

Supplemental Material S6. Communication breakdowns reported by patients.

Theme	Sub-Theme	Number of participants [ID]	Percentage (N = 25)	Quote
Difficulty making requests	Items	2 [1, 21]	8%	It was a mirror request. Decided it did not matter. I asked for something, but they didn't understand me. I tried to whisper, but they did not get it.
	Adjust positioning	1 [17]	4%	I tried to tell the nurse to adjust my position to a certain point. I whispered and pointed. They did not get it and I just gave up.
	Contact family	1 [25]	4%	I tried to ask the nurses to call my family members but they did not get it.
	Bathroom	1 [7]	4%	I tried to tell them that I was in pain, and I have to poop, but I can't breathe or speak. I gave up communicating the message as I understood that they were trying to save my life. They just came back and cleaned up the poop later.
Difficulty communicating medical needs		4 [5, 7, 9, 15]	16%	When the BIPAP was on, it wasn't put on correctly and was making a very weird noise. Causing pain. Family was here all the time advocating for her. One time I was sitting in a chair and bleeding - I was in extreme pain, and the nurses were trying to move me from the chair to the bed. I wanted to tell them that I was in pain and felt I was going to poop. I tried to tell them that I was in pain and I have to poop, but I can't breathe or speak. I gave up communicating the message as I understood that they were trying to save my life. They just came back and cleaned up the poop later. Yes. The corner of a tape was on my right eye lid. The doctors asked me do you always have a lazy eye? Or they suspected there were some issues going on. My hands were restrained and I got a tube in my mouth. I have no way to tell them it was just the corner

			of the tape. I cried. I told them what happened three days later. It was very frustrating.
Giving up communicative attempts due to frustration	2 [6, 11]	8%	Emotionally distraught after failed tracheotomy, so I decided to give up communicating and just hoped for an ice chip.
Communication difficulties with family members	3 [5, 11, 22]	12%	Last weekend, when the kids were here, I was trying to talk - but the kids told me, "I am so sorry I cannot understand you". I was frustrated and gave up speaking.
			They (family members) were trying to figure out what I wanted to say but they end up saying I'm sorry I don't understand that.
Avoiding further questions	1 [23]	4%	I always nod yes to avoid more questions from people.