A visit to the doctor: shared decision making supported by outcome information in chronic kidney disease

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1

General introduction and thesis outline

1.1 General introduction and thesis outline

Meet Mrs. Smiths, a 67 year old woman. She is about to go to her appointment with her nephrologist, which as she knows now is the name of 'a doctor specialized in kidneys'. For five years, she has been visiting her nephrologist every half year for a check-up. Although familiar with her doctor, she is always a bit nervous. Will my results still be good? Is my kidney function declining? The visit starts as usual. First, they have some small talk regarding the traffic followed by the infamous question: 'How are you doing?'. 'Good' she replies thinking 'Shouldn't you know? You have my lab results!'. But before the lab results are discussed the nephrologist addresses a longlist of topics including her diet, salt intake, exercise and blood pressure, measured 15 minutes before her visit by a nurse. She mostly nods while regretting the salty pizza she had the previous evening and hoping the doctor does not notice her nervousness. Then, finally, the lab results! The nephrologist reads from a screen that her kidney function is stable, 28 instead of 30 last time. That is two points less! she blurts out. Yes, but over time it barely makes a difference and it's more or less a straight line, replies the nephrologist calmly. Unconvinced she nods. The nephrologist continues: cholesterol is a bit high, but your electrolytes are fine. My what?! she thinks. But she nods again, not wanting to be a burden. The nephrologist suggests dosing up her blood pressure medication and prescribing a new pill. Sitatine or something. She is not entirely thrilled since she already can hardly keep track of all her different medications. She walks out the consultation room, SHOOT, now I forgot to mention my dizziness and low blood pressures when I measure at home.. oh well.. It probably doesn't matter that much anyway...

1.1.1 A patient with chronic kidney disease encounters many decisions

Mrs. Smits suffers from chronic kidney disease (CKD), a chronic condition characterized by progressively reduced kidney function. The incidence of CKD is rising due to factors such as population growth, aging, and increasing rates of diabetes, obesity and hypertension. CKD typically involves gradual decline in kidney function, which may eventually result in the need for kidney replacement therapy (KRT), including different types of dialysis or kidney transplantation [1,2] . In Dutch clinical practice, patients with advanced CKD are treated by a nephrologist. These patients have a remaining kidney function of an eGFR (glomerular filtration rate) below 30 mL/min/1.73m^2 or proteinuria (protein leakage into urine because of damaged kidneys) exceeding 300 mg/g [3]. The primary treatment goal in CKD management is to slow down kidney function decline and delay or prevent the need for KRT [3].

Patients with CKD regularly visit their nephrologist for check-ups or ‘healthcare visits’. During these visits information is exchanged between patient and clinician. This information exchange is important to inform patients about their condition, which enhances ‘patient activation’ - ‘having the knowledge, skills, and confidence for managing your own health’ [4]. Many treatment decisions are made during these visits. Most decisions relate to the overall treatment goal of CKD: slowing down kidney function decline. These decisions often involve lifestyle changes (e.g., limit salt intake, limit protein intake, lose weight, stop smoking) and long-term medications (e.g., hypertension medication, cardiovascular prevention including cholesterol-lowering medication), which require patient commitment [3,5]. However, these decisions may not always feel like active choices to patients, including Mrs. Smits. Still, it is the patient who must implement these decisions to reach effective treatment.

Involving patients in decision-making can improve patients’ willingness and ability to implement decisions made, thus enhancing CKD management. A widely accepted strategy in today’s healthcare to involve patients in medical decisions is Shared Decision Making (SDM). SDM entails a collaborative decision-making process between patient and clinician. A commonly used description of the SDM process outlines four steps (**Box 1**): 1) informing the patient that there is a decision to be made and that the opinion of the patient is important, 2) explaining the options including their pros and cons, 3) discussing patients’ preferences while the clinician supports the patient’s deliberation, 4) jointly discussing patient’s wish to make the decision, decide together or defer the decision and discuss follow-up [6].

Studies show that patient involvement by means of SDM improves treatment adherence and clinical outcomes [7–11]. Besides these benefits, it can be considered an ethical imperative to involve patients in decision making as it directly impacts patients’ daily life and helps ensure care is tailored to their needs [12,13]. In the Netherlands, SDM is an important theme included in the Dutch National Health Agreement (*Integraal Zorg Akkoord, IZA)* which includes the aim to provide care that best fits the patients’ circumstances [14]. Studies have also reported the desire for patients to engage in SDM in their medical care [15,16].

In Nephrology, SDM is already recognized as crucial for the KRT decision; the decision between available kidney replacement therapies such as hemodialysis, peritoneal dialysis, kidney transplantation or conservative therapy [17,18]. The KRT decision is a major preference-sensitive decision with multiple options which all significantly affect patients' lives, yet in different ways. Recently, a decision tool was developed to facilitate SDM in this context [19].

However, the role of SDM in more common, less complex CKD decisions is not well understood. Furthermore, it is not known how these common CKD decisions are currently made and to what extent patients are involved in these decisions. Additionally, a research gap exists in determining when SDM is considered appropriate for different types of decisions in all medical fields. This leads to our first objective:

Objective 1: Determine the extent to which SDM is appropriate in routine medical decisions and assess current practice in decision making in CKD.

1.1.2 The information exchange during CKD healthcare visits - discussing outcome information.

Outcome information can support treatment decision-making during healthcare visits. "Outcome information" (or 'outcomes') is an umbrella term for information that describes the results of provided care. The concept is grounded in the economic and strategic framework of value-based healthcare (VBHC), introduced globally in 2006. VBHC is a strategic framework that can be used to structure and improve healthcare in such a way that the value of care is increased. Value is defined as the outcomes of care relative to the costs [20]. Thus, to determine value in healthcare, information about outcomes, particularly outcomes that matter to patients, is essential. In the context of VBHC, outcomes are measured and utilized at two distinct levels [21]. First, at the level of patient-clinician interactions, outcomes help for disease monitoring and to facilitate SDM [22,23]. Second, at an aggregated level, outcomes are used to drive quality improvement efforts [24–26].

The Santeon collaborative provides an example of both individual and aggregated use of outcomes in healthcare. This collaborative is also the context of this thesis. Santeon is a collaboration of seven Dutch teaching hospitals, including: Canisius Wilhelmina Hospital in Nijmegen, Catharina Hospital in Eindhoven, Maasstad Hospital in Rotterdam, Martini Hospital in Groningen, Medisch Spectrum Twente in Enschede, Onze Lieve Vrouwen Gasthuis in Amsterdam, and Sint Antonius Hospital in Utrecht and Nieuwegein. These hospitals collectively measure patient outcomes per medical condition and compare results to improve care [27]. As part of the '*Outcome-oriented Care*'- program ("Programma Uitkomstgerichte zorg)", a research and implementation program funded by the Dutch Ministry of Health, Welfare and Sports, Santeon hospitals have worked together to incorporate outcome information into daily clinical practice, supporting SDM, in three patient groups: patients with breast cancer, stroke or chronic kidney disease [28,29] .

In this thesis we focus on the use of outcome information at the patient-clinician level, specifically on how outcome information can improve decision making and patient involvement in disease management. We distinguish four different types of outcome information that can be used in patient-clinician interactions.

First, as illustrated by the case of Mrs. Smits, outcome information can consist of results from clinical tests or measurements administered to the patient of which the clinician reports the results (e.g., blood pressure measurements or lab results). Second, patients can provide outcome information themselves. This information, for example regarding physical symptoms, functioning or overall well-being, can be measured using standardized questionnaires known as Patient Reported Outcome Measures (PROMs). PROMs can be disease-specific, e.g., the Dialysis Symptom Index [30] assessing physical and mental symptoms, or generic (PROMIS-10), assessing overall mental and physical health [31]. Third, outcome information can include aggregated data such as risks based on predictive models (e.g., predicting survival rate per treatment or disease progression), or "patients like me" models, which compare an individual patient to a broader population [32]. **Figure 1** shows how different types of outcome information can support SDM [29].

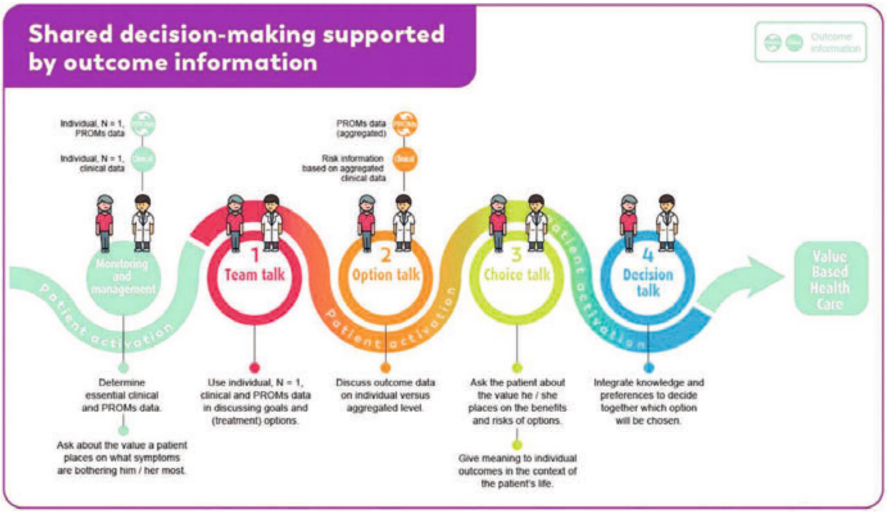

Figure 1. How outcome information can be used to engage in SDM. PROM=patient reported outcome measures.

While the benefits of PROMs in healthcare visits are increasingly described in studies [33–36], research remains limited in exploring the full range of types of outcome information and their preferred use during healthcare visits. Given the rapid advancements in collecting and processing outcome data, it is crucial to better understand how discussing different types of outcomes affects treatment decision making. This will help prioritize which outcomes should be discussed during healthcare visits. Exploring the perspectives of both patients and clinicians on different existing and emerging types of outcome information is a valuable contribution to the literature, which typically focuses on only one outcome type or perspective [33–36]. This leads to our second objective:

Objective 2: Explore patients' and clinicians' preferences in discussing different types of outcome information during healthcare visits.

1.1.3 Stimulating patient involvement through discussing outcomes.

Outcome information plays a crucial role in information exchange during healthcare visits, contributing to both informing patients and SDM. In both ways (informing and SDM) patient activation is stimulated as it equips patients with the information needed to manage their health and patients are more involved in their own care when SDM is implemented [37,38]. Research has demonstrated that higher levels of patient activation are associated with improved clinical outcomes because of better self-management [39–41], and are instrumental in engaging in SDM. Conversely, SDM itself can foster greater patient activation [38,42]. However, in the early stages of CKD, when patients have a residual function between 45-15 mL/min/1.73m^2, studies reveal that patient activation levels are low [43,44]. These patients often lack sufficient awareness of their condition [45], struggle to understand treatment goals [45,46], and exhibit poor medication adherence [47]. Qualitative research highlighted that patients frequently report unmet information needs, indicating gaps in the communication process [48].

To improve patient activation levels and support SDM, it is crucial to enhance the information exchange during healthcare visits. Currently, the use of outcome information is limited, often confined to clinical outcomes such as laboratory results or basic measurements such as blood pressure or weight. PROMs or other types of outcomes, such as prognostic models or "patients like me" models are rarely, if ever, utilized [28,49]. Furthermore, as illustrated by Mrs Smith's healthcare visit, much of the information is conveyed verbally, despite evidence that new verbal information is difficult to retain [50]. Data visualization has been shown to improve information comprehension [51–53] yet is only minimally employed, often limited to basic graphs displayed in electronic health records.

To address this gap, our goal is to improve the exchange of outcome information during healthcare visits to foster patient activation and facilitate SDM. Specifically, our third objective is to develop an innovative tool for presenting outcome information during healthcare visits: a CKD dashboard. We aim to develop this dashboard through a co-creation process with both patients and clinicians and evaluate the impact of usage of the dashboard on patient activation and SDM.

Objective 3: Develop and evaluate a CKD dashboard, a novel way to visualize outcome information during healthcare visits, and assess its impact on SDM and patient activation.

1.2 Aims and thesis outline

This thesis aims to address the three objectives introduced above:

1) Determine the extent to which SDM is appropriate in routine medical decisions and assess current practice in decision making in CKD.
2) Explore patients' and clinicians' preferences in discussing different types of outcome information during healthcare visits.
3) Develop and evaluate a CKD dashboard, a novel way to visualize outcome information during healthcare visits and assess its impact on SDM and patient activation.

In three different parts these objectives will be addressed.

Part one: Shared Decision Making in Chronic Kidney Disease – broadening the scope

The focus of the first part of this thesis is on SDM: when it should be applied, and how it is currently applied. Before we dive into the role of SDM in CKD, we will explore in **chapter 2** whether SDM literature offers guidance for which decisions in any medical field SDM should be applied. Is it mainly for decisions characterized as being major and preference-sensitive or is it relevant to other kinds of decisions as well?

In **chapter 3** we zoom in on CKD healthcare visits: what decisions frequently occur in that setting and how do patients experience these decisions. Who made the decision according to them? We also study what patients' preferences are in decision making: who should make those decisions? In addition to the patient perspective, we analyze real-life CKD healthcare visits: who makes the decisions according to independent observers?

Part two: Discussing outcome information in healthcare visits: current practice and preferences

In the second part we aim to get a better general understanding about patients' and clinicians' perspectives on different types of outcome information and how to discuss them during healthcare visits. We broaden our scope in **chapter 4** to breast cancer in addition to CKD. In this chapter we share the findings of simultaneous interviews with patients and their treating clinician (dyadic interviews) to study their (shared or opposing) perspectives regarding different types of outcomes: clinical outcomes, patient-reported outcomes, comparisons with aggregated data, and prediction models. In **chapter 5** we zoom in on one type of outcome information specifically: risk prediction models. We assess the current use and preferences of both patients and clinicians regarding the use of risk prediction models in CKD practice and provide clinical recommendations for their use.

Part three: A novel way to discuss outcomes during healthcare visits: the CKD dashboard

In part three we describe the process of co-development (**chapter 6**) and evaluation (**chapter 7**) of an innovation attempting to optimize the use of outcome information during CKD healthcare visits. The innovation is the CKD dashboard, a digital interactive dashboard visualizing patients' outcomes. The dashboard can be opened on a screen and discussed during healthcare visits. It consists of clinical outcomes (e.g., blood pressure or laboratory results) visualized per treatment goal, and patient-reported outcomes (symptoms and generic outcomes, including overall mental and physical health). Data visualization strategies are applied to maximize ease of comprehension of the information included in the dashboard. In **chapter 7** we provide results of a multicenter study in which we evaluate the impact of the dashboard on patient activation and SDM.

Finally, in **chapter 8,** we provide a summary of the main results of our different studies. Additionally, the results will be discussed including implications of the findings for practice and future perspectives.

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