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Protocol

The stigma of mental health, homelessness and intellectual disability, development of a national stigma survey with an intersectional gender perspective

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ABSTRACT

Background: Social stigma towards people with mental health problems, homeless people or people with intellectual disabilities leads to a significant restriction of their human rights. Such stigma, which is associated with different conditions of vulnerability, has been assessed over time through surveys. However, intersectional stigma due to gender is often not assessed in these studies as they only analyse the data for this variable separately. Therefore, presented here is the first national survey in Spain on the social stigma associated with mental health problems, homelessness and intellectual disability. This proposal considers the importance of gender and intersectional stigma.
Methods: A qualitative-quantitative methodology is used by means of a computer assisted web interviewing survey. A gender perspective is proposed both in the development of the questions and in the measurement and analysis of the data. To this end, three versions of the questionnaire are developed: a neutral, a male and a female version.
Conclusions: The results are intended to have an impact on social and equality policies for people with mental disorders, homeless people and people with intellectual disabilities.
Trial Registration: The study has the approval of the deontological commission of the faculty of psychology and is registered in clinical trials.

Keywords: Women, Discrimination, Homelessness, Mental illness, Intellectual disability

INTRODUCTION

Stigma is traditionally defined as a deeply devaluing attribute that degrades and demeans the person who carries it. Therefore, people with different conditions such as homelessness (HPs), intellectual disabilities (IDPs) or people with mental health problems (MHPs) have been systematically stigmatised and discriminated against over time. As a result, their rights and access to social and health opportunities are significantly reduced.[1]

This stigmatisation process in groups with vulnerable conditions has differential characteristics when related to gender. Historically, women have been discriminated against in different religions, countries and communities. It is known that there is a gender gap that affects women in the workplace, socially and even in access to health

care. The intersectional discrimination hypothesis suggests that different stigmatising conditions may interact with each other, increasing the discrimination and stigma experienced by women and leading to more negative outcomes.[2] As an example, a woman who also has MHPs, is an HP or has ID will have each of these conditions added to the pre-existing discrimination she receives for being a woman. As such, there are systematic reviews and meta-analyses that support this approach.[3-5] These investigations report that there is an apparent perception of women as less capable in the workplace. Furthermore, they suggest that women who have experienced domestic violence and abuse are more likely to suffer from depressive disorders, anxiety disorders and post-traumatic stress disorder (PTSD). Other research identifies distinctive features in the discrimination experienced by homeless women. Features such as violence, predation or victimisation, or greater internalised stigma and the assumption of stereotypes such as delinquency, drug addiction or illness.[6,7] Regarding women with intellectual disabilities, Taggart et al. report on the scarce literature and conclude that women with intellectual disabilities are more likely to experience mental health problems. They highlight influential factors in this relationship such as a lack of opportunities, stigmatisation and poor support networks.[8]

The prevalence of stigma associated with mental health problems, homelessness and intellectual disabilities has been documented in a number of studies. Social stigma surveys exist internationally, such as in the INDIGO programme, and the Global Survey on Stigma in Mental Illness, with 229 countries being represented.[9,10] On a national level, research on social stigma in mental health can be found in countries such as the United Kingdom, Argentina, Japan, Australia or Switzerland.[11-15] In Spain, a representative population-based survey on mental health stigma is known, although only at the regional level in Catalonia.[16] This study shows the existence of low levels of this variable in the Catalan population.

Regarding homeless people, at European level, Brandon et al launched a stigma survey in 11 EU cities, finding high levels of stigma, with references to the dangerousness and infectiousness of homeless people.[17] In the United States, there also exists a research study on attitudes towards homeless people carried out by Phelan et al.[18] More recently in this field, there is an European survey with data from Spain, which found a lack of knowledge about the collective and stigmatising beliefs.[19]

Finally, a recent study published in 2021 assesses stigma towards people with intellectual disabilities in a global survey that took place in 17 countries. The results suggest that those with more contact with intellectual disabilities show less stigma.[20] In addition, at a national scale, there is a research study in Switzerland, which analyses prejudice towards this group.[21] Regarding intellectual disability, a study by the university college of London finds that the word "retarded" is still used to refer to people with intellectual disabilities.[22]

In spite of the importance of these studies, it should be noted that none of them include a gender approach in the design and development of the research. They do include women in the sample and they disaggregate the statistical analyses by gender. To date, and as far as we are aware, there are no studies that take gender into account in the evaluation instruments themselves, in order to make a methodological adjustment beyond the theoretical adjustment involved in the differential analysis of the data. Commonly, the instruments used in assessment do not generally have inclusive language, and are often formulated in masculine, or at best use neutral language (e.g., persons). Thus, gender-specific differences are more likely to be left unaddressed when assessing stigma. For example, many stigma questionnaires include vignettes of cases on which attitudes are assessed. Is it the same to include a vignette of a man or a woman? Would we get the same levels of stigma and the same stereotypes if we ask about John or about Mary? It is therefore necessary to make gender explicit in the assessment instruments themselves, in order to eliminate possible biases that may be included, adjusting the items to ask for "women with...", "men with...", "people with..." etc. The primary aim of this research is to describe the stigma experienced by people belonging to three highly vulnerable populations (people with mental health problems, homeless people and people with intellectual disabilities), all the while approaching the research from a gender perspective. To this end, a measurement methodology that takes into account male and female biases is included. Furthermore, it is proposed that the opinion of stigmatised people in the survey is included by means of a mixed qualitative-quantitative methodology. In this manner, the development of the first survey on stigma associated with the conditions of mental disorder, homelessness and intellectual disability in Spain is presented. In addition, it is developed considering gender in the definition of variables and study problems, in the sampling, in the design of measurement instruments, in the statistical analysis and in the elaboration of conclusions.

METHODS

Study procedure and design

This research employs a mixed methodology, linking quantitative and qualitative methods.[23] Firstly, a qualitative study (focus groups and in-depth interviews) is carried out in the vulnerable populations of interest (MHPs, HPs, IDPs). Relevant stigma issues are discussed in order to get the perspective of the affected people themselves. Then, upon consideration of the results obtained and the previous literature, the quantitative survey is developed with three versions in its application: one neutral, one male and one female. The exact period of the study was between February 2021 and January 2022.

All results obtained are processed in accordance with Regulation (EU) 2016/679 of the European Parliament

and of the Council of 27 April 2016 on the protection of personal data. In all quantitative and qualitative evaluations, information about the study is provided and informed consent is requested, with the confidentiality of the information obtained and the identity of the participants in the qualitative study being assured. Participation in the quantitative study will be anonymous.

The study has the approval of the deontological commission of the faculty of Psychology of the Complutense University of Madrid (Ref. 2020/21-026) and is registered in clinical trials with registration number NCT05174962. The process followed to carry out the research is shown in (Figure 1).

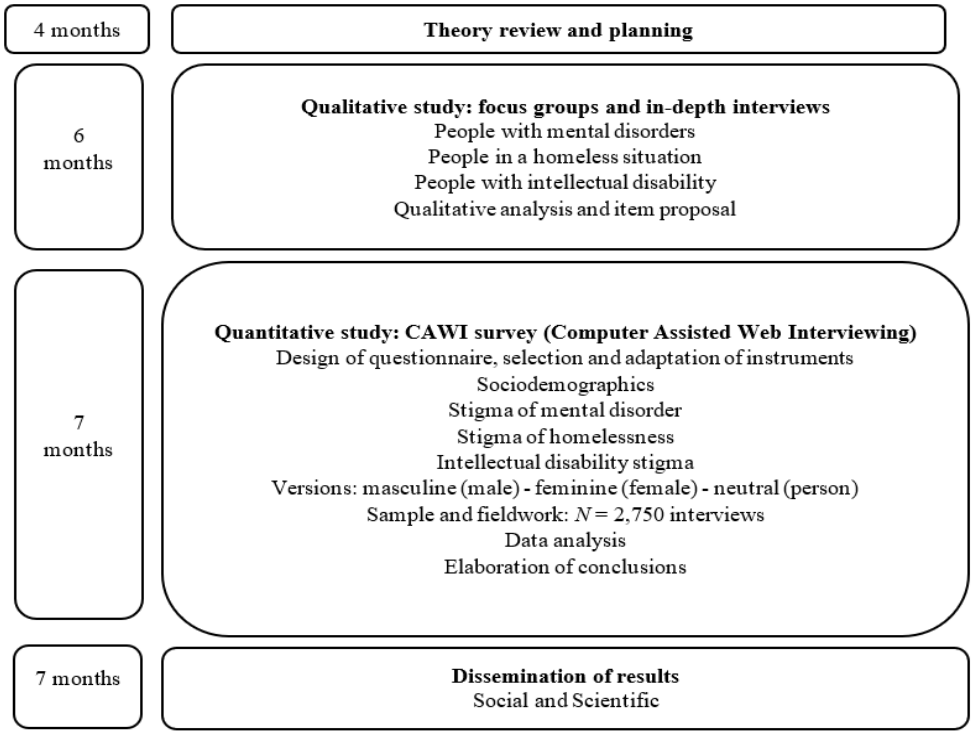

Figure 1: Design outline and planned timetable.

Participants

Qualitative study: two relatively homogeneous focus groups of 8-12 people with MHPs are created, having one group of men and one of women. These groups are complemented with 2-3 interviews with members who, although belonging to the group, can be considered as key informants due to their different characteristics from the groups already formed (older person, homosexuality, transsexuality, stay of more than 20 years in the hospital unit, etc.). This same strategy is repeated in HPs. In IDPs, a similar strategy is also adopted, although the necessary adaptations and aids are provided to enable participants to get by in research groups and interviews. These aids consist of reducing the number of participants in the groups (6-8) and adapting the language. It is important to re-emphasise the need to include the opinions of women with mental health problems, homeless women and women with intellectual disabilities. This is why this is considered when forming the focus groups.

Quantitative study: an approximate sample size of N = 2750 persons is estimated. The sample is composed of the general population over 18 years of age obtained by consumer panel methodology. The sampling conditions guarantee a confidence level of 95.5% and p=q=0.50, the error is ±1.88% for the total sample, ±10% for communities with 100 cases, ±8.16% for 150 cases and ±5.76% for 300 cases. In order to obtain a representative sample of the Spanish population, quotas by sex and age group are included, as well as data for each of the 17 autonomous communities by means of simple affixation. This ensures a minimum of 100 surveys per autonomous community in order to obtain readings for each of them. Moreover, it also allows for a rural-urban analysis in the sample as a whole and in the most populated autonomous communities.

Qualitative study procedure

The aim of the qualitative phase is to explore the psychological experiences, related to stigma, of people who have any of the three conditions of the study. Furthermore, it seeks to include this first-person perspective in the development of the methodology. Firstly, data collection is carried out through focus groups and in-depth interviews. Once the content of these focus groups has been transcribed verbatim, a thematic analysis is conducted to identify and extract interpretations of stigma in relation to each of the proposed conditions. Three independent analysts, experts in the field of each group, apply a thematic analysis to the transcripts. The

results of the analyses and the resulting categories are pooled in different meetings, with the supervision and arbitration of a fourth researcher, who mediates in case of disagreement. The strategy used to evaluate the quality of the qualitative information is based on methodological triangulation, complementing the information from the focus groups with interviews and a literature review. This strategy guarantees the inclusion of an approach that optimises the gender perspective from the beginning of the study.

Quantitative study procedure

Having identified the dimensions and characteristics of stigma as perceived by people with the conditions described earlier, a quantitative assessment instrument is developed to capture the current needs and experiences of those affected. In addition, other previously proven and validated quantitative assessment instruments are considered. The resulting battery of items and tests is applied to a random sample to achieve national representativeness.

Variables and instruments: standardized psychometric assessment instruments with reliability and validity indices demonstrated in previous studies are proposed to measure the different variables of interest. Socio-demographic data and data relating to having had or having any of the three conditions of the study are included. In addition, the survey asks about the habitual use of the media to stay informed, focusing on the question: If a person with any of the following conditions commits a crime, should their condition be included when reported in the media?

Social distance desire: The degree of closeness to the various conditions assessed is evaluated by means of 3 questions. Additionally, the future intention to have contact with the various conditions assessed is analysed using the reported and intended behaviour scale (RIBS).[24] Furthermore, a question on the opinion of services for people with mental disorders, homelessness and intellectual disabilities is included.

Information on mental disorders: attitudes towards mental disorders are assessed using the Scale for Community Attitudes towards the Mentally Il; CAMI in its Spanish version validated in an adolescent population.[25,26] Attributions about stigma in mental health problems are assessed using the attribution questionnaire-9; AQ-9.[27] It is a shortened Spanish version of the attribution questionnaire-27, consisting of 9 items instead of 27 items.[28] Regarding disclosure of mental disorders, a question is asked about disclosure behaviour when confronted with a condition suffered by a family member, friend, acquaintance, oneself, etc.

Information on intellectual disabilities: Attitudes towards disability are assessed using the attitudes to disability scale; ADS.[29] It is one of the most comprehensive scales for assessing stigma in intellectual disability. It was developed as part of an international study by the world health organization, in which Spain participated alongside other countries.

Information on homelessness: Attitudes towards homeless people are measured using the survey of attitudes towards homeless people; SHP.[30] This scale is composed of 9 Likert-type items.

Qualitative questions: Thirty-six questions are included on key aspects of stigma highlighted by people with mental health problems, homelessness and intellectual disabilities participating in the focus groups of the qualitative study. This provides further ecological validity to the study. All these instruments and variables are resumed in (Table 1).

Table 1: Variables assessed in the studies and instruments used.

Variables assessed	Instruments
Socio-demographic variables	Questions on socio-demographic data (age, sex, level of education, economic background, work, etc.).
Personal mental health, homelessness and intellectual disability conditions	Questions on mental disorder, homelessness and disability. Questions on stigmatising language.
Media use	Questions on regular use of media (radio, television, print media, internet, etc.).
Social distance	Questions on the degree of closeness to the conditions assessed. Questions about the opinion of services for these groups. Reported and intended behaviour scale; RIBS.[24]
Attitudes towards mental health problems	Scale for community attitudes toward the mentally ill (CAMI).[26,27] Attribution Questionnaire-9 (AQ-9).[27]
Disclosure of mental health problems	Questions about opinions and attitudes towards disclosure of mental health problems, and the ability to talk about them.
Attitudes towards intellectual disability	Attitudes to disability scale (ADS).[29]
Attitudes towards homelessness	Survey attitudes toward homeless people (SHP).[30]
Variables drawn from qualitative research	Items on key aspects of stigma highlighted by participants in the focus groups of the qualitative study.

Gender perspective

Since one of the major aims of the study is to maintain a gender perspective and to analyse intersectional stigma, three versions of the questionnaire are proposed: one with a male referent, one with a female referent, and one with a neutral referent. The scales used in the evaluation (CAMI, AQ-9, ADS, SHP), as well as the items derived from the qualitative study, are asked in feminine, masculine and neutral, thus developing three different questionnaires. In all three cases, the language is adapted, making specific references to male, female, or neutral gender (person), thus changing the gender of the characters in each scale. In addition, questions are included from the qualitative research, which takes into account the testimony of women who suffer stigma in the three groups. A double input table will be obtained that will allow women's attitudes towards women with mental illness, women living homeless or women with disability to be analysed separately from their attitudes towards men with the same conditions. The same will apply to males and non-binary people. Furthermore, the use of a contrast group with a neutral formulation (person) will make it possible to find out: (a) whether the sum of the male and female questionnaires is comparable to the traditional neutral strategy for the sample of females (F4 vs. F5), males (M4 vs. M5), non-binary (NB4 vs. NB5) and the total sample (F4+M4+NB4 vs. F5+M5+NB5); b) the influence of the use of the neutral term person on gender bias, by being able to compare independently the attitude of the total sample towards males and females with a mental disorder (F2+M2+NB2), with the attitude when a neutral term (persons) is used (F3+M3+NB3). This is summarised in (Table 2).

Table 2: Double input table with the different conditions and gender adjustments.

Sample (n=2,750)									
% expected	**Women-47.5**			**Men-47.5%**			**Non-binary-5%**		
Attitude towards study conditions	W1-if "women" have it 47.5%	W2-if "males" have it 47.5%	W3-if "people" have it 5%	M1-if "women" have it 47.5%	M2-if "males" have it 47.5%	M3-if "people" have it 5%	NB1-if "women" have it 47.5%	NB2-if "males" have it 47.5%	NB3-if "people" have it 5%
	W4-Total W+M		W5	M4-Total W+M		M5	NB4-Total W+M		NB5

W1=Women towards women; W2=Women towards men; W3=Women towards people; M1=Men towards women; M2=Men towards men; M3=Men towards people; NB1=Non-binary towards women; NB2=Non-binary towards men; NB3=Non-binary towards people; W4=total women + total men; W5=total neutral; M4=total women + total men; M5=total neutral; NB4=total women + total men; NB5=total neutral.

Data analysis

Descriptive statistics, odds ratios and logistic regressions will be carried out, and explanatory models will be constructed in an attempt to parameterise the influence of social stigma on the daily functioning of affected individuals. For this purpose, structural equation models (SEM) together with multilevel models, allow the identification of the variables that affect both at individual and group level. In all cases the data will be disaggregated by gender (male, female and non-binary) and by instrument referent (male, female or neutral).

Expected results

With the application of the designed survey, it is expected to assess the presence of stigmatising attitudes towards people at risk of social exclusion in the Spanish population, after having taken gender into consideration. Significant levels of social stigma towards the three samples are expected to be found.[31-33] Keeping in mind the theoretical and methodological approach of the present research, it is possible that results will be found indicating that women suffer double discrimination which in neutral or male-biased measurement instruments would be difficult to identify. It is hoped that the strategy along with the instruments will make it possible to identify the intersections between the conditions of vulnerability contemplated in the study and the gender of the person answering the survey, as well as that of the person being asked about. It is also expected that, following the analysis of socio-demographic variables, there will be differences in the responses according to gender, finding differential levels of stigma in women in the three conditions.

DISCUSSION

There is currently no information available on the levels of stigma present in the Spanish population. In addition, stigma associated with gender and other conditions has traditionally been ignored, despite the fact that intersectionality aggravates the consequences of discrimination.[34,35]

Studies with scientific rigour in which quantitative methodology plays an important role are common and similarly, those using a qualitative methodology also exist. However, a mixed combination of quantitative and qualitative approaches is less common. The qualitative methodology used takes the form of focus groups of each target group from which themes have been elicited. These themes have been translated into items added to the quantitative material and are expected to contribute to improving or complementing these tools. This methodology gives the role of protagonist to the people affected and is in line with the recommendations of Paton

et al for the design of studies with sensitive groups in the process of recovery.[36]

As for the gender perspective, the efforts made here to understand and describe its influence are in line with the recommendations made by other authors, who stress that a sufficient allocation of resources will undoubtedly lead to higher quality studies.[37] Furthermore, the intersectionality of this design relates gender to other conditions that are traditionally highly stigmatised (mental disorder, homelessness and intellectual disability). Not only does this promise to provide insight into specific areas that have been little explored so far, but it is also expected to have an impact on social policies, equality and social justice.[38] In short, there are reports that indicate the presence of social stigma towards the groups included in this survey.[39,40] These are studies carried out in Anglo-Saxon countries, so it is considered relevant to have data from a national survey in the Spanish population. From the Chair against Stigma Grupo 5-UCM we consider it essential, in the case of verifying the existence of these negative attitudes, to have this information in order to design actions that promote the development of more inclusive social contexts. This data will help to build policies of equality that improve the quality of life of people with mental health problems, homeless people and people with intellectual disabilities, not forgetting the necessary gender perspective associated with the stigma of these conditions.

CONCLUSION

This study is the first survey developed at national level in Spain on the social stigma associated with mental health problems, homelessness and intellectual disabilities. In this sense, there is little research worldwide that studies stigma towards conditions such as being homeless or having an intellectual disability. Furthermore, adding a gender focus to the data analysis will allow us to know who stigmatises more on the basis of their gender. In addition, including a gender focus in the assessment itself allows for a better understanding of which gender would be more stigmatised if they belonged to any of the conditions in the study. In this way, a better understanding of the state of the art will improve the objectives and strategies used to fight stigma, and improve the health and quality of life of all those affected.

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