

Participatory film-making with people with dementia in long-term social care

Research findings

KEY POINTS FROM THE RESEARCH

- Activities already on offer within the care environment at the beginning of the study were frequent and varied; however, participants were not always fully engaged with the activities.
- It was possible to adapt participatory film-making for use with participants with dementia across a wide age-range and level of abilities. Subject areas participants chose independently for their films were diverse, but there was a strong focus on early life history and familiar places.
- Signs of well-being increased during the film-making activity, and continued to be enhanced when participants were watching their films after the intervention had ended. Film-viewing facilitated social interaction between participants and other residents. There was evidence of potential for breaking down barriers between residents with and without dementia.
- There was consistent evidence that the people who took part had capacity for higher levels of social participation than were routinely offered. During the study there was some evidence at the research site of a general shift toward more meaningful activity in the activities provided by staff. Stakeholders considered film a powerful medium for enabling the voices of people with dementia to be heard more widely.

This study explored the impact of participant-led film-making (Participatory Video) on meaningful activity, well-being and social participation for ten people with dementia living in long-term social care.

- Costs of implementation were low, with free software used throughout. However, wider implementation of the participatory film-making approach might require changes in current deployment of staff.

BACKGROUND

Activities provided for people with dementia in care homes often fail to take account of their individual abilities, interests or choices. Group activities may be based on the assumption that all participants will enjoy the same things and benefit equally from them.

The researchers' previous observations showed that during such activities people taking part were often disengaged or bored and/or frustrated. Claims by staff about the success of activities were often based on enthusiastic responses from a small number of participants, while the voices of those who were not able to take part, or did not want to, were less often heard.

This study explored the potential for a personalised film-making approach called Participatory Video (PV) to enhance well-being and social

The study represents independent research funded by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). The views expressed are those of the authors and not necessarily those of the NIHR, SSCR, Department of Health, or NHS.

NHS
National Institute for
Health Research



participation for people with dementia. PV has been developed for use with people who are prone to social exclusion as a way of facilitating their voices to be heard.

FINDINGS

Fifteen eligible participants were identified. These were people living in long-term social care who were over 65, had a confirmed diagnosis of dementia, and whose current levels of well-being or social involvement gave staff members cause for concern. Of the 15, two died during the study, and it was not possible to proceed with three others for practical or ethical reasons unconnected with the film-making process itself. The remaining ten (two men, eight women) participated in all stages of the study. Their age range was 76 to 99 years (average 87). In accordance with the Mental Capacity Act (2005) personal or nominated consultees were appointed for the seven participants who did not have capacity to consent for themselves.

Profile of existing activities in the care environment

At the beginning of the study the researchers observed each participant for one hour when he or she was taking part in an activity already provided by the care environment, for example, a music or art group. The Behaviour Category Coding frame from Dementia Care Mapping (University of Bradford, 2008) was used for this baseline measure of activity. A

letter code is used to represent different types of activity. In Figure 1 the vertical axis shows the percentage of time spent in each kind of activity.

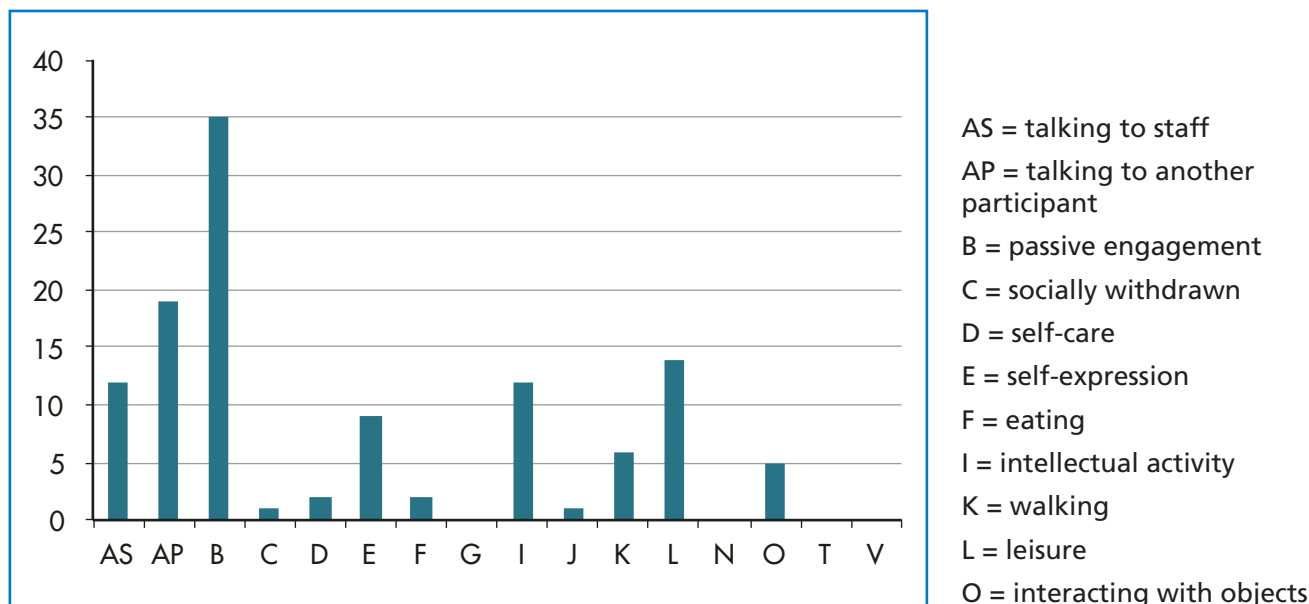
At baseline participants were engaged in activities with high potential for well-being (e.g. E = expression; I = intellectual; L = Leisure) for 31% of the time. For the same amount of time (31%) participants were either not taking part in an activity at all, or only doing so in a passive role. Some codes, e.g. G = going back, or reminiscence, did not feature at all in the baseline observation period.

Impact of participatory video on meaningful activity and well-being

Each participant had six one-hour sessions with the researchers to choose a subject for their films, identify images, develop a storyboard, create a slideshow and add sound tracks. Subjects chosen included: childhood evacuation from London to the Fens, growing up by the sea, moving from a slum clearance area to new social housing, and joining a cycling club. All themes related to early personal life history, and the majority focused on a specific geographical place.

Meaningful activity and well-being mid-way through the participatory video activity were compared with baseline. The predominant activity codes during the film-making process were G (Going back or reminiscence) 59%, AP (Articulation/talking to another participant)

Figure 1: Baseline activities



29% and E (Creative expression) 9%. There was an increase in the number of positive indicators of well-being on our measure and a decrease in indicators of ill-being during the film-making process.

Participants’ responses to their own film

It was predicted that some of the benefits to participants would arise from interaction with the researchers and other participants. While this is a desirable outcome in itself, we also wanted to find out whether there was any added value from the film-making activity. To test this, the well-being measure was repeated when participants were watching their own films at least one week after the intervention ended.

The study found that there was no significant reduction in participants’ well-being when they were watching their films without researcher intervention. This suggests that film may have some specific benefits due to the permanent record created following the creative process and the potential for participants to watch their films after the study has ended.

Changes in the activity programme at the care environment

After the six-week intervention the researchers observed each participant again for one-hour using the same measure as at

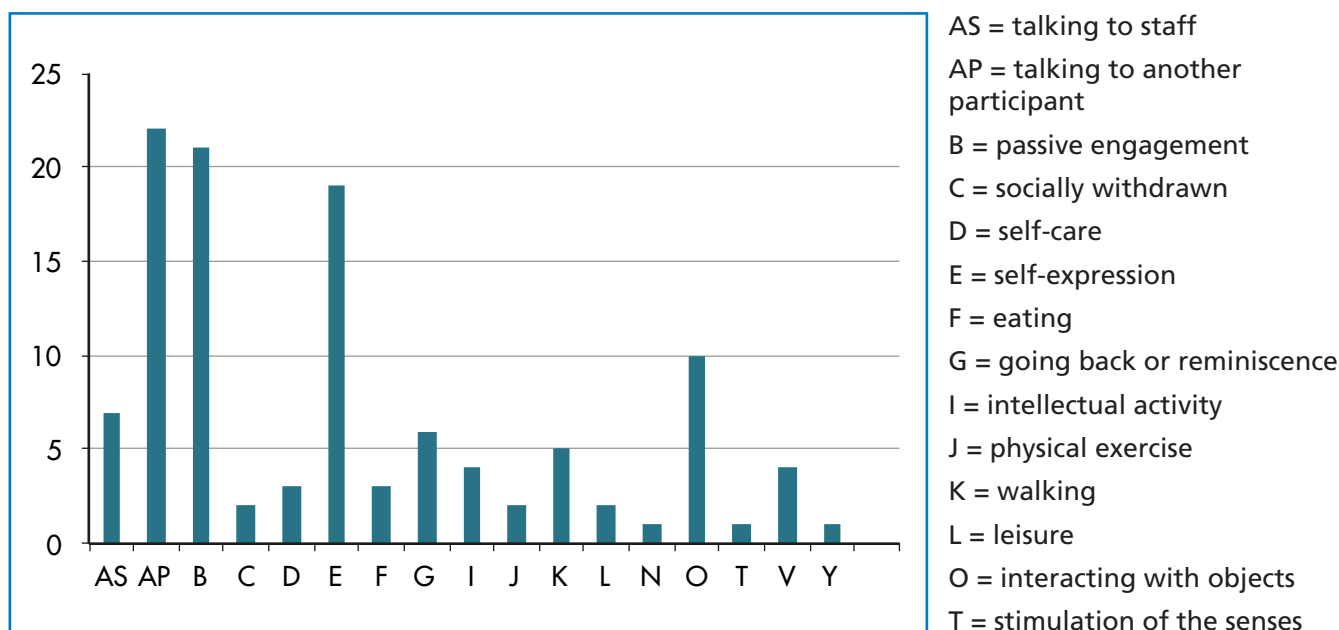
baseline. This was to find out whether there had been any changes in the kinds of activity staff of the home were now providing as a result of the study (see Figure 2).

The research team observed most of the same behaviour categories, but differences in the percentage of time spent in them. For example, self-expression (E) more than doubled by comparison with the baseline, measures, whilst disengagement (combined B and C codes) reduced from 31% to 21% of total time. The overall range of activities also increased slightly; for example the G code for reminiscence, which did not feature at all at baseline, now accounts for 5% of the time. Physical exercise (J) and stimulation of the senses (T) also appear. For eight out of ten participants well-being during this observation period also increased by comparison with the baseline.

Social interaction and participation

To assess levels of social participation, the researchers used an 8-rung ladder in which the lowest rung, ‘Manipulation’, refers to activity or inactivity which is against participants’ wishes. ‘Consultation’ within the care environment is the middle rung. The highest rung ‘Citizen Power’ refers to participant-directed activities which extend beyond the immediate care environment and into wider society. Observations against this scale were

Figure 2: End-point activities



supported by an objective summary of events and activities taken part in by each participant before and after the intervention.

The study found that all participants had more capacity for social participation than was being met at the outset, and levels of social participation increased during the study. Social interaction within the care environment was evidenced by, for example, participants spontaneously looking at their films and storyboards with other residents, including those who did not have dementia. By the end of the study six of the ten participants had also taken part in forms of social participation that extended beyond the immediate care environment including: local history websites; the organisation's newsletter; an event at a local theatre; having films entered in a film festival; joining a service user panel.

Stakeholder feedback

Two end-of-study film screening events were followed by a discussion group with four of the participants, four relatives, and four staff members. A chaplain and a regional manager from the host organisation, and a commissioner of adult social care services were also consulted. Staff members who had identified concerns about the participants' well-being and participation commented on the value of handing over decision-making to the participants, and also thought the films had an important social history function.

A variety of ways of using PV were suggested: inducting new staff; inclusion in care planning; showing to schoolchildren; and filming activities and outings to watch later on TV. One participant moved to nursing care during the study and staff of the new home found her film useful during this transition.

ABOUT THE STUDY

The study was carried out by researchers at the University of Bradford. The research used mixed methods to compare meaningful activity, well-being, and social participation before, during and after a participatory film-making activity with ten people with dementia in residential social care. Well-being was measured by the Bradford Well-being Profile and meaningful activity by the Behaviour Category Code from Dementia Care Mapping. Social Participation was measured using an adapted form of Arnstein's Ladder of Citizen Participation.

A dissemination DVD and step-by-step guide to 'Participatory film-making in adult social care' have been produced.

For further information contact Dr Andrea Capstick (01274 235192; a.j.capstick@bradford.ac.uk).

The main concern identified was the time required to sustain the activity. It was suggested that this would stem from more efficient use of staff time, since at present one-to-one time is not always used effectively due to lack of staff confidence. Family members, volunteers and students on work experience could also be taught to use PV. The step-by-step guide currently in production will provide a structured format for doing so. The process itself, carried out entirely using free software, is inexpensive and requires only an Internet-connected PC.