

Dementia care for persons ageing with intellectual disability – developing non-pharmacological strategies for support

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Overview

Textbooks, academic articles and information guides about dementia often give suggestions to carers about adapting the home environment, reinforcing the importance of music or reminiscence, and strategies that may lessen symptoms associated with dementia. Television programmes and media articles are taking an increased interest in such interventions in practice. However, such resources or features rarely, if ever, have clear application for people who also have an intellectual disability. This demonstrates the importance of conducting non-pharmacological (non-drug) intervention studies with participants who have an intellectual disability and who continue to remain excluded from mainstream dementia research (Watchman, 2016). Non-drug interventions represent a broad array of environmental, psychosocial and non-medical approaches aiming to reduce the impact of behavioural and psychological changes that can be associated with dementia (Jokinen, 2014). This chapter discusses findings from a study in Scotland, UK on the effects of implementation of non-drug interventions with people who have an intellectual disability and dementia, specifically focusing on the examples of two individuals where a design change to the home environment, music playlist and reminiscence activity were implemented.

A focus on dementia is warranted due to increased prevalence in people with an intellectual disability, particularly among people with Down syndrome who are more

susceptible to developing the condition at a younger age. At least one third of individuals with Down syndrome in their 50s, and more than half of those who live to 60 or over, will develop dementia (Strydom, 2017). This compares to dementia prevalence rates of 7.1 per cent of those aged over 65 who do not have an intellectual disability (Prince et al, 2014). People with other intellectual disabilities are also more likely to develop dementia than the general population, although this is not as prevalent as in people with Down syndrome (Royal College of Psychiatry, 2015).

Discussion of literature

Findings from the available evidence suggest that non-pharmacological interventions may have potential benefits on some of the behavioural and psychological symptoms of dementia. Woods, O'Philbin, Farrell, Spector and Orrell's (2018) systematic review of reminiscence with people who have dementia (not Down syndrome) identified some positive impacts on cognitive function, communication/interaction, quality of life, and mood. However, the effects are inconsistent across different types of reminiscence work and different contexts (for example, care home or community). It is argued that there may be little benefits beyond 'in the moment' enjoyment of the activity (Woods et al, 2018). Reminiscence-type activities have been incorporated into several pilot projects for use with people with intellectual disability and dementia. This includes a pilot support group that used life story books and cognitive games (Rosewarne, 2001) and a pilot memory café (Kiddle, Drew, Crabbe & Wigmore, 2016).

There is a dearth of research exploring how support providers respond to changing needs in people with intellectual disability and dementia. Staff burden was a common

theme in Courtenay, Jokinen and Strydom's (2010) study, alongside concerns around availability of staff training and models of care. Iacono, Bigby, Carling-Jenkins and Torr (2015) found that staff experienced difficulty in responding to the unpredictability of behaviour change in clients. This included struggling to identify whether the behaviour change related to symptoms or progression of dementia. Staff were uncertain about what changes to expect in the person, and when these were likely to occur. This was translated in their practice into 'taking each day as it comes', use of ad-hoc strategies to respond to changing needs, and being proactive rather than reactive.

Crook, Adams, Shorten and Langdon (2016) explored the impact of reminiscence activities with a group of five participants with intellectual disabilities and dementia. Participants took part in three 30-minute sessions of life story books, rummage/memory boxes, and no intervention (no structured activity), with each participant trying all three activities (nine in total) over nine consecutive days. The researchers delivered the sessions and used 'dementia care mapping' as a method to record mood and engagement (via a 'mood engagement value') and behaviour. These were combined to provide an overall well-being/ill-being score. The reminiscence options led to improved wellbeing compared to no intervention for all the participants. Use of memory boxes and life story books led to an increase in communication, expressive and intellectual behaviours. Overall association was made with increased well-being and positive changes in behaviour, although there was variation in findings from different interventions: for one participant the memory box led to higher well-being scores, for another the life story book had the largest well-being impact.

In the UK, there has been a growth in the use of music-based activities including singing groups, personalised music playlists, and music therapy. Whilst many memories can be lost as dementia progresses, it has been suggested that 'musical memory' can be retained (Jacobsen et al, 2015). This ability to reconnect with music, and the memories that familiar music can evoke, has been linked to people with dementia connecting with their sense of self, feelings of belonging, increased engagement, communication, improved mood, and enhanced relationships (Mendes, 2015). However, the evidence base on the impact of music is inconclusive with Baird and Samson (2015) suggesting that music activities may be little more beneficial than other pleasant activities. One systematic review suggested a positive impact, although the evidence was considered low (Ueda, Suzukamo, Sato & Izumi, 2013).

The role of music has been considered in two pilot projects with people with intellectual disabilities and dementia. Ward and Parkes (2017) explored the potential benefits of Singing for the Brain, a service developed by the Alzheimer's Society, UK that uses singing as a way in which people can take part in a stimulating, fun activity (Alzheimer's Society, 2012). Staff reported that the groups helped lift participants' mood and gave them more energy, and participants themselves enjoyed the singing. Singing as a group helped participants to bond with each other. A number of staff members felt that the intervention had a lasting impact on mood, over the whole day on occasions. The sessions were reported as having a calming effect on participants who were agitated, and to impact on memory. Some participants reminisced about songs and their links to family members. Bevins, Dawes, Kenshole and Gaussen (2015) undertook a pilot of a music therapy group for five people with intellectual disability and dementia. Whilst some longer-term changes

were observed, including changes in communication and mood, it was difficult to determine whether these changes came about as a result of taking part in the music therapy group, or from other factors in that person's life.

More literature is available that suggests strategies to improve the design of the built environment for people with dementia in the population generally, including for instance the impact of the spatial layout of buildings, increased levels of lighting, reduced noise levels, use of colour and contrasts, and personalised living environments: these have suggested a therapeutic effect that helps well-being, independence and behaviour (Marquardt, Buetker & Motzek, 2014). Janicki, Dalton, McCallion, Baxley and Zendell (2005) explored the provision of small group home care for people with intellectual disabilities, considering the physical characteristics of the homes, and the environmental adaptations that had been made in response to changes in behaviour as a result of dementia. The homes that had been specifically built for people with dementia tended to include fenced yards, paths that could be used to walk freely, increased lighting, signage, and universal design features that would allow wheelchair accessibility. The authors argue that dementia friendly homes have a universal benefit, regardless of whether people have an intellectual disability alongside the dementia. De Vreese et al (2012) explored a combination of related environmental and psychosocial interventions for people with intellectual disabilities and dementia. Interventions included staff-oriented interventions such as training; environment-oriented interventions including lighting and signage; and client-oriented interventions such as daily individual and group activities, music, physical activities, and animal assisted activities.

The experiences of two anonymised participants from the study in Scotland of non-drug interventions are presented here to illustrate the effect and challenges of the

different personalised non-pharmacological interventions faced during the UK study. The study included 16 participants with intellectual disability and dementia, 22 social care support staff and involved 5 co-researchers with intellectual disability. Ethical approval was provided by the appropriate human participants committee with informed consent provided by all participants. A multi-method approach to data collection was taken involving pre, mid and post testing:

- goal attainment scales (linked to personal goals) to determine individualised interventions and subsequent rating with participants to determine if goals were achieved
- semi-structured interviews with staff
- Neuropsychiatric Inventory Questionnaire with staff (NPI-Q)(Cummings et al, 1994). The NPI-Q is a measure of behavioural and psychological symptoms of dementia.
- bespoke behaviour change tool to observe in the moment effects on the participants
- photovoice to visually record perceptions of people with an intellectual disability
- researcher field notes
- intervention diary completed by staff to record the date, time, duration and frequency of interventions

Jim

Jim was a 69-year-old man living in supported accommodation with three other people with intellectual disability, and 24-hour staff support. Jim had a diagnosis of

vascular dementia. Jim's care plan was heavily focused on issues relating to his behaviour, which was identified by staff as a key challenge; staff attributed changes in his behaviour to dementia. Jim could become very unsettled and agitated, which led to shouting, swearing, aggression, and self-harm. This was distressing for Jim and upsetting for the other residents living in the flat. Jim had difficulties with maintaining his morning routines, in particular around personal care. Staff tried to use 'de-escalation techniques', such as giving Jim time alone and a different staff member providing support, however these were rarely effective.

In consultation with Jim, use of a personalised music playlist and reminiscence memory box were agreed. His personal goals included remembering family and important memories, and not feeling anxious and worried. Jim's support team were initially unsure about whether the interventions would have a positive impact, expressing concern that if Jim was agitated then the interventions would not help him. Jim was provided with an mp3 player and headphones for his music (intervention two times per week over the 6-month period, and 'as required' if he became agitated), and a box with which staff could support him to create his own memory box (also twice week, on different days to the music, and 'as required').

I went to Jim's flat to offer him the activities and we sat together and put together the box (it was flat-packed). Jim engaged with me in holding the box and putting it together and repeating back to me when I talked about things he could put in it... It was genuinely surprising how much he liked it. He held it, looked at it, he was smiling and his face was relaxed, after a little while he went off to show other people his new box (Researcher fieldnotes)

Jim's team had limited knowledge of his life before he moved into his current home and found it challenging initially to identify things that he might like to keep in his box, and to select songs that were meaningful to him. This was often a process of trial and error. A lack of Internet access in the flat posed further barriers as the support worker had to download songs remotely before Jim was able to play them. Jim tried in-ear headphones but did not like these, he subsequently tried over-the-ear headphones before settling on using a small speaker. Television theme tunes worked well and were meaningful for him, he enjoyed listening to them and identifying the television show that the song came from, and this initiated conversations about the programmes. Jim talked about other songs and memories they evoked, including songs that made him think about his mum:

'Sometimes there'll be a song, and he'll be like 'oh my mum liked that song', and then he'll start telling me about his mum, and how she used to play the records, and have a dance and things like that' (Support Worker, transcribed interview notes)

Jim listened to his playlist with one of his flatmates and they chatted together about the music. This had a positive impact on their relationship (which could otherwise be fraught) although on some occasions there was tension, for instance if Jim wanted to listen to his music and his flatmate sang too loudly over the songs. Sometimes he found it difficult to remember the songs or to get his words out. Jim was very specific about who he wanted to do the interventions with; by the end of the project he only chose to do them with his keyworker Katherine and refused other members of staff. Key positive impacts of the music playlist included helping him at times when he was feeling unsettled. There were two reported occasions when Jim was becoming very agitated and the music helped him to feel calmer and more relaxed.

'Jim's mood was becoming very elevated, he was stuttering, and his speech was very fast and loud. I asked would he like to listen to his music. I played some music for him. He became relaxed, his speech slowed down, his mood was less elevated.' (Support Worker, intervention log)

Jim remained very proud of his memory box. He personalised it himself and enjoyed looking through it, talking about the items in his box, and arranging them. This included childhood story books, television show memorabilia, photos, and artwork.

'Katherine (support worker) advised that Jim had been excited about me coming out as he was looking forward to showing me the new things he had put in his box. His body language suggested he was proud of it, he showed me the tv book he has in it, he was interested in this and enjoyed looking through the pictures and pointing people out. He showed me his items but did not pass me them to look at – staff said afterwards he likes the box so much he doesn't want other people holding the items'
(Researcher field notes,)

Jim's support worker learned more about Jim in the process of helping him put together the memory box. It led to increased conversation and communication between them as Jim talked about the items in his box and this triggered memories; this was also the case with his music playlist. Using both interventions led to improved relationships with his keyworker as she learned more about Jim and spent time doing the interventions with him.

'It's good to get an insight, because we didn't know. Like the Mr Men, or holidays, or music his mum liked, we're finding out now. Now we have a

tiny idea of things that he done in the past. And what he liked to do'.

(Support Worker, transcribed interview notes)

Key benefits of the memory box and music combined included improved mood, engagement, communication and observed behaviour during the times that Jim took part in the interventions. These positive effects of both interventions could last for several hours. Jim enjoyed the interventions and was happier and more relaxed when he was doing them. He engaged with the activities, sitting up straight, talking about the songs or the items in his memory box. Sometimes he could become a little frustrated if he could not find an appropriate word, or was struggling to remember a memory. In these instances, he would change the track on his mp3 player or move onto another item in his memory box.

At the start of the 6-month intervention period, Jim was on a high dose of the anti-psychotic medication quetiapine, alongside 'as required' benzodiazepine medication for use when he was agitated. By the end of the project Jim's anti-psychotic medication was significantly reduced and his support worker was unable to recall the last time staff needed to give him 'as required' medication. She attributed this directly to the impact of the interventions. The positive impact for Jim had a beneficial wider impact on the flat as everyone was more settled as a result.

'It's absolutely amazing I think, just something that's so so simple. I'm amazed with psychiatrists, it's like 'we'll try this drug, we'll up that drug', but why are they not suggesting this? Before you we didn't really know, we knew with the dementia training they talked about the music and that, but we didn't really have any insight into how changing this can be for a

person, make their quality of life so much better' (Support Worker, transcribed interview notes)

Lucy

Lucy was a 55-year-old woman with Down syndrome who lived in her own flat with support three times a day, alongside additional support to help her with housework, shopping, and to enable her to meet up with her best friend once a week. She had a cat at home. Lucy described having lots of interests, including a season ticket to watch the local football team, going to discos, swimming, and watching soap operas. She worked at a café one day a week and attended a drop-in centre once a fortnight. Her support worker felt that music was very important to Lucy and that it helped both her mood and to feel less confused. She had been diagnosed with dementia a year previously, type unspecified. When Lucy was confused she could become upset about the loss of her parents. Sometimes Lucy could be forgetful, but staff reported that she had 'good days and bad days'. Prior to her diagnosis, she was very independent and on a good day was still able to manage most tasks independently with just a little support, although she was reported as needing increasing help with her everyday activities. Lucy had some difficulties with the design in her flat. This included environmental problems with crossing the threshold into the bathroom; the bathroom flooring was very shiny, which Lucy struggled to walk on. The lighting in the bedroom was also an issue, as it was very dark and hard for Lucy to see properly.

Two interventions were agreed with Lucy as part of the study: a music playlist (two times per week on a planned basis or 'as required' if she became upset or confused) and one-off design changes, which consisted of changes to the bathroom floor (o

make it more accessible and to the bedroom lighting. Staff changes led to significant delays in implementing the interventions but after recruitment Lucy's new support worker helped her to create a music playlist. Although this had a largely positive impact on her mood, communication and interaction (she often started singing and dancing to the music with the staff member, enjoying listening to it with her), there was one occasion where the music had a negative impact, and six occasions when it had both a positive and negative impact. Although Lucy's favourite group had been Abba, this music led to her becoming upset and tearful and staff needed to adapt her playlist:

I don't put Abba on anymore... sometimes she will go down, you know, but it's hard to tell... Westlife, that dropped her right down, and it wasn't a sad song, it was quite an up beat one. But it had that effect, and I thought I won't do that one again. It's trial and error (Support Worker, transcribed interview notes)

Once the most appropriate music had been identified for Lucy's playlist, this helped to raise her mood when she was feeling upset, and at times reduced confusion. She sang along to the songs, danced with staff, and enjoyed the music. This positive impact lasted throughout the time that the staff member was present in Lucy's flat.

'Played iPod through kitchen cd player, trying to sing along, giggling and improved mood, after lunch was dancing +++, still wandering around the house but kept coming back giving whoops of delight, very animated. Hugging and kissing me saying 'I love you'. Ask Lucy if she wanted music every day, replied 'Yes yes yes everyday'. (Support Worker, intervention log)

Although the music was experienced positively by Lucy, there were on-going difficulties with engaging the wider staff team in this process. Issues around staff confidence in using mp3 players alongside motivation and other time issues, acted as barriers.

'You will see quite a big gap on the last lot [of recording], there is not as many pages because I was off or I haven't been supporting her... It takes a while for people to understand how important it is. I will do more memos and stuff because it needs to be done properly, it's not about just putting a radio on' (Support Worker, transcribed interview notes)

Delays and problems with the proposed changes to the lighting and bathroom flooring lasted throughout the entire intervention period. Within this timeframe, Lucy experienced a significant progression in dementia, becoming increasingly restless, confused and distressed. Her support package was increased however not to the level that her support worker felt she needed. The lighting was installed eight months behind schedule, but within a few weeks Lucy had been admitted to an assessment centre. The bathroom floor was installed whilst Lucy was at the assessment centre, however the multidisciplinary team subsequently made the decision that it was unsafe for her to return home, and she moved permanently into a care home for people with intellectual disabilities.

Study implications

Co-researchers with intellectual disability engaged in photovoice methodology during the study and pictorially recorded their perspectives on reminiscence, music playlists and design changes. Photovoice combines photography with social action, typically providing a tool for underrepresented populations to raise awareness of aspects

affecting their own communities (Wang & Burris, 1994). Co-researchers understood the aims of the interventions and believed that their peers benefitted from them. A co-researcher who observed design changes discussed how they helped with being safer at home; his subsequent photographs and discussion of his images reflected the security he observed and that he also felt in his own home.

There were key 'in the moment' impacts of the interventions for both Jim and Lucy, as there were for other participants over the 12-month period. 75% of individualised goals set were considered by the participants with intellectual disability and dementia to have been met, or to have exceeded expectations by the end of the implementation period. Analysis suggests that there were consistently more goals achieved by participants living in smaller group homes with up to three peers with intellectual disability, than when living alone or in a larger group home including a residential care home for older people. Individualised interventions were appropriate both as regular activities for participants to enjoy independently or with staff and peers, plus as tools to help with distress, agitation, and confusion. The importance of 'in-the-moment' behaviour changes was recognised with a consistent positive effect (81%) recorded on behaviour, mood, and agitation, an increase in communication, and positive changes noted in body language. Engagement and interaction increased during the activities, including talking more about memories, about songs and singers, and singing. The interventions had an impact on mood, with the majority of reporting suggesting that participants were happier during the interventions. However, there were also a small number of occasions when participants could become upset, in particular in relation to reminiscence and music. Staff commonly spoke about the interventions as a 'distraction' that they used as

tools with which to take participants' minds off an issue that was causing them to be upset or agitated. This was not always effective but often helped.

There was no global change in NPI-Q scores over the intervention period. The severity of symptoms associated with dementia rose slightly to the midpoint of each 6-month cycle and decreased towards the end, a similar trajectory to other studies and associated with decreasing mobility and progression towards more advanced stage of dementia (Chow et al, 2015). However, there was wide variation between participants and recognising the limitation of the small sample makes it difficult to make inferences. The findings from the combined data collection measures suggest that whilst there were a small number of occasions in which interventions had a variable impact, broadly they had a positive immediate and short-term effect with potential for reduction in medication.

This has a wider reach beyond the study due to the high rates of prescriptions of antipsychotic medications, and over-medication experienced by people with intellectual disabilities (Sheehan et al, 2015). National guidance recommends prioritising the use of non-pharmacological interventions for the behavioural and psychological changes that can be associated with dementia (US Department of Health and Human Services, 2011; NICE, 2018) with recognition of the importance of non-pharmacological interventions for people with dementia. However, in reality medication is often prescribed; this often includes anti-psychotic drugs which carry serious risks of side effects including increased mortality (Ma et al, 2015).

Study findings support research identifying positive impacts of non-pharmacological interventions. This includes the beneficial impact of reminiscence on well-being and communication for people with intellectual disabilities and dementia (Crook et al,

2016; Kiddle et al, 2016). Findings also support research identifying music as an enjoyable activity that has a positive impact on mood (Bevins et al, 2015), alongside a calming effect on people who are agitated (Ward and Parkes, 2017). However, alongside the positive impacts of the music and reminiscence interventions, the small number of occasions when participants became upset indicates the need for caution when planning these types of interventions. Some of the participants in the study grew up in long-stay hospitals or institutions; periods of their life that they did not have positive memories of and did not wish to recall. This reflects the very different life trajectories faced by many older people with intellectual disability. Interventions need to be tailored to the individual with, for instance, reminiscence focusing on an area of the person's life that would most promote their well-being; this may actually be around their current life rather than previous experiences.

Key issues

- People with intellectual disability remain over-medicated with changes in behaviour often attributed to progression of dementia without considering the effect of polypharmacy. Many types of psychotropic medicines have been used to manage behaviour or reduce agitation, including antipsychotics, antidepressants, mood stabilisers and sedatives despite limited evidence for efficacy in people with intellectual disability. Changes in behaviour or an increase in agitation should not automatically be attributed to dementia – the effect of medication, in addition to staff approaches and communication, should be investigated.

- Individualised person-centred interventions (in which the person with intellectual disability has control and choice as far as possible), if safely implemented, can be appropriate both as regular activities for participants to enjoy, and as tools to help with distress, agitation, and confusion. The importance of 'in-the-moment' behaviour changes should be recognised with a consistent positive effect noted on observed behaviour and agitation, an increase in communication, positive changes in body language and potential decrease in psychotropic medication.
- People with intellectual disability and dementia remain a digitally excluded population. Although the intention was to implement the most appropriate intervention based on individual goals and preferences, this is not always possible due to a lack of Internet access or lack of digital awareness of support staff, for example downloading music or reminiscence apps online. Future planning, and indeed future-proofing, social care services must take this into account and plan for a more digitally adept population.
- Participants enjoyed the interventions as stand-alone pleasurable activities including both the one-to-one nature of engaging with staff members or peers and for individual enjoyment. Staff reflected on how involvement in the project had enabled them to learn more about the participants, thus leading to improved relationships. Participants learnt new skills around technology (using mp3 players and tablets) and re-engaged with previous interests and skills. Participants took ownership of their interventions and this gave a sense of pride.

Conclusion

An emphasis on non-pharmacological interventions is not currently extended to people with intellectual disability and dementia, nor is it yet widely included in staff training or organisational induction activities. A culture change is required in health and social care services to avoid starting again, or ‘reinventing the wheel’ whenever a new diagnosis of dementia is made, so that organisations have strategies for supporting their ageing population, many of whom may have dementia in mid-later life. The example of this study identified that staff teams faced a number of challenges around implementing non-drug interventions; this included ‘finding the time’ to do the interventions, new support teams and lack of staff confidence or motivation. Implementation was most effective when whole teams engaged with the process and saw the benefits of the interventions in practice, when managers gave active support to the process, and staff were given time within their roles to undertake the interventions. Key recommendations for practice therefore include the need for specifically allocated staff members or key workers to take a lead in the implementation process and ensure regular use; training for staff teams to develop required skills, knowledge and confidence around non-drug interventions; and the incorporation of interventions into individual care plans, to ensure these are recognised strategies to support the person with intellectual disability and dementia rather than an addition to every day support.

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