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Treating ICU patients with respect can facilitate healing and reduce later mental health problems: A patient perspective.



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Had a lung transplant Aug 2013

- 6+ weeks in Hospital
- 4+ weeks in ICU

Significant Negative Mental Impact

- Still struggling with it



Purpose

- Bring attention to the negative impact that long term ICU stay
 - Can have on mental health and physical healing
- To affect change and improve care in ICU
 - Help health professionals, families and patients, minimize the mental impact
- This talk is about giving a patient's perspective
- What I say here may seem harsh
 - I am describing how I perceived what was happening, while intubated in the ICU
 - Perceptions of reality were distorted but linked to actual experiences.
- Communication was the biggest hurdle
 - I couldn't talk: Could no longer be my own advocate
 - Limited communications abilities
 - Medical personnel and family did not understand what I was going through

Outline

- My stay in the Intensive Care Unit (ICU)
 - Examples of issues
 - Events leading up to self-extubation
 - Restraints: Why they can be harmful to patients
- Impact of hospital treatment on my mental health
 - Experiences still feel real
- Suggested improvements

Timeline

Hospitalized 6+ Weeks

4+ weeks in the ICU

I had two extended stays in the ICU with 1 day break in between

- I was intubated with an Endotracheal tube for most of my ICU stay
- The first time lasted 8 days
- The second time lasted 22 days

My First Awareness (OR)

- I became aware very early, I believe it was either during surgery or just after.
 - I was in a crazy hallucinatory dream state. I snapped out of it when I thought I heard the surgeon talk.
 - Returned back to the hallucinatory dream state when further sedated
- While being transported to the ICU I tried to pull out my tracheal tube
 - I thought with my actions I had ruined the lung transplant
 - I was dead but my spirit remained

My stay in the ICU: Mental state

Delusions : What I think I heard was not necessarily correct.

- I had a recurring, never-ending drug-induced nightmare in the ICU
 - The horror only subsided when I escaped to a spirit world
 - Where I felt free
 - I was being fed aerosolized macaroni and cheese
- This nightmare ended when the tracheal tube was removed and I could talk.
 - Conceded to my Mom that I might have lungs after all and might survive.
- I was sent back to the ICU and reluctantly agreed to be intubated again.
- My mental state went from bad to worse.
 - Drug induced delirium and hallucinatory dreams
- *Delirious* experiences linked to negative interactions with some of the healthcare staff

I hated being drugged and feeling the loss of mental control.

Drugs given in the ICU

Hydromorphone
Methotrimeprazine

Midazolam,
Propofol

Quetiapine
Haloperidol

My experiences felt real and they still do

- I was partially living in a fantasy world
 - Stimulus from the real world had significant impact on what happened.
 - I always returned to some kind of reality whenever family or friends visited.
- In my mind I thought a few healthcare staff individuals
 - Were doing experiments on me
 - Were persuading others to participate
- I was tied up in many of my “fantasies” resulting in panic
 - Coincided with me actually being tied up
- My analytical cognitive function seemed to function OK
 - I adapted to my perception of the ‘real’ world, which was completely scrambled

To me the ICU experience felt like torture

- I felt captive
 - Mostly immobile, constantly exposed, and very uncomfortable
 - My opinions, requests and wishes were often ignored
 - Often tied down, which gave me nightmares and triggered panic
 - One of my worst experiences was being restrained
 - Despite protest
- Inadequate communication with the healthcare staff
 - Not enough effort made to communicate
 - Often felt abandoned
 - Healthcare staff talked about me but not to me
 - I did not have a bell
- The the physical pain wasn't the worst
 - It was the mental pain

All these factors contributed to the erosion of my mental state,
delirium, and loss of trust.

Healthcare staff

Treatment in the ICU, was very variable.

- I was anxious during shift changes
 - Hoping to get a nurse or other staff that I really liked
 - Dreaded being “cared” by a few individuals who I felt were uncaring

Seemed to be under the belief that I wasn't aware and would not have any recollection of events.

- So they treated me as such without realizing the negative mental impact

Actions that I considered "good" care

- I was treated with compassion, respect and talked to as a human being.
- Things were explained and I was asked for permission before doing procedures.
- These practitioners where flexible, would think "outside the box".
- Realized that patients have different personalities.
- Calmed me down and made me feel safer.
- One nurse said they might as well do work in my room while monitoring me
 - Explained things and talked to me, took time to try to understand me
 - Felt very comforted
 - **Communication and explanations are key**

Examples of Inconsiderate Care

- Retaliation
 - Refusal to bathe me
 - Forceful insertion of NG Tube
- Ignoring my request to see my X-rays
- Mask forced over my mouth while I was being held down
- No reporting my discomfort back to the Dr
 - Nebulized antibiotics were burning my throat

Effect of my ICU experience

Many of these easily avoidable incidents and approaches contributed to my feeling of paranoia and persecution and resulted in scarring of my mind

- I felt trapped and I became convinced that I would never get out of the hospital
- I kept telling myself I had to take the high road and forgive everyone. I think I instinctively did that because if I hadn't my anger would have consumed me and I never would have survived.
- In the end I waited for my opportunity to escape

Self-extubation 4+ weeks post surgery

I felt the need to self-extubate for survival

- I was restrained too much
- Mistreatment and harmful approaches
- Lack of communication
- I could not take it any longer

I wanted the torture to stop and I wanted to be heard!

Self-extubation and later

I waited for my opportunity to escape. When the nurse left

- I discretely worked on pulling the urinary, NG and tracheal tubes out, but could not pull out chest drainage tubes without causing significant damage.
- I could talk now
- I asked for the doctor and refused further medical treatment
 - Mainly because I didn't want to be sedated and silenced
 - After 3 hours of negotiations with family and Dr's,
 - I agreed to put oxygen back on the condition
 - That I would be listened to and treated with respect

Changes in attitude of staff

- After self-extubation I gained my ability to talk.
 - I could now explain my needs
 - Ask questions
 - My care by the nurses improved dramatically.
- There were still some issues
 - Usually after friends and family were gone

Restraints:

Why they can be harmful to patients

- Before surgery, I informed my Dr. that tying me down should be avoided, given my predisposition to panic when restrained.
 - Apart from immediately after surgery, I was aware enough that I was neither a danger to myself nor others.
- Try to talk to patients and ask them
- Caused severe emotional stress – feeling mistreated and contributed to my paranoia
- It prevented my body from focusing on healing and likely contributed to my excessively long stay in the ICU.
- **Avoid restraint unless absolutely necessary**

Psychiatrists

I believe a psychiatrist or a psychologist should have been involved in my care from the start.

- Attempt to discover what my issues were and understand my personality
- Come up with strategies to help.

Impact on my mental health

- Insomnia
- Lack of trust
- Withdrawn
- Difficulty connecting with new people
- I can anger quickly (verbal not physical) when exposed to specific interactions like lack of respect, defending certain actions
- I am back to 80% work and functioning, but not enjoying life.
- Possible short-term memory loss and loss of focus.
- Suppressed feelings
 - feeling hurt, happiness, elation, excitement

Education of all healthcare staff

Physicians, Nurses, Respiratory Therapists and family involved in ICU patient care.

- Educating all Healthcare staff and family about
 - The potential awareness of patients in the ICU
 - The negative impact indifference makes
 - The power of showing compassion
 - The importance of the mental health of Patient
- Would improve their approach significantly.

Improvements in communication

- Involve psychiatrist/psychologist early for assessment
- Involve speech pathologists for improved communication
- Make patient feel secure and respected. Listen to their needs and wishes.
 - Get to know patient
- Assume patient understands (is aware) and explain your actions. If they don't get it, there is no harm done.
- Use of a tablet or iPad instead of alphabet placard
 - may make it easier for the patient to express him/herself.
- Be accommodating. There are often many medically accepted methods to treat a patient – choose the one that best fits each patient.

Other Improvements

- Ask for consent before initiating physical procedures
- Avoid restraining patients unless absolutely necessary, in which case make sure staff is on hand to calm down and reassure the patient.
- Give patient access to a clock and a calendar and discuss current events.
- Actively involve family in care plans. -- they may give you insight into patients personality.
- Make sure patients get enough sleep

Examples and thoughts

- I do believe that many thought they were doing the right thing
 - While unintentionally working against me
 - Delaying the healing of my body and causing permanent harm to my mind.
- Don't kick family out of the room during changes,
 - Assume patient wants them to stay and ask if the patient wants family to leave
- My worst moments was when I felt abandoned and alone
- Talking to patient either by psychologists or healthcare staff
 - Can be much more calming then sedation by drugs.
- Admit mistakes, no one is perfect

Final Words

I believe that the approach of nurses or other health care professionals in the ICU would significantly improve if they were educated about patient awareness and the negative potential impact of their perceived indifference

The intubated patient sees things differently

- Influenced by drugs and inability to adequately communicate needs

Help patient understand that you care

Show Compassion, gain patients trust

- They feel very vulnerable

The presence of family members is invaluable

- Talk to the patient and reassure them
- The patients can still hear even though it is not apparent.