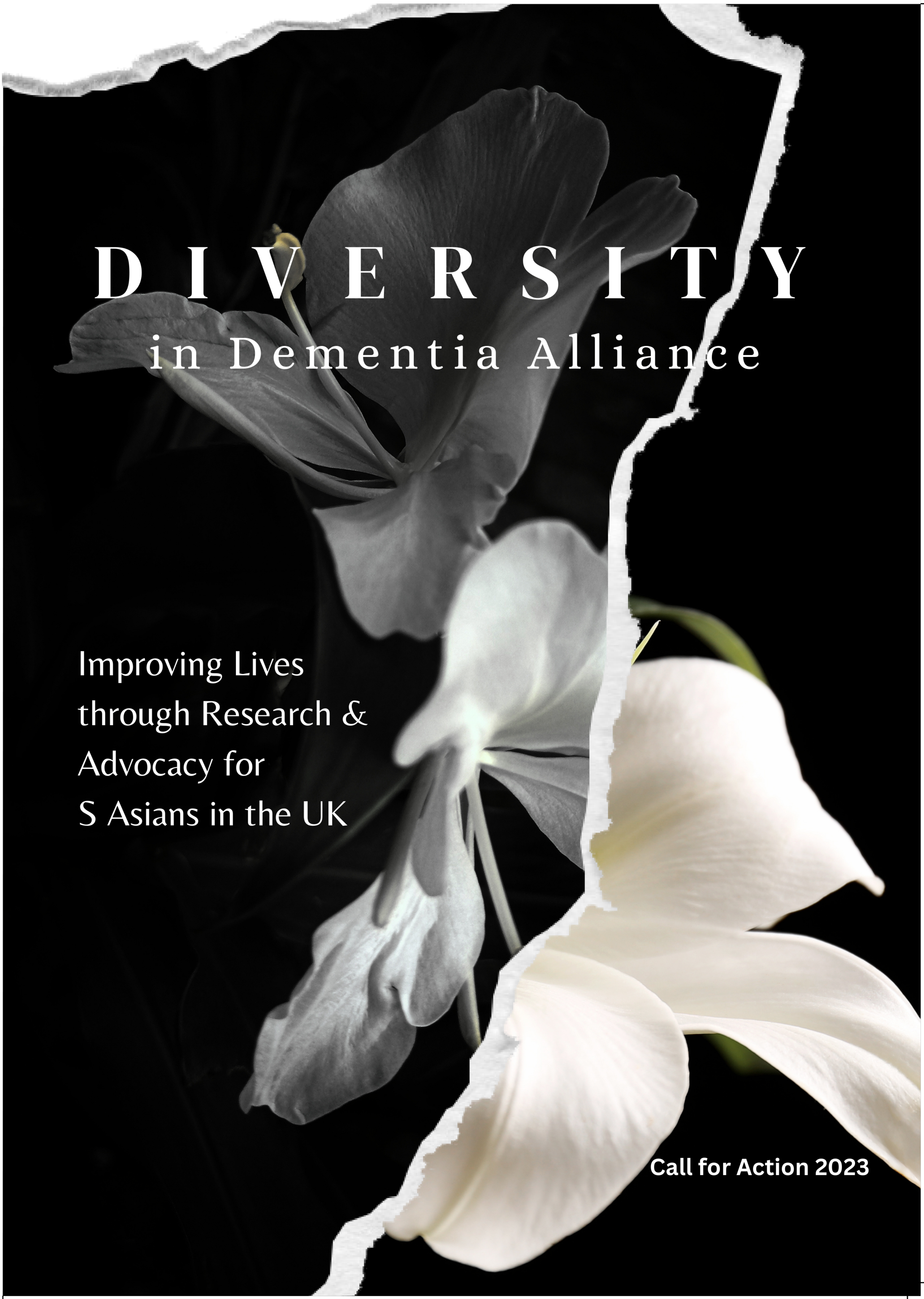

DIVERSITY
in Dementia Alliance

Improving Lives
through Research &
Advocacy for
S Asians in the UK

Call for Action 2023

DIVERISTY IN DEMENTIA ALLIANCE

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2023 CALL FOR ACTION

CALL FOR ACTION

Dementia mars the lives of people across the globe and is becoming a major contributor to the burden of disease and the need for care, as the population of the world ages. Dementia also affects young people with devastating effects on young families, children and livelihoods.

In societies with diverse populations, the impact of inequalities is disproportionately borne by people with dementia and their families from minority or marginalised backgrounds. The impact is wide-ranging from a general lack of awareness, social and religious stigma, exclusion, diagnostic delays, inappropriate assessment tools, inadequately trained health professionals and care staff, and cultural incompetency, to a lack of diversity awareness among organisational leaders, government departments and policymakers.

There is ample evidence from research of the causes of inequalities and examples of interventions which are culturally adapted and competent, but still only a drop in the ocean.

It is time for action. The Diversity in Dementia Alliance was formed as a brainchild of Sir Al Aynsley-Green who has personally and professionally witnessed the devastating impact of inadequate and insensitive care systems on patients, and Ramesh Mehta who spent his working life campaigning for equality, diversity and inclusion. The group was set up to explore what the experience might be for patients from minority ethnic backgrounds, grappling with dementia. This alliance has a mission to bring forth a ‘collaboration of the willing’ to implement actions that can improve lives through research and advocacy.

The first Diversity in Dementia Symposium hosted at the national conference of the British Association of Physicians of Indian Origin, in Manchester on Sunday 7 October 2023 proposes to focus on the implementation of actions from research on improving the lives of South Asians in the UK with dementia.

This report provides a brief outline of the evidence in the area of diversity and disparity in the diagnosis, treatment and care of South Asian patients with dementia and focuses on the actions required. This is also an open call for all individuals and organisations with shared interests to join the alliance.

Rosemary's story

I have been a doctor for more than 50 years, during which time I have seen so much courage and outstanding care for people with appalling illnesses cancers, motor neuron disease, and painful conditions, many as they approach the end of life. But nothing prepared me for the reality of the suffering of my own beloved, adored and beautiful wife of 57 years, Rosemary, as she succumbed to the cruelty of vascular dementia.

As I have seen for myself, dementia really is a cruel illness, compelling carers to see first-hand the unravelling of everything that made the life companion so much loved. At the end of her life, Rosemary didn't know who she was, who I was, not recognise her children or grandchildren or any memory of the wonderful lives we spent together.

Against the spirit of our marriage vows, I was compelled to admit her to a memory care home at the point of carer burnout. I visited her every day for nine months to spoon-feed her in the face of massive weight loss when she refused food from anyone other than me. During the 3-year descent, she developed kidney cancer-needing major surgery. I had to confront at a huge emotional cost the hospital which demanded I leave her at the door to experience surgery entirely unsupported. Eventually, they agreed to allow me to be with her as a carer so I could contribute to her care.

And then finally, she fell in her care home fracturing her hip. The emergency services demanded that she should be admitted to the hospital for her hip to be pinned under surgery – on a day with a 6-hour wait for an ambulance, 2 hours outside A&E, and up to 12 hours on a trolley in a frightening environment waiting for someone to assess her fitness for surgery. Had she been judged fit, postoperatively she would require a difficult rehabilitation (that she couldn't understand) back to life with severe dementia. I refused to call an ambulance and insisted against much opposition, on palliative care.

A compassionate GP agreed, and a diamorphine drip was setup by wonderful community nurses to relieve her pain and distress, she died quietly in my arms three days later. The care staff held our hands, they cried with us when she finally slipped peacefully away, and they came to her funeral.

Now, I've had to confront the first anniversary of her death, a further experience I was completely unprepared for, undermining the equilibrium I had achieved beforehand.

So, what insights have I learned?

- The lack of knowledge and support available to help new people and their carers facing the journey through dementia is dreadful. I was 'on my own Jack' in navigating the swamps of appalling services for dementia.
- The extremes of compassion
- The need for carers to have the courage to demand palliative care against entrenched attitudes in staff.
- The reality of confronting the first anniversary of death.

Rosemary and me in 1965

Sir Al Aynsley-Green
Professor Emeritus, University College London

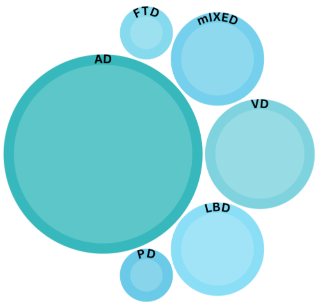
EPIDEMIOLOGY

Dementia is one of the most important health issues affecting societies across the world as the populations age. The World Health Organisation, estimates currently, more than 55 million people have dementia worldwide, over 60% of whom live in low-and middle-income countries. Projected increases in cases can largely be attributed to population growth and ageing, although their relative importance varies by world region, with population growth contributing most to the increases in sub-Saharan Africa and population and ageing contributing most to the increases in East Asia. [1] Dementia prevalence in Asia has previously been found to be lower than in Western populations, but recent studies show that age-specific prevalence rates are similar globally. Overall dementia prevalence is expected to rise dramatically across Asia due to maturing populations.[2]

Every year, there are nearly 10 million new cases. [3] Dementia is currently the seventh leading cause of death and one of the major causes of disability and dependency among older people globally. In the UK around 900,000 people are believed to be affected, this number is expected to rise to 1.5 million within the next decade.[4] A comparison of data from varying parts of the UK's health system reveals differences in recorded dementia diagnosis, indicating that the recording of dementia diagnosis needs to be tightened. [5]

In 2019, dementia cost economies globally 1.3 trillion US dollars, approximately 50% of these costs were attributable to care provided by informal carers (e.g. family members and close friends), who provide on average 5 hours of care and supervision per day. There is a considerable economic cost in the UK associated with the disease estimated at £23 billion a year, which is predicted to triple by 2040. This is more than the cost of cancer, heart disease and stroke.[4]

PATHOPHYSIOLOGY



Definition
Young-onset (onset <65 years)
Older onset (onset >65 years)
Alzheimer’s Dementia
Vascular dementia
Other causes including Lewy Body, Fronto-temporal and mixed

Alzheimer's disease

Mitochondrial damage plays an important role in AD and has been related to amyloid-beta or tau pathology or to the presence of specific presenilin-1 mutations. Elevated reactive oxygen species/reactive nitrogen species production and defective mitochondrial dynamic balance contribute to and may also be the consequence of AD-related pathology. [6]

Alzheimer's disease (AD) is the most common form of dementia and numerous studies reported a higher prevalence and incidence of AD among women. Although women have longer lifetimes, longevity does not wholly explain the higher frequency and lifetime risk in women. It is important to understand sex differences from the literature on the biological change of AD from macroscopical neuroimaging to microscopical pathologic change (neuronal degeneration, synaptic dysfunction, amyloid-beta and tau accumulation). There are sex differences in cellular mechanisms related to AD (neuroinflammation, mitochondria dysfunction, oxygen stress, apoptosis, autophagy, blood-brain-barrier dysfunction, gut microbiome alteration, bulk and single-cell/nucleus omics) and possible causes underlying these differences including sex-chromosome, sex hormone and hypothalamic-pituitary-adrenal (HPA) axis effects. [7]

PATHOPHYSIOLOGY

Vascular Dementia

Vascular cognitive impairment and dementia (VCID) is commonly caused by vascular injuries in cerebral large and small vessels and is a key driver of age-related cognitive decline. Severe VCID includes post-stroke dementia, subcortical ischemic vascular dementia, multi-infarct dementia, and mixed dementia. While VCID is acknowledged as the second most common form of dementia after Alzheimer's disease (AD) accounting for 20% of dementia cases, VCID and AD frequently coexist. In VCID, cerebral small vessel disease (cSVD) often affects arterioles, capillaries, and venules, where arteriolosclerosis and cerebral amyloid angiopathy (CAA) are major pathologies.

White matter hyperintensities, recent small subcortical infarcts, lacunes of presumed vascular origin, enlarged perivascular space, microbleeds, and brain atrophy are neuroimaging hallmarks of cSVD. The current primary approach to cSVD treatment is to control vascular risk factors such as hypertension, dyslipidemia, diabetes, atrial fibrillation and smoking.

However, causal therapeutic strategies have not been established partly due to the heterogeneous pathogenesis of cSVD but there is evidence for a probable overlapping aetiological pathways focusing on hypoperfusion/hypoxia, blood-brain barriers (BBB) dysregulation, brain fluid drainage disturbances, and vascular inflammation to define potential diagnostic and therapeutic targets for cSVD. [8]

Other Causes

Genetics

Only a small proportion of all individuals with dementia suffers from a familial form of dementia, caused by an autosomal dominant mutation. Mutations in several genes (including Aβ precursor protein, presenilin 1, and presenilin 2) have been shown to cause AD, but these genetic forms of AD account for less than 5% of all cases. The largest proportion of AD cases is therefore “sporadic”. However, genetic factors also seem to influence non-familial cases of AD.

Biomarkers

Both neuroimaging and cerebrospinal fluid can provide useful surrogate markers that give a more direct impression of the pathology.

INEQUALITIES

Gender

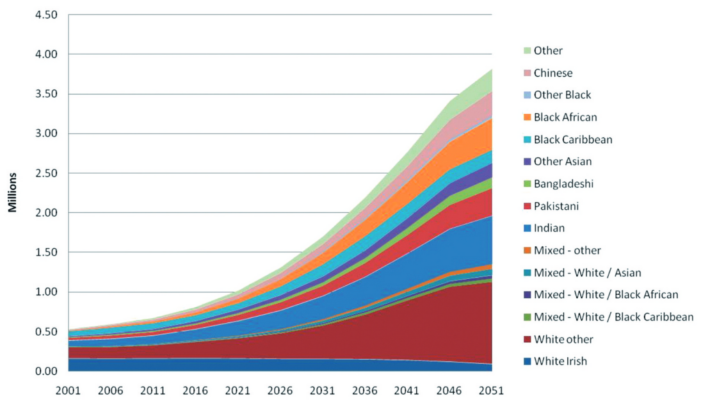
Like many other conditions, dementia does not affect everyone equally. Women are disproportionately affected by dementia, both directly and indirectly. Women experience higher disability-adjusted life years and mortality due to dementia and also provide 70% of care hours for people living with dementia. Lower educational attainment in women can be associated with an increased risk of dementia-related death independent of common risk behaviours and comorbidities.[9]

Ethnicity

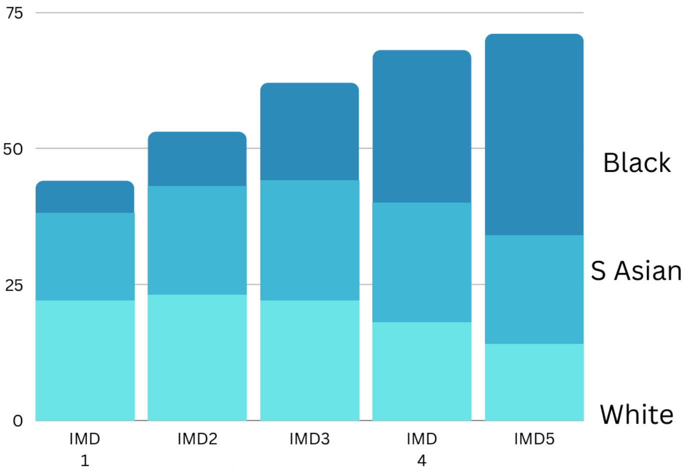
Ethnicity as a concept subsumes and conceals the impact of migration, education, health beliefs, culture, socio-economic status, and societal bias. [10,11] It is well documented that minority ethnic status is an independent contributor to many inequalities in society including health outcomes. There are limited studies of prevalence, diagnosis and service organisation or delivery in the UK of minorities including South Asians. There are even fewer clinical trials of culturally appropriate interventions for minority people with dementia. [12] It is recognised that the instruments used to assess cognitive function are culturally or linguistically biased, with one fundamental issue being language ability. [13] Illiteracy adds another layer of complexity, as only 35% of older Asians in a UK city were found to be able to speak English, 21% could read and write English, and 73% could read and write in their first language. False positive results using Mini-Mental State Examination, a fundamental screening tool for dementia, were found to be 6% in non-cognitively-impaired white people and 42% in non-impaired Black people. Cognitive assessment tests can therefore underestimate the abilities of minority ethnic groups, which can lead to unreliable outcomes or overdiagnosis. [14]

The contributors to dementia such as education, hearing loss, hypertension, obesity, excess alcohol consumption, physical inactivity, smoking, high cholesterol, depression, diabetes, social isolation, and air pollution are risks for people from all ethnic backgrounds.[15,16] However, people from the Black ethnic group appear to have a higher incidence (Odds ratio 1.43) of dementia diagnosis and are younger than those from the Asian ethnic group (Odds ratio 1.17) who had a similar incidence compared with the white majority ethnic group. [15,17]

Figure 1: The ethnic minority population of England and Wales aged 65 and over



Source: Lievesly, N (2010). The future ageing of the ethnic minority population of England and Wales. London: Runnymede Trust



proportional prevalence based on deprivation; 1= least, 5=most deprived

INEQUALITIES

It is estimated that those from minority ethnic backgrounds were less likely to have a confirmed diagnosis of dementia, indicating that the diagnosis may also be delayed or missed in this group due to lack of access. [18] Awareness of dementia appears to be suboptimal in ethnic minority cohorts in the UK which may contribute to delay in seeking help. [19,20] This lack of awareness led in many cases to the normalisation of dementia as part of getting older, preconceived ideas that dementia was not a disease. It was therefore not treatable and so the perceived need to seek medical intervention was absent. [20]

Migrants

There is a discrepancy between healthcare record studies and population surveys supporting the view that many migrants remain undiagnosed. Migrants from Asia and Africa seem to be at significantly increased risk of dementia in Europe since the prevalence rates in their countries of origin are generally not higher than those for natives in Europe.[21]

South Asian families and dementia

What we know from previous research: Approximately 25,000 people from ethnic minority communities live with dementia in the UK. The largest single grouping is people whose origins are in South Asian countries. People from these communities are at greater risk of developing dementia. However, they are less likely to access support at all points of the dementia care pathway, so are more likely to seek help in a crisis or at a later stage in the condition.

There are also differences in how people from South Asian communities use dementia services. Symptoms of dementia are more likely to be missed or misinterpreted by NHS and other services; As South Asian people are more likely to receive a diagnosis at a later stage of their illness, this limits their access to NICE-recommended treatment. People from South Asian communities are also more likely to seek support from local community organisations they are familiar with than from NHS and statutory services. The differences in access to help can mean that compared with white British people, South Asian people living with dementia and their carers are potentially disadvantaged.

INEQUALITIES

Delay in treatment/ Mistreatment

Among people with dementia, Asian groups tend to receive less potentially beneficial symptomatic treatments and Asian and Black groups are prescribed antipsychotic drugs for longer than White ethnic groups. [22] At dementia diagnosis, there are substantial differences in noncognitive mental health symptoms and pharmacotherapy across ethnic minority groups and compared with the white British majority population. Some of these differences might reflect access/treatment inequalities or implicit unconscious bias related to ethnicity, influencing both. [23]

Many reported a lack of knowledge, familiarity and awareness of services available to those with dementia, further compounded by an inability to successfully navigate the system with language barriers.[20] In many cases the attitudes of Primary Care Physicians were seen to reinforce the normalisation of ‘memory loss as part of ageing’, resulting in the minimisation of carer concerns and failure to reach a diagnosis. Services routinely lack cultural awareness and diversity for interacting with different cultural communities. Those services that did cater to the needs of minority patients were often geographically widely dispersed with long waiting lists, resulting in poor accessibility for carers and patients.[20]

Dementia Awareness

Significant amount of evidence that there is a lot of stigma attached to dementia in the South Asian communities. Whilst families may recognise the early signs of dementia such as memory loss, they struggle with changes associated with advanced-stage dementia. Dementia is often confused with mental health problems and families try to hide the diagnosis. Families have limited knowledge about the condition beyond the early signs and symptoms. Although there has been significant dementia awareness work, dementia is still mistaken as ‘just being old age’. Dementia awareness raising has mainly relied on translating leaflets into different languages. Research suggests that people prefer face-to-face dementia education preferably in a community setting.

INEQUALITIES

Assessment

Some barriers hinder the neuropsychological assessment of culturally diverse populations regarding language, culture, education and lack of suitable tests. Furthermore, individuals from diverse backgrounds are often unfamiliar with being cognitively tested. Most research has addressed the influences of language barriers, education and literacy, culture and acculturation. The European Cross-Cultural Neuropsychological Test Battery (CNTB)[24] and the Rowland Universal Dementia Assessment Scale (RUDAS) are well-validated across European countries. However, cross-cultural cognitive assessment is still a developing field in Europe, and further development is needed. [25] RUDAS-S is at least as accurate as MMSE-SR for detecting dementia in memory clinics. It can be used for all patients undergoing a cognitive assessment, irrespective of their cultural, language, and educational background. However, there is a need for other cross-cultural cognitive tests to complement RUDAS-S to extend cognitive examination. [26] [27]

Stigma, Religious or Cultural Beliefs

The stigma around mental health and dementia are fairly consistent themes, evident in many studies, demonstrating deeply held community myths or beliefs, carers and family members displaying feelings of guilt, denial, fear, embarrassment or shame, leading to denial and concealment of the condition.[20] Of particular importance was the concept of ‘outsiders’ often related to issues of trust and perceptions of racism, thus the lack of choice or culturally competent care can be a major hindrance.

Barriers to accessing specialist help for dementia included: not conceptualising dementia as an illness; believing dementia was a normal consequence of ageing; thinking dementia had spiritual, psychological, physical health or social causes; feeling that caring for the person with dementia was a personal or family responsibility; experiences of shame and stigma within the community; believing there was nothing that could be done to help; and negative experiences of healthcare services. [28] Gender-based caregiving also appears to interfere with religious ideologies while religiously appropriate healthcare services were deemed of great importance for successfully accessing those services.[29]

INEQUALITIES

There are methodological hurdles in the classification of minorities - It can result in the misclassification of individuals due to the heterogeneity that exists even within ethnic minorities, with subgroups differing within themselves in terms of many facets including language, culture, and religion. [30] The hurdles in designing interventions include community and patient education, as well as cultural competency of health services.

Diversity & Intersectionality

- Professionals

A meta-synthesis of data found limited evidence on the impact of healthcare professionals and care workers' culture on providing person-centred dementia care. The intersection of culture and dementia included understanding dementia, care and family roles. [31] Acculturation of migrant healthcare workers into the culture of the host country and workplace and support with communication are necessary for providing person-centred dementia care.

- Carers

Strategies, including the engagement of South Asian communities, demonstration of cultural competency, provision of incentives and benefits, language sensitivity through translators and translated materials, and the development of trust and personal relationships, were crucial determinants of dementia care delivery.

Erosion of Trust by the Pandemic

- At the structural level, there is inequity highlighted by differential outcomes and treatment of minority groups during the COVID-19 pandemic, a growing lack of trust in authorities/ Government confusion in its public messaging, and the anxiety sometimes leading to a boycott of media by some communities.
- At the organisational level, there is a perception of lack of person-centred and culturally sensitive care from healthcare professionals, as well as concerns around care homes as places of safety.
- At the neighbourhood community level, there is a distrust of strangers, as well as a strengthening of culturally cohesive relationships and, at the individual level, factors such as knowledge of services, identity, and faith influenced the experience.[32]

INEQUALITIES

Impact

Long before dementia is diagnosed, there is a progressive reduction in various mental and physical activities, but this is chiefly because its gradual onset causes inactivity and not because inactivity causes dementia. [33] The identifying features of dementia (from a logistic regression model for early detection) in primary care are disorientation and wandering, behaviour change, altered personality, self-neglect, and difficulty in managing socially. [34] The intra-ethnic heterogeneity is often found to be greater than inter-ethnic group variation in the diagnosis of dementia; supporting the view that ethnicity as a category may not be the only determinant in delayed or missed diagnosis. However, the experiences of people with dementia and their carers show that the important issues for service providers to consider are language, religious beliefs observance of cultural practices (including food and personal care), social support and coping mechanisms.[10] There is a paucity of cross-cultural studies of the behavioural and psychological aspects of dementia.

The impact of dementia can be devastating for those affected as their cognitive functions disintegrate, followed by basic functions - thus creating often unsurmountable challenges for those who love and care for them. The impact of dementia extends to families, especially when of young onset, affecting adversely, earnings, and livelihood, leading to significant mental anguish and hardship for all. As dementia progresses there is increasing dependence on care and a huge impact on health and social care services.

YOUNG -ONSET DEMENTIA

Young-onset dementia

The impact of young onset dementia (YOD) (age < 65 years) is especially challenging with the needs of families being almost entirely hidden. [35] Dementia at a relatively young age is unexpected, distressing, and can have devastating consequences for the person, and his or her partner and children. There are over 40,000 people with early-onset dementia (under the age of 65 years) in the UK [36] Prevalence rates of YOD have been estimated between 67 to 81 per 100 000 in the 45 to 65-year-old age group thus there are currently approximately 10 000 patients with YOD in the UK. [37] The overall global age-standardized prevalence of YOD is 119.0 per 100,000 population in the age range of 30 to 64 years, corresponding to 3.9 million people aged 30 to 64 years living with YOD in the world. Subgroup analyses showed the prevalence between men and women to be similar. [38]

YOD poses a diagnostic challenge and may present with a wide variety of subtle behavioural, cognitive, psychiatric, or neurological symptoms. While the degenerative dementias characteristically affect older patients, they are also an important cause of YOD: Alzheimer's disease is the commonest single cause of YOD with an estimated 3000 cases in the UK, followed by vascular dementia and frontotemporal lobar degeneration. The young onset forms of these diseases are frequently familial, including rare forms such as degenerative dementias as a variant of Creutzfeldt-Jakob disease typically occur in younger people. Because it occurs at a time of life when people are usually active and productive and supporting elderly parents or children/young people, YOD impacts employment, financial security and the mental health of young people in affected families.

Challenges for ethnic minority YOD

There is research based on dementia generally in South Asian families and others that expose the serious inequities and disadvantages that occur in the different cultural backgrounds in such families. Experiences of accessing services are mostly negative. Dementia services are often found to be ill-informed about how to support persons with young onset dementia, with pre-existing mental health conditions, from an ethnic minority.[39] Similar to the findings with older patients with dementia, those with YOD from minority ethnic backgrounds were found to have used memantine and cholinesterase inhibitors less often than those from a White ethnic background. [40] The differential effects on family functioning have not been researched but impacts on the children of those diagnosed are likely to be considerable, given the larger size of South Asian families.

Culturally Competent Solutions

Combatting the current one-size-fits-all model, the South Asian Dementia Pathway Toolkit [41](ADaPT) aims to provide more accessible, tailored resources enabling services to provide more culturally appropriate care. As part of the ADAPT study, a rapid review of diagnostic tools found 3 tools that had been culturally adapted and translated for the South Asian population - ACE3, RUDAS and MoCA. Designed to address the uphill struggle that many people from South Asian backgrounds face, the toolkit includes short films, animations, awareness-raising materials, assessments and post-diagnostic support – all of which have been culturally and linguistically adapted for people from South Asian communities.[42] This case study provides a paradigm shift in the design of services. There are many commonalities in the challenges facing dementia services in the UK generally (let alone in South Asian families) with those for children's services.[43]

GAP ANALYSIS

BENEFITS

1 **Information**

Awareness about dementia and health literacy amongst minority ethnic groups by developing culturally sensitive and appropriate materials. Such materials should respect all perspectives, challenge negative stereotypes, be suited to different linguistic abilities and educational levels, portray people from a range of ethnic communities, and use appropriate methods and channels of communication.

2 **Collaboration**

Build and maintain collaborative relationships with members of the relevant communities and/or gatekeepers to develop and implement appropriate tools and materials in these communities.

3 **Cultural Competency**

Undergo training in cultural awareness, sensitivity and competence to improve communication and build relationships with people from minority ethnic groups, thereby helping ensure timely, accurate and differential diagnoses and treatment of dementia amongst members of minority ethnic groups.

4 **Communication**

Using culturally sensitive/fair and appropriately validated screening, assessment and diagnostic tools for people from minority ethnic groups, administered with the help of qualified/trained interpreters (preferably with medical accreditation) when needed. Mere translations are not sufficient.

5 **Vigilance for Inequalities or bias**

Be attentive to and address interpersonal and structural discrimination against people from minority ethnic groups within healthcare systems. Recognise that inequity is not always directly linked to culture but is often inextricably bound to other variables such as income, education and housing.[44]

6 **Promoting Lifestyle**

Targeting lifestyle factors in tailored health education programs might eventually reduce socioeconomic inequalities in (brain) health. Effective public health programs in dementia prevention and care must consider this vulnerable group's needs and resources before deciding on the most appropriate preventative measures at the individual, societal, and political levels.[45]

DEMENTIA
DIAGNOSIS

PATIENT JOURNEY

A needs-based journey in which the needs of the person, the family and the staff at each milestone are defined thus allowing a different, but holistic approach to the design of services, and further study especially in the different cultural groups within South Asian and other ethnic groups.

First realisation

The first realisation that all may not be well in cognitive function usually involves observation by family members. Willingness to seek help depends on perceived social pressure from significant others around help-seeking; attitudes are influenced by stigma, beliefs, embarrassment around help-seeking and mistrust of healthcare professionals. [46]

Primary care

The point of contact with primary care and the use of screening tools which are culturally competent and either in their own native language or supported by appropriately trained interpreters.

Diagnosis

Referral to a memory clinic- which has the resources for providing a diverse and culturally competent assessment, investigations and modifiable risk factors, providing resources for health promotion and overlap with mental health conditions. Consideration of treatment options - early use of disease-modifying medication.

Disease progression

Living with dementia- support for those diagnosed and their carers including educational resources, health and social care, support for dependent children and financial considerations

End of life & beyond

Decline towards the end of life - preparation for advanced dementia including consideration of lasting power of attorney, providing for community or culturally appropriate advocates.

Family follow up

Providing a psychologically safe space for coping with disease, removal of stigma, social awareness and community support.

IMPLEMENTATION FRAMEWORK

01

ALLIANCE

- RESEARCH & IMPLEMENTATION

02

PROMOTE

- BRAIN HEALTH FROM INFANCY TO OLD AGE

03

EDUCATION & AWARENESS

04

VALIDATE

- CULTURALLY COMPETENT INTERVENTIONS AND PREVENTION STRATEGIES

05

ENGAGE COMMUNITIES

IMPLEMENTATION FRAMEWORK

06
SUPPORT LIVLIEHOOD

07
AMPLIFY THE VIEWS OF YOUNG CARERS

08
FOCUS ON YOUNG-ONSET-DEMENTIA

09
CO-DEVELOP CULTURALLY TAILORED MODELS OF CARE

10
POLICY & COMMISSIONING

Actions on dementia

ALLIANCE - AIMS

Creating an alliance for collaboration of ‘the willing’ - Healthcare organisations, charity organisations, academic institutions and those representing or advocating for people from minority or marginalised communities with a shared interest in improving the diagnosis and care of lives affected by dementia. The alliance will aim to -

- Co-develop algorithms tackling disparities which will be of value to researchers[47]
- Expand the vignettes of spectrum of disease and challenges of care by amplifying voices of those from marginalised communities. [12]
- Explore the specific determinants of inequalities in dementia care for those with multiple deprivations, minority backgrounds and their carers
- Explore evidence based interventions for improving care and support carers from diverse backgrounds
- Establish and sustain public-professional partnerships including voluntary professional organisations

PROMOTE BRAIN HEALTH FROM INFANCY TO OLD AGE

Promoting brain health for the entire lifespan can lead to reductions in incidence, prevalence and improve outcomes

- Develop and implement early population-level interventions backed by community investments such as improved education and living conditions. [48]
- Tackle known risk factors - People from South Asian backgrounds may be at a higher risk of developing dementia due to risk factors such as diabetes, and hypertension. The Dem-SAFE study exploring knowledge of risk factors and barriers to behaviour change amongst South Asian and African-Caribbean communities.
- Promote healthy lifestyles that addresse barriers and includes all sections of society
- Co-design and deliver dementia risk awareness workshops and social media campaigns that is culturally adapted for all communities.[49]
- Co-develop pilot sites, engage community leaders and organisations to initiate interventions as well as research ready population (Dementia Champions)
- Develop and advocate for curriculum that promotes knowledge of brain health and actively dispels prevalent myths
- Focus on pre-conception health and reduction of risk in pregnancy
- Stimulate intellectual development and preservation of cognitive reserve

Actions on dementia

EDUCATION & AWARENESS

Current educational content is not tailored to address the barriers, cultural or religious beliefs in minority sections of communities.

- Develop content with education and linguistic experts, that includes the full range of symptoms presenting in diverse socio-cultural backgrounds. Amplify and broadcast case studies using the full range of communication channels from barber shops, faith or religious gatherings, workshops and social media. [50]
- Deliver content with via embedded and engaged voluntary care sector groups as opposed to health care professionals.[51-52]
- Focus on tackling stigma - engage primary care to include early signs of dementia/ memory; and provide culturally competent tools to discuss the issues with stigma;
- Develop the use of Artificial intelligence to provide tools for self-screening and support primary care professionals to improve efficiency
- Research - Co-develop tools which are culturally competent and free of bias

DEVELOP & VALIDATE CULTURALLY COMPETENT TOOLS

The uptake of most diagnostic services is influenced by service users' minority ethnic backgrounds, communication difficulties, poor knowledge about dementia, inadequate cultural sensitivity of care workers, and a lack of suitably adapted dementia services are some of the main barriers. [53]

- Recognise the diverse range of communities and faiths in a multi-cultural society
- Develop and validate a whole range of culturally tailored suite of assessment tools and resources which are made readily available
- Train in culturally competent care and appoint professionals with responsibility for outreach.[54]
- Increase access to culturally tailored (mainstream) person-centred services, rather than segregated or specialised services.[10]

ENGAGE WITH COMMUNITIES

Engaging with marginalised communities is crucial for tackling disparities. Tools such as the Barts Exploratory Model Inventory-D can serve as a useful tool, in research and perhaps practice, to assess the barriers to dementia service uptake in this population and their understanding of dementia.[55]

- Create a cohort or biobank of individuals from different ethnic backgrounds to study prevention strategies and for better recruitment of participants in research.
- Encourage the use of culturally competent interpreters, translation of study materials, use of bilingual and bicultural researchers.
- Engage as partners developing mutually respectful relationships with community-based organisations and institutions.[56]
- Ensure that such relationships are well-resourced, sustained and a live forum is maintained for post-research communication of results, answering queries and dispelling myths.

Actions on dementia

SUPPORT ING LIVLIEHOODS

Patients from ethnic backgrounds have multiple deprivations, often find themselves struggling to pay for care services.[57] Not surprisingly, minority ethnic families are more involved in the provision of personal care and support. They are often unaware of support and resources available and remain excluded due to language barriers or bureaucracy.

- Raise awareness in communities of domiciliary services and especially those that have bilingual workers to support people in their home
- Have a library of community members with direct experience and are willing to act as advocates, champions or patient pathway navigators
- Train and equip social workers and community inreach staff in the intricacies of the support and living allowance application processes
- Tackle and remove barriers of bureaucracy and complicated processes for councils and government departments in accessing support for living costs or allowances

CHILDREN & YOUNG CARERS

- Consider, understand and amplify the views and impact on children, grandchildren and young people, with special consideration given to girls and young women as often they are expected to be key carers.
- Engage and equip children as ambassadors for reducing stigma in communities
- Engage children's services, healthcare organisations, mental health support for young people to develop appropriate resources for different age ranges
- Support young carers, their livliehoods with available allowances
- Engage, explore and support the impact of demenita on children's mental health

YOUNG-ONSET DEMENTIA

Minority ethnic patients with Young Onset Dementia are more likely to live in a care instituion or be homeless, exhibit problematic behaviours and neuropsychiatric symptoms but are less frail and less dependent for activities of daily living. Financial strain and loneliness are more common in people with YOD. Carers of people with YOD are more likely to feel distress, anger, or depression, and families of people with YOD are more likely to feel overwhelmed.[58]

- Research should facilitate inclusion through community engagement, collecting information on multiple aspects of age, deprivation, ethnic diversity, and adjusting/substratifying to analyse the impact of ethnicity on dementia.[56]
- Alliance aims to support ongoing studies, such as ongoing DYNAMIC study (NIHR funded and at Uni of Bradford) to pay attention to diversity in social care for people with YOD and help develop/implement recommendations
- Include experts in YOD care in the collaboration
- Consider and support the impact on mental health, social exclusion and loss of educational attainment, and future livliehood for young -onset dementia
- Develop additional support for families with YOD and their overlap with mental health conditions

Actions on dementia

CO-DEVELOP CULTURALLY TAILORED RESOURCES

Consider co-development and co-production of culturally tailored health and social service models - primarily focussing on flexible ‘Needs-based services’. Understanding local context, especially in marginalised communities, and how power and conflict affect the health of the most vulnerable is critical. South Asian carers are more culturally obligated to provide care, and feel less prepared which leads to higher levels of burden, anxiety and depression.[59]

- Co-design and co-production of culturally tailored care services engaging with councils, social services, healthcare providers and local government
- Provide education, social and financial support for family carers
- Expel the commonly perceived barriers of feeling discriminated, cultural insensitivity and mistrust from inadequately trained or equipped health and care professionals. Develop and deliver training resources/ courses for health and social care professionals to improve their knowledge and confidence in delivering person-centred culturally competent care.[60]

POLICY & COMMISSIONING

It is mportant both for services to have a more ethnically diverse workforce and for health and social care professionals from South Asian communities to be more visible. This is seen as central to increasing trust and increasing the likelihood that people will access these services.

- Providing equity of services - Carry out an Equality Impact Assessment (e.g. https://eput.nhs.uk/wp-content/uploads/2014/02/eiaguidance.pdf) for all new service developments to provide evidence that they meet the requirements of the Public Sector Equality Duty or otherwise reduce health inequality.
- Ensuring that there is diversity at all levels requires services to identify appropriate recruitment strategies and to actively manage career progression. Funding for all dementia services should be dependent on organisations demonstrating that they have met equality targets.
- Auditing services. Existing dementia services should - Ensure that data about the ethnicity of service users is collected. While most services ask practitioners to do this, they may not always do so either because they feel embarrassed to ask service users or because they don’t see the point in doing so. Use this data to audit the take-up of services broken down by clients’ ethnicity. Population projections for older (https://www.poppi.org.uk) and younger (https://www.pansi.org.uk) people can help to identify anticipated levels of uptake, against which current levels of service provision can be compared. Where inequalities of service uptake are identified, service managers need to develop an action plan to remedy this. Commissioners should consider innovative methods of funding services to ensure equity of uptake.
- Greater flexibility about service provision - Statutory services should be more flexible around service provision, including the hours and days that they will be open. For instance, during Ramadan, services may need to be available in the evenings, not just during the day.
- Continuity of funding. Funding for community sector organisations should be on the same basis as for statutory services, rather than being based around specific projects that perhaps last for just one or two years.
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CONCLUSION

Excluding ethnic minorities from research based on language, race, ethnicity, or culture fails to live up to the principle of justice, a core guiding principle in medical research, ethics and care provision. An overwhelming majority of care providers think that providing dementia care and support services to minority ethnic service users is challenging. Strategies for overcoming cultural and linguistic barriers are sparse. There is incontrovertible evidence that the experiences and outcomes of dementia for people and families in Black and minority ethnic communities are significantly worse.

Addressing these challenges demands equality, diversity and inclusion in research, engagement, education, and political action, this is the purpose of the new Alliance. There is a need for compassion in services, a focus specifically on the impact of young onset dementia, and a new practical approach to the design of services based on assessing the needs (and not the professional silos) of the person, the family and of staff at each milestone in the journey through to end-of-life care.

NEXT STEPS

Diversity in Dementia Alliance has agreed a set of targets to achieve in the next 3 years (2023-2026)

- Seek funding from different sources - community, corporate, charity and government sectors to support its mission
- Develop a cohort of research ready population which includes carers and all age groups from all the Black and minority ethnic communities
- Develop and support the work of Dementia Champions in all communities - starting with Bradford, Leicester and London
- Develop a suite of culturally adapted resources for awareness, education, diagnosis and care for patients with dementia from minority ethnic communities
- Develop a special task force for young onset dementia and young carers from minority ethnic backgrounds.
- Amplify and advocate the voices and stories of patients and carers from minority ethnic backgrounds
- Present the progress at the next BAPIO National Conference in Bristol in 2024 through a Diversity in Dementia Symposium

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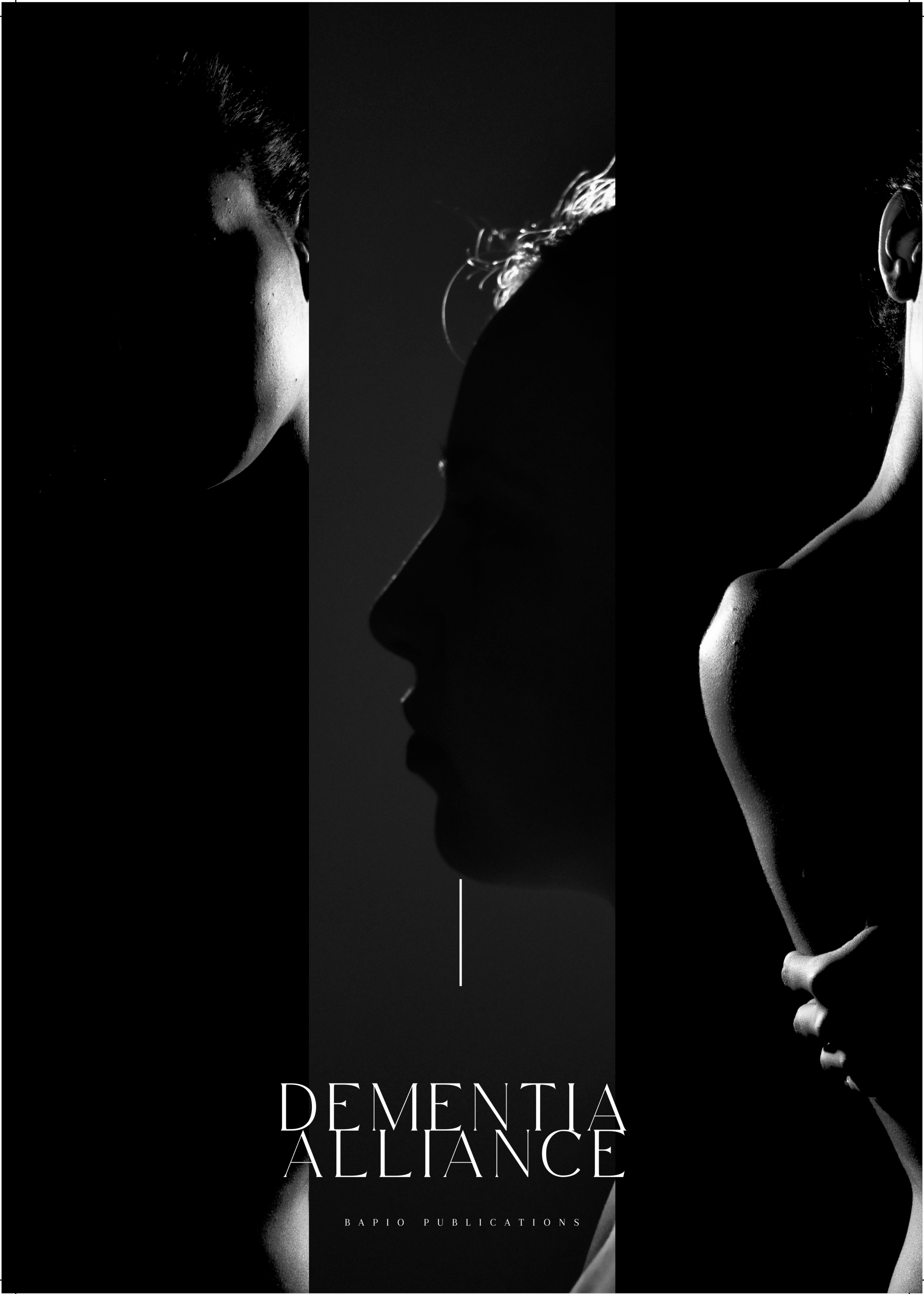

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