Decision Aids in the ICU: a scoping review

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ABSTRACT

Objective The purpose of this scoping review was to synthesise the effectiveness and acceptability of decision aids for critically ill patients and family members in the intensive care unit (ICU).

Methods A systematic search of four electronic databases and grey literature was undertaken to identify relevant studies on the application of decision aids in the ICU, without publication date restriction, through March 2023. The methodological framework proposed by Arksey and O’Malley was used to guide the scoping review.

Results Fourteen papers were ultimately included in this review. However, only nine decision aids were available, and it is noteworthy that many of these studies focused on the iterative development and testing of individual decision aids. Among the included studies, 92% (n=13) were developed in North America, with a primary focus on goals of care and life-sustaining treatments. The summary of the effect of decision aid application revealed that the most common indicators were the level of knowledge and code status, and some promising signals disappeared in randomised trials.

Conclusions The complexity of treatment decisions in the ICU exceeds the current capabilities of existing decision aids. There is a clear gap in decision aids that are tailored to different cultural contexts, highlighting the need to expand the scope of their application. In addition, rigorous quality control is very important for randomised controlled trial, and indicators for assessing the effectiveness of decision aids need to be further clarified.

INTRODUCTION

Critical care medicine has made considerable advances in recent years, resulting in improved survival rates for patients with the most severe diseases. However, this progress has also highlighted the growing need for a family-centred model of care. Patients admitted to intensive care units (ICUs) are vulnerable and suffer from a variety of conditions with multiple concurrent problems. Medical decisions and end-of-life decisions in the face of an uncertain disease trajectory can be complex and time-sensitive.

Unfortunately, despite efforts to provide comprehensive information to families, studies have identified information gaps between physicians and patients, leading to an inconsistent understanding of treatment and lower-quality decision-making. Furthermore, many patients and family members report experiencing stress and decision conflicts during their time in the ICU, which can persist even after discharge. One study found that 70% of family members of ICU patients had anxiety symptoms and 35% had depressive symptoms. In addition, one-third of family members have PTSD (Post Traumatic Stress Disorder symptoms). These distressing symptoms can interfere with patients’ and surrogates’ understanding of the information provided by the physician, resulting in lower-quality decision-making. Ultimately, this exerts a significant impact on patient outcomes.

In response to the challenges faced in medical decision-making, decision aids (DAs) have been proposed as a tool to support clinicians and patients in making informed and evidence-based decisions. The core concept of DAs is defined by the International Patient Decision Aid Standards (IPDAS) as tools designed to help people engage in decisions about healthcare choices, provide information about choices, and help patients clarify their values and preferences. The most recent update, a Cochrane review, which included 105 randomised controlled trials (RCTs) with 31 043 participants, showed that DAs can improve users’ knowledge about choices, making them more aware of their values and perceive risks more accurately. DAs reduce decision conflict, increase satisfaction with medical communication, and do not worsen health outcomes compared with conventional treatment. Best practice guidelines also suggest the use of a shared decision-making approach to improve the quality of decision-making in the ICU.
Therefore, DAs play an important role in the treatment of critically ill patients.

To enhance the development of effective DAs for supporting ICU patients and their surrogates, a comprehensive systematic review of previously published DAs is of paramount importance. Therefore, the primary objective of this study was to conduct a rigorous scoping review that provides valuable insights. By doing so, we aimed to identify potential avenues for further research, ultimately striving to improve the decision-making experience for critically ill patients and surrogates.

METHODS

Our study was undertaken in accordance with the five stages of Arksey and O’Malley’s scoping review framework: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data and (5) collating, summarising and reporting the results. We also used the PRISMA-ScR checklist to ensure the quality of this scoping review (online supplemental file A). A protocol for this scoping review was published in Open Science Framework registries (registration DOI: https://doi.org/10.17605/OSF.IO/U5JWR).

Step 1: identifying the research questions

To complete the purpose of this study, the following research questions were identified:

1. What are the publication trends of DAs in the ICU?
2. What DAs are available for ICU patients and their surrogates?
3. How effective are these DAs?
4. What is the degree of usability and acceptance of DAs?

Step 2: identifying relevant studies

A systematic search of the PubMed/Medline, Web of Science, Embase and Scopus databases and grey literature was undertaken from inception to March 2023. Databases were searched using search terms derived from MeSH and subject headings, such as “Intensive Care Units” or “ICU” or “Critically ill patients” and “Decision Support Techniques” or “Decision Support Technic” or “Decision Support Model” or “Decision Aids” in the title or abstract of records. The search strategy and search strings were developed by the research team. The full search strategy is provided in online supplemental file B.

Step 3: study selection

We followed the predetermined inclusion and exclusion criteria to guide selection in this scoping review. The protocol was included to expand the understanding of the application of DAs in the ICU. The inclusion criteria were as follows: (1) The study setting was in the ICU (including neonatal ICU, neurological ICU and emergency ICU); (2) The study topic was a DA used by patients or surrogate decision-makers and (3) The study design included RCTs, observational studies, case–control studies, and qualitative studies and protocols. The exclusion criterion was non-English language studies. We added a study to the category of studies awaiting classification until we were able to obtain the full text. There was no limit on the publication date to ensure that all evidence was captured.

All results were exported into EndNote V.20, and duplicates were removed. Then, the results were imported into Rayyan (https://rayyan.ai) for blinded title and abstract screening. Two authors (YL and QZ) screened the title and abstract; one (YL) focused on shared decision-making, and the other (QZ) had experience in evidence-based medicine. Disagreements were settled by the third author (YT).

Step 4: charting the data

A data extraction form was created to extract relevant information from the selected studies, which included the following categories: (1) authors/year/country, (2) setting, (3) sample, (4) method, (5) participants, (6) format, (7) component, (8) outcomes and (9) IPDAS. The data were extracted independently by two authors (YL and QZ), and discrepancies were eliminated after negotiation. The third author (YT) reviewed all the data.

Step 5: collating, summarising and reporting the results

All extracted data were used for discussion by the research team until they were consistent with the purpose of the scoping review. Two methods of data analysis were used in this study: (1) descriptive analysis, including the number of studies, publication trends and distribution and (2) content analysis, in which qualitative data were brought together to construct descriptive themes.
Presentation of DAs in the ICU

These tools are primarily based on the Ottawa Decision Support Framework (ODSF) and are available in paper-based or web-based presentations. Three DAs29 31 32 presented a family-centred video that described the ICU setting and the process of CPR or defibrillation. One study29 used a more advanced tool based on computers or tablets, providing an interactive process that prepared for the family meeting by video. Additionally, four studies26 27 33 35 used web-based platforms to facilitate the embedding of predictive models. These models automatically analysed patient data to generate a personalised patient report, aiding in shared decision-making. In three studies,30 37 38 the clinical outcomes of patients were presented in an icon array, with clear and visual graphics to facilitate decision-making.

The effectiveness of DAs in the ICU

The ODSF was used to guide the development of DAs.39 This framework was used to summarise the results section of the included literature. Based on the ‘Decision Outcomes’ section of the ODSF, we divided the studies into three themes: (1) decision quality, (2) quality of decision-making process and (3) impact, and we categorised the content into seven subthemes (table 1). Six studies25 27 29–32 explored the effects of DAs on patients and surrogates, with knowledge, preferences and health as the outcome indicators most frequently used to assess DAs. It is worth highlighting that several smaller or mixed-method trials indicated that DAs showed a promising signal in their results25 31 32, but most effects did not persist in a randomised manner.27 29 30 In particular, the series of studies conducted by Cox et al25 demonstrated that the use of DAs led to reduced clinician-surrogate discordance, decreased hospital costs, improved decision conflict, and enhanced quality of communication and comprehension (p<0.05) when assessed in a before-and-after study design. However, on evaluation in a randomised manner, the results showed a notable difference only in decision conflict (p=0.041).27

Five studies25 27 30–32 validated the effect of DAs on the quality of decisions, including knowledge and decision preferences. There was no statistically significant difference in the code status change, but all studies demonstrated that DAs could improve knowledge.

Four studies25 27 29 30 explored the effects of DAs on the quality of the decision process, including decision stages, expectations and satisfaction. Clinician-surrogate concordance and quality of communication were the most commonly used indicators. We found divergent findings: although DAs slightly improved discordance and decision quality, they did not reach significant differences in these two studies.27 29

Three studies25 27 30 explored the effectiveness of DAs on impact, including health and health resources. Anxiety and depressive symptoms, PTSD, and mortality were the most common outcomes. One study30 reported a potential reduction in 3-month mortality associated with

Patient and public involvement

None.

RESULTS

Overview of included studies

A total of 2731 articles were retrieved from four electronic databases. After duplicates were removed, 1082 records were screened by title and abstract. From a review of 32 full-text articles, 14 were ultimately included in this scoping review, as shown in the PRISMA flow chart diagram (figure 1).

Ten studies25–32 were conducted in the USA, followed by Canada33–35 (n=3), and only one study36 was conducted in China. Of the 14 included studies, there were 5 RCTs,27 29 30 32 34 4 mixed-method studies,28 35–37 2 observational studies,26 38 1 qualitative study33 and 2 quasi-experimental studies.25 31 Only one study35 did not evaluate the effect of DA application. Online supplemental table 1 presents an overview of the studies’ traits.

Publication trends

The earliest study was published in 2012, and the greatest number of studies were published in 2021, with three studies.29 36 38 Six studies25–30 36–38 were published in the last 3 years. Trends are illustrated in figure 2.

DAs available in the ICU

In the set of 14 studies selected for this review, it is noteworthy that only 9 DAs are available in the ICU, with a substantial portion of these studies demonstrating the iterative development and testing of individual DAs.25–30 37 These DAs have primarily focused on end-of-life care and life-sustaining treatments. Six studies focused on goals of care,25–30 34 37 38 three studies developed DAs for CPR,25–27 three studies for prolonged mechanical ventilation,25–27 one study for neonatal parents35 and another study for renal replacement therapy.36

Figure 2  Publication trends of DAs.
the use of DAs (p=0.05). Furthermore, it is worth noting that at long-term follow-up, surrogates that used DAs exhibited increased psychological distress, which may be attributed to the higher psychological distress experienced by caregivers of ICU survivors.

**Usability and acceptability of DAs in the ICU**

The results of five studies that employed the System Usability Scale to measure the usability of items indicated an average score greater than 80, with the highest score being 87.5/100. However, one of the studies found lower scores among users aged 56 and above, and the majority of users (93%) preferred a web-based interface. Furthermore, three studies investigated physicians’ attitudes towards DA use, with one study reporting positive feedback from physicians who found the DAs helpful in guiding communication with and understanding the opinions of agents. Comments included ‘brings forwards issues that may not be discussed’, and the DAs were highly recommended for use in family meetings.

**DISCUSSION**

In this scoping review, we synthesised currently published studies on DAs in the ICU and reported the current status of their application and evaluation of effectiveness. While many studies have systematically reviewed DAs, this is the first scoping review of medical decision-making among critically ill patients in the ICU.

Medical decision-making for critically ill patients requires careful consideration of various options and weighing their pros and cons, making it suitable for promoting shared decision-making in the ICU. Our findings indicate that DAs in the ICU mainly focus on life-sustaining treatment and goals of care, leaving ample room for further development. An illustrative example is that extracorporeal membrane oxygenation (ECMO) is often a last resort for critically ill patients and has shown an upward trend in recent decades, particularly after the Covid-19 pandemic. Despite its potential benefits, ECMO is a costly intervention, and individuals who survive ECMO treatment often encounter psychological or cognitive challenges while experiencing a diminished quality of life. These difficulties may be influenced by the level of family support and the quality of interactions with healthcare providers. Consequently, the development of DAs focused on ECMO could represent a crucial area for future research.

Our review showed a noticeable transition from traditional paper-based formats to web-based formats in DAs, accompanied by the integration of personalised predictive models to enhance the accuracy of predicted outcomes. Interestingly, studies found no significant impact of the DA format on decision quality. However, it is important to acknowledge that tablet-based DAs, although more convenient, may present challenges in terms of user-friendliness for older individuals. Therefore, both paper-based and web-based formats should take into consideration the user experience of the ageing population to ensure accessibility and usability. In addition, the integration of artificial intelligence (AI) holds great potential in the design of DAs. Notably, a study demonstrated that AI-enabled DAs can effectively enhance decision quality and shared decision-making without significantly prolonging consultation time. Moreover, AI has the capability to continuously monitor the newest studies and stay up to date with the latest evidence-based medical evidence. Machine learning algorithms are extensively used to process large volumes of data for predicting ICU mortality. This is particularly important, as prognostic uncertainty is one of the primary factors contributing to psychological stress experienced by surrogates.

Although some meta-analyses show disagreement in the effects of DAs on several outcome indicators, it is widely accepted that DAs have potential benefits. For example, two meta-analyses focusing on DAs in cancer showed that they can significantly increase users’ knowledge, reduce decision conflict and improve decision satisfaction. In contrast, another meta-analysis that included 14 RCTs found that DAs did not improve knowledge.

### Table 1 The outcomes of DAs in the ICU

<table>
<thead>
<tr>
<th>Primary theme</th>
<th>Secondary theme</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of decision-making</td>
<td>Knowledge</td>
<td>4 (66)</td>
</tr>
<tr>
<td>5/6 (83%)</td>
<td>Comprehension of diagnosis/prognosis</td>
<td></td>
</tr>
<tr>
<td>25 27 31 32</td>
<td>CPR knowledge</td>
<td></td>
</tr>
<tr>
<td>31 32</td>
<td>Understanding of CPR options</td>
<td></td>
</tr>
<tr>
<td>25 30</td>
<td>Preferences</td>
<td>3 (50)</td>
</tr>
<tr>
<td>25 32</td>
<td>Code status change</td>
<td></td>
</tr>
<tr>
<td>30 32</td>
<td>ICU discharge</td>
<td></td>
</tr>
<tr>
<td>Quality of decision-making</td>
<td>Decision stage</td>
<td>3 (27)</td>
</tr>
<tr>
<td>25 27 30</td>
<td>Decision conflict</td>
<td></td>
</tr>
<tr>
<td>25 27</td>
<td>Decision regret</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Expectations</td>
<td>3 (27)</td>
</tr>
<tr>
<td>25 27 30</td>
<td>Clinician-surrogate concordance</td>
<td></td>
</tr>
<tr>
<td>25 30</td>
<td>Satisfaction</td>
<td>4 (36)</td>
</tr>
<tr>
<td>25 27 29 30</td>
<td>Quality of communication</td>
<td></td>
</tr>
<tr>
<td>25 27 29</td>
<td>Perception of care centredness</td>
<td></td>
</tr>
<tr>
<td>Impact</td>
<td>Health</td>
<td>3 (50)</td>
</tr>
<tr>
<td>25 27 30</td>
<td>Anxiety and depression</td>
<td></td>
</tr>
<tr>
<td>3/6 (50%)</td>
<td>PTSD</td>
<td></td>
</tr>
<tr>
<td>27 30</td>
<td>Mortality</td>
<td></td>
</tr>
<tr>
<td>25 30</td>
<td>Health resources</td>
<td>2 (33)</td>
</tr>
<tr>
<td>25 30</td>
<td>Length of stay</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hospital costs</td>
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| CPR, Cardiopulmonary Resuscitation; DAs, decision aids; ICU, intensive care unit; PTSD, Post Traumatic Stress Disorder.
or decision conflict. Our findings align with previous research, demonstrating that certain promising signals diminished when examined in randomised studies. It is important to recognise that the utilisation of DAs alone may not sufficiently alleviate the psychological distress experienced by surrogates of critically ill patients. Therefore, integrating DAs with complementary interventions aimed at addressing prolonged grief symptoms among surrogates is warranted. Many studies support the idea that multiteam, structured communication improves outcomes for relatives.\textsuperscript{54,55} Additionally, ensuring stringent quality control measures in randomised experiments is crucial to prevent potential contamination between clinicians and optimise study outcomes. Ultimately, integration of the best medical evidence with patient values is key for making high-quality surrogate decisions. Thus, the evaluation of DAs should prioritise their alignment with patient preferences and values, as relying solely on measures of knowledge and decision conflict may not be sufficient. One such example is the utilisation of eight questions designed to prompt agents to contemplate how various impairments impact a patient’s quality of life.\textsuperscript{56} These questions serve as a guide to stimulate thoughtful consideration of patient values. Consequently, it is recommended that tools based on this framework be developed to facilitate the evaluation of the value clarification process. In addition, brain-computer interfaces may help unresponsive patients patent preferences,\textsuperscript{57,58} and extremely promising and novel devices may be widely available in the future.

This review found that 92\% (n=13) of DAs were developed in North America; however, preferences regarding end-of-life care are culturally sensitive.\textsuperscript{59} In Asia, Confucianism and filial piety play an influential role, individuals’ end-of-life wishes are greatly influenced by family members,\textsuperscript{60} and death is a taboo topic in some regions.\textsuperscript{61} Therefore, availability is limited by the lack of localised DAs, and there is a necessity to develop DAs in multiple languages according to national culture.

In addition, despite the positive attitudes of users and physicians towards DAs,\textsuperscript{62} discussions regarding patient values and preferences remain inadequate in clinical practice.\textsuperscript{63,64} A cross-sectional study that surveyed 13 ICUs in the USA found that only 8.2\% of ICU physicians incorporated patient preferences in actual treatment situations.\textsuperscript{65}

While time constraints may be a barrier to the use of DAs, a systematic evaluation that included 63 studies showed that applying shared decision-making does not necessarily require longer consultation times. To reduce the risk of increased consultation duration, a theory-based, multi-level implementation approach may be helpful. Communication skills can also influence the use of DAs, and some models have been developed to guide communication, such as the communication-centred epistemic model of shared decision-making\textsuperscript{66} and the model for collaborative decision-making.\textsuperscript{66}

**Strengths and limitations**

This study was reported strictly in line with PRISMA-ScR guidelines, and the study protocol was registered in the Open Science Framework to ensure transparency of the process. A comprehensive review of DAs was conducted to reveal the gap between further research and clinical practice.

However, there are some limitations that need to be acknowledged. First, our search was limited to studies published in English, which may have led to the exclusion of relevant studies published in other languages. Second, some DAs were presented as web pages or published in non-indexed journals, and we could not access essential elements for summarisation, which may have led to incomplete data extraction. Third, the protocol was also included, which may have been missing some important data but expanded the scope of DAs. Despite these limitations, this scoping review provides valuable insights into the current state of DAs in the ICU and identifies areas for future research and development.

**CONCLUSIONS**

This scoping review provides a comprehensive synthesis of the application of DAs in the ICU. The implementation and advancement of DAs in the ICU hold promise for improving the quality of care and promoting a family-centred approach in critical care medicine. However, the majority of DAs focus on life-sustaining treatment and goals of care, representing only a small portion of the complex decision-making needs in the ICU, and there is also a lack of culturally adapted DAs. It is crucial to recalibrate and standardise evaluation indicators for DAs to facilitate more seamless development. Furthermore, effective implementation of DAs requires strengthening and integrating the key role of healthcare providers in the shared decision-making process in the ICU.

**Contributors** YL and YT developed the search strategy. YL and QZ were involved in study screening and data extraction. YT is the guarantor of the study and responsible for the study design, team coordination and supervised the research process. YL drafted the first version of the manuscript, and all authors critically revised the manuscript for intellectual content and approved the final version to be published.

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 REFERENCES
3 Cuypers M, Lammers RED, de Vries M, et al. Prostate cancer survivors with a passive role preference in treatment decision-making are less satisfied with information received: results from the PROFILES registry. *Urol Oncol* 2016;34:482.


