegd werd door de observatoren genoteerd. We voerden een thematische analyse uit van de transcripties van deze observaties. Er werden 49 verpleegkundigen geobserveerd, gedurende totaal 215 uur.

De bevindingen laten zien dat verpleegkundigen het zelfmanagement van de patiënt op een directe manier ondersteunen door het zelfmanagement van de patiënt te bespreken, en op een indirecte manier door de betrokkenheid van de patiënt bij de zorg te vergroten en door het perspectief van de patiënt centraal te stellen. Vrijwel alle communicatie bestond uit korte gesprekken tijdens de uitvoering van andere zorgtaken, vaak als eenrichtingsverkeer van informatie van de verpleegkundige naar de patiënt of als vraag van de verpleegkundige aan de patiënt. Verpleegkundigen vragen patiënten naar hun zelfmanagement thuis en naar gevoelens die samenhangen met hun gezondheidssituatie. Zij betrekken patiënten bij hun zorg door hen te informeren over de inhoud en planning van de verpleegkundige zorg. Ze moedigen patiënten aan om hun mening te geven over de verpleegkundige zorg en stimuleren participatie, vooral als het gaat om ADL-taken of het innemen van medicijnen.

Geconcludeerd kan worden dat verpleegkundigen methoden hebben om het zelfmanagement van hun patiënten te ondersteunen, maar dat het een ad hoc activiteit lijkt te zijn, het lijkt geen integraal onderdeel te zijn van de dagelijkse praktijk. Ook lijkt het erop dat verpleegkundigen niet alle mogelijke zelfmanagementbehoeften van patiënten ondersteunen, omdat er weinig of geen aandacht werd besteed aan zelfmanagementvaardigheden zoals zelfcontrole of het omgaan met de symptomen van de ziekte. Daarnaast werden patiënten vooral betrokken bij verpleegkundige zorg gerelateerd aan ADL taken en het innemen van medicijnen en minder bij andere mogelijke (toekomstige) zelfmanagementtaken.

## Verpleegkundige interventies ter ondersteuning van zelfmanagement

We hebben de huidige literatuur bekeken om de interventies in kaart te brengen die verpleegkundigen hebben overwogen of gebruikt om zelfmanagement van volwassen patiënten te ondersteunen tijdens een opname in het ziekenhuis. **Hoofdstuk 4** beschrijft de resultaten van deze scoping review van de literatuur, uitgevoerd volgens de methode van het Joanna Briggs Institute. Er werd een database-search uitgevoerd in Pubmed, CINAHL, PsycInfo, Cochrane, Embase en in bronnen voor niet formeel uitgegeven documenten ('grey literature'), resulterend in 3719 potentieel relevante documenten. Na het verwijderen van duplicaten, het beoordelen van de geschiktheid van de overgebleven documenten en het doorzoeken van de referentielijst van in aanmerking komende documenten, werden in totaal 83 documenten geïnccludeerd. We hebben een kwalitatieve analyse uitgevoerd van de beschrijving van de interventies in de gevonden documenten.

Het resultaat bestaat uit drie thema's: de verschillende activiteiten die verpleegkundigen (kunnen) uitvoeren ter ondersteuning van het zelfmanagement van opgenomen patiënten; de aspecten van zelfmanagement waarop deze activiteiten zich richten; en informatie over de interventieprocedure.

De volgende zelfmanagement ondersteunende activiteiten zijn gevonden: onderwijs geven; advisering en coaching; verantwoordelijkheid vergroten door zorgtaken over te dragen; mantelzorgers betrekken; en de overgang van ziekenhuis naar thuis ondersteunen.

Het doel van bijna alle interventies was het vergroten van de kennis van de patiënt over het gezondheidsprobleem. Daarnaast lag de focus op één of meerdere vaardigheden die nodig zijn om zelfmanagement uit te voeren. Sommige gevonden interventies hadden een zeer beperkte focus, wat de vraag oproept of ze het zelfmanagement van patiënten daadwerkelijk beïnvloeden. Desalniettemin kunnen alle activiteiten worden gezien als een manier om de kennis van en het vertrouwen in het managen van de eigen gezondheid te vergroten.

Informatie over de procedure om de interventie uit te voeren was vaak beperkt en onvoldoende om de interventie in een ander ziekenhuis te reproduceren. Meer dan de helft van de interventies werd uitgevoerd binnen het zorgtraject van de patiënt langs verschillende instellingen. Deze interventies startten tijdens de ziekenhuisopname en werden voortgezet na ontslag.

De scoping review van de literatuur bracht de interventies in kaart die verpleegkundigen kunnen gebruiken om het zelfmanagement van

volwassen patiënten te ondersteunen tijdens een ziekenhuisopname. De meeste activiteiten binnen deze interventies maken deel uit van de reguliere verpleegkundige zorg, maar de inhoud kan veranderen door de focus te leggen op het ondersteunen van het zelfmanagement van de patiënt. Een relatief nieuwe activiteit is het overdragen van zorgtaken aan de patiënt. Verpleegkundigen kunnen hun zelfmanagementondersteuning verbeteren door de hiervoor genoemde interventies met een focus op zelfmanagement te ontwikkelen voor hun eigen patiëntenpopulatie. Het is belangrijk om hierbij aandacht te geven aan alle benodigde zelfmanagementvaardigheden en aan het overdragen van zoveel mogelijk verantwoordelijkheid voor zelfmanagementtaken aan de patiënt tijdens het verblijf in het ziekenhuis.

## Mening van deskundigen

Op basis van de hiervoor genoemde onderzoeken hebben we een voorlopige versie van de conceptualisatie van de verpleegkundige ondersteuning van het zelfmanagement van patiënten tijdens een ziekenhuisopname ontwikkeld. In **hoofdstuk 5** beschrijven we de Delphi studie die we hebben uitgevoerd om de geschiktheid en volledigheid van deze conceptualisatie te bepalen. We vroegen de mening van experts in een Delphi-studie met twee rondes. Het expertpanel bestond uit drie groepen deelnemers: patiënten die recent ontslagen waren van een interne, chirurgisch, of cardiologische verpleegafdeling van twee algemene ziekenhuizen (n=9); afdelingsverpleegkundigen die ervaring hebben met het ondersteunen van zelfmanagement, werkzaam op de hiervoor genoemde afdelingen (n=12); en onderzoekers met wetenschappelijke expertise op dit gebied uit Nederland, Duitsland, Zweden, Italië en de VS (n=9). De classificatieprocedure van de RAND/UCLA Appropriateness Method (RAM) werd gebruikt om de geschiktheid te classificeren van elke verpleegkundige activiteit die in de voorlopige versie van de conceptualisatie wordt genoemd.

De voorlopige versie van de conceptualisatie bestond uit 43 verpleegkundige activiteiten, geclusterd in 6 sets, die de 6 aspecten weergeven waaruit de ondersteuning van verpleegkundigen voor opgenomen patiënten bestaat (zie Kader 1). Tijdens de Delphi-rondes zijn geen nieuwe aspecten van zelfmanagementondersteuning gedefinieerd. Wel zijn 15 nieuwe activiteiten toegevoegd aan bestaande sets en zijn enkele tekstuele aanpassingen gedaan. Er zijn activiteiten samengevoegd, aangevuld of verplaatst naar een andere set. Eén activiteit is verwijderd omdat deze elders al werd genoemd. De definitieve versie van de conceptualisatie bestaat uit 56 verpleegkundige activiteiten verdeeld over de 6 sets.

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- 1 Huidige zelfmanagement van de patiënt herkennen en ondersteunen
  - 2 Inzicht en bewustzijn van de patiënt met betrekking tot de eigen gezondheidssituatie vergroten
  - 3 De patiënt helpen bij het omgaan met de ziekte en de gevolgen van de ziekte
  - 4 De betrokkenheid en verantwoordelijkheid van de patiënt voor de persoonlijke zorg vergroten
  - 5 Mantelzorgers en/of familie betrekken bij de zorg voor de patiënt
  - 6 De overgang van ziekenhuis naar huis begeleiden
- 

**KADER 1** ASPECTEN DIE SAMEN DE CONCEPTUALISERING VORMEN VAN DE VERPLEEGKUNDIGE ONDERSTEUNING VAN HET ZELFMANAGEMENT VAN PATIËNTEN TIJDENS EEN ZIEKENHUISOPNAME

Het expertpanel was het eens over de geschiktheid en volledigheid van de conceptualisering (met mediane panelbeoordelingen tussen 7-9 en DI's tussen 0,0 en 0,37) en identificeerde ook een aantal vraagstukken met betrekking tot de genoemde activiteiten en de reikwijdte van het concept. Panelleden benadrukten het belang van het betrekken van patiënten bij deze verpleegkundige activiteiten en het afstemmen van de activiteiten op de behoeften, capaciteiten en omstandigheden van de patiënt. Er werden verschillende opmerkingen gemaakt over de vraag of bepaalde activiteiten het zelfmanagement ondersteunen of als algemene verpleegkundige zorg kunnen worden beschouwd. Enkele respondenten vroegen zich af of bepaalde activiteiten niet zelfzorg ondersteunen in plaats van zelfmanagement en of sommige activiteiten niet gericht zijn op patiëntenparticipatie in plaats van zelfmanagement. Dit weerspiegelt de verschillende opvattingen en meningen over het begrip zelfmanagement.

De activiteiten van de conceptualisering moeten niet op zichzelf worden beschouwd, maar als een samenhangend geheel waaruit kan worden gekozen, afhankelijk van de behoeften, wensen en mogelijkheden van de patiënt. De meeste activiteiten zijn in abstracte termen beschreven en hebben verdere inhoud nodig die gericht is op het ondersteunen van zelfmanagement van een specifieke patiënten populatie.

## Discussie en implicaties voor verpleegkundigen

In **hoofdstuk 6** geven we een overzicht van de belangrijkste bevindingen van de onderzoeken en de belangrijkste overwegingen met betrekking tot de bevindingen en de gebruikte methoden. De eerste onderzoeken (**hoofdstuk 1** en **hoofdstuk 2**) zijn gericht op oudere patiënten en het ondersteunen van het zelfmanagement van de patiënt tijdens een ziekenhuisopname. In de volgende onderzoeken (**hoofdstuk 3-5**) hebben we ons gericht op het zelfmanagement van alle volwassen patiënten en ook op de manier waarop verpleegkundigen kunnen zorgen voor de continuïteit in het zelfmanagement van de patiënt, bijvoorbeeld door aan te sluiten op het zelfmanagement van de patiënt voor de ziekenhuisopname en door de patiënt voor te bereiden op zelfmanagement na de ziekenhuisopname.

In de wetenschappelijke literatuur bestaat geen duidelijkheid over het concept zelfmanagement en worden de begrippen zelfzorg en zelfmanagement vaak als synoniemen gebruikt. In de onderzoeken van dit proefschrift hebben we, daar waar relevant, rekening gehouden met het feit dat het verschil tussen deze concepten onduidelijk is. Zo hebben we in de kwalitatieve analyse van de focusgroep interviews ook de tekst meegenomen waarin de verpleegkundige ten onrechte het woord zelfzorg gebruikte in plaats van zelfmanagement.

De groeiende zorgvraag heeft in Nederland geleid tot het ontwikkelen van het rapport 'Kader Passende Zorg', waarin het Zorginstituut Nederland beschrijft wat er moet gebeuren om de zorg toekomstbestendig te maken. Belangrijke uitgangspunten van dit landelijke programma zijn het betrekken van patiënten bij de zorg en de focus op gezondheid in plaats van ziekte. Het ondersteunen van het zelfmanagement van patiënten is dus essentieel voor de toekomstige gezondheidszorg.

Uit ons onderzoek komt naar voren dat zelfmanagement-ondersteuning geen vast onderdeel lijkt te zijn van het dagelijkse werk van verpleegkundigen op verpleegafdelingen in het ziekenhuis. Om dit te veranderen kunnen verpleegkundigen een aantal dingen doen. Essentieel is dat verpleegkundigen zelf het belang inzien van zelfmanagement van patiënten tijdens een ziekenhuisopname, het ondersteunen hiervan erkennen als hun professionele taak en daar prioriteit aan geven in hun dagelijks werk. Door een hoge werkdruk moeten verpleegkundigen vaak keuzes maken over welke verpleegkundige zorg ze prioriteit geven. Deze keuzes worden onder meer gemaakt op basis van welke zorguitkomsten van belang worden geacht. Zelfmanagement moet dus worden beschouwd als een belangrijke

verpleegkundige zorguitkomst willen verpleegkundigen het als een essentieel onderdeel gaan beschouwen van hun werk. Verpleegkundige prioritering wordt ook beïnvloed door de afdelingscultuur en de verwachtingen van anderen. Als verpleegkundigen zelfmanagementondersteuning duidelijk als taak krijgen toegewezen dan kunnen zij dit integreren in de dagelijkse praktijk.

Vraagstukken rondom het ondersteunen van zelfmanagement, zoals het omgaan met veranderende rollen en verantwoordelijkheden, worden beïnvloed door opvattingen van verpleegkundigen over wat goede zorgverlening inhoudt en wat als goed zelfmanagement wordt beschouwd. Vanuit het oogpunt van verpleegkundigen kan goed zelfmanagement worden gezien als het opvolgen van het advies van zorgprofessionals, terwijl het vanuit het perspectief van de patiënt kan betekenen dat het advies moet worden aangepast om goed te kunnen leven. Verpleegkundigen dienen deze vraagstukken te bespreken binnen het zorgteam en ook met patiënten.

Verpleegkundigen kunnen ondersteuningsprogramma's ontwikkelen die aansluiten bij het zorgtraject van de patiënt langs verschillende zorgorganisaties. De zorg die de patiënt zelf verleent, oftewel het zelfmanagement van de patiënt, dient te worden beschouwd als onderdeel van dit zorgtraject en de ondersteuning van de verpleegkundige dient gericht te zijn op het continueren hiervan. Voor de verpleegkundige zorg tijdens een ziekenhuisopname betekent dit dat verpleegkundigen het zelfmanagement van de patiënt erkennen; de patiënt in staat stelt zelfmanagementtaken tijdens de opnameperiode te continueren voor zover dat past bij de wensen, behoeften en mogelijkheden van de patiënt; en dat de patiënt wordt voorbereid op zelfmanagement na ontslag.

Zelfmanagement staat centraal in de veranderingen die nodig zijn om de zorg toekomstbestendig te maken. Daarom moet zelfmanagementondersteuning op beleidsniveau worden geprioriteerd en onderdeel zijn van het verpleegkundig onderwijs. Daarnaast is onderzoek nodig om de effectiviteit van de hiervoor genoemde interventies op het zelfmanagement van patiënten te onderzoeken.

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# Curriculum Vitae

Caroline Otter was born on September 7th 1959 in Zwolle, the Netherlands. After high school, she moved to Hoogeveen where she trained as a nurse at the Bethesda Hospital. She successfully completed the 4 year in-service training program in 1981 and moved to Groningen.

Her first job as a registered nurse was in 'Room 1' a surgical ward of the University Medical Center Groningen. Even in those days Room 1 already was an outdated historic nursing ward that consisted of one long corridor with 8 patients on one side and 16 patients on the other side, separated only by half walls and 2 swinging doors, ending in a room with 7 more patients. She then worked at the Internal Medicine Outpatient Clinic, the Internal Medicine Emergency Ward and at the Cardiac Care Unit. Here she completed the, again in-service, program for Intensive Care Nursing.

Because she was motivated to steer her career towards nursing education and professionalization in the Nursing domain, she trained as a teacher for healthcare institutions at the Hanze University of Applied Sciences, Groningen from 1987 to 1989 and continued her studies at the Utrecht University of Applied Sciences to become a nurse educator. During these years she worked as a practice nurse educator in the, what is nowadays top clinical Martini hospital in Groningen.

Since she was convinced of the importance of scientific research within the Nursing domain, she started studying Nursing Science at Maastricht University in 1991, alongside her work as a practice nurse educator. In 1995 she graduated and received her master degree on a study into the validity, reliability and usability of a care burden instrument.

In the years that followed, she worked at the Martini Hospital in various positions: Healthcare Staff Member, Organizational Advisor, HR Advisor and Nurse Researcher. Between 2011 and 2021 she was chair of the Nursing Advisory Council (VAR) and guided a change from a council that provides (un)solicited advice only to a Nursing Committee that has authority and mandate in the Nursing domain and which participates in the board of directors of the hospital. In 2015, she started as an external PhD candidate at the Julius Centre for Health Sciences and Primary Care, Nursing Science, of the University Medical Centre Utrecht. Her research took place within the Professorship 'Self-management of somatic patients in hospitals', a professorship that was initiated in a partnership of the Martini Hospital and the Hanze University of Applied Sciences. The subject of her research arose from her ambition to enhance nurses' support of self-management for patients during hospital admission. Also, she believes it of importance that patients have their role in care decisions and in the implementation of care. This can improve the quality of nursing care and can bridge the gap between hospital and home.

From January 2022, Caroline Otter has a parttime position besides her activities at the Martini Hospital, as a Nursing Domain Advisor within Santeon, a partnership between seven top clinical hospitals.

