David A. Rier

From three sides now: reflections on an ICU journey as patient, parent, and researcher

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Dedicated to my grandson.

D. A. Rier (✉)

Department of Sociology and Anthropology, Bar-Ilan University,
52900 Ramat Gan, Israel

e-mail: David.Rier@biu.ac.il

In the winter of 1997, I spent 19 days in a Jerusalem ICU with pneumonia; this time included 15 days on a ventilator. Thankfully I recovered, happily resuming my career as a medical sociologist. What I did not grasp then was that my hospitalization represented the start of a journey, weaving together the personal and professional.

Professionally, my hospitalization led me to focus on the patient's experience of critical illness. Since then, I have helped run a small pilot study in New Zealand, conducted various periods of ICU observation in New York and Sydney, spent briefer periods observing or visiting ICUs in several countries, and designed a study I hope to launch in Jerusalem. Throughout, my ICU patient experiences, and what I observe in other ICUs, play off one another, shaping how I understand each one.

For example, an important aspect of my own hospitalization involved patient disclosure. To maintain my spirits, the ICU doctors and nurses presented me with an optimistic spin on my situation, colluding in a benign conspiracy of selective disclosure even as they presented a darker—but more accurate—picture to my wife. In today's era of the empowered patient and the “right to know”, this behavior might seem paternalistic or

outdated. Yet I remain deeply grateful. For I was too sick and weak to have handled the true picture: I *needed* the sanitized version. The staff's constant support, and their optimistic front, helped sustain my will to live and—I am convinced—contributed to my survival. Throughout my ICU stay, I almost always took for granted that I would recover. In sharing this story with physicians, I have sometimes encountered resistance and even hostility from those convinced that any such withholding of information from patients is unethical. On the basis of my own experience, I disagree, at least for extremely ill patients. But what do other patients, themselves, think? In my own research, I plan to ask former ICU patients about what they had been told regarding their condition while still very sick. How and when were they eventually informed of how sick they had been? And, finally—in retrospect—what, when, how, and by whom would they have liked to have been told about their true condition?

There is another side to this particular story, for my 1997 hospitalization was neither our family's first nor its last ICU experience. In 1988, our very premature triplets had spent months in a NICU. As far as I know, the triplets' doctors were perfectly frank in their explanations and answers to our many questions in that pre-Google era, when they were virtually our only source of information. We remain grateful, and recommend similar openness with parents in similar situations.

As I was writing the present piece, one of those triplets bore a child with serious cardiac defects, who spent weeks in NICUs in two different cities. Thus, meters from where I had once been an ICU patient, I sat in the winter of 2014 staring at my new grandson's saturation monitors...as I had at his mother's, over a quarter of a century ago.

Yet now there were differences. For instance: as an ICU researcher, by now I had spent months following ICU doctors around in several hospitals during patient rounds and at their units' daily clinical conferences. I was thus acutely aware (as I had not been in 1988, or in 1997)

that what doctors said to patients' families at the bedside could differ considerably from what they said to each other (sometimes, mere moments later) outside families' earshot. I thus tried to focus on what the doctors were not saying, and noticed that much depended on how family members framed their question. For example, doctors might tell you the results of each specific test, without ever putting this into its wider context, unless the family specifically pressed. In short, I had learned to listen with two sets of ears. Moreover, online websites and parent support groups (unavailable in 1988) helped me make some sense of what the doctors were—and were not—saying, and to fill in the many blanks their explanations often left.

Still, all this was not simple. The doctors, while consistently friendly and kind, often displayed amusement as I scribbled down the technical terms that they rattled off to one another. It seemed not to occur to some of them that I might have resources (not just the Internet, but also textbooks and physician friends) to pursue my own inquiry. Moreover, between their workload and rotations of both doctors and family at the baby's bedside, our interactions were often too limited and rushed for me to explain that I had a bit of medical knowledge, and wished to hear as much as they could tell me. And, since there were certain key technical terms the doctors never used in front of us, it took me weeks even to know which online parents' support groups to join. Overall, I played a form of ICU "Kremlinology", trying to piece together doctors' sometimes-cryptic, fragmentary explanations, body language, and various other clues into some semblance of a picture of diagnosis and prognosis. Still, I realize the doctors had to consider both me and the baby's parents, and had too little time and contact with us perfectly to cater to our varying disclosure needs. Also, the implications of the initial diagnosis were genuinely horrifying, and I do not really blame the doctors for not sharing (what was then) quite the full story with us.

Ideally, before answering a given family member's questions, ICU nurses and doctors could ask (or try to sense) how detailed an answer they preferred. For their part, family with the resources and inclination can become "educated consumers" better able to ask the key, *informed* questions about their loved one's condition. Staff must recognize that relatives now have Google, support groups, and other resources. Yet these sources can needlessly scare lay relatives, making it even more important for physicians to provide accurate, realistic information for those requesting it. At least, relatives

should formulate and write down questions in advance, to make best use of their limited time with doctors. Finally, to offset the time pressure, maybe sometimes physicians could answer the family's questions via e-mail, giving each side time to think.

Life experience and research intertwined in another area as well. As a patient, I had been in an "open-plan" ICU, in a bay opening onto a central room, with staff and (thanks to a liberal visitation policy) visitors circulating freely. I had enjoyed personal attention from the staff, received many visitors, and never felt alone. However, my observation periods and visits to ICUs around the world showed me that a closed, single-room design is becoming more popular, with individual patients walled off from the rest of the unit. Sometimes, nurses sit outside the room, sometimes even around the corner, completely out of the patient's sight. Often, there is a strict protocol of gowning, gloving, and scrubbing on entering and exiting the room. Such policies have obvious benefits for infection control. Who can argue with that? But, thinking back to my own patient experience, I noticed something that has not attracted much discussion: such arrangements can deny patients crucial company and emotional support. I thus plan to ask patients whether they would prefer the isolation and quiet of single rooms, or the activity and sociability of open designs. Similarly, reflecting my own ICU patient experience of welcoming—but sometimes being exhausted by—frequent visitors, I plan to ask patients specifically about visitor volume and frequency. Meanwhile, though, it is worth exploring ways to alleviate potential isolation for those in single rooms, at least for those patients who would prefer some company.

A corollary point involves communication. While intubated during my own hospitalization, I communicated with nurses and visitors (and sometimes doctors) via writing, and found this immensely helpful. Many patients lack sufficient cognitive and motoric ability for writing, at least during much of their ICU stay. Yet my observation of various ICUs suggests "untapped demand" amongst patients for communication. With single-patient rooms, and nurses not routinely near the patient's bedside, this can be increasingly easy to overlook.

My journey continues, but already I have learned that the patient experience can circle back and echo in ways many and varied.

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