



Memories of the ventilator: Trauma, personal mythology and the role of medical museums

December 2021

Cornelia (Nina) Thompson

Mphil/PhD Student

UCL, Institute of Archaeology

cornelia.thompson.18@ucl.ac.uk

East Radcliffe Positive-Negative Respirator Machine
Thackray Museum of Medicine, online collection catalogue

Why the ventilator?

- As a case study to look at how medical museums consider the role of personal experience, including trauma, in their exhibitions.
- In the context of Covid-19: at the height of the pandemic in January, there were around 4,000 patients on ventilators. Currently about 900 (based on 7 day average; <https://coronavirus.data.gov.uk/details/healthcare>)
- The particular experience of being in intensive care and on a ventilator, including 'delusional memories'.

Why the ventilator?

- **Challenge:** just presenting the technical aspects or medical understandings of ventilators does not account for patient experience.
- Potential tension between reality of ventilators as lifesaving and beneficial and the complicated emotional realities of the experience of mechanical ventilation.

Ventilators – patient experience

- High risk of post-ICU PTSD (up to 25-35%)
(Hoffman 2013; Johns Hopkins 2015)
- Risk increased by sedation and mechanical ventilation.
(Wade *et al* 2013)
- Particular feature of ‘delusional memories’.
(Guttormson 2014; Hosseini *et al* 2012; Hoffman 2013)
- The use of diaries and family presence in supporting patients and improving outcomes around PTSD.
(Nielsen *et al* 2019; Pattison *et al* 2019)
- Challenge of Covid – this kind of support not possible.

Trauma-informed approaches

- Trauma theory addresses common ‘mistakes’ in teaching trauma:
 - Expecting to fit within known or comfortable narratives.
 - Expecting processing on a certain timeline.
 - Assuming an ‘innocent’ audience, or that those observing cannot relate to the experience being explained.

(Culbertson 1995; Herman 1992; Jolly 2011)

- Witnessing: recognizing its value and treating it as an intentional process one must choose to participate in.

(Culbertson 1995; Felman & Laub 1992; Herman 1992)

Medical museums in a post-Covid world

- Can provide clarity and a way to understand individual experience.
 - Example diaries or detailed accounts of patient care – value of understanding what happened to them when they cannot remember.
- Can offer support and validation around experience, including delusional memories.
 - Discussing the presence and effects of delusional memories – helping demystify and normalize the experience.
 - Validating this experience and its serious emotional impacts.
 - Increasing understanding of survivor experience among members of the public.
 - Providing a means for survivors to connect with others and/or process the experience with loved ones.

Resources and approaches for medical museums

- Places that work to provide both factual context and narratives of patient and practitioner experience.
 - Can validate individual experience by creating a shared memory that includes or has space for these varied experiences (LaCapra 2014)
- Resources of both objects and narratives – can work to create an evocative and effective experience. (Dudley 2010; Pearce 2010)
- As spaces used to soliciting visitor feedback and engaging visitors in conversations around issues of illness, health and wellbeing.
- The value in creative approaches, audience-lead approaches, validating and allowing for various individual experience.
- Contributing to individual and community wellbeing through:
 - Supporting interpersonal connection and understanding
 - Opportunities for processing and meaning-making
 - Providing context for individual experience
 - Increasing understanding of the experience of others(see Chatterjee and Noble 2013 for broader conversation on wellbeing)

Examples and ideas for practice

- Hosting events and groups to allow people to share experiences.
- Creating spaces for reflection within the museum.
 - Example from Old Operating Theatre Museum & Herb Garrett (research partner) of 'waiting room' reflection space.
- Designing galleries to facilitate deeper engagement and allowing visitors to choose to engage with potentially upsetting material.
 - Example of oral histories used by Anaesthesia Heritage Centre (research partner).
- Creative and visitor-lead approaches (working with artists, creative opportunities for reflection, etc.)

Examples and ideas for practice

- Catch Your Breath exhibition - collaboration with Durham and Derwentside Breathe Easy group 2019
 - Discussing chronic breathlessness among those who have lived experience through various medical conditions.
 - Centring the deeply felt weight of that experience.
 - Visited Catch Your Breath exhibition, reacted with poems
 - This poem inspired by a device to counter collapsed lungs that had been used on a participant as a childhood – described as ‘shocked’ by encountering this object; inspired a deep reflection.
 - An example of how museums can create space for people to process their own experiences and to allow sharing with the broader public.

Poem by Sylvia Hocking
From [RCP Blog - Sharing the Unsharable](#)

The Breathing Box

*Now: an exhibit at the library –
a box with doors which open
to display a cylinder, tubes,
needles, a plunger on top
to blow up ‘magic’ to inflate
an air duct
to collapse*

my diseased lung and promote healing.

*Back then: I would lie on a table
and wait in dread for the needle
to be inserted, the plunger
to be pressed, while staring
at the ceiling.*

*Now: I stare at the scarring
of pin holes left after years
of needles. Was all this worth it?*

Yes.

All to breathe.

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