

NIH Public Access

Author Manuscript

Psychol Med. Author manuscript; available in PMC 2014 October 01.

Published in final edited form as: *Psychol Med.* 2013 October ; 43(10): 2191–2202. doi:10.1017/S003329171200298X.

Embarrassment When Illness Strikes A Close Relative: A World Mental Health Survey Consortium Multi-Site Study

Brian K. Ahmedani, PhD^{1,2}, Sheryl Pimlott Kubiak, PhD², Ronald C. Kessler, PhD³, Ron de Graaf, PhD, MSc⁴, Jordi Alonso, MD, PhD⁵, Ronny Bruffaerts, PhD⁶, Zahari Zarkov, MD⁷, Maria Carmen Viana, MD, PhD⁸, Y.Q. Huang, MD, MPH, PhD⁹, Chiyi Hu, MD, PhD¹⁰, Jose A. Posada-Villa, MD¹¹, Jean-Pierre Lepine, MD, HDR¹², Matthias C. Angermeyer, MD¹³, Giovanni de Girolamo, MD¹⁴, Aimee N. Karam, PhD¹⁵, Maria Elena Medina-Mora, PhD¹⁶, Oye Gureje, MD, PhD, DSc, FRCPsych¹⁷, Finola Ferry, BSc¹⁸, Rajesh Sagar, MD¹⁹, and James C. Anthony, Ph.D²⁰ [Professor]

¹Center for Health Policy & Health Services Research, Henry Ford Health System

²School of Social Work, Michigan State University

³Department of Health Care Policy, Harvard Medical School

⁴Netherlands Institute of Mental Health and Addiction

⁵IMIM-Institut de Recerca Hospital del Mar, Parc de Salut Mar and Pompeu Fabra University (UPF)

⁶Universitair Psychiatrisch Centrum, Katholieke Universiteit Leuven (UPC-KUL)

⁷Bulgaria National Center of Public Health and Analyses

⁸Department of Social Medicine, Federal University of Espírito Santo (UFES)

⁹Institute of Mental Health, Peking University

¹⁰Shenzhen Institute of Mental Health and Shenzhen Kangning Hospital

¹¹Pontificia Universidad Javeriana, Instituto Columbiano Del Sistema Nervioso - Clinica Montserrat

¹²Hôpital Lariboisière Fernand Widal, Assistance Publique Hôpitaux de Paris

¹³Austria, Center for Public Mental Health

¹⁴IRCCS Centro S. Giovanni di Dio Fatebenefratelli

¹⁵Department of Psychiatry and Clinical Psychology, Saint George Hospital University Medical Center, Balamand University Medical School

¹⁶National Institute of Psychiatry, Mexico

¹⁷WHO Collaborating Centre ofr Research and Training in Mental Health, Neurosciences, and Substance Abuse AND Department of Psychiatry, University of Ibadan

Corresponding Author: Brian K. Ahmedani, PhD, Center for Health Policy & Health Services Research, Henry Ford Health System, One Ford Place, Suite 3A, Detroit, MI, 48202, bahmeda1@hfhs.org; telephone: +1 313-874-5485; fax +1 313-874-7137.

¹⁸School of Psychology, University of Ulster

¹⁹Department of Psychiatry, All India Institute of Medical Sciences

²⁰Department of Epidemiology, Michigan State University

Abstract

Background—This global study seeks to estimate the degree to which a family member might feel embarrassed when a close relative is suffering from an alcohol, drug, or mental health condition (ADMC) versus a general medical condition (GMC). To date, most studies have considered embarrassment and stigma in society and internalized by the afflicted individual, but have not assessed family embarrassment in a large scale study.

Method—In 16 sites of the World Mental Health Surveys (WMHS), standardized assessments were completed including items on family embarrassment. Site matching was used to constrain local socially shared determinants of stigma-related feelings, enabling a conditional logistic regression model that estimates the embarrassment close relatives may hold in relation to family members affected by an ADMC, GMC, or both conditions.

Results—There was a statistically robust association such that subgroups with an ADMCaffected relative were more likely to feel embarrassed as compared to subgroups with a relative affected by a GMC (p<0.001), even with covariate adjustments for age and sex.

Conclusions—The pattern of evidence from this research is consistent with conceptual models for interventions that target individual- and family-level stigma-related feelings of embarrassment as might be part of the obstacles to effective early intervention and treatment for ADMC conditions. Macro-level interventions are underway, but micro-level interventions also may be required among family members, along with care for each person with an ADMC.

Keywords

Family Embarrassment; Stigma; World Mental Health Surveys; Psychiatric Conditions

Introduction

Alcohol, drug, and mental health conditions (ADMC) have surfaced as major public health challenges of our time (Demyttenaere *et al.* 2004; World Health Organization [WHO], 2001). In addition, ADMC are considered prominent causes of disability adjusted life years (Buka, 2008; Hugo *et al.* 2003; World Health Organization [WHO], 2004a). Unfortunately, patients with ADMC often face barriers to care. To illustrate, in the United States, an estimated eight year median lag-time separates depression onset and treatment services entry; for alcohol and other drug disorders, the median is five years (Wang *et al.* 2005).

Stigma-related feelings about illness are among the barriers, leading World Psychiatric Association leaders to make recommendations for ameliorative interventions (Sartorius *et al.* 2010). In this context, stigma can be defined broadly 'to encompass the negative stereotypes and prejudicial beliefs that people may hold, as well as discriminatory or inequitable practices that may result' (Sartorius *et al.* 2010). In research on this construct, it has been

typical to study self stigma (e.g., patients' feelings about themselves) and social stigma as manifest in a desire to increase 'social distance' between self and ADMC (Alonso *et al.* 2008; Brohan *et al.* 2010; Brohan *et al.* 2011; Crocker, 1999; Jorm and Oh, 2009). This study focuses on a unique aspect of social stigma – investigating whether family members are more often embarrassed by their relatives' mental health as compared to general medical conditions.

As background, manifestations of social stigma have been studied at the macro- and microlevel as potential barriers that separate the illness-affected person from prompt access to effective services (Ahmedani *et al.* 2011; Alonso *et al.* 2008; Alonso *et al.* 2009; Cao *et al.* 2010; U.S.Surgeon General, 1999; World Health Organization [WHO], 2001). Here, individuals with ADMC are regularly perceived as dangerous or violent and are frequently avoided (Crocker, 1999; Dudley, 2000; Goffman, 1963). Apparently, these stigma-related feelings have not changed appreciably over time (Pescosolido *et al.* 2010), and the mass media sustain negative portrayal of these conditions (Corrigan *et al.* 2003; Dietrich *et al.* 2006; Klin and Lemish, 2008; Sayce, 2000). Moreover, in relation to many ADMC conditions, victims often are told that they should be able to 'pull themselves together' and to control themselves without help (Corrigan *et al.* 2000; Corrigan *et al.* 2001; Crisp *et al.* 2000). These examples illustrate a variety of ways to conceptualize and measure social stigma – e.g., social distance, dangerousness, and controllability (Ahmedani, 2011).

The ADMC, in particular, seem to evoke stigma-related feelings more often than general medical conditions (GMC), although the evidence base from rigorous research on this topic needs development. For instance, in some research, levels of stigma-related feelings attached to schizophrenia and cocaine addiction have been found to be greater than corresponding levels as attached to the cancers; individuals with more severely stigmatized psychiatric conditions have been believed to be able to control their symptoms more readily, and perceived controllability of the condition may help explain some observed variations (Corrigan *et al.* 2000).

Despite variation within ADMC, there still remains an overarching issue in societies around the world, such that ADMC are viewed less favorably than GMC. To illustrate, within the US, public support for government health care funding to treat GMC is substantially greater than support for funding of ADMC services (McSween, 2002). Also, public health promotion and prevention campaigns in Australia are more prevalent for GMC (Jorm *et al.* 2006). The many gaps in the evidence base have elicited recommendations for new international health research agenda that will foster a more complete understanding of variations in stigma attached to illnesses and to psychiatry (Weiss and Ramakrishna, 2006; Sartorius *et al.* 2010).

In theory, there is another reason to study social stigma as it is manifest within family systems. Application of a social systems perspective, with the individual as a focus, clarifies the family as one of the closest subsystems of society to the individual's system, and this gives the family special leverage in relation to the individual's decisions and behavior (Robbins *et al.* 2005; Stier and Hinshaw, 2007; Wahl, 1999). More specifically, ADMC, unlike most GMC, may create unique burdens on family members, causing isolation from

the community at large, with potential loss of extra-familial support and friendship-related social capital (Lefley, 1989). Once a close relative is affected by an ADMC, family members may themselves feel stigmatized, blamed, and embarrassed (Corrigan *et al.* 2006; Ostman and Kjellin, 2002). Behavioral manifestations of these stigma-related feelings include concealment of the close relatives' illnesses, and possibly self-blame about the events leading up to the relative suffering from an ADMC (Hinshaw, 2005; Phelan *et al.* 1998).

One of the most well-studied social stigma constructs is 'social distance,' the primary topic in a recent review (Jorm and Oh, 2009). To illustrate, according to estimates from Sweden (Ostman and Kjellin, 2002), 18% of individuals thought that their close relative with an ADMC would be better off dead; it also is noteworthy that 40% believed that they, themselves, had developed an ADMC from their association with their afflicted family member. From Hong Kong, there is evidence that ADMC-associated social stigma as felt by a family member is greater for schizophrenia than for diabetes (Lee *et al.* 2005). In addition to 'social distance,' one of the unifying constructs in the empirical stigma research on familial reactions to ADMC may be 'embarrassment,' which we have adopted here, consistent with its application in prior research (Alonso *et al.* 2008; Alonso *et al.* 2009; Link and Phelan, 2001; Phelan *et al.* 1998). Embarrassment was chosen as a measure of stigma for two main reasons: 1) its use extends WMHS research highlighting the extent of personal embarrassment (Alonso *et al.* 2008; Alonso *et al.* 2009), and 2) the WMHS protocol measured embarrassment by asking family members about their relatives' health conditions; other social stigma variables were not measured.

In this project, the focus is on the construct of 'embarrassment' as a facet of stigma-related feelings that can affect the lives of family members. This research project places illness-associated family embarrassment as a response variable in a conceptual model such that its occurrence is expressed as a function of whether close relatives have been affected by a burdensome ADMC only, by a GMC only, or by both. Instead of asking the family member to attribute the embarrassment to one or another of the close relative's health conditions, we have estimated the strength of association that links these feelings of embarrassment with each group of conditions. Use of a 'fixed effects' conditional logistic regression model has made it possible to constrain macro-level influences such as society-wide social stigma, even though the WMHS research protocol had no explicit measurement of these sources of variation in embarrassment felt at the individual level.

Purpose of the Study

The main aim of the current study is to assess 'family embarrassment' as a construct of social stigma in representative samples drawn, recruited, and assessed in 16 different sites of the World Mental Health Surveys. Furthermore, this study estimates the degree to which family embarrassment is associated with having one or more close relatives affected by burdensome ADMC only, GMC only, or both, with covariate adjustment for sex and age, while mitigating the influence of socially-shared or macro-level influences on embarrassment via within country matching and conditional logistic regression. We hypothesize that family embarrassment will be greater towards individuals with ADMC as

compared with GMC, but will be greatest for the GMC+ADMC group because comorbidity may result in greater embarrassment for the family.

Methods

The World Mental Health Surveys (WMHS) consist of coordinated household surveys with nearly 120,000 participants in 23 sites distributed across world regions, including Africa (Nigeria and South Africa), the Americas (Brazil [São Paulo], Colombia, Mexico, and the United States), Asia (China, Japan [11 Metropolitan areas], India [Pondicherry], Iraq, Israel, and Lebanon), Europe (Belgium, Bulgaria, France, Germany, Ireland, Italy, the Netherlands, Romania, Spain, and Ukraine), and Oceania/South Pacific (New Zealand). The initial protocol consisted of two independent surveys in the People's Republic of China (PRC: Beijing and Shanghai). In this study, 16 sites with complete data on family embarrassment contribute information for the study estimates (combined n=81,144), which includes the combination into one site of samples from both PRC sites, based on a convention established by the WMHS team. Table 1 lists sites contributing data for this research project.

A thorough presentation of the study development and methods has been published elsewhere (Kessler and Ustun, 2004). In brief, after standard field survey sampling and recruitment of consenting adult participants, the assessment plan included administration of standardized modules from the World Mental Health version of the WHO Composite International Diagnostic Interview (CIDI 3.0). These modules were used to assess psychiatric conditions and other variables in a fully structured interview schedule format; an optional module covered aspects of family burden. The sample sizes of participants, shown in Table 1 for the WMHS sites that administered the interview module on family burden, ranged from 2,372 participants in the Netherlands to 12,335 in PRC. The institutional review boards responsible for each site-specific data collection reviewed and approved the field survey protocols.

The survey was administered in two parts, either via face-to-face interviewing by a staff member, or by computer assisted interview, with standardized survey items that had been translated, back-translated, and harmonized to local languages. The English language instrument is available online (http://www.hcp.med.harvard.edu/wmhcidi/index.php). Readers are encouraged to contact administrators for other language versions via information on the website. Part I, which consisted of screening questions and the assessment of demographic information, some psychiatric conditions, and basic health status, was administered to those who agreed to participate; more than 70% of the sample participated (Alonso *et al.* 2008; Kessler and Ustun, 2004). All participants who reported having a history of psychiatric symptoms, as well as a probability subsample (approximately 25%) of those who did not, were asked to complete Part II. The Part II content varied slightly by site but typically included items that assessed lower prevalence mental disorders and special topics such as family burden, including family embarrassment (Kessler and Ustun, 2004).

Health Conditions

Questions about burdensome health conditions among close relatives were asked in the family burden section of the WMHS interview, Part II (i.e., the subsamples). Figure 1 shows the WMHS branching protocol for this section and how the final analytical sample was derived. First, participants sampled to complete the family burden module were asked a question about the number of close living family members including their spouse/partner, parents, children, and brothers and sisters. When participants acknowledged having one or more family members, they were directed to health condition questions of the following form and a list of conditions: "Do any of your close family members have any of the following health conditions?" (World Health Organization [WHO], 2004b). The list included: 1) cancer, 2) heart problems, 3) serious memory problems, 4) mental retardation, 5) permanent physical disabilities such as blindness or paralysis, 6) other chronic physical illnesses, 7) alcohol or drug problems, 8) depression, 9) anxiety, 10) schizophrenia or psychosis, 11) manic-depression, and 12) other serious mental health problems.

Participants answering "Yes" to any condition were asked a question about 'family burden.' The question was: "The next questions are about how your life is affected by the health problems of your [RELATIVE/relative(s)]. Taking into consideration your time, energy, emotions, finances, and daily activities, would you say that (his/her/their) health problems affect your life: a lot, some, a little, or not at all?" Respondents who answered 'a lot' or 'some' routed into a series of questions, including the family embarrassment item. No other participants were asked about embarrassment.

For clarity, we note that in response to the questions about health conditions affecting their close relatives, participants might say 'yes' to all, some, no more than one, or none of the 12 conditions. At least one 'yes' answer was required for routing into the family burden items. Based on the observed data, the health conditions were sorted to form two inter-correlated variables 1) GMC (items 1-2 & 5-6), and 2) ADMC (items 3-4 & 7-12). Subgroups of participants were formed by crossing these variables, making it possible to study an ADMC-only subgroup, a GMC-only subgroup, and comorbidity subgroup. Table 1 provides the frequency and proportion of participants whose assessment indicated that a close relative was affected by at least one health condition, stratified by health condition category and by site. We note an ambiguity when both a GMC and an ADMC were mentioned. The comorbidity of GMC and ADMC is observed within the family, not necessarily within a single close relative. That is, one of the relatives might have been affected by a burdensome GMC, with a different close relative affected by a burdensome ADMC. Alternately, the participant might be mentioning a single individual, with burden from two comorbid individual conditions.

Family Embarrassment

Once a participant acknowledged 1) having at least one family member with at least one listed health condition and 2) feeling burdened by the condition(s), each was asked, "How much do (his/her/their) health problems cause you embarrassment?" (World Health Organization [WHO], 2004b). The possible response options for this question were 'a lot', 'some', 'a little', and 'not at all.' Answers of 'a lot', 'some', or 'a little' were considered as

Page 7

family embarrassment. The item was collapsed into a binary format, so as to harness the conditional logistic regression matching approach and to estimate 'any degree' of embarrassment versus no embarrassment. Table 1 includes a sample description of participants, stratified by site.

Analyses

All WMHS sites with equivalent question structure and usable data for 'embarrassment' and 'health condition' contributed data, as shown in Figure 1. Participants were grouped by site, and the individual-level analysis plan was carried out with site-level matching. The main analysis involved a conditional form of multiple logistic regression, with the log odds of burdensome family embarrassment expressed as a function of ADMC, GMC, age and sex. Small sample sizes within some sites imposed constraints on more detailed modeling. By conditioning on each site, we take into account the fact that each WMHS site conducted autonomous field research operations according to the common protocol. The substantive implication is that participants at one site who feel embarrassed are compared to participants who do not feel embarrassed at that same site. The regression models yield slope estimates on the natural log scale. We have exponentiated these estimates and the text describes the patterns of association in the form of the resulting odds ratio estimates. Post-estimation analyses included probes into several assumptions, including the possibility that variation in the odds of embarrassment might be driven by variation in the participants' assessments of being burdened by the health conditions of family members. In addition, due to the fact that analysis of site-matched individual-level data does not permit explicit weighting for sample selection probabilities (SSP) or post-stratification adjustment factors (PSAF), the postestimation analyses included a stratification approach. The main analysis was repeated for each of 10 strata, formed by taking deciles of the SSP-PSAF analysis weight distribution. We also compared the conditional model results with estimates from a weighted unconditional logistic regression model with area of residence held constant via dummycoded indicator covariates, and variance estimation for complex samples. Essentially the same point estimates were obtained, and the conditional model yielded slightly smaller variance estimates and narrower confidence intervals, in contrast with what others have sometimes found in the form of noteworthy differences with respect to both point estimates and variances, with the possibility of differences in inference (Brumback et al. 2012). The unconditional model estimates are available upon request. The study estimates, 95% confidence intervals, and p-values are presented for the main analyses.

Results

Table 1 shows the proportion of participants whose data indicate having a family member with one or more burdensome health conditions, as well as individuals who felt embarrassed, stratified by site. Overall, 6% of participants had a family member with a burdensome GMC (n=4,870) and 3.7% had a family member with a burdensome ADMC (n=3,025). Slightly fewer (2.9%) described the comorbidity situation (n=2,378). Sitespecific variations in these 'GMC only,' 'ADMC only,' and 'GMC+ADMC' proportions, based on weighted survey data, are being reported in other publications by the WMHS stigma work group, thus, the weighted estimates are not reported here (Alonso *et al.* 2008;

Alonso *et al.* 2009). In total, ~33% of participants (n=1,295), who were asked about embarrassment (n=3,930), felt at least 'a little' embarrassed about a relative's condition. This equated to 11.7% (n=460) who were embarrassed 'A lot', 11.7% (n=458) 'Some', and 9.6% (n=377) 'A little.' Furthermore, 24.9% (n=527 of 2,113) of participants with relatives who had GMC only felt embarrassed, as compared to 49.5% (n=397 of 802) in the ADMC only group, and 36.6% (n=371 of 1,015) in the GMC+ADMC group.

Table 2 presents estimates from conditional logistic regression analyses with covariate adjustment for age and sex, and with site-level matching. Here, the reference is family embarrassment in relation to relatives with GMC only. The subgroup of participants in families with ADMC only were more often embarrassed by the condition (exponentiated slope estimate yields odds ratio, OR = 3.7; p<0.01). This also was found for those in families where both ADMC and GMC were present (OR = 2.2; p<0.01). In a comparison, the 'ADMC only' subgroup was more likely to feel embarrassment than the 'ADMC+GMC' subgroup, even with covariate adjustment for age and sex (OR = 1.7; p<0.01), although neither age nor sex were associated with family embarrassment.

To probe into the unexpected result that comorbid GMC and ADMC was associated with lower odds of family embarrassment, we conducted a post-estimation exploration of the possibility that family burden might be occurring more frequently in the 'ADMC only' subgroup. As displayed in Table 3, the subgroup with both GMC and ADMC in the family has greater odds of describing family burden, as compared to the 'GMC only' subgroup (OR = 2.0; Table 3); the contrast with the 'ADMC only' subgroup also is noteworthy. The estimated odds of family burden for the 'ADMC only' subgroup is not appreciably different from the 'GMC only' subgroup (OR = 1.07; p = 0.168), indicating that the 'ADMC only' subgroup members are more likely to feel embarrassed but not to have greater family burden.

In post-estimation analyses with respect to sampling weights, we found no appreciable variation in the estimates across weight variable deciles with one possible exception (Figures 2 and 3). The exception involved the 8th decile (Figure 3), where the estimated association for the 'GMC+ADMC' subgroup was modestly larger than the value reported in Table 2. The original full sample coefficient was 0.79, whereas the 8th decile subsample estimate was 2.8. As noted in the methods section, the unconditional logistic regression approach with weights and variance estimation for complex samples yielded consistent estimates with no meaningful change in conclusions.

Discussion

The main finding of this study is greater occurrence of family embarrassment when a close relative is affected by a burdensome ADMC as compared to a GMC. One novel aspect of this finding is that local site matching was used to constrain socially shared influences on feelings of embarrassment, which vary from country to country. In consequence, the resulting estimates pertain to the occurrence of family embarrassment as it is experienced at the subgroup and individual level within each site. With the between-site macro-level influences held constant, the subgroup with both ADMC and GMC was more likely than the

'ADMC only' and 'GMC only' subgroups to describe burden of illness; even so, the 'ADMC only' subgroup was more likely to feel embarrassed, suggesting that embarrassment is not strictly a function of the associated burden felt by the family member.

Before more detailed discussion, several limitations deserve attention. First, the WMHS project did not include stigma research as a primary aim. Hence, this study sheds light on the 'family embarrassment' facet, but not other stigma constructs. In addition, some stigmatized GMC (e.g., epilepsy) were not mentioned in the WMHS items. Further, the placement of the stigma questions in Part II, with constrained sub-sample sizes, has limited the modeling of potential explanations for observed variations, including variations in the occurrence of family embarrassment from site to site. Noting that translation/back-translation may not provide complete measurement equivalence results (Shrout *et al.* 2008), we must speculate that variations in language, understanding, and perhaps perceived burden or severity of the ADMC or GMC conditions under study might help account for the observed site-to-site variations, but the WMHS project was designed to document but not to explain such differences.

Second, we turned to the conditional form of logistic regression with site-matching in order to derive estimates in a fashion that constrains socially shared sources of variation site-by-site, akin to what is done in behavioral genetics and other family research, but this 'fixed effects' approach does not permit use of analysis weights. A counter-balanced strength is that essentially the same conclusions were derived during post-estimation exploratory analyses, including a post hoc use of the unconditional logistic regression model with sampling weights and variance estimation for complex sample data as described elsewhere (Heeringa et al., 2010).

Finally, we had hoped to study stigma variation across individual ADMC, but the Part II sample size constraints thwarted this aim. In this regard, the driving influence was the number of survey respondents who were drawn into the sample for the Part II modules, a number that proved to be too small for our pre-planned analyses and too small for individual country estimates. Here, again, in future research focused more on stigma it should be possible to achieve disorder-level specificity in the estimated associations with odds of family embarrassment and social distance.

Implications

Notwithstanding these limitations, the evidence from this study is generally consistent with observations from other single site research. In a departure from typical stigma research, we did not ask the participants to tell us whether they are embarrassed by ADMC in specific. Instead, we asked whether burdensome health conditions might have affected a close family member, and separately, we asked whether there might have feelings of embarrassment. We then estimated the degree of association between the odds of feeling embarrassed and the nature of the health condition, without requiring the participants to tell us whether it was the ADMC that caused them to feel embarrassed. With this approach, we avoided problems faced when participants are required to have insight into the specific causes of their feelings. The result is stronger evidence that stigma-laden feelings such as family embarrassment are

more often occurring when a close relative has one of the ADMC. The demonstrably greater occurrence of family embarrassment in association with ADMC as compared to GMC highlights the importance of the ongoing work of the World Psychiatric Association and others who are trying to reduce stigma attached to psychiatry and psychiatrists (Sartorius *et al.* 2010). There is some evidence of increasing levels of stigma in this context, despite a greater understanding of mental illness in many societies (Phelan and Link, 1998).

Targeted anti-stigma campaigns represent an important part of within-country and global initiatives (Corrigan *et al.* 2001; Evans-Lacko *et al.* 2011; Thornicroft *et al.* 2008). These campaigns, including the network of the World Psychiatric Association, have centered on groups such as medical personnel, police, and journalists (Thornicroft *et al.* 2008). Nonetheless, targeted campaigns may not be enough on their own unless paired with other systematic changes (Pinfold *et al.* 2003).

The findings provoke ideas about anti-stigma campaigns that have focus on family members, perhaps mounted in complement with other targeted campaigns. Family focused initiatives may reduce family subsystem level barriers to care, perhaps by changing the attitudes and beliefs of the family, who are often an afflicted individual's closest support network. As noted, practitioners need to pay more attention to family members' experiences of discrimination and stigma (Thornicroft *et al.* 2008). In theory, via strengthening of individual's support system (i.e., the family), the individual patient may be more likely to become engaged in a treatment process that yields success, with a shift of disorder severity toward milder forms and away from more severe forms associated with delayed care. Similarly, afflicted individuals with relatives who are less embarrassed may be less fearful of seeking treatment. Of course, there is no need to start design of family focused antistigma campaigns from scratch. There already are promising interventions (Adeponle *et al.* 2009; Copello *et al.* 2005; Glynn *et al.* 2006).

Conclusions

Using an approach that has constrained the influence of between-site macro-level differences, and without requiring participants to know and to state the specific causes of embarrassment, we find that family embarrassment is quite tangibly manifest in association with burdensome ADMC. Family embarrassment may lead to the concealment of an individual's condition and impose barriers to care, unnecessarily lengthening the duration of the condition, and thereby increasing the population prevalence, and possibly yielding more serious consequences due to treatment delay. We have described several novel features of this research, including its focused look at subgroups and individuals within countries. The resulting evidence is good reason to strengthen family focused anti-stigma initiatives, in addition to national-scale anti-stigma campaigns.

Acknowledgments

The author wishes to acknowledge Drs. Cliff Broman and Rena Harold for their reviews, comments, and feedback which improved the final paper; John Troost's assistance with forest plots; and the many WMHS-affiliated principal investigators and researchers whose hard work produced the survey data. The World Health Organization World Mental Health Survey (WMHS) Initiative was funded and supported in several ways: NIH grants R01MH070884, R13MH066849, R01MH069864, R01DA016558, R01MH059575, U01MH60220, R01MH61905, R01DA016558

(JCA), T32DA021129 (BA, JCA), and K05DA015799 (JCA). Additional funding was from the John D. and Catherine T. MacArthur Foundation, the Pfizer Foundation, the Fogarty International Center (FIRCA R01-TW006481), the Pan American Health Organization, the Eli Lilly & Company Foundation, Ortho-McNeil Pharmaceutical, Inc., GlaxoSmithKline, Bristol-Myers Squibb, Ministry of Social Protection in Colombia, the European Commission (Contracts QLG5-1999-01042; SANCO 2004123), the Piedmont Region (Italy), Fondo de Investigación Sanitaria, Instituto de Salud Carlos III, Spain (FIS 00/0028), Ministerio de Ciencia y Tecnología, Spain (SAF 2000-158-CE), Departament de Salut, Generalitat de Catalunya, Spain, Instituto de Salud Carlos III (CIBER CB06/02/0046, RETICS RD06/0011 REM-TAP), the Lebanese Ministry of Public Health, the World Health Organization, Fogarty International, Act for Lebanon, anonymous private donations to IDRAAC, Janssen Cilag, Roche, Novartis, the National Institute of Psychiatry Ramon de la Fuente (INPRFMDIES 4280), the National Council on Science and Technology (CONACyT-G30544-H), and the Pan-American Health Organization, the Federal Ministry of Health in Nigeria, the Substance Abuse and Mental Health Services Administration, the Robert Wood Johnson Foundation (RWJF; Grant 044708), and the John W. Alden Trust. The epidemiology of mental disorders study in India was supported by WHO/DGHS and helped by R . Chandrasekaran, JIPMER. The WMH staff was instrumental in implementing the survey protocol, fieldwork, and data analysis. A list of the WMHS publications can be found at http://www.hcp.med.harvard.edu/wmh/. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health or the other agencies that provided funding support.

References

- Adeponle AB, Thombs BD, Adelekan ML, Kirmayer LJ. Family participation in treatment, postdischarge appointment and medication adherence at a Nigerian psychiatric hospital. Br J Psychiatry. 2009; 194:86–87. [PubMed: 19118334]
- Ahmedani BK. Mental Health Stigma: Society, Individuals, and the Profession. J Soc Work Values Ethics. 2011; 8:41–416. [PubMed: 22211117]
- Ahmedani BK, Kubiak SP, Rios-Bedoya CF, Mickus M, Anthony JC. Willingness to treat drug dependence and depression: comparisons of future health professionals. Subst Abuse Rehabil. 2011; 2011:43–51. [PubMed: 21731413]
- Alonso J, Buron A, Bruffaerts R, He Y, Posada-Villa J, Lepine JP, Angermeyer MC, Levinson D, de GG, Tachimori H, Mneimneh ZN, Medina-Mora ME, Ormel J, Scott KM, Gureje O, Haro JM, Gluzman S, Lee S, Vilagut G, Kessler RC, Von KM. Association of perceived stigma and mood and anxiety disorders: results from the World Mental Health Surveys. Acta Psychiatr Scand. 2008; 118:305–314. [PubMed: 18754833]
- Alonso J, Buron A, Rojas-Farreras S, de GR, Haro JM, de GG, Bruffaerts R, Kovess V, Matschinger H, Vilagut G. Perceived stigma among individuals with common mental disorders. J Affect Disord. 2009; 118:180–186. [PubMed: 19285349]
- Brohan E, Elgie R, Sartorius N, Thornicroft G. Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: the GAMIAN-Europe study. Schizophr Res. 2010; 122:232–238. [PubMed: 20347271]
- Brohan E, Gauci D, Sartorius N, Thornicroft G. Self-stigma, empowerment and perceived discrimination among people with bipolar disorder or depression in 13 European countries: the GAMIAN-Europe study. J Affect Disord. 2011; 129:56–63. [PubMed: 20888050]
- Brumback BA, Dailey AB, Zheng HW. Adjusting for confounding by neighborhood using a proportional odds model and complex survey data. Am J Epidemiol. 2012; 175:1133–1141. [PubMed: 22510274]
- Buka SL. Psychiatric epidemiology: Reducing the global burden of mental illness. American Journal of Epidemiology. 2008; 168:977–979.
- Cao H, He N, Jiang Q, Yang M, Liu Z, Gao M, Ding P, Chen L, Detels R. Stigma against HIVinfected persons among migrant women living in Shanghai, China. AIDS Educ Prev. 2010; 22:445–454. [PubMed: 20973664]
- Copello AG, Velleman RD, Templeton LJ. Family interventions in the treatment of alcohol and drug problems. Drug Alcohol Rev. 2005; 24:369–385. [PubMed: 16234133]
- Corrigan P, Markowitz FE, Watson A, Rowan D, Kubiak MA. An attribution model of public discrimination towards persons with mental illness. J Health Soc Behav. 2003; 44:162–179. [PubMed: 12866388]

- Corrigan PW, River LP, Lundin RK, Penn DL, Uphoff-Wasowski K, Campion J, Mathisen J, Gagnon C, Bergman M, Goldstein H, Kubiak MA. Three strategies for changing attributions about severe mental illness. Schizophr Bull. 2001; 27:187–195. [PubMed: 11354586]
- Corrigan PW, River LP, Lundin RK, Wasowski KU, Campion J, Mathisen J, Goldstein H, Bergman M, Gagnon C, Kubiak MA. Stigmatizing attributions about mental illness. Journal of Community Psychology. 2000; 28:91–102.
- Corrigan PW, Watson AC, Miller FE. Blame, shame, and contamination: the impact of mental illness and drug dependence stigma on family members. J Fam Psychol. 2006; 20:239–246. [PubMed: 16756399]
- Crisp AH, Gelder MG, Rix S, Meltzer HI, Rowlands OJ. Stigmatisation of people with mental illnesses. Br J Psychiatry. 2000; 177:4–7. [PubMed: 10945080]
- Crocker J. Social stigma and self-esteem: Situational construction of self-worth. Journal of Experimental Social Psychology. 1999; 35:89–107.
- Demyttenaere K, Bruffaerts R, Posada-Villa J, Gasquet I, Kovess V, Lepine JP, Angermeyer MC, Bernert S, de GG, Morosini P, Polidori G, Kikkawa T, Kawakami N, Ono Y, Takeshima T, Uda H, Karam EG, Fayyad JA, Karam AN, Mneimneh ZN, Medina-Mora ME, Borges G, Lara C, de GR, Ormel J, Gureje O, Shen Y, Huang Y, Zhang M, Alonso J, Haro JM, Vilagut G, Bromet EJ, Gluzman S, Webb C, Kessler RC, Merikangas KR, Anthony JC, Von Korff MR, Wang PS, Brugha TS, guilar-Gaxiola S, Lee S, Heeringa S, Pennell BE, Zaslavsky AM, Ustun TB, Chatterji S. Prevalence, severity, and unmet need for treatment of mental disorders in the World Health Organization World Mental Health Surveys. Journal of the American Medical Association. 2004; 291:2581–2590. [PubMed: 15173149]
- Dietrich S, Heider D, Matschinger H, Angermeyer MC. Influence of newspaper reporting on adolescents' attitudes toward people with mental illness. Soc Psychiatry Psychiatr Epidemiol. 2006; 41:318–322. [PubMed: 16424966]
- Dudley JR. Confronting stigma within the services system. Soc Work. 2000; 45:449–455. [PubMed: 11029900]
- Evans-Lacko S, Brohan E, Mojtabai R, Thornicroft G. Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. Psychol Med. 2011:1–13.
- Glynn SM, Cohen AN, Dixon LB, Niv N. The potential impact of the recovery movement on family interventions for schizophrenia: opportunities and obstacles. Schizophr Bull. 2006; 32:451–463. [PubMed: 16525087]
- Goffman, E. Stigma: Notes on the Management of Spoiled Identity. Prentice Hall; Englewood Cliffs, NJ: 1963.
- Heeringa, SG.; West, BT.; Berglund, PA. Applied Survey Data Analysis. CRC Press; New York: 2010.
- Hinshaw SP. The stigmatization of mental illness in children and parents: developmental issues, family concerns, and research needs. J Child Psychol Psychiatry. 2005; 46:714–734. [PubMed: 15972067]
- Hugo CJ, Boshoff DE, Traut A, Zungu-Dirwayi N, Stein DJ. Community attitudes toward and knowledge of mental illness in South Africa. Soc Psychiatry Psychiatr Epidemiol. 2003; 38:715– 719. [PubMed: 14689176]
- Jorm AF, Barney LJ, Christensen H, Highet NJ, Kelly CM, Kitchener BA. Research on mental health literacy: what we know and what we still need to know. Aust N Z J Psychiatry. 2006; 40:3–5. [PubMed: 16403031]
- Jorm AF, Oh E. Desire for social distance from people with mental disorders. Aust N Z J Psychiatry. 2009; 43:183–200. [PubMed: 19221907]
- Kessler RC, Ustun TB. The World Mental Health (WMH) Survey Initiative Version of the World Health Organization (WHO) Composite International Diagnostic Interview (CIDI). Int J Methods Psychiatr Res. 2004; 13:93–121. [PubMed: 15297906]
- Klin A, Lemish D. Mental disorders stigma in the media: review of studies on production, content, and influences. J Health Commun. 2008; 13:434–449. [PubMed: 18661386]

- Lee S, Lee MT, Chiu MY, Kleinman A. Experience of social stigma by people with schizophrenia in Hong Kong. Br J Psychiatry. 2005; 186:153-157. [PubMed: 15684240]
- Leflev HP, Family burden and family stigma in major mental illness. Am Psychol. 1989; 44:556–560. [PubMed: 2648907]
- Link BG, Phelan JC. Conceptualizing stigma. Annual Review of Sociology. 2001; 27:363-385.
- McSween JL. The role of group interest, identity, and stigma in determining mental health policy preferences. J Health Polit Policy Law. 2002; 27:773-800. [PubMed: 12465779]
- Ostman M, Kjellin L. Stigma by association: psychological factors in relatives of people with mental illness. Br J Psychiatry. 2002; 181:494-498. [PubMed: 12456519]
- Pescosolido BA, Martin JK, Long JS, Medina TR, Phelan JC, Link BG. "A disease like any other"? A decade of change in public reactions to schizophrenia, depression, and alcohol dependence. Am J Psychiatry. 2010; 167:1321-1330. [PubMed: 20843872]
- Phelan JC, Bromet EJ, Link BG. Psychiatric illness and family stigma. Schizophr Bull. 1998; 24:115-126. [PubMed: 9502550]
- Phelan JC, Link BG. The growing belief that people with mental illnesses are violent: the role of the dangerousness criterion for civil commitment. Soc Psychiatry Psychiatr Epidemiol. 1998; 33(Suppl 1):S7-12. [PubMed: 9857774]
- Pinfold V, Huxley P, Thornicroft G, Farmer P, Toulmin H, Graham T. Reducing psychiatric stigma and discrimination--evaluating an educational intervention with the police force in England. Soc Psychiatry Psychiatr Epidemiol. 2003; 38:337–344. [PubMed: 12799785]
- Robbins, SP.; Chatterjee, P.; Canda, ER. Contemporary human behavior theory: A critical perspective for Social Work. Allyn & Bacon; Needham Heights, MA: 2005.
- Sartorius N, Gaebel W, Cleveland HR, Stuart H, Akiyama T, rboleda-Florez J, Baumann AE, Gureje O, Jorge MR, Kastrup M, Suzuki Y, Tasman A. WPA guidance on how to combat stigmatization of psychiatry and psychiatrists. World Psychiatry. 2010; 9:131-144. [PubMed: 20975855]
- Sayce, L. From psychiatric patient to citizen: Overcoming discrimination and social exclusion. St. Martin's Press, Inc; New York: 2000.
- Shrout PE, Alegria M, Canino G, Guarnaccia PJ, Vega WA, Duan N, Cao Z. Testing language effects in psychiatric epidemiology surveys with randomized experiments: results from the National Latino and Asian American Study. Am J Epidemiol. 2008; 168:345–352. [PubMed: 18550562]
- Stier A, Hinshaw SP. Explicit and implicit stigma against individuals with mental illness. Australian Psychologist. 2007; 42:106-117.
- Thornicroft G, Brohan E, Kassam A, Lewis-Holmes E. Reducing stigma and discrimination: Candidate interventions. Int J Ment Health Syst. 2008; 2:3. [PubMed: 18405393]
- U.S. Surgeon General. Mental health: A report of the US Surgeon General. Center of Mental Health Services, National Institute of Mental Health; Rockville, Maryland: 1999. Anonymous
- Wahl OF. Mental health consumers' experience of stigma. Schizophr Bull. 1999; 25:467-478. [PubMed: 10478782]
- Wang PS, Berglund P, Olfson M, Pincus HA, Wells KB, Kessler RC. Failure and delay in initial treatment contact after first onset of mental disorders in the National Comorbidity Survey Replication. Arch Gen Psychiatry. 2005; 62:603-613. [PubMed: 15939838]
- Weiss MG, Ramakrishna J. Stigma interventions and research for international health. Lancet. 2006; 367:536-538. [PubMed: 16473134]
- World Health Organization [WHO]. World Health Report 2001 Mental health: new understanding, new hope. World Health Organization; Geneva, Switzerland: 2001.
- WHO., editor. World Health Organization [WHO]. The World Health Report 2004: Changing History. Geneva, Switzerland: 2004a.
- World Health Organization [WHO]. The World Mental Health Composite International Diagnostic Interview. 2004b

NIH-PA Author Manuscript



Figure 1. Process for identifying individuals who were queried about embarrassment towards close relatives with health conditions in the World Mental Health Surveys



Figure 2. Weight Variable Deciles for Observed ADMC-only Association in Table 2



Figure 3. Weight Variable Deciles for Observed ADMC+GMC Association in Table 2

_
~
_
_
_
_
0
-
-
-
_
_
_
<u> </u>
-
\mathbf{O}
<u> </u>
_
_
~
~
0)
2
_
-
C-
CD
\mathbf{O}
_
_
+

Table 1

NIH-PA Author Manuscript

Unweighted sample distributions of burdensome health condition in a close relative, nature of the condition, and family embarrassment, by site. Data

from the World Mental Health Surveys.

Ahmedani et al.

		Respondents with at least one c exclusive h	lose relative in one of the fol ealth condition groups:	lowing mutually	Number of respondents who	Number of respondents who
Site	Total sample size, n	GMC [*] only, n(%)	ADMC [*] only, n(%)	GMC & ADMC, n(%)	were asked about embarrassment (% of all respondents)	felt embarrassment (% of those asked embarrassment question)
Africa						
Nigeria	6,752	36 (1)	60 (1)	56 (1)	38 (1)	22 (58)
The Americas						
Brazil - São Paulo	5,037	635 (13)	860 (17)	526 (10)	685 (14)	389 (57)
Colombia	4,426	181 (4)	141 (3)	88 (2)	216 (5)	45 (21)
Mexico	5,826	279 (5)	238 (4)	165 (3)	261 (5)	93 (36)
USA	9,836	631 (6)	499 (5)	578 (6)	624 (6)	94 (15)
Asia						
PRC*-Beijing/Shanghai	12,335	785 (6)	211 (2)	121 (1)	678 (6)	115 (17)
India-Pondicherry	2,992	36 (1)	110 (4)	8 (0.3)	55 (2)	41 (75)
Lebanon	2,857	169 (6)	25 (1)	45 (2)	100 (4)	26 (26)
Europe						
Belgium	2,419	135 (6)	47 (2)	61 (3)	74 (3)	33 (45)
Bulgaria	5,318	238 (4)	45 (1)	58 (1)	168 (3)	163 (97)
France	2,894	147 (5)	85 (3)	64 (2)	123 (4)	(62) (79)
Germany	3,555	253 (7)	56 (2)	67 (2)	106 (3)	17 (16)
Northern Ireland	4,340	533 (12)	333 (8)	238 (5)	346 (8)	51 (15)
Italy	4,712	210 (4)	47 (1)	57 (1)	88 (2)	64 (73)
Netherlands	2,372	399 (17)	174 (7)	191 (8)	205 (9)	26 (13)
Spain	5,473	203 (4)	94 (2)	57 (1)	163 (3)	19 (12)
All Sites	81,144	4,870 (6)	3,025 (4)	2,378 (3)	3,930 (5)	1,295 (33)

Psychol Med. Author manuscript; available in PMC 2014 October 01.

Page 17

* GMC, general medical condition; ADMC, alcohol, drug, or other mental health condition; PRC, People's Republic of China.

_

Table 2

Estimated association linking type of family health condition with occurrence of family embarrassment, based on conditional form of multiple logistic regression. Data from the World Mental Health Surveys.

	Coefficient**	SE	<i>p</i> -value	95% CI
Family situation [*] :				
GMC only (reference subgroup)	-	-	-	-
ADMC condition only subgroup	1.30	0.10	< 0.001	1.1, 1.5
GMC and ADMC subgroup	0.79	0.11	< 0.001	0.6, 1.0

GMC, general medical condition; ADMC, alcohol, drug, or other mental health condition.

** Estimated slope coefficient from the regression model. Exponentiated, this estimate is interpretable as an odds ratio. Exp(1.3) = 3.7; Exp(0.79) = 2.2, as explained in the text.

Table 3

Estimated association linking type of family health condition with occurrence of family burden, based on conditional form of multiple logistic regression. Data from the World Mental Health Surveys.

	Coefficient**	SE	<i>p</i> -value	95% CI
Family situation: [*]				
GMC only (reference subgroup)	-	-	-	-
ADMC only subgroup	0.07	0.05	0.168	-0.03, 0.2
GMC and ADMC subgroup	0.67	0.06	< 0.001	0.6, 0.8
Age	-0.009	0.001	< 0.001	-0.01, -0.006
Sex (ref. = female)	-0.17	0.04	< 0.001	-0.2, -0.1

*GMC, general medical condition; ADMC, alcohol, drug, or other mental health condition.

** Estimated slope coefficient from the regression model. Exponentiated, this estimate is interpretable as an odds ratio. Exp(0.07) = 1.07; Exp(0.67) = 1.95, as explained in the text.