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AGING, ART, AND CREATIVITY SYMPOSIUM



THE TRANSFORMATIVE POTENTIAL
OF ART IN ENHANCING THE LIVES OF OLDER ADULTS
18 September - University of the Sunshine Coast

AG
Australian
Association of
Gerontology



- ‘Patient Participation Engagement with arts-based research: Transcultural and transgenerational approaches’.
- Professor Persephone Sextou, Leeds Beckett University
- Ageing, Art, and Creativity Symposium
- University of Sunshine Coast, Australia.
- 18 September 2023.



- This talk aims to share my research about the **potential of applied theatre in paediatric healthcare settings.**



- The talk is guided by the belief that participatory theatre together with digital arts/tech apps is not only a form of entertainment and distraction, but also a powerful tool for education, improving the children's wellbeing during their hospitalisation.
- I will share my Arts-Based participatory Research (ABPR) methodologies with children, families, nurses, hospital teachers and play specialists.

- Co-design processes at the National Health System in England involve a collaborative approach to designing and developing healthcare services and interventions.
- This approach aims to empower patients and their families, by giving them a voice in the research process and allowing them to contribute to the development of healthcare services and interventions that are more patient centred.
- It also offers communities greater control over the research process and provides opportunities to learn and reflect from their experience.

- ABPR brings together children and young people's advisory groups, mental health services, healthcare professionals, families, and other stakeholders to work together in the design process.
- The objective is to ensure that ABPR is ethically and artistically created and produced to meet the needs, preferences, and abilities of specific groups of patients who will use it in healthcare services.

ABPR values in paediatrics

- Ownership
- Agency
- Audience/child participation with the artist
- Audience/child interaction with digital apps
- Subtle forms of engagement with technology

- Can audience participation in theatrical activities inform user interaction in virtual immersive worlds?
- Can digital technology become a valuable tool in the development of bedside theatre performance in a healthcare setting?

Applied theatre model in Paediatrics

- A form of engagement, entertainment, escapism, normalisation of the hospital experience and education.
- A powerful tool for social wellbeing for children in hospitals and older people in care homes.
- A Co-design, Patient Participation and Engagement process
- A collaborative approach to designing and developing more humane patient/resident-centred health and social care services.
- An empowerment of patients and families giving them a voice in the research process.

Arts-based methodologies in Paediatrics

- Applied theatre principles and practice
- Qualitative methods: interviews, diaries, creative writing, poetry, drawings, video analysis
- Quantitative methods: questionnaires, surveys, clinical data
- Co-design NIHR and NHS guidelines
- Public Participation & Engagement (PPE)
- Patient Participation & Involvement (PPI)
- Co-design and consultation (CAMHS-child & adolescents mental health services, schools)

Co-Design

Patient Participation Involvement & Engagement

- Patients and families
- Healthcare professionals such as nurses
- The arts & Health committees in hospitals
- Hospital teachers
- play specialists
- Creative therapists
- Youth Groups (x- NHS service users)
- Children & Adolescents' Mental Health Services (CAMHS)
- City Council creatives
- School staff
- staff and residents
- University staff and students
- Online group consultation, Practice-based arts Workshops, Feedback forms

Data collection

- Research ethical approvals are obtained by academic institutions, NHS REC and Hospital sites' R&Ds
- Children inpatients. Wards: nephrology, dialysis, oncology, paediatric surgery, cardiac, neurosurgery, burns centre, general paediatrics, complex care, PICU
- Artists
- Hospital teachers
- Families and carers.
- Researchers collect data with assistance from hospital teachers and nurses. We usually take opportunistic samples from those children on the wards which are available to hospital staff on the days that they are working on the wards. Consents are collected on the day.

Hospitalised children's stories in applied theatre

Aiming to contextualise applied theatre in paediatrics, I discuss

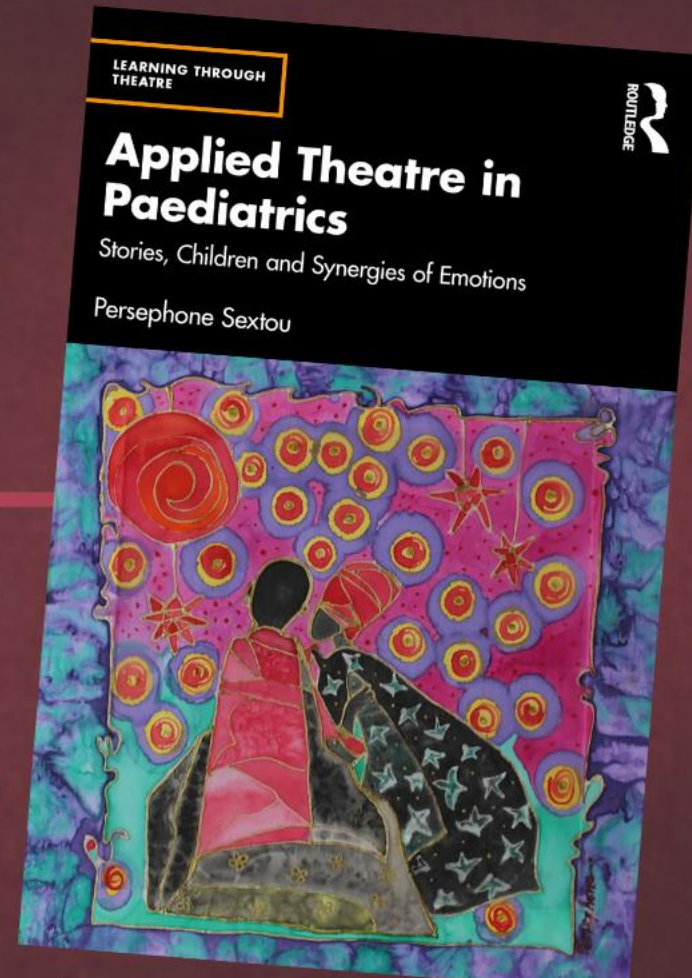
- the synergistic nature of audience participation in bedside performance to argue that the exchange of strength or weakness, power or vulnerability, control or obedience relates to the actor-child relationship.
- how stories between reality and fictionality provide a safe and positive environment for a reassuring experience.
- the actor's reactivity to the child-patient as a participant in performance rather than as a patient.
- the importance of evaluation as an act of caring for these audiences.

 Routledge
Taylor & Francis Group

Applied Theatre in Paediatrics

Stories, Children and Synergies of Emotions

This book explores applied theatre practice for children in environments of illness and cure and how it can powerfully normalise children's hospitalisation experience.



Applied performance, puppetry and hospital tuition

- This chapter explores the benefits of “Bird Island”, an applied theatre project that aimed to improve children’s engagement with tuition in paediatrics by using stories and puppets.
- The focus of the chapter is not on performance as a primary tool for schoolwork but instead as an artistic product with inherent opportunities for expansion in education that the teachers could benefit from.
- The chapter will conclude with my reflections on the use of puppetry in participatory performance in paediatrics and its limitations and possibilities in clinical settings.



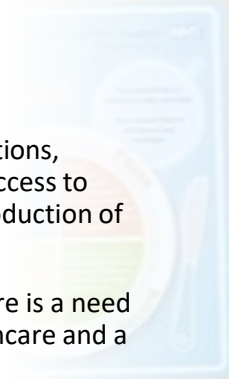
Caring enough is never enough: Training actors on emotional skills

- What does it mean to work as an actor in a professional environment dominated by illness?
- How does the actor feel when they are exposed to images of illness, pain and death?
- I will argue for the need to raise awareness of the value of
- the demand for training the artist on professional skills and emotional competencies to perform in clinical settings. I have written this chapter hoping that the actor's perspective becomes meaningful in the clinical setting.



The Future: questions and recommendations

- I raise some logical questions for arts organisations, healthcare providers, and researchers about access to technology, power and knowledge and the production of applied theatre work in paediatrics.
- I conclude the chapter with a critical view; there is a need for change in the provision of the arts in healthcare and a need for action to ensure a sustainable future.
- Recommendations for actions by artists, healthcare providers, governments, and local authorities are offered to argue for a more balanced healthcare system that will provide opportunities for the arts to play an instrumental part in healthcare during children's treatment and recovery.
- The arts are rich and powerful and deserve an equal place rather than playing the 'poor relative' role in healthcare.



Rocket-Arts project

- 'Rocket-Arts' aimed to make a difference in children patients' social and emotional wellbeing and improve their engagement with creative activities and education during their treatment.
- Institution: Newman University Birmingham, CADLAB @PSextou
- Site: Birmingham Children's Hospital, England (NHS Trust)
- Grants: BBC Children in Need, The Lottery Community Fund



Rocket-Arts project

- ▶ Inspired by Simba, our family cocker spaniel, I wrote a story about Simba, the therapy dog, who travels to space in his fancy spacesuit and lands on a rocky planet far away from the Earth. There he discovers a space cave with a lake. The water is crystal clear and red roses grow on the rocks. Simba meets the cave dragon, a friendly creature with carrots for ears, a garlic for a nose and an egg plant for a tail. Together they have adventures swimming, diving and having fun.
- ▶ It is a story of escapism and friendship.
- ▶ Experimentation with a digital programme for making an animation cartoon film online
- ▶ Six interactive worksheets- literacy exercises
- ▶ Hospital teachers' i-pads – children watched the film and worked on the learning resources online with support from their teachers at the James Brindley Academy, Birmingham Children's Hospital.
- ▶ The training of the teachers on how to use the film and the worksheets took place on zoom during COVID-19.



Rocket-Arts goes digital during the Covid-19 lockdowns

► We used VFX Compositing to combine images of toy tableaux with background images to make the appearance of a single picture. The composite process was done on-set and in-camera.

Concept, story, scenario, images, production:
@Psextou2020

Shot design, VFX compositing, editing: Yi Ann
Kok



A Rocket-Arts Story film

- We set up tableaux with the same space rocket and playmobil toys that we used on the wards. We took pictures of the tableaux scene-by-scene to create a storyline for the film.



'Here I am Flying!'

A TOY-BASED EDUCATIONAL FILM FOR CHILDREN WHO ARE ADMITTED TO HOSPITAL FOR HAVING A SCAN.

[HTTPS://WWW.YOUTUBE.COM/WATCH?V=AZF6HLI0R2W&t=35](https://www.youtube.com/watch?v=AZF6HLI0R2W&t=35)



Funded by BBC CiN and
National Lottery Awards for
All



@Perspehone Sextou 2021

STORIES told by Children in Paediatrics

- Stories are original creations of verbal improvisation with puppets, playmobile toys and objects as well as creations of responding to animation films and online activities.
- Children recalled their experiences as characters of the story, reimagined the setting and events to create their own stories in synergy with storytellers, and hospital tutors. Thus, each story expresses unique moments of unrehearsed audience participation.
- Stories articulate children's voices, personas, expressions, style and feelings of those children through fiction.
- No story is based on commercial films and storybooks. No story is repeated or retold. They are all original, created spontaneously in the moment.
- Stories aid to understanding the language of children's pain for a better assessment and management of pain by healthcare professionals through the Arts.

Stories of illness and escapism

Introduction to stories

Jane: The piano is on fire

Sheila: A moon made of cheese

Paul: The naughty wolf

Alex: My grandfather's wellies

Sandy: We need the pancakes

Claire: Silence

Karim: No!

Lisa: A robot who could not dance

Melissa: The Planetary

Margaret: A park for the animals

- These are Stories stitched on a land between reality and fiction. Each story is followed by a critical discussion about the synergies between the artist and the child, the child and the teacher, the medium and the participant.

Melissa's story

The astronaut looked out of the window of his spaceship to see the Moon had changed colour. It was black. 'That's strange!' He got off the spaceship to look at himself and see what was happening. The sky was empty of stars. he did not know what to do. He went back to his spaceship to call Andy, his friend on Earth and tell him about the Moon changing colour. ANDY said that the Moon changes colours when it changes moods. The astronaut looked at the Moon again. The Moon was a black hole because there were no stars. He had an idea. He makes paper stars, paints them yellow, and makes them float; the sky is full of them. The Moon turned from black to yellow. But the stars ran out of float and fell off the sky. The sky is empty. The Moon realised the stars were fake and turned from yellow to red. The astronaut was waiting to see if the Moon would change colour. Why is the sky empty? Where did the real stars go? Will they come back? The real stars appeared. They only went to bed because it was morning. The astronaut got into his spaceship to fly back to Earth. The moon is like a giant lightbulb."

Reference: Sextou (2023), p. 47-38.

Allan's story

▶ Once upon a time there was a pair of wellies in a village shop. They were waiting for someone to buy them. One day an old man went into the shop. He pointed to the wellies and said, "Ah I like these!" It was autumn, the sun was shining, and it was beautiful. He lived close to the park. There was a lake there. He put on his boots, took his basket and polls and went off to the park. Wellies were happy. The wellies were fishing buddies with the old man. One day the man fell from a cliff and couldn't walk. His foot was swollen. Could be broken. "Ah just what I needed" he said between his teeth. He called for help and his brother came and carried him home. He couldn't walk and did not go fishing that day. His boots were sad. The next day the old man was not well. He stayed in bed. The doctor visited him and gave him orders "Stay at home!" His wellies were sad again.

▶ One day the man died. It was winter. So, his boots got angry and walked away. "We can go anywhere" they said. They walked on the road and went to the park and jumped in the snow. They got all muddy! They returned home to dry off. The house was quiet. "Stupid man. Why did you die?"

▶ Reference: Sextou (2023), p. 39.

Applied theatre model in paediatrics

findings

- normalise children's hospitalisation experience (improved communication with clinical staff, distraction from pain, improvement of mood, better sleep, give them something to discuss with families, improved co-operation with taking medication)
- engagement with hospital tuition helping with transition back to school)
- offer children opportunities to communicate emotions to family and healthcare professionals for a further understanding of children's experience
- give children the language of pain to express how they feel towards a better assessment of children's physical and emotional state
- reframe a difficult experience in hospital from a new perspective.

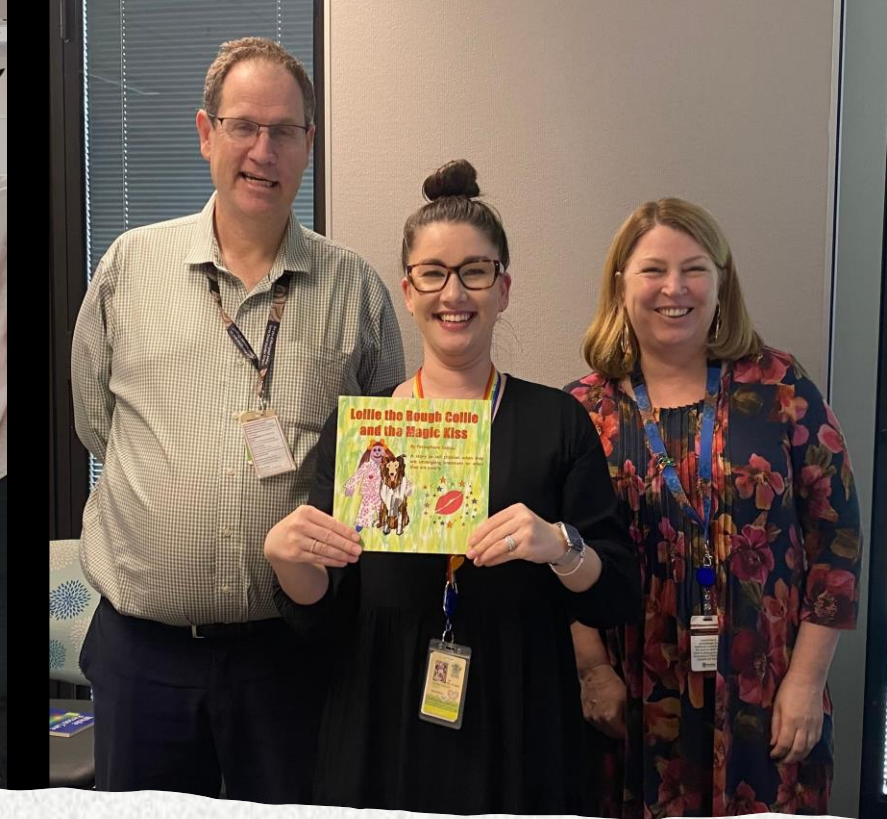
Some thoughts for the future

The dilemma this work addresses is not arts' purpose in health, but creativity's 'centrality' to the overall experience of the arts during hospitalization when vulnerable children need to be listened to, respected and supported.

Constant gov funded provision of the arts in child healthcare

Use of the applied theatre values of active participation to improve

- child experience of perioperative anxiety
- Child and family education of hospital procedures
- assessment and management of pain in child healthcare
- awareness of children's rights amongst clinicians



- At Queensland Children's Hospital leading a workshop on Applied Theater in Pediatrics
- With
- Dr Anthony Herbert and his team at Palliative Care
- Researchers from Griffith University, Queensland University of Technology
- Healthcare professionals, artists and the Starlight Team at QCH

picture @PSextou



- At Queensland Children's Hospital participating in the 'Future Stories' VR demonstration to the Physio Hospital Team

picture @PSextou



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