Participatory community-based arts for older people living with dementia in the community: how are they evaluated? A scoping review

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Abstract

Although the interests in participative arts for people living with a dementia has increased over the last decade, what is yet to be reviewed is how participatory community-based arts activities for this group of people are evaluated. The overall aim of the following scoping review is to understand the scope of measurement/evaluation methods/approaches used in studies that recruited participants with dementia from the community (not from health/clinical or residential aged care settings or nursing homes) and delivered community-based participatory arts activities/programs (not art therapy programs) to them.

The methodological framework by Arksey and O’Malley (2005) for undertaking a scoping review article was applied to this study. Collation, summarizing and reporting the results was carried out considering the research questions. 7 articles met inclusion/exclusion criteria published from 2013 to 2020. The type of arts activities included co-designs and co-creation of various types of arts (n=1), museum visiting and art-making activities (n=4), artistic education-based program (n=1), group singing (n=1).

This scoping review shed light on the paucity of research in which older people living with dementia were recruited from the community (not healthcare/clinical settings) to participate in participatory community-based art activities. Also, the results revealed that evaluation of participatory community-based arts activities for older people living with dementia in the community should include methods/techniques to get a deeper insight into the participants’ values and perspectives and the social interaction benefits of such programs.

What is known about this topic and what this paper adds

What is known about this topic?
- The number of people living with dementia is increasing globally, and people living with dementia tend to live in the community, which is attributable to advantages in terms of preserving a sense of belonging, security and familiarity, as well as a sense of identity and autonomy. Participatory community-based arts activities without being constituted as a therapy aim to promote health and well-being in those living with dementia. Participatory community-based arts activities - defined broadly as a series of art activities in which individuals participate actively in community settings and are mainly provided by artists with no particular background in health education can foster social inclusion and community involvement in those living with dementia in the community. Results revealed that evaluation of participatory arts activities/programs (not art therapy programs) to them.

What this paper adds?
- Few studies recorded the effect of participatory community-based arts activities on people living with dementia in the community and included social engagement as an outcome measure.
- Most results from research on art-based approaches for people living with dementia in the community are more provisional than compelling. More rigorous metrics are required to assess the outcomes of participatory community-based arts programs (particularly social engagement aspects) for those living with dementia in the community.

Introduction

Global life expectancy has increased since 1950 by 22.4 and 23.7 years for men and women respectively.1 An increase in the prevalence of dementia is one consequence of population ageing.2 The number of people living with dementia is projected to reach 75 million by 2030 and around 132 million by 2050.3 As a consequence, the World Health Organization (WHO) recognized dementia as a health-care priority for the coming decades.4 People living with dementia experience functional decline, which negatively impacts physical and cognitive capacity.5,6 Because of the progressive detrimental effects on memory, cognition, language, behavior, planning, motivation, and judgement,7 people with dementia may also experience social consequences which deter them from remaining active in their community. The stigma associated with dementia is a major issue,8 and may result in intentional and non-intentional exclusion of individuals living with dementia from participating in mainstream society. This has negative implications for individuals living with dementia and society more generally.9 The majority of people living with dementia continue to live within their communities,10 often cared for by a family member. Ongoing social inclusion for both the person living with dementia and their caregiver offers tangible benefit given the relationship between social connection, social support and overall health.11 Broader community benefits can also result, for example, support for the continued participation of people with dementia in community activities can lead to generally enhanced understanding of dementia.
which can have a significant effect on well-being of people living with dementia and their families.12

Various types of community engagement activities are designed to ensure people living with dementia, their families and caregivers, are supported to retain their connection to the community. Such activities include co-creation programs,13 reminiscence programs,14 leisure activities,15 physical and exercise activities,16 and community gardening activities,17 to name a few.

Among various opportunities to contribute meaningfully to community engagement, there is growing evidence that community-based arts programs contribute to well-being and community improvement.18,19 Additionally, the social advantages of taking part in participatory arts activities include peer support, collaborative interactions with art facilitators and enhanced social skills.20,21 For instance, Burnside et al. (2017) demonstrated that participation in art museum activities (including an art gallery tour combined with art-making classes) for people with dementia provided the opportunity for recreation, socialization and respite. However, the study’s participants have acknowledged such programs can also have more profound personal and relationship benefit such as relationship affirmation, normalization and personal growth.22 Activities such as group singing were reported to be likely to positively contribute to the experience of the relationship between couples where one partner is living with dementia.23

Participatory art activities can be broadly described as a set of art activities in which individuals actively participate and are chiefly delivered in community settings by artists with no specific health education background.24 The objectives and goals of participatory arts initiatives differ from the practice of art therapists who are normally health care workers/professionals working in healthcare environments (hospitals or hospices), and seeking to ameliorate specific conditions.25 Rather than clinical outcomes as emphasized in art therapy, participatory arts activities are primarily a means of engaging older people- including those with dementia- within the community. Given this outcome measures, the evaluation approach to assess the outcomes of each initiative should be specifically chosen to reflect such differences.26

The beneficial and instrumental function of arts activities and their capacity to improve participants’ health, wellbeing or quality of life have been the primary focus.27-31 For older adults, including those living with dementia, sometimes measures of physical or cognitive function have been used to assess the outcomes.32,33

Although participatory arts initiatives are well known, both in practice and in the literature, the effectiveness of activities’ content is sometimes overemphasized, and relatively little consideration has been devoted to the design and evaluation of such activities and their health benefits for older adults living in the community.25 This supports the increasing need for relevant evaluation methods/approaches to assess community-based participatory arts and potentiate results of social engagement for people living with dementia.34

Additionally, it is crucial for every program (including participatory community-based arts programs) to have a variety of evaluation instruments/approaches appropriate to the needs of the participants (such as those living dementia) which measure/assess the impacts across the right outcome measures or evaluation approaches.35,36

Otherwise, the impact of a program can be overlooked or exaggerated without choice of appropriate tools. So, the choice of relevant outcomes, and robust tools to measure those, is a vital stage in designing the evaluation of activities and programs intended for older people, particularly those living with dementia.37,38

This raises the question of how participatory community-based art activities delivered to those living with dementia in the community are evaluated and whether there are gaps regarding the range of outcome measures or evaluation methods/approaches applied to specifically assess the success of such activities for people living with dementia in the community. It needs to be mentioned here that, although very recent literature39 has specifically explored the overall impact and holistic benefits of participatory community-based arts activities for people with early to moderate stages of dementia, a scoping review has not yet been applied to explore an overview to participatory community-based arts programs for older people living with dementia in the community and consider the implications of designing their activities to include participants with dementia. The results may also raise the importance of approaches to capture the perceived effectiveness of such programs more broadly, considering their initial aims and goals.

Materials and Methods

A scoping review is a tool to review, explore and map a wide range of research activity of various methods and quality and to assess the breadth/deepth and gaps or opportunities of a field.40,41

The Methodological Framework underpinned by Arksey and O’Malley (2005) was adopted in this study which encompasses 5 stages: i) defining the research question to be addressed; ii) identifying relevant/potential studies; iii) study selection; iv) charting the data; and v) collating, summarizing and reporting the results.42

Determine the purpose

The purpose of this study was to identify the measurement tools used to evaluate arts activities’ outcomes delivered within the context of community for older people living with dementia. The scope of participatory art activities was defined as those types of arts-focused activities in which the
main intents were getting people engaged in participatory art activities and being socially active or promoting health and wellness and designed for and delivered to older people residing in the community rather than health or clinical settings. The arts activities were diverse and included, but were not limited to music, dance, theatre, creative activities, painting, and drawing.

Considering the existing overlap in the literature regarding the concept of participatory community-based arts activities and art therapy, we elected to use search logs including art therapy at the first stage of our search and in the next step apply explicit inclusion and exclusion criteria to titles/abstracts and then to full-text articles. This search strategy helped the researchers to ensure that those arts projects run as community-based arts activities, but titled art therapy were not inadvertently excluded from the search.

Identify potential studies


Screen and select studies

Our inclusion criteria were: i) primary research study; ii) included aspects of participatory arts activities; iii) intended to be for older adults living with dementia; iv) arts activities for older people living in the context of the community (both selective attendance and invited by researchers); v) research published in English within the last 10 years from available international literature; vi) qualitative, quantitative, and mixed-method studies. Our exclusion criteria were: i) studies without any evaluating methods to define outcomes; ii) audience participation or non-participatory arts activities; iii) review articles; iv) art therapies, arts therapy is defined as the clinical use of multi-art forms - including but not limited to music, drama, and visual arts to accomplish individualized goals by the art therapists not the artists or art facilitators, within a therapeutic relationship; v) the studies in which the participants were recruited from aged care facilities, nursing homes, aged centers, clinics, and hospitals; vi) all studies which were not for older people with dementia. Also, the studies in which participants were recruited from health care settings have not been eliminated if the participants were recruited from the community rather than the specific health care setting.

The rationale of excluding the studies where recruitment of older people living with dementia had not occurred in the community while the activity/intervention occurred in the community was to highlight the paucity of studies in the field of art and dementia in which participants were community-dwellers living with dementia and were recruited from the community not aged care centers, health clinics or nursing homes.

The titles/abstracts were initially screened, and further screening was conducted on the full texts and a total of 7 studies (7 published articles) were included for data extraction (Figure 1). The list of all studies can be found in Table 1. The McMaster critical appraisal tools (McMaster Critical Review Form - Qualitative Studies (Version 2.0) and McMaster Critical Review Form - Quantitative Studies) were used to appraise the studies. Being freely available as well as their appropriateness for various research designs motivated the authors to choose these tools for this scoping review study. Differences and conflicts in the appraisal results were further discussed until consensus was reached between the authors.

All selected qualitative studies met the following criteria: the purpose has been stated clearly with a relevant literature review, the methods were congruent with the study purpose and theoretical perspective of the research, the study design was appropriate to the research question, with sample size, data collection, and data analysis described in detail and the conclusions were appropriate given the study findings.

Also, all selected quantitative studies had a clear purpose, relevant background literature review, well-described study design, containing details on sampling strategies. Furthermore, the outcomes area and evaluating methods were reported, and the studies had a clear description of the intervention, statistical analysis was reported in the results, conclusions and implications were appropriately described based on the study methods and results. The quality of mixed-method studies also was assessed against the parameters appropriate to methods used as described above.

Collating, summarizing and reporting the results

The extracted data were reviewed to determine the most suitable method for summarizing the findings. A content analysis was conducted to further analyze some concepts, including how the arts activities was conceptualized by the authors and the content of arts activities applied in the study, in order to synthesize this data into categories.

Results

All included participatory community-based arts activities’ characteristics that emerged from the qualitative, quantitative and mixed-method studies are summarized in Table 1, including the design, types of arts activities, the assessed/evaluated content, evaluation methods, outcomes and limitations regarding applied evaluation methods.

Types of arts programs

All 7 articles which met inclusion and exclusion criteria were published from 2013 to 2020. The types of arts activities included co-design and co-creation of various types of arts (n=1), museum visiting and art-making activities (n=4), various artistic education-based program (n=1), and group singing (n=1).

Participants’ consent (both written and verbal) was sought in all studies.

Museum-based activities

Among the four museum-based studies, two had quite bigger population size (around 100) and the other two had smaller population size (less than 50). Except for one study, caregivers (formal caregivers, family members or friends) were included as participants. The rationale for excluding caregivers in the study by Camic et al. (2019) was to assess the feasibility of the activity without the presence of family members or near friends. Also, in all four studies, people with mild to moderate dementia level were included. As part of the recruitment strategy, organizations such as Alzheimer associations were involved in all museum-based studies, along with referrals from local physicians and newspaper advertisements. Except for one study which had a wait-list control group, all other gallery-based studies were non-controlled studies. The shortest study consisted of eight weeks period and the rest were
longer interventions; up 12 months or two years. The art viewing in three studies was accompanied by art-making sessions, and only in one study, the museum object handling sessions were followed by non-memory-related open discussions rather than art-making sessions. Except for one study, the museum staff or art educators were trained according to standards such as visual thinking strategies (VTS), and TANDEM training manual, and dementia awareness training to work with and communicate with people living with dementia.

**Mixed types of arts activities**

Two studies used mixed types of arts activities either for educational purpose or for involving older people with dementia in co-designing and co-creation programs. Only in one study, the carers were included in the intervention. Both studies had a small sample size with no control group; however, only in one study the small sample size and composition was reported as a limitation. One study lasted for two months while the other was 4 months.

Both studies were set up in series workshops but with different approaches and using various types of arts. In the study by Tsekleves et al. (2020) participants and research team joined in a creative co-design phase, utilizing a range of artistic and tactile materials (Table 1). However, in the other study by Ullán et al. (2013) workshops consisted of viewing materials of diverse artists’ works, commenting on them, following by conducting specific personal cyanotype work.

**Singing**

Only in one study, group singing was used as an intervention for 17 couples where one had dementia (mild to moderate) and were still living in their own homes. Interestingly, there were differences in the types of singing activities; people living with dementia and their spouses engaged in either time-limited or ongoing singing sessions combined with singing and art viewing ending in a performance, or with music-making sessions, or with a movement group; which reportedly provided researchers with a unique opportunity to compare the results from various intervention groups.

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**PRISMA 2009 Flow Diagram**

[Flow diagram showing the PRISMA 2009 flow of study selection process.]
<table>
<thead>
<tr>
<th>Authors’ names</th>
<th>Study Design</th>
<th>Type of art activity</th>
<th>The measured concept/ the research’s initial aim</th>
<th>Measurement tools</th>
<th>Outcomes</th>
<th>Any limitation reported regarding measurement tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Tsekleves, Bingley, Luján Escalante, &amp; Gradinar (2020))</td>
<td>Qualitative</td>
<td>Co-creation of a collaborative collage/co-designing/ constructing miniature gardens</td>
<td>Whether such participatory creative practices that engage people with dementia can be considered as purely co-design (program-based)</td>
<td>Observations/audio recordings/ photography/ video recordings/post-workshop focus group with facilitator and caregivers</td>
<td>Participatory arts activities and co-design are most accessible as collaborative mixes of co-design and co-creation</td>
<td>Not available</td>
</tr>
<tr>
<td>Camic, Hubert, &amp; Kimmel (2019)</td>
<td>Quasi-experimental design</td>
<td>Museum object handling and discussing series of non-memory-related questions</td>
<td>Subjective wellbeing in dementia</td>
<td>Clinical dementia rating/the Canterbury Wellbeing Scale (CWS)/Audio recording</td>
<td>Participants largely showed a marked and statistically significant positive change in overall wellbeing scores following the intervention</td>
<td>Not directly soliciting participant’s responses to the program</td>
</tr>
<tr>
<td>Camic, Tischler, &amp; Pearman (2014)</td>
<td>Mixed-methods pre-post design</td>
<td>Art viewing/Art making</td>
<td>Social inclusion/caregiver burden/quality of life/daily living activities</td>
<td>The Addenbrook’s cognitive examination revised (ACE-R)/ neuropsychiatric inventory (NPI-Q)/the Dementia Quality of Life (DEMQOL-4)/the Zarit Burden Interview (ZBI)/the Bristol Activities of Daily Living scale (BADLS)/Semi-structured interviews/Field notes and detailed observational data</td>
<td>No difference in scores was found between the sites for caregiver burden (ZBI), activities of daily living (BADLS) and quality of life (DEMQOL). However, the natic analysis indicated potential benefits of this novel intervention</td>
<td>Lack of measure specificity in relation to the type of intervention/ small sample size/standardized measures were unable to demonstrate significant difference to caregiver burden/quality of life/daily living activities</td>
</tr>
<tr>
<td>Unadkat et al. (2017)</td>
<td>A qualitative design</td>
<td>Group singing</td>
<td>To assess impact of signing on relationship between the person with dementia and their spouse</td>
<td>The clinical dementia rating (CDR) scale/Semi structured interviews based on grounded theory</td>
<td>The group singing experience is likely to contribute positively to the experience of the relationship/CDR was not assessed after the intervention</td>
<td>The caregivers’ views were overly represented due to their better cognitive agility and verbal ability/ The potential effect of researcher assumptions</td>
</tr>
<tr>
<td>Ullán et al. (2013)</td>
<td>An exploratory qualitative study</td>
<td>Contemporary artistic educational program</td>
<td>To appraise whether people with early dementia could participate in a program of this kind and to determine their viewpoint and experience</td>
<td>Observation/focus group with professional caretakers/Mini-Mental State Examination (MMSE)</td>
<td>Dementia was not an obstacle to participation in the program/ MMSE was not assessed after the intervention</td>
<td>Not available</td>
</tr>
<tr>
<td>Schall, Tesky, Adams, &amp; Pantel (2018)</td>
<td>Randomized wait-list controlled study</td>
<td>Museum visits and artistic activity</td>
<td>To assess the emotional state/well-being/quality of life</td>
<td>Mini-Mental-Status Examination (MMSE)/Alzheimer’s Disease Assessment Scale-Cog (ADAS-Cog)/The Geriatric Depression Scale (GDS)/The Quality of Life in Alzheimer’s Disease (QoL-AD)/The Neuropsychiatric Inventory (NPI)/The Questionnaire of General Habitual Well-being/ The observations</td>
<td>Significant improvements in participants’ self-rated quality of life/Statistically significant positive changes with medium effect sizes in emotional wellbeing/The total Neuropsychiatric Inventory was significantly lower after the intervention/No significant changes in cognitive status, severity of dementia or depressive mood</td>
<td>Self-report measurements were reported to be a limitation when participants are asked to self-assess particular aspects of quality of life/Lack of standardized instruments for measuring significant social and interactive parameters in art-based interventions</td>
</tr>
<tr>
<td>Burnside, Knecht, Hopley, &amp; Logsdon (2017)</td>
<td>Qualitative grounded theory analysis</td>
<td>Gallery tours and art classes</td>
<td>To explore the components and specific effects of an art museum program from the perspectives of persons with dementia and their care partners</td>
<td>Semi-structured telephone interviews with both persons with dementia and care partner/Mini-mental State Exam (MMSE)</td>
<td>Factors such as the museum space itself, the facilitation process, and socialization with other participants were identified as important to the experience</td>
<td>Lack of formal quantitative assessments to assess the impact of programs on people living with dementia/limited elucidation of feedback through phone interview</td>
</tr>
</tbody>
</table>
Evaluative content

Program intent and outcome assessed varied. While in one study (2014) the main focus was on the nature of the program and to assess how to leverage the advantages of co-creation or co-design in creating a workspace layout that may help carers and support staff when designing activities for people living with dementia; in another three studies (2022, 2023, 2028) the participants’ experiences were the main outcome evaluation. The rationale for choosing the evaluation methods was different in each study. In one study (2022) it was based on the researchers’ assumption that obtaining knowledge of the participants’ experiences would provide valuable details for the continued growth, progress and assessment of those programs. However, the in-depth analysis of participants’ experience in two other studies (2023, 2027) was conducted to determine whether these individuals might be able or willing to engage in the system and how such interventions would add to their quality of life, or to assess how such programs might be beneficial for those living with dementia as well as their partners. Being more focused on participants’ benefits, subjective wellbeing was assessed in two studies (2023, 2024) with the aim of better understanding of cognitively stimulating, creative, socially rewarding and engaging activities for people living with dementia, without depending on reminiscence, past experience or memory. Also, other potential outcomes such as social inclusion, caregiver burden, and daily living activities were only assessed in one study (2026) based on integrating three different theoretical insights (the constructivist museum model, the uncommitted potentiality of change and positive influences of arts on health promotion). Quality of life was assessed in two studies (2024, 2026).

Considering the assessed content and aims of the included studies, results of this scoping review revealed that in only two studies (2023, 2027) social inclusion was specifically targeted. However, even if not basically initially identified, the social engagement aspects of participatory arts programs were acknowledged in another three studies (2021, 2025, 2028).

Evaluation approaches

Cognitive assessment tools

Except for one study (2021) which did not include any cognitive assessment tools, various evaluation methods were implemented for various purposes such as assessing the level of participants’ impairment for inclusion purposes (2022, 2023, 2024, 2027, 2028, 2029) and to use as a measure of functional decline in people with dementia before and after the intervention (2026) among which mini-mental state exam (MMSE), was the most common, either administered as the sole cognitive impairment evaluation approach (2022, 2023) or in combination with other cognitive assessment tools such as Alzheimer’s disease assessment scale-Cog (ADAS-Cog). (2024) Also, severity was determined using other evaluation methods/approaches such as the clinical dementia rating (CDR) scale in the study by Unadkat et al. (2017). Only in one study, caregivers’ perspective was assessed using Addenbrook’s cognitive examination revised version (ACE-R) along with the neuropsychiatric inventory (NPI-Q) (an evaluation approach used by carers to identify neuropsychiatric symptoms in older adults) as proxy.

Tools to assess wellbeing

Two different scales were administered as pre-test, post-test to assess the emotional and subjective wellbeing of participants. Although both scales were self-rating and based on pictorial and visual response system, the questionnaire of general habitual well-being used by Schall et al. (2018) was shorter with seven faces ranging from very happy to very sad. Moreover, the Canterbury wellbeing scale (CWS) was implemented by Camic et al. (2019) with the rationale that this scale has been designed to be used by people living with dementia, having advantages such as being visual, easy-to-administer, providing minimal distraction, not being unpleasant and suitable for use in various community settings. Using the standard well-being scales in both studies, researchers were able to demonstrate marked, significantly positive change in participants’ well-being following the intervention. The only difference was that in the study by Camic et al. (2019) detailed results showed larger positive increases in wellbeing in early stage participants compared to those in mild stage of the condition.

Tools to assess quality of life

To assess quality of life, the dementia quality of life (DEMQOL-4) questionnaire and quality of life in Alzheimer’s disease (QoL-AD) questionnaire were used. Both scales were administered as self-assessment pre-post-test tool. Although the intervention group demonstrated significant improvement in self-reporting quality of life (QoL-AD) in the study by Schall et al. (2018), self-assessed quality of life in the study by Camic et al. (2014) remained stable after the intervention.

Other standard evaluation methods

Four more standard measurement tools were used in two studies (2024, 2026) for various purposes. Two of the scales were assessed by the carers including the Zarit burden interview (ZBI) (which is a 22 item scale to assess the severity of caregiver perceptions of burden or stress in caring for people living with dementia), and the Bristol Activities Of Daily Living Scale (BADLS) to assess the ability of people living with dementia to do daily activities. Although no statistically significant difference in scores was found between the sites for caregiver burden (ZBI) and activities of daily living (BADLS), there was a marginal movement towards reducing the carers burden over the duration of the study, which was reinforced more clearly by thematic studies.

The other two standard scales were administered as pre-post-tests to assess depressive symptoms of the participants and neuropsychiatric symptoms of people with dementia. Although the geriatric depression scale (GDS) was considered suitable for assessing depressive symptoms in older adults, the neuropsychiatric inventory (NPI) was a more dementia specific scale, designed to assess 12 neuropsychiatric symptoms usually found in dementia such as delusions, agitation, depressed mood, anxiety or apathy. Both scales demonstrated beneficial effects of the intervention on depressive symptoms and dementia related behavior (particularly agitation and apathy).

Qualitative evaluation methods

A broad spectrum of qualitative assessment tools was used in all studies, even as the sole method of collecting data or as a mixed methods approach with different quantitative scales. Qualitative evaluation approach for collecting data to assess the benefits of interventions.

In 5 of the studies, social inclusion was specifically targeted. However, even if not basically initially identified, the social engagement aspects of participatory arts programs were acknowledged in another three studies. Considering the assessed content and aims of the included studies, results of this scoping review revealed that in only two social inclusion was specifically targeted. However, even if not basically initially identified, the social engagement aspects of participatory arts programs were acknowledged in another three studies.
Limitations regarding evaluation methods

A wide range of limitations regarding evaluation methods/approaches and scales to assess the effectiveness of interventions were discussed in almost all included studies. For instance, some limitations were related to the lack of focus on the intervention such as lack of explicitly seeking answers from the participants related to the intervention$^{45}$ or the lack of measure specificity in relation to the type of intervention.$^{28}$

Also, in some studies, attention was called to the need for tailored standardized measurement tools to assess the target parameters such as social and interactive parameters$^{46}$ as well as mood, communication, social engagement, and other salient outcomes$^{22}$ in arts-based interventions for people living with dementia; creation and validation of those scales was strongly recommended due to the lack of clear outcome evaluation approaches/methods.$^{22}$

Moreover, in some cases the limitation was not due to the lack of suitable scale, instead it was related to the lack of application in dementia research. To illustrate, the visual analogue scale (VAS) was reported to be suitable yet neglected scale in dementia research.$^{45}$ A paucity of visual/pictorial scales, was reported to be a limitation specially when seeking self-report from people living with dementia beyond a certain degree of cognitive impairment.$^{46}$

Furthermore, some limitations were reported as the result of using qualitative design such as the potential effect of researcher assumptions and overly representing caregivers’ points of view due to their better cognitive and verbal ability while conducting interview sessions.$^{23}$ However, in another study,$^{28}$ using thematic analysis of observations and field notes successfully demonstrated the benefits of the implemented intervention, while the results of standardized scales failed to support the same outcome.

Discussion

There are a range of examples of community-based art activities designed and delivered solely for older people with dementia, recruiting participants from aged care settings, including aged care, community mental health services and in-patient centres or delivering art activities in day centres recruiting participants from the same centres or continuing-care retirement community or in-patient centre. Although the research described in abovementioned studies delivered art activities in the community, some might claim it couldn’t be considered as a genuine community-based research as recruitment was limited to discrete areas; so, as far as community-based art activities are concerned, the results of this study indicated that there are only a few studies described as recruiting their participants from the general population rather than clinical/health care settings.$^{13,22,23,28,45-47}$

Despite a large volume of literature being available in the domain of arts, few studies reported the impact of participatory arts activities on older community residents living with dementia and included social engagement as an outcome evaluation approach.$^{45,55-57}$

This study confirms that that the characteristics of arts activities within the context of the community which determine that it is, in fact participatory community-based art, are not clear. Analysis of the literature on participatory arts activities in the community is complicated by the absence of a clear definition for community-based art programs. This result is also in line with previous studies.$^{25,33}$

Furthermore, results revealed that despite the perceived importance of participatory community-based arts activities for older people living with dementia, there remains a paucity of evidence in this field. This finding is consistent with that of Zeilig et al. (2014), who critiqued the participatory arts programs for people living with dementia and emphasized the necessity for more studies which take place over longer periods, for a broader spectrum of people living with dementia, and studies which utilize a variety of assessment processes.

Most results from research on art-based approaches for people living with dementia in the community are more indicative than compelling. This might partially be due to methodological limitations such as the absence of control groups, the choice of evaluation methods/approach, brief intervention times and limited sample sizes, or focusing on the long-term impact of arts projects. These results also, match those observed in earlier studies.$^{31,46}$

The most obvious finding to emerge from the analysis is that, a very limited array of outcomes were evaluated in the limited number of studies that met inclusion criteria; this might foreground the potential benefits of considering participants’ perspectives in generating a wider range of outcomes which are not only relevant to the intervention but also are consistent with what people living with dementia value.$^{28}$

Although robustly designed evaluation methods/approaches are necessary to determine if an intervention is effective, assessing the outcomes of participatory arts programs (particularly social engagement) for older people living with dementia in the community is challenging. This might be due to the likelihood that evaluation is often tailored to justifying the funding or demonstrating that the provision of art in the health arena is cost-effective, rather than seeking insight into the perceived impacts of such art activities on the participants. Although the arts emphasis is on participation, social interaction, sensation, imagination, and meanings, such factors might be more challenging to test, particularly for those living with dementia;$^{31}$ which supports a need for focus on these elements, particularly social engagement factors, and taking them into consideration when designing, running and evaluating arts programs for those living dementia.

Regarding the evaluation approaches chosen, interview sessions and observations were the preferred evaluation method/approach to assess the outcomes of participatory arts programs. Interview sessions were also reported by participants to be more desirable as they can chat freely with another person regarding their perspectives rather than addressing a questionnaire.$^{29}$ Comparison of this finding with those of other studies such as Hubbard et al. (2003) confirms the usefulness of interview and observations for privileging the voice of people living with dementia. However, particular care must be taken to account for the potential effect of researcher assumptions,$^{23}$ which was also supported by other studies,$^{59,60}$ as well as the differences in retold stories of the experience of dementia in interviews with couples when one has a diagnosis of dementia.$^{61}$

Reviewing the suitability of standardized measures for older people living with dementia against rigorous criteria including the conceptual and measurement model, reliability, validity, responsiveness, interpretability, respondent and administrative burden, cultural and language adaptations is strongly recommended. Such evaluation approaches need to be complemented with qualitative approaches that enable the exploration of the perceived effectiveness of participatory art in a more comprehensive way including the social inclusion aspect of participatory arts programs.

As stated by Weitzman and Levkoff (2000), incorporating qualitative and quantitative approaches for minority elders in health studies is useful in ensuring that the quantitative assessments remained culturally relevant and in dealing with some of reliability issues with qualitative data.

Alternative approaches to evidence collection might assist policymakers and community-based arts agencies to compare
findings and further understand the potential of community-based arts for people living with dementia, particularly in fostering social engagement.

Implications for future research and practice

Although there are methodological limitations, this scoping review presents a series of findings arguing the importance of the selection of measurement tools/evaluation methods or approaches to assess the outcomes of participatory community-based arts activities for older people living with dementia. Participatory community arts have been demonstrated to deliver benefits across multiple social parameters.46,62

There is a definite need for finding appropriate measurement tools or evaluation methods/approaches to assess the outcomes of participatory community-based arts programs for older people living with dementia. This may include generating more standardized and tailored scales as well as combining qualitative and quantitative research and considering the opinions, expectations and values of people living with dementia.

Conclusions

This scoping review was undertaken to investigate the existing measurement tools and evaluation methods/approaches used for assessing the outcomes of participatory arts activities in the community for older people with dementia. The study contributes to our understanding of the impact of participatory community-based arts programs for older people living with dementia. This would be a fruitful area for further work in order to generate a richer pool of data for available and useful assessment tools to be used by researchers in evaluating the outcomes of community-based arts activities planned, organized and delivered to a wide range of participants in the community including older people with dementia.

Evaluation of community-based arts programs for older people living with dementia should include methods to gain deeper insight into the impacts of arts programs while considering participants’ values and perspectives and the social interaction benefits of such programs.

Study limitations

The main weakness of this study was the limited availability of research on participatory arts programs for older people with dementia in the community. Also, the scope of this study was limited in terms of only discussing the programs for older people; it would also be useful to extend future research to continue to survey the measurement tools or evaluation methods/approaches and the main outcomes sought on younger people living dementia. Also, the study did not include passive arts programs.

References

24. Stickley T, Wright N, Slade M. The art of recovery: outcomes from participatory arts activities for people using mental