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Decision coaching for people with kidney failure: A case study

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Abstract

Background: Little is known about the usefulness of decision coaching for people with kidney failure facing decisions about end-of-life care.

Objectives: To investigate experiences of people with kidney failure who received decision coaching for end-of-life care decisions.

Design: We conducted a prospective case study bound by time (September to December 2021), location (one nephrology department), and guided by the Ottawa Decision Support Framework.

Participants: Adults with kidney failure facing end-of-life care decisions.

Measurements: A nurse trained in decision coaching screened for unmet decisional needs with the SURE test and provided decision coaching using the Ottawa Personal Decision Guide. Postcoaching, the participants were rescreened using the SURE test and interviewed to explore their experience with decision coaching. Change in SURE test findings was analysed descriptively and systematic text condensation was used for the analysis of interviews. Recorded decision coaching sessions underwent content analysis using the Decision Support Analysis Tool.

Results: Decision coaching was provided to four adults with kidney failure. Median pre-SURE test score was 2.5 (range 2–4) and posttest score was 3 (range 3–4), indicating a decrease in decisional needs. Participants described that decision coaching provided an overview of features of options to consider, identified remaining decisional needs for further discussion with relatives and health professionals and clarified next steps. Median Decision Support Analysis Tool score was 9 (range 8–9).

Conclusions: After decision coaching, results suggest that the participants experienced fewer decisional needs and seemed clearer about the next steps in the decision making process.

KEYWORDS

chronic kidney disease, decision coaching, end-of-life care, health professionals, skills

INTRODUCTION

Kidney services constantly strive to improve treatment as the disease burden and mortality rate of people with kidney failure is high (O'Halloran et al., 2018). People diagnosed with kidney failure, defined as an estimated Glomerular filtration rate of less than 15 mL/min/1.73 m^2 (NICE, 2021) are typically offered dialysis, conservative kidney management or a kidney transplant to manage their kidney disease and reduce the impact of disease on their health and daily life. The most common symptoms observed in people with kidney failure are pain, dyspnoea, restless legs, nausea, fatigue and decrease in physical function (Murtagh et al., 2007). As kidney failure is a long-term health problem that worsens over time, treatment aims are to manage symptoms and slow disease progression (Winterbottom et al., 2020). Although not all people with kidney failure will die from kidney disease, most are faced with several decisions concerning their health and daily life as they approach end of life (Winterbottom et al., 2020). Decision coaching may be an intervention to support people with kidney failure in these complicated decision-making processes. Decision coaching is defined as:

> A non-directed support delivered by a health care provider to help patients prepare to actively participate in making a health decision. (Jull et al., 2021)

LITERATURE REVIEW

As kidney failure progresses, people face decisions about end-of-life care (EoLC). These decisions are highly emotional for people with kidney failure and their relatives, as there is a great deal of uncertainty about the best course of action when approaching end of life (Davison, 2010).

EoLC is defined as:

> The care and support given in the final weeks and months of life, and the planning and preparation for this. For some conditions, this could be years. (NICE, 2019)

When facing EoLC options, people with kidney failure and their relatives can feel overwhelmed, experience decisional conflict and have unmet decisional needs (Murray et al., 2009). Decisional conflict is defined as uncertainty about the best choice among competing actions involving risk, loss, regret or challenges to personal life values (Garvelink et al., 2019; O'Connor, 1995). Modifiable factors influencing decisional conflict are feeling uninformed, unclear about what matters most and unsupported (Garvelink et al., 2019; Stacey et al., 2020). Davison (2010) reported important elements of EoLC from the perspective of adults including: the need for detailed information about their medical condition (e.g., prognostic information); being informed about treatment options, including withdrawal from dialysis; planning for the future in case of death; and having physical symptoms managed by the nephrology team. People with kidney failure have an unrecognised extent of symptom burden, comparable with that of people with cancer (Murtagh et al., 2007). During treatment and progression of the disease, kidney care services are central in helping people with kidney failure prepare for end of life and provide them with knowledge and information about palliative care options and advance care planning (ACP). Sudore et al. (2017) define ACP as a process supporting adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care.

However, planning for EoLC and ACP discussions are not a part of routine nephrology care (Davison, 2010; Davison et al., 2015), and there are often delays in talking about EoLC with adults (Eneanya et al., 2015). Furthermore, health professionals (HPs) need skills to support people with kidney failure and their relatives in making EoLC decisions (O'Hare et al., 2016). Bekker et al. (1999) defined an informed decision as one where a reasoned choice is made by an individual using relevant information about the advantages and disadvantages of all possible courses of action, respecting individual beliefs. Supporting people to make reasoned or informed decisions requires interventions enabling active thinking, such as decision coaching by a third party or patient decision aids (PtDAs) (Stacey et al., 2017). They are designed with components that provide information about options and associated consequences, help people evaluate the options in accordance with their values, guide in making decisions based on a trade-off between benefits and harms, and prepare people to engage with health providers. Searching through an international A to Z inventory of PtDAs (, 2006) identified one PtDA in the area of EoLC and kidney failure that focused on withdrawal from dialysis, rather than preparing for EoLC and other important options requiring consideration such as life-sustaining treatment, place of death, and so forth. (Healthwise, 2022). A recent review of PtDAs in kidney disease and Google search did not identify any focusing on EoLC for people with kidney failure (Engels et al., 2022).

As there is no consistent clinical guideline for staff to support EoLC decisions for people with kidney failure and no PtDAs (Davison, 2006; Davison et al., 2008; Holley et al., 2007), the overall aim of this research was to investigate experiences of people with kidney failure who received decision coaching for EoLC decisions and answer the following questions:

- *How* did decision coaching influence the decisional needs of adults with kidney failure facing decisions about EoLC?
- *What* was the quality of the decision coaching sessions?
- *How* did the adults with kidney failure experience the decision coaching sessions for EoLC decisions?

MATERIAL AND METHODS

Study design

We conducted a prospective case study according to Yin (2017) and guided by the Ottawa Decision Support Framework (ODSF, 1998;

Stacey et al., 2020). The strength of case studies is that they provide a structure for examining a situation within real-life context, data collection from multiple sources and triangulation across data sources. Furthermore, case studies analyse in-depth responses to questions such as 'how', 'what' and 'why' (Crowe et al., 2011; Walshe et al., 2004; Yazan, 2015). Data sources for our case study included pre and postintervention quantitative data, quantitative measures of intervention quality and qualitative interviews to explore the participant's experiences with the intervention. For the purpose of our study, the case was bound by time (September to December 2021) and one nephrology department in Denmark serving a population of approximately 800,000.

Theoretical framework

The ODSF was used for the selection of interventions and outcome measures. The hypothesis underlying the ODSF is (Stacey et al., 2020) when decision support is provided to address identified peoples' decision-making needs there will be an improved decision-making process and outcomes (Stacey et al., 2020). The three elements in the framework are (1) assessing a person's decisional needs, (2) provide decision support tailored to the person's needs using PtDAs, coaching and/or counselling, and (3) evaluating the decisional outcomes.

Participants

Adults living with kidney failure on either haemodialysis or having had a kidney transplant were recruited through the nephrology department of a Danish academic hospital, providing care to approximately 4500 people with kidney disease. Participants were identified by the clinical team if they answered yes to this question, 'Would you be surprised if this patient died in the next 12 months?' (Javier et al., 2017). A clinical staff member who knew the person with kidney failure approached the person to inform him/her about the project and ask if the researcher could approach him/her with further information on the project. Eligible participants had kidney failure, were ≥18 years old, able to read and speak Danish, willing to sign a written consent form and were at a stage of their illness trajectory where they were facing EoLC decisions. The participants could decide to include a relative during the decision coaching session.

Interventions

Decision coaching was provided by the first author, a registered nurse with expertise in providing EoLC for adults with kidney failure and trained in decision coaching. Decision coaching has been shown to improve participants' knowledge (Jull et al., 2021). The decision coach followed the Ottawa Personal Decision Guide (OPDG, 2002), a generic approach that can be used by decision coaches to guide people to identify their decision-making needs, plan the next steps, track their progress and share their views about the decision with others. The OPDG has been translated into Danish (Finderup & Baker, 2016). Previous studies found that when the OPDG is used with explicit information about options, benefits and harms, people have improved knowledge and decreased decisional conflict (Arimori, 2006; Lawson et al., 2020).

Procedures

The trained decision coach screened participants for decisional needs using the SURE test (Légaré et al., 2010). The decision coach (LEB) guided the participations in the process of decision-making by completing the OPDG together with the participant (OPDG, 2002). At the end of the session, the decision coach repeated the SURE test to screen for remaining decisional needs and made plans with the participant for addressing these decisional needs. The decision coaching sessions were video recorded by one of the co-authors (C. L. M., L. T. H., or I. R.). After the session, a brief qualitative semistructured interview was conducted by the co-author to explore the participants' knowledge, values and experiences regarding decision coaching about EoLC options (Kvale & Brinkmann, 2018).

Instruments

The SURE test was used to monitor changes in decisional needs. The SURE test, a short version of the Decisional Conflict Scale based on the ODSF, can be used to screen for decisional conflict in clinical practice (Garvelink et al., 2019). The test includes four items each measuring a unique decisional need (uninformed, unclear values, unsupported, unsure about best option). Each item gives a score 1 if the answer is 'yes' and 0 if the answer is 'no'. If the total score is less than 4, the person is experiencing clinically significant decisional conflict. The instrument has an α coefficient of 0.86, a Cronbach α of 0.65 indicating moderate internal reliability and is responsive to change after decision support (Légaré et al., 2010).

The brief Decision Support Analysis Tool (DSAT-10) (Stacey et al., 2008) was used to measure the quality of decision coaching. The instrument is based on the ODSF and used to analyse video or audio-recorded interactions between a decision coach and the person facing the decision. The DSAT-10 has been tested for inter-rater reliability and has shown a κ coefficient of 0.55 and the ability to distinguish between a trained and an untrained decision coach (Stacey et al., 2008). The co-authors completed the online training manual (DSAT-10, 2015) and independently scored the video recordings of the sessions (C. L. M., L. T. H., or I. R.). A flowchart showing the study design is shown in Figure 1.

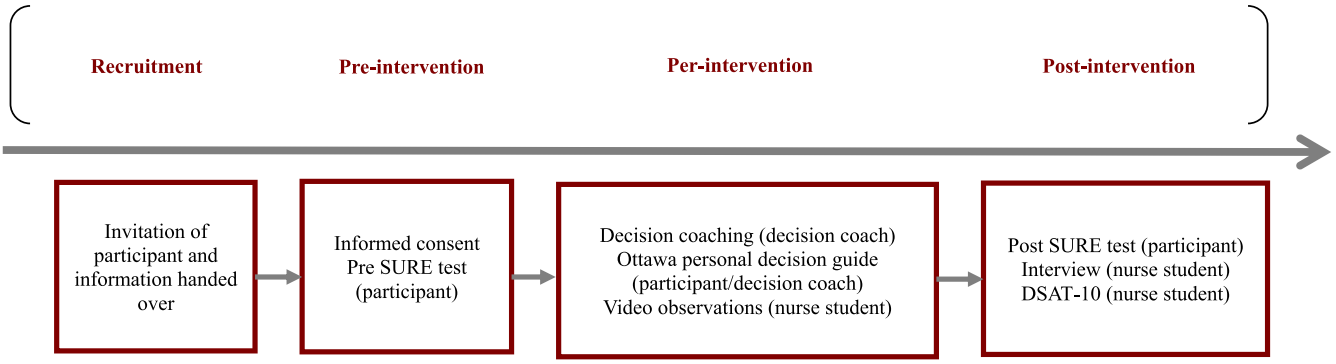

FIGURE 1 Flowchart of study design.

TABLE 1 Characteristics of participants.

	Gender	Age (years)	Treatment	Decisions
Participant 1	Male	>80	Dialysis	To travel or not
Participant 2	Female	>60	Kidney transplant	Life-saving treatment or not
Participant 3	Male	>60	Dialysis	When to initiate palliative treatment
Participant 4	Female	>60	Kidney transplant	Dialysis or conservative kidney management

TABLE 2 Pre and postintervention SURE test (range 0–4).

	Participant 1		Participant 2		Participant 3		Participant 4	
Sure of myself		√	√	√			√	√
Understand information	√	√	√	√	√	√	√	√
Risk-benefit ratio	√		√	√		√	√	√
Encouragement		√			√	√	√	√
	Pre	Post	Pre	Post	Pre	Post	Pre	Post

Data analysis

Data were entered into Excel. The pre and postintervention SURE test scores were compared descriptively (Légaré et al., 2010), the DSAT-10 score was analysed using content analysis (Stacey et al., 2008) and qualitative interview findings were analysed using systematic text condensation described by Malterud (2012). Using questions consistent with the case study design, the findings were triangulated by comparing identified decisional needs, with the decision support provided and the participants' experiences of the provided decision coaching (Yin, 2017).

Ethical considerations

The study was conducted as a part of a graduate nursing course with ethics approval from the University of Ottawa (NSG6133/6533). We obtained written consent from the four participants before the decision coaching sessions.

RESULTS

Four adults with kidney failure facing decisions about EoLC consented to participate. The decision coaching sessions, carried out in Danish, took place between September and December 2021 at a place of the participant's choice (in person at home or at the hospital or online using the videoconferencing platform 'Zoom'). The participants were men and women ranging in age from 60 to 90 years. In one of the decision coaching sessions, a relative of the participant was present. An overview of the characteristics of the participants is shown in Table 1.

How did decision coaching influence their decisional needs?

The median total preintervention SURE test score was 2.5 out of 4 (range 2–4) and posttest score was 3 (range 3–4) suggesting a decrease in decisional needs (Table 2). Two participants had an

TABLE 3 Results from the DSAT-10 evaluations of four decision coaching sessions (range 0–10).

	Participant 1	Participant 2	Participant 3	Participant 4
1. Identify uncertainty about making a decision	1 point	1 point	1 point	1 point
2. Timing for when decision needs to be made is discussed/acknowledged	1 point	1 point	1 point	1 point
3. Stage of decision-making: assessed or self-evident	1 point	1 point	1 point	1 point
4. Hear and acknowledge or assess in interaction knowledge of options and potential benefits of options and potential harms of options	1 point	1 point	1 point	1 point
5. Intervened knowledge of options and potential benefits of options and potential harms of options				
6. Discuss importance of benefits and discuss importance of harms	2 points	2 points	2 points	2 points
7. Hear and acknowledge or assess in interaction others' involvement in the decision	1 point	1 point	1 point	1 point
8. Intervened others' involvement in decision		1 point	1 point	1 point
9. Summarise the next steps to address the patient's decision-making needs	1 point	1 point	1 point	1 point
Total score	8 points	9 points	9 points	9 points

improvement in their decisional conflict score, one participant did not have any decisional conflict before the intervention; this was unchanged after the intervention. The results of the questions about being 'Sure of myself' and 'Encouragement' showed that for both questions, one participant answered 'yes' in the postintervention SURE test, two remained the same and one did not answer the question. In both the pre and postintervention SURE test, all participants answered 'yes' to the question 'understand information', indicating their decision needs were not about feeling uninformed on the benefits and risks of each option. The median scores of both the pre and postintervention SURE test are below 4, indicating participants continued to have some decisional needs causing decisional conflict following decision coaching.

What was the quality of the decision coaching sessions?

The results of the DSAT-10 evaluations of the decision coaching sessions with the four participants are shown in Table 3.

The median DSAT-10 score was 9 out of 10 (range 8–9). In all the sessions, the decision coach lost points for 'knowledge' because it was limited to discussing one or two of the three factors (e.g., options, possible benefits and possible harms). To achieve a one-point score for this element of the DSAT-10, the decision coach has to facilitate factual knowledge within all three factors. In one of the sessions, the decision coach lost a point for the element 'Others' involvement in the decision'.

When findings were triangulated with their SURE test scores, participants said they felt informed on the SURE test but the decision coach did not help them become more informed of the options, benefits and harms. This indicated that the participants were not aware of what they did not know and that decision coaching alone was not sufficient for increasing knowledge.

How did the adults with kidney failure experience the decision coaching sessions?

Participants' experiences with decision coaching, described in the interviews, led to three themes: (1) provides an overview and more nuances to the decision; (2) may lead to more questions; (3) generates a need for further explanation about the decision.

Decision coaching provides an overview and more nuances to the decision

The participants experienced that the decision coaching sessions provided an overview and refined the decision to help them with more nuances to the decision they had to make and supported their reasoning about the benefits and harms. This structure helped the participants' decision-making process.

> It has definitely provided more nuances (.) It has provided some broader perspectives, than I had before. (Participant 3)

Another participant pointed out that it had been rewarding for her because, through the decision coaching session, she became aware of details about the options that she was not aware of. This information had led her to think further about these details and helped her to consider benefits and harms of the decision.

> It might very well have led to that we are going to talk about some of these elements [benefits and harms of the decision options] tonight over a glass of red wine. It cannot be ruled out. (Participant 4)

She also pointed out that the OPDG might be a support in relation to other decisions.

> Now it is just me who is the person with a chronic disease, but (.) it could just as well be (husband) […]. So, it has given me some thoughts. (Participant 4)

One participant explained that during numerous hospitalisations the HPs had asked her which treatment she wished to have and whether she thought of the treatment as life-saving. After the decision coaching session, she had a feeling of not being fully aware of what life-saving treatment was, but the decision coaching had made it clearer to her.

> Then you would (.) better be able to outweigh the benefits and harms, that is, because what does it really include, life-saving treatment? (Participant 2)

The decision coaching had not made her fully aware of what to decide, but she recognised that the decision coaching had structured the decision problem enabling her to reason about the benefits and harms and the consequences for her life. Moreover, it had provided a framework to help her reach a decision.

Another participant also found that decision coaching provided her with a greater understanding of the types of decisions to make, as well as different options.

> Well, it has definitely been rewarding […]. We have discussed some elements, which I at least have not even thought of. So, because it is not relevant right now, I hope not […]. So, it has definitely made me think. (Participant 4)

Decision coaching may lead to more relevant information seeking

The participants experienced that the decision coaching helped formulate the decision problem, and provided a framework to be able to ask for more detail about specific options.

> So, I have not gained any more clarification than I already had. I may have gained clarification that I do not quite know what it is I have decided. It might have to be more specific. (Participant 2)

A participant said that he was not sure that the decision coaching would necessarily change his decision, but he thought the new perspectives he had gained from the conversation were positive.

In general, the participants struggled a little in deciding which decision they wanted to discuss during the decision coaching session. One participant expressed that she did not quite understand the concept of the conversation.

> But what you have conducted, that is not to provide decision coaching to people is it? (Participant 2)

The general picture for the four participants indicates that it has not been clear to them what the purpose of the decision coaching was.

Decision coaching generated a need for further explanation about the decision

After the decision coaching sessions, the participants experienced a continuing need for clarification about the decision and the consequences of making the decision.

During the interview, one participant expressed that after decision coaching, she still felt unclear about some of the elements included in the decision. She needed further explanation of the elements of the decision.

> I am a little unsure of the decision, so it would be nice to be able to get things explained a bit. (Participant 2)

Furthermore, one participant described that she needed an explanation of what the different types and ways of receiving life-saving treatment consisted of.

> If you choose not to receive life-saving treatment, then it might be that you should have some support for that. That is, to be explained what it actually comprises. (Participant 2)

In addition, another participant stated that he needed support to implement the decision.

> I am completely clear that if I have to go somewhere, then, I need some support or advice. (Participant 1)

The interviews indicated that decision coaching created an overview of elements to consider in the decision and identified decisional needs for further discussion with relatives and HPs. It did not lead to a final decision but the participants became clearer about the next steps along the pathway of the decision-making process.

When triangulating these findings with the SURE test and the DSAT-10 score there was a consensus around knowledge, indicating participants felt the decision coaching resulted in having more questions. Associated with this finding were comments that participants had a clearer awareness of the types of decisions after the decision coaching.

DISCUSSION

This case study investigated the use of decision coaching as a guided process for four adults with kidney failure facing EoLC decisions. The results from the SURE test suggest a pattern of decreasing decisional

needs after coaching, suggesting some needs were met. Decision support was provided in the form of decision coaching with the OPDG, but the element of 'Knowledge' on the DSAT-10 was inadequate across all participants. Despite this limitation, the findings from the participants' interviews indicated that decision coaching provided an overview and scaffolding about the decision, leading to a clarity enabling more question-asking and identifying a need for further information and details to help address remaining decisional needs. These findings lead us to the following points of discussion.

Although the decision coach was an HP with expertise in providing EoLC for adults with kidney failure, she did not have specific evidence on the benefits and harms about these specific EoLC decisions. The OPDG guides the process of decision-making and is not prepopulated with evidence-based information about options; if a decision coach has specialist knowledge, they would be able to integrate further facts within the session (Lawson et al., 2020). It is likely using a PtDA and/or evidence-based information within the session could support a decision coach to talk through more details of the health condition, the decision and balanced information about all options, benefits and harms, and helps people clarify the importance of features and outcomes of options (Jull et al., 2021; Stacey et al., 2017). A randomised controlled trial study by Brown et al. (2019) used decision coaching and a PtDA for people with kidney failure deciding between dialysis and conservative kidney management. The study showed that the decision-support intervention increased the participants' knowledge of the benefits and harms of dialysis, but the decision coaching and PtDA did not focus on EoLC. It is likely that decision coaching for EoLC decisions could be better supported by having a PtDA, and staff training on how to use the resource effectively in practice.

A key element of decision quality is knowledge (O'Connor et al., 2002). From the SURE responses, participants felt they were informed about the decision at baseline. However, this subjective assessment may not be a sufficient surrogate for knowledge. The interview findings indicated participants wanted more information and may not have had the knowledge they needed to make an informed decision. It may mean that the SURE test is not sufficient to provide feedback about participants' knowledge requirements before the decision coaching session. According to ODSF (1998), feeling informed is a process measure but actual knowledge is an important outcome of decision support relevant for informing clinical practice and research. PtDAs have strong evidence that they improve knowledge and some PtDAs include questions to test peoples' knowledge (Hoefel et al., 2020). Further consideration of ways to support people with kidney failure should include ways to verify peoples' actual knowledge of options.

The quality of the decision coaching was assessed qualitatively through the interviews, exploring the participants' perception of the decision coaching sessions and what they had gained from the sessions about their EoLC decisions. This method also elicited findings that decision coaching helped structure the decision problem, and helped participants identify what further details they needed about the options and consequences to understand EoLC. Decision coaching supports people to participate in the decision-making process and may be an element that can support a more shared decision-making process between people with kidney failure and HPs. However, other elements are likely to include a PtDA and shared decision-making training of specialist HPs. In Denmark, some healthcare decisions can only be made with a physician for legal reasons (e.g., if the patient does not wish to be resuscitated). These findings suggest decision coaching training within clinical teams could be an important contribution to service quality, ensuring patients and their relatives, are informed and have sufficient decision literacy to make shared decisions during consultations with their physician.

Strengths and limitations

The main strengths of this study are: an in-depth analysis from triangulating across three different types of data; a rigorous research process supported by separating the people involved in interviews, analysis of interview data and the scoring of the DSAT-10 from those delivering the decision coaching. The main limitations of this study are: the small sample size, only one relative of a participant participated; the lack of this design to be able to capture the impact of the decision coaching on subsequent decision-making with the physician.

IMPLICATION FOR CLINICAL PRACTICE

This study illustrated that decision coaching supported the participants' to consider making decisions about EoLC as their kidney failure was worsening. Although decision coaching appeared to be helpful to prepare participants for discussing this decision, having access to a PtDA or evidence-based information designed specifically for EoLC decisions is likely to enhance their preparation for shared decision-making between adults with kidney failure, their relatives and HPs. Previous research has shown that a PtDA combined with the OPDG was helpful for people considering decisions about dialysis treatment and they reached a high-quality decision (Finderup et al., 2020).

CONCLUSION

Our results suggest that the use of a decision coaching intervention involving the OPDG to guide the discussion appeared helpful to prepare people with kidney failure to make decisions about EoLC. After the decision coaching session, the participants seemed to experience fewer decisional needs. The sessions helped represent the decision problem and supported participants to reason about their options, which may have prepared them to engage within the next steps for making EoLC decisions.

AUTHOR CONTRIBUTIONS

All authors fulfil the four ICMJE requirements for authorship. Authors' contributions to the manuscript: Louise Engelbrecht Buur

drafted the manuscript. Caroline Løntoft Mathiesen, Lotte Timmerby Holm, Ida Riise conducted the data collection and data analysis. Louise Engelbrecht Buur, Jeanette Finderup, Hilary Louise Bekker and Dawn Stacey designed the project, provided academic supervision, revised and approved the final manuscript. All authors read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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