

Links between autism stigma, ethnicity and culture

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What is stigma?

- The term 'stigma' originally comes from the Greek word 'stig' which means "a mark, dot, puncture". Ancient Greeks used it to highlight slaves or anyone of inferior social status.
- This meaning carries on today; when someone is 'stigmatised' it means we have been marked or labelled as inferior and different (in a negative way). When the public stigmatise people we call this 'social stigma' or 'public stigma'
- Unfortunately there is an abundance of evidence that autistic people (and their families) are stigmatised (we'll look at this more closely in a few minutes)

Should we care?

- Yes. Because there are a whole range of nasty consequences for people who experience stigma. Just a few include:
 - Stereotypes/negative beliefs e.g. incompetence, character weakness, dangerousness
 - Negative emotional reactions e.g. fear, anger, pity
 - Discrimination e.g. social exclusion/rejection/avoidance, employment discrimination, hate-crime, mate-crime, negative professional responses
 - Poor mental health and wellbeing e.g. depression, self-harm, loneliness, hopelessness
 - Self-stigma i.e. believing and accepting the public stigma's view of you. This can lead to even worse mental health, concealment and the 'why try' effect (Corrigan et al, 2009)

But is stigma a problem for autistic people and their families?

- Yes, exactly because of the consequences previously highlighted.
- Lots evidence exists that highlights disproportionately higher rates of social exclusion (Bancroft et al, 2012), loneliness (Mazurek 2014; Anderson, 2014), employment discrimination (Redman et al, 2009), stigma by health and social care professionals (Crabtree, 2007; Resch et al, 2010; Dababnah and Parish, 2013)
- We know that mental health problems are more common for autistic people than compared to wider general population – highly likely stigma contributes to these.

Few examples from own research

- *“Since having my autistic daughter, I have often been ignored by people and friends, and not included. This has made me feel hurt as I feel very lonely, and also I feel hurt on my daughter's behalf that people have made judgements about us. Luckily my daughter is oblivious but I have often felt hurt and down”*
- *“My sister once told me that since my son was diagnosed with autism she wouldn't ever have another baby incase she ended up like me and her child ended up like mine”*
- *“I was once told by a passer by that I should buy a gag for my daughter who had become distressed during a meltdown while shopping and that a good mother would be able to stop her from crying - I felt devastated”*

Does culture and ethnicity play a role?

- Let's look at some of the (inter-linked) reasons why it very likely does:

Reason 1: Knowledge about autism

- It's well known that possessing poor knowledge about a phenomenon increases the likelihood of stigma towards it.
- Obeid et al (2015) looked at autism knowledge among University students in the United States (n=346) and Lebanon (n=329).
- They found that both groups were stigmatising but the US students overall had higher knowledge and lower stigma
- Interestingly, they also found that both group had many misconceptions and they were group specific e.g. the Lebanese students were much more likely to believe
 - that autistic individuals lack interest in social interaction
 - are deliberately uncooperative,
 - that autism is caused by negative parenting,
- Whereas the US students more frequently believed that:
 - all autistic people had learning difficulties
 - that socio-economic inequalities do not hamper access to services
- *Take home message:* different cultural groups have different levels of understanding and knowledge meaning type and degree of stigma likely to vary across cultures.

Reason 2: Service provision

- One of the reasons why knowledge is poorer in some cultures is because there is less service provision (Grinker et al, 2011)
- Therefore, it is reasonable to expect that in cultures and communities where there is less available and accessible high quality service provision, higher rates of stigma will exist.
- Prior research has shown this: higher rates of misconceptions about autism in the Middle East and developing countries where services and resources are lower (e.g. Saudi Arabia: Alqahtani, 2012; Nepal: Kharti et al, 2011; Nigeria: Bakare et al, 2009; Pakistan: Imran et al, 2011)
- This is likely to be a 'chicken in the egg' issue – as stigma reduces in a community, we should expect services to increase (policy shifts)

Reason 3: Collectivist cultures

- Previous stigma research has found that ‘collectivist cultures’ (which prioritise community interdependence and shared group norms and values) are more likely than individualist cultures (which place priority on personal independence, goals and values) to stigmatise people who deviate from the norm.
- This is partly because such people are more likely to be identified in the community due to high surveillance levels, which such cultures rely upon in achieving their goals of interdependence and group conformity (Papadopoulos et al, 2013).
- Dababnah & Parish’s (2013) qualitative study of Palestinian parents reported that *“discrimination and stigma from extended family members and the larger community intensified parents’ feelings of shame and experiences of social isolation”* (p1670) leading parents admitting to actively hiding their situation from others due to community surveillance
- In Guler et al’s (2017) qualitative study of autism in South Africa, one parent states, *“You ... you know ... it’s that our culture. He doesn’t want to come out of the box. So he (my uncle) said that this information (his child’s ASD) must stay as it is ... a secret”* (p9)

Reason 4: Religion

- In the mental illness research domain, there is strong evidence that higher levels of religious faith are linked with higher rates of stigma (e.g. Wisneski et al, 2009; Tzouvara & Papadopoulos 2014).
- Part of the reason for this might be because higher religiosity tends to be found in communities where services are less available, inaccessible and/or are distrusted
- Nwokolo (2010) highlights that among Nigerian rural communities, where influence of religion is particularly great and so few professional services exist, it is common for families to turn to exorcism.
- Bankole (2016) agrees, arguing that in many African cultures autism is viewed to be the result of a curse or from witchcraft.
- Alqahtani (2012) has shown how Saudi Arabian parents tend to rely on cultural interventions involving religious healers, and attribute autism to the 'evil eye' which ascribes one's misfortunes to "envy in the eye of the beholder"
- Guler et al's (2017) study of autism in South Africa also reported cultural perceptions of an autistic child being cursed: *"people will think that my child has been bewitched or ... bad things happened in our house ... maybe my aunt is not happy with me and she just cursed my child or cursed me or something."* (p5)

Reason 4: Health inequalities

- We know ethnicity is a key determinant of health (and social) inequalities in England (and beyond)
- This results in BAME communities being less likely to be able to access to autism services
- This increases the risk of lower understanding, knowledge and awareness which in turn increases the likelihood of stigma manifesting.
- If minority groups do access services but then experience poor cultural sensitivity and awareness from service providers, they may reject these services.
- Services then lose the opportunity to engage with the community and boost understanding, and the risk of stigma remains.

So...what can we do?

A few reasonable actions:

1. Understand what is driving stigma within and across cultures. This makes sense because we can tackle the universal problems such as autism knowledge, but also the drivers unique to each culture. This means more research and building of theoretical underpinning of stigma
2. Boost high quality service provision and access, and ensure staff are culturally competent and sensitive
3. Prioritise anti-stigma campaigns and approaches among communities with most stigma, such as those which are collectivist, rural, more religious, less service provision, and highest levels of economic inequality
4. Build evidence-based stigma protection interventions for autistic people and their families that take culture into account. Without these, the risk of self-stigma remains high which could severely wellbeing and long-term outcomes

Thank you for listening

References for citations used in this presentation available on request

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