



Discussion paper

Evaluating arts-based programmes for people with dementia, and their impact on wellbeing

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Contents

Introduction.....	1
What is evaluation?	1
Methods of evaluation.....	1
Evaluation design	1
Repeated measures	2
Ethical issues	2
Wellbeing.....	3
Measuring wellbeing: questionnaires.....	3
Warwick-Edinburgh Mental Well-being Scale (WEMWBS)	3
Office for National Statistics subjective well-being	4
World Health Organization Wellbeing Index.....	4
Disadvantages of using questionnaires	4
Measuring wellbeing: other methods	5
Evaluating the impact on wellbeing	5
People with dementia: Issues and case studies	6
Case study: Healthbridge evaluation.....	9
Case study: Evaluating the Enriched Opportunities Programme.....	10
Case study: Mental Health Foundation: evaluation of peer support groups	11
Case study: UCL Museum Wellbeing Measures Toolkit.....	12
Case study: National Gallery of Australia	13
Case study: Greater Cincinnati chapter Wellbeing observation tool.....	14
Useful resources.....	16
Community Evaluation Northern Ireland (CENI).....	16
New Economics Forum (NEF).....	16
ONS Measuring National Wellbeing project	16
Warwick-Edinburgh Wellbeing Scale.....	17
What Works Centre for Wellbeing	17
ARK Ageing Programme	21

Introduction

Over the last few years, there has been an increasing emphasis in the research literature on the concepts of positive mental health and well-being which have become important public health and policy issues (Lloyd and Devine, 2012). Evidence of the importance of these concepts is highlighted by the recent interest by the United Kingdom (UK) Government in the happiness and well-being of the nation, with measures of both now included in general population surveys (for example, Understanding Society, and the Northern Ireland Health Survey). For such measures to be useful, however, Dolan et al. (2011) argue that they must be theoretically rigorous, policy relevant and empirically robust.

In 2010, Community Evaluation Northern Ireland (CENI) produced a review of evaluation practice in the voluntary and community sector, which this highlighted the shift to an outcomes-focussed approach to funding in recent years. This brings challenges for organisations in understanding the methods and skills needed to implement an outcomes-focus to evaluation. This Discussion Paper highlights key issues related to evaluating the outcomes of an arts-based intervention or programme for people with dementia, with a particular focus on participants' wellbeing.

What is evaluation?

An evaluation can be seen as a research project which reviews and determines whether an initiative or programme has been worthwhile in terms of delivering what was intended and expected. Evaluations can be used for different purposes, but usually involves evaluating the processes involved in a particular programme, and/or to measure the impact or outcomes of delivering this programme. The results or outputs of the evaluation can then be used to help develop more effective and efficient services and programmes. In addition, the outputs can be used to show the value to participants of delivering the programme, which can be used for lobbying or fundraising purposes. The outputs of an evaluation are also important outside an organisation, as they can provide evidence of programmes that are effective ('what works' or 'what doesn't work'), or examples of good practice.

Methods of evaluation

There are different types of evaluations depending on what is being evaluated and the purpose of the evaluation. One important distinction in evaluation types is that between **formative** and **summative** evaluation. Formative evaluations strengthen or improve what is being evaluated -- they help form it by examining the delivery of the program or technology, the quality of its implementation, and the assessment of the organisational context, personnel, procedures, inputs, and so on. In other words, they look at the process of running the programme. Summative evaluations, in contrast, focus on what happens after the programme has been delivered, and what the outcomes are. Outcomes can be described as any changes that have taken place after someone has taken part in an intervention or programme. Therefore, outcomes-based evaluations measure any changes (such as increased levels of wellbeing, or different behaviours), and also try to establish whether these changes are as a result of the particular programme or intervention.

Evaluation design

As well as deciding on whether to focus on the process, outcomes, or both, of a programme, the design of an evaluation, other design issues are important, such as repeated measures, control groups, and ethics.

Repeated measures

The repeated measures approach involves measuring the outcome (for example, wellbeing) at different points in time, usually before and after a programme has taken place. This allows the impact of a programme to be assessed. Thus, it is important that wellbeing is recorded before the programme starts (the 'baseline'). Further measurements are then taken at the end of the programme. In many studies, measurements are taken at different stages throughout the programme. They can also be taken some time after the programme has ended, to assess if the programme has had lasting impact.

Control groups

Sometimes wellbeing changes due to the participant being involved in a programme. However, sometimes wellbeing can change due to other factors. In order to assess whether the effect on wellbeing is due to participation in the programme or not, a control or comparison group should be incorporated into the evaluation, where feasible. This is a group of people with similar characteristics to programme participants, but who are not taking part in the programme.

For example, if a programme is being carried out in a residential home, half the residents could participate in a programme, whilst the other half (the control group) do not. However, all the residents would take part in the evaluation. The researchers would measure the wellbeing of all residents at the start of the programme, and at the end. If there was a change in wellbeing among the programme participants, but not among the control group, then this would suggest that the impact is due to participating in the programme. However, if there was the same change in wellbeing among all residents, then this could suggest that the impact is due to some other factor. The most important feature of using this method is that participants are randomly assigned to the programme and control group (or are 'matched' on a range of characteristics). Only in this way is it possible to ascertain the causal link between participation in the programme and the outcomes being measured.

Ethical issues

Ethical issues are important to address in any research, including evaluations. For example, Clarke et al. (2013) note that their evaluation of dementia services sought to ensure that the interests of participants were respected; that nobody came to any harm; that the rights of individuals were respected; and that participants were valued and treated fairly in every decision that was made. Informed consent is an important part of this process, whereby participants are informed about what their participation involves, and that they consent to this. In particular, Clarke and colleagues highlight that researchers must acknowledge the complexities of the process of consent by people with dementia. Another important consideration is the decision as to who is to be included/excluded when the intervention is being implemented. Some people suggest that if an intervention/programme is perceived to be of benefit then it should be offered to everyone, not just to one group. However, the key issue is that the outcome has not been tested, in other words, we do not know whether or not the programme/intervention works. Therefore, it is necessary to ensure it is effective before rolling it out to everyone.

All research projects involving Health and Social Care Service patients or patient records, Northern Ireland Prison Healthcare Service, nursing and/or residential homes require ethical approval from the Office for Research Ethics Committees Northern Ireland (ORECNI). Those that involve research with Health and Social Care staff and/or facilities require approval from the Health Trust's Research and Development Offices.

Wellbeing

There is no universally agreed definition of wellbeing and the term is often used interchangeably with 'life satisfaction', 'happiness' and 'quality of life' (Statham and Chase, 2010; Selwyn and Riley, 2015). What is agreed, however, is that wellbeing is multifaceted (Delle Fave et al., 2011; Forgeard et al., 2011; Dodge et al., 2012) and encompasses both objective (such as, income, education, health) and subjective (such as, inter-personal relationships, autonomy) aspects of a person's life (Bowling, 2011; Casas, 2011; Forgeard, et al., 2011; Selwyn and Riley, 2015; Statham and Chase, 2010).

A report by Michaelson and colleagues in 2012 provided a useful description of wellbeing:

Well-being can be understood as how people **feel** and how they **function**, both on a personal and a social level, and how they **evaluate** their lives as a whole. To break this down, how people **feel** refers to emotions such as *happiness* or *anxiety*. How people **function** refers to things such as their *sense of competence* or their *sense of being connected to those around them*. How people **evaluate** their life as a whole is captured in their satisfaction with their lives, or how they rate their lives in comparison with the best possible life.

(Michaelson et al., 2012, p. 6)

Therefore, if someone feels that they function well, have positive feelings day-to-day and overall and think their lives are going well, then they can be seen as having higher well-being than those who do not. This is sometimes referred to as 'flourishing'.

The term positive mental health is often used in both policy and academic literature, interchangeably with the term mental well-being (Tennant et al., 2007). The World Health Organization (2004) stated that positive mental health is the 'foundation for well-being and effective functioning for both the individual and the community' and defined it as a state 'which allows individuals to realise their abilities, cope with the normal stresses of life, work productively and fruitfully, and make a contribution to their community.'

Measuring wellbeing: questionnaires

There are many ways of measuring wellbeing, a number of which involve questionnaires. Questionnaires provide a quick way of gathering numeric (quantitative) information from many people, which can then be analysed statistically. They also allow information to be gathered at different times in order to measure change statistically. Three popular examples of measuring wellbeing among adults using a questionnaire are outlined below. Michaelson et al. (2012) provide useful information relating to these questions, as well as suggesting other questions that should be asked.

Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

The Warwick-Edinburgh Mental Well-being scale is used to monitor the mental well-being of groups of people over time and between groups. It consists of 14 positively worded statements. It was specifically designed to measure both the feeling and functioning aspects of positive wellbeing, in other words, whether a person is 'flourishing'. Respondents are asked to say how often each statement has applied to them over the previous two weeks. The response options are: 'none of the time', 'rarely', 'some of the time', 'often', and 'all of the time'. A shorter, seven-item version of the scale has now been developed.

The 14-item version of the scale is used in many large-scale surveys, such as the Northern Ireland Health Survey.

There is no cost for using the WEMWBS scale. However, because it is copyrighted, users should request permission and register their project. More information is available at <http://www.healthscotland.com/scotlands-health/population/Measuring-positive-mental-health.aspx>

Office for National Statistics subjective well-being

The Office for National Statistics (ONS) has developed a set of four questions about respondents' feelings, in order to assess subjective well-being. For each of the four statements (life satisfaction, feeling that what you do is worthwhile, happiness yesterday, and anxiety yesterday), respondents give a score between 0 and 10 which reflects how much it applies to them.

More information on the ONS Measuring National Wellbeing project is available at <http://www.ons.gov.uk/ons/guide-method/user-guidance/well-being/index.html>

World Health Organization Wellbeing Index

The World Health Organization Wellbeing Index (WHO-5) is a questionnaire that measures current mental well-being (over the previous two weeks). It consists of five statements, and respondents are asked to indicate how often each statement has applied to them over the previous two weeks. The statements relate to feeling cheerful and in good spirits; feeling calm and relaxed; feeling active and vigorous; waking up fresh and rested; and daily life being filled with things of interest. The response options are 'all of the time', 'most of the time', 'more than half of the time', 'less than half of the time', 'some of the time', and 'at no time'. This scale is used internationally and might be considered when international comparisons are important as it has been translated into many languages. It has been shown to be a reliable measure of emotional functioning and can help to screen for depression.

Michaelson et al. (2012) suggest that several scales, as well as a question on social trust, should be included in an evaluation questionnaire, if space and finances permit. This is because these sets of questions focus on different aspects of wellbeing. In addition, using additional well-being measures can be useful, especially where the research team expect that a programme may have an impact on specific aspects of wellbeing. These may include questions measuring self-esteem, engagement, optimism, resilience, competence or autonomy.

Disadvantages of using questionnaires

As outlined above, there are many advantages to using questionnaires to assess well-being. However, there are also several disadvantages. For example, questionnaires are often self-completion (that is, completed by the respondent). However, this relies on the respondent having appropriate visual, motor, cognitive, language and literacy levels. One solution is for a researcher to read out the questions, and record the spoken answer from the respondent. Whilst this deals with literacy and other issues, it results in other problems. Respondents may be unhappy about answering sensitive questions, or they may feel that they should give socially-acceptable answers (social desirability bias).

Measuring wellbeing: other methods

As well as using questionnaires, there are other ways of gathering information on wellbeing. These include:

- Research interviews
- Discussion groups and focus groups
- Research diaries (where people write down their feelings, behaviours and activities over a set timeframe)
- Observation of participants

Most of these methods provide information in the form of words (qualitative data) and can be used alongside questionnaire data to help explore findings in more detail. The advantage of these qualitative methods is that they can help researchers to understand not just whether a programme or intervention works but also *why* it works (or does not work). Disadvantages include the longer time taken to set up, carry out, transcribe and analysis interviews or focus group.

Evaluating the impact on wellbeing

The What Works for Wellbeing website (<http://whatworkswellbeing.org/what-works/evaluation-wellbeing-impact/>) identifies six key points relating to evaluation the impact of a programme on wellbeing:

1. Know what you want to achieve, know exactly what your programme entails, and why it matters
2. See if there is a change by capturing data at different times (for example, before, during and after the end of the programme)
3. Understand if your project is causing the change using a control or comparison group
4. Understand if the impact can be shown repeatedly
5. Show that your project or approach can be scaled up and used by others with the same outcome
6. Continuously learn from practice

People with dementia: Issues and case studies

There has been discussion about how best to measure the impact of pharmacological, psychological, educational, social interventions with people with dementia, especially given the complexity of the condition. More recently, there is agreement that researchers need to measure self-reported outcomes (such as quality of life), as well as cognition or behaviour. However, measuring quality of life in dementia is more challenging, for example, due to poor recall, time perception, insight and communication. Nevertheless, some new measures have been developed, such as DEMQOL (see Mulhern et al., 2013). DEMQoL (completed with people with dementia) and DEMQoL-proxy (completed by carers on behalf of people with dementia) measure health-related quality of life (HRQoL), which reflects a person's subjective perception of a health condition on their life. Both of these have been developed specifically for use with people with dementia and their carers (see Mulhern et al., 2013). DEMQoL uses a 28-item, whilst the DEMQoL-proxy uses a 31-item questionnaire answered by care-givers on the person for whom they care.

Clarke et al. (2013) make a strong case for the ethical responsibility of involving people with dementia, as well as their carers, within evaluation work. In particular, this stance recognises the importance of valuing people with dementia, as well as the contribution that they make to communities and societies. Thus:

If we fail to believe that the person with dementia is still a person in their own right, then we may easily fall into the habit of treating them as less than a person. Services for people with dementia need to place the person with dementia and the centre of their planning and service evaluation. We must hold on to the fact that the services we provide exist to serve the person with dementia – and that we cannot know that we are doing this unless we find some way of finding out from the person themselves.

Cheston *et al.*, 2000, p 478 cited in Clarke et al. (2013, p. 41)

It has been shown that methodologies can be developed and modified in order to allow people with dementia to participate in evaluation. Thus, this section provides case studies of evaluation tools and methods that have been used with people with dementia. However, care must be taken that these are appropriate. For example, the Bradford Well-being Profile (Bradford Dementia Group, 2008) is a tool to enable practitioners to monitor how individual people with dementia are faring psychologically and socially. However, the authors note that this type of well-being profiling is not well suited for using as an outcome measure in evaluation studies.

Clarke and colleagues (2013) acknowledge that interviewing people with dementia requires a well-considered and executed consent process, which may be revisited many times throughout the interview process. In their study, the design of the evaluation sought to be inclusive of people who were unable to consent to taking part. In those situations, a separate consent process involving a consultee (such as a carer) was set up. That study also made provision for loss of mental capacity in a participant, by including appropriate statements on the consent form.

Other challenges identified by Clarke et al. include

- Inarticulateness, due to the use of language being influenced by lack of self-esteem, social isolation, anxiety, and language skills.
- Unresponsiveness, meaning that open questions get limited responses.

- A concrete frame of reference, with difficulty generalising from experience and thinking in abstract terms.
- Problems with time, so that it may be difficult for people to ‘tell their story’.

In particular, research interviews often ask for information from interviewees that is both reflective and prospective. However, such a reliance on memory and anticipation means that this form of data collection can sometimes be difficult for people with dementia. Thus, an appropriate interviewing style includes directly-worded questions, validates the participant, reduces anxiety, and avoids asking about frequencies or time sequences.

Other research by Clarke and Keady (2002) identifies six features as being essential in collecting data with people with dementia:

- Sufficient engagement to allow confirmation of issues raised – through repeated interviews.
- A mutually trusting relationship – through a sustained period of engagement.
- A collaborative approach with the person with dementia, allowing a mutual process of agenda setting.
- Minimising anxiety and tiredness – considering the duration, pacing and location of data collection.
- Emotional engagement by the researcher so that the person is clearly valued, and know that they are valued, for their knowledge.
- Detailed attention to reliable data recording, using observational recordings as well as tape recordings.

Clarke and colleagues (2013) suggest that it is important to clearly defining the remits of the research relationship whilst also valuing people’s contributions. Therefore, that research team marked ‘endings’ of the research relationship, for example, with a card or small bunch of flowers to show appreciation for input. The Principal Investigator also wrote a letter of thanks to the participants and their carers.

Algar, Woods and Windle (2014) provides a very useful review of ways to measure quality of life among people with dementia. Whilst highlighting that people at all stages of dementia can give their views on what affects their quality of life, they discuss some of the limitations of using self-reported measures. For example, this could limit the number of participants as many measures use exclusion criteria based on cognitive or communication abilities. Furthermore, participants may be able to complete a self-report questionnaire at the start of programme that is being evaluated, but disease progression and changes in cognitive function could mean that they cannot complete the questionnaire at the end of the programme.

The use of visual or verbal prompts by family carers can be useful. For example, in one interview a carer was able to remind the person with dementia about the Peer Support Network group by using the nickname that the facilitator used, which enabled the person with dementia to recall the meeting that she had been at the previous day (Clarke et al., 2013). Carers or other informants are often used to provide information by proxy when the participant is unable to do so. Thus, for example, the team behind the DEMQOL quality of life instrument (Mulhern et al., 2013) developed a version to be completed by people with dementia, as well as a proxy version to be completed by a carer. Algar, Woods and Windle (2014) highlight that previous research has shown that caregiver’s proxy reports underestimate ratings of quality of life, especially when the participant is more cognitively impaired.

Thus, other evaluation methods have been developed, that do not rely on self-reporting in questionnaires or interviews. In particular, Algar, Woods and Windle (2014) argue that the dynamic nature of psychosocial interventions implies that the use of standardised quantitative self-report measures to measure their impact may not capture their full effect. There has been an increased interest in the use of creative therapies, which requires robust evaluations. However, Algar, Wood and Windle argue that the methods of evaluation used in these studies were poor, with inappropriate measurement tools which focus on clinical outcomes, rather than quality of life. In addition, observational methods can capture the unique effects that creative activities may have, such as increasing engagement, activity and social interaction.

There are issues to be considered when using observational methods. In particular, only a limited number of people can be observed at one time, several observers may need to be involved, the length and timing of the observations. Some evaluations have videoed their observations, which means that all the evaluators are watching the same recording at the same time. However, these recordings could be hampered by technical issues, or something as simple as someone moving in front of the camera and obscuring the view of participants. Thus, Algar, Wood and Windle contend that a combination of video and live observation would be preferable, for example, as it provides a backup if data is missed during a session. Of course, the evaluators need to consider what impact the use of a video would have on the participants.

The following case studies provide information on quantitative, qualitative and mixed-methods evaluations. Some of these programmes involve participants who are living at home, whilst others involve participants based in a residential home. Each evaluation method has advantages and limitations, and so a mixed-method approach may be most appropriate. In addition, gathering data from participants, carers and programme facilitators will gather the widest range of data possible.

Case study: Healthbridge evaluation

This evaluation focused on demonstration Dementia Adviser and Peer Support Network services set up following recommendations from the National Dementia Strategy for England (Department of Health, 2009). These services aimed to provide people with dementia and carers with information, guidance and advice, thus enabling access to a wide range of support including social groups that enabled peer learning. One of the three aims of this national evaluation was to assess the influence of the services on the well-being of people with dementia and carers.

The evaluation had a complex design, including both quantitative (questionnaires) and qualitative (in-depth interviews) data collection. The authors stress that the involvement of people with dementia and carers was integral to the evaluation. There was a strong emphasis on enabling those without capacity to provide informed consent and those for whom English was not a preferred language. Data collection tools and documentation for use by people with dementia and carers were developed in partnership with Voices North (older people, including those with dementia and carers, who are committed to supporting research).

The questionnaires were completed by people with dementia and their carers who had accessed the demonstration sites, as well as a control group from an area with no access to demonstrator site services. DEMQoL (completed with people with dementia) and DEMQoL-proxy (completed by carers on behalf of people with dementia) measure health-related quality of life (HRQoL), which reflects a person's subjective perception of a health condition on their life. Both of these have been developed specifically for use with people with dementia and their carers (see Mulhern et al., 2013). DEMQoL uses a 28-item, whilst the DEMQoL-proxy uses a 31-item questionnaire answered by care-givers on the person for whom they care. For both questionnaires, the researcher asks the questions and records the responses of the participant. All questions focus on how three main areas have been for the person in the last week: the person's thoughts and feelings; their memory in general; and everyday life.

This report highlights that DEMQoL has been previously applied within the context of an evaluation, such as an evaluation of the impact of a therapeutic garden which involved 12 people with dementia, and in the evaluation of a memory service.

The authors note several important points about the evaluation. Firstly, questionnaires were always administered by a researcher and so took place within the context of the research relationship. Secondly, researchers used large-print flash cards, which allowed people to choose their response. Thirdly, the questionnaires were invaluable in exploring the experiences of people in the later stages of dementia, for whom more abstract questions about the services were hard to engage with. The researchers found that interviewing people away from the service site meant that there were no environmental cues to the discussion topics. However, the focus and structure of the questionnaires gave prompts that helped people to talk about their well-being and quality of life.

Case study: Evaluating the Enriched Opportunities Programme

The Enriched Opportunities Programme aims to improve well-being, diversity of activity, health, and staff practice in nursing home care for people with dementia. Brooker et al. (2007) carried out an evaluation of the programme, and involved 127 residents with a diagnosis of dementia or enduring mental health problems in three specialist nursing homes in the UK. A repeated measures approach was used, in that quantitative and qualitative data were collected at three points over a twelve-month period in each nursing home, with a follow-up 7 to 14 months later.

All residents in the nursing homes were invited to participate. Consent was obtained from the residents, and from their relatives. If a resident was unable to provide consent, two members of staff who knew them well were asked to make a judgement about whether that person would be likely to have any objections to taking part.

Given the high level of cognitive impairment and the difficulty that people with dementia might have in clearly describing events in the nursing home, this research used an observational method to measure outcomes. Dementia Care Mapping (DCM) provides a measure of the diversity of activity and occupation of participants, as well as observed indicators of well-being and ill-being. This tool has been used in several evaluations to assess the impact of innovative interventions, such as group reminiscence, aromatherapy, sensory stimulation groups, intergenerational programs, and horticultural therapy.

People with mild to moderate dementia were asked for their subjective opinion of well-being and quality of life, by using the Dementia Quality of Life Instrument – (D-QOL). The 29 items in this questionnaire fit into five scales assessing the subjective experience of dementia.

This article highlights that there is a lack of good outcome measures in mental health and well-being in dementia care that are sensitive to any changes in the lives of people with dementia, particularly in those with more advanced dementia.

Furthermore, the authors suggest several limitations to their research:

- While the indicators within DCM appear to be sensitive to change over time, this is a very time-intensive method. While very rich data are produced, short forms of the DCM might be more suitable for research that focuses on an overall group, rather than on individual participants.
- Given that DCM relies on observations by the researcher, it does not allow them to assess the effect of the Enriched Opportunities Programme during times that they were not observing the participant. The authors also highlight that they did not explore the effectiveness of the programme.
- The DQOL did not prove useful in this context. It may be that other dementia specific quality of life measures may have been more sensitive to change over time. For example, the QOL-AD consists of 13 questions, and can be completed by someone with dementia, or their carer.

Case study: Mental Health Foundation: evaluation of peer support groups

The Mental Health Foundation carried out an outcomes evaluation of the impact of three peer support groups for people in the early stages of dementia living in extra care housing (Chakkalackal and Kalathil, 2014). Each group ran once a week for six months and was led by an experienced facilitator. A different activity was carried out each week. At the end of six months, it was hoped that the groups would become self-sustaining or be sustained through local support. One aim of these groups was to reduce social isolation and feelings of loneliness, and so the evaluation assessed the impact on mental health and wellbeing of group participants, plus any family members or carers who attend. Other aims of the group and of the evaluation related to memory loss and care needs.

The outcomes evaluation is based on a mixed methods design, meaning that both quantitative and qualitative data were collected from group participants:

- *Quantitative:* A questionnaire included the short Warwick-Edinburgh mental well-being scale. Participants completed the questionnaires with the assistance of a researcher: the researcher read the questions out to participants, and then manually recorded their responses. The questionnaire was carried out at three points in time: at the start of the project, at 6 months, and at 9 months.
- *Qualitative:* Individual semi-structured interviews were carried out with participants from all groups at 6 months, and at 9 months. The research asked participants open ended questions on several topics, including expectations about the group, and any changes that taking part in the group has made.

The facilitator of the peer group identified potential participants based on their level of cognitive and physical functioning, who were then approached by the researcher about being involved in the evaluation following the facilitator's introduction. Easy-read information sheets and consent forms were prepared. Verbal consent and the signature of a witness were when a participant was unable to sign.

The authors identified several limitations to this outcomes evaluation. In particular, the small sample size and additional factors (for example, death, hospitalisation or people moving away), the findings on the quantitative measures were limited. The researcher had initially planned to include a control group of housing scheme tenants who were not participating in the groups. However, this was difficult as the participant group was very diverse in terms of abilities. Therefore, it was difficult to identify a control group that was quite different from the participant group.

A process evaluation (which explored the processes of setting up and maintaining the peer support groups) was carried out separately, in order to be impartial.

Case study: UCL Museum Wellbeing Measures Toolkit

The UCL Museum Wellbeing Measures Toolkit (Thomson and Chatterjee, 2013) provides tools (Generic Wellbeing Questionnaires, and Wellbeing Measures Umbrellas) to assess levels of wellbeing due to participation in museum and gallery activities. The focus is on psychological wellbeing as an indicator of the mental state of the individual. While there are other aspects of wellbeing (for example, physical or social wellbeing), the authors focus on levels of self-reported changes in mood and emotion, as these aspects of wellbeing are more likely to change as a result of a short intervention, such as a museum activity.

Generic Wellbeing Questionnaire

The Generic Wellbeing Questionnaire has a short (six statements) or full (12 statements) version. Each of the statements are written in the past tense and relate to an aspect of emotion or quality of life experienced by a participant while taking part in an activity (for example, 'I felt happy'). The participants are asked to rate each statement out of five, depending on the extent of agreement with it. However, the response options seem to refer to how often the participant felt this particular emotion: 'none of the time', 'not very often', 'some of the time', 'very often', 'all of the time'.

The questionnaires can be given to participants to complete by themselves after an activity, or the statements can be read out by a facilitator. The first six statements of the full version exactly match the statements of the short version. One advantage is that participants who have started the full version can stop after the first six items. The full questionnaire was tested with 20 older adults with moderate to severe dementia taking part in weekly museum-related outreach activities. This led to the development of the short version, to capture essential elements of wellbeing among people who find it challenging to complete the longer version. These participants found the use of complete statements (for example, 'I feel happy') easier to understand and rate than single words. In particular, the use of short sentences is a more concrete, less abstract task for people with severe dementia.

Wellbeing Measures Umbrella

The umbrella is a hexagonal shape with six sections of different colours. Each section has a word next to it related to a wellbeing mood or emotion, as well as the numbers from one to five. Participants are asked to rate the extent to which they feel the wellbeing word at that moment by circling the appropriate number. The Umbrella is highly visual and intuitive to complete: the greater the number, the more intense the colour and the bigger the area it takes up.

There are four versions of the Umbrella, each consisting of different words: 'Positive Wellbeing Umbrella – Generic'; 'Negative Wellbeing Umbrella – Generic'; 'Positive Wellbeing Umbrella - Older Adult' and 'Positive Wellbeing Umbrella - Younger Adult'. A variety of colour schemes were tested, resulting in warm colours for the Positive Wellbeing Umbrella, cool colours for the Negative Wellbeing Umbrella, richer colours for the Older Adult Umbrella and fluorescent colours for the Younger Adult Umbrella.

The Questionnaires and the Umbrellas can be used after an activity. However, the authors state that, ideally, they should be used twice: before the activity to act as a baseline measure, and after the activity. This means that changes in wellbeing can be compared. The 'before' and 'after' measures can also be taken over time, for example, at the start of a programme, several week later, and at the end. For older adults with mild to moderate dementia, the wellbeing umbrellas were completed successfully. However, for those with moderate to severe dementia, the Generic Wellbeing Questionnaire was preferred.

Case study: National Gallery of Australia

MacPherson, Bird, Anderson, Davis and Blair (2009) describes an evaluation of the National Gallery of Australia's (NGA) art viewing programme for people with dementia. The programme involved taking people with dementia to discuss artworks at the Gallery. The main aim of the project was to explore whether participants could significantly engage in an activity which is at a higher intellectual and sensory level than programmes often provided to people with dementia. It was based on work by Artists for Alzheimer's (ARTZ) in the USA, which aims to promote quality of life for people with dementia by providing an intellectually stimulating environment in which they are actively engaged with other people and with artworks. The programme is said to improve the wellbeing of people living with dementia and their carers, and reduce negative symptoms such as withdrawal and agitation. However, MacPherson and colleagues note that these claims have not been formally evaluated.

The programme involved 15 participants, seven of whom were people with dementia living at home and or in residential care. The criteria used for inclusion in the programme were a diagnosis of dementia, people whom staff believed would benefit from the programme, and people who were able to hold at least a simple conversation. Informed written consent was obtained from all participants, supplemented by carers/guardians where appropriate.

The evaluation involved two methods. Firstly, systematic observation was undertaken, by filming the session. Two independent raters observed the films and coded participant activity, arriving by consensus at operational definitions for a range of behaviours as indicators of affect, for example enjoyment. This was undertaken in weeks 1 and week 5, in order to look a change over time. Secondly, focus groups were held for participants, carers, and NGA Educators after the programme, in order to explore perceptions and experience of the programme. Transcripts were analysed by two raters independently using grounded theory, which involves open coding of the material to identify core categories (themes) and the properties of those categories (sub-themes). Themes are not specified prior to coding.

MacPherson and colleagues note that the systematic observation method meant that rich and valuable data during the sessions was gathered, which may be missed by using standard QoL questionnaires, especially with more severe levels of dementia. This was especially important as the positive effects related to the programme did not last, and so may not have been picked up by the use of QoL questionnaires completed after the programme.

Case study: Greater Cincinnati chapter Wellbeing observation tool

The Memories in the Making (MIM) art activity programme was developed by the Alzheimer's Association in California, which focuses on the wellbeing of individuals who are living with dementia. The programme provides participants with the opportunity for enhanced sensory stimulation; the pleasure of being involved in the creative process; an enhanced sense of well-being; and an increase in self-esteem and quality of life as a result of the creation of something valuable (Gross et al., 2015). Participants are provided with watercolour or acrylic paints, brushes, and paper, and are encouraged by a facilitator to either copy a picture that is provided as a model, or to paint freestyle. The participants were only given as much assistance as was necessary to enable the artist to exercise their creative process. The painting not only exhibits the essence of the artist at the present moment, but also communicates a remembered experience that can no longer be articulated in words.

Three evaluations of MIM have been carried out, and focus on improvements in psychological well-being while participants were actively engaged in artistic activity. The most recent evaluation (Gross et al., 2015) looked at the MIM effects during, in the middle and after the 12-week MIM programme. 76 participants living in one of four residential care homes took part, all of whom were in late-middle to advanced stages of dementia. To evaluate the effects of MIM art activities on participant well-being, participants were rated on seven domains of well-being that comprise the Greater Cincinnati Chapter Well-Being Observation Tool (which was originally designed specifically for use in assessing MIM effectiveness):

1. Interest
2. Sustained Attention
3. Pleasure
4. Negative Affect
5. Sadness
6. Self-Esteem
7. Normalcy

There are five response options (never, rarely, some of the time, most of the time, always). Interns completed the tool on the first, sixth and twelfth sessions. Care home staff members completed the instrument to on each of the same days as interns, but outside the confines of the MIM sessions and at times that were convenient to them. Therefore, intern ratings reflected participant functioning during MIM art activity sessions, and staff ratings reflected functioning outside those sessions, across a wider range of times and contexts.

Algar, Woods and Windle (2014) highlight that this tool has the advantage in that it was specifically developed for a psychosocial intervention, and in particular, a visual arts intervention, and seems to give a detailed picture of how the person with dementia experiences the art sessions. It also appears to be sensitive enough to show differences within sessions and within activities.

However, other research has highlighted problems in the construction of the measures within the tool. For example, Gross and colleagues (2015) suggest that the instrument measures two domains of well-being, rather than seven. They also suggest the need to make the rating scales clearer and more objective and to anchor rating scale points more carefully. A larger number of scales contributing to each well-being domain subscale score would likely improve reliability, as would more thorough training of observers in the use of the instrument.

Gross and colleagues also undertook a qualitative evaluation, consisting of journal entries written by the interns at the conclusion of each session. Whilst these did not provide enough information for any deep qualitative analysis, the researchers felt that they were more sensitive to subtle and fleeting program benefits than the problematic wellbeing tool. Several improvements were suggested by Gross et al. that could be made when evaluating MIM: use highly trained observers who are familiar and comfortable with dementia and thoroughly trained in the assessment process; evaluate participants one at a time; use an extensive collection of psychometrically sound instruments; more thoroughly evaluate behaviour samples, ideally from video recordings; take measurements at frequent and regular intervals both during and following MIM sessions.

Useful resources

Centre for Research into Reading, Literature and Society, University of Liverpool

The main aim of the Centre for Research into Reading, Literature and Society (CRILS) is to take literature from English departments out into other disciplines and the wider human world. In particular, they have undertaken several research projects all focusing on the benefits of reading to the mental health of individuals and the societies in which they live.

<http://www.liv.ac.uk/psychology-health-and-society/research/reading-literature-and-society/>

Community Evaluation Northern Ireland (CENI)

CENI helps organisations and their funders to plan for and capture outcomes, and use the results to inform learning and improve effectiveness. In particular, their Measuring Change initiative offers a practical and low-cost solution to capturing the 'hard to measure' qualitative difference that community and voluntary activity makes to people, organisations and communities.

<http://www.ceni.org/measuring-change-approach>

Dementia Specific Health Related Quality of Life Measures

This site provides information on dementia-specific health-related quality of life measures

<http://www.dementia-assessment.com.au/quality/>

New Economics Forum (NEF)

NEF is a think tank promoting social, economic and environmental justice, and much of its work focuses on wellbeing – see <http://www.neweconomics.org/> They produce different types of resources, including publications and toolkits, for example,

The **Measuring Well-being** handbook on measuring well-being is produced by the Centre for Well-being at New Economics Forum (Michaelson et al., 2012). It is designed primarily for voluntary organisations and community groups delivering projects and services, to help them kick-start the process of measuring well-being outcomes.

The **Prove It!** Toolkit was developed to help organisations evaluate a community project by:

- Involving volunteers and beneficiaries in telling the project's story.
- Looking beyond the 'easy-to-count' to the important changes for the participants and their communities.
- Investigating how change takes place, and how to improve impact.
- Sharing and building on the learning gained from peoples' experiences of taking part.
- <http://www.nefconsulting.com/our-services/evaluation-impact-assessment/prove-and-improve-toolkits/prove-it/>

ONS Measuring National Wellbeing project

<http://www.ons.gov.uk/ons/guide-method/user-guidance/well-being/index.html>

Warwick-Edinburgh Wellbeing Scale

<http://www.healthscotland.com/scotlands-health/population/Measuring-positive-mental-health.aspx>

What Works Centre for Wellbeing

This Centre aims to improve the wellbeing of the people in the UK by bringing together the best evidence, making it easy to use and easier to make.

<http://whatworkswellbeing.org/>

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ARK Ageing Programme

The ARK Ageing Programme is a resource within ARK to support engagement between the age and academic sectors. We do this by encouraging and facilitating the production of research that will support lobbying and advocacy, and the sophisticated use of information and evidence by the age sector. In addition, we aim to embed ageing research within Queen's University Belfast and Ulster University.

This programme of work will transfer existing knowledge between the academic, policy and voluntary and community sectors, as well as identify and fill key research and information gaps. These activities will be wide ranging, such as:

- recording public attitudes to ageing issues,
- undertaking secondary analysis of key datasets,
- holding research seminars and policy round tables on key issues identified by the age sector,
- running research workshops for the voluntary and community sectors,

Funded by The Atlantic Philanthropies, as well as Queen's University Belfast and Ulster University, this programme of work will run from October 2013 to December 2016.

For more information, visit www.ark.ac.uk/ageing or find us on Facebook

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