Evaluation of a telehealth solution developed to improve follow-up after kidney Transplantation

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Evaluation of a telehealth solution developed to improve follow-up after kidney transplantation: A qualitative study

Abstract

Aim: To explore patients’ and healthcare professionals’ experiences of using a telehealth solution developed to improve follow-up after kidney transplantation.

Background: Transplantation is the treatment of choice whenever feasible for patients with end-stage kidney disease. However, it implies lifelong adherence of self-monitoring, medicine and other restrictions to ensure successful outcomes. Based on user involvement a telehealth solution was developed to support patients and healthcare professionals post-transplantation.

Design: An explorative qualitative study with a phenomenological-hermeneutic approach.

Methods: The developed app and workflow for follow-up were tested by patients and healthcare professionals, and evaluated with interviews. In total, 16 patients and 20 healthcare professionals participated. Individual interviews were conducted with the patients, four nurses participated in two sets of interviews, and 16 doctors participated in a focus group. Data were analysed with inspiration from Ricoeur’s theory of interpretation, on three levels: Naïve reading, structural analysis and critical interpretation and discussion. The COREQ checklist was applied in reporting the study.
Results: Three themes emerged: Challenging conditions for training sessions, telehealth improves patient reflection and collaboration, and telehealth gives patients a voice in consultations. In a challenging time post-transplantation patients found the app easy to use; it facilitated support and reflection on how to manage. It also supported both patients and healthcare professionals at follow-up consultations in terms of enhanced preparation, improved dialogue, and enabling consultations by phone.

Conclusion: The study showed that patients and healthcare professionals found the app and workflow valuable and easy to use. The Patient Data feature in the app, has potential as a communication tool. However, adjustments and further investigations are needed to develop the solution.

Relevance to clinical practice: The potential of telehealth brings new opportunities to provide treatment and care to newly transplanted patients. Telehealth can support both patients and health professionals by improving dialogue and collaboration.

Keywords: Patient experiences, technology, qualitative study, renal nursing, transplantation

Introduction

This study explores the perspectives of both patients and healthcare professionals (HCPs) in a qualitative evaluation of a telehealth solution developed to be used after kidney transplantation.

The study is part of a larger participatory design study, in three phases, to develop new ways to structure and improve the transplantation process (Clemensen et al., 2017). In the first phase, patients’ and HCPs’ experiences were explored to identify needs in the transplantation process. The second phase involved the design and development of a telehealth solution to support the identified needs in collaboration with patients and HCPs. Finally, in the third
phase, the telehealth solution was evaluated by way of gathering the users’ experiences. This study, reports on the third phase.

A total of, 554 individuals were enlisted for kidney transplantation in Denmark in 2018, and in the same year 236 patients received a kidney from either a living or a deceased donor (Scandiatransplant, 2019). Kidney transplantation is the treatment of choice for end-stage renal disease whenever feasible, as it implies survival benefit, higher quality of life and reduced medication for patients, compared with dialysis (Landreneau et al., 2010; Oniscu et al., 2005). However, transplantation involves new challenges in patients’ lives, requiring patients to manage lifelong self-monitoring, medical adherence and obligations to ensure successful transplantation outcomes (Been-Dahmen et al., 2018; Jamieson et al., 2016; Lorenz et al., 2019).

Background
A recent study of patients’ experiences has identified the challenges patients face in terms of treatment burden, described as treatment workload and self-management and their impact on patient well-being. The challenges that arise include having to acquire new knowledge, monitoring, medication, follow-ups, self-management, and psychosocial limitations (Lorenz et al., 2019). Patients find themselves in a new learning process towards self-management after transplantation, and have to learn how to take care of the kidney graft (Been-Dahmen et al., 2018; Jamieson et al., 2016; Wiederhold et al., 2011). During this testing time, patients need help and support. A study of patients and HCPs’ experiences recommended a holistic approach that would address emotional and social issues alongside the medical approach, to help patients cope with various challenges post-transplantation (Been-Dahmen et al., 2019). The study requested that medical issues be addressed together with other issues of concern to patients (Been-Dahmen et al., 2019). This is echoed in other studies, where patients also request that social and emotional factors beyond their disease also be addressed (Brett et al., 2018; Wiederhold et al., 2011). However, there is a lack of knowledge and studies to investigate how to involve
and support patients on a practical level, and how it could be performed in clinical practice.

As part of our larger study mentioned above, we developed a telehealth solution to support patients and HCPs after kidney transplantation. The solution consisted of a mobile app and a workflow for follow-up. Prior research has found promising potential in telehealth to improve health outcomes in patients with chronic conditions (Lee et al., 2018; Whitehead & Seaton, 2016). Kidney recipients seem to have a positive attitude towards telehealth, and including use of apps for smartphones (McGillicuddy et al., 2013; O’Brien et al., 2018; Vanhoof et al., 2018). The use of telehealth in post-transplantation follow-up shows potential in the support of patients (Andrew et al., 2018; van Lint et al., 2015). Telehealth consultations were found in one study to provide the same satisfaction among patients as in face to face sessions, and the patients’ understanding of their condition were improved (Andrew et al., 2018). Furthermore another study showed, home-based self-monitoring to be well received by patients after transplantation; it increased patient satisfaction, and frequent measurements improved detection of hypertension (van Lint et al., 2015). Moreover, in general, studies point to telehealth as an acceptable approach to improving medication adherence, because patients seem to be receptive to technology (Browning et al., 2016; Cote et al., 2018; McGillicuddy et al., 2015). However, research on other ways to improve the kidney transplantation process using telehealth seems to be a sparsely investigated field, in which more research is needed. Therefore, the aim of this study was to explore patients’ and HCPs’ experiences of using a telehealth solution developed to improve follow-up after a kidney transplant.

**Methods**

**Design**
The study was an explorative, qualitative study that took a phenomenological-hermeneutic approach (Ricœur, 1976). The core of the study was the
participants’ experiences. The study design provided insight into, and knowledge and understanding of the patient and HCP participants’ experiences and perspectives of using the telehealth solution in their daily lives and in clinical practice. Data were gathered through semi-structured interviews and a focus group (Kvale & Brinkmann, 2014). The use of focus groups in phenomenological-hermeneutic research has been discussed as incompatible. However, the focus group discussion was applied to open up new perspectives and encourage exchanges of experiences between the doctors (Bradbury-Jones et al., 2009). This provided a rich understanding of the doctors unique lived experiences when using the solution, as they discussed and reflected together in relation to their profession as doctors.

Setting
The study took place in a Danish kidney transplant centre at a university hospital where patients are hospitalized for approximately one week during transplantation. Following the transplant, they attend regular follow-ups at the out-patient clinic: twice a week for the first month, then once a week, with the follow-ups becoming less frequent over time; after one year they attend follow-up every six months.

The telehealth solution
Patients and HCPs collaborated in developing a solution, guided by the needs of the users in clinical practice (Blinded). The telehealth solution took the form of a new workflow for follow-up consultations and an app for kidney transplant patients as listed in Table 1.

<Insert Table 1>

The app included a knowledge base with texts and videos relevant to patients in the transplantation process, and contained the feature Patient Data, which was developed to support the workflow for follow-up. The Patient Data feature enabled patients to report self-monitoring data on an ongoing basis and answering of five questions before every follow-up consultation. The questions
were defined by patients and HCPs, to capture how the patients were doing at home. The five questions concerned fluid, appetite, activity, mood, and medication. Each question had five pre-defined answers represented by an illustrative statement. The answers were on a continuum from no problems to serious problems, as a qualitative assessment from the patients. The content of Patient Data is listed in table 2.

<Insert Table 2>

The new workflow for follow-up enabled patients to have alternate consultations by phone (and alternate consultations face to face), thus giving patients more time at home, and less disruption to their daily lives. The workflow consisted of two training sessions with nurses at the out-patient clinic. ‘Training session 1’ before discharge was structured around the use of the Patient Data feature. The aim was to provide knowledge to understand and answer the questions contained in Patient Data, and the overall practical use of the app to report data. In connection with the first follow-up after discharge, ‘training session 2’ was conducted, structured around the patients’ reflections and questions after having used the app and the Patient Data feature at home for the first time. The patients would receive five questions in the app before each follow-up, and self-monitoring data could be registered on an ongoing basis. At follow-up, the doctor could read the reported answers and measurements in the electronic medical journal. This was the procedure before each consultation, regardless of whether it was a consultation in the out-patient clinic or by phone. By reporting patient data, consultations could be held in person or by phone, on an alternating basis. Thus, the new workflow was supported by the Patient Data feature in the app.

The workflow is illustrated in Figure 1.

<Insert figure 1>
Patients included in the current study tested the workflow and the Patient Data feature in the app for four months. Patients were included during admission for transplantation, participated in the training sessions, and used the app on their own devices – which could be smartphones, tablets or computer. At the outpatient clinic, nurses held the two training sessions with the patients, and doctors used information reported in the Patient Data feature at follow-up consultations. At the end of the test period, interviews and a focus group was conducted.

Participants
Testing of the new workflow and the app involved the three groups of participants included in this study: Patients, nurses, and doctors.

Patients
Patients transplanted between May and December 2018, with a kidney from a living or deceased donor, were all consecutively included by the first author face to face at the hospital. Whenever possible the patients were informed in advance of the study in writing. Inclusion criteria: Danish-speaking patients admitted for kidney transplantation over the age of 18. Of 28 patients invited to participate, 10 patients declined, because of lack of mental and physical resources [five], language barriers [two], mentally impaired [two] and no device [one]. Two patients dropped out before the follow-up training sessions, one because of lack of resources, and one because he later regretted his agreement to participate, because it involved the use of an app. In total, 16 patients participated in the evaluation of the telehealth solution, with a mean age of 50 (Range: 21-67). There was an equal distribution between genders and donor type, and four patients had been transplanted once before. The patients are presented in Table 3. All participated both in the testing and the following interviews.

<Insert Table 3>
HCPs

Purposeful sampling according to gender and experience in the transplantation field was used to include HCPs from the out-patients clinic. The inclusion criteria were experience with the telehealth solution in follow-up post-transplantation. They received a mail with information of the study and an invitation to participate in the evaluation. Nurses working at the out-patient clinic participated in an interview. Two sets of interviews were conducted with the nurses together two at a time. The four participating nurses had between 10 and over 30 years of experience. A focus group was conducted with the doctors at the department, as a continuation of a staff meeting. In total, 16 doctors participated, representing nine consultants and seven junior doctors. Nurses and doctors were interviewed when the test period ended, in April 2019.

Data collection

Data was collected from September 2018 to April 2019 using interviews and a focus group, as illustrated in Figure 2. The patients’ narrations of their lived experiences with the telehealth solution in daily life and the HCPs experiences from clinical practice generated data to inform a qualitative evaluation from a user perspective.

Interviews

Individual, semi-structured interviews with patients were held at the hospital or in their homes, based on their choice. The aim was to explore patient experiences of using the telehealth solution in everyday life and the tested workflow. The interviews lasted 24-83 minutes (average 45 minutes).

Organisational circumstances led to two sessions of group interviews with the nurses in pairs, and not a focus group as planned. The group interviews were held at the out-patient clinic during working hours. The aim was to explore the
nurses’ experiences of the training sessions and of their informal contact with the patients at the out-patient clinic. The interviews lasted 40-50 minutes.

A semi-structured interview guide was used in both interviews with the patients and the nurses, guiding the participants to unfold and narrate freely about their experiences. Through open-ended questions, the patients were for example asked: “What were your experiences of being at home? And how did you experience using the telehealth solution at home?” And a question to the nurses was: “How did you experience the training with the patients?” The interview approach revealed nuanced experiences, end reflections arose in the interview situation. The nurses could also reflect and inspire each other during the interviews (Kvale & Brinkmann, 2014).

Focus group
The doctors participated in a focus group held in a conference room on the ward, during working hours. As preparation, they had answered five questions in advance about their use of the telehealth solution to support their reflections, and for the researchers to inform an interview guide. All answered the questions by way of a webpage. The focus group lasted 37 minutes. Interaction between the participants is important when conducting a focus group. Thus, the aim was to encourage the participants to reflect about the use of the telehealth solution with each other, rather than addressing the moderator (Kitzinger, 1995). A semi-structured interview guide with open-ended questions to facilitate reflection and discussion was used, with questions such as: “How did Patient Data influence the consultation?” (Kitzinger, 1995; Krueger & Casey, 2015). The first author acted as moderator, and the last author participated as co-moderator, observing non-verbal communication and supplementing with elaborating questions.

All interviews were conducted by the first author, who is experienced in qualitative research and renal care; however she is not involved in clinical work. The interviews were recorded and transcribed verbatim by the first author. The entire research team planned the research process and discussed the findings.
in the study. This researcher triangulation enhanced the study validity (Malterud, 2001). The consolidated criteria for reporting qualitative research (COREQ) were applied in reporting the study (Supplementary file 1).

**Ethical considerations**
The participants were informed about the study and aims orally and in writing, in accordance with applicable ethical rules (Helsinki, 2018). Patients gave written informed consent to participate in the test period, and both patients and HCPs gave written informed consent to be interviewed. The study was approved by the Danish Data Protection Agency, journal number: 15/48886.

**Data analysis**
The software programme NVivo 11 was used to systemize the analysis that was inspired by the French philosopher Ricoeur. The transcribed interview data were analysed as one coherent text that consisted of data from interviews with patients, nurses and doctors. By combining the three groups of participants a rich data set was provided. Based on Ricoeur’s theory on narrative and interpretation, the data analysis was conducted in a dialectical movement between the three levels: Naïve reading, structural analysis and critical interpretation and discussion (Ricoeur, 1976). An initial understanding of the text was gained in the naïve reading, where the text was read with an open mind to get an impression of what the text is about. During the structural analysis, the text was opened up to a deeper interpretation. The text was divided into units of meaning to identify meaning across the text material based in ‘what is said’. Through further interpretation, units of significance were identified as descriptions of ‘what the text is talking about’. The units identified a movement from the participants’ quotations to a deeper understanding and interpretation of the text where themes emerged. The themes emerged in an ongoing internal validation with the text itself, between the parts and the whole, by comparing the identified parts of data with what was captured by the entire coherent data set. The structural analysis represented the beginning of a movement from an individual to an universal level, which was achieved in the final critical
interpretation and discussion of the emerged themes in relation to theory and research literature (Pedersen, 1999/2005; Ricœur, 1976). The structural analysis is illustrated in Figure 3.

<Insert Figure 3>

The themes will be presented by an illustrative quotation, and will be followed by an interpretation representing the meaning of the lived experience gathered across the data material (Pedersen, 1999/2005).

Results

The naïve reading revealed that the telehealth solution seemed to support patients during the time soon after transplantation – a period that patients experienced as a life-changing situation, involving challenges and worries. Among the patients, the telehealth solution appeared to be valuable and easy to use. Among HCP, there also seemed to be positive perceptions of the telehealth solution.

Through the structural analysis, three themes emerged: Challenging conditions for training sessions, telehealth improves patient reflection and collaboration, and telehealth gives patients a voice in consultations. The themes presented in Figure 4 will be interpreted in the following, where (P) refers to patient, (N) refers to nurse, (D) refers to a junior doctor and (C) refers to consultant.

<Insert Figure 4>

Challenging conditions for training sessions

At the time of ‘training session 1’ ahead of discharge, patients had limited resources, due to their physical postoperative symptoms, and there was various readiness for training:
“At that time [the time of the training] I was in a bad way, so I didn't get that much out of it” (P2). And a nurse said: “There have been patients who have been ready and some who have not been ready [...] everyone would really like to do as much as possible [...] but it has simply been too much for some of them, and others have said ‘I'll find a way’, and it has actually been pretty easy for them” (N1)

Even though the patients could not take in much of the training that took place ahead of discharge, all the patients were motivated to participate. At that time, patients were experiencing a lack of mental and physical resources and they felt groggy, in pain or tired. The nurses completed and adapted the training to meet the patients’ individual needs. When recalling the training, patients focused on the practical information. Despite the fact that the training situation was not conducive for learning, the telehealth solution was used unproblematically, as a part of everyday life at home.

The use of the Patient Data feature supported patients and created new routines in everyday life: “It takes five minutes, frankly it's nothing, I like to do it while I’m having my morning coffee and then that’s it [...] now it has just become something I do” (P10). Patients were familiar with using both apps and smartphones, and found the telehealth solution to be intuitive. Reporting data in the app was easy and quickly done, without burdening daily life. On the contrary, it seemed to provide a new routine and give the patients control and peace of mind. It supported everyday life by structuring their obligations to care for their health, the reporting of measurements, and it enabled follow-up by phone. It also made reported data available for patients to provide certainty and knowledge about their kidney function.

The ‘training session 2’ was challenged by organisational circumstances. A nurse said:

“I miss the fact that it [training session 2] has been prioritized. Some of the training sessions have actually been done while taking time to put the medication in a bag, so it has not been any more
Lack of structured time for follow-up training, due to, e.g., patient appointments being changed, caused frustration among nurses because it then had to be done on top of the usual tasks at the out-patient clinic. This could be the reason why the patients did not recall having follow-up training, as it ended up being merged with standard procedures at the clinic, such as receiving medicine and setting a time for the next appointment.

Insufficient follow-up training was problematic, because patients needed knowledge and support about how to manage in everyday life: “I would say it is incredibly complex, in the sense that, when the doctor says it, it sounds logical and totally correct, but when you come home, then what, because then if I make a slight deviation, it is the same or is it a new situation” (P5). At home, it was challenging to transfer health information into their everyday lives. That made patients uncertain and created a need for support and training. At the follow-up training, patients had been home for a few days, and had gained limited experience of using the telehealth solution in everyday life.

**Telehealth improves patient reflection and collaboration**

In the patients’ opinion, the intention of Patient Data was to provide the doctor with information about their condition. However, other benefits of using Patient Data to report self-monitoring data and answer questions related to their wellbeing were uncovered, such as improved self-reflection and preparation for follow-ups: “It is actually good to get the questions […] because you are reminded that you just have to deal with it […] I get a reminder to think about it” (P13). Patient Data was perceived to be significant because it provided a basis to deliver information about patients’ wellbeing, and information related to the kidney functioning, such as hydration, medication and measurements. Use of Patient Data made the patients reflect on their condition and wellbeing after the transplant. It also prepared them for consultations, as they became aware of what questions to ask. Patient Data provided a complete overview of how
reported data developed over time in the telehealth solution. This illustrated coherence between, e.g., symptoms and the doctors’ prescriptions. This gave the patients a greater understanding of their situation and what was required of them. Patient Data also provided hope and guidance: “I hope to be so stable that I can answer the same each time, that will be perfect [...] so it’s working well, that will be good” (P2). Patients used the reported answers as a guideline to assess their well-being and if the kidney graft was functioning well. Stability – in the sense of giving the same answers over time – could be seen as a goal, and provided hope that the kidney functioning would develop positively in the future. Beyond the four months test period, the patients continued using Patient Data. They valued it because it allowed them to track the reported data.

The doctors’ experiences supported the finding from patients that Patient Data improved patient reflection: “I think it’s good that one gets the patients to think about how they are doing, and the different aspects they ask about” (C7).

Doctors found that Patient Data facilitated patient reflection on their condition, and prepared patients for consultations, and that it supported self-care that was important for transplanted patients. Preparation and reflection could also include patients adding free text, which was used for personalised questions or as a reminder about issues they wanted to address. However, the patients considered it important that the doctor responded to the free text otherwise, it had no value.

**Telehealth gives patients a voice in consultations**

Patient Data strengthened the focus on issues that were important for the patients: “I feel, in any case, that it’s taken seriously [...] I have got answers to the things that I have set out” (P4). Patient Data provided a voice for the patients in the consultations, and there were feelings of being taken seriously when they reported data and their questions were answered. However, during some of the consultations, it appeared that the doctors did not always address the Patient Data: “I don’t think that the doctors use them [Patient Data feature] a lot. I have experienced that, when I come over here, they ask about things that
I’ve already answered that morning, so I say, I’ve written to you about that this morning, and that’s a bit disappointing” (P10). Patients relied on the doctors being prepared, and it was disappointing when the doctors did not access the Patient Data.

Consultations by phone were appreciated by the patients: “... at the start, anyway, it was agghh tiring to have to come all the way over here […] because I wasn’t well, so it was really gruelling to have to come here” (P2). Travelling a long distance for consultations was taxing for the patients, both physically and mentally. It was stressful, difficult, time-consuming, and tiresome to have to cope with. Consultations by phone were perceived to be similar to meeting at the out-patient clinic: “We talk about the same things, but it’s something else sitting in front of one another […] actually it doesn’t matter, but it’s just different, and I think it’s fine to have phone consultations, because you can of course ask about the same things” (P7). Phone consultations were quick and easy to conduct. The dialogue was experienced to be shorter and more to the point. However, the type of consultation had no influence on the content, and patients felt equally free to ask questions on the phone. Despite the efficacy of the phone, patients also felt that it was essential to meet the doctor, in order to maintain a relationship: “But I also think that it’s nice, once in a while, to be able to see the doctor face to face […] it’s probably just a personal preference, and it’s not because there is any difference, but because it isn’t just, like, a ‘Hi, everything fine, ok, bye’” (P8). On the phone, the non-verbal communication was missing, and it was important for the patients sometimes to meet with the doctor in person. It gave the patients confidence, and supported an individual approach. The face to face communication was more nuanced, as it was supported by body language and visual input. They could look at and reflect together on biomarkers or blood pressure graphs on the computer. This nuanced communication could be one reason why patients preferred meeting at the out-patient clinic if complications occurred.
Doctors found the Patient Data feature useful, but the value was dependent on the type of consultation:

“It’s most useful during phone consultations, because you can prepare, you have an idea of how it’s going, before you call the patient. When I take a patient in to a physical meeting, then I can easily see, as soon as the person approaches, whether they are well, and I can’t do that on the phone” (C1).

Doctors used the Patient Data feature in the consultations, and they considered the feature to be useful to some extent. They were provided with significant knowledge about the patients’ condition and needs, and preparation for phone consultations. During face-to-face consultations, they relied on a clinical assessment based on the patient’s appearance. The Patient Data feature became less relevant, as it covered issues they addressed in routine practice, so sometimes they forgot to access the data. However, the less experienced doctors found support in feature:

“Personally, I have used it as a support tool, what is it we have to remember to go through with these patients, so for me, as a junior doctor, it has also been a professional support [...] and in that way I think it’s a good tool” (D6).

The Patient Data feature guided the junior doctors’ observations and clinical assessment of the patients and was a reminder of issues relevant to address with kidney recipients. The telehealth solution was integrated in the electronic medical record which made it easy to access the reported data and well known to the HCPs.

**Discussion**

The study showed that patients experienced reporting of Patient Data in the app easy and unproblematic, despite the fact that the timing of the training sessions was not conducive, given that they had very recently been transplanted.
However, lack of follow-up training was problematic, as the patients needed support to transfer the knowledge received from the HCPs into actions in everyday life. Use of the Patient Data feature improved patient reflection and gave them a voice in consultations. This was acknowledged by the doctors; however, the experienced doctors found that Patient Data did not address new issues, and they could sometimes forget to use it, to the patients’ disappointment.

In the current study, patients were more receptive to practical information than training needed to master everyday life. Similar challenging conditions for training were found in a study of patients’ experiences with training during admission in the early post-operative phase (Urstad et al., 2012). The study identified that emotional, physical and drug-related aspects negatively affected patients’ ability to concentrate and learn (Urstad et al., 2012). They found that the patients found it difficult to apply theoretical knowledge at home, as they had few experiences of transferring knowledge during admission (Urstad et al., 2012). Training of patients after discharge would be more useful at a time when the physical and emotional post-operative symptoms have settled, and patients have gained experiences of the transfer of health information and knowledge into their everyday lives. Hence, the timing of the training in the current study seemed to be placed too close to discharge. However, the patients could benefit more if the planned training sessions were postponed.

The Patient Data feature in the app could be a communication tool to facilitate collaboration between patient and HCP. That is important, as collaboration and partnership was found to be significant for medication adherence in kidney transplantation in another study (Williams et al., 2016). Partnership was facilitated by dialogue between patients and HCPs to give patients an understanding of their medication and involve them in decision making; however, it was not always achieved. Instead, communication took the form of one-way conversations, led by the HCPs that left the patients with minimal opportunity to contribute (Williams et al., 2016). In the current study, reporting of
data led to reflections and prepared patients for follow-up by making them aware of how they actually felt and significant questions to be asked. Support and preparation of the patients to contribute to conversations could give them a say, and thereby decrease the risk of one-way conversations. Even if the patients did not address the issues themselves, their “voice” could be heard through their reported data in the app.

The use of the app to report data and answers in the Patient Data feature contributed with individual experiences to the consultations, and addressed aspects other than the medical. A study of a nurse-led support intervention for kidney recipients revealed the importance of addressing both emotional and social issues in addition to medical issues. Even if there were many medical problems (Been-Dahmen et al., 2019). Also, the value of patients’ individual experiences was important to increase quality of care (Been-Dahmen et al., 2019). This underlines the significance of the focus on individual experiences in the app in the current study. However, the impact depended on the doctors’ use of the Patient Data feature at follow-up. Been-Dahmen et al. discussed how the skill level of HCPs strongly influenced the outcomes of an intervention, and training both before and booster sessions during implementation were of importance in their study (Been-Dahmen et al., 2019). In our study training for HCPs could be a way to increase both the motivation, use, and awareness of the Patient Data feature. The doctors were most motivated to use the feature for consultations by phone. Training and knowledge about the benefits patients gain from using the Patient Data feature could be a motivation to use it continuously. In addition, the Patient Data feature represented a new approach by explicitly asking for patients’ individual experiences and assessments before each follow-up consultation. This new approach requires a change of the HCPs’ mind-set, and training in involving the patient perspective by using the Patient Data feature could be an element to support this.

To explain the telehealth solutions’ impact on both patients and HCPs a post-phenomenology approach is applied. This approach is concerned with how
technology shapes the relationship between humans and technology, using concepts to describe technological mediation, constitution and multi-stability (Rosenberger & Verbeek, 2015). According to the post-phenomenological approach, technology is not a neutral force, but is regarded as playing an actively mediaty role in human-world relations (Rosenberger & Verbeek, 2015).

The workflow for follow-up mediated a new way of interaction between patient and HCP by enabling telephone consultations. While patients appreciated the telephone consultations, because it meant they did not have to travel, they feared an impersonal and shallow relationship with the HCP if they only had contact by phone. Telephone interaction was without body language and the chance to look at illustrations on the computer, so the interaction was solely dependent on the use of the voice and words. This could be accommodated by providing video consultations. However, in the development of the telehealth solution both patients and HCPs agreed on choosing phone consultations, as they were most familiar with that.

The use of the app also had an impact on patients and HCPs. Doctors could assess and interpret the patients’ data and answers in the consultation together with the patient. In this way, the Patient Data feature constituted a communication tool, giving patients an active role as a dialogue partner. Patient Data could also be interpreted by the doctor before the consultation, which constituted Patient Data as a tool that gave patients a voice, albeit the meaning attributed to what the patients had written in the free text depended on the doctors’ interpretation. And, sometimes, Patient Data was not used by doctors in consultations. This showed how the app feature became constituted by the way it was used, and how the use affected the role of both patients and HCPs.

The various ways in which Patient Data could be used illustrated the multi-stability of the telehealth solution. The study further revealed the multi-stability of the telehealth solution, as Patient Data also facilitated patient reflection,
prepared the doctors before telephone consultations and supported the younger doctors in conducting follow-up consultations. The telehealth solution affected clinical practice – however, not in a deterministic way. The function depended on how it was used in the relationship between patient and HCP.

There are limitations to our study, as it was a single-centre study, where 16 of 28 patients completed the test period. The participants had an average age of 50 years (range 21–67). An older population could have provided different experiences with the telehealth solution, as they may not be as adept with technology. However, the six patients we included ≥ 60 years did not experience any difficulties with the use of technology. The telehealth solution was found to have potential to improve the treatment and care in the kidney transplantation process. However, it requires adjustments and further investigation to make that improvement significant. An adjustment could e.g. be to replace phone consultations with video consultations to accommodate the patients’ requests for face to face communication, and use of body language and visual inputs in the dialogue. As a strength, there could be potential for use of the telehealth solution in relation to patients with other chronic conditions or other kinds of transplant recipients.

**Conclusion**

This study is unique because, to our knowledge, it is the first study to develop and evaluate a telehealth solution in collaboration with patients and HCPs in the kidney transplantation process. New knowledge was provided in relation to the use of technology, and showed telehealth as valuable for both patients and HCPs. In a challenging time close to transplantation, the telehealth solution was easy to use, and facilitated support and reflection among patients. At consultations, the telehealth solution supported both patients and HCPs, and enabled consultations by phone. There was a need for adjustment of the appropriate time to introduce training sessions for patients, and training for the
HCPs in using the telehealth solution. The study showed that Patient Data has potential as a communication tool to improve dialogue and collaboration.

**Relevance to clinical practice**
In clinical practice, the test of the telehealth solution showed promising potential, and therefore implementation of the solution could be a significant contribution to the support and involvement of patients in standard kTX care. This would lead to new opportunities and ways to facilitate dialogue and collaboration, and improve transplantation outcome.

For patients, the telehealth solution offers a structuring and support of the self-assessment and monitoring tasks carried out at home. In the collaboration between patients and HCPs, the patients are supported in expressing how they are managing in everyday life. The workflow makes it possible for the patients to have follow-ups by phone, which brings more flexibility and freedom into their lives, because contact with the HCPs can take place from a distance, which will be timesaving for the patients.

For the HCPs, the solution implies a new way of performing their work with phone consultations and training sessions. The telehealth solution introduces a new approach to treatment and care in the transplantation process, by giving the patients a say, and starting the conversation based on the patients’ reported data and questions.

**Acknowledgements**
The authors wish to thank the patients and HCPs for participating in the study and the designers from the IT-company MedWare. This work was supported by EWII, the Danish Kidney Association, the Region of Southern Denmark, Odense University Hospital and the Danish Council of Nurses.

**Conflict of interest**
No conflicts of interest have been declared by the authors.
What does this paper contribute to the wider global clinical community?

- The findings of this study provide new knowledge about patients' experiences of undergoing a challenging period after kidney transplantation, during which telehealth can support new routines in everyday life, reflections and preparations for follow-up.
- The findings demonstrate how healthcare professionals can be supported by telehealth in patient training and follow-up consultations with patients after kidney transplantation.
- The study reveals new potential in telehealth to support patients and healthcare professionals in the kidney transplantation process, both individually and jointly, by improving dialogue and collaboration.

References


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### Tables

**Table 1**

<table>
<thead>
<tr>
<th>The telehealth solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>- An app for kidney transplant patients</td>
</tr>
<tr>
<td>- A workflow for follow-up</td>
</tr>
</tbody>
</table>

Table 1: An overview of the telehealth solution

**Table 2**

<table>
<thead>
<tr>
<th>Patient Data feature</th>
</tr>
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<tbody>
<tr>
<td>Self-monitoring measurements</td>
</tr>
<tr>
<td>---------------------------------</td>
</tr>
<tr>
<td>- Blood pressure</td>
</tr>
<tr>
<td>- Pulse</td>
</tr>
<tr>
<td>- Temperature</td>
</tr>
<tr>
<td>- Weight</td>
</tr>
<tr>
<td></td>
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Table 2: Content listed for the Patient Data feature of the app
Table 3: Participants’ characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age (Years)</th>
<th>TX type</th>
<th>No. of TX</th>
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</tr>
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<td>Living</td>
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</tr>
<tr>
<td>P6</td>
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<td>Living</td>
<td>1</td>
</tr>
<tr>
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<td>Female</td>
<td>59</td>
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<tr>
<td>P8</td>
<td>Female</td>
<td>21</td>
<td>Living</td>
<td>2</td>
</tr>
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<td>P9</td>
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<tr>
<td>P16</td>
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Figure 1: The new workflow with training sessions and use of the Patient Data feature in the app.
Figure 2: An overview of the data collection

Figure 3: Illustration of the structural analysis, during which themes emerged

Figure 4: Themes emerged in the structural analysis
Figure 1: The new workflow with training sessions and use of the Patient Data feature in the app
Testing the app and workflow for follow-up until four months post-transplantation

Training sessions 1+2 with the patients

Testing the app and workflow for follow-up until four months post-transplantation

Individual interviews with 16 patients

Paired interviews with 4 nurses

Focus group with 16 doctors
<table>
<thead>
<tr>
<th>Units of Meaning</th>
<th>Units of Significance</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is said</td>
<td>What the text is talking about</td>
<td>Emergence of key themes</td>
</tr>
<tr>
<td>“It is actually good to get the questionnaires [...] because you are reminded that you just have to deal with it [...] I get a reminder to think about it” (P13)</td>
<td>Using the Patient Data feature made patients reflect on their situation, and it prepared them for the follow-up by e.g. making the patients aware of what questions to ask</td>
<td>Telehealth improves patient reflection and collaboration</td>
</tr>
</tbody>
</table>

Figure 2: Illustration of the structural analysis where themes emerged
Figure 3: Themes emerged in the structural analysis