Carol’s journey in Critical Care: An Enlighten Project case study

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Highlights

- **Critical care experience strongly influenced by local environment**
- **Stage of ICU journey influenced response to environment**
- **View perspective of patient strongly influenced ICU experience**
- **Personalised lighting and visual aesthetics positively influenced ICU experience**
- **Personalised patient environment control positively influenced ICU experience**
- **Importance of narrative medicine**

Abstract

Background

The Enlighten Project seeks to explore how awareness of the physical environment in critical care may impact patient well-being and recovery and whether simple changes may improve outcomes.

Methods

In this study we follow the journey of a long stay critical care patient, recording her observations and memories of her experiences in different bed spaces of both an Intensive Care Unit (ICU) and a High Dependency Unit (HDU) at James Cook University Hospital, Middlesbrough.

Results

Patient’s account gave insight into the patient’s eye view from various critical care bed spaces and how different positions across a unit can impact patient experience. Different bed positions and side rooms yielded different degrees of positive and negative responses, causing varying levels of comfort/discomfort and contentment/distress.

Conclusions

Patient’s eye view perspective strongly influenced Carols’ experience in Critical care, and she displayed a positive attitude to personalised lighting, aesthetics, and levels of environmental and communication control, which were introduced to the her during the study.

Keywords

Enlighten, view perspective, design, delirium, sensory

Introduction

In 2020, Coronavirus catapulted critical care into public awareness, shining a spotlight on the function and design of these specialist units. Most of us, thankfully, would never have visited an Intensive Care Unit (ICU) and would have little knowledge of the design of such environments. With the rapid construction of field hospitals, offering intensive care on an industrial scale, the media presented detailed images of the layout, structure and equipment one would expect to find, thus heightening public awareness of the nature of critical care departments.

What can be seen in such imagery is the stark clinical nature of the typical ICU. Designed with infection control and the administration of crucial medical treatment in mind, a typical bed space is highly functional in appearance, constructed of easy to clean (and often colourless) surfaces/materials. What distinguishes such spaces from more general hospital wards is the presence of a vast range of equipment and monitors which surround each bed and there is an absence of the entertainment systems/TVs, etc more usually available to hospital patients.

Functionality is key and it is common for such spaces to be uniformly lit by electric lighting, having few or no windows. ICU seems an alien environment and despite consistent research demonstrating the therapeutic quality of windows - particularly a view on to nature, colour and imagery, intensive care is stripped of such things, designed purely for medical purposes.

One explanation for the lack of attention to well-being and patient experience in the design of ICU may be that historically, critical care patients were generally unconscious during their stay, thus unaware of their surroundings. This is no longer the case, with current practice favouring a reduction in medication to ensure patients maintain awareness as much as possible during their stay. Delirium is a very common, but refractory clinical state, common in intensive care, occurrence rates ranging from 14–56% and hospital mortality rates ranging from 25–33%. It is characterized by fluctuating disturbances in cognition, mood, attention, arousal, orientation and self-awareness. Patients in ICUs and HDUs find the 24-hour activity cycle, hustle-and-bustle, frequent disturbances, and uncomfortable light and noise levels challenging, and we propose that this influences the levels of delirium. Patients may spend weeks, months and, in some cases, years in this environment.

Objectives

To gain insight into what it is like to be a long-term critical care patient, probing aspects of how the environment impacts their experience. In particular, the patients view from a hospital bed - how this varies at different locations within a unit - and how this, along with the stage of their clinical journey, may be of influence in their perceived feelings of comfort/discomfort. We also explore the influence of personalised lighting, aesthetics, and levels of environmental and communication control, introduced to the patient during the study.

Methods

A retrospective case study was performed with a consented individual patient, Carol, who spent 18 months in ICU and HDU in a tertiary care, academic-affiliated hospital. The patient was asked to describe her journey in detail from entry to critical care as a diagnosed Guillain–Barré syndrome patient, her period spent firstly in the ICU and, thence, for an extended period in HDU in James Cook University NHS Trust Foundation hospital, to identify the positive and negative aspects of her critical care experience. The patient was asked to describe the effects of a personalised diurnal lighting and projector set up, and the prototype control and communication tablet provided by the Enlighten Research team.

Results

Carol, a 46 year old patient, was interviewed by critical care doctor and researcher Dr Edel Mcauley and Dr Laura Johnston, artist and post-doctoral researcher, about her experience in both ICU and the HDU over an eighteen-month period in 2018-2019. Carol was asked to describe her memories of her journey through critical care with reference to the environment and the various bed spaces she occupied during this time and to explain what she felt was good or bad about the spaces and identify any changes that would have improved her experience. At the time of the interview Carol was approaching the end of her time in critical care and was about to be moved to a neurology ward.

Carol's account gave insight into the patient's eye view from various critical care bed spaces and how different positions across a unit can impact patient experience. Different bed positions and side rooms yielded different degrees of positive and negative responses, causing varying levels of comfort/discomfort and contentment/distress. It is the policy of the unit that patients are moved every 30 days to give some variety to their experience of ICU. For many patients, stays in ICU do not exceed 30 days but for long stay patients like Carol, they will experience the varying conditions of multiple bed positions.

The main issues identified by the patient were the levels of lighting and available natural light; lack of views out of the unit; feelings of social isolation/connection; boredom; and the trauma caused by witnessing the distress/illness/morbidity of others. Social interactions, with carers, staff, patients were largely positive for Carol and the degree of availability of this was found to vary depending upon bed location.

Carol's bed space timeline/journey.

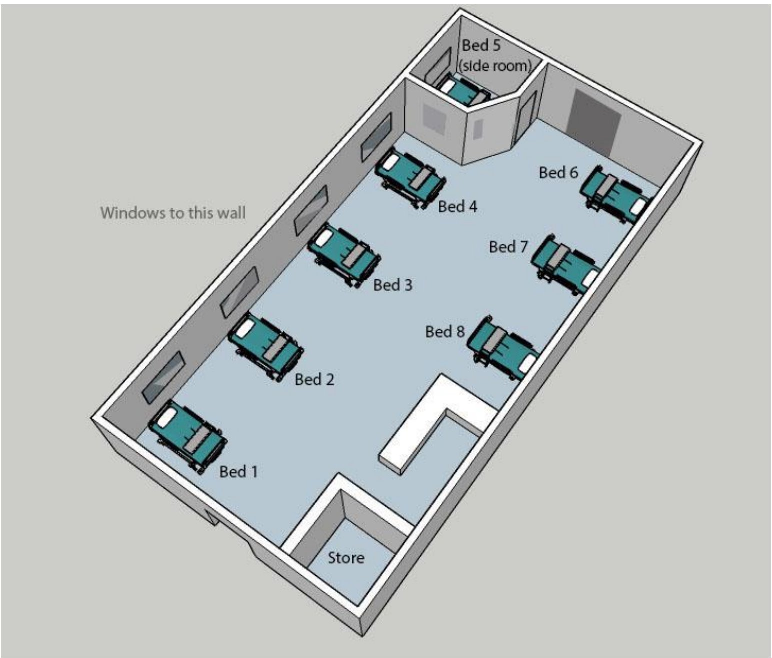

Figure 1. PLAN OF ICU

When first admitted to hospital, Carol’s condition left her unable to move or breathe without assistance, and intubated ventilation left her unable to communicate verbally. During a prolonged period in ICU, Carol occupied two side rooms of differing layouts and various bed spaces on the main ICU ward. She reported having no memory of arriving in ICU but clearly remembered the side room and that it appeared to be *‘a box’* with no views out at all. Although there was a small window in this room, Carol had no view of it from her bed. What she could see were white ceiling tiles, square ceiling lights, blank walls and a door on to the ward.

She explained that it felt…

‘…As if you were the only one there.... It was quite, quite isolating’

Figure 2. View of the ceiling, from the patients position in a critical care side room

Moved to another ICU side room, this time with no window or natural light but a glass panel on to the main ICU ward which was found to give positive benefit.

‘ *it was much better, because there was a big long window that you could see out, you couldn’t actually see any patients bed spaces, but you could see heads…curtains being opened and closed and people moving about’*

Seeing such movements acted as a distraction for Carol and provided something to attend to. This connection to what was happening in the wider ward, although limited, reduced the feeling of isolation for Carol and improved her experience.

Bed 6, positioned at the far end of the unit, opposite the entrance to a side room, was particularly difficult for Carol. She reported that the space felt gloomy and remote. This area received little or no natural light, being far from the series of windows on the opposite side of the ward and daylight was blocked by the walls of the side room opposite. In contrast, when moved to bed 1, opposite the nurses’ station, the constant coming and going of staff and visitors was found to be a comfort. On this side of the unit, windows are located behind the beds. Patients have no view out.

Carol enjoyed the increased social aspects of bed 1 and as a result ‘*felt part of the ward then’.* She was able to see comings and goings and where things were moved to in the unit. At times, nurses would ask for Carol’s help in locating items, knowing that she would have observed the various activities of the day.

‘The nurses used to ask me “Carol, whose got the keys?”’

She was then able to update nurses with information about locations of moved items and in this way experience a sense of connection and involvement. Carol also described how she would talk to the patient in the neighbouring bed even though they were unable to reply.

‘*I used to say “Right, my favourite TV programme is coming on so if you don’t mind please don’t talk!’… ‘I used to chat but he doesn’t remember any of it… I got friendly with his wife.’…*

Figure 3. View on to side room

Figure 4. View on to nurses’ station

A move to bed 4, more centrally located in the unit, again, with the windows directly behind the bed positions, Carol found particularly distressing…

‘You could see every bed, see everywhere. I could actually see patients so confused they had to be restrained by the nurses for their own safety. Death too, just to see the families there and how upset they were….it was horrible. And then at the side of me, I only had a glance, I could see the bed to the side of me, there was a man - I didn’t know what was wrong with him, I didn’t ask, it frightened me too much. I glanced and, that haunts me to this day as well, seeing his face, [his injury] *its, yeah, that was just horrible. Seeing him and the patients who passed, their families and just everything that was happening to me, it just all sort of built up, I was just so upset about it I couldn’t stop crying. Yeah, it was awful’*

Due to Carol’s obvious trauma and distress, she w

.as swiftly moved back to bed 1, when available, after a stay of around 36 hours in bed 4. Carol’s awareness of the distress of others seemed heightened by the experience of bed 4, and she commented that she noticed the distress of relatives coming and going from the unit much more.

‘...with what I experienced there…it was too much being in an intensive care unit and awake…and a long stay patient. I was too long in there’

She remained in bed 1 until her move to a side room in the High Dependency Unit (HDU).

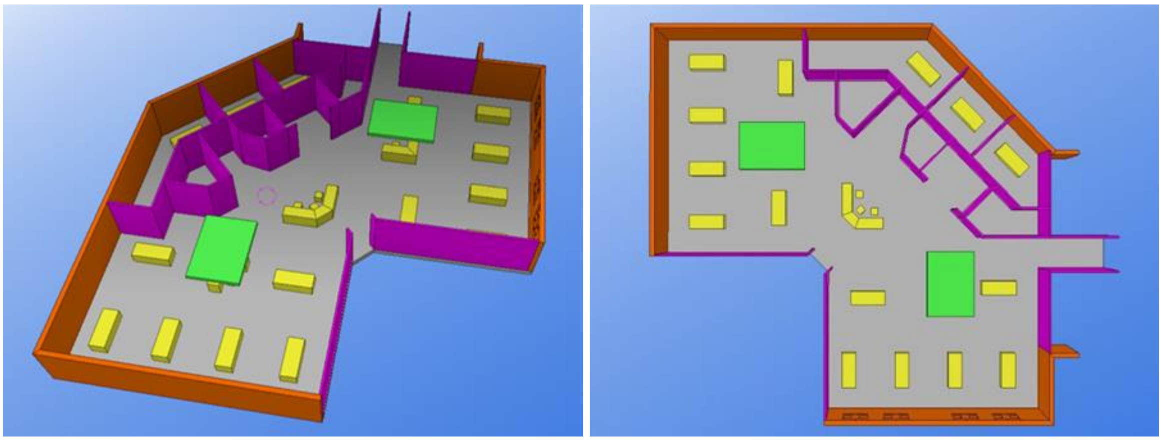

Figure 3 HDU Schematic. The HDU comprises 16 beds in the main unit and a number of side rooms, all facing in different directions and patients experience variable light and sound, and views in different positions and at different times of the day.

The move to HDU was seen positively by Carol as an indication of her condition slowly improving. In ICU, the nurse-to-patient ratio is one to one. In HDU this ratio is one nurse to t..wo patients and so Carol experienced longer periods alone. Still intubated, and unable to move her limbs unassisted, Carol initially felt some anxiety in the side room. She was able to alert the nurses by pressing the alarm with her head, but delays in response at times caused anxiety, particularly when there were issues with her tracheostomy tube.

Despite such anxieties, the privacy the side room provided at this stage of Carol’s journey, was greatly appreciated. Being separate from the wider unit, she valued not having to witness distressing events and her family were able to personalise her space with photos of relatives and pets. She also had a TV and aerial which had been brought in from home.

The isolation felt in a side room during the initial stages of her admission was no longer an issue for Carol and the thought of being moved into an open ward was firmly rejected. Carol felt very strongly about this.

'…I feel we should have a say. If now, if someone said I have to move to the open ward, I would say no - I am not moving. Back then I didn't think I had a choice. I am a bit stronger now and no, I am not moving!'

The side room had a window which can be seen from the bed, receiving good levels of natural light and with a view onto the sky above and corrugated steel roofing and external hospital walls.

'…You can see the pigeons and I never thought I would like to see pigeons!!'

Enlighten Project Interventions – devices and control

During her stay in critical care, the Enlighten Project research team worked with Carol to trial simple interventions which we hoped would improve patient experience. Lack of control is a massive issue for critical care patients, and for those on ventilation, communication is a major problem. In the early stages of Carol's admission, Eye Gaze technology was introduced to enable Carol to spell out words and sentences to staff and family by looking at a screen and selecting letters. However, this created frustration for Carol as others tried to communicate for her, guessing what she was taking time to spell out, and sometimes getting this wrong. Carol reflected that greater patience would have helped to ease her feelings of helplessness and isolation.

'Frustrating so frustrating, especially when you were nearly getting the word and family, or doctors or nurses spoke for you before you had actually finished it, and it was wrong. And they think it's right, and I can't tell them, I can't do anything'

Her experience of Eye Gaze was initially negative due to technical issues but eventually, with practice, this improved, and once achieved, Carol described a feeling of freedom from entrapment, at last able to express herself and relate to others.

'It was amazing…even the grandchildren could do it, it was fab, it was like I'd been released'

We introduced a lamp which was positioned by Carol's bed during her stay in ICU bed 6. This lamp subsequently moved with Carol from bed to bed during her journey through critical care. The lamp was designed to subtly change colour during the course of the day, mimicking changes in daylight. Early mornings began with warm sunrise colours, changing to a blue-white day light, until the evening transition to warm sun set colours. Our intention was to bring a sense of the natural world into the clinical setting and to assist in orientation by injecting a sense of time, with hope to aid sleep, normalise circadian rhythms, and minimise delirium. On introduction of the lamp, to what Carol had described as a 'gloomy' space she reports…

'…there were lots of comments from the nurses, coming in every morning on a day shift saying it was lovely to see the orange light and waking up to it was nice'

Carol commented that the warm sunset colours were uplifting and said she found comfort in observing the changes, she realised it started to change once visitors had left in the evening suggesting a time association. Each time Carol moved beds, she specifically requested that the lamp be set up for her.

Whilst Carol was in HDU the team introduced a projector with a library of images and videos that could be projected onto the ceiling or walls. The aim of this was to create an alternative view from a hospital bed, providing interest and distraction and a link to the outside world. Designed to fix onto the pendant system by each bed, housing the monitors and equipment, patients can select and view a range of images of landscapes, art works, animals, or imagery brought in from home. Carol particularly liked to run a video of a log fire. This she would leave running for hours and enjoyed the movement and changeability. Carol felt the projection device would have been of particular benefit in the early stages of her admission when she spent hours on end looking at white ceiling tiles. She felt that projection of colourful images and videos on to the ceiling would have been very much appreciated.

A simple prototype control system for the lamp and projector was introduced. This consisted of a basic tablet, operated by touch or voice control. At this stage, Carol had limited movement in her hands and found touch control challenging. The voice control proved more promising, but at times did not work for Carol as her voice was quite weak. Carol's family were shown how to operate the device and they were able to select the images or videos

Carol expressed an interest in. They commented that this offered patients a degree of control of the environment, being able to operate the projector and the lamp from the hospital bed.

Discussion

Carol's story reveals how different bed spaces in ICU provide varying experiences and that views from a hospital bed elicit different emotional responses. Carol found the lack of natural light, particularly experienced in bed 6, distressing. The importance of natural light for health and well-being has been the subject of much research. Further research, particularly in the unusual setting of critical care is needed. For hospital patients, a lack of access to natural light has been found to result in reduced immune response and impacted recovery (1). The varying wavelengths of natural light during the night and day, influence the production of key signalling molecules in the body and brain, including melatonin and histamine, respectively following a circadian pattern. Melatonin, controlled by natural light in the red wavelength region, modulates the main cellular components of the innate immune response. Similarly, histamine, induced by the blue end of the spectrum, influences many immune cell types involved in the regulation of innate and adaptive immune responses (2). The design of the critical care unit in which Carol received treatment is clearly not ideal in supporting exposure to this vital natural element.

Critical care is a highly stressful environment and memories of experiences can stay with patients long after discharge from hospital. In some cases the trauma caused by these experiences result in symptoms of PTSD post discharge (3). In Carol's account, her experience at times was deeply distressing and memories of both the events that she witnessed and the effects of the environment continued to cause her upset at the time of interview.

Carol's experience of side rooms varied during her stay. When first admitted to ICU she experienced a sense of fear and isolation in the side room. Later in HDU, she valued the privacy and separation from the wider unit the side room offered.

Bed spaces varied in terms of the levels of social connection Carol experienced. Bed 1 nearest the nurse's station was highly appreciated by Carol. This provided a view directly on to the nurse's station and on to the area close to the visitors' entrance. Her interaction with staff provided a sense of purpose and social connection and she was able to engage with visitors as they entered the unit. These interactions Carol felt were crucial to her sense of wellbeing.

The view from bed 1 offered distraction from the wider environment. This contrasts with the view from bed 6 at the far end of the unit which looked onto an internal wall, creating a sense of isolation and the view from bed 4 in the centre of the unit which had a direct view on to a number of bed spaces.

Carol's family played a positive role in her journey through critical care, providing support, communication and personalisation of her bed space. Her family brought in items from home including photographs of her family and her dogs. Involving the family in the care process has immense benefits and to play an active role it is vital that family members are updated on developments (4). Carol's communication difficulties meant that she was unable to provide updates herself to her visitors. Carol initially struggled with the eye-gaze technology and frustration grew for both herself and her family. The device was new to staff and it took time for them to familiarise themselves with it and provide the assistance and support to Carol and her family. Complex communication tools can be a challenge in this setting. Without training, following operating instructions can be difficult for family members and patients, resulting in many abandoning the technology in favour of simpler options (5). Typically, staff and families will use alphabet or communication boards, pointing to letters to build words and sentences. This can be incredibly slow and cause frustration. Once appropriate training was put in place, Carol and the whole family were able to communicate quickly and efficiently using the Eye-Gaze technology and this Carol found liberating. She was able to express herself to staff and participate in discussions around her care. This involvement provided her with a greater sense of control, reducing stress and her sense of vulnerability. Lack of control is a major affective issue for patients in the ICU environment. (6)

The installation of the lamp provided Carol with diurnal lighting. The aesthetic effects of warm-coloured light brought a sense of comfort to her surroundings. She enjoyed it and made sure that the light travelled with her when she was moved to different bed spaces in the unit.

The introduction of the projector provided Carol with a library of visual images and she particularly enjoyed the flickering flame effects of a log fire. Carol preferred the dynamic moving images to still photographs. Although Carol had regained some hand movement at this stage, the touch screen control was too difficult for her to operate. She had some success with the voice control but at times this did not respond to her voice and she had to rely on staff or family members to operate the device. Further development of the responsiveness of this technology must be carried out to enable all patients to operate the device.

In HDU Carol had a direct view on to a window form her bed in the side room. The view the window provided, although limited (mainly of the hospital roof structure), had a beneficial impact. Carol was able to see the sky and notice changes in the weather. She was surprised by her enjoyment of simple aspects of nature provided by this view and commented that she became interested, for the first time, in pigeons which she could see on the roof. The window brought welcome distraction and a connection to the natural world which Carol found to be beneficial. Observing changes in the weather and natural light through the window, provided Carol with a sense of time, contrasting with the highly clinical and disorientating nature of the ICU environment where no views on to the outside world were available (7).

Even in highly clinical settings such as intensive care it is possible to be more sensitive to individuals' sensory environment, view perspective, engagement needs and preferences. This can reduce the feeling of isolation, formality and seriousness, therefore reducing the potential for anxiety, distress and delirium (8). This present study highlights the importance of narrative medicine for ICU patients, carers and professionals [9].

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