

# THE LIVED EXPERIENCE OF ADULTS RECEIVING MECHANICAL VENTILATION

An Interpretative Phenomenological Analysis

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### MEET THE CO-AUTHORS





### BACKGROUND & AIMS

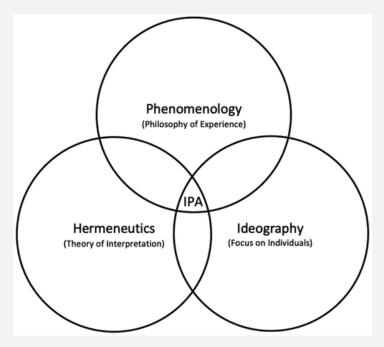
- Mechanical ventilation is essential for survival and recovery for several ICU patients, but may expose patients to a variety of unpleasant physiological and psychological experiences.
- Exploring the lived experience of patients on mechanical ventilation (MV) can provide valuable insights into their physical, emotional, and psychological well-being during their stay in an ICU.

#### AIMS

- To explore the lived experiences of adults who received MV
- To identify strategies to improve their holistic wellbeing during and after their hospital stay

### DESIGN & METHODS

- Qualitative approach
- Interpretative Phenomenological Analysis



- Purposive sampling (7 participants)
  - Adults who received invasive MV in a general ICU in Malta for at least 4 days
  - Fluent in Maltese and / or English
  - Discharged at least one month prior to the study

### DESIGN & METHODS

#### Data Collection

- Semi-structured interviews (c. I hour)
- Open-ended questions and prompts (conversation style)
- Attention to non-verbal cues
- In person or online according to participants' preferences
- Data analysis (based on Smith et al., 2022)
  - Exploratory noting (descriptive and interpretative; key quotes + non-verbals)
  - Identification of experiential statements
  - Searching for connections within and between transcripts
  - Consolidation of personal experiential themes (PET)
  - Underpinned by peer debriefing and reflexivity

### **FINDINGS**

Personal Experiential Themes	Experiential Statements
Delivered into the hands of others	<ul> <li>Voicelessness</li> <li>Dependence</li> <li>Lack of control &amp; resignation</li> <li>Facing an unfamiliar environment</li> </ul>
Living in a disconnected world	<ul> <li>Real dreams &amp; nightmares</li> <li>Hallucinations and Illusions</li> <li>Family detachment</li> </ul>
An agonising experience	<ul><li>Pain and Suffering</li><li>Long term emotional burden</li></ul>
Supportive encounters	<ul> <li>Support from Health care workers</li> <li>Being supported by the family network</li> <li>Spirituality as a powerful means of alleviating suffering</li> </ul>

- The worst thing is not being able vocalise...plus in my case I had no movement. I couldn't use thumbs up for 'yes' and thumbs down for 'no'. So that is super frustrating...the only thing I could do was chew on the tube. They used to tell me 'stop it', but it was the only way I could take out my frustration. Maria
- Imagine, just being able to move your eyes. It was defeating for me, and defeating for them [health care workers]. The sadness engulfs you more than the pain because you're there lying face up, unable to speak, waiting for time to pass **Żaren**
- I would try to call them but I couldn't speak. I could only move my eyes, and they would still go on their way! Rosario

## PET 1: DELIVERED INTO THE HANDS OF OTHERS

Voicelessness

- Dependence
- Lack of control & resignation
- Facing an unfamiliar environment

- It's like when you have a car and you push the driver away from the steering wheel and you take his place to take control. During ventilation I felt I know what's happening and what I should do but couldn't because I didn't have the power to do so. It's not a very nice feeling. Rosario
- I could not even move with the things I had...a tube inserted here, another one inserted from there, you must be careful not to squash it and that you do not accidentally pull it out [tracheostomy tube]. You have to sleep with your face up when you are used to sleeping on your side. Victor
- My rebellious character emerged during ventilation and I knew what was happening and the things I wanted to do, but physically I could not do it. Once I let go and I said 'enough is enough! I don't have the ability. I'm going to die!' And I gave up [clears throat] Rosario

## PET 1: DELIVERED INTO THE HANDS OF OTHERS

Voicelessness

Dependence

• Lack of control & resignation

• Facing an unfamiliar environment

- Everyone is rushing around trying to help and it's so noisy. Some machines make noises like you're in a horror movie...its horrible. I felt like someone was attacking me. Whenever they close the bins while you are asleep, there's a bang...it's so annoying! I wish I could get up and place a piece of rubber [laughing] Maria
- The ITU is continuously lit up...people coming in all the time **Rita**
- The nurses' perfume would nearly kill me; they would come to one side and I would try to turn my head the other side [laughs] Zaren
- I would hear machines and I thought that I was being transferred to Germany for treatment and flying back home...every time I would go and come back. I was hearing the [dialysis] machines, and I thought that I was at an airport somewhere **Rosario**
- I told the doctor, 'Switch off that fridge, please'. And he told me, 'If I switch it off you'll die; it's providing you with oxygen'. Ġużeppi

## PET I: DELIVERED INTO THE HANDS OF OTHERS

- Voicelessness
- Dependence
- Lack of control & resignation
- Facing an unfamiliar environment

- I found myself in a strange country...There were terrorists. I was living with them in the mountains...I had a time limit to leave otherwise I would die. I knew I had to get out of there, but physically I could not do it. Imagine the panic that overcomes you...Another time I said, 'I'm going to die so I need to accept it'...And in fact I died and I saw my own funeral; and the place that I went to...another place: heaven. Rosario
- ...the Mafia captured me and I couldn't get away from those people. I couldn't escape...I was even considering suicide...if I wasn't going to be killed by them, a heart attack would kill me anyway...
- ...When they woke me up from the induced coma, my son was near me and I told him [panicked voice]: 'What are you doing here?! Leave now! Leave or they'll get you too'. I also dreamt that my wife died and that my house burned down! Victor
- They're experimenting on us and now they're going to kill us...it's frightening...I was getting worried...people used to stare at me as if they're telling me, 'Are you okay? We're going to kill you!' Nobody told me so, but you start thinking... Rosario

## PET 2: LIVING IN A DISCONNECTED WORLD

• Real dreams & nightmares

Hallucinations & Illusions

• Family detachment

- I love the sea and I felt like I was in an engine room of a ship among those engines working;. I could have been hallucinating, but I don't know...Lost. Bastjan
- Once I saw a beautiful woman glowing in white...I saw the Virgin Mary. Rosario
- Probably nobody would believe that I could see things...I think it's because of the morphine or I would see a bird flying, and I would be awake...I spent two days dreaming that they were cutting me up with a chainsaw. Other times, I would wonder, 'What is that old man doing there in the middle?' It would be nothing, or just bedsheets...
- When my mother had cancer and she used to tell me, 'I'm seeing ants'. And I would tell her, 'There aren't any ants, mum!' But having gone through this now I think, 'She really used to see them'. **Rita**
- I imagined myself putting my hand in my mouth, pardon me, and pulling out nails...I believed that my body was growing nails and I was scared, swallowing and choking because I was scared to swallow...It felt like I was touching something inside me that felt like a dry lung, and I was shocked. Zaren

## PET 2: LIVING IN A DISCONNECTED WORLD

- Real dreams & nightmares
- Hallucinations and Illusions

• Family detachment

- Two months without seeing my wife, my children...you start crying at the thought...you can't see them and that's very hard. I didn't suffer; the ones at home did. I just suffered because I couldn't see them...I would hear their voice on my mobile phone and they would not know whether I'm going back home or not. Ġużeppi
- I have a 7-year old daughter and she depends on me. I think as a parent we all have this fear: Are we going to be here for our children? And if not, who is going to take care of them? What's going to happen?...It's not the fear of being in the ITU; it is more the fear of detachment from my family—Maria
- I was really depressed because I could not speak so I couldn't say anything to my family. While I was intubated no one could come to the hospital. They suffered more than I did...if I were to put myself in their shoes, I would die. Victor

## PET 2: LIVING IN A DISCONNECTED WORLD

- Fears & nightmares
- Hallucinations and Illusions

Family detachment

- I used to ask them for morphine and the nurse would tell me, 'I already gave you'. But it meant that I was in pain. When they pulled out the tube from my mouth, that was the most excruciating pain one could feel...My throat was sore for a whole month after the ventilation. Rita
- I would feel as if I was literally choking during those fifteen or twenty minutes when they would wash me. I would suffer so much that I would remain weak until night time.
- On the monitor, my heart and breathing were normal. They (health care workers) would look at the screen and tell me, 'You're fine'. But they were wrong, because the suffering I went through is terrifying. Żaren

#### PET 3: AN AGONISING EXPERIENCE

- Pain and Suffering
- Long term emotional burden

- I'll never forget what the ITU staff did for me. If I needed ten pillows, they would get me ten pillows...they treated me like royalty! They don't do just do their nursing job, but they are dedicated to the patient. Rita
- I found great help, thank God. They used to play songs to help me. They gave me a lot of attention and would continuously tell me encouraging words. I felt so respected by these kind gestures...incredible help! **Żaren**
- I can't even describe how much help I received. Doctors and nurses kept coming to check on me. Whenever I got a bout of coughing, the nurse would rush to me to [perform suctioning]...they're so dedicated these people! They're on a mission. Victor
- I had huge support. My parents...everyone was super super supportive. Also, I knew that my daughter was being well cared for by my friends. I had a good support network...A friend of mine came and learned how to use the communicational chart and I really communicated well with her. Maria

### PET 4: SUPPORTIVE ENCOUNTERS

 Receiving support from Healthcare workers

- Being supported by the family network
- Spirituality as a powerful means of alleviating suffering

- Many prayed for me...even the nuns at the monastery prayed for me. Everyone prayed. I am not a very religious person I just go for Sunday mass, basically. But I do believe that prayer is powerful. Victor
- I had rosary beads. And I told the nurse, 'Touch this rosary because it's from Jerusalem.' Rita
- I asked them for a holy card as soon as I opened my eyes Bastjan

### PET 4: SUPPORTIVE ENCOUNTERS

 Receiving support from Healthcare workers

 Being supported by the family network

 Spirituality as a powerful means of alleviating suffering

### STRENGHTS & LIMITATIONS

#### **STRENGTHS**

- First local study to explore lived experiences of former ICU patients
- Places (former) ICU patients centre stage

#### **LIMITATIONS**

- Limited memories
- All participants from a single unit
- Excluded patients who could not speak
   Maltese or English
- Possible misinterpretations of participants' experiences

### IMPLICATIONS FOR PRACTICE

- Assessment of body language and facial expressions
- Communication charts
- Augmentative and alternative communication (AAC)
- Music therapy
- Simple changes to ICU environment
  - Physical layout
  - Noise & light control
- Use of VR and AR
- ICU diaries
- Improving follow up services
- Flexible & extended visiting hours and facilitating video calls
- Multidisciplinary approach, including spiritual care





### IMPLICATIONS FOR RESEARCH

- More local & international studies exploring patients' experiences
- Exploring nurses' perceptions of challenges in communicating with patients receiving MV
- Further investigation on the impact of delirium and PICS on (former) patients & their family
- Investigating the impact of post-ICU rehabilitation clinics and follow up services
- Studies on factors facilitating and hindering sleep
- Exploring ICU personnel's awareness and perceptions on pain and sedation assessment and management
- Studies on the experience of family members and the impact of more flexible visiting hours.

#### Thank you for your attention!

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