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PATIENT-CENTREDNESS AND EMPOWERMENT IN HOSPITAL CARE

MEASUREMENT, PRACTICE AND EXPLORING AN INTERVENTION TO ENHANCE IT

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LIST OF ABBREVIATIONS

CFI	Comparative Fit Index
CPSET	Care Process Evaluation Tool
EBCD	Experience Based Co-Design
FoCF	Fundamentals of Care Framework
ICC	Intracluster Correlation
ICS	Individualised Care Scale
I-CVI	Item Content Validity
IOM	Institute of Medicine
JCI	Joint Commission International
PaCT-HCW	Patient Participation Culture Tool for Healthcare workers
PREM	Patient Reported Outcome Measure
PAM-13	Short form of the Patient Activation Measure
QPP	Quality from the Patient’s Perspective questionnaire
RMSEA	Root Mean Square Error of Approximation
SD(s)	Standard Deviation(s)
SRMR	Standardised Root Mean Square Residual
VIF	Variance Inflation Factor
WHO	World Health Organisation

CHAPTER 1

GENERAL INTRODUCTION

In the face of improving quality of care, patient-centred care has internationally become a growing issue of importance in health care. The concept has gained increased attention in a variety of patient groups and healthcare settings including primary care, mental health care, and hospital care. The latter setting wil be the focus of this dissertation. Patient-centred care premises patient preferences, needs, and values and is characterised by a positive and trusting healthcare professional – patient relationship (Feo et al., 2018; Wolfe, 2001). Such a relationship focusses on the patient's essential needs to ensure his/her physical and psychosocial wellbeing (Feo et al., 2018). Nurses play a pivotal role in the support and provision of patient-centred care as nurses' behaviours are fundamental for delivering care that meets patients' unique health needs (Feo et al., 2018). For example, supporting patients to actively participate in determining preferred care and thereby recognising patients' experiential knowledge as equal and complementary to theirs, are essential to establish patient-centred care (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). The pursuit of patient-centredness in contemporary health care has also led to an increased focus on the empowerment of patients; enabling patients to take control over decisions and actions affecting their health (WHO, 2012).

Consistent with healthcare policy internationally, the Belgian Federal Government underlined the importance patient empowerment (Paulus, Van den Heede, & Mertens, 2012) and patient participation to establish patient-centred hospital care. In 2013, the government started a multi-annual programme to improve a patient-centred approach in quality of care and patient safety in hospitals. Despite the increased attention for both patient-centred care and patient empowerment, little is known about perceptions of patients and nurses regarding the support and provision of patient-centred care in Belgian hospital wards (Flemish part) and the empowerment of Flemish hospitalised patients.

The introduction of this dissertation starts with a description of the origins of and the evolution towards patient-centred care and patient empowerment. It will also be described how the two concepts relate to each other and what is known about patient-centred care and patient empowerment in hospitals internationally. In the second section, it will be discussed what is known about patient-centred care and patient empowerment in Belgium hospitals (Flemish part). In the third section, it will be become clear that focus of this dissertation, the pursuit of patient-centredness and empowerment of patients in hospital care, is inevitably intertwined with fundamental nursing care. Further, a promising nurse-led communication tool to enhance a patient-centred approach in hospitals will be introduced. This introductory chapter concludes with an overview of the research aims and an outline of the dissertation.

1. THE ORIGINS AND EVOLUTION OF PATIENT-CENTRED CARE AND PATIENT EMPOWERMENT

1.1 Patient-centred care

The term of patient-centred care first appeared in medicine and evolved as a reaction to illness-oriented medicine and dissatisfaction with unilateral influence of physician power (Balint, 1969; Lambert et al., 1997). In 1969, Michael and Enid Balint introduced the term in their work 'The possibilities of patient-centred medicine' and defined it as care in which the patient is understood as a unique human-being (Balint, 1969). However, the roots of this value can be traced back to Florence Nightingale (Lauver et al., 2002; Nightingale, 1992). Since the professional development of the nursing practice, one of the premises of nursing care has been the patient's individuality, differentiating nursing from medicine by focussing on the patient rather than on the disease (Lauver et al., 2002; Nightingale, 1992).

Since the 1960s, the interest in patient-centred care has continued to grow and has become an important paradigm in health care (Wolfe, 2001). A trend underlying the increased interest in patient-centred care was the acknowledgment and gradually the prioritisation of the role of quality in health care (Marjoua & Bozic, 2012). In 2001, the Institute of Medicine (IOM) presented in their report 'Crossing the Quality Chasm' a five-step agenda for building a stronger health system and improving quality of health care (Wolfe, 2001). Patient-centred care was added as one of the six aims for improvement and was defined as care that is respectful and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions (Wolfe, 2001). Furthermore, The World Health Organisation (WHO) has highlighted the importance of patient-centred care as an effective method to improve quality of care (WHO, 2013; WHO, 2015). This is not surprising as more and more evidence exists on the benefits and positive impact of patient-centred care. For example, studies within primary care showed that a patient-centred approach improves patients' health status, patients' social well-being, and satisfaction with care and leads to reduced hospitalisations and reduced needs of patients to access more specialised care (Bertakis & Azari, 2011; Kuipers, Cramm, & Nieboer, 2019; Stewart et al., 2000). Within mental health care, benefits are shown for reducing depression symptom levels (Cooper et al., 2013). A study that focussed on patient-centred care in the hospital context concluded that the implementation of patient-centred care could increase patient self-care ability and improve satisfaction with care and quality of life (Poochikian-Sarkissian, Sidani, Ferguson-Pare, & Doran, 2010). Also, across a wide range of conditions, including chronic heart failure (Ulin, Malm, & Nygårdh, 2015) and cancer (Radwin, Cabral, & Wilkes, 2009; Venetis, Robinson, Turkiewicz, & Allen, 2009) beneficial effects of the components of patient-centred care are shown.

A systematic review on patient-centred approaches to health care concluded that patient-centred care had a positive impact on emotional well-being and perceived quality of care of patients (McMillan et al., 2013). The review of Rathert, Wyrwich, and Boren (2013) reported strong evidence for positive influences of patient-centred care on self-management in patients with diabetes and satisfaction with care in various patient groups. Besides the positive effects of patient-centred care on the individual patient level, studies have also reported on decreased costs for the healthcare system, decreased utilisation of healthcare services, and decreased readmissions (Bertakis & Azari, 2011; Delaney, 2018).

The increased focus on patient-centred care has and its positive impact has led to thorough examination of the concept in different concept analysis (Castro et al., 2016; Jakimowicz & Perry, 2015; Leplege et al., 2007; Lusk & Fater, 2013; McCormack & McCance, 2006; Morgan & Yoder, 2012; Scholl, Zill, Härter, & Dirmaier, 2014), and the development of different patient-centred care frameworks and models attempting to conceptualise it (Constand, MacDermid, Dal Bello-Haas, & Law, 2014; Lor, Crooks, & Tluczek, 2016; Santana et al., 2018). A recent published review of reviews of patient-centred care by Håkansson et al. (2019) has identified nine themes present in the concept of patient-centred care: (1) empathy, (2) respect, (3) engagement (being present and committed), (4) partnership, (5) communication, (6) shared decision-making, (7) holistic focus, (8) individualised focus, and (9) coordinated and integrated care. Having multiple components, the concept is difficult to reduce to one single definition. However, many of the nine elements presented by Håkansson et al. (2019) can be found in the definition proposed by Castro et al. (2016), which has been used throughout this dissertation: "*A biopsychosocial approach and attitude that aims to deliver care that is respectful, individualised and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy, and shared knowledge".* The study of Castro et al. (2016) specifically focuses on the analysis of patient empowerment, patient participation, and patient-centred(ness) in hospital care, and determines the antecedents, attributes, and consequences of the concepts. Some of the elements proposed by Håkansson et al. (2019) are in the study of Castro and colleagues (2016) more considered as antecedents for patient-centred care than as specific attributes (e.g. coordination and integration of care, communication, patient participation). According to Castro and colleagues (2016), a first key attribute of the concept is a biopsychosocial focus in which there is attention for both the disease and illness experience of the patient (Castro et al., 2016). Healthcare professionals should not only pay attention to experience of physiological malfunction, but should strive to illuminate what it means for the patient to live with the illness (Seidlein & Salloch, 2019). Other key attributes include (1) treating the patient as a unique person which means understanding expectations, preferences, goals, needs, perceptions, and experiences of the patient through his/her eyes and (2) a sustainable and genuine relationship in which there is exchange of experiential knowledge and clinical knowledge (Castro et al., 2016). Besides multiple definitions, an array of alternative terms have been used to describe the concept of patient-centred care, including patient-centredness, relationship-centred care, client-centred care, client-centred practice, consumer-centred care, user-centred care, person-centred care, and individualised care (Castro et al., 2016; de Silva et al., 2014; Santana et al., 2018). The latter term warrants further attention as in this dissertation the Individualised Care Scale (ICS) is used to measure patient-centred care in Belgian (Flemish) hospital wards (Suhonen, Leino-Kilpi, & Välimäki, 2005a; Suhonen, Gustafsson, Katajisto, Välimäki, & Leino-Kilpi, 2010a). Suhonen, Stolt, and Papastavrou (2019) recently published a book in which they investigated the concept of individualised care and the various proposed definitions, depending on the context of health care. They indicated that both the concepts of individualised care and patient-centred care share the same theoretical basis, which rests on the principles of holism (Suhonen, Stolt, & Papastavrou, 2019). In the ICS, individualised care is operationalised as: *"A type of nursing care delivery which takes into account patients' personal characteristics in their clinical situation (= condition), personal life situation, and preferences and promoting patient participation and decision-making in his/her care".* Although the ICS is a measurement scale of the individualised care concept, it does measure the broad holistic concept of patient-centred care (Castro et al., 2016; Suhonen et al., 2019). The items of the measurement scale reflect different key attributes of the patient-centred care definition proposed by Castro et al. (2016).

1.2 Patient empowerment

The concept of empowerment is rooted in the social action ideology of the 1960s and the self-help movements in the 1970s and 1980s (Gibson, 1991; Hage & Lorensen, 2005; Kieffer, 1984). These movements brought questions of ethics, social justice, and empowerment to the fore, which increased attention towards the concept of empowerment in various domains such as politics, education, and health care (Green, Boaz, & Stuttaford, 2020; Roberts, 1999). International policy statements such as the 'Declaration of Alma-Ata' (Declaration of Alma-Ata, 1978) and the 'Ottawa Charter on Health Promotion' (WHO, 1986), formed the basis of the growing importance of empowerment in health care. Gradually the empowerment concept (defined as 'patient empowerment' in health care) has gained increased attention and importance, reflecting a fundamental change from paternalism towards an ethic of supporting patient empowerment, in which patients are seen as equal partners that can actively participate and make informed decisions (Barr et al., 2015; Roberts, 1999).

Patient empowerment has been internationally recognised as an essential element of high-quality care (Delnoij & Hafner, 2013; WHO, 2015). In their programme 'Health 2020', the WHO has set patient empowerment as the main goal for achieving better results in health care (WHO, 2012). It offers patients the opportunity to increase autonomy in their treatment, and eventually, to gain more control over their own lives (Aujoulat, Young, & Salmon, 2012; Castro et al., 2016; Cerezo, Juvé-Udina, & Delgado-Hito, 2016; Holmström & Röing, 2010). Literature distinguishes between immediate, intermediate and long-term outcomes of patient empowerment (Bravo et al., 2015). Participation in decision-making and achieving self-management could be considered as immediate consequences associated with patient empowerment (Bravo et al., 2015; Castro et al., 2016; Holmström & Röing, 2010; Werbrouck et al., 2018). Patient outcomes such as quality of life, well-being and patient satisfaction with life could be considered as intermediate outcomes of patient empowerment and improved health as a possible long-term outcome (Bravo et al., 2015).

Definitions of patient empowerment in literature are diverse. Gibson firstly attempted to define the concept for the domain of health care in 1991 (Gibson, 1991): *"Empowerment is a social process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their own lives. Even more simply defined, empowerment is a process of helping people to assert control over the factors which affect their health"*. Her concept analysis showed that the concept is complex and multi-dimensional, making it difficult to operationalise it (Gibson, 1991). Since then, several definitions/conceptual frameworks have been developed mainly focussing on frail elderly and patients with chronic conditions such as diabetes and chronic obstructive pulmonary disease (Bravo et al., 2015; Castro et al., 2016; Holmström & Röing, 2010). Also, within healthcare domains such as health promotion, mental health, and health education the concept has been widely studied (Castro et al., 2016; Holmström & Röing, 2010). Specifically for the hospital context, the most recent definition of patient empowerment, which has been used through this dissertation, is determined in the concept analysis of Castro et al. (2016): *"A process that enables patients to exert more influence over their individual health by increasing their capacities to gain more control over issues they themselves define as important".* The concept is characterised by personal change in relation to others, self-determination (having the right and ability to make own choices), and can be seen as an enabling process (Castro et al., 2016). In order to achieve patient empowerment, a dialogue in which patients are invited to tell the history of their illness, active patient participation by involving patients in decisions that affect their quality of life, a patient-centred approach, and enhancing patients' competencies are essential (Castro et al., 2016).

It should be noticed that the concept of patient empowerment remains complex, that it can be approached from different perspectives (patient, healthcare professional or the healthcare system), that it can lead to different interpretations (e.g. a theory, a process, an intervention, an outcome) and is not only situated at the level of interactions between patients and healthcare professionals but also at the meso-level (healthcare systems) and the macro-level (policy) (Castro et al., 2016). As a result, measurement of the concept is complex and suffers from lack of clarity and consensus on core constructs (Barr et al., 2015). The systematic review by Barr et al. (2015) found 38 distinct constructs of patient empowerment in 19 measurement scales. In the review, it was also shown that there was considerable overlap with the constructs captured by other measures not purporting to be measures of patient empowerment, such as enablement and patient activation.

The term ‘patient activation’ warrants further attention as in this dissertation patient empowerment is measured by the short form of the Patient Activation Measure (PAM-13) (Hibbard, Mahoney, Stockard, & Tusler, 2005; Rademakers, Nijman, van der Hoek, Heijmans, & Rijken, 2012). Although patient activation is a related concept of patient empowerment, both are closely intertwined and relate to an increased ability and motivation of patients to control their own health and life (Fumagalli, Radaelli, Lettieri, & Masella, 2015). The main difference is that patient activation is more focused on specific improvement goals or refers to specific diseases (Fumagalli et al., 2015). In the comprehensive review on concepts and measures of patient empowerment by Cerezo, Juvé-Udina, and Delgado-Hito (2016), it was indicated that the PAM-13 provides a robust measure of patient empowerment. Based on a recent systematic review on patient empowerment, the PAM-13 is one of the most comprehensively measures of patient empowerment that shows acceptable evidence for validity and reliability (Pekonen et al., 2020) and covers the elements of the definition as proposed by Castro et al. (2016). Further, a strength of the PAM-13 is that it is the only instrument that also includes the element patient’s knowledge (Pekonen et al., 2020). This element is one of the essential elements for a successful participation process (Castro et al., 2016; Pekonen et al., 2020).

1.3 How do the concepts of patient-centred care and patient empowerment relate to each other?

The terms of patient-centred care and patient empowerment are complementary or related to each other, but frequently used interchangeably in literature. However, they are not the same (Bonsignore et al., 2014). Patient-centredness is a necesarry process or a means of achieving empowerment for individuals, as it increases patients’ ability and motivation to control their own health and life (Fumagalli et al., 2015; Holmström & Röing, 2010; Pulvirenti, McMillan, & Lawn, 2014). According to Castro and colleagues (2016), the three concepts of patient participation, patient-centred care, and patient empowerment are closely interrelated. They state that by increasing patient's rights and opportunities to exert influence on and be involved in the decision-making about own care (patient participation), patient-centred care (which is characterised by a biopsychosocial approach and an attitude that aims to deliver care that is respectful, individualised, and empowering) will be facilitated (Castro et al., 2016). This in turn will empower patients to exert more influence over their own health by enhancing their capacities to gain more control over issues important to them (Castro et al., 2016). Thus, patient participation can be seen as a strategy to achieve patient-centred health care, which in turn will facilitate patient empowerment with in the end improved quality of hospital care or quality of life (Castro et al., 2016). It should be noticed that the process model of Castro and colleagues (2016) was not empirically tested. In Figure 1, the relationship between the concepts is shown.

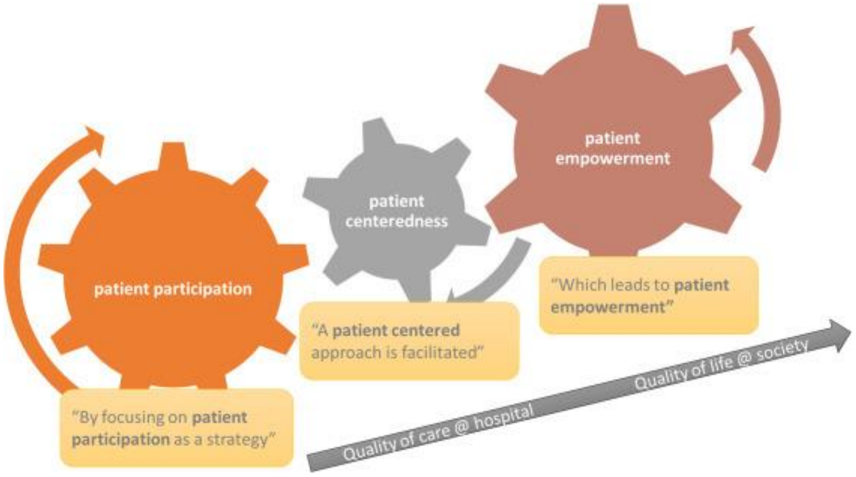

Figure 1. Castro's process model for concepts of patient participation, patient-centred care, and patient empowerment (Castro et al., 2016)

Yet, a recent scoping review indicates that patient empowerment is just a dimension of patient participation and can not be regarded as a 'broader' concept than patient participation and patient-centred care (Halabi et al., 2020). Halabi and colleagues state that patient empowerment is a precondition for partnership in care and should therefore be considered as a lever of patient participaton (Halabi et al., 2020). However, when looking more detailed at the results of the scoping review, the authours refer to patient empowerment as adopting a partnership attitude; commitment to a partnership process that requires acknowledging a patient's ability to self-manage his or her illness (Halabi et al., 2020). It is clear that there is a discrepancy between the two studies in how patient empowerment is defined. Halabi and colleagues rather refer to it as an antecedent (adopting a partnership attituted) that is crucial for patient participation, wheras Castro and colleagues (2016) define its true meaning as enabling patients to exert more influence over their own health and to self-manage their own care.

1.4 Role of the nurse in the support and provision of patient-centred hospital care and empowerment of patients

Nurses play a pivotal role in the support and provision of patient-centred hospital care and in the support of patient empowerment. Nurses employ behaviours that are fundamental for delivering care that (1) meets patients' unique health needs, preferences, and values, (2) understands patients' expectations, perceptions, and experiences, and (3) increases patients' capacity to act on issues that they themselves define as important (Castro et al., 2016; Feo et al., 2018). Examples of such behaviours include being present, engaging with patients, and working with patients to set, achieve, and evaluate progression of goals. To deliver care that is respectful, individualised, and empowering, developing a positive, sustainable, genuine, and trusting nurse-patient relationship is essential (Castro et al., 2016; Feo, Rasmussen, Wiechula, Conroy, & Kitson, 2017; Feo et al., 2018). The nurse-patient relationship has been studied over decades and is described as a professional, therapeutic relationship established to enable nurses to plan, provide, and evaluate care that meets patients' unique health needs (Feo et al., 2017). It forms the basis for care that is individualised and patient-centred (Kitson, Marshall, Bassett, & Zeitz, 2013a; Feo et al., 2017; Feo et al., 2018).

1.5 Measurement of patient-centred care and patient empowerment in the hospital context

As previously discussed, healthcare policy today strongly advocates the importance of adopting a patient-centred approach and supporting patient empowerment, as these approaches have the potential to improve quality of patient care (WHO, 2012; WHO, 2015). As a result, there are various studies in different healthcare contexts and in different patient groups examining the extent to which care is patient-centred (de Silva et al., 2014) and whether patients feel empowered to exert influence over their own health and to self-manage own care (Garattini & Padula, 2018). A common approach to measure the extent to which care is patient-centred or supporting patient empowerment is by asking them (de Silva, 2014). Mirrorwise healthcare professionals can be asked whether they perceive the care they provide is patient-centred. Over the years, more than 200 tools for measuring patient-centred care were developed (de Silva et al., 2014). As indicated in the previous section, the ICS is a generic measurement tool that allows for measuring the broad holistic concept of patient-centred care in the hospital context. Alongside the ICS, the Measure of Processes of Care (for parents' perceptions of family-centred care), the Person-centred Care Assessment Tool (for residential care homes), the Person-centred Climate Questionnaire (for measuring the extent to which hospital and long-term residential care for older people is person-centred), the Client Centred Care Questionnaire (for home nursing care), the Oncology Patients' Perceptions of the Quality of Nursing Care, and the Smoliner Scale are the most commonly cited validated measurement instruments on the broad holistic concept of patient-centred care (de Silva, 2014; Köberich & Farin, 2015). However, the ICS is the only generic instrument that allows measurement of patient-centred hospital care from the patient and the nurse perspective. For measuring patient empowerment in the hospital context, the PAM-13 is one of the most comprehensively measurement instruments (Pekonen et al., 2020).

Internationally, several studies have been conducted that measured patient-centred care from the patient and/or nurse perspective and patient empowerment in the hospital context. Suhonen and colleagues conducted several studies in surgical and orthopaedic in-patient wards in Sweden (Berg, Idvall, Katajisto, & Suhonen, 2012; Kalafati, Lemonidou, Dedousis, & Suhonen, 2007; Suhonen, Välimäki, & Leino-Kilpi, 2005b; Suhonen, Gustafsson, Katajisto, Välimäki, & Leino-Kilpi, 2010b). In 2012, Suhonen and colleagues measured and compared nurses' and patients' perceptions (working and staying on surgical wards) on patient-centred care in five European countries (the Czech Republic, Cyprus, Finland, Greece, and Hungary), and in 2018 they conducted an international comparison study on hospitalised cancer patients' perceptions of patient-centred care in four European countries (Sweden, Finland, Greece, and Cyprus). In 2011, Suhonen and colleagues conducted an international comparison study (Finland, Cyprus, Greece, Portugal, Sweden, Turkey, and the United States of America) on nurses' perceptions regarding patient-centred care. Also in other countries such as Germany (Köberich, Feuchtinger, & Farin, 2016) and Turkey (Arslan, 2015), studies on patient-centred hospital care were conducted. Regarding patient empowerment, measurement is mostly disease-specific and focusses mostly on patients with long-term conditions (Pekonen et al., 2020).

2. PATIENT-CENTRED CARE AND PATIENT EMPOWERMENT IN THE BELGIAN HOSPITAL CONTEXT

Besides the international attention for patient-centredness and patient empowerment, the Belgian Federal Government has underlined the importance of patient-centred care and patient empowerment (Paulus et al., 2012). They consider a culture shift towards patient-centredness by putting patients' experiences and outcomes as a priority in healthcare policy and management (Desomer et al., 2018; Federal Public Service Health, Food Chain Safety and Environment, 2013; Flemish Patients Platform, 2011; King Baudouin Foundation, 2007).

Between 2013 and 2017, the Belgian Federal Public Service for Health funded a multi-annual programme to improve patient participation and a patient-centred approach in quality of care and patient safety in hospitals. The general themes of the programme were: safety management, leadership, communication, and patient and family empowerment (Federal Public Service Health, Food Chain Safety and Environment, 2013). It was opted to choose themes that were embedded within accreditation standards for hospitals.

Despite the initiatives to improve patient-centred care and patient empowerment, little is known about perceptions of patients and nurses regarding the support and provision of patient-centred care in Belgian hospital wards (Flemish part) and the empowerment of Belgian (Flemish part) hospitalised patients. To date, there is only one empirical study on patient empowerment in Flanders, focussing solely on patients undergoing hemodialysis (Van Bulck et al., 2018). Measurement of patient-centred care is limited to the Health Interview Survey by the Scientific Institute of Public Health. The institute included four questions of a questionnaire (dedicated to patient experiences with physician care) published by the Organisation for Economic Cooperation and Development in their survey (Vrijens et al., 2016). Results of the questionnaire showed that patient satisfaction was very high on the four selected items (e.g. physician spending enough time with patients during the consultation). Some aspects of patient-centred care are also included in the satisfaction questionnaire initiated by the Flemish Patient Platform (Bruyneel et al., 2017). In order to measure patient-centredness in Flemish hospital wards, this dissertation will translate and psychometrically validate the Finnish ICS to establish its suitability for the Flemish hospital context (Suhonen et al., 2005a; Suhonen et al., 2010a). The ICS will not only allow to measure patients' and nurses' perceptions of patient-centred care, but also to compare them. For measuring patient empowerment in the hospital context there is already a valid and reliable tool available, namely the PAM-13 (Hibbard et al., 2005; Rademakers et al., 2012).

3. COMMUNICATION AS A FUNDAMENTAL OF NURSING CARE AND THE TELL-US CARD AS STRATEGY TO ENHANCE PATIENT-CENTREDNESS

The focus of this dissertation, the pursuit of patient-centredness and patient empowerment in hospital care, is inevitably intertwined with fundamental nursing care.

3.1 Communication as a fundamental of nursing care

Fundamentals of care can be described as key elements of care, encompassing physical, psychosocial, and relational aspects that are required for every patient regardless of their clinical condition or the setting in which they are receiving care (Feo & Kitson, 2016; Kitson, Conroy, Wengstrom, Profetto-McGrath, & Robertson-Malt, 2010). They are entwined with the current patient-centred care paradigm as they are embedded in the conceptualisation of patient-centred care or linked with the concept (Castro et al., 2016; Feo et al., 2018; Kitson et al., 2013a; Kitson, Dow, Calabrese, Locock, & Athlin, 2013b). The fundamentals of care are part of the Fundamentals of Care Framework (FoCF) that was designed in order to better understand the complex interactions between personal self-care needs when healthy and fit and how these needs chance with illness and disability (Kitson et al., 2010). The framework consists of three dimensions namely the nurse-patient relationship, the context of care, and the fundamentals of care that are essential for high-quality patient-centred fundamental nursing care (Kitson, Conroy, Kuluski, Locock, & Lyons, 2013c; Kitson & Muntlin Athlin, 2013d; Feo & Kitson, 2016; Feo et al., 2018).

According to the FoCF, communication is one of the fundamentals of care (Feo & Kitson, 2016; Feo et al., 2018; Kitson et al., 2010). Communication enables patients into taking a more active role in their care and to facilitate a patient-centred approach in hospital care, communication is crucial (Castro et al., 2016; Tobiano, Marshall, Bucknall, & Chaboyer, 2016). Through communication, patients are given the possibility to be involved in decisions about their care and are updated about their planned and continuing care (Feo & Kitson, 2016). Key elements of the FoCF such as: 'ability to cope', 'being involved and informed', and 'addressing concerns and frustrations of the patient', stress the importance of communication in health care and the need to consider individual patient characteristics with more attention in order to establish patient-centred care (Kitson et al., 2010; Feo & Kitson, 2016; Feo et al., 2017).

3.2 The Tell-us card as strategy to enhance patient-centredness?

The Tell-us card is a straightforward nurse-led communication tool that can be used to improve a patient-centred approach in hospital care (Jangland, Carlsson, Lundgren, & Gunningberg, 2012). It is a communication tool that helps to develop a genuine relationship with the patient being cared for and addresses some of the psychosocial (e.g. being involved and informed, having interests and priorities considered, feeling able to express opinions and needs) and relational elements (e.g. active listening, engaging with patients, being present and with patients) of the FoCF that are essential to ensure the patient's psychosocial wellbeing (Feo et al., 2017; Feo et al., 2018). The tool enables nurses to anticipate the patient's needs, concerns, and preferences with input from the patient. During their admission or in preparation for discharge, patients can write their needs, preferences, and concerns on the card. The tool also supports nurses to (1) engage with and focus on the patient, (2) consider needs from the patient perspective, and (3) get to know the patient and use the information on the card to inform care decisions (Feo et al., 2017; Feo et al., 2018). In Figure 2, the relationship between the Tell-us card, the FoCF and the previously described concepts in shown.

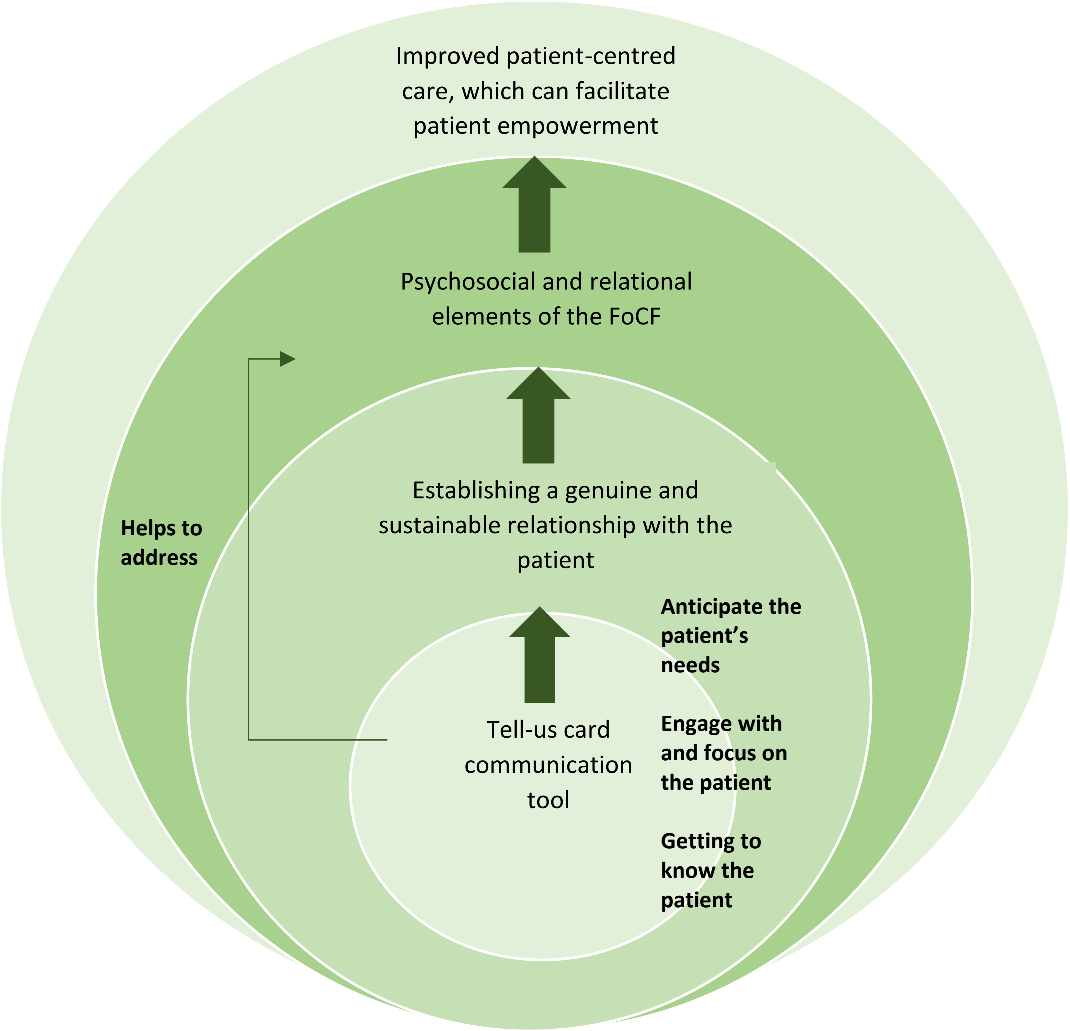

Figure 2. Relationship between the Tell-us card, the FoCF and patient-centredness

The Tell-us card was developed and tested in Sweden by Jangland, Carlsson, Lundgren, and Gunningberg (2012). They tested the effectiveness of the Tell-us card in a population of patients admitted to a surgical hospital ward and showed that by using the tool, patients' capabilities to participate in decisions concerning their nursing and medical care improved. The card enabled patients to express what was most important to them during their hospitalisation. Patients felt comfortable using the card as it encouraged them to state questions or concerns that they would otherwise have not raised or addressed (Jangland et al., 2012). As the Tell-us card looked a promising tool for enhancing a patient-centred approach in hospital care (Jangland et al., 2012), it was choosen to implement the tool in Belgian (Flemish part) hospital wards (surgical wards, internal wards, rehabilitation wards, and maternity wards). The implementation of the Tell-us card was embedded in the multi-annual programme (2013 - 2017) of the Belgian Federal Government to improve a patient-centred approach in hospital care. As part of the programme, the ‘Patient Participation Culture Tool for healthcare workers (PaCT-HCW)’ for measuring the patient participation culture on regional and university hospital wards was developed in 2014 (Malfait, Eeckloo, Van Daele, & Van Hecke, 2016). The results of this PaCT-HCW assessment were feedbacked towards the different participating wards through two seminars and two different projects to improve a patient-centred approach were presented: (1) the implementation project on bedside shift reporting and (2) the implementation project on the Tell-Us Card. In this dissertation, the results on the Tell-us card project will be presented. Simultaneously with the implementation of the Tell-us card in Flemish hospital wards, the tool was also implemented in Dutch hospital wards (van Belle et al., 2018). As the projects were closely intertwined, it was decided to also validate the ICS for the Dutch hospital context and to include the Dutch data in the comparison of nurses’ and patients’ perceptions of patient-centred care.

It should be noticed that the implementation of interventions in clinical practice can be complex and challenging (Richards & Hallberg, 2015). Before the actual implementation, a key step is to perform an assessment of barriers and enablers that will influence the adoption of the intervention. Insights in these barriers and facilitators are essential to be able to anticipate on them and to enhance the possibility of a successful implementation. As stressed by different ‘how-to-implement’ models, it is important to understand which factors inhibit or facilitate the process of change (Pronovost, Berenholtz, & Needham, 2008; Wensing & Grol, 2017). Different methods (e.g. focus groups, non-participant observation, interviews) and tools (e.g. The Organisational Readiness to Change Asesessement) exist to explore barriers and enablers to evidence implementation (Richards & Hallberg, 2015; Wensing & Grol, 2017).

4. GENERAL OBJECTIVES AND OUTLINE OF THE DISSERTATION

The main objectives of this dissertation were (1) to validate a tool to measure patient-centred care for the Flemish and Dutch hospital context, (2) to measure and compare Dutch-speaking patients' and nurses' perceptions of patient-centred care, (3) to measure patient empowerment in Flemish hospital wards, (4) to examine barriers and enablers for the implementation of the Tell-us card in Flemish hospital wards, and (5) to evaluate the implementation process and effectiveness of the Tell-us card in Flemish hospital wards.

The main objectives resulted in the following research questions:

1. Is the ICS a valid and reliable instrument to assess perceptions of patient-centred care for the Dutch and Flemish hospital context? **(Chapter 2)**
2. What are Dutch-speaking nurses' and patients' perceptions of patient-centred care and how do they compare? **(Chapter 3)**
3. How empowered are patients admitted to Flemish hospital wards? **(Chapter 4)**
4. What are potential barriers and enablers to the implementation of the Tell-us card in Flemish hospital wards? **(Chapter 5)**
5. To which extent do nurses and midwives follow the structured content protocol for the implementation of the Tell-us card? **(Chapter 6)**
6. What is the effect for patients of receiving the Tell-us card intervention in comparison to patients not receiving it concerning patient-centred care, patient empowerment, and quality of care? **(Chapter 6)**
7. What is the effect for nurses/midwives delivering the Tell-us card intervention in comparison to nurses/midwives not delivering it concerning, communication with the patient, patient participation culture, patient-centred care perceptions, coordination of the care process, and work interruptions? **(Chapter 6)**

Following chapter 1 (i.e. general introduction), chapter 2 describes the results of the psychometric validation study of the Dutch ICS. Chapter 3 presents the results of a secondary analysis of a cross-sectional study to measure and compare Dutch-speaking nurses' and patients' perceptions of patient-centred care. Chapter 4 provides the results of a secondary analysis of a cross-sectional study to measure patient empowerment in Flemish hospital wards. In chapter 5, the results of a qualitative study to investigate the potential barriers and enablers for the implementation of the Tell-us card in Flemish hospital wards are presented. Chapter 6 provides the results of multicentre study with a non-equivalent control group pretest-posttest design to evaluate the process (qualitative) and effectiveness (quantitative) of the Tell-us card communication tool in Flemish hospital wards. Finally, chapter 7 provides a general discussion of the study results, methodological considerations, recommendations, and a general conclusion.

An overview of the objective of each chapter, also describing the used methodology can be found in Table 1.

Table 1. Overview of the studies and methods used in each chapter of this dissertation

Chapter	Title	Aim	Methodology
2	The Dutch Individualised Care Scale – A psychometric validation study	Translating and psychometrically assessing the ICS for patients and nurses for the Flemish and Dutch healthcare context	The ICS was translated into Dutch using a forward–backward translation process. Minimal linguistic adaptations to the Dutch ICS were made to use the scale as a Flemish equivalent. Omega, Cronbach's alpha, mean inter-item correlations and standardised subscale correlations established the reliability and confirmatory factor analysis the construct validity of the ICS.
3	Individualised care in Flemish and Dutch hospitals: comparing patients' and nurses' perceptions	Comparing patients' and nurses' perceptions of individualised care, taking into account the perceptions of nurses and patients of 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.	Secondary analysis of cross-sectional data collected from 845 patients and 569 nurses of Dutch regional and university hospitals. The ICS was used to measure the perceptions of individualised care.
4	Patient empowerment in Flemish hospital wards: a cross-sectional study	Measuring empowerment of patients admitted on Flemish hospital wards and exploring the association between patient empowerment and patient-centred care, health literacy, patient- and context-related characteristics.	Secondary analysis of cross-sectional data collected in nine regional hospitals and one university hospital in Flanders. Patient empowerment was measured by the PAM-13.
5	Barriers and enablers for the implementation of a hospital communication tool for patient participation: A qualitative study	To investigate potential barriers and enablers prior to the implementation of the Tell-us card.	Qualitative study using semistructured individual interviews. with (head)nurses, nurse assistants and midwifes from three maternity wards, two surgical wards, two medical wards and one rehabilitation ward.
6	Evaluating the effectiveness of a communication tool to improve patient-centred care in hospital wards: a nonequivalent control group study in patients, nurses, and midwives'	To evaluate the implementation of the Tell-us card in Flemish hospitals.	A multicentre study with a non-equivalent control group pretest-posttest design.

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CHAPTER 2

THE DUTCH INDIVIDUALISED CARE SCALE FOR PATIENTS AND NURSES – PYSCHOMETRIC VALIDATION

Chapter based on:

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ABSTRACT

Aims and objectives: Translating and psychometrically assessing the Individualised Care Scale (ICS) for patients and nurses for the Flemish and Dutch healthcare context.

Background: Individualised care interventions have positive effects on health outcomes. However, there are no valid and reliable instruments for evaluating individualised care for the Flemish and Dutch healthcare context.

Design: Psychometric validation study.

Setting and participants: In Flemish hospitals, data were collected between February and June 2016, and in Dutch hospitals, data were collected between December 2014 and May 2015. Nurses with direct patient contact and a work experience of minimum 6 months on the wards could participate. Patient inclusion criteria were being an adult, being mentally competent, having an expected hospital stay of minimum 1 day, and being able to speak and read the Dutch language. In total, 845 patients and 569 nurses were included.

Methods: The ICS was translated into Dutch using a forward–backward translation process. Minimal linguistic adaptations to the Dutch ICS were made to use the scale as a Flemish equivalent. Omega, Cronbach's alpha, mean inter-item correlations and standardised subscale correlations established the reliability and confirmatory factor analysis the construct validity of the ICS.

Results: Internal consistency using Omega (Cronbach's alpha) ranged from 0.83 to 0.96 (0.82–0.95) for the ICS-Nurse and from 0.88 to 0.96 (0.87–0.96) for the ICS-Patient. Fit indices of the confirmatory factor analysis indicated a good model fit, except for the root mean square error of approximation, which indicated only moderate model fit.

Conclusion: The Dutch version of the ICS showed acceptable psychometric performance, supporting its use for the Dutch and Flemish healthcare context.

Relevance to clinical practice: Knowledge of nurses' and patients' perceptions of individualised care will aid to target areas in the Dutch and Flemish healthcare context in which work needs to be undertaken to provide individualised nursing care.

1. INTRODUCTION

Since the professional development of the nursing practice by Florence Nightingale, one of the premises of nursing care has been the patient's individuality (Nightingale, 1992). Respect for the individuality and uniqueness of all persons receiving nursing care is considered mandatory according to the International Council for Nurses. Due to the shift from the biomedical model to the holistic paradigm over the last century, there has been an increasing attention towards tailored healthcare interventions and individualised care in clinical practice and research (Wolfe, 2001). Literature indicates that individualised nursing care is considered important by both nurses and patients (Teeri, Leino-Kilpi, & Välimäki, 2006) and has the potential to improve healthcare quality. A number of studies have shown that individualised nursing has a positive effect on patient satisfaction with nursing care (Arslan, 2015; Frampton & Guastello, 2010; McMillan et al., 2013; Suhonen et al., 2012), mobility, recovery, and self-care ability (Poochikian-Sarkissian, Sidani, Ferguson-Pare, & Doran, 2010), and patients' reported quality of life (McMillan et al., 2013; Suhonen, Välimäki, Katajisto, & Leino-Kilpi, 2007). It also has the capacity to decrease healthcare-associated costs (Delaney, 2018). Further, a systematic review on job satisfaction for professionals showed some positive effects on general job satisfaction, job demands, emotional exhaustion and personal accomplishment among professionals delivering individualised care (van den Pol-Grevelink, Jukema, & Smits, 2012).

Suhonen, Leino-Kilpi, and Välimäki (2005a) have developed and psychometrically evaluated the Individualised Care Scale (ICS), which permits measuring the perception on individualised care of nurses and hospitalised patients. In this study, a Dutch translation and psychometric evaluation of the ICS for patients and nurses were carried out to establish whether the Finnish model also fits the data retrieved from patients and nurses in the Flemish and Dutch hospital settings.

2. BACKGROUND

The concept of individualised care is one of the many variations in the terminology used to define patient-centred care (de Silva, 2014; Santana et al., 2018), and various tool for measuring the concept of patient-centred care exist (de Silva, 2014; Köberich & Farin, 2015a; Ree, Wiig, Manser, & Storm, 2019). Measurement tools attempt to measure either the holistic concept or specific subcomponents such as shared decision-making (Santana et al., 2018). The rapid review of de Silva (2014) indicates that the commonly used measurement tools in published research about the broad holistic concept of patient-centred care are as follows: the Measure of Processes of Care, the Person-centred Care Assessment Tool, the Person- centred Climate Questionnaire and the ICS. Yet, they are of no better quality than other measurement instruments, as studies that compare the merits of different measures are lacking (de Silva, 2014). In the systematic review of Köberich and Farin (2015a), four instruments that measure perceptions of patient-centred nursing care were reported: the ICS, the Client Centred Care Questionnaire, the Oncology Patients' Perceptions of the Quality of Nursing Care Scale, and the Smoliner Scale. This study will focus on the validation of the ICS (Suhonen et al., 2005a; Suhonen, Gustafsson, Katajisto, Välimäki, & Leino-Kilpi, 2010a). Of the above mentioned measurement tools, the ICS is the most generic measurement instrument that focuses on the broad holistic concept of patient-centred care. Furthermore, the ICS allow to measure both nurses' and hospitalised patients' perceptions of individualised care.

Suhonen, Välimäki, and Katajisto (2000a) define individualised nursing care as nursing care that takes into account the individuality of the patient and facilitates patient participation in decision-making. Research suggests that patients vary substantially in their preferences for participation in decision-making, ranging from preferring to co-decide, to fully relying on the clinical expertise of their health provider (Levinson, Kao, Kuby, & Thisted, 2005). Providing individualised care means assessing differences in patient characteristics, preferences, and perceptions and tailor healthcare interventions accordingly (Hagsten, Svensson, & Gardulf, 2004; Levinson et al., 2005; Suhonen, Välimäki, Leino-Kilpi, & Katajisto, 2004).

2.1 The ICS

The ICS is a Finnish, bi-partite, Likert-type scale that allows the assessment of both nurses' and hospitalised patients' perceptions of individualised nursing care by means of two separate ICS scales, namely the ICS-Patient and the ICS-Nurse (Suhonen et al., 2005a; Suhonen et al., 2010a). Each scale contains 34 items, divided into two subsections. For the ICS-Patient, the first section (ICSA-Patient) consists of 17 items and was designed to measure patients' views of how individuality was supported through specific nursing interventions. The second section (ICSB-Patient) consists of 17 items and measures how patients perceive individuality in their care. Both sections consist of three subscales that consecutively measure (i) patient characteristics in the clinical situation (ClinA and B, seven items), (ii) the patient's personal life situation (PersA and B, four items) and (iii) decisional control over care by the patient (DecA and B, six items). The scale is formatted into a five-point Likert scale (1 = fully disagree, 2 = disagree, 3 = neither disagree nor agree, 4 = agree, 5 = fully agree). The ICS was mirrored in order to measure nurses' perceptions of (i) how they support patients' individuality through specific nursing activities (ICSA-Nurse) and (ii) the evaluation of maintaining individuality in their provided care (ICSB-Nurse). Both sections also consist of three subscales: (i) clinical situation (ClinA and B, seven items); (ii) personal life situation (PersA and B, four items); and (iii) decisional control over care (DecA and B, six items). A higher score on the ICSA section indicated that nursing activities were perceived as highly individualised. A higher score on the ICSB section indicated a higher perception of individuality in patients' care (Suhonen et al., 2005a; Suhonen, Välimäki, & Leino-Kilpi, 2005b).

Individualised care is considered to be one of the key characteristics in assessing quality of care. A proper translation and validation of the ICS is necessary in order to determine whether the scale can be used in its original form or needs adaptations due to cultural differences. This also could enhance the assessment of cross-cultural effects of individualised healthcare interventions on clinical outcomes. Currently, the ICS has been translated in English, Greek, German, Turkish, Swedish, Spanish, and Portuguese and used in several international studies (Acaroglu, Suhonen, Sendir, & Kaya, 2011; Amaral & Suhonen, 2014; Arslan, 2015; Berg, Suhonen, & Idvall, 2007; Köberich, Suhonen, Feuchtinger, & Farin, 2015b; Rodríguez-Martín, Martin-Martin, & Suhonen, 2019; Suhonen et al., 2010b). There were no previous studies that measured patients' and nurses' perceptions of individualised care conducted in Flanders and the Netherlands. Measuring both patients' and nurses' perceptions of individualised care will aid to identify the extent to which nurses and patients share the same understanding of the care provided (Suhonen, Gustafsson, Katajisto, Välimäki, & Leino-Kilpi, 2010c; Suhonen et al., 2011). This study focused on translating the ICS for Flanders and the Netherlands and assessed its reliability and construct validity through confirmatory factor analysis on Dutch data from both nurses and patients.

3. METHODS

3.1 Translation of the ICS

The ICS was translated from English into Dutch, using the forward–backward translation procedure. The English ICS was translated into Dutch independently by two senior researchers with adequate skills in English (C1 level) and with profound expertise in individualised health care. One independent certified English linguist translated the Dutch ICS back to English. The original ICS and the back-translated ICS were compared, and semantic alterations to the Dutch scale were made accordingly. For the ICS-Nurse, alterations were made to seven items and for the ICS-Patient to ten items (e.g. from 'The nurses talked with me about the feelings I have had about my condition' to 'The nurses talked with me about my feelings regarding my condition'). Minimal linguistic adaptations to the Dutch ICS were made to use the scale in Belgium as a Flemish equivalent. For both the ICS-Nurse and the ICS-Patient, alterations were made to seven items. Adaption from Dutch to Flemish was carried out by a group of two Flemish senior and two junior researchers in nursing science. Item content validity (I-CVI) was established by asking five patients to judge the wording and comprehensibility of the items, and seven students following a master's programme in nursing sciences (combining the programme with a job in nursing care) reviewed the items regarding comprehensibility, relevancy and linguistic correctness using the content validity indexing technique. It was opted to use master's students because they were able to assess the comprehensibility and relevancy of the items from their position as a student researcher and their position as a nurse. First, the I-CVI was calculated by dividing the number of raters giving a rating of either 3 or 4 on the 4-point Likert scale (ranging from totally disagree to totally agree), by the total number of raters (Polit & Beck, 2016). However, as the I-CVI does not, on its own, correct for chance agreement among the raters, a formula that integrates an I-CVI score into a modified kappa statistic calculation that corrects for chance was used (Polit, Beck, & Owen, 2007). The modified kappa evaluation criteria are as follows: Fair 0.40–0.59; Good 0.60– 0.73; and Excellent_0.74 (Polit et al., 2007). Of the items, 9% were rated as fair, 18% as good and 73% as excellent. In this study, both versions, the Dutch (The Netherlands) and the Flemish (Belgium) ICS scale, were considered as one single scale, because of its minor differences. We therefore refer to the scale as the Dutch ICS.

3.2 Psychometric evaluation of the ICS

Setting

For the validation of the Dutch ICS, data collected in Flemish (Flanders) and Dutch hospitals (The Netherlands), participating in two improvement projects to enhance patient participation in hospitals (the implementation of bedside shift reporting and the implementation of the Tell-us card) were used. Flemish hospitals are situated within the Dutch-speaking, Flemish Community (Flanders) of Belgium. No hospitals of the French-speaking, Walloon Community (Wallonia) of Belgium were included.

In Flanders, quality coordinators, chief nursing officers, and chief medical officers from all Flemish regional hospitals (n = 68) and university hospitals (n = 3) were invited to engage in the improvement projects. Exploratory meetings took place with head nurses, chief nursing officers, and chief medical officers to discuss eligibility in the study. Wards for surgery, geriatric care, internal medicine, medical rehabilitation, and maternal care were included. Hospitals willing to participate had to give an informed consent signed by the chief executive officer.

In the Netherlands, three surgical wards and one cardiology ward residing within the same university hospital and one cardiology ward of a regional hospital were invited to engage in the study. Exploratory meetings took place with ward managers to discuss eligibility in the study. Hospitals willing to participate had to give an informed consent signed by the ward manager.

In total, nurses on 34 wards and patients on 29 wards of two hospitals in the Netherlands and ten hospitals in Flanders participated in the improvement projects. An overview of all included wards per hospital and per improvement project is presented in Table 1.

Table 1. Overview of all included wards per hospital and per study

Study	Hospital	Discipline	Nurses per hospital (n)	Patients per hospital (n)
Tell-us card Flanders	Hospital A	General surgery 1, General surgery 2, General surgery 3	35	101
	Hospital B	General surgery, Oncology, Maternity	53	101
	Hospital C	Maternity	16	30
	Hospital D	Locomotor rehabilitation, Heart and Lung Diseases, Neurology/Nephrology	33	56
	Hospital E	Maternity	20	39
	Hospital F	Neural rehabilitation	11	6
	Hospital G	Maternity	17	34
Tell-us card the Netherlands	Hospital H	Neurosurgery, Head and Neck surgery, Orthopaedics, Cardiology	63	109
	Hospital I	Cardiology	42	24
Bedside Shift Report Flanders	Hospital A	Locomotor rehabilitation, Neural rehabilitation	25	39
	Hospital B	Orthopaedics/General surgery/Rheumatology, Orthopaedics/Traumatology, Locomotor rehabilitation, Neurosurgery	70	115
	Hospital C	Geriatrics	20	N/A[a]
	Hospital G	Geriatrics, General surgery	46	41 (Geriatrics N/A[a])
	Hospital J	Geriatrics	35	N/A[a]
	Hospital K	Cardiopulmonary rehabilitation, Orthopaedics, Neurology	40	63
	Hospital L	Cardiopulmonary rehabilitation, Neural rehabilitation/Physiology, Orthopaedics	43	87
	TOTAL		**569**	**845**

[a] N/A = Not available

Participants

Nurses with direct patient contact and a work experience of at least 6 months on the ward were eligible for participation in the studies. Adult patients (age > 18) mentally competent with adequate ability to speak and read the Dutch language and with an expected hospital stay of at least 1 day were included. Being mentally competent was assessed by the nurses of the ward. Patients who had trouble remembering, learning new things, concentrating and making decisions due to medication side effects, delirium, depression, dementia, and other mental illnesses were excluded. Also, patients who were intellectually disabled due to trauma before birth, trauma during birth, inherited disorders, and chromosome abnormalities were excluded.

Data collection

In Flanders, data were collected between February and June 2016, and in The Netherlands, data were collected in between December 2014 and May 2015. A list of the hospitalised patients who met the inclusion criteria was available for the researchers. In Flanders, the ICS for the patients was distributed by a member of the research team and recollected after 2 hours. If patients did not have the opportunity to complete the questionnaire in time, a collection box was available on the ward. If patients were in the impossibility of filling in the questionnaire themselves due to motoric difficulties, a member of the research team or sometimes a study nurse with no affiliation to the research team assisted the patient by filling in his answer. In The Netherlands, 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 closed envelope. By weekly visits to the wards (in The Netherlands by regular visits and weekly emails), nurses were reminded of filling in the questionnaire. A collection box was available on the ward. After 1 month, the questionnaires were collected by a member of the research team. Nurses who did not fill in the questionnaire upon collection were addressed personally by the head nurse and again invited to participate.

Analysis

Statistical analyses were performed using SPSS 25 (SPSS Inc, Chicago, IL, USA), R statistical software packages, and AMOS 22 (SPSS Inc). Descriptive statistics (percentages, means and standard deviations (SDs)) were reported to describe both patients' and nurses' socio-demographic characteristics. To check whether the missing items were missing (completely) at random, it was compared whether the socio-demographic characteristics of the respondents (nurses/ patients) with missing data differed from those of the respondents (nurses/patients) without missing data.

The full sample of nurses and patients was recoded into a group of respondents with at least one missing item on the ICS scale and a group of respondents without missing items. Characteristics of the group of respondents with at least one missing item and the group of respondents with no missing items were compared using chi-squared tests and t-tests.

The reliability of the subsections and the subscales was examined in relation to the instrument's internal consistency by calculating both Omega and Cronbach's alpha coefficients, and the homogeneity of the instrument (mean inter-item correlations, item-to-total correlations and standardised subscale correlations). As Cronbach's alpha has been shown to be unrelated to a scale's internal consistency and a fatally flawed estimate of its reliability, it is more appropriate to report Omega (Peters, 2014). However, other studies assessing the internal consistency reliability of the ICS always report the Cronbach's alpha. Therefore, Cronbach's alpha was also reported in this study. This allows to compare the internal consistency reliability of the Dutch ICS with those reported in other studies.

The matrix of adequate internal consistency in light of item count and sample size provided by Ponterotto and Ruckdeschel (Ponterotto & Ruckdeschel, 2007) was used to determine the relative strength of the Omega and Cronbach's alpha coefficients. Mean inter-item correlations situated within a 0.30–0.70 range were considered satisfactory (Ferketich, 1990). Item-to-total correlations were acceptable against the criteria of $r > 0.30$ (Munro, 2005).

Construct validity was investigated using structural equation modelling in the form of a confirmatory factor analysis. An a priori assumption of the underlying structure (Suhonen et al., 2010a), with two subsections that each contains three corresponding subscales, was made. Factor loadings and standard errors were reported. Factor loadings that exceeded the criterion of 0.30 were regarded as good indicators of the respective subscales (Hair, Black, Babin, Anderson, & Tatham, 2010). Because the chi-square statistics may be inflated by larger sample sizes and is no longer relied upon as a basis for acceptance or rejection, fit indices, which are less dependent on sample size, were interpreted (Schermelleh-Engel, Moosbrugger, & Müller, 2003, Vandenberg, 2006). A comparative fit index (CFI) > 0.90 suggests a good model fit, while values > 0.95 suggest an excellent model fit. For the standardised root mean square residual (SRMR), values lower than 0.08 indicate a good model fit. For the root mean square error of approximation (RMSEA), values of less than 0.07 indicate good model fit (Hooper, Coughlan, & Mullen, 2008; Hu & Bentler, 1999; Lei & Wu, 2007). Model modifications on the basis of modification indices or the Lagrange multiplier test were conducted (Whittaker, 2012).

Modification indices showed that model fit would improve if certain items were allowed to correlate (Whittaker, 2012). Consistent with the recommendations of Hermida (2015), the number of possible error correlations was limited to a minimum, allowing only error correlations between items that were similar in formulation or meaning.

Ethical considerations

This study was approved by the Institutional Review Board of the study hospitals in Belgium (B670201526903) and the Netherlands (2014-1350). Informed consent was obtained from all patients and nurses through provision of detailed information on the purpose of the improvement project (Tell-us card or Bedside shift reporting) and the confidentiality.

4. RESULTS

4.1 Patients' and nurses' characteristics

Due to no differences in characteristics between patients (nurses) with at least one missing item and patients (nurses) without missing items on the ICS, data from patients (nurses) with one or more missing values (for patients 193 cases and for nurses 37 cases) were eliminated. In total, 845 patients from eleven hospitals and 569 nurses from twelve hospitals were included in the analysis. The sample size is sufficiently large to give adequate power for the statistical analyses, as the recommendation is using a sample that is ten to twenty times the number of parameters to be estimated in the confirmatory analyses (Lei & Wu, 2007; Polit & Beck, 2016). The mean age of the patients was 57 (SD = 19.3). More than half of the patients were females (57%). 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%). The average amount of days of hospital admission was 11.2 days (SD = 17.4).

Nurses were on average 40 (SD = 12.5) years old and mostly female (90%). Half of the nurses had a bachelor degree (51%), 42% had a vocational degree and almost 3% had a university degree. About 4% of the participants were nursing assistants. Most nurses had 1–5 years of work experience (24%) or 20 or more years of work experience (31%) and were fully employed (43%). An overview of all patients' and nurses' characteristics is presented in Table 2.

Table 2. Descriptive statistics for patients and nurses

		Patients (n = 845)	**Nurses (n = 569)**
Age Mean (SD)		56.5 (19.3)	39.7 (12.5)
Days of hospital admission Mean (SD)		11.2 (17.4)	
Gender n (%)	Male	363 (43.1)	58 (10.2)
	Female	479 (56.9)	511 (89.8)
Level of education (patients) n (%)			
	< Bachelor	551 (65.8)	
	Bachelor	203 (24.3)	
	Master	83 (9.9)	
Level of education (nurses) n (%)			
	Nurse assistant[a]		22 (3.9)
	Vocational nurse[b]		237 (42.1)
	Bachelor educated[c]		288 (51.2)
	Master educated[d]		16 (2.8)
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)	
Years of nurses' work 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)
Work status			
	< 50%		87 (16.0)
	50%–99%		222 (40.9)
	100%		234 (43.1)
Employment status			
	Employed	277 (39.0)	
	Unemployed	24 (3.4)	
	Student	16 (2.3)	
	Disabled	65 (9.0)	
	Retirement	329 (46.3)	
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[e]	80 (14.1)
	Surgical	300 (35.5)	160 (28.1)
	Medical rehabilitation	192 (22.7)	103 (18.1)
	Mixed surgical/internal	29 (3.4)	25 (4.4)

[a] One year of education at level 3 of the European Qualifications Framework (EQF).
[b] Three years of education at level 5 of the EQF to obtain a diploma in Nursing.
[c] Three years of education at level 6 of the EQF to obtain the degree of Bachelor in Nursing.
[d] Five years of education at level 7 of the EQF to obtain the degree of Master in Nursing
[e] N/A = not available

4.2 Construct validity

To assess construct validity, a confirmatory factor analysis was carried out. All paths from the subscales to the items were statistically significant at the 5% level. For patients, standardised factor loadings ranged 0.61–0.85 (0.53–0.86) for ClinA-Patient (ClinB-Patient), 0.71–0.83 (0.58–0.83) for PersA-Patient (PersB-Patient) and 0.58–0.84 (0.50– 0.86) for DecA-Patient (DecB-Patient). For nurses, factor loadings ranged 0.73–0.85 (0.64–0.87) for ClinA-Nurse (ClinB-Nurse), 0.63–0.76 (0.67–0.79) for PersA-Nurse (PersB-Nurse) and 0.62–0.83 (0.47–0.85) for DecA-Nurse (DecB-Nurse). An overview of the standardised factor loadings is provided in Addendum 1. The CFI did reach the cut-off value of > 0.90 for the sample of patients on both subsections and for the sample of nurses on the ICSB subsection. The SRMR did reach the cut-off value of < 0.08 for both the sample of nurses and patients on both subsections. Contrastingly, the RMSEA did not reach the cut-off value of < 0.07 for both the sample of nurses and patients on both subsections. In Table 3, an overview of the fit indices is given.

Table 3. Summary of model fit of the Dutch version of the ICS for nurses and patients

	Nurses				**Patients**			
	Items (n)	SRMR[e]	CFI[f]	RMSEA[g]	Items (n)	SRMR[e]	CFI[f]	RMSEA[g]
ICSA[a,c]	17	0.0524	0.893	0.103	17	0.0463	0.917	0.089
ICSB[a,c]	17	0.0391	0.945	0.076	17	0.0445	0.925	0.089
ICSA[b,d]	17	0.0484	0.922	0.089	17	0.0408	0.945	0.073
ICSB[b,d]	17	0.0377	0.959	0.066	17	0.0422	0.942	0.079

[a] ICSA = Individualised Care Scale – Scale A; [b] ICSB = Individualised Care; [c] Without post-hoc modifications; [d] With post-hoc modifications; [e] Standardised root means square residual (an acceptable value is below 0.80); [f] Comparative fit index (an acceptable value is more than 0.90); [g] Root mean square error of approximation (an acceptable value is below 0.07)

Because (i) the correlation matrix of the reliability analysis showed high correlations (> 0.70) between items 6 & 7 and 15 & 16, (ii) modification indices suggested adding error correlations between certain items, and (iii) two experts in scale development agreed that items 6 & 7 and 15 & 16 had similar item content, error correlations were added between those items. This resulted in a better model fit. However, the RMSEA still did not reach the cut-off value of < 0.07 for the sample of nurses on the ICSA subsection and for the sample of patients on both subsections. An overview of the error correlations is given in Table 4.

Table 4. Overview of error correlations

	Items 6 & 7	**Items 15 & 16**
ICSA-Patient[a]	‘Made an effort to find out how the condition has affected me’ & ‘Talked with me about what the condition means to me’	‘Helped me take part in decisions concerning my care’ & ‘Helped me express my opinions on my care’
ICSB-Patient[b]	‘The way the condition has affected me has been taken into account in my care’ & ‘The meaning of the illness to me personally has been taken into account in my care’	‘I have taken apart in decision-making concerning my care & ‘The opinions I have expressed have been taken into account in my care’
ICSA-Nurse[a]	‘I make an effort to find out how their health condition has affected them’ & ‘I talk with patients about what the health condition means to them’	‘I help patients take part in decisions concerning their care’ & ‘I encourage patients to express their opinions on their care’
ICSB-Nurse[b]	‘I took into account the way the health condition has affected them’ & ‘I took into account the meaning of the health condition to the patient’	‘Patients took part in decision-making concerning their care’ & ‘I took into account the opinions patients expressed about their care’

[a]ICSA = Individualised Care Scale – Scale A; [b]ICSB = Individualised Care Scale – Scale B

4.3 Internal consistency reliability

The Omega coefficients for ICS-Nurse and the ICS-Patient ranged from 0.83 to 0.96 and from 0.88 to 0.96. The Cronbach’s alpha coefficients for ICS-Nurse and the ICS-Patient ranged from 0.82 to 0.95 and from 0.87 to 0.96. Standardised subscale correlations ranged from 0.78 to 0.89 for the ICS-Nurse and from 0.70 to 0.87 for the ICS-Patient. All item-to-total correlations in both ICS-Nurse and ICS-Patient were higher than 0.30. Mean inter-item correlations ranged from 0.50 to 0.68 for the ICS-Nurse and from 0.52 to 0.63 for the ICS-Patient. However, there was more variation in the individual inter-item correlations. An overview of the values is displayed in Addendum 2.

5. DISCUSSION

Individualised care is an important aspect to be considered in providing qualitative nursing care and developing nursing care interventions (Suhonen et al., 2004). It is therefore essential to use a valid and reliable measuring instrument to assess both nurses' and patients' perceptions of how individualised care is provided. The Finnish ICS was developed and psychometrically validated to measure perceptions of individualised care in a Finnish healthcare context.

5.1 Construct validity of the Dutch ICS

Confirmatory factor analysis supported evidence that the structure of the ICS corresponds to the Dutch sample data. The CFI did reach the cut-off value of > 0.90 for the sample of patients on both subsections and for the sample of nurses on the ICSB subsection. The SRMR did reach the cut-off value of < 0.08 for both the sample of nurses and patients on both subsections. However, even after allowing for error correlation between the items (i.e. item 6 & item 7; item 15 & item 16), the RMSEA did only reach the cut-off value of < 0.07 for the ICSB- Nurse, indicating only moderate fit (Musil, Jones, & Warner, 1998). The results of this study are similar to those of the German version of the ICS-Patient, supporting evidence for the construct validity of the Dutch ICS. Values of the German version are (values for ICSB in parentheses) 0.090 (0.090) for the RMSEA, 0.092 (0.091) for the CFI and 0.05 (0.05) for the SRMR (Köberich et al., 2015b). However, fit indices of the Finnish ICS-Nurse (values for ICS-Patient in parentheses) showed a better model fit, with values of 0.062 (0.076) for the RMSEA, 1.00 (not reported) for the CFI and 0.015 (0.021) for the SRMR (17.20).

All the factor loadings of the Dutch ICS exceeded the criterion of 0.30 and were therefore regarded as good indicators of their respective subscales (Hair et al., 2010). The factor loadings for the ICS-Patient and the ICS-Nurse subscales are similar to those in the studies of Suhonen et al. (2010a) and Suhonen et al. (2005a). When looking at the factor loadings in the cross-cultural comparison study of Suhonen et al. (2010b), some factor loadings are lower in the Finnish, Greek, Swedish, and British ICS compared with the factor loadings in the Dutch ICS.

5.2 Internal consistency reliability of the Dutch ICS

Item-to-total correlations, inter-item correlations, and standardised subscale correlations supported evidence for the homogeneity of the ICS-Nurse and ICS-Patient for the Dutch sample data. All item-to-total correlations were acceptable against the criteria of r > 0.30. Mean inter-item correlations were adequate against the criteria of 0.30–0.70, and the standardised correlations between subscales were all high indicating substantial similarity between subscales. Internal consistency using Omega and Cronbach's alpha coefficients was good to excellent, with coefficients of 0.95–0.96 for the subsections and coefficients of 0.82–0.95 for the subscales (Ponterotto & Ruckdeschel, 2007). This indicates that the items of the tool fit together conceptually and represent the same phenomena within the sample. However, reliability coefficients over 0.9 might be an indication of redundancy in measuring intended construct within items (Köberich et al., 2015b; Streiner, Norman, & Cairney, 2015). Similar results were reported in other studies assessing the internal consistency of the ICS (Acaroglu et al., 2011; Köberich et al., 2015b; Rodríguez-Martín et al., 2019; Suhonen et al., 2010b). Suhonen et al. (2010b) suggested that given the high internal consistency for the subsections or subscales, it might be possible to shorten the questionnaire further. Based on the results of this study, high correlations (> 0.70) between items 6 & 7 and items 15 & 16 and similar item content of these items, we suggest to shorten the questionnaire through deleting item 6 or 7 and item 15 or 16.

5.3 Study limitations

Some limitations need to be taken into account in the interpretation of the results. First, data were collected on a range of various wards (surgical wards, internal wards, geriatric wards, maternity wards, and rehabilitation wards). However, there was no sufficient power to do a hierarchical or stratified model with hospital ward as a variable (Dyer, Hanges, & Hall, 2005). Second, in this study test–retest reliability as part of the evidence of ICS's reliability was not assessed. This might be considered as a limitation of this study. Third, since only a small percentage of the items were rated as fair regarding content validity, it was decided to retain these items. However, this could have affected the construct validity of the Dutch version of the ICS and could be an explanation for RMSEA not reaching the cut-off value of < 0.07 for the sample of nurses on the ICSA subsection and for the sample of patients on both subsections (Polit et al., 2007). Fourth, adding post hoc inter-item modifications might result in estimating data-driven models that are potentially not generalisable across samples (Chou & Bentler, 1990; Green, Thompson, & Babyak, 1998). That is, the model may fit the particular data of the sample without a chance of being reproduced in other populations (Bandalos, 1993). Fifth, no patients were involved in judging the relevance of the ICS items. Nevertheless, the patient perspective had already been thoroughly examined in previous studies (Suhonen, Välimäki, & Katajisto, 2000b; Suhonen et al., 2004). Last, no specific scales to assess cognitive impairment were used.

6. CONCLUSION

Overall, the study on the Dutch version of the ICS showed adequate psychometric performance, supporting its use for the Dutch population. Internal consistency reliability was good, supporting the reliability of the scale. Moreover, acceptable model fit suggests that there is sufficient evidence to sustain the construct validity of the Dutch version of ICS.

7. RELEVANCE TO CLINICAL PRACTICE

Knowledge of nurses' and patients' perceptions of individualised care will help to target areas in the Dutch and Flemish healthcare context in which work needs to be undertaken to provide care adapted to the individuality of the patient and will help to be more aware of the obstacles to provide individualised nursing care (Suhonen, Välimäki, & Leino-Kilpi, 2002; Suhonen et al., 2004). Also, using a valid and reliable instrument to assess perceptions of individualised care for the Dutch and Flemish healthcare context will enhance clinical practice by allowing researchers and healthcare workers to develop individualised care interventions and measure their effects on several clinical and patient outcomes (Suhonen, Välimäki, & Leino-Kilpi, 2002; Suhonen et al., 2004).

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CHAPTER 3

COMPARING DUTCH-SPEAKING NURSES’ AND PATIENTS’ PERCEPTIONS OF INDIVIDUALISED CARE

Chapter based on:

Theys, S., van Belle, E., Heinen, M., Malfait, S., Eeckloo, K., Beeckman, D., Verhaeghe, S., & Van Hecke, A. (2021). Individualised care in Flemish and Dutch hospitals: comparing patients’ and nurses’ perceptions. *Scandivanvian Journal of Caring Science*s. Doi:10.1111/scs.13016

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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.

Design: Cross-sectional design.

Methods: 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 analysed. 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.

1. 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 characterised by inclusivity and equity in the professional–patient relationship (Håkansson et al., 2019). Nevertheless, even though patient-centred care is a core component of health care (de Silva, 2014) 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 (Papastavrou et al., 2016; Suhonen et al., 2012a). 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 (2005a) 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'.

2. 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 (Wolfe, 2001). Over the years, patient-centred care has been conceptualised differently but there is still not one clear definition of the concept and variation in terminology exists (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016; de Silva, 2014). 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. 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 (Castro et al., 2016). Both the concepts of individualised care and patient-centred care share the same theoretical basis, which rests on the principles of holism (Suhonen et al., 2019).

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. 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 (Suhonen, Välimäki, & Katajisto, 2000).

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 (McMillan et al., 2013; Rathert, Wyrwich, & Boren, 2013; Suhonen, Välimäki, Katajisto, & Leino-Kilpi, 2007; Suhonen et al., 2012b), and reduces depression symptom levels (Cooper et al., 2013). Individualised care can also contribute to general job satisfaction and personal accomplishment among healthcare professionals (van den Pol-Grevelink, Jukema, & Smits, 2012).

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. (2012a), analysing 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.

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. 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.

Notwithstanding the studies of Papastavrou et al. (2016) and Suhonen et al. (2012a) 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.

3. METHODS

3.1 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 socio-demographic and context-related variables are associated with these perceptions.

3.2 Design and participants

A secondary analysis of a cross-sectional study in which data were collected on wards participating in two studies focussing 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 (Malfait, Eeckloo, Lust, Van Biesen, & Van Hecke, 2017; Theys et al., 2020; Theys, Van Hecke, Akkermans, & Heinen, 2021; van Belle et al., 2018).

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 (Theys et al., 2021). 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 (Theys et al., 2021). In total, 845 patients on 34 wards and 569 nurses on 29 wards were included in the analysis (Theys et al., 2021).

3.3 Data collection

The data were collected in Flanders (ten hospitals), the Dutch-speaking part of Belgium, and the Netherlands (two hospitals) (Theys et al., 2021). 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 (Theys et al., 2021). In Flanders, data were collected between February and June 2016, and in the Netherlands between December 2014 and May 2015 (Theys et al., 2021).

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 (Theys et al., 2021). Information sessions on the implementation projects were organised (Theys et al., 2021). Wards for surgery, geriatric care, internal medicine, medical rehabilitation, and maternal care were included (Theys et al., 2021). Psychiatric wards, paediatric wards, psychogeriatric ward, palliative wards, emergency or intensive care wards, day hospitals, burns units, and outpatient clinics were excluded (Theys et al., 2021).

The researchers received a list (from the head nurses) indicating which hospitalised 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 (Theys et al., 2021).

If patients did not have the possibility to complete the questionnaire in time, a collection box was available on the ward (Theys et al., 2021). 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 (Theys et al., 2021). 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 (Theys et al., 2021). 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 (Theys et al., 2021). 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 (Suhonen et al., 2005a) and the ICS-Nurse (Suhonen, Gustafsson, Katajisto, Välimäki, & Leino-Kilpi, 2010a). 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 (Suhonen, Stolt, Puro, & Leino-kilpi, 2011). ICSB measures how patients perceive their care as individual to them and how nurses perceive the maintenance of individuality in care provision (Suhonen et al., 2011). 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) (Suhonen et al., 2005a; Suhonen et al., 2010a). 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) (Suhonen, Välimäki, & Leino-Kilpi, 2005b). 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 hospitalisation, habits, family) (Suhonen et al., 2005b). 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 decsion-making and expressing opinions) (Suhonen et al., 2005b). 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 (Suhonen et al., 2012a). A high score on the ICSB subsection indicates a higher perception of individuality in patients' care (Suhonen et al., 2012a). The ICS was previously psychometrically validated for the Dutch healthcare context (Theys et al., 2021). The Dutch version of the ICS showed acceptable psychometric performance, supporting its use for the Dutch and Flemish healthcare context (Theys et al., 2021). 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 (Theys et al., 2021). The model fit suggested sufficient evidence to sustain the construct validity of the Dutch ICS (Theys et al., 2021). 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 (Chew, Bradley, & Boyko, 2004; Theys et al, 2020): (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?' (Chew et al., 2004; Theys et al., 2020). 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) (Hibbard, Mahoney, Stockard, & Tusler, 2005; Theys et al., 2020). 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 (Rademakers et al., 2012a; Theys et al., 2020).

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).

3.4 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.

3.5 Data analysis

All analyses were conducted using SPSS 25.0 (IBM, 2017). The categorical variables were described using frequencies (percentages) and the continuous variables were described using means, medians, and SDs. To analyse 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 (Heck, Thomas, & Tabata, 2014).

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 (Yoo et al., 2014).

4. RESULTS

4.1 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). Patients were on average 57 (SD = 19.3) years old and 57% of the patients were female (Theys et al. 2021). 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%) (Theys et al. 2021). The median hospital admission was 5 days. An overview of all patients' and nurses' characteristics can be found in Table 1 and 2 (Theys et al., 2021).

The mean age of nurses was 40 years (SD = 12.5). Most nurses (90%) were female (Theys et al., 2021). Fifty-one percent of the nurses had a bachelor degree, 42% a vocational degree, and almost 3% had a university degree (Theys et al., 2021). Around 4% of the participants were nursing assistants (Theys et al., 2021). 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%) (Theys et al., 2021).

Table 1. Characteristics for patients

		Patients (n = 845) [a]
Age mean (SD)		56.5 (19.3)
Gender n (%)	Male	363 (43.1)
	Female	479 (56.9)
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)
Type of hospital		
	University	325 (38.5)
	Regional	520 (61.5)
Type of ward		
	Internal medicine	178 (21.1)
	Maternity	146 (17.3)
	Geriatric	N/A[b]
	Surgical	300 (35.5)
	Medical rehabilitation	192 (22.7)
	Mixed surgical/internal	29 (3.4)

[a] Numbers for the demographic characteristics of participants may not total 845 due to missing data

[b] N/A = Not available

Table 2. Characteristics for nurses

		Nurses **(n = 569)** [a]
Age mean (SD)		39.7 (12.5)
Gender n (%)	Male	58 (10.2)
	Female	511 (89.8)
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' work 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)
Work percentage		
	< 50%	87 (16.0)
	50%–99%	222 (40.9)
	100%	234 (43.1)
Type of hospital		
	University	186 (32.7)
	Regional	383 (67.3)
Type of ward		
	Internal medicine	125 (22.0)
	Maternity	76 (13.4)
	Geriatric	80 (14.0)
	Surgical	160 (28.1)
	Medical rehabilitation	103 (18.1)
	Mixed surgical/internal	25 (4.4)

[a] Numbers for the demographic characteristics of participants may not total 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

4.2 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 3 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 (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 4, 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 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.

Table 3. 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: patients' and nurses' views of how individuality was supported through nursing activities

[b] ICSB = Individualised Care Scale – Scale B: how patients perceive their care as individual to them and how nurses perceive the maintenance of individuality in care provision

[c] Clin = clinical situation: patients their feelings, needs, abilities, health condition, meaning of illness

[d] Pers = personal life situation: previous experiences of hospitalisation, habits, family

[e] Dec = decisional control over care: knowledge preferences, patients' wishes, opportunities for decsion-making and expressing opinions

[f] Range: 1-5

[g] MD = Mean difference

[h] CI = confidence interval

[*] p-value < 0.05

Table 4. Differences between nurses and patients concerning individualised care on ward level

		Maternity			**Internal medicine**			**Surgery**			**Medical rehabilitation**			**Mixed surgery/internal medicine**		
		Mean[f]	**MD**[g]	**p**	**Mean**	**MD**	**p**	**Mean**	**MD**	**p**	**Mean**	**MD**	**p**	**Mean**	**MD**	**p**
ICSA[a]*	Nurse	4.429	0.492	< 0.001*	4.194	0.604	< 0.001*	4.215	0.471	< 0.001*	4.278	0.771	< 0.001*	4.202	0.862	< 0.001*
	Patient	3.936			3.590			3.744			3.507			3.341		
ClinA[c]	Nurse	4.562	0.251	< 0.001*	4.290	0.460	< 0.001*	4.350	0.340	< 0.001*	4.386	0.704	< 0.001*	4.366	0.839	0.001*
	Patient	4.311			3.829			4.011			3.681			3.527		
PersA[d]	Nurse	3.938	0.741	< 0.001*	3.989	0.859	< 0.001*	3.932	0.663	< 0.001*	3.993	0.726	< 0.001*	3.930	0.844	0.003*
	Patient	3.197			3.130			3.269			3.267			3.086		
DecA[e]	Nurse	4.601	0.609	< 0.001*	4.227	0.610	< 0.001*	4.246	0.495	< 0.001*	4.337	0.855	< 0.001*	4.193	0.900	< 0.001*
	Patient	3.992			3.617			3.751			3.452			3.293		
ICSB[b]	Nurse	4.477	0.271	< 0.001*	4.110	0.246	0.005*	4.142	0.154	0.018*	4.171	0.398	< 0.001*	4.193	0.407	0.042*
	Patient	4.206			3.864			3.988			3.773			3.732		
ClinB[c]	Nurse	4.648	0.339	< 0.001*	4.305	0.410	< 0.001*	4.311	0.280	< 0.001*	4.427	0.599	< 0.001*	4.406	0.573	0.009*
	Patient	4.309			3.895			4.032			3.828			3.833		
PersB[d]	Nurse	4.072	0.410	< 0.001*	3.867	0.342	< 0.001*	3.910	0.238	0.001*	3.915	0.271	0.014*	3.790	0.419	0.082
	Patient	3.662			3.526			3.672			3.644			3.371		
DecB[e]	Nurse	4.546	0.099	0.187	4.048	0.006	0.945	4.097	0.048	0.483	4.040	0.253	0.018*	4.060	0.204	0.313
	Patient	4.447			4.054			4.144			3.787			3.856		

Note: No data for geriatric patients available

[a]ICSA = Individualised Care Scale – Scale A: patients' and nurses' views of how individuality was supported through nursing activities; [b]ICSB = Individualised Care Scale – Scale B: how patients perceive their care as individual to them and how nurses perceive the maintenance of individuality in care provision; [c]Clin = clinical situation: patients their feelings, needs, abilities, health condition, meaning of illness; [d]Pers = personal life situation: previous experiences of hospitalisation, habits, family; [e]Dec = decisional control over care: knowledge preferences, patients' wishes, opportunities for decsion-making and expressing opinions

4.3 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 5, an overview of the results is provided.

Table 5. Multilevel results for the Dutch and Flemish patients

			ICSA[a]		
	Estimate	**Mean**[f]	**P***	**95% CI**[g]	
				Lower bound	**Upper Bound**
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

4.4 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 6, an overview of the results is provided.

Table 6. Multilevel results for the Flemish patients

			ICSA[a]		
	Estimate	**Mean[f]**	**P***	**95% CI[g]**	
				Lower bound	**Upper Bound**
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

4.5 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 7, an overview of the results is provided.

Table 7. 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 work 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
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

5. 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 hospitalisation 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.

Our results are in line with those from the study of Suhonen et al. (2012a) in which differences in assessments of individualised nursing care were found in nurses and patients of five European countries. In each participating region, nurses scored significantly higher than patients (Suhonen et al., 2012a). 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). 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 decsion-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 behaviours appeared a major hindrance for supporting patient participation (Theys et al., 2020c; Tobiano, Marshall, Bucknall, & Chaboyer, 2016), an essential antecedent of individualised care (Castro et al., 2016). For example in the study of Theys et al. (2020c), it was found that nurses and midwives were hesitant towards the implementation of a hospital communication tool for patient participation. Tobiano, Marshall, Bucknall, and Chaboyer (2016) found that nurses controlling approach, influenced by organisational issues and pressure to complete tasks, was in conflict with an individualised approach to care.

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 (Bolster & Manias, 2010). 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) focussing on transgressive behaviour 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. 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 (van Belle et al., 2020).

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.

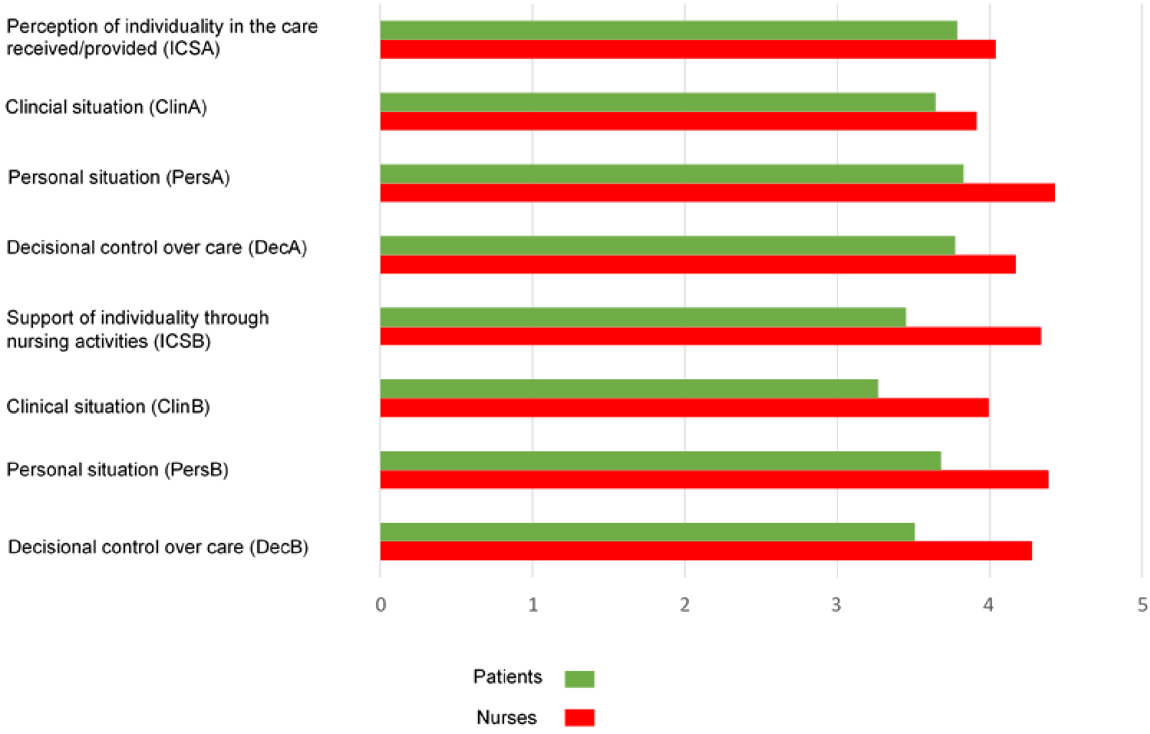

Figure 1. Differences between patients’ and nurses perceptions of individualised care for rehabilitation wards

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 (King, & Hoppe, 2013; Van Humbeeck et al., 2020). If nurses 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 (Rasheed, Younas, & Sundus, 2019; Vandecasteele et al., 2015). 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 (Han & Kim, 2016; Rasheed, 2015; Rasheed et al., 2019).

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), Papastavrou et al. (2016), and Suhonen et al. (2012a). 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. 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 (Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014). In line with earlier studies, our study also found that age (PersA) and years of work experience (DecB) had a positive association with nurses' perceptions of individualised care (Idvall et al., 2012; Rodríguez-Martín, Stolt, Katajisto, & Suhonen, 2016). 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 (Idvall et al., 2012; Rodríguez-Martín et al., 2016).

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 (Land & Suhonen, 2009; Suhonen, Välimäki, Katajisto, & Leino-Kilpi, 2006) and could be explained by a more critical stance (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015) and higher expectations (Rademakers, Delnoij, Nijman, & De Boer, 2012b) 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 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.

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.

5.1 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 (Theys et al., 2021). 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 (Heck et al., 2014).

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 (Polit & Beck, 2016). 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 (Rodríguez-Martín et al., 2016) and health status of the patient (Suhonen et al., 2006). 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 (Polit & Beck, 2016). 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 (Berg et al., 2012; Köberich, Suhonen, Feuchtinger, & Farin, 2015; Suhonen et al., 2010c; Suhonen et al., 2012a; Suhonen et al., 2018). The systematically higher scores might indicate that there is a methodological flaw in how the ICS is presented to patients.

6. 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.

7. 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 (multi-stakeholder 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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CHAPTER 4

MEASURING PATIENT EMPOWERMENT IN FLEMISH HOSPITALS

Chapter based on:

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ABSTRACT

Objective: Measuring empowerment of patients on Flemish hospital wards by the Short form of the Patient Activation Measure (PAM-13) and exploring the association between patient empowerment and patient-centred care, health literacy, patient- and context-related characteristics.

Methods: Secondary analysis of data collected in nine regional hospitals and one university hospital in Flanders between February and June 2016. Patients needed to be admitted for at least 1 day, aged 18 years or over, and mentally competent with adequate ability to speak and read the Dutch language. Independent t-tests, one-way ANOVA and multivariable regression analysis were performed.

Results: Mean empowerment was 58. Of the 670 patients, 22.7% tended to be unprepared to play an active role in their health care, 22.2% were struggling to manage own health, 39.4% reported to take action to maintain and improve own health, and 15.7% reported having confidence to perform adequate behaviours in most circumstances. Multivariable analysis showed that patients living together with family, a partner or a friend ($p = 0.018$), with higher health literacy ($p < 0.001$), and with higher perceptions of individuality in patients' care ($p < 0.001$) had higher empowerment scores.

Conclusion: The multivariable analysis found three variables associated with patient empowerment and provided empirical evidence for the interrelatedness between patient-centred care and patient empowerment. Future research should use a clear framework to make sure that all relevant determinants of patient empowerment are included. Interventions to improve patient empowerment should incorporate patient characteristics and elements of both health literacy and patient-centred care.

1. INTRODUCTION

As part of the evolution from the traditional paternalistic models towards more collaborative models of healthcare delivery, patients are stimulated to be co-producers of their own health (Bravo et al., 2015). Against the backdrop of this evolution, the concept of patient empowerment has gained considerable importance (Bravo et al., 2015; Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016; Cerezo, Juvé-Udina, & Delgado-Hito, 2016; Fumagalli, Radaelli, Lettieri, & Masella, 2015; Holmström & Röing, 2010). The empowerment concept must be perceived in the light of a broader empowerment paradigm and has its foundation in the social action and self-help movements in the 1960s and the 1970s (Hage & Lorensen, 2005; Kieffer, 1984; Zimmerman, 1995). Gradually, patient empowerment as a concept has gained considerable importance in health care. Different policy statements, such as the Alma Alta Declaration (Herbert, Gagnon, Rennick, & O'Loughlin, 2009) form the basis for its growing importance. However, there is not yet a widely agreed-upon definition of patient empowerment because it is a complex, multi-level concept (Castro et al., 2016; Fumagalli et al., 2015). A first attempt to define the concept for the healthcare context was done in the 1990s by Gibson (Aujoulat, d'Hoore, & Deccache, 2007; Gibson, 1991). Gibson's study showed that it was difficult to think of patient empowerment consistently and in operational terms (Aujoulat et al., 2007; Gibson, 1991). A recent concept analysis of Castro et al. (2016) defined patient empowerment as: *"A process that enables patients to exert more influence over their individual health by increasing their capacities to gain more control over issues they themselves define as important".*

Nonetheless, patient empowerment is internationally recognised as an essential element of high-quality care (Delnoij & Hafner, 2013), as the concept offers patients the opportunity to increase autonomy in their treatment, and eventually, to gain more control over their own lives (Aujoulat, Young, & Salmon, 2012; Castro et al., 2016; Cerezo et al., 2016; Holmström & Röing, 2010). Literature distinguishes between immediate, intermediate and long-term outcomes of patient empowerment (Bravo et al., 2015). Increased self-management of own health is one of the most frequent immediate consequences associated with patient empowerment (Bravo et al., 2015; Castro et al., 2016; Holmström & Röing, 2010; Werbrouck et al., 2018). Quality of life, well-being, and patient satisfaction with life are considered as intermediate outcomes of patient empowerment and improved health as a possible long-term outcome (Bravo et al., 2015).

There is a growing body of studies that aim to measure patient empowerment (Barr et al., 2015; Garattini & Padula, 2018; Holmström & Röing, 2010) and its associated factors (Bos-Touwen et al., 2015; Chiauzzi et al., 2016; Köhler, Tingström, Jaarsma, & Nilsson, 2018; Prey et al., 2016; Van Bulck et al., 2018; van Vugt et al., 2018). Many studies have focussed on outpatients or inpatients with particular chronic conditions such as diabetes, cancer, and chronic obstructive pulmonary disease (Barr et al., 2015; Cerezo et al., 2016; Holmström & Röing, 2010). The concept is also widely measured in other healthcare contexts, such as genetic counseling and mental health (Barr et al., 2015; Cerezo et al., 2016; Holmström & Röing, 2010). Health literacy was raised as an important variable to consider in patient empowerment because low health literacy compromises patients' abilities to understand medical information and to use it effectively, influencing their capacities to manage their own health (Bravo et al., 2015; Couture, Chouinard, Fortin, & Hudon, 2018; Holmström & Röing, 2010; Schulz & Nakamoto, 2013). Further, three concept analyses (Bravo et al., 2015; Castro et al., 2016; Holmström & Röing, 2010) have described the interrelatedness between the concepts of patient-centred care (defined by an array of terms such as individualised care) and patient empowerment. Patient-centred care, which implies the individual participation of the patient and which is built on a relationship of mutual trust, empathy, and shared knowledge, seems to be a precondition in facilitating patient empowerment (Bravo et al., 2015; Castro et al., 2016; Holmström & Röing, 2010). It should be noticed that although the connection between patient-centred care and patient empowerment has been questioned and discussed in detail in the literature, to date, empirical data remain lacking.

Despite the importance, research related to patient empowerment in Flanders is limited. In Flanders, there is only one empirical study on patient empowerment (Van Bulck et al., 2018), focussing solely on patients undergoing hemodialysis. Therefore, the first objective of this study was to measure empowerment, as reflected in the Short form of the Patient Activation Measure (PAM-13), of patients hospitalised on Flemish hospital wards. Additionally, this study aimed to explore the relationship between patient empowerment and some of its possible associated factors.

2. METHODS

2.1 Study design and setting

This cross-sectional study presents the secondary analysis of data collected in nine regional hospitals and one university hospital in Flanders participating in a governmental programme starting two improvement projects to enhance patient participation in hospitals (the implementation of bedside shift reporting and the implementation of the Tell-us card) (Malfait, Eeckloo, Lust, Van Biesen, & Van Hecke, 2017a; van Belle et al., 2018). Quality coordinators, chief nursing officers, and chief medical officers from all Flemish hospitals received information sessions on the improvement projects. Subsequently, hospitals were invited to communicate interest to participate. Wards for surgery, internal medicine, medical rehabilitation, and maternal care were included. Patients willing to participate need to be admitted at hospital for at least 1 day, aged 18 years or over, and mentally competent with adequate ability to speak and read the Dutch language. In total, 864 patients were included in the analysis.

2.2 Measurement

For the project on bedside shift reporting, data were collected between May and June 2016. The self-reported questionnaires, on paper, were completed independently or with a study nurse, who had no affiliation with the research team, if patients were in the impossibility of filling in the questionnaire themselves.

For the project on the Tell-us card, data were collected between February and March 2016. The self-reported questionnaires, on paper, were completed independently or together with a member of the research team.

Patient empowerment

Patient empowerment was measured by the PAM-13. The scale was developed and validated by Hibbard, Mahoney, Stockard, and Tusler (2005) after which it was translated and validated ([α] = 0.88) in Dutch by Rademakers, Nijman, van der Hoek, Heijmans, and Rijken (2012). The PAM-13 is a unidimensional scale in which items are sequenced by the difficulty of activation (Hibbard, Mahoney, Stockard, & Tusler, 2005). The scale is formatted into a four-point likert-scale ranging from totally disagree to totally agree and non-applicable. The PAM-13 survey scoresheet, that has an underlying scoring algorithm, was used to calculate the patients' PAM-13 score (Insignia Health, 2020). Higher PAM-13 scores (range 0–100) reflect higher levels of patient activation (Hibbard et al., 2005; Rademakers, Nijman, van der Hoek, Heijmans, & Rijken, 2012). The score can be converted into four levels of activation (Barr et al., 2015; Hibbard et al., 2005): (1) being disengaged and overwhelmed with the task of managing one's health (≤ 47.0), (2) become aware but still struggling to manage one's health (47.1–55.1), (3) actually taking action to maintain and improve one's health (55.2–72.4), and (4) maintaining behaviours and pushing further (≥ 72.5).

Patient-centred care

Patient-centred care was measured by the ICS-Patient (Suhonen, Leino-Kilpi, & Välimäki, 2005). The ICS-Patient is a Likert-type scale designed to measure hospitalised patients' perceptions of individualised care. The scale consists of two subsections with each containing 17 items. The first section (ICSA) explores patients' views of how individuality was supported through specific nursing interventions. The second section (ICSB) explores how patients perceive individuality in their care while in hospital. The answering categories per item are 5-point Likert scales ranging from fully disagree to fully agree. The higher the scores (range: 0–85), the more support is provided through nursing interventions to individualised care and the higher the degree of individuality in care perceived by the patients (Suhonen et al., 2005). The Dutch version of the ICS-Patient was validated by Theys, Van Hecke, Akkermans, and Heinen (2021) and showed high internal consistency and good construct validity (ICSA [α] = 0.96; ICSB [α] = 0.96).

Health literacy

Health literacy was measured by 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', (3) 'How often do you have someone help you when you read hospital materials'. These three questions facilitate the identification of patients with inadequate health literacy. 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- and context-related characteristics

Based on prior literature (Bos-Touwen et al., 2015; Bravo et al., 2015; Garattini et al., 2018; Hibbard & Greene, 2013; Prey et al., 2016; Van Bulck et al., 2018) and theoretical foundation the following variables were collected: (1) type of hospital, (2) type of ward, (3) days of hospital admission, (4) age, (5) gender, (6) educational level, (7) ethnicity, (8) profession, and (9) living situation.

2.3 Ethical considerations

The study protocol was approved by the Ethical Committee of Ghent University (B670201526903), and the local ethics committees of the participating hospitals. Informed consent was obtained through the provision of detailed information on the purpose of the studies and the confidentiality. Data were collected and analysed anonymously.

2.4 Data analysis

Statistical analyses were performed using SPSS 25.0 (IBM, 2017). Questionnaires with more than 20% of the answers missing (more than three items missing) were excluded (Insignia Health, 2020). Other studies have reported cut-off values between 25% and 10% (Duprez, Beeckman, Verhaeghe, & Van Hecke, 2017; Malfait, Eeckloo, & Van Hecke, 2017b). Questionnaires were checked on response patterns to exclude acquiescence bias. Descriptive statistics (frequencies, percentages, means, and SDs) were used to describe the sample and the study variables. For the ICS, sum scores were computed for both subsections by counting the item responses for each subsection and then dividing this by the number of items in the subsection. For health literacy, sum scores were computed by counting the responses per question and then dividing this by the number of questions. To calculate the total PAM score, the scoring sheet of Insignia Health (2020) was used. Study variables in association with patient empowerment were examined using inferential statistics. By using skewness and kurtosis, a histogram, and a Q-Q plot, the assumptions of normality were checked and approved. Continuous variables in association with patient empowerment were tested using Pearson correlation coefficients. Categorical variables with two groups in association with patient empowerment were tested using independent sample t-tests, and with three or more groups using one-way analysis of variance.

Last, variables with $p < 0.05$ in the univariable analyses were combined into a multivariable regression model. In advance, dummy variables were created for all categorical variables. Stepwise regression was used to identify variables associated with patient empowerment. 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 (Yoo et al., 2014).

3. RESULTS

3.1 Participants and demographics

Due to missing data and cases with repetitive response patterns, a total of 670 patients were included for further analysis. Of these patients, 57.9% were female with a mean age of 57.73 (SD = 18.97). Most patients were retired (49.3%), had an education lower than bachelor's degree (61.0%), and lived together with a partner, friend or family (68.9%). The average amount of days of hospital admission was 11.48 days (SD = 17.25). The majority of the patients were hospitalised on surgical wards (35.8%). The average PAM score was 57.94 (SD = 12.40). Of the patients, 22.7% tended to be overwhelmed and unprepared to play an active role in their health care (PAM level 1), 22.2% were still struggling to manage own health (PAM level 2), 39.4% reported to take action to maintain and improve own health (PAM level 3), and 15.7% reported to have confidence and being able to perform adequate behaviours in most circumstances (PAM level 4). Table 1 provides an overview of the patient- and context-related factors.

Table 1. Patient- and context-related factors and patient empowerment scores of the patients

	N	n (%)	Mean (range), SD[a]
Age	663		57.73 (18-95), 18.97
Sex	670		
Male		282 (42.1)	
Female		388 (57.9)	
Living situation	668		
Alone		186 (27.8)	
Together with family/partner/friend		460 (68.9)	
Residential care		22 (3.3)	
Educational level	665		
Lower than bachelor		406 (61.0)	
Bachelor		194 (29.2)	
Master or higher		65 (9.8)	
Employment status	668		
Employed		249 (37.3)	
Unemployed		23 (3.4)	
Student		8 (1.2)	
Disabled		59 (8.8)	
Retirement		329 (49.3)	
Health literacy	652		2.39 (1-5), 0.85
ICSA	670		3.53 (1-5), 0.88
ICSB	670		3.83 (1-5), 0.81
Days of hospital admission	641		11.48 (1-155), 17.25
Type of ward	670		
Maternity		117 (17.5)	
Internal		135 (20.1)	
Medical rehabilitation		150 (22.4)	
Surgical		240 (35.8)	
Mixed internal/surgical		28 (4.2)	
Type of hospital	670		
Regional		465 (69.4)	
University		205 (30.6)	

Patient activation measure	670		57.94 (14.50-90.17), 12.40
Level 1 (score: ≤ 47.0)		152 (22.7)	
Level 2 (score: 47.1–55.1)		149 (22.2)	
Level 3 (score: 55.2–72.4)		264 (39.4)	
Level 4 (score: ≥ 72.5)		105 (15.7)	

[a] SD = standard deviation

3.2 Univariable analysis

Univariable analysis revealed eight variables significantly associated with patient empowerment. Lower age, higher health literacy, higher perception of how nurses support patients' individuality through specific nursing activities (ICSA), and higher perception of individuality in patients' care (ICSB) were associated with higher patient empowerment scores. Higher patient empowerment scores were found in patients with a master's degree or higher compared to patients with an education lower than bachelor's degree, and in patients with a bachelor's degree compared to patients with an education lower than bachelor's degree. Patients who lived together with a partner, a friend or family, had higher patient empowerment scores compared to patients who lived alone. Participants who were retired had lower patient empowerment scores compared to patients who were employed. Participants hospitalised on maternity wards had higher patient empowerment scores compared to patients hospitalised on surgical, internal, medical rehabilitation, and mixed surgical/internal hospital wards. Patient empowerment scores were not significantly associated with gender, ethnicity, days of hospital admission, and type of hospital. An overview of the patient- and context-related factors associated with patient empowerment is provided in Table 2.

Table 2. Univariate associations between patient- and context-related factors and patient empowerment

Pearson correlation	**Mean PAM (SD[a])**	**Pearson's r**	**p-value**
Age	N/A[b]	r = -0.160	< 0.001*
Health literacy	N/A[b]	r = -0.272	< 0.001*
Days of hospital admission	N/A[b]	r = -0.031	0.426
ICSA	N/A[b]	r = 0.272	< 0.001*
ICSB	N/A[b]	r = 0.311	< 0.001*
Independent sample t test	**Mean PAM (SD[†])**	**t (df)**	**p-value**

Sex		**t = -1.849 (668)**	**0.065**
Male	**56.90 (11.93)**		
Female	**58.69 (12.70)**		
Type of hospital		t = -0.626 (668)	0.531
Regional	57.49 (11.26)		
University	58.14 (12.88)		
One-way analysis of variance	**Mean PAM (SD[†])**	**F (df)**	**p-value**
Living situation		F = 7.635 (667)	0.001*
Alone[c]	55.46 (12.28)		
Together with family/partner/friend	59.10 (12.24)		0.002*
Residential care	52.99 (11.67)		0.643
Educational level		F = 6.971 (664)	0.001*
Lower than bachelor[c]	56.56 (12.69)		
Bachelor	59.44 (11.73)		0.020*
Master or higher	61.66 (12.22)		0.006*
Employment status		F = 4.546 (667)	0.001*
Employed[c]	60.56 (11.97)		
Unemployed	56.08 (11.61)		0.453
Student	58.20 (13.03)		0.984
Disabled	56.28 (11.14)		0.116
Retirement	56.38 (12.75)		0.001*
Type of ward		F = 6.514 (669)	< 0.001*
Maternity[c]	62.81 (10.91)		
Internal	55.90 (12.00)		< 0.001*
Medical rehabilitation	56.05 (12.61)		< 0.001*
Surgical	57.83 (12.52)		0.003*
Mixed internal/surgical	58.44 (13.30)		0.443

[a]SD = standard deviation; [b]N/A = not applicable; [c] = reference group; *p-value < 0.05

3.3 Multivariable analysis

Prior to composing a multivariable analysis, the eight univariable significant variables were tested for collinearity. Both ICS subsections were correlated (r = 0.836) and the tolerance values (ICSA = 0.290; ICSB = 0.288) were below 0.4 (Yoo et al., 2014). The ICSB subsection was selected to be entered in the analysis because this variable was most strongly associated with patient empowerment. The variable age was removed from the analysis, as this variable had a VIF of 5.277 and the tolerance value was below 0.4 (Yoo et al., 2014). After conducting the multivariable analysis, three variables remained significantly associated with patient empowerment (Table 3). Higher health literacy, higher perception of individuality in patients' care (ICSB), and living together with family, a partner or a friend were significantly associated with higher patient empowerment scores. The R^2 of the model was 0.146. The tolerance values in the final model were all above 0.4, indicating acceptable correlations between the independent variables in the final model (Yoo et al., 2014).

Table 3. Multiple linear regression analysis for association between patient- and context-related factors and patient empowerment

	Unstandardised Coefficients		**Standardised Coefficients**			**95% Confidence Interval for B**	
	β	**Std. Error**	**Beta**	**t**	**Sig.**	**Lower Bound**	**Upper Bound**
(Constant)	47.795	2.976		16.060		41.951	53.639
Health literacy	-2.905	0.551	-0.201	-5.273	< 0.001*	-3.986	-1.823
ICSB	3.990	0.574	0.260	6.951	< 0.001*	2.863	5.118
Living condition							
Living together with family/partner/friend†	2.378	1.003	0.88	2.370	0.018*	0.408	4.348

†Living alone = reference group; *p-value < 0.05; Multiple linear regression R^2: 0.154

4. DISCUSSION

4.1 Level of empowerment

The first aim of this study was to measure the level of empowerment of patients hospitalised on Flemish hospital wards. Findings revealed that the average empowerment score was 58 and that the majority of the patients were in PAM level 3. More than half of the patients (55%) did take charge of their own health. Nevertheless, there is room for improvement and attention should be paid to the implementation of interventions that aim to support patient empowerment while patients are admitted at hospital.

The distribution of PAM levels in our population is dissimilar to those found in the study of Van Bulck et al. (2018), a previous Flemish study on patient empowerment in patients undergoing hemodialysis. In that study, patients had an average empowerment score of 51, and most patients (44%) were in PAM level 1 (Van Bulck et al., 2018). It should be noticed that comparing the empowerment levels is difficult as the cut-off points for the PAM levels 3 and 4 in our study differ from those in the study of Van Bulck et al. (2018) and other studies using the PAM-13 published before 2018 (Bos-Touwen et al., 2015; Rademakers et al., 2012). In those studies, the cut-off points were, respectively, 55.2–67.0 for level 3 and ≥67.1 for level 4 (Bos-Touwen et al., 2015; Rademakers et al., 2012). Literature could not provide a clear rationale for placing the cut-off points elsewhere. Perhaps there was a tendency for the PAM-13 to overestimate the level of patient empowerment.

The mean empowerment score in our study is also higher compared to the score in the study of Van Bulck et al. (2018). It is likely that the difference could be clarified by the variance in patient population. While Van Bulck and colleagues have focussed on patient empowerment in patients with a specific chronic disease, the objective of this study was to gain a more global insight into the empowerment of patients hospitalised on Flemish hospital wards. This entails that a mix of patients with different chronic diseases and acute diseases were included in the study. In contrast to patients with chronic diseases, patients with acute diseases do not have to cope with their disease and its consequences every day, and the range of decisions to be made by patients with acute illness is limited (Graffigna, Barello, Bonanomi, Lozza, & Hibbard, 2015). Hence, it seems plausible that patient with acute diseases might report higher empowerment scores. In addition, research has also shown that empowerment scores vary depending on the type of chronic disease (Bos-Touwen et al., 2015). However, since no individual data about underlying disease were available it can only be assumed and not determined with certainty that the variance in patient population explains the difference in empowerment score.

When comparing the results with those of Dutch studies (Bos-Touwen et al., 2015; Hendriks & Rademakers, 2014), the empowerment score in our study is similar to that of the general Dutch population. Other international studies have also reported higher scores, up to nearly 70 (Graffigna et al., 2015; Rademakers et al., 2016). Again, as the scoring rules for calculating the PAM-13 score have been adapted over the years and sampling differences exist, it remains difficult to compare the empowerment score and to make any firm statements about whether Flemish patients are relatively (in) active compared to patients in other countries.

4.2 Associated factors

The second aim of this study was to investigate the relationship between patient empowerment and some of its possible associated factors. Multivariable analysis revealed that living situation, health literacy, and patient-centred care were associated with patient empowerment. The R^2 of the model was 0.146, which means that around 14.6% of the variance in patient empowerment could be explained by these three variables. The relatively low R^2 indicates that there is room for improvement in the model. As this study presents the secondary analysis of existing data, some potential factors influencing patient empowerment such as socio-economic status, health status, self-efficacy, depression, perceived personal control over health, participation in shared-decision-making, social support, and underlying disease (Bravo et al., 2015; Bos-Touwen et al., 2015; Chiauzzi et al., 2016; Graffigna et al., 2015; Van Bulck et al., 2018; van Vugt et al., 2018) have not been included.

Future studies on patient empowerment and its associated factors in Flanders should be based on comprehensive literature review regarding factors potentially influencing patient empowerment. The conceptual map on indicators of patient empowerment developed by Bravo et al. (2015) could serve as a starting point and useful framework in setting up future research. In Figure 1, an overview of the possible factors associated with patient empowerment and those examined in the current study is shown.

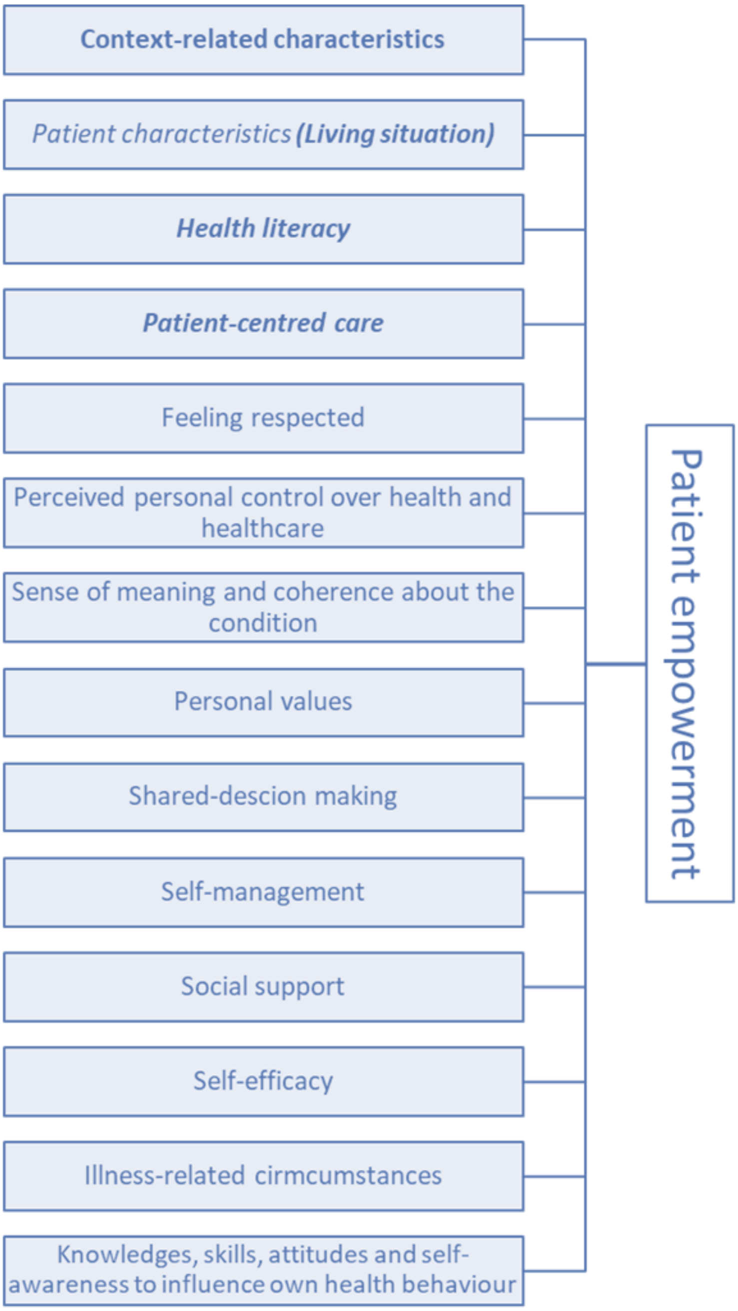

Figure 1. Possible factors associated with patient empowerment, based on the conceptual map of Bravo et al. (2015). Factors in italics are those examined in the study. Factors in italics and in bold print are those found statistically significant in the study.

The figure is based on the conceptual map of Bravo et al. (2015). Our study showed that higher scores on the ICS-Patient correlate with higher empowerment scores, providing empirical evidence for the interrelatedness between the concepts of patient-centred care and patient empowerment. Previously, three concept analyses theoretically described the connection between patient-centred care and patient empowerment (Bravo et al., 2015; Castro et al., 2016; Holmström & Röing, 2010). In the study of Castro et al. (2016), a process model on the interrelationship between the concepts patient empowerment, patient participation and patient-centredness was presented. The findings of this study provide empirical support for this process model, as well as for the conceptual models presented in the studies of Holmström and Röing (2010) and Bravo et al. (2015).

When looking at living situation, patients who lived together with a partner, family or friend had higher empowerment scores compared to patients living alone. In the previous Flemish study on patient empowerment (Van Bulck et al., 2018), it was shown that patients who lived together with someone were more empowered that patients who lived in a residential care home. Our findings did not show a significant difference in empowerment between patients living in a residential care home and patients living with someone. A Dutch study, in which factors associated with patient empowerment in patients with diabetes, chronic obstructive pulmonary disease, chronic heart failure, and chronic renal disease were investigated, also found that living alone was associated with poor empowerment (Bos-Touwen et al., 2015). A possible explanation for the lower empowerment score of patients living alone could be the quantity of received social support (Bos-Touwen et al., 2015). The study results provide also empirical support for the association between health literacy and patient empowerment, and additional support for the process model of Castro et al. (2016) and the conceptual model on patient empowerment of Bravo et al. (2015). In both models, a sufficient level of health literacy is seen as essential for patient empowerment.

4.3 Strengths and limitations

A strength of this study was the relatively large sample size, compared to the other Flemish study on patient empowerment (Van Bulck et al., 2018), and the use of international validated questionnaires. In addition, this study was conducted in multiple hospitals in Flanders, contributing to the generalisability of the findings. Further, the results contribute to the limited knowledge of patient empowerment in Flemish hospital wards and provide support for the growing body of evidence indicating that patient-centred care is essential for facilitating patient empowerment. However, the current study has also some limitations. Firstly, this study presents the secondary analysis of existing data.

The choice of variables and measurement tools was thus determined before this study. Secondly, using the PAM-13 as a measure of patient empowerment may be subject to discussion, as this questionnaire does purport to be a measure of patient activation (Barr et al., 2015; Van Bulck et al., 2018). Nevertheless, the literature indicates that the PAM-13 provides a robust measure of patient empowerment (Cerezo et al., 2016), because the concepts of patient activation and patient empowerment are closely intertwined (Fumagalli et al., 2015), and there is considerable overlap captured in the PAM-13 and other measures of patient empowerment (Barr et al., 2015). Further, using the PAM-13 allows to compare the study results with those of international studies, considering that the PAM-13 is one of the most frequently used measures for patient empowerment in international literature. Thirdly, the data were cross-sectional, impeding any conclusions on causal associations. Fourthly, the questionnaires were self-administered which may have induced social desirability bias (Polit & Beck, 2017). Due to the involvement of the researcher during the data collection of the improvement project on the Tell-us card, participants may have answered questions more positively than the reality of their situation (Polit & Beck, 2017).

5. RECOMMENDATIONS

As previously discussed, the conceptual map on indicators of patient empowerment developed by Bravo et al. (2015) could be used as a clear and useful framework in setting up research on factors associated with patient empowerment. In addition, including underlying disease as an effect modifier will allow to evaluate whether factors associated with patient empowerment are disease-specific or disease-transcending (Bos-Touwen et al., 2015). This could equip healthcare professionals with valuable guidance in developing tailored interventions to support patient empowerment, as patient empowerment is a process tailored to each individual patient (Werbrouck et al., 2018). Further, in line with the recommendations of Van Bulck et al. (2018) future research should investigate patient empowerment and its associated factors in longitudinal research and provide information on the usefulness of these factors in interventions for patient empowerment. Also, further research projects could use more than one measure of patient empowerment simultaneously to provide a more rigorous measure of the concept.

In practice, our findings have implications for the individual treatment of patients. Interventions to improve patient empowerment may be best served by incorporating patient characteristics and elements of both health literacy and patient-centred care. Further, because patients with lower health literacy and living alone without family, a partner or a friend had significantly lower patient empowerment, these factors could be used as screening factors for identifying vulnerable patients. Healthcare workers are likely to need training and support in order to tailor patient empowerment interventions to vulnerable patient groups.

6. CONCLUSION

This study was one of the first studies to measure patient empowerment in Flemish hospital wards. The mean empowerment score in our study was 58. Multivariable analysis revealed that besides living situation and health literacy, patient-centred care was associated with patient empowerment, providing support for the interrelatedness between patient-centred care and patient empowerment.

Future research on patient empowerment and its associated factors should be based on comprehensive literature review and should use a clear framework to make sure that all relevant determinants of patient empowerment are included. Further, the identified determinants of patient empowerment could be used as screening factors for identifying vulnerable patients and should be incorporated in interventions to improve patient empowerment.

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CHAPTER 5

BARRIERS AND ENABLERS FOR THE IMPLEMENTATION OF A HOSPITAL COMMUNICATION TOOL FOR PATIENT PARTICIPATION

Chapter based on:

Theys, S., Lust, E., Heinen, M., Verhaeghe, S., Beeckman, D., Eeckloo, K., Malfait, S., Van Hecke, A. (2020). Barriers and enablers for the implementation of a hospital communication tool for patient participation: A qualitative study. *Journal of Clinical Nursing*, *29*(11-12), 1945-1956. Doi:10.1111/jocn.15055

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ABTRACT

Aims and objectives: To investigate potential barriers and enablers prior to the implementation of the Tell-us card.

Background: Patient participation has the potential to improve quality of care and has a positive effect on health outcomes. In order to enhance participation of patients, adequate communication between patients, their relatives and healthcare professionals is vital. Communication is considered as a fundament of care according to the Fundamentals of Care Framework. A strategy to improve patient participation is the use of the Tell-us card; a communication tool that patients and relatives can use during hospitalisation to point out what is important for them during their admission and before discharge. Investigating barriers and enablers is needed before implementation.

Design: A qualitative study.

Methods: Semi-structured, individual interviews with (head) nurses, nurse assistants and midwifes. Interviews were audio-recorded, transcribed and analysed using the framework analysis method. The COREQ checklist was used.

Results: The need to maintain control over care, reluctance to engage in in-depth conversations, fear of being seen as unprofessional by patients, fear of repercussions from physicians, the lack of insight in the meaning of patient participation, and the lack of appreciation of the importance of patient participation appeared to be majors barriers. Participants also elaborated on several prerequisites for successful implementation and regarded the cooperation of the multidisciplinary team as an essential enabler.

Conclusion: The identified barriers and enablers revealed that nurses and midwives are rather reluctant towards patient participation and actively facilitating that by using the Tell-us card communication tool.

Relevance to clinical practice: A number of issues will have to be factored into the implementation plan of the communication tool. Tailored implementation strategies will be crucial to overcome barriers and to accomplish a successful and sustainable implementation of the Tell-us card.

1. INTRODUCTION

Worldwide, hospitals are continuously challenged to improve health services for the patient (Aiken et al., 2012; Burwell, 2015). The WHO emphasises the role patients and their relatives can have in the improvement of health care by becoming actively involved in their care process (Davis, Jacklin, Sevdalis, & Vincent, 2007; Garrouste-Orgeas et al., 2010; Longtin et al., 2010). Patient participation has been defined by Castro, Van Regenmortel, Vanhaecht, Sermeus and Van Hecke (2016) as: *"The patient's rights and opportunities to influence and engage in decision making about the patients' care through a dialogue attuned to his preferences, potential and a combination of his experiental and the professional's expert knowledge".*

Literature indicates that patient participation improves quality of care (Jangland, Carlsson, Lundgren, & Gunningberg, 2012; Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014), reduces anxiety (Vahdat et al., 2014), improves therapy adherence (Vahdat et al., 2014), reduces the number of readmissions (Gregory, Tan, Tilrico, Edwardson, & Gamm, 2014), leads to better health outcomes (Vahdat et al., 2014; WHO, 2013), and has a positive effect on patient safety and patient satisfaction with care (Jangland et al., 2012; Vahdat et al., 2014). Research also shows that participation of relatives during hospital admissions positively influences the health behaviour of patients and also leads to better health outcomes (Goodridge et al., 2018). During hospital admission, family members have an important role as a supplier of information essential to appropriate care planning (Goodridge et al., 2018; Tobiano, Bucknall, Marshall, Guinane, & Chaboyer, 2016b). Also, when relatives are engaged in care, there appears to be a greater likelihood that they recognise errors in care delivery and that patients adhere to treatment plans (Goodridge et al., 2018).

In order to enhance the participation of patients, adequate communication between patients, their relatives and healthcare professionals is vital (Jangland, Gunningberg, & Carlsson, 2009). Communication is considered as one of the fundaments of care according to the Fundamentals of Care Framework (FoCF), as it has the potential to support patients into taking a more active role in their care (Feo & Kitson, 2016). The FoCF describes fundamental care as the activities that are required for every person, regardless of their clinical condition or healthcare setting (Kitson, Conroy, Wengstrom, Profetto-McGrath, & Robertson-Malt, 2010). The framework was developed as the result of the growing recognition of the importance of patient-centred care (Kitson et al., 2010). Key elements of the FoCF, including: "ability to cope, being involved and informed, and addressing concerns and frustrations of the patient" stress the importance of communication in health care and the need to consider psychosocial factors with more attention in order to establish patient-centred care (Kitson et al., 2010; Kitson, Muntlin, & Conroy, 2014; Feo & Kitson, 2016).

2. BACKGROUND

A possible strategy to improve patient participation is the use of the Tell-us card communication tool. Patients can use the Tell-us card during hospitalisation to point out what is important for them during their admission and before discharge. The study of Jangland et al. (2012) has shown that patients admitted on a surgical ward who used Tell-us cards experienced (1) more possibilities to participate in decision-making, (2) more involvement of nurses, and (3) a more respectful approach by nurses. Patients also asked questions they would not have asked if no Tell-us card was available. In the 2-year follow-up study on the implementation of the Tell-us card in five surgical wards, it was shown that due the implementation of the Tell-us card there was a culture change in which healthcare professionals grew to accept patients' involvement (Jangland & Gunningberg, 2017).

The present study is embedded in the pre-implementation development phase of a larger implementation study of the Tell-us card communication tool in Flemish hospitals, and aimed to investigate potential barriers and enablers prior to the implementation of the tool. This is essential in order to enhance the possibility of successful implementation (Jangland et al., 2012; Purvis, Moss, Denisenko, Bladin, & Cadilhac, 2014; van Belle et al., 2018). An example of the Tell-us card is provided in Addendum 4. Tell-us card includes (1) instructions and tips for the patients and their relatives on how to use the Tell-us card, and (2) information for patients and their relatives on how healthcare professionals work with the Tell-us card.

3. METHODS

3.1 Study design

A qualitative study design was used, as it allows to understand, describe and interpret phenomena as perceived by individuals (Holloway & Wheeler, 2012).

3.2 Population and setting

In the pre-implementation development phase of the Tell-us card project quality coordinators from all Flemish hospitals received an information session on the Tell-us card project. Subsequently, hospitals were invited to communicate potential interest to participate. Three maternity wards, two surgical wards, two medical wards (internal wards), and one rehabilitation ward of four regional hospitals and one university hospital wanted to participate in the Tell-us card project. From all participating hospitals, a heterogeneous sample of 20 nurses, 14 midwifes, five (assistant) head nurses and two nurse assistants were interviewed. Demographic data are presented in Table 1. A minimum of five participants per ward were recruited to ensure a varied sample.

Table 1. Characteristics of participants

Characteristics	n (%)	Mean	Range
	n = 41		
Age (years)		36.5	24-59
Gender			
Female	35 (85.4%)	-	-
Male	6 (14.6%)	-	-
Profession			
Nurse assistant	2 (4.9%)	-	-
Nurse	20 (48.8%)	-	-
Midwife	14 (34.1%)	-	-
(Assistant) head nurse	5 (12.2%)	-	-
Nurses educational level			
Nurse assistant[a]	2 (4.9%)	-	-
Graduated nurse[b]	7 (17.1%)	-	-
Bachelor educated nurse[c]	30 (73.1%)	-	-
Master educated nurse[d]	2 (4.9%)	-	-
Time on ward the ward (years)			
Nurse assistant		15	4-26
Nurse		8.9	0.2-0.27
Midwife		13.2	1-38
(Assistant) head nurse		19.8	6-37

[a] One year of education at level 3 of the European Qualifications Framework (EQF).

[b] Three years of education at level 5 of the EQF to obtain a diploma in Nursing.

[c] Three years of education at level 6 of the EQF to obtain the degree of Bachelor in Nursing.

[d] Five years of education at level 7 of the EQF to obtain the degree of Master in Nursing

3.3 Instruments and data collection procedures

The data were collected through semi-structured individual interviews. The interview guide was based on the contingency model by van Linge (1998), in which ‘contingency (characteristic of the situation)’ and ‘congruence’ are key concepts. The model assumes the necessity of a fit between (1) the demands of an innovation and (2) the characteristics of the context, in order to obtain a successful implementation. Van Linge (1998) distinguishes four dimensions that can be used to analyse the context and demands of an innovation: process structuring, human-resources, political aspects and cultural aspects (van Linge, 1998; van Os-Medendorp et al., 2006). Human resources consists of human knowledge, skills and attitudes, team competencies and personnel management. Culture addresses values, basic assumptions and behaviour of people. The structural dimension characterises organising work processes. The political dimension describes relative power positions and political processes (van Linge, 1998; van Os-Medendorp et al., 2006). Examples of topics from the interview guide in the different dimensions are described in Table 2. Additionally, open-ended questions were asked concerning (1) participants former experiences in working with instruments similar to the Tell-us cards, (2) the strengths and weaknesses of their team they work in, and (3) their believes about the chances of a successful implementation of the Tell-us cards.

Table 2. Interview guide based on the contingency model by van Linge (1998)

Dimension	Description dimension	Topics interview guide	Example of questions
Structure of the ward	Concerns organising work processes	Communication processes: The available structures for communication with patients and their relatives	• How is communication with patients/ family currently organised on the ward? Is there a certain structure? • Are specific communication tools used to communicate with patients and their relatives?
Human resources	Relates human knowledge, skills and attitudes	Knowledge, skills and attitudes: The participants’ competences to use Tell-us cards. Education, skills and insights of participants in healthcare professional-patient communication and patient participation	• What is the current training policy regarding effective communication with patients and their relatives on the ward? • How experienced are the nurses (midwives) of the ward with regard to communication and patient participation?

Culture	Refers to values, attitudes, ideas, customs and social behaviour on hospital- and ward level	Values, basic assumptions and behaviour: Values and attitudes participants attribute to the Tell-us card and how participants manage change	• How are organisational changes in the ward dealt with? • Do you think that the nurses (midwives) of the ward are ready for a more active role of the patient?
Politics	Tackles relative power dynamics and political processes	Power positions and political processes: The respect of participants towards each other, and their readiness to take the responsibility to work with Tell-us card	• Do nurses (midwives) respect each other's expertise and role - do they stimulate each other when implementing innovations? • Are the nurses (midwives) of the ward ready to take on new tasks in their job content like: ○ Enhanced responsibility ○ Confrontation with difficult questions ○ Expressing themselves to the patient

The interviews were conducted in a separate room at the hospital wards between April and June 2016. Interviews lasted between 25 minutes and 82 minutes, with a mean duration of 49 minutes. To anticipate social desirability bias, an open atmosphere was created while guaranteeing privacy of the interview. Prior to the interviews, healthcare professionals received an information session on the Tell-us card implementation project to get a sense of the communication tool. During this information session the concept of patient participation was introduced briefly.

All interviews were moderated by one of the first authours (PhD candidate) who was female. Hand-written notes were taken during and after the interviews. Interviews were audio-recorded and the first sixteen interviews were transcribed verbatim without the convention of dialogue transcription (e.g. silence, sighs, laughter, posture, gestures), because the content was of primary interest (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Data identifying the persons mentioned in the interviews were deleted. Remaining, not transcribed interviews were listened and re-listened by the two first authours and another member of the research team.

4. ANALYSIS

The Framework Method was used for data analysis (Gale et al., 2013). This method is not aligned with a particular epistemological or theoretical approach and can be adapted for use with many qualitative approaches that aim to generate themes (Gale et al., 2013). One of the most defining features of the method is the matrix output: rows (cases), columns (codes) and cells of summarised data providing a structure into which the researcher can systematically reduce the data (Gale et al., 2013). The method allows to compare and contrast data by themes across many cases, while also situating each perspective in context by retaining the connection to other aspects of each individual's account and allows for flexible use along the inductive-deductive continuum (Gale et al., 2013). Data collection and data analysis were executed iteratively with the research team to discuss preliminary findings and to improve subsequent interviewing. Interview transcripts were read and re-read by one of the first authours to familiarise with the data. Also, three other members of the research team read different interview transcripts. After familiarisation, inductive coding was applied on the first sixteen interview transcripts. Some of the interview transcripts were coded independently and some of the interviews were coded together. During the intermediate data analysis codes were compared and discussed by the entire research team in terms of what they told about participants views on barriers and enablers regarding the implementation of the Tell-us card, and then charted into an analytical framework. The analytical framework was applied to all subsequent interview transcripts, also taking into account that possibly new codes could emerge in the following interviews. After coding the data by using the analytical framework, and putting raw data in the matrix, themes were generated by reviewing the matrix and making connections within and between participants and codes. An extract of the framework analysis matrix is provided in Table 3.

Table 3. Extract of the framework analysis matrix

STRUCTURING CODE	**Culture**	**Human resources**
CODE	**Planning of care**	**Description of patient participation**
Internal nurse 1	It is different when relatives ask questions or when they call the ward, because you have to take care of the other patients of the ward. Yeah, it is disturbing. Yeah, … it takes up much of your time.	Patient participation yeah …. we believe it is very important. What I actually mean is that we always ask the patient if he needs help or not. That is one of the things we ask every day so …. It is like a common practice to us.
Head nurse 3	And the patients and their family have become more empowered these days, yeah really. They just walk in and ask all kinds of questions, they think that's normal because that's what they hear now these days: You have the right to be fully informed. But yeah for me … how far do we have to go along with it ...	Euh that patients are informed about their care, so that they can help in their care. To give an example: Tomorrow there is a patient who needs to be nil by mouth before surgery. And when you do communicate this to the patient, you don't want him to say: Oh I didn't know that and I drunk some water …
Midwife 7	It depends on the workload. When everything go as planned and then we get all those questions …. than it is not really a problem, but when we have a lot of work and then patients start to ask all kinds of questions. Yeah, than if feels more like, more of a hindrance actually.	Euhm, we think about the planning of the care, we ask the patient how he thinks about his care. For example when a patient says that he wants for the cleaning-person to come in the afternoon, than we keep that in mind.
	⬇ *Maintaining control over care*	⬇ *Lack of insight in the meaning of patient participation*

5.1 Trustworthiness

Five strategies were used to increase trustworthiness. First, member checking was used to avoid misinterpretation of the data (Holloway & Wheeler, 2012). Participants received a summary of all analysed interviews on ward level and they were asked to provide feedback on the report. Second, researcher triangulation was used to give more depth to the analysis and to enhance its validity (Holloway & Wheeler, 2012). The results were summarised in an analysis text and discussed with the entire research team. At the end, two researchers - not previously involved in the data analysis - read an interview and the analysis text to verify trustworthiness. Third, during analysis and interpretation, meaning of insights in the data was explored to avoid biased interpretations. Fourth, the researcher who conducted the interviews was external to the wards and hospitals, which increased the openness and independence of the participants. Last, variation sampling on participant level was used in order to gain insights into a range of perceived barriers and enablers on the implementation of the Tell-us card and to ensure that a variety of meanings were represented in the sample.

5.2 Ethical considerations

The study was approved by a Flemish hospital's ethical committee (B670201526903) and local ethics committees of the participating hospitals. Written informed consent was obtained from each participant before the interview.

5. RESULTS

The identified barriers and enablers with a selection of quotes are presented in Table 4. Barriers and enablers are grouped into themes that were identified during framework analysis. Themes are subdivided according to the dimensions of the contingency model by van Linge.

5.1 Culture

Maintaining control over care

When participants thought about the future implementation of the Tell-us card, the need to maintain control over care appeared extremely important. Participants expressed to experience many work interruptions due to questions from patients and relatives. By using Tell-us cards participants expected that questions will be bundled, leading to a reduction of the number of patients' calls and therefore helping them to better plan the answering of questions from patients and relatives (quote 1). Some participants also expected that using Tell-us cards would result in questions from patients being more thought-through and less forgotten. Most participants stressed the importance of a time-fixed integration of the tool in daily planning and elaborated on approaching the tool in a more checklist-like manner (quote 2). They feared that the Tell-us cards would undermine their fixed planning of care, due to the tool being an additional task that will require time and effort when faced with difficult questions. Participants described their current practice as overburdened with many non-hands-on-tasks and expected the Tell-us cards to further contribute to this increasing workload.

5.2 Human resources

Fear of being seen as unprofessional

Nurses and midwives feared of being seen as unprofessional and expressed their concern as a fear of being confronted with negative feedback from patients when using Tell-us cards. However, one nurse stated that feedback from patients is essential to improve care. Some participants stressed the importance of clear limitations where patients have a respectful, non-offensive attitude towards healthcare professionals (quote 3). In addition, participants expressed their concern as a fear of being evaluated on their answers in comparison with other healthcare professionals and indicated that patients will not accept questions remained unanswered (quote 4). Furthermore, some participants feared that Tell-us cards will be used to write down complaints that will be passed on to the physician and thought that physicians will depend on the written complaint without the evaluation of the specific context in which the situation occurred.

Lack of insight in the meaning of patient participation

One participant stated to have never heard of the concept of patient participation before the information session on the Tell-us card. Some participants were not able to describe the concept of patient participation. Participants indicating to be able to describe the concept of patient participation sometimes described it as ‘respecting patients wishes’ and ‘giving patients the right to make decisions about their care’. However, they mainly described it as ‘listening to patients’, ‘giving sufficient information to patients’ or ‘stimulating patients to do things by themselves’ (e.g. washing) (quote 5). In addition, some participants indicated little thought is given to patient participation on the ward and involving patients in their care is not considered as important. Participation of patients and suggestions from patients for more customized care were sometimes considered as criticism on the care they provide and more empowered patients were sometimes perceived as ‘being demanding’.

5.3 Structure of the ward

Enhancing or impeding communication with patients

Some participants expected to have a more two-way communication with patients by using the Tell-us cards (quote 6). However, other participants expected being detached from the patient by using Tell-us cards. These participants described their current conversation with patients as direct and spontaneous and believed that the Tell-us card will create a distance by interfering with spontaneous interactions (quote 7). The majority of the participants considered the Tell-us card as an accessible instrument, enabling reluctant patients to ask questions more easily by having the opportunity to write their questions down in advance (quote 8). Participants expected more empowered patients will not benefit from using Tell-us cards as these patients already ask their questions directly.

Prerequisites for successful implementation and use of the Tell-us card

Participants elaborated on several prerequisites they believed will support successful implementation. The majority of the participants emphasised the importance of being informed about the implementation process (quote 9). Two participants suggested a training with an e-learning programme would help to familiarise with the Tell-us cards. Participants also considered it important to explain the benefits of implementing the Tell-us card. A start-up period follow-up throughout the change process, change agents and frequent reminders were considered major enablers in order to counteract fading-out of the intervention (quote 10). Through intermittent evaluations, participants expect feedback on the implementation process by means of (1) interviews with patients about the usage of Tell-us cards, (2) interviews with healthcare professionals to evaluate the experienced difficulties, and (3) listening to the patients who did not use the Tell-us card.

Participants suggested that non-native speaking patients and patients with dementia may need an adjusted Tell-us card. Further, participants stated that visibly presence of the Tell-us card in the patients' room might compromise the privacy of the patient (quote 11). Participants also indicated that patients may be reluctant to write questions concerning emotional aspects and conflict may arise, as the Tell-us card can be used by both the patients and their relatives.

5.4 Politics

Team climate influencing the readiness to work with the Tell-us card

Participants describing their team as dynamic and motivated to change expected a fluent adaption to the Tell-us cards. In these teams, the participants indicated the head nurse was open to constructive feedback and was more stimulating to find creative solutions for practical implementation issues (quote 12). The role of the head nurse as a champion was considered of great importance in these teams. Further, participants in these teams expected no problems when being confronted with difficult questions. Participants, who perceived the team climate as low on opportunities for dialogue between the physician-patient and physician-nurse/midwife, were rather opposed to the Tell-us cards. Participants of this teams expressed that physicians being reluctant to talk to patients would negatively affect the use of the Tell-us cards (quote 13).

The importance of multidisciplinary cooperation

The majority of the participants stressed the importance to involve different healthcare professionals in the use of Tell-us cards (quote 14). One nurse indicated speech therapists should certainly be involved. Further, the cooperation of the physician was considered as crucial for its success. This was supported by the expectation of the participants that Tell-us cards will mainly be used for medical questions. In addition, participants considered involvement of physicians essential, as they often direct the policy of the wards (quote 15).

Table 4. Overview of illustrative quotes of barriers and enablers for the implementation of Tell-us card

Enablers	Barriers
Maintaining control over care	
Quote 1: "In the afternoon at the start of the visiting hours, there is a peak of people who present themselves with questions. As a relative of the patient, it seems to be good to have a communication instrument where you can ask your questions. We as nurses don't always have time for their questions at the nurses' station, when we will be able to answer the questions of relatives at a quiet moment, it seems to be good for the relatives." (nurse internal ward)	*Quote 2: "I think it is important to set a fixed moment where nurses ask for the questions on the Tell-us cards. You could for example plan to check the Tell-us cards during the care in the morning. We definitely have to pick a fixed moment to control the Tell-us cards." (nurse rehabilitation ward)*
Fear of being seen as unprofessional	
Quote 3: "Feedback [from patients on the received care from nurses]on the Tell-us cards…yes…that's not an issue…if I can do something about it, than I will do so, as long as it is formulated in a friendly and polite way." (midwife maternity ward)	*Quote 4: "I also think some questions on the Tell-us card will go beyond our personal expertise. Well, that patients really expect us to have an answer for everything that is on there but that won't always be able to. "(nurse internal ward)*
Lack of insight in the meaning of patient participation	
	Quote 5: [Patient participation is..] "That patients can map out their care more themselves, how they themselves view their stay here. That they aren't entirely dependent on us for everything. At first it's by repeating the information about their care, also by stimulating them to take their care in their own hands as much as possible and allowing patients who had caesarian section to wash themselves as much as possible. Also in respect to the baby-bath: the first time we do it ourselves and after that we supervise. Everyone stimulates and motivates the patients. If we notice e.g. that patients haven't done much themselves yet, we also tell patients that they really have to do more themselves in anticipation of their discharge." (midwife maternity ward)

Enhancing or impeding communication with patients and relatives

Quote 6: “With the Tell-us cards, I expect to have more two-way communication, now there is often one-way communication. Notwithstanding we are available, family doesn’t always ask questions, for example about the course of the treatment.” (nurse internal ward)

Quote 7: “For me, it’s strange to ask patients to write down their questions, the paper between the patient and me creates a distance. Questions from patients are being answered during spontaneous conversations, by reading their questions, it seems like having a more formal interaction with the patient.” (midwife maternity ward)

Quote 8: “I do believe in Tell-us cards, but definitely not for all patients. It’s worth the try, especially for that category who stays silently in the background.” (nurse assistant surgical ward)

Prerequisites for successful implementation and use of the Tell-us card

Quote 9 : “We need an education about the Tell-us cards, with the entire team and not with only a small part of our team. In order to make the implementation of the Tell-us cards successful, we have to be informed about the best practice when working with Tell-us cards.” (nurse rehabilitation ward)

Quote 10: “Changes on the ward often fade, after reminders you see fluctuations in the degree of follow-up. Follow-up and positive reinforcement is important. Highlight the benefits, possibly even magnified.” (nurse internal ward)

Quote 11: “For me, the biggest issue is privacy. Not all visitors are close family, some are curious [of the content of the Tell-us card]. Not everyone should know what you’ve been through.” (nurse rehabilitation ward)

Team climate influencing the readiness to work with the Tell-us card

Quote 12: “We have a very dynamic group, a group that adapts easily to changes. Where I have the theoretical knowledge, owns my team the practice. They can translate the theory into practice. My team complements each other well to translate theory into practice. I believe they will be able to find practical solutions to help succeed the implementation of the Tell-us cards.” (head nurse surgical ward)

Quote 13: “I’m concerned about the physicians, there is still a problem in the field of communication, they are very poorly accessible for questions. They do not expect questions from relatives at all, there are physicians who will do anything to avoid questions”. (nurse internal ward)

The importance of multidisciplinary cooperation

Quote 14: ” What I was also thinking of: if we elaborate on it, perhaps we can think about the multidisciplinary. Because we also get a lot of questions about the social aspects. “What if our mom has to go home?". But every Wednesday we have a multidisciplinary team meeting with the social services, psychologists, occupational therapists … And then we can pass on questions that are kind of multidisciplinary to the other team members ". (nurse internal ward)

Quote 15: “The cooperation of the physician is also important, I think this might be an obstacle. Nurses are an intermediary, the physician determines the policy, if he doesn’t cooperate, it simply won’t work.” (assistant head nurse internal ward)

6. DISCUSSION

The aim of this study was to investigate potential barriers and enablers prior to the implementation of the Tell-us card. The analysis revealed that nurses and midwives want to maintain control over care and were reluctant to engage in difficult and in-depth conversations. Previous research has indicated that avoidance of lengthy conversations with patients may indicate a fear that these conversations can possibly lead to loss of care planning control and that they are considered as very challenging in combination with a high workload (Henderson, 2003). Nurses and midwives in our study described their current practice as overburdened, making it difficult to allocate time for answering questions of patients. The increasing workload can reinforce their need to feel in control over the provision of care and sustain to their fixed planning of care (Vandecasteele et al., 2015). The need to maintain control over care may impede patient participation, as this may indicate that nurses and midwives prefer routines rather than incorporating patients' preferences into care plans (Tobiano, Marshall, Bucknall, & Chaboyer, 2016a; van Belle et al., 2018). A review conducted by Suhonen, Valimaki and Leino-Kilpi (2009) identified the need to get the work done efficiently irrespective of the patients' situation as an impeding factor for individualised nursing care.

Most nurses and midwives in our study were not aware of the actual meaning of patient participation. The concept of participation was introduced in Arnstein's ladder of Citizen Participation (Arnstein, 1969). Arnstein's ladder was fit to the context of health care, and the term 'citizen' was replaced by the term 'patient' (Castro et al., 2016). The ladder of participation for the healthcare context contains five steps: informing, consulting, advising, co-producing and patient driven collaboration (De Wit, Kvien, & Gossec, 2015). Most nurses and midwives in our study seemed only aware of the lowest steps of patient participation. Their vision of patient participation was more focussed on 'giving information to patients' than on 'active participation in decision making' and 'giving patients the right to take control and power over their care'. Indeed, giving information to patients is crucial for successful patient participation, but nurses and midwives should be aware of its broader context (Castro et al., 2016). Our results are in line with the study of Kolovos et al. (2015), where nursing staff also had a narrow vision on the concept patient participation, as their perceptions of it mainly focused on information providing during hospitalisation, communication of symptoms by patients and compliance with the staff's orders. Due to the lack of insight in the meaning of patient participation considering the patient's view as an expert may be less evident in nurses and midwives perceptions (Castro et al., 2016; Sahlsten, Larsson, Sjöström, & Plos, 2008). Besides the lack of insight in the meaning of patient participation, nurses and midwives also lacked appreciation for the importance of patient participation. Previous studies (Larsson, Sahlsten, Segesten, & Plos 2011; Sahlsten, Larsson, Plos, & Lindencrona, 2005) have discussed nurses' paternalistic attitudes and nurses not understanding the importance of treating patients as equal partners. These studies point out that sharing power and responsibilities with patients and an attitude that it is morally right for patients to make own choices and exercise control, are essential for patient participation (Larsson et al., 2011; Sahlsten et al., 2005).

The interviews also showed that nurses and midwives feared being seen as unprofessional when using the Tell-us cards. Similar findings were described in the study of Hrisos and Thomson (2013), where nurses were worried that the involvement of patients to enhance improvement in patient safety would challenge their professional status and integrity. Nurses and midwives in our study may felt uncomfortable with the idea of being challenged by knowledgeable patients and perhaps feel threatened by expert patients (Wilson, Kendall, & Brooks, 2006). In addition, nurses and midwives feared repercussions from physicians due to complaints from patients on the Tell-us cards. They may have such feelings as a consequence of medical dominance and nursing subservience (Benoit, Zadoroznyj, Hallgrimsdottir, Treloar, & Taylor, 2010; Thomson, 2007) and nurses and midwives not feeling confident or assertive enough to communicate and discuss patient care on equal platforms with physicians (Nelson, King, & Brodine, 2008).

The involvement of all members of the multidisciplinary team, in particular physicians, is considered as crucial in order to achieve a successful implementation of the Tell-us cards. In the review of Kajermo et al. (2010) 'other staff being not supportive of the implementation process' was deemed as an obstacle for the implementation of research findings in practice. Despite the cooperation of the physician being seen as essential, some nurses and midwives stated that physicians were rather reluctant to talk to patients, and indicated this could negatively affect the use of the Tell-us cards. In the review of Kajermo et al. (2010) 'physicians not willing to co-operate' was also shown to be a moderate or great obstacle for the implementation of research findings in practice.

6.1 Implementation plan

In order to accomplish a successful and sustainable implementation of the Tell-us card, developing implementation strategies that match theory-based behavioural determinants associated with the identified barriers will be crucial (Wensing & Grol, 2017; van Belle et al., 2018). In Table 5, examples of determinants and examples of the implementation strategies for the identified barriers are shown. The determinants were selected from the following behaviour change theories: Social Cognitive Theory (Bandura, 1991), Theory of Planned Behaviour (Ajzen, 1991), The Behaviour Change Wheel (Michie, Van Stralen, & West, 2011), and The Health Belief Model (Champion & Skinner, 2008), as the barriers found in our study were mostly matched with the determinants in these behaviour change theories.

To overcome the lack of insight in the meaning of patient participation, workshops that provide education on patient participation may be needed to make sure nurses and midwives understand the meaning and broader context of patient participation and see it as an essential part of daily nursing care (Castro et al., 2016; Sahlsten et al., 2005; Tobiano, Marshall, Bucknall, & Chaboyer, 2015). Further, a co-design trajectory in which nurses/midwives and patients act as active partners in the development process of the Tell-us card, may be essential in counter reluctance towards patient participation (Castro et al., 2018). By bringing the perspectives of patients and nurses/midwives together, nurses and midwives may change their perspectives on patient participation and may be stimulated towards a more empowered way of thinking (Castro et al., 2018). Also, involving physicians in the co-design trajectory may tackle the fear of patient complaints and repercussions from physicians as this strategy increases mutual understanding and facilitates an open dialogue among stakeholders (Castro et al., 2018). Reflective education, which focusses on nurses and midwives how to depart from their fixed planning of care in a thoughtful manner, may support them in feeling more confident to increase flexibility in their care and still be in control over the care process (Bramhall, 2014). Likewise, communication skills training and role plays in which nurses and midwives are trained to deal with situations in which communication is difficult, may stimulate them to engage in difficult and in-depth conversations.

6.2 Strengths and limitations

Several strategies were used to increase the trustworthiness of the obtained results in our study. Member checking and researcher triangulation during data-analysis were used. Additionally, an external researcher to the wards and hospitals conducted all interviews. Furthermore, variation sampling on participant level was used to both explore the views of participants who were reluctant of the Tell-us cards and participants who were in favour of the Tell-us cards. Two important limitations were present in our study. The external researcher involved in the Tell-us card project conducted the interviews as well. This could result in participants giving socially desirable answers. However, participants expressed their scepticism towards the implementation of Tell-us cards, which could possibly mean that social desirability was limited. Second physicians were often mentioned as an important influence on a ward’s policy, but only nurses, head nurses, nurse assistants and midwifes were interviewed. Not involving physicians and patients, may have prevented the identification of additional barriers and enablers.

Table 5. Implementation strategies

Barrier	**Determinant (theory)**	**Implementation strategy**
Desire to maintain control over care	Attitude (Theory of Planned Behaviour)	Reflective education, which focusses on nurses and midwives how to depart from their fixed planning of care.
Reluctance to engage in in-depth conversations	Self-efficacy (Social Cognitive Theory)	Before the implementation: Communication skills training and role-plays in which nurses and midwives are trained to deal with situations in which communication might be difficult. During the implementation: One to one sessions with the researcher in which nurses/midwives reflect on situations in which communication is difficult.
Lack of insight in the meaning of patient participation	Knowledge (The Behaviour Change Wheel)	Workshops in which education on patient participation is provided.
Lack of appreciation of the importance of patient participation	Attitude (Theory of Planned Behaviour)	A co-design trajectory in which nurses/midwives, physicians and patients act as active partners in the development process of the Tell-us card.
Fear of repercussions from physicians	Fear (The Health Belief Model)	A co-design trajectory in which nurses/midwives, physicians and patients act as active partners in the development process of the Tell-us card.
Fear of being seen as unprofessional by patients	Fear (The Health Belief Model)	A co-design trajectory in which nurses/midwives, physicians and patients act as active partners in the development process of the Tell-us card. Information sessions for the physicians on the Tell-us card and informing nurses/midwives about these sessions.

7. CONCLUSION

This study has identified important barriers and enablers for the implementation of the Tell-us card to improve patient participation in hospitals. In general, nurses and midwives seemed rather reluctant towards patient participation and actively facilitating that by using the Tell-us card communication tool. The major barriers appeared to be the desire to maintain control over care, fear of being seen as unprofessional by patients, fear of repercussions from physicians, reluctance to engage in in-depth conversations, lack of insight in the meaning of patient participation, and lack of appreciation of the importance of patient participation. Participants also elaborated on several prerequisites for successful implementation and regarded the cooperation of the multidisciplinary team as an essential enabler.

8. RELEVANCE TO CLINICAL PRACTICE

In terms of clinical relevance, the findings of this qualitative study have uncovered a reluctant attitude towards patient participation and actively facilitating that by using the Tell-us card communication tool. This means that the change process should be approached with caution. A number of barriers will have to be factored into the implementation plan of the Tell-us card. Tailored implementation strategies that match theory-based behavioural determinants associated with the identified barriers will be crucial to accomplish a successful and sustainable implementation of the Tell-us card (Wensing & Grol, 2017; van Belle et al., 2018).

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CHAPTER 6

EVALUATING THE IMPLEMENTATION OF A COMMUNICATION TOOL TO IMPROVE PATIENT-CENTRED CARE IN HOSPITAL WARDS

Chapter based on:

Theys, S., Lust, E., Malfait, S., Eeckloo, K., Beeckman, D., Verhaeghe, S., & Van Hecke, A. (2021). Evaluating the effectiveness of a communication tool to improve patient-centred care in hospital wards: a nonequivalent control group study in patients, nurses, and midwives. *Nursing Inquiry.* (Submitted).

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ABSTRACT

Patient-centred care has become ubiquitous in health care. To enable it, communication is crucial. Based on the results of previous studies, the Tell-us card may be a promising tool to improve patient-centred care. To evaluate the effectiveness of the tool in Flemish hospitals, a multicentre study with a non-equivalent control group pretest-posttest design was performed. Experiences of patients and nurses/midwives with the intervention and the content of the tool were also examined. To evaluate the effectiveness, self-assessment questionnaires were collected at baseline (February - June 2016) and three months after implementation (December 2016 - January 2017). General qualitative analysis and linear mixed model analysis were used to analyse the data. Examination of experiences with the tool revealed that nurses/midwives showed reluctance towards it. Also, some patients did not always find the tool useful or had no need to use it. Regarding the effectiveness, no statistical differences were found between the intervention and control groups (of both patients and nurses/midwives) in the evolution over time for the proposed outcomes, including patient-centred care. Overall, the results seem to underline the complexity of enhancing a patient-centred approach in daily hospital practice. It should be questioned whether the tool will be more relevant when it is implemented within specific patient populations or situations rather than be used standardly. Further, future studies should investigate the impact of factors related to the hospital context and the wider health system on interventions promoting patient-centred care.

1. INTRODUCTION

Patient-centred received much attention over the last years as an effective approach for providing high-quality care (WHO, 2015). It is part of the five-step agenda of the Institute of Medicine (IOM) to build a stronger health system (Wolfe, 2001). In order to enable it, communication is crucial (Tobiano, Marshall, Bucknall, & Chaboyer, 2016). In this study, the process and effectiveness of the Tell-us card in Flemish hospitals are investigated, as it is a promising tool to enhance a patient-centred approach in hospital care (Jangland, Carlsson, Lundgren, & Gunningberg et al., 2012).

2. BACKGROUND

According to the IOM, patient-centred care can be defined as care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions (Wolfe, 2001). A more recent study of Castro, Van Regenmortel, Vanhaecht, Sermeus, and Van Hecke (2016) specifies that patient-centred care implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy, and shared knowledge. Yet, there is no universally accepted definition and the concept has been described by various other terms such as patient-centredness, client-centred care, and client-centred practice (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016).

To enable patient-centred care communication is crucial (Tobiano et al., 2016). Communication is fundamental (Feo & Kitson, 2016) and vital for establishing and maintaining a patient-centred relationship (Castro et al., 2016). Through communication, patients are given the possibility to be involved in decisions about their care and are updated about their planned and continuing care (Feo & Kitson, 2016). Yet, many patients report inadequate communication from healthcare professionals, as they do not elucidate details of care in an understandable manner (Feo & Kitson, 2016). For example, basic communication, like presenting oneself to patients, does often not take place (Feo & Kitson, 2016). Observational studies also show that nurses devote more time to tasks such as medication rounds than handling psychosocial and relational needs of the patient (van Belle et al., 2020; Williams, Harris, & Turner-Stokes, 2009).

Bedside shift reporting (Anderson & Mangino, 2006; Gregory, Tan, Tilrico, Edwardson, & Gamm, 2014) and the use of whiteboards in the patient room (Singh et al., 2011; Tan, Evans, Braddock, & Shieh, 2013) are upcoming communication methods in nursing to facilitate a patient-centred approach. In 2012, Jangland, Carlsson, Lundgren, and Gunningberg developed a similar communication intervention in the form of a card (Tell-us card communication tool), than can be placed in the patient room. Using the tool, patients can indicate what is most essential for them during their hospital stay. Healthcare professionals can use it to respond to patients’ preferences, needs, and concerns. In the study of Jangland and colleagues (2012), it was found that the use of the tool improved patients’ capabilities to take part in decisions concerning their nursing and medical care. The subsequent 2-year implementation project of the tool by Jangland and Gunningberg (2017) indicated that nursing staff had more positive attitudes towards the involvement of patients in their care.

As the aforementioned studies showed promising results, we aimed to evaluate the process and effectiveness of the tool in Flemish hospital wards. Our study expands the previous Dutch study by focussing on eight wards with different specialisations (e.g maternity wards, rehabilitation wards). Our hypothesis was that by using the tool nurse-patient/midwife-patient communication will be enhanced, which in turn would improve patient participation, patient-centred care, patient empowerment, and the quality of care. We also expected that enhanced nurse-patient/midwife-patient communication would reduce work interruptions and so facilitate the coordination of the care process (Gregory et al., 2014; Theys et al., 2020). Consequently, it is assumed that the quality of patient care will improve. Our hypothesis is based on the results from the study of Jangland et al. (2012), on evidence regarding the positive effects of bedside shift reporting (Gregory et al., 2014), and on a study of investigating the interrelationship between the concepts patient participation, patient-centred care and patient empowerment (Castro et al., 2016).

3. AIMS

Q1: To which extent do nurses and midwives follow the structured content protocol (summative)?
Q2: Are there effects for patients receiving the Tell-us card intervention in comparison
to patients not receiving it concerning patient-centred care, patient empowerment, and quality of care?
Q3: Are there effects for nurses/midwives delivering the Tell-us card intervention in comparison to nurses/midwives not delivering it concerning, communication, patient participation, patient-centred care, coordination of the care process, and work interruptions?

4. STUDY DESIGN

A multicentre study with unannounced visits to evaluate the process and a non-equivalent control group pretest-posttest design to evaluate the effectiveness of the tool was performed. The hospital and specialisation of the ward were used for matched-control assignment. The experimental wards received the Tell-us card intervention during hospital stay. The control wards received care as usual related to communication aspects.

5. METHODS

5.1 Sample size

Patient empowerment, one of the major outcomes, was used for sample size calculation. A previous study on patient empowerment measured by the Short form of the Patient Activation Measure (PAM-13) (Solomon, Wagner, & Goes, 2012) provided the data. The intracluster correlation (ICC) was taken into account. When all wards have the same size of 25 patients and an ICC of 0.01 is assumed (Adams et al., 2004), a sample of 320 patients in total will achieve at least 80% power to detect a mean difference between the control and intervention group of 5 points on the patient empowerment score at the two-sided 5% significance level, assuming a SD of 14.17 in both groups. This calculation does not take into account potential drop-out.

5.2 Setting and population

Quality coordinators, chief nursing officers, and chief medical officers of all Flemish regional (n = 68) and university hospitals (n = 3) received an invitation. Information sessions were held to communicate on the details of the project. Wards were eligible for participation if no major changes were made or ongoing (e.g. merger of hospital wards). Three maternity wards, two surgical wards, two internal medicine wards, and one rehabilitation ward consented to participate. The control wards, if possible matched based upon hospital and specialisation of the ward, consisted of one maternity ward, one surgical ward, two internal wards, and one rehabilitation ward. Primary inclusion criteria for the nurses/midwives were having direct patient contact and work experience of at least six months on the ward. Patients could participate if they were 18 years or over, stayed at least one day at the hospital, had the ability to speak and read Dutch, and were mentally competent as assessed by a nurse/midwife of the ward caring for the patient.

5.3 Intervention development

Individual interviews with (head)nurses, nurse assistants, and midwifes were conducted to identify barriers and enablers for the implementation of the tool (Theys et al., 2020). A shortened co-design trajectory based on the principles of Experience Based Co-Design (EBCD) (Castro, Malfait, Regenmortel, Van Hecke, Sermeus, & Vanhaecht, 2018) was set up to tailor the Tell-us card to the needs of the different wards. Co-design allows for nurses/midwives and patients to act as active partners in the development process of the tool. The trajectory included for each ward: (1) individual interviews with patients to assess the card-intervention, (2) separate focus groups for patients and nurses/midwives to stimulate debate (Holloway &

Galvin, 2016), and (3) a joint group meeting with nurses/midwives and patients together to redesign and refine the intervention.

5.4 Intervention adoption and implementation

Based on the identified barriers in the individual interviews with nurses/midwives, additional implementation strategies to assist the adoption and implementation were developed. Examples of the strategies are workshops in which education on patient participation is provided and role-plays. An overview of the strategies can be found in the study of (Theys et al., 2020). Furthermore, at each ward a project team was set up to guide implementation. Weekly visits to the ward were scheduled with the project team to evaluate the implementation process, to give and receive feedback, and to discuss questions or confusion regarding the implementation. Within the project team, key nurses/midwives were selected to stimulate the use of the tool. Posters with step-by-step written explanation of how to carry out the intervention were hung up at the nurses' station.

5.5 Data collection

Concerning the process evaluation, experiences of patients and nurses/midwives were examined during the weekly visits to the wards scheduled between October 2016 and January 2017. Further, from January 2017 until May 2017 unannounced visits to the wards were made by the researcher to assess if nurses and midwives followed the structured content protocol. An example of some actions of the protocol can be found in Figure 1. The protocol was tailored according to the specific work processes of each ward. To check if the actions of the protocol were followed, the researcher asked questions to patients and nurses/midwives, observed the content of the Tell-us card, and checked the patient file. If it was unnecessary to perform a certain action (e.g. not informing patients about follow-up actions because no follow-up is needed) this was also marked on the protocol. To evaluate the reliability of the process evaluation, some of the unannounced visits were made by two researchers. Questionnaires were collected at baseline (T0 – February - June 2016) and three months after implementation (T1 – December 2016 - January 2017).

Action	Yes	No	Unnecessary
The patient is informed about the purpose and use of the Tell-us card during the first encounter with the midwife			
The patient uses the Tell-us card			
Questions on the Tell-us card are discussed daily with the patient			
Important questions and follow-up actions are recorded in the patient file			
The patient is informed about follow-up actions			
The Tell-us card is positioned visible and within reach on the nightstand of the patient			

Figure 1. Example of actions on the structured content protocol for a maternity ward

Patients

Patients received the questionnaires before discharge if they met the inclusion criteria and were willing to participate. The questionnaires were retrieved after two hours. If patients were not able to complete the questionnaire in time, they could deposit the questionnaires in a collection box. Patients unable to fill in the questionnaires (e.g. due to motoric difficulties), were supported by a member of the research team or a study nurse with no connection to the research team.

The following demographic variables were considered for the patients: age, gender, level of education, employment status, living situation, days of admission, and health literacy measured by the 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?’.

Nurses/midwives

Nurses/midwives meeting the inclusion criteria and willing to participate received the questionnaires in a sealed envelope and could deposit them in the collection box. They were reminded of filling in the questionnaire by a researcher weekly visiting the wards.

The following demographic characteristics were taken into account for the nurses/midwives: age, gender, level of education, work percentage, and years of work experience in nursing or midwifery.

Outcomes

In Figure 2, the hypothetical relationship between the outcome variables and their corresponding measurement instruments is shown.

Measurement instruments for patients. Patient-centred care was measured by the Individualised Care Scale for patients (ICS-Patient) (Suhonen, Leino-Kilpi, & Välimäki, 2005). The scale is divided in two subsections each consisting of 17 items. The first subsection (ICSA) explores patients' views of how individuality was supported through specific nursing actions. The second section (ICSB) explores how patients perceive individuality in their care while admitted in the hospital. Both subsections compromise of three subscales: (1) clinical situation, (2) personal life situation, and (3) decisional control over care. The answering categories per item are five-point Likert scales ranging from 1 (fully disagree) to 5 (fully agree). The higher the scores (range 0-85), the more patients perceive individuality is supported through specific nursing interventions and the higher the degree of perceived individuality in their care (Suhonen et al., 2005). The Dutch version of the ICS-patient was validated by Theys, Van Hecke, Akkermans, and Heinen (2021b) and showed high internal consistency (ICSA [α] = 0.94; ICSB [α] = 0.95).

Patient empowerment was measured by the Short form of the Patient Activation Measure (PAM-13). The scale, originally developed and validated by Hibbard, Mahoney, Stockard, and Tusler (2005), was translated and validated in Dutch by Rademakers, Nijman, van der Hoek, Heijmans and Rijken (2012) and showed high internal consistency ([α] = 0.88). 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 (Rademakers, Nijman, van der Hoek, Heijmans, & Rijken, 2012).

The quality of care was measured by the short form of the Quality from the Patient's Perspective questionnaire (QPP). The QPP contains 24 items that examine the patient's perspective on four dimensions of quality of care (Larsson & Wilde, 2010): medical technical competence (QPP-MT), physical-technical conditions (QPP-PT), identity-orientated approach (QPP-IO), and socio-cultural atmosphere (QPP-SC). The questionnaire uses a four-point Likert scale ranging from 1 (do not agree at all) to 4 (completely agree) and non-applicable. The questionnaire showed good reliability (QPP-MT [α] = 0.67; QPP-PT [α] = 0.65; QPP-IO [α] = 0.91; QPP-SC [α] = 0.72; Larsson B.W., Larsson G., 2002).

Measurement instruments for nurses/midwives. Patient-centred care was measured by the ICS-Nurse (Suhonen, Gustafsson, Katajisto, Välimäki, & Leino-Kilpi, 2010). The ICS-Patient was mirrored to measure nurses' perceptions of (1) how they support patients' individuality through specific nursing activities (ICSA-Nurse) and (2) the evaluation of maintaining individuality in their provided care (ICSB-Nurse). The higher the scores (range 0-85), the better patient individuality is supported through nursing activities, and the higher nurses' perceptions of individuality in patients' care (Suhonen et al., 2010). The Dutch version of the ICS-nurse was validated by Theys et al. (2021b) and showed high internal consistency (ICSA [α] = 0.94; ICSB [α] = 0.94).

Patient participation was measured by three questions, based on the Patient Participation Culture Tool for Healthcare workers (PaCT-HCW) (Malfait, Eeckloo, Van Daele, & Van Hecke, 2016). Nurses/midwives were asked to score the degree to which patients (1) are informed, (2) are asked for their advice, and (3) can decide on their care. A four-point Likert scale ranging from 1 (do not agree at all) to 4 (completely agree) was used.

Coordination of the care process (COR) and communication with the patient (COM) were measured by a subscale of the Care Process Evaluation Tool (CPSET; Vanhaecht et al., 2007), on a scale ranging from 1 (totally disagree) – 10 (totally agree). The main goal of the CPSET is to define the key characteristics of care processes that are having an impact on the organisation of care processes. The CPSET-COR ([α] = 0.88) is measured by seven items and The CPSET-COM ([α] = 0.83) is measured by four items. Both subscales are seen as two important characteristics of care organisation.

Nurses'/midwives' perceptions of work interruptions were measured with a scale developed by Malfait, Eeckloo, Lust, Van Biesen, and Van Hecke (2017). Nurses/midwives were asked to assess the prevalence of (1) calls for assistance, (2) questions from colleagues/family/patients on the ward, (3) incoming calls from family/other healthcare workers, and (4) calls to other responsible healthcare workers during their last shift, using a five-point Likert scale ranging from 1 (never) to 5 (very often).

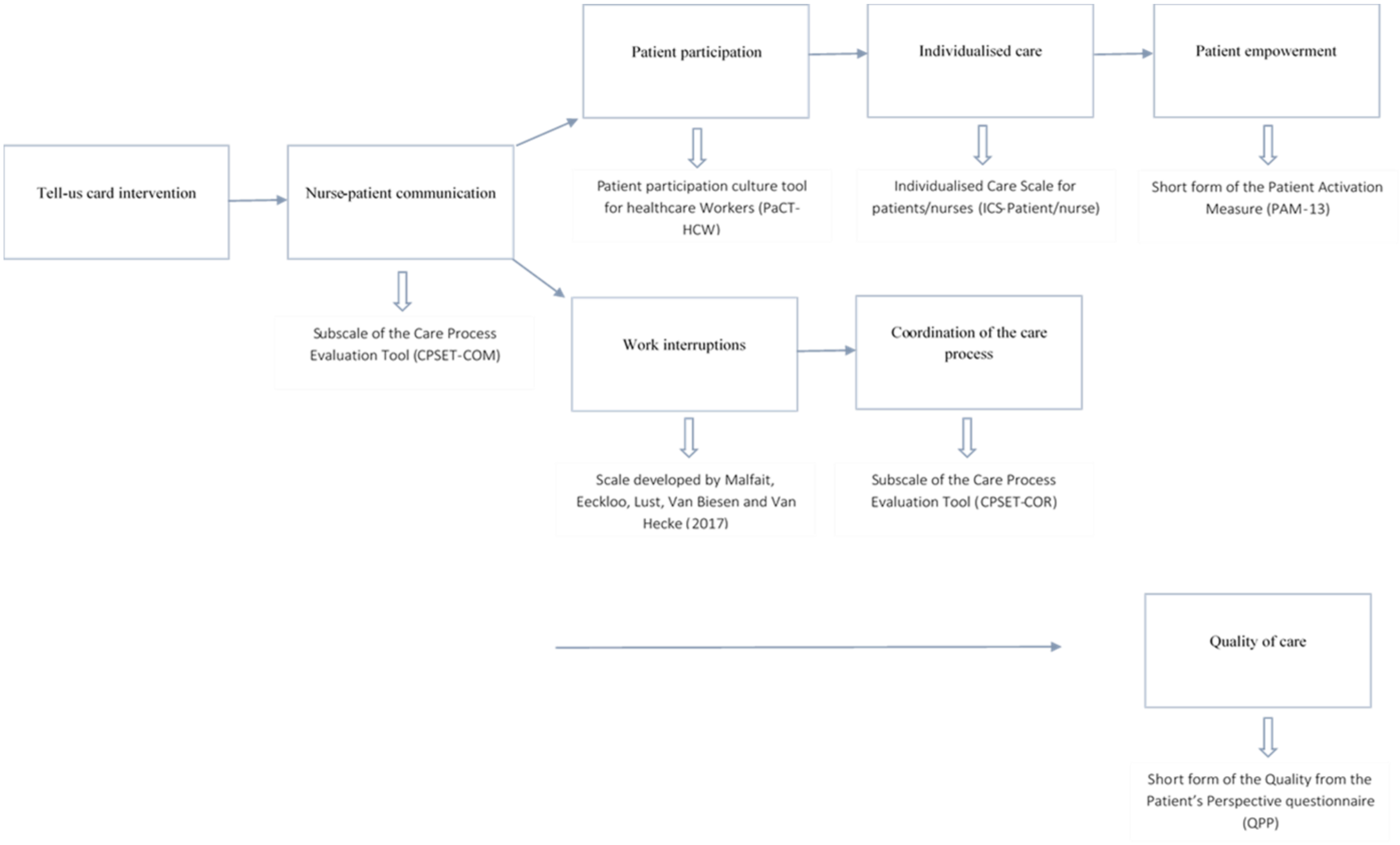

Figure 2. Hypothetical relationship between the outcome variables

5.6 Ethical considerations

The study protocol was approved by the Ethical Committee (B670201526903), and the local ethics committees of the participating hospitals. Informed consent was obtained from all patients and nurses/midwives through provision of detailed information on the purpose of the study and confidentiality.

5.7 Analysis

The experience of patients and nurses/midwives with the implementation and the content of the Tell-us card were analysed through general qualitative analysis. Questionnaires with repetitive response patterns or with more than 20% of the answers missing were excluded (for patients n = 93; for nurses/midwives n = 14). Descriptive statistics were used to describe the response rates and the distribution of the demographic characteristics. When analysing scales, mean item scores were reported except for the PAM-13. For the PAM-13 the mean scale score was reported, conform the scoring rules of Insignia Health (Insignia Health, 2020). To analyse the effect of the intervention, a linear mixed model using SPSS 25.0 (IBM, 2017) was fitted (Heck, Thomas, & Tabata, 2014). For nurses/midwives, a linear mixed model with repeated measures was used as data could be paired. Nurses/midwives or patients were specified as subjects and wards were entered as a random effect in the random coefficients model. To control for potential confounding, the association between demographic characteristics and the outcome variables was analysed. The basic random coefficient models for patients and nurses/midwives included ward in the random effects part and group (intervention vs. control), time (T0, T1), type of ward, type of hospital, and the interaction between group and time in the fixed effects part. The second models controlled for confounding of demographic variables. For all analyses, a significance level of 0.05 was used.

6. RESULTS

6.1 Response rates, drop-out rates, and demographics

Table 1 describes the response rates and drop-out rates. Two intervention wards (nursing wards) dropped out before the implementation of the tool. One intervention ward (nursing ward) dropped out during T1 and one (nursing ward) dropped out before T1. In the latter ward, the project was restarted in April 2017.

In total, 435 patients completed the questionnaires at T0 (mean response rate = 61.81%) and 130 at T1 (mean response rate = 53.77%). One hundred and ninety four nurses/midwives completed the questionnaires at T0 (mean response rate = 68.28%) and 108 at T1 (mean response rate = 68.28%).

Table 1. Response rates per ward for patients and nurses/midwives

			T0						T1					
			Nurses			Patients			Nurses			Patients		
Hospital	**Ward**		**Distributed**	**Returned**	**Response rate**	**Distributed**	**Returned**	**Response rate**	**Distributed**	**Returned**	**Response rate**	**Distributed**	**Returned**	**Response rate**
1 (university)	Internal	Intervention	30	8	26.70%	66	38	57.60%	29	8	27.60%	/	/	/
	Internal	Control	27	22	81.50%	61	35	57.40%	/	/	/	/	/	/
	Maternity	Intervention	48	24	50.00%	75	47	62.60%	48	15	31.30%	65	27	41.50%
2 (regional)	Maternity	Control	23	20	87.00%	52	40	76.90%	23	19	82.60%	42	37	88.10%
3 (regional)	Maternity	Intervention	29	18	62.10%	54	34	62.30%	29	23	79.30%	37	15	40.54%
4 (regional)	Maternity	Intervention	18	18	100%	55	37	67.30%	18	16	88.90%	47	24	51.10%
5 (regional)	Surgical	Intervention	20	13	65.00%	60	44	73.30%	/	/	/	/	/	/
	Surgical	Intervention	19	16	84.20%	53	38	52.80%	/	/	/	/	/	/
	Surgical	Control	18	10	55.60%	57	39	68.40%	/	/	/	/	/	/
6 (regional)	Rehabilitation	Intervention	20	9	45.00%	20	9	45.00%	/	/	/	/	/	/
	Internal	Intervention	15	12	80.00%	58	28	48.30%	15	12	80.00%	29	12	41.40%
	Internal	Control	17	12	70.60%	55	37	67.0%	17	15	88.24%	25	15	60.00%
7 (regional)	Rehabilitation	Control	15	12	80.00%	14	9	64.30%	/	/	/	/	/	/

In Table 2, patients' and nurses'/midwives' demographic characteristics at the two data collection points are given. For patients, the linear mixed model showed that days of admission (PersA), health literacy (ClinA, ICSB, DecB, QPP, QQP-IO, QPP-SC, PAM) living situation (PAM), and employment status (QPP, QPP-IO) were significantly associated with one or more outcome variables (between brackets). Therefore, it was decided to control for these variables in the second models. For nurses/midwives, age (PersA), gender (ICSB, ClinB, DecB, Patient participation, CPET-COM, CPET-COR), level of education (CPET-COM), work percentage (ICSA, ClinA, PersA, work interruptions), and years of work experience (ICSA, ClinA, PersA, DecA, DecB) were significantly associated with one or more outcome variables (between brackets). Therefore, it was decided to control for these variables in the second models.

Table 2. Demographic data for patients and nurses/midwives

Patients		**Intervention**		**Control**	
		T0	T1	T0	T1
Age	(mean)	48.35	37.94	52.47	35.86
Gender	Female	65.9%	93.5%	54.3%	81.4%
	Male	34.1%	6.5%	45.7%	18.6%
Health literacy	(mean)	2.14	1.94	2.32	1.80
Days of hospital admission	(mean)	6.81	7.75	10.48	5.68
Living situation	Alone	14.0%	8.1%	20.3%	9.3%
	With a partner, family or friend	83.8%	90.3%	75.4%	88.4%
	In a service flat, assisted living or a nursing home	2.2%	1.6%	4.3%	2.3%
Level of education	< Bachelor	57.1%	27.9%	55.1%	44.2%
	Bachelor	30.1%	45.9%	34.8%	34.9%
	Master	12.8%	26.2%	10.1%	20.9%
Employment status	Employed	53.5%	75.8%	54.3%	83.7%
	Unemployed	3.9%	6.5%	2.9%	2.3%
	Student	2.6%	0.0%	1.4%	0.0%
	Disabled	7.1%	1.6%	5.1%	4.7%
	Retirement	32.9%	16.1%	36.2%	9.3%

Nurses/midwives		Intervention		Control	
		T0	T1	T0	T1
Age	(mean)	40.04	39.09	37.60	37.57
Gender	Female	92.2%	94.3%	91.8%	96.7%
	Male	7.8%	5.7%	8.2%	3.3%
Profession	Nurse	49.6%	25.7%	74.0%	46.7%
	midwife	50.4%	74.3%	26.0%	53.3%
Level of education	Nurse assistant[a]	2.6%	0.0%	1.4%	0.0%
	Vocational nurse[b]	27.2%	10.0%	27.4%	23.3%
	Bachelor educated[c]	68.4%	84.3%	65.8%	70.0%
	Master educated[d]	1.8%	5.7%	5.4%	6.7%
Work percentage	< 50%	19.6%	21.4%	11.1%	0.0%
	50%–99%	50.0%	44.3%	41.7%	53.3%
	100%	30.4%	34.3%	47.2%	46.7%
Years of nurses'/midwives' work experience	< 1 year	4.3%%	0.0%	6.8%	6.7%
	1 to 5 years	15.7%	11.4%	26.0%	20.0%
	6 to 10 years	20.0%	25.7%	23.3%	20.0%
	11 to 15 years	15.7%	21.4%	11.0%	10.0%
	16 to 20 years	14.8%	18.6%	5.5%	10.0%
	> 20 years	29.5%	22.9%	27.4%	33.3%

[a] One year of education at level 3 of the European Qualifications Framework (EQF).
[b] Three years of education at level 5 of the EQF to obtain a diploma in Nursing.
[c] Three years of education at level 6 of the EQF to obtain the degree of Bachelor in Nursing.
[d] Five years of education at level 7 of the EQF to obtain the degree of Master of Science in Nursing.

6.2 Process evaluation

In total, 215 unannounced ward visits were made. On the intervention ward that dropped out during T1, there were only three visits. Unannounced visits showed that nurses/midwives did not always hand out the Tell-us card, inform the patients about the Tell-us card, follow-up questions on the card, and give writing materials to the patient. Examination of nurses'/midwives' experiences with the tool revealed that some believed that it would be difficult for patients to write down their emotional needs on the card and that the card itself could perform a barrier for in-depth interaction between the patient and the nurse/midwife. The Tell-us card could be more beneficial for interaction with relatives according to some nurses/midwives. Further, some nurses/midwives indicated that there were already sufficient tools available on the ward to promote patient participation and patient-centred care. The process evaluation also revealed that on one nursing ward follow-up of the project was difficult as the head nurse left the ward and that patients did not always use the tool and sometimes used it as an assessment to make judgements on the provision of care. On maternity wards, the tool was mainly used by primipara. Examination of the experiences of patients revealed that they did not always find the card useful and that patients who had previously been admitted to the hospital had no need to use the tool. Patients did not always have questions, preferred to ask them directly to the nurse/midwife, or were afraid to ask ‘stupid’ questions.

Tell-us card content

The Tell-us card was handed out 259 times. In total, the patients filled in 143 cards (56%). On nursing wards, patients mainly wrote questions about their care on the card related to wanting to be informed about or raising concerns about their medical treatment (e.g. when are the worst episodes after chemotherapy). Patients also had questions about discharge and going home. Some patients also wrote about physical discomfort (e.g. I feel nauseous) and had questions about administration and hospital facilities.

On maternity wards, common topics were patients having questions about a caesarean section, giving birth (e.g. are contractions painful for the baby), breastfeeding, premature birth, caretaking for a newborn baby, and going home and self-care at home. Many patients asked also questions about their care and medical treatment and the physical condition of the baby (e.g. how do I know if my baby has swallowing problems). Some patients also wrote about psychosocial discomfort and administration (e.g. application for breastfeeding leave).

6.3 Effect of the Tell-us card intervention for the different patient outcomes

Overall, the linear mixed model analysis without repeated measures (Table 3) showed that there were no statistical differences between the intervention and control groups in the evolution over time. Post hoc analysis of the QPP ($p = 0.014$), QPP-IO ($p = 0.046$), QPP-PT ($p = 0.013$) and QPP-SC ($p = 0.006$) showed that patients in the intervention group scored significantly higher at T1 than at T0.

Table 3. Differences between the intervention and control wards in the evolution over time for patients

		Mean (CI[c])		
Outcome	**Ward**	**T0**	**T1**	**P[a]**
ICSA-patient ***(range 1-5)***	Intervention	3.712 (3.390 - 4.003)	3.830 (3.474 – 4.185)	0.605
	Control	3.807 (3.454 - 4.159)	4.026 (3.627 – 4.426)	
ICSB-patient ***(range 1-5)***	Intervention	3.983 (3.613 – 4.263)	3.981 (3.626 – 4.336)	0.410
	Control	4.063 (3.710 – 4.417)	4.261 (3.869 – 4.653)	
ClinA-patient ***(range 1-5)***	Intervention	4.028 (3.685 – 4.372)	4.150 (3.772 – 4.528)	0.622
	Control	4.128 (3.752 – 4.504)	4.351 (3.928 – 4.774)	
PersA-patient ***(range 1-5)***	Intervention	3.082 (2.739 – 3.425)	3.121 (2.700 – 3.542)	0.453
	Control	3.168 (2.776 – 3.560)	3.406 (2.913 – 3.898)	
DecA-patient ***(range 1-5)***	Intervention	3.756 (3.429 – 4.083)	3.833 (4.462 – 4.204)	0.540
	Control	3.839 (3.475 – 4.202)	4.048 (3.625 – 4.471)	
ClinB-patient ***(range 1-5)***	Intervention	3.985 (3.612 – 4.359)	4.017 (3.611 – 4.422)	0.309
	Control	4.113 (3.709 – 4.517)	4.357 (3.911 – 4.803)	
PersB-patient ***(range 1-5)***	Intervention	3.566 (3.235 – 3.897)	3.641 (3.225 (4.027)	0.414
	Control	3.595 (3.220 – 3.970)	3.860 (3.419 – 4.301)	
DecB-patient ***(range 1-5)***	Intervention	4.121 (3.811 – 4.431)	4.145 (3.799 – 4.490)	0.399
	Control	4.247 (3.904 – 4.589)	4.432 (4.046 – 4.818)	
PAM-13 ***(range 0-100)***	Intervention	57.630 (54.614 – 60.646)	56.672 (52.566 – 60.778)	0.188
	Control	57.141 (53.883 – 60.399)	59.788 (54.911 – 64.664)	
QPP ***(range 1-4)***	Intervention	3.365 (3.310 – 3.600)	3.544 (3.292 – 3.796)	0.702
	Control	3.469 (3.214 – 3.724)	3.604 (3.330 – 3.878)	

QPP-MT ***(range 1-4)***	Intervention	3.576 (3.396 – 3.755)	3.719 (3.510 – 3.929)	0.598
	Control	3.655 (3.450 – 3.859)	3.729 (3.487 – 3.970)	
QPP-PT ***(range 1-4)***	Intervention	3.479 (3.325 – 3.632)	3.699 (3.502 – 3.869)	0.135
	Control	3.589 (3.409 – 3.769)	3.605 (3.369 – 3.840)	
QPP-IO ***(range 1-4)***	Intervention	3.337 (3.072 – 3.602)	3.505 (3.221 – 3.788)	0.982
	Control	3.438 (3.151 – 3.725)	3.609 (3.301 – 3.916)	
QPP-SC ***(range 1-4)***	Intervention	3.387 (3.106 – 3.667)	3.644 (3.346 – 3.942)	0.504
	Control	3.530 (3.231 – 3.830)	3.691 (3.369 – 4.012)	

Note. Second models, controlled for confounding
[a]p-value interaction effect (time*intervention)
[b]p-value < 0.05
[c]CI = Confidence interval

6.4 Effect of the Tell-us card intervention for the different nurse/midwife outcomes

Overall, the linear mixed model analysis with repeated measures (Table 4) showed that there were no statistical differences between the intervention and control groups in the evolution over time. Post hoc analysis for CPET-COR showed that nurses/midwives in the control group scored significantly higher at T1 than nurses/midwives in the intervention group (p = 0.017). Post hoc analysis for patient participation showed that nurses/midwives in the control group scored significantly higher at T0 (p = 0.001) and T1 (p = 0.001) than nurses/midwives in the intervention group. Post hoc analysis for ICSB (p = 0.048), ClinB (p = 0.048), and PersB (p = 0.022) showed that nurses/midwives in the control group scored significantly higher at T1 than nurses/midwives in the intervention group.

Table 4. Differences between the intervention and control wards in the evolution over time for nurses/midwives

		Mean (CI[c])		
Outcome	**Ward**	**T0**	**T1**	**P[a]**
ICSA-nurse *(range 1-5)*	Intervention	4.184 (4.028 – 4.339)	4.085 (3.894 – 4.276)	0.417
	Control	4.181 (3.997 – 4.365)	4.213 (3.958 – 4.468)	
ICSB-nurse *(range 1-5)*	Intervention	4.122 (3.929 – 4.316)	3.946 (3.723 – 4.169)	0.104
	Control	4.127 (3.914 – 4.340)	4.208 (3.934 – 4.482)	
ClinA-nurse *(range 1-5)*	Intervention	4.340 (4.177 – 4.503)	4.264 (4.063 – 4.466)	0.480
	Control	4.268 (4.076 – 4.461)	4.314 (4.043 – 4.585)	
PersA-nurse *(range 1-5)*	Intervention	3.802 (3.649 – 3.956)	3.661 (3.469 – 3.854)	0.815
	Control	3.903 (3.713 – 4.093)	3.716 (3.428 – 4.004)	
DecA-nurse *(range 1-5)*	Intervention	4.240 (4.066 – 4.414)	4.128 (3.918 – 4.338)	0.139
	Control	4.257 (4.057 – 4.456)	4.401 (4.129 – 4.672)	
ClinB-nurse *(range 1-5)*	Intervention	4.330 (4.129 – 4.531)	4.141 (3.906 – 4.376)	0.050
	Control	4.278 (4.056 – 4.500)	4.428 (4.136 – 4.720)	
PersB-nurse *(range 1-5)*	Intervention	3.911 (3.715 – 4.108)	3.668 (3.438 - 3.897)	0.187
	Control	3.915 (3.698 – 4.133)	3.920 (3.626 – 4.214)	
DecB-nurse *(range 1-5)*	Intervention	3.997 (3.778 – 4.217)	3.866 (3.616 – 4.116)	0.183
	Control	4.027 (3.782 – 4.271)	4.114 (3.817 – 4.411)	
CPSET-COM *(range 1-10)*	Intervention	5.897 (5.201 – 6.592)	5.880 (5.133 – 6.627)	0.515
	Control	6.464 (5.728 – 7.199)	6.174 (5.318 – 7.029)	

CPSET-COR *(range 1-10)*	Intervention	7.286 (6.922 – 7.650)	7.253 (6.843 – 7.662)	0.320
	Control	7.570 (7.171 – 7.968)	7.815 (7.319 – 8.311)	
Patient participation *(range 1-4)*	Intervention	2.746 (2.539 – 2.952)	2.705 (2.480 – 2.931)	0.676
	Control	3.086 (2.864 – 3.308)	3.106 (2.840 – 3.371)	
Work interruptions *(range 1-5)*	Intervention	2.156 (1.793 – 2.520)	2.075 (1.680 – 2.470)	0.330
	Control	2.113 (1.715 – 2.512)	2.289 (1.813 -2.766)	

Note. Second models, controlled for confounding
[a]p-value interaction effect (time*intervention)
[b]p-value < 0.05
[c]CI = confidence interval

7. DISCUSSION

The aim was to evaluate the process of the Tell-us card and to evaluate whether it is an effective tool to be used in hospital care. It was hypothesized that using the tool would improve nurse-patient communication, patient participation, patient-centred care, patient empowerment, and the quality of care, and would facilitate the coordination of the care process by reducing work interruptions. Our study could not confirm the aforementioned hypotheses. There were no statistical differences between the intervention and control groups (of both patients and nurses/midwives) in the evolution over time for the proposed outcomes. Although QPP increased significantly over time in the intervention group, it also increased in the control group. As the study shows no significant impact of the tool, discussing potential reasons for intervention 'failure' will be crucial as such knowledge can feedback and support development, implementation, and evaluation of future interventions (Richards & Hallberg, 2015).

First, the implementation of the tool was difficult. Two wards dropped out before the implementation. One ward dropped out before and one ward during the first measurement moment. Unannounced visits showed that nurses and midwives did not always follow the structured intervention protocol and were reluctant towards using the tool. However, it should also be questioned whether nurses and midwives were reluctant towards the tool because they did not believe that it was of added value. They believed that it would be difficult for patients to write down their emotional needs on the card and that the card itself could perform a barrier for in-depth interaction between the patient and the nurse/midwife. Further, patients did not always use the tool, misused it, or did not believe in its usefulness. The reflection should be made if the reluctant attitude of nurses and midwives did facilitate misuse and increased reluctance in use by patients. On maternity wards, it was remarkable that mainly primipara used the tool. On nursing wards, patients who had been previously admitted to the hospital had no need to use it. This might indicate that using the tool might be rather relevant for specific patient populations (e.g. primipara, patients admitted for the first time) instead of using it in every patient.

Second, the effectiveness of interventions is also largely influenced by factors of the context in which they are implemented. Different implementation frameworks such as the Context and Implementation of Complex Interventions framework, the Consolidated Framework for Implementation Research, and The Promoting Action on Research Implementation in Health Services framework stress the importance of understanding and investigating the context before implementation (Damschroder et al., 2009; Harvey & Kitson, 2015; Pfadenhauer et al., 2017). A distinction can be made between the inner context (e.g. hospital setting) and outer context (e.g. wider health system, political context). Future similar intervention studies should further explore the ward and hospital managements' vision and motivation towards patient-centred care. If they support patient-centredness in hospital care, this might have a positive impact on healthcare professionals' attitude towards patient-centred care and their motivation to implement new interventions to improve it (Luxford et al., 2011; Morgan & Yoder, 2012). The influence of hospital accreditation on the hospital managements' motivation towards patient-centred care warrants also further attention. The Tell-us card was part of a larger multi-annual programme (2013 - 2017) of the Belgian Federal Public Service for Health on the importance of a patient-centred approach in quality of care and patient safety. As the programme had links with accreditation requirements for Belgian hospitals, this was an important incentive for the hospitals to participate. However, the danger exists that such an incentive undermines intrinsic motivation towards patient-centred care and is considered as a goal on itself (Ellis et al., 2020; Wynia, 2009).

Third, healthcare policy today, both at the national (Flemish Patients Platform, 2011; King Baudouin Foundation, 2007) and international level (WHO, 2015), strongly advocates participation of patients in all aspects care. However, the ongoing evolution towards more evidence-based nursing can challenge the current approach to patient-centred care (Correa-de-Araujo, 2016; Mackey & Bassendowski, 2017). Protocols and guidelines have been developed to standardise healthcare practices to the best science available (Potter, Perry, Stockert, & Hall, 2017). Their use has shown to have a positive impact on patient outcomes and patient care (Potter et al., 2017). However, the probability exists that due to the standardisation demanded of evidence-based practice, the focus of nursing practice shifts towards a more checklist-like manner of care provision, including the risk that completing tasks is given priority over basic empathetic communication (Oxelmark, Chaboyer, Bucknall, & Ringdal, 2018). A meaningful dialogue with the patient seems to become subordinate, resulting in standardised communication not adapted to the individual patient.

7.1 Methodological considerations

A strength of this study was the rigorous co-designed and tailored implementation of the tool to the specific needs of the wards to increase the chance of success (Richards & Hallberg, 2015). The reliability and the validity of the study were enhanced by the use of validated measurement instruments and by selecting outcomes and hypotheses based on theoretical (Castro et al., 2016) and practical (Gregory et al., 2014; Jangland et al., 2012) understanding of how the intervention would affect change. Last, instead of the traditional methods of repeated measures analysis (e.g. analysis of variance), a linear mixed model analysis was used, taking into account clustering of the data (Heck, Thomas, & Tabata, 2014).

Despite the strengths, some limitation needs to be mentioned. First, a quasi-experimental design is weaker than a randomized controlled trial, as the latter is beneficial in reducing selection bias and balancing groups for confounding variables (Polit & Beck, 2017). Nevertheless, this study controlled for confounding variables, and the hospital and ward type were used for matched-control assignment (Polit & Beck, 2017). Matching reduces bias as the control wards are matched upon certain pre-existing characteristics similar to those observed in the intervention wards. However, it was not always possible to include both an intervention and a control group at each participating hospital. Second, there was a high drop-out rate. Four intervention wards dropped out and 130 patients completed the questionnaires at T1. These drop-out rates limit the generalisability of the findings and affect the adequate numbers for maintaining the power of the study as a sample of 320 patients was needed to achieve 80% power to detect a mean difference between the control and intervention group of 5 points on the patient empowerment score (Polit & Beck, 2017). Also, the inclusion of non-homogenous patient populations might have affected pooling of results, which further limits the power of the study. Third, the response rates should also be addressed as they provide information on possible bias and can affect representativeness of the sample (Fitzpatrick, 2014). Response rates for patients varied between 45% - 77% at T0 and 40% - 88% at T1. For nurses, response rates varied between 27% - 87% at T0 and 28% - 89% at T1. Although there is no consensus about desirable response rates and experts differ in their views on what constitutes an adequate response rate, a response rate of 60% is desirable across all methodologies (Badger & Werrett, 2005). Overall, the response rate in this study can be considered as relatively good. On wards were the response rate is lower, this may lead to a less representative sample. Fourth, the question needs to be addressed whether sustainable conclusions can be made about the effect of the intervention as the intervention was assessed with only one time point (Wang et al., 2017). Fifth, no qualitative evaluation of the Tell-us card intervention through individual interviews with nurses and patients was held. Consequently, no further insight can be provided into reasons such as why patients did not always use the tool, misused it, or did not believe in its usefulness. Last, patients unable to fill in the questionnaires were sometimes supported by a member of the research team. Therefore patients may have answered questions more positively than the reality of their situation (Polit & Beck, 2017).

8. CONCLUSION

This study evaluated the implementation of a communication tool in Flemish hospitals. The intervention did not show improvement in the proposed outcomes. Half of the intervention wards dropped out during the study and the structured intervention protocol was not always followed. Overall, the results seem to underline the difficulty and complexity of enhancing a patient-centred approach in daily hospital practice.

9. RELEVANCE TO CLINICAL PRACTICE

As the tool was mainly used by primipara and patients who had been previously admitted to the hospital had no need to use the card, it should be questioned whether the tool will be more relevant when it is implemented within specific patient populations or situations rather than be used standardly. Further, future intervention studies aiming to improve holistic and patient-centred care in hospitals, should further investigate the impact of factors related to the hospital context and the wider health system such as the ward and hospital managements' vision and motivation towards patient-centred care and the influence of hospital accreditation on motivation towards adopting a patient-centred approach. Also, in today's nursing/midwifery education more attention should be given at communication relating to promoting patient participation and building a trustful relationship with the patient, respecting values, opinions, and needs.

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CHAPTER 7

GENERAL DISCUSSION

1. MAIN INSIGHTS

Considering the available evidence, there is no doubt about the importance of patient-centred care and patient empowerment in hospital care today. The Belgian Federal Government has also emphasised the need of working towards patient-centred care and patient empowerment in Belgian hospitals (Desomer et al., 2018; Federal Public Service Health, Food Chain Safety and Environment, 2013; Flemish Patients Platform, 2011; King Baudouin Foundation, 2007). Yet, little is known about how nurses working and patients staying in Belgian (Flemish part) hospital wards perceive the support and provision of patient-centred care and how their perceptions compare. As there was no reliable and valid tool available for measuring perceptions regarding patient-centred care in the Flemish hospital context, from both the nurse and patient perspective, the first aim of this dissertation was to psychometrically validate the Individualised Care Scale (ICS) (Chapter 2). The results in chapter 2 showed that the internal consistency reliability of the Dutch version of the ICS was good and had an acceptable model fit, sustaining its construct validity. Furthermore, there was no evidence on the level of empowerment of Belgian (Flemish part) hospitalised patients. Therefore, this dissertation also aimed to gain insight in the level of empowerment of Flemish hospitalised patients. Next to the measurement of patient-centred care (Chapter 3) and patient empowerment (Chapter 4) in Flemish hospitals, this dissertation focused on evaluating the process and effectiveness of the implementation of the Tell-us card in Flemish hospital wards; a communication tool that helps to promote and facilitate a patient-centred approach in hospital care (Chapter 6). Prior to the implementation of the tool, barriers and enablers were investigated (Chapter 5), because this is essential to enhance the possibility of a successful implementation process (Wensing & Grol, 2017). As indicated in the introduction section of this dissertation, the Tell-us card tool was also introduced in Dutch hospital wards.

Results from the second study on measurement of perceptions regarding patient-centred care (chapter 3) revealed that the score of Dutch-speaking patients regarding support (mean 3.91) and provision (mean 3.66) of patient-centred care was moderate. High quality of patient-centred care requires a mean score > 4.5 (Berg, Idvall, Katajisto, & Suhonen, 2012). The most remarkable finding was the incongruence between the perceptions of patients and nurses regarding the delivered care, and this across all the participating hospital wards (surgical wards, internal wards, maternity wards, and rehabilitation wards). Nurses perceived that they supported and provided patient-centred care more compared to patients. Another important finding from chapter 3 was that there were high differences between patients' and nurses' views of how decisional control over care was supported through nursing activities. Nurses had higher perceptions regarding their support of patients' decisional control over care compared to patients.

Findings from our qualitative study (Chapter 5) on the barriers and enablers for the implementation of the Tell-us card showed that the need to maintain control over care appeared to be a major barrier for the implementation next to reluctance to engage in in-depth conversations with patients (preferring a more checklist-like manner of communication), fear of being seen as unprofessional by patients, fear of repercussions from physicians, the lack of insight in the meaning of patient participation, and the lack of appreciation of the importance of patient participation. The identified barriers uncovered a rather reluctant attitude towards actively facilitating a patient-centred approach by using the Tell-us card communication tool, and made clear that a number of barriers needed to be factored in the implementation plan of the Tell-us card in order to guarantee its success.

In chapter 3, the ICS was also used to explore socio-demographic (from patients and nurses) and context-related variables associated with perceptions of patient-centred care. For patients, it was found that lower health literacy was significantly associated with lower perceptions of patient-centred care. In chapter 4, which focused on the empowerment of Flemish hospitalised patients, lower health literacy was also significantly associated with lower empowerment scores. Overall, the empowerment scores of Flemish hospitalised patients indicated that more than half of the patients (55%) did take charge of their own health. However, 45% percent of the patients indicated to be overwhelmed and unprepared to play an active role in their health care or were still struggling to manage own health.

Findings from the last study in chapter 6, showed that the Tell-us card had no significant impact on improving a patient-centred approach in hospital care, and the process evaluation revealed that nurses/midwives (as the tool was also implemented on maternity wards) were reluctant towards using the tool and did not always follow the structured intervention protocol. The qualitative study on the barriers and enablers (Chapter 5) already revealed a reluctant attitude. Specific implementation strategies that matched theory-based behavioural determinants associated with the identified barriers were developed. However, the reluctant attitude towards actively facilitating a patient-centred approach by using the Tell-us card communication tool remained. Further, the process evaluation showed that patients did not always use the tool and sometimes used it as an assessment to make judgements on the provision of care. On maternity wards, the tool was mainly used by primipara. Examination of the experiences of patients also revealed that they did not always find the card useful and that patients who had previously been admitted to the hospital had no need to use the tool.

In what follows, two areas of particular interest will be discussed. First, nurses' patient-centred care support and provision and their attitude towards it will be discussed. Second, we will address the implementation of the Tell-us card communication tool as a method to improve a patient-centred approach in Flemish hospital wards. This chapter ends with methodological considerations, recommendations, and a general conclusion.

2. REFLECTIONS ON NURSES’ PATIENT-CENTRED SUPPORT AND PROVISION AND THEIR ATTITUDE TOWARDS IT

Do nurses overestimate their patient-centred care support and provision?

Results from comparing patients’ and nurses’ perceptions of patient-centred care in chapter 3, showed that there was a gap in their perceptions of both the support and the provision of patient-centred care. Other studies investigating the perceived support and provision of patient-centred care by means of the ICS support this finding and show that nurses have more positive perceptions, as compared to patients’ perceptions (Berg et al., 2012; Suhonen et al., 2012). This remarkable finding requires some consideration. As the study in Chapter 3 relied on self-reported data, nurses’ judgement on how they support patients’ individuality through specific nursing activities (ICSA) and how they maintain individuality in their provided care (ICSB) might be too positive, indicating that the care is less patient-centred than nurses think. Overestimation is known to be an important occurrence in behavioural research, questioning whether the results are a valid representation of nurses’ real patient-centred care behaviour (Althubaiti, 2016). Recently, van Belle and colleagues (2020) conducted a study in which they observed nurses’ patient-centred fundamental care delivery. A remarkable conclusion was that many nurses had a task-focused way of communicating and rarely incorporated patients’ needs and experiences in their care provision (van Belle et al., 2020). Other studies also seem to confirm that nurses overestimate their patient-centred care behaviour. Castro and colleagues (2020) investigated the effect of an intervention on the congruence of nurses' and patients' perceptions of patient-centred care. They found that nurses perceived the individuality of care more positively than patients both before and after the implementation of the intervention. Bolster and Manias (2010) conducted a study in which they combined interviews with naturalistic observation to explore the nature of interactions between nurses and patients during medication activities. They found that nurses’ perceptions of their patient-centred care behaviour during medication activities did not align with their actual behaviour; their interactions with patients were sometimes more centred around routines than attuned to the needs and preferences of the patients they cared for (Bolster & Manias, 2010). Also, a qualitative study within the research field of transgressive behaviour found that nurses struggle to incorporate the patient perspective in their interactions with patients (Vandecasteele et al., 2015). A recent study by Van Humbeeck and colleagues (2020), in which was explored how patients and nurses perceived the importance and enactment of values in their health care, found that nurses reported putting the patient in control, treating the patient as a person, conducting shared decision-making, being non-judgmental, and seeing the patient as a unique individual, more than actually provided by them. Based on the results of this dissertation combined with the findings of the previously cited studies, it is reasonable to believe that nurses indeed overestimate their patient-centred care support and provision. Another important conclusion that can be drawn is that solely relying on self-reporting measures may lead to biased results (Althubaiti, 2016).

Are differences between nurses' and patients' perceptions of patient-centred care in itself a problem?

One could argue that the differences found between nurses' and patients' perceptions on the items of the ICS (Chapter 3; Addendum 3) in itself are not a problem if patients do not consider the items as an important aspect of patient-centred care. Yet, in this dissertation nor in other studies with the ICS it was questioned how much importance patients attachted to the different items. This makes it difficult to make firm statements about which aspects of patient-centred care patients value the most. In chapter 3 (Addendum 3), the highest differences between patients and nurses were found on items relating to: (1) support of decisional control over care (e.g. encouraging patients to express their opinions on their care), (2) asking patients about their everyday habits, their experiences of hospitalisation, and the things they do in everyday life, (3) talking about patients' fear, anxieties and meaning of illness, and (4) taking into account fears and anxieties, the meaning of the health condition to the patient, and the feelings patients had about their health condition. The study by Van Humbeeck et al. (2020), found that patients mostly valued aspects of care that enable their opportunity to be truly involved in the decision-making process. Patients also gave high scores to being treated as a unique individual and being seen as a person rather than as a patient with a disease. Linking this dissertation with the study by Van Humbeeck et al. (2020), it is reasonable to conclude that patients find the aspects with the highest differences on the ICS very important. It should be noticed that the importance that patients attach to patient-centred care might vary according to the educational level of patients (Rademakers, Delnoij, Nijman, & De Boer, 2012). However, this was not investigated in the study of Van Humbeeck et al. (2020). Patients with a low education level regard communication, information, and shared decision-making as less important than high-educated patients (Rademakers et al., 2012).

What can we say about nurses' patient-centred care attitude?

Although we did not question the importance nurses' attached to the different aspects of patient-centred care in this dissertation, some reflections can be made about nurses' patient-centred care attitude. Based on the findings in chapter 5, it seems plausible that nurses still consider a rather conservative and reluctant attitude towards patient-centred care. Chapter 5 revealed that nurses showed a lack of appreciation for the importance of patient participation and felt the need to maintain control in their interactions with patients. Tobiano, Marshall, Bucknall, and Chaboyer (2016) also found that nurses have a controlling attitude in their interactions with patients and that such an attitude hinders patients to be involved in their health and health care. Van Humbeeck and colleagues (2020) found that aspects of care with regard to non-judgmental decision-making while putting the patient in control had a lower priority for nurses. Nurses' controlling attitude may suggest that nurses still consider a more task-oriented approach of working (van Belle et al., 2020), inducing a certain degree of paternalistic behaviour (Tang, 2019), and resulting in not understanding the importance of seeing the patients' experiential knowledge as complementary and equal to theirs (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). Equality is a key concept in ethics research within nursing science (Kangasniemi, 2010). It is in fact a basic right that is universal to patients in all settings (Jackson & Irwin, 2011). One could question if equality is achievable in the nurse-patient relationship as professional knowledge, and as a rule power as well, is on the side of the nurse (Brown, 2016; Uhrenfeldt, Sørensen, Bahnsen, & Pedersen, 2018). Power comprises knowledge, skills, and authority that create difference between the nurse and the patient (Kangasniemi, 2010). This unequal distribution of power is to some extent an unavoidable aspect of the nurse-patient relationship (Brown, 2016; Delmar, 2012). What matters is that nurses are aware of the power issues inherent to the relationship and that they question what they can do to expand patient's room for action and control over their health and health care (Delmar, 2012). This requires however a positive and progressive attitude towards the importance of patient participation.

In chapter 5, it was also found that nurses had a reluctant attitude towards engaging in in-depth conversations with patients; they preferred a more checklist-like manner of communication. According to Feo and Kitson (2016) nurses appear to give fundamental care, including psychosocial and relational needs of patients, relatively little priority and value in comparison to other care tasks. In the study of van Belle et al. (2020), it was also found that nurses seem to address more time to physical care than addressing patients' psychosocial and relational needs. A systematic review on nursing-care tasks that are left undone conduted in 488 hospitals across 12 European countries (including Belgium), indicated that comforting/talking with patients is the most frequent nursing care activity left undone (Ausserhofer et al., 2014). This is also confirmed by another review on unfinished nursing care, which indicates that care activities most frequently undone address the emotional and psychological needs of patients rather than the physiological needs (Jones, Hamilton, & Murry, 2015).

What could be the root cause problem of a seemingly reluctant attitude towards patient-centred care and underprovision of it?

In this last point of reflection, propositions that could explain a seemingly reluctant attitude towards patient-centred care and underprovision of it will be discussed.

The quest for greater efficiency in modern health care, including the increased focus on task completion, outcome evaluation, benchmarking, and developing protocols and guidelines to standardise healthcare practices to the best science available, seems to distract the attention from the patient-centred care paradigm and reinforce a task-driven attitude (Feo & Kitson, 2016; Potter, Perry, Stockert, & Hall, 2017). Protocols and guidelines help nurses to make decisions about appropriate care for specific clinical situations (Potter et al., 2017). However, the downside of the standardisation and evidence-based striving demanded by protocols and guidelines may be that the focus of nursing practice shifts towards a more checklist-like manner of care provision, including the risk that completing tasks is given priority over non-physical aspects of care such as basic empathetic communication (Oxelmark, Chaboyer, Bucknall, & Ringdal, 2018). In the book of Bracke (2020), the example of the computer as a barrier for empathetic communication is given. Nowadays, the nurse always brings the computer into the patient room. This helps to systematically check whether no care plan reported in the electronic patient record is left undone. However, the danger exists that a meaningful dialogue with the patient becomes subordinate, resulting in standardised communication not adapted to the individual patient.

Healthcare systems seem also to continue to be predicated on the goal of curing (Feo & Kitson, 2016), with caring aspects still undervalued in favour of more task-oriented and technical aspects of care (Dierckx de Casterlé, 2015; Wiechula et al., 2016). Healthcare systems pay special attention to and show high appreciation for specialised and high-technological medical care (Johnson, 2015; Waidley, 2019). This is of course very important. However, the consequence may be that fundamentals of care and caring behaviours are devaluated by healthcare professionals and are seen as a non-complex activity of care that requires little skill, not worthy of taking up the nurses' time (Feo & Kitson, 2016; Zwakhalen et al., 2018). Against the backdrop of the recent/ongoing coronavirus (Covid-19) pandemic, it became also clear that curing the patient may still prevail over comforting and caring for the patient as policies that embed the principle of patient involvement in healthcare decision making were swept away in the rush to respond to the crisis (Coulter & Richards, 2020; Dichter, Sander, Seismann-Petersen, & Köpke, 2020; Gopichandran, 2020; Richards & Scowcroft, 2020). The protection of the public health became priority, which often resulted in neglecting individual patient preferences, needs, and values (Gopichandran, 2020). Essential elements in the provision of patient-centred care such as communication and shared decision-making faded into the background (Abrams et al., 2020; Gopichandran, 2020; Maaskant et al., 2020; Simpson, Milnes, & Steinfort, 2020). Patients were also frequently denied clinical care for non-emergency conditions without consulting them and without considering how this would affect them (Gopichandran, 2020; Richards & Scowcroft, 2020).

One could also argue that underprovision of patient-centred care results from broader system issues such as (1) decreased financial resources due to societal evolutions such as a shift from acute illnesses towards chronic illnesses and more complex health needs of an ageing population (Hower et al., 2020) and (2) an increasing workload due to staff shortages, resulting in insufficient time to provide patient-centred care (Chan, Jones, & Wong, 2013; Marć, Bartosiewicz, Burzyńska, Chmiel, & Januszewicz, 2019). In chapter 5, Flemish nurses described their current practice as overburdened, making it difficult to allocate time for answering questions of patients. A recent report of the Belgian Health care Knowledge Centre indicated that the average nurse/patient ratio in Belgium is 9.4, which is far above international standards (Van den Heede, 2019). The impact of the increasing workload in Flemish hospitals on the ability to provide patient-centred care should therefore not be underestimated (Van den Heede, 2019). Increasing workload can reinforce the need to feel in control over the provision of care and sustain to a fixed planning of care (Vandecasteele et al., 2015).

A last reflection should be made about the influence of payment models on the provision of patient-centred care. The fee-for-service payment model is still common in a lot of countries (Feldhaus & Mathauer, 2018). In Belgium the fee-for-service payment model still predominates (Gerkens & Merkur, 2020). Literature shows that a fee-for-service payment comes with several disadvantages including overuse, abuse and misuse of care that is not central to patients’ needs (Van de Voorde et al., 2014). The model seems incompatible with patient-centred care (DeVoe, 2020). More and more healthcare systems shift towards value-based payment models, which amongst others includes pay for performance (Nuño-Solinís, 2019). Pay for performance ties reimbursement to metric-driven outcomes, best practices, and patient satisfaction (NEJM Catalyst, 2018). Yet, evidence on the positive effect of pay for performance on health outcomes and its ability to reduce healthcare costs is mixed (Martin, Jones, Miller, & Johnson-Koenke, 2020). Further the qualitative meta-synthesis of Martin and colleagues (2020) describes that pay for performance disrupts patient-centered care, contributes to a loss of holism and patient autonomy, and disrupts the doctor-patient relationship. Patients concerns or preferences are often marginalised (Martin et al., 2020).

3. REFLECTIONS ON THE IMPLEMENTATION OF THE TELL-US CARD

An important part of this dissertation was the implementation of the Tell-us card in Flemish hospital wards. As described in the introduction (Chapter 1) this method seemed promising for enhancing a patient-centred approach in hospital wards based on the study of Jangland, Carlsson, Lundgren, and Gunningberg (2012). Both the implementation process and the effectiveness of the Tell-us card were evaluated.

The process evaluation showed that nurses/midwives remained reluctant towards the Tell-us card (Chapter 6). A reluctant attitude was previously found as a barrier for the implementation of the tool (Chapter 5). The origins of this reluctance were included in themes like control, lack of appreciation of the importance of patient participation, and reluctance to engage in in-depth conversations with patients. The reluctant attitude towards the tool may be a reflection of what was discussed in the previous section; time pressure, undervalueing aspects of care that relate to caring for the patient (communication, addressing patients' psychosocial needs). The reluctant attitude may also be explained by (1) nurses/midwives believing that the Tell-us card is of no added value next to already existing tools on the ward and (2) nurses/midwives believing that the card itself could be a barrier for in-depth interaction between the patient and the nurse/midwife because of the difficulty for patients to write down their emotional needs on it. Further, the process evaluation showed that patients did not always use the tool. Individual patients participating in the Tell-us card project were not asked whether they felt the need to be more involved in their care, thus it could be that some patients had no need to be more involved when they agreed to participate. The tool was also mainly used by primipara (on maternity wards) and patients admitted for the first time (on nursing wards). It should be questioned whether the tool will be more relevant when it is implemented within specific patient populations or situations rather than be used standardly.

Effectiveness is the extent to which an intervention, when used appropriately, achieves the intended effect (Pearson, Wiechula, Court, & Lockwood, 2005). Considering the quantitative effects (Chapter 6), the conclusion is that no overall or generic effects could be found for both patients and nurses/midwives concerning patient-centred care and the other proposed outcomes. Four important reflections should be made about the effectiveness of the Tell-us card for the Flemish hospital context. First, there might be a danger that the Tell-us card limits patient-centred care to task-oriented care and communication because much more steps and elements seem necessary to come to patient-centred care according to the definition of Castro et al. (2016) and the review of reviews by Håkansson et al. (2019). The Tell-us card does not seem to cover all the aspects that are important for providing patient-centred care. Perhaps the Tell-us card has reinforced nurses to work in a task-oriented way. As previously discussed, some societal evolutions such as the quest for greater efficiency in modern health care seems to increase the task-driven attitude of healthcare professionals (Feo & Kitson, 2016; Potter, Perry, Stockert, & Hall, 2017). Further, not all nurses/midwives were intrinsically motivated to use the Tell-us card to improve patient-centred care and mainly saw the tool as a manner to reduce the number of patients' calls. This negative attitude may also have contributed to using the tool in a task-oriented way. It should also be questioned whether the Tell-us card itself is a barrier for in-depth interaction between that patient and the healthcare professional and restricts patients to talk about their emotional needs. Second, the Tell-us card intervention was, as previously indicated, part of a larger multi-annual programme (2013 - 2017) to improve a patient-centred approach in quality of care and patient safety in Belgian hospitals (Federal Public Service Health, Food Chain Safety and Environment, 2013). The general themes of the programme were embedded within accreditation requirements for Belgian hospitals. In Belgium, accreditation is not obligatory. However, most hospitals in Flanders opted for an accreditation process with the Joint Commission International (JCI) or Qualicor Europe (Omzendbrief accreditatie Vlaams minister van welzijn, 2016). An important remark to be made is that the effects on service quality are currently debated (Bogh et al., 2018). A recent systematic review on the impact of hospital accreditation on healthcare quality dimensions presented overall positive results, but indicated that due to the methodological shortcomings the positive impact of accreditation on healthcare dimensions should be interpreted with caution (Araujo, Siqueira, & Malik, 2020). Regarding the impact of accreditation on patient-centred care, the results were mixed (Araujo et al., 2020). Of the seven articles analysing the impact of accreditation on patient-centredness, four articles reported a null effect (Araujo et al., 2020). The system of accreditation is rather bureaucratic (Alkhenizan & Shaw, 2012), characterised by standardisation of processes, and thus possibly distracting from a focus on the patient (Ellis et al., 2020). Further, one could question if hospital accreditation as an incentive undermines intrinsic motivation of hospital management towards patient-centred care and is considered mainly as a means for receiving public recognition of their status (Ellis et al., 2020; Grepperud, 2015; Luxford, Safran, & Delbanco, 2011; Wynia, 2009). This can be supported by the results of this dissertation as four wards dropped out from the improvement project on the Tell-us card after the survey for hospital accreditation. It should be debated whether the current mainstream methods of accreditation should be retained. Some argue that it is a matter of changing the current approaches towards hospital accreditation; more focussing on processes and structural factors that have been shown to be associated with good outcomes (Jha, 2018). However, this does not detract from the question if the hospital motivation for seeking accreditation is the 'right' one and the fact that accreditation is bureaucratic (Alkhenizan & Shaw, 2012), comes with standardisation of processes, and a high workload (Ellis et al., 2020; Jha, 2018).

Third, the study in chapter 6 mainly focused on factors related to the intervention itself, as well as factors related to the individual patient, the individual nurse/midwife, and some factors related to the ward (work processes) that could influence the effectiveness of the intervention. It would have been beneficial if factors related to context of implementation where more closely investigated before the implementation of the Tell-us card (Damschroder et al., 2009; Flottorp et al., 2013; Harvey & Kitson, 2015; Pfadenhauer et al., 2017). Different implementation frameworks such as the Context and Implementation of Complex Interventions framework, the Consolidated Framework for Implementation Research, and The Promoting Action on Research Implementation in Health Services framework stress the importance of investigating factors influencing the effectiveness of the intervention related to the context where the intervention is implemented (Damschroder et al., 2009; Harvey & Kitson, 2015; Pfadenhauer et al., 2017). A distinction can be made between the inner and outer context, which also interact with each other. The inner context includes the local setting (ward, unit, department) and the hospital setting. The outer context includes the wider health system and the geographical, epidemiological, socio-cultural, socio-economic, ethical, legal, and political context (Damschroder et al., 2009; Harvey & Kitson, 2015; Pfadenhauer et al., 2017). For example, commitment by the management of the hospitals where the Tell-us card was implemented towards patient-centredness could have been further explored. As indicated in the introduction part of this dissertation (Chapter 1), the patient participation culture was measured on Flemish hospital wards (Malfait, Eeckloo, Van Daele, & Van Hecke, 2016). However, the survey did not include hospital managers' vision towards patient-centred care. Evidence suggests that hospital management advocating the need for patient-centred care and participation are necessary to really make a change towards a more patient-centred care environment (Luxford et al., 2011; Morgan & Yoder, 2012). Such an environment has a positive influence on healthcare professionals' attitudes, skills, and knowledge (Luxford et al., 2011; Morgan & Yoder, 2012). It should be noticed that the hospital managements' vision towards patient-centred care might be influenced by what is valued within healthcare systems (outer context). As discussed in the first part of this dissertation, it seems plausible that caring aspects are still undervalued in favour of more task-oriented and high-technological aspects of care. This became particularly clear during the Covid-19 pandemic. Further, exploring the nurse/patient ratio (a factor related to the outer context) could also been have important. As previously discussed, increasing workload can reinforce nurses need to feel in control over the provision of care and sustain to their fixed planning of care (Vandecasteele et al., 2015).

Fourth, the multi-annual programme of the Federal Government consisted also of an improvement project on bedside shift reporting next to the improvement project on the Tell-us card. Bedside shift reporting is shift-to-shift report at the bedside of the patient and aims to improve active involvement of patients in their care (Anderson & Mangino, 2006; Ferguson & Howell, 2015). Both projects were simultaneously implemented, sometimes in the same hospitals. At the time, bedside shift reporting was a ‘hot’ topic as it gained increasing international attention because of its beneficial effects, including the improvement of patient safety (Ferguson & Howell, 2015). Consequently, the Tell-us card project received less attention from hospital managers, which may have influenced the motivation of wards to work with the Tell-us card.

4. METHODOLOGICAL CONSIDERATIONS

This dissertation has several strengths and limitations that need to be considered. Two important strengths of this dissertation should be endorsed. First, in chapter 3 and chapter 6 multilevel analysis were used to overcome difficulties with multilevel data clustering (Heck et al., 2014). Traditional multivariable regression techniques treat the units of analysis as independent observations and fail to recognise hierarchial structures, which may lead to an overstatement of statistical significance (Heck et al., 2014). Inferences from multilevel analysis are therefore more reasonable (Heck et al., 2014). Second, this dissertation contributes to the limited knowledge of empowerment and patient-centred care in Flemish regional and university hospitals. The studies were conducted on a large scale and conducted in multiple hospitals, contributing to the generalisability of the findings.

Despite the strengths of this research, there are some limitations that require consideration. In the chapters of this dissertation, many specific limitations were already discussed. In what follows, additional limitations, which are applicable for the entire study, will be discussed.

First, a co-design trajectory based on the principles of Experience Based Co-Design (EBCD) was set up to tailor the Tell-us card to the specifc needs of patients and nurses/midwives of the different wards (Castro, Malfait, Regenmortel, Van Hecke, Sermeus, & Vanhaecht, 2018a). EBCD is a participatory approach, which allows patients and healthcare professionals to work as active partners in intervention development (Castro et al., 2018a). We believed that the participatory approach could help nurses/midwives to change their rather conservative perspective on patient-centred care and would stimulate them towards a more empowered way of thinking (Castro et al., 2018a). However, in this dissertation a ‘light’ version of EBCD (over a period of approximately three months) was implemented, containing three steps: (1) individual interviews with patients to assess the Tell-us card-intervention, (2) separate focus groups for patients and nurses/midwives to stimulate debate on the intervention, and (3) one joint group meeting with nurses/midwives and patients together to redesign and refine the intervention. Normally, a ‘full’ version of EBCD contains eight steps (Castro et al., 2018a). Steps such as gathering patient and nurses/midwives experiences with care through clinical observations, filming interviews with patients, editing the interviews in a trigger film, a staff feedback event to review themes from staff interviews, a patient feedback event to view the edited film and to identify priorities for improving care, and forming co-design working groups to implement the intervention were not followed in the light version of EBCD in this dissertation (Castro et al., 2018a). It could be questioned if following all the steps of EBCD, especially the step in which co-design working groups are formed, would have had a more beneficial effect on motivation towards working with the Tell-us card to improve a patient-centred approach.

Second, although in this dissertation psychometric sound questionnaires were used to measure patient-centred care and patient empowerment, the studies in chapter 3 and chapter 4 relied on self-reported data and thereby represent nurses' and patients' perceptions of patient-centred care and patient empowerment. It is important to be aware of the disadvantages of self-reporting. As previously discussed, nurses' judgement on their own behaviour might be too positive (Althubaiti, 2016). An important consideration for future research is whether existing self-reporting quantitative tools are sufficient to measure these concepts. Research activity should also focus on improving the evidence base of existing measures and synthesising and assessing the quality of existing tools (de Silva, 2014; Feo, Conroy, Wiechula, Rasmussen, & Kitson, 2020).

Third, eight wards started with the Tell-us card intervention (Chapter 6). However, only four intervention wards completed the study until the end. These drop-out rates limited the generalisability of the study results and affected the adequate numbers for maintaining the power of the study (Polit & Beck, 2017).

Fourth, aspects relating to feasibility, meaningfullness, and appropriateness of the Tell-us card were perhaps underinvestigated in this dissertation (Pearson et al., 2005). Qualitative in-depth interviews with patients and nurses/midwives after the implementation of the card could have provided more profound knowledge on bottlenecks/advantages/disadvantages while using the Tell-us card, reasons why patients did or did not use the card, positive and negative experiences of nurses/midwives and patients with the intervention, and the extent to which nurses/midwives and patients appreciated the use of the Tell-us card and found it helpful in improving a patient-centred approach. Fifth, looking at the concepts of patient-centred care and patient empowerment, some aspects/factors that belong to the concept of patient-centred according to the review of reviews Håkansson et al. (2019) also seem to belong to the concept of patient empowerment according to the conceptual map of Bravo et al. (2015). In a more recent concept analysis on patient empowerment of Halvorsen et al. (2020), some findings are also consistent with aspects/factors of patient-centred care. To avoid mixing of concepts and to guide further research, a review of reviews on the antecedents and attributes of both concepts could be of great value.

Sixth, although the ICS is a measure for the broad holistic concept of patient-centred care (Castro et al., 2016; Suhonen, Stolt, & Papastavrou, 2019), soms aspects of the concept such as integration and coordination of care seem not to be incorporated in the measurement instrument. Further critical reflection on the appropriateness of using the ICS for measuring all the aspects of the patient-centred care concept is necessary. Also, there is conflicting information in literature about the appropriations of the PAM for measuring patient empowerment. Although recent literature (Pekonen et al., 2020) indicates that the PAM can be used for measuring the concept of patient empowerment, other literature (Castro et al., 2016) indicates that the PAM is related to behaviour theories and therefore more related to paternalistic models of care. Further research that critically reflects on the appropriateness of using the PAM for measuring the concept of patient empowerment in necessary.

Last, some important aspects such as the reason why nurses/midwives were afraid to engage in in-depth conversations were not further discussed during the interviews of the qualitative study in chapter 5. A consequence might be that the proposed implementation strategies were not tailored to more deep-routed fears, contributing to the failure of the Tell-us card intervention (chapter 6).

5. RECOMMENDATIONS

This dissertation leads to three recommendations for nursing practice and education: the need for more reflective practitioners in nursing, the need to prepare nursing students to be empathetic caregivers, and the relevance of involvement of peer workers to support nurses in providing patient-centred care. The recommendations for nursing management and nursing policy relate to actions, which are needed to realise a culture shift towards transforming hospitals to focus more on patient-centred care.

5.1 Recommendations for nursing practice and nursing education

A need for more reflective practitioners

Previously it was discussed that nurses seem to overestimate their patient-centred care practice and prefer a checklist-like manner of communicating with patients. The latter might be an indication of the increased focus on standardisation of healthcare practices to the best science available, including aspects of communication (Feo & Kitson, 2016; Oxelmark et al., 2018; Potter et al., 2017). While standardisation of healthcare practices is without a doubt needed to ensure that patients receive high-quality care (Potter et al., 2017), it is important not to overstandardise care to prevent nurses from only focussing on what should be done (Bulman & Schutz, 2013). To obtain a balance between standardisation and patient-centred care provision, a striving for more reflective practice in nursing is an essential point for consideration (Bulman & Schutz, 2013; Rasheed, Younas, & Sundus, 2019; Smith, 2016). Reflective practice is an ongoing process of learning and development through examining one's own practice, including personal values, assumptions, experiences, thoughts, feelings, actions, and knowledge (Bulman & Schutz, 2013; Phelvin, 2013; Rasheed et al., 2019). Reflective practice has many benefits such as developing critical thinking about one's practice and thoughtful clinical judgement, enhancing emotional intelligence (how own actions affect others) and empathy (the ability to comprehend what another person is feeling, sympathising with those feelings, and the motivation to respond to those feelings), and improving relationship skills and the ability to consider the perspective of others (Bulman & Schutz, 2013; Goulet, Larue, & Alderson, 2015; Haley et al., 2017; Levett-Jones, Cant, & Lapkin, 2019; Rasheed et al., 2019). To engage in reflective practice, building skills of self-awareness are very important (Bulman & Schutz, 2013), in particular for improving empathy and perspective taking (Gerace, Day, Casey, & Mohr, 2017; Haley et al., 2017; Han & Kim, 2016; Rasheed et al., 2019). Reflective practice can contribute to the professional growth of nurses and aid them in becoming more understanding towards patients, establishing a sustainable nurse-patient relationship, and taking a more critical stance towards the care provided (Bulman & Schutz, 2013; Han & Kim, 2016; Rasheed et al., 2019).

The question is now how we can improve reflective practice in nursing. Belgian nursing curricula should prepare their students for becoming reflective practitioners. Over the last years, reflection in health care has gained increasing importance, resulting in a considerable body of related published literature and the inclusion of reflection in nursing curricula. Nursing curricula have especially been focused on teaching clinical reasoning based on nursing diagnosis (Herdman & Kamitsuru, 2017). Clinical reasoning contains expert knowledge and expert thinking and focusses on problem-solving (Aukes, Cohen-Schotanus, Zwierstra, & Slaets, 2009). According to the float model of Aukes and colleagues (2009), in which the interaction between reflective practice and behaviours is visualised using a metaphor of a float in fishing, clinical reasoning lies just underneath the surface (the part above the surface in the healthcare professionals' behaviour). The deeper layers include scientific thinking and personal reflection. In today's Belgian nursing curricula, it remains unclear how much attention is addressed to the deepest layer of reflective practice (i.e. personal reflection). In 2017, Australian researchers developed a holistic reflective model to assist midwifery students to progressively build reflective practice (Bass, Fenwick, & Sidebotham, 2017). This model for introducing reflective practice in midwifery curricula could provide valuable guidance on how to implement more reflective practice in Belgian nursing curricula.

For nursing practice, the implementation of reflective practice groups on nursing wards could be a means of improving reflective practice (Kurtz, 2019; Lees & Cooper, 2019; Thomas & Isobel, 2019). This could stimulate nurses to engage in reflective practice during their work and gain insight and awareness from their work, challenging them to understand their patients' perspectives and experiences. The use of reflective practice groups is now mainly done within the field of social work and mental health nursing (Lees & Cooper, 2019; Thomas & Isobel, 2019). Reflective practice groups are different from other clinical group supervisions as they particularly focus on relational aspects of clinical practice (Thomas & Isobel, 2019). Recently, a book was published by a clinical psychologist (Kurtz, 2019) to support the modern healthcare context in reflective practice and running reflective practice groups. The book could be a valuable guide in setting up research on the implementation of reflective practice groups on nursing wards.

Preparing nursing students to be empathetic caregivers

The results in chapter 3 (Addendum 3), showed that the highest differences between patients and nurses on the ICS were found on items relating to support of decisional control over care but also on items relating to being treated as a unique individual and being seen as a person rather than as a patient with a disease. Perhaps the latter is an indication that there is a need for more basic empathy in nursing. This can be supported by the experiences of (former) patients whom talk about what excellent care means to them and their experiences with hospital care in Flanders. Their stories revealed that patients felt that nurses or nursing students showed a lack of empathy and were not able to understand experiences through their eyes (Bracke, 2020). Empathy is an essential characteristic of patient-centred care and needed in order to treat patients as unique individuals (Castro et al., 2016).

Nursing education should prepare students to become empathetic caregivers. However, a Dutch study indicated that in today's nursing education bachelor students learn the least about aspects of communication relating to building a trustful relationship, respecting patients' opinion and ideas, and promoting patient participation (Huisman-de Waal, Feo, Vermeulen, & Heinen, 2018). Therefore, we recommend further research investigating national and international curricula to explore if they incorporate sufficient teaching-learning strategies that target skills in the affective domain and to depicture what is already present regarding patient-centred care in their curriculum (as empathy is but one aspect of patient centred care). To date, research on the latter is limited and, to our knowledge, there is only one study from the United Kingdom (Moore et al., 2021) that conducts profound research into the inclusion of patient-centred care in nursing and medical curricula. Curriculum scanning is needed if one wants to critically discuss the time and attention spent on patient-centred care in the education and training of nurses. The study of Moore and colleagues (2021) led to some important conclusions and recommendations such as the need for the development of a competence framework that defines what patient-centred care skills are expected from healthcare professionals and to what level they should be competent in patient-centred care practices at the point of professional qualification.

Involvement of peer workers in order to support nurses in providing patient-centred care

The results in chapter 3 and chapter 4 showed that patients with lower health literacy had significantly lower perceptions of patient-centred care and patient empowerment. These results stress the importance of being sensitive to patient characteristics that could interfere with establishing a sustainable nurse-patient care relationship.

To provide patient-centred care, especially to the most vulnerable patient groups, we propose that nurses should be supported by peer workers. Peer workers are patients with lived experience of health problems who can use their specific experience to benefit and support healthcare professionals (Castro, 2018b; Vandewalle et al., 2018). To date, peer workers are mostly involved in mental healthcare settings and the social domain (social exclusion and poverty) (Castro, 2018b). However, recent research has shown that peer workers can support healthcare professionals working on hospitals wards to deliver care that takes into account the perspective of the patient (Castro et al., 2020).

5.2 Recommendations for nursing management and nursing policy

Rethinking the system of hospital accreditation

As previously discussed, the system of hospital accreditation might undermine intrinsic motivation of hospital management towards patient-centred care (Grepperud, 2015; Luxford et al., 2011; Wynia, 2009). Therefore, hospital management should critically reflect on their motivation for choosing the system of hospital accreditation and if solely relying on the system of accreditation is beneficial for improving patient-centredness in their hospital. Recently, some hospitals in Belgium have decided to partially abandon the system of accreditation. Instead, the hospitals want to focus more on an internal quality policy that is in line with own predefined priorities and needs. Internationally, the system of hospital accreditation is also questioned. For example, in Denmark the government has decided to abolish the system of hospital accreditation (Ehlers, Jensen, Simonsen, Rasmussen, & Braithwaite, 2017). Local politicians and managers had taken the system of accreditation too far; they especially focused on standardisation and management by monitoring compliance, leading to a control and checklist culture (Ehlers et al., 2017).

A plea for strong leadership and a bottom-up approach towards initiatives to improve patient-centredness in hospitals

In chapter 6, it was described that four wards dropped out from the improvement project on the Tell-us card. In order to successfully strive towards more patient-centredness in their hospital, hospital management should invest in strong leaders as this is very important for fostering a change towards more patient-centred care in hospitals and engaging healthcare staff (Bokhour et al., 2018). Advanced practice nurses may be ideally positioned for this. Literature shows that direct clinical practice is the central competency of an advanced practice nurse on which the other six core competencies depend:

guidance and coaching, consultation, evidence-based practice, leadership, collaboration, and ethical decision-making skills (Tracy & O'Grady, 2019). Advanced practice nurses can use their specialised clinical expertise in combination with their clinical leadership skills to manage patient-centred care within the hospital (Lamb, Martin-Misener, Bryant-Lukosius, & Latimer, 2018; Tracy & O'Grady, 2019). They can coach nurses and other colleagues to work towards patient-centred care goals and foster capacity building within healthcare professionals to meet the unique needs of the patients they care for (Lamb et al., 2018). The Tell-us card project was a patient-centred care initiative that was implemented 'top-down'. However, to sustainably embed such initiatives, hospital management needs to develop an approach to change that moves away from imposing it 'top-down' to adopting a 'bottom-up' approach; recognising that frontline healthcare professionals are often best placed to identify needs and priorities (Gabutti, Mascia, & Cicchetti, 2017). Again, the clinical leadership qualities of the advanced practice nurse may be very important to coach and motivate healthcare professionals to identify needs and priorities and come up with approaches to improve patient-centred care (Tracy & O'Grady, 2019).

Developing patient-centred quality indicators to measure progress in establishing patient-centred hospital care

In the first part of the discussion section, propositions that could explain a seemingly reluctant attitude towards patient-centred care were discussed: the high workload for nurses in Belgium which could reinforce them to remain control over care (Vandecasteele et al., 2015), the increased focus on standardisation of processes, and the healthcare system which still seems predicated on the goal of curing (Feo & Kitson, 2016).

To evolve towards a healthcare system were patient-centred care and the more technical aspects of care are equally valued, policy plays an important role. First, there should be invested in nursing staff in order to create more time for patient-centred care (Van den Heede, 2019). However, it is reasonable to believe that having more nurses on a shift will not automatically result in more patient-centred care when such care is undervalued by nurses and the environment in which they work (Feo & Kitson, 2016). Therefore, policy efforts should further focus on developing patient-centred quality indicators to measure progress in establishing patient-centred hospital care (Santana et al., 2019). Currently, the Flemish Indicator Initiative 'Vip^2' aims to improve the quality of patient care by means of clinical process and outcome indicators. The patient satisfaction questionnaire initiated by the Flemish Patient Platform (Bruyneel et al., 2017) is used as an indicator of patient experiences in the Flemish Indicator Initiative. However, this measure does not seem to capture the breadth of assessing patient-centred care. Further, it remains unclear to which extent the Flemish Indicator Initiative focusses on measuring patient-centred care in healthcare structures and processes.

6. CONCLUSION

In patient-centred care, an individual's specific health needs and desired health outcomes are the driving force behind all healthcare decisions (Castro et al., 2016; Feo et al., 2018). Empowerment of patient refers to patients gaining greater control over decisions and actions affecting their own health (Castro et al., 2016). Both concepts have gained increasing importance in the hospital context due to the shift from the biomedical model to the holistic paradigm over the last century. Consistent with this evolution, the Belgian Federal Government has underlined the importance of empowerment of patients and patient-centred hospital care. Despite the increased attention for both concepts, little was known about perceptions of patients and nurses regarding provision of patient-centred care in Belgian hospital wards (Flemish part) and the empowerment of Flemish hospitalised patients. Results of this dissertation showed that there were disparities on how patients and nurses perceived the support and provision of patient-centred care in hospitals. Nurses had in general more positive perceptions than patients. By comparing the results of this dissertation with the results of other observational and qualitative studies, it seemed reasonable to assume that nurses overestimated their patient-centred care support and provision. There were especially high differences on aspects of patient-centred care regarding the support of decisional control over care and treating the patient as a unique individual. Combining these findings with the finding that nurses attitude towards patient-centred care was rather reluctant, included in themes like control and reluctance to engage in in-depth conversations with patients, two important recommendations can be done. First, there is a need for more reflective practitioners in nursing. The increased focus on standardisation of healthcare practices seems to distract from aspects of patient-centred care such as communication. Reflective practitioners might be able obtain a balance between standardisation and patient-centred care support and provision. Second, nursing education should prepare nursing students to be empathetic caregivers that are able to recognise the importance of treating the patient as a unique individual. Further, peer workers should be involved to support nurses to provide patient-centred care and to support patient empowerment, especially in more vulnerable patient groups. The implementation project on the tell-us card seemed to underline the difficulty and complexity of enhancing a patient-centred approach in daily hospital practice. It was remarkable that four wards dropped out from the project after the survey for hospital accreditation. Therefore, hospital management willing to realise a hospital culture in which patient-centred care is valued, should rethink the system of accreditation as it might undermine intrinsic motivation towards patient-centred care. Further, investing in strong leaders such as advanced practice nurses, adopting a bottom-up approach to change, and focussing on the development of patient-centred care quality indicators will be beneficial in realising a culture shift in hospitals towards more patient-centred care.

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SUMMARY

In the face of improving quality of care, patient-centred care has internationally become an important paradigm in health care. The concept has gained increased attention in a variety of patient groups and healthcare settings, including hospital care. Patient-centred care premises patient preferences, needs, and values and is characterised by a positive and trusting healthcare professional – patient relationship. Such a relationship focusses on patients' essential needs to ensure their physical and psychosocial wellbeing. Nurses play a pivotal role in the provision of patient-centred care, as nurses' behaviours are fundamental for delivering care that meets patients' unique health needs. The pursuit of patient-centredness in contemporary health care has also led to an increased focus on patient empowerment. Patient empowerment refers to a process that enables patients to take control over decisions and actions affecting their health.

Consistent with international evolutions, the Belgian Federal Government has underlined the importance of empowerment of patients and patient-centred hospital care. Despite the increased attention for both patient-centred care and patient empowerment, little was known about perceptions of patients and nurses regarding the support and provision of patient-centred care in Belgian hospital wards (Flemish part) and the empowerment of Flemish hospitalised patients. In order to measure perceptions of nurses and patients on the support and provision of patient-centred care in Flemish hospitals, the Finnish Individualised Care scale (ICS) was translated and psychometrically validated **(Chapter 2).** The measurement tool showed adequate psychometric performance, internal consistency reliability was good, and the model fit was acceptable, suggesting that there was sufficient evidence to use the ICS for measuring patient-centred care in the Flemish hospital context. For measuring patient empowerment, there was already a reliable and valid tool available, namely the Short form of the Patient Activation Measure (PAM-13). The results from a cross-sectional study with the Dutch version of the ICS **(Chapter 3)** showed that that there were disparities on how patients and nurses perceived the support and provision of patient-centred care, and this across all the participating hospital wards (surgical wards, internal wards, maternity wards, and rehabilitation wards). Nurses had in general more positive perceptions than patients. The results of measuring patient empowerment in Flemish hospitals **(Chapter 4)** showed that more than half of the patients (55%) did take charge of their own health. However, 45% percent of the patients indicated to be overwhelmed and unprepared to play an active role in their health care or were still struggling to manage own health. Results from the studies in chapter 3 en chapter 4 also revealed that lower health literacy was significantly associated with lower perceptions of patient-centred care and patient empowerment.

Next to measuring patient-centred care and patient empowerment, this dissertation focused on the implementation of a promising nurse-led communication tool 'Tell-us card' to enhance a patient-centred approach in Flemish hospitals **(chapter 6).** Prior to the implementation of the communication tool in Flemish hospital wards, barriers and enablers were investigated, as this is essential to enhance the possibility of a successful implementation **(Chapter 5).** Through qualitative in-depth interviews, it was revealed that nurses and midwives had a rather reluctant attitude towards actively facilitating a patient-centred approach by using the Tell-us card communication tool. Reluctance was included in themes like control, lack of appreciation of the importance of patient participation, and reluctance to engage in in-depth conversations with patients (preferring a more checklist-like manner of communication). Identified barriers were factored in the implementation plan of the Tell-us card in order to guarantee a successful implementation. The Tell-us card was implemented in eight Flemish hospitals wards (surgical wards, internal wards, rehabilitation wards, and maternity wards). Overall, the Tell-us card had no significant impact on improving a patient-centred approach in hospital care. The process evaluation revealed that nurses/midwives did not always follow the structured intervention protocol, and that patients did not always use the card or sometimes used it as an assessment to make judgements on the provision of care. On maternity wards, the tool was mainly used by primipara. Examination of the experiences of patients also showed that they did not always find the card useful and that patients who had previously been admitted to the hospital had no need to use the card. After comparing the results of this dissertation with the results of other observational and qualitative studies, it seemed reasonable to assume that nurses overestimated their patient-centred care support and provision. There were especially high differences on aspects of patient-centred care regarding support of decisional control over care and treating the patient as a unique individual **(Addendum 3).** Combining the latter findings with the finding that nurses had a rather reluctant attitude towards actively facilitating patient-centred care by using the Tell-us card, included in themes like maintaining control over care and preferring a more checklist-like manner of communication, two important recommendations can be done. First, there is a need for more reflective practitioners in nursing. The increased focus on standardisation of healthcare practices seems to distract from aspects of patient-centred care such as communication. Reflective practitioners dare to question themselves and the care they provide and might therefore be able to obtain a balance between standardisation and individualisation of care. Second, nursing education should prepare nursing students to be empathetic caregivers that are able to recognise the importance of treating the patient as a unique individual. Further, nurses should be supported by peer workers to provide patient-centred care and to empower patients, especially in more vulnerable patient groups

The implementation project on the Tell-us card communication tool seemed to underline the difficulty and complexity of enhancing a patient-centred approach in daily hospital practice. Reflecting on the Tell-us card, it should be questioned whether the card will be more relevant when it is implemented within specific patient populations or situations rather than be used standardly. Reflecting on the implementation process, three recommendations can be done. First, hospital management should critically reflect on their motivation for choosing the system of hospital accreditation and if the system of accreditation is beneficial for improving patient-centredness in their hospital. During the implementation of the Tell-us card, four wards dropped out from the project after the survey for hospital accreditation. Second, to successfully strive towards more patient-centredness in hospitals, hospital management should create the ability of involvement of strong leaders such as advanced practice nurses in initiatives to improve a patient-centred approach and adopt an approach to change that moves away from imposing it ‘top-down’ to a ‘bottom-up’ approach. Third, policy efforts should further focus on developing patient-centred quality indicators to measure progress in establishing patient-centred care. This will aid to evolve towards a healthcare system were patient-centred care and the more technical aspects of care are equally valued and will be beneficial for developing positive attitudes towards patient-centred care in hospitals.

SAMENVATTING

Patiëntgerichtheid wordt internationaal steeds meer erkend als een belangrijk onderdeel van de kwaliteit van zorg. Het concept 'patiëntgerichte zorg' kwam reeds onder de aandacht in verschillende patiëntengroepen en domeinen binnen de gezondheidszorg, waaronder ook ziekenhuiszorg. Patiëntgerichte zorg houdt in dat de voorkeuren, behoeften en waarden van de patiënt voorop staan en wordt gekenmerkt door een relatie van wederzijds vertrouwen tussen de patiënt en de zorgverlener. De relatie tussen de patiënt en de zorgverlener is gericht op wat voor de patiënt van belang is zodoende het fysiek en psychosociaal welzijn van de patiënt te waarborgen. Verpleegkundigen hebben een belangrijke rol bij het verlenen van patiëntgerichte zorg aangezien verpleegkundige activiteiten een fundamentele bijdrage kunnen leveren aan zorg die voldoet aan wat voor de patiënt voorop staat en van belang is. Erkenning van het belang van patiëntgerichtheid in zorg heeft ook geleid tot een groeiende aandacht voor het concept van patient empowerment dat verwijst naar een proces dat patiënten in staat stelt om controle uit te oefenen over hun gezondheid en gezondheidszorg.

Het belang van patient empowerment en patiëntgerichte zorg wordt ook door de Belgische federale overheid benadrukt. Desondanks was er weinig bekend over de percepties van patiënten en verpleegkundigen met betrekking tot het ondersteunen en verlenen van patiëntgerichte zorg op Vlaamse ziekenhuisafdelingen en de mate van empowerment van Vlaamse gehospitaliseerde patiënten. Om dit te meten, werd in het proefschrift een bestaand Fins meetinstrument 'The Individualised Care Scale' (ICS) naar het Nederlands vertaald en psychometrisch gevalideerd (**Hoofdstuk 2**). De Nederlandse versie van de ICS vertoonde een goede interne consistentie en constructvaliditeit kon worden aangetoond door middel van een confirmatorische factoranalyse. Voor het meten van patient empowerment was er reeds een valide en betrouwbaar meetinstrument beschikbaar 'The Short Form of the Patient Activation Measure' (PAM-13). De resultaten van een cross-sectionele studie met de Nederlandse versie van de ICS (**Hoofdstuk 3**) toonden aan dat er verschillen waren in de manier waarop patiënten en verpleegkundigen het ondersteunen en verlenen van patiëntgerichte zorg ervaarden. Dit was zo voor alle deelnemende ziekenhuisafdelingen (chirurgische afdelingen, interne afdelingen, revalidatieafdelingen en materniteiten). Verpleegkundigen hadden over het algemeen een positievere perceptie dan patiënten. De resultaten van de studie naar de mate van patient empowerment van Vlaamse gehospitaliseerde patiënten (**Hoofdstuk 4**) toonden aan dat meer dan de helft van de patiënten (55%) zich in staat voelden om de regie te nemen over hun eigen gezondheid. Echter, 45% van de patiënten gaf aan niet voorbereid te zijn om een actieve rol te spelen in hun gezondheidszorg of er moeite mee te hebben. Resultaten van de studies in hoofdstuk 3 en hoofdstuk 4 toonden ook aan dat een lagere gezondheidsgeletterdheid geassocieerd was met een lagere perceptie omtrent patiëntgerichte zorg en patient empowerment.

Naast het meten van patiëntgerichte zorg en patient empowerment, focuste dit proefschrift op de implementatie van de Vertelkaart; een nurse-led communicatie-instrument om patiëntgerichte zorg in Vlaamse ziekenhuizen te verbeteren (**Hoofdstuk 6).** Voorafgaand aan de implementatie van de Vertelkaart werden barrières en facilitatoren onderzocht door middel van kwalitatief onderzoek (**Hoofdstuk 5**). Uit interviews met verpleegkundigen en vroedvrouwen kwam naar voor dat er een zekere terughoudendheid was tegenover het actief faciliteren van patiëntgerichte zorg door middel van de Vertelkaart. Dit werd weergegeven in thema's als 'het willen behouden van controle over de zorg', 'gebrek aan waardering voor het belang van patiëntenparticipatie' en 'een voorkeur voor een meer checklist-achtige manier van communiceren'. In het implementatieplan van de Vertelkaart werd rekening gehouden met de geïdentificeerde barrières en facilitatoren om een succesvolle implementatie te garanderen. De Vertelkaart werd geïmplementeerd in acht Vlaamse ziekenhuisafdelingen (chirurgische afdelingen, interne afdelingen, revalidatieafdelingen en materniteiten). De studie in hoofdstuk 6 toonde aan dat de implementatie geen significante impact had op het verbeteren van patiëntgerichte zorg op de ziekenhuisafdelingen. Uit de procesevaluatie bleek dat verpleegkundigen/vroedvrouwen het interventieprotocol niet altijd volgden en dat patiënten de Vertelkaart niet altijd gebruikten of de kaart gebruikten om een oordeel te vellen over de zorgverlening. Op materniteiten werd de Vertelkaart voornamelijk gebruikt door primipara. Ook bleek dat patiënten de Vertelkaart niet altijd nuttig vonden en dat patiënten die eerder in het ziekenhuis waren opgenomen geen behoefte hadden om de Vertelkaart te gebruiken.

Na vergelijking van de resultaten van dit proefschrift met de resultaten van andere observationele en kwalitatieve studies, leek het aannemelijk dat verpleegkundigen hun patiëntgerichte zorgondersteuning en zorgverlening overschatten. Er waren voornamelijk grote verschillen op aspecten van patiëntgerichte zorg met betrekking tot het bieden van ondersteuning aan patiënten bij het nemen van beslissingen over de eigen gezondheidszorg en het behandelen van de patiënt als een uniek individu (**Addendum 3**). Op basis van deze bevindingen en de bevinding dat verpleegkundigen eerder terughoudend waren tegenover het actief faciliteren van patiëntgerichte zorg door middel van de Vertelkaart, kunnen drie belangrijke aanbevelingen worden gedaan. Als eerste is er nood aan meer reflective practitioners. De toegenomen aandacht voor standaardisatie van zorg lijkt af te leiden van belangrijke aspecten van patiëntgerichte zorg zoals communicatie. Reflective practitioners durven zichzelf en de zorg die zij verlenen in vraag te stellen en zijn zo mogelijks in staat om een evenwicht te vinden tussen gestandaardiseerde en geïndividualiseerde zorg. Verder moet het onderwijs studenten voorbereiden om empathische zorgverleners te worden die het belang inzien van het behandelen van de patiënt als een uniek individu. Als laatste moeten verpleegkundigen ondersteund worden door ervaringsdeskundigen bij het bieden van patiëntgerichte zorg en het ondersteunen van patient empowerment, zeker bij de meest kwetsbare patiëntengroepen.

Het implementatieproject van de Vertelkaart toonde de complexiteit van het verbeteren van patiëntgerichte zorg op ziekenhuisafdelingen aan. De vraag moet worden gesteld of de Vertelkaart relevanter zal zijn wanneer deze wordt geïmplementeerd binnen specifieke patiëntenpopulaties, in plaats van de kaart standaard op alle ziekenhuisafdelingen te gebruiken. Op basis het implementatieproject kunnen nog drie bijkomende aanbevelingen worden gedaan. Ten eerste moeten ziekenhuismanagers kritisch nadenken over hun motivatie om voor het systeem van ziekenhuisaccreditatie te kiezen en of het systeem van accreditatie bijdraagt aan het verbeteren van patiëntgerichtheid in hun ziekenhuis. Tijdens de implementatie van de Vertelkaart stapten vier ziekenhuisafdelingen vroegtijdig uit het project, na de accrediteringsvisitatie. Ten tweede, om met succes te streven naar meer patiëntgerichtheid in ziekenhuizen, moeten ziekenhuismanagers sterke leiders, zoals verpleegkundig specialisten, betrekken bij initiatieven gericht op het verbeteren patiëntgerichte zorg en moeten ze meer focussen op een ‘bottom-up’ aanpak van veranderingsinitiatieven. Ten derde moet gezondheidsbeleid zich verder richten op de ontwikkeling van patiëntgerichte kwaliteitsindicatoren. Dit is nodig om te evolueren naar een gezondheidszorgsysteem waarin evenveel waarde wordt gehecht aan patiëntgerichte zorg als aan technische zorg en zal bevorderlijk zijn voor het ontwikkelen van een positieve houding ten aanzien van patiëntgerichte zorg in ziekenhuizen.

CURRICULUM VITAE

Personalia

Sofie Theys (°1995) finished her secondary school in 2013 (Economie –Moderne Talen, Spes Nostra, Heule). Thereafter, she obtained a Bachelor degree in (social) Nursing (Hogeschool Vives, 2016) and a master degree in Nursing Science (Ghent University, 2018).

Publications

Articles in international peer-reviewed journals (science citation indexed)

Theys, S., van Belle, E., Heinen, M., Malfait, S., Eeckloo, K., Beeckman, D., Verhaeghe, S., & Van Hecke, A. (2021). Individualised care in Flemish and Dutch hospitals: comparing patients' and nurses' perceptions. *Scandivanvian Journal of Caring Science*s. Doi:10.1111/scs.13016

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ADDENDA

Addendum 1 Overview of the standardised factor loadings for patients

	Factor loadings ICSA[a]				Factor loadings ICSB[b]		
Item content	1	2	3	**Item content**	1	2	3
Nurses have …							
1. talked with me about the feelings I have had about my condition	0.76			1. The feelings I have had about my condition have been taken into account in my care	0.84		
2. talked with me about my needs that require care and attention	0.76			2. My needs that require care and attention have been taken into account in my care	0.81		
3. given me the chance to take responsibility for my care as far as I am able	0.61			3. I have assumed responsibility for my care as far as I am able	0.53		
4. identified changes in how I have felt	0.69			4. The changes in how I have felt have been taken into account in my care	0.81		
5. talked with me about my fears and anxieties	0.83			5. Any fears and anxieties of mine have been taken into account in my care	0.85		
6. made an effort to find out how the condition has affected me	0.84			6. The way the condition has affected me has been taken into account in my care	0.86		
7. talked with me about what the condition means to me	0.85			7. The meaning of the illness to me personally has been taken into account in my care	0.86		
8. asked me what kinds of things I do in my everyday life outside the hospital		0.76		8. My everyday activities have been taken into account in my care		0.83	
9. asked me about my previous experiences of hospitalisation		0.76		9. My previous experiences of being in hospital have been taken in account in my care		0.79	

10. asked me about my everyday habits	0.83		10. My everyday habits have been taken into account during my stay in hospital	0.83	
11. asked me whether I want my family to take part in my care	0.71		11. My family have taken part in my care if I have wanted them to	0.58	
12. made sure I have understood the instructions I have received in the hospital		0.70	12. I have followed the instructions I have received in hospital		0.50
13. asked me what I want to know about my condition		0.78	13. I have received enough information about my condition from the nurses		0.78
14. listened to my wishes with regard to my care		0.75	14. The wishes I have expressed have been taken into account in my care		0.86
15. helped me take part in decisions concerning my care		0.84	15. I have taken apart in decision-making concerning my care		0.83
16. helped me express my opinions on my care		0.84	16. The opinions I have expressed have been taken into account in my care		0.84
17. asked me what time I would prefer to wash		0.58	17. I have made my own decisions on when to wash		0.53

[a]ICSA = Individualised Care Scale – Scale A; [b]ICSB = Individualised Care

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Addendum 1 Overview of the standardised factor loadings for nurses

	Item content	Factor loadings ICSA[a] 1	2	3		**Item content**	Factor loadings ICSB[b] 1	2	3
1.	I talk with patients about the feelings they have about their health condition	0.81			1.	I took into account the feelings patients had about their health condition	0.84		
2.	I talk with patients about their needs that require care/attention	0.83			2.	I took into account their needs that require care and attention	0.85		
3.	I give patients the chance to take responsibility for their care as far as able	0.73			3.	Patients assumed responsibility for their care as far as they were able	0.64		
4.	I identify changes in how they have felt	0.79			4.	I took into account the changes in how they felt	0.86		
5.	I talk with patients about their fears and anxieties	0.85			5.	I took into account their fears and anxieties	0.86		
6.	I make an effort to find out how their health condition has affected them	0.78			6.	I took into account the way the health condition has affected them	0.87		
7.	I talk with patients about what the health condition means to them	0.78			7.	I took into account the meaning of the health condition to the patient	0.84		
8.	I ask patients things they did in their everyday life		0.75		8.	I took into account their everyday activities outside the hospital		0.69	
9.	I ask patients about their experiences of hospitalisation		0.67		9.	I took into account their previous experiences of being in hospital		0.68	
10.	I ask patients about their everyday habits		0.76		10.	I took into account patients' everyday habits while hospitalised		0.79	

11. I ask patients whether they want their family to take part in their care	0.63		11. Patients’ families took part in their care if they wanted them to	0.67	
12. I give instructions to patients using language that is easy to understand		0.73	12. I made sure that patients understood the instructions they received		0.69
13. I ask patients what they want to know about their illness/health condition		0.62	13. I gave patients enough information about their illness/health condition		0.67
14. I listen to patients’ personal wishes with regard to their care		0.83	14. I took into account patients’ wishes about their care		0.83
15. I help patients take part in decisions concerning their care		0.81	15. Patients took part in decision-making concerning their care		0.79
16. I encourage patients to express their opinions on their care		0.75	16. I took into account the opinions patients expressed about their care		0.85
17. I ask patients at what time they would prefer to wash		0.67	17. Patients had the opportunity to make their own decisions on when to wash		0.47

[a]ICSA = Individualised Care Scale – Scale A; [b]ICSB = Individualised Care

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Addendum 2 Summary of the reliability analysis of the Dutch version of the ICS for nurses and patients

	Nurses						Patients					
	Items (n)	Cronbach's α	omega Ω	Mean inter-item r^f	Item-to-total correlations	Subscale r^f	Items (n)	Cronbach's α	omega Ω	Mean inter-item r^f	Item-to-total correlations	Subscale r^f
ICSA[a]	17	0.95	0.95	0.51	0.62-0.73		17	0.96	0.96	0.49	0.55-0.67	
		(0.95-0.96)	(0.95-0.96)	(0.29-0.77)				(0.95-0.96)	(0.95-0.96)	(0.28-0.82)		
ClinA[c]	7	0.93	0.93	0.63	0.75-0.78	0.89	7	0.93	0.93	0.58	0.75-0.78	0.87
		(0.92-0.94)	(0.93-0.94)	(0.49-0.77)				(0.93-0.94)	(0.93-0.94)	(0.44-0.76)		
PersA[d]	4	0.83	0.83	0.50	0.55-0.61	0.82	4	0.88	0.88	0.58	0.63-0.67	0.70
		(0.81-0.85)	(0.81-0.85)	(0.42-0.58)				(0.86-0.89)	(0.86-0.89)	(0.49-0.65)		
DecA[e]	6	0.89	0.89	0.53	0.58-0.64	0.78	6	0.91	0.91	0.55	0.54-0.65	0.76
		(0.87-0.90)	(0.88-0.90)	(0.29-0.71)				(0.90-0.92)	(0.90-0.92)	(0.39-0.82)		
ICSB[b]	17	0.95	0.96	0.52	0.44-0.77		17	0.96	0.96	0.52	0.50-0.79	
		(0.95-0.96)	(0.95-0.96)	(0.28-0.83)				(0.96-0.97)	(0.96-0.97)	(0.28-0.82)		
ClinB[c]	7	0.95	0.95	0.68	0.81-0.83	0.86	7	0.95	0.95	0.63	0.80-0.81	0.86
		(0.94-0.95)	(0.94-0.95)	(0.50-0.83)				(0.94-0.95)	(0.94-0.95)	(0.39-0.82)		
PersB[d]	4	0.82	0.83	0.50	0.54-0.60	0.78	4	0.87	0.88	0.56	0.51-0.76	0.85
		(0.80-0.85)	(0.80-0.85)	(0.40-0.58)				(0.86-0.89)	(0.87-0.89)	(0.42-0.70)		
DecB[e]	6	0.89	0.89	0.54	0.44-0.68	0.86	6	0.91	0.91	0.52	0.47-0.51	0.78
		(0.88-0.90)	(0.88-0.91)	(0.30-0.70)				(0.90-0.92)	(0.91-0.92)	(0.27-0.75)		

[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]r = Pearson's correlation coefficient r, $p < 0.5$

Addendum 3 Overview of nurses' and patients' perceptions of patient-centred care (item-level)

	ICSA[a]						ICSB[b]				
	Item content		Mean[c]	MD[d]	P		Item content		Mean[c]	MD[d]	P
1.	Talking with patients about the feelings they have about their health condition	Nurse	4.499	0.369	< 0.001*	1.	Taking into account the feelings patients had about their health condition	Nurse	4.492	0.530	< 0.001*
		patient	4.130					patient	3.961		
2.	Talking with patients about their needs that require care/attention	Nurse	4.497	0.338	< 0.001*	2.	Taking into account needs of patients that require care and attention	Nurse	4.536	0.394	< 0.001*
		patient	4.159					patient	4.142		
3.	Giving patients the chance to take responsibility for their care as far as able	Nurse	4.482	0.214	<0.001*	3.	Patients assumed responsibility for their care as far as they were able	Nurse	4.144	0.091	0.056
		patient	4.266					patient	4.236		
4.	Identifying changes in how patient have felt	Nurse	4.548	0.488	< 0.001*	4.	Taking into account the changes in how patients felt	Nurse	4.421	0.380	< 0.001*
		patient	4.060					patient	4.041		
5.	Talking with patients about their fears and anxieties	Nurse	4.452	0.721	< 0.001*	5.	Taking into account fears and anxieties	Nurse	4.476	0.537	< 0.001*
		patient	3.730					patient	3.939		
6.	Making an effort to find out how their health condition has affected them	Nurse	4.077	0.380	< 0.001*	6.	Taking into account the way the health condition has affected the patient	Nurse	4.360	0.465	< 0.001*
		patient	3.697					patient	3.895		
7.	Talking with patients about what the health condition means to them	Nurse	4.144	0.552	< 0.001*	7.	Taking account the meaning of the health condition to the patient	Nurse	4.326	0.521	< 0.001*
		patient	3.592					patient	3.806		
8.	Asking patients things they did in their everyday life	Nurse	4.192	0.880	< 0.001*	8.	Taking into account patients' everyday activities outside the hospital	Nurse	3.788	0.382	< 0.001*
		patient	3.313					patient	3.406		

9.	Asking patients about their experiences of hospitalisation	Nurse	3.836	0.685	< 0.001*	9.	Taking into account their previous experiences of being in hospital	Nurse	3.875	0.435	< 0.001*
		patient	3.150					patient	3.441		
10.	Asking patients about their everyday habits	Nurse	4.189	0.984	< 0.001*	10.	Taking into account patients' everyday habits while hospitalised	Nurse	3.974	0.290	< 0.001*
		patient	3.205					patient	3.684		
11.	Asking patients whether they want their family to take part in their care	Nurse	3.701	0.432	< 0.001*	11.	Patients' families took part in their care if they wanted them to	Nurse	4.085	0.102	0.062
		patient	3.269					patient	3.984		
12.	Giving instructions to patients using language that is easy to understand	Nurse	4.635	0.718	< 0.001*	12.	Making sure that patients understood the instructions they received	Nurse	4.390	0.113	< 0.007*
		patient	3.917					patient	4.503		
13.	Asking patients what they want to know about their illness/health condition	Nurse	3.900	0.415	< 0.001*	13.	Giving patients enough information about their illness/health condition	Nurse	4.169	0.150	< 0.008*
		patient	3.485					patient	4.019		
14.	listening to patients' personal wishes with regard to their care	Nurse	4.504	0.390	< 0.001*	14.	Taking into account patients' wishes about their care	Nurse	4.362	0.166	< 0.001*
		patient	4.115					patient	4.196		
15.	Helping patients take part in decisions concerning their care	Nurse	4.290	0.450	< 0.001*	15.	Patients took part in decision-making concerning their care	Nurse	4.065	0.187	0.001*
		patient	3.840					patient	3.878		
16.	Encouraging patients to express their opinions on their care	Nurse	4.241	0.531	< 0.001*	16.	Taking into account the opinions patients expressed about their care	Nurse	4.313	0.203	< 0.001*
		patient	3.710					patient	4.110		
17.	Asking patients at what time they would prefer to wash	Nurse	4.402	1.279	< 0.001*	17.	Patients had the opportunity to make their own decisions on when to wash	Nurse	3.412	0.325	< 0.001*
		patient	3.124					patient	3.736		

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[a]ICSA = Individualised Care Scale – Scale A: patients' and nurses' views of how individuality was supported through nursing activities; [b]ICSB = Individualised Care Scale – Scale B: how patients perceive their care as individual to them and how nurses perceive the maintenance of individuality in care provision; [c]MD = Mean difference; [d]CI = confidence interval ; *p-value < 0.05

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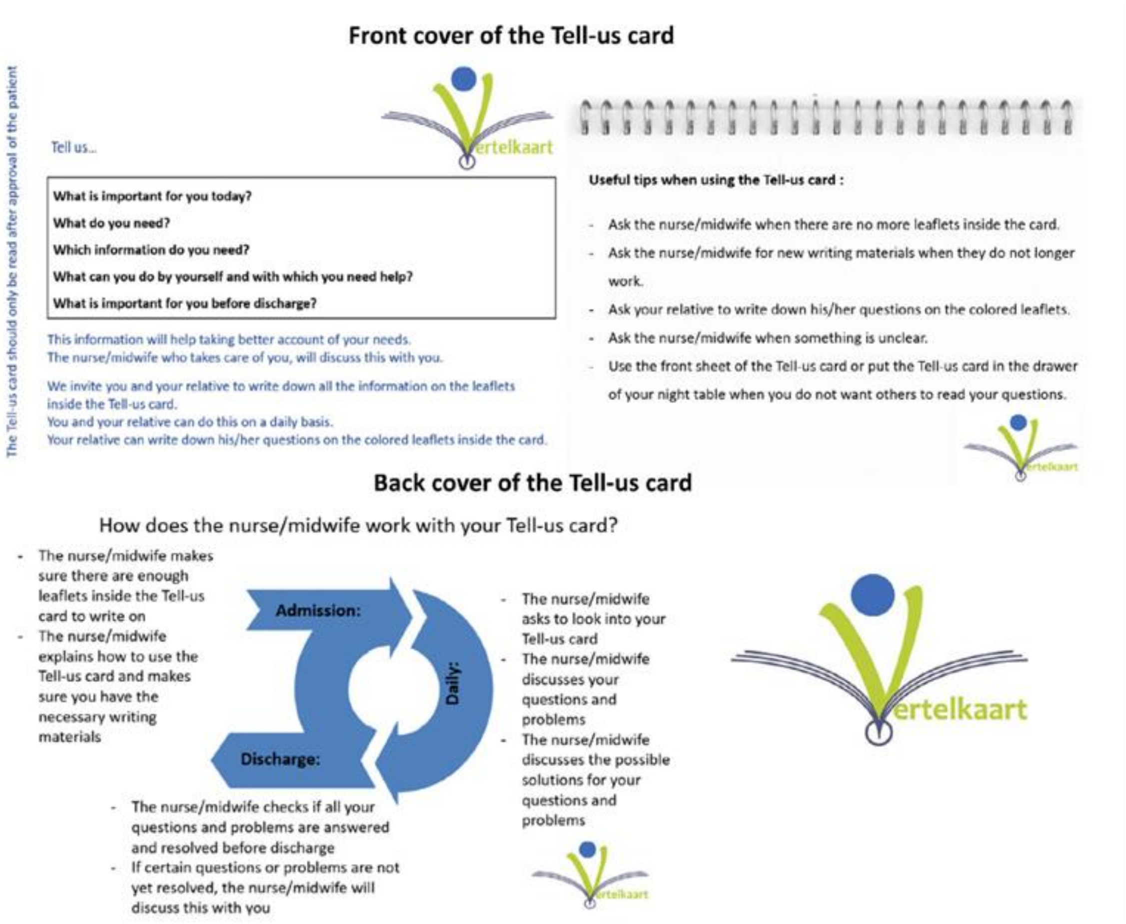
Addendum 4 Example of the Tell-us card



Front cover of the Tell-us card

The Tell-us card should only be read after approval of the patient

Tell us...

What is important for you today?
What do you need?
Which information do you need?
What can you do by yourself and with which you need help?
What is important for you before discharge?

This information will help taking better account of your needs.
The nurse/midwife who takes care of you, will discuss this with you.

We invite you and your relative to write down all the information on the leaflets inside the Tell-us card.
You and your relative can do this on a daily basis.
Your relative can write down his/her questions on the colored leaflets inside the card.

Useful tips when using the Tell-us card :

- Ask the nurse/midwife when there are no more leaflets inside the card.
- Ask the nurse/midwife for new writing materials when they do not longer work.
- Ask your relative to write down his/her questions on the colored leaflets.
- Ask the nurse/midwife when something is unclear.
- Use the front sheet of the Tell-us card or put the Tell-us card in the drawer of your night table when you do not want others to read your questions.

Back cover of the Tell-us card

How does the nurse/midwife work with your Tell-us card?

Admission:

- The nurse/midwife makes sure there are enough leaflets inside the Tell-us card to write on
- The nurse/midwife explains how to use the Tell-us card and makes sure you have the necessary writing materials

Daily:

- The nurse/midwife asks to look into your Tell-us card
- The nurse/midwife discusses your questions and problems
- The nurse/midwife discusses the possible solutions for your questions and problems

Discharge:

- The nurse/midwife checks if all your questions and problems are answered and resolved before discharge
- If certain questions or problems are not yet resolved, the nurse/midwife will discuss this with you

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