

Health inequalities and dementia care: what matters to people living with dementia and their families?

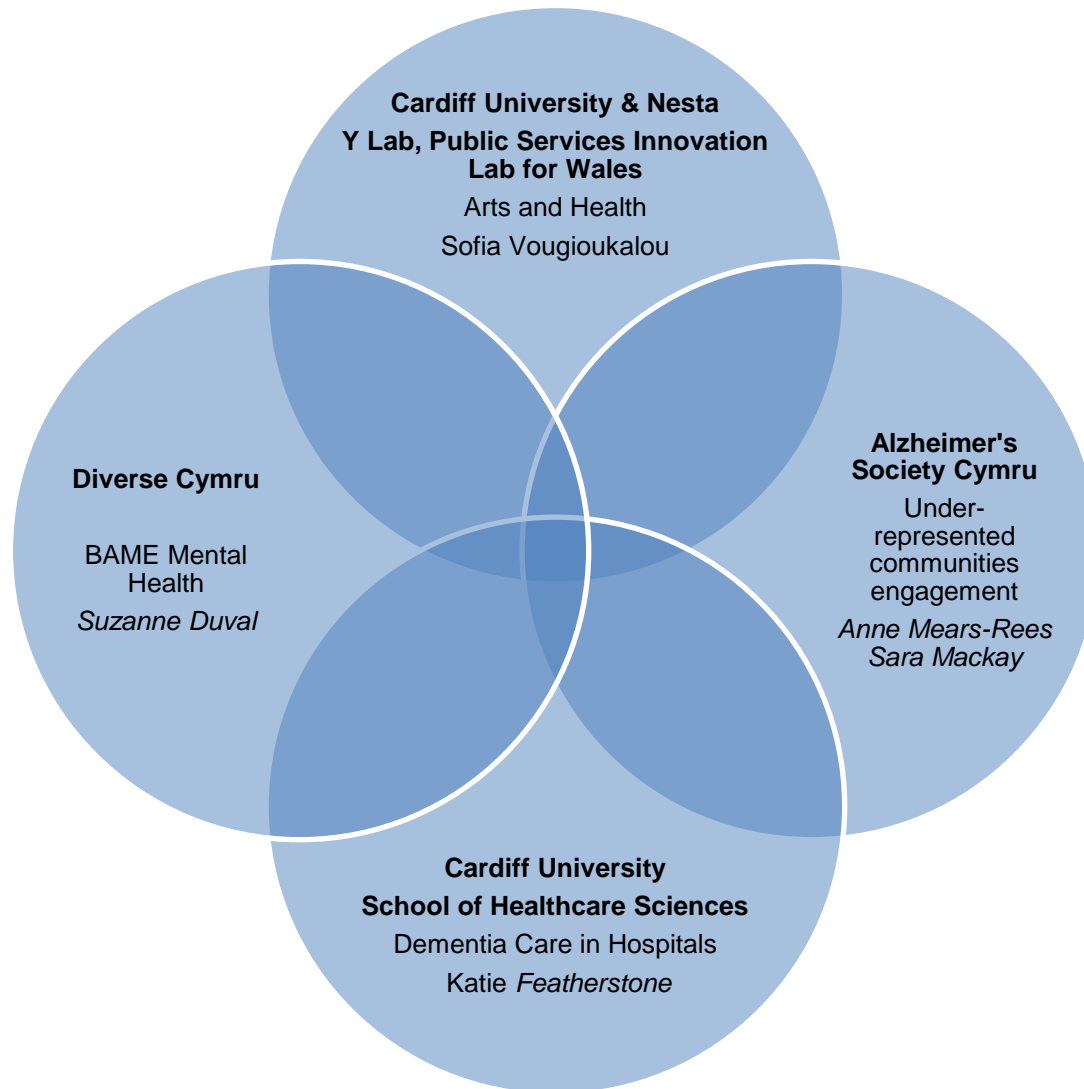


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Background



What is dementia?

- Dementia is a general term for **loss of memory, language, problem-solving** and other thinking abilities that are severe enough to interfere with daily life.
- **Alzheimer's disease** is the most common cause of dementia.
- Many conditions are **progressive**.
- Dementia is caused by **damage to brain cells**. This damage interferes with the ability of brain cells to communicate with each other. When brain cells cannot communicate normally, thinking, behavior and feelings can be affected.
- **Recent memories** go first.
- **Diagnosis** is a process.

Population impact

- In 2015, dementia overtook heart disease and stroke as the UK's **biggest cause of death**
- 2017 it was one of the **top four causes of death** (along with heart disease, stroke and lung cancer)
- Dementia is the **most common pre-existing condition for people who are dying from Covid-19** and for the 25,000 people from Black, Asian and minority ethnic (BAME) backgrounds living with the condition across the UK.
- It is estimated that in the next 40 years that there will be a 7-fold increase in the BME population and only a 2-fold increase in the White community.

Health inequalities in dementia care

- The *Dementia Action Plan for Wales 2018-2022* identified that there are **lower levels of awareness** about dementia and the existence of stigma within some minority ethnic communities in Wales can also result in these groups being under-represented in dementia services.
- Ferguson-Coleman et al. 2014: deaf people's understanding of dementia was hindered by the *lack of sustained social contact* in BSL opportunities for earlier recognition of dementia.
- Fredriksen-Goldsen et al. 2016: LGBT older adults face distinct risk factors such as social isolation, discrimination, barriers to health care access, limited availability of and support for caregivers, and higher rates of certain chronic illnesses
- McParland & Camic 2018: 'double stigma' - duality in managing dementia and identity

Approach

- Community engagement dementia awareness meetings involving 100 individuals from under-represented groups (Sept 2019 – March 2020)
- 1:2:1 or group interviews with 20 people with dementia, their children, friends and carers from under-represented groups (February 2020 – January 2021)
- Involvement of people with lived experiences in the production on filmed performances that reflected these experiences
- Analysis:
 1. **Intersectionality** – similarities and differences between equality strands
 2. **Health inequalities** – access and experiences
 3. **Sociology of stigma** – long-term impact of discrimination
 4. **Performing kinship** – sociobiological expectations, performance and acceptability of caring roles

Disclaimer

- This project did not seek to evaluate dementia care but to better understand participants' experiences and engagement preferences in our dementia research programme.
- Some of the experiences referred to incidents that happened up to 20 years ago where awareness of equalities was limited.
- We are acknowledging institutional constraints that do not allow health and care staff to spend the adequate amount of 1:2:1 time that is required to achieve a good quality of person-centred dementia care.
- We are focused on providing evidence on modifiable practices that are easy to achieve and maximize improvements in patient experience.

Dementia and sexuality

- History of religious and cultural homophobic discrimination
- People go back in the closet when they go to a care home because their memories and perceptions of care homes from 30 years ago were very bad.
- LGBT elders *'don't want to make a fuss'* because in their distant memory the society was very homophobic and would be seen as a problem
- Hospital and care home staff often assume same-sex next of kin are friends
- Hospital staff often know they are a same sex couple but insist on calling them friends.

Dementia and ethnicity

- **Bengali & Somali:** positive experiences, strong cultural and religious references on looking after one's parents, involvement of whole family including *mahram* (guardian) responsibilities
- **Greek:** some negative hospital and care home experiences incl. language, food, managing agitation and restraint
- **Native Welsh speakers:** professional linguistic ability contributed to managing agitation
- **Afro-Caribbean:** issues with the care of frail, elderly who do not have next of kin living closely, culturally-appropriate services, intergenerational communication

'As I walk the last mile of the way'

- Report on BAME experiences of dementia care for the Welsh Government
- Interviews with Afro-caribbean carers

Key themes

- **Denial/conflation with old age**
 - . *Didn't understand about it - didn't even know it was an illness*
- **Stigma**
 - . *Bad genes*
- **Avoidance of seeking help**
 - . *Worry about what other people think, I don't want professionals to think I'm an 'obnoxious Black person'*

Themes - part 2

- **white man's illness**

- *Thought it was a caucasian illness, I didn't think it was a Black thing*

- **Lack of connection with healthcare providers**

- *Receive the news better from someone who looks like them. Take it more on board*

- **Spirituality and protection from God**

- *If you are a Christian you can't get it*

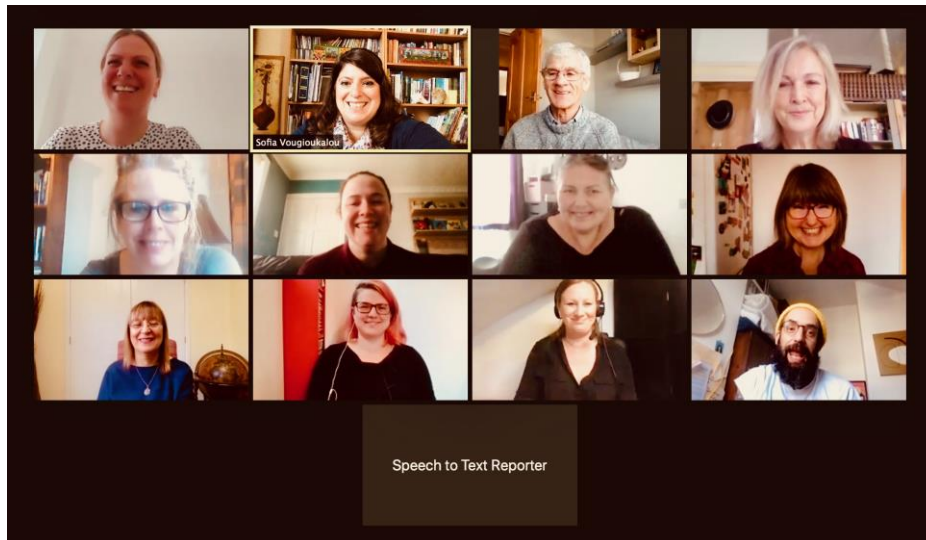
- **Pride**

- **Language**

- *Noone speaks Patois in the care home, will they understand my mother?*

Arts and Health

- Creative and visual methodologies can help participants tap into and communicate 'hard-to-express' emotions and reach wider audiences through data visualization (Mannay 2019, Tarr 2018)
- Participants worked together with artists to use creativity and decide how they wanted to communicate experiences as creative producers, public involvement advisors, script editors and performers.



'The identities of African Caribbean people who came to the United Kingdom as British Citizens have been eroded by terms such as Immigrants, BME, BAME and other derogatory terms.

This art work shares the stories of a generation of people subjected to racism in every aspect of life, from arrival as young ambitious people through to pensioners living with Dementia.'



Jazz Browne, Nubian Life



Stolen Identities

Young, healthy, vibrant, full of excitement
 Ambition and plans for the future
 Teachers, Nurses, Policemen, Drafts Men, Carpenters and
 more
 Saving, dreaming, arranging, leaving
 Family
 Community
 Unity
 And some children behind, temporally
 Believing the adverts and seizing the opportunity to work in
 the Commonwealth
 Commonwealth?
 Stolen Identities
 Vibrancy slowly fading, hopes diminishing, ambition
 thwarted
 5 year plans?
 Hard earned qualifications dismissed
 Starting all over, homeless, room sharing
 Longing for the warmth and freedom of home
 BME!
 Stolen Identities
 Accusations of stealing jobs, stealing women
 Colours fading
 Vibrant blues to dull greys
 SUS Laws, inequality, low pay
 Ingrained sparks of colour burst through
 Faith, pride, strength
 Heads held high
 Love, marriage family
 Blurring colours

Acronyms vs reality

Stolen Identities

M	D	W	I	N	D	R	U	S	H	O	H	U	I
E	I	N	I	I	N	E	A	D	N	E	R	I	N
I	S	A	A	R	T	M	H	A	T	R	E	C	E
A	C	T	E	H	F	N	G	G	F	I	L	O	Q
R	R	F	N	C	M	A	B	S	T	P	M	M	U
A	I	O	R	A	R	P	I	M	T	M	D	M	A
E	M	R	I	E	R	L	A	I	E	E	H	O	L
H	I	E	R	R	E	G	T	T	M	H	B	N	I
O	N	I	I	O	I	H	I	E	M	S	E	W	T
T	A	G	M	T	E	M	N	M	I	I	I	E	Y
D	T	N	N	D	D	T	E	O	M	T	B	A	R
R	I	E	L	R	I	B	R	H	C	I	A	L	M
A	O	R	E	A	M	C	U	C	N	R	M	T	N
H	N	S	R	H	C	H	R	B	N	B	E	H	I

IMMIGRANTS
BME
FOREIGNERS
DEMENTIA
COMMONWEALTH
INEQUALITY
BRITISH EMPIRE
I AM
WINDRUSH
HARD TO HEAR
HARD TO REACH
BAME
DISCRIMINATION

Dementia and disability

- **Sight loss:** information in the care plan not followed, issues with dignity and privacy, assumption that because blind people with dementia cannot see, it doesn't matter if others see them in a compromised state of undress.
- **Down's Syndrome:** early presentation around 30 yrs of age, well organized specialist services in primary care, under- and over- diagnosis because of learning disability.
- **D/deaf:** issues with communication, limited use of BSL interpretation and understanding of lip-reading, staff addressed hearing family members instead of D/deaf carers with primary responsibility for person with dementia, limited physical access to secure environments through audio intercoms.

Dementia and sight loss

Anne's mum's experiences of dementia care



Professional experiences

- I worked with diverse communities while at the Alzheimer's Society Cymru. In order to raise awareness of dementia across the nine strands of equality and to make services more accessible to all.
- All groups with protected characteristics under the Equality Act have faced historic discrimination. Many people are protected by more than one equality strand and face increased barriers to accessing services as a result.

Impact & research-based creative outputs

- Three short films: communication in dementia care for BAME, LGBT and D/deaf people with dementia
 - Digital story to accompany films
 - Piloting with students at Cardiff University
 - Development of baseline and post-viewing questionnaire to demonstrate impact
- ❖ Transferable contributions to other clinical pathways

Drama and dementia education

- Kontos et al. 2020: Evaluated a 12-week drama-based educational intervention to introduce to dementia practitioners person-centred care that emphasizes the notion of embodied selfhood (defined as *non-verbal self-expression*).

Findings:

- new awareness that residents' body movements and dispositions can convey meaning
- seeking biographical information from families
- increased time efficiency
- supporting residents' independence.

Next of Kin



Next of Kin is performance is based on testimonials of Deaf people who use BSL and hard of hearing carers. It highlights the difficulties in communication faced by the next of kin of people living with dementia and how lack of interpretation and good communication deprived them of their right to be equally involved in the end of their loved one's life.

Watch 'Next of Kin' video at this point
(embedded on web page)

Conclusions

- Respect, dignity and equality (or lack of) in the care encounter remain in the extended family's **memory** for a very long time
- Discriminatory experiences lead to negative outcomes and **service avoidance**
- '**Under-representation**' is system-led not deficit-led
- People can live well with dementia but this can only happen with the right support...and we can all be part of it!

Recommendations

- Not being afraid of approaching someone because of the colour of their skin
- Knowing about the person to organise family activities
- Importance of food from the culture of the pwd
- Engage in familiar cultural activities
- Knitting workshops
- Staff speaking community languages ie. Welsh, Patois, BSL, Arabic
- Diverse magazines in care homes/hospitals etc
- Train up families who have lived experience to go into communities
- Have images that look like us in your promotional materials
- Support groups
- Raising awareness
- Getting Black professionals to talk about it
- Black people delivering services
- Black people with lived experience to break down stigma

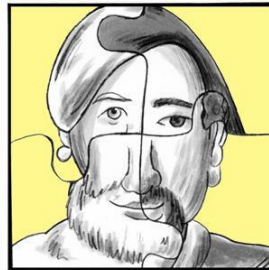
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- Research partners: Katie Featherstone, Jane Mullins, Josie Henley, Rebecca Dimond

The face of dementia is diverse. It is our face.



Dementia and Diversity
Wales



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