



BMJ Open Prospectively investigating the impact of AI on shared decision-making in post kidney transplant care (PRIMA-AI): protocol for a longitudinal qualitative study among patients, their support persons and treating physicians at a tertiary care centre

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ABSTRACT

Introduction As healthcare is shifting from a paternalistic to a patient-centred approach, medical decision making becomes more collaborative involving patients, their support persons (SPs) and physicians. Implementing shared decision-making (SDM) into clinical practice can be challenging and becomes even more complex with the introduction of artificial intelligence (AI) as a potential actant in the communicative network. Although there is more empirical research on patients' and physicians' perceptions of AI, little is known about the impact of AI on SDM. This study will help to fill this gap. To the best of our knowledge, this is the first systematic empirical investigation to prospectively assess the views of patients, their SPs and physicians on how AI affects SDM in physician–patient communication after kidney transplantation. Using a transdisciplinary approach, this study will explore the role and impact of an AI-decision support system (DSS) designed to assist with medical decision making in the clinical encounter.

Methods and analysis This is a plan to roll out a 2 year, longitudinal qualitative interview study in a German kidney transplant centre. Semi-structured interviews with patients, SPs and physicians will be conducted at baseline and in 3-, 6-, 12- and 24-month follow-up. A total of 50 patient–SP dyads and their treating physicians will be recruited at baseline. Assuming a dropout rate of 20% per year, it is anticipated that 30 patient–SP dyads will be included in the last follow-up with the aim of achieving data saturation. Interviews will be audio-recorded and transcribed verbatim. Transcripts will be analysed using framework analysis. Participants will be asked to report on their (a) communication experiences and preferences, (b) views on the influence of the AI-based DSS on the normative foundations of the use of AI in medical decision-making, focusing on agency along with trustworthiness, transparency and

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This longitudinal study will investigate the communication experiences and preferences of patients, support persons and physicians regarding the role and impact of artificial intelligence (AI) on shared decision-making (SDM) following kidney transplantation.
- ⇒ Participants are included consecutively in the study to reduce the risk of selection bias.
- ⇒ Given that this is a qualitative mono-centre study, the generalisability of the findings may be limited.
- ⇒ With this explorative, hypothesis-generating approach, this research helps fill a gap in the literature by providing currently lacking empirical data on AI-assisted SDM in order to inform future research and clinical practice.

responsibility and (c) perceptions of the use of the AI-based DSS, as well as barriers and facilitators to its implementation into routine care.

Ethics and dissemination Approval has been granted by the local ethics committee of Charité—Universitätsmedizin Berlin (EA1/177/23 on 08 August 2023). This research will be conducted in accordance with the principles of the Declaration of Helsinki (1996). The study findings will be used to develop communication guidance for physicians on how to introduce and sustainably implement AI-assisted SDM. The study results will also be used to develop lay language patient information on AI-assisted SDM. A broad dissemination strategy will help communicate the results of this research to a variety of target groups, including scientific and non-scientific audiences, to allow for a more informed discourse among different actors from policy, science and society on the role and impact of AI in physician–patient communication.

INTRODUCTION

Shared decision-making as a core component of optimal patient-centred care

In recent times, researchers, patient advocates and policymakers have increased efforts to shift healthcare from a paternalistic to a patient-centred approach, which focuses on the patient as a person to ensure the highest quality healthcare.^{1–3} This includes shared decision-making (SDM) as a collaborative process that integrates medical expertise with patients' needs and values.^{4,5} SDM has been studied in numerous clinical settings and is advocated when discussing treatment with patients diagnosed with cancer, as difficult trade-offs must be made that require patients' consideration and that it does aim to reach goal concordant care.⁶

Nonetheless, it has received comparatively little attention in solid organ transplantation such as kidney transplantation.⁷ Kidney transplantation is one of the most performed solid organ transplantations and although the application of SDM before and after kidney transplantation has been discussed, very little is known on the role of artificial intelligence (AI) on SDM and how it can be optimised.^{8,9} This is surprising, as there are numerous potentially preference-sensitive decisions that patients, support persons (SPs) and physicians may have to make, such as those related to the management of comorbidities, the impact of treatment on fertility, the use of immunosuppressants and the risk of secondary neoplasms.^{10,11}

Lack of data on the role and impact of AI on SDM

Patients vary in their preferences for involvement in decision-making.^{11–13} Factors that may influence patients' preferences for decision-making include age, gender and current life situation.¹⁴ Preferences may also change over time, for example, as patients' health status changes.¹⁵ As a result, it can be difficult for physicians to elicit patients' decision-making preferences and tailor care accordingly.¹⁵ This has become even more challenging with the introduction of AI as a potential new actant in the clinical encounter. Advanced AI systems, such as decision support systems (DSS), are rapidly making their way into medical research and practice, and research on their impact on the clinical encounter is emerging.¹⁶ In nephrology, in particular, AI could become a valuable tool to improve medical decision-making.¹⁷ Various potential use cases employing AI to predict health parameters and end points around contexts such as kidney transplantation¹⁸ and dialysis^{18–20} have been explored, including earlier versions of the machine learning models used in this study.²¹ Research has mostly focused on technical and medical challenges related to robustness and implementation, with comparatively little attention paid to the impact on the interactions between patients, SPs and physicians as well as ethical and regulatory aspects.²² Also, despite the tremendous enthusiasm surrounding the potential of AI-based DSS to improve medical prognosis, diagnosis and decision-making, there is limited evidence-based communication guidance available to support and

facilitate the implementation of AI-assisted SDM. Further research in this area could facilitate the evaluation and iterative improvement of these technologies and thus benefit healthcare.

SPs' role in SDM remains understudied

SPs are often one of the most important sources of information and advice for patients and have been shown to facilitate patient engagement in SDM.²³ Most patients prefer their SPs to have a say in treatment decisions,^{23,24} with some even preferring their SPs to lead the decision-making process.¹² Patients often feel more confident about their decisions after consulting their SPs.²⁵ The level of SP involvement often increases when patients are facing serious health issues such as kidney transplantation.^{25–27} Involving SPs can help physicians understand and respond to patients' decision-making needs and preferences.²⁸ A few studies have leveraged the connection between patients and their SPs to foster SDM.²⁷ Additionally, there is anecdotal proof indicating that crafting interventions to enhance care with a focus on both patients and their SPs can result in noteworthy enhancements in patient outcomes, such as significant improvements in lifestyle behaviours and health outcomes among survivors of breast cancer and their family members.²⁹ Nevertheless, a research gap exists regarding the involvement of SPs in SDM and the untapped potential of leveraging the patient–SP relationship to amplify patient engagement in healthcare choices.³⁰

How this research will fill this gap

By using an innovative methodology in an interdisciplinary setting, this study will provide currently lacking evidence on the role and impact of AI-based decision support in SDM. To the best of our knowledge, this is the first longitudinal study to assess the communication experiences and preferences of kidney transplant patients, their treating physicians and SPs, on how AI impacts SDM over time and how AI-assisted SDM could be implemented in routine care. Semi-structured interviews will be used to provide in-depth insights into participants' needs and preferences. Qualitative research is particularly suited to explore understudied phenomena and to evaluate the use of new interventions and their integration into standard medical care.^{31,32} Longitudinal qualitative research (LQR) can help understand and reconstruct communication experiences and preferences as they evolve over time.^{31–33} By employing an LQR design, this project will provide new insights into the role and impact of AI on SDM and how it might be channelled to promote rather than undermine or limit patient engagement in healthcare and ensure optimal, patient-centred care. The findings will be used to develop evidence-based communication strategies for AI-assisted SDM.

Objectives

This is a mono-centre longitudinal qualitative interview study employing semi-structured interviews with patients,

SPs and physicians to explore their views on the role and impact of AI-assisted SDM after kidney transplantation.

METHODS AND ANALYSIS

Study design

This is a 2 year, longitudinal qualitative interview study in a German kidney transplant centre. Semi-structured interviews with patients, SPs and physicians will be conducted at baseline and in 3, 6, 12 and 24 months. This is in line with routine care with patients attending the clinic once in a month for the first 6 months after the transplantation and once in every 3 months thereafter. It received funding for 2 years. Anticipated to start on 1 January 2024, this study is expected to end on 1 January 2026. An extension, if possible, is aimed.

This study is part of a larger randomized controlled trial described in detail elsewhere.³⁴

Semi-structured interviews will be used to ask participants about their perceptions of the decision-making process and the resulting treatment decisions. There is no to little risk of selection bias as the participants are included consecutively in the study and not selected individually by the researcher. The participants recruited at baseline and lost to follow-up will be compared. The research team checks regularly on the participants via reminders 2 days before the interview and provides maximum flexibility when scheduling interview appointments.

Inclusion and exclusion criteria

Patients will be enrolled if they have undergone an active kidney transplantation, are scheduled for routine follow-up at the participating Kidney Transplant Centre (KTC), are willing and able to participate in the study and have provided written informed consent. In addition, patients must be able to communicate in German. SPs are eligible if they are 18 years of age or older and can provide informed consent. Physicians, namely, nephrologists, who are working in the participating clinic and responsible for the patients' after-care routine and using an existing AI-based DSS, are also eligible to participate in the study. This DSS assesses the risk of kidney transplant patients for transplant loss, rejections and infections within the next 90 days.²¹ The AI algorithm of the DSS is rigorously developed and pretested before deployment and is monitored by the study team of the technical subproject. The system is based on a Gradient Boosted Regression Tree (GBRT) and has been tested on retrospective data. Included patients will be randomised and assigned to the intervention (treatment with AI) or control group (treatment without AI) to enable comparisons. Within the post kidney transplant care AI research project, there is a quantitative substudy that uses clinical data to assess graft survival and complications such as graft loss and tract infection.

Sample size and recruitment

A total of 50 patient–SP dyads and their treating physicians will be recruited at baseline. Assuming a dropout rate of 20% per year, it is anticipated that 30 patient–SP dyads and 20 treating physicians will be included in the final follow-up. The age and gender of non-consenting patient–SP dyads will be recorded to investigate consent bias.

Eligible patients will be identified from clinic lists prior to their appointment by the treating physician who will inform patients and SPs about the study and ask for consent to speak with a member of the research team who will provide them with verbal and written study information, obtain informed consent and conduct the interview. Consent will also be obtained from the SP accompanying the patient to the appointment. If SPs are not present, the patients will be asked to give a recruitment packet to their SP. Applicants are aware of the need to ensure that data collection does not interfere with the functioning of the clinic. The research team will liaise with clinic staff and provide appropriate training to all research support staff to ensure that the recruitment process is efficient and runs smoothly.

Eligible physicians will be identified by the research team from clinic lists, will be invited to participate and will be provided with verbal and written study information and consent forms.

Data collection

It is planned that data collection for the baseline and 12- and 24-month follow-up interviews will be conducted in person. Data collection for the 3- and 6-month follow-up interviews will be conducted by telephone to reduce the research-related burden on participants. Patients may also appreciate being interviewed by telephone, as they may feel more relaxed when interviewed in this way and may find it easier to rearrange a telephone interview rather than a face-to-face interview.^{35–40} Participants will be able to choose the interview mode according to their preferences. They will be encouraged to express their views on how the AI-based DSS has impacted the physician–patient–SP communication and the decision-making process, in the way they prefer. The narrative approach will be used to elicit the variety and interplay of potential factors related to physician–patient communication in this area, followed by semi-structured questions.³¹ At the end of the interview, participants are given the opportunity to provide additional comments. The research team received intensive training of an interdisciplinary expert team in conducting these interviews to reduce bias in question framing, administration and interpretation. Standardised interview protocols are being used and three researchers will inductively and then deductively code the transcripts independently.

Interview guide and questions

The interview guide was developed based on a literature review and discussions among the interdisciplinary

research team, which included experts in medicine, communication and behavioural science, health services research, ethics and medical informatics. The preliminary interview guide can be found in online supplemental appendix 1. Participants are asked about:

1. Their communication experiences and preferences related to the use of AI in SDM: This will help explore and understand changes in preferred and perceived patient and SP involvement in decision-making, the role and impact of the AI-based DSS in the medical encounter, with a particular focus on AI potentially creating information asymmetries, but also transparency within the process of decision-making, as well as in understanding risks associated with treatment options and acceptance of AI-assisted SDM.
2. Their views on the impact of AI-based decision support on the normative foundations of the use of AI in medical decision-making: Participants will be asked questions about their perceptions of concepts such as trust, transparency or agency (defined as an agent with the capacity to act, and agency denotes the exercise or manifestation of this capacity).⁴¹ They will be asked how they evaluate the tool's outputs and how these outputs are related to their physicians' judgements. Participants may also be asked about their views on the validity, effectiveness and perceived likelihood of error of the system, as well as who is morally and legally responsible for individual treatment decisions.
3. Their perceptions of the use of AI-based decision support in routine care and the barriers and facilitators to its implementation: Participants will be asked about their perceptions of acceptability, ease of use, agreement with specific components of the system's outputs and self-efficacy (ie, belief that one can understand and use the system's outputs). Participants will also be asked about other potential barriers to the use of AI in clinical practice, such as environmental factors like time pressure.

Sociodemographic and disease variables gathered from patients and SPs will include gender, marital status, country of birth, zip code, highest level of education completed, income and perceived health status. SPs will also be asked to self-report their relationship with the patient and whether they live with the patient. All socio-demographic and disease variables will be assessed at baseline and follow-up to account for changes in participants' circumstances that may affect their views and experiences.¹⁴ With patients' permission, information on diagnosis, disease stage and treatments received will be obtained from patients' medical records to reduce the research-related burden on patients.

Data analysis

Interviews will be transcribed verbatim, pseudomised and checked for accuracy by a researcher before being analysed using framework analysis. This approach belongs to a broad family of qualitative data analysis methods often related to 'thematic analysis' or 'qualitative content

analysis'.⁴² As suggested by these approaches, both manifest and latent contents will be analysed, and descriptive and explanatory conclusions will be drawn from the data.⁴³ This qualitative data analysis method will provide a systematic model for mapping and interpreting the data, which is considered appropriate for developing a profound in-depth understanding of participants' communication experiences and preferences.^{44 45} This approach involves analysing both manifest and latent contents in order to draw descriptive and explanatory conclusions from the data.⁴³ Each interview will serve as a unit of analysis, and a journal of reasoning and additional ideas regarding data analysis will ensure transparency of the coding process. Coding will be conducted by two researchers and discussed during regular meetings of the interdisciplinary research team. ATLAS.ti will be used to support the analysis. It is anticipated that data saturation will be achieved with a sample of 30 kidney transplant recipients. Demographics will be presented using appropriate summary statistics.

Patient and public involvement

Patient representatives were involved in conceptualising the study as well as in piloting and further refining study materials, including study information and interview guide. Patients were also involved in piloting the AI-based DSS used in this study. In addition to that, patient representatives are members of the scientific advisory board. The study findings will be used to develop communication guidance for physicians on how to introduce and sustainably implement AI-assisted SDM. The study results will also be used to develop lay language patient information on AI-assisted SDM. A broad dissemination strategy will help communicate the results of this research to a variety of target groups, including scientific and non-scientific audiences, to allow for a more informed discourse among different actors from policy, science and society on the role and impact of AI in physician-patient communication.

Ethics and dissemination

This study will be conducted in accordance with the tenets of the Declaration of Helsinki (1996). The results of this research will be disseminated to various groups, including scientific and non-scientific audiences, through publications in newspapers, public science journals and institutional press releases. Findings will also be presented at congresses, symposia and science communication competitions and through social media channels. Interdisciplinary workshops and communication guidelines on AI-assisted SDM for clinicians and patients will be developed to facilitate the translation of research findings into clinical practice. The results will be summarised in a common governance perspective, highlighting points of connection and interrelatedness of the findings. This will further support an informed discourse between different stakeholders from policy, research and society on the role and impact of AI in medical encounters. Given

the funding period, the study can only conduct a 2-year follow-up.

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