



DGKS Elisabeth Höfler

# FRANKLY SPOKEN

guidance for implementation of patient rights

## How do relatives experience an intensive care unit stay?

In 2002, I interviewed eight relatives in the context of the special education for intensive care with regard to their impressions and experiences at the intensive care unit and their satisfaction with the support their relatives and they themselves were provided. The interviewed persons were relatives of patients at the Traumatological Intensive Care Unit – Univ. Clinic for Anesthetics and General Intensive Medicine Innsbruck, one of the highest ranked intensive care units in Austria.

The hospitalized patients were traumatological patients with polytrauma (multiple serious injuries) including pediatric traumatology, patients of all surgical special disciplines, temporarily also internal and neurological patients.

### Why interview relatives ?

In my opinion, an individual collection of data makes sense, since at each intensive care unit people with the most different characters work and the overall picture of a unit only emerges from their cooperation. In addition, the in-room situation and the organizational procedures are not identical in all hospital wards.

It stands to reason that at an intensive care unit the highest priority is given to the intensive patients; with this article, I would like to provide an insight in the perceptions, the needs and the wishes of the corresponding family members.

### Imprint

In the letter FRANKLY SPOKEN renowned and experienced experts reflect on the implementation of patient rights. The letter is published at irregular intervals in >Lower Austrian Edition Patients' Rights<; since July 2001 it can be downloaded from [www.patientenanwalt.com](http://www.patientenanwalt.com).

Editor: Lower Austrian Patient and Nursing Advocacy, A 3109 St. Pölten, Rennbahnstrasse 29

Tel: 02742/9005-15575, Fax: 02742/9005-15660, E-mail: [post.ppa@noel.gv.at](mailto:post.ppa@noel.gv.at)

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Both patients and their families face completely new situations, which often appear as very threatening. A further aspect is the fact that relatives usually have little or no time to prepare themselves for the presence and the critical dimension of the disease or the injury.

**„A patient arrives at the intensive care unit in a physical crisis. The family, however, enters the intensive care unit in a mental crisis.“**

Roberts (1986)

I presume that a family which is taken seriously and which is respected, more easily endures the time at an intensive care unit than a family which only feels tolerated.

Since the interviews were not made anonymous, I considered it as important to ask the relatives for an interview only after the transfer of their family member. Thus, I wanted to prevent changes in the relatives' behaviour or interpretations from their part.

### **Accessibility of the hospital ward and visiting times**

The changed location of the relatives' access to the Traumatological Intensive Care Unit and the change-over to an interphone system for the announcement of a visit frequently caused problems during the period of the interviews. The signs and labelling were improved within a short time.

The optical design of the staircase was performed in the context of the project Art and Guidance system Traumatological Intensive Care Unit – „Animated technology“ in 2004.

Though they are quite short, the acceptance of the visiting times (2.30 – 4 p.m. and 8 – 9 p.m.) is very high, especially because exceptions are made in single cases. Statements like: „Medical consultants steal my precious visiting time“ meanwhile have become very rare. Importance is attached to the fact that the visiting time is really a time for the family.

Relatives often report even after years how useful it was that the visiting times had been „limited“. Being at the intensive care unit, relatives mostly can not figure out what it means to be faced with a “long and broad way” of a – hopefully successful – recovery. It belongs to the scope of functions of the caregiving team to prepare the relatives for the “time afterwards” and to instruct them to carefully organize the available resources

Based upon requests of the families, also children have the opportunity to visit their sick relative. The visit is preceded by a private conversation with the team, the parents or the nearest relatives and the involved child(ren). After the visit, the experience is discussed and evaluated.

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### **Social Support**

As repeatedly mentioned in the interviews, families of patients with life-threatening diseases deal with existentially decisive questions:

Will my relative completely recover?

What about the future, if my relative does not completely recover?

How will the structure of the family or the relationship change?

Who will be able to take care of the financial protection of the family in the future?

How will the family get over it, if my relative dies?

In most cases, affected families are very glad, when a member of the caregiving team takes time for a conversation. In practice, people often ask questions about the pain the patient experiences, about the function or the significance of tubes and cables and about the colored curves on the observation monitor. In this respect, I often wondered whether the monitor is really so important for the relatives or if talking about it helps to overcome speechlessness, shock and helplessness. Caregiving persons can use such situations to direct the attention to the patient, to take away the fear of contact or to give the relative the opportunity to talk about her/himself.

It clearly emerges from the answers that we increasingly have to turn our attention to the families, when their sick relative has just been admitted to the hospital, if the patient's health condition has worsened or she/he is in the awakening phase, especially in the organic psychosyndrome (note: confusion, agitation caused by drug withdrawal). Feeling safe and knowing that the patient is in competent hands is of utmost importance for building and maintaining confidence. This applies both to the nursing and the medical staff.

A family member mentioned that in the course of the intensive care unit stay she had developed a keen sense for whether the staff was stressed or not. So it was no problem for her, when it happened that the nursing staff did not focus on her so much.

### **Every coin has two sides**

In this context, I would also like to highlight the point of view of the nursing staff. Although the emotional demands of the patient's family are considered, the time is often too short to appropriately focus on the relatives. Many caregivers know from their own professional life that it may be difficult to support and escort a family.

In view of the often very painful events families have to bear, caregiving persons are remembered of their own vulnerability; ethical conflicts often occur in this context. Sympathy, antipathy, age and sex of the family members play an additional role.

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The disappearance of the nursing staff during the visiting time can have different meanings, on the one hand to give the relatives the opportunity to be alone with the patient and on the other hand to use the time for a break or as a self-protection in order to evade the family's personal fate. In this respect, I would like to refer to the indispensability of continuing education in the areas of crisis management and communication; in addition, it is equally important to identify burnout symptoms and to take them seriously.

### **The informative conversation**

In accordance with study results (Millar, 2002) an interviewed woman stated: „The physicians are most competent to inform about the diagnosis, treatment and prognosis. The nursing staff exactly knows about the daily changes and progress of the patient's condition.” If the relatives feel that the nursing staff exactly knows what the physician has mentioned in the informative conversation, this reflects – in my opinion – both the nursing staff's experience and the communication between nursing staff and physicians. A good cooperation is helpful, when organizational hurdles prevent the nursing staff from taking part in informative conversations.

A thoughtful word choice by the staff essentially contributes to the relatives' well-being and satisfaction. As evident from statements of previous patients, a thoughtful word choice should also be considered in the presence of intensive patients. Even though analog-sedated patients do not seem to have a feeling of time and space, it has been repeatedly reported that acoustic impulses are nevertheless perceived.

### **Apparent trifles?**

The patient's appearance seems to attract the family members' attention; neat hair or finger nails, a warming cover, the patient's comfortable position, orderliness at the workplace and avoidance of unnecessary noise are considered as the “visible or sensible” parameters to evaluate how the patient is taken care of.

A woman describes her perception as follows, „In the course of the intensive care unit stay, you get more sensible for everything and everybody, every gesture and every facial expression is interpreted. Every positive sign has a double positive and every negative sign a double negative effect.“

Mindfulness, care and optics make feel safe and show the caregivers' competence.

### **Motivation to participate in caregiving activities**

I noticed that the number of family members who liked to participate in the caregiving activities or who felt like helping, was very high. A nurse from an internal intensive care unit reports the opposite, however. Apart from the sample size and the question, also the persons I interviewed showed different motivations:

I would like to actively contribute to my relative's recovery.

I would like to relieve the staff's burden.

I would like to distract my thoughts through the activity.

I would like to feel close to my relative and to touch her/him tenderly.

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The family's involvement is probably more important as assumed so far, though we know about the positive effect of the parents' care for a child. I highly support the idea to give family members the opportunity to participate in simple caregiving activities for or with the patient. Of course, the voluntariness and the lack of constraint of the involved persons, as well as the patient's safety have top priority.

### **Assistance in self-help**

Families often demonstrate a huge emotional strength, they hardly admit themselves to take a timeout to relax. The longer an intensive care unit stay takes, the higher the risk that proven methods to cope with it are broken. " ... I was offered a conversation with a psychologist, I did not accept the offer, since I thought I would be able to manage it all by myself. Perhaps it would have made sense, I even consider to go to counseling now."

About half of the relatives initially did not feel the need of a supporting conversation by a professional person, but at least considered it in the case of long-term hospitalization.

The offer of psychological support to relatives was expanded by the crisis intervention team in 2003. At the same time, the advanced training „Interaction with people in crisis situations“ was established. The professionalisation and increasing sensibility of the nursing staff benefits the patients, their families, and the nursing staff.

The wide variety of partly already available information (Accessibility of the hospital ward, housing possibilities for relatives, daily routine, support ...) is currently summarized and implemented in a digital media center for visitors.

### **Summary**

Although the sample size is probably not representative compared with the annual number of patients at the Traumatological Intensive Care Unit, the present data clearly demonstrate the strengths and weaknesses of the team and the in-room situation of the Traumatological Intensive Care Unit.

I am very impressed how openly the interview partners talked about happy, sad and partly very burdening issues or events. Through the interview situation, I learned to appreciate the value of a final conversation. In my opinion, a final conversation with the family is an opportunity to clarify unpronounced issues, (at least) to touch upon burdening experiences and to share the joy of positive results.

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The results emphasize the importance of an unbroken disclosure of information to the patients' family. An understanding and patient treatment can help the patient and her/his family to make the stay at the intensive care unit as positive as can be allowed by the circumstances.

Fortunately, things have changed and some stones have been set rolling. It will also furthermore be up to the alertness and the commitment of the overall team to perceive needs and to have the heart to go new directions.

I would like to encourage you to use the wealth of statements as an impulse for reflection and as an opportunity for your own development.

**Who sows one grain, will harvest many grains.**

Literature: Millar B. & Burhard P. Hrsg. (2002), Intensivpflege – High-touch und High-tech. Psychosoziale, ethische und pflegeorganisatorische Aspekte (Intensive care – high-touch and high-tech. Psychosocial, ethical and nursing-organizational aspects). Bern: Hans Huber

**Contacts:**

Elisabeth Höfler, Certified Registered Nurse: Author of the article, University Clinic Innsbruck – Traumatological Intensive Care Unit, Anichstr. 35, 6020 Innsbruck, email: [Elisapeter@tele2.at](mailto:Elisapeter@tele2.at)

Helga Tschugg, Certified Registered Nurse: Head Intensive Care Nurse, Traumatological Intensive Care Unit, email: [helga.tschugg@uklibk.ac.at](mailto:helga.tschugg@uklibk.ac.at)

Mag. Manuela Sax, Certified Registered Nurse: Supervisor of Advanced Training „Interaction with people in crisis situations“, email: [manuela.sax@uklibk.ac.at](mailto:manuela.sax@uklibk.ac.at)

**About the author:**

Elisabeth Höfler born in 1975  
Certified Registered Nurse with  
Spezial Education for Intensive Care

Since 1996 employed at the University Clinic  
for Anesthetics and General Intensive Medicine,  
Traumatological Intensive Care Unit, Innsbruck

1999 – 2001 Basic psychotherapeutic training course.  
Currently training as a certified Qigong – teacher

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