Future stories: co-designing virtual reality (VR) experiences with young people with a serious illness in hospital

Balfour, M., Cattoni, Jan, Sextou, Persephone, Herbert, Anthony, Seear, Lynne, Lobwein, Guy, Gibson, Margaret and Penton, Jennifer

Future Stories: co-designing virtual reality (VR) experiences with young people with a serious illness in hospital.

Michael Balfour, University of New South Wales, Sydney, Australia; Jan Cattoni, Central Queensland University, Cairns, Australia; Persephone Sextou, Sidney De Haan Research Centre for Arts and Health, Canterbury Christ Church University, UK; Anthony Herbert, Queensland Children's Hospital, Brisbane, Australia; Lynne Seear, Queensland Children's Hospital, Brisbane, Australia; Margaret Gibson, Griffith University, Brisbane, Australia; Guy Lobwein, Queensland University of Technology, Brisbane, Australia; Jennifer Penton, Griffith University, Brisbane, Australia,

Corresponding author: Michael Balfour m.balfour@unsw.edu.au

Keywords: Virtual reality; young people; hospital; technology; care; co-design.

Introduction

Although there has been a rich history in applied theatre research that focusses on the relationship between theatre and technology, and a recent focus on the qualities of care and relationality in applied work (Thompson 2015, Hatton, Dunn and Balfour 2019, Stuart Fisher and Thompson 2020) little attention has been paid to the possibilities which a combination of these approaches might offer. In this paper we identify these possibilities within a proof-of-concept pilot, Future Stories, that aimed to explore the ways in which co-designed virtual reality (VR) experiences might be used to support the social needs of young people undergoing treatment in oncology and palliative care in hospital settings. The project focused on the significance of applied intermedial work in enabling improved well-being and agency in participants "beyond the clinical treatment" (Sextou and Monk 2013, 83).

VR has gone from being an expensive prototype to an application that is now in daily use across a range of sectors and with multiple social applications. While the technology is still evolving, its application in medical contexts is apparent in a number of ways, including psychological disorders and mobility issues (Dhiman, et al. 2018, Laver, et al. 2017), anxiety reduction and mental resilience with young people (Vakili, et al. 2014) and pain reduction (Hua, et al. 2015). VR in health care has been used to manage pain and distress associated with a wide variety of known painful medical procedures. In clinical settings and experimental studies, participants immersed in VR may experience reduced levels of pain, general distress/unpleasantness and report a desire to use VR again during painful medical procedures (Das, et al. 2005, Dhiman, et al. 2018).

The project has been informed by the extensive applied theatre literature on integrating theatre with new technologies, as well as the pioneering work of Sextou in understanding the unique qualities of theatre work in hospital settings. We focused on what Sextou (drawing on Edmiston) described as "space-times" in which the participants co-create moments and experiences unavailable to them within the ward (Sextou 2021, 3). As with face-to-face theatre practice, the Future Stories project replicates ward settings in virtual reality to enable a transition from reality to fantasy. By doing that it creates a portal, an escapism through the participants' imagination to other worlds, moments and experiences that are unavailable to them in real life during their hospitalisation. Analysis of the data from the pilot revealed how the combination of relationality and technology created a distraction for the participants (and families) and had a positive impact on their sense of agency and well-being in the hospital (Sextou 2016, Astles 2020).

The research team consisted of trans-disciplinary expertise across the arts, technology, sociology, social work, and medicine.[1] This is key in relation to the sensitivities and ethical nature of the research. The team have been working together to co-design the research since 2017, culminating in a proof-of-concept pilot in November 2019. The logistical and operational outcomes of the pilot have fed directly

---

[1] CIs Balfour, Herbert, Cattoni, Gibson, Holland, Lobwein, Seear, Sextou, Penton (Research Fellow)

into a planned larger study across three hospital sites in Brisbane, Sydney, and Cairns. There has been considerable value in developing working relationships across the disciplines over a period, ensuring that project management, communication strategies, project governance and role clarity have matured and developed in preparation for the proposed main study.

Project Background

Hospitalisation can be a challenging and dislocating experience for young people (Altay, Kilicarslan-Toruner and Sari 2017). The impact of hospitalisation can include higher levels of anxiety, unfamiliarity with the hospital context, and feelings of social isolation from friends and family. These feelings can be intensified if the periods of treatment are prolonged or lead to long stays. For families and children, the experience of hospitalisation includes not only dealing with the complexities of illness, but psychosocial issues connected to anxiety about "procedures, fatigue, fear of relapses, loss of irreplaceable time, fear of dying and feelings of powerlessness" (Barling, Stevens and & Davies 2014, 152).

The reality and experience of hospitalisation for young people are complex and multifarious. These include not just the challenges of managing a serious illness but also the affective dimension of emotional, physical, social, and psychological stress and anxiety. For example, for young people managing a diagnosis of cancer, the emotional psychological domain was one of the most salient unmet needs (Nilsson, et al. 2009). Woodgate (2008) highlights how young people feel that the experience is characterised by loss of control and agency combined with uncertain and negative feelings. Further, more than 50% of young people living with cancer are at high risk of depression and feelings of isolation (Altay, Kilicarslan-Toruner and Sari 2017).

The Future Stories project builds on four core propositions: (1) VR is an immersive technology that can transport users to virtual worlds; (2) Participatory and aesthetic processes enable individuals in hospital to engage in cognitive and affective activities; (3) The combination of creative processes and innovative technology provide broad appeal and fascination for the target age group; (4) The project responds to a need from partner organisations to address the needs of young people in protective isolation in hospital who are undergoing long term care.

The pilot took place in Queensland Children's Hospital (QCH) in Brisbane. QCH is the only standalone tertiary and quaternary paediatric hospital in the state, treating newborns to young people in late adolescence. The hospital identified adolescent oncology and palliative care patients as a key group for the pilot as they often were in protective isolation and often report that other distraction activities within the paediatric context are aimed at younger children. The isolation units also meant this group were frequently restricted to their rooms with visits from others minimised. The creative context of QCH's arts and health program is important to highlight here. QCH has a dedicated manager of arts and creativity activities, and runs an extensive program of special performances, culturally significant art workshops and educational activities. This is an important context, as the underlying philosophy of the research aligned strongly with the QCH's commitment to provide patients with the opportunity to collaborate and engage with creative activities.

Within our pilot study we worked with three participants in individualised bedside workshops over a four-week period, with two artist facilitators working with participants to develop ideas for VR worlds from concept, design, testing, refinement, and a shared presentation with staff and family. Two artist-facilitators, Jan Cattoni, a film maker and former paediatric nurse, and Guy Lobwein, a VR creator and coder worked throughout the residency.

Creative care

Care is "a shifting and unstable concept" and describes health practices, institutional policy, family caregiving, affective elements, biopolitics, and interpersonal relationships (Buch 2015, 279) The multiple understandings of care, particularly drawing on anthropological research, have in common an emphasis on relationality and activity, and as Black argues "social activities of care both constitute and are made relevant by morally/ethically framed relationships with others and oneself" (Black 2018, 80). This echoes Thompson's work on care, where he discusses the need to redraw professional-personal

relationships, arguing that the aesthetic relationship needs to attend to the "intimate and interpersonal" as a critical source of applied theatre's political engagement (2015, 432).

One of the starting points of the project came from the experience in researching play-based work with people with mid to late-stage dementia. The play approach in that project was underpinned by a philosophy drawn from the work of Gaulier and Lecoq which foregrounded the importance of complicité (in the moment connection between performer and audience), relational improvisation, and a 'being with' an audience rather than a 'doing to' (Lecoq 2002). The play-based work was highly individualised, with two elder clowns working with participants at the bedside, in the social spaces, or wandering with the person through the ward. The key to the relational aspects of the play was authenticity: "being in the present and valuing the quality of the moment; validation – creating and holding 'the moment' of connection; lightness – the cosmic fun of discovering and acknowledging little moments of pleasure; acceptance of fictional truths – accepting memories whether true or not as the essence of the storied self" (Balfour 2019, 96). These moments were often fleeting, hit or miss, relational connections. It was in these small moments where there was a ripple of laughter, a shared connection with a song, a space of what Norris describes as "not "safe spaces" but spaces of consensual courage: spaces we are able to agree to stay present inside, with each other" (Norris and Salverson 2020, 38) These small, intimate acts of creative care were about the ways in which play (or indeed other art forms) might open up or reboot relationality in order "to reinvent life by transforming what reciprocity means from its most simple to most complex and unclear exchanges" (Berlant 2011, 5).

Shifting focus into a different medical context, a children's hospital, many of these relational questions underpinned the ways in which Future Stories was developed. Sextou's (2016) work with one-to-one bedside theatre with younger children in hospital informed the ways in which we shaped the design of the work. The creative agenda centred on the intimate interrelationship between facilitators and participant, relationships that were governed by sensitivity, responsiveness, and reflexivity to the moment to moment needs of the individual and medical context. The relational moments in the Future Stories pilot were an attempt to explore the ways in which co-designing visual, narrative, imaginative realms might occur with participants. These small acts were creative encounters, sometimes lasting 30 mins, sometimes shorter than 5.

The affordances of VR

The decision to use virtual reality technologies with young people in hospital was driven by a curiosity in the form and the potential for using it within the context of socially engaged practice. Initially we were interested in how organisations like the United Nations were creating VR films about refugee camps focused on increasing empathy, action, and social change (Arora and Pousman 2015). While these early examples were valuable, the tendency was for 360 documentary films that followed a traditional linear narrative route, rather than exploring the unique qualities of the VR form:

> A hard-driving plot with distinct beginning, middle and end is a great way to control how long an experience takes, but "classic" VR is inimical to this type of authoritarian control – it works best when people can move about and do things in virtual environments in a relatively unconstrained way (Laurel, Strickland and Tow 1998, 181)

The activity and interactivity of the VR form lean more towards a perceptual and emotional experience that depends on the user's action and the environment's responses: "In VR, one is not done unto, but doing" (Laurel, Strickland and Tow 1998, 182). Howard Rheingold, in one of the first books on VR, wrote about its ontology in terms of three interdependent aspects (Rheingold 1991, 34): "One is immersion, being surrounded by a 3D world; another one is the ability to walk around in that world, choose your own point of view; and the third axis is manipulation, being able to reach in and manipulate it".

What we started to realise in examining numerous experiments with VR was that, like immersive theatre, the control of the narrative structure was displaced onto the 'immersant' spectator (Dixon 2006)

The most effective VR experiences were not driven by narrative, but by the sensual encounter with the aural and visual landscape of the VR world. It was a place governed by discovery and viewer-led exploration rather than traditional story. The most effective socially engaged VR examples were experiments where the technology combined with integrating experiences with affective touch, taste, smell, and discovered encounters. Jane Gauntlett's In My Shoes (https://jane-gauntlett.squarespace.com/stories) was a fascinating project that integrated face to face work, performativity and a VR experience to generate understanding and critical engagement with the experiences of people who live with epilepsy. Gauntlett, who has a background in theatre, was violently mugged in 2007, and fell into a coma for three weeks. She suffered a traumatic brain injury because of the attack, and now lives with a neurological condition that encompasses short-term memory problems, as well as epileptic seizures. The In My Shoes screenings took place in small groups (max 15) in a real time café surroundings. The mode of the presentation is carefully socialised as Gauntlet first talks through her personal experiences and provides some context to the project, before asking the immersant to put the VR headset on and put their hands in front of them on the table. The VR film starts, and we view, in the first person, Gauntlett's pair of hands replete with nail polish, sitting in a café opposite another person. The cognitive disjunction is extreme, as the viewer instantly feels the embodied alignment between the 'real' world and the VR experience mirroring each other. The VR film then explores the experience of an epileptic episode, from the first-person perspective, but reflected in the responses to it by the other people in the café. After the VR experiences finishes, the small group of immersants' take off their headsets. Gauntlett then facilitates a discussion with the group about the experience and their responses. In My Shoes has played at international documentary festivals, to general VR festival audiences, with support groups, and importantly at conferences and seminars for clinicians. Gauntlett's work highlighted to us how important it was not to be driven by the fetishization of a new and evolving medium, but to consider how to integrate relationality and technology. As Shaughnessy (2012, 180) argues "pedagogically technology can operate only at a basic and superficial level if it is divorced from the social and interpersonal contexts which frame and shape our everyday realities".

Relationality and intermediality

The integration of drama-based or 'live' face to face creative work with technology has been well documented in the literature (see for example the Special Edition of Research in Drama Education, 17.4 on technology and innovation). The forced pivot of creative work in response to COVID-19 has also inverted the ways in which we all work and play, with the essential consideration of how to negotiate the "the virtual, the real, and the space in-between" (Gallagher, et al. 2020, 643). Post-pandemic it will be interesting to see how our accelerated technological learning over the last couple of years, will enable us to integrate and evolve a new range of practices. Regardless of platform or context, the residual opportunities of applied intermedial work will still, arguably, be focused on the intersections of relationality with mixed forms of media.

Applied theatre research has a strong tradition of experimenting with drama and technology to explore the affordances of intermedial work that combines liveness with digital practices (Carroll and Cameron 2009, Davis 2012, Alrutz 2013). In the early drama education discourse, there was both a fascination in the changing dimensions of technology as well as a binary tension between drama and the digital. As Anderson, Cameron, and Sutton (2012, 469) note technology should not be viewed "as a novelty or an enemy of 'authentic drama practice' but as a part of the landscape". The clear warning is the risk in ignoring a more participatory, do-it-yourself culture of creation and re-creation based on new forms of performance and expression enabled by digital media. For Alrutz (2013) digital storytelling was explicitly an applied theatre praxis which combined live performance with QR codes, video projections, and live social media narratives. Similarly, Paul Sutton's (2012) development of Networked Theatre brought together different dimensions of applied theatre and offline/online performance communities.

The evolution of intermedial discourse has moved from binary positions of 'liveness' and mediatised performance to recognising the relationship is one of mutual dependence. Rather than privileging specific approaches (the technological over the human or embodied) consideration is focused on the ways in which different tools mediate meaning moving the discussion about performance and technology "beyond dualities" (Davis 2012, 502). The lesson from applied theatre research to date, is

for practitioners to not overuse or fetishize new technologies, but to focus and respond to the aesthetic and relational elements, the intentions, and social qualities of the project, rather than on the use of technologies per se.

Co-design and agency

The concept of agency in applied intermedial work has been used in relation to classroom learning (Anderson, Carroll and Cameron 2009, Carroll and Cameron 2009, Bearison and Granowetter 2012) with children from a refugee background (Dunn, Bundy and Woodrow 2012) newcomers in an urban middle school (Maloney 2021) creative projects in School responding to COVID-19 (Gallagher, et al. 2020) and media literacy programmes with young people (Alrutz 2013). Familiar constructivist and libertarian pedagogies derived from Vygotsky and Freire are re-framed in terms of intermedial projects as either enabling greater manipulation and engagement of learning through the technology or enabling participants to become critically engaged prosumers (individuals who create digital products, ideas, and culture that they wish to consume) rather than merely interactive consumers of technology.

Interestingly the concept of agency and participatory co-design are echoed in the technology and design literature. Sanders & Stappers (2008, 6) identified that there has been an evolution from user centred - ideas that get tested on a relatively passive but representative user group – to co-design (or participatory design), that refer to "the not trained in design working together in the design development process".

Significantly, co-design is not a feature of most VR activities in hospital. Many VR projects in hospital are designed as scale-able interventions and experiences designed to address medical treatments, administration of needles, anticipatory anxiety about procedures, or pre-built escapist distraction experiences. For example, an Australian project used animated characters to address the problem of traumatic needle procedures for children (Smileyscope 2020). An earlier study in Japan used virtual reality technology to enable children to enjoy a virtual visit to the zoo, amusement park, or aquarium (Nihei, et al. 1999). In Boston Children's Hospital (Boston Children's Hospital n.d.) VR is used to help doctors explain medical conditions to children with the first iteration of the tool exploring paediatric gastrointestinal topics and using 3D VR imaging to bring an individual's medical records to life as they take an immersive tour through their own insides (Boston Children's Hospital n.d.). These are VR experiences in which participants engage with pre-programmed worlds.

The question for the Future Stories research team was how a participatory and agentic process that involved young people as active co-designers, might offer a different level of ownership and authorship in a VR experience.

Approach

The pilot project was designed as a proof-of-concept process, that encouraged all participants and stakeholders to feedback on the potential benefits and weaknesses of the approach. In line with the philosophy of the project being governed by principles of co-design, the research process sought to position the participants as co-researchers/designers in the critique of the process. We used mixed qualitative research methods, including artist observations, feedback, and interviews to develop our understanding of what creative strategies worked best with the specific needs of the young people in hospital. Each creative session included diverse forms of documentation using still images, audio, or video recording. The type of documentation was determined by discussions with the participants and consent was obtained from each participant/guardian for each session.

Using photogrammetry, the hospital room and lobby were built as virtual 3D spaces using photographs, architectural drawings, and measurements of the actual spaces, thus replicating the look, textures and feel of the hospital environment. Photogrammetry is the science of making measurements from photographs. The input to photogrammetry is photographs, and the output is typically a map, a drawing, a measurement, or a 3D model of some real-world object or scene. These common virtual spaces were designed as a 'sandpit' to play and explore and understand the conventions of VR environments, as well as providing a port of entry and exit to the virtual worlds that were being created. The use of

photogrammetry provided the opportunity to create a limitless range of embeddable assets within the virtual environment including photos, videos, textures, sounds and objects.

[Insert: Figure 1: The external hospital building in the VR world]
[Insert: Figure 2: Inside the VR hospital's common areas]

The preparation lead time for setting up the practical component was complex, involving separate ethics applications for university and health governance.[i] It was also critical to the project that there was institutional buy in from clinicians, nurses, and health professionals. Quite rightly there is a vigorous culture and formal protocols for gatekeeping in hospitals, to ensure the primary health care needs are protected and observed. Considerable time was spent building institutional relationships through presenting the project at various forums and meetings, and working with our co-researcher, Dr Anthony Herbert and Lynne Seear to help us build up trust and rapport with the hospital staff. The need for strong collaboration between the research team and the hospital staff became apparent as patients began to be identified. The potential participants all had complex health issues which meant the team also needed to learn the ward structure of care provision to ensure access in a constantly changing environment. For example, in terms of patients with cancer diagnosis, linking to the Clinical Nurses working with the Bone Marrow Transplant and Youth Cancer Services was critical as they provided advice and input on infection management of patients in isolation.

Participants

Within our pilot the 3 participants who volunteered included two young men, Brice aged 15, Harry aged 17 and a young woman Daniella aged 16 (pseudonyms have been used here to protect the identity of the participants). Brice has spent most of his young life in and out of hospital. He has a progressive neuromuscular disease requiring skilful, careful handling of his body for showering, moving in and out bed, and into his motorised wheelchair. Both Harry and Daniella are oncology patients and during the pilot, Daniella was in a sterile environment to protect her from infection. The project team had to be rigorous in handwashing, wearing gloves and hospital gowns upon entering her room. Harry often experienced severe nausea after chemotherapy and was unavailable until it settled. These sensitivities of care required patience, empathy, adaptation, and responsiveness to changing circumstances and priorities in relation to hospital staff. Access to the participants was guided by the arts-in-health manager, healthcare staff and parents and this was carefully negotiated to respond to the needs of the participants.

The practice

The four-week pilot consisted of two artists in residence, Jan Cattoni and Guy Lobwein, working with young people selected in consultation with health service staff. The pilot was delivered through one-to-one sessions at the participant's bedside and consisted of 4-6 creative sessions. These generally took the shape of three interlinked phases, an initial stage of relationship building and introducing the technology, a co-design stage where the artists and participants worked through ideas for the worlds and the details of the experience (sound, visual, objects, textures). These sessions used a combination of iPads, writing apps, research, and illustrations to map out potential VR worlds. The participants were also encouraged to work on the designs outside of the sessions, which most of them did with relish. The third stage involved them playing with and sharing the worlds with family and health staff. For this latter stage we hooked up the VR headset with a television screen, so that the small bedside audience could see how the VR immersant was navigating the world.

The reflexivity to the context of care, and the need to monitor the moment-by-moment capacity of participants to engage was a critical skill for the artist facilitators. One of the observations about these visits was just how exhausting it can be to be in hospital. Every hour there are beeps from infusion prompts, nursing staff checking in and doing observations, medical staff coming in and out etc. Add to this the various technical and infection control challenges and the participants experience of days that stretch out endlessly and blur together. For the artists the amount of time that it took to establish a relationship with the participant and begin to work creatively with them was considerably longer than anticipated. Often the young people were tired, feeling unwell, inhabiting a noisy environment over

which they have little control, craving the company of their peers as well as dealing with having a serious illness.

These initial encounters were often low key, quiet conversations, and there was a constant checking in with the participant, family members, or health staff about the timing and length of these visits. The team was guided by Cattoni's experience of working with critically ill children and young people and their families. Having this kind of experience on the team was important in establishing strong relationships with the care providers in the specialised environments the team was working in.

The technology was explained and introduced, and often participants were keen to explore the novelty of putting on the headset and the invitation to play in a VR version of the QCH hospital. This gave them an example of the conventions of VR worlds, and they (very quickly) learned how to move, pick up objects, 'teleport', go into lifts, and explore the possibilities of VR. It also enabled participants to grasp the scope of what was possible in the worlds they might create.

Sextou's (2016) practice helped us to consider the spatial conditions of care, and the challenges of configuring the limited space between facilitators and participants. She articulates how important it is to respect and negotiate the intimate space around the bed, and to ask the participant if the distance between them is acceptable and the invitation to play is offered and "removes away the tension and so offers less chance of the child feeling "attacked" in their private bed space" (Sextou and Monk 2013, 86). The intimacy of this kind of facilitated relationship is a very different from traditional group work in applied theatre/performance/drama. It acknowledges the confines of space, the potentially intrusive nature of 1:1 work, and considers how to be attentive to the moment to moment needs of the participant.

The next stage involved working with each of the three young people to develop ideas through sketches, writing, and shared stories. While the team had developed a series of 4-6 sessions (over 5 weeks) with specific activities, it quickly became clear that, on any given day, the participant engagement varied enormously. Treatment modalities, investigations, pain, lethargy, nausea, sadness, despondency, and appointments with the treatment team all influenced the participant responsiveness to the project activities. What the Future Stories team had hoped to achieve in a single session, often took 2-3 visits. Fortunately, the responsive project design meant the artists in residence were able to work within the parameters of the participants' condition at any given time. The workshop approach was flexible enough to accommodate the needs of the young people and their families, with engagement undertaken in person, videoconference, or telephone.

Once the design ideas had been sufficiently developed in the creative sessions, Guy Lobwein coded the individual VR worlds, iteratively developing the worlds in consultation with the participant. Daniella, wanted to recreate her memory of a village in Thailand (place name changed) where she had grown up. She sketched out rough ideas for the village, even adding in the precise specifications about how many chickens there should be ('chicken x 6'). She and her mother supplied the audio for the chicken sounds. Sitting with Guy, she talked about the bridge where the children used to fish, and the plan of where each of the houses were. Other elements of the sound scape were discussed, including the distinctive laugh of her grandmother, which everyone tried to re-create, leading to a fit of the giggles. Guy would always check back in with the design stage, to make sure it was just as Danielle had imagined it. After each consultation levels of detail were added, for example a working playlist to the primitive karaoke machine in the house.

Harry's passion was for BMX biking, and he had been following the opening of a new park in the USA. Harry's desire to re-create the BMX bike was perhaps one of the most challenging, as it involved coding the ability to ride and do stunts. We were able to access the BMX park plans from the creators in the USA, and therefore re-created the world in exacting detail. Brice had been confined to his hospital room for weeks, undergoing treatment for a progressive muscular disease, Spinal Muscular Atrophy (SMA). When he was approached to get involved in the project he said: 'Hell, yeah – I've got nothing else to do'. Brice was fascinated by the moon and had watched many documentaries and volunteered himself as a so-called space nerd. Working with the team, Brice developed a Future Story that sent him to the surface of the moon and enabled him to meet Laika, the Russian dog that was the first to orbit Earth.

Fortunately for us, NASA has enabled an open access mapping of the moonscape, so the recreation of the contours of the moon was accessible.

Reflecting on the co-design process with each participant it was clear how important the slow and careful relationship building was to initiate trust and reassure the participants that getting involved was not a further burden. The experience of the virtual reality conventions, through engaging and playing in the virtual hospital, triggered all kinds of ideas about what they would like to create. For some this was clear from the start and built on their own interests and hobbies e.g., BMX bike, the moon. For Daniella it took a little longer to land on her preferred world. Once the concept had been decided on, what was interesting was the ways in which each of the participants became fascinated by building in further detail, sometimes personal (a particular sound, an object, an active task), at other times technical (ability to do stunts).

In the final playing and sharing stage we rigged up a monitor so that other people in the room could see what the immersant was experiencing. This initially was thought of a safety mechanism in case a participant felt dizzy while wearing the headset. What we discovered was that it accidently socialised the experience for other people in the room. For each of the participants it also enabled them to become tour guides of their world, creating considerable excitement and hilarity, as senior clinicians crashed their VR bikes, or failed to notice assets buried in the landscapes of the world. For families and siblings, it enabled a different kind of interaction, as the participant showed them round the world that they had co-designed.

The idea of relationality

For applied theatre practitioners, regardless of the combination of live and technological innovations (social media, VR, digital storytelling, COVID inspired zoom antics etc) the challenge is how to combine these elements to create meaningful and meaning making experiences. In this guise the applied theatre maker is a "...designer of experience, embracing the digital, the live, the embodied and the conceptual, framing and creating experiences that draw attention, connect, and make us feel 'alive' (Davis 2012, 514)

Given the complexity of the care environment, the foundations of establishing relationships with the hospital were a critical aspect of the project. The term stakeholder gets used frequently in establishing applied projects, the depth of these connections varies from context to context, project to project. In Future Stories the consultative gatekeeper functions of these relationships were integrated over a long period of slow development and planning. Herbert, as director of paediatrics and Lynne Seear as the arts and health manager, were part of the early conversations about the nature and logistics of the project and this relationship evolved into them being a fully integrated part of the research team. The relational process between the arts team and the institutional staff, was not focused on the project management protocols, but an essential aspect of the integrated weave of intention, aesthetics, and care. The relational contours of the project have been shaped and informed by the professional and personal insights of the hospital staff.

The quality of these relationships established in advance of the project were evident in the ways in which the pilot worked in and around the critical work of the hospital staff. Each day started with a brief team 'huddle' with arts and hospital team, to update, inform, and guide how best to manage the visits during the day. This helped to avoid unnecessary visits during times when the participants were undergoing treatment and ensured that the visits were integrated into the health needs of each participant. If the participant had had a sleepless or painful night, visits were deferred until another day. As Thompson (2015, 438) notes these preparatory stages are "not the hidden mechanism of creative endeavour but a valued component of the aesthetics". The experience from the pilot demonstrated how important it was for an arts project working in an area of critical care, to be highly responsive and reflexive to the needs of the participants and the health care priorities, while at the same time finding the spaces where the aesthetics might find the time for meaningful encounters.

The experience of the pilot showed that the amount of time it took to establish a relationship with the participants and then begin to work creatively with them was considerably longer than anticipated. Often the young people were not sleeping, feeling unwell, inhabiting a noisy environment over which they had little control, craving the company of their peers as well as dealing with having a serious illness. Despite signing up for the project, our first visit with Brice was not promising, and he apologised that he felt he wasn't well enough to take part anymore. With his father's encouragement the team dropped by a couple of more times, and it was only a chance conversation about computer coding with Guy, the VR artists, that led to an animated discussion where Brice seemed to go from a sick young man to a tech savvy expert. Brice mentioned an interest in the moon and German Second World War history, and this sparked Guy to sketch up a couple of images of the surface of the moon and soldiers in combat which he passed to the nurses to give to Brice. At the next visit, the nurses said that Brice hadn't stop talking about the drawings Guy had left him. The two drawings were carefully stuck on the wall so that Brice could see them from his bed.

These tentative stages of building relationality may seem to be an almost trivial aspect of an applied project. There's not much literature that reports on the informal conversations that occur between theatre facilitator and participants *before* a workshop starts. In the pilot, these essential, fragile dances were the only way to build 'relational solidarity' with the participants. Small gestures of listening, of respecting the space around the bedside, being reflexive to the moment-to-moment needs of the participants and offering small invitations to connect (the drawings) were derived from a framework of care.

These relational foundations were fundamental to establishing the ways in which the co-design and collaborative nature of the aesthetic work developed. Each of the participants led the pacing of the creative work, gaining confidence and ownership of the ideas over time.

The pilot demonstrated that the iterative co-design and realisation of the VR world experienced strong emotional responses, pleasure, and a sense of connection with the themes. For Daniella the project did not appeal to her as a way of experiencing fantasy, but as an opportunity to relive a memory. The VR world of the town included her blue chickens and guava fruit trees. Daniella had strong memories of her parents laughing with friends and of playing in the street with her friends where a popular game was throwing flip flops at stacked cans put at a distance – a location that was recreated in the VR world.

The response from the pilot demonstrated that when technology is integrated with a relational approach, the focus becomes the feelings the VR worlds generate, and not the mechanics of the medium itself. In all three worlds, the BMX park, the childhood village, and the moon landing the immersant was moved in a dream-like way, away from the everyday view of the hospital room to one that resonated more deeply. The participants reported a strong feeling of embodiment within the virtual environment, even with the absence of a representation of their body.

One of the unexpected elements of the pilot, was the joy of the participants in sharing and becoming tour guides of their world to family members and hospital staff. The simple device of rigging up a monitor so that people in the room could watch how the immersant navigated the space, created a natural audience, and socialised the experience of the VR world. The sheer pleasure that Harry derived from watching medical staff crash bikes, fall over, show their inadequacies in manipulating themselves in the VR world was invaluable. The sharing of the world served to invert the social power dynamic and elevated Harry to a high-status expert, while simultaneously demoting senior staff to hapless virtual amateurs.

The playful participation and witnessing of the VR worlds by others were an important aspect and extension of the relational aesthetics. The delicate intricacies of building trust with each of the participants, and the slow evolution into co-design and invention of the worlds, culminating in small sharing's with family members and staff. As Thompson (2015) highlights these forms of sharing create:

> The shape and feel of the relationships at the heart of the project are its aesthetics – whether presented in front of hundreds or in a small circle in a rehearsal room. In experiencing this type of care, the aim is to cultivate the understanding that regard for others is central to making the

world a better place – where remaining the bystander is an affront to shared feelings of mutual concern (47).

While limited to three participants, the pilot demonstrated the significance of the invisible infrastructures of care of project governance and institutional relationality, in providing a framework for managing and developing creative work with young people in hospital. The project deliberately resisted models of intervention, scalability, and replicability through a re-phrasing of the project as individualised and bespoke. The facets of care were the intimacy of nurturing, sharing, and collaborating on an idea. A world that was temporarily out of reach amid the beeps and squeaks of the hospital room.

The young participants' situations changed from day to day, and even from hour to hour. The pilot underlined the importance and willingness of the team to walk away if it was a 'bad day' and adapt their approach in response to an ever-changing situation contributed to the agency of the participants and their subsequent engagement. What was interesting to observe was the distinctively different approach needed for each participant, which contributed to the distinctive worlds created. In taking this responsive approach, the research team had to be fully engaged with participants, families, and community of carers. As with Brice's example, the first few meetings were consumed by relationship building and establishing trust, as much as introducing the project. The pilot also demonstrated that each participant viewed it as a serious personal project. Participants were observed moving from a state of seeming despondency at the beginning of a session to active engagement within a very short period. The creation of their virtual worlds appeared to have the effect of reinterpreting their lived status as an adolescent with a serious illness in a hospital, into that of a young person actively engaged in creating an alternative space into which they could immerse.

Next steps

In 2022 Future Stories was awarded a major Australian Research Council grant that will expand the pilot to work across three hospital sites in Australia. The full project will explore the affordances of cloud-based technologies, enabling young people in hospital to (securely) share their VR experiences, interact/chat with each other in the worlds, and play across different virtual domains.

Bibliography

All-Party Parliamentary Group on Arts, Health and Wellbeing. 2017. "Creative Health: The Arts for Health and Wellbeing." *Culture Health and Wellbeing Alliance.* Accessed June 2020. https://www.culturehealthandwellbeing.org.uk/appg-inquiry/.

Alrutz, M. 2013. "Sites of possibility: applied theatre and digital storytelling with youth." *Research in Drama Education: The Journal of Applied Theatre and Performance* 18 (1): 44-57.

Altay, N., E. Kilicarslan-Toruner, and Ç. Sari. 2017. "The effect of drawing and writing technique on the anxiety level of children undergoing cancer treatment." *European Journal of Oncology Nursing* 28: 1-6.

Anderson, M., D. Cameron, and P. Sutton. 2012. "Participation and creation in these brave new worlds: technology and innovation as part of the landscape." *Research in Drama Education: The Journal of Applied Theatre and Performance,* 17 (4): 469-476.

Anderson, M., J Carroll, and D. Cameron. 2009. *Drama Education with Digital Technology.* London: Bloomsbury Publishing.

Arora, G., and B. Pousman. 2015. *Clouds Over Sidre.* Within.

Astles, C. 2020. "Walk in/Walk as my Shoes: Puppetry and Prosocial Empathy in Healthcare." *Journal of Applied Arts & Health* 11 (1&2): 29–47.

Balfour, M. 2019. "The politics of care: Play, stillness, and social presence." In *The Routledge Companion to Theatre and Politics*, edited by Helena Grehan Peter Eckersall, 93-97. London: Routledge.

Barling, J.A, J. A. Stevens, and K. M. & Davies. 2014. "The reality of hospitalisation: Stories from family members of their hospital experience for adolescents and young adults living with and dying from cancer." *Contemporary Nurse* 46 (2): 150-160.

Bearison, David J., and L. Granowetter. 2012. *The Edge of Medicine: Stories of Dying Children and their Parents.* Oxford: Oxford University Press.

Berlant, L. 2011. "Austerity, Precarity, Awkwardness." November 21. https://supervalentthought.files.wordpress.com/2011/12/berlant-aaa-2011final.pdf.

Black, S. P. 2018. "The ethics and aesthetics of care." *Annual Review of Anthropology* 47: 79-95.

Boston Children's Hospital. n.d. *Patient Experience.* Accessed August 24, 2020. https://patientexperience.wbresearch.com/blog/boston-children-hospital-vr-strategy-for-kids.

Buch, E.D. 2015. "Anthropology of aging and care." *Annual Review of Anthropology* 44: 277-293.

Bužgová, Radka, and Lucie Sikorová. 2015. "Association Between Quality of Life, Demographic Characteristics, Physical Symptoms, and Unmet Needs in Inpatients Receiving End-of-Life Care: A Cross-sectional Study." *Journal of Hospice & Palliative Nursing* 17 (4): 325-332.

Carroll, J., and D. Cameron. 2009. "Drama, digital pre-text and social media." *RIDE: The Journal of Applied Theatre and Performance* 14 (2): 295-312.

Chan, E., M. Hovenden, E. Ramage, N. Ling, J. H. Pham, A. Rahim, and K. Jeyachanthiran. 2019. "Virtual reality for pediatric needle procedural pain: two randomized clinical trials." *The Journal of pediatrics,* 209: 160-167.

Das, D. A., K. A. Grimmer, A. L. Sparnon, S. E. McRae, and B. H. Thomas. 2005. "The efficacy of playing a virtual reality game in modulating pain for children with acute burn injuries: a randomized controlled trial [ISRCTN87413556]." *BMC pediatrics, 5(1)* 5 (1).

Davies, Betty, John B. Collins, Rose Steele, Karen Cook, Amy Brenner, and and Stephany Smith. 2005. "Children's perspectives of a pediatric hospice program." *Journal of Palliative Care* 4 (21): 252-261.

Davis, S. 2012. "Liveness, mediation and immediacy–innovative technology use in process and performance." *Research in Drama Education: The Journal of Applied Theatre and Performance* 17 (4): 501-516.

Deseille, P. 2008. *Orthodox Spirituality and the Philokalia. .* Kansas: Eight Day Press.

Dhiman, A., D. Solanki, A. Bhasin, A. Das, and U. Lahiri. 2018. "An intelligent, adaptive, performance-sensitive, and virtual reality-based gaming platform for the upper limb." *Computer Animation and Virtual Worlds, 29(2), e1800.* 29 (2).

Dunn, J., P. Bundy, and N. Woodrow. 2012. "Combining drama pedagogy with digital technologies to support the language learning needs of newly arrived refugee children: a classroom case study." *Research in Drama Education: The Journal of Applied Theatre and Performance* 17 (4): 477-499.

Gaab, E. M., G. R. Owens, and R. D. MacLeod. 2014. "Siblings caring for and about pediatric palliative care patients." *Journal of palliative medicine, 17(1), 62-67* 17 (1): 62-67.

Gallagher, K., C. Balt, N. Cardwell, and B. Charlebois. 2020. "Response to COVID-19–losing and finding one another in drama: personal geographies, digital spaces and new intimacies." *Research in Drama Education: The Journal of Applied Theatre and Performance* 25 (4): 638-644.

Gershon, J., E. Zimand, M. Pickering, B.O Rothbaum, and L. Hodges. 2004. "A pilot and feasibility study of virtual reality as a distraction for children with cancer." *Journal of American Academic Child Adolescent Psychiatry* 43 (10): 1243–1249.

Håkanson, Cecilia, and Joakim Öhlén. 2016. "Connectedness at the end of life among people admitted to inpatient palliative care." *American Journal of Hospice and Palliative Medicine* 33 (1): 47-54.

Hatton, N., J. Dunn, and M. Balfour. 2019. "Theatre, Dementia and Relationality." *Research in Drama Education: The Journal of Applied Theatre and Performance* 24 (1).

Hua, Y., R. Qiu, W.Y. Yao, Q. Zhang, and X. L. Chen. 2015. "The effect of virtual reality distraction on pain relief during dressing changes in children with chronic wounds on lower limbs." *Pain Management Nursing* 16 (5): 685-691.

Hubbuck, C. 2009. *Play for sick children: Play specialists in hospitals and beyond.* . London: Jessica Kingsley Publishers.

Kavas, Mustafa Volkan. 2018. "How to increase the quality of a suffering experience: lessons derived from the diary narratives of a dying adolescent girl ." *OMEGA-Journal of Death and Dying* 76 (3): 256-295.

Laurel, B., R. Strickland, and R. Tow. 1998. "Placeholder: Landscape and narrative in virtual environments." In *Digital illusion: entertaining the future with high technology*, edited by Clark Dodsworth, 181-208. Addison-Wesley Professional.

Laver, K. E., B. Lange, S. George, J. E. Deutsch, G. Saposnik, and M. Crotty. 2017. "Virtual reality for stroke rehabilitation." *Cochrane database of systematic reviews, (11).*

Maloney, E. 2021. "Working with propositional stories: digital storytelling as applied theatre praxis with newcomers in an urban middle school." *Research in Drama Education: The Journal of Applied Theatre and Performance* 1-15.

National Alliance Arts and Health Wellbeing. 2012. *Charter for Arts, Health and Wellbeing.* July. https://www.artshealthandwellbeing.org.uk/what-is-arts-in-health/charter-arts-health-wellbeing.

National Arts and Health Framework. 2016. September. https://www.arts.gov.au/national-arts-and-health-framework.

Nguyen, T. N., S. Nilsson, A. L. Hellström, and A. Bengtson. 2010. "Music therapy to reduce pain and anxiety in children with cancer undergoing lumbar puncture: a randomized clinical trial." *Journal of Pediatric Oncology Nursing.*

Nihei, K., K. Shirakawa, N. Isshiki, M. Hirose, H. Iwata, and N. Kobayashi. 1999. "Virtual reality in a children's hospital." *The Turkish journal of pediatrics* 41 Supplement: 73-82.

Nilsson, S., B. Finnström, E. Kokinsky, and K. Enskär. 2009. "The use of Virtual Reality for needle-related procedural pain and distress in children and adolescents in a paediatric oncology unit." *European Journal of Oncology Nursing* 13 (2): 102-109.

Norris, S., and J. Salverson. 2020. "Laughing and yelling in the trouble." In *The Applied Theatre Reader*, edited by Tim Prentki and Nicola Abraham. London: Routledge.

Queensland Children's Hospital. 2020. *Arts in Health.* Accessed August 4, 2020. https://www.childrens.health.qld.gov.au/qch/about-us/arts/arts-in-health/.

Rheingold, H. 1991. *Virtual reality: exploring the brave new technologies.* Simon & Schuster Adult Publishing Group.

Sanders, E.B.N., and P.J. Stappers. 2008. " Co-creation and the new landscapes of design." *Co-Design* 4 (1): 5-18.

Sextou, P. 2016. *Theatre for children in hospital: the gift of compassion.* Bristol: Intellect.

Sextou, P. 2021. "Theatre in paediatrics: can participatory performance mitigate educational, emotional and social consequences of missing out school during hospitalisation? ." *Research in Drama Education: The Journal of Applied Theatre and Performance, 1-* 1-18.

Sextou, P., and C. Monk. 2013. "Bedside theatre performance and its effects on hospitalised children's well-being." *Arts and Health* 5 (1): 81-88.

Sextou, P., and S. Hall. 2015. "Hospital theatre: Promoting child well-being in cardiac and cancer wards." *Applied Theatre Research* 3 (1): 67-84.

Shaughnessy, N. 2012. *Applying performance: Live art, socially engaged theatre and affective practice.* Palgrave Macmillan.

Smileyscope. 2020. *Smileyscope.* Accessed August 26, 2020. https://www.smileyscope.com/.

Sparapani, E. F., D. Callejo Perez, J. Gould, S. Hillman, and L. Clark. 2014. "A global curriculum? Understanding teaching and learning in the United States, Taiwan, India, and Mexico." *SAGE Open* 4 (2).

Sposito, G., A. L. Neri, and M. S. Yassuda. 2015. "Cognitive performance and engagement in physical, social and intellectual activities in older adults: The FIBRA study." *Dementia & Neuropsychologia* 9 (3): 270-278.

Standing Council on Health and the Meeting of Cultural Ministers. 2016. "National Arts and Health Framework." Accessed May 2020. https://www.arts.gov.au/national-arts-and-health-framework.

Stuart Fisher, A., and J. Thompson. 2020. *Performing care: New perspectives on socially engaged performance.* Manchester: Manchester UNiversity Press.

Sutton, P. 2012. "Shaping Networked Theatre: experience architectures, behaviours and creative pedagogies ." *Research in Drama Education: The Journal of Applied Theatre and Performance* 17 (4): 603-616.

Thompson, J. 2015. "Towards an aesthetics of care." *Research in Drama Education: The Journal of Applied Theatre and Performance,* 20 (4): 430-441.

Vakili, V., W. P. Brinkman, N. Morina, and M. A. Neerincx. 2014. "Characteristics of successful technological interventions in mental resilience training." *Journal of medical systems* 38 (9): 113.

Woodgate, R. L. 2008. "Feeling states: a new approach to understanding how children and adolescents with cancer experience symptoms." *Cancer Nursing* 31 (3): 229-238.

---

[i] Ethics approvals was approved by both Griffith University Ethics Committee and Queensland Children's Health. Future stories: investigating the potential of engaging children and their community of carers with virtual reality (VR) experiences in hospital contexts (GU Ref No: 2019/225). Children's Health Queensland (SSA/2019/QCHQ/54691).