

Narratives of health and illness: Arts-based research capturing the lived experience of dementia

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Abstract

Introduction: This paper presents three artists' residencies in a geriatric medicine unit in a teaching hospital. The aim of the residencies was creation of new work of high artistic quality reflecting the lived experience of the person with dementia and greater understanding of service user experience of living with dementia. This paper also explores arts-based research methodologies in a medical setting.

Method: Arts-based research and narrative enquiry were the method used in this study. Artists had extensive access to service users with dementia, family carers and clinical team. Projects were created through collaboration between clinical staff, arts and health director, artist, patients and family carers. Each performance was accompanied by a public seminar discussing dementia. Evaluations were undertaken following each residency. The process of creating artistic responses to dementia is outlined, presented and discussed.

Results: The artworks were well received with repeat performances and exhibitions requested. Evaluations of each residency indicated increased understanding of dementia. The narratives within the artworks aided learning about dementia. The results are a new chamber music composition, a series of visual artworks created collaboratively between visual artist and patients and family carers and a dance film inspired by a dancer's residency, all created through narrative enquiry.

Discussion and conclusion: These projects support the role of arts-based research as creative process and qualitative research method which contributes to illuminating and exploring the lived experience of dementia. The arts act as a reflective tool for learning and understanding a complex

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health condition, as well as creating opportunities for increased understanding and public awareness of dementia. Issues arising in arts-based research in medical settings are highlighted, including ethical issues, the importance of service user narrative and multidisciplinary collaboration in arts and health practice and research.

Keywords

arts-based methods, dementia, artists, narrative

Introduction

This paper presents three artists' residencies in a geriatric medicine unit in a large teaching hospital in Dublin, Ireland. The aim of the residencies was the creation of new work of high artistic quality that would reflect the lived experience of dementia and promote greater understanding of service user experience of living with dementia. This paper also presents and explores arts-based research (ABR) methodologies and the benefits of engaging in this research within a medical setting.

Dementia is a clinical syndrome due to a number of different diseases (such as Alzheimer's disease, vascular dementia, Lewy-body disease, etc.) which is characterised by deterioration in cognitive, behavioural, social and emotional functions (van der Steen et al., 2017). In recent years, a variety of participatory and receptive arts experiences have been made available to people living with a dementia. Many arts activities focus on non-verbal interactions. In particular, people with a dementia have an ability to respond to music up to the latest stages of this condition.

Recent studies regarding arts and dementia programmes include a Cochrane review of music as a treatment for dementia (van der Steen et al., 2017), a study of a web-based participatory art intervention specifically designed for caregivers of persons with dementia to use at home with their loved one (Golden, Gammonley, Hanna Powell, & Wan, 2017) and a comprehensive review of the benefits and challenges of participatory arts activities for people with dementia (Noice, Noice, & Kramer, 2014). Several approaches are visible in scholarly discourse on the arts and dementia: from quasi-pharmacological approaches, seeking to find improvements in standardised clinical measures after exposure to arts activity or formal arts therapies, to collaborative, participatory arts projects with artistic outcomes to aesthetic environmental enhancement. A more recent approach has been recognition of the impact of aesthetic deprivation on well-being in many health and social care settings (Moss & O'Neill, 2014) and to promote artistic activities on the basis of restoring normative aesthetic experiences and quality of life (de Medeiros & Basting, 2014). In this study, the arts were engaged in a different way, acting as a reflective, research tool. In this case the arts had an interrogatory purpose, asking viewers to re-examine commonly held assumptions about dementia (Verner Chappell & Barone, 2012).

Collaborative investigations between researchers and artists are recommended to create a more extensive and cohesive knowledge base (Noice et al., 2014). Major commitments to arts engagement for people with dementia have been made by governments in many countries, alongside calls for more rigorous research as to the benefits of the arts and investment by cultural organisations in dementia-friendly initiatives.

Boydell et al. (2016), however, offer a new focus on the use of the arts in producing and disseminating research and argue for the need to reconsider what counts as knowledge in the light of calls for increased quantitative research in this area. Similarly, the rise of the field of

narrative medicine has allowed a new role for the arts to emerge in healthcare settings, whereby the arts become a tool to illuminate the story of the patient's experience, rather than a clinical intervention to be measured and justified.

Method

ABR methods were used for this project. ABR can be defined as the systematic use of the artistic process as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies (Knowles & Cole, 2008, p. 29). ABR orientates towards qualitative social science, drawing inspiration, concepts, processes and representation from the arts (Knowles & Cole, 2008, p. xi). The process of ABR design in this study echoes Ecker's five phases qualitative problem-solving process of making art: (1) identifying phenomenon; (2) artist gathering data; (3) themes emerge; (4) compose the research text; (5) work is deemed complete, but aims to provoke discussion and reflection rather than necessarily produce a completed art work.

In each residency, the artist engaged with eight people with dementia, at least three family carers and staff in the hospital (specifically geriatricians, specialist nurses, physiotherapists, speech and language therapists, occupational therapists, nursing assistants, porters, catering staff and cleaners). These various experiences (whether working with staff, patients, carers or a combination) were experienced, observed and documented. The resulting artworks arose from analysis of individual stories and experiences, which the artist then interweaved into a coherent whole.

Each residency took the following format:

The artist was in residence in the geriatric medicine unit at a teaching hospital for twelve weeks, for 1–2 days a week. The artist engaged in various activities designed to immerse themselves in, and understand, the experience of dementia. This included observation of the patient, family members and staff in the unit; interviews with patients, staff and family members; accompanying patients through their hospital journey (including attending out-patient appointments, receiving diagnosis, attending MRI scans; attending physiotherapy and speech and language therapy sessions); observing nursing interventions and visiting in-patients at the bedside. Interviews and observation also took place in the day-hospital waiting room of the unit and included visits to family homes of patients and attendance at day centres such as the Alzheimer's Society Day Centre attended by some patients. The three residencies were all conducted between 2011 and 2016.

The artist also engaged in creative sessions with patients as part of their residency, for example art-making sessions for patients in the day-hospital; open rehearsals and performances of music composition in progress and bedside dance sessions.

Patients were selected to participate in the study by clinicians and were generally referred to the artist researchers by doctors, nurses or physiotherapists. Informed consent was given by all participating patients, staff and family members and ethical approval for the study was obtained from the hospital ethics committee. Where the artists conducted interviews with participants, these varied according to the creative processes involved in the residency and participant workshops. For example, one artist recorded and transcribed interviews while another conducted informal interviews post participative workshops. The interviews all focused on the individual experiences of people with dementia, staff and family members.

Ethical approval was obtained from the hospital ethics committee for all ABR projects and the hospital Arts Committee oversaw all arts projects undertaken.

The process of collecting data followed narrative enquiry method. The artist, dancer and composer documented the stories of patients, carers and staff. A combination of audio recording and written notes was made. Researchers also undertook a process of journaling. The artists were in residence, experiencing, reflecting on and gaining insight into the hospital experiences of people with a dementia in a geriatric medicine unit. In addition to this, artists then returned to the studio where this journaling and reflection on the data was transformed into a creative process using their craft. They also undertook book-based research to further explore and understand dementia.

Data analysis

Lemley and Roland (2012) identify eight steps in narrative enquiry (NE) which were followed in this study: (1) decide if NE is appropriate, (2) identify problems or issues to study, (3) gather studies, (4) collaborate actively, (5) consider literature, (6) analyse and interpret data, (7) consider context of stories, (8) re-story. NE was followed in this study, offering a focus on sequences and consequences in a story and the selection, organisation and connecting of meaningful events within the story of living with dementia. The how and why of the story was as important as the content. Participants were actively included throughout the research, through art-making workshops, open rehearsals of the new work and dance workshops at the bedside. Reflexive knowledge was key to the work of the artists, as participants shed light on what was known about the topic and this was expressed through art. The process was reflexive in that knowledge and creative output was created through a circular process between artist and participants. Formal analysis of the interviews was not undertaken (e.g. thematic analysis): rather the stages above were followed.

Results

The results of these residencies can be summarised as (1) the creation of original art works of high artistic quality, (2) opportunities for increased understanding and public awareness of dementia and (3) creation of artworks that have an ongoing role as a tool for students to learn about dementia. The results are presented under these three headings.

Result 1: Creation of original art works of high artistic quality

Composer in residence: Ian Wilson

Wilson is a renowned Irish composer who completed a new chamber work as a result of his residency with people with dementia at the hospital. The six movement work, entitled ‘...therefore I am’ was composed for saxophone, violin, viola and double bass. Wilson undertook his own research outside the care environment, reading books on the ethics and philosophy of Alzheimer care and utilising TV documentaries and online research, as well as undertaking a wide range of observation and interactions with service user, healthcare staff, family members and staff at the local dementia charity day care centre.

Movement one of the work is entitled *The Appointment* and gives an example of how the creation of this work resulted from personal reflection and experiences within the hospital.

The Appointment attempts to convey the busy-ness of an appointment for a person with dementia. Family members are also in the room, they want to be heard and give their opinion and the doctor has to deal with them as well as with the patient. The musical situation of the saxophone is symbolic of that of the patient, not always clearly heard, sometimes overwhelmed by the others. But, when given the chance, when listened to, that line becomes stronger and more assertive. (I Wilson, personal communication, September 2016)

The final movement of the work ends with the string players leaving the stage one by one, leaving the saxophonist (who has represented the person with dementia throughout the work) on his own on the stage. The haunting loneliness of the solo saxophone improvisation that ends the work evokes a strong sense of the isolation, at times, of the person with dementia. Wilson (personal communication, September 2016) states that

We all know how debilitating, even frightening this condition can be, so rather than simply respond to the worst aspects of the condition I tried always to focus on individuals, to see them in front of, or sometimes underneath the effects of dementia. The work's title is a reflection of this focus – what makes us a person, and do we somehow become less of a person when we have difficulty remembering or even thinking? I don't believe so.

Visual artist in residence: Lucia Barnes

Barnes worked with service users and family carers, running art workshops in the day-hospital throughout her residency. The resulting art exhibition entitled *Memory Found* features collaborative work with people with dementia, as well as Barnes' own work. The emphasis of this project was on creating original artwork with patients with dementia and their family, using neuroimaging as a catalyst and stimulus.

Barnes led weekly creative art workshops with service users for 12 weeks. An example of the artwork created is *Internal Mapping Systems* (see Image 1 online). This work is a compilation of collage, text and drawing on board (7 feet × 4 feet). The project originated from the artist's interest in X-rays and neuroimaging, computerized tomography and magnetic resonance imaging scans and the concept of looking beyond the exterior at what is happening beneath the skin. Midway through the project, a selection of images of brain scans was carefully and sensitively introduced to the patients as a new motif to explore. Many of the patients were intrigued by this. With a variety of mark making, they created their different interpretations of what they saw from animal and human forms, to abstract and linear shaped designs (similar to early cave paintings). Barnes reports that the participants talked about how they felt going through the process of simply having a brain scan, how they could hear the hum of the motors going, they felt strapped in, nervous, claustrophobic, frightened. Others reported the feeling of going through a tunnel and the noise as if a crowd of workmen were working in the room. All these experiences were transcribed by the artist and incorporated into the final work. The use of brain scans had to be flexible throughout the study – consent issues meant that participants could not view their own scan, and ethical issues meant that this was avoided in case it caused distress.

Unseen Portrait (Image 2 online) is a large A0 size piece, loosely based on earlier self-portraits created by participants. In this piece, everyone worked together collectively (staff, patients, artists, family members), again using brain scan images as source material. Participants were able to participate in the work on a variety of levels according to their capabilities. A collage was assembled and Barnes concluded the final piece with several layers of acrylic glazes to further enhance the work.

Bessie-The Queen Bee (see Image 3 online) was inspired by the artist's visits to a family carers association in North Dublin. These sessions gave carers an opportunity for self-expression and developing a new skill, as well as a forum to empathise with each other. One carer, S., had cared for her mother, Bessie, who suffered from Alzheimer's disease for seven years, up to her death two years ago. This work is about S's conflicted relationship with her mother. These 16 images of her mother, wearing hats, is about the ongoing relationships, diversity, changes, temperament, challenges, drama and trauma of this woman's colourful life. An accompanying sound piece is a critical accompaniment to the piece. It contains a narrative between two people negotiating a different relationship where there is illness involved.

Dancer in residence: Ailish Claffey

Claffey focused on engaging with service users by facilitating dance experiences at the bedside with people with restricted mobility and movement. A 15 min original dance emerged from this residency, entitled *Between spirit and skin*, and was further developed with Artist Cathy Coughlan, within the HAVOC collaboration (<https://havocdance.com/>), through digital media (Claffey, 2017). Claffey continues to work with people with dementia in a hospital setting. Claffey writes of her original piece *Between spirit and skin*:

Working with people with dementia, I was instantly drawn to the skin (the oldest, most sensitive and largest of the organs). In Western culture where youth is fetishized I felt drawn, almost absorbed into, the skin of the older people I collaborated with. I had a sense that through touch via each person's skin I was meeting the person's very essence and they me. As we age, our other senses may not be as sharp but our need for touch never diminishes. When I work with patients often our dance may be a simple meeting of hands and yet our tiny movements ripple through the body's nervous system recalling and igniting sensations, inviting infinite possibilities and evoking feelings of connection, joy and vitality. My observation is that the initial contact is of paramount importance. One particular man that I worked played a real part in the performance. To begin with he was very subdued, even sad but once we found this connection via the skin he became playful and was smiling from ear to ear. You see at the beginning of the film, hands moving in quite unusual ways. This was inspired by this one patient. His use of intricate finger choreography was amazing and it felt as though his hands/fingers had a life all of their own. As there was no stress involved (no talking or remembering details) he seemed free. I felt we connected on a pre reflexive level, immediate and in the moment. We both left smiling and I had a real sense of playfulness from this frail man who I was so privileged to meet and dance with.

Result 2: Opportunities for increased understanding and public awareness of dementia

Public performances and a public seminar were held to promote the results of each residency. Project managers insisted that service users and family members were the first audience

for all projects and great efforts were made to ensure that all participants (service users, family, clinical staff) were able to access venues for exhibitions, dance performances and concerts.

The aim of these events was to explore the experience of dementia through the prism of the arts; to engage with and understand the experience of dementia from the perspective of patients, family carers and professionals; and to engage students in learning about dementia and the role of arts in healthcare.

A major seminar was held in 2012 at the Royal College of Physicians entitled *Pictures at an exhibition: Art meets the science of Alzheimer's*. The event was a Dublin City of Science, 2012 event. A deliberate decision was made to hold this arts-based event within a medical society building, and the exhibition and music performance brought an innovative quality to this event. Only the visual art and composition were presented – the dance project arose out of the success of this public event and subsequent additional funding from sponsors who regarded the project a success.

Particular insights offered by the exhibition and music performance included personal accounts by audience members of the power of the arts to communicate the emotional experience of dementia and accounts by medical professionals who attended who attested to the impact of the arts to communicate about this disease in a more powerful way than achieved through traditional medical seminars. The media response was enthusiastic and the arts pieces caught the interest of national media and brought the issues surrounding dementia into the public domain. Media coverage of the event increased public awareness and understanding by featuring a number of newspaper reports on dementia. Social media interest and a television documentary were made of Ian Wilson's hospital residency which aired on television in Ireland (https://www.tv3.ie/pr_sub.php?type=1&view_pr=700).

Result 3: Creation of artworks that have an ongoing role as a tool for students to learn about dementia

Composition and fine art students were an integral component of this project as they learned about the role of arts in healthcare and with particular reference to people with dementia. Students were actively invited to the public seminar and presentations on the project were made to both medical students and fine art students across several universities in Ireland. Project leaders developed a Medical Humanities elective module for first year medical students based on the arts and health programme at the hospital and these new artworks are used annually as tools to explore the experience of the person with dementia in student discussions and classes. Alongside film, literature and other arts these works are an important narrative of the dementia experience. Students from both arts and humanities (including nursing, music therapy, fine art and medicine) continue to benefit from these unique art works. It is possible that these artworks have been effective as teaching aids for students due to the higher emotional impact of the arts than text book definitions of dementia. Also, the artworks invite discussion and provoke reactions, which also enable students to engage with teachers in developing their understanding of dementia.

Discussion

This project supports the role of ABR as a qualitative research method which can contribute to illuminating and exploring the lived experience of health and illness. Creative arts

promote themselves as ways of expressing that which cannot be conveyed in conventional language (McNiff, 2008, p. 11). It also indicates a potential role for the arts as a reflective tool for learning about and understanding dementia as well as the importance of creativity within healthcare settings.

A number of challenges and issues arose when bringing artists into medical settings and the issue of appropriate training for artists working in healthcare is relevant (Moss & O'Neill, 2009). The artist brings their expertise in their craft but does not necessarily have clinical knowledge. A successful project, in our opinion, merges the clinical and artistic considerations in the ultimate benefit of the patient. Dr Ronan Collins (personal communication, September 2016), a consultant geriatrician involved in the project comments:

Our sense was of an impoverished experience of (dementia) among the general public and we hoped an artistic interpretation of that experience... could bring fresh insight and understanding to that sense of inarticulacy and ambiguity. The narrative of illness in popular film, art and music allows for greater understanding of the complexities and impacts of disease. As a healthcare professional one sees so much of the bared emotions and raw human state of people when they're ill, that we may at times forget the privilege of that aspect. We also believed an artist in residence has potential to give healthcare staff fresh perspective of the experience of their patients, the experience of dementia and the working of the age related health care unit itself. Aspects of the experience and treatment which strike an artist may not be those anticipated by staff and may be overlooked in terms of significance to patients, family members or colleagues.

ABR is a controversial research method, relatively new and unaccepted in some fields of study. Arguably the greatest challenge presented by ABR is the boundless possibilities regarding project design. It is much easier to approach the design of a research project through a sequence of standard established academic steps (McNiff, 2008, p. 15). This project has highlighted that artistic knowing is different from conventional clinical paradigms and highlights the benefits of bringing the two together. For example, the emotional quality present in the composition, featuring the isolation of the person with dementia and their attempt to assert their voice amongst the cacophony of noise was cited by some audience members as a more powerful experience than reading such accounts in text books. Similarly, the dance piece highlighted how people with dementia respond to touch. It is difficult to quantify the effect of art as it is a subjective experience but in general this project highlighted the emotional intensity of the arts as a unique learning tool, as well as the immediacy and attractiveness of aesthetic means to engage people to think about difficult topics.

Issues arising with this research included ethical issues (service users must never become only research participants but must remain collaborators in any artistic process); sustainable funding (arts projects are precariously financed and this can threaten the completion of such projects, or mean that original new work never reaches performance or public exposure); realistic aims and ambitions (sometimes creative ideas are curbed by realities such as health and safety and infection control and artists have to adjust) and selecting the right artists. Strong, positive partnership with clinical teams is critical to the success of any such project, as well as flexibility on the part of the artist. It is important to note that each of the artists selected was experienced and acclaimed in their own field of arts practice but also had experience of working in arts and health contexts and at the interface between arts and science. The training needs of artists working in healthcare are an important issue that needs

to be addressed. These authors have previously recommended accreditation and registration of artists working in healthcare (Moss & O'Neill, 2009).

ABR arguably affords opportunities for '....developing rich and evocative findings, accessing the voices of people who receive services, and communicating music therapy research findings to a broader audience eager for this information' (Ledger & Edwards, 2011, p. 312).

Further research, however, is warranted in terms of exploring dementia through arts-based methods and studying the potential impact of different art forms within healthcare settings. Huhtinen-Hilden is one of few authors to consider the development and delivery of arts-based care of older people. In a systematic study of ABR in healthcare, only 30 studies met inclusion criteria. Visual arts were the most common art form utilised, followed by performance arts and literary arts. The purposes of using arts in health research were primarily for knowledge production and knowledge translation. Few researchers have given due attention to the process, the critical success factors and the quality of arts-based programmes in hospital care for older people.

ABR rejects paradigmatic science and a static notion of truth in favour of multiple versions of truth which may be fragmentary, fluid and even contradictory. This study has revealed new insights about the experience of the person with dementia through an approach that is highly impactful and emotional. It is arguable that this could not have been as well achieved without arts-based methods being utilised. ABR is said to be effective if viewers are drawn into rethinking their perspective and assumptions and this is the primary benefit of this study.

In conclusion, our hope is that the end point of this process will be greater understanding of dementia, and the creation of high quality art, along with a debate which brings together the scientists and artists engaged in working with people with dementia.

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