Developing Internet interventions to target the individual impact of stigma in health conditions

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ABSTRACT

A number of health problems are associated with significant stigma, a social phenomenon in which individuals become the object of negative stereotypes. In addition to experiencing negative reactions from others, stigmatised individuals and groups can experience harmful consequences when they internalise these negative prevailing attitudes. The objective of this paper was to consider the potential to develop Internet-based health-related interventions explicitly targeting the effects of stigma on the individual. A review of the literature was conducted to synthesise current conceptualisations of stigma and self-stigma across a number of groups, and to identify current intervention developments. Self-stigma reduction strategies developed for in-person services include cognitive reframing, myth busting, contact with other members of the stigmatised group, and disclosure promotion. The development and provision of interventions targeting self-stigma within an online environment is in its infancy. Our review considers there to be particular potential of online interventions for this target, associated with the capacity of the Internet to promote having contact with peers within one's stigmatised group, and for user interaction and empowerment. We conclude that self-stigma is a domain in which there is significant potential for innovation with health-related interventions, and provide a number of recommendations for online intervention development.

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1. Introduction

A number of health problems are associated with significant stigma (Corrigan, 2014), which can lead both to marginalization within society, and to the anticipated reactions of others impacting upon the person's own behaviour and view of themselves. Some of the health problems most frequently associated with stigma include mental health problems (Corrigan, 2007; Corrigan and Watson, 2002b), HIV/AIDS (Lee et al., 2002; Oduguwa et al., 2014), chronic disabilities (Berger et al., 2010), neurological problems such as epilepsy (De Boer et al., 2008), and infectious diseases (e.g. tuberculosis, Baral et al., 2007; leprosy, Tsutsumi et al., 2007). Additionally, some social groups who are a target for health interventions may be subjected to stigma, such as persons who have sex with same-sex partners (Herek, 2009; Herek et al., 2009).

One of the purported advantages of Internet interventions is their potential to make treatment more accessible for individuals concerned

about the stigma attached to mental and physical health problems (Griffiths et al., 2006). However, while there has been development of campaigns targeting community stigma, there has been little consideration of how Internet interventions might support individuals within stigmatised groups (Griffiths et al., 2014), or design considerations of interventions in order to take stigma into account.

In this paper we consider these issues, reviewing contemporary conceptualisations of how community stigma affects individuals, synthesising empirical findings relating to existing interventions, and considering the potential and feasibility of the Internet as a vehicle for delivering interventions that support individuals in dealing with stigma.

2. Conceptualisations of stigma

A basic tenet of social psychology is that societies are comprised of in-groups and out-groups (Hinshaw and Stier, 2008). Community members tend to privilege in-groups and work to maintain in-group boundaries. This preferential treatment helps consolidate identity and provide social protection (Brewer, 1999). Conversely, out-groups may be portrayed homogenously and negatively. According to Goffman (1963), an influential early theorist of social exclusion, stigma is a "discrediting attribute" that reduces the bearer "from a whole and

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usual person to a tainted, discounted one" (p. 3). In contemporary definitions, stigma is understood as an attribute or label (such as a particular diagnosis) that links individuals to negative social stereotypes (Jones et al., 1984; Major and Eccleston, 2004). Examples of such stereotypes include that persons with mental health problems are inherently weak, same-sex attracted men irresponsibly engage in unprotected sex, or that persons who have recovered from infectious diseases remain contagious. Endorsement of particular stereotypes, in turn, may lead to negative effects, and ultimately to behavioural enactment (including particular acts of discrimination as well as broader processes of social exclusion and marginalization) (Corrigan and Penn, 1999).

Much contemporary research into stigma originates in labelling theory, which proposes that the self-identity and behaviour of individuals is strongly influenced by the terms used by the wider community to describe them (Scheff, 1974; Thoits, 1999). Building on these earlier accounts of labelling in mental health (Scheff, 1974), Link and colleagues (Link, 1987; Link, Cullen, Struening, Shrout, and Dohrenwend, 1989; Link and Phelan, 2001) proposed a highly influential "modified labelling" theory of stigma. In their conceptualisation, stigma arises through the convergence of four inter-related components. First, conditions in a society must be such that certain types of human difference (such as mental illness, or a particular skin colour) are distinguished and labelled. Second, these differences must be associated with negative attributes that may include social deviance, negative personal characteristics and threat to others. Third, these negative associations serve to justify an "us versus them" mentality in which stigmatised others are increasingly seen as different and threatening. Finally, this process of linking labels to negative attributes and reconceptualising labelled individuals as "others" leads to significant discrimination and status loss (or social devaluation). Discrimination can take both structural forms (such as governmental policies that implicitly disadvantage individuals with a stigmatised label) and interpersonal forms (such as rejection by friends or colleagues) (Stuber et al., 2008).

The modified iteration of labelling theory developed by Link and others (Link, 1987; Link et al., 1989; Link et al., 2004) also foregrounds the ways in which individuals may be affected by stigma even in the absence of more direct structural and/or interpersonal discrimination and devaluation. Link and Phelan (2001) explain that over the course of growing up, most members of society will come to share not only in culturally salient stereotypes about people with mental illness (as a group) but also become very aware of norms involving the way in which members of the public react to and behave toward such individuals. For those individuals who, typically in late adolescence or early adulthood, are themselves labelled with a mental illness, awareness of the cultural norms and attitudes become personally relevant. Importantly, coping strategies may be positive or negative and include: i) secrecy, ii) withdrawal from interaction except when necessary (i.e., family and significant others), and iii) educating others (Corrigan and Watson, 2002b). Hence, even when affected individuals do not endorse stereotypes about them, attempts to avoid discrimination and devaluation often generate problematic social and economic circumstances (Thoits and Evenson, 2008).

3. Self-stigma

In addition to the direct effects of discrimination and marginalisation, individuals with a "discrediting" attribute or label may also themselves endorse stereotypes about other individuals with that label (e.g., other people with mental illness) and apply these stereotypes to themselves (Corrigan et al., 2006; Livingston and Boyd, 2010), referred to as *self-stigma* or *internalised stigma*. Health-related self-stigma has been identified as a potentially pernicious consequence of belonging to a stigmatised group and a barrier to recovery for affected individuals (Corrigan et al., 2009), and a number of measures have been developed to operationalise this construct in different populations (e.g. Boyd Ritsher et al., 2003; Corrigan et al., 2006; Ross and Rosser, 1996).

Incidence studies have revealed that high levels of self-stigma are experienced by approximately one third of people with severe mental illness (Brohan et al., 2010; West et al., 2011), 25 per cent of people with HIV/AIDS (Lee et al., 2002), and 20–25 per cent of people with depressive and bipolar disorders (Brohan et al., 2011; Yen et al., 2005). In addition, stigma from within the community can hamper recovery from mental illness and can put individuals subjected to stigma from physical health problems at increased risk of developing mental health problems (Manzo, 2004), which may further compound the presence and severity of self-stigma.

In a model of mental health related self-stigma that has been adopted in other groups, Corrigan et al. (2006) describe three component processes: (a) awareness of community stereotypes, (b) personal agreement with those negative stereotypes, and (c) application of those negative stereotypes to oneself. As a consequence of this internalised stigma, affected individuals may experience feelings of pronounced demoralization and low self-worth and resort to ultimately detrimental coping strategies including social withdrawal, secrecy and the foreclosure of earlier ambitions (such as graduating from college or having kids) (Campbell and Deacon, 2006; Corrigan et al., 2009; Link et al., 2001).

4. The consequences of stigma and self-stigma

Social distancing, or a stated preference for avoiding various types of interactions with stigmatised individuals (such as hiring them for a job, or going out on a date) is considered a central manifestation of stigma (Corrigan et al., 2001; Mak et al., 2007). Population-based data suggests that people try to avoid individuals with mental illness across numerous circumstances, even those that require little direct contact (Jorm and Wright, 2008; Stier and Hinshaw, 2007). In a path analytic study, Corrigan et al. (2002) demonstrated that endorsement of prejudicial attitudes regarding mental illness led to socially avoidant behaviour, including an unwillingness to live and work alongside people labelled mentally ill. These attitudes, and the discriminatory behaviour that ensues, have very real implications for the psychological wellbeing and community engagement of individuals with severe mental illness, beyond the impairments resulting from the mental disorders themselves (Corrigan, 2007).

The psychological and social sequelae of self-stigma may also be far-reaching (Yanos et al., 2010). Psychologically, self-stigma is correlated with feelings of shame (Campbell and Deacon, 2006), depression and demoralisation (Corrigan et al., 2003; Link, 1987; Link et al., 1991; Link et al., 1997), diminished hope and self-esteem (Corrigan et al., 2006; Lysaker et al., 2008; Werner et al., 2008), and the exacerbation of illness-related symptoms. Ritsher and Phelan (2004) argue that the most damaging aspect of experiencing self-stigma may be the feeling that one is no longer a full member of society and/or no longer like "normal" community members. Attempts to hide a stigmatised label or diagnosis may further exacerbate a sense of difference, contribute to social isolation, and engender substantial background stress and fear concerning the consequences of inadvertent disclosure (or 'being found out') (Bromley and Cunningham, 2004; Dinos et al., 2004; Goffman, 1963; Rüsch et al., 2005), which may further perpetuate the internal sense of 'otherness' and isolation.

Group membership and identification may play an important role in moderating an affected individual's reaction to stigma (Tajfel and Turner, 1979). High group identification, for instance, may be protective early in the process of 'internalisation' by reducing stereotype agreement and self-concurrence, and strengthening self-esteem and self-efficacy (Crabtree et al., 2010; Yanos et al., 2010). Group identification may also provide a basis for giving, receiving and benefiting from peer social support, in turn increasing resistance to stigma and the rejection of negative in-group stereotypes (Turner et al., 1994).

In Watson and colleagues' (2007) more multi-faceted conceptualisation, the relationship between group identification and self-stigma