

## **Stigma and Need for Care in Individuals Who Hear Voices**

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### **Abstract**

**Background:** Voice hearing experiences, or auditory verbal hallucinations, occur in healthy individuals as well as in individuals who need clinical care, but news media depict voice hearing primarily as a symptom of mental illness, particularly schizophrenia.

**Aims:** This paper explores whether, and how, public perception of an exaggerated association between voice hearing and mental illness might influence individuals' need for clinical care.

**Method:** A narrative literature review was conducted, using relevant peer-reviewed research published in the English language.

**Results:** Stigma may prevent disclosure of voice hearing experiences. Non-disclosure can prevent access to sources of normalizing information and lead to isolation, loss of social support, and distress. Internalization of stigma and concomitantly decreased self-esteem could potentially affect features of voices such as perceived voice power, controllability, negativity and frequency, as well as distress. Increased distress may result in a decrease in functioning and increased need for clinical care.

**Conclusions:** The literature reviewed suggests that stigma has the potential to increase need for care through many interrelated pathways. However, the ability to draw definitive conclusions was constrained by the designs of the studies reviewed. Further research is needed to confirm the findings of this review.

**Keywords:** stigma, public attitudes, auditory verbal hallucinations, voice hearing, psychosis, early intervention

## **Introduction**

The reported prevalence of auditory verbal hallucinations (AVHs), or experiences of hearing voices, in the general population varies from 0.6% to 84%, with a median of 13.2% (Johns et al., 2014). AVHs are considered a symptom of several psychiatric disorders, but also occur in healthy individuals, with some studies suggesting that the majority of individuals who experience AVHs have no diagnosable disorder (Johns, Nazroo, Bebbington & Kuipers, 2002; Lawrence, Jones & Cooper, 2010; Linden et al., 2011). The finding that AVHs can be present in those who are apparently psychologically healthy has generated a body of research examining possible factors that could influence the transition to pathology.

The role that stigma towards AVHs might play in transition to pathology has not yet been explored. At least in the U.S., public perceptions of AVHs are not congruent with the research literature. A recent study of U.S. newspapers (Vilhauer, 2015) demonstrated that an overwhelming majority of news articles depict voice hearing as a symptom of mental illness, most often schizophrenia. As news media can both reflect and influence public attitudes and perceptions (McGinty, Webster & Barry, 2014; Stuart, 2006), this paper explores whether, and how, public perception of an exaggerated association between voice hearing and mental illness might influence the transition to pathology. These questions are worth exploring because such an association may influence both the way voice hearers view themselves, and the way others view voice hearers.

The possibility that stigma could influence need for care is consistent with cognitive models of psychosis, which postulate that pre-existing beliefs and appraisals are relevant to the persistence of positive psychotic symptoms (Garety, Kuipers, Fowler, Freeman & Bebbington, 2001; Garety, Bebbington, Fowler, Freeman & Kuipers, 2007), and that the experience of voice hearing only becomes pathognomonic if voices are appraised in ways that make them distressing (Chadwick & Birchwood, 1994; Brett, Johns, Peters & McGuire, 2009; Morrison, 1998). Many studies have provided support for these models. For example, the Netherlands Mental Health Survey and Incidence Study (NEMESIS), a longitudinal study of individuals in the general population who reported psychotic experiences, demonstrated that emotional appraisal and

intrusiveness of psychotic experiences were modifiers of the predictive power of a clinical outcome (Hanssen, Bak, Bijl, Vollebergh & van Os, 2005).

The research questions were examined through a narrative review of relevant published literature. This review approach was used because conducting a systematic review was impractical; given the dearth of studies dealing specifically with the stigma of voice hearing, the review required a synthesis of research findings relating to various disparate aspects of voice hearing. Potentially relevant research articles published in peer-reviewed journals since 2005 were located through a PsycINFO search, by combining the terms “voice hearing,” “auditory verbal hallucinations,” “psychosis,” “at-risk mental state,” and “schizophrenia,” with the terms “stigma” or “distress.” Only articles in English were considered. Articles that contained relevant findings were identified, and their bibliographies examined for other relevant articles, including some that pre-dated 2005. Several scholarly books on voice hearing and psychosis were also consulted, and their bibliographies examined for additional articles of relevance. Relevant research is discussed below. Topics addressed include voice hearing as a stigmatized experience, secrecy, isolation, voice controllability and power, frequency and intensity of voices, content of voices, and distress.

### **Stigma towards mental illness may extend to those who hear voices**

Goffman (1963) described stigma as “an attribute that is deeply discrediting.” Public stigma encompasses negative stereotypes, prejudice, and discriminative behaviors present in the general public, while self-stigma refers to internalization of these stereotypes, prejudices and discrimination (Corrigan & Watson, 2002). Many qualitative studies (Chin, Hayward & Drinnan, 2009; Jackson, Hayward & Cooke, 2010; Romme, Escher, Dillon, Corstens & Morris, 2009) and personal reports (Gray, 2008; Longden, 2010) suggest that negative stereotypes of voice hearing are often internalized. When AVHs are assumed to be a symptom of mental illness, the stigma of mental illness (Parcesepe & Cabassa, 2013) is likely to extend to those who experience AVHs. Public perceptions of voice hearing as being indicative of mental illness can lead voice hearers to believe, or fear, that they are mentally ill. Such a belief or fear, even in the absence of pathology or a clinical diagnosis could lead voice hearers to anticipate the negative consequences that could ensue from having a mental illness, and particularly schizophrenia. People with schizophrenia are often portrayed negatively in the media (Coverdale, Nairn & Claasen, 2002; Dubugras, Evans-Lacko & de Jesus Mari, 2011; Duckworth, Halpern, Schutt & Gillespie, 2003; Wilson,

Nairn, Coverdale & Panapa, 2000), and social acceptance of people with schizophrenia is poor ((Pescosolido et al., 2010; Schomerus et al., 2012; Thornicroft et al., 2009; Wahl, 1992). Despite evidence to the contrary (Ciompi, Harding & Lehtinen, 2010; Read & Dillon, 2013), schizophrenia is often seen as a lifelong condition, with little hope for recovery (Crisp, Gelder, Rix, Meltzer & Rowlands, 2000; Moncrieff & Middleton, 2015). No studies have specifically examined how this stigma towards schizophrenia might extend to undiagnosed individuals who hear voices.

### **Stigma can promote secrecy, prevent disclosure, and lead to isolation**

Disclosure of voice hearing experiences often elicits responses of alarm from others (Romme, et al., 2009). Several qualitative studies indicate that such responses, as well as internalized stigma, can lead to secrecy about voice hearing experiences (Boydell, Gladstone & Volpe, 2006; Byrne & Morrison, 2010; Chin et al., 2009; Jansen, Woldike, Haahr & Simonsen, 2015). For example, Byrne and Morrison (2010), who interviewed eight young people at risk for psychosis, recruited through an early intervention service in the U.K., found that fear of becoming mentally ill was a central concern. Because of this concern, and the assumption of negative social consequences, the young people studied had tried to keep psychotic-like experiences such as hearing voices to themselves. Holt and Tickle (2014) who examined the data from seven qualitative studies, found that the desire to hide such experiences can lead to isolation. Voice hearers who became thus isolated sometimes turned to their voices for companionship, which resulted in further alienation from society.

### **Internalized stigma and secrecy could lead to distress**

While some individuals who experience AVHs do not find them distressing (Honig et al., 1998; Martin, Thomas, Andrews, Hasking & Scott, 2015; Sommer et al., 2010), others do. Distress is higher in clinical samples of voice hearers than in voice hearers without a need for care (Daalman, Diederens, Hoekema, van Lutterveld & Sommer, 2016; Langer et al., 2015; Laroie, 2012). Although a correlation between distress and diagnosis of mental illness does not necessarily indicate the existence or direction of a causal relationship, it is conceivable that distress may decrease level of functioning, and therefore increase the likelihood that a voice hearer would need clinical care. A decreased level of functioning is also likely to increase the likelihood of a formal schizophrenia diagnosis, according to DSM-5 criteria.

The secrecy resulting from stigma may increase distress. Individuals with a concealable stigma are likely to have poorer self-esteem and more negative affect than those with a visible stigma or no stigma (Frable, Platt & Hoey, 1998; Pachankis, 2007). This is partly because those with concealable stigmas—and voice hearing experiences are often concealable—may not be able to easily find others who share their experiences, and who may be able to provide emotional support, help in the search for meaning, and offer normalizing explanations. In addition, over time, concealed information can come to seem shameful (Pachankis, 2007). Secrecy about voice hearing experiences could potentially have a snowballing effect, as reluctance to seek help if distress ensues could prevent early intervention. Some studies indicate that early psychosocial interventions may decrease the likelihood of transition to psychosis in individuals deemed at high risk (Okuzawa et al., 2014).

Many authors have mentioned that stigmatizing social contexts could negatively affect responses to voice hearing (Chin et al., 2009; Close & Garety, 1998; Hayward, Berry & Ashton, 2011). A recent study of young people at risk of psychosis suggested that experiencing stress as the result of mental illness stigma increases risk of transition to schizophrenia (Rusch et al., 2015), and the authors suggested that interventions and education to target public stigma about at-risk status should therefore be implemented. The study included individuals who had at least one attenuated psychotic symptom, although the authors did not specify how many had AVHs in particular. Pyle et al. (2015) studied 288 people who met criteria for an at-risk mental state, as assessed by the Comprehensive Assessment for At-Risk Mental States, which includes a perceptual abnormalities subscale. They found an association between internalized stigma and both depression and anxiety, and that negative appraisals of unusual experiences at baseline contributed to depression six months later. Distress related to positive symptoms was associated with internalized stigma. Corroborating evidence also comes from a study of voice hearing experiences in 125 people diagnosed with schizophrenia (Birchwood et al., 2004). Using structural equation modelling, these authors found support for their hypothesis that seeing the self as inferior to others in the social world was likely to lead to appraisals of voices as being powerful and threatening, which could in turn lead to distress and depression.

If stigma is partly responsible for distress in response to AVHs, we should see more distress in voice hearers who are in contexts where such experiences are stigmatized, and less distress in contexts where they are not stigmatized. Several studies support this prediction, although it is

important to keep in mind that comparing individuals who are in more and less stigmatizing contexts will tell us not only about distress in relation to social context, but also in relation to diagnosis, because individuals who are in less stigmatizing contexts will be less likely to be diagnosed with a disorder. Davies, Griffin and Vice (2001) studied 18 schizophrenia patients in remission who were not evangelical Christians, 29 evangelical Christians with no diagnosed mental illness, and 55 controls who were neither evangelical Christians nor had been diagnosed with mental illness. They found that 100% of the schizophrenia patients, 59% of the evangelicals, and 28% of controls heard voices. The psychosis group had less positive voice hearing experiences than the controls, who, in turn, had less positive experiences than the evangelical group. Heriot-Matiland, Knight and Peters (2012) did a qualitative study of six clinically-diagnosed and six non-clinical participants with anomalous experiences, including AVHs, and found that non-clinical participants were better able to integrate their experiences, largely because they received more validation and acceptance from others. Cottam et al. (2011) studied 20 psychologically healthy Christians, 15 Christians diagnosed with psychosis and 14 nonreligious individuals diagnosed with psychosis. While voice hearing was perceptually similar in healthy and psychotic individuals, both religious and nonreligious psychotic patients reported more negative voice content, had mostly negative emotional responses to voices and attributed negative personal meaning to voices. The healthy Christians, on the other hand, rarely reported negative emotional responses to voices. The authors found that the healthy Christians assimilated their voice hearing experiences into religious schema more than the Christian patients did. One possible explanation suggested for the difference in schematic processing is that the Christian patients may have understood their voice hearing experiences as being part of an illness. Thus, interpretation of voice hearing experiences as being pathological could have resulted in a more negative emotional response.

**Internalization of stigma could lead to voices being perceived as more powerful, less controllable, and more distressing**

Voice hearers with a clinical diagnosis tend to perceive voices as being less controllable than voice hearers without a diagnosis (Daalman et al., 2011; Honig et al., 1998; Johns et al., 2014). Research indicates that voices perceived as powerful tend to be less controllable and more intrusive, and are often more distressing. For example, a study of 30 voice hearers with psychiatric diagnoses (Hayward, Denney, Vaughan & Fowler, 2008) showed that dominant

voices were perceived as being more intrusive, and that intrusiveness of voices was associated with more distress. Participants in this study were also more likely to desire distance from voices that were perceived as dominant. Relating from a position of distance was significantly associated with distress. Similarly, Sorrell, Hayward and Meddings (2010), who compared 32 clinical voice hearers to 18 non-clinical voice hearers, found that dominance and intrusiveness of voices was associated with distress, as was attempts to relate to voices from a position of distance. Clinical voice hearers were significantly more likely to perceive voices to be more dominant and intrusive, and to relate from a position of greater distance, than nonclinical participants.

Public stigma of AVHs, and ensuing self-stigma, could contribute to less perceived control over voices. Self-stigma involves a decrease in self-esteem and a perception that one is inferior to others (Corrigan & Watson, 2002; Vogel, Wade and Haake, 2006). Two studies, one of 125 schizophrenia patients (Birchwood et al., 2004), and the other of 59 schizophrenia/schizoaffective patients (Birchwood, Meaden, Trower, Gilbert & Plaistow, 2000), indicated that voice hearers' relationships with voices mirror their relationships with others in their social world. Voice hearers who experience themselves as less powerful in relation to other people experience their voices as more powerful, and are more distressed by their voices. Thomas, Farhall and Shawyer (2013) surveyed 38 patients diagnosed with schizophrenia or schizoaffective disorder, and found that negative beliefs about the self (e.g. "I am: unloved, worthless, weak, vulnerable, bad, a failure") were significantly correlated with both perceived power of voices (e.g. my voice is very powerful," "my voice seems to know everything about me") and loss of control beliefs about voices (e.g. "they will take over my mind," "they will make me go crazy."). Similarly, Peters, Williams, Cooke and Kuipers (2012), who studied 46 clinically stable outpatient voice-hearers with psychosis, found that appraisal of voices as being powerful was associated with suicidal ideation, depression, anxiety and low self-esteem. While these studies cannot, due to their cross-sectional design, rule out the possibility that perceived voice power is antecedent to having negative beliefs about the self, it is reasonable to suppose that voices would be perceived as powerful if voice-hearers see themselves as powerless, or as others have suggested (Birchwood et al., 2004; Peters et al., 2012), that a bidirectional relationship might exist between appraisal of voices as powerful and negative beliefs about the self.

The relationship between perceived control and distress may also be a reciprocal one. Jackson et al. (2010) interviewed 12 voice hearers, some of whom had been diagnosed with mental illness. Participants in their study reported that connecting with others who valued and accepted voice hearing experiences gave them a sense of belonging, increased their self-esteem, and took away their fear that they might be mentally ill. Having more self-esteem made it easier for voice hearers to assert control over their voices. Engaging with voices appeared to diminish fear, and improve coping and control over voices.

### **Stigma may influence frequency and intensity of voices**

More frequent AVHs predict a greater need for care (Daalman et al., 2011; Hanssen et al., 2005). Burke, Wood, Zabel, Clark & Morrison (2016) interviewed 12 service users who were either diagnosed with a psychotic disorder or who met criteria for an Early Intervention for Psychosis service, and found that stigma can increase the frequency and intensity of negative voices. One reason for this might be that stigmatized experiences are likely to be avoided, rather than accepted or even tolerated. Studies of experiential avoidance have shown that trying to avoid unpleasant thoughts and emotions tends to increase their frequency as well as the distress associated with them (Goldstone, Farhall & Ong, 2012; Kashdan, Barrios, Forsyth & Steger, 2006). Clinical work with voice hearers suggests that engaging with voices, on the other hand, tends to improve outcome (Romme et al., 2009).

Stigma could also indirectly affect frequency of voices because stigma may increase anxiety and depression. In a recent analysis supported by several first-person accounts from individuals with psychiatric diagnoses, Ratcliffe and Wilkinson (2016), argue that anxiety may play a causal role in AVHs. A study conducted by Myin-Germeys, Delespaul and van Os (2005) lends indirect support to this notion. Using the Experience Sampling Method, they found that the intensity of psychotic experiences fluctuated with daily life stress in psychosis patients who were in remission. The psychotic experiences studied included auditory verbal hallucinations, although these experiences were not studied in isolation. As this was a correlational study, no causal relationship could be established, but the authors suggested that one interpretation could be that minor stressors cause an increase in the intensity of psychotic experiences. Qualitative studies also indicate that voice hearers implicate anxiety and depression in both causing and maintaining voices (Holt & Tickle, 2015).



Greater perceived power of voices may also increase the frequency and volume of voices. Birchwood et al. (2000) studied 59 voice-hearing patients who met criteria for schizophrenia or schizoaffective disorder, and found that patients who appraised their voices as being more powerful tended to rate them as being louder and more frequent. Although causal attributions could not be confirmed, the authors suggested that appraisals of high power could result in perceptions of voices as being more frequent and louder.

### **Stigma may influence content of voices**

AVHs tend to have more negative content in clinical than nonclinical samples (Daalman et al., 2011; Honig et al., 1998; Johns et al, 2014), and negative content predicts distress and contact with mental health services (Beavan & Read, 2010). Qualitative studies (Holt & Tickle, 2015; Romme et al., 2009) suggest that the content of AVHs could be influenced by stigma. According to a metaethnographic study (Holt & Tickle, 2015) that analyzed the data from seven qualitative studies, voice hearers often report that voices magnify their perceived weaknesses. For this reason, Holt and Tickle suggest that it is important to have interventions that enhance voice hearers' sense of self-worth.

In addition, although not specifically about stigma, an ample literature demonstrates that the context in which people live can affect the content of hallucinations (for a review, see Laroie et al., 2014). For example, Luhrmann, Padmavati, Tharoor and Osei (2015) compared 20 people with psychosis in each of three widely divergent locations: San Mateo in California, Chennai in South India, and Accra in Ghana. They found differences in the way hallucinated voices were experienced in these settings. In the San Mateo sample, voices tended to be hated, were interpreted as a symptom of illness, and violent content was common. In Accra and Chennai, on the other hand, voices were often positive, and interpreted in spiritual terms or as relationships with kin. Luhrmann et al. attribute these differences to the different ways people attend to auditory experiences as a result of cultural conditioning, a process they call 'social kindling.' Mitchell & Vierkant (1989), who compared hallucinations reported by psychotic patients in a Texas state hospital in the 1930s and the 1980s, suggest that hallucination content appears to reflect the social environment in the two different time periods. Command hallucinations in the 1930s contained more positive and religious content, while in the 1980s, command hallucinations tended to have negative and destructive content. Similarly, Suhail & Cochrane (2002), who compared three groups of psychosis patients, found that immediate environment had

a greater influence on the content of hallucinations than cultural background. White British and Pakistani British patients had similar content, while the content of British Pakistani patients and Pakistani patients living in Pakistan differed.

### **Summary**

The literature reviewed here suggests that there are many interrelated pathways through which stigma may influence voice hearing experiences. Stigma can lead voice hearers to be secretive about their experiences. Secrecy can prevent access to sources of normalizing information and lead to isolation, loss of social support, and distress. Internalization of stigma and concomitantly decreased self-esteem may lead not only to distress but also to more negative voices, which could further decrease self-esteem. Low self-esteem could make voices seem powerful, which could impact self-esteem further and make voices seem less controllable and more distressing. If voices are seen as stigmatizing, and thus avoided, they may become less controllable and more distressing. Distress and perceived voice power may increase the frequency of voices. Increased distress may result in a decrease in functioning and a transition to a need for clinical care. Thus, stigma could, along with other factors, contribute to making voice hearing experiences pathognomonic. The potential pathways through which stigma may influence voice hearing experiences are summarized in Figure 1. While these pathways are logically consistent with the findings discussed in this review, it is important to note that the causal connections suggested are not definitive, as many of the studies reviewed were based on qualitative data or correlational designs.

### **Implications**

If, as this review suggests, stigma could influence voice hearing experiences, promoting more accurate media representations of voice hearing may be helpful to voice hearers. Accurate online informational resources about voice hearing may also be helpful because people often turn to Internet to find out what their symptoms mean.

It is clear that although some voice hearers appear to not need care, others do need care. Thus, while normalizing voice hearing experiences is critical (Heriot-Maitland et al., 2012; Romme et al., 2009) for reducing stigma, it is also important to ensure that normalization does not become a barrier to accessing treatment if it is needed, as this is a concern some authors have noted (Jansen et al., 2015; Boydell et al., 2006). Providing safe venues where disclosure is possible without encountering stigma may be helpful in this regard.

One way of providing such venues might be through peer support networks, such as those offered through the Hearing Voices Movement (HVM). This movement is based on the perspective that the potential for hearing voices exists in all people, and that its emergence in an individual should not be seen as necessarily indicative of a psychiatric problem (Corstens, Longden, McCarthy-Jones, Waddingham & Thomas, 2014). The HVM values diverse explanations for voices, and acknowledges that most voice hearing experiences can be understood in the context of life experiences. An approach to accepting and integrating voice hearing experiences, rather than eliminating voices, is advocated, and peer support is considered important to achieving this goal (Romme & Escher, 1993). Qualitative studies of voice hearers' experiences suggest that early disclosure of, and discussion about, voices can be helpful, particularly with others who have similar experiences (Hayward, Awenat, McCarthy-Jones, Paulik & Berry, 2015). Identification with a group of similar others provides protection from the negative effects of stigma and allows people to maintain self-esteem (Corrigan & Watson, 2002). Better self-esteem appears to improve ability to cope with voices (Jackson et al., 2010). Such peer groups may be more helpful in the early period after onset of voice hearing than interventions offered by the traditional psychiatric system, as the latter are sometimes experienced as disempowering and stigmatizing (Romme et al., 2009).

### **Further research**

The idea that stigma could contribute to making voice hearing experiences pathognomonic is consistent with the social defeat hypothesis of schizophrenia (Selten, van der Ven, Rutten & Cantor-Graae, 2013), which proposes that social situations interpreted as defeating, through sensitization of the mesolimbic dopamine system, increase the risk of schizophrenia. A large longitudinal study in Sweden (Zammit et al., 2010) provided support for the social defeat hypothesis; individuals who were in circumstances where they failed to fit in with others were more likely to be diagnosed with psychosis. The authors suggest that this result may be due to repetitive stressful experiences such as discrimination, hostility and isolation. The possibility that AVHs could become pathological if voice hearing is interpreted as a situation of defeat, due to an exaggerated association with mental illness and particularly schizophrenia, has not been investigated. Longitudinal studies of voice hearing individuals that examine self-stigma in those who transition to needing clinical care versus those who do not may be instructive.

We still know relatively little about the experiences of voice hearers in the nonclinical population. Public stigma of voice hearing increases the difficulty of studying these individuals, as they do not come to the attention of psychiatric services, and may not volunteer for research studies. Finding ways to study this population may help us understand what makes some people resilient to distress after the onset of voice hearing. Studying the ways in which the experience of voice hearing might differ in people who enter a peer support group versus those who do not may be particularly informative. Does disclosure in a non-threatening context improve coping and reduce distress? How does exposure to normalizing explanations in conjunction with peer advice on coping strategies affect distress? Studies are needed to answer these questions.

**Conclusion**

Stigma has the potential to affect voice hearers even before a diagnosis is assigned or warranted, by virtue of implicit misunderstandings about voice hearing that permeate society, and that are perpetuated by the media. The literature reviewed suggests that stigma could affect need for care through many interrelated pathways. Further research is needed to confirm the findings of this review.

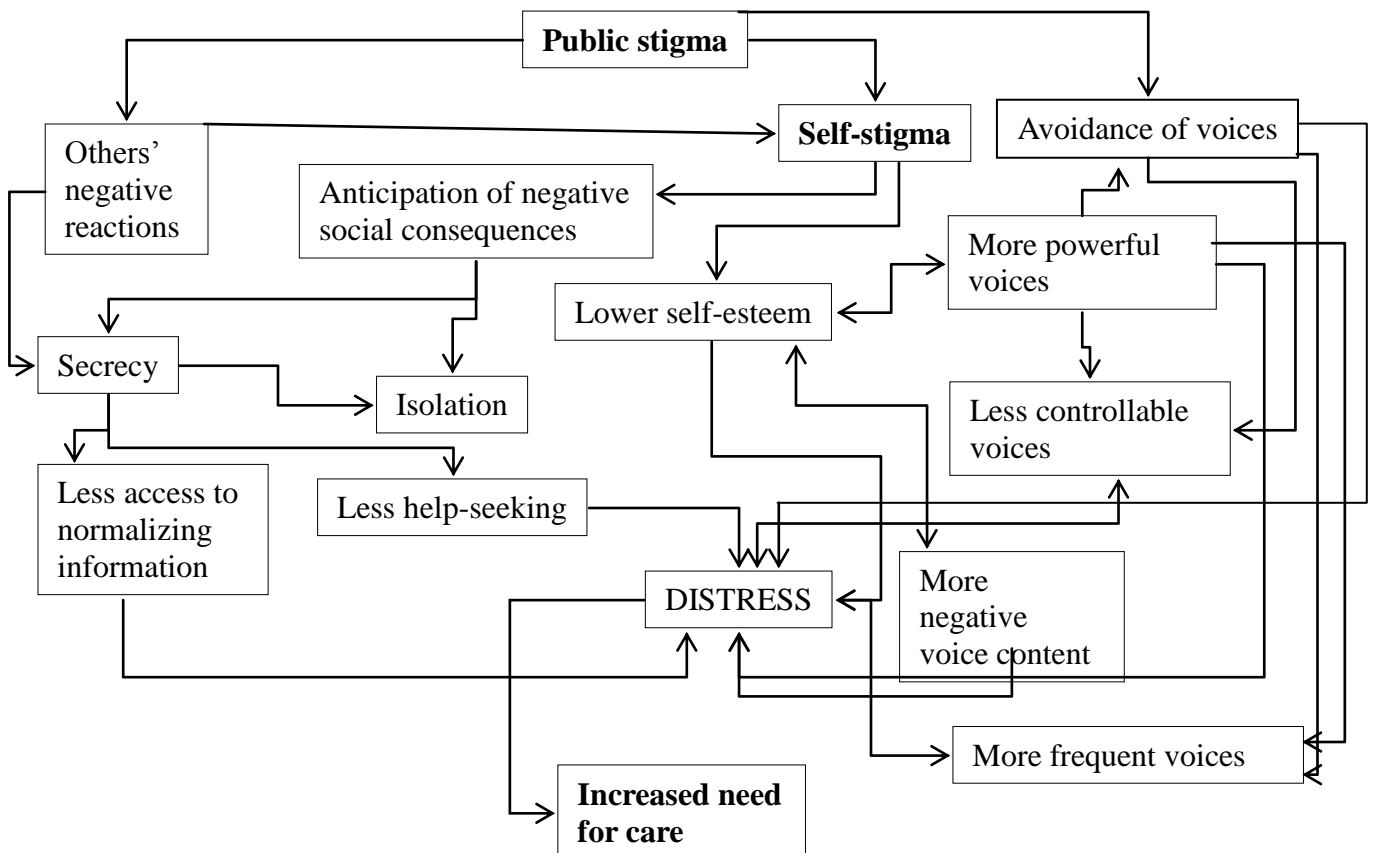


Figure 1: Potential pathways between stigma and need for care

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