“When everything goes to hell, the people who stand by you without flinching — they are your family.”

Jim Butcher

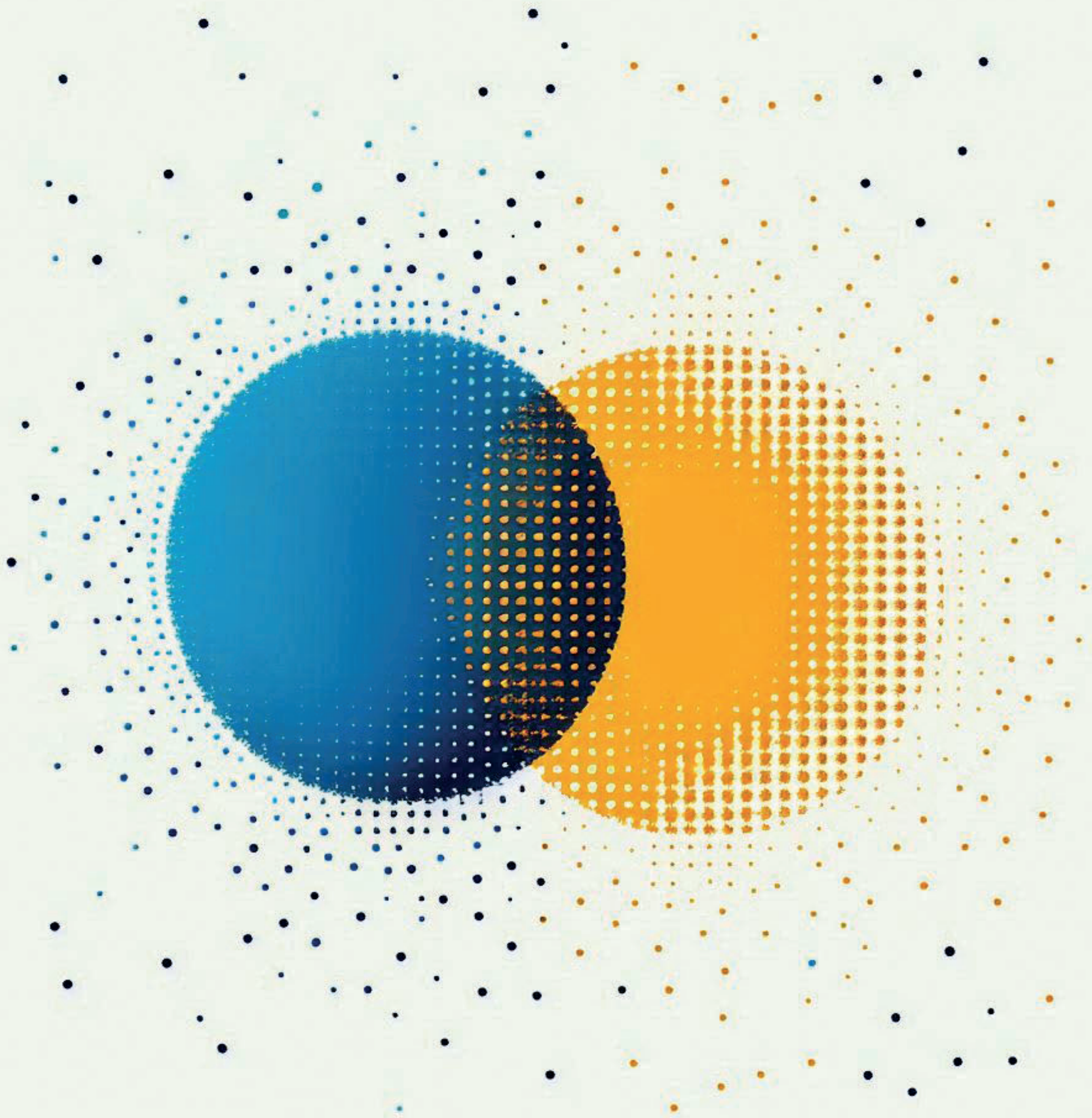
This book highlights the opportunities to improve healthcare services that lie ahead through engaging patients. Listening to patients, their stories, and their experiences can not only be useful in the consulting room, but also at the organizational and the policy levels. To offer appropriate and personalized care that is affordable, patient engagement is essential. Giving patients a voice in how health services are organized may lead to a higher level of well-being of patients in their daily lives. The author has interviewed dozens of patients and healthcare providers to write this book. The author uses the theory of service-dominant (S-D) logic that states that patients are the true creators of real value in healthcare. Here, medical support enables patients to resume their lives as normally as possible, with their family, at work, and enjoying social activities. The setting for the described studies is focused on renal care, but the findings are very practical and can readily be transferred to other patient groups.

HOW TO CREATE VALUE IN HEALTHCARE?

Willem Sierk Sipma

HOW TO CREATE VALUE IN HEALTHCARE?

A service-dominant logic view on patient engagement



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How to Create Value in Healthcare?

A service-dominant logic view on patient engagement

Hoe creëer je waarde in de zorg?

Een service-dominant logic benadering van patiëntbetrokkenheid

Proefschrift

ter verkrijging van de graad van doctor aan de
Erasmus Universiteit Rotterdam
op gezag van de
rector magnificus

Prof.dr.ir. A.J. Schuit

en volgens besluit van het College voor Promoties.
De openbare verdediging zal plaatsvinden op

Woensdag 5 februari 2025 om 13.00 uur

door

Willem Sierk Sipma

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Erasmus University Rotterdam

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Copromotor:	Dr. M.F.C. de Jong

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How to approach this thesis

First, I am pleased that the title of this thesis

“How to create value in healthcare*? A service-dominant logic view on patient engagement*”

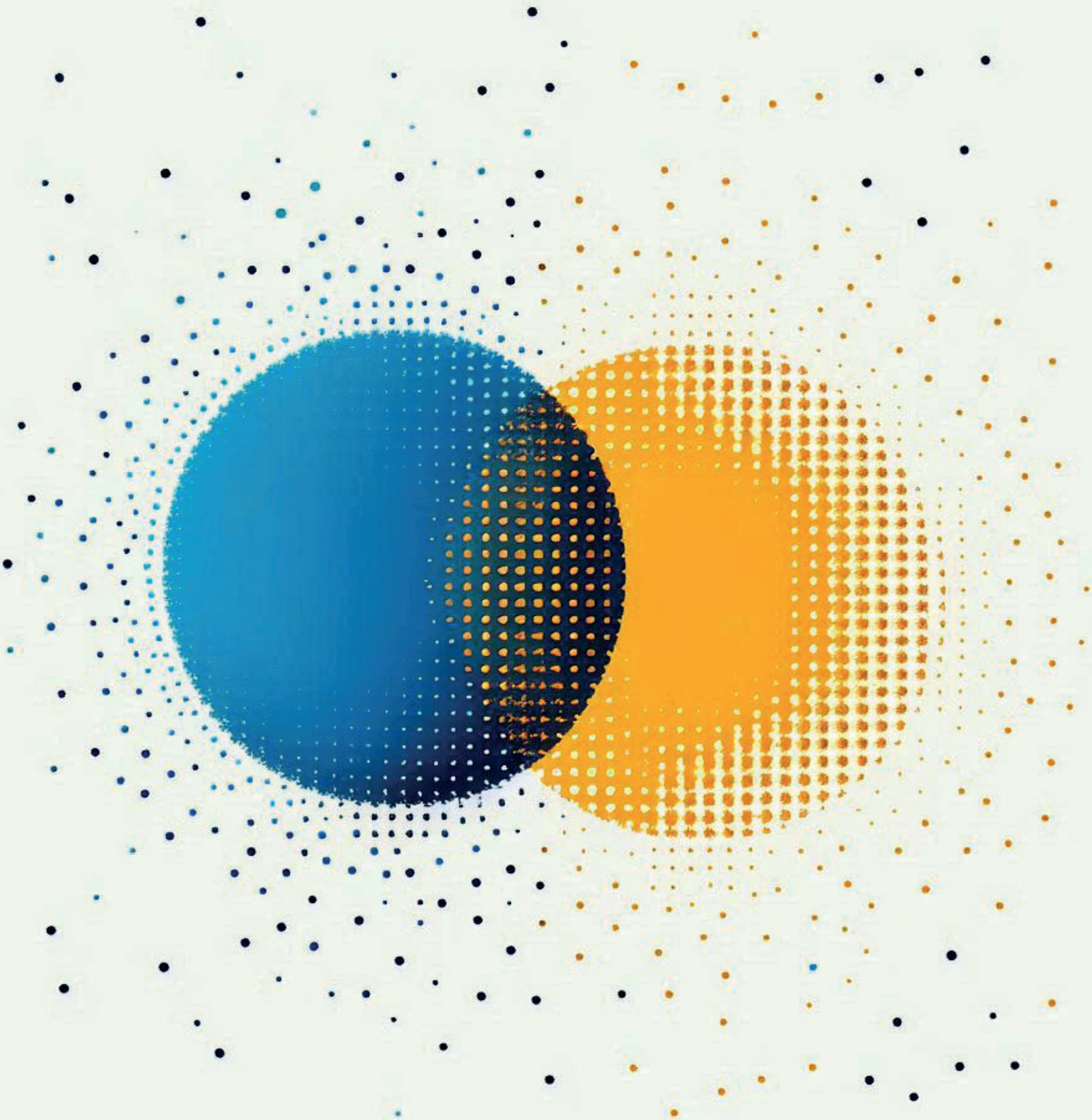
has grabbed your attention.

How you proceed is of course entirely up to you. However, given its length, I will outline the structure to provide some information that might help you decide which approach best suits your interests.

a. First, each chapter can be read on a stand-alone basis. Furthermore, there is no necessity to read them in any particular order.
b. Chapter 1 provides an overview of the entire thesis and the individual chapters and also contains a short introduction to the author and my motivation in conducting this research and writing this thesis.
c. Chapters 2-5 are research papers, published in various journals.
d. Chapters 6 and 7 are invited viewpoint papers representing the authors’ personal views on topics selected by the editors of the respective journals.
e. Chapter 8 ties together the main findings of all the papers from a service-dominant logic perspective and discusses some considerations of value-based care.

I hope you enjoy sharing my journey.

CHAPTER 1



General introduction

A personal introduction

Life doesn't offer us a clear path and it isn't as predictable as many like to assume. Even when you are well educated, have a job with a good salary, are happily married and blessed with three children you can be confronted with misfortune at any time. I know this because I have experienced it. At the age of 48 I found myself suddenly in a situation where doctors took control of my life. From one day to the next I was hospitalized for weeks with an unclear diagnosis that later turned out to be kidney failure. Ten years later, at the age of 58 and having experienced many ups and downs in health, work, and my mental state, I was back on my feet again and I felt the need to research healthcare management, particularly patient engagement and the value of care in terms of patient outcomes.

This thesis reflects the fact that a patient is not just a patient. Every patient is a person with thoughts, hopes, talents, good and bad habits, interests and, in short, a life. A patient is a person with limitations but also with strengths. In my case, my educational background and my working experience turned out to be valuable assets when it came to studying healthcare management and patient engagement. In the past, I had been working in marketing and management consultancy, with ten years of experience in a healthcare insurance company. For this reason, customer centricity and customer service, its management challenges and its impossibilities, have always captured my attention. Over the years these experiences have accumulated into a melting pot of knowledge and led me to believe that there is more to customer service and customer centricity than 'just delivering the right service at the right time' and I wondered: what value do I get from all these magnificent healthcare providers? The study of customer value can have many lenses. Maybe especially in healthcare, as I encountered in my years of personally being a customer, alias 'patient', of healthcare services.

Value in healthcare and customer centricity

The concept of value in healthcare has become increasingly important since the introduction of the concept of value-based healthcare (VBHC) by Porter and Teisberg in 2006 [1]. Although VBHC explicitly refers to value as an outcome of healthcare in relation to costs, outcome-driven healthcare with less attention given to costs has gained popularity in the shift from volume to value in healthcare [2–4]. However, there is a feeling that the efforts of healthcare providers and scholars to create value for the patient overlook the potential active role of patients themselves in creating value. In addition there is support for the idea that patients and patients' experiences can be of value in (re)designing healthcare pathways, procedures, products, and health services [5,6]. When it is applied in practice, this approach to patients (co-)creating value far exceeds the well-known concept of customer centricity.

The concept of customer centricity implies that an organization has to adjust its logistics and procedures such that customers experience maximum service. This suggests that healthcare should be well organized around the patient, leaving the patient as a passive recipient of care rather than an active participant in the care process [7]. However, serving customers/patients requires much more than a focus on the customer/patient's needs alone. I experienced this in my time as a patient. A hospital is a complex organization that is characterized by high professionalism, hierarchic structures, not easy to adjust logistical processes, and a variety of internal and external stakeholders. This influences the possibility and feasibility of patient centeredness. While most hospitals embrace the idea of patient centeredness as a sympathetic ambition, it is an ambition that cannot withstand a reality check. This thesis is about value and value creation in healthcare, with a focus on opportunities for patient engagement to improve care.

Service-dominant logic and value-in-use

Taking into account my professional and personal life experiences, this thesis adopts the perspective of a service-dominant logic (S-D logic) in healthcare. Within the S-D logic, value-in-use and value co-creation are key elements. S-D logic has a history that goes back to Philip Kotler in 1977 who stated that “The key thing about a product is the services it renders” [8, p. 5]. Much earlier, the Greek philosopher Aristotle (384 B.C. – 324 B.C.) had already discussed that value is created by the use of a product [9]. For example, food has to be grown but also eaten.

In the field of marketing, value creation was traditionally a task to be done by the company. In recent decades, the service-dominant (S-D) logic has added the value-in-use concept, which means that a product has itself no value apart from the value customers gain from using the product [10,11]. Hence, customers determine the value when using the product or service, and service providers should therefore consider the users' environment when their product is in use [12]. Opposing the S-D logic, the goods-dominant (G-D) logic views the physical product as the carrier of value and, at the point of exchange, value is transferred from the seller to the buyer. In terms of supply chain management, the customer is at the end of the supply chain. Following the S-D logic, the consuming phase is essential to value creation and takes place after the moment of exchange and out of sight of the provider.

The value-in-use perspective (also referred to as value-in-context) on value creation has been enriched with the idea of balanced centricity. Approaches that use value-in-context and balanced centricity view customer centricity as an unrealistic concept that cannot be fully realized in practice because there is always a tradeoff among diverse actors [13]. S-D logic states that a product has to be used in order to create value for the customer and, according to value-in-context, this value can only be created in a network of suppliers [12,14,15]. Imagine a car seller and a car buyer. The car produces value for the customer when the new owner uses the car, and likely over many years: value does not only occur at the moment of exchange from seller to buyer. Further, in order to be used, petrol or electricity must be available at many places along the road where the buyer is traveling. Furthermore, roads must be available and maintained for the car owner to drive.

In the service-dominant logic, the co-creation of value is essential and, in healthcare, requires the integration of knowledge of different care providers and patients [16]. S-D logic can be helpful in healthcare and this opens up a new empirical field for S-D logic [17–19]. Implementing the S-D logic in healthcare may result in a more integrated service [17]. To quote an oncologist "Oncology practice provides treatment, but that is a fraction of the patients' needs" [17, p. 29]. For organizations to implement S-D logic requires the integrated management of organizational functions, and leadership to align the values of employees and external partners such as suppliers and customers [20]. S-D logic refers to this as the service ecosystem of organizational institutions [21,22]. Applying S-D logic requires insights into organizational settings including collaboration, leadership, change management, organizational culture, and context [23]. Realizing value from the patient's logic needs a thorough understanding of the appropriate value proposition. Although the S-D logic is fairly new, arguably still in its infancy, it is potentially relevant to healthcare. As such, further exploration of the concept in healthcare practice can contribute to theory development [21].

According to the S-D logic, healthcare providers should recognize that the health services they offer are part of a much wider network of providers that supports patients in creating value-in-use and to enjoy their improved health status. This may be a complex task but, as Gummesson states, "Reality is complex whether we like it or not" [14, p. 16].

Following this reasoning, hospitals and associated care providers could ask themselves the question 'what business are we in?' [24]. Are we saving lives, or are we helping patients to have a life? 'What business are we in?' is a strategic question that maybe should be asked in the boardroom of hospitals. The answer to this question might lead to a more medical-focused approach in the hospital or to a broader service approach with the focus on services that help patients get their lives back on track, such as a faster return to work.

Service innovations are often developed in pilot studies. In practice, one sees a lot of pilots, often organized in a collaboration with different healthcare providers, for example to relocate hospital care to primary care or to home care. One can observe that pilots are seldomly part of the bigger picture as to the service portfolio that a hospital is offering, a discussion that should be initiated at the board level. As a result, pilots tend to be isolated islands that are rarely followed by their integration into regular care, and this leads to what Guus Schrijvers, professor emeritus of public health, calls 'pilotitis' [25, p. 177]. Nevertheless, innovative projects with multiple partners can be important structures through which to learn new ways of working with other parties in a value network, to share and accumulate knowledge in practice, to find out which constellations work best, and to enhance interaction capabilities [12].

Setting and research aim

My research setting is the field of chronic kidney failure. Kidney failure is a chronic disease, often with lifelong implications. In particular, patients with end-stage kidney failure need lifelong medical treatment, with either dialysis or kidney transplant as possible treatment options.

In general, patient engagement is increasingly accepted and valued as a concept that can improve healthcare services [5]. Although there is no universally accepted definition of patient engagement, also referred to as patient involvement or patient participation, as a general idea it could be seen as patients' engagement with professionals, institutions, or governments to improve their personal health status, the healthcare organization, or the healthcare system as a whole [26]. However, research into the effect of patient engagement on the actually achieved service improvements is inconclusive [6]. Although patient engagement is potentially valuable for care givers in their efforts to improve healthcare, effectively using patient knowledge to lead to real improvements has remained elusive.

Studies show that effective patient engagement is determined by engagement strategies and contextual factors such as organizational receptiveness and leadership. However, there is a need for additional insights into the relationships between providers and patients in the co-creating process [6]. In this research, the specific marketing approach of the service-dominant logic is used to deepen the knowledge on these relationships. S-D logic describes the broad context of value creation, co-designing with the provider as facilitator of value creation, and with relationships between customers, providers, and networks or constellations of providers who together offer the potential to create value-in-use with the customer or patient [10]. This thesis posits that S-D logic is a theory that is potentially relevant and useful in healthcare because patients are often faced with multiple care givers in a fragmented environment of health suppliers, regulations, and payment systems that together form a complex system of organizational settings [27,28]. S-D logic theory, and insights into its applications, is a developing area and is positioned as an open community where contributions are welcomed and evidence-based research is encouraged [21,29].

The research team in which I have played a part on patient engagement and value-based healthcare uses the S-D logic theory as a framework to reflect on value creation and real value for patients. As such, it recognizes that value is created by a complex system involving multiple actors such as different types of professionals and patients. There are two main topics in this research.

Topic 1: As we are particularly interested in the patient perspective, we focus on what value means to patients and their role in value creation. Sub-topics such as measuring value, codesign, and care pathways are addressed in the various chapters.

Topic 2: We address whether the concept of S-D logic can add to traditional patient-centeredness views in healthcare institutions. Topics including the organization of care, appropriate care, healthcare as a complex adaptive system, and a patient's responsibilities are explored.

Outline of this thesis

This thesis explores patient engagement in different areas of treatment for kidney failure. We explore engagement both in terms of the direct patient – doctor relationship and at the organizational level where healthcare services are designed. In the final chapter, I discuss our findings within the S-D logic framework.

Chapter 2 reports on a qualitative multi-perspective interview study on the use of patient-reported outcome measures (PROMs) in Dutch dialysis care. PROMs are increasingly used in healthcare with the aim of giving more attention to what really matters to patients. Basically, PROMs are questionnaires where patients rate their quality-of-life and report on issues such as social activity, fatigue, and mental and physical condition. We interviewed both healthcare professionals and patients in the early stage of PROM implementation. We found that doctors were sometimes reluctant to ask questions for which there might be answers for which they lack interventions. Patients were very willing to complete the questionnaires but not because they felt it would help them to communicate with their doctor or to cope with their chronic condition. Patients offered two reasons for responding to PROMs: because they are asked to do so and to help other patients if they expect it to improve care for all patients. From this, we concluded that, in order to further implement PROMs and to realize benefits for dialysis care, adequate interventions based on PROM results should be developed. To this end, in April 2022, the PRO-GUIDE project was started to develop treatment interventions based on PROM results to close the gap between measuring and acting upon measured results. The chapter has been published as an article "Facing the challenges of PROM implementation in Dutch dialysis care: Patients' and professionals' perspectives" in PLOS ONE, May 2023.

Chapter 3 describes the development of a specific health service aimed at helping chronic kidney disease (CKD) patients cope with work-related problems. Work is an essential part of life for many CKD patients and earlier research shows that CKD patients often lose their job and feel lost in how to cope with their disease in relation to their work. Problems arise in communicating with their employers and unfamiliarity with employment services may lead to unnecessary loss of income that affects the quality of life. An adapted version of Intervention Mapping (AIM) was used for the systematic development of work-oriented care for use within a hospital. By forming multiple working groups of hospital professionals, occupational health professionals, patients, and senior researchers, a trajectory was followed that consisted of three phases: developing, implementing, and pilot-testing a work-oriented clinical care program. Despite the difficulties of organizing all the necessary meetings due to Corona restrictions, the two-year project resulted in a, so far, successful implementation. We have further concluded that the program could be implemented by other hospital departments and the oncology department is currently working with this program for oncology patients. The chapter has been published as "Development and implementation of work-oriented clinical care to empower patients with kidney disease: an adapted intervention mapping approach" in BMC Health Services Research, April 2023.

Chapter 4 explores how patients are involved in VBHC practices at the organizational level with a particular focus on hospitals. In a systematic review, we questioned to what extent patient engagement in improving healthcare processes had already increased. In doing so, we used Carman's model of a continuum of patient engagement [30]. We found that, in the studies included, that patients are only involved at low levels of patient engagement through questionnaires, interviews, and focus groups. Higher levels of patient engagement, such as in advisory roles and in teams collaborating on care pathway improvement, were rarely used. Here, we would emphasize the importance of VBHC initiatives embracing all levels of patient engagement. The associated article, "The immaturity of patient engagement in value-based healthcare—A systematic review", was published in May 2023 in Frontiers in Public Health as part of the Research Topic "Patient-Centered Communication Skills for Health Professions Education and Healthcare".

Chapter 5 reports on a research project on improving the care path for living kidney donors. The chosen methodology is experience-based codesign (EBCD), an approach introduced by Paul Bate and Glenn Robert [31]. By collecting experiences from donors and healthcare professionals, and letting both groups work together on practical and implementable improvements, we set out to show that codesign, with a balanced centricity around all stakeholders and employing user-generated knowledge, is a workable and acceptable way of improving care pathways that goes beyond the often-hollow phrases that surround the term patient centricity. We identified eleven areas for potential improvement which have been discussed with donors and professionals. After discussions, we were able to set an agenda, prioritizing within these areas. The study resulted in a paper entitled "Improving healthcare services for living kidney donors: an experience-based approach in the Netherlands". The paper has been submitted in October 2024 to Frontiers in Public Health and is currently under review.

Chapter 6 describes the possible benefits of patient engagement in designing new dialysis modalities. In this opinion article, a plea is made for early patient participation when designing equipment to dialyze patients with end-stage kidney disease (ESKD). In the last fifty years, no major breakthroughs have been made in how patients dialyze, and the focus has been on making technical improvements, such as enhancing blood purification, without taking the patient perspective into account. We posit that taking more account of patient perspectives could improve the heavy burden of dialysis treatment in such a way that patients can more easily fit the tight restrictions of dialysis into their lives, thus improving their quality of life. The invitational article “Innovations in dialysis: the user’s perspective” was published in Nature Reviews Nephrology, April 2020.

Chapter 7 is the second invitational paper, this time presenting a perspective on patient’s well-being after organ transplantation. Patient well-being after transplantation is a major concern within the medical profession and the central aim of treatment after a transplant is survival of the graft. Before surgery, patients are already informed about important factors that they can control themselves, such as treatment adherence, diet restrictions including salt and raw fish, physical exercise, maintaining their weight, and monitoring blood pressure. Indeed, effective self-management of health-related issues is of great importance to successful long-term graft survival. By following doctor’s orders, patients can be considered as co-producers of their own health condition. However, although keeping the graft in good shape is a necessary condition for a patient’s well-being, it is not enough. To live a meaningful life after a transplant, patients need to use their regained health to return to work, develop social relationships, enjoy time with family and friends, travel, or, in short, to get back on track. In this article, we argue that healthcare providers should look beyond medical care to improve patients´ chances of long-lasting health by leading a normal life. We do so from the theoretical perspective of a service-dominant logic that states that patients are the creators of value-in-use and that healthcare professionals facilitate this process of value creation. This chapter has been published in December 2023 in a special issue of Transplant International focused on “Living well after organ transplantation”. The paper is entitled “It’s My Life and It’s Now or Never”—Transplant Recipients Empowered from a Service-Dominant Logic Perspective.

All the research reported in this thesis is related to patient engagement and the value of care from a patient’s perspective. As emphasized throughout this introductory chapter, we argue that many patients are indeed active creators of value-in-use and not merely passive recipients of care.

In **Chapter 8**, I reflect on the main findings of our research and provide a more detailed description of S-D logic, its origins in marketing, and its potential in healthcare practice. Two overarching themes are presented: 1) the application of the S-D logic in healthcare; and 2) the role of S-D logic in appropriate care. I then make recommendations for future research and indicate implications for practice. Finally, the thesis ends with methodological reflections and some concluding remarks.

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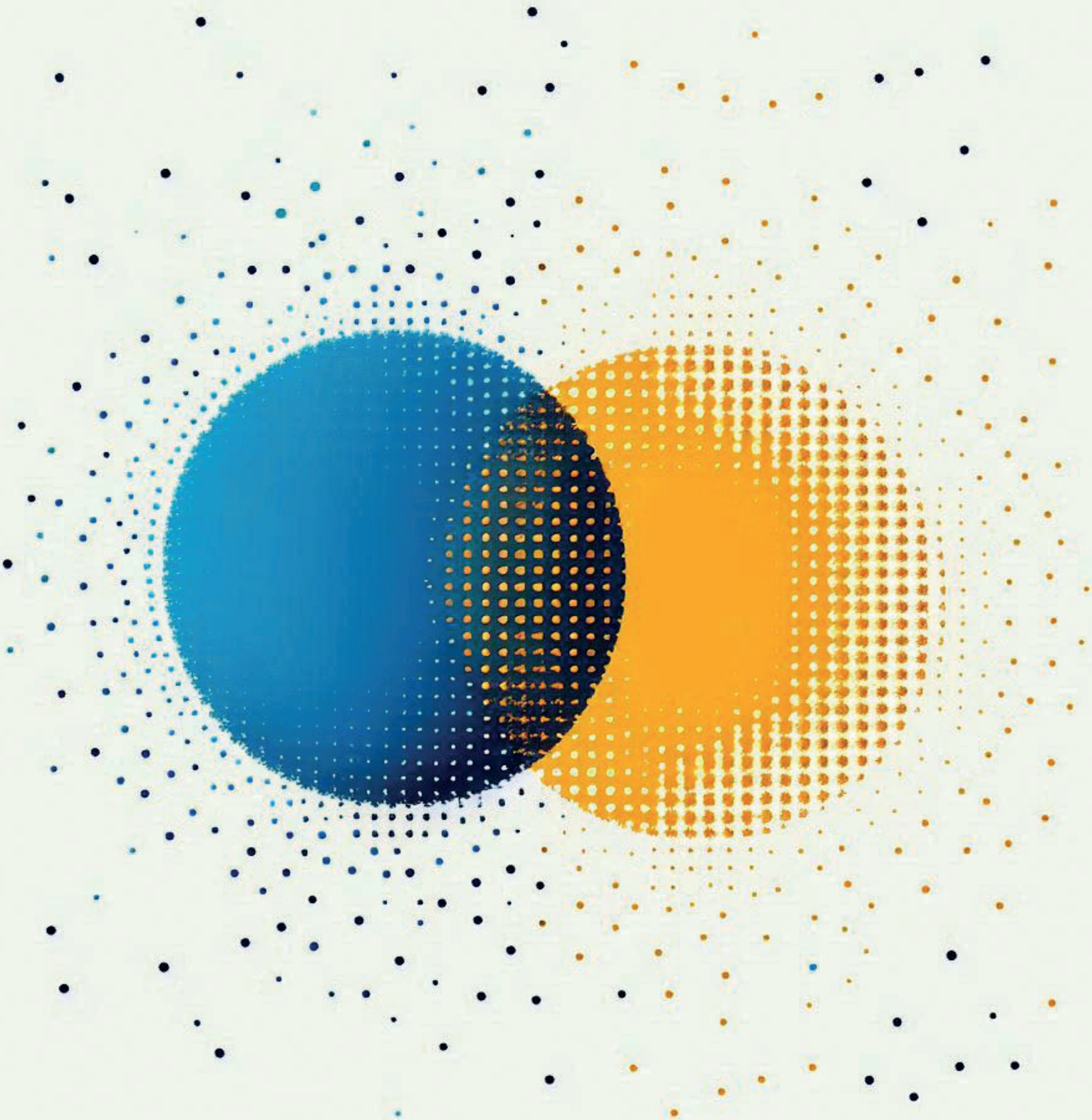
I

RESEARCH

CHAPTER 2



Facing the challenges of PROM implementation in Dutch dialysis care: Patients' and professionals' perspectives

With
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ABSTRACT

Background

Patient Reported Outcome Measures (PROMs) are increasingly used in routine clinical practice to facilitate patients in sharing and discussing health-related topics with their clinician. This study focuses on the implementation experiences of healthcare professionals and patients during the early implementation phase of the newly developed Dutch set of dialysis PROMs and aims to understand the process of early implementation of PROMs from the users' perspectives.

Methods

This is a qualitative study among healthcare professionals (physicians and nursing staff: n =13) and patients (n = 14) of which 12 were receiving haemodialysis and 2 peritoneal dialysis. Semi-structured interviews were used to understand the barriers and facilitators that both professionals and patients encounter when starting to implement PROMs.

Results

The early PROM implementation process is influenced by a variety of factors that we divided into barriers and facilitators. We identified four barriers: patient´s indifference to PROMs, scepticism on the benefits of aggregated PROM data, the limited treatment options open to doctors and organizational issues such as mergers, organizational problems and renovations. We also describe four facilitators: professional involvement and patient support, a growing understanding of the use of PROMs during the implementation, quick gains from using PROMs such as receiving instant feedback and a clear ambition on patient care such as a shared view on patient involvement and management support.

Conclusions

In this qualitative study carried out during the early implementation phase of the Dutch dialysis PROM set, we found that patients did not yet consider the PROM set to be a useful additional tool to share information with their doctor.

This was despite the professionals' primary reason for using PROMs being to improve patient–doctor communication. Furthermore, the perceived lack of intervention options was frustrating for some of the professionals. We found that nurses could be important enablers of further implementation because of their intensive relationship with dialysis patients.

INTRODUCTION

Quality measures in healthcare have long been focused on care processes and clinical status such as objective outcomes (e.g. survival rates) and have historically been dominated by the perspectives of healthcare professionals [1,2]. However, these measurements only partially reflect the value of healthcare as perceived by patients. Patients are in particular interested in healthcare outcomes that matter to them personally such as functional status and quality of life [1]. To measure value of healthcare as perceived by patients, patient-reported outcome measures (PROMs) are increasingly used in routine clinical practice. PROMs are questionnaires that allow patients to systematically share their health-related quality of life scores and disease symptoms with their clinician. The use of PROMs has a number of potential benefits such as to deepen patient–clinician communication, engage patients in their treatment, help clinicians focus on patients' needs, evaluate the effectiveness of interventions, improve overall healthcare quality and, as an overarching goal, contribute to better patient wellbeing [1–5]. The potential benefits of PROMs are widely recognized in healthcare literature for preventive care, primary care, incidental surgery, chronical diseases and palliative care [6–10].

However, these potential benefits are not easily achieved and are hindered by two issues. First, the implementation of PROMs in healthcare settings faces several barriers including patient and physician scepticism about practicability, time constraints, fear of added work, lack of training, administrative burden on patients and staff and a lack of organizational support [3,11–14] that result in a slow dissemination and use of PROMs. Also, sometimes patients do not complete PROMs because of simply forgetting or loss of motivation [15]. Second, there are doubts whether PROMs, once implemented, deliver the benefits they promise [12,16–18]. For instance, recent studies in a variety of chronic diseases found that patients experienced hardly any, or none at all, advantages of completing PROMs [19–21] In addition a Cochrane systematic review concluded that PROM completion makes no or little difference to patients regarding their perception of health and social functioning [18]. In contrast, positive results are also found, for instance in a quantitative study that reported a positive influence of PROMs on patients' self-control [22]. In summary, there is ambiguous evidence that the use of PROMs helps to improve care processes from the patient´s perspective [8,23].

Our study focuses on the introduction of PROMs in the patient group with end-stage kidney disease (ESKD). The worldwide population of patients that need renal replacement therapy is estimated at over two million [2,3], while dialysis treatment incurs high healthcare costs and places a large burden on the health-related quality of life (HRQOL) of patients [24]. Also, although dialysis is seen as a high-tech treatment, there have been only a few major innovations over the last 50 years from the patients' perspective [25]. In addition, symptoms and disease burden are not always recognized by clinicians, where nurses seem to be more accurate than nephrologists [26,27]. Because of the potential benefits of PROMs and indications that PROMs can be of added value to patients with chronic kidney disease (CKD) a standard PROM set was developed for dialysis patients in Dutch renal care [28,29]. We focus this study on the early implementation of this PROM set in Dutch dialysis centres, where early implementation is defined as the phase where 'the decision to introduce the new dialysis PROM set in the dialysis centre has been made and professionals are actually working on implementation in the centre'.

We focus on early implementation because most studies on PROM implementation were conducted either before the implementation process started, in the context of a pilot study or after it was fully implemented [17,20,21,30–35]. These studies mainly focus on the development of a PROM set, the collection, administration and evaluation. Patients and clinicians are often involved in the studies. However, what is happening in a real-life setting during the early implementation phase is rarely studied and we argue that this may lead to a deepened understanding of the challenges that face the implementation of PROMs. Because of the importance of involving patients in designing the implementation process [36], we explicitly involve patients as participants together with clinicians.

The aim of this study is to understand the barriers and facilitators that both patients and professionals, as primary users of the dialysis PROM set, encounter during the early phase of its implementation and the challenges they face in realizing the claimed benefits of PROMs. Our findings can contribute to a better understanding of the operationalization of PROMs in daily practice, which may increase the likelihood of their sustainable use.

METHODS

We have performed a qualitative study using semi-structured interviews and reported the study in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ). The study protocol of this research was approved by the medical ethical commission (METc) of the University Medical Centre Groningen in the Netherlands (METc number 2019/033).

Setting

In October 2018, a dialysis PROM set was introduced in the Netherlands. Dialysis centres are encouraged to use the set, however every centre is independent on how, when and if they introduce PROMs in their centre. The set was developed in close cooperation with Nefrovisie, the Dutch quality institute for nephrology care, and the Dutch Association of Kidney Patients (NVN) and has been accepted as the standard set by all 95 dialysis centres in the Netherlands that together take care of 6,300 dialysis patients. The dialysis PROM set has a solid scientific base and its development is supported by a qualitative and quantitative study that is extensively described by Van der Willik et al [29,37]. The set consists of the SF12 health survey questions [38] plus the 30 questions forming the Dialysis Symptom Index (DSI) [39]. Before the nationwide introduction a pilot study was held in 2016–2017 involving 16 participating dialysis centres and, in addition, patients participated in focus groups. The pilot study showed a highly differentiated pattern among centres, with patient response rates to the PROMs questionnaire varying from 6% to 71%, with an average of 24%. The highest response rates were found in centres with high engagement of professionals. Nevertheless, the pilot study also illustrated that patients were generally positive about PROMs and appreciated the feedback given by their caregivers [37].

The introduction of the PROMs is supported on a national level by Nefrovisie and addresses many of the considerations as described in the User’s Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice [40,41]. This central support offers dialysis centres with a variety of implementation strategies–like central IT support, newsletters, meetings, an informative film for patients, leaflets and factsheets on the website of Nefrovisie. A part of the site is dedicated to PROMs and how to start with PROM implementation in a dialysis center and a frequency of two PROM questionnaires a year is recommended.

A digital approach was chosen to minimize administrative burden, a known barrier in the implementation of PROMs [31]. Patients answer the PROM questionnaire online, get an immediate response with an overview comparing their scores with aggregated reference data and they can fill in their email address and read the results afterwards. The PROMs are stored centrally in 'Renine', the Dutch registry for renal replacement therapy to which dialysis centres have access. Who in the centre can access patient files is up to the dialysis centres to decide. In addition individual files can be downloaded into Diamant, a specialized system to store patient files and patient treatment decisions in the dialysis centre. How and if files are shared with the hospital's electronic health records (EHR) is up to the hospital. See Fig 1 for a schematic overview.

The registry system Renine provides the centres with feedback on how many patients responded to the PROM questionnaire and the average DSI and SF-12 scores on the dialysis centre level.

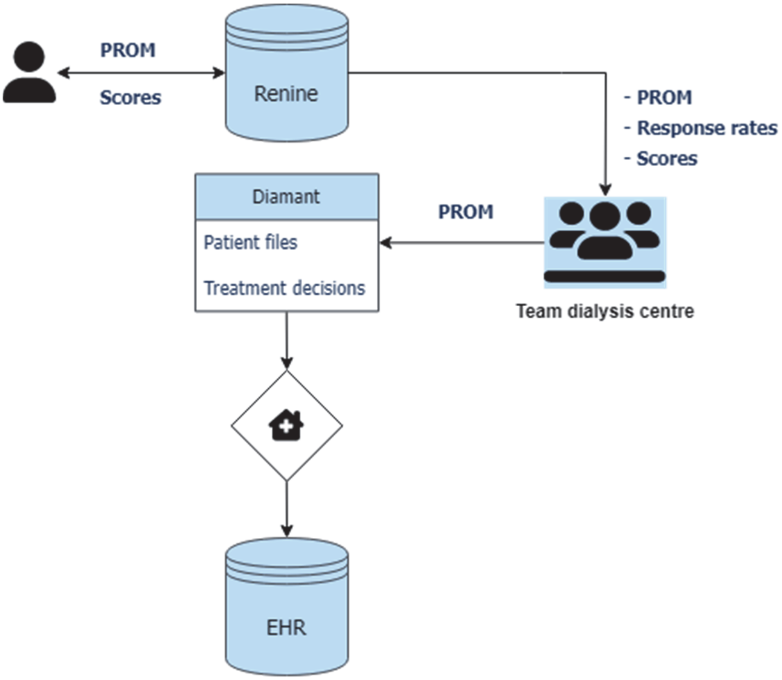

Fig. 1 Involved IT systems

Data collection

We have performed a qualitative study using semi-structured interviews with both professionals–doctors and nursing staff–and patients. A qualitative method was chosen because we wanted to explore and understand the considerations and beliefs regarding facilitators and barriers of both patients and professionals during the early PROM implementation phase. Qualitative research is frequently used to understand beliefs, experiences and interactions of participants [42,43]. We developed a semi-structured interview protocol based on the Measurement Instrument for Determinants of Innovation (MIDI) [44]. Determinant frameworks, such as MIDI, specify determinants that influence implementation outcomes [45]. We considered the MIDI questionnaire framework as suitable for our aim because it addresses the domains of both users and end-users, in our case professionals and patients respectively. The interview protocol is presented here as Appendix I (patients) and Appendix II (professionals). We pilot tested the interview questions with two professionals (one doctor, one nurse) and one patient. All three received a written summary of their interview and gave feedback. We concluded that the interview protocol met our information needs and that no adjustments to the protocol were required.

The selection of centres to be included in our study was made by Nefrovisie (MH) based on the criterion of being in the early implementation phase of PROMs and agreeing to participate in the research. Once permission had been granted, the researcher (WS) contacted centres by email or phone. Two of the centres had some earlier experience with PROMs having been participants during the pilot study. Patients were selected by a professional coordinator, either a doctor or nurse, within the dialysis centre. An inclusion criterion was that they had at least once filled in the dialysis PROM questionnaire. Interviewees were chosen on the basis that the selecting professional believed they might contribute to the research, would be willing to participate and, in some cases, were available for an interview during their dialysis hours. Appointments for the interviews were made by the centre or directly between the researcher and patients, based on convenience. The interviews were carried out from January 2019 until October 2020. All the participants signed informed consent forms. Especially when interviewing the patients, we could benefit from a mutual understanding and empathy because the interviewer was, as a former dialysis patient, familiar with the impact and routine of dialysis. As such, to a certain extent, WS can be viewed as an insider researcher by being part of the dialysis patient community [46]. We had an open conversation with patients, letting them set the pace and allowing them to raise topics that they saw as important regarding the potential use and expectations of PROMs.

Data analysis

The transcribed individual interviews were analysed using open coding with the predefined MIDI determinants used as a starting point for the analysis. During the process of analysing the results, we decided to switch to an inductive way of understanding. We saw that the data we had collected were rich, and the use of inductive reasoning led to useful insights on both facilitators and barriers. As such, we consider the overarching themes of the barriers and facilitators that emerged to be a more accurate reflection of reality and we present the results accordingly, following the inductive themes and not the predefined MIDI determinants. The process of coding, then discussing themes, barriers and facilitators was iterative using the insights gained by the main researchers (WS, KA and MdJ). The afterwards calculated kappa value was above 0.81 which shows a substantial interrater reliability [47]. After analysing 17 interviews we reached a point of data saturation. The coding process was supported by the software of Atlas.ti, version 8.2.

To consider the trustworthiness of this study we refer to the elements credibility, dependability, transferability and confirmability [48]. To enhance the credibility of the data all authors were involved during the research from the study design to discussing the themes and interpret the results. To ensure dependability we described how we collected the data and how we analysed the transcriptions deploying an iterative process supported by coding software. With regard to transferability, although this study is focused on PROMs implementation in dialysis centres, the findings could well be used in other healthcare settings especially in chronic care management. Confirmability was assured by having critical discussions within the research team, continuous checking of concepts and exchanging information.

RESULTS

In total we held 23 interviews with 27 participants, with no one we asked refusing an interview. All interviews were recorded and transcribed verbatim. Three interviews with professionals were multi-person, one couple of two nephrologists and one couple of a nephrologist with a nurse. We also interviewed one group of three participants, of which two nurses and one secretary. The 13 professionals interviewed (doctors, nurses and secretary) were located in nine different Dutch dialysis centres across the Netherlands, four based in university hospitals and five in regional hospitals. During the interview only the respondent(s) and the interviewer were present. Six of the 13 professionals were nephrologists (3 female, 3 male), six dialysis nurses (all female) and one secretary (female). The average length of these nine interviews was 42 minutes, varying from 29 to 51 minutes.

Fourteen patients receiving dialysis treatment were interviewed individually, of which twelve were receiving in-centre hemodialysis and two peritoneal dialysis. The period patients received dialysis treatment varied from 2 years to 21 years, with an average of six years. Interviews were located either at the patient's home (n = 5), during dialysis in the hospital (n = 5), in a private room in the hospital (n = 2), outside but close to the hospital (n = 1) and by phone (n = 1). The last two due to COVID limitations. During the interviews taking place during dialysis treatment, nurses would be walking around and other patients were also present. In three of the other cases, a family member was present in the background. In all these situations, no one intervened and the interview was strictly a one-to-one interaction. The average length of these fourteen interviews was 28 minutes, varying from 13 to 51 minutes. Three patients were female and 11 male, with ages ranging from 42 to 85. Two of the patients had completed the PROM questionnaire during the pilot study. We found that two of the patients we interviewed did not complete the PROM questionnaire and they were excluded from the analysis. Table 1. describes the main characteristics of the included patients.

Table 1. Patient characteristics.

Patient Nr.	Age (y)	Gender (m/f)	Years on dialysis	Dialysis modality	Location of interview
1	65–70	M	2.5	HD	Home
2	65–70	M	4.5	HD	Centre,
3	70–75	M	NA	HD home	Centre
4	55–60	M	2	HD	Centre
6	40–45	F	21	HD	Centre
7	80–85	M	7.5	HD	Phone
8	50–55	F	2	HD	Near centre
9	75–80	F	7	HD	Home
10	60–65	M	8	HD	Centre
11	40–45	M	15	HD	Centre
12	70–80	M	4	HD	Centre
14	50–55	M	20	PD	Home

HD = Haemodialysis.
PD = Peritoneal dialysis.

The analysis of the data resulted in four second-order themes of barriers in the early phase of PROM implementation in the care of dialysis patients: patient indifference to PROMs, scepticism on the benefits of aggregated PROM data, the limited treatment options open to doctors and, finally, organizational and operational issues. Apart from these barriers, we also identified several facilitators that help the implementation of the newly developed dialysis PROMs. These could be grouped into four second-order themes: professional involvement and patient support, a growing understanding of the use of PROMs, quick gains from using PROMs, and a clear ambition on patient care such as a shared view on patient involvement and management support. An overview of barriers and facilitators, together with illustrating quotes is presented in Appendix III. In Appendix III we relate the MIDI determinants to corresponding barriers and facilitators.

Barrier 1: Patient indifference to PROMs

We found that whether PROMs are considered valuable by a patient depends partly on the patient's characteristics and the relationship developed between nurses and patients during dialysis treatment. In general, patients felt indifferent regarding the use of PROMs, not yet feeling that PROMs added to the quality of their treatment. Many could not recall completing the questionnaire although professionals had assured us that all had responded with the exception of two patients who were yet to be given a PROM questionnaire. Below, we highlight the main reasons for this apparent indifference.

Lack of urgency.

We noted a lack of any sense of urgency by patients with regard to completing PROMs because they already interacted intensely with their nurse and doctor. Interviewees felt that a lot of information was already being shared since they interact with their physician during their weekly dialysis sessions. They visit their centre three times a week for four hours and while there share personal and social information with their nurses as is illustrated by: "The most senior dialysis nurse normally connects the patient once every one or two weeks to the dialysis machine. That's the moment to have a deeper conversation with their patient." (nurse 6). Patients confirm this as one patient explained: "I expect little from this [discussing PROM feedback; WS]. I filled in the questionnaire because they asked me to, but we have the opportunity to speak with the doctor or head nurse every Monday." (patient 6). Another patient confirmed this: "After connecting you [to the dialysis machine; WS] on Monday morning they always first ask: 'Do you have anything you want to ask the doctor?'" (patient 8). The same patient had been told not to wait for any questionnaire if they had questions for the doctor. Further, one patient indicated that they expected the nurse and doctor to communicate with each other: "I presume that the nurse also helps prepare the information for the consultation ..." (patient 5).

A nurse who had access to PROM results confirmed that PROMs do not necessarily bring new information to light: "We know the patients so well, to us they [PROMs; WS] offer little new information but it does make the conversation a little easier." (nurse 2). Patients reported themselves to be to be fairly content with their current patient–doctor communications, and PROM questionnaires were not, or only slightly, perceived to contribute to improved communication. Finally, it was noted that unless doctors provide some follow-up to the questionnaire during a consultation it will be even more difficult to motivate patients to respond to the PROMs in the future: "There has to be a follow up, because when the doctor doesn´t discuss it, it´s a waste of our time and that of the patient." (nurse 2). One patient explicitly remembered discussing the results with a specialized nurse: "Later on, I had a conversation about it with the specialized nurse. I got compliments that I maintained such a positive attitude." (patient 7).

Questionnaire fatigue.

During the interviews, patients expressed hardly any real interest in an additional questionnaire. Both professionals and patients reported that questionnaires are part of everyday life for dialysis patients. A consequence of this was a low motivation to complete the PROM questionnaire: doctors and nurses had to put in serious efforts to motivate their patients to fill in the PROM questionnaire. Patient motivation is an issue for professionals as was well-illustrated by one doctor who stated: "The problem we have is that our patients are overwhelmed by all these questionnaires. They suffer from questionnaire fatigue. We really had to put some effort into this to motivate them to respond." (doctor 3). However, most patients did not have strong objections to yet another questionnaire.

Patient characteristics and trust.

The willingness to complete the questionnaire also depends on patient characteristics such as age and critical attitude towards their doctor as was illustrated by a nurse: "Young and more opinionated patients say 'I don't agree, I'm not going to do this' ... the older generation do as the doctor says, the younger generation asks 'why should I do this, what's in it for me and what can I do with this?'. So yes, that's different." (nurse 2).

We found that the willingness to share personal information, which is a part of PROM questionnaires, is also linked to the trust relationship between caregiver and patient. Low trust might hamper open communication between doctor and patient, as was illustrated by a patient who said: "For a few weeks now, I have a new doctor. My early experiences don't encourage me to be more open. I don't know him yet and I'm not going to tell him everything." (patient 5). Another patient was very explicit about the importance of trust: "I'm here for dialysis but I had surgery eight years ago in another hospital. I go there once a year and I always tell more there than here. It's a matter of trust. ... Over there I have already had the same doctor for eight years. Here, it changes every time." (patient 9). A nurse added that PROMs might be particularly helpful for patients who are not open in their communication due to their personality: "In my opinion. we have a group of communicative patients and a group that are more closed. To them this [PROMs; WS] may offer an opening." (nurse 2).

Barrier 2: Scepticism on the benefits of aggregated PROM data

The second theme on barriers that we identified concerns clinicians' and patients' scepticism on the potential benefits of PROMs. We describe them in four subsections that each highlight a different aspect of potential benefits from a different perspective: the usefulness of comparing aggregated PROM data according to patients and clinicians, the feasibility of comparisons according to clinicians, the limited possibilities of aggregated PROMs to reveal differences in HRQOL as an indicator of quality of care and the difficulties with PROMs of following patients' wellbeing over time.

Doubts: Are comparisons useful?

The aggregation of individual PROM data could help in comparing outcomes of different dialysis modalities—such as in-centre versus at-home dialysis—and to compare patient-reported outcomes between centres as an indicator of quality of care. To compare aggregated results needs enough data to be collected over time and a general acceptance of PROMs in the various centres. However, doctors are reluctant to accept the results of any comparisons, as a doctor explained "Whether my patients are doing better or worse than those in a hospital 100 kms from here? I don't think that is relevant." (doctor 2). One patient stated his feeling on this as follows: "I'm not interested in PROMS as quality indicators. I have my own personal support here and I feel at home here." (patient 5). This illustrates the broader impression gained that patients are not very interested in outcome comparisons between dialysis centres.

Although eager to improve healthcare practices, doctors did not consider aggregated PROMs as an adequate measure to compare the quality of medical care as was illustrated by one doctor stating: "I'm sure we will find some differences, however I don't think this will be due to differences in the quality of care." (doctor 4).

Doubts: Are comparisons feasible with large case-mix differences?

Doctors reported concerns on the feasibility of aggregation and comparison because of differences in the case mix of patient groups. Professionals argued that case-mix differences are widespread across and within dialysis centres and goes beyond differences such as dialysis modality, age, causes of renal failure, social differences and occurrences of comorbidity. As one doctor emphasized: "I believe that if you make nationwide comparisons between centres, you should declare the academic hospitals as a special group and, even within them, there are differences." (doctor 3).

Doctors, referring to the possible use of outcome differences by health insurers, stated: "Centres might develop a defensive attitude if that happens. Such as by only offering PROMs to their best patients." (doctor 3) and "I think that would be dangerous. It's so difficult to compare centres." (doctor 6), another added "Our mortality rates are rather high." (doctor 5). Improving care processes based on benchmarking, even though potentially attractive, was considered to be difficult if based solely on PROMs.

Doubts: Do aggregated PROMs reveal differences in HRQOL?

PROMs are often presented as a means to measure HRQOL, but doctors raised serious doubts regarding this during the interviews. PROMs might reveal something about the quality of care, as one doctor explained: "It is possible that, for instance, we'll see differences in terms of a symptom such as cramp. That might say something about the quality of care." (doctor 4). A nurse had a similar view: "Imagine we have low scores on the sexual functioning of our patients. In that case, we could ask ourselves 'are we giving enough information?' ... 'are we doing enough about it?'." (nurse 4). However, there was a reluctance to use PROMs as an indicator of differences in the quality of life, and attributing this to better treatment in one centre than another: "Suppose we find a higher quality of life in medium-sized municipality A as compared to patients in a densely populated urban city environment B. So what? In B, there are many more patients with underlying social problems, such as lower incomes, a high percentage of immigrants and higher unemployment rates. These patients have more health issues. I don't think you can blame healthcare for this." (doctor 4). None of our interviewees expected any meaningful aggregated information from the PROM scores regarding HRQOL issues. This was illustrated by one doctor who argued: "The whole quality of life thing? We couldn't even find differences between night and regular centre dialysis. And, in my experience, the first group tells me they feel better." (doctor 4).

Doubts: The difficulties in following patients over time.

Collected PROMs data can not only be used for aggregation and comparison purposes but also to provide time series information on individual patients. Similar to time series data on medical laboratory results, it could be valuable to follow patients over time and adjust medical and supportive decisions accordingly. However, in order to do this using PROMs, doctors need patients to fill in the questionnaires on a regular basis. Here, although Nefrovisie recommends a distribution of dialysis PROMs, we found that in practice PROMs were only distributed among in-centre haemodialysis patients once a year prior to their scheduled annual extended consultation with a doctor. This was because professionals felt that the yearly consultation was the right moment to discuss the PROMs with their patients, "We want to distribute the PROM prior to the extended consultation, which is once a year." (doctor 5). This low frequency may hinder the effective monitoring of patients over time.

Further, the professionals interviewed emphasized that the conditions of patients undergoing dialysis may well deteriorate over time and that changes in PROM results may not represent the quality of care but, rather, that a greater burden of symptoms may simply reflect their changing medical condition. An interesting aspect related to time-series data is that several doctors mentioned that the symptom burden experienced by patients, as measured by PROMs, can apparently improve while their medical conditions are worsening. They explained this phenomenon by the improved capabilities of patients to accept and cope with their situation. As a nurse described: "Our patients' physical condition may deteriorate severely over time and still their quality of life score remains on the same high level (nurse 2).

Barrier 3: Limited treatment options open to doctors

As the third barrier theme, we saw that doctors did not always have adequate treatment options for the symptoms and poor health outcomes reported by patients. It was also reported that not every doctor is interested in taking a broader view on patient treatment.

Are dialysis doctors motivated?

Referring to the willingness of some colleagues, one doctor argued "Not every doctor invests in the annual extended consultation with their patient. ... To put it bluntly, some nephrologists see dialysis treatment as a tick-box exercise." (doctor 4). This doctor then explained that some colleagues do not consider dialysis as a very exciting and, for them, challenging form of treatment. PROMs are an addition to the doctor's toolbox, and not all doctors are equally motivated to put in the extra effort required.

Are doctors able to adequately intervene?

Another challenge that arises is linked to doctor's capabilities and core specialty. Some indicate they can perfectly well intervene on medical problems, but are not confident over what to do about other patient-reported complaints that go beyond their profession. This was clearly indicated by a doctor who said: "I think PROMs can be a problem for some doctors who will find it difficult to discuss complaints that they cannot do anything about. ... Even to me this is a bit frustrating." (doctor 3). Doctors could find it frustrating to ask people about complaints when they cannot offer any guidance, intervention or support. As another doctor mentioned: "A sexual condition can scare me off and I think 'How can I help?'. The most common response is to refer to a urologist. ... And the same with sombreness and depression." (doctor 6). The tension between asking about symptoms and the perceived lack of treatment options, and the discomfort that then arises, was summarized as follows: "In my opinion, if we ask these things of patients, we also should offer them adequate follow up. I think we are still struggling with this." (doctor 6).

Patients' preferences and protocol conflict.

Professionals also reported a potential conflict with existing medical protocols. PROMs intend to give the patient a voice and more saying in the way they are treated. However, patients' preferences may be in conflict with existing medical protocols. For instance, if patients were to indicate that their HRQOL improves with fewer dialysis treatments they may then ask doctors to deviate from the standard protocol of three four-hour sessions a week, where from a medical standpoint such a reduction would amount to inferior treatment. This potential conflict was clearly expressed by a nurse: "We are assessed on achieving good lab results, but maybe the patient only wants to undergo dialysis twice a week and this improves his quality of life. In terms of the visitation review, we are doing a bad job–but the patient is happier. We have many patients who really do not want a shunt to dialyse, they prefer a jugular catheter. This places us in a bad situation regarding professional guidelines that prescribe the maximum percentage of patients with a jugular catheter." (nurse 2). Here, it is important to note that compliance with protocols is safeguarded through external visitations. As a result, nursing staff who are in many cases responsible for distributing PROMs and motivate patients to respond, might be reluctant to do so if they feel that PROM results may not lead to changes in treatment and that patient preferences are disregarded due to protocol restrictions.

Barrier 4: Organizational and operational issues

Procedural growing pains.

Several centres started enthusiastically, quickly giving PROMs to all of their patients. However, they soon discovered that this procedure could be improved because the conditions of some patients could change in the considerable period that elapsed between answering the PROM questions and their scheduled annual consultation such that the PROM results were no longer adequate. In addition, some centres felt they had to think carefully about other PROM routing issues such as distributing them twice a year might consequently double the number of extended consultations to also twice a year. The PROM might also lead to changing the timing of the annual consultation to before or after the annual multidisciplinary team meeting where patients' conditions are discussed within a team of various disciplines.

It was also discussed during the early implementations whether a nurse should also attend the yearly consultation with the doctor and the patient, because the implementations had revealed that nurses being present might also help improve communication. A nurse described how it could be logistically difficult to distribute PROMs twice a year: "We currently combine it with the annual consultation, and it cannot be right that, a second time, the PROM is not discussed with the patient.. . . That still puzzles us.. . . Maybe we just have to decide to keep it to once a year." (nurse 2). All these possible adjustments to existing routines brought their own planning questions. Overall, the early implementation stage was seen by several of the professional respondents as a learning experience in how to deal with the procedures.

Not only the doctor, but the whole team is needed.

Although PROMs are a tool to enhance communication between patient and doctor, interviewees described how, to make this possible, the whole dialysis centre team has to be involved in the implementation process. Both doctors and nurses indicated that the efforts necessary to get PROMs distributed and returned are mostly put in by nursing staff and the secretariat who, as recognized by the doctors, already have a high workload: "It doesn't take much time from me, but the secretary staff and the nurses, yes it takes them extra time and, nowadays, their workload is already quite high." (doctor 2). The dialysis team as a whole is reported to be crucial to PROM implementation and it was also described how a larger team needs more effort in terms of coordination and motivation to handle the implementation. "All personnel have to be involved if you are striving for a good end result. Knowing my department, I think we will manage this. We only have a small team, which is convenient." (doctor 1). Furthermore, as the doctor explained, the demands on a centre's team can be more complex due to factors such as having multiple locations and a high employee turnover: "A big dialysis centre with more locations, well ... then you would need a more structured approach and you have to train all those teams." (doctor 1).

Nursing staff: Pain but no gain.

Although the importance of nursing staff when working with PROMs was widely recognized by the doctors, several nurses still reported that the information generated by PROMs is often only seen by doctors and patients, with nursing staff being excluded. Some saw this as somewhat unjust as nurses are very close to the patients and spend up to 12 hours a week with them, much longer than the doctors. Further, the non-coded information that nurses gather during dialysis treatment could be valuable but is not normally considered during the annual consultation. Nurses know a lot about individual patients, but this information is not systematically used, as a nurse explains: “I have never noticed that doctors asked us as nurses how we see things. It happens in the multidisciplinary meeting, but by then the annual consultation has already taken place.” (nurse 6). Although this does not directly affect PROM implementation, a feeling of being excluded is not very motivating.

Interference from external and internal turmoil.

In terms of organizational barriers, the professionals interviewed described that mergers, rapid changes in personnel, organizational turmoil, an overload of projects and organizational changes can all interfere with PROM implementation. The timing of the implementation project is therefore important and can be disrupted by external or internal turmoil. One doctor explained this as follows: “I have to motivate colleagues to work with this [PROMs; WS] so I must create acceptance and, even when people change jobs and functions during changing alliances, we have to continue our way of working.. . . Especially in these times with a lot of turmoil [a relocation of the department; WS] I believe that good projects can die because they are started at the wrong moment. To me this is a concern.” (doctor 5).

Inevitable IT nonalignment.

Finally, as part of the operational barriers, interviewees reported that workflow difficulties were arising from the fact that the centre’s dialysis patients’ medical records and the PROM results were kept in a dedicated IT system called Diamant. Interviewees indicated that although results were available in Diamant they could not be accessed through the electronic health record (EHR) system used by the wider hospital. This was an issue because, during the annual consultation, doctors were required to use the EHR system, and not Diamant. As a consequence, these two systems were being used in parallel, increasing the workload when working with PROM responses. A nurse stressed the need for information integration: "We are now printing the digital [PROM; WS] file and then scanning it for insertion into the EHR." (nurse 2). This was supported by a doctor stating: "A connection with our EHR system would be great" and "At the moment it brings additional paperwork, if I want PROM results in the EHR I have to retype them so to speak." (doctor 2). To address this problem, sometimes PROM data are printed out and delivered to the doctor manually. For the short-term, doctors see this as somewhat acceptable, but in the long-term they indicate that this cannot continue because it is too complex and time consuming for everyday routines.

Facilitator 1: Professional involvement and patient support

Involving professionals as implementers.

Once the decision had been made to use PROMs, we found that organizing the PROM implementation could be done by a project team with a few interested colleagues, quality assurance nurses or secretariat staff in cooperation with a nephrologist. Having preparations made by one or two coordinators, rather than doctors, can facilitate the daily use of PROMs in practice. The interviews revealed that the coordinator could for instance be a nurse who already has responsibilities in the field of quality assurance or is following a career path where the coordination of PROM implementation is part of a study trajectory. As one nurse described: "It was decided [PROM implementation; WS]. We just had to implement it. Because I am studying to become a quality assurance nurse I thought it would be perfect to choose this as a topic for my thesis." (nurse 6). During some of the interviews, it was described how the coordinator, a healthcare professional, managed all the preparatory operations such as the distribution of PROMs, staff training and motivation in cooperation with the centre's management team. The planning and distribution of PROMs support was arranged by a central point in the various dialysis centres, for instance by a secretary or support staff such as a quality manager or nurse.

Best practices and lessons from previous experience.

Respondents argued that implementation was also facilitated by having insights into 'best practices' and learning about implementation and daily use of PROMs from other centres. As one nurse explained: “Of course I use the Nefrovisie website and I read a lot there. When I’m sitting at home and I’m scrolling then I think, ‘yeah, that’s also a good idea’. ... This is very convenient and useful to me. I like it.” (nurse 6). Gathering information was reported as being done directly, by mail or phone, or by dedicated newsletters from Nefrovisie. Earlier experiences with PROMs, for instance in a pilot setting, also helped to develop the appropriate operational procedures. Such experience was argued to be a motivation because it showed that the time and effort necessary to implement PROMs were worthwhile. One centre had already been using a similar questionnaire and the switch to this PROM set was not perceived to be a major change. This was explained by a nurse when explaining the switch from their original questionnaire to PROMs: “Yes, that helps of course, because it already felt familiar. The procedure was already known, so in fact not much has changed.” (nurse 4).

One doctor, talking about earlier experiences during a pilot study with the PROMs, said: “When discussing the pilot PROM results with patients I found it very informative that patients have more complaints below the surface than those I discovered during regular visits.” (doctor 1). A very practical lesson that could be learnt from other centres is that a high response rate is not easy to achieve without hard work by the whole team. A doctor explained: “We had a very high response rate, but you really have to make an effort for this. These [dialysis patients; WS] are patients who usually are very tired, make many visits to the hospital and we already ask a lot of them. So, if they don’t see the benefits then it is very hard to get a response.” (doctor 2). The key to achieving a high response rate from patients, as argued by the doctor, was persistency in urging patients to return the PROMs. Another potential lesson is that PROMs are a practical tool that is not difficult to use. Here, several coordinators, nephrologists and patients reported that the questionnaire is easy to understand and easy to complete, with neither patients nor doctors reporting high barriers that had to be overcome to interpret the results.

Organizing support for patients with low health literacy skills.

A doctor explained that some patients may have difficulties with the questionnaire, and require special attention and support: “In particular, the patient who finds this difficult is the patient that also has difficulties expressing himself to the doctor. ... It often seems that this type of patient says they are feeling okay but, in reality, there is much more to it." (doctor 2). It was also argued that it was particularly reluctant or poor literacy patients that needed to be involved because they were the most likely to surprise their doctor with new information they had not shared before.

Respondents described several preparatory activities that could achieve a higher response rate. These involved preparing to help and support patients in completing the questionnaires, linking the annual anamnesis assessment that has some of the same questions with PROMs, providing material support such as tablets, and giving patients the freedom of choice as to where and when they respond, either at home or during dialysis. A patient commented on this: "At home I feel more at ease. (..) I do know how to use a computer but I'm not a freak. Settings are always a bit different and I'm more comfortable when I use my own computer."(patient 3). With regard to the PROM questionnaire itself, some respondents indicated that PROMs are a practical tool and in practice could replace existing, more complex, questionnaires. This was well illustrated by one coordinator who stated: "We were looking for a method to be more patient-oriented. ... We started looking at the positive health perspective and we were almost ready to introduce this but, then, PROMs came along–a beautiful solution specifically targeted at our patient group." (nurse 1).

Facilitator 2: A growing understanding of the use of PROMs

Learning to assess patient responses.

Professionals indicated that increasing experience with using PROMs helps them in understanding patients' responses, intervention options, possibilities for in-centre comparisons and differences in symptoms between centres. One doctor explained this as follows: "I think that's a matter of experience. An item score of 15 or 30 means nothing to me but, at some moment, when you use questionnaires more often, then you master it yourself." (doctor 6). These possibilities may develop over time as more centres and more patients participate provided there is an adequate learning community among professionals and an active exchange of ideas, experience and knowledge. One patient also described this learning curve, illustrating that patients may also need some time to learn: “At first we were thinking ‘what’s this, all these questions?’. And then we filled them in, and we checked the scores. And well, it is a good thing to do this once.” (patient 7). However, the same patient was not enthusiastic about the idea of a repeated questionnaire: “If they would ask me again, I would say: no, rather not.” (patient 7).

The power of using one standard PROM set in dialysis.

It was argued that a necessary condition of learning as a professional group is to use the same PROM set across all related centres. As a doctor explained: “It would be nicer if we all used the same questionnaire in haemodialysis and other CKD treatments, used it in the same way and built experience in the same way. ... At the moment, similar things are worked with, in many isolated situations. That is not necessarily wrong but, if we really want to do something with it in the Dutch nephrology scene, then joint actions would really be better.” (doctor 6). The acceptance of the new standard dialysis set thus enhances the use of a single PROM set and discourages the development of ‘local PROMs’.

Openness to share PROM experiences.

Although the use of a standard set enhances the possibility of exchanging experiences, the willingness and openness of doctors to share their experiences through the use of PROMs is also a necessity as was argued by a doctor: “We have to share these experiences in national task groups and at congresses.” (doctor 5). Patients also appeared willing to share information, not for themselves but for improving care for other patients. Participating in research, such as in the study at hand, may give patients a sense of contributing to the healthcare community. One patient in explaining their motivation for completing questionnaires stated: “I always say, I’m learning from it, but also for another.” (patient 3). Another, to us unexpected, benefit from PROMs is that one patient discussed the PROM results with a family member. In this instance, the PROM results helped the patient share the information that was presented with family, and this helped to reach a better understanding: “What I liked was that afterwards [on returning the PROM; WS] I could print the results. ... I mean, you are always talking about these things but now it’s on paper. ... And my sister told me, what you have filled in and what your scores are, that’s exactly right.” (patient 7).

Facilitator 3: Quick gains from using PROMs

Easy-to-use product.

Related to the PROM set product itself, our interviews suggested that the introduced dialysis PROM set, co-designed with patient involvement and doctors, was ready to go: that it was easy to use, without extensive paperwork due to the digital approach, not too many questions but comprehensive and balanced. Both patients and doctors considered the PROM set to be very practical despite the efforts that still have to be made to actually put them into practice. One patient said “I think the list was extensive, but it wasn't difficult” (patient 12). In addition on completeness and ease of use of the PROM set: “I think they are very complete. (..) And also I feel they are easy to fill in.” (nurse 2)

Receiving instant feedback.

After completing the questionnaire and hitting the Submit button, results are reported back to patients in a matter of seconds, including their overall benchmark in relation to other patients and the wider Dutch population. The professionals in our study said that patients had indicated that this motivates them to respond, and doctors and nurses see this as a positive attribute. As a nurse described, patients appreciate this instant feedback on their questionnaire: “The beauty is, also for the patient, that they get their report straight away, all in colours, which is very convenient.” (nurse 3). The value of instant feedback was also described by a patient who had very thoroughly filled in the questionnaire and studied the outcomes. This patient paid attention to individual scores on the item list and to the average at the end of the questionnaire. The patient was not surprised by the results, but appreciated the confirmation given by the PROM results: “I found it useful. I already knew I'm physically not in good shape. ... I mean, you always talk about it, and now it's crystal clear on paper.” (patient 7).

PROMs as a practical tool and time saver.

Doctors indicated that they regarded PROMs as a practical tool to support their consultation with patients. It helps them to gain a more structured insight into patients' troubles, complaints and symptoms, and that this was a motivator to implement PROMs. Doctors informed that using PROMs helps them to broaden the consultation with regard to topics discussed. PROMs are also a time saver:

they help doctors focus more effectively on the problems that patients themselves report. One doctor said about working with PROMs: “I believe them to be a beautiful tool to use during a consultation. ... I see immediately the topics that I don’t need to ask about anymore. As in ‘are you having complaints about ...?’ ... I can immediately focus on the complaints that patients have reported, which is a great opening for further discussion. It doesn’t cost any time and I can directly aim to talk about relevant complaints.” (doctor 2).

Results are used alongside lab results on phosphate, haemoglobin, parathyroid hormone levels etc. The balance may vary with age as one doctor indicated: “These [lab results; WS] are especially important for patients with a reasonable life expectancy but, obviously, we treat many elderly patients with a lower life expectancy and especially to them the quality of life is very important.. . . A phosphate level of 2.0 or 1.7 doesn’t make much difference. Here, it is more important how this patient experiences his wellbeing. ... And for me, what can I do to improve his life for the time he has left?” (doctor 2). Here, this doctor was demonstrating how PROMs are an aid to discuss issues that go beyond lab results for a specific patient group.

Easy handling and better consultations.

PROMs are considered to be complete and are balanced to the extent that they are easy to work with and ask the right questions. Some questions might be added, but it is recognized that this would complicate the questionnaire. Doctors expect the quality of their annual consultations with in-centre dialysis patients to improve because of the use of PROMs. They also indicate that it especially helps when patients become actively involved and adopt an active communicative attitude. Operational fluency is also enhanced by the easy connection between Nefrovisie-Renine and Diamant. As a secretary put it: “I just have to press ‘save as’ to save the PROM pdf file from Nefrovisie-Renine in Diamant. ... A matter of only a few small steps.” (secretary 1).

Facilitator 4: A clear ambition on patient care

A shared view on patient involvement.

A positive contextual element, related to the work environment of doctors, is having a shared view on patient involvement, both within the professional group of nephrologists and within a centre's nursing team. This is not only regarding the PROMs, which can be considered to be a tool, but also regarding what the PROM set represents: another way of treating patients–with active patient involvement, shared decision making and more attention to non-medical issues. A nurse gave the following argument: "It's different. It's another way of how we work, another way of gathering information and getting different information. Not just medical, but also psychosocial. Yes, I believe this is very important." (nurse 6). A doctor confirmed: "This is of course a topical issue nationwide, the whole issue that patients should have more say in their treatment. In many professional groups, you notice that PROMs are growing in importance. In my opinion this was not yet the case five years ago." (doctor 2). Just like the doctors, the nursing staff also have an open attitude to embracing active patient involvement and this enhances the implementation of PROMs.

Clear leadership.

Further, the interviews indicated that clear leadership has a positive effect. Here, firm statements at the beginning of the implementation process like 'we are going to do this' helps staff to accept PROMs and stresses the fact that PROMS are considered essential for the centre's dialysis care. As a coordinating nurse stated: "There was no choice whether personnel would accept it or not. So, we are just going to do this. Some people see the benefits, others don't and consider it to be nonsense. Well, come on. It just has to be done." (nurse 2). This firmness may even be transmitted to patients: doctors might say 'this is important, so I strongly advise you to fill in this new questionnaire, it helps with your treatment'. One doctor was very firm on this: "Some [patients; WS] did not respond and then we said: 'Here is an iPad and you are just going to fill in the questionnaire', actually being very directive, and 'I am going to tell you the results.'" (doctor 3).

Management support.

Interviewees mentioned that acquiring the extra capacity to organize the introduction of PROMs, set up procedures, motivate colleagues and facilitate patients and staff takes time. Management support for this helps in succeeding. This support came from the management of the centre and not from the top management in the hospital. Several interviewees indicated that top management played no role in the implementation of PROMs, such as a nurse who stated: “We [dialysis centre; WS] are an island within the hospital. We do something because we think it is important.” (nurse 4). This finding indicates that dialysis centres are rather autonomous when it comes to decision-making.

DISCUSSION

To the best of our knowledge, this is the first qualitative study into the barriers and facilitators that arise during the early implementation of PROMs that considers multiple dialysis centres that are all implementing the same PROM set and includes the perspectives of patients, doctors and nurses.

The aim of this study was to understand the barriers and facilitators from a user’s perspective—both patients and professionals—during the early implementation of a newly developed dialysis PROM set. We found implementation to be a knotty process where users–patients, doctors and nurses–each assess PROMs from their own perspectives and with different expectations. These may either facilitate or hamper the use of PROMs.

Patients

Although considerable attention is given to the involvement of patients in the development of PROMs [29,49], little consideration is given to the willingness and motivation of patients to complete PROM questionnaires. The focus has been on the development of easy-to-use questionnaires that will place only a small burden on patients. Nevertheless, when it comes to the dialysis PROMs, our data suggest that patients maintain a neutral attitude towards the use of PROMs and feel no extra motivation to complete them compared to more common questionnaires they are asked to fill in, for instance about the quality of care.

We identified this lack of patient motivation from the indifference that patients demonstrated towards the dialysis PROM set, and concluded that this was partly because they already communicate a lot with nurses during their dialysis treatment. Illustrating this was the fact that quite a few patients, although it was confirmed by the centre that the PROM had been discussed with them, did not recall discussing PROM results with their doctor and some even reported having no need for any discussion. This finding seems to go against recent PROM literature that suggests that patients value discussing PROM results with their doctor and expect there to be benefits [37,50]. However, Damman et al., when assessing PROMs related to Parkinson's disease [51], also found mixed results on the felt needs of patients to discuss PROM data, and especially HRQOL questions, with their doctor, mainly because patients were too busy running their lives. It can be argued that our data suggest that patients perceive the PROM questionnaire as just another tool for doctors to employ. This could be due to the fact that, at the time the interviews took place, this PROM was not yet a standard routine in the dialysis centres.

Recent studies that included patients who at least responded twice to digitally available PROM questionnaires in the field of hematologic care and renal care had similar results on patient motivation, where patients did not consider PROMs as 'a tool for them' [19,21]. We argue that it may take some time for both patients and doctors to learn how to use PROMs in their communication and create additional value for patients. Or, as Staniszweska et al. state, using PROMs and creating patient benefits is a matter of evolution, not revolution [52]. The initial phase of PROM use should perhaps be seen as finding the right way, with adjusting procedures, to discuss the results during a consultation and to deliver support to patients that they recognize to be an outcome of the PROM questionnaire.

In the context of a dialysis centre where there is already close communication between patients and nursing staff in a long-term intensive care setting, patients' motivation may well be initially low for what they themselves call 'yet another questionnaire' when the stimulus to respond does not seem to go beyond 'following doctor's orders'. We note that according to the Dutch dialysis quality protocol patient satisfaction surveys and regular intake questionnaires like the yearly anamnesis are also performed. In addition, Consumer Quality (CQ) scores, short-form Picker experience questionnaire and Edmonton Frailty Scale (EFS) exist for dialysis patients. Patient experience measures are encouraged by the Dutch Ministry of Health, Welfare and Sports [53]. All this can lead to questionnaire fatigue, or loss of interest and motivation.

Here, our results suggest that healthcare professionals, rather than patients, are the key driver in implementing PROMs and that some perseverance is needed during the early stages of implementation. However, for long term success, patients need to be enthused and their experiences and needs should be taken into account by health providers.

A claimed barrier to digital PROMs, such as the dialysis PROM set, is that some patients lack digital skills [1,54]. However, in this regard, the patients that we interviewed showed no hesitation and reported that the digital questionnaire was rather easy, a benefit of a web-based application that was reported earlier [55]. This digital acceptance could possibly be explained by the fact that the elderly, and the vast majority of patients on dialysis are over 65, have now generally developed digital skills. In addition, the new PROM set was developed with high involvement of patients and this may well have resulted in an easy-to-use questionnaire. Further, in some cases, if they considered it necessary, patients received support within the centre, where they could complete the questionnaire, or at home from their family.

Furthermore, we see that PROMs could be used as a tool to support a patient's self-management actions in their daily life [56]. PROMs could make symptoms and concerns more visible and transparent to family, friends, employers and colleagues, and therefore not only help communication with doctors but also within the patient's social environment. If patients were to receive some awareness training on the potential PROM benefits this could increase response rates.

Doctors

We noticed that some doctors can feel uncomfortable about asking the same questions over and over again in different forms when there is a lack of appropriate interventions they can offer in support. This is in line with previous research that shows ambiguity over the benefits of PROMs in haemodialysis care and potentially may lead to a decrease in providers' confidence in symptom management after using PROMs due to a perceived lack of intervention options that even left some providers with 'a feeling of failure' [33]. That doctors may have concerns about raising issues reported in PROMs that they feel they cannot deal with, was also reported in a study in oncology care [57]. We suggest that PROMs may well be effective in terms of boosting symptom awareness, but are not necessarily effective when it comes to symptom management. This disconnection between symptom awareness and symptom management was already being signaled in the early phase of implementation. To improve symptom management based on symptom awareness, and therefore see more benefit from the use of PROMs, professionals could increase their use of existing possible intervention options as suggested in earlier publications [58,59].

The use of aggregated PROM data as a benchmark for quality of care was questioned by doctors due to the large case-mix differences between centres. Recent research in a dialysis setting indeed suggests that case-mix adjustments have to be made [60], as has also been illustrated in stroke care [61]. In addition, doctors indicate that it is difficult, if not impossible, to interpret aggregated PROM results without knowing the patient, their comorbidity, their history and their personality. This is especially true for the SF12 questions that assess HRQOL elements. For example, a patient who has been on dialysis for several years, and has already adjusted their way of life, may, despite a lower health status, report a higher HRQOL than a patient who is recently diagnosed with a severe kidney disease, still has a relatively high health status, but worries about the impact on their life and the possible loss of employment. This phenomenon of patients' shifting HRQOL expectations over time, also known as response shift [62–64], makes it very difficult, or at least challenging, to turn collected raw PROM data into meaningful medical quality-of-care information. Nevertheless, despite the doubts expressed concerning the feasibility of case-mix adjustments, some doctors emphasized that improvements in symptom management could be achieved provided that information on symptom management is openly shared and discussed between centres and among professionals.

In contrast with the largely neutral attitude towards PROMs expressed by patients, we observed that doctors showed a positive attitude in terms of the potential of PROMs to positively influence doctor–patient communication, as is also suggested in the literature [33,50]. It seemed that the majority of the doctors adopted PROM as a practical tool for one main reason: to improve communication with their patients. Barriers reported in the literature, such as difficulty in interpreting PROM results, scepticism on the use of PROMs in the consulting room and the time burden [4,65,66], did not seem to be experienced by our respondents. This difference may be due to the specific setting of dialysis treatment, where doctors and patients see each other frequently, in the case of in-centre dialysis even on a weekly basis, over many years. Therefore, the time burden is not an issue, and interpreting PROM results may be easier because doctors and patients already know each other. We found no scepticism by doctors on the use of PROMs in the consulting room. Instead doctors were curious about the impact of PROMs during consultations and were hoping that discussion of PROMs would lead to a better understanding about patients´ health related concerns. The use of the PROMs was even mentioned as a time saver for doctors, a view corresponding with earlier research that indicates that PROMs allow doctors ‘to be a doctor again’ [5].This is understandable because the PROM results make it easier for doctors to identify which issues to address with patients, rather than needing to run through an extensive list of possible symptoms as was usually the case during the annual consultation. It was also mentioned that doctors did not themselves spend much time on distributing and collecting the PROM questionnaires, that this was done by nursing staff, so the time burden for doctors outside the consulting room is low.

We argue that experiences from the early phase of PROM implementation can be used as a learning tool. Sharing early experiences, questions that arise and solutions found, could lead to a steeper learning curve on how to employ PROMs and take dialysis care to a higher level. All Dutch dialysis care centres now can use the same web-based PROM set with low administrative burden that may lower professionals’ barriers [55]. Although the implementation is organized differently in each centre, the group of professionals shared the view that PROMs could help in the communication between doctors and patients, however whether this turns out to be significant remains to be seen. Nevertheless, we see this shared ambition as a positive element in moving forward with the use of PROMs in dialysis care that is encouraged by supporting implementation strategies like training, meetings, a central helpdesk, informative newsletters and an up to date website full with tips and ideas.

Regarding integration of patient data, literature emphasizes the importance to integrate PROM data with the patient’s electronic health record to overcome practical barriers and to enable comparative effectiveness [67]. In our study we found that a hybrid model was chosen, with an external platform for data collection [68]. Patients and caregivers can access PROM results and comparative data collection is possible for dialysis centres and healthcare professionals, especially nephrologists. For (secretary) staff it is easy to import PROM results from the external platform to the Diamant system. Although this is solution, for now, technically workable, for further and sustainable use of PROMs a few puzzles still remain. In the consultation room doctors often use the hospital's EHR system, that is not integrated with the dedicated dialysis Diamant system. Also, we found no literature on EHR integration that recognizes the use and importance of intermediate workflow systems and patient record systems as Diamant. In addition, independent of technical infrastructure, physicians still have to make a huge effort to correct for case-mix differences and to really understand the meaning of aggregated PROM data statistics [60,64].

Nursing staff

Little attention is given in the literature to the crucial role of nursing and administrative staff when implementing PROMs. Although training and motivating staff and the administrative burden are mentioned [1,69], the interaction between patients and nursing staff and the role that nurses have in implementing PROMs are rarely addressed. However a recent study in cancer care described the experiences of nurses with PROMs and how they were 'wishing for a strategy" to use PROMs in daily practice [70]. We argue that in-centre dialysis patients, who are undergoing treatment over many years three times a week for four hours each time, have a special relationship with nursing staff. This relationship in a haemodialysis setting has recently been studied [71] and it was found that patients rated nurses' caring attitude even higher than nurses rated themselves on six out of the ten dimensions of Watson´s Theory of Human Caring [72] with high scores for humanity, hope, helping relationship, teaching, environment and needs. We posit that, in a dialysis centre, the interactions between patients and nursing staff are more intensive than the relatively short contacts between patients and their doctors. The importance of the tacit knowledge acquired by nursing staff was similarly recognized in an implementation study of PROMs in oncology care [73]. Recent research by Delmas et al.

confirms that nurses are crucial in haemodialysis because, on many dimensions, they have the most intense professional relationships with the patients [71]. Further, Raj et al. [27] suggest that doctors should incorporate the knowledge gained by dialysis nurses because nurses recognize symptoms better than doctors.

Compared to doctors, we would argue that nurses have different, more-personal patient conversations not only on how patients are doing but also on what their needs are, what is worrying them and how they are participating in their social environment. This may well influence patients' attitudes towards PROMs. In terms of implementing PROMs, nurses could have a more explicit motivating role towards patients to improve response rates, they could combine the yearly anamnesis with the PROM questionnaire, they could discuss the results of an in-between PROM with the patient to give it a greater sense of meaning and thereby facilitate a frequency of twice a year, and they could also intervene by referring the patient to, for instance, a psychologist or a social worker. All this could be done under the supervision of a nephrologist.

Lessons for practice

To improve care from a patient´s perspective, long-term collecting of patient outcomes is necessary. We argue that our study shows that significant progress has been made to overcome practical barriers of PROMs, although some of them are still present. This has resulted in an easy-to-use PROM questionnaire for both patients and clinicians, a well-organised digital approach of collecting and distributing PROMs and a strong motivation of clinicians involved in the implementation. However, this not enough to get acknowledgement of patients. Today, patients do not recognize direct benefits of PROMs and to fill in the questionnaire they are mainly motivated by the argument that they are helping their doctor. In our opinion, the most crucial step forward now is to improve support interventions based on PROM results that patients report. When PROMs are used to improve patients' lives, and this is clear to patients, than we feel confident that patient's acknowledgement for the use of PROMs will follow. In summary, we suggest the next step is to close the gap between symptom awareness and symptom management.

Strengths and limitations

Our study has some limitations. First, we only selected centres that were early adaptors of PROMs, which may result in a selection bias towards those who are more reluctant in the acceptance of PROMs. Some centres could not participate in this study because of COVID restrictions and had to postpone the implementation process. However, we believe it is reasonable to assume that this PROM set is widely supported within the professional group of nephrologists. Second, as a result of our choice to select centres that were starting to implement PROMs, we were confronted with a knowledge gap regarding potential PROM benefits between the professionals and the patients that we interviewed. The doctors were well informed on the subject of PROMs through meetings, publications and discussions whereas the patients had only been briefly introduced to the concept. With this knowledge gap and the low awareness of PROMs during the early phase of implementation, a number of the patients even found it difficult to remember completing this particular questionnaire. This knowledge gap is a possible limitation of the research, but we argue it is also as a positive outcome in that this difference in itself is part of the implementation process.

We consider it as a strength that we interviewed a diverse group of nurses and doctors from academic and non-academic centres, and also a diverse group of patients in terms of age, gender and duration of their dialysis treatment. These diverse interviews helped to understand what was happening in the daily setting of PROM implementation. Another strength of this study is that we managed to deepen understanding of patients' considerations on the role of PROMs. Furthermore, another strength is that the results of the inductive coding process were discussed among the authors several times to prevent confirmation bias. Results of the analysis were discussed among all the authors, of which two are experienced nephrologists and one an experienced qualitative researcher in renal care. As a consequence of this continuous reflection on the results, we have no serious concerns over the internal validity of our findings. Also the interview protocol that we used was based on the proven MIDI questionnaire framework on implementation.

Conclusions and suggestions for further research

The dialysis PROM set that we have studied was introduced at the end of 2018 in Dutch dialysis care and is gradually being implemented in multiple centres. At the time of the interviews, PROMs had not yet become part of the daily routine within the centres. Patients completed PROM questionnaires because their doctor asked them to, and were yet to feel that PROMs contributed to better communication with their doctor or a better sense of wellbeing. The main reasons for implementing dialysis PROMs is for doctors to gain a better understanding of their patients and the expectation that it will improve symptom recognition as reported by patients. However, the doctors perceived a lack of intervention options, and this could endanger the long-term use of PROMs. Further, physicians were unconvinced about the possibilities of aggregation and comparisons between centres and treatment results, mainly because of considerable differences in case-mixes. Finally, we show that nurses play an important role in the patient–caregiver relationship and that this relationship could further enable the implementation of PROMs.

To increase understanding of the implementation challenges facing PROMs, we would suggest further research on the motivation of patients to regularly complete PROM questionnaires over a long period of time. We would also suggest evaluating the assumed learning curve: whether it really takes place and whether it helps to meet doctors' expectations on potential PROM benefits. In addition, we would encourage further exploration of the possibilities for improving patient care through supportive interventions, either by doctors or other relevant professional caregivers. Finally, the role of nurses in dialysis centres could be studied further to better understand and enhance the use of their tacit knowledge regarding their patients.

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APPENDIX I. Questions and protocol for patients

All interviews were tape recorded and transcribed. An informed consent form signed by the respondents was required. Forms were administered by the researcher. Interviewees were informed about the aim of the research, and interviewees could decide to withdraw from the research at any time. Published results are anonymized.

1. Questions associated with the user (MIDI determinants 8, 9, 10, 11, 12, 16, 17, 18)

- To what extent does using PROMs have personal benefits/drawbacks for you?
- Could you describe the possible important goals for you as a patient? What do you expect from the PROM questionnaires? Which goals do you think will actually be achieved?
- What do you feel about your responsibility to answer the questions put in the PROMs? What motivates you to answer the questionnaire?
- In your opinion, how do you experience communication with your doctor? To what extent do you expect improvements through the use of a questionnaire like PROM? Can you explain?
- Why would you cooperate (or not) when you are offered the possibility of filling out PROM questionnaires?
- What motivates you to participate?
- How do you interpret the results of PROMs and how would you discuss the results with your doctor?
- How were you informed about the use PROMs? Which caregiver approached you (e.g., doctor, nurse)?

General question: what other comments do you have?

APPENDIX II. Questions and protocol for professionals

All interviews were tape recorded and transcribed. A signed informed consent form from the respondents was required. Forms were administered by the researcher. Interviewees were informed about the aim of the research and could decide to withdraw from the research at any time. Published results are anonymized.

1. PROM product-related questions (MIDI determinants 1, 4, 5, 7)
   - To what extent is it clear how you can work in practice with PROMs? Can you describe this?
   - What is your opinion about the overall complexity of working with PROMs?
   - How well do you think PROMs fit into your day-to-day consultation? Please clarify.
   - In your opinion, does the use of PROMs offer important additional value to your patients? Can you explain how?

2. Questions associated with the user (MIDI determinants 8, 9, 10, 11, 12, 16, 17, 18)
   - What personal benefits/drawbacks does using PROMs have for you?
   - Could you describe the possibly important goals for your patients as you see it?
   - What do you feel about your responsibility as a professional to implement and use PROMs?
   - In your opinion, will patients be generally satisfied or better serviced if you use and discuss PROMs? Can you explain why? (possibly key question)
   - Why might your patients cooperate (or not) when you offer them the possibility of discussing PROMs?
   - How can you motivate your patients to participate?
   - How do you interpret the results of patients’ PROMs and how would you discuss the results with your patients?
   - Are you well informed on all aspects on how to use PROMs in practice? Any missing links?

3. Questions associated with the organization (centre, hospital, group/team; possibly also the broader work environment including colleagues elsewhere) (MIDI determinants 19, 23, 24, 26, 27, 28)

- What support is offered to you regarding the use of PROMs in your centre? By management, other professionals or whatever?
- How do you regard the time needed to use PROMs? Do you see any obstacles, apart from the normal lack of time?
- Which facilities do you have such as equipment, materials or IT support to implement PROMs? Is anything missing that can be seen as an obstacle in your daily practice?
- What other obstacles, in addition to the implementation of PROMs, do you experience in your work environment that affect the use of PROMs?
- How easy is it for you to find information in your work environment about using PROMs?
- What feedback is provided to you about the progress with PROM implementation? What do you expect from this feedback?

General question: What other comments do you have?

APPENDIX III. Illustrating quotes and corresponding MIDI-determinants

Barriers	**Subgroups**	**Illustrating quotes**	**Corresponding MIDI -determinants** [1]
Barrier 1: Patient indifference to PROMs	Lack of urgency	I filled in the questionnaire because they asked me to, but we have the opportunity to speak with the doctor or head nurse every Monday. (p)	Personal benefits/drawbacks (8)
	Questionnaire fatigue	The problem we have is that our patients are overwhelmed by all these questionnaires. They suffer from questionnaire fatigue. (d)	Relevance for client (7)
	Patient characteristic and trust	For a few weeks now, I have a new doctor. My early experiences don't encourage me to be more open. (p)	Patient cooperation (12)
Barrier 2: Scepticism on the benefits of aggregated PROM data	Doubts: are comparisons useful?	Whether my patients are doing better or worse than those in a hospital 100 kms from here? I don't think that is relevant. (d) I'm not interested in PROMS as quality indicators. I have my own personal support here and I feel at home here. (p)	Relevance for client (7); Personal benefits/drawbacks (8)
	Doubts: are comparisons feasible with large case-mix differences?	Our mortality rates are rather high. (d) I believe that if you make nationwide comparisons between centres, you should declare the academic hospitals as a special group and, even within them, there are differences. (d)	Outcome expectations (9)
	Doubts: do aggregated PROMs reveal differences in HRQOL?	Suppose we find a higher quality of life in medium-sized municipality A as compared to patients in a densely populated urban city environment B. So what? (d)	Knowledge (17)
	Doubts: the difficulties in following patients over time	Our patients' physical condition may deteriorate severely over time and still their quality of life score remains on the same high level. (n)	Observability (6)

Barrier 3: Limited treatment options open to doctors	Are dialysis doctors motivated?	Not every doctor invests in the annual extended consultation with their patient. … To put it bluntly, some nephrologists see dialysis treatment as a tick-box exercise. (d)	Professional obligation (10)
	Are doctors able to adequately intervene?	I think PROMs can be a problem for some doctors who will find it difficult to discuss complaints that they cannot do anything about. … Even to me this is a bit frustrating. (d)	Self-efficacy (16)
	Patients' preferences and protocol conflict	We are assessed on achieving good lab results, but maybe the patient only wants to undergo dialysis twice a week and this improves his quality of life. In terms of the visitation review, we are doing a bad job – but the patient is happier. (n)	Compatibility (5)
Barrier 4: Organizational and operational issues	Procedural growing pains	We currently combine it with the annual consultation, and it cannot be right that, a second time, the PROM is not discussed with the patient. ... That still puzzles us. ... Maybe we just have to decide to keep it to once a year. (n)	Procedural clarity (1)
	Not only the doctor, but the whole team is needed	It doesn't take much time from me, but the secretary staff and the nurses, yes it takes them extra time and, nowadays, their workload is already quite high. (d) A big dialysis centre with more locations, well … then you would need a more structured approach and you have to train all those teams. (d)	Staff capacity (21)
	Nursing staff: pain but no gain	I have never noticed that doctors asked us as nurses how we see things. (n)	Social support (13)
	Interference from external and internal turmoil	Especially in these times with a lot of turmoil [a relocation of the department; WS] I believe that good projects can die because they are started at the wrong moment. (d)	Unsettled organisation (26)

	Inevitable IT nonalignment	At the moment it brings additional paperwork, if I want PROM results in the EHR I have to retype them so to speak. (d)	Complexity (4)
Facilitators			
Facilitator 1: Professional involvement and patient support	Involving professionals as implementers	It was decided [PROM implementation; WS]. We just had to implement it. Because I am studying to become a quality assurance nurse I thought it would be perfect to choose this as a topic for my thesis. (n)	Coordinator (25)
	Best practices and lessons from previous experience	Yes, that helps of course, because it already felt familiar. The procedure was already known, so in fact not much has changed. (n)	Procedural clarity (1)
	Organizing support for patients with low health literacy skills	In particular, the patient who finds this difficult is the patient that also has difficulties expressing himself to the doctor. … (d) At home I feel more at ease. (..) I do know how to use a computer but I'm not a freak. Settings are always a bit different and I'm more comfortable when I use my own computer. (p)	Patient cooperation (12); Material resources and facilities (24)
Facilitator 2: A growing understanding of the use of PROMs	Learning to assess patient responses	I think that's a matter of experience. An item score of 15 or 30 means nothing to me but, at some moment, when you use questionnaires more often, then you master it yourself. (d)	Self-efficacy (16) Knowledge (17)
	The power of using one standard PROM set in dialysis	It would be nicer if we all used the same questionnaire in haemodialysis and other CKD treatments, used it in the same way and built experience in the same way. (d)	Subjective norm (15)
	Openness to share PROM experiences	I always say, I'm learning from it, but also for another. (p) We have to share these experiences in national task groups and at congresses. (d)	Patient cooperation (12) Professional obligation (10)

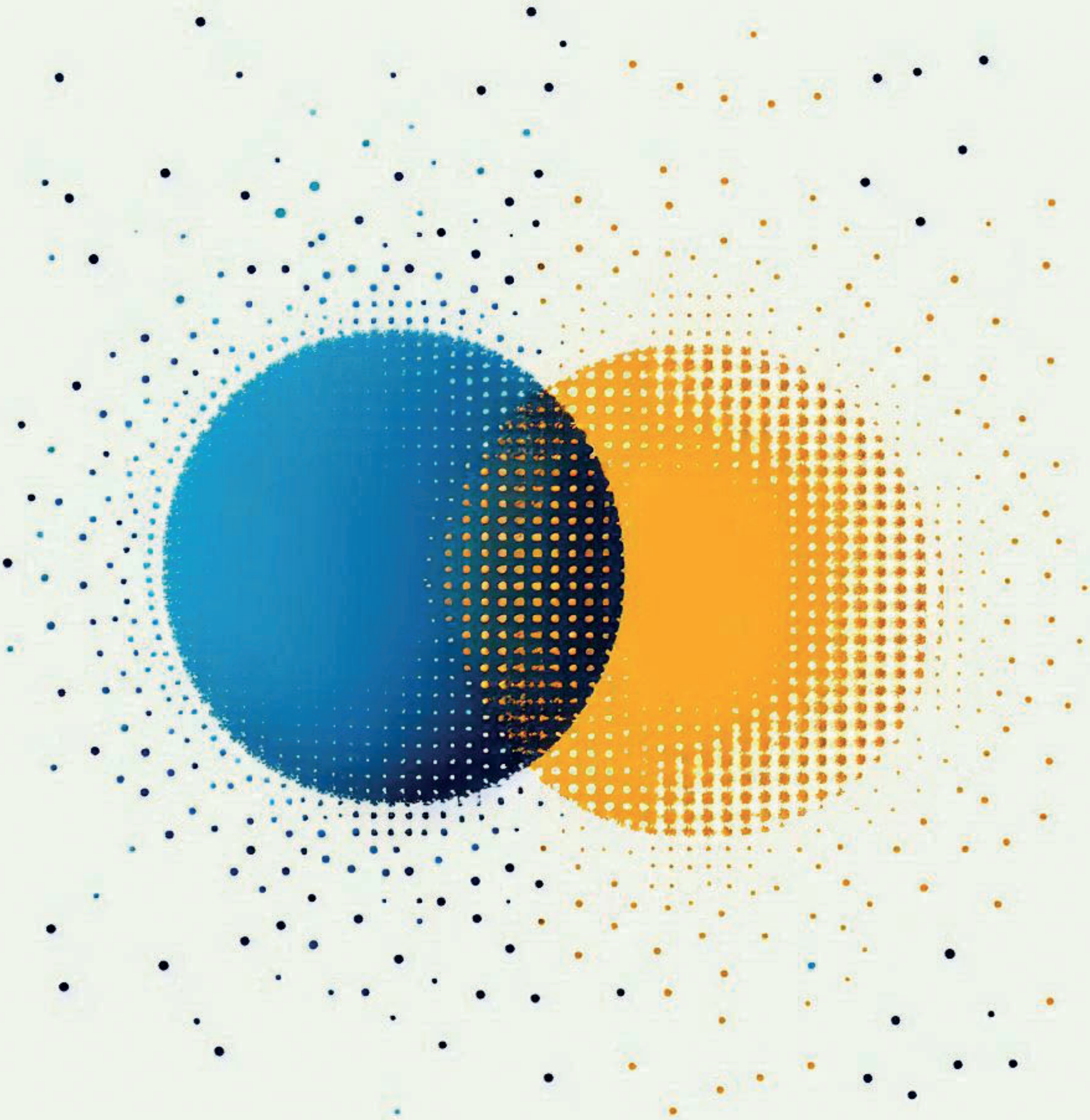
Facilitator 3: Quick gains from using PROMs	Easy-to-use product	I think they are very complete. (..) And also I feel they are easy to fill in. (n) I think the list was extensive, but it wasn't difficult. (p)	Completeness (3) Complexity (4)
	Receiving instant feedback	I found it useful. I already knew I'm physically not in good shape. … I mean, you always talk about it, and now it's crystal clear on paper. (p) The beauty is, also for the patient, that they get their report straight away, all in colours, which is very convenient. (n)	Patient satisfaction (11)
	PROM as a practical tool and time saver	I can immediately focus on the complaints that patients have reported, which is a great opening for further discussion. It doesn't cost any time and I can directly aim to talk about relevant complaints. (d)	Compatibility (5)
	Easy handling and better consultations	I just have to press 'save as' to save the PROM pdf file from Nefrovisie-Renine in Diamant. … A matter of only a few small steps. (s)	Complexity (4)
Facilitator 4: A clear ambition on patient care	A shared view on patient involvement	It's another way of how we work, another way of gathering information and getting different information. Not just medical, but also psychosocial. Yes, I believe this is very important. (n) This is of course a topical issue nationwide, the whole issue that patients should have more say in their treatment. In many professional groups, you notice that PROMs are growing in importance. In my opinion this was not yet the case five years ago. (d)	Professional obligation (10)
	Clear leadership	There was no choice whether personnel would accept it or not. So, we are just going to do this. Some people see the benefits, others don't and consider it to be nonsense. Well, come on. It just has to be done. (n)	Formal ratification by management (19) Coordinator (25)

	Management support	We [dialysis centre; WS] are an island within the hospital. We do something because we think it is important.. (n)	Formal ratification by management (19)

(p) = patient
(d) = doctor
(n) = nurse
(s) = secretary

1. Fleuren MAH, Paulussen TGWM, Dommelen P, Buuren S Van. Towards a measurement instrument for determinants of innovations. Int J Qual Heal Care. 2014;26(5):501–10.

CHAPTER 3



Development and implementation of work-oriented clinical care to empower patients with kidney disease: an adapted intervention mapping approach

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(1) HdeV and WS made equal contributions. BMC does not provide for two first authors.

ABSTRACT

Background
Many people with chronic kidney disease (CKD) have problems to stay at work. Patients and health care professionals (HCPs) see the potential benefit of work-oriented clinical care, yet this care is not manifested in current practice. The aim of this study was to develop and implement a program called work-oriented clinical care for kidney patients (WORK) to support sustainable work participation.

Methods
An adapted version of Intervention Mapping (AIM) was used for the systematic development of work-oriented care in a hospital. Based on the needs of patients and (occupational) health professionals, and in close cooperation with both, a theoretical and empirically based program was developed. Feasibility and clinical utility were assessed among patients with CKD, HCPs and hospital managers. To increase the chances of successful implementation we focused on determinants related to the innovation, the users, the organization (hospital), and socio-political context.

Results
We developed, implemented, and pilot-tested WORK, an innovative program consisting of a care pathway in the hospital that targets patients with work-related questions and tailors the support they receive to their needs. Several practical tools were developed and an internal and external referral structure with a focus on work was implemented. A labor expert was deployed to the hospital to support patients and HCPs with simple work-related questions. The feasibility and clinical utility of WORK were rated positively.

Conclusions
This work-oriented clinical care program provides HCPs in the hospital with the necessary tools to support patients with CKD in dealing with work challenges. HCPs can discuss work with patients at an early stage and support them in anticipating work-related challenges. HCPs can also bridge the gap to

more specialized help if necessary. WORK has the potential for wider application in other departments and hospitals. So far, the implementation of the WORK program was successful, though structural implementation may be challenging.

BACKGROUND

Where in the past having a paid job was often regarded as a risk factor for health, it is now regarded as a determinant of health [1–3]. Work gives meaning and structure to people's lives and leads to better health outcomes [4, 5]. This includes people with kidney disease [6, 7], for whom employment significantly contributes to general well-being, mental health, and quality of life [8, 9]. In this study we focus on working age patients with chronic kidney diseases (CKD) categories G3b5. The ability of many patients with CKD to maintain their work is severely limited by physical and cognitive complaints [10, 11] and, in case of dialysis, by the necessity for timely and intensive medical treatment. Patients experience uncertainty about the course of the illness, their employers' responses, and legislation and regulations [9] and have an increased risk of long-term absenteeism, loss of employment, and loss of income [12]. These patients experience work as a continuous learning process with a constant need for adjustments [13, 14].

Despite these challenges, people with diagnosed CKD across different categories indicate that sustainable work participation is an important goal and many are highly motivated to achieve this goal [13, 15]. Therefore, it is important to give more attention to the work-related challenges people with CKD may experience. This importance is increasingly recognized within curative care [16]. HCPs in the hospital may play an important role in preparing patients with CKD early regarding how treatment may interfere with work and signaling other problems that may arise related to work participation [12]. In addition, HCPs may refer to appropriate work-oriented support outside the hospital. However, current guidance and support in terms of work retention for patients with CKD is still inadequate, and many patients have no place to go with their work-related questions [9]. Moreover, HCPs experience a lack of referral options. For example, though nephrology care has the potential to support patients dealing with the challenges of working with a kidney disease (such as advising them about the choice of dialysis modality [17]), this is not established in current practice [16]. In conclusion, so far there is no culture of work-oriented medical care in hospitals [4, 18–20].

The primary aim of this study was to develop and implement work-oriented clinical care for kidney patients (WORK). For that purpose, we aimed to create a culture that recognizes the importance of HCPs providing work-oriented medical care in the hospital, such that attention to the impact of CKD on the work life of patients becomes a more natural part of care. Feasibility and clinical utility were assessed among patients with CKD, HCPs and hospital managers. The secondary aim was to strengthen the self-direction of patients with CKD by engaging and empowering them.

METHODS

Design

In this study, we used the adapted version of intervention mapping (AIM) [21, 22]. AIM is guided by the six steps of Intervention mapping for development, implementation and evaluation of theory and evidence-based health promotion intervention [23]. In the adapted version, the principles of participatory action research are added, where all stakeholders are working and learning together and have a fair say in the fulfillment of the innovation. Producing and applying knowledge with all stakeholders at the same time provides insight into what may and what may not work. This strategy increases the chance of producing a care innovation that is suitable, acceptable, feasible, and effective and thereby increases the chances of successful adoption and implementation [21]. This study takes a person-centered perspective, putting patients, their way of living, and their personal contexts at the forefront. In addition, this study sees the patient as an active participant in care [24].

Study setting

Our study was initiated by the University Medical Centre Groningen (UMCG), a leading hospital in the northern part of the Netherlands. The Department of Nephrology offers care for patients with early categories of kidney failure and dialysis and transplantation for patients with kidney failure. The UMCG has a full-service Nephrology Department with close connections to other hospitals – both regionally and nationwide. Furthermore, within the hospital setting a separate dialysis unit offers treatment for patients who need less complicated care. This unit has multiple centers around the city of Groningen.

The Dutch healthcare system provides every citizen with full coverage of medical costs regardless of age, employment status, or health care status. It is a hybrid system with central governmental regulation and private insurance companies that contract private healthcare providers such as hospitals. The social security system for patients who lose their jobs for medical reasons is separate from the health care system. Employers are obliged to pay employees during sick leave, for a maximum of two years. Occupational physicians, who are not involved in the medical treatment of patients, support and advice workers and employers on issues related to work and health, in order to reduce long-term sick leave and work disability and to facilitate sustainable employment. During the first two years of sick leave, a labor expert may be involved, who can advise on reintegration options and empower workers to find the right information or support. After two years of sick leave, the employee can be fired. Employees may then receive financial support from a governmental agency called the Institute for Employee Insurance (UWV). To get admitted to the employee benefits scheme (WIA), an insurance physician from UWV must rule on the employee's ability to work. In general, if the employee has no work ability, they can be paid out 70% of the last earned wages, up to a maximum of 100%. When people are partially unable to work, the system encourages them to work: if you have a job, you get paid more and the allowance is only partly reduced. However, the system for self-employed workers, approximately 17% of the Dutch workforce [25], is different. Self-employed workers have no access to the WIA. While many choose private insurance to avoid loss of income, a large group (40%) do not [26], partly because these insurance premiums are high. Thus, if workers get sick and not able to work, they risk living without income and, as a consequence, may rely on their savings during their sick leave.

Establishing project organization and stakeholder participation

The project was organized by establishing a Core team, a Taskforce, and an Advisory Board (see Appendix I). Agreements were made about decision-making, collaboration, learning, and reflection. Participation of stakeholders was secured at four relevant perspectives: 1) patients with all categories of CKD; 2) HCPs in the hospital (nephrologists, kidney care nurse specialists, social workers); 3) occupational health professionals (occupational health physician, labor expert, insurance physician); and 4) researchers with a focus on work and health. Four project leaders of the Core team, who represented all four stakeholder perspectives, were responsible for the project's progress. Each individual member of the Core team acted as coordinator and linking pin to the Taskforce, in which several additional representatives of each of the various stakeholder groups participated. An Advisory Board was formed in order to include knowledge from employer representatives, other hospitals, professional groups, and knowledge institutes and to facilitate the possibility of later extrapolating the knowledge acquired during this project to nephrological departments in other hospitals or to care of other chronic diseases. The Advisory Board met twice during the project, at the beginning and at the end. Furthermore, to seek advice and best practices, regular consultations were held with other groups in the Netherlands that are involved in the development of work-oriented clinical care, including the Maastricht University Medical Center (MUMC), the Radboud University Medical Center (RUMC), and the Fit for Work platform, a group committed to job retention for people with chronic conditions.

Data collection

For the development of the intervention, we carried out the first five prescribed phases of AIM and made a start on the sixth phase [21]. AIM has an iterative nature that allows for moving back and forth between phases and incorporating the feedback of stakeholders, with each phase based on the previous phases. Applying AIM consists of several AIM meetings with the Core team and Taskforce or Advisory Board (see Table 1).

Table 1 Intervention mapping process (adapted from Belansky et al., 2013 [22])

AIM phases	Meeting	Who	Topic
Phase 1: Formulating program goals	*1*	Core team and Taskforce	Personal introduction Introduction of the project Making agreements about decision-making, collaboration, learning and reflection
	2	Core team and Taskforce (in subgroups)	Needs assessment Agree on a definition of work-oriented medical care Validating and refining scientific knowledge about labor participation Identifying gaps in work-oriented care in the hospital Joint formulation and reporting of program goals
Phase 2: Defining change objectives	*3-4*	Core team	Stating expected outcomes for behavior and environment Specifying performance objectives (what or who needs to change) Construct matrices and prioritizing of change objectives
Phase 3: Selecting theory-based methods and practical applications	*5*	Core team and Advisory board	Seek advice and best practices with regard to the development and implementation of work oriented medical care
	6	Core team and Taskforce	Generating program themes, components, scope, and sequence Choose theory- and evidence-based change methods Selecting practical applications and best practices to achieve change objectives
Phase 4: Developing the program	*7-8*	Core team and Taskforce	Converting knowledge into a concrete action plan (who will do what, when and how) Identifying conditions, barriers, and challenges Pilot testing, refining and adjusting materials

	9	Core team and Advisory board	Ask for response from the Advisory board on practical products, planned implementation, and seek advice about dissemination
Phase 5: Adoption and implementation of the program	*10*	Core team	Design implementation plan and strategies Identifying potential users/implementers Defining outcomes of adoption and implementation
Phase 6: Reflection and evaluation	*All meetings*	Core team	Reflection on the process Feasibility and clinical utility

In the years 2020–2021, the Taskforce met 10 times. As a result of COVID-19, some meetings were organized digitally or in hybrid form and some of these AIM meetings took place in subgroups. From the onset, we realized that power dynamics could interfere with the group process, where doctors, nurses and patient were supposed to work together as a group. During the first AIM meetings an external facilitator smoothened the process between the group members, who introduced themselves to each other and shared their background and their interests. This was done in an informal setting and helped to set the rules of open communication and equal contribution. Each meeting lasted approximately two hours. The Core team took turns leading sections of each meeting and taking notes, and jointly completed a debriefing form at the conclusion of the session, so that the results could be included in the further development of the innovation. During the meetings all stakeholders jointly discussed themes, shared knowledge, reflected, learned, and worked together to develop the program. In later phases of development, the role of the Taskforce was to assess (intermediate) products, provide input, contribute with ideas, and validate the WORK program.

In phase six, the first evaluation of WORK focused on feasibility [27] and utility of the program for clinical practice [28]. Feasibility was defined as the extent to which the program proved to be feasible in practice, and clinical utility was defined as the extent to which the program had utility or added value for HCPs and patients, as well as the advantages and disadvantages of working with the WORK program. To explore feasibility and clinical utility, short questionnaires were given to patients with CKD and short semi-structured qualitative interviews were conducted with HCPs and managers in the hospital (Appendices II and III) . This study of the effectiveness of the WORK program is not within the scope of the current paper and will be presented when available in a separate paper.

Data analysis

Minutes and logs of each AIM meeting were kept, and data was transcribed. Subsequently, data was analyzed, and a meeting report provided to the participants. During each following meeting there was reflection in the Core team to validate the findings. The level of implementation (fully, partially, or not implemented) was independently scored by HdV, AV, and WS and discussed until agreement was found. Evaluation of and reflection on the process was conducted during meetings with the Core team. For the evaluation of feasibility and clinical utility, qualitative thematic analyses and descriptive quantitative data analyses were applied.

RESULTS

The WORK project was conducted from February 2020, with the organization of a first meeting with the Taskforce, to November 2022, when the project ended with the evaluation with patients and HCPs. The results are presented here per phase, with the corresponding AIM meetings that took place.

Phase 1: Formulating program goals

Phase 1 involved a needs assessment to identify the needs of patients with CKD and HCPs related to work-oriented care in the hospital. The previously conducted CKD@Work study [9, 11] resulted in themes such as the meaning of work [9], barriers and facilitators of sustained employment [9], and associations between patient characteristics, type of treatment and employment status [10, 11]. These themes were discussed, validated and, if necessary, refined or supplemented, taking into account the different needs that emerged from the different perspectives. Patients with CKD indicated that work is important for participation and income, but that they often have difficulties to stay at work and dealing with complicated administrative procedures in the event of long-term absenteeism. In this regard, patients currently experience little support from the hospital, and they report that more attention to work is warranted. They indicated that the type of treatment they receive can influence their ability to work (see for examples Table 2) and that doctors often do not take interference of treatment on work into account. Patients therefore emphasized the need for work-oriented clinical care and involvement of the nephrologist. Good communication between nephrologist and occupational physician was also recommended, which is rarely the case in practice. Patients also indicated that it is important to them that their own agency be strengthened. The HCPs of the hospital saw it as their task to pay attention to work and to be more aware of the value of work for patients and the role they can play in signaling work challenges, preferably early in the disease process. In particular, nephrologists reported lack of time, knowledge, skills, and referral options, which hinders them from discussing work with patients. They therefore need work-oriented care that can be easily integrated into healthcare, takes little time, and has an easier referral process for patients. There is also a need for easy ways of exchanging information between professionals inside and outside the hospital, a process that is currently encumbered by strict privacy legislation. The occupational health professionals believe that the current focus in the hospital is too centered on medical treatment and not centered enough on the possibilities for patients to participate optimally in work. Occupational health professionals expressed the need to broaden the scope of clinical care and to develop work-oriented clinical care intended to facilitate access to the occupational healthcare already available outside the hospital.

Table 2 Examples to overcome interference of CKD treatment and work

Health care professionals in the hospital can make an effort to coordinate work and treatment. For example:

- Transplant or dialysis schedules can be planned in consultation with the patient, who may have preferences related to work. Dialysis can be performed at times outside of working hours that are more feasible for people still working (e.g., evenings or weekends)
- Exercise shared decision making about dialysis modality. Sometimes an Arteriovenous Fistula / Arteriovenous Graft (AVF/AVG) is needed, but if the patient is on the waiting list for transplant, consider working with a jugular central venous catheter for longer than normal. Peritoneal or hemodialysis: peritoneal dialysis is more flexible, especially the nocturnal form (APD). Discuss the fact that the peritoneum is a wearable artificial kidney
- AVF/AVG placement is always in the least used arm, but that arm must be spared for the rest of life. This limits patients who still (want to) do physical work, or play sports (e.g., tennis)
- Before and after transplant, (vocational) rehabilitation can be recommended. In general, the fitter patients are on the operating table, the faster they will recover and be able to resume work

In all cases, choices must be logistically feasible and medically justified.

In the second AIM meeting, agreement was reached regarding what work-oriented clinical care entails. Work-oriented medical care was defined as “care in the hospital aimed at supporting sustainable employability of patients with CKD who work or want to work and should focus on patients in different categories of the disease (predialysis, dialysis, and transplantation)”. Based on the first meeting, it was established that the benefit of work-oriented care mainly lies in targeting patients and offering simple support and appropriate referral. This entails attention to adapting CKD treatment to the patients’ work context in cooperation with the nephrologist, providing education and information about working with CKD, and, if needed, referring the patient to specialized work-oriented care inside or outside the hospital. We see the hospital as a bridge between patients and work related care, preferably in an early stage of the disease. Offering work and mediating to find work are not part of the WORK program.

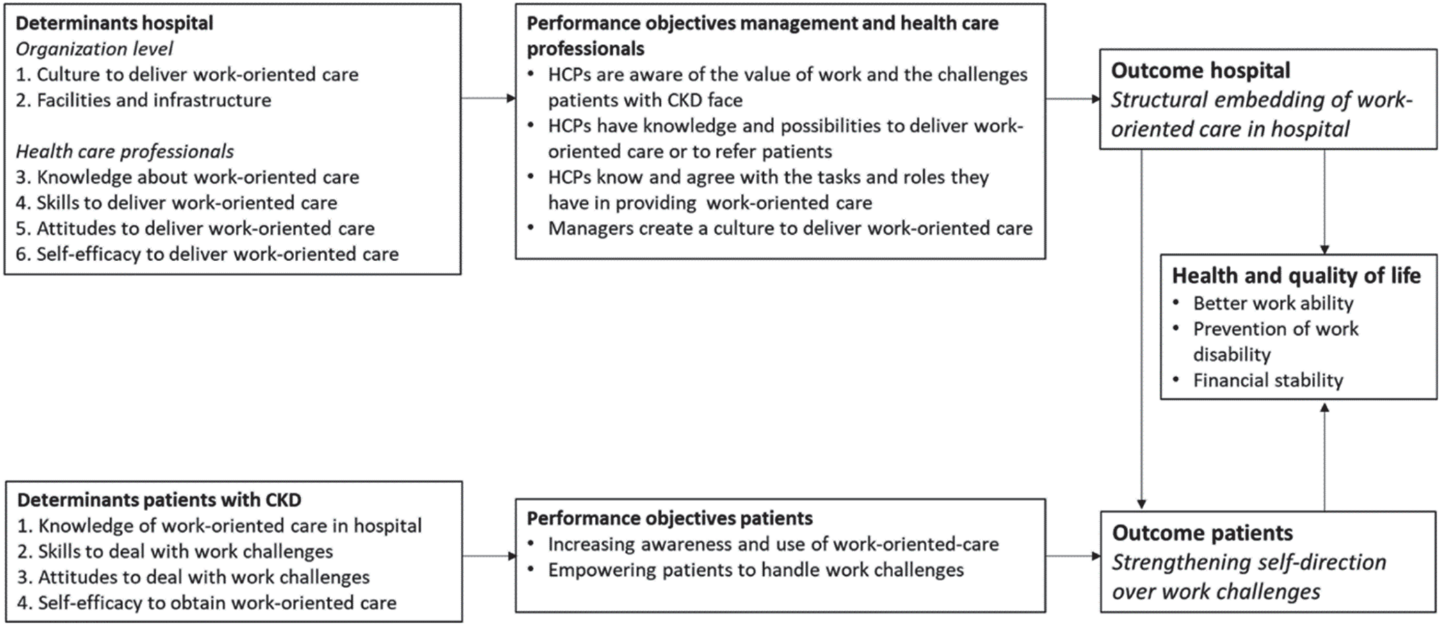
To realize the WORK program, we refined and established two aims: 1) Structural embedding of work-oriented care in the hospital. This goal aimed to create a culture in which the importance of work-oriented medical care is recognized by HCPs (i.e., nephrologists, nurses and social workers), and where attention to work becomes a more natural part of care in the hospital; 2) Strengthening self-direction of patients with CKD to deal with work challenges. The ultimate aim of the program was for patients with CKD to gain better work ability, sustainable employability, and financial stability, which will in turn contribute to better health.

Phase 2: Defining change objectives

In phase 2, during the third and fourth AIM meetings, expected outcomes for the hospital (managers and HCPs) and patients with CKD were discussed. In addition, performance objectives were defined, which indicate what needs to be done to accomplish the outcomes. A logic model of change was developed (Fig. 1) to visualize the determinants that need to be considered in developing the program, the anticipated performance objectives, and the potential outcomes for both the hospital and patients with CKD.

Based on the logic model of change, a matrix of change objectives was constructed (see Appendix II). The performance objectives of both the hospital (management, HCPs) and patients with CKD are presented in the first column of the matrix. The associated change objectives in the following columns indicate what hospital management, HCPs and patients with CKD need to learn or change to achieve the performance objectives. To enable HCPs to learn to apply the WORK program and embed it in the hospital, the Attitude-Social influence-Efficacy (ASE) model [29] was selected and supplemented with knowledge, skills, and facilities. We used the ASE-model because it has proven to be useful for predicting and explaining behavior change among HCPs [30]. These ASE-determinants were translated into change objectives for the work-oriented support intervention.

Fig. 1 A logic model of change



Determinants hospital
Organization level
1. Culture to deliver work-oriented care
2. Facilities and infrastructure

Health care professionals
3. Knowledge about work-oriented care
4. Skills to deliver work-oriented care
5. Attitudes to deliver work-oriented care
6. Self-efficacy to deliver work-oriented care

Performance objectives management and health care professionals
- HCPs are aware of the value of work and the challenges patients with CKD face
- HCPs have knowledge and possibilities to deliver work-oriented care or to refer patients
- HCPs know and agree with the tasks and roles they have in providing work-oriented care
- Managers create a culture to deliver work-oriented care

Outcome hospital
Structural embedding of work-oriented care in hospital

Health and quality of life
- Better work ability
- Prevention of work disability
- Financial stability

Determinants patients with CKD
1. Knowledge of work-oriented care in hospital
2. Skills to deal with work challenges
3. Attitudes to deal with work challenges
4. Self-efficacy to obtain work-oriented care

Performance objectives patients
- Increasing awareness and use of work-oriented-care
- Empowering patients to handle work challenges

Outcome patients
Strengthening self-direction over work challenges

Phase 3: Selecting theory-based methods and practical applications

To accomplish the change objectives of the hospital (management and HCPs) and patients with CKD, several theory-based methods and practical applications were selected (see Appendix III). The selected methods were derived from the literature [23], whereas the practical applications were developed based on consultation with stakeholders during AIM meetings and with the Taskforce and Advisory Board. Some practical applications were also inspired by other initiatives and best practices on work-oriented care according to the Support and Advice Center of the Dutch Association for Kidney Patients, MUMC [31], RUMC [32], and the Fit for Work platform.

Phase 4: Developing the program

During AIM meetings with the Taskforce, the results of phase 3 were converted into concrete tools or actions.

Structural embedding

Most hospital managers and HCPs endorsed the need for work-oriented care. However, a supportive culture, facilities, and infrastructure to provide such care was lacking. Nephrologists mentioned that they lacked time, knowledge, and referral options. Given patients' wishes to involve nephrologists, as well as the Royal Dutch Medical Association's (KNMG) recommendation to incorporate work participation as an essential part of medical care, the Core team decided to involve nephrologists. Subsequently, the aforementioned barriers were anticipated on by developing three work questions (takes little time and requires no knowledge) and by involving high quality work-related expertise of a labor expert from the Center for Rehabilitation UMCG for half-day per week to offer expertise and referral options. The three work questions were integrated in workflow processes and administrative systems of nephrologists, nurses, and social workers in the hospital. As a reminder, the same three work questions were distributed via conversation cards and desk calendars. The basic principle was that the three work questions should be asked to all new patients early in the disease process and then repeated at later moments. In consultation with the HCPs, we decided to give the social worker an important task in coordination (though in other departments this could instead fall to the nurse or nurse specialist). Based on the advice of the relevant work-related experts, we developed an indexation scheme by which social workers can quickly determine when referral to a labor expert is necessary, especially for patients at extra risk of dropout or problems at work. We deployed a labor expert in order to offer this expertise within the hospital. In addition to the labor expert, patients could be referred to the Support and Advice Center of the Dutch Association for Kidney Patients for more long-term support. Referral to a rehabilitation center was also made easier (in case of complex work-related questions).

Strengthen self-direction of patients with CKD

To strengthen the self-direction of patients with CKD, we first of all looked at which existing best practices and informational materials were available that fit the change objectives formulated in Phase 3. For example, materials from the Dutch Association for Kidney Patients and the Fit for Work platform were adopted. Additionally, with the help of a graphic designer, visually appealing and well-arranged program materials were designed. Patients were encouraged to think about work and, if desired, to discuss this with their HCP via brochures ("Keep working, how do I do it?"), discussion cards with the three work questions, posters, messages on the video screens at the outpatient clinic, and information on the program that was added to the invitation letters. Patients who indicated a need for information or support based on the three work questions were referred to the social worker who indicated (on the basis of risk factors) and provided tailor-made care. In many cases, this meant a referral to the labor expert who was present at the outpatient clinic for a fixed part of the week. Tools were also developed to give patients more knowledge about what to expect when working with CKD and how to prepare for it, for example to improve knowledge about legislation and regulations. The patients involved indicated that patients should not be overloaded with written materials, so we limited those materials to what is necessary. For legal questions or support, external referral opportunities were created. In addition, for complex cases referral to vocational rehabilitation was facilitated.

Phase 5: Adoption and implementation of the program

Phase five yielded the development of an implementation plan (i.e., strategies to enable adoption, implementation, and continuation of the program). For this purpose, we used the framework and measurement instrument for determinants of innovations (MIDI) [33].

We anticipated on four categories of determinants that may influence adoption, implementation, and continuation of the program: 1) characteristics of the innovative WORK program, 2) future users (HCPs in the hospital) and end users (patients with CKD), 3) the organization (UMCG and Department of Nephrology), and 4) the socio-political context [33].

The target outcome with regard to adoption is that HCPs understand and endorse the intention of the WORK program, are positive about the rationale and purpose, and are willing to apply it in practice. The ideal implementation outcome is that HCPs involved apply the WORK program in their clinical practice with patients with CKD. The target outcome for continuation is that the WORK program is carried on within the Nephrology Department and expanded to other departments of the hospital. Table 4 shows the authors' retrospective assessment of the extent to which we were able to ensure the achievement of these determinants on a three-point scale (+ , ± , -).

Table 4. Determinants for successful implementation of the WORK program

1. Innovation
- Compatibility with current care (+)
- Complexity (+/-)
- Procedural clarity (+)
- Appealing (+)
- Relevance for patients (+)
- Expected advantage for patients (+)
- Visibility of outcomes (+/-)
- Users involved in development (+)
- Prevalence (+/-)

2. Users (HCPs)
- Awareness of content of innovation (+)
- Knowledge and skills (+)
- Subjective norms (+)
- Job perceptions (+/-)

End users (patients with CKD)
- Knowledge about the program (+/-)
- Patient cooperation (+)
- Patient satisfaction (+)

3. Organization
- Formal ratification by management (+)
- Vision, person-centered care (+/-)
- Material resources and facilities (+)
- Financial resources (+/-)
- Time available (+/-)
- Use of opinion leaders, ambassadors (+/-)
- Use of a coordinator, project group (+/-)
- Information accessible about use of innovation (+)
- Feedback to users about innovation process (+)

- Personal benefits (+/-) - Social support (supervisors, colleagues) (+/-) - Self-efficacy (+) - Overload (-) - Opposing goals or interests (+/-)	- Turbulence in organization, COVID-19 pandemic (-) **4. Socio-political context** - Fit with existing legislation and regulations (+/-) - Work-focused care on political agenda (+/-) - Participatory society, emphasis on self-reliance +) - Cuts to innovation budgets (-)

Innovation

The WORK program was practically and technically compatible with current clinical care. Appealing tools and products were developed that fit in the current treatment and care processes and these were acceptable for clinical practice. For example, we limited the nephrologists’ time investment in this program to a minimum. This is important because adoption in clinical practice is a prerequisite for further implementation. The WORK program is clearly described in a flowchart and is not complicated to understand. After getting feedback on patients’ experiences with the program, we tried to clarify further the relevance and the expected benefits for HCPs. All stakeholders and users were involved in the development of the program, and they all expect advantages of the program for patients with CKD. Although working with kidney disease is a challenge for many patients, these challenges concern a relatively small patient group since more than half of the patients with CKD are older than 65.

Users

In the CKD@Work study, it was already shown that HCPs endorse the importance of work-oriented clinical care. We aimed to further spread this belief in the department through increasing the awareness of other HCPs by informing and involving them from the start. The labor experts provided a short workshop for social workers, and we developed practical tools and the possibility to refer to the labor expert to equip HCPs with knowledge and skills and to increase self-efficacy for offering work-oriented care. Clarity in the hospital around who is responsible for which task was improved, so that HCPs gained confidence to carry out the program. Pilot data showed that both HCPs and patients were satisfied with WORK. Nevertheless, it remained unclear whether HCPs experienced personal benefit by applying the program and whether they experienced support from colleagues or supervisors. HCPs, in particular nephrologists, regularly indicated heavy workloads and therefore had to set priorities (sometimes have other goals and interests, e.g., conducting medical research or believing that work-oriented care is not per se part of being a doctor), which made adoption of the program more difficult.

End users (patients with CKD)

A lot of attention was paid to informing patients about the attention to work in healthcare, including by distributing brochures, discussion cards, and posters. The expectation was that this would provide patients with sufficient opportunity to become familiar with the WORK program and take advantage of it. However, only a small portion of all patients took the initiative to ask work-related questions to their doctor or another HCP. Patients who participated in WORK were very satisfied and really benefited from it.

Organization

Higher management in the hospital supported WORK, and the development was formally ratified. Most managers and HCPs at the department endorsed the need for work-oriented care. Delivering person-centered care is a part of the hospital's vision statement; however, work-oriented care is not mentioned. Material resources and facilities, such as consulting rooms, were identified and made available for use in the program. Financial resources were available for the duration of the study; however, prolongation thereafter is unsure. Although we minimized the time required to provide work-oriented clinical care, some nephrologists still indicated that competing priorities in the hospital restricted the time available to apply the program. To encourage adoption, we identified early adapters and used them as engaged ambassadors who promoted the program within the department. Middle and higher management and HCPs were regularly informed about the program and information was made accessible to patients and HCPs. The COVID-19 pandemic measures forced HCPs and some members of the project group to temporarily be involved in care for

COVID-19 patients. This turbulent phase did not help with the adoption and implementation of the program.

Socio-political context

The Dutch government has created a “participatory society” and emphasizes the need for all people to be self-reliant. A work-oriented clinical care program that supports patients to continue work participation despite illness fits well into this participatory approach. However, work-oriented clinical care and its financing has no formal basis yet. A financial barrier in the continuation of WORK is that funds that were previously available for healthcare innovation have been reduced and there is tremendous competition from costly technological innovation.

Phase 6: Reflection and evaluation

Reflection on the process

A variety of hospital HCPs, patients from diverse backgrounds and external professionals who were already involved in occupational health were brought together to develop practical tools to help patients deal with work challenges. The chosen working method was labor intensive and time consuming. We admire the perseverance of all participants, the energy they had, and the knowledge they shared. Everybody was respectful to other parties and eager to learn from other perspectives, even though at some moments tension between different perspectives was felt. An important success factor of the project was the continuous team cooperation without anyone dropping out. All team members were dedicated throughout the project to produce results, reflect on preliminary findings, and continue to improve them. We feel that the organization of our project, with a dedicated Core team and an extended team with a diversity of participants, highly contributed to this continuous commitment. However, we also encountered some power dynamics during the project. Not all patients felt comfortable entering into discussion with high-educated professionals and expressing their ideas. In addition, tension was sometimes felt between external and internal participants at some moments. We dealt with this by additional communication between the Core team and the concerning participants.

As was mentioned earlier, the original development process (with live meetings and discussions) had to be adjusted due to the sudden emergence of COVID-19 restrictions. As the project continued, it was becoming clear that live meetings with the intended groups were not going to happen again. After two live meetings, all meetings were online using Microsoft Teams. In the early stages of the project not everyone was comfortable using Teams, however as time passed everyone became more comfortable. It is well possible that the enduring commitment to the project was facilitated by the online nature of the meetings, however we feel that live interaction in such an innovative project would have been more satisfactory for the participants.

Evaluation

Feasibility and clinical utility

The feasibility and clinical utility of WORK was evaluated among patients with CKD, HCPs and hospital managers. Questions were focused on satisfaction, practicability, acceptability, accessibility, and comprehensibility.

Patients

Patients' experiences with WORK were explored via a digital survey (Appendix IV). A total of 21 patients completed the digital survey (response: 33%), with a mean age of 46 years (range 23–61), and balanced gender representation. Sixty-six percent of the respondents did not have renal replacement therapy (medication, diet or pre-dialysis), 5% had hemodialysis, and 29% had undergone transplantation. Most patients were permanently employed (17/21) and had contact with an occupational health physician (16/21). A quarter of them did mentally demanding work, another quarter did physically demanding work, and the rest a combination of mentally and physically demanding work.

Patients assessed WORK with an average of 8.3 (with scores ranging from 5–10). All patients indicated that they find the attention for work in the hospital important (21/21) and the majority also reported that the doctor should discuss work with patients (16/21). The majority of patients (14/21) reported that the labor expert has given them more knowledge and motivation to continue working. About half indicated that they had started to do things differently with regard to work (9/19), had more control over their kidney disease (10/18), and had entered into a discussion with the employer (7/15). The majority of patients had also become aware of the obligatory steps that must be taken in re-integration during the first two years of illness (12/18). In all, the results of the evaluation of the clinical utility indicate that WORK may help patients to extend their capabilities to deal with work-related health conditions and allows them to become more self-directed. Most patients experienced WORK as a complete program (18/21). Some patients would have liked the information earlier in the disease trajectory or would have liked more or longer term support from the labor expert.

Health care professionals

Interviews were held with two hospital managers and nine HCPs, i.e. three nephrologists, three social workers, two nurses and the labor expert (Appendix V). Average age of HCPs was 43.4 years (range 26–62 years) and on average they have 21.8 years of experience (range 5–39 years). They were asked to rate WORK on three components 1) the content, 2) the development and 3) the implementation.

The development of WORK was assessed with an average of 8 on a scale from 1–10. The way in which all stakeholders were involved in the development of WORK and the commitment of the project group were both assessed positively, although it was reported that the process was sometimes very demanding.

The content of WORK was also rated with an average score of 8. The involvement of the labor expert was positive, the flow diagram of the care pathway to target patients and tailor the support to their individual needs was pleasant and easy to use, and the three work questions were applicable. The other developed materials, such as the explanation about the Gatekeeper Improvement Act, were rarely used.

The implementation of WORK was assessed with an average score of 8.4. During a period of five months, 68 patients with CKD were referred to the labor expert. The participants indicated that the integration of the three work questions in the electronic patient files provided a reminder to pay attention to WORK. Some HCPs indicated that the referral to the labor expert could have been more user-friendly. They did not fully understand how it worked and needed explanation.

DISCUSSION

Many people with CKD have problems staying employed [12]. Patients and HCPs see the added value of work-oriented care, but so far this has received little attention in hospital care [16]. In collaboration with patients, doctors, nurses, social workers, and occupational and insurance physicians we developed and implemented work-oriented care in a hospital environment. We have focused on achieving two aims: 1) structurally embedding work-orientated care into the hospital, creating a culture in which the importance of work-oriented medical care is recognized by HCPs, and 2) strengthening the self-direction of patients with CKD for dealing with work challenges.

AIM was used for the systematic development, implementation, and evaluation of WORK. The process of developing WORK went well according to plan and timeframe, despite the difficulties arising from the COVID-19 pandemic. The final program was comprised of a care pathway including the targeting of patients (by the nephrologist or nurse), risk stratification, and tailored support. We anticipated needs from different stakeholder perspectives. The tools we developed may give HCPs more guidance to target patients who are struggling with work related issues and to refer these patients, if necessary, for appropriate support. The labor expert deployed for the project provided a point of contact at the outpatient clinic, which improved the accessibility of WORK. The practical tools may help patients to increase their self-management capabilities and to become well informed about the possibilities to work with CKD.

The implementation of WORK went well since most tools were used and appreciated both by HCPs and patients. Although all HCPs regarded the developed care path as rather easy and logical, an important barrier was the actual low readiness of some doctors to use the targeting tool. There is not always room for work-oriented care in nephrologists' job perceptions. We argue that doctors have competing priorities during consultation and logically need to discuss the medical condition of the patients. Excess time to discuss work-related issues is often not available, which was also found by another study [31]. On the other hand, we noticed that a doctor's personal motivation and ambition to provide work-oriented care was helpful to success. The will to provide work-oriented care was also present among the management, however the financial possibility to facilitate this was lacking. Financing work-oriented expertise (such as work provided by the labor expert) currently depends on the goodwill of the department or on temporary financing flows, such as project funds or innovation funds. Only a small portion of all patients took the initiative to ask work-related questions of their doctor. We argue that patients need time to realize that their hospital offers support on work challenges that might arise from their chronic illness. A culture change is not only needed at the HCPs and the hospital, but also among the patients. However, we stress that patients, beyond our scope, may use the practical tools and brochures to enhance their self-management capabilities and may feel no need to ask for additional support in the hospital.

A few limitations of this study should be mentioned. More than half of the people with CKD are 65 years or older and retired. As a result, the subject of "work" was perhaps less self-evident among the HCPs at the Nephrology Department. However, we expect that the results of this study can also be used in other diagnosis groups or other hospitals with a different context. A first exploration among the Departments of Endocrinology and Oncology shows that the need for work-oriented care might be even stronger there. Further, in this study the clinical utility of WORK was found positive, however, we have not yet been able to fully determine whether WORK leads to more self-direction and job retention. We must emphasize that a project of one and a half years is not long enough to structurally embed work-oriented care into the hospital. Within the available time frame, only the first steps of implementation could be taken. Embedding and continuation of this service of work-oriented care is a cultural change that takes more effort and time. We noticed that continuation of work-oriented clinical care needs a broader perspective and discussion about the scope of healthcare within the hospital, both on the department level and on the Board level. Management support may encourage such non-medical initiatives on the work floor. On a national level, we feel it is important that initiatives on work-oriented services in hospitals are combined and that a joint effort is undertaken to find out what is functioning best and what potential benefits it brings for patients and society. We feel this gap should be filled in the upcoming years as more people suffer from chronic illness and the labor market becomes tighter due to an aging population.

Implications for practice

With the present program, work-oriented clinical care was implemented at the Department of Nephrology in the UMCG. Two other departments within the hospital (Endocrinology and Oncology) have already started using the program and supporting their patients with work-related challenges. This is a promising development for continuation, and it can help to make work-oriented care in the hospital a permanent part of healthcare. The knowledge acquired from this work-oriented program, including the tools that were developed, can also be easily converted and used by nephrology departments in other hospitals and for other groups of chronically ill patients.

The main challenges for implementation and continuation are that attention to work must fit into existing care structures, fit the needs of users, fit the vision of the organization, and become embedded in organizational policy. The awareness of HCPs in the hospital regarding work challenges may improve the early identification of patients at risk for prolonged time away from work and may allow for early supportive intervention over the entire care process of patients with CKD [12]. To achieve continuity, advocacy and lobbying are needed to establish the structural (financial) resources to maintain the program.

Implications for research

Further research is needed to gain more insight into how patients can be empowered in returning to work from the hospital. To guide further development and implementation of the program, it will be necessary to explore how and under what circumstances outcomes are achieved. Therefore, the effectiveness of work-oriented clinical care could be examined using realistic evaluation [34]. Realistic evaluation is a theory-driven evaluation method that is increasingly used for studying the implementation of complex interventions within health systems. Realistic evaluation can be employed to explore how the program, with its specified performance- and change objectives, affects the outcomes.

Conclusions

We developed and implemented WORK at the Department of Nephrology in a large hospital. Feasibility and clinical utility of WORK were rated positively. WORK offers HCPs in the hospital the necessary support and tools to empower patients with CKD to cope with work challenges. HCPs can discuss work in an early stage of care, support patients in anticipating potential work challenges, and bridge the gap to more specialized help if needed. So far, the implementation of the program has been successful, though structural implementation may be challenging.

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Abbreviations

AIM	Adapted intervention mapping
HCP	Health care professional
CKD	Chronic kidney disease
WORK	Work-oriented clinical care for kidney patients
UMCG	University Medical Centre Groningen
UWV	Institute for Employee Insurance
WIA	Employee benefits scheme

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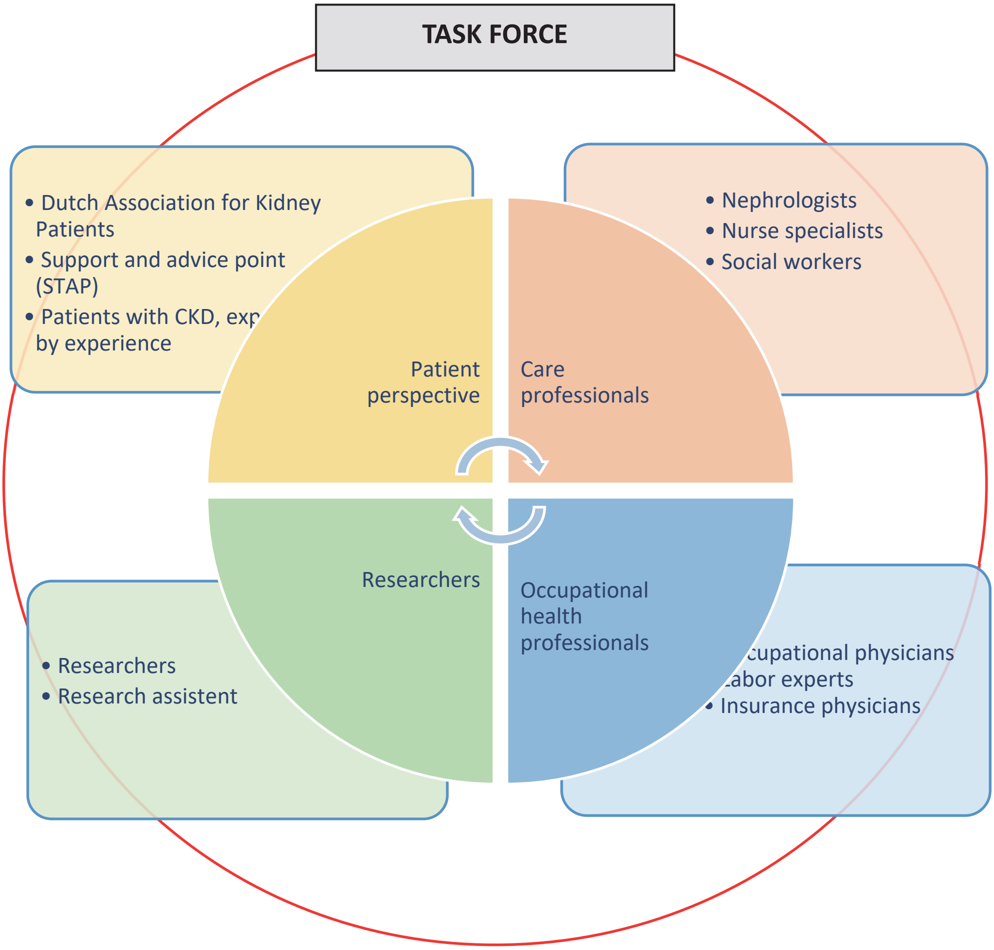
APPENDIX I

Core Team (centre), Taskforce and Advisory Board



ADVISORY BOARD

Representatives of patients with CKD (Dutch Association for Kidney Patients); representatives of the Dutch Association of Occupational Medicine (NVAB), the Dutch Association for Insurance Medicine (NVVG), and the Dutch Association of labor experts (NVvA); representatives of The Confederation of Netherlands Industry and Employers (VNO-NCW), and researchers (National Network Chronically Ill and Work); Experts from hospitals, other initiatives of work-oriented care, and the Fit for Work platform.

APPENDIX II

Matrix of change objectives for HCPs, managers and patients

Performance objectives hospital	**Change objectives management and health care professionals**					
	Knowledge	**Skills**	**Attitude**	**Self-efficacy**	**Social influences**	**Facilities**
Health care professionals						
HCPs are aware of the value of work and the challenges patients with CKD face	HCPs have knowledge and are aware of the value of work for patients, the difficulties patients face	-	-	-	-	-
HCPs have knowledge and possibilities to deliver work-oriented care or to refer patients	HCPs have knowledge of the way in which work-oriented care has been organized within the department	HCPs feel competent and have the possibilities and tools to offer tailored work-oriented clinical care and to recognize risk factors for (future) problems at work	HCPs accept and are positive about the work-oriented care as defined	HCPs feel confident with and believe in their ability to pay attention to work	HCPs and management support colleagues to pay attention to WORK	HCPs have time to pay attention to work

HCPs know and agree with the tasks and roles they have in providing work-oriented clinical care	Nephrologists and nurses know that they can refer patients easily to the social worker or the labor expert based on three ‘work-questions’	HCPs are able to recognize their task in work-oriented clinical care	HCPs in the hospital are motivated to take their role in work-oriented care	HCPs feel confident about their expertise to take their role in work-oriented care	HCPs in the hospital are discussing work-related care with colleagues and putting work-oriented clinical care on the agenda	-
Organizational level						
Managers create a culture to deliver work-oriented care	Managers are increasingly aware of the value of work for patients their role in supporting HCPs in paying attention to work	-	Managers are motivated to put work-oriented care on the agenda and consider this as part of their job	-	Managers’ attention to work a topic for discussion among HCPs as well as among members of the higher management and the board of directors	• Managers offer HCPs time, place to work and tools to pay attention to work • Referral to a labor expert in the hospital is facilitated • Attention for work is incorporated in existing working methods

Performance objectives patients with CKD	**Change objectives patients with CKD**					
	Knowledge	**Skills**	**Attitude**	**Self-efficacy**		
Increasing awareness and use of work-oriented-care	Patients with CKD know that they can go to the HCP in the hospital with questions about work	Patients with CKD are able to use work-oriented support in the hospital	Patients with CKD are positive about the work-oriented care that is offered	-		
Empowering patients to handle work challenges	Patients with CKD are aware of the circumstances that make work easier or more difficult for them, for example the laws and regulations that are relevant to them. Patients with CKD know own responsibilities and what to expect from stakeholders in the re-integration process	• Patients with CKD are able to cope with work-related challenges, such as finding a balance between load and load capacity, the possibility of work adjustments • Patients with CKD are able to ask questions to seek help to handle work related	Patients with CKD are aware of own role and responsibility in handling work challenges	Patients with CKD feel confident and capable to handle work re-lated-challenges		

	Gaining insight in own health status and addressing interference of treatment and work Patients with CKD know who to turn to for support	challenges, for example by asking HCP, the labor expert or the occupational health physician • Patients with CKD are able to decide whether or not to disclose their disease at work • Patients with CKD are able to prepare a consult with the OHP				

APPENDIX III

Overview of selected theoretical methods and practical application for use in the program

A. Hospital: HCPs and management

Change objectives	Theory-based methods	Practical application
Knowledge	Information about work-oriented care	Information (leaflets, mail, letters, intranet, infographics) is distributed to inform HCPs about the program Awareness for work-oriented care is raised via digital screens in waiting areas of the hospital Presentations for HCPs and management
	Awareness	Clarity is provided about specific tasks and roles of HCPs in delivering work-oriented care National reports and guidelines about the need for work-oriented medical care are shared Personal stories of patients who struggle with work challenges are shared (personas)
	Sense making	HCPs are involved and ideas around work-oriented care are exchanged Presentations for middle and higher management to create meaning through dialogue
Skills	Competence training	HCPs learn how to deliver work-oriented care through informal training Tools were developed for HCPs (e.g., three work questions, flowchart on work-oriented care, referral cards, folders for employers)
	Case descriptions	Privacy rules for referral to and consultation with work-oriented specialists were made explicit
	Targeting	HCPs learn how to deliver work-oriented care through case descriptions HCPs learn to identify patients with CKD who are working and need support

Attitude	Modeling	Early adapters are identified and deployed as ambassador
	Public commitment	Ambassadors engage themselves to deliver work-oriented care and announce that decision to colleagues
	Consciousness raising	Personal stories (personas) are distributed of patients who struggle with work challenges Labor expert provides feedback on the results of work-oriented care
Social norms	Goal setting	Work-oriented care is part of the vision/mission of the department/hospital
	Modeling	Managers and supervisors share the need for work-oriented care with HCPs Managers facilitate work-oriented medical care HCPs are reinforced by the achievements of colleagues
	Increasing stakeholder influence	Meeting is organized with a large insurer (MENZIS) that is strongly connected to the hospital Cooperation with the Dutch Association for Kidney Patients
	Nudging	Desk calendars are handed out to remind HCPs to take work into account
Self-efficacy	Structural redesign	Attention for work is integrated in (administrative) systems and protocols Sufficient expertise in the hospital is arranged Work-oriented care is integrated into electronic patients file systems A flow diagram is developed in which targeting, tailoring, and referral with regard to work-oriented care is explained Time needed by nephrologists for work-oriented care has been kept to a minimum
	Feedback	HCPs receive feedback from a labor expert about the results of work-oriented care Work-oriented care is made part of regular meetings in the hospital

	Task clarity	Clarity of tasks and responsibilities in work-oriented care is established
	Mobilizing support	Increase expertise by hiring a labor expert who is present and visible in the department
B. CKD patients		
Change objectives	**Theory-based methods**	**Practical application**
Knowledge	Information about work-oriented care	Information (leaflets, mail, infographics, informational letters) is distributed to inform patients with CKD about work-oriented care in the hospital Video screens are applied to be used in waiting areas of the hospital Article published in a journal for patients with CKD Comprehensibly formulated knowledge is used
	Awareness/Discussion	Nephrologists discuss the interference of treatment and work with patients Social workers or nurse specialists discuss the importance of being proactive with patients Patients are informed about their responsibilities and rights with regard to social security HCPs discuss advantages and disadvantages of disclosure of disease at work
Skills	Guided practice and skills enhancement	Empower patients to ask questions about work challenges Support patients in the decision to disclose or not disclose their disease with an employer Support and prepare patients in the consults they have with employer, occupational physician, and labor expert
	Shared decision-making	Patients discuss how to deal with interference of treatment and work with the nephrologist Patients discuss how to prepare for an operation and how to work on recovery
Attitude	Consciousness	Discuss the possible consequences of CKD for work

	raising	with patients Stimulate patients to ask questions about work challenges Motivate patients to make use of work-oriented care in the hospital and ask for support Challenge patients to be pro-active when it comes to work challenges
	Role modeling	Share cases or personas of patients who managed to stay at work with CKD
	Discussion	Discuss patients' responsibilities in the return-to-work trajectory Discuss the consequences of work disability and job loss
Self-efficacy	Modeling	Distribute personal stories (personas) of patients who solved their work challenges
	Practical support	Share contact information for questions (Dutch Association for Kidney Patients)Provide information about the social security system Refer patients to a labor expert who can be easily consulted Refer patients to the occupational physician or other work-focused specialists outside the hospital
	Empowerment	Provide a folder about CKD to share with the employer HCPs and patients with CKD discuss work challenges and how to overcome them

1. HCPs Health care professionals, CKD Chronic kidney disease

APPENDIX IV

Survey among patients with chronic kidney disease (CKD)

This is a selection of the most relevant topics that have been asked in the survey.

Introduction

1. Do you have paid work?
    - ○ Yes, namely
    - ○ No, I am looking for work (go to question 5)
    - ○ Other, namely ………..
2. How many hours per week do you work (according to contract?) ……….
3. What kind of work do you mainly do?
    - ○ Mentally demanding work
    - ○ Physically demanding work
    - ○ Both

Experiences with work-oriented clinical care for patients with CKD (WORK)

1. How satisfied are you with the work-oriented clinical care that you received?

    Score 1-10 (1= very dissatisfied, 10 = very satisfied)

Explanation ………………..

2. Did the care and/or information provided meet your needs?

    Yes because …….

    No, because …….

3. Are there things you missed?

    Yes because …….

    No, because …….

Response categories: Strongly disagree – Disagree – Neutral – Agree - Strongly agree

Acceptability

1. I think it is important that the hospital pays attention to work
2. I think the doctor in the hospital should talk to his/her patients about work
3. I think that the health care providers in the hospital are sufficiently knowledgeable to discuss questions about work

Clinical utility
Response categories: Not at all true - Not true – Neutral - True - Very true
<u>Due to the focus on work from the hospital</u>,
1. … I started doing things differently concerning work
2. … I feel I have a better grip on working with my illness
3. … I talked to my employer
4. … I know more about the steps that have to be taken when you call in sick

Closing
1. What is your age?
2. What is your gender?
3. At which department are you being treated?
   - ○ Nephrology UMCG
   - ○ Dialysis Center Groningen (DCG)
   - ○ Other, namely ………

APPENDIX V

Interview schedule HCPs and managers

Introduction

1. What is your age?
2. What is your position at work?
3. How many years of experience do you have in nephrology healthcare?

Opening questions

1. Do you pay attention to work in your contact with patients? Why or why not?
2. How do you pay attention to work?
3. Did you do this in a different way before the development and implementation of WORK in the department and if so, how did you do it then?

Key questions

Acceptability

1. Do you consider work-oriented care/attention to work as part of your duties as a doctor/nurse/social worker?
2. Do you feel that management considers attention to work to be important? If so, what does this show? If not, what does this have to do with?
3. Do you feel that your colleagues find attention to work important? If so, what does this show? If not, what does this have to do with?
4. How central do you think work should be in healthcare practice?

Practicability

1. Which elements of WORK did you use and how often? (were the three work questions asked and/or have patients been referred to a social worker or labor expert?)
2. What are your experiences with the labor expert and does the use of a labor expert in the hospital have added value for the care provided to the patient?

Accessibility

1. Did you experience working with WORK easy or difficult? And what made working with WORK easy or difficult? (e.g. were resources easy to find, were questions easy to ask, etc.)

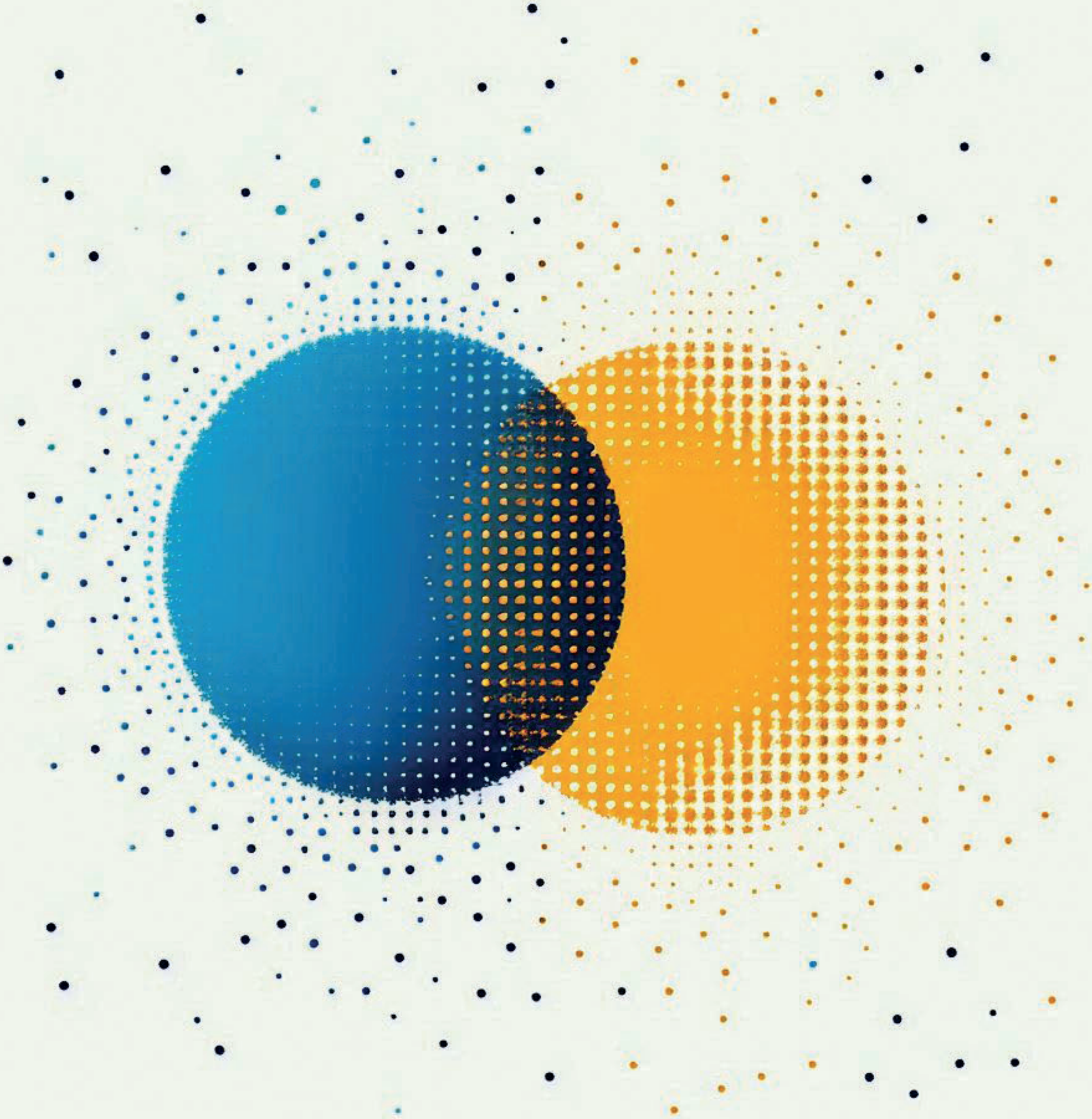
2. If YES to question 1 of practicability: And if so, was the referral to social worker/labor expert and the tools developed easy to use and/or accessible?
If NO to question 1 of practicability: And if not, what were the obstacles you experienced with these elements of WORK?

Applicability
1. Does the focus on work have added value for your work as a healthcare provider?
2. Does the focus on work have added value for patients?
3. Do you plan to continue the focus on work in your patient care? Why/why not? What makes it easier or more difficult for you to do or not to do this?
4. Do you have any important tips for how the implementation of a project like this can be shaped in the future?

Closing
1. These were the questions I wanted to ask. Is there anything else you'd like to add?
2. Do you have any questions for me?
3. In any case, thank you very much for your time and effort in participating in this research. Are you open to me contacting you later for a few additional questions?

Additional questions for managers
1. As a manager, do you think that attention to work belongs in the hospital?
2. How important do you think the attention to work is, and why?
3. How do you think HCPs feel about work-oriented care in the hospital?
4. What do you think is necessary to ensure that WORK can be integrated into the existing system of care provision in the hospital?

CHAPTER 4



The immaturity of patient engagement in value-based healthcare — A systematic review

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ABSTRACT

Introduction

In recent years, Value-Based Healthcare (VBHC) has been gaining traction, particularly in hospitals. A core VBHC element is patient value, i.e., what matters most to the patient and at what cost can this be delivered. This interpretation of value implies patient engagement in patient–doctor communication. Although patient engagement in direct care in the VBHC setting is well described, patient engagement at the organizational level of improving care has hardly been studied. This systematic review maps current knowledge regarding the intensity and impact of patient engagement in VBHC initiatives. We focus on the organizational level of a continuous patient engagement model.

Methods

We performed a systematic review following PRISMA guidelines using five electronic databases. The search strategy yielded 1,546 records, of which 21 studies were eligible for inclusion. Search terms were VBHC and patient engagement, or similar keywords, and we included only empirical studies in hospitals or transmural settings at the organizational level.

Results

We found that consultation, using either questionnaires or interviews by researchers, is the most common method to involve patients in VBHC. Higher levels of patient engagement, such as advisory roles, co-design, or collaborative teams are rare. We found no examples of the highest level of patient engagement such as patients co-leading care improvement committees.

Conclusion

This study included 21 articles, the majority of which were observational, resulting in a limited quality of evidence. Our review shows that patient engagement at the organizational level in VBHC initiatives still relies on low engagement tools such as questionnaires and interviews. Higher-level engagement tools such as advisory roles and collaborative teams are rarely used. Higher-level engagement offers opportunities to improve healthcare and care

pathways through co-design with the people being served. We urge VBHC initiatives to embrace all levels of patient engagement to ensure that patient values find their way to the heart of these initiatives.

1. INTRODUCTION

The concept of value-based healthcare (VBHC) was introduced in 2006 by Porter and Teisberg (1), as a response to the ever increasing and from a societal point of view unsustainable costs of healthcare, a problem that was especially, but not exclusively, present for decades in the US that had the highest costs of care in the world and one of the lowest health indicators (2). In the second half of the 20th century different strategies were pursued to tackle costs varying from fee-for-service payment systems, negotiating prices by both government and private insurers and the introduction of health maintenance organizations (HMOs) for employees. The strategies resulted in a variety of external accountability tools, physicians who feel over controlled and consumer groups (patients) who feel helpless (3). The irony of these approaches was that the system was volume driven, with physicians overproducing thus earning more money and insurers tried to cut both prices and volume in order to control costs. Both mechanisms were not in the interest of patients and people with sickness and diseases. Over the decades new insights were developed that resulted in a growing interest in the concept of value in healthcare. Rather than just focusing on output or lowering costs as isolated management tools, healthcare providers should focus on creating value for patients. Porter and Teisberg introduced the definition of value of any healthcare service as the outcome relative to all the costs incurred to achieve that outcome. They argued that, by following this path, a patient-centered, high quality and affordable healthcare delivery system could be realized. In Europe, EXPH on behalf of the European Commission has defined value broader and introduced four distinct elements of VBHC: personal value (to the patient), technical value (technical achievement), allocative value (distribution of resources), and societal value (contribution to social participation) (4). In this review we limit ourselves to the more narrow definition of VBHC as introduced by Porter and Teisberg (1).

Value for patients is one of the key elements of value-based healthcare (5, 6). To create patient value, in addition to good medical practice, a clear understanding is needed of which outcomes matter most to patients (5, 7). To this end, the use of patient-centered sets of outcome standards is promoted by the International Consortium for Health Outcomes Measurement (ICHOM). Patient

Reported Outcome Measures (PROMs) are increasingly used in the consultation room to measure patient valued outcomes of clinical practice (7–10). In essence, PROMs are questionnaires on a range of health and quality-of-life related issues that are reported by patients themselves and discussed with their doctor.

A second key element of VBHC is the focus on the full cycle of care and the introduction of integrated practice units (IPUs) where care is organized around the needs of patients alongside specialized medical interventions (1, 11). To optimize, from a patient's perspective, the full cycle of care, involving patients in designing patient-centered care pathways can be helpful (12–14). The possibilities and constraints of involving patients in improving health services has been widely studied, including topics such as quality improvement, patient safety, protocol adherence, patient satisfaction, service innovation, and the effectiveness of patient involvement (15–20).

Three frameworks of patient involvement are frequently used (12): Arnstein's (21) ladder of participation, Bate and Robert's (22) continuum of patient involvement and Carman et al.'s (23) continuum of patient engagement. All these frameworks have different angles: Arnstein's (24), a model from the 1960s, focuses on power distribution between actors such as patients and doctors and ignores the value of knowledge diversity. Bate and Robert present a continuum with the most advanced form being experience-based co-design (EBCD) of a care pathway (22). Carman et al. (23) provide a descriptive framework involving three different levels, each along a continuum of patient engagement: the direct care level, the organizational level, and the policy level. On each level, they define a continuum of engagement ranging from consultation through involvement to partnership and shared leadership.

The aim of our study is to present an overview of empirical findings regarding patient engagement in a VBHC context on the organizational level of hospitals. We have chosen to use Carman et al. (23) framework for patient engagement since this makes an explicit distinction between the direct care, the organizational, and the policy levels. The direct-care level is well described in the current VBHC literature and includes outcome measurements, shared decision-making, and costs (8, 21, 22). The policy level concerns societal issues related to healthcare and is only loosely linked to day-to-day clinical practice.

Consequently, this study focuses on the organizational level, covering the hospital unit through to designing the full cycle of care, which is hardly described from the perspective of patient engagement (3, 23).

2. METHODS

This systematic review is conducted and reported following the protocol of Prisma Guidelines for systematic reviews (25). Details are provided in Supplementary material 1. In addition, the authors are trained researchers and the team is highly experienced in conducting systematic reviews. The review was not registered.

2.1 Search strategy

The search strategy was developed in collaboration with an expert librarian from the Erasmus University Medical Centre, Rotterdam, Netherlands. Five databases were searched on 14-01-2022: Embase, Medline ALL, Web of Science Core Collection, Cochrane Central Register of Controlled Trials, and Google Scholar. The search strategy followed PICO to formulate the definitions of the research question. (1) P (patient/ population), patients in a hospital or transmural setting, (2) I (intervention), value-based healthcare, (3) O (outcomes), patient engagement on an organizational level of hospitals. The C (comparator) is not applicable in this study. The search strategy consisted of the two major elements of this systematic review, patient participation and value-based healthcare, plus their plural forms. Supplementary material 2 provides the full search string.

Duplications of any articles were excluded. References were crosschecked and added if not already included. Seven clearly relevant papers were identified in advance of this to check that the search strategy correctly retrieved them.

2.2 Selection process

In advance of the full selection process, five articles were independently screened by two researchers (MV&WS) by title and abstract to check for agreement on inclusion and exclusion criteria. The results were discussed by the two researchers and the results of the screening by these two researchers were fully agreed by both. We made the choice to use Rayyan as a tool to streamline the process. Herewith, both researchers independently screened the titles and abstracts of the papers identified in the search. After both researchers (MV & WS) had screened these articles, they were uploaded in one overview. There was discussion about articles when there was a discrepancy between the two researchers. Consensus was found between the two researchers and these articles proceeded to full text screening. The reasons for excluding a research paper during the next stage, full text screening, were recorded and inconsistent screening outcomes were discussed by the two researchers. Six articles where there was no consensus were reviewed by two other researchers (AF & KA) with four being included and two rejected.

2.3 Eligibility criteria

The eligibility criteria were applied in two phases: title and abstract screening and full text screening. In the first phase (title and abstract screening), the criteria for excluding the studies were “mentioned value-based healthcare as a research topic but no patient engagement or vice versa”, “setting other than a hospital environment or transmural”, “research papers prior to 2006”, “not written in English”, “not peer reviewed”, “not empirical research”, and “conference paper”. We did not include papers published prior to 2006 because Porter and Teisberg (1) introduced the concept of value-based healthcare in 2006. In the second phase (full text screening), patient engagement and value-based healthcare were further explored. The primary outcomes were the level of patient engagement on an organizational level and the integration of the VBHC elements in practice. Patient engagement was defined as active participation by patients in the study described in the research paper. Based on the framework by Carman et al. we investigated the level of patient engagement from an organizational unit (meso-level) perspective. Carman et al.’s model presents a continuum of engagement, whereby consultation, involvement and partnership, and shared leadership are used to define the level of patient engagement from low to high (23). The criteria for excluding the initially identified studies were “direct care (micro-level) in a hospital setting”, “macro-level care in a hospital setting”. This research was aimed at synthesizing the information from the studies that developed new knowledge about patient engagement from an organizational-unit perspective in a value-based healthcare context which was the focus of our study. An integrative approach has been chosen in this systematic review, since the ways in which patients participate in both qualitative and quantitative data can be investigated.

2.4 Data extraction and analysis

Data extraction consisted of three steps of thematic analysis and these were carried out independently by two researchers (MV & WS). Atlas.ti, version 22 was used to facilitate this process. First, the generic characteristics of a study were examined in terms of authors' names, the year of publication, country, medical specialties involved, study design, and number of patients involved. Second, the context of the study in terms of the field of value-based healthcare was examined. We looked for the presence, or absence, of the elements of value-based healthcare proposed by Porter and Teisberg (1): value, outcomes, and costs, and how these were used in the practical design of the study. Finally, to examine the context of patient engagement, we inductively analyzed how patients were involved, what level of patient engagement was apparent based on the model of Carman et al. which patient engagement outcomes were reported and to what extent the participation of patients contributed to the results of the study.

Due to the focus of the research question, a narrative approach has been chosen for displaying and presenting the data in tables. As a result, a meta-analysis was not undertaken and the results were analyzed descriptively and thematic. This was necessary given the studies' heterogeneity for study designs, participants, objectives and results.

2.5 Quality assessment

The mixed methods appraisal tool (MMAT) (26) was used to assess the quality and risk of bias in the 21 studies included. The MMAT was developed for systematic reviews that combine qualitative, quantitative, and/or mixed studies (27, 28). Moreover, the MMAT was developed for the appraisal stage of systematic reviews and facilitates the appraisal of empirical studies including observational studies. MMAT facilitates the appraisal of five research categories:

qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies, and mixed methods studies. Following the quality criteria as described in the MMAT user guide, two researchers (MV & WS) have both independently of each other assessed each study and after discussion, the scores were decided together. The qualitative (n= 5), quantitative (n= 9), and mixed-methods (n= 7) studies were subjected to their own screening categorization that involves a set of five unique criteria. For each criteria, a "yes" response was scored "1" and a "no" or "can't tell" scored "0". An overall score of "5" means that all the quality criteria are met; a score of "0" that none of the quality criteria are met (26). We converted this to the score "5" is high, score "4" and "3" is medium, and "2", "1" and "0" is low.

3. RESULTS

The search strategy yielded a total of 2,915 articles across the five databases. A total of 1,533 articles remained after removing duplicates. A total of 21 articles remained after the title and abstract, followed by full text, screening. Further details can be found in Figure 1.

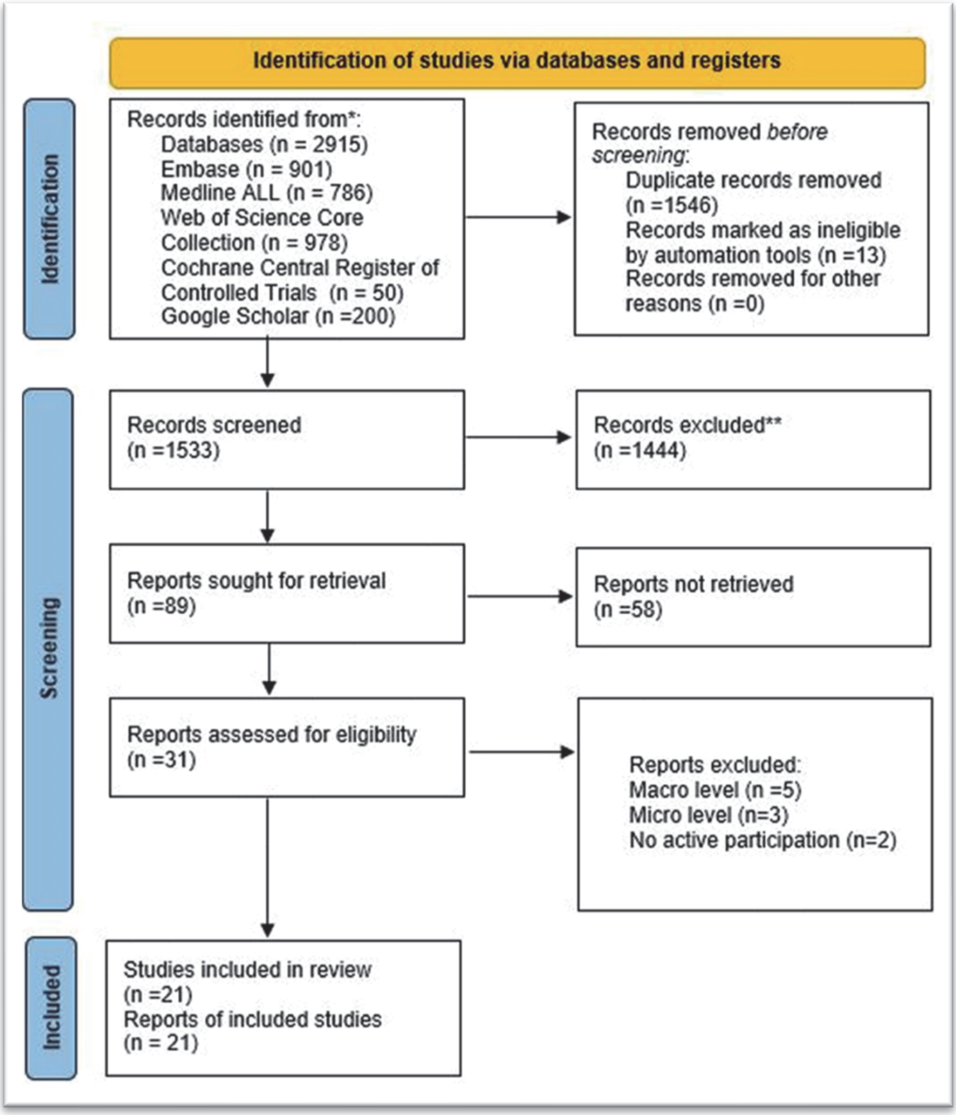

Figure 1. PRISMA flow diagram

A schematic representation of all results of the 21 studies is provided in **Table 1 below**.

Table 1 General characteristics and relevant elements of the studies *(multiple pages)*

References	Country	Specialties involved	Study design	Number of patients involved	Value-based healthcare elements	Objective	Level of participation	Results of patient participation	Illustrative quote
Anderson et al. (29)	United States	Not mentioned	Qualitative	23	Value	To create an understanding of to what extent seriously ill patients value a cardiopulmonary resuscitation (CPR) discussion with their doctor.	Involvement	A strong doctor-patient relationship was an essential context for CPR discussions. Participants also valued relationships with hospital doctors. In total of 50% reported no preference between the videos; 35% preferred the information-focused one, and 15% the value-based video.	*“After viewing both videos, participants were asked which model they would prefer for discussing CPR with a hospital doctor”*
Hennink et al. (30)	The Netherlands	Gastroenterology Clinical genetics	Quantitative	64	Value, outcome, and costs	Lynch Syndrome patients evaluated the care delivered to these patients in their department and formulated outcome measures relevant to patient value.	Involvement	The relevance of all six outcomes was confirmed by the patients in the survey and mean scores varied from 7.2 to 9.9.	*“These patients were invited to participate in this survey and to complete a questionnaire that assessed the importance of the outcomes (on a scale 1–10) in the cycle of care identified by the specialists”*

References	Country	Specialties involved	Study design	Number of patients involved	Value-based healthcare elements	Objective	Level of participation	Results of patient participation	Illustrative quote
Van Citters et al. (31)	United States	Orthopedics Anesthesiology	Mixed methods	2	Value	1: To develop a generalizable care pathway using inputs from clinical, academic, and patient stakeholders. 2: Identify system and patient-level processes to provide safe, effective, efficient, and patient-centered care.	Consultation involvement	Study used different stakeholder categories to develop a generalizable care pathway that outlines 40 processes to improve care, 37 techniques to avoid waste, and 55 techniques to improve communication.	*"Patient-level discussions were designed to validate concepts identified by care teams and included pleasing and disappointing features of care; factors that are contributed to safety, efficiency, or patient and family experience; and advice for providers"*
Kaplan et al. (32)	United States	Urology	Qualitative	7	Value, outcome, and costs	To implement patient ethnography to support the quality improvement infrastructure and improve patient centeredness.	Consultation	Themes emerged from the interviews that were considered of low value to the patient, they had identified five improvements targeted at the low-value themes. Three of these had been implemented.	*"These discussions sought to understand patient perspective, context and the care experience surrounding their treatment"*
Li et al. (33)	United States	Gastroenterology	Quantitative	53	Value, outcome, and costs	To test the hypothesis that telemedicine in the form of telecare will increase value while achieving high satisfaction for patients with inflammatory bowel disease.	Consultation involvement	The telemedicine clinic enabled patients to save, on average, $62 in out-of-pocket costs. In 77% of the patients continued to use telemedicine as their preferred follow-up method.	*"After the visit, the patients fills out a post-visit survey that included questions about the patient's experience of the visit, time and money saved by not driving the appointment, and preference for further visits"*

References	Country	Specialties involved	Study design	Number of patients involved	Value-based healthcare elements	Objective	Level of participation	Results of patient participation	Illustrative quote
Bernstein et al. (34)	United States	Orthopedics	Quantitative	185	Value, outcome, and costs	To determine if PROMIS, used as a part of routine orthopedic clinical care, is associated with improved patient experience.	Consultation	Patients who used PROMIS were 89% more likely to feel that the provider spent enough time with them, 81% more likely to recommend this provider office to another patient, and rated the provided significantly higher on a scale from 0 to 10.	*"Only the subset of CGCAHPS questions directly related to patient experience and satisfaction were included"*
Coppess et al. (35)	United States	Pediatrics	Quantitative	56	Value, outcome, and costs	To evaluate whether an OPPS/cost method can be used for value-based evaluation of healthcare delivery with patient experience as an element of it.	Consultation	A 1.7% reduction in costs, improvement in objective and subjective outcomes of 47.4 and 7.3% respectively, and stable patient experience was seen with the clinic location change.	*"Patient/family experience is a measure of satisfaction with the guardian/provider interaction. The survey is performed via email and phone within 3 days after a patient's visit and scored utilizing an structured query language script as standard practice for the institution independent of this study"*

References	Country	Specialties involved	Study design	Number of patients involved	Value-based healthcare elements	Objective	Level of participation	Results of patient participation	Illustrative quote
Eppler et al. (36)	United States	Hand surgery	Qualitative	99	Value, outcome, and costs	To develop a better understanding of the surgery and recovery experience of hand surgery patients, specifically focusing on knowledge gaps, experience, and the surgical process.	Consultation involvement	Four themes were developed from the thematic analysis: (1) being prepared and informed for the process of surgery, (2) regaining hand function without pain or complication, (3) patients and caregivers negotiating the physical and psychological challenges of recovery, and (4) financial and logistical burdens of undergoing hand surgery.	*“The questionnaire was composed of 8 open-ended questions, asking about various aspects of their treatment, and recovery including patient education, challenges, preparation, and success”*
Rosseel et al. (37)	Denmark	Cardiology	Quantitative	637	Value, outcome	To deliver data on patients’ perceived values and health-related quality of life following surgical aortic valve replacement (SAVR) and transcatheter aortic valve replacement (TAVR) in a real-world, all-comers patient population.	Consultation	Both physical (42 vs. 11%) and mental (30 vs. 11%) impacts of the intervention and the recovery period were experienced as more stressful by SAVR as compared to TAVR patients. In both groups, 10% of the patients reported no change in health-related quality of life (HR-QoL), whereas HR-QoL improved in 76 vs. 83% and worsened in 14 vs. 7% of the SAVR and TAVR populations, respectively.	*“The questionnaires in this study were specifically designed to capture patients and informal caregivers’ perioperative experience as well as the patients’ HR-QoL before and after aortic valve replacement”*

References	Country	Specialties involved	Study design	Number of patients involved	Value-based healthcare elements	Objective	Level of participation	Results of patient participation	Illustrative quote
Wickramasinghe et al. (38)	Australia	Obstetrics Gynecology	Mixed methods	10	Value	The study was designed to assess patient compliance, satisfaction, level of glycemic control achieved, and healthcare professional satisfaction.	Consultation involvement	From the patient perspective, five *a* priori themes were included, and thematic analysis served to reveal two others. In addition, all patients preferred to have standard care plus the mobile solution rather than only the standard care approach. Many ideas for further enhancement were provided by the patients.	*“The questionnaire at the conclusion of the study was designed to ascertain overall satisfaction with the technology solution and allow for any recommendations moving forward”*
Depla et al. (39)	The Netherlands	Obstetrics Gynecology	Mixed methods	26	Value, outcome	To study the feasibility of using PROMs and PREMs in Dutch perinatal care, addressing both women’s and professionals’ perspectives.	Consultation Involvement	The majority of women (76%) wanted to discuss their PROM answers with a care professional, and 81% their PREM answers. Most women (86%) preferred to discuss their answers with an obstetric care professional. Over half of the women agreed that PROMs/PREMs supported shared decision-making (58%), ability to raise issues (60%), and the patient-clinician relationship (52%).	*“To evaluate usability and experiences, separate evaluation surveys were composed for both patients and obstetric care professionals, regarding barriers and facilitators to using the PROM/PREM questionnaires in daily practice”*

References	Country	Specialties involved	Study design	Number of patients involved	Value-based healthcare elements	Objective	Level of participation	Results of patient participation	Illustrative quote
Dronkers et al. (40)	The Netherlands	Oncology	Mixed methods	166	Value, outcome	To provide an initial evaluation of Healthcare Monitor (HM) after implementation and seek new insights into how patients experience HM.	Consultation involvement	HM users more often experienced that their physician had a complete picture of them and took action in response to their specific complaints.	*“Patients were interviewed on the added value of HM and on how they think of HM in general” “We also asked questions about the length of the consultation and asked patients to rate their subjectively experienced quality of care ranging between 1 and 10”*
Fahner et al. (41)	The Netherlands	Pediatrics	Quantitative	20	Value	To clarify how parents of children with life-limiting conditions contemplate the future and under which conditions parents share these future perspectives with clinicians caring for their child.	Involvement	Four main themes were identified when parents were asked to envision the future of their child. It was seen that: 1) there is a focus on the near future, 2) future perspective are intertwined with present and past experiences, 3) future perspectives range from a disease-related orientation to a value-based orientation, and 4) there is no “sharing without caring”.	*“Several triggers stimulated them to contemplate the future. [..] These questions made parents think about their underlying values and influence of these values on future decision making”*

References	Country	Specialties involved	Study design	Number of patients involved	Value-based healthcare elements	Objective	Level of participation	Results of patient participation	Illustrative quote
Goretti et al. (42)	Italy	Bariatric surgery	Mixed methods	2,122	Value, outcome, and costs	To redesign the organizational bariatric pathway by implementing a VBHC strategy to achieve excellent clinical outcomes and improved quality of life without increasing costs.	Consultation involvement	There were three categories of recommendations with a total of seven elements that formed the basis for redesigning the bariatric pathway. The interventions confirm the positive impact of bariatric surgery on clinical outcomes and significant improvements in the quality of life for morbidly obese patients.	*"Patients were interviewed by clinicians to collect their experiences and suggestions to improve their pathway of care"*
Pennucci et al. (43)	Italy	Cardiology	Mixed methods	162	Value, outcome	To evaluate the feasibility of a digital-based continuous collection and reporting of PROMs and PREMs for patients with chronic heart failure.	Consultation	The system has been successfully implemented. Response rates have been consistently above 50%, demonstrating patients' willingness to participate. All the involved stakeholders acknowledged the feasibility of the design.	*"At baseline, patients were asked questions exploring the quality of care before the index hospitalization and during the hospital stay. [..] After 1 month, the questions were related to the experience of care during the hospitalization"*
Van Veghel et al. (44)	The Netherlands	Cardiology	Quantitative	669	Value	To evaluate the effects of a pilot study regarding enhancing regional integration on patient-relevant clinical outcomes and patient satisfaction.	Consultation	The non-significant improvement has, over time, led to significantly better outcomes for patients referred from the study-referring hospital compared to patients referred from other hospitals. The level of satisfaction improved and achieved statistically significant higher scores for various items.	*"On a scale from 1 to 10, patients where asked "To what extent are you satisfied with. . . ", followed by the specific 28 items. [..] Patients were asked to give an overall grade of the delivered care in both hospitals on a scale from very bad (=1) to excellent (=10)"*

References	Country	Specialties involved	Study design	Number of patients involved	Value-based healthcare elements	Objective	Level of participation	Results of patient participation	Illustrative quote
Young et al. (45)	United States	Intensive care Neurosurgery	Quantitative	269	Value, outcome	To evaluate the clinical and financial outcomes, as well as the impact on the patient experience, for patients who participated in the STP and bypassed the intensive care unit (ICU) level of care	Consultation	Admitting selected, but generally otherwise healthy, postoperative craniotomy patients directly from the PACU to the step-down unit, bypassing the ICU, is safe and, as one might expect, can result in cost savings ($422,128) and does not adversely affect the patient (73 vs. 86%) or provider experience (87.5%).	*“Surveys were distributed for patients and nurses to document their satisfaction with the program””*
Ahluwalia et al. (46)	United Kingdom	Orthopedics	Quantitative	53	Value, outcome and costs	To assess the safety, efficiency, cost-effectiveness, and differences in clinical and patient outcomes of day surgery unit (DSU) care for ankle fracture treatment	Consultation	The DSU pathway improves the value of healthcare delivery with high patient satisfaction scores when compared to the traditional pathway (7.7 vs. 6.3). The model demonstrates predictably good clinical outcomes (no associated complications) with a financial cost benefit (£2018) over the in-patient admission care model for selected patients.	*“A telephone satisfaction poll was conducted [..] patient satisfaction was graded out of 10, with 10 representing exemplary service continuing down to 0, which represents the worst healthcare experience possible”*

References	Country	Specialties involved	Study design	Number of patients involved	Value-based healthcare elements	Objective	Level of participation	Results of patient participation	Illustrative quote
Najafabadi et al. (47)	The Netherlands	Neurosurgery Radiotherapy	Mixed methods	31	Value	To evaluate the structure of current meningioma care and identify issues and potential high-impact improvement initiatives.	Involvement	Following the grounded theory approach, issues were eventually categorized into a thematic framework consisting of the following three themes: (1) availability and provision of information, (2) care and support, and (3) screening for (neurocognitive) rehabilitation. Following up on these issues, 16 solutions were identified during focus groups.	*“Using the thematic framework from step 1, participants were asked to identify issues regarding their meningioma care trajectory, as well as possible solutions for these issues”*
lejko et al. (48)	United States	Pulmonology	Qualitative	31	Value, outcome, and costs	To elicit from patients with chronic obstructive pulmonary disease their prioritization of an established set of patient-informed value elements.	Involvement	Initially, participant responses informed the selection of eight elements as the key aspects for the Phase 2 language refinement. With feedback from a patient advocate, and additional patient participants, elements were refined, rephrased, or modified, and the list was reduced to six value elements.	*“We developed an instrument that first asked participants about the clarity of an overarching choice task question for the future-stated preference instrument. Next, we asked participants to consider a proposed statement for each of the elements retained after Phase 1, framed as attributes”*

References	Country	Specialties involved	Study design	Number of patients involved	Value-based healthcare elements	Objective	Level of participation	Results of patient participation	Illustrative quote
Kasalak et al. (49)	The Netherlands	Radiology	Quantitative	58	Value	To investigate how patients experience a radiologist—patient consultation of imaging findings directly after neck ultrasonography (US), and how much time this consumes.	Consultation	Patients who did not discuss the US results with the radiologist were significantly more worried during the examination ($P = 0.040$) and had significantly higher anxiety levels after completion of the US examination ($P = 0.027$) than patients who discussed the results with the radiologist. The median duration of US examinations that included a radiologist-patient consultation was 7.57 min compared with 7.34 min for those without this consultation.	*"Patients in both randomization arms were asked to fill in a paper-based survey to share their experience with the US examination and their view on the radiologist-patient consultation of US results at the end of the examination"*

3.1 General characteristics

The studies were all published between 2013 and 2022. Nine studies were conducted in the United States (29, 31–36, 45, 48), seven studies in The Netherlands (30, 39–41, 44, 47, 49), two in Italy (42, 43), one in Australia (38), one in Denmark (37), and one in the United Kingdom (46). Nine studies had a quantitative design (30, 33–35, 37, 44–46, 49); seven studies a mixed methods design (31, 38–40, 42, 43, 47) and five a qualitative design (29, 32, 36, 41, 48). In total, 4,743 participants were involved in the 21 studies, ranging from 2 patients (31) to 2,122 patients (42). All 21 studies were conducted in hospitals: 14 studies in a single hospital (29, 30, 33–35, 37, 40–43, 46–49), five studies in multiple hospitals (31, 36, 38, 44, 45), one in a single hospital and in patients' homes (32), and one in multiple hospitals and at home (39).

3.2 Quality assessment

The quality assessment resulted in classifications of "high" (13 studies), "medium" (8 studies), with none categorized as "low". Consequently, no studies were excluded on the basis of the MMAT. Overall, the quantitative studies tended to achieve higher quality scores than the mixed methods and qualitative studies. A detailed overview and the explanations of the scores of the quality assessment are provided in Supplementary material 3 of the published version.

3.3. Patient participation in a value-based healthcare context

3.3.1. Value-based healthcare context

Nine studies discussed value, outcome, and costs in relation to each other (30, 32–36, 42, 46, 48) of which six investigated the costs from an organizational perspective (30, 32, 34, 35, 42, 46) and three from a patient perspective (33, 36, 48). Five other studies discussed both value and outcomes but not costs (37, 39, 40, 43, 45), three of which investigated patient-reported outcomes (39, 40, 43) and two studies clinical outcomes (37, 45). Seven studies discussed only value (29, 31, 38, 41, 44, 47, 49). In these articles, the focus on value was not linked to outcomes and costs, but more on patient value in terms of what patients consider important.

3.4. Levels of patient engagement

Nine studies indicated only the level of consultation (32, 34, 35, 37, 43–46, 49), and five the level of involvement (29, 30, 41, 47, 48). In addition, seven studies included both these aspects of patient engagement (31, 33, 36, 38–40, 42). None of the studies reported patient engagement at the “partnership and shared leadership” level. A schematic representation is provided in **Table 2** below.

TABLE 2 Studies at the different levels of patient engagement

	Consultation	Consultation and involvement	Involvement	Partnership and shared leadership
Direct care (micro-level)				
Organizational design and governance (meso-level)	(32, 34, 35, 37, 43–46, 49)	(31, 33, 36, 38–40, 42)	(29, 30, 41, 47, 48)	
Policymaking (macro-level)				

The findings in the reviewed papers, insofar as they relate to the levels of patient engagement that emerged from the thematic analysis, in terms of level of engagement, type of studies and their modalities, data collection methods, role of patients related to the level of patient engagement, outcomes patient engagement and results of patient engagement reported are included in three different tables. The details for each level are discussed below.

3.5. Consultation

For the nine studies (32, 34, 35, 37, 43–46, 49) that were limited to the consultation level of patient engagement (23), we investigated how the level of engagement “consultation” was implemented in practice. Further details can be found in **Table 3** below.

3.5.1. Type of studies and their modalities

Eight of nine studies have an observational study design (32, 34, 35, 37, 43–46) of which four are cohort studies (32, 43, 44, 46), and four cross-control studies (34, 35, 37, 45). One study has a randomized study design, which is a prospective randomized study (49).

3.5.2. Data collection methods

Seven of nine studies used either a questionnaire or a survey (34, 35, 37, 43–45, 49). In one study the questionnaire or survey was combined with a workshop (43). One study relied completely on interviews for collecting data (32), and another used a telephone satisfaction poll (46).

3.5.3. Outcomes of patient engagement

Based on the role of patients, one or two outcomes were reported. Five of nine studies reported two outcomes in their article (32, 34, 37, 43, 49) and four studies one outcome (35, 44–46). Five studies reported patient satisfaction as outcome of patient engagement (34, 35, 44–46), five studies patient experience (32, 34, 37, 43, 49), two studies quality of care (32, 43), one study patient perspective (49) and one study patient health- related quality of life.

3.5.4. Results of patient participation reported

Six of nine studies show that the role of patients and their input is substantial used in the results and conclusion of the study (32, 34, 37, 43, 44, 49), two studies show that the results were included as part of more results (35, 46) and one study shows that is used minimally in the results (45). In the studies which the results were included as part of more results, one study focuses either on financial and clinical outcomes (46) and one either on financial outcomes (35). In the study which the results were minimally used focused heavily on financial and clinical outcomes (45).

3.6. Consultation and involvement

Seven studies addressed the level of consultation and involvement (31, 33, 36, 38–40, 42). Further details can be found in **Table 4** below.

3.6.1. Type of studies and their modalities

Six of seven studies have an observational design (31, 33, 36, 39, 40, 42), of which two are cohort studies (33, 42), two are cross-sectional studies (36, 39), one a cross-control study (40), and one a multiple case study (31). One of seven studies has a randomized design, which is a cross-over clinical trial (38).

Table 3 Consultation level of engagement.

References	Level of engagement	Type of studies	Modalities	Data collection methods	Role of patients related to the level of engagement	Outcomes patient engagement	Results of patient engagement reported
Kaplan et al. (32)	Consultation	Observational	Cohort study	Interviews	Patients were asked in the interviews about their perspective, context and care experience. The central question at the crux of each interview was about what about the care was dissatisfying.	Patient experience Quality of care	Five improvements emerged from the interviews with patients, three of them have been implemented
Bernstein et al. (34)	Consultation	Observational	Cross-control study	Questionnaire/ survey	Patients filled out a questionnaire/survey and only the questions directly related to patient experience and patient satisfaction were included.	Patient experience Patient satisfaction	The questionnaire showed significantly higher scores for patients that used PROMIS and the PROMIS has a positive impact on the patient experience
Coppess et al. (35)	Consultation	Observational	Cross-control study	Questionnaire/ survey	Patients filled out a questionnaire/survey by phone or e-mail within 3 days after a visit and scored patient satisfaction on scales ranging from 3 to 11.	Patient satisfaction	Results for patient satisfaction are mentioned as part of the OPPS/COST method
Young et al. (45)	Consultation	Observational	Cross-control study	Questionnaire/ survey	Patients were given a satisfaction survey to assess their respective impressions of the hospital stay and of the recovery pathway.	Patient satisfaction	The conclusions focused heavily on clinical and financial outcomes, and just looked to check that there were no adverse patient experiences
Van Veghel et al. (44)	Consultation	Observational	Cohort study	Questionnaire/ survey	Patients were asked to fill out a questionnaire/survey on patient satisfaction on a scale from 1 (very bad) to 10 (excellent).	Patient satisfaction	The patient satisfaction results were used to further improve care management and promote the quality of outcomes for referred patients
Kasalak et al. (49)	Consultation	Randomized	Prospective randomized study	Questionnaire/ survey	Patients were asked to fill out a paper based questionnaire/survey to share their experience and their view on the consultation.	Patient experience Patient perspective	Compared two groups of patients and concluded that the group that underwent neck ultrasonography were generally satisfied

Pennucci et al. (43)	Consultation	Observational	Cohort study	Questionnaire/survey Workshop	Patients were asked to measure disease-specific outcomes and they were asked questions related to patient experience and quality of care	Patient experience Quality of care	The inputs of patients allowed the feasibility of the design to be acknowledged
Rosseel et al. (37)	Consultation	Observational	Cross-control study	Questionnaire/survey	To capture patients perioperative experience as well as the patient's health-related quality of life before and after aortic valve replacements	Patient experience Patient health-related quality of life	The results of patient experiences were used to make a comparison between SAVR and TAVR patients
Ahluwalia et al. (46)	Consultation	Observational	Cohort study	Telephone satisfaction poll	Patients were asked by a telephone satisfaction poll how satisfied they were on a scale of 1 (worst experience) to 10 (exemplary service).	Patient satisfaction	The results showed the benefits, both clinical and financial outcomes, and patient satisfaction was a part of this

Table 4. Consultation and involvement level of engagement.

References	Level of engagement	Type of studies	Modalities	Data collection methods	Role of patients related to the level of engagement	Outcomes patient engagement	Results of patient engagement reported
Van Citters et al. (31)	Consultation and involvement	Observational	(Multiple) case study	Interviews multi-stakeholder panel	Patients participated in a semi-structured telephone interview and included factors that contributed to safety, efficiency, or patient and family centered care experience (consultation) and validation of concepts and advice for providers in terms of improving care and efficiency (involvement).	Patient experience Validation of concepts Patients' advice for providers	Developed a generalized care pathway with various stakeholders, but patients were just a small part of it (2/48)
Li et al. (33)	Consultation and involvement	Observational	Cohort study	Questionnaire/ survey	Patients filled out a pre-visit questionnaire/survey about their current disease state including quality outcome measures. After the visit, the patients filled out a questionnaire/survey with questions related to the patient's experience of the visit, time and money saved by not driving to the appointment (consultation) and preference for further visits (improvement).	Quality outcome measures Patient experience Patients' time and money saved Patient preferences	Based on the patients' answers, their experiences, the time and money saved, and the preferred follow-up method were mentioned
Eppler et al. (36)	Consultation and involvement	Observational	Cross-sectional study	Questionnaire/ survey	Patients were asked to fill out an open-ended questionnaire/survey with 8 questions about various aspects of their treatment, and recovery including patient education, challenges, preparation and success (consultation). Patients were asked to respond and gave feedback on the questionnaire (involvement).	Treatment aspects Challenges for recovery Feedback/advice of patients on a questionnaire	The high-quality criteria based on the patients' answers are clearly categorized in four themes

Depla et al. (39)	Consultation and involvement	Observational	Cross-sectional study	Questionnaire/ survey Focus group	Patients were asked to fill out a questionnaire/survey at one time-point (T1-T5) for patient experiences and patient preferences (consultation. To evaluate usability and experiences, separate questionnaires/surveys were composed, regarding barriers and facilitators to using the questionnaire/survey in daily practice (involvement).	Patient experience Barriers and facilitators	Both women's and professionals' experiences and barriers and facilitators were noted as equally important
Dronkers et al. (40)	Consultation and involvement	Observational	Cross-control study	Questionnaire/ survey Interviews	Patients were asked to fill out a 12-item patient experience questionnaire with a 4 point Likert scale (consultation). Patients were interviewed on the added value of Health Monitor and how they think of HM in general in terms of barriers and facilitators (involvement).	Patient experience Barriers and facilitators Added value	The experiences of patients that used and did not use the healthcare monitor were compared and the barriers and facilitators that patients mentioned were reported
Goretti et al. (42)	Consultation and involvement	Observational	Cohort study	Interviews	Patients were interviewed by clinicians to collect the patients and their family shared experiences (consultation) and suggestions to improve their pathway of care (involvement).	Patient experience Suggestions to improve the care pathway	The collection of experiences and suggestions led to three categories with a total of seven elements
Wickramasinghe et al. (38)	Consultation and involvement	Randomized	Crossover clinical trial	Questionnaire/ survey	Patients were asked to filled out a structured questionnaire/survey at four specific stages to ascertain overall satisfaction with the technology solution (consultation) and allow for any recommendations moving forward (involvement).	Patient satisfaction Recommendations for alternate exercise	Five a priori themes were included, and thematic analysis uncovered two new themes

3.6.2. Data collection methods

Five of the seven studies used a questionnaire or survey (33, 36, 38–40), one in combination with interviews (40). In one study, interviews were the only data collection method used (42) and in one study interviews were combined with a multi-stakeholder panel (31).

3.6.3. Outcomes of patient engagement

All seven studies reported the outcomes of both levels consultation and involvement. Three of seven studies reported three outcomes (31, 36, 40), three reported two outcomes (38, 39, 42) and one study reported four outcomes (33). At the level of consultation five studies reported patient experience as outcome of patient engagement (31, 33, 39, 40, 42), one study patient satisfaction (38), one study quality outcome measures and time and money saved (33), and one study treatment aspects and challenges for recovery (36). At the level of involvement two studies patient's advice as outcome of patient engagement (31, 36), two studies barriers and facilitators (39, 40), one study validation of concepts (31), one study preferences for further visits (33), one study added value of a healthcare monitor (40), one study suggestions to improve the care pathway (42), and one study recommendations for alternate exercise (38).

3.6.4. Results reported

Six of seven studies show that the role of patients and their input is substantial used in the results and conclusion of the study (33, 36, 38–40, 42), and one study shows that it is used minimally (31). In the study which the results were minimally used there were just two patients that participated in a total of 48 participants (31). In the other six studies there were different results reported. One study mentioned patients' experiences, time and money saved and the preferred follow-up method (33), one study mentioned the high-quality criteria based on patients' answers (36), another study mentioned the patient and professional experiences and barriers and facilitators as equally important (39), another study mentioned the experiences and barriers and facilitators of two groups of patients (40), another study mentioned the experiences and suggestions which led to three categories with a total of seven elements to improve their pathway of care (42) and one study mentioned two new themes based on the thematic analysis with patients (38).

3.7. Involvement

Five studies addressed the involvement level (29, 30, 41, 47, 48). Further details can be found in Table 5 below.

3.7.1. Type of studies and their modalities

All five studies have an observational design (29, 30, 41, 47, 48), of which three are cross-sectional studies (30, 41, 47), one cross- control study (29), and one case study (48).

3.7.2. Data collection methods

Two studies used questionnaires (30, 48), two studies interviews (29, 47), and one study used interviews in combination with a focus group (41). The data collection methods in the five studies have led to different roles of patients in relation to the level “involvement” of patient engagement.

3.7.3. Outcomes of patient engagement

All studies reported one outcome and there are different outcomes reported. One study focused on patient preferences (29), one on domain and value importance (48), one on the relevance of outcomes (30), one on the underlying values and influence of values for future decision-making (41), and one on discussing the care trajectory, the issues related to the care trajectory and the possible solutions for these issues (47).

3.7.4. Results reported

All studies show that the role of patients and their input is substantial used in the results and conclusion of the study. One study mentioned the preferences of patients clearly (29), one study mentioned six different subgroups important to the specific patient population (48), another study provided confirmation by the patients of all six relevant outcomes (30), another categorized four main themes to envision the future (41), and one study identified, on the basis of a grounded theory approach, three issues and sixteen solutions for these issues (47).

Table 5 Involvement level of engagement.

References	Level of engagement	Type of studies	Modalities	Data collection methods	Role of patients related to the level of engagement	Outcomes patient engagement	Results of patient engagement reported
Anderson et al. (29)	Involvement	Observational	Cross-control study	Interviews	Patients viewed videos and commented on the overall approaches and specific discussion components	Patient preferences	The percentages of the patients preferring the different models are clearly mentioned
Slejko et al. (48)	Involvement	Observational	Case study	Questionnaire/survey	Patients were asked which value elements that were the most important to them in making decisions about treatment to manage their condition.	Domain and value element importance	Resulting in six subgroups of value elements important to a specific patient population
Hennink et al. (30)	Involvement	Observational	Cross-control study	Questionnaire/survey	Patients assessed the importance of outcomes and were invited to formulate their own outcomes	Relevance of outcomes	Showed confirmation by the patients of all six relevant outcomes
Fahner et al. (41)	Involvement	Observational	Cross-control study	Interviews Focus group	Patients were asked to elucidate the perspectives on contemplating the future	Underlying values Influence values for future decision-making	Categorized four main themes to envision the future
Najafabadi et al. (47)	Involvement	Observational	Cross-control study	Interviews	Patients discussed the whole meningioma care trajectory and for each part of the care trajectory the relevant themes. Patients were asked to identify issues as well as possible solutions for this issues.	Discussing care trajectory Identify issues Possible solutions	The grounded theory approach identified three issues and 16 possible solutions

4. DISCUSSION

To the best of our knowledge, this is the first systematic review that investigates the communication between patients and healthcare providers at the organizational level of hospitals and throughout the full cycle of care in a VBHC setting. We found that it was most commonly interviews and questionnaires, that can be seen as examples of low-level engagement, that were deployed to engage patients in designing new care pathways and quality improvement projects. Higher-level engagement tools, such as focus groups, co-design experience, collaborative teams, advisory committees, and joint decision-making, are rarely used to improve healthcare in hospitals. This is remarkable in value-driven care approaches that claim to take patient-centeredness and creating patient value as the starting point.

This low level of patient engagement in VBHC is also illustrated by the roadmap for implementing VBHC that has recently been presented by an expert working group from nine large European University Hospitals (50). The roadmap does not pay any attention to patient engagement beyond the advice to develop patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) to measure outcomes and experiences. Our conclusion that higher levels of patient engagement should be pursued is supported by the work of Berwick (3). Today, according to Berwick, we are in an era where there is great emphasis on mandatory measurements and a clash between professional autonomy and these tools for external accountability. Berwick emphasizes the importance of “hearing the voices of the people served” in what he envisions as a new era for medicine and healthcare. The expected benefits of this new era are reduced mutual distrust among by actors in the field, a greatly reduced administrative burden for all, and, by incorporating healthcare users of and their families in co-design activities, improved services.

VBHC research that focuses on the level of direct care demonstrates that patient-reported outcome measures are increasingly used in the consulting room to discuss treatment and outcome preferences between doctors and patients. PROMs could also be used to improve healthcare quality and result in higher levels of patient engagement such as shared decision making (24–29, 31–33). However, we found that higher-level engagement is not yet current practice in VBHC initiatives at the organizational level. Furthermore, our review shows that the organization of the care process and improvements to care pathways are hardly influenced by patient engagement. Only one paper reported the implementation of an improved care process that was a result of patient engagement (32). The possibilities to improve care pathways by using high-level patient engagement strategies extend to experienced-based co-design, involving patient advocates in the organization of care and in influencing patient organizations (12, 16, 51–55). However, we also recognize the risk of tokenistic patient engagement (12, 16). Tokenistic engagement may demotivate patients to participate. To avoid this pitfall, the importance of "creating a receptive context" is stressed, along with open communication, honesty, and trust between doctors, patients, and other participants (12, 56).

Furthermore, the results of our systematic review at the organizational level show that, although low levels of patient engagement do inform healthcare providers about the values held by patients, once this input has been made by patients and their family members, they are no longer involved in improving healthcare services. Patients and families are rarely involved in collaborative thinking about ways to improve healthcare, even though the literature suggests that higher levels of patient engagement can increase the likelihood of improving care processes (12, 16, 52, 53, 57). To determine what is of value to patients, in other words what matters most to patients, patients have to be engaged in the development of healthcare services (52). To summarize, we believe that higher levels of patient engagement at the organizational level (e.g., involvement in redesigning care processes) can be of tremendous value when implementing VBHC.

4.1 Strengths and limitations

A strength of our study is that it focuses on organizational level patient engagement in a VBHC setting, a field that to the best of our knowledge has not previously been addressed in a systematic review. This is a developing and relevant field because both VBHC and patient engagement are of growing importance in improving healthcare and in the ongoing shift from volume-driven to value-driven healthcare delivery. In addition, VBHC initially focuses on the needs of patients at the direct care level, whereby this systematic review shows that there are already 21 papers at the organizational level of patient engagement in a VBHC context.

There are five limitations in this study. First, we specifically included empirical research in the VBHC field that involved any form of patient engagement. By only including current research related to hospital care, we did not include primary care or chronic care for the elderly in nursing homes. The motivation for limiting ourselves to research involving hospitals was prompted by the fact that VBHC always aims to improve the full cycle of care, and so hospitals are always an element in this. Second, as a result of our 21 included articles, 19 papers were observational and two randomized. Due to this, there may be a limited level of evidence, however, this study shows that the observational articles contain a relatively large number of cohort and cross-control studies that are in the highest levels of observational studies (58). Third, due to the choice of MMAT as quality assessment tool, we did not analyze inconsistency and publication bias, which could be important items for assessing the quality of the studies. Fourth, we only included peer-reviewed publications, which may mean that we have overlooked relevant VBHC initiatives. Finally, the perspective of this study is limited to the definition of VBHC as introduced by Porter on patient and organizational level. Although Porter's definition may have evolved over time, especially in Europe, allocative and societal value play hardly a role in his definition.

5. CONCLUSION

This study included 21 articles, the majority of which were observational, resulting in a limited quality of evidence. Our main contribution is highlighting that extensive patient engagement, as a valuable approach to improving healthcare at the organizational level in a VBHC setting, is rarely used. Current engagement tools between care providers and patients rarely go beyond the communication level of interviews and questionnaires. While this form of communication may be of value to care providers seeking to improve healthcare, it ignores the possibilities of higher-level engagement such as co-design and collaboration. Higher-level engagement would provide an opportunity to improve healthcare and care pathways through co-production with the people being served. We would urge VBHC initiatives to embrace all levels of patient engagement to ensure that patient values find their way to the heart of these initiatives.

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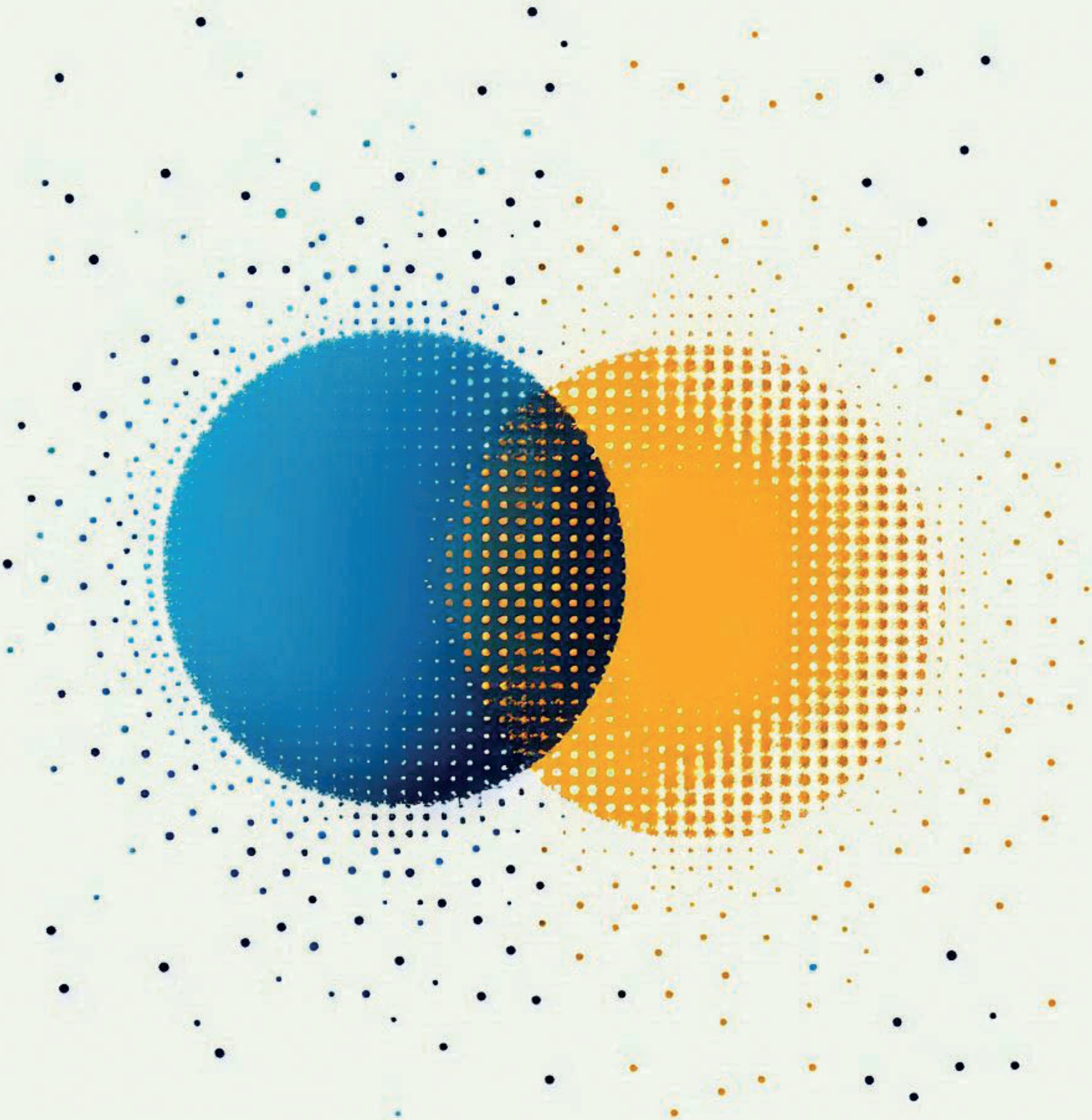
CHAPTER 5



Improving healthcare services for living kidney donors: an experience-based approach in the Netherlands

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ABSTRACT

Living kidney donors voluntarily donate one of their kidneys to someone suffering from end-stage kidney disease. Transplantation is a life-saving opportunity for these patients and generally provides an increase in quality of life. A major goal of research and practice related to living kidney donation concerns the safety of the donor. In comparison, only limited research has been carried out on donor experiences of the donor journey in the full cycle of care. To gain further insight into this, we have performed an experience-based co-design (EBCD) study in a major transplant center in the Netherlands. EBCD is a research approach where professionals and patients share experiences with the purpose of improving the healthcare journey. We identified eleven areas for potential improvement: from intake, throughout surgery and hospitalization, to homecare and aftercare. Donors indicated the importance of person-specific information during the admission process, accurate communication with health professionals and attention to recovery after surgery. Nevertheless, no one regretted their donation, and the overall experience was positive. An important finding for professionals is that donors feel like ‘normal’ patients and want to be taken care of even though they are healthy. Just like other patients, they can be anxious before surgery and some may have concerns about recovery. Although this is a single-center study, the results should be relevant for all transplant centers that are interested in improving donor experiences. We concluded that the EBCD approach, when embedded in a local context, is a valuable tool for bringing patients’ experiences to healthcare improvement.

INTRODUCTION

End-stage kidney disease (ESKD) is life-threatening and requires lifesaving treatment in the form of either dialysis or a kidney transplant. Today, kidney transplantation is the best medical intervention for most ESKD patients, offering a longer life expectancy and an increased quality of life at a much lower cost than dialysis [1–4]. Kidney transplants can either be performed with a deceased donor or with a living kidney donor. Globally, in 2021, around 95,000 kidney transplants were performed, of which 35,000 were from living donors [5]. Living kidney donation (LKD) is geographically widespread and is performed in around 90 countries. We observed that encouraging LKD has been successful and the number of LKDs now exceeds the number of deceased kidney donations in countries that lack an active deceased kidney donor program [6]. Living kidney donors voluntarily undergo surgery and donate one of their two kidneys to an ESKD patient. These are of great value to patient care, as their donations save many lives. Consequently, the care of living kidney donors is of utmost importance [7,8].

To date, many studies regarding LKD have focused on issues such as the medical suitability of the donor, donor safety, donor motivation, and psychological fitness [1,9–15]. However less research has been done on the donors' personal experiences of the complete donor procedure. Donor stories have been well documented by donors themselves to inform others, but not with the aim of improving donor care [16–19]. The wider literature describes well how patient experiences and patient involvement can be used to improve care pathways [19–24]. Therefore, in this study, we collected donor experiences to explore the possibilities to improve the donor care pathway. Our study was inspired by the well-documented experience-based co-design (EBCD) approach that brings both patient 'user' experience and healthcare professional experience to healthcare improvement [25,26]. EBCD has its roots in the United Kingdom and is applied in a variety of settings to improve healthcare and patient experiences [24,27–29]. EBCD is a time and resource intensive approach to quality improvement and EBCD projects are customized according to the context, and conducted and reported in different ways [24,30,31]. However, the core remains: to bring patients' experiences to healthcare improvement.

This study has three research questions: a) how do donors experience the current donor care pathway?; b) where in the care pathway do donors and healthcare professionals see room for improvement?; and c) which of these improvements should be prioritized in the views of donors and care providers? Through this study we aim to enhance the awareness in the transplant community that donors have personal experiences that go beyond the medical risk analysis of donorship and that these experiences can be used to improve the service provided to the vital group of living kidney donors.

METHODS

Setting

This single-center study was situated in the University Medical Center Groningen (UMCG) in the Netherlands. The UMCG is a major academic hospital where all types of transplants are performed including kidney, liver, lung, heart, and stem cells. In the UMCG, a multidisciplinary kidney transplant team consisting of nephrologists, surgeons, specialized nursing professionals, and a variety of supporting staff members coordinates all kidney transplants. To date, the UMCG has performed over 5,000 kidney transplants and, over time, developed an active LKD program. As a result, more than 50% of the annual transplants involve living kidney donors. Using the EBCD approach, this study sought to identify areas for improvement in the care process of the LKD program.

The EBCD approach

The main characteristic of EBCD is that patients and professionals work together to improve a given care pathway. A detailed description of the EBCD approach can be found in the literature [25,26]. Using EBCD, areas of improvement can be found in the moments when professionals and living kidney donors interact. When such interactions have a high impact on the experience of donors they are also referred to as ‘moments of truth’. As far back as 1990, the importance of managing these moments of truth in service delivery was extensively described by Christian Grönroos [32].

The full cycle of the EBCD approach consists of six stages: a) setting up the project, b) data gathering from professionals, c) data gathering from patients/donors, d) discussing the results with participants and an initial co-design of an improved care pathway, e) organizing teams for detailed co-design, and f) a celebration event. Given the complexity of the approach and the significant burden on participants' time, it is not uncommon to adjust the approach to achieve a better fit with a given context [31,33–35]. Consequently, we customized EBCD to the UMCG context and focused on the first four stages to answer our three research questions.

We started with the first stage, setting up the project, which included developing inclusion criteria for participants. The study was approved by the Medical Ethical committee (METc) of the UMCG (2022/173). All participants were given written information about the study prior to the interviews and signed an informed consent form.

In the second stage, data gathering from professionals, we interviewed nine members of the transplant team (including nephrologists, living kidney donation coordinators, nurse specialists, physician assistant, and social workers). We interviewed them face-to-face, five individually and four in pairs of two. The interviews were summarized by the interviewer and approved in writing by the interviewees. We used a discovery interview technique, aiming to produce a topic list to be used as an interview guide in the face-to-face interviews with the donors [20,36]. After we developed the topic list (Table 1) we started the third stage.

We consider the third stage of EBCD, gathering data on donors' experiences, as the heart of the process because the ultimate goal of EBCD is to bring user experience to the care improvement process. Data can be gathered in different ways, for instance with surveys or by collecting patient narratives [37,38]. Supported by earlier studies, we chose to collect patient narratives as an appropriate way to collect in-depth and detailed insights into the donors' experiences and to identify areas for potential improvement [21,24,30,31]. We selected nine donors who, following our inclusion criteria, had not had any severe medical issues following surgery. Except one participant who donated shortly after the interview due to circumstances. One donor declined to participate but eight were willing to share their personal donor journey with us. Six donors were female, two were men. The donors' ages varied between 44 and 74 (mean 56 years) and the time elapsed of seven donors since donation varied between three weeks and 40 months (mean 17 months). The donors' lived experiences were captured in personal stories and resulted in detailed insights into how they experienced the entire donation care pathway from intake and screening to inpatient care and aftercare. As researchers, we concluded that inviting additional donors would not produce significant additional information.

In the fourth stage, discussing results, we first analyzed the data from the interviews and focused on identifying areas for improvement. Two authors (MvL, WS) performed a thematic analysis [39,40] using Atlas.ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) for initial coding and, after discussion, extracted 11 themes from the data as possible areas for improvement [41].

The next step in the fourth stage was to organize two separate sessions, for professionals and for donors, to discuss the results with both groups. All the participants received the analysis in advance and were asked to think about priorities in the themes for improvement. The first session with professionals was face-to-face, the second session with donors was a virtual meeting using Microsoft Teams (Microsoft Corporation, Albuquerque, New Mexico, United States). Notes were taken during both sessions. Three authors (MvL, WS, AV) were present during the session with professionals, two (MvL, WS) in the MS Teams meeting with donors. We concluded that the 11 themes were recognized by both groups. The group discussions also included an initial setting of priority themes that could be useful for organizing the fifth stage, co-designing improvements in the chosen areas.

Table 1. Topic list for interview with donors

1. Introduction and gaining a mutual acquaintence; explanation of research design.

2. The inside story
   a. Reason, what happened and how did it go. From registration to donation and aftercare (if applicable)
   b. Exciting moments, uncertainties, joys and/or disappointments. Contacts with UMCG. Experiences throughout the entire process. What stuck with the donor in a positive or less positive (negative?) sense.
   c. Timeline of donation process and where we are now?

3. Stocktaking
   a. Who were the key people on the UMCG side? What were your experiences with them?
   b. Were there gaps in the moments of contact? Or too much? Which ones?
   c. Had there ever been any ambiguities? How were they resolved?
   d. In hindsight, what was the most stressful thing in the entire process?
   e. Were there any predetermined expectations about the process from sign-up to donation? Was the reality different, if so how?
   f. What were your experiences with aftercare? What else was expected? Permanent aftercare or ‘full stop’ at some point?
   g. Are aftercare payments going smoothly? What costs do donors bear themselves, is that perceived as reasonable?

4. Specific
   a. Was dealing with work discussed? Planning at work, even after admission during recovery. Did the donor have any questions about that? Does the donor expect anything from this through UMCG?
   b. How is admission to the UMCG experienced? Are other departments involved? (surgery?).
   c. Did the recovery go as expected? Could everything be arranged at home? How?
   d. Looking back, what was disappointing and what wasn’t so bad?

5. What could be different?
   a. Given the experiences, what would donors do differently in terms of donor screening, kidney donation, aftercare, etc. More specifically: what would donors recommend UMCG to do differently?
   b. Which topics do donors think deserve more attention? And where can it be ‘taken down a notch’?

RESULTS

In this section, the 11 themes, the possible areas for improvement, are presented in detail. Since this paper focuses on the inputs from donors, the quotes to support the themes are selected from the donor interviews. The 11 themes that emerged are introduced with a short explanation in Table 2.

Table 2. Themes/areas for improvement

Nr.	Themes – Areas of improvement	Explanation
1	Communicate carefully at crucial moments	Think about approvals, adjusted planning (postponements for example), hitches, delays, etc. Personal communication: careful and with the right information. Especially focused on essential moments in the entire process for the donor and recipient.
2	Do not overlook the donor's social network	Donors like recipients are not alone. They live in a context and receive questions from their environment: about the process, the risks, etc. Families may be worried.
3	Let other donors share their stories	Contact with other donors who are further along in the process, who are also in the middle of it, or who have already done everything, is greatly appreciated.
4	Improve coordination between the Nephrology and Surgery wards	Donors who stay on the Nephrology ward do not have very good experiences of this. The feel 'forgotten' on rounds, no surgeon at the bedside, do not feel cared for as a patient.
5	Remember: always a personal approach	Donors are generally satisfied. Nevertheless, there are also some poorer experiences throughout the process. Some of them have to do with treatment in the preliminary phase, but also during admission. Such moments are experienced as annoying.
6	Create excellent experiences: give personal service	Donors greatly appreciate the service they receive. Calm explanations, responses to situations or questions. For example, an offer to take pictures of the operation, arranging another room because of fear of contamination. Keep in mind any concerns they may express about the recipient. Donors are not only concerned with themselves, but also with the recipient.
7	Personalize advice on getting back into good shape after surgery	Donors recover differently. The common thread is that, in the long run, things turn out well, but initial recovery (possibly lasting months) after donation there are some limitations.
8	Be explicit about long-term aftercare for donors	It can be somewhat unclear when aftercare ends: when will I be healthy again?, a donor asked.
9	Organize home care after kidney donation	Home care, mapping out the home situation and the first weeks at home after donation is very important for both donor and recipient. Especially in the case of partner donations or donors living alone.

10	Align donor services at the regional and the university hospital	Donors consider a regional hospital or GP to be a good first contact to look at their suitability for donorship. The UMCG has a different view on this. The hospital is concerned that donors will be incorrectly rejected, or that donorship will be discouraged on incorrect grounds. There is a tension here.
11	Organize adequate support from the general practitioner after LKD	Donors have to rely on their GP for all kinds of medical questions. They would appreciate it if their GP was well informed about being a donor.

1. Communicate carefully at crucial moments

The interviews revealed that, during the donation process, some moments are experienced as critical by the donors. Such moments include medical approval for donation, setting a date for surgery, and when the surgery is postponed at the last moment due to urgent events in the hospital. During these crucial moments, both donors and their families can be in a heightened mental state than normal. If communication at such moments is not carefully executed, this can cause feelings of frustration, disappointment, or anger. An example was donor B, who stated: “I was already in the hospital and at the last moment the surgery was cancelled. Without any consideration, they told me, ‘We’ll see you again in three weeks’. I had carefully planned my business activities for this specific date and put a lot of effort into communicating with my suppliers and customers. So, I got very angry at that moment, whereas in a normal situation, I’m seldom or never angry.”

2. Do not overlook the donor’s social network

In the donor care process, information on the process and potential risks are strongly directed at the living kidney donor, and sometimes to the recipient of the donated organ. However, in the interviews, donors indicated that their social context, involving family, colleagues, and neighbors, often lacked accurate information. Donors indicated that those in their social network can also be anxious about risks, especially since many people have no idea what living kidney donation encompasses. Donor E: “My children were worried that I, being their mother, would not be in such a good shape after the donation. So, we had an explanatory conversation on this with the donation coordinator just before the surgery. That helped a lot. Looking back, we should have done this earlier.”

3. Let other donors share their stories

The majority of our interviewees had a long period, often many years, to get used to the idea of being a living kidney donor. The main reason for this was that the intended recipient’s illness often resulted in a slow decline of the kidney function before a transplant was appropriate. Donors received a lot of information on LKD, including brochures, oral information in the hospital, and links to numerous websites. An additional way of getting information that was mentioned by donors was to have contact with previous donors. We found that some donors had heard or read the stories shared by earlier donors. These contacts were highly appreciated and could be initiated in spontaneous meetings, for example in the waiting area of the hospital. Donor C: “I really appreciated contact with other donors. I also received a small book with donor stories and how they had experienced the kidney donor process.”

4. Improve coordination between the Nephrology and Surgery wards

Donors are usually hospitalized in the surgical ward of the UMCG, where living donors are admitted both before and after the nephrectomy procedure. Due to COVID-related restrictions and personal preferences, for instance when a parent donates a kidney to a child, some donors were instead hospitalized on the nephrological ward of the UMCG, whilst still being under care of a surgeon. The nephrological ward, where the transplant recipients are also admitted, is located at a different place in the hospital, a walk of some 500 meters from the surgical ward. A number of donors experienced a lack of attention at this ward due to not being a kidney patient, seeing the ward’s daily routine being organized to take care of kidney patients. A practical example of this was given by donor A: "Patients received an information folder during admission. When I asked at the front desk about my information folder it became clear that there were none for donors.

5. Maintain a personal approach

Although donors were content with how they were addressed by staff members, in some cases they felt unheard in face-to-face meetings. One example was given by donor C: “One consult with a professional was highly unpleasant. I didn’t feel respected, I felt vulnerable, and the professional seemed uninterested. I had a nasty feeling afterwards, which was in huge contrast with all my other contacts with the personnel of the UMCG.” Although such experiences were exceptions, nevertheless they are remembered. We noted that donors again and again stressed that the overall experience in the hospital was positive. Although negative personal experiences do occur and are potentially dissatisfiers, the consequence was not a dissatisfied donor.

6. Create excellent experiences: give personal service

Elements of personal service are highly appreciated. We found that donor experiences can be positively influenced by letting donors know that exceptions to the routine procedures are possible in case of personal circumstances or personal needs. For instance, donor B mentioned that, on their request, photographs could be taken during the surgery. This was important to the donor as the donor was an active volunteer and wanted to give information on LKD and use the pictures during presentations to share personal experiences as a donor. In another example, donor A stated that, although they were medically ready to be discharged by the hospital, they were allowed to stay a few more days because of personal circumstances: “This made me feel at ease again.”

7. Personalize the advice to get in good shape following the surgery

There are differences in the time that donors need to recover, varying from weeks to months, and the issues they experience after the nephrectomy. One donor in our study indicated that they were still not fully being recovered more than a year after the donation. Some donors experience pain, others can be insecure as to what is normal. All have in common that they are admitted to the hospital in good health and leave the hospital in a reduced physical condition. Also, donors differ on their need for assistance to speed up the recovery process. Donor E said “I arrived in the hospital in perfect condition, when I left, I was in a poor condition. I would have preferred to get some help or be given suggestions on how to regain my good condition.” However, after a while, some felt insecure about which daily activities they could safely undertake again, such as running or working in the garden.

8. Be explicit about the long-term aftercare for donors

The transplant center offers different forms of medical follow-up once the donor has been discharged from the hospital. Follow-up includes checking on the donor by phone and, after some weeks, a medical check including an iothalamate-measured glomerular filtration rate (mGFR) for testing the kidney function [42]. These tests are repeated after five and ten years, as a service to donors who appreciate medical checks. Donors are also advised, in line with international living kidney donor guidelines, to undergo annual health checks, either in the hospital or by visiting their general practioner (GP) [43–45]. Donors differed in their wishes regarding follow-up care. Donor F said: “Couldn’t we just visit a GP for check-ups, and shouldn’t we end the follow-ups when we’re feeling okay?”, whilst donor A stated “I prefer check-ups in the UMCG, because they have all my medical records and they know me well.” We observed that, after a time, the surgery and the donation move into the background in the lives of the donors. In other words: life goes on. Shared decision-making could be important for donors in making the correct informed decisions on long-term check-ups.

9. Organize home care after kidney donations

Especially for donor-recipient couples and for donors who live alone it is important that they receive appropriate home care after the donation. Although the hospital tries to arrange seamless care with external homecare suppliers, this can go wrong. Donor G experienced this: “Home care was requested by the hospital, and I really needed it, I couldn’t lift anything, not even a pan with a meal. However, although a six-week period of supportive home care was requested, I didn’t get any help at all.” The absence of home care makes daily-life immediately after arriving back home very difficult for donors and donor-recipient couples. Another donor did receive home care and highly appreciated this. Although home care providers are external organizations and it may be difficult to ensure a commitment, to donors it would be very helpful if the UMCG could be given priority when requesting home care.

10. Align donor services at the regional and the university hospital levels

In the Netherlands, transplant centers have full responsibility for the donor screening process and for all the steps involved, including mental and physical eligibility. However, donors might prefer an initial screening in a regional hospital closer to home. We observed a tension between the specialists' desire for a highly professional matching process in the academic setting and the donor-service approach involving some regional prior testing that would be more convenient for the donor. Specialists were concerned that mismatched blood types between donor and recipient might cause a potential donor to be rejected by a regional hospital, whereas they knew that this incompatibility could in some cases be overcome with special treatment. Donor G explained the benefits of an initial regional screening, "I really appreciated that the first tests were undertaken in my own hospital. After that I was referred to the transplant center." The upside of regional screening for the UMCG could be that potential donors who are clearly not suitable, for instance for sound medical reasons, are not unnecessarily referred to the UMCG. Therefore, aligning the services between regional hospitals and the UMCG could be beneficial for both hospitals and potential donors.

11. Organize adequate support from general practitioners after LKD

The healthcare system in the Netherlands is characterized by a prominent role being given to the general practitioner (GP). Some donors indicated that they did not experience adequate support from their GP when they experienced health issues after the LKD. Although GPs are informed about any kidney donations by patients registered at the GP practice, they do not always know how to react to medical concerns by kidney donors. For example, donor A was unnecessarily referred to a nephrologist in the transplant center by his GP. "In the consulting room the nephrologist was clearly surprised by the referral because my complaints were not related to the donation and I was asked 'Why are you in our hospital?', and I replied 'My GP sent me.'." Given the diversity among GPs, it may be difficult to organize adequate support and to develop the specialized knowledge needed, however donors would appreciate having a well-informed GP.

Appreciation

In addition, by listening to the donors´ stories and experiences, the interviews also resulted in many compliments from the donors toward the staff members involved in the entire cycle of kidney donation. All the donors were content with the way they were informed about the donation process and with the personal contacts with staff members during all stages of the donation procedure. Also, the easy accessibility of members of the transplant team, the practical information, and the specific information for getting financial compensation that was given to those who were employed or who were independent entrepreneurs were highly appreciated. Also, donors did experience that it was only a small step to make a phone call to the UMCG for some advice after returning home. Furthermore, all donors stated that they would donate again if necessary and no one regretted the decision to become a donor. We noticed that it also became clear that donors themselves can benefit from LKD as illustrated by donor G who stated “Now we can enjoy our lives together again.”

Priorities

To gain an initial impression of which areas of potential improvement matter most, we also discussed priorities with donors. We found that priorities were determined by personal circumstances. For instance, for donor-recipient couples it was for home care. As a result, the ranking of priorities varied and at first all areas for improvement seemed equally important. Nevertheless, we concluded that careful communication at crucial moments, a personal approach, and advice on how to recover after surgery warranted the highest priority for donors because of the impact of these aspects on the overall experience. In addition, the professionals interviewed indicated that some suggested improvements would be complex to realize, such as organizing home care and support for the general practitioner because these health providers are external, independent organizations beyond the direct influence of the transplant center.

DISCUSSION

Kidney transplants are of great value in the treatment of end-stage kidney disease (ESKD), and live kidney donation (LKD) is recognized by the World

Health Organization (WHO) as an opportunity to reduce the shortage in organ donations [46]. In modern healthcare, patient experiences matter. Here, bringing doctor's and patient's knowledge together, and viewing patients' personal experiences as a special kind of knowledge, may lead to better care experiences by patients [25]. Although this approach to practicing medicine is of growing importance, in the field of living kidney donation, the donor's safety dominates [7,44] and less attention is paid to donors' experiences. To fill this gap we performed a customized EBCD study to identify aspects that would help improve donors' experiences during the entire donation journey. To the best of our knowledge, this is the first EBCD study in the field of LKD. By interviewing and discussing their experiences with nine transplant professionals and eight living kidney donors we were able to identify 11 areas for improvement. The personal stories showed a wide variety of experiences, both positive and negative, ideas for improvement, and personal benefits regarding kidney donation.

Our first research question was 'how do donors experience the donor care pathway?'. Overall, donors were very satisfied with the donation experience. It also became clear that donors were very motivated to help those close to them and, as reported in earlier research, experience personal benefits from donating a kidney [47]. Further, none of our sample regretted the decision to donate and all said 'they would do it again', which is consistent with earlier research [15,47]. The stories told by the donors not only revealed areas that could be improved, but also deeper motivations and experiences that offer providers insights on what matters to donors in the donation process. To summarize these experiences in one phrase we could say that 'donors need to feel they are being taken care of'. This reflects that donors can be just like normal patients: some are anxious when visiting the hospital, nervous before surgery, need security and reassurance after surgery, and can be unsure what will happen after leaving hospital [48]. Indeed, at some points, they need a little more personal attention because they are healthy and not sick. Maybe a good comparison that occurred to us is the extra personal care and attention given to pregnant women and those who just have given birth.

As an answer to our second research question, ‘where in the care pathway do donors and healthcare professionals see room for improvement?’, we found 11 areas where improvements could give donors a better experience. These areas encompass multiple aspects of the kidney donor pathway. Most of the identified themes related to personal encounters and information regarding the donor’s patient journey. Donors indicated the importance of personal information during their admission, good communication with the health professional during crucial moments of the donation process, contact with other donors, and a personalized approach. Also, themes regarding recovery after surgery, the organization of home care after leaving hospital, the role of regional non-academic hospitals, and adequate briefing of the general practitioner were important. The themes indicated clear and often key moments in the donor care pathway that could be improved. We found support for these issues when discussing them with the professionals. Overall, we concluded that donors, even though they are very healthy, should be considered as ‘normal’ patients with similar needs, anxieties, and expectations.

Our third research question was ‘which of these improvements should be prioritized in the views of donors and care providers?’. Here, careful communication, a personal approach, and recovery after surgery are the improvement areas that would have the greatest impact on the donation experience. Nevertheless, all the themes should be seen as important, and donors’ priorities vary with their personal context and needs.

We acknowledge that there will be barriers to achieving improvements. We found that some improvements will be difficult to realize because of the complexity of the healthcare system. For instance, transplant centers and the primary care system do not yet offer integrated post-donation care, and this may be a long-term challenge [8]. The same is true for organizing home care. We concluded that, for an individual improvement, the impact on the donor and its feasibility are two dimensions that need to be considered in setting an implementation agenda. We believe that such an agenda might help to determine which areas should be chosen for detailed co-design, which is the next stage of EBCD. We would stress that continuous co-design, although the next logical step, is not an easy task. We encountered many practical difficulties in meeting with the professionals and donors in individual groups, let alone meeting both groups at the same time in the same location. Doctors and donors have jobs and other obligations, many donors live at a distance from the hospital and travelling to a meeting can consume a whole day. Activities require resources and time, both from donors and from professionals. So, although we saw that, during the project, all participants were eager to participate, getting everybody together for group sessions proved a difficult task. Therefore, although we have successfully identified areas of improvement, this is not enough to ensure a successful co-design and implementation stage. A major challenge will be to keep all the participants together during all stages of an EBCD project. Such difficulties have also been addressed in earlier research [31,49].

Reflecting on the use of EBCD, we believe that, when fully applied, EBCD is a highly time and effort consuming effort and, furthermore, does not consider implementation. Implementation requires organizational change and needs professional guidance, especially in complex organizations like hospitals. This may explain why successful EBCD projects with real change are rarely described in the literature and, as such, the evidence is ambiguous [30,31,34]. Patients' stories do give valuable insights into how they experience healthcare services, but this is insufficient to improve these services [49].

The main lesson we learned is that really listening to the stories of patients and of donors can generate a lot of inspiring and practical ideas for improving care pathways. A customized version of EBCD would be a good starting point because experiences matter and this approach may bring healthcare to a more patient-engaged level to organize care based on 'hearing the voice of the people served' [50,51].

Strengths and limitations

This study has some limitations that should be taken into account when interpreting the results. First, the study was conducted in a single large transplantation center in the Netherlands. The results of applying this adopted EBCD approach should be seen in this context. However, this also makes EBCD a powerful tool, because of the involvement of local professionals and patients, and several of the identified themes are universal such as 'communication at crucial moments'. Second, the donors in our study all experienced a rather uneventful donation process without major complications whereas, in reality, a variety of medical complications can occur after kidney donation.

Despite these limitations, we were able to formulate several avenues for improving donor care that are very practical and may be of use in many hospitals across the transplant community. We used EBCD as an established method for improving patient care, and the use of storytelling proved to be an appropriate way to identify areas in the donor care pathway that could be improved [21,26]. The customized EBCD approach was useful in involving donors and professionals and may inspire care givers to broaden their view on how donors experience the donation process. We suggest two areas where future work could be beneficial: first, more research is needed on donor experiences and how to optimize these in different stages of the donor journey; and, second, seeking new ways to customize EBCD approaches such that they are less time and resource consuming but still lead to the ultimate goal: bringing users' experiences to healthcare improvements.

In conclusion, this study shows that a customized EBCD approach can identify valuable and practical opportunities for improving patients' experiences, and that some of these opportunities are relatively easy to implement.

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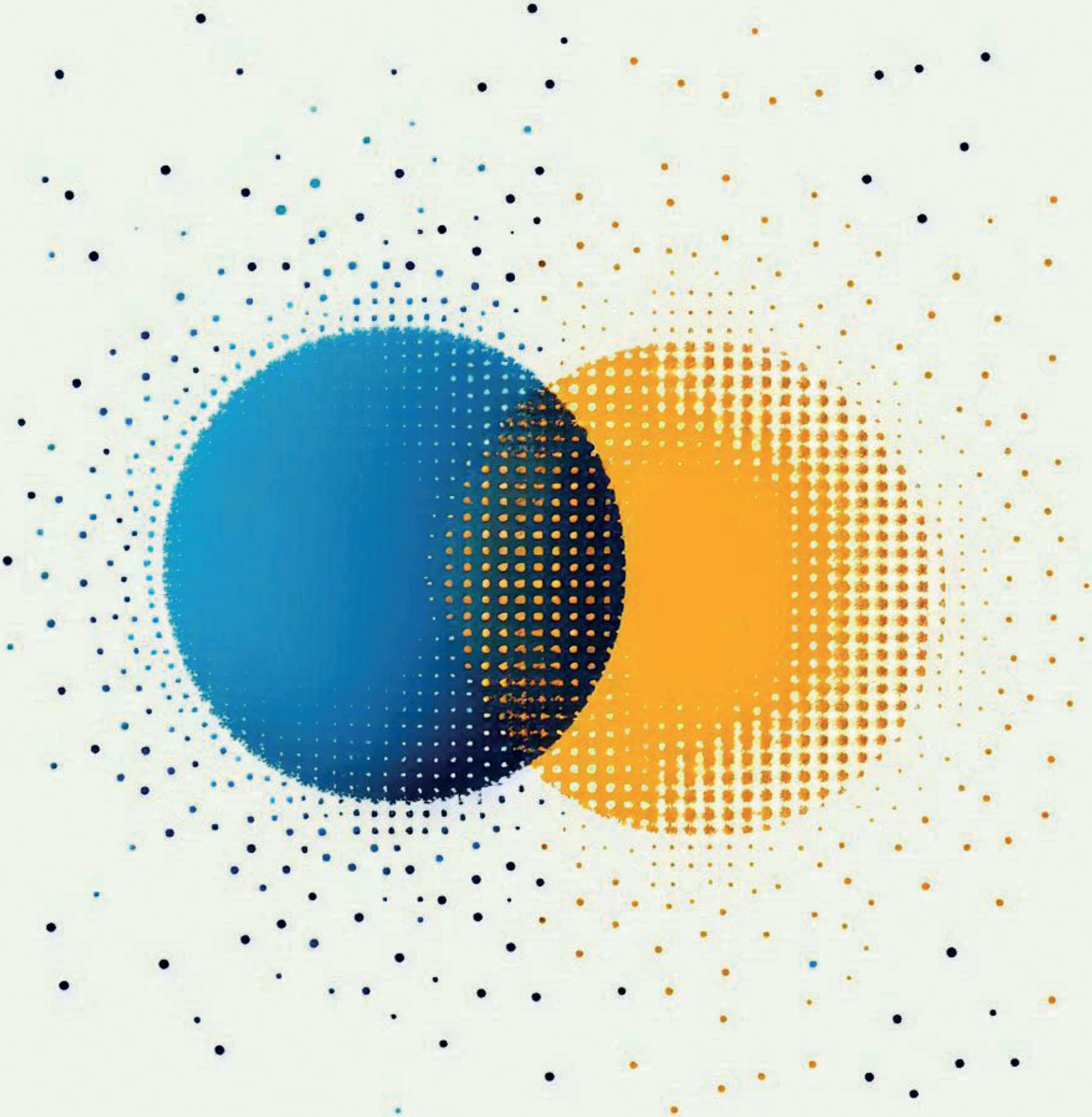
II

OPINION

CHAPTER 6



Innovations in dialysis: the user’s perspective

With
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Nature Reviews Nephrology, 2020

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The need for innovation in dialysis is long overdue. As past and present users of dialysis we are fully aware of the limitations of current dialysis modalities. The time for complacency is over — developers must engage with dialysors to ensure that our needs are met so that we can live the best life possible. Let us share our dream for devices that will enable us to enjoy life.

There is no doubt that the mainstay therapy for kidney failure — dialysis — has a negative impact on quality of life (QoL). Dialysis affects the ability of an individual to participate in activities such as family life, sports, travel or work. Although mortality has improved somewhat over the past 25 years, only ~24% of individuals aged 18–54 years remain employed — an important indicator of social participation — at initiation of dialysis, compared with 85% employment among healthy, age-matched individuals (1). Given the negative impact of dialysis, how do we enable dialysors, in all their diversity, to find their new normal and achieve the best QoL possible while living with a chronic illness? We believe that technological advances may help to achieve this goal.

Notice that we avoid the term 'patient', which we perceive as a term used to describe a passive receiver of healthcare services. Rather, we use 'dialysor' to describe an individual who lives an active lifestyle, including work, involvement in family life and travel, where the only limitation is that they must regularly connect to a machine to stay alive (Supplementary Box 1).

The current state of innovation for the treatment of kidney failure is appalling; devices have remained largely unchanged over the past few decades. This lack of innovation does not stem from a lack of demand. The global burden of chronic kidney disease (CKD) is enormous with tremendous societal and economic costs. Indeed, CKD has even been described as "the most neglected chronic disease" (2). It is time to move past the status quo (3). Dialysis technology has not followed the path of Moore's Law of rapid technological development (4) and we conclude that necessary developments to facilitate improvement in healthcare, such as miniaturization and optimal performance, have bypassed the world of kidney patients. What developers have seemingly failed to grasp is that most dialysors want, above all, a treatment that allows them to feel good and continue with their daily activities. Instead, most dialysis machines, either currently under development or recently arrived in the marketplace, may provide somewhat improved performance, but they are not user friendly nor do they markedly improve QoL over older models. Current devices often require extensive training in order to use them, complex water systems, consumables that overwhelm the average household and they cannot be easily transported (if they can be transported at all). Although performance and safety are important, few dialysors want to be tied to a machine controlled by others, or on a rigid schedule. Nor do they want a machine that is unwieldy, complicated and restrictive. In short, although research may have improved the specifications (that is, the clearance of solutes) of dialysers these improvements have not been made with the needs and desires of dialysors in mind. Medical goals do not necessarily coincide with consumer preferences.

We consider the impact of such oversight by describing the experience of hypothetical personas. Personas are used as a tool to help developers imagine the user's challenges in daily life, their interests, characteristics, social environment, traits, age, job, preferences, likes and dislikes.

Our first persona is Mrs N. She loves to travel and refuses to be a passive dialysor. She lives alone and values her independence above everything else in her life. She has maintained excellent residual kidney function for the past 7 years, and because of this, she needs the ability to adjust her treatment daily to compensate for sporadic kidney function. An improvement over current options would be a smaller dialysis device that can analyse the amount and quality of dialysis, based on her residual kidney function. For example, because her kidneys are working, albeit not at 100%, a treatment may remove too much phosphorus or potassium, leaving her depleted. She needs a treatment that can fine-tune her blood purification and ultrafiltration. Additionally, she is energetic and travels extensively so she wants a device that maintains her QoL, can be adjusted at each treatment to compensate for existing function, and can be used without direct clinician supervision, all on her own schedule.

Now imagine Mr H. He has required specialized health care from the day he was born. Dialysis for him is only one of many obstacles to overcome and is not even the most influential on his QoL. Despite his diverse health needs, he has no trouble using a dialysis machine alone and has found independence from dialysis clinic schedules. He also needs a home dialysis device. His primary concern is the effectiveness of his dialysis, with the ability to do longer hours on dialysis to maintain his health. However, he also prefers a portable device since he works and travels extensively. His motorized wheelchair is perfect for storing dialysis equipment.

Mr W. is also a dialysor who was diagnosed with kidney failure at the age of 48. As a result of continuous fatigue, both mental and physical, he lost his job and his career, but not his spirit. He rigorously safeguards his independence and ability to care for his family. His goal is not to be a patient, but also not to bring his treatment home. He initially attended a nearby dialysis clinic for 12 hours a week, and ultimately — after 10 months on dialysis — received a transplant from a family member. He can't help but wonder what device he will use if or when his transplanted kidney fails. The most annoying part of centre dialysis was the strict schedule. He dialysed during 'home rush hours' and therefore missed socializing with his family while they enjoyed dinner and talked about their experiences of the day. Next time he would prefer a flexible schedule that allows him 'on demand' or 'drive through' dialysis, although preferably not at home. He prefers a social context like a community or shopping centre, with remote monitoring, click-on blood access, a comfortable chair, high blood purification and variation in the length and frequency of dialysis as he pleases independent of hospital restrictions and high-care specialist attention. To meet his demands a technology and health service provider is needed that enables this flexibility in time and place and that supports his quest to prolong independence on dialysis.

For each of these personas to live their best lives they must have the opportunity to identify the best treatment option for them and use a device that meets their individual needs and goals. For personas such as those we have described, the wait for innovation is long overdue. From manufacturers to dialysis providers, the field has been guided by complacency when it comes to improving QoL for dialysors, who are 'locked in' and can only escape by getting a transplant or dying. Fortunately, we are now beginning to see a movement towards innovation in kidney replacement therapy (KRT) that aims to improve lives. While we applaud that KRT innovation is finally emerging, when comparing the predicted time for these innovations to reach the market with the expected life span of a dialysor, our elation might be reserved for future generations.

We have a clear dream. We envision a dialysor in need of KRT walking into a full-service clinic, examining an array of options, devices and treatments, and, with the guidance of a knowledgeable and caring clinician, opting for the treatment and device that fits their personal lifestyle and goals. We appeal to KRT developers to obtain a thorough understanding of the values of dialysors by engaging with us from day one, in order to devise individualized solutions, and not one-size-fits-all modalities. We look forward to working with KRT innovators and stand ready to discuss what dialysors want, need and demand. The status quo is no longer acceptable. Help us to live a meaningful life; a life in which we dialyse to live and do not live to dialyse.

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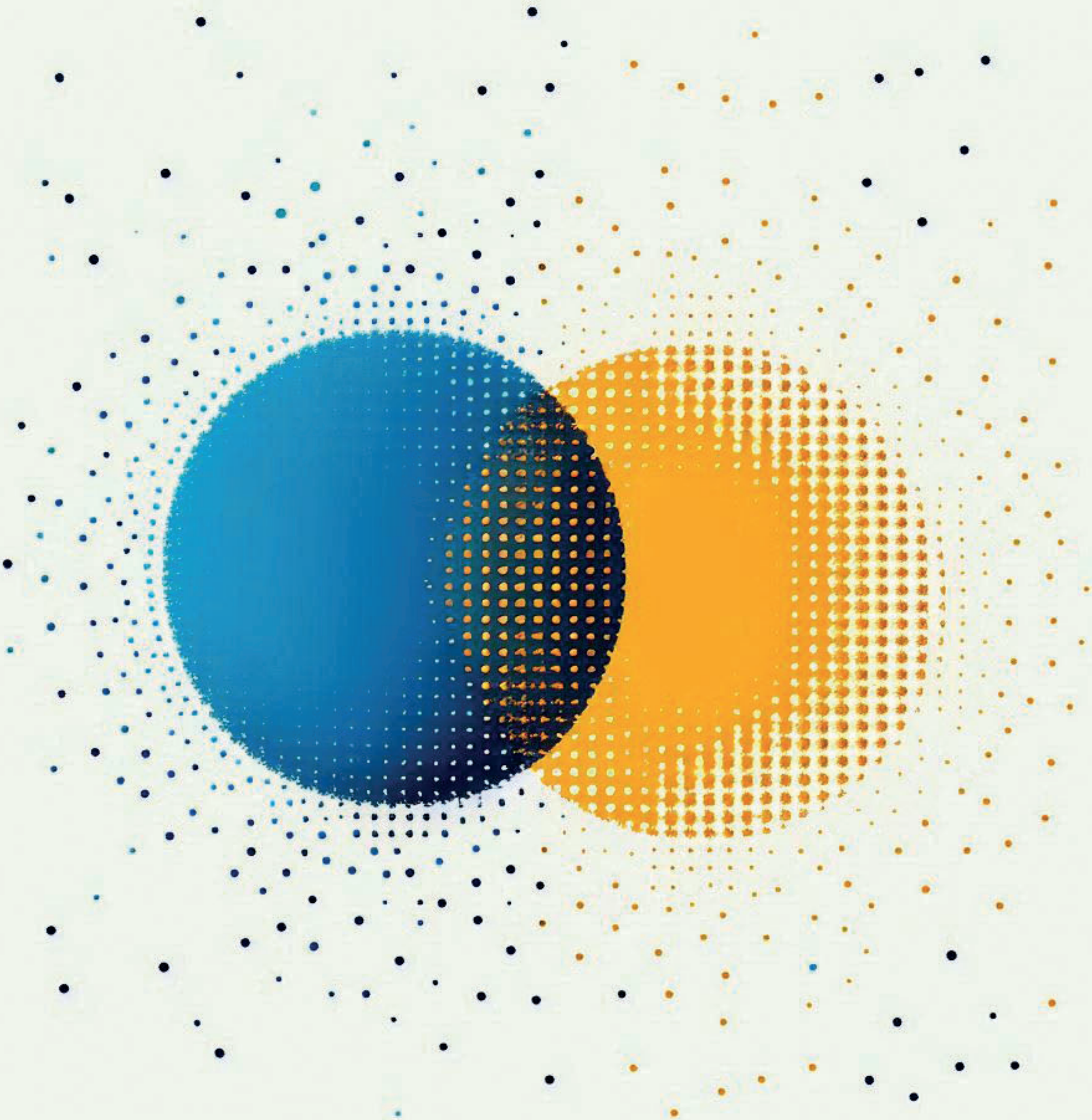
Supplementary Box 1 | About the authors.

Nieltje Gedney is current Treasurer and past Vice President of Home Dialyzors United (https://www.homedialyzorsunited.org/). She is active on the Policy and Advocacy Committee and has spoken at numerous events including meetings of the Alliance for Home Dialysis, the American Kidney Fund, the National Kidney Foundation, the SONG initiative, the annual Dialysis Conference, The Kidney Project and Kidney Health Initiative (KHI). She is a contributor to the Kidney Views Blog and to Seminars in Nephrology. Her patient advocacy stems from experience on Capitol Hill beginning at age 16, where she learned that power in numbers can bring about change.

Wim Sipma holds master degrees in Business Economics, Health Administration and Global Ebusiness Management. He has 30 years' experience in marketing and strategy with a focus on healthcare insurance. He started dialyzing over 12 years ago and received his second transplant in 2015. He writes for the nationwide magazine of the Dutch Kidney Patients Association, works part-time as a researcher at the University Medical Center Groningen and is a PhD candidate at the Erasmus School of Health Policy & Management where he specializes in the creation of value in healthcare through patient involvement.

Henning Søndergaard is a psychologist with a Master's Degree from the University of Copenhagen, specializing in health psychology. He currently works as a counsellor and a teacher for the Danish Kidney Association. He has had kidney issues his whole life related to his spinal bifida, which also has made him a lifelong wheelchair user; he has been on home haemodialysis for 8 years. He is a sought-after speaker at conferences and other events and works extensively with researchers, industry and clinicians in Europe and North America.

CHAPTER 7



“It’s My Life and It’s Now or Never” — Transplant Recipients Empowered From a Service-Dominant Logic Perspective

With
Dr. M.F.C. de Jong
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Transplant International, 2023

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ABSTRACT

Patient well-being after an organ transplant is a major outcome determinant and survival of the graft is crucial. Before surgery, patients are already informed about how they can influence their prognosis, for example by adhering to treatment advice and remaining active. Overall, effective self-management of health-related issues is a major factor in successful long-term graft survival. As such, organ transplant recipients can be considered as co-producers of their own health status. However, although keeping the graft in good condition is an important factor in the patient's well-being, it is not enough. To have a meaningful life after a solid organ transplant, patients can use their improved health status to once again enjoy time with family and friends, to travel and to return to work -in short to get back on track. Our assertion in this article is twofold. First, healthcare providers should look beyond medical support in enhancing long-term well-being. Second, organ recipients should see themselves as creators of their own well-being. To justify our argument, we use the theoretical perspective of service-dominant logic that states that patients are the true creators of real value-in-use. Or as Bon Jovi sings, "It's my life and it's now or never."

INTRODUCTION

In 2021, when the Corona virus pandemic resulted in many planned transplant operations being postponed, around 144,000 organ transplants were still performed globally. Most of these were kidney transplants (66%), followed by liver (24%), heart (6%), and lung (4%). Those 2021 data are based on the Global Observatory on Donation and Transplantation (GODT) data, produced by the WHO-ONT collaboration [1]. Organ transplants are generally the preferred treatment to improve the lives of patients suffering from organ failure [2, 3]. It is safe to say, thanks to the current high standards in organ transplant procedures, and despite the serious conditions of patients suffering from these life-threatening diseases, that, in 2021, many lives were not only saved but also improved through organ transplants. Through this, many of the organ transplant recipients and their families are now able to resume their life in a more-or-less normal way. This is an impressive worldwide achievement of all the professionals involved.

As an illustration of this, the first author (WS) of this paper is a kidney transplant recipient who has regained his well-being. He has also been a volunteer for the Dutch Kidney Patients Association for over a decade and is therefore familiar with the topic of living well after an organ transplant.

It is important that organ transplant recipients understand their personal responsibility in protecting the functioning of their new organ. In this article we distinguish two domains where patients are responsible. The first domain is "responsibility from a medical perspective," the second is 'about "responsibility from a personal well-being perspective." In the first domain, healthcare professionals encourage patients to take all the necessary steps to protect the functioning of their new organ. This includes adhering to the prescribed medication, maintaining a healthy diet and having sufficient physical activity. This first domain is part of normal medical practice, also referred to as 'the health factory' [4], and falls within the scope of healthcare services as "diagnosing and treating illness and promoting health." The second domain is about personal well-being, including quality of life. The sense of well-being has been associated with feelings such as experiencing positive emotions, of having self-control to a certain extent, and a sense of purpose [5]. In 2001, the World Health

Organization (WHO) described well-being as a subjective state of mind that goes beyond “the mere absence of disease” and is rather “a state of complete physical, mental and social well-being” [6, 7]. Our view is that, within the personal domain, patients create their own value of living, their quality of life, and their feeling of well-being. To justify our argument, we use the theoretical framework of the service-dominant (S-D) logic. S-D logic is a holistic approach to delivering healthcare services with an active role for patients to create value. S-D logic has several similarities and differences compared to the integrated care concept and chronic care management (hereafter referred to as integrated care). In the next section we introduce S-D logic and we compare S-D logic with integrated care. Then, we discuss the relationship between S-D logic and well-being. Finally, we suggest four themes in introducing of the S-D logic in practice.

SERVICE-DOMINANT LOGIC AND INTEGRATED CARE

During the past decades the S-D logic framework has been developed to present a different perspective on value (co-) creation [8–10]. The traditional view in service innovation on the creation of value has been that providers deliver value to the customer, hence the service provider is the value creator [10, 11]. The S-D logic, however, distinguishes between value creation from the perspective of the provider and of the customer [10, 12–15]. According to the S-D logic, the service provider creates potential value in the provider sphere, whilst the provider and the customer together co-create value in the joint sphere. In healthcare the doctor and the patient interact in the joint sphere and co-creation is realized because doctors and patients know different things and integration of their knowledge and dialogue may lead to improved and personalized interventions [4]. Furthermore, the patient, in this case the organ recipient, is the independent creator of value-in- use (real value) in the customer sphere (Figure 1, adapted from Grönroos and Voima [16]). Once dismissed from the hospital after surgery the patient is on his own and, beyond self-management on health-related issues, is working hard to regain his normal life activities. This is all done in the customer sphere and highly determines the patient’s well-being.

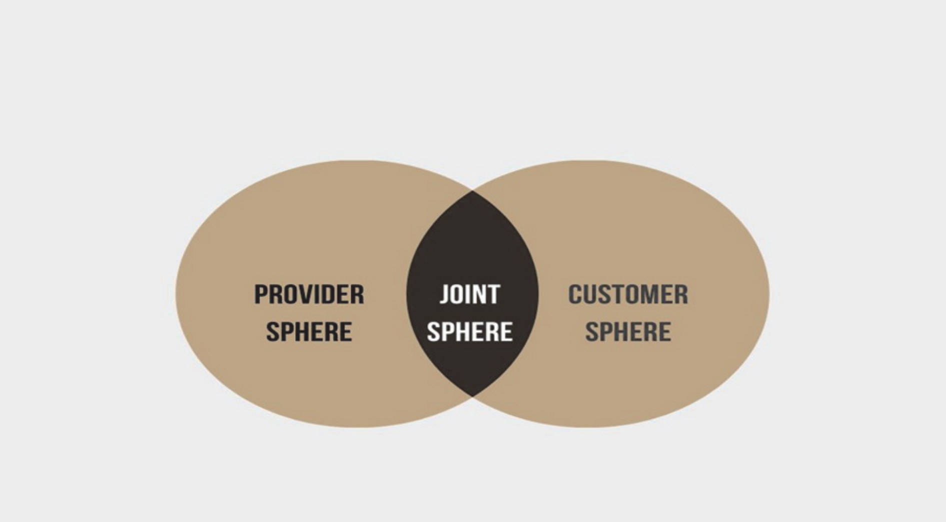

FIGURE 1 | Value Creation Spheres (adapted from Grönroos and Voima [16]).

A central theme in the S-D logic is "value-in-use" (or real value), stressing that a service in itself has no value and that value comes from its use. For transplant recipients this means that after surgery and the first recovery they resume their lives as well as possible. Patients are the creators of value and well-being in their personal lives, for instance by getting back to work. The S-D logic, with value-in-use as the core value-driver, has already been applied to healthcare [4, 17–20]. As is illustrated in the example above, S-D logic views patients as the creators of value in their private lives after having received medical care, in this case after having received a new functioning solid organ. This calls for a thorough understanding of patients' daily environment because their home situation (customer sphere in Figure 1) is key to value creation and personal well-being. In the context of living well after an organ transplant, the S-D logic framework highlights the importance of a supportive environment for recipients since well-being is more than "just" a well-functioning new organ. A practical example in the consulting room is that, when informing patients about the possibilities of an organ transplant, the doctor mentions "you might get back to work again" (value-in-use perspective) instead of "we can transplant you with a new organ" (medical service perspective).

S-D logic can be compared with the integrated care approach. Integrated care is a well-known approach in healthcare service delivery and was developed as an answer to fragmented specialization in healthcare and especially adds value to the service of patients with chronic care needs [21–26]. Integrated care focuses on coordinated medical support to improve healthcare through the lens of patients, although it can also be considered as a multipurpose approach to develop a cost- effective, coherent care system [24, 26]. Similar to S-D logic, integrated care models are associated with interprofessional partnerships, interorganizational collaboration, patient engagement and setting patients in the heart of health service [14, 17, 27–30].

We argue that integrated care, in terms of S-D logic, is mainly focused on the joint sphere (Figure 1), the area where a variety of healthcare providers and patients interact. Where integrated care models promote a system that delivers coordinated and optimal care for and together with patients, S-D logic considers the patient as an asset, an active producer of value. We argue that this is a different way to patient involvement than described in current integrated care models. In integrated care the patient is a receiver of care whereas in the service-dominant logic approach patients are (co-)creators of value in their home environment and doctors are considered as facilitators, enabling patients to create value. We argue that this is an important and valuable addition to the role of the patient in healthcare services that aim to improve patients' well-being. Therefore, the implementation of the S-D logic in healthcare offers a different perspective on service for patients than the paradigm that the set of medical interventions themselves deliver value, which we feel is the common premise of integrated care. A quote from an oncologist illustrates this: "Oncology practice provides treatment, but that is a fraction of the patients' needs" [31]. To facilitate organ recipients in moving on with their lives requires supportive facilities in the patient sphere. In practice, this means that patients and care providers need to discuss what is needed for the patient to live well after an organ transplant, which specialized care within or outside the hospital can be utilized and what challenges the patient foresees. These services might go beyond the medical profession and could be offered by different professionals. To realize this, a culture of collaboration and an external orientation is needed along with patients' awareness of their active role [10, 32]. Where patients cannot fully bear that responsibility themselves, interaction with the care provider becomes especially important. In summary, both S-D logic and integrated care promote patient centeredness. However, in our view S-D logic goes a step further by considering the patient as a resource and (co-creating) value goes beyond cooperation [33]. Value-in-use is created by the patient in the patient sphere and outside the sight of the medical profession [14, 30], which is less addressed in integrated care.

WELL-BEING OF ORGAN TRANSPLANT RECIPIENTS

If we consider the organ recipients' well-being from the S-D logic perspective and in terms of value-in-use, we can argue that well- being is created by the organ recipients themselves after discharge from the hospital and independent of the monitoring by healthcare professionals. This creation of value by organ transplant recipients is a process that evolves out of the sight of the medical profession. During the period when patients are restoring their sense of well-being, for instance by once again socializing with their family, finding the energy to read a book, enjoying cooking, visiting cinemas and theatres, continuing their studies, reintegrating into the workplace and daring to travel again, the well-functioning of their new organ facilitates this process. In essence, this is the key message of the S-D logic: medical health services, providing diagnoses, surgery, and aftercare, should be seen as facilitators (or enablers) for patients to attain the highest possible level of well-being. The organ transplant is an indispensable starting point for patients to regain their lives, but after the operation, they have to move forward themselves. We were told of a case of a nephrologist who asked a kidney transplant patient during a regular consultation:

"How are you doing?", and the patient responded, "I think my kidney is doing well." However, this was not what the nephrologist, who was also interested in the broader context of the patient's well-being, meant. For the professional, the most important outcome of an organ transplant is also that organ recipients regain their lives. Although this point of view may not be groundbreaking, to serve organ recipients based on the S-D logic raises some issues. We therefore now discuss four themes related to the introduction of the S-D logic in the daily practice of organ transplant actions: the awareness that healthcare providers are facilitators, the complex process of achieving well-being, managing an S-D logic-oriented service network and rethinking value-based healthcare.

Healthcare Providers Are Facilitators

First, transplant healthcare providers (tHCPs) should acknowledge that they are a crucial, but not the only, part of their patients' struggles to regain their lives. While tHCPs offer potential value, this still has to be converted into value-in-use by their patients. The tHCP's role is to facilitate patients to give meaning to their lives, and a successful complex health intervention such as an organ transplant alone is not enough. In addition to saving a life, tHCPs can have an important role in patients having a life. After providing a correct diagnosis, an organ transplant and high-quality care, the creation of real value by the organ transplant recipient continues. Here, value-in-use should be focused on well-being, which is up to the patient, possibly with support of other, possibly non-medical, facilitating health services. For instance, it is acknowledged that having a job is an important factor in a patient's feeling of well-being [34]. Although it is certainly recognized by physicians that they can contribute to patients returning to work, it is not yet part of the collective mindset in hospitals [35]. There is a need to admit that healthcare services, even if excellent, are a part of what a patient needs: transplants are not the complete story of the patient's journey but a necessary step that should open up a broader, more holistic, view on life after an organ transplant.

The Complex Process of Achieving Well-Being

Second, it needs to be recognized that creating well-being is a process that involves various actors surrounding the sphere of the patient, and that achieving patients' psychological ownership of their well-being is complex [36]. Further, the development of services to support the creation of well-being affects the entire healthcare service system. Well-being is multidimensional and is influenced by many aspects such as health, employment, income, and relationships [37] and, given that these influences may change over time, it is not an easy task for tHCPs to identify their role in this complexity. For instance, it is suggested that recovering and regaining quality of life after a liver transplant is influenced by the occurrence of depression before a transplant [38], illustrating the complexity of achieving well-being. We can picture two roles for tHCPs beyond their core medical task: a) to motivate the organ transplant recipient to take personal responsibility for the creation of well-being; and b) to have some knowledge on related services that might help patients who are confronted with issues such as loneliness or loss of income or job.

Managing an S-D Logic-Oriented Service Network Partnership

Third, management has the responsibility to make decisions on the scope of services to be offered by the organization, either at the unit (department) or at the organization (hospital) level. The scope of services that are offered beyond medical care should be discussed. These extended services should aim to support organ recipients in creating well-being in their daily lives. For instance, since employment is considered an important influence on well- being [39, 40], a possible service would be to support work retention. Similarly, budget coaching and relationship coaching are possible additional services because coping with chronic illness may affect income and relationships [41, 42]. There is no need for hospitals to offer these extended health services themselves, there may be other more suitable providers to turn to for support. Here, the role of the hospital would be to connect with external providers and align the provided service levels. The S-D logic refers to these extended health services, offering collaborative care to realize a holistic service approach, as the service ecosystem [18, 43]. This ecosystem is characterized by multiple actors, most likely from different organizations, that together create a context to enable value creation by the organ recipient. Although moving a hospital to an S-D logic-oriented service network partnership is a managerial challenge [32], we believe that transplant recipients may benefit from this transition.

Rethinking Value-Based Healthcare

Fourth, when adopting the value-in-use paradigm, there is a need to rethink the concept of value-based healthcare (VBHC). Value-based healthcare focuses on 'what matters most to patients' and relates these outcomes to costs [44], although what this means in practice is somewhat unclear [45]. In practice, the concept of VBHC focuses mainly on the direct healthcare context and less on the broader context of well-being as described in this paper. We notice that the majority of quality metrics in solid organ transplantation focuses on safety and effectiveness although a plea is made for more patient involvement and a focus on what really matters to patients in an broader healthcare context [46]. Patient reported outcome measures (PROMs) are considered to represent the patient's perspective but are hardly used in the clinical practice of kidney transplants [47]. However, the benefits of PROMs are mainly described in terms of better doctor-patient communication and improved healthcare self-management of patients [48] thus leaving out the possibilities of value creation in the patient's sphere. We can imagine that in the future PROMs, being the backbone of value-based healthcare (VBHC), evolve and take the daily life of transplant recipients into consideration. In our view, accepting the paradigm that healthcare organizations are the enablers of value creation, and that organ transplant recipients are the creators of value-in-use, would lead to a more prominent role for patients' self-determination [49]. Whereas VBHC is aiming to create value for the patient, we argue that value is created with and by the patient. On this basis, we would urge the intensification of patient involvement in designing healthcare services on the grounds that patients are the co- creators of value in healthcare and well-being [50–54].

CONCLUSION

The well-being of organ transplant recipients is not only realized through good medical practice. Keeping the graft in good condition and sustaining long-term graft survival are important facilitators for organ recipients to regain their lives. Embracing the paradigm of S-D logic by the professional transplant community may lead to a supportive healthcare service system that in addition to high medical quality transplants, also takes into consideration the capabilities of transplant recipients to regain their daily life, in all its aspects. After all, transplant recipients could sing along with Bon Jovi "It's my life and it's now or never."

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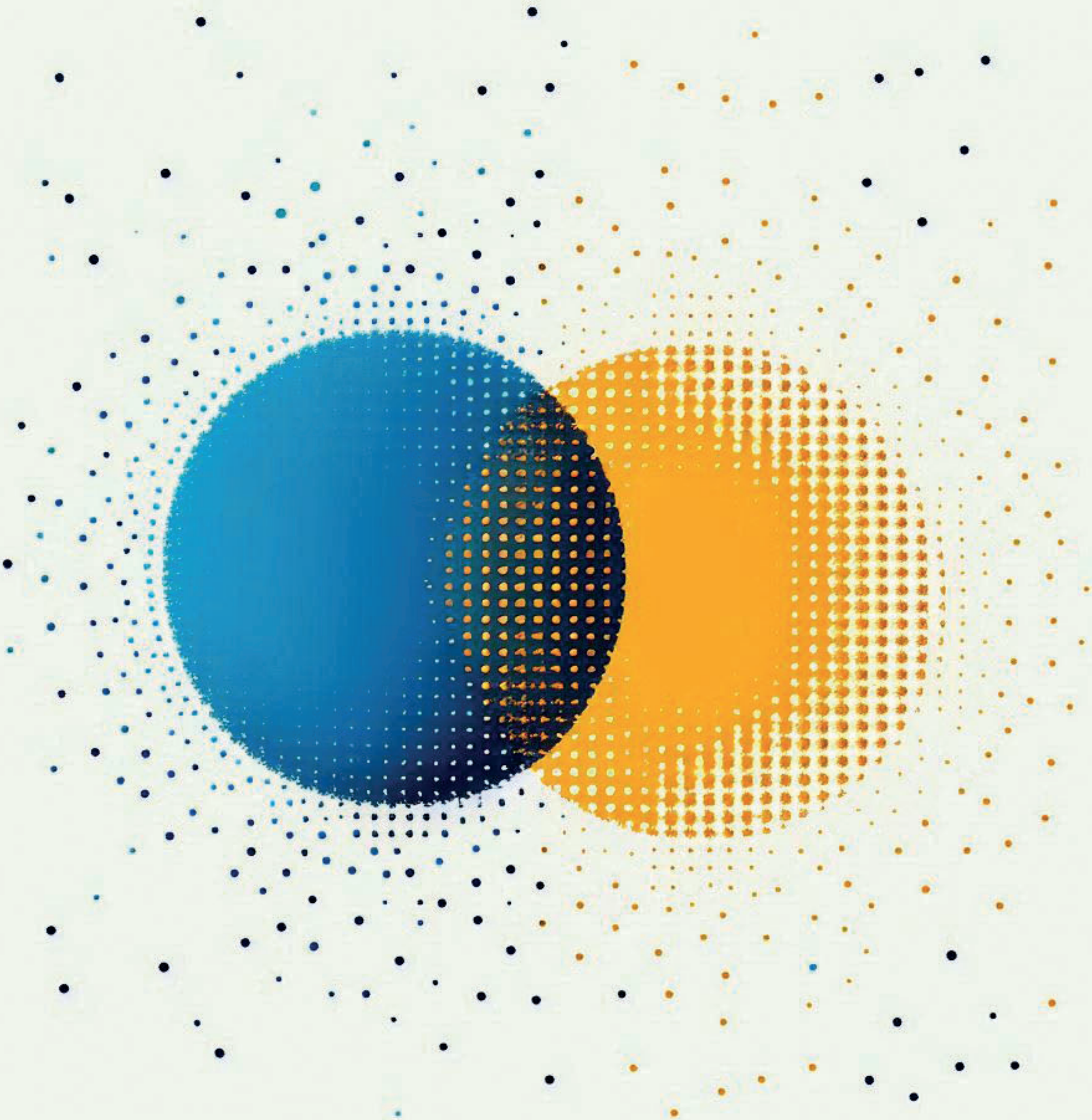
CHAPTER 8



General discussion

INTRODUCTION

Healthcare costs are rising around the globe and governments are increasingly concerned about these rising costs from an economic perspective. The aim in many countries is to provide an affordable and high-quality healthcare service that is accessible to all citizens. The era of unlimited growth in healthcare supply, due to new technologies and new medications and diagnoses, seems to be coming to an end. The growing demand for healthcare is creating friction with workforce shortages and the finite growth of budgets. Both in the cure sector and in chronic care, this friction is of growing concern. Healthcare demand is also increasing due to ageing populations and the number of people with chronic diseases. Already by 2022, 59% of the Dutch population had a chronic disease, and 96% of the population aged over 75 had at least one chronic disease - and these figures are below the European Union average [1].

As a response to the ever-increasing demand for healthcare services and the need to control costs, the concept of value in healthcare has been developed. The basic idea is to find a balance between the costs of (incremental) healthcare supply and the value it delivers to patients. In short, policymakers and healthcare providers are seeking to 'deliver value for money' instead of just 'delivering' In terms of providing insights into the costs of outcomes, current cost accounting is activity based since volume is funded instead of outcome. Value-based healthcare requires value-based accounting and this remains a challenge for the future [2]. In addition to costs, the concept of value itself is a topic of debate and research. Value can be considered from different perspectives such as the patient's, healthcare providers', insurers', or society. This thesis focuses on value from the patient's perspective, the process of value creation and the various actors that are involved in the creation of value in healthcare. As we are particularly interested in the patient perspective, we focus on what value means to patients and their role in value creation. Patients are the prime beneficiaries of healthcare services and therefore their perspective is highly relevant. We use the theory of service-dominant logic as a framework to understand the meaning of value for patients and the value creation process.

In this chapter, we start by summarizing the main results of this research. Then, we will elaborate on the potential benefits of applying service-dominant logic (S-D logic) for healthcare services. Finally, we try to envisage the merging of S-D logic with value-driven healthcare (‘appropriate care’, in Dutch ‘passende zorg’) and the leadership and change challenges facing healthcare that are needed to turn plans and policies into reality. In this thesis, we explore new insights into the applicability of the S-D logic in healthcare, the facilitators, and the barriers. This is relevant because the S-D logic is new in healthcare and contextual contributions are being encouraged [3, 4]. At the end of this general discussion, recommendations are made for future research.

Main findings

This research focuses on the meaning of value for patients. Value has also been described as ‘what matters most to patients’ [5, 6] and creating such value requires patient engagement and knowledge of what is important to patients. The quest for the meaning of value is ongoing.

Michael Porter, who is the driving force behind the concept of value-based healthcare (VBHC), defines value in healthcare as outcomes for patients divided by costs [7]. Traditionally, quality is measured by clinical outcomes, compliance to evidence-based guidelines, and process measures. Those outcomes that matter most to patients, according to Porter, can be measured by patient-reported outcomes (PROMs). Measuring PROMs includes questionnaires on a patient’s functional status that cover the whole cycle of care. PROMs are viewed as a helpful tool to improve communication between doctors and patients and to support the process of shared decision-making. ICHOM, the International Consortium for Health Outcomes Measurement, includes PROMs established by Porter and has currently published 46 PROM sets that cover different diseases. Five sets have been developed for chronic kidney disease by an international project team chaired by a Dutch nephrologist. We conducted a qualitative study of the early implementation stage of a PROM set used in dialysis care in the Netherlands, interviewing both patients and professionals. We found that patients were not highly motivated by the PROM questionnaires and only returned the questionnaire ‘because the doctor asked them’. An important reason for this was their lack of confidence that PROMs would be of additional value in helping them with disease management. This also held for the care providers who collected the PROMs and discussed them with their patients. They felt that some of the answers received required actions that were beyond their professional scope leaving them with a feeling of discomfort. The study is included as Chapter 2 of this thesis.

One of the problems that patients with chronic kidney disease face is staying in work. Previous research showed that the ability to continue working is of great value to many of such patients and that they experience a lack of support from the hospital to retain their jobs [8–10]. In a two-year action-oriented research project we developed, implemented, and pilot-tested WORK, an innovative program consisting of a care pathway in the hospital. WORK targets patients with work-related questions and tailors the support they receive to their needs. Several practical tools were developed and an internal and external referral structure with a focus on work was implemented. WORK was developed with a group of internal and external professionals including occupational health doctors. The study showed that the WORK program was clinically feasible, appreciated by patients, and also applicable in other areas related to chronic diseases. The study is reported in Chapter 3 of this thesis.

Determining value for patients with appropriate patient engagement strategies is a challenge. In Chapter 4 we describe Carman's model of patient engagement [11]. Carman et al. (2013) distinguish three levels: the direct care level, the organizational level, and the policy level. On what is called 'the continuum of patient engagement', three strategies of engagement are defined: consultation, involvement, and partnership. Shared decision-making in the consulting room is an example of partnership (the highest level of engagement) on the level of direct care. In our systematic review of patient engagement in VBHC initiatives we focused on the organizational level. We found that higher levels of patient engagement strategies such as advisory roles and collaborative teams are not yet common practice in VBHC initiatives. We also identified the risk of tokenistic patient engagement that might demotivate patients to participate. The systematic review can be found in Chapter 4 of this thesis.

A kidney transplant is in many cases the preferred treatment for patients with end-stage kidney disease (ESKD). Living kidney donation (LKD) is of great importance in reducing the shortage of suitable organ transplants. Addressing the lived experiences of donors to find areas for improvement in the care pathway of LKD donors has hardly been described and most studies focus on the medical issues associated with LKD. To fill this gap, we performed a study where both donors and professionals were involved. Inspired by the method of experience-based (co-)design (EBCD) described by Bate and Robert [12, 13] we found eleven areas for potential improvement. We ranked these improvements based on insights from both donors and professionals. We found that donors were broadly satisfied with the donor process although there was room for improvement. A more personal approach would be appreciated, both in the hospital and after discharge. Practical examples of a more personal approach include better communication, especially in the event of last-minute changes in scheduling the surgery, and more tailored advice on how to recover at home. None of the interviewed donors expressed any regret about donating. We also found that donors themselves often benefit from the donation, for instance because their quality of life together with a close recipient improves significantly. Finally, we saw that donors, although notionally healthy individuals, could be seen as normal patients with their own anxieties and needs. The study can be found in Chapter 5 of this thesis.

Not all patients with ESKD are able to benefit from organ transplants. Those that cannot are forced to undergo lifelong dialysis several times a week for many hours. Dialysis is an intensive treatment, both physically and mentally. ESKD patients on dialysis depend on machinery to stay alive. In an invitational comment article in Nature Review Nephrology, we state that while such current kidney replacement therapies (KRT) keep patients alive, they hardly give them the freedom to live a life. Further, while innovation and miniaturization is all around us in healthcare, for instance with highly sophisticated and focused tools for diagnosis, treatment, and medical surgery, such innovations are absent in dialysis technology. Consequently, chronic kidney disease has been referred to as ‘the most neglected chronic disease’ [14]. We appeal to KRT developers to obtain a thorough understanding of the values held by dialysis receivers by engaging with them from day one in order to develop personalized solutions, and not rely on one-size-fits-all modalities such as dialyzing. This paper can be found in Chapter 6 of this thesis.

After sometimes many years of dialysis, chronic fatigue, and very limited social activities, ESKD patients who successfully undergo an organ transplant are eager to resume a normal life. Transplant professionals recognize that more can be offered to patients than the technical transplantation procedure itself. To promote this, Transplant International, the official journal of the European Society for Organ Transplantation (ESOT), published a special issue entitled “Living well after organ transplantation” to which we were invited to contribute a Point-of-View article. Using the theoretical S-D logic perspective, we posited that real value in healthcare is created by patients themselves. Based on the S-D logic perspective, we explained that transplant professionals should be viewed as value facilitators rather than value creators. This article forms Chapter 7 of this thesis and, inspired by the song by Bon Jovi, is entitled “It’s My Life and it’s Now or Never”.

Overarching theme 1: S-D logic, value co-creation, and value-in-use

A brief description of S-D logic

In this section, we describe the S-D logic and its roots in marketing in more detail. We also show how Chapters 2 – 7 can be viewed from the S-D logic perspective and how S-D logic’s way of thinking can be useful in seeking to improve healthcare services.

S-D logic is a theoretical framework within the field of marketing and considers the nature of value, value creation, and value exchange. As such, S-D logic can be highly relevant for healthcare research at least by using it as a lens to study patient value and to offer a holistic view on healthcare services. The S-D logic theory consists of eleven foundational premises (FP) that were established in 2016 after its first introduction in 2004 by Vargo and Lusch [15, 16]. Within the scope of this thesis, we selected the following three FPs to focus on because, in our opinion, they clearly illustrate the importance of active patient engagement in creating value in healthcare.

- FP 6 states that value is always co-created by multiple actors, and always including the beneficiary. This means that a patient is not a ‘target’ (passive operand) who should solely be engaged, but an active operant (co-producer) in the co-creation of value.

- FP 7 states that actors cannot deliver value but can participate in the creation and offering of value propositions. In healthcare terms, this means that the hospital or a team of care professionals cannot produce value, but merely can make a value offer or an offer of resources.
- FP 10 states that value is always, uniquely and phenomenologically, determined by the beneficiary. This means that the hospital/team/professional(s) cannot determine the value of the services provided. Only the patient can, for instance by creating value by getting well after a transplant and resuming a normal life. This also means that the same service can have different outcome values for different beneficiaries. S-D logic refers to this stage of value creation as value-in-use or value-in-context.

In addition, the S-D logic also defines service ecosystems as a network of multiple actors who co-create value by offering their products and services together in a networked environment where these combined services are used by the beneficiary to create value-in-use. The required coordination is carried out by institutions, not necessarily in the sense of organizations, but also in the form of norms and procedures that emerge. A brief example that illustrates value-in-use is the motor car: while a car needs fuel and roads to travel, travel plans are made by the car owner who, by using the car for work or pleasure, is the creator of value-in-use.

The marketing roots of S-D logic and its development

Marketing theory and applications have evolved over the years and a good description of these developments, including S-D logic, can be found in two recent books by Philip Kotler and his co-authors [17, 18].

Theodore Levitt (1925-2006) published his famous article “Marketing Myopia” in HBR in 1960 and is considered to be the founding father of modern marketing [19]. Levitt warned organizations that they were focusing too much on the product (for instance trains) that they were delivering and not enough on consumers’ needs (for instance fast transportation). An overly narrow focus on the product or service might make companies blind to new entrants. Soon after, the well-known 4P marketing mix model was introduced by Jerome McCarthy and became popular in marketing practice in the decades that followed [20]. The 4P (Product, Price, Place, Promotion) model was a practical toolbox, without a theoretical framework, and became popular in a time when physical goods dominated the economy. However, marketing science evolved, and service marketing and relationship marketing were developed in the 1980s and 1990s as alternative approaches [21–23].

Service marketing and relationship marketing highlight the importance of service and of relationships with customers and, gradually, one-to-one marketing and communication became fashionable. In this era, customer-centricity gained attention because embedding customers' personal preferences was introduced into the marketplace of traditional mass-produced goods. Although the economy was focused on a mix of goods and services, goods and the exchange of goods were still the economic core, leading to the term goods-dominated logic (G-D logic).

In 2004 there was a paradigm shift in marketing when Vargo and Lusch introduced their theory based on a service-dominant logic (S-D logic) [15]. This theory is now embraced by the marketing academic field and has been adjusted several times to become a more general theory [16]. For instance, the term 'customer' has been replaced by 'beneficiary', indicating a broader field of application than commerce. A second important modification has been the concept of a 'service ecosystem'. This indicates that value-in-use does not only require a single organization to deliver a service. Instead, a constellation of different organizations creates an ecosystem or context in which the beneficiary is able to create value-in-use. This ecosystem consists of a network of organizations that are interconnected, either loosely or more formally. Beneficiaries are, within the S-D logic theory, integrators themselves: the car owner drives along the roads, follows the signs, and fuels the car. This goes beyond concepts such as supply chain management (SCM) and mutual contracting of businesses with service level agreements (SLAs). SCM and SLAs can support a service ecosystem, but the service ecosystem requires more: a deeper understanding of the value-creating context of the beneficiary. In addition, institutions can be responsible for coordinating or integrating a diversity of resources that are required within the network. Institutions and institutional arrangements should enable the realization of the needs and wishes of the beneficiaries [25]. An important consequence of value-in-use is that the created value may differ between beneficiaries, depending on their personal context and use [24]. In addition, because under the S-D logic the creation of value-in-use starts after goods are exchanged, the consuming stage does not destroy value but rather creates it. Nevertheless, S-D logic is not seen as a finished theory and may evolve further [25, 26].

In healthcare, patient-centricity is still a popular topic but has proven to be challenging as a single objective. This is perhaps not surprising since healthcare service delivery is a complex system with many actors and possible conflicts of interest which makes it almost impossible to arrange all processes around ‘just’ one stakeholder - the patient. In today’s complex world, the stance on customer/patient centricity needs rejuvenating. To quote Gummesson: “Service is not created just by the supplier and the customer. It is created in a network of activities involving a host of stakeholders” [27]. In his opinion, fulfilling the needs of customers is too narrow an objective. Many stakeholders are involved whose demands should be taken into account. Gummesson argues that the customer-centricity model of marketing cannot – and has not – been implemented in practice and strongly needs reconsideration. He suggests a balanced centricity view, going beyond the satisfaction of customer demands, and refers to network theory, complexity theory, and the many-to-many marketing theory of S-D logic as possible ways to move forward. We argue that the S-D logic could deepen the meaning of patient centricity, giving it a broader perspective in the sense that patients are not viewed as passive victims around whom healthcare should be organized, but as active participants who work together with healthcare providers and, in addition, are responsible for their own well-being in their personal context. An early glimpse into the possibilities of S-D logic in healthcare was already described in 2016 by Joiner and Lusch [3].

The main contribution of S-D logic in our view and from our perspective is giving an active role to the patient in creating value-in-use. This component of value is easily overlooked in today’s healthcare. The real value of any medical support, either physical or mental, is created by the patients who try to get back on track. That is why, for instance, support such as helping patients who suffer financial problems and debts is important in helping them regain control over their lives. Naturally, the need for these and other services differs among patients: not only are medical interventions personalized, the same holds for facilitators in the personal context of patients. It is important to recognize that, within this personal context where patients are creators of value, patients have a significant responsibility and should not be victimized or confronted with paternalistic attitudes. Overall, we argue that the healthcare system, following the shift “from volume to value” should move on and shift from “saving a life” to “having a life”.

S-D logic reflections from our research

The research in this thesis illustrates practical examples of the above-mentioned founding premises. For instance, in Chapter 2 on PROM implementation and Chapter 6 on developments in dialysis, we describe how actors (patients) can actively participate in offering value propositions. Patients are very willing to share their perspectives to design and use PROM questionnaires, and we saw that patients’ knowledge can be valuable to the design of new dialysis modalities. In the design of VBHC initiatives we found, in Chapter 4, that few efforts seem to have been made to let patients participate in such initiatives at the organizational level to improve potential value propositions. In Chapter 3, on the design of a practical work retention program in the hospital, we described a project where multiple actors, including the beneficiaries, co-designed a practical program that was also implemented in the hospital. Chapter 3, on work retention, and Chapter 5, on donor care, illustrate the importance of the service ecosystem. Work retention requires multiple actors including the hospital, the employer, UWV (the public service provider regarding unemployment and incapacity of work), legislation, and of course the kidney patients themselves. In the donors’ daily lives, employers, family, and homecare organizations are involved. Patients and donors are not passive operands but active operants. Both Chapter 2, on PROM implementation, and Chapter 7, on living well after a transplant, stress the importance of value-in-use (also referred to as value-in-context) being created by the beneficiaries themselves. In general, PROM questionnaires are very carefully developed, but more attention should be paid to how value can then be created based on the completed PROMs. It is not the case that PROM results, when discussed in the consulting room, automatically translate into value. The lesson from S-D logic here is that a real understanding of a patient's context may help facilitate the beneficiary in creating value-in-use. Chapter 5 also illustrates that both donors and recipients can be beneficiaries of a kidney transplant. S-D logic theory describes the mutual exchange of services, where actors can be both providers and beneficiaries at the same time. Although donors in general, are considered as 'resources' who 'deliver' a valuable organ, they are also beneficiaries of the donation themselves. This was illustrated by a donor I interviewed saying 'now we can live together again'.

Suggested by the S-D logic, conversations in the consultation room could change, allowing more room for motivational interviewing (MI), for example on the role of lifestyle [3]. Instead of giving advice on diets, losing weight, or drinking no more than half a liter of water a day (a common restriction for patients on dialysis), MI would ask patients: "what do you prefer to drink?", "can you describe situations that are difficult for you to keep diet restrictions?", "what kind of activities do you like to undertake?". Based on such personalized conversations, motivated and personal choices can be made, stretching into the patient's daily life. Since the context determines the value-in-use of the service offered by health providers, MI might help to reveal this context and may help in offering more holistic support. We would argue that patients want some control back in their lives or, as a strategy consultant once put it, "people do not resist change, they simply don't want to be changed".

The main lesson from adopting S-D logic that we generate from these examples is that the lens of the patient's daily life should always be looked through in patient care, and in improving care, whether it be medical improvements, pathway improvements, or at higher levels such as legislation and national programs.

Overarching theme 2: Appropriate care

The implementation of S-D logic in healthcare may offer a more integrated service, moving away from the G-D logic approach where medical interventions are in themselves considered to deliver value. A current problem in realizing value in healthcare is seen as the fragmented approach and service delivery [28, 29] aiming at organ treatment, disease treatment, or saving lives. This is particularly a problem for people with multimorbidity, who already make up 33% of the Dutch population.

In this section we discuss the principles of appropriate care as defined in the Netherlands and published in subsequent reports [30–32]. The National Agreement on Appropriate Care - Integraal Zorg Akkoord (IZA) - was published in 2022 on behalf of 15 leading representative partners in the Dutch healthcare sector, including hospitals, homecare organizations, medical professionals, health insurers, patient organizations, and government agencies. Partners agreed to shape a sustainable future in healthcare based on the following four principles:

a. Appropriate care is value driven.
b. Appropriate care is created around and together with the patient.
c. Appropriate care is delivered in the right place.
d. Appropriate care is about health rather than illness.

According to these principles, healthcare is effective when it is consistent with the state of scientific knowledge and practice, has value for the patient, and ensures efficient use of resources. There is a strong emphasis on regional cooperation among healthcare providers, and agreements on the concentration and spreading of health services must be made. Also, since care is to be delivered at the right time in the right place, primary care will be strengthened to allow the aging population to live in their own homes. In an attempt to control the demand for healthcare, attention is also paid to preventing health problems and to encouraging healthy behavior. The IZA presents lofty ambitions for a healthcare ecosystem, and this aligns with ideas underpinning the S-D logic. We offer three observations based on the S-D logic perspective on the ambitions of the IZA. First, one should be prepared for the organizational challenges that lie ahead; second, give patients a real voice by effective patient engagement; and, third, utilize the power of patients to create value in healthcare. We elaborate on these three challenges below.

The first thing we notice is that there are many organizational challenges involved. The contours of the IZA outline, in terms of S-D logic, are a service ecosystem in which healthcare organizations must open up and maintain strong relationships with other healthcare providers to ensure that patients find a fluid and integrated network of providers that enables them to take control of their lives. Meeting this challenge is not an easy task, especially given the current health service delivery system has evolved over many decades and resulted in a complex adaptive system. Complex adaptive systems are characterized by fuzzy organizational boundaries, internalized rules of behavior, independently working actors with a high personal freedom of acting and decision-making, unpredictable human behavior, independent subsystems that also influence each other, and unpredictable long-term outcomes of the system due to changing internal patterns of behavior [33–35]. Complexity is the result of differences in the interests of stakeholders. Furthermore, understanding their behavior would not be sufficient to understand the system's behavior [36, 37]. Healthcare institutions offer a complex structure of services, in a context that is faced with regulations on the levels of professionals, insurers, and government agencies and is subject to a fairly rigid decision-making structure [24]. Although all the important existing partners have signed the IZA, it will not be an easy task to realize the ambitions as formulated in the IZA, which makes the outcomes of the agreement highly uncertain. Although system structures in healthcare seem rigid in general, during the COVID pandemic the whole system proved to be agile and able to change quickly when circumstances demand rapid action.

Second, since the codesign of appropriate care is a pillar in the IZA, important challenges on patient engagement lie ahead. A true understanding of patient engagement and the difficulties of patient representation as actors, and as a useful countervailing power, in a complex environment is crucial. Without such an understanding and the creation of supporting facilities, patient engagement easily becomes tokenistic. A lack of patient-support might lead to unclear responsibilities, difficult to understand meetings, and reports that overwhelm patient representatives and engaged patients. An example of support to patient engagement are training activities as offered by the independent Dutch foundation (www.involv.nl) that has (free) nationwide training and education programs to professionalize patient engagement. On a European level the European Patients' Academy on Therapeutic Innovation (EUPATI) provides education and training for effective patient engagement in medicines research and development (www.eupati.eu). Also action research (AR) may enhance effective patient engagement because innovative AR projects are coping the barriers to effective patient engagement such as inequalities in power distribution and unequal access to information. The multi-actor approach of AR stimulates collaborative knowledge development by encouraging open-mind discussions and a joint understanding of challenges. Therefore action researchers can be called “orchestrators” of co-innovation [38].

A third comment is that the IZA overlooks the power of patients to convert healthcare propositions into value-in-use. Patients are the creators of value-in-use by making decisions on the use of a large range of healthcare services. Following the S-D logic, the patient is the ultimate resource integrator and therefore value is not determined by providers but by the beneficiaries of the services or products that are offered. Or, to quote a well-known English proverb, “the proof of the pudding is in the eating”. The focus in the IZA, as we read it, seems to be on delivering a good service at an affordable price. Although this is a necessary step to future-proof healthcare, it is still highly product-oriented in the way that many actors are expected to work together to deliver a coordinated and integrated service. This could leave little room for beneficiaries/patients to integrate resources themselves. A better understanding of value-in-use might suggest possible innovations in healthcare that are now overlooked because of a lack of attention. When different patient segments are well understood, a differentiated offer might emerge instead of a single offer that seems ‘the best’. I feel that it is important to leave people with choices within their personal daily lives despite the possible limitations they encounter. In normal life people have choices, so why should they be forced along one predetermined care pathway once they are a patient? As one patient I interviewed said: the hardest thing for me is to lose control over my life.

Implications for future research

To gain a deeper understanding of how to implement value in healthcare we would recommend further research into three main issues raised in this thesis: patient engagement, creating value-in-use, and managing change in healthcare. Although these issues are interrelated, we offer some directions for each issue.

Patient engagement can improve outcomes for individual patients and may help to improve healthcare at the organizational and policy levels. Not all patients with lived experiences are equipped with the necessary knowledge or skills to engage in their own care or to represent a group of fellow patients. In addition, in patient engagement “it takes two to tango”, which means that providers will also have to be open to patients having roles as valuable co-producers and co-designers at all levels. A change in culture from paternalism to partnership requires new consumer and provider behavior [39, 40]. We feel that knowledge of patient engagement strategies may contribute to better healthcare for all.

Effective patient engagement is also important if one is to realize value-driven healthcare, which is a major focus in healthcare reform. So far, we have encountered little research on creating value through patients. There are many examples of how providers can offer value propositions to patients such as improving medical interventions, designing and promoting healthy behavior, and increasing research on effective use of medication. However, these are all examples of creating value *for* the patient rather than creating value *by* the patient. We argue that further research on creating value-in-use and on the context of the patient’s daily life could contribute to better matching facilities to patients’ needs. It could even lead to less demand because patients can make better choices when the impacts on their daily lives are taken into account.

In this thesis we have regularly described the complexity of healthcare and healthcare management. To reach the next level of quality in care, with a broad perspective on patients’ lives, this complex system needs to be gradually changed to a smooth and agile running operation covering all levels in healthcare. The goals and procedures on the policy, organizational, and patient levels should ideally align to be effective. We argue that improved knowledge on leadership, change management, and strategic management might help to accomplish the goals of value-driven healthcare.

Practical implications

Medical specialists do not need to become overwhelmed by becoming involved in new ways of communicating with patients, asking them all kinds of questions about their daily lives. Patients often feel much more comfortable talking to nurses or social workers who have time for real conversations and who do not wear white coats. Also in the interviews reported in this thesis we observed that nurses are good listeners, are trusted by patients, and already collect considerable reliable information on the daily activities of their patients. The same is true of social workers and other non-medical staff. Their opinions should also be integrated in care planning and patient activation.

The role of co-producer of value, as described in this thesis, will not fit comfortably with every doctor or every patient. The dissemination of co-producing will follow the well-known trajectory of early-adopters, the majority, and laggards. In addition, healthcare will continue to need specialists who focus on specialized medical interventions. Not everyone has to be an integrator.

Methodological reflection

In this thesis we have used various methodologies to unravel the problems we sought to solve, to explore the worlds that we wanted to learn about, to find answers to certain questions, and to share our opinions on certain topics. In this section we reflect on our approach: research is a craft and as with any craft learning by doing is valuable [41].

Our study on PROM implementation was designed as a qualitative study, using interviews with patients, doctors, and nurses. This study design fitted our goal of exploration and gaining insights into the personal experiences of actors in the early stage of PROM implementation. Initial conversations went smoothly and fluently. However, although we had prepared a semi-structured interview protocol to guide us, we were forced to follow a different path. The open conversations meandered around the predetermined topics and this flexibility enabled a smooth conversation and made the interviewees feel at ease. We believe this resulted in very honest and open revelations about the interviewees' first impressions of PROMs. Also, the fact that the interviewer was a former dialysis patient helped the patients and staff members feel able to open up. As a result, we heard many more stories than we were able to use in the associated research paper.

Our second study, on the development of support to stay at work, was very different. Unlike the first research project, the second was highly interactive with all participants, including a core group of project members all connected to UMC Groningen. A project was organized using adapted intervention mapping, a tool for community-based participatory research [42]. Meetings were to be held every three months with all project participants, subgroups were formed, one of which was a patient group, and the core group would meet every two weeks. After the first kick-off meeting, we had to drastically adjust our plans. The COVID pandemic struck and resulted in minimizing personal contacts. Consequently, all our planned meetings were cancelled and we had to think how to go ahead. After some reflection, we decided to go ahead using Teams as our meeting platform. Nowadays, this may seem everyday practice, but back then it was a novelty to which we were not accustomed. We experienced a steep learning curve but over time almost all felt comfortable using Teams. We also learned that the old-fashioned telephone was easy to use for communicating with project members who did not have easy access to the internet or other needed facilities. An important lesson in this study was again to be flexible. Looking back, we can see that the COVID pandemic did influence the project's process, but not the project results.

The third research activity was a systematic review that followed a very structured path. With two main researchers, who interacted on almost a weekly basis, we finished the research in just over a year. We both enjoyed the meetings, again using Teams, and exchanged our findings, doubts, and ideas. Although the method was very structured, at some points we had to make decisions such as on what literature to include and what to exclude. Discussions usually led to an agreement and the few unresolved issues were decided by our co-authors. Once again, we experienced that solid research involves teamwork.

Our fourth research project was inspired by Experience-Based Co-Design (EBCD), an appropriate method because we wanted to use the lived experiences of kidney donors and professionals to improve the care pathway for living kidney donors. To date, the vast majority of research had focused on medical or psychological issues linked to kidney donation. Realizing that our research was a novel addition to the field, we carefully described the type of donors we wanted to include, and we invited only donors who had followed a relatively normal clinical course. We found that donors were very willing to tell their stories, praised the way they were treated by staff but, at the same time, were not slow to criticize things that caused anxiety or could be improved. It was a heartening experience to see that praise and criticism could be so well combined in just one conversation of on average 45 minutes. We also saw that EBCD took a lot of time which proved very inconvenient for medical staff and meetings were difficult to schedule. However, when attending an EBCD course in London, we learned that EBCD can be adjusted to suit the context. We gratefully embraced this opportunity to make the steps more practicable. The study also resulted in an unexpected and important finding: that donors also benefit from their donation.

The fifth paper published on our research was an invitational opinion article and required a different approach. It was written together with two co-authors who had similar backgrounds as engaged kidney patients. We concentrated on the key message we wanted to get across to readers of Nature Reviews Nephrology: to involve patients in future designs of dialysis modalities in such a way that their lives would improve. Our theme was ‘patients not only want to survive, they want to live’. Co-writers came from the USA and Denmark, and we all faced the same challenges while living with a kidney disease. We observed that the healthcare systems differed, but the challenges presented by the illness did not.

Our last paper was a Point-of-View article submitted on the invitation of Transplant International. This was a peer-reviewed paper in a special issue “Living well after a transplant” and we were asked to highlight the patient perspective. As a theoretical background, we choose the S-D logic theory to demonstrate that patients themselves are responsible for creating value-in-use after the transplant that was offered by medical professionals and, most importantly, by their donors. We learned that this theory can help structure ideas and proved useful in clearly demonstrating a point of view.

Then the big question: would we change anything in our approach after these experiences? Well, that’s a question that cannot really be answered. It is impossible to cross the same river twice, because the river changes and the traveler changes. However, looking back, we realize that research is often done verbally and requires the power to listen and to speak. I started this study as a former kidney patient, being the recipient of a well-functioning kidney transplant. This may have helped me to connect with the participants, both staff and patients. Unfortunately, I ended the study being diagnosed with ALS. As a result, I lost my power to speak, which makes it difficult to interview people. Difficult, but in my view not impossible. With proper supportive facilities and 'with a little help from my friends' (Joe Cocker) I might even extend my scientific journey. We hope that everyone can participate in science, no matter their limitations.

Concluding remarks

The history of a healthcare organization provides a useful insight and background into its development over time. We recommend that anyone interested in reforming healthcare, cost containment, and value- for-patients to dive into the roots and origins of the Dutch or any other country.

In the Netherlands in the 19th century locally organized healthcare funds were raised, often by doctors, labor unions, or religious communities. Coverage also included the costs of a funeral, maybe a good idea in extending today's health coverage. In 1942, after decades of debate in Dutch parliament, the German occupier installed a national law on health coverage (Ziekenfondswet), a mandatory insurance for all below a certain annual income level. This law affected 62% of the population and was, again after decades of debate in parliament, reformed in 2006 when the current system of health insurance for all was introduced.

A direct reason for this new system was the concern over ever-rising costs. Debates on healthcare costs started following the oil crisis in 1973. In the second half of the 1980s, the contours of the 2006 reform emerged and at the same time ambitious reports were published on how to contain costs. New technology, an ageing population, and unproven medical treatments were blamed. Also, it was argued, hospitals should cooperate more, with each other and with primary care and home care organizations in order to reduce the time patients spend in hospitals. The causes of rising costs and the goals of cost containment have hardly changed over time.

Nevertheless, the quality of Dutch healthcare is excellent overall. Maybe the biggest challenge is to make everyone, including providers, patients, and the wider population aware that healthcare cannot solve all health problems. There is a limit to what medicine can do, despite all the new technologies and the efforts of the many who work in healthcare. Meanwhile, let us work on value-driven healthcare realizing that it is not systems but people who create value.

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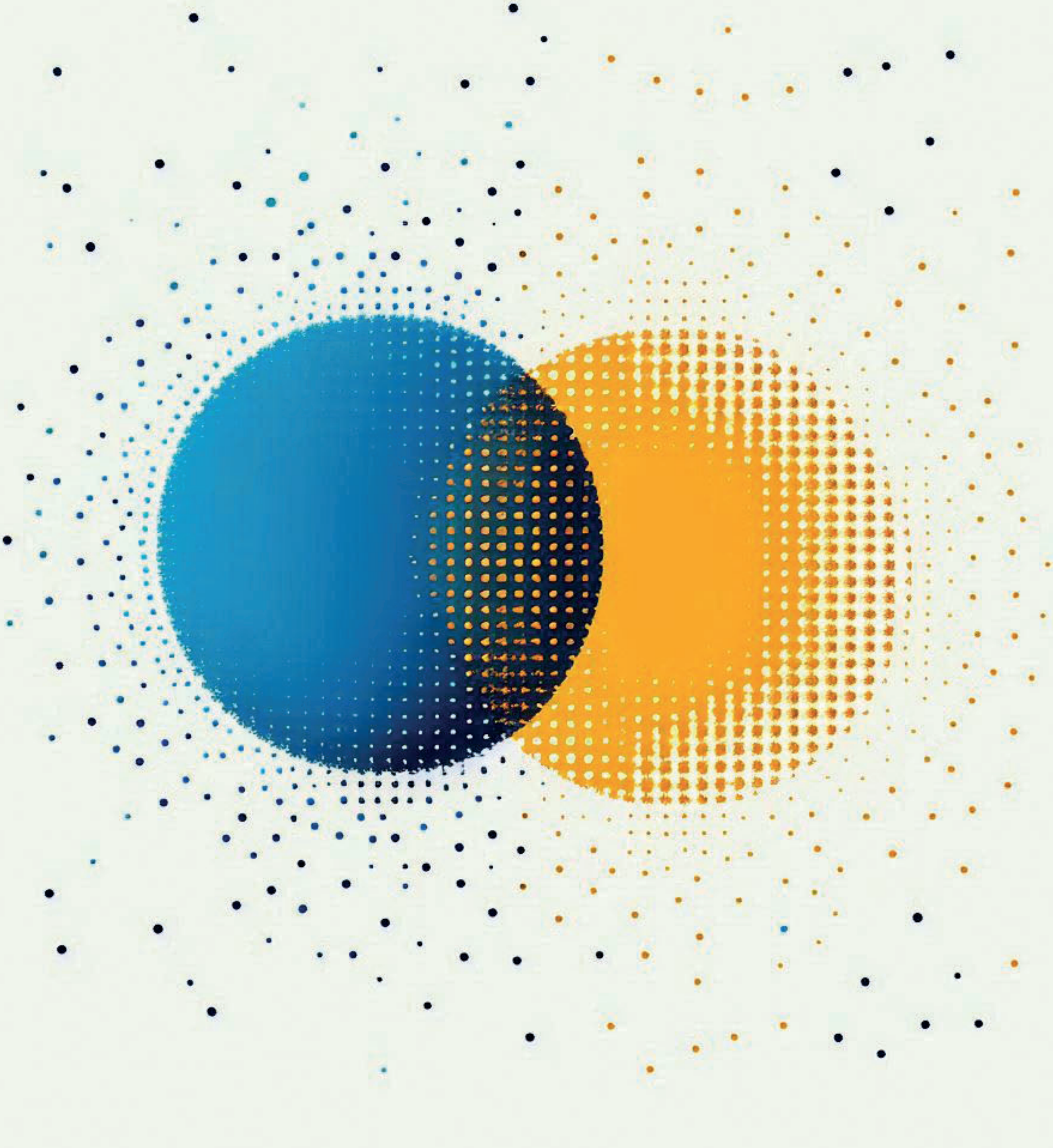
APPENDICES



Summary

Nederlandse samenvatting

Dankwoord

About the author

PhD Portfolio

SUMMARY

Chapter 1 presents an overview of the thesis that consists of two main parts: the first includes four research papers and the second includes two opinion papers. The chapter introduces the theory of service-dominant logic (S-D logic) that describes the value-in-use concept, where value is determined by the customer during the use of a product or service. S-D logic can be used in healthcare and emphasizes the importance of patient engagement, where patients are active participants in healthcare services. According to S-D logic, the patient is the creator of value in healthcare and healthcare providers are facilitators of value creation. The thesis delves into the challenges and opportunities of patient engagement to improve healthcare from the patient´s perspective.

Chapter 2 presents a qualitative study that examines the early implementation of a new set of Patient-Reported Outcome Measures (PROMs) in Dutch dialysis care. PROMs are questionnaires designed to empower patients in sharing and discussing health-related concerns with their healthcare providers. While they offer potential benefits like improved patient-doctor communication and a better understanding of patient needs, their successful implementation faces several challenges such as patient indifference to PROMs, questionnaire fatigue and organizational turmoil. By collecting the experiences and perspectives of healthcare professionals and patients, the research aims to understand the process of early implementation and identifies the barriers and facilitators encountered by both groups.

Chapter 3 describes the development of a program called WORK (work-oriented clinical care for kidney patients). Numerous individuals with chronic kidney disease (CKD) face challenges in maintaining employment. Both patients and healthcare professionals (HCPs) recognize the benefits of work-focused clinical care, although this approach is not currently practiced. The WORK program was developed and implemented to offer a tailored care pathway in hospitals for patients with work-related issues. Tools were created to strengthen self-direction of patients including brochures (“Keep working, how do I do it?”)

and messages on the video screens at the outpatient clinic. Alongside, a referral structure focused on employment concerns was developed to support care providers in the consulting room. A labor expert was introduced to the hospital to address basic work-related inquiries. The feasibility and clinical utility of the program were evaluated and received positive reviews. Implementation has thus far been successful, although ongoing incorporation may face financial obstacles.

Chapter 4 is a systematic review that analyzes 21 studies focusing on patient engagement in value-based healthcare (VBHC) initiatives at the organizational level of hospitals. VBHC aims to improve healthcare by focusing on patient value, which involves understanding what matters most to patients and how to deliver it efficiently. The study found that the most common methods for involving patients are questionnaires and interviews, which are considered low-level engagement strategies. Higher-level engagement, such as advisory roles, codesign, or collaborative teams, are rarely employed. The study emphasizes the importance of incorporating higher-level engagement strategies to improve healthcare and care pathways by co-designing with patients.

Chapter 5 uses the experience-based codesign (EBCD) approach to understand how living kidney donors perceive the care process at a major transplant center in the Netherlands. Living kidney donation (LKD) is a life-saving procedure for people with end-stage kidney disease. While research focuses on medical issues as donor safety, less attention is given to the donor experience. The EBCD approach aims to incorporate user experience into the improvement of healthcare. In an EBCD project the experiences of both donors and care providers were collected. Through interviews with donors and healthcare professionals, eleven areas for improvement were identified, including careful communication at crucial moments, advice on getting back into good shape after surgery and clarity on long-term aftercare. Despite these areas for improvement, donors expressed their satisfaction with the overall experience. The EBCD approach has proven to be valuable in identifying practical improvements based on donors' real-world experiences.

Chapter 6 is a patient perspective article and argues that dialysis technology needs a major overhaul to improve the quality of life (QoL) for people living with kidney failure. The authors, themselves (former) long-term dialysis users, emphasize that current devices haven't significantly changed in decades, despite the widespread burden of chronic kidney disease (CKD). The article highlights the limitations of current dialysis technology: bulky machines, complex water systems, restrictive schedules and a lack of personalized treatment options. Developers have overlooked the needs and preferences of CKD patients, focusing solely on performance metrics. Fictional personas illustrate the diverse needs of CKD patients: Mrs. N, a traveler seeking independence and flexibility in treatment; Mr. H, a person with complex health needs desiring a portable and effective device; and Mr. W, a dialysis user seeking a flexible schedule and a social context for treatment. A future is envisioned where persons who need dialysis have access to a range of treatment options, personalized devices, and knowledgeable clinicians who help them choose the best fit for their lives. They call upon developers to engage with dialysis users early in the innovation process to create individualized solutions that prioritize QoL and allow them to live meaningful lives, not simply exist while on dialysis.

Chapter 7 applies the concept of service-dominant logic (S-D logic) and value-in-use in a patient perspective article. S-D logic views patients as the true creators of value in their lives and this shifts the focus from the provider-centered "health factory" to the patient's individual experience, where their own actions contribute to a better well-being. After an organ transplantation medical aspects are important but not enough: for transplant recipients it's about living a full life again. Applying S-D logic, the chapter describes that organ transplant recipients, once discharged, are the creators of value by returning to work, socializing, traveling, and engaging in activities they enjoy. While healthcare providers offer essential medical support, it's ultimately the patient who determines the quality of life. This perspective requires a shift in mindset, where healthcare providers acknowledge their role as facilitators in the patient's journey to well-being. It also emphasizes the need for supportive services that go beyond medical care like help with work retention, budget coaching and relationship support, to help patients navigate the challenges of life after a transplant.

Chapter 8 summarizes the main findings of the research, focusing on the meaning of value for patients. The thesis explains the origin and main themes of S-D logic and emphasizes the role of patients to create value-in-use, a role that is often overlooked. In addition, the ambitions of the national agreement on appropriate care in the Netherlands are described. This agreement aligns with the ideas of S-D logic by promoting cooperation between care providers to serve patients and involving patient representation actively. Three challenges that lie ahead are pointed out: organizational challenges, especially on working in cooperation with external providers, challenges on patient engagement and understanding the power of patients to create their own value-in-use in daily life.

NEDERLANDSE SAMENVATTING

Hoofdstuk 1 geeft een overzicht van dit proefschrift dat uit twee delen bestaat: het eerste bevat vier onderzoeksartikelen en het tweede bevat twee opinieartikelen. Ook introduceert dit hoofdstuk de service-dominant logic theorie (S-D logic) en beschrijft daarbij het begrip ‘waarde-bij-gebruik’ (value-in-use). Volgens dit begrip wordt de waarde van een product of dienst gecreëerd door de klant tijdens de gebruiksfase. Door toepassing van S-D-logic in de gezondheidszorg wordt het belang van patiëntbetrokkenheid benadrukt, waarbij patiënten actieve participanten zijn in het zorgproces. Volgens S-D-logic is het de patiënt zelf die waarde creëert in de zorg en hebben zorgverleners een faciliterende rol bij deze waarde creatie. Het proefschrift onderzoekt de uitdagingen en mogelijkheden van patiëntbetrokkenheid om de zorg te verbeteren vanuit het perspectief van de patiënt.

Hoofdstuk 2 beschrijft een kwalitatief onderzoek naar de beginfase van de implementatie van Patient-Gerapporteerde Uitkomst Metingen (in het Engels afgekort als PROMs) in de Nederlandse dialysezorg. PROMs zijn vragenlijsten die zijn gemaakt om patiënten te helpen om aan gezondheid gerelateerde problemen te delen en te bespreken met hun zorgverleners. PROMS hebben potentiele voordelen, zoals een betere communicatie tussen patiënt en arts en een beter begrip van de behoeften van de patiënt. Maar succesvolle implementatie kent verschillende belemmeringen zoals onverschilligheid van patiënten voor PROMs, de veelheid aan vragenlijsten die patiënten al krijgen en organisatorische ontwikkelingen zoals een hoog personeelsverloop in de zorg. Door de ervaringen en perspectieven te verzamelen van zowel zorgprofessionals als patienten, wil dit onderzoek de belemmerende en bevorderende factoren voor beide groepen in de vroege fase van implementatie beter begrijpen.

Hoofdstuk 3 gaat over de ontwikkeling van het programma BAAN (Bevorderen van duurzame ArbeidspArticipatie bij Nierpatiënten). Veel mensen met chronische nierziekte (in het Engels afgekort als CKD) krijgen te maken met forse uitdagingen bij het behoud van hun werk. Zowel patiënten als zorgverleners zien voordelen in het bieden van werk gerelateerde zorg in het ziekenhuis, hoewel dat in de praktijk nog niet gebeurt. BAAN werd ontwikkeld en geïmplementeerd om een op maat gemaakt zorgpad in ziekenhuizen aan te bieden voor patiënten met werk gerelateerde problemen. Ook werden praktische hulpmiddelen gemaakt om zelfsturing van patiënten te versterken, waaronder posters en brochures ("Blijven werken, hoe doe ik dat?”) en er werden berichten geplaatst op de informatieschermen van de polikliniek. Daarnaast werd een eenvoudige verwijzingsstructuur opgesteld voor artsen ter ondersteuning in de spreekkamer. Verder werd een arbeidsdeskundige in het ziekenhuis aangesteld om patiënten te helpen met hun vragen over werk en ziekte. Haalbaarheid en nut van het programma werden geëvalueerd en kregen positieve beoordelingen. Het ontwikkelde programma bleek succesvol, maar beperkte financiële middelen kan blijvende inbedding bemoeilijken.

Hoofdstuk 4 is een systematisch literatuuronderzoek dat 21 studies analyseert die gaan over patiëntbetrokkenheid op het organisatieniveau van ziekenhuizen bij value-based healthcare (VBHC) initiatieven. VBHC is in Nederland bekend onder de naam waardegedreven zorg. VBHC streeft naar verbetering van zorg door een focus te leggen op voor de patiënt belangrijke uitkomsten en om deze uitkomsten kosteneffectief te bereiken. De studie wees uit dat voor het betrekken van patiënten de meest voorkomende methoden vragenlijsten en interviews zijn, methoden die worden beschouwd als een lager niveau van patiëntbetrokkenheid dan hogere methoden als adviesrollen, codesign en samenwerkingsteams. Deze hogere niveaus worden nauwelijks gebruikt in VBHC studies. De literatuurstudie benadrukt het belang van hoger niveau patiëntbetrokkenheid om zorg en zorgpaden door gebruik van codesign samen met patiënten te verbeteren.

Hoofdstuk 5 maakt gebruik van de experience-based codesign (EBCD) methode om te begrijpen hoe nierdonoren bij leven het zorgproces ervaren in een groot Nederlands transplantatiecentrum. Nierdonatie bij leven is een levensreddende operatie voor mensen met eindstadium nierfalen. Veel onderzoeken richten zich op de medische aspecten van donatie zoals donorveiligheid en besteden minder aandacht aan hoe donoren de zorg rondom donatie ervaren. De EBCD methode heeft als doel patiëntervaringen te integreren in de verbetering van de zorg. In dit EBCD project werden de ervaringen van zowel donoren als zorgverleners verzameld. Door het houden van interviews met donoren en zorgprofessionals werden elf verbeterpunten geïdentificeerd, waaronder zorgvuldige communicatie op cruciale momenten, advies over herstel van conditie na de operatie en duidelijkheid over nazorg op lange termijn. Ondanks deze verbeterpunten uitten de donoren in zijn algemeenheid hun tevredenheid over de ervaring van hun nierdonatie. De EBCD methode bleek geschikt om praktische verbeteringen te bepalen op basis van donor ervaringen.

Hoofdstuk 6 is het eerste opinieartikel en stelt vanuit patiëntperspectief dat dialysetechnieken een grondige herziening nodig hebben om de kwaliteit van leven (QoL) voor mensen met ernstig nierfalen te verbeteren. De auteurs, zelf (voormalig) gebruikers van dialyse, benadrukken dat de huidige dialyseapparatuur decennialang niet significant is veranderd, ondanks het wijdverspreid voorkomen van chronisch nierfalen (CKD). Het artikel beschrijft nadrukkelijk de beperkingen van de huidige dialysetechnologie: omvangrijke machines, complexe watersystemen, voor patiënten beperkende schema ' s en een gebrek aan gepersonaliseerde behandelopties. Ontwerpers van dialysesystemen hebben te weinig oog voor de behoeften en voorkeuren van CKD patienten en zijn nog te zeer gericht op medisch-technische prestaties. Fictieve personas illustreren de uiteenlopende behoeften van CKD patiënten: mevrouw N is een fervent reiziger en zoekt in een behandeling onafhankelijkheid en flexibiliteit; de heer H heeft een complexe gezondheidssituatie en wil een draagbaar en effectief dialyseapparaat; en de heer W zoekt voor zijn behandeling een flexibel schema met een sociale context. De schrijvers stellen zich een toekomst voor waarin personen die dialyse nodig hebben, toegang krijgen tot een verscheidenheid aan behandelopties, gepersonaliseerde apparaten en deskundige zorgverleners die hun helpen een passende dialysevorm te kiezen waarmee hun leven zo normaal mogelijk kan doorgaan. Ze roepen makers van dialyseapparatuur op om al vroeg in het ontwikkelproces met dialysegebruikers in contact te komen voor het creëren van geïndividualiseerde oplossingen die kwaliteit van leven centraal stellen en waarin niet *overleven* maar *leven* centraal staat.

Hoofdstuk 7 is het tweede opinieartikel en past service-dominant logic (S-D logic) en het concept van waarde-bij-gebruik (value-in-use) toe vanuit het perspectief van mensen die getransplanteerd zijn. S-D logic beschouwt patiënten als degenen die waarde creëren in hun eigen leven en dit verschuift de focus van de aanbod-gerichte “zorgfabriek” naar de persoonlijke ervaringen van patiënten, die door zelf actie te ondernemen bijdragen aan de verbetering van hun eigen welzijn. Na een orgaantransplantatie zijn medische aspecten belangrijk, maar niet voldoende voor het welzijn van transplantatiepatiënten: voor hen gaat het erom weer vol leven in het leven te staan. Vanuit S-D logic, beschrijft het hoofdstuk dat, eenmaal ontslagen uit het ziekenhuis, de patiënt waarde creëert (value-in-use) door terug te keren naar werk, te reizen, te socialiseren en deel te nemen aan allerhande leuke activiteiten. Want waar zorgverleners essentiële medische ondersteuning bieden, is het uiteindelijk de patiënt die de kwaliteit van leven bepaalt. Deze zienswijze vereist een verschuiving naar een mindset waarin zorgverleners hun rol zien als faciliteerder van patiënten in hun weg naar een beter leven. Het benadrukt ook de noodzaak van een ondersteunend aanbod dat breder is dan strikt medische zorg, zoals hulp bij werkbehoud, budget coaching en relatieondersteuning, om getransplanteerde patiënten sterk te maken om alle uitdagingen van het leven weer aan te gaan.

Hoofdstuk 8 geeft een samenvatting van de belangrijkste bevindingen, met nadruk op de betekenis van waarde voor patiënten. Het proefschrift gaat in op de oorsprong en de belangrijkste thema ' s van S-D logic en benadrukt de rol van patiënten om waarde bij gebruik (value-in-use) te creëren, een rol waar vaak geen rekening mee wordt gehouden. Vervolgens worden de ambities van het Nationaal Zorg Akkoord over passende zorg beschreven. Dit akkoord sluit aan bij de ideeën van S-D logic door het promoten van samenwerking tussen zorgaanbieders en door een vertegenwoordiging van patiënten actief te betrekken bij de zorg. Drie uitdagingen voor de toekomst worden genoemd: organisatorische uitdagingen, vooral rondom de samenwerking met andere externe aanbieders, uitdagingen op het gebied van patiëntbetrokkenheid en het begrijpen van de kracht van patiënten om persoonlijke waarde te creëren in hun dagelijks leven.

Dankwoord

Dit proefschrift gaat terug tot 21 januari 1959, de dag dat ik als Willem Sierk Sipma (roepnaam Wim) werd geboren in Leeuwarden. De afgelopen 66 jaar heb ik van alles geleerd, gedaan en meegemaakt. Dit dankwoord gaat daarom verder dan de afgelopen ruim zeven jaar dat ik aan dit proefschrift heb gewerkt. Ik neem u graag kort mee in de periode van vóór mijn PhD tijd omdat de mensen die ik daar ontmoette mede hebben bijgedragen aan wie ik nu ben.

Mijn schooltijd begon op wat toen heette ‘de lagere school’, waar ik een goede basis legde qua kennis en blijvende vriendschap. Daarna volgde het Stedelijk Gymnasium, wat later tevens een succesvol huwelijksbureau bleek te zijn. Omdat ik vooral interesse had in het dagelijks functioneren van bedrijven volgde ik na het eindexamen in 1977 het driejarige fulltime programma bedrijfskunde aan de huidige Nyenrode Business Universiteit. Een programma van leren, wonen en leven op de campus. Op mijn 21^{e} ontluikt alsnog de academische belangstelling en in 1983 studeer ik af in de bedrijfseconomie aan de Rijksuniversiteit Groningen. Daarna volgen verschillende functies bij meerdere bedrijven. Ik ontdekte dat mijn belangstelling vooral uitging naar, wat ik noem, ‘buiten naar binnen vertalen’. Maatschappelijke ontwikkelingen, klantgedrag, gedrag van andere aanbieders en van de overheid vertalen naar het strategisch beleid van organisaties. Ik volgde verdiepende postdoctorale masterstudies in Tilburg (Strategie en Management voor Organisaties in de Gezondheidszorg) en Rotterdam (Global Ebusiness Management). Alles leek voorspoedig te gaan en toen, net 48, werd ik plotseling ziek. Nierfalen.

Een nieuwe periode brak aan, met geheel nieuwe ervaringen. Ik ontmoette nieuwe mensen en fijne mensen, allemaal met indringende verhalen. Als schrijver voor het tweemaandelijkse magazine van de Nierpatiënten Vereniging Nederland (NVN) ben ik gedurende tien jaar bij artsen en nierpatiënten op bezoek geweest om naar hen te luisteren, wat ze dachten en wat ze bezighield. Wanneer we als redactie bijeen zaten ontspon zich altijd een levendige discussie over wat we als kern naar onze lezers wilden overbrengen. In 2015 kreeg ik een nier van een levende donor. Het was even spannend, maar de nier doet het uitstekend en daar ben ik heel dankbaar voor.

Iedereen die ik in bovenstaande periode heb ontmoet en gesproken: dank jullie wel, jullie vormen de voedingsbodem waarop dit proefschrift heeft kunnen groeien.

Langzamerhand bedacht ik me dat het, in ieder geval voor mijzelf, interessant zou zijn om mijn werkervaring, mijn opleiding en mijn opgedane ervaring als patiënt in te zetten voor wetenschappelijk onderzoek en te bundelen in een proefschrift. Promoveren is niet alleen een wetenschappelijke uitdaging maar ook zeker een relationele. Waarmee ik doel op de samenwerking die je aangaat met allerlei mensen met verschillende achtergronden. De PhD expeditie begon voor mij met het op papier zetten van een aantal ideeën voor onderzoeken en een professor te vinden die mijn promotor wilde zijn. Zodoende sprak ik in het voorjaar van 2017 af met Kees Ahaus in Groningen. Kees, ik zag in jou meteen een uiterst vriendelijke man met veel kennis, bedachtzaam en met een vrolijke uitstraling. Ik mocht je gelijk. Je waarschuwde me ‘dat het best zwaar’ was en dat vele anderen gaandeweg het traject afvielen. Maar gelukkig zag je het met me zitten. Met een handdruk hebben we toen onze samenwerking bezegeld. En Kees, ik heb er geen moment spijt van gehad en ik ben blij dat ik met jou ben meeverhuisd naar Rotterdam. Dank voor je begeleiding, je ideeën en je vertrouwen. Je bent een belangrijke factor in het feit dat ik deze expeditie heb kunnen afronden. Datzelfde geldt voor Margriet de Jong als mijn copromotor. In mijn eerste ontmoeting met jou interviewde ik je voor het magazine van de NVN. Dat deden we op jouw kamer in het UMCG aan de Kidney Alley. Je had aan het begin van je loopbaan een management opleiding voor medisch specialisten gevolgd en daar vroeg ik je naar omdat de meeste artsen zoiets pas doen aan het einde van hun loopbaan. Je had een kort maar krachtig antwoord: “Nu heb ik er jarenlang wat aan”. Toen Kees en ik jaren later bij je op de kamer kwamen om je als copromotor te vragen waren we snel rond. Mijn proefschrift zou gaan over patiëntenzorg in de nierwereld en dat past enorm goed bij je, zoals onder meer blijkt uit je vele columns voor de NVN. Jouw betrokkenheid bij de onderwerpen waarin ik mij heb verdiept was altijd groot en maakten mijn ontdekkingsreis van de afgelopen jaren een stuk lichter. Daar voeg ik aan toe je razendsnelle en bondige commentaren op de vele concept teksten die ik je voorlegde, de tel ben ik kwijtgeraakt. Het was ook fijn om jou als arts erbij te hebben, want daardoor kon je vaak net even de juiste bewoordingen aangeven die in de wereld van nefrologen gebruikelijk zijn. Veel dank voor al je inbreng Margriet.

Wat ik Margriet en Kees tot slot nog wil meegeven: we vormden een fijn team met elkaar en ik heb met veel plezier met jullie samengewerkt. Dank daarvoor.

Onderzoek doen en publiceren over die onderzoeken is niet iets dat je alleen doet. Het is een teamsport. Waarin je elkaar corrigeert, aanvult en helpt, maar elkaar ook wat gunt. Wetenschap is teamwork. Alle artikelen in dit proefschrift zijn ontstaan door teamwork en mijn dank gaat uit naar al mijn coauteurs. Naast Kees en Margriet zijn dat, in alfabetische volgorde van hun voornaam: Annemieke Visser, Arie Franx, Haitze de Vries, Henning Søndergaard, Marc Hemmelder, Marco van Londen, Michael van der Voorden, Nieltje Gedney, Ron Gansevoort, Sandra Brouwer en Yvette Meuleman. Allen reuze bedankt voor jullie inzet. Mijn dank gaat ook uit naar Giles Stacey, onze native speaker, die alle aangeleverde Engelstalige papers vakkundig een waardevolle upgrade gaf. Thanks Giles.

Een paar van de hierboven genoemde coauteurs geef ik nog wat extra aandacht. Ik begin met Michael van der Voorden. Michael, we zaten samen in hetzelfde schuitje van extern promovendus. Het was een hele belevenis om gezamenlijk aan een systematic review te werken, wat voor ons beiden toch een beetje taaie materie is. We hadden elkaar nooit ontmoet maar de digitale kennismaking verliep prima en het hele jaar dat we samen aan ons onderzoek werkten ging alles heel soepel. Natuurlijk was het veel werk en moesten we veel uitzoeken. Maar we waren allebei praktisch ingesteld en we konden allebei een flink tempo aanhouden. En, belangrijk, we hebben veel kunnen lachen tijdens onze Teams sessies. Dat we heel wat jaren in leeftijd schelen maakte helemaal niets uit. Heerlijk om met je gewerkt te hebben Michael, bedankt.

Twee anderen die ik hier wil noemen zijn Annemieke Visser en Haitze de Vries. Annemieke en Haitze, jullie waren twee jaar mijn collega's binnen het project BAAN. Dat was fantastisch. Annemieke als regisseur c.q. projectleider en als ons wetenschappelijk geweten. Haitze en ik, heel kort samengevat, als respectievelijk contactpersoon naar bedrijfsartsen en patiënten. Maar dat niet alleen. Met elkaar en de andere teamleden hebben we een prachtig product neergezet met BAAN. En dat alles in de volle COVID-19 periode, die direct begon na onze eerste gezamenlijke bijeenkomst met alle deelnemers. Het project werd daardoor een extra uitdaging, maar het is ons gelukt en we mogen best trots zijn op wat we bereikt hebben. Ik kijk er met veel plezier op terug. Dank jullie wel.

Onderzoek kan niet zonder deelnemers, althans niet de onderzoeken die ik veelal deed. Voor die onderzoeken heb ik veel mensen mogen spreken de afgelopen jaren. Patiënten, hun naasten en zorgverleners uit alle windstreken van Nederland, soms ver weg en soms dichtbij. Patiënten en naasten sprak ik in ziekenhuizen, dialysecentra en bij mensen thuis. Van jullie heb ik prachtige verhalen mogen noteren. Verhalen hoe jullie vorm geven aan je leven, verhalen met soms onbegrip, soms boosheid, soms verdriet en soms met gelatenheid. Maar, eigenlijk zonder uitzondering, altijd vol moed en, naar mij toe, heel open en persoonlijk. Ik dank jullie allemaal.

Dat geldt ook voor de zorgverleners die ik sprak. Jullie maakten tijd voor mij, ondanks alle drukke agenda's van iedereen. De open gesprekken gaven mij inzicht in de dagelijkse praktijk en waren een verrijking voor de verschillende onderzoeken. Ik dank jullie zeer.

Elk artikel kent voorafgaand aan publicatie één of meerdere review rondes en die stellen het geduld van de auteurs flink op de proef. Maar ook de reviewers, allemaal wetenschappers, hebben een druk bezette agenda en het is fijn dat ze de tijd nemen om commentaar te geven op een ingezonden manuscript. Dankzij hun commentaar heb ik de ingezonden manuscripten kunnen aanpassen tot de artikelen zoals die nu zijn gepubliceerd. De reviewers droegen daardoor bij aan de kwaliteit en daarvoor dank ik hun hartelijk.

Aan het eind van het promotietraject breekt een spannende periode aan want de beoordelingscommissie moet goedkeuring geven aan mijn onderzoek. Ik ben de leden van de beoordelingscommissie zeer erkentelijk voor hun tijd om mijn proefschrift te lezen en te beoordelen. Hester van de Bovenkamp (voorzitter), Willem Jan Bos en Tijn Kool: heel hartelijk bedankt. Mijn dank en waardering gaat natuurlijk ook uit naar de overige leden van de promotiecommissie: Isabelle Fabbricotti, Astrid Janssens en Anne Stiggelbout. Dank jullie wel.

Tot slot een speciaal dankwoord aan de belangrijkste mensen in mijn leven, mijn gezin. We hebben heel wat meegemaakt met zijn allen. Lieve Dedmer, jij zorgde voor mijn PhD computer. Je hebt alles voor me uitgezocht, geïnstalleerd en onderhouden. Dat was een essentiële bijdrage waar ik niet zonder had gekund, dankjewel. Lieve Wieger, jij zorgde voor de nodige ontspanning. Onze reizen zal ik nooit vergeten en ook onze reis in mei 2024 door West-Amerika met de hagelwitte Ford Mustang cabrio en ons bezoek aan jouw opleidingsplaats Phoenix was onvergetelijk. Super bedankt. Lieve Berber, wat was je vereerd toen ik je als paranimf vroeg. En ik ben blij dat je daarmee instemde. Jouw vrolijkheid en warmte zijn voor mij goud waard. Blij dat je mijn dochter bent. Dank je wel. Tot slot, de rots in de branding van ons gezin: Rieteke, al meer dan 35 jaar mijn echtgenote en nu mijn paranimf. Fijn om jou aan mijn zijde te hebben Rieteke. De branding gaat bij ons flink te keer en dan is zo’n stevige rots noodzakelijk en fijn tegelijk. En gelukkig heb je prachtige hobby’s zodat ik me rustig kon terugtrekken in mijn werkkamer om te schrijven aan dit proefschrift. Lieve Rieteke, reuze bedankt voor al je support.

Dan zou ik nu kunnen eindigen met dit dankwoord dat begon op 21 januari 1959. Maar er zijn nog twee mensen die ik wil bedanken: mijn ouders. Pap en Mam, dankjewel. Ik weet zeker dat jullie trots op me zouden zijn geweest en dat is een fijne gedachte.

ABOUT THE AUTHOR

Willem Sierk (Wim) Sipma was born in Leeuwarden on January 21, 1959. Pulitzer Prize winner Fred Kaplan described 1959 as The Year Everything Changed [1]. In 1959, the microchip was invented and the world started to develop in the direction we know today. Wim grew up in the decades after 1959 when huge technological, social, and cultural changes occurred. The landing on the moon, the first home computer with 32K memory (imagine!), the first connected computer networks (beep-beep). After finishing high school, Wim studied and lived for three years on the campus at Nyenrode Business University (Breukelen). He holds master degrees in Business Economics (Groningen), Management of Health Administration (Tilburg), and Global Ebusiness Management (Rotterdam).

Wim has over 30 years of experience in marketing and business strategy in several business areas, including healthcare insurance and healthcare organizations. He also held positions for over a decade on healthcare supervisory boards.

In his 40s, he was diagnosed with end stage kidney disease and joined the editorial staff of the two-monthly magazine of the Dutch Kidney Patients Association. Over the next ten years he published the stories of patients' experiences. He also interviewed numerous care professionals about medical innovations, their insights and ideas. Meanwhile, after recovering and still driven by human curiosity, he decided to use his professional background and personal experience for scientific research into healthcare. He accepted the challenge of completing a PhD at the Erasmus School of Health Policy & Management (ESHPM) which has resulted in the publication of this book.

Wim focused his research on patient engagement and the interplay between patients and healthcare professionals in improving healthcare services. He applies the service-dominant logic (S-D logic) theory to describe how patients are the true creators of value in healthcare and that healthcare organizations and policymakers can benefit from actively engaging with patients.

He intends to continue his work with grey hair and colorful thoughts.

Wim Sipma
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1. Kaplan F. 1959: The Year Everything Changed. Wiley; 2010.

PhD Portfolio
W.S. Sipma

Erasmus University Rotterdam
PhD Period: September 2017 – October 2024
Promotor: Prof. dr. ir. C.T.B. Ahaus
Co-promotor: Dr. M.F.C. de Jong

Courses/training (Year)		**Workload (EC)**
Multivariate Data Analysis (2017)	University of Groningen - Faculty of Economics and Business	5.00
English presentation course (2018)	University of Groningen - Faculty of Economics and Business	2.50
Organizational Behavior for the Research Master (2018)	University of Groningen - Faculty of Economics and Business	5.00
Research Project (2018)	University of Groningen - Faculty of Economics and Business	5.00
Projectmanagement course (2018)	University of Groningen - Faculty of Economics and Business	0.00
English writing course (2018)	University of Groningen - Faculty of Economics and Business	2.50
Research Proposal (2019)	University of Groningen - Faculty of Economics and Business	5.00
Case Study Research (2019)	University of Groningen - Faculty of Economics and Business	5.00

Workshop Scientific Integrity (2019)	University of Groningen - Faculty of Economics and Business	0.00
Publishing Workshop (2019)	University of Groningen - Faculty of Economics and Business	0.00
Design in Healthcare: Using Patient Journey Mapping (2023)	Delft University of Technology	0.00
Experience-Based Co-Design (2023)	Point of Care Foundation, London UK	0.00
		------ +
Total EC		**30.00**

Oral Presentations

Implementatie PROMs in de (nierdialyse) spreekkamer
Universitair Medisch Centrum Groningen
Januari 2019

Mixing the views of patients and professionals: the challenges of PROM implementation in Dutch renal care
Symposium SWON, Sociaal Wetenschappelijk Onderzoek Nefrologie
Via Teams vanwege COVID-19
November 2020

Bevorderen van duurzame Arbeidsparticipatie bij Nierpatiënten
Symposium SWON, Sociaal Wetenschappelijk Onderzoek Nefrologie
Nierstichting Bussum
December 2023

Additional Publication

Wim Sipma, Haitze de Vries, Ron Gansevoort, Annemieke Visser
Patiënt zelf aan zet om perspectief op werk levend te houden
Baanbehoud is aandachtspunt van zorgverleners rondom chronische nierpatiënt
Medisch Contact, Nr. 46, pag. 26-27, 18 november 2021