

University of Groningen

## Focus on functioning in person-centered nurse-led diabetes care

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DOI:  
[10.33612/diss.213502879](https://doi.org/10.33612/diss.213502879)

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*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2022

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*  
Wildeboer, A. (2022). *Focus on functioning in person-centered nurse-led diabetes care: an exploration of views of patients and healthcare providers, in particular the nursing profession, on person-centered diabetes care and patient factors affecting health outcomes*. [Thesis fully internal (DIV), University of Groningen]. University of Groningen. <https://doi.org/10.33612/diss.213502879>

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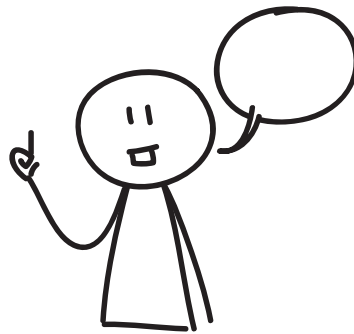
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# General Discussion and Conclusion

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## INTRODUCTION

Type 2 diabetes mellitus (DM2) is one of the most common chronic conditions worldwide, and its rising prevalence has been recognized as a major global health challenge [1]. The success of DM2 treatment, i.e., optimal glycemic control and prevention of complications [2], largely depends on the patient's ability and willingness to self-manage the disease in daily life, including lifestyle adaptations, following advice, and adhering to medication. However, some patients may not be able to self-manage their chronic condition adequately [3]. To support patients' self-management and coping with their chronic condition, a person-centered care approach is recommended [2,4]. Person-centered care entails being respectful of and responsive to persons' preferences, needs and values, as well as ensuring that persons' values guide all clinical decisions [5,6]. It implies active participation of patients in their health care [7] and a holistic, biopsychosocial perspective from healthcare providers [8], including shared decision-making [9].

The aim of this thesis is to explore reference points for healthcare providers, in particular the nursing profession to provide sustainable and high-quality person-centered care. Personal views of patients and healthcare providers can affect the extent to which person-centered care is applied. Therefore, views of patients and healthcare providers on elements of person-centered care were explored in this thesis. In particular patients' views on participation in their health care and views of nurses and specialized doctors' assistants on a biopsychosocial care approach and shared decision-making. Moreover, patient factors, such as health literacy [10], patient activation for self-management [11], and diabetes distress, [12] are important essential factors to consider in person-centered care. Therefore, these patient factors were also examined as they may affect health outcomes, such as glycemic control and health services use.

The main findings will be discussed first. Next, a reflection on this thesis and a synthesis of the main findings will be presented, followed by a general conclusion.

### **Main findings**

The main findings of the studies in this thesis are discussed in two parts, reflecting two different research topics and associated research methods.

Part I consists of Chapters 2-4. In this part, the main findings of the first three studies exploring views of patients and healthcare providers on elements of person-centered care, are discussed. In particular, patient participation, the biopsychosocial care approach, and shared decision-making. These studies were conducted using a qualitative research method. In addition, each of the three studies used a model or framework to guide the study. The Feldman-Stewart framework [13] was used in the first study (Chapter 2); the core set for DM of the International Classification of Functioning, Disability, and Health (ICF) [14] in the second study (Chapter 3); and the concept of shared decision-making [15] in the third study (Chapter 4).

Part II consists of Chapters 5 and 6. The studies presented in these chapters were conducted using a cross-sectional design and explored patient factors affecting health outcomes. The first study of Part II (Chapter 5) examined the association between health

literacy and health services use. Andersen's behavioral model of health services use [16] guided this study. The second study (Chapter 6) examined the association between patient activation for self-management, diabetes distress and glycemic control in terms of glycosylated hemoglobin (HbA1c in mmol/mol). HbA1c reflects the average blood glucose for the last two to three months. This outcome measure is a common health indicator of glycemic control [2]. Both studies used the same dataset of 352 patients with DM2 in several general practices in the Northeast region of the Netherlands. Data were collected between January 2020 and September 2020.

## Part I Views of patients with DM2 and healthcare providers<sup>1</sup> on person-centered care

**Research question 1 (Chapter 2): which factors help and hinder active patient participation in consultations with nurses and specialized doctors' assistants in general practices, according to patients with DM2?**

Person-centered care implies active participation from patients in their health care [7]. To understand helping and hindering factors affecting the engagement of patients with DM2 in consultations with their healthcare provider, a qualitative study was conducted in several general practices in the Middle of the Netherlands. In Dutch primary care, diabetes care is predominantly provided by 'POH-S' (in Dutch: Praktijk Ondersteuner Huisarts-Somatiek). This position is often performed by nurses or specialized doctors' assistants. Two semi-structured focus groups with seven and five patients with DM2 took place and eight individual semi-structured interviews were held with patients with DM2 who received diabetes care from their healthcare provider in the general practices. The median age of the participating patients was 71.5 years (interquartile range 68.0-77.8), and the majority of the patients had low or middle education levels.

The Feldman-Stewart framework for patient-professional communication within the healthcare setting was used to organize the findings of this study. This framework includes four key components: patients' communication goals, personal attributes that determine how patients address their goals, the communication process, and the environment in which the communication takes place. The framework shows that five key patient attributes (*needs, beliefs, values, skills, and emotions*) affect the content and form of each message patients convey [13].

This study revealed that the personal needs, beliefs, and skills of patients with DM2 act as helping as well as hindering factors, that may affect their participation in consultations with their healthcare providers in general practices. Participation in medical

<sup>1</sup> In Dutch primary care setting, diabetes care is predominantly provided by POH-S (in Dutch: Praktijk Ondersteuner Huisarts-Somatiek). This position is often performed by nurses or specialized doctors' assistants.

consultations refers to actively contributing to the care process by, for example, asking questions, expressing concerns, and stating preferences [17]. Using the framework, we found that patients' need for a trusting relationship with their healthcare provider and the presence of a spouse were helping factors in taking an active role in consultations. In addition, patients' belief that there is enough time available for them and patients' skills in personal preparation for the consultations were also mentioned as helping factors. The majority of patients in the current study seldom felt the need to participate more actively in their consultations. This attitude was most likely caused by patients' belief that their condition is not serious due to the absence of complications and associated absence of disease burden [18]. Lacking the need or motivation to participate and readjustment to another healthcare provider were mentioned as hindering factors for active participation. Moreover, lack of skills, such as forgetting to ask questions and ineffectively expressing thoughts, was reported as a barrier to taking an active role. The participating patients were primarily older adults, which is to be expected as DM2 often affects the elderly, and their lack of the skills mentioned above could be age-related (e.g., memory problems) or related to their lower levels of education. Overall, participating patients did not mention any issues associated with the relationship with their healthcare provider. Their satisfaction with their role in the consultation could be explained by the fact that their healthcare provider have enough time for them and sufficient knowledge [19,20]. Moreover, patients may consider their consultations to be a biomedical check-up only [21].

The conclusion of this study was that helping and hindering factors for patient participation should be taken into consideration by healthcare providers when providing person-centered care based on a relationship of trust to patients with DM2. When participation is impeded by factors such as skills that patients lack, helping factors (e.g., presence and support of a spouse) should be encouraged by healthcare providers.

**Research question 2 (Chapter 3): how relevant is a biopsychosocial care approach in terms of ICF according to nurses involved in care for patients with DM2?**

Person-centered care implies a biopsychosocial perspective from healthcare providers [8]. This perspective takes into account persons' biomedical, emotional, social, and behavioral dimensions of health, including personal values and other issues of importance in their lives [6]. This two-round Delphi validation study examined the relevance of a biopsychosocial care approach according to 27 Dutch registered nurses (nurse practitioners, nurses specialized in diabetes care, and nurses in general practices) involved in diabetes care.

Because the concept of functioning is an essential part of the biopsychosocial model and highly relevant to nursing care, the International Classification of Functioning, Disability and Health (ICF) core set for DM [14] was used in this study. The ICF is helpful for nursing care, as it can ensure that potentially relevant aspects of a person's functioning are taken into account [22]. An ICF core set is a selected set of categories out of the whole ICF, related to a specific health condition and includes the

components of functioning (body functions and structures, and activities and participation) and contextual factors (environmental and personal factors). An ICF core set can serve as a minimal standard for the assessment and reporting of a person's functioning and health. The research question was answered by exploring the content validity of the ICF core set for DM from nurses' perspective in a two-round Delphi study.

This study showed that content validity of the ICF core set for DM was partially supported by the expert panel of nurses. In total, 46 (54.1%) categories of a total of 85 from the initial ICF core set for DM were found to be relevant. Most of these categories were derived from body functions and structures. Less support for content validity was found for ICF categories derived from environmental factors. Categories related to *physical and emotional support* and categories related to *the attitude of persons that influence an individual's behavior and actions*, received little support. A total of 55 additional categories, previously identified by patients with DM as meaningful categories [23], were also presented to the expert panel of nurses. The panel judged 17 (30.9%) of these ICF categories to be relevant. ICF categories on which no agreement was reached were predominantly derived from activities and participation (e.g., *transferring oneself*) and from environmental factors (e.g., *assets*). Some panel members also mentioned additional missing categories in the ICF core set for DM. Two of these categories were judged as relevant by the whole panel. These categories were *sensations related to muscles and movement functions* and *communicating with—receiving—spoken messages*. The latter is related to health literacy, a widely recognized determinant of health [24]. The high level of agreement on the biomedical categories can be explained by the fact that Dutch healthcare providers strictly adhere to guidelines from the Organization for General Practitioners [25]. These guidelines focus on medical outcomes and are associated with body functions and structures. Another explanation for this finding could be that the majority of the panel worked in secondary care. Patients with DM2 are referred to this setting when they need medical treatment for their complications. Although patients indicate that ICF categories ranging from biomedical to psychosocial are meaningful to them, they may expect a biomedical focus from healthcare providers during clinical encounters [21].

This study showed that the expert panel of nurses partially supported the content validity of the ICF core set for DM. Environmental factors received little support. It was concluded that nurses' agreement on predominantly biomedical ICF categories indicates a biomedical focus in diabetes care. The nursing profession should be aware of a potential gap between the current biomedical focus and a recommended biopsychosocial approach in care for patients with DM2 in order to provide person-centered care in which all relevant aspects of a person's functioning are considered.

**Research question 3 (Chapter 4): how relevant is shared decision-making in care for patients with DM2, according to nurses and specialized doctors' assistants in general practices?**

One of the cornerstones of person-centered care is shared decision-making, which involves patients in decisions regarding their health [9]. To support shared decision-making, decision aids can be used [26]. This qualitative study explored the views of staff in

general practices (i.e., nurses and specialized doctors' assistants), in 17 primary care general practices in the North of the Netherlands towards shared decision-making. Moreover, the applicability, usefulness, and feasibility of a newly developed decision aid were evaluated. In total, 24 interviews were conducted.

The concept of shared decision-making [27] was used to develop the decision aid and to guide the interviews. In general, four steps in shared decision-making can be distinguished. Step 1: the professional informs the patient that a decision had to be made and that the patient's opinion is important. Step 2: the professional explains the options, and the pros and cons of the options. Step 3: the professional and patient discuss the patient's preferences. Step 4: the professional and the patient make or defer the decision.

This study showed that the majority of the staff expressed a positive view towards shared decision-making, in particular towards exchanging information, providing education, and involving patients in treatment decisions. Most of the respondents confirmed the usefulness of the decision aid in stimulating effective shared decision-making. A positive view towards shared decision-making was associated with using the decision aid as intended, more often. Moreover, by using the decision aid, several respondents expressed that they became aware of their paternalistic approach, meaning that they were previously not used to actively involving patients in the decisions regarding their health and treatment. Although the decision aid fitted well within the current practice, its use by the staff appeared to be limited. On average, the decision aid was used to its full extent in only 46% of the patients. An explanation for this finding could be a conflict between the content of the decision aid and protocol-based care, as reported by several respondents. For example, the decision aid offered the option of 'no intervention', whereas the protocol may recommend treatment [28]. In addition, some respondents viewed their patients as passive and not motivated to take action. This form of pessimism among primary care physicians and nurses has been observed before, particularly concerning lifestyle changes of patients [29]. However, some patients still wanted the healthcare provider to decide, which has been identified as 'welcomed paternalism' [30]. According to several respondents, many of their patients already had well-regulated diabetes. In such cases, some respondents found the decision aid not useful. Others still perceived the decision aid as useful because it showed them they were taking the right steps.

The results of this study demonstrated that the staff in the general practices, who mainly consisted of specialized doctors' assistants, expressed a positive view towards shared decision-making, which appeared to be a facilitator to using the decision aid. Vice versa, the decision aid helped apply shared decision-making because it stimulated a two-way conversation. However, experiencing a conflict between the content of the decision aid and protocol-based views of the staff seemed to be a barrier to using the decision aid. This study concluded that more research is needed to investigate the extent to which staff in general practices has the intention and ability to apply shared decision-making, taking protocol deviations into account.

## Part II Patient factors affecting health outcomes in person-centered care

### **Research question 4 (Chapter 5): what is the association between health literacy and health services use when controlled for several patient characteristics in patients with DM2?**

A cross-sectional study in 352 patients with DM2 was conducted to answer the research question of this study. Health services use is an often investigated and relevant health outcome because it may reflect the need for self-management support [31]. Considering the rising prevalence of DM2, this health outcome is particularly relevant for delivering tailored care that meets the needs of an increasing number of patients with DM2. Because several studies showed associations between limited health literacy and poor health outcomes [33,34] including more health services use [35], this study examined the impact of health literacy on health service use, controlled for several other patient characteristics.

Andersen's behavioral model of health services use [16] guided this study. This model states that health services use is determined by environmental factors (societal factors and healthcare system) and patient characteristics, categorized as predisposing, enabling, and health-related need factors.

This study showed that a total of 107 patients (30.4%) demonstrated limited health literacy, which was in line with the prevalence in the general population in the Netherlands [36]. Patients with limited health literacy were significantly older ( $p=0.035$ ), reported lower health status ( $p=0.015$ ), lower self-management activation scores ( $p=0.004$ ), and used more medication ( $p<0.001$ ). This study confirmed that patients with limited health literacy made more use of health services per year (median=18, IQR=10;26) than patients with sufficient health literacy (median=12, IQR=8;19) ( $p<0.001$ ). However, the impact of health literacy on health services was reduced when controlling for patient characteristics. Regarding Andersen's behavioral model of health services use, health-related need factors were significantly associated with health services use, including medication use, glycemic control, diabetes distress, and health status. Medication use was the most crucial factor contributing to the explained variance of health services use. This indicates that a higher amount of medication is associated with more health services use. Moreover, medication use was found to be a mediator in the association between health literacy and health services use. People with limited health literacy may need medical treatment more often than people with sufficient health literacy. Given that patients with limited health literacy have difficulties understanding and complying with medical advice [33], they rely heavily on comprehensible information provided by healthcare providers [37]. When healthcare providers are unaware of patients' limited health literacy, understandable information may not be provided.

After controlling for several patient characteristics, this study showed that medication use (i.e., amount of medication) had the strongest association with health services use and acted as a mediator in the association between health literacy and health services use. This implies that patient characteristics as well as healthcare



providers may influence health services use; the latter in their role as prescribers. This study concluded that awareness of health literacy is vital because it will lead to diabetes care that is more efficient and responsive to the individual patient's needs.

**Research question 5 (Chapter 6): what are the associations between patient activation for self-management, diabetes distress and glycemetic control in patients with DM2?**

This study in 352 patients with DM2 from general practices in the Northeast region of The Netherlands demonstrated that 149 (42.4%) patients reported low levels of patient activation for self-management. In total, 49 patients (14%) reported diabetes distress, which refers to the 'negative emotional or affective experience resulting from the challenge of living with the demands of diabetes' [38]. The sample's median (interquartile range) HbA1c was 53 (47.0;61.0) mmol/mol. This study showed that a total of 29.7% of the variance in HbA1c could be explained by the use of blood glucose-lowering medication, patient activation for self-management, and diabetes distress. It is not surprising that blood glucose-lowering medication predominantly (27.3%) explained the variance in glycemetic control. After all, medication aims to lower the blood glucose level to make patients feel better physically and prevent complications. Patient activation for self-management explained only a small but significant part of the variance in glycemetic control (0.7%) in the current study. An explanation for this association may be that patients with low activation levels experienced barriers (e.g., lack of skills, knowledge, and motivation) to perform adequate self-management and therefore had worse glycemetic control than patients with higher activation levels. Almost half of the sample in the current study had low activation levels. The older age of the sample can explain the high number of patients with lower levels of self-management activation, higher body mass index, lower education levels, more limited health literacy, and lower health status [39]. Diabetes distress also explained a small but significant part of the variance in HbA1c (1.6%). However, the prevalence of diabetes distress in the current study (14.0%) was lower than previously reported [40]. This finding may also be explained by the older age of the sample [41]. While the effect of diabetes distress on glycemetic control has been previously noticed [40], the direction of this association is, however, less clear and can be interpreted in a two-fold way. On the one hand, HbA1c may be a determinant for diabetes distress, indicating that worries about complications due to elevated HbA1c may increase diabetes distress [42]. When HbA1c decreases, for instance, due to medication use, worries and fears about complications may diminish. On the other hand, diabetes distress may be a determinant for HbA1c, indicating that elevated levels of distress may increase HbA1c.

The study demonstrated that almost 30% of the variance in HbA1c could be explained, indicating that 70% of the variance in HbA1c remains unexplained. It was concluded that to achieve and maintain optimal glycemetic control, a biopsychosocial care approach is recommended in which nurses address medication use, patient activation levels for self-management, and diabetes distress. Future studies are needed to explore additional factors glycemetic control.

## REFLECTION ON THIS THESIS

### Relevance

A person-centered care approach is recommended to support patients' self-management and coping with their chronic condition(s) [4], including DM2 [2]. Implementing person-centered care is challenging, however, due to its multidimensional nature that includes respect for patients' values, preferences, and expressed needs; provision of information and education; access to appropriate care; emotional and physical support; involvement of family and friends; and coordination and continuity between and within health services [6]. Patients and healthcare providers experience several challenges in performing self-management and applying a biopsychosocial care approach that includes shared-decision making, respectively. To provide sustainable and high-quality person-centered care, healthcare providers need reference points in daily care delivery. Therefore, patients' perspectives (Chapter 2) and nurses' perspectives (Chapters 3 and 4) on elements of person-centered care (i.e., participation, biopsychosocial care approach, and shared decision-making) were explored. We also examined several patient factors (Chapters 5 and 6), which are essential factors to consider in person-centered care for people with DM2, as these factors may affect health outcomes.

### Methods

Different study methods were used to explore reference points for healthcare providers, in particular nursing, as presented in Chapters 2- 6 of this thesis. In the first three studies (Part I of this thesis), a qualitative research method was used. By using a combination of in-depth individual interviews and focus groups methods (Chapters 2 and 4), it was possible to collect relevant information. A two-round Delphi study (Chapter 3) had a high response rate, this probably resulted from the anonymous environment and accessibility in terms of location and time. A framework or model was used to guide all three studies. This proved very helpful for maintaining focus and setting boundaries for the studies. Two studies (Part II of this thesis) used a quantitative research method. A significant part of the collected data was obtained from validated self-reported questionnaires. These were highly applicable in clinical practice due to their compactness.

### Limitations

A limitation of this thesis concerns the generalizability of the results. Overall, the results are valid for the population where the participants came from. The healthcare providers in general practices involved in diabetes care, consisting of nurses and specialized doctors' assistants (Chapters 2 and 4), participated in the studies as a so-called POH-S (in Dutch: *Praktijk Ondersteuner Huisarts-Somatiek*). Because this function is typical for the Netherlands, an international comparison may be difficult. Moreover, in Chapter 2, recall bias might have affected the results, because patients were asked about experiences in the past. In Chapter 3, the predominant secondary care work setting of participating nurses may have contributed to the preference for biomedical

categories. In Chapter 4, the views towards shared decision-making and the use of a decision aid of healthcare providers involved in diabetes care, who mainly consist of specialized doctors' assistants, may be more positive in compared with staff in other Dutch general practices, because all participants were trained in motivational interviewing and risk communication when using the decision aid before the study started. In Chapters 5 and 6, responses to self-reported questionnaires (PAM and PAID) may have been sensitive to social desirability bias, meaning that participants answer the questions rather too positively. This may have led to underestimations of the strength of associations. Moreover, patients may be unaware of their own lack of understanding or feel ashamed of their limited health literacy and therefore may have answered questions regarding health literacy too favorably. A total of 43% of patients did not respond to the invitation (including a reminder) to participate, this may have led to selection bias. The participating patients came from a region in the Northeast of the Netherlands; therefore, it is possible that they are not representative for the entire population of patients with DM2 in the Netherlands, for example, due to lower social economic status and education levels [43] or higher prevalence of obesity in this region [44]. However, a large and varied sample of patients with DM2 was involved in the studies, including the elderly. In general, due to the cross-sectional design, no conclusions could be drawn from the data regarding the cause and direction of associations.

## SYNTHESIS OF THE FINDINGS

The aim of this thesis was to explore reference points for healthcare providers, in particular the nursing profession to provide sustainable and high-quality, person-centered care for patients with DM2. This section synthesizes the findings of the studies of this thesis.

### **Patients' perspective**

In this thesis (Chapter 2) helping and hindering factors in active participation in health care were explored according to patients with DM2. Participation in medical consultations refers to actively contributing to the care process by, for example, asking questions, expressing concerns, and stating preferences [17]. It was found that patients' active participation in health care depends on their needs, beliefs and skills.

The median age of the participating patients with DM2 (Chapters 2, 5, and 6) was approximately 71 years, which is to be expected because DM2 predominantly affects the elderly [45]. The majority of the participants had low or middle education levels and the median (interquartile range) body mass index of the sample in Chapters 5 and 6 was 30 (27.0;34.2) kg/m<sup>2</sup>, which corresponds to the prevalence rates of overweight in the region from which the participating patients came [44]. As previously noticed, these patient characteristics are highly associated with patient activation for self-management [39] as measured with the Patient Activation Measure [46]. Indeed, in the

quantitative studies, a large proportion of the study population (149 participants; 42%) reported low activation levels for self-management (Chapter 6). Patients with low activation scores are predominantly passive recipients of care who believe that their healthcare providers are in charge of their health [46]. In contrast, patients with the highest activation scores engage in recommended health behaviors and take action to improve their health. Moreover, nearly one-third ( $n=107$ , 30.4%) of the participants was found to have limited health literacy (Chapter 5), which is in line with the prevalence in the general population in the Netherlands [47,48]. Limited health literacy is not always clear to healthcare providers due to overestimation of patients' health literacy [49] or patients' own unawareness or feelings of shame [50]. Patients with DM2 who receive education from healthcare providers have to apply this education in daily life, which requires basic health literacy skills to perform self-management tasks adequately [43].

Considering patients' characteristics (e.g., higher age, limited health literacy, low education levels, and low levels of patient activation for self-management), it is not surprising that patient-reported helping and hindering factors in active participation are predominantly related to their (lack of) skills. In particular, patients lacked skills in taking the lead, expressing thoughts, and preparing for consultations. Patients reported a trusting relationship with their healthcare provider to be a helping factor to more active participation in health care. A relationship of trust usually develops over time and can help passive or lower educated patients discuss their emotions and concerns. Moreover, a trusting relationship is also essential for patients suffering from emotional distress related to DM2.

In conclusion, patients' needs, beliefs and skills regarding patient participation should be taken into consideration by healthcare providers when providing person-centered care to patients with DM2. In the context of a trusting relationship, healthcare providers should address patients' skills and expectations concerning their own role in the management of their health. Healthcare providers can also influence these expectations by communicating about the expected role of both patients and healthcare provider from the perspective of person-centered care.

### **Perspective of healthcare providers, in particular the nursing profession**

This thesis revealed a gap between the current biomedical focus of nurses involved in diabetes care and the desired biopsychosocial approach in which patients' daily functioning takes a central position (Chapter 3). An explanation for the biomedical focus of nurses in diabetes care can be found in the organization of care. Over 20 years ago, medical tasks were protocolled and largely delegated from physicians to nurses [51,52]. Nowadays, nurses as well as specialized doctors' assistants provide care to patients with DM2 according to an integrally financed disease management program [53], and use tools that are primarily embedded in the biomedical model, including frequent monitoring of biomedical indicators [25].

Because the success of diabetes care in terms of health outcomes such as glyce-mic control, largely depends on patients' ability and willingness to self-manage their disease in daily life, the biomedical focus of healthcare providers in diabetes care

should be broadened to a biopsychosocial focus, that takes the daily functioning of patients as a starting point. Functioning pertains to how people function in everyday life, in the performance of activities, and in various areas of life. According to the WHO's conceptual health model [54], patients' functioning includes body functions (e.g., mental functions), activities (e.g., applying knowledge), and participation (e.g., participation in consultations). Patients' state of functioning can be influenced by personal characteristics, such as age, and education level. Moreover, their health condition can affect daily functioning when they experience impairments that interfere with what matters to them in life [55]. This holds particularly true for the occurrence of diabetes complications. Environmental factors can also influence patients' functioning, for instance, when healthcare professionals support self-management or prescribe medication. The concept of functioning is particularly relevant for nurses because nursing focuses on functioning and human responses to sickness, disability, or limitations instead of a particular pathological condition. Holistic nursing principles were found to be theoretically consistent with the ICF [56]. Moreover, functioning has been introduced as the third health indicator [57], complementing the established first indicator of morbidity and the second indicator of mortality.

In conclusion, this thesis recommends taking a person's state of functioning as a central point of reference for healthcare providers, in particular the nursing profession, in providing diabetes care, rather than the chronic condition from which the patient is suffering. This recommendation is in line with previous research expressing the wish of patients that "healthcare providers understand that it is not just all about HbA1c" [58]. In addition, a shift towards a tailored care approach in which patients' functioning directly determines the care process is, in terms of health services use, also beneficial for delivering sustainable care [57]. For example, while frequent monitoring may be useful for patients with poorly controlled DM2, a less stringent follow-up for patients with normal HbA1c levels may be equally effective and probably less costly [57], as was shown in this thesis. Also, this thesis found a substantial number of patients with limited health literacy and high use of health services, mediated by medication use. Given that patients with limited health literacy have difficulties understanding and complying with medical advice [33], they are highly dependent on comprehensible information provided by healthcare providers. Their position as prescribers enables them to detect limited health literacy and respond to it. However, when healthcare providers are not aware of a patient's limited health literacy, a mismatch can occur between the care provided and the patient's needs [51]. For example, it may lead to an increase in medication prescriptions due to (unintended) non-compliance and, consequently, more use of health services.

To apply a biopsychosocial care approach in which patients' functioning is leading, several tools are available. For example, the International Classification of Functioning, Disability, and Health (ICF) [59] can be used. The ICF provides a unified and standardized terminology for describing an individual's functioning and influencing contextual factors. Functioning can be registered and monitored in terms of ability ranging from able-bodied to disabled [60]. In addition, to support healthcare providers, the Dutch Diabetes Federation (NDF) developed a comprehensive consultation model in

which patients' functioning is taken as a reference point of care [61,62]. It consists of an extensive annual assessment that includes biomedical factors and patient factors, such as skills, knowledge, illness perceptions, and social context. Both patients and healthcare providers have approved this structured diabetes consultation model, which seems applicable in daily practice [61].

Furthermore, this thesis (Chapter 4) explored a previously noticed perception-reality gap with regard to shared decision-making and a decision aid [9] by studying views of nurses and doctors' assistants. Shared decision-making is a form of patient care that offers the potential for practicing evidence-based diabetes care while putting patients' at the center of their health by taking their values, preferences, needs, and circumstances into account [9,63]. It implies that healthcare providers and patients jointly participate in patient health decisions, including evidence-based treatments [64]. Its relevance to person-centered nursing care has been presented previously [65]. Most respondents, who were in this study predominantly specialized doctors' assistants, were positive about shared decision-making and the newly developed decision aid. The value of decision aids has been recognized before and is encouraged increasingly in practicing person-centered care, because it helps healthcare providers support patients in their pursuit of good health [66,67]. Moreover, despite an already high baseline level of diabetes care reflected by HbA1c, previous research found strong indications that shared decision-making further improves outcomes with regard to intensity of treatment and prioritizing treatment goals [68]. Some respondents expressed that they became aware of their paternalistic approach through using the decision aid. This means that they were not actively involving patients in decisions related to their health and treatment. In the purest form of this paternalistic approach, the patients passively consent to the professional's treatment choice [69]. This finding is relevant, for a national survey recently conducted in the Netherlands showed that healthcare providers overestimate the extent to which they apply shared decision-making [70]. This survey showed that 7 out of 10 healthcare providers pre-select treatment options, indicating that they do not take patients' preferences into account. In addition, it appears that at least a quarter of all patients finds it challenging to make decisions together with their healthcare provider [70]. Considering this knowledge, a nationwide campaign in the Netherlands to promote shared decision-making was launched recently (September 2021), lasting 16 months [71].

In conclusion, this thesis demonstrated a predominantly biomedical focus of nurses involved in diabetes care in which patients' health condition is leading, rather than the recommended broader biopsychosocial focus in which patients' functioning is leading. The finding indicates that there is room for improvement with regard to person-centeredness in care for patients with DM2. Nowadays, healthcare providers, in particular the nursing profession, are given biomedical protocols to provide diabetes care, instead they should be provided with instruments that take patients' actual and desired state of functioning as the central point of reference, including influencing patient factors. Furthermore, this thesis partly confirmed a previously noticed perception-reality gap with regard to shared decision-making, in particular from the perspective of specialized doctors' assistants involved in diabetes care. This thesis recommends

further implementation of shared decision-making, as it may encourage an evidence-based person-centered care approach, in particular by using decision aids [64].

## PRACTICAL IMPLICATIONS

The findings of this thesis have several implications for clinical practice, education, and future research.

### **Clinical practice**

- To optimize person-centeredness in diabetes care, a biopsychosocial care approach in clinical practice is recommended. A key implication for clinical practice is that healthcare organizations, including health insurers, should change the terms (e.g., reimbursement) of diabetes care in general practices in such a way as to encourage a biopsychosocial care approach, instead of the current biomedically oriented approach.
- Nursing is based on a biopsychosocial professional profile [72] and the nursing profession plays a key role in self-management support of patients with DM2. Applying a biopsychosocial approach has proven challenging for those who have not received training in biopsychosocial theory and its application [73] therefore, this thesis argues for a nurse-led POH-S function in primary care settings. An additional suggestion is to change the job title 'praktijkondersteuner'(POH-S) into 'praktijkverpleegkundige' (in English: practice nurse), which also helps in the international evaluation of person-centered (diabetes) care.
- Whereas until recently biomedical protocols guide diabetes care delivery, this thesis argued that healthcare providers and in particular the nursing profession, should be offered instruments in which patients' functioning serves as a reference point. From this reference point, facilitators and barriers to active patient participation and common patient characteristics (e.g., health literacy, knowledge, skills, diabetes distress, medication use) affecting health outcomes (e.g., glycemic control, health services use) use should be considered in care delivery.
- To support shared decision-making, which is a key element of person-centered care, supportive tools and evidence-based decision aids should be used to encourage a two-way conversation in diabetes health care delivery [62].

### **Education**

- To promote person-centeredness in diabetes care, it is recommended that healthcare providers, in particular the nursing profession, reflect on their vision and fundamental role in care delivery, including their rituals and routines [74]. Critical professional reflection should be a regular topic in nursing education and training programs.
- Healthcare providers and in particular the nursing profession, should be trained

in applying a biopsychosocial care approach, which implies taking patients' functioning as a point of reference. Different tools are available for this purpose, including the diabetes consultation model of the NDF [62]

- To support person-centered diabetes care, both patients and healthcare providers need to be empowered to apply shared decision-making. Therefore, healthcare providers and in particular the nursing profession should be trained in the principles of shared decision-making in their regular education and in specific training programs, and they should encourage patients to engage in communication [75].
- Healthcare providers may require training in communication skills to respond to patients' needs, values, wishes, and expectations, particularly regarding patients at risk for poor health outcomes. For example, to respond to the needs of patients with limited health literacy, healthcare providers can be trained in the teach-back method [76] to explore whether patients understand the information they are given.

### Future research

- The added value of practical tools and training programs for a biopsychosocial care approach have to be determined in clinical practice from the perspective of healthcare professionals, in particular the nursing profession and patients.
- The extent to which healthcare providers has the intention and ability to apply shared decision-making, taking protocol deviations into account, should be evaluated.
- This thesis found that 30% of the variance in glycemic control (HbA1c) could be explained by biomedical and psychosocial patient factors, including blood glucose-lowering medication, patient activation for self-management, and diabetes distress. Future research is needed to identify additional factors associated with glycemic control, including mutual influences.

## GENERAL CONCLUSION

The rising prevalence of DM2 has a profound impact on care resources. Therefore, this thesis aimed to explore reference points for healthcare providers, in particular the nursing profession, to provide sustainable and high-quality person-centered diabetes care. This thesis concluded that there is room for improvement with regard to person-centeredness in diabetes care, in particular by applying a biopsychosocial care approach and further implementation of shared decision-making. Considering that the success of DM2 treatment depends on patients' ability and willingness to self-manage their disease in daily life, this thesis recommends that a person's state of functioning should be the central point of reference for healthcare providers and in particular the nursing profession in providing person-centered care, rather than the chronic condition from which the patient is suffering. In addition, it is recom-



mended to take health-related, personal, and environmental factors that can influence a person's functioning into consideration in care for patients with DM2. The findings of this thesis have several implications for clinical practice, education, and future research. These implications offer potential ways to guide healthcare organizations and healthcare providers, particularly the nursing profession, to provide tailored care that meets the needs of an increasing number of patients with DM2.

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