

## The Arts and Dementia



#### **Tom Dening**

30<sup>th</sup> November 2018







ROYAL College of Physicians of Edinburgh

#### Hearts and Dementia??





The Arts and Dementia\_RCPE



#### Overview

- Arts and health
- Arts and dementia
- Concepts and methods
- TAnDem doctoral training centre
- Looking ahead
- Final thoughts





### Arts and health

Health Soc Care Community. 2018;26:458-473.

REVIEW

The impact of the arts in healthcare on patients and service users: A critical review

Melanie Boyce BA, MSc, PhD<sup>1</sup> | Hilary Bungay MA, PhD<sup>2</sup> | Carol Munn-Giddings BA, MA, PhD<sup>1</sup> | Ceri Wilson BSc, PhD<sup>1</sup>

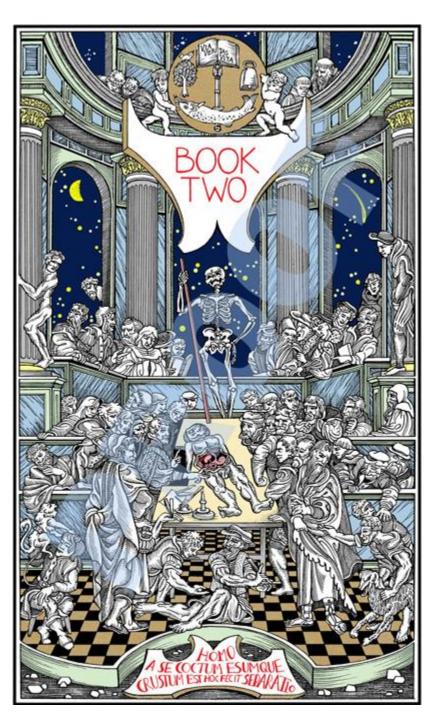


Rebecca Gordon-Nesbitt

February 2015

#### Arts and health 2

- various types of evidence
- but increasing interest
- health humanities as an academic discipline
- studies suggest e.g. better surgical outcomes for patients exposed to music (Boyce et al., 2018)
- good evidence for beneficial effects of arts engagement over time (Gordon-Nesbitt, 2015)
  - most of the studies reviewed were Nordic
  - needs replication from other longitudinal studies



#### Arts and dementia



#### the Arts

- often labelled as 'interventions'
- this implies a health context
- related to health and health is where the money is
- but actually they are at least as much about human experience
- so we find ourselves contorted by language

#### Evidence

- conflicting types of evidence:
  - rational, RCT-type research that gets into health guidance, e.g. UK NICE guidelines
  - what is observed, e.g. the power of arts to bring transfiguration
- conflicting types of people assessing the evidence:
  - for example, the question, 'Do arts therapies work?'

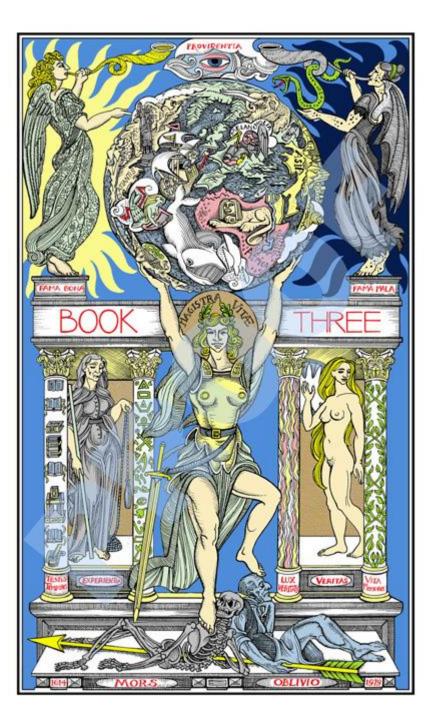
#### Challenges for arts practice & research

- what are acceptable methodologies?
- what outcomes are genuinely important?
- what works for whom, when and under what circumstances?
- dialogue with sceptics, e.g. commissioners about value of arts and activities

#### Arts and dementia: research

To summarise, in one slide:

- numerous studies
- several reviews e.g. Beard 2011, Gaugler & Cowl 2014, Young et al 2016
- focus on clinical outcomes, behaviour etc
- small samples, limited follow-up
- variable methodology
- limited input from people with dementia





#### Doctoral Training Centre for The Arts and Dementia







30/11/2018

UNITED KINGDOM · CHINA · MALAYSIA

#### TAnDem

- is a Doctoral Training Centre (2015-19) funded by the Alzheimer's Society
- and a partnership between the Association for Dementia Studies at the University of Worcester and the Centre for Dementia, University of Nottingham
- joint leads: Prof Justine Schneider (N) & Prof Dawn Brooker (W)







TAnDem Conference, Nottingham, September 2016

#### TAnDem: purpose

- to create new knowledge about the impact of arts-based activities and interventions on people with dementia and their carers, both professionals and family or friends
- to build research capacity: at least 6 PhD students
- exploit complementary expertise of supervisors from both universities

#### TAnDem: opportunities

- engage directly with practising artists as co-researchers, consultants or research subjects
- active involvement of people with dementia and their carers
- conferences on the arts and dementia organised by our students, with world-class speakers
- systematic focus on making a difference to people with dementia

### Support for students

- a community, with shared opportunities for future projects
- students join a larger community of PhDs at each institution
- action learning sets and regular academic meetings of TAnDem supervisors and students
- dementia events in Nottingham & Worcester
- Alzheimer's Society monitors provide oversight and advice

#### Current status

- currently 7 students
- one completed, 3 in write-up
- 3 students started October 2016
- annual TAnDem conferences held 2016, 17, 18
- for information about all the projects:

https://www.worcester.ac.uk/discover/tandem-meet-ourstudents.html



### Future plans

- current students to graduate successfully
- build research capacity by supporting our PhDs to attain postdoctoral fellowships
- potential to add further studentships to the existing TAnDem cohort
- future funding and new collaborations beyond 2019



30/11/2018

#### An international taxonomy of arts interventions for people living with dementia Emily Cousins, Nottingham

- includes: review of what are the principles guiding arts interventions in dementia?
- focus group interviews including expert practitioners and public representatives
- Delphi study to test and refine 'principles'
- case study of music therapy in Denmark

#### Purpose

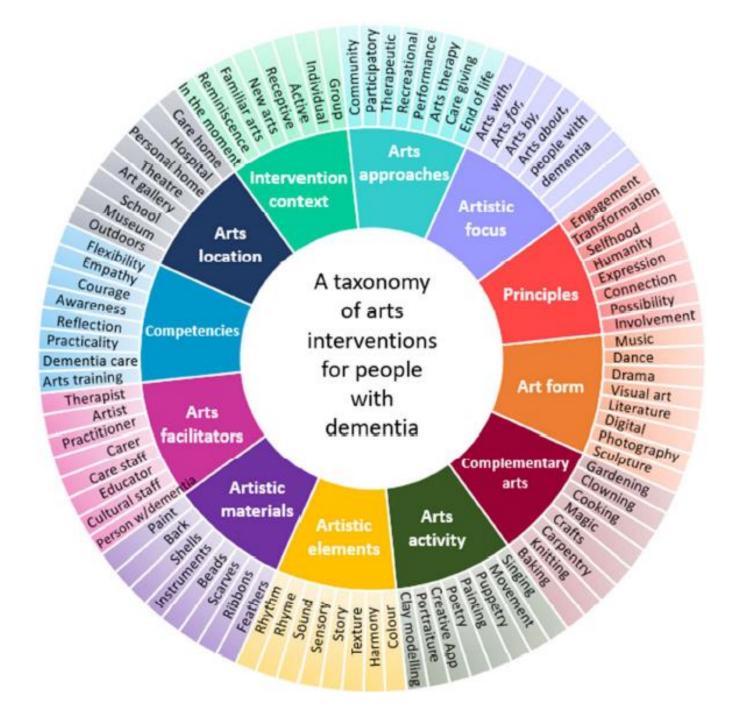
- currently no consensus on definitions and descriptions of arts activities
- aim to develop a common language of classification, in order to:
- illustrate the rationale for different creative approaches and priorities
- support the evaluation and improvement of arts interventions
- improve communication about their benefits and impact to be communicated more effectively

### A taxonomy of arts interventions in dementia

- taxonomy = science of classification
- used realist approach, literature review, focus groups and case study to develop classification, comprising:
- 12 dimensions: Principles; Art form; Complementary arts; Arts activity; Artistic elements; Artistic materials; Arts approaches; Intervention context; Arts location; Competencies; Arts facilitators; Artistic focus.

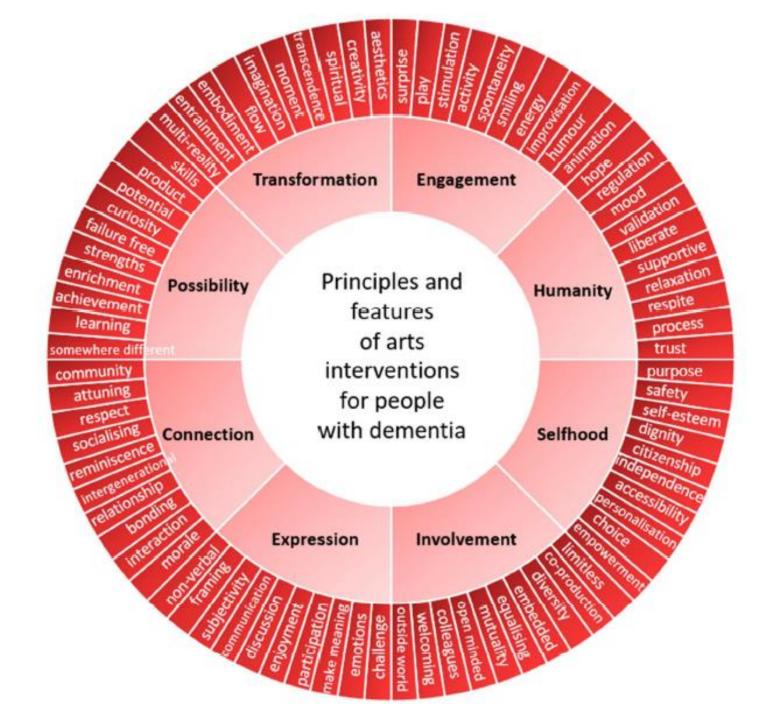
Cousins et al. (2018) <u>Arts and Health doi.org/10.1080/17533015.2018.1490787</u>

Cousins et al. Gerontologist (in press, hopefully)



#### Principles

- of more theoretical interest than some of the other dimensions
- closely related to how arts interventions 'work'
- in realist terms, this is akin to Mechanisms
- 8 identified, each with a set of underlying features:
  - engagement, humanity, selfhood, involvement, expression, connection, possibility and transformation



# Evaluating arts-based activities for people living with dementia: Methodological challenges and possible solutions Karen Gray, Worcester

- critical review to identify common categories of methodological challenge, e.g. methods, measurement, ethics, values
- stakeholder interviews and focus groups
- development of appropriate case studies

## Methodological challenges

Relevant factors include:

- individual perceptions
- hidden assumptions
- underlying social and political structures
  Leading to issues with:
- contextual variability
- ethics
- value judgements
- interpretation of meaning

Critical reflections on methodological challenge in arts and dementia evaluation and research Dementia 0(0) 1–10 © The Author(s) 2017 Reprints and permissions: sagepub.co.uk/journalsPermissions.nav DOI: 10.1177/1471301217734478 journals.sagepub.com/home/dem

Karen Gray and Simon Chester Evans Association for Dementia Studies, University of Worcester, UK

Amanda Griffiths Division of Psychiatry and Applied Psychology, School of Medicine, University of Nottingham, UK

Justine Schneider Institute of Mental Health, University of Nottingham, UK

#### Possible solutions

- different research designs
- systems thinking
- realist approaches
- increased emphasis on qualitative findings
- better evaluations:
  - evaluation designed (& funded) at outset of project
  - standard reporting frameworks
  - agreement on relevant outcomes

#### Evaluating arts interventions in residential homes Emma Broome, Nottingham

- based around Nottingham *Imagine Arts* programme for care homes
- includes: evaluation of artist feedback
- realist review of care staff engagement
- evaluation of impact of training workshops for care staff
- test realist theory of care staff involvement in arts interventions

#### The crucial role of activity co-ordinators

Realist lit review: creative arts programs, that involve and engage staff, can facilitate enhanced interactions and improve care strategies, which in turn leads to the recognition and validation of personhood in residents with dementia

Case study findings:

- activity co-ordinators had a central role
- preparatory sessions between arts practitioners and care home staff were also important to ensure success

Participatory arts in care settings: A multiple case study: Innovative practice

Emma Broome, Tom Dening and Justine Schneider University of Nottingham, UK

## Observational findings

- high level of personally enhancing actions during arts sessions
- notably: fun, warmth, celebration, inclusion
- these mainly stemmed from activity co-ordinators
- personal detractors less common
- most frequent was ignoring
- most often committed by other staff not involved in the activity

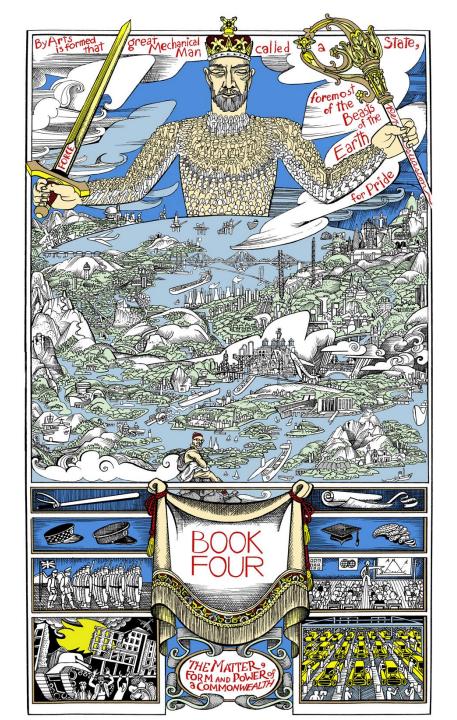
#### Benefits for residents and staff

There are potential benefits when care personnel are involved in arts interventions:

- staff participation led to better engagement of residents and staff development
- external creative and cultural programmes are more likely to be sustained after initial input

However there are still barriers to integrating arts into care practice

• care personnel, including managers, need to understand the potential benefits of integrating creative and cultural provision into care settings



#### Where next?



# Plenty of public and research interest

- Reports & initiatives
  - All-Party Parliamentary Group on Arts, Health & Wellbeing
  - Dementia friendly arts venues
  - Arts & Older People in Scotland
- Research programmes
  - Created Out of Mind
  - cARTrefu
  - Dementia and Imagination
- apps galore, e.g. Armchair Gallery
  - https://armchairgallery.co.uk/
  - https://youtu.be/UrN54o0scbY

All-Party Parliamentary Group on Arts, Health and Wellbeing Inquiry Report

The Arts for

Healthand

Wellbeing

Creative

Health:

#### Late Opening:

Arts and Older People in Scotland



Andrew Eaton-Lewis Commissioned jointly by The Baring Foundation and Luminate, Scotland's creative ageing organisation. Funded by The Baring Foundation



Becoming a dementia-friendly arts venue: A practical guide



July 2017

The Arts and Dementia\_RCPE

#### 8.6 The Arts and Dementia

In 2015, an estimated 850,000 people in the UK were living with a form of dementia. The same number was thought to be undiagnosed. As the population ages, it is estimated that this figure will increase to over one million by 2021 and two million by 2051 (with a seven-fold increase in BAME communities compared to a two-fold increase in the general population).<sup>305</sup> Replicating the health inequalities that persist in society, higher educational levels and occupational attainment, as well as participation in the intellectual, social, physical and creative aspects of life, are associated with slower cognitive decline in older adults.<sup>850</sup> Diet, drinking, exercise and

Arts participation in care homes helps to safeguard mental health, wellbeing and independence in older people.

smoking also modify the risk of dementia. Older complexity than generic therapies or drugs.<sup>63</sup>

families; and the option of personal budgets, so that resources can be used in a way that works best for individual patients'.<sup>4</sup><sup>20</sup> The NICE quality standard for dementia independence and wellbeing included the recommendation that 'People with dementia are enabled, with the involvement of their earers, to take part in leisure activities during their day based on individual interest and choice'.<sup>504</sup> People with dementia can be challenged to take part in activities they might not have previously contemplated, with positive outcomes.

The arts have a part to play in many aspects of dementia, from delaying its onset and diminishing its severity to improving quality of life for people with dementia and their carers.<sup>96</sup> At one of our Inquiry meetings, Dr Sebastian Crutch– a clinical and research neuropsychologist working in the Dementia Research Centre at

UCL's Institute of Neurology and on a Wellcome-funded project exploring dementia and the arts called Created Out of Mind<sup>99</sup> – pointed out that there are many different types of dementia and everyone will have a different journey, but creative activity has more flexibility to address that

#### 8.6.1 Delaying Onset

If the onset of Alzheimer's disease (which accounts for 62 percent of dementias) could be delayed by five years, savings between 2020 and 2035 are estimated at £100bn.<sup>966</sup> For every person with dementia living at home rather than in residential care, savings of £341 per month (£11,296 per year) are made; if five percent of admissions could be delayed by a year, £55m would be saved.<sup>94</sup>

As already mentioned, research suggests that sustained later-life musical training enhances therapy may may difference, creativ significant differ dementia and the

A 2014 study o that - as comparappreciation- parart over 10 week connectivity in t stress reduction a 2015, researchers worked with BBC establish which a Healthy but fairly

Arts participation enhances brain function, improving resilience to dementia.

> neural plasticity, potentially bolstering resistance to dementia.<sup>396</sup> A study of the Rhythm for Life project at the Royal College of Music probed this preventative effect and found a positive impact for older adults learning to play an instrument.<sup>390</sup> A longitudinal study of 459 people aged over 75,

learning somethin skills and staying (standing while socialising with o to account for the An RCT in Fi

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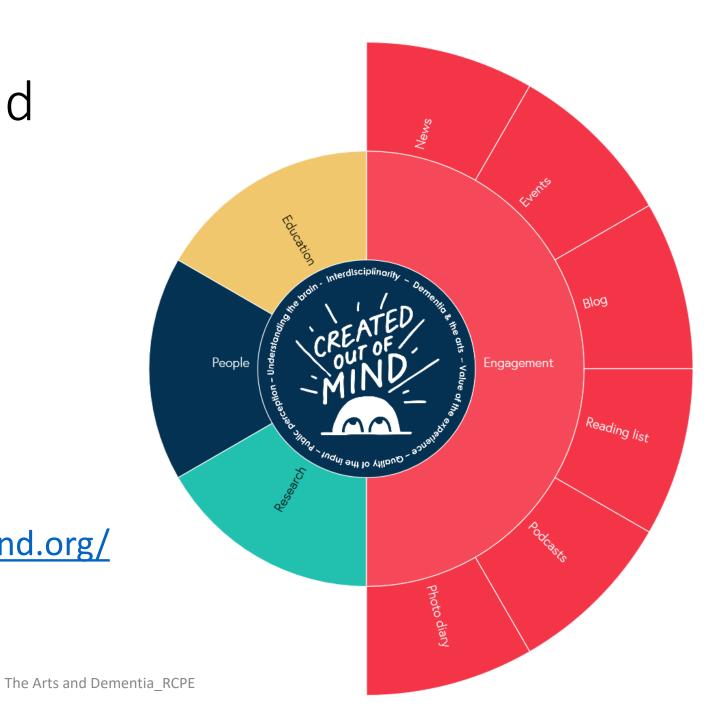
#### Created out of Mind

research included:

- People and Perceptions
- In the Moment

each with sub projects

http://www.createdoutofmind.org/



#### cARTrefu [= to reside, in Welsh]

- involved 20% of care homes in Wales
- 1952 hours of free arts were delivered in 2015-17
- evaluation: 793 care home residents and 272 care staff took part
  - participating in cARTrefu significantly improved residents' well-being and attitudes of staff towards residents, especially those living with dementia.
  - staff also gained the confidence to lead creative activities themselves.
- A second phase, cARTrefu II, has been funded until 2019.
- <u>https://www.ageuk.org.uk/cymru/our-work/arts-and-creativity/cartrefu/</u>



## Dementia and Imagination

**To cite:** Windle G, Newman A, Burholt V, *et al.* Dementia and Imagination: a mixed-methods protocol for arts and science research. *BMJ Open* 2016;**6**:e011634. doi:10.1136/bmjopen-2016-011634

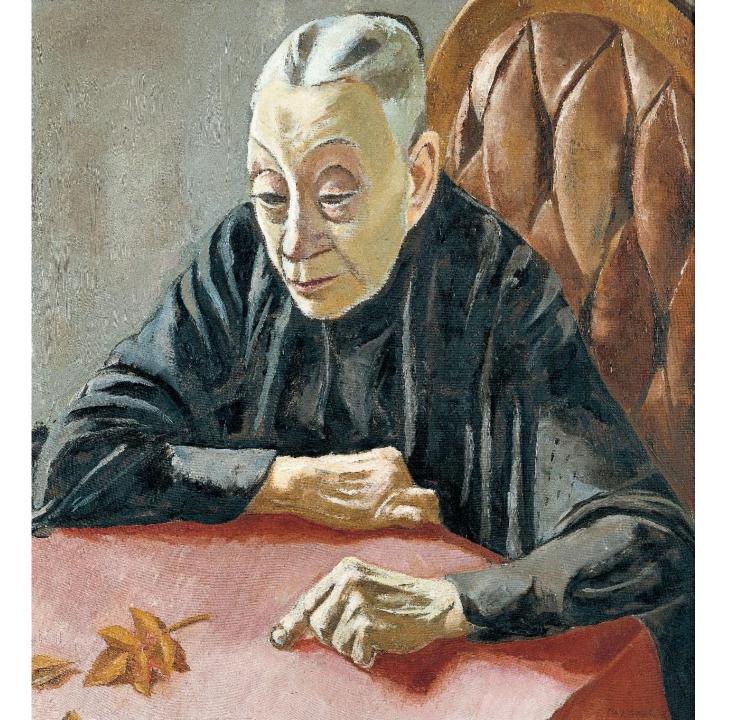


Can art improve quality of life and well-being? If it does make a difference, how does it do this—and why? Does it have wider social and community benefits?

- mixed methods study of a visual arts intervention
- <u>not</u> an RCT
- weekly 2-hour sessions across NHS, care homes and community settings
- N = 100 people living with dementia
- N = 100 family and professional carers
- includes health economic data and qualitative exploration of perceptions of social connectedness

http://dementiaandimagination.org.uk/

# Final thoughts



### 1. Imagine the Arts were a drug...

- with the ability to heighten awareness, attention, engagement
- to generate well-being and sometimes transfiguration
- and with no side effects to speak of

THEN you'd make a fortune selling it SO why do we have to argue for it? SURELY this is a matter of social justice

# 2. Abolishing dementia

- when a session goes well, the contributions of people with dementia are as valid as anyone else's
- you can't tell who has dementia and who doesn't
- having dementia (temporarily) carries no social disadvantage
- so the dementia is eliminated, no wonder that people feel better

#### Acknowledgements

- Alzheimer's Society for funding TAnDem
- colleagues & students, especially
  - Emily Cousins
  - Karen Gray
  - Emma Broome



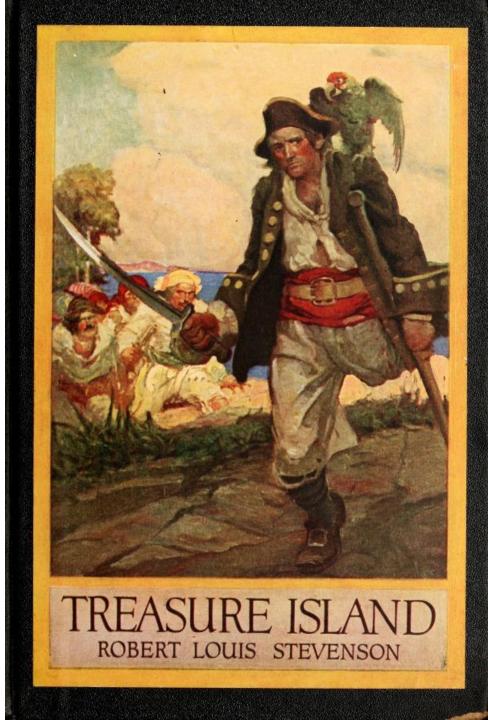
Doctoral Training Centre for The Arts and Dementia





### Thank you! <a href="mailto:tom.dening@nottingham.ac.uk">tom.dening@nottingham.ac.uk</a>





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