

EXCHANGE WALES

Black Lives Matter

Black and Minority Ethnic Carers

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BACKGROUND TO PhD RESEARCH

There is increased prevalence of LLCs amongst some BME groups

The BME parent carer voice was missing. Dearth of research with BME carers of children with LLCs.

Identify barriers to formal support?

Explore the role of religion and culture – does it form a barrier to formal support

Professional perspective- their views and experiences of working with BME parent carers

Shed light on the lived experience of this group of families University of South Wales Prifysgol De Cymru

METHODOLOGY (Doctoral Study)

The study was about the support systems of the parent carers of BME children with LLCs.

The approach adopted was a mixed methods design that incorporated qualitative and quantitative approaches.

The quantitative element played a lesser role, and involved analysing data from Wave 5 of the Millennium Cohort Study.

The qualitative element involved interviews with the parent carers of BME children with LLCs (and professionals in the field).

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What is known about carers?

Physical & Mental Health

Financial impact

Social isolation

Siblings

Academic Discourse and Beliefs

BME families do not access formal support because:

- Against cultural beliefs
- Religion prohibits them
- They have a greater resource of informal care (family / friends)

FINDINGS (Qualitative)

Religion is not a barrier to accessing formal support

Informal support parent carers valued support from friends and families but identified barriers to this support – distance and complexity of caring role and responsibilities

Formal support need for respite, peer support, social events and trips, financial support (benefits, housing adaptations, etc.) University of South Wales Prifysgol De Cymru

FINDINGS RELIGION

Carers views:

"I do read my Quran quite often. I find it quite comforting. It's actually important in hospitals and hospices, to actually have those sort of facilities", Adnan's father.

Ruby's mother no longer attended her temple after someone told her that her daughter was disabled due to some bad act in her past.

"Religion makes allowances for extraordinary situations like those of our children", Rehana's mother.

Practitioners' views:

"We found it [assessments of religious and cultural needs] weren't complete anywhere near as often as we'd like". Karen

"Sometimes assumptions are made". Angela

"I don't feel confident. There's always the fear that you're going to offend. We avoid any tricky questions". Nadine

"Staff say, 'No, we don't want to ask, we're not comfortable with asking people's religion'. It's more about them than the families". Hema

FINDINGS Professionals

'Racial' and ethnic stereotypes of BME families

Stigma and blame – BME families experienced this both from professionals and community

Lack of confidence to address and assess religious and cultural needs

Recommendations for **Practice**

Avoid assumptions and stereotypes based on race and ethnicity

Adopt an intersectional approach -

Decolonise research – "nothing about us without us".

Decolonise the teaching curriculum (Health, Education, and Social Care

Training for staff – focus should be on their own religious and cultural beliefs, micro-aggressions, unconscious bias, et al.

Demonstrate anti-racist / anti-oppressive practice

Utilise resources such as culturagrams to support assessment. Address cultural and religious needs,

Challenge stereotypes and assumptions based on'gace' and ethnicity.

Recommendations

for Social Work Adopt a proactive approach -more frequent contact with families

A multi-agency approach should be adopted across social care, health and education.

Presence of a social worker at the time of diagnosis (or very soon after) could help support a family during this challenging time

TAKE HOME MESSAGE

- To affect change, we have to embrace change.
- **Rethink the narrative around BME groups -** Avoid 'racial' and ethnic stereotypes
- **Review and redesign services** to consider diverse contexts and need. Consult people. They are the experts of their lives.
- Organisational policies and procedures communicate to all staff.
- Improve quality of data on race and ethnicity
- Training for staff Microaggressions / unconscious bias.
- Responsibility for equality and diversity work –shared; not left to BME staff.
- Ask yourself, what will success look like?





THANK YOU FOR LISTENING!

QUESTIONS?