

## *Talking with parents*

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## **Introduction**

Communicating with parents of ill children can be quite difficult for anaesthetists as well as for other doctors and caregivers. However communication is the basis for informed patient consent for all kind of medical treatment. In addition, communication with parents and children is an opportunity to establish a shared relationship and an open communication that will create a feeling of trust and confidence. Talks with parents include the preoperative visit, asking for informed consent, the postoperative information of parents and a variety of talks when in charge of the paediatric ICU.

Parents can experience psychological stress and even trauma when confronted with worrying or grave information about their child's health. Due to this stressful situation we cannot expect that they will be self-reflective and controlled, or will follow normal rules of conversation.

A good understanding of basic psychological principles and communication skills are necessary to manage these situations successfully.

## **The psychology of parents**

When confronted with complicated, worrying or grave information about their child's health, parents will experience sorrow, anxiety, and stress. Parents use different coping strategies to handle these situations. Based on findings about how adult patients with cancer react to their situation, we know that some parents will display "avoidance behaviour", trying to avoid information about unpleasant situations of their child. Others may seek to obtain any available information about the child's situation showing "monitoring behaviour".<sup>[1]</sup> Parents of children with life threatening diseases such as cancer or children with chronic illness may often experience conflict with health care providers. These conflicts can be due to

- Lack of correct information
- Concern about procedures or content
- Structural problems with unequal power or resources
- Different values and ideals
- Poor communication or uncontrolled emotions.

Although conflict situations are generally viewed as negative, they can be productive if they result in behavioural change and reconciliation of interests [2]

We should realize that these parental reactions are part of a coping strategy which is necessary to handle psychological stress. We should also be able to identify emotions and respond adequately using communication skills.

### **The preoperative visit**

In most cases, the preoperative meeting is the first occasion when parents will talk to the anaesthetist. Beside receiving relevant information from the parents and explaining the anaesthetic procedure to them, the physician also has the opportunity to establish rapport.[3] It is the ethical and legal responsibility of the anaesthetist to give detailed information about the intervention, the anaesthetic procedure, the risk of anaesthesia and possible alternatives. This may be in the form of an open interview with a check list that will help to focus on the important topics. The results of anamnesis, physical examination, parental information and parental consent should be well documented in accordance with national regulations and institutional rules. There is some concern about the extent of the disclosure of anaesthetic risks and how much information we should give to parents in order to avoid unnecessary anxiety of both the parents and the child. Studies show that when detailed information was given to adult patients they felt more satisfied but also became more uncomfortable, more tense and depressed.[4-5] However, no negative effect on patients' preoperative stress was found among men undergoing hernioraphy when they were provided with detailed risk information.[6] Kain et al presented data to parents of children undergoing surgery and found that parents desire comprehensive preoperative information, and moreover the parental anxiety level did not increase when they were provided with highly detailed anaesthetic risk information.[7] Based on these findings it seems that due to different coping strategies, "monitoring" parents will benefit from more detailed information whereas "avoiding" parents may experience more psychological stress when provided with detailed risk information.

### *Risk information*

Communicating about risks should involve a two way process in which doctors and parents exchange information and opinions about those risks. When talking about side effects of a particular treatment we should avoid using labels such as “nerve injury” or “allergy”. Instead we should explain symptoms, duration and consequences and the probability of their appearance. In most cases, parents do not understand statistical information, largely due to the poor presentation of the information.[8] This may impair communication of risks, which can have serious consequences. Instead of telling single event probabilities such as “Your child has a 0.2% chance of a side effect from this drug”, it is more effective to use frequency statements: “Two out of every 1000 patients have a side effect from this drug”. Frequency statements always specify a reference class.

“Framing” means the expression of information in different ways, such as positive or negative. The information about a treatment’s outcome can be described as 97% chance of survival (positive) or 3% chance of dying (negative). It is evident that positive framing is more effective in persuading patients and also parents of sick children to take the option of a risky treatment. Whenever there is a risk of influencing decisions, doctors and other healthcare professionals should balance the use of verbal expressions and use both positive and negative frames: “Two out of every 1000 patients have a side effect of this drug, but on the other hand 998 out of 1000 children using this drug will not have any side effects”.

Graphical displays of information and visual aids of risk information can help parents to understand the meaning of numbers. There are several visual tools available which show frequency numbers together with the reference class.[9] Their use increases the effectiveness of risk communication.

### **Communication skills for specific situations**

When giving parents worrying or grave information about their child, paediatric anaesthetists can be confronted with emotional reactions such as anxiety, depression or even aggression. This can happen postoperatively, when we have to inform parents about intraoperative complications, or

on the paediatric ICU when information is given about a child's medical condition and prognosis. It is important to understand that these reactions are part of the individual coping strategies of the parents and that the communicative skills of doctors and care givers will help the parent to handle the situation.

Recently, publications about the role of family members of critically ill patients on ICUs and their interaction with caregivers have shown that effective physician communication minimizes stress for the family and will improve family satisfaction.[10] These basic skills are

- Empathetic communication
- Sharing prognostic information
- Shared decision-making. [11]

Whereas these publications mostly describe the interactions between family members of adult ICU-patients and caregivers, the proposed communication skills can also be adapted to the interaction of doctors and parents of critically ill children.

#### *Empathetic communication*

Empathy is generally understood as identifying with or experiencing the feelings or thoughts of another person. Empathetic communication with parents includes identifying and responding to their emotions. One powerful skill of empathetic communication is "active listening" a verbal skill of responding to another person's communication. It was first introduced by the psychologist Carl Rogers in 1951 and can now be trained in "Effectiveness Training Courses".[12] "Active listening" involves listening attentively, then giving feedback about your understanding of the meaning of the sender's message.[13] "Active listening" should be used when parents confront doctors with their emotions. It will enable two-way communication and will help the parents to cope with the stressful situation.

#### *Sharing prognostic information*

Sharing prognostic information and checking understanding are essential communication skills to involve family members such as parents in decision making with doctors and other caregivers.

Open discussion about a child's prognosis includes uncertainty and the worry that disclosing a prognosis will destroy hope.[11] A recently published survey of 194 parents of children with cancer revealed no evidence that prognostic disclosure makes parents less hopeful. Instead, disclosure of a prognosis by the physician can support hope, even when the prognosis is poor.[14] Therefore empathetic disclosure of prognosis is especially important as the prognosis worsens.[10]

#### *Shared decision-making*

Recent studies have shown that family members of patients prefer to share decision making on the ICU. In 2005, several critical care societies issued a consensus statement advocating shared decision-making about life support on ICUs.[10-11] Family members and parents vary concerning the degree of involvement in decision-making. Therefore doctors and other caregivers should first assess the family preference for the role of decision making and adapt their communication strategy accordingly.[10]

#### **Conflict of interests**

The author has no conflict of interests to declare

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