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COURTESY STIGMA AND HEALTH CONDITIONS: SYSTEMATIC LITERATURE REVIEW [1]

Daniel Augusto Costa Maldonado [2 3], Orcid: http://orcid.org/0000-0002-8931-2224
Leonardo Fernandes Martins [4], Orcid: http://orcid.org/0000-0002-0941-6294
Telmo Mota Ronzani [5], Orcid: http://orcid.org/0000-0002-8927-5793

ABSTRACT. The scientific literature consistently points out that groups historically targeted by social stigma experience deleterious effects in different spheres of life. Despite its gravity and pervasiveness, there are still gaps in the investigation of the topic, such as that focused on the Courtesy Stigma, which is experienced by people who have affective or professional ties with the stigmatized individual. This article aimed to present the state of the art on Courtesy Stigma through a systematic review of original empirical studies published in peer-reviewed journals and indexed in the main databases related to the research field (PsycNET (APA), Pubmed, Bvs Brasil, CAPES, SciELO, and Pepsic journals). As keywords for the search for abstracts, we used: courtesy stigma, affiliate stigma and associative stigma. Altogether, 94 complete texts met the inclusion and exclusion criteria. Studies have shown that the Courtesy Stigma has been investigated predominantly among family members of people who have some type of problem related to their mental health, in addition to parents of children with some type of disability.

Keywords: Stigma; courtesy stigma; literature review.

ESTIGMA DE CORTESIA E CONDIÇÕES DE SAÚDE: REVISÃO SISTEMÁTICA DE LITERATURA

RESUMO. A literatura científica aponta consistentemente que grupos historicamente alvos de estigma social experimentam efeitos deletérios, em diversas esferas da vida. A despeito da sua gravidade e pervasividade, ainda existem lacunas na investigação do tema, tais como aquela voltada para o Estigma de Cortesia, que é vivenciado por pessoas que possuem vínculos afetivos ou profissionais com o indivíduo estigmatizado. O presente artigo teve como objetivo apresentar o estado da arte sobre estigma de cortesia, por meio de uma revisão sistemática de estudos empíricos originais publicados em periódicos revisados por pares e indexados nas principais bases relacionadas ao campo de

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[2] Department of Psychology, Institute of Human Sciences, Universidade Federal de Juiz de Fora. Juiz de Fora-MG, Brazil. CNPq Productivity Scholarship.
[3] E-mail: malcosta@gmail.com
[4] Department of Psychology, Graduate Program in Clinical Psychology, Pontifícia Universidade Católica do Rio de Janeiro, Brazil.
[5] Department of Psychology, Institute of Human Sciences, Universidade Federal de Juiz de Fora, Juiz de Fora-MG, Brazil.

investigação (PsycNET (APA), Pubmed, Bvs Brasil, Periódicos CAPES, SciELO, e Pepsic). Como palavras-chave, para a busca dos resumos, utilizou-se: estigma de cortesia, estigma de afiliação e estigma de associação. Ao todo, 94 textos completos atenderam aos critérios de inclusão e exclusão. Os estudos apontaram que o estigma de cortesia tem sido investigado predominantemente entre familiares de pessoas que possuem algum tipo de problema relacionado com sua saúde mental, além de pais de crianças com algum tipo de deficiência.

Palavras-chave: Estigma; estigma de cortesia; revisão de literatura.

ESTIGMA DE CORTESÍA Y CONDICIONES DE SALUD: REVISIÓN SISTEMÁTICA DE LA LITERATURA

RESUMEN. La literatura científica señala constantemente que los grupos históricamente afectados por el estigma social experimentan efectos nocivos en diferentes ámbitos de la vida. A pesar de su gravedad y omnipresencia, todavía hay vacíos en la investigación del tema, como el centrado en el estigma de cortesía, que experimentan las personas que tienen vínculos afectivos o profesionales con el individuo estigmatizado. Este artículo tuvo como objetivo presentar el estado del arte sobre el estigma de cortesía a través de una revisión sistemática de estudios empíricos originales publicados en revistas revisadas por pares e indexados en las principales bases de datos relacionadas con el campo de investigación (PsycNET (APA), Pubmed, Bvs Brasil , CAPES, SciELO y revistas Pepsic). Como palabras clave para la búsqueda de resúmenes, utilizamos: estigma de cortesía, estigma de afiliación y estigma de asociación. En total, 94 textos completos cumplieron con los criterios de inclusión y exclusión. Los estudios han demostrado que el estigma de cortesía se ha investigado principalmente entre miembros de la familia de personas que tienen algún tipo de problema relacionado con su salud mental, además de los padres de niños con algún tipo de discapacidad.

Palabras clave: Estigma; estigma de cortesia; revisión de literatura.

Introduction

According to the World Health Organization [WHO] (2001), social stigma can be understood as a mark associated with shame and/or disapproval. As a result, stigmatized people, when marked, become part of a group of individuals who are rejected, discriminated against and excluded from full participation in different sectors of society. In this broader perspective, stigma would be related to a set of stereotypical formations, prejudiced attitudes and discriminatory behaviors. This process would be supported by a social structure that tends to place certain population groups in a position of dominance and superiority, to the detriment of others that come to occupy a subjugated position. Several deleterious effects arise as a result of this segregation, causing stigmatized people to have difficulty accessing housing, employment, health, among other fundamental rights (Corrigan, 2000; Mak & Cheung, 2008).

Erving Goffman (1922-1982), one of the seminal authors in the field, defines social stigma as an attribute or mark carried by some individuals whose "[…] discrediting effect is very great, sometimes it is also considered a defect, a weakness, a disadvantage" (Goffman, 1975, p. 6). The phenomenon could still be classified into three types of stigma, related to

the origin of the mark, namely: abominations of the body, linked to some physical trace of deformity; character deviations, linked to a moral failure; racial, which would involve ethnic, racial, cultural or even religious beliefs (Goffman, 1975).

Studies in the area of stigma have privileged public perceptions about the groups of the population that are the target of stigma, as well as the psychological effects generated in stigmatized individuals, including those related to the endorsement and internalization of negative and discrediting evaluations, which, because they are culturally shared, they become public domain, and can be endorsed by the person who has a mark that is stigmatized, even if it is somehow disguised (Bambauer & Prigerson, 2006; Fife & Wright, 2000; Mark & Cheung, 2008). Such an internalization process would have the following consequences for the stigmatized individual: a decrease in self-esteem, as one of the effects of negative self-assessment; the intensification of negative emotions; in addition to behavioral changes that included social withdrawal (voluntary ostracism), as well as the attempt to disguise their stigmatized status in situations of social interaction (Corrigan & Watson, 2002).

One of the groups that has predominantly been the object of study on this topic are people who have some type of suffering or impairment resulting from problems related to their mental health. Stigmatization of these people leads to greater difficulty in seeking help, adhering to some type of treatment, in addition to impacting their own performance related to the achievement of personal goals and a greater propensity to abandon academic or vocational activities (Corrigan, Larson, & Rusch , 2009, Clement et al; 2015). Added to these losses is the fact that these people would tend to develop a greater feeling of shame, in addition to a consequent decrease in self-esteem (Corrigan & Watson, 2002; Corrigan et al., 2009).

Despite advances in theoretical definitions of social stigma, the body of empirical evidence about the effects and the identification of effective intervention strategies to reduce it (Corrigan et al., 2009, Clement et al., 2015), little has been studied on the stigma of courtesy, which is experienced by people who have affective or professional bonds, living closely with individuals who are targets of stigma. The evidence and literature syntheses that guide research and intervention programs in the area are mostly focused on the person who owns the mark, with little emphasis on the negative consequences associated with people linked to the first (Corrigan & Watson, 2002; Corrigan et al., 2009).

Classically, the concept of courtesy stigma arises to characterize the stigma experienced by the person who “[…] relates to the stigmatized individual through the social structure, a relationship that leads the wider society to regard both as one person” (Goffman, 1975, p. 28). More precisely, it is possible to consider that individuals who do not have a derogatory attribute, but who live with people who do, may also be stigmatized. This process implies the resulting devaluation or discrimination due to its association with the stigmatized individual (Wong, Kong, Tu, & Frasso, 2018). An additional feature is that the stigma of courtesy, unlike the social stigma, has a diffuse characteristic, since it is not limited to the individual aspects of the stigmatized person, confirming, in a way, how pervasive this phenomenon is (Mo, Lau, Yu, & Gu, 2015).

The fact is that, regardless of the nature of the origin of the stigma of courtesy, it has the potential to produce objective and harmful effects on the lives of people close to the stigmatized individual, and can be as harmful as the stigma affecting the latter (Wong et al., 2018). An aggravating element of this situation is the fact that victims of courtesy stigma, despite often playing a crucial role in the life of a victim of direct stigma, may end up exhibiting behaviors of social withdrawal, breaking bonds of support, in an attempt to hiding

their social status or helping a person who is stigmatized (Hansen, Szaflarski, Bebin, & Szaflarski, 2018).

Thus, the goal of this article was to carry out a systematic review of the literature on the concept of courtesy stigma, in order to present the state of the art on the subject and to know what are the main advances in the area, thus presenting gaps in the scientific literature together with the proposal for a research program in the area.

Method

The report of this systematic literature review was carried out based on the Preferred Report Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations (Galvão, Pansani, & Harrard, 2015), with the aim of increasing future reproducibility. Therefore, a literature search was conducted involving the concept of courtesy stigma as the main subject in articles indexed in the PsycNET (APA), Pubmed, Bvs Brasil, CAPES Journal Portal, SciELO and Pepsic Psychology databases. The keywords Courtesy Stigma, Affiliate Stigma and Associative Stigma were used.

These databases were selected because that they all include a significant number of articles in the most diverse areas of study in psychology and related health subjects. The criterion for choosing the keywords was first to check for their occurrence in the DeCS/MeSH (Health Sciences Descriptors) and, although they were not, the keyword Courtesy Stigma was kept because it was a term initially used by Goffman (1992- 1982), a canonical author in the area of stigma, while the keywords Affiliate Stigma and Associative Stigma were maintained by the conceptual approach they established with the former.

As inclusion criteria, only articles published in English, Portuguese or Spanish, whose central theme was the stigma of courtesy and which were original and empirical studies were considered. A period of time was not established in relation to the year of publication of the articles. The articles were included until the year 2019.

First, the titles and abstracts of the articles were read and analyzed for inclusion criteria proposed in this literature review, so that articles that did not meet these criteria were discarded. Subsequently, duplicate articles were eliminated and the remaining articles were read in full. To facilitate the process of analyzing the articles, descriptive categories were created based on the methodological approach, the country of origin of the article, the target audience of the courtesy stigma, the contexts covered, the instruments used and the type of study carried out.

Results

The electronic search in the databases returned a total of 564 abstracts, of which 314 were eliminated because they were duplicates, 156 studies were eliminated by reading the titles and abstract content, resulting in 94 full texts that met the inclusion criteria and were read in full (Figure 1).

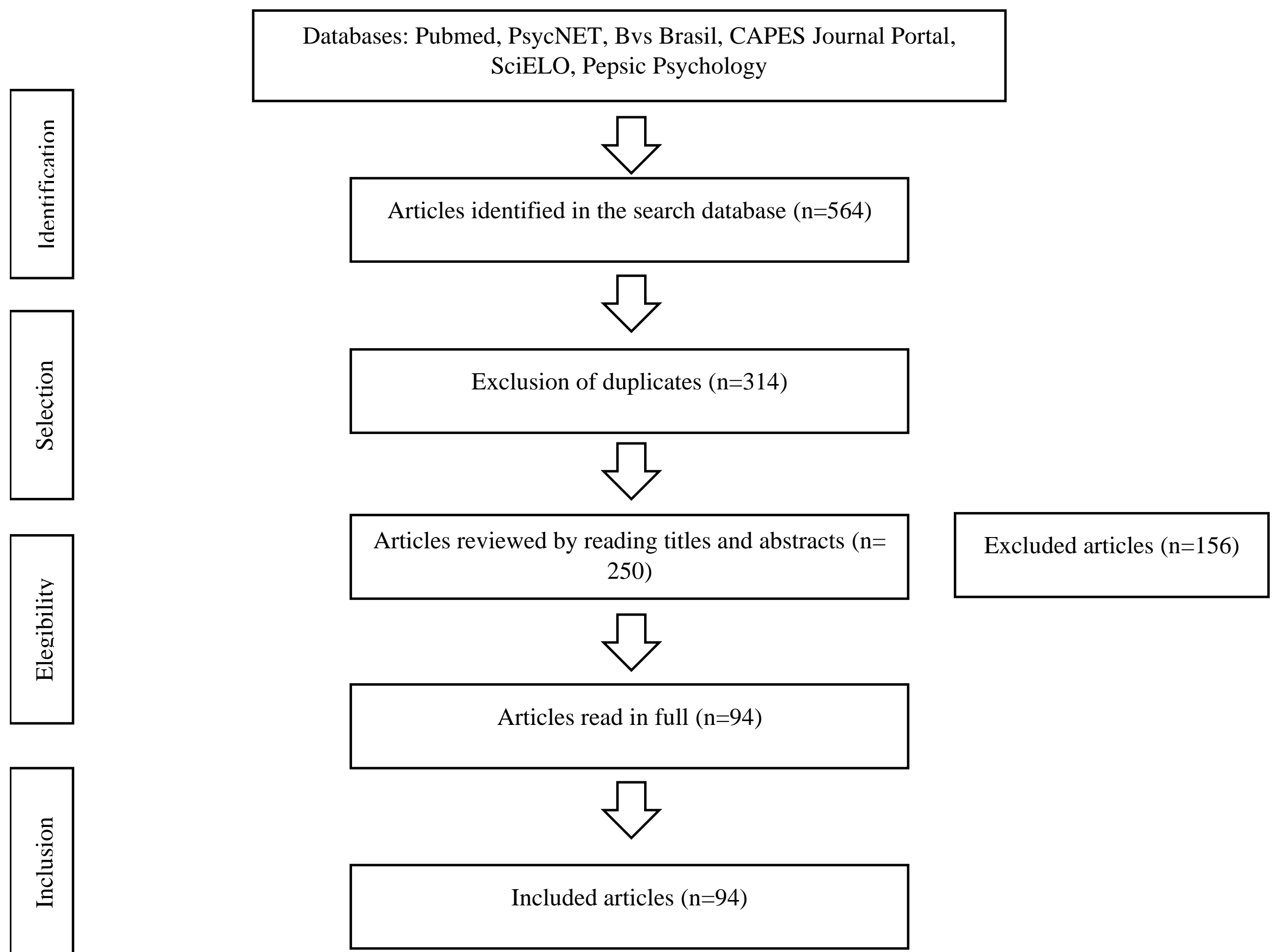

Figure 1
PRISMA Flowchart. Procedures for identification and selection of articles included in the literature review.
Source: The authors.

Considering the methodological approach, the predominance of articles using a quantitative approach can be seen, corresponding to 56.4% total studies included. Qualitative approaches corresponded to 38.3% and only a small percentage (5.3%) used quantitative and qualitative approaches in an integrated way (Table 1).

The United States of America (USA) was the country with the most published articles - with 30 publications (31.9%), followed by China with 14 articles (14.9%), the United Kingdom with 11 articles (11.7%), Israel with six articles (6.4%) and India with five (5.3%). Taiwan, Australia, Canada had four studies published each and together accounted for 12.8% total articles included. The Others category included South Korea, Turkey, Morocco, Belgium, Germany, France, Nigeria, Malaysia, Iran, the Caribbean and Ghana. Each of these countries had only one study, with the exception of Belgium with three published

articles and Malaysia, Germany and Ghana with two published articles. The combined percentage of the Others category corresponded to 17.0% (Table 1).

Table 1
Relationship between the methodological approach/country and the number of articles found/percentage

Methodological approach	Articles found/ (%)
Quantitative	53/(56.4%)
Qualitative	36/(38.3%)
Mixed	5/(5.3%)
Country	
USA	30/(31.9%)
China	14/(14.9%)
United Kingdom	11/(11.7%)
Israel	6/(6.4%)
India	5/(5.3%)
Taiwan, Canada and Australia	12/(12.8%)
Others	16/(17.0%)

Source: The authors.

With regard to the research target audience, family members are predominantly the main group of interest for the study of courtesy stigma, representing 78.7% total number of articles. Mental health professionals and health professionals appear soon after, but in significantly lower frequencies, representing 9.6% and 5.3% of the surveys (Table 2)

Mental health professionals and health professionals were classified separately in Table 2, because some articles specifically work on the concept among professionals who work with mental health patients, such as people with psychotic disorders and severe depressive disorder, while other articles address professionals who work in the health area, but who care for patients who do not fit into the category of mental health users, such as the elderly and children with some type of non-psychiatric disorder.

In the Others category, there were professionals from NGOs, university students, teachers and the general population. In the first case, the articles address the stigma concept of courtesy among professionals working in NGOs that provide services to sex workers (Phillips & Benoit, 2013). In relation to university students, this grouping was used to evaluate hypothetical or real cases involving courtesy stigma. In the case of teachers, the stigma of courtesy refers to the fact that these professionals work in schools intended for special students and, finally, for the general population, that is, readers of a web page that analyzed a real case involving the stigma of courtesy (Table 2).

Table 2
Relationship between the target audience and the number of articles found/percentage

Target audience	Articles found/ (%)
Family members	74/(78.7%)
Mental health professionals	9/(9.6%)
Health professionals	5/(5.3%)
Others	6/(6.4%)

Source: The authors.

Regarding the contexts addressed, the articles examining the concept stigma of courtesy, linked to mental health users, represented 38.3% articles included. This area is studied mainly considering people who provide care to a family member with some type of psychiatric disorder. Children with disabilities appear as the second most addressed context, representing 25.5% articles included and most of these studies focus on the stigma of courtesy among parents of children who have some type of disability (Table 3)

Another context addressed in the articles refers to the population with HIV (Human Immunodeficiency Virus), representing 8.5% included studies. The stigma of courtesy in these cases results from a family member, such as HIV-negative adolescents born to HIV-positive mothers, dyads of family caregivers, such as the mother responsible for caring for a child with HIV or the wife responsible for caring for her husband with HIV, HIV-positive adolescents born to HIV-positive mothers, who experience both the internalized stigma, for being HIV carriers, and the courtesy stigma for being children of mothers with HIV. In the marital sphere, there is also the study of HIV-negative people who are in an intimate relationship with an HIV-positive partner and who, for that reason, would also be targets of the stigma of courtesy (Table 3).

Studies on neurological diseases in old age also represents 8.5% articles included. The stigma of courtesy in this case is mainly exploited by adult children caring for their elderly parents diagnosed with Alzheimer’s. Some articles establish as inclusion criteria that the elderly person has a diagnosis of Alzheimer’s or some other type of dementia and that caregivers are the main informal caregivers, that is, they provide emotional and instrumental care and assistance without remuneration (Table 3).

Studies on homosexuality represent 3.2% articles included and the stigma of courtesy, in this case, is studied mainly among children of parents who came out as homosexual or in relation to family members and close friends of homosexual people (Table 3).

The use of alcohol and other drugs also represent 3.2% articles included and the stigma of courtesy is studied among parents of adolescent drug users. The stigma of courtesy related to parents and the discredit they experience in the community and institutions, including school, police and judicial systems, is very similar to the stigma of courtesy experienced by parents of adolescents with mental health disorders (McCann & Lubman, 2017). Still in this context of consumption of alcohol and other drugs, a specific article addresses how alcohol affects families that have a ‘heavy drinker’, emphasizing the stigma of courtesy witnessed by children who have parents who abuse alcohol (Tamutiene & Laslett, 2016) (Table 3).

The Others category addresses the stigma of courtesy in different contexts, such as the stigma witnessed by mothers of mass murderers, such as the school massacres that occurred in the Columbine region and in the city of Newtown in the USA, stigma among health professionals working in long-stay institutions for the elderly, the stigma witnessed by teachers from special schools, stigma of nurses who perform abortions, stigma among people who have family members with leprosy or epilepsy and the case of health professionals who worked in the Ebola outbreak, in Africa, in 2014, who were stigmatized after returning to their countries of origin, due to fear on the part of the population that they were carrying the Ebola virus (Table 3)

Table 3
Relationship between the contexts and the number of articles found/percentage

Context	Articles found / (%)
Mental health	36/(38.3%)
Children with disabilities	24/(25.5%)
HIV/(AIDS) and Neurological diseases in old age	16/(17.0%)
Homosexuality, alcohol, and other drugs	6/(6.4%)
Others	12/(12.8%)

Source: The authors.

The Affiliate Stigma Scale (ASS) was the most used instrument to measure courtesy stigma, appearing in 28.7% articles included. Indirect measurement and validation studies together accounted for 20.2% articles included. The first concerns studies using different instruments in an integrated way to indirectly measure the stigma of courtesy construct, since such instruments were not originally designed for this purpose. The second refers to studies validating the ASS for different countries and population contexts (Table 4).

Other scales used were Stigma Scale for Caregivers of People with Mental Illness (CPMI), Clinician Associative Stigma Scale (CASS) Parents' Internalized Stigma of Mental Illness (PISMI), Perceived Courtesy Stigma Scale (PCSS), Family Stigma Scale (FSS) and Devaluation of Consumer Family Scale. In the case of the CPMI, this instrument was used in four articles, the PCSS and the CASS in three articles, while the other scales were used in only one article (Table 4).

Interviews, observation and focus groups were used in 31.9% total articles included, and such approaches were found mainly in qualitative studies. The category Others refers to different techniques of qualitative studies, such as content analysis of publications on internet pages and material collected via online research, which was used in four articles and the narrative technique used in only one article (Table 4).

Table 4
Relationship between the instruments used and the number of articles found/percentage

Instruments used	Articles found / (%)
Structured instruments	59/(62.8%)
Interview, observation, and focus group	30/(31.9%)
Others	5/(5.3%)

Source: The authors.

Discussion

Courtesy stigma has been studied around the world using different contexts and target populations, however, there is a predominance of studies that seek to analyze it among family members of mental health patients (Catthoor et al., 2015; Ostman & Kjellin, 2002). This finding in relation to the target audience of courtesy stigma is consistent with Goffman's conception (1975) that stigma tends to propagate from the person who is the central target of stigma. For this author, stigma spreads in 'waves of decreasing intensity', which means that the stigmatized individual would be like the 'epicenter' of all the stigma conferred on them by society, since they carry traits and characteristics seen as socially deleterious (Catthoor et al., 2015; Ostman & Kjellin, 2002).

In this way, the stigmatized individual as the 'epicenter' of the stigma would tend to spread a certain burden of stigma towards the people they live with, so that the closest people would receive a greater burden of stigma, while the individuals further away would receive lower levels. Following this reasoning, it is to be expected that the people closest to the stigmatized individual, such as family members, who generally have direct contact and greater contact with the stigmatized individual, would tend to be a group that is more representative of the stigma of courtesy construct in compared to mental health professionals who, despite being targets, are located in a more peripheral layer (Catthoor et al., 2015; Larson & Corrigan, 2008).

A very common target population found in the articles are parents responsible for caring for children with schizophrenia and how the stigma of courtesy affects different domains of these people's lives. Among them, the affective domain, which has pointed to feelings of helplessness, feeling emotionally disturbed or being under great pressure due to having a family member with a mental illness. Changes in the behavioral domain are also frequent as a result of trying to deal with the guilt and shame associated with a family member with schizophrenia and are manifested in maintaining a more discreet profile in society, avoiding going out and talking to that relative. Finally, the cognitive domain also undergoes changes as these family members begin to question their place in society, also derived from the discrimination witnessed by them in different public spaces (Wong et al., 2018).

Some studies with parents of children with severe mental illness show that the stigma of courtesy produces harmful effects in the lives of these people and that these are similar to the effects on the stigmatized individual, so that parents and children would be affected based mainly on three factors: the endorsement of negative social stereotypes towards people with mental illness, social withdrawal and alienation as a way of trying to avoid discomfort and social judgment, and the perception that they are not full members of society due to experiences of discrimination and devaluation (Zisman-Ilani et al., 2013).

From the point of view of predictive factors related to courtesy stigma, a specific study carried out in Nigeria with family members of people with chronic mental illness, points out that the negative effects of this type of stigma, such as the increase in the caregiver burden, would be closely linked with the variables: levels of education and income, residential location, in the sense that families are located in rural or urban areas and further away from or closer to a health unit, degree of severity of the disease, relationship between the caregiver and the family and the number of family members (Olangundoye, Akhuemokhan, & Alugo, 2017).

Another data in relation to the context of mental health concerns studies comparing the intensity of the stigma of courtesy experienced by family members of people with different psychiatric disorders. Such studies show that family members of individuals with schizophrenia tend to suffer from higher levels of courtesy stigma compared to family members of individuals with bipolar disorder and depression. Therefore, relatives of people with schizophrenia would present greater social burden, emotional burden and caregiver burden, the latter related to the burden spent on caring for this relative. In addition, these family members would also have a greater decrease in self-esteem, increased anxiety and more severe depression (Chang, Yen, Jang, Su, & Lin, 2017). In this way, it is also verifiable that the stigma of courtesy among parents of psychotic individuals is more intense when compared to parents of individuals with mood and anxiety disorders (Baron, Salvador, & Loewy, 2018).

Studies with mothers of children with cerebral palsy shows that the stigma of courtesy, experienced in the subjective dimension, is as determinant for maternal suffering as the objective burdens related to the difficulties and exhaustion present in the act of caring. In this sense, mothers' perception of public discrimination against people with disabilities would be an example of a subjective burden that would increase maternal suffering (Green, 2003).

In relation to research involving children with developmental and learning problems, such as Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder (ADHD), there is a study specifically on courtesy stigma among Chinese mothers of children diagnosed with autism, which exports that they would tend to present a greater amount of depressive symptoms (Zhou, Wang, & Yi, 2018). In the case of ADHD, the stigma of courtesy is verified especially in the school environment, where parents are identified as responsible for the 'problem student', and feelings of guilt for the assignment of poor parental care are increased (Koro-Ljungberg & Bussing, 2009).

In the field of neurological diseases in old age, studies addressing the different types of dementia, such as Alzheimer's disease, are significant. The stigma of courtesy, in these cases, is studied mainly in the impact it has on caregivers who have a family member diagnosed with Alzheimer's, so that such impact is translated into changes in cognitive attributes, such as the perception of being negligent in care, in emotional reactions such as negative emotions of anger, fear and shame and behavioral reactions, such as hiding from having a family member with Alzheimer's, isolation and failure to seek help (Abojabel & Werner, 2016).

Studies comparing the effects generated between different types of stigma, including the stigma of courtesy, point to findings such as the case of adolescents born to mothers with HIV who are also carriers of the same virus. In this case, the stigma internalized by the adolescent, for being HIV positive, together with the stigma of courtesy for being the child of a mother with HIV, contributes to the increased risk of depression. On the other hand, courtesy stigma, analyzed as an isolated factor, not only contributes to an increased risk of depression but also to an increased risk of psychoactive substance use (Earnshaw, Kidman, & Violari, 2018).

The literature review also showed that some studies work the courtesy stigma as a distinct concept from the affiliation or association stigma, the latter two understood as being very close, but the first is more used to refer to individuals who provide care to some family with the stigmatic mark and the second for health professionals who serve people who are also stigma targets.

In this way, the stigma of affiliation or association would correspond to the internalization of the public stigma of courtesy, being, therefore, a result of the self-stigmatization by those associated with stigmatized people. An example would be family stigma, understood as a type of affiliation stigma, insofar as family members internalize the stigma of public courtesy in relation to the disability of a particular family member (Mak & Cheung, 2008).

By this logic, the stigma of courtesy would be facing a social dimension or the way in which the public domain stigmatizes not only the individual with the stigmatic mark but also the people who are associated with it. Therefore, the stigma of courtesy becomes a problem when it becomes a stigma of affiliation or by association, that is, when people associated with the stigmatized individual begin to internalize the public stigma of courtesy, as is the case with predominantly found in this review on family members of mental health patients (Mak & Cheung, 2008)

Final considerations

The stigma of courtesy has been studied predominantly among family members of mental health patients and parents of children with some type of disability. Other groups, such as mental health professionals and health professionals in general, have also been studied about the courtesy stigma construct, but at significantly lower frequencies.

There is a lack of research aimed at studying the stigma of courtesy in specific groups, such as users of alcohol and other drugs, which appear in only three articles out of the 94 final articles included in this review. Also noteworthy is the concentration of studies in specific countries, such as the USA and countries on the Asian continent.

Research on the stigma of courtesy has also pointed to the numerous variables of individual life that are affected, ranging from emotional problems to affective, cognitive and behavioral alterations. On the other hand, there are few studies aimed at intervention and reduction of the stigma of courtesy, even knowing the harmful effects that this type of stigma causes in people's lives.

Thus, there is a greater need for studies that prioritize strategies to reduce the stigma of courtesy in different segments of the population, since there is already a considerable number of studies focusing on variables in the lives of individuals who are affected by it. In this sense, studies that intervenes both in the stigmatized population and in the stigmatizing population would be important to propose mechanisms that mitigate the harmful effects of stigma and, in the specific case of courtesy stigma, interventions of this type become even more subtle, precisely because they are a stigma that does directly affect the person, but as a product of being associated with a stigmatized individual.

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