“Because human interaction still needs to be there” – Expectations and needs of kidney transplant patients and their support persons regarding AI-based DSS: A qualitative study at a tertiary care center

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Zeineb Sassi[1] MSc; Sascha Eickmann[2] PhD; Roland Roller[3] PhD; Bilgin Osmanodja[4] MD; Jakob Joachim Spencker[5] MD, MA; Ömer Ege Ömero?lu[4] MD; Aljoscha Burchardt[3] PhD; Michael Hahn[6] MTh; Peter Dabrock[6] Prof Dr; Sebastian Möller[3, 7] Prof Dr; Klemens Budde[4] Prof Dr; Anne Herrmann[8, 9, 10] Prof Dr

[1]Department of Epidemiology and Preventive Medicine, Medical Sociology Faculty of Medicine University of Regensburg Regensburg DE
[2] Institute of General Practice and Palliative Medicine Medical School Hannover Hannover DE
[3] German Research Center for Artificial Intelligence (DFKI) Berlin DE
[4] Department of Nephrology and Medical Intensive Care Charité - Universitätsmedizin Berlin, Corporate Member of Free University of Berlin, Berlin Institute of Health Berlin DE
[5]Medical Doctor Department of Nephrology and Medical Intensive Care Charité - Universitätsmedizin Berlin, Corporate Member of Free University of Berlin, Berlin Institute of Health, Humboldt- University of Berlin Berlin DE
[6] Institute for Systematic Theology II (Ethics) Friedrich-Alexander-Universität Erlangen-Nürnberg (FAU) Nuremberg DE
[7] Quality and Usability Lab Technical University of Berlin Berlin DE
[8]Department of Epidemiology and Preventive Medicine, Medical Sociology Faculty of Medicine University Regensburg Regensburg DE
[9]Department of Internal Medicine III University Hospital Regensburg Regensburg DE
[10] Bavarian Centre for Cancer Research (BZKF) Regensburg DE

Corresponding Author:
Zeineb Sassi MSc
Department of Epidemiology and Preventive Medicine, Medical Sociology
Faculty of Medicine
University of Regensburg
Dr. Gessler – Straße 17
Regensburg
DE

Abstract

Background: Artificial intelligence (AI) is increasingly used to support many areas in medicine, including clinical decision-making. Although AI-based decision support systems (DSS) offer benefits such as early risk detection and treatment optimization, little is known about how patients and their support persons (SPs) perceive the role and impact of these tools.

Objective: This study explores expectations and informational needs of kidney transplant patients and SPs regarding the use of AI-assisted DSS in clinical care and its impact on shared decision-making (SDM).

Methods: As part of a longitudinal qualitative study, 36 semi-structured interviews with kidney transplant patients and their SPs were conducted at a German kidney transplant centre (KTC). Participants were asked about their views on the role and expectation of AI in their post-transplant care and how they perceive trust, communication and (shared) decision-making with the use of AI. Interviews were transcribed, pseudonymized, and analysed using framework analysis.

Results: Participants valued AI for identifying risks related to transplant loss, rejection, and infections and supporting physicians with data-driven treatment recommendations but emphasized that final decisions should remain with physicians. Many feared AI could depersonalize care and negatively impact physician-patient communication due to the lack of “human touch”. Participants expressed limited understanding of how AI-DSS work and a need for simple, accessible explanations on the operations of AI-based DSS (e.g. informational leaflets). While most participants doubted that AI could replicate empathy, some acknowledged that AI might be perceived as more attentive and caring than rushed physicians, who often have a lack of time for adequate communication with their patients.

Conclusions: Patients and SPs advocate for the use of AI in follow-up care when it enhances rather than replaces human decision-making. Trust and acceptance hinge on transparency, accountability, and preserving the “human touch” in clinical

encounters. Educational tools are needed to better inform patients about how AI could be used to support optimal care.

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Authors: Zeineb Sassi[1], Sascha Eickmann[2], Roland Roller[3], Bilgin Osmanodja[4], Jakob J. Spencker[4], Ömer Ege Ömeroğlu[4], Aljoscha Burchardt[3], Michael Hahn[5], Peter Dabrock[5], Sebastian Möller[36], Klemens Budde[4], Anne Herrmann[178]

1. Department of Epidemiology and Preventive Medicine, Medical Sociology, University Regensburg, Germany
2. Institute of General Practice and Palliative Medicine, Medical School Hannover, Hannover, Germany
3. German Research Center for Artificial Intelligence (DFKI), Berlin, Germany
4. Department of Nephrology and Medical Intensive Care, Charité - Universitätsmedizin Berlin, Corporate Member of Free University of Berlin, Berlin Institute of Health, Humboldt-University of Berlin, Berlin, Germany
5. Institute for Systematic Theology II (Ethics), Friedrich-Alexander-Universität Erlangen-Nürnberg (FAU), Erlangen, Germany
6. Quality and Usability Lab, Technical University of Berlin, Berlin, Germany
7. Department of Internal Medicine III, University Hospital Regensburg, Regensburg, Germany
8. Bavarian Centre for Cancer Research (BZKF)

Corresponding author:
Zeineb Sassi
Dr. Gessler – Straße 17
93051 Regensburg
Zeineb.sassi@klinik.uni-regensburg.de

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Conclusions: Patients and SPs advocate for the use of AI in follow-up care when it enhances rather than replaces human decision-making. Trust and acceptance hinge on transparency, accountability, and preserving the "human touch" in clinical encounters. Educational tools are needed to better inform patients about how AI could be used to support optimal care.

Introduction

The Impact of Artificial Intelligence on Medical Decision Support in Nephrology

Artificial Intelligence (AI) has the potential to transform healthcare by improving diagnostic accuracy, supporting medical decision-making and enhancing patient care [1]. In various medical fields such as radiology, oncology, and cardiology [2], the successful use of AI has supported early detection, personalized treatment planning, and risk prediction, providing a comparative context for its emerging role in nephrology where AI-based decision support systems (DSS) are growing as valuable tools to assist healthcare professionals. In the context of post-transplant care, particularly for kidney transplants, these systems may predict outcomes such as graft survival, detect patients at risk for rejection and optimize medication regimens. They can improve patient management by identifying trends and patterns in patient data that may not be easily recognized by human physicians [3]. Post-transplant care involves complex, long-term decision-making processes that require close monitoring and individualized treatment adjustments. For example, managing immunosuppressive therapy demands high levels of patient-physician interaction, making kidney transplant recipients particularly sensitive to changes introduced by AI-based DSS [1–4]. By analyzing extensive patient data, AI systems provide insights—such as predictive modeling for graft survival—that complement traditional clinical assessments [5]. While AI offers significant potential to enhance post-transplant care, integrating these technologies into clinical practice presents several challenges. Effective AI systems depend on high-quality standardized data. However, healthcare data often originate from diverse sources with varying formats and standards, leading to interoperability and integration challenges [3, 6, 7]. Such lack of standardization impedes AI model training and deployment,

potentially compromising their accuracy and reliability [8]. Moy et. al.‘s scoping review highlights that patients' needs and expectations are often overlooked in the development and application of AI technologies, underscoring the critical need to incorporate patients and end-user perspectives in healthcare AI design [9, 10]. Patients are rarely involved in the design of AI systems and often have a limited understanding of how these technologies work, including their underlying data and limitations. This lack of knowledge may foster uncertainty and unaddressed concerns, which in turn can undermine trust [9, 10]. To counteract this, it is essential to identify and integrate the expectations and needs of patients and their SPs, as their preferences directly shape the acceptance and effectiveness of AI technologies in healthcare.

Shared Decision Making (SDM): The importance of understanding patient preferences and concerns in medical decisions

SDM refers to a collaborative process in which patients and physicians jointly make treatment decisions, with patient values and preferences serving as a central guiding principle [11] . In the context of AI, SDM gains particular importance, since patients often hold complex and ambivalent views on the role of AI in their care [12]. In post-kidney transplant follow-up care, patient engagement in SDM is vital, as treatment decisions often involve balancing complex risks, such as graft rejection [13, 14]. Patients fear that AI may reduce the “human touch” of healthcare, leading to depersonalized treatment [15, 16]. They also express worries about data privacy and security [17, 18], potential diagnostic errors or misjudgments in rapidly changing health conditions [18–20] , and a lack of transparency in algorithmic decision-making [20, 21] . Such concerns highlight the need to understand patient perspectives and integrate them into SDM, as acceptance of AI-based decision support depends on patients’ trust and willingness to engage in these technologies.

While prior literature has addressed general patient attitudes toward AI in healthcare, empirical evidence on patient and SP expectations regarding AI-based SDM in nephrology remains lacking. Most studies focus on physician perspectives, leaving patient and SP voices underrepresented [9]. In Germany, there is no qualitative evidence on experiences with AI-based care in high-stakes contexts such as kidney transplantation. This study addresses this gap by providing first insights into expectations and needs related to AI-based DSS within a German transplant center.

SPs role in AI-assisted SDM matters

SPs, such as family members are key sources of patients’ health information and play vital roles in diagnosis, treatment, and recovery [22]. Previous research indicated that surrogate decision makers, such as family members, make approximately 75% of the decisions for hospitalized patients with life-threatening illnesses [23]. Despite the importance of SPs in patient care, their perspectives—particularly in post-transplant contexts—remain largely underexplored [24, 25].
In addition to that, SPs face unique concerns when participating in decision-making throughout a patient’s healthcare journey with these concerns being intensified with the introduction of AI. Navigating complex medical AI systems adds both emotional and practical challenges, as SPs must support patients while also understanding and interpreting AI-generated data and recommendations [4]. One prominent concern for SPs is information overload, where frequent AI alerts and large

volumes of data can create cognitive stress rather than support. SPs also worry that AI may weaken the emotional connection between patients and their treating physician, potentially leading to feelings of isolation [26, 27]. Additionally, SPs fear that overreliance on AI may reduce personalized care in medical decision-making [28], and they may feel uncertain about endorsing treatment decisions if they do not understand how AI functions or how it influences patient care [29].
In all, these emotional and practical concerns illustrate that SPs are not only critical to patient care but also pivotal stakeholders in AI-based SDM. Understanding and integrating their perspectives and expectations is therefore essential to ensure that AI systems support both patients and their SPs effectively.

Patient-centered care through studying patients' and SPs' perspectives on AI-based decision-making

AI-based DSS are increasingly applied in high-stakes medical contexts, including post-transplant care, where they can support complex clinical decisions. The effectiveness of these systems, however, depends not only on technical performance but also on their alignment with patient-centered care principles, particularly SDM, which integrates patient preferences, values, and the perspectives of SPs [11, 23, 30].

Patients and SPs bring their own expectations and concerns to medical decision-making, which strongly influence the acceptance of AI. Previous research indicated that mistrust in medical AI is common and often stems from limited knowledge of its functioning, personal experiences, and concerns about data privacy, potential errors, and depersonalization of care [31]. SPs—who frequently act as surrogate decision makers and key sources of patient health information [32]—face additional challenges, including the cognitive burden of AI-generated information, uncertainty about AI's impact on patient outcomes, and anxiety that AI may reduce personalized care [4, 24, 26–29, 32]. Emotions such as anxiety play a decisive role in shaping SPs' engagement with AI-based technologies, influencing whether they accept or reject these tools [32] .

Despite these insights, qualitative research examining how AI-based DSS affects SDM in nephrology remains scarce. Existing studies often focus on general patient attitudes or physician perspectives, leaving the voices of patients and SPs underrepresented. This study addresses this gap by exploring the expectations and needs of patients and SPs regarding AI-based DSS in post-transplant care. By capturing these perspectives, the research aims to inform the development and implementation of AI technologies that support SDM, enhance patient autonomy, foster trust, and align with patient-centered care principles, such as transparency and accountability.

Methods and Analysis

Study design

This study is part of a 2-year, longitudinal qualitative interview study conducted as part of an interventional study in a German kidney transplant center (KTC). The protocols for both the interventional study as well as the nested interview-study have been published before data collection and the study has been registered (NCT06056518) [13, 14]. Semi-structured interviews with patients

and their support persons were conducted at baseline and are reported here. The AI-based DSS applied in this study assesses the risk of kidney transplant patients for graft loss within the upcoming 360 days [28]. The system has been rigorously developed and pretested before deployment and is monitored by a team of technicians supporting the technical subproject of this study [28, 33].

Sample and recruitment

Eligible patients were identified by study physicians after applying all inclusion and exclusion criteria to the entire transplant cohort of the KTC. All patients were provided written, informed consent for the study intervention as well as the interview study. Written informed consent was also obtained from the SP accompanying the patient to the appointment [14]. The ethics committee of Charité - Universitätsmedizin Berlin approved this study (EA1/177/23, date of approval 19.09.2023).

Inclusion and exclusion criteria

Patients were eligible if they were 18 years or older, had undergone kidney transplantation and had a functioning kidney graft with an estimated glomerular filtration rate <30 ml/min/1.73m^2. They were scheduled for routine follow-up at the participating Kidney Transplant Center (KTC) and had provided written informed consent. Patients and their SPs were able to communicate in German. SPs were eligible if they were 18 years of age or older and could provide informed consent.

Data collection

Consenting patients and SPs were contacted by a researcher to arrange an interview appointment. Participants could choose the interview mode according to their preferences. All participants indicated that they preferred to be interviewed via telephone. Interviews were scheduled according to the patients' and SPs' availability, to reduce research-related burden on participants. With semi-structured interviews, participants were encouraged to express their views on how AI-based DSS may impact physician–patient–SP communication and the decision-making process, in the way they prefer. The narrative approach was used to elicit the variety and interplay of potential factors related to physician–patient communication in this area. At the end of the interview, participants were given the opportunity to provide additional comments or questions. The researchers received intensive training of an interdisciplinary expert team in conducting these interviews to reduce bias in question framing, administration, and interpretation. Additionally, standardized interview protocols were used to document each interview.

Interviews

The interview guide was developed based on a literature review [34, 35] and discussions among the interdisciplinary research team, which included experts in medicine, communication and behavioral science, health services research, ethics, and computer science. Participants were asked about their expectations regarding the use of AI-based DSS, particularly in the context of SDM. Topics included patients' communication preferences, perceptions of trust, transparency, and responsibility in relation to AI-based DSS, as well as anticipated benefits, risks, and barriers to implementing this tool in routine care [14].

Data analysis

Interviews were transcribed verbatim and pseudonymized. Two trained researchers reviewed each transcript for accuracy by comparing it against the original audio recordings, correcting any transcription errors and ensuring completeness.

The data were then analyzed using framework analysis, which allows for both inductive and deductive coding [36]. Initially, two researchers conducted independent open coding, identifying

concepts and patterns emerging directly from the data (inductive coding). Based on these initial insights and the study's guiding research questions, a framework of analytical categories was developed and applied to the data (deductive coding) [36].
To enhance the credibility and consistency of the coding process, the two researchers discussed discrepancies and reached consensus through iterative refinement of the coding framework. The qualitative data management software ATLAS.ti was used to organize, code, and retrieve relevant data segments efficiently. The results of the analysis were discussed in close collaboration with the entire interdisciplinary research team.

Results

A total of 36 participants were included in the final analysis. Of these, 61% (n = 22) were male and 39% (n = 14) were female. Interviews were conducted together with an SP in 58% (n = 21) of cases; among those, 9 SPs (43%) were identified as the participant's spouse**.** 42% (n = 15) of the patients stated that they preferred not to involve an SP in the call. Participants' ages ranged from 37 to 74 years (Mean = 57, SD = 11). 16 participants resided in Berlin, while 20 lived elsewhere in Germany.

The duration of the interviews varied, with an average mean length of 34 min (SD = 14 min). The median interview length was 32 min.

Table 1. Patients' sociodemographic and transplantation-related characteristics

Characteristic	Participant (n = 36)
Age in years, mean (SD)	57 (11)
Range	37-74
Gender	
Male	61% (22)
Female	39% (14)
Involvement of SP	
yes	58% (21)
spouse	43% (9)
other	57% (12)
no	42% (15)
Time since kidney transplantation	
<1 year	0% (0)

1-5 years	11% (4)
5-10 years	17% (6)
>10 years	72% (26)
Place of residence	
Berlin	44% (16)
Germany, not Berlin	56% (20)

Patient's perceived benefits and expectations on the use of AI-based decision making

Patients expressed mixed feelings when asked what they generally associate with AI in healthcare. Some (42%) were open and optimistic, viewing AI as a helpful tool that could support them and their physicians by providing additional insights for individualized treatment and improved SDM. A commonly mentioned benefit was AI's ability to process vast amounts of data quickly and potentially identify treatment options or risks that a human doctor might overlook. As one participant explained:
"It can be a help, like if it reminds the doctor that a certain value is off and that medication B shouldn't be given. That's a help. But in the end, if it still gets prescribed, well, then it's a human error" (male, 57 y.o.).
Patients also recognized the potential of AI to enhance communication between healthcare providers by transferring patient data, which could enable more coordinated and informed care.
Another participant emphasized AI's potential to broaden clinical perspectives, stating that it may "*show people possibilities that might not have come to their minds at that moment" (male, 55 y.o.).*
Importantly, participants emphasized that they expect the AI not to make decisions independently.
"*Yes, together with the doctor, yes—on its own, no," (male, 71 y.o.)* summarized one patient when asked about AI making medical decisions regarding his treatment. Another commented, *"Definitely to be part of the decision-making—that's exactly the trend that's developing right now" (male, 63 y.o.)*, underscoring the growing desire for collaborative approaches in which AI supports, but, according to most participants, does not replace human judgment and patient involvement.

While many acknowledged that AI can provide rapid and comprehensive analysis, potentially identifying patterns in lab results or drawing insights from large datasets, participants emphasized that AI should only serve as a supportive tool in the decision-making process. As one patient with her SP put it, "*Ultimately, the doctor should still be the one in charge of my treatment decision. The AI should just support them. That's my view" (female, 50 y.o.).*

Another participant praised AI's analytical capabilities but highlighted the importance of human oversight: *"The AI has much faster access to a lot more data than my treating physician. […] It might raise a red flag when something is off, but then the doctor looks at it and says, 'Okay, what's going on here?' […] And then we go back to the doctor-patient conversation, trust, competence. That's [the] key" (male, 65 y.o.).*

Patients' and SPs' fears and concerns regarding AI-based DSS

Most patients (78%) expressed concerns about AI's inability to replicate the human qualities of empathy and individualized care, a care that meets their unique needs, preferences, and values to understand their decision preferences. They feared that AI-based care including decision support may create distance between them and their treating physicians, who, according to the patients, are better equipped to understand their concerns, unique circumstances, medical history, and preferences, avoiding a one-size-fits-all approach. They emphasized that while AI could be helpful, physicians should not rely on “machines” and thus not leave the decision solely to the AI-based DSS. The majority of patients and their SPs (83%) emphasized that their trust in final decisions regarding their care should always rest with their treating physician. Physicians should never rely too heavily on automated systems, as one patient noted:

[…]”It should never end up in a situation where the doctor no longer thinks and it becomes an automatic process, and if we were to be very dystopian, that eventually no doctor would be there at all, but rather we would feed data to the AI, which then says, "Do this and that," and we would only execute it […] So, it [the DSS] should never replace a doctor!” (male, 57 y.o.)

In addition to that, patients and their SPs also identified several weaknesses and potential fears in relation to AI-supported DSS. The most common concerns were related to the lack of “human touch” (80%), referring to the absence of empathy, emotional understanding, and personalized communication that physicians offer in navigating complex treatment decisions.

“Because human interaction still needs to be there […] People don’t want to only talk to a computer. - They also want to have the human element” (male, 48 y.o.)

Participants also expressed concerns about the potential for AI to make errors or miss important context about a patient’s condition. Many patients feared that overreliance on AI could lead to a loss of personalized care (78%) and treatment decisions, where their unique needs and circumstances might be overlooked.

The Impact of patients’ and SPs’ knowledge gaps on AI-based DSS

Notably, many patients and SPs expressed limited understanding of how AI-based DSS functions within medical settings (86%), which often led to skepticism and uncertainty. A recurring theme was the concern about data privacy and the potential misuse of sensitive health information. Several participants voiced fears about who has access to their medical data and how it is processed, particularly if AI systems are used without sufficient transparency or oversight.

One participant reflected this concern, saying, “*If data about your body, your health, your care is stored and evaluated, it’s fine - as long as it’s not misused and that’s my fear when I say this” (female, 72 y.o.).*

Another patient noted, “*I hope [AI] turns out to be positive. But it could also go the other way. After everything we’ve experienced in recent years, I’m not sure whether I could really put my trust in it.* [...]

Ultimately, the final decision should always be ours" [Patient, SP and physician] (female, 38 y.o.) This quote captures the cautious optimism expressed by many–acknowledging potential benefits while remaining wary of unintended consequences or overreliance on technology.

In addition, patients consistently emphasized the importance of transparent and accessible information about how AI is used in their post-transplant care. They expressed a desire to better understand the technology's role, benefits, and risks to feel more secure and involved in decision-making processes. Transparency, for many, was a key factor in building trust in AI-assisted SDM.

Overall, while patients recognized AI's potential to contribute valuable insights, many stressed that only a physician can contextualize these insights and make appropriate, individualized decisions through direct conversation and shared understanding. According to most of the participants, trust in AI therefore depends not just on its accuracy but on how clearly its role is communicated and how responsibly it is integrated into the decision-making process.

Perceived impact of AI-based DSS on SDM

Across interviews, participants expressed a strong desire to actively participate in the decision-making process between physicians and the AI-based DSS. Rather than seeing AI as a substitute for the physician or the patient's perspective, many envisioned a triadic model of decision-making involving the patient and the SP as one unit, the physician, and the AI-based DSS. This approach was perceived as enriching the process, increasing trust, and reinforcing the patient's role in their care.

One patient articulated this ideal of SDM powerfully, *"[…] But if the results are reviewed together and I, as the patient with my partner, can also help decide – then there are three things that can be brought into it: the technology, the doctor, and myself as* the patient" *(male, 57 y.o.).*

Across multiple interviews, patients and their SPs consistently emphasized the importance of transparency in AI-based decision-making. They expressed a desire to understand not only how the AI system itself generates recommendations, but also how these recommendations are integrated into their physician's decision-making process. For instance, one SP described an ideal scenario in which AI would become part of a joint consultation, allowing both patient and physician to review and discuss the AI's input together: *"We [the patient and I] would find it good if we could look at the AI together with the doctor, for example, to see what data it has about him. If I had the chance to look at the computer, too. I would like that – that both the doctor and I see the same thing. So really a kind of teamwork with the AI, the doctor, and us*" (*male, 63 y.o.).*

At the same time, not all participants felt sufficiently included in current decision-making processes. Some reported a lack of involvement and insufficient dialogue about treatment choices – particularly in relation to potential AI-based recommendations: *"If I were included, I would want to be asked: Did you understand this? Is it okay for you? - But I don't think I will be asked that (female, 38 y.o.)."*

Table 2. Main themes derived from the interview data

Theme	Participant (n= 36)
Previous experience with AI-based medical devices	
yes	58% (21)
male	90% (19)
female	10% (2)
no	42% (15)
General attitude towards the inclusion of AI in healthcare	
Rather Optimistic	42% (15)
Rather pessimistic	14% (5)
mixed	44% (16)
Trust in AI-based DSS regarding final treatment decisions	
More trust in AI-based DSS	0% (0)
More trust in treating physician	83% (30)
mixed	17% (6)
Concerns expressed with the integration of AI in the treatment	
Perceived personal lack of knowledge about the AI-assisted DSS	86% (31)
Perceived lack of “human touch” (e.g. empathy) of treatment	80% (29)
Fear of less personalized treatment	78 % (28)
Other	44% (16)
Perceived impact of AI on SDM	
Desire to include AI-assisted DSS in SDM	62% (22)
Desire for more transparency on how the AI-based DSS generates treatment recommendations	86% (31)
No perceived impact	0% (0)

In summary, AI was seen as having the potential to enhance SDM, especially when its use facilitates dialogue, offers additional perspectives, or helps physicians explain and justify their decisions. However, participants made clear that realizing this potential depends on the physician’s

communication style and the extent to which the patient has been introduced and informed about the AI and is treated as an equal partner in the decision-making process.

Discussion

This qualitative study provides insights into how kidney transplant patients and their SPs perceive AI-based DSS in their post-transplant care, especially in the context of SDM. While participants largely welcomed AI as a supportive tool, they consistently emphasized the irreplaceable role of human judgment and the fear of the loss of “human touch”, meaning emotional connection and individualized care. These findings point to a critical challenge for future implementation: how to meaningfully integrate AI into the clinical encounter without eroding the essential elements of SDM: Charles et al. [37] define SDM as an interactive process requiring at least two active participants, typically the physician and the patient, each contributing to the decision with their expertise and values. In our findings, patients envisioned a triadic model involving the patient, the SP and the treating physicians, in which AI serves not as a third decision-maker but as an adjunct participant, one that provides additional information but does not replace human actors. This aligns with Elwyn et al.’s model of SDM, which underscores the importance of team talk, option talk, and decision talk, emphasizing collaborative deliberation based on trust and clarity [11]. Yet, our participants made clear that this process depends heavily on whether AI can be transparently explained and meaningfully integrated into conversations, without diminishing their own agency or emotional safety.

Patient- and human-centered AI: Empowering patients through co-design

Many patients lack understanding of how AI-based DSS work, revealing a clear need for patient-focused approaches to AI development. Patient-centered and human-centered AI aims to ensure that these technologies are designed not merely for efficiency, but to align with patients’ values, expectations, and experiences. Co-design is crucial in this context: involving patients as partners in the development process helps ensure that AI systems are understandable, transparent, and sensitive to patients’ concerns. International efforts, such as the European Commission’s Ethics Guidelines for Trustworthy AI, stress that AI must be explicable, human-centered, and designed with stakeholder engagement, foremost including patients. In addition to that, there is a growing recognition that explainable AI (XAI) must be designed not only for regulatory transparency but also for patient comprehension [38]. While Initiatives such as the SPIRIT-AI guidelines [39] or the CONSORT-AI [40] extension have focused on professional audiences, future efforts must expand to systematically include patients in shaping how AI fits into care processes and SDM. Without active efforts to co-design and involve patients in development and train clinicians in communicating about AI, there is a risk of eroding trust or creating asymmetries in SDM. Thus, the findings reinforce that effective integration of AI into SDM is not only a technical challenge but a collaborative and communicative one. For AI to genuinely promote SDM in transplant care, it must be introduced in a

way that strengthens, rather than displaces the patient-SP-physician relationship.

The “human touch” in the age of AI: Empathy, emotion, and patient perspectives

Interestingly, while many participants doubted that AI could replicate the so-called "human touch," this skepticism merits deeper examination. The term “human touch” was used by participants to denote a complex interplay of empathy, emotional understanding, nonverbal cues, and situational sensitivity - aspects that are perceived as central to patient-centered care. This translates into the ability to recognize and respond to a patient's emotional state, convey reassurance, and build rapport–capacities typically associated with human caregivers. According to most of the participants (73%), the concept of empathy is presumed to be uniquely human. However, emerging studies suggest that AI-based chatbots or support tools may sometimes be perceived as more empathetic or nonjudgmental than rushed or fatigued physicians, especially in structured communication contexts (e.g., symptom checks, emotional support) [8, 41–43]. While our participants viewed AI as inherently lacking empathy, it remains unclear whether this is an ontological limitation or simply a function of current design and communication strategies. This area warrants further investigation, as the perceived emotional competence of AI may shape both trust and acceptance.

AI literacy and the “AI package leaflet”: Building understanding and trust through transparent information

Moreover, the findings highlight that knowledge gaps are a significant barrier to the acceptance of AI in SDM. Patients and SPs often expressed uncertainty about how AI arrives at its recommendations, who controls the data, and what exactly the system "knows" about them. To address this, structured informational tools, such as package leaflets for AI systems, may help bridge this gap [28, 33, 44] . Such a tool might include: The purpose of the AI-DSS, what type of data it uses, how it generates risk estimates, what its limitations are, how well it performs for which specific subgroups and a brief disclaimer of who is accountable for final decisions. This concept aligns with emerging international efforts to enhance algorithmic transparency and patient-centered communication [39, 40]. In this light, an “AI package leaflet” could serve as a translation interface between technical system design and patient-centered AI-supported care and decision-making. It would also support the ethical imperative of informed consent, which in the context of AI not only requires understanding treatment options but also the nature and role of digital tools involved [45]. Ideally, such information should also be co-designed with patients, evaluated for health literacy, and tested in different clinical settings to ensure it meets the diverse informational needs of users [45]. Transparent, accessible information like this is key to supporting informed consent, fostering trust, and empowering patients to participate actively in AI-assisted SDM.

Conclusion

Our findings support previous research suggesting that patients’ needs and expectations regarding AI technologies have often not been explicitly studied [9, 10]. In the context of nephrology and SDM,

our study shows that patients and their SPs particularly emphasize concerns about a potential loss of “human touch” in treatment due to increased reliance on AI, as well as a lack of trust in AI-based DSS stemming from limited understanding of these technologies [31, 46].

However, participants welcomed AI-based DSS as a supportive tool – but emphasized its role as a supplement in SDM, though not a replacement for human judgment. Hereby, the successful integration of AI-based DSS into post-transplant care may depend less on technical precision but on its alignment with the interpersonal and ethical foundations of SDM, including the preservation of the “human touch”.

Uncertainty about how AI works, its potential benefits and its challenges for medical encounters revealed patients' knowledge gaps, highlighting the need for further patient involvement in the design of these tools as well as improved patient information strategies such as AI "package leaflets". Such strategies may strengthen patient trust through improved patient-physician communication on AI and help patients and SPs in becoming involved in decisions related to their care. Future efforts should focus on developing and testing interventions that help ensure that technological innovations support the delivery of optimal patient-centered care.

Limitations

Limitations of this study may be the potential influence of social desirability and interviewer effects. Given the sensitive nature of discussing personal health decisions and emerging technologies such as AI, participants may have been inclined to express favorable views or to align their responses with what they perceived as the expectations of the interviewer. Also, participants’ baseline familiarity with AI or digital health tools was not systematically assessed. As a result, differences in technological literacy may have influenced how participants understood and reflected upon the role of AI in shared decision-making processes. The study is subject to recall bias as participants reflected retrospectively on clinical appointments. The sample was recruited purposefully at a single German Transplant Center, which limits the generalizability of the findings to broader transplant populations.

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Author contributions

AH devised the project, together with PD, KB and SM. ZS wrote the manuscript with input from all authors. AB, RR, BO, JJS, ÖEÖ, MH and SE critically reviewed the article and added remarks on

their field of expertise. ZS accepts full responsibility for the finished work and controlled the decision to publish.

Conflicts of Interest

None declared.

Data Availability

The datasets generated and analyzed during the current study are available from the corresponding author on reasonable request.

Abbreviations

AI: Artificial Intelligence

DSS: Decision Support System

SDM: Shared Decision-Making

SP: Support Person

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Supplementary Files

TOC/Feature image for homepages

Patient meets AI.