# PERSON-CENTERED FUNDAMENTAL CARE

## EXPLORING PATIENT PARTICIPATION IN HOSPITALS

Elise van Belle

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## Exploring patient participation in hospitals

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The studies in this thesis were funded by ZonMw (the Netherlands Organization for Health Research and Development) program “Tussen Weten en Doen II” (grant 520002003), and by the Netherlands Federation of University Medical Centres (NFU), program “Sturen op Kwaliteit” (grant 8392010042).

**ISBN**
978-94-6473-131-6

**Design/lay-out and print**
Promotie In Zicht | www.promotie-inzicht.nl

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## Proefschrift

ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. dr. J.H.J.M. van Krieken,
volgens besluit van het college voor promoties
in het openbaar te verdedigen op

maandag 19 juni 2023
om 14.30 uur precies

door

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geboren op 15 maart 1987
te Nijmegen

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# General introduction

Given the global trends in health care such as an ageing population, exponential increase in chronic illness, and complex health conditions with multi-morbidities, there is an expectation that self-care, management of a chronic illness, public health, and health promotion will continue to be significant challenges. These challenges are no different in the Netherlands. It is apparent that healthcare use is outgrowing the economic growth and availability of healthcare personnel. Currently one in seven working adults is needed is sustain our healthcare system, which will rapidly increase to an alarming one in three people in 2060.[1] This ratio is unsustainable for society. Recently the Dutch 'Zorginstituut Nederland' published a plan for action for the Dutch government called 'Passende Zorg'.[2] It indicates what actions are needed to ensure health care is future-proof by listing actions to make care more person-centered, durable and sustainable. As nurses and nurse assistants attribute to about one third of the total healthcare professional workforce, their impact on health care is significant.[3] It is therefore imperative to facilitate research on advancing nursing practice to ensure the quality and safety of current and future care.

## Fundamental nursing care

Nurses are in the unique position to help patients from the moment of birth to the last breath drawn. They care for people with acute and chronic conditions and in different care settings, which implies a great disparity in practice. They do however have common care practices needed by all patients they care for, and these activities can be summarized as fundamental care.[4] Fundamental nursing care involves actions on the part of the nurse that respect and focus on a person's essential needs to ensure their physical and psychosocial wellbeing. These needs are met by developing a positive and trusting relationship with the person being cared for as well as their family/carers.[5] The Fundamentals of Care Framework (FoCF) (figure 1) outlines what is involved in the delivery of safe, effective, and high-quality fundamental care.[5, 6] The framework describes three interrelated dimensions: 1) nurse-patient relationship, 2) integration of care needs, and 3) context in which care is delivered.[5] Central to the framework is the relationship between the patient and the nurse. After establishing this relationship, the nurses use their relational skills to meet the patient's fundamental physical and psychosocial care needs. The third dimension indicates what contextual factors of care delivery can hinder or enable the delivery of high-quality fundamental care.[5]

There is growing evidence that these fundamentals of care are poorly executed in acute care settings, due to a dominance of the biomedical model, a managerial approach to care, and the devaluing of fundamental care by nurses.[7] Nurses

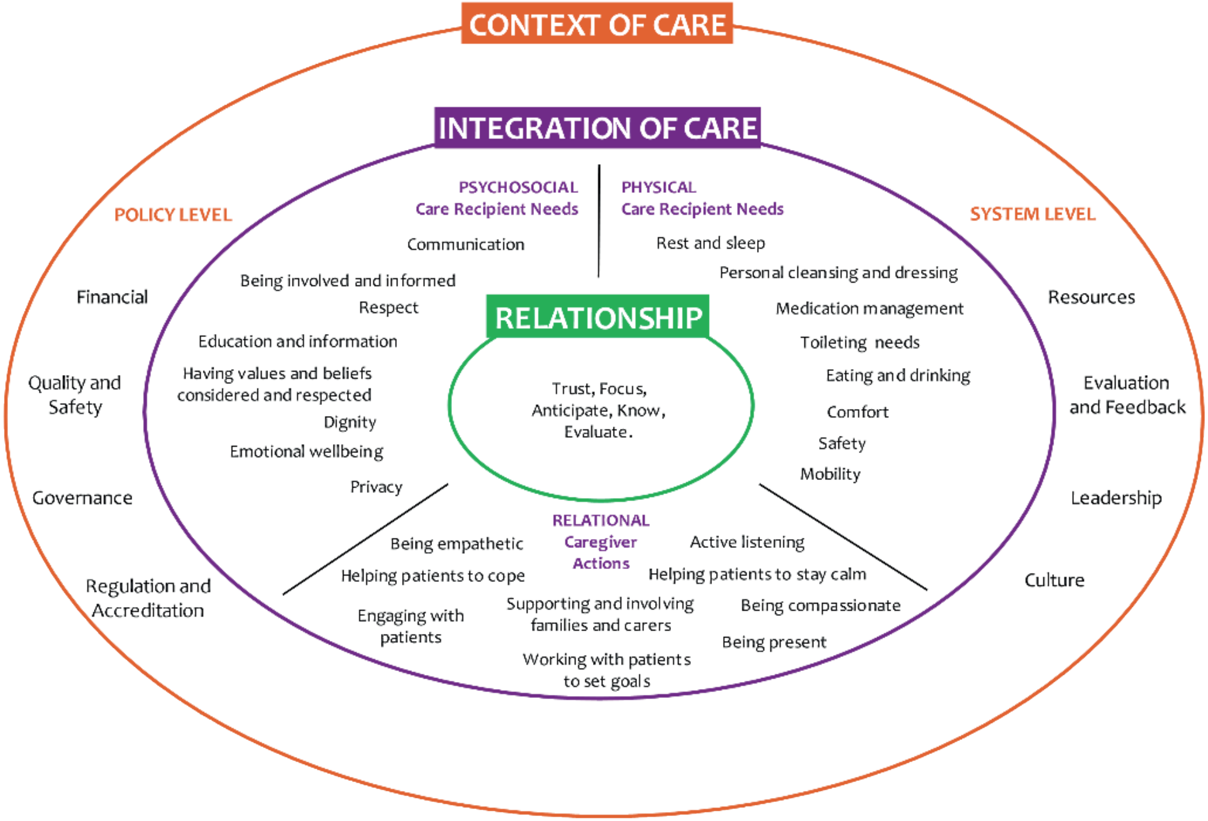

**Figure 1** The Fundamentals of Care Framework[5]

appear to give fundamental care little priority, and highly specialized and technical forms of nursing care are often seen as more prestigious than fundamental nursing care. [8] This has caused a division in care delivery, with more educated and experienced nurses carrying out technical, cure-directed acts, and fundamental care often being delivered by other professionals. [9] Evidence suggests that student nurses perceive care tasks as existing in a hierarchy, with fundamental nursing care positioned at the bottom relative to more complex technical skills. [10] They indicate to view fundamental care as being common sense and doubt whether such care should be part of their education. [11] This can be explained as many fundamentals of care such as personal hygiene, nutrition and mobility are usually self-care activities that one can undertake for themselves, and are thus in everyone's skillset. Other nursing care activities as managing an IV are not typical self-care activities and therefore fall outside the realm of common sense. [12] This view however undermines the complexities of providing integrated fundamental care to a consistent high standard. It requires specialized knowledge and clinical reasoning skills to integrate a persons' individual psychosocial, physical and relational needs while maintaining a trusting relationship and accounting for context.

When fundamental care is lacking, this may result in inadequate, incomplete, omitted, or even harmful care. [13] Missed nursing care is associated with increased mortality[14] and has negative implications on the occurrence of adverse events such as medication errors, falls, hospital-acquired infections and pressure ulcers[15], readmission[16] and on nurses self-experienced moral distress[15] and job satisfaction. [16] There is also a strong relationship between the number of items of missed care and nurses perception of reduced quality of nursing care. [17] Ball et al. indicated that most nurses report one or more care activity having been left undone due to lack of time in their last shift. Most frequently left undone was comforting or talking with patients (66%), educating patient (52%) and developing/updating nursing care plans (47%).[17] Talking, or communicating is however regarded by patients as an essential fundamental care need. [18] Effective communication is defined in the NANDA classification as a pattern of exchanging information and ideas with others that is sufficient for meeting one's needs and life's goals. [19] It is the key component of establishing the nurse-patient relationship and therefore fundamental care delivery. Respectful, emphatic and effective communication is essential in any patient-to-nurse encounter as daily care activities like bathing and dressing, eating and walking require frequent verbal and non-verbal communicative interactions. [20]

## Person-centered care

The nurse-patient relationship is about approaching the patient in an individual way; it consists of developing trust with the patient, being able to focus on the patient, giving the patient undivided attention, anticipating the patient's needs and concerns, getting to know the patient and evaluating the quality of the relationship. [21] A positive, trusting relationship helps nurses deliver key aspects of person-centered care, such as supporting patients to make informed decisions, acting as a patient advocate, and reconciling different perspectives between the patient, their family and healthcare professionals. [20] Person-centered health care is an approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants of a healthcare system that respond to their needs and preferences in a humane and holistic way. [22] Person-centered care is defined as a key concept of quality of care. [23] It focusses on health care that involves patients via greater decision-making and choice, and is sensitive to patients' unique psychosocial, cultural and emotional needs. [24] Person-centeredness closely relates to the concepts of patient empowerment and patient participation. Empowerment is described as a process that enables patient to exert more influence over their individual health by increasing their capabilities to gain more control over issues they themselves define as important. This leads to better self-management, coping and decision-making. [25] Patient participation is described as revolving around patients' rights and opportunities to influence and engage in the decision-making about their care through a dialogue attuned to their preferences, potential and a combination of his experiences and the professional's expert knowledge. [25] Patient participation can be seen as a strategy to make health care person-centered, and will make patients feel empowered (see figure 2). [24, 25]

## Patient participation

Eldh (2006) states that a prerequisite for patient participation is a patient–health professional interaction that includes communication characterized by respect, empathy, and recognition of the patient as an individual as well as a partner in the healthcare team. [26] Through effective communication patients can participate in their care, for instance by setting achievable short-term and long-term goals to regain control over their bodily functions, but also to regain a sense of personal integrity and sense of self. [24] Patient participation is possible on different levels of engagement, ranging from information, consultation, advice, and collaboration to control over care, with the level of participation increasing at each step. [27] It can

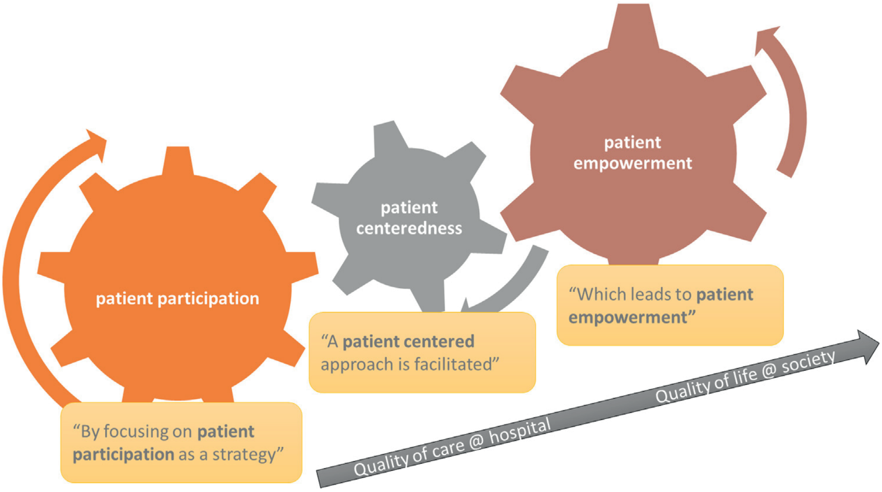

**Figure 2** Process model for concepts of patient empowerment, patient participation and patient centeredness [25]

also take place at different levels of patient care: micro (individual care), meso (service development, planning, delivery and evaluation of care, education and training of health care providers) and macro (policy-making). [25] Examples from practice are participation in nursing bedside handover and bedside medical rounds, shared decision-making, gathering and reacting to patient feedback, establishing patient councils, and using an electronic patient record with patient access. Evidence shows that enhancing patient participation results in lowering patients' anxiety levels and enhancing adherence to treatment and advice[28, 29], can increase patient safety[30, 31], and shorten hospital stay. [32, 33] It also positively influences clinical outcomes such as decreasing the likelihood for obesity and smoking, and lowering systolic blood pressure and rehospitalization rates. [34] Next to that, patient participation contributes to keeping our healthcare sustainable in the future, as it can prevent extensive (over)treatment when patients are active participants in deciding when not to treat. [2, 35] However, observational studies show that nurses try to enact patient-centered care, but mainly due to the nurses' controlling approaches quality communication is not always achieved. [36, 37] Patients' participation in fundamental nursing care during hospitalization is often lacking as there is little dialogue between patients and nurses on what the patients expect or the way in which they want to participate[38] and care and discharge plans often fail to take patient preferences into consideration. [28]

Although nurses describe patient participation as achievable and beneficial to patients, they seem to mainly view participation as informing the patients. [39] Barriers experienced by nurses to initiate patient participation are a lack of time[40], the patient being frail or of poor health[40-42], have difficulties with the lack of medical knowledge by patients. [43] Angel et al. (2015) describes how health care professionals act as gatekeepers of patient participation; deciding when and who can participate. [40] However, patients seem to be influenced by preference rather than capabilities in choosing to be active, collaborative or passive[42] and indicate that they are hindered by to participate by overwhelming illness, lack of knowledge, or low self-esteem about being able to participate in care; rather handing over the responsibility to their health care provider. [44] Patients further indicate to be discouraged to participate when they experience a lack of empathy or emotional connection from their nurse, and when health care professionals have a paternalistic attitude (e.g. trying to be controlling or secretive). [44]

Effective nurse-to-patient communication forms the base of patient participation, but evidence on interventions to enhance patient participation in essential nursing care activities is limited. Researchers suggest that enhancing patient participation is a complex process as they require the uptake of new skills for both patients and nurses in engaging patients in care, and because of nurses controlling behavior which seem to restrict participation. [36] Also, when the nurses initiates participation, the patient might react with a wide variety of questions or needs according to their individual skills or experiences, so any intervention cannot have a set protocol in how to handle these conversations and incorporate the patients preferences into care.

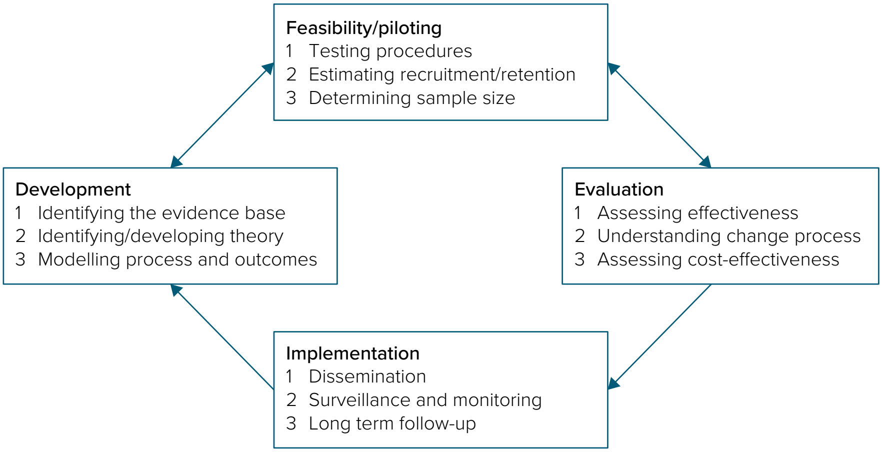

**Figure 3** Key elements of the Medical Research Council framework[45]

Its' outcomes therefore have a high variability and require skills, flexibility and creativity from the nurse. Therefore, to increase chances of successful implementation, it is advisable to use systematic approaches for the designing, testing and implementing patient participation practices in nursing care. A well-known framework in health care improvement is the Medical Research Center (MRC) framework for complex interventions[45] The framework divides complex intervention research into four phases: development or identification of the intervention, feasibility, evaluation, and implementation. It leads to good theoretical understanding of how an intervention causes change, so that weak links in the causal chain can be identified and strengthened.

## Necessity

Results of an observational study showed that in facilities where patients' outcomes (assessed by quality indicators such as low rates of falls, pain, etc.) were assessed as 'good', staff were more focused on fulfilling residents' fundamental care needs. [46] As our nursing shortages are further increasing in the near future[2] and the RN-4CAST study describing a 7% increase in the likelihood of a patient dying with every patient added to the current average nurse's workload in the hospital[47], focusing on effective fundamental nursing care is imperative. Research however shows that the current evidence for fundamental nursing care interventions is sparse, of poor quality and unfit to provide evidence-based guidance to nurses. [48] Therefore, ZonMw, the Netherlands Organization for Health Research and Development, has funded the Basic Care Revisited study as part of the 'Tussen Weten en Doen II' program. In 2014, this unique collaboration between three Dutch universities was set up to study elements of fundamental nursing care. [13] In the Basic Care Revisited project eight studies researched interventions to improve communication, eating and drinking, bathing and dressing, and mobility in three different care settings. This thesis focusses on improving patient participation through effective communication between nurses and patients.

## Aims of this thesis

This thesis general mission is to improve patient participation in clinical practice. To fulfill this mission, we aimed to tailor and pilot a communication tool to improve patient participation for nurses in Dutch hospitals. Furthermore, we aimed to provide insight in difficulties with patient participation by examining differences in experienced levels of participation in nurses and their patients, and observing how person-centered fundamental care was being carried out in daily practice. Finally, we aimed to give guidance to hospitals on how to ensure patient participation on all levels of their organization.

## Outline of this thesis

Chapter 2 describes following the first step of the MRC framework in systematically tailoring the Tell-us Card intervention was to the Dutch hospital setting using the framework of Intervention Mapping. [49] This led to feasibility phase of the MRC framework, in which the Tell-us Card was tested on four hospital wards by means of a cluster randomized controlled pilot study, as described in chapter 3. After that we return to the development phase, and in chapter 4 investigate variations in perceptions between nurses and their patients on experienced person-centered care. Chapter 5 presents results of a qualitative study on how nurses incorporate a person-centered approach during their fundamental care activities. Chapter 6 describes the international Delphi study which lead to the assembly of a guidance of best practices for hospitals to assess and enhance their level of patient participation on all levels of the organization. Chapter 7 discusses the findings of this thesis in a broader context and presents implications for practice, education and future research.

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# 2

# Tailoring of the Tell-us Card communication tool for increased patient participation using Intervention Mapping

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Journal of Clinical Nursing, 2018

## Abstract

**Background:** Even though patient participation is essential in any patient to nurse encounter, care plans often fail to take patients' preferences into account. The Tell-us Card intervention seems promising, but needs to be tailored and tested before implementation in a different setting or on large scale. Aims and objectives: To describe the tailoring of the Tell-us Card intervention for enhanced patient participation to the Dutch hospital setting by using Intervention Mapping as a systematic approach.

**Methods:** Intervention Mapping consists of: (1) identification of the problem through needs assessment and determination of fit, based on patients and nurses interviews and focus group interviews; (2) developing a logic model of change and matrices, based on literature and interviews; (3) selection of theory based methods and practical applications; (4) producing program components and piloting; (5) planning for adoption, implementation and sustainability; and (6) preparing for program evaluation.

**Results:** Knowledge, attitude, outcome expectations, self-efficacy and skills were identified as the main determinants influencing the use of the Tell-us Card. Linking identified determinants and performance objectives with behaviour change techniques from the literature resulted in a well-defined and tailored intervention and evaluation plan.

**Conclusions:** The Tell-us Card intervention was adapted to fit the Dutch hospital setting and prepared for evaluation. The Medical Research Council-framework was followed, and the Intervention Mapping approach was used to prepare a pilot study to confirm feasibility and relevant outcomes. This article shows how Intervention Mapping is applied within the Medical Research Council framework to adapt the Tell-us Card intervention, which could serve as a guide for the tailoring of similar interventions.

## Introduction

Caring for the patients' basic needs, also known as the essentials of nursing practice or fundamentals of care, is at the heart of the nursing profession.[1] These essentials of nursing care articulate aspects that are fundamental to all patients' health and wellbeing, regardless of diagnosis, cultural background or health care setting. To understand the complex interactions between personal self-care needs when healthy and fit, and how those needs change with illness and disability requires a specific range of knowledge which is assumed to be known, yet this is not the case.[1] In today's complex and fast changing health care environment the importance of these essential nursing care activities seem to have become undervalued, and form a rather neglected area in research.[2] In the Netherlands a large project called 'Basic Care Revisited' has started in which three universities collaborate in eight intervention studies on the essentials of nursing care conducted in three different settings: (acute) hospital care, institutionalised long-term care, and homecare.[3-5] The themes addressed within this collaborative project are bathing and dressing, communication, mobility, and nutrition. The current paper focuses on nurse-to-patient communication aiming at enhancing patient participation in the hospital setting.

## Background

Patient participation in care is a concept which often is used interchangeably with terms such as patient-centeredness, shared decision-making, patient empowerment and person centred care. Various definitions of the term patient participation are used. Castro et al. (2016) define it as revolving around a patient's rights and opportunities to influence and engage in the decision-making about his care through a dialogue attuned to his preferences, potential, and a combination of his experiences and the professional's expert knowledge. [6] Enhancing patient participation results in lowering patients' anxiety levels and enhancing adherence to treatment and advice, [7, 8] can increase patient safety, [9, 10] and shorten hospital stay. [11, 12] It also positively influences clinical outcomes such as decreasing the likelihood for obesity and smoking, and lowering systolic blood pressure and rehospitalisation rates. [13] Next to that, extensive (over)treatment can be prevented when patients are active participants in deciding when not to treat. [14] Patient participation can be seen as a strategy to make health care patient centred, and will make patients feel empowered. [6, 15]

Eldh (2006) states that a prerequisite for patient participation is a patient–health professional interaction that includes communication characterized by respect, empathy, and recognition of the patient as an individual as well as a partner in the health care team. [16] Respectful, emphatic and effective communication is essential in any patient-to-nurse encounter as daily care activities like bathing and dressing, eating and walking require frequent verbal and non-verbal communicative interactions. [15, 17, 18] Effective communication is defined as a pattern of exchanging information and ideas with others that is sufficient for meeting one's needs and life's goals. [19] Through effective communication patients can participate in their care, for instance by setting achievable short term and long term goals to regain control over their bodily functions, but also to regain a sense of personal integrity and sense of self. [15] Observational studies show that nurses use communication as a way to enact patient centred care [20], but that quality communication is not always achieved, due mainly to the nurses' controlling approaches. [21, 22] Patients' participation in essentials of nursing care during hospitalization is often lacking as there is little dialogue between patients and nurses on what the patients expect or the way in which they want to participate[23] and care and discharge plans often fail to take patient preferences into consideration. [7] Effective nurse-to-patient communication forms the base of patient participation, but evidence on interventions to enhance patient participation in essential nursing care activities is limited.

A promising intervention to improve patient participation during hospital admission is the 'Tell-us Card'. [24-26] The Tell-us Card is a communication tool developed in Sweden which aims to facilitate communication between nurses and patients. Patients are invited to write on the Tell-us Card what is important for them at that moment or in preparation for discharge from the hospital. By means of this card, patients' preferences and needs can be elicited, and can be acted upon by nurses. Jangland and colleagues (2012) tested the effectiveness of the Tell-us Card in a population of patients admitted to a surgical hospital ward and demonstrated that the use of the Tell-us Card in this patient group resulted in significant improvements in patients' abilities to participate in decisions about their care. [24] Jangland et al. (2012) recommended further research for improvement and implementation of the Tell-us Card communication tool. [24]

Although the Tell-us Card intervention is seemingly uncomplicated, the use of this communication tool in daily nursing care can be considered as a complex intervention. [27] The required behaviour is currently not practiced by nurses, and there is a wide variability of personalised outcomes on which nurses should be able to act. The Medical Research Council (MRC) framework for the development of complex interventions states that it is best practice to systematically develop interventions, using the best available evidence and appropriate theory before testing them in pilot studies. [27] To do so, the Intervention Mapping (IM) framework[28] will be used to systematically tailor the Tell-us Card intervention to the Dutch hospital situation. This framework is used for the planning, development, implementation and evaluation of health-related interventions, as well as for the adaptation of existing interventions to a different setting. As literature, theory and evidence give guidance how to successfully tailor and implement interventions, the IM framework offers steps and guidance when and how to use these components in program planning. This paper describes the tailoring of the Tell-us Card intervention to the Dutch hospital setting by using Intervention Mapping as a systematic approach.

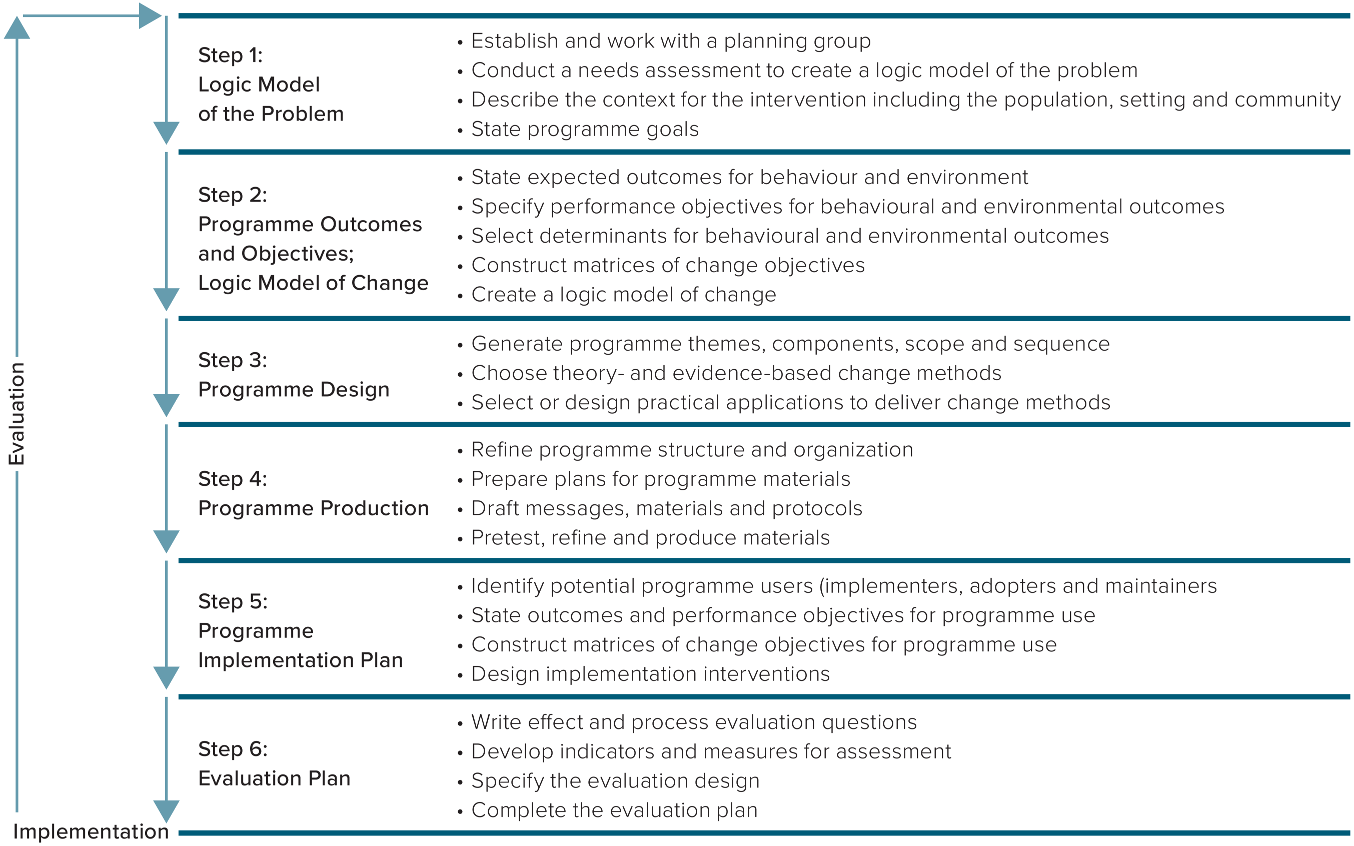
## Methods

The process of IM consists of six steps and requires the involvement of target groups, as well as the use of evidence and theory. The full process of IM consists of: (1) identification of the problem through needs assessment and determination of fit with the problem; (2) developing a logic model of change and matrices; (3) selection of theory based methods and practical applications; (4) producing program components and piloting; (5) planning for adoption, implementation and sustainability; and (6) preparing for program evaluation (Figure 1). Intervention Mapping is furthermore considered as an iterative process.

### Step 1 Logic Model and needs assessment

Table 1 shows an overview of the individual and focus group interviews held to explore patients' and nurses' perceptions with regard to patient participation during hospital admission and the use of the Tell-us Card. Focus group interviews with nurses were additionally held to stimulate group interaction and encourage the nurses to explore and clarify their individual and shared perspectives on the topic. [29]

All interviews were tape-recorded and transcribed and subsequently analysed independently by two researchers (EvB, MH), following the basic principles of grounded theory as the researchers wanted to collect and analyse the data to allow relevant ideas to develop, without a hypothesis or preconceived theories to be tested. [29] No framework was used in the analysis as this might block the awareness of major concepts emerging from the data. All interviews were coded by line-by-line analysis, which were grouped together to develop categories. By constantly comparing incoming data for their fit with existing categories the concepts were critically looked at. These categories were reassembled through



| | |
|---|---|
| **Step 1:<br>Logic Model<br>of the Problem** | • Establish and work with a planning group<br>• Conduct a needs assessment to create a logic model of the problem<br>• Describe the context for the intervention including the population, setting and community<br>• State programme goals |
| **Step 2:<br>Programme Outcomes and Objectives;<br>Logic Model of Change** | • State expected outcomes for behaviour and environment<br>• Specify performance objectives for behavioural and environmental outcomes<br>• Select determinants for behavioural and environmental outcomes<br>• Construct matrices of change objectives<br>• Create a logic model of change |
| **Step 3:<br>Programme Design** | • Generate programme themes, components, scope and sequence<br>• Choose theory- and evidence-based change methods<br>• Select or design practical applications to deliver change methods |
| **Step 4:<br>Programme Production** | • Refine programme structure and organization<br>• Prepare plans for programme materials<br>• Draft messages, materials and protocols<br>• Pretest, refine and produce materials |
| **Step 5:<br>Programme<br>Implementation Plan** | • Identify potential programme users (implementers, adopters and maintainers<br>• State outcomes and performance objectives for programme use<br>• Construct matrices of change objectives for programme use<br>• Design implementation interventions |
| **Step 6:<br>Evaluation Plan** | • Write effect and process evaluation questions<br>• Develop indicators and measures for assessment<br>• Specify the evaluation design<br>• Complete the evaluation plan |

**Figure 1** Intervention Mapping process

**Table 1** Characteristics of interviews with nurses and patients

| | Characteristics | Sampling | Aim |
|---|---|---|---|
| Interviews nurses (n=12) | Male/female: 3/9<br>Age: 36 (22-55)*<br>Work exp.: 8 (1.5-37)* | Purposeful sampling for heterogeneity on:<br>• Gender<br>• Years of work experience | • Target group involvement for tailoring the intervention<br>• Input for e-learning |
| Interviews patients (n=25) | Male/female: 14/11<br>Age: 64 (40-90)* | Convenience sample of:<br>• Adult patients,<br>• >24 hours care<br>• mentally and physically able<br>Approached by nurses, informed consent | • Target group involvement for tailoring the intervention<br>• Input for e-learning |
| Focus group interviews (n=3)<br>1. Cardiology ward (n=7)<br>2. H&N surgical ward (n=4)<br>3. H&N surgical ward (n=4) | 1. Cardiology male/female: 2/5<br>Age: 40 (25-58)*<br>Work exp.: 21(13-25)*<br>2. H&N surgery male/female: 0/4<br>Age: 48 (34-56)*<br>Work exp.: 14 (6.5–23)*<br>2. H&N surgery male/female: 0/4<br>Age: 44 (35-50)*<br>Work exp.: 12 (1.5-34)* | Purposeful sampling for heterogeneity on:<br>• educational level<br>• personal characteristics (age, gender, work experience) | • Creating awareness<br>• Target group involvement for tailoring the intervention<br>• Input for e-learning |

*in years, mean (range)

axial coding to form theoretical ideas and themes. [29] Analysis was assisted by memos made during the interviews. The coding was done by two researchers and results compared and discussed before continuing on to further steps. Analysis was done by computer, using Atlas.ti. [30]

### Step 2 Matrices of Change Objectives

In the second step, matrices were developed by the researchers in which identified performance objectives were crossed with determinants of behaviour in order to define the behaviour change objectives of nurses and patients. The formulation of program and performance objectives for the different target groups was conducted by the research group. Selection of determinants was based on the findings in step 1 and literature on behaviour change.

### Step 3 Theoretical Methods and Practical Applications

Theoretical methods and practical strategies for behaviour change[31, 32] were selected based on the finding in step 1 and 2. De selection of methods and practical strategies was conducted by the researchers (MH, EvB and JC) and strategies found were integrated in program components and material.

### Step 4 Program production

The fourth step consisted of composing program materials and testing these with the patients and nurses described in step 1. The original author[24] consented for the use and translation in the Dutch language. The final lay-out of the Tell-us Card was determined based on the original card and the comments of the nurses and patients with regard to the layout. Additional tools to assist implementation were developed in this stage.

### Step 5 Adoption and Implementation

Adoption and implementation was addressed in all steps of the process. In the focus group and individual interviews specified in step 1, ward-specific barriers and facilitators as experienced by the nurses and patients were explored so they could be paid attention to in all following steps. Also, involvement of both patients and nurses in the designing of the intervention was expected to enhance intervention adoption and implementation with nurses. [32]

### Step 6 Evaluation Planning

In the final step of IM the effect and process evaluation of the intervention was planned. The process analysis will be prepared following the six steps described by Saunders et al. (2005), who describe a method in which evaluative data can be used to fine-tune the intervention (formative) as well as making a judgement about the extent to which the intervention was implemented (summative). [33]

### Ethical approval

According to the Dutch national legislation and as judged by the local Medical Ethics Committee, the CMO Arnhem – Nijmegen, the study is non-invasive and does not fall under the scope of the Medical Research Involving Humans Subjects Act (WMO). [34] All patients provided written informed consent, while nurses provided oral consent. Data was handled anonymously and stored separately from respondents' personal information.

## Results

### Step 1 Logic Model and needs assessment

Patients from the head/neck surgical ward (n=11) and from the cardiology ward (n=14) consented to participate in interviews. Most patients appeared to have some idea about the concept of patient participation, and mainly described it as being adequately informed, being able to ask questions, and being involved in decision making.

> *Respondents 2, 75-year-old female: "I appreciate it when doctors and nurses consult with me and that I am invited to ask questions. I would like to know why they do the things they do."*
>
> *Respondent 4, 46-year-old female: "I've noticed a change in informing patients in the last few years. They explain a lot more, and ask for your opinion and your feelings. I think that's a good thing."*

Patients expect their health care providers to take an active role in initiating participation, but most of them consider themselves able to initiate a conversation if they have urgent questions. Most patients wanted to use the Tell-us Card for being informed about their daily schedule and important appointments, and some patients wanted to use it as a way to communicate their questions or feelings. When asked about discharge, patients wanted to be involved in discharge planning, and wanted to be informed about the do's and don'ts at home. Patients also wanted their spouses or family to be more involved in their care. Most patients regarded the Tell-us Card as useful for asking questions and raising concerns easier.

The nurses described patient participation as a collaboration with the patient, in which the patient and the nurse both take an active role.

> *Nurse 6, Gynaecology and Urology ward: "[Participation is..] When I would let the patient do more himself, so to say. Because that is essentially what you aim at with patient participation"*
>
> *Nurse 9, Head and Neck surgical ward: "For me, patient participation is the patient taking part in his own care process or healing. Specifically that would mean that the patient thinks along with us. He doesn't really have to do something, but that he thinks about what's best for him and how he can play a role in it."*

Nurses saw informing patients as their main task with regard to patient participation, through which they hope to achieve a sense of awareness and stimulate patients to take responsibility for their health. Nurses also thought that patient participation would demand more time and effort, resulting in a higher workload, but were motivated to invest if it would benefit the patient. Nurses acknowledged the trend that patients want to be more involved in their care, and were positive about using the Tell-us Card to improve patient satisfaction and getting more insight in patient's preferences and needs.

### Step 2 Matrices

Specific performance and behavioural objectives were formulated based on the literature and results from the individual and focus group interviews. The matrices specify what a program participant will have to do (performance objective), and are then examined in light of behavioural determinants to generate change objectives. These specify what needs to change in the determinants of behaviour in order to accomplish the performance objective. For example, (table 2, PO1): In order to give the patients a Tell-us Card on a daily basis it is required that the nurses' attitude towards the use of the card is that it is important to do so (A1), therefore the nurse needs to know why it has to be offered on a daily basis (K1), the nurse needs to be convinced that she is able to do so (SE1), and the nurse needs to be convinced that handing out the card and discussing its' content will improve patient participation in care and will lead to better outcomes (OE1).

### Step 3 Theoretical Methods and Practical Applications

Based on the interviews and literature the change objectives deemed most important by the researchers were selected from the matrices. These were matched with theory and strategies on behaviour change methods[31, 35] and implementation strategies[32] to achieve an evidence based approach on behaviour change. Table 3 displays an overview of this process, including the resulting implementation strategies. These strategies are: an e-learning module to meet the needs of the behavioural objectives regarding knowledge, the assignment of a core group of nurses as role models, visits to the ward for education, feedback, and encouragement, informational letters for patients and nurses for instruction and a kick off meeting to encourage and educate nurses.

## Step 4 Producing program components

Combining the input from nurses and patients with methods for behaviour change and implementation led to the selection of program components, as shown in table 3. Digital registration forms were developed in collaboration with an ICT assigned nurse, the IT department and the researchers (MH & JC). An e-learning module was developed to inform and educate the nurses about patient participation, and the goal and use of the Tell-us Card intervention (see table 3 for content). An e-learning module is easy accessible at any time or place and guarantees a uniformity of the knowledge delivery. It was developed by the researchers (JC & MH) of which one is a teacher and an expert in the development of electronic training modules for nurses. The training ends with a short questionnaire to assess self-efficacy, as an estimation of efficacy predicts how nurses will actually deal with the intervention. [36]

## Step 5 Planning for Adoption, Implementation and Sustainability

Involving the target group is an important strategy for adoption and implementation of any intervention. The nurses in focus group interviews regarded good communication skills as a precondition to inform patients and elicit their needs. Perceived barriers focussed on practical problems such as the extra time it would take, the moment in time at which the card should be handed out and at what time the card could be discussed. The e-learning was adapted to address these barriers and the module underlined the importance of patient participation and the use of the Tell-us Card (table 3) by showing quotes from patients and thoughts from fellow nurses from the individual interviews. It furthermore showed benefits of patient participation and tackled some misconceptions raised during the focus group interviews (“you don’t have to fulfil every wish or demand the patient has”). Also the nurses’ concerns about dealing with issues or questions from patients upon which the nurses had no (immediate) answer was addressed.

Furthermore, at each ward a core group of nurses was formed to guide implementation, to stimulate the use of the Tell-us Card, and to provide feedback. This group was also asked to provide input on logistic. Visits to the ward were scheduled with these key nurses and ward management to give and receive feedback and encourage the team. In a kick-off meeting the intervention officially started with a celebratory moment to positively reinforce the nurses and to repeat instructions for using the Tell-us Card.

**Table 2** Performance objectives, determinants and change objectives

| Performance objectives | Attitude | Knowledge | Self efficacy and skills | Outcome expectation |
|---|---|---|---|---|
| **Inviting the patient to use the Tell-us Card** | | | | |
| PO1. The nurse gives the patient a Tell-us Card on a daily basis | A1. The nurse states that is important to give the patient the Tell-us Card daily | K1. The nurse knows why the Tell-us Card has to be offered to the patient each day | SE1. The nurse states to be convinced that he/she is able to offer patients the Tell-us Card on a daily basis. | OE1. The nurse expects to improve patient participation when the card is handed out daily |
| PO2. The nurse actively invite patients to state on the Tell-us Card what is important to them or before discharge form the ward. | A2. The nurse states that it is important to invite the patient to tell what is important for him/her on that moment or with regard to discharge form the hospital | K2.1. The nurse knows why the patient needs to be actively invited to use the Tell-us Card<br>K2.2. The nurse knows how the patient needs to be actively invited to use the Tell-us Card | SE2. The nurse states to be convinced that he/she is able to actively invite the patient to state what is important to them at that moment or with regard to discharge from the hospital. | OE2. The nurse expects to gain better insight in the patients' needs or wishes when the patient uses the Tell-us Card |
| PO4. The nurse tells patients that it is important to be actively involved in their care | A4. The nurse values patients to be actively involved in their care | K4. The nurse knows how to tell patients to be actively involved in their care<br>K4.2 The nurse knows why it is important actively involve the patients in their care | SE4. The nurse is convinced that he/she can inform the patient that it is important to be actively involved in their care | OE4.1. The nurse expects to be an adequate informant<br>OE4.2. The nurse believes that actively involved patients achieve better health outcomes |

## Step 6 Planning for Evaluation

Process analysis was prepared following the 6 steps described by Saunders et al. (2005).[33] A description of the program (step 1) and a description of a complete and acceptable delivery (step 2) are mentioned in the previous IM steps. In step 3 the matrix (IM step 2) was analysed to see which program and change objectives were suitable for evaluation. Experiences of nurses and patients, content of the Tell-us Cards, actions formulated based on this content, and insight in numbers of patient using the Tell-us Card, were identified as important issues. With regard to process evaluation (4) it was decided that all Tell-us Cards would be collected by the researchers to examine the content and the number of patients reached with the intervention. Nurses were required to note what actions followed on the issue noted on the patients' Tell-us Card. Thoughts and experiences with the Tell-us Card are gathered in a questionnaire for nurses and additional observations will be carried out to register actual performance of the intervention. In step five (5) contextual factors of the wards which could have affected the intervention will be examined by discussing results with ward management. The last step (6) concerns finalising the process-evaluation plan.

To evaluate an effect pre-and post-intervention, the questionnaire for patients will include the "Quality from the Patient's Perspective - short form" [37] to measure patients' perception of participation, the Individualised Care Scale[38] to explore the concept of personalized care, and the EQ-5L-5D questionnaire[39] as a quality of life indicator. Nurses perspectives will be assessed by using the Individualised Care Scale for nurses[40] and qualitative methods for fidelity to the intervention and nurses' experiences in the use of the Tell-us Card.

**Table 3** Description of determinants, methods and applications

| Determinant & Change objective | Methods |
|---|---|
| **Knowledge** | |
| The nurse knows that actively involved patients achieve better health outcomes | Provide information about behaviour-health link[31] by advance organizers[35] |
| The nurse knows how the Tell-us Card intervention has to be carried out | Model or demonstrate the behaviour[31] by modeling[35] and providing opportunities for social comparison[3 35]<br>Provide instruction[31] by active learning[35], advance organizers[35], and cooperative learning[35]<br>Educational meetings[32] by advance organizers[35], implementation intentions[35], and persuasive communication[35] |
| **Attitude** | |
| The nurse feels supported by her colleagues in using the Tell-us Card intervention | Provide information about colleagues' approval[31, 32] by modeling[3] and information about others' approval[35]<br>Stimulate discussion[32] between nurses by mobilizing social support[35] and guided practice[35] |
| The nurse has peers who set a good example in the use of the Tell-us Card intervention | Assigning role models[32] and prompt identification as a role model[31] by modeling[35], public commitment[35] and mobilizing social support[35] |
| The nurse values the patients' opinions and thoughts about their care | Provide information about patients' perspective[32] by shifting perspective[35] |
| **Self-efficacy** | |
| The nurse feels able to use the Tell-us Card intervention | Provide general encouragement[31], providing feedback on performance[31] by mobilizing social support[35], consciousness raising[35], feedback[35], and providing opportunities for social comparison[35] |

| Applications | How context and parameters were taken into account |
|---|---|
| E-learning in which information is provided | Context: E-learning can be accessed at convenient time. Parameter: schematic representations; an overview of current knowledge, adjusted to knowledge level shown in focus group interviews |
| E-learning in which a video is shown of a nurse and patient demonstrating the use of the Tell-us Card intervention. Step-by-step written explanation of how the intervention must be carried out in the e-learning and on posters for the nurses' station, and on informational letters to all nurses. Presentations on ward meetings and during a kick-off event at the start of the intervention period. | Context: E-learning can be accessed at convenient time. Parameters: a role play video of the intervention as example and comparison with their own behaviour. Schematically displaying the intervention in the e-learning and on posters as a reminder. Introducing and discussing the Tell-us Card during meetings to encourage nurses toward the adoption of the intervention. |
| E-learning in which quotes from peers are shown, and questions posed where nurses are prompted to discuss/solve the answer with other colleagues and are asked to try the intervention together. | Context: E-learning can be accessed at convenient time. Parameters: quotes from interviews with nurses to show positive and critical remarks of colleagues to motivate change and adoption. The interaction stimulates caring, openness and acceptance with support for behavioural change |
| Forming a core group of nurses | Context: Number of nurses in core group are determined by ward size.<br>Parameters: Engaged core group nurses are asked to perform and stimulate the correct use of the intervention and provide social support to colleagues. |
| E-learning in which quotes from patients are shown | Context: : E-learning can be accessed at convenient time. Parameters: Quotes from individual interviews with patients to encourage nurses to take the perspective of the patient to increase the adoption |
| Core group members report feedback from the team to the researchers, and wards are visited by the researchers | Context: core group members are easy approachable to colleagues to report feedback, and visiting the ward is a low-key approach in talking to the nurses.<br>Parameters: Specific feedback is given, nurses are given the opportunity to talk about the use of the Tell-us Card, and their behaviour encouraged by the researchers. |

**Table 3** Continued

| Determinant & Change objective | Methods |
|---|---|
| **Self-efficacy** | |
| The nurse is able to critically review the intervention and communicate his/her thoughts about it | Prompt barrier identification[31] and reviewing practice and feedback[32] by planning coping responses[35] and discussion[35] |

## Discussion

This article shows how the methodological framework of Intervention Mapping (IM) is used to tailor the Tell-us Card intervention to the Dutch hospital setting. As the MRC-model states that a systematical developmental phase is required before pilot testing the intervention, [27] IM was chosen for its framework of six steps containing clear guidelines on which actions need to be undertaken in each phase. Combining needs and experiences of nurses and patients with evidence-based knowledge about implementation and behaviour change theory are essential elements in this. It provided a useful framework which guided the researchers through a systematic process that considers the user input from nurses and patients, and the theoretical foundation upon which to build the intervention. It encouraged the assessment of thoughts and perceptions of the stakeholders throughout the process, which might enhance the optimal use of the intervention.

Patient participation in care is challenging as is stipulated in literature by Sahlsten et al., [41] who described inexperience of nurses and patients with the full domain of patient participation. Congruent with other research there was a discrepancy between nurses' views, who would promote patient participation through dialogue and knowledge sharing, and the patients' who want to be listened to, and want to be regarded as individuals. [22, 23] As Eldh et al. (2006) discuss, supplying a patient with information about his condition does not automatically lead to the patient incorporating this knowledge in their daily lives and taking responsibility for their health. [23] Both, nurses as well as patients, regard the Tell-us Card to be a feasible tool to support patients in stating what is important to them, and to help patients discuss these issues with nurses.

| Applications | How context and parameters were taken into account |
|---|---|
| Focus group interviews in which nurses are invited to think of barriers and facilitators, and meetings in which the use of the Tell-us Card is discussed | Context: Based on predefined characteristics for heterogeneity, nurses were asked to join the focus group on their ward.<br>Parameters: While designing the intervention, nurses in focus group interviews identifies potential barriers and ways to overcome these. Reviewing of practice at ward meetings where nurses were encouraged to openly debate about the Tell-us Card intervention |

Although nurses were positive about the intervention, most nurses regarded their already busy workload as a barrier. Previous studies indicate that a high workload[42-44] and a desire to maintain control[21, 45] might hinder patient participation in nursing. In the study conducted by Henderson et al. (2003) nurses stated to lack time for patient participation and that they purposefully asked closed questions or otherwise minimized the amount of contact between them and their patient when busy to avoid lengthy conversation. [21] However, observations in that study showed that these nurses continued to use closed questions even when not busy, and that most nurses were not prepared to share their knowledge and decision-making power with patients. As the Tell-us Card intervention is based upon taking the time for patient participation and talking with patients, the perceived lack of time and attitude towards participation will demand attention during implementation.

An intervention like the Tell-us Card for improved patient participation during hospital admission might seem easy to accomplish. However, the thorough analysis and adaptation of the intervention based on a systematic approach like the framework of Intervention Mapping[28, 31, 35] shows the complexity of the intervention and stipulates the importance of tailoring the intervention adequately to the specific setting. Understanding the underlying mechanisms that influence adoption of the Tell-us Card for enhanced patient participation in the Dutch hospital setting is an essential step before implementation and assessing effectiveness. This will enhance the quality of further research and save time later on, as awareness of barriers for adaptation are identified and anticipated on. [32] The development of a theoretical understanding of the likely process of change is also stressed by the MRC-framework, as it provides important information about the design of both the intervention and evaluation. [27]

The purposive sampling of nurses, selected by the wards contact persons, might be regarded as a limitation for this may have resulted in a selection bias; for instance with regard to the attitude or motivation of the selected nurses to participate. However, the contact person and the researchers deemed the groups diverse enough to be representative for the ward. Also, the selection of patients during their admission to the hospital might have affected the patients' ideas about participation in care. Patients might have been more critical or have had the opportunity to think more independently when they would have been interviewed outside the hospital, sometime after admission. [46] Also focus groups of patients in which participation during admission is discussed might have strengthened the input from patients. [47]

As this low-cost communication tool focuses on patient participation in the fundaments of care, the Tell-us Card intervention is likely to fit in other care settings as well. However, due to the inexperience[22, 23] in nurses with patient participation regarding discussing a patient's individual need and acting upon this need, the developmental and implementation phase of this intervention require close attention. To ensure an optimal fit to the health care providers and patients of other wards, a similar systematic approach in implementation is advised.

## Conclusion

Patient participation is at the heart of nursing care. In the development of the Tell-us Card intervention nurses showed a basic understanding of patient participation and regarded effective communicating as fundamental in care. The Tell-us Card, a seemingly uncomplicated intervention, needs a thorough understanding and preparation. A pilot study is needed to confirm feasibility of the intervention. An overview of the methodological advantages of using the IM framework within the MRC-framework was given, which showed that following the IM framework is useful to grasp the full domain of tailoring the Tell-us Card intervention for enhanced patient participation in nurses and patients.

### Practical implications

This article shows how the systematic approach of Intervention Mapping is applied to adapt the Tell-us Card communication intervention and could serve as a guide for the tailoring of similar interventions. The extensive steps of IM were successfully completed, guiding the researchers in adapting the Tell-us Card intervention to ensure a thorough developmental phase, as advised by the MRC-framework. As not many interventions exist aiming at enhancing patient participation in nursing care, we believe that the Tell-us Card intervention is beneficial for the basic care for patients in hospitals, and fills a need in patients and nurses for true attention to the patient.

## Acknowledgement

We would like to thank the nurses and patients of the Head and Neck surgical ward of the Radboud university medical center and the Cardiology ward of the Jeroen Bosch hospital for their collaboration.

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# 3

# Effectiveness and feasibility of the Tell-us Card communication tool to increase in-hospital patient participation: a cluster randomized controlled pilot study

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Scandinavian Journal of Caring Sciences, 2020

## Abstract

**Background:** Patient participation is fundamental to nursing care and has beneficial effects on patient outcomes. However, it is not well embedded yet and little is known on how nurses could effectively stimulate patient participation in hospital care. The Tell-us Card is a communication tool for inviting patients to talk about their preferences and needs, and to increase patient participation in daily care. Objectives: To assess feasibility and early effectiveness of the Tell-us Card communication tool for enhanced patient participation during hospitalization.

**Method:** A pilot cluster randomized controlled study design was used including four nursing wards. Effectiveness was measured with the Individualized Care Scale (ICS) and the Quality from the Patients' Perspective (QPP) questionnaire. Linear mixed model analysis was used for analysis. Feasibility was assessed with an evaluative questionnaire for patients and nurses and by reviewing the content of Tell-us Cards using the Fundamentals of Care Framework (FOCF) for analysis. Ethical approval was attained.

**Results:** Data of 265 patients showed a significant increase at one intervention ward on the ICS (effect size 0.61, $p = 0.02$) and most ICS subscales. No effect was visible on the QPP. The majority of patients regarded the intervention as beneficial; nurses however experienced barriers with incorporating the Tell-us Card into daily care. Analysis of the Tell-us Card content showed many elements of the FOCF being mentioned, with most patients indicating psychosocial needs like being involved and informed.

**Conclusions:** This pilot study showed a positive early effect of the Tell-us Card communication tool on patient participation, although integration in daily nursing care appeared to be complex and an optimal fit has not yet been reached. Patients were positive about the intervention and wrote meaningful issues on the Tell-us Cards. More research is needed on how to incorporate patient participation effectively in complex hospital care.

## Introduction

Hospitalized patients' participation in care is challenging but has various beneficial effects in patient safety,[1] adherence to therapy or lifestyle advices,[2] and both patient[3] and healthcare professionals work satisfaction.[4] There is not one clear definition of patient participation, and the concept is interchangeably used with terms like patient-centeredness, shared decision-making, person-centered care, and patient empowerment or engagement. Patient participation in nursing practice is defined by Sahlsten et al. as an established relationship between nurse and patient, a surrendering of power or control by the nurse, shared information and knowledge, and active engagement together in intellectual or physical activities.[5] This established relationship forms the core of effective patient participation and person-centered care.[6] Participation can be enacted at different degrees ranging from the patient being informed to being in full control and can be situated at the micro-, meso- and macro-level.[7] To achieve this partnership, the patient's view as an expert must be considered important and requires activation of both the patient as well as the healthcare provider.[8]

Communication should therefore be characterized by respect, empathy and recognition of the patient as an individual as well as a partner in health care.[9] Communication is also defined as a fundamental of care and foundation of any healthcare provider to patient interaction.[10] Through effective communication, patients can participate in their care by setting achievable short- and long-term goals to regain control over their bodily functions as well as to regain a sense of personal integrity and sense of self.[11] Observational studies show that the nurses' controlling approaches can be a hindering factor.[12] Patient-centered communication and patient participation is often lacking in during hospitalization as there is little dialogue between patients and nurses on what patients expect or how they want to participate.[5] Also, care and discharge plans often fail to take patient preferences into consideration.[13] Overall patient participation in acute health care is lacking, and evidence on interventions to improve patient participation in fundamental nursing care is limited.[6]

A promising tool to improve patient participation during hospitalization is the Tell-us Card (Tell-us Card).[15-17] The Tell-us Card is a postcard-sized paper card which is handed to patients on a daily basis. Patients are invited to write down what is important to them for that day or before discharge. At a mutually agreed moment of time, the content of the card is discussed and possible follow-up actions are planned and registered in the patient's file. Jangland et al. tested the effectiveness of the Tell-us Card in a population of Swedish patients admitted to a surgical nursing ward and showed significant improvements in patients' abilities to participate in decisions about their care.[17] Following the MRC framework for complex interventions, the Tell-us Card needs to be tailored and pilot tested to explore feasibility and small-scale effects before implementation in other settings.[18] In this pilot trial, the researchers set out to (1) determine small-scale effects of the Tell-us Card intervention, (2) evaluate user experiences and (3) evaluate the appropriateness of outcome measures. The general aim of this study therefore was to assess feasibility and early effectiveness of the Tell-us Card in the Dutch hospital setting.

## Methods

### Design

To assess feasibility and early effectiveness, a cluster randomized controlled study (CRTC) design was used. With this design, we aimed to compare effects within and between clusters. As nursing care can differ between surgical and internal specialties, two surgical wards and two cardiology wards were included. Both surgical wards resided within the same university hospital, as well as one of the cardiology wards. The other cardiology ward (intervention group) was located in a nearby regional hospital. The wards were assigned to either control or intervention by a random draw by an independent researcher. Assessments were conducted at baseline (T0) and 3 months after the start of the intervention (T1). The CONSORT statement extension for randomized pilot and feasibility trials was used for reporting.[19]

### Participants

All adult patients (age > 18) with an expected hospital stay of at least one day and a diagnose fitting the wards specialism were included. Patients were excluded if they were not able to speak or write in Dutch, had mental impairments, or were not willing or able to give informed consent. The surgical cluster consisted of a head and neck surgical ward and a ward for neurosurgical and plastic surgery. The cardiology wards both admitted patients with acute and chronic cardiac conditions. At T0 patient characteristics were compared to determine comparability. Nurses working on the wards were vocational of bachelor educated, and had a nurse-to-patient ratio of 1:4 during the day and 1:6–8 during the evenings.

### The Tell-us Card intervention

The Tell-us Card is a communication tool to elicit what patients regard as important at that moment or before discharge (Box 1). The control group received care as usual. Permission to use the Tell-us Card was obtained from the original researcher.[17] The card was translated to Dutch by the authors and slightly modified based on input from the wards' nurses.[20]

**Box 1** Tell us Card protocol

The nurse…

1. Gives the double sided Tell-us Card once a day to each patient.

   **Side A:** “Tell us! We want to involve you in your care as much as possible. What is important to you today or before discharge? What are your needs, or what information do you want? What do you want us to know about you as a person? Are there arrangements that need to be taken care of? What things can you do yourself, and where do you need help with? We would like to invite you to write down your questions, wishes, worries and ideas on the back of this card. The nurse who takes care of you will discuss these with you.”

   **Side B:** “Tell us! Write down on this card what is important to you. Your nurse will discuss this with you”. Followed by: “This is important for me: ……………………………… ………………………………………………………………………………………………………………………… ……………………………………………………………………………………………………………………….”.

2. Goes back to the patient after an agreed amount of time to discuss the card and to talk about what is important.
3. Establishes with the patient if/what follow-up actions are needed and by whom.
4. Reports the findings and agreed upon actions in the patient’s file.
5. Reports back to the patient if/what follow-up actions are undertaken.

## Preparing for implementation

In line with the MRC framework,[21] the implementation of the Tell-us Card was systematically tailored using the Intervention Mapping framework.[22] As described in van Belle et al. 2018, focus group meetings were conducted after T0 assessment to identify the nurses’ knowledge, skills, attitude, self-efficacy and outcome expectations regarding the intervention, which was used in the training.[20] Nurses were trained by means of an e-learning and group discussion. At both wards, a core group of nurses was formed to guide implementation by stimulating the use of the Tell-us Card, addressing questions from the nurses and providing feedback. Additional strategies during the intervention period included educational and feedback visits to the wards’ nurses where the study procedures were repeated, questions from nurses answered and progress on received questionnaires was shared.[20] The patient questionnaires were piloted with four patients and deemed understandable and acceptable in length.

## Study procedures

All included patients received written and verbal information about the study and signed an informed consent. At T0 and T1, patients at the intervention and control wards fitting the inclusion criteria received a questionnaire with a prepaid return envelope to be filled in at home after discharge. Nurses were trained to ask patients' consent to participate and were responsible for handing out the questionnaire upon discharge. All activities aimed at the nurses, such as focus groups and training, started after T0 assessments. The filled in Tell-us Cards were stored in a closed container in the nurses' station.

## Primary outcomes

Effectiveness was assessed by a patient questionnaire at T0 and T1 including demographic information, the Individualized Care Scale (ICS)[23] and the Short form Quality of the Patients Perspective questionnaire.[24] The Short form Quality from the Patients Perspective (QPP) questionnaire is an 18-item scale and measures four dimensions of care: medical–technical competence (four items), an identity-orientation approach (10 items), physical–technical conditions (three items) and socio-cultural atmosphere (five items) (Table 3).[24] Items were rated on a scale of 1 ('do not agree at all') to 4 ('completely agree'); additionally, each item had a 'not applicable' response alternative. It was chosen to compare results with the Swedish Tell-us Card study.[17] Translation from English to the Dutch language was conducted by two Dutch researchers and a certified translator using a forward–back translation.[20] The ICS is a 34-item scale assessing the individualized care experience.[23,25] The scale is divided into two parts of 17 questions each: (A) the practice of individualized care during nursing interventions and (B) the perception of individuality in care. Both parts include three domains: the clinical situation (seven items), the personal life situation (four items) and decisional control over care (six items) (Table 2). See Appendices S1 and S2 for the abbreviated questions and item scores on the QPP and ICS. Each item is rated on a 5-point scale of 1, fully disagree, to 5, fully agree with the statement. The scale has a neutral midpoint and has been validated for the Dutch healthcare context.[26] Results of the questionnaires were examined on missings and distribution to evaluate usefulness and feasibility. Feasibility was assessed by examining the content of the Tell-us Cards and asking nurses and patients by means of a questionnaire about their experiences with the Tell-us Card. In this questionnaire, they were asked to indicate how often they used the Tell-us Card, if they were properly instructed, if they perceived the card as helpful and to what extent they appreciated the use of the Tell-us Card. With each question, there was the opportunity to add remarks.

## Sample size

To assess effectiveness in a small-scale pilot study without a predetermined level of precision it is advised to have a sample size of 24–30 patients to get a reliable estimation on the effect of the intervention.[27] This study set out to include 35 patients at each ward at T0 and T1.

## Analysis

SPSS was used for the quantitative analysis.[28] Means, standard deviations, ranges and percentages were used to describe the data, and t test and chi-square analysis were used to calculate differences between wards at T0. Because of the hierarchical structure of this study (patients nested within wards), the analyses were based on a linear mixed-effect model for the ICS and QPP outcomes. Reported differences are changes in score between T1 and T0 and between intervention and control wards. Statistical significance in all tests was assumed at the 0.05 level, based on two-sided tests. Reported effect size signifies the change on the 4- or 5-point scale. The content of the Tell-us Card was analyzed by using framework analysis and thematic analysis.[29] Data were categorized according to the Fundamentals of Care Framework[30] as this gives a full overview of physical, psychosocial and relational needs. Additional thematic analysis was used for results not fitting the framework. Coding was done independently by two researchers (EvB and MH); afterwards, codes were compared and differences discussed until consensus was reached. The open questions in the questionnaire were analyzed using independent open coding (EvB and MH), following axial coding and the identification of themes.[29]

## Ethical considerations

The study was approved by the regional Ethical Review Board (approval number 2014-1350) and the participating ward's management. According to the Dutch national legislation and as judged by the local Medical Ethics Committee, the study is noninvasive and does not fall under the scope of the Medical Research Involving Humans Subjects Act.[31] Patients and nurses were informed about the right to decline from participation without giving any reason at any time. All data were analyzed anonymously, with to persons retraceable information stored separately from the data.

# Results

The study took place between November 2014 and July 2016. Quantitative baseline data were gathered on four wards in a 6-month period from December 2014 to May 2015. The intervention period started on both wards in October 2015 and lasted 3 months. The data at T1 were gathered between December 2015 and July 2016, with a mean duration of 3.5 months.

## Participant flow and recruitment

Twenty per cent of the patients at the surgical ward and 10% of the patients at the cardiology ward did not meet the inclusion criteria. A total of 265 patients completed the questionnaire, with 144 patients at T0 and 121 patients at T1 (Figure 1). The response rate varied between 35% and 57% at T0, and between 41% and 58% at T1. At the surgical intervention ward, 14 of the 20 nurses (70%) filled in the evaluative questionnaire; at the cardiology intervention ward, this was 42 out of the 60 nurses (70%). The Tell-us Card was handed out 158 times to 107 individual patients; 123 times to 72 patients (mean 1.7 per patient) at the surgical ward, and 41 times to 35 patients (mean 1.2) on the cardiology ward. In total, 108 cards (70%) were filled in by patients.

The T0 measurements were completed within the predetermined 3-month period. At T1, both cardiology wards met the patient sample of 35 within this time period, with the intervention ward including 37 patients. However due to incomplete informed consent forms, six questionnaires needed to be excluded from analysis, resulting in 31 included patients. The surgical cluster experienced difficulties in following up the study protocol with regard to informed consent procedures and handing out questionnaires at discharge. Therefore, the data collection period at the surgical cluster was extended to 5 months, after which 25 and 26 patients at, respectively, the intervention and control ward had returned the questionnaire. Patients at the surgical intervention ward were not able to assess feasibility of the Tell-us Card because the intervention period ended before the start of T1 assessments. As it was hypothesized that the intervention period enhanced patient participation within the care process, it was decided to conduct effectiveness analysis as planned.

## Patient characteristics

t Tests and chi-square tests showed no significant difference at T0 of patient characteristics within the clusters with respect to age, gender, educational level and length of admission (Table 1). On average, 63% of the respondents at the cardiac wards were male, and 40% at the surgical wards. At T1, only gender

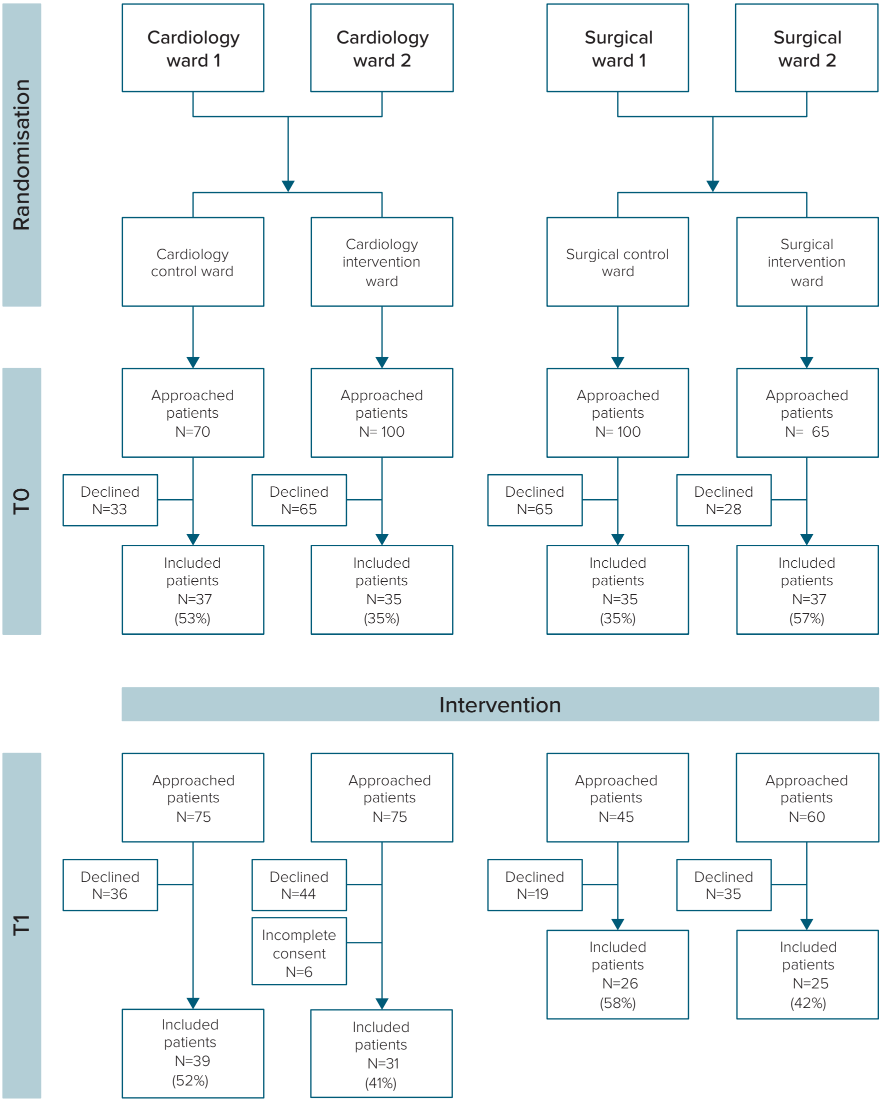

**Figure 1** Flow of patients through the study

differed significantly (p = 0.007) at the cardiology ward, with more men being included in the intervention ward. The study participants age ranged from 24 to 90 years (mean 67, SD 11.3) at the cardiology, and from 20 to 88 years (mean 54, SD 15.0) at the surgical wards.

**Table 1** Patient characteristics

| | Cardiology | | | | | |
|---|---|---|---|---|---|---|
| | T0 | | | T1 | | |
| | Control *n* = 37 | Intervention *n* = 35 | P value * | Control *n* = 39 | Intervention *n* = 31 | P value * |
| **Gender** | | | 0.62 | | | 0.007 |
| Male (%) | 27 (73) | 23 (66) | | 16 (41) | 23 (72) | |
| **Age** | | | 0.86 | | | 0.96 |
| Median age (SD) years | 67.7 (12.8) | 65.8 (9.4) | | 66.9 (11.8) | 68.5 (11.0) | |
| **Level of education[1]** | | | 1.00 | | | 0.11 |
| Primary education (%) | 12 (32) | 11 (31) | | 16 (43) | 9 (31) | |
| Secondary education [2] (%) | 12 (32) | 11 (31) | | 11 (28) | 17 (59) | |
| Bachelor degree or higher (%) | 13 (32) | 12 (35) | | 10 (26) | 3 (10) | |
| **Length of admission** | | | 0.62 | | | 0.49 |
| 1–2 days (%) | 0 (0) | 1 (3) | | 3 (8) | 1 (3) | |
| 3–4 days (%) | 8 (22) | 8 (23) | | 12 (31) | 4 (13) | |
| 5–6 days (%) | 12 (32) | 11 (32) | | 3 (8) | 7 (23) | |
| 7–9 days (%) | 4 (11) | 6 (17) | | 8 (20) | 8 (26) | |
| 10 or more days (%) | 10 (30) | 7 (20) | | 11 (30) | 8 (26) | |

* *P* value were based on Chi-square test for categorical variables, and t-test for continuous variables

[1]= Level of education is defined following the ISCED 2011[48]

[2]= Secondary education and post-secondary, non-tertiary education

## Primary outcomes and estimation

### Individualized Care Scale

The linear mixed-effect model analysis for the cardiology patients shows a significant improvement at T1 on 6 out of 9 (sub)scales (Table 2). This effect is established at different levels; the total ICS scale (effect size 0.61, p = 0.02), both part A (ES: 0.62, p = 0.04) and part B (ES: 0.73, p = 0.004), and subscales ICS-A Personal life situation (ES: 0.89, p = 0.03), ICS-B Personal life situation (ES: 1.07, p = 0.002) and ICS-B Decisional control over care (ES: 0.57, p = 0.01). Results in the surgical cluster showed no significant differences between T0 and T1. In both control wards, there appears to be a declining trend over time, as five out of six subscales score lower on T1 at the surgery wards, and four out of six at the cardiology ward. The scores of the four wards show quite similar patterns. Looking at the results of the ICS, only 22% of the items had a mean score below 4.00 on the 5-point scale, with a lowest mean score of 3.14 (addendum 1 ipv supplement s1). The highest

| Surgical | | | | | |
|---|---|---|---|---|---|
| T0 | | | T1 | | |
| Control<br>*n* = 37 | Intervention<br>*n* = 35 | P value * | Control<br>*n* = 26 | Intervention<br>*n* = 25 | P value * |
| | | 0.13 | | | 0.41 |
| 10 (29) | 17 (46) | | 10 (38) | 12 (50) | |
| | | 0.33 | | | 0.08 |
| 52 (13.4) | 58.6 (18.4) | | 51.7 (15.1) | 63.8 (12.4) | |
| | | 0.73 | | | 0.65 |
| 9 (24) | 7 (20) | | 5 (19) | 6 (24) | |
| 15 (41) | 17 (48) | | 10 (38) | 13 (52) | |
| 13 (35) | 9 (26) | | 11 (42) | 6 (24) | |
| | | 0.82 | | | 0.33 |
| 10 (28) | 10 (27) | | 15 (59) | 3 (12) | |
| 6 (17) | 6 (16) | | 3 (11) | 4 (16) | |
| 8 (23) | 8 (22) | | 3 (11) | 4 (16) | |
| 9 (26) | 7 (19) | | 3 (11) | 6 (24) | |
| 2 (6) | 5 (14) | | 2 (8) | 8 (32) | |

scoring subscale (on all wards at both T0 and T1) concerned the nurse inviting the patient to be involved in his or her care (ICS-B decisional control over care), with mean scores ranging from 4.03 to 4.66.

This is mainly due to the questions concerning the items ‘patients’ ability to follow instructions received in the hospital’ (range 4.66–4.97) and ‘patients making their own decision on when to wash’ (range 4.34–4.87). The questions in this subscale (ICS-B Decisional) relating to ‘patients’ expressed wishes have been considered in care’ (range 4.03–4.60) and ‘patients taking part in decision-making’ (range 3.87–4.43) scored lower. The two lowest scoring subscales on all wards concerned incorporating the patient’s personal life situation into the hospital care (both subscale A and B), with average scores of 3.51 for subscale A and 3.72 for subscale B. The question ‘nurses asking about previous experiences of hospitalization’ (range 2.59–3.58) scored either lowest or in the bottom 3 on all wards.

**Table 2** Individualized Care Scale

| | Cardiology | | | | | |
|---|---|---|---|---|---|---|
| | Control | | Intervention | | | |
| | Mean T0 (SD) | Mean T1 (SD) | Mean T0 (SD) | Mean T1 (SD) | Effect* | *p* |
| | *n* = 37 | *n* = 39 | *n* = 35 | *n* = 31 | *n* = 142 | |
| Individualized Care Scale | 4.19 (0.66) | 3.93 (0.87) | 3.86 (0.86) | 4.21 (0.57) | 0.61 | 0.02 |
| ICS-A | 4.06 (0.77) | 3.71 (1.01) | 4.03 (0.92) | 4.06 (0.63) | 0.62 | 0.04 |
| ICS-A Clinical | 4.26 (0.83) | 4.09 (1.01) | 4.03 (0.94) | 4.14 (0.83) | 0.28 | 0.37 |
| ICS-A Personal | 3.49 (1.15) | 3.75 (1.36) | 3.14 (1.22) | 3.75 (0.89) | 0.89 | 0.03 |
| ICS-A Decisional | 4.20 (0.74) | 4.22 (1.05) | 3.95 (0.91) | 4.22 (0.71) | 0.58 | 0.05 |
| ICS-B | 4.30 (0.60) | 4.01 (0.78) | 3.92 (0.89) | 4.37 (0.57) | 0.73 | 0.004 |
| ICS-B Clinical | 4.30 (0.72) | 4.25 (0.89) | 3.96 (1.00) | 4.25 (0.72) | 0.52 | 0.07 |
| ICS-B Personal | 3.94 (0.91) | 3.62(1.10) | 3.33 (1.12) | 4.08 (0.84) | 1.07 | 0.002 |
| ICS-B Decisional | 4.61 (0.47) | 4.66 (0.78) | 4.03 (0.70) | 4.66 (0.48) | 0.57 | 0.01 |

*Reported differences are changes in score between T0 and T1 and between control and intervention ward.

## Quality of the Patient's Perspective

The results on the QPP showed no significant change at any of the wards at T1. Also, approximately 75% of all mean scores ranged between 3.50 and 4.00 (Table 3), meaning that patients scored high on the questionnaire's 4-point scale at T0 and T1. The highest scoring question on all wards concerned 'the patient's friends and family being treated well' (range 3.80–4.00) (supplement 2 ipv appendix s2). The lowest scoring questions were about 'whether the care was determined by the patient's requests and needs, rather than staff procedures' (range 3.13–3.63) and 'talking to the doctor in private when the patient wanted' (range 2.71– 3.63). The latter was answered by 43% of patients as being 'not applicable' (NA), making it one of the three items with highest NA rates. Others were 'being able to talk to a nurse in private' (35% NA) and 'having access to necessary care equipment' (35% NA). As patients were asked to fill in two questionnaires, the data showed no signs of fatigue or inconsistencies, or higher numbers of questions that were not answered.

## Feasibility

The evaluative questions were answered by 31 cardiology patients. Most patients (78%) received the Tell-us Card once. Patients indicated that the aim of the card was clear (96%). About three quarters of the patients (74%) indicated the card had helped 'somewhat' or 'very much' to tell the nurse what was important to them. Patients responded to the open question 'What do you think of the Tell-us Card?'

| Surgical | | | | | |
|---|---|---|---|---|---|
| Control | | Intervention | | | |
| Mean T0 (SD) | Mean T1 (SD) | Mean T0 (SD) | Mean T1 (SD) | Effect* | *p* |
| *n* = 35 | *n* = 26 | *n* = 37 | *n* = 25 | *n* = 123 | |
| 4.20 (0.57) | 3.90 (0.82) | 4.01 (0.96) | 3.93 (0.77) | 0.22 | 0.45 |
| 4.10 (0.66) | 3.74 (1.01) | 3.88 (0.97) | 3.81 (0.87) | 0.29 | 0.38 |
| 4.26 (0.62) | 3.82 (0.89) | 4.04 (0.93) | 4.03 (0.94) | 0.43 | 0.17 |
| 3.49 (1.15) | 3.35 (1.43) | 3.65 (1.24) | 3.43 (1.07) | 0.01 | 0.98 |
| 4.26 (0.71) | 3.94 (1.06) | 3.98 (1.10) | 3.80 (0.93) | 0.14 | 0.69 |
| 4.28 (0.62) | 4.06 (0.80) | 4.04 (0.97) | 4.06 (0.82) | 0.24 | 0.43 |
| 4.35 (0.64) | 3.93 (1.04) | 4.12 (1.05) | 4.04 (0.98) | 0.34 | 0.32 |
| 3.87 (1.01) | 3.66 (1.08) | 3.70 (1.08) | 3.55 (0.90) | 0.07 | 0.86 |
| 4.44 (0.64) | 4.44 (0.53) | 4.31 (0.91) | 4.41 (0.73) | 0.11 | 0.70 |

that it helped them raise issues, they saw it as a tool to improve the quality of care, and that they used the card as a means to write down their experiences or questions. Some patients indicated that they preferred not to use the card and just talk to the nurses. All nurses on the surgical ward and 73% of the nurses on the cardiology ward felt they had been well-instructed on how to use the Tell-us Card. At both wards, about two-thirds of the nurses (62%–64%) indicated that they had used the Tell-us Card one to three times during the intervention period. About one-third of the nurses (31%–29%) on both wards stated to have used it more than five times. A majority of the nurses (82% at cardiology and 62% at the surgical ward) indicated that they did not think that the Tell-us Card really helped patients to express what was important to them. Main barriers for nurses were that they felt it had little additional value, and patients not knowing what to write down. Nurses also stated to expect their patients to speak up and to prefer face-to-face conversation instead of a card, which indicates regarding the card as a substitute for conversation instead of a tool to initiate conversation. Additionally, registering the content and follow-up of the Tell-us Card in the patients' file and handing out questionnaires at discharge were regarded as administrative burden.

### Tell-us Card content

The content of the 108 Tell-us Cards was coded based on the physical, psychosocial and relational elements of the Fundamentals of Care Framework (FoCF). Many cards raised more than one topic, such as a cardiology patient writing 'Important

**Table 3** Quality from the Patient's Perspective

| | Cardiology | | | | | |
|---|---|---|---|---|---|---|
| | Control | | Intervention | | | |
| | Mean T0 (SD) | Mean T1 (SD) | Mean T0 (SD) | Mean T1 (SD) | Effect* | p |
| | n = 36 | n = 34 | n = 35 | N = 31 | n = 136 | |
| Quality from the Patient's Perspective | 3.74 (0.33) | 3.78 (0.68) | 3.61 (0.36) | 3.64 (0.58) | - 0.02 | 0.91 |
| Medical–technical competence | 3.79 (0.41) | 3.78 (0.49) | 3.72 (0.44) | 3.63 (0.63) | - 0.08 | 0.64 |
| Identity-oriented approach | 3.77 (0.38) | 3.70 (0.48) | 3.60 (0.49) | 3.65 (0.61) | 0.12 | 0.50 |
| Physical–technical conditions | 3.61 (0.48) | 3.63 (0.55) | 3.59 (0.47) | 3.63 (0.62) | 0.02 | 0.90 |
| Social cultural atmosphere | 3.72 (0.43) | 3.61 (0.58) | 3.56 (0.52) | 3.63 (0.60) | 0.18 | 0.34 |

Reported differences are changes in score between T0 and T1 and between control and intervention ward.

for me is to empathize, that they listen to me, give me the right advice, and give me genuine attention'. In this example, three elements were coded (empathy, active listening and being involved and informed). Framework analysis leads to the identification of 149 individual codes connected to 24 of the 29 fundamentals of care (Table 4). Two topics, a hygienic environment and being satisfied about care, were not part of the FoCF. Most cards related to the psychosocial elements of the FoCF, with 'being involved and informed', 'having interests and priorities considered and respected', and 'being satisfied about care' being used in 78 of the 149 identified issues.

Many patients want to be informed about medical treatment and results from examinations. A cardiology patient: 'Talk to me when the medication is changed. Why they change it and information on what I am taking them for. This is not always happening'. Patients wanted nurses to inform them about self-care at home or at the hospital, explain their actions during care and let them know what the day was going to be like. All physical elements of the FoCF were identified. Most were about eating and drinking, rest and sleep, and comfort. A surgical patient stated 'I feel really bad. Did not sleep last night. Despite pain medication my pain did not significantly decrease. I have cold sweats, I am nauseous, my stomach hurts and I feel weak. I want to go home, but only if I get sufficient pain medication'. Also, all nine relational elements were identified, with patients wanting the nurses and other healthcare professionals to be friendly, respectful, involved and to pay attention to them as a person. A patient on the cardiology ward wrote 'I want a

| Surgical | | | | | |
|---|---|---|---|---|---|
| Control | | Intervention | | | |
| Mean T0 (SD) | Mean T1 (SD) | Mean T0 (SD) | Mean T1 (SD) | Effect* | p |
| N = 35 | n = 26 | n= 37 | n = 25 | n = 123 | |
| 3.81 (0.25) | 3.72 (0.24) | 3.68 (0.46) | 3.76 (0.27) | 0.06 | 0.56 |
| 3.84 (0.31) | 3.82 (0.26) | 3.71 (0.51) | 3.89 (0.24) | 0.05 | 0.64 |
| 3.93 (0.30) | 3.70 (0.37) | 3.68 (0.56) | 3.77 (0.31) | 0.04 | 0.79 |
| 3.82 (0.35) | 3.74 (0.47) | 3.66 (0.51) | 3.73 (0.48) | 0.08 | 0.52 |
| 3.73 (0.37) | 3.63 (0.35) | 3.67 (0.52) | 3.65 (0.49) | 0.13 | 0.30 |

personal conversation which shows that the nurse understands me. Sharing laughter and tears, a pat on the back, holding your hand. Being there for the patient who has been in an emotional rollercoaster since being admitted'. Some patients wrote that they were anxious or fearful about pain, examinations, or anything happening to them and needed help coping or staying calm. A surgical patient responded 'I am afraid of choking, I want to be sure this won't happen and to have help with this at home'.

**Table 4** Tell-us Cards themes

| Physical elements | No. of cards | Psychosocial elements | No. of cards | Relational elements | No. of cards |
|---|---|---|---|---|---|
| Personal cleansing | 2 | Communication | 2 | Active listening | 2 |
| Toileting needs | 1 | Being involved and informed | 29 | Empathy | 1 |
| Eating and drinking | 5 | Privacy | 1 | Engaging with patients | 6 |
| Rest and sleep | 5 | Dignity | 0 | Compassion | 6 |
| Mobility | 3 | Respect | 0 | Being present | 1 |
| Comfort | 10 | Education and information | 0 | Supporting and involving families and carers | 1 |
| Safety | 4 | Emotional well-being | 1 | Helping patients to cope | 5 |
| Medication management | 4 | Choice | 1 | Working with patients to set, achieve, and evaluate progression of goals | 3 |
| Hygienic environment* | 5 | Having values and beliefs considered and respected | 0 | Helping patients to stay calm | 7 |
|  |  | Social engagement, company, and support | 1 |  |  |
|  |  | Feeling able to express opinions and needs without care being compromised | 0 |  |  |
|  |  | Having interests and priorities considered and accommodated | 24 |  |  |
|  |  | Being satisfied about care* | 19 |  |  |

* is not part of FoC framework

## Discussion

The results showed a significant impact of the Tell-us Card intervention on most (sub)scales of the ICS at one intervention ward. Patients were most satisfied with the domain of decisional control. Incorporating the patient's personal life into care and determining care based on patients' needs scored the lowest. There was no significant effect on the Quality from the Patient's Perspective questionnaire (QPP). Patients valued the Tell-us Card and wrote down a variety of topics. Nurses experienced difficulties in using the Tell-us Card communication tool despite their training and involvement in tailoring the intervention to their wards. The topics on the Tell-us Cards reflected most of the elements of patient participation,[5] as patients stressed the importance of good relationships with nurses, they wanted to be informed, to express their wishes and needs regarding discharge or home care, and they wanted to share their worries. Also the core of the Fundamentals of Care Framework is related to these outcomes, which describes a positive professional relationship being based on trust, focus, knowing, anticipation and evaluation.[32] A trusting relationship is regarded as essential in identifying patients' needs, and necessary for nurses to be responsive and attentive to changes in a patients' health condition.[32] Difficulties experienced by the nurses in this study underlined the unfamiliarity with patient participation in acute health care.[6] Although a patient-centered approach is stressed at the (inter)national level and is recognized to have a significant impact on patient outcomes,[33,34] applying it in daily practice remains challenging. Nurses emphasized their lack of time and the patient's unfamiliarity with being an active participant in care as problematic, which is in line with barriers identified in previous research on patient participation.[12,35,36] The Tell-us Card might not be regarded as the most appropriate tool for enhanced patient participation, as nurses indicated the tool to redundant and experienced difficulties in incorporating the intervention in daily care; patients however valued the card and addressed important topics. Literature shows that nurses in general feel confident about their communication skills in promoting patient participation[37,38] but also that staff communication is often perceived as disconnected and inadequate[39-41] with nurses limiting or even avoiding communication.[12,42] Literature also shows that healthcare professionals and patients mainly understand patient participation as giving or receiving information,[43] and patients often perceive an imbalance in power.[42,44] In addition, most of today's nursing education insufficiently incorporates how to address patient participation adequately in daily care.[45] This requires from nurses to take the lead in enhancing patient participation in their care, as the patient's confidence to participate will diminish when nurses display behaviors that are unsupportive of patient participation.[41] In the literature several factors are identified as enabling. Tobiano et al. (2018) advised informing patients about their role in care, and making the care process predictable for the patient while leaving room for tailored participation levels.[35] Involving patients in care planning and discussing long and short-term goals as well as discussing process conflicting expectations and roles[41,46] are regarded as beneficial to proactively empower patients to participate.[8,39,47] Evidence suggests that nurses in strategic leadership positions as well as ward or hospital management advocating the need for patient-centered care and participation are necessary to really make a change towards a more patient-centered care.[48] Thus, without participation-focused leadership and a clear vision on how patient participation should be enacted, the adequate use of a tool for enhanced patient participation such as the Tell-us Card will remain difficult. Lastly, the appropriateness of the measurement instruments needs to be discussed. QPP results were skewed, with only 5% of the mean scores lower than 3.00 on the 4-point scale, and 75% above 3.50. This means that patients were already very satisfied with the items, leaving very little room for a significant change in small samples. It may therefore not be useful in detecting change in patient participation level. Additionally, several questions were regarded as not applicable by a high number of patients. Janglands' Swedish study of the Tell-us Card did find significant results on this scale and reported lower values of 'not applicable'.[17] This might be due to cultural differences between the two countries. Although the results on the ICS were also positively skewed, in line with the Finnish validation study (25), a significant change was detected regardless of the small sample. The ICS therefore seems appropriate for measuring patient participation in nursing care in the Dutch hospital setting.

## Strength and limitations

A strength of this study is the cluster randomized controlled design, enabling the researchers to assess effectiveness in a complex environment and test the adequacy of the measurement instruments. Also, the developmental process preceding this pilot provided a solid base. Nevertheless, some limitations need to be mentioned. A first limitation that needs to discussed is the fact that patients of the surgical intervention ward included at the T1 assessment did not receive a Tell-us Card. As the Tell-us Card was handed out 123 times during the 3-month intervention period before T1 assessments, the intervention was expected to enhance the nurses' behavior regarding patient participation. T1 assessments on perceived patient participation at the surgical wards were therefore carried out as planned. The results showed no significant improvement on the ICS scale, as opposed to the cardiology intervention ward. This finding however might be further strengthening the indicated effect of the actual use of the Tell-us Card communication tool. A second limitation of the study lies in the fact that there might have been some selection bias due to nurses choosing patients they felt were more suitable or receptive for the use of the Tell-us Card instead of giving it to all patients. Follow-up research could benefit from assessing whether and how patient characteristics relate to a need or ability to participate in care and how nurses act upon with these differences. Third, Flottorp et al. stressed the importance of considering various influencing factors before implementation.[49] This study mainly focused on issues related to the intervention itself, as well as the individual nurse and patient factors. Future research might benefit from incorporating also other, external influences related to implementation like the capacity for organizational change, including clinical nurse leadership and management

## Conclusion

The Tell-us Card intervention was aimed at one of the most fundamental care elements in nursing; communicating effectively with patients about their individual needs and abilities. This pilot study showed a positive early effect of the Tell-us Card communication tool on patient participation, although integration in daily nursing care appeared to be complex and an optimal fit has not yet been reached. Patients were positive about the intervention and wrote meaningful issues on the Tell-us Cards. More research is needed on how to incorporate patient participation effectively in complex hospital care.

## Acknowledgements

We thank the patients, nurses and nurse managers of the participation wards for their valuable time and efforts in this study, Ir. Reinier Akkerman for his statistics guidance and Josien Caris, MSc., from the HAN University of Applied Sciences, Nijmegen, for her assistance with the development of the e-learning module.

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**Supplement 1** Mean scores per item Individual Care Scale

| | Cardiology | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Control | | | | Intervention | | | |
| | ICS A | | ICS B | | ICS A | | ICS B | |
| Mean (SD)<br>Abbreviated question | T0 | T1 | T0 | T1 | T0 | T1 | T0 | T1 |
| 1. Feelings about illness/health condition | 4.41 (1.14) | 4.22 (1.25) | 4.19 (1.00) | 4.08 (1.18) | 4.09 (1.12) | 4.30 (1.02) | 4.03 (1.16) | 4.26 (0.97) |
| 2. Needs that require care and attention | 4.49 (0.99) | 4.41 (1.09) | 4.51 (0.65) | 4.25 (0.88) | 4.32 (0.95) | 4.43 (0.97) | 3.88 (1.25) | 4.35 (0.84) |
| 3. Chance to take responsibility as far as possible | 4.62 (0.86) | 4.58 (0.94) | 4.50 (0.61) | 4.56 (0.70) | 4.53 (0.86) | 4.40 (1.00) | 4.38 (1.01) | 4.47 (0.73) |
| 4. Identify changes in how they have felt | 4.30 (0.85) | 4.14 (1.07) | 4.14 (0.95) | 3.86 (1.22) | 4.30 (0.85) | 4.28 (1.03) | 4.03 (1.21) | 4.55 (0.69) |
| 5. Talk with patients about fears and anxieties | 4.11 (1.27) | 3.89 (1.37) | 4.22 (0.94) | 3.94 (1.09) | 3.67 (1.36) | 3.69 (1.23) | 3.91 (1.28) | 3.97 (1.20) |
| 6. Find out how their health conditions affect them | 4.00 (1.13) | 3.56 (1.34) | 4.19 (0.94) | 3.75 (1.18) | 3.50 (1.31) | 3.87 (0.97) | 3.85 (1.15) | 3.97 (1.07) |
| 7. What the illness/health condition means to them | 3.89 (1.24) | 3.69 (1.39) | 4.28 (1.09) | 3.83 (1.30) | 3.82 (1.33) | 3.97 (1.00) | 3.79 (1.29) | 4.30 (0.95) |
| 8. What kinds of things they do in their everyday life | 3.76 (1.36) | 3.58 (1.61) | 3.84 (1.09) | 3.30 (1.19) | 3.45 (1.58) | 3.77 (1.15) | 3.09 (1.40) | 3.77 (1.15) |
| 9. Previous experiences of hospitalization | 3.16 (1.54) | 2.59 (1.50) | 3.50 (1.32) | 3.21 (1.43) | 2.88 (1.36) | 3.48 (1.26) | 2.85 (1.33) | 3.80 (1.10) |
| 10. Everyday habits | 3.70 (1.47) | 3.09 (1.58) | 4.05 (1.15) | 3.42 (1.48) | 3.00 (1.30) | 3.74 (1.13) | 3.44 (1.40) | 4.13 (1.01) |
| 11. Family to take part in their care | 3.32 (1.36) | 3.29 (1.66) | 4.32 (1.11) | 4.21 (1.18) | 3.25 (1.50) | 4.03 (1.10) | 3.84 (1.32) | 4.58 (0.77) |
| 12. Instructions to patients | 4.69 (0.58) | 4.51 (0.99) | 4.97 (0.16) | 4.66 (0.80) | 4.23 (0.98) | 4.55 (0.77) | 4.91 (0.39) | 4.90 (0.31) |
| 13. What they want to know about illness/health condition | 4.00 (1.11) | 3.86 (1.14) | 4.56 (1.00) | 4.42 (1.11) | 4.06 (1.14) | 4.16 (1.00) | 4.52 (0.83) | 4.71 (0.53) |
| 14. Patients' personal wishes with regard to their care | 4.59 (0.60) | 4.14 (1.31) | 4.54 (0.65) | 4.31 (0.96) | 4.27 (0.98) | 4.42 (0.81) | 4.03 (1.09) | 4.60 (0.72) |
| 15. Help patients take part in decisions | 4.17 (0.97) | 3.97 (1.40) | 4.27 (0.93) | 4.11 (1.11) | 4.00 (1.03) | 4.37 (0.72) | 3.87 (1.07) | 4.35 (0.84) |
| 16. Encourage patients to express their opinions | 4.03 (1.13) | 3.60 (1.38) | 4.51 (0.65) | 4.26 (0.99) | 4.12 (1.14) | 4.45 (0.78) | 4.06 (1.00) | 4.59 (0.63) |
| 17. Ask patients at what time they would prefer to wash | 3.66 (1.26) | 2.97 (1.65) | 4.78 (0.42) | 4.42 (1.20) | 2.79 (1.43) | 3.21 (1.60) | 4.52 (1.06) | 4.87 (0.43) |

| Surgical | | | | | | | |
|---|---|---|---|---|---|---|---|
| Control | | | | Intervention | | | |
| ICS A | | ICS B | | ICS A | | ICS B | |
| T0 | T1 | T0 | T1 | T0 | T1 | T0 | T1 |
| 4.24 (1.08) | 3.64 (1.38) | 4.11 (1.13) | 3.58 (1.50) | 4.22 (1.25) | 4.08 (1.19) | 3.97 (1.36) | 4.12 (1.17) |
| 4.62 (0.70) | 4.44 (0.87) | 4.60 (0.74) | 4.23 (1.11) | 4.49 (1.04) | 4.32 (1.15) | 4.25 (1.27) | 4.28 (1.10) |
| 4.76 (0.50) | 4.31 (1.23) | 4.66 (0.68) | 4.42 (1.07) | 4.46 (1.09) | 4.44 (0.96) | 4.39 (0.96) | 4.32 (0.95) |
| 4.47 (0.79) | 4.00 (1.02) | 4.54 (0.70) | 3.88 (1.18) | 4.08 (1.20) | 3.88 (1.13) | 4.31 (1.18) | 4.04 (1.17) |
| 4.09 (0.93) | 3.69 (1.19) | 4.36 (0.78) | 4.00 (1.20) | 4.05 (1.10) | 4.04 (1.17) | 4.14 (1.19) | 3.88 (1.36) |
| 3.82 (1.06) | 3.35 (1.47) | 4.27 (0.88) | 3.80 (1.32) | 3.46 (1.33) | 3.64 (1.32) | 3.76 (1.21) | 3.76 (1.30) |
| 3.85 (1.08) | 3.38 (1.44) | 3.91 (1.13) | 3.64 (1.41) | 3.54 (1.35) | 3.80 (1.25) | 3.77 (1.40) | 3.88 (1.27) |
| 3.76 (1.42) | 3.52 (1.74) | 3.53 (1.24) | 3.40 (1.50) | 3.78 (1.46) | 3.32 (1.25) | 3.21 (1..27) | 3.00 (1.29) |
| 3.58 (1.50) | 3.12 (1.56) | 3.50 (1.29) | 3.25 (1.26) | 3.53 (1.54) | 3.29 (1.27) | 3.56 (1.19) | 3.29 (1.27) |
| 3.50 (1.46) | 3.65 (1.44) | 3.94 (1.13) | 3.73 (1.40) | 3.65 (1.38) | 3.40 (1.26) | 3.85 (1.33) | 3.48 (1.23) |
| 3.45 (1.39) | 3.12 (1.66) | 4.41 (0.82) | 4.16 (1.07) | 3.60 (1.50) | 3.64 (1.47) | 4.11 (1.24) | 4.40 (0.91) |
| 4.57 (0.82) | 4.23 (1.39) | 4.74 (0.78) | 4.85 (0.37) | 4.44 (1.08) | 4.20 (1.26) | 4.69 (0.89) | 4.92 (0.28) |
| 3.77 (1.06) | 3.56 (1.45) | 4.34 (1.19) | 4.46 (0.86) | 3.83 (1.36) | 3.32 (1.57) | 4.19 (1.28) | 4.36 (1.22) |
| 4.60 (0.74) | 4.35 (1.16) | 4.40 (0.95) | 4.35 (0.98) | 4.37 (1.09) | 4.29 (1.12) | 4.20 (1.28) | 4.20 (1.23) |
| 4.49 (0.78) | 4.27 (1.19) | 4.43 (0.74) | 4.27 (0.96) | 4.00 (1.31) | 4.20 (1.08) | 4.11 (1.26) | 4.12 (1.30) |
| 4.37 (0.77) | 4.00 (1.23) | 4.38 (0.99) | 4.28 (1.17) | 3.89 (1.33) | 4.12 (1.05) | 4.20 (1.13) | 4.44 (0.82) |
| 3.71 (1.36) | 3.15 (1.54) | 4.34 (0.73) | 4.48 (0.82) | 3.31 (1.35) | 2.76 (1.33) | 4.46 (0.92) | 4.42 (1.06) |

**Supplement 2** Mean scores per item Quality from the Patients Perspective questionnaire

| | Cardiology | | | |
|---|---|---|---|---|
| | Control | | Intervention | |
| Mean (SD)<br>Abbreviated question | T0 | T1 | T0 | T1 |
| 1. Physical caring | 3.86 (0.44) | 3.69 (0.69) | 3.46 (0.88) | 3.77 (0.65) |
| 2. Medical care | 3.97 (0.18) | 3.83 (0.56) | 3.83 (0.46) | 3.80 (0.61) |
| 3. Pain relief | 3.88 (0.33) | 3.78 (0.51) | 3.78 (0.42) | 3.60 (0.94) |
| 4. Treatment waiting time | 3.61 (0.79) | 3.82 (0.46) | 3.81 (0.48) | 3.36 (0.95) |
| 5a. Information before procedures | 3.74 (0.51) | 3.75 (0.55) | 3.74 (0.51) | 3.68 (0.77) |
| 5b. Information after procedures | 3.76 (0.44) | 3.75 (0.50) | 3.73 (0.58) | 3.64 (0.78) |
| 5c. Information after procedures | 3.72 (0.65) | 3.35 (0.84) | 3.43 (0.77) | 3.64 (0.76) |
| 5d. Responsible persons | 3.76 (0.65) | 3.67 (0.53) | 3.39 (0.83) | 3.36 (1.08) |
| 5e. Responsible persons | 3.94 (0.25) | 3.75 (0.65) | 3.50 (0.84) | 3.69 (0.74) |
| 6. Participation | 3.66 (0.70) | 3.45 (0.77) | 3.52 (0.71) | 3.64 (0.76) |
| 7. Commitment (doctors) | 3.85 (0.57) | 3.81 (0.62) | 3.58 (0.75) | 3.50 (0.79) |
| 8. Commitment (nurses) | 3.75 (0.44) | 3.73 (0.61) | 3.70 (0.68) | 3.73 (0.64) |
| 9. Empathic and personal (nurses) | 3.69 (0.67) | 3.59 (0.76) | 3.59 (0.78) | 3.60 (0.77) |
| 10. Respect (doctors) | 3.91 (0.38) | 3.87 (0.53) | 3.73 (0.76) | 3.73 (0.64) |
| 11. Nutrition | 3.76 (0.50) | 3.59 (0.69) | 3.61 (0.75) | 3.61 (0.69) |
| 12. Care equipment | 3.55 (0.69) | 3.86 (0.35) | 3.75 (0.55) | 3.69 (0.48) |
| 13. Care room characteristics | 3.67 (0.65) | 3.58 (0.72) | 3.45 (0.71) | 3.70 (0.70) |
| 14. Secluded environment | 3.43 (0.98) | 3.13 (1.10) | 2.71 (1.10) | 3.06 (0.94) |
| 15. Secluded environment | 3.78 (0.42) | 3.46 (0.90) | 3.43 (0.87) | 3.43 (0.84) |
| 16. General atmosphere | 3.76 (0.55) | 3.79 (0.58) | 3.85 (0.44) | 3.76 (0.69) |
| 17. Family and friends | 3.94 (0.24) | 3.92 (0.49) | 3.91 (0.29) | 3.80 (0.61) |
| 18. Routines | 3.57 (0.77) | 3.41 (0.76) | 3.13 (0.94) | 3.63 ( 0.74) |

| Surgical | | | |
|---|---|---|---|
| Control | | Intervention | |
| T0 | T1 | T0 | T1 |
| 3.88 (0.33) | 3.76 (0.44) | 3.65 (0.80) | 3.95 (0.21) |
| 3.77 (0.65) | 3.84 (0.37) | 3.76 (0.68) | 3.92 (0.28) |
| 3.88 (0.41) | 3.91 (0.29) | 3.62 (0.99) | 3.96 (0.21) |
| 3.82 (0.39) | 3.77 (0.43) | 3.76 (0.68) | 3.76 (0.54) |
| 3.88 (0.41) | 3.65 (0.69) | 3.75 (0.65) | 3.96 (0.20) |
| 3.85 (0.44) | 3.79 (0.41) | 3.59 (0.76) | 3.84 (0.37) |
| 3.81 (0.54) | 3.48 (0.67) | 3.55 (0.83) | 3.74 (0.62) |
| 3.69 (0.63) | 3.58 (0.81) | 3.58 (0.84) | 3.80 (0.65) |
| 3.86 (0.43) | 3.81 (0.40) | 3.76 (0.55) | 3.68 (0.56) |
| 3.78 (0.49) | 3.71 (0.55) | 3.43 (0.92) | 3.56 (0.58) |
| 3.79 (0.48) | 3.65 (0.49) | 3.69 (0.80) | 3.80 (0.65) |
| 3.94 (0.24) | 3.88 (0.33) | 3.75 (0.77) | 3.80 (0.50) |
| 3.85 (0.36) | 3.63 (0.71) | 3.69 (0.79) | 3.72 (0.54) |
| 3.91 (0.28) | 3.88 (0.33) | 3.83 (0.56) | 3.80 (0.71) |
| 3.68 (0.73) | 3.88 (0.33) | 3.71 (0.64) | 3.67 (0.58) |
| 3.92 (0.28) | 3.94 (0.25) | 3.73 (0.67) | 4.00 (0.00) |
| 3.89 (0.40) | 3.62 (0.70) | 3.61 (0.69) | 3.64 (0.70) |
| 3.45 (0.83) | 3.33 (0.98) | 3.35 (0.93) | 3.53 (0.92) |
| 3.73 (0.55) | 3.64 (0.63) | 3.80 (0.41) | 3.33 (1.11) |
| 3.74 (0.51) | 3.81 (0.49) | 3.72 (0.61) | 3.75 (0.53) |
| 3.97 (0.18) | 4.00 (0.00) | 3.94 (0.34) | 3.92 (0.41) |
| 3.57 (0.63) | 3.28 (0.89) | 3.52 (0.80) | 3.46 (0.72) |

### 4

# Individualized care in Flemish and Dutch hospitals: comparing patients' and nurses' perceptions

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Scandinavian Journal of Caring Sciences, 2021

## Abstract

**Background:** Providing patient-centred care has been recognised as vital for today's healthcare quality. This type of care puts patients at the centre contributing to positive patient outcomes, such as self-management and patient autonomy. Empirical research comparing nurses' and patients' perceptions of the support and provision of patient-centred care is limited and focuses solely on nurses and patients working and staying on surgical wards. Aims and objectives: Comparing patients' and nurses' perceptions of patient-centred care, taking into account the perceptions of nurses and patients on different types of hospital wards, and exploring if patient empowerment, health literacy, and certain socio-demographic and context-related variables are associated with these perceptions.

**Methods:** Cross-sectional design. Data were collected in ten Flemish (February - June 2016), and in two Dutch (December 2014 - May 2015) hospitals using the Individualised Care Scale (ICS). A linear mixed model was fitted. Data from 845 patients and 569 nurses were analyzed. As the ICS was used to measure the concept of patient-centred care, it is described using the term 'individualised care'.

**Results:** Nurses perceived that they supported and provided individualised care more compared to patients as they scored significantly higher on the ICS compared to patients. Patients with higher empowerment scores, higher health literacy, a degree lower than bachelor, a longer hospital stay, and patients who were employed and who were admitted to Dutch hospitals, scored significantly higher on some of the ICS subscales/subsections. Nurses who were older and more experienced and those working in Dutch hospitals, regional hospitals, and maternity wards, scored significantly higher on some of the ICS subscales/subsections.

**Conclusion:** Nurses perceived that they supported and provided individualised care more compared to patients. Relevance to clinical practice: Creating a shared understanding towards the support and provision of individualised care should be a priority as this could generate more effective nursing care that takes into account the individuality of the patient

## Introduction

During the last decade, patient-centred care became a key attribute in healthcare services as it has been recognised as essential for today's healthcare quality (WHO, 2015). Patient-centred care puts patients at the centre and is characterized by inclusivity and equity in the professional–patient relationship.[1] Nevertheless, even though patient-centred care is a core component of health care[2] challenges arise in daily practice. Literature seems to indicate that nurses and patients have different perceptions of patient-centred care and of the level at which it is delivered.[3,4] However, empirical research that compares nurses' and patients' perceptions of the support and provision of patient-centred care is limited and focuses solely on nurses and patients working and staying on surgical wards. As the Individualised Care Scale (ICS) developed by Suhonen, Leino-Kilpi, and Välimäki (2005) will be used to measure the concept of patient-centred care, we will refer to the concept of patient-centred care using the term 'individualised care'.[5]

## Background

In 2001, the Institute of Medicine (IOM) described patient-centred care as care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.[6] Over the years, patient-centred care has been conceptualized differently but there is still not one clear definition of the concept and variation in terminology exists.[2,7] In the concept analysis of Castro, Van Regenmortel, Vanhaecht, Sermeus, and Van Hecke (2016) it is described that patient-centred requires individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy, and shared knowledge.[7] In this study, we focused on the concept of patient-centred care, measured by the ICS. The ICS is one of the most commonly used scales that measures the broad holistic concept of patient-centred care.[7] Both the concepts of individualised care and patient-centred care share the same theoretical basis, which rests on the principles of holism.[8] Individualised nursing care is defined by Suhonen, Välimäki, and Katajisto (2000) as care that takes into account personal characteristics of the patient in the clinical situation (the condition of the patient), the personal life situation and promoting patient participation and decision-making in the patient's care.[9] Nurses have a key role in the provision of individualised care. By taking into account the patient's health problem, the reactions induced by hospital admission, and the situation in which patients have been admitted to the hospital, individualised care in hospitals is accomplished.[9]

Studies have shown that providing individualised care can contribute to positive patient outcomes such as self-management, patient satisfaction, patient autonomy, perceived quality of care, and health-related quality of life, [10-13] and reduces depression symptom levels. [14] Individualised care can also contribute to general job satisfaction and personal accomplishment among healthcare professionals. [15] Despite the physical and emotional benefits of individualised care for patients and nurses, literature indicates that inconsistencies between nurses' and patients' perceptions of individualised care exist. In the study of Suhonen et al. (2012), analyzing both patients' and nurses' perceptions of individualised care in five European countries, it was found that nurses assessed that they supported patient individuality more compared to patients. [4] Another more recent study by Papastavrou et al. (2016) on decisional control over care, found that nurses rated their abilities in helping patients to decide how to be involved in healthcare decisions higher than their patients did. [3] Studies within other fields of nursing practice also found that nurses are not always aware of the patients' perspective and tend to have different views of the care provided. For example, the results in the study of Zhao, Akkadechanunt, and Xue (2009) confirmed that nurses had higher perceptions of the quality of nursing care than patients. [16] Notwithstanding the studies of Papastavrou et al. (2016) and Suhonen et al. (2012) have contributed to the development of individualised care in clinical practice, these studies focus solely on the assessment of individualised care in surgical wards.

There is a need to further explore how patients and nurses differ in their perceptions of individualised care, taking into account the perceptions of nurses and patients working and staying on different types of hospital wards. This will help to identify discrepancies in nurses' and patients' perceptions of individualised care and related factors, which can be used to improve individualised care.

## Methods

### Aims

The aim of this study was two-folded: (1) to compare Dutch-speaking patients' and nurses' perceptions of individualised care, taking into account the perceptions of nurses and patients of different types of hospital wards and (2) exploring if patient empowerment, health literacy, and certain sociodemographic and context-related variables are associated with these perceptions

## Design and participants

A secondary analysis of a cross-sectional study in which data were collected on wards participating in two studies focusing on improvement projects to enhance patient participation in hospitals (i.e. a study on the implementation of Bedside shift reporting and a study on the implementation of the Tell-us card; a communication tool that patients can use to report what is important for them during their hospital admission and before discharge. [17-20] Nurses who worked on the participating wards were invited to participate if they had direct patient contact and work experience of at least six months on the ward. [19] Criteria for selecting the patients were: being aged 18 years or over, able to speak and read Dutch, having an expected hospital stay of minimum one day, and being mentally competent as assessed by the assigned nurse. [19] In total, 845 patients on 34 wards and 569 nurses on 29 wards were included in the analysis. [19]

## Data collection

The data were collected in Flanders (ten hospitals), the Dutch-speaking part of Belgium, and the Netherlands (two hospitals). [19] In both Dutch-speaking countries, data were collected as baseline measurement on wards that participated in the two aforementioned improvement projects to enhance a patient-centred approach in hospitals. [19] In Flanders, data were collected between February and June 2016, and in the Netherlands between December 2014 and May 2015. [19]

## Flanders

Quality coordinators, chief nursing officers and chief medical officers from all Flemish regional hospitals (n = 68) and university hospitals (n = 3) received an invitation from the Federal Public Service for Health for participation in the two aforementioned improvement projects. [19] Information sessions on the implementation projects were organized. [19] Wards for surgery, geriatric care, internal medicine, medical rehabilitation, and maternal care were included (Theys et al., 2021). [19] Psychiatric wards, paediatric wards, psychogeriatric ward, palliative wards, emergency or intensive care wards, day hospitals, burns units, and outpatient clinics were excluded. [19]

The researchers received a list (from the head nurses) indicating which hospitalized patients on the included wards met the inclusion criteria. The ICS for patients was distributed on the included wards in the hospital by a member of the research team and recollected after two hours. [19] If patients did not have the possibility to complete the questionnaire in time, a collection box was available on the ward. [19] If patients were not able to fill in the questionnaire due to motoric difficulties, a member of the research team (Tell-us card project) or a study nurse with no affiliation to the research team (Bedside shift reporting project) assisted the patients. [19] The ICS for the nurses was disseminated in a sealed envelope. Researchers visited the wards weekly to remind the nurses of completing the questionnaire.

### The Netherlands

Two surgical wards and one cardiology ward of the same university hospital and one cardiology ward of a regional hospital were invited to participate in the study on the implementation of the Tell-us card. [19] Preliminary meetings took place with ward managers to discuss eligibility for the study. Patients received a questionnaire with a prepaid return envelope to be filled in at home after discharge. The questionnaire for the nurses was distributed in a sealed envelope. [19] Nurses received two reminders by email to complete the questionnaire.

### Measurement

The ICS was used to assess patients' and nurses' perceptions of individualised care. The ICS, originally developed in Finland, is a bi-partite scale that contains 34 items. The scale allows to measure both nurses' and patients' perceptions of individualised nursing care by means of two separate ICS-subsections: the ICS-Patient[5] and the ICS-Nurse. [21] Both subsections contain 17 items and have the same two-part (ICSA and ICSB) structure. ICSA measures patients' and nurses' views of how individuality was supported through nursing activities. [22] ICSB measures how patients perceive their care as individual to them and how nurses perceive the maintenance of individuality in care provision. [22] Three subscales are involved in both subsections: (1) the clinical situation of the patient (ClinA and B, seven items), (2) the personal life situation of the patient (PersA and B, four items), and (3) decisional control over care of the patient (DecA and B, six items). [5, 21] The first subscale examines how nursing interventions have supported individuality in the clinical situation and how nurses and patients perceive individuality in the clinical situation (items relating to the patients their feelings, needs, abilities, health condition, meaning of illness). [23] The second subscale examines how nursing interventions have supported the personal life situation of the patient and how nurses and patients perceive individuality in the personal life situation of the patient (items relating to previous experiences of hospitalization, habits, family). [23] The third subscale examines how nursing interventions have supported decisional control over care and how nurses and patients perceive individuality in decisional control over care (items relating to the power of patients to participate in their care; knowledge preferences, patients' wishes, and opportunities for decision-making and expressing opinions). [23] The answering categories per item are 5-point Likert scales ranging from fully disagree to fully agree. Both subsections have a separate total score. The higher the ICSA subsection scores, the better the patient individuality is supported through nursing activities. [4] A high score on the ICSB subsection indicates a higher perception of individuality in patients' care. [4] The ICS was previously psychometrically validated for the Dutch healthcare context. [19] The Dutch version of the ICS showed acceptable psychometric performance, supporting its use for the Dutch and Flemish healthcare context. [19] Internal consistency using Omega ranged from 0.83 to 0.96 for the ICS-Nurse and from 0.88-0.96 for the ICS-Patient. [19] The model fit suggested sufficient evidence to sustain the construct validity of the Dutch ICS. [19] For patients, the following socio-demographic and context-related variables were included: age, gender, level of education, living situation, employment status, days of admission, wards categorized in accordance to their specialty (surgery, internal medicine, medical rehabilitation, or maternity), region/region (Flanders or the Netherlands), and type of hospital (regional or university).

Patients' health literacy was measured using three questions developed by Chew, Bradley, and Boyko (2004): (1) 'How confident are you filling out medical forms by yourself?', (2) 'How often do you have problems learning about your medical condition because of difficulty understanding written information?', and (3) 'How often do you have someone help you when you read hospital materials?'. [18, 24] The answering categories per question are 5-point Likert scales ranging from never to always. Higher scores (range: 0–15) reflect greater problems with reading and understanding information.

Patient empowerment was measured by the Short form of the Patient Activation Measure (PAM-13). [18, 25] The answering categories per item are four-point Likert scales from 1 (totally disagree) to 4 (totally agree) and non-applicable. Higher total PAM-13 scores (range 0-100) reflect higher levels of patient activation. [18, 26]

The following socio-demographic and context-related variables for nurses were included: gender, age, years of work experience in nursing, work percentage, level of education, type of hospital (regional or university), wards categorized in accordance to their specialty (surgery, internal medicine, maternity, medical rehabilitation, or geriatric), and region/region (Flanders or the Netherlands).

## Ethical considerations

This study was approved by the Ethical Committee of Ghent University (B670201526903) and Radboud University (2014-1350), and the ethic committees of the participating hospitals in Flanders and the Netherlands. All nurses and patients participating in this study gave a written informed consent.

## Data analysis

All analyses were conducted using SPSS 25.0. [27] The categorical variables were described using frequencies (percentages) and the continuous variables were described using means, medians, and SDs. To analyze the differences between nurses' and patients' perceptions of individualised care, a linear mixed model was used. A random intercept for the patients nested within wards was specified to take into account the multilevel structure of the data. [28] To explore possible variables associated with nurses' and patients' perceptions of individualised care, all variables with $p < 0.010$ were included in a multilevel, multivariable model. Backward selection ($p < 0.05$) was used to determine which variables best explain the data. For the variables employment status, empowerment, and health literacy only data for the Flemish patients were available. Therefore, additional analyses were conducted for the Flemish patients including the aforementioned variables. To identify multicollinearity between the variables in the model, the tolerance and variance inflation were calculated. The tolerance value needs to be above 0.4 and the variance inflation factor (VIF) needs to be below 4. [29]

## Results

### Characteristics of the participants

Part of the data were previously published in the psychometric validation study of the Dutch ICS by Theys et al. (2021). [30] Patients were on average 57 (SD = 19.3) years old and 57% of the patients were female. [30] Most patients (71.1%) lived together with a partner, friend or family, had an education lower than bachelor's degree (66%), and were retired (46%). [30] The median hospital admission was 5 days. An overview of all patients' and nurses' characteristics can be found in Table 1.

The mean age of nurses was 40 years (SD = 12.5). Most nurses (90%) were female. [30] Fifty-one percent of the nurses had a bachelor degree, 42% a vocational degree, and almost 3% had a university degree. [30] Around 4% of the participants were nursing assistants. [30] Most nurses had one to five years of work experience (24%) or 20 or more years of work experience (31%) and were fully employed (43%).[30]

### Comparison between nurses' and patients' perceptions of individualised care

Statistical results showed significant differences between nurses' and patients' perceptions on all subsections and subscales of the ICS, except for the DecB subscale. Table 2 provides an overview of the multilevel analyses concerning the differences in perceptions on the ICS.

Nurses (mean 4.24) scored significantly higher ($p < 0.001$) than patients (mean 3.66) on how individuality is supported through nursing activities (ICSB). Concerning the perceptions of individuality in the care received and provided (ICSA), nurses

**Table 1** Demographic characteristics for patients and nurses

| | | Patients (n = 845) [a] | Nurses (n = 569) [a] |
|---|---|---|---|
| Age mean (SD) | | 56.5 (19.3) | 39.7 (12.5) |
| Gender n (%) | Male | 363 (43.1) | 58 (10.2) |
| | Female | 479 (56.9) | 511 (89.8) |
| Health literacy mean (SD) | | 2.5 (0.85) | |
| Empowerment mean (SD) | | 57.72 (12.7) | |
| Days of hospital admission median | | 5 | |
| Level of education patients n (%) | | | |
| | <Bachelor | 551 (65.8) | |
| | Bachelor | 203 (24.3) | |
| | Master | 83 (9.9) | |
| Living condition n (%) | | | |
| | Alone | 185 (26.0) | |
| | With a partner, family or friend | 506 (71.1) | |
| | In a service flat, assisted living or a nursing home | 21 (2.9) | |
| Employment status | | | |
| | Employed | 277 (39.0) | |
| | Unemployed | 24 (3.4) | |
| | Student | 16 (2.3) | |
| | Disabled | 65 (9.0) | |
| | Retirement | 329 (46.3) | |
| Level of education nurses n (%) | | | |
| | Nurse assistant[b] | | 22 (3.9) |
| | Vocational nurse[c] | | 237 (42.1) |
| | Bachelor educated[d] | | 288 (51.2) |
| | Master educated[e] | | 16 (2.8) |
| Years of nurses' working experience n (%) | | | |
| | < 1 year | | 28 (4.9) |
| | 1 to 5 years | | 139 (24.4) |
| | 6 to 10 years | | 107 (18.9) |
| | 11 to 15 years | | 71 (12.5) |
| | 16 to 20 years | | 48 (8.4) |
| | > 20 years | | 176 (30.9) |

**Table 1** Continued

| | | Patients (n = 845) [a] | Nurses (n = 569) [a] |
|---|---|---|---|
| Work percentage | | | |
| | <50% | | 87 (16.0) |
| | 50%–99% | | 222 (40.9) |
| | 100% | | 234 (43.1) |
| Type of hospital | | | |
| | University | 325 (38.5) | 186 (32.7) |
| | Regional | 520 (61.5) | 383 (67.3) |
| Type of ward | | | |
| | Internal medicine | 178 (21.1) | 125 (22.0) |
| | Maternity | 146 (17.3) | 76 (13.4) |
| | Geriatric | N/A[f] | 80 (14.0) |
| | Surgical | 300 (35.5) | 160 (28.1) |
| | Medical rehabilitation | 192 (22.7) | 103 (18.1) |
| | Mixed surgical/internal | 29 (3.4) | 25 (4.4) |

Part of the data were previously published in the psychometric validation study of the Dutch ICS by Theys et al.[19]. [a] Numbers for the demographic characteristics of participants may not total 845 or 569 due to missing data. [b] One year of education at level 3 of the European Qualifications Framework (EQF). [c] Three years of education at level 5 of the EQF to obtain a diploma in Nursing. [d] Three years of education at level 6 of the EQF to obtain the degree of Bachelor in Nursing. [e] Five years of education at level 7 of the EQF to obtain the degree of Master in Nursing.

(mean 4.16) scored also significantly higher (p<0.001) than patients (mean 3.91). When comparing both parts of the ICS, differences between patients' and nurses' scores were higher on the ICSA than on the ICSB. Concerning the subscales of the ICSA, the highest mean difference (0.743) was found on the personal situation (PersA) subscale, and the lowest mean difference (0.445) was found on the clinical situation (ClinA) subscale. Among the ICSB subscales, the highest mean difference (0.396) was found on the clinical situation (ClinB) subscale, and the lowest mean difference (0.051) was found on the decisional control over care (DecB) subscale.

In table 3, differences between nurses and patients concerning individualised care on ward level are shown. For all the different wards, nurses scored significantly higher than patients and mean differences were higher on the ICSA than on the ICSB. For the DecB subscale, no differences in scores were found, except in medical rehabilitation wards. Concerning the subscales of the ICSA, the highest mean differences were found for the maternity and internal wards on the personal

**Table 2** Differences between nurses and patients concerning individualised care

| | | Mean[f] | MD[g] | P | 95% CI[h] | |
|---|---|---|---|---|---|---|
| | | | | | Lower bound | Upper bound |
| ICSA[a] | Nurse | 4.238 | 0.581 | <0.001* | 4.140 | 4.336 |
| | Patient | 3.658 | | | 3.563 | 3.752 |
| ClinA[c] | Nurse | 4.349 | 0.445 | <0.001* | 4.247 | 4.450 |
| | Patient | 3.904 | | | 3.807 | 4.001 |
| PersA[d] | Nurse | 3.974 | 0.743 | <0.001* | 3.873 | 4.075 |
| | Patient | 3.231 | | | 3.138 | 3.324 |
| DecA[e] | Nurse | 4.283 | 0.634 | <0.001* | 4.171 | 4.395 |
| | Patient | 3.649 | | | 3.541 | 3.757 |
| ICSB[b] | Nurse | 4.158 | 0.251 | <0.001* | 4.067 | 4.249 |
| | Patient | 3.907 | | | 3.820 | 3.995 |
| ClinB[c] | Nurse | 4.361 | 0.396 | <0.001* | 4.267 | 4.455 |
| | Patient | 3.965 | | | 3.875 | 4.055 |
| PersB[d] | Nurse | 3.921 | 0.303 | <0.001* | 3.837 | 4.004 |
| | Patient | 3.617 | | | 3.539 | 3.695 |
| DecB[e] | Nurse | 4.078 | 0.051 | 0.205 | 3.968 | 4.187 |
| | Patient | 4.027 | | | 3.920 | 4.134 |

[a]ICSA= Individualised Care Scale – Scale A; [b]ICSB= Individualised Care Scale – Scale B; [c]Clin= clinical situation; [d]Pers= personal life situation; [e]Dec= decisional control over care; [f]Range: 1-5; [g]MD= Mean difference; [h]CI= confidence interval; *p-value < 0.05

situation (PersA) subscale and for the medical rehabilitation and mixed surgical/ internals wards on all subscales. When looking at the subscales of the ICSB, the highest mean differences were found for the medical rehabilitation and mixed surgical/ internals wards on the clinical situation (ClinB) subscale.

## Variables associated with patients' perceptions of individualised care

### Multilevel results for the Dutch and Flemish patients

The multilevel analysis showed significant associations between patients' perceptions of individualised care and days of hospital admission (ICSA, ClinA), level of education (ICSB, PersA, PersB), and region (ICSA, DecA, DecB). Patients admitted to Dutch hospitals, patients with a degree lower than bachelor, and those with a longer hospital stay scored significantly higher on some of the ICS subscales/ subsections. In Table 4, an overview of the results is provided.

**Table 3** Differences between nurses and patients concerning individualised care on ward level

| | | Maternity | | | Internal medicine | | |
|---|---|---|---|---|---|---|---|
| | | Mean[f] | MD[g] | p | Mean | MD | p |
| ICSA[a][*] | Nurse | 4.429 | 0.492 | <0.001* | 4.194 | 0.604 | <0.001* |
| | Patient | 3.936 | | | 3.590 | | |
| ClinA[c] | Nurse | 4.562 | 0.251 | <0.001* | 4.290 | 0.460 | <0.001* |
| | Patient | 4.311 | | | 3.829 | | |
| PersA[d] | Nurse | 3.938 | 0.741 | <0.001* | 3.989 | 0.859 | <0.001* |
| | Patient | 3.197 | | | 3.130 | | |
| DecA[e] | Nurse | 4.601 | 0.609 | <0.001* | 4.227 | 0.610 | <0.001* |
| | Patient | 3.992 | | | 3.617 | | |
| ICSB[b] | Nurse | 4.477 | 0.271 | <0.001* | 4.110 | 0.246 | 0.005* |
| | Patient | 4.206 | | | 3.864 | | |
| ClinB[c] | Nurse | 4.648 | 0.339 | <0.001* | 4.305 | 0.410 | <0.001* |
| | Patient | 4.309 | | | 3.895 | | |
| PersB[d] | Nurse | 4.072 | 0.410 | <0.001* | 3.867 | 0.342 | <0.001* |
| | Patient | 3.662 | | | 3.526 | | |
| DecB[e] | Nurse | 4.546 | 0.099 | 0.187 | 4.048 | 0.006 | 0.945 |
| | Patient | 4.447 | | | 4.054 | | |

Note: No data for geriatric patients available
[a]ICSA= Individualised Care Scale – Scale A; [b]ICSB= Individualised Care Scale – Scale B;
[c]Clin= clinical situation; [d]Pers= personal life situation; [e]Dec= decisional control over care;
[f]Range: 1-5; [g]MD= Mean difference; [*]p-value < 0.05

### Multilevel results for the Flemish patients

The multilevel analysis showed that a higher empowerment score and higher health literacy were significantly associated with higher scores on the ICS subscales/subsections (except for health literacy on ClinA). Patients who were employed and had a longer hospital stay scored significantly higher on ClinA. Patients with a degree lower than bachelor scored significantly higher on ICSB and PersB. In Table 5, an overview of the results is provided.

| Surgery | | | Medical rehabilitation | | | Mixed surgery/internal medicine | | |
|---|---|---|---|---|---|---|---|---|
| Mean | MD | p | Mean | MD | p | Mean | MD | p |
| 4.215 | 0.471 | <0.001* | 4.278 | 0.771 | <0.001* | 4.202 | 0.862 | <0.001* |
| 3.744 | | | 3.507 | | | 3.341 | | |
| 4.350 | 0.340 | <0.001* | 4.386 | 0.704 | <0.001* | 4.366 | 0.839 | 0.001* |
| 4.011 | | | 3.681 | | | 3.527 | | |
| 3.932 | 0.663 | <0.001* | 3.993 | 0.726 | <0.001* | 3.930 | 0.844 | 0.003* |
| 3.269 | | | 3.267 | | | 3.086 | | |
| 4.246 | 0.495 | <0.001* | 4.337 | 0.855 | <0.001* | 4.193 | 0.900 | <0.001* |
| 3.751 | | | 3.452 | | | 3.293 | | |
| 4.142 | 0.154 | 0.018* | 4.171 | 0.398 | <0.001* | 4.193 | 0.407 | 0.042* |
| 3.988 | | | 3.773 | | | 3.732 | | |
| 4.311 | 0.280 | <0.001* | 4.427 | 0.599 | <0.001* | 4.406 | 0.573 | 0.009* |
| 4.032 | | | 3.828 | | | 3.833 | | |
| 3.910 | 0.238 | 0.001* | 3.915 | 0.271 | 0.014* | 3.790 | 0.419 | 0.082 |
| 3.672 | | | 3.644 | | | 3.371 | | |
| 4.097 | 0.048 | 0.483 | 4.040 | 0.253 | 0.018* | 4.060 | 0.204 | 0.313 |
| 4.144 | | | 3.787 | | | 3.856 | | |

## Variables associated with nurses' perceptions of individualised care

The multilevel analysis showed significant associations between nurses' perceptions of individualised care and age (PersA), years of work experience (DecB), type of ward (ICSB, DecA, DecB), type of hospital (PersA), and region (ICSB, PersA, DecA, DecB). More experienced and older nurses and nurses working in Dutch hospitals, regional hospitals, and maternity wards scored significantly higher on some of the ICS subscales/subsections. In Table 6, an overview of the results is provided.

**Table 4** Multilevel results for the Dutch and Flemish patients

| | Estimate | Mean[f] | P* | 95% CI[g] | |
|---|---|---|---|---|---|
| | | | | Lower bound | Upper Bound |
| ICSA[a] | | | | | |
| Days of hospital admission | 0.004 | | 0.032 | 0.0004 | 0.008 |
| Region | | | 0.039 | | |
| The Netherlands | | 3.968 | | 3.626 | 4.310 |
| Flanders | | 3.569 | | 3.410 | 3.728 |
| ICSB[b] | | | | | |
| Level of education | | | 0.029 | | |
| <Bachelor | | 3.945 | | 3.813 | 4.077 |
| Bachelor | | 3.798 | | 3.636 | 3.959 |
| ClinA[c] | | | | | |
| Days of hospital admission | 0.028 | | 0.046 | 0.0004 | 0.055 |
| PersA[d] | | | | | |
| Level of education | | | 0.014 | | |
| <Bachelor | | 3.299 | | 3.166 | 3.431 |
| Bachelor | | 3.063 | | 2.875 | 3.251 |
| DecA[e] | | | | | |
| Region | | | 0.009 | | |
| The Netherlands | | 4.083 | | 3.730 | 4.437 |
| Flanders | | 3.548 | | 3.384 | 3.711 |
| PersB[d] | | | | | |
| Level of education | | | <0.001 | | |
| <Bachelor⁋ | | 3.723 | | 3.596 | 3.851 |
| Bachelor | | 3.381 | | 3.209 | 3.552 |
| master | | 3.301 | | 3.065 | 3.537 |
| DecB[e] | | | | | |
| Region | | | 0.019 | | |
| The Netherlands | | 4.389 | | 4.064 | 4.714 |
| Flanders | | 3.953 | | 3.802 | 4.103 |

Note: No significant associations were found for the ClinB subscale
[a]ICSA= Individualised Care Scale – Scale A; [b]ICSB= Individualised Care Scale – Scale B; [c]Clin= clinical situation; [d]Pers= personal life situation; [e]Dec= decisional control over care; [f]Range: 1-5; [g]CI= confidence interval; ⁋= reference category; *p-value <0.05

**Table 5** Multilevel results for the Flemish patients

| | Estimate | Mean[f] | P* | 95% CI[g] | |
|---|---|---|---|---|---|
| | | | | Lower bound | Upper Bound |
| | | | ICSA[a] | | |
| Empowerment | 0.015 | | <0.001 | 0.007 | 0.019 |
| Health literacy | -0.117 | | 0.007 | -0.201 | -0.032 |
| | | | ICSB[b] | | |
| Empowerment | 0.013 | | <0.001 | 0.010 | 0.020 |
| Health literacy | -0.133 | | 0.001 | -0.213 | -0.054 |
| Level of education | | | 0.017 | | |
| <Bachelor | | 3.898 | | 3.553 | 3.894 |
| Bachelor | | 3.724 | | 3.498 | 3.957 |
| | | | ClinA[c] | | |
| Empowerment | 0.017 | | <0.001 | 0.110 | 0.022 |
| Days of hospital admission | 0.005 | | 0.020 | 0.0008 | 0.009 |
| Employment status | | | 0.003 | | |
| Employed | | 3.989 | | 3.520 | 4.074 |
| Retirement | | 3.705 | | 3.521 | 3.889 |
| | | | PersA[d] | | |
| Empowerment | 0.098 | | 0.009 | 0.002 | 0.017 |
| Health literacy | -0.111 | | 0.046 | -0.220 | -0.002 |
| | | | DecA[e] | | |
| Empowerment | 0.012 | | <0.001 | 0.006 | 0.018 |
| Health literacy | -0.157 | | 0.001 | -0.251 | -0.063 |
| | | | ClinB[c] | | |
| Empowerment | 0.016 | | <0.001 | 0.010 | 0.021 |
| Health literacy | -0.111 | | 0.011 | -0.196 | -0.026 |
| | | | PersB[d] | | |
| Empowerment | 0.015 | | <0.001 | 0.008 | 0.021 |
| Health literacy | -0.129 | | 0.011 | -0.228 | -0.030 |
| Level of education | | | | 0.006 | 0.018 |
| <Bachelor⁋ | 3.684 | | | 3.534 | 3.835 |
| Bachelor | 3.305 | | <0.001 | 3.122 | 3.488 |
| master | 3.217 | | <0.001 | 2.952 | 3.482 |
| | | | DecB[e] | | |
| Empowerment | 0.015 | | <0.001 | 0.009 | 0.019 |
| Health literacy | -0.129 | | 0.001 | -0.208 | -0.050 |

[a]ICSA= Individualised Care Scale – Scale A; [b]ICSB= Individualised Care Scale – Scale B; [c]Clin= clinical situation; [d]Pers= personal life situation; [e]Dec= decisional control over care; [f]Range: 1-5; [g]CI= confidence interval; *p-value <0.05; ⁋= reference category

**Table 6** Multilevel results for nurses

| | Estimate | Mean[e] | p* | 95% CI[f] | |
|---|---|---|---|---|---|
| | | | | Lower bound | Upper Bound |
| **ICSB[a]** | | | | | |
| Region | | | | | |
| The Netherlands | | 4.414 | 0.025 | 4.212 | 4.616 |
| Flanders | | 4.168 | 0.019 | 4.073 | 4.263 |
| Type of ward | | | | | |
| Maternity[d] | | 4.600 | | 4.258 | 4.942 |
| Surgical | | 4.200 | 0.030 | 4.074 | 4.325 |
| Internal medicine | | 4.170 | | 4.020 | 4.320 |
| **PersA[b]** | | | | | |
| Age | 0.006 | | 0.011 | 0.0013 | 0.0106 |
| Region | | | 0.003 | | |
| The Netherlands | | 4.197 | | 4.031 | 4.363 |
| Flanders | | 3.864 | | 3.781 | 3.947 |
| Hospital | | | 0.003 | | |
| Regional | | 4.150 | | 4.038 | 4.262 |
| University | | 3.917 | | 3.802 | 4.032 |
| **DecA[c]** | | | | | |
| Region | | | 0.013 | | |
| The Netherlands | | 4.542 | | 4.349 | 4.735 |
| Flanders | | 4.290 | | 4.200 | 4.380 |
| Type of ward | | | | | |
| Maternity[d] | | 4.727 | | 4.390 | 5.006 |
| Surgical | | 4.299 | 0.023 | 4.178 | 4.421 |
| Internal medicine | | 4.326 | 0.031 | 4.182 | 4.470 |
| **DecB[c]** | | | | | |
| Years of working experience | | | 0.017 | | |
| >20 years | | 4.204 | | 4.074 | 4.335 |
| 1 to 5 years | | 4.369 | | 4.234 | 4.504 |
| Region | | | 0.002 | | |
| The Netherlands | | 4.390 | | 4.203 | 4.578 |
| Flanders | | 4.076 | | 3.986 | 4.166 |
| Type of ward | | | | | |
| Maternity[d] | | 4.700 | | 4.379 | 5.021 |
| Surgical | | 4.140 | 0.007 | 4.016 | 4.264 |

**Table 6** Continued

| | Estimate | Mean[e] | p* | 95% CI[f] | |
|---|---|---|---|---|---|
| | | | | Lower bound | Upper Bound |
| DecB[c] | | | | | |
| Internal medicine | | 4.118 | 0.006 | 3.977 | 4.258 |
| Geriatric | | 4.075 | 0.004 | 3.888 | 4.263 |
| Mixed surgical/internal | | 4.205 | 0.030 | 3.871 | 4.538 |
| Medical rehabilitation | | 4.161 | 0.008 | 3.996 | 4.327 |

Note: No significant associations were found for the ICSA subsection and the ClinA, ClinB and PersB subscales

[a]ICSB= Individualised Care Scale – Scale B; [b]Pers= personal life situation; [c]Dec= decisional control over care; [d]= Reference category; [e]Range: 1-5; [f]CI= confidence interval; *p-value <0.05

## Discussion

The primary aim of this study was to compare Dutch-speaking nurses’ and patients’ perceptions of individualised care, taking into account the perceptions of nurses and patients of different hospital wards. Multilevel analysis showed that nurses (mean 4.16) scored significantly higher on how individuality was supported through nursing activities (ICSA) compared to patients (mean 3.91). Nurses (mean 4.24) and patients (mean 3.66) also differed significantly on how individuality was perceived in the care provided and received (ICSB). These results were seen across all hospital wards. Patients and nurses of maternity wards gave the highest assessments on both the ICSA and ICSB. Overall, it should be noticed that patients had a relatively good perception of how individuality was supported through nursing activities (ICSA; e.g. supporting patient participation, addressing patients’ needs, and taking into account previous experiences of hospitalization through nursing activities) and perceived their care as relatively individual to them (ICSB; e.g how patients’ needs, previous hospital experiences, and knowledge preferences were taken into account in the patient care). However, according to Berg, Idvall, Katajisto, and Suhonen (2012) a high quality of individualised nursing care requires a mean score > 4.5. [31]

Our results are in line with those from the study of Suhonen et al. (2012) in which differences in assessments of individualised nursing care were found in nurses and patients of five European countries. [4] In each participating region, nurses scored significantly higher than patients. [4] In the study of Papastavrou et al. (2016), also conducted in five European countries, it was shown that there were disparities between nurses’ and patients’ perceptions of decisional control over care (DecB subscale).[3] Our study showed significant differences for patients' and nurses' views of how decisional control over care (the power of patients to participate in their care; knowledge preferences, patients' wishes, and opportunities for decision-making and expressing opinions) was supported through nursing activities (DecA subscale). This can be explained by nurses wanting to maintain control over provision of care. Previous studies have shown that nurses' controlling behaviors appeared a major hindrance for supporting patient participation,[32, 33] an essential antecedent of individualised care.[7] For example in the study of Theys et al. (2020), it was found that nurses and midwives were hesitant towards the implementation of a hospital communication tool for patient participation.[32] Tobiano, Marshall, Bucknall, and Chaboyer (2016) found that nurses controlling approach, influenced by organizational issues and pressure to complete tasks, was in conflict with an individualised approach to care.[33]

It is remarkable that there is an overall incongruence between nurses' and patients' perceptions of the support and provision of individualised care. This might indicate that there is a discrepancy between what nurses think they do and the care they actually provide and thus the care provided being less responsive to individual patient preferences and needs than nurses think.[34] Besides nurses wanting to maintain control over care, it also seems plausible that nurses find it difficult taking into consideration the patient's perspective. Qualitative research by Vandecasteele et al. (2015) focusing on transgressive behavior in care relationships found that nurses generally perceive the relationship with the patient from their own point of view, and do not necessarily insert the individual patient perspective in their interaction with patients.[35] Difficulties experienced by the nurses for incorporating an individualised approach during care were also observed in a multi-site ethnography study by van Belle et al. (2020). The study demonstrated that although some nurses achieve to do so, providing individualised care in hospitals remains difficult, as most nurses are not able to incorporate the physical, relational, and physical elements of care.[36]

The study results provide insight into the gap between nurses and patients of their perceptions of the support and provision of individualised care. The results, as shown in Figure 1, could be feed-backed towards the different wards. The information as provided in Figure 1 has the potential to stimulate awareness among nurses regarding the support and provision of individualised care.

A shared understanding towards the support and provision of individualised care and being sensitive towards the patient perspective could generate more effective nursing care that takes into account the individuality of the patient.[37, 38] If nurses

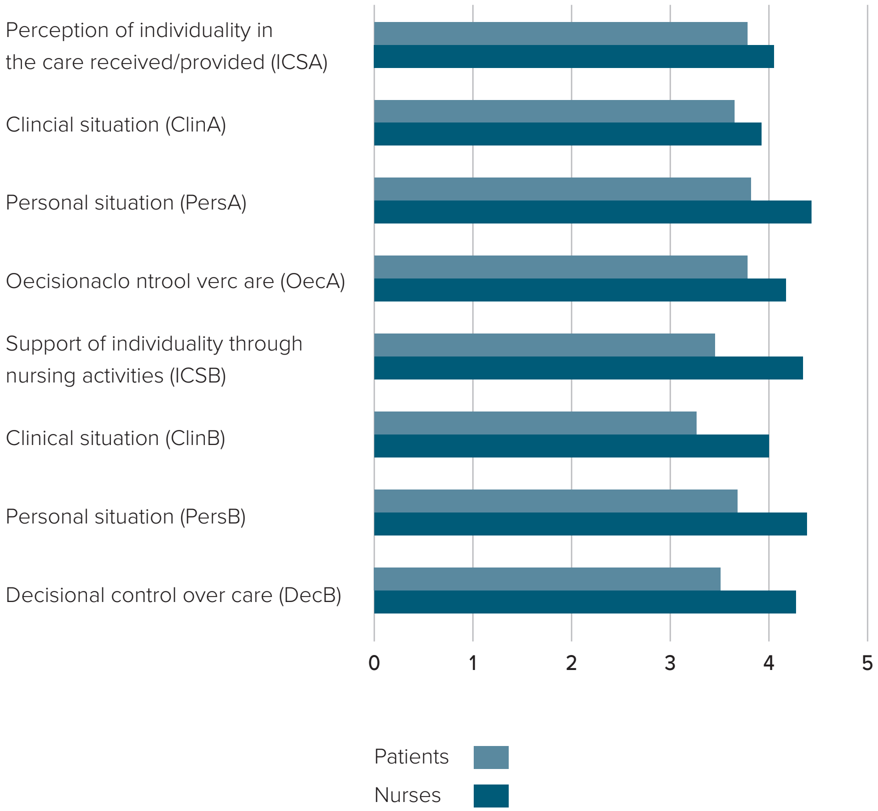

**Figure 1** Differences between patients’ and nurses perceptions of indivisualized care for rehabiliation wards

think that the care is individualised per se or if they are a priori convinced that the care they provide already incorporates individual patient preferences, needs, and values, changing existing interactions between patients and nurses will be challenging. Reflecting on one’s own perceptions of individualised care; how these perceptions emerge or where they emanate from, could be a starting point and essential in creating awareness among nurses to provide care that is more individualised and incorporates the patients’ perspective. [35, 39] Self-awareness will contribute to professional growth of nurses and will aid in becoming more understanding towards patients, establishing an effective nurse-patient relationship, and taking a more critical stance towards the care provided. [39-41]

The secondary aim of this study was to explore if patient empowerment, health literacy, and certain socio-demographic and context-related variables are associated with nurses' and patients' perceptions of individualised care. Compared to patients and nurses in Flanders, those of the Netherlands scored significantly higher on how individuality was supported through nursing activities (ICSA), on the maintenance of individuality in care provision (ICSB), on how nursing interventions have supported decisional control over care (DecA), on individuality in decisional control over care (DecB), and on how nursing interventions have supported the personal life situation of the patient (PersA). Between-country differences were previously found in the studies of Idvall et al. (2012), [42] Papastavrou et al. (2016), [3] and Suhonen et al. (2012a). [4] As mentioned by Idvall et al. (2012) it is possible that the individual foci of nursing practice are perceived differently by nurses and patients within different cultures. [42] Type of hospital and type of ward were also significantly associated with nurses' perceptions of individualised care. Nurses working in regional hospitals and maternity wards scored significantly higher on the maintenance of individuality in care provision (ICSB), on how nursing interventions supported decisional control over care (DecA), on how decisional control was actually delivered by nurses (DecB), and on how nursing interventions have supported the personal life situation of the patient (PersA). The unique features of the patient population on maternity wards, predominantly young and healthy women, may have influenced nurses' perceptions of individualised care. Younger and female patients and patients with less severe conditions generally take on a more active role in their care. [43] In line with earlier studies, [42, 44] our study also found that age (PersA) and years of work experience (DecB) had a positive association with nurses' perceptions of individualised care. In literature, it has been reported that expertise and life experience (age) can have a positive impact on nurses ability to deliver individualised patient care. [42, 44]

For patients, certain socio-demographic variables were associated with their perceptions of individualised care. Patients with a degree lower than bachelor had higher perceptions of individuality as regards their own care (ICSB). These results are similar to other research results[45, 46] and could be explained by a more critical stance[47] and higher expectations[48] towards care of patients with a higher educational attainment. The longer the length of stay in the hospital the more patients regarded that their individuality was supported through nursing interventions (ICSA). Land and Suhonen (2009) reported similar results[45] but Suhonen, Välimäki, Katajisto, and Leino-Kilpi (2006), Suhonen et al. (2010b), and Ceylan and Eser (2016) found no significant association with the duration of hospital stay. [46, 49, 50] Although literature provides no clear explanation, it is likely that higher perceptions could be explained by patients becoming acquainted with the nurses and other healthcare professionals caring for them. Further lower health literacy and lower scores of patient empowerment were significantly associated with lower perceptions of individualised care.

## Strengths and limitations

This is the first study to compare both nurses' and patients' perceptions of individualised care, taking into account the perceptions of nurses and patients of different types of hospital wards. Data were collected using the Dutch version of the ICS, which showed adequate psychometric performance. [19] A large group of Dutch-speaking patients (n = 845) and nurses (n = 569) on different hospitals wards and in different regional and university hospitals were involved in the study, providing a representative view of the perceptions of individualised care of both groups. Multilevel analysis were used to overcome the difficulties for the multilevel data clustering and inferences from multilevel analysis are more reasonable. [28]

However, there are some limitations to this study. First, due to the cross-sectional nature of the study, it was not possible to study causal associations between nurses' and patients' demographics and individualised care as would be possible in a longitudinal design. Second, the use of a self-reporting questionnaire makes it unclear if perceptions of individualised care of the respondents present a clear representation of reality. [51] Third, no subgroup analyses for patients and nurses of geriatric wards could be performed because no data for geriatric patients were available. Fourth, although it is stated in the aims that the perceptions of nurses' and patients' were compared, there were also 22 nurse assistants included in the sample. However, results did not differ without the inclusion of nurse assistants. Fifth, inherent to the nature of the secondary analysis of existing data, the available data were not collected to address the particular research question. Therefore, it is likely that nurses' and patients' perceptions may depend on other important variables besides those presented in this study. Examples are type of nursing system[44] and health status of the patient. [46] Also, three variables, patient empowerment, employment status, and health literacy, were not available for the Dutch sample. Another problem is that data collection procedures were not entirely the same for the different samples (Flanders and The Netherlands) and the different improvement projects (Tell-us card and Bedside shift reporting). For example, during the data collection of the improvement project on the Tell-us card in Flanders a member of the research team was involved, therefore patients may have answered questions more positively than the reality of their situation. [51] Last, it seems odd that the scores on the ICSB-patient section are higher than on the ICSA-patient section, as you cannot provide individualised care (ICSB-patient) without supporting it through nursing interventions (ICSA-patient). Also in other studies using the ICS, the scores on the ICSB-patient are systematically higher than on the ICSA-patient.[4, 31, 52-54] The systematically higher scores might indicate that there is a methodological flaw in how the ICS is presented to patients.

## Conclusion

Results show that there is a gap between nurses' and patients' perceptions of individualised care. Nurses perceived that they supported patients' individuality and provided individualised care during nursing activities more compared to patients. This could be a major barrier when implementing interventions aiming to improve individualised care. Creating a shared understanding towards the support and provision of individualised care should be a priority as this could generate more effective nursing care that takes into account the individuality of the patient.

## Relevance for clinical practice

Reflecting on one's own perceptions of individualised care; how these perceptions emerge or where they emanate from, could be a starting point and essential in creating awareness among nurses to provide care that is more individualised and incorporates the patients' perspective. Self-awareness may contribute to professional growth of nurses and aiding in becoming more understanding towards patients, establishing an effective nurse-patient relationship, and taking a more critical stance towards the care provided. Future research that focusses on in-depth qualitative interviews with patients, (head) nurses, nurse managers, and research experts in the field of individualised care (multistakeholder perspective) could also be vital for identifying the root cause problem of the differences in perceptions and could shed further light on what is needed to counter the discrepancy between nurses' and patients' perceptions of individualised care. Further, lower health literacy and lower scores of patient empowerment were significantly associated with lower perceptions of individualised care. Therefore, nurses are likely to need training and support in order to tailor the provision of care to vulnerable patient groups, enabling them to be more involved in their care.

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# 5

# Exploring person-centered fundamental nursing care in hospital wards: a multi-site ethnography

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Journal of Clinical Nursing, 2019
Special Issue Fundamentals of Care

## Abstract

**Background:** Effective person-centered care is at the heart of fundamental nursing care, but it is deemed to be challenging in acute healthcare as there is a strong biomedical focus and most nurses are not trained in person-centered fundamental care delivery. We therefore need to know if and how nurses currently incorporate a person-centered approach during fundamental care.

**Methods:** Focused ethnography approach. Observations of 30 nurses on three different wards in two Dutch hospitals during their morning shift. Data were collected through passive observations and analyzed using framework analysis based on the fundamentals of care framework. The COREQ guideline was used for reporting.

**Results:** Some nurses successfully integrate physical, psychosocial, and relational elements of care in patient interactions. However, most nurses were observed to be mainly focused on physical care, and did not take the time at their patients' bedside to care for their psychosocial and relational needs. Many had a task-focused way of working and communicating, seldom incorporating patients' needs and experiences or discussing care planning, and often disturbing each other.

**Conclusions:** This study demonstrates that although some nurses manage to do so, person-centered fundamental care delivery remains a challenge in hospitals, as most nurses have a task-focused approach and therefore do not manage to integrate the physical, relational, and physical elements of care. For further improvement attention needs to be paid to integrated fundamental care and clinical reasoning skills.

## Introduction

Meeting the fundamental care needs of patients is essential for optimal safety, recovery, and positive experiences within any healthcare setting.[1] While fundamental care is not a new concept, increasing attention is being placed on the ways in which it is delivered in practice.[2, 3] Fundamental nursing care is deeply entwined with person-centered care, which has become the cornerstone of quality healthcare in many developed countries and is explicitly referenced in health care policies,[4, 5] and in Huber's holistic vision on health.[6] Person-centered care focuses on healthcare that involves patients through giving them greater influence in decision-making and choice, and which is sensitive to the patients' unique physical, psychosocial, cultural, and emotional needs.[7] The literature demonstrates that person-centered care has the potential to reduce the length of hospital stays and to positively influence the maintenance of patients' functional performance.[8] However, enacting person-centered fundamental nursing care remains challenging.

## Background

Kitson et al. (2010) have defined the fundamentals of care (FoC) as the basic elements of nursing care.[1] They encompass the physical, psychosocial and relational elements of care, and are required for every patient regardless of the patient's clinical condition or setting. The FoC Framework (FoCF) was developed to demonstrate how the FoC is related to the nurse-patient relationship and the care setting in which nursing care is to be delivered.[9, 10] At the core of the FoCF lies the nurse-patient relationship, which is essential for effective nursing care. The nurse-patient relationship is about approaching the patient in an individual way; it consists of developing trust with the patient, being able to focus on the patient, giving the patient undivided attention, anticipating the patient's needs and concerns, getting to know the patient, and evaluating the quality of the relationship.[11] Nurses who successfully use these relational elements of care can work effectively to meet the patient's fundamental needs.[12] There is however little evidence on how nurses actually integrate the patient's fundamental care needs.[13] Although Feo et al. (2017) recently published a guideline with recommendations for the nurse-patient relationship, these recommendations still need to be tested on its validity and alignment with the other FOCF dimensions.[14]

We know that delivering effective person-centered fundamental care is complex, requiring nurses to take into account their patients' unique experiences, wishes, and abilities which all have to be integrated into a personalized care plan.[15] We also know that many of today's nurses are not sufficiently trained in fundamental care delivery,[16] or how to effectively involve patients in their own care.[17] Although nurses stress the importance of person-centered care where patients can participate,[18, 19] difficulties are apparent from research demonstrating that nurses overestimate the patient-centeredness of their care, as compared to the patients' experiences.[20, 21] In a study by Jangland et al. (2017) on the patients' perspective of care delivery in surgical hospital wards, it was found that the high-tempo culture lead to patients not receiving optimal physical or emotional support.[22] The literature suggests that the current acute healthcare setting does not enable effective patient participation,[23] as it has a strong biomedical focus and places little priority on fundamental, person-centered nursing care,[12] making patient participation hard to achieve.[24, 25]

With the current focus on person-centered and holistic care, and a growing population of elderly patients with complex health conditions,[12] we need to generate insights into how to improve person-centered fundamental care. Therefore, this study's objective is to gain insights into daily practice, by investigating person-centeredness and patient participation in fundamental care delivery by nurses in hospitals as a first step.

## Methods

### Design

A focused ethnographic approach, utilizing the direct observation of care, was used to gain insights into person-centeredness and patient participation in fundamental care delivery in the hospital setting. Observation is considered integral to a focused ethnography, because it provides the best opportunity to view participants' behavior in the context of the real world.[26] The researchers acted as passive participants, observing nurses in their daily work. The COREQ guideline was used for reporting.[27]

### Setting

To obtain a broad insight, the study was conducted on three nursing wards in two hospitals in the Netherlands: a cardiology and a geriatrics ward in a regional hospital, and a surgical ward in a university hospital. In the cardiology ward, adult patients were admitted with acute cardiac problems such as myocardial infarction or arrhythmias. Patients with chronic heart failure were also admitted. In the geriatric ward, older patients with acute medical problems were treated. The surgical ward was a neurosurgical and plastic surgery ward where adult patients were treated with conditions relating to the brain or spine. The ward also admitted patients undergoing reconstructive surgery. In all three wards, patients were cared for by registered nurses with a vocational or bachelor degree. In all the wards a nurse to patient ratio of 1:4 was common during the day, and the maximum ratio was 1:10 in the evenings. Each room consisted of one to four beds.

## Participants

To be included in the study, the registered nurses were selected on the basis of age, gender, level of education, and work experience, in order to ensure that there was maximum variation. They were selected with the help of their manager, who provided the nurses with information on the study and asked for their permission to be observed. All the patients older than 18 were eligible for inclusion. Patient were excluded if they did not consent to be observed, or if the nurse deemed that the patient was not suitable for observation because cognitive impairment or severe distress. The nurses and patients were informed that care in general would be observed, but were not informed about the specific aim of the study in order to avoid bias.

## Data collection

Observations were conducted at the start of the nurses' morning shift. The morning was chosen because it is traditionally a time with substantial patient interaction and fundamental nursing care delivery, such as helping patients with eating and drinking, handing out medication, washing, and mobilizing patients. The observations lasted for a minimum of 2.5 hours, starting at the morning shift handover and ending after those 2.5 hours at a natural moment of choice for the researcher (e.g. waiting for ward rounds or a patient interaction to end). Observations were conducted by three trained researchers, one for each of the three different wards, so as to minimize researcher bias. Each researcher performed the observations on one ward and thus became familiar with the patient care, the ward, and the nursing team. All the researchers were registered nurses and had or were finalizing their Masters' degree in Nursing. The first researcher (EvB) was trained in qualitative research, and she co-observed and co-transcribed the first observation period of the other researchers (JG, LC) to ensure consistency.

Before starting the observations, an observation guide was developed based on an earlier work by Conroy. [28] This guide provided prompts for information about the observed events, such as the location, date, time, and specification of basic care needs, and was used during the observations for recording field notes. As a verbatim description of the whole event was not feasible, code words and abbreviations were developed. The fieldnotes were transcribed directly after each observation to capture as much as possible of what was observed. The transcripts consist of rich data describing the setting, the nurse's behavior, the nurse's actions, communication and notes on perceptions of the nurse's attitude, and any non-verbal communication such as body posture or eye contact. To avoid observer bias, the transcripts were written as neutrally and objectively as possible without making judgments. The observers were trained to be aware of their own experience as a nurse, and they reflected on any bias or personal feelings they might have through reflective notes after each observation period, and through discussions with each other. As an additional member check, the transcripts were provided to the observed nurses, and they were asked if they agreed with the transcript or if they wanted to add to or rectify any of its passages.

During the observations, the researchers wore nurse's scrubs to conform with the attire of the observed nurses and indicate their own background as nurses. The nurses were informed that the observations were designed as non-participatory ones to observe the nurse's natural behavior without intervening, but if patient safety was endangered or there were high levels of distress by nurse or patient, the researcher would be able to assist. To increase rapport and decrease the self-consciousness of nurses being observed, the researcher had informal chats with the nurses before and during the observations, unless the nurses were in the presence of a patient or doing so would disturb the nursing process. Patients and nurses were told that all actions would be followed, but that both could indicate if the patient needed privacy on which the researchers would step outside the curtain or room. Data collection stopped after saturation was reached.

## Data analysis

Analysis was conducted through framework analysis using the FoCF. [9] In addition, all the data were screened for additional codes and themes, also known as thematic analysis. First, the researcher read the transcripts to establish an overview of the data. Second, the FoCF was used as the initial coding framework, and open coding was used for the text fragments that did not fit into the categories. Third, categories were revised and subcategories were developed. Fourth and finally, the researchers searched for patterns, associations, concepts, and explanations in the data. All the transcripts were analyzed using Atlas.ti. [29] Thematic and open coding was conducted independently by three researchers (EvB, MH, JG), with two researchers coding the transcripts for each ward. In the cases of the cardiology and surgical ward, one of the coding researchers had also collected the data to incorporate the lived experience or elaborate on context. The other researcher provided a neutral view. The data collector of the geriatrics ward was contacted to provide background information on the transcript when necessary. Codes were compared and differences discussed until consensus was reached. Memos were written during the coding process to capture impressions and help the identification of themes and patterns during analysis.

### Ethical considerations

According to the Dutch national legislation and as judged by the CMO Arnhem-Nijmegen, who was the local Medical Ethics Committee, the study (file nr 2017-3244) is non-invasive and does not fall under the scope of the Medical Research Involving Humans Subjects Act (WMO). [30] According to this law, as no identifying information from patients was gathered, written consent was not necessary. Participants were explicitly informed and both the researcher and attending nurse asked for their permission. They were also notified of their right to withdraw. If either the researcher or nurse doubted the patient's cognitive state, the patient's close relative was asked to provide written informed consent. All the nurses provided written consent and approved of the transcripts in writing. Data were analyzed anonymously and stored separately from the nurses' personal information.

## Results

A total of 30 observation periods were conducted, with 10 periods on each ward. The observations at the surgical ward were carried out from July to August 2017, while the observations on the geriatric and cardiology wards took place from February to April 2018. The observation periods lasted for a minimum of 2.5 hours and a maximum of 3.0 hours, and they all occurred between 7:30 and 11:00 A.M.

### Nurses

All 30 nurses who were approached consented to be observed and checked the transcripts. No changes had to be made, as all the nurses approved the transcripts. According to the wards' management, the sample was representative of the wards' nurses (Table 1). We see that there is a lower mean number of patients per nurse on the surgical ward. Management confirmed that this is common during the morning as patients either leave for surgery before the day shift, or are admitted for surgery in the afternoon.

### Patients

All 102 patients who were approached by the researchers consented to the observation. For four patients, the nurses deemed the observation as being too emotionally stressful and asked the observer not to follow her into the room, so these patients were not approached by the researcher and were not observed. Five patients were deemed by the nurse to be cognitively impaired, but still suitable for observation. Those patients were asked (if contact was possible) if they objected to the observation, and those who were capable of doing so consented verbally. Two patients were not able to indicate objections, and

**Table 1** Nurse characteristics

| | Surgery | Cardiology | Geriatrics |
|---|---|---|---|
| N | 10 | 10 | 10 |
| Male/female | 1/9 | 2/8 | 1/9 |
| Mean age years (range) | 40.7 (23-62) | 33.5 (24-53) | 29.9 (23-41) |
| Mean work experience years (range) | 13.9 (1-38) | 8.75 (0.5-31) | 6.0 (1-18) |
| Mean no. of patients per nurse | 2.6 | 4 | 3.6 |

patients' families were contacted for permission. From all five families, additional written consent was obtained. On several occasions the observer was asked to assist, for example to help turn a patient in bed or to help make the bed when the patient was in the bathroom. The observer agreed to do so if it did not interfere with the observation. In two cases the researcher had to step in during the observation because of patient safety: on one occasion a patient lost consciousness in a bathroom, and on the other a patient almost fell.

The 30 transcripts were coded. 23 were coded by two researchers, while 7 transcripts were single coded and checked by a second researcher because of the high level of consensus between the researchers at that point. Open coding resulted in just one extra code: "coordination of care". All codes of the FoCF were used in the analysis (see Table 2).

Coding was done by assigning the relevant fundamental care element to an observation. The assigned code was often a combination of codes which described the situation. For example, for an observation of a nurse washing a patient and talking about the patient experiencing pain, the codes 'personal cleansing and dressing' and 'comfort' would relate to the patient's physical care, the codes 'communication' and 'education and information' would relate to the interaction's psychosocial part, and the codes 'active listening' and 'empathy' would relate to relational skills. Some FoC elements were difficult to discern, as they seem alike and sometimes two elements can describe a situation. This was most obvious in the combinations 'active listening' and 'being present', 'choice' and 'being involved and informed', and, on occasion, 'empathy' and 'compassion'.

Analysis of the codes lead to three themes: 1) Fundamental care elements, describing what elements were visible during morning care 2) Personalized care versus task-oriented care, which related to the level of person-centered fundamental care and 3) Coordination of care, involving the tasks the nurses performed when not at the patient's bedside.

**Table 2** Elements of fundamentals of care frequency

| Physical | No. codes | Psychosocial | No. codes | Relational | No. codes |
|---|---|---|---|---|---|
| Personal cleansing and dressing | 212 | Communication | 151 | Active listening | 13 |
| Toileting needs | 50 | Being involved and informed | 207 | Empathy | 43 |
| Eating and drinking | 91 | Privacy | 40 | Engaging with patients | 44 |
| Rest and sleep | 37 | Dignity | 18 | Compassion | 46 |
| Mobility | 93 | Respect | 43 | Being present and with patients | 22 |
| Comfort | 106 | Education and information | 34 | Supporting and involving families and carers | 5 |
| Safety | 226 | Emotional well-being | 13 | Helping patients to cope | 20 |
| Medication management | 157 | Choice | 44 | Working with patients to set, achieve and evaluate progressions of goals | 3 |
| | | Having values and beliefs considered and respected | 2 | | |
| | | Social engagement, company and support | 4 | Helping patients to stay calm | 14 |
| | | Feeling able to express opinions and needs without care being compromised | 14 | | |
| | | Having interests and priorities considered and accommodated (where possible) | 3 | | |
| Coordination of care | 203 | | | | |

## Fundamental care elements

This theme describes what fundamentals of care were observed and what nurses spent most of their time doing. For the majority of the observation periods, the nurses took care of the patients' physical needs (Table 2). Most of that time was spent on helping or stimulating patients to wash and dress ('personal cleansing and dressing'); preparing, checking, and handing out medication ('medication management'); as well as conducting safety checks and measures including vital signs, assessing the patients' mental state and physical wellbeing, and risk reduction activities such as preventing infections or falls ('safety'). Nurses helped patient with mobility, which mainly involved moving from the bed to a chair or the bathroom. The nurses also asked about comfort-related topics such as pain levels, nausea, body warmth, or if the patients were feeling comfortable in their bed or chair. Nurses sometimes asked patients about what or when the patients wanted to eat or drink, but this task was mostly performed by the kitchen staff. Nurses were sometimes observed asking or talking about rest and sleep (quality), and the patients' toiletry needs or bowel movements. The FoCF's psychosocial and relational elements were less frequently observed during morning care than its physical elements (Table 2). The most frequently observed psychosocial elements were 'communication' and 'being involved and informed', and the most frequent relational elements were 'compassion, 'engaging with patients', and 'empathy'. The elements that were seldom observed were relational elements: 'supporting and involving families and carers', and 'working with patients to set, achieve and evaluate progressions of goals'. The psychosocial elements were also infrequently observed: 'having values and beliefs considered and respected', 'social engagement, company and support', and 'having interests and priorities considered and accommodated (where possible)'.

## Personalized care versus task-oriented care

Observed care ranged from personalized care to more task-oriented care. All the nurses appeared to be concerned with the patients' wellbeing, and would respond in a friendly manner when patients were not feeling well or were distressed. Differences were observed in how this was enacted, with some nurses displaying more empathy, compassion, and more active listening. These nurses appeared to be truly present with the patient and they interacted and connected with the patients' more explicitly. Where the nurses were observed giving more attention to the patient, an increase in the combinations between the physical, psychosocial, and relational elements of fundamental care was observed. An example is illustrated in the observation below, where a nurse was caring for a patient on bedrest in a single bed room:

> *'The nurse has a calm and friendly way of talking. She explains clearly what she is going to do. The nurse helps the patient with undressing, and says that the patient may help. The patient helps. The patient indicates that something is wrong. The patient cannot find the right word. The patient points to her cheek. The nurse asks "jaw?" The patient says "yes". The nurse asks if she is in pain, the patient says "yes". The nurse says that pain in the jaw muscle is common after the operation the patient has had, and explains why. … The nurse asks how the patient experienced the operation yesterday. The patient tells to have experienced little anxiety. The nurse continues washing, the patient is naked, and the nurse covers the patient with towels. The patient tells about the rest of the admission, and the nurse continues washing, frequently seeking eye contact … The nurse helps the patient dress. The patient wants to do parts herself. The nurse encourages the patient by softly saying "well done" during the dressing.'* (Nurse 5 ward 1)

This nurse incorporated different relational and psychosocial elements in the physical action 'personal cleansing and dressing'. She informed the patient of her actions and involved her in the care, letting the patient decide what she could do herself. She was supportive and encouraging when the patient wanted to dress herself. The nurse was attentive to the patient's speech impairment (compassionate and respectful), she picked up on the patient's signals of not being comfortable, and acknowledged those signals by telling the patient why she was uncomfortable and not to worry (education and information, helping patient to cope, empathy). She paid attention for possible emotions regarding the operation by bringing the operation up (empathy), and her nonverbal behavior signaled that she was present with the patient and engaged in active listening. While doing so, she was helping the patient wash, took care of the patient's privacy and comfort by covering her up with towels, and helped her get dressed.

However, most nurses were more task-focused in their interactions. The next observation describes a nurse helping a patient on bedrest to wash in a single bed room:

> '*The nurse raises the bed to work level and removes the sheets from the patient. The patient is wearing an operation gown without underwear. The nurse removes the intravenous access point on the patient's foot. The pager goes off, the nurse looks at it, says 'I will be right back', and walks out the door. She leaves the patient with the bed still high and without covers … The nurse comes back a few minutes later and tells the patient she is sorry for having to leave. The patient says that it is no problem and that he was comfortable.*

> *The nurse tells that she is there to check the vitals, and to help washing. The nurse checks the vitals. The nurse gives some explanations to me (the observer), not to the patient. The nurse cleans up … The interaction between the nurse and the patient is friendly. Much eye contact and the nurses has a calm appearance. The nurse hands over washcloths to the patient, suggests that the patient washes his face and arms himself, and that she will help with the rest. The patient agrees. During the washing there is little conversation aside from giving instructions, both don't initiate conversation. The patient makes less eye contact during washing. The patient needs to roll aside to change the bed, the nurse gives instructions. I (the observer) assist with turning upon being asked by the nurse, although the patient appears to be able to turn himself. This was not discussed. The nurse is washing the patient's buttocks when her pager goes off, room no. 17 is calling. The nurse picks up her phone and calls a colleague to go to the other patient, instructing her on what the question probably will be. The patient is still on his side, the nurse ends the call, and continues washing. There is little communication during the washing.'* *(*Nurse 1 ward 1)

Although the nurse had a friendly way of communicating with the patient by making eye contact and having a friendly tone of voice, she was mostly focussed on her task which was washing the patient and cleaning the sheets. There were several opportunities to change the interaction: the nurse could have covered the patient up when she needed to leave the room, and not placed a telephone call while washing the patient's privates (respect, dignity, comfort, privacy). Additionally, she gave the observer information when checking the vitals, but this was not directed at informing the patient. There also appeared to be a lack of communication and involvement during the washing. She directed the way that the patient was washed and turned without asking for the patient's wishes or abilities, and did not use this time to connect with the patient. No explicit attention to psychosocial or relational elements could be observed, even though there was plenty of time to do so. The first nurse went through similar tasks and appeared to connect.

Most nurses were observed to attend to their patients' privacy, especially in rooms with multiple beds. Curtains were closed when a patient needed to get undressed, and for subcutaneous injections and putting on stockings, even when the patients indicated that it was unnecessary. The observer was also asked to stay outside the curtains while some patients were being washed. However, this high regard to privacy did not apply to other nurses who were entering from behind the curtains or into the bathroom. Nurses were often observed entering a privacy-sensitive situation such as the patient washing, dressing, or being on the toilet with little notice. They often walked straight into the room. Patients however did not seem bothered by this behavior. These encounters with fellow nurses mostly concerned discussing general patient care planning. The nurses would also report back on performed tasks, or discuss other patients either anonymously (e.g. "your patient in bed 26") or with mentioning that other patient's name, in the presence of the patient being attended to. One example is this interaction where the observed nurse A was washing an undressed patient in room 4:

> '*Nurse A is washing the patient. Nurse B knocks at the door and walks in. Another patient in room eight is discussed by the nurses regarding comfort and extra medication. Nurse A asks Nurse B if she had the impression that the patient was not comfortable during washing. Nurse B answers that the patient was gasping. She leaves the room. Nurse A resumes washing and starts chatting with the patient, talking about the cold weather and the patient's dog. A kitchen assistant knocks and walks in. She asks if the family of the other patient in room eight should be offered breakfast. Nurse A tells her to do so because they are holding a vigil for the patient (the patient is dying). "Would you like to wear slippers or shoes?" nurse A asks her patient.'*
> (Nurse 4 ward 3)

Most observations started with nurses asking patients questions about safety and essential care-related topics like pain, nutritional and bowel status, sleep quality, and the patients' vital signs. The patient's responses were documented, and nurses moved on to the next question. Most nurses appeared to have a standard way of checking these items, repeating the same line of questions in the same way with all the patients. However, many nurses did not follow up on the patients' answer by inquiring further or taking actions to address the topic raised. The questions did not appear to be a deliberate inquiry for further action to be taken, nor were they seen to be incorporated into care planning. Issues were often followed-up by referring to a doctor who would come by later, or by offering medication. This lack of follow-up is visible in the following interaction between a nurse and a cardiac patient:

> '*The nurse asks if the patient has slept well. The patient says that she finally had a good night's sleep. The nurse says that that is nice. The patient indicates that she is a bit dizzy from the sleep medication. The nurse responds that that is possible. The patient says that a good night's sleep is worth a lot. The nurse agrees. …'*

The nurse gave a short response, mainly indicating that she had heard the patient. Dizziness however is a common side effect of cardiac medication, and might lead to an increased fall risk and general discomfort. The dizziness could have been explored further.
The encounter continues:

> *'(..) The nurse asks if the patient has pain. The patient says to have pain in her mouth. The nurse asks if this pain is new. The patient explains that she had this for a longer time, and that it is caused by a dry mouth. The nurse asks if the patient has water. The patient says no, and that the air is very dry in the ward. The nurse agrees and gets the patient some water. The patient says that the fluid restriction she is on is not helpful for the dry mouth. The nurse says that this is indeed difficult. She asks if the patient can turn off her own apnea machine.'* (Nurse 6 ward 2)

At first, the nurse's response seems short but appropriate. However, it becomes apparent that the hospital air is dry and that patient has a fluid restriction, causing a dry mouth and thirst. Many patients struggle with complying with fluid restrictions, and offering water is not the appropriate response considering the fluid restriction. The nurse could have explored other options to tackle the dry mouth with the patient, and talk about the experienced discomfort to promote therapy adherence. The specific FoC elements aimed at patient participation in care: 'being involved and informed', 'having interests and priorities considered and accommodated (where possible)', 'supporting and involving families and carers', and 'working with patients to set, achieve and evaluate progressions of goals', were observed in a variety of ways. The element of 'involving and informing patients in care' was most often observed during personal cleansing and dressing. Nurses asked about the patients' ability to wash and dress themselves, and discussed with the patients where they needed help. They informed the patients about their actions, and gave instructions on what they could do. Nurses focused their communication on explaining their actions to the patients. Patients were rarely informed about what to expect during the rest of the morning or the day, or discharge from the hospital. Most conversations were observed to be one-sided, with nurses giving information and explaining their actions. Nurses were seen to inquire about the patients' preferences mostly by giving the patients a choice between two options, such as if they preferred to wash or eat first, if they preferred to take a shower or wash with (prepackaged, heated) washcloths, or if they wished to eat at the bedside or at the table. Patients were seldom observed indicating that they wanted something other than the two options provided. The following elements were rarely observed: 'asking about and discussing patients' needs and goals for recovery', 'empowering patient to ask questions', 'discussing family involvement in care', 'inquiring about a patient's life outside the hospital', and 'discussing the patients' need for information on disease or treatment'.

## Coordination of care

Observations of the nurses' actions when they were not at their patients' bedsides were placed under the theme of coordination of care. These actions mainly concerned communication between nurses about patient care, general ward management such as planning medical rounds or admissions, and asking each other questions. These actions either occurred during unplanned interactions such as meeting each other in the hallway and checking whether they were on schedule, or when nurses deliberately looked for colleagues to either check on what tasks needed to be done, or to report back on accomplished tasks. These interactions occurred in hallways and in patient rooms. Another frequently observed interaction was nurses looking and asking around for colleagues to assist them in patient care. Frequently, the nurses who were asked for assistance were in patient care themselves, and were interrupted by a colleague stepping into the room. In this example, nurse A has just finished washing and is helping a patient to get dressed:

> *"Nurse B walks into the bathroom and asks for help in the medication room. "I'll be right there", responds Nurse A. She continues to help the patient getting dressed. Nurse A puts on the patient's shoes and helps the patient stand up with a walker. Nurse C comes in and says: "can I ask you something?" Nurse A responds: "I'll be right there." Nurse C leaves. The patient is helped with sitting down in his wheelchair and is comfortable. Nurse A leaves the room."* (Nurse 1 ward 3)

Nurses were rarely observed being paged away by patients; they were mainly called away by other nurses or other professionals. Usually, they were called to discuss logistical issues such as when to start medical ward rounds, to answer questions (e.g. "do you know how to…"), or to assist with patient care (e.g. washing, transportation, medication checks). Communication with other professionals during care delivery in the morning was observed frequently, with nurses receiving questions, messages, or tasks to plan or perform for their patients. Nurses were often handling different tasks or conversations at the same time. One example of this situation is described in the following observation:

> *'Nurse A walks in the hallway. Nurse B inquires if the nurse can go into medical rounds. Nurse A agrees. She walks past the secretary who asks her about a*

> *patient being admitted in the afternoon. Nurse A tells her that she is busy, and that she has to do the medical round, and that she also has a multidisciplinary deliberation in the afternoon. Meanwhile, Nurse C asks if she can do anything to help her. Nurse A responds that she still needs to wash the patient in room 1. Nurse C responds that she will help this patient. Nurse A tells Nurse C that she appreciates this and tells the secretary that she can admit the patient at 11:30.'* (Nurse 5 ward 3)

## Discussion

The results of this study gave in-depth insights into how fundamental care delivery is enacted. Analysis of the observations led to the identification of three major themes; fundamental care elements, personalized care versus task-oriented care, and coordination of care. The results demonstrated that nurses were focused on physical care delivery in a task-driven manner, and that psychosocial aspects such as addressing patient goals, care planning, and patient participation were less frequently observed. Additionally, nurses were often seen interrupting each other's care process, which hindered a person-centered approach of integrated fundamental care delivery.

### Fundamental care elements

All the FoC elements were observed during this study, although some occurred more frequently than others. We observed that nurses spent most of the time taking care of the patients' physical needs, like washing and dressing and medication management, as well as in performing safety checks such as taking vital signs and filling in safety and comfort checklists. This is unsurprising, as the morning is traditionally a time which revolves around physical care. However, a number of relational and psychosocial FoC elements were rarely observed, and in general they occurred less frequently than the physical elements, confirming a dominant biomedical focus in acute healthcare (Feo & Kitson 2016).[12] International literature also indicates that nurses rarely discuss a disease's emotional aspects or explore the patient's feelings actively,[31] and they rarely report the undertaking of actions to address or improve the patients' psychosocial needs.[32] Other studies have also reported the difficulty of nursing students with identifying the patients' psychosocial and relational needs.[33] The communication that was observed was often directly related to the physical action or to small talk. Although small talk is important in establishing a nurse-patient relationship, it might also create an atmosphere unsuitable for dealing with emotional or more difficult issues.[34]

## Personalized care versus task-oriented care

Observations within this theme demonstrated that nurses have different ways of building and maintaining professional relationships with patients. Some nurses were observed to have a more person-centered approach as they used various elements of psychosocial care and relational skills when taking care of a patients' physical needs, confirming that integrated fundamental care delivery is feasible.[12] Most nurses however showed little integrated care, seeming to be focused on task completion and physical care rather than using the time to connect with the patient. Even though this was visible in most physical care aspects, the lack of follow up on health status inquiries and picking up on patient cues is the most alarming as it not only threatens the person-centeredness of care, but also the quality and safety of nursing care. Gathering patient information starts the clinical reasoning process, which is an essential feature of health care practice. According to Higgs et al. (2001), clinical reasoning in nursing is the process of making professional judgments, by evaluating the quality and contribution of available evidence to enhance problem solving, and by considering the extent to which the evidence available is sufficient to make decisions on diagnosis and treatments options that are relevant to the patient's nursing care requirements.[35] Results from the current study however indicate that nurses often assess their patient clinical status in a way that seems aimed at task completion. This confirms previous research that nurses perceive themselves as acting in a person-centered way, but are observed to be centered on routines rather than individual patient assessment and management.[18] Nurses often inform patients about what they are doing at that moment, but seldom stimulate actual participation or patient involvement in care. The assessments nurses made often appeared to not be followed-up by any other action, thereby hindering the incorporation of patient signs and symptoms into clinical reasoning. If there was follow-up on the patients' indicated health status, this was often through referral to medical care, such as medication or a doctor's visit, or to allied health services (e.g. arranging a physiotherapist). This confirms the notion that fundamental care in hospitals is becoming more fragmented.[12] Next to not actively asking follow-up questions, observations showed that nurses also often did not pick up or follow up on indirect patient cues that something is worrying them.[36] This confirms previous findings that that about half of all patient cues are responded to with distancing behavior from nurses,[37, 38] even though it is known that following up on patient cues leads to (more) disclosure of concerns by patients.[38] Asking follow-up questions and picking up on patient cues means having attention to both physical and psychosocial care. The lack hereof prevents the nurse from progressing from data collection into the process of clinical reasoning. The ability to perform integrated fundamental care and clinical reasoning skills are therefore entwined.

To improve clinical reasoning, nursing curricula have increasingly been focused on teaching clinical reasoning based on nursing diagnosis. [39] The use of nursing diagnosis was however seldom observed, also no care plans were made or discussed with patients. This was apparent in the almost complete absence of the codes 'working with patients to set, achieve and evaluate progressions of goals', 'having values and beliefs considered and respected', and 'having interests and priorities considered and accommodated (where possible)'. Most nurses focused their tasks and communications mainly on physical care and did not explicitly incorporate elements of psychosocial care, even though results show that there was plenty of opportunity within the nurse-patient interaction to do so, confirming that such care does not take up more time or resources. [34] Even though nurses perceive a lack of time as a barrier for patient involvement[19, 40] and integrated care, [41] McCabe (2004) further demonstrated that nurses do not communicate sufficiently in a patient-centered way even when they have the opportunity to do so, and that patients perceive nurses in general as being more aimed at task completion than on communicating. [34] Physical care then becomes more of an act, rather than an opportunity to connect with a patient as a means to provide patient-centered care, [42] even though the quality of the relationship between the nurse and the patient is significantly linked to improved health outcomes such as symptom relief and improvements in clinical and functional status. [43]

According to Kitson (2014), this focus on the patient as a body to do things to, rather than a person to engage with, is reinforced by electronic nursing records that are built on physical care and identify discrete diagnostic and nursing interventions, without demonstrating how these interventions come together to create an integrated care plan and positive experience for the patient. [44] The lack of a focus on person-centered fundamental nursing care in most nurses can also be explained by health care systems which are increasingly focused on task completion, outcome evaluation, and benchmarking, [12] and by the pressure on nursing care from shorter admission times and increases in older patient with complex care requirements. [45] Australian research found that nurses complete an average of 72.3 tasks per hour, and spend only about 37% of their time with patients, which translates to approximately 3.1 hours per 8.5-hour shift. [46]

## Coordination of care

This study's results demonstrate that nurses often interact with each other to discuss patient care, resulting in frequent disturbances during morning care where patient privacy is occasionally threatened. Consistent with this study's findings, other studies have demonstrated that nurses are often interrupted by other nurses seeking help in patient care. [47] During interruptions in care, nurses often did not take their patients' privacy into consideration. Nurses were observed entering privacy-sensitive situations, such as the patient washing, being in the toilet, and having conversations. The nurses would then demand immediate attention from the attending nurse and often ignored the situation they had entered. The literature indicates that a lack of environmental privacy, impaired health, and old age all impact the loss of patient dignity in hospitals, and that this loss threatens the feelings of being comfortable, in control, and valued. [48] Baillie et al. (2009) also found that nursing staff was often unaware of how their interactions affect dignity and privacy, which might be strengthened by our findings that the patients often did not seem bothered when the nurses came in or were disturbed, thereby providing few clues to nurses as to whether they were affected. [48] A recent study however demonstrated that for older patients, dignity and respect are core values that need to be met in the interpersonal care relationship. [49] In previous studies, nurses indicated that they were hindered in having conversations with patients because they were busy and were called away often, and would like to have more time to talk to patients. [40] Studies confirm that nursing care is often interrupted, with research indicating that on average there are 2 to 5.6 interruptions an hour per nurse. [46, 50] Nurses report lower levels of satisfaction with their performance and higher levels of emotional exhaustion on days with large amounts of workflow interruptions. [51] Interruptions also have an effect on patient safety, with nurses making more mistakes when interrupted. [52] Therefore, even though in the current study patients did not seem bothered by nurses being called away, having to divert attention, or entering privacy sensitive situations, such behavior can still cause several psychosocial problems, raise safety concerns, and affect work satisfaction.

## Reflection on Fundamentals of Care

Although the FoCF was valuable for analysis, it was at times difficult to differentiate between elements like ‘active listening’ and ‘being present’; ‘choice’ and ‘being involved and informed’; or ‘empathy’ and ‘compassion’, as interactions could comprise both elements.

## Further research

Findings have shed light on some issues which might prove valuable to further pursue in advancing person-centered fundamental care. Our findings suggest a direct link between a nurse’s ability to provide integrated care and effective clinical reasoning. This, amongst the question what nurse characteristics influence care delivery and the impact of care disturbances, could be further investigated with an experimental study design in which effectiveness of integrated fundamental care in clinical reasoning is assessed.

### Limitations:

The main limitation of this study is that a certain degree of observer bias might be unpreventable. As all three observers were nurses, it is possible that while observing fellow nurses, their own professional views were reflected in the observations, transcripts and analysis. The researchers took precautions to minimize bias by using an observation guide, by discussing the transcripts with the observed nurses, by reflecting and talking about the experiences with each other, and by double coding most of the transcripts. Rigor was enforced by the main researcher co-observing and co-transcribing for consistency, and by the other observers helping in coding and analyzing. Another limitation is the timing, as the observations for the morning interactions do not automatically translate to the rest of the day. The researchers however felt that the nurses' characters and working styles were apparent from the 2.5 hours of observation in the morning, and the focus on how the nurses integrated psychosocial care with relational skills during physical care could be observed well. A strength of the study was the immersion in the nursing care. The aim was to act as much as possible as a passive observant, and only intervene in case patient safety was threatened. However, it felt more natural and immersive for the researcher to occasionally assist nurses in their work such as by helping change a bed, when doing so did not disrupt the observation. Many nurses stated that they were quickly used to the presence of the observer, feeling like the observer was a colleague who they were showing around (something they were used to), and did not feel like they were being judged by the researcher writing everything down. The researchers felt that without their own experience as nurses, the observations could not have provided accurate insights into practice, resulting in rich and realistic descriptions of the care provision.

## Conclusion

This study demonstrates that few nurses integrated psychosocial care and relational skills in their patients' physical care. Nurses were often seen to be more task-oriented in communication, mainly gathering information and telling patients about current tasks. This implies that the care provided was often not patient-centered and that patient participation was seldom stimulated, even though we saw that there is ample opportunity within an interaction to do so. It is therefore possible to have person-centered fundamental nursing care in fast-paced hospital wards, but it needs extensive attention to be improved, with a focus on the integration of psychosocial and relational care into physical care and the clinical reasoning process. Quality of care and person-centeredness can be further improved by attentiveness to patient cues. Frequent disturbances should also be limited as it hinders a person-centered fundamental care approach.

## Relevance to clinical practice

This study gave in-depth insights into the level of person-centeredness of fundamental nursing care delivery. Nurses were often observed to be rather task driven with less attention to integrating the psychosocial and relational aspects of care while attending their patients' physical needs. However, there were some good examples which indicated that there was sufficient opportunity to do so, making it something that can be improved. Integrating physical, psychosocial, and relational care elements in daily practice and in the process of clinical reasoning is needed for high quality, person-centered, fundamental care delivery, in which patients are actively involved in their care.

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# 6

# Creating a guidance for hospital boards of directors to improve patient and family participation; A Dutch national quality improvement project

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*In submission*

## Abstract

**Background:** Family and patient participation leads to improved patient safety and quality of care. Although an abundance of initiatives exist, central policy on how to best enact participation is lacking in many Dutch hospitals, and insight into currently used activities and interventions is minimal. This study aimed to develop a comprehensive guidance of best practices for hospitals to enhance participation at the micro, meso, and macro levels, giving boards of directors a tool to assess and direct efforts to enhance the current level of patient participation.

**Methods:** A modified Delphi method was used to reach a consensus about promising and implementable practices within a panel of 36 experts on patient and family participation. A list of best practices was identified from the literature and evaluated in three Delphi rounds based on usefulness and feasibility. Respondents rated items on a 9-point Likert scale. The results were used to create a guidance, which was disseminated within all seven university hospitals in the Netherlands and evaluated on usability and uptake by questionnaire a year later.

**Results:** A guidance of 10 best practices for family and patient participation was assembled, aiming efforts at different organizational levels. Evaluation a year later showed that six out of the seven hospitals had implemented four of the best practices, had plans to improve upon the other points, and found the guidelines helpful in planning future improvements.

**Conclusion:** This study shows that successful patient and family participation in hospitals requires sustained effort and dedication by a board of directors, policy makers, and health care providers. The created guidance can be used to assist a board of directors to best direct their efforts on these different organizational levels, and ongoing budget and educational opportunities must be allocated to help frontline workers integrate participation in their daily practice.

# Introduction

## Problem description

Person-centered health care consciously adopts the perspectives of individuals, families, and communities and sees them as participants as well as beneficiaries of health systems that respond to their needs and preferences in a humane and holistic way.[1] It requires people to have the education and support they need to make decisions and participate in their own care. Patient and family participation is possible on different levels of engagement, ranging from information, consultation, advice, and collaboration to control over care, with the level of participation increasing at each step.[2] It can also take place at different levels of patient care: micro (individual care), meso (service development, planning, delivery and evaluation of care, education and training of health care providers) and macro (policy-making).[3] The challenge for hospitals lies in creating opportunities for family and patients to participate on all levels.

## Available knowledge

Patient participation has various benefits such as increased patient safety[1,4] and satisfaction[5,6] and is defined as a key element of quality of care by the World Health Organization.[7] Therefore, many hospitals worldwide have launched initiatives to enhance the level of patient and family participation in day-to-day interactions with health care workers, in department policy, and on the hospital board level. Numerous tools, evidence-based interventions, and best practices are available for implementation and, just as in other countries, many Dutch hospitals report departments and wards launching their own initiatives to help patients and their families participate in care. They also indicate, however, that a central policy on how to best enact participation is lacking, and most hospitals do not have an overview of which activities or interventions are running. The abundance of interventions and lack of central overviews call for guidelines for hospital board members on what interventions are most effective in terms of monetary value and quality of care to enhance family and patient participation.

## Rationale

The guidelines will be offered as a tool for boards of directors to help set strategic goals and question department representatives about their efforts toward family and patient participation. This tool will give departments responsibility and an obligation to undertake actions to improve. Additionally, it will offer them guidance on how to implement and evaluate the effects. The guidelines focus on the efforts of health care workers on themes that will effectively improve increased family and patient-participation-related outcomes. The practical use of the guidelines will be evaluated after release to assess their usability and uptake.

### Specific aims

This study aims to develop a comprehensive guide of promising and implementable best practices for hospitals to enhance their levels of participation at the micro, meso, and maso levels, giving boards of directors a tool to direct and assess efforts to enhance hospitals' current levels of participation.

## Methods

### Context

In 2020, the Netherlands had 71 hospital organizations spread over 116 locations.[8] Seven of these were university hospitals, which differ from general hospitals in their focus on highly specialized care, scientific research, and education, making them leaders in innovation and evidence-based care. Given these characteristics, this quality improvement project focused on these hospitals. Academic hospitals are funded publicly by taxes and obligatory health insurance fees. They are presided over by a board of directors and consist of medical, scientific, and educational departments. The SQUIRE[9] and CREDES[10] guidelines were used for reporting.

### Measures

First, a literature review was conducted to find existing indicators for patient and family participation in hospitals. Search terms consisted of (synonyms of) patient participation, quality indicator, performance measures, structure indicator, process indicator, outcome indicator, health care quality, patient satisfaction, patient, caregivers, family, hospital, and health clinic (see box 1). The databases EMBASE, PubMed, and CINAHL were used. The search, however, yielded 316 hits, which consisted mainly of quality improvement projects and protocols and included only one suitable article.[11] Thus, as the scientific literature gave little information on indicators for patient and family participation in hospitals, this study consisted of three steps to create and evaluate a comprehensive guide for practice:

1) An international gray literature search was conducted to assemble best practices. This was done by searching gray literature databases, the internet, and documents of international institutions such as the Agency for Healthcare Research and Quality (AHRQ), Planetree, the Institute for Family-Centered Care, the Pickert Institute, and the Dutch Participatiekompas. Search terms included: Patient centered/centred care, patient-centered/centred care, patient participation, patient engagement in care, family participation, family engagement in care, caregiver participation, caregiver engagement in care, shared decision making, shared decision-making, participative decision-making, participatory medicine, medical engagement, quality indicators, quality improvement, and patient council.

2) A consensus on best practices was achieved. A selection had to be made from the abundance of best practices, and this was done by seeking the consensus of experts on patient participation. The Delphi technique,[12] in which a panel of experts is asked to rank items in several rounds of questionnaires, reducing the items based on consensus to whichever are deemed the most important, was used. In three rounds, (inter)national experts on patient and family participation were asked to fill in a digital questionnaire, scoring each item on a 9-point scale. In the first round, participants rated the best practices on usefulness (1 = not useful, 9 = very useful), in the second round, participants rated the items on practical feasibility (1 = not feasible, 9 = very feasible), and in the third round, respondents were asked to choose the top three practices they deemed positively challenging and feasible for the near future. In round one, participants had the opportunity to comment on the presented best practices or add new ones, and in each round, the list of items decreased according to set criteria. These rounds resulted in a final list of best practices, which was assembled into guidelines containing detailed information on the items.

3) An evaluation was conducted by the academic hospitals to determine usability and uptake. In the year after the release of the final list of best practices, an evaluative survey was taken among academic hospital representatives tasked with patient and family participation in their hospitals. This survey consisted of three parts. Part one contained general questions about the use of the list (are you familiar with the list, were you the one to implement this in your hospital, and how much did the list help you to improve patient and family participation, rated on a scale of 1–9,). In part two, respondents were asked to rate how much each item was being used on a 9-point scale (1 = not at all, 9 = on every ward in the hospital) and to give three examples of how it was enacted. Part three consisted of questions on whether the hospitals were measuring patient participation outcomes and how, what good practice each hospital was planning to start within the next two years, which of the items the respondent would like their hospital to uptake within five years, and what each would need to enhance the level of participation in their hospital.

## Participants

Experts on patient and family participation from an (unpublished) earlier international study on patient participation were approached for the Delphi questionnaire. Within the Netherlands, a selection of experts, such as members of boards of directors, representatives of patient organizations, researchers, and hospital staff were asked to join, with the aim of achieving a variation in respondents. In the last evaluative step, all the Dutch academic hospitals were approached through the network of academic hospitals and their Patient as Partner workgroup to find a suitable representative who had been working with the guidelines.

### Analysis

After each round, the Delphi analysis was done following predetermined conditions to decide if an item was included, excluded, or needed to be discussed within the project group. Medians were calculated to assess scores. Items were automatically included in the next round if they reached a median usefulness or feasibility score of ≥ 8 with ≥ 70% of the respondents scoring them at a 7 or higher. Items reaching only one of these two criteria or bordering inclusion were labeled doubtful and discussed within the project group to determine inclusion or exclusion for the next round. Items added by respondents were discussed on appropriateness and overlap with existing items before they were added to round two. Items clearly not meeting the criteria were excluded.

### Ethical considerations

The local medical ethics review board waived the need for full ethical review. All participants were informed about the goal of the study and gave informed. Participants were informed of their right to withdraw from the study at any moment. All data was gathered, analyzed, and stored following the declaration of Helsinki and Good Clinical Practice guidelines.

## Results

### Gray literature

The gray literature search yielded 212 best practices and recommendations. As this number was too high to be reviewed in the Delphi study and because of overlap between items, the project group made a first selection by individually scoring each item for usefulness and feasibility. In a consensus meeting, all items were discussed based on their score, and overlapping concepts were examined, resulting in a reduction to 73 items categorized in eight domains (table 1).

### Delphi consensus

For the Delphi questionnaire, 72 (inter)national experts were approached. Of these experts, 36 people consented to join the study, 15 declined, and 21 did not respond. The 57 consenting and unresponsive people were approached following the opt-out principle, leading to 14 declining the invitations for the second and third round. Response rates varied between 74% and 63%. The group members varied in professional backgrounds, including representatives of patient organizations (n = 6), researchers (n = 16), consultants (n = 8), and hospital boards of directors and employees (n = 6). About half of the group were Dutch, and others were mainly from the USA, the United Kingdom, Canada, and Australia. See table 2 for details. The Delphi questionnaires started July 2017 and ended October 2017.

**Table 1** Categories of gray literature items

| Category | No. of items |
|---|---|
| Tools aimed at human resource management | 13 |
| Tools aimed at advising or participating in decision-making within the organization | 13 |
| Tools for gathering patient experiences | 10 |
| Tools for family participation | 10 |
| Tools used during hospital admission | 7 |
| Tools used in an outpatient clinic or before hospital admission | 7 |
| Tools directed at general policymakers or board of directors | 9 |
| Other tools | 4 |
| Total | 73 |

**Table 2** Respondent demographics

| | Round 1 | Round 2 | Round 3 |
|---|---|---|---|
| N (% response rate) | 36 (63%) | 28 (65%) | 32 (74%) |
| Ratio men/women | 9/27 | 7/21 | 7/25 |
| Profession | | | |
| Medical doctor | 1 | 1 | 4 |
| Researcher | 10 | 8 | 8 |
| Teacher/professor in medical domain* | 6 | 5 | 5 |
| Professor (research)* | 6 | 5 | 5 |
| Hospital policy consultant | 4 | 3 | 5 |
| Independent healthcare consultant | 4 | 2 | 2 |
| Member board of directors | 0 | 1 | 0 |
| Patient (representative) | 6 | 6 | 5 |
| Country of residence | | | |
| The Netherlands | 20 | 15 | 15 |
| United States of America | 4 | 3 | 6 |
| Australia | 4 | 4 | 3 |
| Belgium | 2 | 2 | 2 |
| United Kingdom | 3 | 2 | 3 |
| Sweden | 1 | 1 | 1 |
| Germany | 1 | 0 | 1 |
| Canada | 1 | 1 | 2 |

* several respondents indicated multiple professions and were assigned to their first answer

In the first round, 36 out of 57 experts responded on how useful the items were in improving family and/or patient participation. Results led to the exclusion of 24 items and inclusion of 45 items (see figure 1). Four items were open for discussion based on their scores, and five items were added by respondents. The remarks

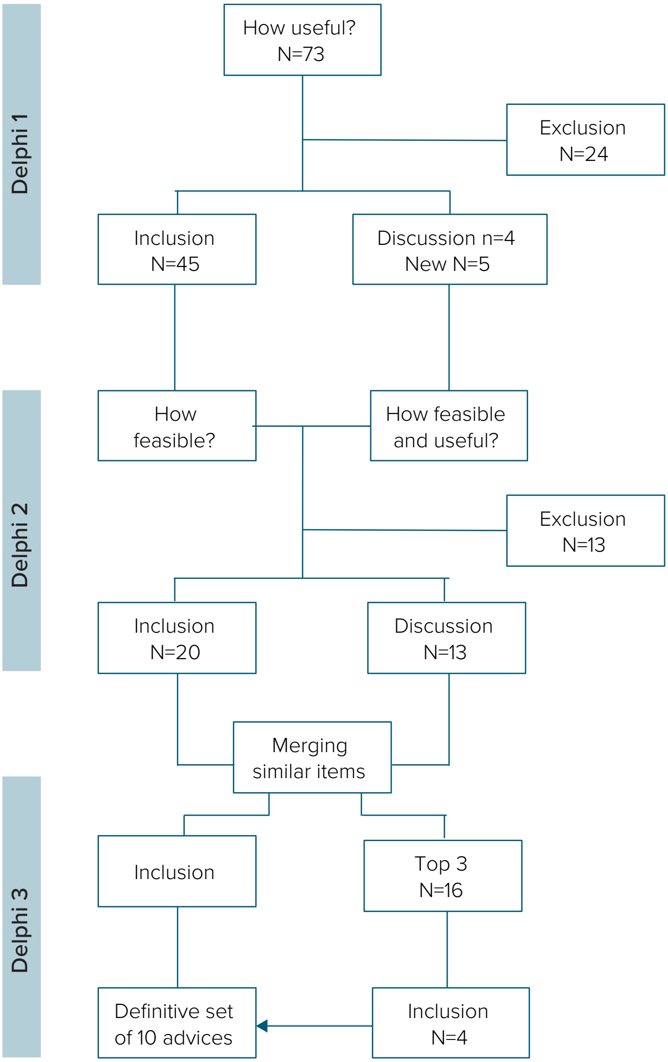

**Figure 1** Flowchart Delphi study

made by respondents were used to lead the discussion on the new and discussable items, leading to the inclusion of these items in round two. In the second round, 43 questionnaires were sent out, and 28 experts responded.

They were asked to comment on the feasibility of the 45 included items and to reconsider the usefulness and feasibility of the discussion and the newly added items. This lead to an inclusion of 20 items, exclusion of 13 items, and discussion of 13 items. All included and discussion items were reviewed by the project group to examine for overlap or mergeable items. Of the 33 items, 26 could be summarized into six more general best practices. For example, the different methods of gathering feedback from patients and family were summarized into "Continuously gather feedback from patients and their families." In the third round, 43 questionnaires were sent out and 32 experts responded. Respondents were asked to review the 26 excluded and discussion items and choose the top three items which would be a positive and feasible challenge for their hospital in the near future. This led to a clear preference for four items, which were added to the six already included ones. The ten final recommendations with corresponding actions are displayed in table 3.

## Evaluation

One year after these best practices were developed, in October 2018, their uptake and usability was evaluated. Six of the seven academic hospitals participated in this evaluation (see table 4).

The practices that were best implemented according to hospital representatives were gathering of continuous feedback (median: 7 out of 9), patient representatives in councils and committees (median: 8), participation in the hospitals' vision statements (5x yes), structural budget for participation (6x yes), boards of directors attending patient council meetings (5x yes, 1x don't know), having EHRs (6x yes), and patient access to EHRs (6x yes). The patients' use of the files, however, was scored a median of 3.5. Challenges consisted of the following: patient participation in human resource management (median: 1.75), participation in yearly staff training (median: 2), discussion of participation preferences upon admission (median: 4), and invitation of patients and family to take part in multidisciplinary consultations (median: 4). Respondents scored the guidelines' helpfulness in improving patient participation with a median of 7.5. Answers on requirements to further improve participation could be grouped into four categories: health care professionals' education, hospital policy and leadership, general support resources (tools and time) for health care professionals and implementation, and involvement of patients in education and research.

**Table 3** Final selection of best practices

| Best practice | Advice |
|---|---|
| 1. Gathering continuous feedback from patients and their families | The five ways to gather patient and family experiences are as follows: explicitly inviting patients and family to share their experience or feedback, the storytelling method, the patient journey, observations of delivered care with patients, and experience-based co-design in quality improvement initiatives. An important note from experts is that these experiences should not only be gathered but also acted upon, and department heads should be able to report to both their boards of directors and patients what actions followed the feedback. |
| 2. Use of shared decision-making tools in discussing treatment options | Shared decision-making is regarded as vital for the quality and safety of care and assumes two-way communication to assess and incorporate patients' wishes and preferences in decisions on treatment courses. Prerequisites for effective shared decision-making are education and training of health care professionals and supplying them with shared decision-making tools. Special attention should be paid to patients with low health literacy. |
| 3. Discussion by nurses of the patients' needs and their families' wishes to participate upon admission | Patients and families' wishes, and opportunities which might be unknown to them, should be discussed and registered soon after hospital admission. This sends a clear message that participation is stimulated and expected whenever possible and indicates to families that their participation is valued. |
| 4. Family and patient participation in Human Resource Management | Valuing and stimulating patients to participate in care should be the goal of all hospital employees. The importance of participation should therefore be emphasized during job applications, and attitude, actions, and progress should be discussed during annual job evaluations. This places expectation and responsibility with the professionals and shows managerial leadership in promoting participation. |
| 5. Patient representatives in hospital councils and committees | As patient participation should be enacted on all levels of the organization, it is important to include patient and/or family (representatives) in hospital councils and committees such as ethical committees, quality and safety council, safety rounds, moral deliberations, and hospital construction committees. It requires also an active patient council advising the board of directors. They should receive training and financial compensation to be active and full participants. |
| 6. Self-evaluation by boards of directors | Commitment by board members to clear and strong policy around participation results in successful and lasting change in the organization. The following items have been identified as important actions in this process and should be used as self-evaluation on a boards' own level of patient- and family participation efforts: the hospital having a strategic plan to increase participation, describing a commitment to participation in the hospital mission statement, providing clear instructions on or examples of how to enact participation in daily care, retaining room in the financial year plan to support participation, board members' attending the patient advisory group meeting at least once a year, and department managers' being responsible for their departments' participation activities. |

| | |
|---|---|
| 7. Use of an electronic patient file | Insight into their own medical information is crucial in improving patients' control over their health. Although patients have a legal right to access their own medical records, requests for access are often met with a lack of understanding from professionals. When access is made standard care, patients are better informed about their own personal health, leading to more in-depth conversations with their health care professionals and more insight into disease progression. Another advantage is that patients can be given access to add their own health information, such as at-home blood pressure measurements, to their records. |
| 8. Hospital staff's attending a yearly training in which patient and family participation is explicitly incorporated | In current practice, participation is not part of standard policy, and it has only recently been added to nursing and medical curricula. Most health care professionals, therefore, do not receive education on effective communication or participation in their hospitals. If it is expected that coaching patients into participation is part of their basic skill set, it is vital that all health care professionals receive structural education to build and maintain these skills. Training should incorporate the following: awareness of their own barriers, how to stimulate participation during the different phases of the treatment process, how to stimulate participation within different patient demographics such as patients with low literacy or different cultural backgrounds, communication skills, and the consequences of ineffective communication strategies. |
| 9. Patients and their families' being invited to take part in multi-disciplinary consultations | Patients and/or their families should be actively invited to be members of the health care team and decide the manner in which they wish to participate. This requires patients to have access to important information on their conditions and treatments, and patients with low health literacy should receive tailored help to empower them to participate. This requires health care professionals to treat their patients as their partners in treatment and assume coaching roles. |
| 10. Patients and their families' participating in bedside rounds and bedside shift handover | Having day-to-day care planning and decision-making with the patients enables them to be informed and involved in the care process. The biggest opportunities lie within the daily medical ward rounds and nurses' handovers, which should both take place at the patients' bedsides. It is important to adjust (non)verbal communication to the patients' levels and abilities to actively invite the patients' involvement in the conversation. |

**Table 4** Evaluation questionnaire

| | Median (range) | Yes/no/ don't know | N |
|---|---|---|---|
| To what extent are the following items of the guidance implemented in your hospital? | | | |
| Gathering continuous feedback (1 = not at all, 10 = everywhere in the hospital) | 7 (6–8) | | 6 |
| Shared decision-making tools (1 = not at all, 10 = everywhere in the hospital) | 5.5 (4–7) | | 6 |
| Discussion by nurses of participation at admission (1 = not at all, 10 = everywhere in the hospital) | 4 (2–7) | | 5 |
| Human resource management (1 = not at all, 10 = everywhere in the hospital) | 1.75 (1–5) | | 4 |
| Representatives in councils and committees (1 = not at all, 10 = everywhere in the hospital) | 8 (6–9) | | 5 |
| Self-evaluation by boards of directors | | | |
| Does your hospital have a strategic plan to improve patient and family participation? | | 4x yes<br>2x no | 6 |
| Does the hospital's vison on care describe the importance of patient and family participation? | | 5x yes | 5 |
| Does the board of directors have a budget to support patient and family participation? | | 5x yes<br>1x no | 6 |
| Do members of the board of directors join the patient council meeting at least once a year? | | 5x yes<br>1x don't know | 6 |
| Does the board of directors discuss efforts toward patient and family participation during quarterly performance reviews with departments? | | 3x yes<br>2x no<br>1x don't know | 6 |
| Electronic health record (EHR) | | | |
| Does the hospital use an EHR? | | 6x yes | 6 |
| Can patient access their own EHRs? | | 6x yes | 6 |
| To what extent do patients use/view their EHRs? (1 = none, 10 = all patients) | 3.5 (3–7) | | 5 |
| Yearly staff training (1 = not at all, 10 = everywhere in the hospital) | 2 (1–6) | | 5 |
| Involvement in multi-disciplinary consultations (1 = not at all, 10 = everywhere in the hospital) | 4 (3–5) | | 5 |
| Participation in bedside rounds and shift handover (1 = not at all, 10 = everywhere in the hospital) | 5 (3–8) | | 5 |
| How much did the guideline help you to improve patient and family participation? (1 = not at all, 10= very much) | 7.5 (4–8) | | 5 |

## Discussion

This study aimed to give guidance to hospital boards of directors to improve and monitor their activities regarding patient participation in care. A list of 10 interventions on the micro, meso, and macro levels was developed using a Delphi study method with national and international experts. This guidance was then disseminated in all academic hospitals in the Netherlands by the Netherlands Federation of University Medical Centres (NFU). A survey a year later amongst the university hospitals showed that several of its preconditions for participation had been met or actions for improvement undertaken, such as hospitals indicated gathering feedback and having a hospital vision and budget for participation, EHRs, and patient representatives in councils and committees. Most respondents indicated the guidance had helped achieve this. However, looking at the different organizational levels, some remarks are to be made.

At the micro level, challenges consist of participation in multidisciplinary consultations, with bedside rounds and nurse hand-over, and discussion of needs and opportunities for participation upon admission. Also, integration of participation in yearly staff training was scored insufficiently. This indicates that although there is vision and effort from boards of directors, there is work to be done in the actual delivery of patient and family participation in care. For participation to reach the bedside, particular attention should be paid to design and implementation, as the presence of these items does not automatically lead to participation. For example, all hospitals indicated that they used EHRs and offered patient access. However, EHRs in themselves are only a precondition for participation as involvement is not fostered simply by allowing patients access to their health records. Real involvement of patients within EHRs requires more efforts. First, patients need to be involved in an early stage of the development of the EHR to ensure the design is as simple, unambiguous, and clear as possible.[13] Implementation should also account for factors known to negatively impact EHR uptake by patients, such as age, gender, ethnicity, educational attainment, and number of comorbidities.[14] Also, solutions are needed for presenting and communicating health data as patients have difficulties understanding medical terminology used in lab reports, doctor's notes, and other content.[15] Patients need further guidance on how to access and navigate EHRs and how to interpret their own data. In our study, for example, use of EHR patient portals only scored a 3.5 out of 9. Policy, EHR developmental teams, and healthcare professionals need to be aligned to encourage patients to use EHRs to be involved and well prepared for their consultations and be active participants in contact with their care professionals.

The use of shared decision-making (SDM) tools is placed at the maso layer, and scored sufficiently at a 5.5 out of 9. SDM as indicated in this study, was specifically used to make choices regarding treatment options in physician-to-patient consultations. However, in a broader sense, SDM can be practiced by all health care professionals, especially by nurses, who can and must play a vital role in integrating patients' values and needs in the SDM process.[16] Truglio et al. (2018) have defined prerequisites for successful SDM and for involving patients in care. These prerequisites include working on a mutually trusting and respectful relationship where patients are invited and encouraged to participate, as patients who feel trusted and respected are more open to sharing information with their health care providers. Another prerequisite is mutual information exchange, involving active listening and readiness as well as receptiveness to explore patients' feelings and preferences, creating a sense of compassion instead of a more authoritarian approach and helping patients to reflect and gain insight into the issues at hand. A third prerequisite is a context that facilitates SDM and participation for both patients and health care professionals.[17] Patients, for example, who are accompanied by family members are more likely to engage in SDM. The participation of health care professionals, meanwhile, needs to be facilitated by time and access to resources.[17] Helpful tools include digital engagement applications such as electronic registries, automated risk prediction algorithms, automated decision support tools, and natural language processing.[18] Within SDM, there should be awareness of the patient's values and beliefs as they impact the patient's beliefs about SDM and the value placed on SDM.[17] It is clear that these are complex competencies that need to be trained and maintained, as indicated in the meso layer of the guidance. However, the evaluation in this study shows that yearly staff training on participation is poorly implemented. It is a common misconception that health care professionals already possess sufficient skills for effective patient-centered communication and tailoring care to the patients' needs. It has also been shown that nurses overestimate their own level of participatory care when compared to their patients' views,[19] underlining the importance of governance on providing staff with the necessary education.

The macro level relates to hospital policy and is connected to the items focusing on patient participation within human resource management, patient representation in boards and committees, the self-evaluation items for a board of directors, and the use of an EHR. The literature indicates that on a European scale, patient engagement is rarely seen in quality improvement management such as developing quality criteria, participating in quality committees, or discussing the results of quality improvement projects.[20] Our results show that hospital boards need to communicate and promote strong person-centered visions and show exemplary behavior themselves. This is also emphasized in the literature, which indicates the impact hospital leadership has on culture and quality management,[21] making its commitment imperative for success. This can be achieved by making patient and family participation an obligatory subject for hospital divisions to work and report on. This can increase participation as studies show an association between discussing quality performance at executive board meetings and quality compliance and clinical quality implementation.[22]

Respondents in our study chose from all 73 items, which were not presented in organizational levels. It is noticeable that respondents collectively decided all three levels, micro, meso, and macro, were necessary to make a change. Groene et al (2009) have shown a positive association between well-established quality improvement systems and the implementation of patient-centered strategies. These associations, however, seemed weaker at the ward level than at the hospital level.[23] It is therefore important to put vision into action at the patient level as our study shows that the items aimed at the micro level scored insufficiently on current practice. The risk lies within leadership being confident in their efforts for improvement while bedside practice is lagging. This is supported by Groene et al (2009), who reported that hospital policy makers claimed to have strategies ensuring patient privacy but that when checked with health care professionals at the same hospital, this was much less frequently answered affirmatively.[23]

We acknowledge that this study took place before the COVID-19 pandemic, which posed great challenges for health care organizations and their efforts toward patient participation. While some person-centered care activities, such as telemedicine, have seen an enormous uptake in the last three years,[24] the struggles felt by both patient and health care professionals due to COVID-19 restrictions have resulted in an enormous setback of patient and family participation.[25,26] This however emphasizes the ongoing need for compassionate, person-centered care, and advocacy for patient and family participation.

## Summary and Limitations

This study has developed guidance for hospital policy makers on how to improve and focus their efforts to encourage patient and family participation on the micro, meso, and macro levels. As the literature mainly consists of best practices, the use of the Delphi method is a strength of this study. Through expert consensus, this reduced the wide range of advice and best practices into a clear and short list of advice on how to best focus action. Both Dutch and international respondents made results applicable for international use. Another strong point is the evaluation after a year, showing that the guidance is usable in practice and has been well received.

Some limitations on this study are to be noted. First, the guidance is aimed at the boards of directors of academic hospitals, but only one member of a board participated in the study. Participating respondents, however, were experts in the field and gave their opinions based on their knowledge and experience within hospital settings. Second, the project group made two reductions in the set of items to eliminate overlapping concepts or summarize them into a bigger category. This was done before the first questionnaire and after the second. Following the Delphi method, these could have been evaluated by the respondent for better verification of the results. However, the project group did this independently, rating each item, and the group results were discussed until consensus was reached before progressing into the next questionnaire round. The researchers considered the risk of bias smaller than the risk of respondents opting out because of the questionnaire's being overly time-consuming and repetitive. Third, the guidance was released in the Netherlands without a baseline measurement or implementation by the project group as this was out of the scope of this study. An in-depth comparison before and after the release of the guidance on its use could not be made, aside from the hospitals' indicating the usefulness of the guidance after its implementation.

## Conclusions

This study showed that successful patient and family participation in hospitals requires sustained effort and dedication by boards of directors, policy makers, and health care providers. The created guidance can be used to assist boards of directors to best direct their efforts on different organizational levels; however, ongoing budget and educational opportunities must be allocated to help frontline workers integrate participation in their daily practice. Further research on improving patient and family participation in hospitals can follow up on this study by (1) testing the effectiveness of items in the guidance, (2) looking into appropriate implementation strategies of the items, and (3) by establishing process and outcome indicators for health care providers, policy makers, and patients on the current state of patient participation and identifying opportunities for further improvement.

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# 7

# General discussion

In this thesis we studied patient participation using quantitative and qualitative methods. We tailored and tested a complex intervention to improve patient participation during hospital admission, provided insight in how person-centered care is practiced, and how experiences between nurses and patients differ. Finally, this thesis gives direction for how patient participation in hospitals is best enacted. These studies confirmed the importance of person-centered fundamental nursing care and how crucial the nurse-patient relationship is. We have also seen that patient participation in care remains challenging to implement.

In this chapter we reflect on the main findings, considerations regarding the theoretical and methodological choices and implications for clinical practice, education, policy-making and future research.

## Main findings

This thesis started after the identification of the Tell-us Card as a promising intervention to improve patient participation in nursing care. As it was regarded a complex intervention, the steps of the Medical Research Council (MRC) were followed to systematically tailor and test the Tell-us Card before its implementation in the Dutch hospital setting. See Addendum 1 for the final Dutch Tell-us Card layout.
First, we tailored the Tell-us Card to the Dutch hospital setting using Intervention Mapping (chapter 2). Knowledge, attitude, outcome expectations, self-efficacy and skills were identified as the main determinants influencing the use of the Tell-us Card. Linking identified determinants and performance objectives with evidence-based behavior change techniques resulted in a well-defined and tailored intervention and evaluation plan. To test the feasibility and early-effectiveness of the Tell-us Card, a pilot study was carried out (chapter 3). The data of 265 patients showed a significant increase at one of the two intervention wards. The majority of patients regarded the intervention as beneficial, and analysis of the Tell-us Card content showed many care elements of the Fundamentals of Care Framework being mentioned, with most patients indicating psychosocial needs. Nurses however experienced barriers with incorporating the Tell-us Card into daily care. They indicated that they did not think the Tell-us Card was helpful as they felt it was of too little additional value, was time-consuming, and they struggled with patients not knowing what to write down. Nurses stated to expect their patients to speak up and to prefer face-to-face conversation instead of using a card. Therefore, although the Tell-us Card did show a significant early effect and patients were positive about it, integration in daily nursing care appeared to be complex and the intervention was deemed not-feasible in its current form (chapter 3).

Therefore, as the MRC framework advises, we returned to the developmental phase to conduct empirical work to investigate how the deliverers and recipients of the intervention behave in order to construct a theory of behavior change appropriate for the planned intervention.[1] Chapter 4 describes how we compared the perceptions of 845 patients and 569 nurses on individualized care, and explored the association between these perceptions and various variables. Nurses and patients had received an identical questionnaire (the Individualised Care Scale) during the Tell-us Card pilots and other studies on patient participation in the Netherlands and Belgium. Results show a significant difference between nurses and their patients, with nurses (mean 4.24) scoring their level of supporting individuality in nursing activities significantly higher ($p < 0.001$) than patients (mean 3.66). Significant associations were found between patients' higher perception of individualized care and a longer hospital stay, an educational level below bachelor, higher health literacy, and higher empowerment scores. Dutch patients rated the experienced level of individualized care significantly higher compared to patients from Flanders. For nurses, there was a significant association between a higher perception of individualized care given and a higher number of years of work experience and higher age, and for those working on maternity wards, those working in a regional hospital, and those working in the Netherlands.

As we noticed that nurses' view on how they enact person-centered care did not fully correspond with actual practice, we observed patient care on hospital wards (chapter 5). We identified that some nurses were able to work in a person-centered way by combining physical, psychosocial and relational elements of care. They appeared to do this within the same care activities and timeframe as their colleagues who had a more task-focused way of working and communicating. This study gave insight in how this impacted the quality of care, hindering patient participation and showing less signs of clinical reasoning on the patients' signs and symptoms during these encounters.

These results led to taking in a broader view on what might be necessary to improve patient participation in hospitals, as the influence of context is emphasized as important in both the MRC[2] and the Fundamentals of Care[3] framework. Chapter 6 describes the development and evaluation of a best practice guidance for hospital managers on how to enhance patient and family participation. Results showed that international experts deemed it necessary to undertake action on all levels, from best practices for bedside professionals to policy making, and actions from the board of directors. An evaluation one year later showed that the developed guidance was regarded useful in directing efforts to improve patient participation, and that several best practices even had been implemented.

See table 1 for a summary of the main findings of all studies.

**Table 1** Thesis overview

| | Chapter 2 | Chapter 3 |
|---|---|---|
| **Study** | Tailoring of the Tell-us Card to the Dutch hospital setting using the Intervention Mapping method. | Piloting the feasibility and early effectiveness of the Tell-us Card with a cluster randomized controlled pilot study on in four hospital wards. |
| **Data** | Needs assessment through 12 interviews with nurses, 25 interviews with patients, 3 focus group interviews with nurses. | Early effectiveness: questionnaire data of 128 intervention ward patients, and 147 control ward patients.<br>Feasibility: questionnaire data of 56 intervention wards nurses, and 158 Tell-us Cards. |
| **Main findings** | - Identified barriers and facilitators are combined with fitting behavior change objectives for optimal implementation<br>- Nurses and patients regard the Tell-us Card to be a feasible tool<br>- Needs assessment indicates a difference in view on patient participation by nurses and patients. | Early effectiveness:<br>- Significant change in one of the questionnaires in one intervention ward.<br>Feasibility:<br>- Patients indicate that the Tell-us Cards is helpful.<br>- Tell-us Card content showed most elements of the Fundamentals of Care Framework, with the need for psychosocial care most often mentioned.<br>- The Tell-us Card was deemed not feasible by nurses, mainly because of their lack of time and the patient's unfamiliarity with being an active participant.<br>- The Individualized Care Scale seems a feasible questionnaire for follow-up research, the Quality from the Patients Perspective does not because of positively skewed results at baseline. |
| **Implications** | - The Tell-us Card is deemed feasible resulting in progression to the piloting phase of the MRC model.<br>- Intervention Mapping is an extensive method to ensure a thorough developmental phase. | - The Tell-us Card shows signs of effectiveness on experienced patient participation and is valued by patients. It is however experienced as not feasible by nurses in practice. This leads to returning to the developmental phase of the MRC model. |

**Table 1** Continued

| | Chapter 4 | Chapter 5 | Chapter 6 |
|---|---|---|---|
| **Study** | Comparing patients and nurses’ perception of person-centered care and exploring if various variables are associated with these perceptions. | Exploring how nurses in hospitals enact person-centered fundamental care. | Developing a best practice guidance for hospitals to enhance patient and family participation, and evaluate its use. |
| **Data** | Questionnaire data of 845 patients and 569 nurses in Belgium and the Netherlands.<br>Nurses and patients received the same questionnaire. | Observations of 30 nurses on three hospital wards during morning care delivery.<br>Observations lasted 2.5 to 3 hour each. | - Results of a three-round modified Delphi study with 36 international experts on patient and family participation.<br>- Questionnaire on usability and uptake after a year |
| **Main findings** | - Nurses score their level of person-centered care provided significantly higher than patients did.<br>- Significant association between a patients’ higher perception of individualized care and: longer hospital stay, educational level lower than bachelor, being admitted to a Dutch hospital, higher health literacy, higher empowerment.<br>- Significant association between a higher nurses’ perception of individualized care and: more years or work experience and higher age, working in regional hospital, a maternity ward, or a Dutch hospital | - Most nurses are focused on physical care, and have a task-focused way of working and communicating.<br>- Some nurses successfully combined physical, psychosocial and relational elements of care in their interactions.<br>- Nurses often interrupt each other’s care process, in which patient privacy is often not taken into consideration. | - A guidance of 10 interventions on micro, meso and macro level of a hospital was developed.<br>- After a year six out of the seven academic hospitals in the Netherlands have implemented several best practices<br>- The guidance was deemed helpful in improving patient and family participation. |

**Table 1** Continued

| | Chapter 4 | Chapter 5 | Chapter 6 |
|---|---|---|---|
| **Implications** | - Nurses' perception of providing more individualized care as compared to their patients might be a major barrier in implementing person-centered care.<br>- Patients with low health literacy and empowerment experience lower individualized care and therefore need extra attention | - Person-centered care is a prerequisite for integrated fundamental care.<br>- Person-centered care does not take up more time or resources<br>- A lack of integrated fundamental care seems to hinder the nurse in effective clinical reasoning. | - Successful patient and family participation in hospitals requires sustained effort and dedication by boards of directors, policy makers, and health care providers<br>- ongoing budget and education must be allocated to help frontline workers integrate participation in their daily practice |

## Reflections on main findings

### Patient participation

The findings of this thesis describe a challenging view on practice: nurses indicated that the intervention to facilitate patient participation was of little added value, preferring a face-to-face conversation, and questionnaires show that nurses rate their own skills in providing individualized care as high. This might indicate that nurses do not need support in patient participation. However, their opinion differs significantly from their patients who rate the individualized care received as lower, and observations showed that most nurses did not use person-centered communication during fundamental care delivery. This leads to examining what barriers were experienced when piloting the Tell-us Card and what they teach us.

### Tell-us Card barriers

To start, the appropriateness of the Tell-us Card as a tool to facilitate participation is debatable, as other research groups who have attempted feasibility studies on the intervention have had similar results to our study. Research groups in England[4] and Belgium[5] have also tested the Tell-us Card using the same outcomes, and both groups did not find any significant effects and experienced multiple barriers. They encountered similar difficulties (chapter 3), such as nurses not following up study protocol, [4, 5] and nurses experiencing time constraints. [4] A lack of time is an often-named barrier in studies on patient participation. [6-8] However, we also learned that (chapter 5) person-centered communication during care might not take more time, and in the end might be timesaving. Nurses often work under an almost always present and not to be underestimated pressure, and need to make choices when work pressure is too high. [9] Communication, education, care and discharge planning, decision-making, and emotional and psychological care have been reported as most frequently omitted care activities. [10, 11] On the other hand, it was reported that psychosocial care aspects were seen to be left undone also when nurses did have the time. [12] This suggests a separation between physical care tasks and psychosocial care in practice, seeing communication or psychosocial care as a stand-alone act, instead of the proposed integrated care as described in the fundamentals of care framework. [13]

Our studies have shown several barriers when using the Tell-us Card, such as a lack of insight into the meaning of patient participation (chapter 3), and a task-focused way of working and communicating (chapter 5), which have been also described as hindering in various other studies on patient participation. [14, 15] Also a need to maintain control and a reluctance to engage in in-depth conversations by nurses are described as barriers to participation. [16-18] Both other Tell-us Card studies experienced skepticism by nurses, with nurses believing they were already providing person-centered care, finding the Tell-us Card too formal, and perceiving it as an unnecessary addition to something that is already routinized care. [4, 5] This leads to the thought that nurses who generally do not have a person-centered approach to care might have experienced the Tell-us Card and facilitating participation as a task to perform instead of a manner of communicating and collaborating with patients.

## Nurses' view on participation

Sahlsten et al. (2008) defined patient participation in nursing care as an established relationship between nurses and patients, a surrender of power or control by the nurses, shared information and knowledge, and active engagement together in intellectual or physical activities. [19] Nurses in our study mainly described and showed participation as informing the patient (chapter 2, 3 and 5). Research shows that hospital nurses are intrinsically motivated for patient participation, [7, 20] but especially in more acute situations, patient participation seems to be omitted more easily, [21] with nurses indicating that they are the experts in the situation which complicates participation. [8] Patients in acute care however experience a lack of communication on what was happening to them in the acute phase, and missed information on how to initiate lifestyle changes in their everyday life or medication before discharge. [22]

The discrepancy between how patients experience participation and how it is delivered by nurses is often described. [23, 24] Research shows that nurses in general feel confident about their communication skills in promoting patient participation, [25, 26] but that patients view communication often as disconnected and inadequate[27, 28] and that nurses are seen to limit or even avoid communication. [17] A recent review (2022) shows that nurses often dominate the communication and focus on treatment and much less on psychosocial issues. [29] When asked what hinders patient participation, nurses indicate to use a pragmatic perspective to prioritize the fixed daily structure of the day instead of integrating patients' needs. [30] In this study of Bahlman-van Ooijen et al. (2022) nurses indicated that they got questioned by colleagues when they had not completed all their tasks at the end of their shift, even though this occurred because of their patients' preferences. The work and cultural pressure with respect to task completion was considered by nurses as barriers to show leadership behavior and enhance patient participation. [30]

## Patients' view on participation

This thesis shows that patients appreciated the Tell-us Card (chapter 3) and felt that they were able to use it to indicate their needs. Several studies on patient participation indicate that patients are much willing to participate in their care, [31] and that they feel able to do so. [32] One study found that patients consider question prompt lists and information on how to prepare for their care appointments and communicate in them as supportive to participate in care. [32] In the English Tell-us Card study, patients indicated that they were very aware of the nurses' time constraints, and that their willingness to ask for support was influenced by how nurses interacted with them. Patients would make fundamental care requests to nurses who appeared engaged and actively encouraged patients to ask for support. However, nurses were often described as distracted or disengaged. [33] Patients' participation is affected by how nurses communicate with them, with patients using a more active communication style when nurses are positive, empathetic or prosocial. [29]

Participation needs to be tailored to the person, depending on their skills and abilities, which may differ within one person between moments. Nurses in our study (chapter 3) have been seen to choose which patients they actively invite to participate, as is also described in literature. [5, 34] This mechanism will most likely negatively impact persons with challenges in participation, such as low literate patients[32] or people experiencing language barriers. In the Dutch population, it is estimated that 2.5 million, or 1 in 6 people, are low literate. [35] This is an enormous part of our patient population who are challenged in reading, writing and/or calculus, and often have lower health literacy skills.[36] These lower health literacy skills are associated with a range of poor health outcomes, such as being less healthy, less able to deal with chronic diseases, less knowledge about health and having difficulties reading information on medicine packages or hospital forms.[36] A Dutch study showed that when people are not sure about their understanding of medical terms, they were also less confident about interacting with a care provider.[37] Therefore, they are placed at an extra disadvantage when nurses also decide not to invite them to participate.

### Moving forward

The most important barrier to successful implementation of patient participation seems to be the nurses' attitude, knowledge and skills related to patient participation and creating a person-centered relationship. Nurses underestimating their own competencies is a complicating factor herein. Current advice on what actions need to be undertaken at the individual nurses' level is: training nurses in participation-enabling communication skills,[17, 38, 39] debunking nurses' misconceptions about patient participation,[40] and involvement of nurses and patients throughout the changing process.[39]

It seems that person-centered fundamental care is a step-wise development. First, as we have seen that the nurse-patient relationship is the basis for person-centered care, nurses need to be trained in establishing this relationship. Then, these person-centered skills can be applied in fundamental care delivery in order to achieve integrated care. Research and quality improvement might therefore not be aimed at using an intervention such as the Tell-us Card where participation might be recognized as a solitary care activity, but person-centered care and participation need to be addressed as an attitude and more general approach to care.

## Person-centered care

We have seen that even though nurses struggle with patient participation, they generally are compassionate (chapter 5) and get joy in work from being able to do something meaningful for their patients.[41] Research shows that when nurses are able to work in a person-centered way, this not only increases quality of care but also the nurses' job satisfaction[42, 43] and is associated with lower burn-out rates amongst nurses.[43, 44] The lack of a focus on person-centred fundamental care in most nurses can be explained by healthcare systems which are increasingly focused on task completion, outcome evaluation and benchmarking,[13] and by the pressure on nursing care from shorter admission times and increases in older patient with complex care requirements. [45] Chapter 6 of this thesis therefore focusses on the context; efforts to be undertaken to ensure that person-centered care can be enacted, since behavior change is imperative because of the challenges the nursing profession is facing in the coming years.

## Person-centered care and health technology

Next to the need of developing relational skills as we have discussed in the previous paragraphs, this brings attention to the nurses' work environment and the support this offers to providing person-centered care. A main recommendation to increase participation in care from chapter 6 is the use of patient-accessible electronic health records (PAEHRs). The use of medical technology and information and communication technology (ICT) is rapidly increasing in healthcare, aiding mostly patients with chronic conditions by for instance monitoring body measurements and symptoms, and interacting with their healthcare providers. Studies show that this has a positive impact on patient empowerment and health-related quality of life. [46] An example is remote monitoring, where patient reported symptoms can be collected between visits provides opportunities to aid decision-making and have the potential to make care more person-centered. [47] Also PAEHRs are seen as a positive influence on person-centered care as a means of patient empowerment, supplying information and patient involvement. [48] The (PA)EHR also provides opportunities for nurses be guided through new person-centered ways of gathering patient information in admission interviews or discharge planning, and using patient reported data in their care provision. However, research also indicates that patient data in a (PA)EHR is not yet structured in a way which aids person-centered care[49], and that there is a need to better organize, manage, and display information in the EHR for health care providers to facilitate decision-making.

## Future proof nursing and person-centered care

With the current challenges in providing healthcare in our (aging) population with complex health conditions and the alarming shortages of nurses, a recent report on "Passende zorg" lists actions to ensure the Dutch quality and safety of care. [50] Key point in regard to this thesis is that health care professionals will need to approach patients in a more person-centred way, helping them decide what care fits best. Nurses can do this by supporting patients to make informed decisions, acting as a patient advocate, and reconciling different perspectives between the patient, their family and healthcare professionals.

Shared decision-making (SDM) is a well-known manner of involving patients in care and one of the key action points in keeping the Dutch healthcare system sustainable. SDM usually refers to medical care, but can be practiced by all health care professionals and especially by nurses, who can and must play a vital role in integrating patients' values and needs in the SDM process. [51] SDM for nurses is described to have communication and relationship-building as the foundation. Within SDM this is specified as building a trusting and respectful relationship where SDM is invited and encouraged, creating a partnership where there is collaboration and a sharing of power, bi-directional communication and exchange of information, while taking both the patients context and nurses' work environment into account. [52] As this thesis indicates that most nurses' communicational and relationship-building skills need improvement for enhanced patient participation in a challenging work environment, it is crucial for a future proof workforce and healthcare that these skills are trained.

Research does show that person-centred care interventions are difficult to implement in practice. Both small-scale interventions in nursing care as the Tell-us Card, but also big, national campaigns such as the "Samen Beslissen" campaign have shown very little improvement in shared decision-making. [53] It is therefore imperative that - next to generating new insight in advancing nursing practice - new knowledge is effectively implemented in care, and unnecessary care de-implemented. The second key point from the "Passende zorg" report in relation to this thesis is choosing for value-based care to account for financial and health care staff sustainability. An important task in the coming years is to view the effectiveness of our care more critically by creating and implementing outcome measures that reflect the efforts put into fundamental care. Nurse-sensitive outcomes are increasingly recognized as important ways to measure the effects and quality of nursing care. Currently, most quality of nursing care indicators are process or outcome indicators, and rarely reflect fundamental care. [54] Nurse representation on steering committees of the quality databases increased the likelihood of indicators related to aspects of fundamental care being included threefold. Routine recording of process indicators of nursing care also makes nursing and its' contribution to healthcare outcomes immediately visible to decision makers, thereby placing the quality of nursing on decision makers' agenda. [54]

## Moving forward

Evidence suggests that nurses in strategic leadership positions as well as ward or hospital management advocating the need for person-centered fundamental care and patient participation are necessary to really make a change towards a more patient-centred care [30, 55] Improvement of clinical practice might benefit from specifically targeting clinical academic nurses to role model person-centered care and integrate this in their own quality improvement projects and/or research as they are drivers of change by bridging the gap between science and practice.

However, recent research amongst nurses with a bachelor and master's degree shows that only few could describe how they could use leadership skills to be that role model for patient participation themselves.[30] Therefore, dedicated leadership together with skilled clinical academic nurses should encourage and support nurses to reflect on their attitudes and ways of working to increase person-centred care.

## Methodological considerations

We decided to conduct a thorough developmental phase using the Intervention Mapping (IM) methodology, as advised by Craig et al.[56] IM was the right fit for this project, as it is a method which increases the ability to map strategies to specific barriers and facilitators of implementation, with a particular focus on the mechanisms and methods that will bring about the needed changes. IM created several opportunities for stakeholder engagement in the tailoring of the Tell-us Card. However, with progressing insight into patient participation, follow-up research can benefit from more patient engagement in the form of co-creation.

Other approaches or frameworks to shape the developmental phase of the MRC framework are described in guidances by Bleijenberg et al.[53] and O'Cathain et al.[57] or alternatives such as the Utrecht intervention model[58] or the Behavior Change Wheel.[59] Although we have experienced the IM methodology as a good basis for our pilot, the choice for one of these other frameworks or methods probably would have led to similar components as they all share stakeholder engagement, needs analysis and using evidence-based behavior change methods. The most important lesson learned is the benefit of a thorough developmental phase on being very explicit about designing, planning and evaluation health care interventions to reduce research waste. Further, looking at the updated MRC framework[2] and the insight we have gained about person-centered care, the developmental and piloting phase in this thesis might have benefited from a wider scope beyond the nurse and patient, and take more consideration of the context of care.

## Implications

The findings of this thesis lead to recommendations for research, education, clinical practice and policy-making, which are depicted in figure 1 according to the fundamentals of care framework.

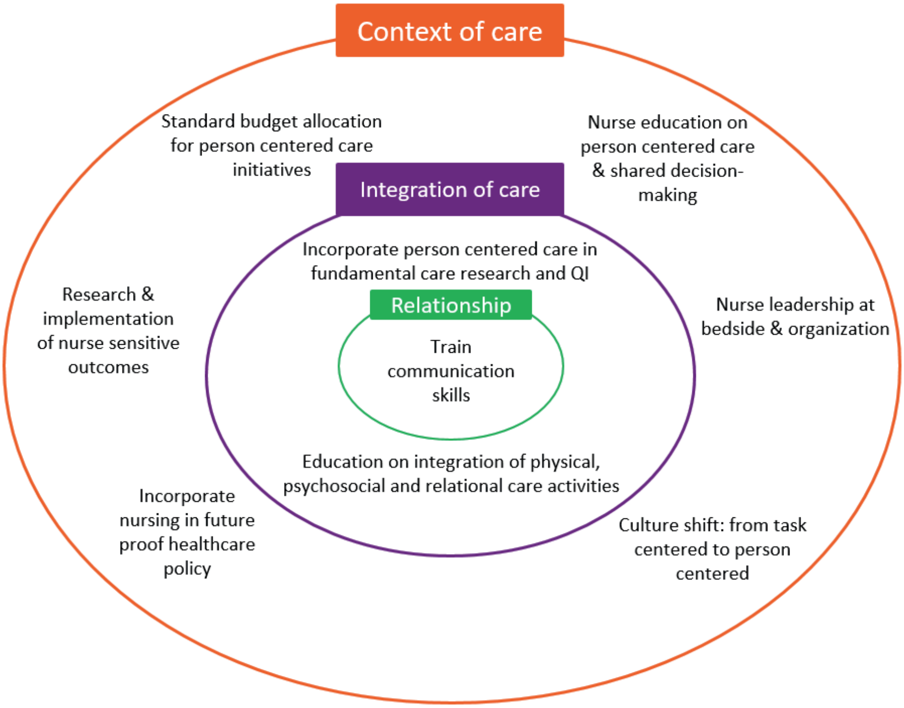

**Figure 1** Recommendations research, education, clinical practice and policy-making

## Implications for research

When patients were asked what aspects of fundamental care should be prioritized in research, the top five consisted of three topics concerning communication, [60] indicating how important this is to them. The Tell-us Card was piloted using a randomized controlled trial. However, with todays' knowledge about the cultural and contextual challenges surrounding person-centered care, follow-up research would not initially be advised to use a similar design. It would therefore be advised to use a more collaborative approach such as action research in co-creation with patients and nurses, as it is based on cycles of planning, action, evaluation and critical analysis to gain in-depth knowledge and experience about effective components and mechanisms on patient, nurse and ward-level. These components can then be tested in other places to determine what is useful for the general population, and which ones might be context-dependent.

Leading from the discussion earlier in this chapter, research on patient participation could benefit from actions on multiple topics:

- Co-creation: Including patients in every step of the research process will increase chances of actually benefitting clinical practice, and thus reduce research waste. It should therefore be standard practice in determining research topics and carrying out (nursing) research; certainly when studying person-centered care.
- Patients: developing tools to facilitate participation for people who might be challenged to participate in care, such as people with low literacy or health management skills, or language barriers.
- Nurses: research on how to teach nurses integrated, person-centered, fundamental care delivery, what tools might benefit them, and how clinical nurse leadership and management are of influence.
- Context: research on nurse-sensitive outcomes and using these to create indicators of excellent nursing care will create awareness about the necessity and effects on quality and safety of care.
- Research on physical fundamental care elements should always incorporate a person-centered care approach and communicative skills when developing their intervention to enable integrated fundamental care delivery.
- Collaboration: Research is greatly benefited from international collaborations and networks on this topic, such as the International Learning Collaborative.

## Implications for education

Research indicates that nursing students have little appreciation for fundamental care delivery[61] and seems to be invisible during theoretical education. [62] A pilot study on integrated fundamental care in nursing curricula found that students find it difficult to combine physical fundamentals of care with psychosocial fundamentals, and argue that this be taught separately first to avoid cognitive overload. [63] Later in the curriculum these can be combined to reach integrated care, and showing these students that this type of communication does not require a great deal of time. Fundamental care should be introduced early-on in lectures, skills sessions and workgroups, using and repeating consistent terminology. To teach person-centered fundamental care, students could benefit from roleplay, practicing on fellow students and actors. Patient representatives in lectures and workgroups, and even as curriculum developers are key to increase awareness and person-centered care skills with students, but currently still many initiatives with patients in education are isolated, small events for targeted groups instead of being a sustainable part of the curriculum. [64]

Further, the nursing curriculum can benefit from teaching about the complexities of fundamental care in hospitals, how integrated fundamental care delivery leads to more effective clinical reasoning, and the impact integrated care has on nurse-sensitive outcomes.

## Implications for clinical practice

To achieve person-centered fundamental care, it needs to be embedded in clinical practice. This begins by nurses acknowledging the importance of person-centered fundamental care and using their leadership skills to advocate for it within their organization. To achieve this, it is imperative to educate nurses of all educational levels. Bachelor and vocational nurses need to be taught how to integrate person-centered care in their daily care provision, and shown the value of the care by creating feedback loops using nurse sensitive outcomes. A key player is the clinical academic nurse who can integrate a person-centered approach and patient involvement in their quality improvement projects and clinical research. They are able to quickly pick up on new scientific insight on person-centered fundamental care, and are clinical leaders showing and teaching their colleagues new ways of approaching patients. A requirement is a strong vision on fundamental nursing care by nurse management who can prioritize and enable nurses to shift from task completion and outcome evaluation to integrated fundamental care provision. As this requires effort on multiple layers of the organization, it is imperative that nurses play key roles in management positions throughout the hospital.

Hospitals and other health care organizations are advised to take several actions to ensure person-centered fundamental care delivery. They need to have ongoing attention to provide training for nurses to develop and maintain their skills, incorporating the insight that nurses over-estimate the level of person-centered care they are providing. This requires of organizations to be explicit about their vision and efforts on person-centered care, and commit to allocate budget for education and quality improvement projects.

## Implications for policymaking

As this thesis emphasizes the role that nurses can and should play in ensuring that our healthcare is future proof, it is imperative that quick action follows. Nurses and researchers need to be facilitated, empowered and placed in leadership positions to work on the development and implementation of person-centered care and nurse-sensitive outcomes in care. Also, we advise that subsidizing parties require the explicit integration of person-centered care in fundamental care research projects. This acknowledges the importance of a person-centered care interaction on physical care delivery, and trains nurses in how to enact person-centered care in specific care encounters.

## Overall conclusion

A prerequisite for person-centered fundamental care is the nurses' ability to create an effective nurse-patient relationship. Those skills can then be applied to integrate physical, psychosocial and relational care activities into a person-centered approach. These are competencies that every nurse is able to develop, however there are complicating contextual factors such as the focus on task-completion and culture in hospitals make it complex behavior to change. Improvement of person-centered fundamental care therefore will be needed on several levels of the organization and by making the integration of person-centered care a required component in fundamental care improvement projects and research, in which patients as well as nurses and health care organizations will benefit.

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# ADDENDUM

# Addendum 1 The Dutch Tell-us Card

Tell-us Card

## Vertel het ons!

Wij willen u de best passende zorg geven.

Vertel ons daarom wat voor u van belang is. Op de achterkant van deze kaart staan onderwerpen waar u hierbij aan kunt denken.

De verpleegkundige die voor u zorgt zal dit met u bespreken.

ZonMw Radboudumc

## Vertel het ons!

Datum: ..............................

Kruis aan of noteer wat voor u van belang is;

☐ Hoe ziet mijn dag er uit?
☐ Medicatie
☐ Ik wil graag een privégesprek
☐ Ik maak mij zorgen over…
☐ Ik heb hulp nodig bij…
☐ Wat kan ik zelf doen?
☐ Wat kan of mag mijn familie?
☐ Ontslag uit het ziekenhuis
☐ Zorg thuis
☐ ...........................

Ruimte voor toelichting:

.............................................................................................

.............................................................................................

# Uitleg 'Tell-us Card'

## Stap 1: De patiënt krijgt de Tell-us Card van de verpleegkundige

De verpleegkundige informeert de patiënt over het doel en gebruik van de Tell-us Card.

!

Het doel van de Tell-us Card is om de zorg zo goed mogelijk af te stemmen op de wensen en mogelijkheden van de patiënt. Daarom wordt gevraagd wat voor hem of haar belangrijk is.

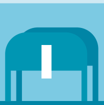
Samen kom je tot de best passende zorg!

De patiënt denkt na over wat hem of haar bezig houdt en schrijft dit op. Familie en naasten kunnen hierbij helpen of zelf aangeven wat ze belangrijk vinden.

## Stap 2: De verpleegkundige bespreekt de Tell-us Card met de patiënt

De verpleegkundige komt op een later moment bij de patiënt terug om de kaart te bespreken. Indien nodig kan dit worden overgedragen aan een collega. In dat geval wordt de patiënt hierover geïnformeerd.

De verpleegkundige vraagt door naar de betekenis van wat de patiënt heeft opgeschreven.



De verpleegkundige bespreekt met de patiënt wat hij zelf kan of wil doen. Hiermee houdt de patiënt zoveel mogelijk de regie, en oplossingen passen dan het beste bij de situatie van de patiënt.

Welk vervolg is nodig?
- moet er iets geregeld worden? Zo ja, wat, wanneer en door wie?
- wil de patiënt of familie iets weten?
- was een gesprek hierover misschien al voldoende?

Het gesprek wordt afgerond met een korte samenvatting. Indien nodig wordt een volgend contactmoment gepland.

## Stap 3: Verwerk de bevindingen

De verpleegkundige noteert gemaakte afspraken in het verpleegkundig dossier en verwerkt dit in het zorgplan.

# Addendum 2 Summary & samenvatting

## Summary

Nurses care for people with acute and chronic conditions in different settings, which implies a great variation of the care they provide. Common care practices needed by all patients can be summarized as fundamental care. Fundamental nursing care involves meeting a persons' essential physical, psychosocial and relational needs and is central to the delivery of high-quality care. Examples of these care activities are ensuring the patients' safety or comfort, eating and drinking, mobility, ensuring emotional wellbeing and education and information. The basis to meet these physical, psychosocial and relational care needs is a positive and trusting relationship with the person being cared for, and their family and carers. The lack of emphasis on fundamental care by nurses can result in inadequate or even harmful care. Missed fundamental nursing care is associated with increased mortality and adverse events, such as medication errors, falls, hospital-acquired infections, and pressure ulcers. Vital to effectively delivering high-quality fundamental care is a person-centered approach by the nurse. Person-centered care is a key concept of modern-day quality of care which consciously adopts the perspectives of individuals, families and communities, and sees them as participants of a healthcare system that respond to their needs and preferences in a humane and holistic way. When patients are enabled to participate in their care, they can influence and engage in the decision-making about their care based on their preferences and potential, combining their personal experiences, wants and needs in life with the professional's expert knowledge. This can result in lower anxiety levels, improved adherence, increased patient safety, and can prevent extensive (over)treatment. However, although the importance of participation in care is apparent, patients' participation in fundamental nursing care during hospitalization is often lacking.

This thesis therefore aimed to improve patient participation in clinical practice. This was done following the steps of the Medical Research Framework in which we tailored and piloted the Tell-us Card communication tool to the Dutch hospital setting, explored difficulties with patient participation by examining differences in experienced levels of participation in nurses and patients, and observing how person-centered fundamental care was carried out in daily practice. Finally, a guidance was created on best practices for hospitals to ensure patient and family participation in their organization.

In **chapter 2** the Tell-us Card intervention was tailored to the Dutch hospital setting using the Intervention Mapping framework. This is a systematic approach to tailoring an intervention and planning for its’ implementation and evaluation in practice. Based on patients and nurses interviews and focus group interviews, knowledge, attitude, outcome expectations, self-efficacy and skills were identified as the main determinants influencing the use of the Tell-us Card. These barriers and facilitators were combined with fitting behavior change methods and implementation strategies. The selected strategies were: an e-learning module to meet the needs of the behavioural objectives regarding knowledge, the assignment of a core group of nurses as role models, visits to the ward for education, feedback, and encouragement, informational letters for patients and nurses for instruction and a kick off meeting to encourage and educate nurses. In the next step the research materials such as the e-learning and digital registration forms, and the layout of the Tell-us Card were finalized based on nurse and patient input. The core group of nurses was assembled to guide implementation, stimulate the use of the Tell-us Card at the ward, and provide feedback to the researchers. Finally, the program and change objectives were analysed to determine suitable evaluation methods, a process evaluation plan was formed, and the questionnaires to test the effect on patient participation determined. This process resulted in a well-defined and tailored intervention and evaluation plan, and nurse and patients indicated that they regarded the Tell-us Card a feasible tool for practice.

Following the development phase, the next step was to pilot the Tell-us Card intervention. **Chapter 3** describes the cluster randomized controlled pilot study in four hospital wards to test the feasibility and early effectiveness of the Tell-us Card. Effectiveness was measured with the Individualized Care Scale (ICS) and the Quality from the Patients’ Perspective (QPP) questionnaire, and feasibility was assessed with an evaluative questionnaire for patients and nurses and by reviewing the content of Tell-us Cards using the Fundamentals of Care Framework for analysis. In the trial two cardiac and two surgical wards were included, and within both specialties was one intervention and one control ward. All patients received care as usual, and in addition, the patients on the intervention wards received the Tell-us Card intervention. Linear mixed model analysis on the data of the 265 patients showed a significant increase in individualized care at one of the two intervention wards. The majority of patients regarded the intervention as beneficial, and analysis of the Tell-us Card content showed many care elements of the Fundamentals of Care Framework being written down by patients, with most patients indicating psychosocial needs. Nurses however experienced barriers with incorporating the Tell-us Card into daily care. They indicated that they did not think the Tell-us Card was helpful as they felt it was of too little additional value, was time-consuming, and they regarded it as difficult when patients did not know what to write down. Nurses stated to expect their patients to speak up and to prefer face-to-face conversation instead of using a card. Therefore, although the Tell-us Card did show a significant early effect and patients were positive about it, integration in daily nursing care appeared to be complex and the intervention was deemed not-feasible in its current form.

Chapter 4 and 5 describe the return to the developmental phase to further investigate daily practice and its' barriers and possibilities for patient participation. In **chapter 4** we compare patients' and nurses' perceptions of patient-centered care across different types of hospital wards, and explore the associations between patient empowerment, health literacy, socio-demographic and context-related variables with these perceptions. The data was collected from ten Flemish and two Dutch hospitals using the Individualised Care Scale which has a nurse- and patient-version, and included 845 patients and 569 nurses. A significant difference ($p < 0.001$) was found between nurses and their patients, with nurses (mean 4.24) perceiving that they provided more individualized care than patients (mean 3.66) reported. Higher patient empowerment, higher health literacy, a lower education level, longer hospital stay, and admission to Dutch hospitals were associated with higher person-centered care among patients. Older and more experienced nurses, those working in Dutch hospitals, regional hospitals, and maternity wards, had higher scores. These findings highlight the importance of considering the patients' and nurses' perceptions and differences when wanting to improve person-centered care.

**Chapter 5** describes observations of patient care in hospitals to explore how nurses enact person-centered fundamental care delivery. In this study we observed 30 nurses caring for 102 patients on a surgical, geriatric, and a cardiology ward. Ten observations were done on each ward during morning care and lasted between 2.5 – 3 hours each. The study shows that nurses spent most of their time helping or stimulating patients to wash and dress, preparing, checking, and handing out medication, and conducting safety checks and measures. The psychosocial and relational elements of fundamental care were less frequently observed. Some nurses were seen to successfully combine physical, psychosocial, and relational elements of care in patient interactions within the same care tasks and timeframe as their colleagues, but most nurses were observed to be mainly focused on physical care. Many had a task-focused way of working and communicating, seldom incorporating patients' needs and experiences or discussing care planning, and often disturbing each other. Although most nurses have a compassionate approach, this study shows that most nurses did not incorporate psychosocial care or encourage patient participation when helping patients with their physical fundamental care needs. An important task lies in teaching nurses how to effectively integrate physical and relational care into physical care provision in order to achieve person-centered care.

These results led to taking in a broader view on what might be necessary to improve patient participation in hospitals. In **chapter 6** we describe the development and evaluation of a best practice guidance for hospital managers on how to enhance patient and family participation at micro, meso, and macro levels. As scientific literature gave too little information on evidence-based interventions, a grey literature search was conducted to identify best practices and recommendations for improving patient and family participation in academic hospitals. This yielded 212 items, which were individually scored by the project group for usefulness and feasibility, resulting in a reduction to 73 items categorized into eight domains. These items were input for our Delphi study with 36 international experts on patient and family participation, consisting of patient representatives, health care professionals, researchers, consultants, and hospital boards of directors. In the first Delphi round, experts were asked to rate the usefulness of the items. In the second round, experts were asked to rate the feasibility of the included items. In the third round, experts were asked to choose the top-three items that would be a positive and feasible challenge for their hospital in the near future. This resulted in a guidance of ten best practices, aiming at different levels in the organization. A year after dissemination, the guidance was evaluated with six of the seven academic hospitals in the Netherlands. The hospitals indicated to have implemented several of the best practices, had made plans to improve upon the other points, and found the guidance helpful in improving patient and family participation within their hospital. We concluded that that successful patient and family participation in hospitals requires sustained effort and dedication by a board of directors, policy makers, and health care professionals, and that the created guidance can assist a board of directors to best direct their efforts on different organizational levels.

**Chapter 7** is the general discussion in which the main findings of this thesis are presented, a reflection on the main findings of this thesis is described, and implications are presented. This thesis demonstrated the complexities of improving person-centered care and patient participation in nursing care in hospitals. Despite a thorough developmental phase to create an optimal fit with clinical practice, the Tell-us Card was regarded as not-feasible during the pilot trial. Replicating Tell-us Card studies in other counties show similar results with comparable barriers and challenges. The reflection further discusses reasons why person-centered care is challenging in hospitals, the benefits of and opportunities within person-centered care, and preconditions such as leadership skills and creating outcome measures that reflect the quality of fundamental care.

The methodological considerations describe how the thorough development phase of the Tell-us Card was a great strength. However, new insight on the importance of context suggest that a wider scope beyond the nurse and patient would be beneficial for future interventions. Also, this thesis included stakeholder engagement, but future research can benefit from more patient involvement for instance in the form of co-creation of interventions.

The implications in the areas of research, education, clinical practice and policymaking are discussed. In terms of research, it is suggested that a collaborative approach, such as action research in co-creation with patients and nurses, be used to gain in-depth knowledge and experience about effective components and mechanisms on patient, nurse, and ward-level. Research should focus on patient participation, developing tools to facilitate participation, teaching nurses integrated person-centered fundamental care delivery, and developing and implementing nurse-sensitive outcomes. In education, fundamental care should be introduced early on, and students should be taught the complexities of fundamental care in hospitals, and the impact integrated care has on nurse-sensitive outcomes. Clinical practice should focus on embedding person-centered fundamental care in nursing practice, educating nurses of all educational levels, and prioritizing fundamental nursing care by nurse management. Policymakers need to facilitate and empower nurses and researchers to work on the development and implementation of person-centered care and nurse-sensitive outcomes, and subsidize parties should require the explicit integration of person-centered care in fundamental care research projects.

We conclude that the ability to create effective nurse-patient relationships is crucial for providing person-centered fundamental care. However, contextual factors such as task-completion focus and hospital culture make it difficult to change current behavior. Improving person-centered care will require changes at multiple levels of the organization and the integration of person-centered care into improvement projects and research, benefiting patients, nurses and healthcare organizations.

# Samenvatting

De verpleegkundige praktijk is erg divers, verpleegkundigen zorgen voor mensen met chronische en acute aandoeningen in verschillende soorten zorgorganisaties. Toch is een groot deel van de zorgactiviteiten die zij uitvoeren relevant voor alle patiëntengroepen in alle zorgsettings, dit wordt essentiële zorg genoemd. Essentiele zorg gaat om het voldoen aan de fysieke en psychosociale behoeften van een persoon en is een voorwaarde voor het leveren van hoogwaardige zorg. Voorbeelden van deze zorgactiviteiten zijn het waarborgen van de veiligheid of comfort, eten en drinken, mobiliteit, het zorgen voor emotioneel welzijn, en onderwijs en informatieverstrekking. Deze fysieke en psychosociale behoeften worden vervuld door een positieve vertrouwensrelatie met de persoon die wordt verzorgd en hun naasten te ontwikkelen. Het ontbreken van aandacht voor essentiële zorg door verpleegkundigen kan leiden tot ontoereikende of zelfs schadelijke zorg. Gemiste essentiële verpleegkundige zorg wordt geassocieerd met een verhoogde mortaliteit en incidenten zoals medicatiefouten, vallen, ziekenhuisinfecties en decubitus. Een persoonsgerichte benadering is een voorwaarde voor hoogwaardige essentiële zorg. Persoonsgerichte zorg is een belangrijk onderdeel van de huidige kwaliteit van zorg, en draait om het verlenen van zorg die is afgestemd op iemands persoonlijke behoeften, wensen en voorkeuren van individuen en hun naasten, en hen beschouwd als actieve deelnemers van het zorgproces waarbij rekening wordt gehouden met hun behoeften en voorkeuren. Als patiënten in staat worden gesteld om deel te nemen aan hun zorg, ook wel patiëntparticipatie genoemd, kunnen ze invloed uitoefenen en deelnemen aan de besluitvorming over hun zorg op basis van hun voorkeuren en eigen mogelijkheden, waarbij ze hun persoonlijke ervaringen en wensen in het leven combineren met de kennis van de professional. Wanneer patiënten participeren in zorg kan dit leiden tot vermindering van angst, verbetering van de therapietrouw, verhoging van de patiëntveiligheid, en kan uitgebreide (over)behandeling voorkomen worden. Hoewel het belang van patiëntparticipatie duidelijk is, ontbreekt het hier in de ziekenhuiszorg nog te vaak aan.

Dit proefschrift heeft daarom als doel om patiëntparticipatie tijdens verblijf in het ziekenhuis te verbeteren. Hierbij zijn de stappen van het Medical Research Council (MRC) Framework gevolgd. Dit begon met het aanpassen en testen van de Tell-us Card (Vertelkaart) interventie voor gebruik in Nederlandse ziekenhuizen. Daarna zijn uitdagingen rondom patiëntparticipatie in kaart gebracht door het meten van ervaren niveaus van patiëntparticipatie bij verpleegkundigen en hun patiënten, en door te observeren hoe persoonsgerichte essentiële zorg in de dagelijkse praktijk werd uitgevoerd. Ten slotte werd een leidraad ontwikkeld met best practices om patiënt- en familieparticipatie in de ziekenhuizen te verbeteren en waarborgen.

In **hoofdstuk 2** werd de Vertelkaart interventie aangepast aan de Nederlandse ziekenhuissetting met behulp van het Intervention Mapping framework. Dit is een systematische benadering voor het ontwikkelen of aanpassen van een interventie, en het plannen van de implementatie en evaluatie in de praktijk. Door middel van (focusgroep)interviews met patiënten en verpleegkundigen werden kennis, houding, uitkomstverwachtingen, het vertrouwen in eigen gedrag (self-efficacy) en vaardigheden geïdentificeerd als de belangrijkste determinanten die het gebruik van de Vertelkaart beïnvloeden. Deze barrières en faciliterende factoren werden gecombineerd met passende gedragsveranderingsmethoden en implementatiestrategieën. De geselecteerde strategieën waren: een e-learningmodule om te voldoen aan de kennisbehoefte, de toewijzing van een kerngroep van verpleegkundigen, bezoeken aan de afdeling voor scholing, feedback en aanmoediging, opstellen van informatiebrieven voor patiënten en verpleegkundigen, en een kick-off bijeenkomst om verpleegkundigen te enthousiasmeren en aanvullende uitleg te geven. In de volgende stap werden op basis van input van verpleegkundigen en patiënten de onderzoeksmaterialen zoals de e-learning, digitale registratieformulieren en het ontwerp van de Vertelkaart afgerond. De kerngroep van verpleegkundigen werd samengesteld om de implementatie te begeleiden, het gebruik van de Vertelkaart op de afdeling te stimuleren en feedback te geven aan de onderzoekers. Ten slotte werden de programma- en veranderingsdoelstellingen geanalyseerd om geschikte evaluatiemethoden te bepalen, werd een procesevaluatieplan gevormd en werden de vragenlijsten geselecteerd die het effect op patiëntparticipatie testen. Dit grondige proces resulteerde in een op maat gemaakte interventie- en evaluatieplan, waarbij verpleegkundigen en patiënten aangaven dat ze de Vertelkaart een haalbaar instrument vonden voor de praktijk.

Na de ontwikkelingsfase was de volgende stap om de Vertelkaart interventie te testen in een pilotstudie. **Hoofdstuk 3** beschrijft de cluster gerandomiseerde gecontroleerde pilotstudie op vier ziekenhuisafdelingen om de haalbaarheid en tekenen van effectiviteit van de Vertelkaart te testen. De effectiviteit werd gemeten met behulp van de Individualized Care Scale (ICS) en de Quality from the Patients Perspective (QPP) vragenlijst, en de haalbaarheid werd beoordeeld met een vragenlijst voor patiënten en verpleegkundigen en door de inhoud van de gebruikte Vertelkaart te analyseren met behulp van het essentiële zorg raamwerk. De trial omvatte twee cardiologische en twee chirurgische afdelingen, met in elk specialisme een interventie- en een controleafdeling. Alle patiënten ontvingen reguliere zorg en daarnaast ontvingen de patiënten op de interventie-afdelingen de Vertelkaart interventie. Lineair mixed model analysis van de gegevens van de 265 patiënten liet een significante toename zien bij één van de twee interventie-afdelingen. De meerderheid van de patiënten vond de interventie prettig, en analyse van de inhoud van de Vertelkaart toonde veel elementen van essentiële zorg waarbij de meeste patiënten psychosociale behoeften aangaven. Verpleegkundigen ervaarden echter belemmeringen bij het gebruik van de Vertelkaart in de dagelijkse zorg. Ze gaven aan dat zij de Vertelkaart te weinig toegevoegde waarde had, de interventie tijdrovend was, en ze moeite hadden met patiënten die niet wisten wat ze op de kaart moesten opschrijven. Verpleegkundigen gaven aan dat zij verwachtten dat hun patiënten het aangeven als zij iets nodig hebben of willen bespreken, en ondanks dat de Vertelkaart een hulpmiddel is om een gesprek op gang te brengen, gaven verpleegkundigen aan het idee te hebben dat patiënten de voorkeur geven aan een persoonlijk gesprek in plaats van een kaart. Hoewel de Vertelkaart dus een significant effect liet zien en patiënten er positief over waren, bleek de implementatie in de dagelijkse zorg complex te zijn en werd de interventie niet haalbaar geacht in zijn huidige vorm.

Hoofdstuk 4 en 5 beschrijven de terugkeer naar de ontwikkelingsfase van het MRC framework om de dagelijkse praktijk en de barrières en mogelijkheden voor patiëntparticipatie verder te onderzoeken. In **hoofdstuk 4** vergelijken we het ervaren niveau van persoonsgerichte zorg tussen patiënten en verpleegkundigen op verschillende soorten ziekenhuisafdelingen en onderzoeken we de associaties tussen dit ervaren niveau en patiënt empowerment, gezondheidsvaardigheden, en verschillende socio-demografische en context-gerelateerde variabelen. De gegevens werden verzameld van tien Vlaamse en twee Nederlandse ziekenhuizen met behulp van de Individualised Care Scale die een identieke verpleegkundige en patiënten versie heeft, en omvatte 845 patiënten en 569 verpleegkundigen. Er werd een significant verschil (p <0,001) gevonden tussen de ervaring van verpleegkundigen en hun patiënten, waarbij verpleegkundigen een hoger niveau van geïndividualiseerde zorg ervaarden te verlenen (gemiddelde score van 4,24) dan patiënten dit ervaarden te ontvangen (gemiddelde score van 3,66). Hogere patiënt empowerment scores, hogere gezondheidsvaardigheden, een lager opleidingsniveau, een langer ziekenhuisverblijf en opname in Nederlandse ziekenhuizen waren geassocieerd met een hoger ervaren niveau van persoonsgerichte zorg onder patiënten. Oudere en meer ervaren verpleegkundigen, en verpleegkundigen die werkzaam zijn in Nederlandse ziekenhuizen, regionale ziekenhuizen of kraamafdelingen hadden een hogere scores. Deze bevindingen benadrukken het belang van het rekening houden met de verschillen in ervaren verleende en ontvangen persoonsgerichte zorg tussen verpleegkundigen en patiënten bij het verbeteren van persoonsgerichte zorg.

**Hoofdstuk 5** beschrijft het observeren van patiëntenzorg in ziekenhuizen om te onderzoeken hoe verpleegkundigen persoonsgerichte, essentiële zorg verlenen. In deze studie hebben we 30 verpleegkundigen geobserveerd die voor 102 patiënten zorgden op een chirurgische, geriatrische en cardiologieafdeling. Op elke afdeling werden tien observaties uitgevoerd tijdens de ochtendzorg en deze duurden ieder tussen 2,5 en 3 uur. Uit de studie blijkt dat verpleegkundigen het grootste deel van hun tijd besteden aan het helpen of stimuleren van patiënten om zich te wassen en aan te kleden, het voorbereiden, controleren en uitdelen van medicatie, en het uitvoeren van veiligheidscontroles en het meten van vitale functies. De psychosociale en relationele aspecten van fundamentele zorg werden minder vaak waargenomen. Sommige verpleegkundigen slaagden erin fysieke, psychosociale en relationele elementen van zorg succesvol te combineren in interacties met patiënten binnen dezelfde zorgtaken en tijdspanne als hun collega's, maar de meeste verpleegkundigen waren voornamelijk gericht op fysieke zorg. Velen hadden een taakgerichte manier van werken en communiceren, waarbij zelden expliciet gevraagd werd naar en rekening gehouden werd met de behoeften en ervaringen van patiënten, of gesproken werd over zorgplanning, en waarbij verpleegkundigen elkaar vaak stoorden tijdens de patiëntenzorg. Hoewel de meeste verpleegkundigen een empathische houding hebben, liet deze studie zien dat de meeste verpleegkundigen tijdens het verlenen van de fysieke essentiële zorg beperkte aandacht hebben voor psychosociale zorg of het actief stimuleren van patiëntparticipatie. Deze studie laat zien dat om tot persoonsgerichte essentiële zorg te komen, het noodzakelijk is om verpleegkundigen te leren hoe zij psychosociale en relationele zorg effectief kunnen toepassen tijdens het verlenen van fysieke zorg.

Deze resultaten leidden tot een bredere kijk op wat nodig zou kunnen zijn om patiëntparticipatie in ziekenhuizen te verbeteren. In **hoofdstuk 6** beschrijven we de ontwikkeling en evaluatie van een leidraad voor ziekenhuismanagers over hoe patiënten- en familieparticipatie op micro-, meso- en macroniveau in academische ziekenhuis verbetert kan worden. Omdat de internationale wetenschappelijke literatuur te weinig informatie gaf over op evidence-based interventies, werd verder gezocht in de grijze literatuur om best practices en aanbevelingen voor het verbeteren van patiënten- en familieparticipatie te identificeren. Dit leverde 212 items op, die onafhankelijk werden beoordeeld door de projectgroepleden op bruikbaarheid en haalbaarheid, wat resulteerde in 73 items die gecategoriseerd zijn in acht domeinen. Deze items werden in onze Delphi-studie voorgelegd aan 36 internationale experts op het gebied van patiënten- en familieparticipatie, bestaande uit patiëntvertegenwoordigers, zorgverleners, onderzoekers, beleidsadviseurs en leden van de Raad van Bestuur. In de eerste Delphi-ronde werd gevraagd om de bruikbaarheid van de items te beoordelen. In de tweede ronde werd gevraagd om de haalbaarheid van de opgenomen items te beoordelen. In de derde ronde werd gevraagd om de top drie items te kiezen die een positieve en haalbare uitdaging zouden vormen voor hun ziekenhuis in de nabije toekomst. Dit resulteerde in een leidraad van tien best practices, gericht op verschillende niveaus in de organisatie. Een jaar na de uitgave werd de leidraad geëvalueerd met zes van de zeven academische ziekenhuizen in Nederland. De ziekenhuizen gaven aan verschillende best practices te hebben geïmplementeerd, plannen te hebben gemaakt om de andere punten te verbeteren en de richtlijn nuttig te hebben gevonden bij het verbeteren van patiënten- en familieparticipatie. We concludeerden dat succesvolle patiënten- en familieparticipatie in ziekenhuizen inspanning en toewijding vereist van een Raad van Bestuur, beleidsmakers en zorgverleners, en dat de gecreëerde leidraad behulpzaam is om te sturen op het verbeteren van patiënt- en familieparticipatie.

**Hoofdstuk 7** beschrijft de algemene discussie van dit proefschrift met een overzicht van en een reflectie op de belangrijkste resultaten, en aanbevelingen worden gedaan. Dit proefschrift beschrijft de complexiteit van het verbeteren persoonsgerichte zorg en patiëntparticipatie in de verpleegkundige zorg in ziekenhuizen. Ondanks een grondige ontwikkelingsfase om een optimale fit met de klinische praktijk te creëren, werd de Vertelkaart tijdens de pilotstudie als niet haalbaar beschouwd. Studies naar de Vertelkaart uitgevoerd in andere landen laat vergelijkbare resultaten zien met vergelijkbare barrières en uitdagingen. De reflectie bediscussieert redenen waarom persoonsgerichte zorg in ziekenhuizen uitdagend is, de voordelen en mogelijkheden binnen persoonsgerichte zorg en voorwaarden zoals leiderschap en het creëren van verpleegsensitieve uitkomstmaten.

In de methodologische overwegingen beschrijven we hoe de ontwikkelingsfase van de Vertelkaart een grote kracht was. Voortschrijdend inzicht over het belang van context suggereert echter dat een bredere scope dan alleen op de verpleegkundige en de patiënt nuttig zou zijn voor toekomstige interventies. Ook kan toekomstig onderzoek profiteren van nog meer betrokkenheid van patiënten in bijvoorbeeld de vorm van co-creatie.

Aanbevelingen zijn gedaan op het gebied van onderzoek, onderwijs, klinische praktijk en beleid. Op het gebied van verder onderzoek naar persoonsgerichte zorg en patiëntparticipatie in de verpleging wordt een collaboratieve aanpak zoals actieonderzoek in co-creatie met patiënten en verpleegkundigen aangeraden, om kennis en ervaring op te doen over effectieve componenten op patiënt-, verpleegkundige- en afdelingsniveau. Onderzoek zou zich moeten richten op het ontwikkelen van tools om participatie te vergemakkelijken, het onderwijzen van verpleegkundigen over geïntegreerde persoonsgerichte essentiële zorgverlening en het ontwikkelen en implementeren van verpleegsensitieve uitkomstmaten. In het onderwijs zouden studenten nog meer moeten worden onderwezen over de complexiteit van essentiële zorg in ziekenhuizen, de impact die geïntegreerde zorg heeft op verpleegsensitieve uitkomstmaten, en het gebruik daarvan. In de klinische praktijk zou er gefocust moeten worden op het integreren van persoonsgerichte essentiële zorg, het opleiden van verpleegkundigen van alle opleidingsniveaus, en het prioriteren van essentiële verpleegkundige zorg door verpleegkundig management. Beleidsmakers kunnen verpleegkundigen en onderzoekers beter faciliteren om te werken aan de ontwikkeling en implementatie van persoonsgerichte zorg en verpleegsensitieve uitkomstmaten, en subsidieverstrekkers kunnen de integratie van persoonsgerichte zorg in onderzoeksprojecten naar fundamentele zorg meer benadrukken.

Dit proefschrift concludeert dat de vaardigheden van verpleegkundigen om een effectieve professionele relatie te creëren een voorwaarde is voor het bieden van persoonsgerichte essentiële zorg. Dit zijn vaardigheden die iedere verpleegkundige kan ontwikkelen, echter maken contextuele factoren zoals een taakgerichtheid en de ziekenhuiscultuur het moeilijk om die persoonsgerichte essentiële zorg te geven. Het verbeteren van persoonsgerichte zorg vereist veranderingen op meerdere niveaus van de organisatie, en de integratie van persoonsgerichte zorg in verbeterprojecten en onderzoek naar essentiële zorg.

# Addendum 3 Research data management

This thesis is based on the results of human studies, which were conducted in accordance with the principles of the Declaration of Helsinki. The medical and ethical review board Committee on Research Involving Human Subjects Region Arnhem Nijmegen, Nijmegen, the Netherlands has given approval to conduct these studies. Additionally, the study in chapter 4 was approved by the medical and ethical review board Committee on Research Involving Human Subjects of Ghent University, Ghent, Belgium and the study described in chapter 5 was approved by the medical and ethical review board of the Rijnstate hospital, Arnhem, the Netherlands. All participants declared informed consent to participate in this research or had a proxy sign this for them when not capable. No incentives were provided to participants.

The data was collected at the Radboud Institute for Health sciences (IQ healthcare), and additionally for chapter 4 at the University Centre for Nursing and Midwifery, Ghent University, and at the Rijnstate hospital, Arnhem, for chapter 5. The raw data, the digitally processed files and the analyzed data of these studies, except for the Belgian part of the raw data of chapter 5, are stored at the secured I-drive of the Radboudumc, department IQ healthcare. The informed consents and paper-recorded questionnaires are stored in the department archive of the Radboud Institute for Health Sciences, IQ healthcare, Nijmegen, the Netherlands. The Belgian data of chapter 5 is stored in the department archive of the Ghent University. In all studies, a unique participant code was created for each participant, warranting the privacy of the participants. The codes and the data were stored separately.

The studies described in this thesis were funded by ZonMw (the Netherlands Organization for Health Research and Development) program “Tussen Weten en Doen II” (grant 520002003), and by the Netherlands Federation of University Medical Centres (NFU), program “Sturen op Kwaliteit” (grant 8392010042). The funders had no influence on the study design, the data collection, data analysis, the writing or submitting of the articles.

The data will be saved for 15 years after termination of the respective studies. Using these patient data in future research is only possible after a renewed permission by the patient as recorded in the informed consent. The datasets analyzed during these studies are available from the corresponding author on reasonable request.

# Addendum 4 List of publications

E. van Belle, S.M.G. Zwakhalen, J. Caris, A. Van Hecke, G. Huisman-de Waal, M. Heinen. (2018). Tailoring of the Tell-us Card communication tool for nurses to increase patient participation using Intervention Mapping. Journal of Clinical Nursing. DOI: 10.1111/jocn.13968

E. van Belle, J. Giesen, T. Conroy, M. van Mierlo, H. Vermeulen, G. Huisman-de Waal, M. Heinen. (2020). Exploring person-centred fundamental nursing care in hospital wards: A multi-site ethnography. Journal of Clinical Nursing. DOI: 10.1111/jocn.15024

E. van Belle, G. Huisman-de Waal, H. Vermeulen, M. Heinen. (2020). Feasibility and early effectiveness of the Tell-us Card communication tool to increase in-hospital patient participation: a cluster randomised controlled pilot study. Scandinavian Journal of Caring Sciences. DOI: 10.1111/scs.1290

S. Theys, E. van Belle, M. Heinen, S. Malfait, K. Eeckloo, D. Beeckman, S. Verhaeghe, A. Van Hecke. (2021). Individualised care in Flemish and Dutch hospitals: Comparing patients' and nurses' perceptions. Scandinavian Journal of Caring Sciences. DOI: 10.1111/scs.13016

E. van Belle, M. Heinen, N. Langenkamp, D. Ubbink, A. Vroom, H. Vermeulen. Creating a guidance for hospital boards of directors to improve patient and family participation; A Dutch national quality improvement project. *In submission.*

W. Bahlman-van Ooijen, E. van Belle, A. Bank, J. de Man-Van Ginkel, G. Huisman-de Waal, M. Heinen. (2022). Nursing leadership to facilitate patient participation in fundamental care: An ethnographic qualitative study. Journal of Advanced Nursing. DOI: 10.1111/jan.15329

E. van Belle, A. Eskes, H. Vermeulen. Kritisch bekeken: Improving patient participation in a challenging context: a 2-year evaluation study of an implementation project. (2017). Nederlands Tijdschrift voor Evidence Based Practice 2017-3/4

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E. van Belle, M. Diebels, I. Heijnen, M. Pondman, L. Smulders, F. Verbeek. (2020) De brug tussen evidence en praktijk. TvZ 2020-6

E. van Belle, M. Heinen. Uitgelicht: Patiëntparticipatie in het ziekenhuis. (2023). TvZ 2023-1

## Addendum 5 Over de auteur

Elise van Belle werd op 15 maart 1987 geboren in Nijmegen. Zij behaalde haar HAVO diploma in 2007 bij het vavo ROC Nijmegen, waarna zij de opleiding tot verpleegkundige aan de Hogeschool van Arnhem en Nijmegen volgde. Dit was op duale wijze bij het Radboudumc. Na diplomering in 2011 heeft zij kortstondig als wijkverpleegkundige gewerkt, waarna zij startte als flex verpleegkundige in het Radboudumc. In het jaar erna is zij de master Verplegingswetenschap aan de Universiteit Utrecht gaan studeren, en behaalde dit diploma in 2015.

In 2013 is zij als verpleegkundige op de Cardiologie van het Radboudumc gaan werken, waar zij zich als aandachtsveld richtte op verpleegkundig wetenschappelijk onderzoek. In april 2016 startte Elise haar PhD traject naar patiëntenparticipatie in de verpleegkundige ziekenhuiszorg binnen het Basic Care Revisited programma. Zij deed dit in deeltijd en combineerde het met haar werk als verpleegkundige. Als verpleegkundige ontwikkelde zij zich in 2017 tot verpleegkundig wetenschapper. In deze functie werkte zij op de afdeling Cardiologie onder andere aan kwaliteitsprojecten, deskundigheidsbevordering van verpleegkundigen en studenten begeleiding. Daarnaast heeft zij zich in het ziekenhuis actief beziggehouden met het verbeteren van de functie en positie van de verpleegkundig wetenschapper en heeft zij als eerste voorzitter van het platform verpleegkundig wetenschappers een belangrijke rol gehad in het succes van dit platform. Zij was mede-initiatiefnemer en -organisator van de ziekenhuisbrede Mangomomenten dag, die in het teken stond van mooie en betekenisvolle momenten voor patiënt en zorgverlener onder de aandacht te brengen. Ook initieerde, ontwikkelde en implementeerde zij met collega's ziekenhuisbrede materialen zoals de ELLI-meting voor de verpleegkundige functiedifferentiatie, en de COVID toolkit met verpleegkundige diagnoses die tijdens de eerste COVID golf verpleegkundigen een handreiking bood in het zorgen voor deze destijds nieuwe patiëntengroep. Elise was daarnaast uitvoerend onderzoeker in 2020 voor de knelpuntanalyse "Familieparticipatie in de wijkverpleegkundige zorg", en in 2021 bij de proefimplementatie "Richtlijn verpleegkundige en verzorgende verslaglegging".

Sinds 2021 is zij werkzaam als onderzoeker bij de leerstoel Verplegingswetenschap van het UMC Utrecht. In deze functie is zij docent aan de Klinische Gezondheidswetenschappen van de Universiteit Utrecht, werkt zij als projectlid van de werkgroep Wetenschap en Innovatie aan de ontwikkeling en implementatie van de academische werkplaatsen in het UMC Utrecht, en zal zij onderzoek gaan opstarten naar persoonsgerichte, essentiële zorg.

# Addendum 6 Dankwoord

Met de afronding van dit proefschrift, rond ik ook een hoofdstuk uit mijn leven af. De metafoor van de beklommen berg haal ik hierbij toch ook maar aan. Want hoewel de top altijd in zicht bleef was de weg ernaartoe niet altijd duidelijk, moesten er creatieve omwegen gevonden worden en was er een incidenteel te overbruggen ravijn. Maar daar sta ik dan toch. En ik sta daar niet alleen. Hoewel mijn naam op dit boekje staat, heb ik het voorrecht gehad daarbij geholpen, gecoacht en geïnspireerd te zijn door velen. Ik heb in dit traject veel mogen leren over mijzelf en het doen van onderzoek. Bij deze een poging hen allen te danken.

Allereest wil ik hierbij de deelnemers van mijn studies noem, mijn dank aan alle patiënten en verpleegkundigen die hebben meegedaan aan de studies waar ik veel van heb morgen leren. Zonder jullie had dit onderzoek niet plaats kunnen vinden.

Veel dank gaat uit naar mijn promotieteam, prof. dr. Hester Vermeulen, prof. dr. Ann Van Hecke, en dr. Maud Heinen. Beste Hester, een jaar na mijn aanstelling als PhD'er kreeg ik jou als mijn promotor en wat heb ik veel van je mogen leren sinds die tijd. Je was al snel duidelijk over de potentie die je in mij zag als verpleegkundig onderzoeker en -leider, wat flink heeft bijgedragen aan mijn zelfvertrouwen en de ontwikkeling die ik hierin heb doorgemaakt. Ik liep altijd geïnspireerd weer onze overleggen uit. Bedankt voor je goede voorbeeld en je persoonlijke betrokkenheid door de jaren heen. Ann, officieel ben je pas in de laatste fase aan mijn promotieteam toegevoegd, maar je bent al sinds vroeg in het traject betrokken bij de studies rondom de Tell-us Card die bij jullie in Gent ook liep. Bedankt voor de zeer welkome en leerzame toevoeging die je bracht de voltooiing van mijn proefschrift, en met name je hartelijke woorden hierbij. En dan Maud! Lisette koppelde ons in 2014 en dat bleek een hele goede match. Negen jaar samenwerking van onderzoeksstage naar afstudeer begeleiding, kort daarna de start van mijn PhD, en later de projecten die we samen gedaan hebben. Lieve Maud, de grootste dank voor de totstandkoming van dit proefschrift gaat toch wel naar jou. Van promotie overleggen met heerlijke kopjes koffie op IQ, naar online meetings tijdens de COVID, en uiteindelijk keukentafel overleggen; je stond altijd voor mij klaar op zowel wetenschappelijk inhoudelijk vlak als persoonlijke ontwikkeling. Lief en leed zijn voorbij gekomen de afgelopen jaren, en je adviezen om af en toe een pas op de plaats te maken, nee te leren zeggen, en soms juist door te zetten hebben mijn de eindstreep doen halen. Ik heb veel gehad aan je adviezen over werk-privé balans, en je coaching in mijn ontwikkeling als onderzoeker. Daarnaast was het ook hartstikke gezellig om samen te werken en ik hoop dat we op korte termijn nieuw onderzoek kunnen gaan opzetten.

Graag dank ik de leden van de manuscriptcommissie, prof. dr. Maria van den Muijsenbergh, prof. dr. Evelyn Finnema, en dr. Mark van den Boogaard voor het beoordelen van mijn manuscript.

Beste IQ collega's, met in het bijzonder de VW junioren en kamergenoten die ik in de loop van de (pre-COVID) jaren heb gehad, bedankt voor de gezellige tijd en hoognodige peer-support! Rixt, Ward en Lieke, jullie waren mijn eerste kamergenoten. Ik denk met plezier terug aan onze etentjes, en Rixt hartstikke leuk dat we weer collega's zijn in Utrecht! Harm en Gerda, we zijn ongeveer gelijk begonnen aan het BCR onderzoek, jullie op voeding. Bedankt voor alles wat ik van jullie hierover heb mogen leren daardoor en het gezamenlijk optrekken in onderzoek. Benjamin, je passie voor de wijkverpleging en je vermogen om te babbelen zijn indrukwekkend! Bedankt voor alle gezelligheid. Jeltje, van "mijn VW student" naar zelf ondertussen ook bijna gepromoveerd! Ontzettend knap, en jammer dat we elkaar door de COVID zo weinig hebben kunnen zien. En in het bijzonder dank aan Julia en Marscha, naast het optrekken in onderzoek zijn we vriendinnen geworden. Jullie support was de laatste jaren onmisbaar. Laten we snel weer gaan borrelen! Marscha, mijn 3$^{e}$ paranimf, bedankt voor al je hulp en tips tijdens de afronding van dit proefschrift, het was net als al je gezelligheid onmisbaar.

Dan ook mijn andere IQ VW collega's: Getty Huisman-de Waal, als co-auteur ben je bij verschillende artikelen betrokken geweest, bedankt voor al je input en bereidheid om mee te denken, en de vele gezellige gesprekken die we hebben gehouden in de jaren. Je enthousiasme is aanstekelijk. Anita Huis, wij werkten samen in de knelpuntanalyse familieparticipatie in de wijkverpleegkundige zorg waar ik van je heb mogen leren, dank voor het gezellige informele contact wat we in de loop van de jaren gehad hebben. En natuurlijk Annick Bakker, dank voor je ondersteuning in de projecten en je geweldige plan-vaardigheden om afspraken voor elkaar te krijgen!

Mijn onderzoeken waren zeker niet zo geslaagd zonder de overweldigende ondersteuning van mijn oud-collega's van het Radboudumc. Om met de Cardiologie te beginnen, en supporter van het eerste uur: Mieke Postma-Niens, jou moet ik toch wel als eerste noemen. Als mijn "baas" stond je voor mij klaar vanaf het begin van mijn promotie door mee te denken in creatieve mogelijkheden om mij de kans te geven te ontwikkelen, onderzoek te kunnen uitvoeren, en leuke dingen te doen als verpleegkundig wetenschapper. Er is heel wat gebeurt in mijn jaren op de Cardio en je hebt altijd voor mij klaar gestaan met een brede lach of een tissue. Dankjewel. Sabine van Someren - Damen, ook jou ben ik dankbaar voor alle ondersteuning in de loop der jaren. Je kwam op de afdeling toen mijn promotietraject al liep, maar je vond het gelijk leuk wat ik deed. Met het grootste enthousiasme dacht je met mij mee en schoof je mij naar voren in de organisatie. Uren hebben we op je kamer zitten praten omdat een van ons weer een idee had wat we de ander ééééven wilden voorleggen. Jullie zijn beide wat ik iedere wetenschapper gun: bevlogen en intelligente leidinggevenden met visie die met volledige steun en enthousiasme voor mij hebben klaargestaan. Ook hier dank voor Lonneke van Reeuwijk, nu ook Utrechts collega. Dankzij jouw visie en commitment heeft mijn promotietraject plaats kunnen vinden.

Dan uiteraard al mijn lieve, gezellige en fijne oud-collega's van de verpleegafdeling Cardiologie. Wat ik nou precies aan het doen was geen idee, maar jullie support was er altijd. Ik heb veel steun en motivatie gehaald uit alle gesprekken met jullie. Midden in een verpleegkundig team staan heeft ontzettend veel bijgedragen aan mijn eigen ontwikkeling en aan mijn onderzoeken. In het bijzonder dank aan mijn collega-wetenschappers van C4, Merel Diebels, Linda Smulders en Henrita van Zetten. Merel en Linda, we hebben gezamenlijk mooie dingen opgezet zowel op de afdeling als in het ziekenhuis en ik heb door de jaren heen veel aan jullie support gehad om door te zetten met mijn PhD. Ik hoop dat we contact blijven houden, ook al was het alleen maar voor de peer-support, hè Lin ;) Henrita, topper, jij komt er wel.

Dan ook mijn Mango-sisters: Merel Diebels, Maran Wessels en Inge Schouten. Wat een leuk project en goede samenwerking hadden we! Maran, we hadden op de afdeling al snel een klik, ik ben blij dat daar een vriendschap uit ontstaan is. Ook mijn dank aan alle inspirerende leden van het platform verpleegkundig wetenschappers! Ik vond het hartstikke leuk om twee jaar voorzitter te zijn en ieder samen met mij te zien ontwikkelen als wetenschapper in de zorg. Specifiek ook Cariline Roosen en Wilmieke van Ooijen die ik via IQ heb leren kennen voor zij verpleegkundig wetenschapper werden, dank voor de leuke samenwerking. In het Radboudumc mijn dank voor de inspirerende samenwerkingen met onder andere de VAR en het team van Toekomstbestendig Verplegen.

Ik wil ook graag mijn (niet meer zo-) nieuwe collega's van het UMC Utrecht bedanken! Ondanks een gekke start toch een heel warm welkom binnen een leuk en zeer deskundig team. In het bijzonder natuurlijk Lisette Schoonhoven. Lisette, je stond al aan mijn start bij IQ healthcare, en door de jaren heen inspireerde je mij bij bijeenkomsten. Toen was daar de vacature voor post-doc in jouw team, en wat een mooie kans om door te groeien heb je mij daarmee gegeven. Dank voor je vertrouwen en ondersteuning in het eerste jaar en de rust die dat gaf om te herstellen. Nu op naar mooie projecten, ik kijk uit naar onze verdere samenwerking! Dan mijn leuke VW collega's Sigrid Vervoort, Heleen Westland, Judy Ammerlaan, Thóra Hafsteindottír, Dewi Stalpers, Nienke Bleijenberg, Jaap Trappenburg, Tiny Jaarsma, Elke Loskamp, Stefan Kuiper, en alle promovendi. Bedankt voor jullie mentale support en tips in dit staartje van mijn PhD, en de leuke samenwerkingen die we aan het opstarten zijn.

Deze steun en het vieren van mijn laatste mijlpalen kwam eveneens van mijn collega's van spoor 4 Toekomstbestendig Verplegen en de werkgroep van de academische werkplaats DIGD. Bedankt voor jullie enthousiasme! Tenslotte ook dank voor mijn collega's in onderwijs; Saskia Weldam, Debbie ten Cate, Hetty Ockhuysen, en Thóra; bedankt voor jullie goede tips bij mijn eerste blok WVP, en het meeleven in de afronding van dit proefschrift.

Mijn geweldige vriendinnen Froukje, Pepita, Rosy en Nikki, wat moet ik zonder jullie. Bedankt voor de hoognodige ontspanning in de afgelopen jaren en de interesse in mijn werk. Wat heb ik geluk dat jullie altijd voor mij klaarstaan en ik ben dankbaar voor alles wat we samen hebben meegemaakt. Pepita, 30 jaar vriendschap, wat bijzonder! Heel wat lief en leed langs gekomen, fijn dat we vriendinnen zijn. Froukje, momenteel wat verder van elkaar vandaan en druk met onze kindjes, maar dank dat je (soms letterlijk) dag en nacht voor me hebt klaargestaan; op naar de volgende 25 jaar samen. Rosy, wat gezellig dat je in Nijmegen bent komen wonen, nu er meer tijd vrij komt hopelijk vaker woensdag-baby-dates doen! Nikki, onze vriendschap begon (moeizaam, haha) op de HBO-V en samen gingen we ook naar de Verplegingswetenschap. Waar ik het onderzoek in ging, koos jij voor onderwijs. Als geen ander snap en deel je mijn passie en soms lichte frustratie met ons mooie werk en vak, wat ontzettend fijn is geweest om te kunnen delen. Bedankt dat je op deze mooie dag naast mij staat.

To my dear family in-law. Thank you for all the unconditional love you have given me since we first met. The trips to your homes in Florida and Curaçao have given me the much-needed relaxation and respite from the Dutch cold weather. I've enjoyed all the quality-time we got to spend together, and hopefully will for many years to come. Sunil, especially thanks to you for being the little brother I never had. I love our conversations and the comfort I feel around you. Thanks for being the cutest uncle for Annabel. Hope we get to meet again soon.

Heel graag wil ik mijn ouders, broers en schoonzus bedanken voor alle steun in de loop van de jaren. Lieve pap en mam, bedankt dat jullie mij altijd gesteund hebben in mijn ambities en voor mij klaar stonden op moeilijke momenten. Pap, de magische zin ‘Ik weet niet zo goed wat ik met deze opleiding wil, maar het is belangrijk voor mij dat ik het ga doen’ was voldoende voor jou om mijn keuze voor de wetenschap volledig op iedere manier te ondersteunen. Dankjewel voor al je hulp en wijsheden door de jaren heen. Wat heb ik geluk met Archi als vader. Mam, bedankt voor je oneindige zorgzaamheid, luisterend oor en tafels vol heerlijk eten. Ik ben dankbaar voor het goede voorbeeld je hebt gegeven als zelfstandige vrouw en lekker pietluttig zijn als het aankomt op teksten schrijven. Zeker sinds Annabel er is, is je steun onmisbaar. Dankjewel. Lieve broers, Bart en Peter. We lopen de deur niet bij elkaar plat, maar ik weet dat jullie er altijd voor mij zijn. Als ik midden in de nacht ergens gestrand zou zijn bel ik jullie als eerst – wat waarschijnlijk ook al wel eens gebeurd is, haha. Jullie zijn mij heel dierbaar. Schone zus, lieve Biba. Het is nog gezelliger in de familie sinds jij erbij bent. Bedankt voor al je interesse in mijn werk en je inspirerende carrière binnen de zorg; leiderschap straalt van je af. Dankjewel dat je mijn paranimf bent, met jou erbij krijg ik het wel geregeld!

Liefste Sunder, van de zuster en de dokter naar de doctor en de dokter. Onze liefde begon op het werk, en het is een factor die ons blijft verbinden; het is fijn om elkaars wereld te begrijpen als je beide veel geeft om wat je doet en daar extra tijd in wilt investeren. Bedankt voor al je liefde, steun en rust in dit traject, en luisterend oor als het even tegenzat. Onze mooie reizen, festivals en avonden dansen waren de perfecte manier om mijn gedachten te verzetten. Ik ben trots en vol liefde dat jij mijn partner en liefste vader van Annabel en baby-in-de-buik bent.

Aller allerliefste Annabel, mama van jou mogen worden is het mooiste wat mij is overkomen. De liefde is overweldigend. Wat geniet ik van met jou zijn, mijn zonnetje.

# Addendum 7 PhD portfolio

**Name PhD candidate:**
Elise van Belle
**Department:**
Nursing science, IQ healthcare
**Graduate school:**
Radboud institute for Health Sciences

**PhD period:**
01/04/2016 – 01/02/2023
**PhD supervisor:**
Prof. dr. Hester Vermeulen
Prof. dr. Ann van Hecke
**PhD Co-supervisors:**
Dr. Maud Heinen

| Training activities | Year(s) | ECT |
|---|---|---|
| **Courses** | | |
| - Scientific Writing | 2017 | 3.0 |
| - RIHS introductory course | 2017 | 1.0 |
| - Summerschool European Academy of Nursing Science (EANS) Malmö | 2017 | 3.5 |
| - Kwalitatieve analyse | 2017 | 0.5 |
| - Opfriscursus statistiek met SPSS voor PhD studenten | 2017 | 1.5 |
| - Basis cursus regelgeving en organisatie voor klinisch onderzoekers (BROK) | 2017<br>2018 | 1.5<br>1.5 |
| - Presentation Skills | | |
| - Summerschool European Academy of Nursing Science (EANS) Gent | 2018 | 2.0 |
| - Scientific Integrity | 2018 | 1.0 |
| - Summerschool European Academy of Nursing Science (EANS) Lissabon | 2019 | 2.0 |
| **Seminars & lectures** | | |
| - 9 PhD/Nursing science Nijmegen meetings | 2017 – 2020 | 0.9 |
| - PhD bijeenkomst presentatie en workshop observationeel onderzoek | 2017 | 0.5 |
| - NFU werkgroep Patiënt als partner presentatie | 2017 | 0.5 |
| - Openbare VAR bijeenkomst Radboudumc. Presentatie en workshop | 2019 | 0.5 |
| **Conferences** | | |
| - Tussen Weten en Doen II netwerkbijeenkomst. Poster | 2017 | 0.5 |
| - NFU Sturen op kwaliteit Meet & Greet. 2 workshops | 2017 | 2.0 |
| - International Forum on Quality and Safety in Healthcare Poster presentatie | 2018 | 1.0 |
| - Netwerkbijeenkomst Tussen Weten en Doen II. Presentatie/ workshop | 2018 | 1.0 |
| - European Academy of Nursing Science Winter summit. Presentatie | 2019 | 1.0 |
| - Care4; International Scientific Nursing and Midwifery Congress. 2 presentaties | 2019 | 2.0 |
| - European Academy of Nursing Science, summer conference. Poster | 2019 | 0.5 |

| | | |
|---|---|---|
| Other | | |
| - Organisatie jaarlijkse dag Mangomomenten in Radboudumc | 2018 - 2020 | 3.0 |
| - 4 peer reviews scientific journals | 2019 - 2020 | 2.0 |
| **Teaching activities** | | |
| Supervision of internships | | |
| - 6 thesis supervision bachelor nursing students, HAN University of Applied Sciences | 2016 - 2018 | 6.0 |
| - 4 thesis supervision master students Clinical Health Sciences, Utrecht University | 2017 - 2020 | 8 |
| - 2 research project (grant proposal) supervision, bachelor (bio) medical sciences, Radboud University | 2017 - 2018 | 3.5 |
| - 3 “Meet your PhD” students, bachelor (bio)medical sciences, Radboud University | | 3.0 |
| Total | | 53.4 |

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