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Abstract

Family-centered care is an important component of holistic nursing practice. This is particularly so in the speciality of critical care where the impact on families of having a family member admitted to intensive care is well recognised. Family-Centered Care Guidelines have been recently developed by an international group of nursing, medical and academic experts for the American College of Critical Care Medicine/Society of Critical Care Medicine. These Guidelines explore the evidence base in five key areas of family-centered care**:** family presence in the intensive care unit; family support; communication with family members; use of specific consultations and intensive care team members; and operational and environmental Issues. Review of the considerable body of evidence in this area identified that research continues to be of an overall low-level quality, with still much research to be performed to provide better evidence for nursing practice. This paper outlines evidence in each of the Guideline areas and makes recommendations as to how critical care nurses can use this information to guide family-centered care practice.

Introduction

Nurses have long recognized that intensive care is provided not only to the critically ill patient; but it also extends to supporting and working with family members. [1,2] While families were traditionally perceived as passive visitors in the intensive care unit (ICU), a more nuanced understanding is developing of the active contribution that families make as part of the healthcare team. This acknowledges their role as patient protectors, facilitators, historians, coaches, and voluntary caregivers. [3] Families are central to the practice of

intensive care and to the continued support and care required by the patient following critical illness.

However, there is a significant physiological and psychological burden on families of having a critically ill family member in the ICU. [4,5,6] The importance of supporting families is therefore widely acknowledged in health care, with the concept of family-centered care (FCC) underpinning many international health practice guidelines. [7,8,9] Given the essential role that nurses hold in intensive care, it is important that nurses are aware of best FCC practices and of the guiding evidence base in this area.

In this paper, we explore the nursing implications of the recently published 'Guidelines for FCC in the Neonatal, Pediatric and Adult Intensive Care Unit' from the American College of Critical Care Medicine/Society of Critical Care Medicine. [10] An international expert group of 21 medical, nursing and academic experts in the field worked to develop these over a two year period (2014-2016). This follow-on paper is written by the nursing membership of the group. Here, we outline the Guidelines project, provide summaries of the evidence base in each section of the Guidelines, and highlight how content from the Guidelines can inform bedside nursing practice.

Overview of the FCC Guidelines project

The Council of Medical Specialty Societies (CMSS) Principles for the Development of Specialty Society Clinical Guidelines framework [11] was used to develop the Guidelines. Initially, a structured literature search strategy identified qualitative research that explored patient, family and clinician perspectives of FCC in the ICU. PubMed, CINAHL, Web of

Science, and PsycINFO databases were searched for qualitative studies published since 1994. Search terms included intensive care, critical care, critical care nursing and family centered/centred. Two hundred and twenty eight studies were included. Key patient/family, and clinician FCC related areas were developed from thematic analysis.

Priority areas in these fields were synthesized to develop PICO (P: Population of interest, I: Intervention, C: Compared to What, O: Outcomes) questions.[12] The evidence from quantitative studies testing FCC interventions was used to answer the PICO questions. Studies were identified by undertaking a rigourous systematic review that followed Preferred Reporting Items for Systematic Reviews (PRISMA) and Meta- Analyses Guidelines. [13] Search terms were similar to those used in the earlier literature review but with focus on randomised trials, prospective experimental, and observational studies. Two hundred and nine studies were included and reviewed using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) methodology [14] to assess levels of evidence. Quality and consensus checks were used during these procedures. Recommendations for practice were based on the strength of evidence and the study results. Data management was facilitated by use of RefWorks®. Patient and family members were consulted and informed the project. Full details of the project are published elsewhere. [10] The Guidelines make recommendations in five areas: family presence in the ICU; family support; communication with family members; use of specific consultations and ICU team members; and operational and environmental Issues. These provide the structure for this paper. A summary of recommendations as to how these Guidelines can be implemented across all domains of nursing practice (direct care, leadership, research) is provided in Table 1.

Family Presence in the ICU

Families value the opportunity to be at the bedside of their loved one in the ICU and this important aspect of FCC is the first area to be explored in the Guidelines. While the presence of family members at the bedside 24 hours a day may be challenging [15] and perceived to increase the workload of staff, [16] evidence has shown improved outcomes when family members are present and engaged with their family member's care in the ICU. [17-19] Observational work in this area has focussed on how open or flexible visiting practices impact on family satisfaction. [20-22] However, there are no trial reports to inform how this visiting may best be undertaken. With little high level evidence to guide practice, the Guidelines recommend that family members of critically ill patients be offered open and flexible family presence at the bedside. Nurses at the bedside have an important role in helping families manage such presence while balancing the needs of families with the patient's clinical needs.

Interdisciplinary rounds provide an opportunity for the clinical team and family members to engage in, and be informed about, goals of care. Robust evaluation work with validated family-centred outcomes is still needed. However, there is low-level evidence demonstrating that family members who participate in family-centered rounds report greater understanding and involvement in decision-making and satisfaction with clinical team communication than those who do not. [23-25] Family presence on rounds can also support and improve family member decision making. [26,27] As family involvement in interdisciplinary rounds is recommended in the Guidelines, nurses can continue to facilitate

family participation in clinical rounds, enabling families to raise questions and engage in dialogue with clinicians during rounds.

A final area explored in this section and one that garners strong professional opinion is family member attendance during resuscitation. There is descriptive and qualitative work that explores clinician and family member attitudes to this practice across pediatric and adult intensive care settings, however, there are few clinical trials to inform practice. It is clear that some family members want to be present during resuscitation and gain support and comfort from this. [e.g. 28-30] However, physicians are less supportive of this practice, having concerns about family interference in procedures, impaired staff performance, and increased litigation risk identified as potential barriers. [e.g. 31-34] It is unsurprising, then, that ICUs have been slow to adopt this practice, even though family presence at resuscitation has been recommended since the original practice guidelines. [7] Understanding such challenges, there is opportunity for clinical nurses to work with physicians and family members and reach a mutually agreeable way forward regarding family presence during resuscitation. The presence of a support person for families during resuscitation is recommended mainly through evaluations of nurse and physician values found in the qualitative literature, and not experimental evidence. Thus, we would suggest that nurses are well placed to lead the re-design of the resuscitation team to include a family support person.

Family Support

Frequently patients in the ICU are too ill to participate in in their care, to communicate, or to participate in decision-making. Family caregivers often face multiple

stressors related to the emotional burden of the intensive care experience while having to serve as proxy decision makers for their critically ill loved one. The FCC Guidelines provide a rigorous evaluation of the evidence to provide support for the family of critically ill patients and makes specific recommendations for family support that include family education, family involvement in caregiving, communication and decision support tools, and peer-to-peer support. The strongest evidence, from moderate quality studies, was the positive impact on family member anxiety and stress when informational leaflets about the ICU were provided. [35] In addition, there was a positive change in parent competence, confidence and psychological health in family members of critically ill children when they were offered teaching about participating in their child's care. [36,37] A major challenge in making substantial Guidelines recommendation about use of effective family support interventions was the lack of robust evaluation studies. Although clinical trials have been undertaken, [38,39,40] these trials did not test standardized family training/education programs. Variation in the format, duration and intent of these programmes renders comparison difficult.

The remaining Guidelines recommendation for family support includes the use of family education programs, peer-to-peer support, ICU diaries, decision support tools and communication tools, all based on low levels of evidence. Two of the recommendations, teaching families how to contribute to caregiving and peer-to-peer support, are specific to critically ill children because of insufficient research in adult critical care settings. It is evident that research investigating impact on outcomes associated with post-ICU clinics, peer-to-peer support programs in areas other than pediatrics, and methods to teach family members how to function in the surrogate decision-maker role is warranted. While diary programs are well received and preliminary data support the use of diaries to reduce family

stress and depression, [41-43] further study is needed to explore the best method to launch a diary program and to increase confidence in results to date. [44-46]

All family support recommendations made in the Guidelines have direct relevance to nursing practice, education and research. From a practice perspective, direct care nurses will implement the majority of the family support interventions. Therefore establishing nursing staff as champions for family support is critical. Specific plans for family support or involvement could be added to the daily plan of care. The family involvement plan should be concise, easy to navigate, well-supported with education and practice standards, be associated with appropriate staffing levels, and evaluated by continuous quality improvement tools. Physician and nursing leadership at the ICU and hospital levels are in key roles to advocate for resources and interdisciplinary collaboration to ensure all families of the critically ill receive the recommended support. Nurses working in education can use a family nursing theory foundation to support skill training in the curriculum through direct interaction, webinars, on-line courses, and simulation experiences with directed feedback. Nurse scientists can focus on closing the gaps and improving the quality of the evidence for family support of critically ill patients.

Communication with Family Members

The FCC Guidelines address the importance of communication between ICU family members and clinicians. Specifically, one focus of the Guidelines was to evaluate outcomes from research concerning the effectiveness of communication that occurs within interdisciplinary family meetings. The ability to make recommendations from this body of research was limited due to the primarily observational nature of the research to date.

However, the Guidelines suggest that routine interdisciplinary family conferences be held in the ICU. This suggestion was based on research findings that families who participated in conferences demonstrated more satisfaction with care, [47] experienced less conflict, [48] and reached consensus more often. [49] The type of communication that occurs during a family meeting significantly influences outcomes. That is, when family members have more time to talk during a meeting (vis a vis the clinicians), [48] when clinicians show empathy [50] and assure family members that they will not be "abandoned", [51] and when family members feel that they are participating in decision-making to their degree of comfort, [52] family satisfaction is improved. Intentional structuring of conversations during a family conference such as use of empathy, using statements of support, and emphasizing clinician support with family decision-making may provide comfort to families and improve their satisfaction. [53] These actions may even decrease family symptoms such as anxiety and depression after the ICU experience. [54] Family conferences may decrease ICU patient length of stay, [49] but this finding is equivocal. [55,56]

It is likely that the effectiveness of family conferences depends on clinician preparation in communication techniques. Clinician training has clearly shown an improvement of clinicians' self-perceived confidence and skills in their communication abilities. [e.g.57-60] Improvement in skills were related to the length of training, with longer training demonstrating greater improvement in skills. However, in the limited number of communication training studies, impact on patient or family outcomes has not received in-depth exploration. Thus, the Guidelines could not recommend any specific training method such as didactic training, role-plays and/or simulation that would affect important outcomes.

Nurses have important roles in family conferences since they often have the most established relationships with the family. They can communicate empathy, help establish trust, provide information and support, and continue and clarify information after the conference. Research is warranted on the effectiveness of ICU nurse communication training on improved family outcomes. Decreasing short- and long-term family anxiety, depression, and post-traumatic stress may leave family members healthier and with memories that they contributed to goal-directed decisions in the best manner possible.

Use of Specific Consultations and ICU Team Members

Care given to critically ill patients and their families requires the coordination of, and input from, many specialists. While this philosophy is common in clinical practice, research to guide practice in this area is limited. The few studies about consultation services outlined in the FCC Guidelines mainly focused on palliative care utilization. While some studies demonstrated reduction in ICU and hospital LOS [61-63] following use of palliative care, results were equivocal. [64, 65] There was a similar lack of high-level evidence about use of ethics consultation with a range of non-standardised ethics consultation approaches investigated. [66-69] As we await further work in this area, it is important that nurses have a high level of awareness of patients who may benefit from palliative care and ethics consults. In situations where there is potential for conflict with or within families, proactive engagement with these teams should occur.

Use of psychology consultation services are not mainstream, with only 4-29% of ICUs worldwide reporting use of these and few well-described observational studies to inform use of psychology consults in FCC. [70 - 72] There is indication that psychological support, when

combined with video and written support material, can reduce family anxiety levels. [73] Use of cognitive behavioral therapy can also reduce the level of depression and anxiety in family members. [74,75] Work in this area originates from neonatal and trauma ICUs, however, these results may be transferable to distressing situations experienced in other ICU settings. With such an under-developed evidence base, the implications for nurses can only be speculative. However, we suggest that the critical care nurse can remain vigilant for families experiencing emotional trauma and crisis and hold discussions with families regarding the support that psychologists can bring. Critical care nurses can also consider whether specific information packs for families about traumatic situations (for example, attempted/successful suicide, child death, violent and sudden death) could be prepared in ICU as practice development initiatives. Family education pamphlets regarding the possible utility of referral for counseling may be obtained at www.sccm.org.

Social workers are well utilized in ICU practice. However, there were few studies [76,77] to guide recommendations about this role in the FCC Guidelines. Until work in this area is better developed, nurses should continue to recognize the value of social workers in providing support to families. Similarly the role of spiritual advisor in ICU has received little empirical attention, although the availability of spiritual care is important to families. [78] Such support can improve overall family satisfaction with ICU care, [79] especially at end of life. [80] Given this, nurses can identify spiritual support for families who may benefit.

While the above team members are complementary to nursing, a developing nursing consultation role is that of Navigator, a care coordinator who acts as a consistent communicator with family members. In randomized trials, the Navigator role reduced

depression in ICU family members at six months [81] and increased family satisfaction with physician communication. [82,83] These roles are early in their development and there is no consensus on whether there are associated ICU and hospital cost savings. However, what is clear in these roles is that communication continues to be paramount in FCC, and that nurses are important in meeting family information needs.

Operational and Environmental Issues

Nurses are key to delivering on, and driving forward, local ICU operational and environmental issues. However, empirical studies on operational issues are few, and are usually single-sited and observational in nature. Given that family members rely on nurses for support and the provision of quality information, the impact of specialised communication programmes was one operational area discussed. However, the Guidelines note that the impact of communication training programmes for nurses is not well explored, although there is some evidence of reduced ICU length of stay [84] and improved quality of communication between ICU families and nurses [85] following involvement of a specialist trained in communication on the ICU team. Even with these limited data, the Guidelines re-assert that that training be provided to help ICU nurses with family communication and support.

Noise reduction is a further operational issue explored in the Guidelines due to the well-known adverse effects of noise on patients and staff. [86-89] There is low-level evidence that single, private rooms reduce noise and improve family satisfaction, [90.91] even though the increased workload on nursing staff is recognized. [92] Given this, the Guidelines suggest

implementation of noise reduction practices with use of single rooms in ICU. Therefore nurses are advised to be aware of situations where noise reduction should be supported. Nurses should be fully engaged in the design of new ICU's so that patient, family and staff needs can be fully considered.

The adverse effects of sleep deprivation in ICU families and the need for sleeping areas for families are well documented. [93-95] Although the impact of sleep promotion for families has not been evaluated, nurses should be mindful that if families are visiting for extended periods, rest periods can be encouraged as part of self-care. ICUs personnel could assess provision of sleep surfaces within or near patient areas and try to offer space specifically designated for ICU family members.

One of most stressful and challenging operational issues in ICU is the withdrawal of life supporting therapies. The potential stress to patients, families and staff necessitates efforts to provide the best care possible. The limited number of studies evaluating use of protocols in withdrawal of life support [96-98] focus on clinician, not family-centred, outcomes. There is higher quality evidence [99] that use of a protocol for sedation and analgesia can support symptom management. Given that nurses are key to end-of-life processes, protocols can be helpful to guide complex decisions about the use of sedation and analgesia, and should be implemented.

A further area explored in the Guidelines was use of unit-based polices and processes to promote a FCC approach. Although studies are limited to single site and of low-level evidence, there is evidence that unit-based policies that focus on care informed by the integration of families in care as opposed to care driven by traditional authoritarian hospital

values, can reduce hospital readmission days [84] and increase family satisfaction. [85] Recognizing that further research is required, there is support for instituting FCC polices in ICU. Nurses should take the lead in developing local work groups to develop and implement FCC policies.

Conclusions and recommendations for future research in the area

Critical care nurses have many opportunities to influence all aspects of FCC outlined in the Guidelines. However, as recommendations were constructed from low-level evidence, further research is needed. In particular, given the interdisciplinary nature of intensive care and the construction of appropriate teams to deliver FCC, the outcomes of each discipline need to be quantified and assessed. Although nurses often lead the way in innovations to support families and their engagement in their family member's care, greater effort is needed to test the effectiveness of these interventions in comparative trials. This is especially timely given the recent development of the specialized family support Navigator role, often undertaken by nurses. The education necessary to fulfil this role and outcomes associated with deploying this model warrant further investigation. Concerning communication with families, best practices in development of communication training programs and the involvement of family inclusion in rounds has yet to be identified.

Finally, unit-based policies of FCC are usually developed and endorsed at the local level, yet there is no established best practice to standardize these efforts. Simple issues that seem inherently obvious, such as the effect of consistency in nurse staffing or the delivery of culturally sensitive nursing care, have not been evaluated in the ICU environment. Progress has been made since the original guidelines were published in 2007,[7]

yet there are many opportunities for practice improvements and further research in the area of FCC.

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Table 1. Recommended Applications of FCC Guidelines on Nursing Interventions, Nurse Leaders and Nursing Research

Guideline Areas	Direct Nursing Care	ICU Nursing Leadership	Nursing Research
Family Presence: Family visitation policies Presence during rounds Presence during resuscitation	Encourage family presence, welcome family on rounds, prepare family for presence on rounds, offer presence during resuscitation.	Amend resuscitation team policies to add a family liaison, provide education for clinical nurses on how to adjust to family presence, offer debriefings for staff following change in practice.	Identify outcomes associated with family facilitators. Studies looking at 'presence preference' and outcomes associated with adhering to the preference either to stay home or be present are needed.
Family Support: Assisting in care Post ICU clinics	Teach families meaningful bedside care activities, refer families to peer-to-peer support programs, write	Develop family education programs, adopt a framework such as facilitated sense-making[100] or Creating Opportunities for Parent	Evaluate outcomes associated with post-ICU clinics, peer to peer support programs and methods to teach family members how to

Use of diaries and follow up Surrogate decision making	caring messages in diaries and teach families how to use the diary. Refer patients for debriefing on dairies at end of ICU stay or post-discharge.	Empowerment (COPE)[101] to support family inclusion in care. Develop a peer-to-peer support program. Develop a diary program.	function in the surrogate decision-maker role are warranted. Further study is needed to understand effective methods to launch a diary program and associated outcomes.
Communication: Routine family meetings Communication training (role/play, simulation)	Advocate for family conferences, assess and report potential conflict between family and clinical team. Be aware of importance of empathetic listening and proactive	Develop structure for conferences. Consider adoption of communication methods, such as VALUE[102] or SPIKES.[103] Provide training opportunities for staff to develop best practice communication strategies. Ensure debrief facilities available.	Best practices in development of communication training programs have yet to be discovered. The nature of the programs (discipline specific or interdisciplinary), duration of programs, and style of instruction require further study

	communication with families.	Develop written information for families about specific ICU experiences.	to determine what yields the best clinical/family outcomes.
Consultation Services: Ethics Palliative care Psychological support/counseling Social work/physical therapy	Be aware of local consultation services available e.g. palliative care, ethics consultation, psychologist services, social workers and spiritual support. Know how and when to refer families, especially in conflict and end-of-life situations.	Consider available consultation services, identify gaps in service provision, and work to develop future service plans in order to support ICU families. Ensure information available for staff to make timely referrals. Consider developing role of family navigators (care coordinator or communication facilitator) for family members.	Evaluation work to assess and quantify outcomes of nurses as part of interdisciplinary team required. Determine impact of early psychological interventions for families. More detailed exploration of specialized family support liaisons and education to support this role is needed.

Operations and Physical Environment: Engagement in decisions ICU Design (noise reduction, comfort) End of Life support	Engage in decision-making about care and support family members in this. Know local and hospital-wide policies the support FCC. Consider noise levels within the ICU environment and take action to minimize disruption to families e.g. use of single room, reduce monitor alarms. Monitor for signs of sleep deprivation in families and work to	Develop and implement protocols to ensure adequate and standardized use of sedation and analgesia during withdrawal of life support. Review/develop hospital-wide FCC policies. Ensure noise awareness and noise reduction practices are included in orientation programs for new ICU staff. Consider availability of family sleep surfaces in/near to the ICU.	Evaluate effectiveness of clinical protocols at end-of-life. Policies of family centered care are widely endorsed, yet there is no established best practice to standardize these efforts. Simple nursing issues, such as the effect of consistency in staffing, or the delivery of culturally sensitive care has not been evaluated in the ICU environment. Empirical evidence regarding outcomes of family space in ICU design is required.

	develop a schedule of rest periods.		