

The Golden Window

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Shreepali Patel & Dr Topun Austin

The Golden Window explores the state of suspension induced by the application of therapeutic hypothermia to newborns who have experienced traumatic birth to protect and repair the damaged brain. As such it attempts to consider the neural basis of human consciousness within this state of stasis. The audiovisual project hopes to communicate the impact of scientific technological developments and understand and explore the human condition in relation to critically ill newborn infants and their families on a neonatal intensive care unit. This exhibition has been created for the Ruskin Gallery by filmmaker Shreepali Patel in collaboration with Dr Topun Austin, Consultant Neonatologist, Rosie Hospital, Cambridge.

Filming on NICU

I first met Shreepali following some national media coverage of a relatively new cooling treatment for newborn babies who had been starved of oxygen at birth. The Sun newspaper described how we 'freeze dead babies' and bring back to life', and the treatment had been pioneered in Cambridge. The fact that the babies were not frozen, nor dead and that it was not something pioneered in Cambridge didn't seem to deter the journalist from running with the story. I was therefore slightly wary and skeptical when she first made contact to discuss cooling. However, while my other experiences with broadcast media have been very much fact driven and 'personal story' focused, it was soon clear that Shreepali wanted to attempt something quite different to the traditional linear documentary. As part of the background research, Shreepali joined one of the morning ward rounds in the Neonatal Intensive Care Unit (NICU) and it was fascinating watching her watching us watching the babies.

Whilst most film crews operate to tight schedules and can be disruptive with large amounts of equipment and lighting, the approach used here was much more low key. The idea was to come to the unit for a few days and 'see what happened'. A small office, which I had recently vacated, became their base and within the tight confines of that room a studio was built. Filmmakers, cameramen and sound engineers went about their business in a much more unobtrusive way. Parents, doctors and nurses were invited into the little 'film booth' to speak directly to Shreepali. From a personal viewpoint, having had previous experience of speaking direct to camera, the set made for a much more informal and conversational encounter than the more stilted and scripted traditional approach. For me, this was only really apparent when viewing the final film. One only has to see the parents to realize how this approach allowed them to open up in a really powerful way.

With no script and no agenda it was difficult to see the direction the film was going to take. I'm not sure even the filmmaker new either. Rather like an impressionistic painting, they were attempting to capture certain themes – science, emotion, consciousness....and using the different colours and brushes of their trade I think they have succeeded.

Topun Austin September 2013

The Film

This project was designed to work across a number of platforms: the single screen (cinema); the multi-screen Ruskin digital gallery; online; and cross-platform (under construction). The project uses film and sound recorded over a single 72-hour period within NICU (the aproximate 'cooling period' of Baby J) and magnetic resonance imaging (MRI) scans. The film was created to reflect the intense and often surreal environment of NICU - the bubble world, and as such uses close up and point of view filming to accentuate the journey of a baby undergoing the cooling treatment and the details of the unit. The sound was recorded on the unit and on location (ambulance) and woven together to compose the sound design, which once again was intended to accentuate the hyper real world of NICU. The 72 hours are significant in terms of the science, i.e. the application of therapeutic hypothermia AND how this time may seem suspended to the parents and carers. The countdown clock reminds of how time can pass so slowly and at times very quickly. The project loops twice, once with the interviews and voice-overs included, and once without. The former, provides an insight into the thoughts and emotions of the carers - doctors, nurses and parents, it also provides the 'science behind the cooling'. The second loop is devoid of these voices and instead presents the sounds and details for the viewer to absorb and reflect upon.

The overall aim of the audiovisual project was to demonstrate how something that we are all familiar with (cold) can be used after birth to protect and repair the damaged brain, as well as stimulate a debate about the 'cumulative' experience of all those involved with the care of newborns within the Neonatal Intensive Care Unit.

The research time spent in the Neonatal Intensive Care Unit brought to light the tension between science and emotion within NICU, where a 'bleep' on the machines means something different to a parent, nurse or doctor. Often the parents felt hopeless in the face of all the machines. However, it became increasingly clear that the emotionally led instincts of touching and talking to the baby by parents were equally as important in the healing process. This complex mixture of science and emotion seemed best evoked by interweaving some aspects of traditional documentary storytelling with a more immersive cinematic experience. The multi-screen nature of the gallery facilitates the unfolding of the cumulative stories embedded within NICU. The filming style (choice of lenses, recording sound and sound design and the way interviews were filmed) was very much dictated by the need to reflect the heightened sense of reality within this 'bubble world'.

Interviews

The interviews were filmed next to the unit, with parents and staff emerging temporarily from NICU. The interviews projected and screened are filmed reflections of the interviewees. The diagram below illustrates the filming set up of the interviews.



The interviewee (A) sat within a small blacked out section of the room (C) looking at and talking directly to the filmmaker (B) through a clear piece of framed glass (D) which created a 'reflective' window. The camera (E) and the glass was juxtaposed in such a way as to allow the interviewee's reflection to be filmed (as though looking straight at the camera). Some of the interviewees commented that it felt almost womb like, similar to the incubators that the babies were resting in. The space, how the interviews were filmed and the environment was designed to allow the carers to reflect upon their own thoughts, experience and emotions away from the tense environment of NICU.



Camera set up for the interviews with cinematographer Tim Sidell. Dr Austin looking directly at the director with camera placed at an angle alongside him



The 'reflected' interview

The Look

Macro, tilt and shift lenses were used to pick out the details of NICU. Slow pans and the point of view of the baby reinforced this sense of heightened reality that the parents felt whilst in this 'bubble world'.



Slow pans and held shots of the family as they spent time with Baby J



Filming with the macro lens to pick out the detail in the unit

The Sound

The soundscape, created entirely from diegetic sound (the unit, simulators and ambulances), was designed to create a world from chaos (the emergence of the baby, birthing, monitors, ambulances) to an almost dreamlike state where the muted sounds of the 'real' world hopefully simulates the infant point of view with a slowing heart beat as the temperature drops, creating an impressionistic world of suspension.



The majority of the audio was recorded separately in the unit. Sound designer Tim Henbury recording in the unit

Bubble of NICU

The birth of a newborn baby should be a joyous occasion. However, for some babies a critical lack of oxygen and blood flow to the brain at the time of delivery can result in a condition of altered neurological state known as hypoxic-ischaemic encephalopathy (HIE). HIE is a major cause of death and lifelong disability in the world. It is estimated that of the 4 million neonatal deaths worldwide a quarter is due to HIE. In the developed world around 1-2/1000 infants born will suffer from HIE. Survivors are at high risk of developing cerebral palsy, epilepsy and severe learning difficulties.

The birth of a baby with HIE is traumatic to all involved. Often there are clues during the labour that the baby may be running into trouble. A sense of urgency develops amongst midwives and doctors to get the baby out. The mother may be rushed to the operating theatre for an emergency Caesarian section to deliver the baby. The lifeless infant is placed on a resuscitaire and the neonatal team begins the task of resuscitating the baby. Talking to parents after the event, they often struggle to recall what went on during this time. The first they know the baby has been admitted to the neonatal intensive care unit. Mother and father are left alone, unsure whether their baby will survive.

In the neonatal intensive care unit, the first few hours after the birth of a baby with HIE is frenetic: the baby is connected to numerous drips, tubes and monitors. A ventilator takes over breathing, drugs support the heart and circulation and infusions provide essential sugar and electrolytes. A special blanket is placed over the baby to cool the body in an attempt to protect the brain. Sensors are placed on the head to monitor electrical brain activity, xrays are ordered, an ultrasound of the brain is done.

After the immediate drama around birth silence descends on the unit – the only audible sounds are the various alarms and constant hum of the ventilator. The baby lies in the in a state of suspended animation, cool to touch, with just the flashing lights from the monitors alluding to the life sustained by this technology.

For parents entering a neonatal intensive care unit for the first time, the environment is daunting. Parents often describe a feeling of helplessness; scared to touch their baby they are often transfixed on the monitors. The nurses provide a lifeline - human contact amongst the myriad of technology. Hours are spent by the cotside: the parents watch all the comings and going; doctors do their ward rounds, talking quietly to each other, fluids are calculated, blood tests are taken, infusions changed. The surreal 'normality' of NICU.

Cooled for what seems a lifetime, after 72 hours the baby is slowly rewarmed. The future remains uncertain, but the journey out of the bubble of NICU has begun.

A Brief History of Cooling

In the 1950's a Swedish obstetrician, Bjorn Westin, in an attempt to develop a treatment for 'asphyxia neonatorum' – or the pulseless baby at birth – carried out a clinical study where infants who were severely depressed at birth were immersed in a cold water bath to rapidly cool the body. Cooling was stopped either when the baby started breathing or the body temperature fell below 27°C. Nine out of the ten infants survived and at the age of ten none of the survivors showed any evidence of disability or cerebral palsy.



An illustration of the water bath used by Westin and colleagues in the 1950's (from: Westin B et al. Surgery 1959;45:868-79).

Throughout the 1960's Westin continued to advocate the use of cooling, however it never gained widespread acceptance. This was in part due to a seminal piece of work by an American neonatologist, William Silverman, who published a study into thermal care of premature infants. In his study of 182 premature infants he showed that those nursed in a relatively 'cold' incubator (temperature 28°C) had a higher chance of dying compared to those nursed in a 'warm' incubator (temperature 32°C). Although the effect on survival was seen mainly in very tiny babies (<1000g), this study was one of the key drivers that led to the concept of the 'warm chain' where every effort is made to keep the newborn infant warm, regardless of whether they were premature or born at term, or what their condition at birth was.

The Science of Cooling

It was not until the late 1980's and early 1990's that hypothermia as a way of protecting the brain was revisited by neonatal researchers. Osmond Reynolds, a neonatologist at University College London, was interested in what was happening at a cellular level in the brain of infants born with HIE. Using the then new technology of magnetic resonance, his group was able to measure energy levels in the newborn brain. To their surprise they found that instead of the damage from being instantaneous, most of the damage following HIE occurred 24-72 hours after birth.



One of the first dedicated neonatal MRI scanners at University College Hospital. Because of the strong magnetic field all the monitoring and intensive care equipment has to be kept a safe distance from the scanner. Infusion lines and sensors pass through an 'umbilical cord' into the scanner



A series of phosphorus magnetic resonance spectra from a newborn baby with severe HIE. Each of the peaks (1-7) represents chemicals in the brain. 5,6,7 is for ATP – the main energy molecule in cells.

Despite being born in very poor condition and suffering from HIE the initial scan at 8 hours is normal.

Over the next 48 hours the energy levels fall (peaks 5, 6, 7) which correspond to cell death and permanent brain injury. This raised the possibility that an intervention just after birth may stop this process and prevent cell death.

(From Wyatt JS et al. Arch Dis Child 1989;**64**:953-63.)

It appears that the lack of oxygen to the brain results in signals being sent to brain cells, which result in a type of 'organised' cell death, known as 'apotosis'. Because this is not instantaneous it raises the possibility that there is a 'window' in which treatments can be developed to prevent permanent brain injury. Instead of an expensive pharmacological solution, researchers found that cooling the body, by a few degrees celcius, in experimental models appeared to arrest the program of organized cell death, in such a way that when the temperature was restored, the cells survived.

From Bench to Bedside

The challenge then for researchers was how to translate this basic scientific research into clinical practice; particularly given the practice of keeping babies warm was so set in stone. In the late 1990's the first clinical studies of controlled therapeutic hypothermia were carried out. The primary aim of these early clinical studies was to assess the safety of cooling infants with HIE. Although experimental evidence pointed to the potential benefit of hypothermia, questions still remained as to how long the baby should be cooled for, to what temperature and by what means. In an attempt to minimize any potential harmful systemic effects of cooling, the first studies used a specially designed water filled 'cool cap' to cool the head while keeping the body warm. However other early studies showed that cooling the whole body to 33°C was not only much simpler, but also in the intensive care unit, could be done safely with minimal side effects.



One of the first baby's cooled using a specialised 'cool cap' on the neonatal intensive unit at University College Hospital, in the late 1990's. The tubes coming out of the cap contain cold water that circulates around the head keeping it cool.

Following these pilot studies a number of randomized controlled trials were set up to determine whether moderate hypothermia led to an improvement in survival without disability in infants with HIE. Results from three large studies, two run from the UK, published between 2005 and 2008, showed that mild hypothermia for 72 hours not only improved survival, but in those who did survive, a significant number of infants had normal neurological development at 18-24 months of age.

The early experimental work of Reynolds and other groups in the 1980's which subsequently informed first pilot clinical studies and eventually large multicentre RCT's is a great example of translational research, with high quality basic science improving clinical outcomes. However for translational medicine to reach its true endpoint it must be shown to improve clinical outcome not only in the context of clinical trials but also in the reality of routine clinical practice.

Cooling – Standard of Care

In 2010 the National Institute of Health and Clinical Excellence (NICE) and British Association of Perinatal Medicine (BAPM) recommended that therapeutic hypothermia should be the standard of care for infants with HIE. Because these infants are usually born in poor condition unexpectedly in any hospital setting, and cooling should be done in specialized neonatal intensive care units, the approach taken in the East of England is to develop a coordinated network-based approach. A specialized neonatal neuroprotection nurse provides training and support on the early management of these infants to staff in all 17 hospitals in the region. Babies are transferred to one of 3 specialist 'cooling' centres by a dedicated neonatal emergency transport team (the Acute Neonatal Transfer Team – ANTS). The ANTS team has a special cooling mattress to ensure that the infant is cooled as soon as possible after birth. The development of this service was recognized with a major award given by NICE in 2012.



The Acute Neonatal Transfer Team (ANTS) ambulance at the Rosie Hospital in Cambridge. Since 2009 they have transferred more than 150 babies across the region for cooling.

Future Research

The management of these babies goes beyond just cooling. Often suffering from multi-organ failure these babies can be very sick and require a lot of intensive care. Only once the cooling has finished and the baby is rewarmed and awakens from this period of 'hybernation' can medical staff begin to assess the likelihood of long-term brain injury. Specialised monitoring and imaging, including MRI, is used to identify brain injury at an early stage. In Cambridge doctors and scientists are developing new technologies to detect seizures, commonly seen in babies with HIE. Using specialized light sensors they are studying the effect of cooling and seizures on blood flow in the brain. It is hoped that this research will enable doctors to identify the most vulnerable infants at an earlier stage.

Scientists in Bristol and London are studying the effect of an anaesthetic gas, Xenon, for protecting the brain alongside cooling, and there is promise from a number of other drugs. Where 15 years ago the only treatment offered was supportive, there is real hope that these babies will benefit from a range of new 'neuroprotective' treatments in the coming years.

The Production Team

The project was created in collaboration with: students and graduates of the Cambridge School of Art (Nick Howard, Clare Unsworth, Adam Broder, Lisa Kirkham and Reeta Vaparma); Sophie Jackson (coproducer), Tim Sidell (Director of Photography), Joseph Maestrangelo (focus puller) and Tim Henbury (Sound designer); the generous support of Smoke and Mirrors (Andrew Salem and Duncan Russell and Clearcut (Mal Woolford and Jamie Hartland); all at the Rosie Hospital, Cambridge; the Cambridge School of Art, ARU and CoDE.



Links

www.BeBoP.nhs.uk

The East of England Neonatal Neuroprotection site contains information for healthcare professionals and families including links to support groups.

www.bliss.org.uk The UK charity for premature and sick babies. Also contains links to support groups.

www.cuh.org.uk/cms/rosie-hospital Link to the Rosie Hospital, where the Golden Window was filmed.

www.anglia.ac.uk/ruskingallery The Ruskin Gallery where the film was exhibited

www.anglia.ac.uk/csa Cambridge School of Art





