

# Finding meaning in the intensive care nurse-family member experience



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## ESPAÑOL

### Encontrando el significado de la experiencia de un miembro de la familia en cuidado intensivo

#### Palabras clave

Experiencias, miembros de la familia, cuidado intensivo

#### Resumen

- Este artículo describe la experiencia personal de una enfermera de cuidado intensivo cuyo hermano fue admitido a la unidad de cuidado intensivo.
- Expresado en sus propias palabras, describe vívidamente la experiencia emocional de ser un miembro de la familia con alguien cercano admitido en cuidado intensivo con una enfermedad que amenaza la vida.
- En gran medida, destaca el rol que los enfermeros de cuidado intensivo tienen con la familia, y como un acercamiento cuidadoso y sensible puede hacer una gran diferencia.

## SUMMARY

- This paper describes the personal experience on an intensive care nurse whose brother was admitted to an intensive care unit.
- Told in her own words, it vividly portrays the emotional experience of being a family member when someone close is admitted to intensive care with a life-threatening disease.
- Importantly, it highlights the role that intensive care nurses have with the family, and how a caring and sensitive approach can make a big difference.

## INTRODUCTION

As an undergraduate nurse I had a passion for intensive care and opted to go there for my final ten weeks of clinical practice. I loved everything about the intensive care unit. I thought a lot about the experience of the families I met. I adore my family and I could not even imagine how hard it must be for these families. I wanted to have a better understanding of their needs in order to support them more effectively so I chose to do a special topic. I did some research into the needs of the families of critically ill patients. This gave me some

insight into the intensive care experience from their perspective. I vowed to use my new-found understanding to underpin my practice when I finally reached my goal and became an intensive care nurse.

Being an ICU nurse was everything I knew it would be and more; I loved it. I developed a strong rapport with families and did as much as I could to make their experience more bearable. Their personal stories touched me deeply and I watched as day after day they sat at the bedside of their loved ones. I admired their strength and their faith. Occasionally, I wondered what it would be like if I were in that chair and it were my loved one, but I could not bear that thought. It was too hard.

Sadly, one day, the unbearable did happen for me. The following is a reflection of my experience.

## REFLECTION

My heart thumped loudly in my ears and I struggled to hide my shaking hands. I fought to suppress the feeling of panic that was quickly overpowering me. My innate sense of danger triggered a flight response but I felt trapped. His fury was building and I could no longer make sense of his demands. I watched him desperately struggle to break the stretcher straps, the only threads between myself and inevitable harm. I desperately tried to distract him to disarm the rage. I talked about his children saying their names over and over and trying to re-orientate him. I worked to keep my voice calm and reassuring. For a short while the rage dissipated. I wiped his brow with a damp flannel and bathed my equally sweaty hands.

Minutes later the desperate struggling and accompanying fury started again. I knew that whatever happened in the next 20 minutes was beyond my control. I had done all I could do and I was powerless. With that realisation came a sense of numbness. A protective mechanism I am sure.

He had end-stage liver failure and was encephalopathic. He was being transported by ambulance to hospital to be stabilised and assessed for the possibility of a liver transplant, a procedure that would surely save his life. The ambulance had to turn back. Once in sight of our destination a sense of relief washed over me but I also felt a deep sadness. As I looked at the angry dangerous stranger in front of me I wondered if he would ever reach the tertiary hospital. He was my little brother.

As the stretcher was wheeled down the corridor, three orderlies held him down. I mechanically walked in front of him hoping my weak legs would not let me down. The rest of the family were still at the hospital. I worried how I could explain our return and how well I could hide how shattered I felt. I hoped that they would not see him until he was sedated.

After a medical review, the intensivist quietly and seriously asked me, "What would he want?" The words swam round and round in my head. How many times had I heard that before? I replied, in a voice that sounded far too calm to be mine, "A new liver."

Arrangements were then made to airlift him, intubated and sedated, to a tertiary hospital.

I knew I had to see the rest of the family but once again the flight response threatened to whisk me in the opposite direction. I was strong and supportive as a nurse. I busied myself helping to prepare him for the flight to Auckland. I faced my family the same way I faced all the families of critically ill patients. I was not ready to subscribe to this nightmare. I turned down the offer to travel to Auckland with my family. I needed time on my own, time to think about what had happened, and time to gather my strength.

On my own I thought about the day, and about my family and about what might lay ahead. I thought about all the families I had seen in the same position. I thought about his death and his funeral and when I felt as low as I could feel, I drew on strength I did not even know I had. Today, I decided, I did not have to think about that. Today he was alive. I decided I was not prepared to spend the little bit of energy I had left grieving over something that may never happen. When I saw the family I said the same thing to them. It was really all about today; today was OK. We had so much to be thankful for. He could have been killed in an accident or had an inoperable disease but he didn't, he had the possibility of a full recovery.

As we looked around the waiting area at the tertiary hospital it became evident that some families did not share our luxury of hope. We also had one another. The entire family had arrived. Today we were blessed and as I looked around I had a very strong feeling that tomorrow would be OK.

The hours ticked by as we waited to see him before we settled. The staff at the tertiary hospital had arranged accommodation for all of us before we arrived. It was a relief not to have to search for accommodation in a strange city in the middle of the night. I hoped that the nurse caring for him would be as considerate and take a minute of her time to consider us, the family of the critically ill. Sitting in the waiting room was hard. I could no longer busy myself with his care and assume my professional role, my most effective coping mechanism. I focused once again on today. Today we had hope.

Day after day I fed myself the same dose of hope. The days turned into weeks as we waited for him to be put on the list for organ donation. On two occasions he was re-intubated and sedated and his ability to sustain his own life long enough to receive a new liver was questionable. Eventually he was put on the top of the list and we knew that the next compatible liver would be his. I could not help thinking about the families we had met in the waiting room. Every instinct in me wanted to comfort them and tell them that today was OK and maybe tomorrow would be too. It disturbed me terribly that for our loved one to live, another young life must end and it disturbed me terribly that I so desperately wanted that to happen.

I kept myself busy commuting and working as many of my rostered shifts as I could. I also had studies to complete and a house shift to organise. I was fine because I was too busy to think about how disturbed I felt. I think I functioned at a much lower level but I kept myself too busy to notice. I was managing everything and that took all I had. At work I nursed other families' loved ones. I watched a teenager with a head injury airlifted to a tertiary hospital. I watched an elderly gentleman lose his younger brother, and I watched critical patients stabilise and leave our ICU. I nursed in a very detached way, a way I did not think I could ever be. The sincere caring nurse who enjoyed every minute she spent with her valued patients and families was replaced by someone busy, task focused and highly distracted,

and I was too numb to even care.

The evening of my mother's birthday we got a phone call to say that my brother was going to theatre for his liver transplant. We all left for Auckland. Once again we sat in the waiting room and watched others who did not share our luxury of hope. One family member started telling jokes, another paced the floor, two went outside for cigarettes and one was tearful. The children provided a welcome distraction. I busied myself getting drinks and had such a strong urge to sing, it surprised me. I thought about all the Maori families who sang around their loved one's bedside. I wished I could do that. By evening the rest of the family arrived. Once again, I felt we were blessed.

Eighteen hours after he went to theatre, my brother arrived back in his bed space. Two by two we took turns visiting. It was 0300 and we were weak with tiredness and the sheer stress of the waiting. At the bed space I quietly talked to his nurse and thanked her for considering us, the family of the critically ill, and as I left the unit I quietly wished for her that she never be in a position to fully understand how I felt.

For me sitting on that chair beside the bed was like standing on the edge of a cliff waiting for someone to decide whether or not they would push me off and knowing that I could not influence that decision in any way. I felt completely helpless. Sitting at the bedside, being there was all I could do and I silently begged the nurses, "Please don't take that off me."

The nurses, knowing I was an intensive care nurse, did not treat me the same as the rest of the family. Some would handover to me, showing me blood results, charted medication and intravenous fluids, ventilation settings, and discussing the daily plan. Others would not speak to me and appeared defensive answering my questions. One nurse highlighted how much smaller the unit I worked in was and how advanced their ICU was in comparison. I smiled at her and thought how sad it was to see a nurse so focused on her own importance in the light of this critical experience. This experience belonged to us and I knew it would stay with us for the rest of our lives changing some of our fundamental beliefs and values and determining future direction. I was not really sure why this nurse thought the size of her intensive care unit had any significance at all.

Unrealistic expectations highlighted how little some of the nurses understood about my experience and made me feel miserable and uncared for. I guess the nurses and medical staff had expectations of what I should know and how I should be as a nurse.

On reflection, I experienced almost everything I had read about but my prior knowledge neither prepared me nor eased the agony of my situation. I understood the experience but not the meaning of the experience. I understood families need to be with their loved ones but I did not understand what it felt like to be separated.

Nurses' actions that meant the most, were the things that showed they cared and had considered how best to be supportive. For example, when the nurses said we could not visit until after doctors' rounds, one nurse told us what time they started and suggested we visit briefly prior to the round. The nursing staff would discuss his condition on the day, but one nurse sat at the bed space and looked over the notes from the previous days and discussed the trend as well as the plan and expectations for his progression. On a particularly difficult day one nurse put her hand on my shoulder and said she knew how hard it must be for us. At work everyone asked how my brother was and when I would return to work. One nurse asked me how I was.

Every welcoming smile, every thoughtful, considerate comment and every caring action made an unbearable experience bearable and now when I see a family member sitting at the bedside I can honestly and sincerely look them in the eye and say I understand.