Interventions using digital technology to promote family engagement in the adult intensive care unit: An integrative review

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ABSTRACT

Background: Family engagement is a key component of safe and effective care in the intensive care unit (ICU). As the COVID-19 pandemic has accelerated the adoption of digital technologies in healthcare settings, it is important to review the current science of family engagement interventions in the ICU using digital technology.
Objectives: This integrative review aimed to identify and evaluate studies that used digital technology to promote family engagement in adult ICUs and synthesize study findings.
Methods: Following the methodology of Whittemore and Knafl, PubMed, CINAHL, Web of Science, and Scopus were searched. We included studies conducted in the adult ICU setting; involved family engagement during ICU stay; and used digital technology to engage family members. We excluded studies that were not peer-reviewed or in English. Study findings were assessed using the model of family engagement in the ICU
Results: Of 2702 articles, 15 articles were analyzed. Various technologies (e.g., web-, tablet-, or SMS-based tools, video-conferencing, etc.) were used to provide information; augment the decision-making process; provide virtual access to family conferences or interdisciplinary rounds. While varying among interventions, "Information sharing" and "activation and participation" were most commonly addressed within the family engagement model. In studies that addressed the components of family engagement more comprehensively, interventions enabled tailoring of information with two-way communication and active family involvement in decision-making processes.
Conclusions: Future research should use more robust methods and develop interventions with close inputs from families. We recommend using conceptual components of family engagement to ensure comprehensiveness of the intervention.

Introduction

Family engagement is an important component of safe and effective person-centered care in the intensive care unit (ICU). Family engagement in the ICU is defined as an active partnership between health professionals and families to improve health outcomes, quality of care, and safety and delivery of healthcare.[1] Although family caregiving or informal caregiving is a term that is used to describe unpaid care which goes beyond the care typically expected in a relationship,[2] family engagement is different. This paper addresses family engagement in the ICU, which is not necessarily the same as family caregiving or informal caregiving. According to Brown et al., family engagement can include direct care activities, communication of values and goals of care, and methods to enhance respect and dignity.[1] Of note, family engagement is not equivalent to family-centered care, which is "an approach to health care that is respectful of and responsive to individual families' needs and values."[3] Instead, family engagement may be a component of family-centered care.[4]

Active family engagement in patient care, communicating the patient's and families' values and goals, and decision-making processes are recognized as invaluable aspects when providing healthcare.[5] Over the last decades, studies have reported the potential benefits of family engagement on patient care in the ICU and post-ICU recovery.[6,7] Several interventions such as family bedside visitation,[8] family presence during resuscitation,[9] ICU diaries,[10] music or pet interventions,[11,12] and patient/family advisory councils[13] have been developed and tested to improve patient and family satisfaction, shorten length of ICU stay, or reduce adverse psychological outcomes

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for both patients and their families. Family engagement is also a core element of the ABCDEF bundle (Assess, Prevent, and Manage Pain; Both Spontaneous Awakening Trials and Spontaneous Breathing Trials; Choice of analgesia and sedation; Delirium: Assess, Prevent, and Manage; Early mobility and Exercise; and Family engagement and empowerment),[14] an evidence-based care coordination and management strategy that aims to improve outcomes for critically ill patients.

Digital technology has become more central in our lives, and the ICU has long been a technology-rich environment. Moreover, the coronavirus disease 2019 (COVID-19) pandemic has accelerated the adoption of digital technologies in healthcare settings. Owing to the COVID-19 restrictions on bedside family presence in the ICU, interventions using digital technologies were documented in the popular press as an alternative to in-person visitation.[15] These interventions have allowed families to have limited views and communication with their critically ill family members.[16,17] COVID-19 pandemic also prohibited other aspects of care from being used, such as family-clinician conferences, family presence at rounds, orientation guides, and ICU diaries. These restrictions are likely to be present in modified forms for the foreseeable future, preventing families from maintaining their roles in treatment decision-making processes as care partners and as voice of patients.

Interventions using digital technology may also enable family engagement, regardless of the families' presence at the bedside. Despite the increasing use of digital technology and the importance of family engagement in the ICU, to our knowledge, no studies to date has extensively examined or synthesized any findings to evaluate the current state of family engagement interventions in the ICU using digital technology. Considering the current gap in the literature, this integrative review aimed to (1) identify and evaluate studies that have used digital technology to promote family engagement and (2) assess the findings on how digital technology-based interventions involved family caregivers to promote family engagement in ICUs.

Methods

Study design

This integrative review was conducted following the methodology of Whittemore and Knafl,[18] which allows for the integration of both quantitative and qualitative research findings. This method was selected to include all quantitative and qualitative perspectives to describe and evaluate the studies that used digital technology to promote family engagement in the ICU.

For this review, we included the following variables of interest: target population (family members of ICU patients), concept (digital technology-based intervention), and context (adult patients admitted to ICUs). Family members were defined as those who primarily provide physical, emotional, financial, or spiritual support to their loved one admitted to the ICU. Considering the rapidly expanding scope of digital technology, we set a quite broad definition which includes tools, systems, devices, or resources using a computer, Internet, or mobile devices to generate, store or process data, or communicate.

Search strategies

An initial search was conducted to determine if there were previous reviews on this topic to avoid duplication. We searched the International Prospective Register of Systematic Reviews (PROSPERO) and the Cochrane Library to ensure the absence of any similar reviews on the family engagement intervention in ICUs using digital technology. Three authors (JS, JC, and JT) designed the search strategies with assistance from a health science librarian.

Table 1
Summary of database search terms.

Databases	Keywords
PubMed	(((((((((((((((((((tele*[Title/Abstract]) OR ("M-health"[Title/Abstract])) OR (mhealth[Title/Abstract])) OR ("M health"[Title/Abstract])) OR ("E-health"[Title/Abstract])) OR (Ehealth [Title/Abstract])) OR ("E health"[Title/Abstract])) OR (digital [Title/Abstract])) OR (web*[Title/Abstract])) OR (app[Title/Abstract])) OR (platform[Title/Abstract])) OR (video*[Title/Abstract])) OR (audiovisual[Title/Abstract])) OR (electronic [Title/Abstract])) OR (mobile[Title/Abstract])) OR (computer [Title/Abstract])) OR (virtual[Title/Abstract])) OR (application[Title/Abstract])) AND ((((((((caregiv*[Title/Abstract]) OR (carer*[Title/Abstract])) OR (relative*[Title/Abstract])) OR (families[Title/Abstract])) OR (family[Title/Abstract])) OR (spouse*[Title/Abstract])) OR (partner*[Title/Abstract]))) AND (((((("intensive care"[Title/Abstract]) OR ("critical care"[Title/Abstract])) OR (ICU[Title/Abstract])) OR ("critical illness"[Title/Abstract])) OR ("critically ill"[Title/Abstract])) AND ((english[Filter]) AND (alladult[Filter]) AND (2000:2021[pdat])) Filters: English, Adult: 19+ years
CINAHL	AB (tele* OR "m-health" OR mhealth OR "m health" OR "e-health" OR ehealth OR "e health" OR digital OR web* OR app* OR platform OR electronic OR video* OR comput* OR mobile OR audiovisual OR virtual) AND (family OR caregiv* OR relative* OR spouse* OR partner* OR families) AND ("intensive care" OR "critical care" OR "critical illness" OR icu) OR TI (tele* OR "m-health" OR mhealth OR "m health" OR "e-health" OR ehealth OR "e health" OR digital OR web* OR app* OR platform OR electronic OR video* OR comput* OR mobile OR audiovisual OR virtual) AND (family OR caregiv* OR relative* OR spouse* OR partner* OR families) AND ("intensive care" OR "critical care" OR "critical illness" OR icu) Limiters - Published Date: 20000101-20211231; English Language; Age Groups: All Adult
SCOPUS	TITLE-ABS-KEY (tele* OR "M-health" OR mhealth OR "M health" OR "E-health" OR ehealth OR "E health" OR digital OR web* OR app OR application OR platform OR electronic OR video* OR computer* OR mobile OR audiovisual OR virtual) AND TITLE-ABS-KEY (family OR caregiv* OR relative* OR spouse* OR partner* OR families) AND TITLE-ABS-KEY ("intensive care" OR "critical care" OR "critical illness" OR icu OR "critically ill") AND NOT (neonat* OR adolescent* OR pediatric OR infant* OR child* OR teen*) AND (LIMIT-TO (PUBYEAR, 2021) OR LIMIT-TO (PUBYEAR, 2020) OR LIMIT-TO (PUBYEAR, 2019) OR LIMIT-TO (PUBYEAR, 2018) OR LIMIT-TO (PUBYEAR, 2017) OR LIMIT-TO (PUBYEAR, 2016) OR LIMIT-TO (PUBYEAR, 2015) OR LIMIT-TO (PUBYEAR, 2014) OR LIMIT-TO (PUBYEAR, 2013) OR LIMIT-TO (PUBYEAR, 2012) OR LIMIT-TO (PUBYEAR, 2011) OR LIMIT-TO (PUBYEAR, 2010) OR LIMIT-TO (PUBYEAR, 2009) OR LIMIT-TO (PUBYEAR, 2008) OR LIMIT-TO (PUBYEAR, 2007) OR LIMIT-TO (PUBYEAR, 2006) OR LIMIT-TO (PUBYEAR, 2005) OR LIMIT-TO (PUBYEAR, 2004) OR LIMIT-TO (PUBYEAR, 2003) OR LIMIT-TO (PUBYEAR, 2002) OR LIMIT-TO (PUBYEAR, 2001) OR LIMIT-TO (PUBYEAR, 2000)) AND (LIMIT-TO (LANGUAGE, "English"))
Web of Science	(TI = ((tele* OR "m-health" OR mhealth OR "m health" OR "e-health" OR ehealth OR "e health" OR digital OR web* OR app OR application OR platform OR electronic OR video* OR computer* OR mobile OR audiovisual OR virtual) AND (family OR caregiv* OR relative* OR spouse* OR partner* OR families) AND ("intensive care" OR "critical care" OR "critical illness" OR "critically ill" OR icu))) OR (AB = ((tele* OR "m-health" OR mhealth OR "m health" OR "e-health" OR ehealth OR "e health" OR digital OR web* OR app OR application OR platform OR electronic OR video* OR computer* OR mobile OR audiovisual OR virtual) AND (family OR caregiv* OR relative* OR spouse* OR partner* OR families) AND ("intensive care" OR "critical care" OR "critical illness" OR "critically ill" OR icu))) OR

(continued)

Table 1 (*Continued*)

Databases	Keywords
	(AK = ((tele* OR "m-health" OR mhealth OR "m health" OR "e-health" OR ehealth OR "e health" OR digital OR web* OR app OR application OR platform OR electronic OR video* OR computer* OR mobile OR audiovisual OR virtual) AND (family OR caregiv* OR relative* OR spouse* OR partner* OR families) AND ("intensive care" OR "critical care" OR "critical illness" OR "critically ill" OR icu))) AND LANGUAGE: (English) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, BKCI-SSH, ESCI, CCR-EXPANDED, IC Time-span=2000-2021

We searched four databases: PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, and Scopus. In Table 1, we summarized the combination of search terms for each database. We matched search terms to database-specific indexing terms. To identify additional relevant papers, we manually searched reference lists of the retrieved papers that met the inclusion criteria.

The inclusion criteria were studies that were (1) conducted in the adult ICU setting, (2) involved family engagement during the patient's ICU admission, (3) involved technology use as a way to engage and communicate with family members, (4) were published in English, and (5) published between January 2000 and January 2021. The exclusion criteria were as follows: (1) studies of case reports, reviews, editorials, theses, descriptive commentary, prototypes, conference abstracts, unpublished master's theses or doctoral dissertations, (2) studies that were conducted in non-adult ICU settings (e.g., neonatal or pediatric ICUs), (3) studies involved family engagement during post-ICU discharge and (4) studies did not include family members as the main target sample. We limited our scope to adult ICU settings because family engagement in pediatric or neonatal ICUs is different from adult ICUs, and providing care for a child undergoing ICU admission involves different challenges (e.g., altered parent-child bonding).

Study screening and selection

For screening and selection, all the studies were imported into Covidence, an online systematic review software (www.covidence.org). First, each author independently screened all the titles and abstracts using the eligibility criteria. After excluding the irrelevant papers, each author independently screened the full texts of the initially screened papers. For each step, following the independent screening process, all three authors discussed any discrepancies and reached a consensus on the eligibility of each study. The final sample consisted of 15 papers.

Quality evaluation of the selected studies

The three authors independently evaluated the quality of the selected studies using the Mixed-Methods Appraisal Tool (MMAT) version 2018,[19] and discussed any discrepancies before reaching a consensus. The MMAT tool allows for the evaluation of multiple study designs, including quantitative, qualitative, and mixed-methods designs. Different quality criteria are applied for different study designs, which helps to consider the unique characteristics of each design. The MMAT comprises two sections. The screening section consists of two screening questions regarding the clarity of the research questions and the sufficiency of the collected data to address

the research questions. The second section comprises five sets of quality criteria with three response options (yes, no, or can't tell) for each study design. An overall quality score was assigned to each study using asterisks that ranged from "none" (none of the quality criteria were met) to "*****" (all five criteria were met).[19]

We also reviewed the interventions described in these papers using the Template for Intervention Description and Replication (TIDieR) guidelines and checklist[20] (Table S1, see Multimedia Appendix 1). The TIDieR guidelines were established to determine the quality of the intervention description in order to improve replicability. The checklist includes the areas that should be addressed in sufficient detail to evaluate intervention reporting by researchers.

Data extraction and synthesis

One author (JS) extracted data, and then two authors (JC and JAT) validated the extracted data. Fig. 1 presents an overview of the search results and selection process used in this study in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram.[21] Overall, 3979 possible citations were identified from the databases (PubMed, 670; CINAHL, 1030; Web of Science, 893; Scopus, 1386). Of these studies, 2702 remained after removing 1277 duplicate records. After title screening and abstract review, a further 2653 and 28 studies were excluded, respectively. Of the 21 papers assessed for eligibility, seven were excluded for the following reasons: not directed at family members (*n* = 3), not a full research paper (*n* = 2), lacking an exclusively technology-based strategy (*n* = 1), and conducted in a non-adult ICU setting (*n* = 1). An additional record was identified by citation searching. Finally, a total of 15 studies were included in the review.

For the final review, we extracted the following data from the selected articles: author, year of publication, region, design, sample, setting, measures and data collection methods, main findings, and study quality. We also extracted the characteristics of digital technology-based interventions in each study: purpose, main content, target users, types of technology, interaction, and personalization, if any.

To determine the comprehensiveness of each intervention used in the selected studies, we used an analytical framework, the family engagement model introduced by Brown et al.[1] The model, which was developed with the input of key stakeholders, including families, clinicians, researchers, and administrators, comprises five conceptual components of family engagement in the ICU: collaboration, respect and dignity, activation and participation, information sharing, and decision making.[1] Collaboration includes the coordination of care by health professionals and active participation with patients and their families. By respecting the individuality of patients and their families and treating them with compassion, health professionals support their choices and individual needs. Additionally, by encouraging patients and their families to acquire skills and knowledge, family members can become active participants and provide "voice" to the care plans. Health professionals communicate essential information to patients and their families that can contribute to increased understanding, decreased uncertainty, and assist with decision making. Finally, health professionals further provide individualized information and encouragement to assist in treatment decision-making.

Results

Study characteristics

The 15 selected studies include 8 non-experimental (3 quantitative descriptive, 3 qualitative, and 2 mixed-methods) and 7 experimental (3 quasi-experimental and 4 randomized controlled trials) studies. For non-experimental studies, the common aims were to investigate the participants' perceptions or user experiences with interventions using various technologies (e.g., text messages and
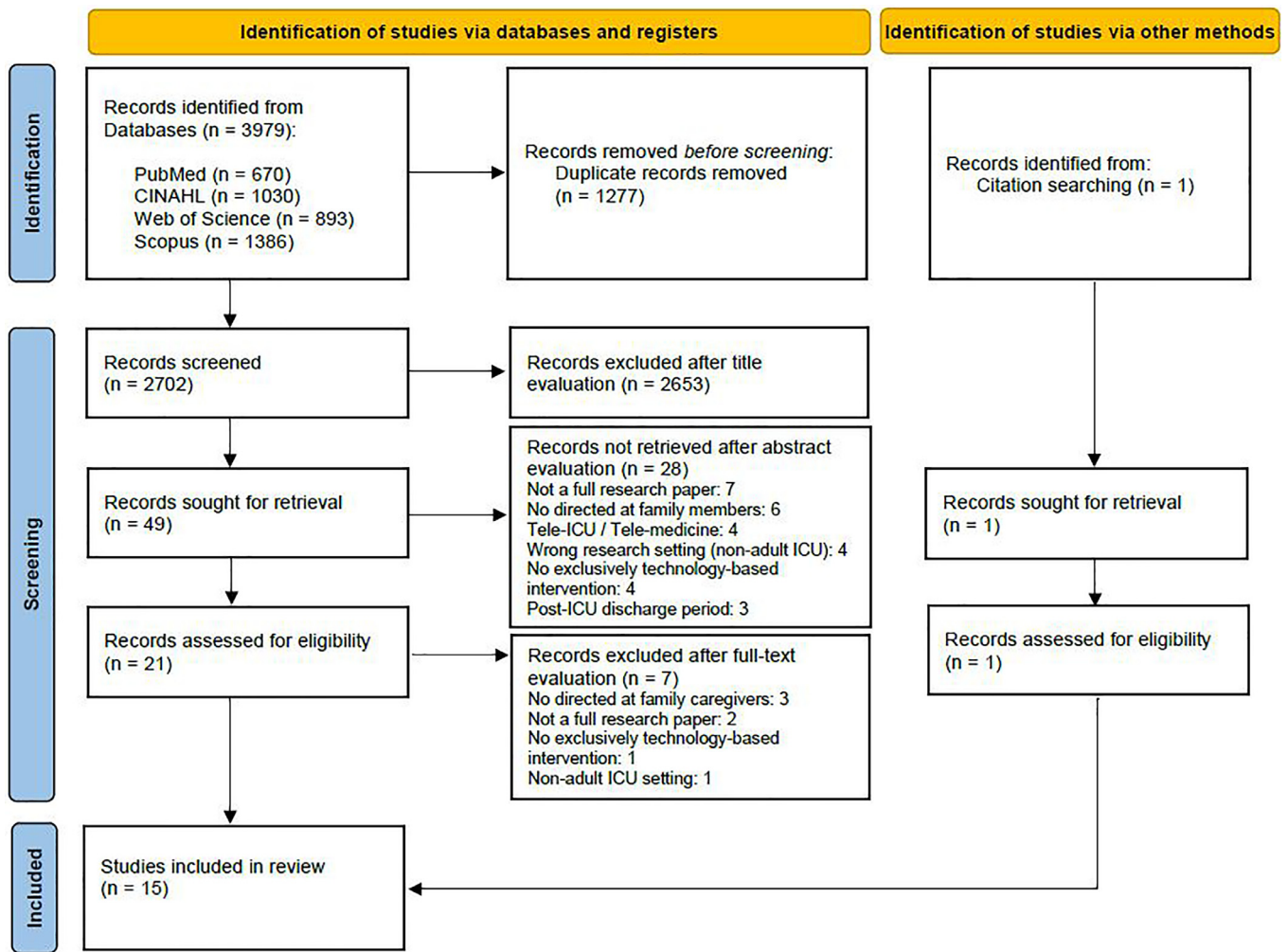
Fig. 1. PRISMA flowchart of the literature search and study selection process.

interactive decision-making tools). Seven experimental studies tested the interventions to provide education,[22−24] support decision making,[25−27] and deliver family meetings.[28]

Characteristics of selected studies are summarized in **Table 2**. The studies included varying sample groups. While seven studies included only family members, eight studies also included patients and/or clinicians in addition to family members. Most studies had not identified the family members' relationships with patients. In four studies that provided details about the family members' relationships with the patients, most of the family participants were patient spouses. Several of the family members were classified as surrogate decision-makers ($n = 5$). Most studies included the patient's clinical characteristics, such as ventilatory status or decisional capacity, as part of the family inclusion criteria. The sample sizes in each study ranged from 26 to 156 for quantitative descriptive, 19 to 230 for qualitative/mixed-methods, and 52 to 416 for experimental studies. The types of ICUs included medical,[25,29−32] surgical,[33] cardiovascular,[22,29,34] neuro,[25,28] oncology,[30] and COVID-19[35] ICUs. Eight studies were conducted at a single site in a single unit,[22,23,28,31−35] five at a single site in multiple units,[25,27,29,30,36] and two in multiple centers.[24,26] Most of the studies were conducted in the United States (10 out of 15), and the rest were conducted in other countries, including Italy ($n = 2$), Australia ($n = 1$), China ($n = 1$), and Iran ($n = 1$). The majority of the studies were conducted between 2015 and 2020 ($n = 14$).

Characteristics of interventions

The various types, purposes, and features of each intervention were captured in the selected studies (**Table 3**). The interventions included web-, tablet-, SMS-, or video-based technologies to help families understand the ICU environment, illness, or treatment plan and augment participation and decision-making in family meetings. Telepresence using video conference, telephonic, or robotic technologies was also used for virtual access to the patient or to provide patient updates and information during multidisciplinary rounds or family conferences. Several interventions in the selected studies provided individualized information or tailored coaching based on the needs and input into the tools by the patients or their families.[23,26,30,31,35,36] For example, if the family member indicated that the patient was receiving a particular therapy, information about this therapy could then be accessed.[23] However, this information was not tailored or individualized. In the interventions that enabled two-way communication among users,[25−27,30,31,33,35,36] the features enabled an exchange of questions and answers among families and clinicians or allowed the clinicians to view the families' input and prepare for the family conference in advance. In some studies, interventions involved virtual visits/telepresence using video calls, phones, or robots to enable collaboration between clinicians and families in real time to enhance treatment decision-making and facilitate family meetings.[28,32,33,35]

Table 2
Summary of selected studies.

Author (year)/ Country	Study design	Purpose	Sample/ Setting	Measures and data collection	Findings	MMAT Quality appraisal (Max *****)
Bastin et al. (2019) / USA	Cross-sectional study	To evaluate perceptions of television-based education among patients, caregivers, nurses, and other care providers in the ICU.	*Providers (n = 114): Staff nurses (n = 97), other health care professionals (n = 17) *Patients and caregivers (n = 74) Medicine & cardiovascular ICUs at an academic medical center	Likert scale survey of perceptions of the effects of television-based education on patient/family anxiety, satisfaction, knowledge, and health-related decision making. Patient and caregiver surveys were administered directly through the television screen in the patient's ICU room after they watched educational videos.	62% of patients and families strongly agreed that the videos increased satisfaction, 61% rated the quality of the videos highly, 71% strongly agreed that the videos were easy to understand, and 39% strongly agreed that they preferred television based education to traditional methods. Patients and caregivers are more optimistic than providers regarding the benefits of television-based education (P < .001).	***
Carlucci et al. (2020) / Italy	Qualitative	To present analysis of family satisfaction during the pilot stage of remote family conference and? patient visits project	Family members (n = 19) ICU of the COVID hospital	Questionnaire assessing the quality of service perceived by the user Qualitative evaluation of the project via telephone survey	The information given to families were considered 100% excellent. Continuous contact with the patient and the physicians alleviated the suffering status of families. Qualitative evaluation showed that more frequent interviews with medical staff and news updates through SMS would be desirable.	N/A (didn't pass the screening questions)
Chiang et al. (2017)/ China	A randomized controlled trial	To determine whether 'education of families by tab' about the patient's condition was more associated with improved anxiety, stress, and depression levels than the 'education of families by routine'.	Main family caregivers (n = 74) : 'education of families by tab' intervention (n = 39) vs. 'education of families by routine' control (n = 35) An ICU in a public district hospital	Family anxiety and depression: Depression Anxiety Stress Scale − Chinese (C-DASS) was administered pre- and post-intervention Family satisfaction: Society of Critical Care Medicine's Family Needs Assessment Questionnaire (SCCMFNA) - Communication and Physical Comfort Domain was completed post-intervention	Intervention group did not show significantly lower stress and anxiety scores compared to control group. Significant group interaction effect was observed from the 2 depression subscale measurements (P < 0.01; P = 0.09) with a medium effect size. Information need satisfaction was not significantly different (intervention mean 26.53, SD 5.66; control mean 26.68, SD 4.95; P = 0.327).	*****
Cox et al. (2019) / USA	Multicenter, parallel, randomized clinical trial.	To determine effects of a web-based decision aid about prolonged mechanical ventilation (PMV) on prognostic concordance between surrogate decision makers (SDMs) and clinicians.	Patients on PMV (n = 277) Surrogates (n = 416) Clinicians (n = 427) Intervention (138 patients, 137 primary SDMs, 73 additional SDMs) vs. Control (139 patients, 138 primary SDMs, 68 additional SDMs) 13 medical, surgical, trauma, cardia, and neurologic ICUs at 5 hospitals	Concordance on 1-year survival estimates: Clinician-surrogate concordance scale Surrogates experience -uncertainty in decision making: decisional conflict scale -satisfaction with clinician communication: quality of communication questionnaire -comprehension of diagnosis, treatment, and prognosis: medical comprehension scale -psychosocial distress: Hospital Anxiety and Depression Scale, posttraumatic stress symptom inventory	Concordance improvement did not differ between intervention and control groups (P = 0.60). Intervention primary surrogates had greater reduction in decisional conflict than control surrogates (P = 0.041). No significant group differences on medical comprehension, communication, or surrogates' psychosocial distress were found.	****

Table 2 (*Continued*)

Author (year)/ Country	Study design	Purpose	Sample/ Setting	Measures and data collection	Findings	MMAT Quality appraisal (Max *****)
Dalal et al., (2016) / USA	Mixed - methods	To evaluate a web-based, patient-centered toolkit (PCTK) for enrollment strategy, use and usability of patient tools, and the content of patient-generated messages.	Patients and family care-givers (*n* = 239) :119 patients, 120 care-givers MICU (*n* = 103; 26 patients, 77 caregivers) and Oncology units (*n* = 136; 93 patients, 43 caregivers)	Usage of the PCTK by participants System Usability: System Usability Scale (SUS) Satisfaction: Likert scale satisfaction rating Qualitative analyses: message contents and all patient feedback	Of 239, 200 patients (84%) used the PCTK for 1-4 days and 158 (66%) sent at least one message to providers. Use of educational content was highest for medications and test results. The mean SUS score was 74.0 (16.7) and 72% of respondents were satisfied or extremely satisfied with PCTK. The most common clinical theme identified in messages sent by patients and caregivers within the PCTK was health concerns, needs, preferences, or questions.	***
de Havenon et al. (2015) / USA	Prospective, non-randomized, pilot study	To test the effects of virtual family meeting with conference calling or Skype videoconferencing on family satisfaction and efficiency of decision making about patient care.	Family members who opted for audiovisual intervention (*n* = 29) vs. control (*n* = 59) A neurocritical care unit at a large academic hospital	Family meeting survey (6 items) assessing satisfaction with the meeting and decision-making process Survey was administered after the standard family meetings (1st stage) and after the second meeting with videoconference option (2nd stage) whether or not they opted for the audiovisual intervention	No significant group differences were found between groups on the family satisfaction with the decision-making process, making decisions that were reflective of the patient's wishes, unresolved issue, agreement on patient wishes, and overall satisfaction.	N/A (didn't pass the screening questions)
Ernecoff et al. (2016) / USA	Qualitative	To explore key stakeholders' perceptions of an interactive tablet-based and video-driven communication and decision support tool	Surrogates and care providers (*n* = 58) : 30 surrogates and 28 care providers MICU in a university hospital	One-on-one in-depth, semi-structured interviews asking -perceptions about the acceptability and usefulness of the tool -design suggestions for refinements of such a tool Interviews were conducted by one trained researcher in a private room adjacent to the ICU or by telephone	95% (55/58) of participants perceived the proposed tool to be acceptable Identified potential benefits include being helpful for families to prepare for the surrogate role and for family meetings, giving surrogates time and a framework to think about the patient's values and treatment options. Key design suggestions included: conceptualizing the tool as a supplement to rather than a substitute for communication; making access the tool flexible; incorporating interactive exercises; using video and narration to minimize the cognitive load; and building an extremely simple user interface	*****
Gorman et al. (2020)/ Australia	Prospective observational study	To test 1) whether real-time SMS updates could be efficiently delivered to families and 2) these SMS updates would be accepted and welcomed by families	Patients (*n* = 91) and family (*n* = 156) Cardiac surgery ICU	Likert scale questionnaire asking participants' perceptions of the SMS service Families were followed up with a telephone call after the discharge and questionnaire was administered	All five SMS messages were successfully sent for 91 patients to 114 participants (73%). Families perceived SMS service as reassuring, easy to follow, and helpful to keep participants informed. Almost all felt the SMS service did not increase anxiety. All disagreed with the SMS service being intrusive and would recommend the service to other families.	****

Table 2 (*Continued*)

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Author (year)/ Country	Study design	Purpose	Sample/ Setting	Measures and data collection	Findings	MMAT Quality appraisal (Max *****)
Mistraletti et al. (2017)/ Italy	Prospective multicenter before-and-after study	To assess the effectiveness of information brochure and website on communication intended to improve the psychological outcome and family members' understanding of what is happening to long-stay ICU patients	Relatives: Before (control, $n = 144$) vs. after (intervention, $n = 179$) Nine ICUs in both urban and rural hospitals, university and non-university hospitals)	Family understanding of medical information: comprehension assessment interview (CAI) Family healthcare satisfaction: critical care family needs inventory (CCFNI) Family anxiety and depression: hospital anxiety and depression scale (HADS) Family post-traumatic symptoms: short screening scale for PTSD Relatives completed questionnaires after they attended an interdisciplinary family conference.	Of the 179 relatives, 131 (73%) stated they had read the brochure and 34 (19%) reported viewing the website. The intervention was associated with an increased correct understanding of the prognosis ($P = 0.04$) and the therapeutic procedures ($P = 0.03$). The intervention was significantly associated with a lower incidence of post-traumatic stress symptoms (Poisson coefficient = −0.29, 95% CI −0.52-0.07). The intervention had no effect on the prevalence of symptoms of anxiety and depression.	*****
Pignatiello et al. (2019) / USA	Cross-sectional data analysis of a longitudinal randomized controlled trial	To compare the differences in cognitive load reported by SDMs of the critically ill exposed to two different decision support interventions (video-based VS. avatar-based aids), while controlling for their age.	Surrogate decision makers ($n = 97$) Video-based aid ($n = 47$) Avatar-based aid ($n = 50$) 4 ICUs in a tertiary medical center	Cognitive Load Scale (CLS): measuring intrinsic and extraneous cognitive load CLS was administered immediately after the electronic decision aid	Intrinsic and extraneous cognitive load of video-based decision support were lower than avatar-based decision support. While controlling for age, mean levels of intrinsic cognitive load were not significantly different from one another ($P = .14$), whereas extraneous cognitive load was significantly different from one another between the two study groups ($P = .001$).	***
Sasangohar et al. (2020) / USA	Qualitative	To document family members' experience with virtual ICU visits during COVID-19 pandemic	Family caregivers ($n = 230$) Virtual ICU	A short interview designed to elicit - family members' feelings experienced during the virtual visit - barriers, challenges or concerns faced using virtual-ICU visit - opportunities for improvements Family members were interviewed post-visit via phone	Over 86% of participants had positive sentiments and shared feelings of happiness, joy, gratitude and relief to be able to visit their family members. Reported barriers include inability to communicate due to patient status, technical difficulties, lack of touch and physical presence and frequency and clarity of communication with team. Suggested improvements included on-demand access, improved communication with a care team, improved scheduling process, and improved system feedback and technical capabilities.	*****
Sucher et al. (2011) / USA	Prospective observational study	To assess how patients and families would perceive robotic telepresence aiding morning rounding process	Patients ($n = 24$) and their families ($n = 26$) Surgical ICU in a tertiary hospital	Likert scale survey asking opinions and attitudes toward the use of robotic telepresence Patients and families who had interaction with the robot completed survey anonymously	93% of participants were comfortable with the robot, and 84% reported that communication was easy. 90% did not perceive the robot as annoying and 92% did not believe that the doctor cared less about them because of the robot. 92% supported the continued use of the robot.	****

Table 2 (*Continued*)

Author (year)/ Country	Study design	Purpose	Sample/ Setting	Measures and data collection	Findings	MMAT Quality appraisal (Max *****)
Suen et al. (2020a)/ USA	Mixed-methods	To develop and pilot-test the Family Support Tool, an interactive web-based tool to help individuals navigate the complexities of surrogate decision making in the ICU	Phase 1: 30 surrogates and 28 ICU care providers Phase 2: 3 people with surrogate decision-making experience 1 intensivist, 1 palliative care physician, 1 ICU nurse, 1 social worker and 1 pastor. Phase 3: 6 surrogates Phase 4: development Phase 5: 9 surrogates and 4 ICU physicians	Phase 1: design of the preliminary schematic of the tool Phase 2: engage key stakeholders to refine the preliminary design Phase 3: user testing of low-fidelity prototype Phase 4: creation of a high-fidelity prototype Phase 5: user testing of high-fidelity prototype	Technology development successful Surrogates judged the final tool as highly usable, acceptable and effective. The tool helped them to consider goals of care. Surrogates actively making decisions in the ICU judged the final tool to be highly usable, acceptable and effective. All surrogates reported the tool helped them consider goals of care and all indicated they would recommend the tool to a friend.	*****
Suen et al. (2020b)/ USA	Two-arm single blind patient level randomized trial	To assess the feasibility, usability, acceptability, and perceived effectiveness of a communication intervention that pairs proactive family meetings with an interactive web-based tool to help surrogates prepare for clinician-family meetings.	Patients and their primary surrogates (*n* = 57) : intervention (*n* = 27) vs. control (*n* = 25) 1 neuroscience ICU and 1 medical ICU in a tertiary hospital	Usability and acceptability: System Usability Scale (SUS) and acceptability questionnaire were administered before the first family meeting Perceived effectiveness: internally generated Likert scale questionnaire was administered to intervention group immediately after the first and second family meeting Quality of communication questionnaire: Quality of Communication questionnaire was administered to both intervention and control group at 3-mos follow-up	Surrogates reported that the tool was highly usable, acceptable, and effective. Compared to the control group, the intervention group reported higher overall quality of communication and higher quality in shared decision-making, but difference was not statistically significant	*****
Ziyaefard et al. (2019) / Iran	Quasi-experimental	To evaluate the effects of virtual social media-based education on anxiety and satisfaction among family members of patients in the ICU following coronary artery bypass graft surgery (CABG).	Family members of post-CABG patients in the ICU (*n* = 100) Intervention (*n* = 50) vs. control (*n* = 50) ICU of Cardiovascular, Medical, and Research Center	Family anxiety: Spielberger State-Trait Anxiety Inventory (STAI) Family satisfaction with ICU: ICU family satisfaction questionnaire	Intervention (virtual education) was effective in improving family satisfaction ($P <0.001$). Intervention group had lower degrees of anxiety than the control group ($P < 0.001$).	***

Findings of the selected studies

Non-experimental studies

Most non-experimental studies examined the participant's perceptions of the intervention. The acceptability and usability of the digital technology were assessed via qualitative interviews[31] or using quantitative instrument, such as the System Usability Scale (SUS),[30] and participants reported good acceptability and usability. Other outcomes reported include families' perceptions toward the intervention itself,[33] service quality,[34,35] effects of the digital technology on knowledge and decision-making,[29] and barriers/concerns or suggestions to the digital technology.[31,32] In two studies, satisfaction with the intervention was also reported as an outcome using investigator-developed Likert scale questionnaires[29,30] and reported satisfaction in a majority of participants (62%[29] and 72%[30]).

Emotional responses of families were assessed in three studies using either qualitative interviews[32] or internally developed surveys.[29,34] One study reported that television-based education helped 63% of participants reduce their anxiety using a self-reported survey question.[29] Another study assessed if the SMS messages of patient treatment and progress sent to family members were intrusive or made them feel anxious, and over 72% of participants responded the SMS did not induce negative emotions.[34] Qualitative findings of another study reported that over 86% of participants had positive sentiments about being able to visit their loved one virtually, but some had mixed feelings since seeing the patient intubated contributed to sadness.[32] In the same study, the technology provided a degree of closure for many who lost their loved ones.

Experimental studies

One study considered intervention usability measured using the SUS and perceived effectiveness using an internally generated Likert scale questionnaire.[25] The family support communication tool was highly usable (mean SUS summary score 82.4) and effective (mean score 4.4 ± 0.2, where 1 'not at all' to 5 'extremely well').

Satisfaction was considered as an outcome in four experimental studies, including satisfaction with the decision-making process (self-developed questionnaire),[28] healthcare satisfaction (Critical Care Family Needs Inventory),[24] family satisfaction with ICU (ICU family satisfaction questionnaire),[22] and satisfaction with informational needs (communication and physical comfort domain of Society of Critical Care Medicine Family Needs Assessment).[23] One study that tested a virtual social network-based education reported improved family satisfaction when the changes in the median of the satisfaction scores before and after the intervention were compared between groups ($P < 0.001$).[22]

Family members' psychological outcomes were measured in several experimental studies. Anxiety was considered as an outcome in four studies using well-validated measures, including Hospital Anxiety and Depression Scale (HADS),[24,26] Spielberger State-Trait Anxiety Inventory,[22] and Depression Anxiety Stress Scale (DASS).[23] Among four studies that compared between-group outcomes, only one study that tested the virtual social network-based education reported significant reduction of anxiety in the intervention group ($P < 0.001$).[22] Effects of the intervention on depression was examined in three studies using HADS[24,26] and DASS.[23] No significant effect on depression was found in all three studies, but one study found a significant group interaction effect.[23] PTSD-related symptoms were reported in two studies using the Post-traumatic Stress Symptom Inventory[26] and the short screening scale,[24] respectively. One study found an association between the intervention and a lower incidence of PTSD-related symptoms in families during the ICU stay.[24]

Family involvement outcomes were also included as either primary or secondary outcomes in several experimental studies. Families'

understanding of medical information was measured in two studies using the Comprehension Assessment Interview[24] and the medical comprehension scale,[26] respectively. Communication with clinicians (Quality of Communication questionnaire),[25,26] prognostic concordance between families and clinicians (Clinician-surrogate Concordance Scale),[26] uncertainty in decision making (Decisional conflict scale),[26] and family cognitive load (Cognitive load scale)[36] were also reported in experimental studies. Additionally, studies also reported the intervention effect on improving correct understanding of the prognosis and the therapeutic procedures[24] and a reduction in decisional conflict.[26]

Study evaluations

Based on the MMAT study quality ratings, six of the studies met 100% of the criteria (*****), three met 80% (****), and four met 60% (***) (**Table 2**). Two of the studies did not pass the screening questions.[28,35] None of the studies addressed all the items on the TIDieR checklist (**Table 3**). All of the studies described the intervention and identified the problem. The studies included details about the digital technologies involved and the deliverers of a given intervention. Seven studies included interventions tailored to the specific needs of the family. Most studies included a single intervention session, although there were two studies that used iterative processes to refine the technology. Only one study included planned monitoring of intervention fidelity, but the results of the plan were not reported.

Conceptual elements of ICU family engagement

As summarized in Table 4, we analyzed how the selected studies addressed each element of family engagement in their intervention using the framework by Brown et al.[1] Interventions in most studies (9 of 15) addressed one or two elements.[22−24,28,32−36] "Information sharing"[22−27,29−31,33−36] and "activation and participation."[22,25−31,35] were the most commonly addressed elements. Four studies addressed all five elements in their interventions which were on supporting shared the process of shared decision-making.[25-27,30] The rest of the interventions involved only one or two engagement components.

Discussion

Since the first official guidelines of family support in the ICU were published in 2007,[3] family members have been well acknowledged as essential care partners to improve outcomes for critically ill patients. Living in a time of digital transformation, which promises expanded potentials of better connection, communication, and customization using digital technologies, various efforts have been made to use digital technology to engage family members of the critically ill. In this integrative review, we identified and evaluated studies investigating digital technology-based interventions to promote family engagement in the ICU. Overall, the studies varied in their designs, objectives, and types of technology used. Our review is timely because this is one of the first integrative reviews that evaluated digital technology-based ICU family engagement interventions over the past 20 years based on an established conceptual framework.

In our review, across the variety of digital technologies, most commonly involved engagement element was information sharing. Only four studies[25−27,30] addressed all five family engagement components while the rest of the interventions involved only one or two of the engagement components. The study that introduced virtual visitations using smartphones, tablets, or computers during the COVID-19 pandemic[32] addressed the respect and dignity family engagement component by providing patients and their families the opportunity to interact with one another and remain connected. The studies used

Table 3

Summary of family-engagement Interventions.

Author (year)	Intervention	Purpose	Main content	Target users	Interaction (two-way communication)	Personalization (tailoring)	TIDieR framework (1-12)
Bastin et al. (2019)	Video (television) -based education program	To combine video instruction to patient/family education	Introduction to the ICU; fall prevention; pain management; preventing health-acquired infections	Patients and families	Not described	Not described	8
Carlucci et al. (2020)	Remote family conference and patient visits via phone and video calls	To enhance family members' participation and provide daily clinical updates	Daily clinical updates; medical information pertinent to the patient's condition;	Family, patient, clinicians	Communicating families' concerns with clinicians	Provision of medical information pertinent to the patient's condition	9
Chiang et al. (2017)	Tablet-based family education package	To educational and informative content by comprehensive and standardized information and systematic way of provision using audiovisual features	Information about ICU care and specific information of patient's disease or specific treatment	Family	Not described	Content was explained depending on the needs of individual patients	8
Cox et al. (2019)	Interactive web-based decision aid	To support the shared decision-making process for prolonged mechanical ventilation	Definition of prolonged ventilation; decision options for goals of treatment; function of surrogates in decision making; family support needs	Family	Basis of an algorithm informed by responses within the tool	Individualized prognosis	8
Dalal et al. (2016)	Patient-centered toolkit: A web-based patient-facing and provider-facing tools	To enhance collaborative decision making via education and patient-family-provider communication	Navigate plan of care; establish recovery goals, input preferences and rate priorities; access medical records; educational content	Family, patient, clinicians	Exchange questions and answers among patients, families, and clinicians; Communication among clinicians	Tailored safety tips and reminders	10
de Havenon et al. (2015)	Conference calling or Skype teleconferencing before provider-family meeting	To improve robust decisions about patient care by increasing families' participation in the decision-making process and enhancing the effectiveness of family meetings	Not described	Family, clinicians	Not described	Not described	8
Ernecoff et al. (2016)	Interactive, tablet-based communication and decision support tool	To prepare the family for conversations with clinicians; to give clinicians tailored information about the family and patient before the family meeting; to promote a personalized relationship between clinician and family	Orientation to the ICU; principles of surrogate decision making; question prompt list and opportunity to write down questions; a values clarification exercise; education about treatment pathways; eliciting surrogates prognostic information; psychosocial resources.	Family, clinicians	The tool is programmed to interact with families; Clinicians can view families' input	Tailored information was communicated with clinicians	9
Gorman et al. (2020)	Real-time SMS updates	To simply provide five pre-written messages related to key information about patient care to families during the ICU care	Five specific clinical landmark events were sent at ICU admission; extubation; morning ward round; decision to discharge; and discharge from the ICU.	Family	Not described	Not described	8

Table 3 (*Continued*)

Author (year)	Intervention	Purpose	Main content	Target users	Interaction (two-way communication)	Personalization (tailoring)	TIDieR framework (1-12)
Mistraletti et al. (2017)	Website information tool	To provide families with knowledge of the ICU environment and patient's illness and enhance communication between providers and families	Knowledge of ICU environment and treatment; family's role during the ICU care; illustration of post-ICU discharge expectations; emotional validation; stories of former ICU patients or relatives	Family	Not described	Not described	8
Pignatiello et al. (2019)	Two electronic decision aid tools: video-based avatar-based	To support communication and decision-making between surrogates and clinicians	Video-based decision aid: a short visual content discussing strategies for effective communication between providers and families, advocating for loved ones, and alternatives to consider. Avatar-based decision aid: an interactive virtual decision support led by an avatar decision coach; sharing patients' story, patient's background, assessing their needs, discussing care plan	Family, clinicians	Video-based decision aid: Not applicable Avatar-based aid: two-way communication between family caregivers and a critical care team to discuss the care plan	Video-based decision aid: Not applicable Avatar-based aid: to provide decision coaching based on family caregiver's input and needs	8
Sasangohar et al. (2020)	Virtual ICU technology: Virtual visitation via smartphones, tablets, or computers	To enable virtual family members in the ICU room	Not applicable	Family, patient	Not applicable	Not applicable	7
Sucher et al. (2011)	Robotic telepresence multidisciplinary roundings	To augment the multidisciplinary rounding process	Not applicable	Family, patient, clinicians	Real-time two-way audio-video communication among patients, families, and clinicians	Not applicable	9
Suen et al. (2020a,b)	Interactive web-based family support tool	To support communication and shared decision-making for surrogates	Orientation to the ICU, emotional support, self-care tips, and families' expectations, questions, and understanding of patient's values and preferences,	Family, clinicians	Surrogates complete modules prior to a scheduled family meeting; Clinicians receive a one-page summary of surrogates' responses prior to family meeting surrogates' responses	Not described	8,9
Ziyaefard et al. (2019)	virtual social network-based education program via social media	To alleviates family caregiver anxiety and satisfaction	information about ICU conditions, hospital rules, and postoperative clinical situations, principles of taking care of patients at home and hospital, necessary diet and medications, level of patients' activity at home, wound management, rehabilitation of patients	Family caregivers	Not described	Not described	8

Table 4
Conceptual elements of the family engagement framework addressed by the selected studies.

Author (year)	Decision making	Information sharing	Collaboration	Respect and dignity	Activation and participation
Bastin et al. (2019)	V	V			V
Carlucci et al. (2020)		V			V
Chiang et al. (2017)		V			
Cox et al. (2019)	V	V	V	V	V
Dalal et al. (2016)	V	V	V	V	V
de Havenon et al. (2015)	V				V
Ernecoff et al. (2016)	V	V	V		V
Gorman et al. (2020)		V			
Mistraletti et al. (2017)		V	V		
Pignatiello et al. (2019)		V			
Sasangohar et al. (2020)				V	
Sucher et al. (2011)		V		V	
Suen et al. (2020a)	V	V	V	V	V
Suen et al. (2020b)	V	V	V	V	V
Ziyaefard et al. (2019)		V			V

tablet-based tools suggest that the same digital tool can either be simply designed for one-way information delivery[23] or more complexly designed with extended features, such as video-driven communication or as decision-support that require collaborative communication and active partnerships between healthcare professionals.[31]

Although acceptability and usability were elicited from the families participating in these studies, only a few achieved constant family feedback during the process of designing the intervention.[25,27] User-centered design, participatory technology development, or human-centered design, which consider the user an integral part of the design process, are commonly used terms in developing interventions using digital technology.[37] Designers using such an approach actively seek input from users, both in controlled and natural settings, to determine which technological features are usable and attractive to the intervention. When introducing digital technology to improve family engagement, adopting user-centered design principles is essential for crafting an intervention that is reliable, less complicated, and, therefore suitable for families to use.

The potential for digital technology to contribute to stress in ICU family members may be a legitimate concern. In this review, only a few studies mentioned family emotional reactions to the use of digital technology. One study assessed whether the intervention itself (SMS messages) was intrusive or made family caregivers feel anxious using survey questionnaire.[34] Another study found that the technology (virtual ICU visitation) contributed family feelings of sadness while exploring their feelings by qualitative interviews.[32] Moreover, most studies did not take into account individual characteristics such as education level, age or comfort with technology. Future studies need to include assessment of potential emotional distress while using technology and consider any facilitators or barriers that might influence the access or acceptance of digital technology.

The effectiveness of digital technologies has been shown in informal caregivers of persons with dementia.[38] Similar to the studies in our review, many of these interventions supported the information needs of informal caregivers and described important support services. However, unlike the studies in our review, the focus of interventions for dementia caregiver population has been to increase social support, deliver psychological therapy, and assist with the behavioral management of the care recipient.[39] These studies targeted important caregiver outcomes such as social support, caregiver burden,[40] and depression.[41] In contrast, in our review, only a few studies[22–24,26] examined the effects of the intervention on family members psychological outcomes such as anxiety, depression, and PTSD-related symptoms. This is likely due to the infancy of digital technology research in families of the critically ill. Although several experimental studies reported promising results in family satisfaction,[22] anxiety,[22]

and family involvement outcomes,[24,26] most studies included in this review were still at the early stage of intervention development or mainly focused on usability testing. Moreover, many studies used investigator-developed survey questions instead of validated measures, which limits our ability to compare and synthesize study findings. Given the current state of the evidence, more rigorous experimental studies are warranted.

The COVID-19 pandemic revealed the critical importance of family presence on promoting the comfort of patients and families and reducing distress in ICU staff.[42–44] During the pandemic, families were only able to contact their loved ones using digital technologies with phone- or tablet-based applications. Considering the time and traveling costs of making in-person visits that many families experienced prior to the pandemic-mandated visitation restriction, technological strategies were an attractive alternative to in-person family visits that can provide seamless connection among families, patients, and ICU staff. However, to our knowledge, no studies have engaged families in the design considerations for technological strategies for remote visitation.

This review had several limitations. Although we included four major databases, we did not include all databases available for our search strategy. Therefore, we might have missed some studies that met our inclusion criteria. We limited our search to the use of digital technology-based strategies in only ICU inpatient settings and not during post-ICU periods. Considering the crucial role that families play during recovery from critical illness, there may be value in including studies conducted during post-ICU periods. The search was limited to only the inpatient phase of critical illness owing to the differences in the goals and contexts of care for family engagement after ICU discharge.[36] Future reviews should focus on family engagement strategies for post-ICU recovery and outcomes. Since only studies written in English were included, this review was limited to studies from developed countries (the United States, Europe, Australia, China, and Iran).

There has been an acceleration in the development of digital technologies, and the public is becoming more comfortable with technological solutions to common problems. Considering the pervasive use of technology in ICUs, this search may have missed relevant recent information because we limited our search to only research and excluded prototype papers, case reports, editorials, and descriptive commentaries. Moreover, the profound impact of the COVID-19 pandemic on clinical care in ICUs suggests that this topic will need to be revisited in the near future, as continued innovation of technologies to improve family engagement in ICUs is anticipated.

Conclusions

Although the importance of family engagement in the ICU setting is recognized, the evidence has not yet been fully established. Digital

technology offers attractive solutions to overcome the challenges of engaging family members in the ICU. Findings from our review revealed that most digital technology-based interventions addressed the basic level of needs, such as simple one-way communication from clinician to family members. We recommend further testing of interventions using digital technology to address the collaboration and decision-making elements of family engagement.

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Declaration of Competing Interest

No conflict of interest has been declared by the authors.

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