

How to deal with parents in difficult situations?

Prof Sanjay Patole, MD, DCH, FRACP, MSc, DrPH
Centre for Neonatal Research and Education
University of Western Australia, Perth



Common causes of parental distress

- **Failure of communication**
- Technological advances and complexity of care
- Unreasonable expectations
- Doctor Google
- The dangerous equation - "*Costly treatment is good treatment*"
- Differences in faith, religion, culture, and belief systems
- Decisions based on **paternalism**



Dealing with parents in difficult situations

Essential skills

- Effective communication
- Breaking bad news
- Negotiation
- Conflict resolution
- Risk management
- Active listening with compassion
- Emotional intelligence



Emotional intelligence

Self-awareness

- The ability to recognise and understand your moods, emotions, and drives, **and their effect on others**

Self-regulation

- The ability to control or redirect disruptive impulses and moods, ability to suspend judgment- **to think before acting**

Motivation

- A passion to work for reasons that go beyond money or status

Goleman D. Harvard Business Rev 1990



Emotional intelligence

Social skill

- Proficiency in managing relationships and building networks, ability to find common ground and build rapport
- Friendliness with a purpose, moving people in the direction you desire.

Empathy

- The ability to understand the emotional makeup of other people

Goleman D. Harvard Business Rev 1990



Difference between empathy and sympathy

- Both are feelings concerning other people.
- **Sympathy:** 'Feeling with'- compassion for or commiseration with another person.
- **Empathy:** 'Feeling into'- the ability to project one's personality into another person and more fully understand that person.
- **We feel empathy when we've "been there",** and sympathy when we haven't.

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- **Sympathy:** **Recognition** that another person is **suffering**.
 - **Empathy:** When **one feels** the other person's **pain or suffering**
 - A person expresses sympathy, but shares empathy.
 - *‘Detached concern is not empathy ‘ –Halpern 2003*

 - **Is it OK to get emotional when talking to parents in distress? Yes**

'Professional distance' has its human limits



Deborah Orr. The Guardian 2015 March

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- Can emotional intelligence be acquired? **Yes and No**

Goleman D. HBR 1990

- Can empathy be acquired and lost? **Yes**

- *‘Ultimately it is only the patient who can tell us whether the doctor has empathy or not’.*

Singh S. MedGenMed 2005

- *‘data suggest that empathy is indeed hard to teach, and may in fact be lost during medical training’.*

Feighny 1998, Wilkes 2002, Markham 1979



Non-verbal communication

- Body language, especially eye contact
- Tone and pitch of voice
- **Listen, Listen, Listen actively and with compassion**
- **The healing touch**
- Physician attire

Talking to parents in difficult situations

General principles

- **Recognise the emotions, be well prepared**
- **Remember the 3 'C's: Cool, Calm, Controlled**
- **Confirm the baby's identity and the problem.**
- **Check beforehand whether the parents are comfortable with the meeting place and the participants.**
- **Greet them with an appropriate emotional response, address the baby by name and the correct gender.**

Patole S. JPCH 2001



Talking to parents in difficult situations

- Disclose the **main reason** for the meeting and the level of your professional anxiety or worry.
- **Begin with the positive** aspects involving the baby's clinical course *briefly* before discussing the main problem.



Talking to parents in difficult situations

Specific points

1. Use simple **non-medical words**, **diagrams** to explain the nature of the problem, the time it was suspected or diagnosed and specify *whether*:

(a) the diagnosis is final or provisional (? more investigations, ? type, ? available locally);

(b) the problem is life threatening, potentially debilitating or minor;



Talking to parents in difficult situations

(c) the problem is treatable or not. *If treatable:*

- does the treatment involve side effects, pain or discomfort?;
- how long would the treatment last ?;
- how would we know whether it is working or not?;
- what will happen if we don't treat the problem ?;
- do we have time to think about the treatment options ?.

(d) *If it is not treatable*, could we minimise pain or discomfort?



2. Are there any common as well as rare **differential diagnoses**?

3. Summarise the nature of the problem, treatment options, and anticipated outcome(s) including recurrence.

4. Give the parents **time to absorb the information. Listen** to their thoughts (*and silence*) and answer their questions.



5. Choose timing for repeat discussion or **follow up meeting**, and for the availability of close **family members** who may have missed the first discussion.

6. If possible and appropriate, explain briefly the division/ nature of the **staff in the nursery**.

7. Reassure that at any given time there are at least two staff members directly involved in the care of their baby, and the consultant on call is always available to talk to them.



8. Always **document the details** of the discussions for the benefit of team members and also from the medicolegal point of view.

9. During the day to day discussions it is important to **avoid** providing the family with a **litany of results** when all they wish to know is how the baby is doing in the most general terms.

10. There is a thin line between including the family in decision making and being overly dictatorial in management of their baby.

Patole S. JPCH 2001 Aug



Dealing with extremely difficult situations

- Parents know when the inevitable is nearby. These are the times when they will be searching for a **ray of hope**.
- Try to find it to help them to cope with the situation and be able to participate in the decision making involving their child.
- Even under the worst possible circumstances, **there is always some ground for hope** making the journey toward the inevitable less painful for the parents.

Patole S. Pediatrics 2000 July

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- A gradually fading ray of hope is less crushing to the spirit compared with sudden darkness ushered in by brutal honesty.
 - Don't let medicolegal fears override compassion, empathy.
 - Always respect differences in faith, belief system, and culture.

Patole S. Pediatrics 2000 July,

- Don't promise what you can't deliver
- Denial is common, don't force but **repeat and reinforce** facts

Corke C, Milnes S. Erudite Medical Books 2008

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- **Detailed documentation** is important not only from the medicolegal point of view but also for others in the team.
 - **It is OK to let others take over** if building rapport with the family is difficult despite best efforts
 - **Watch out for compassion fatigue; do not feel shy to ask for help.**

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- Listen with compassion
 - "The most important thing in communication is hearing what isn't said" *Peter Drucker*
 - "The art of conversation lies in listening" *Malcom Forbes*



When communication fails

- Continued efforts to communicate make matters worse.
- Withdraw gracefully and give someone else a chance to start afresh with an advantage of knowing the background.
- When surrogates make demands that cannot be fulfilled, involve a third party (e.g. colleague, priest, advocate).
- If the matter seems to be heading towards the court –document everything in detail.

Communication for the Intensive Care Specialist

Corke C, Milnes S, Erudite Medical Books 2008



Template for handling complex interactions

Think about

- Particular issues in the scenario
- Possible emotions, thoughts, or actions of the parents and family members
- Actions expected from you
- Things you might say
- **Things you should not say**

Communication for the Intensive Care Specialist

Corke C, Milnes S. Erudite Medical Books 2008



‘Cure sometimes, treat often and **comfort always’**

- Hippocrates



Autonomy vs. Paternalism

Core bioethical principles

- **Autonomy:** Patient decides what is in her/his best interest
- **Beneficence:** Treatment, care should benefit the patient
- **Non-Maleficence:** Avoidance or minimisation of any harm
- **Justice:** Individualistic ideal of no prejudice, and wider social implication of greater good

- **Paternalism:** Doctors making decision which they ‘believe’ are in the patient’s best interest, without input from surrogates.
- **Don’t get carried away by paternalism**