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Implementation and use of patient-reported outcome measures in routine nephrology care

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General introduction and thesis outline

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Healthcare is shifting towards a more person-centred approach.[1-3] More attention is paid to the patients' perspective, aiming at a personalised and holistic treatment that fits the patient's preferences and needs. Insight into patient-reported outcomes (PROs), such as health-related quality of life (HRQOL) and symptom burden, is therefore becoming increasingly important in healthcare.[4, 5] Patient-reported outcome measures (PROMs) systematically assess such outcomes and can facilitate the process of adapting to what is important to the patient.[4-7] But, how to integrate PROMs into a routine care setting and how to use PROMs to achieve this personalised and holistic treatment? This dissertation provides insight into and practical knowledge of the implementation and use of PROMs in routine nephrology care.

Chronic kidney disease

Chronic kidney disease (CKD) is a progressive condition characterized by a decreased kidney function based on a glomerular filtration rate (GFR) of less than 60 mL/min per 1.73 m², or markers of kidney damage, such as albuminuria, present for at least 3 months.[8, 9] Globally, the prevalence of CKD is estimated around 10%[10, 11], and is expected to further increase due to the aging population and the increasing number of people with diabetes and hypertension.[12] Worldwide, about 0.5% of the people has advanced CKD (GFR < 30 mL/min per 1.73 m²) and 0.1% has kidney failure (GFR < 15 mL/min per 1.73 m²).[8, 11] Patients with kidney failure have the choice to receive kidney replacement therapy (KRT) to prolong life, or comprehensive conservative care, which aims at maintaining HRQOL, optimal symptom management and slowing down disease progression.[13, 14] There are two general types of KRT, namely kidney transplantation or dialysis treatment (e.g. peritoneal dialysis or haemodialysis).[8, 14] Peritoneal dialysis treatments are every day or night and are performed from home by the patient (and any caregivers) or with help of a machine.[15] Haemodialysis treatments are usually 3 times a week for approximately 3-5 hours per dialysis session, performed at the dialysis centre or at home.[15] Patients need on average 5-7 hours to fully recover after each haemodialysis session[16, 17], underlining the invasiveness and high impact on people's life.[18] The choice for which treatment fits the patient best is generally based on availability of treatment (e.g. kidney donor and dialysis options at home or in a centre nearby), clinical characteristics (e.g. the patient's health status, medical risks and potential health benefits), and the patient's characteristics and his values, preferences and needs (e.g. what someone finds important in life).[8, 13, 18, 19]

Outcomes in patients with chronic kidney disease

CKD is a growing public health problem causing a high disease burden and healthcare costs.[12, 18, 20, 21] Advanced CKD is associated with a high cardiovascular morbidity, increased mortality and hospitalizations, and has a major impact on people's life.[9, 18, 22] Patients with advanced CKD experience numerous physical and emotional symptoms, such as fatigue, itching, muscle cramps, sleep problems, sexual problems and depressive symptoms, which have a major impact on their HRQOL.[23-26]

Nephrology care traditionally focusses on clinical measures, such as mortality, laboratory values and blood pressure. Although PROs, like HRQOL and symptom burden have been regarded as highly important by patients and healthcare professionals[27-31], these outcomes often remain unknown, undiscussed and undertreated in regular practice.[25, 32] This is partly because patients do not share everything by themselves, for instance because some topics may be difficult to talk about, or because patients assume that their symptoms cannot be treated, or are not related to their CKD or treatment for CKD.[33-35] Additionally, it may be challenging for healthcare professionals to inquire about the wide range of symptoms and needs that patients experience, for example due to time or intervention limitations.[32, 36]

Last decade, healthcare is shifting towards a more person-centred approach, including nephrology care.[1-3, 37] In addition to the traditional clinical measures, there is a stronger focus on the patient's perspective and outcomes that matter to patients.[5, 37, 38] Systematic assessment of PROs can solve the under-recognition of outcomes like HRQOL and symptom burden, and support this personalized and holistic treatment approach.[25, 39] PROs consider experienced health and should thus be assessed from the patient's perspective. PROs can be systematically assessed using PROMs.[40-42]

Patient-reported outcome measures

PROMs are questionnaires that assess aspects of patients' perceived health, such as HRQOL and symptom burden. PROMs are reported by the patients themselves; support may be offered when filling in PROMs, as long as responses reflect the patient's perspective.[40-42]

Many different PROMs exist, using various measurement methods and characteristics. For example, PROMs are often classified as either generic or specific for a certain disease, condition or treatment.[40, 41] Generic PROMs include widely relevant health aspects and are particularly suitable for heterogeneous populations (e.g. multimorbid populations like CKD), and enable comparisons across populations and treatments.[40, 41] A specific PROM is tailored to a certain disease, condi-

tion or treatment, and is particularly suitable for comparisons within a population, as they are usually better able to detect smaller or specific changes.[40, 41] Furthermore, PROMs can be fixed (i.e. nonadaptive) or adaptive. Traditional PROMs are fixed, meaning that it contains the same questions and order for any patient at any timepoint. Adaptive PROMs are relatively novel in healthcare and make use of computerized adaptive tests (CATs), in which the next question is selected based on the answer to previous questions, adapting to the patient's ability.[43] An example of an adaptive PROM is the Patient-Reported Outcomes Measurement Information System (PROMIS).[43] Moreover, PROMs can vary for instance in the underlying measurement method, number of questions, recall period, scoring scale and method, and reference standard.[44] The features of the PROM influence the interpretation of the PROM-scores.[42] In contrast to well-known clinical measures such as blood pressure, healthcare professionals, patients and researchers are often not yet familiar with the interpretation of PROM-scores. Understanding of the PROMs and the interpretation of its PROM-scores are needed for optimal use in clinical practice.

Many different PROMs are available[41, 44-47] and which PROM is suitable for clinical practice does not only depend on the characteristics (e.g. generic or specific, measurement method and scoring) and psychometric quality (e.g. validity and reliability) of the available PROMs, but also on the population and clinical setting.[42] For example: the purpose of measuring the PRO (e.g. use during consultations), the setting (e.g. opportunity to integrate into workflow) and the homogeneity of the population (e.g. variation in experienced health or digital skills). Hence, it is important to deliberately select PROMs, so that they fit routine practice. For nephrology care, the 12-item Short-Form Health Survey (SF-12) to assess generic HRQOL was recommended by an European expert consensus group.[48] Moreover, they underlined the importance of measuring symptom burden in addition to HRQOL, but no consensus was reached on the preferred PROM to assess symptom burden.[48]

The potential of using PROMs in healthcare

PROMs have the potential to contribute to a more person-centred approach.[3, 4, 49-51] PROMs can provide insight into and a more complete picture of how the patient is really doing by incorporating the patient's perspective, complementary to traditional clinical measures. Hence, using PROMs may enhance shared decision making and facilitate personalized treatment.[6, 7, 50, 51] Moreover, literature suggests that the use of PROMs may even result in better health outcomes, for example better symptom management, less hospitalizations and better HRQOL.[5, 52] However,

the majority of existing literature is theoretical and little research has been done in nephrology care.[6, 50, 53] Therefore, research in real-world nephrology care is needed to examine these potential benefits of using PROMs.

Theoretically, the use of PROMs can contribute to clinical practice at multiple levels: at individual patient-level and at aggregated population-level. For example, individual PROM-results can support shared decision making by facilitating patient-professional communication and discussion about patients' experiences and needs.[6, 7, 50, 51] Aggregated PROM-results can inform patients (and healthcare professionals) about prognosis, treatment and factors influencing PROs.[6] In addition, aggregated PROM-results can be used to evaluate healthcare quality.[6, 54, 55] Ideally, PROMs are integrated into routine care in such a way that it provides valuable information at both the individual patient-level and the aggregated population-level.[55, 56] These different purposes must be taken into account and require a structured approach in the implementation of PROMs into routine care.

Implementation of PROMs into routine nephrology care

In nephrology, the importance of PROs is widely recognized and first steps are taken to identify outcomes that matter to patients by the Standardised Outcomes in Nephrology (SONG) initiative[57] and by the International Consortium for Health Outcomes Measurement (ICHOM).[58] However, PROMs have not been widely implemented yet into routine nephrology care.[48, 59] A few examples exist and show that implementation can be challenging, for instance reaching adequate response rates, incorporation into the workflow, and struggles due to lack of knowledge on how to interpret, discuss and intervene on PROM-results.[60-63] Furthermore, literature suggests that the incorporation of PROMs requires engagement from all people involved: patients, healthcare professionals, researchers and policy makers.[61, 62, 64] Patients receiving dialysis treatment have frequent healthcare encounters and dialysis care has a strong infrastructure, which provides a good basis for reaching all people involved and implementation into the existing workflow.[65]

In the Netherlands, we establish a nationwide project to develop and implement PROMs into nephrology care (PROMs-NNL), in close collaboration with all relevant stakeholders: patients (Dutch Kidney Patients Association; NVN), healthcare professionals (Dutch Federation for Nephrology; NFN), researchers (Leiden University Medical Centre; LUMC) and the healthcare quality institute of nephrology care (Nefrovisie Foundation). PROMs will be part of the data collection in RENINE, the Dutch renal registry (www.renine.nl), to ensure nationwide support and minimal burden for healthcare centres.[48, 66] PROMs will be firstly introduced within routine dialysis care, given the relatively easy to reach population and suitable clinical set-

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ting.[65] The PROMs-NNL project comprises the following four steps to implement PROMs into routine nephrology care in the Netherlands (Figure 1):

Step 1: determine information about which PROs is important and for what purpose.
Step 2: select the best suitable PROMs to measure these PROs, taking into account the aim and setting.
Step 3: pilot test the use of PROMs in clinical practice; are these PROMs suitable and what are feasible methods to collect and provide feedback on PROM-results?
Step 4: make adjustments based on the lessons learned and implement PROMs into routine care at national level. Implementation involves using, evaluating and adjusting iteratively to achieve optimal use of PROMs.

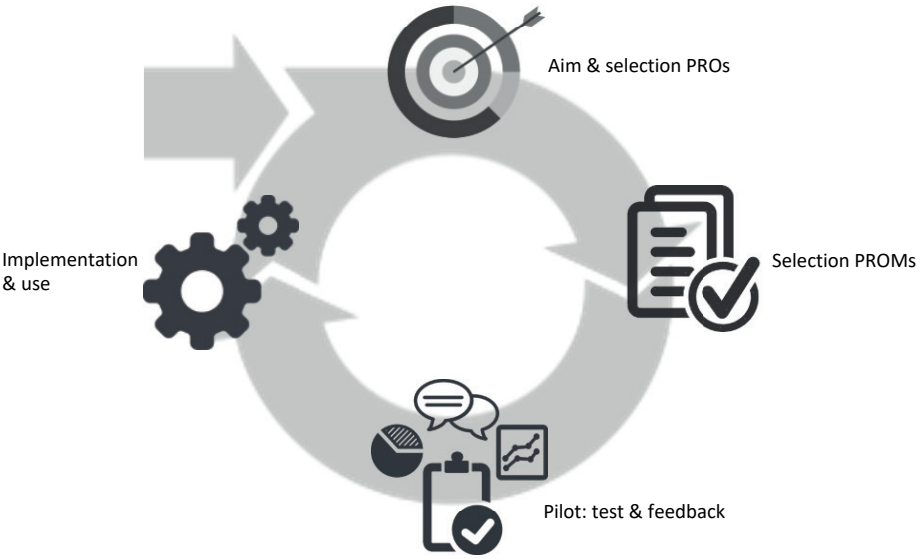

Figure 1. Steps for implementation of PROMs into routine care (PROMs-NNL study).

This dissertation comprises the scientific research performed in each step and aims to provide insight into and practical knowledge of the implementation and use of PROMs in routine nephrology care.

Outline of this thesis

The existing literature shows that HRQOL and symptom burden are highly prioritized by patients and healthcare professionals.[24, 27-29] Information about these PROs can contribute to a personalized treatment both at individual patient-level during consultations and at aggregated level to better inform patients and to evaluate healthcare quality.[6, 50, 54, 55] Therefore, these predetermined aims and PROs are used in the second step.

Chapter 2 describes the selection of the best suitable existing PROM to assess disease-specific symptom burden for routine assessment in nephrology care. We use a four-phase mixed methods approach, including a systematic literature search to identify existing PROMs and symptom clusters, assessment of PROMs based on predefined criteria regarding content validity, and selection based on feedback of two panels with patients and experts. In **Chapter 3**, we examine and compare psychometric properties of two recommended and commonly used generic PROMs to assess HRQOL. This study investigates the content, construct validity and test-retest reliability of seven PROMIS CATs in comparison with the SF-12 in patients with advanced CKD.

Chapter 4 describes the experiences and results of the first introduction of PROMs into Dutch routine nephrology care; the third step. We conduct a pilot study in 16 dialysis centres across the Netherlands, covering a quarter of all Dutch patients receiving dialysis treatment. We use quantitative and qualitative research methods to explore the use and collection of PROMs (e.g. PROM-scores and response rates), and the provision of feedback on PROM-results (e.g. patients' views on individual feedback) as part of routine dialysis care. Building on the findings, the PROMs infrastructure can be optimized for implementation and use of PROMs in routine dialysis care throughout the Netherlands (the fourth step).

At population level, PROM-results can be used to evaluate healthcare quality and to inform patients and professionals about the effects and course of disease or treatment. In **Chapter 5**, we explain how funnel plots can be used to compare healthcare providers on PROs to evaluate healthcare quality. This review provides insight into the use and interpretation of funnel plots by explaining the basic principles, pitfalls and considerations when applied to PROs, using examples of the first year routinely collected PROMs-data from Dutch dialysis care (i.e. RENINE/PROMs registry data). **Chapter 6** shows an example of aggregated PROM-results that can be used to inform patients and healthcare professionals. In this chapter, we use the RENINE/PROMs registry data of 2978 patients to investigate the impact of itching on HRQOL in patients receiving dialysis treatment. The effects of itching on HRQOL and interactions with sleep problems and psychological symp-

toms are examined both cross-sectionally and longitudinally over a 2-year period. For optimal use of PROMs in individual patients, knowledge on how to interpret and discuss PROM-results is needed. In **Chapter 7**, we explain the different types and characteristics of PROMs and provide guidance on how to interpret individual PROM-scores and changes in PROM-scores over time. Concepts such as minimal detectable change, minimal important change and response shift are explained and illustrated with examples from nephrology care. In **Chapter 8**, we investigate how to optimally discuss PROM-results as part of routine care. Individual semi-structured interviews are performed to gain in-depth understanding of patients' and healthcare professionals' experiences with and perspectives on discussing PROM-results in routine dialysis care.

Finally, in **Chapter 9** we summarize and discuss our results, and provide suggestions for future research and clinical implications regarding the implementation and use of PROMs in routine care.

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