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9 771377 756005 03

© Julie Vermeir

Julie F. Vermeir
Brisbane, Australia

ORCID ID 0000-0002-2931-6629

j.vermeir@qut.edu.au

©Darryl O'Callaghan

Darryl M. O'Callaghan
Brisbane, Australia

ORCID ID 0000-0002-4376-9181

dmocallaghan@optusnet.com.au

Authors' website:
redblanketmiracle.com

The Power of Listening

Engaging the Consumer

Darryl O'Callaghan and Julie Vermeir are survivors of a road trauma that happened in 2010. Their article provides insight into their journey as patient and wife, and the lessons that can be learnt.

Darryl's Story

There are many courageous souls who have lost their lives attempting to climb Mt Everest. Those who attempt such a climb arrive at the foot of the mountain after many years of preparation and training. They are extremely fit, possess all the best climbing gear and have an experienced support team. Yet there is still no guarantee they will make it to the summit, just as there is no assurance that they will not lose their lives trying.

When I woke up in the intensive care unit (ICU) after three weeks in an induced coma, I didn't realise at that time that I was at the foot of my own Everest.

I had been involved in a head-on motorcycle accident with a wayward car trailer, and sustained catastrophic injuries. The right side of my body was largely crushed. I had sustained a collapsed right lung, badly bruised left lung, fractures to 12 ribs, a tear to my right atrium, multiple fractures to my pelvis, a shattered right shoulder, internal organ damage, and the list went on. I was barely clinging to life.

On the day of the accident, doctors and surgeons worked tirelessly on me for many hours, yet despite all their efforts, they were still struggling to keep me alive. That evening they told my family that due to the extent of my injuries they did not expect me to survive the night.

I did survive, but now a torturous physical and mental journey stood before me. With no training, a severely broken body and no mental preparation, I was going to have to climb my own mountain. It was the first time in my life that I truly understood why people lose their will to live. Every day, my body was in a battle, in a war that appeared impossible to win.

As if my injuries were not bad enough, I then contracted pneumonia and sepsis while in the ICU. I was running an extremely high fever from the infection and my body felt like it was always on fire. I had absolutely no strength left to fight, and what was I fighting for anyway? I was paralysed by drugs and could not move. I had no idea if I would have any kind of quality of life if I made it out of the ICU. How easy it would have been for me to simply give up. But I had a wife and a baby daughter. They gave me purpose and a reason to live.

I made it out of the ICU after 35 days of enduring what I could only describe as sheer physical and mental torture. But this was only base camp. I still had a huge mountain to climb, one which would require every last ounce of determination and mental strength I had, because physically I was spent.

Julie's Story

Ascending a virtual Everest is not just a journey for the patient; it is also one the patient's family must undertake. The moment they receive that phone call telling them that their loved one has been involved in an accident, their lives are changed forever. Like the initial trauma victim, family members have not trained for such a journey—one which is filled with high levels of stress and anxiety that seem not to subside for days, weeks, even months on end, until they know their loved one is out of danger. These emotional challenges are often accompanied by physical symptoms, such as loss of appetite, tension headaches and insomnia. Despite undergoing their own trauma, families are often not recognised and treated as traumatised victims themselves. They are merely regarded as family members of a patient.

When Darryl's accident occurred, we had only been married for three years and we were first-time parents of a 10-month-old girl named Siana. Each day I would sit beside Darryl's ICU bed praying that his condition would improve and that my daughter would still have a father. For many weeks, I did not know if he would survive. He underwent a barrage of operations whilst in an induced coma and every day was the same: one moment he appeared to be improving, the next it looked like his body would succumb to the catastrophic injuries it had sustained. Although he was the one with all the broken bones, I was the one with the breaking heart and a head that was being compressed by the enormous stress I was under. Despite the gravity of the situation, I was not recognised as a traumatised victim, and society expected me to return quickly to my normal duties. I was to make sound decisions about my husband's treatments, look after my daughter and return to work so that the bills could be paid, all without missing a beat.

What got me through each day was my faith in God and the support of family and friends, many of whom were also dealing with their own symptoms of trauma, particularly Darryl's family. From a hospital perspective, we were just "bed 22's family", and nobody was there to provide us regular counsel and help us climb that mountain. Such help would have been welcomed, especially in the early days when we were summoned by doctors to attend family meetings. We dreaded those meetings, as we had seen other families come out of them absolutely shattered, leaving us to

believe that a meeting was a sign of bad news. Indeed we often did not know the nature and purpose of the meetings, which created further uncertainty, adding to the enormous stress we were already under. This, coupled with the fact that we each held a different perspective, made it difficult to process the information adequately. We would hear the same words and yet each of us would have a different interpretation of what was said.

Pathways in Trauma Survival

We would suggest there are two pathways in trauma survival: the one the direct victim of trauma takes, and the one family and friends take (often the journey of the 'silent victim'). The challenges can be similar, but at the same time quite different. The patient has to overcome the enormity of dealing with the physical aspects, which may include serious injuries or sickness, or both. There is also the mental challenge of dealing with the environment of an ICU facility, feeling scared and alone, and dealing with the uncertainty of what lies ahead. These physical and mental challenges continue beyond the ICU walls, often intensifying during major transitions, such as from the ICU to the ward, to rehabilitation and moving home. Making it home is far from the end of the journey for many patients. It is simply another stage camp on their gruelling climb back to hopefully something of a normal life.

Family members on the other hand are confronted with an out-of-control rollercoaster ride of emotions. They have to grapple with the initial shock of their loved one's condition as well as navigate their way through a medical labyrinth of ICU equipment, jargon, treatments, forms, numerous medical staff, and even sometimes police and lawyers. They have to deal with all this while their normal life commitments go on. The bills keep coming, work still needs to be attended, children need to be cared for and schooled. However, there is less time, and possibly less or no money coming in if the primary income earner is the one in the ICU. The family effectively has to go into their own survival mode simply to get through each day.

Despite this, do hospital staff treat these people as trauma victims? Our experience was no. Families are largely left to fend for themselves. It's not because hospital staff do not empathise with them or are unwilling to help, but rather because they have limited capacity. In such a context, it is clear that hospital resources get directed to the person who is most at risk of dying—the obvious trauma victim.

The Opportunity

This is only a small insight into the incredible challenges and pressures faced by patients and their families. We could write a 30-page article and still only touch the surface of the journey we undertook. Until we travelled that path ourselves, we had no real appreciation as to the enormity of the difficulties posed by a catastrophic trauma, and the incredible courage, strength and resilience all who are involved must have to conquer the mountain of adversity that such a trauma throws at us.

> "making it home is far from the end of the journey for many patients"

As the saying goes, "if you truly want to understand someone's perspective, walk a mile in their shoes". Obviously, this is not practical when it comes to experiencing a trauma caused by something such as a road accident, and that is why we believe consumer engagement is so important. It may well be one of the missing pieces of the jigsaw puzzle for many medical teams in their never-ending pursuit to improve outcomes not just for patients but also their families.

Survivors of trauma are truly the custodians of a wealth of knowledge that should never be wasted. For it is people like us who truly understand what the climb to Everest is like. Mountaineers attempting to climb Mt. Everest will engage the services of people who have climbed the mountain before, to learn as much as possible, so that their chances of success can significantly improve. So why would medical professionals not also prepare in the same diligent manner, by asking trauma victims for guidance on what can be done to improve the outcomes for those unlucky enough to follow in similar footsteps. By gaining such valuable insight, medical professionals would be far better equipped to support patients and their families in making their ascent up that mountain.

The Consumer Experience

We have been consumer representatives in a large hospital in Brisbane, Australia for the past 18 months, and during that time we have been pleasantly surprised by the eagerness of medical teams to accept us into their various committees. We've been welcomed to sit alongside senior doctors, nurses, allied health professionals and members of hospital executive staff and provide our input into decisions. However, we have also observed that for some people engaging the consumer is more of a box ticking exercise, to say the consumer's perspective has been sought. For others, the role of the consumer is seen as an important piece in creating a more holistic picture of how to care for patients and their families.

We expect service lines that seriously engage the consumer will see a step change in the way they deliver their services. However, others will meanwhile continue along the same path they have trodden for some time, never truly understanding the missed opportunity.

The Challenge We Propose to You

The questions for all medical professionals, in particular ICU medical staff, are simple: do you truly know what it is like to lie in an ICU bed fighting for your life? Do you know what it is to sit in a waiting room day after day, night after night, not knowing whether your loved one will survive? If the answer to these questions is yes, you have an insight that many do not. We would be very surprised if that experience did not in some way change your thoughts on how medical services should be delivered. If you have no such insight, then what have you to lose by engaging with the consumer? Maybe a little of your time; but in return, it may just be an eye opening experience that changes the way you practise medicine forever. A change that will hopefully enable you and your colleagues to help ease the horrific and arduous ascent up a mountain that no patient or family would ever consciously choose to travel. A change achieved through the power of listening! ■