

Research Article

Engaging in Participatory Community-Based Arts: Perspectives of People Living with Dementia

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For people living with dementia, participatory community-based art activities have the potential to enhance the dignity of the individual, reaffirm a sense of identity, and provide social engagement. To identify opportunities to enhance the inclusion of people living with dementia in participatory community-based arts activities, this study sought the insights of people living with dementia. People living with dementia were invited to participate in semistructured group interviews to share their insights about participatory community-based arts activities. Interviews were analysed thematically to explore perceptions of benefits, opportunities, and ways to enhance participation in such activities. Participation in community arts was perceived to deliver benefits to social engagement and potentially reduce stigma through offering an education opportunity. Three key areas were identified as ways to enhance the engagement of people with dementia: knowing about the existing opportunities, accessing the activities (in terms of transport, venue proximity, timing, and wayfinding), and receiving support while attending the activity. Adequate information, easy access, a welcoming and inclusive atmosphere, the facilitators' enabling approach, and a judgement-free environment are desirable features which are congruent with dementia-inclusive arts activities. Enhanced engagement of people living with dementia may reduce stigma and improve community education.

1. Background

Participatory community-based arts activities have the potential to augment the dignity of the individual and reaffirm a sense of identity for older people, including people who have a diagnosis of dementia [1]. Participatory community-based art activities are defined as those art activities or programs taking place within the community context at openly accessible locations, open to any community participant, designed and delivered by artists with a goal of active creative participation rather than a passive attendance, but not necessarily focused on amelioration of any health condition [2, 3]. Participatory arts aim for spontaneous interaction and deep engagement, which promote social interactions [1, 4], with a focus on the process of being engaged in the art making itself [5]. Community-based art is typically discriminated from art therapy by key characteristics such as delivery in community, arts, and cultural

venues rather than clinical settings, facilitation by artists or art facilitators instead of art therapists [2], and with social engagement rather than health indicators as the primary outcome.

Activities intended to support older people to engage within their communities must be accessible, affordable, and well communicated [6]. For those living with dementia, this is more critical, as difficulty accessing appropriate services is one of the major sources of frustration and harm [7]. Even where opportunities exist, people living with dementia may experience difficulties in participating in social activities, given the cognitive, perceptual, and physical impairments that may present [8]. Additional support may be required to manage participation risks to enable and empower participation, and foster enjoyment of activities in the wider community [9]. People living with dementia who experience symptoms such as withdrawal, agitation, anxiety, or impulsivity may also benefit from more person-centred

attention. It is not only dementia and its symptoms that potentially impact on an individual's self-esteem, confidence, and willingness to engage in community settings, but also the attitudes and understanding of dementia in those with whom they interact [10, 11]. Dementia stigma [12] might lead participants with dementia (and their carers) to feel unwelcome [13], embarrassed, frustrated, or aggrieved, leading them to avoid activities which exacerbate these feelings [14]. Community-based arts activities have the potential to empower people to rely on what they can do and learn, as opposed to the abilities they are lacking or struggling with as a result of dementia [15] and to challenge this stigma. Little attention to date has been applied to the uptake and suitability of community-based art for the purpose of social engagement among people living with dementia.

To build participatory community-based arts experiences, which better meet the needs of people living with dementia, the opinions and perceptions of people living with dementia should be sought. This study explored participatory community-based arts activities and the engagement of people living with dementia with particular focus on barriers and enablers to engaging in such activities. If participatory community-based arts activities are to offer a benefit in the long-term to people living with dementia, then the emphasis should be placed on the perspectives of people living with the condition as key stakeholders [16].

2. Methods

2.1. Methodological Approach. The design and delivery of appropriate care and services should incorporate users' perspectives and insights [17]. People living with dementia were interviewed to share their experiences to inform understanding [18, 19]. A qualitative thematic analysis of face-to-face group interviews of people living with dementia was employed to explore the perspectives of those living with dementia towards participatory community-based arts activities. Qualitative research methods are commonly used by researchers to answer questions about the meaning, perspective, and experiences of people [20]. Generally, qualitative research methods have been defined as a naturalistic and interpretive approach in which the phenomena are explored [21]. Older people living with dementia are amongst the most excluded group in societies [22]. Hence, a qualitative research approach/method will provide clear opportunities to respect the dignity of individuals, to enable those living with dementia to contribute to research and to share experiences, opinions, and understanding, and at the same time, this research method reflects a desire to fully understand social issues which affect the group directly or indirectly. In this study, the researcher sought to include people living with dementia who could participate in conversations which acted to gather data in a supportive manner from those who wished to participate. There are key obstacles to conducting qualitative dementia research, including determining capacity to provide informed consent, engaging in effective communication, and ensuring the credibility of data [23, 24]. However, in this study, these

issues were addressed by following the person-centred principles of accommodating needs, gaining consent, and establishing a safe place for persons living with dementia to openly share their thoughts.

2.2. Ethical Approval. Ethics approval was obtained from the Tasmanian Human Research Ethics Committee (Social Sciences) on 17th July 2017 (Ethics Reference: H0018167).

2.3. Recruitment and Consent. Since people with dementia at different stages of their condition and age might have very different needs and opinions [25], a convenience sample of older people with dementia and people with Younger Onset Dementia (YOD) were recruited from three established support groups which usually meet weekly (supported by a peak dementia body with whom the research group had an established relationship). The intention of these local support groups for older people living with dementia is to provide a safe and supportive environment where individuals can connect socially with others who are going through similar experiences. These groups can help people living with dementia to maintain social connections, reduce isolation, and improve their overall well-being. The services are provided free of charge and funded through a range of sources, including government grants, donations, and fundraising efforts.

For the purposes of this study, a formal diagnosis of dementia was not sought from participants. Rather, participants were recruited from established dementia support groups and self-reported their diagnosis of dementia. It should be noted that the study did not aim to confirm the diagnosis of dementia through medical records or other diagnostic tests, nor did it seek further information about their clinical status. Instead, the focus of the study was to explore the experiences and perceptions of individuals who are members of dementia support groups, where membership is voluntary for people with a diagnosis of dementia. This allowed for a valuable exploration of the perspectives of individuals living with dementia who are actively involved in support groups. Members of the Younger Onset Dementia support group were people who had received a diagnosis of dementia under the age of 65.

All participants were able to consent verbally and participate in the conversation. Prior to the interview, the first author (a PhD candidate) accompanied by a second author attended the support groups to meet potential participants and to provide them with an opportunity to become adequately informed about the research study, ask questions, and become accustomed to the researchers. A familiar support worker was available to address participants' needs and to assist the researcher with building rapport. The intention and content of the research were discussed by the researchers with the participants both prior to interview and in the interview session. Persons with dementia were presumed to have the capacity to consent, unless established otherwise [26]. The participants gave informed consent in both oral and written form before the interview, and a process consent approach was followed in which the

participants were reminded of their right to withdraw or temporarily halt the interview at any time, and they were offered the opportunity to receive support from their preferred carer if they wished.

2.4. Participants. Three participants were from the women's group (mean age 75.8), six from the men's group (mean age 73.6), and three from the YOD group (mean age 59.3). The participants of this study were invited from the established dementia support groups in the general community. Recruitment was open to anyone who expressed interest and had the ability to provide informed consent. No selection criteria were applied other than the requirement for consent. All eligible individuals who expressed interest in participating were included in the study.

2.5. Data Collection

2.5.1. Interviews. The initial intent of the researchers was to conduct individual interviews; however, potential participants indicated a preference to undertake group interviews to enable support to be provided by their group peers. All sessions were held at the regular group meeting location with a familiar support worker present with the participants' consent. Reflecting on the ethical requirement of respect for participants, the interviews were flexible, recognising that rescheduling or discontinuing the session might be required if the participants were tired, or identified they needed a break. Interviews were recorded with the consent of the participants and notes were taken to provide context for the researcher during analysis. Interviews were guided by an open-ended interview schedule (Appendix A).

The interview schedule was developed based on the research questions and included a series of flexible open-ended questions to allow for follow-up questions and discussion. Feedback was sought from experienced colleagues on the wording, clarity, and relevance of the questions, and revisions were made where required. Interviews took an average of 45 minutes. The recordings were transcribed verbatim by one author, and transcripts were independently audited by a second author for accuracy. Transcripts were not returned to participants.

2.6. Data Analysis. Thematic analysis was used to identify, analyse, and report themes informed by the inductive approach of Braun and Clarke [27]. Following familiarisation with the transcripts, initial themes were identified using a coding-recoding strategy [28]. Three authors separately coded subsets of the data set and compared the results, from which final themes were identified. The participants' own words were used to illustrate the themes and subthemes. To protect the anonymity of participants, the subthemes that were derived from their own words were anonymized by assigning them with labels rather than using their names or identifying information (Younger Onset Participant (YOD), Women's Group Participant (WGP), and Men's Group Participant (MGP)). The findings and conclusions were

critiqued collaboratively throughout the research process by three authors to achieve a rich interpretation of the meaning. The Consolidated Criteria for Reporting Qualitative Research (COREQ) [29] checklist was used to ensure that all details required for transparent and credible reporting of the study were provided (Appendix B).

3. Findings

3.1. Experience of Participatory Arts. Of the three participants in the women's group, one was currently involved in participatory art activities through individual singing lessons and pottery (a group activity), while the others had past experience in drawing, singing, and painting activities. Two of the six participants in the men's group had no clear connection to arts programs. The remaining participants were involved in activities undertaken some years ago or at school age. The three participants in the younger onset group had past experience of attending arts activities. One was particularly interested in the arts and reported being involved in different creative arts. Overall, participants were interested in being engaged in participatory community-based arts programs in a direct way and moreover, happy to have their opinions canvassed through the research process:

“It is great giving us the opportunity to discuss our point of view because nobody hears what we say and my wife is the only person who knows what I do and all my friends in (Town name), they don't even know who I am because I go hide from them.” (YGP1).”

During the course of the interviews key aspects of participatory community-based arts were explored. These included practical suggestions on how participation might be fostered, the potential for deeper involvement in the design and review of arts activities and the perceived benefits of participating in community arts.

3.2. Fostering Participation. Three key themes related to participation were as follows: navigating and accessing information about participatory community-based arts activities; attending the opportunity itself; and being supported when participating.

3.2.1. Navigating and Accessing Information: Knowing about It. Being able to find information about the availability of programs was considered essential but challenging by members of all groups:

“Well, if I could find one in the community, I'd give it a go, yeah. That's for sure.” (WGP1).”

Almost all participants of the three groups indicated they had limited knowledge about any current and existing arts activities in the community:

“... I don't actually know of any art groups out there that I could approach. I wouldn't know how to find out if there

are community-based art groups out there. That is what would stop me, simply because I wouldn't know." (YGP2)."

Some participants could name possible information sources such as the diary pages of the local paper, local councils' webpages, local council areas' arts precincts, and social media such as Facebook or Twitter, or search engines, but did not use them personally. For example, one participant commented:

"My wife says that it's so easy, with the internet so you just log onto the internet, and you can look up and there it is on the browser or whatever it is called." (YGP1)."

Many participants echoed their reliance on spouses or carers to find information:

"I don't use Facebook and that's cause my wife knows everything, so it doesn't matter." (MGP1)."

Having access to sufficient detailed information was important as familiarity with the activity was also an incentive to participate. For example, one of the interviewees said:

"Well, I'd certainly like pottery and I've done that before, which makes it-if you've done it before, like at school or whatever, it makes it easier to get back into it. Yeah." (WGP1)."

3.2.2. *Attending the Community Arts Opportunity: Getting There.* Accessibility factors such as timing, location and transport were important for participants. This was often expressed in terms of their age or capacity:

"Age. I'm older than anybody else here, I'm almost 85 and going out at night is a bit of a problem now so it restricts you." (MGP3)."

Additionally, day programs were considered by some to be essential:

"Day activity. That's why I'm here." (MGP1)."

Having practical support to attend an opportunity was an important consideration. One individual for example stated that:

"...my husband, he does the driving and that, like to get me places." (WGP2)."

Musing on not being able to drive anymore and relying on others for transport, one member of the younger onset group commented:

"I think one of the things that I would have a problem with, is transport. ... Because none of us can drive so we depend on other people to get to places" (YGP2)."

Navigation issues were also a concern if transport wasn't available:

"... we don't drive anymore. We can walk, but we will get lost; so, we don't want to walk." (YGP1)."

The physical location and suitability of the venues was also of importance. Suitability was associated with the traveling distance to the venue as well as some physical features:

"But obviously one's physical separation from the venue is one, how far does one have to travel? What facilities and what services are available to bring one there etc, etc?" (MGP2)."

Self-image and perception of their own capabilities and interests was also discussed by one of the participants as a possible impediment to going to arts activities.

"Wouldn't you have to overcome the barrier in your mind, that prevents you from accepting the idea that it's something you might be interested in doing? It really is a question of motivation and overcoming resistance perhaps, [resistance that might be saying] 'ah well, I'm okay the way I am, I can't be bothered.'" (MGP2)."

3.2.3. *Being Supported When Participating: Being There.* When considering the experience of participation, the skills and capacity of the facilitator of the program was important to participants. One of the participants from the women's group referred to her experience in attending a dementia specific group activity and considered the role of art facilitator to be an important and supportive part of the program.

"One of our ladies that I work with on the Monday group, she's good with the arts and everything. That's good." (WGP2)."

Poor prior experiences could also be an inhibitor to attendees. One of the participants from the men's group reflected on a negative experience of attending an arts session within a dementia group and commented that artists'/art facilitators' prejudice and lack of appreciation of the individual's creativity might act as a barrier. He commented:

"One in particular was N's effort which certainly had some merit, I'm sure it did so I suggested that we should get it in the [Art Prize]. The person who was guiding this group said, 'oh no, that's landscapes.' I said 'well what's wrong? We can interpret that as landscape.'" "Oh no, nothing like it." "Okay." Prejudging. Not seeing the humour, that's the worst part." (MGP2)."

Having access to the materials required for "having a go" at a new activity without undue preparation was a positive aspect:

“*we have got access to anything we basically want to do, artwork or anything. The art facilitators would say “come on, let’s go do some painting, let’s go do some drawing, let’s go do some whatever, we can cook some food too.” (YGP1).*”

Being accompanied by a person who they know (a family member or friend), was considered to be a helpful support to remove anxiety and the pressure of being alone in the session:

“*If it was just me, I’d be wanting to have somebody else there with me, at least for the first time. . . . well, you are not on your own. You know, you’re not all sort of like tense and everything.” (WGP1).*”

Another participant thought that modelling from others would give her confidence to attend the same activities. She commented:

“*Yeah. . . if I saw someone who was doing it and it looked as though it was a reasonable thing to do, I wouldn’t hesitate to say, Yeah, I’ll have a go at that.” (WGP1).*”

Different elements of the mood or atmosphere of the arts sessions were important considerations for people with dementia including the reaction of other attendees. Feeling secure was one concern:

“*. . . how they would respond to having someone with dementia in their art group and how they might feel. In this environment [YOD group], we are really safe. . . I mean, I would love to do it, but that might be one thing that I might need to know a little bit about, that we were actually genuinely welcome.” (YGP2).*”

One of the participants from the younger onset group disclosed some concerns about other attendees’ (people without dementia) feelings about having someone with dementia in the same group. He commented:

“*They might have a different feeling about us, they might feel uncomfortable having people with dementia in the same room, I don’t know. You will get those kinds of things.” (YGP3).*”

Despite such concerns, being open about their dementia diagnosis were considered a positive factor that may bring benefits. Others, familiar with dementia, could be a source of assistance:

“*. . . it’s nice to know that those people will give you some help if you need it, or they will help you out if you have got a problem.” (YGP2).*”

The absence of any judgement about how people execute their art was also considered an enabling factor by one of the participants from the men’s group:

“*. . . what people do that you might think’s crazy, or stupid, or mad or, they’re off the planet, but to them it’s very important. . . So, you don’t judge anybody because they do it for different reasons and that’s where the world’s gone wrong in my view. People judge too much.” (MGP6).*”

The significance and necessity of considering and accepting individual differences and needs during the activity, was important:

“*Sometimes, you can press the right buttons for people to get them smiling or get them to talk get them to understand more or learn more and all this type of stuff. Some people are either shy or they just sit in the background.” (MGP6).*”

3.2.4. *Contributing to the Design and Review of Arts Activities.* The opportunity to extending engagement with community arts beyond the art activity itself, by contributing to the design or offering feedback or evaluation of activities was also discussed. When asked about this, participants in all three groups felt they had much to offer, tempered by some concerns about the commitment this would involve.

All three groups expressed a willingness to be involved in working with others to design arts activities:

“*I’m quite happy to work with other people. It doesn’t worry me in the slightest.” (WGP1).*”

Although some felt less well positioned depending on their personal perspective:

“*When you get to 85, you’re not going to learn something new; so, I would find it very hard to participate.” (MGP4).*”

One participant touched on the possible opportunities to express his creativity that participation in design might offer. While acknowledging some changes associated with dementia, he believed that dementia has had some positive impacts on him as well, he commented:

“*My wife told me that I have lost the filter; so, I don’t know how sometimes to behave, because it runs over me, but I think at the same time, it has given me a lot more imagination. I can’t imagine things not working but they always would work.” (YGP2).*”

Being involved with designing art activities was deemed by another participant as an opening to expand their dementia-dedicated group/organisation and to demonstrate their capabilities (as people living with YOD) to the community, and he suggested:

“*If I am invited to a group, I just explain to them how our group can participate in any outings to community.” (YGP1).*”

There was general agreement that engagement in arts programs by people living with dementia offered the opportunity to challenge misconceptions and stigma.

“... nobody knows what dementia is really about. What I was saying earlier, people see the dementia name and they think that people with dementia have got wheelchairs, walking sticks and look us, we are doing somersaults, we are running, we are jogging, we are jumping.” (YGP1).”

This would offer opportunities to tailor programs or address issues and deficiencies:

“The idea of having a program and then continually revalidating the program to make sure that it is pursuing, and serving, purposes that are still valid... see whether it is capable of being adapted into something more worthwhile, or maybe just recognise that it has run its course.” (MGP2).”

3.3. Perceptions of the Benefits of Participatory Community-Based Art. Participatory community-based arts activities were seen by all three groups as opportunities for socialising, interacting with other people, and sharing their skills:

“I enjoyed doing it because of socialising, and the biggest problem that we’ve got, is we don’t meet with other people” (MGP3).”

Participation could extend beyond the art activity itself and offer new opportunities for cognitive engagement:

“I mean, rather than attempting to create art... appreciation activities might be something to do, that is pick up some ideas as to why Mona Lisa’s smile is such an enigmatic one. But just a thought.” (MGP2).”

For some, engagement in arts activities offered the opportunity to be creative, but also to express their personhood, and take pride in being recognised by others for their creativity:

“We have got people out in the community that can see what we have done. It is out there on the billboard, or it’s what they can have a look at, and they can find out and they can see what people with dementia can do.” (YGP3).”

This was seen as an opportunity to engage and educate the community:

“Showing our work in the community so they can see what dementia people can do, even though we are not like your normal dementia people.” (YGP1).”

The opportunity to express and explore their capabilities outside a dementia-specific environment or group was also welcomed:

“I guess, I would love to be a part of a wider group to a certain extent... just to actually explore something that is way out of my comfort zone right now... but I would love to get out and have some fun and I guess, let that group know that we are still people.” (YGP2).”

4. Discussion

This study explored perceptions of engagement with participatory community-based arts activities from the perspective of people living with dementia. Key themes were synthesised resulting in a participant informed model (Figure 1) to enhance inclusivity in such activities. Key elements are ensuring potential participants have sufficient information and are aware of the opportunities, delivery of the opportunities at accessible locations and appropriate times, and that informed and respectful support was available to enable active participation. Through effective collaboration with people living with dementia, design could be enhanced, delivering on outcomes of importance to both the people living with dementia, and the wider community.

Participation is more than the quantifiable performance of an activity [30]. Outcomes can include agency, engagement, purpose, meaning, satisfaction, and acquisition of skills [31]. In addition to creativity, learning, enjoyment, and communication for people with dementia [15], the participants in this study saw that the benefits could extend beyond the people living with dementia, to other attendees at the sessions-offering opportunity for engagement, enlightenment, and community education.

Arts activities offer the opportunity to challenge stigma by connecting people living with dementia with other community groups [3], and they deliver social benefits for both older [2, 32, 33] and younger people living with dementia [34].

The model for dementia-inclusive participatory community-based arts comprised three key components: knowing about it, getting there, and being there, together with opportunities for participation in both the design and review of activities.

“Knowing about it” or awareness of an opportunity, or the tools to search for an opportunity, are essential first steps in engaging with any activity [35]. While the participants in this study expressed an interest in attending participatory community-based arts activities, almost all had limited or no knowledge about how to access information about the available opportunities and limited confidence in using social media or other approaches. Lack of access to the information about existing services (clinical, health, or community services) has been reported to be among the unmet needs of people living with dementia [36, 37], and this also applies to the arts. Previous studies indicate that people living with dementia may be quite unsure about how to navigate or access information despite an understanding of the sources of information such as Facebook, Google, and local newspapers [38]. The quality of information is equally important. Quality is the accuracy, usability, and comprehensibility of the information [39, 40]. Improving both the accessibility and quality of information on participatory

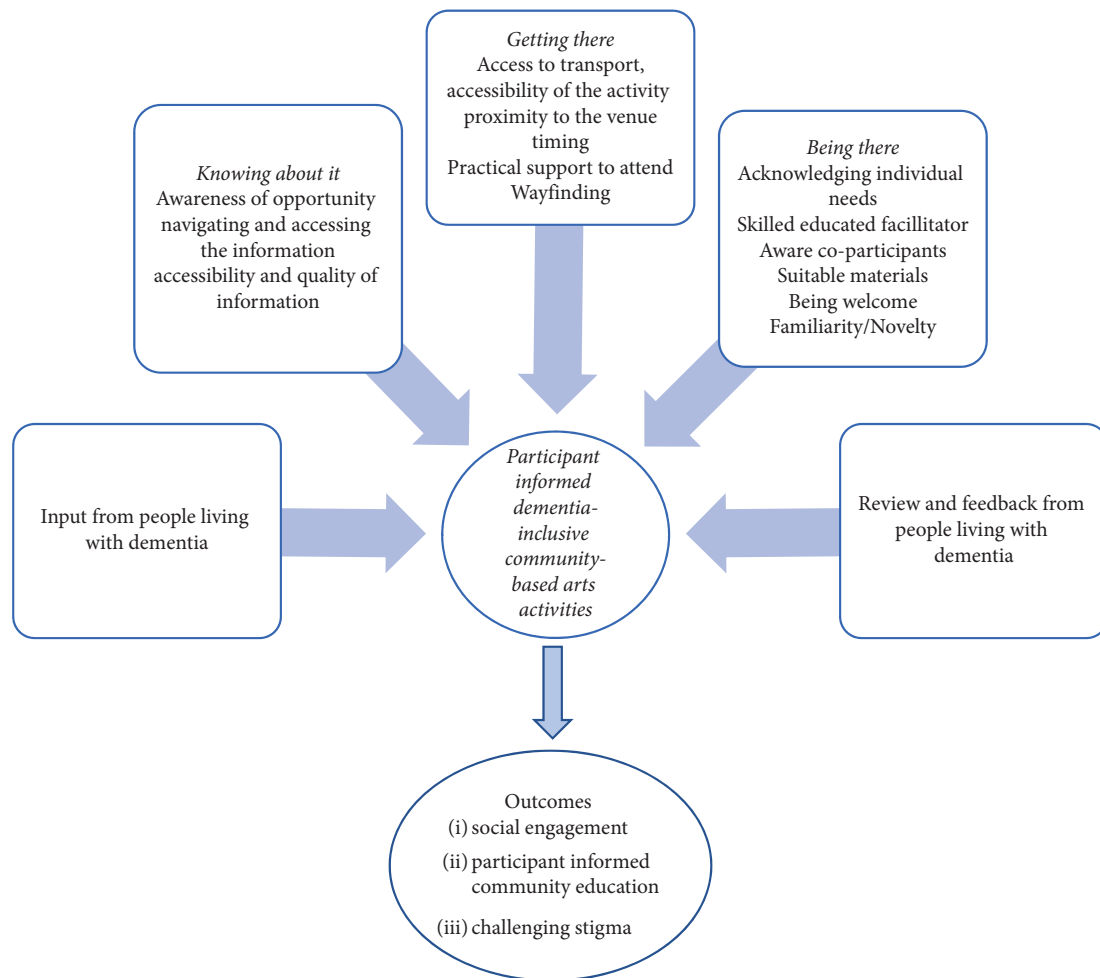


FIGURE 1: The key elements to create dementia inclusive participatory community-based arts (from the perspective of people living with dementia).

community-based arts activities for those living with dementia is an essential step to broader engagement.

“Getting there” was also a critical aspect of engagement. Reliance on others to access social opportunities is common for people living with dementia [41]. Ageing impacts the transport needs of people in general [42], with at least one-third of older people reporting unmet travel needs which are exacerbated with a diagnosis of dementia [43]. Greater reliance on others for transportation and social support is associated with an adverse effect on quality of life [44] and can add to carer responsibilities [45], thus consideration should be given to the location and timing of community arts events. While walking proximity to services and facilities has been shown to be associated with ongoing use of community services [46], adequate seating, lighting, shelter, and well-maintained pathways [47], navigation triggers [48], appropriate signage, and landmarking [49] need to be considered in developing inclusive art opportunities.

“Being there” encompasses the experience at the arts activity itself. Suitable arts opportunities should balance creativity and novelty with familiarity. The benefits of familiarity with both the activity and people are reflected in other studies where people with dementia may be more

likely to participate when their surroundings, objects, and activities are familiar to them [8, 50]. In a research study [51], individuals with dementia were able to reminisce about experiences associated with familiar songs, and the person’s confidence in their abilities was strengthened by an ability to recall lyrics and rhythm. In another study also using a mixture of a new and familiar music for dancers living with Parkinson’s disease was also found helpful in making participants feel more confident [52]. Even professional artists attending an art activity showed a higher level of engagement (in comparison to amateur artists) when they leveraged their familiarity, previous knowledge, and understanding about the activities’ content [53].

Creative expression in artistic activity has been found to be an important way for people with dementia to express and access emotions even when cognitive abilities are diminishing [4, 54]. The novelty and creativity of the activities may be an incentive to participation when it contrasts with the daily routine [1, 55]. People living with some forms of dementia, particularly frontotemporal dementia, may also express increased creative activity as the condition progresses [56]. Participation might also be accommodated through leveraging the inherently flexible and inclusive

nature of arts activities to allow participants to “go with the flow” of the activity [57] if specific needs are accommodated [58]. Decreased participant involvement may result if individuals feel their presence is not acknowledged and their particular needs are not heard, understood, or catered for [59]. Better engagement may result when people’s needs related to their capacity are met [60]. Seeking the perspectives of those living with dementia on what might make activities meaningful to them, and may fulfill their needs has been shown to improve the design of activities [50], a sentiment with which the participants in this study concurred.

Poor self-image and social confidence of people living with dementia can lead to their social withdrawal [61, 62]. Hence, it is crucial to consider that for some people living with dementia, participating in community-based arts might help overcome a negative self-image. Empowerment might occur at two levels, the individual level, and the community level. At the individual level, perceptions of “self” could be enhanced through acknowledging who a person has always been in the past and who a person is now, and their current capabilities [58]. At the community level, familiar activities might boost self-esteem and self-perception [63]. The co-attendance of familiar people can contribute to participants’ engagement with broader social opportunities and encourage their involvement in various activities in a community [64]. Being recognised is reported to facilitate a sense of connection and a belonging [65]. As with residential aged care, familiarity with faces and the environment may instill a sense of home and enable adjustment to new environments [66].

People living with dementia envisage their involvement with participatory arts as an opportunity to build community understanding of dementia. A lack of dementia-specific education or experience may result in providers feeling ill-equipped to support people with dementia in their activities [67]. Changed behaviours associated with dementia may be a concern for facilitators and, in the absence of appropriate education, may lead to misunderstanding, exacerbate stigma [14], and lead to withdrawal from activities [68]. Forgetting and loss of skills can perpetuate feelings of embarrassment, shame, and guilt, leading to the avoidance of activities [69] if not handled sensitively. In addition to an enhanced understanding of dementia, community-based artists may benefit from acquiring skills typically obtained through art therapy training such as interpersonal sensitivity, observational skills, awareness of group dynamics, and an ability to create psychological safety [70], an issue raised in this study. Providing education for artists/art facilitators in core values such as effectively promoting the autonomy and selfhood of the participant with dementia, incorporating person-centred core values such as compassion and empathy might enhance the success for all participants [71, 72].

That people living with dementia saw themselves as the conduit of this education argues for their greater engagement in the design of the programs themselves. The active connection of individuals with dementia with others, the experience [73] of meaningful involvement with another person, group, or environment, can provide comfort,

wellbeing, and sense of belonging [74, 75], but the decision whether or not to disclose a dementia diagnosis can be fraught. For some participants disclosure of their condition to other people attending arts activities was felt to be beneficial, but not without its risks. Thus, societal attention and support are required to ensure their needs of those who choose to disclose their diagnosis are recognised, and their interests are protected [76]. The inclusion of people living with dementia in the design of participatory community-based arts offers an opportunity to address the inhibitors to participation, identify suitable supports whilst educating the community about dementia.

Connecting people living with dementia and their carers to the available services in the community may require a proactive approach to promoting programs to enable effective navigation, access, and use [77]. Social prescribing is recently gaining support [78–80] to directly connect people, including people living with dementia, to a different range of nonmedical activities. Social prescribing can be defined as referring service-users to a range of nonclinical community activities [81], including exercise classes, art therapy, community groups, social services, housing support, and befriending services [82]. Improving access to social activities and opportunities for engagement of people living with dementia was recognised as one of the priorities for communities to become dementia-friendly in Dementia Australia’s first national survey of people living with dementia in 2014 [83]. However, navigation, accessing, and sourcing community services is still reported to be among the challenges of implementing social prescribing approaches [84], as is the lack of integration of such activities into existing referral processes [78]. Living alone [85], problems related to using technology-based information [86], being among culturally and linguistically diverse groups [87], and the stage of dementia [88] are further considerations which might impede access to information.

The provision of locally available, community-based, coordinated opportunities that emphasise integration and value individuals’ endeavours, and rights, to live as well as they possibly can [89] is the ideal. It is important that service providers listen to the voices of those living with dementia, to provide opportunities that are tailored [90].

4.1. Limitations. This study recruited participants from dementia-dedicated groups hosted by a provider of dementia support. Different strategies were employed to promote the study and reach participants in the broader community; however, our inability to recruit people living with dementia from other community-based groups revealed the insufficient representation of those living with dementia in many activities in the community. In deference to participant requests, we undertook the interviews as group interviews raising the risk of having dominant individuals expressing their viewpoints in group discussion and minimising the input of others. Every attempt was made to manage dominant voices in group interviews through addressing individuals while asking questions and opening the opportunity for their contribution. Although the fact

TABLE 1: Consolidated criteria for reporting qualitative research) checklist.

Topic	Item no.	Guide questions/Description	Reported on page no.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	6
Credentials	2	What were the researcher's credentials? e.g. PhD and MD	6
Occupation	3	What was their occupation at the time of the study?	NA
Gender	4	Was the researcher male or female?	NA
Experience and training	5	What experience or training did the researcher have?	NA
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	6
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. bias, assumptions, reasons, and interests in the research topic	6
Domain 2: Study design			
Theoretical framework			
Methodological orientation and theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, and content analysis	8
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, and snowball	7
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, and e-mail	7
Sample size	12	How many participants were in the study?	7
Nonparticipation	13	How many people refused to participate or dropped out? Reasons?	NA
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, and workplace	7
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	7
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data and date	7
Data collection			
Interview guide	17	Were questions, prompts, and guides provided by the authors? Was it pilot tested?	8
Repeat interviews	18	Were repeats interviews carried out? If yes, how many?	NA
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	8
Field notes	20	Were field notes made during and/or after the interview or focus group?	7
Duration	21	What was the duration of the interviews or focus group?	8
Data saturation	22	Was data saturation discussed?	NA
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	NA
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	8
Derivation of themes	26	Were themes identified in advance or derived from the data?	8
Software	27	What software, if applicable, was used to manage the data?	NA
Participant checking	28	Did participants provide feedback on the findings?	NA
Reporting			

TABLE 1: Continued.

Topic	Item no.	Guide questions/Description	Reported on page no.
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?	9-19
Data and findings consistent	30	Was each quotation identified? e.g. participant number	Y
Clarity of major themes	31	Was there consistency between the data presented and the findings?	9-19
Clarity of minor themes	32	Were major themes clearly presented in the findings? Is there a description of diverse cases or discussion of minor themes?	9-19

that participants of each group knew each other from regularly attending the same groups was helpful from some aspects, their reliance on the minority of group participants to answering questions may have limited the capture of the viewpoints of the quieter participants.

The most important limitation lies in the fact that only one of the participants interviewed in this study had current experience of participatory community-based arts activities. Undoubtedly, it would have been beneficial to additionally recruit a group of people living with dementia who were currently participating in participatory community-based arts, particularly to explore facilitators. Exploring their lived experiences as well as their viewpoints about the elements which might support or act as a barrier in accessing information, accessing the activity, and being involved in the activity could expose solutions to some of the access issues raised.

Analysing the data from the first interview before proceeding with collecting data from other groups might have provided additional avenues of exploration. This could have provided the researcher with an opportunity to learn from the first interview and to apply the learned lessons to the rest of the interviews in order to obtain more in-depth data about specific areas of interest. Despite this, the findings from the different groups were rich and informative and important differences and similarities emerged. We knew little about the cognitive status of individuals, or the staging of dementia. This might also be considered among the limitations of this phase of the study, but the aim of this research was to capture the insights from those living with dementia who are presently living within the community irrespective of the stage of their condition, and all participants met this criterion. Understanding more about their present living arrangements, activities, and interests, however, might have provided further context for their responses.

5. Conclusions

This study shed light on the desirable features which are congruent with dementia-inclusive participatory community-based arts activities including adequate information, easy access, a welcoming and inclusive atmosphere, the facilitators' enabling approach, and a judgement-free environment. Participatory community-based arts should celebrate being "in the moment" and remove any emphasis on correctness or accuracy [3], instead allowing participants to freely use their imaginations to reconnect. Engaging in artistic activities has the potential to benefit all individuals involved and may offer a novel approach to delivering dementia education that directly involves people with dementia.

Appendix

A. Semistructured Interview Sample Questions

People living with dementia

- (i) In your own words could you please tell me why you are interested in this study?

- (ii) Can you tell me about what helps you become engaged in participatory community-based arts?
- (iii) Can you tell me about what stops you from being engaged in participatory community-based arts?
- (iv) What types of arts activities would you like to have access to?
- (v) Have you even given feedback or helped in designing/delivering participatory community-based arts activities?
- (vi) Would you like to participate in designing/delivering participatory community-based arts activities?

B. (Consolidated Criteria for Reporting Qualitative Research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A (see Table 1).

Data Availability

The data and materials that support the findings of this study are made available from the corresponding author upon request.

Additional Points

As a result of stigma, people living with dementia may become isolated, marginalised, and excluded from the community. Social inclusion through community engagement can improve feelings of connection for people living with dementia. Participatory community-based arts activities offer an opportunity for social inclusion of people living with dementia. We provide a model for design of dementia-inclusive participatory community-based arts activities informed by people living with dementia. Information about the activity reaches people living with dementia and their caregivers, family, or friends. The activities are accessible to people living with dementia. People living with dementia are supported by an informed artist, in a judgment-free and socially safe environment.

Ethical Approval

This research was conducted as part of a PhD project at the University of Tasmania and Wicking Dementia Research and Education Centre 17 Liverpool Street, Hobart TAS 7001.

Disclosure

This research was part of a PhD project supported by the University of Tasmania Graduate Research Scholarship. Open access publishing is facilitated by the University of Tasmania, as part of the Wiley-University of Tasmania agreement via the Council of Australian University Librarians.

Conflicts of Interest

The authors declare that there are no conflicts of interest.

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