

Determining Best Practices for Family Participation in ICU Rounds Toolkit

Guidelines & Tools

What Makes ICU Rounds Patient and Family Centered?

Current guidelines recommend that family be invited to attend ICU bedside rounds as a way to improve communication and increase satisfaction. However, there is little guidance as to how participation can be optimized so that family members feel valued as a team member while respecting the vulnerabilities of having a critically ill loved one. Recent literature has used the term ‘family-centered rounds’ when families receive an invitation to attend and are provided with a summary of information discussed and an opportunity to ask questions. This approach was largely modeled after a traditional ICU rounds framework without patient or family member input. The drawback of such an approach is that the attending family member may not be comfortable or aware of the opportunity to adopt the roles of the patient voice and co-decision maker in this setting. In our observational multicenter study of adult ICU rounds, we identified six foundational elements of family-centered rounds related to decision-making and communication:

1. **Invitation**
2. **Orientation**
3. **Active Engagement**
4. **Summary**
5. **Questions**
6. **Communication Follow Up**

How Do We Make It Happen?

We analyzed and identified the defining structures and processes of the six elements. We identified facilitators and barriers to each element. A multidisciplinary provincial working group reviewed the facilitators and barriers and worked with us to develop packages of 'tools' to maximize and mitigate facilitators and barriers. Tool ideas were generated from collective review of study observations, reported literature, personal experience, and a one-day creative workshop.

We have summarized the six elements, with associated structures, processes, and tools within this guide and toolkit for healthcare providers and families as a way to facilitate patient and family centered adult ICU rounds.

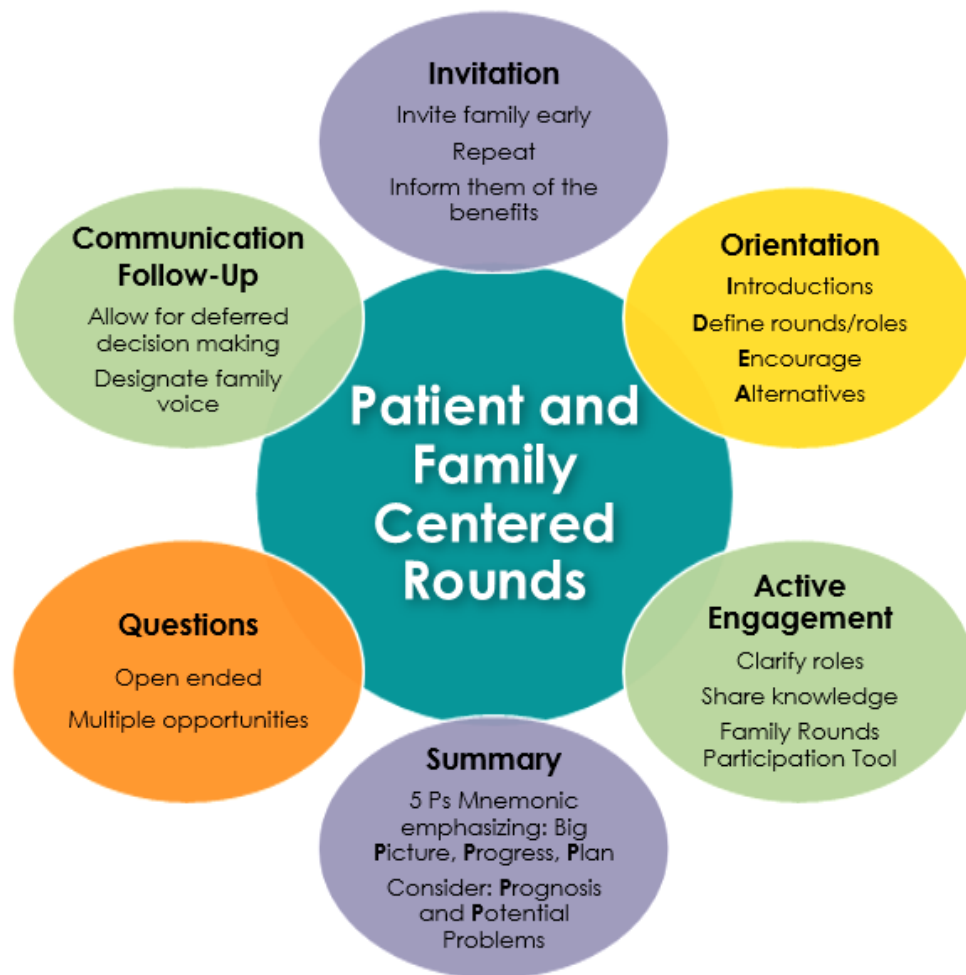


Figure 1 - The six elements that informed the development of the toolkit

1. INVITATION TOOLS

Having a Provider Approach

Elements important to the invitation include explaining rounds, and the associated benefits, limitations, and alternatives.



- Invite family to attend rounds the next day as the next point of contact.
- Provide a brief definition of rounds including time and place.
- Discuss the benefits of rounds from the family viewpoint
- Discuss the limitations of rounds from the family viewpoint
- Offer alternatives to communication if they couldn't make rounds.

If family is interested in attending rounds, this would be a good opportunity to ask about which family members will attend and the family spokesperson.

So as to not overwhelm family, further information as to the structure of rounds can occur just prior to rounds during the "Orientation."

2. ORIENTATION TOOLS



1) Healthcare provider approach

Much of the orientation can happen immediately before rounds (e.g. Nurse-led orientation before rounds, or social worker if available). Whether orientation is done with or without the ICU team present, it should include:

Introductions/Invitation

Definition of rounds

Encouragement to family member (to advocate and ask questions), and

Alternatives.

Introductions

It is important to take the time for full introductions prior to starting rounds any time family are present, not only the first time family join. (Not knowing a family member's name can be a significant barrier!) Both the family and the rounding team should be introduced. Family member introductions should include their name, relationship to the patient and how they are involved in the patient's care, such as:

"This is Mary. She is Joe's wife. They have lived together here in Calgary for 50 years."

(Follows **NOD** acronym used in healthcare: Name, Occupation, Duty). The healthcare team members can then introduce themselves by their name and occupation at the beginning of rounds or right before they speak during rounds.

Invitation and Definition

"We are starting rounds shortly. We will be reviewing why Joe is in the ICU and talk about a plan for his care as a team. Would you like to join in?"

It is important to let the family know that these are work rounds so there will be a large team and a lot of medical language, and reassure them that a summary in non-medical terms will be provided at the end. Language might include:

"You'll see a fairly large group in rounds as there are many healthcare providers on our team. You will hear a lot of medical terminology during rounds; we will make sure that you receive a good explanation at the end and have a chance to ask questions to make sure you have a good understanding."

Encourage

Inform family about how they can participate in rounds and encourage them to both observe and actively participate. To encourage participation, inform them of their multiple roles:

- a) Their role in providing information about the patient's condition and how they were managing at home; and
- b) Their role as the patient's voice and the expert on the patient's values and wishes; and
- c) Their role in co-developing plans that are consistent with the patient's goals.

They can be asked how they would like to participate, and informed that they are not required to attend or participate. Wording might include:

"You are welcome to attend rounds, although this is optional and there are many ways to obtain information outside of rounds. If you choose to join rounds, you can watch and listen to our discussion and also ask questions. You are also here as the person who knows Joe best, and we would appreciate your input. We do our best to make sure he's comfortable, however if you have ideas about what we can do differently or hear plans that do not reflect what he would want, we invite you to share this with us."

Alternatives

Family should be informed about opportunities to talk with the doctor and nurses outside of rounds, for example:

"If you prefer to stay by Joe's side we can come in after rounds to let you know the key points."

"If you still have questions after rounds or want a longer time to talk, we can plan to meet together another time."

"If you cannot attend rounds, we can meet when you come in or talk over the phone."

3. ACTIVE ENGAGEMENT TOOLS

1) Family Note-taking Template/Rounds Participation Framework



One potential barrier to active family engagement during rounds is lack of clarity around their potential roles. Common members of an ICU care team, such as physicians, nurses, respiratory therapists, pharmacists and dietitians are aware of how their expertise allows them to contribute to patient management during rounds. Presentations during rounds often follow a standardized format (e.g. MD admission history, RN systems, RT ventilator settings). However, family members may not have a framework as to how to actively contribute to rounds. As journaling and note-taking is a common tool used by family members in the ICU, we have created a template with points for family members to think about in advance as a way to help prepare them to actively participate during rounds.

| Family Note-Taking/Rounds Participation Template | |
|--|--|
| <p>Patient's Goals</p> <p>(These questions help the team in goal setting for your loved one. Please consider how your loved one would answer these questions for themselves.)</p> | <p>What would my loved one want?</p> <p><i>"He would never want to be short of breath just sitting still."</i></p> <p>What would my loved one want to avoid?</p> <p><i>"Living with any pain. He's very proud and would hate if any body functions were cared by a stranger permanently."</i></p> <p>What would be acceptable to my loved one?</p> |

| | |
|---|---|
| | <p><i>"He wouldn't mind the breathing tube if he had a reasonable shot of coming off after a good trial."</i></p> |
| <p>About the Patient</p> <p>(You may have knowledge of your loved one from before they were hospitalized that will help direct the care team. The team may ask you to comment on some of these aspects.)</p> | <p>Values and goals</p> <ul style="list-style-type: none"> -Use box above to guide this <p>Baseline Function and Quality of Life</p> <ul style="list-style-type: none"> -Mobility -Ability to eat full diet -Cognition -What does patient think of current living situation? <p>Experience</p> <ul style="list-style-type: none"> -Does patient seem in pain or discomfort? -Does patient seem emotional? (e.g. anxious, depressed) -Does patient seem confused? |
| <p>Optional Notes from Rounds</p> <p>(Please use this space to record notes from rounds.)</p> | <p>Option to describe local rounds format for family here.</p> |
| | |

| | |
|--|---|
| <p>Summary Take Home Message</p> <p>(The team should provide a summary for you at the end of rounds, including diagnosis, progress, and important upcoming tests and procedures. If this is missed, please request a summary from the team.)</p> | <p>Big Picture: "Pneumonia"</p> <p>Progress: "Is today better, same or worse?"</p> <p>Plan: "Check on CT scan results"</p> <p>"Central line IV today"</p> <p>"Turn off sedation"</p> |
| <p>Questions</p> <p>(After a summary of your loved one's status and plan for the day, you may have questions for the team. You can write down questions ahead of time so that you remember them. You can also ask a healthcare provider to ask the questions on your behalf.)</p> | <p>Examples of questions we frequently receive:</p> <p>"Can you explain to me what you meant by SBT?"</p> <p>"How come he is still asleep?"</p> <p>"Can we try a sleeping pill tonight?"</p> <p>"When will the results for the test be back?"</p> <p>"When do you expect him to get the breathing tube out?"</p> <p>"How common is this kind of confusion?"</p> |

2) Provider approach

Family members are often asked if they have any questions at the end of rounds, although in a closed question format that doesn't fully engage family members as a partner in care. There may be opportune time to engage family members when planning patient care (e.g. direct questions to engage family as a resource) If not, simple open-ended questions to family before or after the summary helps to involve the family members as the patient's advocate.

"Are there other things you want us to know about how Joe's doing?"
"What do you think Joe would think?"

"Is there anything else that you think Joe would want to know?"

3) Addressing the limitations of medical terminology

Medical language and abbreviations have been mentioned as a barrier by providers and family alike. However, this can be overcome by a good summary. Most families understand that medical terminology is used during rounds as part of provider communication and teaching and despite the medical terminology, also appreciate the opportunity to see how the team functions. Explicitly indicate before beginning rounds that a summary will be given at the end. A jargon dictionary was seen as unnecessary and does not substitute for healthcare provider explanations.

SUMMARY TOOLS



1) Healthcare provider approach

A patient and family oriented summary is captured through the **5 P's mnemonic**:

1. Big Picture:

"Joe has a severe lung infection and the bacteria in his blood has put his body into shock."

2. Progress:

"Because of old lung damage from smoking, he is very sick and this is a very serious hospital admission. Since getting the breathing tube yesterday, he's more stable and on less oxygen."

3. Prognostication:

"I don't see him being getting the breathing tube out before next week."

4. Plan:

"Today we are getting a scan of his chest to make sure there's also not a lung clot."

5. Potential problems:

"He's really weakened and we're expecting electrolyte levels in his body to drop as we give him nutrition."

The 5 P's is meant to guide team members in providing effective patient and family oriented summaries that address common and meaningful elements of patient care. It is also a message that is relevant for the whole team to consistently hear as a way of setting clinical goals. It does not need to be overly prescriptive and should be modified to suit the team, patient, and family context. Summaries may need to occur multiple times to match family needs and the 5 P's mnemonic helps to keep the message consistent and concise.

5. QUESTION TOOLS

1) Healthcare provider approach

1. Be more inviting for questions: "Do you have any questions?" can be rephrased as:

"Was there anything that you didn't hear or understand that you'd like to talk about later?"



as a way of adding depth when inviting questions.

2. Using open questions: Avoid asking leading questions and questions that put pressure on family to answer. Not all families will have questions.

"What do you think Joe would want to know? What would he want to do?"
"What didn't we get to touch on today that we can talk about later?"

3. Offer multiple opportunities to ask questions again: Bedside nursing staff should ask family again if they have questions after the rounds team leaves as family collect their thoughts or prefer to speak to one person rather than in a

group. Nurses are in a position to reinforce information from rounds and provide clarification in a more relaxed setting.

4. Encourage families to write down questions or ask them ahead of time:

Family can write their questions in a journal as one way to remember them during rounds. Journals are also a way for multiple family members to update each other or add questions. Offer this as an option with an explanation to how the journals can be used.

"Some of our families find it helpful to capture their thoughts, experiences, questions, concerns so they don't forget and can talk about them later (for example, during rounds). Would you like to give it a try?"

In addition to journaling and asking questions, question boxes or envelopes within the patient's room are another option. Whiteboards for questions pose as a visible reminder.

5. Encourage questions from family unable to attend rounds: Families who cannot join rounds frequently pose questions and concerns to nursing during later visits or over the phone. A mechanism to pass family questions along during nursing report/handover is important so as to not lose communication opportunities outside of rounds. During rounds, nurses can advocate as the 'family voice' and pose questions for family who are unable to attend. As with all action items, assigning an appropriate team member as task owner to provide the answers to these questions to family unable to join rounds is important to close the loop.

6. COMMUNICATION TOOLS



1) Deferring communication to a family meeting

Matching the purpose and format of communication is important. Provide families with the option of deferring decision-making when appropriate to reduce the associated stress of making an immediate decision or providing an opinion right away. Knowing there is a time for follow up communication can be reassuring to families.

Healthcare provider approach:

"I'll have a better idea of the treatment options after I talk to your oncologist/review Joe's chart...can we schedule a meeting later?"

Family member approach:

"I don't really understand and I think our daughter should be here before we make any decisions. Can we schedule a meeting later?"

Setting up a scheduled time for a meeting can help ensure that all family members who want/need to be present are available and can participate, interdisciplinary representatives from the healthcare team can be present, and an agenda for the meeting is established. Include the bedside nurse and other members of the ICU team in family meetings whenever possible. Legible documentation in the chart about the discussion and decisions that occur in family meetings allow members of the healthcare team who were unable to attend to be aware of the conversations that took place.

2) Phone conversations

The following points can cue staff as to the information that is important to obtain from family and the information that should be provided to family.

- Family relationship and context.
- Family understanding of the situation.
- Provide patient status – better, same or worse?
- Provide plan for the day.
- Provide timeline for next meeting.
- Screen for awareness of the option to attend rounds.
- Screen for barriers to in-person attendance.
- Screen for need for a scheduled formal meeting.

Our point prevalence study showed phone updates were largely done by bedside nurses. When a significant discrepancy in the family's understanding of the patient's condition during a phone conversation is noted, this should be brought to the attention of the attending physician.

Confirm the family member's identity to ensure patient confidentiality is maintained (eg: asking the patient's middle name for the first conversation and then establishing a password for future phone conversations). Identifying a designated family representative for consistency is helpful, although this need not be exclusive, depending on family availability.

Participants emphasized the importance of consistent messages from all healthcare providers who communicate with the family, whether in person or by phone.

3) Designated 'patient and family voice' during rounds

Consider designating a healthcare provider as the 'patient and family voice' when family members are not able to attend rounds. The designated patient/family voice can raise questions that the family had, and convey the responses to these questions back to the family. In our research, the bedside nurse most commonly took on this role.

Provider script:

**"Joe's wife Mary (use name to personalize) won't be coming in today but she did have some questions yesterday..."*

"Mary already left but she knows about the CT scan results."

4) Other family meeting tools suggested in interviews/described in literature:

- Time-based checklists for family touch points may be useful to maintain continuity of communication as the patient's status changes.
[1, 2]
- Patient/family navigators help the family understand the healthcare information and processes along the entire healthcare journey.^[3]
The navigator could be a social worker, spiritual health practitioner, or a person trained specifically for this role.

REFERENCES:

1. Huffines, M., et al., *Improving Family Satisfaction and Participation in Decision Making in an Intensive Care Unit*. Critical Care Nurse, 2013. **33**(5): p. 56-69.

2. Seaman, J.B., et al., *An Integrated Framework for Effective and Efficient Communication with Families in the Adult Intensive Care Unit*. Annals of the American Thoracic Society, 2017. **14**(6): p. 1015-1020.
3. Torke, A.M., et al., *The Family Navigator: A Pilot Intervention to Support Intensive Care Unit Family Surrogates*. American Journal of Critical Care, 2016. **25**(6): p. 498-507.