

# Medical Consent: Is It Ever Truly Informed?

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*WRITER'S COMMENT: For most of us, medical emergencies are thankfully rare. However, the infrequency of such occurrences can also make it difficult to develop any real understanding of important issues in our own health care. A trip to the emergency room can be both frightening and disorienting. Based on my own experiences as a patient, I've grown to appreciate that hospital visits can feel a bit like a "hit-and-run" experience, leaving one with only marginal awareness of what is truly happening. When I set out to write a case study for UWP 104F, I chose to address the anxiety and confusion that a patient may experience, and how these emotions can cloud our ability to make sound judgements on our own behalf. I found this story to be exceptionally compelling and did my best to tell it as it happened. In particular, my goal was to draw the reader's attention to the nuances of communication in the urgent setting, and how profoundly these can affect outcomes in our health and well-being.*

*INSTRUCTOR'S COMMENT: I first met MacAlistair (Mac) Colquhoun in fall 2015, when he took my course on Visual Rhetoric (UWP 12). At the beginning of the quarter, I was concerned for him—a first-year science student in a course that had been created with design students in mind. I need not have worried. Mac's lively prose style and the effort he put into mastering new genres made him a standout in the class. He brought the same effort to bear in the lay audience case study that he composed in my Writing in the Health Professions course in winter 2017. This assignment—which requires writers to dip into the storyteller's toolbox—is often difficult for the students in this course,*

*who are more accustomed to scientific genres and writing styles. Where other students hesitated, Mac jumped into the work with the enthusiasm of one who enjoys a challenge. In his case study, he shows that he has a keen sense of narrative structure, character development, and pacing. He engages readers from the start, but also leaves us with a sense of the greater purpose of this case study—to draw attention to problems with informed consent within the medical profession.*

—Melissa Bender, University Writing Program

In a corner room of an obstetrician's office in Los Angeles, a nurse pumped away at the blood-pressure cuff wrapped around Barbara MacMillan's<sup>1</sup> arm. Dr. MacMillan was more than 8 months into her first pregnancy, and prenatal check-ups such as this one had become routine. Her baby boy was set to be delivered in only a few weeks, and Dr. MacMillan was in a permanent state of elation. As a physiologist, MacMillan had been following her baby's development closely. At her 6-week visit, she'd heard its heartbeat for the first time. At around 12 weeks, she'd felt the first kick. In her 20th week, she'd learned she was going to have a boy. Now she thought almost exclusively of the grainy ultrasound that showed her son's small figure.

On the other side of the blood pressure cuff, things weren't so cheery. The nurse had encountered an issue while taking the woman's vital signs. Her first blood pressure reading for MacMillan had seemed suspect. When the second and third measurements came out identical to the first, she'd grown concerned.

Nurse Brown blurted out a few words to placate her patient, who'd seen a look of concern cross the nurse's face, then slipped out of the room to get the doctor. MacMillan was *hypertensive*—her blood pressure was too high. Though hypertension is not uncommon in older pregnant women—Dr. MacMillan was 40 at the time—the nurse had also found protein in her urine, and this was troubling. Taken together, these two signs were indicative of a greater, potentially fatal condition.

Women who are older than 40, and who are experiencing their first pregnancy, are at especially high risk for a complication called *preeclampsia*

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<sup>1</sup> All names have been changed to protect the privacy of individuals.

(1). Preeclampsia is characterized by high blood pressure and kidney damage. The condition is thought to be caused by abnormal blood vessel formation in the placenta. However, its effects extend beyond the womb to various other organs. If left untreated, preeclampsia deteriorates into a serious condition that is life-threatening to both mother and child.

Hoping to avoid these complications, Nurse Brown rushed out immediately to find the obstetrician, Dr. Smith. In her haste, she'd neglected to tell MacMillan what was happening, reasoning that an explanation would be better delivered by the doctor. Though preeclampsia was something she checked for every day, it was rare for her to find it.

If not a regular occurrence in Dr. Smith's office, preeclampsia is a relatively common pregnancy complication across the globe. The condition affects between 4.5 and 11.2% of yearly pregnancies in developed countries (1) and is responsible for nearly 20% of maternal deaths in the US (2). Once diagnosed, preeclampsia can be definitively treated by delivering the child and removing the malformed placenta. If left undetected, however, preeclampsia can rapidly progress into *eclampsia*, which is defined by seizures, kidney failure, and severe cardiovascular problems in the mother. The signs of preeclampsia tend to manifest after 20 weeks into pregnancy, but its onset can be abrupt. For this reason, expecting mothers are routinely scheduled for pre-natal care visits, with increasing frequency towards the end of their pregnancy.

Well aware of these consequences, Dr. Smith was determined to prevent them from happening. Just a few minutes after the nurse had rushed out of the office, the seasoned obstetrician stormed in. He interrogated one nurse while another attempted to soothe the weeping MacMillan, whose emotions had become uncharacteristically erratic. The scenario was not ideal. They were pressed for time, and no one had yet told the patient what was happening. Dr. Smith had erroneously assumed that the nurse had informed MacMillan about her condition. Now he hurried through a truncated explanation of preeclampsia. He told her what they'd seen, and he told her what would happen in the coming hours. She would be admitted to the ICU. They would perform another test to see if the baby could survive delivery. If the test was satisfactory, she'd be taken directly to the operating room. She may be seeing her child 5 weeks sooner than she'd originally anticipated. Did she understand her condition? Was she aware of the risks? Had he made it all clear?

Dr. MacMillan nodded wearily. Between the shock of the evening's

events and her hypertension, her head was spinning. She'd heard the words "preeclampsia", "delivery", and "ICU" and wasn't in the mood to delay her treatment by asking extraneous questions. Dr. Smith excused himself from the office, and a different nurse came in with a wheelchair to take MacMillan to the ICU. As she was wheeled out, the mother's head whirled with information. Despite her background in science, she had little understanding of the night's events and desperately hoped nothing would happen to her child. She breathed heavily and rested her head back on her chair. It would be a long night, she thought.

Unfortunately, the confusion Dr. MacMillan felt as she was whisked towards the ICU is common among patients. Especially in time-sensitive scenarios, doctors may not fully explain the implications of a disease or its treatments. Even if doctors do take the time to explain, patients can be distracted, or otherwise incapacitated, by the trauma of diagnosis and misinterpret what they're being told. Recent studies have shown that patients absorb little of what doctors tell them, even in ideal circumstances. For example, in a study of patients suffering from high cholesterol, only 57% were aware of what a normal cholesterol level was, and fewer than 20% were familiar with the side effects of their prescribed drugs (3). Dr. MacMillan should represent a relatively sophisticated patient; in the midst of her health crisis, however, she admits she caught little of what the doctor said.

Meanwhile, Dr. Smith faced a hefty decision: deliver the baby immediately, ensuring the mother's safety, or manage the condition with drugs and delay delivery until the baby was more developed. Preterm delivery would not be without risk. Of the birth defects associated with early delivery, several are fatal and many others lead to a significant decrease in quality of life for the child. Common problems for premature babies include an increased risk of cerebral palsy, learning and developmental disabilities, underdeveloped lungs or other organs, and increased susceptibility to life-threatening infection.

Dr. Smith had no time to share any of this with the patient. If there was evidence the infant could survive outside of the womb, he would choose to deliver the child immediately. Delaying delivery can be dangerous for both mother and child, potentially exacerbating symptoms for both. Dr. Smith was hoping to avoid such a scenario. Since Dr. MacMillan's child was relatively far along in its development, it could likely survive preterm delivery. However, the doctor was concerned about

the infant's lungs. Would it be able to breathe?

To find out, Dr. Smith ordered an invasive test of MacMillan's amniotic fluid, the fluid surrounding the infant in the womb. The test itself carried its own potential complications, but Dr. Smith felt the risks were justified. If a baby's lungs have matured well enough, they start to produce *surfactant*, a type of natural detergent which keeps the lungs from collapsing and allows the baby to breathe air. Babies start to produce sufficient amounts of surfactant around 34 weeks of gestation, an increase in production tied to the secretion of a molecule called lecithin. In a *lung maturity test*, doctors measure the ratio of lecithin to other molecules in the amniotic fluid to gauge the infant's lung maturity. If the ratio is high enough, the baby's lungs are ready to breathe air. Dr. MacMillan lay quietly on a table while physicians and nurses probed her via ultrasound and used a syringe to withdraw some of her amniotic fluid. In a few minutes the test was completed, and in few hours they had their results. The ratio was high, the baby was ready. With that, Dr. Smith was convinced. Dr. MacMillan was immediately scheduled for a cesarean section.

In the operating room, Dr. MacMillan felt remarkably calm. She felt nothing past her chest. They had given her anesthesia, and drapes were drawn so she couldn't see the procedure unfold. In the early morning hours, doctors removed a crying infant, towed him off, and handed him over to the beaming mother. At 5 a.m., just 12 hours after Dr. MacMillan had come in for her neonatal checkup, she sat in a hospital bed holding her child. With the placenta removed, her preeclampsia was resolved. It would only take a few weeks for the proteinuria and hypertension to subside.

Though Dr. MacMillan and her baby were saved, she went home with as little understanding of preeclampsia as she had come in with. It was only several days after her surgery that she learned the implications of her condition. Still, she believes she would have agreed to the chosen procedure even if she'd known of the alternate treatments Dr. Smith had been considering.

In MacMillan's case, everything turned out fine. Her physician made the correct decision to deliver, and she went home happily. However, patient-doctor communication is still a vital part of medicine. Medical decisions are not meant to be left to the doctor alone. Unless patients are incapacitated, as is the case in some trauma victims, physicians are required

to obtain informed consent from their patients before performing most procedures or complex medical tests. The American Medical Association has advocated the importance of shared decision-making in medicine (3), citing cases where a patient's personal beliefs have conflicted with doctor's prescribed treatments. Though doctors are better informed than patients, ethical considerations have made informed consent a necessary part of patient rights.

Still, informed consent entails more than blind patient agreement. The National Library of Medicine defines informed consent as follows:

1. You are informed. You have received information about your health condition and treatment options.
2. You understand your health condition and treatment options.
3. You are able to decide what health care treatment you want to receive and give your consent to receive it (4).

Though Dr. MacMillan agreed to her procedure, she had little understanding of why it was being done and what alternatives existed. Today, she agrees her understanding of preeclampsia at the time did not meet the three criteria for informed consent mentioned above. Even as a physiologist, the urgency of the circumstance clouded her understanding of the subject.

The issue of misinformed consent cannot be solved merely by requiring doctors to spend more time explaining procedures to patients. Any future policy changes may need to draw upon different tactics. Perhaps by changing the ways doctors are taught to interact with patients, or by shifting the burden of obtaining consent to other healthcare professionals, patients will gain an adequate understanding of their conditions to make informed decisions.

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