“The experiences and care needs of LGBTQ+ people affected by dementia: a systematic review” and “An evaluation of the implementation and routine clinical effectiveness of the Newcastle Model for behaviours that challenge in dementia”

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1 Thesis Abstract

Background

Dementia is a syndrome caused by various diseases or injuries that affect the brain. It causes progressive decline in cognitive function resulting in impaired memory, understanding, learning, language and judgement. This is usually accompanied by increasing decline in the individual's ability to regulate their emotions and behaviour.

Systematic review: Current generations of Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ+) people have lived through marked pathologisation of their minority status. LGBTQ+ people report poorer health outcomes and experience social inequalities that increase modifiable risk factors for developing dementia. They are more likely to require residential care than heterosexual peers as they age. This review sought to identify the experiences and care needs of LGBTQ+ people affected by dementia, and those who care for them, and critically appraise the quality of the current evidence base.

Empirical: Behaviours that challenge (BtC) such as physical and verbal aggression are displayed by most people living with dementia (PLwD) to some extent. They are associated with poorer quality of life, caregiver burden, institutionalisation, and distress. The Newcastle Model (TNM) is an intensive formulation driven intervention conceptualising BtC as attempts to meet unmet needs. It posits BtC and distress throughout the system reduce when the PLwD's unmet needs are identified, understood and addressed. There is an emerging evidence base demonstrating the effectiveness of this approach. This study aimed to a) evaluate the effectiveness of the routine clinical implementation of TNM in two behaviour support services (BSS-A

and BSS-B) and b) compare the effectiveness of standard and shortened delivery versions of TNM.

Methods:

Systematic review: A systematic search of electronic databases was conducted to identify papers that explored the experiences and care needs of LGBTQ+ people affected by dementia. All designs were included. The methodological quality of papers was assessed. Findings were synthesised using narrative synthesis.

Empirical paper: Retrospective analysis of routinely collected clinical data from two specialist behaviour support services (BSS-A and BSS-B) that use TNM was conducted. The Cohen Mansfield Agitation Inventory (CMAI), a measure of BtC, was administered at baseline and post-intervention. Mixed two-way ANOVAs were used to analyse the difference within participants CMAI scores pre and post intervention, between behaviour support services, and shortened and standard delivery formats of TNM.

Results

Systematic review: 24 papers were included. The sources were heterogeneous, and quality of the included papers varied considerably. The evidence synthesis was informed by the highest quality qualitative papers (n=8) and cross checked against other evidence sources. Three themes were identified: ‘Impact of gender and sexual identity on experiences of dementia’; ‘Experiences of navigating health and social care systems’ and ‘Characteristics of culturally competent dementia care’.

Empirical Paper: 210 participants were included: 143 in BSS-A and 67 in BSS-B. There was a significant reduction in CMAI scores post intervention ($p< .05$) in both services, across shortened and standard delivery formats. There was no difference in patient outcome (p>.05) when BSS-A was following the standard TNM protocol (mean delivery duration 23.2 weeks) or the condensed version (mean delivery duration 11.7 weeks).

Conclusion

Systematic Review: The current evidence base is small and of varying methodological quality. LGBTQ+ people affected by dementia experience unique challenges and have specific care needs that vary within the LGBTQ+ population. Further research is warranted.

Empirical Paper: TNM is an effective intervention for reducing BtC in PLwD. The model has ecological validity, demonstrated by two different behaviour support teams outwith that of the TNM developers. A condensed model protocol may promote fidelity to the model and reduce intervention duration whilst maintaining clinical effectiveness.

2 Lay Summary

‘Dementia’ is a word used to describe a group of symptoms that include memory loss and difficulties with thinking, problem solving and language. It leads to changes in people’s behaviour and mood. Dementia is a progressive condition which means it gets worse over time. Living with dementia can be a very difficult experience for people with the condition, their loved ones and other caregivers.

Systematic Review: Older Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ+) people have lived through decades where they could be judged or discriminated against because of their sexuality or gender identity. Compared to heterosexual (‘straight’) people, LGBTQ+ people report having poorer health and are more likely to live in poverty. It is thought this, and the effects of being discriminated against, makes LGBTQ+ people more ask risk of developing dementia. LGBTQ+ people are more likely to live alone and need nursing home care as they get older. Despite this, we do not know much about the experiences of LGBTQ+ people that have dementia, LGBTQ+ people that care for people living with dementia or how to provide the best care for them. A detailed search of online databases was carried out to find all the published articles that have explored the experiences of LGBTQ+ people living with dementia and their caregivers. 24 papers were identified. The quality of them varied. Care homes were seen as places for straight people. LGBTQ+ people worried that they would be discriminated against in care homes and thought they might need to hide their sexuality. Memory loss in dementia took away this choice. LGBTQ+ people have specific dementia care needs. More research in this area is needed.

Empirical Study: Most people living with dementia display behaviours such as shouting, kicking, swearing, and hitting out at some point. This is because they need something (e.g. to be free from pain, to connect with other people, or to do a meaningful task). Dementia makes this hard to communicate through words because of the way it affects our brain. This can cause people living with dementia and those caring for them a lot of distress. The Newcastle Model is a treatment delivered by psychologists and nurses who specialise in dementia. It aims to help care home staff and loved ones work out what the person with dementia is trying to communicate through their behaviour. A plan to meet the person's needs is then developed. This study aimed to test how well the Newcastle Model works. Care home staff were asked to rate how distressed the person with dementia was before and after they received the Newcastle Model treatment. We also tested if a version of the Newcastle Model delivered over a shorter period of time was as good as the longer version. The Newcastle Model reduced distressed behaviour in people living with dementia. The shorter version of the treatment worked as well as the longer version.

3 Thesis Overview

This research portfolio thesis consists of two papers relating to different aspects of dementia care. Paper 1 presents a systematic review exploring and critically appraising the current evidence base on the experiences and care needs of LGBTQ+ people affected by dementia. Paper two presents an investigation of the routine clinical effectiveness of the Newcastle model for behaviours that challenge in dementia.

The intended research study for the empirical paper was a qualitative investigation seeking to understand how people with severe and enduring mental health difficulties experience growing older. Drawing from a life course perspective, the study aimed to explore the life histories of older people living with severe and enduring mental health difficulties. It sought to understand how people navigate any stigma associated with mental health difficulties and ageing that they encounter. It also aimed to explore how mental health services can best support people with severe and enduring mental health difficulties as they age and transition through services.

The study received ethical approval from the South East Scotland Research Ethics Committee in early March 2020. Shortly after this a national lockdown was announced. An emergency halt to all research projects was imposed. After consideration of the potential ethical issues of conducting sensitive interviews during the initial phases of a global pandemic which had resulted in people not being able to access their normal support structures, the project was no longer deemed viable, and a new research project had to be developed.

Different options within the remaining time available were explored. The initial proposed new empirical project was a mixed methods exploration of the routine implementation of the Newcastle Model by specialist behaviour support teams. Qualitative interviews with clinicians delivering the Newcastle Model intervention, and care home staff receiving the intervention, were planned. This was intended to accompany the routine clinical data the behaviour support services had collected for service evaluation and research purposes. It would also have offered insight into the experiences of receiving the intervention during the initial phases of the COVID-19 pandemic, which significantly affected the care home sector. However due to delays caused by the COVID-19 pandemic, it was determined that it was not feasible to obtain the necessary ethical approval and conduct a mixed methods evaluation in the time available. Furthermore, care home and NHS staff were under unprecedented pressure at this time. Therefore, it was determined that use of a clinical dataset was the most appropriate course of action in the circumstances. A gap in the literature concerning the lack of published data relating to the routine clinical effectiveness of the Newcastle Model outwith the model developers was identified. Two different behaviour support services had collected pre and post intervention outcome measures for all patients who received the Newcastle Model intervention. Furthermore, one of the behaviour support services had implemented a shorter delivery format of The Newcastle Model, also collecting pre and post intervention outcome measures. The findings from this project are presented in the empirical paper.

4 Systematic Review

The experiences and dementia care needs of LGBTQ+ people affected by dementia: a systematic literature review and narrative synthesis

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This chapter has been prepared in accordance with the author guidelines for the peer reviewed journal *Dementia* (see Appendix A)

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4.1 Abstract

Background

Current generations of Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ+) people have lived through marked pathologisation and marginalisation of their sexual/gender minority status. LGBTQ+ people experience poorer health outcomes and social inequalities that increase modifiable risk factors for developing dementia. LGBTQ+ people report fear accessing health services, due to anticipated and actual experiences of discrimination. LGBTQ+ people are more likely to require residential care than heterosexual peers as they age. This review sought to identify the experiences and care needs of LGBTQ+ people affected by dementia, and those who care for them, and critically appraise the quality of the current evidence base.

Methods

A systematic review and narrative synthesis was conducted. Systematic searches of EMBASE, Medline, PsychINFO, ASSIA Sociological Abstracts, CINHAL and Proquest etheses were undertaken during February 2021. Published papers of any design were included.

Results

24 studies were included. The sources were heterogeneous, comprising of qualitative, mixed methods studies, case studies, first person reflective accounts and reports from multi-stakeholder events. Quality of the included papers varied considerably. The evidence synthesis was informed by the highest quality qualitative papers (n=8) and cross checked against other evidence sources. Three themes were identified: ‘Impact of gender and sexual identity on experiences of dementia’; ‘Experiences of navigating

health and social care systems' and 'Characteristics of culturally competent dementia care'.

Conclusion

The current evidence base is small and of varying methodological quality. LGBTQ+ people affected by dementia experience unique challenges and have specific care needs that vary within the LGBTQ+ population. Further research is warranted.

Keywords: Dementia; LGBTQ+; sexuality; gender identity; systematic review

4.2 Introduction

4.2.1 Overview of Terminology

LGBTQ+ is a frequently used acronym describing Lesbian, Gay, Bisexual, Transgender, Queer, and other sexual and gender identities. ‘Queer’ is a reclaimed slur that has been used by those wishing to reject specific labels of sexual and/or gender identity (Stonewall, 2020). It is noted that ‘queer’ is still considered a slur by some members of the community, particularly older members (Westwood & Price, 2017). Like Cousins et al. (2020), this paper sought to be inclusive of diverse LGBTQ+ communities and associated languages and identities, and thus uses the term LGBTQ+. References to ‘LGB’ or ‘LG’ used in this paper reflect the terminology used in the original source.

4.2.2 LGBTQ+ Older People

In line with an increasing ageing population, the number of LGBTQ+ older people, typically defined as those aged 65+, is also rising. In the USA, approximately 2.7 million people aged 50+ and 1.1 million people aged 65+ currently identify as LGBTQ+(Fredriksen-Goldsen, 2016; Fredriksen-Goldsen & Kim, 2017). Projected figures are set to double by 2060. In the UK, figures from an annual population survey suggest that 2.2% of the population identify as LGB (Office for National Statistics, 2018). Only 6.7% of men and 7.4% of women who reported identifying as LGB were aged 65+.

The current generations of LGBTQ+ older people have experienced considerable pathologisation of their sexual and gender minority status (Fredriksen-Goldsen, 2016). Kneale et al. (2019) note that most people considered on an ageing trajectory (aged

50+) living in the UK today have lived through social and legislative conditions that permitted discrimination across multiple domains for sexual minorities. The American Psychiatric Association defined homosexuality as a psychiatric disorder in the diagnostic and statistical manual until 1974 (American Psychiatric Association, 1968). So called “treatments” included electrotherapy and conversion therapy (Smith et al., 2004). Despite advances in legislation decriminalising same-sex acts during the 1960s and 1970s, the environment remained hostile to LGBTQ+ people (Kneale et al., 2020). The HIV/AIDS epidemic then had a devastating impact on the health, wellbeing and social networks of the LGBTQ+ community (Kneale et al., 2020). This was further compounded by the UK government introducing Section 28 of the Local Government Act which banned “promotion” of homosexuality in schools. More recent advances in legislation and medical treatment have meant LGBTQ+ people have more access to the rights heterosexual people enjoy, and antiretroviral treatment has reduced the rate of HIV/AIDS infections. Yet the long-term impact of exposure to adversity and discrimination on the health and well-being of LGBTQ+ older people is not known (Kneale et al. 2020).

Despite the socio-legal advances brought about through activism and changes in societal attitudes, LGBTQ+ older people continue to face significant social and health inequalities compared to heterosexual peers (Westwood et al., 2020). A body of research demonstrates that the LGBTQ+ community report poorer health and poorer experiences of healthcare than the general population (Correro & Nielson, 2020; Fredriksen-Goldsen, 2016; Fredriksen-Goldsen et al., 2018; Westwood et al., 2020). Inequalities in health status in LGBTQ+ people have been attributed to: a) social inequalities, including minority stress, a term describing the unique impact of repeated exposure to prejudice and discrimination throughout the lifecourse on wellbeing

(Meyer, 1995); b) health risk behaviours linked to adaptation to stress (e.g. smoking, use of substances); and c) loneliness and isolation (Westwood et al., 2020).

Kneale et al. (2019) conducted a systematic scoping review examining the differences between older LGBTQ+ and non-LGBTQ+ people's health and care needs, including 48 papers. The findings demonstrated inequity for LGBTQ+ older people across physical and mental health, social care, exposure to violence, and loneliness. Older LGBTQ+ people were more likely to engage in harmful health behaviours and have difficulty accessing health care that appropriately considered their sexuality in a non-stigmatising, accommodating way. Mainstream social care environments were identified as "focal points" for inequity in the health and care of LGBTQ+ older adults. The authors described these as 'heteronormative spaces' that compromised LGBTQ+ older peoples' identities and relationships, increasing the risk of poorer care outcomes. Again, there was evidence to suggest that LGBTQ+ older people had weaker social networks which increased the risk of social isolation, loneliness and requiring formal social care. The authors highlight that LGBTQ+ older people are not destined to follow such trajectories, noting studies that have implicated LGBTQ+ focussed support groups in offsetting social isolation and loneliness, enabling successful negation of age-related transitions. A further systematic review and meta-analysis of sources of individual participant data by the same authors found that LGB people aged 50+ were more likely to report poor health (Kneale et al., 2020). Men aged 50+ who did not have a heterosexual orientation reported more long-term conditions and health related limitations. Gay and bisexual men were more likely to report low life satisfaction whilst LGB women reported poorer self-rated health and increased rates of smoking and frequent alcohol consumption.

LGBTQ+ older people are also more likely to report a history of mental health difficulties and to experience psychological distress in old age than heterosexual counterparts. McCann & Brown (2019) conducted a narrative review of the published literature investigating the experiences and perceptions of LGBTQ+ people regarding their mental health needs. Fourteen papers were included in the review. As with other reviews in the area, LGBTQ+ identity emerged as a theme. LGBTQ+ people were rendered invisible and subject to negative attitudes and behaviour relating to both their sexual and gender identity, and stereotypes associated with the ageing process. The considerable mental health impact of a lifetime of stigma, marginalisation and prejudice which forced people to hide their sexual identity to ensure physical, social and economic survival was noted. Participants feared disclosing their LGBTQ+ identity in aged care settings. The review concluded that LGBTQ+ older people remain at risk of health disparities due to difficulties accessing and using appropriate healthcare settings. Identified risk factors included: internalised homophobia, loneliness, drug and alcohol use, depression and suicidality. Experiences of stigma and discrimination were detrimental to health and wellbeing. Despite this, some LGBTQ+ older people had developed coping strategies in response to these detrimental life experiences that increased their resilience to stressors.

The impact of living through such discrimination and pathologisation of sexuality has contributed to members of the LGBTQ+ community being fearful of accessing health services (Westwood et al., 2020). Healthcare experiences are often linked with anticipated/experienced discrimination and health care providers not understanding the needs of LGBTQ+ people. There is also evidence of stigma in healthcare contexts (Dorsen, 2012; Eskici et al., 2021; King, 2015). LGBTQ+ older people are more likely to require residential care and less likely to receive sexuality affirming care than heterosexual peers (Westwood, 2016b). LGBTQ+ people are more likely to live alone, be childfree, and be estranged from their biological family (Westwood, 2020). A recent systematic review exploring the perceptions of community dwelling LGBTQ+ adults regarding sexuality and sexual expression in residential care suggested that participants feared discrimination from other residents and care staff (Mahieu et al., 2019). Participants feared a loss of their sexual identity, perceiving care settings as heterosexual environments lacking privacy and not accepting of LGBTQ+ identities. The importance of maintaining sexual identity through connection with the LGBTQ+ community (and associated fears of losing this) along with the importance of same sex partners (and fears that they would not be involved in the care process) were identified. Some studies found participants were keen to have access to LGBTQ+ specific residential care facilities. LGBTQ+ friendly characteristics, defined as staff with competencies in caring for LGBTQ+ residents and equality with other residents, were desired. Access to LGBTQ+ communities and support from "families of choice" was protective.

4.2.3 Dementia in the LGBTQ+ community

Dementia is a syndrome caused by various diseases or injuries that affect the brain such as Alzheimer's disease and cerebrovascular disease, typically, but not exclusively, affecting older people (World Health Organisation, 2020.) Dementia causes progressive deterioration in cognitive function resulting in impairment in memory, thinking, comprehension, learning, language and judgement which tends to be combined with decline in the individual's ability to regulate their emotions, social behaviour and motivation (WHO, 2020). A lack of understanding and awareness of dementia can result in barriers to diagnosis and care. The physical, psychological, social and economic impact of dementia on the individual, their loved ones, carers and at a societal level is marked (WHO, 2020). It is difficult to estimate numbers of LGBTQ+ people living with dementia in the UK (Price, 2008). To date there are no published official figures. Extrapolating from number of people living with dementia in the UK and estimated proportion of the population that identify as LG, McParland & Camic (2018) suggested there were up to 56,000 gay or lesbian people with dementia.

The prevalence of modifiable risk factors for dementia, such as low mood, cardiovascular disease, smoking, lower educational attainment, obesity and limited social engagement, is higher amongst LGBTQ+ older people (Fredriksen-Goldsen et al., 2018). Combined with the impact of minority stress, this is thought to increase the risk of developing cognitive impairment and dementia (Correro & Nielson, 2020; Fredriksen-Goldsen et al., 2018). Despite this, McGovern (2014) refers to members of the LGBTQ+ community affected by dementia as “the forgotten”, noting that despite a proliferation of literature relating to dementia, research relating to LGBTQ+ experiences of dementia has not followed the same trajectory.

LGBTQ+ older people are at risk of experiencing dual discrimination pertaining to their age and sexuality. Coined ‘double invisibility’, LGBTQ+ older people face ageist stereotypes which assume they have no interest in expressing their sexuality combined with the assumption of heterosexuality (Mahieu & Gastmans, 2015). This is further compounded for LGBTQ+ older people living with mental health difficulties/long term conditions, meaning that “triple stigma” associated with age, sexuality and health status puts the individual at further risk of mental health difficulties, isolation, loneliness and disrupted support networks (McCann & Brown, 2019). This is also applicable to LGBTQ+ older people living with dementia.

The experiences of LGBTQ+ people living with dementia (PLwD) are poorly understood and tend to be neglected in research (Barrett et al., 2015; Price, 2008; Westwood et al., 2020; Westwood & Price, 2017). It has been argued that disregarding the needs and experiences of LGBTQ+ people living with dementia may be related to beliefs held by some care providers that people with dementia lose their sexual orientation or gender identity (Barrett et al., 2015).

4.2.4 Current evidence base

Interest in this field of research is growing, evidenced by more recent narrative reviews of research considering the experiences and needs of LGBTQ+ people affected by dementia. Furthermore, the first book dedicated to this area of research and practice was published in 2017 (Westwood & Price, 2017). McGovern (2014) conducted a narrative review relating to ageing, the LGBTQ+ experience and dementia, concluding that there were two overarching themes in the research: cohort membership and cultural competence of caregivers. McGovern (2014) suggested that the loss of self and identity for LGBTQ+ people differentiates dementia from other chronic illnesses. McGovern (2014) posited that the onset of dementia heightens and increases challenges for LGBTQ+ carers and PLwD in unique ways. She highlighted the intersection of sexuality, stigma and illness, noting the legacy of homophobia and discrimination that current cohorts of LGBTQ+ older people have endured. McGovern (2014) highlighted that dementia can result in forced disclosure of sexual identity and outlined the lack of culturally competent care experienced by the LGBTQ+ community, making suggestions for social work research and practice.

Another narrative review synthesised findings from multiple sources (Westwood, 2016b). These comprised of a literature review, qualitative interviews with lesbian and bisexual women exploring aging, gender and sexuality from an equalities perspective, data from a dementia service's equality impact assessment and the author's professional activities. Three themes were identified: early diagnosis and treatment, community support and residential care provision**.** The author concluded ageing and gender put women at greater risk of dementia than men, with both recent and historical experiences of discrimination resulting in lesbian/bisexual women being wary of healthcare providers. Varying personal histories meant differences in access to intergenerational support amongst lesbian, bisexual and heterosexual women with dementia. Under-recognition of support needs, avoidance of services due to past experience of discrimination, and care not designed to meet the needs of lesbian and bisexual women increase the risk of premature admission to residential care. Westwood (2016b) concluded that residential care provision does not validate and support the lived experiences and identities of lesbian and bisexual women with dementia, with women choosing to hide their sexuality and life history to feel safe.

As part of a wider literature review concerning neurological disabilities in people who identify as LGBTQ+ Moreno et al (2017) described 17 accounts relating to dementia. They concluded that dementia was the most common neurodisability in LGBTQ+ people. Fear of discriminatory care due to sexual/gender identity was documented across all types of neurodisability (Moreno et al., 2017). Finally, the most recent narrative review in this area sought to give a broad overview of the literature relating to the needs of LGBTQ+ PLwD (Cousins et al., 2020). Three themes were identified: increasing awareness of the needs of LGBTQ+ PLwD, challenges for PLwD (living with memory problems, remembering the past, reminiscence, personal relationships and receiving care) and recommendations for improving practice and care.

Whilst the aforementioned literature reviews provide important insights into the experiences of an under-researched population, there are limitations in the body of work outlined, leading to an evidence gap that this study seeks to fill. Most of the reviews did not document how the searches were conducted and how evidence sources were selected for inclusion (Cousins et al., 2020; McGovern, 2014; Westwood, 2016b). Furthermore, none of the literature reviews explicitly outlined the how the evidence was synthesised nor conducted quality appraisal of the evidence (Cousins et al., 2020; McGovern, 2014; Moreno et al., 2017; Westwood, 2016b)**.**

4.2.5 Aim of SR

This study sought to address this gap and extend the current evidence base through identifying, critically evaluating, and synthesising the findings from articles included in electronic databases that have explored the experiences of LGBTQ+ people affected by dementia and those providing care for them, using a systematic review approach. Given the relatively small literature identified in previous reviews in this area, the review sought to identify the widest range of perspectives of stakeholders in LGBTQ+ dementia care. The stakeholders identified were as follows:

a) LGBTQ+ people living with dementia (either living with the condition themselves or caring for someone living with dementia) given their direct lived experience of dementia and dementia care.
b) Health and social care professionals providing dementia care, given the literature outlined above highlighting concerns from LGBTQ+ people regarding healthcare professionals attitudes towards them.
c) LGBTQ+ people considering their future dementia care needs, given their lived experience of navigating health and social care as members of the

LGBTQ+ community and the impact this may have had on their needs and perspectives on accessing dementia care in the future. This was identified as an important perspective, given the evidence base outlined above highlighting the fears LGBTQ+ experience with regards to accessing health and social care.

d) LGBTQ+ people caring for someone with dementia (LGBTQ+ or otherwise) based on previous work by Price (2008, 2011, 2012), included in previously published reviews in this area, which demonstrated the challenges LGBTQ+ people faced when providing care for someone with dementia and the implications this had for them considering their own future dementia care needs.

The following research questions guided the review:

1. What are the experiences and needs of LGBTQ+ people living with dementia?
2. What are the experiences and needs of LGBTQ+ people caring for someone living with dementia?
3. What are the experiences and needs of health and social care professionals caring for LGBTQ+ people living with dementia?
4. What are the perceived future dementia care needs of LGBTQ+ identifying people?
5. What is the quality of evidence in this area?

The review was conducted in accordance with a protocol informed by the York Centre for Systematic Reviews framework (CRD, 2009).

4.3 Methods

4.3.1 Search strategy

Initial scoping searches combining the terms “dementia” AND “LGBT” (and their associated MESH terms) were conducted to identify any previous systematic reviews and published work in this field. The PROSPERO database was also searched to identify any ongoing/newly registered systematic reviews in this area. These searches identified that no systematic reviews have been conducted and the published literature in this area is relatively small.

The first author (KK) conducted a systematic search of the following online databases during February 2021: EMBASE, Medline, PsychINFO, ASSIA Sociological Abstracts and CINHAL. Further searches of Proquest etheses were conducted to identify theses in this area.

The search terms and search strategy were developed through the provisional scoping searches and consultation with an information specialist (RS). No limits were set on publication date. The aforementioned databases were searched using the following search terms:

LGBTQ [exploded) OR lgbt* or homosexual* or lesbian* or bisexual* or transgender* or gay or "sexual minorit*" or "gender minorit*" or sexuality or queer

AND

Dementia [exploded] OR dement* OR Alzheimer* OR “cognitive impair*”

Subject heading and keyword search terms were conducted, and the results were imported into Covidence systematic review management software. Duplicates were removed, and titles and abstracts were screened against the inclusion criteria listed below to assess suitability for inclusion in the review. The researcher was overly inclusive at the first stage and included papers for full text review where there was ambiguity/no abstract available. The first author read the full texts of papers identified as meeting inclusion criteria at the title and abstract search and made decisions about eligibility. The second author, DG, was consulted to resolve queries about the eligibility of studies. Reference list checks were conducted for all papers included in the final review.

This review aimed to identify published papers that reported the experiences of LGBTQ+ people affected by dementia, their caregivers or health and social care staff caring for LGBTQ+ people affected by dementia. Therefore, the search was not restricted by methodology or publication date. The inclusion and exclusion criteria below were applied during the selection stage.

4.3.2 Inclusion Criteria

1. Published papers held in electronic databases (of any design) investigating the experiences of LGBTQ+ people living with dementia
2. Published papers held in electronic databases (of any design) investigating the experiences of LGBTQ+ people providing care for someone living with dementia
3. Published papers (of any design) exploring LGBTQ+ people’s perspectives on dementia care (current or anticipated future dementia care needs)
4. Published papers (of any design) investigating caregivers’ experiences/attitudes towards caring for LGBTQ+ people with dementia

4.3.3 Exclusion Criteria

1. Papers not written in English language
2. Papers that do not include primary data
3. Retrieval of the paper not possible

4.3.4 Data extraction

Data was extracted from studies that met review inclusion criteria using a standardised data extraction form that was piloted prior to use. This included: Author, year of publication, country, participant characteristics (e.g., age, gender identity, role (e.g. PLwD, formal/informal carer), sample size, outcome measures used (if applicable), key findings, conclusions, implications for practice). For qualitative studies, descriptions of themes and sub-themes were extracted. For papers reporting case studies, multi-stakeholder events and first-person reflective accounts, the key findings of the articles were summarised by the researcher and documented in the data extraction form.

4.3.5 Quality Assessment

The methodological quality of each study meeting inclusion criteria for the review was evaluated using the Critical Appraisal Skills Programme (CASP) tool for qualitative research (CASP, UK.), and the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) for mixed methods studies. The first author (KK) conducted quality assessment, where applicable, of included papers. Quality assessment was not applied to case studies, first person reflective accounts and reports of multi-stakeholder events. A portion of the papers (n=3) were independently rated by a second rater (AW).

Quality appraisal was not used as a decision-making tool to determine study inclusion given this review aimed to identity as many data sources as possible in an underrepresented, under-researched population. The decision to include data from papers with methodological limitations (such as poor quality or designs such as first-person accounts and case studies) was taken to ensure that important data was not omitted. Rather, greater weight was given to the findings of the studies appraised to be of higher quality in the data synthesis. The source of evidence is noted throughout the evidence synthesis to contextualise the findings according to their methodological quality.

4.3.6 Data Synthesis

The data included in this review is drawn from heterogenous sources, of varying quality, from multiple stakeholder perspectives. Thus, it was determined that narrative synthesis was the most appropriate means to synthesise the findings in relation to the aims of the review, given its inductive stance to integrating data from multiple sources. Guidance on conducting narrative synthesis (Popay et al., 2006) describes four key elements to the synthesis process:

- Developing a theory of how the intervention works, why, and for whom
- Developing preliminary synthesis of findings in included studies
- Exploring relationships in the data
- Assessing the robustness of the synthesis

Popay et al. (2006) state that whilst their guidance focussed on conducting syntheses in systematic reviews of research-based evidence on the effect of interventions or factors shaping implementation, the process can also be applied to reviews considering the needs or preferences of particular population groups, as is the case for the current review. Thus, the evidence synthesis sought to explore and identify the experiences and dementia care needs of LGBTQ+ people affected by dementia rather than develop a theory of how interventions work, why and for whom.

In accordance with the Popay et al. (2006) guidance, key findings related to the review aims were extracted from each of the papers using the pre-piloted data extraction form. A preliminary data synthesis was created by tabulating the key findings from each paper, grouped by methodology in the first instance. An inductive approach to coding was utilised to develop a preliminary thematic framework based on the common themes derived from the themes and sub-themes from qualitative studies that were of higher quality (n=8). This was then applied to the remaining qualitative studies (n=2), and other evidence sources. The sources and quality of evidence underpinning the themes are documented in table 4. They are also outlined throughout the results section (e.g., qualitative study, case study, reflective article) to allow the reader to contextualise methodological quality and potential generalisability of the findings.

4.4 Results

4.4.1 Description of included studies

24 articles identified by the electronic searches met criteria for inclusion in the review. The identification process is outlined in figure 1 below.

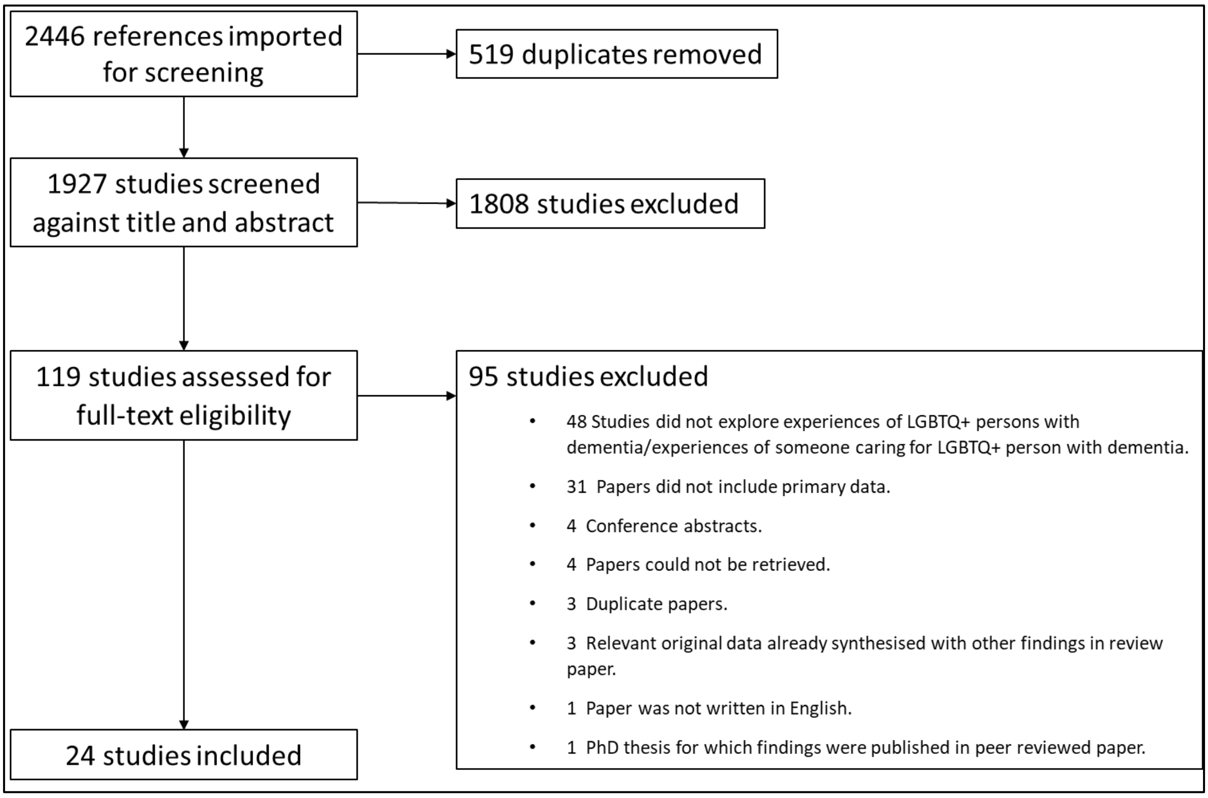

Figure 1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009).

The characteristics of included articles are detailed in table 1. Most of the articles related to a UK context (n=11), with the remaining papers relating to the USA (n=4), Australia (n=2), Canada (n=1) and Turkey (n=1). A further six articles did not report a location (location is inferred in the table below). A wide variety of methodologies were utilised, outlined in Table 1.

Table 1: Summary of characteristics of included articles

Author	Location	Design & Methods	Participants
Archibald (2006)	Not reported; appears to be UK. *	Reflective article including case study & summary of findings of what appears to be a research study	Participants in study mentioned not reported. "Christine" - case study described; an older woman with dementia and a history of mental health difficulties whom care home staff believe is attracted to women.
Barrett et al. (2015)	New South Wales, Australia	Qualitative; semi-structured interviews	30 LGBT people sampled (age range 47-79 years; mean 65). Included interviews with 9 PLwD. No bisexual, intersex or transgender participants recruited. 6 service providers (4 senior managers, 1 psychiatrist and one other not specified).
Constable 2011	UK	Qualitative (semi structured interviews using biographical research methods)	6 carers of PLwD, 3 of whom identified as LGBTQ+; 2 lesbian women, 1 gay man. Relevant findings were extracted.
DiNapoli et al. (2013)	Alabama, USA	Mixed methods (staff questionnaire assessing knowledge AD, sexuality + attitudes towards sexuality); educational intervention regarding older people and dementia; focus group facilitated by case study)	100 care home staff members. 93% female; 83.2% African American; 88% identified themselves as heterosexual.
Dixey (2013)	Not reported; appears to be UK*	Personal reflective article from perspective of lesbian woman whose late partner had early-onset dementia	Lesbian woman who cared for partner with early onset dementia
Duffy (2014)	Sydney, Australia	Critical practice reflection on four cases identified by case file review. Selection criteria: "recent cases as this helped to highlight issues faced by the current cohort of LGBTQ+ older people"	4 case studies selected; 2 relevant to current review: Case 1: "Tony", 78-year-old gay man with dementia admitted to hospital with deterioration in dementia. Case 4: "Jim", 75-year-old gay man with dementia living in a residential care facility.

Dykewomon (2018)	Not reported; appears to be USA*	Reflective personal essay	Lesbian woman whose partner of 27 years died from Lewy body dementia
Knocker (2006)	UK	Reflective opinion piece	Researcher in dementia and sexuality; lesbian woman.
Marshall (2015)	Canada	Case study	94-year-old transgender woman living with dementia. Transitioned in 80s. Married for 66 years to wife (until she died).
McParland & Camic (2018)	UK	Qualitative; 10 semi-structured interviews analysed using IPA.	Four women and three men with dementia and their same-sex partners, two were with individuals with dementia (one gay male and one lesbian female interviewed with a close friend) and one was a lesbian that had previously cared for her same-sex partner with dementia. Only lesbian and gay identifying participants recruited.
Meadows et al. (1999)	England, UK	Qualitative (semi-structured interviews; no information on analysis provided)	11 caregivers (8 male, 3 female). Six were partner of patient cared for, 2 close friends and 3 caregivers were patient's mother. All patients described as homosexual men.
Monks & Shaw (2017)	Not reported; appears to be UK*	Report of stakeholder event & training	>30 attendees (exact number not reported). Health professionals, people with dementia, carers; some identified as LGBTQ+)
Moore (2002)	Northwestern North Carolina, USA	Qualitative evaluation	5 lesbian & 2 gay male caregivers for partners with dementia. Age range of partners 51-71 years, with average time in caregiving role 4 years. Average length of relationship: 30 years.
Newman (2005)	UK	Personal reflective article on experience of being gay carer and L+G helpline volunteer	First person reflective account of caregiving for gay partner living with dementia and volunteering for LG helpline for carers of PLwD.
O' Kelly (2015)	Not reported; appears to be UK*	Case study	"Eve", a transgender woman in her 60s diagnosed with dementia and living in residential care. Eve underwent gender reassignment surgery and commenced hormone therapy in her 40s.

Page et al. (2015)	North Wales, UK	Description of appreciative inquiry method project with older members of the trans community	Older members of transgender community and mental health nurses (no other information reported)
Price (2010)	UK	Qualitative; semi-structured interviews analysed using thematic comparative method (Glaser & Strauss, 1967).	10 male, 11 female participants (gay or lesbian) who care for PLwD - included caring for parents, partner or friend.
Price (2011)	UK	Qualitative study (semi-structured interviews; data analysed using thematic comparative method)	Part of larger 21 participant project. 11 Female respondents: 8 carers for parent with dementia, 2 for other relative and 1 partner. 3 of these participants in long term partnerships
Price (2012)	UK	Qualitative study (semi-structured interviews; data analysed using thematic comparative method)	10 gay men & 11 lesbian women (16 cared for parents, 2 for other relatives, 2 for friends and 1 cared for partner). All White British. Age range 23-67. Highly educated and politically active.
Putney (2018)	Northeastern USA	Qualitative study: inductive thematic analysis of focus group data	N = (50) consisted of LGBT participants aged 55-87 (mean 67); 78% white, 57% female
Sarikaya & Sarikaya (2018)	Turkey	Case study	74-year-old woman diagnosed with dementia. Considered heterosexual throughout lifetime. Displaying sexual advances towards men and women, referred to as ‘inappropriate sexual behaviour’.
Scharaga 2020	USA	Case study	85-year-old transgender woman. Transitioned in her 70s. Diagnosed with Alzheimer's disease.
Ward (2000)	Not reported, appears to be UK*	Opinion piece incorporating two case study examples of two gay men living with dementia.	Researcher & dementia charity outreach worker
Ward (2005)	London & SE England, UK	Mixed methods study involving 11 care homes: interviews with care staff, textual analysis of care home documents, observations & researcher reflective diaries; filming resident interactions	27 residential care staff (no other characteristics reported).

*Inferred through author affiliation

4.4.1.1 Qualitative studies

Nine studies adopted a qualitative approach, utilising semi-structured interviews (n=8) or focus groups (n=1). One study (Moore, 2002) reported the findings of a qualitative evaluation of a phone support group for LGBTQ+ carers of PLwD but did not state how the data was collected. Most studies sampled caregivers of LGBTQ+ PLwD/ LGBTQ+ caregivers of PLwD. Three papers (Price, 2010, 2011, 2012) reported the findings from one qualitative study with 11 lesbian women and 10 gay men caring for PLwD. A PhD thesis (Constable, 2011) conducted a study with caregivers of PLwD, a proportion of whom identified as LGBTQ+; relevant findings were extracted. Two studies, (Barrett et al., 2015; McParland & Camic, 2018) included participants with dementia as well as caregivers. One study, (Putney et al., 2018), conducted focus groups with LGBTQ+ people (without dementia) regarding their anticipated future care needs; findings relevant to dementia care were extracted. Ward et al. (2005) conducted semi-structured interviews with care home staff, textual analysis of care home documents and observed interactions within care homes.

4.4.1.2 Mixed methods studies

One study (Di Napoli et al., 2013), examined attitudes and knowledge relating to sexuality in residential staff caring for PLwD using a mixed methods design incorporating a cross-sectional questionnaire and focus groups with staff.

4.4.1.3 Case studies

Five papers reported case studies. Three (Marshall et al., 2015; O'Kelly et al., 2015; Sarikaya & Sarikaya, 2018) concerned trans women; two of whom were experiencing distress and confusion related to their gender identity in the context of cognitive decline associated with dementia, whilst one paper reported the process of a neuropsychological assessment with a woman diagnosed with dementia who transitioned later in life. Sarikaya & Sarikaya (2018) report a case study of a woman considered heterosexual throughout her life who consistently began making sexual advances towards women when she developed dementia. The authors conceptualised this as sexually inappropriate behaviour in the context of dementia and treated her with antipsychotic medication which reportedly stopped the behaviour. Finally, Duffy & Healy (2014) reported two case studies derived from a hospital records review of two gay men living with dementia who were admitted to hospital, considering the implications of their sexuality on their dementia care needs from a social work perspective.

4.4.1.4 First person/reflective accounts

Two papers, in the form of personal reflective essays, reported the experiences of two lesbian women caring for their partner who died from dementia (Dixey,2016; Dykewomon, 2018). One paper was a reflective account on the experiences of a gay man caring for his partner with dementia, and the process of setting up a helpline for lesbian and gay caregivers for PLwD (Newman, 2005). Three reflective articles were written from the perspective of researchers who explored sexuality and dementia in their work. Ward (2000) reflected on his experiences of being a support worker and researcher, using two case examples of gay men with dementia to illustrate key issues he had encountered. Archibald (2006) also utilised a case example of care home staff perceptions and responses to a woman with dementia who they believed was a lesbian accompanied by an overview of findings from what appears to be qualitative interviews with older lesbians. Finally, Knocker (2006) wrote a short article reflecting on the process of preparing a resource pack outlining how residential care managers can provide inclusive services for LGBTQ+ people. She highlighted key points for practice and described her interaction with a lesbian woman with dementia, reflecting on the significance of being able to converse with her, another lesbian woman.

4.4.1.5 Reports of multistakeholder event

Page et al. (2016) reported the process of using an appreciative inquiry approach, involving older members of the transgender community and mental health nurses, to co-create priorities for mental health care. Dementia care for transgender older adults was identified as a key priority. Monks & Shaw (2017) briefly reported the process, general findings and suggested implications for practice from an event held with PLwD, healthcare professionals and carers, exploring the needs of LGBTQ+ PLwD.

4.4.2 Methodological quality

The CASP scoring guidance suggests that rather than using a scoring system, three broad issues should be considered when appraising a qualitative study: if the study is valid (section A), the results (section B) and if the results will help locally.

Two of the studies (Constable, 2011; McParland & Camic, 2018) were of very high quality. The majority of the remaining studies appeared to be of reasonable quality (Price, 2010, 2011, 2012; Putney et al., 2018; Ward et al., 2005), noting that each of the papers by Price reported different findings from the same study. It was unclear from the reporting of some papers if the relationship between the researcher and participants was considered (Price, 2010, 2011, 2012; Putney et al., 2018; Ward et al., 2005). Three papers did not appear to have considered this (Barrett et al., 2015; Meadows et al., 1999; Moore, 2002).

The overall findings of one paper (Barrett et al., 2015) appeared to suggest that the data was collected in a way that addressed the research issue however this was unclear from the reporting. Similarly, some papers did not provide enough information to determine if the data analysis was sufficiently rigorous (Barrett et al., 2015; Price, 2012; Putney et al., 2018; Ward et al., 2005).

Two papers (Meadows et al., 1999; Moore, 2002) did not report enough information to determine the validity of the findings. They did not report clear aims for the research and whilst it appeared that a qualitative methodology was likely appropriate, this was not explicitly addressed in the papers. Data analysis did not appear to be sufficiently rigorous and the findings were not sufficiently clear. There was no consideration of ethical issues in one of the papers (Moore, 2002). Therefore, these papers were not included in the initial synthesis of papers to develop the thematic framework.

However, it is important to note that identification of quality and methodological weakness can be challenging, as studies are often poorly reported, without this necessarily being indicative of poor quality (Dalton et al., 2017). No studies were excluded from the review on the basis of poor methodological quality.

	Section A: Validity						Section B: what are the results?			Section C: value of results locally
	Screening Questions									
	Q1. Clear statement of aims	Q2: Qualitative methodology appropriate?	Q3. Research design appropriate to address aims?	Q4. Appropriate recruitment strategy?	Q5. Data collected in a way that addressed research issue?	Q6. Relationship between researcher and ppts considered?	Q7. Ethical issues considered?	Q8. Data analysis sufficiently rigorous?	Q9. Clear statement of findings?	Q.10 How valuable is the research?
Barrett et al. (2015)	✓	✓	✓	✓	?	×	✓	?	✓	✓
Constable (2011)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
McParland & Camic (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Meadows et al. (1999)	?	?	?	?	?	×	?	×	×	?
Moore (2002)	?	?	?	?	?	×	×	×	×	?
Price (2010)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Price (2011)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
Price (2012)	✓	✓	✓	✓	✓	?	✓	?	✓	✓
Putney et al. (2018)	✓	✓	✓	✓	✓	?	✓	?	✓	✓
Ward et al. (2005)	✓	✓	✓	✓	✓	?	?	?	✓	✓

Figure 2: Summary of CASP quality assessment for qualitative studies

	Methodological quality criteria				
	5.1 Adequate rationale for using MM design to address research question?	5.2 Different components of study effectively integrated to answer research question?	5.3. Outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4. Divergences and inconsistences between qualitative and quantitative results adequately addressed?	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Di Napoli et al. (2013)	×	×	×	?	?

Figure 3: Summary of MMAT quality assessment for mixed methods studies

One study incorporated quantitative and qualitative methods (Di Napoli et al., 2013). The paper reported using a mixed method design (focus groups with participants alongside a semi-structured questionnaire exploring knowledge and attitudes towards sexual expression in older people). However, it did not provide justification for using mixed methods, and reported very little of the qualitative component. The MMAT requires the quality of both components of a mixed methods study to be high to be considered good quality, thus this study is not rated of good methodological quality.

4.4.3 Findings from thematic synthesis

Three overarching themes were identified to illustrate the experiences of LGBTQ+ people affected by dementia and their dementia care needs. These are based on the strongest quality of evidence then cross referenced against lesser quality studies and other evidence sources (case studies, first person reflective accounts, reports on mutli-stakeholder events) as outlined in table 4 below.

Table 2: Themes and subthemes identified from the thematic synthesis of findings

Overarching themes	Subtheme	Evident in higher quality qualitative studies	Evident in lower quality qualitative studies/evidence sources
Impact of gender and sexual identity on experiences of dementia	*Implications of cognitive decline on expressions of gender/sexual identity*	Barrett et al. (2015); Putney et al. (2018)	Duffy et al. (2018); Sarikaya & Sarikaya (2018); Marshall et al. (2015); Page et al. (2015)
	Navigating relationships with family of origin and caregiving	Barrett et al. (2015); Constable (2011); Price (2011)	Scharaga et al. (2020); Marshall et al. (2015)
	Anticipating needs not being met by caregivers	Price (2012); Putney et al. (2018)	Page et al. (2016); Ward (2000)
Experiences of navigating health and social care system	*Impact of heteronormative environments*	McParland & Camic (2018); Constable (2011); Price (2012); Ward et al. (2005)	Newman (2005); Dixey (2016); Knocker (2006); Moore (2002); Ward (2000); Meadows et al. (1999)
	Discrimination/homophobia in health/social care settings	McParland & Camic (2018); Putney et al. (2018); Barrett et al. (2015)	Marshall et al. (2015); Archibald (2006); Di Napoli et al. (2013)
	Managing disclosure of sexual/gender identity	McParland & Camic (2018); Price (2010); Barrett et al. (2015)	Moore (2002); Newman (2005); Ward (2000); Archibald (2006); Duffy & Healy (2014)
	Protective role of partner/family of choice	McParland & Camic (2018); Barrett et al. (2015); Price (2011)	Dykewoman (2018); Moore (2002)
Characteristics of culturally competent dementia care	*Safe spaces that enable expression of sexual/gender identity*	McParland & Camic (2018); Putney et al. (2018); Barrett et al. (2015); Price (2012)	Page et al. (2016); Duffy & Healy (2014); Newman (2005)
	Enhancing visibility	McParland & Camic (2018); Putney et al., 2018; Price (2012)	Monks & Shaw (2017); Duffy & Healy (2014); Knocker (2016); Newman (2005);
	Support for caregivers/family of choice	McParland & Camic (2018); Barrett et al. (2015); Constable (2011)	Moore (2002); Meadows et al. (1999)
	Role of policy, legislation and governance	Price (2012); Constable (2011);	Marshall et al. (2015); Monks & Shaw (2017); Duffy & Healy (2014); Newman (2005); Ward (2000); Meadows et al. (1999)
	Role of professional care staff	McParland & Camic (2018); Price (2010); Putney et al. (2018); Ward et al. (2005)	Monks & Shaw (2017); Di Napoli et al. (2013); Ward (2000)

4.4.3.1 Theme 1: Impact of gender and sexual identity on experiences of dementia

Implications of cognitive decline on expressions of gender/sexual identity

The relationship between cognitive decline and sexual and/or gender identity resulted in another layer of complexity in LGBTQ+ participants' experiences. This was evident in two of the higher quality qualitative papers, with further detail and insight gained from lower quality evidence sources. This was particularly relevant to the experiences of transgender PLwD.

Participants in the two papers exploring LGBTQ+ adults' perspectives on their future care needs cited fears that cognitive impairment might mean that they would not remember their gender or sexual identity (Page et al., 2016; Putney et al., 2018) or that PLwD may inadvertently "out" or mis-gender transgender family members who had not disclosed their transition, and the distress this would cause (Page et al., 2016). Some papers described cognitive decline compromising the ability to make informed choices about who information about sexual and/ or gender identity was shared with. This manifested as LGBTQ+ PLwD openly disclosing their sexual identity in a way they had not previously, reported in studies sampling multiple stakeholders (LIST) and three case studies describing gay and transgender PLwD (Barrett et al., 2015; O'Kelly et al., 2015; Duffy et al, 2014 This may have implications for others, as outlined by Duffy et al. (2014), who detailed a case study describing a gay man with dementia, who had previously been very guarded regarding his sexual identity, disclosing a previous sexual relationship with a friend who was not "out", placing strain on the relationship.

Further detail was outlined in three case studies. Sarikaya & Sarikaya (2018) described the case of a woman with dementia, considered heterosexual throughout her life, who began making consistent sexual advances towards women when she developed dementia. The authors conceptualised this as inappropriate sexual behaviour for which they prescribed an antipsychotic, resulting in the extinction of the behaviour. They suggest that the woman may have experienced “homosexual drives” that became evident with the decline in her cognitive functioning. Based on the available information, it appears that this conceptualisation and intervention was uncritical of assumptions being made about the woman’s sexuality.

A further two case studies reported incidences of transgender women who had transitioned (taken steps to live as the gender they identified with) later in life (Marshall et al., 2015; O’Kelly et al., 2015). On occasion they experienced confusion and distress related to their gender identity as their dementia progressed. As both PLwD were no longer deemed to have capacity to make decisions related to their gender identity, ethical dilemmas emerged for healthcare staff in relation to capacity to consent to continuing to receive hormone replacement therapy (O’Kelly et al., 2015) and how they should address the PLwD given their gender ambiguity (Marshall et al., 2015).

Navigating relationships with family of origin and caregiving

Some studies (both higher and lower quality) described LGBTQ+ participants experiencing conflict with their family of origin. In a study sampling LGBTQ+ PLwD, LGBTQ+ caregivers of PLwD and staff caring for them, Barrett et al. (2015) reported that increasing cognitive impairment placed LGBTQ+ PLwD at risk of having decisions made about their care by family members that were not in keeping with how they had expressed their gender or sexual identity throughout their lives. Examples included not recognising or involving same-sex partners in care planning and decision making, and not recognising gender identity or advocating gender affirmative care for the PLwD. Richer detail of situations where this was evident was provided a case study of a transgender woman with dementia whose daughter did not recognise their gender identity (Marshall et al., 2015). Furthermorea PhD thesis using a qualitative methodology included accounts of LGBTQ+ PLwD having decisions made by biological family members which directly contradicted with how they had lived their lives, e.g. presenting the person as heterosexual in hospital settings and excluding family of choice (Constable, 2011).

Price (2011) interviewed 11 lesbian women who were caring for PLwD (partners or family members). For some participants, this meant providing care for family members who had rejected or discriminated against them because of their sexuality. This resulted in challenging situations of navigating caregiving for and with family members who were not accepting of their sexuality. For some participants, providing care for a family member with dementia offered an unexpected opportunity to re-assess relationships as the cognitive impairment resulted in their attitudes “softening”. Other participants reported their family members forgetting their sexual identity altogether.

For some LGBTQ+ people, there was uncertainty and fear about who would provide care for them, as they did not have a partner or children or they had been rejected by their family of origin. Putney et al. (2018) described this as highlighting participant’s

(LGBTQ+ people reflecting on their future care needs) vulnerability, with participants recognising that their health could deteriorate unpredictably but many did not have a support system to facilitate them staying at home or the financial means to move into retirement communities. This was evident in a case study of a transgender woman diagnosed with dementia who reported being socially isolated and lonely in a residential facility after experiencing family and community social support rejection after her gender transition in her 70s (Scharaga et al. 2020).

Anticipating needs not being met by care providers

Fears of dementia care needs not being met due to care providers not acknowledging, respecting or discriminating against based on sexual and/or gender identity were evident in some accounts. A higher quality study with lesbian and gay caregivers of PLwD (partners or biological family members) questioned if they would receive culturally sensitive care having observed predominantly heterosexual family members struggle to get person centred care (Price, 2012). Participants reported the importance of privacy, fearing it would be removed through dementia, and had consistent concerns about not being able to maintain links with other lesbian and gay people if they became dependent on care.

These sentiments were shared by LGBTQ+ people in a higher quality qualitative study exploring their future care needs (Putney et al., 2018) and a lower quality paper describing an appreciative inquiry process regarding the perceived future care needs of transgender older people (Page et al., 2016). Participants questioned if their safety and wellbeing could be entrusted to healthcare providers, wondering if they would respond appropriately if cognitive impairment resulted in them returning to a time when they identified with another gender or were not “out” (Page et al., 2016; Putney et al., 2018). Furthermore, in a reflective article, Ward (2000) described a case example of a gay man with early onset dementia feeling anxious about being alone and losing his identity through accessing care services, which made him reluctant to disclose his current circumstances to health and social care professionals.

4.4.3.2 Theme 2: Experiences of navigating health and social care systems

Impact of heteronormative environments

Some papers described health and social care environments operating from a heteronormative stance, rendering other sexual identities as invisible and not recognising the significance of families of choice. This was evident in some of the higher quality qualitative studies (Constable, 2011; McParland & Camic, 2018; Price, 2012; Ward et al., 2005) and many of the first-person reflective accounts.

Whilst acknowledging the challenges shared with heterosexual PLwD when accessing health and care services, LGBTQ+ people and their partners experienced the added challenge of their relationships and sexuality being erased in the process (McParland & Camic, 2018). This was also evident in a multiple qualitative methods investigation involving 11 Jewish care homes in south east England. Analysis of care files, assessment documents and care planning materials found that there was no mention of residents’ sexuality (Ward et al., 2005). In the qualitative interview component exploring expression of sexuality in PLwD, only one of the 27 care home staff referred to homosexuality, describing anxiety and lack of knowledge in how to respond to a female resident expressing a sexual preference for other women.

Evidence from the case study and reflective first-person account data added to this. In his reflection on his role as a carer for his partner living with dementia, Newman (2005) noted that the sources of information on dementia he was given assume that dementia only affects heterosexual married couples, stating his desire for affirmation that experiences of gay carers are as valid as heterosexual carers and worthy of the same support. This stance was shared by Dixey (2016), who described the loneliness of her minority status and not being viewed as the same as heterosexual couples. Similarly, in an article reflecting on her identities as dementia researcher and lesbian, Knocker (2006) described an interaction with a lesbian woman with dementia in her researcher role, reflecting that the woman's sexuality had become invisible in residential care and fearing that her own relationship with her partner would not be recognised if she had to enter residential care in the future.

Heteronormative assumptions also manifested as not having the same next of kin rights and entitlement to involvement in a partner/ family of choice's care in studies that sampled LGBTQ+ caregivers of a LGBTQ+ PLwD (Constable, 2011; Meadows et al., 1999; Moore, 2002; Newman, 2005; Ward, 2000) in some cases despite having had more meaningful involvement in the PLwD's life and provision of their care than the family of origin (Constable, 2011). Price (2012) found that lesbian caregivers' experiences of observing predominantly heterosexual relatives or friends struggle to get person-centred care was the catalyst to them considering how their sexuality might impact on their care if they were to develop dementia, making plans to ensure that their sexuality and life were not invalidated and erased.

Discrimination/Homophobia in health/social care settings

Experiences of anticipated, suspected and experienced homophobia were described in some of the higher quality papers. Some lesbian and gay caregivers of PLwD and their partners described health and social care staff appearing awkward around them, and expressed uncertainty whether this was to do with their sexuality as their couple hood was not acknowledged (McParland & Camic, 2018). Other carers reported incidences of their partner not being accepted into residential care settings due to their sexuality (Barrett et al., 2015). Concerns about experiencing homophobia in residential care settings were also identified by Putney et al. (2018) in focus groups with LGBTQ+ older people regarding their anticipated future care needs and in interviews with LGBTQ+ PLwD and their caregivers (Barrett et al., 2015).

Lower quality evidence sources also reflected this. Marshall et al. (2015) described the social isolation and ostracism from other residents experienced by a transgender woman experiencing gender ambiguity in the context dementia related cognitive impairment. Archibald (2006) described the case of a woman who was seeking affection from same sex residential care staff. This reportedly resulted in staff believing that the woman was a lesbian, and consequently she was cared for with the minimum amount of touch, particularly in relation to personal care tasks. The author reflected that the woman was very lonely due to minimal interactions with staff and other residents, and that her quality of life was compromised.

A mixed methods study (of lower quality) exploring attitudes towards sexual expression amongst residents with 100 residential care home staff found that participants had neutral attitudes about late life sexuality in nursing home facilities in a cross-sectional questionnaire (Di Napoli et al., 2013). However, participants reported more negative attitudes about same sex couples and that sexual behaviour between same sex couples should be discouraged, despite indicating that sexual expression amongst residents with dementia should not be discouraged. In focus group discussions, staff indicated that sexual expression occurred in residential facilities, however group discussion of same sex sexual expression was described as “rare” by the authors.

Managing disclosure of sexual/gender identity

If, how, when, and the degree of choice experienced in relation to disclosure in health and social care settings was addressed in many papers, ranging from the highest to lowest levels of methodological quality. In a study exploring the experiences of gay men and lesbian women who were caregivers for a PLwD (in the role of friend/partner/biological family member), Price (2010) reported that respondents were “out” to varying extents, with the need for formal care provision in people’s homes serving as a catalyst regarding if, when and how they disclosed their sexuality. Price (2010) categorised disclosure decisions into four strategies: “active disclosure”, referring to when participants disclosed their sexuality, often to manage incorrect heterosexual assumptions made by care providers; “passive disclosure” whereby participants did not discuss their sexuality but had visible “clues” in their homes that they were not prepared to hide. “Passive non-disclosure” described a strategy whereby the person does not disclose their sexuality and it is not immediately obvious however they do not claim a heterosexual identity, which was linked to a sense of needing to hold back and not having the emotional energy to “out” themselves given the energy devoted to having a caregiving role. Other participants did not disclose their sexuality because the opportunity or necessity did not emerge. Finally, “active non-disclosure” was conceptualised as a strategy where participants chose to pass as heterosexual; none of the participants engaged in this strategy, which Price (2010) suggested may be attributable to the difficulty of doing this whilst arranging and receiving community and residential care.

Participants in McParland & Camic (2018) (LGBTQ+ PLwD and their partners/family of choice) described the difficulties of navigating the “double stigma” of homophobia and dementia. Some had become accustomed to experiencing homophobia and developed strategies to manage this, however dementia became an additional stigmatised aspect of their identity and an added level of complexity that influenced decision making. McParland and Camic (2018) described a duality between participant’s experiences of heterosexism: some made decisions to pass as heterosexual, described as active non-disclosure by Price (2010), whilst others actively challenged heterosexist assumptions.

The role of fear and stress associated with disclosure, and the implications for safety, was highlighted in some papers. Barrett et al. (2015) described participants experiencing stress related to how information about their sexual identity was shared, given their historic experiences of using “passing” as heterosexual as a safety strategy against homophobia. Similarly, participants in Putney et al. (2018) (LGBTQ+ people considering their future care needs) reported that they planned to conceal their sexual identity to protect themselves from discrimination in residential care should they require it in later life. A lower quality study reported that participants attending a support group for lesbian and gay caregivers of PLwD also reported concern about disclosing their sexual identity and the impact this would have (Moore, 2002). Concealment was described as a survival strategy in a society that lesbian and gay elders experienced as homophobic.

This theme was also evident in some of the lower quality evidence sources. In a personal reflective account on being an LGBTQ+ caregiver Newman (2005) suggested that the legacy of criminalisation and homophobia resulted in unique experiences for lesbian and gay carers of PLwD. He suggested that the protective strategies they had developed were put at risk when dementia necessitated them interacting with health and social care. This was evident in the description of a case study of a gay man with dementia who found questioning regarding his sexuality and sexual behaviour intrusive and insensitive, experiencing anger at losing ownership over his disclosure decisions after health professionals “outed” him in his medical notes (Ward, 2000).

Reflecting on a series of four case studies of LGBTQ+ older people, two of whom were diagnosed with dementia, Duffy & Healy (2014) noted that there were differing levels of “out”, with the oldest older people most at risk of invisibility to service providers with regards to their sexual identity. In a personal reflective piece, Archibald (2006) suggested that the subtleties involved in disclosure were dependent on how “out” the PLwD is with whom and when. She describes the act of balancing the discrimination that can be associated with sexuality disclosure with the need for identity. Of note, for some, dementia removed the opportunity to make choices about disclosure of gender/sexual identity resulting in PLwD (and people in their lives) being outed in a way that may have not occurred previously (Barrett et al., 2015; Duffy & Healy, 2014).

Furthermore, in a study sampling LGBTQ+ PLwD, LGBTQ+ caregivers and healthcare professionals caring for LGBTQ+ PLwD, Barrett et al., (2015) reported that the bodies of transgender PLwD told the story of their gender history, with reliance on care providers removing the choice to disclose this information.

Protective role of partner/family of choice

The key role of partners and family of choice in navigating the experience of dementia, and consequential interactions with health and social care systems, was evident in three of the higher quality studies sampling LGBTQ+ PLwD and LGBTQ+ caregivers (Barrett et al., 2015; McParland & Camic, 2018; Price, 2011). This was also reflected in a lower quality study with lesbian and gay caregivers of LGBTQ+ PLwD (Moore, 2002) and reflective essay by a lesbian woman who care for her wife when she developed dementia (Dykewomon, 2018). Intimate relationships provided safe spaces where sexual and gender identities were valued, and personhood was maintained. They offered emotional support and acted as buffers and protection from discrimination and homophobia (Barrett et al., 2015; McParland & Camic, 2018; Moore, 2002).

For LGBTQ+ caregivers, family of choice provided a carefully constructed care system to meet the support needs of caregivers, many of whom experienced complex relationships with their family of origin. Price (2011) described the strength of lesbian communal living and community networks which often incorporated support from friends and ex-partners. This was also outlined in a reflective essay, where

Dykewomon (2018) described her experience of needing to rely strongly on lesbian friendship networks to make sense of her belief systems earlier in life and the importance of this network to manage caring for her partner when she developed dementia.

4.4.3.3 Theme 3: Characteristics of culturally competent dementia care

Safe spaces that enable expression of sexual/gender identity

Given repeated experiences of marginalisation and stigmatisation associated with their sexual/gender identity, safety in dementia care was key. In a study sampling LGBTQ+ PLwD and their caregivers, McParland & Camic (2018) conceptualised 'safety signals' as messages others sent to LGBTQ+ people affected by dementia relating to how safe sexual identity disclosure would be. These were considered verbal or non-verbal signs of acceptance of same sex relationships.

Whilst the course of dementia is progressive, some studies sampling LGBTQ+ caregivers and health professionals caring for LGBTQ PLwD suggested that sexuality and gender identity remained constant and was not lost (Barrett et al., 2015; McParland & Camic, 2018). Another lower quality study sampling transgender older people identified participants' desire for transgender dementia care to support and facilitate expression of gender and sexual identity in a respectful and dignified way in response to cognitive and functional decline (Page et al., 2016).

Connecting with other LGBTQ+ people cultivated safety. LGBTQ+ adults considering their future care needs cited the importance of connection with other LGBTQ+ adults and believed that having openly LGBTQ+ staff members would increase their sense of safety in residential care (Putney et al., 2018). The role of lesbian and gay specialist provision was discussed by some lesbian and gay carers of PLwD as having value through a shared culture and understanding (Price, 2012). Price (2012) suggested that this related to broader concerns about identity and sense of self being undermined. Participants in another study suggested an overall preference for LGBTQ+ inclusive rather than exclusive environments (Putney et al., 2018).

This was also reflected in lower quality evidence sources. A reflective article written by a gay man reflecting on caring for his partner outlined how a lesbian and gay carers' network facilitated a sense of being “equally different” through peer support (Newman, 2005). Another reflective article reported the value of finding a residential care home that supported a gay couple's relationship, meaning that gay friends felt comfortable to visit. Conversely, another case study described a gay man's distress in a care home where he was separated from other gay men (Duffy & Healy, 2014).

Enhancing Visibility

As previously highlighted, many LGBTQ+ people affected by dementia experienced their sexual/gender identity as rendered invisible in health and social care settings. Based on their findings, some higher quality qualitative studies sampling LGBTQ+ PLwD and LGBTQ+ people considering their future care needs concluded that services should signal safety through visual messages of inclusion (e.g. representations of non-heterosexual couples), given the legacy of homophobia and cognitive challenges of dementia (McParland & Camic, 2018; Price, 2012; Putney et al., 2018). Further case studies of gay men living with dementia (Duffy & Healy, 2014), opinion pieces by academics and a gay man caring for his partner (Knocker, 2006; Newman, 2005) and implications for practice identified at a multi-stakeholder event with health professionals and LGBTQ+ people (Monks & Shaw, 2017) supported this conclusion. Monks and Shaw (2017) and Knocker (2006) (who identifies as a dementia researcher and lesbian) also suggested changes to documentation and language to recognise non-heterosexual family structures.

Support for caregivers/family of choice

Papers sampling LGBTQ+ primary caregivers/family of choice demonstrated difficulties in their relationship to the PLwD being recognised and the implications this had for their own wellbeing. Partners/family of choice reported being treated differently to heterosexual couples, leading to experiences of loneliness and isolation, with little support available as their role in the relationship changed as dementia progressed (Barrett et al., 2015; Constable, 2011; McParland & Camic, 2018; Moore, 2002).

Some also expressed a desire for signposting for support after their loved one had died (Constable, 2011; Meadows et al., 1999).

Role of policy, legislation and governance

Some papers (ranging in quality) sampling LGBTQ+ caregivers and professionals working with LGBTQ+ PLwD highlighted the difficulties that arose when the wishes of the next of kin appeared to conflict with the wishes of the PLwD. This occurred in a case study whereby a transgender woman living with dementia was deemed to have lost capacity to make decisions with regards to expression of their gender identity (Marshall et al., 2015). It was also evident that governance/legal processes did not recognise the status of family of origin/same sex partners in papers of varying quality sampling LGBTQ+ caregivers/ care staff supporting LGBTQ+ PLwD (Constable, 2011; Meadows et al., 1999; Moore, 2002; Newman, 2005; Price, 2010; Ward et al., 2005; Ward, 2000).

The importance of social workers being familiar with legal processes and the rights of LGBTQ+ older people was highlighted in one paper reporting two case studies of gay men living with dementia, suggesting that family of origin should not be assumed as automatic decision makers (Duffy & Healy, 2014). Another paper sampling health professionals and LGBTQ+ people (number not reported) suggested that better governance for care providers is required to recognise non-heterosexual family structures (Monks & Shaw, 2017).

This was evident in two of the higher quality papers sampling LGBTQ+ caregivers (Constable, 2011; Page et al., 2016; Price, 2010), supported with more information from other sources of lower quality.

Role of Professional care staff

Few papers reported the experiences or perspectives of professional care staff. The small number of studies that sampled professional care staff suggest that they may be less comfortable supporting sexual identity/sexual expression in LGBTQ+ PLwD (Di Napoli et al., 2013; Ward et al., 2005). Of note, the study by Di Napoli (2013) was considered poorer quality.

Some qualitative studies sampling LGBTQ caregivers and LGBTQ+ (McParland & Camic, 2018; Price, 2010) and LGBTQ+ people considering their future care needs (Putney et al., 2018) concluded that staff training was required to promote anti-discriminatory and anti-oppressive practice.). This conclusion was also supported in lower quality sources: a reflective article by a dementia researcher (Ward, 2000) and reported findings from a multi-stakeholder event with health professionals and LGBTQ+ people (Monks & Shaw, 2017).

Reflection on synthesis process

The themes were identified through an inductive process of identifying common themes and subthemes across the highest quality studies, searching for similarities and differences. This thematic framework was then applied to lower quality evidence sources. This meant that the synthesis was grounded in findings from the highest quality sources, ensuring it remained robust, whilst incorporating findings from lower quality papers that further elucidated identified themes. This approach balanced the rigour required to maintain a robust review whilst obtaining greater depth and detail regarding some issues from lower quality sources. This is particularly applicable to the findings relating to transgender people living with dementia which would not have been as represented if lower quality sources were omitted from the review. The quality of sources was referred to throughout the synthesis, allowing the reader to contextualise the findings within the potential methodological limitations of the source and thus the validity and generalisability of the findings. The researcher discussed their interpretations of the study findings and process evidence synthesis with the second author and peer researchers in order to consider their own response to the data and how it might influence the synthesis.

4.5 Discussion

4.5.1 Overview of findings

This review, to our knowledge, is the first to systematically identify, quality appraise and synthesise accounts published in electronic databases detailing the experiences of LGBTQ+ people affected by dementia, and their caregivers. The data was from heterogeneous sources, with varying levels of methodological quality. It synthesised multiple experiences and perspectives of LGBTQ+ people affected by dementia in different ways: LGBTQ+ people considering what care they would require should they develop dementia in the future; LGBTQ+ people caring for someone living with dementia (who may or may not identify as LGBTQ+); LGBTQ+ PLwD and staff or non-paid caregivers providing care for LGBTQ+ PLwD.

The current study highlights the ongoing paucity of high-quality research relating to the experiences of the aforementioned stakeholders. In an earlier narrative synthesis McGovern (2014) characterised this (heterogeneous) population as “the forgotten”. The findings from this study demonstrate this is still the case at present. Only 11 papers using a methodology suitable for appraisal with formal quality appraisal tools were eligible for inclusion in the review. Eight of these were appraised to be of sufficient methodological quality to be confident in the validity of the findings. Of note, three of these papers reported different findings from the same dataset (Price, 2010, 2011, 2012). The author noted that recruitment of 21 participants took four years, and the sample was predominantly comprised of white, middle class politically engaged individuals. Most of the available data represents the perspectives of LGBTQ+ caregivers of PLwD, most of whom identified as lesbian or gay. Bisexual and transgender participants are underrepresented throughout the current evidence base. There were very few studies that sampled LGBTQ+ PLwD or staff caring for LGBTQ+ PLwD.

The current study found commonalities across LGBTQ+ PLwD / LGBTQ+ people caring for someone with dementia/ LGBTQ+ people considering their future dementia care needs. Stakeholders from these groups consistently reported actual or anticipated discrimination in health and social care settings from professional caregivers and other residents. Sexual/gender identities were frequently not acknowledged and non-heteronormative family/support structures were not recognised. The act of caring for a loved one (who openly identified as LGBTQ+ or otherwise) resulted in LGBTQ+ people without dementia considering what their care would be like if they were to go on to develop the condition themselves. For many this was a confronting experience, with LGBTQ+ people fearing that their sexuality would be rendered invisible or lead to discriminatory care.These findings support the same conclusions drawn in previous, less methodologically robust narrative literature reviews in this area (Cousins et al., 2020; Fredriksen-Goldsen, 2016; Moreno et al., 2017; Price, 2008; Westwood, 2016b). They also reflect shared concerns identified in systematic reviews and other studies examining the wider experiences of LGBTQ+ older people (without dementia) interfacing with different health and social care settings (Addis et al., 2009; Caceres et al., 2020; Kneale et al., 2019; Mahieu et al., 2019; McCann & Brown, 2019; Stinchcombe et al., 2017; Westwood, 2016).

Another finding in line with the extant literature was the protective nature of partners/ family of choice. These were carefully curated networks, often incorporating partners and other LGBTQ+ people, offering safe spaces to express sexual and gender identities. Again, this was identified as an important factor by LGBTQ+ people considering their future dementia care needs, LGBTQ+ people caring for someone living with dementia and LGBTQ+ PLwD. Anticipated/actual separation from family of choice/wider LGBTQ+ community was a source of distress. Again, this is a well-established finding within the wider literature (Caceres et al., 2020; Mahieu et al., 2019) and supports conclusions from previous less methodologically robust reviews in this area (Cousins et al., 2020; Fredriksen-Goldsen, 2016; Moreno et al., 2017; Price, 2008; Westwood, 2016b). Of note, the role of partners/family of choice appeared to be even more significant for LGBTQ+ living with dementia than other conditions. Cognitive and functional impairment associated with dementia had implications for the individual being able to advocate for their wishes, and placed them at risk of having choices made by their family of origin that were not aligned with their values or wishes (Constable, 2011; Barrett et al., 2015; Marshall et al., 2015). This differentiates LGBTQ+ people living with dementia from peers without a cognitive impairment, as the ability to choose non-disclosure as a safety strategy is removed.

The complexity of issues around disclosure of sexual/gender identity has been documented in previous studies and less rigorous literature reviews (Cousins et al., 2020; Fredriksen-Goldsen, 2016; Moreno et al., 2017; Price, 2008; Westwood, 2016b). This review supports the conclusions drawn. As previously outlined, LGBTQ+ older adults have lived through considerable marginalisation, discrimination and pathologisation for their sexual identity (Fredriksen-Goldsen, 2016). For many, this necessitated concealment of sexual identity as a safety strategy (Moore, 2002;

Newman, 2005) and as previously outlined, many LGBTQ+ older people considering their future care needs suggested they may utilise this strategy to ensure safety in residential care (Caceres et al., 2020; Mahieu et al., 2019). The studies included in this review highlighted the complexity of this issue for LGBTQ+ people affected by dementia For many, dementia and the associated cognitive impairment removed the choice of concealment, whilst also recognising the distress associated with having to conceal one's sexual identity. Requiring dementia care often "outed" participants through exposure to health and social care practitioners in their homes. Other incidences of LGBTQ+ people living with dementia outing themselves or others, in a way they previously would not have, were documented (Barrett et al., 2015; Duffy & Healy, 2014; McParland & Camic, 2018).

The present review extended the findings to provide preliminary insight, predominantly from lower quality study designs, relating to gender identity and dementia. Evidence in the current review, notably primarily from case studies, suggested that transgender people living with dementia had specific, additional care needs that appear to differ from LGB people living with dementia. Two case studies (Marshall et al., 2015; O'Kelly et al., 2015) and a qualitative paper interviewing health professionals who had provided care to LGB and transgender PLwD (Barrett et al., 2015) described incidences where the PLwD experienced distress and confusion regarding their assumed gender identity (Marshall et al., 2015; O'Kelly et al., 2015). This manifested as fluidity in their gender identity that was not previously present, in line with cognitive impairment, and was a source of distress for the PLwD and those in the system around them. In some cases, the family of origin made decisions relating to their relative's gender expression that were incongruent with the person's relative's life history and values (Barrett et al., 2015; Marshall et al., 2015).

There was very limited evidence exploring the experiences and perspectives of staff providing care for LGBTQ+ PLwD, with only one study solely sampling care home staff. Therefore, the conclusions that can be drawn about the knowledge, needs and experiences of staff providing care for LGBTQ+ PLwD is limited. From the included case studies, it was apparent that care home staff were challenged by working with someone with dementia who did not consistently identify with a binary gender identity. This is noteworthy, given that care home staff are likely to be accustomed to working with other aspects of a person with dementia that are fluid, such as their memory and temporal orientation. This begs the question of why gender fluidity poses such a challenge? The more established literature on expression of (primarily heterosexual) sexuality in older people/people with dementia, implicates organisational culture, societal attitudes, concepts of care and staff attitudes as contributing factors to facilitation (or restriction) of sexual expression (King et al., 2019). King et al. (2019) posit that organisational culture is key, influencing how staff provide care and the extent to which sexuality is perceived as a right within organisational practices and beliefs. Residential care staff attitudes can result in people living with dementia's right to sexual expression being neglected or discouraged (Bauer et al., 2013; Tarzia et al., 2012). As identified in this review, there is evidence of care home staff reporting more negative attitudes towards same sex sexual expression than in heterosexual residents (Di Napoli et al., 2013). This may also be the case with regards to residents' expressions of gender fluidity which were influenced by cognitive impairment. Further exploration of this phenomenon is required to effectively support staff to provide gender affirmative dementia care. This is particularly important, given that future cohorts of older people may increasingly present with such difficulties, given the shift in societal attitudes and increasing numbers of people openly identifying as LGBTQ+, as evidenced in the most recent population level surveys (Office for National Statistics, 2018).

The perspectives of transgender and intersex people living with dementia are not represented in the current review beyond case studies, which are written from the perspective of care providers. Only two studies sampled transgender participants; 3 out of 50 older adults considering their future care needs identified as transgender (Putney et al., 2018) and transgender older adults considering their future care needs (sample size was not reported) (Page et al., 2016). They wished to be treated with dignity and respect, and to be supported to maintain their gender identity should they develop dementia. Previous research conducted with transgender participants regarding ageing and end of life care identified that transgender older people fear finding themselves in situations described in the case studies included in this review. Some participants considered suicide, which they conceptualised as euthanasia, to avoid their wishes not being respected (Witten, 2014). A scoping review of the end-of-life care needs of LGBTQ+ older people noted that transgender individuals have specific health needs (including hormone therapy), however many of the reviewed studies did not represent transgender individuals to the same extent as LG participants (Stinchcombe et al., 2017). The authors cautioned against interpreting findings from studies sampling lesbian and gay participants as representative of the experiences of bisexual or transgender people. In line with this, Westwood (2016) highlighted the importance of ideas of intersectionality, and questioned if it is helpful to consider dementia care in relation to a single ‘LGBT’ identity. The findings of the current review support this, highlighting the need for future work with different sections of the wider LGBTQ+ community, and the implications of the different intersections they experience and how this impacts their dementia care journey. To date, the evidence base lacks the perspectives and experiences of LGBTQ+ PLwD/LGBTQ+ people caring for someone living with dementia who are not middle class, white, predominantly highly educated and politically engaged.

4.5.2 Implications for practice

The overarching dementia care needs of LGBTQ+ people identified in this review included: safe spaces that facilitate expression of sexual and gender identities, enabling connection with partners and family of choice and members of the wider LGBTQ+ community; visual messages signalling safety and inclusion (including incorporating non-heterosexual couples in residential care brochures; acknowledging non-heterosexual partner/family structures in the broadest sense, in documentation and language used; flags and other signs that demonstrate LGBTQ+ inclusivity). This supports the findings of previous research with LGBTQ+ older adults that explored factors signalling a welcoming healthcare environment for LGBTQ+ people (Croghan et al., 2015). From the limited available evidence, transgender PLwD may require support to manage any distress that emerges from cognitive decline resulting in them experiencing confusion regarding their gender identity, which may fluctuate as their dementia progresses. This group of participants appeared particularly vulnerable to decisions being made about their care (including gender expression) that were not in line with how they had expressed their gender identity throughout their life. Health and social care staff have an important role to play in ensuring the dementia care transgender PLwD receive reflects the wishes of the PLwD. These may conflict with that of the family of origin. There was not sufficient evidence to draw reliable conclusions about any differences in dementia care needs between other sections of the communities that fall under the LGBTQ+ umbrella.It follows that signals of safety and inclusion need to be accompanied with the provision of culturally sensitive care. Many studies included in this review concluded that training was required to equip health and social care staff with the skills to practice in culturally competent ways that address the needs of LGBTQ+ affected by dementia. A recent systematic review of educational interventions seeking to educate health and social care staff on the needs of LGBTQ+ older people concluded that there was evidence of increased knowledge but less impact on attitudes and skills (Jurček et al., 2021). Further research with more robust study designs is required to identify the best way to equip staff with the necessary skills. Building on core competencies for practice with LGBTQ+ older people and their families, based on extant literature at the time, Fredriksen-Goldsen et al. (2018) identified ten key competencies required by staff working with LGBTQ+ older people with cognitive impairment/dementia which encapsulate the findings of the current review. Some of these include: critically evaluating personal attitudes towards LGBTQ+ older people and dementia and understand their influence; understanding the historical, cultural and social contexts that negatively influence LGBTQ+ people living with dementia; supporting caregivers and being able to address needs and changes in relationships with the person with dementia, partners, caregivers and others; understanding ways that services can create welcoming, affirmative environments for LGBTQ+ PLwD dementia, and understanding ways local laws address the needs of LGBTQ+ older people and their caregivers. Emerging evidence also demonstrates that changes are required at all organisational levels, accompanying staff training, to promote inclusive practice towards LGBTQ+ older people (Lecompte et al., 2020).

4.5.3 Implications for research

The evidence-base regarding the experiences of LGBTQ+ people affected by dementia is small. The perspectives of LGBTQ+ people living with dementia were not prominent in this review. Most of the included literature was from the perspective of people in an informal caregiving role to the person living with dementia. This review only identified two studies (Barrett et al., 2015; McParland & Camic, 2018) that included the perspectives of LGBTQ+ people living with dementia. Whilst it is of great importance to represent caregivers' perspectives, documenting the experiences of LGBTQ+ people living with dementia is necessary. Future research should seek to include the perspectives of LGBTQ+ people living with dementia both through direct participation in research studies, and involvement in research design and governance through coproduction models.

Older adults identifying as LGBTQ+ are not a homogeneous group. This review highlighted some evidence to suggest that the experiences and dementia care needs of transgender people with dementia differ from cisgender people. A recent position paper outlining a research agenda to advance research involving LGBTQ+ older people in the UK identified research addressing LGBTQ+ diversity and intersectionality as a research priority (Westwood et al., 2020). The authors assert that there has been little comparison of health experiences amongst interacting and intersecting social differences including age, gender class and ethnicity. They argue purposive sampling would provide greater insight into diversity and intersectionality, allowing the development of targeted health interventions for LGBTQ+ subgroups. Furthermore, Westwood et al. (2020) assert that there is a lack of large-scale quantitative data on LGBTQ+ older peoples' health, and that larger datasets are required to measure health inequalities and develop and target interventions. This is in-keeping with the findings of the current review; all of the identified evidence relating to LGBTQ+ PLwD was derived from small samples, with three of the ten included qualitative studies reporting findings derived from the same sample of 21 lesbian and gay carers of PLwD.

There is very little evidence regarding health and social care staff perceptions and experiences of providing care for LGBTQ+ PLwD, and this review did not identify any studies evaluating training staff to support LGBTQ+ affected by dementia. Research evaluating both if/how healthcare service policies, procedures and practices are LGBTQ+ inclusive, and interventions to develop healthcare staff competencies was another research priority identified by Westwood et al. (2020) that is supported by the findings of this review.

4.5.4 Limitations

There are some limitations to this review. Only papers written in English language were included, potentially omitting papers with relevant findings written in other languages. The included papers were of varying methodological quality. A number were first person reflective accounts or case studies which potentially limits the representativeness and generalisability of the findings. The synthesis was dependent on the authors' interpretations of their findings. Given the reporting and methodological quality of some of the papers it is not possible to determine how representative of the datasets these were.

The searches, selection of included studies, data extraction and quality appraisal were performed one author. Had resources been available, two authors independently completing this task would have reduced the likelihood of bias influencing the process.

Furthermore, three of the included qualitative papers that formed the initial thematic framework that was then cross-checked with other lower quality studies to produce the evidence synthesis reported different themes derived from the same dataset (Price 2010, 2011, 2012). The author noted that these participants were primarily highly educated, politically active and urban dwelling and subsequently more able to challenge oppressive practice. More generally, most papers reporting location were from the UK, USA and Australia. The findings may therefore lack socio-demographic and cultural diversity, limiting the generalisability of the findings.

Finally, it is possible that other relevant papers (particularly relating to LGBTQ+ older peoples' anticipated dementia care needs) were not identified if 'dementia' was not included as a keyword for the article. To negate against this, the author was overly inclusive at the title and abstract screening stage, however it is possible relevant papers were missed.

4.6 Conclusion

This systematic review used a robust methodology to identify and critically evaluate the current literature relating to the experiences of LGBTQ+ people affected by dementia and their dementia care needs. The current evidence base is small. LGBTQ+ people affected by dementia experience unique challenges and have specific care needs that vary within the LGBTQ+ population. Further research, informed by principles of intersectionality, is required.

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5 Empirical Paper

An evaluation of the implementation and routine clinical effectiveness of the Newcastle Model for behaviours that challenge in dementia

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5.1 Abstract

Background

Behaviours that challenge (BtC) such as physical and verbal aggression, are common and displayed by most people living with dementia to some extent. They are associated with poorer quality of life in people living with dementia (PLwD), caregiver burden and distress. The Newcastle Model (TNM) is an intensive individualised formulation driven intervention. It conceptualises BtC as the expression of unmet needs in PLwD. Specialist practitioners facilitate the development and implementation of an intervention plan to address unmet needs in collaboration with care home staff. This study aimed to a) evaluate the effectiveness of the routine clinical use of TNM in behaviour support teams outwith the model developers, and b) compare the effectiveness of standard and shortened delivery versions of TNM.

Method

Retrospective analysis of routinely collected clinical data from two specialist (BSS-A and BSS-B) behaviour support services that have adopted TNM was conducted. The Cohen Mansfield Agitation Inventory (CMAI), a measure of BtC in PLwD, was administered at baseline and post-intervention. Mixed two way ANOVAs were used to analyse the difference within participants CMAI scores between behaviour support services, and different delivery formats of TNM.

Results

210 participants were included:143 in BSS-A and 67 in BSS-B. There was a significant reduction in CMAI scores post intervention ($p< .05$) in both services, across all delivery formats. There was no difference in patient outcome (p>.05) when BSS-A was

following the standard NCM protocol (mean delivery duration 23.2 weeks) or the condensed version (mean delivery duration 11.7 weeks).

Conclusion

TNM, delivered by specialist practitioners, is an effective intervention for reducing BtC in PLwD. The model has ecological validity, with significant reductions in BtC achieved when delivered by two different behaviour support teams outwith that of the TNM developers. A condensed model protocol may promote fidelity to the model and reduce intervention duration whilst maintaining clinical effectiveness.

Keywords: Dementia; challenging behaviour; Newcastle Model; psychological formulation

5.2 Introduction

5.2.1 Dementia

Dementia is an umbrella term used to describe a range of conditions characterised by progressive loss of brain cells and associated deterioration in cognitive function above changes expected as part of an ageing process (James & Jackman, 2016; World Health Organisation, 2019). Dementia affects memory, thinking, orientation, comprehension, the ability to learn new information, calculation, language and judgement. This process is commonly experienced alongside impairment in emotional control, social behaviour, and motivation (WHO, 2019). Dementia has a significant impact on the individual affected and those in the system around them.

The WHO (2019) estimate that between 5-8% of the general population aged 60+ have dementia. In the first publication of estimated prevalence of dementia in Scotland, the Scottish Government (2016) estimated that 16,712 people were newly diagnosed with dementia in 2014 and that this number was estimated to increase by 17% to 19,473 by 2020. The MODEM study (Wittenberg, Hu, Barraza-Araiza & Rehill, 2019) estimated that there are almost 885,000 people with dementia in the UK, 46,800 of whom live in Scotland. In line with the ageing population and an increase in lifespan, the total number of people living with dementia in Scotland in 2040 is expected to rise to 115, 200 representing a 74% change.

Dementia is frequently associated with behaviours such as hitting, grabbing, kicking, spitting, shouting, physical sexual assault, verbal sexual advances, pacing, following others, repetitive questions/requests for help, apathy and urinating in inappropriate places (James & Jackman, 2017). There is considerable debate surrounding terminology, and the implications of the terms used, to describe people living with dementia (PLwD) experiencing distress. Finkel et al., (1997) coined the term "behavioural and psychological symptoms of dementia (BPSD) to describe "symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia". This typically describes: psychosis (delusions/ hallucinations), agitation, aggression, depression, anxiety, apathy, disinhibition, irritability, motor disturbances and disturbed eating and night time behaviours (Kales et al., 2015).

However, it has been argued that describing distressed behaviour as "BPSD" or "challenging behaviour" neglects the social context expressions of stress and distress are situated in. Behaviours that Challenge (BtC) is an alternative term, defined as an expression of distress by the PLwD (or those in the environment around them) that is underpinned by unmet physical or psychological needs. BtC can be an attempt by the PLwD to maintain their identity and wellbeing or to alleviate discomfort or distress (Bird, & Moniz-Cook, 2008; Moniz-Cook & James, 2017). James and Jackman (2017) highlight that BtC are not unique to PLwD and argue that they should not be pathologised and viewed within a medical model, rather, investigated and understood in the context of the current situation and the PLwD's life history. They note that BtC are a social construct, and thus the perceptions and tolerance of those witnessing the BtC will vary (James, 2011; James and Jackman, 2016).

The majority of residents living in nursing/care homes have dementia, with prevalence rates in UK nursing/care homes estimated to be between 55% and 91% (Stewart et al., 2014). The prevalence of BtC in PLwD is high, and are displayed by most PLwD to some extent (Savva et al., 2009). It is estimated that more than 90% of PLwD display at least one BtC throughout the course of living with dementia (Azermai, 2015; C. G.

Ballard et al., 2009; Lyketsos, 2007). BtC have significant implications for PLwD and those in the systems surrounding them. Experiencing agitation is associated with lower quality of life in PLwD living in care homes (Livingston et al., 2017). Research has demonstrated that BtC are associated with strain, burnout and distress in health and social care professionals (Brodaty et al., 2002; Etters et al., 2008; Holst & Skär, 2017; Miyamoto et al., 2010; Scott et al., 2011). BtC are also correlated with placement breakdown, institutionalization and death in PLwD, and stress and distress in informal carers/relatives of PLwD (Baharudin et al., 2019; Black & Almeida, 2004; Finkel et al., 1997; Okura et al., 2011; Okura & Langa, 2011; Scarmeas et al., 2005, 2007; Yaffe et al., 2002).

5.2.2 Formulation-led Interventions for BtC

The National Institute for Health and Care Excellence (2018) guidelines state that psychosocial and environmental interventions should be offered as first line treatment for BtC. There is limited evidence for the efficacy of pharmacological treatments for BtC (Tible et al., 2017). Antipsychotic medication should only be offered if PLwD are at risk of harming themselves or others, or they are experiencing agitation, hallucinations or delusions that are causing them severe distress. However specific guidance relating to the theory, rationale and practicalities of alternatives to pharmacological intervention is not provided (Medea et al., 2020). Medea et al. (2020) argue such lack of clarity may have unintentionally led to use of medication as a first line response to BtC.

In practice, antipsychotic medication is frequently used as a first line response to BtC. The risks associated with antipsychotic medication use in PLwD was highlighted by the work of Banerjee (2009) who concluded that that an additional 1,800 deaths a year above that expected in this population were attributable to antipsychotic use. Since the report was published there have been several initiatives to reduce antipsychotic use through preventative strategies, safer prescribing and promote the use of non-pharmacological interventions in response to distressed behaviours (Brechin et al., 2013).

The British Psychological Society (Brechin et al., 2013) outlined a stepped care model (figure 4) describing different levels of assessment and treatment input required in response to BtC. Individualised formulation-led interventions delivered by specialist practitioners in conjunction with carers/care staff are recommended for more complex presentations of BtC.

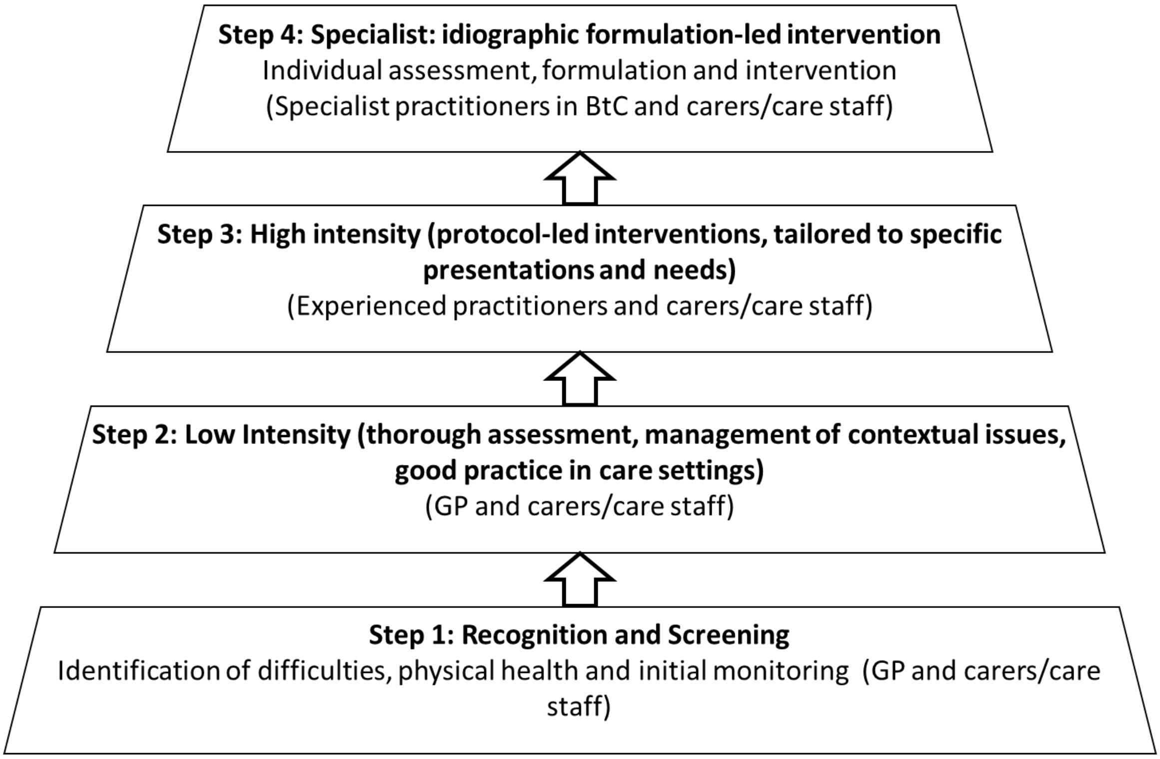

Figure 4: Stepped care model for responding to BtC (Brechin et al., 2013).

There is an emerging evidence base for the effectiveness of formulation-led interventions in response to BtC in dementia. Bird et al. (2009) suggest that routinely applied standardised psychosocial/pharmacological treatments often do not account for the multiple causal factors both underlying BtC and resulting in behaviours being perceived as ‘challenging’. The use of formulation-led interventions in dementia care is increasing (James, Mahesh, et al., 2020). Scotland’s Dementia Strategy (Scottish Government, 2017) and ‘The Matrix’ (2015) recommend psychological approaches in response to BtC in dementia, particularly formulation-led interventions that identify the individual needs of the PLwD.

An earlier Cochrane review of functional analysis-based interventions for BtC identified that positive effects were evident post intervention in relation to frequency of BtC and caregiver reaction, however these were not maintained at follow up (Moniz-Cook et al., 2012). The authors concluded that whilst functional analysis based interventions showed promise in dementia care, there was not enough evidence to draw conclusions about efficacy. More recently Holle et al. (2017) conducted an integrative systematic review describing and examining individualised formulation led-interventions for managing BtC in people living with dementia. The review identified 37 papers, 13 of which provided empirical data. Fourteen different types of individualised formulation led interventions were identified, eight of which were designed specifically for use in nursing/residential homes. The included interventions were similar in structure but varied in content and emphasis. The majority of approaches suggested three categories of factors result in BtC: a) patient related factors (physical/mental health difficulties), b) environmental factors (e.g. overstimulation) and c) caregiver related factors (e.g. relationship, communication style and care practices). Most interventions focused on the PLwD and environmental factors. Most interventions were comprised of: a) analysis of behaviour and/or analysis of causes of behaviour and b) development/introduction of treatments. Six of the included studies measured the effect of the intervention of the PLwD. Holle et al. (2017) concluded that the effects of interventions on PLwD were diverse, with only half of the studies demonstrating a significant reduction in BtC compared with a control group. In response to this review, Medea et al., (2020) conducted a further literature review seeking to update the findings. They posit that five formulation-led interventions were omitted from the original review and identify five further examples that have since been developed. They also argue that the original review misattributed The Newcastle Model (described below), arguing that it did not reflect changes to its content over time.

5.2.3 The Newcastle Model

The Newcastle Model (TNM) (James et al., 2006) is a 14-week, high intensity idiosyncratic formulation-led approach incorporating individualised assessment, formulation and intervention provided by specialist teams for use in 24-hour care settings. This sits within step 4 of the stepped care model outlined in figure 4. TNM is a holistic model, viewing BtC as expressions of unmet needs. It posits that this occurs as the result of the complex interplay between the PLwD’s life story, personality, cognitive abilities, current or past mental health difficulties, physical health, medication and the social environment (see figure 5). It is a systemic behavioural model, conceptualising caregiver’s responses to BtC as key factors in the maintenance and resolution of BtC (James & Jackman, 2017). The model draws upon components from several theoretical frameworks including Kitwood’s person centred conceptualisation of dementia (Kitwood, 1997), the unmet needs model (Algase et al., 1996; Cohen-Mansfield, 2000) and Cognitive Behavioural Therapy (Beck, 1976).

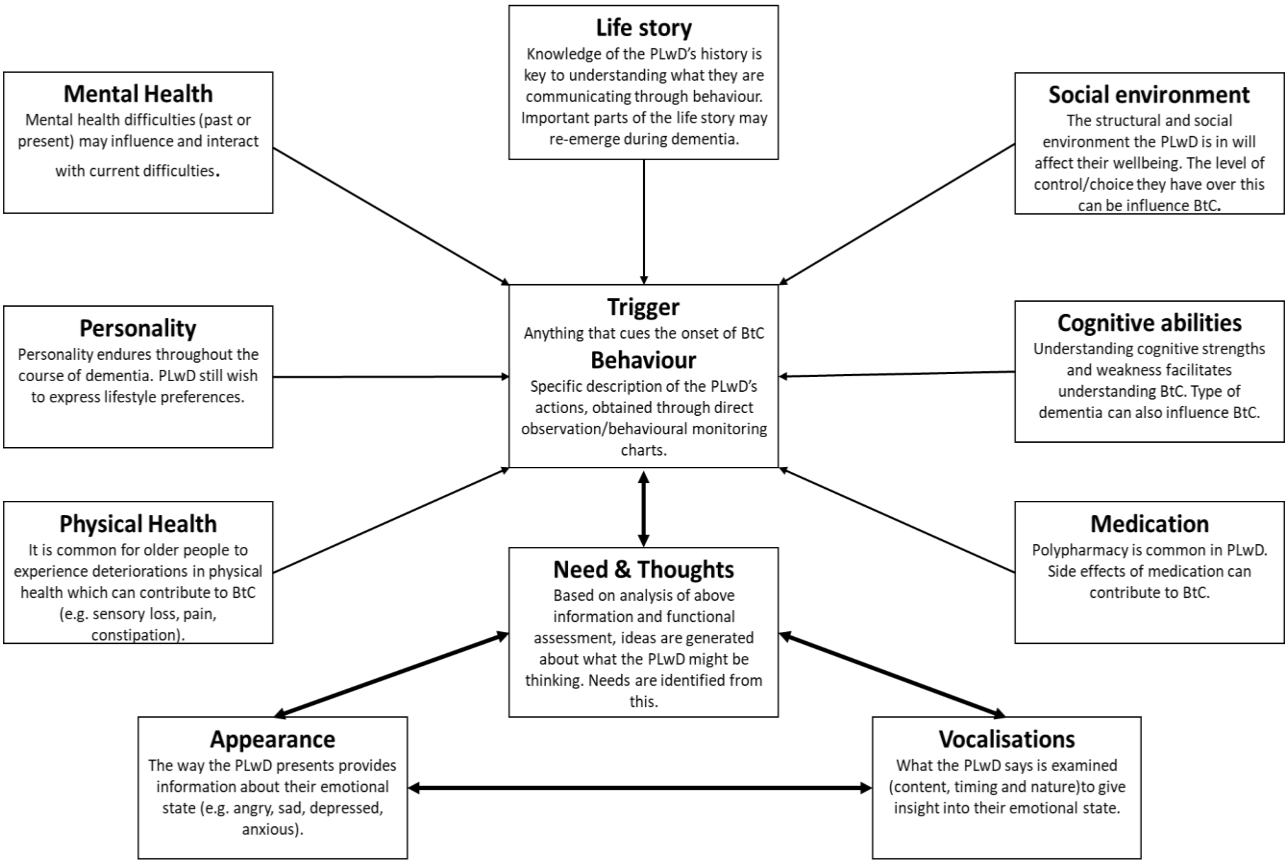

Figure 5: Overview of the Newcastle Model formulation adapted from James & Jackman (2017)

The most intensive work occurs in the first five weeks which incorporates information gathering from the PLwD, their family and care staff, collaboratively developing a formulation of the PLwD's unmet needs and a personalised intervention plan to address them in an information sharing session (ISS). The clinician remains in contact with the care home staff and PLwD's family for the second half of the programme to ensure that staff are supported to carry out interventions and amend the formulation and planned interventions if necessary. A more detailed description of how the intervention is delivered in practice is provided in table 3.

A recent study examining UK clinicians' views on use of individual formulation-led approaches in response to BtC found that TNM was the most frequently used formulation-led intervention (James, Mahesh, et al., 2020). Of the 378 respondents, 76% reported using formulations to inform their interventions. Half of those reported using TNM approach.

There is preliminary evidence supporting the efficacy of the TNM. Wood-Mitchell et al. (2006) reported a significant reduction in frequency and severity of distressed behaviour in 46 PLwD (Measured by the Neuropsychiatric Inventory Nursing-Home, NPI-NH (Cummings et al., 1994)), and a reduction in caregiver distress in response to TNM being delivered by the team that developed TNM. The audit demonstrated that only 5% of patient referrals to the behaviour support team (between 2005-2006) were admitted to hospital, and 9% were transferred to other care settings. A similar reduction in distressed behaviour and distress in caregivers was reportedly evidenced in an unpublished audit (n=15) from a behaviour support team in West Lothian (Wilson, 2016; as cited in James & Jackman, 2017). Qualitative analysis of survey responses indicated that staff developed a greater understanding of the PLwD and the distress they were experiencing following TNM intervention (Bryony, 2009 as cited in James & Jackman, 2017). A recently published case study described the successful use of TNM to support care home staff manage sexualised behaviours and verbal aggression displayed by a person living with dementia (Rickardsson & Crooks, 2021).

In a recent opinion piece reflecting on the evolution of TNM intervention over the past 21 years, James and Birtles (2020) refers to a cluster RCT involving 12 care homes assessing an intervention (incorporating staff training, facilitated case formulation and supervision from a clinical psychologist) as TNM. At 12 month follow up there was a significant reduction in psychotropic medication use in care homes that had received the intervention, but no significant difference in BtC (measured by the CMAI) between the intervention and control conditions (Fossey et al., 2006).

5.2.4 Rationale for the current study

To date, we were not able to identify any other published studies evaluating the routine clinical implementation of the Newcastle Model out with that of the intervention developers. In a recent paper James & Birtles (2020) state that the model has undergone iterations and revisions over the past two decades that it has been in use in various formats. We sought to evaluate the effectiveness of the recent routine implementation of the model in two independent behaviour support services.

NHS Lothian has behavioural support services which provide specialist support for people with a diagnosis of dementia living in care homes. All teams have adopted TNM to assess and respond to distressed behaviours in patients referred to the service. The primary critique of TNM is the length and intensive nature of the approach (James & Jackman, 2017). Jackman and James (2017) report that 30-35% of patients did not require the full 14-week intervention programme. Thus one of the behaviour support teams in NHS Lothian began trialling a condensed 6-9-week version of TNM in October 2018. This was developed by clinicians in the behaviour support service as part of a quality improvement initiative. The condensed version aims to deliver the same assessment and intervention model in a shorter timeframe, meaning that the information sharing session to collaboratively create the intervention care plan (normally occurring in weeks 4-5), occurs sooner. The aim of this was to create quicker patient flow within the behavioural support service, with shorter waiting times to receive treatment and intervention for patients and caregivers in distress.

Previous unpublished service evaluations on smaller datasets concluded that there was no difference in patient outcome when TNM was delivered as the shorter condensed delivery format compared to the longer standard delivery format. However these analyses were underpowered, so reliable conclusions about the comparative effectiveness of the condensed delivery format on patient outcome could not be drawn. A sufficient dataset was now available to enable these conclusions to be drawn.

5.2.5 Study Aim

This study used a retrospective analysis of routinely collected clinical data with the aim to evaluate: a) the effectiveness of the routine clinical use of TNM in behaviour support teams outwith the model developers, and b) compare the effectiveness of different service delivery options on patient outcome.

Effectiveness of the intervention was measured by change in the primary outcome measure, the Cohen Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield et al., 1989), a widely used measure of BtC in PLwD in clinical settings and research studies (see section 5.3.5 for further details).

5.2.6 Research Questions

The primary research question guiding this research was:

> *"What is the routine clinical effectiveness of TNM intervention delivered by two specialist behaviour support teams?".*

The secondary research question was:

“What is the impact of a condensed delivery format of TNM on patient outcome?”

It was hypothesised that:

a) There would be a significant reduction in BtC (measured by the disruptiveness and frequency scores on the CMAI) post delivery of TNM intervention compared to baseline pre intervention scores.

b) There would be no difference in patient outcome in standard and condensed delivery formats of TNM intervention.

5.3 Methods

5.3.1 Design

A retrospective study design was used. NHS staff working in behavioural support services in NHS Lothian record clinical data in asset registered databases for audit, service development and research development purposes. Data from 2016 to 2020 was extracted from two databases by two Assistant Psychologists employed in the behavioural support services, with routine access to the data in their clinical role, in accordance with R&D and Caldicott regulations. The data was fully de-identified prior to the researcher receiving it.

5.3.2 Ethics

Ethical approval to access the data and conduct the study was obtained from the NHS Lothian Caldicott Guardian (see Appendix D) and the University of Edinburgh Health in Social Science Research Ethics Committee (see Appendix E). The researcher consulted with the NHS Lothian Ethics Scientific Officer and sought advice regarding whether NHS ethical review was required. They were advised that NHS ethical review would not be required where data is routinely collected for clinical and service evaluation purposes and anonymised to the researcher. Thus, the use of this data assumes that patients provide data to the NHS in the knowledge that it may be used for purposes that are in the public interest, such as evaluating and improving clinical interventions.

5.3.3 Intervention

As previously outlined, the Newcastle Model (James, 2011; James & Jackman, 2017), detailed in table 1 below, was delivered following the standard ‘5 plus 9’ protocol in BSS-A prior to the implementation of a condensed delivery format model. The differences in delivery times are outlined. BSS-B uses the standard ‘5 plus 9’ treatment model.

The intervention was delivered by clinicians in two specialist behaviour support services which are comprised of Mental Health Nurses, Trainee Clinical Psychologists, Assistant Psychologists and led by a Clinical Psychologist. Each clinician manages a small caseload and is supervised by a Clinical Psychologist. The two services cover different regions of the NHS Lothian catchment area.

Table 3: Description of The Newcastle Model approach (original and BSS-A modified condensed version)

Description of intervention Phase		**Standard ‘5 plus 9’ NCBT treatment Model (James, 2011; James & Jackman 2017)**	**Condensed Model (BSS-A)**
		Duration	
Intensive treatment phase	Begin assessment process. Ensure BtC has not arisen from acute infection/transient difficulty (e.g. pain from fall, constipation, delirium). Resume contact with care home staff, gather further information to gain detailed account of difficulties (interview staff, PLwD, care home observations, case file review). Detailed analysis of behaviour through behaviour monitoring charts. Pre-treatment outcome measure administered. Information collected analysed, greater clarification reached. Family of PLwD contacted (if this has not already occurred).	Weeks 1-5	Weeks 1-3
Information Sharing Session	Specific session (duration 1 hour) facilitated by therapist with care home staff and family member of PLwD. Aim is to develop shared understanding of BtC situated in wider context. This process allows staff to speculate on the unmet needs of the PLwD and identify interventions to address them. It is key that staff develop the intervention to promote ownership of the treatment process (James & Jackman, 2017).	Weeks 4-5	Weeks 3-4
Tweaking and support phase	Therapist assimilates formulation and agreed care plan. Care home staff asked to sign to assess how well information is disseminated.	Weeks 6 onwards	Weeks 5-9

Ongoing staff support: visits to care home to ensure interventions are carried out consistently. Modelling, teaching and advice provided by therapist. Formulation and interventions amended if necessary.	Weeks 7-11
Discharge arranged unless exceptional reasons for continuing input. Discharge interview and post-intervention outcome measure completed.	Weeks 12-14

Adapted from James and Jackman (2017).

5.3.4 Participants

Data was included from participants who: a) had received a diagnosis of dementia and were living in a nursing/residential home within the NHS Lothian health board area; b) had received TNM intervention (standard or condensed format) in response to behaviours that challenge delivered by an NHS Lothian behavioural support team, and c) there were pre and post intervention outcome measures completed.

5.3.5 Measures

The primary outcome measure was the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield et al., 1989) a 29-item outcome measure used to measure agitated behaviours (see appendix E for a list of the behaviours). It is completed by a proxy, typically by a care staff member who knows the PLwD well. A range of agitated behaviours are rated by frequency of the occurrence of the behaviour (on a likert scale of 1-7; ranging from never to several times an hour) and disruptiveness to staff, other residents and family members on a likert scale of 1-5 (not at all to extremely) during the past two weeks. Total scores for ***frequency*** and ***disruptiveness*** of agitated behaviours occurring are calculated by summing the responses to each of the 29 items. Higher total scores reflect greater severity of agitation. A more recent study by the CMAI developer used a CMAI score (total frequency) of 42 as criterion for minimal levels of agitation (Cohen-Mansfield et al., 2010). They calculated this cut off as equivalent to a resident displaying physically agitated behaviours (restlessness and pacing) at a rate of several times a day combined with verbally agitated behaviour (repeating sentences and questions) at a rate of several times a week. However, this cut off score has not been widely adopted in research or practice.

The CMAI has undergone iteration since it was first developed. Originally the CMAI was found contain three structures: physical aggression, verbal aggression, and non-aggressive behaviour (Cohen-Mansfield et al., 1989). Later studies identified four factors, splitting non-aggressive behaviour into verbally aggressive and non-aggressive behaviour in addition to physically aggressive and physically non-aggressive behaviour (Cohen Mansfield, 1991). This four-factor structure is most frequently used to date. Other studies have suggested different factor structures (e.g. a recent study by (Kupeli et al., 2018), found a two factor structure). Notably the sample was from an acute hospital rather than residential care setting, for which the CMAI was originally developed.

The CMAI has previously been used in studies measuring the effects of individualised formulation led-interventions on BtC in PLwD (Holle et al., 2017) and wider evaluations of psychosocial interventions in dementia (Ballard et al., 2015). The internal reliability and validity of the measure has been demonstrated (Finkel et al., 1992; Zuidema et al., 2011).

The CMAI is administered pre and post intervention by the behavioural support teams to assess the effectiveness of their intervention utilising The Newcastle Model. Total frequency and disruptiveness scores on the CMAI were recorded for patients pre and post intervention. Full data at the sub-scale level of the CMAI was not available.

5.3.6 Analysis

All analyses of pre and post intervention outcome measure data (total CMAI frequency and disruptiveness scores) were performed using IBM SPSS version 25. Statistical tests were considered significant at $p< 0.05$. Descriptive data was inspected for outliers and assumptions for parametric analysis. Descriptive statistics were used to describe the sample and explore if there were any differences in characteristics between patients within and between the two behaviour support services, to identify any covariates that may need to be controlled in the analyses.

Two-way mixed ANOVAs were used to determine the effectiveness of the intervention: if there were differences within pre and post intervention CMAI scores (frequency and disruptiveness) between the standard and condensed versions of TNM intervention. A two-way mixed ANOVA was also performed to determine the routine clinical effectiveness of the delivery of the standard version of TNM by comparing pre and post intervention CMAI frequency and disruptiveness scores in two different behaviour support services.

5.3.7 Power calculation

Apriori power calculation for repeated measures ANOVA was conducted using GPower version 3.1.9.7 to identify the minimum sample size required for adequate statistical power. The calculation was made for a within-between interaction for two groups with two measurements with a medium effect size (.025) and alpha error probability of 0.05. The estimated total sample size required was 128 participants.

5.4 Results

Data from 2016 to March 2020 (for BSS-A) and 2018 to March 2020 (for BSS-B) was accessed, totalling 210 participants across the two behaviour support services (143 in BSS-A and 67 in BSS-B). In accordance with the study inclusion criteria, the data from 14 participants in BSS-A and 19 participants in BSS-B were removed as full pre and/or post intervention CMAI data was missing. The remaining data was screened for data entry errors, missing values and outliers. The procedure for managing outliers is outlined below.

Descriptive statistics

Descriptive statistics were used to explore and qualitatively describe the characteristics of patients who received TNM across the two behaviour support services, and the different delivery formats (standard and condensed) within BSS-A.

Table 4: Participant Characteristics

	BSS-A		**BSS-B (n=48)**
Variables	Standard (n=66)	Condensed (n=63)	
Age (SD)	82.27 (7.89)	83.06 (7.42)	81.14 (7.18)
Gender	(n=66)		
Women	43 (65.1%)	41 (65.1%)	31 (64.6%)
Men	23 (34.8%)	22 (34.9%)	17 (35.4%)
Type of dementia			
Alzheimer's	4 (19.4%)	23 (36.5%)	19 (41.3%)
Vascular	7 (33.3%)	11 (17.5%)	13 (28.2%)
Mixed	5 (23.8%)	5 (7.9%)	7 (15.2%)
Unspecified	4 (19.0%)	16 (25.4%)	6 (13.0%)
Lewy bodies	1 (4.5%)	2 (3.2%)	1
Alcohol related	0	0	0
Missing data	45 (68.2%)	6 (9.5%)	2(4.2%)
Prescribed psychotropic medication at baseline			
Antidepressant	6 (27.3%)	11 (18.6%)	Information not recorded
Benzodiazepine	2 (9.1%)	6 (10.2%)	
Antipsychotic	5 (22.7%)	8 (13.6)	
Polypharmacy	3 (13.6%)	25 (43.3%)	
None	6 (27.3%)	9 (15.3%)	
Missing data	44 (66.7%)	4 (6.3%)	
Primary distressed behaviour			
Physical aggression	8 (40%)	26 (43.3%)	Information not recorded
Verbal aggression	4 (20%)	12 (20%)	
Depressive symptoms	0	1 (1.7 %)	
Distress during personal care	2 (10%)	9 (15%)	
Placing self on floor	0	1 (1.7%)	
Repetitive behaviours	3 (15%)	0	
Trying to leave	2 (10%)	1 (1.7%)	
Wandering	0	1(1.7%)	
Sexualised behaviour	0	1(1.7%)	
Psychosis	1 (5%)	3 (5%)	
Anxiety	0	5 (8.3%)	
Missing data	46 (69.7%)	3 (4.8%)	

As outlined in Table 4, the gender and age composition of each of the samples was similar. From the available data, the composition of types of dementia varies within the samples but follows a broadly similar pattern of Alzheimer’s disease being the most common type of dementia, followed by vascular, mixed and unspecified types.

One of the behaviour support services, BSS-A, records the primary reason for referral to the service. In both groups (standard and condensed delivery) physical aggression was the most common reason for referral, followed by verbal aggression.

Table 5: Intervention Characteristics

	BSS-A		**BSS-B**
Variables	**Standard (n=66)**	**Condensed (n=63)**	**(n=48)**
Mean intervention duration in days (SD)	162.20 (88.65) (Min:20; Max: 480)	83.06 (7.42) (Min: 43; Max: 281)	156.09 (58.77) (Min: 74; Max: 281)
Missing data	0	4 (6.3%)	2 (4.2%)
Placement risk status at assessment			
At risk	29 (61.7%)	25 (42.37%)	13 (27.1%)
Not at risk	18 (38.3%)	34 (57.6%)	35 (72.9%)
Missing data	19 (28.8%)	4 (6.3%)	0
Hospital admission during intervention			
Hospital admission	5 (7.6%)	5 (8.3%)	Data not collected
No hospital admission	61 (92.4%)	55 (91.7%)	
Missing data	0	3 (4.8%)	

The average intervention duration (calculated from date of initial assessment to discharge) in the BSS-A standard delivery model was 162.19 days (23.17 weeks) compared to 83.06 days (11.7 weeks) in the condensed delivery model. The average intervention in BSS-B, using the standard delivery format, was 156.09 days (22.29 weeks).

In the BSS-A standard delivery condition, 61.7% of the patients’ placements were deemed “at risk” by the staff member at the nursing/residential home at the initial assessment compared to 43.37% in the condensed model. Less placements (27.1%) were rated as “at risk” in the BSS-B condition.

The mean CMAI total frequency and disruptiveness scores at baseline (see table 3) were similar across the services and intervention delivery models within services.

Only 7.6% of patients receiving the standard TNM and 8.3% of patients receiving the condensed delivery format of TNM were hospitalised during the intervention.

Primary Research question: What is the routine clinical effectiveness of TNM intervention delivered by two specialist behaviour support teams?”.

To explore the routine clinical effectiveness of the Newcastle model (standard delivery format) delivered in two different behaviour support services, two two-way mixed ANOVAs were conducted to determine if there were differences in CMAI total frequency and disruptiveness scores. The behaviour support service (BSS-A or BSS-B) was the between subjects factor and CMAI total frequency and disruption scores (at baseline and post intervention) were the within subjects factors.

Prior to analysis, histograms visually inspected for distribution alongside scores for skewness and kurtosis. Based upon these analyses all variables were normally distributed except for the post total disruption score which showed evidence of kurtosis (>2). Therefore, scores were windsorized for 5 participants (Field, 2018). Further visual inspection of histograms alongside scores for skewness and kurtosis values were within acceptable parameters for normal distribution. Assumptions of homogeneity of variance and covariance were assessed by Levene’s test ($p > .05$) and Box’s M test ($p > 0.001$). The assumption of sphericity was also met.

Table 6: Comparison of mean CMAI scores between behaviour support services

Variable	**Condition**	**Baseline** Mean (SD)	**Post-intervention** Mean (SD)
CMAI total frequency score	BSS-A (n=66)	65.00 (17.29)	48.65 (13.30)
	BSS-B (n=48)	71.04 (16.58)	46.79 (14.93)
CMAI total disruptiveness score	BSS-A (n=66)	50.46 (12.90)	37.44 (7.85)
	BSS-B (n=48)	55.43 (13.47)	35.77 (7.41)

The results of the two way mixed ANOVA demonstrated that there was a statistically significant interaction between time and intervention delivery mode on both CMAI frequency scores, $F_{(1,112)}= 4.46$, $p < .05$, $\eta_p^2 =.038$, and disruptiveness scores, $F_{(1, 112)} = 6.85$, $p< .05$, $\eta_p^2= .058$ (see figures 6 and 7). Degree of change was greater in BSS-B, for both frequency and disruption, because baseline scores were higher for both of these variables in BSS-B.

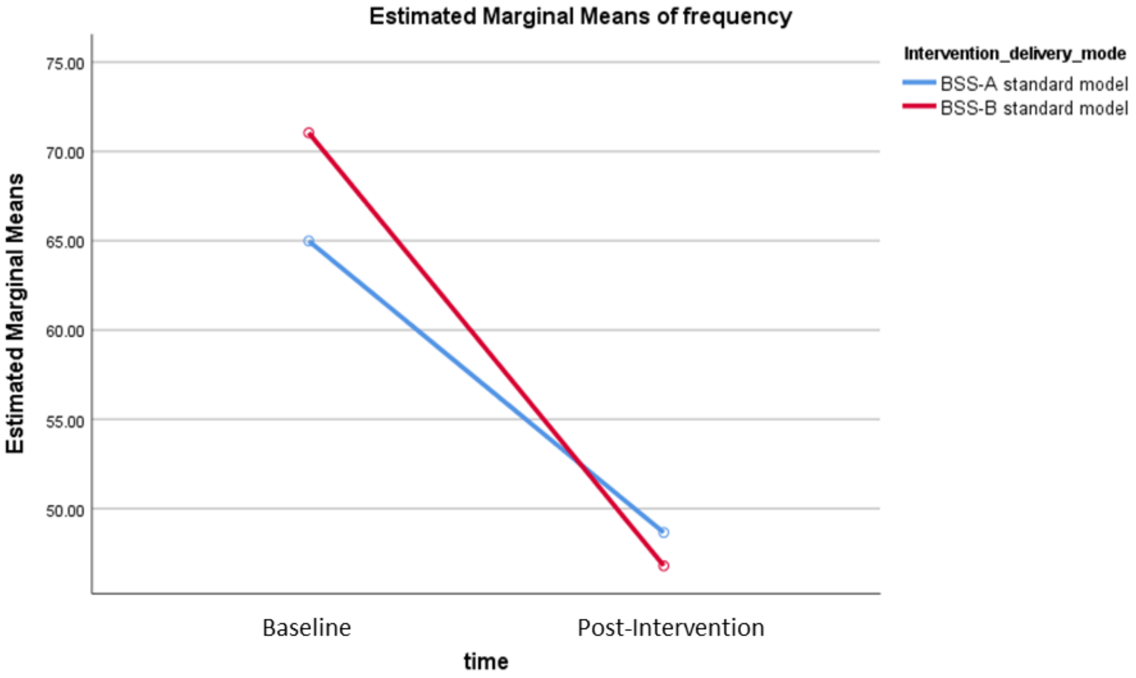

Figure 6: Estimated Marginal means of BSS-A and BSS-B CMAI frequency scores pre and post intervention

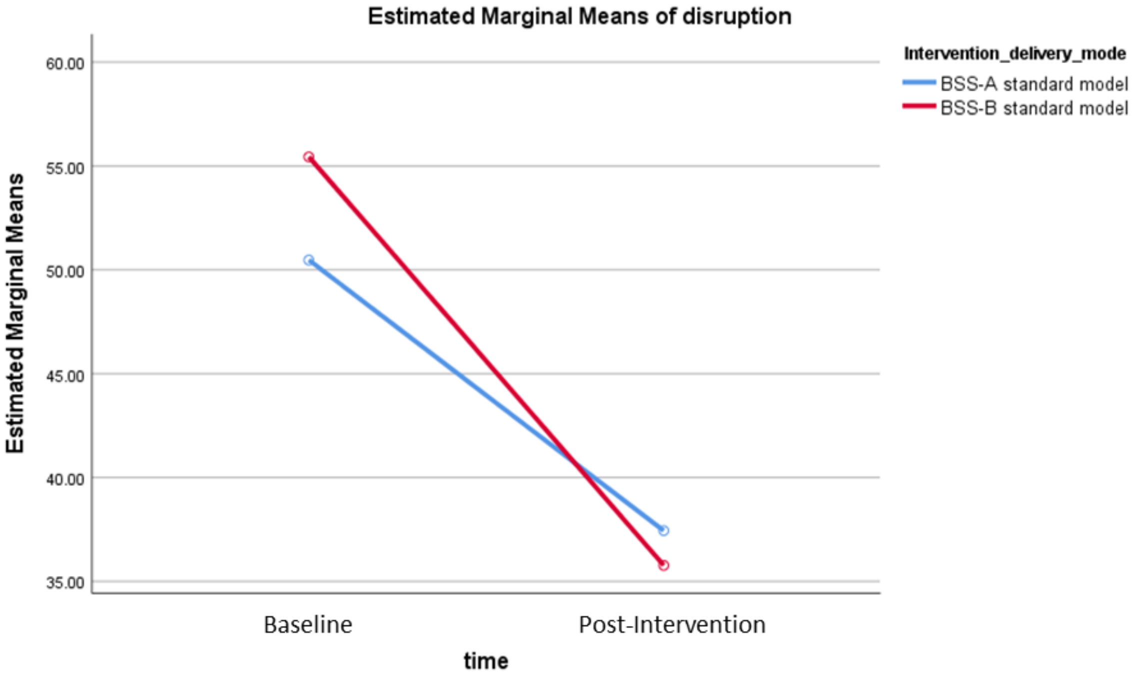

Figure 7: Estimated Marginal means of BSS-A and BSS-B CMAI disruption scores pre and post intervention

Secondary research question: What is the impact of a condensed delivery format of TNM on patient outcome?

Two two-way mixed ANOVAs were conducted to determine if there were differences in CMAI total frequency and disruptiveness scores between the standard and condensed delivery of TNM pre and post intervention. The CMAI total frequency and disruptiveness score (measured at baseline and post intervention) was the within subject factor. The intervention delivery format (standard or condensed model) was the between subject factor.

Prior to analysis, histograms were inspected alongside scores for skewness and kurtosis. Based upon these analyses, all variables were normally distributed except for the post-intervention disruptiveness scores which showed evidence of skew and kurtosis. As a result, outliers were identified and scores for five participants were windsorised (Field, 2018). Further visual inspection of histograms alongside scores for skewness and kurtosis values were within acceptable parameters for normal distribution. Assumptions of homogeneity of variance and covariance were assessed by Levene's test (*p*> .05) and Box's M test (*p* > 0.001). The assumption of sphericity was also met.

Table 7: Comparison of means and standard deviations on the CMAI (frequency and disruption scores)

	Condition	**Baseline**	**Post-intervention**
Variable		Mean (SD)	Mean (SD)
CMAI total frequency score	Standard Model (n=66)	64.98 (17.29)	48.65 (12.30)
	Condensed Model (n=63)	66.17 (15.29)	53.95 (14.91)

CMAI total disruptiveness score	Standard Model (n=66)	50.46 (12.91)	37.48 (7.95)
	Condensed Model (n=63)	53.00 (12.43)	40.81 (9.05)

The results of the two way mixed ANOVA demonstrated that there was a main effect of time which showed a statistically significant reduction in CMAI frequency scores between baseline and post intervention in CMAI frequency scores $F_{(1,127)} = 85.30$, $p<.005$, $\eta_p^2 = .402$, indicative of a medium effect size (see figure 8). This was also the case for CMAI disruptiveness scores $F_{(1,127)} = 134.02$, $p<0.05$, $\eta_p^2 = .513$, indicative of a large effect size (see figure 9).

There was no statistically significant interaction between time and intervention delivery mode on CMAI frequency scores, $F_{(1,127)} = 1.77$, p= .186, $\eta_p^2 = .014$), or disruptiveness scores $F_{(1, 127)} = .136$, p=.713, $\eta_p^2 = .001$ (see figures 3 and 4). Both interventions performed similarly across both pre and post intervention timepoints.

Similarly, the main effect of group showed that there was no statistically significant difference in mean CMAI frequency scores $F_{(1,127)}=2.174$, $p=.143$, $\eta_p^2 = .017$, or disruptiveness scores, $F_{(1, 127)} = 3.529$, $p = .063$, $\eta_p^2 = .027$, between the standard and condensed delivery models.

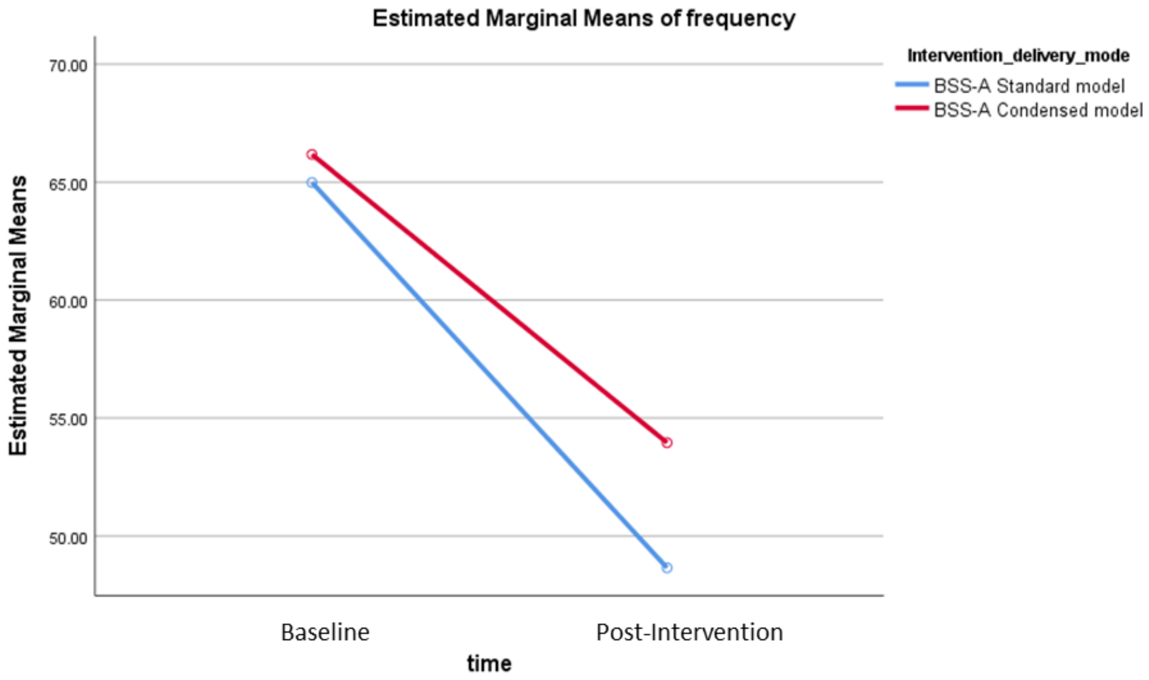

Figure 8: Estimated Marginal means of CMAI frequency scores between BSS-A standard and condensed delivery models

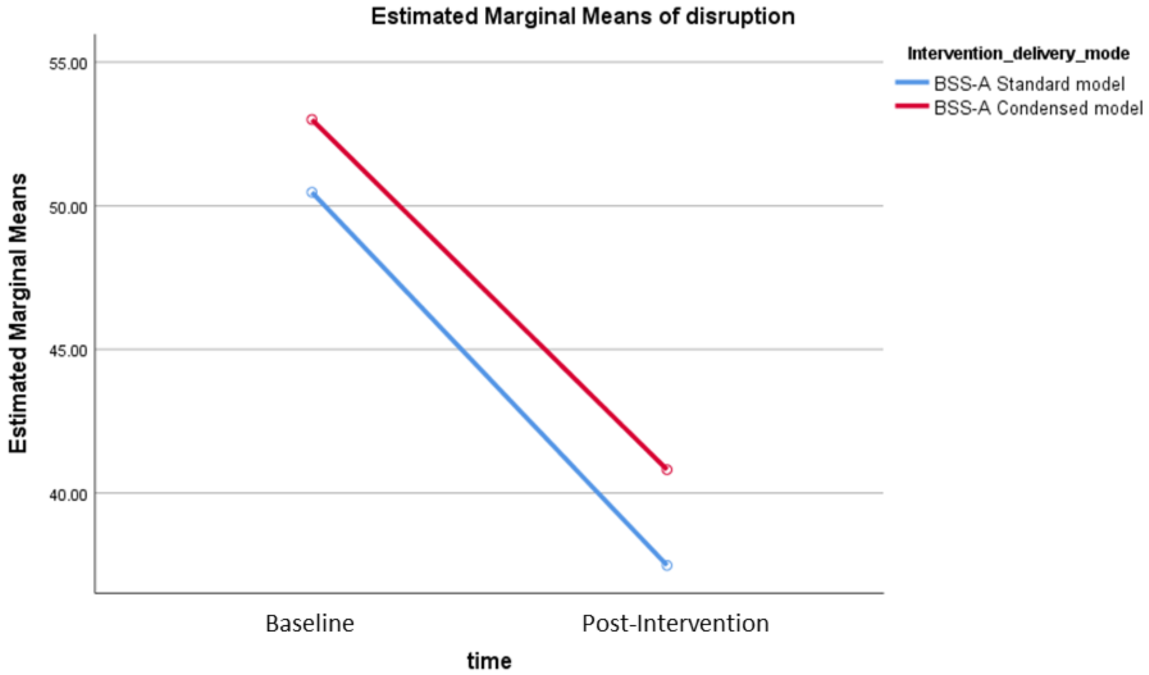

Figure 9: Estimated Marginal means of CMAI disruption scores between BSS-A standard and condensed delivery model

5.5 Discussion

This study demonstrated that the Newcastle Model intervention, delivered by specialist behaviour support teams outwith that of the model developer, resulted in a significant reduction in BtC in PLwD. This was demonstrated across two independent behaviour support teams with different staff members and clinical leads, suggesting the results are not solely attributable to the skill set of an individual team.

Despite 61% ("standard" delivery format) and 42% (condensed delivery format) of the referring care homes rating the PLwD's placement being "at risk" because of their BtC, only a small proportion (7.6% in the standard and 8.3 condensed model) of those receiving TNM intervention were hospitalised.

These findings are in line with the available previously published data on the effectiveness of TNM in clinical settings (Wood-Mitchell et al., 2006). The current findings contribute to the evidence base by demonstrating that the Newcastle Model has ecological validity, with significant reductions in BtC evident when then intervention was delivered by teams independent of the developer. This is significant considering that one of the most consistent findings from clinical and health services research is the failure to translate research findings into routine clinical practice (Grimshaw et al., 2012). The current findings also support the growing evidence base demonstrating the effectiveness of individualised formulation-led interventions in response to BtC in people living with dementia (Holle et al., 2017).

This study evaluated the effectiveness of a condensed format of TNM intervention, designed to be delivered in a shorter timeframe (6-9 weeks) than the standard version of TNM (12-14 weeks) developed by James, 2011; James & Jackman, 2017). There was no significant difference in patient outcome, measured by the CMAI, between the standard and condensed delivery models. Both delivery models led to a significant reduction in frequency and disruptiveness of patient agitation ($p < 0.05$). It is of note however that the average duration of the standard delivery model was 23.17 weeks and the condensed model was 11.7 weeks, longer than outlined in the respective protocols.

Whilst the average duration of the condensed delivery format was longer than outlined in the protocol (6-9 weeks), it demonstrated that the same reduction in BtC was achieved in TNM intervention delivered over a longer duration. This has implications for service delivery, as shorter intervention duration means that patients referred to the service because of difficulties managing their distressed behaviour can be seen by behaviour support services more quickly. Faster intervention implementation has implications for distress levels in the person living with dementia, families/loved ones of the PLwD, and care home staff. It could also potentially lead to fewer hospitalisations, given that a very small proportion of PLwD receiving TNM intervention from behaviour support services required hospitalisation. This has financial implications, as outlined by (Wood-Mitchell et al., 2006), given the high cost of inpatient treatment.

It is noteworthy that there is variation in intervention duration within and between the standard and condensed delivery formats. Many factors out with the control of service providers influence intervention duration. The responsiveness and engagement of care home staff, along with the baseline level of training staff have received in understanding and responding to BtC, are likely to contribute to intervention delivery and outcome. In a recent survey, health professionals working in dementia care reported that the benefit of formulation-based approaches was considerably limited if care staff did not support or implement formulation led strategies (James, Mahesh, et al., 2020). Factors such as pre-established relationships with care homes (developed through working with them to deliver the intervention to other residents) may also influence intervention delivery duration, potentially reducing the time required due to familiarity with the approach. There will also be variation within behaviour support service clinicians' level of expertise, experience, and familiarity with delivering TNM intervention which may influence intervention duration. Additionally, factors such as acute illness in the PLwD that have a direct effect on behaviour (e.g. development of an infection whilst receiving TNM) may extend intervention duration. Changes to psychotropic medication, which require ongoing monitoring in initial stages, may also increase intervention duration.

Nevertheless, on average, the same reduction in BtC was achieved in approximately half the time when BSS-A were implementing the condensed model protocol. One possible explanation for this may be due to an intended shorter delivery format promoting closer fidelity to the intervention model.

Referring to Cognitive Behaviour Therapy, Waller and Turner (2016) suggest three key basic components are required to deliver effective therapy: a) the therapy has to work (an effective set of therapeutic techniques are available); b) the patient has to engage with the therapy; c) the clinician has to deliver evidence-based therapies appropriately. Therapeutic drift has been conceptualised as failure to deliver evidence based treatments as intended when the required resources to achieve this are available to the therapist (Waller & Turner, 2016). This can be a conscious or unconscious process. A narrative review of the evidence relating to therapist drift identified a wide range of factors that can influence this phenomenon. These included: knowledge base, beliefs and attitudes about treatments, philosophical stance, the therapist's perception of their own skill level, sole use of clinical judgement as opposed to it informing flexible implementation of protocols, therapist safety behaviours (e.g. avoiding certain therapeutic techniques, particularly behavioural methods) and interpersonal and institutional factors (Waller & Turner, 2016).

The first phase of the Newcastle Model is a highly structured process of information gathering, assessment and collaboratively developing the formulation and subsequent intervention plans to address unmet needs with care home staff. The second phase of the model delivery involves maintaining contact with care homes to support intervention implementation and "tweak" as necessary. This may involve amending the formulation in response to future information obtained and modelling and teaching skills to care home staff. As outlined above, whilst this stage is influenced by the extent to which care home staff can engage with clinicians, and other contributing factors, it is possible this phase of the intervention is more amenable to therapeutic drift. It could be that a shorter, more intensive delivery of the intervention means that clinicians adhere more closely to the theoretical model, are more driven by the formulation and implementation of evidence based strategies to meet identified unmet needs, and deviate less from this. The standard Newcastle Model protocol recommends that discharge should occur at 12-14 weeks unless in "exceptional circumstances". What constitutes exceptional circumstances is not clearly defined, and the success (or lack) of the intervention may be perceived and interpreted differently by both clinicians and intervention recipients. This may influence the extent to which the clinician provides ongoing input and further 'tweaking' and monitoring. Further research is required to explore this in more detail, and determine if therapeutic drift is a contributing factor to intervention duration.

5.5.1 Strengths & Limitations

To our knowledge, there are no other published studies evaluating the implementation and routine clinical effectiveness of the Newcastle Model outwith that of the model developers. This study also provided preliminary data to support the effectiveness of a shorter delivery format for TNM, demonstrating that shorter intervention duration was as effective as longer intervention duration. As outlined above, this has direct implications for service delivery and patient outcome.

There are however several limitations of this study, most of which are related to the limits of retrospective analysis of routine clinical data collection. The study used a single outcome measure to assess the impact of the intervention. Whilst the CMAI is a validated measure used widely in this field of research, it would have been beneficial to record additional outcomes to evaluate the effectiveness of the intervention. Furthermore, complete sub-scale data was not available therefore analyses could only be conducted with total CMAI scores. Whilst analyses with the total frequency score alone is routinely conducted in this field of research, analyses at the sub-scale level would have added further depth and detail to the data analysis.

A previous service evaluation of the TNM used the NPI-NH (Wood-Mitchell et al., 2006). Whilst there is a high correlation between the two measures (Finkel et al., 1992), a study comparing the measures found the CMAI was more sensitive to change (Zuidema et al., 2011). However, the NPI-NH also captures other components of BtC such as changes in mood, evidence of delusions or hallucinations and changes in eating/sleeping behaviour not measured in the CMAI. Using both outcome measures would have demonstrated that there was a reduction across broader domains of BtC.

Severity of dementia was not measured. Whilst the Newcastle Model was designed to be used with people with severe dementia, dementia severity may have implications for the effectiveness and duration of the intervention. Outcome measures such as (e.g. the Functional Assessment Staging Scale (Reisberg, 1988)) could have been used to assess this. This is also applicable to co-occurring mental health difficulties and experiences of trauma, which were not formally recoded in the routine outcome clinical dataset. These factors could influence the complexity of the PLwD's presentation which potentially has implications for the effectiveness of the intervention. Using quality of life as an outcome measure in PLwD pre and post intervention (e.g. the DEMQoL (Smith et al., 2005)) would also have reflected the holistic approach the Newcastle Model adopts to understanding BtC.

Furthermore, due to the nature of the data (collected routinely as part of clinical practice), it is not known if the same informant always completed the pre and post intervention measure. Given the relative subjectively of assessing BtC in this way (different care staff may have different perceptions and thresholds for behaviours), this could have influenced the way behaviour was appraised in the CMAI.

TNM conceptualises staff perceptions, care home culture and staff behaviour as key contributors to the development, maintenance, and resolution of BtC. Whilst the disruptiveness scale of the CMAI measures the extent to which the agitated behaviour impacts the PLwD and/or those around them (residential care staff and/or other residents), other measures of the impact of BtC on staff, such as the Maslow Burnout Inventory, as seen in similar studies (Holle et al., 2017) would have been useful addition to evaluate the wider effects of the intervention beyond frequency and duration of BtC.

As previously outlined, it is recommended that psychotropic medications are not used as a first line treatment for BtC due to the risks associated (NICE, 2018). Medication usage (but not dosage) was recorded pre intervention for some participants in this study, however there was no post intervention medication use recorded. Reduction or change in medication use has been used as a measure of intervention effectiveness in related studies (Fossey et al., 2006) and could have been used as a secondary outcome measure in the present study had the data been recorded.

Intervention duration was calculated from time of initial assessment to discharge. A more accurate way of evaluating effect of the different delivery formats could be “dose” of intervention, recording the number of therapeutic contacts the clinician has with the care home in addition to the duration of the intervention.

Finally, as the data is derived from a routine clinical dataset, outcome measures were only collected at baseline and end of treatment. A post intervention follow up measure (e.g. at 3 or 6 months) would have allowed investigation of whether the significant reduction in BtC was maintained over time.

5.5.2 Implications for Research and Clinical Practice

This study provides initial evidence to suggest that delivery of TNM over a shorter duration is as effective at reducing agitation in PLwD than over a longer duration. As previously outlined, this has implications for service delivery, patient outcome and staff wellbeing.

From a broad theoretical perspective, the results of the present study support the primary theoretical assumption of TNM: that BtC will reduce/distinguish if they are conceptualised as expression of unmet needs, understood within the context of the person's current circumstances and life history, and actions to meet the person's needs are taken. The study demonstrates that individualised formulation driven interventions using this approach significantly reduced BtC in individuals who had been referred to a specialist behaviour support service due to the complexity of their presentation. The finding that patient outcome was the same across shorter and longer delivery formats may indicate that the primary mechanism of change occurs at earlier stages in the intervention (e.g. after the information sharing session, which is a focal point of the Newcastle Model). Further research is required to determine when this change occurs and the most effective duration and frequency of specialist clinician input post ISS.

In their latest paper, James, Reichelt, et al., (2020) continue to seek to identify mechanisms of change in treatments for BtC. They suggest a new direction for TNM, proposing that concepts from positive behaviour support, an approach used to support people with learning disabilities displaying BtC could enhance the model. They note that these suggestions are theoretical and are in the process of being evaluated empirically.

Future research further elucidating mechanisms of change could also investigate predictors of intervention duration and effectiveness, examining factors related to the PLwD. This could include dementia severity (i.e. is intervention duration impacted by how advanced someone's dementia is and the impact this has on the ways they are able to communicate distress and the sense care staff are able to make of this). The types of distressed behaviour the PLwD is displaying may also influence intervention duration (e.g. is intervention duration influenced by severity of physical aggression displayed or behaviours associated with higher level of stigma such as sexualised behaviour, for example?). Future research could also explore whether the presence of co-occurring mental health difficulties/ a history of trauma in the PLwD affects the duration of intervention, e.g. do staff require longer support after the information sharing session to implement trauma informed interventions to meet the PLwD’s needs to reduce their distress.

Factors related to care home staff characteristics may also influence intervention duration. This may include the level of training care staff have received on understanding and responding to distress and BtC in PLwD prior to receiving TNM intervention from behaviour support services. Relatedly, staff attitudes and understanding of BtC, the expression of distress in dementia and their attitudes towards the use of psychological interventions to manage BtC may influence the duration, and indeed the effectiveness, of TNM intervention. Factors such as care home staff familiarity with the intervention (i.e. if the care home have had previous input from behavioural support services using TNM for other residents) may also influence the duration of the intervention.

Finally, therapist factors such as type of professional training, years of clinical experience and self-efficacy may also play a role in intervention efficacy, as previously outlined. These could also be considered as variables in future research assessing the effectiveness of TNM.

Small n repeated measures designs could also be utilised to identify when the mechanisms of change in the intervention occur (i.e., how long after the delivery of the information sharing session and what “dose” of the intervention is required). This could have implications for informing when the most effective time to deliver the ISS and in determining how effective the monitoring and ‘tweaking’ phase as it increases in duration.

To date there is limited research investigating the experiences of care home staff and families of PLwD involved in individualised formulation driven interventions for BtC in dementia. Holle et al. (2017) identified three studies investigating the barriers and facilitators to implementation of such interventions (none of which used TNM). A qualitative approach sampling both care home staff receiving the TNM intervention, and behavioural support staff delivering the intervention, could provide greater insight into the experiences of receiving and delivering TNM over a shorter timeframe. This may elucidate if greater adherence to the model is a contributing factor to shorter duration time. Regularly assessing fidelity to the model in clinical supervision may be a way of ensuring the intervention is delivered over a shorter duration whilst maintaining clinical effectiveness.

5.6 Conclusion

In conclusion, this study sampled clinical data collected by two different behaviour support services over a period of approximately four years that demonstrated the routine clinical effectiveness of Newcastle Model intervention. A condensed delivery format of the model was as effective at reducing BtC as the standard delivery format. Further exploration of this, and factors impacting the delivery and effectiveness of TNM in response to BtC in dementia is warranted.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

Ethical approval was obtained for the reported analysis of data sources (see Appendix D & E).

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6 Appendices

6.1 Appendix A: Submission guidelines for Dementia (relevant sections)

Manuscript Submission Guidelines:

This Journal is a member of the Committee on Publication Ethics.

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/dementia to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of Dementia will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere. Please see our guidelines on prior publication and note that ***Dementia* may accept submissions of papers that have been posted on pre-print servers;** please alert the Editorial Office when submitting (contact details are at the end of these guidelines) and include the DOI for the preprint in the designated field in the manuscript submission system. Authors should not post an updated version of their paper on the preprint server while it is being peer reviewed for possible publication in the journal. If the article is accepted for publication, the author may re-use their work according to the journal's author archiving policy. If your paper is accepted, you must include a link on your preprint to the final version of your paper.

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1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia. Biomedical and overly clinical research articles will not be accepted.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

If you would like to receive this list please e-mail Sarah Campbell, Book Review Editor at Sarah.Campbell@MMU.ac.uk and you will be added to our reviewer list. We welcome suggestions of books to review at any time. Also, if you have read a book that you think would be of interest to the journal and would like to review it, we also welcome unsolicited contributions.

Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

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2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
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All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should be placed on the title page. Your main text should include a Declaration of Conflicting Interests (if applicable), any notes and your References but should be completely blinded.

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Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

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It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a ‘Declaration of Conflicting Interests’ statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that ‘The Author(s) declare(s) that there is no conflict of interest’. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

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For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient’s actual written informed consent with your article, as this in itself breaches the patient’s confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient’s hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

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The journal is committed to facilitating openness, transparency and reproducibility of research, and has the following research data sharing policy. For more information, including FAQs please visit the SAGE Research Data policy pages.

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3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

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4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.2 Language

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'.

Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PLWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language, as do the Alzheimer Society of Canada, both of which are useful for guidance.

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

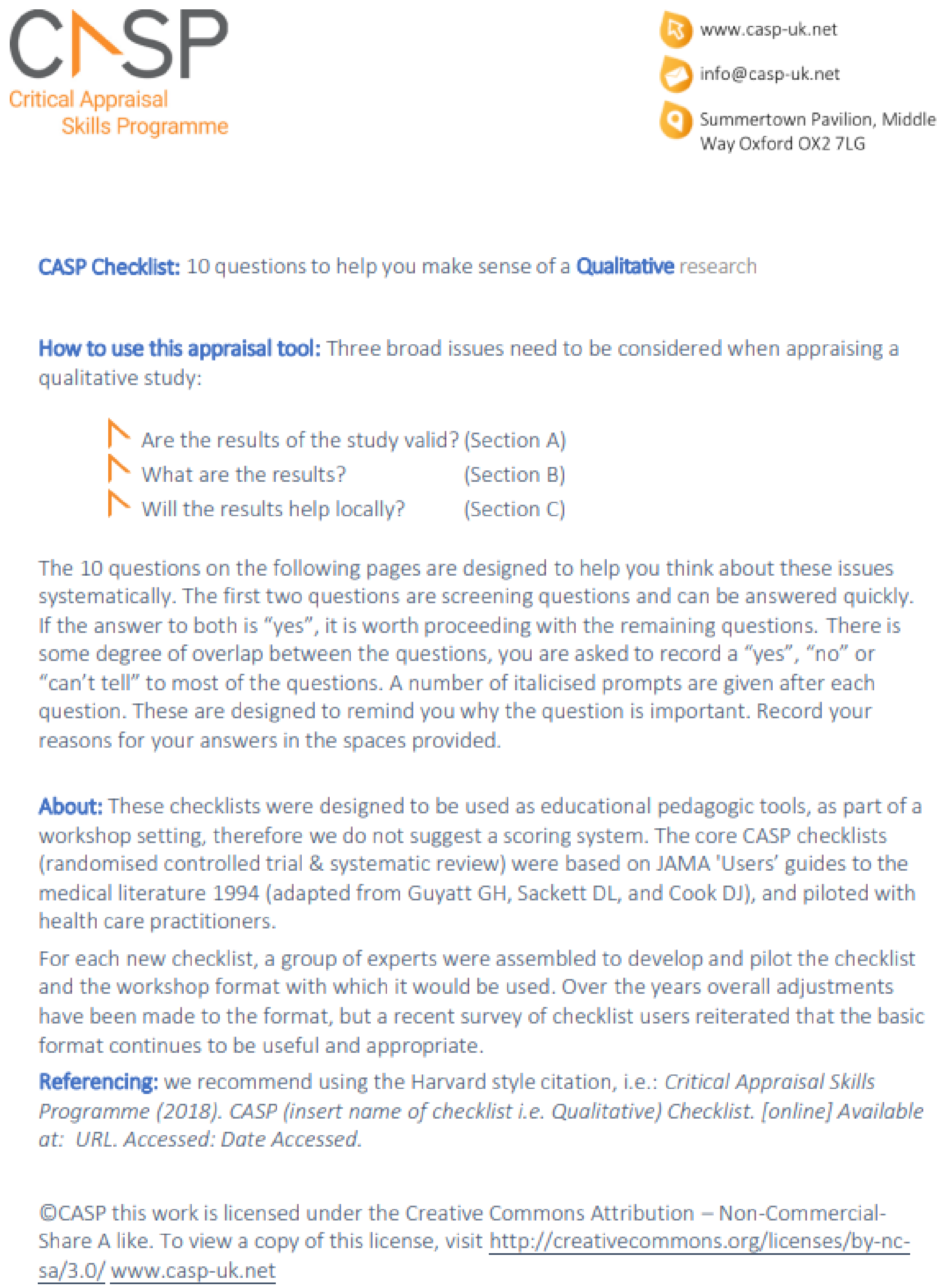
4.4 Supplemental material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.5 Reference style

Dementia adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

6.2 Appendix B: Critical Appraisal Skills Programme Checklist



CASP
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CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference: Putney et al (2018)

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments: Clear research question linked to lit outlined in intro.

2. Is a qualitative methodology appropriate?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments: Sought to understand LGBT OAs anticipated care needs and fears re: residential care.

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments: Chose to use focus groups to faciliate participants to feel more comfortable sharing expereinces with others with similar characteristics.

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments: Explanation of how and where participants selected. Efforts made to hold focus groups in different locations to recruit a more diverse sample

5. Was the data collected in a way that addressed the research issue?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments: Data collected in focus groups. Justification re: why focus groups appropriate. Efforts made to hold focus groups in different locations to recruit a more diverse sample. Saturation discussed briefly.

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☑
No ☐

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments: Not enough detail to determine this.

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments: Ethical approval sought & granted. Detailed explanation of consent process and efforts to ensure confidentiality maintained. Resourse list post focus group provided. Pseudonymns used.

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☑
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

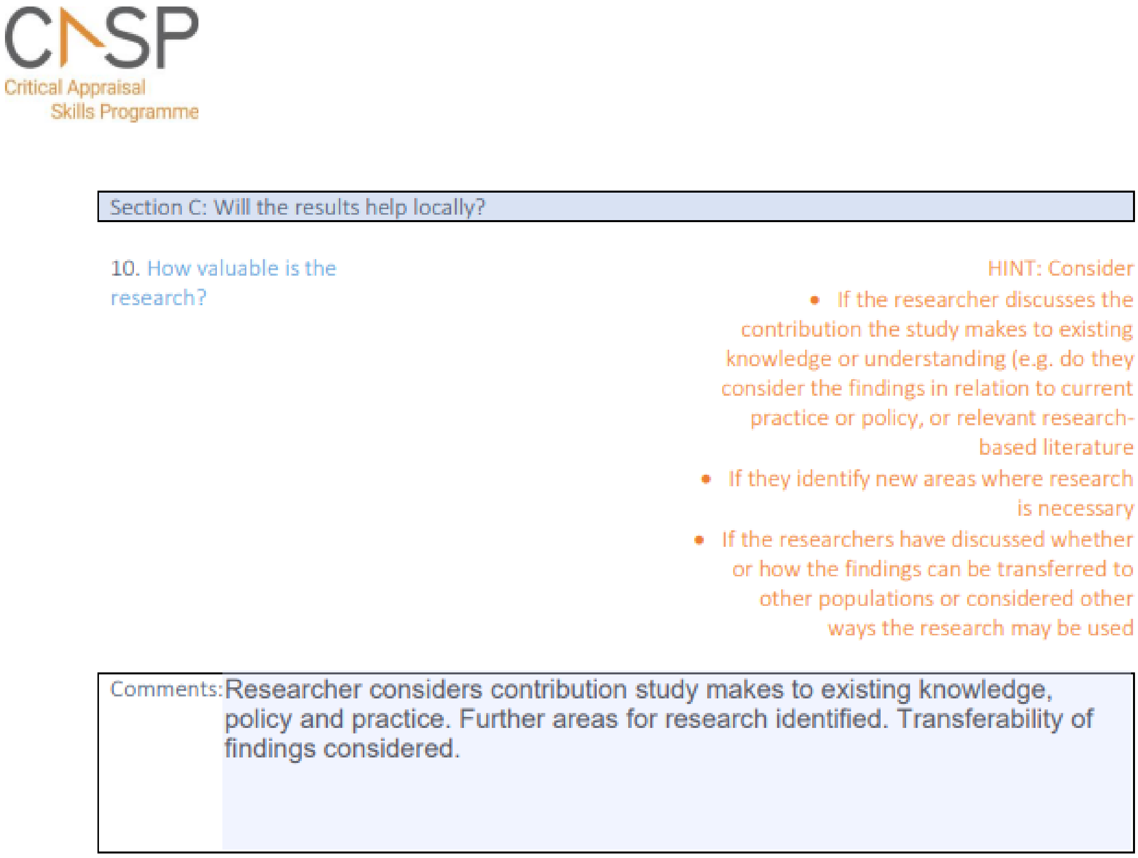
Comments: Some description of analysis process and how themes identified. Some data presented to support findings -perhaps not enough? No note of critical examination of role by researchers - did not that 3 researchers analysed transcripts independently. No thematic map.

9. Is there a clear statement of findings?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments: More than one analyst. Findings are explicit. Considered in context of other research. Bias in sampling methods acknowledged.



CASP
Critical Appraisal
Skills Programme

Section C: Will the results help locally?

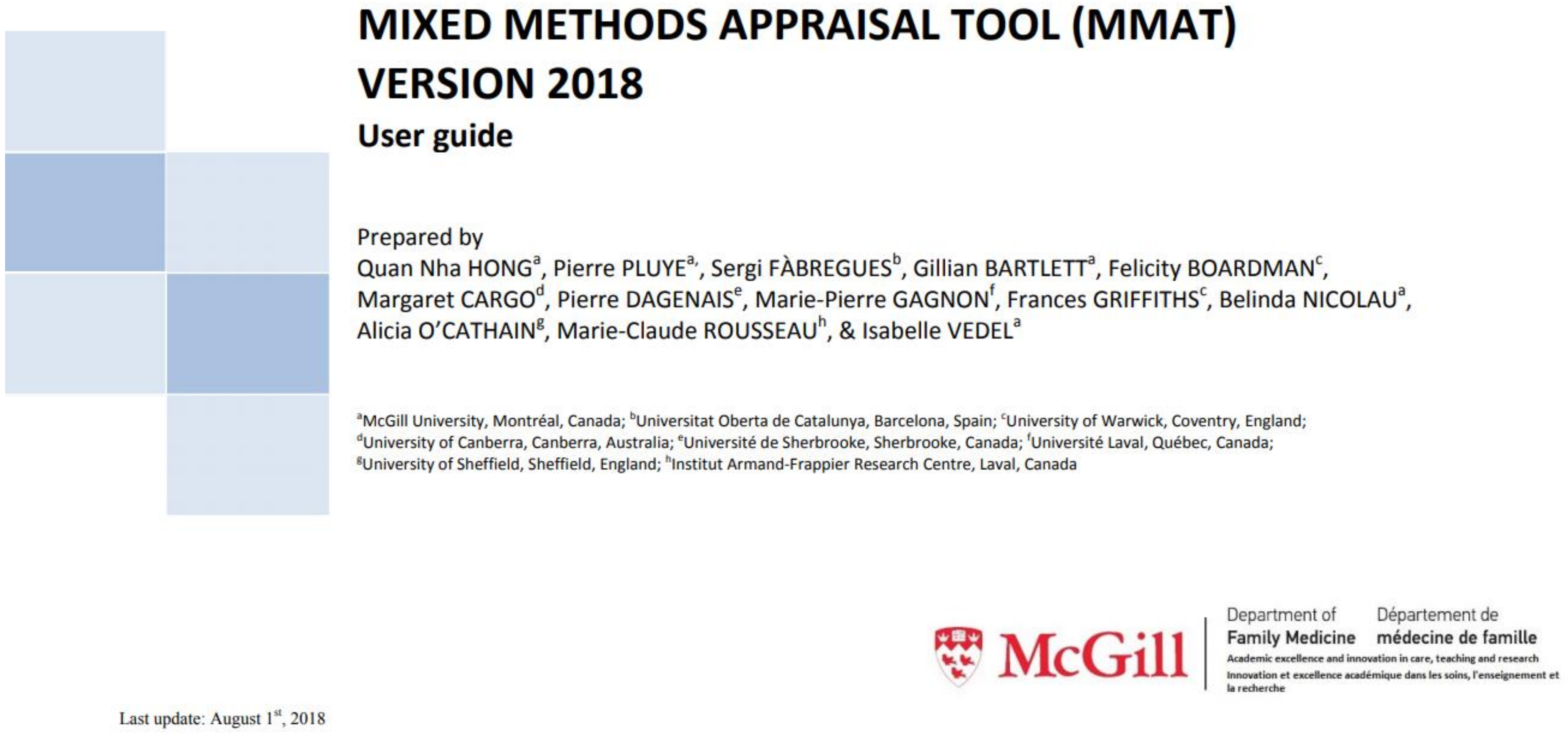
10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments: Researcher considers contribution study makes to existing knowledge, policy and practice. Further areas for research identified. Transferability of findings considered.

6.3 Appendix C: Mixed Methods Appraisal Tool



MIXED METHODS APPRAISAL TOOL (MMAT)
VERSION 2018
User guide

Prepared by
Quan Nha HONG[a], Pierre PLUYE[a,], Sergi FÀBREGUES[b], Gillian BARTLETT[a], Felicity BOARDMAN[c], Margaret CARGO[d], Pierre DAGENAIS[e], Marie-Pierre GAGNON[f], Frances GRIFFITHS[c], Belinda NICOLAU[a], Alicia O'CATHAIN[g], Marie-Claude ROUSSEAU[h], & Isabelle VEDEL[a]

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McGill | Department of Family Medicine | Département de médecine de famille
Academic excellence and innovation in care, teaching and research
Innovation et excellence académique dans les soins, l'enseignement et la recherche

Last update: August 1st, 2018

What is the MMAT?

The MMAT is a critical appraisal tool that is designed for the appraisal stage of systematic mixed studies reviews, i.e., reviews that include qualitative, quantitative and mixed methods studies. It permits to appraise the methodological quality of five categories to studies: qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies, and mixed methods studies.

How was the MMAT developed?

The MMAT was developed in 2006 (Pluye et al., 2009a) and was revised in 2011 (Pace et al., 2012). The present version 2018 was developed on the basis of findings from a literature review of critical appraisal tools, interviews with MMAT users, and an e-Delphi study with international experts (Hong, 2018). The MMAT developers are continuously seeking for improvement and testing of this tool. Users' feedback is always appreciated.

What the MMAT can be used for?

The MMAT can be used to appraise the quality of empirical studies, i.e., primary research based on experiment, observation or simulation (Abbott, 1998; Porta et al., 2014). It cannot be used for non-empirical papers such as review and theoretical papers. Also, the MMAT allows the appraisal of most common types of study methodologies and designs. However, some specific designs such as economic and diagnostic accuracy studies cannot be assessed with the MMAT. Other critical appraisal tools might be relevant for these designs.

What are the requirements?

Because critical appraisal is about judgment making, it is advised to have at least two reviewers independently involved in the appraisal process. Also, using the MMAT requires experience or training in these domains. For instance, MMAT users may be helped by a colleague with specific expertise when needed.

How to use the MMAT?

This document comprises two parts: checklist (Part I) and explanation of the criteria (Part II).

1. Respond to the two screening questions. Responding 'No' or 'Can't tell' to one or both questions might indicate that the paper is not an empirical study, and thus cannot be appraised using the MMAT. MMAT users might decide not to use these questions, especially if the selection criteria of their review are limited to empirical studies.
2. For each included study, choose the appropriate category of studies to appraise. Look at the description of the methods used in the included studies. If needed, use the algorithm at the end of this document.
3. Rate the criteria of the chosen category. For example, if the paper is a qualitative study, only rate the five criteria in the qualitative category. The 'Can't tell' response category means that the paper do not report appropriate information to answer 'Yes' or 'No', or that report unclear information related to the criterion. Rating 'Can't tell' could lead to look for companion papers, or contact authors to ask more information or clarification when needed. In Part II of this document, indicators are added for some criteria. The list is not exhaustive and not all indicators are necessary. You should agree among your team which ones are important to consider for your field and apply them uniformly across all included studies from the same category.

How to score?

It is discouraged to calculate an overall score from the ratings of each criterion. Instead, it is advised to provide a more detailed presentation of the ratings of each criterion to better inform the quality of the included studies. This may lead to perform a sensitivity analysis (i.e., to consider the quality of studies by contrasting their results). Excluding studies with low methodological quality is usually discouraged.

How to cite this document?

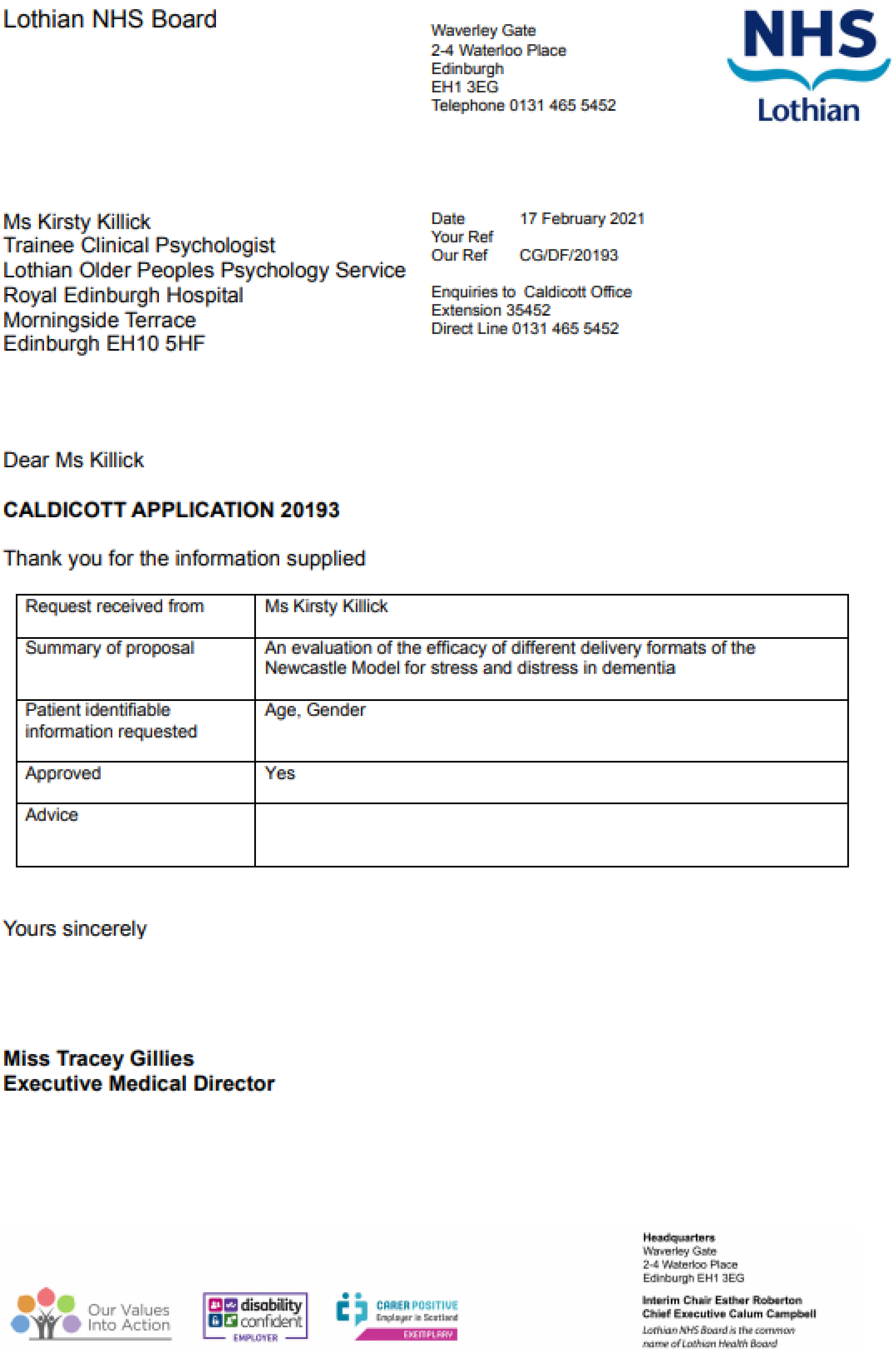
Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, Gagnon M-P, Griffiths F, Nicolau B, O'Cathain A, Rousseau M-C, Vedel I. Mixed Methods Appraisal Tool (MMAT), version 2018. Registration of Copyright (#1148552), Canadian Intellectual Property Office, Industry Canada.

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

5. Mixed methods studies	**Methodological quality criteria**
Mixed methods (MM) research involves combining qualitative (QUAL) and quantitative (QUAN) methods. In this tool, to be considered MM, studies have to meet the following criteria (Creswell and Plano Clark, 2017): (a) at least one QUAL method and one QUAN method are combined; (b) each method is used rigorously in accordance to the generally accepted criteria in the area (or tradition) of research invoked; and (c) the combination of the methods is carried out at the minimum through a MM design (defined *a priori*, or emerging) and the integration of the QUAL and QUAN phases, results, and data. Common designs include (this list if not exhaustive): **Convergent design** The QUAL and QUAN components are usually (but not necessarily) concomitant. The purpose is to examine the same phenomenon by interpreting QUAL and QUAN results (bringing data analysis together at the interpretation stage), or by integrating QUAL and QUAN datasets (e.g., data on same cases), or by transforming data (e.g., quantization of qualitative data). **Sequential explanatory design** Results of the phase 1 - QUAN component inform the phase 2 - QUAL component. The purpose is to explain QUAN results using QUAL findings. E.g., the QUAN results guide the selection of QUAL data sources and data collection, and the QUAL findings contribute to the interpretation of QUAN results. **Sequential exploratory design** Results of the phase 1 - QUAL component inform the phase 2 - QUAN component. The purpose is to explore, develop and test an instrument (or taxonomy), or a conceptual framework (or theoretical model). E.g., the QUAL findings inform the QUAN data collection, and the QUAN results allow a statistical generalization of the QUAL findings. Key references: Creswell et al. (2011); Creswell and Plano Clark, (2017); O'Cathain (2010)	5.1. Is there an adequate rationale for using a mixed methods design to address the research question? Explanations The reasons for conducting a mixed methods study should be clearly explained. Several reasons can be invoked such as to enhance or build upon qualitative findings with quantitative results and vice versa; to provide a comprehensive and complete understanding of a phenomenon or to develop and test instruments (Bryman, 2006).
	5.2. Are the different components of the study effectively integrated to answer the research question? Explanations Integration is a core component of mixed methods research and is defined as the "explicit interrelating of the quantitative and qualitative component in a mixed methods study" (Plano Clark and Ivankova, 2015, p. 40). Look for information on how qualitative and quantitative phases, results, and data were integrated (Pluye et al., 2018). For instance, how data gathered by both research methods was brought together to form a complete picture (e.g., joint displays) and when integration occurred (e.g., during the data collection-analysis or/and during the interpretation of qualitative and quantitative results).
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? Explanations This criterion is related to meta-inference, which is defined as the overall interpretations derived from integrating qualitative and quantitative findings (Teddlie and Tashakkori, 2009). Meta-inference occurs during the interpretation of the findings from the integration of the qualitative and quantitative components, and shows the added value of conducting a mixed methods study rather than having two separate studies.
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? Explanations When integrating the findings from the qualitative and quantitative components, divergences and inconsistencies (also called conflicts, contradictions, discordances, discrepancies, and dissonances) can be found. It is not sufficient to only report the divergences; they need to be explained. Different strategies to address the divergences have been suggested such as reconciliation, initiation, bracketing and exclusion (Pluye et al., 2009b). Rate this criterion 'Yes' if there is no divergence.
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? Explanations The quality of the qualitative and quantitative components should be individually appraised to ensure that no important threats to trustworthiness are present. To appraise 5.5, use criteria for the qualitative component (1.1 to 1.5), and the appropriate criteria for the quantitative component (2.1 to 2.5, or 3.1 to 3.5, or 4.1 to 4.5). The quality of both components should be high for the mixed methods study to be considered of good quality. The premise is that the overall quality of a mixed methods study cannot exceed the quality of its weakest component. For example, if the quantitative component is rated high quality and the qualitative component is rated low quality, the overall rating for this criterion will be of low quality.

6.4 Appendix D: Caldicott Approval Letter



Lothian NHS Board

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 465 5452

NHS
Lothian

Ms Kirsty Killick
Trainee Clinical Psychologist
Lothian Older Peoples Psychology Service
Royal Edinburgh Hospital
Morningside Terrace
Edinburgh EH10 5HF

Date 17 February 2021
Your Ref
Our Ref CG/DF/20193

Enquiries to Caldicott Office
Extension 35452
Direct Line 0131 465 5452

Dear Ms Killick

CALDICOTT APPLICATION 20193

Thank you for the information supplied

Request received from	Ms Kirsty Killick
Summary of proposal	An evaluation of the efficacy of different delivery formats of the Newcastle Model for stress and distress in dementia
Patient identifiable information requested	Age, Gender
Approved	Yes
Advice	

Yours sincerely

Miss Tracey Gillies
Executive Medical Director

Our Values Into Action

disability confident EMPLOYER

CARER POSITIVE Employer in Scotland EXEMPLARY

Headquarters
Waverley Gate
2-4 Waterloo Place
Edinburgh EH1 3EG

Interim Chair Esther Roberton
Chief Executive Calum Campbell
Lothian NHS Board is the common name of Lothian Health Board

6.5 Appendix E: University of Edinburgh Ethics Application & Approval

University of Edinburgh, School of Health in Social Science

Research Ethics, Integrity and Governance

The forms required when seeking ethical approval in the School of Health and Social Sciences have now been merged into this single electronic document. The sections you are required to complete will depend on the nature of your application. Please start to complete the form from the beginning and proceed as guided. On completion the *entire* document should be submitted electronically to your section's ethics administrator using the email addresses detailed on the final page.

Applications submitted without appropriate documentation will be returned.

Please work your way through this form, reading the questions and accompanying information carefully. Sections highlighted in yellow are mandatory, so you must answer all the questions in these sections.

Aside from the mandatory questions you won't always need to answer all of the questions in the form. Section 1 "your project details" includes a set of filter questions that determine the rest of the questions you need to answer. Please read the notes carefully to make sure you answer the right questions. The notes contain hyperlinks so you can jump directly to the relevant section.

Sections highlighted in yellow are **mandatory**. These must be completed for every application.

Section 1: Introduction
Section 2: Your project details
Section 3: Description of the research
Section 4: Potential risks to participants and researchers
Section 5: Participants and data subjects
Section 6: Participants or data subject information and consent
Section 7: Confidentiality and handling of data
Section 8: Security sensitive material
Section 9: Copyright
Section 10: Good conduct in collaborative research
Section 11: Good conduct in publication research

SECTION 1: Introduction

This is a:

New application for ethical approval – first submission ☒
A resubmission following reviewer comments ☐
A resubmission with requested amendments ☐

Please select your School:

☒ School of Health in Social Science

Please select your subject area

☐ CPASS
☒ Clinical Psychology
☐ Nursing Studies

It is each researcher's responsibility to check whether their project requires Sponsorship, Caldicott Approval, R&D approval, and/or IRAS. https://www.ed.ac.uk/health/research/ethics/sponsorship-and-governance

If the project requires any of these, these need to be secured prior to submitting this application.

Please tick the relevant box before proceeding:

I have checked and this project does not require Sponsorship, Caldicott, R&D and/or IRAS approval ☐

My project requires Sponsorhip ☐	Sponsorship letter attached ☐
My project requires Caldicott approval ☒	Caldicott approval letter/e-mail attached ☐
My project requires R&D approval ☐	R&D approval letter/e-mail attached ☐
My project requires IRAS approval ☐	IRAS approval letter/e-mail attached ☐

External Research Ethics Approval

Does your research project require the approval of any other institution and/or ethics committee, nationally or internationally?

Please state the name of the review body and the current status of your application (for example, submitted, approved, deferred, or rejected)? Please include any known submission / approval timelines.

SECTION 2: Your project details

2.1 Project details

Your name: Kirsty Killick

Please enter your project title: An evaluation of the efficacy of different delivery formats of the Newcastle Model for stress and distress in dementia

Modelling

Proposed Project Start Date: January 2021

Proposed Project End Date: 1/5/21

Q1. Are you a member of staff or a student?

☐ Staff member

Supplementary questions for staff members only:

List the names and institutions of any Co-Investigators working with you on the project.

☒ Student

Supplementary questions for students only:

What type of student are you?

Postgraduate

Please provide your course title or programme name

Doctorate in Clinical Psychology

Who is your supervisor?

Dr David Gillanders

Q2. Please indicate any external ethical guidance your project has to adhere to. For example, the British Psychological Society (BPS), the British Academy, the British Association of Sport and Exercise Sciences (BASES)

British Psychological Society (BPS)

2.2 Participants

Q3. Will you be collecting or generating any new data (including autoethnographic writings)?

☐ Yes
☒ No

Q4. Will you be extracting, re-coding or using existing data that contains sensitive information (i.e., identifiable information)?

☐ Yes
☒ No

If the answers to both Q3 and Q4 are 'no' you are not required to complete:

Section 4: Potential risks to participants and researchers
Section 5: Participants and data subjects
Section 6: Participant or data subject information and consent

2.3 Security-Sensitive Material

Q5. Does your research project fit into any of the following security-sensitive categories?

☐ Your research project is commissioned by the military.

☐ Your research project is commissioned under an EU security cell.

☐ Your research project involves the acquisition of security clearances.

☐ Your research project concerns groups which may be construed as terrorist or extremist

If you answer 'yes' to any of the questions above you must complete Section 8 Security Sensitive Material. You must answer all questions in the section.

2.4 Good Conduct in Collaborative Research

Q6. Will your research project involve collaborative work?

☐ Yes
☒ No

Selecting "Yes" to this question means you must complete Section 10 "Good conduct in collaborative research" later in the form. You must answer all questions in the section.

2.5 Project Funding

Q7. Is funding required for your research project? (To be completed by staff only)

Please indicate how the project will be financially supported.

2.6 Knowledge Exchange and Impact

Q8. Will there be any knowledge exchange and impact activities associated with this project? (To be completed by staff only)

2.7 Consultancy Potential

Q9. Could your research project lead to potential consultancy activities in the future? (To be completed by staff only)

SECTION 3: Description of the research

Q10: Please use the box below to describe your research; including a background summary, rationale, research questions and hypotheses, methodology, procedures. If you have identified ethical considerations that are not addressed in other parts of the form, please outline and discuss them here.

Background Summary

'Dementia' includes a range of conditions characterised by progressive loss of brain cells and deterioration in cognitive function that is greater than normal ageing (James & Jackman, 2016; World Health Organisation, 2019). Dementia affects memory, thinking, orientation, comprehension, the ability to learn new information, calculation, language and judgement. Impairment in emotional control, social behaviour and motivation are also common (WHO, 2019). In line with the ageing population and an increase in lifespan, the total number of people living with dementia in Scotland is expected to rise to 115, 200 by 2040, representing a 74% change.

Dementia is frequently associated with behavioural disturbances such as hitting, grabbing, kicking, spitting, shouting, physical sexual assault, verbal sexual advances, pacing, following others, repetitive questions/requests for help, apathy and urinating in inappropriate places (James & Jackman, 2016). These behaviours can be understood as expressions of stress and distress occurring in a social context, described as "behaviours that challenge (BtC). Research suggests that prevalence rates of dementia in UK nursing and care homes is estimated to be between 55% and 91% (Stewart et al., 2014). It is estimated that more than 90% of PLwD display at least one BtC throughout the course of living with dementia (Azermai, 2015; Ballard et al., 2009; Lyketsos, 2007). BtC are associated with significant implications for PLwD, informal carers and health and social care professionals (Livingston et al., 2017).

Interventions for BtC

The NICE (2018) guidelines state that psychosocial and environmental interventions should be offered as first line treatment for distress in dementia, with antipsychotic medication only offered if PLwD are at risk of harming themselves or others or they are experiencing agitation, hallucinations or delusions that are causing them severe distress. In practice, antipsychotic medication is frequently used as a first line response to distressed behaviours. 'Scotland's Dementia Strategy' (2013) and 'The Matrix' (2015) advocate psychological approaches in response to stress and distress in dementia, particularly formulation-led interventions that identify the individual needs of the PLwD.

The Newcastle Model (TNM) (James et al., 2006) is a 14 week high intensity intervention incorporating individualised assessment, formulation and intervention provided by specialist teams for use in 24-hour care settings. TNM views BtC as expressions of unmet needs, proposing that this occurs as the result of the complex interplay between the PLwD's life story, personality, cognitive abilities, mental health difficulties, physical health, medication and the social environment. It is a systemic behavioural model, conceptualising caregiver's responses to BtC as key factors in the maintenance and resolution of BtC (James & Jackman, 2016). The most intensive work occurs in the first five weeks which incorporates information gathering from the PLwD, their family and care staff, collaboratively developing a formulation of the PLwD's unmet needs and a personalised intervention plan to address them. The clinician remains in contact with the care home staff and PLwD's family for the second half of the programme to ensure that staff are supported to carry out interventions and amend the formulation and planned interventions if necessary.

There is preliminary evidence supporting the efficacy of the TNM in the form of service audits. Wood-

Mitchell et al. (2007) reported a significant reduction in frequency and severity of distressed behaviour in PLwD, and a reduction in caregiver distress in response to TNM being delivered by the team that developed TNM. The audit demonstrated that only 5% of patient referrals to the behaviour support team (between 2005-2006) were admitted to hospital, and 9% were transferred to other care settings. A similar reduction in distressed behaviour and distress in caregivers was evidenced in an audit from a behaviour support team in West Lothian (Wilson, 2016; as cited in James & Jackman, 2017). Qualitative analysis of survey responses indicated that staff developed a greater understanding of the PLwD and the distress they were experiencing following TNM intervention (Bryony, 2009 as cited in James & Jackman, 2017).

Rationale for the current study

NHS Lothian has three behavioural support services which provide specialist support for PLwD living in care homes. All teams have adopted TNM to assess and respond to distressed behaviours in patients referred to the service. One of the critiques of TNM is the length and intensive nature of the approach. Jackman and James (2017) report that 30-35% of patients did not require the full 14-week intervention programme. The behaviour support teams in NHS Lothian began trialling a condensed 6 to 9 week version of TNM in October 2018. The condensed version delivers the same assessment and intervention model in a shorter timeframe, meaning that the information sharing session (normally occurring in weeks 4-5) occurs sooner to collaboratively create the intervention care plan. The aim of this was to create quicker patient flow within the behavioural support service, shorter waiting times to receive treatment and a quicker response to intervene for patients and caregivers in distress. An unpublished service evaluation in 2018 which compared patient outcome for patients who had received the full and condensed model respectively found no significant difference in patient outcome, however the author noted that the statistical analyses conducted were underpowered.

More recently, the COVID-19 pandemic necessitated the behaviour support teams delivering TNM via remote means such as telephone and videoconference. To date there is no known published literature evaluating the impact of different delivery formats of TNM on patient outcome. The extant literature for psychosocial interventions delivered to care home staff through remote means is limited.

Aim

The three behavioural support teams operating within NHS Lothian have collected routine outcome measures for all patients who have received TNM in respective databases since February 2018. Data will be de-identified prior to the research team receiving it. The proposed research project aims to conduct a retrospective analysis of routinely collected outcome measures to evaluate: a) the effectiveness of the routine clinical use of TNM in behaviour support teams outwith the model developers, and b) compare the effectiveness of different service delivery options on patient outcome.

Research Questions

The primary research is*:* What is the routine clinical effectiveness of TNM intervention provided by three specialist behaviour support teams*?*

The secondary research questions are

What is the impact of a condensed delivery format of TNM on patient outcome?

What is the impact of a remote-hybrid delivery format during the COVID-19 pandemic on patient outcome?

Methodology

NHS staff working in the three behavioural support services in NHS Lothian record clinical data in asset registered databases for audit, service development and research development purposes. This includes:

Demographic data

patient's age, gender and geographic location of care/nursing home

Service involvement data

date of referral to the service, length of time waiting to receive input from the service, length of service involvement in patient care, number of patient contacts.

Clinical outcome (primary outcome measure)

The Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, Marx & Rosenthal, 1989) is a 29-item outcome measure used to measure agitated behaviours. It is completed by a proxy, typically a care staff member who knows the resident well. Different agitated behaviours are rated by frequency of the occurrence of the behaviour (on a scale of 1-7; ranging from never to several times an hour) and disruptiveness to staff, other residents and family members on a scale of 1-5 (not at all to extremely). The CMAI is administered pre and post intervention by the behavioural support teams to assess the effectiveness of their intervention

A retrospective research design will be utilised to analyse the above data. A staff member who has routine access to the database as part of their clinical role will extract and anonymise the above data from each of the three behaviour support team's databases and securely transfer to the researcher in accordance with local R&D and Caldicott principles.

The following criteria will be used to determine which patients are included in the data analysis:

Inclusion Criteria:

Patients must have a diagnosis of dementia

Patients must be living in a nursing/care home within NHS Lothian health board.

Patients must have received TNM (standard, condensed or remote-hybrid model) in response to BtC associated with dementia.

Patients must have received TNM delivered by one of the three NHS Lothian behavioural support teams.

Data collected from February 2018 (when the same data is available from all three NHS Lothian behavioural support services).

Exclusion Criteria

Patients for whom there are no pre and post intervention primary outcome measures completed (CMAI)

Patients who did not receive TNM (full, condensed or hybrid model).

Patients who are receiving ongoing TNM intervention from the behaviour support services who do not have a routine outcome measure collected pre intervention and post an equivalent amount of time receiving TMN (e.g. 9 or 14 weeks dependent on the delivery format of TNM they are receiving)

Sample size

In the X , sample size for each of TNM delivery formats are as follows:

Standard TNM delivery (assessment commenced during 2016-End of September 2018): 77 patients
Condensed Model (initial assessment commenced between October 2018 to end of February 2020): 66 patients
Remote hybrid delivery model (initial assessment from March 2020): 11 (at present, data will be continue being collected, and analysis will be conducted in February 2021).

The X behavioural support service (which uses the standard TNM only) has data for 88 patients from February 2018 to present.

The X behavioural support service (which also uses the standard TNM only) has data for 97 patients from February 2018 to present.

Power calculation

GPower calculation indicates that 15 participants in each group (standard, condensed and remote hybrid) will be adequate to detect partial eta squared values of 0.4.

Analysis

Descriptive statistics will be used to describe the sample and explore if there are any differences in characteristics between patients who receive the standard, condensed and hybrid-remote delivery model of TNM.

A mixed ANOVA will be applied to test for differences in patient outcome between different delivery formats of TNM.

Primary Ethical Consideration

The analysis is of de-identified routinely collected patient data which is stored for clinical, service evaluation and research purposes. Thus, patients have not explicitly consented for their data to be used for a research project. Therefore, the use of this data is based on the assumption that patients provide data to the NHS in the knowledge that it will be used for purposes that are in the public interest, such as evaluating and improving clinical interventions. The researcher has consulted with the NHS Lothian Ethics Scientific Officer and sought advice regarding whether NHS ethical review was required. They were advised that NHS ethical review would not be required where data is routinely collected and anonymised to the researcher. An application for Caldicott approval for access to this data for research purposes has been submitted and is pending. The data will be fully anonymised by a member of the direct clinical care team in accordance with Caldicott principles. The researcher will only have access to de-identified data.

SECTION 4: Potential risks to participants and researchers

Q11. Is your research project likely or possible to induce any psychological stress or discomfort in the participants or others, indirectly associated with the research?

☐ Yes
☐ No

If "yes" state the types of risk and what measures will be taken to deal with such problems

Q12. Does your research project require any physically-invasive or potentially physically harmful procedures?

☐ Yes
☐ No

If "yes" give details and outline procedures to be put in place to deal with potential problems.

Q13. Does your research project require the use of privacy-invasive technology, such as CCTV, biometrics, facial recognition, vehicle tracking software?

☐ Yes
☐ No

If "yes" - Give details and outline procedures to be put in place to deal with potential problems.

Q14. Does your research project involve the investigation of any illegal behaviour or activities?

☐ Yes
☐ No

If "yes" - Give details of any illegal behavior or activities you may investigate

Q15. Is it possible that your research project will lead to awareness or the disclosure of information about child abuse or neglect?

☐ Yes
☐ No

If "yes" - Indicate the likelihood of disclosure and the procedures to be followed if you become aware that a child has been or may be at risk of harm

Q16. Is it likely that dissemination of research findings or data could adversely affect participants or others indirectly associated with the research?

☐ Yes
☐ No

If "yes" - Describe the potential risk for participants/data subjects of this use of the data. Outline any steps that will be taken to protect participants.

Q17. Could participation in this research adversely affect participants and others associated with the research in any other way?

☐ Yes
☐ No

If "yes" - Describe the possible adverse effects and the procedures to be put in place to protect against them.

Q18. Is this research expected to benefit the participants, directly or indirectly?

☐ Yes
☐ No

If "yes" - Give details of how this research is expected to benefit the participants.

Q19. Will the true purpose of the research be concealed from the participants/data subjects?

☐ Yes
☐ No

If "yes" - Explain what information will be concealed and why.

Q20. Will participants/data subjects be debriefed at the conclusion of the study?

☐ Yes
☐ No

If "no" – Why will participants / data subjects not be debriefed?

Q21. At any stage in this research could researchers' safety be compromised, or could the research induce emotional distress in the researchers?

☐ Yes
☐ No

If "yes" - Give details and outline procedures to be put in place to deal with potential problems.

Please tick to confirm you agree with the following:

I will adhere to School guidance on risk assessment and health and safety and will seek advice on project and travel insurance prior to project commencement.

☐ I agree

☐ I do not agree

☐ Not applicable

SECTION 5: Participants and data subjects. For autoethnographic research also include those who may feature in your writings.

Q22. How many participants or data subjects are expected to be included in your research project?

Q23. What criteria will be used in deciding on the inclusion and exclusion of participants/data subjects in your research project?

Q24. Are any of the participants or data subjects likely to be under 16 years of age?

☐ Yes
☐ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q25. Are any of the participants or data subjects likely to be children in the care of a Local Authority?

☐ Yes
☐ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q26. Are any of the participants or data subjects likely to be known to have additional support needs?

☐ Yes
☐ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q27. In the case of participants with additional support needs, will arrangements be made to ensure informed consent?

☐ **Yes**

☐ **No**

If "yes" – What arrangements will be made?

If "no" – Please explain why not

Q28. Are any of the participants or data subjects likely to be physically or mentally ill?

☐ Yes
☐ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q29. Are any of the participants or data subjects likely to be vulnerable or likely exposed to harm in other ways?

☐ Yes
☐ No

If "yes" - Explain and describe the nature of the vulnerability and the measures that will be used to protect and/or inform participants/data subjects.

Q30. Are any of the participants or data subjects likely to be unable to communicate in the language in which the research is conducted

☐ Yes
☐ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q31. Are any of the participants or data subjects likely to be in a relationship (i.e., professional, student-teacher, other dependent relationship) with the researchers?

☐ Yes
☐ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q32. Are any of the participants or data subjects likely to have difficulty in reading and/or comprehending any printed material distributed as part of the study?

☐ Yes
☐ No

If "yes" - Explain and describe the measures that will be used to protect and/or inform participants/data subjects.

Q33. Describe how the sample will be recruited.

Q34. Will participants receive any financial or other material benefits as a result of participation?

☐ Yes
☐ No

If "yes" - What benefits will be offered to participants and why?

Section 6: Participant or data subject information and consent

Q35. Will written consent be obtained from all participants or data subjects?

☐ Yes
☐ No

If "yes" – attach participant information sheet and consent form
If "no" – explain why not and how consent is obtained (e.g. orally), and/or if consent cannot or should not be sought for some reason, please provide a clear case and rationale for this

Q36. Have you made arrangements to tell participants what information you will hold about them and for how long?

☐ Yes
☐ No

If "yes" - what arrangements have been made?

Q37. Have you made arrangements to tell participants whether you will disclose the information to other organisations?

☐ Yes
☐ No

If "yes" - What arrangements have been made?

Q38. Have you made arrangements to tell participants whether you will combine that information with other data?

☐ Yes
☐ No

If "yes" - What arrangements have been made?

Q39. In the case of children participating in the research, will the consent or assent of parents be obtained?

☐ Yes
☐ No

If "yes" - Explain how this consent or assent will be obtained

If "no" – Please explain why you won't be obtaining consent

Q40. Will the consent or assent of children participating in the research be obtained?

☐ Yes
☐ No

If "yes" - Explain how this consent or assent will be obtained

If "no" – Please explain why not

Q41. In the case of participants who are not proficient in the language in which the research is conducted, will arrangements be made to ensure informed consent?

☐ Yes
☐ No

If "yes" – What arrangements will be made?

If "no" – Please explain why not

Q42. Does the activity involve using cookies or tracking individual's activity on a website or the Internet in general?

☐ Yes
☐ No

If "yes" – Describe the arrangements, you have put in place to obtain informed consent for the use of these tools?

SECTION 7: Confidentiality and handling of data

Q43. What information about participants/data subjects will you collect and/or use?

Pre and post Newcastle Model intervention scores on the Cohen Mansfield Agitation Inventory (CMAI)
Which behaviour support team delivered the intervention
Type of dementia
Primary distressed behaviour referral to behaviour support team was received for
Antipsychotic medication use
Psychotropic medication prescribed at time of referral to behaviour support service
Date of initial screening, assessment and discharge and if patient was admitted to hospital during the intervention.
Number of face-to-face visits during COVID-19
If family members were present at the information sharing session (a key component of the Newcastle Model intervention)

Q44. Will you collect or use NHS data?

☒ Yes
☐ No

If "yes" – what NHS data will you collect or use?

All of the data described above is collected as part of routine clinical care in NHS Lothian Older People's Psychology Service behaviour support teams. It will be de-identified prior to the researcher accessing it.

Q45. What training will staff who have access to the data receive on their responsibilities for its safe handling? Have all staff who have access completed the mandatory data protection training on the self-enrolment page of Learn?

The staff who will have access to the patient identifiable data are NHS Lothian employees and have completed staff training in Information Governance and data protection as part of NHS Lothian mandatory training. They are aware of their responsibilities and obligations to protect patient confidentiality.

The Doctorate in Clinical Psychology programme is overseen by the British Psychological Society and regulated by the HCPC and requires trainees to complete good clinical practice training to ensure that they are aware of their responsibility to protect patient confidentiality. The researcher has completed the mandatory data protection training on the self-enrolment page of Learn. The researcher has also attended a Caldicott Guidance seminar facilitated by Dr Rosalind Evans, Local Area Tutor on 5th December 2019.

All members involved in the research team will sign a supervision contract with includes a confidentiality agreement where they will comply with legal codes of practice to ensure patient confidentiality as well as lawful data protection and storage.

Q46. Will the information include special categories of personal data (health data, data relating to race or ethnicity, to political opinions or religious beliefs, trade union membership, criminal convictions, sexual orientations, genetic data and biometric data)

☒ Yes
☐ No

If "yes" – Explain what safeguards e.g. technical or organisational you have in place; including any detailed protocols if this requires special and/or external processing, storage, and analysis.

This research project is using only existing routine outcome measures stored in information asset registered databases that are collected by the behaviour support services for service evaluation purposes. Two assistant psychologists, who have access to these databases containing patient identifiable information through their respective roles in the X Behavioural Support Service, Y behavioural support service and Z behavioural support service will prepare an anonymised excel database for the researcher under the supervision of two clinical psychologists. An anonmysed participant code will be assigned to each patient in the database in place of identifiable information. The corresponding primary outcome measure (CMAI scores) and demographic information will be entered accordingly, creating a de-identified database.

The anonymous excel spreadsheet database will be stored securely on an NHS Lothian secure server for until the researcher is given access. The de-identified database will then be transferred in accordance with a secure transfer protocol and stored securely on the University of Edinburgh Microsoft 365 cloud storage for data analysis. The researcher or their academic supervisor will have no access to patient identifiable information at any point and no patient identifiable information will leave NHS Lothian.

The staff who will have access to the patient identifiable data are NHS Lothian employees and have completed staff training in Information Governance and data protection as part of NHS Lothian mandatory training. They are aware of their responsibilities and obligations to protect patient confidentiality. All staff accessing the identifiable patient data have received mandatory training in maintaining patient confidentiality and data protection as part of their NHS Lothian staff induction.

If you answered "no" to this question, please skip Q56 and continue answering the rest of the questions..

Q47. Please indicate how your research is in the public interest:

☒ Your research is proportionate
☐ Your research is subject to a governance framework
☐ Research Ethics Committee (REC) review (does not have to be a European REC)
☐ Peer review from a funder
☐ Confidentiality Advisory Group (CAG) recommendation for support in England and Wales or support by the Public Benefit and Privacy Panel (PBPP) for Health and Social Care in Scotland
☐ Other

Q48. It is essential that you identify, and list all risks to the privacy of research participants. You will then need to consider the likelihood of the risks actually manifesting and the severity of harm if the risks actually manifest.

Risk	**Likelihood of risk manifesting**			**Severity of harm**		
	Remote	**Possible**	**Probable**	**Minimal**	**Significant**	**Severe**
Identifiable due to data linkage	🟥	☐	☐	🟥	☐	☐
Identifiable due to low participant numbers	🟥	☐	☐	🟥	☐	☐
Identifiable due to geographical location	🟥	☐	☐	🟥	☐	☐
Identifiable due to transfer of data	🟥	☐	☐	🟥	☐	☐
Identifiable due to access of data	🟥	☐	☐	🟥	☐	☐
Insert more rows as appropriate	☐	☐	☐	☐	☐	☐

Please use this text box to record any other risks and the likelihood of them occurring, along with the severity of harm.

Please identify measures you could take to reduce or eliminate risks identified as possible/significant or probable/severe.

Q49. Will information containing personal, identifiable data be transferred to, shared with, supported by, or otherwise available to third parties outside the University?

☐ Yes
☒ No

If "yes" - Please explain why this necessary and how the transfer of the information will be made secure. If the third party is based outside the European Economic Area please obtain guidance from the Data Protection Officer.

Q50. Other than the use by third parties, will the data be used, accessed or stored away from University premises?

☒ Yes
☐ No

If "yes" - Describe the arrangements you have put in place to safeguard the data from accidental or *deliberate access, amendment or deletion when it is not on University premises, including when it is in transit, and (where applicable) it is transferred outside the EEA.*

The confidential patient data is generated and stored within NHS Lothian. Only de-identified data will be transferred from NHS Lothian to the University of Edinburgh in accordance with a secure data transfer protocol.

Q51. Will feedback of findings be given to your research project participants or data subjects?

☐ Yes
☒ No

If "yes" - How and when will this feedback be provided?

If "no" - Please provide rationale for this.

As the data required for this project has been collected as part of routine clinical care, consent for this specific data analysis was not sought. Consent to use this data is based on an understanding that NHS routine outcome data is used to evaluate and improve routine clinical care, which is in the public interest. The contact details of patients for whom the data is collected are not available to the researcher. Many of the participants, for whom the data is collected would lack the capacity to understand the feedback of the findings due to cognitive impairment associated with dementia. Some of the patients for whom data is collected are likely to be deceased.

The findings of the research will be fed-back to clinicians delivering the Newcastle Model intervention in the behaviour support teams.

Q52. How do you intend to use/disseminate the results of your research project?

The results of the research project will be reported in a doctoral thesis written in partial fulfilment of the Doctorate in Clinical Psychology. The results may also be written up for publication in a peer reviewed journal article.

The researcher will also present the findings to the behaviour support teams and wider Lothian Older People's Psychology Service.

SECTION 8: Security-sensitive material

The Terrorism Act (2006) outlaws the dissemination of records, statements and other documents that can be interpreted as promoting or endorsing terrorist acts.

Q53. Does your research involve the storage on a computer of any such records, statements or other documents?

☐ Yes
☒ No

If "yes" - Please tick 'Yes' to indicate that you agree to store all documents on that file store

Q54. Might your research involve the electronic transmission (for example, as an email attachment) of such records or statements?

☐ Yes
☐ No

If "yes" - Please tick 'Yes' to indicate that you agree not to transmit electronically to any third party documents stored in the file store

Q55. Will your research involve visits to websites that might be associated with extreme, or terrorist, organisations?

☐ Yes
☒ No

If "yes" - You are advised that such sites may be subject to surveillance by the police. Accessing those sites from University IP addresses might lead to police enquiries. Please acknowledge that you understand this risk by ticking 'Yes'

☐ Yes
☐ No

By submitting to the ethics process, you accept that your School Research Ethics Officer and the convenor of the University's Compliance Group will have access to a list of titles of documents (but not the contents of documents) in your document store. Please acknowledge that you accept this by ticking 'Yes'

Please confirm that you have contacted your School Research Ethics Officer to discuss security-sensitive material by ticking 'Yes'

☐ Yes, I have contacted my School's Research Ethics Officer
☐ No, I have not contacted my School's Research Ethics Officer

Section 9: Copyright

Q56. Does your project require use of copyrighted material?

☐ Yes
☒ No

If "yes" please give further details

Section 10: Good conduct in collaborative research

Q57. Does your project involve working collaboratively with other academic partners?

☐ Yes
☒ No

If “yes” - Is there a formal agreement in place regarding a collaborative relationship with the academic partner(s)?

If “no” - Please explain why there is no formal agreement in place?

Q58. Does your project involve working collaboratively with other non-academic partners?

☒ Yes
☐ No

If “yes” - Is there a formal agreement in place regarding a collaborative relationship with the non-academic partner(s)?

All members involved in the research team will sign a supervision contract.

If “no” - Please explain why there is no formal agreement in place.

Q59. Does your project involve employing local field assistants (including guides/translators)?

☐ Yes
☒ No

If “yes” - Is there a formal agreement in place regarding the employment of local field assistants (including guides and translators)?

If “no” - Please explain why there is no formal agreement in place

Q60. Will care be taken to ensure that all individuals involved in implementing the research adhere to the ethical and research integrity standards set by the University of Edinburgh?

☒ Yes
☐ No

If "no" - Please explain why care will not be taken

Q61. Have you reached agreement relating to intellectual property?

☒ Yes
☐ No

If "no" - Please explain why you have not reached agreement

Section 11: Good conduct in publication practice

In publication and authorship, as in all other aspects of research, researchers are expected to follow the University's guidance on integrity.

By ticking yes, you confirm that full consideration of the items described in this section will be addressed as applicable

☒ Yes
☐ No

Subsequent to submission of this form, **both the applicant and their supervisor should review any alterations in the proposed methodology of the project.** If the change to methodology results in a change to any answer on the form, then a resubmission to the Ethics subgroup is **required.**

The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

ALL forms should be submitted in electronic format. Digital signatures or scanned in originals are acceptable. The applicant should keep a copy of all forms for inclusion in their thesis.

Kirsty Killick	[redacted]	16.10.20
Applicant's Name	Applicant's Signature	Date signed
	David Gillanders	26.10.2020
*Supervisor Signature[1]	Supervisor Name	Date

*NOTE to Supervisor: Ethical review will be based only on the information contained in this form. If countersigning this check-list as truly warranting all 'No' answers, you are taking responsibility, on behalf of the HSS and UoE, that the research proposed truly poses no ethical risks.

ISSUES ARISING FROM THE PROPOSAL

The applicant should respond to these comments in section below.

Signature:

Position:

Date:

APPLICANT'S RESPONSE (If required)

Signature:

Date:

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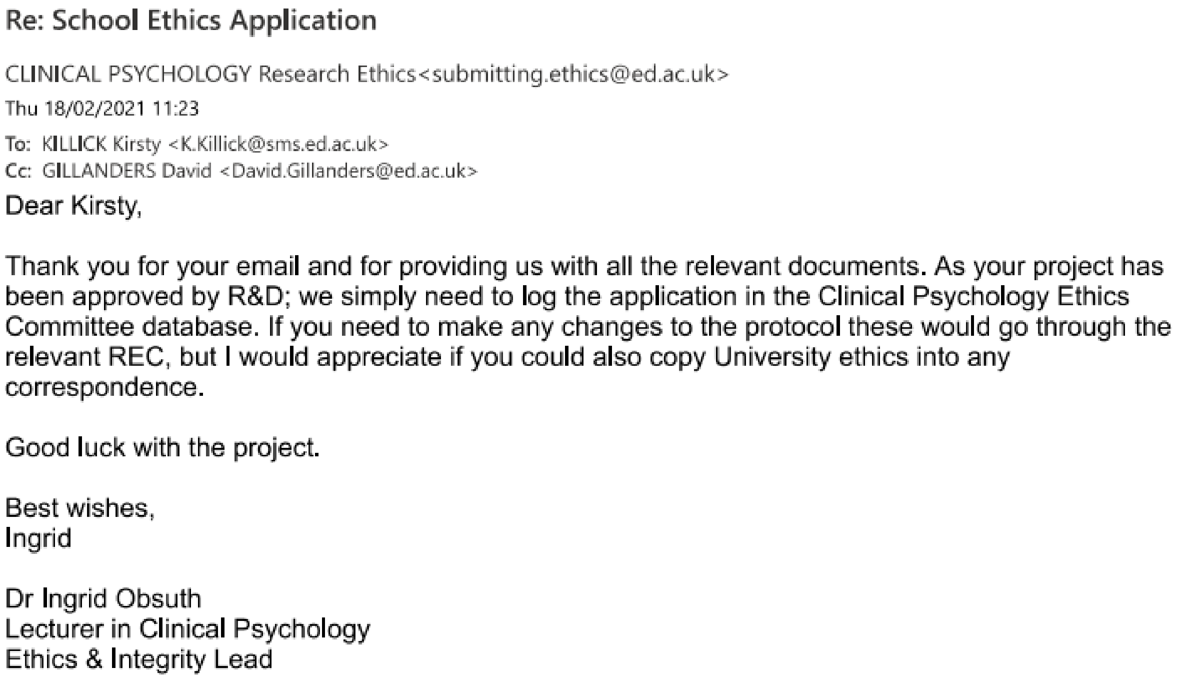
[1] Not required for staff applications



Re: School Ethics Application

CLINICAL PSYCHOLOGY Research Ethics<submitting.ethics@ed.ac.uk>
Thu 18/02/2021 11:23
To: KILLICK Kirsty <K.Killick@sms.ed.ac.uk>
Cc: GILLANDERS David <David.Gillanders@ed.ac.uk>

Dear Kirsty,

Thank you for your email and for providing us with all the relevant documents. As your project has been approved by R&D; we simply need to log the application in the Clinical Psychology Ethics Committee database. If you need to make any changes to the protocol these would go through the relevant REC, but I would appreciate if you could also copy University ethics into any correspondence.

Good luck with the project.

Best wishes,
Ingrid

Dr Ingrid Obsuth
Lecturer in Clinical Psychology
Ethics & Integrity Lead

6.6 Appendix F: List of Cohen Mansfield Agitation Inventory behaviours

Cohen Mansfield Agitation Inventory Agitated Behaviours
Pacing, aimless walking
Inappropriate dress, disrobing
Spitting (include at meals)
Cursing or verbal aggression
Constant request for attention or help
Repetitive sentences or questions
Hitting (including self)
Kicking
Grabbing onto people or things
Pushing
Throwing things
Strange noises (weird laughter or crying)
Screaming
Biting
Scratching
Trying to get to a different place (out of the room, building)
Intentional falling
Complaining
Negativism
Eating/drinking inappropriate substances
Hurt self or other
Handling things inappropriately
Hiding things
Hoarding things
Tearing things or destroying property
Performing repetitious mannerism
Making verbal sexual advances
Making physical sexual advances
General restlessness