

The Initial Impact of the Coronavirus Disease 2019 Pandemic on ICU Family Engagement: Lessons Learned From a Collaborative of 27 ICUs

OBJECTIVES: To describe the impact of coronavirus disease 2019 on family engagement among ICUs participating in a multicenter collaborative promoting implementation of family-centered care projects and to report sites' experiences with the collaborative itself prior to its cancelation due to the pandemic in March 2020.

DESIGN: Cross-sectional survey.

SETTING: Twenty-seven academic and community ICUs in the United States and South Korea.

SUBJECTS: Site leaders.

INTERVENTIONS: Prior to March 2020, all sites had participated in 6 months of webinars, monthly calls, and listserv communication to facilitate projects and to collect preimplementation family satisfaction and clinician perception data.

MEASUREMENTS AND MAIN RESULTS: Planned projects included ICU orientation initiatives (12, 44.4%), structured family care conferences (6, 22.2%), and ICU diaries (5, 18.5%). After cancelation of the collaborative, 22 site leaders (81.5%) were surveyed by phone from June 2020 to July 2020. Twenty (90.1%) reported having stopped their site project; projects that continued were 1) a standardized palliative extubation protocol and 2) daily written clinical summaries for families. Sites described significant variability in visitor restriction policies and uncertainty regarding future policy changes. Four sites (18.2%) reported that their hospital did not provide personal protective equipment to visitors. Regarding video conferencing with families, 11 sites (52.4%) reported clinicians' using their own personal devices. Two-hundred twelve family surveys and 346 clinician surveys collected prior to cancelation highlighted a broad need for family support. When leaders were asked on a scale from 0 to 10 how helpful collaborative activities had been prior to cancelation, mean response was 8.0 (SD 2.5).

CONCLUSIONS: While the collaborative model can help promote ICU family engagement initiatives, coronavirus disease 2019 has impeded implementation of these initiatives even among motivated units. ICUs need adequate personal protective equipment for visitors and video conferencing capabilities on hospital devices while strict visitor restrictions continue to evolve.

KEY WORDS: caregivers; coronavirus disease 2019; family nursing; intensive care units; patient-centered care; quality improvement

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Incorporating families as ICU team members and providing support to families are critical components of high-quality critical care (1–4). Since the onset of the coronavirus disease 2019 (COVID-19) pandemic, visitor restriction policies and stress on hospital resources have impeded family engagement (5–7). Several groups have authored statements on how best to promote family-centered care amidst COVID-19 restrictions so that progress made toward incorporating families in ICU care is not lost (5, 6, 8). However, there is scarce multicenter data recording the effects of the pandemic on ICU quality improvement initiatives to promote family-centered care, despite recognition that family engagement is of utmost importance.

Following the success of the 2016–2017 Society of Critical Care Medicine (SCCM) Patient-Centered Outcomes Research (PCOR)-ICU Collaborative—a U.S. collaborative of 63 ICUs, each of which participated in 10 months of national conference calls, webinars, online eCommunity assignments, and centralized pre-/postfamily and clinician data collection to facilitate implementation of a variety of local family-centered care projects (9)—SCCM launched the Family Engagement Collaborative (FEC) in September 2019 with a similar objective. While regularly scheduled collaborative activities were canceled in March 2020 due to the then-emerging pandemic, the collaborative provided us an opportunity to understand how the pandemic had affected ICU family-centered care projects across sites, how sites were adjusting to evolving visitor restrictions, and how the collaborative model could be refined. Our objectives of this study were thus 1) to describe the impact of COVID-19 on ICU family engagement among participating FEC sites and 2) to report on sites' experiences with the collaborative model prior to cancellation.

MATERIALS AND METHODS

Study Design, Including Institutional Review Board Approval

From June 2020 to July 2020, we administered a telephone survey to the site leader of each ICU that had actively participated in the FEC from September 2020 to February 2020, prior to its cancellation in March 2020. The Yale School of Medicine Human Research Protection Program determined that this project did not meet their formal definition of human subjects research.

Family Engagement Collaborative Description

Similar to PCOR-ICU (9), the purpose of the FEC was to encourage ICUs to identify and implement a local quality improvement project in 2020 that would be likely to have a positive impact on family-centered care. In addition to an MD principal investigator and SCCM staff, the FEC leadership included a family member of a prior ICU patient with experience in promoting ICU family engagement. Participating sites were asked to submit a \$2,500 fee to SCCM to partially offset the cost of staff time needed for FEC activities.

From February 2019 to June 2019, 37 ICUs indicated interest in FEC participation after an international effort to recruit sites. We set up an online SCCM Connect listserv to facilitate communication among sites. From September 2019 to October 2019, self-identified multidisciplinary leaders from each site participated in a series of seven introductory 1-hour interactive webinars conducted by topic experts and designed to assist sites with local project selection, project implementation, and outcome assessments (**Supplemental Digital Content 1**, <http://links.lww.com/CCX/A556>).

From October 2019 to December 2019, we encouraged sites to finalize their choice of project and their methods for measuring project impact. We encouraged sites to use the Gap Analysis Tool associated with SCCM's Family-Centered Care Guidelines to help identify project ideas and local family advisors (1, 10). We also encouraged sites to plan measurement of project impact via pre-/postimplementation data collection from families and clinicians. For pre-/postassessments of family satisfaction with ICU care, we recommended the 24-item Family Satisfaction with the ICU Survey (FS-ICU 24R) (11), a recently revised version of an established survey tool with established validity and reliability (12). For pre-/postassessments of clinician perceptions of local family-centered care initiatives, we recommended the Institute for Patient- and Family-Centered Care (IPFCC) Intensive Care Self-Assessment Inventory (13). We created a Research Electronic Data Capture (REDCap) database at SCCM for sites interested in collecting these particular surveys anonymously for their pre-/postmeasurement of project impact.

By December 2019, 27 sites had committed to implementing local family engagement projects in 2020

(**Supplemental Digital Content 2**, <http://links.lww.com/CCX/A557>). One site was from South Korea; all other sites were located in the United States. We began monthly conference calls to encourage sites to initiate their plans for collecting local preimplementation data and planned a series of bimonthly educational webinars for 2020. We encouraged sites to begin implementing their local projects in early 2020 after collection of preimplementation data, with plans to have sites collect postimplementation family and clinician data in late 2020.

In consultation with SCCM leadership, we canceled FEC activities in March 2020 due to the escalating COVID-19 pandemic, after three conference calls and one educational webinar (on lessons learned from PCOR-ICU). Sites were given refunds of their initial participation fees. We encouraged all sites to continue their local project implementation if able.

Participants

For this postcancellation survey study, we recruited a single member of the core leadership team from each of the 27 sites that had expressed a formal commitment to implementing a local project in 2020.

Variables/Data Sources/Measurement

We developed a phone survey with 15 questions that asked site leaders to report on several topics related to the pandemic, ICU family engagement, and their participation in the FEC. The survey requested that site leaders provide us with a copy of their institution's most recent publicly available written visitor restriction policy. The survey questions underwent an iterative review and revision process among the authors to optimize content and face validity and were initially piloted among five sites, with phone responses manually entered into a Qualtrics (Provo, UT) form. No additional changes were made to the content of the survey following the initial piloting period. The full text of the final survey version is available in **Supplemental Digital Content 3** (<http://links.lww.com/CCX/A558>).

We collected the following variables about each participating site from the formal collaborative list-serv assignments, before the FEC was canceled: type of unit, Gap Analysis Tool results, selected FEC project, selection of pre- and postimplementation project

assessments, and presence/absence of family advisor input in project planning. We confirmed site selection of an FEC project with site leaders during the phone survey.

Statistical Methods

We analyzed survey responses using standard descriptive statistics in IBM SPSS Statistics 26 (IBM Corp., Armonk, NY). For open-ended survey questions, two members of the study team (D.Y.H., Q.Z.) reviewed the responses recorded from phone interviews and performed a qualitative analysis to assign responses into thematic categories. All of the collected written visitor restriction policies were also reviewed by two study team members (D.Y.H., Q.Z.), with special attention paid to types of exceptions for ICU visitors allowed by each policy.

For those sites that had collected some preimplementation FS-ICU 24R and IPFCC Clinician data before FEC cancellation, data were analyzed using standard descriptive statistics. Scores for individual items on the FS-ICU 24R, the satisfaction with care and decision-making subsections, and the overall survey were calculated by the survey's standard algorithm of converting 5-point Likert responses to a 100-point scale and obtaining mean responses (11). Missing data were excluded from analyses.

RESULTS

Characteristics of Sites

Table 1 describes the 27 ICUs that actively participated in the FEC before its cancellation. Seventeen of 27 sites (63.0%) completed the Gap Analysis Tool, which can identify multiple gaps in family-centered care for an individual site (10). The most commonly identified opportunities for project implementation were structured family care conferences (16, 94.1%), ICU diaries (11, 64.7%), and ICU orientation guides/educational programs (11, 64.7%). The most common actual projects selected by the 27 actively participating ICUs for implementation during the FEC mirrored the Gap Analysis Tool results: ICU orientation guides/educational programs (12, 44.4%), structured family care conferences (6, 22.2%), and ICU diaries (5, 18.5%).

For pre-/postimplementation measurements of project impact, 16 sites (59.3%) had planned to use the FS-ICU 24R via the SCCM REDCap database for

TABLE 1.
Description of 27 Units Participating in the Family Engagement Collaborative

Descriptor	<i>n</i> (%)
Type of ICU	<i>n</i> = 27
Medical/surgical combined	10 (37.0)
Medical ^a	5 (18.5)
Pediatric	5 (18.5)
Surgical	3 (11.1)
Neurologic	2 (7.4)
Cardiac	2 (7.4)
Family-centered care gaps initially identified via Gap Analysis Tool ^b	<i>n</i> = 17
Structured family care conferences	16 (94.1)
ICU diaries	11 (64.7)
ICU orientation guides/educational programs	11 (64.7)
ICU family navigators	5 (29.4)
Family presence during resuscitation	2 (11.8)
Validated decision support tools for family	2 (11.8)
Family-centered rounds	1 (5.9)
Other	2 (11.8)
Selected projects for the collaborative	<i>n</i> = 27
ICU orientation guides/educational programs	12 (44.4)
Structured family care conferences	6 (22.2)
ICU diaries	5 (18.5)
Family-centered rounds	4 (14.8)
Family presence during resuscitation	2 (7.4)
Protocol for withdrawal of life support	1 (3.7)
Physical therapy protocol for ventilated patients	1 (3.7)
Written daily summaries of patient care for families	1 (3.7)
Selected pre-/postoutcome measures	<i>n</i> = 27
Family Satisfaction with Care in the ICU	16 (64.0)
Institute for Patient- and Family-Centered Care Clinician Inventory	12 (48.0)
Other standardized family outcomes	8 (32.0)
Other standardized clinician outcomes	2 (8.0)
Qualitative interviews/internally developed surveys/other	7 (25.9)

(Continued)

TABLE 1. (Continued).
Description of 27 Units Participating in the Family Engagement Collaborative

Descriptor	n (%)
Family advisor input regarding project planning/implementation	n = 27
Yes	14 (51.9)
In process	6 (22.2)
No/not answered	7 (25.9)

FEC = Family Engagement Collaborative.

^aOne medical ICU from South Korea; all other sites located within the United States.

^bSeventeen of 27 sites reported utilization the Gap Analysis Tool during the planning months of their FEC participation. For any given site, the tool can identify multiple gaps. However, we asked each of the 27 sites to eventually pick a single project for the purposes of FEC participation.

measuring family satisfaction, while 12 (44.4%) had planned to use the IPFCC Clinician Inventory (also via SCCM REDCap) for measuring clinician perceptions of ICU family engagement. At the time that the FEC was canceled, 212 FS-ICU 24R and 346 IPFCC surveys had already been collected during the preimplementation time period, all from U.S. sites. Family demographic data collected via the FS-ICU 24R is available in **Supplemental Digital Content 4** (<http://links.lww.com/CCX/A559>). Mean scores for individual items on the FS-ICU 24R, the satisfaction with care and decision-making subsections, and the overall survey are available in **Supplemental Digital Content 5** (<http://links.lww.com/CCX/A560>) (mean overall FS-ICU 24R score 87.0, SD 14.5). Clinician demographic data collected via the IPFCC survey is available in **Supplemental Digital Content 6** (<http://links.lww.com/CCX/A561>). Responses for individual items on the IPFCC survey are available in **Supplemental Digital Content 7** (<http://links.lww.com/CCX/A562>). Among 293 respondents to the question, only 67 (22.9%) reported that their ICU had “very well” provided a range of informational and educational programs and materials that were available to patients’ families.

Post-FEC Survey Participants and Impact of Pandemic on Local Projects

Following cancellation of the FEC, 22 of 27 site leaders (81.5%) participated in the phone survey, from June 9 to July 17.

Twenty of 22 sites (90.1%) reported having to stop their local project implementation due to the

pandemic. The only two sites that reported continuing their site’s family engagement project despite the pandemic were implementing 1) a standardized palliative extubation protocol and 2) daily written summaries for families of patients lacking capacity to make general decisions. Nineteen of the 20 sites that stopped their projects (95.0%) reported interest in continuing their project in the future, albeit at an unspecified time point.

Visitor Restriction Policies and Visitor Screening

Supplemental Digital Content 8 (<http://links.lww.com/CCX/A563>) reports information about visitor restrictions, screening, and provision of personal protective equipment (PPE). When asked about the peak of the pandemic in their respective ICUs, two sites (9.1%) reported having had a strict no-visitor policy without any exceptions. The remaining sites all reported a variety of exceptions for specific categories of patients.

Regarding current policies in June 2020 to July 2020, 16 sites (72.7%) supplemented their survey responses by also providing us a copy of their institution’s most updated visitor restriction policy. Among all 22 sites, 20 (90.9%) had evolved to the point of allowing some visitors for all non-COVID patients during limited hours. However, the number of visitors allowed per patient and the specific categories of patients who were allowed greater visitation flexibility varied among ICUs. Only three sites (13.6%) reported having any knowledge of their hospital’s timeline for

further relaxing visitor restrictions. Additionally, only one site reported having on-site COVID-19 testing for all visitors (4.5%). Fourteen sites (63.6%) reported providing PPE for all approved visitors, while four (18.2%) reported not providing PPE for visitors at all.

Methods of Communication and Engagement With Families

Table 2 reports survey items related to communication and engagement with families following the onset of the pandemic. All but one site (95.5%) reported using video conferencing with families; however, 11 sites (11/21, 52.4%) reported clinicians' using their own personal devices for conferencing, either exclusively or in conjunction with hospital devices. Among the 20 sites that reported the hospital providing video

conferencing devices for staff, on average approximately one device had been provided to staff for every 13 ICU beds, and only 13 sites (65.0%) reported being confident that the hospital devices were encrypted.

Collaborative-Specific Feedback

When all site leaders were asked to rate on a scale of 0–10 how helpful the FEC had been prior to its cancellation (0 = “not helpful,” 10 = “very helpful”), mean response was 8.0 (SD 2.5). **Table 3** summarizes free-response feedback about the FEC activities and structure. Seven site leaders (25.9%) suggested that a future FEC could benefit by focusing more on sites implementing a specific standardized project, as opposed to another future collaborative promoting a variety of different project ideas among interested sites.

TABLE 2.
Communication and Engagement With Families ($n = 22$)

Survey Item	<i>n</i> (%)
Use of video conferencing technology	<i>n</i> = 22
Yes	21 (95.5)
No	1 (4.5)
Source of video conferencing devices	<i>n</i> = 21
Provided to staff by ICU or hospital	10 (47.6)
Staff using personal devices only	1 (4.5)
Both	10 (47.6)
Are the devices encrypted?	<i>n</i> = 20
Yes	13 (65.0)
No	1 (5.0)
Not sure	6 (30.0)
Strategies suggested by sites to engage ICU families in the midst of visitor restrictions ^a	<i>n</i> = 22
Video conferencing with families	17 (77.3)
Implementing more flexible visitor restriction policies when possible	6 (27.3)
Allowing families to participate in morning rounds via video	5 (22.7)
Other ideas ^b	4 (18.2)

^aSeveral sites suggested multiple strategies.

^bOther ideas included 1) displaying pictures of patients' families in patients' ICU rooms; 2) providing a “stuffed handheld heart” for each coronavirus disease patient and their family; 3) focusing on preparing families for discharge planning; and 4) working with a local patient/family advisory council virtually to discuss further ideas.

DISCUSSION

Prior to its cancelation, the ICUs involved in the SCCM FEC had rated the collaborative's core educational webinars, monthly networking calls, and listserv communications as valuable with regards to facilitating local family-centered care projects. As sites prepared to implement their local projects, preimplementation data suggested that both families and clinicians perceived a strong need for improved family engagement across participating ICUs. However, after the collaborative was canceled in March 2020, the majority of sites stopped their local project implementation due to pandemic. Visitor restriction policies were strict at the height of the pandemic but evolved, albeit with significant variability. Sites reported a high reliance on video conferencing with families, but our results suggest that units have been under-resourced with regards to encrypted hospital devices necessary to facilitate conferencing.

Family engagement is widely recognized as a critical component of high-quality critical care (1, 2, 4).

However, even prior to the COVID-19 pandemic, significant barriers to implementing family-centered care in ICUs existed (3, 14), with SCCM making investments in creating guidelines and national initiatives to help ICUs overcome local barriers (1, 9). This study does support the SCCM experience from the 2016-2017 PCOR-ICU Collaborative that the collaborative format is well-received by participating ICUs (9). However, our study is one of the first to provide multicenter data on the negative impact of COVID-19's on ICU family engagement initiatives, even among a cohort of ICUs that was otherwise very motivated to implement local quality improvement projects.

Many of the core recommendations from the 2017 SCCM FCC Guidelines take for granted open or flexible family presence at the bedside that the pandemic continues to disrupt (9). Several groups and organizations in the past year have released consensus statements regarding what high-quality family-centered care should theoretically encompass during the COVID-19 era (5, 6, 8). Our study highlights basic yet crucial challenges that hospitals and ICUs have to address to

TABLE 3.
Free-Response Feedback About the Activities and Structure of the Family Engagement Collaborative Prior to Cancelation (*n* = 22)

Feedback	<i>n</i> (%)
Suggestions to improve the collaborative experience	
Shift focus of collaborative to implementing standardized projects across all sites	4 (18.2)
More collaboration between sites doing the same project	3 (13.6)
More resource-sharing and networking opportunities	2 (9.1)
Easier navigation with online website and email exchanges	2 (9.1)
Having a centralized institutional review board protocol for the collaborative	2 (9.1)
Focus on projects related to cultural differences among international sites	1 (4.5)
More structured timeline for pre-/postimplementation data collection	1 (4.5)
Earlier communication to sites regarding standardized outcome tool availability	1 (4.5)
Positive comments	
Good communication and engagement among sites	6 (27.3)
Nonspecific approval of the collaborative activities	4 (18.2)
Helpful training/orientation period at the beginning of the collaborative	3 (13.6)
Valuable learning from other participating sites	3 (13.6)

successfully adapt their models of family engagement amidst evolving visitor restriction policies: uncertainty regarding when visitor restriction policies might be safely relaxed (8), insufficient number of hospital-provided devices for video conferencing with families (15), and provision of adequate PPE (16) for allowed visitors.

This study has limitations. Because this study focused exclusively on the experience of the FEC, our sample size is small. However, we point out that those sites that paid a fee to participate in the collaborative comprise a self-selected group with known enthusiasm for implementing family-centered care projects and that the barriers due to COVID-19 that our study identified even at these enthusiastic centers are likely to exist for other ICUs. While we achieved a high response rate (81.5%) of all possible FEC sites who could have participated in this survey study, nonresponse bias is always possible. Response rates for the preimplementation FS-ICU 24 and IPFCC surveys among participating sites were not recorded (9). Last, our survey asked participating site leaders to recall the specifics of their hospitals' visitor restriction policies, but it is possible that some leaders may have recalled details incorrectly. To mitigate this limitation, we asked site leaders to provide written copies of their current visitor restriction policies when possible.

CONCLUSIONS

Our survey study suggests that the COVID-19 pandemic has made the promotion of traditional family-centered care projects difficult in ICUs. We have illuminated several barriers that need to be addressed, including prioritization of PPE for approved visitors and adequate secure video conferencing equipment. Further work on understanding how best to provide protective supplies for visitors and increase the availability of teleconferencing equipment is critical. Creative approaches to maximizing family engagement amidst visitor restrictions are needed.

As ICUs adapt to promote family engagement that is seen as valuable by both families and clinicians (17, 18), another SCCM-wide collaborative similar to PCOR-ICU and the FEC would likely be valuable (9). However, regarding the implementation of another FEC in the future, more consideration might be given to connecting sites that are pursuing similar family-centered care projects, perhaps by coordinating the details of implementation and possible study protocols.

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