Maintaining Wellbeing through the Arts for People Living with Dementia

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What are Participatory Arts?

Participatory arts:

• Involving any arts or multi-arts
• Group-based community settings
• Professional artists and practitioners
• Promoting health and wellness
• Active engagement

(zeilig, killick and fox, 2014)
Participatory Arts for Dementia

- **Strength-Based Approach:** Demonstrate individual skills and capacities.

- **Maintaining skills and learning new skills** supported by the arts (Unadkat et al, 2017)

- **Stigma around ‘loss’ in dementia:** Memory loss, mood changes, motor function, verbal impairments...
Participatory Arts for Dementia

▪ In-the-moment:
  o ‘It’s the taking part that counts’

▪ Sense of community:
  o Encouraging social inclusion
  o Combining social and creative activities

(e.g. Wilkinson, 2002; Moyle et al, 2011; Johnson et al, 2017)
‘Setting the Scene’: ‘a series of creative sessions enabling people to share, create and connect.’
(Theatre by the Lake, 2020)
Research Aims and Interests

▪ The Role of Different Art Forms e.g. art-making, music, dance, storytelling
▪ How to Best Sustain the Attention and Engagement of Participants
▪ The Influence of Setting, Objects and Group Relations
▪ The ‘Voices’ of Participants Living with Dementia

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Research Methodology: Participatory Action Research (PAR)

Data collection: Multi-methods informed by ethnography
- Participant observation
- Visual methods (photography and video)
- Ethnographic/in-the-moment conversations
- Dyadic interviews (a person with dementia and their carer together)
- Action learning discussion groups
- Video/photo elicitation

Flexible, iterative, repetitive methodology
- Social change, justice, service improvements
Research Methodology: Participatory Action Research (PAR)

**Phase 1: Pilot Study – brief ‘action and reflection’ cycle**
- Four session visits
- Testing materials (forms, consent forms, surveys)
- Two interviews

**Phase 2: Beginning main fieldwork using traditional four-step PAR cycle**
- Eight session visits
- Three dyadic interviews and two group interviews with theatre staff
- A nine-member action learning group

**Phase 3: Repeat Phase Two plus new actions/refinement of activities**
- Seven visited sessions
- Five dyadic interviews and two interviews with theatre staff
- A sixteen-member action learning group

**Phase 4: Post-fieldwork. Develop preliminary findings and research dissemination**
- Occasional visits maintained to sessions (not recorded)
- Deliberative panel, open exhibition and content for toolkit/guidebook (postponed)
Findings: Redefining ‘Voice’

‘Voice’: Any verbal or non-verbal way that participants communicated, interacted or engaged with each other or an activity.

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‘Voice’ and Choice

Importance of facilitators and session themes

Multi-arts approach:
• Choice and satisfaction in group settings
• Different benefits, different senses

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Jenn, Ray and Rachel during ‘Wedding’ theme
### ‘Voice’ and Choice

**Importance of facilitators and session themes**

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‘My Favourite Things’
'Voice' and Video Elicitation

‘Sam: And we all try to... to... stick, stick... we all... want to be... we’re with her and everything. And we give her ‘come on come on’, you know?

Deborah: Oh to encourage her?

Sam: Yes, encouragement-

Deborah: -oh that’s kind.’

(Dyadic interview with Sam – person with dementia – and wife Deborah)
‘Voice’ and Video Elicitation

‘Harriett: /Ah look at this [turns attention to video clip playing].
Interviewer: Oh yes, that’s Rob and Maura together drawing.
Harriett: Aww it was so lovely because... seeing their... the people who are connected and, and it’s just so beautiful, because I feel like as though I wasn’t there for my family, in the way that, I’m here, for other families.’

(An individual interview with Harriett - person with dementia - who lives alone)
‘Voice’ and Beyond – Material Culture

Conversation starters, narrative memories and objects as part of a social network
Conclusion: Reflecting on’ Setting the Scene’

- **Social** connection, **creative** self-expression and individual **strengths**
- Role of facilitators – **in-the-moment, person-centred, with humour**
- **Multi-sensory** stimulation: **visual methods** and **session props**
- Making research accessible using **inclusive** methods to support ‘**voice**’

Thank you very much for listening.
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