MATERIAL OBJECTS AND OLFACTORY STIMULI: DEVELOPING A MULTI-SENSORY STIMULATION INTERVENTION FOR PEOPLE WITH DEMENTIA LIVING IN CARE HOMES

FEDERICA D'ANDREA

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ABSTRACT

Background: Multi-sensory stimulation intervention is a sensory approach that has received interest within the field of dementia care. This is consistent with the literature highlighting the importance of promoting opportunities for appropriate sensory experiences for people living with dementia. The encouraging results on object handling as a well-being focused intervention and the unique relationship between olfaction, memory, and emotion, prompted exploration of the therapeutic potential of tactile and olfactory stimulation for people with dementia.

Aims: This research aimed to explore the potential of multi-sensory stimulation and develop a novel theory- and evidence-based multi-sensory stimulation intervention (MSI) for people with dementia living in care homes.

Method: The study followed the Medical Research Council framework for the development and evaluation of complex interventions. A background literature review of multi-sensory stimulation interventions, a scoping review of object handling interventions, a rapid and realist review of olfactory interventions, including online surveys (n = 20), were conducted to identify relevant evidence and theories. To inform the MSI design, one-to-one interviews with stakeholders with expertise on olfaction (smell) (n = 5) and heritage objects (n = 2) took place. In addition, a series of qualitative taster sessions with care professionals (n = 4), relatives of people with dementia (n = 5), and older people without a diagnosis of

dementia (n = 4) were conducted to identify areas for refinement and to ensure the acceptability, practicability, and appropriateness of MSI design.

Results: The results of the literature reviews formed an evidence base from which MSI was designed alongside the findings of the interviews with olfactory and archival experts which helped to answer a number of questions in relation to the materials and procedures of the first MSI version (MSI-1). Findings from the taster sessions highlighted the potential benefits of the multi-sensory stimulation interventions to people with dementia in supporting individual expression and relationship building, and identified strategies for promoting engagement and participation within the intervention sessions. The stakeholders' feedback on MSI-1 resulted in a refined second version (MSI-2), that included tailored and inclusive materials and themes, and the creation of guide and resources for supporting care professionals in the preparation and delivery of MSI.

Conclusions: The study demonstrates the importance of material objects and olfactory stimuli and their benefits within dementia care, resulting in an innovative intervention that can support people with dementia to access sensory, engaging, and enjoyable activities in care home settings. The study contributes to knowledge by developing a better understanding of olfactory and object handling interventions, identifying their theoretical underpinning, and by making recommendations for optimal content, and delivery of multi-sensory stimulation interventions within care home settings. Future research should explore the use and efficacy of MSI in care settings.

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PUBLICATIONS AND DISSEMINATION ACTIVITIES

Peer review publications

- D'Andrea, F., Dening, T., & Tischler, V. (in preparation). Object handling for people living with dementia: a scoping review.
- D'Andrea, F., Tischler, V., Dening, T., & Churchill, A. (accepted for publication). Olfactory stimulation for people with dementia: a rapid review. Submitted to *Dementia,* May 2021 and accepted January, 2022.

Other publications

- Tischler, V., & D'Andrea, F., (2021). Multi-sensory stimulation. In Psychosocial interventions and dementia: understanding, knowing, implementing (Guide Pratique). Fondation Médéric Alzheimer. Retrieved from https://www.fondation-mederic-alzheimer.org/psychosocial-interventions-and-dementia-our-guide-understanding-knowing-implementing?fbclid=IwAR1hoCFIRm-
- Tischler, V., & D'Andrea, F. (2020). Using memory box objects and smells for people living with dementia: guidance for carers. Retrieved from Boots United Kingdom (UK) website http://www.boots.com/dementia-friends
- D'Andrea, F., Tischler, V., & Dening, T. (2020). The development of a multi-sensory stimulation intervention for people with dementia living in care homes. *Alzheimer's Association International Conference.* doi:10.1002/alz.043522

- D'Andrea, F., Tischler, V., Dening, T., Churchill, A., & Hui, E. K. (2020). The effects of olfactory stimuli on people with dementia: a rapid review of the literature. *PROSPERO.* Retrieved from https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020202670

International conference presentations

- Quick oral presentation at the 31st Alzheimer Europe Conference (online). November 2021. *Olfactory stimulation in dementia care: a rapid review*.
- Poster presentation at the 30th Alzheimer Europe Conference (online). October 2020. *Building a realist programme theory for a novel intervention: a mixed-methods approach.*
- Poster presentation at the Alzheimer's Association International Conference (online). July 2020. *The development of a multi-sensory stimulation intervention for people with dementia living in care homes.*
- Poster presentation at the 29th Alzheimer Europe Conference, The Hague, Netherlands. October 2019. *Object handling for people with dementia: A scoping review.*

National conference, seminar and symposium presentations

- Oral presentation at the Doctoral Research in Progress Seminars, University of West London. June 2019. *Using olfactory stimulation: a multi-sensory stimulation intervention in care home for people with dementia.*

- Oral presentation at the Doctoral Students' Conference, University of West London. May 2019. *Object handling for people with dementia: A definition and theoretical model.*
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- Oral presentation as a part of the Dementia Seminar Series, University of West London. November 2018. *A multi-sensory stimulation intervention based on olfactory stimulation.*
- Oral presentation at the Flavour Symposium, University of West London. November 2018. *Smell and flavour: Odour and memory.*
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- Oral presentation at the Postgraduate Research Conference 'Seeds of Knowledge', University of Worcester. July 2018. *Multi-sensory approaches in dementia care.*

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INTRODUCTION TO THE PROJECT

This study sought to explore the potential use and therapeutic benefit of smells and heritage objects in dementia care, through a series of iterative investigations aimed at developing and designing a novel theory- and evidence-based multi-sensory stimulation intervention (MSI) for people living in care homes. For the purpose of this thesis, the abbreviation MSI is used to refer to the new intervention which is developed. MSI-1 and MSI-2 are used to distinguish the MSI first and second version respectively.

Among psychosocial interventions, there is growing support for the use of multi-sensory stimulation interventions. Multi-sensory stimulation interventions include many types of programmes involving the stimulation of two or more senses (sight, sound, touch, taste, and smell) using different techniques. Over the years, there have been a number of reviews that sought to assess the benefit of multi-sensory stimulation interventions (e.g. Cheng et al., 2019; Pinto et al., 2020; Sánchez et al., 2013; Strøm et al., 2016). Yet it is unclear if and how multi-sensory stimulation interventions are effective for people with dementia due to the lack of quality evidence (e.g. Cheng et al., 2019; Pinto et al., 2020).

In the literature, the sensory modalities most used in multi-sensory stimulation interventions have been limited to visual, audio, and tactile sensations, with less attention to olfaction. This is despite evidence demonstrating the link between

olfactory sense and quality of life (Ballard et al., 2002; Burns et al., 2011; Croy & Hummel, 2017; Herz, 2016), and the power of smells to trigger emotions and autobiographical memories, given the close relationship between olfaction, memory, and emotional processing at the neuroanatomical level (e.g. Chu & Downes, 2000; Glachet & El Haj, 2019; Herz et al., 2004b).

There is evidence demonstrating the positive value of objects in providing opportunity for engagement and well-being in people living with dementia (e.g. Camic et al., 2019; Johnson et al., 2017a). The sensory experience associated with handling, exploring, and discussing objects can provide opportunities for multiple forms of individual expressions and interactions from verbal to non-verbal engagement.

Encouraging results on the therapeutic benefits of exploring objects through touch and other sensory modalities, including smell, were identified in a prior project in care homes (Griffiths et al., 2019) that used thematic boxes, including olfactory stimuli via heritage items. Further explorations of olfaction and tactile sensations are warranted, given the powerful link of olfaction to emotional processing and memory, and the positive findings from recent studies on object handling.

In line with the overarching framework used, the Medical Research Council (MRC) framework for the development and evaluation of complex interventions (Craig et

al., 2008), the study comprised four dynamic and iterative phases involving different groups of stakeholders.

The initial phase of the MRC framework (Craig et al., 2008) concentrated on identifying and reviewing published research evidence and relevant theory underpinning multi-sensory stimulation, object handling and olfactory interventions to inform decisions about MSI design. To further support the intervention development, a theory-driven realist approach was used to create a theoretically-informed understanding of how one component of the MSI, olfactory stimulation, works within care home settings. At the early stage, interviews with stakeholders including experts on olfaction (smell) and people working with heritage items were conducted to gather advice on materials and procedures which were incorporated in the MSI-1. As part of the MRC modelling stage (Craig et al., 2008), feedback from key stakeholders was gathered to refine and tailor the MSI-1 to the needs of people with dementia, paying attention to the context and potential barriers to future implementation. The study culminated in the further refinement of MSI-1 and the development of MSI-2.

THE IMPACT OF CORONAVIRUS DISEASE (COVID-19) ON THE RESEARCH: AN UNANTICIPATED CHALLENGE

The initial aim of the research, as developed at the beginning of the study, was to explore the experience and perspective of people with dementia living in care homes in relation to multi-sensory stimulation interventions and the MSI-1. The research protocol was revised during the course of the investigations to respond to the constraints imposed by the COVID-19 pandemic. This section describes the impact of COVID-19 on the present research, including disruption of the planned research and subsequent changes made to the study.

COVID-19 is an infectious disease caused by a severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). From December 2019, the disease spread rapidly worldwide and, in the middle of March 2020 the WHO declared COVID-19 a global pandemic (WHO, 2020). Dementia is one of the most important conditions associated with increased mortality from COVID-19 (Office for National Statistics, 2020). At the end of March 2020, the UK's national data on the incidence and mortality rate from COVID-19 in people with dementia, especially those living in care homes, was unclear. Worrying figures have been seen in other countries, such as Italy, reporting high numbers of deaths among people living in care homes (La Repubblica, 2020; Trabucchi & De Leo, 2020).

Due to the highly contagious nature of the virus, the high mortality among people with dementia and following the lockdown measures introduced in the UK on 23rd March 2020, it was necessary to reshape the research planned in care homes. This had involved bringing the doctoral student (author), care professionals and residents together in close proximity. The initial research protocol included qualitative exploration of MSI-1 through taster sessions as well as a feasibility and acceptability study to take place over the spring and summer of 2020. The qualitative taster sessions were designed to gather the residents' opinions, perceptions and attitudes towards multi-sensory stimulation interventions and MSI-1 components and protocol through small group discussions (approximately 2-3 participants) based on a topic guide and a range of representative potential items of the MSI-1. The mixed-method feasibility and acceptability study was aimed to test whether a further systematic study could be done by assessing the integrity of the study protocol, recruitment process, acceptability and feasibility of the intervention procedure and outcome measures, considering any procedural challenges that were not anticipated in the initial research design, and exploring the opinions and experiences of people with dementia during and at the end of the sessions. Overall, these investigations aimed to provide unique and valuable knowledge about the residents' perspectives and experience with multi-sensory stimulation interventions, and significant insight into MSI-1, indicating whether the intervention materials and protocol would be relevant and appropriate for them.

In response to the COVID-19 outbreak, to abide by national lockdown and social distancing measures required as a response to the pandemic, and to progress the study, creative and innovative solutions to collect residents' perceptions and opinions were explored. Several resources such as "Collecting Qualitative Data: A practical guide to textual, media and virtual techniques" (Braun et al., 2017) and a 'live' Google document, "Doing fieldwork in a pandemic" (Lupton, 2020), provided useful guidance on how to adapt in-person methods to digital research which could enable safe participation and the respect of lockdown restrictions.

The possible use of technology, online sessions, or data collection from care professionals or caregivers were considered. However, these methods are likely to require care professionals and family caregiver engagement, time, and energy. Mindful that the COVID-19 pandemic has had a significant impact among those groups, creating unprecedented burden, the decision was taken to re-design the research, with the support of the supervisory team. The empirical research activities initially planned were replaced with a realist review, a theory-driven research approach synthesis, to elicit the underpinning 'active ingredients' of olfactory interventions. At this stage, extensive reading of the literature was conducted by the author to familiarise herself with the realist method before articulating the focus and objective of the review.

Overall, the research project has been challenging due to the COVID-19 pandemic. The lockdown restrictions, the high risk of the adverse consequences of COVID-19 for people with dementia, the uncertainty about the progression of the disease, and limited PhD timeframe prompted the need to adapt the research. As a result of the changes undertaken, people with dementia could not be directly involved and contribute to the production and design of the MSI. This is an important limitation of the research which is discussed further at the end of the thesis. On the other hand, the research changes made in response to COVID-19 have strengthened the MSI development process, rigorously exploring possible underpinning mechanisms of olfactory stimulation and providing a unique opportunity to scrutinise the active ingredients associated with smell-based interventions in dementia care. Consequently, the revised programme of research is reported in this thesis as outlined below.

STRUCTURE OF THE THESIS

Chapter 1 outlines the context for the study, including definitions, conceptualisation, and the impact of dementia. This chapter includes a description of care home settings and psychosocial interventions in dementia care.

Chapter 2 presents a critical discussion of the literature on multi-sensory stimulation interventions and considers two specific sensory modalities which are of direct relevance to the study: olfaction and touch.

Chapter 3 offers an overview of the aims, overarching methodology and methods used in the study.

Chapter 4 presents a scoping review of the evidence available on object handling interventions and an operational definition model.

Chapter 5 describes a rapid review exploring the effectiveness and characteristics of olfactory stimulation.

Chapter 6 presents a realist review of olfactory interventions with the aim of identifying the theoretical underpinning of olfactory stimulation for people with dementia living in care homes.

Chapter 7 outlines how the findings of the evidence syntheses and qualitative investigations with stakeholders informed the design of MSI. The chapter presents the details of MSI-1 design.

Chapter 8 describes the method and results of qualitative explorations of MSI-1 with groups of key stakeholders. The chapter presents how these findings informed the refinement and design of MSI-2.

Chapter 9 summarises and discusses the study findings, methods used, strengths and limitations, and outlines the key implications of the research.

LIST OF ABBREVIATIONS

AD	Alzheimer's Disease
ADAS-cog	Alzheimer's Disease Assessment Scale - cognitive subscale
BPSD	Behavioural and Psychological Symptoms of Dementia
CMAI	Cohen-Mansfield Agitation Inventory
CMO	Context-Mechanism-Outcome
COVID-19	Coronavirus Disease
DLB	Dementia with Lewy Bodies
FAST	Functional Assessment Staging Test
FIM	Functional Independence Measure
FTD	Frontotemporal Dementia
GBSS-J	Gottfries, Bråne, Steen Scale - Japanese version
HAD	Hospital Anxiety and Depression scale
HDS-R	Hasegawa's Dementia Scale Revised version
IRPT	Initial Rough Programme Theory
MMAT	Mixed Methods Appraisal Tool
MMSE	Mini Mental State Examination
MMSE-C	Mini-Mental State Examination - Chinese version
MRC	Medical Research Council
MSI	Multi-sensory Stimulation Intervention
MSI-1	Multi-sensory Stimulation Intervention first version
MSI-2	Multi-sensory Stimulation Intervention second version

MWM-OA	Museum Wellbeing Measure for Older Adults
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NPI	Neuropsychiatric Inventory
NPI-C	Neuropsychiatric Inventory - Chinese version
OP	Older People
OSIT-J	Odor Stick Identification Test for Japanese
PANAS	Positive and Negative Affect Scale
PAS	Pittsburgh Agitation Scale
PRISMA	Reporting Items for Systematic Review and Meta-Analysis
PROSPERO	International Prospective Register of Systematic Reviews
PwD	People with Dementia
RCT	Randomised Controlled Trial
SAM	Self-Assessment Manikin
TDAS	Touch-panel type Dementia Assessment Scale
TEMPau	Test Episodique de Mémoire du Passé
TIDieR	Template for Intervention Description and Replication
VaD	Vascular Dementia
VAS	Visual Analog Scales
ZBI-J	Zarit caregiver Burden Interview - Japanese version
WHO	World Health Organization

GLOSSARY OF TERMS

Anosmia: complete loss of sense of smell.

Aromatherapy: form of complementary therapy that involves the use of a range of essential oils directly applied to the skin surface or inhaled using e.g. a diffuser or vaporiser.

Care professionals: this may include people working in a care home setting such as team managers, care workers, and activity coordinators.

Compound: substance made up of molecules of at least two elements.

Context: social, cultural, spatial, and institutional settings in which an intervention is introduced, including characteristics of the individuals, localities, situations, or systems of interpersonal and social relationships.

Context-Mechanism-Outcome configuration: proposition stating the relationship between specific features of context, mechanisms and outcomes. They are used in realist methodology to express causal connections.

Diffuser: device used to disperse odours and essential oils into the surroundings.

Essential oil: chemical compound (or substance) derived from plants, flowers, or leaves. Chemical substances manufactured in a laboratory to imitate essential oils are known as synthetic fragrance oils.

Initial Rough Programme Theory: initial underlying assumptions on how, why and for whom a programme is expected to work.

Malodour: term used to describe an unpleasant odour.

Material objects: physical items existing in our environment such as everyday items, heritage objects or memorabilia.

Mechanism: element of reasoning and reaction of an individual or a collective agent (e.g. health-care service) to resources embedded in a programme (e.g. intervention materials) provided within specific context.

Multi-sensory stimulation intervention: programmes that stimulate two or more senses such as sight, sound, touch, taste, and smell using different stimuli and approaches e.g. Snoezelen. The abbreviation **MSI** is used for the purpose of the thesis to indicate a novel multi-sensory stimulation intervention developed within the PhD project.

Odour: or **smell** are interchangeably used to indicate chemical compounds (or substances) with pleasant and unpleasant connotations.

Older people: refers to people aged 65 years old or over.

Olfaction: or **sense of smell** refers to the sensory system through which odours are perceived.

Olfactory stimulation: stimulation of the olfactory system through sniffing or exposure to odours.

Outcomes: changes triggered by mechanisms within a specific context.

Programme theory: explicit model or theory describing the underlying assumptions about how and why an intervention is expected to work.

Realist methodology: seeks to generate causal explanations on why and how an intervention work (or fails to work) by identifying underlying causal mechanisms in specific contextual conditions that contribute to achieve the outcomes.

Relatives of people with dementia: this includes family members of people with dementia who are residents in care home.

Smell: please refer to the definition of 'odour' above.

Stakeholders: person or group with significant interest and expertise in a topic of interest. They comprise care professionals, academic experts, olfactory experts, archivists, relatives of people with dementia, older people, clinicians, and activity coordinators for people with dementia.

Well-being: multidimensional construct referring to individual experiences in physical, psychological and social domains such as positive emotions, mood, sense of purpose, social engagement, life satisfaction, fulfilment, good physical health, and positive functioning.

ETHICAL APPROVAL

The study was approved by the University of West London's Nursing, Midwifery and Healthcare Ethics Committee, ethical approval reference number: UWL/REC/CNMH-00489 in October 2018, and the revised protocol by the University of West London Biomedical Sciences Committee, ethical approval reference number: UWL/REC/CNMH-00735 in July 2020.

CHAPTER 1 INTRODUCTION

This chapter provides an overview of the context to the study, including the epidemiology and definition of dementia, and its key cognitive and non-cognitive symptoms. The shifting conceptualisation of dementia is articulated through outlining models of dementia, from the biomedical to a more holistic approach. The chapter then considers the impact of dementia, describes care home settings and the importance of providing psychosocial interventions in dementia care.

1.1 Ageing and the epidemiology of dementia

Dementia is increasingly recognised as a global healthcare challenge and considered one of the major causes of disability and dependency among older people worldwide (World Health Organisation [WHO], 2012). It was estimated that there were 47 million people living with the condition worldwide in 2015, and epidemiological studies indicate that this number is set to double every 20 years, to 78 million in 2030 and over 139 million by 2050 (WHO, 2021a). In 2019, approximately 885,000 people with dementia were living in the UK, this number is projected to increase by 80%, reaching almost 1 million in 2024 and 1.6 million in 2040 (Wittenberg et al., 2019). The growing global number of people with dementia results from the increasing number of ageing people and from the

increased life expectancy of most populations around the world (WHO, 2017). Although dementia is not a normal part of ageing, the total number of new cases are related to old age, which is the main risk factor. The annual incidence of dementia is 0.69% before the age of 65 years and it rises to around 1.54% at age 80-85 years (WHO, 2015).

1.2 Definitions and types of dementia

Dementia is an umbrella term, describing a syndrome caused by a number of diseases that affect the brain (Winblad et al., 2016). Dementia is characterised by a progressive deficit in one or usually more cognitive domains that substantially compromises social and/or occupational functioning (Dening & Sandilyan, 2015). Depending on the number of clinical manifestations and the degree of restriction in daily activities, people with a diagnosis of dementia can be described as having mild, moderate or severe dementia (Alzheimer's Society, 2015). In the early stage of dementia, signs and symptoms are specific (e.g. difficulties in remembering names) and various strategies can be implemented for reducing their impact on functioning in daily life. As dementia progresses, the symptoms tend to be more restricting and gradually the person with dementia becomes more dependent and inactive, especially in the later stage where neurocognitive and physical changes (e.g. reduced ability to walk, sit or swallow) become more pronounced (Steinberg et al., 2008).

There are several types of dementia that tend to affect people differently, especially in the early stage. The most common form of dementia is Alzheimer's Disease (AD), affecting between 50-75% of people with dementia in the UK (National Institute for Health and Care Excellence [NICE], 2021). The second most common type is Vascular Dementia (VaD), which is responsible for about 20% of cases in the UK (NICE, 2019). In many cases, AD and VaD present together, and this condition is called mixed type dementia (NICE, 2021). Less common types of dementia include Dementia with Lewy Bodies (DLB) accounting for 15% of the cases in the UK and Frontotemporal Dementia (FTD), which represents 5% of the UK cases (NICE, 2019). In this thesis, the word dementia is used to refer to all types of dementia.

1.3 Symptoms of dementia

Cognitive symptoms

Memory loss is the most common cognitive symptom and is a core feature in most types of dementia. People with dementia can experience impairment in semantic memory (common knowledge about objects, facts and meanings that are not drawn from personal experience), episodic memory (autobiographical information), and visuospatial memory (information about colours, shapes, location, and movements).

In addition to memory problems, people with dementia can present other symptoms such as aphasia, a complex language and communication disorder affecting the ability to name objects or retrieve specific words. As dementia progresses, difficulties in understanding and producing language can occur. A related disorder to aphasia is agnosia, which affects the person's ability to recognise objects, persons, smells, and sounds in the absence of sensory impairments. Due to the brain failing to integrate perception, memory and identification, people in moderate or advanced stages of dementia might not be able to recognise objects (visual agnosia), familiar faces (prosopagnosia) or places (environmental agnosia).

Other cognitive deficits include executive dysfunction (difficulty in problem solving, self-monitoring, planning, and judgment), attention deficits (poor selective and sustained attention, inability to shift and divide attention), dyspraxia (inability to co-ordinate and perform known actions), anosmia (complete loss of olfactory function), dysgraphia (difficulty with writing) and dyslexia (difficulty with reading).

Non-cognitive symptoms

Non-cognitive symptoms include responsive behaviours, also known as neuropsychiatric symptoms or Behavioural and Psychological Symptoms of Dementia (BPSD), and problems in activities of daily living. They are as clinically

relevant as cognitive symptoms as they strongly correlate with the degree of functional and cognitive impairment (van der Linde et al., 2016).

In the dementia literature, the term responsive behaviour has been introduced recently to replace the term BPSD in order to move away from labelling and to encourage thinking about the meaning behind what has been referred to as challenging behaviour (Alzheimer Society of Canada, 2017). This new term supports the assumption that responsive behaviours as verbal and physical actions may occur due to unmet needs (e.g. feeling lonely, or bored) or in reaction to social and physical environment (e.g. too much noise) (Alzheimer Society of Canada, 2017; Hancock et al., 2006; Herron & Wrathall, 2018). Responsive behaviours include for example, agitation, aberrant motor behaviour, anxiety, irritability, depression, apathy, disinhibition, delusions, sleep or/and appetite changes (Herron & Wrathall, 2018). Despite there being a marked inter-individual variability, most people tend to develop one or more responsive behaviours throughout the course of dementia (Tible et al., 2017). Their appearance is related to a more rapid progression of the condition, which may lead to earlier institutionalization (Toot et al., 2017).

The cause(s) or determinant(s) of the responsive behaviours are complex and multifactorial. The neurobiological (brain changes and medication), psychological (premorbid personality features and responses to stress), and social

(environmental and caregiver factors) aspects interact with each other (Kolanowski et al., 2017; Tible et al., 2017). Cohen-Mansfield et al. (2009) argue that responsive behaviours are the expression of unmet needs that are the result of an imbalance in the interaction between personality, previous habits, environment, and current physical and psychological states. Cohen-Mansfield and colleagues (2015), in their study exploring the role of unmet needs contributing to responsive behaviours of people living in care homes, suggest that residents' responsive behaviours could be reduced by addressing their needs which included, in order of importance, social interaction, sensory stimulation, meaningful activities and discomfort. This is particularly important as it acknowledges the multidimensional nature of responsive behaviours and the role of the environment, and offers insight into a more complex conceptualisation of dementia which is supported by new theoretical models of the condition. This point is discussed further in the section below which outlines the shift in the paradigm of dementia that has occurred over the past 20 years, from considering dementia as a disease to a more holistic reconceptualization of the experience of dementia.

1.4 Models of dementia

The models of dementia are powerful tools that provide frameworks to conceptualise and understand the condition. In the context of dementia, models

inform and shape care approaches, policy, and wider society, modifying social and cultural perceptions and attitudes toward the condition (Innes & Manthorpe, 2013).

Historically, the biomedical model of dementia was the dominant approach. This model states that dementia is a disease defined by progressive neurological changes in the brain (Lyman, 1989). The inherent focus on impairment and pathology leads to treatment and management of dementia based on pharmacological interventions, that neglect to consider the social and psychological dimensions of the condition (Innes & Manthorpe, 2013). Evidence indicates the absence of a direct and linear correlation between brain damage and clinical manifestations of dementia, demonstrating the inconsistency and over-reductionism of the biomedical approach (e.g. Balasubramanian et al., 2012; Snowdon, 2003). For instance, analysis post-mortem of older people has revealed a higher or lower degree of cerebral damage which was not predicted from cognitive performance in neuropsychological tests (Snowdon, 2003). This sort of evidence has encouraged researchers to look beyond the standard biomedical model for the construction of a holistic approach to dementia and care.

Several models and theories have been developed to describe dementia as a dynamic interplay between biopsychosocial, person and environment factors. Such models include Dröes's Adaptation-Coping framework (1991), which argues that people with dementia strive to maintain a sense of control and balance in

different emotional, cognitive and social tasks, adopting adaptive strategies. People with dementia constantly try to ‘regain balance’ and the extent to which they do depends on the cognitive demand of a situation, alongside the person’s ability and resources to respond to it. According to this model, responsive behaviours in dementia may be the result of ineffective coping mechanisms used by people with dementia to regain equilibrium.

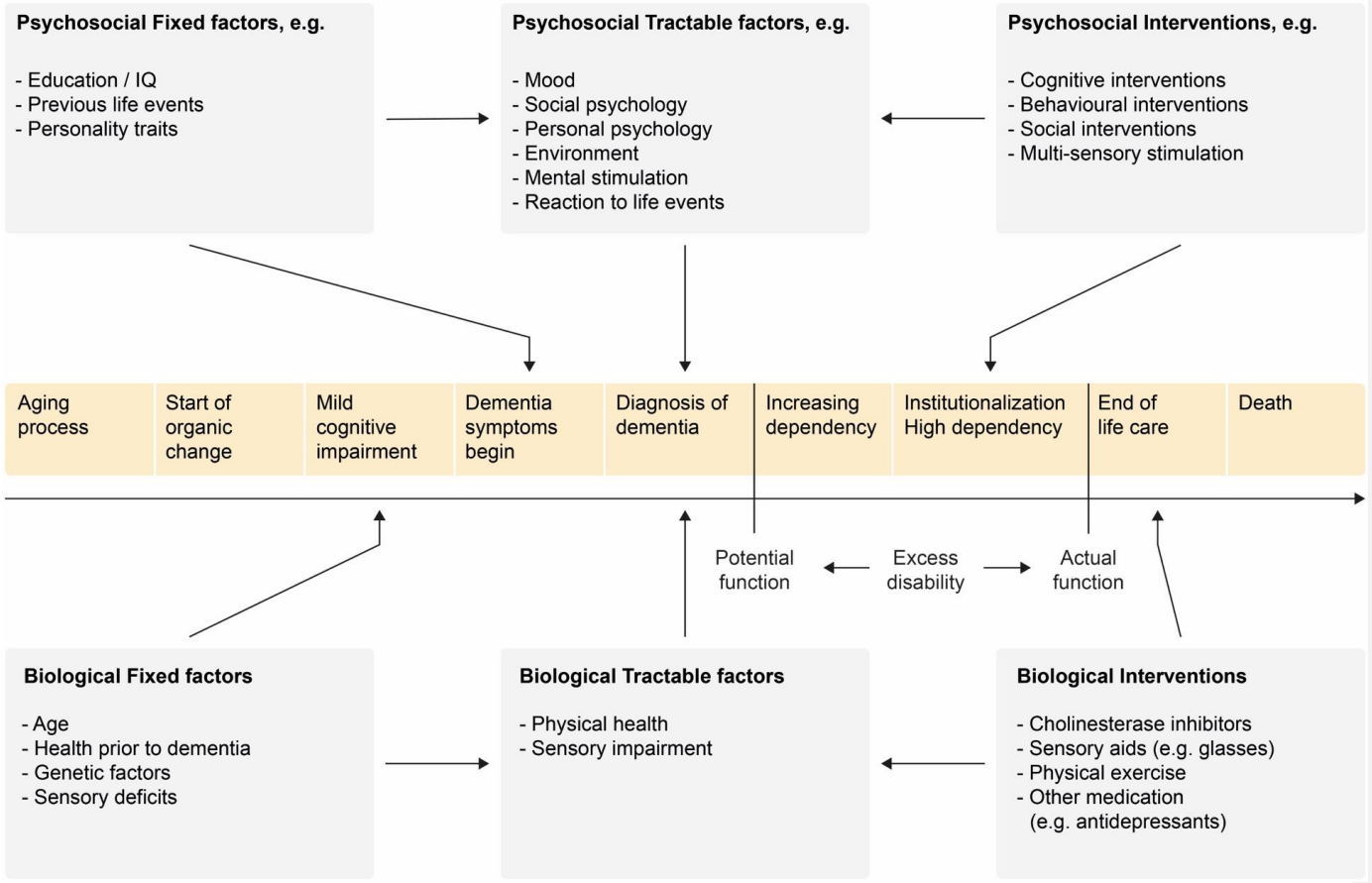
The subsequent dialectical model of dementia proposed by Kitwood (1993) provides a coherent framework including the interconnection between neurological deterioration and psychological factors such as personality, personal history, and social psychology. This model foregrounded the unique individual experience of dementia, leading to a shift in the way dementia was perceived, affirming the importance of ‘personhood’ defined as ‘a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust’ (Kitwood, 1997, p. 8). Kitwood proposes the notion of ‘malignant social psychology’ which outlines how contexts and caregiving relationships can devalue and dehumanise a person living with dementia by stigmatising, objectifying, outpacing, infantilising, or ignoring the individual. He suggested that recognition of personhood of people with dementia promotes the application of a person-centred approach to dementia care.

The biopsychosocial model of dementia proposed by Spector and Orrell (2010), embraces past research and theories in a pragmatic model aimed to guide researchers and practitioners.

The model offers a more comprehensive and accurate representation of dementia by describing the inter-relationship between two main domains: psychosocial and biological. Both domains include fixed (not changeable) and tractable (changeable) factors. This means that some aspects of dementia are beyond the control of the person and their environment such as age and previous life events, whereas others can be modified, e.g. mood, sensory impairments and environment (Figure 1.1).

Breaking down the factors contributes to promoting dementia as a process where change, adaptation, and improvement are possible, through medical and psychosocial interventions (Spector & Orrell, 2010). Psychosocial interventions broadly refer to non-pharmacological interventions focused on maintaining, promoting or improving psychological, social and functional abilities (McDermott et al., 2019; Moniz-Cook et al., 2008).

Figure 1.1 Biopsychosocial model of dementia (adapted from Spector & Orrell, 2010)



Acknowledging the complex nature of dementia contributes to a recognition of the need to explore and develop effective and innovative approaches to care with the focus on the individual's needs, resources, and contextual factors. However, although Spector and Orrell's model (2010) has had a positive influence and acted as a practical tool for practice, it has been criticized for not appropriately addressing the physical domain of dementia (Keady et al., 2013). Keady et al. (2013) propose the bio-psycho-social-physical model of dementia which expands the biopsychosocial model to incorporate five components of physical domain (e.g. physical well-being; physical health and examination; physical care; physical treatment; and physical environment). The main difference of this model from the previously biopsychosocial models is that it recognises the importance of the body, and the physical dimensions of care within the experience of living with dementia (Keady et al., 2013).

The value of the body is also embraced in the notion of embodiment, and the sociological meaning of embodied actions. The notion of embodiment suggests that individuals experience the world through their body which is also the vehicle of outwards expressions of self through actions, gestures, and movement (Kontos, 2005; Kontos & Martin, 2013). This suggests that people living with dementia maintain their identity and sense of self through their body (Kontos, 2005).

Building upon this context, the concept of dementia was extended by citizenship models. Bartlett and O'Connor (2010) adopted the term social citizenship to emphasise the role of people living with dementia as active social agents in their everyday lives within a social environment. This paradigm aimed at restoring the sense of agency and the retained control of people with dementia, shifting the focus from passive recipients and needs-based care to a 'human rights-based' approach, which allows and reinforces the right of people with dementia to live independently, to maintain their legal capacity, and to participate in social life (Cahill, 2018).

The importance of focusing and promoting individual resources, capacities, independence and autonomy within the community is increasingly advocated by the European research organisation INTERDEM (Early detection and timely INTERvention in DEMentia) network (www.interdem.org) and its Manifesto (Vernooij-Dassen et al., 2021), and integrated in current policies see e.g. '*Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives'* (WHO, 2021b).

The shift from a biomedical model towards social paradigms has contributed to recognising the active role of people with dementia within society. This in turn has shaped research and practice in dementia care, promoting the development and

implementation of services and interventions that support engagement, individual strengths, and expression of people with dementia.

1.5 Impact of dementia

Given the available estimates and increased longevity as seen in Section 1.1, it is possible to consider dementia as a worldwide public health priority (WHO, 2012). The symptoms of dementia and the frequent occurrence of comorbid medical conditions (e.g. diabetes, hypertension) (All-Party Parliamentary Group on Dementia, 2016; Bunn et al., 2014) profoundly affect the lives of both those living with the condition and their family caregivers (Connell et al., 2001; Lindeza et al., 2020). The condition has significant social and economic impact on health and social care services (WHO, 2015), with the global societal costs of dementia estimated to be over £1.6 trillion by 2030 (WHO, 2017). In the UK the total costs to society in providing treatment, care and support for those with dementia have been calculated to be over £34 billion per year (Alzheimer's Society, 2021).

The long-term and progressive nature of the condition along with the multiple comorbidities coexisting with dementia (including mental health, disabilities, and long-term conditions) can profoundly compromise the ability of people with dementia to carry out essential tasks in daily life. As the symptoms of dementia progress, people with dementia can become more dependent. Care, supervision,

and support in everyday living are usually required, especially at more advanced stages.

It is well documented that caregiving is highly challenging and may be associated with psychological (e.g. depression, poor quality of life and well-being) and physical burden (e.g. hyperglycaemia and compromised immune system responses) (Karg et al., 2018; Pinquart & Sörensen, 2007). Poor caregiver physical and psychological health can have direct implications on the care outcomes for people living with dementia such as depression, poor quality of life, and mortality (Connell et al., 2001; Etters et al., 2008; Feast et al., 2016). The caregiver challenges also have multiple policy implications. For instance, physical and mental health burdens impact the ability of family members to care for their relatives increasing the risk of early institutionalization (Spitznagel et al., 2006; Toot et al., 2017). According to current figures, around 251,000 people with dementia were living in care homes in the UK in 2019 (Wittenberg et al., 2020). With the prevalence of dementia continually increasing, the demand for care home places is projected to rise to 417,000 by 2025 and 667,000 by 2040 (Wittenberg et al., 2020). The following section provides an overview of the dementia care settings by outlining a definition of a care home and considering some of the issues related to this social care setting.

1.6 Care home settings

In the UK, the term ‘care home’ refers to residential and nursing homes. Residential homes are accommodation offering 24-hour support and assistance in personal care and daily activities, whereas nursing homes offer the same care in addition to qualified nurse assistance (National Health Service [NHS], 2019a). For the purpose of this thesis ‘care home’ is used to cover both types of care accommodations.

The majority of care home residents have complex health needs with high levels of depression, pain, mobility issues and incontinence (Goodman et al., 2017a). Public policy emphasises the need for implementing more holistic approaches and high quality, evidence-based interventions in care homes in order to improve the quality of care provided to residents (Department of Health and Social Care, 2009; NICE, 2013). However, despite this, studies have identified several barriers to implementing person-centred and relational care within care home settings, such as lack of time, high staff turnover, inadequate care professionals’ dementia-related knowledge, and insufficient resources (Kormelinck et al., 2020; McArthur et al., 2021).

In most care homes, care professionals are involved in the delivery and provision of primary care services alongside personal care tasks such as dressing and washing (Goodman et al., 2017a; Spilsbury et al., 2011). The high intensity work

within the daily routine has been found to promote a task-oriented approach to care, which focuses and prioritises on task completion and tends to be oriented towards physical needs (Kadri et al. 2018, Rapaport et al., 2017). Lack of time, resources and the pressure of a task-oriented system valuing the execution of tasks have a significant impact on the opportunity for interaction, engagement, and intimate relationship between care professional and residents (Kadri et al., 2018).

High physical and psychological workloads (Kentischer et al., 2018; Seidel & Thyrian, 2019; Zwijsen et al., 2014) often alongside poor remuneration and lack of career structure have also been linked to increasing levels of care professional' burnout (i.e. emotional and physical exhaustion) and low quality of care (Costello et al., 2019). This suggests that it is important to develop effective strategies and interventions that could be implemented and integrated into daily care practice to promote meaningful engagement, relationship, and quality of life of residents without increasing the workload for care professionals.

The growing number of care home residents living with one or more comorbid conditions, and the task-oriented versus person-centred practices and its effects on care staff and the care provided, demonstrate the need to design effective interventions for people with dementia that consider the complexity and specificity of the context, which is likely to shape how interventions are delivered and their efficacy. The following section presents non-pharmacological interventions for

people living with dementia and provides an overview of the best evidence on a range of psychosocial interventions in dementia care.

1.7 Non-pharmacological interventions for people with dementia

Due to the longstanding assumption that dementia is merely a neurological disease, pharmacological interventions have been granted priority in dementia treatment. Pharmacological treatments such as antipsychotics, sedatives, antidepressants, and mood stabilising drugs are often seen as first-line interventions to manage responsive behaviours, such as agitation, wandering, and aggression, despite presenting a high risk of harmful side effects such as metabolic abnormalities, stroke, and epilepsy/seizures (Atti et al., 2014; Coupland et al., 2011). Drug treatments can temporarily alleviate symptoms, or slow down their progression, but they are often associated with side effects and are not suitable for all those with dementia (Douglas & Smeeth, 2008; Lemay et al., 2013; Mittal et al., 2011).

In the absence of a cure, there is increasing interest in the application of psychosocial interventions aiming to improve behaviour, cognition, quality of life and well-being of those living with dementia. A variety of interventions have been developed and evaluated. These include, for instance, sensory interventions, reminiscence therapy, art interventions, music therapy, cognitive stimulation therapy, environmental modifications, and reality orientation. In recent years, there

has been an increase in evidence highlighting the benefits of psychosocial interventions as an effective approach to promote positive behaviours, cognition, well-being and quality of care for people with dementia (Ballard et al., 2018; Campbell et al., 2020; Livingston et al., 2017). Although extensive systematic reviews on the effectiveness of psychosocial interventions are available (e.g. Livingston et al., 2014; McDermott et al., 2019; O'Connor et al., 2009), there is a lack of consensus as to what works best. This is due to the inconsistency of findings between reviews evaluating similar interventions, difference in the review quality, and in the categorisation of various psychosocial interventions between reviews (McDermott et al., 2019). Four commonly used interventions in dementia care, which are further discussed throughout the thesis, are presented: reminiscence therapy, occupational therapy, cognitive stimulation therapy, and reality orientation therapy.

Reminiscence therapy

Reminiscence therapy has been widely used with people with dementia. It aims to encourage participants to recall and discuss past experiences and events using tangible prompts such as music, photographs, and other materials, in a one-to-one or group context. By linking with long-term memories, which are often preserved and therefore usually easier to access for a person with dementia, reminiscence therapy aims to increase levels of communication, self-confidence, and mood. Evidence from a Cochrane review examining the effectiveness of reminiscence

therapy indicated potentially beneficial effects on cognition, mood, and communication (Woods et al., 2018). Although the growing body of evidence available allowed an overall conclusion on the effect of reminiscence therapy on people with dementia, this review was unable to consider the impact of different forms of reminiscence programme used due to a lack of detailed procedures used in the studies. The NICE recommends group reminiscence therapy for people with mild to moderate dementia (NICE, 2018).

Occupational therapy

Occupational therapy refers to practical and purposeful activities that allow people with dementia to maintain the ability to perform activities of daily living and to participate in social activities. Occupational therapy session(s) may involve the implementation of daily activities such as dressing and meal preparation, identification of stressors or distractions, and adjustment of activities and environment to enhance engagement and participation of people with dementia. Occupational therapy is recommended by NICE for improving functional abilities for people with dementia (NICE, 2018). A randomised controlled trial (RCT) (Graff et al., 2006) of 10 one-hour sessions of home-based occupational therapy over five weeks demonstrated improved activities of daily living, quality of life, mood and health status of people with dementia and decreased level of assistance needed. Positive outcomes were also found for caregivers including an increased sense of competence, quality of life and mood. In line with these findings, a

systematic review of occupational therapy studies implemented in home settings found a positive effect on behaviours and quality of life in those with dementia (Bennett et al., 2019).

Cognitive stimulation therapy

Cognitive stimulation therapy is an evidence-based treatment involving fourteen or more sessions of themed activities, which typically run twice weekly for six-eight weeks. Cognitive stimulation therapy aims to stimulate cognitive function based on the assumption that less cognitive activity accelerates cognitive decline in both dementia and normal ageing. Cognitive stimulation therapy has been widely evaluated using rigorous methodology such as RCT (e.g. Aguirre et al., 2010; Orrell et al., 2017; Spector et al., 2003). These studies show improvements in cognition, social interaction and quality of life and positive effects on the behaviour of people with dementia. Cost-effectiveness analysis found that cognitive stimulation therapy is a cost-effective psychosocial intervention compared to usual care (Knapp et al., 2006). Currently, cognitive stimulation therapy is the only non-pharmacological intervention recommended for the management of cognitive symptoms of mild to moderate dementia (NICE, 2018).

Reality orientation therapy

Reality orientation therapy aims to reorient people with dementia through a repeated and meaningful stimulation of time-place-person orientation.

Studies focusing on the assessment of the efficacy of reality orientation therapy suggest that this therapy has the potential to be an effective strategy for improving cognitive function, well-being, and reduction of responsive behaviours of people with dementia. A systematic analysis (Spector et al., 2001) reported some evidence that reality orientation therapy has positive effects on both cognitive function and behaviour in people with dementia. These results, however, should be interpreted with caution due to the limited number of studies using RCTs.

In summary, despite the increasing number of studies assessing the effectiveness of psychosocial interventions such as those mentioned above, there is insufficient evidence to draw a conclusion on the best practice currently available for people with dementia in different stages of the disease and in different settings. International and national clinical guidance (NICE, 2018; WHO, 2015) recommends the use of non-pharmacological interventions as first-line treatment for the management of agitation and other responsive behaviours in dementia care, as they are safe and unlikely to require medical supervision. The present study focuses on multi-sensory stimulation interventions for people living with dementia. The following chapter presents the literature on multi-sensory stimulation interventions and their application in dementia care, and explores existing research around olfaction and touch.

CHAPTER 2 LITERATURE REVIEW: MULTI-SENSORY STIMULATION INTERVENTIONS

This chapter explores the literature on multi-sensory stimulation interventions. The chapter first includes an examination of the definition of multi-sensory stimulation intervention, its theoretical underpinning and evidence within this research area. Olfaction is then considered with regard to its characteristics and peculiar processes together with the description of olfactory interventions in dementia care. The literature review concludes with a description of the tactile sense and object handling interventions.

2.1 Multi-sensory stimulation interventions

2.1.1 Definition

Among psychosocial interventions, multi-sensory stimulation interventions have received interest within the field of dementia care, particularly for the management of responsive behaviours. Multi-sensory stimulation intervention is often equated with the Snoezelen concept. The term ‘Snoezelen’ is a combination of two Dutch words, “snuffelen” and “doezelen”, the equivalent in English being “sniffing and dozing” (Sánchez et al., 2013). It refers to a specially equipped environment

(Figure 2.1) including, for example, coloured optic fibres, bubble tube lamp, aroma air spray and digital interactive panels where colours, sounds and images can be changed by touching the screen. This equipment is purposefully designed to provide a sensory enriched experience that stimulates primary senses and has relaxing effects (Chung & Lai, 2002). It was originally developed in the 1970s as an intervention for people with learning disability (Hulsegge & Verheul, 1987), and in the early 1990s, it was introduced in dementia care (Hope et al., 1998). This method is also known as a ‘multi-sensory stimulation room’, ‘multi-sensory environment’, ‘sensory room’ or ‘Snoezelen room’.

Figure 2.1 Snoezelen (licensed under © Mindaugas - stock.adobe.com)

Other interventions using different approaches and low-tech sensory materials aiming at stimulating two or more senses (sight, sound, touch, taste and smell) have been developed, among them themed boxes, multi-sensory tools, and multi-dimensional programmes such as Sonas or Namaste Care (see Cheng et al., 2019; Pinto et al., 2020).

Multi-sensory themed boxes are containers filled with objects such as everyday items used for stimulating senses, providing shared engagement, and promoting interaction or reminiscence in people with dementia (Cheng et al., 2019). Multi-sensory tools can be playful or personalised objects aiming to facilitate tactile stimulation and enhance relationships with people living with dementia (Treadaway et al., 2019). An example of a playful object is LUMA, an interactive, hand-held crafted wooden object developed from the LAUGH (Ludic Artefacts Using Gesture and Haptics) project (Treadaway, 2018) to stimulate the senses through touch, the lights change colour, and a bird song plays (Fennell et al., 2019). The Sonas programme is a sensory intervention focused on stimulating all five senses, promoting communication, and enhancing engagement and relaxation among people with dementia. This is achieved using various activities such as percussion instruments, smells, and listening to poetry and proverbs (Strøm et al., 2017). The Namaste Care intervention is a multi-dimensional programme for people with dementia living in care homes which focuses on integrating sensory,

physical, and emotional elements with individualised resident activities. It aims to reduce isolation and improve quality of life, especially for those in the advanced stages of dementia (Bray et al., 2021; Bunn et al., 2018).

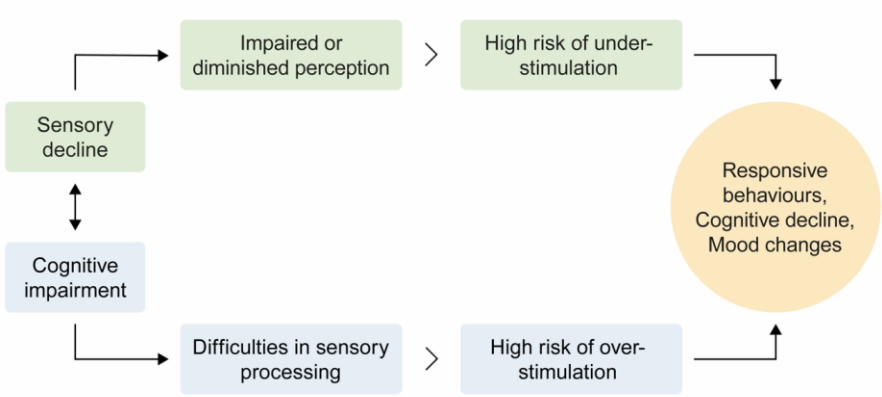
Due to the variety of interventions used to stimulate senses, Baker et al. (2001) highlighted the need to develop a clear definition of what a multi-sensory stimulation intervention is, to encourage consistency among findings. They proposed that multi-sensory stimulation 'refers to a process and/or an approach rather than a room or a piece of equipment. If the process is understood, it can be applied creatively rather than by operating a piece of apparatus' (Baker et al., 2001, p. 82).

This thesis uses the term multi-sensory stimulation intervention to refer to studies including Snoezelen and programmes that stimulate senses using different stimuli and approaches.

2.1.2 Theoretical frameworks supporting multi-sensory stimulation interventions

The theoretical underpinnings supporting multi-sensory stimulation interventions posit that the responsive behaviours, mood changes, and cognitive impairments associated with dementia are interrelated with the sensory decline (Figure 2.~~Figure 2.~~2) (Humes & Young, 2016; Roberts & Allen, 2016).

Figure 2.2 Diagram of the potential interactions between sensory and cognitive functioning, mood, and responsive behaviours



Age-related sensory changes (e.g. limited vision and hearing) are exacerbated by dementia, and the extent of these changes are different for each individual, depending on the neurological impairment, medication management, physical and social environment (Bakker, 2003). Hearing loss, a decreased ability to identify smells, changes in taste and vision influence the way people experience and interact with the environment. Due to sensory changes, people with dementia may require more stimulation (e.g. strong stimuli, greater contrast between objects) to reach the minimum level (threshold sensitivity) of sensation to detect stimuli (Humes & Young, 2016). Consequently, the absence of appropriate activities and

sensory enriched experiences put people with dementia at risk of sensory deprivation (Haigh & Mytton, 2016).

Sensory deprivation can be defined as a state in which a person is subject to a reduction of sensory stimulation on one or more of the senses due to sensory impairments and environment restrictions (absence of or limited sensory stimuli) (Kovach, 2000). Long-term sensory deprivation may lead to changes in cognition, mood and behaviour such as depression, disorientation, irritation, apathy and anxiety (Cohen-Mansfield et al., 2015; Haigh & Mytton, 2016; Ward-Smith et al., 2009). This is partly due to the notion that sensory impairments and consequent prolonged sensory deprivation could directly alter cortical structure and function (Whitson et al., 2018), and indirectly lead to self-withdrawal and social isolation (e.g. Boamah et al., 2021) which in turn are negatively associated with cognitive functioning. According to this last hypothesis, for example, people with reduced perception may engage less in interpersonal interactions and social communication.

Other authors claim that when sensory input is suboptimal, additional cognitive resources are needed to decode the stimuli (cognitive compensation) leaving fewer resources to encoding and integrate sensory information and context (see for review: Roberts & Allen, 2016). This may lead to poor adaptive responses to the environmental input e.g. confusion, irritability, and disorientation. Studies,

especially those on the auditory modality, suggest that providing sensory aids e.g. hearing aids, and an appropriate level and quality of stimulation could strongly influence an individual's cognitive abilities (e.g. Amieva et al., 2015; Maharani et al., 2018). Further evidence in support of this comes from studies on dementia prevention which found hearing loss to be the largest potentially modifiable risk factor for cognitive decline (Livingston et al., 2020).

In contrast, cognitive impairments impact the individual's ability to process and moderate external sensory input (Baker et al., 2003), making normal stimuli confusing and negatively impacting the performance on complex perceptual tasks (Roberts & Allen, 2016). Hence, overstimulating environments can generate or increase maladaptive behaviours such as irritability and aggression. According to the Sensory Integration Theory (Ayres, 1972), behavioural responses cannot be attributed to neurological change alone, but are the result of a sensory integrative process that combines the ability of the individual to process information and the complexity of the information itself. Ayres (1972) suggests that the ability to cope with the environment diminishes in the absence of adequate levels of stimulation. It is argued that each individual has a sensory profile constituting what makes them feel 'just right', and not overwhelmed or deprived of stimulation (Kelley et al., 2003).

The relationship between individual characteristics and environmental demand is explained by the Model of Sensory Processing (Brown & Dunn, 2002). This model suggests that each person has a distinctive threshold and strategies (active or passive) for responding to sensory stimulation. Though people using passive strategies may internally respond to stimuli, they might not take action to change their environments, whereas people with active tendencies may tend to control the type and amount of sensory input in their environments e.g. in a case of a busy environment, a person using a passive strategy would remain in the room and react with frustration whereas those using active strategy would move and find a place with a lower level of sensory stimulation.

The concept of 'sensoristasis' was introduced in the Model of Imbalance (Kovach, 2000) as an explanation of how optimal functional performance can occur in people with dementia. Sensoristasis is a state of equilibrium between sensory-stimulating and sensory-calming activity. Kovach (2000) proposed that people living with dementia have decreased thresholds and diminished ability to regulate and maintain the sensoristasis. According to this model, a sensoristasis imbalance affects behaviours and functions negatively. Indeed, too much high-stimulus activity can exceed an individual's stress threshold. This may occur if the person is required to process complex or high amounts of information. This can be experienced by people with dementia when they are for example in communal

areas in care homes which are often very noisy and where different activities take place. On the other hand, low levels of stimulation can create a state of deprivation. This may be the case when people are left alone in their room or when the opportunity for people with dementia to initiate their own activity is obstructed by care professionals and family caregivers, e.g. reducing the number of individual daily activities (shopping or opportunities to make tea or use functional objects e.g. curling tongs or a hairdryer) (Lee & Bartlett, 2021).

Both conditions, under- and over-stimulation, can lead to 'intrapsychic discomfort' in people with dementia causing a decline in activities of daily living, social skills, well-being and potentially an increase in agitation (Kovach, 2000). According to this model, equilibrium of the sensory state, sensoristasis, can be achieved by balancing sensory stimulation with sensory calming activity.

These theories and models offer a framework for the implementation of multi-sensory stimulation interventions for people with dementia. They all suggest that appropriate multi-sensory experiences (excessive stimulation versus sensory deprivation) are essential to maximising a person's potential. Tailoring environmental demand and providing activity at the 'just right challenge' supports people with dementia to adjust and process information, reducing intrapsychic discomfort. In turn, adequate use of sensory stimulation may increase well-being,

quality of life, social interactions, and support the management of behavioural manifestations of dementia.

2.1.3 Multi-sensory stimulation interventions: evidence in dementia care

In the UK, the National Institute for Health and Care Excellence has recognised the important role of ongoing sensory stimulation in the management of responsive behaviours such as agitation and distress in people with dementia (NICE, 2018). Nevertheless, there is a lack of evidence to support the use of multi-sensory stimulation interventions. As a result of the growing interest in establishing the effectiveness of multi-sensory stimulation interventions in dementia care, several reviews have assessed effects focusing on different sensory stimulation approaches (e.g. Cheng et al., 2019; Chung & Lai, 2002; Nagayama et al., 2014; Sánchez et al., 2013; Smith & D'Amico, 2019; Strøm et al., 2016), outcomes (e.g. Dimitriou & Tsolaki, 2017; Livingston et al., 2014; Lorusso & Bosch, 2018; Silva et al., 2018), settings (e.g. Cabrera et al., 2015; Seitz et al., 2012; Turner, 2010), and stages of dementia (e.g. Hui et al., 2021; Pinto et al., 2020).

There are some positive results regarding the short term impacts of multi-sensory stimulation interventions in people with dementia. A systematic review (Silva et al., 2018) on multi-sensory approaches in managing neuropsychiatric symptoms found evidence supporting the effectiveness of multi-sensory stimulation interventions in domains such as agitation, aggressive behaviours, and verbal agitation. These

findings are in line with the results of previous reviews showing a positive effect of multi-sensory stimulation interventions on behaviours and agitation in people with dementia (Livingston et al., 2014; Sánchez et al., 2013; Strøm et al., 2016). However, whilst it is well documented that multi-sensory stimulation interventions may be useful for reducing agitation and behavioural symptoms in dementia, there is still little evidence on longer term effects. Indeed, only a few studies included reported sustainable benefits in behavioural outcomes, for example, at eight (Maseda et al., 2014a; Sánchez et al., 2016a) and twelve (Milev et al., 2008) weeks after the intervention.

Positive impact on mood has also been reported following multi-sensory stimulation interventions (Cheng et al., 2019; Pinto et al., 2021; Sánchez et al., 2013; Strøm et al., 2016). For example, an intervention based on a multi-sensory approach integrated into daily morning care, using preferred stimuli of residents such as favourite soap fragrance, grooming products or colour of clothes, reported generalised positive effects on mood and well-being as participants showed statistically significant improvements in video-observed apathy, aggressive behaviour, loss of decorum, rebelliousness, and depression (all $p < .05$), a higher degree of enjoyment, response to speech (all $p < .01$) and happiness ($p < .001$) in comparison to the control group who received usual care (van Weert et al., 2005a). Similarly, Ozdemir and Akdemir (2009) found a significant improvement in

depression and anxiety (both p = .001) in people with mild dementia, following an intervention which combined music therapy, painting pictures of inanimate and animate subjects (e.g. animals, foods, vehicles, people and fruits), and time–place–person orientation activities e.g. writing the date and the name of location on the drawing paper. These results were found immediately and also three weeks after the intervention. Although this study showed statistically significant benefits of multi-sensory stimulation intervention in reducing mood disorders, these findings should be interpreted with caution due to a lack of control group. In a 16-week study of Snoezelen versus a music group intervention, Sánchez et al. (2016b) found significantly improved anxiety (p = .021) and depression (p = .006) scores for those with severe dementia compared to music group following sensory stimulation eight weeks after the end of the intervention, demonstrating long-term benefits.

The literature reviews suggest that multi-sensory stimulation interventions have potential to support mood, well-being, and quality of life for people with dementia, both during the programme session and after the intervention's completion. Providing such interventions may be particularly relevant in care homes as up to four in ten older people living in residential care in the UK experience mood disorders (e.g. anxiety and depression) (Stewart et al., 2014).

Other research (e.g. Maseda et al., 2014a, 2014b) has shown that multi-sensory stimulation contributes to stabilising cognitive deterioration but only a few studies (e.g. Collier et al., 2010; Ozdemir & Akdemir, 2009) reported a statistically significant improvement in this domain. Using Assessment of Motor and Process Skills, a significant positive improvement ($p = .04$) in the process abilities of activities of daily living and cognition in people with moderate to severe dementia was found following multi-sensory stimulation (Collier et al., 2010). Significant changes ($p = .001$) in the Mini Mental State Examination score were also reported immediately and three weeks after the end of the intervention in Ozdemir and Akdemir's study (2009). Considering the limited number of studies evaluating the effect at cognitive level, it is difficult to determine to what extent multi-sensory stimulation interventions may reduce cognitive decline.

Likewise, only a few studies have investigated whether multi-sensory stimulation improves communication for people with dementia. van Weert et al. (2005b) suggested that multi-sensory stimulation interventions could improve interactions between residents and care professionals in care home settings. They found significant improvements in participants' verbal and non-verbal communication (e.g. eye contact, smiling, affective touch) in comparison to the control group who received the usual morning care routine. An immediate effect in the frequency of

spontaneous talking was also found in people with severe dementia following multi-sensory stimulation intervention (Maseda et al., 2014b).

These findings were confirmed by studies focusing on care professionals and family caregivers who reported improved interpersonal relationships with the person with dementia alongside increased well-being and job satisfaction following use of a sensory room (Cox et al., 2004; Riley-Doucet, 2009).

Despite the evidence above, the scientific effectiveness of interventions based on multi-sensory stimulation interventions is still fairly limited. For instance, other studies did not find a significant difference between experimental and control groups in mood (Baillon et al., 2004; Baker et al., 2003), quality of life (Hutson et al., 2014), cognition (Baker et al., 2003), communication (Hutson et al., 2014; Strøm et al., 2017) and behaviour (Baillon et al., 2004; Hutson et al., 2014). One study (Sánchez et al., 2016a) found worse results on agitation, aggression, and cognitive function.

The mixed findings of such studies may be due to their poor methodological quality (e.g. absence of control group, small sample size, insufficient information reported), the variety of treatment approaches, and outcome measures used, that make it difficult to delineate an overall conclusion in relation to the effect of sensory stimulation (e.g. Pinto et al., 2020; Sánchez et al., 2013; Silva et al., 2018; Strøm et al., 2016). Cheng et al. (2019) argue that lack of evidence should not be

seen as lack of efficacy but instead as an indication of the need for further multi-sensory stimulation intervention studies. Future research should use more rigorous methodology including a control group, larger samples, methods that enable capture of the effects within the sessions, which may be lost or not appropriately captured with post-intervention measurements. Furthermore, future studies should also clearly describe the protocol used, so that it becomes possible to identify the key elements of different approaches to multi-sensory stimulation, and to evaluate their relative benefits.

Considering the stage of dementia and setting, Pinto et al. (2020) found that the majority of multi-sensory stimulation studies included people with a moderate to severe stage of dementia living in institutionalised settings. This may be due to the potential high concern regarding sensory deprivation or sensoristasis imbalance that can be experienced by this group (Pinto et al, 2020). In addition, the multi-sensory stimulation intervention could be used with people in the later stage of dementia who present severe communication and cognitive impairments. Multi-sensory stimuli offer opportunities for sensory experiences in which response could be embodied rather than verbal (van Weert et al., 2005b). Understanding and promoting embodied experiences are important for people living with dementia. Gestures, movements, facial expressions, and sounds become the way by which people with dementia can communicate their internal states (e.g. pain),

respond to external stimuli (e.g. room temperature or objects), express their self-identity (e.g. preference) and maintain a sense of agency, especially in the severe or advanced stage of dementia (Kontos, 2005; Kontos & Martin, 2013).

Overall, theoretical models and the existing studies described above (Sections 2.1.2 and 2.1.3) suggest that multi-sensory stimulation interventions may contribute to minimise the effect of sensory changes and reduce responsive behaviours associated with dementia. Some evidence also reveals that multi-sensory stimulation interventions may enhance mood, verbal and non-verbal communication, and social interactions between people with dementia and care professionals and family or informal caregivers. In the context of this evidence and in response to the growing number of people living with dementia, there is a need to explore innovative multi-sensory stimulation approaches to care. This prompted the interest in this programme of study to further investigate the use of multi-sensory stimulation intervention with people with dementia, particularly in relation to tactile and olfactory stimulation. The motivation to undertake this study arises from the relative lack of research on these areas (Cheng et al., 2019; Strøm et al., 2016). Although there is a long tradition of studying the role of objects in therapeutic settings such as reminiscence or occupational therapy, the use of activity based on handling objects as a well-being focused intervention in dementia care is relatively recent (Camic et al., 2019). Olfactory stimulation has received

less attention in dementia care compared to other sensory modalities, despite its well-established connection with memory and emotion (Herz, 2016). Therefore, due to the limited literature surrounding olfactory stimulation and object handling interventions with people with dementia, the current research was devised to investigate them and their associated benefits.

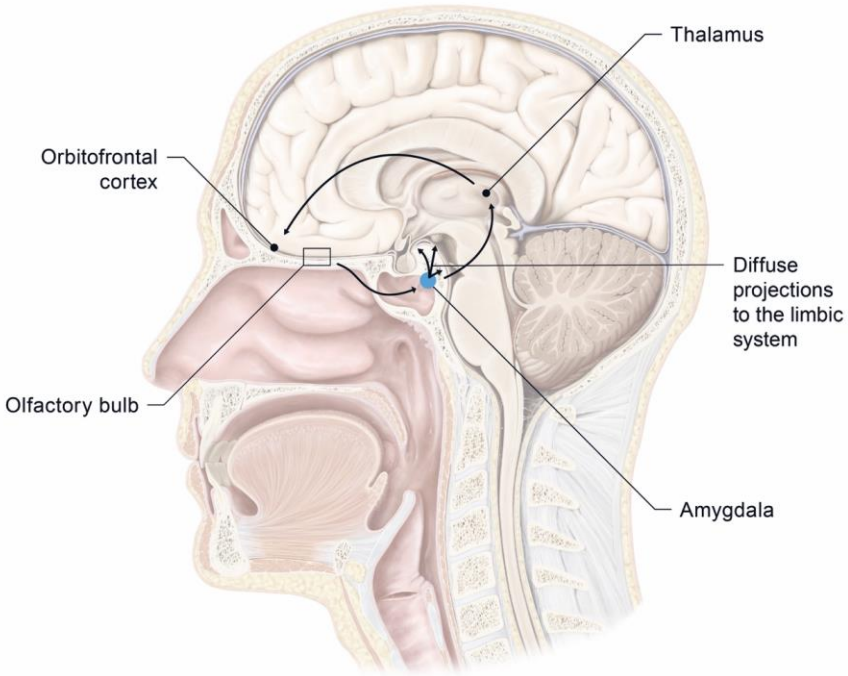
2.2 Olfaction

2.2.1 Olfactory processes and their connection with memory and emotion

The sensory modalities most often used in multi-sensory stimulation interventions for people with dementia have been limited to visual, audio, and tactile sensations, with fewer studies focussing on olfaction (Strøm et al., 2016). This is notable when considering that olfaction is a potent sense. This is because it mediates interaction with the external world in different ways, and is intimately connected to our emotions, memories, behaviours and way we react, our ability to know ourselves and others, and to enjoy foods and beverages (Doty & Kamath, 2014). Due to its 'invisible' nature, and the dynamic and complex physical properties, olfaction has been under-investigated, unlike other senses such as vision (Barwich, 2020). Olfaction research as well as public awareness of the importance of smell have both been boosted by the experience of partial loss of smell (hyposmia) or anosmia due to COVID-19 (Agyeman et al., 2020; Moein et al., 2020).

The most distinctive characteristic of olfaction is the well-documented relationship with memory and emotional processes at the level of brain anatomy (Chu & Downes, 2000; Herz et al., 2004b; Maratos et al., 2001; Yeshurun & Sobel, 2010). Incoming smells after reaching the olfactory receptor cells in the olfactory epithelium inside the nasal cavity are first processed and coded by the olfactory bulb, which can be considered an 'offshoot' of the brain, as shown in Figure 2.~~Figure 2.~~3.

Figure 2.3 Olfactory pathway (licensed under Science Photo Library)



From the olfactory bulb, odour information is then passed to the olfactory cortex and brain areas that are responsible for associative learning, expression and human emotion: the amygdala and hippocampus (Dolan, 2002; Herz et al., 2004b). Functional magnetic resonance imaging shows activations of those areas when odours are presented (Gottfried et al., 2004; Herz et al., 2004b).

It should also be noted that compared to other sensory modalities olfaction is the only sensory system to have a direct connection with the amygdala-hippocampal

complex (Herz, 2016). This may explain why memories evoked by smells are more emotionally intense than memories triggered by other sensory cues such as visual, auditory or tactile stimuli (Arshamian et al., 2013; Herz & Schooler, 2002; Willander & Larsson, 2006, 2007). Consistent with this, Herz and colleagues (2004) used functional magnetic resonance imaging and found that the amygdala is more activated when participants recall memories triggered by olfactory cues than when memories are elicited by the same items presented using visual cues. As suggested by the authors this unique activation is due to the emotional connotation of the memories. A cross-modal comparison study (Herz, 1998) compared odours with verbal, visual, tactile and musical stimuli as associated memory cues found no difference in terms of accuracy in memories mediated through the varied sensory modality cues examined. However, differences were identified in the emotional salience of memories. Those memories triggered by odour cues, known as odour-evoked memories, were significantly more emotional than memories elicited by the other stimulus types. Smells therefore extend the recollections of the memory content to the emotions connected to the memory.

The emotional property of odour-evoked memories may explain why a memory triggered by smell elicits the strong feeling of being transported to the original time and place - known as “Proust effects” (Chu & Downes, 2000) from the literary anecdote reported by Marcel Proust, to be suddenly brought back to a moment of

his childhood biting a cake that had been dipped in Linden tea. This is a remarkable feature of odour memories. Barwich proposed that smells ‘evoke presence, an immediate physical embodiment’ (2020, p. 126) that is so vivid and real as to produce the feeling of being transported into a different time and place. In support of the empirical evidence, neuroimaging studies have shown brain activations during odour-evoked memories not only in the area associated with the memory retrieval and olfactory processing but also in those regions related to visual imagery (olfactory gyrus and precuneus) and emotions (limbic and temporal regions) (Arshamian et al., 2013; Svoboda et al., 2006).

Interestingly, Herz claims that ‘not only do odours trigger emotions, they can also become emotions’ (2009b, p. 11). This phenomenon (also known as odour-emotional conditioning) occurs when a new association is created by pairing an unfamiliar smell with an emotion (e.g. frustration). Subsequent exposure to the frustration-associated odour alone acts as a proxy causing a feeling of frustration and related changes in behaviours (Herz et al., 2004a). Odour-emotional conditioning could have considerable implications when considering that a positive odour-association could lead to enhanced positive emotions and behaviours. Thus, the experience of odour-evoked memory differs from other memory evoked by other sensory modality cues in its emotionality.

In addition, it has been found that odour-evoked memories are less frequently thought and talked about (Chu & Downes, 2000; Willander et al., 2015; Willander & Larsson, 2006), lacking a lexicon of suitable words (Winter et al., 2018), associated to high emotional arousal (Willander & Larsson, 2007) and localised to the first decade of life compared with memories evoked by verbal and visual stimuli which are more related to young adulthood (Miles & Berntsen, 2011; Willander & Larsson, 2006). This phenomenon is called a *reminiscence bump* (Rubin et al., 1998). Furthermore, odour-evoked memories have been shown to be associated with higher levels of positive affect compared to memories cued by verbal labels (i.e. name-odour) (e.g. Willander & Larsson, 2007) or visual form (Herz, 2004) or music (e.g. Barrett et al., 2010). These findings were confirmed by the neurological evidence put forward by Arshamian et al. (2013), who reported a greater activation in areas (i.e. temporal gyrus and temporal pole) implicated in the processing of pleasant memories in the odour cue compared to a verbal cue presentation.

Although there is evidence of positive and pleasant memories recalled through olfactory stimulation, it should be noted that odour can also trigger negative memories and emotions, notably when they are associated with traumatic events in an individual's past experience (Toffolo et al., 2012). Thus, interventions based

on olfactory stimulation need to consider that smell can be anchored to negative memories and emotional states, and therefore may cause distress.

2.2.2 Olfactory stimulation in dementia care

Reduced sense of smell has been reported in individuals with dementia (Murphy, 2019; Olofsson et al., 2021). Studies have found a relationship between cognitive impairment and olfactory function (Park et al., 2021), and that changes in olfaction occur in the early stage of the disease and sometimes even before the person manifests the onset of clinical symptomatology (e.g. Alves et al., 2014; Murphy, 2019). This can be explained by the fact that some areas involved in olfactory processing such as hippocampal regions are associated with neuropathological changes in AD (Murphy, 2019). These findings have led to increased interest in investigating olfactory function at the level of neuroanatomy as a biomarker of dementia (Murphy, 2019).

Other studies have focused on exploring the potential therapeutic benefits of olfactory stimulation in dementia care. Since odour-evoked memories are emotionally intense and tend to be positive, odours can be considered the 'best' cues to memory (Herz, 1998; Herz, 2016). El Haj et al. (2018) compared autobiographic memories (or memory of personal experiences) evoked by odours, music and odour-and-music-free memories in terms of specificity, emotion and vividness in people with AD. Findings showed that among people with a mild stage

of dementia autobiographic memories elicited by odours and music had similar positive effects on the domains evaluated. This is an important finding since music is renowned as an emotionally evocative stimulus (Dowlen et al., 2021; Van Der Steen et al., 2018) and it is often considered an important component of dementia care (Cuddy et al., 2017). El Haj et al. (2018) found that the retrieval time for memories evoked by odours was significantly shorter than music-evoked memories. The authors speculated that odour cues may promote involuntary and direct retrieval, which requires little cognitive control (e.g. concentration, attention). In 2019, Glachet and El Haj found that people with mild dementia self-assessed their autobiographic memories recalled after odour exposure as more positive and specific. Using Self-Assessment Manikin, a non-verbal pictorial assessment technique measuring both arousal and emotional valence, this study also reported that odour-evoked memories were accompanied by more subjective reliving and higher arousal compared to memories recalled from an odour-free condition. In a similar vein, another study (Glachet et al., 2019) reported a higher number and greater specificity of memories for those participants in the experimental condition (i.e. odour exposure) compared to no odour condition.

As reported in the above-mentioned studies, the unique properties of odour-evoked memories were also found in people living with dementia. Thus, these findings support the use of odour cues to stimulate autobiographic memories in

dementia care. Since odours can trigger pleasant and emotional autobiographic memories, olfactory stimulation may positively affect mood and social interaction and overall increased self-identity, quality of life and well-being of those with dementia.

Other studies suggest that the olfactory sense may link to implicit memory, which can remain intact in people with dementia (Degel et al., 2001; Degel & Köster, 1999; Fleischman et al., 2005). Implicit memory refers to previous experiences unconsciously influencing later behaviour without conscious awareness (White et al., 2015). This means that implicit odour memory may influence behaviours (e.g. food intake or craving for cigarettes) or mood (e.g. reduction in anxiety or depression) (Herz, 2016).

Although the links between olfaction, memory and emotional processes have been demonstrated, the use of odour stimulation in dementia care is still limited. Most research on olfactory stimuli for people with dementia has involved aromatherapy, using a range of essential oils directly applied to the skin surface or inhaled using e.g. a diffuser or vaporiser (Sowndhararajan & Kim, 2016) to affect the brain and the body. Aromatherapy is supported by the proposition that the constituents of essential oils may influence behaviour and alter mood states through the central nervous or endocrine systems (Arruda et al., 2012). For instance, the key constituents of lavender oil e.g. linalyl acetate and linalool, are associated with

sedative and calming effects (Lis-Balchin & Hart, 1999). Aromatherapy has been greatly used in the treatment of responsive behaviour and to improve sleep. The results of these studies are mixed, and only a few have provided evidence for effectiveness (e.g. Ball et al., 2020; Fung et al., 2012; Xiao et al., 2021). The mixed findings of such studies may be due to scientifically inadequate quality of studies as suggested by a fairly recent Cochrane review (Ball et al., 2020) as well as cultural, gender and personality differences affecting the perceived quality of the odours which could mediate and influence the physiological effects (Herz, 2009a). Further studies are needed to understand the mechanisms behind this intervention and in what circumstances aromatic chemicals can modulate physical and psychological changes.

Other studies exploring the potential of smell in dementia care have incorporated olfactory stimulation with other multi-sensory activities (Maseda et al., 2014a; Maseda et al., 2014b; Sánchez et al., 2016b). One such intervention is Namaste Care. A review (Bunn et al., 2018) of those interventions reports calming effects of odour stimulation (e.g. lavender diffused in the room, use of massage oil). Further evidence comes from Griffiths et al. (2019), who investigated the effect of a multi-sensory stimulation intervention using heritage and olfactory items (e.g. soap, shaving stick) in people with mild to moderate dementia. Positive impacts were reported in terms of high engagement and enhanced mood and emotion following

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the multi-sensory sessions. In particular, olfactory stimuli were found to be beneficial for people with dementia. Indeed, positive changes in feelings after smelling the olfactory items were reported by some participants.

From the evidence above and the unique connection between olfaction, memory and emotion, it seems feasible that people with dementia might benefit from olfactory stimulation. However, further research is needed to explore the potential of odour stimulation in dementia care (Strøm et al., 2016).

2.3 Touch

2.3.1 Touch and dementia care

Touch plays a fundamental role across the lifespan as we use it to learn about the physical environment, guide actions, and interactions (Solway et al., 2016). It becomes particularly important in the later stage of life due to deterioration in the senses of sight and hearing (Behrman et al., 2014). Exploring material objects, defined as 'physical items that fill our environment throughout our lives that we use, possess, wear, covet, discard and experience in a myriad of ways every day' (Solway et al., 2016, p. 1), through touch and other sensory modalities can assist older people to organise and integrate information from different senses, leading to multiple encoding of information processing, which in turn can facilitate new learning (Paddon et al., 2014; Shams & Seitz, 2008). Encoding refers to the

process of converting external input into a meaningful perceptual experience. This process starts with perception including identification, organization and interpretation of sensory information. Combining and integrating multiple sources of sensory information such as semantic, olfactory, tactile, visual input can help to create a more coherent representation of the world. For instance, it has been suggested that the combination of handling, looking and talking about objects may enhance triple coding effects (Thomson et al., 2012).

Building upon the existing cognitive theoretical models (Craik & Lockhart, 1972; Lockhart & Craik, 1990), Thomson et al. (2012) suggest that when verbal, touch and visual sensory information are presented together, they become connected with each other in the short-term memory (i.e. working memories) during the encoding, and integrated with previous experiences and knowledge from long-term memory. This process results in a deeper elaboration (or cognitive processing) of the physical material information which leads to more connections being laid down in memory. These views have been supported by a review of the literature which found that older people (without a diagnosis of dementia) benefit more from receiving multimodal stimulation compared to unimodal stimulation, in performing tasks such as detection or judgment tasks (de Dieuleveult et al., 2017). Indeed, a sensory-enriched experience enables stimuli to be encoded into multi-sensory representations thereby activating a wider network of brain regions compared to

those invoked by unisensory encoding, and thus facilitating older people in performing tasks (de Dieuleveult et al., 2017; Lehmann & Murray, 2005; Matusz et al., 2017) and also compensating for a decline or loss of a unisensory modality (Peter et al., 2019). Therefore, touch combined with other sensory modalities may provide opportunity for multi-sensory experiences which can be beneficial for people with dementia (Camic et al., 2021). Pinto et al. (2020) argue that it would be important to further explore multi-sensory integration in people with dementia.

Giachritsis (2008, p. 75) argued that touch could be considered as the 'ultimate sense' which enables us to create a complete representation of the world. The mechanisms involved in tactile object analysis and the anatomical correlates of those mechanisms are still poorly understood. Tactile object recognition is likely a priori to involve a number of stages including the initial encoding of elementary sensory data, the integration of sensory information to form a coherent tactile representation of the object, and the association of that tactile representation with semantic knowledge about the object (Crutch et al., 2005).

Neuropsychological evidence put forward by Critchley (2008) suggested that there is a close relationship between touch and emotional systems in the brain, which could explain the sense of well-being that may be evoked through touch. Reflecting these important neurological and functional aspects, objects such as

sensory cushions or muffs (also known as ‘twiddle muffs’) made with soft fabric, buttons, zips, beads, ribbons have been widely used with people with dementia.

Lanceley and colleagues state that objects can act as “a repository or container for projections of different and difficult states of mind” (2012, p. 810). For instance, a growing number of care homes use dolls to comfort residents, drawing on evidence for the benefits of doll therapy (Ng et al., 2017). The use of material objects is also central to reminiscence and occupational therapy. Rowlands (2008) also suggested that older people with dementia benefit from handling familiar material objects because the objects have the potential to prompt memories, restore life histories and express the identities of individuals.

2.3.2 Object handling interventions

Increasing evidence supporting the value of using material objects in health and social care comes from object handling interventions. Object handling involves several senses, including touch. Despite the growth in the use of this intervention in dementia care, there is no clear definition of what object handling is. As further discussed in Chapter 4, there are however some elements common to the practice. This includes offering or choosing a material object, and participants having the opportunity to explore, reflect and respond to it. The type of material objects that can be used range from everyday items, heritage objects or other types of curio or memorabilia.

Much of the evidence available on object handling interventions assesses the impact of items from museum and gallery collections, a practice defined here as heritage object handling. Findings from heritage object handling sessions show that handling and discussing heritage items can increase participants' well-being, social inclusion, provide intellectual stimulation, and prompt memories as well as create links to the present (Camic et al., 2019, 2021; Solway et al., 2015; Thomson & Chatterjee, 2016). For instance, Camic et al. (2019) found statistically significant positive changes ($p < .001$) in the overall well-being score among people with mild to moderate dementia ($n = 80$) following a group session where a range of five to six heritage objects (e.g. tiger's skull, fossilised seaweed, Victorian candle snuffer) were introduced and discussed among the group members. Similar results were reported from a crossover study design (Johnson et al., 2017a). This study found increasing well-being in participants undertaking a group museum-based intervention compared to the control group who took part in a social occasion where foods and drinks were provided. These findings may suggest that the positive outcomes obtained from object handling session(s) could not be attributed to group or social factors.

Given what has been outlined in Section 2.3.1, one possible explanation for the positive benefits of object handling interventions could be attributed to the multidimensional experience of touch. Indeed, it seems that exploring an object

through touch and other sensory modalities enables a multiple encoding of the sensory information, facilitating new learning. The new learning might enhance a positive change in participants' mood. This hypothesis is supported by qualitative evidence showing that participants often express a sense of privilege in being able to touch heritage collections and acquire new knowledge associated with them (Ander et al., 2013; Johnson et al., 2017a).

Another possible explanation for the beneficial effects of handling objects may be found in the social engagement associated with the activity. Objects can be used as a catalyst for conversation, novel thoughts, memories and personal experiences that can be shared with the facilitator or other members of the group. This may boost interpersonal relationships, self-identity and enrich the participants' experience associated with the activity.

Moreover, it has been argued that the intrinsic physical and material properties of the objects (e.g. size, colour, texture) may promote a wide range of interactions (Camic et al., 2021) and provide satisfaction in their own right (Ander et al., 2013; Camic & Chatterjee, 2013). As regards other attributes (e.g. colour), Tischler and Clapp (2020) reviewed the therapeutic value of the olfactory properties of objects. They claim that distinctive and olfactory-rich heritage items such as shaving cream from a well-known brand (e.g. Albany) have recognisable odours and packaging that can trigger curiosity, are associated with personal experiences, and promote

meaningful conversations. Likewise, Bembibre and Strlič argue that ‘smell can be considered as an intangible property of tangible heritage and inextricably linked to it’ which can trigger an hedonic response, contribute to a more personal connection to the items, and increase learning and enjoyment (2017, p. 11). In recent years, the power of smells in the context of cultural heritage has been further recognised (e.g. Bembibre & Strlič, 2017; Camic et al., 2021). Camic et al. (2021) recommend to consider the olfactory experiences when planning object handling sessions. In 2020, the project *Odeuropa* was launched to trace and collect European smell heritage (e.g. text, objects, painting), forming an online encyclopaedia (Odeuropa, 2020).

Based on the available studies, object handling interventions can be considered to be a psychosocial well-being focused intervention (Camic et al., 2019). Further studies need to investigate its effectiveness and to what extent factors such as type of stimuli, length of the intervention and procedure may impact the outcomes.

2.4 Summary

This literature review has sought to identify and understand the existing evidence and theoretical underpinning of multi-sensory stimulation interventions. Studies have demonstrated positive effects when using multi-sensory stimulation interventions in the management of responsive behaviours associated with dementia. A few studies also reported improved mood, cognitive function, and

communication in people with dementia. Although these studies suggest positive benefits in people with dementia following multi-sensory stimulation interventions, there is a need for further research to establish their effectiveness. The current investigation is supported by underpinning theories of multi-sensory stimulation interventions which suggest that sensory stimulation may promote a balance between over- and under-stimulation, reduce responsive behaviours associated with dementia, and promote well-being and quality of life. This chapter also specifically considered olfactory and tactile sensations. The important role of touch in understanding and connecting with the surrounding world, and the promising results on object handling interventions as well as the unique relationship between olfaction, memory, and emotion, indicate the need for more research on multi-sensory stimulation intervention focusing on olfactory and tactile stimulation for people with dementia.

In response to this, the present research sought to explore and develop the use of archival objects and olfactory items within an innovative intervention.
The following chapter presents the overarching aims and framework used to conduct this research.

CHAPTER 3 METHODOLOGY

This chapter presents the rationale, research paradigm, and overall aims underpinning the research. An overview of the four studies undertaken within the MRC framework (Craig et al., 2008), and ethical considerations are also outlined. Details of the research methods used, participants, the analysis processes along with findings of each study are presented as stand-alone chapters (Chapter 4-8).

3.1 Rationale for the research

The current research responds to increasing interest in multi-sensory stimulation interventions within the field of dementia care and the need to create innovative and evidence-based care provision. As discussed in Chapter 2, evidence shows a clear interlink between sensation and cognition, mood and responsive behaviours. The detrimental effects of sensory deprivation and, conversely, the positive benefits found in engaging in multi-sensory stimulation sessions suggest that sensory stimulation can have a potential therapeutic impact in maintaining functional and cognitive ability as well as the quality of life for people with dementia.

Among multi-sensory stimulation interventions, there is limited literature that explores the potential of olfactory stimulation. This is despite the extended literature demonstrating the power of smells in triggering autobiographical memories and positive emotions, given the unique relationship between olfaction, memory, and emotional process at the neuroanatomical level (Section 2.2). Drawing upon Griffiths et al.'s study (2019) demonstrating the potential role of smell and archives in developing and facilitating care provision in dementia care, the current research sought to extend these findings.

3.2 Aims and objectives of the study

The overall aim of this study was to develop and design a novel theory- and evidence-based multi-sensory stimulation intervention, including olfactory and tactile stimulation. The MSI has been designed for people with dementia living in care homes who may have less opportunity to initiate their own activity or receive appropriate stimulation due to the task-focused approach of care and concerns regarding possible safety risks (Kadri et al., 2018; Lee & Bartlett, 2021). As such, there is a clear need for exploring a new solution that may be able to provide opportunity for sensory stimulation, social engagement, and residents' self-expression.

To increase the probability of designing a successful intervention, this study focused on MSI development which includes all research activities undertaken prior to a formal feasibility or pilot study (O'Cathain et al., 2019a). Turner et al. (2019) define as 'successful' those interventions that are effective, feasible to be delivered in the real world, able to meet the needs of users, acceptable to key stakeholders and relevant to the health and social context. The MSI development addressed the following objectives:

1. To explore and assess the available evidence on multi-sensory stimulation interventions.
2. To identify the theoretical underpinning of the MSI.

3. To design a theory- and evidence-based MSI for people living in care homes.
4. To assess the acceptability, practicability, and appropriateness of the MSI.

3.3 Research paradigm

A paradigm is a coherent set of beliefs and assumptions that provide the analytic lens to view and understand reality (Braun & Clarke, 2013). It is underpinned by *ontology* - understanding of the nature of reality in relation to human interpretation; *epistemology* - understanding of the nature of knowledge and the relationship with the knower; *axiology* - understanding of the nature of value; and *methodology* - the approach to acquire knowledge (Haigh et al., 2019). It has been argued that the notion of paradigm underlies research methodology and practice (Crotty, 1998). For the scope of this chapter, three main paradigms in social research are presented: positivism, interpretivism, and critical realism.

Research in the dementia field has been mainly conducted under the positivist paradigm, largely reflecting the historical dominance of the biomedical model of dementia, as outlined in Section 1.4. Positivist philosophy asserts that an objective truth exists independently of individual perception, and theories can be generalised to other contexts (Willig, 2013). Earlier dementia studies, rooted in positivism, were concerned with the investigation and hypothesis testing of the biomedical causes of the disease and pharmacological treatments by applying

quantitative methodology (Bond & Corner, 2001). Reflecting the growth of holistic understandings about the nature of dementia as not merely a result of biological process of cognitive decline but also a socially constructed experience negotiated and interpreted by those living with the condition, their carers and wider society (Górska et al., 2018), the positivist paradigm appeared inadequate to investigate and capture the meaning of the human experience of dementia.

Moving away from the traditional positivist approach, an interpretivist paradigm is concerned with understanding the subjective human experience and meaning given to a phenomenon. This reflects the fundamental principle of the interpretivist approach asserting that all knowledge, such as the perception of the world, is mediated by individual interpretation and contextual factors. This implies that multiple socially constructed realities exist and are equally valid (Lincoln & Guba, 1985).

Sitting between the interpretivist and positivist paradigms, lies critical realism (Wynn & Williams, 2012). Critical realism accepts that there is a social reality that can be observed objectively through our senses. However, this observation is influenced by social, historical, personal frames (Mukumbang, 2021). Haigh et al. claim that ‘while entities exist independently of our ability to perceive and conceive that they exist, we do use our minds to construct systems’ (2019, p. 3). Critical realism, therefore, assumes that independent structures can influence the actions

of actors in a specific setting while recognising the role of the subjective knowledge and reasoning of these actors (Mukumbang, 2021).

A key feature of critical realism is the stratification of reality, 'which links objective/unobservable social structure and subjective/observable human agency in its causal explanation' (Hu, 2018, p. 135). Bhaskar (1998) suggests that reality is stratified into different levels including the real, the actual, and the empirical. At the real level, there are a set of existing structures that have the potential to generate changes. When these existing structures are activated (mechanisms), they generate social phenomena which take place at the actual level. Social phenomena are a subset of events occurring in the 'real' that could be observed or not at the empirical level which is related to human perception and experience (Mukumbang, 2021).

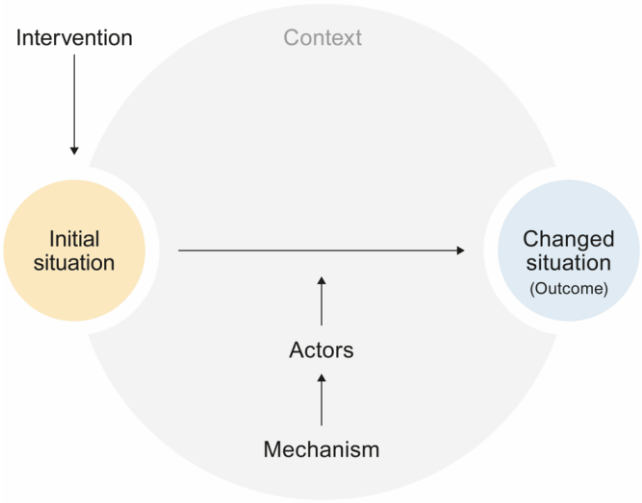
Therefore, actual phenomena can be perceived by the knower (researcher and participants) through abstraction and making inferences about the structures and causal processes that underlie the phenomena because they are often hidden and invisible (Wynn & Williams, 2012). Consistent with interpretivism, critical realism recognises the importance of the ideas, narratives, experience in the interpretation of reality, but uses this knowledge to explore causal explanations (Mukumbang, 2021). By recognising both an independent and subjective reality, critical realism is

distinct from the traditional positivist and interpretivist paradigms (Haigh et al., 2019).

3.3.1 The study paradigm and qualitative methods

Critical realism has increasingly been employed to study dementia (Bunn et al., 2018; Gordon et al., 2018; Handley et al., 2017; Kontos et al., 2011; Tak et al., 2019). Critical realism appeared the most appropriate paradigm for the current research. It is able to capture the complexity of dementia and dementia care practice, recognising the importance of individual actions which can support, challenge or modify a social phenomenon (Górska et al., 2021; Kontos et al., 2011). Moreover, it acknowledges the complexity of reality and social phenomenon, such as psychosocial interventions, overcoming some of the limits of positivism (Fletcher et al., 2016). According to realist philosophy, social phenomena are caused by underlying generative mechanisms, known as generative causation (Pawson, 2013). From a realist perspective, interventions such as MSI work by changing or altering the physical and social context. As shown in Figure 3.1, context is intrinsically involved in the causal process as the changes occurring trigger mechanism(s) which produce intended (or unintended) outcomes (Wong et al., 2013b).

Figure 3.1 A generative configuration of realist theories (adapted from Mukumbang et al., 2018b)



A mechanism refers to a dynamic interplay between resources offered by the programme (the intervention components) and the reasoning of individuals (the different reactions produced by resources) (Dalkin et al., 2015). It is the participants' responses to the resources provided that lead to changes. Some of the mechanisms are expected to be consistent with the intervention design but others may be unanticipated and not directly observable. To summarise, mechanisms generate outcomes, and they can be subject to changes in context and participants. In this, the interaction of both context (C) and mechanism (M) leads to an outcome (O).

Although both qualitative and quantitative methods have been adopted within critical realist research, qualitative research is generally preferred (Fletcher, 2017). Qualitative methods enable researchers to gain a more accurate understanding of the 'real world' by capturing and embracing people's experiences and actions as well as their unconscious intentions or tacit skills (Hu, 2018). Furthermore, qualitative methods enable investigation of the causal explanations underpinning a social phenomenon, even those not directly observable, thereby shaping knowledge and creating new insights within the research compared to quantitative studies (Fletcher et al., 2016; Hu, 2018). The research presented in this thesis, therefore, has employed a qualitative design.

Based on this paradigm, this study focuses on the development of MSI and its components by taking into account the potential underpinning mechanisms and the social context where the intervention is implemented throughout the phases undertaken within the study framework, which is outlined in the next section.

3.4 Intervention development framework

With the growth of interest in the implementation of optimal health and social care, several frameworks and guidelines (e.g. Intervention Mapping, Behaviour Change Wheel) (Wight et al., 2015) have been published to guide the development and evaluation of psychosocial interventions. These emphasise the importance of intervention development and pre-trial evaluation to maximise effectiveness

(O'Cathain et al., 2019a), and prevent problems arising during full-scale evaluation (e.g. issues of acceptability, compliance, recruitment and retention) (Levati et al., 2016). Overall, this can reduce the research waste from developing interventions that have no worthwhile impacts on health and social care (Ioannidis et al., 2014). Although there is a considerable emphasis in the literature on the importance of carefully developing complex interventions, not all studies clearly report the decision-making process, method and findings behind a full trial. For this reason, Hoddinott defines the process of intervention development as the 'Cinderella' of complex intervention trial design (2015).

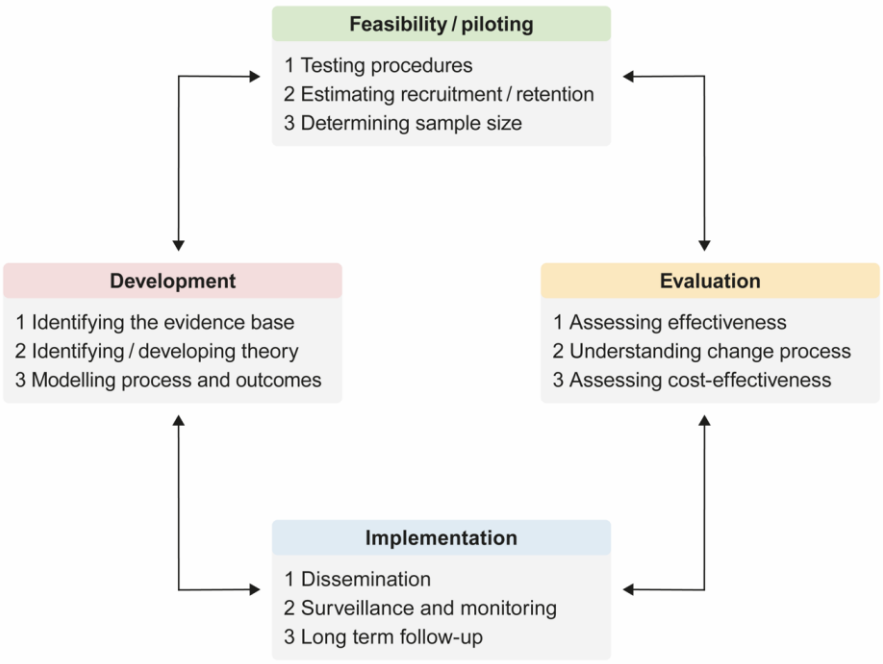
The Medical Research Council (MRC) framework for the development and evaluation of complex interventions is one of the most internationally cited sources of guidance in health services research (Craig et al., 2008). As much valuable experience and evidence have accumulated since the framework was updated in 2008, the MRC and National Institute for Health Research have jointly commissioned an update of the guidance that was published in September 2021 (Skivington et al., 2021). The information reported below refers to the 2008 version (Craig et al., 2008) as the research in this thesis was undertaken before the 2021 update was available.

The MRC guidance (Craig et al., 2008) focuses on the development of complex interventions such as MSI. Complex interventions are defined as those that

include several interacting components, such as a number of possible outcomes, a number of groups targeted (e.g. individuals, community units and/or whole populations), and interactional components (Craig et al., 2008). Due to the complex nature of the interventions, the framework provides a description of the main stages, their key functions and activities that should be undertaken in the research process, highlighting the need for greater focus on the early phases of the intervention development. The main stages include development, feasibility/piloting, evaluation, and implementation. As recommended by the guidance, these stages should be considered as part of an iterative process rather than as sequential or even a circular process (Figure 3.2~~Figure 3.2~~).

Given the clear formulation of the different stages of complex intervention development process ranging from theory identification to RCT evaluation, and the iterative nature of the process that is described by the framework, this research selected the MRC framework to guide development and design of the MSI.

Figure 3.2 Key elements of the MRC development and evaluation process (adapted from Craig et al., 2008)

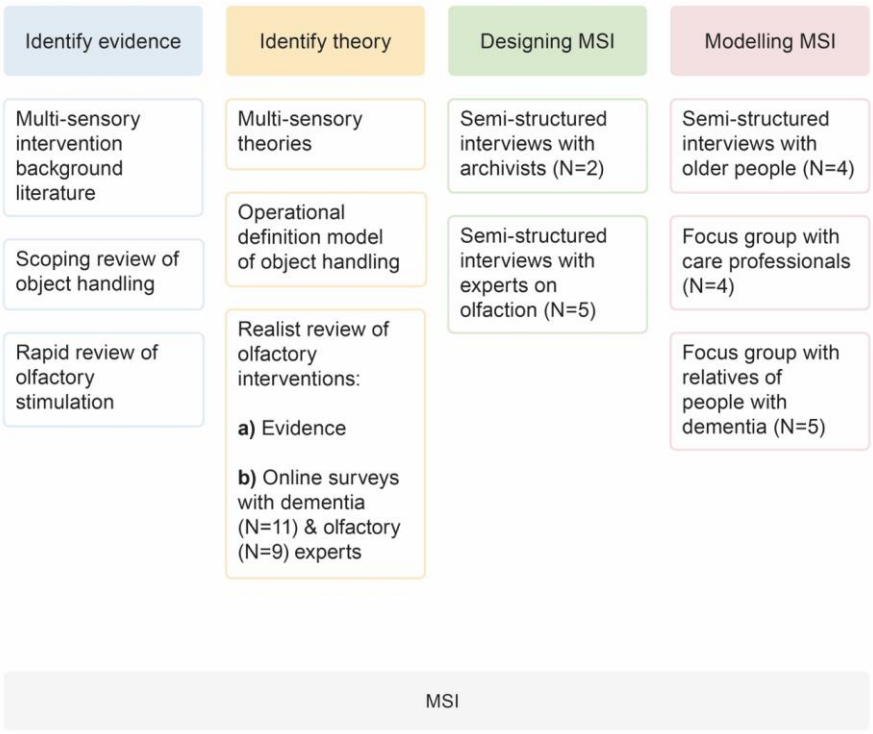


The MRC framework divides the development phase into three different activities: identifying the evidence base; identifying/developing appropriate theory; modelling process and outcomes. Accordingly, the current study followed a multiphase approach. The key actions undertaken in each step of the MSI development are illustrated in Figure 3.3~~Figure 3.3~~ and described in more detail below in a linear and sequential fashion to enhance clarity. However, in practice, the intervention development followed a dynamic and iterative process, as each step is interlinked with and often built upon the previous step.

The iterative process in the development of MSI involved reviewing the literature, theories and drawing on stakeholder feedback by moving backwards and forwards between primary and secondary data. The rationale for using an iterative process was to enable a better understanding of the intervention components and the mechanisms of actions, and to explore and improve the intervention's acceptability, feasibility, and relevance at an early stage of its development (Yardley et al., 2015).

In this study, a theory- and evidence-based approach for the intervention development as recommended by the MRC guidance (Craig et al., 2008) was combined with a stakeholder-engaged approach. The rationale for this was that although theories and evidence from primary studies such as RCTs can inform the effectiveness of an intervention and its components, they rarely provide guidance on what the key factors are and the best approach to implement them (O'Cathain et al., 2019a). Furthermore, key stakeholders can facilitate and support the development of an intervention which is tailored to the real context. Therefore, stakeholder engagement throughout the development process was considered important to complement the findings from existing theory and evidence as well as to maximise the MSI success (Yardley et al., 2015).

Figure 3.3 The key research activities in the MSI development



3.4.1 Identifying the evidence base

To design an effective MSI for people with dementia, the intervention development focused on the review of published research evidence. This phase aimed to identify the relevant literature and to consider the intervention intended outcomes and components (Craig et al., 2008). The results of the literature reviews provided information regarding the potential effectiveness and relevant outcomes of the intervention (Petticrew et al., 2013).

Following a preliminary scoping of the literature, several recent reviews on multi-sensory stimulation interventions were found (see Section 2.1.3). Therefore, a formal evidence synthesis was not undertaken for multi-sensory stimulation interventions, but instead existing reviews were consulted in line with the MRC framework (Craig et al., 2008).

To further explore and understand the evidence-base for the proposed MSI components, two reviews were undertaken. These were, respectively, a scoping review of object handling interventions and a rapid review of olfactory stimulation for people with dementia. The methodological basis for each of these reviews is discussed in the remainder of this section.

Scoping review

A scoping review approach to synthesise the evidence on object handling interventions for people with dementia was selected as the most appropriate method over a standard systematic review in this research. As the name suggests, the scoping review is a useful tool to map the emerging area and to explore a broad range of review questions by including a wide range of study designs in comparison to systematic reviews which mainly focus on RCTs (Munn et al., 2018).

As mentioned in Section 2.3.2, object handling interventions are relatively new in dementia care and therefore a scoping review approach provided a

comprehensive understanding of the types of available evidence, and diverse procedures and outcomes associated with interventions (Chapter 4) that have been used to inform the next steps of the MSI design. This review method has been previously used in other studies within the MRC framework to explore how interventions have been conducted and to investigate under-explored areas (e.g. Williams et al., 2020).

Despite their explorative nature, scoping reviews apply methodological rigour, with an unbiased and transparent approach. This study followed the methodological framework for review proposed by Arksey and O'Malley (2005), which has been highly influential and further extended by other authors (e.g. Peters et al., 2015, 2020). The current available guidelines for conducting (e.g. Lockwood et al., 2019; Munn; et al., 2018; Peters et al., 2020, 2021) and reporting (Tricco et al., 2016, 2018) scoping reviews have established this approach as a valid methodology in relation to other types of review of the literature.

Rapid review

A rapid review of olfactory stimulation was performed to explore the existing evidence in the literature about the use of olfactory stimuli with people living with dementia, including the administration methods and materials used (Chapter 5). Rapid review, also known as a 'rapid synthesis review', is a form of knowledge synthesis that has been increasingly employed to provide relevant evidence and

guidance for health systems in a timely and cost-effective manner (Hamel et al., 2021). This synthesis approach shares several characteristics and components with systematic reviews, but it overcomes the barriers often associated with conducting the latter, such as time and cost. This is achieved by streaming and accelerating the traditional review process using various approaches e.g. reducing the number of databases searched, excluding grey literature or using a single reviewer for all stages of the review, with or without verification by a second reviewer. For instance, the average time needed to complete a systematic review, typically sixty-seven weeks (Borah et al., 2017), is shortened to five or twelve weeks in the rapid review (Tricco et al., 2015). The rapid review is therefore a useful approach to facilitate informed decision making in a limited amount of time.

The choice of using a rapid review in the present study was based on the need to uncover the outcomes associated with olfactory stimulation in dementia care within a fixed timeframe; to systematically and transparently assess the effectiveness of this intervention; and to inform the realist review that is described in the following Section 3.4.2.

Despite their increasing popularity, at the time there was no standard method for conducting and reporting rapid reviews (Tricco et al., 2017), which has been published later in 2021 (Garritty et al., 2021). Varied approaches have been used in the literature including a fixed structure (Best et al., 1997) or an incremental and

iterative approach (Jahangirian et al., 2011). This study followed a practical guide to conduct rapid review (Tricco et al., 2017) developed by World Health Organization and Alliance for Health Policy and Systems Research.

Both scoping and rapid reviews included qualitative, quantitative and mixed methods research designs. Combining different research designs allows researchers to gather a deep understanding of the evidence available and maximises the benefits of conducting a combination of quantitative and qualitative review. Quantitative reviews provide information on the study efficacy, whereas qualitative synthesis may provide information on how and why an intervention was effective or not in a specific context.

One of the main challenges of reviewing complex interventions is the high heterogeneity due to the variation in the way the interventions are designed and delivered. To enhance clarity and produce information that could inform the MSI design, the scoping and rapid reviews focused on identifying the outcomes as well as components, process, and duration of olfactory and object handling interventions.

3.4.2 Developing appropriate theory

The MRC framework (Craig et al., 2008) states clearly that the success of a complex intervention depends on the extent to which the intervention theory/ies

predicts and explains the likely process of change. Although the MRC framework (Craig et al., 2008) emphasises the need to build and test theory, there is not clear guidance on how to undertake this process. Different frameworks and toolkits, such as the Theory of Change tool (De Silva et al., 2014) or Behaviour Change Wheel (Michie et al., 2011), have been developed to support the design of theoretical interventions. However, they often simplify the reality to a linear sequential process (behaviour-determinant-intervention), failing to capture the complexity of social realities by excluding the contextual dimensions (Fletcher et al., 2016). Wong and colleagues argue that "research or evaluation designs that strip away or 'control for' context with a view to exposing the 'pure' effect of the intervention limit our ability to understand how, when and for whom the intervention will be effective" (2013b, p. 9).

An increasing number of authors recognise the importance of tailoring the intervention to the local context and various population subgroups as these elements, by interacting with the components of the interventions, can produce different and sometimes contradictory outcomes.

Increasingly, realist review and evaluation have been indicated as a robust methodologies to facilitate a theoretical understanding of complex social phenomena, taking into account the dynamics and complexity of health and social care context by using mainly secondary and primary data respectively (Fletcher et

al., 2016; Palm & Hochmuth, 2020; Wong et al., 2013a). Review and evaluation investigations are a specific form of realist research underpinned by principles of realist philosophy.

3.4.2.1 Realist review

Realist review approach was selected to gain a theoretical understanding of the underpinning programmes operating within MSI for people with dementia living in care home. By considering the complexity of social reality, such as care homes, realist review provides a novel perspective to the research area, adding details into existing literature. Realist review, also known as 'realist synthesis', is a research synthesising strategy to review evidence, which compared to the traditional review methods, e.g. systematic review, has an explanatory rather than an efficacy testing focus (Pawson et al., 2005). It is important to note that realist review 'is not a research method' but rather 'a *logic of inquiry'* as argued by Pawson et al. (2004, p. 37). Within the realist methodological orientation, a range of approaches and existing methods has been employed in the literature to generate programme theory (Booth et al., 2020).

This study extended the proposed realist review stages (Pawson et al., 2005; Wong et al., 2013a) by embracing a novel approach to realist review proposed by Cooper et al. (2020), known as 'evaluative synthesis'. Evaluative synthesis reduces 'the boundaries between realist evaluation and realist synthesis' (Cooper

et al., 2020, p. 2), allowing researchers to integrate relevant research evidence and stakeholders' experiences together to enhance the explanatory potential of the programme theory. This approach was chosen due to the core philosophical assumptions behind the study design rooted in the importance of stakeholder experiences, and to overcome the problems that could arise from using a solely data-driven approach, such as rediscovering what is already well established in the theoretical literature, or failing to identify the mechanisms in action and different levels of contextual complexities (e.g. individual, care professional, care home management) (Shearn et al., 2017).

Stakeholder engagement can be an important component of the realist approach (Pawson et al., 2004; Rycroft-Malone et al., 2014), typically used as a form of consultation to develop, refine and test the programme theory. Several authors have highlighted the contributions of key stakeholder engagement in the review process, including extending the researchers' understanding of the review topic (e.g. Goodman et al., 2017a); defining the review scope (e.g. Bunn et al., 2018; Rycroft-Malone et al., 2012); streamlining the search process (e.g. De Weger et al., 2018; Saul et al., 2013); and validating the findings (e.g. Bunn et al., 2018; Saul et al., 2013; Weetman et al., 2019). However, compared to Pawson et al.'s recommendations (2004), in this study the information gathered by stakeholders is considered as primary data. Cooper et al. (2020), when discussing the benefits of

integration of primary and secondary data in their study, suggested that the inclusion of stakeholder input as primary data sources facilitates transparency in the process and validation of the emerging theory. Based on this realist approach, the realist review followed an iterative and multi-phased process, cycling between empirical literature searching and data collection, and constant refinement of and evidencing of emerging programme theories.

Acknowledging that complete and comprehensive reviews may be impossible due to the multiple perspectives and contributory processes operating within a complex intervention such as multi-sensory stimulation interventions, and the considerable and sustained investment required over time, the early stage of the review focused on clarifying the scope of the review through a process of exploration and enquiry (Greenhalgh et al., 2015; Rycroft-Malone et al., 2012; Wong et al., 2016). Pawson et al. describe the task involving the identification of the review questions as 'the swamp'; researchers therefore should recognise the 'uncertain', 'iterative' and time-consuming nature of this process (2004, p. 14).

Different strategies can be used to narrow the purpose of the review. Wong et al. (2013b) suggest, for example, focusing the review on a particular e.g. country, timeframe; narrowing the research questions; investigating a sub-set of programmes within a programme family (e.g. cognitive stimulation therapy rather

than all psychosocial interventions); or making a clear decision about the extent of the research comprehensiveness.

In this study, to refine the scope of the review and to narrow the MSI components that might be explored and explained, an informal review of the literature was guided by a priori knowledge of the literature in multi-sensory stimulation interventions (i.e. a scoping review of object handling, olfactory and multi-sensory stimulation interventions background literature). By reviewing the studies looking for intended outcomes and potential explanations, a list of explanatory 'if-then' statements was created to develop a preliminary, generic understanding of what might support MSI outcomes in care homes. Each statement included the study references, outcomes intended, abstract theory (if any) cited, and the authors explanations about how the intervention was thought to work.

The results of this initial stage were discussed with the supervisory team via email, discussion chains, and meetings. Through this iterative process, five outcomes of interest were identified as relevant: (1) responsive behaviours; (2) quality of life and well-being in the moment/during session; (3) quality of life and well-being enduring beyond the session; (4) care home staff outcomes; (5) specific effects of odour stimulation.

Through further discussions with the supervisory team, the theory construction of one aspect of MSI was prioritised: olfactory stimulation. This decision was heavily

influenced by the results of the literature showing inconsistency of findings (e.g. Ball et al., 2020), the role of multiple variables (e.g. individual preference, experience, expectation) in influencing the olfactory intervention outcomes (Herz, 2009a, 2016; Holmes & Ballard, 2004) and the recent published study exploring the mechanisms underpinning museum object handling interventions as part of a doctoral research project (Dickens, 2020) which was published later in a peer review journal (Camic et al., 2021). It was recognised that building an empirical basis for investigating how olfactory interventions may work for people with dementia was required. The realist review, therefore, aimed to develop a theoretical understanding of the components and explanatory mechanisms through which olfactory stimulation may generate changes in people with dementia living in care homes. To uncover and articulate theoretical assumptions of how, why, and under what conditions olfactory stimulation works, various strategies were employed in a complementary way, including the results of the rapid review, supplementary scoping literature reviews and data gathered from online surveys with stakeholders including non- and academic experts on dementia and olfaction. The purpose of primary data gathered from the online surveys was to explore the participants' own assumptions about the programme and to refine the tentative causal explanations identified from the literature.

Different authors have used a variety of approaches to analysing primary data in realist research. This is unsurprising considering that ‘data analysis is not a specific method but a way of interrogating programme theory’ which should move between both inductive and deductive logic (Greenhalgh et al., 2017, p. 8). In this study, analysis of the primary data was conducted using Miles, Huberman and Saldaña’s (2014) qualitative analysis strategy approach, also known as matrix analysis. There were various reasons for adopting the Miles et al. (2014) qualitative method of analysis. Firstly, it is grounded in realist philosophy (Maxwell, 2012). The authors recognise that ‘social phenomenon exist not only in the mind but also in the world and that some reasonably stable relationships can be found among the idiosyncratic messiness of life’ (Miles et al., 2014, p. 7). In line with this, Miles et al.’s method also acknowledges the active role of a researcher in making meaning within the process of analysis. This was considered important as the methods of realist enquiry encourage transparency, particularly regarding the influence of the researcher in the interpretation of sources. Secondly, this analytic method enables the use of an a priori conceptual framework grounded in the researcher’s initial understanding of the phenomena while including flexibility to enable the data to modify the theory throughout inductive inquiry (Miles et al., 2014). Thirdly, the systematic approach of the method captures how the conceptual framework evolves as the study progresses, enhancing transparency and comprehensiveness of the analytic process. This is relevant to the realist

methodology which is based on testing and refining programme theory through an iterative process. Fourthly, Miles et al.'s approach to data analysis has been previously employed in a realist review by Mukumbang et al. (2018a) to develop their initial programme theory which combined primary and secondary data.

3.4.3 Designing MSI

This stage of the intervention development aimed to design the MSI key components and procedures. The term 'development' and 'design' are often used interchangeably (O'Cathain et al., 2019b). In this study, 'design' is used to refer to the process during which decisions were made about the intervention contents, format and delivery approach (O'Cathain et al., 2019b). In line with the MRC framework (Craig et al., 2008), MSI was drawn from research evidence and theories underpinning olfactory stimulation, object handling and multi-sensory stimulation interventions. The evidence, and causal assumptions underpinning positive outcomes associated with the interventions guided the decision-making process. In practice, the choices such as number of sessions, length, material characteristics were drawn by comparing the study design and results, and by taking into account theoretical considerations.

3.4.3.1 Stakeholder interviews

A challenge often associated with an intervention design process based only on the review of evidence is the unclear or inconsistent nature of the evidence

available (Rousseau et al., 2019). Due to their nature, complex interventions may present high heterogeneity and as mentioned above in this chapter (Section 3.4.1), primary studies may fail to inform the best practice. To further support the design process, therefore, expertise and experiential knowledge were sought from a group of professional stakeholders alongside published research evidence. Interviews with olfaction and archival expert stakeholders were conducted before beginning the intervention design. The rationale for involving the stakeholders at this stage was to explore and understand more about the peculiar characteristics of smells and the fundamentals of smell administration methods such as dosage, odour volatility, and the experience of archivists in using their collections with people with dementia (O'Cathain et al., 2019a). Stakeholder evidence also provided the opportunity to think about the acceptability and feasibility of the MSI at an early stage.

A semi-structured interview method was selected as it facilitates a rich understanding of the topic of interest by offering a balance between the flexibility of an open-ended interview and the rigidity of a structured interview (DiCicco-Bloom & Crabtree, 2006). Using a set of guiding questions (topic guide), this method allows investigation of the areas of interest as well as exploration of other issues emerging from the dialogue with the interviewees (Jamshed, 2014).

The findings of the qualitative investigations with stakeholders informed the

MSI-1 design.

3.4.4 Modelling and refining MSI

Once MSI-1 was developed, a series of taster sessions were undertaken to refine it. The process of refining the intervention under development by assessing the intervention components is also known as optimisation (Levati et al., 2016). The aim of this stage is to assess whether the different intervention components work or not and to inform final modification to the draft intervention before embarking on further evaluation, such as a pilot study or full-scale RCT (Levati et al., 2016).

Different approaches can be used. Some authors have combined the evaluation of the intervention components with either piloting investigation of the outcomes (e.g. Clyne et al., 2013; Lewis et al., 2013) or assessing its cost-effectiveness (Burr et al., 2011). This study used the most common optimisation approach adopted in the literature within the MRC framework, where the insight from a group of key stakeholders was gathered and incorporated from the outset, before pilot testing (Levati et al., 2016; O'Cathain et al., 2019a). This approach was considered to be appropriate for the purpose of the study focusing on stakeholders' perceptions and opinions regarding multi-sensory stimulation interventions and MSI content, components, and procedure. Focus groups and semi-structured interviews with various stakeholders were conducted, including care professionals, relatives of people with dementia and older people without a diagnosis of dementia.

Feedback received was incorporated into the MSI-1, resulting in the development of an optimised version of the intervention, MSI-2. Thus, the involvement of stakeholders is a fundamental element of the development process that could help to detect and assess potential barriers to effective implementation of MSI in the care home, and the appropriateness of the intervention for people with dementia (Bleijenberg et al., 2018). This step was also considered relevant for ensuring the appropriateness and acceptability of procedure and content (Yardley et al., 2015), and identifying any potential issues related to the intervention (O'Cathain et al., 2019a). This is in line with other evidence that emphasises the key role and value of stakeholders in strengthening the intervention development by providing important information likely to lead to successful interventions (Levati et al., 2016).

3.5 Ethical considerations

In the present research, ethical considerations were applied at each stage of the research process, from the initial choice of the research design to the publication of the results and provision of feedback to participants. Emphasis was placed on minimising risks and maximising benefits of taking part in the study. Considering the nature of qualitative enquiry focusing on investigating social phenomena through the experiences of people, two main ethical issues are frequently associated with qualitative research: researcher and participant relationship and

power imbalance; and potential risks of emotional distress (Houghton et al., 2010; Karnieli-Miller et al., 2009; Sivell et al., 2019).

Houghton et al. (2010) argue that research must be mindful and reflect on the potential imbalance in the participant-researcher relationship and how this may influence voluntary participation in the research. This is particularly relevant when studies are conducted in care settings or work place, and involve potentially vulnerable groups. Potential participants may feel obliged to take part in the research assuming potential negative consequences if they decide not to participate such as changes in the quality of care services provided to their relatives, or job role and duties. To guarantee that participants enter the study voluntarily and are not feeling coerced, several authors have suggested that research should embrace the principle of autonomy, providing clear information about the study and about the right to freely decide whether to continue on the study, with the option to withdraw at any time without giving any reason (e.g. Karnieli-Miller et al., 2009).

The current research involved a variety of groups e.g. experts on olfaction, dementia, archivists, care professionals, relatives of people with dementia, and older people. In the recruitment process, detailed information about the study including the voluntary nature of the participation, research procedure, potential benefits and risks were provided and explained in the Participant Information

Sheet. This aimed to empower the potential participants and ensure they could make an informed decision on whether or not to participate. Where the participants' identification and recruitment (i.e. relatives of people with dementia and care professionals) was facilitated by a care home director or a care home manager, research protocol and the key points of international ethical and scientific quality standards for conducting research and taking consent (Health Research Authority, 2020) were explained to ensure voluntary participation in the study. In addition, prior to consent, those who showed interest in the research met the author, who clearly explained to relatives of people with dementia and care professionals that a decision not to take part would not affect in any way the care provided to their family member living in the care home or their job position, respectively. Guidance and support on any potential ethical issues or concerns related to the power relationship were identified, discussed and addressed during the regular supervision meetings through the study. As this study does not include people with dementia, lack of mental capacity to give consent was not considered to be an issue.

Regarding the risk of emotional distress, research investigating sensitive issues e.g. racism may expose participants to higher level of distress and emotional harm (Richards & Schwartz, 2002). Although this research does not involve discussions about directly sensitive topics, it was considered that during the study activities,

the conversation may relate to dementia and any relationships that participants may have with people living with dementia. Participants may discuss their relative or others, which could trigger emotional distress. Furthermore, some of the research sessions with stakeholders included olfactory items and materials objects as prompts to stimulate conversation and explore the MSI materials. The sensory items could potentially trigger negative or unpleasant personal experiences or feelings.

Due to the individual and unique nature of the participants' experiences, it is difficult to accurately predict how people could react to a specific discussion or smells. Therefore, Draucker et al. (2009) argue that researchers must define a clear strategy and guidelines on how to respond if any adverse reactions arise or a participant feels uncomfortable while taking part in the research. In line with this recommendation, a distress protocol (Appendix 1) including a series of actions to protect participants from harm was developed and put in place if any signs of verbal or non-verbal distress were observed during the course of the study. In the case of any unanticipated situations arising, individual support could be provided to participants and prompt (within 24 hours) guidance sought from the supervisory team.

The study protocol was reviewed and received a favourable assessment from the University of West London Ethics Committee. Ethical approval for the initial stages

of the study was granted on the 15 October 2018 (Ref: UWL/REC/CNMH-00489); for the later changes made to the initial protocol due to the COVID-19 pandemic which included the realist review investigation with stakeholders, approval was sought and granted on the 24 July 2020 (Ref: UWL/REC/CNMH-00735).

This chapter has set out the evidence from which this thesis draws upon and the methodological background. The remainder of the thesis follows the plan outlined here; that is, **Chapter 4** scoping review of object handling interventions, **Chapter 5** rapid review of olfactory stimulation, **Chapter 6** realist review of olfactory interventions, **Chapter 7** MSI design process, **Chapter 8** MSI taster session with stakeholders, **Chapter 9** discussion of the results, methods, strengths and limitations, implications of the study, and conclusion. The next chapter, Chapter 4, outlines the evidence available on object handling interventions for people with dementia and presents an operational definition model.

CHAPTER 4 OBJECT HANDLING INTERVENTIONS: SCOPING REVIEW OF THE LITERATURE AND DEVELOPMENT OF AN OPERATIONAL DEFINITION MODEL

This chapter presents the development and results of a scoping review of object handling interventions for people living with dementia. It also includes an early attempt to define an object handling intervention by developing an operational definition and model. In line with the first step of the MRC framework (Craig et al., 2008) for developing complex interventions, namely 'identifying evidence', the review aimed to map the existing evidence available to date and its characteristics. The results from this review informed the development of MSI, as discussed at the end of the chapter.

4.1 Introduction

As mentioned in the previous chapter (Section 3.4.1), to develop effective interventions the MRC framework (Craig et al., 2008) recommends undertaking a review of the existing evidence to identify the intervention components, procedures and protocols used in order to understand both what works and the impact of variables such as intensity or duration of the sessions on the outcomes. Whilst systematic review and meta-analysis are considered to be the most valid synthesis approaches to assess the effect(s) of an intervention and its causality (Craig et al., 2008; Peters et al., 2020), it is not always applicable if there is marked heterogeneity between the studies included. The current research has instead used a scoping review approach. The rationale behind this choice was the lack of

knowledge regarding the area of investigation, i.e. object handling interventions for people with dementia. Although scoping reviews have several similarities with the systematic review method, their focus is mainly on summarising the main, overarching findings (Lockwood et al., 2019; Munn et al., 2018). This synthesis method is 'more appropriate to assess and understand the extent of knowledge in an emerging field or to identify, map, report, or discuss the characteristics or concepts' compared to systematic review (Peters et al., 2020, p. 2121). At the time the review was conducted, there was no published research that sought to gather the evidence on object handling for people with dementia. Therefore, it was not possible to predict whether there was an adequate number and quality of studies that could be included in a systematic review, or to develop research questions concerning the effectiveness of the intervention based on a precise set of outcomes (Munn et al., 2018). In order to address these uncertainties, an initial screening of the literature was conducted to determine the volume of relevant evidence (Tawfik et al., 2019). The results of this search showed that the literature included a relatively small number of studies using several research designs. Most importantly, it emerged that there was not a clear definition of what object handling is, which would have posed some difficulty in developing specific and precise inclusion criteria to be used to assess the study eligibility in the systematic review. The screening of the literature therefore indicated the need for a more exploratory synthesis. Based on the reasons mentioned above, a scoping review was

conducted as it incorporates a range of study designs, and also addresses questions beyond those related to treatment efficacy, such as mapping evidence and concepts/definitions in a research area (Lockwood et al., 2019).

4.2 Aims and objectives

4.2.1 Aims

The aim of this review was to provide an overview of available object handling interventions, and to map the outcomes relating to the impact of the intervention on people living with dementia. It was anticipated that this would have helped to define what constitutes object handling in dementia care settings.

4.2.2 Objectives

- To identify methods and procedures that have been used in object handling interventions.
- To identify the outcome/s associated with object handling interventions.
- To assist in establishing a definition of object handling interventions.

4.3 Methods

The scoping review was guided by Arksey and O'Malley's methodological framework (2005) which was further refined by Peters and colleagues (2015). The framework includes: defining the research questions; identifying the eligibility

criteria and the research strategy; searching for relevant studies; selecting studies; charting the results; collating, summarising and reporting the results.

The inclusion criteria and methods for the review were pre-specified in a protocol, reviewed by the supervisory team. Consistent with guidance on scoping reviews conducted at the time (Arksey & O'Malley, 2005; Peters et al., 2015), the protocol was not registered.

Details of the method used to conduct the review are presented below and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses Extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al., 2018).

4.3.1 Eligibility criteria

Inclusion criteria

Studies were included if they were written in English and where participants were considered by authors as having dementia even if specific diagnoses were not provided. No specific restrictions regarding geographical and time limits on the publication, age, subtype and severity of dementia were applied.

In the absence of an agreed definition of object handling, an operational definition was created for the purposes of the review by identifying some similarities in the implementation across studies. The definition of an object handling intervention

was as follows. It consisted of a programme based on offering or choosing an object, with participants having the opportunity to explore, reflect and respond to it, before moving to another item. The object(s) used could be of any type, from everyday items to museum artefacts. Group or individual sessions were included. Studies were included if object handling was combined with another activity (e.g. art viewing).

Exclusion criteria

Articles describing interventions for use solely by caregivers or care professionals were excluded. Studies were also excluded if they did not meet the above definition of object handling. These included studies that focused on cognitive training, doll therapy, reminiscence therapy, occupational therapy, Montessori-based activities, art making and art viewing. Unpublished papers, study protocols, dissertations, and websites were also excluded.

4.3.2 Search strategy

The review search in the sources listed below was conducted in November 2018 and updated in June 2021 to ensure that all relevant articles were included in the review.

The studies were identified using the following databases: CINAHL, PsycINFO, MEDLINE, PsycARTICLES, Academic Search Elite and Art Full Text. Reference

checking and hand searches were also undertaken for each study selected. A combination of key terms was used (Table 4.1). The Boolean operator 'NOT' was included to exclude animal studies. The search strategy was developed with advice from a specialist health librarian at the University of West London.

Table 4.1 Summary of search terms

Search	Terms
#1	object OR handling OR museum* OR objects
#2	dement* OR alzheim*
#3	mice OR rat
	#1 AND #2 NOT #3

4.3.3 Selection of sources of evidence

Electronic search results were downloaded into New RefWorks, a reference management software. A single reviewer (the author) screened titles and abstracts identified by the electronic search and applied the selection criteria to potentially relevant papers. Titles for which an abstract was not available were included for subsequent review of the full article. For articles that could not be obtained through institutional holdings available to the author and supervisors, attempts were made to contact the author to procure the article.

The full text of potentially eligible studies was read independently by the author and a second reviewer to assess eligibility. Some authors were contacted asking

for information or clarification if needed. Studies were excluded during this phase if they were found to not meet the eligibility criteria. Any uncertainties related to a study selected during the screening process were resolved through discussion between reviewers.

4.3.4 Data charting process

Data were extracted using a checklist including country, study design, study aim(s), participant demographic characteristics (i.e. age, types and stage of dementia), intervention frequency and duration, materials, setting, outcome measures, and relevant outcomes related to the study aim(s). Furthermore, the terms and protocol used to refer to object handling intervention were extracted for each included article. The study characteristics were imported into an Excel spreadsheet. Data charting process was verified by a second reviewer who checked the accuracy of the data on a random 30% sample of studies. Methodological quality of the studies included in the review was not assessed given that the focus of a scoping review is to provide an overview of the existing literature. This is consistent with the methodological framework used and standards for scoping reviews (Arksey & O'Malley, 2005; Peters et al., 2015, 2020).

4.3.5 Synthesis of the results

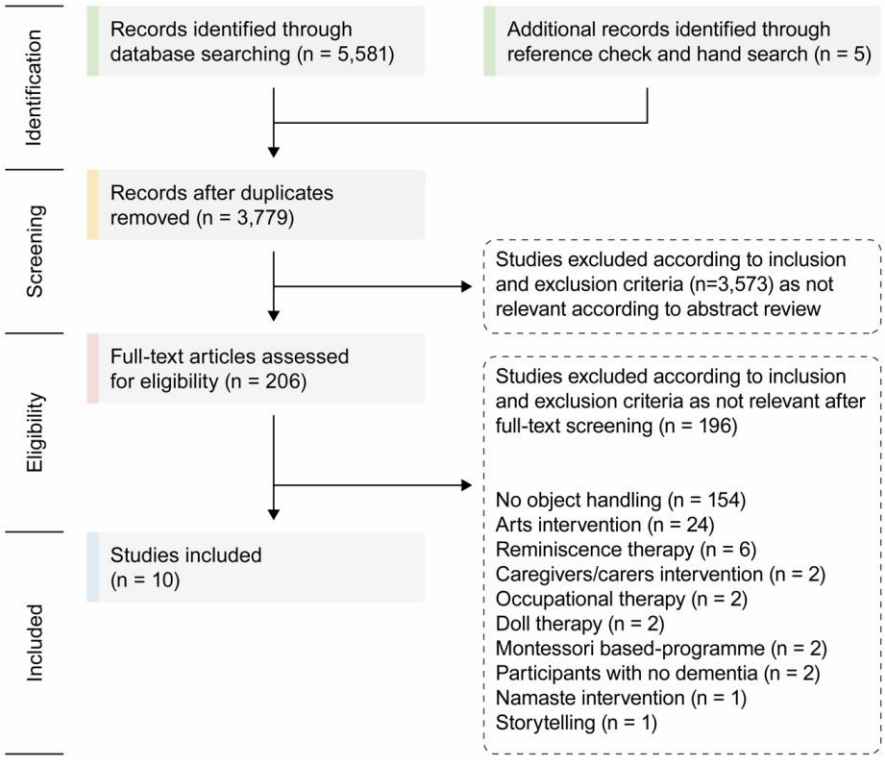
Studies included were presented in a narrative format in relation to the objectives of the review (Arksey & O'Malley, 2005). The details of the study methods and procedures were grouped under main categories including participants' characteristics, settings, intervention protocol and materials, study design and outcome measures (Peters et al., 2020). Key outcomes reported by the studies were also included in the synthesis with the aim to determine the range of evidence associated with object handling interventions (Peters et al., 2015). A summary of the relevant data from the studies included is also provided in a tabular form (see Table 4.2).

4.4 Results

4.4.1 Sample

The literature search identified 5,581 articles. Duplicate articles were removed (n = 3,779) and inclusion and exclusion criteria applied. Based on titles and abstracts, 206 studies were selected to be further assessed for eligibility. A total of ten articles (including two additions following hand-search and reference check) were identified as meeting the inclusion criteria. An overview of the selection process can be seen in Figure 4.1.

Figure 4.1 PRISMA flow diagram of scoping review of object handling interventions



The ten articles included four studies solely on object handling and six articles combining object handling with other activities that, despite the eligibility criteria focusing primarily on handling objects, were deemed by consensus to warrant

inclusion. This was in part because of the very few studies that assess object handling interventions and the overall aim to map the existing literature. Those studies involving multiple activities were included if their aim was not clearly one of the interventions listed in the exclusion criteria (e.g. reminiscence, art making). All ten studies were from Europe and varied in design, methodology, number of participants and measures.

4.4.2 Participants

Across the ten studies, participants were recruited from a variety of settings, including hospitals, community-based centres and care homes. Sample size ranged from 2–158 participants aged between 62–94. Only five studies reported the level of dementia severity: five included people with mild to moderate dementia (Camic et al., 2019; Griffiths et al., 2019; Hendriks et al., 2019; Johnson et al., 2017a; Thomson et al. 2018), and only one study included those with advanced dementia (Norberg et al., 1986). Four studies (Camic et al., 2019; Hendriks et al., 2019; Innes et al., 2021; Johnson et al., 2017a) reported the types of dementia. Griffiths et al. (2019) and Thomson et al. (2018) did not report the type of dementia diagnosis; Innes et al. (2021) did not provide information on the stage of dementia, whereas two other studies (Ander et al., 2013; Thomson et al., 2012) reported neither the stage and type of dementia.

It is important to note that Roe et al. (2016) and Thomson et al. (2018) did not include the precise number of people living with dementia who took part in their study. Roe et al. (2016) recruited participants for the museum and gallery programme from care homes (n = 8) and supporting living facilities (n = 9). The study authors did not provide information about the participants having a confirmed diagnosis of dementia as they were attending the intervention as 'citizens or members of the public' (Roe et al., 2016, p. 552). Thomson et al. (2018) reported having included people with mild to moderate dementia, without disclosing further details. The choice of including Thomson et al. (2018) and Roe et al. (2016) was to provide an overview of the available studies. In other circumstances, such as in the screening process of a systematic review, these studies would have been excluded.

As well as people with dementia, six studies included also informal caregivers (Innes et al., 2021; Johnson et al., 2017a; Roe et al., 2016), health and care professionals (Ander et al., 2013; Griffiths et al., 2019; Roe et al., 2016) and other participant groups, such as neurological rehabilitation and oncology inpatients as well as outpatients (Ander et al., 2013; Thomson et al., 2012). Table 4.2 summarises the sample characteristics.

4.4.3 Settings

The studies took place in different settings. Five studies were delivered on museum and gallery sites (Hendriks et al., 2019; Innes et al., 2021; Johnson et al., 2017a; Roe et al., 2016; Thomson et al., 2018), two in care homes (Griffiths et al., 2019; Norberg et al., 1986), one combined sessions in a day centre and at a museum (Camic et al., 2019), one study took place in both a hospital and in a care home (Thomson et al., 2012), and one in a health care setting (Ander et al., 2013).

4.4.4 Procedure and materials

All interventions were group based, apart from three studies (Innes et al., 2021; Norberg et al., 1986; Thomson et al., 2012) that used one-to-one sessions, and one study (Ander et al., 2013) which delivered both group and one-to-one sessions. The interventions ranged from 1–16 sessions for a period of one week to six months. The time for each session ranged from 20 minutes to 2.5 hours, as shown in Table 4.2. Most of the studies incorporated object handling session(s) with various activities such as museum and gallery visits, music, massage, art viewing and art making.

Table 4.2 Characteristics of studies included

Author & Country	Study design & Setting	Sample	Mean/ range age	Intervention	Target outcome & Measures	Results
Innes et al. (2021) UK	Mixed method design Museums	24 PwD[j] 42% AD[a] 21% Mixed dementia 24 Caregivers	62-94	Object handling Storytelling Visiting museum	Subjective well-being Interviews Mood questionnaires	Participants 'enjoyed' and 'valued' their participation. Mood questionnaires showed an increase in mood scores from pre-post session of 26% for people living with dementia and 20% for care partners.
Camic et al. (2019) UK	Quasi-experimental (non-randomised design) Day centre & museum	80 PwD[j] 50 early 30 mild 37 AD[a] 24 VaD[k] 4 Mixed-types 2 HIV-related	74.81 ± 7.6	Object handling (h)[c] 1 session 60 min	Subjective well-being Clinical Dementia Rating Audio-recorded VAS[l]	Significant improvement of well-being in both settings and stages of dementia, but higher effect in early-stage than mild. Younger participants benefit most from the intervention.
Griffiths et al. (2019) UK	Qualitative Care home	13 PwD[j] Mild to moderate 3 Care professionals & other staff	-	Object handling (h)[c] 6 sessions 6 weeks 120 min	Emotional responses & engagement Interview	Positive engagement, social interactions and emotions.

Table 4.2 *(Continued)*

Author & Country	Study design & Setting	Sample	Mean/ range age	Intervention	Target outcome & Measures	Results
Hendriks et al. (2019) NL	Quantitative (cross-sectional observational design) Museums	72 PwD[j] 10 mild 27 moderate 13 severe 20 AD[a] 7 VaD[k] 2 FTD[b] Other 14	81.33 ± 7.64	Art viewing Object handling (h-m)[c d] 1 session 90 min	Engagement & interactions Observation Questionnaires Assessment of Art Attributes	Active responsive and interactions in those with moderate levels of impairment. Increasing responsive with objects compared to artworks.
Thomson et al. (2018) UK	Mixed method Museums	115 (not all participants with dementia) Mild to moderate dementia	65-94	Art making Art viewing Object handling (h)[c] 10 sessions 10 weeks 120 min	Psychological well-being MWM-OA[h] Participants' diaries Interview	Significant improvement in well-being.
Johnson et al. (2017a) UK	Quasi-experimental (non-randomised crossover design) Museum	36 PwD[j] Early to mild 3 MCI[f] 17 AD[a] 8 Mixed-types 5 FTD[b] 4 VaD[k] 30 caregivers	74 ± 7.6 PwD[j] 66 ± 9.95 Caregiver	Object handling (h)[c] Social activity (i.e. refreshment break) Art viewing 1 session 115 min	Subjective well-being Clinical Dementia Rating Questionnaire VAS[l]	Significant increase in well-being following object handling and art viewing but not during social activity. The increase was significantly greater from object handling than art viewing.
Roe et al. (2016) UK	Qualitative Museum	17 participants 10 Care professionals 1 Caregivers	75-92	Object handling (h)[c] Visiting museum Art making 6 sessions 24 weeks 180 min	Subjective well-being Observation, interview Field notes & session summary	Positive benefit reported on well-being, mood, social engagement and memories.

Table 4.2 *(Continued)*

Author & Country	Study design & Setting	Sample	Mean/ range age	Intervention	Target outcome & Measures	Results
Ander et al. (2013) UK	Qualitative Health care settings	42 PwD[j] 40 Neurological rehabilitation in/out patients 8 Healthcare staff	-	Object handling (h)[c] 1 - 8 sessions over 1 - 16 weeks (Participants took part in one or multiple sessions)	Emotions, feelings & life experiences Interview Observation Field notes	Positive benefit reported on well-being, emotion, and participation. Stimulating social inclusion and new learning.
Thomson et al. (2012) UK	Mixed method Hospital & care home	10 PwD[j] 40 Neurological rehabilitation in/out patients 94 Oncology patients 14 Acute and elderly care 21 Control group	-	Object handling (h)[c] Pictures (c.g.)[e] 1 session 40 min	Psychological well-being, subjective well-being & happiness PANAS[i] VAS[l]	Increasing wellness, happiness and positive mood in experimental group compared to control group. Negative mood decreased in both groups but no significant difference between groups were found.
Norberg et al. (1986) S	Case study Care home	2 PwD[j] Severe	87 & 83	Object handling (m)[c] Touch Music 16 sessions 2 weeks 70 min	Physical & physiological responses Observation, video & audio-recorded, pulse & respiration rate	Lower frequency of eye blinking, higher verbal reactions and pulse rate during music compared to objects handling and massage.

[a](AD) Alzheimer's Disease; [b](FTD) = Frontotemporal Dementia; [c](h) = heritage objects; [d](m) = modern objects; [e](c.g.) = control group; [f](MCI) Mild *Cognitive Impairment; [g](MMSE) = Mini Mental State Examination; [h](MWM-OA) = Museum Wellbeing Measure for Older Adults; [i](PANAS) = Positive and Negative Affect Scale; [j](PwD) = People with Dementia; [k](VaD) = Vascular Dementia; [l](VAS) = Visual Analog Scales.*

Roe et al. (2016) evaluated a museum programme, namely ‘Coffee, Cake and Culture’, considered as an art programme. During the programme, participants were invited to ‘engage in a variety of sensory experiences’ through a range of activities that integrated handling and discussing objects, as well as artefacts with storytelling and art-making based upon the museum and gallery collection (Roe et al., 2016, p. 549). Innes and colleagues (2021) similarly engaged participants with heritage collections alongside storytelling and museum tours.

A multi-sensory stimulation intervention (Griffiths et al., 2019) combined handling and discussing heritage objects with olfactory stimulation. During the sessions, objects were introduced and passed around by participants, who were encouraged to engage with and discuss them. In Thomson et al. (2018) and Hendriks et al.’s (2019) ‘museum-based social prescription’ and ‘interactive museum programme’ respectively, handling and discussing heritage objects were combined with museum visits and arts activities. Museum-based social prescription is a type of social prescribing that refers to creative activity prescribed by health and social care professionals, often a general practitioner, to address needs such as chronic health problems or loneliness (Drinkwater et al., 2019).

Object handling, massage and music (religious and popular songs) sessions were integrated and administered in a systematic way in Norberg et al.’s study (1986).

Objects were introduced to participants one at a time, whilst the researcher was talking about them.

In the object handling session delivered by Johnson et al. (2017a), objects were presented and passed around the group one at a time, giving the participants the opportunity to explore, share personal associations and comments on the physical properties of the items. To encourage individual and group engagement, facilitators asked questions about participants' experience as they handled and observed the items.

A similar object handling protocol was used in three other studies (Ander et al., 2013, Thomson et al., 2012; Camic et al., 2019). Camic and colleagues (2019, p. 791) placed the emphasis on the importance of using 'non-memory-related' prompts in order to move away from the reminiscence approach e.g. 'Would you have this as a decoration in your home?' or 'How does this object make you feel?'. In Thomson et al.'s (2012) protocol, participants were asked to choose the first item to explore and to explain their choice. Prompts focusing on the emotional and physical properties of the items rather than on participants' autobiographical memories were also used in this study, including stimulating questions such as 'What do you think it feels like?' or 'How does it make you feel?'.

Table 4.3 shows the terminology and describes the object handling procedures used in the studies mentioned. There are clearly some similarities between these

descriptions. Consistent with the definition of object handling provided in the Eligibility criteria~~Eligibility criteria~~ (Section 4.3.1), the object handling procedure comprised introducing the objects and giving participants the opportunity to explore and engage with them on different levels (e.g. physical, emotional, meaning and historical features). Several studies used prompts to promote conversations, as described above.

Table 4.3 Object handling procedure of the studies included in the review

Article	Terminology	Procedure
Innes et al. (2021, p. 4)	Heritage programme	The programme is 'designed to provide authentic, creative, site-specific, multi-sensory experience focussing on the 'here and now' experiences in a safe dementia-aware environment. The programme's 'Three S's' model combines sensory stimulation, storytelling (based upon historical information) and period spaces exploration. Individual sessions are designed and delivered by creative facilitators, representing a range of artistic disciplines including sculpture, dance and music, who work to a detailed brief but are given considerable creative freedom in choosing aspects of the site's 'story' to develop their ideas.'
Camic et al. (2019, pp. 790-791)	Object handling OR museum object handling (when refer to museum)	Objects were 'presented to the group, shown to all members without first informing them about the function or name of the object. The object was then handed from member to member so that each individual was given time to have a tactile experience with the object and to have a closer look. As the object was passed around, the facilitator asked a series of non-memory-related questions.' 'As each member of the group shared their feelings and opinions, the facilitator encouraged participants to speak more about their responses while holding the objects. When each object made a circuit around the group, it was placed in the centre of the table for all to continue to view.'

Table 4.3 *(Continued)*

Article	Terminology	Procedure
Griffiths et al. (2019, p. 3)	Multi-sensory intervention	'During the sessions, the facilitator introduced the box and passed round the items. Whilst objects were handled, the facilitator asked questions about the contents and encouraged conversation between the participants. This continued until all the items had been examined.'
Hendriks et al. (2019, p. 860)	Museum tour	'For each tour, four to six different art works are selected around the theme and presented.' 'The guide asks open questions (e.g., about the colours, aesthetic preferences), stimulates interaction between the people with dementia and their caregivers and between the participants, and gives small assignments to be executed in couples, including drawing assignments, to "adopt the same pose as a figure in the artwork' or 'talk about the object in couples.'
Thomson et al. (2018, p. 30)	Museum-based social prescription	'Programmes of engaging, creative and socially interactive sessions, […] comprising curator talks, behind-the-scenes tours, object handling and discussion, and arts activities inspired by the exhibits.'
Johnson et al. (2017a, pp. 594, 597)	Object handling OR museum object handling (when refer to museum)	'Object handling sessions comprise tactile, visual, and conversational exploration of authentic museum artefacts.' 'Objects were presented one at a time and people had the opportunity to hold, examine, and talk about them as a group as they were passed round. Questions about impressions of the objects included sensory descriptions, preferences, and reflections; associations and anecdotes were encouraged.'
Roe et al. (2016, p. 549)	Art programme	'Over the course of the programme various activities occurred with varying levels of engagement. […] the participants were able engage in a variety of sensory experiences through the diverse range of activities. Visitors looked at or handled a variety of objects, in particular contexts, read exhibition materials, discussed them and took home materials to read and show others.'
Ander et al. (2013, pp. 209-210)	Museum object handling	Handling session 'provided opportunities for learning and discussion about the history and use of these objects [museum objects]'. 'Questions were phrased to encourage touching and exploration of the objects.'

Table 4.3 *(Continued)*

Article	Terminology	Procedure
Thomson et al. (2012, p. 69)	Museum object handling	'Participants were invited to choose their first museum object/photograph and suggest reasons for their choice.' The questions that 'followed prompted discussion related to the physical and emotional properties of each object/photograph in turn […]. Facilitators referred to fact sheets to address specific questions.'
Norberg et al. (1986, p. 475)	Object presentation	'Object presentation consisted of trials to stimulate the patient's auditorily, tactilely, olfactorily and visually. The patients were allowed to smell, touch and watch objects and the researcher talked about them.'

Nine studies investigated the distinctive value of heritage object handling for people with dementia, of which three (Ander et al., 2013; Griffiths et al., 2019; Thomson et al., 2012) used a box to present items to the participants (each containing an eclectic range of objects such as a tiger's skull, fossilised seaweed, Victorian candle snuffer, Islamic porcelain, old shavers and infant feeding bottles). Two one study (Griffiths et al., 2019; Norberg et al., 1986) included everyday items such as wood, hay, soft soap, yarn, cloves, cinnamon.

Two out of ten studies reported how the objects were selected: based on their tactile, visual, and kinaesthetic properties (Thomson et al., 2012), or on the unfamiliarity and unusual physical features of the items (Camic et al., 2019).

4.4.5 Study design and outcome measures

Among the ten studies included in the review, half used a quasi-experimental design (Camic et al., 2019; Hendriks et al., 2019; Johnson et al., 2017a; Thomson et al., 2012; 2018), which aims to test a causal hypothesis but does not involve randomisation. Three studies used a qualitative design (Ander et al., 2013; Griffiths et al., 2019; Roe et al., 2016), one was a mixed methods design which combines both qualitative and qualitative approach (Innes et al., 2021), and one used a case study (Norberg et al., 1986).

Four studies used interviews to gather data (Ander et al., 2013; Griffiths et al., 2019; Innes et al., 2021; Roe et al., 2016), visual analogue scales were used in three studies (Camic et al., 2019; Johnson et al., 2017a; Thomson et al., 2012), four used observation (Ander et al., 2013; Hendriks et al., 2019; Norberg et al., 1986; Roe et al., 2016) and three studies used questionnaires along with other measurement tools (Innes et al., 2021; Hendriks et al., 2019; Johnson et al., 2017a). Thomson et al. (2018) used the Museum Wellbeing Measure for Older Adults (MWM-OA) (Thomson & Chatterjee, 2014, 2015), a scale assessing well-being following museum and object handling interventions designed to be administered to older people. Only one study (Norberg et al., 1986) examined physical reactions, recording movements of the eyelids, mouth, and head as well

as physiological reactions, such as pulse and respiration rate but it did not specify the methods that were used to measure these.

Most of the studies (n = 6) investigated the impact of object handling session(s) on the well-being either of participants with dementia or the caregivers supporting them. Four of those studies focused on the participants' subjective well-being (Camic et al., 2019; Johnson et al., 2017a; Roe et al., 2016; Thomson et al., 2012). Well-being is a multidimensional construct, including social, psychological, and physical domains, though there is not a complete consensus as to how it should be defined (All-Party Parliamentary Group on Arts Health and Wellbeing, 2017). Those studies assessing subjective well-being did so by means of self-report measures, such as visual analogue scales, which were used in three studies to provide ratings of key aspects of subjective well-being: happiness, engagement, confidence and optimism.

Ander and colleagues (2013) explored the individual experience, emotions and feelings in relation to the object handling session(s). The remaining three studies focused on the impact of different types of stimuli and stimulation, such as engagement and emotion (Griffiths et al., 2019; Hendriks et al., 2019) and physical responses (Norberg et al., 1986).

4.4.6 Outcomes for people with dementia

Five of the studies documented well-being impacts for participants with dementia (Camic et al., 2019; Johnson et al., 2017a; Roe et al., 2016; Thomson et al., 2012, 2018).

Johnson et al. (2017a) examined the effect of object handling in comparison to art viewing and to a period of social activity in the form of a refreshment break (involving consumption of food and drinks). The results indicated increased well-being following object handling ($p < .002$) and art viewing ($p < .006$) sessions but not after the social refreshment break. This effect was higher following object handling intervention than art viewing. Data from feedback forms showed that most participants (55%) preferred discussing and manipulating heritage objects compared to the art discussion session (36%).

Thomson et al. (2012) found that handling objects significantly increased the positive mood ($p < 0.001$), wellness ($p < 0.01$) and happiness ($p < 0.003$) of participants compared to sessions based on looking at the same object presented as a photograph, as indicated by improved scores on visual analogue scales. Although the findings showed a decrease of negative mood scores, there was no significant difference between the two conditions.

‘Beautiful’ and ‘gorgeous’ were a few participants’ comments on the objects handled in the programme described by Roe et al. (2016). The sessions stimulated positive and enjoyable feelings, promoting increased well-being of those living with dementia.

In line with this finding, Camic et al. (2019) reported a statistically significant increase ($p < .001$) in well-being in participants with early and moderate dementia who participated in object handling in both a museum and day centre. The intervention benefits were significantly larger in younger participants ($p < .03$) and in those with early-stage dementia ($p < .007$). No gender differences were found in the well-being score.

Significant positive change between pre- and post-session in the total well-being scores ($p < .001$) was also found in Thomson et al.’s study (2018). Quantitative analysis showed that two items of the MWM-OA, ‘enlightened’ and ‘absorbed’, were rated higher than the other four emotions (active, cheerful, encouraged and inspired) after each session (e.g. smallest increase post-session $p <. 026$). When interviewed, participants commented that they felt absorbed while learning new information and skills during the session.

Enjoyment, increasing positive emotion, and vitality were reported by Ander et al. (2013) as key themes. These results were linked to an increasing sense of social inclusion and identity derived from the interaction between participant, museum

collections and the group. Participants referred to looking forward to the sessions and they were positive about the non-directive approach of the sessions: ‘you can choose how much … and what you want to do or say’ (Ander et al., 2013, p. 211).

Although the qualitative study of Griffiths et al. (2019), exploring a multi-sensory stimulation intervention using selected items from an archive collection, did not directly measure well-being, the authors reported high engagement in all participants, regardless of the level of cognitive decline, and a positive effect on mood.

Hendriks et al. (2019) found statistical differences between engagement with the activity and interactions with other group members according to the severity and types of dementia. People with mild dementia or those with a diagnosis of VaD were more responsive and interactive compared to those with moderate dementia and Alzheimer or other types of dementia. The authors proposed an explanation for this difference, suggesting that people with mild and VaD may retrieve more personal memories, which might directly affect levels of engagement with the session. Moreover, the analysis of the association between responsiveness and specific types or features of items used showed that objects, such as historical items or crockery, were more engaging than artworks.

A case study (Norberg et al., 1986) compared the effect of music, massage, and object presentation in two persons in an advanced stage of dementia. Physical

reactions, such as lower frequency of eye blinking and higher verbal reactions, were observed during music stimulation. Both participants did not show any specific physical response to massage and object presentation. According to the authors, a possible explanation of the findings is that participants were not able to perceive the objects due to major sensory impairments.

4.4.7 Outcomes for care professionals and informal caregivers

A total of five studies involving care professionals, other staff and/or facilitators (Ander et al., 2013; Griffiths et al., 2019; Roe et al., 2016) and informal caregivers for people with dementia (Innes et al., 2021; Johnson et al., 2017a; Roe et al., 2016) explored whether attending object handling sessions in a supportive role had positive effects for them.

Johnson et al. (2017a) invited caregivers to complete the same visual analogue scales as the participants with dementia, and their quantitative analysis of these scores showed a significant increase in subjective well-being after object handling ($p < .003$).

Overall, qualitative data indicated that staff and caregiver participants enjoyed the sessions, e.g. Innes et al. (2021) found that all caregivers reported to have enjoyed at least one aspect of each session; Griffiths et al. (2019) quoted staff

using words like ‘lovely’, ‘emotional’, ‘uplifting’, ‘warm and welcoming’. Exploring heritage items was found to be stimulating and to enhance new learning.

Care professionals working in dementia settings reflected on how objects became the main topic in conversations. Participants found that talking about objects was a valuable way to stimulate and engage people with dementia. Roe et al. (2016) found that objects facilitated meaningful discussion between staff and care home residents, shifting the focus from dementia and the caring relationship to broader, non-clinical subjects, thus helping to build and sustain relationships. Care professionals reported that seeing the person in a social context helped to change the way they thought about ‘dementia’ and enabled them to create relationships focused on the person rather than on their disease and disabilities. When interviewed, facilitators noted that mutual engagement and co-construction of the meaning of objects contributed to decreasing power imbalances and hierarchies between facilitators, care professionals, and people with dementia. For instance, some facilitators commented on the process of knowledge exchange and how they learnt from the residents (Roe et al., 2016); others underlined how staff became involved on ‘an equal footing’ to the residents with dementia through the sessions (Griffiths et al., 2019 p. 5).

4.5 Discussion

This scoping review included ten studies focused on assessing the impact of object handling intervention in relation to mainly subjective and psychological well-being, and emotional response. Other outcomes such as physical response, engagement and interactions were investigated as well. Most studies used qualitative or quasi-experimental designs. These can offer insights into the most effective features of object handling and capture the benefits of object handling at an individual level and in relation to social interactions 'in the moment'.

Most of the studies on object handling place the emphasis on using objects as tools to create a space where participants could engage and connect with the items and other participants 'here and now'. Moving beyond reminiscence and shifting the focus from the past to the present experience of people with dementia, recognises the value of being in the moment. The concept of 'in the moment' related to people with dementia has been recently defined as 'a relational, embodied and multi-sensory human experience' embedded of personal value, significance and meaning (Keady et al., 2020, p. 7). This definition highlights that, for a person living with dementia, moments can be initiated both by themselves, through the recall and response of a particular stimuli, or from the interpersonal interaction with other people.

Some evidence suggests that object handling interventions are associated with increased well-being, positive emotion, and social inclusion in participants with dementia, and can help to facilitate new learning and meaningful conversation for caregivers and people with dementia. However, the scoping review was simply concerned with describing the studies and the observed outcomes. Attempting a synthesis of their effectiveness was beyond its aim.

Included studies encompassed different settings and varied greatly in terms of factors such as number of sessions and length of intervention. Some studies in the review included other activities such as art viewing and art making alongside object handling. Moreover, there was no clear indication if there is an optimum number of sessions or an optimum duration of interventions. On the one hand, comments were recorded at interview about the cumulative benefits of regular sessions, yet studies that offered only a single session (Camic et al., 2019; Johnson et al., 2017a; Hendriks et al., 2019; Thomson et al., 2012) reported similar benefits to others with more sessions.

Five out of ten studies reported the participants' stage of dementia. Mainly, people with mild to moderate dementia were included and only one study involved severe dementia, so there is currently limited evidence as to what extent object handling may be useful for people with advanced dementia.

Regarding the materials used, most of the studies incorporated heritage objects. Given the historical and unusual features of museum and gallery items, and heritage objects are likely to have stimulated curiosity or to have connected with the earlier years of participants' lives. One feature of studies using heritage collections (Griffiths et al., 2019; Camic et al., 2019) was the sometimes ambiguous nature of the objects; it appears that this may be important in capturing participants' attention, curiosity and providing them with a cognitive challenge. It has been argued that curiosity is closely related to well-being as it can drive new learning, creativity and social connection, each of which can be both a form of and a pathway to well-being (Kador & Chatterjee, 2020; Phillips et al., 2015).

This review provides an overview of the empirical evidence available on object handling interventions and reveals considerable variety of design and procedures used in the studies. Such heterogeneity may be due to a lack of definition of what an object handling intervention is. Therefore, from the review, the initial concept of object handing was reviewed, and an operational definition model was developed.

4.6 Operational definition model of object handling intervention

A theoretical understanding of the components and likely domains of action of an object handling intervention was developed by drawing on the results of the scoping review, existing theories and evidence. In summary, this was undertaken as follows. Existing theories and evidence were explored by reading broadly

around concepts of objects and of object handling, for example literature relating to engagement, developmental psychology and educational research, and especially papers describing object handling interventions with different groups of participants (e.g. students, mental health groups). Studies were mainly identified through reference checking the studies included in the review, alongside a set of key articles provided by professional stakeholders, which also included the supervisory team.

Observations from this diverse literature and the findings of the scoping review were then used to draft a first version of the operational model of object handling. The content of the first version was reviewed by professional health and social care, as well as dementia specialists in a series of individual discussions. The feedback gathered from the professional stakeholders was integrated into the model, leading to a revised version of the operational definition. The decision to establish iterative consultations with people with expertise in the subject under discussion was taken in order to extend and enrich the analysis of the literature and to help to critically review and refine the operational model. The following sections of this chapter describe these processes in more detail.

4.6.1 Background literature on objects in theory and practice

Several authors have discussed the role of material objects in defining the self and creating a sense of identity based on Vygotsky's (1967) assumption that the multi-

sensory interaction with objects plays an important role in the development of self-awareness and sense of identity. Camic (2010) found that material objects may act as symbols of self and connect us with others and places. The concept of material objects as a repertory of personal identity may be particularly meaningful for people living with dementia in care homes. This is supported by Stevens et al.'s (2019) explanatory model for the value of the object in the context of dementia care settings, which proposed that objects make an important contribution to preserving a state of identity. Material objects have been found to connect with others across time and space, such as in the past through autobiographical memories, and with the future through the actions taken to preserve items to pass to the future generation. For example, Buse and Twigg (2014) describe how handbags for women with dementia living in a care home transcended their functional use and embodied symbolic meanings. Handbags provide a 'private' and 'safe' inner world as they become the place to carry personal possessions and symbolise boundaries between private (e.g. bedroom) and public (e.g. care home common areas) spaces.

The psychoanalytical tradition emphasises the role of objects as a mental and emotional representation of individual internal psychological processes. Authors who were influenced by Melanie Klein's work on object relations included Donald Winnicott (1953), who developed ideas around transitional objects. The term

‘transitional object’ is used to describe external material objects, such as the cloths and teddy bears of infants, which can have symbolic meanings as a result of projections of the internal word (Winnicott, 1953). Objects when acting as a container of feelings or different state of mind, have a strong link with an individual's sense of identity (Lanceley et al., 2012). This is reflected in the study by Stephens et al. (2013), who explored the concept of transitional objects in a care home setting. The study observed that objects and the way residents interact with them have a specific significance, demonstrating that the notion of transitional objects may be applicable in relation to people with dementia. For example, they observed a resident carrying and sleeping with a knitted doll named after her husband.

Material objects as mental representations of possible relationships among things, people and events may explain how object handling sessions may evoke memories and emotions. It is, therefore, possible to speculate that emotion and reminiscence processes are elicited by the personal meaning attributed to objects.

Another potential effect of handling and discussing objects may occur at the level of cognitive processes. Thomson et al. (2012) and Paddon et al. (2014) hypothesised that object handling interventions may affect cognitive functions and lay down new connections in the brain, as a result of encounters with novel stimuli, prompting memories and social interaction. Exploring material objects through

different senses, discussions and reminiscence processes may implicate a multiple coding (e.g. dual or triple coding), which leads to neuronal growth.

Paddon et al. (2014) investigated psycho-educational features accounting for the changes found in hospital patients following a heritage object handling intervention. Although this paper was about heritage object handling, it was not directed at people with dementia, so not included in the review. Nonetheless the authors have considered theoretical aspects, so it is appropriate to cite it here. According to Paddon et al. (2014), the outcomes of object handling sessions are determined by the balance and the frequency of occurrence of certain 'features' that are peculiar to participants (e.g. self-esteem, positive interactions) or to the facilitator (e.g. encouraging engagement, giving information). Each of the features identified following thematic analysis was distinct but closely interlinked. Therefore, facilitators' skills, knowledge and attitude are fundamental to encourage engagement and build trust and rapport with participants. This is consistent with the findings of other studies (e.g. Camic et al., 2019). In contrast, participants actively engage and become immersed in the process of object handling. Given the opportunity to handle and look at objects, participants are actively involved in the exploration of the physical characteristics of the objects as well as in the process of thinking and meaning-making by directing questions, and sharing

opinions within the group. Participants' knowledge, experiences and personal values are brought into the sessions, and integrated with the sensory information. This is consistent with the findings of a recent study with people with dementia (Camic et al., 2021).

According to a conceptual literature review of objects and psychological theory (Solway et al., 2016), several elements occurring through engagement with objects and facilitators contribute to the positive benefits of object handling interventions. Curiosity and speculation about the objects can enhance discussion, social interaction, and engagement. Objects can also serve as a catalyst for new associations and ideas, which may lead to new learning. Several studies reported 'new learning' from their qualitative analysis as one of the main themes, which is often associated with positive change in mood (Camic et al., 2019; Griffiths et al. 2019; Solway et al., 2015; Thomson et al., 2018). Educational research suggests that adult participation in learning has a direct effect on well-being by encouraging people to develop resources and cognitive capacities (Kador & Chatterjee, 2020). The National Health Service identifies 'keep learning' as one of the five actions to improve well-being by boosting self-confidence, and the feeling that life has meaning and purpose (NHS, 2019b).

To identify which factors create the conditions for such mechanisms behind the outcomes of object handling intervention, the theoretical framework of

engagement (2009) proposed by Cohen-Mansfield and colleagues was considered. According to this framework, the degree of engagement in people with dementia, defined as 'the act of being occupied or involved with an external stimulus', is affected by interactions between person, stimuli and environmental attributes (Cohen-Mansfield et al., 2009, p. 2). This model can help in understanding and making sense of the object handling process.

By exploring theories and evidence, potential elements influencing and determining the object handling process and its outcomes were drawn together. From this, a first draft of the operational definition model was created.

4.6.2 Consultations with care professionals and clinical researchers

The next step in the development was to refine and validate the model through several meetings with the supervisory team and a group of professional stakeholders. A group of academic and clinical dementia specialists (n = 4), and staff working in dementia care settings (n = 4), e.g. care home managers, were invited to contribute critical feedback on a list of proposed construct domains. Ethical approval for the consultations was not sought.

Professional stakeholders individually evaluated the list of domains for coherence and for overlapping constructs, using a checklist form (Appendix 2). The form included a description of the model, and tables where participants could express

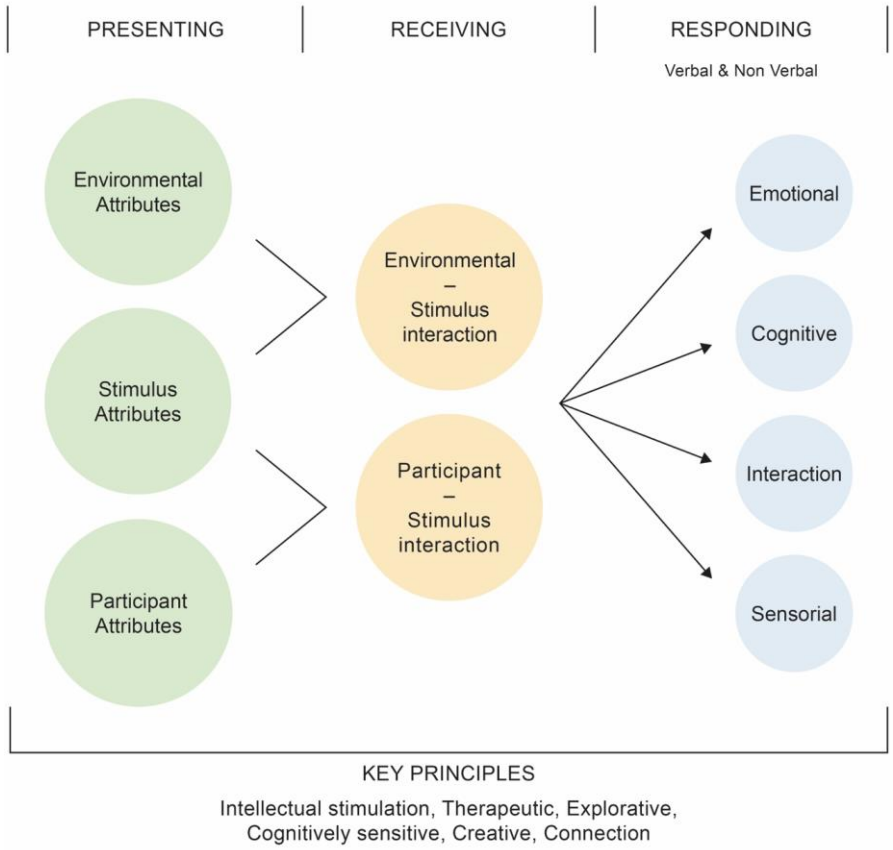
their agreement or disagreement with the model domains. They were also asked to suggest any relevant constructs that had been omitted from the list. For further clarification, one-to-one sessions were conducted with the consultants to discuss the comments they had given. Those interviews were informal and were not recorded.

4.6.3 Final operational definition model

The results from the feedback enabled the generation of a list of domains, which fed into the development of the final operational definition model. Two infographic models were created. Further feedback on the infographic models was gathered from the supervisory team in order to establish the extent of agreement with regard to which infographic is most explicative and easy to understand.

The proposed operational definition (Figure 4.2) suggests that object handling has the following essential components: presenting, receiving, and responding. Furthermore, the operational definition model may be conveyed in terms of a set of underlying factors (principles) as described in the work of Cousins et al. (2020). Each of these constructs is briefly presented below.

Figure 4.2 Operational definition model of object handling



4.6.3.1 Presenting

The way the object is introduced and presented may be influenced or even determined by environment, participant, and stimulus attributes (Table 4.4).

Table 4.4 Factors that influence object presenting

Environmental attributes	Participant attributes	Stimulus attributes
Location	Gender	Shape
Number of people	Age	Size
Social context	Ethnicity	Weight
Cultural context	Level of dementia	Texture
Room temperature	Type of dementia	Surface characteristic
Room light	Person's attitude to objects	Object history
Room noise	Previous experiences	Object role
Facilitator competencies	Person's mood on the day*	Object meaning
Time stimuli presentation*	Physical and sensory impairment*	Smell
Seating arrangement*	-	Colour*
Duration of session*	-	Density*

***** *Factors included following the consultations*

Environmental attributes

Environmental attributes include, for example, the location where the sessions are held; the number of people in the session; the social and cultural context; the level of temperature, noise, and light; the time of day of stimulus presentation, as well as the facilitator competencies. According to a recent taxonomy (Cousins et al., 2020) facilitator competencies include training and skills, such as flexibility, empathy, practicality, intuition, tacit knowledge, knowledge of the objects used in the programme, and having an engaging attitude.

Participant attributes

Relevant participant characteristics include such aspects as age, gender, level of dementia, physical and sensory abilities, and their likely previous experiences and familiarity with the items.

Stimulus attributes

Stimulus attributes include physical features of the material object, such as shape, size, weight, density, smell, and texture, as well as non-physical or intangible aspects such as the object's meaning, role and history.

4.6.3.2 Receiving

The second component of object handling is the 'receiving' stage, which refers to the moment when the participants physically interact with the material objects. This process is determined by the mutual intersection of material object, subject and environment.

Environment-stimulus interaction

The physical spaces and social context in which object handling interventions are encountered can influence how the person engages with the items. For instance, a supportive and encouraging environment is more likely to be perceived by participants as a safe space to explore and engage with the objects (environment-stimulus interaction).

Participant-stimulus interactions

The interaction between the sensory, physical, and material characteristics of the objects and the person's attributes will influence how the person reacts on receiving the object. Some stimuli may be more interesting for individuals than others. One example of a participant-stimulus interaction is the degree to which the person has shown a preference for this type of stimulus in the past. How the person receives and interacts with the object will also be affected by their individual characteristics and their past interests and experiences, such as hobbies or work.

4.6.3.3 Responding

Receiving of the material object is followed by the participant's response, which can be seen as complex patterns of emotions, cognitions, sensations and interactions, that may be expressed through verbal and non-verbal communication. Equally, manifesting no response is a perfectly legitimate way of responding.

Emotional

Participants may experience one or likely a range of emotions, which define the subjective experience. Emotions such as 'happiness', 'anger', 'sadness' and 'boredom' might be expressed through the overt expression of emotion, or by non-

verbal and/or physiological responses such as body language, sweaty palms or a racing heartbeat.

Cognitive

Participants are actively engaged in meaning-making which occurs through interaction and communication with the group members or the facilitator. A variety of cognitive domains such as attention, sensory integration, memory, and executive function are typically involved during the object handling process.

Interaction

Objects can facilitate verbal and non-verbal communication. People may respond by talking about the stimulus with the facilitator or group members. However, people may react to the object non-verbally, through physical engagement, exploring and manipulating objects, or by using a bodily interaction, such as body posture, direction of gaze and gestures, without any explicit, verbal reference to what they mean.

Sensorial

Handling objects promotes the exploration of the items in a multi-sensory manner. For instance, a person can engage with the item using one or more of the five senses including visual, olfactory, and tactile sensory modalities.

4.6.3.4 Principles

Cousins et al. (2020) developed a taxonomy of the key components of arts interventions in dementia. One of the most important dimensions of this system was the concept of principles, a term used to identify the key components in generating an arts intervention. The list of eight principles derived by Cousins et al. (2020) was used to re-examine the papers reviewed in this chapter, and those that are relevant are summarised in Table 4.5.

Table 4.5 Descriptions and lay summaries of the principles involved in object handling as an intervention in dementia

Principle description	Principle lay summary
Intellectual stimulation: object handling promotes thinking, meaning-making, information transfer and new learning.	The object handling enables thinking.
Therapeutic: object handling facilitate symbolisation, affect, embodiment, well-being, identity, feelings of belonging, reminiscence, social and cultural inclusion.	The object handling can address the needs of people.
Explorative: object handling engages, stimulates, and triggers curiosity.	The object handling promotes investigative behaviours.
Cognitively sensitive: object handling can be adapted and modelled to the participants' cognitive resources.	The object handling is sensitive to individual differences.
Creative: object handling provides the opportunity to think creatively about touch and objects.	The object handling allows imagination and creative process.
Connection: object handling can facilitate connection to the self and to others, enhancing group-building and encouraging interaction within the group.	The object handling enables social interactions.

4.7 Conclusion and recommendation for future research

The review highlighted that there are a relatively small number of studies of object handling in dementia. The studies varied considerably in their designs and methodologies. It is also important to note that heritage objects were used in most of the dementia-focused object handling studies. There may however be similar studies that have not used this specific term, or the keywords used in the research strategy. This may explain the relatively small range of studies identified and included in the review.

It is therefore important to bring together the published studies using object handling as their stated approach, with the aim of using more precise terminology and definitions, which will encourage consistency in study design and reporting. The operational definition of object handling intervention derived from this review lays the groundwork for creating a common terminology across those studies, encouraging future studies to examine and assess the complexity of object handling intervention, its components, and the mechanisms by which object handling may exert its beneficial effects. Indeed, there is little evidence to inform how object handling interventions work, apart from the recent publication by Camic et al. (2021) exploring the impact of object handling sessions on well-being in museum settings.

Future research should focus on identifying the benefits and even negative impacts (Kinsey et al., 2021) of object handling sessions in people with dementia as well as care professionals and informal caregivers using qualitative methods that enable the capture of 'in the moment' effects. However, future research may also benefit from mixed methods and rigorous quantitative design, such as RCT, which could offer the opportunity to assess the effect size in relation to control group outcomes, lending further weight to the value of object handling as distinct to other, non-specific factors such as the nature of the group or environmental setting.

4.8 Strengths and limitations of this review

The results of this review extend the initial definition of object handling, exploring the components and likely domains of the intervention action, ultimately resulting in the operational definition model. A strength of the review is that a new theory-based operational definition of object handling was constructed from the literature encompassing many different disciplines. Drawing on broader evidence provides a comprehensive overview of the concept and potential mechanisms affecting object handling outcomes. Although the operational definition model was developed from papers included in the review, other papers identified through reference checks, and other key studies identified by professional stakeholders, there is the risk that relevant papers may have been missed.

A limitation of the synthesis approach used, is that the review does not include information related to the effectiveness of the intervention due to the fact that quality assessment is not performed within this method (Arksey & O'Malley, 2005). It should be acknowledged, that object handling interventions are relatively new in dementia care, and this study aimed to provide a comprehensive overview of the studies that have been published to date.

To clarify the boundaries between object handling intervention and other interventions in dementia care (e.g. occupational or reminiscence therapy) and to strengthen the review process, it would have been useful to summarise the characteristics of the studies using material objects which were excluded from the review.

Further limitation lies in the lack of geographic diversity of the studies included which may affect the generalization of the findings. Indeed, most of the studies reviewed are from UK. Another limitation is the bias towards heritage objects in the studies so far published. There is a need for more studies involving the handling of everyday material objects since these are by definition highly accessible.

4.9 Summary and implications for MSI development

This review, bringing together studies of object handling interventions, assesses the available evidence, and explores the study designs and outcomes. Given the

evidence outlined above, it could be stated that people with dementia may benefit from object handling interventions as a means of improving well-being, mood, and social inclusion.

The results from this review have been used to create an operational definition model and to build a better understanding of the factors involved in the process of object handling in people with dementia. As reported by the operational definition model, object handling interventions comprise presenting the object to participants (or allowing them to choose) followed by a period of exploration, reflection and response. It is likely that the impact of the intervention is related to dynamic interactions between the characteristics of the materials, the person, the environment, and the way in which the materials are delivered in the session/s. The effects of the intervention may be expressed at verbal and non-verbal levels. Beneficial effects may also be manifested in various ways, either during or after the session, and they may also be verbal or non-verbal. Such understandings provide the framework for the development and validation of future object handling interventions. Based on this, the findings of the review were used to support the development of MSI, such as the intervention protocol (e.g. procedure and materials), and to consider mechanisms by which object handling interventions may promote positive outcomes. However, due to the explorative rather than explanatory nature of the review, the decisions made were based on the included

study recommendations on which components may work best, as outlined in Chapter 7.

In the next chapter, a rapid review of olfactory stimulation in dementia care that evaluates the effect of olfactory stimulation for people with dementia is presented, along with the methods and procedures used, as part of the MRC step - identifying existing evidence.

CHAPTER 5 RAPID REVIEW OF OLFACTORY STIMULATION IN DEMENTIA CARE

This chapter presents the methods and results of a rapid review of olfactory stimulation for people living with dementia. The study evaluated benefits surrounding the use of olfactory items in dementia care and provides insights into intervention designs. In line with the MRC framework (Craig et al., 2008), the results of the rapid review formed the core evidence-base to inform the MSI design along with the findings of the scoping review of object handling and the background literature review. The results of this review were also used to inform an explanatory analysis of how and why olfactory interventions work, which is discussed in Chapter 6.

This review was accepted for publication in a peer-review journal *Dementia* in January 2022 (D'Andrea et al., 2022).

5.1 Introduction

Several studies have reviewed the effects of aromatherapy, a commonly used olfactory intervention, on a variety of outcomes concerning people with dementia

over the last decade. This suggests a recent growth in interest seeking to extend the limited evidence of its efficacy. A fairly recent Cochrane systematic review (Ball et al., 2020) evaluated the efficacy and safety of aromatherapy for people with dementia. Two other previous systematic reviews assessed the use of aromatherapy in dementia care. One of these (Kim et al., 2019) focused on the potential benefit of aromatherapy to decrease agitation in individuals with dementia. The other (Fung et al., 2012) explored the impact of aromatherapy on responsive behaviours and cognitive function.

In the context of the present review, it is pertinent to note that all reviews included only studies with RCT design. Although quantitative evidence is informative regarding efficacy in relation to defined outcomes, the findings from qualitative or mixed methods studies provide a more comprehensive synthesis (Dixon-Woods et al., 2005). This is particularly relevant in the context of health and social care, which often include complex interventions. Thus, combining and integrating data on the study effectiveness and individuals' experiences or preferences can offer an in-depth understanding of the study's conclusions, and intervention complexity (Lizarondo et al., 2020). The results of a review incorporating different methodologies and types of research questions regarding experience (qualitative) and effectiveness (quantitative) are considered extremely useful for guiding informed-choice in the development of a novel intervention and to support

decision-makers (Bressan et al., 2017; Lizarondo et al., 2020). Furthermore, the three systematic reviews included aromatherapy administered by massage or touch. Although there is limited evidence, studies on touch have reported benefits of massage practice by itself i.e. without olfactory stimuli (Hansen et al., 2006; Zhao et al., 2020). This suggests that any positive findings from studies applying olfactory stimuli by massage or touch might not be the result of the odour only, but the effect of tactile stimulation or their interaction.

Building on the reviews of aromatherapy, this review is the first to use a mixed methods approach to synthesise the evidence on olfactory stimulation in dementia care and to focus solely on olfactory stimulation interventions excluding those combining olfactory elements with other activities such as massage.

5.2 Aims and objectives

5.2.1 Aims

To conduct a rapid review on the impact of olfactory stimulation on cognitive function, communication, quality of life, responsive behaviours, pain, and physical functioning for people with dementia.

5.2.2 Objectives

- To synthesise the qualitative, quantitative and mixed-methods evidence on the impact of olfactory stimulation.

- To assess the effects of different types of odours used, and identify, if any, patterns in their effects.
- To review the different ways in which olfactory stimuli are administered, and identify, if any, patterns in their effects.

5.3 Methods

A protocol to clearly lay out the scope and the methodology of the review was developed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) for Protocols (Moher et al., 2015). The protocol (D'Andrea et al., 2020) has been registered in the International Prospective Register of Systematic Reviews (PROSPERO) (registration number CRD42020202670).

5.3.1 Eligibility criteria

This review aimed to evaluate the use of olfactory stimuli in dementia care. Olfactory stimuli may include household items providing an olfactory experience such as soap, essential (or natural) oils and synthetic fragrance oils. Studies of any design, using quantitative, qualitative, or mixed methods that reported the results of olfactory stimulation for people with dementia were included. No geographical or time limits on the publication were imposed on the search.

Inclusion criteria

Studies were included if they met the following criteria: (1) participants were considered by study authors as having dementia even if specific diagnoses were not provided and no specific restrictions regarding age, subtype and severity of dementia were applied; (2) the study used olfactory stimuli; (3) the effects of olfactory stimuli were reported. Studies that compared olfactory stimulation with other interventions such as those combining massage with essential oils (aromatherapy massage vs olfactory stimulation) were eligible for inclusion.

Exclusion criteria

Studies were excluded if they met any of the following criteria: (1) the study only reported on the olfactory function of the participants rather than the effects of the stimuli; (2) aromatherapy using massage or touch, multi-sensory stimulation intervention, Sonas programme, Namaste Care programme and any study combining olfactory stimulation with other activities; (3) unpublished papers, study protocols, dissertations and review papers; (4) studies not in English language.

5.3.2 Search strategy

The review systematically searched and identified all relevant published studies using the following databases: CINAHL, PsycINFO, Medline, PsycARTICLES, Academic Search Elite and Chemical Senses. The databases were selected to reflect the interdisciplinary nature of the topic.

A combination of Boolean operators and truncations were used as summarised in Table 5.1. Hand searching for references in included papers was conducted. The search strategy was checked by a specialist health librarian at the University of West London. The review search was conducted in July 2020 and updated in April 2021.

Table 5.1 Summary of search terms

Search	Terms
#1	Dement* OR alzheim* OR mixed dementia* OR vascular dementia OR Lewy Body
#2	olfactory OR smell OR scent OR perfume OR odor* OR odour* OR aroma*
#3	intervention OR activit* OR session OR reminisc* OR memor* OR experienc*
#4	dysfunction OR impairment
	#1 AND #2 AND #3 NOT #4

5.3.3 Screening and selection procedure

Electronic search results were downloaded into Rayyan, software for semi-automated screening that streamlines the selection of eligible studies (Ouzzani et al., 2016). Screening and study selection approaches used in rapid reviews are highly variable, with up 40% of studies using a single reviewer at various stages (Tricco et al., 2015). In this study, two independent reviewers were involved in the screening and study selection process. As recommended in the practical guide (Tricco et al., 2017), the author independently screened all articles by reading titles

and abstracts against the inclusion and exclusion criteria. A random subset (20%) of electronic search results was independently screened by a second reviewer to minimise the risk of selection bias through inappropriate exclusion of relevant studies. Any discrepancies were resolved by consensus and discussion between the two reviewers.

Titles for which an abstract was not available or unclear were included for subsequent review of the full article. Where articles were not obtained through institutional holdings available to the reviewer, attempts were made to contact the study authors to procure the article. Included articles were then assessed for eligibility by the author, which involved reading the full text. In addition, backward citation searching and forward citation tracking were conducted on included articles to identify any missing studies. Any articles from the hand search that met the inclusion criteria were included for review.

5.3.4 Data extraction process

Similar to the screening process, the number of independent reviewers involved in the data extraction varies between rapid review studies (Tricco et al., 2015). As recommended by Tricco et al. (2017) and later by the Cochrane guidance (Garritty et al., 2021), this study used a single-reviewer extraction approach with a second reviewer checking the accuracy of extractions. For each included article, the author extracted data using a pre-specified data extraction table (using an Excel

spreadsheet) previously piloted by the author and an independent researcher. The extraction table included for each study: author/s, year of publication, country, design, participant information (i.e. sample size; age; subtype and stage of dementia), setting, aim, description of the intervention and stimuli, outcome measures and a summary of findings. The second reviewer checked for accuracy and completeness of the extracted data. If any discrepancies occurred, the two reviewers collaboratively worked to reach a consensus through discussion. Study authors were not contacted for clarification or obtaining information in the case of missing data.

5.3.5 Quality assessment of the studies

The Mixed Methods Appraisal Tool (MMAT) version 2018 (Hong et al., 2018) was used to assess the methodological quality of the included studies. MMAT has been designed to critically appraise qualitative, quantitative, and mixed methods studies by acknowledging the distinctive characteristics specific to each method and has been widely used in mixed method systematic reviews (Hong et al., 2019).

The quality assessments of all the studies were conducted by the author who applied the MMAT checklists (mixed methods, qualitative, and quantitative research divided into randomised controlled, non-randomised, and descriptive). The second reviewer independently assessed a subset (20%) of articles. For each

study, a description of MMAT domains that were not addressed and how confident the authors were regarding the study findings based on the risk of bias assessed was presented. An overall quality score for each paper was presented using stars (*) as descriptors that provide information on the risk of bias. There is not a cut off value within the updated MMAT version (Hong et al., 2018) for weighting the studies. In doing so, MMAT acknowledges the literature suggesting that presenting a global score does not provide a comprehensive description of the quality of the studies (Higgins & Green, 2008). However, in a recent publication the MMAT authors recognised the practical use of categories when performing and reporting the analysis, and then supported their use in combination with a description of what aspects of studies are problematic (Hong, 2020). In this study, therefore, arbitrary overall scores were created where 5-star indicates low risk, 4-star or 3-star moderate risk and 2-star or 1-star high risk. Furthermore, details of each study quality assessment are provided in the results (Section 5.4.8). All eligible studies were included, and none was excluded based on quality assessment but the level of confidence in the study results was clearly reported within the synthesis. Any differences in judgment of the methodological quality of the study between the two reviewers were resolved through discussion.

5.3.6 Data synthesis

A narrative synthesis was used to synthesise the results. The included studies were grouped in relation to the domains investigated (e.g. responsive behaviour), odour type, and olfactory delivery methods. The study characteristics and outcomes were described, and similarities and differences between interventions were highlighted. A meta-analysis was not conducted due to the heterogeneity in the designs, interventions, outcomes and measurement tools used, as well as intervention effects.

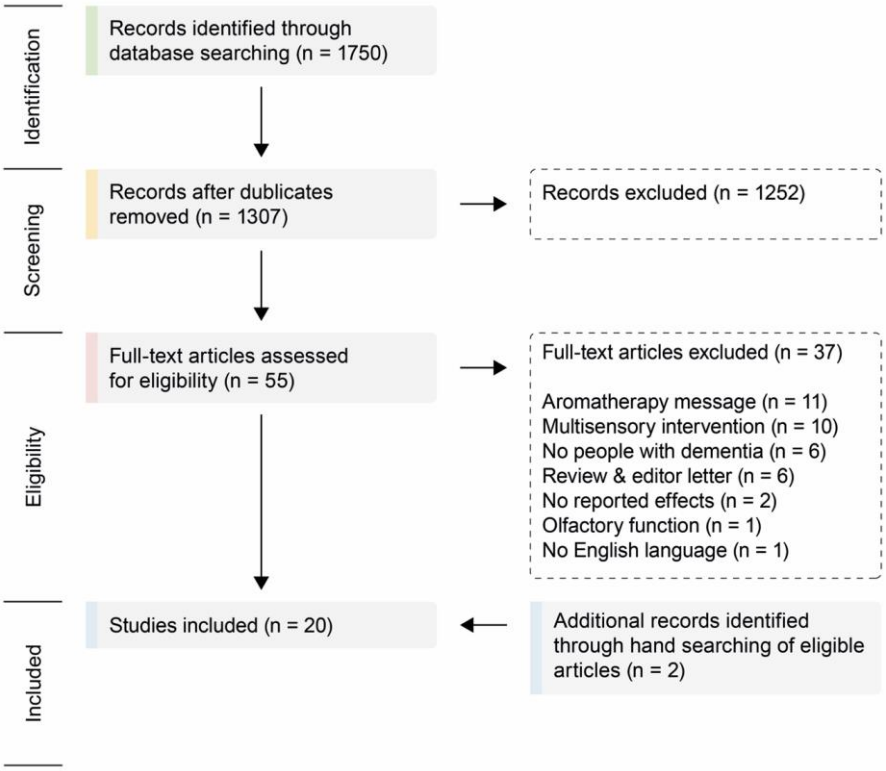
To enhance transparency and replicability of the review, and in the absence of a PRISMA extension for reporting rapid review (Stevens et al., 2018) (at the time, under development), a PRISMA statement (Moher et al., 2009) was integrated with a list of key reporting items for rapid review (Tricco et al., 2017). This served as a guide to strengthen methodology and knowledge synthesis tailored to the objectives of the rapid review.

5.4 Results

Database searches up to and including 07 April 2021 returned 1750 articles. Duplicate articles (n = 443) were removed, and 1252 papers were excluded as they did not meet the inclusion criteria. A total of 55 articles were selected for full-text assessment and 18 were included in the review. Additionally, hand-searching was conducted based on these 18 eligible articles. This involved checking the

reference lists of the articles and also forward citation tracking. By doing so a further two articles were deemed eligible for inclusion. An overview of the study selection process is shown in Figure 5.1. A total of 20 articles were therefore included for review.

Figure 5.1 PRISMA flow diagram of the rapid review of olfactory stimulation



5.4.1 Study design

The methodological design of studies was analysed according to the classification of Hong et al. (2018). The majority of the studies included used a quasi-experimental design. Among the 14 quasi-experimental studies, five implemented a non-randomised design (El Haj et al., 2018; Glachet et al., 2019; Glachet & El Haj, 2020a, 2020b; Gray & Clair, 2002; Lopis et al., 2021), five used a non-randomised cross-over design (Holmes et al., 2002; Jimbo et al., 2009; Snow et al., 2004; Sulmont-Rossé et al., 2018; Takeda et al., 2017), and two used a pre-post design (Henry et al., 1994; Moorman Li et al., 2017). Five studies used an experimental design, including a randomised cross-over design (Lin et al., 2007), a single-blind randomised controlled trial (Fu et al., 2013; Smallwood et al., 2001; Takahashi et al., 2020) and a double-blind randomised placebo-controlled trial (Sakamoto et al., 2012). Brooker et al. (1997) conducted a case study. No qualitative or mixed methods studies were identified from the search strategy used. An overview of the studies is given in Table 5.2.

5.4.2 Study setting and country

A total of 11 studies were conducted in Europe (France n = 7, United Kingdom n = 4), five in Japan, three in the United States, and one was conducted in Australia. The studies took place in different settings. Eight studies were carried out in care or nursing homes (Fu et al., 2013; Gray & Clair, 2002; Holmes et al., 2002; Lin et

al., 2007; Sakamato et al., 2012; Snow et al., 2004; Sulmont-Rossé et al., 2018; Takeda et al., 2017), three in hospitals (Brooker et al., 1997; Henry et al., 1994; Smallwood et al., 2001), one study took place in a day centre (Moorman Li et al., 2017). Eight studies did not provide information about the settings.

5.4.3 Participants

A total of 844 participants were included across the 20 studies. The ages of the participants ranged from 61 to 98 years. Two studies neither provided age range or mean age (Smallwood et al., 2001; Snow et al., 2004). The sample sizes ranged from 4–180 participants.

The included studies varied greatly in terms of stages and subtypes of dementia. Six studies included people with mild dementia (El Haj et al., 2018; Glachet and El Haj, 2019, 2020a, 2020b; Glachet et al. 2019; Lopis et al., 2021), one with moderate dementia (Sakamato et al., 2012) and six with severe symptoms (Brooker et al., 1997; Henry et al., 1994; Holmes et al., 2002; Smallwood et al., 2001; Snow et al., 2004; Takeda et al., 2017). Three other studies included those with different stages of dementia, including mild to moderate (Takahashi et al., 2020), moderate to severe (Lin et al., 2007; Sulmont-Rossé et al., 2018). Some included participants with various stages of dementia, accounting for 14.8% mild, 37.7% moderate and 47.5% severe in Fu et al.'s (2013) study, and 50% mild to moderate and 50% severe dementia in Jimbo et al.'s (2009) study.

Table 5.2 Overview of study characteristics

Authors & Country	Study design & Setting	Sample	Mean/ range age	Study aims	Intervention procedure	Measures
Lopis et al. (2021) F	Quasi-experimental (non-randomised design; between-subject design) -	60 PwD[r] 60 OP[n] 60 Young adult Mild AD[a]	80.9 ± 6.2 (exp) Control: 80.1 ± 6.2 OP[n] 22.2 ± 2.9 Young adult	Assess the frequency and phenomenological characteristics (emotional valence, emotional intensity, memory vividness, and rarity) of odour-evoked autobiographic memories compared those recalled by visual and auditory cues.	Participants were asked to recall memories after presenting and labelling either 4 odours, 4 sounds (i.e. cutting bread, crunching apple, wood crackling, wine bottle opening), or 4 pictures (French bread, apple, a wood fire, wine bottle).	MMSE[o]; Frontal Assessment Battery; verbal fluency task; episodic memory with 5-word test; forward and backward digit spans; 15-item Geriatric Depression Scale; Mini International Psychiatric Interview 5.0.0; Likert scales for assessing emotional valence and intensity, vividness, and rarity of the memory as well as stimuli property.
Glachet & El Haj (2020a) F	Quasi-experimental (non-randomised design) -	24 PwD[r] (exp.) 25 OP[n] (control) Mild AD[a]	85.12 ± 5.68 (exp.) 84 ± 8.5 (control)	Investigate the phenomenological characteristics (specificity, arousal and emotional valence) and retrieval time of past events and future thinking.	Participants retrieved 1 past and 1 future event for 2 minutes in a free-odour condition and after odour exposure. The sessions were counterbalanced and one week apart.	MMSE[o]; Grober and Buschke's task; Geriatric Depression Scale; SAM[s]; TEMPau[v]; reaction time between the end of the instruction and the beginning of the narrative.

Table 5.2 *(Continued)*

Authors & Country	Study design & Setting	Sample	Mean/ range age	Study aims	Intervention procedure	Measures
Glachet & El Haj (2020b) F	Quasi-experimental (non-randomised design) -	24 PwD[r] (exp.) 25 OP[n] (control) Mild AD[a]	85.12 ± 5.68 (exp) 84 ± 8.5 (control)	Investigate the effects of odour exposure on access to self-concept (i.e., psychological self, physical self, or social self).	Participants produced self-related statements of their identity (including roles, personality traits or physical traits) within 1 minute following odour and odour-free exposure. The sessions were counterbalanced and one week apart.	MMSE[o]; Grober and Buschke's task; Geriatric Depression Scale; Span task (forward and backward span); SAM[s]; phonemic and semantic fluency tasks; total of self-concept statements.
Takahashi et al. (2020) JAP	Experimental (single-blind randomised controlled) -	36 Mild-moderate AD[a] Care professionals	76.2 ± 9.8 (exp) 75.8 ±7.8 (control)	Evaluate the effects of ethanol with and without cedar extracts on caregiver burden, residents' responsive behaviours and cognitive function.	Exp. group was exposed to ethanol with cedar diffused in the living room and bedroom, and sprayed into clothing and bedding over eight weeks. Control was exposed to ethanol without cedar. Evaluation: pre-, after four weeks, and post-intervention.	OSIT-J[q]; NPI[p]; ZBI-J[x]; ADAS-cog[b].
Glachet et al. (2019) F	Quasi-experimental (non-randomised design; within-subject design) -	26 PwD[r] (exp.) 28 OP[n] (control) Mild AD[a]	72.69 (exp) 70.82 (control)	Assess the effect of odour exposure on the retrieval of recent and remote memories	Participants recalled two autobiographical memories related to childhood, adulthood and last five year in 1 free-odour and 1 odour (i.e. coffee) session.	MMSE[o]; Grober and Buschke's task; span tasks; HAD[l]; TEMPau[v].

Table 5.2 *(Continued)*

Authors & country	Study design & Setting	Sample	Mean/ range age	Study aims	Intervention procedure	Measures
Glachet & El Haj (2019) F	Quasi-experimental (non-randomised design) -	25 PwD[r] (exp.) 23 OP[n] (control) Mild AD[a]	82.04 ± 7.34 (exp) 80.91 ± 9.87 (control)	Explore the impact of olfactory cueing on autobiographic memories (i.e. arousal, valence, subjective reliving and specificity) and its relationship with depression	Participants recalled autobiographical memories in 1 free-odour and 1 odour session	MMSE[o]; HAD[l]; SAM[s]; Grober and Buschke's task; Subject reliving; TEMPau[v]
El Haj et al. (2018) F	Quasi-experimental (non-randomised design) -	28 PwD[r] (exp.) 30 OP[n] (control) Mild AD[a]	73.25 ± 6.71 (exp) 71.75 ±8.05 (control)	Compare the specificity, emotion, retrieval time of odour-, music-evoked and no sensory cueing autobiographical memories	Participants recounted 2 events after odour, music exposure, and control session. Between the two retrievals, an executive task was performed. Counterbalance session with a 3- to 5-day interval between sessions	MMSE[o]; Grober and Buschke's task; HAD[l]; Executive function: verbal fluency task, the Plus–Minus task, Stroop task; TEMPaus[v]; emotion and mental time travel rate Likert-scale; reaction time
Sulmont-Rossé et al. (2018) F	Quasi-experimental (non-randomised crossover design) Nursing home	32 PwD[r] Moderate to severe AD[a]	86.8 mean 75-98 range	Evaluate the impact of olfactory priming in food intake and eating behaviours	Participants took part in a total of (alternated) 2 control lunches and 2 primed lunches, every 2 weeks. Room odorization started 15 min before lunch and ended before serving the main course	MMSE[o]; Food intake: weighing plates pre, post consumption; proxy observation of resident's behaviours during lunch time

Table 5.2 *(Continued)*

Authors & Country	Study design & Setting	Sample	Mean/ range age	Study aims	Intervention procedure	Measures
Moorman Li et al. (2017) US	Quasi-experimental (pre- and post-design) Adult daycare centre	23 PwD[r] -	83 mean 73-97 range	Evaluate the effects of aromatherapy on restlessness/ wandering, agitation, anger, anxiety; comparison of age cohorts, gender, and behaviour frequency	Lavender oil was diffused in a room for 20 min twice a day (morning & mid-afternoon) for 2 months	Behaviour/Intervention Monthly Flow Record observation pre- (a 2-months) and post-intervention
Takeda et al. (2017) JAP	Quasi-experimental (non-randomised crossover design) Nursing home	19 PwD[r] Severe dementia -	80.7 ± 9.1	Evaluate the effects of aromatherapy on symptoms of sleep disturbance	The residents' pillows were wrapped for 20 days with a towel with no odour, followed by 20 days with a scented towel during the night	MMSE[o]; FIM[t]; times of going to bed and rising; NPI[p]; 24h sheet-type body vibrometer; sleep disturbances
Fu et al. (2013) AU	Experimental (single-blind randomised controlled) Long-term care facilities	67 PwD[r] 9 Mild 23 Moderate 29 Severe 29 dementia 16 AD[a] 3 VaD[w] 8 no diagnosis 5 other dementia	84 ± 6.36 61-93 range	Compare the effect of aromatherapy (oil spray), placebo (water spray) and a combination of aromatherapy and hand massage to reduce responsive behaviours	3 groups received a combination of aromatherapy & hand massage, or aromatherapy, or placebo control, twice a day 7 days a week for 6 weeks. Hand massage. Evaluation occurred at baseline, week 2-4-6, and post-test	MMSE[o]; CMAI-SF[d]

Table 5.2 *(Continued)*

Authors & Country	Study design & Setting	Sample	Mean/ range age	Study aims	Intervention procedure	Measures
Sakamato et al. (2012) JAP	Experimental (double-blind randomised controlled) Nursing homes	72 (exp) 73 (control) Moderate dementia -	84.2 ± 7.8 (exp) 84.1 ± 7.7 (control)	Investigate the effects of lavender on fall incidence in nursing home residents	24h olfactory stimulation from a lavender patch attached to the inside of the resident's clothes near the neck for 360 days	Number of resident falls; Barthel Index; MMSE[o]; CMAI[c] ; Vital Index; St. Thomas's Risk Assessment Tool in Falling Elderly Inpatients
Jimbo et al. (2009) JAP	Quasi-experimental (non-randomised crossover design) -	28 PwD[r] 21 Care professionals 9 Mild to moderate 19 Severe 17 AD[a] 3 VaD[w] 8 other dementia	86.1 ± 6.9	Assess the effect of aromatherapy on cognitive function	Aromatherapy in 2 rooms (morning & evening) for 28 days. The intervention was preceded by a control period of 28 days and followed by a 28-days wash out period (no intervention). Evaluation: pre-control condition, pre- and post-aromatherapy, post a wash out period	GBSS-J[k]; TDAS[u]; FAST[h]; HDS-R[m]; head computed tomography; blood analysis and biochemical examination; ZBI-J[x]
Lin et al. (2007) JAP	Experimental (crossover randomised design) Care homes	70 Moderate to severe 44 AD[a] 21 VaD[w] 5 other dementia	78.29 ± 4.06 69-89 range	Compare the effect of lavender aromatherapy with a control condition (sunflower odour)	Participants received both conditions which lasted 3 weeks each and were 2 weeks apart. 1h exposure to odour during sleep time at night. Evaluation: pre- post-intervention (week 0-3), pre-post control (week 5-8)	CMAI[c] Chinese version; CNPI[f]; CMMSE[e]

Table 5.2 *(Continued)*

Authors & Country	Study design & Setting	Sample	Mean/ range age	Study aims	Intervention procedure	Measures
Snow et al. (2004) US	Quasi experimental (non-randomised crossover design) Nursing homes	7 Severe dementia AD[a] -	-	Investigate effects of an essential oil on the frequency of agitated behaviours; participants' olfactory functions	Each participant had an absorbent fabric sachet with aroma [lavender (A) & thyme (B)] and no aroma oil [unscented grapeseed C)] pinned to their shirt near the collarbone every 3-h, for a total of three applications per day, over two weeks for each condition (total of ten weeks). The condition followed ABCBA order	CMAI[c]; SIRS[t]; olfactory functioning: identification (sniff and name task), discrimination (2-odours discrimination task); participants ' reactions (recorded verbatim in the above two tasks)
Gray & Clair (2002) US	Quasi-experimental (non-randomised crossover design) Care homes	13 -	-	Examine the effects of aromatherapy on the administration of medications (i.e. frequencies of resistive behaviours, time of administer medications, gender difference for frequency and time-administration)	20 min before morning medication administration, a cotton ball with essential oil (lavender vera, sweet orange or tea tree) or without aroma (control) was taped to the participants' lapel. Each of the four conditions was repeated in a random order 4 times for a total of 16 administrations	Video records for the duration of the medication administration

Table 5.2 *(Continued)*

Authors & Country	Study design & Setting	Sample	Mean/ range age	Study aims	Intervention procedure	Measures
Holmes et al. (2002) UK	Quasi-experimental (non-randomised crossover design) Long-term care facility	15 Severe dementia 4 AD[a] 7 VaD[w] 3 DLB[g] 1 FTD[j]	79 ± 6.3	Evaluate the effect of aromatherapy steam on agitated behaviour	Each participant was exposed for 2h (4-6 pm) in a communal area to a total of 5 odour and 5 placebo (water) sessions on alternate days, over a period of two weeks	Pittsburgh Agitation Scale
Smallwood et al. (2001) UK	Experimental design (single-blind randomised control design) Hospital	21 Severe dementia -	66.8 ± 11.5	Compare the impact of aromatherapy massage, plain oil massage and aromatherapy and conversation on responsive behaviours	Participants were randomly allocated in aromatherapy massage, or massage or aromatherapy intervention provided twice weekly	15 minutes video records 4 times a day twice during two-weeks at the baseline. Participants' behaviours were recorded after receiving intervention
Brooker et al. (1997) UK	Single case study Hospital	4 Severe dementia 2 AD[a] 1 AD[a] & Parkinson 1 FTD[j]	74-91 range	Evaluate the impact of aromatherapy, aromatherapy massage, massage only and no treatment on agitation.	Participants randomly received between 8-12 sessions of each four conditions (lavender oil delivered via fan; lavender and massage; massage; no treatment) over a 3-month period. Each session lasted 30 minutes	Agitation observation scale 1h after intervention, rated at 1-minute intervals

Table 5.2 *(Continued)*

Authors & Country	Study design & Setting	Sample	Mean/ range age	Study aims	Intervention procedure	Measures
Henry et al. (1994) UK	Quasi experimental (pre- and post-design) Hospital	9 Severe dementia -	-	Assess the effect of aromatherapy on the number of night time hours spent asleep	Each participant was exposed to lavender aromatherapy in the bedroom during the night. Over a seven-week period: two weeks sleep observation; the third week the lavender was diffused only in the female dormitory; the fourth week only in the male dormitory; the final three weeks in both dormitories	Total hour sleep: sleep observation between 12 am to 7.30 am at half hourly intervals

[a](AD) Alzheimer's Disease; [b](ADAS-cog) = Alzheimer's Disease Assessment Scale-Cognitive Subscale; [c](CMAI) = Cohen-Mansfield Agitation Inventory; [d](CMAI-SF) = Cohen-Mansfield Agitation Inventory Short Form; [e](DLB) = Dementia Lewy Body; [f](FAST) = Functional Assessment Staging Test; [g](FIM) = Functional Independence Measure; [h](FTD) = Frontotemporal Dementia; [i](GBSS-J) = The Gottfries, Bråne, Steen Scale; [j](HAD) = Hospital Anxiety and Depression Scale; [k](HDS-R) = Hasegawa's dementia scale; [l](OP) = Older People without a diagnosis of dementia; [m](MMSE) = Mini-Mental State Examination; [n](CMMSE) = Mini-Mental State Examination Chinese version; [o](CNPI) = Neuropsychiatric Inventory Chinese version; [p](NPI) = Neuropsychiatric Inventor; [q](OSIT-J) = Odor Stick Identification Test for Japanese; [r](PwD) = People with Dementia; [s](SAM) = Self-Assessment Manikin; [t](SIRS) = Severe Impairment Rating Scale; [u](TDAS) = Touch-panel type Dementia Assessment Scale; [v](TEMPau) = Test Episodique de Mémoire du Passé; [w](VaD) = Vascular Dementia; [x](ZBI-J) = Zarit Caregiver Burden Interview Japanese version.

Most of the studies (n = 12) included people with AD for a total of 427 participants (Fu et al., 2013; Holmes et al., 2002; El Haj et al., 2018; Glachet & El Haj, 2019, 2020a, 2020b; Glachet et al., 2019; Lin et al. 2007; Lipos et al., 2021; Snow et al., 2004; Sulmont-Rossé et al., 2018; Takahashi et al., 2020), whilst four included people with VaD with a total of 34 participants (Fu et al., 2013; Holmes et al. 2002; Jimbo et al., 2009; Lin et al., 2007), two included two people with FTD (Brooker et al., 1997; Holmes et al., 2002), and one included three participants with DLB (Holmes et al., 2002). Three studies included 'other dementias' for a total of ten participants. Subtypes of dementia were not provided in four studies (Henry et al., 1994; Gray & Clair, 2002; Smallwood et al., 2001; Takeda et al., 2017). Gray and Clair (2002) and Moorman Li et al. (2017) provided no information about participant stages and subtypes of dementia, although their participants did have a clinical diagnosis of dementia.

Among the 20 studies, eight used a control group composed of older people of similar age to those with dementia (n = 5) (El Haj et al., 2018; Glachet et al., 2019; Glachet & El Haj, 2019; 2020a, 2020b), people with dementia with the same demographic characteristics to the experimental group (n = 2) (Sakamoto et al., 2012; Takahashi et al., 2020), and older and young people (n = 1) (Lopis et al., 2021). Jimbo et al. (2009) and Takahashi et al. (2020) included health and care professionals and informal caregivers in their sample.

5.4.4 Olfactory stimuli

Across the 20 different studies, a total of 20 different olfactory materials were used. Table 5.3 summarises the odours used, study domains, and administration methods. The smells used were mainly pure, diluted, or in a mixture of two or more odours. Only a few studies reported information regarding concentration and dosage, as shown in Table 5.3.

The selection of olfactory materials was based on physical and physiological effects as reported by previous studies, or participants' responses such as odour preferences assessed pre-intervention (3 studies): Takeda et al. (2017) asked participants to select and express their preference for one of 3 oils presented; whereas Glachet and El Haj (2020a, 2020b) used olfactory items that were rated by participants as easy to detect and familiar. One study did not record the rationale for the smells chosen.

Lavender was the most commonly used scent. This essential oil was used in 13 studies primarily to reduce responsive behaviours (n = 8) (Brooker et al., 1997; Gray & Clair, 2002; Holmes et al., 2002; Fu et al., 2013; Lin et al., 2007; Moorman Li et al., 2017; Smallwood et al., 2001; Snow et al., 2004) such as agitation, falls (n = 1) (Sakamoto et al., 2012), or to improve sleep patterns (n = 2) (Henry et al., 1994; Takeda et al., 2017) or cognitive function (n = 1) (Jimbo et al., 2009).

Among these studies, two articles (Jimbo et al., 2009; Takeda et al., 2017) combined lavender oil with orange oil for their calming properties.

Orange and coffee were the next most common odours used. Coffee was used to explore and evaluate participants' autobiographic memories in five French studies (El Haj et al., 2018; Glachet & El Haj, 2020a, 2020b; Glachet et al., 2019; Lopis et al., 2021), suggesting that this is a distinctive smell which is likely to be associated with an individual's past. Orange was used for a variety of reasons, including eliciting memories (Glachet & El Haj, 2020a, 2020b), reducing responsive behaviours (Gray & Clair, 2002), increasing sleep (Takeda et al., 2017) and enhancing cognitive function (Jimbo et al., 2009).

Cinnamon was used in three studies aiming to elicit odour-evoked memories (Glachet & El Haj, 2019, 2020a, 2020b).

5.4.5 Olfactory administration methods

Olfactory stimuli were administered using a variety of methods and procedures across the studies as summarised in Table 5.3.

Table 5.3 Overview of the olfactory stimuli and administration methods

Domain	Study	Odours	Administration method & dosage
Autobiographical memory	Lopis et al. (2021)	Apple Coffee Fresh-cut grass Laundry	Inhalation - sniffing sticks
	Glachet & El Haj (2020a) - Glachet & El Haj (2020b)	Peach Orange Grass Cinnamon Chocolate Coffee Coconut	Inhalation - bottles scented oil
	Glachet et al. (2019)	Coffee	Inhalation - bottles scented oil
	Glachet & El Haj (2019)	Cinnamon	Inhalation - bottles scented oil
	El Haj et al. (2018)	Coffee Vanilla	Inhalation - bottles scented oil

Table 5.3 *(Continued)*

Domain	Study	Odours	Administration method & dosage
Responsive behaviour	Takahashi et al. (2020)	Ethanol with cedar leaves	Inhalation & Spray - wood (i.e. rattan) sticks (2.3 ml of distilled liquid delivered per day at room temperature) and spray type onto clothing and bedding a few times a day. Concentration: 20 gr of cedar leaves cut into 1 cm strips and added to 200 ml of a 20% ethanol solution. This solution was distilled to 50% ethanol at 60°C under a lowered pressure (170 hpa) with a rotary evaporator.
	Moorman Li et al. (2017)	Lavender	Inhalation - diffuser Diffuser in 1000 square feet in size and in a moderately open space for 20 min twice a day, once in the morning and once in the mid-afternoon. The estimated oil output ranges from 0.75 to 1.3 ml over 15 minutes.
	Fu et al. (2013)	Lavender (*Lavandula angustifolia*)	Spray - direct spray onto individuals' upper chest within a 30 cm distance. Concentration: A 3% lavender mist, consisting of 75 drops of pure 100% lavender oil was mixed with 4 ml essential oil solubilizer and 125 cc purified water.
	Lin et al. (2007)	Lavender (*Lavandula angustifolia*) Sunflower (control condition)	Inhalation - two diffusers A cotton pad with two drops of essential oil placed in each of the two diffusers positioned at each side of participant's pillow during sleep at night for at least 1 h. Concentration: Pure undiluted lavender

Table 5.3 *(Continued)*

Domain	Study	Odours	Administration method & dosage
	Snow et al. (2004)	Lavender (*Lavandula angustifolia*) Thyme oil (*Thymus vulgaris*) Unscented grapeseed oil	Fabric - sachet Two drops of pure undiluted oil placed on a 2 x 2-inch absorbent fabric sachet pinned to the front of each participant's shirt near the collarbone, every 3 hours for a total of three applications per day. Concentration: Pure undiluted oils
	Gray & Clair (2002)	Tea tree (*Melaleuca alternifolia*) Sweet orange (*Citrus aurantium*) Lavender (*Lavendulan officinalis*)	Fabric - cotton-ball placed over the mouth of a four-ounce oil bottle, and the bottle was inverted completely for no more than two seconds before it was returned to the upright position. The cotton-ball taped to the lapel of resident.
	Holmes et al. (2002)	Lavender	Inhalation - three aroma steam diffusers Concentration: 2% lavender
	Smallwood et al. (2001)	Lavender	Inhalation - diffuser
	Brooker et al. (1997)	Lavender	Inhalation - fan
Physical function	Sakamato et al. (2012)	Lavender	Paper patch (size: 1 cm x 2 cm) attached to the inside of the resident's clothes near the neck for 24 hours for 360 days.

Table 5.3 *(Continued)*

Domain	Study	Odours	Administration method & dosage
Eating behaviour	Sulmont-Rossé et al. (2018)	Meat odour “sauté de boeuf” (lit. “Beef stir-fry”)	Inhalation - diffusers Distributing in the room 90-s puffs every 30-s for the large diffuser and 30-s puffs every 30-s for the two small diffusers over 30 minutes.
Sleep	Takeda et al. (2017)	Japanese cypress, Virginian cedarwood cypress, pine oil blend True lavender True lavender - sweet orange	Fabric - pillow wrapped in a towel with essential oils. A range of 2 - 5 drops (0.1–0.25ml).
	Henry et al. (1994)	Lavender	Inhalation - electric fan The amount of essential oil varied: two drops (one at 10 pm & one at 3 am) in day 1; four drops at the same time in day 2; three drops in day 3 and subsequent nights.
Cognition	Jimbo et al. (2009)	Rosemary - lemon Lavender - orange	Inhalation - electric fan Concentration: A mixture of 0.04 ml lemon and 0.08 ml rosemary essential oil. A mixture of 0.08 mL lavender and 0.04 mL orange essential.

Inhalation

An inhalation method was used in fifteen studies. Among these, eight studies used diffuser tools, such as fans or steam diffusers (Brooker et al., 1997; Henry et al., 1994; Holmes et al., 2002; Jimbo et al., 2009; Lin et al., 2007; Moorman Li et al., 2017; Smallwood et al. 2001; Sulmont-Rossé et al., 2018).

Lin et al. (2007) placed two diffusers next to the participants' pillows for at least one hour during sleep at night. Similarly, Henry et al. (1994) diffused lavender oil in the participants' bedrooms overnight using an electric fan for four weeks. In another study, participants were exposed to a mixture of essential oils with stimulating properties (lemon and rosemary oil) for two hours in the morning and with calming properties (lavender and orange oils) for 90 minutes in the evening (Jimbo et al., 2009). Two other studies administered lavender oil twice a day. Moorman Li et al. (2017) diffused lavender for 20 minutes in a common area of a day care centre in the morning and once in the mid-afternoon. Smallwood et al. (2001) diffused the lavender oil in a room twice a week across four times during the day (before 10 am, 11 am, 2 pm, 3 pm) for a total of eight sessions over four weeks.

Lavender oil was diffused in participants' bedrooms for 30 minutes in 8-12 sessions over a three-month period (Brooker et al. 1997) and in a communal area for two hours in five sessions over two-weeks period (Holmes et al., 2002). Meat

aroma (“sauté de boeuf”, lit. “beef stir-fry”) was diffused in a nursing home’s dining room 15 minutes before lunch as olfactory priming for triggering food-related mental representations, aiming to stimulate appetite (Sulmont-Rossé et al., 2018).

Two studies used sniffing sticks (i.e. pens contain a fibre stick filled with scents) and reed diffuser (Lopis et al., 2021; Takahashi et al., 2020 respectively) and five studies used odour bottles (El Haj et al., 2018; Glachet et al., 2019; Glachet & El Haj, 2019, 2020a, 2020b). Participants were asked to place the bottles under their nose and breathe normally, whilst closing their eyes and mouth. This procedure was conducted when participants were asked to retrieve memories, self-related statements in response to the question “Who am I?” or think about future events.

Fabric and Patch

Sakamato et al. (2012) used a scent-infused lavender paper patch attached to the inside of the resident’s clothes near the neck for 24 hours for 360 days. A similar method of administration was used by Gray and Clair (2002). A scented cotton-ball was taped to the lapel of each resident 20 minutes before the morning medications for four days for each of the three odours used. Snow et al. (2004) applied lavender oil for two weeks and thyme oil for the following two weeks to an absorbent fabric sachet pinned to the front of each participant’s shirt near the collarbone, Takeda et al. (2017) applied essential oil to a towel wrapped around participants’ pillows for 20 days.

Spray

Sprays were used in two studies. In one, lavender, or water (control group) was sprayed directly onto individuals' skin on their upper chest (Fu et al., 2013). In the other study, the aroma was sprayed on participants' clothing and bedding a few times a day though the exact number of applications was not specified (Takahashi et al., 2020).

5.4.6 Olfactory functioning screening tools

Only eight studies conducted a screening of the participants' olfactory function pre-intervention. Takahashi et al. (2020) used a standardised tool, the Odor Stick Identification Test – Japanese version (OSIT-J) (Saito et al., 2006). This test is composed of 12 odours that are familiar to the Japanese population (e.g. rose, roasted garlic, wood, and Japanese cypress). For each scent, participants were asked to select the correct name of the stimulus sniffed (e.g. roasted garlic) from three possible alternative names, including the right answer (e.g. wood, coffee and roasted garlic). Other studies (Brooker et al. 1997; Gray & Clair, 2002; Sulmont-Rossé et al., 2018) recorded the participants' verbal and non-verbal reactions to the odours to assess whether they were able to perceive smells.

Snow et al. (2004) measured olfactory functioning using several approaches graded according to different levels of cognitive ability. In the olfactory identification task, participants were asked to choose the correct name of a smell

presented from three options. During the olfactory discrimination task, participants needed to determine whether two stimuli were the same or different. Finally, a verbatim record of participants' reactions was recorded when they were presented with the odorants (e.g. coffee, peanut butter, soap) in both tasks.

Two studies (Glachet and El Haj, 2020a, 2020b) asked their participants to self-assess their threshold and familiarity regarding seven odours (i.e. lemon, orange, grass, cinnamon, chocolate, coffee, coconut and peach) on a 5-point Likert scale ranging from 0 = "not at all" to 5 = "very well", whilst one study (Lopis et al., 2021) asked their participants to self-assess the quality of their own visual, auditory and olfactory sense on a 6-point Likert scale ranging from 0 (very poor) to 5 (perfect).

Those who scored nine or more incorrect items in the OSIT-J (Takahashi et al., 2020) or self-reported that they could not perceive odours (Brooker et al., 1997; Gray and Clair, 2002) were considered to have a poor sense of smell, and were excluded from the studies. In contrast, those with a poor sense of smell were included in Snow et al. (2004), Lopis et al. (2021), Glachet and El Haj (2020a, 2020b), and Sulmont-Rossé et al.'s (2018) studies.

5.4.7 Outcome measurements

The studies included in the review examined olfactory stimulation in relation to a variety of outcomes: responsive behaviour, cognitive function, balance, sleep, and

appetite. Responsive behaviours were assessed using standardised measurements such as the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994), the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, 1997) and the Pittsburgh Agitation Scale (PAS) (Rosen et al., 1994). Four studies evaluated the responsive behaviours of people with dementia using observational methods (e.g. video records or observation form such as Behaviour/Intervention Monthly Flow (MED-PASS Inc. and Heaton Resources, Dayton, OH).

Cognitive functions were measured using different standardised tools such as Alzheimer's Disease Assessment Scale-Cognitive Subscale (ADAS-cog) (Rosen et al., 1984), the Japanese version of the Gottfries, Bråne, Steen Scale (GBSS-J) (Homma et al., 1991); a touch-panel type Dementia Assessment Scale (TDAS) (Inoue et al., 2011); Functional Assessment Staging Test (FAST) (Sclan & Reisberg, 1992); Hasegawa's dementia scale (HDS-R) (Igarashi et al., 1995). Odour-evoked memories were assessed using Self-Assessment Manikin (SAM) (Lang, 1980); Test Episodique de Mémoire du Passé (TEMPau) (Piolino et al., 2002). El Haj et al. (2018) included an assessment of executive functions such as verbal fluency through a verbal fluency task, flexibility assessed by the Plus–Minus task, and inhibition measured by the Stroop task.

Various aspects of physical functioning were assessed. For example, food intake was measured by weighing plates before and after consumption and through

proxy observation of residents' behaviours during lunchtime. Balance was evaluated by calculating the total number of falls. The Barthel index was used to measure performance in activities of daily living e.g. personal care or mobility. Sleep patterns were assessed by measuring the total time spent sleeping and using a variety of approaches, including a 24h monitoring device sheet-type body vibrometer recording the activities of an individual lying on the mattress; times of going to bed and rising; sleep disturbance observations (sleep latency; difficulty maintaining sleep; the number of times of early morning awakening).

5.4.8 Study quality

Each study was assessed using the MMAT version 2018 (Hong et al., 2018). The key methodological issues in the RCT studies include poor quality and reporting of the randomisation process, participants' adherence to the study, comparability of the experimental and control group at baseline, and completeness of outcome data reported. In the majority of quantitative non-randomised studies, it was unclear whether the interventions were administered as intended and if confounders were considered in the design and analysis, due to a lack of information. Sources of possible bias identified in the single case study included in the review were lack of data presented in the paper and information on participants inclusion and exclusion criteria. For a summary of risk of bias see Appendix 3.

An overall quality score for each study was developed by rating each MMAT domain as 1 if the study reported appropriate information and as 0 (zero) if the domain was not met or if the information reported was unclear. The highest score was four and the lowest was one. Five out of 20 studies had a MMAT score of 2-star or less. The scores are presented in Table 5.4.

5.4.9 Intervention effects

The effects of olfactory stimulation in each of the domains investigated in the studies included in the review are discussed in detail below and summarised in Table 5.4.

Table 5.4 Summary of the research outcomes and quality assessments

References	Findings	MMAT
Lopis et al. (2021)	Higher number of memories were recalled by older people, followed by PwD[f] and young adult. Visual stimuli evoked significantly more ($p < .05$) and rarer ($p < .05$) memories than odours, and odours stimuli produced more memories than auditory stimuli in PwD[f]. No significant differences were found in emotional valence and vividness memories between groups and type of sensory stimuli. PwD[f] ($p = .01$) and older people ($p < .05$) rated their memories significantly more emotionally intense than the young adult group; no difference was found for the type of stimuli. PwD[f] evoked significantly more memories in the age between 0-18 ($p < .05$); no differences for type of stimuli and age were found.	***
Glachet & El Haj (2020a)	Significant increase in both groups in phenomenological characteristics of past and future (apart from specificity for control group) events after odour-exposure. Significantly shorter reaction time ($p = .001$) for past event in PwD[f] after odour exposure; Significantly shorter reaction time for the control group for past event (with or without odour, respectively $p = .01$ and $p = .005$) and future event (with odour) ($p = .03$).	***

Table 5.4 *(Continued)*

References	Findings	MMAT
Glachet & El Haj (2020b)	Significant increase of the number of self-related statements in odour condition compared to odour-free condition in PwD^{f} ($p < .001$) and control group ($p < .05$). Significant increase of psychological self-statements in odour condition for PwD^{f} ($p < .05$). No difference in social and physical statements in both condition and groups.	***
Takahashi et al. (2020)	Significant decreases ($p < 0.5$) in agitation, anxiety and irritability in the exp. group at four and eight weeks. No significant difference in cognitive function between the two groups. Significantly lower caregiver burden ($p < .05$).	*
Glachet et al. (2019)	Significant increase in number of childhood ($p < .05$), adulthood ($p < .01$) and recent ($p < .01$) memories after odour-exposure than without odour. PwD^{f} significantly retrieved more specificity childhood ($p < .01$), adulthood ($p < .01$) and recent ($p < .01$) memories after odour exposure compared to odour-free condition. Regarding the temporal gradient of memories, PwD^{f} produced more adulthood memories than childhood memories, and more childhood memories than recent memories with or without odour exposure.	***
Glachet & El Haj (2019)	Significantly higher arousal ($p < .01$), subjective reliving ($p < .05$), specificity ($p < .01$), and positive ($p < .01$) odour-evoked autobiographical memories than for memories evoked without odour only in PwD^{f}. Negative correlation between depression scores and emotional valence, arousal and subjective reliving in PwD^{f}.	***
El Haj et al. (2018)	Memories retrieved after odour and music exposure in PwD^{f} had higher specificity, emotional arousal, mental time travel, and shorter retrieval time than in the control condition. Retrieval time was much shorter after odour exposure than music exposure.	****
Sulmont-Rossé et al. (2018)	A significant effect of olfactory priming in meat food intake ($p = .04$). A positive effect in vegetable consumption ($p = .06$) compared to the control condition. Significant increase in residents' interest toward the meal in the primed lunch. This effect was no longer observed when the priming session was replicated two weeks later with the same priming odour and menu.	****

Table 5.4 *(Continued)*

References	Findings	MMAT
Moorman Li et al. (2017)	Non-significant reduction (p =.06) in the frequency of responsive behaviours pre- and post-intervention. In the analysis of individual responsive behaviours, significant decrease only for the frequency of agitation pre- and post-intervention. Participants in the 70-85 age cohort showed a significant decrease in agitation post-intervention then those ranging from age 86-100. There was no significant difference for effects of gender on any of the four behaviour responses investigated.	**
Takeda et al. (2017)	Total sleep time (p <.05) and sustained sleep period (p <.05) were significantly longer in the intervention period than in the control. Early morning waking in the intervention period was significantly less (p =.01) compared to that in the control. Total daytime sleep could not be adequately measured, and it was omitted from the analysis. No significant differences in other sleep measurements were observed.	****
Fu et al.(2013)	No significant effect was found following aromatherapy alone and aromatherapy combined with massage on participants' responsive behaviours.	****
Sakamato et al. (2012)	Fewer falls in the lavender group, significant decrease in CMAI[c] (p =.04) from baseline to 12-month follow-up. No difference between the two groups for any of the outcomes investigated.	***
Jimbo et al. (2009)	A significant improvement in four GBSS-J[e] items (p <.05) and TDAS[g] (p <.05) after aromatherapy. Participants with AD[a] showed significant improvement in total TDAS[g] scores (p <.01). Blood analysis and biochemical examination showed no significant changes. Results from ZBI-J[h] score showed no significant changes.	***
Lin et al. (2007)	Significant effects were found in CCMAI[b] (p <.001) and CNPI[d] (p <.001) after odour condition. Independent sub-analysis showed no significant difference on odour condition response based on gender and subtype of dementia.	***
Snow et al. (2004)	No significant treatment effects were found following the two odour conditions compared the control condition.	**
Holmes et al. (2002)	Nine residents (60%) showed an improvement, five (33%) showed no change and one participant (7%) showed a worsening of agitated behaviour during aromatherapy compared with placebo.	***
Gray & Clair (2002)	No significant difference in behaviours or duration of medication administration and gender influence across the four conditions.	**

Table 5.4 *(Continued)*

References	Findings	MMAT
Smallwood et al. (2001)	No significant difference between the treatments, although consistent reduction in agitation following the aromatherapy massage. Significant time difference occurred between 3-4pm between aromatherapy massage (p <.05) and only aromatherapy (p =.05).	***
Brooker et al. (1997)	Findings varied considerably between individuals. The observations showed benefit for two people only following just aromatherapy or massage. Other two participants reported an increase of agitation following all treatment conditions apart the aromatherapy-massage for one of them.	***
Henry et al. (1994)	A significant increase in the total of hours slept following aromatherapy (p <.01).	*

[a] (AD) = Alzheimer's Disease; [b] (CCMAI) = Cohen-Mansfield Agitation Inventory Chinese version; [c] (CMAI) = Cohen-Mansfield Agitation Inventory; [d] (CNPI) = Neuropsychiatric Inventory Chinese version; [e] (GBSS-J) = The Gottfries, Bråne, Steen Scale; [f] (PwD) = People with Dementia; [g] (TDAS) = Touch-panel type Dementia Assessment Scale; [h] (ZBI-J) = Zarit Caregiver Burden Interview Japanese version. Risk of bias: (*****) low; (****) or (***) moderate; (**) or (*) high.

Responsive behaviours

Mixed findings on the effect of olfactory stimulation on responsive behaviours were reported. Moorman Li et al. (2017) reported a significant decrease in the frequency of observed agitation following two months of odour exposure during activities in a day care centre. These improvements were not found in other domains observed (restlessness/wandering, anger, and anxiety). The decrease in agitation of people with dementia was significantly larger in participants aged 70-85 age compared to those aged 86-100. There was no gender difference in the results in all four domains.

Improvements in responsive behaviours, such as agitation, anxiety and irritability, were reported by Takahashi et al. (2020) in the experimental group after environmental exposure to an ethanol cleaning solution with added cedar fragrance and distilled solution with cedar sprayed on clothing and bedding, compared to the control group who were exposed to the ethanol solution without cedar fragrance.

Sakamoto et al. (2012) found a significant decrease in the CMAI score following a 12-month period of olfactory stimulation using a patch worn by residents in nursing homes. A significant decrease was also found in the NPI Chinese version (Choy et al., 2001) and CMAI scores after a three-week period of one hour of lavender exposure at night compared to the control condition i.e. the same procedure with sunflower oil (Lin et al., 2007). Sub-analysis showed no significant difference in odour condition response based on gender and subtype of dementia (i.e. AD and VaD).

Four studies did not report significant benefits after olfactory stimulation in people with dementia (Fu et al., 2013; Gray & Clair, 2002; Smallwood et al., 2001; Snow et al., 2004). Smallwood et al. (2001) administered lavender oil or a control oil either via a diffuser or massage, twice a week for four weeks. Analysis of video recordings of participants' motor behaviours after two aromatherapy treatments (diffuser or massage) and the placebo conditions found no significant differences

between the three groups. Snow et al. (2004) assessed the effect of an absorbent fabric administered via sachet for two different aromas and one with no aroma. The study followed an ABCBA intervention design (A=lavender oil, B = thyme oil, C = unscented grapeseed oil). Each intervention condition lasted two weeks, for a total of ten weeks. No statistical difference on the CMAI scale was reported across the three conditions.

No significant effects were found in Fu et al.'s (2013) study, which was assessed at moderate risk of bias. This used olfactory stimuli via oil spray on residents' upper chests, and compared this to aromatherapy hand massage and placebo (water spray). No significant improvements in CMAI-short version scores were reported at any point during the odour administration at five time points (pre-test, week 0; week 2; week 4; post-test, week 6; follow-up week 12). Gray and Clair (2002) examined the effects of an infused cotton-ball taped to the lapel of residents for 20 minutes, whilst medications were administered in terms of frequencies of resistive behaviours, time taken to administer medications, and gender difference. No significant differences occurred in behaviours, duration of medication administration and gender across four conditions: a cotton-ball without odour and with lavender, sweet orange, or tea tree. Each of the four conditions was repeated four times for a total of 16 administrations.

Mixed findings were reported in two studies (Brooker et al., 1997; Holmes et al., 2002). Brooker et al. (1997) reported that two participants had reduced agitation following the aromatherapy intervention whereas two other participants showed increased agitation. Similarly, Holmes et al. (2002) found that nine residents showed an improvement, five reported no change, and one participant had increased agitation following an aromatherapy intervention compared with a placebo. Taking into account the subtypes of dementia, three participants with AD showed positive benefit, one reported no change. Of the seven participants with VaD five showed improvement and two showed no change. Of the three people with a diagnosis of DLB two showed no change, one person worsened, and the only participant with FTD showed reduced agitation.

Autobiographical memory

Five studies reported that smell is an effective cue for triggering autobiographic memories with one suggesting that it can facilitate future thinking (the capacity to project oneself into the future) (El Haj et al., 2018; Glachet et al., 2019; Glachet & El Haj, 2019; 2020a; Lopis et al., 2021). All these studies compared the participants' responses following one session of odour exposure and one session with no odour (control condition), apart from Lopis et al. (2021) who conducted a session using pictures as a comparison to the olfactory stimuli and El Haj et al.

(2018) who conducted three sessions: odour exposure, music exposure, and control condition.

Glachet and El Haj (2019) found that odour-evoked memories were more positive, specific, vivid, and associated with higher emotional arousal compared to memories triggered in the odour-free condition. Additionally, El Haj et al. (2018) found that odour-evoked autobiographical memories had a shorter retrieval time compared to memories triggered following music exposure. Similar findings were reported in a study (Glachet & El Haj, 2020a) that evaluated the effect of odour exposure on past events and future thinking. Participants exposed to the odour condition reported past and future events which were associated with higher specificity, arousal and emotional valence, and shorter retrieval time for past events but not for future events which was found only in the control group.

Glachet et al. (2019) also reported that olfactory stimuli triggered a significantly higher number of recent (i.e. last five years) and remote (childhood, adulthood) memories compared to an odour-free condition. While a more recent study (Lopis et al., 2021) comparing the impact of odour, auditory and visual cues in retrieval of autobiographic memories found that visual stimuli led to recall of more and rarer memories and overall, a better retrieval performance across auditory and odour stimuli. Furthermore, odour-evoked memories were not significantly more emotional than those recalled following pictures or sounds.

Cognitive function

Mixed results were reported on the benefits of olfactory stimulation on cognitive functions in people with mild to moderate dementia, with one study showing positive effects (Jimbo et al., 2009) and one no effects (Takahashi et al., 2020).

Jimbo et al. (2009) investigated the effect on cognitive functions after exposure to two odour mixtures combining stimulating and calming pharmacological properties in the morning and evening. The results showed a significant improvement in the scores of four GBSS-J items and the overall score of TDAS. Interestingly, participants with a diagnosis of AD greatly improved in the TDAS ($p < 0.01$) compared to the other participants. In contrast, no significant difference in ADAS-cog was found in Takahashi et al.'s study (2020) between the control and experimental group.

Self-concept

Glachet and El Haj (2020b) evaluated the role of smell as a cue to enhance the retrieval of self-related knowledge (i.e. self-concept). It includes the psychological, physical and social self-related mental representations about who we are (e.g. traits, beliefs, values, social status, roles and physical attributes) and includes cognitive and affective judgments about ourselves. The authors reported that participants exposed to the odour condition generated significantly more self-related statements in response to the question "Who am I?" compared to the

odour-free condition. In particular, smells triggered more self-statements associated with the psychological dimensions of the self.

Sleep

Two studies supported the use of olfactory stimulation to reduce sleep disturbance in people with severe dementia. Henry et al. (1994) found a significant increase in total hours slept after four weeks of exposure to a room odour overnight compared to an odour-free condition. Takeda et al. (2017) reported a significant effect when using aromatherapy overnight, including longer total sleep duration, sustained sleep period, and less early morning waking. Sleep patterns and residents' behaviours were measured by comparing the data from the NPI and a 24-hour sheet-type body vibrometer collected during the 20 days when the resident's pillow was wrapped in a towel without oil (control condition) and the following 20 days when the essential oil was introduced to the pillow surface.

Appetite

One study assessed the effect of olfactory stimulation on food intake (Sulmont-Rossé et al., 2018), in which participants were exposed to a meat odour in the dining room for 15 minutes before serving the main course during two lunches that were alternated with the control condition (two scent-free lunches). A significant effect of the olfactory priming was found with a 25% increase in meat consumption, and an increase in vegetable consumption approaching significance

compared to the control condition. Behavioural measurements also showed a significant increase in residents' interest in the meal in the scent-primed lunch condition. However, this effect was no longer observed when the intervention was replicated two weeks later with the same priming odour and the same menu.

Balance

Positive results were found in the only study in this review focusing on the effect of smells on physical functioning. Sakamato et al. (2012) reported that nursing home residents who wore a lavender patch for almost a year experienced fewer falls and adverse events compared to those who did not wear a patch.

5.5 Discussion

A total of twenty studies were included in this review, exploring the effects of olfactory stimulation in relation to three main domains: responsive behaviour, cognitive functions, and physical functioning, including sleep, appetite, and balance.

In line with previous reviews (e.g. Ball et al., 2020), the findings from the current review showed that olfactory interventions were not associated consistently with decreasing frequency of responsive behaviours for people with dementia exposed to the olfactory stimulation. These findings arose from ten studies included in the review assessing responsive behaviours, among which four reported positive

outcomes, four found no significant effect of olfactory stimulation, and the effects observed in two studies reported variable responses. The extent to which olfactory intervention could improve cognitive functioning is unclear due to mixed findings, limited evidence and quality of some studies.

The current review confirms olfactory stimuli as effective cues to stimulate positive, emotional, specific and less considered autobiographic memories in people with dementia. Glachet and El Haj (2020b) demonstrated that odour exposure can positively impact self-related knowledge (self-concept). The findings of the present review suggest that olfactory stimuli could play a role in supporting the identity of people with dementia as they enhance autobiographic memories and access to self-concept.

A surprisingly limited body of evidence was found on the impact of olfactory stimulation on physical functioning, such as sleep, food intake and balance. This is despite literature stating that smell cues can modify eating behaviours (Zoon et al., 2016), enhance sleep patterns (Velasco-Rodríguez et al., 2019), and improve balance and postural control (Freeman et al., 2009). Although limited, the current review provides evidence of the benefit on the total and sustained hours slept of people with dementia following overnight odour exposure for 3-4 weeks. A significant odour priming effect was found for food intake. However, the increase in meat and vegetable consumption observed was not noted on the second exposure

to the same odour priming after 2 weeks (Sulmont-Rossé et al., 2018). Authors suggested several explanations for this finding that should be further explored, such as changes on olfactory functioning over time, the exact odour exposure time and habituation effect. One study measured the impact of olfactory stimulation on balance and reported a significant effect following prolonged exposure to the olfactory stimulus.

Overall, the encouraging results found on physical functioning suggests that there continues to be a need for further research to assess the effect of olfactory stimulation in relation to these relevant areas. Evidence suggests that sleep disturbances, common in all types of dementias, are often managed with sedative medications which are associated with high risk for side effects (Deschenes & McCurry, 2009; Ooms & Ju, 2016). Falls are associated with poor functioning and mortality (Becker & Rapp, 2010) and eating disorders such as weight loss with malnutrition (Liu et al., 2014).

The various outcomes reported were evaluated through quantitative studies, which surprisingly constituted the only sources of evidence of olfactory stimulation in dementia care. While quantitative research is particularly useful to investigate outcome effects, there are some limitations to consider when applied in dementia research on olfactory intervention. For example, quantitative methods do not enable capture of participants' perspectives on the nature of change and positive

effects that are likely to occur ‘in the moment’ at the verbal and non-verbal level (Webb et al., 2020). Furthermore, as most people with severe dementia might present communication difficulties, observational measures may be helpful to investigate the potential role of olfactory stimuli in dementia care. Non-invasive physiological measures such as skin conductance or cardiovascular response using new technologies and instruments could also provide valuable information about the experience of people with dementia participating in olfactory intervention (Walker et al., 2021). Qualitative or mixed methods designs could extend the quantitative findings by offering insights into the participants’ olfactory experiences.

The included studies varied greatly in terms of administration methods, procedures, and outcomes. The high heterogeneity found in the intervention protocols and the limited number of studies for each outcome (i.e. sleep, food intake, cognitive function, balance) made comparisons between the studies difficult. There is some evidence that different approaches used to administer olfactory stimuli may lead to different outcomes. Among the three studies that did not report significant improvements in responsive behaviour, scent-infused fabric, or body oil spray was used. These application methods might be associated with habituation effects, that is a decrease in individual’s response due to the continual and long exposure to an odour. Continuous exposure to an odour, for example in

the same environment, reduced the perceived strength of that odour over time (Pellegrino et al., 2017). This means that fragrance-infused fabric attached to clothing, or fragrance applied to the skin might eventually no longer be perceived by the wearer, if the habituation effect is not controlled by, for instance, presenting the odour at varying intervals. Other factors such as the source, grade, valence, and dilution of olfactory stimuli might have potential implications in the habituation effect (Pellegrino et al., 2017), affecting the success of the interventions. In this review, inferences regarding the habituation effect and odour concentration on the outcomes could not be made due to the limited information reported by the included studies.

It remains unclear if other factors, such as the number of sessions and the length of interventions, might play a role in the reported outcomes. Repeated and prolonged odour exposure (e.g. every day for almost one year) were associated with positive outcomes. There is evidence showing that olfactory sensitivity is greatly reduced following 20 minutes of constant exposure, and dramatically diminished if the odour is encountered throughout the day (Dalton & Wysocki, 1996; Stuck et al., 2014). Nevertheless, there is also evidence to suggest that olfactory stimuli at subthreshold levels (unconscious perception) may influence behaviour and responses to the surrounding environment (Dalton et al., 2000). Further research is needed to draw firm conclusions about the most appropriate

smell administration methods for people with dementia and to identify other factors influencing the outcomes.

Regarding olfactory stimuli, the majority of studies used lavender oil to reduce responsive behaviours. Lavender has a long history of medicinal use and has been employed for its sedative and calming properties (Cavanagh & Wilkinson, 2002; Wilcock, 2006; Sayorwan et al., 2012). Although it has been widely used in olfactory stimulation, specific pharmacological effects of lavender aromatherapy are difficult to distinguish from any innate or learned preference for this scent (Bradley et al., 2009). This may also explain the mixed results observed in the studies included. It is worth noting that a limited number of different odours were used within the same study (a maximum of seven in one study). This means that some outcomes may be attributed to the specific odour and conditions in the experiment.

Among the studies included only three considered the participants' smell preferences and familiarity. Smell preference and past experience create the framework upon which response to odour takes place (Herz, 2016). This is particularly relevant in the context of triggering autobiographic memories or behaviour change. Inter-individual characteristics can modulate the degree to which odours elicit responses. Therefore, it could be expected that stage and subtype of dementia as well as individual olfactory function may influence the

outcomes. The majority of the studies included people with AD and VaD. There were very few studies involving people with FTD and DLB; so, there is currently limited evidence as to what extent olfactory stimulation may be useful for these groups and whether the subtype of dementia could be relevant to outcomes.

Although people with dementia may present an impaired sense of smell, only eight studies assessed the participants' olfactory functioning. It was therefore unclear to what extent participants had an olfactory experience or indeed if they could perceive the odours at all. Olfactory screening at baseline can increase certainty that the participants are able to perceive the smells presented. Standardised screening tests, such as smell identification tasks, might present practical limitations when used with people with dementia who often present communication difficulties (e.g. aphasia), especially in the later stage of the disease. The recording via observation of participants' verbal and non-verbal reactions to smells present an alternative way to screen the olfactory functioning of people with dementia. However, due to the large inter-individual variability of people's responses this method might lack standardisation. Future studies should investigate the best methods to investigate olfactory screening.

The encouraging results found in the present review suggest that olfactory exposure might be considered a potentially effective non-pharmacological intervention for people with dementia and indicate several directions for future

research. Due to the diversity of approaches used and the methodological limitations, it was not possible to draw any clear conclusion about the efficacy of olfactory stimulation. Inferences on the effects of different types of olfactory stimuli and the way in which they are administered were limited by the lack of information reported by the studies. A systematic and clear reporting of evidence could enable conclusions and procedures to be tested and would inform future research and clinical practice.

Given the variety of procedures used to stimulate the olfactory sense it is important that protocol-driven decisions, processes, and findings are clearly and transparently reported. Several checklists and guides have been developed to improve intervention reporting, such as the 12-item Template for Intervention Description and Replication (TIDieR) (Campbell et al., 2018). In aiming to support evidence synthesis and achieve consistency in the reporting of studies, a list of recommended minimum reporting items for olfactory intervention studies has been created (Table 5.5), which can be used alongside the well-established checklists.

The proposed minimum reporting items aims to maximise both uptake and impact of future research, as well as enhancing systematic investigation and reporting. This will enable more robust findings and conclusions about olfactory stimulation interventions and help to inform future clinical practice.

Table 5.5 Recommended minimum reporting items for describing the procedure and materials used in olfactory interventions

Item	Item description
Administration method	Provide a description on how olfactory stimulation was implemented. For example: • Describe who administrated the intervention and any person responsible for monitoring. Provide information of training and expertise of intervention provider • Describe and provide the reason for the administration methods used (bottle, diffuser, patch) • Other materials or resources provided as part of the olfactory stimulation (e.g. pictures, objects), if applicable • Describe how the smell is introduced to the participants. Provide information on whether the smell is described or named • Provide information on the dosage • Describe any strategy to control or reduce habituation effect • Describe the size of the surface where the odour is applied, if applicable
Olfactory stimuli	Describe how and the reason for selection of the olfactory materials, and their features. For example: • Compounds (pure, diluted, or mixed) • Concentration • Odour evaporation characteristics • Where relevant, describe physical characteristics of the sources containing the odour (size, decorations, labels or logos)
Frequency and duration	Describe when the olfactory stimulus was administered, duration, and if applicable, number of stimulations.

5.6 Strengths and limitations of this review

The review has benefitted from the inclusion of a range of study designs and methods that provided an overview of the field, and a rich source of data on olfactory interventions and their effects. As mentioned in the exclusion criteria in

Section 5.3.1, studies where olfactory stimuli were used in combination with other sensory activities or massage were excluded from the review. This strengthened the research results by reducing the risk that any positive findings identified could be related to variables other than olfactory stimulation. From a methodological viewpoint, the quality of this review was enhanced by developing a formal review protocol and registration. The screening, eligibility process and methodological quality appraisal were made by two independent reviewers thus minimising the risk of selection bias and providing transparency in the formulation of the findings.

There are some limitations in this review. Only studies published in English were included. While there were positives to a single-reviewer approach with verification of a subset of articles by the second reviewer, such as reducing the time and streamlining the review process, this approach may leave the review open to bias and errors. The inclusion criteria could have neglected some important information. In particular, the decision to exclude studies that used touch or massage alongside olfactory stimuli was made to exclude contamination of purely olfactory effects by tactile stimulation. However, doing so means that this review could not explore the interaction of different forms of olfactory stimulation. Finally, publication bias could have affected the overall conclusions. It is recognised that studies with negative results are often unreported, which consequently may misinform the review's conclusions (Mlinarić et al., 2017).

5.7 Conclusion and recommendation for future research

This review has shown a wide variety of intervention approaches and limited information regarding the interventions, which made it challenging to draw firm conclusions. Despite the heterogeneity of methods in the included papers, the results of the included studies are generally in favour of the use of olfactory stimulation.

The use of olfactory stimulation interventions in dementia care is an emerging area of research warranting attention, since current data suggests that smells may promote physical health, cognitive and behavioural changes, with minimal or no adverse events (Ball et al., 2020). Given that smells trigger positive emotional and autobiographic memories, olfactory stimulation might be useful to improve the quality of life and well-being of people with dementia and those who care for them.

Future research should systematically investigate the conflicting outcomes reported, by clarifying why and how olfactory stimulation works. To this aim, high methodological quality of studies and detailed research protocols are required to allow examination of similarities and differences and to compare effects are recommended. This should be aided by the proposed minimum reporting items listed in Table 5.5.

Qualitative investigations could provide further insights into the experience of olfactory stimulation and any factors associated with positive outcomes.

Previous experience, preference and cultural context play a relevant role in how people perceive odours and in predicting individuals' responses. Therefore, further studies should take these factors into account (Herz, 2016). Finally, olfactory stimulation effects on those with different types of dementia should be investigated. This is because dementias affect the olfactory system differently (Alves et al., 2014; Olofsson et al., 2021), and olfactory stimulation effects would be expected to differ.

5.8 Summary and implications for MSI development

This review has showed promising results to support further investigation of olfactory stimulation as a non-pharmacological intervention for people with dementia. Although the review did not identify the 'best practice' in olfactory stimulation, key methodological considerations were recognised providing useful guidance for the design of MSI for people with dementia. For instance, in the development of MSI, attention should be paid to selecting the administration method and procedure. If habituation effects are not taken into account, repeated exposure to a stimulus can progressively reduce the perception to odours, thus modifying the individual's response. With regards to the olfactory materials,

understanding an individual's characteristics and preferences could allow the intervention to be tailored for each person and thus maximise its benefit.

The review also highlighted that participants were often considered as passive recipients of the olfactory stimulation, rather than active contributors to the intervention process. Most of the studies involved the introduction of smells into the environment, such as in a living room or bedroom, and focused on the clinical outcomes. Only a few studies asked participants to report their emotion or memories in response to smells. However, it is important to note that these studies followed an experimental protocol, which focused on assessing the features of the information reported rather than capturing the experience of people living with dementia who took part in the olfactory stimulation. This highlights a gap in the literature regarding the development of interventions focusing on the experience of people with dementia when engaging in olfactory stimulation as active contributors of the dynamic and interactive process underpinning olfactory interventions.

The findings of this review promote a better understanding of the outcomes associated with olfactory intervention and the potential benefits for people with dementia. Based on this, the findings of this review have been the starting point for further exploration of why and how observed positive outcomes may occur, as well as subsequent variations in the intervention results. These are discussed in Chapter 6, which presents the findings of a realist review of olfactory stimulation.

CHAPTER 6 REALIST REVIEW OF OLFACTORY INTERVENTIONS

This chapter builds on an earlier synthesis of olfactory stimulation (see Chapter 5) and moves beyond efficacy and descriptive accounts to uncover the explanatory mechanisms and context through which olfactory interventions may generate changes in people with dementia living in care homes. As part of the MRC 'identify and develop theory' step, this study sought to further consolidate the theory underpinning the MSI. It does so by exploring and extending the evidence on the mechanisms by which olfactory intervention might achieve the intended outcomes. In this chapter a realist review approach was employed to understand why, how and in what circumstances olfactory interventions may work. The chapter describes the iterative process undertaken within the review methods and the results. It describes how this process has helped to identify the underlying potential causal explanations that may underpin olfactory interventions for people with dementia living in care homes.

6.1 Introduction

The evidence of olfactory intervention efficacy and recommendations for its implementation are limited (e.g. Ball et al., 2020; Bowles et al., 2005). The rapid review in Chapter 5 identifies its potential in dementia care, such as enhancing

positive behaviours, cognition, and physical functioning changes such as improvement in the appetite, balance, and sleep. Chapter 5 also describes the inconsistencies in the findings and difficulties in comparing and synthesising the current evidence to identify 'key ingredients' or components that might influence the intervention's effectiveness. Following this, further investigation is needed to fully elucidate the underpinning causal mechanisms and processes mediating the effectiveness of olfactory interventions.

Realist review methodology was adopted as the most appropriate approach for this investigation. It supports the building of explanations of what works for whom, how, and why complex interventions achieve an observed outcome (Pawson et al., 2005). Furthermore, realist inquiry takes into account several contextual influences. This is particularly relevant considering the variability of the population under investigation (in terms of severity, type of dementia, and the person's age), the heterogeneity of olfactory intervention protocols, the numerous factors modulating the odour responses (e.g. culture, previous experience), and the complexity of health and social care settings such as care homes.

An understanding of how an intervention achieves the intended or observed outcomes, and any barriers and facilitators for success provides relevant information to inform and direct the further development and evaluation of an intervention (Fletcher et al., 2016) as well as potentially providing an explanation

of the mixed findings observed within the rapid review (Chapter 5) and other syntheses of literature (e.g. Ball et al., 2020).

The logic and the purpose of realist review focused on assessing the literature by looking for explanations and generating explicit descriptions or a 'programme theory' (Wong et al., 2013a). A programme theory refers to an explicit model or theory describing the underlying assumptions about how an intervention is meant to work and achieve its objective(s) (Pawson et al., 2005). The starting point of the realist review is to articulate an Initial Rough Programme Theory (IRPT) (Pawson et al., 2004; Wong et al., 2013b). The IRPT is the initial sketch of a theory which becomes the object of the inquiry (Wong et al., 2013a). The IRPT is revised and refined during an iterative process of seeking new information to support the causal explanations until they ultimately become a refined programme theory. Potential causal explanations are generated by exploring the interactions between the context (C) within which the olfactory intervention is provided, the underlying mechanisms (M) (resources and reasoning) triggered by the intervention, and the intended outcomes (O). This dynamic relationship and interaction are captured within the Context-Mechanism-Outcome (CMO) configurations (Wong et al., 2013b).

Due to time constraints, the realist review focused on developing IRPT using a systematic and transparent approach as recommended by Realist and Meta-

narrative Evidence Syntheses: Evolving Standards (RAMESES) guidance on the organisation and reporting of realist review (Wong, et al., 2013b). Following the realist explanatory approach, this study therefore aimed to examine the underpinning mechanisms and identify the underlying assumptions by which olfactory interventions might achieve desired outcomes with people with dementia living in care homes. Considering the role of contextual factors in supporting and mediating the causal mechanisms, some mechanisms and outcomes may be context-specific. Therefore, this study limited the investigation to a care home setting. The decision was made because: (1) care homes are of particular interest to the overall aim of this study to design a multi-sensory stimulation intervention for this setting (see Section 3.2); (2) care homes, day care centres and hospitals are settings too diverse to be assessed within one review.

To help the reader navigate through the realist terminology used in this chapter, the Glossary (p. xxxi) provides definitions of the key terms for realist review.

6.2 Aims and Objectives

6.2.1 Aims

To develop an initial theoretical understanding of how, why, and in what circumstances olfactory interventions can produce intended outcomes in people with dementia living in care homes and care professionals.

6.2.2 Objectives

- To identify mechanisms that could be considered the active ingredients associated with olfactory stimulation outcomes for care home residents and care professionals.
- To map how these mechanisms are associated with the outcomes.
- To determine the characteristics of participants and contexts that could be considered as barriers and facilitators of olfactory stimulation implementation.
- To explore under what circumstance key features of olfactory interventions (mechanisms) produce desired outcomes for people with dementia.

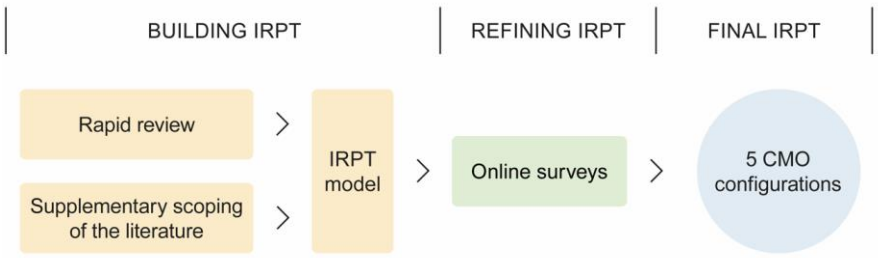
6.3 Methods

Programme theory development includes an iterative process, with several stages and sub-stages characterised by the constant process of seeking evidence, comparing, integrating, making-decisions, and synthesising (Wong et al., 2013a). The stages undertaken were adapted from Cooper et al. (2020). This included a phase that involves building the theoretical framework by searching for relevant evidence and synthesising the phenomena and key factors supporting the intended outcomes, with a particular focus on identifying underlying assumptions and theories. This process led to the articulation of an IRPT. The IRPT was refined through stakeholders' responses to online surveys aiming to explore the

participants theories on how the intervention works and their opinions about the IRPT.

Given the complex and iterative nature of realist review, each phase and the procedures undertaken are summarised in Figure 6.1 and presented below in a linear fashion to enhance clarity.

Figure 6.1 Realist review procedure



6.3.1 Phase 1 - Building IRPT from the literature

To investigate the conceptual landscape of olfactory interventions, the results of the rapid review (Chapter 5) were used alongside a supplementary scoping of the literature to ensure all relevant evidence, such as aromatherapy massage studies, were included to build the programme theory.

The included studies were used to clarify the programme intended outcomes and as a sampling framework to examine the theoretical foundations and any

suggested underpinning mechanisms that explain how, why and in what circumstances the intervention works in practice. In addition to these, the information obtained from the literature at this stage served to articulate an initial model of the programme components and their relationships, and to identify any aspects of the programme that required further investigation with the stakeholder group.

6.3.1.1 Rapid review

As discussed in Chapter 5, the objectives of the rapid review were to identify and map the existing literature on olfactory interventions for people with dementia. In particular, the rapid review aimed to uncover the content and nature of the interventions, the intended pattern of outcomes, and the circumstances or context under which each intervention has been used. For realist purposes, the underpinning theoretical foundations of each study were extracted (Rycroft-Malone et al., 2012). A description of the data extraction process is provided in Section 6.3.1.3. A full description of the search strategy of the rapid review can be found in Section 5.3.

6.3.1.2 Supplementary scoping of the literature

In keeping with the realist inquiry, an inclusive approach was taken at this stage. Studies that did not fulfil the inclusion criteria of the rapid review were screened and included if they provided information and/or theoretical discussion which could

contribute to the understanding of the conceptual and theoretical landscape of the intervention, and how it is supposed to work (Rycroft-Malone et al., 2014; Wong et al., 2013a). To ensure that the literature had been adequately summarised, a complementary search was conducted, including forward and backward citation tracking, and two additional databases searched (details of the search strategies are provided in Table 6.1). Throughout the review, a set of articles from the author's prior knowledge were included when relevant, for instance if they contributed to challenging or supporting the data extracted. Researchers existing knowledge and contacting experts and stakeholders for evidence have been widely used in realist review (e.g. Bender et al., 2021; Pearson et al., 2015; Weetman et al., 2019) to identify resources that would otherwise be missed with protocol driven search strategies (Greenhalgh & Peacock, 2005).

Table 6.1 Databases and search terms supplementary scoping of the literature

Database searched	Search	Terms
CINAHL PsycINFO MEDLINE PsycARTICLES Academic Search Elite Art Full Text	#1	Aromatherapy OR essential oil* OR aroma therapy OR olfactory stimulation OR olfactory OR smell OR scent OR perfume OR odor* OR odour* OR aroma*
	#2	Care home OR residential care OR nursing home OR residential home OR long term care
	#3	Dement* OR alzheim* OR mixed dementia* OR vascular dementia OR Lewy Body
	#4	Care staff or caregiver* or care professional*
		(#1 AND #2 AND #3) (#1 AND #2 AND #4)

6.3.1.3 Data extraction and quality appraisal

Studies were carefully read to identify theories, frameworks, models, and any explanations of the causal chains by which olfactory interventions can achieve the studied outcomes. Data were extracted by including excerpts from journal articles or a summary of underlying assumptions and theoretical framework within a particular study or group of studies. The information extracted was tabulated in an Excel spreadsheet. This also included data on: type of source (e.g. review or study), study reference, information on settings, facilitator, and sample characteristics (subtype and severity of dementia), summary of salient results, underlying assumptions and theoretical framework articulated in the study(ies). The same attention was given to study outcomes as well as explanations by the study authors. In the realist review, the latter provide a rich source of data to investigate how the intervention is supposed to work or not (Bunn et al., 2018).

In contrast with other syntheses e.g. systematic reviews, rigour and relevance are used as the quality appraisal criteria for realist review. Due to the explorative nature of the IRPT building process, papers were included regardless of their design and methods. However, the relevance of the papers was examined in relation to the purpose of study as to whether they contributed to developing the IRPT. The question ‘Does it contribute to theory building?’ was used to guide the

appraisal of the evidence. Irrelevant studies and systematic reviews that did not provide relevant or new information were excluded.

6.3.1.4 Analysis and synthesis process

Constructing the IRPT used Wong et al.'s (2013b) strategy, working backward from the specific intended outcomes. This means that the studies were critically revised by asking questions such as 'why' and 'how' the pre-identified outcomes were achieved to gain a preliminary understanding of what the main generative causations are. The data extracted were deconstructed, where possible, in the form of explanatory 'if-then' statements about what might support olfactory intervention outcomes for care home residents. 'If-then' statements contain often implicit references to the potential context and mechanisms underpinning the intervention (Bunn et al., 2018). To reduce potential bias, the explanatory statements were presented and discussed with the supervisory team and then used to develop the IRPT, which was presented to key stakeholders in Phase 2 described in the following section. The IRPT is illustrated in Figure 6.3 in Section 6.4.1 of the Results.

6.3.2 Phase 2 - Stakeholders' perspectives

This stage of the study involved testing and refining the IRPT against primary data representing the perspectives of stakeholders. In response to the global pandemic, a digital research method was employed for the study, including online surveys.

The stakeholder involvement served four key purposes within the research: (1) exploring the key informants' assumptions about olfactory stimulation, including what were considered essential components of the intervention, how it was thought to work and on what outcomes; (2) informing and refining understanding of the theories underpinning the intervention; (3) maintaining relevance and accuracy to practice; (4) enhancing transparency of the method and process employed to generate the emerging ideas about the interventions.

Ethical approval was granted for this research from University of West London Biomedical Sciences Committee (Ref: UWL/REC/CNMH-00735, 24/07/20).

6.3.2.1 Sample

A purposive sample was employed to ensure that people with relevant experience and expertise were included. Experts on dementia and olfaction were included in the study. In line with the study's philosophical position (Section 3.3), multiple points of views could potentially contribute to developing a comprehensive understanding of the underlying intervention components (Manzano, 2016).

The number of stakeholders recruited was guided by the need to include a heterogeneous sample for exploring the initial model but not too large to be unmanageable within the study timeframe. From a methodological point of view, the sampling method for this study did not rely on the conventional concept of saturation. The reasoning for this is that IRPT is not confirmed or rejected

exclusively through primary data but through an iterative process including multiple data sources such as published studies (Manzano, 2016).

6.3.2.2 Participant recruitment

A group of potential stakeholders was identified based on their experience and expertise in olfaction and/or dementia care and invited to participate in the study through email correspondence. The email included preliminary information about the research and a link to access a participant information sheet and consent form.

Informed consent

Participants were provided with the complete details of the study (via participant information sheet) before data collection commenced. The participant information sheets included contact information, study aims, data collection procedure, potential benefits and risks, and steps taken to maintain anonymity and confidentiality of the participants, written in language accessible for a non-expert audience (Appendix 4). This ensured that the participants were fully informed to make a decision on whether or not to participate in the research and had the opportunities to ask for further information.

Informed consent was sought using electronic methods (i.e. eConsent) which included a typed name and tick box declarations as explicit consent agreement (Appendix 5) (Health Research Authority and Medicines and Healthcare products Regulatory Agency, 2018). Once participants had consented, a link to initiate the

online survey was provided. Participants were excluded from the study if they did not complete the full survey. This ensured that participants' withdrawal rights were respected as it may not have been clear whether the participant intended intentionally to withdraw from the online survey by closing a web browser. All participants completed the online survey in full.

6.3.2.3 Data collection

Informed by the findings of the literature, two online surveys were designed to explore possible causal explanations of programme outcomes in the context of care home settings and in order to investigate the IRPT. To this end, the IRPT model was shared with the participants through a short video before the beginning of the online survey. This is in line with the realist technique of enquiring 'teaching-learning'. This technique involves the researchers making participants aware of the conceptual framework under investigation by explicitly presenting it (teaching), and giving the participants the opportunity to clarify and explain their point of view in relation to it. In turn, the researchers have the opportunity to learn from the participants' comments (learning) (Manzano, 2016; Mukumbang et al., 2020). Mukumbang et al. claim that through this process 'the respondent becomes more of a participant in the meaning-making process than simply a source of information' (2020, p. 494).

A series of realist theory-driven open-ended and ‘agree and disagree’ questions were developed to investigate intervention outcomes, the role of context, mechanisms such as beliefs and attitudes, along with possible relevant intervention factors such as olfactory administration method. Participants were asked to rate their degree of agreement with statements drawn from the literature related to CMO on a Likert scale, from strongly agree to strongly disagree. The two online surveys (Survey 1 and Survey 2) were slightly adapted based on the experience and expertise of the stakeholders and therefore their potential contribution toward the IRPT. The Survey 1 for dementia care academics and people working with residents in care homes mainly focused on collecting contextual information and mechanisms associated with care home settings such as care professionals’ training, care home management approach, and residents (Appendix 6). Whereas the Survey 2 for olfactory experts targeted the theoretical framework and tentative propositions on the mechanisms underpinning responses triggered by smells (Appendix 7).

The surveys were designed using the Jisc online platform. Jisc is a United Kingdom not-for-profit company that supports higher education and research. The online surveys were piloted within the supervisory team and with two independent researchers external to the research to ensure the comprehensiveness, clarity, and simplicity of the questions formulated (Braun et al., 2021).

6.3.2.4 Data management

All information gathered during the research was treated confidentially. The e-Consent forms and survey responses were stored according to the Jisc survey information security which is managed in conformance with the requirements of the international standard for information security (i.e. ISO/IEC 27001), ensuring the security of the datacentre and virtualisation aspects of the service.

At the end of the data collection process, the anonymised survey responses were exported and entered into a qualitative data analysis software, namely NVivo12 (QSR International, 2020). All computer-held data including the participants' consent forms, study database, and survey responses, are held securely in encrypted password-protected files for five years according to the University of West London's code of research conduct and research ethics (University of West London Research Ethics, 2020). After this time, they will be disposed of securely.

6.3.2.5 Data analysis

Thematic analysis was used to analyse the data. Thematic analysis includes a set of approaches focusing on identifying patterns and meaning within and across a dataset (Braun & Clarke, 2019, 2021a, 2021b). This study undertook a 'codebook approach' (Miles et al., 2014) which involve the generation of preliminary codebook to help the analysis. Miles et al.'s (2014) qualitative method of analysis, previously employed in the development of initial programme theory (Mukumbang

et al., 2018a), was adopted as it is grounded in the critical realist philosophy, recognising the existence of an objective world as well as a subjective reality. This analytic method also enables the use of an a priori conceptual framework grounded in the researcher's initial understanding of the phenomena while including flexibility that enables theory modification throughout inductive inquiry (Miles et al., 2014). Furthermore, the systematic approach of the method captures how the conceptual framework evolves as the data analysis progresses, enhancing transparency and comprehensiveness of the process. This is relevant to the realist methodology which is based on testing and refining programme theory through an iterative process.

Miles et al. (2014) propose that data analysis is a 'continuous' and 'iterative' process comprising three components: data condensation, data display, drawing and verifying conclusions. Data condensation has been described as 'the process of selecting, focusing, simplifying, abstracting, and/or transforming the data' (Miles et al., 2014, p. 12). Data condensation occurs early in the study process, when the researcher formulates the research questions, selecting and focusing the area of interest, and ends when the final report is completed. Another major component of the method is data display. Miles et al. (2014) suggest that displaying the data in an organised and accessible form can support further understanding. Conclusions are often verified, and the degree of verification can range from a short excursion

back to the database to replicating the finding within a new dataset. In this study, the process of conclusion drawing started when patterns in the form of CMO configurations were identified. The ‘plausibility’ and ‘sturdiness’ of the meanings developed throughout the analysis process were tested by reading the codes generated and their relevant data segments; re-reading and re-examining the dataset, looking at any explicit relationship between codes suggested by participants and regular discussions with the supervisory team. The CMO configurations were then identified and formulated. The following section describes the process undertaken for data analysis.

6.3.2.6 Procedures

The analysis process followed two major stages. The first stage involved identifying the context, mechanisms, and outcomes. The second stage focused on synthesising the results, which involved the generation of potential explanatory propositions (causal inferences) of how context and mechanisms are linked and interact with each other to produce outcomes (CMO configurations). This is in line with the realist inquiry approach that emphases the importance of moving beyond ‘the level of description of the data [...] to offer causal explanation’ (Wong et al., 2013b, p. 46). An outline of the phases employed in the data analysis process of the online surveys is shown in Table 6.2.

Table 6.2 Analytic process for surveys (adapted from Miles et al., 2014)

Stage	Process undertaken
Stage 1 Pattern code identification	The surveys were imported into NVivo. NVivo was used to aid the analysis and to capture the complex and iterative process of theory generation throughout the realist review process (Dalkin et al., 2021).
	In line with the analysis method, a conceptual framework for the data analysis process was developed applying the realist philosophical 'lens'. CMO coding framework adapted from Mukumbang et al.'s work (2018a) was used as start list of codes or pre-designed node (Appendix 8). In NVivo, nodes are often synonymous with codes and allow to gather relevant data under communal themes or pattern codes. Pattern codes refers to 'explanatory or inferential codes, ones that identify an emergent theme, configuration, or explanation' (Miles et al., 2014, p. 86).
	The participants' responses were read and re-read in an active way, to gain an overview of what is in the data and to look for anything that might be a potential context, mechanism, or outcome.
	Segments of the texts linked to the influential context, possible mechanisms, and outcomes were coded under the corresponding node (context; mechanism: resource, reasoning; outcome: immediate, intermediate, long-term). Child nodes or 'sub themes' were created to store specific information provided in each domain.
	Similar codes were clustered into pattern codes.
	The pattern codes, their respective codes and data segments were reviewed, involving re-considered labels, and re-negotiated codes that do not seem to be part of any overarching pattern codes.
Stage 2 Data synthesis - CMO configurations	To help to see interconnections, the pattern codes and codes were visually displayed in mind maps in NVivo, supporting data analysis and interpretation.
	The dataset was checked to identify specifically where respondents talk about potential CMO configurations. Pattern codes, codes, and their potential relationships were placed in a table under the appropriate column (context, reasoning, resource, or outcome), supported by participants' quotes. Each row provides a representation and presentation of a preliminary explanation of how olfactory intervention could work which were narratively described in the form of 'if-then'. They were visually displayed in mind maps, see Appendix 9 for an example.
	The preliminary CMO configurations alongside the evidence supporting the statements were presented to the supervisory team for further discussion and challenge. Throughout the iterative discussions with the supervisory team, CMO configurations were scrutinised and refined which included grouping and re-labelling. Writing, drawing connections promoted engagement with the data and reflection.

6.4 Results

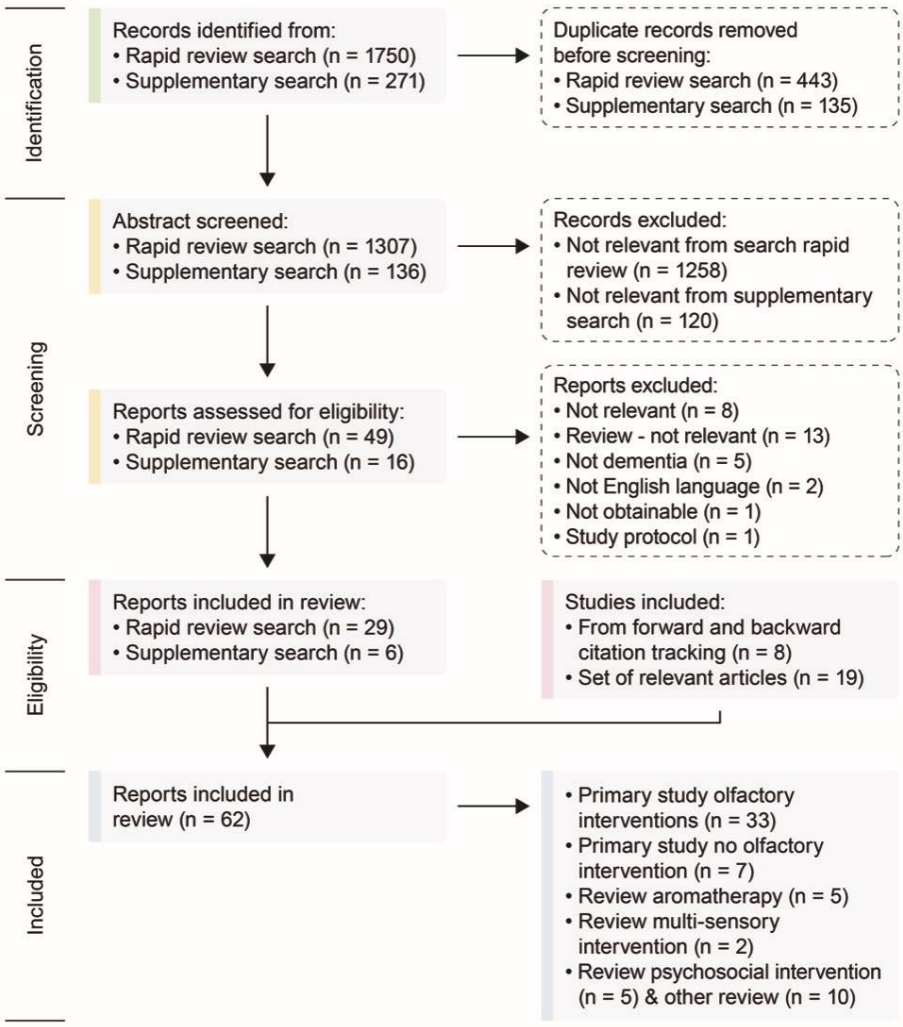
6.4.1 Synthesis of evidence

A total of sixty-two articles were included. Twenty were included from the rapid review (Chapter 5), nine papers on aromatherapy massage rejected from the rapid review were included because the realist review was not limited to olfactory-only interventions, and six more from the supplementary search. Eight studies were added from forward and backward citation tracking, and finally a total of nineteen articles identified separately were iteratively included during the course of the review to build and refine the programme theory. Figure 6.2 summarises the search process.

Outcomes

The rapid review (Chapter 5) showed that studies on olfactory interventions included three main groups of outcome measures: responsive behaviour, cognition (including self-concept), and physical functioning (e.g. sleep, appetite, balance). By scoping the supplementary literature, studies on aromatherapy massage provided further support for positive outcomes of olfactory intervention on responsive behaviour (Ballard et al., 2002; Fujii et al., 2008; Kaymaz & Ozdemir, 2017; Watson et al., 2019; Yang et al., 2016a). In line with the rapid review, other studies did not report significant effects (Leach et al., 2021; O'Connor et al., 2013; Yang, et al., 2016b; Zalomonson et al., 2019).

Figure 6.2 PRISMA flow diagram of the realist review of olfactory interventions



Additionally, six studies measured the effect on mood (O'Connor et al., 2013; Yang et al., 2016a; 2016b) and quality of life (Ballard et al., 2002; Burns et al., 2011; Leach et al., 2021), three of which reported significant positive benefits (Ballard et al., 2002; Yang et al., 2016a; 2016b). Evidence was found of the positive effect of olfactory stimulation on care professionals and caregivers, such as reduction in care burden (Jimbo et al., 2009; Johannessen, 2013; Lin et al., 2019; Kaymaz & Ozdemir, 2017).

Further to these findings, the focus of the review was narrowed to identify the olfactory programme theory associated with positive impacts on seven intended outcomes of interest: care professionals burden and residents' outcomes (responsive behaviours, cognition, physical functioning, mood, self-identity, and quality of life).

Potential contextual factors

The context refers to information about participants (who), the physical and social setting characteristics (where) and the intervention (what). The evidence showed great heterogeneity in programme design and procedure used across the included studies (such as olfactory stimuli; duration and length of the intervention; administration methods). In seven of the sixteen studies included that were

conducted in care home settings (Ballard et al., 2002; Gray & Clair, 2002; Moorman Li et al., 2007; O'Connor et al., 2013; Sakamato et al., 2012; Sulmont-Rossé et al., 2018; Zalomonson et al., 2019) the olfactory intervention was administered by care professionals but information on training and resources allocated to support this was not always provided. In five studies the intervention was administered by the research team (Fu et al., 2013; Takeda et al., 2017; Watson et al., 2019; Yang et al., 2016a and b) and four did not provide information on the intervention facilitator (Fujii et al., 2008; Holmes et al., 2002; Snow et al., 2004; Yang et al., 2015). Generally, these studies did not provide details of how the setting may have interacted with the intervention components. Therefore, a set of papers focusing on other psychosocial interventions implemented in care homes was reviewed. These included Ballard et al. (2018), Lawrence et al. (2012, 2016), Mileski et al. (2018); Rapaport et al. (2017).

Lawrence et al. found that care home staff play ‘a crucial role in initiating, directing and maintaining activities’ (2012, p. 347). Therefore, social care professional training, knowledge, and mentoring have been found to be key factors for the successful implementation of psychosocial interventions (Ballard et al., 2018; Rapaport et al. 2017). Organisational support, such as the attitude of care home managers toward psychosocial strategies and interventions, time and resource

allocation, have important implications for the practice (Lawrence et al., 2012, 2016).

Regarding the participants' characteristics, studies varied greatly in terms of dementia subtype and severity. Therefore, it is unclear whether these factors can impact the outcomes. Most studies suggest that AD presents identification impairment, and less difficulties in odour detection (Alves et al., 2014). However, different olfactory dysfunction profile has been observed between AD cases and among other types of dementia. McShane et al. (2001), found that people with DLB diagnosis may experience impaired odour detection compared to AD. In line with this finding, the only study (Holmes et al., 2002) involving people with DLB did not find any positive effect of olfactory intervention. McShane et al. (2001) also suggested that evidence regarding AD and impaired odour detection could be due to a misdiagnosis of AD. This raises a question as to whether the inconsistent olfactory intervention findings may be due to subtypes of dementia.

Individual characteristics such as residents' olfactory impairment (Rahayel et al., 2012), stage and type of dementia (Alves et al., 2014; Holmes & Ballard, 2004; McShane et al., 2001), symptoms of dementia (such as responsive behaviours), preference and past experience (Herz, 2016) were considered as potential facilitators and barriers to the intended outcomes in the IRPT. According to the

realist approach, context shapes and constrains the mechanisms. Potential mechanisms underpinning olfactory programmes are described below.

Description of potential mechanisms

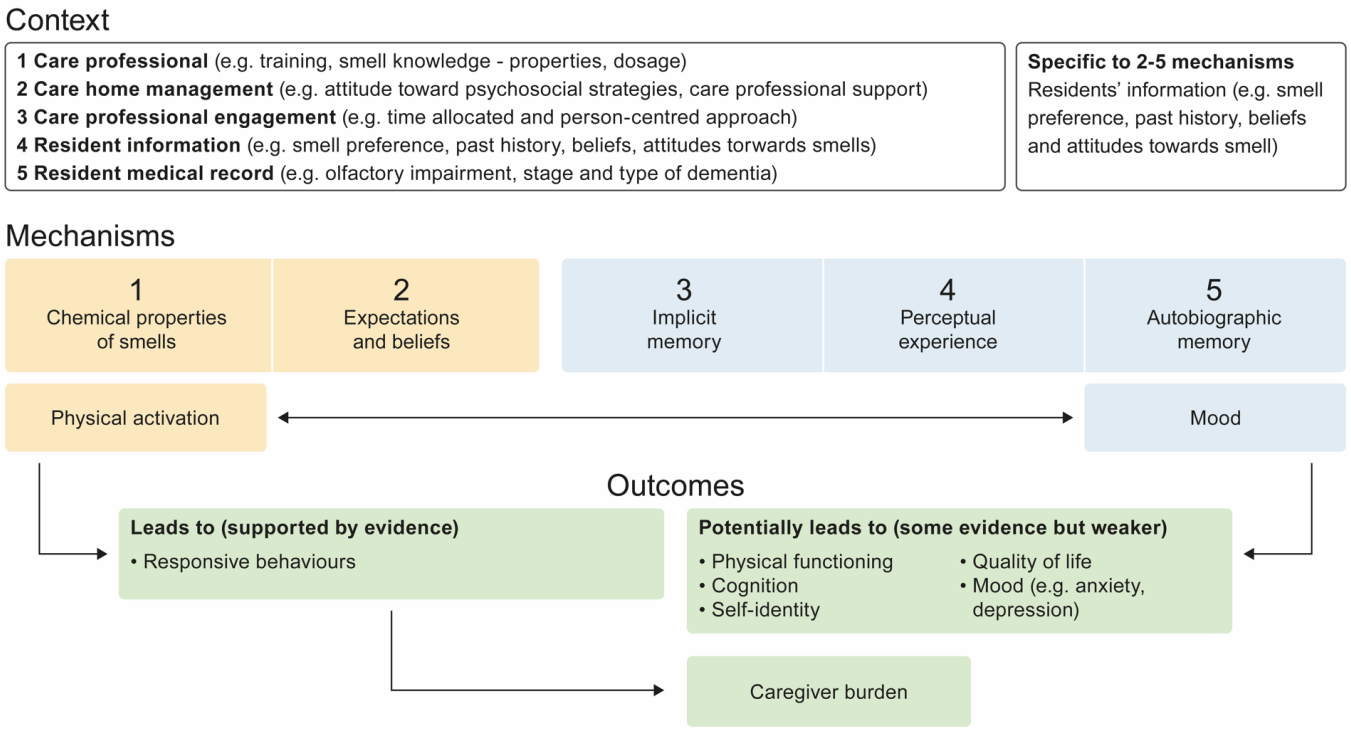
By working backwards from the expected outcomes, the studies were mapped focusing on what the studies revealed about potential mechanisms and their links with outcomes and contextual factors. This process resulted in the development of the IRPT model (Figure 6.3).

Five possible mechanisms were identified, including chemical properties of smells, expectations and beliefs, implicit memory, hedonic response, and autobiographic memory.

Several studies included in this review (e.g. Fu et al., 2013; Fujii et al., 2008; Takeda et al., 2017; Yang et al., 2015; Yang et al., 2016a and b) suggest that the pharmacological properties of smells directly interact and affect the endocrine system and/or the autonomic and central nervous systems (Sayorwan et al., 2012; Schuwald et al., 2013; Scuteri et al., 2019). Therefore, the IRPT suggests that mood, physiological and behaviour changes are influenced by the chemical properties of odour. However, there is evidence showing that an odour compound requires 20 minutes to act pharmacologically. This is the time needed for a compound to enter the bloodstream and cross the blood-brain barrier (Herz,

2009a). Therefore, it is likely that responses observed immediately after a smell exposure are elicited or mediated by other mechanisms.

Figure 6.3 Infographic showing the IRPT



Subjective expectations and beliefs can crucially influence physical responses (such as skin temperature, pulse rate, breathing rate, and blood pressure) and indirectly the mood (Campenni et al., 2004). Some studies show that the chemical nature of smell itself plays a secondary role in the creation of olfactory stimulation in the presence of expectations and beliefs regarding the odour (see for a review Herz, 2009a). Indeed, expectations and beliefs associated with a smell can mediate whether the smell have stimulating or relaxing effects. So, according to this, the psychological factors can override or even drive the physiological responses (e.g. Herz & Von Clef, 2001; Holmes & Ballard, 2004).

Further to this, it has been suggested that olfactory sensations may be an effective means of stimulating implicit memories (Ball et al., 2020). Although deterioration of explicit memory is a prominent symptom of dementia, some studies suggest that implicit memory can remain intact in affected people (e.g. Degel et al., 2001). The implicit memory may trigger an emotional response based on the person's previous experience associated with smells. Within a clinical setting, for example, a case study showed that the smell of diesel of large trucks triggered anxiety, with uncomfortable and guilty feelings in a Vietnam War veteran (Vermetten & Bremner, 2003).

Another mechanism included in the IRPT refers to the perceptual experience, i.e., whether an individual likes or dislikes a specific odour. There is evidence that both

the emotional and physical states produced by the smells could be explained by the subjective hedonic evaluations of a smell; that is, whether it is perceived as pleasant or unpleasant (Ball et al., 2020; Holmes & Ballard, 2004). Some studies show that personal like or dislike of smell is directly related to the mood change that occurs (Herz, 2009a).

Finally, smell has been found to be unique in its ability to enhance autobiographical memory. Odour-evoked autobiographical memories could therefore have specific qualities, for instance, they are significantly more emotional and more pleasant than those elicited by other sensory cue modalities, such as auditory or visual (El Haj et al., 2018; Glachet & El Haj, 2019, 2020a, 2020b; Gray & Clair, 2002; Herz, 2016; Lopis et al., 2021). Odour-evoked autobiographical memories could have therapeutic effects in people with dementia. Studies including the recall and discussion of past events in dementia care e.g. reminiscence therapy (Woods et al., 2018) suggest positive effects associated with this practice such as increasing communication, and promoting self-identity, quality of life, and well-being.

Overall, based on the IRPT model, it is speculated that the mechanisms ‘chemical properties of smells’ and ‘expectations and beliefs’ have a direct impact on physiological changes and indirectly on mood. Whereas the mechanisms ‘implicit memory’, ’perceptual experience’, ‘autobiographic memory’ act primarily to modify

the emotional state and subsequently the physical state. This is consistent with the neuroanatomy of the olfactory system which is associated with memory and emotional brain areas (Dolan, 2002; Gottfried et al., 2004; Herz, Eliassen, et al., 2004b).

The next steps in the IRPT building process explored stakeholders' experiences of olfactory programmes, and then synthesised the final overarching theoretical framework into CMO configurations.

6.4.2 Stakeholder findings

Demographic characteristics

Twenty stakeholders took part in the study. Of those, two people were recruited who had been referred by other study participants for their expertise in the research topic. In total, participants included eleven experts on dementia care and nine people with expertise in olfaction. Occupation, experience of facilitating or participating in olfactory intervention/activity, years of working in dementia or olfactory sectors are presented in Table 6.3.

Table 6.3 Sample characteristics

Sample	Occupation (N = 20)	Participated and/or facilitated olfactory intervention/activity			Working with/caring for PwD	
		N (%)	Years	Context %	N (%)	Years
Dementia experts	5 Activity coordinators (e.g. creative activities; olfactory interventions) 4 Researchers 1 Occupational therapist 1 Care home manager	10 (91%)	2.4 ± 1.6	63% Care home 18% Hospital 9% Museum	11 (100%)	5.5 ± 4.5
Olfactory experts	9 Researchers	8 (88%)	9.7 ± 9.9	66% Clinical practice 33% Research 11% Care home 11% Museum	3 (33%)	6.3 ± 4.1

PwD = People with Dementia

Findings of the online surveys

The analysis of the online surveys generated individual pattern codes under each of the category of the coding framework which are summarised below along with example quotes (OE: olfactory expert; DE: dementia expert). Details of the analysis including pattern codes, explanations and supporting quotes are also presented in Appendix 10.

In summary, stakeholders indicated that olfactory stimulation is associated with multiple immediate, and intermediate outcomes, and one long-term outcome as shown Table 6.4.

Table 6.4 Classification of olfactory programme outcomes

Immediate outcome	Intermediate outcome	Long-term outcome
New and past associations	Behavioural change	Quality of care
Social interactions	Boost relationship	
Emotional response	Self-identity	
Physical response	Care professional burden	
	Cognitive function	
	Mood change	
	Quality of life	

From the analysis, potential mechanisms were identified (Table 6.5). Mechanisms were classified under the category ‘resource’ (intervention components introduced that enhance a change) and ‘reasoning’ (changes produced by resources).

Table 6.5 Classification of olfactory programme mechanisms (resources and reasoning)

Resources	Reasoning
Smell as a trigger	Comfort and familiarity
Training	Physical changes
Smell administration matter	Positive and negative hedonic experience
Structure and regular activity in the care routine	Curiosity and intrigue
	Unconscious and implicit perception

Pattern codes related to the programme context were also found from this analysis i.e. ‘Physical settings’, ‘Knowledge’, ‘Attitude and motivation’, and ‘Orientation approach to care’. Stakeholders emphasised the key role of care managers in

organising the resources, such as training, and providing the support needed to implement the intervention in daily care:

> *"From my experience when the manager finds something important, they can train or advise their staff accordingly and change their attitudes."* (DE2)
>
> *"If you don't have support from management in terms of making time for training or resources it would be very difficult to implement such a program as staff tend to be quite time and resource-poor in such settings."* (DE5)

Skilled and knowledgeable care professionals in terms of the residents' preference, and biography as well as olfactory intervention benefits, materials, and administration methods were considered important for tailoring the intervention to residents' "preferences, experiences and sensitivities" (OE2) and for the success of the intervention:

> "*Care professionals must see the value in smell as a tool in order to ensure that the smell therapy is ongoing and carried out effectively for the patient."* (DE4)
>
> *"Understanding the potential benefits and the intent behind the interactions has to be beneficial."* (DE8)

Respondents emphasised that expectation and attitude of residents may also act as a facilitator or barrier to olfactory intervention intended outcomes:

> "*There is definitely a placebo side to it as you could tell someone it has a*

benefit even it has no pharmacological effect, and it would change behaviour." (OE4)

"*The positive attitude towards a stimulus or a situation can have effect on both psychological and, consequently, physical changes within a subject.*" (OE6)

From the analysis, both unfamiliar and familiar smells (Resources – 'Smell as a trigger') have the potential to facilitate enjoyable and positive feelings and/or trigger new associations, past events, and experiences:

"Linalool [a key compound in lavender oil] *would still cause a relaxing sensation whether it is familiar or not due to its neurological efficacy."* (OE4)

"A new smell can also be objectively pleasing and have a positive effect." (OE8)

"A familiar smell has a positive impact on the mood and on the psychological status of a person." (OE6)

Other resources such as odour intensity, administration methods (Resources – 'Smell administration matter') and procedures (Resources – 'Structure and regular activity in the care routine') e.g. regular sessions and pictures or verbal prompts, were considered by participants to be important drivers of the possible activation of the reasonings:

"*Since the goal is to achieve positive effects, and since dementia patients often have very poor odour identification abilities, one would need to explain what the odour is, in order to have people understand what is going on and harvest any positive effects.*" (OE2)

"My experience is that regular, repeated sessions were an enjoyable activity and facilitated mood-boosting conversations about autobiographical histories." (DE8)

Familiar protocol and smells may promote reasoning such as a sense of 'Comfort and familiarity' which in turn facilitate engagement, interaction, connection, and positive feelings:

"*It may remind a person of a memory of people, time and place and a sense of identity and centredness, which in turn may console, calm, bring joy and the possibility as a chain reaction on behaviours/mood."* (DE5)

Other central mechanisms of olfactory programme identified were playfulness, intrigue, curiosity (Reasoning – 'Curiosity and intrigue') and the hedonic experience associated with a smell and discussing about it (Reasoning – 'Positive and negative hedonic experience') which may capture the residents' attention, stimulate enjoyable interactions, promote discussion of past events, experience, and positive (or negative) feelings:

"*Because we are asking them to focus their attention on a sense which is often overlooked - it becomes new and exciting."* (DE4)

"The response may be dependent on the smell and its perceived pleasantness. Responses could be enjoyment, stimulation, arousal, relaxation, humour, hunger, disgust etc. Specific to people with dementia, smell may elicit reminiscence, storytelling, memory sharing." (DE1)

'Physical changes' and 'Unconscious and implicit perception' were recognised as other potential mechanisms underpinning olfactory programme:

"Reactions related to the senses are often involuntary and could be subconscious." (DE8)

"[…] *Odours may affect mood via these physiological changes, but again, it is probably not a clear-cut cause-and-effect situation."* (OE2)

The analysis of stakeholder surveys led to the identification of a series of CMO configurations which shaped the IRPT model.

6.4.3 Overarching synthesis and IRPT

Following the evidence review and the stakeholder surveys, the data were reviewed to identify emergent theory and interactions between the CMO components, in which case, outcomes of interest were reviewed and refined (Table 6.6). Olfactory intervention outcomes were distinct between care

professionals (care burden) and residents (well-being, cognition, responsive behaviours). Outcomes such as quality of life, self-identity, mood, social interactions were integrated under the outcome ‘well-being’. Cognition included past and new associations. Physical responses as an outcome were not further explored because of limited data provided by the stakeholders and the specificity of the topic (chemistry) which was beyond the author’s knowledge.

Table 6.6 Outcomes of interests of olfactory stimulation programme

Resident outcome	**Care professional outcome**
Responsive behaviours	Care burden
Well-being (social interactions, self-identity, mood, quality of life)	
Cognition (New and past associations)	

A list of 12 ‘if-then’ statements was drafted in the form of CMO configurations. For each statement, stakeholders’ quotes were included as evidence. Consensus discussion was used to refine this initial list of 12 ‘if-then’ statements into a smaller number of comprehensible and independent statements throughout regular discussions with the supervisory team. From this process, various and fragmented CMO configurations were gathered related to the implementation programme and the outcomes of interest.

To achieve clarity as well as reflect the complexity of the implementation chain of an olfactory programme, it was decided to separately describe the potential causal

process for outcomes and successful implementation. This promoted the development of a coherent overarching framework from where the final IRPT was created. A similar method has been used by Fick and Muhajarine (2019) to create the candidate initial programme theory for overweight and obese intervention for children from their complex and 'messy' findings.

The following five CMO configurations describe the final IRPT.

6.4.3.1 CMO 1: Supportive leadership, positive attitude, training for successful implementation

If care managers have a positive attitude toward person-centred approach (C), knowledge on olfactory intervention and its value (C), and resources (Mresource) and support (Mresource) are provided, care professionals will become more motivated and knowledgeable about the intervention (Mreasoning) and residents (Mreasoning), and increase confidence and skills (Mreasoning), which will lead to enhanced commitment and adherence to implementing the intervention (O).

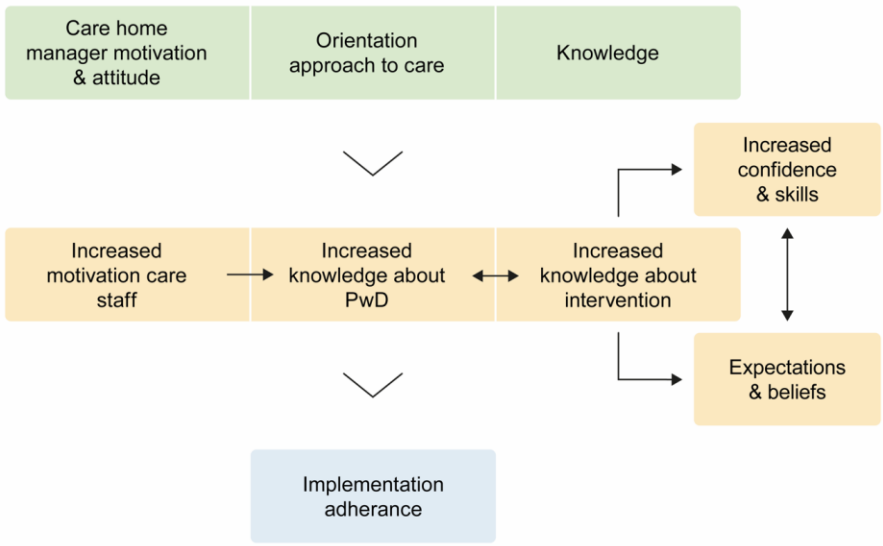
Olfactory interventions within care homes are complex, and they require active engagement of multiple stakeholders and adaptations to care practice. Qualitative data identified care home manager willingness and care professionals' engagement as central to the programme's success. Ongoing on-site support in

terms of guidance and resources (e.g. physical setting, training, allocation time, access to materials) was reported to facilitate implementation into routine care.

Lack of time and a task-focused approach to care and workload were considered as barriers across stakeholders and the literature (Bunn et al., 2018; Lawrence et al., 2012, 2016; Miller et al., 2021; Rapaport et al., 2017). Rapaport et al. (2017), in a systematic review of the effective elements of psychosocial interventions, found that if care professionals have the support of management regarding a new intervention, this will have positive impacts on team motivation, attitude and confidence. Stakeholders supported this suggesting that *"[…] if managers do not advocate for olfactory stimulation, then it's not top of* [care professional] *mind"* (DE7).

Care home manager supervision, guidance and relevant training opportunities could lead care professionals to gain professional competences, knowledge, and an understanding of the benefits of olfactory interventions for residents and themselves. This in turn can enhance engagement and motivation 'to prioritise new ways of working' (Rapaport et al., 2017 p. 8). Therefore, both care professionals' expertise and motivation can affect successful compliance and intervention implementation (Johannessen, 2013; Mallon et al., 2019). Figure 6.4 summarises the CMO configuration.

Figure 6.4 CMO 1: configuration for implementation adherence



6.4.3.2 CMO 2: Residents' changes and direct effects of odour in care professionals

If care professionals have sufficient resources (C), motivation (C), skills and knowledge (C), and, then appropriate and sensitive use of olfactory stimuli with residents (Mresource) will promote physical (i.e. relaxing) and positive emotional changes in care professionals (Mreasoning) as well promote positive emotions and behaviour in residents (Mreasoning) which helps ease the work stress for care professionals, leading to improved job satisfaction, care burden, quality of care, and staff retention (O).

There is some evidence suggesting that olfactory interventions have a positive effect on care professional burden, in terms of reducing exhaustion, distress as well as uncertainty (e.g. Chen et al., 2015; Johannessen, 2013).

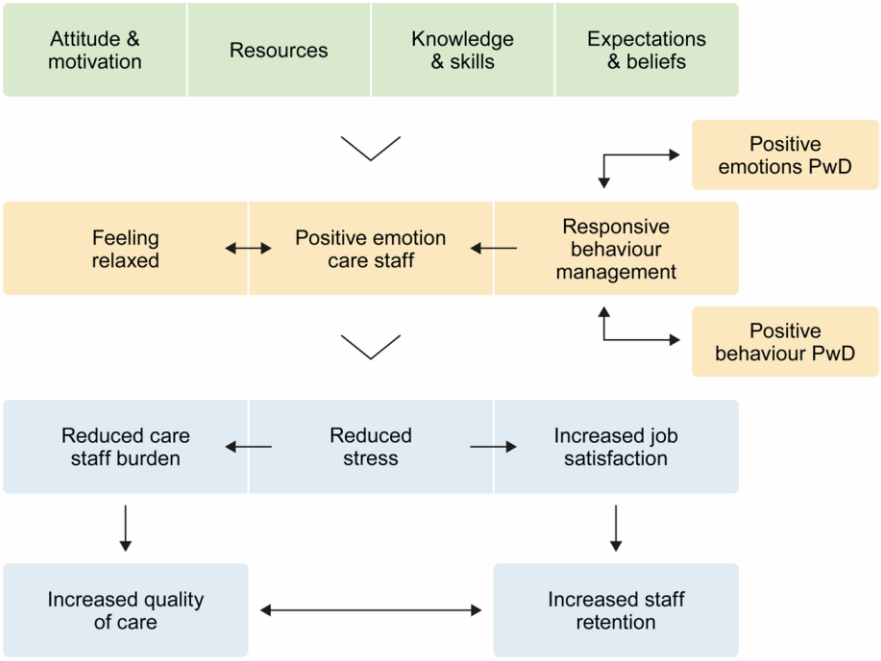
Some studies (Jimbo et al., 2009; Lin et al., 2019; Takahashi et al., 2020; Kaymaz & Ozdemir, 2017) evaluating the impact of olfactory interventions for people with dementia on informal caregivers and care professionals suggest that a decrease in care burden is associated with positive effects of olfactory intervention in people with dementia. Studies (Kaymaz & Ozdemir, 2017; Takahashi et al., 2020) show that when a resident's responsive behaviours decreased, care professionals felt less stressed. It is noteworthy that no positive effects in care professionals' burden were found when residents showed improved cognitive function following olfactory stimulation (Jimbo et al., 2009). This suggests that there might be a connection between care professionals and resident outcomes, especially in relation to responsive behaviours. This is not surprising considering that formal carers may spend more time caring for people with dementia who experience behaviours such as wandering and aggression (Lindt et al., 2020; Yous et al., 2019).

An olfactory intervention within a care home setting can have both indirect and direct positive effects on care professionals. Johannessen (2013) found that support of management, training on olfactory intervention and smell properties were perceived as stimulating and important for the professional carers

development. Care professionals felt empowered by learning about complementary therapy as an alternative to drug treatments for the management of residents' responsive behaviours or sleep disorders. Furthermore, there is evidence that smells have a positive emotional impact (Johannessen, 2013; Miller et al., 2021). In Johannessen's study, health and social care staff of nursing homes felt that the essential oils were 'spreading joy' (2013, p. 3). This was also highlighted by stakeholders who reported that "*olfactive stimulation activity can be fun for all* [care professionals and residents] *and would definitely reduce their care burden*" (DE7).

Studies that assessed the use of essential oils among care professionals working in acute care settings found positive effects such as decreasing stress, improved energy, and positive perceptions of the work environment (Chen et al., 2015; Johnson et al., 2017b). Distress among care professionals is a significant factor that can lead to job dissatisfaction, burnout, and nursing staff turnover (Johnson et al., 2017b). Therefore, it was speculated that reducing care professionals' distress can have an overall positive impact on staff well-being and the quality of care provided. Figure 6.5 summarises the CMO configuration.

Figure 6.5 CMO 2: configuration for care professional outcomes



6.4.3.3 CMO3: Comfortable and enjoyable feeling to support residents' well-being

Within a supportive environment (e.g. resources, training, physical space) (C), if care professionals have sufficient skills and knowledge (C) to implement tailored interventions using relevant and familiar smells (Mresource), residents will feel enjoyment (Mreasoning), intrigued (Mreasoning) and comfortable (Mreasoning). This will increase residents'

mood (O), social interactions (O), level of relaxation (O) and autobiographic memories (O), leading to increased well-being (O).

The use of relevant olfactory stimuli and tailored administration methods were perceived to be key components to enhance social interactions, autobiographic memories, emotional and physical responses. It was speculated that these outcomes could lead to improved well-being of residents (Ballard et al., 2004; Herz, 2016). There is evidence to suggest that individual differences influence how people respond to the same stimuli. Such differences included attitude, past experiences, preferences and beliefs (Herz, 2009a, 2016; Holmes & Ballard, 2004). In the early stage of IRPT development (Figure 6.3), individual expectations, beliefs and perceptual experiences were considered as mechanisms of the programme. By questioning 'why', 'how', they were assessed as contextual factors at the individual level. The methodological challenges in defining context and mechanisms are discussed in Section 6.7.

Individualised administration methods were considered important. Participants suggested that intervention administration methods that are "*well tolerated*" and "*appreciate"* can trigger more comfortable feelings and a positive attitude towards the olfactory intervention in residents. Visual or verbal prompts could meet residents' abilities and promote a sense of familiarity supporting engagement and positive feeling. Due to the variety of approaches used, it was not possible to

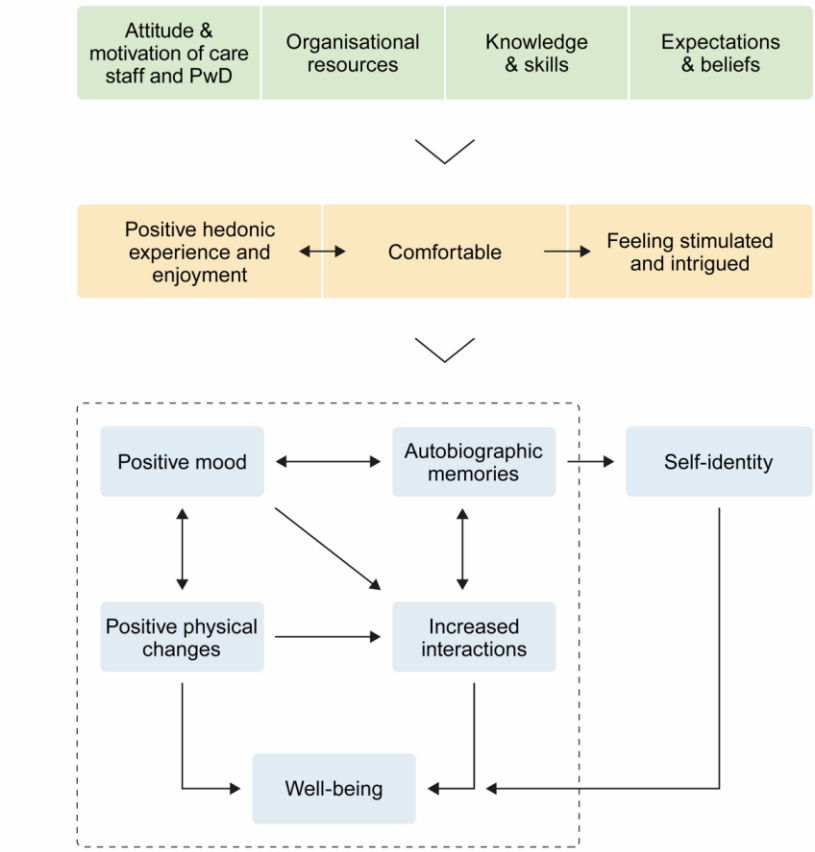
establish from the literature whether there is an association between olfactory methods of administration/delivery and study outcomes (Nguyen & Paton, 2008).

Whilst some sensory stimulation studies referred to the importance of personalising intervention materials based on individual preferences and sensitivities, in order to increase the number of people accessing the intervention (Livingston et al., 2014) and reducing the risk of unintended overstimulation (Lorusso et al., 2017; Sulmont-Rossé et al., 2018), only a limited number of olfactory intervention studies included a pre-intervention assessment of the materials being used (D'Andrea et al., 2022). Results supported by Van Vracem et al. (2016) suggested that familiar and relevant smells can stimulate curiosity, engagement, and promote feelings of enjoyment, comfort, security and trust in people with dementia. They also "*create a good/beneficial atmosphere in care homes*" (OE5) as suggested by stakeholders.

It is therefore suggested that comfortable and familiar feelings combined with the emotions associated with the odour-evoked memories (El Haj et al., 2018; Glachet et al., 2019; Glachet & El Haj, 2019; 2020a; Lopis et al., 2021) could improve mood (Herz, 2016; Yang et al., 2016a; 2016b), and promote a sense of relaxation (Masaoka et al., 2012). Results suggested that reminiscence activity stimulated by smells can also boost self-identity and a person-centred relationship. Sharing their memories "*remind*[s] *people of what they've done and who they are, so they do*

not just feel like a patient with dementia" (DE11). One participant commented that "*memories bring empathy and the person opposite them can clearly see them as valued individuals*" (DE2). However, the evidence to support this is limited. Only one study was found on the effect of olfactory intervention on self-concept (Glachet & El Haj, 2020b) and this study did not directly measure outcomes on the social interaction and relationship between participants or facilitator. Figure 6.6 summarises the CMO configuration.

Figure 6.6 CMO 3: configuration for well-being outcome



6.4.3.4 CMO 4: Knowing the person and odour-related effect to manage responsive behaviours

If residents and care professionals have positive attitudes toward olfactory stimulation (C), resources (C) are provided to implement the intervention in

everyday care practice (Mresource) and care professionals are knowledgeable about smell characteristics (e.g. relaxing properties, pleasantness) (Mresources) and residents' preference, and biography (Mresources), then these lead to diminished responsive behaviour (O) because residents might have a positive hedonic experience (Mreasoning), feel relaxed (Mreasoning), and perceive the setting as pleasant (Mreasoning) and comforting (Mreasoning).

Responsive behaviour was the most common outcome measured in olfactory interventions for people with dementia (Fujii et al., 2008). Data were extracted from four reviews (Ball et al., 2020; Holmes & Ballard, 2004; Livingston et al., 2014; Nguyen & Paton, 2008) and 17 primary studies which contributed to identify potential causal explanations.

The chemical properties of odour (Sayorwan et al., 2012; Schuwald et al., 2013; Scuteri et al., 2019) and hedonic attributes (Herz, 2009a; Holmes & Ballard, 2004) are likely to play a key role in creating a calming feeling in people with dementia. Numerous sources emphasised that odour compounds with sedative properties (e.g. lavender, sweet orange) can induce a state of relaxation by entering in the body via the bloodstream and directly influencing the activity of the central nervous system (e.g. Ballard et al., 2002; Dobetsberger et al., 2011; Moorman et al., 2007; Takahashi et al., 2019). Studies, however, identified that odour outcomes can be

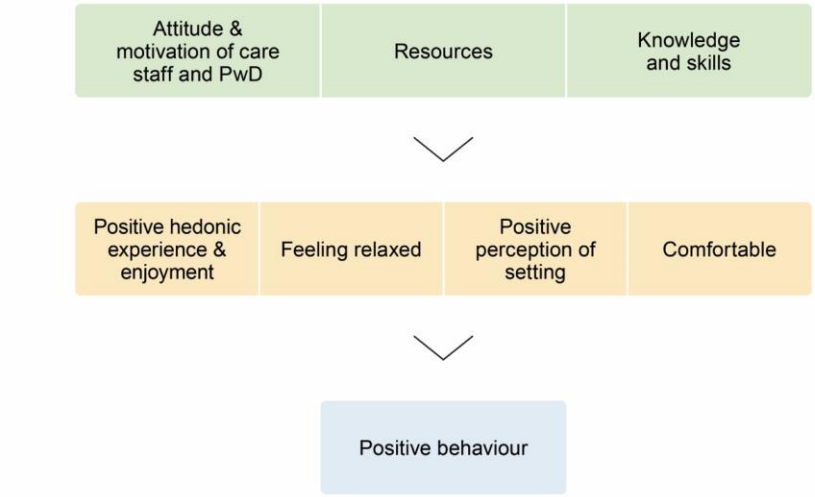
influenced and mediated by psychological phenomena, in particular expectancies, beliefs, attitude, and hedonic individual experience of an odour (Herz, 2009a; Holmes & Ballard, 2004). Herz and colleagues found that the 'emotional effects of odours are not intrinsic to the odorants themselves but rather are due to the hedonic or emotional responses that have been associated to them' (2004a, p. 331). Consequently, odours with a strong positive (or negative) association can influence the individual's response independently from the properties of the compound. This might explain the heterogeneity of the study findings on responsive behaviour outcome.

Smell perceived as pleasant can enhance positive emotional change (Herz, 2009a; Holmes & Ballard, 2004). There is evidence suggesting that a positive odour ambience can promote prosocial behaviours and comfortable feelings (Herz et al., 2004c; Herz, 2009a). This is particularly relevant within the context of the care home setting, which may be associated with malodour or cleaning products odours solutions. Stakeholders working in care home settings stressed the importance of "*extinguishing the bad smells"* (DE2) and integrating structured and regular olfactory sessions into daily care.

Together these findings suggest that potential mechanisms underpinning behavioural outcomes are enhanced by the complementary effect of odour compounds and subjective odour perception. Therefore, promoting care

professionals' knowledge of residents as well as the physiological effects of odours is important for the success of an intervention. Absence of basic information about olfactory stimuli and residents were perceived as challenges. Figure 6.7 summarises the CMO configuration.

Figure 6.7 CMO 4: configuration for responsive behaviour outcome



6.4.3.5 CMO5: Capturing the attention and promoting meaningful conversations

If people with dementia have a positive attitude, and care professionals have access to resources and information about resident's preferences (C) and biography (C), relevant smells will be selected for the intervention (Mresource) which will stimulate an involuntary retrieval process

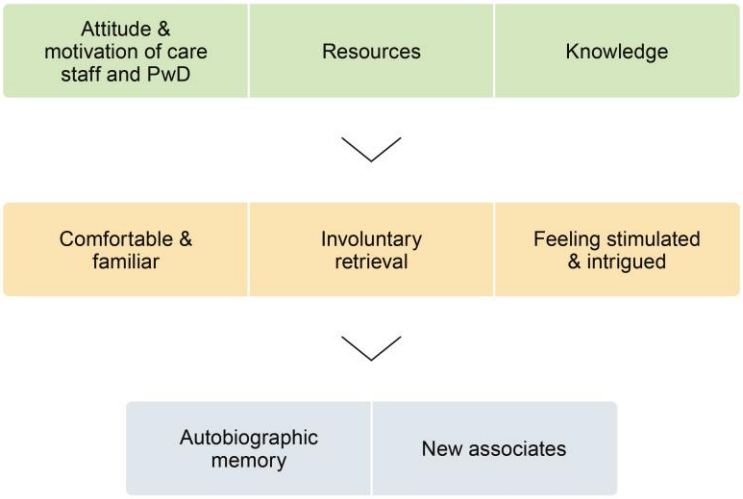
(Mreasoning), capture the resident's attention (Mreasoning), promote comforting and familiar feeling (Mreasoning), leading to stimulate the recall of past events, personally significant people (O) and the creation of new associations (O).

Data on the olfactory intervention effects on cognitive function in people with dementia was extracted from nine studies which mainly focused on autobiographic memories (El Haj et al., 2018; Fujii et al., 2008; Glachet et al., 2019; Glachet & El Haj, 2020a, 2020b; Jimbo et al., 2009; Lopis et al., 2021; Takahashi et al., 2020). According to the stakeholders, knowing the residents' preferences and relevant smells can help to stimulate a sense of familiarity which could be reassuring and comforting. Familiar smells can induce the Proust effect by evoking an involuntary memory without a deliberate effort to retrieve it (El Haj et al., 2018; Glachet & El Haj, 2020a). Such an effect is produced by neural activity of olfactory systems and affective brain regions (e.g. Dolan, 2002; Gottfried et al., 2002). Besides the Proust effect, respondents suggested that either unfamiliar or familiar smells can capture the residents' curiosity, attention and stimulate a conversation which could lead to retrieval of individual's anecdotes or events and create new associations: "O*ne woman spoke of using her scent to create a sense of presence in the care home. Whilst another* [resident] *associated certain scents with specific times of*

day and occasions, e.g. that fresh, light perfume should be worn in the morning and that heavier, rich scents should be worn in the evening" (DE7).

There is evidence supporting the notion that odour-evoked autobiographical memories are accompanied by strong emotions (Glachet & El Haj, 2019, 2020b; Herz & Schooler, 2002). Mirroring these results, stakeholders considered autobiographic memories as a central aspect of olfactory intervention outcomes for eliciting positive emotion in residents. Furthermore, olfactory stimuli could also be used to facilitate projections into the future (Glachet & El Haj, 2020a) and conversations on new topics, as suggested by respondents. Figure 6.8 shows the CMO configuration for cognitive outcome.

Figure 6.8 CMO 5: configuration for cognitive outcome



6.5 Discussion

The purpose of this realist review was to map out what mechanisms contribute to successful outcomes in olfactory interventions offered to care home residents with dementia. Five CMO configurations were generated that describe how various positive outcomes may be achieved, both for residents and for care professionals. These are: supportive leadership, positive attitude, and training; residents' changes and direct effects of odour; comfortable and enjoyable feelings; knowing the person and odour-related effects; and capturing the attention and promoting meaningful conversations. The outcomes of interest were refined during the review

process. The findings identified further outcomes that have received less attention in the literature, such as well-being, social inclusion, and self-identity. This suggests that there is a gap in the literature regarding relevant outcomes for assessing olfactory interventions.

There is great variation in the procedures and methods used in these studies. Limited information was found in this study to understand which group of participants (subtype and severity of dementia) may benefit most from the intervention. Evidence on the role of contextual factors influencing the outcomes and interacting with the mechanisms was often lacking. Stakeholder involvement was therefore used within the realist review to provide valuable information that further explored the complexities of olfactory stimulation programme, strengthening the research findings as discussed in Section 6.6.

The iterative analysis and synthesis suggest that some of the components such as ‘allocation of resources’ and ‘manager support’ which initially seemed merely practical elements, were instead found to play a relevant role in creating opportunities for motivating care professionals and understanding the importance of olfactory intervention within the care home system. They could act as facilitators or barriers to the successful implementation of the intervention as part of daily care. This resonates with previous realist reviews on interventions for people with dementia living in care homes (Bunn et al., 2018; Crosbie et al., 2019; Goodman,

et al., 2017b). For instance, Bunn et al. suggest that Namaste Care can be adopted in care homes if staff are ‘given permission’ to implement the intervention by allocating resources, time, relevant training, and support (2018, p.9).

A major result from the IRPT is that enjoyment and familiarity may be important sub-components underpinning the positive outcomes in olfactory intervention for people with dementia. These data provide new insights into the way that best practice can involve people with dementia in olfactory interventions. The mechanisms generated suggest that participants have an active role in mediating the interaction between odour compounds and response. This was often neglected in olfactory interventions for people with dementia which often consider only the direct connection between chemical properties of the odour and the expected physical changes.

In the present realist review, studies focusing on care professional burden were included. Although there has been found limited evidence assessing the impact of olfactory interventions in care professionals working in care home settings, some studies reported decreased staff burden as a direct effect of odour exposure and changes occurring to the residents and care home system, for example management of responsive behaviour, additional senior management support, and training.

Overall, this IRPT provides the foundation for developing and testing a coherent theoretical framework accounting for how olfactory interventions work for people with dementia living in care homes. From the analysis, it is possible to identify four principal circumstances under which olfactory interventions are likely to achieve the intended effects. These are:

1) Positive attitudes, realistic expectations, and beliefs on the benefits of olfactory interventions for individuals (care professionals and residents) should be enhanced in order to promote participation and engagement in the programme.

2) Olfactory interventions require the engagement and commitment of care professionals. This may be achieved through the provision of guidance, training, information on the intervention and its potential benefits. Commitment and adherence to the intervention depends on the opportunities provided to build the care professional's confidence and skills in delivering the intervention, appropriate physical settings, and time allocation.

3) Olfactory interventions should encourage playfulness and curiosity in the participants. These mechanisms can be affected by variation in the intervention materials, procedure, and administration methods, and enhance positive outcomes.

4) The intervention materials and administration methods should include stimulating attributes and at the same time a degree of familiarity which triggers mechanisms such as reassurance, comfort, and trust. This may be achieved by tailoring the intervention to the individual's characteristics and personal biography. For instance, familiar smells are more likely to spark conversations and trigger positive emotional responses.

6.6 Strengths and limitations

This review is the first study to apply realist methods to investigate olfactory interventions. The advantage of the realist approach is that it can explicitly consider the complexity of the interactions between programme and contextual factors. Application of the realist method has suggested some potential key mechanisms underpinning the programme which supported the development of initial theoretical explanations and in turn this may generate further theoretical and practical developments in this area. These mechanisms range from organisational and leadership variables to the experiences and beliefs of individual residents.

The realist method employed in this study to build the IRPT is a novel approach of enquiry. Compared to the traditional realist review where stakeholders act as consultants in the process, this study has incorporated stakeholders' expertise as primary data. Stakeholder involvement in the development of the IRPT strengthens the research findings in several ways. First, the online surveys helped

to extend the understanding of the programme and go beyond what is already established in the literature. Based on their knowledge and experience, stakeholders emphasised different components that were perceived as essential to achieving positive outcomes for care professionals and residents living in care homes. Secondly, they helped to uncover the reasoning as to why residents engage with the programme and highlighted the context in which these factors operate. Third, extracting information on what works, and why, from the stakeholder group increased the care practice relevance of the study results within the real world of care homes. Overall, the data collected from the stakeholders facilitated a deep understanding of the mechanisms, context and the complex interlink between them that contributes to consistency and transparency of decision-making in the development of the IRPT.

From a methodological standpoint, a realist review is iterative and possibly more challenging compared to a traditional systematic review (Pawson et al., 2004). It was challenging to create the IRPT from a complex context such as care home settings. In particular, it was challenging to identify the CMO configurations due to the multiple variables and different focuses that could be examined within the programme theory. This is both a strength and limitation of the realist enquiry. It is acknowledged that the judgment of a group of investigators may slightly differ from that of others who look at the same phenomena. This raises the question of

interpretation bias in the programme theory formulation. The answer to this is that knowledge creation is a cumulative and iterative process, whereby new knowledge is built on previous knowledge. The present work provides an exploratory account of the causal processes underpinning olfactory interventions and does not provide a definitive theory. As such, the IRPT developed requires further testing which would confirm, reject, and refine it further.

Subsequent testing of the IRPT to validate it was not performed due to time and resource constraints. The realist review is one component of the overall doctoral project and was conducted by one investigator (the author). Therefore, its focus was constrained to mapping out how programmes are supposed to work related to a range of selected outcomes. This study provides the foundation for further studies that could explore patterns and substantive theories underpinning the final programme theory.

A further limitation is the sample's characteristics. Stakeholders from different backgrounds were included and, while this provided the opportunity to investigate the phenomenon from multiple perspectives, it included some limitations. Firstly, the heterogeneity of the sample may have reduced the potential to generate meaningful patterns and themes across the dataset (Robinson, 2014). On the other hand, this limitation was attenuated by the process involving moving between primary and secondary data. Secondly, although stakeholders with

experience of working closely with people with dementia were included, the experiences and opinions of people living with dementia were not obtained. The IRPT could be further developed by investigating olfactory intervention from the point of view of intervention users, i.e. people living with dementia in care homes.

Another potential limitation is that the screening of the studies and the analysis were undertaken by a single researcher (the author). This is to some extent mitigated by the fact that the stakeholder group and the supervisory group discussions have provided opportunities to challenge and refine the IRPT.

Finally, there is also a limitation around culture and the fact that this study is limited to care home contexts, which are a less important component of dementia care in non-Western societies (Alzheimer's Disease International, 2013), so the findings may be limited in how widely they can be applied.

6.7 Reflections on the process of creating the IRPT

One of the challenges encountered in developing the olfactory IRPT was a lack of guidance and the heterogeneity of methodologies used in realist reviews. Different methods are employed among the literature. This is not surprising, as Pawson and Tilley (2004) recommended using the best methods for conducting the realist review, taking into account the study aim, resources, and timeframe. Furthermore, despite realist review being widely applied in health and social care research, its

use is relatively recent. As such, the methodological evidence base about realist synthesis is gradually built from the growing published work (Lacouture et al., 2015).

Classification and conceptualisation of context and mechanisms were challenging. As explained in Section 6.3.1.2, CMO configurations were identified by moving backwards from the intended outcomes of the intervention. As the realist review process progressed and the causal questions 'why' certain mechanisms create changes and 'how' they are activated by the context were addressed, the complexity of the IRPT became evident. By examining the potential CMO configurations in more detail, it appeared that some of the mechanisms identified in the IRPT model were not directly associated with the changes, and other intermediate processes were involved. A new hierarchy and a different set of relationships were identified. The information gathered as the realist review progressed showed a more complex programme than what was initially formulated. The relationships between CMO configurations were non-linear and not straightforward, but instead multi-causal and multi-directional. This highlighted the nature of realist methodology which is not mechanical as had been initially thought: it was expected to find CMO configurations lying in an orderly causal sequence. Mind maps and infographics were useful tools to visually represent the causal relationships between CMO configurations and overall, how the programme

was supposed to work and why it might not work. A series of ‘tube’ maps with multiple and colourful circuits were developed resembling the London underground map (e.g. see Appendix 9).

The complexity depicted by the visual tools led to the third challenge of the study, which included organising and synthesising the programme. It was important to articulate the IRPT in a way that could capture accurately the intricacy of the process yet avoiding confusion or over-simplification. The IRPT was formulated and refined through several meetings with the supervisory team.

Although some authors advocate for the use of substantive theories to build the IRPT (Herepath et al., 2015; Shearn et al., 2017), it was not found practical to incorporate them. Firstly, the focus of the realist review was not clear at the beginning of the review. It was refined and narrowed through the iterative process. Then, it was challenging to build a conceptual framework of existing abstract theories without knowing the main focus of the IRPT. Furthermore, selecting one theory over another as a framework from which the IRPT is developed could limit the explorative nature of this phase of realist review.

The realist review approach has provided a unique opportunity to answer questions related to how, why and in what circumstance programmes embedded in a specific social system i.e. care homes work. However, its flexibility and lack of practical prescriptions demand great time, intensive effort and specific researcher

skills, including a high degree of expertise in reasoning, research methods, and expertise in the topic being investigated (Fick & Muhajarine, 2019; Rycroft-Malone et al., 2012).

6.8 Conclusion and recommendation for future research

This realist review identified five CMO configurations that explore how key mechanisms operating in an olfactory programme within the care home setting interlink to generate the intended outcomes for people with dementia and care professionals. These findings should inform care practices and future research aiming to test the initial hypothesis.

This study established the groundwork for further investigation and analysis and thus testing of the CMO configurations. Future research could therefore confirm or disconfirm the emergent programme theory in relation to the literature through theoretical saturation (Cooke et al., 2018) and using additional follow-up data collection with stakeholders (Braun et al., 2021). It is expected that this iterative process would contribute to producing a refined set of theories. Further to this, refinements of the programme theory could be achieved by testing the underpinning active ingredients with people with dementia in a case study, where different components and their interactions could be explored and evaluated (Fletcher et al., 2016). The final programme theory would also benefit from the inclusion of substantive theories such as the notion of embodiment,

person-centred and relational care, or the principles of reminiscence therapy, which could assist the transferability of the body of knowledge identified (Shearn et al., 2017).

6.9 Summary and implications for MSI development

The realist review findings provide an explanation of why, how and in what circumstances olfactory intervention achieves the outcomes of interest, including implementation and intervention effectiveness. This includes outcomes regarding decreased care professional burden and improved residents' well-being and cognition, and reduction in responsive behaviours. The IRPT suggests that changes should operate concurrently at individual and organisational levels to ensure the intended outcomes. Evidence emphasised the need for supportive leadership and management, motivated, skilled, and knowledgeable care professionals, plus the positive attitude of residents and care professionals involved in the intervention. It also highlighted the importance of stimulating curiosity. The emerging key mechanisms underpinning olfactory programmes for people with dementia living in care homes are pleasant, relaxing feelings, familiarity, and comfort. In addition to this, reduced responsive behaviours of residents, were considered important underlying mechanisms of positive care professional outcomes.

This realist review provides evidence-based recommendations about olfactory interventions for people with dementia, extending the findings of the rapid review of olfactory stimulation (Chapter 5).

Adopting the realist approach within the MRC framework (Craig et al., 2008), theory development phase, has helped to build an initial olfactory programme theory and uncovers the complexity of the programme if implemented within care home settings. These findings enrich the understanding of contextual dimensions, underpinning mechanisms and the right circumstances for successful olfactory interventions in a care home. Although the proposed theoretical framework is not final, the IRPT is a valuable aid development of the MSI. The recommendations derived from the IRPT supported the refinement of MSI, as outlined in the following chapter, Chapter 7.

Chapter 7 outlines the process undertaken to develop the MSI, providing an overview of the evidence and theories as well as qualitative investigations with stakeholders that contributed to the MSI design. The chapter also presents the MSI-1 design in detail alongside the results of interviews with stakeholder experts on olfaction and archive professionals that contributed to the decision-making process of MSI-1 materials and procedure.

CHAPTER 7 DESIGNING MSI: IDENTIFYING THEORIES, EVIDENCE AND STAKEHOLDER INVOLVEMENT

This chapter describes the process undertaken and how the previous work from Chapter 2 to 6 informed MSI design for people with dementia living in care homes. The intervention development process followed three principal activities, as set out in the MRC framework (Craig et al., 2008). These included synthesis of the evidence in the literature, identification of the potential theoretical underpinnings of MSI, and modelling, including interviews with stakeholder experts on olfaction and archivists that were undertaken prior to drafting MSI-1 materials and procedures.

This chapter addresses the third objective (Section 3.2) of the overall thesis, designing a theory- and evidence-based intervention for people living with dementia, by illustrating how theories and evidence informed the decision-making process of MSI design, including selection of procedures, contents, and materials. Details of the MSI-1 design are also provided at the end of this chapter.

7.1 Introduction

As described in Section 3.4, the MSI development was guided by the MRC guidelines for the development and evaluation of complex interventions (Craig et

al., 2008). Accordingly, the intervention development process followed an iterative and non-linear process, during which multiple resources were integrated to inform and refine the MSI design. These included background literature review of multi-sensory stimulation interventions (Section 2.1); a scoping review of object handling interventions (Chapter 4); a rapid review of olfactory stimulation (Chapter 5); a realist review of olfactory stimulation (Chapter 6); interviews with stakeholders (the present Chapter); and taster sessions with stakeholders (Chapter 8).

The main findings of this work, apart from the taster sessions with stakeholders which are presented in Chapter 8, are synthesised below under the three main MRC activities of the development phase: evidence, theory, modelling.

7.2 Evidence

Evidence from the literature was used to map out the characteristics of multi-sensory stimulation, olfactory and object handling interventions, and their effectiveness. Specifically, this step aimed to identify the studies' characteristics, whether there are any specific factors associated with success, what group of participants in terms of type and stage of dementia could benefit most from MSI, and what outcomes are likely to be observed.

The background literature provides some evidence that multi-sensory stimulation interventions can improve behaviours and mood in people with dementia, as well

as having a positive effect on the mood of care professionals (Section 2.1). Due to the limited number of studies available, it is yet to be clarified whether or not multi-sensory stimulation interventions have positive effects in domains such as cognition and communication for people with dementia. The scoping review indicated that the most commonly reported outcomes associated with object handling session/s are increased well-being, social interactions, evoked memories, and new learning in people with dementia (Chapter 4). The rapid review of olfactory stimulation suggests that odours are powerful stimuli for eliciting positive changes in behaviours, physical functioning (sleep, food intake, balance), well-being and cognition including increased autobiographic memory retrieval and improvement in self-concept (Chapter 5 and Section 6.4.1). Taken together, the results of the reviews form an evidence-base from which the MSI was developed, demonstrating the potential of such interventions to influence positive changes in outcomes such as well-being, social inclusion, behaviour, cognition and physical health for people with dementia.

From the synthesis of the evidence, it was not possible to identify for whom MSI might be most effective due to the heterogeneity of samples within the studies reviewed. Most studies performed multi-sensory stimulation interventions with residents at mild to severe and moderate to severe stages of dementia (Pinto et al., 2020). Olfactory interventions were mainly conducted with those at the mild

and severe stages of dementia (Chapter 5). Regarding object handling, the studies focused predominantly on mild to moderate dementia (Chapter 4) but there is evidence that people at early stages of dementia experience a larger positive impact following the intervention (Camic et al., 2019). Thus, it was difficult to demarcate what group of participants in terms of severity of dementia could benefit most from the MSI. However, considering that the effect of object handling is greater in the early stage of dementia and sensory deprivation may accelerate cognitive decline (Humes & Young, 2016; Strawbridge et al., 2000; Whitson et al., 2018) and be related to an increased dependence in activities of daily living, social isolation and responsive behaviours (e.g. Baker et al., 2003; Maharani et al., 2018; Pinto et al., 2020), the use of MSI with people living with mild to moderate dementia may be justified.

Synthesis of the procedures and materials used in the reviewed studies were used to guide the MSI design. The explorative qualitative study by Griffiths and colleagues (2019) was particularly informative in the design of MSI-1. A detailed description of how Griffiths et al.'s study (2019) and other evidence informed MSI-1 procedures and materials selection is summarised below in Section 7.6.

7.3 Theory

The potential MSI outcomes and how these changes can be achieved may be understood using the existing models, theoretical frameworks, and the results of

the realist review (Chapter 6) which identified the potential mechanisms underpinning olfactory stimulation programme and optimal conditions for success.

According to the biopsychosocial model of dementia (Section 1.4), the inter-relationship between tractable and fixed factors influences 'the point at which the symptoms of dementia begin, the speed and nature of the deterioration' (Spector and Orrell, 2010 p. 959). The model suggests that tractable factors such as environment, mood, social and personal psychology can be modified using multi-sensory stimulation. People with dementia living in care homes are at risk of under- or over-stimulation due to various factors, which include their own cognitive and sensory impairments but also environmental factors, such as noisy communal areas or isolated single bedrooms or restriction in their activities (Haigh & Mytton, 2016; Jakob et al., 2019; Lee & Bartlett, 2021). As described in Section 2.1.2, there is evidence to suggest that sensory deprivation or being exposed to too much sensory stimulation (e.g. communal areas in care homes) can lead to the development or exacerbation of responsive behaviours. In line with the Model of Imbalance (Kovach, 2000), MSI may provide a balance between over- and under-stimulation. Stimulating primary senses in a controlled and tailored setting (e.g. a small group in a quiet space) can offer the opportunity for addressing the sensory needs of the individual, which can in turn improve behaviours, mood and quality of life (Cohen-Mansfield et al., 2015; Jakob & Collier, 2017b).

Vozzella (2007) argued that sensory stimulation can increase quality of life by enabling people to interact with others while engaging in an activity. Social interactions may play a role in further enhancing the benefits of MSI. For instance, in the context of object handling interventions, verbal interactions between care professionals, residents and facilitator help to promote inclusion, meaningful relationships and conversations focused on the objects and person (Camic et al., 2021). It could be also argued that group participants can relate to each other at the non-verbal level through bodily understanding e.g. exchange of expressive gestures, facial expressions or the movements of hand (Kontos & Martin, 2013).

Discussions about objects, especially those with historical or intriguing features, have been found to enhance memories, meaning-making, new learning, ideas and associations (Camic et al., 2019, 2021; Griffiths et al., 2019). For example, an artefact could prompt meaningful conversations about a specific historical time, how that item changed across time or trigger related personal experiences, thus facilitating the acquisition of new knowledge and associations.

Some authors (Paddon et al., 2014; Thomson et al., 2012) argue that these processes may also contribute to the promotion of self-identity. It is well-known that material objects can have a personal meaning that help to maintain a sense of self (Section 4.7.1). Handling and exploring material objects can also facilitate self-expression (Camic et al., 2021). Using material objects in combination with

olfactory stimuli can potentially boost a sense of self and identify. Olfactory processes involve areas of the brain such as the amygdala and other limbic structures that remain relatively intact in people with dementia. By activating these sub-cortical structures, olfactory stimulation elicits intense emotion and autobiographical memories which are often positive (e.g. El Haj et al., 2018; Glachet & El Haj, 2019, 2020a; Glachet et al. 2019). Pleasant emotions and memories may induce positive feelings, improvement in mood and strengthens the connection between an individual's past and present (Herz, 2016) and self-concept (Glachet & El Haj, 2020b).

Beyond the effect of specific sensory stimulations, such as touch and olfaction, MSI may promote well-being and quality of life of people with dementia by incorporating aspects of person-centred care. Yates et al. (2015) suggest that Kitwood's principles of person-centred care (e.g. respecting choices, valuing the person's history, feelings and strengths) may be mechanisms through which improvements in quality of life can occur. Therefore, elements of the person-centred approach were incorporated in the MSI, by valuing the individual's sensory experience, and the person's life history, opinions, beliefs, and emotions as outlined in Section 7.6. Reflecting and expanding upon the person-centred approach to dementia care, the MSI aims to recognise and promote the sense of

agency of people with dementia throughout the session, thus enabling them to participate and express themselves in a variety of ways.

The causal explanations found from the realist review of olfactory interventions (Chapter 6) enable identification of a range of practical components that may facilitate intervention success. These include the supportive role of care home managers, consideration of residents' and care professionals' attitudes and beliefs, delivery methods and intervention materials, and care professionals' skills and knowledge. A balance between novel and familiar was identified as important to stimulate mechanisms such as comfort and curiosity in people with dementia.

The realist review evidence highlighted the importance of developing effective interventions that could be implemented and integrated into daily care practices without increasing the workload for care professionals. One type of multi-sensory stimulation intervention, Snoezelen, has been criticised as care homes are required to purchase costly equipment, care professionals need appropriate training and knowledge on how to use the equipment**,** and extensive time is needed for implementation which is incompatible with a busy care home environment (Collier & Jakob, 2017). In contrast, Cheng et al. (2019) suggest that multi-sensory stimulation interventions involving thematic boxes and a group approach are the most promising because they are easy to implement with

minimal training and supervision as well as cost-effective. This supports and reinforces the rationale provided in Section 3.1 for the MSI development.

7.4 Designing and modelling process

The third step of the development process focuses on the designing and improvement of MSI with stakeholders. Prior to designing the MSI and selecting the materials, stakeholders including experts on olfaction and archivists were approached to gather their advice and expertise on smells and handling heritage objects, which in turn informed the identification of materials and procedures for MSI-1. Details of the study design, participants, and results are provided in Section 7.5 below.

As part of the modelling, the next chapter, Chapter 8, describes the process to refine and assess the acceptability and appropriateness of the MSI-1 through a series of sessions with stakeholders, including care professionals, older people without diagnosis of dementia and relatives of people with dementia. The results of those sessions supported the development of a second version of the intervention (MSI-2), which is outlined in Section 8.5.

7.5 Stakeholder involvement in MSI-1 design

7.5.1 Sample

The sample was purposive and participants recruited using a snowball technique,

with the aim to involve people who would be likely to have expertise in olfaction and heritage items. Snowball sampling refers to a purposive method based on recruitment of study participants using the network of an initial person or persons who have access to a target population (Naderifar et al., 2017). Thus, the recruitment process began by contacting a staff member of Boots UK archive and a research fellow from Givaudan UK, who agreed to identify other potential participants within their companies whom they believed would provide useful insights into smell and heritage items. Givaudan UK is the world's largest fragrance and flavour manufacturer. Boots UK is a pharmacy-led health and beauty retailer with approximately 2500 stores across the United Kingdom and Ireland. Boots UK archive contain a large and varied collection of objects, tracing the history of the international retailer from its first days as a herbalist store in Nottingham in the mid-19th century to its position as a modern global brand.

The olfactory experts (n = 5) were recruited from different departments within the company: malodour (i.e. unpleasant smells) researcher, neuroscience researcher, oral care analyst, sensory science technologist, and malodour technologist. At the time, the archivists (n = 2) had approximately four years of experience in using the company collection in public engagement events (e.g. ‘The Imagination Café’ – a showcase focused upon dementia research and potential use of archive objects in a therapeutic setting (Tischler et al., 2020)) and in activities with people with

dementia, especially those living in care home across the UK. These activities included a range of objects including olfactory items from their company archive which were stored inside a suitcase and presented to people with dementia. The olfactory items were administered either using tissues or paper strips such as those used in perfume shops to smell the perfume samples.

7.5.1.1 Ethical considerations

Ethical approval was sought and granted for this research from the University of West London's College of Nursing, Midwifery and Healthcare Ethics Committee (UWL/REC/CNMH-00489).

A participant information sheet (Appendix 11) with all details of the study and the researcher's contact information was provided to the potential participants during the recruitment process by the archive manager and Givaudan research fellow. Information about the study procedure and objectives was reiterated before the beginning of the interview, and then participants' written consent (Appendix 12) was sought in person.

7.5.2 Procedure

A topic guide (Appendix 13) was designed to facilitate the conversation during the semi-structured interviews with archivists and olfactory experts. For the purposes of the study, the topic guide included prompts focused on different potential approaches, techniques or materials that can be used, and any practical issues

that should be considered in the intervention design which specifically included object handling and smells. The interviews with the olfactory experts included questions on practical issues such as: ‘What is the best way to present smells?’ and ‘What actions can be taken to avoid people being overwhelmed by smells?’ Due to the archivists’ previous experience in using the archive collection in care home settings, the interviews focused on questions such as ‘What are possible positive and negative responses of people living with dementia to archive collection objects?’ and ‘What themes/topics have arisen from previous sessions?’. Both topic guides were reviewed by the supervisory team for clarity and comprehensiveness. A portable device was used to audio-record the semi-structured interviews, which has a double advantage as it captured the participants’ responses in full, avoiding losing the details of the conversation, and enabled the researcher to focus on the participant and any potential follow-up questions (Braun & Clarke, 2013). The audio-recordings were transcribed by the author removing any participants’ identification information from the transcriptions.

7.5.3 Analysis

This study applied thematic analysis to analyse the one-to-one interviews with experts. Thematic analysis has been widely used in qualitative data analysis in critical realism research (Mukumbang, 2021). This approach allows the development of patterns of meaning across the dataset through a reflexive

process and thoughtful engagement with the data (Braun & Clarke, 2019, 2021). The present analysis used an inductive process focused on identifying the explicit or surface meaning of the data (semantic themes) using the six stages of analysis proposed by Braun and Clarke (2006; 2019) (Table 7.1). This approach was considered more suitable to examine the content of the dataset because the aim of the interviews was to identify information on procedure, strategies, materials and administration methods that in turn could inform the MSI design.

Table 7.1 Thematic analysis (adapted from Braun & Clarke, 2006, 2019)

Phase	Description of the process
Familiarisation	A process of familiarisation with the data started with listening and transcribing the recordings, which took place straight after the interview sessions. At this stage, to each participant was attributed a code to replace their name, and any information that could identify the person was removed from the transcription to guarantee anonymity and confidentiality. The codes given are used throughout the thesis. Immersion in the data was obtained by re-reading transcriptions several times and taking notes of any information potentially interesting to the overall research questions.
Generating initial coding	The transcriptions were uploaded into NVivo software. Working systematically through the entire dataset, the coding process began by allocating descriptive labels to the text. Generated codes were applied to fragments of the dataset, and where needed new codes were created. Codes were shared with the first supervisor to reflect on the coding process and assumptions that were made in coding the data.
Searching for themes	Looking for themes, the codes were reviewed. At this stage, some codes formed a main theme, whereas others were grouped under other themes according to their relevance within the dataset.
Reviewing themes	Themes were checked at the level of the coded data extracts and in relation to the entire dataset, in order to ensure the themes had sufficient data supporting them and were relevant in relation to the entire dataset.

Naming and defining themes	This is the final step for refining themes which included defining the name and description of the aspect of the data the theme captured.
Producing the report	The results of the analysis are presented using an analytic narrative supported by a selection of quotations. Participants' extracts are presented using speech marks "" and include brackets [] when there are omitted words in a sentence or information supporting the clarity of the quote.

7.5.4 Findings

The study aimed to gather specific information on procedures, potential barriers, features and types of items that could in turn support the MSI design process. The master and subordinate themes are reported in Table 7.2.

Master and subordinate themes are presented, including quotes and brackets to identify whether the participant was an archivist (A) or olfactory expert (O) e.g. (A1) and (O1).

Table 7.2 Master and subordinate themes - stakeholders

Master theme	**Subordinate theme**
(1) Connecting	(1.1) Embodying individual differences (1.2) Focusing on the person (1.3) Embracing emotions
(2) Creating a comfortable atmosphere	(2.1) Trust (2.2) Familiarity
(3) 'Ingredients' for the sessions	(3.1) Administration method (3.2) Sensory material features

(1) Master theme: Connecting

The term ‘connecting’ refers to the way in which engaging with the olfactory items and objects supports connection related to the self, people, and specific spaces and times. Interacting with the items can spark conversations, emotions and memories, which create a space where people can connect with their story, experiences, feelings and other group members. This master theme has three subordinate themes: (1.1) Embodying individual differences, (1.2) Focusing on the person, and (1.3) Embracing emotions.

(1.1) Embodying individual differences

This describes the importance of considering the individuals’ differences to enhance connection with the items and the group within the session. Individual differences can impact the way participants interact with the items:

> “*They like to put things on* [wearable sensory items e.g. jewellery, hat]*, not everybody, some people did not want to put things on.*” (A2)
>
> “*For people who are used to a strong background odour, it may be quite difficult to sense and appreciate the change of odour because they are subjecting to a quite strong background*.” (O4)

Some participants suggested considering physical and sensory impairments of people with dementia when planning the session:

> “*Some of the residents or people involved in the sessions had arthritis and they may be struggling a little bit more* [to open/explore objects].” (A2)

"*Some people cannot smell at all; some people have a strong sense of smell.*" (O1)

Participants also spoke about how knowledge of the person can enable use of relevant materials which could stimulate interest, a sense of familiarity, and engagement in the residents. One participant talked of her experience:

"*There was a former member of staff* [from the archivist's company] *living in a care home where we went. It was a person that I knew, and I knew what could interest him. It was an old annual report* [an item containing employees' details of a company]*, which he was looking through; it was unusual because it was not an object but an archive.* […] *He couldn't remember where he worked or when he was born. When he opened the annual report, he could see the face of people that he remembered; there were just their initials but he said their full name and he spent a good 20 minutes looking at the document.*" (A1)

Similarly, other participants commented on the subjective nature of associations and memories triggered by materials, especially smells, and therefore the importance of knowing the person:

"I think it would be to try to understand as best you can the subject, what are they like, and perhaps you can talk with their relatives to know where they grow up. [...] *There might be a particular smell, for example the smell*

of fish and chips or the sea air may be something that could trigger specific memories. I think for me that would be the logical things to understand a little bit about each of those participants because one odour might do for one but no do very much for the other." (O5)

"I think if you could have good smells of things that people were likely to have come across, they used during their lives." (O3)

Participants indirectly stressed the importance of contextualising the items in their relevant historical period. They reflected on what products, trends, habits, and behaviours were common in the childhood and adult life period of people now aged of 65-80 years. This suggests that items should be selected considering individual differences as well as the social and cultural historical period that may be of relevance to older people.

(1.2) Focusing on the person

'Focusing on the person' relates to directing the attention or valuing individual experience to create opportunities for engaging and sharing moments which could connect participants. Respondents highlighted the importance of spending sufficient time with each person during the session. They reflected upon how this could be achieved by discussing three main practical aspects, including size of the group, practical support, number of items used, and administration method. For

example, a respondent spoke about the number of people taking part in the session and the importance of having a small group:

> "*The last time when* [archivist colleague] *and I did a session, there were around twenty people. It was impossible to divide time, and you want to give to everybody equal amount of time. I would say six or max eight people is a good number of people because you get time to spend with each of them; nobody feels to be left out for a long time and there is a good chance that people start to have chat on their own. This would be something that I am really firm about, because it has an impact on the outcome of the session.*" (A2)

Another respondent spoke about the importance of having appropriate support within the session based on her experience:

> "*If there are just two or three of you* [facilitator/support]*, it is not enough to keep the attention of all of them and that feels disappointing because some really engage with the items but those that are not, we do not really have time to guide them through it*." (A1)

Participants spoke not only about the group size but also about the number of materials and methods to use in order to ensure that everyone could engage at the same time. Participants stressed the importance of using "*enough objects of interest*" (A2) within the sessions according to the number of people taking part in

the group. One participant spoke of the optimal number of materials for a group of five people:

> "*I would probably say twenty per session. Sometimes things just fall flat. Giving the session, it is better to have things in the box that you decide not to use rather than run out. That is much worth*." (A1)

Similarly, some participants discussed the method of presenting the items which seemed important for the stakeholders to promote the group engagement.

> "*Normally I have enough of this* [olfactory items] *that they share, or they have one each or one between two because it is much nicer to smell and then talk to your neighbour; and that, sort of, starts the conversation. I give them time to talk, so everybody smells the same things at the same time and then talking about it*." (O2)
>
> "*I suppose that if you have a room full of people, it would be nice for them to all smell the sample at the same time, so then you haven't got that waiting for it.*" (O4)

Participants reflected on the questions used in the session that could support and empower people with dementia in their interaction with the items. Some recommended directing the focus of the conversations on the individual's opinions, and associations, instead of recognition:

"I am doing a lot of talks to [a charity for people with limited vision], a *lot of them* [member of the charity] *tend to be quite elderly and they struggle to come up with the terms, but it is about how you phrase it. If you say 'does it remind you something?' they would come up with the memories more easily than they would come up with the name.*" (O2)

"*'Do you think this is for men or woman?' That is another way to present smells which it is less about what it is or whether it remind you of any things but just what do you think about the smell. And this works quite well*." (A2)

(1.3) Embracing emotions

This theme highlights the emotional connotations attributed to and carried by objects and smells. The emotional attachment that individuals can form with objects and smells, and the memories stimulated by them can trigger strong emotional responses from people living with dementia. An illustrative example of an emotional response and consequent mood change when interacting with stimuli was provided by one participant:

"*At the beginning of the session, he was quite frosty, he was questioning why he was there, he did not really want to engage. […] after that* [looking at the annual report] *he was charming, happy that we come and quite emotional at the end of it. That was a very interesting change in mood from one item, it was incredibly powerful*." (A1)

A respondent with experience of working with care home residents spoke of how people were inclined to share their feelings or experiences:

> "*I found that people are very willing to talk about their smell memories, normally they are good, normally they want to share them a lot.*" (O4)

Previous experiences can shape and determine an emotional relationship with items, thus emphasising the subjective nature of the response and the links to the subordinate theme (1.1) 'embody individual difference':

> "*Personally, I have very fond memories of being on a farm when I was a child. So, it would be farm smells, and even today I do not find them particularly offensive because it reminds me of pleasant holidays.*" (O1)

Alongside positive emotions, participants reflected upon the potential negative emotions that can be evoked by smells or particular items (e.g. hand mirror). For instance, one participant reflected on the distress that some people may experience by seeing their reflection in a mirror. As the dementia progresses, people with dementia may not always recognise themselves (Kelsick et al., 2021).

> "[…] *if somebody has dementia, it can affect their appearance and suddenly show to somebody what they look like, they might not recognise themselves in the mirror, and it could be upsetting to see how they changed*." (A2)
>
> "*It is tricky because sometimes very rarely a smell is associated with a bad memory, and you never know when it would happen*." (O2)

However, another participant suggested that emotional experiences triggered by the sensory items, even sadness or nostalgia, should not be considered negative.

(2) Master theme: creating a comfortable atmosphere

This theme refers to the importance of providing a space where people can feel comfortable within the group setting and the items. Ensuring that participants feel comfortable, for example by handling familiar objects, can increase the degree of participation and engagement in the session. Notably, the concept of being comfortable was also applied to those who facilitate the session. For example, one participant suggested that if there is a positive response to the first items presented, this could boost facilitators' confidence, making them more comfortable within the session. This theme is underpinned by two subordinate themes: (2.1) Trust and (2.2) Familiarity.

(2.1) Sub-theme: Trust

This highlights the importance of building a sense of trust between people with dementia and the facilitator to support the activities undertaken in the session. One participant spoke of the importance of how to introduce the items:

> "[…] *We think that some people imagined that we were there to sell the items because we turn out with the suitcase* [a suitcase was used to store the items] *and put things out. The generation they are, probably had people come to their house to sell stuff in a suitcase. For instance, some people*

say 'I do not want to buy them'. When we ask if they want to try the hat on, they answer 'no thanks, I am alright'." (A2)

Similarly, other participants explained that people who are feeling suspicious, or mistrustful tend to disengage or refuse to interact with the items and the group:

"*They think that we try to sell them* [archive items] *but less with objects that are not necessarily things that you would see in the shop. It is a shame because they are almost dismissing, and they do not want to engage with them. Sometimes they do not want to look at them.*" (A1)

"*I think people find it easier to smell an object. Particularly, if you have the paper strips that are very small, people quite often would say 'I cannot smell anything' or they don't hold near enough because they are a little bit anxious about what you have given them or whether it would smell nice*." (O2)

The above examples demonstrate that the perception of being in a safe and trusting relationship supports participants to engage with the items and the group.

(2.2) Sub-theme: Familiarity

Connecting closely with the subordinate theme (2.1) 'Trust', 'Familiarity' describes how the procedure, space and group, are important for people living with dementia as it may promote a sense of security and control of the process. Together, trust and familiarity can promote engagement and self-expression within the session.

Participants talked about the cumulative effect of repeated sessions, suggesting that a structured session and clear procedure could contribute to promoting recognition and familiarity:

> "*When we did* [a previous intervention] *six weeks in a row in a care home, we brought everything in a suitcase. After week four or five, one of the residents said that 'she knew that something exciting was going to happen because she saw the little blue suitcase'. […] she obviously remembered the suitcase.*" (A1)
>
> "*I think that it is much more about people really understanding the layout of the session. There was definitely an advantage of doing it more often* [multiple sessions]; *definitely, they were just more accepting what you were doing and willing to take part*." (A2)

Participants commented on the physical and social context where the session takes place, suggesting the importance of space and the presence of familiar people to participants:

> "*The environment is also important; someone they are comfortable with or familiar and there are carers in the room."* (A2)
>
> *"I think that if you know the group it is great. So if it is somebody that already works in the care home where you have already got that trust that*

would be different from us going in. You can ask some questions that you know how they may respond." (A1)

(3) Master theme: 'Ingredients' for the sessions

This theme clusters together some of the practical advice and suggestions from the participants concerning the types and features of materials and administration methods that could be used within MSI. The two subthemes underlying this theme are: (3.1) Administration method and (3.2) Sensory material features.

(3.1) Administration method

Participants talked of olfactory administration methods, which are discussed in the following Section 7.6.2. Participants emphasised their concern for the safety of people with dementia, such as avoiding overwhelming smells and adverse medical reactions:

"*A glass jar with a cotton pad at the bottom or soborods* [a sealable plastic jar with a cotton pad] *gives the standard distance from where you are smelling it.*" (O4)

"*We also used pots that we passed around, but you have to be careful that the liquid does not spill, or they do not try to put their finger inside, it may be that someone has an allergic reaction to something, which are the risk with pots*." (A1)

"*The thing to be careful with it is the liquid, we were worried that they can drink it.*" (A2)

Other participants reflected on the use of visual prompts, such as pictures or original packaging of the olfactory items which could support people with dementia to contextualise the smell and reduce potential distress:

"*I think soap is brilliant because it is intrinsic to the thing, when you remove the smell from the object is much harder to recognise the smell.*" (A1)

"I think it definitely helps them if it is the original items because you got this obvious connection with what it is rather than put into the paper and ask to guess what it is." (A2)

(3.2) Sensory material features

Participants suggested a list of key features of the smells and objects that could be important to enhance engagement and elicited response, see Table 7.3.

Table 7.3 Suggested features of items

Features of smells:	**Features of objects:**
Everyday smells	Distinctive texture
Familiarity	Including explorative touch
Strong and intense	Familiarity
	Wearable

A common feature for both smells and objects is the notion of familiarity. Participants suggested that familiar items are more likely to evoke memories, conversations, and overall engagement.

Furthermore, archivists were asked questions about their previous experiences of using heritage objects within thematic boxes in a previous study (Griffiths et al., 2019), such as what themes or items work best. Details of how archivists' feedback was used to inform the themes of MSI are provided in Section 7.6.

7.6 Designing MSI-1

The findings of the interviews with experts, alongside the key results derived from reviews of the theory and evidence, were brought together to design the first draft of a theory- and evidence-based multi-sensory stimulation intervention. It is important to acknowledge here that the results of the realist and rapid reviews did not inform the proposed MSI-1 because at the time of drafting the MSI-1 they had not yet been conducted.

The MSI-1 combined olfactory and material objects in a novel intervention, tailored for people with dementia living in care homes. The following sections provide a description of the decision-making process and rationale involved in designing the intervention structure, procedure and materials.

7.6.1 Structure and duration of MSI-1

The MSI consists of ten group sessions twice a week, for five consecutive weeks. There is good evidence that group interventions can be beneficial for care home residents (Cheng et al., 2019). Comprehensive evidence of the impact of group activities was reported in a previous study (Cohen-Mansfield, 2018), which demonstrated that residents of care homes were significantly more engaged, less sleepy and with positive mood when they were involved in a group activity, regardless of the content (e.g. games, holiday discussion, choral singing), compared to unstructured time. This was confirmed via informal observations made during a series of events as part of the Boots UK campaign on dementia awareness and on the potential use of archive objects during the Dementia Action Week in 2018. One of these sessions was recorded as a film that shows how residents of a care home interacted with the Boots archive collection (see www.boots.com/health/dementia-friends).

As regards the timing and frequency of sessions, it was not possible to delineate whether there is an optimum number, frequency, and duration of sessions for the success of multi-sensory stimulation interventions due to the heterogeneity of procedures used (e.g. Chen et al., 2019; Pinto et al., 2020). Pinto et al. (2020) found that the most frequently reported ‘dose’ of sensory stimulation interventions comprised 30-minute sessions, delivered twice a week over a four-week period.

Stakeholders commented on the positive effects of repeated sessions on people with dementia in terms of promoting a sense of familiarity. Similarly, Griffiths et al. (2019) reported the cumulative benefits of multiple sessions (n = 6) as increased engagement was observed through the sessions. Therefore, it was reasoned that including four extra sessions in the MSI-1 may increase the benefits associated with the intervention.

Regarding the session duration, the stakeholder group recommended longer sessions of up to two hours. MSI-1 sessions were planned to last one hour to ensure that the intervention is appropriate for residents, who may be frail, and feasible for care homes that may already have a busy daily schedule. Each session follows a consistent structure. This includes introduction activity, intervention activity and session closing/summary. As interview findings indicated, a clear session plan provides continuity and consistency across the sessions, which helps the residents to become familiar with the activity. This is also supported by group cognitive stimulation therapy findings, where structured sessions with a clear outline are a key feature of the programme (Yates et al., 2014).

The structure of the intervention activity was informed by object handling studies and the operational definition model of object handling (Section 4.7.3). Most of the published studies on olfactory stimulation (e.g. D'Andrea et al., 2022) and some

multi-sensory stimulation interventions (e.g. Pinto et al., 2020) have used a passive stimulation approach. This approach emphasises passive participation within the session, with it being assumed that sensory stimulation, e.g. a pleasant smell, can be beneficial in absence of an active engagement. These consider people as passive recipients instead of active agents.

In contrast, the MSI-1 session outline includes introduction of materials by a facilitator, followed by passing items around the group, allowing time for everyone to handle, smell and comment on them, should they wish to do so. Each sensory item from the box that has been explored should be displayed on a table, allowing participants to choose whether they want to engage further with one or more of them. This session format promotes stimulation of the primary senses, active participation and engagement of the participants according to their abilities and cognitive resources (Camic et al., 2021), giving everyone the opportunity to choose when, how and what level they wish to participate (Griffiths et al., 2019). Care professionals involved in that study reported that the inclusive nature of the intervention was a key element for promoting residents' participation and the feeling of being part of a group (Griffiths et al., 2019).

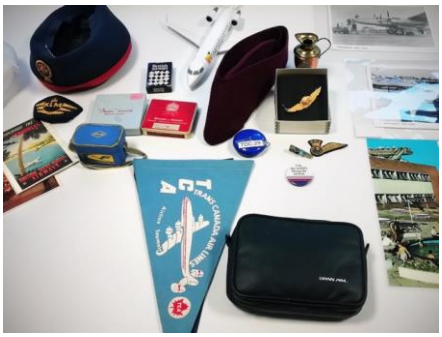
Based on the study protocols of Camic et al. (2019), Griffiths et al. (2019) and Thomson and Chatterjee (2016), meaningful conversations among the group can be stimulated by asking questions such as 'What does the object feel like?' 'What

do you find interesting about it?' 'Do you like the scent?'. As the findings suggested, prompts were purposively selected that place value on participants' opinions and feelings rather than factual answers, thus increasing individuals' confidence in expressing themselves.

7.6.2 Materials for MSI-1

Each session employs a box with heritage and olfactory items grouped by themes (Table 7.4). Heritage items were selected from the Boots UK and Heathrow Airport archives (Figure 7.1). The Heathrow archive collection traces the story of Heathrow from 1946. There are more than 800 items within the collection including official documents, promotional materials, airline souvenirs, cabin bags and model aircraft. The Boots UK company archive contains about 5000 boxes of documents and other printed matter and around 800 boxes of varied collection of objects, tracing the history of the international pharmacy-led health and beauty retailer from its first days as a herbalist store in Nottingham in the mid-19th century to its position as a modern global brand. These archives were selected as both are well-known companies in the UK. This means that their collections are likely to be recognisable to individuals of all ages in the UK, and can therefore potentially be utilised for therapeutic benefit. Furthermore, there is evidence demonstrating the value of Boots UK archival objects in the care of those living with dementia (Griffiths et al., 2019; Tischler & Clapp, 2020).

Figure 7.1 Example of Boots UK (left) and Heathrow (right) archive items



The themes were adapted from Griffiths et al.'s (2019) multi-sensory boxes. Themes that had received positive responses were incorporated into MSI-1, such as 'Parenthood', 'Childhood' and 'Christmas'. Notably, many stakeholders when discussing the benefits of olfactory stimulation and its role in triggering vivid and emotional memories spontaneously reported smells and related memories associated to Christmas. This may suggest that Christmas is associated with distinctive odours and happy moments. In contract, the theme 'Illness' was less successful in stimulating participants' interest (Griffiths et al, 2019), so it was removed. Some themes were modified, for instance 'Out on the town' was split into three themes 'Walking in the city', 'Time to go out' and 'Leisure time', and 'Daily routine' was replaced by 'Personal care'. Two new themes were also introduced into MSI-1: 'Travelling' and 'School'.

Table 7.4 The MSI-1 themes and materials

Week	Theme	Material objects	Olfactory items
1	Travelling	Ashtray, stewardess beret, metal jug, fly BOAC tape measure, wing cabin, crew brevet.	Cigarette tin, flight bag, chocolate box, sun cream, seaside.
2	Walking in the city	Train ticket, umbrella, gloves, camera.	Cut grass odour, ground coffee, Petrichor odour (summer rain), steam train.
3	Time to go out	Hats, scarves, ties, handbag, jewellery, powder compact, lipstick, wallet, braces, comb, money.	Floral perfumes (lilac or rose), brilliantine hair cream.
4	Childhood*	Dolls, owl puppet, spinning top, first aid kit, building blocks, leather satchel, Brownies/Scout stuff, kids magazine/ annuals/comics, roller skates, birthday badge/card.	TCP, Germolene, cough mixture, liquorice, disinfectant.
5	Household treasure	Teacup, rolling pin, tea pot, shopping basket, milk bottle.	Lavender bags for wardrobe, disinfectant, polish, roasting smell, toast bread, bacon, washing powder.
6	Parenthood*	Feeding bottle, feeding bowl, bibs, oral pacifier, rattle, baby cutlery, nappies, nappy pin, blanket.	Baby soap, baby lotion, baby powder.
7	School	Books, crayons or pen box, poster or photos, slate, ruler, pencil case, satchel, school cap, Prefect badge, exercise book, abacus.	Ink, chalk dust (chalkboards), glue or school paste, leather, cabbage.
8	Leisure time	Picnic hamper, picnic rug, binoculars, camera, National Trust guidebook, library card, theatre programmes, cinema tickets, football programmes.	Popcorn, cut grass, fish and chips (vinegar).
9	Christmas*	Cards, advent calendar, baubles, wrapping paper, tinsel, crackers.	Cinnamon, orange, pine tree odour, almond, vanilla, satsuma.
10	Personal care	Sponge, hairbrush, shavers, deodorant bottle, poster and photos, hair rollers, flannel, loofah, shower cap, Kirby grips, hairdryer, nail clippers, tweezers, toothbrush.	Shaving stick, Cremolia soap, talcum powder, Cold cream, carbolic soap, hair shampoo.

**Themes included in the Mementos multi-sensory boxes (Griffiths et al., 2019).*

Heritage items

The process of identifying appropriate items for the intervention was supported by Boots UK and Heathrow archive staff. A range of items was selected in discussion with archivists. These were reviewed focusing on their physical features (e.g. shape, size, colour, material), history, role and potential to trigger curiosity and conversations. Objects that are difficult to be handled or that could trigger distressing memories, e.g. associated with wartime, were excluded.

The stakeholders also advised on the use of items that supported 'explorative touch', for example items that could be opened and explored, such as handbags or tins. It was also suggested that wearable items such as hats, ties and gloves are powerful stimuli, they bring the group together because they can be worn and may provoke others to react and comment. As discussed in Section 4.7.1, items such as handbags can also carry symbolic and personal meanings (Buse & Twigg, 2014; Stephens et al., 2013) which may enhance engagement and emotional response.

Regarding the number of objects per session, it is unclear whether there is an optimum number to be used. In previous research, Johnson et al. (2017a) found that five to six objects were a good number to handle and discuss within a one-hour session. Camic et al. (2019) suggested that 8-10 items may provide additional opportunities for engagement and kinaesthetic experiences within the

session. Similarly, the archivists recommended a larger number of objects per session (i.e. 10 to 20 items) to maximise variety, opportunities for exploration and to accommodate diverse participants' interests and capacities. Therefore, it was reasoned that a range of items between 8 to 15 would be a reasonable number to use within a session of MSI-1.

Selection of olfactory items

The olfactory stimuli used by Griffiths et al. (2019) were adapted based on a dataset of olfactory stimuli (Tischler & Clapp, 2020), and the results of an unpublished study ('Smell a Memory') (Tischler et al., 2019).

Tischler and Clapp (2020) assessed the potential therapeutic benefit of a range of olfactory items from the Boots UK archive, developing a list of product profiles for items with high potential for use in sensory stimulation sessions, including such information as a description of the product, the year(s) in which it was produced, and the olfactory ingredients used. Some of these items, such as an antiseptic soap bar (carbolic soap), a scented hair oil (brilliantine), talcum powder or hair shampoo, were included in MSI-1.

In addition to the items from Boots, other olfactory stimuli (odours) were included. Consideration was given to select a set of odours appropriate for use with a

UK-based population as it has been reported that the response to odours is influenced by a person's cultural background, which provides the framework upon which odours are experienced and perceived (Herz, 2016). For example, Ferdenzi et al. (2016) found that wintergreen, an aromatic plant with a minty odour and flavour, was perceived as unpleasant by French people compared to Canadians from Quebec because this odour is often used in medication products, such as balms for muscle care, in France. Therefore, MSI-1 odours were selected from a UK-based study, 'Smell a Memory'.

Smell a Memory was conducted in 2019 by the University of West London in collaboration with Givaudan. The research aimed to describe the olfactory experiences of older people and identify whether there are relevant odours, and to adapt a set of odours developed and evaluated in Singapore (Ong et al., n.d.) for the UK population. From the Smell a Memory study, a list of distinctive and strong odours related to the participants' past and everyday life were developed. Some relevant odours reported by the participants were powdered or ground coffee, toast and fresh bread, cut grass, wet rocks, bacon and roses (see a full list in Appendix 14).

All odours for use in MSI-1 will be created by Givaudan UK according to the international standard (International Fragrance Association https://ifrafragrance.org/safe-use/standards-documentation) and olfactory objects

will be provided by Boots UK archive which holds original formulations for odours, medications, and cosmetics.

Administration of olfactory items

In the design phase, consideration was given to identifying the most appropriate methods to present olfactory stimuli. Griffiths et al. (2019) used a combination of Boots' olfactory items, such as soap, toothpaste and fragrances of lavender and lilac sprayed onto a paper strip. The findings from the stakeholders' interviews indicated that paper strips and modern odour containers such as unlabelled bottles often hold little interest for people with dementia. It appears that using paper strips and removing the smell from its context (i.e. packaging) is highly artificial, as most real-life experiences are multi-sensory. For example, the experience of smelling fresh lavender whilst walking through a garden is different from smelling it in talc applied to the body. In addition, a paper strip may fail to deliver a sufficiently strong stimulus for the person to detect it. Tischler and Clapp (2020) suggested that packaging and branding may provide important visual appeal as well as give clues and context to olfactory elements. These benefits can be extended if they are from an era that resonates with the individual.

Olfactory experts suggested the use of a sealable jar with a cotton pad, such as soborod, based on their professional experience in testing smells with panellists i.e.: a group of customers or consumers who are recruited to describe their

sensory experiences regarding a new product. It is important to note that their panellists are healthy adults of mixed ages and not older people living with dementia. The soborod helps to preserve the smell for a long time, reduces the diffusion of the smell in the surrounding environment during the session, and is also easy and safe to handle. In the absence of any other evidence on the most appropriate method for presenting olfactory stimuli, a combination of olfactory objects and soborods with odours was included.

7.7 Discussion

Following the MRC guidelines for complex interventions, MSI-1 was built by reviewing existing evidence and theories and by using the findings from analysis of interviews with archivists and olfactory experts. The key findings of the development process are summarised in Table 7.5 in line with the TIDieR checklist (Campbell et al., 2018).

Table 7.5 MSI-1 description according to the TIDieR checklist (Campbell et al., 2018)

TIDieR Item		Description of the item
Name		Multi-sensory stimulation intervention (MSI)
Why	Rationale	People with dementia living in care home have high risk of sensory deprivation or over-stimulation (e.g. common areas in care homes) which can lead to the development or exacerbation of the responsive behaviours, diminish quality of life and mood.

Table 7.5 *(Continued)*

TIDieR Item		Description of the item
	Theory	Multi-sensory stimulation offers the opportunity for addressing the individual sensory needs through a balanced sensory stimulation.
	Goal	To improve well-being, social inclusion, behaviour, physical health, and cognition.
What	Materials	Place the 8-15 selected olfactory and object items related to each theme in a box or case.
	Procedures	Introduce the activity: inform the participants of the aim and characteristics of the activity such as spend time exploring some interesting items together. Intervention activity: presenting one item to each participant or let participants choose one from the box. Facilitator should encourage each participant to handle and examine the objects. Allow participant time to do this. When they are finished, the facilitator can handle the object and smell it as well and make comments, responding to what the participants said or did. Prompts can be used if needed to stimulate conversations. Repeat, until all items in the box have been handled and discussed. End session: thank participants for taking part. Participants can be asked if they have any items or topic preferences for the next session.
Who		Group sessions of 5-6 participants. More appropriate for people with mild to moderate dementia. Facilitator could be anyone with good communication skills, knowledge of the participants and general information about the intervention benefits and olfactory safety standard.
How		The intervention is delivered face-to-face in a group setting.
Where		Within care home setting. A quiet, relaxing, well-ventilated room, clear from other items or smells (e.g., air fresheners) with chairs and table.
When		10 sessions completed twice a week, for five weeks. Each session lasting up to one hour: activity introduction (10 minutes); intervention activity (40); closing (10 minutes).
Tailoring		The programme themes and materials can be tailored based on each participant's preferences. Facilitator can think about objects that each person with dementia (participant) enjoys now or in the past, including their preferred smells. Facilitator can ask residents, find out more about their life, or investigate what was popular when they were in their late teens or early 20s.

This MRC phase is an essential component for the intervention's development. It helps to identify the likely changes associated with the intervention, and the theoretical framework within which those changes occur. Establishing the probable active components of the intervention 'may lead to better-developed interventions, and also to better-designed evaluations', including appropriate and reliable measures for assessing the changes (Craig et al., 2008, p. 17).

The experts' involvement in the development process has been valuable. Their professional experience and knowledge helped to answer questions in relation to the identification of suitable intervention materials and optimal procedures. Their input also supported development of how to implement the intervention and any potential barriers in delivery of MSI-1, as recommended by the MRC guidelines (Craig et al., 2008).

The next phase in the development of the intervention focused on gathering feedback on the acceptability and appropriateness of MSI-1 through focus groups and interviews with care professionals, older people without a diagnosis of dementia and family members of people with dementia. The following chapter describes the qualitative investigations which enabled the refinement of MSI-1.

CHAPTER 8 MODELLING PHASE: INVOLVEMENT OF STAKEHOLDERS IN THE INTERVENTION DEVELOPMENT

As part of the modelling of the MRC framework (2008), this chapter presents the process of refining MSI-1 through the input of stakeholders. The chapter describes a series of interviews and focus groups with care professionals, relatives of people with dementia, and older people. The data gathered from stakeholders ensured that the MSI-1 content and procedure were appropriate, relevant, practicable and acceptable for people with dementia living in care homes. This study addresses the fourth objective (Section 3.2) of the research which consisted of refining and assessing the appropriateness, practicability, and acceptability of MSI-1. The results from these sessions informed the development of MSI-2.

8.1 Introduction

After articulating the MSI-1, as described in Chapter 7, it was important to explore its key components and content from the stakeholders' point of view. As discussed in Section 3.4.4, it is often recommended to obtain stakeholders' feedback prior to any further complex feasibility and evaluation investigations (e.g. Levati et al., 2016; O'Cathain et al., 2019a; Yardley et al., 2015). At this stage, therefore, a

series of taster sessions using qualitative data collection was conducted to identify potential issues or unintended consequences associated with the MSI-1, to assess the acceptability, practicability and appropriateness of MSI-1, and find adaptations that could be integrated into the MSI-2.

8.2 Aims and Objectives

8.2.1 Aims

To refine and assess the appropriateness, practicability, and acceptability of MSI-1.

8.2.2 Objectives

- To explore stakeholders' perceptions of the multi-sensory stimulation interventions.
- To assess and refine MSI-1's contents, materials, and procedure.
- To identify any barriers and unintended consequences related to the MSI-1 content and implementation.

8.3 Methods

8.3.1 Study design

Qualitative methods including focus groups and one-to-one semi-structured interviews were selected for this study.

Ethical approval was sought and gained from the University of West London's College of Nursing, Midwifery and Healthcare Research Ethics Committee (Ref: UWL/REC/CNMH-00489, 15/10/18).

8.3.2 Sample

Purposive sampling was employed to recruit key stakeholders with relevant professional or personal experience who could contribute to addressing the research objectives. Participants were included in the study if they did not have medical conditions, such as allergies, skin sensitivities, or immune system deficiencies, as they could be more sensitive to odours and may experience allergy symptoms or worsening asthma symptoms from exposure to odours during the study.

8.3.2.1 Recruitment process

Care professionals, relatives of people with dementia and older people were identified as key stakeholders. Older people were recruited from a coffee morning group that took place every month in a North London library. Initial contact was made with the library manager who agreed to support the study by providing a contact for the coffee morning and a venue for conducting the study. From this, arrangements were made to present the research to the library group members, who were provided with copies of the participant information sheet (Appendix 15). People who expressed interest in taking part in the research were contacted

individually via telephone or email after one week to enable them time to consider their participation in the study.

Care professionals and relatives of people with dementia were recruited from a private care home in South London. Recruitment was conducted after the care home director accepted the invitation to participate in the study. The author was invited to participate in a meeting between care professionals, managers and relatives of the care home residents. During the meeting, the author explained the procedure and aims of the research and provided copies of the participant information sheet (Appendix 16) for both care professionals and relatives of people with dementia. Phone contact with those who took part in the meeting was made by a care home manager approximately one week later, to enquire whether care professional and relatives wished to take part in the research.

Written consent (Appendix 17) was provided by participants at the beginning of the research activity. To further ensure that participants were fully informed, research procedure and data confidentiality information were re-discussed prior to obtaining consent.

8.3.2.2 Sample characteristics

A total of 13 people took part in the taster sessions. All participants had professional or life experience with people living with dementia. The first group comprised four older people without a diagnosis of dementia, aged 64-72, who

had personal experience (family members or friends) with dementia. The care professional group (n = 4) was composed of three females and one male. They were all permanent staff with at least four years of experience in working directly with people with dementia in a care home. The last group, relatives of people with dementia (n = 5), consisted of three females and two males, with a mean age of 58 years. Their family members were living in a care home for at least six months and had a moderate stage of dementia, apart from one participant whose parent had advanced dementia. Participant data are summarised in Table 8.1.

Table 8.1 Demographics of information taster sessions

Older people		**N = 4**
Gender	Female	3
	Male	1
Age range		64-72
Care professionals		**N = 4**
Gender	Female	3
	Male	1
Mean years of care experience		12.5 (range 4-30)
Relatives of people with dementia		**N = 5**
Gender	Female	3
	Male	2
Age range		53-65

8.3.3 Data collection

Semi-structured interviews and focus groups were conducted to gather participants' opinions on multi-sensory stimulation interventions for people with dementia, and to explore the MSI-1. Data were collected from the four older people by individual semi-structured interviews and from care professionals and relatives using one focus group for each group.

An advantage of qualitative methods is that they facilitate gathering of rich details that provide a comprehensive picture of the participants' views in relation to the subject of investigation. The key feature of focus groups is the interactive nature of the discussion derived from the interplay of participants (Massey, 2011). Focus group discussions can provide insight into participants' perceptions, beliefs and opinions, as well as revealing the shared meaning and understanding of a phenomenon among a group (Mukumbang, 2021). The rationale for using separate focus groups with care professionals and relatives of people with dementia was that participants from both groups have something in common, i.e. they provide care, albeit as a professional or family member, respectively. This suggests that there was a homogeneity among participants in relation to their experience, which is one of the main criteria of the focus group sample characteristics (Krueger, 2014).

One-to-one semi-structured interviews were considered more appropriate to use with the four older people without a diagnosis of dementia, as they might not share similar experiences and/or be comfortable to discuss a topic related to dementia in a group setting. Dementia is often perceived as a sensitive topic by older people due to concerns associated with their personal health (Alzheimer's Disease International, 2019).

Although some authors assert that the group dynamics and the interactive nature of focus group discussion offer the opportunity to produce rich information which would not emerge in an individual interview setting, there is evidence that both methods have similar ability to generate unique information (Guest et al., 2017).

8.3.4 Procedure

After giving written consent, participants were asked to complete a screening form (Appendix 18) that assessed the presence of any medical conditions. The screening form was adapted from the participants' recruitment questionnaire provided by Givaudan Ltd. In the event, none of the participants presented any of the medical conditions listed in the screening form.

Four one-to-one semi-structured interviews with older people, and two focus groups, one with care professionals and one with relatives of people with dementia

living in a care home took place face-to-face between May and October 2019 (Table 8.2).

Table 8.2 Summary of the procedure used in the modelling phase

Participants	Method of data collection
Older people	One-to-one semi-structured interviews
Care professionals	Focus group
Relatives of people with dementia	Focus group

Each session was facilitated by the author using a topic guide to promote conversation on the research topic of interest. A document outlining MSI-1 (themes and materials) was given to the participants as a reference. Furthermore, a selection of olfactory items and heritage objects from MSI-1 was displayed during the sessions and used to stimulate discussion and as visual cues. Each session, lasting approximately 60 minutes, was audio-recorded on a portable device.

8.3.4.1 Topic guide

Focus groups and interviews were facilitated via prompts aimed at exploring the importance of multi-sensory stimulations, and whether the themes and items from MSI-1 were likely to elicit positive responses in people with dementia. The same set of prompts (Appendix 19) was used as a discussion framework for both focus groups and adapted for the interviews, after being discussed with the supervisory

team. The sessions began with general questions about the role and importance of sensory stimulation for people with dementia, such as “In your opinion, can sensory stimulation sessions make any difference in your family member/ friend/ resident?” After a brief presentation of MSI-1, a series of specific questions focused on themes and materials selected in MSI-1 were discussed, such as “What do you think about the suggested themes and items?”, “How confident you feel your family member/ friends/ residents would be participating in a session like that one? In what way?”.

8.3.5 Analysis

Thematic analysis was used to identifying, analysing, organising, describing and reporting patterns across the whole dataset, including interviews and focus groups (Braun & Clarke, 2019). This method was considered appropriate for this explorative study, aiming to explore and understand the experience of the participants and gain knowledge about the way in which MSI-1 can be appropriate, practical, and acceptable for residents living in care homes.

Due to the specific nature of the research questions, the development of coding and themes was both descriptive and interpretive. This means that the semantic content of the data was captured, while examining the underlying ideas, conceptualisations, and assumptions by moving beyond the explicit content of what participants said. This is consistent with the critical realist underpinning this

thesis which acknowledges that person' perspective is informative of reality while subjective and contextual. Moreover, TA enables the capture of rich detail about participant's experience in relation to multi-sensory stimulation interventions and MSI-1 and the understanding of the context in which these experiences arise.

According to Braun and Clarke's guidelines (Braun & Clarke, 2006, 2019) the following steps were undertaken:

- The audio recordings were transcribed and reviewed by consulting the notes taken during the data collection in order to clarify the context of the discussions (e.g. participants' non-verbal responses expressed during the sessions).
- The dataset was re-read several times and uploaded in NVivo. Line-by-line segments of the transcriptions were coded at both semantic and latent levels using an inductive approach.
- The first supervisor revised the coding of one interview and focus group with the purpose of reflecting on, if any, different perspectives and standpoints.
- The coded data were reviewed separately according to source (care professionals, relatives of people with dementia and older people). The codes were linked together to generate themes.

- Themes were then refined, and master and subordinate themes were created according to their relevance within the dataset.
- Finally, the themes were defined, named and described in a detailed analysis alongside the participants' extracts.

8.4 Findings

Master and subordinate themes derived from interview and focus group data (Table 8.3) are presented alongside illustrative participants' quotes (OP: Older People; CP: Care Professional; R: Relative of people with dementia).

Table 8.3 Master and subordinate themes of focus groups and interviews

Master theme	Subordinate theme
(1) Multi-sensory stimuli: a tool for expression	(1.1) Multi-sensory experience (1.2) (Un)predictable response
(2) Promoting engagement	(2.1) Less is better (2.2) Contextualising (2.3) Multi-sensory stimulation and care home practice
(3) Properties and qualities	(3.1) Confidence in MSI-1 (3.2) (Re)consider the MSI-1 content

(1) Master theme: Multi-sensory stimuli: a tool for expression

This theme illustrates the potential of multi-sensory stimulation intervention as a form of expression for people with dementia. The theme places emphasis on the responses of people with dementia when interacting with the sensory stimuli. These act as tools through which individuals can express emotions, memories,

opinions, and ideas, and which support the self and connection with others. Participants spoke about the experience related to the sensory materials, generally considered 'positive', implying pleasant memories and positive emotions. However, participants also acknowledged that such responses might not always be positive, but may sometimes trigger unpredictable responses or be negative.

This master theme has two subordinate themes: (1.1) Multi-sensory experience and (1.2) (Un)predictable response.

(1.1) Subordinate theme: Multi-sensory experience

Participants mentioned the importance of sensory stimulation and the variety of benefits related to the sensory experience. They felt that it is essential for people living with dementia to engage in activities that can stimulate their senses. One person emphasised the role of senses:

> "[Senses] *make us conscious of the world around us*". (OP2)

In the focus groups and interviews, participants reported the potential positive effects of multi-sensory stimulation interventions for people with dementia, citing benefits such as increased self-confidence and self-identity, as well as the promotion of social inclusion, relaxation and conversations:

> *"You can tell somebody why you like that smell, for example, or how you recognised that smell. Walking out in the streets you can smell all sorts of things.* […] [smells] *trigger memories and conversations, let's say a flower*

or something, you can remember 'ah, I know that smell'." (OP2)

"*A nice smell can relax people.*" (OP1)

A family carer added that sensory stimulation sessions could offer people with dementia the opportunity to share "[their] *own opinions about things"* (R1). Other respondents also mentioned that smelling odours, listening to songs, and handling objects can trigger memories and emotions, which could support and build a sense of 'self':

"*Using smells, sound and touch and stuff like that, I think it is really good because it also gives people with dementia a sense of self in a way, because sometimes you can smell something, and it brings a memory back and you can remember certain things*." (CP3)

Furthermore, participants reported that sensory items can be used as a form of expression both verbal and non-verbal. The value of the non-verbal nature of multi-sensory stimulation interventions was emphasised. For instance, respondents suggested that sensory stimulation is effective for engaging people with dementia at different stages of the condition, especially those with communication difficulties.

"I guess as dementia progresses, perhaps it is even more important to offer some sort of sensory [stimulation activities], *when you know, there is not the level of conversation. To be able to engage with an*

object, whatever it be, whether it is a smell or touch, it would be lovely for them to be able to experience that even if it is non-verbal." (R1)

"It could just stimulate a good feeling or a good sign that they [residents] do not even need to communicate." (CP2)

(1.2) Sub-theme: (Un)predictable response

Although all participants expressed positive views on the value of multi-sensory experience, there were some concerns about the negative emotions and memories that sensory stimulation could trigger.

"[Sensory stimuli] *can evoke different emotions, memories which can be either good or bad."* (CP3)

"A lot of time we do wartime songs at the day centre. Sometimes they [residents] *are in tears."* (CP2)

Interestingly, CP4 followed by rhetorically questioning whether challenging emotions such as sadness and melancholia should be considered negative responses and thus avoided:

"Is it a bad thing? When [resident] *sings the wartime songs, it is so deep for her". (CP4)*

Unpredictable and negative responses as well as potential risks associated with multi-sensory materials were discussed among the focus groups with family carers

and care professionals. Safety was perceived as important. For instance, some participants reflected on practical issues related to the use of objects:

> *"*[My mum] *she tries to eat it* [object] *as well, she tries to bring everything to her mouth."* (R2)
>
> *"We have got some residents that they would just pick it up* [soap from Boots UK collection display on the table] *put in their pocket or try to eat. We had to remove all the soap from* [resident's] *room because she was eating them."* (CP4)

The potential negative response of olfactory stimulation was also mentioned. Participants shared anecdotes from their previous experiences of using odours with their residents, suggesting that sometimes odours can be overwhelming, trigger distress and negative behaviours as well as intense emotions, which could have negative connotations. For this reason, appropriate materials and procedures were perceived as key factors for the success of the intervention.

> "*We did have different smells* [fragrance diffusors] *for different floors but that did trigger their behaviours, so we had to stop it.* […] *If smells or perfumes are too strong, they can be overstimulating."* (CP1)
>
> *"Sometimes it can get overwhelming for some; it depends on what kind of memories they experience."* (CP3)

(2) Master theme: Promoting engagement

This highlights strategies and contextual factors that could contribute to promoting engagement and participation of people with dementia during multi-sensory stimulation intervention. Participants spoke of practical ways in which residents can be kept involved in multi-sensory stimulation interventions, such as group size, and methods of displaying the objects during the session. They also spoke about the importance of considering individuals' preferences, abilities, and background as well as the cultural and historical context, which could impact both the engagement level and overall success of the intervention sessions. Care home practices were incorporated within this master theme, exploring the ways established routines and approaches to care in this specific setting can facilitate or prevent residents' engagement in multi-sensory stimulation intervention.

The 'Promoting engagement' master theme includes three subordinate themes: (2.1) Less is better (2.2) Contextualising (2.3) Multi-sensory stimulation and care home practice

(2.1) Subordinate theme: Less is better

This theme explores ways to create a supportive environment, both physically and in terms of the social setting, which could enhance the concentration and full involvement of people with dementia with the sensory materials. Although participants pointed out that the group setting can enrich the multi-sensory

experiences, adding benefits to the sessions by sparking conversations and offering the opportunity to share memories and opinions, they also mentioned the importance of having a small group. Having a limited number of people in the session was considered crucial to enhance engagement. Respondents identified the number of people in the group as key to the success of the intervention. When asked to suggest a reasonable number, there was a consensus among relatives of no more than five people per session:

> *"A small group is really important."* (R1)
>
> *"My mum in a small group seems to try a lot more."* (R2)
>
> *"I was here when my mum was here* [day centre] *one day and she was part of a small group, maybe five people. It seems to work. More than that I think it may become too crowded."* (R5)

Participants also discussed the importance of physical space, suggesting that a quiet place free from distractions can promote attention, engagement, and participants' responses.

> *"If there are too many distractions, obviously, their* [people with dementia] *attention is everywhere, but if you have a concentrated group, a quiet zone and you really care what you trying to get from them, some people can keep their attention longer."* (CP3)

Other participants spoke of the length of the session and how it might impact the success of the sessions. Based on their previous experiences in facilitating activities with people with dementia, participants expressed a preference for sessions of approximately 15-20 minutes rather than longer sessions.

They reflected on how short sessions could support people with dementia in focusing their attention on the activity. Although there are great individual variations, people with dementia may have difficulty concentrating, and long sessions could enhance disengagement.

> *"*[…] *depends on how engaged they are; it could go on for longer than 20 minutes, but you will find some* [residents] *will switch off."* (CP4)
>
> *"It is not boring in fact, but it depends on how long. They cannot keep the attention, they will walk away* [interrupted by another participants]. *You should have to keep it short, like 15 minutes."* (CP1)
>
> *"We now keep our activities very short, maximum 15 to 20 minutes. Because they are really enthralled for the first 5 to 10 minutes and then that's it, their interest is gone."* (CP2)

This in turn links with the importance of selecting procedures for presenting the materials that could support people with dementia. Most agreed that materials should be introduced one at a time and passed around the group, allowing time for everyone to handle/smell and comment on the items.

"I think time to experience one object before you move on to the next object, to be able really to experience all of the different senses, touching it, feeling it, seeing it, smelling it, and to talk about it." (R1)

Some participants pointed out that if the materials were presented together, the persons with dementia could struggle to concentrate and focus their attention. In turn, this might generate feelings of being overwhelmed, confused and frustrated rather than enjoyed.

"My experience is that if there is a whole group and things, it would just be overwhelming […] *I think it would be very confusing to have a whole great range of objects."* (R1)

(2.2) Subordinate theme: Contextualising

Participants discussed the importance of individual differences, such as people's historical, and cultural contexts, when designing multi-sensory stimulation interventions. Some respondents acknowledged the importance of conducting an initial assessment with relatives as well as people with dementia to identify participants' preferences regarding the materials and themes, and to then design sessions which could enhance engagement and discussions according to the individual's interests.

"I think it would be very important to try and individualise it [the session] *to each person."* (R1)

"[individualised materials] *on what may spark memories."* (R2)

However, care professionals noted that residents' information about their past life before the institutionalization is often not available, even to the family.

"The problem is that a lot of family members, they haven't got this information, so that is difficult." (CP4)

"*We do not know the life history of some residents; in some cases we know nothing about their past.*" (CP2)

Participants also discussed the importance of considering the stage of dementia of people taking part in the multi-sensory stimulation intervention. Cognitive and communication impairments impact how people engage, interact with and respond to the sensory items. One participant suggested tailoring the multi-sensory stimuli to the individual's abilities by selecting materials that could enrich the sensory experience and did not need higher cognitive processing, such as textiles, fabric or smells, when involving people in the later stages of dementia:

"I think you would need to have two different groups. The ones that would not necessarily give you verbal responses, but you have to look at the non-verbal signs. With that kind of group, you need a lot of texture and a lot of smells as opposite of objects per se because I do not think they would be [interrupted by another participant – suggested words missing: 'able to give

a verbal response']. *The other groups, I think, objects and stuff like handbags may be quite good because they can verbally give you feedback*." (CP3)

Procedures and materials should be selected not only considering individual preferences and characteristics, but also the historical and cultural context experienced by people with dementia in their earlier lives. Participants emphasised that items, smells, and their social meaning and use could differ depending on the historical period. For instance, care professionals reflected on their experiences trying to stimulate conversations about objects during mealtimes, underlining how difficult it was to engage the residents at this time of the day, perhaps because eating was not considered a time for socialising when the residents were younger:

"*It* [objects stimulation at lunch time] *has not been successful with the table* [residents]. *I am wondering whether that it is because it has been done on the dining table. I know a lot of our residents when they were eating, they were told not to speak, mealtime was not a sociable experience back in the day*." (CP1)

The relationship between historical period and the relevance of materials was similarly discussed by other participants, who spoke of the need to

consider gender roles in society and age in the selection of specific items for the intervention:

> *"My friend's husband had dementia, but he was pretty good, obviously there are different levels. He wasn't allowed to drive. He used to be with my friend a lot. He would always go out and say 'I am going to wash the car' because he remembered doing it. He made a cup of tea; he could make a cup of tea but she* [OP3's friend] *found it hard because there was not much that he was interested in, even looking at the television. I think it is a little bit more difficult with men* [to get them interested]*."* (OP3)
>
> *"Stimulation is good, it is essential, absolutely essential, but the right age and gender stimulation is important. My dad would remember the Old Spice, this is the only cologne that he would wear."* (OP4)

(2.3) Subordinate theme: Multi-sensory stimulation and care home practices

Participants described their direct or indirect experiences of multi-sensory practice within the care home. For example, care professionals spoke of how they have been trying to incorporate aromatherapy and other multi-sensory activities alongside daily care practice to promote a person-centred care approach:

> *"We tried that - the first thing in the morning – that's what we tried to get our carers to do, instead of just going in. Trying to get memories using photo and using music."* (CP3).

Interestingly, although participants acknowledged that the multi-sensory stimulation intervention facilitates embodied and non-verbal experiences as described in the theme '(1.1) Multi-sensory experience', they often commented on impaired verbal and cognitive responses such as failure to recognise the materials or of memory recall:

> *"I think mine* [mum]*, she is pretty much too far gone, anyway. She is almost pretty much unable to recognise anything*." (R2)
>
> "*It* [a sensory item] *may trigger a memory but when they are at that point* [referring to those in the later stage of dementia] *you wouldn't be able probably to get that from them, to find out what memory was."* (CP1)

This may suggest that people who struggle with verbal communication may be excluded or have less opportunity to participate in multi-sensory stimulation interventions or activities.

Participants also commented on the potential difficulties of involving care professionals in the delivery of the intervention. One of the main concerns was that care professionals are often task-orientated and would not be able to provide stimulation using sensory objects appropriately:

> *"Our carers are very task-orientated; they do not think about the bigger picture."* (CP2)

Similarly, another participant discussed how care professionals tend to prioritise more physical task aspects of care over person-centredness, and how this approach to care may be due to a lack of staff:

> *"My mum was watching television most of her time, because two or three ladies* [care professionals] *could not look after all residents. They made sure they were clean, they made sure they were fed. But there wasn't the stimulation there that she needed and other people needed.* […]*, she didn't have the one-to-one which made her go down-hill quicker in my opinion*.*"* (OP1)

It was also suggested that facilitators' skills and knowledge about participants were key factors in delivering the intervention effectively.

> *"It is about the people who present the sessions, knowing the people* [those with dementia]." (R1)
>
> *"It is easy if you got somebody leading the session, who really cares* [about residents]*, who wants to do it.* [Facilitator role] *It's not just a job.* […] *The facilitator is very, very important. Everything can be good if the person running the group or leading the discussion is engaged.* […] *It depends a lot on the presentation."* (OP1)

Furthermore, the absence of knowledge and experience about the materials were found to be barriers in delivering the multi-sensory stimulation interventions. It was

suggested that the use of cards with prompts could support the care professionals in their role of session facilitators.

> *"If there would be prompts on the cards, on what kind of questions to ask for evoking a memory along with maybe a picture of what it is you are talking about, that may work because then they* [care professionals] *don't have to start from scratch.* […] *This would make easier for the carers."* (CP1)

(3) Master theme: Properties and qualities

This master theme focuses on the participants' opinions on MSI-1 and its content. This theme explores the participants' attitudes toward the MSI-1 and outlines how confident they are as to whether people with dementia would take part and engage in MSI-1 sessions.

This theme also encapsulates the participants' feedback on the contents and materials. The findings from the data collected in this study highlight the importance of carefully considering the topic of the session and items in order to promote a positive experience for people with dementia and reduce the risk of a negative response. This theme has two subordinates: (3.1) Confidence in MSI-1 and (3.2) (Re)consider the MSI-1 content.

(3.1) Confidence in MSI-1

After seeing the MSI-1 presentation, participants were asked to give their opinions about the intervention and consider how confident they felt that people with dementia would join in and enjoy the sessions. The general perception of MSI-1 was positive. All participants noted several potential benefits of taking part in the sessions, including improvements in mood, and increasing social interactions.

> *"It* [MSI-1] *may encourage them* [people with dementia] *to talk to the person they have been sitting next to for weeks in the care home. And say 'oh I remember I had a Brownie 127 camera in the early 60s'. They may share a little bit of conversation or find something in common"* (OP4)
>
> *"I think it can be very valuable. I can see it particularly in a small group, I can see it could hopefully trigger some sort of responses, and help different people. […] Hopeful it can build the confidence to be able to share something. And I think it would be a quite nice sort of trigger for different people to be able to experience things in different ways."* (R3)
>
> *"This would be amazing for a lot of people to have activities like this. Some would benefit more than others."* (R2)

Participants pointed out MSI-1 could trigger both verbal and non-verbal expressions and that sometimes people may not express themself although this does not mean that the sensory stimulation did not have an impact on them:

> *"From some people, you do not have any reaction at all. It does not mean to say that they did not like the session, or they did not like the experience of it." (*OP3)
>
> *"*Just by looking [the items], *internally they are glowing because they are thinking of something."* (OP4)

Although participants seemed to value MSI-1 and its potential benefits, mixed responses were found regarding how confident they were that people with dementia could enjoy and engage in the activities. Most of the participants felt that people with dementia would like the intervention.

> *"I think they would engage with it."* (OP1)
>
> *"My mum would like to talk about them* [session themes and items]." (R4)
>
> *"She* [participant's mum] *might like to touch objects in a small group."* (R2)

Nevertheless, some family carers anticipated that their family members would not engage in the activities because they would not be able to identify the sensory materials. At least two relatives commented that their family member would have

this difficulty. R5 commented that her mother would not recognise the materials and R3 agreed that hers would not either. However, one relative added: "*but she* [R5's mum] *may still enjoy it*" (R1), emphasising that although people with dementia might not be able to identify the sensory materials, for instance naming the objects or recalling their function, they can experience a sense of enjoyment by taking part in MSI-1.

(3.2) Sub-theme: (Re)consider the MSI-1 content

Perceptions about the quality of the intervention contents were overall positive. Many commented on how the Boots UK items were likely to be familiar and recognisable. In turn, they had the potential to promote memories and conversations.

> *"Interestingly, the Boots name itself is a trigger because it is all there was; there was not very many chemists basically to go to. That logo has never changed since they've started, it is itself a trigger. 'Boots, oh yeah I used to go to Boots', 'oh yeah Boots is in the high street'. That is positive, I think."* (R5)

When participants were asked to review the themes and materials of MSI-1, there was a general agreement among the stakeholders. 'Childhood', 'Household treasure' and 'Christmas' were perceived as highly positive sessions. From the participants' point of view, those themes could trigger

positive memories and feelings. This means that these themes are likely to be of interest of people with dementia and promote engagement. Participants suggested that ‘Christmas’ might not be appropriate during the summer season and across diverse communities and instead recommended changing it to ‘Festivities’ in order to adapt the topic of the session depending on the period of the year (Easter, Christmas, etc.) and cultural background.

Other themes such as ‘Travelling’, ‘Parenthood’ and ‘Leisure time’ were considered good sessions for stimulating engagement, discussion, and positive mood. Participants suggested that their relatives, residents or friends may enjoy talking about these topics.

Although ‘Leisure time’ and ‘Travelling’ were considered positive themes, participants commented about the appropriateness and relevance of the materials selected. For instance, some respondents noted that some items related to the leisure time session (e.g. National Trust guidebook) were common for particular demographic groups but may not be something that a lot of people would respond to or have memories about. One participant suggested a new item for inclusion:

> *“An old copy of the Radio Times or a copy of the television paper. The Radio Times was the one that everybody had it.”* (OP1)

Similarly, there was a consensus that the items selected for the travelling session from the Heathrow archive (such as wing cabin crew brevet, fly BOAC tape measure) were not things that some older people would relate to. Participants agreed that in the past people used to travel within the country, to the countryside or seaside, by means of trains and buses. Not everyone had the opportunity to travel outside of the UK by flight, as it was expensive.

> *"Travelling is very positive, but I don't think those examples* [items of travelling session] are *for that generation."* (OP1)
>
> *"The residents' holidays were in Britain."* (CP2)
>
> "[Those] *travel items would not be associated with the concept of travelling as before people used to travel within the country. Items related to trains could be more relevant for older people*." (CP1).

However, one participant suggested that some people could be indirectly familiar with the same travel items:

> *"The funny thing is that they know about aircraft by watching Hollywood films, people go from one place to another, it was very glamorous. Then I think it would link with the films."* (R5)

Regarding the sessions 'Personal care' and 'Time to go out', respondents felt that the two themes could be incorporated together as people would associate personal care with getting ready to go out.

"Personal care and time to go out could be combined. For people of their era, they would always wear ties in and out of the house. They would put jewellery on or put lipstick on and have braces etc. just for going to the shops or going to work, just going to the pub." (R5)

'School' was the only theme that received a mixed response. A few participants expressed the view that school was a great topic, and they felt that people with dementia would love talking about it. In contrast, some relatives stated that their family members would not enjoy talking about school and the materials related to it, and it could be a very sensitive topic for someone of their age as it could trigger memories of wartime.

"My mum hated school, anything related to school." (R2)

"[My mum] *is a Londoner and during her time there was the war, they were evacuated, and they didn't go to school. This topic would lead to another* [war memories]*."* (R5)

In contrast, some felt that their parents would enjoy recalling 'negative' memories about school.

"*He would enjoy talking about school. He wouldn't necessary want to remember and go back to it, but he would quite like to talk how awful it was."* (R1)

The ‘Walking in the city’ theme was perceived as less successful compared to other MSI-1 themes. However, the materials selected were rated positively.

> *“My dad worked in the city and this theme would trigger a lot of memories, the train ticket, going to work every day. The smell of smog would trigger work memories.”* (R1)

8.5 Refining MSI-1

The thematic findings and participants’ suggestions relating to the content and procedure of MSI-1 were combined and used to produce the MSI-2. Although several changes were made, the overall format of MSI-1 was maintained. Based on the participants’ feedback, the themes and materials were revised and adapted to be more suitable for people with dementia. MSI-2 also includes resources and guides for supporting care professionals in the preparation and facilitation of MSI-2.

Table 8.4 shows how MSI-1 items and themes were refined and the modifications incorporated in MSI-2. As a result of the stakeholders’ feedback, the theme titles of MSI-1 session were refined. ‘Christmas’ was modified into ‘Festivities’, ‘Travelling’ was replaced with ‘Holiday’ and ‘Personal care’ was incorporated under the theme ‘Time to go out’. Although the feedback on ‘School’ was mixed and some participants suggested that this topic may stimulate emotional memories (wartime), the theme was incorporated in MSI-2. The

rationale for including it was that everyone has experiences or anecdotes linked to school, which provides a platform through which people with dementia can share their life stories. As described in Section 2.3.1, material objects and smells can be invested with personal meanings and experiences, which sometimes may stimulate challenging emotions such as grief or melancholy. The emotional responses to stimuli, though possibly perceived as negative and potentially distressing for people with dementia, should be seen as a form of individual expression, and MSI-2 should create a safe and supportive space where the individual can experience such emotions.

The different items suggested by the participants were included in MSI-2. Feedback on the appropriateness of the content was addressed by revising and modifying the olfactory stimuli and material objects. Some items were incorporated into other sessions, whilst others were removed from the study, and new items were included. Details of the changes made are shown in Table 8.4.

Knowing the sensory properties, history and meaning of the items was perceived as an important requisite to promote the effective implementation of MSI-1 in care home practice (see subordinate theme (2.3) ‘Multi-sensory stimulation and care home practice’).

Table 8.4 Refining MSI-1 themes and materials

	MSI-1			MSI-2		
Week	**Theme**	**Material objects**	**Olfactory items**	**Theme**	**Materials objects**	**Olfactory items**
1	Travelling	Ashtray, stewardess beret, metal jug, fly BOAC tape measure, wing cabin crew brevet.	Cigarette tin, flight bag, chocolate box, fish and chips or vinegar, sun cream, calamine lotion.	Holiday	Train ticket#, stewardess beret, metal jug, fly BOAC tape measure, wing cabin crew brevet, camera.	Flight bag, chocolate box, fish and chips or vinegar, sun cream, calamine lotion, **seaside smell* (OP3), Old Holborn-tobacco* (OP3).**
2	Walk in the city	Train ticket, umbrella, gloves, camera.	Cut grass odour, coffee beans, smog odour, petrichor odour (summer rain).	Walk in the city	Umbrella, gloves, ashtray#, handbag#, **sweeties* (OP4), items about theatre or restaurants* (R4), tube or street map* (OP2).**	Cut grass odour, ground coffee, petrichor odour (summer rain).
3	Time to go out	Hats, scarves, ties, handbag, jewellery, powder compact, lipstick, wallet, braces, comb, money, hats.	Floral perfumes (lilac or rose), brilliantine hair oil.	Time to go out	Clothes and accessories (e.g. hats, scarves, ties, braces, jewellery) powder compact, lipstick, wallet, comb, money, hairdryer#, **cigarette tin#* (R4).**	Floral perfumes (lilac or rose), brilliantine hair oil, #shaving stick, **coal dust * (OP1), polished leather shoes* (OP3)**, **hair spray* (OP2).**
4	Childhood	Dolls, owl puppet, spinning top, first aid kit, building blocks, leather satchel, Brownies/ Scout stuff, kids magazine/ annuals/comics, roller skates, birthday badge/card.	TCP, Germolene, cough mixture, liquorice.	Childhood	Dolls, owl puppet, spinning top, first aid kit, building blocks, leather satchel, Brownies/Scout stuff, kids magazine/annuals/comics, roller skates, birthday badge/card, **teddy bear* (OP2).**	TCP, Germolene, cough mixture, liquorice, **cod liver oil provided by NHS* (OP3).**

Table 8.4 *(Continued)*

Week	Theme	Material objects	Olfactory items	Theme	Materials objects	Olfactory items
5	Household treasure	Teacup, jelly mould, rolling pin, tea pot, shopping basket, milk bottle, pac-a-mac.	Lavender bags for wardrobe, disinfectant, polish.	Household treasure	Teacup, jelly mould, rolling pin, tea pot, shopping basket, milk bottle, pac-a-mac.	Lavender bags for wardrobe, disinfectant, polish, **freshly made cakes* (OP4), paraffin smell* (OP3), washing powder* (OP4), anti-moth ball* (OP2).**
6	Parenthood	Feeding bottle, feeding bowl, bibs, oral pacifier, rattle, baby cutlery, nappies, nappy pin, blanket.	Baby soap, baby lotion, baby powder.	Parenthood	Feeding bottle, feeding bowl, bibs, oral pacifier, rattle, baby cutlery, nappies, nappy pin, blanket, **Vaseline* (OP3).**	Baby soap, baby lotion, baby powder, **sterilising tablets* (OP4).**
7	School	Books, crayons or pen box, poster or photos, slate, ruler, pencil case, satchel, school cap, prefect badge, exercise book, abacus.	Ink, chalk dust (chalkboards), glue or school paste.	School	Books, crayons or pen box, poster or photos, slate, ruler, pencil case, satchel, school cap, prefect badge, exercise book, abacus. **plasticine* (OP3).**	Ink, chalk dust (chalkboards), glue or school paste.
8	Leisure time	Picnic hamper, picnic rug, binoculars, camera, National Trust guidebook, library card, theatre programmes, cinema tickets, football programmes.	Popcorn, cut grass.	Leisure time	Picnic hamper, picnic rug, binoculars, camera, library card, theatre programmes, cinema tickets, football programmes**, old copy of the Radio Times, copy of the television paper* (OP1).**	Popcorn, cut grass, **fishing smell* (OP2) or pork pie* (OP4).**

Table 8.4 *(Continued)*

Week	Theme	Material objects	Olfactory items	Theme	Materials objects	Olfactory items
9	Christmas	Cards, advent calendar, bauble, wrapping paper, tinsel, crackers.	Cinnamon, orange, pine tree odour.	Festivities	Identify relevant objects related to a celebration. E.g. Christmas: cards, advent calendar, bauble, wrapping paper, tinsel, crackers**, paper chains* (OP3).**	Identify relevant items related to a celebration. E.g. Christmas: cinnamon, orange, pine tree odour, a**lmond* (CP4), cooking smells* (CP4), scented candles* (OP4).**
10	Personal care	Sponge, hairbrush, shavers, deodorant bottle, poster and photos, hair rollers, flannel, loofah, shower cap, Kirby grips, hairdryer, nail clippers, tweezers, toothbrush.	Shaving stick, Cremolia soap, talcum powder, Cold cream, soap.	(Removed session)		

**: Items included from the stakeholders*
#: Items previously included from other MSI-1 theme.

Participants suggested that to support and empower the care professionals in providing MSI-1 in care home daily practice, cards with details about the objects and prompts should be included, to guide and facilitate the session. In response to this, a fact sheet (Appendix 20) with recommendations for preparing and delivering the MSI-2 sessions was developed from the stakeholders' responses and adapted from Multisensory Stimulation practical sheet (Fondation Médéric Alzheimer, 2021) (Appendix 21). Cards with prompts that can be used during the intervention were included. Two examples of draft cards can be seen in Appendix 22. These were considered useful tools for care professionals who will deliver the intervention.

8.6 Discussion

This study focused on gathering stakeholders' views on multi-sensory stimulation interventions and explore whether the components and procedure of MSI-1 would work for people with dementia within a care home setting. This reflects other literature that recommends early involvement of key stakeholders during the development process to increase optimal design and anticipate potential implementation issues.

The findings indicate that although most participants showed a positive attitude toward the multi-sensory stimulation interventions, some of them pointed out the potential negative effects associated with objects, particularly olfactory stimulation (e.g. trigger negative memories and emotions), underlining the importance of

tailoring the content of the intervention based on the preference and history of the group participants in order to minimise negative responses.

Several factors were identified as relevant for the success of the sessions, such as having a small group of participants, a skilled and knowledgeable facilitator and conducting the sessions in a quiet room, which may bring the participants 'into the moment' and maximise the degree of their engagement and sustained attention. This highlights the role of context in influencing the responses of people with dementia in line with the realist philosophy, and the biopsychosocial model of dementia (Spector & Orrell, 2010) (Section 1.4).

Several comments were made about the appropriateness of MSI-1 materials and themes. Whilst some were perceived as potentially stimulating and enjoyable, others were judged as not relevant or leading to a sensitive discussion (e.g. wartime). This suggests that special attention should be given when selecting the content and materials of the intervention.

The findings presented above were summarised into a list of recommendations for implementing multi-sensory stimulation interventions (Table 8.5). Table 8.5 informed the refinement of MSI-1 and has broader implications for further studies involving people with dementia living in a care home.

Table 8.5 Recommendations for implementing multi-sensory stimulation interventions

Area	Recommendation
Design	• Initial assessment with people with dementia or their relatives to identify participants' preferences, interests and biography, which could be useful information to tailor the intervention. • The materials and procedure of the multi-sensory stimulation intervention should be tailored to participants' sensory abilities and cognitive impairments. • The materials should be familiar to the participants. • The materials should be selected considering individual preference, biography, social and historical period. • The procedure of delivering sensory stimuli is important and special consideration should be given to selecting a method that could minimise or avoid participants' distress and overwhelming feelings. • Procedures should allow time for the participants to engage and explore the sensory items. • Careful consideration of the safety of the materials used should be given, considering for instance the risks of harm for the participants.
Setting	• Session should be undertaken in a small group. • Intervention should be set in a quiet room. • The session length should be short, approximately 15-20 minutes. • Adequate care support should be provided during the session.
Staffing	• Care professionals should give importance to verbal and non-verbal responses of the participants. • Care professionals facilitating the session should be knowledgeable of the materials and the participants' preferences and past history. • Staff facilitating or supporting the intervention sessions need to be aware of the potential emotional and physical risks for the participants.

8.7 Strengths and limitations

The primary strength of this study is that stakeholders' involvement and feedback provided experiential knowledge, which in turn enabled the development of a more practicable, acceptable, and appropriate MSI-2. The involvement of stakeholders also provided the starting point for reflections on the implementation of MSI-1 and any potential barriers within the care home settings, which are included in the recommendations listed in Table 8.5. The number of recommendations identified could be informative for other multi-sensory stimulation interventions for people with dementia taking place in care homes.

The use of focus groups and interviews made it possible to address the research questions and, at the same time, enabled exploration of further relevant details brought to the session by participants. The research contributes to extending the existing literature emphasising the value of using qualitative research in the development of successful interventions.

Care professionals involved in the refinement of MSI-1 were recruited from only one care home which may limit whether these findings represent the wider group of care homes. Recruiting care professionals from one setting may limit the opportunity to take into account variation in approach to care and other contextual factors which may interact with the MSI-2.

The absence of people with dementia from the stakeholder group has limited the understanding of the acceptability, appropriateness, and practicability of MSI-2. It was not possible to include them for practical reasons, including the high risk of COVID-19 for people living with dementia, the safety of those involved in the study, and limitations of time. In future, gaining the perspectives of people with dementia should be a priority as it could increase the chance of developing an intervention that is engaging, relevant, accessible, and tailored to the needs of users.

8.8 Conclusion

The modelling phase described in this chapter was an essential part of the intervention development process. The involvement of stakeholders in the design process resulted in the creation of a refined MSI-2. Designing MSI-2 in collaboration with key stakeholders enhanced the acceptability and practicability of the MSI within a care home setting. It is important to carefully consider the sensory items, residents' preference and biography, and environmental features in order to implement enjoyable and engaging sessions. Practical information on settings, residents' characteristics, and previous participants' experiences with multi-sensory activities can help to identify potential barriers associated with MSI implementation at the early stages of its development.

The following chapter summarises the overall findings from the research presented in this thesis and reflects upon the research methods, their strengths and limitations, and suggests areas for future investigation and implication of the research.

CHAPTER 9 DISCUSSION AND CONCLUSIONS

This final chapter summarises the main findings of the research in relation to the study objectives and to the current literature, outlining how this work contributes to the area of multi-sensory stimulation interventions and dementia care. This is followed by a discussion of the methodology used together with the strengths and limitations of the work. Finally, the study implications are considered, and future directions are suggested.

9.1 Summary of findings

The purpose of this study was to explore and provide evidence underpinning the benefits of multi-sensory stimulation interventions for people with dementia, and to describe the development and design of a novel theory- and evidence-based MSI for people with dementia living in care homes. The MSI development activities undertaken within this study were guided by the MRC guidelines for the development and evaluation of complex interventions (Craig et al., 2008). According to the MRC framework (Craig et al., 2008), the study focused on the three main activities of the MRC development phase. A summary of the results of each phase and contribution to knowledge is presented below, guided by the study objectives.

9.1.1 Multi-sensory stimulation interventions: features and benefits

The study focused on exploring the importance of sensory experience in people with dementia and identifying the evidence on multi-sensory stimulation interventions, with the focus on olfactory and tactile sensations. The aim of this phase was to address the first objective of the study:

1. To explore and assess the available evidence on multi-sensory stimulation interventions.

As discussed in Section 2.1, several approaches have been used to stimulate the primary senses of people with mild to severe dementia. The results of the reviews on multi-sensory stimulation interventions were consistent in terms of the mixed findings amongst studies, with some reporting positive impacts, while others showed no significant benefits. Generally, multi-sensory stimulation interventions demonstrated a positive short-term effect on responsive behaviour and mood, and a mixed impact on cognitive and communication outcomes. Whilst not providing conclusive evidence, the studies reviewed highlighted the need for further investigations in the area of multi-sensory stimulation interventions, considering the strong correlation between sensory function, cognitive decline, and dementia symptoms (Park et al., 2021; Pinto et al., 2020).

The findings from stakeholders presented in Chapter 8, collected in the later stages of the study, generate insights on the benefits of multi-sensory stimulation

interventions within care homes. This research found that sensory experiences are an important part of people with dementia life and there are multiple benefits of multi-sensory stimulation interventions, such as promoting sensory and relaxation experiences, self-expression, self-confidence, and interactions with others at different levels. This evidence highlights that sensory stimulation can provide opportunities for sharing life stories, opinions, experiences and emotions, connecting with care professionals and other residents. Thus, sensory materials can have a role in supporting expression and selfhood in people with dementia and provide opportunities to promote new ways of connecting and communicating at verbal and non-verbal levels (Dowlen et al., 2021; Ozdemir & Akdemir, 2009).

This is important in light of the findings in the subordinate theme '(2.3) Multi-sensory stimulation and care home practice' in Section 8.4 which showed that while care professionals, relatives of people with dementia and older people recognised the value of the sensory experience as a vehicle of expression at the non-verbal level (gesture, facial expression), they tend to focus their attention mainly on the person's verbal response such as memory retrieval. A person living with dementia might not be able to verbally express themself or tell their story. It is, therefore, important that key stakeholders recognise and embrace the embodied experience of people living with dementia whilst they engage with the multi-sensory stimuli (Kontos & Martin, 2013).

A scoping review and a rapid review were completed to synthesise the studies on object handling and olfactory interventions for people with dementia. The one presented in this thesis was the first study to review the literature on object handling interventions for people with dementia. As described in Chapter 4, the scoping review of object handling included ten studies, most of which incorporated group sessions focusing on handling and discussing heritage objects, with other activities such as museum and gallery visits, music, massage, and art viewing. Studies reported a range of benefits including improved well-being, mood, enjoyment, and social inclusion in people with dementia. These reflect the results of a recent study of museum-based interventions for people with dementia that reported positive social benefits, mood improvement and feelings of enjoyment (Camic et al., 2021). Highlighting the similarity and diversity of object handling interventions has enabled the capture of a rich picture of the characteristics and nature of the studies. The exploration of the definitions and attributes underpinning the concept of the object handling intervention enabled the construction of a new theory-based operational definition of object handling. The results from this study contribute to promoting consistency of terminology and improve the way further object handling interventions are developed and evaluated in social care settings. In turn, these studies can contribute to increasing the quality of the evidence-base in psychosocial interventions in dementia care.

Within the rapid review (Chapter 5), there was considerable heterogeneity among the studies in relation to the odours used and methods of application, with most studies dispensing lavender oil and using diffuser as the most widely applied method. The review has identified mixed results for the benefits of olfactory stimulation on responsive behaviours and cognitive function in people with dementia, whilst findings have demonstrated the effective role of smell as a cue for triggering autobiographic memories. There was some evidence suggesting that studies using administration methods and procedures that control habituation effects were associated with an improvement in responsive behaviours. Although clear conclusions could not be drawn due to the various procedures used, this result resonates with other studies. A recent meta-analysis on the effectiveness of aromatherapy on agitation and aggression in people with dementia (Xiao et al., 2021) found that olfactory interventions, including long odour exposure for more than four weeks, are associated with reduced effects.

Findings from the rapid review also showed that using olfactory stimulation has benefits in physical functioning of people with dementia, such as an increase in sleep duration, food intake and an improvement in balance. Overall, this rapid review concurs with the literature supporting the view that olfaction is closely connected with health and well-being (e.g. Herz, 2016; Papazian & Pinto, 2021). The review also highlighted that very few studies involved people with dementia in

the selection of olfactory stimuli. Only three of twenty studies took into consideration participants' odour familiarity and preference. This contrasts with the literature emphasising the importance of tailoring stimuli to the preference of the individual (Herz, 2009a, 2016; Holmes & Ballard, 2004; Lawrence et al., 2012) to improve the success, acceptance, and satisfaction regarding olfactory interventions (Xiao et al., 2021).

Furthermore, the rapid review contributes to a deeper understanding of olfactory stimulation and the ways it has been offered to people with dementia. Generally, findings demonstrate that participants were not actively involved in the interactions with the stimuli, but rather their participation within the intervention was passive, limited to being exposed to a smell for instance. This is important in the context of dementia practice and in the design of innovative interventions and resources. The shifting from seeing a person with dementia as a passive recipient to an active contributor has several implications. Firstly, it promotes a sense of agency in residents within the olfactory intervention, for instance, allowing them to select their olfactory items, to decide upon the ways they wish to engage with the items and whether to stop. Secondly, it enables a shift in the focus on the experience of people with dementia 'in the moment' rather than solely on clinical outcomes. Finally, providing opportunities for embodied experience, valuing individuality, and recognising the agency of people with dementia within care home settings may

have a broader impact on dementia care practice. Overall, in accordance with other reviews in this area (Fung et al., 2012; Xiao et al., 2021), the findings suggest the use of olfactory intervention to be promising for people with dementia.

Positive effects on care professionals were reported in both object handling and olfactory interventions, such as improved well-being, mood, and reduced distress. Object handling interventions also provide opportunities for mutual engagement between care professionals and residents. There is evidence that this can reduce power imbalance (Griffiths et al., 2019), boost relationships (Roe et al., 2016), and modify attitudes towards people living with dementia (Camic et al., 2021) which in turn may increase the quality of care.

The findings presented in this study contribute to extending existing current literature in the wider area of psychosocial interventions in dementia care, demonstrating that multi-sensory stimulation interventions, tactile and olfactory stimulation practices have positive benefits for people with dementia. This research found that engaging with sensory items can support selfhood, positive mood, enjoyment, and social inclusion, address responsive behaviours, and potentially impact cognitive functions and health. The sensory experience embedded within multi-sensory stimulation interventions offers an invaluable opportunity for expression, connection, and interaction that can occur at the verbal and non-verbal level within the session. This highlights the importance of focusing

‘in the moment’ to understand the lived experience of people with dementia and considering multi-sensory stimulation interventions as an appropriate vehicle to engage and connect with people who have reduced or impaired ability to verbalise. Furthermore, the study provides a detailed account of the current evidence in relation to procedures, approaches and materials. Not only do these findings contribute to identifying the intervention dimensions which could have a positive impact on people with dementia, it also forms the base from which the MSI was developed.

9.1.2 Building a theoretical understanding of MSI

After identifying the components and intended or observed outcomes associated with multi-sensory stimulation interventions, and specifically with object handling and olfactory interventions, the study aimed to address the second objective of the study:

2. To identify the theoretical underpinning of the MSI.

Attention was given to understanding the MSI conditions or the key resources needed to trigger the mechanisms of change within the context of the care homes. The background literature (Chapter 2), the operational definition of object handling (Section 4.7), and a realist review of olfactory stimulation (Chapter 6) were used to develop a theoretical understanding of how, why, and in what circumstance MSI could be successfully implemented and achieve the intended outcomes in a care

home setting. These findings mirror some of the themes identified within stakeholder investigations throughout the study (Section 7.5; Chapter 8), which help to explain the process that could occur within the MSI and the optimal circumstances to ensure the success of MSI.

This research has identified that leadership within care home settings is critical to assist staff in accessing the resources, and initiating, and maintaining an intervention. A supportive leadership team in turn helps improve care professionals' skills, and confidence and modify their and residents' expectations, beliefs, and attitude. These are important elements for enhancing engagement and adherence (Lawrence et al., 2012).

Learning about residents' personal history and preferences directly from them or relatives provides an opportunity for tailoring the intervention to the preferences, interests, and abilities of the individual. This is in line with the NICE recommendations (NICE, 2018) advocating tailored activities and interventions for people with dementia. Research has shown that individualised interventions enhance engagement, positive hedonic experiences and the interest of people with dementia (Cohen-Mansfield et al., 2007; Lawrence et al., 2012).

Another important process through which MSI can promote positive outcomes is a sense of trust and familiarity. These can contribute to creating a comfortable and secure atmosphere in which people with dementia can express themselves, share

experiences and feelings, and interact and connect with others. This has important implications for further studies to investigate how to create such as atmosphere or environment within the sessions. For instance, Camic et al. (2021) stressed the importance of the facilitator role in empowering and increasing participants well-being in the object handling sessions.

Another important factor identified is the concept of novelty of the procedure and materials which create the conditions for capturing attention and enhancing participant's curiosity and playfulness within the session. These could lead to increased opportunities for creative exploration, new ideas and associations, and meaning-making opportunities. As Dickens (2020) notices, novel objects can support participation by enhancing multi-sensory and kinaesthetic experiences, which ultimately empower people with dementia by meeting their abilities, as described by Thomson et al. (2012) in the triple coding model.

The findings of the present study concur with the current literature highlighting the importance of novelty and familiarity but also suggest that novelty may enhance a sense of discomfort, together with a feeling of distress and mistrust which could have a negative impact on people with dementia. An important result of the presented work highlights the importance of balancing familiarity and novelty within the intervention.

The last mechanisms underpinning the intended outcomes of MSI that were identified are pleasure and enjoyment gained from engaging with and exploring the sensory items, as well as from the interactions with others regarding the sensory stimulus.

Overall, the findings emphasise the active role of participants within olfactory and object handling stimulation process, together with the need for different processes ranging from leadership to engaging with the residents' personal histories and preferences in order to optimise MSI for people with dementia. These results present important implications in dementia care practice.

9.1.3 Shaping theory and evidence into MSI

The theory and evidence summarised above were incorporated to address the third objective of the thesis:

3. To design a theory- and evidence-based MSI for people living in care homes.

The identification of effective components within the literature was hampered by the considerable variety of procedures and designs used with people with dementia. Despite the heterogeneity, many of the key characteristics of the studies synthesised were included in MSI design. Interviews with stakeholders' experts on

olfaction and archival items have been used to inform and address uncertainties relating to the components of MSI.

This research demonstrates that creating a comfortable atmosphere and connecting with people with dementia at an emotional and individual level are important factors for promoting engagement and empowering people with dementia to express themselves and share their ideas or opinions. These can be enhanced by small groups and short sessions, delivered in a supportive and quiet setting. Furthermore, residents should be encouraged to interact with the materials in the way and at the level (verbal and non- verbal) of their choice. This in turn can improve a sense of agency.

The findings of this research suggest that sensory materials which are familiar, or to a certain extent ambiguous, and which present different ways to interact with (e.g. wearing them) are more likely to be engaging. Familiar items provide opportunity for storytelling, including spontaneous memory recall, sharing experiences and emotions associated with the materials. Although reminiscence is not the core aim of MSI, it is important to acknowledge that memories are embedded within human interactions. In their new conceptual framework of 'being in the moment', Keady et al. (2020) suggest that recalling and revisiting past events enable to re-connect and re-live the 'moment' as part of a continuum of moments moving forwards in times. The reminiscence effect enhanced by familiar

items can therefore be seen as a means for creating a space for promoting connections, enjoyment, interactions, and engagement in the present. For instance, the life story approach combined within psychosocial interventions (e.g. dance, music, doll therapy) was found to extend the benefit for people with dementia, promoting focused and insightful thinking (Lawrence et al., 2018). On reflection, whether the person might or might not recognise the sensory items, having the opportunity to explore familiar objects may promote a sense of comfort and familiarity.

On the other hand, Camic et al. (2019) advocate for novel and unusual items detached from personal and shared social meaning in order to reduce reminiscence-oriented sessions, which could potentially isolate those from different backgrounds and be stressful for others. This research suggests that these risks could be mitigated if the facilitator is knowledgeable about participants and skilled in creating conditions that promote connection and active participation.

Knowing the participants could provide invaluable information for engaging the person at the individual level within the sensory items, interpreting and responding appropriately to residents' experience and response which could be either at the verbal and non-verbal level, as well as facilitating the use of appropriate ways to engage and reassure participants during the sessions, creating a trustful atmosphere. This also would enable the assessment of the risk and safety of the

MSI (e.g. adverse medical reaction, negative emotion or memories associated with a sensory item) to a single individual using a person-centred approach. Ultimately, it promotes care professionals' appreciation of residents as individuals with their own identity and story (Kitwood, 1997). On reflections, individualisation is not only preparatory, with the care professionals bringing their knowledge about the residents into the session, but also within the session as residents can share new information which enhances connection and individualised responses.

The findings from this research suggested that facilitator knowledge and skills are important contextual factors. Other contextual information such as participants' characteristics, care home system, procedure and stimuli features, as well as their interactions identified through the study, contributed to a deeper understanding of the ways in which MSI may be implementable and effective. These findings could also inform the design of other activities or interventions, by supporting the selection of olfactory items or material objects and procedures in which the materials are administered to create engagement and positive impacts for residents living in a care home setting. Therefore, the study offers important insights for clinical practice and for researchers more broadly.

9.1.4 Refining MSI

The final phase of the research focused on the last objective of the study:

4. To assess the acceptability, practicability, and appropriateness of the MSI.

The acceptability, practicability, and appropriateness of MSI-1 were explored with key stakeholders. Participants explored solutions that could support the participants' engagement within the sessions. The findings emphasised the need to create a comfortable social and physical space which could promote feelings of relaxation and offer fewer distractions, which in turn supports the participants' attention to the activities offered. Examples of things that can support people with dementia engagement include, but are not limited to, small groups, short sessions, sequential of presentation material and tailored sensory stimuli reflecting personal interests, historical period, and cognitive and sensory ability.

These findings also highlighted the need to consider the practitioner who facilitates the intervention, along with the social and physical context in which the intervention is implemented. Participants listed specific issues, including approach to care, skills, knowledge about materials and residents, that could act as barriers to implementing the MSI within routine home care settings. Informed by the stakeholders' feedback, written materials, including a fact sheet with guidance and cards with prompts, were integrated in the MSI-2 provided to support care

professionals in their role. However, in order to empower and promote a sense of agency, it is important that the facilitator engages in the exploration and discovery process without assuming an excessively directive role, which could increase inequality in the relationship (Dickens, 2020).

Overall, the findings from this study refined and tailored the MSI-2 to the care home context and what stakeholders perceived as the needs of people with dementia. A list of recommendations on optimal circumstances for the success of multi-sensory stimulation interventions within care home settings (see Table 8.5) was produced to inform intervention developers and practitioners.

9.2 Methodological considerations

Study design

As discussed in the methodology Section 3.4, the present study is situated in the intervention development phase of the MRC framework (Craig et al., 2008). According to the MRC guidelines, the study followed a dynamic and iterative process, moving backward and forwards between primary and secondary data in the development process. Existing literature was identified and synthesised using systematic methods, and used to develop theory and evidence. Stakeholders were involved at all stages of the study and a range of qualitative methods were implemented to capture their voices. Feedback from the stakeholders and evidence gathered from the literature generated, shaped and refined knowledge

serving as a basis for the design and refinement of the MSI. The following section discusses and reflects on the methodology used in reviewing the evidence, and collecting data from stakeholders at each step of the development phase. It also considers the range of research activities and methods undertaken within the context of the updated MRC framework (Skivington et al., 2021).

9.2.1 Systematic approach to the literature

Three different review methods (scoping review, rapid review and realist review) were employed based on the scope and evidence available in the literature, and the circumstances (e.g. time, resource) at the time the study was conducted. Focusing the rapid and scoping reviews on the specific components of the MSI to explore how they were used and delivered in other studies was important to gain an in-depth understanding of the components and their potential integration within the MSI.

For each review, methodological guidelines were followed to support replicability and transparency in the rigorous process of conducting, synthesising, and reporting findings. This was not always a straightforward process. For instance, despite the popularity of rapid reviews, the guidance available for conducting and reporting such reviews were limited at the time the study was undertaken (Tricco et al., 2017). Moreover, available definitions of scoping reviews were inconsistent (Munn et al., 2018; Tricco et al., 2016), along with a misleading idea among the

published literature that scoping reviews are simply a general review of the literature or rather a ‘smaller’ systematic review (Peters et al., 2021). Over the last few years, a series of articles and methodological guidance have been published in relation to increase consistent procedure and reporting among rapid review (Garritty et al., 2021; Hamel et al., 2021) and scoping review studies (Lockwood et al., 2019; Munn et al., 2018; Peters et al., 2020, 2021). The updated scoping review guidance, for example, recommends publishing or registering the review protocol to ensure transparency, rigour, and reproducibility (Peters et al., 2020). Peters et al. (2021) discuss the advantage of incorporating stakeholder consultations in the scoping review steps and other synthesis approaches, although future study are needed in this area.

By including stakeholders in the realist review process, this study extends the current literature and demonstrates that involving stakeholders within evidence synthesis can lead to in-depth understanding of the topic investigated, contextualisation, and relevance of the investigation.

The MRC framework (Craig et al., 2008) has been criticised for the lack of focus on context at the early stage of the intervention development. This was acknowledged in the newest published MRC guidance (Skivington et al., 2021), to such an extent that context has become one of the core elements of the latest updated version. In line with the definition used within the thesis, context has been

defined as ‘dynamic’ and ‘multi-dimensional’, including physical, social, cultural, political, or economic characteristics of the health and social system in which an intervention is delivered. It is assumed that the same intervention might not work in the same way in different contexts.

Embracing this perspective, this project sought to understand the care home settings, accounting for the care approach, residents’ characteristics, physical space, and the wider social contexts, such as care home leadership, care professionals and residents’ relationships. The realist methodology was adopted to explore the underpinning causal mechanisms of olfactory stimulation, with the scope of investigating the interactions between mechanisms and context through an innovative procedure involving stakeholders as providing primary data.

This resonates with updated MRC guidance (Skivington et al., 2021), which suggests the ‘best practice is to develop a programme theory at the beginning of the research project with the involvement of diverse stakeholders, based on evidence and theory from relevant fields, and to refine it during successive phases’ (Skivington et al., 2021, p. 4). Although the realist review is not new in the context of developing theory for complex interventions, the application of this method to studying the mechanism underpinning olfactory interventions within dementia is novel. Furthermore, this study explores a new approach to carrying out the realist

review, using evidence from the literature alongside a qualitative stakeholder investigation.

As discussed in Section 6.7, a number of challenges were encountered in the implementation of the realist review, such as the lack of methodological consensus, the difficulty in the classification and conceptualisation of context and mechanisms, and in organising and synthesising the programme. Furthermore, due to unfamiliarity with the approach, an understanding of the key components underpinning realist review enquiry was developed prior to designing the study. This process was challenging due to limited guidance and the multiple methods used in realist reviews. On the one hand, the lack of rigid guidance stimulated interest in exploring innovative approaches. On the other hand, it created uncertainty. Several published realist reviews within the dementia literature and other disciplines were summarised and discussed with the supervisory team to gain an overview of the approaches used in the literature and understand what could best fit with the aim of the present study.

Although challenging, such method have enabled the contextual factors associated with a complex social care setting such as care homes to be uncovered. Upon reflection, the reviews of the literature undertaken within the study supported familiarisation with the available evidence and development of a deeper understanding of the current intervention practice in dementia. Employing

different approaches to review the literature also facilitated learning the peculiarities and methods of multiple synthesis approaches.

9.2.2 Stakeholder involvement

Stakeholders were engaged in different phases of the MSI development process, including in the theory development, design process, and modelling. This is in line with the updated MRC guidance (Skivington et al., 2021) which advocates the need for key stakeholders to engage in each phase of the intervention development from early stage to the evaluation and implementation to increase the intervention impact.

A range of data collection methods was used within the research based on the purpose of the investigation. For instance, through one-to-one interviews with the stakeholders with expertise in olfactory and archival items, it was possible to target questions based on their knowledge and skills, and ultimately develop a deeper understanding of the feature of sensory materials which in turn guided the MSI-1 design.

The MSI-1 taster sessions included traditional research methods such as semi-structured interviews and focus groups, supported by a table depicting the key components of MSI-1 (themes and materials) and a sample of olfactory items and material objects. Focus groups were employed to understand the participants'

beliefs and experience regarding multi-sensory stimulation interventions and explore their perceptions on the key components of the MSI-1.

With the care professionals, the focus group format encouraged reflections on the participants' practice, and experience, and provided opportunities for in-depth interactions. The pre-existing relationship facilitated an atmosphere of trust and confidence which enabled participants to fully engage with the group discussion. A different group dynamic was found with relatives of people with dementia, who needed more time to build up the group trust.

Semi-structured interviews were used with older people based on the assumption that participants might feel uncomfortable discussing the topic of investigation in a group setting (Alzheimer's Disease International, 2019). Semi-structured interviews offered the opportunity to gain deeper understanding, whereas focus group discussion would have offered the opportunity to explore the group perceptions and beliefs.

The MSI-1 table (themes and materials) alongside potential olfactory items and material objects displayed in front of the participants were used for a dual purpose during the sessions, as prompts to stimulate discussion and as visual and written cues to enhance participants' engagement with the content, materials, and procedure of MSI-1. It is not clear to what extent using these elicitation tools alongside the interviews and focus groups helped the participants to visualise

MSI-1 and the potential experience of people with dementia within it. Elicitation tools to support and complement data collection, such as visual cards, have been successfully used in other studies (Casais et al., 2016; Niedderer et al., 2017). In reflecting upon the process undertaken to refine the MSI-1, multiple sessions with the same participants would be useful to promote a better understanding of MSI-1 and allow time for reflection on the MSI-1 components and how they may be improved.

Online surveys were used to explore the olfactory programme theory and refine the tentative IRPT model (Figure 6.3). Within the online surveys, a short video was used to incorporate the realist 'teaching and learning' technique (Section 6.3.2.3): presenting the tentative IRPT model and offering the participants the opportunity to comment on it and provide further insight on how, and why the programme is expected to work.

One of the challenges of this technique is the risk of acquiescence response bias referring to the tendency of participants to agree with the assumptions or theory presented regardless of the content (Mukumbang et al., 2020). To reduce this risk, the agree-disagree statements included an empty text box where participants could make free text comments to articulate and extend their responses. Furthermore, open-ended questions were used to explore how and why olfactory interventions work according to the participants.

The use of a videoclip (6.3.2.3) to present IRPT rather than textual material was chosen to create personal contact with the participants in the online survey described in Chapter 6 and include an 'interactive' experience. It was hoped that this would increase participants' engagement within the survey and completion rate. Although no inferences could be made as to whether the videoclip enhanced engagement with the online surveys or acquiescence response bias, nonetheless all participants who agreed to take part completed the online survey and articulated their responses, apart from one person who only responded to the Likert scales.

9.2.3 Involving people with dementia in research

The section below reflects on the importance and implication of involving people with dementia in research, aiming at designing innovative interventions or resources intended for them.

Over the last decade, the active participation of people with dementia in research has received increasing interest across different topics. The involvement of people with dementia provides unique opportunities to build knowledge about the meaning of living with dementia from people with lived experience. This can help overcoming researchers' or designers' preconceptions around dementia, and to create a better understanding of the individual resources and capabilities. These

could be empowered through appropriate design and a better definition of the problem, exploring creative solutions and new design opportunities.

Several studies have successfully integrated the voice of people with dementia not merely as participants but as co-researchers in exploring issues or as co-designers of innovative interventions (e.g. Treadaway et al., 2019; van Rijn et al., 2010). The terms co-researcher and co-designer are used to move away from the perspective of ‘user’ as a mere research subject towards a collaborative partnership where people living with dementia are involved from the process of building a research proposal to analyse data and co-authoring papers (Dening et al., 2020; Tsekleves & Keady, 2021).

The MinD project is an example of a participatory co-design study aiming to design with and for people with dementia resources for enhancing mindful self-empowerment, subjective well-being, meaningful and equitable social interaction and engagement (Niedderer et al., 2017). Participation of people with dementia in research not only positively contributes to successful design process and implementation, but it also has positive effects for people with dementia, such as feeling valued, proud, and understood, as well as increasing social interactions and engagement in activities (Leorin et al., 2019; Wang et al., 2019). People with dementia have a lot to offer to society: co-design and having an active role in the decision-making in research could help people living with dementia to connect with

their community, confirming their role as citizens, boosting their identity and self-esteem, and promoting dignity (Rodgers, 2018).

To understand the experiences of people living with dementia and to work successfully in partnership with them, it is essential to employ creative and novel research methods. For the MinD project, Niedderer et al. (2017) developed an interdisciplinary co-design methodology which included multiple methods ranging from consultations and brainstorming to traditional research methods such as focus groups and interviews. Fleetwood-Smith et al. (2021) proposed a novel approach to explore the perspectives of people with dementia and promote engagement, which embraces sensory, creative and embodied methods. The latter is relevant when working with people with dementia considering the methodological challenges of traditional methods involving verbal responses in capturing the individual's needs and experiences expressed non-verbally such as through gestures, body movements, and gaze (see e.g. Buse & Twigg, 2016; Dowlen et al., 2021; Fleetwood-Smith et al., 2021).

In response to the COVID-19 pandemic, the initial research protocol for this study was reviewed in the light of the UK government restrictions. As a result, the lived experiences of people with dementia unfortunately could no longer be included in the research. The process of redesigning the initial study protocol was influenced by reflections on ethical challenges. This was between, on the one hand, the

ethical value of doing no harm and protecting care home residents and care professionals who would be vulnerable from COVID-19, and on other hand ensuring the rights of people with dementia to be involved in the research and in the decision-making process of the MSI development.

Questions such as ‘What is the right thing to do?’ or ‘Is it better to gather the voices of people with dementia with the help of care professionals or not to collect them?’ were considered with the supervisory team. It was difficult to answer to these questions. Furthermore, there were, and remain, stringent restrictions on visiting care homes and prohibiting group activities, for instance. Therefore, limiting the participation of people with dementia in the present study was deemed the best way forward to ensure the safety of the participants and the author, compliance with the national regulations, and completion study.

However, in response to the COVID-19 pandemic, some other studies have adapted their methods to virtual or remote approaches, but not without challenges, as discussed during the plenary session ‘Learning the lessons of COVID-19 in nursing and residential care’ at the 31st Alzheimer Europe Conference (e.g. Capstick, 2021; Tischler et al., 2021).

Firstly, residents with hearing or communication impairments found it challenging to use telephone or videoconferencing. Secondly, technologies rely on care professionals’ skills. Care professionals often lacked the confidence and skills to

use devices and apps such as Zoom or WhatsApp. Even care professionals who were more familiar and skilled with the technology were often unable to support other colleagues and residents due to workload pressures during the pandemic. Finally, care homes often had limited technical capacities, such as absence of Wi-Fi and technical devices such as tablets. When technical support and devices were provided, care professionals' limited skills in using technology were still often significant barriers. Overall, it is important to reflect on the lessons learned in the time of COVID-19 and to undertaking research to create innovative solutions that would ensure the participation of people with dementia in research, and also to respond to challenging situations such as the ongoing pandemic.

9.3 Strengths and limitations

The components of the MRC framework (Craig et al., 2008) alongside qualitative stakeholder investigations were employed in this study for the development of MSI. Incorporating the findings of the existing literature with the experience and expertise of key stakeholders helped to better understanding the benefits of multi-sensory stimulation interventions and provided a strong foundation for an implementable, theory- and evidence-based MSI.

The MSI development was built on the promising pilot study of Griffiths at al. (2019) and the existing evidence base on multi-sensory interventions including olfactory and object handling interventions. The reviews provided a

comprehensive synthesis of this evidence. Using systematic approaches to literature searches with broad inclusion criteria (qualitative, quantitative, and mixed designs) ensured that all evidence, even that which did not report significant benefits, were considered. However, there is the possibility that relevant literature was not included, for example, due to the variety of terminology used to refer to object handling interventions.

The rigour of the syntheses was enhanced using a standardised approach to the search and guidelines for each review method. However, one author was chiefly responsible for the screening of the studies and their interpretation. The eligibility, data charting of the scoping review and data extraction of the rapid review was supported by an external reviewer who independently assessed and checked a subset of papers. The author independently screened and judged the eligibility of the study in the realist review; however, the interpretation of the findings was guided by stakeholders and the supervisory team. The close collaboration with the supervisory team, the external reviewer and stakeholders may have partly offset possible selection and synthesis bias.

The active involvement of stakeholders throughout the development process lends strength to the research findings. Firstly, engaging with key stakeholders, such as olfaction experts, archivists, care professionals, relatives of people with dementia, and older people, served as a way to gain knowledge about their perception of the

needs of people with dementia and related settings, identifying emerging priority and designing a tailored and appropriate MSI-2. Secondly, the unique perspective of stakeholders offered the opportunity to develop MSI-2 which is likely to reflect the real-life context of care homes. This has important implications for effective intervention implementation and evaluation. For example, stakeholder involvement enhanced relevance and contextualisation of MSI-2, and enabled anticipation of barriers and facilitators that could be encounter during its implementation in the care home settings (Vernooij-Dassen & Moniz-Cook, 2014). Stakeholder engagement also provided opportunities for knowledge exchange (Concannon et al., 2014). Their involvement offered the opportunity to learn from their lived experiences and expertise. It might have also served to raise awareness about dementia and psychosocial interventions in the dementia care sector and wider community (Jakob & Collier, 2017a). For example, discussing the multi-sensory stimulation intervention and its impact might have provided opportunities for care professionals to reflect on their care practice and to promote new ways of working. This may, in turn, contribute to promoting dissemination as an iterative process, as well as the development of innovation in dementia care (Vernooij-Dassen & Moniz-Cook, 2014).

A potential limitation associated with this work is that, due to COVID-19, the study did not include the empirical data gathering as planned in the original study

protocol. For this reason, a further limitation should be considered. The MSI-2 relies solely on proxy feedback. As outlined in Section 9.2.3, it is essential to include people with lived experience of dementia in studies regarding dementia care, in particular in research focusing on treatments and interventions, as they have lived experience about what could be useful for them. Although stakeholders supported the process of tailoring MSI-2 to what was perceived to be more appropriate, useful and acceptable for people with dementia based on their experience and knowledge, it is acknowledged that the experiences and perceptions of people with dementia may differ from care professionals or family carers, as seen in other studies (e.g. Popham & Orrell, 2012; Spector & Orrell, 2006). This means that MSI-2 might not be relevant, acceptable, enjoyable, or appropriate from the point of view of people living with dementia. A few studies have, however, found evidence on the accuracy and congruency among stakeholders and people living with dementia (e.g. Boyer et al., 2004; Ngu et al., 2015).

Despite the limited empirical elements within this research, the changes made to the initial plan due to COVID-19 pandemic led to new findings extending the knowledge on the mechanisms underpinning the olfactory programme. This work strengthens the development of the MSI which was informed by the key ingredients of the olfactory programme identified in the realist review and created

opportunities for further theoretical and practical developments in this area. Although the realist review provided a unique opportunity to investigate an initial theoretical explanation of olfactory programmes using novel methods, it included several limitations that were discussed in detail in Section 6.6, such as the interpretation bias, the impact of a single reviewer undertaking the study screening, the lack of IRPT testing and sample heterogeneity.

The study might have benefited from early engagement of stakeholders in its initial conceptualisation. Exploring their needs and perceptions concerning multi-sensory stimulation interventions could inform and provide the basis for designing MSI-1, including the generation of design concepts to take forward in the development, generation of possible ideas and solutions, and the creation of innovative design. This initial process could have the potential to stimulate creative ideas and to provide insights into the lived experience of people with dementia and those who are caring for them (Dening et al., 2020). However, the design concept developed in this study drew upon the reviews of the literature and the author's previous experiences of volunteer work with people with dementia and older people using sensory items. The design solutions were guided by the evidence along with the involvement of olfactory experts and archivists who supported the development of more detailed design ideas.

Another potential limitation of the study is that the olfactory investigations, including rapid and realist reviews, did not inform the MSI-1 design. The study might have benefited from exploring the key findings of IRPT in relation with the MSI-1 together with stakeholders. However, all the stages undertaken within the research contributed to the MSI-2 as it emerged.

The intervention development process undertaken in this study involved collaborating with business organisations, including Givaudan Ltd, Heathrow Airport archive, and Boots UK archive. The collaborative relationships developed throughout the study not only facilitated use of a range of specific resources, such as fragrances and products, but also provided the opportunity to access expertise on the neuroscience of smell and archival collections. Working closely with industry has been very valuable for the study as it promoted innovation and knowledge transfer (Dening et al., 2020).

A Knowledge Transfer Partnership project has been developed in order to retain and consolidate collaboration between industry and academia, which in turn could extend the knowledge in olfactory research with older people and facilitate the development of innovative products.

9.4 Implications and future research directions

The study has a number of implications for research, policy and dementia care practice. The implications are presented in the section below. Appendix 23 summarises the public engagement and dissemination activities undertaken during the PhD.

9.4.1 Implications for research

- Given that the major limitation of this research is the lack of involvement of people with dementia, further work is needed to include the lived experience of people with dementia and to investigate their perceptions and experiences in relation to multi-sensory stimulation interventions and MSI-2. This may be achieved using creative methods (e.g. Fleetwood-Smith et al., 2021) or video, that could capture the sensory, emotional and embodied experience of people with dementia with sensory materials at verbal and non-verbal levels (Tsekleves & Keady, 2021).
- This study has used traditional methods such as surveys, interviews and focus groups. Further studies should include innovative methods to support stakeholders in imagining the MSI and to create a more concrete visualisation of the intervention components, procedures, and overall experience. Iterative process should be applied in the refinement of the intervention, such as multiple sessions with the same stakeholders to

support the development of participants' reflections and ideas in relation to the components being investigated.

- The results demonstrate that objects and olfactory items could trigger emotions, memories and promote self-identity. This indicates the potential that MSI can have in care home settings to enhance pleasant and enjoyable feelings, interactions, and to boost self-identity. Further study should explore both 'in the moment' experiences as well as the longer-term effects of the interactions and sensory stimuli. The new conceptual framework of 'being in the moment' experience as a continuum of moments (Keady et al., 2020) could be applied for such investigations.
- The findings from this study advocate for the need to consider the sensory experiences of people with dementia. As demonstrated by the rapid review (Chapter 5), the current practice of olfactory interventions often allocates a passive role to people with dementia. This is despite the clear evidence in the realist review that people with dementia are active contributors in olfactory interventions. Individual past experiences, preferences and beliefs of people with dementia should be acknowledged and embraced as they influence how individuals engage and respond to the olfactory items.
- The need to explore the impact of culture, ethnicity and gender within the sensory stimuli such as the material objects and olfactory stimuli selected for the intervention emerged. It is important to create interventions which

are inclusive and accessible to people from different backgrounds and genders.

- Further studies, such as a feasibility study of the intervention design, should focus on MSI uncertainties (Skivington et al., 2021). In particular, the duration, frequency, and level of adherence to the intervention should be investigated. Overall, there is a need to explore the optimal 'dose' of multi-sensory stimulation intervention considering characteristics of the setting.
- In line with the MRC framework (2008), the review of the evidence identified potential outcomes that are associated with MSI such as improvements in the quality of life, social inclusion, behaviour, cognition and physical health. A feasibility study of the evaluation design should measure and assess changes in people with dementia in these identified outcomes (and, possibly even in unintended outcomes) and collect data to support the refinement of hypotheses about the causal mechanisms and their interactions with the contextual factors (Skivington et al., 2021). Methods, such as video, that could enable the capture of the experiences of people with dementia in the outcomes of interest should be used.
- Given the importance of staff knowledge and skills to facilitate a successful intervention, further research could focus on the co-design with key stakeholders of visual materials and guidance such as the fact sheet and

the draft cards with prompts that could support and promote care professionals to engage with MSI and residents in daily care practice.

- There is potential for the employment of olfactory stimulation to reduce, and maybe even reverse, the decline of olfactory function, and wider health and cognitive benefits as well as improving quality of life. Further studies should focus on olfactory stimulation, such as olfactory training, which has been found to influence the functional and structural organisation of olfactory brain areas as well as improving olfactory functioning, and reducing mood disorder e.g. depression and improving cognitive function in adult and older people (Birte-Antina et al., 2018; Hummel et al., 2009; Wang et al., 2004). Limited evidence is available for people with dementia (Chen et al., 2022; Olofsson et al., 2021). Therefore, it seems important that future studies confirm the impact of olfactory stimulation in people with dementia and explore the ways olfactory training might contribute to prevent olfactory loss, and to promote health and well-being benefits in the wider population of older people.

9.4.2 Implications for policy and dementia care practice

- Considering the importance of sensory stimulation to support and maintain identity and well-being, and to reduce responsive behaviours, there is the need for care provider policies to reflect on how interventions promoting

sensory stimulation, such as MSI, can be integrated into the care home routine practice. Residents could benefit from regular engagement with everyday sensory stimuli, especially those which may be less likely to be encountered in care home settings, such as the smell of cut grass or seaside.

- The study found that care home managers have an important role in advocating for successful implementation of the intervention. Policy makers should ensure that care leadership understands the importance of multi-sensory stimulation intervention for people with dementia and provides opportunities for residents to engage with such interventions, and to support staff to implement it within their routine practice.
- There is a necessity to emphasise the importance of individual sensory experience and the different ways people can communicate beyond verbal dimensions. As such, care professionals, researchers, and informal caregivers should be trained to capture, interpret and respond to embodied and non-verbal responses of people with dementia in order to understand their lived experience.
- Care provision policy should support opportunities for the development and promotion of care professionals' skills and knowledge, encouraging self-initiated activities (e.g. engage with residents using everyday materials

objects), and valuing their work. This could shift the focus from a task-oriented care to a more holistic approach focused on the well-being of the person with dementia.

- This research highlights the importance of involving people with dementia in research. Co-research or co-design is vital to create impactful solutions and resources for those who are living with dementia. Ethical policy surrounding the involvement of people with dementia in research should be adapted to facilitate their inclusion throughout the research process as experts regarding their own problems, experiences, wishes and needs.

9.5 Conclusion

This study explored the importance of multi-sensory stimulation interventions for people with dementia living in care homes by reviewing the evidence in relation to their effectiveness and theoretical underpinnings for people with dementia and gathering insight into their use from the stakeholders.

The findings suggest that sensory stimuli are central to people with dementia. Not only do they support representation and response to the environment, but they also hold a potential therapeutic value, such as improvement of mood, quality of life, well-being, cognition and reduction of responsive behaviour.

These findings were used as the basis for the development of a novel theory- and evidence-based multi-sensory stimulation intervention. The MSI design aims to promote sensory experiences for residents, opportunities for connection and social interactions, and comfort and pleasure for people with dementia.

Although the need for future investigations exploring the experience of people with dementia in relation to the MSI and assessing its feasibility, MSI can be a useful tool to stimulate the senses, to support residents' engagement in meaningful and enjoyable activities and to maintain their identity and a sense of agency in care home settings.

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APPENDICES

Appendix 1: Distress protocol

Distress protocol

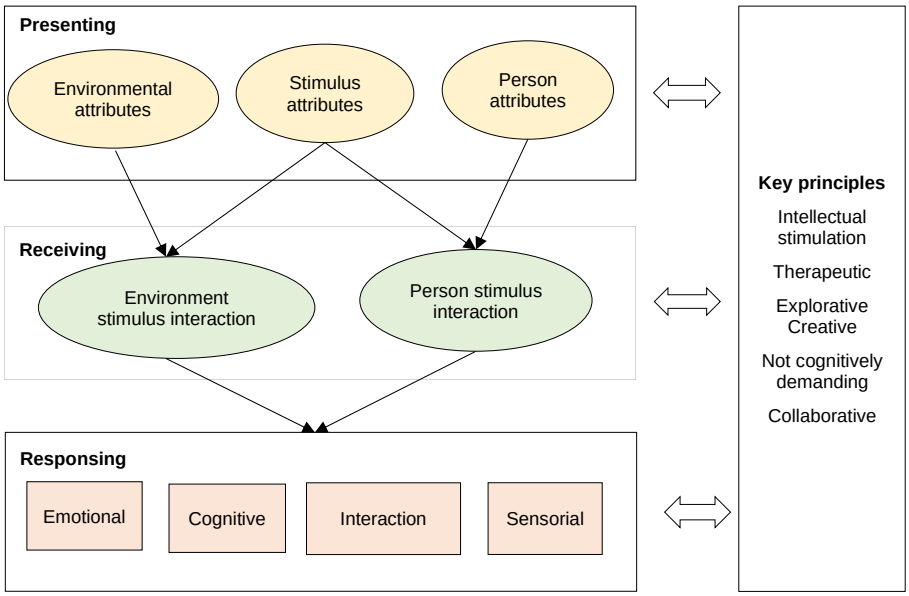
The researcher has a clinical background and will observe and monitor the stress levels of participants and any signs of distress.

In case participants become uncomfortable or distressed while in interviews and focus groups, the following actions will be taken by the researcher:

1. Stop the session and suggest a break with refreshment.
2. The researcher will accompany the participants to a quiet area.
3. Provide immediate support to the person.
4. Spend time with the participant to discuss their concerns, if appropriate. If the participant needs time alone, the researcher will respond according to the situation.
5. The research will ask the participant if they would like the researcher to contact a person of their choice.

6. If the participant wishes to carry on, the session will be completed. If the participant decides to interrupt the session, support will be provided until they are stable.
7. If it is appropriate, the participant will be recommended to speak to a counselling service to discuss their concerns.
8. With the participant's consent, a follow-up phone call will be made the following day to ensure the participant's status.
9. The researcher will report the event to the principal supervisor and the care home manager will be informed.
10. A log of the event will be created which describes the occurrence.

Appendix 2: Checklist object handling operational model



Model description

1. Object presentation

One or more objects should be presented for participants to interact with and discuss about. Object presentation may be influenced and determined by environment, person and stimulus attributes.

1.1 Environmental attributes

Setting characteristics may influence the way objects are presented.

Environmental attributes include:

	Agree	Disagree
Location		
N. people in the session		
Social context		
Cultural context		
Level of room temperature		
Level of noise		
Level of light		
Time of stimulus presentation		
Facilitator competence (flexibility, empathy, training)		

Would you include other components? If so, please list them below

_____

1.2 Person attributes

Various characteristics of the person are likely to impact the way objects are presented. Our model considers:

	Agree	Disagree
Gender		
Age		
Level of dementia		
Ethnicity		
Person's attitude toward objects		
Previous experiences		
Familiarity with the items		

Would you include other components? If so, please list them below.

_____

1.3 Stimulus attributes

The stimulus attributes that may affect the level of engagement and curiosity.

Stimulus attributes include:

	Agree	Disagree
Shape		
Size		
Weight		
Density		
Texture		
Object meaning		
Object role		
Object history		

Would you include other components? If so, please list them below.

_____

Overall comments on 'object presentation' phase:

_____

2. Receiving

It is in the mutual intersection of object, subject and environment that determine the way the person receives the object.

2.1 Environment-stimulus interaction

The physical spaces and social context in which object handling intervention are encountered can influence how the person engages with the items. A supportive and encouraging environment, for example, is more likely to be perceived as a safe space to explore and engage with the objects.

Comments:

_____

2.2 Person-stimulus interactions

The interaction between the physical and material characteristics of the objects and the person' attributes influence the way the person interacts with the object. Some stimuli may be more interesting for certain people than others. One example of a person-stimulus interaction is the degree to which the person has shown a preference for this type of stimuli in the past.

Comments:

_____

Overall comments on 'receiving' phase:

_____

3. Responding

3.1 Emotional

Participants may experience one or likely a multi-dimensional range of emotions, which define the subjective experience. Emotions such as 'happiness', 'anger', 'sadness' and 'boredom' might be expressed through the actual expression of emotion, such as body language, or the physiological response, such as sweaty palms or a racing heartbeat

3.2 Cognitive

Participants are actively engaged in meaning-making which occurs through interaction and communication with the facilitator or other participants, the object, personal experience. A variety of cognitive domains such as attention, sensory integration process, memory and executive functions are involved during the object interaction.

Comments:

_____

3.3 Verbal/non-verbal interactive

Objects can facilitate verbal and non-verbal communication. People may respond by talking about the stimulus with the facilitator or groups. However, people who do not react to verbal conversation may react to the object through physical engagement, exploring and manipulating objects, and a bodily interaction, such as body posture, direction of gaze and gestures without any explicit, verbal reference to what they mean.

Comments:

_____

3.4 Sensorial

Holding and manipulating object may stimulate other sense modality, such as vision and olfaction. For instance, a person can engage with the item using one or more of the five senses.

Comments:

_____

Overall comments on 'responding' phase:

_____

4. Key principles

*****(Underling the term you think is more appropriate)

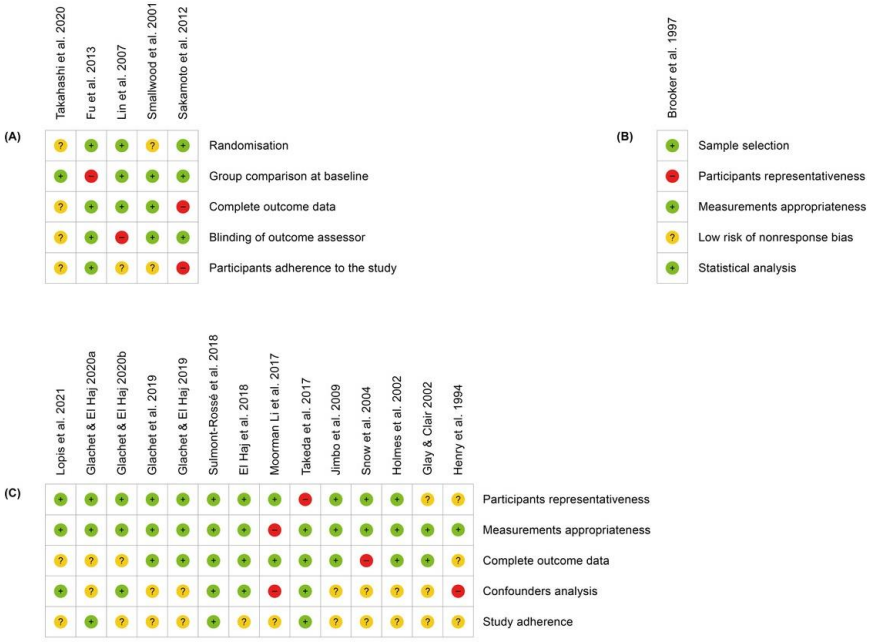
	Agree	Disagree
Intellectual stimulation or Educational*****		
Therapeutic		
Explorative		
Not cognitively demanding		
Creative		
Connection or Collaborative*****		

Would you include other principles? If so, please list them below.

_____

Appendix 3: Summary of risk of bias in studies

The figures summarise risk of bias for the included studies in the appropriate Mixed Methods Appraisal Tool (MMAT) category: (a) randomised controlled trial studies; (b) quantitative descriptive study (c) quantitative non-randomised studies.



Appendix 4: Participant information sheet for experts on dementia and olfaction

UWL/REC/CNMH-00735

INFORMATION SHEET

Title of study: Using olfactory stimulation in a multi-sensory intervention in care home for people with dementia.

You are being invited to participate in an online survey as part of a doctoral student project. This study is funded by the University of West London doctoral scholarship and conducted by the doctoral student Federica D'Andrea under the supervision of Prof. Victoria Tischler, Prof. Tom Dening and Dr Anne Churchill. Before you decide whether to take part in this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please feel free to contact me at federica.d'andrea@uwl.ac.uk

Thank you for reading this information sheet.

What is the purpose of the study?

This study aims to provide an understanding of the underlying processes (or mechanisms) contributing to the positive outcomes of olfactory stimulation for

people with dementia. Olfactory stimulation refers to a variety of activities involving smell(s) used in ways to change environment or to enhance therapeutic effects, such as well-being or positive mood.

Why have I been asked to take part?

You have been invited to take part because your experience can help us to identify the key components of olfactory stimulation for people with dementia.

Do I have to take part?

It is up to you to decide. If you would like to take part, we will then ask you to complete a consent form before participating. You will be also asked permission to be re-contacted in the future to be invited to take part in the later stage of this research by the doctoral student, Federica D'Andrea. You are free to withdraw at any time, without giving a reason. If you withdraw from the study, all data and information collected from you will be destroyed.

What will happen to me if I take part?

If you decide to take part in the research by signing the consent form, you will be asked to fill in a survey. The survey will include a series of questions and tentative assumptions about olfactory stimulation, including what are considered essential components of the intervention, how it is thought to work, and on what outcomes. You will be asked to give your opinion based on your experience and expertise. The entire procedure will be done online and take approximately 20 minutes.

What are the possible disadvantages and risks of taking part?

Due to the nature of the research, it is not possible to guarantee complete control over confidentiality due to the potential for hacking and other malicious activity. Even if Internet Protocol (IP) addresses are not collected, tracking links are not used, and identifying information is not requested within the survey itself, there is

still the potential for breaches of anonymity and confidentiality in online surveys that are beyond the researcher's control.

What are the possible benefits of taking part?

If you decide to take part, the information we get from this research may help us to have a better understanding of the key factors of olfactory stimulation and overall improve the care of people living with dementia.

Will my taking part in the study be kept confidential?

All information collected about you during the course of the study will be kept strictly confidential. During the data gathering process, your response will be stored in Amazon Web Services in conformance with the requirements of ISO 27001, and then exported in researcher's laptop without any identifying details under secure conditions for 5 years according to the University of West London's code of research conduct and research ethics. After this time your data will be disposed of securely. For further information, please see the Data Management and Storage Statement link below.

What will happen to the results of the research?

Data collected will be used to write sections of the doctoral student's PhD thesis and they may be presented at educational events such as conferences or used to write a paper for publication in academic journals. This may include verbatim quotes. The participant's name will be anonymized, but the role – for example, academic expert or care staff might accompany the quote.

Who has reviewed the study?

The study has been reviewed and approved by the University of West London Biomedical Sciences Research Ethics Committee.

For more information about this research, please contact:
Federica D'Andrea
MPhil/PhD student School of Nursing, Midwifery and Healthcare
University of West London
St Mary's Rd, London, W5 5RF
Mobile: ****

Email: federica.d'andrea@uwl.ac.uk

If you have any complaints about this study, please contact:
Dr John Hughes
Chair of Biomedical Sciences Research Ethics Committee.
University of West London
St Mary's Rd, London, W5 5RF
Email: john.hughes@uwl.ac.uk

If appropriate, a counselling service contact:
https://www.nhs.uk/conditions/counselling/

Data Management and Storage Statement pdf:
https://static.onlinesurveys.ac.uk/media/account/298/survey/658252/question/data_management_and_storage_st.pdf

Appendix 5: Consent form for experts on dementia and olfaction

UNIVERSITY OF WEST LONDON
The Career University

UWL/REC/CNMH-00735

Consent Form

If you are interested in taking part in the study, please tick the box 'YES' below to indicate your consent and insert your name and email address on the following page.

- I understand that my personal data from this study will remain strictly confidential.
- I understand that the data resulting from my participation may be used for purposes of publications and presentations, and that no personal identifying information will be used for those purposes.
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason for withdrawing.
- I understand the risks associated with online research such as hacking and other malicious activity which are beyond the research control.
- I agree to take part in the study.

I have read and agreed to all terms and conditions*.

YES ☐ NO ☐

Please confirm that you agree to take part in this study by entering your full name as a signature*.

(*A required field)

Appendix 6: Survey 1 for dementia experts

OLFACTORY STIMULATION SURVEY

Before beginning the survey, I would like to invite you to watch the video below that explains the study aims and our initial findings on how smell contributes to the positive outcomes associated with olfactory stimulation for people with dementia. You can also choose to skip the video and move directly to the survey by click 'Next' at the bottom of the page.

[Video]

Instructions:

The statements below concern the relationship between olfactory stimulation and its outcomes for people living with dementia. The aim of these questions is also to explore for whom and in what circumstance olfactory stimulation may or may not work. Decide on the extent to which you personally disagree or agree with each statement and tick the appropriate box. Then complete the text box if necessary. There are no right or wrong answers.

1. A smell must be familiar to a care home resident in order to have a physical impact (e.g. skin temperature, pulse rate, breathing rate, and blood pressure).

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

2. A smell must be familiar to care home residents in order to have psychological impacts (e.g. improved mood/ self-esteem, strengthens the connection between one's past and present, produces feelings of social connectedness, elevates optimism).

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

3. The subjective rating of a smell as pleasant or unpleasant can affect corresponding changes in mood (pleasant smell – improved mood; unpleasant smell – worsened mood).

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

4. An emotional experience associated with a smell can be triggered if an individual is exposed to the same smell once again.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

5. Smells can trigger an effect only if a person is aware of it.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

6. The volatile compounds of a smell inhaled via the nose can enter the bloodstream and affect the autonomic/central nervous system and/or endocrine system producing physiological changes (e.g. pulse rate, blood pressure).

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

7. To what extent do you agree that the physical changes enhanced by volatile compounds of a smell can affect psychological changes (e.g. mood)?

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

8. An individual's beliefs and expectations associated with a smell (e.g. beneficial qualities) have direct impacts on physical and psychological changes.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

9. The way smells are delivered (e.g. using a diffuser, patch or massage) influences how olfactory stimulation can affect psychological and/or physiological changes.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

10. Care professionals' knowledge on smells (e.g. smell proprieties, dosage) is essential to implement olfactory stimulation in a care home setting.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

11. The severity of dementia symptoms negatively affects olfactory stimulation outcomes (i.e. reduced responsive behaviours, disrupted sleep, improved mood and food intake etc.).

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

12. Sub-types of dementia (e.g. Alzheimer's disease, Dementia with Lewy bodies, Vascular dementia, Frontotemporal dementia, Mixed dementia) might determine different olfactory stimulation outcomes (e.g. positive or worse effects).

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

13. Can care home residents' past memories - triggered by smells - elicit the following outcomes in people with dementia? Select any that apply:

☐ Boost residents' identity
☐ Life satisfaction
☐ Improved mood
☐ Quality of life
☐ All of the above
☐ None of the above

Explain more about your answer here_____

14. What approach to deliver the smells do you think is more effective for stimulating people with dementia living in care home? Select any that apply:

☐ Diffuser (e.g. electronic vaporise, rattan sticks)
☐ Patch
☐ Spray type dispensers for rooms
☐ Spray type dispensers for clothing
☐ Bottle/jar container
☐ Hand massage
☐ I do not know

Explain more about your answer here_____

15. How would you introduce a smell to people with dementia? Select any that apply:

☐ Brief description of the smell without naming the odour (e.g. clue cards with characteristic or general information associated with a smell)
☐ Brief description of the smell naming the odour
☐ Pictures
☐ Brief description of smell and pictures
☐ Smell should not be introduced
☐ I do not know

Explain more about your answer here_____

Instructions

The following questions aim to explore your experience and opinion(s) about the use of olfactory stimulation in dementia care. Please complete the text boxes below.

16. In your opinion, why might olfactory stimulation enhance residents' behaviours and emotional state?_____

17. In your opinion, what resources are needed for using smell effectively in a care home setting? _____

18. Do you have any other comments about the use of olfaction with people living with dementia?_____

Please complete the following demographic questions.

19. Your Occupation: _____

20. Have you participated and/or facilitated activities using smells before? Yes: ☐ No: ☐

    If yes, what type of activities have you been facilitating? or involved with?
    _____

    For how long have you been organising? olfactory activities?
    _____

    In what context have you been using olfactory activities?
    _____

21. Have you worked with people with dementia?
    _____

    If so, for approximately how many years? _____

Would you like to submit your survey responses?

☐ Yes, I want to submit my survey responses
☐ No, I want to withdraw from the study

Thank you very much for taking the time to complete this survey.

Your responses will contribute to refining the Olfactory Stimulation Programme Theory (OSPT) model and direct further scoping of the literature.

Appendix 7: Survey 2 for olfactory experts

OLFACTORY STIMULATION SURVEY

Before beginning the survey, I would like to invite you to watch the video below that explains the study aims and our initial findings on how smell contributes to the positive outcomes associated with olfactory stimulation for people with dementia. You can also choose to skip the video and move directly to the survey by click 'Next' at the bottom of the page.

[Video]

The survey should take you approximately 20 minutes to complete. You may decide to complete a portion of the survey and return later to finish the rest by 20 November 2020.

The following questions aim to explore your experience and opinion(s) about the use of olfactory stimulation in dementia care. Please complete the text boxes below.

1. In your experience, what are the response(s) of people with dementia when they experience a smell? _____
2. In your opinion, why might olfactory stimulation enhance residents' behaviours and emotional state (e.g. positive mood)?_____
3. In your opinion, what resources are needed for using smell effectively in a care home setting?_____
4. Do you have any other comments about the use of olfaction with people living with dementia?_____

Instructions: The statements below concern the relationship between olfactory stimulation and its outcomes for people living with dementia. The aim of these questions is also to explore for whom and in what circumstance olfactory stimulation may or may not work. Decide on the extent to which you personally disagree or agree with each statement and tick the appropriate box. Then complete the text box if necessary. There are no right or wrong answers.

5. A smell must be familiar to a care home resident in order to have a physical impact (e.g. skin temperature, pulse rate, breathing rate, and blood pressure)

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

6. Smells can trigger a response only if a resident is aware of it.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

7. The way smells are delivered (e.g. using a diffuser, patch or massage) influences how olfactory stimulation can affect residents' responses.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

8. Olfactory stimuli introduced in a group or one-to-one session can boost residents' self-identity, self-esteem and enhance feelings of social connectedness.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

9. The training (e.g. on psychosocial interventions, person-centred approach) of care professionals who are directly involved in residents' care and activities delivery is relevant to implement olfactory stimulation in a care home setting.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

10. Care professionals' knowledge on smells (e.g. smell proprieties, dosage) is essential to implement olfactory stimulation in a care home setting.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

11. Care home managers influence how olfactory stimulation is implemented (e.g. care staff training, resources, and time allocated for olfactory stimulation).

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here
_____

12. Care home managers have an impact on care professionals' attitudes toward olfactory stimulation.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

13. The severity of dementia symptoms negatively affects olfactory stimulation outcomes (i.e. reduced responsive behaviours, disrupted sleep, improved mood and food intake etc.).

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

14. Sub-types of dementia (e.g. Alzheimer's disease, Dementia with Lewy bodies, Vascular dementia, Frontotemporal dementia, Mixed dementia) might determine different olfactory stimulation outcomes (e.g. positive or worse effects).

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here
_____

15. Care professionals might benefit (e.g. by reducing their care burden) from olfactory stimulation implemented for residents living in a care home.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree
☐ I do not know

Explain more about your answer here_____

16. Can care home residents sharing memories of their own lives (during an olfactory stimulation activity) lead to the following? Select any that apply:

☐ Understanding of residents' needs
☐ Positive attitudes towards dementia
☐ Person-centred approach
☐ Boost relationship between residents and care professional(s)
☐ All of the above
☐ None of the above

Explain more about your answer here_____

17. Can care home residents' past memories - triggered by smells - elicit the following outcomes in people with dementia? Select any that apply:

☐ Boost residents' identity
☐ Life satisfaction
☐ Improved mood
☐ Quality of life
☐ All of the above
☐ None of the above

Explain more about your answer here_____

18. What approach to deliver the smells do you think is more effective for stimulating people with dementia living in care home? Select any that apply:

☐ Diffuser (e.g. electronic vaporise, rattan sticks)
☐ Patch
☐ Spray type dispensers for rooms
☐ Spray type dispensers for clothing
☐ Bottle/jar container
☐ Hand massage
☐ I do not know

Explain more about your answer here
_____

19. How would you introduce a smell to people with dementia? Select any that apply:

☐ Brief description of the smell (e.g. clue cards with characteristic or general information associated with a smell) without naming the odour
☐ Brief description of the smell naming the odour
☐ Pictures
☐ Brief description of smell and pictures
☐ Smell should not be introduced
☐ I do not know

Explain more about your answer here_____

Please complete the following demographic questions.

20. Your occupation/role: _____

21. Have you participated and/or facilitated activities using smells before? Yes: ☐ No: ☐

    If yes, what type of activities have you been facilitating/ or involved with?
    _____

    For how long have you been organising/participating in olfactory activities?
    _____

    In what context have you been using olfactory activities?
    _____

22. Have you worked/cared with people with dementia?
    _____

    If so, for approximately how many years? _____

Would you like to submit your survey responses?

☐ Yes, I want to submit my survey responses

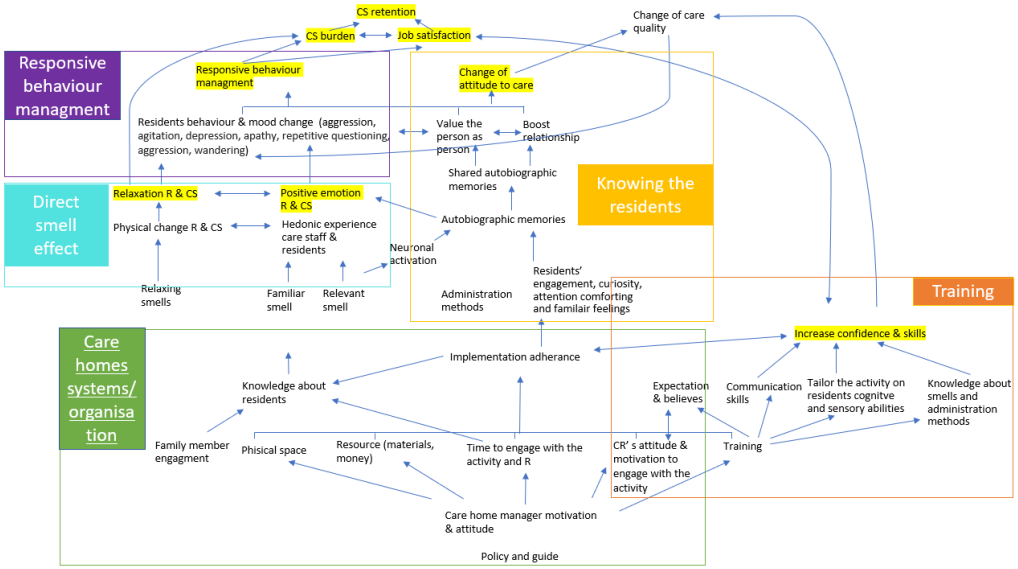
☐ No, I want to withdraw from the study

Thank you very much for taking the time to complete this survey.
Your responses will contribute to identify the key components of olfactory stimulation for people with dementia and direct further scoping of the literature.

Appendix 8: Data code manual (adapted from Mukumbang et al., 2018a)

Category		Definition	Coding Rules
Context		Context refers to salient conditions that are likely to enable or constrain the activation of programme mechanisms.	Components of both the physical and the social environment that favour or disfavour the expected outcomes.
Mechanisms	Resource	Resources are intervention components introduced into a pre-existing context in such a way as to bring about a change in, or enhancement of, stakeholder reasoning. 'Resources' = intervention components introduced into a pre-existing context.	Knowledge or physical components of the intervention that are used to achieve an expected outcome or considered as a constraint.
	Reasoning	Reasoning is the stakeholders' responses to the resources provided that leads to the changes in thoughts, beliefs and/or behaviour demonstrated in the programme outcomes. Reasoning' = what changes these resources will produce?	Any change in the stakeholders e.g. attention, perception, that are generated by the resources.
Outcomes	Immediate outcome	Describes the immediate effect of the olfactory stimulation interventions	Immediate outcome typically refers to changes in emotion, physical activation, knowledge, or awareness, as these types of changes typically precede changes in behaviours, mood or practices.
	Intermediate outcome	Intermediate outcomes refer to behavioural, mood changes that follow the immediate outcomes.	Codes here define a move from direct outcomes to intermediate outcomes, identified through the indirect impact of the activity and accountability of the programme.
	Long-term outcome	Refer to change in the medium- and long-term, such as a patient's health status, and impact on community and health system.	The codes here represent the further indirect impact of the activity demonstrating the lesser accountability of the programme.

Appendix 9: Example of mind map from the realist review



Appendix 10: Master and pattern codes: analysis of survey data

Category	Pattern code	Explanation	Supporting quotes
Immediate outcomes	Emotional response	One of the immediate outcomes identified by respondents is related to changes in the individual's emotional status. The pattern code 'emotional response' emphasises the immediate response mediated by changes in the psycho-neural processes (Tyng et al., 2017) following olfactory stimuli or odour-evoked memories. These changes result in emotional valence experience (pleasure-displeasure) and emotional arousal (high-low activation/calming-arousing). Participants agreed that "smell can be uplifting" for people with dementia and care staff. Certain smells are associated with a particular emotion "shaped by previous experiences". Stakeholders, mainly people working with people with dementia, mentioned how smells can also trigger negative responses.	"I think it [emotional response] is because olfactory stimuli are often associated with an event or a memory. For example, smells of ginger and cinnamon can evoke memories of Christmas and feelings of warmth." (DE6) "[…] a bad smell might have a negative effect on someone's behaviour that requires staff's attention." (DE2) "It might depend on the memories - not all memories are positive." (DE3)
	Physical response	Physical response is related to the physical reactions to smell. Participants agreed that smell can generate a physical response. However, it is unclear from the participants' responses whether the physical responses are activated solely by the volatile compounds of smell or by odour-evoked memories or/and emotions. Most of the participants agreed that physiological responses could be elicited regardless of whether the smell is familiar or not.	"I think they may have to at least have had some emotional connection to that smell to have a physiological impact. Hopefully positive of course." (DE7) "Odours may affect mood via these physiological changes, but again, it is probably not a clear-cut cause-and-effect situation." (OE2). "Familiar smells could intrigue memories but like with everyone a strong unfamiliar smell could have a physical effect." (OE2)

Appendix 10 *(Continued)*

Category	Pattern code	Explanation	Supporting quotes
	New and past associations	Autobiographic memories were identified as immediate outcome of olfactory interventions. To some of the participants, not only does smell provide the opportunity for creating connections with the past, but it also connects the individual with the present, bringing people in the moment and supporting the creation of new associations. Olfactory experts highlighted that a smell does not need to be encountered in the past. New associations can be created.	"Drawing upon my experience, I have seen people with dementia talk about passionately about their favourite perfume. For example, one woman spoke of using her scent to create a sense of presence in the care home. Whilst another, associated certain scents with specific times of day and occasions […]. These examples suggest that certain smells can evoke particular feelings, emotions and associations. The ways in which scent can be associated with other aspects of daily lives and can also transport people to imagine different events or occasions is particularly interesting." (DE2) "They might bring people into the moment or remind them of the past." (DE1) "Though people can learn new associations, too". (OE1)
	Social interactions	Another immediate outcome is an increase in interactions. Smells were identified to act as a prompt for new conversations on different topic which are not related to care. They also provided the residents with the opportunity for sharing personal past experiences, beliefs, and thoughts. This is illustrated by two participants who reported their own experience. Some participants also commented that smell can become the central topic of conversation with care staff.	"In terms of everyday smells in the care home - the smell of food often proves a point for discussion and can provoke interest. For example, I have assisted with cookery sessions in a care home and on entering the room the smell of what was baking / cooking immediately provoked discussions about recipes, favourite meals and so forth. It also provoked reflection regarding the food available in the care home." (DE10) "I have personally witnessed how a particular smell can recall a memory instantaneously which often leads to the person talking about that memory." (DE7) "Creates a shared participation experience […]. May spark further conversations." (DE3).

Appendix 10 *(Continued)*

Category	Pattern code	Explanation	Supporting quotes
Intermediate outcome	Mood change	According to the olfactory experts, changes in mood are associated with the emotion elicited by pleasant smells. Whereas dementia experts agreed that changes of mood are trigged by the odour-evoked memories. Similarly, to the emotion pattern code, stakeholders suggested that mood can have positive and negative valence. Interestingly, most of olfactory experts agreed that psychological responses including mood changes can take place even when the person is not aware of the smell.	"Connection to one's past is often positive especially if you introduce a scent prompt that usually has positive effects (chocolate, roses, etc.). Remembrance of things past improves mood that will improve quality of life." (DE8) "The perceived pleasantness of the odour is very strongly associated with the mood outcome." (OE2) "When a person is not 'immediately' aware of an odour, it may influence the mood 'unconsciously'." (OE5)
	Quality of life	There was a consensus among both groups of participants that olfactory intervention improves the quality of life of residents. Participants suggested that quality of life often is associated with mood change and regular implementation of olfactory intervention into care practice.	"Positive odorants generally increase quality of life." (OE1) "depending on the severity of the disease smells can trigger a positive memory in the patient which therefore enjoys that moment. It would be great if these 'smells-related memories' could boost more stable aspects such as quality of life." (OE5) "I think quality of life can only be improved if done on a regular basis" (DE4)
	Behavioural change	Changes in the behaviour were considered another outcome of olfactory intervention. Some participants commented on how behavioural changes may occur even when the smell is not associated with relevant memories. Olfactory experts also emphasised that individual's attitude and beliefs can significantly impact the behaviours of those taking part in the olfactory intervention.	"I believe that, even with dementia, a smell would still be able to cause a psychological change without a strong memory connection. There are times when there is no strong association with a smell but a definite change in behaviour as a result." (OE4) "There is definitely a placebo side to it as you could tell someone it has a benefit even it has no pharmacological effect, and it would change behaviour." (OE7)

Appendix 10 *(Continued)*

Category	Pattern code	Explanation	Supporting quotes
	Care staff burden	Stakeholders reported that care staff can have direct benefit from participating or facilitating olfactory intervention. Some participants suggested that other factors may be associated with the positive outcome in care staff such as “job satisfaction”, “behaviour management”, “residents with higher levels of well-being.”	“The olfactive stimulation activity can be fun for all and would definitely reduce their care burden.” (DE7) “Positive effects on the clients they may well have the same effect on the carers: it would depend on the smells as I suspect there would be a generation gap which might affect response to smells. I don't know if this would reduce carer burden in itself though: maybe as a way of managing stress in work.” (DE11)
	Self-identity	Some of the participants suggested that olfactory intervention could impact the “sense of identity and centredness” of residents. According to the participants increase of self-identity is the effect of the odour-evoked memories.	“Our perception of our lives is based on our narrative about it. Having the chance to narrate life stories is materializing one's life.” (DE2) “It can be useful in terms of reminiscence to remind people of what they've done and who they are, so they don't just feel like a patient/client with dementia”. (DE11)
	Boost relationship	Improved relationship between people with dementia and staff or other residents is considered an intermedia outcome of olfactory intervention, as captured from the quotes. One participant commented on the value of being in a group.	“The more interaction and socialization that can occur from sharing memories allows fellow residents and caretakers into the windows of each other’s lives. It’s a holistic effect that is more often positive.” (DE7) “What results is often a positive emotional state, and sometimes they discover something amongst themselves that they have in common more than fellow residents living with the same disease.” (DE7) “I do think that such activities can support relational approaches to care.” (DE10)

Appendix 10 *(Continued)*

Category	Pattern code	Explanation	Supporting quotes
Long-term outcomes	Quality of care	A few quotes suggest that olfactory intervention can provide the opportunity or the "permission" to engage with the residents and learn more about them. This could impact the quality of care provided to residents and enhance a person-centred care approach.	"To help further understand the life story of the person and potential triggers too." (DE5) "That it seems to me to have direct relevance for people with dementia, therapeutically and person centred." (DE5) "'Permission' to spend quality time with residents." (DE1)
Context	Attitude and motivation	Analysis suggested that attitude and motivation of people with dementia, care staff and care home managers are important contextual elements. For the participants in the survey, care manager attitude was identified as "crucial" to direct resources such as money, time and care staff support, in order to promote and facilitate care staff's engagement, training and positive attitude toward the intervention. A lack of support from the leadership and care managers was perceived as a significant barrier for the successful implementation and compliance of olfactory intervention. Stakeholders stressed that a supportive environment is essential to ensure that care staff engage with the intervention considering the significant workloads and turnover. Olfactory experts emphasised that expectations and attitude of people with dementia may also act as facilitators or barriers to olfactory intervention intended outcomes.	"From my experience when the manager finds something important, they can train or advise their staff accordingly and change their attitudes." (DE2) "The activities directors have their own budgets and determine the schedules." (DE7) "I think it is important to motivate both care professionals and the patients about the importance of using this type of protocol for having beneficial effect in people with dementia" (OE7). "Positive attitude and engagement for staff as initially adding to workload, they need to be interested. Engaging families/friends where possible." (DE11) "The positive attitude towards a stimulus or a situation can have effect on both psychological and, consequently, physical changes within a subject." (OE6)

Appendix 10 *(Continued)*

Category	Pattern code	Explanation	Supporting quotes
	Knowledge	Participants agreed that care staff's knowledge about residents and olfactory intervention had an influence on the compliance and results of the intervention. According to the responders, care staff should have a clear understanding of the underpinning of olfactory intervention and the potential benefits to residents and the health care system in order to commit and administer the intervention. Some participants commented on the importance of tailoring the intervention to residents' "preferences, experiences and sensitivities" in order to use effectively smells within a care home setting. Lack of knowledge on residents was perceived as a challenge to intervention success.	"Well initiated staff who really understand the importance of enhancing smell." (OE9) "Some professionals are aware of the effect of olfactory, but mostly not." (DE11) "Understanding the potential benefits and the intent behind the interactions has to be beneficial." (DE2) "It's challenging, though, because they [care staff] also need key information about the patients." (OE1) "[…] another to make sure it is tailored to the right people." (DE6)
	Supportive environment	A pattern code was related to the physical space and its characteristics. Stakeholders agreed on the lack of physical and private spaces in care homes. This was supported by olfactory experts who commented on the link between individual differences and the physical environment, suggesting that open and communal spaces could be a barrier to the delivery of individualised olfactory intervention. A few participants commented on the sometimes distinctive "care home smell" attributed to the residents' personal hygiene difficulties. It was considered important to 'clean' the environment from other surrounding smells before implementing the intervention. Therefore, particular attention should be given to the physical setting where olfactory intervention is provided.	"Not all odorants are similarly valence for particular individuals. So, scenting an entire wing of a care facility would not be helpful." (OE1) "Using patch or dispensers for clothes allow to personalise the odour stimulation rather than use the same stimulus for all the residents in a room." (OE7) "I think that bad smell is a big issue in care homes. Extinguishing the bad smells should be the starting point." (DE2) "Care homes are typically associated with unpleasant or synthetic smells (due to the use of cleaning products). I think it is interesting to consider both the use of olfaction within an activity but also within the broader dementia care setting." (DE9)

Appendix 10 *(Continued)*

Category	Pattern code	Explanation	Supporting quotes
	Orientation approach to care	The orientation approach to care, task-oriented approach versus person-centred approach, was identified as a context pattern code from the dataset. Stakeholders suggest that effective communication skills, trustful relationship with the residents, time residents and care staff spend in engaging with psychosocial intervention and various activities beyond personal care (e.g. washing, eating) are contextual elements that may influence the mechanisms in action in olfactory interventions.	"Support from care staff to engage with the smells". (DE1) "As the facilitator of these activities, it is my responsibility to build a relationship with the residents so they feel that they can 'open up' and express themselves." (DE7) "[…] the need to know how to interact and can instinctively guide and implement sessions with their residents." (DE7)
Resources	Smell as a trigger	The main source that olfactory intervention introduces in the context describes above is olfactory stimuli. Olfactory stimuli regardless of their characteristics can trigger a response(s). All participants agreed that familiar and relevant smells evocate more emotional and positive memories. While familiar smells may be strongly linked with emotions and memories, smells that were not encounter previously (new smell) or do not have any personal significance (unfamiliar smell) for residents can also trigger a response. This response can be modulated by the smell compound properties or whether the smell is perceived as pleasant.	"A familiar smell has also a positive impact on the mood and on the psychological status of a person." (OE6) "Linalool [Key component in lavender oil] would still cause a relaxing sensation whether it is familiar or not due to its neurological efficacy." (OE4) "Familiar smells could intrigue memories but like with everyone a strong unfamiliar smell could have a physical effect." (DE2) "A new smell can also be objectively pleasing and have a positive effect I think" (OE8)

Appendix 10 *(Continued)*

Category	Pattern code	Explanation	Supporting quotes
	Training	Participants suggested that professional training can provide care staff with a core of skills for facilitating the intervention which will promote confidence and empowerment, consequently contributing to the successful implementation of the intervention. While most participants commented on the importance of having formal training or "basic knowledge of the smells", a few stakeholders suggested that care staff could facilitate the intervention "without the need for particular knowledge" by following the intervention protocol as it was created and evaluated.	"They should be aware about the chemical composition and the effect some dosage can have on the mood but also on the physiological and psychological changes it might lead to the subject tested." (OE6) "It is important that those delivering olfactory stimulation have the necessary skills, training and confidence" (DE10)
	Smell administration matter	Odour intensity and administration method were considered by participants important drivers of the possible activation of the reasoning. Some participants suggested that to reduce the effect of the cognitive decline associated with the condition, olfactory items should be presented alongside supplementary information or prompts such as pictures or verbal clues.	"A picture would be best as it would always be in front of the person with dementia. The person would forget the association if told verbally. I would say visual is better." (OE4) "I would describe the original context though [during odour presentation]. 'We're going to the beach. Isn't it nice to be on a beach?'. Not 'this is the smell of the beach'." (OE3)
	Structure and regular activity in the care routine	Concepts such as continuity, regularity were identified across the datasets. Structured and regular olfactory sessions if integrated into the daily care could guarantee an adequate level of olfactory stimulation as people living in care homes a less opportunity to be exposed to a variety of smells, as well as create the 'space' for residents and care staff to engage together.	"My experience is that regular, repeated sessions were an enjoyable activity and facilitated mood-boosting conversations about autobiographical histories." (DE8) "I consider that olfaction can represent […] an important component in daily life to increase and stimulate the cognitive function and elicit good memories which can positively impact on mood and behaviour (even if for brief moments)." (OE5)

Appendix 10 *(Continued)*

Category	Pattern code	Explanation	Supporting quotes
Reasoning	Comfort and familiarity	A sense of comfort and familiarity appeared to be central mechanisms of action for the success of olfactory interventions. According to the participants, how residents may feel can impact upon the ways they engage with the olfactory intervention. Familiar items and protocol can facilitate feelings of comfort, security, and trustfulness in people with dementia, providing opportunities for engagement, interaction, and connection. On the other hand, unfamiliar or novel methods materials may enhance a sense of discomfort and feeling of distress and mistrust, which could have negative impact.	"It may remind a person of a memory of people, time and place and a sense of identity and centredness, which in turn may console, calm, bring joy and the possibility as a chain reaction on behaviours/mood." (DE5) "Being reminded of these events, memories, and people can result in positive experiences for people with and without dementia. It almost transports people to another place, so for a resident who perhaps feel that they are in an unfamiliar environment (the care home), being provided this sense of familiarity can be reassuring and comforting." (DE6)
	Physical changes	Most of olfactory experts agreed that physical changes enhanced by the volatile compounds of a smell can consequently affect (directly or indirectly) psychological changes. This suggests that a physical change is a potential mechanism underpinning the olfactory intervention outcomes.	"In our study using wearable devices during olfactory stimulation, we have observed changes in autonomic nervous system parameters related to smell inhalation." (OE7) "Physical and psychological changes are related so if one on the two is enhanced it may affect the other." (OE8)
	Positive and negative hedonic experience	Participants emphasised the potential that olfactory intervention can have in providing positive moments for care staff and people with dementia. It is suggested that particularly pleasant and familiar smells can provoke positive feelings and enjoyable interactions. Even smell perceived as unpleasant could evoke a "reaction and discussion".	"The response may be dependent on the smell and its perceived pleasantness. Responses could be enjoyment, stimulation, arousal, relaxation, humour, hunger, disgust etc. Specific to people with dementia, smell may elicit reminiscence, storytelling, memory sharing." (DE1) "Normally, familiar smells can lead to an increase in odour pleasantness, therefore physiologically activating relaxation mechanisms." (OE6)

Appendix 10 *(Continued)*

Category	Pattern code	Explanation	Supporting quotes
	Curiosity and intrigue	Another mechanism identified by the participants is curiosity. Some respondents explained that people with dementia's attention may be captured by a smell and the novelty of the activity which seems to create a powerful opportunity for a shared moment, individuals express themselves and "bring people into the moment" (DE1). Other participants suggested that playfulness, intrigue, and curiosity are keys mechanisms for triggering olfactory responses.	"People with dementia pay attention to smells and I have been using smell to start conversations and stimulate memories." (DE2) "Because we are asking them to focus their attention on a sense which is often overlooked- it becomes new and exciting." (DE4) "I often ask the residents to try and describe and guess what the smell is. I then give hints with clue cards, and then show photos of the smell." (DE7) "Just to try and appeal to all and create a bit of variety/mystery." (DE8)
	Unconscious and implicit perception	Implicit or unconscious perception was also identified as another mechanism of action to determinate positive change in participants taking part in olfactory intervention. For instance, one participant commented on how smell is often used by retailers to modify consumer behaviour. Another participant provided an example from her/his own experience as a facilitator of olfactory intervention when a smell has triggered a specific behaviour that is congruently associated with the stimulus. Cocoa smell stimulates appetite for chocolate.	"Reactions related to the senses are often involuntary and could be subconscious." (DE1) "Sometimes, smells can trigger a psychological response even when the subject is not aware of it, at least at the beginning of the stimulation." (OE6) "Think smells can be passively effective in the same way that music can be (e.g. the use of background music." (DE7) "Scent machines are used in shops to improve sales, and many are not aware of the effect." (OE4)

DE = Dementia Expert; OE = Olfactory Expert.

Appendix 11: Participant information sheet experts on olfaction and archival collections

UWL/REC/CNMH-00489

INFORMATION SHEET

Title of study: Using olfactory stimulation in a multi-sensory intervention in care home for people with dementia.

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information.
Take time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

What is the purpose of the study?
Multi-sensory approach is an intervention based on stimulating senses through a combination of olfactory (smell), tactile (touch) and visual (sight) stimuli. There is evidence that this approach can help to stimulate and entertain, as well as enhance quality of life, communication and cognitive ability in people living with dementia. However, there is a need to evaluate these further and to explore other sensory approaches such as smell, which has received less attention compared to other sensory modality.

The aim of this study is therefore to develop a structured intervention, selecting a range of objects and smells, which could be effective at stimulating discussion in people with dementia during a group session that could be delivered in a care home.

Why have I been chosen?

You have been invited to take part because your opinions, feedback and beliefs as well as your experience in scents or archive collection, can help the research team to select a range of items that can be used as part of a multi-sensory intervention for people with dementia living in a care home.

Do I have to take part?

It is up to you to decide whether or not to take part in this study. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part you are still free to change your mind at any time without giving a reason, before or during the study and any unprocessed data previously supplied will be withdrawn from the study.

What will happen to me if I take part?

If you will decide to take part to the research project, you will be asked to participate in an interview with the researcher.

Following discussion, you will have the opportunity to ask the researcher any questions. If you agree to take part by signing the consent form, each participant will be asked to:

1. Meet with a researcher (Federica D'Andrea) for between 20 minutes and 40 minutes, sitting together in a quiet room. During this meeting you may take as many breaks as you want or feel necessary.
2. The researcher (Federica D'Andrea) will ask you questions relating your area of expertise. These responses will be audio recorded by the researcher.

What are the possible disadvantages and risks of taking part?

The interview aims to gather information about your knowledge, opinions and beliefs in your area of competence, and the level of risk in taking part is therefore minimal. In the unlikely event that you feel uncomfortable or distressed while taking part in an interview, it will be stopped immediately.

What are the possible benefits of taking part?

If you decide to take part, the information we gather from this session may help us to improve the care of people living with dementia and to develop a structured intervention using objects and smells that could be delivered in a care home setting.

Will my taking part in the study be kept confidential?

All information collected about you during the course of the study will be kept strictly confidential. Data from the interview will be used to design a multi-sensory intervention, and to write sections of the researcher's PhD thesis. This may include verbatim quotes. Your name will be anonymised, and an identification code used, but your job title - for example researcher or archivist - might accompany the quote. All data is stored without any identifying details under secure conditions for 5 years according to the University of West London's code of research conduct and research ethics. After this time your data will be disposed of securely.

Who is organising and funding the research?

The research is funded by a University of West London doctoral scholarship. The researcher (Federica D'Andrea) is undertaking the study as part of her PhD programme. She is supervised by Professor Victoria Tischler (University of West London), Professor Tom Dening (University of Nottingham) and Dr Anne Churchill (Research Fellow, Givaudan Ltd), supported by the Boots UK archive.

What will happen to the results of the research?

The results will be published in academic journals or presented at conferences focussing on health and social care. No participants will be identified in any publication arising from the study. We will make arrangements for participants to be informed of the progress of the research and the results through newsletters and meetings.

Who has reviewed the study?

The study has been reviewed by the University of West London's College of Nursing, Midwifery and Healthcare Research Ethics Committee.

Who can I contact for further information?

For more information about this research, please contact:

Federica D'Andrea,
MPhil/PhD student School of Nursing, Midwifery and Healthcare
University of West London
St Mary's Rd, London, W5 5RF
Mobile: ****

Email: federica.d'andrea@uwl.ac.uk

If you have any complaints about this study please contact:

Professor Victoria Tischler
Professor of Arts and Health / Head of Dementia Care Centre
School of Nursing, Midwifery and Healthcare,
University of West London
St Mary's Rd, London, W5 5RF
Email: victoria.tischler@uwl.ac.uk

Thank you for considering taking part in this research study!

Appendix 12: Consent form for experts on olfaction and archival collections

UNIVERSITY OF WEST LONDON
The Career University

UWL/REC/CNMH-00489

Consent Form

Title of study: Using olfactory stimulation in a multi-sensory intervention in care home for people with dementia.

Name of Researcher: Federica D'Andrea

Please Initial Boxes

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that all information given by me about me or other people will be treated as confidential by the research team. ☐
4. I agree to take part in the above study. ☐

Please sign below

Name of participant_____ Signature_____ Date_____

Name of researcher_____ Signature_____ Date_____

Appendix 13: Topic guide for one-to-one semi-structure interviews with olfactory experts and archivists

Interviews with archivists and olfactory experts in order to identify themes and a wide range of material objects and smells.

Olfactory experts - prompts:

1. What are, if any, the most popular scents in the UK? And why?
2. What is the best way to administer smells?
3. How many odours can be smelled by a person in one session lasting approximately 40 minutes?
4. What is the best way to present smells?
5. What actions can be taken to avoid people being overwhelmed by smells?
6. How would you administer olfactory stimuli to people with dementia who may experience a reduced sense of smell?

Archivists - prompts:

1. What do you think could be/or should be included in a multi-sensory stimulation intervention, and why?
2. From your experience, what are possible positive and negative responses of people living with dementia to archive collection objects?
3. What items may be more engaging for people with dementia?
4. What themes/topics have arisen from previous sessions?
5. If you think back to your previous experience on using heritage objects with residents of care homes, what would you change in terms of session procedures and materials?

Appendix 14: List of relevant odours for older people in the UK

Vanilla
Bacon
Baked bread
Ground coffee
Fresh lemongrass
Cabbage water
Roasted meat smell
Guava
Banana
Raspberry
Satsuma
Orange
Toast bread
Fried onion
Melty cheese
Vinegar
Fish and chips
Cooking apples

Roses
Lilac
Cut grass
Washing soap/powder/liquid
Smell of baby
Anti-moth bag
Coal dust
Disinfectant
Smell of chalk
Tobacco
Stewed tea
Burning leaves
Burning wood
New cotton fabric
Summer rain
Cooking raspberry
Peppermint
Lemonade

Appendix 15: Participant information sheet for older people

UNIVERSITY OF WEST LONDON
The Career University

UWL/REC/CNMH-00489

INFORMATION SHEET

Title of study: Using olfactory stimulation in a multi-sensory intervention in care home for people with dementia.

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

What is the purpose of the study?

Multi-sensory approach is an intervention based on stimulating senses through a combination of olfactory (smell), tactile (touch) and visual (sight) stimuli. There is evidence that this approach can help to stimulate and entertain, as well as enhance quality of life, communication and cognitive ability in people living with dementia. However, there is a need to evaluate these further and to explore other sensory approaches such as smell, which has received less attention compared to other sensory modalities.

The aim of this study is therefore to develop a structured intervention, selecting a range of objects and smells, which could be effective at stimulating discussion in

people with dementia during a group session that could be delivered in a care home.

Why have I been chosen?

You have been invited to take part because your opinions, feedback and beliefs can help the research team to select a range of items that can be used for a multi-sensory intervention for people with dementia living in a care home.

Do I have to take part?

It is up to you to decide whether or not to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to change your mind at any time without giving a reason, before or during the study and any unprocessed data previously supplied will be withdrawn from the study.

What will happen to me if I take part?

If you will decide to take part in the research, you will be asked to participate in an interview with the researcher.

Following discussion, you can ask the researcher any questions you may. If you agree to take part by signing the consent form, all participants will be asked to:

1. Meet with a researcher (Federica D'Andrea) for between 20-40 minutes, sitting together in a quiet room. During this you may take as many breaks as you want or feel necessary.
2. The researcher will introduce discussion, asking you to smell and handle a range of objects and odours from Boots UK archive.
3. You will be asked to give verbal feedback about the items, e.g. enjoyment and pleasantness, and any other comments. These responses will be audio recorded by the researcher.

What are the possible disadvantages and risks of taking part?

The interview aims to record your opinions and feelings related to the items and smells explored. The session involves smelling scents and odours, so in order to minimize risk, prior to your participation you will be asked to inform the researcher of any known allergies, medical conditions, or hypersensitivities that may place you at an increased risk for adverse effects. Some examples of conditions you must disclose are: allergies (e.g., airborne, food, metal, etc), skin sensitivities, immune system deficiencies, diabetes and high blood pressure. If any such conditions exist, you may be excluded from a session (Safety standard guidance provided by Givaudan Ltd).

If you feel uncomfortable or distressed while taking part in the interview, the activities will be stopped immediately.

What are the possible benefits of taking part?

If you decide to take part, the information we get from this session may help us to improve the care of people living with dementia and to develop a structured intervention using objects and smells that could be delivered in a care home setting.

Will my taking part in the study be kept confidential?

All information collected about you during the course of the study will be kept strictly confidential. Data from the interview will be used to design a multi-sensory intervention, and to write sections of the researcher's PhD thesis. This may include anonymous verbatim quotes. All data is stored without any identifying details under secure conditions for 5 years according to the University of West London's code of research conduct and research ethics. After this time your data will be disposed of securely.

What if something goes wrong?

If you have any concerns please contact the researcher. If any problems arise, the activities will be stopped e.g. if participants appear to be stressed or uncomfortable.

Who is organising and funding the research?

The research is funded by a University of West London doctoral scholarship. The researcher (Federica D'Andrea) is undertaking the project as part of her PhD studies, supervised by Professor Victoria Tischler (University of West London), Professor Tom Dening (University of Nottingham) and Dr Anne Churchill (Research Fellow, Givaudan Ltd), supported by the Boots UK archive.

What will happen to the results of the research?

The results will be published in academic journals or at conferences focussing on health and social care issues. No participants will be identified in any publication or presentation arising from the study. We will make arrangements for participants to be informed of the progress of the research and the results through newsletters and meetings.

Who has reviewed the study?

The study has been reviewed by the University of West London's College of Nursing, Midwifery and Healthcare Research Ethics Committee.

Who can I contact for further information?

For more information about this research, please contact:

Federica D'Andrea
MPhil/PhD student School of Nursing, Midwifery and Healthcare
University of West London, St Mary's Rd, London, W5 5RF
Email: federica.d'andrea@uwl.ac.uk Mobile: ****

If you have any complaints about this study please contact:

Professor Victoria Tischler
Professor of Arts and Health / Head of Dementia Care Centre
School of Nursing, Midwifery and Healthcare,
University of West London, St Mary's Rd, London, W5 5RF
Email: victoria.tischler@uwl.ac.uk

Thank you for considering taking part in this research study!

Appendix 17: Consent form for care professionals, relatives of people with dementia and older people

UNIVERSITY OF WEST LONDON
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Consent Form

Title of study: Using olfactory stimulation in a multi-sensory intervention care home for people with dementia.

Name of Researcher: Federica D'Andrea

Please Initial Boxes

5. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
6. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
7. I understand that all information given by me about me or other people will be treated as confidential by the research team. ☐
8. I agree to take part in the above study. ☐

Please sign below

Name of participant_____ Signature_____ Date_____

Name of researcher_____ Signature_____ Date_____

Appendix 18: Screening form for medical conditions for assessing stakeholders' eligibility in the focus groups and interviews

Title of study: Using olfactory stimulation in a multi-sensory intervention in care home for people with dementia.

Name(s): _____

Before the project starts:

The sessions involve smelling scents and odours, so in order to minimise risk, prior to your participation you must inform the researcher of any known allergies, medical conditions, or hypersensitivities that may place you at an increased risk for adverse effects. If any such conditions exist, you may be excluded from a study. All of your answers will be treated in strictest confidence.

THANK YOU FOR TAKING PART

Allergies (e.g., seasonal allergies, food, metal, etc.) Yes ☐ No ☐

(if yes please provide futher information)

_____

Skin sensitivities Yes ☐ No ☐

(if yes please provide futher information)

_____

Immune system deficiencies Yes ☐ No ☐

(if yes please provide futher information)

_____

Diabetes Yes ☐ No ☐

(if yes please provide futher information)

_____

High blood pressure Yes ☐ No ☐

(if yes please provide futher information)

_____

Sensory impairments Yes ☐ No ☐

(if yes please provide futher information)

_____

Pregnant Yes ☐ No ☐

(for care professionals and relatives of people with dementia)

Appendix 19: Topic guide questions for facilitating focus groups and interviews with relative of people with dementia, care professionals and older people

Welcome, Thanks and Presentation of the focus group
Consent forms reiterate issues of confidentiality and set ground rules. Questions.
Participant introduction.
General questions about multi-sensory intervention (olfactory stimulation and object handling).

1. What did you think about stimulating senses? Is it important?
2. In your opinion, can sensory stimulation sessions make any difference in your family member/ friend/ resident
3. What do you think about sensory stimulation programmes?
4. In your opinion, is there anything particularly helpful about stimulating your family senses? Is there anything particularly unhelpful about stimulating your family senses? Do you find it boring, fun, and childish, like being back at school…?

Presentation of the first draft of the intervention. Pass around copies of a table with ten themes.

Prompts to facilitate discussion if needed:

5. What do you think about the different suggested themes?
6. Is there anything particularly good-bad about themes and the items included?
7. Are there any items you would like to suggest with regards this theme?

8. In relation to (theme, e.g. Walk in the city, Time to go out, Childhood...)
    a. How confident you feel (your family/friend/ cared for would be participating in a session like that one? In what way?
    b. What sorts of things you (your family/friend/resident) enjoy manipulating and discussing? e.g. talking more/less about current affairs, daily life, personal memories.
    c. How frequently would you (your family/friend/residents) initiate activities like that one?
    d. How much would you (your family/friend/residents) enjoy doing this activities?
    e. How easy is it for you (your family/friend/residents) to do these activities?

Concluding question

9. Is there anything else that you would like me to know about your opinions on what it has been commented on this focus group?

Thank everyone for participation, reiterate confidentiality, give further opportunity to ask questions.

Appendix 20: A fact sheet with recommendations for preparing and delivering the MSI-2

Pre-session tasks (15 minutes)

- Select a quiet, well-ventilated room with chairs and table. You might want to clear other items or smells (e.g. air fresheners) away and ensure you won't be disturbed during the activity. This will create space and quality time for you and the participants.
- Place the sensory materials in a box or case. This creates a sense of mystery and anticipation.

Multi-sensory stimulation intervention (30 minutes)

- Start by presenting one item to each participant or let them choose one from the box. Pass it around the group. When you present a scent/smell, instruct the participant to breathe normally and present the next smell approximately 2-5 minutes later, to avoid overwhelming the senses.
- Note how each participant interacts with the object (including smelling it if appropriate). Encourage each participant to handle and examine the objects, by allowing them time to explore the object's sensory properties and to comment if they wish.
- When they are finished, you can handle the object and smell it as well and make comments, responding to what the participants said or did. You can ask questions as prompt to elicit participants' feelings and opinions about the objects to stimulate group discussion. For instance: do you like it? Does it have a smell? How does the object feel? What does the object make you think of? Do not ask for factual information such as if they know what it is or

what it is for as they may feel like they are being tested. Prompts should be used flexibly within the session based on the participants' responses.

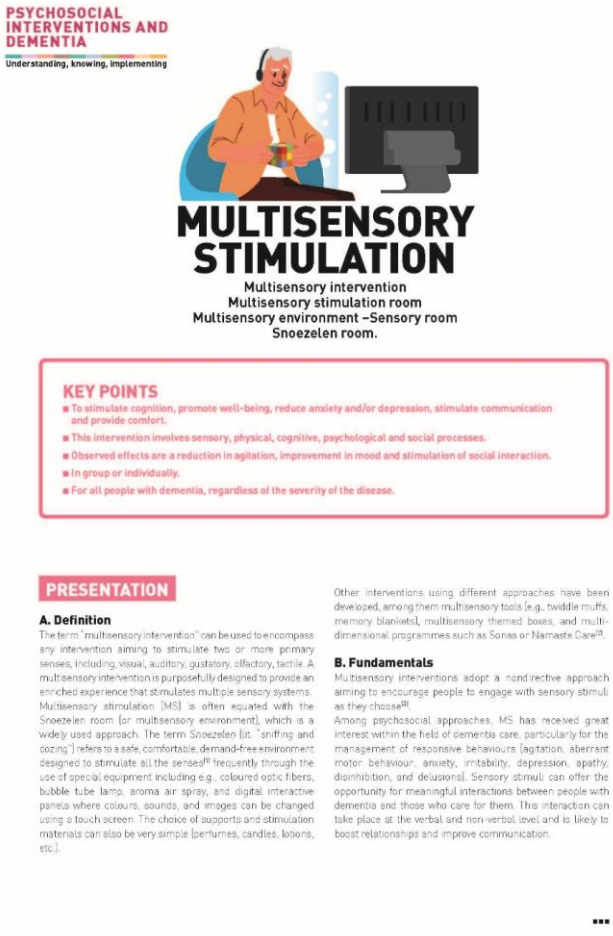
- People who present communication impairments should be engaged at the sensory level e.g. handling and smelling items rather than discussing/commenting. It is recommended that you engage with the
- participants' feelings and emotions expressed through facial expressions and body posture. An empathetic response may include verbalising the feelings and emotions observed.
- If other people (e.g. care professionals, family members) take part in the session, they are to participate in the activity.
- Repeat, until all items in the box have been handled and discussed. It may be that a few items trigger a lot conversation and there is not time to explore further sensory items within the timeslot. If an item does not interest the participants or they do not respond, you can move onto another one in the box.
- Place the items explored in the centre of the table, giving the participants the opportunity to go back to them if they wish.

End session: (5 minutes)

- Bring the session to a close, thank participants for taking part. Introduce the topic of the next session and ask if they have any item preferences. You can use this information to adapt the sensory materials to the participants' preferences.

Appendix 21: Multisensory stimulation practical sheet (Fondation Médéric Alzheimer, 2021)

Total downloaded copies: 214 (179 in French and 35 in English)



PSYCHOSOCIAL INTERVENTIONS AND DEMENTIA

Understanding, knowing, implementing

MULTISENSORY STIMULATION

Multisensory intervention
Multisensory stimulation room
Multisensory environment –Sensory room
Snoezelen room.

KEY POINTS

- To stimulate cognition, promote well-being, reduce anxiety and/or depression, stimulate communication and provide comfort.
- This intervention involves sensory, physical, cognitive, psychological and social processes.
- Observed effects are a reduction in agitation, improvement in mood and stimulation of social interaction.
- In group or individually.
- For all people with dementia, regardless of the severity of the disease.

PRESENTATION

A. Definition

The term "multisensory intervention" can be used to encompass any intervention aiming to stimulate two or more primary senses, including visual, auditory, gustatory, olfactory, tactile. A multisensory intervention is purposefully designed to provide an enriched experience that stimulates multiple sensory systems.
Multisensory stimulation (MS) is often equated with the Snoezelen room (or multisensory environment), which is a widely used approach. The term *Snoezelen* (lit. "sniffing and dozing") refers to a safe, comfortable, demand-free environment designed to stimulate all the senses[81] frequently through the use of special equipment including e.g., coloured optic fibers, bubble tube lamp, aroma air spray, and digital interactive panels where colours, sounds, and images can be changed using a touch screen. The choice of supports and stimulation materials can also be very simple (perfumes, candles, lotions, etc.).

Other interventions using different approaches have been developed, among them multisensory tools (e.g., twiddle muffs, memory blankets), multisensory themed boxes, and multi-dimensional programmes such as Sonas or Namaste Care[78].

B. Fundamentals

Multisensory interventions adopt a non-directive approach aiming to encourage people to engage with sensory stimuli as they choose[81].
Among psychosocial approaches, MS has received great interest within the field of dementia care, particularly for the management of responsive behaviours (agitation, aberrant motor behaviour, anxiety, irritability, depression, apathy, disinhibition, and delusions). Sensory stimuli can offer the opportunity for meaningful interactions between people with dementia and those who care for them. This interaction can take place at the verbal and non-verbal level and is likely to boost relationships and improve communication.

MULITSENSORY STIMULATION

THEORETICAL BACKGROUND

A. Processes involved

The theoretical underpinning supporting MS posits that responsive behaviours and cognitive impairment associated with dementia are closely related to sensory decline.

Due to age-related sensory changes (e.g., limited vision and hearing) which are exacerbated by the condition, people with dementia may require more stimulation (strong stimuli, greater contrast between objects) in order to maximise perception. Consequently, the absence of appropriate activities and sensory enriched experiences put people with dementia at risk of sensory deprivation, defined as a prolongated lack of stimulation[4]. Empirical evidence demonstrates the detrimental effects of long-term sensory deprivation including changes in mood and behaviour such as depression, disorientation, irritation, apathy, and anxiety[5].

As cognitive function deteriorates in dementia, the individual's ability to process and integrate external sensory information and to understand context are reduced[6]. Therefore, overstimulating environments which may exceed an individual's tolerance threshold can generate or increase maladaptive behaviours such as aggression and irritation. Tailoring environmental demand and providing appropriate sensory stimulation supports people with dementia to adjust and process information, reducing discomfort and confusion. In turn, MS may increase well-being, quality of life, social skills and support the management of behavioural manifestations of dementia.

B. Neurophysiological correlates

Sensory information is transmitted via neuronal networks to the brain, which interprets one's environment. Neuroscientific studies suggest that older people benefit more from receiving multimodal stimulation compared to unimodal stimulation, in performing tasks such as detection or according judgement[7].

A sensory-enriched experience enables stimuli to be encoded into multisensory representations thereby activating a wider network of brain regions compared to those invoked by unisensory encoding, thus facilitating older peoples' task performance.

SCIENTIFIC EVALUATION

There is some evidence suggesting that MS has a positive impact on people with dementia in reducing responsive behaviours (e.g., agitation, irritation), improving mood, facilitating interactions and interpersonal relationships with other care home residents and with carers.

A few studies reported positive benefits for carers following multisensory interventions including reduced caregiver stress, increased well-being, and job satisfaction[8-9]. However, the scientific effectiveness of interventions based on multisensory approaches is still fairly limited. The limited body of evidence, poor quality of studies, and variety of intervention protocols make it difficult to delineate an overall conclusion in relation to the effect of MS. Further research is needed to draw firm conclusions about its effectiveness and the key elements of different approaches to MS.

There are no cost-effectiveness studies to date. However, it possible to speculate that MS utilising everyday objects e.g., perfume, candles, scented body lotion, since these are by definition highly accessible, hold promise as an individualised, easy-to-implement, cost-effective intervention.

IMPLEMENTATION AND PRACTICAL ADVICE

A. Training and/or knowledge required to provide the intervention

The authors suggest that MS facilitators should have training and education about dementia, good communication skills, and knowledge about the participants (e.g., past history, hobbies, etc.). This creates a person-centred care approach aiming to empower participants using bespoke activities created for each individual. This should result in appropriate support and engagement for people with dementia, thereby improving overall well-being for both residents and care staff or family supporters.

B. Practical and clinical advice

The following practical guide is created for supporting the development and implementation of a multisensory intervention using themed boxes for people with dementia[10-13]. The example provided focusses primarily on tactile and olfactory (smell) stimulation. The following advice can also be applied to other kinds of sensory stimulation.

MULITSENSORY STIMULATION

THERAPEUTIC INTENTION	RECREATIONAL INTENTION
Participants profile All people with dementia, regardless of the severity of the disease.	Open to anyone.
Indications ■ Cognitive: memory, sensory integration, attention, and executive functions. ■ Psychological: social interaction, mood, quality of life, well-being, communication, responsive behaviour, anxiety and depression.	Sensory stimulation, engagement in meaningful activity and socialisation.
Contra-indications Risk of allergic reactions; skin irritation; emotional distress due to overstimulation or negative memories.	Idem.
Contributors Occupational therapist; psychologist; psychomotor therapist; trained care staff or artist facilitator; two (or more) staff to support the session (if working in a group).	Anyone with good communication skills and knowledge of the participants.
Setting of intervention A quiet, relaxing, well-ventilated room with chairs and table. You might want to clear other items or smells (e.g., air fresheners) away and ensure you won't be disturbed during the activity. This will create space and quality time for you and the participants.	Quiet environment.
Dosage Group sessions of 5-6 participants. ■ Period: 6 weeks. ■ Frequency: once per week. ■ Length: 15 minutes (preparation); 45-60 minutes (intervention). Participants should be given enough time to explore and comment on the materials according to their capacities. *The intervention can also be offered individually. In this case, it is important that the participant does not feel examined/tested.*	Not specified.
Session sequencing Item selection: think about objects that each people with dementia (participant) enjoys now or in the past, including their preferred smells. You can ask them, find out more about their life, or investigate what was popular when they were in their late teens or early 20's. Create six themed activities (e.g., childhood, vacations) based on each participant's preferences. Place the selected items related to each theme (6-8 is a good number to ensure variety) in a box or case. Introduce the activity: let the participants know that you would like to spend time exploring some interesting items together. Multisensory activity*: start by presenting one item to each participant or let them choose one from the box. Note how each participant interacts with the object (including smelling it if appropriate). Encourage each participant to handle and examine the objects. Allow them time to do this. When they are finished, you can handle the object and smell it as well and make comments, responding to what the participants said or did. Repeat, until all items in the box have been handled and discussed. For individual sessions, it is possible to remove the objects from the box and display them on a table. The participant will be able to choose the objects that interest him/her. The facilitator can also choose the objects that attract the participant's curiosity and attention the most. End session: thank participants for taking part and ask if they have any items or topic preferences for the next session.	Introduce items and activity, allow participants time to handle, explore, and comment, if they wish.
Observance / Attendance If an item does not interest the participants or they do not respond, you can move onto another one in the box. Be aware that people with dementia may have impairments such as a reduced sense of smell so do not worry if they do not respond. You may therefore choose items that have strong smells or focus on objects to handle and discuss instead. People with dementia may present physical impairment or pathologies that reduce mobility such as arthritis. If so, offer support to handle and explore the items.	Not specified.
Assessment E.g., COMMUNI-CARE scale; Observation of the participant's verbal and non-verbal responses *via* video recording; Visual analogue scales.	Not specified.

MULITSENSORY STIMULATION

*** Recommendations:**

Allow time for participants to explore the object's sensory properties and to comment if they wish. Do not ask if they know what it is or what it is for as they may feel like they are being tested.

When you present a scent/smell, instruct the participant to breathe normally and present the next smell approximately 2-5 minutes later, to avoid overwhelming the senses.

If appropriate ask for opinions and not for factual information. For instance: do you like it? Does it have a smell? How does the object feel?

People who present communication impairments should be engaged at the sensory level e.g., handling and smelling items rather than discussing/commenting. It is recommended that carers engage with the participants' feelings and emotions expressed through facial expressions and body posture. An empathetic response may include verbalising the feelings and emotions observed.

FOR MORE INFORMATION

- Using memory box objects and smells for people with dementia: guidance for carers https://www.boots-uk.com/our-stories/treasured-items-from-the-boots-uk-archive-help-to-rekindle-memories-in-people-with-dementia/

ABOUT THE AUTHORS

Victoria Tischler is Associate Professor, European Centre for Environment and Human Health, University of Exeter Medical School. She is a Chartered Psychologist and Associate Fellow of the British Psychological Society. Her research interests focus on creativity and mental health and multisensory approaches to dementia care. She is co-executive editor of the journal Arts and Health.

Federica D'Andrea, is a third-year PhD student from the University of West London. Her research focuses on the development and design of a novel theory- and evidence-based multisensory intervention including olfactory and tactile stimulation for people with dementia. She is interested in innovative provision, quality of life promotion, ageing, and mental health.

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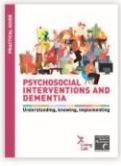
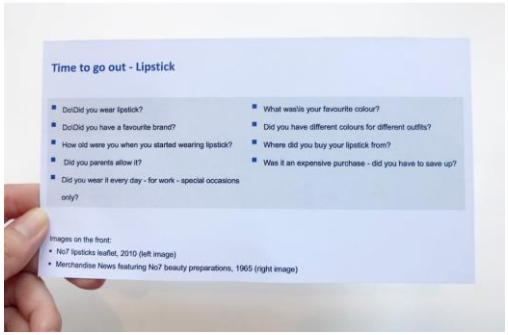


This sheet corresponds to a chapter of the guide ***Psychosocial interventions and dementia: understanding, knowing, implementing*** directed by the Fondation Médéric Alzheimer.

Fondation Médéric Alzheimer
30 rue de Prony 75017 Paris
www.fondation-mederic-alzheimer.org
contact : fondation@med-alz.org

Living Lab

Appendix 22: Examples of MSI-2 cards with visual and verbal prompts



Appendix 23: Public dissemination and engagement events

- Hosting ‘Touch Heritage’ at the University of West London. As part of Dementia Awareness Week, people with dementia, their relatives and carers were invited to take part in the event to explore the therapeutic potential of handling and discussing heritage objects. May 2019.
- Co-presenting at The Memory Way Café the Boots UK archive history and collections to the residents and relatives of the Otto Schiff, a care home in London. January 2019.
- Supporting the Imagination Café - pop-up art installation focuses on creative activities and morning tea designed for people with dementia. The Menier Gallery, London. May 2018.
- Participating in the Boots UK film launched during the Dementia Action Week showing residents of Nightingale House Care Home in London taking part in a memory box session using the Boots archive items. https://www.youtube.com/watch?v=ShIDoYPVS4M. May 2018.
- Co-organising ‘Stimulating all the senses: art, food, music and dementia’ at the University of West London. As part of the Being Human festival, the event attended by people with dementia and their carers showcased a range of innovative ‘dementia-friendly’ approaches developed at the University’s Dementia Care Centre. November 2017.