Arts-based activities for people living with dementia: Are they particularly challenging to evaluate?

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Four topics

- Stories
- Evaluation
- Context
- Values



"When people ask me what work I do, I end up talking in stories [...] For instance, this woman Ruth, she's screaming and shouting, trying to scratch me, calling me Hitler [...]. Everybody was upset with her and, you know, shouting at her, telling her to shut up. And so I pulled out of my bag a great big bouquet of red roses, plastic red roses, and I said to the group, 'Shall we give Ruth these roses because I think she's probably very upset about something?' And they all said 'yes', and I gave her the roses. A big smile came over her face and she held on to the roses and she was quiet. That act of yielding to somebody's anger, not taking it personally, giving her a bit of love through the exchange of some plastic red roses, changed the atmosphere...."

[From interview with artist practitioner.

Participant pseudonym]

What might this story tell us about the challenges of evaluating arts practice?

The arts	Evaluation challenge
Adaptive, flexible, intuitive by nature	Arts activities resist replicability
All involved free to make choices	Tricky to recruit and maintain participant groups
Effects at unexpected times and places	May not be ideally suited to certain study designs
What if 'atmosphere' is the thing that changes?	Existing measures may be unsuitable
Every individual has a history	It may not be easy to find out about or control for that history
Multiple individuals and groups involved	Stakeholders likely to differ on desired aims and outcomes



What does the literature tell us might be wrong with evaluation currently?

- Lack of 'rigour'
- Not underpinned with theory
- Little understanding of the mechanisms at work in arts activity
- Few longitudinal studies
- Lack of appropriate measures, or measures inappropriately applied
- Studies overly focused on bio-medical view of dementia
- May not get to the heart of the experience of people with dementia



Where does evaluation happen?

Academic or policy level

Arts & cultural / health & care organisations

Reflective practice of individual artists



What is evaluation?

There are many definitions of evaluation, but here are three we like:

- The process of determining the merit, worth or value of something.*
- Using systematic, data-based inquiries aboutwhatever is being evaluated.[†]
- A process undertaken for purposes of improvement, decision making, enlightenment, persuasion.[‡]

An evaluation has to be specifically designed to address the questions being asked and the nature of the intervention being evaluated. This means using different methods, working in different settings, with varied populations and data, under specific constraints of time, expertise and resources, both human and financial.

- Scriven M. Evaluation thesaurus. Sage Publications, 1991.
- † American Evaluation Association (www.eval.org), 2004
- \$\frac{1}{2}\$ Shadish W, Cook T, Leviton L. *Foundations of program evaluation*. Sage Publications, 1990.

The Health Foundation (2015).

http://www.health.org.uk/publication/evaluation-what-consider



Key methodological challenges

What are appropriate ways of 'knowing' and research practice for a cross-disciplinary field?

What makes for an ethical evaluation?

How is meaning communicated and interpreted?

How do evaluators account for complex contexts?

Where is value located?





Complex interventions

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BMJ 2008; 337 doi: https://doi.org/10.1136/bmj.a1655 (Published 29 September 2008)

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Evaluating complex interventions is complicated. The Medical Research Council's evaluation framework (2000) brought welcome clarity to the task. Now the council has updated its guidance



Complex contexts: uncertainty in practice

"Context consists of a constellation of active interacting variables" (Damschroder et al. 2009). Consider the uncertainties involved in accounting for the effects of:

- Setting in which arts activity is experienced, its physical space, routines and practices
- Personal and clinical histories, cultural demographies and aesthetic and other preferences
- Cultural, social and relational networks of participants
- Policies, practices and discourse surrounding the arts



What is valuable?

Differing views...

About what constitutes 'valuable' evidence

About the value of the arts and culture in general

About the place of the arts within professional dementia care practice

raise the questions

What is the evidence for?

How to measure impact? Instrumental? Economic? What if access to the arts is simply a 'moral good'?

What's valuable for a person with dementia? For a healthcare professional? For an artist?



Back to the artist's story

"It's instinctive, it's intuitive, it's spontaneous, it's flying by the seat of your pants, it's in the moment.

It's all those things I don't know how you quantify..."

[From interview with artist practitioner]

Horses for courses

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THEORY AND METHODS

Evidence, hierarchies, and typologies: horses for courses

M Petticrew, H Roberts

J Epidemiol Community Health 2003;57:527-529

Debate is ongoing about the nature and use of evidence in public health decision making, and there seems to be an emerging consensus that the "hierarchy of evidence" may be difficult to apply in other settings. It may be unhelpful however to simply abandon the hierarchy without having a framework or guide to replace it. One such framework is discussed. This is based around a matrix, and emphasises the need to match research questions to specific types of research. This emphasis on methodological appropriateness, and on typologies rather than hierarchies of evidence may be helpful in organising and appraising public health evidence.

criteria that are used to appraise public health interventions.6 This provided a valuable guide to the other types of public health knowledge that are needed to guide interventions, and also outlined the role of different types of research based information; particularly observational and qualitative data. At its heart is a recognition that the hierarchy of evidence is a difficult construct to apply in evidence based medicine, and even more so in public health, and the paper points to the continuing debate about the appropriateness of relying on study design as a marker for the credibility of evidence. Our paper further pursues this issue of the hierarchy of evidence, and advocates its revision on two main grounds. It also suggests a greater emphasis on methodological appropriateness rather than study design.

s water fluoridation effective in reducing dental caries in children? Do children learn better in small classes? Can young offenders be "scared straight" through tough penal measures? Can the steep social class gradient in fire related child deaths be reduced by installing smoke alarms?

Anyone faced with making a decision about the effectiveness of an intervention, whether a social intervention, such as the provision of some form of social service, or a clinical intervention, or a decision about the provision of a therapeutic intervention, is faced with a formidable task. The

Box 1 An example of the "hierarchy of evidence" 17 18

- 1 Systematic reviews and meta-analyses
- 2 Randomised controlled trials with definitive results
- 3 Randomised controlled trials with nondefinitive results
- 4 Cohort studies
- 5 Case-control studies
- 6 Cross sectional surveys
- 7 Case reports

"End point users, policy makers, and practitioners in particular ask many questions about interventions that are not just about effectiveness." (Petticrew & Roberts,, 2003)



Summary

Yes, arts-based activities for dementia can be challenging to evaluate. But:

- Horses for courses
- Complex contexts, uncertainty and differing perspectives on value might encourage us to employ diverse, creative and flexible methodological approaches



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http://www.worcester.ac.uk/discover/tandem-phdstudentship.html





