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Unravelling the contexts of stigma: from internalisation to resistance to change.

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Abstract

This special edition on 'Understanding and Challenging Stigma' seeks to further our understandings of the types of representations and practices through which stigma is perpetuated, the social contexts within which they are produced and reproduced, and the possibilities for agency, resistance and intervention. In this introductory piece, we outline three broad approaches to stigma in the existing literature – individual, macro-social and multi-level. Aligning ourselves with the latter, we discuss how social effects become sedimented in the individual psyche in ways that often make it difficult for stigmatised group members to resist their devalued social status. This insight frames our discussion of the papers in this volume – which cover various types of stigma, drawing on research in six countries. We focus on the ways in which the papers contribute to our understandings of (i) the material, political, institutional and symbolic contexts of stigma; (ii) the possibility of resistance to stigma; and (iii) the types of interventions most likely to facilitate such resistance. We conclude that the fields of social and community psychology have a central role to play in advancing the types of understandings that are so urgently needed to inform effective multi-level stigma-reduction interventions.

The editors of this special edition are keenly aware of the limited effectiveness of strategies to reduce particular forms of illness stigma. This highlights the need for more communication between stigma researchers across various contexts to improve stigma theory, research methods and the planning and assessment of anti-stigma interventions. We have therefore brought together papers that explore stigma across various categorisations – disease (diabetes, tuberculosis, AIDS), race/ethnicity, immigration status, occupation (sex work), sexuality (gay men) and health-related behaviours (smoking), drawing on qualitative research in Ghana, India, Zambia, Tanzania, South Africa and England. The papers deal with various dimensions of stigma: causes, modes of expression, consequences and responses. Each seeks to understand the complexity of the social psychological contexts within which stigma arises, and how it might be challenged or resisted.

Goffman (1963) characterises stigma as a "mark" of social disgrace, arising within social relations and disqualifying those who bear it from full social acceptance. Marks take various forms: "abominations of the body" such as physical deformities, alleged "blemishes of individual character" such as mental illness or unemployment or "tribal identities", such as religion or ethnicity. People who possess such characteristics acquire a "spoiled identity" associated with various forms of social devaluation.

Some argue that it is important to distinguish between stigma (understood as negative ideologies or attitudes) and discrimination (negative behaviours) (e.g. Deacon, this volume). Others define stigma as a blend of affective, cognitive and behavioural responses, with the primacy of each factor resulting from variable interactions between the nature of the stigma, the context in which it is encountered, and individual differences amongst interactants (e.g. Heatherton et al., 2005).

The stigma literature is diverse, with three broad trends: the first two representing a polarisation between individual and macro-social levels of

analysis, and the third seeking to build bridges between these (Deacon et al., 2005).

Individualistic explanations for stigma – often drawing on social cognition approaches – examine psychological attributes of perpetuators or targets, or inter-individual interactions between them (e.g. Herek et al. 2002), paying limited attention to social power, inequality and exclusion. They tend to focus on the stigmatiser more often than the stigmatised, and are often associated with interventions that implicitly align stigma with ignorance, seeking to reduce stigma by providing people with 'the facts' about an illness or about stigmatised groups.

When attention is given to the stigmatised, this falls within individual-level models of stress and coping (e.g. Levin and van Laar, 2006). Existing social relations are usually taken as given. The burden of adjustment falls on stigmatised individuals – with their responses conceptualised in terms of their individual abilities to adapt to the stress of stigma. Individual counselling is often the associated intervention for stigmatised people.

The failure of individual-level approaches to effect widespread stigma reduction has led to an alternative focus on the links between stigma and wider macro-social inequalities (e.g. gender, ethnicity). Such analyses suggest that stigma is not something that individuals impose on others, but a complex social process linked to competition for power, tied into existing mechanisms of dominance and exclusion (Parker and Aggleton, 2003). Macro-social analyses imply that interventions such as anti-discrimination legislation or poverty-reduction will assist in stigma reduction. But taking this view can mean that researchers pay little attention to the individual psychological dimensions of stigma.

It is possible to straddle individual and macro-social analyses. Link and Phelan (2001) define stigma as the co-occurrence of: labelling, stereotyping, categorical in-group/out-group separation, status loss and discrimination, emphasising the exercise of power as an essential element. Rooting their

explanations in psychoanalytic theory rather than social cognition, Crawford (1994) and Joffe (1999) highlight the processes through which the individual and social are inextricably intertwined in the construction of stigma. They argue for a universal human fear of uncertainty and danger. Individuals project this onto identifiable out-groups – responding negatively towards them to distance themselves from the threat. Whilst such 'othering' is common across societies, the targets of stigma often vary, with choice of the 'other' reflecting wider power differentials in particular settings.

Combining macro-social and psychological analyses facilitates a better understanding of individual compliance, change and resistance to stigmatisation. For example, Crawford's (1994) study of AIDS stigma in the United States analyses how the stigmatisation of people with HIV/AIDS (compounded by the association of HIV/AIDS with marginalized out-groups such as intravenous drug users, gay men, sex workers and ethnic minorities) reinforces a conservative 'middle American' social morality – which requires people to police their behaviour in ways that support the economic and political status quo.

Faced with multiple layers of social disadvantage, it may be difficult for people to challenge their stigmatised status. This is particularly problematic because 'power is seldom conceded without a demand' (Bulhan cited in Seedat, 2001). Social elites seldom voluntarily give up their power without a vigorous demand from excluded groups. Given the social and intra-psychic benefits of 'othering', the 'non-stigmatised' may have a complex and multi-layered investment in maintaining the symbolic status quo.

This 'self-policing' is deeply social psychological, rooted in the complex mechanisms through which the social becomes sedimented in the individual psyche. Even when members of stigmatised groups are not exposed to overt and direct acts of discrimination, individuals who carry stigmatised markers may 'internalise' negative representations of their status (Goffman, 1963). This may lead to loss of confidence and self-esteem, undermining the likelihood that they will challenge their devalued status.

What are the implications for anti-stigma activists? Here we would argue against a simplistic view of power which regards stigmatised people as passive victims of inexorable social forces, ignoring that where there is power, there may also be the potential for individual/ collective resistance. In certain conditions stigmatised people may contest, even transform, stigmatising representations and practices. Much remains to be learned about the types of representations and practices through which stigma is perpetuated, the social contexts within which they are produced and reproduced, and the possibility of agency and resistance. It is here that we locate this volume's contribution.

Unravelling the contexts of stigma

Each paper contributes to particular specialist literatures – perspectives too rich and varied to summarise here. In this section we seek only to highlight how papers contribute to understandings of the material, political, symbolic and institutional contexts that support the stigmatisation of various groups; undermining or enabling opportunities for group members' agency and the development of positive, active self-definitions that might inform individual/collective resistance to stigmatisation.

Material contexts

At the material level, poverty/deprivation are potent drivers of the stigmatisation of diabetics in Ghana (de-Graft Aikins), of people with tuberculosis (TB) in Zambia (Bond and Nyblade) and African migrants with AIDS in England (Dodds). The combined effects of poverty and gender discrimination make Indian sex workers particularly vulnerable to stigmatisation (Cornish). Poverty also serves undermines resistance to stigma. The psychologically disempowering effects of deprivation mean that working class British smokers are far less able to withstand the stigmatisation of smokers than their middle class counterparts (Farrimond and Joffe). The social psychology of deprivation also significantly reduces the likelihood of stigmatised group members taking full advantage of health campaigns (e.g.

anti-smoking campaigns) or potentially life-saving HIV/AIDS treatment in South Africa (Mills).

Political contexts

Conceptualising 'political' in terms of the operation of power in social relations, each paper provides insights into political contexts of stigma. The term 'layered stigma' highlights that stigma may follow existing social faultlines, deepening existing divisions between e.g. men and women, rich and poor. Deacon warns against simplistic associations between stigma and existing power differentials, however, saying that stigma may sometimes affect members of high status groups, or create new social faultlines. As such, it is not always a replication of existing power relations, but also sometimes a new source of power inequalities.

Dodds shows how AIDS stigma 'overlaps' with other sources of social marginalisation in the UK, including homophobia, xenophobia and racism. Layers of stigma preserve social structures in the on-going constitution and reconstitution of 'insider' and 'outsider' groups. Dodds's findings highlight the complexity of overlaps and their effects – showing how the positioning of people with AIDS in other social hierarchies shapes the extent and type of stigma that they faced. E.g. whilst the experiences of gay white men with AIDS are extremely negative, the experiences of black African migrants with AIDS are even worse in the face of additional layers of marginalisation resulting from lack of access to British nationality, citizenship and cultural integration.

Institutional contexts

Several papers show how institutional contexts facilitate stigmatising representations and practices. The public health system plays a key role in perpetuating the TB stigma in Zambia through its overly zealous isolation of TB sufferers (Bond and Nyblade). Posters depicting smoking as a disgusting habit may unintentionally reduce the likelihood of working class smokers

quitting. They may play into the complex processes that undermine the confidence and self-esteem of deprived groups in England, and their sense of control over their health – with well-intentioned campaigns more likely to perpetuate than remove health inequalities (Farrimond and Joffe).

However just as institutions create stigmatising contexts, they also open up spaces for resistance and social change. The success of the Indian Sonagachi Project shows the role a well-networked NGO can play in challenging stigma in conditions of poverty and exclusion (Cornish). The church plays a key role in stigmatising people with HIV/AIDS in Tanzania, yet it also opens up spaces within which people are starting to problematise this stigmatisation (Hartwig et al.). These insights echo Foucault's warning against simplistic and unidimensional accounts of power and oppression, keeping us alert to ever-present possibilities for resistance even in unexpected places (Foucault, 1980).

Symbolic contexts

Using the term 'symbolic' to refer to the frameworks of understanding within which people make sense of their life experiences, each paper throws light on the symbolic contexts within which stigma is constructed, internalised or resisted. Mills' discussion of non-verbal gestures used to communicate about peoples' HIV/AIDS status in South Africa reveals the rich seam of metaphors through which stigma is expressed – reminding us not to limit explorations of the symbolic to the verbal realm alone.

De-Graft Aikins maps out the representational field in which people make sense of diabetes in Ghana – including wider representations of unhealthy lifestyles and the supernatural. She highlights the interpenetration of the symbolic and the material, showing how poverty shapes how people give meaning to illness. The symbolic-material link is also emphasised in Cornish's account of how representations of 'rights' are mobilised by activists to redefine the occupation of sex work in a less stigmatising way, whilst emphasising that

calls to 'rights' are most likely to lead to effective collective action when accompanied by the possibility of real material changes to peoples' lives.

Disease stigmas may be multiplied when layered with other stigmatised conditions. Bond and Nyblade highlight how TB stigma is exacerbated through its link with AIDS in Zambia. Whilst the symbolic link between TB and AIDS reflects the biomedical reality of co-infection, the biomedical co-existence of diabetes and AIDS is less common. However, diabetes is often incorrectly linked to AIDS through the shared symptom of weight loss. This leads to equally distressing and debilitating consequences for people with uncontrolled diabetes in Ghana, as de-Graft Aikins demonstrates in her contextualisation of diabetes experience within interlocking cycles of biophysical disruption, financial destitution and psycho-social neglect.

Agency and resistance

Howarth argues that in certain conditions stigmatised people may contest and even transform stigmatising representations and practices – and that a social psychology of stigma needs to take account of human capacity for agency, and to allow for the possibility of resistance and change. She emphasises that social knowledge is "always in the making ….. constantly reworked, resisted and transformed as we find new ways of mastering our constantly changing realities". Stigmatising representations are not always internalised. Negative representations may jar with an individual's or group's experience of themselves, leading to resistance and the renegotiation of previously stigmatising representations in a more positive light.

Furthermore, stigma will not always be a disadvantage. Stigmatised identities might even become a platform for group mobilisation and resistance. In exceptional circumstances, people might even gain status if they 'come out' with a stigmatised characteristic e.g. in the South African Treatment Action Campaign, with its assertive 'HIV positive' message (Deacon)

In some cases, agency and resistance may arise spontaneously. However where stigma overlaps with other forms of social devaluation, external support or intervention may be necessary to facilitate resistance by devalued groups. For example, an 'external change agent' of some sort may work with members of stigmatised communities to develop the skills, support networks and resources that enable them to (i) think critically about their negative social representation; (ii) develop a sense of confidence and capacity to challenge it; (iii) collectively negotiate locally appropriate and realistic individual and collective anti-stigma strategies; and (iv) identify and build the types of strategic alliances most likely to facilitate effective action (Campbell, Nair and Maimane, in press).

From analysis to action

Elsewhere, we have lamented the mismatch between the copious research into 'what stigma is', and minimal research on 'what to do about it' (Deacon et al., 2005). Several papers in this volume seek to address this problem, commenting on implications of their findings for stigma-reduction interventions.

De-Graft Aikins supports her argument for multi-faceted interventions through her account of the interplay of factors (biophysical, economic, symbolic, social psychological and structural) that drive diabetes stigma. In addition to health education and improved service delivery, she highlights the potential for self-help groups to help provide psycho-social support for diabetics. However, the most fundamental driver of stigma in her context is material: poverty and under-resourced health services. She highlights two recent 'landmark' developments in Ghana – a National Insurance Scheme providing medical cover for chronic illnesses, and a Disability Bill providing the disabled with free access to medical care (following a rights-based approach).

Focusing narrowly on small-scale church-based interventions, Hartwig et al. emphasise the value of workshops in providing space for reflection in a complex and contradictory environment, and for the construction of narratives

about ways in which individual religious leaders have creates opportunities to challenge stigma.

Cornish provides a detailed social psychological account of the processes through which the Sonagachi Project has successfully challenged the stigmatisation of sex work. She shows how the social psychological realm is deeply penetrated by the material and symbolic in ways that open up the possibilities of resistance and change, with skilful facilitation, and under exceptional circumstances. The project challenged the fatalism undermining women's agency in conditions of poverty and many-layered social devaluation through a double pronged approach. Efforts to facilitate alternative and positive self-understandings went hand in hand with the possibility of real material changes in peoples' daily lives, such that the material and symbolic were intertwined as "complementary aspects of a single process of politicised change".

Stigma is a quintessentially social psychological topic: a phenomenon rooted in the individual psyche, yet constantly mediated by the material, political, institutional and symbolic contexts referred to above. Community psychology also has a key role to play in advancing our understandings of the possibilities for collective resistance and for stigma-reducing psycho-social change. Much remains to be learned about the mechanisms through which individuals and communities may resist stigma, and the contexts which facilitate or hinder this process – we hope this volume contributes to this challenge.

Acknowledgements

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