

SUPPORTING PATIENTS LIVING WITH DEMENTIA DURING A PANDEMIC

Digital Theatre and Educational Spaces

Education Studies

Collection Editor

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Dr Nicola Abraham and Ma. Victoria Ruddock SUPPORTING PATIENTS LIVING WITH DEMENTIA DURING A PANDEMIC Digital Theatre and Educational Spaces

The Education Studies Collection

Collection Editor Dr Janise Hurtig



For the students, patients and NHS staff who have worked with us on this journey and the friends and family who have supported us, we would like to say a huge thank you for your creativity, playfulness and collaboration.

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Abstract

This book tells the story of how digital applied theatre was adapted to support patients living with dementia across hospitals in a pandemic. The challenges, successes and opportunities that this unusual project, Innovating Knowledge Exchange (IKE), created are shared in this book that acts as a guide to person-centred online practice that can be applied to care home, assistive living and hospital contexts. The narratives of the book share insights into horizontal team structures as ways of supporting students learning this evolving practice that adapted to COVID-19 restrictions and in doing so opened up a whole new world of possibilities for creative practice to support the wellbeing of older adult patients in acute hospital contexts. We hope you find the journey of the evolution of this new type of practice as useful and exciting to read as we have to live, dream and advance.

Keywords

Dementia; healthcare; higher education; applied theatre; practical experience; stories; students; virtual learning; pedagogy; education studies.

Notes on contributors

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Learning objectives

This book addresses the following five learning objectives. The aim is to enable readers to step into the shoes of the practitioners who have worked with us, across disciplines, in order to learn about dementia and applied theatre in care contexts.

Objective one

• To engage readers in a journey of discovery through vignettes of project experiences to help support understanding about the ways in which facilitators can work responsively online in acute hospital settings with patients living with dementia.

Objective two

• To offer insights into best practice working digitally within arts and health hospital contexts.

Objective three

• To provide suggested assignments to support students' learning and development as community arts and health practitioners creating practice to improve wellbeing.

Objective four

• To develop readers' understanding of the importance of reciprocity in digital applied theatre projects to avoid extractive ways of working that aren't as dementia-friendly as they could be.

Objective five

• To think about how we navigate social identities in digital spaces to build connections through creativity.

Introduction

We begin our tale in the middle of a global pandemic. We locate our story in acute hospitals within Medicine for the Elderly wards in London, UK, working with people living with dementia through digital applied theatre projects. We have two main characters in this tale: Vic, a Healthcare Assistant in the Dementia Care Team, and Nicky, a senior lecturer in applied theatre practices. This may sound like an odd pairing to you, but for us the projects we discuss and the journey we share in this book are the culmination of five years of collaborative projects between applied theatre practitioners and a Dementia Care Team who work within a National Health Service (NHS) Trust in the United Kingdom. With funding from Research England and the Office for Students, we were able to more than quadruple the number of projects we offered to creatively engage with patients living with dementia in hospital wards.

The pandemic and lockdown hit in March 2020, which could have thrown our plans to upscale our in-person work into disarray. However, as a partnership, we are dedicated to innovation; our one rule for working together is to "say yes" to ideas and discover ways to make our ideas a reality. We decided to continue with our plans despite the pandemic for this reason, and for the added reason that the urgent need to support patients living with dementia only increased in the pandemic. This is because of the change in rules in hospitals and care homes that meant visitors were no longer allowed to see their relatives in person. The impact of COVID-19 and long hospital stays has been detrimental for the wellbeing of patients and care home residents across the board, but particularly for people living with dementia. The projects we will discuss in this book are the result of collaborations between clinical specialist nurses and applied theatre practitioners working and studying in a drama school. Each project locates the patients who take part as artists at the heart of the work. There are six main projects that we make reference to as case study examples of practice in action. The projects are summarised below for context.

Auchi Street

 This is a collaborative film-making project that is facilitated with patients living with dementia and/or undergoing dialysis. The project creates a collective fictional narrative, which patients then help to script, cast, direct or perform. The project team of applied theatre practitioners then film and edit the piece to premiere on the ward for patients, staff, family and friends.

Wonder VR

 This is a project that usually happens one-to-one through a workshop that engages patients in creative tasks that explore places they like or would like to see. The stories are transformed into VR360 video experiences that students film and edit to present back to patients, in order to bring to life their stories as an immersive experience. This can help to transport a patient to a place they miss, would like to see or have invented.

Life in Lyrics

• This is a song-writing project that works one-to-one with patients living with dementia to engage in experiences of

music. The project is about sharing our love of music, singing along to our favourite songs, thinking about how we feel about music and forming ideas for an original song that is then co-written with patients, recorded and transferred to CD.

Hear Me Out

 This is a podcasting project that connects family, friends and patients in hospital. It is a storytelling project that shares recollections, current thinking and future dreams and often involves recordings from siblings and children. Recordings are then edited into one podcast that all parties can listen to, to hear one another's voices as a form of celebration of life stories and as a comfort when families are unable to be together because of the pandemic.

Intergen

 This is an intergenerational project that connects school children with patients living with dementia. The project has many models depending on the collaborative partners at the time and has involved collaborative storytelling, solving mysteries together and sharing stories of inspiration between patients and children/young people.

Your Story Your Way

 This project asks participants to think about stories that communicate an aspiration or cherished experience, explored through a creative workshop. The participants can then ask for their story to be represented in any way they wish. For example, we have had requests for audiobooks, animations, puppets, paintings, radio shows, music videos, poems and performances, to name but a few.

Digital applied theatre

The term "digital applied theatre practice" underpins our values, ethics and the creative approach to all of our projects. So what exactly do we mean by this phrase? Applied theatre is an umbrella term that has been used to describe a set of practices that have similar traits. For example, often practices under this umbrella are focused around making theatre with, by and for communities (Prentki and Preston, 2009). Applied theatre practices are also concerned with participation, socio-political contexts, responsive cultural practice, development, challenging oppression and advocating for social changes; applied theatre means to use theatre as a tool to address these themes. The practices under the umbrella of applied theatre take place in a range of contexts including schools, prisons, hospitals, care homes, refugee centres, detention centres, community centres and on the streets. Practices working with communities are sensitive to cultural differences and seek to understand the interests, circumstances and context of the communities that they engage with to avoid neo-colonial models of practice that assume superiority of Western values and middle-class sentiments. Being open and responsive are core gualities inherent in applied theatre practices, and guestioning the ethics of different approaches is the subject of much debate and ongoing critical thinking to help advance the field to continue being politically aware and engaged and to model best practice (Kerr, 2009). Applied theatre practice is responsive to the needs of the community and not only requires practitioners in this field to be artists leading participants as co-artists, but also seeks to be supportive of participants as a community. Kay Hepplewhite (2021) offers a useful summary of responsivity in applied theatre practice.

Responsivity foregrounds the participants as an ethical proposition. The practitioner operates at their most *responsive* when they are aware of the participants' experiences and how they can enable potential outcomes. However, the practitioners' own *response* and being open to development is also a key component of their expertise; they share a focus on impact and change.

(2021:4)

Hepplewhite's discussion of responsivity in applied theatre also brings to light how important it is for applied theatre practitioners to be open and adaptable to the needs and context of the community they are working with. This is a key priority for our practice with patients living with dementia to ensure that we offer person-centred practice that locates the participant as artist at the heart of our work. The second point that Hepplewhite raises concerns the priorities of applied theatre practitioners, which are often bound by funding agendas that prioritise a focus on the economic and social benefit of applied theatre in different contexts (see social prescription, Calderón-Larrañaga et al., 2021). This can be a competing demand when trying to locate the value in applied theatre practice because we also have to balance the impact that participants themselves locate in the projects that they take part in, and these can clash with or not register on funding impact assessment indicators.

A further issue within the field that warrants discussion is the focus on change as a measure of worth. Kelly Freebody et al. (2018:6) detail the challenges of understanding what constitutes, and what is meant by, change in applied theatre, placing caution

on practices that "see the world through its problems worth fixing". This framing raises questions about whether practitioners approaching applied theatre are seeing their participants "from a deficit perspective" (2018: 6) and seeing communities as a problem to fix. This is arguably the very neo-colonial power imbalance we want to avoid in applied theatre practice. For this reason, it's certainly a perspective that we do not follow in our projects, because we want to *challenge* stigma and prejudiced perceptions of people living with dementia rather than feeding into that stigma. In our practice, we start from a position of viewing the participant as an artist, and we agree that it is part of the creative process to find the most accessible and inclusive routes to working with each individual to celebrate identity and value the ideas that we have the privilege of learning from our participants.

Finding ways for applied theatre practice to support people living with dementia is important. Sheila McCormick (2017) discusses the role of the arts as an alternative model of intervention that can support people living with dementia by offering cognitive stimulation, social interaction and communication to improve quality of life. McCormick argues that creative arts offer an opportunity for positive connection for people living with dementia and practitioners.

Looking to creative approaches to meeting the needs of people with dementia has helped to support people to continue to live well in their community through fostering connections and meeting the needs of individuals through the arts at what can be a challenging time for anyone affected by dementia.

(2017: 227)

In this reading of the impact of arts for people living with dementia it is clear that there is a need for meaningful activities which embody the qualities of responsive practice and are adaptable and enjoyable for participants. In adapting our practice for the pandemic, it was important that our model of applied theatre practice maintained the same values that we had in-person within our new digital practice. Practically speaking, this looks like applied theatre workshops in song-writing, film-making, storytelling and podcasting that have been facilitated partly over Zoom by student practitioners and supported by specialists in dementia and navigating clinical environments and a specialist in applied theatre and technology. For us, digital tools have opened up a new type of practice in applied theatre, one that patients have experienced as less invasive than in-person work. They have also allowed us to transcend the limits of social restrictions to connect with care homes, schools and hospitals around London safely at a time when the need for creative engagement and social interaction has increased. This book charts what we have learnt from the process of translating applied theatre practice in person to an online digital practice that continues to embody the values of person-centred practice.

Sharing stories

In this book, we have placed a strong emphasis on honesty and transparency as a way to articulate and share our learning by drawing upon our own experience. You will see our names in brackets when we change authorial voice to signal whose story you are hearing at different points in the text, like this: **[Vic]** or

[Nicky] or **[Both]**. Experience and personal narrative are woven into the fabric of each chapter, and we invite readers to reflect and add their own stories to the tapestry of stories that we have offered.

Both of us value learning from, with and within our teams of students, and from and with our participants. To do this, we need to understand one another's positions and reasons for taking part in the field. In the next section, we offer a first glimpse of our practice of sharing by charting our personal journeys and interests in working in the arts and health as an evolving field of practice.

Vic's story

[Vic] Since I was little, I knew I was different from other kids my age. I used to love to sing and dance; I started singing when I was three years old, and my dad encouraged me to pursue this interest. I learnt to sing even before I learnt to read; my Dad used to dictate the lyrics of my favourite songs to me, and I learnt them by heart before recording them on a multiplex cassette tape with my sister. We would then send the cassette tape to my mum, who was working overseas as a charge nurse in a dialysis unit. These tapes were my musical letters to my mum, to let her know that I loved her, and I thoroughly enjoyed the process of learning and making her these gifts, knowing the joy they would bring her. I started singing as a member of our community choir a few years later. As a child, I preferred spending time with older adults in my family rather than playing with other children my age. I remember always feeling fascinated listening to the conversations between my grandparents and enjoyed looking

at their facial expressions while they were talking with each other – they were always animated storytellers and I enjoyed and have taken on these traits myself.

I should also mention that I grew up with my grandparents, so they were very close to me, especially my nan, who passed away with dementia. Because of her, I was inspired to work with older adults, especially people living with dementia. It was partly as a tribute to my nan, but also to make sure people living with dementia feel valued and heard – both important things for good quality of life. My devotion and passion were amplified further when I started my nursing degree for my bachelor of science in the Philippines, where I was born.

I have always seen a synergy between arts and health, and I continued to find ways to pursue both interests while I was at college. For example, while I was training to be a nurse, I was also a member of a university-based theatre company called "Tiatro", which means "theatre". In Tiatro, I was the assistant choreographer and a singer who, on behalf of my college, represented the school at local competitions. I also taught other members of the theatre group dance choreography that was a combination of street dance and modern dance. I really enjoyed the feeling that you get when you perform, and the excitement of creating something from scratch. Learning about performance at the same time as studying nursing, I could see a natural connection evolving between both fields, particularly in the way that the arts could be used to improve wellbeing.

As a result of this life experience during my college years, I developed a strong interest in the purpose of the arts in clinical settings. I always asked myself, *how am I going to incorporate arts*

into healthcare now I can see the potential of the arts to improve wellbeing? I wasn't expecting that this opportunity would arise during my career in the National Health Service (NHS). Before I worked with Nicky and for the Dementia Care Team, I worked in Medicine for the Elderly wards in London, UK, and tried my best to bring the arts into my practice. For example, while my patients were eating their breakfast, I sang to them, and they greatly appreciated and enjoyed this experience. I would even take requests, asking patients for song preferences and ideas!

What also touched my heart is that even though the patients were very poorly and in pain, when they heard music, their facial expressions changed, and they enjoyed singing along with me. Even though sometimes we'd be singing our own versions of the songs, it didn't matter; what mattered was that they appreciated what I did for them. That inspired me to continue to sing for my patients every day during breakfast time. I hadn't realised that someone had witnessed what I'd done to make patients' experience better in hospitals, but I soon found that my line manager at the time was amazed by the impact of this gesture of creative kindness. My approach was also acknowledged by broader patient specialist teams in the Trust, which encouraged me further to use my imagination, passion and creativity to improve patient care.

In July 2021, Imperial launched a gratitude festival for NHS staff and one of the events was *Imperial's Got Talent*, calling upon staff across the Trust to submit acts to be judged by leaders in Imperial. Our act was a collaborative song called *Have a Little Faith* (Abraham, 2021a), which was performed by staff from a Medicine for the Elderly ward in addition to staff from the dementia care team. I sang the lead vocal, and Nicky and her dad wrote the music and lyrics. Little did we know that our submission would reach the grand final, where it was judged by Elton John and David Furnish and awarded first place. This recognition meant a lot to the staff, and allowed us to celebrate the collective artistic talents of NHS staff. The competition represented yet another way to integrate the arts into healthcare.

I was excited to be given the opportunity to work on the Innovating Knowledge Exchange (IKE) project with Nicky, which is a digital applied theatre project in acute hospital settings, because I hadn't realised arts and health could be connected in so many ways. The impact of this combination is significant for patient wellbeing through positive creative engagement. This type of cognitively stimulating interaction helps patients to feel more alert, more positive and more valued during their stay.

You would also be shocked to learn how many patients are also artists and share a passion for creativity. It always amazes me how having a patient who holds the same passion as you makes work in the hospital easier, because of the innate connection that naturally evolves. With this connection, you build rapport with one another and build trust in the process. Part of my work embodies person-centred practice, which happens in creative exchanges. Working with creative collaborative partnerships to offer bespoke, engaging workshops makes a significant difference to the lives of our patients while they are in hospital or in care homes. I have learnt that by incorporating my artistic knowledge with my medical knowledge in my own way, I can inspire others and improve the wellbeing and experience of the people in hospital who I have the privilege of working with. My advice to those interested in arts and health is to embrace your imagination, share your talents, apply them to different contexts and to not be afraid to try, offer, revise and advance your practice – that's how you change the world.

My focal point of inspiration is my patients and a simple thank you from them means a lot to me and inspires me to push myself to do more for them. This is why I am paying this lesson forward to you in the hope that you will continue to inspire others. I would like to task you with passing forward your passion and talents too. It just goes to show that what you do can make a difference.

Nicky's story

[Nicky] My journey into arts and health started with a situation I faced in my teenage years that inspired me to understand how theatre could make a difference to the lives of communities. It began when I was around 13 years old; my parents had divorced, and at that point this wasn't really heard of in my community. There were some "friends" who turned their backs on me, and others who just didn't know what to say. For respite, I would go to a youth club in my hometown. It had a tuck shop, a sports hall and a small theatre space with a stage and a wooden DJ box. The theatre was often occupied by the kids I was a bit scared of; they were popular and had a reputation of "don't mess with me". I would spend time with a close group of friends playing basketball and talking to the lady who ran the tuck shop. She must have been in her mid-eighties, and she loved children. She always made us feel welcome and liked to sit and chat to us about life, ambitions, and our interests. We adored this lady, and she was a big part of our experience in the youth centre – and, clearly, interacting with children and young people held equal value for her. Then one day we came in and the youth leader who was in charge sat us down and said they were losing funding and would have to close. This was devastating news to all of us, and I remember thinking: I really can't lose this place, rough around the edges though it is, it's too important, because it's just ours for this time once a week and it makes all the difference.

Igathered my friends, who were all worried too, and said what can we do, and what do we have? I had a slightly scratched karaoke CD in my bag, and they had ideas for a script that could unite the songs. We sketched out a plan but needed to use the theatre, so we had to be brave and talk to the kids who owned that space to seek their help – not something I was looking forward to then. I remember taking a deep breath, walking into the hall, my friends in a line close behind me, looking a little terrified about what we were about to do. I was told to leave the second I entered the room, but I held firm, heart pounding in my chest, and explained in brief what was going to happen to the youth club and that we had a plan to raise money to save it. After ducking a few flying shoes that were poorly aimed at my head, the group dispersed and, to our amazement, many people stayed to help us.

It was certainly not an easy process; there were walk-outs, strops, tantrums and disagreements. But there was also a lot of laughter, new friendships and a strong unified need to make this plan a success. After a month of rehearsing at school, and in the youth club, we'd devised a one-hour show complete with post-show karaoke and invited everyone we knew. I remember waiting behind the dusty stage curtains and being so nervous I thought I might be sick, but fortunately I wasn't! We all had everything crossed in the hope people would actually show up. Walking on stage to start, I wanted to cry; the auditorium was packed full of people – familiar faces, new faces, teachers, friends, relatives, neighbours, community members we'd never met and local press had come to cover the show and support us. We did our best, and though I'm sure it wasn't anywhere near the quality of a professional show, it got a lot of laughs, and people sang along, and we raised hundreds of pounds and saved the youth club.

I remember thinking at that time how much better and stronger I felt being with a community, albeit a dysfunctional one at times, to achieve something together. That feeling still stays with me every time I start a new academic year with my students. I decided, after that show, to spend my life understanding how we got past our differences and fought for what we believed in, and how we could give that feeling to other people. I hope my students will benefit from what I have understood and do the same for their communities in their practices.

The opportunity to work with older adults in a clinical context arrived in 2016. I'd achieved my PhD researching impact and change in applied theatre for young people, and was in my second year as a lecturer in applied theatre practices. A rogue email meant for someone else arrived for me from our reception team, who thought I may be able to help. A hospital in London had sent an e-mail asking if drama schools could offer some theatre to put on for patients in Medicine for the Elderly wards. I was intrigued by this idea and thought of my work with people living with dementia from previous projects, and community activist groups run by older adults, and how much I learnt and

loved working with both groups. I replied straight away and met with a consultant nurse in dementia and delirium from the Dementia Care Team and her colleague, a healthcare support worker from the same NHS trust. I explained in that first meeting that we could of course create theatre for patients but wondered how they felt about making theatre with patients, explaining that applied theatre locates participants at the heart of the practice. We devised our first project, working in two-week cycles to deliver inperson workshops in day rooms on wards for patients living with dementia. This happened through a series of workshops, held over two weeks and culminated in a participatory performance devised with patients, which repeated three times. Following the success of this project, we were then challenged by Jo and her team to create an interactive project for older adults undergoing dialysis treatment and created Auchi Street - a collaborative filmmaking project, working bed-to-bed and involving patients in the creation of everything from narrative to casting, scripting and set design.

At the same time as this project, I developed an interest in learning how to make VR360 films as immersive experiences, and proposed to Jo an idea for a project called Wonder VR to offer patients in long-term hospital care a way to see the places they missed. We have created over 40 films now for patients. This project became the most popular one we offered during the pandemic, with people staying longer in hospital when they caught COVID, and missing places that were part of their daily routine. The more projects we created, the more we realised that there were increased opportunities and possibilities, and a need for more interventions on a more regular basis. A charity we worked with, attached to the trust, created a fellowship project that enabled us to extend our work further. This idea had a junior doctor taking charge of an intergenerational project, which she asked me to help deliver. We offered training workshops in dementia and communication through drama in schools and sessions for patients and children; this combined my previous and my current research and ignited a strong desire in me to recreate the connections I felt with the lady in the tuck shop all those years ago for the young people I was encountering. I knew both age groups could bring joy to each other, so I was delighted to bring my students to join me in facilitating a range of workshops over two years for the Intergen project.

In December 2019, there was an opportunity to apply for a joint bid for Knowledge Exchange funding from Research England and the Office for Students, which would enable us to deliver projects all year round to all wards in the trust. This would also enable us to upscale our training for students by the dementia care team and I, by both sharing our experience and guiding them through live practice on various projects. We weren't deterred by the pandemic, having already had to make 15 collaborative projects happen in digital form for our second-year students when lockdown hit the UK in the spring and summer terms of 2020. We took a leap of faith and from this we learnt to adapt, and continued to grow our work online, with students joining and learning via Zoom, while Vic and I, alongside other members of the Dementia Care Team, supported patients in person. We engaged students in developing more projects with us, including a project on music called Life in Lyrics, a podcast called Hear Me Out and a project celebrating patient stories called Your Story

Your Way. When the opportunity came to share our knowledge of online practice and versions of our work, we jumped at the chance to write down and share what we have learnt over the past two years with you, in the hope that you will support older adults living with dementia and see the urgency of practice in this field online. We are fortunate to have safe online practice available to us; a decade ago, I think we would have struggled to support older adults, and now we have learnt that online practice is both less invasive and more creative and playful as a COVID-safe way to continue offering meaningful interactions for patients and residents living with dementia.

What will your story be?

We're excited to take you on this journey of discovery with us. We hope that you seek opportunities to collaborate and offer your skills, artistry, care and support for partnerships with other educational and healthcare contexts, and that our guidance is useful. We also advise you to always seek guidance from experts you are working with and to follow their rules, regulations, precautions and advice at all times. This has been vital for our practice. We also know that advice and guidance changes as research develops and grows, so we advise you to keep up to date with training and learning in this field, and to work with expert partners to ensure you offer best practice. This book maps the things we have learnt that we hope you find useful, but what we did is just one path and way of working. What follows enabled us to deliver bespoke creative practice for people living with dementia during a global pandemic; we hope it helps you as you develop your own stories.