



## ORIGINAL ARTICLE

# A person-centred approach to implementation of psychosocial interventions with people who have an intellectual disability and dementia—A participatory action study

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**Abstract**

**Background:** Numbers of people with an intellectual disability and dementia present a global health and social challenge with associated need to reduce stress or agitation and improve quality of life in affected individuals. This study aimed to identify effectiveness of psychosocial interventions in social care settings and, uniquely, explore use of photovoice methodology to develop dialogue about dementia.

**Methods:** This mixed-method participatory action study used individualised goal-setting theory with 16 participants with intellectual disability and dementia, and 22 social care staff across 11 sites. Five co-researchers with intellectual disability were part of an inclusive research team collecting data using existing and bespoke tools including photovoice. Analysis used descriptive and inferential statistics and framework analysis.

**Results:** Seventy four percentage of individual goals met or exceeded expectations with reduction in some “as required” medication. Qualitative findings include themes of enabling care and interventions as tools for practice. Photovoice provided insight into previously unreported fears about dementia.

**Conclusions:** Individualized psychosocial interventions have potential to reduce distress or agitation.

## 1 | INTRODUCTION

The World Health Organization estimates that 200 million people worldwide have an intellectual disability. Of this number, approximately 250,000 families in the United States, 60,000 in the UK and 45,000 in Canada are affected by Down syndrome (World Health Organisation, 2018). As recently as the 1980s, life expectancy remained below 20 years for people with Down syndrome; this is now over 60 years in developed countries (Ng, Flygare Wallén, & Ahlström,

2017). This has resulted in awareness that dementia disproportionality affects people with Down syndrome at an earlier age, average fifty-five, and is associated with mortality in 70% of adults (Hithersay et al., 2019). People with intellectual disabilities other than Down syndrome are also more likely to develop dementia earlier, on average approximately 10 years prior to that experienced by the population without an intellectual disability (British Psychological Society, 2015). Such demographics demonstrate the global importance of identifying appropriate support for people ageing with intellectual disability.

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Psychosocial interventions can replace or complement medication. This includes social, physical or cognitive supports that aim to maintain or improve functional and interpersonal relationships whilst increasing quality of life and reducing perceived negative behaviour change associated with dementia. The importance of psychosocial interventions in managing behavioural changes for people with dementia but without an intellectual disability is recognized in legislation such as the National Alzheimer's Project Act, USA (US Department of Health & Human Services, 2011), and clinical guidelines (National Institute of Health & Care Excellence, 2018). Such inclusion is not seen in guidelines or legislation relating to people with intellectual disability (Watchman et al., 2017). MacDonald and Summers (2020) identified eight practice-based implementation studies in their systematic review. These studies were limited to music-orientated groups, rummage boxes, memory cafes and dementia support groups and recognized that very few of the commonly seen psychosocial interventions in the population of people with dementia have been implemented with people who have both an intellectual disability and dementia.

A series of Cochrane reviews have been conducted in the field of psychosocial interventions in dementia care for people who do not have an intellectual disability. Examples of reviews include music therapy, which was found to have potential to reduce depressive symptoms and overall behavioural problems, and may improve quality of life and anxiety. However, this intervention appeared to have little to no effect on agitation or aggression (van der Steen et al., 2018). Reminiscence had a probable effect on cognition and mood, although no clear effect on agitation or functioning in activities of daily living (Woods, O'Philbin, Farrell, Spector, & Orrell, 2018). Cognitive stimulation had a small benefit on quality of life and well-being, although no impact on mood, activities of daily living or behaviour (Woods, Aguirre, Spector, & Orrell, 2012). Exercise-based interventions did not benefit cognition or neuropsychiatric symptoms (Forbes, Forbes, Blake, Thiessen, & Forbes, 2015), whilst a review of the impact of the built environment found inconsistencies (Marquardt, Buetker, & Motzek, 2014). Key gaps in the research were the lack of views of participants with intellectual disability and dementia, lack of clarity in the benefit of the interventions and a lack of studies taking a mixed-method approach using a number of domains. Further, there appears a lack of research on person-centred approaches to implementing psychosocial interventions, despite recognition that a responsive approach to changing need is essential when supporting an older population of people with intellectual disabilities (Strydom, Dodd, Uchendu, & Wilson, 2020). Person-centred care involves professionals working collaboratively with people to support them effectively manage and make informed decisions about their own situation and tailored the services provided to the needs of the individual (The Health Foundation, 2016).

Photovoice has become increasingly recognized as an accessible method to involve people with intellectual disabilities in research (Povee, Bishop, & Roberts, 2014). However, no known studies have used this approach to explore dementia in people with intellectual

disability. Photovoice uses photography in a specific fieldwork context to document the reality for participants in typically under-represented populations (Wang & Burris, 1994). Previous use of photovoice in research with people who have either an intellectual disability or dementia identified numerous process challenges including difficulties in obtaining information from participants (Booth & Booth, 2003), obtaining informed consent from people who appeared in the photographs (Tajuria, Read, & Priest, 2017) and communication difficulties (Heffron, Spassiani, Angell, & Hammel, 2018). Other photovoice challenges included camera management (Evans, Robertson, & Candy, 2016) and difficulties for participants in understanding some concepts of the research itself (Tajuria et al., 2017).

## 2 | STUDY DESIGN AND METHODS

### 2.1 | Research questions

1. Does individualized goal setting have a positive effect on behaviour and quality of life of people with intellectual disability and dementia?
2. What are the challenges and facilitators experienced by social care support staff when implementing individualized psychosocial interventions?
3. How does photovoice methodology enable co-researchers with intellectual disability to develop dialogue about dementia in practice?

### 2.2 | Study design

A mixed-method participatory action approach design was used that aimed to involve community-based stakeholders (Wisdom & Cresswell, 2013) enabling an understanding of the effectiveness of the intervention from different participant perspectives, awareness of the practical application of the interventions and triangulation of data to corroborate findings and promote rigour. Such an approach ensured that a voice was given to participants through involving people who then take actions to improve their own situation (Baum, MacDougall, & Smith, 2006). This study did not use a convergent design to compare qualitative and quantitative data or use one set of data to explore the other, but did integrate both qualitative and quantitative data into a narrative in discussion of the findings (Tarn, Paterniti, & Orosz, 2013). Our approach included five co-researchers with intellectual disability who were involved in the initial grant application, the project advisory board over a 3-year period, photovoice training, data collection over a ten-month period and study dissemination.

The qualitative arm involved semi-structured interviews with support workers and photovoice. This included a descriptive approach involving explanation and observed association (Bowling, 2011). The present authors hypothesized that *the implementation of person-centred approach to implementing individualized psychosocial interventions*

would improve the behaviour and quality of life of people with intellectual disability and dementia through meeting individual goals. The quantitative arm involved longitudinal and cross-sectional surveys to identify the effect of the intervention, whilst structured observation identified behaviour change in the moment after each intervention. The study was undertaken in two consecutive cycles, with ethical approval given by the appropriate human participant committees.

### 2.3 | Setting

The setting was the home environment of the participants with an intellectual disability and dementia which included:

1. Living alone with limited outreach support from social care providers.
2. A small group home with between one and three other residents with an intellectual disability.
3. A larger group home with between four and seven other residents with intellectual disability.
4. A generic care home for older people (not intellectual disability-specific) in a unit with up to twenty other residents who did not have an intellectual disability.

### 2.4 | Sample

Opportunistic sampling was used to recruit participants with intellectual disability and dementia and their support staff via two national third-sector intellectual disability organizations. The aim was to recruit 10 to 15 participants and 10 to 15 support staff for each cycle to implement the interventions. Additionally, the organizations were asked to identify individuals with an intellectual disability who had existing experience of dementia in their peer group who were interested in taking part as co-researchers.

Cycle 1 inclusion criteria included participants with an intellectual disability and dementia who had capacity to consent to take part and wished to do so. Cycle 2 criteria included people with either a more profound or complex intellectual disability, or who were at a more advanced stage of dementia that required consent from a welfare guardian, or a person authorized to make best interest decisions on their behalf. This was in line with the Adults with Incapacity (Scotland) Act (Scottish Government, 2000) with actions informed by the British Psychological Society Assessment Checklist (2008) to determine capacity to consent. This process considered if the participant met three criteria by demonstrating freedom of choice and absence of coercion, a general understanding of the research and its intentions, and an understanding of possible risks and benefits. If all three standards were met, capacity was assumed. If not, then after determining whether any further steps could be taken to enhance capacity (such as providing further information or giving participants more time to come to a decision), the individual would not be considered to have capacity to consent. This process was repeated after

one week to reaffirm choice to participate at which point the decision was accepted and the present authors proceeded to complete the consent process.

In cycle 2, lack of capacity was determined by the organizations, due to either the severity of their lifelong intellectual disability or progression of dementia. A family member or significant other individual was already in place and authorized to make decisions about inclusion in research.

Staff at participating organizations were informed about the study by members of the research team at staff meetings. A senior manager, as gatekeeper, then identified and approached people with intellectual disability and dementia who might be interested in taking part. These individuals and their social care support staff were given participant information sheets, including an easy-read version. A clear distinction was drawn, and stated on the accessible information sheet, between the goals of research versus the goals of service delivery to ensure that no delivery of service was affected by the research. Bias was further minimized by ensuring that gatekeepers were not involved in determining inclusion criteria, nor did they have access to data.

This process was affirmed when two potential participants with intellectual disability and dementia in cycle 1 declined to take part when approached by their organization and in cycle 2 when participation was not considered to be in the best interest by a close relative.

The inclusion criteria for social care staff in both cycles were as follows:

- employed at one of the two collaborating organizations
- agreeable to the research team providing information and initial support with each intervention and to complete associated recording.
- ability to provide ongoing support in order to implement the intervention

This study also took place over an extended data collection period of 12 months, addressing gaps identified in earlier studies.

### 2.5 | Psychosocial Interventions

A person-centred approach to the implementation of the interventions followed the Health Foundation (2016) principles: affording people dignity, compassion and respect; care that is personalized, coordinated and enabling. A goal-setting intervention strategy developed by Locke, Shaw, Saari, and Latham (1981) was adopted with personalized goals self-set by participants in cycle 1 and agreed collaboratively with social care staff in cycle 2. Goals typically related to improving mood; a desire to reduce anxiety, confusion and agitation; wanting to feel "*more like myself*"; engagement in new or previously enjoyed activities; and personal safety. Relevant psychosocial interventions to meet these goals were chosen by participants based on their needs and preferences. *Jenny's Diary*, a pictorial resource to

support conversations about dementia with people who have an intellectual disability (Watchman, Tuffrey-Wijne, & Quinn, 2015), was used as a starting point to discuss interventions in an accessible way with the participants (cycle 1) or the participants and their closest relative or welfare guardian (cycle 2). The psychosocial interventions featured in *Jenny's Diary* included use of technology such as iPad and tablet, design changes to the home, improved signage and cues, gardening, faith and spiritual reminiscence, although lack of Internet access affected 12 of the 16 participants with an intellectual disability and dementia.

Consistent with goal-setting theory where multiple interventions or goals can prove to be more effective (McEwan et al., 2015), both the number and timing of the interventions varied. For example, a design change to the home environment was a one-time intervention, whilst reminiscence or music playlists were a daily or weekly activity. Some interventions, such as aromatherapy and pet therapy, relied on local services being available (see Table 1). The interventions were implemented over six months, cycle 1 from 2017 to 2018 and cycle 2 from 2018 to 2019.

## 2.6 | Data collection

### 2.6.1 | Quantitative data

A bespoke behaviour change tool was developed to measure the effect of interventions on behaviour "in the moment" as no suitable existing tool was identified (see Supplementary Material 1). Following each intervention, social care staff completed an intervention diary and the behaviour change tool (RQ1). The number and type of interventions were recorded by date, time and duration alongside staff comments. "In the moment" behaviour change was recorded using four domains of observed behaviour, observed mood, body language and verbal communication. This was coded as having a positive or negative effect, a positive and negative effect, no effect or declined. The effect of one-time interventions, such as a design change to the home environment, was measured at regular intervals alongside other data collection.

The Neuropsychiatric Inventory Questionnaire (NPI-Q) (Cummings et al., 1994) was completed by the social care staff who supported participants with the interventions (RQ1). Whilst neuropsychiatric symptom manifestations have been shown to be present with increased frequency as dementia progresses, Kaufer et al. (2000) noted that staff may also become familiar with observation and reporting symptoms as they become more experienced. Neuropsychiatric symptoms were assessed in terms of severity on a three-point scale (1—mild; 2—moderate; 3—severe). The total NPI-Q severity score represented the sum of individual symptom scores and ranges from 0 to 36. Carer (staff) distress was rated on an anchored 0- to 5-point scale from 0 (not distressing at all) to 5 (extremely distressing). One previous study has adapted the original NPI for assessing problem behaviour among people with intellectual disabilities (Lundqvist, Hultqvist, Granvik, Minton, &

Ahlstrom, 2019). However, this included the category of self-harm and identifying existing problem behaviours. This was not considered specific to dementia, nor would it support identification of change in behaviour post-intervention; therefore, the tool was not used in its adapted format. The NPI-Q was completed by the same staff member at three data collection time points: the start of the 6-month intervention period (T1), mid-point (T2) and at the end of the 6-month period (T3).

Additionally, in cycle 2 only, the researcher completed the Quality of Life in Advanced Dementia (QUALID) instrument (Weiner et al., 2000) with social care staff to determine whether quality of life of participants was responsive to changes in behaviour due to the intervention (RQ1). The QUALID instrument is a late-stage, dementia-specific questionnaire with a one-week window of observation. It provides information about the patient's quality of life through assessments made by proxy informants. The scale consists of 11 items, comprising both positive and negative dimensions of concrete and observable mood and performance, each indicative of quality of life in late-stage dementia. The items are rated by frequency of occurrence on a five-step scale, and scores are summed to range from 11 (best QoL) to 55 (worst QoL). The instrument was completed at T1, T2 and T3 time periods on each occasion reflecting on the previous seven days of implementation. Whilst the QUALID instrument has been validated in patients with advanced dementia (Falk, Persson, & Wijk, 2007), it has not previously been used with people who also have an intellectual disability. The developers' permission was obtained for both NPI-Q and QUALID.

Participants with intellectual disability and dementia completed the goal attainment (pictorial) scale (Kiresuk & Sherman, 1968) at T3 time period (RQ1).

### 2.6.2 | Qualitative data

Qualitative data collection methods were the same for cycles 1 and 2. Semi-structured interviews were conducted with social care staff at three time periods during each cycle: T1, T2 and T3. The interview schedule explored staff perception of the effect of the intervention on the person with intellectual disability and dementia (RQ1) and challenges and facilitators to implementation (RQ2). The first interview lasted approximately 20–30 min with second and third lasting 30–40 min. All were audio-recorded, transcribed verbatim and anonymized with field notes simultaneously taken.

Photovoice (Kiresuk & Sherman, 1968) enabled co-researchers with an intellectual disability to capture perception of the interventions and share views of effectiveness (RQ1). Inclusion in this study was instrumental in determining whether the methodology facilitated a dialogue about dementia in practice (RQ3). In terms of the process, our approach saw a divergence from other photovoice studies as co-researchers attended seven workshops over a ten-month period to learn about dementia, photovoice, use of cameras and data analysis. A mini printer was provided so that images could be printed out at workshops. The co-researchers

**TABLE 1** Psychosocial interventions descriptions

Intervention	Description
Reminiscence	Discussion of past activities, events and experiences, with the aid of prompts (e.g. photographs, familiar items from the past, music and archive sound recordings) that may be physical (box or scrapbook) or digital such as iPad or computer (Woods et al., 2018).
Music	Use of music with an individual, group or community to improve well-being (van der Steen et al., 2011). Example interventions are individualized playlists, dementia choir and tea dance.
Arts and crafts	Creative activities such as making a collage, greetings cards, painting by numbers, knitting, clay modelling.
Namaste care	An intensive programme integrating compassionate care with individualized sensory activities for people with advanced dementia at the end of their lives (Bray, Atkinson, Latham, & Brooker, 2018). This was available only where staff were training in its delivery.
Aromatherapy	Use of pure essential oils from fragrant plants to help relieve health problems and improve quality of life (Forrester et al., 2014).
Animal therapy	Interaction between a person and an animal, facilitated by a human handler, with a therapeutic goal such as providing relaxation and enjoyment (Filan & Llewellyn-Jones, 2006).
Robotic animal	A robotic animal is an artificially intelligent machine made to look and act like a real animal (e.g. a robotic cat that breaths, purrs and meows).
Twiddlemuff	A twiddlemuff is a double thickness hand muff with buttons or sensory fabric attached inside and out. It is designed to provide a stimulation activity for restless hands.
Board games and jigsaws	Activities such as jigsaws, crossword puzzle, board game or electronic game.
Design changes to accommodation	To reduce physical obstacles that may lead to falls; improve mobility and safety; enhance way finding and orientation, for example changes to lighting, adaptations to stairs and assistive technologies (Marquardt et al., 2014).
Adapted cutlery	Knives, forks and spoon that have been adapted for people with weak grip or limited movement.
Cooking	Preparing and cooking food or baking.
Activity planner	Display board to inform residents what is taking place that day.
Time tracker	Changes colour as time advances (like a large sand timer) in order to help the participant understand remaining time until an event or activity, for example when staff shift changes would happen.
Cognitive games	Offers a range of activities for people with dementia for general stimulation of cognitive abilities (Aguirre et al., 2012).
Physical activity and exercise	Planned, structured or repetitive exercise adapted to level of mobility

visited a convenience sample of four study participants from cycles 1 and 2 over a six-month period during 2018–2019 to observe the interventions and take photographs for later discussion among the research team as part of analysis. All lived within travelling distance of the co-researchers, and no photographs were taken of participants. After group discussion and selecting a choice of preferred images, the co-researchers were interviewed individually to reflect on their photographs and observations of the interventions, which is a further divergence from typical photovoice studies. This involved asking questions around the content and

discussion of the meaning of photographs taken. Interviews were recorded and transcribed verbatim.

## 2.7 | Data analysis

Data were analysed individually with the exception of the NPI-Q and QUALID (cycle 2 only) which were combined to identify correlations with specific variables. Analysis of the interview data for cycles 1 and 2 was combined.

### 2.7.1 | Quantitative data

Data from the interventions diary, bespoke behaviour change tool, goal attainment scale, QUALID and NPI-Q were entered onto SPSS version 22 for analysis (IBM Corp, 2013). Descriptive statistics were used to present frequency and effect for each intervention across both cycles. The goal attainment scale derived an aggregated goal score for each participant using the calculation provided by Turner-Stokes (2009), with a score of 50 or over indicating that overall goals were achieved. A lower QUALID score represented an indicator of higher quality of life. The goal score was dichotomized into a new variable, taking on value 0 if the goal score was less than 50 or the value of one otherwise. A Bayesian logistic regression model then used the new variable as an outcome, adjusting for cycle 1 or 2 and the type of accommodation, whilst also allowing for an individual-level random effect. Pearson correlations were computed to explore potentially linear relationships between the QUALID measurements and NPI-Q. Correlations measures were computed to explore the relationship between changes in scores for the NPI-Q Symptom Severity Score, NPI-Q Carer Distress Score and the QUALID.

### 2.7.2 | Qualitative data

Data from semi-structured interviews and photovoice interviews were entered onto NVivo software version 12 (QSR International Pty Ltd, 2018). Semi-structured interviews with staff used framework analysis following seven stages outlined by Gale, Heath, Cameron, Rashid, and Redwood (2013). An a priori coding structure was based on the interview schedule and person-centred care themes (Table 2). Two researchers independently coded the transcription, and themes were compared and discussed with a third researcher.

The process of conducting photovoice took place over a 10-month period of monthly workshops. Photovoice data were analysed in a three-stage process:

- selection of photographs by co-researchers
- individual and group contextualization with discussion of images
- coding to identify issues, themes and theory

A six-stage process as outlined by Braun and Clarke (2006) was followed for coding involving an initial process of familiarization with the data through transcription, multiple readings of the transcripts, photographs and accompanying labels. The labels were "tags" attached to each photograph and represent the co-researchers' own descriptions of their photographs. This stage of analysis involved open coding and re-coding: searching for themes and producing "thematic maps" of the possible relationships between the data followed by reviewing and defining those themes in consultation with the co-researchers. This was not a linear process as there was a movement back and forward between coding and potential themes until a clear thematic structure was defined.

**TABLE 2** A priori coding for framework analysis of interviews

#### Characteristics of person with intellectual disability/dementia

1. Participant characteristics
2. Main challenges for person pre-intervention
3. Behaviours affecting person pre-intervention
4. Behaviours affecting persons carers/friends/family

#### The interventions and their impact

1. Description of intervention(s)
2. Intended goal of intervention
3. Staff perception of reason for intervention
4. Effect of intervention(s) on the person, negative/positive
5. Effect of intervention on other people negative/positive
6. Influence of context on intervention
7. Any changes to intervention made

#### Facilitators and challenges of implementing the intervention

1. Facilitators to undertaking intervention
  - Person-centred approaches
  - Capacity/capability of staff
  - Capacity/capability of participant
  - Resources
2. Barriers to undertaking intervention
  - Person-centred approaches
  - Capacity/capability of staff
  - Capacity/capability of participant
  - Resources/information
3. Ideas for improving intervention

#### Overall changes for person with intellectual disability and dementia

1. Changes associated with dementia
2. Changes associated with behaviour and impact
3. Views on continuing intervention

## 3 | FINDINGS

### 3.1 | Biographical data

Twelve social care staff and seven people with intellectual disability and dementia were recruited in cycle 1 in six care settings. A further ten social care staff and nine people with intellectual disability were recruited in cycle 2 in five settings. As maximum participant numbers were not reached in either cycle, all who met the inclusion criteria were able to take part with no additional selection process required. The characteristics of participants with intellectual disability and dementia are described in Table 3. The mean age for participants with Down syndrome was 51.5 years, and 71 years for other types of intellectual disability.

### 3.2 | Bespoke behaviour change forms and intervention diaries

Participants each had between two and six interventions, the mode was three ( $n = 5$ ) and the mean five (see Supplementary Material 2). The behaviour change tool was completed on 605 separate occasions across all four domains over the 12 months of cycle 1 ( $n = 240$ ) and cycle 2 ( $n = 365$ ). Non-completion of the behaviour change form occurred on 54 occasions.



**TABLE 3** Characteristics of participants with intellectual disabilities and dementia

Participant	Age	Gender	Down syndrome	Dementia diagnosis <sup>a</sup>	Living environment
<i>Cycle one</i>					
1	56	Male	Yes	<1 year	Lives alone with outreach support from social care provider
2	57	Female	Yes	<1 year	Lives alone with limited outreach support from social care provider
3	77	Female	No	<1 year	Lives alone with limited outreach support from social care provider
4	38	Female	Yes	<1 year Alzheimer's disease	Lives alone with limited outreach support from social care provider
5	67	Female	No	<1 year	Lives alone with limited outreach support from social care provider
6	55	Female	Yes	1 year Alzheimer's disease	Lives alone with limited outreach support from social care provider
7	69	Male	No	3.5 years Vascular dementia	Small group home with 1–3 other residents who have an intellectual disability
<i>Cycle two</i>					
8	54	Female	Yes	3 years Alzheimer's disease	Generic care home—no other residents with intellectual disability
9	63	Female	Yes	2 years	Lives alone with outreach support from social care provider
10	54	Male	Yes	20 months	Larger group home with 4–7 other residents who have an intellectual disability
11	63	Male	Yes	1 year	Larger group home with 4–7 other residents who have an intellectual disability
12	68	Female	Yes	2 years	Larger group home with 4–7 other residents who have an intellectual disability
13	62	Female	Yes	6 years Vascular dementia	Larger group home with 4–7 other residents who have an intellectual disability
14	54	Female	Yes	<1 year	Small group home with 1–3 other residents who have an intellectual disability
15	63	Male	Yes	1 year Alzheimer's disease	Small group home with 1–3 other residents who have an intellectual disability
16	40	Male	Yes	<1 year	Small group home with 1–3 other residents who have an intellectual disability

<sup>a</sup>Type of dementia stated if shared with individual at diagnosis

The overall effects of the interventions were recorded as 80% in cycle one and 81% in cycle two, showing a positive “in the moment” effect. Over 80% of recordings for music playlists demonstrated positive effect across both cycles. Reminiscence, whilst positive across both cycles, was less effective in cycle 2, with 16% of recordings showing no effect. In cycle 1, aromatherapy had the most positive feedback, whilst in cycle 2 this was adapted cutlery, Namaste care, design changes and a dementia singing group (not intellectual disability-specific), with 100% of forms showing a positive effect, although the use of these interventions was limited. The interventions with no positive effect were as follows: the visual time tracker in cycle 1 and twiddle muffs, activity planners and a local community tea dance for people with dementia (not intellectual disability-specific) in cycle 2 (see Supplementary Materials 3 and 4).

### 3.3 | Goal attainment scale

In cycle 1, 32% of goals were either met and 43% exceeded expectations. In cycle 2, 35% of goals were met and 37% exceeded expectations (Table 4).

Taking “living alone” as a reference category, the present authors found that more than 75% of participants in the study living in small group accommodation (with up to three other residents and onsite support) were more likely to have their goals met than those living alone. Those living in larger care homes with more than 3 other residents were less likely to have their goals met than participants who lived alone.

### 3.4 | Neuropsychiatric inventory Questionnaire (NPI-Q)

In both cycles, average NPI-Q scores for measuring dementia symptom severity increased marginally from baseline to mid-point and then decreased slightly at endpoint, although there was variation between participants with recognition that the sample size limits inference. In cycle 1, there was a general trend towards scores decreasing from baseline to endpoint, whereas in cycle 2 this trend was less apparent. Paired-samples *t* tests found no significant difference in NPI-Q scores between baseline and mid-point, baseline and endpoint, or mid-point and endpoint over both cycles 1 and 2. In cycle 1,

**TABLE 4** Goal attainment scaling outcomes by intervention

Cycle one		Outcomes			
Intervention	Number of Goals	Better than expected	As expected	Goal not met	Unable to assess
Reminiscence	10	3	5	2	
Music playlist	5	4	1		
Aromatherapy	3	1			2
Cooking	2	2			
Time tracker	1			1	
Exercise	1		1		
Design changes—flooring	1				1
Design changes—lighting to living room and bedroom	1	1			
Design changes—lighting to bedroom	1		1		
Design changes—curtains	1	1			
Design changes—night lights	1				
Cognitive games	1				
Total	28	12 (43%)	9 (32%)	4 (14%)	3 (11%)
Cycle two					
Music playlist	10	8	2		
Reminiscence	14	3	9	2	
Exercise	2		2		
Tea dance	2			2	
Namaste care	7	2	3	2	
Board games/Jigsaw	4			4	
Design changes—lighting to bedroom	1	1			
Design changes—adaption to stairs	1	1			
Adapted cutlery	1	1			
Arts and crafts	8	1	5	2	
Cooking	1		1		
Twiddlemuff	3			2	1
Animal therapy	4	4			
Robotic cat	1	1			
Dementia singing group	1	1			
Activity planning	2			2	
Total	62	23 (37%)	22 (35%)	16 (26%)	1 (2%)

average staff distress scores increased from 3.33 at baseline to 4.87 at mid-point, to 6.07 at endpoint. In cycle 2, average scores increased from 2.38 to 2.63 at mid-point to 3.88 at endpoint. However, paired-samples *t* tests found no significant difference between scores at either of the time intervals (see Supplementary Materials 5 and 6).

### 3.5 | Quality of Life in Advanced Dementia (QUALID) Scores

The mean QUALID scores reduced from 23.25 at baseline to 20.13 at mid-point and rose again to 24.63 at the end of the intervention period for cycle 2 participants. As with the NPI-Q scores, there was fluctuation between participants. Paired *t* tests found

no significant difference between scores at either of the time intervals.

The present authors found evidence of a strong correlation between NPI-Q scores across every time measurement and of a strong-to-moderate correlation between QUALID scores. This indicated the likelihood of participants remaining at similar levels from baseline to the end of the intervention period. The endpoint QUALID score was strongly correlated with the NPI-Q measures across all three time points, suggesting a relationship for participants between quality of life in advanced dementia and behavioural and psychological symptoms. Conversely, the baseline and mid-point QUALID scores were not correlated with any of the NPI-Q measures.

Between baseline and endpoint, there was a weak correlation between changes in severity of symptoms and the QUALID



( $r = 0.22$ ). However, there was a moderate-to-strong correlation between changes in QUALID and NPI-Q carer distress ( $r = 0.56$ ). This confirmed that as quality of life in advanced dementia worsened, staff distress increased. Concurrent validity was tested by comparing the mean changes in scores in participants who improved ( $n = 5$ ) based on the NPI-Q and those who did not ( $n = 3$ ). A decrease in 4 points in baseline score is considered to be clinically meaningful. The mean change in QUALID was similar between groups, suggesting that the QUALID instrument may not be responsive to changes in behavioural and psychological symptoms of dementia (see Supplementary Materials 7 and 8).

### 3.6 | Semi-structured interviews with staff

Staff confirmed that the interventions had positive effects, reporting reduction in participant's distress and agitation, improvement in mood, communication and social interaction. Staff frequently described the interventions as "*bringing them back*," for example seeing personalities resurface or making renewed eye contact with staff.

And when you look at some of the things with him, and carry on, you kind of see wee (small) parts of him coming back, the smiling, and the cheeky faces.

Participant 23

Some activities, for example music playlist and reminiscence, were effective as a distraction for participants when they become agitated. Such positive effects lasted a few hours with some participants reportedly benefiting for the remainder of the day. Longer-term benefits were apparent with staff commenting that overall many participants were more alert, motivated and settled.

Yes, it settled her down. And it takes her away from whatever was upsetting her, and it gives her more focus....., almost like a distraction, it worked.

Participant 05

Two key themes relating to facilitators and barriers to implementing the interventions were identified: "enabling care" and "interventions as tools for practice" (Table 5).

#### 3.6.1 | Enabling care

Enabling care, a key component of person-centred care, facilitated implementation of interventions. Having, and exercising, choice over which interventions were selected and how often they were undertaken was an example of enabling participants to take an active role in their own support. Some interventions required staff to spend one-to-one time with participants, which participants enjoyed

and staff believed facilitated positive relationships. Other interventions were undertaken independently, with occasional prompts from staff, which gave greater control to participants.

Her communication has come on leaps and bounds, just talking about things that she maybe wouldn't have talked about before. Like technology wise, it's helped her, and it's just given her that little bit of responsibility of her own.

Participant 13

Whilst participants not being "*in the mood*," too tired or only wanting to undertake the intervention with certain staff could be a barrier to implementation, staff were respectful of such preferences.

#### 3.6.2 | Interventions as tools for practice

The second theme was related to how the interventions were used. This was in the context of initial reticence among some staff who perceived them as task-oriented, time-consuming to set up and "*something else to do*" that participants might not engage in or benefit from. Despite such barriers, implementation was facilitated if staff were flexible and willing to try out the interventions at different times. As staff became more confident using the interventions, undertaking them in a proactive and timely manner to reduce the likelihood of a person becoming agitated, they perceived them as less of a task and recognized that the interventions actually saved time.

Yeah, the staff are doing it and don't even actually realise that it's an intervention now, because when they're working with [person] they'll be like oh right [person's] like this, this is what we'll do. It's had a positive impact.

Participant 05

The personalized memory box, music playlist and adult art were so effective at helping two participants that their need for "as required" benzodiazepine medication drastically reduced during the six-month intervention period from almost daily before the study began to just once during the latter months of implementation.

### 3.7 | Photovoice findings

Co-researchers with intellectual disability reported limited prior understanding of dementia although, conversely, they were increasingly witnessing diagnosis among their peer group. This adapted process of conducting photovoice methodology facilitated a developing discourse around dementia which saw three key dementia-related themes emerged from the analysis.

### 3.7.1 | The importance of friendship

All co-researchers expressed uncertainties around changes they had observed with the “unknown” dominating their conversations. This included experience of friends “disappearing” with no explanation, represented by a photograph of a flip chart with a question mark on it; and their emphasis on the importance of maintaining friendship as dementia progressed, represented by a photograph of a group holding hands and another of coffee cups.

### 3.7.2 | Involvement in future planning

The importance of the person with dementia being involved in planning for their longer-term care needs was highlighted, for example asking where “home” would be as dementia progressed, alongside the importance of making environmental design changes as required. Photographs taken to stimulate discussion included images from *Jenny's Diary* (Watchman et al., 2015), cash and household items such as a Hoover, crockery and washing machine.

### 3.7.3 | Fear of dementia

The psychosocial interventions were reported by researchers with an intellectual disability as helping participants understand what was happening on a day-to-day basis at a practical level, but not helping to explain dementia or its progression. Some co-researchers had experienced institutional living when they were younger and expressed fear that peers may have to move to such a service, evidenced through the photograph taken of a “dementia friendly” sign on a door. The co-researchers reflected on their own future support wishes including the potential of having to change support teams and how relationships with peers or a partner may change.

## 3.8 | Study limitations

The study included an opportunistic sample of 16 people with an intellectual disability and dementia and 22 support staff, which may be considered small. However, there is not a recommended sample size for participatory action research, rather the informants should reflect the needs of the target group (Heslop, Burns, Lobo, & McConigley, 2017). The authors believe that the consistency of the results across the different data collection methods suggests credibility in conclusions. Furthermore, most available studies sought the perception of support staff rather than the person with intellectual disability and dementia. This typically included evaluation of a single large group activity or tool such as Dementia Care Mapping, rather than seeking individual preference and behaviour change which was a key element of our study (see, e.g., Schaap,

Fokkens, Dijkstra, Reijneveld, & Finnema, 2018; Ward & Parkes, 2017).

Only six of sixteen participants with an intellectual disability had been given a diagnosis of their specific sub-type of dementia, that is Alzheimer's disease, vascular dementia or dementia with Lewy bodies. This awareness can ensure relevant information, resources and support specific to the type of dementia. For example, antipsychotics, commonly prescribed for people with intellectual disability, can cause severe reaction in Lewy body dementia (Chauncey Spears et al., 2019). Whilst not affecting the study findings, this would have provided greater clarity over biographical data.

Finally, due to the importance of consistent and familiar staff, and the different location of participants, it was not possible to guarantee that the same staff implemented interventions in the same way; thus, inter- and intra-rater cannot be reliably determined. However, in recognition of this limitation and to reduce potential heterogeneity in ratings, all staff received the same training in advance of the study and were observed in early implementation of the interventions by the researcher.

## 4 | DISCUSSION AND IMPLICATIONS

### 4.1 | Effectiveness of person-centred psychosocial interventions

Staff claims that the interventions benefited participants were corroborated by the behaviour change tool and the number of goals met. This supports earlier research identifying benefits of reminiscence on well-being and communication for people with intellectual disabilities and dementia (Crook, Adams, Shorten, & Langdon, 2016), and music which had a positive impact on mood (Bevins, Dawes, Kenshole, & Gaussen, 2015) and agitation (Ward & Parkes, 2017). Such findings are in keeping with previous Cochrane reviews (van der Steen et al., 2018; Woods et al., 2018). Conversely, the Cochrane reviews identified no impact of music or reminiscence on agitation or aggression, although it is recognized that the sample size and participant criteria differ in this study. Whilst the Cochrane reviews found no evidence of harm caused by music or reminiscence, this study found that some participants became upset at a song or memory, highlighting the need for a sensitive approach. Likewise, cognitive games were effective distractions tool for agitation in this study in contrast to studies that found no impact of cognitive stimulation on behaviour (Aguirre, Woods, Spector, & Orrell, 2012). Animal-assisted interventions proved effective interventions for a number of participants including individuals with advanced dementia in line with the findings of Aarskog, Hunskar, and Bruvik (2019) in their systematic review.

Findings suggest that those living with up to three peers were more likely to have their goals met than those living alone or in larger group homes. Whist interpreted with caution as it may also be related to greater level of need of those living in larger settings, this is consistent with a wider evidence base considering inequities in

**TABLE 5** barriers and facilitators to implementation of psychosocial interventions

Facilitators	Barriers
<i>Enabling care</i>	
<ol style="list-style-type: none"> <li>1. Participant exercising choice over interventions.</li> <li>2. Participant could undertake some interventions independently.</li> <li>3. Interventions enjoyed by participant.</li> <li>4. Interventions personalized for participant.</li> <li>5. Spending 1–1 time with participant to set up and undertake intervention.</li> <li>6. Staff enjoyed getting to know participant better.</li> <li>7. Prioritizing interventions alongside activities of living tasks.</li> <li>8. Introduce intervention as a fun activity as opposed to a chore.</li> <li>9. Introduce intervention before progression of dementia.</li> </ol>	<ol style="list-style-type: none"> <li>1. Participants not “in the mood” or too tired for intervention.</li> <li>2. Communication difficulties for participants could lead to frustration.</li> <li>3. Some participants would only engage with interventions with certain members of staff.</li> <li>4. Some specific music or photographs may make participant unhappy.</li> <li>5. Lack of staff or family who knew participant well.</li> <li>6. Reliance on external appointments or need to bring services in.</li> <li>7. Transport difficulties, particularly in rural locations.</li> </ol>
<i>Tools for practice</i>	
<ol style="list-style-type: none"> <li>1. Teamwork, good communication and an identified staff leader to coordinate interventions.</li> <li>2. Building rapport and positive relationships with participants.</li> <li>3. Staff increased confidence in undertaking interventions.</li> <li>4. Staff recognized the intervention as preventing agitation reducing the need for “as required” anti-psychotic medication.</li> <li>5. Staff willing to be flexible and try new interventions.</li> <li>6. Intuitive technology as a tool for interventions</li> <li>7. Varied and multiple interventions.</li> <li>8. Staff witnessed interventions benefiting participants' mood.</li> <li>9. Undertaking intervention in a timely manner de-escalated agitation.</li> </ol>	<ol style="list-style-type: none"> <li>1. Initial lack of ownership of interventions as a support team.</li> <li>2. Low staff to participant ratios.</li> <li>3. Time-consuming to train staff and set up interventions.</li> <li>4. Significant time to refurbish/adapt the physical environment.</li> <li>5. Initial reticence of staff to implement the intervention as it was a change in established ways of working, and perceived as “something else to do”</li> <li>6. Initial staff scepticism that participants would not engage with interventions or that they would not work.</li> <li>7. Transitioning from task-centred care to person-centred approach.</li> <li>8. Lack of Internet access.</li> <li>9. Lack of digital confidence and skills of some social care staff.</li> <li>10. Some participants required ongoing support with technology.</li> </ol>

experience of accommodation between people with intellectual disabilities and dementia (Bigby, 2010).

## 4.2 | Challenges and facilitators in implementation for social care staff

It was evident that some staff teams changed their practice with an increase in confidence to continue with implementation and initiate wider organizational change. This reflects work in the field of intellectual disability that reports on how including perspectives directly from people with intellectual disability and dementia in research can influence practice (removed for anonymity). Staff became more aware of psychosocial interventions as alternatives to medication, something that had previously gone unquestioned. This is in contrast to the use of medication as a first response to agitation, which is widely reported across Europe and North America despite guidelines worldwide calling for a reduction in their use (Maidment et al., 2018).

Whilst technology facilitated some interventions, a challenge was evident in relation to digital exclusion and participant lack of Internet access. Across the UK, whilst rates of Internet use have increased among all population groups, 22% of disabled adults (compared to 9% of non-disabled adults) have never accessed the Internet. Likewise, staff lacked experience of the technology. This reinforces findings from studies identifying barriers around digital confidence

and skills in the social care sector, for example staff perception that people with intellectual disabilities were not receptive to digital technology (Clifford Simpican, Shivers, Chen, & Leader, 2017). Whilst digital technologies offered potential benefits, participants did require support with some digital reminiscence tools. Other interventions, such as the traditional memory box, could be interacted with independently.

## 4.3 | Photovoice to develop dialogue about dementia

Photovoice methodology has led to new learning about dementia from the perspective of people with intellectual disabilities, findings that are already influencing practice (Watchman, Mattheys, Doyle, Boustead, & Rincones, 2020). New findings include co-researcher's reflection on their own perceptions of dementia including impact on relationships and the fear of a return to institutional care. Internationally, the history of intellectual disability services is one of institutionalization (Johnson & Traustadottir, 2005). In Scotland, the long-stay hospital closure period ended in 2005 (Scottish Commission for Learning Disability, 2014). A number of older people with intellectual disabilities spent many years themselves living in institutional care or have peers who lived through this period of segregation. Seeing peers “disappear” after a diagnosis of dementia is consistent with published research (Wilkinson,

Kerr, & Rae, 2003) and with concern about progression of dementia and effects of ageing (Lloyd, Kalsy, & Gatherer, 2007).

Consistent with the aims of photovoice methodology, social action was evidenced at the individual and community levels. Co-researchers with intellectual disability have since delivered training about dementia to their peers based on learning during the study and have facilitated a dementia conference for people with an intellectual disability. Additionally, co-researchers have delivered presentations at an international conference and produced an accessible summary to disseminate findings (see Supplementary Material 9). However, policy shift is required to provide resources on an ongoing basis to support meaningful longer-term engagement with wider reach.

## 5 | SUMMARY

The present authors have evidence from a range of data collection methods to support the effectiveness of person-centred psychosocial interventions as part of a goal-setting process in reducing agitation or distress and increasing quality of life associated with dementia. The implementation of self-selected interventions afforded participants respect and promoted care that was personalized and enabling, ultimately giving more control to the person with intellectual disability. Inclusion of co-researchers with an intellectual disability provided new insight for practice about fear of dementia and impact on future support, relationships and housing. Given the incidence and prevalence of dementia among the global population of people with intellectual disability, the voice and lived experience of the person should continue to be embodied in both practice and research to inform and shape support services.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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