

The effects of shame and stigma on patient care

Stigma in healthcare has been associated with a range of negative outcomes, such as delays in seeking treatment, avoiding clinical encounters and mental distress. This editorial discusses the experience of stigma and argues that understanding shame anxiety and adopting 'shame-sensitive' practice is beneficial in healthcare.

Acknowledging stigma has become very useful in healthcare. It helps both practitioners and patients make sense of the social impact of an illness or condition. Stigma can reveal how the experience of ill health may coincide with a range of negative social events, such as discrimination, judgement, social exclusion, vilification, ostracism, labelling, loss of status, prejudice and unfair treatment, among others (Link and Phelan, 2001). People with a number of illnesses or conditions, such as obesity, HIV or lung cancer, are commonly stigmatised for their association with purportedly 'negative' lifestyle habits. Infectious diseases are also heavily stigmatised because of fears around contamination and infection, while many other conditions are stigmatised merely because they deviate from widespread standards regarding what is 'good', 'healthy' or 'acceptable'. However, it is important to note that stigma in the clinic may not be at all health-related, but nonetheless be health-relevant. Stigma associated with low literacy levels, poverty, social deprivation, food insecurity, homelessness, criminal justice, sexual violence, domestic abuse or other traumas may be highly relevant in healthcare contexts.

Overall, the negative impacts of health-related stigma are serious and directly affect health and health outcomes. As Corrigan and Penn (1999) noted:

'Stigma's impact on a person's life may be as harmful as the direct effects of the disease.'

There is a large body of health research that correlates stigma to a range of phenomena that can directly impact on health outcomes, for instance delays in seeking treatment, avoidance of clinical encounters, prolonged risk of transmission, poor adherence to treatment, mental distress, mental ill health and an increased risk of the recurrence of health problems (Heijnders and Van Der Meij, 2006). Overall, living with stigma increases stress, decreases one's capacity to cope, negatively affects mental health and may limit one's access to healthcare and health resources.

Recognising stigma?

While the burdens and consequences of stigma have long been recognised in the health literature, there remains some ambiguity about how stigma is experienced by people who live with it, and also how healthcare workers are to adequately recognise stigma and work in a way that helps to reduce its negative effects. The philosopher Phil Hutchinson (2022) noted that stigma can be hard to find 'in the wild': it is both everywhere, but also hard to define. Stigma is not experienced directly (as one might experience the pain or discomfort associated with an illness), instead it is a 'category term' used largely by researchers to make sense of negative social phenomena, such as discrimination and prejudice, while the individuals experiencing these phenomena are unlikely to use the term 'stigma' to describe their own experiences. The exceptions, of course, are those from highly politicised patient communities, such as those with HIV or myalgic encephalomyelitis (also called chronic fatigue syndrome), who have co-opted the language of stigma as a helpful tool in their patient activism.

While the idea of what is termed 'health-related stigma' has been discussed at length in the academic literature, it remains 'one of the most significant – and least understood

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– barriers to health promotion and disease prevention around the globe’ (Zhu and Smith, 2021). Stigma’s enduring mystery in part lies in how it shows up in patients’ first-hand experiences of healthcare. As Bennett et al (2016) noted in relation to HIV, ‘the mechanism by which stigma may cause distress remains largely unknown’.

Shame and stigma

A useful and accessible way for clinicians to understand how stigma is experienced, and hence how it can impact clinical encounters and interfere with healthcare, is to focus on its emotional dimension. If a person lives with stigma, then they most likely live with shame, or more accurately, they live with the constant fear of feeling shame or actively being shamed when their stigmatised condition or circumstance is noticed. This means that people living with stigma may become anxious about being made to feel that they are ‘less than’, that they are ‘unworthy’, that they are ‘contaminated’ or ‘disgraced’ in some way, and will be treated in negative ways as a result. Because the experience of shame, or even just the anticipation of shame, can challenge rationality and reason, the ‘necessity’ to avoid shame can come at the cost of even harming oneself, for instance by not seeking medical help even when the person is aware of a health issue. Understanding the experiential features of shame can give healthcare professionals a greater sensitivity to stigma and its impacts in clinical settings and encounters.

It is clear that shame is a powerful force in medicine that can have clinical impacts (Davidoff, 2002). However, shame remains a frequently unacknowledged and underemphasised aspect of clinical encounters within healthcare. As a result, Davidoff (2002) described shame as the ‘elephant in the room’ in healthcare. Shame is something ‘so big and disturbing that we don’t even see it, despite the fact that we keep bumping into it’. Of course, shame is a common experience for patients. As the physician Aaron Lazare noted in his seminal 1987 article entitled Shame and humiliation in the medical encounter:

‘...patients may experience physical or psychologic limitations as defects, inadequacies, or shortcomings... Treatments and their side effects may be potential sources of further shame and humiliation: mastectomies, the loss of hair, and impotence are examples.’

Shame can very easily be incited and exacerbated in clinical encounters. Interactions with healthcare professionals often involve unequal power relationships, a worry about being judged, the exposure and scrutiny of many aspects of the self that may be potentially ‘shameful’, such as one’s circumstances, coping behaviours, body, illnesses and mental health status, along with other vulnerabilities. In physical examinations, exposing one’s body, especially when it might be put into strange positions, or when one’s sexual organs are examined, can feel inherently shameful or even humiliating. If one is living with stigma, and already experiencing high levels of shame or the anticipation of shame, then healthcare encounters, where shameful exposure may feel inevitable, can feel particularly threatening to one’s feeling of psychological safety. This may be the case regardless of the attitude, intentions or demeanour of the clinicians the patient comes into contact with (Dolezal, 2022).

Having basic shame competence – or the ability to acknowledge and address shame, while avoiding shaming – is imperative for healthcare professionals, and recent work on developing principles for shame-sensitive practice will be important when considering how to reduce the effects of shame and stigma on patient care (Dolezal and Gibson, 2022). Clinicians working on the front line must be able to recognise shame and shame dynamics, and manage situations and encounters so that the negative effects of shame (eg withdrawal, avoidance) do not interfere with patient care.

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Key points

- Understanding stigma can reveal how the experience of ill health may coincide with a range of negative social events, such as discrimination, judgement, social exclusion, vilification, ostracism, labelling, loss of status, prejudice and unfair treatment.
- Stigma and its impacts can be difficult to recognise in practice.
- If an individual lives with stigma, they will most likely live with shame, or more accurately, they live with the constant fear of feeling shame or actively being shamed when their stigmatised condition or circumstance is noticed.
- Shame is a frequently unacknowledged and underemphasised aspect of clinical encounters within healthcare.
- Healthcare workers must be able to recognise shame and shame dynamics, and manage situations and encounters so that the effects of shame do not interfere with patient care.

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