Navigating end of life conversations with families

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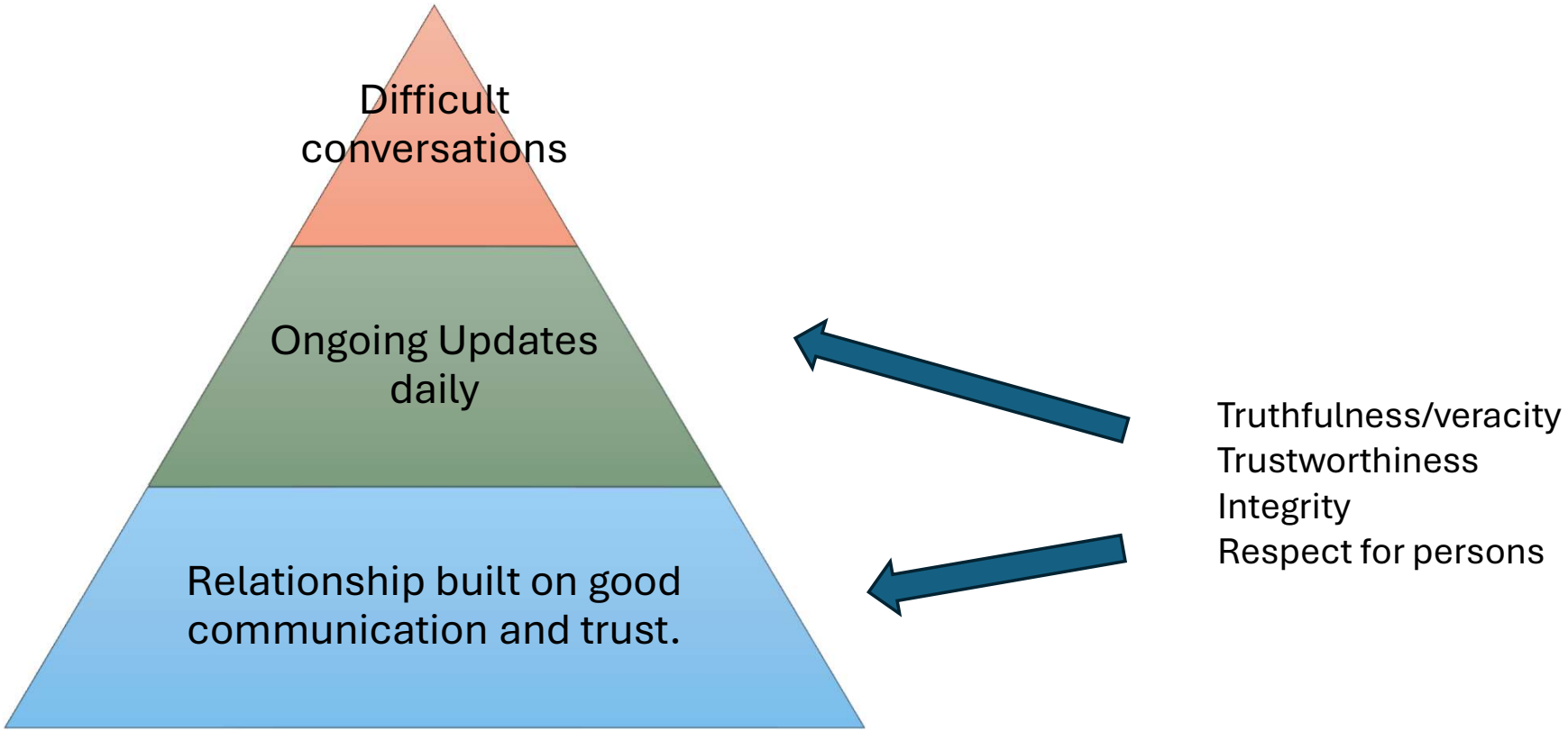
The foundation



Communicating with families of children in PICU

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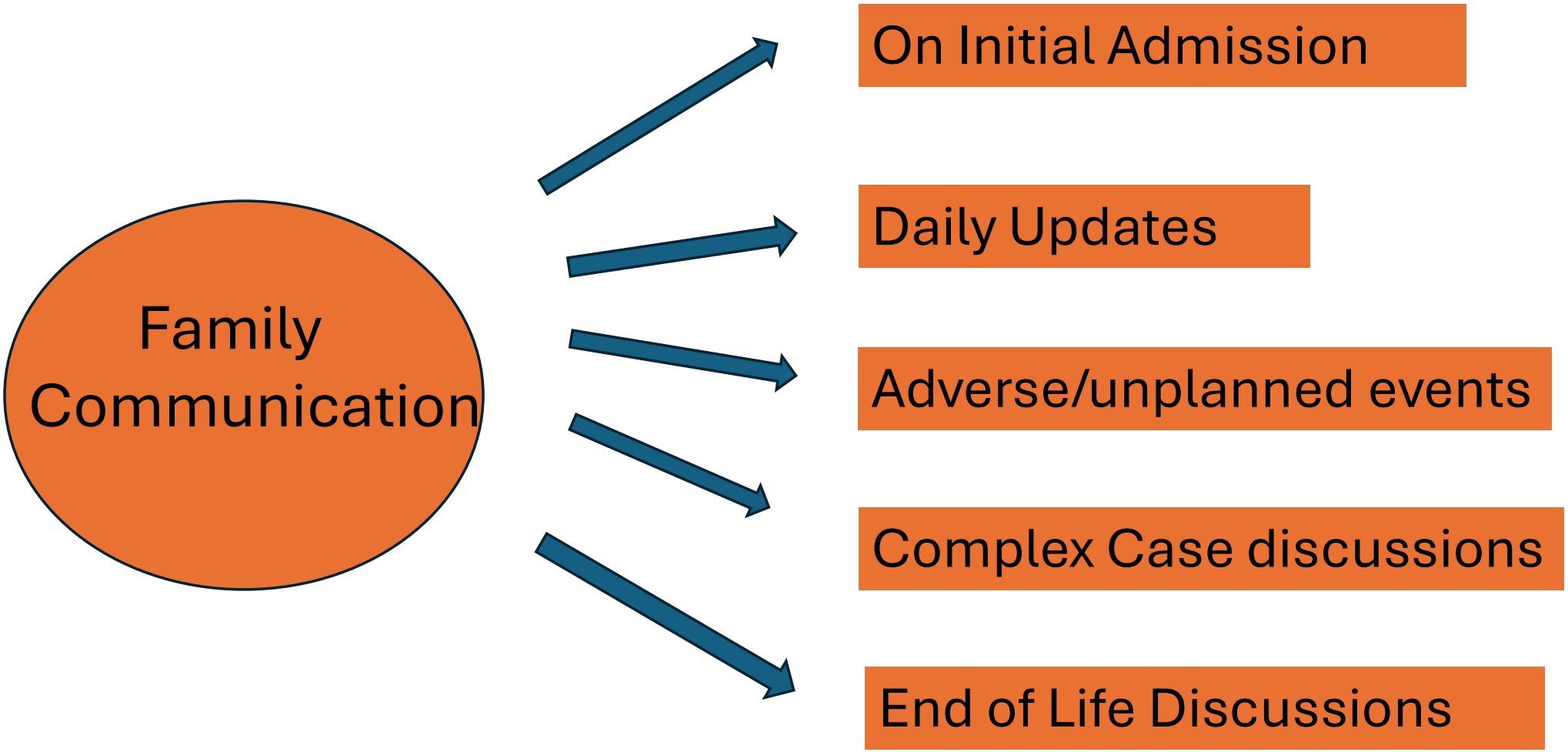

Family Communication
On Initial Admission
Daily Updates
Adverse/unplanned events
Complex Case discussions
End of Life Discussions

Sharing information on admission

- Introductions
- Visiting /lodging; other logistics
- Infection control
- Monitors and machines
- Lines, devices, feeding
- Analgesia and sedation
- Clinical condition, pathophysiology, disease severity
- Treatment plan, and expected outcomes

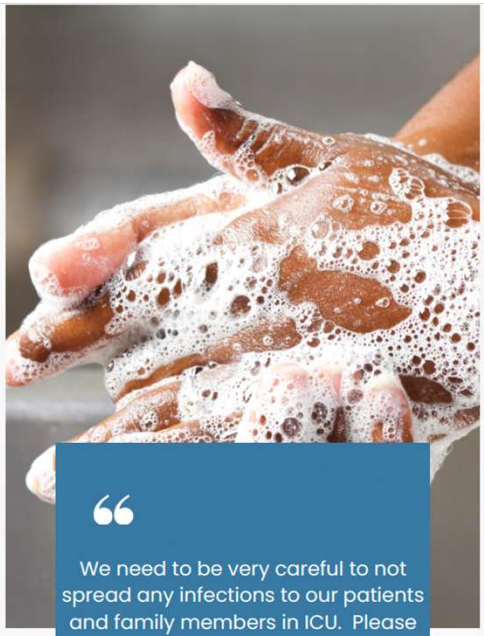
Get In Touch

Contact Information

Visiting hours:

Phone Number

First Floor:
Second Floor:
Switchboard:



> We need to be very careful to not spread any infections to our patients and family members in ICU. Please wash your hands with soap and water and dry them with paper towel provided at the sinks, as you enter the ICU. Please help us by making sure you roll up your sleeves and put on a plastic apron when visiting by the bedside of your child. This helps to prevent the spread of infections.

Chris Hani Baragwanath Academic Hospital

Welcome to the PICU

What is the Paediatric Intensive Care Unit?

This is a special hospital ward which cares for patients who are very sick (critically ill). This intensive care unit looks after both Adults and Children.

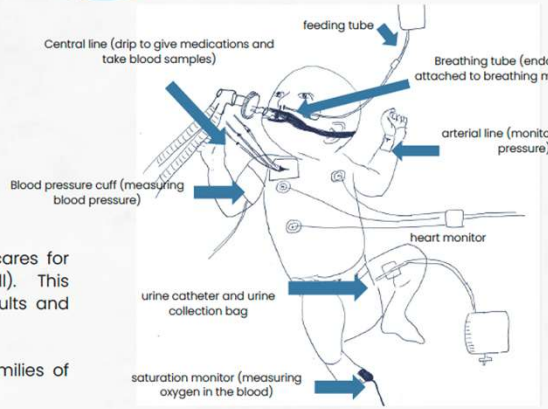
This pamphlet is specifically for the families of children admitted to the ICU.

We understand that the Paediatric Intensive Care Unit can be a scary place when you see it for the first time.

There is a large team of people working in the ICU to help your child get better, including: Professional Nurses, Paediatric Specialists in ICU, Doctors, Surgeons, Dietitians, Physiotherapists, Occupational Therapists, Speech and Language therapists, Clinical technicians, administrative staff and cleaning staff.

The senior Paediatric Intensivist on duty for the week will make sure they speak to you every day during visiting hours to update you on your child's condition, and answer any questions you may have.

Please feel free to ask anything you do not understand and we will do our best to clarify for you. You may also speak to the nurses who look after your baby and they will be able to give you an update on your child's condition.



What are all the monitors and wires on my child?

Your child will be attached to equipment which measures the heart rate, oxygen levels, blood pressure, temperature and breathing rate.

- ✓ Most children in ICU will not be able to eat normally and we will place a feeding tube through their mouth or nose into their stomach which will feed them liquid food which the dietitian prescribes to meet all their nutrition needs.
- ✓ Your baby will have a central line placed on admission - this is a type of drip which allows us to take blood samples and give medication.
- ✓ Your child may have a breathing tube which goes into the trachea (breathing pipe) and connects to a ventilator (breathing machine). This is needed for children who need their breathing to be supported.

Commonly Asked Questions:

Why does my child need to be in ICU?
Your child requires specialised care that cannot be provided in a normal ward. This may be because one of their body organs (e.g lungs, heart, kidneys) need special support.
Children may also be admitted to the PICU after a big surgical operation for monitoring and pain control.

Will my child be ok?
Rest assured, we will do everything in our capacity to ensure that your child has the best possible outcome. However, the children who are admitted to the ICU are critically ill, and sometimes, despite our best efforts, children do die. We will communicate with you about your child's condition daily so that you are always aware of the progress being made.

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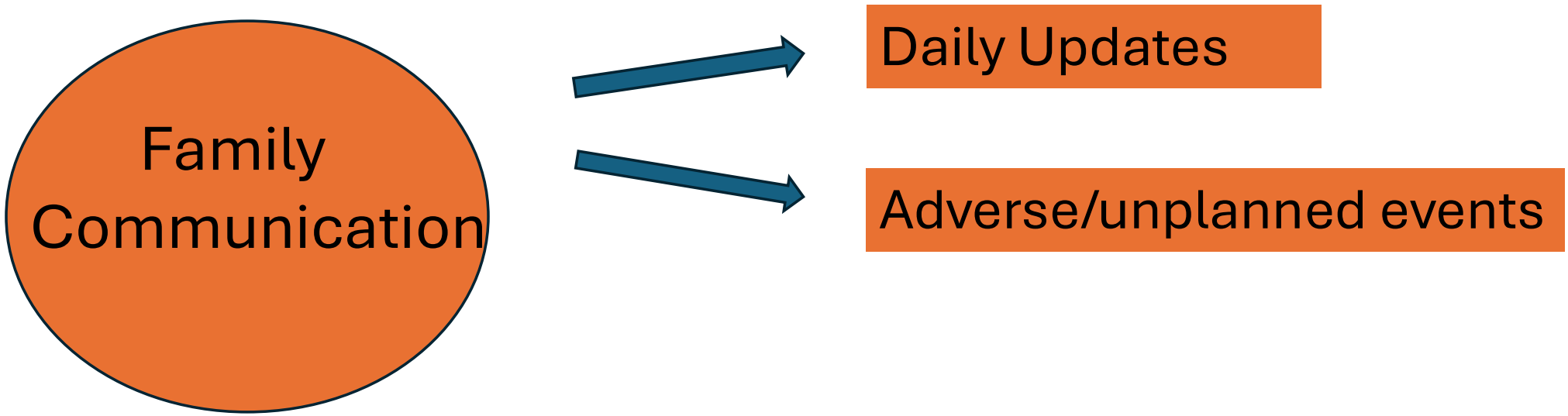
How long will my child stay in ICU?
It is difficult to answer this question as each child is unique and their problems are different. The course of each patients stay is often unpredictable and please be prepared for possible setbacks and challenges on the way.

What are the risks of being in ICU?
Complications may occur from the problem which has caused your child to need to be in ICU. Complications may also occur from being in ICU and the devices we use. These include blood stream infections, lung infections from the ventilator, pressure sores, and complicatons from the drips and lines we use.


Family Communication
Daily Updates
Adverse/unplanned events

PACES tool

RESEARCH ARTICLE Open Access

Development and evaluation of the feasibility and effects on staff, patients, and families of a new tool, the Psychosocial Assessment and Communication Evaluation (PACE), to improve communication and palliative care in intensive care and during clinical uncertainty

Irene J Higginson[1*], Jonathan Koffman[1], Philip Hopkins[2], Wendy Prentice[1], Rachel Burman[1], Sara Leonard[2], Caroline Rumble[1], Jo Noble[2], Odette Dampier[2], William Bernal[2], Sue Hall[1], Myfanwy Morgan[3] and Cathy Shipman[1]

Higginson *et al. BMC Medicine* 2013, **11**:213
http://www.biomedcentral.com/1741-7015/11/213

Patient Name _____

Date of Birth _____

Hospital Number _____

Date and time of Admission _____

Date and time form Completed _____

Staff member completing form _____

Key family Contact _____

1. Family details including key relationships

If yes to any of the following, detail the action taken below:

Children under 18?	☐ Yes	☐ No
Guardianship issues of any children	☐ Yes	☐ No
Vulnerable adults?	☐ Yes	☐ No

2. Social Details

Including employment, religious, spiritual and cultural needs; perceptions of hospital/ICU

Financial Concerns?	☐ Yes	☐ No
Religious/Spiritual Needs?	☐ Yes	☐ No
Language/Cultural Needs?	☐ Yes	☐ No
Transport/ Parking Needs?	☐ Yes	☐ No
Other supportive Needs?	☐ Yes	☐ No

Details/ Action Taken:

3. Patient Preferences

Has the patient previously expressed view about any treatment/care wishes?

☐ Yes ☐ No

Specify:

Has the patient expressed a preference for place of care?

☐ Yes ☐ No

Specify

Does the patient have an advance directive/statement?

☐ Yes ☐ No

Details and action taken

☐ Not appropriate to discuss currently (must give reason)

4. Communication and Information

Is the patient aware of the current situation and likely outcome?

☐ Yes ☐ No, Alert ☐ No, decreased consciousness

Is the next of kin aware of the current situation and likely outcome?

☐ Yes ☐ No

Names of people information about patient to be given to:

Information about the ICU been explained?

Visiting hours	☐ Yes	☐ No
Patient information leaflet been given?	☐ Yes	☐ No
Who to ask for information?	☐ Yes	☐ No
Who the different staff members are?	☐ Yes	☐ No

5. Any other concerns/issues

Useful Contact Numbers:

Palliative Care Team:
Adult : Dr Sobekwa 0827734003
Paediatrics: Nonkosi 0725904529

Social worker Department 011 9339949

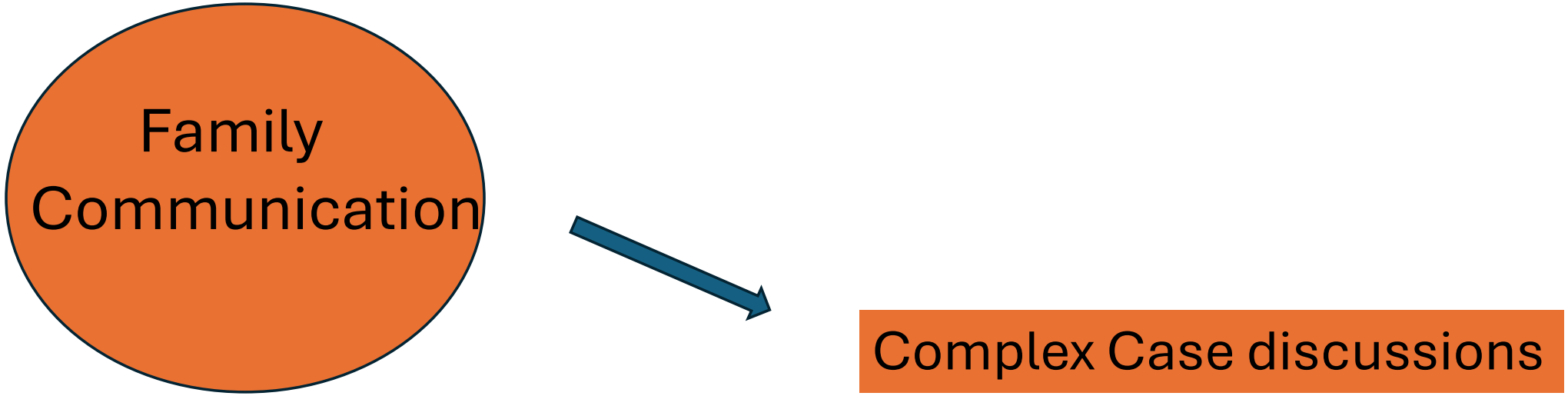
Psychology Department 011 9339765

Lodging for mothers

6. Communication Update

Please complete each time the patient/ next of kin / other is updated.

Date	Update given by		Update given to	Communication documented?		
	Name	Designation		Yes/no	Medical notes	Nursing evaluation


Family Communication
Complex Case discussions

Complex case Discussions

Bioethical Inquiry
https://doi.org/10.1007/s11673-024-10381-9

ORIGINAL RESEARCH

Check for updates

Complex Decision-Making in Paediatric Intensive Care: A Discussion Paper and Suggested Model

Melanie Jansen · Katie M. Moynihan · Lisa S. Taylor · Shreerupa Basu

Received: 12 July 2023 / Accepted: 27 June 2024
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PICU Complex Decision Making Process

Set up

Book quiet room, with high level teleconferencing facilities.
Meeting time – 90 minutes.
Participants:

- Medical, nursing, and allied health representation from all relevant specialties
- Social work, pastoral care or other representative to communicate patient and family perspective
- Designated facilitator
- "Devil's advocate"
- Clinical ethics

Facilitator welcomes everyone, explains the process and rules of engagement. (See script in Appendix 1)
All participants introduce themselves – name, department and role.

Information Gathering

1. Clinical facts - *A nominated clinician will provide a summary of the clinical situation*
   - Is everyone in agreement regarding the clinical situation?
   - Is there more clinical information that needs to be gathered?
   - Are there any other opinions we should seek?
   - What is the patient/family's perception of the clinical situation? Is this impacting clinical care – if yes, how?
2. Facts of the felt experience
   - How is the patient/family feeling? What matters most to them?
   - How do the clinicians involved feel? What are the main frustrations, worries, or positive feelings about the case?
   - Are there important people whose felt experience has not been explored?

Clarifying of Questions

What is the main problem?
What question/s do we need to answer to work through this problem?

Analysis of perspectives, values, and principles

Discuss each relevant perspective, clarifying the values and principles that are important to the participants and how these inform their position on what we should do.
Pause to ask:

- Is there any bias in our thinking that we haven't explored?
- Has everyone had the opportunity to share their perspective?

Plan Discussion and Development

1. What are the possible ways to move forward?
2. What are reasons for and against the available options (how do we weigh the significance of each value in this case)?
   An example of how rationales may be expressed includes
   - *It is justifiable to do … because …*
   - *The possible harms arising are … To ameliorate these harms we can:*
   - *To carry this plan out effectively we need …*
3. Engage in deliberation about the similarities and differences of different people's reasons in support of each possible way forward.
   Examples of exploratory questions include:
   - *I would weigh the importance of X higher than Y, because….. How have you weighed it up?*
   - *What evidence supports your claim that…..?*
   - *Could you clarify what you mean by….?*

Pause to consider

- Are we showing any signs of groupthink?
- Have we interrogated our reasoning for bias?
- Request input from the Devil's Advocate.

PICU Complex Case Deliberation – Documentation Template

Date: Patient Details

Time:

Attendees

Facilitator:

Intensivist on service:

Devil's advocate:

Others (name and specialty)

Medical case summary

Facts of the felt experience

Key questions addressed in the deliberation

Values, perspectives, and principles identified

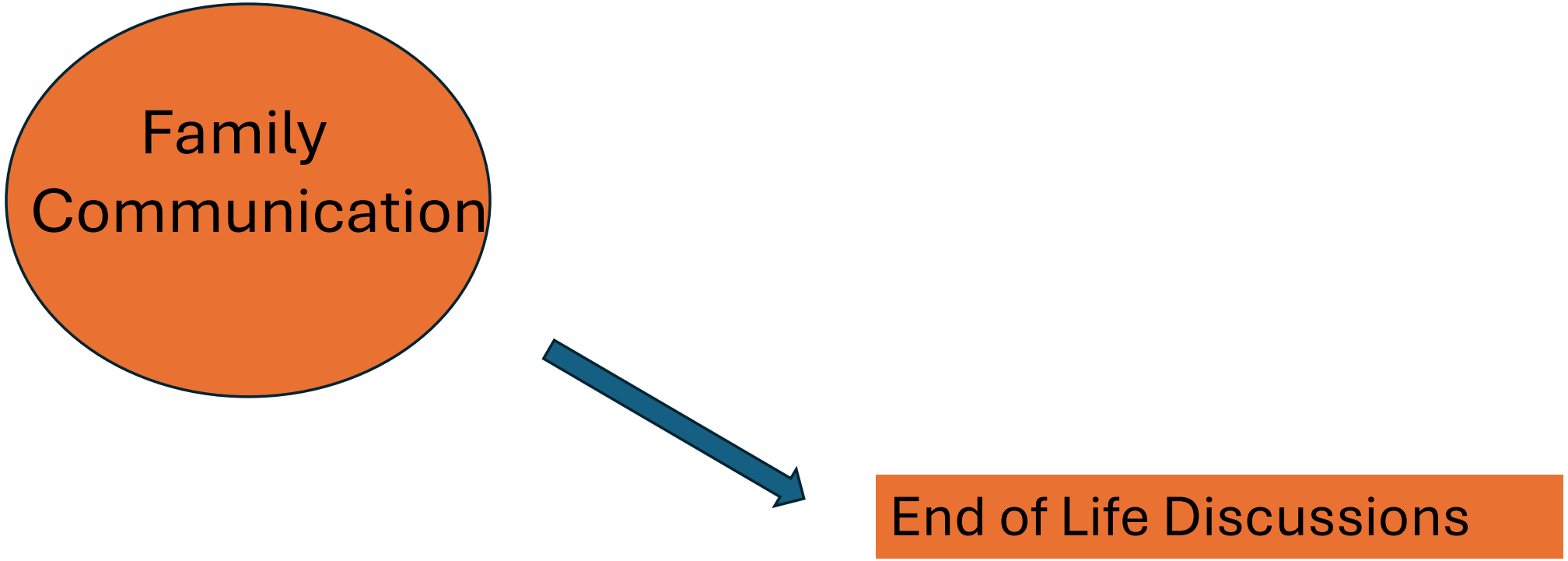
Summary of proposed management plan (including rationale)

These notes were made available for review by all attendees and were confirmed as reflective of the discussion.

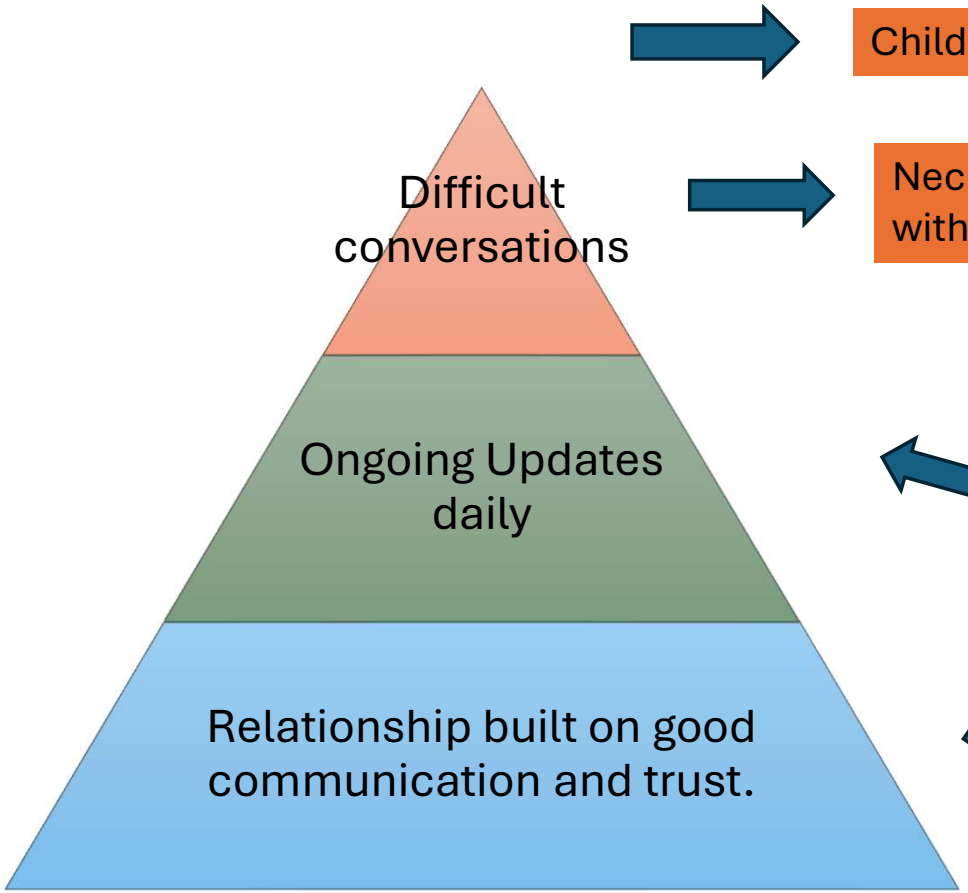
The decision and underlying rationale developed today will be documented, along with any dissensus, and all present will have an opportunity to confirm the documentation before it is included in the medical record. All complex case deliberations will be reviewed and analysed retrospectively for quality improvement purposes.

We ask the people invited to participate in the deliberation to approach it with patience, open-mindedness, and curiosity. View the deliberation as an opportunity to hear the views of others and develop further understanding, rather than solely as an opportunity to persuade others to your way of thinking. The cases are complex and our thoughts and emotions can be difficult to articulate. Accept that it takes time, and cognitive and emotional effort, to ensure that we gather all relevant information and explore all possible ways forward.

The usual standards of professional behaviour apply in this deliberation. It is the facilitator's role to ensure that all voices are heard, that the deliberation is comprehensive, thoughtful, and reasoned, and that we keep to a practical timeframe.


Family Communication
End of Life Discussions

Navigating end of life conversations



Child is dying/Has died

Necessary for withdrawal/limitation of treatment

Palliative care involvement EARLY on!

Truthfulness/veracity
Trustworthiness
Integrity
Respect for persons

“Futility” vs “Inappropriate Therapies”

“ICU interventions should generally be considered inappropriate when there is no reasonable expectation that the patient will improve sufficiently to survive outside of the acute care setting, or when there is no reasonable expectation that the patient’s neurologic function will improve sufficiently to allow the patient to perceive the benefits of treatment”

Kon et al 2016

Withdrawl/Witholding of life-sustaining therapies

- Life is limited in quantity
- Life is limited in quality
- Informed competent refusal of treatment

Larcher V et al Arch Dis Child 2015 (supp2) s1-23

LEARN Model

L **Listen** with sympathy and understanding to the patient's/ parent's perception of the problem

E **Explain** your perceptions of the problem

A **And** discuss differences and similarities

R **Recommend** treatment

N **Negotiate** agreement

Practical Guidance

- Take into account the context.
- Remember its not an “all or nothing”
- Clarify what parents are asking
- Try to collaborate with family
- Maintain professional integrity
- Seek support and engagement of other members of the multidisciplinary team.

Shared Decision Making

Both parents and health care providers are involved in making decisions for paediatric patients, as both are presumed to have some second-person knowledge of the child's own wishes, values and goals

However: neither of them are going to be the ones to live with the results of these decisions.

The Best Interest Standard

"Children are not property, are not objects, are not a means to an end, but have moral claims of their own"

Bester 2019

Beneficence

- Best Interest Standard all things considered (for child)
- For whom? Parent / Child
- Overarching benefit as well as short-term
- Rights to “open future” and “Rights in trust” (future autonomy)

Non-maleficence

- Avoid high-risk, low-probability interventions which may cause suffering disproportionate to benefits

Justice

- Responsible stewardship of resources (esp in resource-limited environments)

Human Dignity

Paediatric Disclosure

Age and developmental capacity are important

Children should be allowed opportunity to participate in their care to the extent possible

Its not an “all or nothing” (false dichotomy)

Religious/cultural considerations


Time


Time
Don’t take families grief personally
Look after your own wellbeing too

No end to care

You matter because you are you, and you matter to the last moment of your life. We will do all we can to help you not only to die peacefully, but also to live until you die”

- Dame Cicely Saunders