**The ‘Senses Framework’: A relationship-centred approach to co-producing dementia events in order to allow people to live well after a dementia diagnosis**

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**ABSTRACT**

Dementia is a progressive disorder that affects how the brain works, and in particular the ability to remember, think and reason. It affects speech, mood, mobility, behavior and how people perceive and respond to the world around them. Contemporary approaches to understanding dementia encourage society to think about how people can live well in their communities. These approaches focus on ensuring that people with dementia see the diagnosis not as the end of their life, but rather as the beginning of a new chapter of their life. This study explores how arts events specifically tailored for people with dementia can help those with a dementia diagnosis to live well after their diagnosis. In this study, we have undertaken qualitative research in the form of semi-structured interviews with festival organisers and event managers in order to understand the value of arts festivals and events in the context of dementia care. In this paper, we present areas of best practice within the Arts and Culture sector and offer recommendations for improvement in how festival and event managers make their arts events accessible and a positive experience for those living with dementia. The key theoretical contribution of this paper is the proposition of a theoretical framework that explores dementia arts events as they relate to a palliative model on relationship-centred care for people living with dementia – the ‘Senses Framework’ – and we apply this framework from social care in an arts events context.

**Keywords:** Dementia; Quality of Life; Senses Framework; Co-Creation; Collaboration; Festival and Event Management

**INTRODUCTION**

Dementia is a progressive disorder that affects how the brain works, and in particular the ability to remember, think and reason (NHS, 2020). People with dementia (PWD) may become confused or have problems thinking or doing things they used to find easy. It affects speech, mood, mobility and how people perceive the world around them. Dementia is not a disease in itself, but a syndrome comprised of symptoms that may accompany a number of diseases that affect the brain, including: Alzheimer’s disease; vascular dementia; frontotemporal dementia; or Lewy bodies dementia (NHS, 2020). When someone has dementia, it not only affects that person, but also their loved ones and those close to them and in the wider community. Before their diagnosis, PWD carried out ‘normal’ lives within their communities and celebrated milestones coinciding with normal human development. Like everyone else, they may have travelled, engaged with forms of arts and culture, attended various festivals and events, married, had civil partnerships, raised families and had careers. This study aims to investigate how arts events can remain accessible and inclusive for people living with dementia so that they can continue to participate in arts activities and events after a dementia diagnosis.

 In 2012, the UK’s (then) Prime Minister, David Cameron, launched a Dementia Challenge that led to an increase in dementia awareness, policy improvements, research and readiness across public and private sectors in the UK and has since secured additional support from subsequent administrations (Alzheimer’s Disease International, 2019). In 2018, Edinburgh-based activist group Health and Social Care Alliance Scotland launched the Social Programme – a joint initiative between the National Museums of Scotland, National Library of Scotland, National Museums of Scotland and Edinburgh Zoo –which is a social club for anyone affected by dementia; PWD and their carers are invited to enjoy a multitude of themed events in a relaxed, stress-free environment across Edinburgh and the Lothians (Health and Social Care Alliance Scotland, 2018). In light of the country’s National Dementia Strategy (Banerjee, 2010), Connell and Page (2019) conducted research on destination readiness for dementia-friendly visitor experiences found the UK to be a trailblazer for dementia-readiness from a global standpoint.

People in the early stages of a dementia diagnosis are still largely neurotypical members of and contributors to society (Crampton, Dean, Eley & AESOP Consortium, 2012) engaging to the same leisure’s and pleasure’s they were accustomed to pre-diagnosis. This includes attendance at mainstream festivals and events. Engaging in arts experiences contributes to an individual’s wellbeing (Arts Council England, 2007). In particular, engagement in participatory arts (i.e. engaging in making art rather than passive consumption of arts) significantly contributes to a person’s sense of their wellbeing (Noice et al., 2013). Such arts events that involve participants in the creation of art help create positive memories, social relationships and contribute to positive psychological wellbeing (Noice et al., 2013). Engagement in arts activity is also linked to improved health and reduced feelings of loneliness (Cohen et al., 2006; Koga & Timms, 2001).

This research study focuses on ways in which to make arts events more accessible for PWD and their carers through the examination of value creation and strategic stakeholder engagement and how this impacts existing and developing dementia-specific market and product-enhancing policies (Dredge, 2016; Darcy, 2012b; Dementia Engagement & Empowerment Project, 2012). A detailed literature review is presented that examines the role of identity and empowerment within a health and social care context. We explore the ‘senses framework’ as a model that promotes a relationship-centred approach to the care provided to PWD (Nolan et al., 2006). This framework serves as the basis for interpreting how relationship-centred approaches to event co-producing can be applied in the context of arts events for PWD. In addition to examining strategic approaches event creation (Crowther, 2014), the literature review examines human-rights based approaches to dementia care, which includes the provision of access to leisure. The methodology is presented, followed by a discussion of the findings of this study. The paper concludes with the presentation of the theoretical model being proposed in this paper, which blends the findings of the study with the senses framework.

**LITERATURE REVIEW**

Currently, there is no cure for dementia. In the UK alone, there are an estimated 850,000 people living with dementia, and that number is expected to grow to over two million by 2050 (Prince et al., 2014). 1 in 6 people over the age of 80 has dementia and 70% of people living in care homes also have dementia or severe memory problems (Alzheimer’s Society, 2020). 52% of the population know someone who has been diagnosed with a form of the disease (Alzheimer’s Disease International, 2019). Alzheimer’s disease is the most common form of dementia and affects 50-75% of people with a dementia diagnosis (Alzheimer’s Society, 2020). Vascular dementia affects up to 20% of people diagnosed with dementia; Lewy bodies dementia affects between 10-15% of people diagnosed with dementia; and frontotemporal dementia affects up to 2% of those with a dementia diagnosis (Alzheimer’s Society, 2020). 42% of UK adults admitted that dementia is the health condition they fear being diagnosed with most in the future (Alzheimer’s Disease International, 2019). In 2015, research estimated that one in every three people born in the country will develop dementia in their lifetime (Office of Health Economics, 2015).

These figures suggest the importance of developing intervention policies and for the approach to and conversation surrounding dementia to drastically change. We must actively provide strategies on how to [re] integrate and empower people living with and caring for those with a dementia diagnosis into the community and improve social-user involvement (Luxmoore, Marrett, Calvert, Calvert, Foy, Smith & Collier, 2018). Dementia is undeniably one of the greatest contemporary social challenges we face and is often negated in terms of country-wide policy creations and commissions (Banerjee, 2010).

Zeisel (2010) argued that by connecting dementia clients through environments that can temporally withstand the course of the disease, such as music, various visual art forms and sensory experiences, it may be possible to better foster connections with others and their milieus**.** Inclusion may be societal fostered for PWD through various events that engage with familiar objects and places, serving as catalysts for connection for those affected (Phillips & Evans, 2018). Several studies highlight the positive impact of entertainment engagement on PWD, their carers and quality of life (Lem, 2015; Vanderark, Newman, Bell & Akron, 1983; Clair, 2000). This type of engagement promotes a greater sense of community (Jepson, 2019; Krause, 2007) by contributing to enhanced feelings of competence (Hays & Minichiello, 2005), improved emotional and mental health (Di Lorito, Birt, Poland, Csipke, Gove, Diaz-Ponce & Orrell, 2017; Litherland & Williamson, 2013; Lesta & Petocz, 2006) and leads to an increased sense of personal empowerment (Sixsmith et al., 2007).

Certain studies have highlighted the positive impact of entertainment and the creative arts on PWD and individuals’ quality of life (see Jepson, 2019; Zeisel, Skrajner, Zeisel, Wilson & Gage, 2018; Lem, 2015; Camic, Tischler & Pearman, 2014;Clair, 2000; Vanderark et al., 1983). According to Arts Council England’s (2007, p. 5) the ‘creative arts’ are defined as “literature and writing, theatre and drama, dance, music and visual arts, which include crafts, new media, moving image and combined arts”. Research has shown that dance has measurable physical and mental health benefits in PWD including strength, stamina, balance and an increase in mental alertness (Jepson, 2019; The Centre for Policy on Ageing, 2011). It is beneficial also in preventing falls which can have a significantly negative impact on a person’s overall health and wellbeing, surgery and hospitalisation. Other studies (see Schneider, 2018; McDermott, Ridder, Baker, Wosch, Ray & Stige, 2018; Livesey, Morrison, Clift & Camic, 2012; Clift & Hancox, 2010) have showcased the health benefits of music therapy and choral singing for PWD, as it allows individuals to exercise focus and breath control – a known combatant of stress, depression and anxiety (Van der Steen Soest-Poortvliet, Van der Wouden et al., 2017; Petrovsky, Cacchione & George, 2015) – and encourages social commitment (Schneider, 2018). Music therapy/musical outlets have also been shown to effectively reduce apathy (Goris, Ansel & Schutte, 2016), alleviate agitation (Fang, Ye, Huangfu et al., 2017; Abraha, Rimland, Trotta et al., 2017; Ray & Mittelman, 2017), improve sleep cycles (Kligler, Teets & Quick, 2016) and counteract cognitive decline through learning (Jepson, 2019) in PWD. Entertainment events and the creative arts offer a social platform for PWD to remain connected and enrich their overall wellbeing.

The recent BBC TV show “Our Dementia Choir with Vicky McClure” has highlighted in popular culture that events – such as dementia choral singing groups – provide a sense of togetherness, achievement and purpose for people with dementia and their loved ones. There has been a rise in the number of events that provide opportunities for people with dementia to live a good life and enjoy activities such as music and art with other people with dementia, and their carers. Festivals and events provide both educational and entertainment opportunities for people living with dementia and their carers outside the normal challenges of everyday life, in effect, creating communitas (Livesey et al., 2012; Clift & Hancox, 2010). Communitas in such events is achieved two-fold: firstly, through creation of a sense of belonging in which everyone is an equal and valued member of the community; and secondly, through social inclusion where the activity becomes accessible to marginalised or disadvantaged groups such as people living with dementia (Livesey et al., 2012).

From a supply side, dislodging the biomedical model of dementia and replacing it with a person-centred approach (see Kitwood, 1997a, 1997b, 1997c) allows society to understand those affected as “living with” instead of “dying from” the disease. This social approach to understanding dementia encourages us to think about how people can live well in our communities (Cantley, Woodhouse & Smith, 2005; Williamson, 2012; Caine, 2014; Shakespeare, Zeilig & Mittler, 2019) after a dementia diagnosis. Such approaches focus on ensuring that people with dementia see the diagnosis not as the end of their life, but rather as the beginning of a new chapter of their life. For people living with a dementia diagnosis, events can be seen as a means of social inclusion that allow individuals to foster social networks, combat [social] isolation and loneliness, regain a sense of citizen identity (McConnell, Sturm, Stevenson, McCorry, Donnelly, Taylor & Best, 2019) and increase their overall quality of life.

There is a growing area of literature surrounding social care and palliative care and making sure that people with dementia can live actively in their own home and remain connected to their community. Kitwood’s (1997c) sociological perspective suggests that a person’s emotional and social history, cultural values, and the daily practices in caring for affected persons can, in fact, exacerbate the disease. However, one area of dementia care that is under-explored is the value that events specifically produced for people with dementia and their carers have on being able to allow people with dementia to live well.

This research project sets out to explore how events specifically tailored for people with dementia and their carers can help those with dementia live well after their diagnosis. The research aims to create a theoretical framework that identifies the roles and values of various stakeholders at dementia events and identifies how the best outcomes can be achieved through co-creation and co-production of such events. This model can then be used by event managers when co-creating events for and with people living with dementia.

*People with Dementia: Identity and Empowerment*

Empowerment is a term often used within health care and social work intended to challenge stigma and facilitate greater freedoms to PWD. A recent study sought to co-produce a definition of empowerment with PWD (McConnell et al., 2019). The following definition was agreed upon based on their findings:

“A confidence building process whereby PWD are respected, have a voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources.” (p. 9)

Conceptually, the term ‘empowerment’ is multi-faceted, as it employs constructs at micro, meso and macro levels. The fundamental – or microlevel – application of the term is an individual’s ability to secure personal control and critical awareness of one’s socio-political position (Barr, Scholl, Bravo, Faber, Elwyn & McAllister, 2015; McConnell et al., 2019). At an organisational health management — or mesolevel – organisational constructs depend on empowerment to mean active participation in decision-making and individuals being listened to more so than simply heard. At a socio-political – or macrolevel – empowerment includes support to confront social exclusion, actively participate in dementia-specific policy creation, service commissions and community outputs, have autonomy and improve one’s quality of life (Perkins & Zimmerman, 1995; McConnell et al., 2019).

 The relative infancy of the dementia advocacy movement has been fueled by a global assumption that people with dementia lack the mental capacity and ability to speak out on matters affecting them. Regrettably, this unfounded notion has led to the exclusion of PWD’s expert by experience perspective, deflecting frontline activism to caregivers and other secondary advocates (McConnell et al., 2019; Shakespeare et al., 2019; Bartlett, 2014). This dismissal of PWD expertise by experience leads to power struggles, and such empowerment and identity issues are often rooted in these power struggles, especially within marginalised communities like dementia communities (Dementia Engagement & Empowerment Project, 2012).

***The Senses Framework***

Service delivery for PWD is not without its challenges. These challenges can be experienced as a result of an individual’s limited capacity to engage socially, acting in a way that may cause concern or distress to themselves or those around them (James, 2011; Zimmerman, Sloane & Reid, 2014). Initially, Kitwood’s (1997a, 1997b, 1997c) understanding of personhood and empowerment fostered the development of a person-centred service model that prioritised the relational capacity and interdependence specific to personhood within a community-specific dementia support outreach programme in Sheffield, England (Perks, Nolan, Ryan, Enderby, Hemmings & Robinson, 2001). A key finding of this study (see Kitwood, 1997a, 1997b, 1997c) was the importance of the triadic relationship formed between healthcare professionals, family carers and PWD. Although this work was originally focused on older people rather than specifically PWD, Nolan, Davies & Grant (2001) developed the impact of ‘relationship-centred’ dementia care services through the ‘Senses Framework’ (Davies, Nolan, Brown & Wilson, 1999; Nolan, 1997; Nolan, Davies & Grant, 2001; Nolan, Brown, Davies, Keady, Nolan & Keady, 2006). This framework (Figure 1) is used to promote high quality relationship-centred care for PWD until end-of-life, and is based on six key principles, namely senses of: achievement, belonging, continuity, purpose, significance and security (Nolan et al., 2006). This understanding of relationship-centred care suggests that exceptional care can only be achieved when all of the ‘senses’ are experienced by each member of the triadic relationship and encourages a more comprehensive vision of dementia care and research (Nolan, Ryan, Enderby & Reid, 2002).

By enriching the festival and event environment with the conscious inclusion of dementia-specific considerations, as defined by the ‘Senses Framework’, event managers have the potential to transform socio-cultural views of what constitutes quality of life, especially in relation to PWD, their carers and families and event managers themselves. Research suggests that this relationship-centred approach would also address the economic, environmental and political relationship between dementia diagnosis and quality of life, as it captures “…the importance of the interaction among people as the foundation of any therapeutic or healing activity” (Tresolini & The Pew-Fetzer Task Force, 1994, p. 11; Ryan, Nolan, Reid & Enderby, 2008).

**[Insert Figure 1]**

***Barriers and Facilitators to Participation***

*Marginalisation*

Even with advances being made by dementia activists, PWD are still marginalised within their communities as a result of barring practices and outlooks – whether deliberate or not. The root cause of marginalisation against the dementia community is due in large part to ignorance amongst the neurotypical majority and a lack of implemented accommodations to better service the accessibility needs of PWD. The instrumental power exercised by certain organisations, service providers and event managers deters PWD maximising their choice and autonomy in certain environments (McConnell et al., 2019). Instrumental power disallows intervention or empowerment of/by individuals and marginalised groups (McConnell et al., 2019). In the service and healthcare profession, practitioners tend to exercise power at the expense of their patients’ power. The experience design of everyday life has not been seamlessly designed to accommodate users with memory, communication, mobility and/or behavioural impairments, and furthermore, staff may lack the proper training required to assist such individuals (Darcy, 2012a, 2012b; Caine, 2014). As a result, PWD face multiple barriers in achieving full participation in daily leisure activities. Entertainment venues such as theatres, dance halls and cinemas offer periodic dementia-friendly events, but when planning and organisational skills are no longer one’s forte, maintaining a social calendar becomes increasingly challenging. Issues pertaining to physical and social accessibility are not necessarily mutually exclusive, and oftentimes, carers and health professionals forget the fundamental needs required of personhood: a sense of belonging, social significance and the power of physical touch and/or intimacy (Nolan, Brown, Davies, Keady, Nolan & Keady, 2006**;** Shakespeare, 2014**;** Watson, 2019)**.** For PWD, these factors highlight current discriminatory practices and encroach upon their dignity and citizenship. Evidence suggests that unsupportive environments contribute to increased levels of anxiety, agitation and potential humiliation (Darcy, 2012a) in people living with dementia (Walters & Jepson, 2019). Whilst a lack of inclusive arts events for PWD can lead to social isolation and loneliness, inclusive approaches to arts participation include personal benefits such as: sense of purpose, increased levels of self-worth and esteem; improved confidence and self-efficacy (Wood, Jepson & Stadler, 2018).

*Co-Creation and Collaboration*

The manner in which individuals and/or groups see themselves in relation to activities aimed at participation and empowerment promotion is a critical issue. In order to combat this, community-based initiatives for PWD need to reflect a heightened interest in the social conditions that affect those living with the illness (Dementia Engagement & Empowerment Project, 2012). Event management-specific implementation of facilitative power throughout planning and production processes would not only empower PWD, but would enable a productive redesign of event sector outputs, led by an expert by experience perspective (McConnell et al., 2019). In its application, facilitative power becomes a method of co-production intended to enhance suitability and relevance of event creation all the while building confidence in service users (National Institute for Health Research, 2014; Needleman, 2014; Brett, Staniszewska, Mockford, Herron-Marx, Hughes, Tysall & Suleman, 2014a; Brett et al., 2014b). Reporting of co-creation and co-production including PWD is a relatively new advancement, and as such, limited academic publications exist (Di Lorito et al., 2017; Rivett & Rivett, 2017; Littlechild, Tanner & Hall, 2015; Tanner, 2012; Litherland & Williamson, 2013; McConnell, 2019; Luxmoore et al., 2018). However, it is evidenced that the benefits of co-production involving PWD far exceeds the advantage of expert by experience input— the inclusion of multiple perspectives reflect a more complete experience (McConnell, 2019). Co-creators with dementia have reported an appreciation for their input being valued and an opportunity to exercise their cognitive abilities as well as an overall increase in mood (Stevenson & Taylor, 2019). In addition, empowerment was cited as a likely outcome of such participation, as the benefits of new learning also provided an agency to influence how PWD are understood (Di Lorito et al., 2017).

Event organisers are becoming increasingly more involved in event creation that requires collaborations and/or partnerships (Getz, 2005). Informed by collaboration theory (Gray, 1989; Jamal & Getz, 1995), the development of co-created and co-produced dementia-conscious events could be considered an additional policy domain within the festival tourism sector. These types of projects exist only to the extent that collaborating parties are invested in its success. With the collaboration and partnership of PWD, their carers and event managers/organisers, this project posits the merit in increasing individuals’ perception of quality of life after a dementia diagnosis. This establishment of ‘federational’ partnership (see Long, 2000) might also include additional incentives in which the tourism, events and healthcare sectors work together on a permanent basis. Eventually, this partnership may result in the development of a cross-cultural policy that promotes limitless dementia-friendly environments. This type of collaborative partnership would make strategic event creation a more multi-layered responsibility (Crowther, 2014) and would require clearer objectives and flexibility in implementation and ownership of programme deliverables (Long, 2000; Getz, 2005).

***Stakeholders and Strategic Event Creation***

In marrying the ideology behind Nolan et al.’s (2006) ‘Senses Framework’ with strategic event creation, efforts would be guided by an ‘outcome obsessed’ and stakeholder-centred approach (Crowther, 2014). Circling back to the quality of life experienced by PWD, let it be reiterated that they have all lead an ‘ordinary’ life before their dementia diagnosis. Even when one’s memories begin to fail them, research shows that support designed to engage PWD with certain objects and places may act as a catalyst for connection and recollection (Phillips & Evans, 2016). As able-minded thinkers, factions of the event creation and management sector are obligated by attendee expectations (Holbrook & Hirschman, 1982) and the commercial experiences (see Zomerdijk & Voss, 2010) dominating society to deliver an event experience designed with users and the experience economy (Pine & Gilmore, 1998) in mind. Crowther (2014) concedes that the overstimulation of daily sensory experiences demands event creators to deliver exponentially greater event stimulation each time. Arguably, events designed with PWD in mind negate this ‘standarised’ requirement—instead of being ‘bigger and better’, what if event creators and managers focused on the nostalgic element, recreating events and festivals that celebrated repetition and the familiar and a sense of comfort and ease within the experience?

 The level of competitiveness within the event marketplace prompts event creators and managers to expand into specialist markets, producing dynamic experiences for marginalised populations such as those requiring additional mobility, sensory or visual support. Equal opportunities and considerations for minority groups and accessibility are becoming a socially ‘hot topic’. As of 2015, seniors (aged 50+) and people with disabilities accounted for over 20% of the global population (Vila, Darcy & González, 2015). As of 2019, this demographic were responsible for over 40% of the UK’s consumer demand, spending more than £319 billion per year with one of the fastest growing sectors for older consumers being recreation and leisure (International Longevity Centre UK, 2019). Understandably, this has resulted in the increased efforts of Destination Marketing Organisations (DMOs) and tourism/attraction managers to facilitate and promote accessibility globally, as one’s freedom of life is recognised as a basic human right (Rickly, 2018; Buhalis, Darcy, & Ambrose 2012).

***Human rights-based approaches to dementia care***

From a policy and social perspective, it is widely recognised that there is a need to ensure a human rights-based approach for PWD. PWD are often denied their human rights both in the community and in care homes (World Health Organization, 2015). PWD are often physically or medically restrained, beaten, abused and have their belongings stolen from them (World Health Organization, 2015). To that end, many nations have recognised the need for a human rights-based approach to dementia care. In Scotland, for example, the Scottish Parliament recognised that PWD were being denied human rights due to social and cultural barriers (including a lack of awareness of PWD needs amongst the general population and a lack of training and respect from care givers (World Health Organization, 2015). In 2009, the Scottish Parliament passed a Charter of Rights for PWD and their Carers, (Scottish Government, 2011). In 2011, the Scottish Government launched the National Dementia Strategy which outlined six key human rights for PWD: one of which is the right to as independent as possible and to be included in the community (Scottish Government, 2011). This human right is further explored in the strategy and includes the right to access leisure and cultural life in the local community where they live, and the right to participate in physical and social activity and undertake lifelong learning (Scottish Government, 2011).

**METHODS**

*Design*

There were three distinct phases of this research: (1) a comprehensive and critical review of relevant literature pertaining to (a) the biomedical understanding of dementia and how, through the arts, individuals may live well with the disease after a diagnosis, and (b) how UK and Ireland’s Arts and Culture sector are implementing dementia-conscious considerations into strategic event creation. (2) Engage in conversations with Arts and Culture organisations to establish/identify: (a) the facilitators and/or barriers to providing dementia-friendly event programming, and (b) the best practices within organisations that provide dementia-friendly programming so as to create a list of recommendations for strategic event creators on how to facilitate dementia-accessibility. (3) through data analysis, create a theoretical framework that identifies (a) the roles and values of various stakeholders within dementia events, and (b) identify how the best outcomes can be achieved through co-creation and co-production with members of the dementia community of these events.

This qualitative study employed an inductive approach with a semi-structured interview design that examined the diversity of different types of events within the UK and Ireland that may or may not cater to people living with dementia. Eight semi-structured interviews took place between November 2019 and April 2020, each lasting between 30 minutes and 1 hour. The research team drew from a selection of six conversational prompts that examined the merit in dementia-friendly inclusion at festivals, any potential organisational projects (completed or future) that may include dementia considerations, existing knowledge about governmental policies and/or funding pertaining to dementia events and the barriers in creating dementia events.

*Participants*

Initially, a list of potential participants was created through examining the webpages of several well-known, UK-based dementia support organisations such as Alzheimers Scotland, Alzheimers UK and Arts4Dementia. Subsequently, the producers of the dementia-friendly events advertised through these channels were contacted to gauge interest in study participation. The authors also subscribed to several online forums created for the wider UK dementia community to gauge potential participatory interest from PWD, their carers and medical professionals working within the care of older people.

The scope of inclusion criteria were as follows:

1. Individuals working as event managers, creative producers or community engagement personnel in the festival and event industry within the UK and/or Ireland;
2. DMO’s or stakeholders working within the events or cultural tourism sector or within accessibility policy creation in the UK and/or Ireland;

Participants were recruited through the team’s personal and professional contacts throughout the UK and Ireland. 28 invitations to participate were distributed to various individuals and organisations involved in festival and/or event creation, community engagement, motivational speaking, education and gerontology. Individuals who agreed to participate in the study were introduced to the parameters of the research and informed of their rights as voluntary contributors to the investigation. Informed consent was gained from all research participants at the beginning of each interview. Interviews were conducted through video messaging platforms or by telephone.

Eight individuals employed across seven arts and culture organisations partook in the study. Two of the organisations produce one major annual event and have no direct affiliations with PWD or older people; one organisation produces one major annual event, several minor events throughout the year, and cater to an older audience demographic but are not directly affiliated with PWD; a further two organisations produce one major annual event but are part of larger organisations who supplement major programming with outreach events throughout the year and work directly with PWD and/or older people; one organisation facilitates weekly music outreach programming specifically for older people and PWD; and one organisation is an art and culture pillar within the community that collaborates with other key art and culture stakeholders to facilitate annual dementia-friendly socials for PWD and their carers.

*Ethics*

This project received full ethical approval from Edinburgh Napier University Business School’s Research Integrity and Ethics Committee who were satisfied that there was no risk of harm to any research participant. Prior to Covid-19, the research team had intended to interview PWD at festivals and events. To facilitate this, a research team member who is a Nurse Consultant with the NHS and Senior Lecturer in the School of Health and Social Care was recruited into a central research role within the team with the intention of being present at all interviews with PWD to ensure participant welfare and continuous informed consent. The onset of the pandemic meant that this particular avenue for research is yet to be explored.

*Qualitative Data Analysis*

Each interview was recorded using an electronic recording device and transcribed verbatim. Braun and Clarke’s (2006) framework was used to complete a manual thematic analysis of interview data. Key points made by participants were coded under common categories, helping to define trends in the results and ultimately establish key themes.

*Thematic Analysis*

The thematic analysis resulted in three main themes, divided into six categories (*Table 1*). Coding allowed the authors to extricate and highlight recurring themes and valuable data from each interview (Fisher & Buglear, 2007). The tracking of overarching themes aided in the triangular comparison, validation and/or invalidation of existent theoretical concepts; this was done through multi-modal source comparison (Glaser & Strauss, 1967; Corbin & Strauss, 2015). These themes are to be considered central findings for this study.

**[Insert Table 1]**

**RESULTS**

*Socio-Political Impact*

This theme consists of two categories: lack of dementia accessibility awareness and policy promotion to encourage comprehensive accessibility considerations for events within the Arts and Culture sector and additional resources to combat fundamental barriers. Greater support is needed from key policy-making stakeholders (i.e. governmental agencies and dementia-specialist organisations such as Alzheimer’s UK, Age UK, etc.) to educate and promote dementia accessibility awareness and inclusion within festivals and events.Only two participants were able to recall sources from which additional funding for dementia-specific initiatives could be applied for, evidence that dementia is not yet at the forefront of the accessibility conversation within events.

All participants confirmed that their respective organisation’s accessibility policies reflect government requirements for baseline accessibility (including mobility and at times sensory challenges with minor considerations made to the visually and/or hearing-impaired), however, does not encompass what “all-access” accessibility should entail in order to cater for all marginalised groups. On accessibility within events, participant 2, Arts Programme Manager and Artistic Director, states:

“Within an audience…made up of so many different audiences…how do you cater for each and every one of those equally? …what most people do is…cater for the ones that are easiest to cater for and those would be people who don’t have [more complicated] disabilities like…dementia.”

As public bodies, Arts and Culture organisations sit within the Equality Act (2010) and should strive to demonstrate accessibility and promote the involvement of marginalised groups with protected characteristics— dementia undoubtedly falls within this subset (*Participant 6, Music and Older People’s Manager*). The senses framework articulates that only good care can be achieved when the sense of belonging is experienced (Nolan et al., 2006), and thus inclusivity must be incorporated in events that are to appeal to PWD.

In the present study, it was substantiated that dementia-specific accessibility promotion and programming inclusivity within arts organisations impacts the need for additional resources such as funding, staffing and specialised training. It was also apparent that this is a lack of awareness and a need to educate on the value of this customer segment. However, government austerity has greatly impacted the funding available for ‘non-essential’ services such as the Arts and Culture sector; research by the County Councils Network (CCN) revealed that £400m has been cut from arts and culture budgets since 2010, reducing non-care services to a legal minimum (Ryan, 2019). Because of this, most organisations must heavily rely on private funding in order to deliver content. With accessibility currently at the forefront of the equality conversation, the Arts and Culture sector are expected to incorporate ‘best practices’ and deliver on accessible trends within consumer products; monetary support above and beyond baseline funding is required to do so. All participants noted a lack of funding and staff as the primary barriers in facilitating dementia events:

“In an ideal world, we would love to hit every single one of those accessibility requirements. However, the reality is very different… it does come back to money and funding, and we’re a very, very small team…[of] about four and a half full time employees throughout the year” (*Participant 3*).

“[Our organisation] has aspirations of creating content and creating training courses that take [dementia accessibility] into account, but we need to make sure that we have the skills to write that content… it’s upskilling internal staff and then as part of the training for temporary staff, including a little bit about how to work with different audiences… That takes funding and time” (*Participant 1*).

A more aggressive approach to dementia accessibility policy promotion would undoubtedly encourage third party donors to endorse their support for funding dementia-specific event initiatives. The increase in funding would allow for an increased number of full-time staff members (including specialised staff) who have experience working with marginalised communities such as people with dementia and their carers. Organisations with wider networks of agencies connected to older people are often favoured by funders because of the niche marketability of their work and/or event programming. Organisations such as Age Scotland, Age and Opportunity, National Museum of Scotland and Capital Theatres are established producers/facilitators of dementia-specific work and as such tend to secure a funding majority because of the low risk/high result outcome.

*Event Planning and Execution*

Participants acknowledge the merit in and social benefit to broadening the scope of festival and event accessibility to include PWD. Participant interviews explored the feasibility of layering dementia friendly accessibility over top of established events versus creating events specifically designed for the PWD community. Participant 5 stated:

“[Organisations] have to be careful around providing events for people who are marginalised or harder to reach… [A dementia event] may fail because [some organisations] are not coming at it from a point of knowing how to reach [PWD] properly… or have the time or… resources to do so effectively.”

Three other participants acknowledge the value in established events developing inclusive programming for PWD, however, suggested that in doing so, PWD and their carers may be (un)intentionally segregated from the overall intended event experience. Within the senses framework (Nolan et al., 2006), this links to the sense of significance, which articulates that good care can only be achieved when people feel that they matter and are accorded value and status. Participant 3 asks, “how do we adapt our existing events to suit [PWD] without segregating them?”

Any potential for new project development or outreach initiatives is often dictated by organisational programming cycles. In addition to this, festival organisations face further challenges because of the limitations on audience-specific touchpoints and market presence throughout the year. Furthermore, as previously discussed, these organisations lack a consistent staffing volume— an operational attribute required to facilitate the creation of additional projects outwith the main festival period.

Conversely, new outreach initiatives and/or programming within organisations such as museums, art galleries, theatres, etc. are guided by strict operational deadlines (i.e. brochure production, curatorial onboarding, season selection, etc.). Like any type of programming element, the development of dementia-specific outreach projects or programming would require an organisational capacity to operate within and adhere to a timeline. This type of programming inclusion would likely require a separate project and dedicated team.

Establishing a collaborative in-house team was identified as a viable solution for effectively developing new dementia-specific outreach programming, in essence establishing a ‘federational’ partnership (Long, 2000). This team would include (but not be limited to) strategic event creators, community engagement/outreach personnel and PWD and their carers. One participant offers: “when you are building an event, it absolutely has to be designed with, for and by those people that you want to attract” (*Participant 5*). This reinforces the value of collaboration with PWD and their carers, as it exemplifies the relevance of an ‘expert by experience’ perspective (McConnell et al., 2019; Shakespeare et al., 2019; Bartlett, 2014). As members of an organisation that facilitate dementia events, two participants shared the benefits of their experience with co-creation and collaboration, as one of their primary event coordinators lives with dementia:

“We had quite a lot of…feed-ins when it [came] to training… You *have* to involve people who… have lived experience… [because] when someone’s on board who has dementia, you are…getting the clearest perspective [possible]… We never could have run this without Sarah\*… I don’t believe we would have had the success we’ve had without [her]” (*Participant 4*).

By establishing these types of collaborative partnerships in-house, arts organisations have the opportunity to curtail PWD segregation and event adaptability challenges. The senses framework outlines the importance of the sense of purpose: to enjoy meaningful activity (Nolan et al., 2006). Within arts events, and as outlined by participant 4, meaningful activity for PWD can realistically only be achieved when events and activities are co-produced by PWD. The sense of security is also more likely to be achieved when events are co-produced by PWD for PWD because participants will feel safe psychologically in an environment where their needs are catered for by a co-producer who has expertise by experience in those needs.

*Community Outreach and Engagement*

Community outreach and engagement was not the primary focus of this study; however, both were mentioned by most participants as an understated link connecting arts and culture programming and collaborations with the greater dementia community. The importance of “…unearthing the invisible community networks [within] festival and event settings…” (*Participant 3*) was highlighted by several participants in reference to best practices in effective collaboration with PWD, other organisations and funders. Several dementia-inclusive programming providers suggested that a grassroots approach was the best tactic to integrate dementia events into new project initiatives. They offered that national portfolio organisations such as Alzheimer’s Scotland, Age Scotland or Age UK should indisputably be involved in collaboration (*Participant 4, Participant 5*) but not initially. Instead, three participants (*Participant 4, Participant 5*, *Participant 6*) suggested that local organisations that have successfully facilitated dementia events should be approached first (i.e. dementia socials, coffee mornings, outreach programs, venues, etc.). As a result, those eager to expand into dementia programming “…will get a better understanding of how [the event(s)] actually lived” (*Participant 7*), and how to adapt them for future projects within their respective organisations. This could also include the integration of more relaxed environments with considerations made to brighter lighting, softer music and the presence of additional dementia-friendly trained staff.

In terms of support, organisations like Life Changes Trust and HammondCare prioritise funding from the bottom up so as to “…highlight and prove the social…and monetary [benefit] of providing organisations, big and small… and proving [that they have] a positive impact” (*Participant 5*). In addition to funding, these organisations also provide an array of educational support, additional resources and network access to other locally and nationally funded communities. Building relationships with such stakeholders that can provide financial, education, and networking support is an important example of why stakeholder engagement is essential for events (Getz et al., 2007). Afterall, all organisations need resources and through collaboration, common goals can be achieved (Getz & Page, 2016). Development of partnerships and networks with external actors provide opportunities for: finding shared agendas; further grants and funding opportunities; and development and implementation of best practice (Bowdin et al., 2011). Indeed, fully engaged external organisations and other actors should be part of the decision-making process in order to be effective co-producers of events as close collaboration, as opposed to opposition, is key (Van Niekerk & Getz, 2019).

As a theme, inclusivity and empowerment are reflective of the greater need for larger arts organisations-led outreach and community engagement initiatives in order to better understand their community demographic. Establishing community touchpoints will provide key insights to the inclusivity demands of potential audiences, aiding in the marriage of accessibility and inclusivity for PWD and their carers and arts and culture programming. This is reflective of the macrolevel construct identified in several other studies (Perkins & Zimmerman, 1995; McConnell et al., 2019). Participant 2 explains an intergenerational relationship outreach initiative embedded within the Irish school curriculum. This project — entitled ‘My Gran Can’— challenges school children to share what their grandparents can do. This type of community outreach not only smooths the stopgap between the intergenerational divide but encourages the creation of a positive role model for aging.

Upon completion of community-specific market research, one Edinburgh-based events organisation expanded their product offering to include dance sessions in care homes because it was made apparent, “…we were engaging with a very specific group of people…but weren’t reaching the ones that needed us most (*Participant 7*). Similarly, Participant 6 highlighted the importance of a longitudinal commitment to time within his music and dementia outreach programme:

“From an arts perspective, success in working with PWD and their carers should not be measured by the length of time it takes, but rather *how* effectively you are able to get know them and what resonates… [you can’t] just make assumptions that… someone with later stage dementia isn’t still there. Because they are. And my job is to discover who [they] are and what [they like] and the tool I have is music.”

Regarding dementia events, the success of community outreach and engagement is defined by the level of programming inclusivity and individual empowerment (Livesey et al., 2012; Clift & Hancox, 2010). Research over the last decade has explored the role of artistic platforms in connecting PWD and their carers to the larger community and the role of arts programming in fostering a higher quality of life after a diagnosis (Jepson, 2019; Zeisel et al., 2018; Lem, 2015; Camic et al., 2014; Ziesel, 2010). Similarly, the present study substantiated the significance of dementia-based arts programming and its effect on inclusivity, empowerment and heightened quality of life. Participant 6, a Music and Older People’s Manager confirms: “…if you can ease the burden for people with dementia and also for their carers, you’ve done something amazing because [these events] are about de-stressing and connecting people”. Music events, and other arts events that provide sensory experiences e.g. visual art forms allow PWD to enjoy an improved quality of life through fostering social connections with others (Zeisel, 2010) and momentarily using such events as opportunities for neurotypical experiences and escapism from the physiological effects of living with dementia.

**CONCLUSION**

*Theoretical Contribution*

**[Insert Figure 2]**

By adapting the ‘Senses Framework’ (Figure 1) to reflect findings and data analysis, Figure 2is presented as a theoretical model depicting how arts organisations can produce dementia events through a relationship-centred collaboration with field experts and experts-by-experience. The epi-centre of the model identifies the fundamental objectives that must be met in order to be successful. At a Microlevel, the six senses intrinsic to high quality relationship-centred care establishes a foundation for organisational considerations; these considerations must be met throughout the event creation process to effectively foster an enriched quality of life for PWD (Barr et al., 2015; McConnell et al., 2019). This will root projects in a critical awareness and understanding of PWD’s social position on empowerment.

At a mesolevel, the framework offers recommendations for physical touchpoint involvement at a community and/or state-level. These touchpoints include: organisation-specific strategic event creators and content developers; PWD and their carers; healthcare and/or medical professionals who work specifically with PWD and/or older people; local organisations and/or venues who facilitate/produce dementia events (i.e. dementia socials, coffee mornings, outreach programs, etc.); and larger charitable dementia/aging organisations which can be used as an educational and training resource. Involvement with stakeholders at the mesolevel can contribute towards new partnership and networking opportunities and the ability to exploit these networks for shared funding and grant opportunities; implementation of best practice; and shared pooling of resources (Bowdin et al., 2011). Where committee-style involvement is not possible, it is recommended that those groups be approached for expert-by-experience contribution.

As per this study’s findings, the macrolevel depicts three catalysts of successful dementia event creation— 1) influence and promote state policy to affect change surrounding dementia accessibility and organisational resource barriers (i.e. project funding, staffing and dementia education and training); 2) actively facilitate community outreach and engagement initiatives with the greater dementia community to allow dementia accessibility and its subsequent impact on quality of life to remain at the forefront of the social issues conversation. This type of community engagement permits organisations to not only build connections with PWD and their carers, but to also connect with additional dementia-specific community initiatives— it is about human connection, creating a social network and expanding one’s reach; 3) by broadening the scope of inclusivity and effectively collaborating with the right groups of people, arts organisations are more likely to be successful in producing dementia events for the demographic that needs them most.

The inclusion of these dementia-specific considerations within strategic event creation may aid event managers in transforming the socio-cultural understanding of inclusivity (Di Lorito et al., 2017; Litherland & Williamson, 2013), empowerment (Sixsmith et al., 2007) and quality of life (McConnell et al., 2019) as it pertains to PWD, their carers and their families. On a larger scale, the implementation of this relationship-centred approach to strategic event creation may highlight the importance of social interaction as a therapeutic activity for PWD (Tresolini & The Pew-Fetzer Task Force, 1994) and address the socio-economic and socio-political effect of community engagement with PWD and their overall perceived quality of life (Ryan et al., 2008).

Even organisations that produce only one major festival or event per year have the opportunity to impact PWD’s quality of life. This can be achieved through a collaborative approach to operational planning with the on-boarding of an expert-by-experience advisory committee. Together, the team can co-create programming content and plan and design future events. These efforts within arts organisations foster engagement and create a platform that encourages social commitment (Schneider, 2018), promotes community involvement (Jepson, 2019; Krause, 2007) counteracts cognitive decline through learning (Jepson, 2019) and contributes to enhanced feelings of competency (Hays & Minichiello, 2005) and improves overall emotional and mental health (Di Lorito et al., 2017; Litherland & Williamson, 2013; Lesta & Petocz, 2006). For PWD, the event experience is not necessarily dictated by the event itself, rather the journey taken to create something meaningful, empowering and engaging for a wider community.

*Limitations and Future Research*

 Although this study supports existent research on the positive impact of dementia events and perceived quality of life for PWD (i.e. promotes community involvement, encourages social commitment, promotes learning and competency and improves one’s overall emotional health and mental well-being), due to its small scale, it is difficult to draw generalisable conclusions about the effectiveness of the model proposed. This study was restricted by the onset of Covid-19 which prevented the possibility of investigation with PWD and their carers, impacted the overall sample size and affected the data collection process. It is our intention to undertake a larger-scale study involving PWD and their carers is required to determine the impact of co-creation and collaboration in strategic dementia event creation on individuals’ quality of life after a dementia diagnosis. Future research should expand into additional geographic locations so as to better understand arts organisation-specific initiatives in facilitating dementia events to broaden the scope of inclusion at a global level. Future research would benefit from participant observation at events and the staging of an actual dementia event and employing a mixed methods approach to data collection; this addition would allow researchers to implement and test the theoretical framework to strategic event creation and quantitatively measure the impact of co-creation/collaboration between event organisers and PWD and their carers on quality of life during the analysis process.

*Conclusions*

 By integrating the senses framework with theories in strategic event creation, this research examined the collaborative feasibility of festival and event managers opening accessibility to PWD and their carers and making the experience a positive and impactful one. The success of dementia events is dependent on the accuracy of arts organisations in collaboratively producing programming for the needs of their intended audience. This work contributes to the creation of a theoretical model that outlines six key principles (achievement, belonging, continuity, purpose, significance and security), each of which should govern dementia-specific organisational projects, the types or groups of people whose involvement is required in the project and the means in which to best-achieve said objectives. If properly implemented, this framework should result in the successful delivery of dementia events within arts organisations.

This study has highlighted the need for a greater awareness of the value of this audience, the accessibility needs of PWD and the importance of event organisers adapting their events to suit this need. It is imperative that event organisers and managers not only understand the challenges and barriers associated with dementia events, but actively pursue overcoming them by engaging with the appropriate resources within the wider community. This type of relationship-centred approach with community stakeholders is at the epicenter of combating barriers surrounding funding, staffing and educational resources. In terms of practical guidance for event managers within arts organisations, resources such as Alzheimer’s Society’s Dementia-friendly arts guide and Euan’s Guide are exceptional reference points for event producers and arts venues interested in becoming dementia-friendly.

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**NOTES**

1. Interview questions are available from the corresponding author
2. \*Names and certain details have been altered to assure anonymity

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**FIGURES AND TABLES**

**Figure 1. The ‘Senses Framework’**

(Source: Davies, Nolan, Brown, & Wilson, 1999; Nolan, 1997; Nolan et al., 2001, 2003; retrieved from [https://www.sheffield.ac.uk/polopoly\_fs/1.811379!/file/Senses\_Framework\_Posters.pdf](https://www.sheffield.ac.uk/polopoly_fs/1.811379%21/file/Senses_Framework_Posters.pdf))

**Figure 2: The ‘Senses Framework’: A relationship-centred approach to co-producing dementia events in order to allow people to live well after a dementia diagnosis.**

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**Table 1. Thematic analysis: themes and categories**

|  |  |  |
| --- | --- | --- |
| **Theme** | **Category** | **Number of participants discussing this category** |
| Socio-political impact of or impacting upon dementia events | Dementia accessibility awareness and policy promotion | 8 |
| Resources: funding, staffing, education and training | 8 |
| Event planning and execution | Dementia event vs. event that is dementia-friendly | 6 |
| Seasonal programming and time constraints | 4 |
| Community outreach and engagement | Grassroots approach | 3 |
| Inclusivity | 7 |