

Better
Health
Briefing

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**Internalised
stigma as a
barrier to access
to health and
social care
services by
minority ethnic
groups in the UK**

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Key messages

- 1 The concept of stigma covers a number of interrelated components, such as stereotyping, labelling, loss of status, power exertion and discrimination. Externalised stigma results from the actions of external players, internalised stigma is an individual's own sense of devaluation and discrimination.
- 2 Black Africans and other minority ethnic groups in the UK are likely to perceive themselves as outsiders, hence they are likely to experience stigma. This may have knock on effects, such as shunning health and social care services.
- 3 Evidence suggests that HIV positive Black Africans in the UK are likely to conceal their HIV status and to forfeit potential sources of social support because of internalised stigma.
- 4 There is need for research into internalised stigma among minority ethnic groups in the UK to inform current and future campaigns addressing stigma. Such research and subsequent interventions should involve all stakeholders involved in services targeting minority ethnic groups in the UK.

Introduction

Stigma is a widely researched phenomenon (Goffman, 1959, 1963; Jones and Corrigan, 2014; Link and Phelan, 2014; Rüschi and Thornicroft, 2014; Segal, 2014) because all aspects of human life, such as health and wellbeing, business, employment, sexuality, race and ethnicity, can be stigmatised. Several studies have documented the role of stigma as a barrier to access and use of health and social care services in different settings, most of them offering suggestions on how to minimise the impact on those at risk of stigmatisation (Chapple *et al.*, 2004; Larkan, 2004; Fakoya *et al.*, 2008; Obermeyer *et al.*, 2011; Kang, 2013; Link and Phelan, 2014). For example, there have been calls for cultural competency training for health and social care professionals involved in services accessed by minority ethnic groups (Airhihenbuwa *et al.*, 2013; Dinos, 2014). Despite the availability of research and subsequent interventions, such as *See Me* and *Time to Change*, stigma remains a constant risk factor for ill-health and wellbeing amongst vulnerable groups, particularly minority ethnic communities in the UK (Dinos, 2014; Owuor, 2014; Marlow *et al.*, 2015).

Most research and subsequent interventions into stigmatisation focus on tackling external stigma, defined here as stigma directed towards individuals by external players, for example, friends, family and members of the community or wider society. This article rather examines the issue of internalised stigma, that is, the individual's own sense of devaluation and discrimination. It is informed by existing literature and findings from a pilot qualitative research study involving HIV positive immigrant Black African men and their families living in London. The paper concludes with policy and practice suggestions to tackle health issues relating to stigma.

1 The concepts of stigma and the outsider complex

Each human has a unique identity comprised of their individual personality traits as well as their family history, gender, sexuality, religion, ethnicity, social class and many other personal attributes. When an individual's identity or attributes are not accepted by their community, social networks or family, then the concept of stigma becomes relevant. The concept of stigma covers a number of interrelated components such as stereotyping, labelling, loss of status, power exertion and discrimination (Airhihenbuwa *et al.*, 2013). The term thus derives different meanings depending on the context in which it is used and different scholars have defined stigma differently depending on the disciplinary or situational context of their work (Goffman, 1963; Jones *et al.*, 1984; Obermeyer *et al.*, 2011; Kang, 2013). For instance, Goffman (1963) defined stigma as a deeply discrediting attribute that reduces the bearer from being a "whole", usual individual to a tainted and discounted person. Stafford and Scott (1986) defined stigma as an individual's characteristic that is contradictory to a social group's norms and shared beliefs about an individual's expected behaviour.

According to Tajfel (2010), humans naturally cluster into groups and identify outsiders on the basis of perceived common and distinctive characteristics such as geography, country, shared history or culture. Prejudice is a key driver of stigma, that is, unfounded beliefs directed towards individuals because of their traits or attributes (Baral *et al.*, 2007). Logie and Gadalla (2009) observed that the general public, overall, hold negative attitudes towards what they perceive as a threat, whilst Scambler (2009) noted that social groups will discriminate between the 'normal' and 'abnormal' and 'insiders' versus 'outsiders'.

In any given social setting, individuals perceived to have deviant or "spoilt identities" are thus discriminated as outsiders or less worthy members of the society because they are considered less normal by the majority (Goffman, 1963). According to Goffman, stigma entails living daily life with an attribute that is deeply discrediting to the bearer. These traits can vary depending on the dominant social norms, but may include ethnicity, sexual orientation, gender, sex, religious identities, visible disabilities, body size or invisible disabilities that can discredit the individual when they are unearthed. For example, an individual who is asymptomatic HIV-positive can easily become discredited and stigmatised if their HIV status becomes known. Stigmatisation is therefore the means of distancing deviants from a group (Engebretson, 2013).

However, societal norms do change over time and, moreover, in multicultural societies such as the UK, values vary and may be accepted or rejected by different individuals depending on attributes such as their ethnicity, religion or social status. Homosexuality, for example, is more highly stigmatised in sub-Saharan Africa and its diaspora (Paparini *et al.*, 2008) than among the native white British population, although covert forms of homophobia and discrimination still prevail in the UK (Owuor, 2014). Another example is the meaning of bodyweight. Obesity is a global public health concern both in rich and resource limited settings, however, a study in South Africa found that individuals fear losing weight lest they are stigmatised for having HIV (Duncan *et al.*, 2014). Individuals from such regions are likely to view body weight differently from the rest of the UK population.

Gagnon (2012) noted that the visibility of stigmatised conditions is critical since it affects the potential for concealment, which in turn can affect the perceptions and responses of both the stigmatised and those doing the stigmatising. As Bohle (2013) pointed out, attributes evolve into stigma depending on the cultural and social norms and belief systems of a social group, as well as individual experiences.

The working definition of stigma adopted for this article is taken from Young *et al.* (2013) who defined stigma as a socially and culturally embedded process through which individuals experience stereotyping, devaluation and discrimination. This can lead to harmful internalised beliefs or actions by those stigmatised and may cause negative health outcomes. This definition captures the internalisation of stigma - the focus of this article.

2 Black and other minority ethnic groups as outsiders in the UK

According to the Office of National Statistics (ONS, 2012), there were approximately 11.2 million individuals who identified themselves as non-White British living in England and Wales by 2011. People from minority ethnic backgrounds in the UK generally have worse health outcomes and experience higher poverty than the general population, with variation between and within different ethnic groups (Patient, 2011). Minority ethnic groups are also less represented in politics, limiting their participation in policy processes (Wood and Cracknell, 2014) : by 2014, minority ethnic groups made up only 4.2% of the House of Commons (27 members) , but 12.9% of the total population (ONS, 2011).

Members of minority ethnic groups in the UK may be at greater risk of stigmatisation (Kern, 2013) due to discernible attributes, such as religious and racial characteristics, that make visible their status as immigrants or descendants of immigrants, irrespective of their actual citizenship. Subsequently, in a society that has become less tolerant of immigrants, they may be viewed as economic migrants who stay dependent on the welfare system (Owuor, 2014), “benefits scroungers” (Fogg, 2013) or “health tourists” (National Aids Trust (NAT), 2008). Such unfavourable public attitudes are linked to perceptions of social threats such as overcrowding and strain on public services (Migration Watch, 2013), unemployment, crime (British Futures, 2013) and the spread of certain diseases, including HIV (Wohlgemut *et al.*, 2012). Recent government policies such as the Immigration Act 2010, which promises to make living in the UK tougher for illegal immigrants (Home Office, 2014), are likely to further fuel negative attitude towards members of minority ethnic groups. As Neckles (2014) noted, such laws, and resultant public attitudes, risk causing further alienation or ‘othering’ of minority ethnic communities, whilst any other non-visible attribute experienced by members of particular communities that become known, (Engebretson, 2013), for example diagnosis with HIV or mental illness, would only further compound their stigmatisation.

As Douglas (1966) argued, impurity and dirt acquire wider cultural significance in relation to prevailing understandings about a social order. Furthermore, it takes power to stigmatise (Segal, 2014). Stigma is thus dependent on economic, political and social power imbalances between the stigmatised and those doing the stigmatising and individuals are more likely to be stigmatised if they are perceived to be socio-economically deprived. This is significant since minority ethnic communities in the UK are significantly more likely to be socio-economically deprived compared to the native White British majority (Burns *et al.*, 2007; Bécares *et al.*, 2009). Negative perceptions may also be transferred from those directly affected by a stigmatised attribute onto associated groups and individuals (Logie and Gadalla, 2009). This can lead to increased vulnerability, social isolation, physical violence, gossip and censure for family members and, by implication, wider minority ethnic communities (Ogunmefun *et al.*, 2011). Consequently, individuals from these communities may perceive themselves as deviants from the rest of the UK population.

Internalised stigma occurs when stigmatised individuals accept prejudice directed towards them as true (Larkan, 2004; Hasan *et al.*, 2012; Overstreet *et al.*, 2013) and is characterised by subjective perceptions of devaluation, marginalisation, shame and isolation (Boyd *et al.*, 2014). Individuals imagine how others perceive them and absorb possible responses to their attributes (such as being gay, an immigrant African with HIV, experiencing mental illness, etc.). Internalised stigma is also a key risk factor for mental illness (Rüsch *et al.*, 2014; Li *et al.*, 2015), which is common among minority ethnic groups in the UK, particularly Black Africans (Boydell *et al.*, 2012; NHS, 2014). Minority ethnic groups in the UK are thus at risk of internalised, anticipated or self-stigma (Quinn *et al.*, 2014; Segal, 2014).

There is evidence (Boyd *et al.*, 2014; Dinos, 2014) suggesting that internalised stigma can lead to various other negative outcomes for the affected individuals, such as lowered self-esteem, impaired social

adaption, limited social support and reduced access and use of health and social care services. Sinha (2008) observed that attitudes towards asylum seekers, in particular, as a burden on services and a vector for HIV transmission, has resulted in them being discouraged from accessing health services. Indeed, evidence indicates that many Black Africans in the UK, particularly men, test late for HIV (Wohlgemut *et al.*, 2012; Mukolo *et al.*, 2013). A related study by Elford *et al.* (2008) found reported cases of stigmatisation of immigrant men who have sex with men (MSM). However, they noted that it is difficult to determine the stigmatised attributes of individuals with intersecting identities, such as sexuality or membership of minority ethnic groups in the UK.

Internalised stigma can also perpetuate general stigma by creating a vicious cycle. For example, when those at risk of marginalisation avoid services due to internalised stigma or they present what they believe others would like to see in them (Goffman, 1959), they increase their risk of ill health. This may in turn perpetuate the negative stereotypes attributed to such groups. For instance, members of minority ethnic groups from South East Asia tend to have higher rates of diabetes but are less likely than the general British population to access preventive care services (Patient, 2011), due to factors including limited knowledge of services or of diabetes, competing priorities and a lack of culturally appropriate services. In most cases individuals from these backgrounds only come into contact with healthcare when they need secondary care for diabetes, thus perpetuating perceptions of these groups as being “hard to reach” or disinterested in managing their own healthcare.

Individuals who experience self-stigma may also project negative attitudes onto those they perceive to be stigmatising them, especially public services or individuals associated with such services. For example, two surveys (Dodds *et al.*, 2008; Hickson *et al.*, 2009) involving African people in England found that some individuals avoided testing for HIV because they believed they would be deported if they tested positive.

3 Internalised stigma as a barrier to accessing social support by HIV positive African immigrants in London, UK

This section is based on the findings of a qualitative PhD research study by Owuor (2014), involving immigrant men originally from East Africa, and their partners, living in London. The study was approved by Human and Health Sciences School Research Ethics Panel (SREP), at the University of Huddersfield. The aim of the study was to explore what it means for the men and their family members to live with diagnosed HIV and examine how services could best meet the needs of such individuals.

The study involved in-depth interviews with 23 participants: 5 HIV sero-concordant couples, 6 HIV-positive men, 5 workers from HIV service-provider agencies. A sero-discordant couple, where one was HIV negative, based on his most recent test, were also interviewed to get the perspectives of affected family members. Apart from four participants who were ‘open’ about their HIV status, most of the participants faced a dilemma regarding whether or not to disclose their HIV positive status to their social contacts due to the fear of being stigmatised.

Several key themes illustrating the role of internalised stigma in preventing access to health and social care emerged from the work.

Concealment of HIV status

Fourteen of the participants in the study had concealed their HIV status from most of their social contacts, including selected members of their family, wider social networks and from various health and social care professionals. Although aware of the importance of disclosure in accessing social support, the relevant participants remained very wary of the risk of the information reaching unintended individuals (however, despite their efforts to conceal their status from certain individuals, some participants believed that they might be aware of it).

Some of the participants reported cases of outright stigmatisation. For example, a participant said a friend had refused to share cutlery with him, and another said that his brother had discontinued all forms of social contact with him after he told him of his condition. However, the majority of those concealing their status based their decisions on the fear of unknown outcomes, rather than personal experiences (as there is no clear cut boundary between internalised and external stigma, it is not suggested that internalised stigma was the solitary factor leading individuals to conceal their status).

Apart from HIV specialists and HIV support workers from community organisations directly involved in their treatment and care, the participants concealing their status instead either tried to avoid or conceal their status from the professionals they engaged with, such as dentists, immigration officers, housing officers and social workers. They only sought services they absolutely needed, shunning away from what they considered non-essential. By attempting to conceal their status from certain individuals in their social networks, these participants forsook potential sources of support and limited their access to services which might be key to care and treatment.

Fear of stigmatisation leads to protective actions

A fear of stigmatisation and discrimination was the main reason highlighted by participants for concealing HIV status. Although all were on successful treatment and did not exhibit any stereotypical signs of ill health or HIV, such as severe weight loss, internalised stigma kept them guarded about their HIV status. For instance, many of the participants travelled across London in search of 'safer' HIV-related services far away from where they lived to avoid the risk of being spotted by individuals familiar to them or their family members. Many also avoided HIV support groups closest to them because they feared that someone familiar to them may be in such a group and would reveal their illness to unintended individuals who may in turn stigmatise them.

Most participants said they had not actually been stigmatised or discriminated against because, apart from their sexual partners and HIV clinicians, very few other people knew about their condition. But they perceived a very high risk of being stigmatised based on the experiences of their peers or other HIV positive people they had heard about from the media.

Only four participants in the study had 'come out' and were happy to reveal their HIV status to the people they interacted with. This was as part of their involvement in work to raise awareness of HIV. They said that, having lived with HIV for more than ten years, they did not actually experience negative reactions from the people they interacted with and who they disclosed their status to, as they had initially feared, and had decided that the best approach was to confront stigma rather than hide.

Relationship between multiple stigmatised attributes

In addition to the risk of HIV-related stigma, the study population had several other stigmatisable attributes: immigrants, low socio-economic status, African ethnicity and skin colour. The study population reported often being stigmatised in the UK as health tourists taking advantage of free healthcare. These experiences, or anticipation, of stigmatisation resulting from ethnic or socio-economic traits (Anderson,

2008a; Rudolph *et al.*, 2012) or from stereotypes relating to the exploitation of healthcare services (NAT, 2008) fit with the literature.

The relationship between HIV and perceptions of morality and faith

The participants originated from countries where HIV infection is largely moralised or perceived as a punishment for an individual's sins (Braid, 2001; Groves *et al.*, 2012; Owuor, 2014). Some participants internalised these societal views and avoided potential sources of support from their families, friends or communities because they believed that they would be deficient of their moral expectations. One participant said that she had concealed her HIV status from her family because she believed that her 'staunch' Christian family would consider her immoral. Although she had lived in the UK for 12 years without travelling back to her country of origin (because she was awaiting the outcome of her asylum application), she believed that by concealing her status from her family, she was ensuring that she retained their moral view of her. In practice, she didn't know if they still held such negative views of HIV, since knowledge and attitudes had changed a lot during the time she was away. Further, she feared potential character judgements from friends and fellow church members: *'I think they have taken me as somebody with good morals. And I don't want to taint that.'*

Her account illustrates the moralisation of HIV infection, with those infected deemed to be deficient, irrespective of how they might have acquired the disease.

4 Implications for policy and practice

There is legislation to protect those vulnerable to stigmatisation in the UK. The Equality Act 2010 consolidates previous legislation and outlaws discrimination relating to nine protected characteristics including gender, race and disability (Department for Culture, Media and Sports, 2010). However, the existence of legislation has not in practice always ensured that those vulnerable to stigma and discrimination are protected.

There have also been concerted efforts to tackle stigma and to improve access to health and social care by minority ethnic groups, especially in the area of mental health (Corlett, 2012; Dinos, 2014). However, there remains a need for research into internalised stigma amongst these communities to inform current and future UK campaigns to improve uptake. Internalised stigma among minority ethnic groups in the UK is a complex issue without clear cut cause-effect relationships, because it may be layered, with both perceived and real experiences of stigma relating to a number of different attributes including ethnicity, religion, culture and immigration history.

Such research should adopt a community-based participatory research approach (CBPR). Evidence suggests that CBPR can effectively be used to address stigma and discrimination, including internalised stigma (Grande *et al.*, 2014). CBPR is an approach that engages the participants in the entire process of research, conception, design and implementation of interventions. It has been used in various settings to address social inequalities and to facilitate the involvement and ownership of health or social care interventions by marginalised communities (Cacari-Stone *et al.*, 2014; Henderson and Rubin, 2014; Lorway *et al.*, 2014; Muhammad *et al.*, 2014; Nunn *et al.*, 2014). Freudenberg and Tsui (2014) noted that CBPR can also be used to shape policies by creating harmony between evidence and power in the policy-making process. For instance, a study exploring stakeholders' perspectives of an oral health promotion initiative, which targeted pre-school children in deprived communities in the UK, found that the participants subscribed to a community-based approach to improving access to services and stressed the need for

shared responsibility and communication (Henderson and Rubin, 2014). Another project carried out in India involving self-identifying MSM sex workers found that CBPR was very effective in mobilising community participation and increased their access to sexual health services.

Research indicates that in some settings, there have been attempts to rename stigmatised conditions in order to modify public attitudes (Chiu *et al.*, 2014; Corrigan, 2014; Ellison *et al.*, 2015). Although renaming conditions remains a contested approach, a UK-based study that explored the impact of renaming schizophrenia as 'integration disorder' (Ellison *et al.*, 2015) found that the name change led to reduced attributions of dangerousness to the condition while at the same time creating more social distance. The researchers observed that renaming conditions has a complex effect on stigma and requires further research.

In the HIV field, terminologies have evolved with advancements in knowledge about the disease. HIV-positive individuals are no longer termed as AIDS sufferers or carriers (UNAIDS, 2011). In the UK, various HIV service-provider organisations have changed their names or the services they provide partly, but not always, as a way of tackling stigma. However, Corrigan (2014) cautions that relabelling can at times yield little impact on stigma and carries the risk of diverting attention from the actual problem (stigma itself). However, as the United Nations Joint program on HIV and AIDS (UNAIDS) noted in their guidelines on appropriate terminology, language shapes beliefs and can have a significant influence on behaviours: terminology such as the 'fight' against HIV is avoided because it sounds combatant and may lead to transference from the fight against the disease to the fight against people living with the disease (UNAIDS, 2011). It is therefore worthwhile to involve all relevant stakeholders involved in services targeting minority ethnic groups in the UK to explore possible use of terminologies to minimise stigma.

Conclusion

There are concerted efforts to minimise the harmful effects of stigma on those most at risk, such as members of minority ethnic groups in the UK. Policy makers and service providers should be aware that members of minority ethnic groups in the UK may internalise stigma as a result of structural, political and socio-economic factors that position them as marginalised population groups and subsequently may avoid public services such as health and social care. Although efforts abound that aim to tackle stigma towards members of minority ethnic groups, there is less focus on tackling internalised stigma. Yet internalised stigma is a key part of the wider stigma debate that leads to ill health, enhances stereotypes that are publicly associated with membership of the stigmatised groups and prevents those who perceive themselves at risk of stigmatisation from accessing health and social care services. Practitioners should be aware that internalised stigma can lead to modifications of individual's social role and behaviour, which may include avoidance of services as the individuals attempt to make themselves less prominent to minimise the impact of their stigmatised attributes. There is therefore a need for research into internalised stigma to inform anti-stigma interventions and to increase awareness amongst health and social care professionals of the vulnerability of minority ethnic service users to self-stigmatisation and reticence towards services.

Resources

Time to Change

www.time-to-change.org.uk

Time to Change is a national initiative aimed at tackling stigmatisation and discrimination of people with mental illness in the UK. The programme includes a specific focus on stigma and discrimination in black and minority ethnic communities, for example, through the proactive recruitment and training of "champions" from minority ethnic groups. Their website also has several resources for stakeholders involved in mental health work targeting minority ethnic groups in the UK. The project focuses on perceived stigmatisers (the general public) and the social environment or structural stigma (Corrigan and Fong, 2014), rather than internalised stigma.

Stop Stigma Now

www.stopstigma.org

The US-based National Alliance for Medication Assisted Recovery (NAMA-R) programme, *Stop Stigma Now*, aims to tackle internalised stigma in addition to external stigma. The organisation works to enhance the self-esteem of people on methadone treatment and their families by challenging prejudices towards methadone treatment and confronting negative presentations of methadone treatment in the media, politics, religion and civil society. Although they target external stigma, they also target internal stigma which erodes one's self esteem. They work illustrates the complexity involved in stigma-related interventions, with the need to recognise internalised stigma not as a solitary entity, but rather a part of the whole, which needs equal focus.

References

- Airhihenbuwa, CO, Ford, CL and Iwelunmor, JI (2013) 'Why culture matters in health interventions: Lessons from HIV/AIDS stigma and NCDs', *Health Education and Behavior* <http://sph.umd.edu/sites/default/files/files/Why%20Culture%20Matters%20HEB.pdf>
- Anderson, J (2008) 'Coming and going: Some aspects of care among migrants with HIV in the UK', *Journal of Infection*, 57, pp.11–15.
- Baral, S, Karki, D and Newell, J (2007) 'Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study', *BMC Public Health*, 7,1, pp.211 www.biomedcentral.com/1471-2458/7/211
- Bécares, L, Nazroo, J and Stafford, M (2009) 'The buffering effects of ethnic density on experienced racism and health', *Health and Place*, 15,3, pp.700–708.
- Bohle, LF (2013) *Stigmatization, discrimination and illness: Experiences among HIV-Seropositive women in Tanga, Tanzania*, Universitätsverlag Göttingen.
- Boydell J, Morgan C, Dutta R, Jones B, Alemseged F, Dazzan P, Morgan K, Doody G, Harrison G, Leff J, Jones P, Murray R, and Fearon P (2012) 'Satisfaction with inpatient treatment for first-episode psychosis among different ethnic groups: A report from the UK AESOP study', *International Journal of Social Psychiatry*, 58,1, pp.98–105.
- Boyd JE, Adler EP, Otilingam PG and Peters T (2014) 'Internalized Stigma of Mental Illness (ISMI) Scale: A multinational review', *Comprehensive Psychiatry*, 55,1, pp.221–231.
- Braid, M (2001) 'On the margin', *The Guardian*, Society, p. 6, 28 November 2001 www.theguardian.com/society/2001/nov/28/aids.publichealth2
- British Futures (2013) *State of the nation: Where is bittersweet Britain heading?*, London www.britishfuture.org/national-conversations/britain/new-report-where-is-bittersweet-britain-heading
- Burns FM, Imrie JY, Nazroo J, Johnson AM and Fenton KA (2007) 'Why they wait? Key informant understandings of factors contributing to late presentation and poor utilization of health and social care services by African migrants in Britain', *AIDS Care*, 19, pp.102–108.
- Cacari-Stone, L, Wallerstein, N, Garcia, AP and Minkler, M (2014) 'The promise of community-based participatory research for health equity: A conceptual model for bridging evidence with policy', *American Journal of Public Health*, 104, 9, pp.1615–1623.
- Chapple, A, Ziebland, S and McPherson, A (2004) 'Stigma, shame, and blame experienced by patients with lung cancer: qualitative study', *British Medical Journal*, 328 www.ncbi.nlm.nih.gov/pmc/articles/PMC428516/
- Chiu, HFK, Sato, M, Kua, EH, Lee, M, Yu, X, Ouyang, WC, Yang, YK and Sartorius, N (2014) 'Renaming dementia—an East Asian perspective', *International Psychogeriatrics*, 26, 6, pp.885–887.
- Corrigan, PW (2014) 'Erasing stigma is much more than changing words', *Psychiatric Services*, 65,10, pp.1263–1264.
- Corrigan, PW and Fong, MWM (2014) 'Competing perspectives on erasing the stigma of illness: What says the dodo bird?', *Structural Stigma and Population Health*, 103, 0, pp.110–117.
- Department for Culture, Media and Sports (2010) *Equalities Act 2010* www.gov.uk/equality-act-2010-guidance
- Dinos, S (2014) 'Stigma creating stigma: A vicious circle', *Psychiatric Bulletin*, 38,4, pp.145–147 <http://pb.rcpsych.org/content/pbrcpsych/38/4/145.full.pdf>
- Dodds, C, Hickson F, Weatherburn, P, Reid, D, Hammond, G, Jessup, K and Adegbite, G (2008) *Bass Line 2007 survey: Assessing the sexual HIV prevention needs of African people in England*, London: Sigma Research www.sigmaresearch.org.uk/files/report2008b.pdf
- Douglas, M (1966) *Purity and danger: An analysis of concepts of pollution and taboo*, London: Routledge.
- Duncan, PR, Howe, LD, Manukusa, Z and Purdy, S (2014) 'Determinants of obesity and perception of weight in hypertensive patients in rural South Africa', *South African Journal of Clinical Nutrition*, 27,2, pp.56–62 www.ajol.info/index.php/sajcn/article/download/108609/98409
- Elford, J, Ibrahim, F, Bukutu, C, and Anderson, J (2008) 'HIV-Related discrimination reported by people living with HIV in London, UK', *AIDS and Behavior*, 12,2, pp.255–264 <http://openaccess.city.ac.uk/3387/1/Discrimination%20experienced%20by%20people%20living%20with%20HIV%20in%20London%20September%202007%20text%20and%20tables.pdf>
- Ellison, N, Mason, O and Scior, K (2015) 'Renaming schizophrenia to reduce stigma: Comparison with the case of bipolar disorder', *The British Journal of Psychiatry*, 206, 3.
- Engebretson, J (2013) 'Understanding stigma in chronic health conditions: Implications for nursing', *Journal of the American Academy of Nurse Practitioners*, 25, 10, pp. 545–550.
- Fakoya, I, Reynolds, R, Caswell, G and Shiripinda, I (2008) 'Barriers to HIV testing for migrant black Africans in Western Europe', *HIV Medicine*, 9, pp.23–25.
- Fogg, A (2013) 'Benefits 'scroungers'? Britain isn't convinced', *The Guardian*, 10 September 2013 www.theguardian.com/commentisfree/2013/sep/10/benefits-scroungers-british-social-attitudes
- Freudenberg, N and Tsui, E (2014) 'Evidence, power, and policy change in community-based participatory research', *American Journal of Public Health*, 104,1, pp.11–14.
- Gagnon, M (2012) 'Understanding the experience of reconstructive treatments from the perspective of people who suffer from facial lipoatrophy: A qualitative study', *International Journal of Nursing Studies*, 49,5, pp.539–548.
- Goffman, E (1963) *Stigma: Notes on the management of spoiled identity*, Penguin: London.
- Goffman, E (1959) 'The presentation of self in everyday life', in Calhoun, C, Gerteis, J, Moody, J, Pfaff, S and Virk, I (eds.) (2002) *Contemporary Sociological Theory*.
- Grande, SW, Durand, MA, Fisher, ES and Elwyn, G (2014) 'Physicians as part of the solution? Community-based participatory research as a way to get shared decision making into practice', *Journal of General Internal Medicine*, 29,1, pp.219–222 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3889937>

References

- Groves, AK, Maman, S and Moodley, D (2012) 'HIV+ women's narratives of non-disclosure: Resisting the label of immorality', *Global Public Health*, 7, pp.799–811 www.ncbi.nlm.nih.gov/pmc/articles/PMC4083735/
- Hasan, MT, Nath, SR, Khan, NS, Akram, O, Gomes, TM, and Rashid, SF (2012) 'Internalized HIV/AIDS-related stigma in a sample of HIV-positive people in Bangladesh', *Journal of Health, Population, and Nutrition*, 30, pp.22 www.ncbi.nlm.nih.gov/pmc/articles/PMC3312356/
- Henderson, E and Rubin, G (2014) 'A model of roles and responsibilities in oral health promotion based on perspectives of a community-based initiative for pre-school children in the UK', *British Dental Journal*, 216, 5, pp.E11–E11.
- Hickson, F, Owuor, J, Weatherburn, P, Reid, D, Hammond, G and Jessup, K (2009) *Bass Line 2008-09: Assessing the sexual HIV prevention needs of African people in England*, London: Sigma Research www.sigmaresearch.org.uk/files/report2009h.pdf
- Home Office (2014) *Immigration Act 2014* www.legislation.gov.uk/ukpga/2014/22/contents
- Jones, EE, Farina, A, Hastorf, AH, Markus, H, Miller, DT and Scott, RA (1984) *Social stigma: The psychology of marked relationships*, New York: W.H. Freeman & Company.
- Jones, N, and Corrigan, PW (2014) 'Understanding stigma' in Corrigan, PW (ed.) *The stigma of disease and disability: Understanding causes and overcoming injustices*, pp. 9–34, Washington DC: American Psychological Association.
- Kang, E (2013) 'Stigma and stigmatization', in Loue, S (ed.) *Mental health practitioner's guide to HIV/AIDS*, New York: Springer, pp. 393–395.
- Kern, S (2013) 'Britain: Immigration seen as top problem', *Gatestone Institute International Policy Council* www.gatestoneinstitute.org/3549/britain-immigration
- Larkan, F (2004) 'Narratives and silences in discussions of AIDS/HIV amongst young people in Mpumalanga, South Africa', *Irish Journal of Anthropology*, 7,1, pp.53–68 http://eprints.maynoothuniversity.ie/1965/1/FL_IJA_VII_04_fin.pdf
- Li, H, Holroyd, E, Lau, J, Li, X (2015) 'Stigma, subsistence, intimacy, face, filial piety, and mental health problems among newly HIV-diagnosed men who have sex with men in China', *Journal of the Association of Nurses in AIDS Care*.
- Link, BG and Phelan, JC (2014) 'Mental illness stigma and the sociology of mental health', *Sociology of Mental Health*, pp. 75–100.
- Logie, C and Gadalla, TM (2009) 'Meta-analysis of health and demographic correlates of stigma towards people living with HIV', *AIDS Care*, 21,6, pp.742–753.
- Lorway, R, Thompson, LH, Lazarus, L, du Plessis, E, Pasha, A, Mary, PF, Khan, S and Reza-Paul, S (2014) 'Going beyond the clinic: confronting stigma and discrimination among men who have sex with men in Mysore through community-based participatory research', *Critical Public Health*, 24,1, pp.73–87.
- Marlow, LAV, Waller, J and Wardle, J (2015) 'Barriers to cervical cancer screening among ethnic minority women: A qualitative study', *Journal of Family Planning and Reproductive Health Care* <http://jfprhc.bmj.com/content/early/2015/01/12/jfprhc-2014-101082.long>
- Migration Watch (2013) *What is the problem?* www.migrationwatchuk.org/what-is-the-problem
- Muhammad, M, Avila, M, Belone, L, Wallerstein, N, Sussman, AL and Duran, B (2014) 'Reflections on researcher identity and power: The impact of positionality on community based participatory research (CBPR) processes and outcomes', *Critical Sociology*.
- Mukolo, A, Villegas, R, Aliyu, M and Wallston, KA (2013) 'Predictors of late presentation for HIV diagnosis: A literature review and suggested way forward', *AIDS and Behavior*, 17, 1, pp.5–30.
- National Aids Trust (NAT) (2008) *The myth of HIV health tourism* www.nat.org.uk/Media%20Library/Files/PDF%20documents/Myth-of-HIV-Health-Tourism-Oct-2008.pdf
- National Association of People Living with HIV Australia (NAPWA) (2009) *The criminalisation of HIV transmission in Australia: Legality, morality and reality* http://criminalisation.gnppus.net/sites/default/files/2009_napwa_monograph.pdf
- National Health Service (NHS) (2014) 'Mental health', *NHS Choices* www.nhs.uk/Livewell/Blackhealth/Pages/Mentalhealth.aspx
- Nunn, A, Sanders, J, Carson, L, Thomas, G, Cornwall, A, Towey, C, Lee, H, Tasco, M, Shabazz-El, W, Yolken, A, Smith, T, Bell, G, Feller, S, Smith, E, James, G, Shelton Dunston, B and Green, D (2014) 'African American community leaders' policy recommendations for reducing racial disparities in HIV infection, treatment, and care: results from a community-based participatory research project in Philadelphia, Pennsylvania', *Health Promotion Practice*, 16,1, pp.91-100.
- Obermeyer, CM, Bajjal, P and Pegurri, E (2011) 'Facilitating HIV disclosure across diverse settings: A review', *American Journal of Public Health*, 101, pp.1011–23 www.ncbi.nlm.nih.gov/pmc/articles/PMC3093267
- Ogunmefun, C, Gilbert, L and Schatz, E (2011) 'Older female caregivers and HIV/AIDS-related secondary stigma in rural South Africa', *Journal of Cross-Cultural Gerontology*, 26,1, pp.85–102 www.ncbi.nlm.nih.gov/pmc/articles/PMC3701133/
- Office of National Statistics (ONS) (2012) *2011 Census: Population Estimates for the United Kingdom, 27 March 2011* www.ons.gov.uk/ons/rel/census/2011-census/population-and-household-estimates-for-the-united-kingdom/stb-2011-census--population-estimates-for-the-united-kingdom.html
- Overstreet, NM, Earnshaw, VA, Kalichman, SC and Quinn, DM (2013) 'Internalized stigma and HIV status disclosure among HIV-positive black men who have sex with men', *AIDS Care*, 25, pp.466–71 www.ncbi.nlm.nih.gov/pmc/articles/PMC4270468
- Owuor, JOA (2014) *Disclosure, concealment and exposure: How black immigrant men from East Africa living in the UK and their families manage communication about HIV-positive status*, Huddersfield: University of Huddersfield <http://eprints.hud.ac.uk/23321> - cannot access without password
- Paparini, S, Doyal, L and Anderson, J (2008) 'I count myself as being in a different world': African gay and bisexual men living with HIV in London. An exploratory study', *AIDS Care*, 20, pp.601–5.

References

- Patient (2011) 'Ethnic matters', *Patient.co.uk* www.patient.co.uk/doctor/ethnic-matters
- Quinn, DM, Quinn, DM, Williams, MK, Quintana, F, Gaskins, JL, Overstreet, NM, Pishori, A, Earnshaw, VA, Perez, G, Chaud, SR (2014) 'Examining effects of anticipated stigma, centrality, salience, internalization, and outness on psychological distress for people with concealable stigmatized identities', *PLoS ONE*, 9,5 http://digitalcommons.uconn.edu/cgi/viewcontent.cgi?article=1024&context=libr_oa
- Rudolph, AE, Davis, WW, Quan, VM, Ha, TV, Minh, NL, Gregowski, Salter M, Celentano DD and Go, V (2012) 'Perceptions of community and family level injection drug user (IDU) and HIV related stigma, disclosure decisions and experiences with layered stigma among HIV positive injection drug users in Vietnam', *AIDS Care*, 24, pp.239–44 www.ncbi.nlm.nih.gov/pmc/articles/PMC3289061
- Rüschi, N, Zlati, A, Black, G and Thornicroft, G (2014) 'Does the stigma of mental illness contribute to suicidality?', *The British Journal of Psychiatry*, 205, 4, pp.257–259 <http://bjp.rcpsych.org/content/205/4/257> - cannot access without password
- Rüschi, N and Thornicroft, G (2014) 'Does stigma impair prevention of mental disorders?', *The British Journal of Psychiatry*, 204, 4, pp.249–251 <http://bjp.rcpsych.org/content/204/4/249> - cannot access without password
- Scambler, G (2009) 'Health-related stigma', *Sociology of Health & Illness*, 31, 3, pp.441–455.
- Segal, SP (2014) 'Self-stigma and organizational empowerment in combined-community mental health and consumer-run services: Two randomized controlled trials', *Recovery, empowerment, and shared decision-making*, Society for Social Work and Research 2014 annual conference, 19 January 2014 <http://sswr.confex.com/sswr/2014/webprogram/Paper20054.html>
- Sinha, S (2008) 'Seeking sanctuary: Exploring the changing postcolonial and racialised politics of belonging in East London', *Sociological Research Online*, 13, 5.
- Stafford, M, and Scott, R (1986) 'Stigma, deviance, and social control' in Ainlay, S, Becker, G and Coleman, L (eds.), *The dilemma of difference*, pp. 77–91, New York: Springer US.
- Tajfel, H (2010) *Social identity and intergroup relations*, Cambridge: Cambridge University Press.
- UNAIDS (2011) *UNAIDS Terminology Guidelines*, Geneva: United Nations Joint Programme on HIV and AIDS www.unaids.org/sites/default/files/media_asset/JC2118_terminology-guidelines_en_0.pdf
- Wohlgemut, J, Lawes, T and Laing, R (2012) 'Trends in missed presentations and late HIV diagnosis in a UK teaching hospital: A retrospective comparative cohort study', *BMC Infectious Diseases*, 12, pp.72 www.biomedcentral.com/1471-2334/12/72
- Wood, J and Cracknell, R (2014) *Ethnic minorities in politics, government and public life*, London, United Kingdom: House of Commons www.parliament.uk/briefing-papers/SN01156.pdf
- Young, WB, Park, JE, Tian, IX and Kempner, J (2013) 'The stigma of migraine', *PLoS ONE*, 8, e54074 <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0054074>

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