What will people think of me? Measuring the anticipated risk of disease related stigma

Although the stigmatizing aspects of diseases such as leprosy, HIV/AIDS, mental illness, and obesity are widely acknowledged, little attention has been paid to quantifying the impact of the anticipated risk of being labeled with a stigmatized disease on health-related behaviors (Smith, Ferrara & Witte, 2007). Certain health-related behaviors such as preventative behaviors and diagnostic behaviors are tied to stigmatized diseases. Engaging in those behaviors becomes not only an admission of risk, but involves the acceptance of a stigmatized identity (e.g. being "at-risk"). Thus, just as do considerations of the physical risk for a disease, the risk of the negative consequences associated with having a stigmatized disease can influence health-related behavior.

These motivations may be mediated in part by perceptions of the level of stigma associated with a disease; individuals who anticipate greater risk as a result of being labeled with a disease are more likely to avoid behaviors that lead to identification with that health condition. For example, increased perceptions of stigma lead to delays in testing for HIV and other STDs (Chesney & Smith, 1999; Fortenberry et al., 2002), and decrease individuals perceptions of their vulnerability for a disease (Young, Nussbaum & Monin, 2007). In addition, individuals who believe that seeing a psychiatrist is a stigmatized behavior are less likely to seek professional help for depressive symptoms (Barney, Griffiths, Jorm & Christensen, 2006).

Thus, the central concept of interest in this study is anticipated risk of disease-related stigma, termed *anticipated stigma*, operationalized as: the subjective perception of the magnitude of social penalties associated with being identified as possessing a stigmatizing health condition. Anticipated stigma includes considerations along three dimensions: (1) psychological consequences, such as shame and loss of self-esteem; (2) interpersonal consequences, such as social disqualification and rejection; and (3) structural consequences, such as denial or limitation of opportunities (Herek, Capitanio & Widaman, 2003). Anticipations of stigma do not necessarily correspond to discrimination as experienced by stigmatized individuals, nor do they represent agreement with the stigmatizing attitudes. That is, individuals can anticipate disease-related stigma even if they don't endorse it and even if their expectations don't reflect the reality of experiences of those who have the disease.

While stigma in general is a construct that is popular in the literature, the concept of anticipated stigma has not been sufficiently developed with populations who are not *already* suffering from the disease of interest (for example see Herek, 2009; Pinel, 1999; Scambler & Hopkins, 1986). Thus, I propose this study to add to this literature by focusing on these anticipatory expectations. Based on a review of the literature, no scale focusing on this construct has, to date, been developed and tested for its psychometric properties. Such as scale, which can produce reliable and valid data, is essential for efforts to understand and reduce the negative consequences of disease-related stigma.

Current Study

The objective of this study is the construction and validation of a multiple-item scale which produces reliable and valid data for the measurement of latent construct *anticipated stigma*. A preliminary draft of the scale has been created based on existing scales, qualitative reports of individuals' subjective experiences, expert opinion, research findings, and theory. This draft includes items measuring respondents' agreement with statements such as, "If I became ill with HIV, the virus that causes AIDS, other people would…[look down on me, feel uncomfortable around me, treat me as inferior]," and "if I became ill with influenza, the virus that causes the flu, I would…[want it to remain secret, feel guilty, worry about people discriminating against me]."

The next step for this study is to pilot test the items on the scale by conducting in-depth interviews with a sample of 5-10 people which includes members of the target populations. Subsequently, to test the psychometric properties of the scale, the final collection of items will be administered via an Internet-based survey to 200 respondents recruited through Luth Research's panel, a random, probability sample of the population. The use of the Internet is effective for collecting data about sensitive or difficult topics; individuals are more willing to share personal information and experiences electronically than through traditional survey methods (Rhodes, Bowie & Hergenrather, 2003).

To assess the validity of the scale, other constructs theoretically related to anticipated stigma such as attribution of responsibility and perceived-risk will also be measured. In addition, this study will determine whether the scale produces reliable and valid data for different populations and for different health conditions. To accomplish this goal, the functioning of scale will be examined among various social groups, including racial/ethnic minorities, women, youth, and the elderly. Because the stigma of a disease is thought to become "layered" on top of preexisting group stereotypes (Herek & Glunt, 1988), these groups should report more anticipated stigma as compared to the general population. In addition, flu, cancer, and HIV, diseases associated with varying degrees of stigma (see Albrecht, Walker & Levy, 1982), will be assessed using this scale. HIV is thought to be linked with greater stigma than flu or cancer; thus, respondents should report greater anticipations of stigma association with HIV than with the other two conditions. To assess potential response bias, respondents will be asked to complete measures of social desirability.

After data collection, statistical procedures from true-score and item response theory will be used to select those items on the scale which best predict anticipated stigma. The goodness of the instrument and model fit will then be evaluated by examining its psychometric properties, including reliability and validity. Based on the findings, a final scale will be created. Once assessed and validated, the final scale should prove useful for researchers who are interested in assessing the anticipation of disease-related stigma.

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