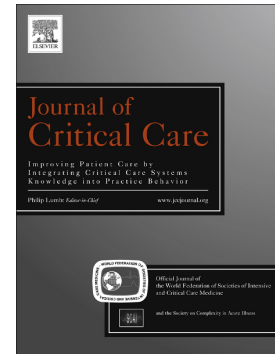# Accepted Manuscript

Patient and family engagement in the ICU: Report from the task force of the World Federation of Societies of Intensive and Critical Care Medicine

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Patient and Family Engagement in the ICU: Report from the Task Force of the World Federation of Societies of Intensive and Critical Care Medicine

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1. Background

A growing body of literature internationally highlights the benefits of patient and family engagement in the Intensive Care Unit (ICU). Several studies have addressed patient centered care and strategies to engage family members to promote best outcomes for critically ill patients.[1-2] Providing high quality family-centered care has been identified as a basic skill for ICU clinicians.[3] Internationally, the focus on meaningful patient and family engagement in the ICU has gained the attention of critical care trials groups[4] and is reflected in international guidelines for family-centered care in neonatal, pediatric and adult ICUs.[5] A recent systematic review and meta-analysis of the outcomes of patient and family focused interventions in the ICU demonstrated an impact on ICU length of stay and improved family satisfaction, patient experience, medical goal achievement, and patient & family mental health outcomes.[1] However, the majority of the studies in that review were based in the United States. The degree to which specific types of patient and family focused practices are being implemented worldwide is not known.

As part of a series of Task Forces developed by the World Federation of Societies of Intensive and Critical Care Medicine (WFSICCM)[6-21], an international organization with over 85 societies in over 75 countries of the world, a survey was conducted to assess the types of patient and family engagement practices being implemented worldwide.

2. *Objective*

The purpose of this international cross-sectional survey was to collect information on patient and family engagement initiatives in the ICU, as well as barriers and strategies to implementation.

3. Methods

An online survey was used to collect information from WFSICCM country members. Institutional review board approval for the study was received from Rush University Medical Center, Chicago, Illinois, USA. A 21 item survey assessed information on patient and family centered care practices; ICU demographic information including type of ICU, bed size, typical ICU length of stay; and the city, region, and country location of the ICU. The survey consisted of an overview informing participants that the information provided would be used to inform the global critical care community of current initiatives as well as strategies and potential barriers to implementing patient and family engagement to enhance ICU care delivery. A 3-point Likert scale was used to assess the degree to which patient and family engagement practices had been adopted, whether fully, partially, or not at all. Two open-ended questions assessed the types of strategies that had been found helpful to promote patient and family centered care/engagement in the ICU, as well as the type of barriers encountered.

The survey was developed with input from all members of the study team and underwent multiple iterations. A process of construct and content validation was performed using a panel of content experts with several iterations of revision until consensus was achieved. The survey was pilot-tested for face validity prior to use with 10 ICU practitioners. Feedback from end-users was used to further refine the survey, which was then distributed via an email link to WFSICCM country member representatives to distribute to their respective members. Data were collected with use of Research Electronic Data Capture (REDCap), a secure, web-based application (https://www.project-redcap.org/). The survey was open for a 6 month timeline from June through November, 2017.

4. Results

A total of 345 responses were received from 40 countries (Figure 1; Table 1). A response rate could not be calculated as it was not known how many persons received the email survey request. The ICUs settings represented university and academic facilities (52.9%, n=181), public hospitals (25.1%, n=86), military/government (4.7%. n=16) and others such as community, private and rural critical access hospitals (17.3%, n=59). ICU specialty types included mixed medical surgical ICUs (73.5%, n=250), medical (12.1%, n=41), surgical (10%, n=34) and others including cardiac, pediatric, trauma, neuroscience, and burn ICUs (4.4%, n=15). Hospital bed capacity ranged from 5 to 1500 (median 470) and ICU bed size ranged from 4 or less up to 65 (median=16). Surveys were completed by intensivists (n=107, 31.4%), ICU Directors (n=74, 21.7%), ICU nurse managers (n=33, 9.7%) and others including ICU educators, charge nurse, fellows, clinical nurse specialists, and consultant anesthesiologists.

A number of methods of promoting family engagement in the ICU were identified including open/flexible family presence (visitation), family information brochures, families on rounds, involving the family in care of the patient, and family presence during invasive procedures or resuscitation, among others (Table 3). However, wide variation in practices were reported. Of those responding to individual survey questions, some (39.6%, n=136) reported that open visitation practices in the ICU had been fully adopted, while others (38.1% (n=130) reported visiting hours were somewhat open, and 22.3% (n=76) reported visiting hours were not open (Figure 2). Just over half (53.8%) of respondents reported that structured patient and family care conferences were held to review goals of care (Figure 3). Some (15.9%, n=54) reported that family-centered rounds were conducted to enable family members to listen to rounds and

participate by offering information and/or asking questions, while others reported this was "somewhat" in place (27.9%, n=95) and more than half (56.2%, n=191) reported "not at all" (Figure 4).

Practices such as the use of patient and family ICU diaries were reported by 32.7% (n=111), the use of music or pet therapy in the ICU was reported by 55% (n=188), and the use of a patient and family advisory group by 30.5% (n=104) (Figure 5).

Majority (61.2%, n=109) provided written materials on the ICU to family members. More than half (58.6%, n=199) of the ICUs identified that information was disseminated to families about ways to assist with care of their loved one in the ICU. Practices such as family presence during resuscitation were reported to be fully (12%, n=41) or somewhat adopted (33%, n=113) by less than half, with less reporting family presence during invasive procedures (20.5%, n=70) (Figure 6; and electronic supplemental tables).

Barriers

A number of barriers to implementing patient and family centered care practices were identified including a shortage of manpower, cultural norms, staff resistance, time, lack of space with multi-bedded rooms or open ICUs that impede widespread family presence, perceived workflow interruption, lack of skill among nurses, lack of recognition among physicians about the importance of family inclusion, practitioners being uncomfortable with family being present, and literacy barriers. Lack of medical leadership that promotes family involvement, inconsistent application between staff, and concern about infection control were also cited. Despite the fact that family centered care practices in the ICU are widely supported in countries such as the

United States, Canada, Australia and New Zealand, a large number of comments about barriers were also reported from respondents from those countries.

Strategies

Specific measures to address clinician resistance to family engagement initiatives included engaging frontline staff to understand benefits through staff education, showcasing successful cases/experiences to ICU staff, piloting initiatives to promote staff comfort and acceptance, development of specific approaches/procedures regarding practices, gaining ICU leadership support, among others (Table 4).

A total of 252 respondents provided open ended comments. Descriptive analysis was used to review responses and identify recurring themes. Themes reported included addressing staff resistance and changing the culture in the ICU. One respondent from Europe shared "The biggest problem here in my country is the culture of healthcare workers and facilities. The best strategy is to try to change this culture among health care workers and institutions." A respondent from Asia shared "Custom is the highest barrier in what the staff do in the ICU". A respondent from the USA cited "Focusing on the staff is important. If they don't feel supported then engagement and willingness to change suffers. Using a 'just try it' approach that emphases ongoing feedback and revision of the intervention" is beneficial.

Another from the United Kingdom shared "reluctance from some nursing and medical staff in participating – active encouragement at the bedside" has been beneficial. A respondent from Australia shared "discussion and engagement of staff and use of time" is a helpful strategy. "The

project has seemed to gain more acceptance over time and enthusiasm through just being more visible."

Some respondents identified the need for ICUs that have been successful in implementing initiatives to disseminate lessons learned. One respondent from Europe identified "best practice examples from more experienced ICUs would be useful". An in-depth qualitative analysis is being conducted as a secondary manuscript to further assess for differences in country responses.

5. Discussion

The results of the study indicate that while a number of patient and family engagement initiatives are being implemented in the ICU worldwide, there is variation in the degree to which best practices are integrated in clinical practice. Additionally, as reported in this study, barriers to implementing patient and family engagement in the ICU exist universally, even in countries that have adopted practices such as open flexible family presence. Among the types of patient and family engagement practices, providing written information to families, family care conferences, and frequent communication were reported more than practices such as open flexible family presence, use of diaries, or pet or music therapy. Practices such as family presence on rounds, or during resuscitation or invasive procedures have not been widely adopted.

Wide variability in global practices suggests that further study on strategies to implement and sustain patient and family engagement in the ICU remains necessary to standardize practice.

Several recent studies have highlighted the impact of extended visitation in the ICU. In a single center study of 286 ICU patients comparing a restricted visitation model (4.5hr/d) to an extended visitation model (12hr/d), the extended visitation model was associated with reduced occurrence of delirium and shorter length of delirium/coma and ICU stay.[6] Similarly, a recent study had

similar findings comparing 245 patients whose relatives could stay up to 6 hours and 268

patients whose relatives could visit any time for up to 24 hours a day compared to a standard

time of four half-hour visits. The 24 hour extended visiting policy was associated with a

reduction in the incidence of delirium.[22] A recent systematic review and meta-analysis of 16

studies on flexible versus restrictive visiting policies in the ICU identified that flexible ICU

visiting hours have the potential to reduce delirium and anxiety symptoms among patients and to

improve family members' satisfaction.[23]

A number of barriers to implementing patient and family engagement in the ICU were reported

in this study, with unit culture, staff resistance, lack of space and time, clinicians being

uncomfortable with family being present, and uncertainty about the benefits being cited most

frequently by respondents.

Strategies that were identified to promote patient and family engagement in the ICU include

daily communication and regular meetings with the family, flexible family presence, including

families on rounds, and involving families in patient care. However, a lack of empirical evidence

exists to guide clinicians on how to most efficiently implement practices, reduce barriers, and

increase facilitators. The use of implementation science to study factors that influence the

effective use of family engagement innovations in practice would be beneficial.

The impact of cultural differences and perceptions toward family involvement in the ICU also

needs further exploration. A scoping review of articles addressing patient ICU discharge

processes written in 5 languages (English, Portuguese, Spanish, Dutch, Korean) identified

similar themes related to addressing patient and family needs and experiences and providing accurate information.[24] Similarly a study focusing on improving ICU discharge planning conducted in the Netherlands found that patients and family members identified the need for effective discharge information and supportive written material.[25] However, a recent study identified that despite common emphasis on the role of the family, differences in physician perceptions and practices existed for end-of-life care in the ICU among clinicians in China, Korea and Japan, highlighting how cultural differences can impact ICU care.[26] Similarly, variations in clinician perceptions and practices toward family engagement in the ICU may also impact implementation of family-centered clinical practices.[27]

Examples of useful strategies for promoting involvement of family in the ICU exist that can be replicated. Since February 2014, the International Research Project for the Humanization of the Intensive Care Units (Proyecto HU-CI) has been focusing on the need to redesign ICUs around the world. This project began in Spain, has been adopted in more than 20 countries, and has been extended beyond the ICU, to include urgent and emergency care, oncology, pediatrics, and neurology.[28] Components of the project include promoting family communication, flexible ICU visiting, and family participation in care; focusing on patient well-being and satisfaction; and team training for clinicians to enhance communication skills, teamwork, resiliency, active listing and compassion (http://humanizandoloscuidadosintensivos.com/es/inicio/)

Global campaigns such as this can help to raise awareness, disseminate successful strategies, and identify barriers to promoting patient and family engagement in the ICU. Ultimately, improving partnerships with families can help to optimize the quality of ICU care for both patients with life-threatening illness and their family members.[29,30]

Limitations

This study has a number of important limitations. First, the sample of ICUs represents a convenience sample and we were unable to determine the survey response rate. We are unable to assess the potential for non-response bias, although we would hypothesize that ICU leadership interested in this topic may be more likely to participate and therefore this may represent an over-estimate of patient and family engagement in the ICU. Second, although there was a large number of ICUs and countries, with 40 countries represented, some countries were represented by 1 or 2 ICUs. Third, these data represent self-reported patient and family engagement practices by clinicians, which may not represent actual practices. Fourth, the survey was only distributed in English. Due to a low response rate from South America and Spain, the survey has recently been translated into Spanish for a second targeted study in Spanish-speaking countries. Finally, the results may not represent all practices being implemented in ICUs since there may be some practices that we did not ask about.

Summary and Conclusions

While it is evident that ICUs globally are adopting practices to create an environment that promotes patient and family involvement, continued efforts are needed to optimize meaningful patient and family engagement. Additional research on the benefits of family engagement in the ICU would help to provide an evidence base to advocate for its consideration in all ICU settings. Additionally, sharing successful implementation techniques, tactics, and strategies can help clinicians to address barriers to implementing patient and family engagement in the ICU.

Key Points

1. A number of patient and family engagement initiatives are being implemented worldwide,

however there is variation in the degree to which best practices are integrated in clinical practice.

2. Barriers to implementing patient and family engagement in the ICU exist universally, and

include but are not limited to: unit culture, staff resistance, lack of space and time, and

uncertainty about the benefits.

3. Strategies for promoting patient and family engagement in the ICU include daily

communication and regular meetings with the family, flexible family presence, including

families on rounds, and involving families in patient care.

4. Further research and shared successes in translating research into practice remain necessary to

standardize practice for family engagement in the ICU.

Acknowledgement

The authors disclose they have no conflicts of interest

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Table 1. Responses by Country

Country and Response Rate			
United States	57	Ghana	2
India	46	New Zealand	2
Japan	35	Oman	2
South Africa	32	Sierra Leone	2
Canada	21	Sri Lanka	2
Turkey	21	Bosnia and Herzegovina	1
South Korea	14	Croatia	1
France	10	Denmark	1
Unknown	10	Greece	1
Belgium	8	Greenland	1
Saudi Arabia	8	Israel	1
Australia	7	Lesotho	1
Jordan	7	Macedonia	1
Mexico	7	Malwai	1
United Kingdom	7	Namibia	1
Germany	6	Netherlands	1
Austria	5	Nigeria	1
Brazil	3	Portugal	1
England	3	Qatar	1
Spain	3	Slovenia	1
Sudan	3	Sultanate of Oman	1
Bangladesh	2	Sweden	1
Finland	2	Zimbabwe	1

Unknown= not declared by participant

Table 2: Countries reporting fully adopted practices from at least one participant

FP at Resuscitation	FP on Rounds	Advisory Group	Integrative Practices	Pt Family Conferences	Diaries	Open Flexible Family Presence (Visiting)
Belgium	Austria	Austria	Australia	Australia	Australia	Australia
Canada	Belgium	Belgium	Austria	Austria	Austria	Belgium
India	Canada	Bosnia and Herzegovina	Belgium	Belgium	Belgium	Bosnia and Herzegovina
Japan	India	Canada	Canada	Canada	Bosnia and Herzegovina	Brazil
Spain	Japan	Greece	France	France	Brazil	Canada
Sweden	Jordan	India	India	India	Canada	Denmark
The Netherlands	Mexico	Japan	Japan	Israel	Greece	England
USA	Saudi Arabia	South Africa	Jordan	Japan	India	France
	South Africa	Jordan	South Africa	Jordan	Jordan	Germany
	Spain	New Zealand	Saudi Arabia	Saudi Arabia	Mexico	Greenland
	Turkey	Turkey	Sudan	South Africa	Saudi Arabia	India
	USA	USA	Sultanate of Oman	Spain	South Africa	Japan
			Turkey	Sudan	Spain	Jordan
			UK	Sultanate of Oman	Sweden	Mexico
			USA	Turkey	Turkey	New Zealand

				UK	UK	Portugal
				USA	USA	Saudi
						Saudi Arabia
						Sierra Leone
						South Africa
						Spain
						Sri Lanka
						Sudan
						Sultanate of Oman
						Sweden
						The Netherlands
						Uk
						USA

Legend: FP, family presence, Pt= Patient. USA= United States of America, UK= United Kingdom

Table 3: Methods of Family Engagement in the ICU

Daily conversations with relatives about progress
Include families on rounds
Ethics consultationsa
Family care conferences to discuss goals of care
Open/flexible visitation
Family support specialist roles, use of social workers or psychologists
Multidisciplinary rounds taking place in the patient room
Involving family in care of the patient, such as oral care, bathing, range of motion, feeding
Family information booklet/pamphlet
ICU diaries
Personalizing patient's room
Family presence during invasive procedures or resuscitation
Family satisfaction surveys

Table 4: Strategies to Address Clinician Resistance to Family Engagement Initiative

Engage frontline staff to understand benefits
Staff education
Showcase successful cases/experiences to ICU staff
Pilot initiatives to promote staff comfort and acceptance
Development of specific approaches/procedures regarding practices
Provide evidence reviews – staff respond to changes with a strong evidence base
ICU leadership adopting and supporting practice
Staff communication training

Highlights

- A number of patient and family engagement initiatives are being implemented worldwide, however there is variation in the degree to which best practices are integrated in clinical practice.

- Barriers to implementing patient and family engagement in the ICU exist universally, and include but are not limited to: unit culture, staff resistance, lack of space and time, and uncertainty about the benefits.

- Strategies for promoting patient and family engagement in the ICU include daily communication and regular meetings with the family, flexible family presence, including families on rounds, and involving families in patient care.

- Further research and shared successes in translating research into practice remain necessary to standardize practice for family engagement in the ICU
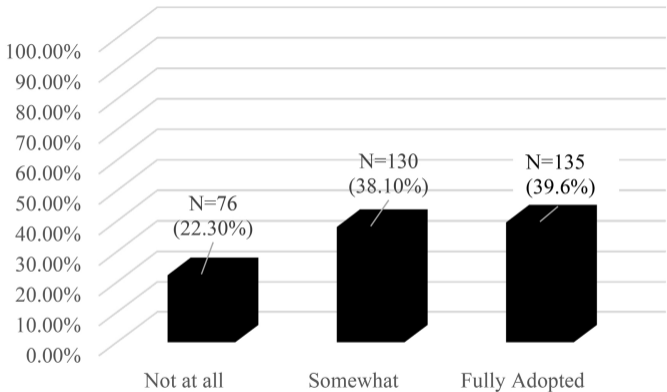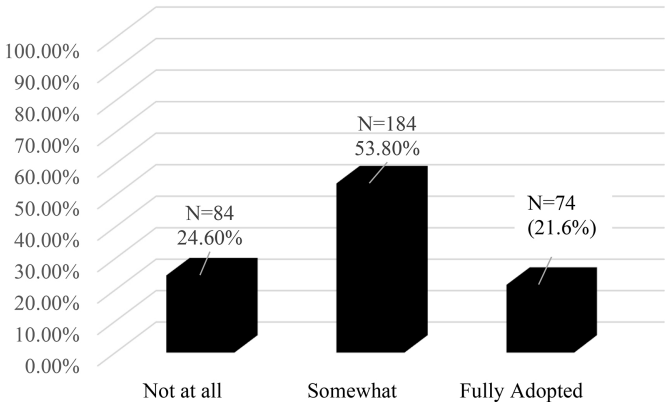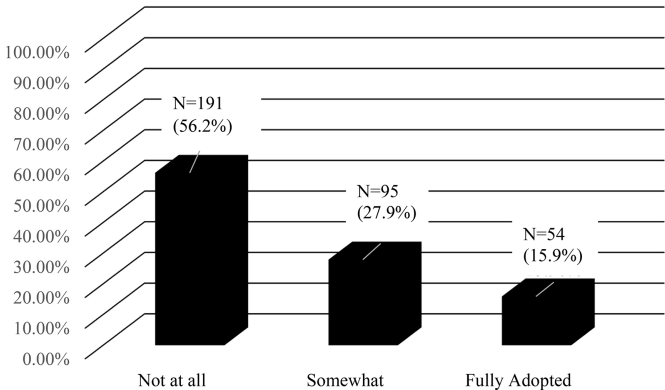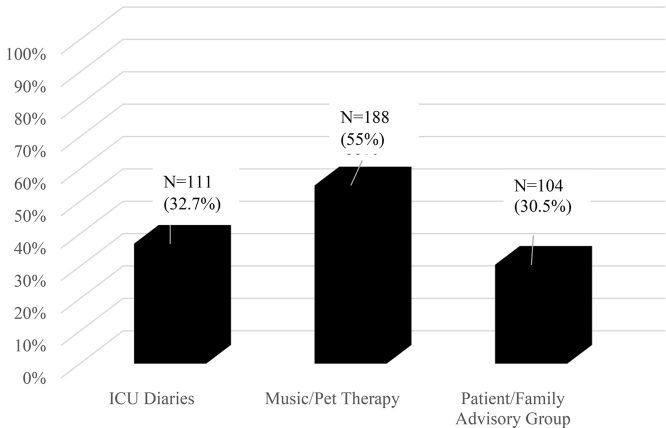
Figure 1

Figure 2

Figure 3

Figure 4

ICU Diaries — N=111 (32.7%)

Music/Pet Therapy — N=188 (55%)

Patient/Family Advisory Group — N=104 (30.5%)

Figure 5

Figure 6