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A Pilot Study of a Novel Method of Measuring Stigma about Depression Developed for Latinos in the Faith-Based Setting

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Abstract In order to understand the effects of interventions designed to reduce stigma about mental illness, we need valid measures. However, the validity of commonly used measures is compromised by social desirability bias. The purpose of this pilot study was to test an anonymous method of measuring stigma in the community setting. The method of data collection, *Preguntas con Cartas* (Questions with Cards) used numbered playing cards to conduct anonymous group polling about stigmatizing beliefs during a mental health literacy intervention. An analysis of the difference between *Preguntas con Cartas* stigma votes and corresponding face-to-face individual survey results for the same seven stigma questions indicated that there was a statistically significant differences in the distributions between the two methods of data collection ($\chi^2 = 8.27$, $p = 0.016$). This exploratory study has shown the potential effectiveness of *Preguntas con Cartas* as a novel method of measuring stigma in the community-based setting.

Keywords Stigma · Measurement · Methodology · Community-based interventions · Mental health · Latinos

Introduction

Stigma is a set of negative attitudes and beliefs held by society (societal or public stigma) or the individual (internalized or self-stigma) (Corrigan and Penn 1999). Goffman (1963), p. 163, one of the most important theorists on stigma, defined stigmatized groups as "having a mark or condition" that results in their devaluation and marginalization from society. For Goffman, stigma is socially constructed and is dependent upon relationships and social context. The stigmatized individual has a social identity that is discounted or discredited by the public. Public or societal stigma occurs when large segments of the population agree with this negative stereotyping and labeling (Corrigan et al. 2012). Stereotypes of persons with mental illness include the misconceptions that all persons with mental illness are violent, unpredictable and to blame for their illness. Public or societal stigma results in status loss and discrimination in housing, employment and other social sectors and disproportionately affects people with less power, resources and political influence (Link and Phelan 2001). Internalized or self-stigma is the incorporation of society's stigmatizing attitudes into one's self-perception and identity. This creates a diminished self-esteem which affects help-seeking behaviors, diagnosis, treatment acceptability and outcomes, family functioning and social interactions (Jorm et al. 2006; Pyne et al. 2004). From a social justice perspective, the stigmatization of mental illness, worldwide, is one of the primary reasons that mental health care lags behind the treatment of other chronic illnesses (World Health Organization 2013).

Factors Affecting Stigma

Through public health campaigns, societal attitudes about treatment have improved (Parcesepe and Cabassa 2013); however, some stereotypes and perceptions of dangerousness of the individual have increased in spite of increased public awareness about mental illness (Jorm et al. 2012;

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Pescosolido et al. 2010). Moreover, the media continues to foment stigma through inaccurate and sensationalist stories of acts committed by persons with mental illness. Factors influencing the level of stigma are an individual's beliefs about the causes and severity of mental illness, perceived effectiveness of treatment and the long-term consequences of mental illness (Parcesepe and Cabassa 2013). In turn, these beliefs are influenced by demographics, level of education, race, ethnicity, culture and religion. Stigmatizing beliefs about mental illness are more likely to be endorsed by Latinos, Blacks and immigrants (Cabassa et al. 2007; Interian et al. 2007; Nadeem et al. 2007; Vega et al. 2010). However, results of these studies represent study samples comprised of mixed Latino sub-ethnic groups, such as Mexicans, Puerto Ricans, Cubans and Dominicans, who are culturally different in many ways and have had very different immigration experiences. These studies are of questionable validity because they generalize about Latinos as a whole and miss the cultural nuances in help-seeking, experiences of mental illness and stigma that vary by subgroup (Alegria et al. 2007; Sanchez et al. 2014).

Latinos and Stigma about Mental Illness

People of Hispanic origin (Latinos), currently at 55 million, are the largest minority group in the United States, representing 17 % of the population (United States Census Bureau 2013). By 2060, it is predicted that Latinos will make up 29 % of the United States population, or approximately 119 million residents (Krogstad 2014). Latinos experience significant health disparities in mental health care compared to non-Hispanic whites (Alegria et al. 2008; Warden et al. 2009; SAMSHA 2015). Only half of Latino immigrants with severe mental health disorders received any type of mental health treatment (SAMSHA 2015). Disparities in access to and quality of mental health treatment are due, in large part, to lack of health insurance, language barriers and poverty (Alegria et al. 2007; González et al. 2010; SAMSHA 2015). However, when taking into account these factors, Latino mental-health-care utilization is still half that of non-Hispanic whites (SAMSHA 2015). Latinos rely upon religious leaders and alternative healers to avoid the stigma associated with seeking help for mental illness, thus disparities in utilization may be a function of religious and cultural values about mental illness (Villatoro et al. 2014). Cultural values and mores including 'what matters most' to be a full-fledged member of a group and conversely, what constitutes deviant behavior are transmitted through a process of socialization (Dijker and Koomen 2006; Yang et al. 2007). Thus, there is a moral component to stigma that serves to preserve cultural values and protect against perceived threats.

Religion is a conduit for moral values and therefore, some religious teachings may contribute to moral judgments about the causes of mental illness. Attribution theory suggests that people create causal explanations for negative outcomes (such as an illness) (Weiner et al. 1988). This theory provides a theoretical understanding of how religious beliefs contribute to the development of stigma. In a survey among Muslim, Jewish and Christian religious leaders' explanatory models of mental illness, causes were varied and attributed to a mix of social and spiritual factors including personal life events; structural factors such as poverty, and unemployment; modern life and the loss of spiritual values; and supernatural causes (Leavey et al. 2016). Religious and supernatural causal attributions of illness include the belief that mental illness is the result of moral or spiritual failings, demonic possession, witchcraft and occult practices (Leavey et al. 2016, Pargament 1997; Webb et al. 2008). Caplan et al. (2010) have shown that among Latino immigrants, stigma about depression is directly related to beliefs about "malevolent" supernatural forces and sinfulness as perceived causes of depression. In order to understand the mechanisms underlying the development and perpetuation of stigma, and the effects of large- or small-scale interventions designed to reduce mental health stigma, we need culturally sensitive, valid and appropriate measures of stigma.

Measurement of Stigma

Stigmatizing attitudes about mental health fall into several broad areas including: (1) attitudes towards people with the illness (societal or public stigma); (2) perceived or felt stigma by members of a stigmatized community and experiences of discrimination; (3) internalized or self-stigma and (4) discriminatory practices perpetuated by the media, institutions and society (Van Brakel 2006). Within these areas there are several means of measuring stigma about mental illness which fall into two larger categories: explicit and implicit measures. Implicit assessments of stigma are conducted in the laboratory setting and use reaction times to assess automatic unconscious associations or pairings of word phrasings such as "mental illness" and "blame." Explicit measures include surveys and self-report questionnaires which assess deliberate conscious responses. The present study focuses on explicit measurement of attitudes towards persons with mental illness or societal stigma.

Corrigan et al. (2000) theorized that the basic components of societal stigma consist of: emotional reactions and prejudice; cognitions or attitudes and beliefs that may result in stereotypes of a group of people; and behaviors that are based on cognitions and emotions which, ultimately, lead to discrimination. There have been various measures that attempt

to capture the underlying constructs of emotions, cognitions and behaviors. A measurement technique that captures cognitions and stereotypes is the Semantic Differential Technique (Osgood et al. 1957). This approach uses adjectives that are opposites and are attached to a label. The participant is asked to rate their beliefs on a scale containing the two opposite adjectives as the anchors. For example, "mentally ill" might be paired with "selfish" or "generous." A similar rating scale is applied to a neutral subject such as "average person" as a point of comparison. This method of assessment has excellent reliability as a measure of stereotyping.

Another example of a scale that measures the cognitions and attitudes associated with societal stigma is the "Community Attitudes towards Mental Illness" scale (CAMI). CAMI examines authoritarianism, benevolence, social restrictiveness and community health ideology and is specifically designed for the community setting. Therefore, it includes questions about community mental health facilities and deinstitutionalization (Taylor and Dear 1981). It has been shown to have adequate reliability in United States and Canadian samples, ranging from 0.68 to .88 for the four subscales (Van Brakel 2006).

Measures that are based upon the underlying construct of attribution theory (Weiner et al. 1988) capture the respondent's emotional reactions (pity, anger) towards people with mental illness (Link et al. 2004). If the person is believed to be responsible for his/her actions, the public is likely to react with anger and punishment, whereas, if the behavior is believed to be uncontrollable or the result of illness, the public is likely to react with pity. Corrigan (2003) created the Attribution Questionnaire, which uses vignettes and word pictures to assess the public's beliefs about causes of mental illness and the extent to which a person with mental illness is culpable for his/her disease. The scale assesses beliefs about personal responsibility in three items and captures emotions, such as fear, anger and pity, and behavioral intentions through two subscales measuring helping/avoidant behavior and coercion/segregation. The subscales had acceptable to good reliability ranging from 0.70 to 0.89.

Social distance scales attempt to measure the behavioral component of stigma with scales that assess a person's willingness to interact with the stigmatized groups. The degree of interaction varies from superficial to extremely intimate (as in marriage). Social distance scales have good to excellent internal reliability ranging from 0.75 to 0.90 (Link et al. 2004). Predictors of social distance are lower level of education, lack of familiarity with people with mental illness, older age and stereotypical beliefs, such as the belief that people with mental illness are dangerous. One of the major critiques of social distancing scales is the finding that Social Distance is an indirect measure of behavior and, therefore, actual behavior may not correspond to the stated behavior (Link et al. 2004).

The validity of explicit measures is called into question by social desirability bias and the need to present oneself in a positive light, which creates a reluctance to endorse negative attitudes towards other people. The rapid automatic responses that are measured in implicit assessments of stigma differ from the deliberative, self-report responses of explicit assessments of stigma (Gawronski and Bodenhausen 2006) and can be used to predict cognitive, affective and behavioral outcomes. One such measure is the Brief Implicit Association Test (BIAT) (Sriram and Greenwald 2009) which can be used to measure implicit stereotypes about mental illness by classifying a series of words into categories, such as "Mental Illness" versus "Physical Disability" and attribute categories, such as "Guilty" versus "Innocent."

There are several important drawbacks to many of the above-mentioned methods to assess level of stigma for the purposes of evaluating change in stigma in interventional research. As mentioned above, explicit, self-report questionnaires are subject to social desirability bias among the general public, potentially underestimating the true level of stigma. Although unconscious implicit measures avoid this threat to validity, the necessity of administration in the laboratory setting with specialized equipment can create undue participant burden, particularly for low-income, vulnerable populations who may lack transportation, child care or time off from work. Moreover, it is an impractical form of measurement for interventions targeted to community-based interventions. Items in stigma measures also do not capture cross-cultural or religiously based differences in beliefs about mental illness (Martin et al. 2008). Cultural mechanisms that contribute to the development of stigma can be identified and operationalized (Yang et al. 2013b) and when these culture-specific constructs are added to conventional measures, there is greater predictive value of the measure (Yang et al. 2013a). Therefore, it is imperative to begin to identify creative solutions to measuring effects of stigma interventions. The purpose of this pilot study is to preliminarily test a new anonymous method of measuring stigma in the community setting.

Hypothesis 1 Level of stigma measured anonymously in the aggregate will be greater than level of stigma measured with face-to-face questionnaires.

There are no known conflicts of interest in this investigation.

Methods

Design

We conducted a sub-analysis of a pilot study to evaluate the feasibility and acceptability of "El Buen Consejo," a

psychoeducational and treatment engagement intervention delivered within the faith-based setting. Data were collected over a period of three years, between 2012 and 2015, from three separate churches that participated in the pilot study.

Study Sites

The three faith-based communities (FBCs) included a Presbyterian church in New York City (Church 1), a Catholic church in Portland, Maine (Church 2), and a Methodist church in New York City (Church 3). Each site included a diverse group of Latinos (see Table 1).

Recruitment

Congregants were recruited from the churches listed above. The recruitment first entailed a brief overview of the study given by the research staff during the Sunday morning service or mass. Congregants were encouraged to attend not only if they had a self-perceived mental health need, but also to obtain information that could help a family member or loved one who may have been suffering from mental illness. At Churches 1 and 3, the faith-based leader gave a sermon about mental illness, which served to aid in recruitment via clerical sanctioning of the importance of the program. At the end of services, congregants were handed pencils with contact information for the research study and were asked to call if interested in learning more about the study. Additionally, a sign-up sheet was circulated so that interested congregants could be contacted by the research staff to arrange a convenient time and private location to further describe the study, obtain consent and conduct the baseline assessment. All consent forms and data-collection measures were read aloud to participants in their language of preference.

Inclusion Criteria

(1) Members of the respective congregations or the community it served who self-identified as 1st or 2nd generation Latinos; (2) men or women age 18 or older; (3) individuals who were competent to consent and had completed a written consent form; and (4) able to understand Spanish.

Exclusion Criteria

(1) Persons who did not meet the above criteria; and (2) and had intent or plan to attempt suicide.

Participants

Sixty-four participants completed baseline data: 30 individuals at Church 1, 15 at Church 2 and 19 at Church 3.

Table 1 Description of the Sample

Sample characteristics (n = 64)	
*Variable**	
Age	53 (18)
Gender	
Female	47 (73)
Income level	
<$5000–$9999	19 (30)
$10,000–$29,999	21 (33)
≥20,000	16 (25)
Refused or don't know	8 (12)
Educational level	
8th grade or less	10 (16)
Some high school	6 (10)
GED or high school	14 (22)
Some college or technical school	15 (23)
College Grad or Grad school	18 (28)
Refused or don't know	1 (1)
Country of origin	
United States	9 (14)
Dominican Republic	36 (56)
Central American/South American/ Cuban	10 (16)
Puerto Rican	9 (14)
Religious congregation	
Church 1 (Presbyterian)	30 (47)
Church 2 (Catholic)	15 (23)
Church 3 (Methodist)	19 (30)
Preferred language	
Spanish	51 (80)
Number of years lived in the US	27 (17.2)
Ethnic identity	
Dominican	40 (62)
Central American/South American/ Cuban	12 (19)
Puerto Rican	12 (19)
Work status	
Full-time	22 (34)
Part-time	8 (13)
Retired/disabled	20 (31)
Student	2 (3)
Not employed currently employed	12 (19)
Have read about mental health before	
Yes	44 (70)
Church Attendance	
More than once per week	28 (44)
Once per week	29 (45)
One to three times per month	3 (5)
Less than once per month	4 (6)
Intervention sessions attended	
0	17 (27)

Table 1 continued

Sample characteristics (n = 64)	
1	10 (16)
≥2	37 (57)

* For categorical variables, number and percentages are reported in parentheses. For continuous variables, means and standard deviations are reported in parentheses

Participants in the sub-analysis were a subgroup of the 46 (72 %) of participants who attended at least one session of El Buen Consejo and met the following inclusion criteria:

1. Attended a session that included *Preguntas Con Cartas* (Questions with Cards), a method of anonymous group voting.
2. The session that included *Preguntas Con Cartas* had only participants who had baseline data at the time of attendance (i.e. no walk-ins).
3. Participants signed an attendance sheet.

Twenty-two participants met the above criteria.

Intervention

The intervention was carried out during four separate 2-hour group sessions. Each group ranged from six to twelve people. At Church 1, sessions were repeated with different groups for those who missed previous sessions or who newly enrolled in the study. Session 1 (from which these data were derived) consisted of a discussion of beliefs about mental illness, and societal and personal attitudes towards persons with mental illness, followed by a more in-depth discussion of depression and participants' beliefs about the role of faith and causes of depression. The second session was a presentation by speakers who shared their personal experiences of mental illness that was sponsored by the National Alliance on Mental Illness. The third session consisted of a presentation by a bicultural mental-health professional about treatments for depression and community resources. The last session discussed steps to create caring congregations. For a further description of the intervention see Caplan and Cordero 2015.

Data Collection

Data were ascertained using two different methodologies, anonymous group stigma voting and the use of face-to-face interviews with identical questions. The first method of data collection was a method of anonymous group stigma voting developed by the author; *Preguntas con Cartas* (Questions with Cards). During the educational session, a question was projected on a powerpoint slide. *Preguntas con Cartas* was a selection of questions from the Personal Depression Stigma Scale (PDSS) and Religiously Based Societal Stigma questions. (See Measures below for a description of the scales). These questions were:

1. "Depression is a sign of personal weakness."
2. "It's better to avoid people with depression so that you don't develop this problem."
3. "The problem with people with depression is their lack of faith in God."
4. "People with depression could 'snap out of it' or get rid of it by willpower alone."
5. "People with depression are dangerous."
6. "If I had depression, I would not tell anyone."
7. "I would not vote for anyone who has or has had a history of depression."

Underneath the question on the slide, there was a list of Likert scale responses ranging from "1," strongly agree to "5," strongly disagree. Participants were provided with sets of playing cards numbered from 1 to 5 to correspond to the Likert scale responses. They were then instructed to select a card representing their answer and to place it face-down in the middle of the table. Results for the entire group were tabulated and recorded for an aggregate group level response. The questions used in the educational session were the same questions that participants had responded to as part of the face-to-face interviews.

Measures

Religiously Based Societal Stigma

In the absence of a validated religious-stigma scale, we used two items to assess this construct based on the literature and the related constructs of positive and negative religious coping (Pargament et al. 2000); (Wesselmann and Craziano 2010). The two items were "Depression is a sign of personal weakness;" and "The problem with people with depression is their lack of faith in God." Item responses conformed to a 5-point Likert scale, from 1 (strongly agree) to 5 (strongly disagree).

Personal Depression Stigma Scale (PDSS)

This 9-item Personal Depression Stigma scale reflected individual personal beliefs about depression labeled "personal stigma" (Griffiths et al. 2004), as opposed to what the individual believes are the attitudes of the general public (perceived stigma). It was translated into Spanish by two native speakers using the back translation method described by Brislin (1970). Participants' responses conformed to a 5-point Likert scale—strongly agree, agree, neither agree nor disagree, disagree, and strongly disagree with a

possible total score ranking from 9 to 45, with lower scores equal to greater stigma. The original nine-item scale had a reliability of $\alpha = 0.77$ (Griffiths et al. (2008).

Data Analysis

We used univariate analyses to describe the psychosocial and clinical characteristics of the sample using SPSS. Data analysis for the Likert-scale responses to *Preguntas Con Cartas* (anonymous group polling) and face-to face questions used descriptive statistics to identify the distributions of scores with strongly agree and agree merged and strongly disagree and disagree merged to form a trichotomous variable with neutral. For analysis of the difference between *Preguntas con Cartas* votes and face-to-face individual survey results, we performed a chi- square goodness-of-fit test to determine if there were differences in the distributions between the two methods of data collection. The remaining participants who participated in the *Preguntas con Cartas* stigma voting were matched according to their corresponding face-to-face individual survey results. Distributions across all of the seven questions stated above were pooled and represented 225 observations. To evaluate if the subsample of participants who participated in *Preguntas con Cartas* voting were different from those who did not, we performed Chi square goodness-of-fit test comparing the distribution of votes between both groups.

The Study was Approved by Rutgers University Internal Review Board.

Results

Table 1 shows the demographic and psychosocial characteristics of the sample. More than half of the sample was of Dominican ethnic background. The mean age of the sample was 53; almost three quarters were female. More than half of the sample was out of the workforce or unemployed and earned less than $20,000 annually. Although more than half of the sample had been living in the country for more than 20 years, the vast majority (80 %) preferred to be interviewed in Spanish. More than three quarters of the sample attended one or more sessions.

An analysis of the difference between *Preguntas con Cartas* stigma votes and face-to-face individual survey results for the seven stigma questions stated above indicated that there was a statistically significant differences in the distributions between the two methods of data collection ($\chi^2 = 8.27$, $p = 0.016$). Figure 1 shows the differences in distribution between the two groups. The anonymous responses were significantly more likely to be "agree or strongly agree," indicating greater stigma. There

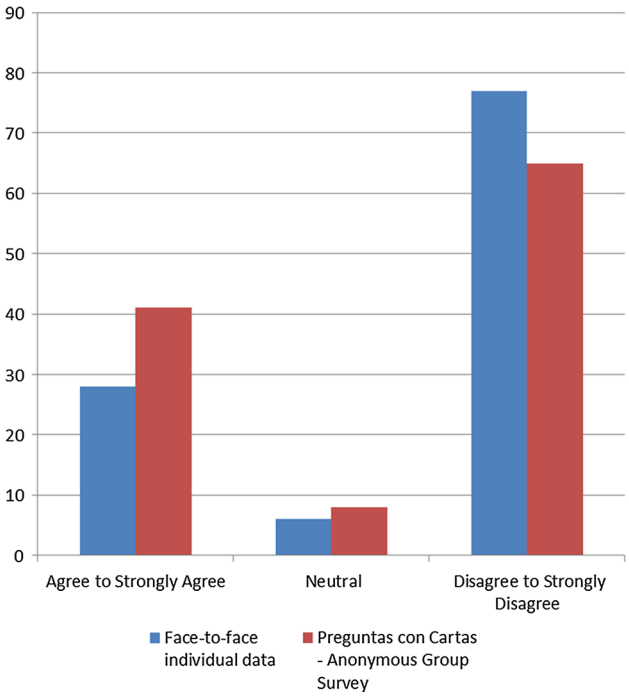

Fig. 1 Distribution of face-to-face individual data compared to anonymous group survey results

was no difference between the participants who met the inclusion criteria for the *Preguntas con Cartas* stigma votes and those who did not ($\chi^2 = 2.37$, $p = 0.31$).

Discussion

This exploratory study has shown the potential for the effectiveness of *Preguntas con Cartas* as a novel method of measuring stigma in the community-based setting. Stigmatizing attitudes about mental illness and treatment create a major barrier to health care, particularly for low-income racial and ethnic minorities. Attitudes such as the belief that depression is a sign of personal weakness, the reluctance to disclose personal problems outside of the family and a strong value on self-reliance are common among Latinos (Jang et al. 2011; Jimenez et al. 2013; Villatoro et al. 2014). These stigmatizing attitudes towards persons with mental illness may be perpetuated via the social networks of religious communities and religious teachings. Faith healing and treatment of mental illness consisting of confession of sins, trusting in God, prayer and individual willpower, are frequently associated with negative attitudes towards psychotherapy and pharmacological treatment (VanderWaal et al. 2011; Vargas et al. 2015; Villatoro et al. 2016; Vega et al. 2010). Nevertheless, given the importance of religion for many Latinos and the use of religion as a coping mechanism in times of distress, faith-based organizations

play an important role in providing health education, health promotion and partnering with community health organizations to increase access to mental health care for those in need. Although some religious teachings may exacerbate stigma, the tenets of most religious groups emphasize tolerance and acceptance of all people. Thus, social desirability bias becomes an extremely likely threat to validity in the measurement of stigma among religious populations.

Valid measures of stigma are needed to increase our understanding of stigma and factors contributing to stigma, to measure the degree of stigma among particular groups and to assess the effectiveness of interventions designed to reduce stigma (Van Brakel 2006). Corrigan and Shapiro (2010) suggest a number of methods to reduce the social desirability bias inherent to survey measures. These recommendations include: allowing the participant to fill out the survey anonymously, designing multi-factor Randomized Controlled Trials with pre- and post-testing, and third-party unobtrusive behavioral observations. All of these recommendations, however, require a specific set of circumstances for implementation. The anonymous survey will not work with a low-literacy population and/or in a situation where one is trying to assess characteristics of the individual that may contribute to his/her particular responses. Similarly, behavioral observation will only work in unique circumstances, and even then, is subject to ethical considerations if the participant is behaving in an illegal or incriminating manner.

The generalizability of this study is limited by a small sample size. The sample size was limited by the unique constraints of community-based research. Although it was clearly stated that congregants needed to fill out baseline data prior to participating in the educational sessions, in many cases, congregants chose to ignore this request and participated by a walk-in basis, thus all of the votes in a session had to be discarded since we did not have a method of distinguishing among the anonymous voters who had had baseline data. Moreover, in some instances among the group voters, it may have been possible that some people voted twice and some people did not vote at all. Careful observation of the behaviors of the participants generally precluded this event. However, it is possible that we were unable to obtain a precise correspondence to individual votes. Nevertheless, the tendency for anonymous voters to display greater stigma was clear from the results.

In sum, *Preguntas con Cartas* makes use of anonymous polling in a manner that is convenient and easy to administer with diverse groups. Preliminary data show that it is less vulnerable to the social desirability bias inherent to explicit measures. Questions used in the *Preguntas con Cartas* addressed some religiously-based stigma, however, future research could use culturally-tailored stigma items embedded within stigma measures to address cultural influences of stigma. In this study, anonymous stigma voting was accomplished with the use of simple numbered playing cards; for larger groups, the same method of anonymous voting could be achieved using *i-Clicker*© technology (Macmillan 2016), a classroom technology primarily used to conduct anonymous polling in the context of large college lectures. Future research could replicate the present study to determine if the findings are valid for larger groups.

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