

X-SYSTEM AND THE CHALLENGES OF DEMENTIA

The following short paper describes five areas of intervention where X-system may offer support for dementia care. The paper is accompanied by two literature reviews.

The first is based on the Mental Health Foundation UK's 2013 study *An Evidence Review of the Impact of Participatory Arts on Older People*, the first literature review of its kind. Although the review is concerned with ageing populations as a whole, and more with participatory approaches to music and the arts than passive listening, it is directly relevant to the needs of those with dementia, and relates to all proposed X-System areas of intervention, in particular area 5.

The second literature review is a selected version of X-System's health review, focussing on dementia and on other challenges that frequently accompany the condition (for example neurological disorders and more generalised mental health problems). The review is also expanded to include reference to other related art forms, including visual art, literature, theatre and dance, which may be effective partners to music in supporting dementia care.

The two reviews constitute the evidence base for the five proposed areas of intervention.

Proposed area of Intervention 1: *streaming familiar music to individuals with dementia*

Rationale

People with dementia frequently retain musical memory (including, for example, the words of songs) when other memories and language are lost, and the experience of music may offer tangible benefits in quality of life, sense of self, sense of belonging and communication with others. It may also offer the opportunity for sufferers and caregivers to manage the agitation and disruption normal in the mid and late stages of disease. The proposal is for a simple individualised music streaming service, to deliver familiarity, comfort and a sense of identity to users.

Content

The content may be aggregated in the first instance by interviewing the individual, their family and carers. A simple questionnaire would establish their age, the musical culture in which they were raised, and their favourite genres, artists and works of music, particularly those associated with their younger years. X-System may then search for these categories and produce randomised playlists of the same. In this case, X-System offers little more than systems such as Pandora, Spotify and iTunes, other than privileged access to the wide-ranging Omnifone platform. The benefits of X-System lie in the potential for further refinement of the intervention, and in particular in its capacity to deliver emotional entrainment (see proposed area of intervention 2).

Delivery

Delivery of music to people with dementia can be problematic. As a rule, dementia is accompanied by reduction in hearing frequency thresholds, and often by impatience with the very technologies that may most help, e.g. hearing aids, headphones etc. This is an area that needs far more general discussion - in particular with hearing aid, headphone and speaker manufacturers - in relation to comfort, durability, frequency response etc. In instances where people do not wish to use headphones, there are interesting opportunities to use new directional speaker technologies, and hidden speaker systems, for example in pillows and armchairs, some of which are already

available commercially. Here again there is a need for more discussion and research.

Proposed area of intervention 2: *streaming familiar music to individuals with dementia to achieve useful levels of arousal and counterarousal*

Rationale

Playlists aggregated from familiar and favourite repertoires may be streamed to individuals in entrainment sequences, using programmes for both arousal and counterarousal to support the needs of both individuals and their carers. For example there may be entrainment sequences to lead listeners from a state of high agitation to calmness, or conversely to arouse the user and help stimulate them to be active. There may also be sequences to maintain a particular level of arousal or counterarousal, or to entrain more complex profiles - for example beginning with counterarousal to support a sedentary session, entraining to arousal to prepare for eating, then counterarousal to settle down again.

Content

The initial content, as in area of intervention 1, may be aggregated from music familiar to and enjoyed by the user - often, in the case of dementia, associated with their younger years. The content may then be analysed by X-system to establish predicted levels of neurophysiological arousal or counterarousal for each track. Tracks may subsequently be streamed to achieve entrainment effects such as those described above, by searching for incremental changes in arousal-related values.

For example, for users who may have enjoyed North Indian music in their younger years, a search of classical raga/tal-based repertoire may produce the following possible entrainment sequence from relaxation to arousal. Bilawal, the raga of the “ether”, identified by X-System as spacious and relatively relaxing (see the opening alap section, beginning at an arousal level of 0.03), is capable of gentle arousal in gat and jhalla expressions, and may lead incrementally towards the much darker and more arousing Puriya Danashri, often associated with the element of fire, which begins with a moderately arousing alap (at an arousal level of 0.15) and ends with a very high level of excitement and intensity. Here the graphs indicate overall predicted neurophysiological

arousal values - achieved by combining values from all analytical algorithms.



The starting point for the entrainment is of course important. To achieve the neurophysiological equivalent of the “Huygens” entrainment effect, the music streaming should ideally begin close to the current state of arousal of the listener. This may be achieved by one of two methods: 1. by the subjective judgements of carers; in this case the carer would have identified the user as being very calm (at approximately 0.03 on a scale of arousal from 0 to 1) or 2. by real-time autonomic sensor data, such as heart rate and/or skin conductance, which may not only identify the current state of arousal of the user, but may also monitor the progress and effectiveness of the entrainment sequences themselves.

Delivery

The delivery issues are the same as for area of intervention 1

Proposed area of Intervention 3: *streaming familiar music to groups of individuals with dementia*

Rationale

There are many settings where people with dementia share space with others, for example in the communal areas of care homes. These situations afford opportunities for shared social experiences through music, including a shared sense of self, sense of belonging and communication with others.

Content

The results of individual questionnaires relating to personal history and preferred music may be used to identify repertoire common to all members of a group. Most groups of people in care homes tend to be of a similar generation and usually relatively similar cultural backgrounds. There is as a rule common repertoire or at least one that overlaps. So for example in a care home in Edinburgh where the authors worked, the majority of residents were of local, Scottish Central Belt origins, a few from England and one from Trinidad. The English and Trinidadian residents did not know the Glasgow/Edinburgh children's songs, like *Ally Bally Bee*, but did know some of the Harry Lauder repertoire (for example *Roamin' in the Gloamin'*) as well as some Scottish traditional melodies (for example *Ye Banks and Braes*). Everyone knew the Cockney and music hall songs - like *Roll out the Barrel*, or *Daisy, Daisy*. Everyone knew the Cole Porter classics.

When the common repertoire has been identified, X-System may search for similar examples and generate randomised streaming sequences.

Delivery

The diffusion of recorded music in communal spaces of care homes and hospitals may be problematic. The high volume necessary to make the music audible to everyone, including those with poor

hearing, may be a thoroughly brutalising experience for those with relatively good hearing.

There needs to be more creative thinking about sound diffusion in these circumstances.

Once again, new technologies such as directional and armchair speakers may be used to create environments where someone with poor hearing at one end of the room may listen to the music at a higher volume than someone with good hearing at the other end. It is possible to diffuse sound in such a way as to create specific acoustic “hot spots” for people with specific hearing needs (which may include customised frequency spectra as well as customised amplitude).

Proposed area of intervention 4: *streaming familiar music to groups of individuals with dementia to achieve useful levels of arousal and counterarousal*

Rationale

There are times in both care home and hospital settings when it would be helpful for care staff to be able to calm or stimulate collectively groups in communal spaces: for example to prepare people for exercise, washing, eating or sleeping. X-system generated entrainment sequences may help fulfil this role.

Content

The content would be aggregated as in area of intervention 3, and analysed and streamed as in intervention 2. Sensors may of course in theory be used to identify the average of collective arousal indices as a starting point - but it is more likely in practice that carers would make a judgement about the general level of arousal in the communal space.

Delivery

The systems for delivery would be the same as those proposed for intervention 3.

Proposed area of intervention 5: a hybrid approach

As literature review A (below) makes clear, participatory activities in the creative/community arts may be valuable for people who are challenged by the process of ageing and for those with dementia. These may include activities such as community singing, and creative work in music, visual arts, theatre, movement and language, leading to presentations of songs, music theatre, dance and artwork exhibitions. In the care home setting, interdisciplinary work in the creative arts (combining music with visual art, movement etc.) may be especially effective.

These activities may further be combined with proposed X-System interventions 1 to 4. For example X-System streamed repertoire may be harmonised with the repertoire for community singing, offering a support for and reinforcement of memory of both music and words, emotional engagement and joy. Similarly music may be streamed either to individuals or in communal places that corresponds to repertoires used for movement work. Streamed music may be used to stimulate visual art work in “real time”. Songs composed by residents may be streamed to residents in combination with repertoires appropriate to the collective experience.

The X-System team has wide experience of implementing such hybrid programmes across several different continents and cultures.

TWO LITERATURE REVIEWS

Music and the creative arts are the right of all, and may have a **positive impact on the growing challenges of human ageing, including disorders such as dementias**. Paper A summarises the findings of the Mental Health Foundation UK's 2013 study *An Evidence Review of the Impact of Participatory Arts on Older People*, the first literature review of its kind, which focuses on **mental and physical wellbeing** as well as the **community and social context**. Paper B includes relevant sections of X-System's health review paper, which explores the **medical and healthcare perspective** and the applications of **music and creative arts therapies**. The studies are followed by general and clinical bibliographies respectively.

Review A: An Evidence Review of the Impact of Participatory Arts on Older People

Mental wellbeing

- Increased confidence and self-esteem amongst participants were perceived benefits of participatory art engagement.
- There appears to be added value gained from performing to an audience across all art forms in terms of participants' feelings of accomplishment and the amount of positive feedback they receive.
- Through participatory art, older adults can embrace new and positive aspects to their identity and life role.
- Involvement in community arts initiatives may be particularly important in counterbalancing the mental wellbeing difficulties associated with periods of loss which can increase the risk of low mood, anxiety and social isolation.
- For older adults with dementia, participatory art can help improve cognitive functioning, communication, self-esteem, musical skills, pleasure, enjoyment of life, memory and creative thinking.
- Becoming involved in art activities can however cause frustration when individuals find that they are not able to meet their own expectations (or what they perceive to be others' expectations) of

achieving a desired but unobtainable standard of artistic expression or skill.

– Through participatory art many individuals exceed their personal expectations about what they could achieve, which enhances their mental wellbeing.

Physical wellbeing

– Particular art forms may lend themselves more than others to significant **physical health improvements (such as cardiovascular, joint mobility and breathing control)**, including dance, singing and playing musical instruments.

– The absorption of the creative processes involved in engaging with participatory arts that are not obviously physically exerting can lead to an **increase in the levels of general daily activity that older people undertake** which should have a positive effect on their physical wellbeing.

Communities

– There is clear evidence that participatory arts programmes provide

opportunities for meaningful social contact, friendship and support

within the art groups themselves as well as improving relationships between those living in care homes and prisons.

– Altruism, experienced through participatory art when it is used as a means of **'giving something back' to the community can have a positive impact on community beneficiaries as well as for the individuals participating in the art.**

– Participatory art that involves people with dementia accessing their community or interacting with professionals **serves to address age discrimination by raising awareness and expectations within the wider community** and can help to **break down stereotypes and reduce stigmatising attitudes and behaviour.**

- Participatory art that involves those with dementia along with their informal carers has proved to be an effective way of breaking down barriers in the relationship between those two groups. **Increased fellowship and raised expectations about the depth and quality of the care relationship can be achieved** and then reinforced in other areas of life.
- In day and residential care settings participatory art can **foster a better sense of social cohesion and community for those with dementia.**

Society

- Large scale, high profile festivals have the potential to **positively transform attitudes to older people**; particularly when intergenerational events are included in the festival.
- Participatory art is a powerful tool that **can contribute towards challenging and breaking down both the self and external stigmas of being older** that pervade popular societal culture.
- Participatory art can be used to **bring people together in a way that helps individuals in marginalised groups mitigate the negative effects of stigma and self-doubt on their wellbeing.**

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Review B: X-System literature review: a medical/ healthcare approach to the problems of ageing

CARE OF THE ELDERLY

Outcomes of using music and drama with groups of elderly patients have included improvements in cognitive and psychological well-being measures, word and listening recall, problem solving and self-esteem **(1)**. Work with movement, including tai chi, has brought significant improvements in physical functioning and ambulation, and borderline significant improvements in Sickness Impact Profile **(2)**.

Music therapy may serve as a valuable part of a combined treatment policy for the elderly **(3)**, and may be particularly effective in the treatment of alzheimers and related dementias. Musical memory usually remains intact in these conditions, and the experience of music may offer tangible benefits in quality of life, sense of self, sense of belonging and communication with others. It may also offer the opportunity for sufferers and caregivers to manage the agitation and disruption normal in the mid and late stages of disease **(4-12)**.

NEUROLOGICAL DISORDERS

Music may be helpful in dealing with the onset of neurological problems **(13)**, and valuable in the treatment of brain damage following head trauma, in particular in aphasia rehabilitation **(14)**. Melodic Intonation Therapy has proved especially effective in speech recovery for victims of accidents and strokes **(15-17)**.

Creative music therapy has been applied successfully to coma patients who were otherwise unresponsive **(18)**, and has proved to be an effective way of engaging adults with profound additional support needs **(19)**, through sensory exposure, temporal auditory structures, memory recall and cognitive sequencing **(20)**.

In certain phases of Parkinson's Disease, music interventions may bring "spectacular" results in improvement of gait and mobility **(21)**. These results are essentially temporary, but may persist beyond sessions and have a powerful impact on patient self-respect,

empowerment and well-being. In general music is highly interactive with the motor cortex **(22)**, and may offer support to movement and motivation in general for older people including those with dementia.

MENTAL HEALTH

In general terms, creative arts interventions in mental healthcare may offer patients self-expression and ways of establishing communication with others **(23-25)**. These experiences may be either active, involving participation in creative activities **(26)**, or passive, involving looking, watching or listening **(27, 28)**. Arts interventions are particularly effective in preserving and maximising patients' sense of self **(29)**, in nurturing creativity, which is linked to some of the biological mechanisms of mental health **(30)**, and as a support to facilitate counselling **(31)**, which may be useful in earlier stages of dementia.

Creative writing, literature and poetry may help individuals organise and regain control over their own inner world, thus enhancing mental well-being **(32)**. There have been a number of approaches to the use of expressive and therapeutic writing in mental health care **(33)**, including developing personal narratives of mental illness which may help both patients and families **(34)**. These narratives may also give insight into how disease emerges and manifests itself, give hope where treatments have been successful **(35)**, and offer to staff a picture of the "whole person" **(36)**.

Therapeutic storytelling and poetry therapy may have positive clinical outcomes, possibly, among other reasons, because patients may project their experiences into the lives of others **(37)**. There is a need for more scientific research **(38)**, but in one study, guided reading resulted in significant reductions in levels of depression among patients **(39)**. There are arguments that the introduction of arts and humanities into the training and education of medical and nursing staff may support their understanding of the cultural, social, ethnic and economic factors influencing the behaviour of patients **(36)**.

Therapeutic theatre may have a positive effect on deficits in communication, cognition and social skills **(40)**, and drama therapy has proved effective in addressing the deeper psychological needs of people with dementia to express and understand their own world **(41)**, while the practice of drama itself may challenge the hierarchies of participants and promote empathy and understanding between patients, mental health carer students, and teachers alike **(42)**.

From the period of the 1920s and the pioneering work of Hans Prinzhorn and others, visual art has been used to help achieve personal expressiveness, to diagnose the psychiatric conditions of patients (through their own artwork) and to provide insights into the understanding of illnesses such as dementia **(43-46)**. Pictures and murals have been used in psychiatric units to calming effect, for example in the care of dementia, where significant decreases in patient agitation have been recorded **(47)**.

Social dance may support spontaneous activity and enhance physical mobility **(48)**. Studies have shown that dance in dementia care creates a supportive environment and helps patients achieve a state of independence **(49,50)**. Singing has been shown to increase the quality of life for people with progressive dementia, to provide comfort and awareness, inclusion of people from different social and cultural backgrounds **(51,52)**, increase verbal communication, stimulate collaboration in day-to-day tasks, improve mood and reduce agitation **(53)**. The fact that musical memory normally remains largely intact in Alzheimers and related dementias **(54)** means that carers may provide valuable therapeutic effects by singing familiar tunes during daily routines **(55,56)**, and that patients may, through singing, improve faculties such as face-name recognition **(53,57)**. In Alzheimers treatment, familiar music from the past lives of patients has stimulated long-term memory, encouraged positive behaviour **(58)**, prompted recall of personal history, and brought increased levels of alertness and happiness **(59,60)**.

Reviews of literature in the area of arts and mental health suggest that music is one of the most useful tools available to care givers, and may play a vital role in helping to deal with the behavioural

problems of mental health and dementia patients, including eating and sleeping patterns, memory loss and other disorders **(61)**. Listening to music may bring significant decreases in agitated behaviour, and the effect may last for an hour after the listening experience **(62-64)**. Preferred music is particularly effective (except in cases of severe dementia) **(65)** and may significantly reduce aggressive behaviour. In one study 80% of patients showed significant decreases in aggressive behaviour and increased cooperation with caregivers **(66)**. Improvements have been recorded in sleeping patterns **(67)**, in mental health rehabilitation where music has been used as a complement to medication **(68,69)**, in anxiety levels and communication **(70)**, and in social functions among Alzheimers patients **(71,72)**.

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