

Title: Formulation of a symbolic violence scale questionnaire: the importance of the epistemological, theoretical, and methodological construction of the object of study

Author: Xavier Gimeno Torrent (<https://www.xaviergimeno.net>, https://twitter.com/Xavier_Gimeno)

Affiliation: Department of Sociology, Universitat Autònoma de Barcelona (Autonomous University of Barcelona)

Correspondence to: xavier.gimeno@xaviergimeno.net

Funding details: This research is part of the project “The circuit of symbolic violence in Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME): Development of a symbolic violence scale” which has not received or is receiving any public or private funding or crowdfunding in any of its stages for any purpose. The author also does not receive any funding or remuneration.

Disclosure statement: No conflict of interest at all.

Acknowledgments: This research has been carried out within the framework of the Sociology PhD program of the Department of Sociology of the Universitat Autònoma de Barcelona (Autonomous University of Barcelona). I would like to sincerely thank Rosa Matas Serra for her invaluable help with the revision of the English translation of the original version non-shortened of the symbolic violence scale questionnaire.

Abstract: *Objective:* The objective of this article is to develop a version 0 or preliminary of the symbolic violence scale in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). Given the general lack in the international panorama of measurement instruments that provide standardized and comparable information on the social circumstances surrounding these patients and this disease, obtaining such a scale is urgent. *Method:* For this purpose, first the epistemological, theoretical, and methodological foundations of what, based on Pierre Bourdieu’s approaches, have been considered to be a good scale questionnaire, are presented. Secondly, based on previously existing qualitative materials, the relevant quantitative analyses were carried out (analysis of co-occurrences of keywords, multidimensional Mahalanobis-Fisher-Wilks tests, and finally analysis of bivariate contingency tables) in order to isolate the most significant keywords, which, together with the review of the qualitative materials and in accordance with the 3 proposed construction principles, should serve as the basis for the questions of the scale questionnaire to generate the identification of the people surveyed with the questions. *Results:* In this way, a scale questionnaire was obtained consisting of 46 items with indirect questions of objective facts based on concrete examples extracted from the analyses carried out. The last step was to summarize the scale items with ChatGPT 3.5 Turbo.

Keywords: CFS/ME, epistemology, methodology, object of study, questionnaire, scale, symbolic violence, theory.



© Xavier Gimeno Torrent. The authorship of this document is duly registered with CEDRO, the official entity for the collective management of intellectual property and reprographic rights in Spain. (<https://www.cedro.org>).

How to cite: Gimeno Torrent, X. (2024). Formulation of a symbolic violence scale questionnaire: the importance of the epistemological, theoretical, and methodological construction of the object of study. Gray literature. Version 0 preliminary pretest of the symbolic violence scale in CFS/ME. <https://www.xaviergimeno.net/papers/formulation-symbolic-violence-scale>.

1. Objectives of the study, background-theoretical contextualization, and analytical model

The topic of this article is the development of a symbolic violence scale questionnaire to study the specific case of what I have called the circuit of symbolic violence in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). There is no knowledge of any similar scale, and a search in Google Scholar, the database with the greatest scope and linguistic diversity, far above Scopus or Web of Science (Martín-Martín et al., 2018, 2021), reveals that there is no precedent in this regard. Only the reference of a single academic production was located, a bachelor's thesis in which a scale of symbolic violence had been forged to study an issue without any connection with it, gender relations and sexism in Peru (Pecho Ricaldi, 2017). On the other hand, the consultation of my own database on all known productions from 1990 until now devoted to the social study of CFS/ME, which currently has 362 references, is in continuous evolution and right now has a completeness rate of 90% because some references are missing as of 2020, nor does it include any comparable instrument, apart from two scales measuring stigma among CFS/ME sufferers (Jantke, 2011; Terman et al., 2020), and another measuring attitudes towards CFS/ME (Shlaes et al., 1999), perspectives that also have nothing to do with the one adopted in this work.

Thus, the present research is framed within the paradigm of symbolic violence, a field of study of which Pierre Bourdieu was the precursor and main theorist, whose foundations of the particular application I have explained in another article (Gimeno Torrent, 2022). In fact, the present work is the continuation of the analyses carried out in that previous article with the aim of constructing a measurement instrument that allows obtaining generalizable and internationally comparable data on all the social aspects that affect CFS/ME, producing the invisibility of the disease and the relegation and social disintegration of the sick. For the purposes of this research, symbolic violence is, to put it very briefly, a structural process from which the legitimate way of seeing and defining social reality is imposed, what is socially thinkable and unthinkable, that is, a common sense, and a cognitive advantage is given to what is established that is constituted as such (Bourdieu, 2001a:210-211). Regarding this research, one of the main consequences of this fact is that some patients and diseases are favored and others are relegated and made invisible. The main social structure that explains these effects is the existence of a hierarchy of diseases. In other researches, I have been able to verify how, among a list of 230 diseases in Western contexts, there is an extraordinarily stable ordering of diseases throughout the observed period 2008-2021, which entails a clear division between about 70 visible and legitimized diseases led with great advantage by cancer, and other diseases that are clearly not very visible and not legitimized, which are the remaining diseases. It is to be expected that this classification will be deeply imbued with gender inequalities, which have not yet been researched in the available database of 230 diseases. This hierarchy is generated in the interrelation between the scientific field, the media meta-field, and the social space. This social structure is incorporated and naturalized by agents in the form of principles of vision and division. In this way, this violence is based on two defining features: 1) the internalization and normalization of a form of knowledge that becomes "profoundly obscure to itself," invisible, unnoticed, that is not recognized as such violence (Bourdieu, 1999:126, 2001b:37-38), and 2) that it does not emerge spontaneously in an organized way from rationality, calculation, consciousness, decision, intention or any other name the logicism inherent to the theoretical logics may take, of which the theory of rational choice or methodological individualism are two typical examples, as opposed to practical sense (Bourdieu, 1990, 2000, 2001b:37-38, 2017).

This poses a serious problem. How to approach the study of an object that is invisible and that cannot be interrogated from the assumptions of the philosophies of consciousness transmitted by conventional language? The transcendence of this question, which derives from everything explained so far, will be seen more clearly from a concrete example, extracted from a real research. In 2021, the Barcelona health survey asked the following question: "In the last year, have you experienced any type of discrimination because of...? You have felt upset, you have been denied something, you have been harassed or you have felt inferior..." (Bartoll-Roca et al., 2021:166). The phenomenon that this question attempts to capture is fully circumscribed within the field of study of symbolic violence, but it does so without having the necessary epistemological, theoretical, and methodological tools. In the 2021 Barcelona health survey, the

results of this specific question showed a clear gradient by age, for both men and women, *when it came to stating* that they had suffered discrimination, so that the younger the age, the more discriminations. In turn, according to social classes, “the highest percentage of people *who stated* [my italics] that they had suffered some discrimination were women from more affluent classes, around 21%” (Bartoll-Roca et al., 2022:47). These two results are clearly counterintuitive and contrary to what good sociological common sense, intuition, or good judgment would dictate, and anyone with a little insight would realize this. What these results are revealing to us is that the younger the age (for men and women) and the higher the social class (only for women from affluent classes), the greater the degree of awareness of discrimination, which is not at all comparable to greater discriminations. In a question like this respondents express their degree of adherence to the values conveyed by the question, in this case, the fight against discrimination and inequalities. Explained in this way, these results make all the sense in the world and are totally coherent, especially in a historical and social context like the current one that is especially sensitive to these issues. The latter is a key element to interpret the age gradient and very probably also the social class gradient, particularly in the case of affluent classes that are always willing to make a profit, social benefit from *noble causes*, and much more when it comes to the cause of feminism, which is usually the heritage of women. On the other hand, the mania with gradients among medical epidemiologists is well known, and will probably lead many of them to believe that the question is exemplarily well formulated and, thus, they will also take their results as good, when it is very clear that ‘gradients’ are no guarantee of anything, but could often be indicators of constructed measurement artifacts, which rather than measuring the phenomenon, record the effects produced by the measurement instrument and the symbolic violence engendered by the survey relationship between respondent and interviewer, as is the case. The objective of a well-constructed structured questionnaire is precisely to “ask,” so both the role of respondent and interviewer and the possible distortions introduced by this relationship should be minimal, but the possibilities of capturing the full range of possible responses should be maximum and calculated to the millimeter. If this question had asked about specific cases and examples of discrimination extracted from a theoretically well-constructed in-depth research, such absurdities would not have been obtained and the percentages of discrimination would have decreased drastically.

One can learn a lot from bad examples and this question leaves a very important lesson to retain. That when researching any type of issue directly or indirectly related to symbolic violence, these same difficulties will arise if the pertinent precautions are not taken, whether the context is favorable to the question and the answer on these matters, which, as has just been seen, leads to overrepresentations, as if not, which leads to underrepresentations. As Bourdieu and Passeron stated at the time (1966b), “the sociologist must register even in the minor of his technical acts, elaboration of a questionnaire, coding, analysis of a statistical table, etc., a theory of the knowledge of the object, a theory of the object, and a theory of what it is to know the object experimentally.” That is, these precautions are of 3 types. The first are the epistemological ones, or the “theory of the knowledge of the object.” The previous question is an archetypal example of what Pierre Bourdieu called scholastic fallacy (2000:49-92), in which the respondent is asked to be his own analyst because he is considered the repository of the knowledge of the cause (Bourdieu, 2017:251-252; Bourdieu & Passeron, 1966b) about the phenomena that affect him, which would be directly graspable through experience. This is analogous and is based on the same principles on which the class self-perception questions are based, where respondents are asked “to what social class they belong;” that is, it is based in “ordinary sense-experience” and the “individuals in particular at which substantialist realism stops” (Bourdieu, 1987:3). This type of approach was criticized years ago by authors such as Goldthorpe and Lockwood (1963). One should also see the comments by Bourdieu, Chamboredon and Passeron based on this same article on this same thing (Bourdieu et al., 1991:179-180). In the question at hand: “In the last year, *have you experienced ...*” [my italics]. In the specific formulation of the questions, this is reflected in what has been called the ‘illusion of transparency’ since these are questions that seem immediately accessible to understanding, as Kant said, but they transmit to the respondents some poorly controlled meanings that lead to erroneous responses. These meanings usually come from the prenotions of spontaneous sociology that spread from an uncontrolled, unscientific use of conventional language (Bourdieu & Passeron, 1966a, 1966b). In the question at hand, mainly the

term “discrimination,” accompanied secondarily by the expressions “you have felt upset, you have been denied something, you have been harassed or you have felt inferior,” which are conspicuous by their manifest imprecision and are full of ambiguities (is feeling upset about something or having someone denied something discrimination?). The antidote to all this is epistemological vigilance (Bourdieu et al., 1991; Bourdieu & Passeron, 1966b).

The question of substantialist realism has just been mentioned, a topic of primary importance regarding the second precautions to be considered, the theoretical ones or the “theory of the object.” Opposed to this type of essentialism carried out by ordinary sense-experience, individuals in particular, the prenotions of spontaneous sociology, and an unscientific use of conventional language, is the primacy of the structure and the coherent system of facts. In contrast, a question like the previous one, “In the last year, have you experienced any type of discrimination because of...? You have felt upset, you have been denied something, you have been harassed or you have felt inferior...,” continually appeals to what the respondent “feels” or “has experienced.” That is, in no case are objective indicators of discrimination asked, ‘questions of fact’ as opposed to ‘questions of opinion,’ because precisely the question is framed within the realm of the opinion of the respondent. In this case, a good way to do it would be from concrete examples. But concrete examples of what? Well, of each of the dimensions of the phenomenon studied. But how, if does this question not pay any kind of attention to the total structure of the phenomenon but instead focuses on the individual? Unlike the sectional knowledge of the individual (Bourdieu, 1972:1105-1106n1), scientific knowledge aspires to the whole. In other words, it is evident that if a phenomenon is not adequately and scientifically conceptualized, it is impossible to go that far. All this clearly shows that whoever wrote this question did not know what he should ask because he did not have the slightest idea of what he was looking for. The antidote to all this is a theoretically well-founded construction of the object of study (Bourdieu et al., 1991:33-56).

And finally, in full consonance with everything said so far, the question at hand is a paradigmatic example of the type of direct questions that, as has been seen, convey a false sense of clarity and should never under any circumstances be asked in a survey (Bourdieu & Passeron, 1966b). So, here come the third precautions to consider, the methodological ones or the “theory of what it is to know the object experimentally.” In order to formulate the questions of a questionnaire, pre-eminence is given to indirect questions; “that is, those questions that seem to be directed towards ‘a’ when in fact they are directed towards ‘b.’” If such a privilege is granted to these questions “it is basically because the predominance given to these questions embodies the philosophy, the obedience to the principle of non-consciousness” (Bourdieu & Passeron, 1966b). When we talk about the principle of non-consciousness, we are not saying that people do not have knowledge about what is happening to them, in any way. What is stated is that they have a sectional knowledge, of a very small part of ‘reality,’ and that total knowledge of a phenomenon is only possible from the relevant analytical models, a topic that has just been discussed. To achieve this knowledge with an instrument such as a questionnaire, indirect questions are preferred to capture indirect indicators of objective facts, and are organized according to the principles established by the previously developed analytical models.

2. Method and techniques

This is how, based on the epistemological, theoretical, and methodological principles just explained, a scale questionnaire of the circuit of symbolic violence in CFS/ME was developed (section 3.5). It consists of 46 items with indirect questions about objective facts based on concrete examples extracted from the analyses carried out that will be described below. In the non-shortened version of the scale (Annex 4, section 4), they usually take the form of relatively long narrative statements full of examples to provide the necessary context in the form of the detailed semantic fields that will allow to obtain successfully the automatic shortened items with ChatGPT 3.5 Turbo. Response categories consist of a 5-point Likert scale: strongly agree; agree; neither agree or disagree, not sure, indecisive, or indifferent; disagree; strongly disagree.

Both in order to ensure that the respondents’ answers really referred to objective facts of their daily lives and to guarantee that the questions effectively brought out this unnoticed violence, efforts were made to ensure that the person surveyed identified with these statements based on

examples. The starting point to achieve this objective were the quantitative and qualitative analyses previously carried out on the 77 letters to the editor written by people affected by CFS/ME, which laid the foundation for the construction of the object of study and resulted in the circuit of symbolic violence in CFS/ME' analytical model (Gimeno Torrent, 2022). But the fundamental raw material for this article has been qualitative analyses. At that time, a qualitative thematic content analysis was carried out based on the iterative reading of those 77 letters. All the procedural details in this regard are described in that article (Gimeno Torrent, 2022). As a result, an analytical model was obtained with 13 mechanisms of symbolic violence (themes) and 46 submechanisms (subthemes) (section 3.1).

Next, with the 623 fragments coded by themes and subthemes resulting from the previous qualitative thematic content analysis, a database was created to obtain a list of keywords. Each of these fragments was duly identified individually and according to their classification per themes (13 mechanisms) and subthemes (46 items). Next, this database was analysed using the co-occurrence analysis module of the VOSviewer software. As a result, the list and graphic representation of the 316 most relevant keywords of the 77 letters were obtained (section 3.2).

But the most decisive step was the next one. Each of these keywords had a relevance score from which it was possible to know its importance in the co-occurrence network. Thus, based on this list of the 316 keywords, multidimensional Mahalanobis-Fisher-Wilks tests were carried out to associate the keywords with the items for which they had greater medium relevance. To carry out these analyses the statistical software XLSTAT was used (Lumivero, 2023). In this way it was possible to link the relevant keywords with each of the 13 mechanisms and 46 items of the symbolic violence circuit. The level of complexity of the system was significantly reduced, going from 316 keywords to 176. These were the 176 keywords associated in a statistically significant way ($p < 0.0001$) with each of the 46 items that should be part of the symbolic violence scale in CFS/ME (section 3.3).

Additionally, to definitively validate both the qualitative thematic content analysis and the analytical strategy based on the Mahalanobis-Fisher-Wilks multidimensional tests, a bivariate contingency table analysis was carried out. Here XLSTAT was used again (Lumivero, 2023). The hypothesis to be tested was that the grouping of keywords resulting from the co-occurrence analysis should be similar to that obtained from the combination of qualitative thematic content analysis and Mahalanobis-Fisher-Wilks. If this was true, it meant that both the qualitative thematic content analysis and the Mahalanobis-Fisher-Wilks multidimensional tests classified the contents in the same way. That is, they endorsed the validity of the analyses carried out. And so it was, as can be seen in section 3.4.

Finally, in accordance with all these developments, version 0 or preliminary of the symbolic violence scale in CFS/ME was developed (section 3.5). Once this first version of the scale items was obtained, they were summarized in the form of first-person questions of no more than 20 words with ChatGPT 3.5 Turbo (GULL AG, 2023). I consider that the long narrative explanations full of examples of the first non-shortened version of the items have been an essential requirement to provide context to ChatGPT 3.5 Turbo when it comes to successfully obtaining the shortened version of the items, a task in which it has practically not been necessary to provide any instructions to this program, most likely thanks to this fact, which is why throughout this article I have so strongly highlighted these long narrative statements from the first original version of the scale.

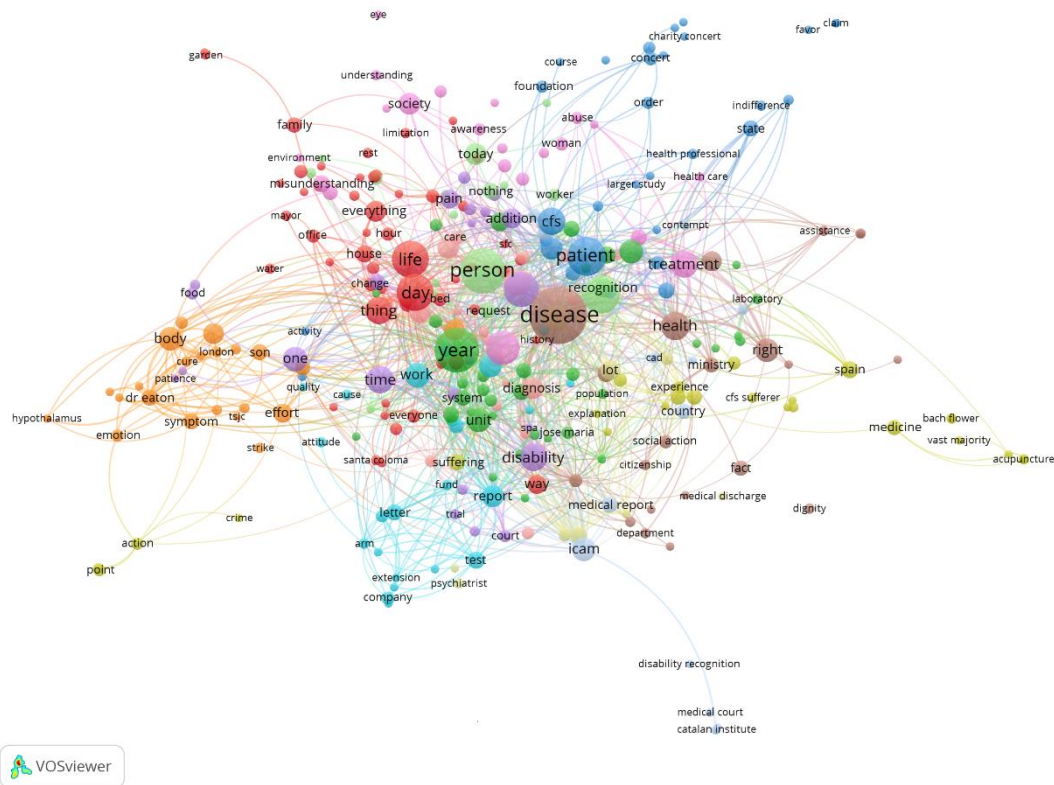
3. Results and analyses

3.1. Qualitative thematic content analysis of the 77 letters to the editor: counting per themes-mechanisms (13) and sub-themes-sub-mechanisms (items) (46)¹

Counting per themes and subthemes
Non-recognition (169 occurrences; 27%)
ITEM 1: Non-recognition of the sick and the disease (54; 32%)
ITEM 2: Non-recognition of patients as human beings (31; 18%)
ITEM 3: Violation of the right to dignity of affected families (4; 2%)
ITEM 4: Delay of recognition requests as a mechanism of resignation and non-recognition of CFS patients (5; 3%)
ITEM 5: Judicialization of disability recognition (2; 1%)
ITEM 6: Violation of the rights of CFS patients (25; 15%)
ITEM 7: <i>Double bind</i> (3; 2%)
ITEM 8: Humiliations and systematic mistreatment of CFS patients by Public Administration as a deterrent strategy for the recognition of disabilities (34; 20%)
ITEM 9: Difficulty of the patient to accept himself and his limitations; internalization of the denial of recognition (5; 3%)
ITEM 10: Repeated social abuse to patients (6; 4%)
Institutionalized un-care (99 occurrences; 16%)
ITEM 11: Medical un-care (67; 68%)
ITEM 12: Socio-sanitary un-care (1; 1%)
ITEM 13: Social services un-care (3; 3%)
ITEM 14: Discrimination resulting in un-care (5; 5%)
ITEM 15: Scientific un-care (23; 23%)
ITEM 16: Condescension (1 occurrence; 0%)
Authorized imposition of illegitimate verdicts (97 occurrences; 15%)
ITEM 17: Authorized imposition of illegitimate verdicts (43; 44%)
ITEM 18: Assignment of successive verdicts over time until correctly diagnosed (15; 16%)
ITEM 19: Arbitrary determination of a maximum period of incapacity for work for a disease that is chronic and without treatment (9; 9%)
ITEM 20: Doxical imposition (30; 31%)
Delegitimization (68 occurrences; 11%)
ITEM 21: Decredibilization (26; 38%)
ITEM 22: Incomprehension (20; 30%)
ITEM 23: Delegitimization (13; 19%)
ITEM 24: Generalized questioning of CFS patient (9; 13%)
Disintegration (103 occurrences; 16%)
ITEM 25: Consequences over identity of labor disintegration (2; 2%)
ITEM 26: Necessary re-adaptation of CFS patient and his social circle to the social rhythms and customs required by the disease (8; 8%)
ITEM 27: Conflicts between customs and labor/social rhythms of sick and non-sick (8; 8%)
ITEM 28: Social, labor-productive and labor-reproductive disintegration (52; 50%)
ITEM 29: Lack of expectations (16; 15%)
ITEM 30: Divorces (3; 3%)
ITEM 31: Resistance to social and labor disintegration and difficulty of adaptation to it (14; 14%)
Imposition of discourse (8 occurrences; 1%)
ITEM 32: Imposition of heroic discourse (5; 62%)
ITEM 33: Imposition of normality discourse (2; 25%)
ITEM 34: Imposition of non-victimist/non-self-pitying discourse (1; 13%)
Euphemization (24 occurrences; 4%)
ITEM 35: Making a virtue of necessity (24; 100%)
Silencing (8 occurrences; 1%)
ITEM 36: Silencing (4; 50%)
ITEM 37: Silencing behaviors (4; 50%)
Invisibilization (9 occurrences; 2%)
ITEM 38: Invisibilization (5; 55%)
ITEM 39: Without any sign capable of operating as negative symbolic capital (2; 22%)
ITEM 40: Absence of biological markers (2; 22%)
Isolation (17 occurrences; 3%)
ITEM 41: Isolation as a product of disintegration (15; 88%)
ITEM 42: Isolation as a protective mechanism (2; 12%)
ITEM 43: Uncommunication (2 occurrences; 0%)
Self-blaming (24 occurrences; 4%)
ITEM 44: Self-blaming (17; 71%)
ITEM 45: Psychologization of symbolic violence with the effect of self-blaming (6; 25%)
ITEM 46: Medicalization of symbolic violence (1; 4%)

¹ This table is a slightly modified version of the Annex originally published in Gimeno Torrent (2022).

3.2. Keyword co-occurrence analysis with VOSviewer: graphic representation of the network of 316 keywords



3.3. Mahalanobis-Fisher-Wilks multidimensional tests' per item

Mechanism	Item (description)	Group	Keyword	Medium relevance
Non-recognition	Item 1 (Non-recognition of the sick and the disease)	8	disease	0.043
		8	dignity	0.102
	Item 2 (Non-recognition of patients as human beings)	3	indifference	0.078
		7	hunger strike	0.033
		10	reality	0.023
		4	point	1.206
	Item 3 (Violation of the right to dignity of affected families)	1	husband	0.413
		1	daughter	0.344
		7	son	0.247
		3	claim	0.528
		3	resolution	0.528
		3	in favor of	0.311
		1	everyone	0.272
		11	request	0.193
		7	after x a half years	0.189
		3	place	0.172
		8	assessment	0.159
		3	State	0.127
		2	year	0.115
		8	Min. S. A. Citize.	0.106
		7	TSJC	0.104
		8	ministry	0.09
		8	Min. S. A. Citize.	0.077
		10	job	0.702
		5	go to court	0.530
		10	euro	0.529
		10	judge	0.527
		10	absolute disability	0.523
		5	trial	0.473
		5	justice	0.373
		5	INSS	0.275
		5	disability	0.241
		5	time	0.106
		4	Min. S. A. Citize.	0.224
		8	right	0.151
		8	health	0.133
		9	information	0.102
		4	profession	0.073
		5	justice	0.06
	Item 7 (Double bind)	13	medical discharge	0.282

Mechanism	Item (description)	Group	Keyword	Medium relevance
Non-recognition	<i>Item 7 (Double bind)</i>	12	ICAM	0.252
		6	ICAM doctor	0.245
		10	medication	0.19
		10	absolute disability	0.174
		2	specialist	0.17
		11	request	0.161
		8	work activity	0.155
		10	october	0.139
		10	type	0.137
		8	assessment	0.133
		6	report	0.113
		13	lot	0.096
		10	diagnosis	0.091
		11	doctor	0.089
		12	contempt	0.211
		4	humiliation	0.076
		9	abuse	0.069
	<i>Item 8 (Humiliations and systematic mistreatment of CFS patients by Public Administration as a deterrent strategy for the recognition of disabilities)</i>	1	limitation	0.51
		1	rest	0.331
		1	door	0.239
		1	thing	0.15
		9	help	0.146
		1	water	0.135
	<i>Item 9 (Difficulty of the patient to accept himself and his limitations; internalization of the denial of recognition)</i>	9	abuse	0.39
		2	forgiveness	0.362
		2	government	0.32
		2	population	0.31
		2	percentage	0.254
		9	woman	0.232
		2	week	0.224
		4	public health	0.054
		9	institutions	0.302
		9	help	0.243
Institutionalized un-care	<i>Item 10 (Repeated social abuse to patients)</i>	2	area	0.58
		2	treatment unit	0.375
		5	spa	0.232
		2	healthc. soc.-san. care	0.213
		2	Hospital Clinic	0.161
		3	patient	0.16
		3	assume the cost of	0.153
		5	fibromyalgia	0.151
		7	in my condition of	0.148
		2	rheumatologist	0.145
		5	member	0.137
		5	INSS	0.11
		2	jose maria	0.102
		8	generalitat	0.097
		7	reason	0.086
		6	cause	0.084
		6	number of patients	0.071
		2	laboratory	0.242
		2	research	0.24
		3	larger study	0.13
		3	medical test	0.121
		3	in order to	0.101
		6	fund	0.073
		10	medication	0.05
		12	ICAM	0.079
		6	report	0.071
		5	disability	0.067
		1	CFS	0.048
		10	5 or 10 minutes	0.032
		10	evidence	0.029
		1	medical history	0.026
		7	symptom	0.116
		1	doctor's office	0.074
		13	all kind	0.056
		10	diagnosis	0.055
		6	chronic fatigue	0.047
		2	specialist	0.034
		6	secondary symptom	0.033
		9	sick leave	0.271
		3	scale	0.134
		1	day	0.115
		6	extension	0.099
		6	work	0.095
		7	cure	0.091
		3	activity	0.068
		3	age	0.048
		6	international classification	0.03
		4	acupuncture	0.571
		4	shiatsu	0.381
		4	homeopathy	0.357
		4	medicine	0.263
		4	Bach flower	0.238
		4	alternative therapy	0.23
		7	Dr. Eaton	0.21
		5	food	0.168
		7	body	0.151
		7	London	0.066
Authorized imposition of illegitimate verdicts	<i>Item 11 (Medical un-care)</i>	4	public health	0.054
		9	institutions	0.302
		9	help	0.243
		2	area	0.58
		2	treatment unit	0.375
		5	spa	0.232
		2	healthc. soc.-san. care	0.213
		2	Hospital Clinic	0.161
	<i>Item 13 (Social services un-care)</i>	3	patient	0.16
		3	assume the cost of	0.153
		5	fibromyalgia	0.151
		7	in my condition of	0.148
		2	rheumatologist	0.145
		5	member	0.137
		5	INSS	0.11
		2	jose maria	0.102
	<i>Item 14 (Discrimination resulting in un-care)</i>	8	generalitat	0.097
		7	reason	0.086
		6	cause	0.084
		6	number of patients	0.071
		2	laboratory	0.242
		2	research	0.24
		3	larger study	0.13
		3	medical test	0.121
	<i>Item 15 (Scientific un-care)</i>	3	in order to	0.101
		6	fund	0.073
		10	medication	0.05
		12	ICAM	0.079
		6	report	0.071
		5	disability	0.067
		1	CFS	0.048
		10	5 or 10 minutes	0.032
	<i>Item 17 (Authorized imposition of illegitimate verdicts)</i>	10	evidence	0.029
		1	medical history	0.026
		7	symptom	0.116
		1	doctor's office	0.074
		13	all kind	0.056
		10	diagnosis	0.055
		6	chronic fatigue	0.047
		2	specialist	0.034
	<i>Item 18 (Assignment of successive verdicts over time until correctly diagnosed)</i>	6	secondary symptom	0.033
		9	sick leave	0.271
		3	scale	0.134
		1	day	0.115
		6	extension	0.099
		6	work	0.095
		7	cure	0.091
		3	activity	0.068
	<i>Item 19 (Arbitrary determination of a maximum period of incapacity for work for a disease that is chronic and without treatment)</i>	3	age	0.048
		6	international classification	0.03
		4	acupuncture	0.571
		4	shiatsu	0.381
		4	homeopathy	0.357
		4	medicine	0.263
		4	Bach flower	0.238
		4	alternative therapy	0.23
	<i>Item 20 (Doxical imposition)</i>	7	Dr. Eaton	0.21
		5	food	0.168
		7	body	0.151
		7	London	0.066
		7	London	0.066

Mechanism	Item (description)	Group	Keyword	Medium relevance
Authorized imposition of illegitimate verdicts	Item 20 (Doxical imposition)	7	cure	0.054
Delegitimization	Item 22 (Incomprehension)	9	understanding	0.226
		5	incomprehension	0.224
		9	society	0.144
		9	misunderstanding	0.129
	Item 23 (Delegitimization)	9	woman	0.214
		5	cancer	0.127
		9	writing	0.116
		5	name	0.108
		5	complex disease	0.034
		4	crime	0.274
		5	trial	0.105
	Item 24 (Generalized questioning of CFS patient)	11	someone	0.049
Disintegration	Item 25 (Consequences over identity of labor disintegration)	4	profession	1.816
	Item 26 (Necessary re-adaptation of CFS patient and his social circle to the social rhythms and customs required by the disease)	1	limitation	0.159
		1	thing	0.141
		1	at the moment	0.127
		5	daily life	0.125
		1	life	0.103
		6	quality of life	0.072
	Item 27 (Conflicts between customs and labor/social rhythms of sick and non-sick)	1	hour	0.28
		1	rest	0.207
		2	week	0.168
		2	normal life	0.148
		11	today	0.137
		7	effort	0.107
		5	force	0.084
		3	activity	0.076
	Item 28 (Social, labor-productive and labor-reproductive disintegration)	10	job	0.094
	Item 29 (Lack of expectations)	3	path	0.133
		1	life	0.077
	Item 30 (Divorces)	1	husband	0.55
		7	case	0.071
	Item 31 (Resistance to social and labor disintegration and difficulty of adaptation to it)	1	Santa Coloma	0.287
		1	Manuela	0.188
		1	mayor, mayor's office	0.161
		4	politics	0.134
		1	affair	0.128
		2	last year	0.117
		3	part	0.107
		6	I have in my head	0.086
		1	give up the reins	0.085
		1	at the moment	0.073
		7	expressions of affection	0.072
		6	letter	0.046
Imposition of discourse	Item 32 (Imposition of heroic discourse)	7	body	0.542
		1	control	0.25
		1	hour	0.224
		1	bed	0.217
		9	mind	0.176
	Item 33 (Imposition of normality discourse)	1	daughter	0.689
		2	week	0.671
		1	home	0.485
		11	face	0.345
		1	school	0.288
Euphemization	Item 35 (Making a virtue of necessity)	1	spring	0.372
		1	garden	0.344
		1	plant	0.12
		1	mine	0.117
		5	patience	0.116
		1	sunset	0.116
		1	mother	0.062
Silencing	Item 36 (Silencing)	6	arms	0.225
Invisibilization	Item 38 (Invisibilization)	3	age	0.107
		2	population	0.372
		2	percentage	0.304
		9	in the eyes of	0.262
	Item 39 (Without any sign capable of operating as negative symbolic capital)	6	number of patients	0.071
		2	sign	0.495
	Item 40 (Absence of biological markers)	11	person	0.077
		5	pain	0.377
Isolation	Item 41 (Isolation as a product of disintegration)	6	medical test	0.331
		1	anyone	0.116
		1	house	0.084
	Item 42 (Isolation as a protective mechanism)	3	[patients] association	0.589
		1	home	0.485
		4	end	0.227
Self-blaming	Item 44 (Self-blaming)	7	body	0.213
		1	world	0.154
		9	mind	0.103
		4	action	0.932
	Item 45 (Psychologization of symbolic violence with the effect of self-blaming)	7	emotion	0.421
		8	important thing	0.148
		6	cause	0.07
		6	attitude	0.058

3.4. Association measures between quantitative and qualitative keywords grouping

It might be thought that the analysis just carried out, with which a classification of the keywords according to qualitative items and mechanisms of symbolic violence has been obtained (section 3.3), and the analysis of co-occurrences of keywords that has produced another grouping of keywords (section 3.2), should present certain coincidences. That is, whether with one method (quantitative analysis of co-occurrences and clusters) or the other (qualitative thematic content analysis), the same keywords should be part of the same groups. Verifying this would also serve not only to validate the previous qualitative thematic content analysis (section 3.1), but also the analysis strategy deployed in the previous section 3.3; that is, they would validate each other.

This is exactly what will be done next. Given that what we have are two variables, namely, on the one hand the grouping of keywords based first on the qualitative thematic content analysis and then on the multidimensional Mahalanobis-Fisher and Wilks' lambda tests, and on the other the clustering of keywords from co-occurrence analysis, the analysis strategy is quite simple. It is only necessary to carry out a bivariate contingency table analysis to see, first, if these two variables are dependent or independent (the hypothesis is that they are highly dependent), and then, if their degree of association is high or low (the hypothesis is that they will be very intense associations).

Due to the relatively small number of keywords with statistically significant associations obtained (215, in reality there are 176 keywords, but some are part of more than one group) and the relatively high number of groups (13 for one variable and 11 for the other), it is expected that many of the cells of the contingency table will contain less than 5 cases, which will exceed the traditional 20% of cells with less than 5 cases that is conventionally considered the threshold for administering the Chi-square test (Agresti, 2007:40, 156; Howell, 2011). So, to overcome the non-compliance with the assumptions of the asymptotic method (fundamentally, that the data set is large), it will be necessary to base the test carried out on 5,000 Monte Carlo simulations to adapt the sample size to the stipulated requirements of the Chi square test (Hope, 1968; Howell, 2011). Because of this same requirement of 5 or more cases per cell in the contingency table, it will be necessary to use Fisher's exact test instead of statistics such as adjusted residuals, which are also based on Chi-square, to measure local associations between variables in the cells.

Mechanism		G1	G2	G3	G4	G5	G6	G7	G8	G9	G10	G11	G12	G13	TOTALS
SELFBLAM	F	1	0	0	1	0	2	2	1	1	0	0	0	0	8
	%	2.38%	0.00%	0.00%	6.25%	0.00%	10.53%	11.11%	8.33%	6.25%	0.00%	0.00%	0.00%	0.00%	3.72%
	Signific. (Fisher)	1.000	1.000	1.000	0.467	1.000	0.150	0.137	0.373	0.467	1.000	1.000	1.000	1.000	
ISOLATO	F	1	0	0	0	0	0	0	0	0	0	0	0	0	5
	%	0.14%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	2.33%
	Signific. (Fisher)	0.052 (a)	1.000	0.373	0.523	1.000	1.000	1.000	1.000	1.000	1.000	1.000	1.000	1.000	
INSUNCAR	F	0	8	5	1	4	3	2	1	2	1	0	0	0	27
	%	0.00%	34.78%	26.32%	6.25%	18.18%	15.79%	11.11%	8.33%	12.50%	6.67%	0.00%	0.00%	0.00%	12.56%
	Signific. (Fisher)	1.000	0.003	0.071 (c)	0.700	0.492	0.714	1.000	1.000	0.700	0.600	1.000	1.000	1.000	
DISINTEG	F	14	3	3	2	2	3	3	0	0	1	1	0	0	32
	%	33.33%	13.04%	15.79%	12.50%	9.09%	15.79%	16.67%	0.00%	0.00%	6.67%	14.29%	0.00%	0.00%	14.88%
	Signific. (Fisher)	0.001	1.000	1.000	1.000	0.542	1.000	0.736	0.221	0.138	0.705	1.000	1.000	1.000	
DELEGIT	F	0	0	0	1	5	0	0	0	5	0	1	0	0	12
	%	0.00%	0.00%	0.00%	6.25%	22.73%	0.00%	0.00%	0.00%	31.25%	0.00%	14.29%	0.00%	0.00%	5.58%
	Signific. (Fisher)	0.129	0.371	0.606	1.000	0.003	0.606	0.605	1.000	0.001	1.000	0.335	1.000	1.000	
EUPHEMIZ	F	6	0	0	0	1	0	0	0	0	0	0	0	0	7
	%	14.29%	0.00%	0.00%	0.00%	4.55%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	3.26%
	Signific. (Fisher)	0.000	1.000	1.000	1.000	0.536	1.000	1.000	1.000	1.000	1.000	1.000	1.000	1.000	
AHIV	F	4	1	3	6	2	6	6	0	1	3	0	1	1	34
	%	9.52%	4.35%	15.79%	37.50%	9.09%	31.58%	33.33%	0.00%	6.25%	20.00%	0.00%	33.33%	33.33%	15.81%
	Signific. (Fisher)	0.248	0.138	1.000	0.025	0.540	0.090 (c)	0.045	0.221	0.477	0.712	0.600	0.405	0.405	
IMPDIS	F	6	1	0	0	0	0	1	0	1	0	1	0	0	10
	%	14.29%	4.35%	0.00%	0.00%	0.00%	0.00%	5.56%	0.00%	6.25%	0.00%	14.29%	0.00%	0.00%	4.65%
	Signific. (Fisher)	0.005	1.000	0.606	1.000	0.604	0.606	0.591	1.000	0.546	1.000	0.287	1.000	1.000	
INVISI	F	0	3	0	0	1	2	0	0	0	0	0	0	0	8
	%	0.00%	13.04%	0.00%	0.00%	4.55%	10.53%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	3.72%
	Signific. (Fisher)	0.560	0.042	1.000	1.000	0.585	0.150	1.000	1.000	0.467	1.000	0.236	1.000	1.000	
NONRECOG	F	8	7	6	4	7	2	4	10	5	10	3	2	2	70
	%	19.05%	30.43%	31.58%	25.00%	31.82%	10.53%	22.22%	83.33%	31.25%	66.67%	42.86%	66.67%	66.67%	32.56%
	Signific. (Fisher)	0.043 (b)	1.000	1.000	0.590	1.000	0.839 (b)	0.435	0.000	1.000	0.007	0.685	0.248	0.248	
SILEN	F	0	0	1	0	0	1	0	0	0	0	0	0	0	2
	%	0.00%	0.00%	5.26%	0.00%	0.00%	5.26%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.93%
	Signific. (Fisher)	1.000	1.000	0.169	1.000	1.000	0.169	1.000	1.000	1.000	1.000	1.000	1.000	1.000	
TOTALS		42	23	19	16	22	19	18	12	16	15	7	3	3	215 (100%)

(a) However significant the association established in this cell is, it cannot be highlighted because there are 0 cases in this cell.

(b) It does not seem very advisable to highlight this association as significant because the proportion corresponding to the number of cases is lower than the average proportion. Apparently, this statistic is rather reflecting an under-representation.

(c) The association for this cell is bordering the significance threshold for $\alpha=0.05$.

As can be seen, the forecast regarding the need to resort to Monte Carlo simulations has been fulfilled, because of the 143 cells in the table, 126 (88%) contained less than 5 cases. This magnitude far exceeds the traditional 20% of cells with less than 5 cases that is conventionally considered permissible to safely administer the Chi-square test.

The value of the Chi square test from Monte Carlo simulations has been 199.095, very far from the critical value of 152.127 that would mark the independence between variables, which

for $GL=10$ is associated with a probability that both variables are independent <0.0001 . This implies that, for $\alpha=0.05$, the hypothesis of association between the two variables must be accepted and the null hypothesis rejected, so that there is a clear relationship between the classification of keywords based on the quantitative analysis of co-occurrences and clusters and the one based first on qualitative thematic content analysis and then on multidimensional Mahalanobis-Fisher and Wilks' lambda tests. That is, from two different methods, very similar results have been reached. It should also be said that the intensity of the association between the classification of keywords based on both methods is very high, and very surprising given the usual conservative tendency of the statistics used, such as the contingency coefficient, which here takes a value of 0.693, or Cramer's V, with a value of 0.304. These statistics usually underestimate the intensity or strength of the real association (López Roldán & Lozares Colina, 1999:18). But beyond these statistical indicators, in the table these strong associations have been represented visually based on the coincidence between the cells with associations marked as significant (with their values in red font) and the majority concentration of observations in the yellow cells (from 5 cases) to red (14 cases) —the cells with different shades of green range from 0 to 4 cases and precisely this, the relative lack of observations, is what we wanted to highlight with the green tones. These 17 cells (12% of the total) that contain 5 or more cases (keywords) concentrate 56% (120) of the observations. This means that there is not a dispersion of the cases in many cells but in a few: those in which certain mechanisms of symbolic violence and certain groups of co-occurrences of keywords coincide. In summary, there is a clear similarity between the two keyword classification methods, which proves the complementarity between qualitative approaches based on thematic analysis of texts and quantitative approaches based on the analysis of keyword co-occurrences.

3.5. Symbolic violence scale in CFS/ME (shortened version with ChatGPT 3.5 Turbo)

	4. Strongly agree	3. Agree	2. Neither agree or disagree, not sure, indecisive, or indifferent	1. Disagree	0. Strongly disagree
1. The State does not recognize my CFS/ME, denying me rights such as sick leave, benefits, disability pensions and other aid.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. The State treats me like a number, with indifference, I am invisible, without respect or humanity, in a cruel and undignified way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. The lack of recognition of CFS/ME by the State affects my family daily, causing much suffering.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. The State makes you wait a long time for the disability impact assessment and resolves claims late to discourage you from applying for recognition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Despite going to court, the INSS and the judge have denied me recognition of CFS/ME disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. The Ministry of Social Action and Citizenship violates my rights when it does not recognize my disability due to CFS/ME, when the judicial system does not help me, and when Department of Health does not inform me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My direct environment does not understand that doctors say that I am sick and cannot work, but the ICAM gives me a medical discharge, ignoring the diagnoses.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. The medical assessment tribunals and ICAM doctors have mistreated, humiliated, and despised me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I cannot accept the limitations of CFS/ME, I feel helpless, and I do not think others can accept me like that either.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. The State should apologize to me for the abuse, mistreatment, insults, and humiliation that I have suffered from them since I became ill.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. As a CFS/ME patient, I feel helpless and abandoned by public healthcare system, without adequate medical care or specialists.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. My severe CFS/ME requires daily care from my family members, affecting their work, leisure, and well-being, but institutions do not help us.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. CFS/ME has left me without income, but the State does not help me financially despite my difficult situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I feel discriminated against due to lack of access to CFS/ME diagnosis and treatment units in my area.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I believe that the State does not support public research into CFS/ME in our country.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Sometimes, civil servants and professionals treat me superiorly, making me feel bad and unable to respond for fear of the consequences.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. The ICAM does not respect medical diagnoses, they discharged me without considering my medical reports and tests because they consider that I have a psychosomatic illness and nothing is wrong with me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. After many years, doctor visits, misunderstandings, and misdiagnoses, I finally received the diagnosis of CFS/ME.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. The ICAM forced me to return to work without respecting medical criteria for economic reasons, just because my leave was ending.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I use alternative therapies such as acupuncture, shiatsu, homeopathy, Bach flowers, Zen, and yoga to alleviate my suffering.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I constantly feel that people do not believe my illness, they think I am faking it to draw a pension. This, for example, has had employment consequences when it comes to being able to request sick leave from my company, among others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Very often I feel misunderstood by doctors, public administrations, society, family, and friends due to CFS/ME.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	4. Strongly agree	3. Agree	2. Neither agree or disagree, not sure, indecisive, or indifferent	1. Disagree	0. Strongly disagree
23. Very often I have to endure being told, from someone talking to my face or behind my back, that I am crazy, neurasthenic, hysterical, exaggerated, lazy. Sometimes I have been afraid to take sick leave for fear that they will think I am lazy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I feel constantly judged by my direct environment, who do not understand my illness and give me unsolicited advice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. CFS/ME has forced me to give up my profession, leisure activities, family life, and social contact, completely changing my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. CFS/ME has disrupted my life and the lives of my loved ones, who have had to adapt to its limitations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I try to follow normal rhythms of life, but my health limitations cause conflicts with friends, work, and daily activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. My life has changed drastically due to the disease. I have lost my job, my daily activities, and my social life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I feel like I am death in life, this disease has left me without hope or illusions, plunged into a well of uncertainty, despair and absolute discouragement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. My couple gets fed up with me because of CFS/ME. He/She has divorced or separated from me, has thought about it, or is about to do so.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. It is difficult for me to accept my illness and change my lifestyle and I resist because it is like stopping feeling useful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. CFS/ME affects me physically and emotionally, but it will not defeat me. My will is stronger than the disease.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I pretend to be fine; I smile on the outside and cry secretly so as not to alienate those around me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I avoid seeking compassion or pity, I do not want to be seen as a victim of my illness, I prefer not to feel sorry for myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I have learned to value everyday life, patience, and serenity. The disease has taught me to be happy with small things that life puts in front of you.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. I prefer to keep the fact that I suffer from CFS/ME private, I do not want others to know about my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. I sometimes hide my CFS/ME patient identity for fear of the repercussions on my life, especially at work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I feel invisible, as if my illness did not exist for anyone, imperceptible in the eyes of society.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Because I do not look disabled, people think I am fine and do not have any illnesses. This makes me feel like what happens to me does not matter to anyone.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. If there were objective medical tests for CFS/ME, the illness would be less invisible and patients would be more well-regarded.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. I hardly leave the house, nor do I have contact or talk to anyone. I am very alone.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. At home I feel protected and I avoid going out due to the discomfort of interacting with people who do not understand my situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. I would really like to have someone with whom I could talk and communicate, a person who would be willing to listen to me sincerely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. For a long time, I thought I was lazy, unable to organize myself, blaming myself for my chronic illness and believing that my illness was me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. I have been recommended to change my way of thinking and approaching life to cure CFS/ME with psychological therapy, and I am following it or have followed it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. I have been prescribed anxiety and depression pills to relieve CFS/ME, following medical advice, and I am taking or have taken medication.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Conclusion

This entire chain of analyses and cross-testing certifies that the process of developing version 0 or preliminary of the scale has all the guarantees. But perhaps the most important thing is that its final result ensures that the question statements appeal to the daily life of the person surveyed so that he/she can feel identified with the aspects that appear in the statement. It is precisely this requirement of ensuring that respondents feel identified with the question statements that explains why keyword co-occurrence analysis and multidimensional Mahalanobis-Fisher-Wilks tests were used to isolate keywords and associate them with each one of the items that should be part of the scale: precisely to generate this identification by using in these statements some keywords that other patients had previously used in the materials analysed. In turn, the writing of the statements is closely based on the review of the qualitative analyses, and when it has been considered pertinent, more or less literal examples extracted from these researches have been incorporated. These aspects are unavoidable when it comes to obtaining the statements of questions in the form of indicators of facts with which the respondents must feel identified and reflected as essential requirements to obtain answers that are as representative as possible of the social circumstances that have occurred to them and that surround CFS/ME. And this is how I humbly consider that the epistemological, theoretical, and methodological principles that I believe any questionnaire worthy of the name must comply with have been satisfied.

References

- Agresti, A. (2007). *An Introduction to Categorical Data Analysis* (2nd ed.). Wiley.
- Bartoll-Roca, X., Pérez, C., & Artazcoz, L. (2021). *Manual metodològic de l'Enquesta de Salut de Barcelona 2021*. Agència de Salut Pública de Barcelona. <https://www.aspb.cat/wp-content/uploads/2022/11/ASPB-Manual-Enquesta-Salut-2021.pdf>.
- Bartoll-Roca, X., Pérez, C., & Artazcoz, L. (2022). *Informe de resultats de l'Enquesta de Salut de Barcelona del 2021*. Agència de Salut Pública de Barcelona. https://www.aspb.cat/wp-content/uploads/2022/11/ASPB_Enquesta-Salut-Barcelona-2021.pdf.
- Bourdieu, P. (1972). Les stratégies matrimoniales dans le système de reproduction. *Annales. Économies, Sociétés, Civilisations*, 27, année(4-5), 1105-1127. https://www.persee.fr/doc/ahess_0395-2649_1972_num_27_4_422586.
- Bourdieu, P. (1987). What Makes a Social Class? On The Theoretical and Practical Existence Of Groups. *Berkeley Journal of Sociology*, 32, 1-17. <https://www.jstor.org/stable/41035356>.
- Bourdieu, P. (1990). *The Logic of Practice*. Stanford University Press.
- Bourdieu, P. (1999). *The Weight of the World: Social Suffering in Contemporary Society*. Stanford University Press.
- Bourdieu, P. (2000). *Pascalian Meditations*. Stanford University Press.
- Bourdieu, P. (2001a). *Langage et pouvoir symbolique*. Fayard/Seuil.
- Bourdieu, P. (2001b). *Masculine Domination*. Stanford University Press.
- Bourdieu, P. (2017). *Anthropologie économique: Cours au Collège de France (1992-1993)*. Raisons d'agir/Seuil.
- Bourdieu, P., & Passeron, J.-C. (1966a). *Introduction à la sociologie I: Sociologie et Sociologie spontanée* (Film). IPN. <https://www.xaviergimeno.net/sociology-tv/bourdieu-passeron-i>.
- Bourdieu, P., & Passeron, J.-C. (1966b). *Introduction à la sociologie II: Vigilance épistémologique et pratique sociologique* (Film). IPN. <https://www.xaviergimeno.net/sociology-tv/bourdieu-passeron-ii>.
- Bourdieu, P., Chamboredon, J.-C., & Passeron, J.-C. (1991). *The Craft of Sociology: Epistemological Preliminaries*. Walter de Gruyter. <https://doi.org/10.1515/9783110856460>.
- Gimeno Torrent, X. (2022). The circuit of symbolic violence in Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME) (I): A preliminary study. *Health Care for Women International*, 43(1-3), 5-41. <https://doi.org/10.1080/07399332.2021.1925900>.
- Goldthorpe, J. H., & Lockwood, D. (1963). Affluence and the British Class Structure. *The Sociological Review*, 11(2), 133-163. <https://doi.org/10.1111/j.1467-954X.1963.tb01230.x>.
- GULL AG. (2023). *ChatGPT Español*. <https://chatgpt.es>.

- Hope, A. C. A. (1968). A Simplified Monte Carlo Significance Test Procedure. *Journal of the Royal Statistical Society. Series B (Methodological)*, 30(3), 582-598. <https://doi.org/10.1111/j.2517-6161.1968.tb00759.x>.
- Howell, D. C. (2011). Chi-Square Test: Analysis of Contingency Tables. In M. Lovric (Ed.), *International Encyclopedia of Statistical Science* (pp. 250-252). Springer. https://doi.org/10.1007/978-3-642-04898-2_174.
- Jantke, R. L. (2011). *Development of the Chronic Fatigue Syndrome and Myalgic Encephalomyelitis Stigma (CFSMES) Scale* [MA dissertation, Roosevelt University]. <https://www.proquest.com/openview/a7b7934e1fdeee702d1d694f8d3a0e7f>.
- Lopéz Roldán, P., & Lozares Colina, C. (1999). *Anàlisi bivariable de dades estadístiques*. Universitat Autònoma de Barcelona.
- Lumivero. (2023). XLSTAT statistical and data analysis solution [Computer software]. Lumivero. <https://www.xlstat.com/en/>.
- Martín-Martín, A., Orduna-Malea, E., Thelwall, M., & Delgado López-Cózar, E. (2018). Google Scholar, Web of Science, and Scopus: a systematic comparison of citations in 252 subject categories. *Journal of Informetrics*, 12(4), 1160-1177. <https://doi.org/10.1016/j.joi.2018.09.002>.
- Martín-Martín, A., Thelwall, M., Orduna-Malea, E., & Delgado López-Cózar, E. (2021). Google Scholar, Microsoft Academic, Scopus, Dimensions, Web of Science, and OpenCitations' COCI: a multidisciplinary comparison of coverage via citations. *Scientometrics*, 126, 871-906. <https://doi.org/10.1007/s11192-020-03690-4>.
- Pecho Ricaldi, P. L. (2017). *Sexismo ambivalente, pensamientos patriarcales y violencia simbólica intra e inter género en Lima y Huancayo* [BA dissertation, Pontificia Universidad Católica del Perú]. <http://hdl.handle.net/20.500.12404/9129>.
- Shlaes, J. L., Jason, L. A., & Ferrari, J. R. (1999). The development of the Chronic Fatigue Syndrome Attitudes Test. A psychometric analysis. *Evaluation & the health professions*, 22(4), 442-465. <https://doi.org/10.1177/01632789922034400>.
- Terman, J. M., Awsumb, J. M., Cotler, J., & Jason, L. A. (2020). Confirmatory factor analysis of a myalgic encephalomyelitis and chronic fatigue syndrome stigma scale. *Journal of health psychology*, 25(13-14), 2352-2361. <https://doi.org/10.1177/1359105318796906>.



METHODOLOGICAL, STATISTICAL, AND RESULTS ANNEXES

FROM THE ARTICLE “FORMULATION OF A SYMBOLIC VIOLENCE SCALE
QUESTIONNAIRE: THE IMPORTANCE OF THE EPISTEMOLOGICAL,
THEORETICAL, AND METHODOLOGICAL CONSTRUCTION OF THE OBJECT
OF STUDY”

XAVIER GIMENO TORRENT
xavier.gimeno@xaviergimeno.net
<https://www.xaviergimeno.net>

Content

Annex 1: Qualitative thematic content analysis of the 77 letters to the editor	17
<i>Annex 1.1: Examples drawn from the letters of each mechanism of symbolic violence</i>	<i>17</i>
<i>Annex 1.2: Counting per themes-mechanisms and sub-themes-sub-mechanisms (items).....</i>	<i>20</i>
Annex 2: Keyword co-occurrence analysis with VOSviewer	21
<i>Annex 2.1: Table of identified keywords</i>	<i>21</i>
<i>Annex 2.2: Graphic representation of the network of 316 keywords</i>	<i>25</i>
Annex 3: Quantitative analyses to obtain keywords and validate qualitative analysis	25
<i>Annex 3.1: Mahalanobis-Fisher-Wilks multidimensional tests ' per item</i>	<i>25</i>
<i>Annex 3.2: Association measures between quantitative and qualitative keywords grouping .</i>	<i>29</i>
Annex 4: Version 0 or preliminary of the symbolic violence scale in CFS/ME.....	31
1. <i>Research presentation letter for participants.....</i>	<i>31</i>
<i>Version for individual participants</i>	<i>31</i>
<i>Version for collective participants</i>	<i>32</i>
2. <i>Tips and instructions for answering the survey.....</i>	<i>34</i>
3. <i>Demographic and health data</i>	<i>35</i>
4. <i>Symbolic violence scale in CFS/ME (original version non-shortened)</i>	<i>39</i>
<i>Acronyms and explanation</i>	<i>43</i>
5. <i>Black and white lists.....</i>	<i>44</i>
6. <i>Survey quality assessment</i>	<i>44</i>
7. <i>Duration of individual and group interviews of the second phase.....</i>	<i>45</i>
<i>Some explanatory notes about the survey</i>	<i>45</i>
References	47

Annex 1: Qualitative thematic content analysis of the 77 letters to the editor¹

Annex 1.1: Examples drawn from the letters of each mechanism of symbolic violence (13 themes and 46 sub-themes [items])

Non-recognition

[ITEM 1: Non-recognition of the sick and the disease:] “They deny me the condition of chronic condition disease [...].”

[ITEM 2: Non-recognition of patients as human beings:] “How sad to know that as people we do not count for much.”

[ITEM 3: Violation of the right to dignity of affected families:] “It is very painful what my daughter and my husband suffer [said by a woman CFS patient].”

[ITEM 4: Delay of recognition requests as a mechanism of resignation and non-recognition of CFS patients:] “The request for a first disability impact assessment, a function that depends on the Catalan Ministry of Social Affairs and Citizenship, takes two years to be attended. Everyone who has requested it, knows it. The request for a subsequent review of the disability impact assessment also takes two years to be attended. Everyone who has requested it knows it.”

[ITEM 5: Judicialization of disability recognition:] “At the time I was denied disability by the Spanish Social Security Administration, but after going to trial, a social court granted me absolute disability due to an accident at work. After two years, the Superior Court of Justice denied me disability.”

[ITEM 6: Violation of the rights of CFS patients:] “High Court of Justice of Catalonia ruled that fibromyalgia is a reason to obtain absolute disability, and these people ignore so that you despair and give up.”

[ITEM 7: *Double bind*:] “In October 2015 I applied for absolute disability and they sent me to the Catalan Institute of Medical Assessments (CIMA) for an assessment. CIMA’s doctor told me that my disability was totally justified. In February 2016, after delivering a lot of reports from different specialists, they notified me that they rejected my request. I do not understand how they can omit the diagnosis of so many doctors who agree that I cannot do any kind of common daily or work activity and that they ignore the 11 different medications that I have to take each day.”

[ITEM 8: Humiliations and systematic mistreatment of CFS patients by Public Administration as a deterrent strategy for the recognition of disabilities:] “His illness is not recognized by the Spanish Social Security Administration, so by pure process they decide to make his life more difficult [...]. They take away her joy. They discourage her. They take away her desire to fight. They kill her little by little. And nobody feels responsible. She wants to be happy, but her illusions are stolen. It seems incredible that our society, instead of helping CFS patients, could destroy the small steps that they are taking.”

[ITEM 9: Difficulty of the patient to accept himself and his limitations; internalization of the denial of recognition:] “It is very hard to accept weakness; it has cost me 40 years. With psychological help I have done it and now I know that life can continue even if you have poor health, you can lean on all the good things you have and continue to live and be useful and capable of something.”

[ITEM 10: Repeated social abuse to patients:] “Because abuse is being told that you need a good fucking when what really happens is that you are extremely sick.”

Institutionalized un-care

[ITEM 11: Medical un-care:] “I do not have doctors to take care of me.”

¹ This Annex 1 is a slightly modified version of the Annex originally published in Gimeno Torrent (2022).

[ITEM 12: Socio-sanitary un-care:] “The situation has also affected his family. Her husband lost his job because he had to constantly take care of Sílvia and her two children, who have grown up living with the mother’s illness. ‘They do not deserve this burden without anyone helping us.’”

[ITEM 13: Social services un-care:] “institutions do not help them.”

[ITEM 14: Discrimination resulting in un-care:] “There is the ironic paradox that a small bonus has been applied to me in a spa because I am a member of a club. And, nevertheless, in my condition of fibromyalgia and severe chronic fatigue syndrome patient, recognized by the Spanish Social Security Administration, no right protects us.”

[ITEM 15: Scientific un-care:] “What we really need to cure ourselves is research.”

Condescension

[ITEM 16: Condescension:] “On the other hand, before the explanation I gave to the psychologist about how helpless we were the affected by these diseases on the part of public healthcare system, she told me that it is due to the lack of consensus around these diseases [...]”

Authorized imposition of illegitimate verdicts

[ITEM 17: Authorized imposition of illegitimate verdicts:] “CIMA’s doctor has made her stand on tiptoe and move her arms up and down, and just with this he has told her to return to duty overlooking all medical reports.”

[ITEM 18: Assignment of successive verdicts over time until correctly diagnosed:] “It took me six years to find a doctor who could explain what I had.”

[ITEM 19: Arbitrary determination of a maximum period of incapacity for work for a disease that is chronic and without treatment:] “They say I am able to work only because the sick leave is finishing.”

[ITEM 20: Doxical imposition:] “What I see every day is how many people try all kinds of things, like her, looking to lighten their suffering.”

Delegitimization

[ITEM 21: Decredibilization:] “What do they think, that I invent my illness? That doctors invent my medical history?”

[ITEM 22: Incomprehension:] “At the beginning, everyone understands me, but this changes as outbreaks arise because of the increased effort [in the workplace]. Then nobody understands me.”

[ITEM 22: Incomprehension:] “If society in general and our families in particular come to know CFS, at least we will have the comfort of their understanding.”

[ITEM 23: Delegitimization:] “and then in addition to all that, they call them neurasthenic, hysterical, exaggerated...”

[ITEM 24: Generalized questioning of CFS patient:] “As a CFS affected, I am very angry and fed up with having to continually explain myself.”

Disintegration

[ITEM 25: Consequences over identity of labor disintegration:] “I have had to sacrifice my profession, my life.”

[ITEM 26: Necessary re-adaptation of CFS patient and his social circle to the social rhythms and customs required by the disease:] “We can control many things, but not everything. [...] We have made all the changes that were in our hands.”

[ITEM 27: Conflicts between customs and labor/social rhythms of sick and non-sick:] “Do not be angry if yesterday I told you that today we would see us, but today I cannot stand it anymore and I cancel the appointment.”

[ITEM 28: Social, labor-productive and labor-reproductive disintegration:] “Being healed means being able to eat what you want without feeling bad, going to work and fulfilling your responsibilities without bursting, running the household, taking care of your children and having time and strength to enjoy leisure time, among many other things.”

[ITEM 29: Lack of expectations:] “There is no self-projection into the future.”

[ITEM 30: Divorces:] “My husband got fed up with me.”

[ITEM 31: Resistance to social and labor disintegration and difficulty of adaptation to it:] “I resisted recognizing that I had to change my life, because for me work was not a sacrifice. I had a good time. I enjoyed.”

[ITEM 31: Resistance to social and labor disintegration and difficulty of adaptation to it:] “I, who went to [X] every day and who was in contact with so many people... That part has been very hard, I am still adapting.”

Imposition of discourse

[ITEM 32: Imposition of heroic discourse:] “but you have not chosen well at all, because in another body you could have been more harmful if possible, on a psychological level, so you have failed in that purpose. Since we have to live together, I am getting to know you thoroughly, studying you, so as not to provoke your outbursts of unbridled violence that hurt my physique so much. Although, remember, you only have my body.”

[ITEM 33: Imposition of normality discourse:] “I spend the week pretending I’m fine and crying secretly [...].”

[ITEM 34: Imposition of non-victimist/non-self-pitying discourse:] “His prospects are grim, but he resists self-pity.”

Euphemization

[ITEM 35: Making a virtue of necessity:] “But I would not like to convey a pessimistic view of my situation. [...] That this has made me learn. That here I have realized that you have to be happy with the little things that life puts you ahead.”

Silencing

[ITEM 36: Silencing:] “I have never wanted to make public something that I considered too personal.”

ITEM 37: Silencing behaviors: Some patients send anonymous or signed letters with their acronyms. This is assimilable to the silencing, since the person hidden that suffers from CFS.

Invisibilization

[ITEM 38: Invisibilization:] “It is imperceptible in the eyes of society.”

[ITEM 39: Without any sign capable of operating as negative symbolic capital:] “These people do not look bad, they can walk, they do not have the signs that usually define a disabled person.”

[ITEM 40: Absence of biological markers:] “It is lacking of any physiological marker could identify it.”

Isolation

[ITEM 41: Isolation as a product of disintegration:] “Well, think that they are people who live... Some live in the most absolute loneliness.”

[ITEM 42: Isolation as a protective mechanism:] “I just leave home; I feel protected there.”

Uncommunication

[ITEM 43: Uncommunication:] “[...] that they feel lonely [...]”

Self-blaming

[ITEM 44: Self-blaming:] “For years I have come to think that I had lost my mind or that I was a lazy person who did not know how to run the household and take care of my son.”

[ITEM 45: Psychologization of symbolic violence with the effect of self-blaming:] “No miracle: I have worked hard to learn about what is happening to me, to understand it..., and to change myself, to correct my old psychic structure, which was harmful to me.”

[ITEM 46: Medicalization of symbolic violence:] “Did you get medication to cope with depression? Yes.”

Annex 1.2: Counting per themes-mechanisms (13) and sub-themes-sub-mechanisms (items) (46)

Counting per themes and subthemes
Non-recognition (169 occurrences; 27%)
ITEM 1: Non-recognition of the sick and the disease (54; 32%)
ITEM 2: Non-recognition of patients as human beings (31; 18%)
ITEM 3: Violation of the right to dignity of affected families (4; 2%)
ITEM 4: Delay of recognition requests as a mechanism of resignation and non-recognition of CFS patients (5; 3%)
ITEM 5: Judicialization of disability recognition (2; 1%)
ITEM 6: Violation of the rights of CFS patients (25; 15%)
ITEM 7: <i>Double bind</i> (3; 2%)
ITEM 8: Humiliations and systematic mistreatment of CFS patients by Public Administration as a deterrent strategy for the recognition of disabilities (34; 20%)
ITEM 9: Difficulty of the patient to accept himself and his limitations; internalization of the denial of recognition (5; 3%)
ITEM 10: Repeated social abuse to patients (6; 4%)
Institutionalized un-care (99 occurrences; 16%)
ITEM 11: Medical un-care (67; 68%)
ITEM 12: Socio-sanitary un-care (1; 1%)
ITEM 13: Social services un-care (3; 3%)
ITEM 14: Discrimination resulting in un-care (5; 5%)
ITEM 15: Scientific un-care (23; 23%)
ITEM 16: Condescension (1 occurrence; 0%)
Authorized imposition of illegitimate verdicts (97 occurrences; 15%)
ITEM 17: Authorized imposition of illegitimate verdicts (43; 44%)
ITEM 18: Assignment of successive verdicts over time until correctly diagnosed (15; 16%)
ITEM 19: Arbitrary determination of a maximum period of incapacity for work for a disease that is chronic and without treatment (9; 9%)
ITEM 20: Doxical imposition (30; 31%)
Delegitimation (68 occurrences; 11%)
ITEM 21: Decredibilization (26; 38%)
ITEM 22: Incomprehension (20; 30%)
ITEM 23: Delegitimation (13; 19%)
ITEM 24: Generalized questioning of CFS patient (9; 13%)
Disintegration (103 occurrences; 16%)
ITEM 25: Consequences over identity of labor disintegration (2; 2%)
ITEM 26: Necessary re-adaptation of CFS patient and his social circle to the social rhythms and customs required by the disease (8; 8%)
ITEM 27: Conflicts between customs and labor/social rhythms of sick and non-sick (8; 8%)
ITEM 28: Social, labor-productive and labor-reproductive disintegration (52; 50%)
ITEM 29: Lack of expectations (16; 15%)
ITEM 30: Divorces (3; 3%)
ITEM 31: Resistance to social and labor disintegration and difficulty of adaptation to it (14; 14%)
Imposition of discourse (8 occurrences; 1%)
ITEM 32: Imposition of heroic discourse (5; 62%)
ITEM 33: Imposition of normality discourse (2; 25%)
ITEM 34: Imposition of non-victimist/non-self-pitying discourse (1; 13%)
Euphemization (24 occurrences; 4%)
ITEM 35: Making a virtue of necessity (24; 100%)
Silencing (8 occurrences; 1%)
ITEM 36: Silencing (4; 50%)
ITEM 37: Silencing behaviors (4; 50%)
Invisibilization (9 occurrences; 2%)
ITEM 38: Invisibilization (5; 55%)
ITEM 39: Without any sign capable of operating as negative symbolic capital (2; 22%)
ITEM 40: Absence of biological markers (2; 22%)
Isolation (17 occurrences; 3%)
ITEM 41: Isolation as a product of disintegration (15; 88%)
ITEM 42: Isolation as a protective mechanism (2; 12%)
ITEM 43: Uncommunication (2 occurrences; 0%)
Self-blaming (24 occurrences; 4%)
ITEM 44: Self-blaming (17; 71%)
ITEM 45: Psychologization of symbolic violence with the effect of self-blaming (6; 25%)
ITEM 46: Medicalization of symbolic violence (1; 4%)

Annex 2: Keyword co-occurrence analysis with VOSviewer

Annex 2.1: Table of identified keywords, co-occurrence network (group), frequency of occurrence, and relevance score

Keyword	Group	Frequency	Relevance score
abandonment	8	2	0.8923
absolute disability	10	4	0.5231
abuse	9	4	1.1685
access	10	3	1.1962
account (take into account)	13	2	0.4109
action (also Ministry of Social Action and Citizenship [Min. S. A. Citize.])	4	4	2.7952
activity	3	2	0.6094
acupuncture	4	3	5.7084
addition (in addition)	5	10	0.2409
adequate health care	8	2	2.2797
affair	1	2	1.7866
affectation	2	2	0.6422
age	3	2	0.4279
alternative therapy	4	2	3.45
anguish	5	4	0.9687
anyone	1	5	0.8716
anything	6	4	0.9557
area	2	4	0.9664
arm	6	3	0.9013
assessment	8	5	0.398
assistance	8	3	0.5221
association (patients association)	3	3	1.1785
attention (healthcare and socio-sanitary care [healthc. soc.-san. care])	2	4	1.0653
attitude	6	3	0.3491
auditorium (L'Auditori)	3	2	0.7259
awareness	9	4	0.8466
bach flower	4	2	3.5686
barcelona	3	6	0.489
bed	1	5	1.0853
beginning	1	2	0.9541
biomechanical test	11	2	0.5731
body	7	14	0.9038
budget cut	2	3	0.7527
cad	12	3	0.5217
cancer	5	3	0.8274
cap	2	2	0.7021
care	10	5	0.7847
case	7	11	0.2116
catalan association (Catalan CFS Association)	4	2	1.6492
catalan institute (Catalan Institute of Medical Assessments (Catalan acronyms are ICAM))	12	2	2.2246
catalonia	2	7	0.5069
cause	6	3	0.4204
center (disability impact assessment center, private healthcare center, mental health center)	2	6	0.2002
certain disease (certain diseases are ignored and the sick are discriminated against, and they are not respected)	2	2	2.0579
cfs	3	19	0.4439
cfs me (CFS/ME)	2	3	1.3091
cfs sufferer	4	3	1.0666
change	1	5	1.4301
charity concert	3	2	1.5314
child	1	4	1.2272
chronic fatigue	6	13	0.2344
chronic fatigue syndrome	2	31	0.1575
chronic fatigue syndrome myalgic encephalitis	2	2	1.3547
cinema	1	2	2.3319
citizenship (Ministry of Social Action and Citizenship [Min. S. A. Citize.])	8	3	0.53
claim	3	2	2.6391
company	6	5	0.6344
complex disease	5	2	0.4374
computer	1	3	1.6397
concert	3	5	0.69
condition	7	3	0.7383
consequence	13	4	0.3623
contact	1	3	1.0405
contempt	12	3	2.3866
control	1	2	1.2509
cost (economic cost, social cost in suffering and humiliation for the sick, personal cost in difficulty in assuming the limitations imposed by the disease)	3	5	0.7632
country	12	6	0.4105
course (of course)	3	2	0.594
court (social court, go to court)	5	4	0.5295
crime	4	2	2.4665
crisis	11	2	0.666
cure	7	3	0.817
daily life	5	2	0.9998
daughter	1	2	1.3775
day	1	35	0.1721
degree (degree of disability, degree of severity)	8	8	0.2583
department (Department of Health, Department of Social Action and Citizenship [the same as Ministry of Social Action and Citizenship])	8	3	0.5535
depression (postpartum depression, recurrent depression disorder)	13	8	0.4016
desire	7	2	1.2797
diagnosis	10	12	0.2737
dignity	8	3	1.0515
disability	5	19	0.2409
disability pension	8	3	0.889
disability recognition	12	2	1.5907
disease	8	85	0.1055
doctor	11	36	0.1332
door	1	4	1.1968
dr eaton	7	7	1.0481
effect (also psychological effects)	6	4	0.5299
effort	7	9	0.4282
emotion	7	4	1.2624

Keyword	Group	Frequency	Relevance score
end	4	6	0.4537
environment	9	2	1.3953
euro	10	5	1.0576
everyone	1	5	0.679
everything	1	11	1.3377
evidence	10	6	0.308
example (for example)	1	3	0.5843
experience	4	4	0.4702
explanation	4	2	1.2974
expression (also expressions of affection)	7	2	1.0067
extension	6	2	0.8926
eye (also in the eyes of)	9	2	1.3121
face	11	4	0.6897
fact	8	6	0.3973
family	1	6	1.2261
favor (in favor of)	3	2	1.554
fibber	NN	3	0
fibromyalgia	13	17	0.1778
fibromyalgia patient	1	2	1.0875
fibromyalgium	5	7	0.3779
food	5	4	1.2563
force	5	4	0.6756
forgiveness	2	2	2.1716
foundation (foundation for CFS patients, Jordi Savall Foundation)	3	4	0.5595
front (in front of people, life puts in front of you)	11	2	0.529
fund	6	3	0.8389
future (also projection of the future)	NN	3	0
garden	1	2	4.1251
generalitat	8	2	0.4866
government	2	4	1.9201
great day (Serrat charity concert, and his song "Today can be a great day")	3	2	1.5338
group (collective of CFS sufferers, group of people aware of CFS)	12	5	0.5202
half (after x and a half years [after x a half years])	7	4	0.9444
hand (on the other hand, in our hands, in his hands)	4	6	1.1226
head (also hospital unit head, I have in my head)	6	2	1.2018
health	8	21	0.4748
health authority (also health Administration)	12	4	0.643
health care	9	2	0.9362
health professional	3	3	0.7875
help	9	5	0.73
history (medical history)	1	2	0.5506
home	1	5	0.9705
homeopathy	4	3	3.5686
hope	7	2	1.232
hospital	2	8	0.5455
hospital clinic (Hospital Clínic is the name of a public hospital)	2	5	0.4021
hour	1	5	1.1211
house (also council house)	1	8	0.6293
household (do the household chore)	1	2	1.4099
humiliation	4	2	1.287
husband	1	4	1.6501
hypothalamus	7	2	1.4623
icam (former ICAM, current SGAM; Catalan acronyms)	12	15	0.3775
icam doctor	6	2	0.7363
illness	9	30	0.4473
immunological disease	2	2	1.468
important thing	8	2	0.889
improvement	7	3	1.2412
incomprehension	5	4	1.1181
indifference	3	3	0.8089
information	9	7	0.635
inss	5	3	0.5504
institution (political and social estates, institutions)	9	5	0.9063
international classification (of diseases)	6	2	0.274
joan manuel serrat (a renowned Spanish singer)	3	2	1.329
job	10	12	0.7017
jose maria	2	4	0.5115
judge	10	3	1.0537
justice	5	3	0.7451
justification	10	2	0.4387
kind	13	2	0.8423
knowledge	9	3	1.0393
laboratory	2	3	1.8552
lack (lack of recognition, healthcare, training and knowledge, specialists, money, scientific rigor, respect)	2	9	0.3824
lady	12	2	2.1878
larger study	3	2	1.4958
last year	2	2	1.6329
leave (sick leave, leave the house, leave behind, leave it)	13	4	0.3783
letter (also formal letter request)	6	7	0.3234
life	1	35	0.2062
limitation	1	3	1.2754
london	7	3	0.9876
loneliness	NN	2	0
lot	13	10	0.2891
manuela	1	2	1.3182
mayor (also mayor's office)	1	3	1.1274
medical assessments (medical assessment tribunal, ICAM [Catalan Institute of Medical Assessments])	12	2	2.2246
medical court (or medical assessment tribunal)	12	2	2.6147
medical discharge	13	2	0.8457
medical history	11	2	0.9247
medical report	12	7	0.359
medical test	3	2	1.3873
medication	10	4	0.5705
medicine	4	6	1.9745
member	5	2	0.6825
mind	9	6	0.8777
mine	1	2	1.4096
minister	11	2	2.0037
ministry (Ministry or Department of Health, Ministry or Department of Social Action and Citizenship [Min. S. A. Citize.])	8	6	0.451
minute (in five minutes they consider you fit to work, what counts are 10 minutes with the medical examiner)	10	2	0.6829

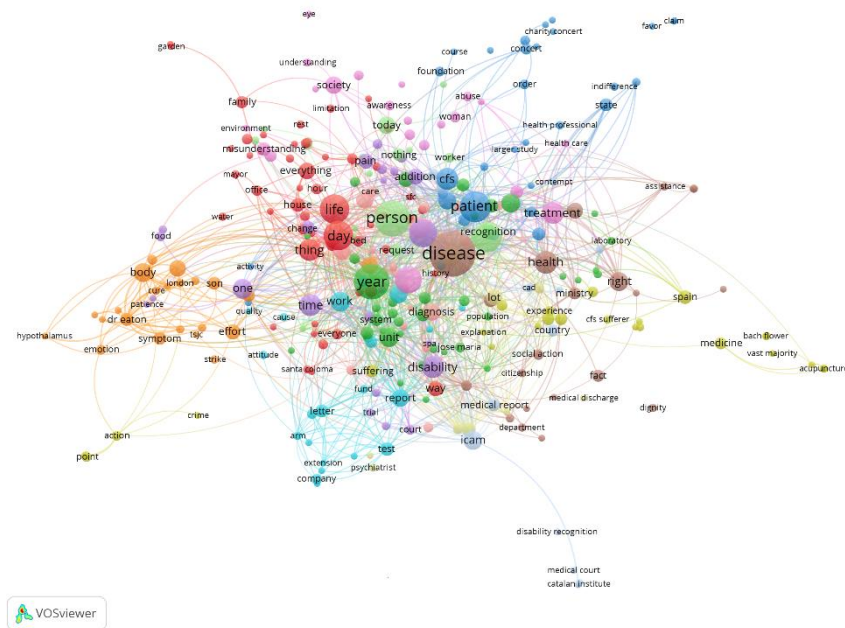
Keyword	Group	Frequency	Relevance score
misunderstanding	9	8	0.3695
moment (at the moment)	1	2	1.0154
money	10	5	0.6895
month	1	8	0.3404
morning	1	3	1.776
mother	1	2	1.4818
multiple chemical sensitivity	3	7	0.2951
myalgic encephalomyelitis	4	5	0.7133
myalgic encephalopathy	12	2	0.4959
name (of CFS, the word appears negatively connoted: ridiculous, simple, incredible, unfortunate, ambiguous name)	5	5	0.4664
need	7	3	0.7202
nonsense	10	2	0.7651
normal life	2	2	1.1807
norway	3	2	1.2339
norwegian government	2	2	2.0576
nothing	11	7	1.0262
number (always with negative connotations: patients who are a "number" or increasing)	6	5	0.3538
october	10	3	0.418
office (doctor's office, public officer, or simply "office")	1	5	0.5574
one	5	16	0.4414
order (in order to)	3	4	1.1585
pain (in most cases they talk about added pain [symbolic violence] to the pain caused by CFS)	5	9	0.7535
part	3	12	0.4992
path	3	4	1.0663
patience	5	2	1.3959
patient	3	39	0.1994
pension	8	2	0.9994
pensioner	11	2	0.5564
percentage	2	3	1.521
person	11	53	0.077
phone	1	3	0.9365
place	3	3	0.8597
plan	3	5	0.4676
plant ([flower] plant)	1	2	1.4367
point (point, point out, point at me)	4	4	4.8221
politic (politics)	4	2	1.8818
politician	2	2	1.5266
population	2	3	1.8598
private healthcare (also private healthcare clinics)	10	2	1.5766
problem (mental, economic, work, financial, credibility, health, problem with doctors)	12	8	0.3962
profession	4	3	1.8164
professional	9	2	0.9269
professionalism	11	2	0.7853
psychiatrist	13	3	0.895
psychologist	2	5	0.5335
public administration	10	18	0.2257
public health (public healthcare system)	4	5	0.7197
public social security system	4	2	2.0072
quality (quality care, quality of life)	6	2	0.5768
question (also to question, it is no longer a question of, a question of)	6	6	0.4107
reality (they are denied their diagnostic reality, the most perverse side of this reality)	10	3	0.3573
reason	7	6	0.4313
recognition	2	9	0.4215
rein (take the reins [of my life], give up the reins [of the city council])	1	2	1.1873
relation (also in relation to)	12	3	0.6255
report	6	12	0.3379
request	11	7	0.482
research	2	14	0.4592
resolution (resolution [of the claim])	3	2	2.6391
resource (economic and assistance, financial, community resource)	2	4	0.4677
respect	1	4	0.4522
responsibility	2	3	1.2205
rest	1	3	1.6525
rheumatologist	2	3	0.7274
right	8	15	0.5391
role	7	2	0.986
santa coloma	1	3	1.3394
scale	3	4	0.6036
school	1	2	0.575
second visit	2	2	1.3544
secondary symptom (secondary symptom [of stress, of various physical and psychological effects])	6	2	0.4881
section	9	2	0.8447
sentence (judicial sentence, categorical and authoritative affirmation)	10	2	0.8203
serrat (Joan Manuel Serrat, a renowned Spanish singer)	3	2	1.2307
sfc (CFS, Spanish acronyms)	1	2	1.0249
shame	1	3	0.6276
shiatsu	4	2	5.7084
sick leave	9	3	2.4347
sick person	8	10	0.4234
sign	2	2	0.9906
situation	10	12	0.2536
social action (Ministry of Social Action and Citizenship [Min. S. A. Citize.])	8	5	0.3847
society (usually associated with terms such as raising awareness, misunderstanding, lack of support and visibility, lack of knowledge of CFS, disintegration of patients)	9	12	0.7224
sofa	1	2	2.2028
someone (also "a CFS patient")	11	3	0.4442
something	7	11	0.5886
son	7	7	0.4939
spa	5	2	0.5796
spain	4	8	0.7525
specialist	2	7	0.2545
spring	1	2	4.4595
state (State, welfare State, to affirm, health condition)	3	7	0.6366
strength	1	6	0.9508
strike (also hunger strike)	7	3	0.3382
stroke (a series of rights that they are now erasing at a stroke, forgetting all the reports with a stroke of the pen)	6	2	1.0965
sufferer	5	3	0.709
suffering	4	7	0.7844
sunset	1	2	1.3923
symptom (also wide range of symptoms)	7	7	0.8718
syndrome	2	7	0.4936

Keyword	Group	Frequency	Relevance score
system (it always refers to the State or the health Administration, it always has negative connotations)	2	6	0.359
telethon	9	4	1.0624
test (diagnostic or medical test)	6	8	0.6613
thing	1	20	0.3758
time (second time, at the time, one more time, it was high time, this time, it is time for, until the day it is time, each time, every time, they have a terrible time, I was having a good time, at the time, at times)	5	19	0.2124
today	11	12	0.5492
treatment (medical treatment, also treatment, always with negative connotations: "vexatious treatment")	9	20	0.4446
trial	5	3	0.9462
tsjc (TSJC, Tribunal Superior de Justicia de Cataluña, Superior Court of Justice of Catalonia)	7	2	0.5207
type	10	3	0.4114
undersecretary	11	2	2.4183
understanding	9	3	1.5094
unit (diagnosis and treatment unit)	2	14	0.4689
vast majority	4	2	0.9305
view (also point of view)	4	3	4.8755
walk	1	2	2.1695
water	1	3	0.6729
way (by judicial way/means, by the way, look the other way, the way we are, along the way, way of life, the way, way)	1	9	0.5651
week	2	4	1.3428
wife	6	2	0.4753
woman	9	5	1.3901
work	6	16	0.2148
work activity	8	3	0.4657
worker	11	4	0.5042
world	1	4	1.3065
world health organization	8	2	0.3935
writing	9	2	1.502
year	2	50	0.1442

To obtain this list of keywords, a database was created with the 623 fragments coded by themes and subthemes as a result of the previous qualitative thematic content analysis. Each of these fragments was duly identified individually and according to their classification per themes (13 mechanisms) and subthemes (46 items). Subsequently, each of the 623 fragments had to be translated into English since VOSviewer's co-occurrence analysis function is based on a natural language processing algorithm that is only available for texts in English and the original language of the texts was Spanish.

The analysis of co-occurrences has been based on the full counting instead of the fractional counting method. For the purposes of subsequent Mahalanobis-Fisher-Wilks analyses this would seem to be the best option, since this would allow a calculation of the medium relevance score that would be determined not only by the relevance score of each keyword but also by the number of times that the same keyword appears, which is precisely what favors the full counting method, in which the representativeness of a counting unit is weighted by its number of appearances (Perianes-Rodríguez et al., 2017; Van Eck & Waltman, 2023:33-35), something that would seem very relevant when it comes to calculating averages, at least in this case. In contrast, the fractional counting method would not give any weight to the frequency of appearance of keywords, because this is precisely its objective: that the number of appearances does not count. This may be essential in certain situations, but not in this case, where rather the opposite is required. Thus, this analysis was based on the full counting of the 319 words in the database of 623 text fragments that appeared 2 or more times. Words classified as "NN" (No Network) were not part of the network; they were the 3 keywords that did not have any link with any of the others, which makes the total of 316 words connected within this network of co-occurrences.

Annex 2.2: Graphic representation of the network of 316 keywords connected to each other per co-occurrence group (13 groups)



Annex 3: Quantitative analyses to obtain the most relevant keywords per item and to validate the previous qualitative thematic content analysis

Annex 3.1: Multidimensional Mahalanobis-Fisher (local) and Wilks' lambda (global) tests – table of statistically significant associations between keywords and items ordered by mechanism, item and medium relevance score per item (from highest to lowest)

Mechanism	Item (description)	Group	Keyword	Medium relevance	
Non-recognition	Item 1 (Non-recognition of the sick and the disease)	8	disease	0.043	
	Item 2 (Non-recognition of patients as human beings)	8	dignity	0.102	
		3	indifference	0.078	
		7	hunger strike	0.033	
		10	reality	0.023	
	Item 3 (Violation of the right to dignity of affected families)	4	point	1.206	
		1	husband	0.413	
		1	daughter	0.344	
		7	son	0.247	
	Item 4 (Delay of recognition requests as a mechanism of resignation and non-recognition of CFS patients)	3	claim	0.528	
		3	resolution	0.528	
		3	in favor of	0.311	
		1	everyone	0.272	
		11	request	0.193	
		7	after x a half years	0.189	
		3	place	0.172	
		8	assessment	0.159	
		3	State	0.127	
		2	year	0.115	
		8	Min. S. A. Citize.	0.106	
		7	TSJC	0.104	
		8	ministry	0.09	
		8	Min. S. A. Citize.	0.077	
		Item 5 (Judicialization of disability recognition)	10	job	0.702
			5	go to court	0.530
	10		euro	0.529	
	10		judge	0.527	
	10		absolute disability	0.523	
	5		trial	0.473	
	5		justice	0.373	
	5		INSS	0.275	
	5		disability	0.241	
	5		time	0.106	
	Item 6 (Violation of the rights of CFS patients)	4	Min. S. A. Citize.	0.224	
		8	right	0.151	
		8	health	0.133	
		9	information	0.102	
		4	profession	0.073	
		5	justice	0.06	
	Item 7 (Double bind)	13	medical discharge	0.287	

Mechanism	Item (description)	Group	Keyword	Medium relevance
Non-recognition	<i>Item 7 (Double bind)</i>	12	ICAM	0.252
		6	ICAM doctor	0.245
		10	medication	0.19
		10	absolute disability	0.174
		2	specialist	0.17
		11	request	0.161
		8	work activity	0.155
		10	october	0.139
		10	type	0.137
		8	assessment	0.133
		6	report	0.113
		13	lot	0.096
		10	diagnosis	0.091
		11	doctor	0.089
		12	contempt	0.211
	<i>Item 8 (Humiliations and systematic mistreatment of CFS patients by Public Administration as a deterrent strategy for the recognition of disabilities)</i>	4	humiliation	0.076
		9	abuse	0.069
		1	limitation	0.51
	<i>Item 9 (Difficulty of the patient to accept himself and his limitations; internalization of the denial of recognition)</i>	1	rest	0.331
		1	door	0.239
		1	thing	0.15
		9	help	0.146
		1	water	0.135
	<i>Item 10 (Repeated social abuse to patients)</i>	9	abuse	0.39
		2	forgiveness	0.362
		2	government	0.32
		2	population	0.31
		2	percentage	0.254
		9	woman	0.232
		2	week	0.224
		4	public health	0.054
		9	institutions	0.302
		9	help	0.243
Institutionalized un-care	<i>Item 11 (Medical un-care)</i>	2	area	0.58
	<i>Item 13 (Social services un-care)</i>	2	treatment unit	0.375
		5	spa	0.232
	<i>Item 14 (Discrimination resulting in un-care)</i>	2	healthc. soc.-san. care	0.213
		2	Hospital Clinic	0.161
		3	patient	0.16
		3	assume the cost of	0.153
		5	fibromyalgia	0.151
		7	in my condition of	0.148
		2	rheumatologist	0.145
		5	member	0.137
		5	INSS	0.11
		2	jose maria	0.102
		8	generalitat	0.097
		7	reason	0.086
		6	cause	0.084
		6	number of patients	0.071
		2	laboratory	0.242
		2	research	0.24
		3	larger study	0.13
		3	medical test	0.121
		3	in order to	0.101
	<i>Item 15 (Scientific un-care)</i>	6	fund	0.073
		10	medication	0.05
		12	ICAM	0.079
		6	report	0.071
		5	disability	0.067
Authorized imposition of illegitimate verdicts	<i>Item 17 (Authorized imposition of illegitimate verdicts)</i>	1	CFS	0.048
		10	5 or 10 minutes	0.032
		10	evidence	0.029
		1	medical history	0.026
		7	symptom	0.116
		1	doctor's office	0.074
		13	all kind	0.056
	<i>Item 18 (Assignment of successive verdicts over time until correctly diagnosed)</i>	10	diagnosis	0.055
		6	chronic fatigue	0.047
		2	specialist	0.034
		6	secondary symptom	0.033
		9	sick leave	0.271
		3	scale	0.134
	<i>Item 19 (Arbitrary determination of a maximum period of incapacity for work for a disease that is chronic and without treatment)</i>	1	day	0.115
		6	extension	0.099
		6	work	0.095
		7	cure	0.091
		3	activity	0.068
		3	age	0.048
		6	international classification	0.03
		4	acupuncture	0.571
		4	shiatsu	0.381
		4	homeopathy	0.357
	<i>Item 20 (Doxical imposition)</i>	4	medicine	0.263
		4	Bach flower	0.238
		4	alternative therapy	0.23
		7	Dr. Eaton	0.21
		5	food	0.168
		7	body	0.151
		7	London	0.066

Mechanism	Item (description)	Group	Keyword	Medium relevance
Authorized imposition of illegitimate verdicts	Item 20 (Doxical imposition)	7	cure	0.054
Delegitimization	Item 22 (Incomprehension)	9	understanding	0.226
		5	incomprehension	0.224
		9	society	0.144
		9	misunderstanding	0.129
	Item 23 (Delegitimization)	9	woman	0.214
		5	cancer	0.127
		9	writing	0.116
		5	name	0.108
		5	complex disease	0.034
		4	crime	0.274
		5	trial	0.105
	Item 24 (Generalized questioning of CFS patient)	11	someone	0.049
Disintegration	Item 25 (Consequences over identity of labor disintegration)	4	profession	1.816
	Item 26 (Necessary re-adaptation of CFS patient and his social circle to the social rhythms and customs required by the disease)	1	limitation	0.159
		1	thing	0.141
		1	at the moment	0.127
		5	daily life	0.125
		1	life	0.103
		6	quality of life	0.072
	Item 27 (Conflicts between customs and labor/social rhythms of sick and non-sick)	1	hour	0.28
		1	rest	0.207
		2	week	0.168
		2	normal life	0.148
		11	today	0.137
		7	effort	0.107
		5	force	0.084
		3	activity	0.076
	Item 28 (Social, labor-productive and labor-reproductive disintegration)	10	job	0.094
	Item 29 (Lack of expectations)	3	path	0.133
		1	life	0.077
	Item 30 (Divorces)	1	husband	0.55
		7	case	0.071
	Item 31 (Resistance to social and labor disintegration and difficulty of adaptation to it)	1	Santa Coloma	0.287
		1	Manuela	0.188
		1	mayor, mayor's office	0.161
		4	politics	0.134
		1	affair	0.128
		2	last year	0.117
		3	part	0.107
		6	I have in my head	0.086
		1	give up the reins	0.085
		1	at the moment	0.073
		7	expressions of affection	0.072
		6	letter	0.046
Imposition of discourse	Item 32 (Imposition of heroic discourse)	7	body	0.542
		1	control	0.25
		1	hour	0.224
		1	bed	0.217
		9	mind	0.176
	Item 33 (Imposition of normality discourse)	1	daughter	0.689
		2	week	0.671
		1	home	0.485
		11	face	0.345
		1	school	0.288
Euphemization	Item 35 (Making a virtue of necessity)	1	spring	0.372
		1	garden	0.344
		1	plant	0.12
		1	mine	0.117
		5	patience	0.116
		1	sunset	0.116
		1	mother	0.062
Silencing	Item 36 (Silencing)	6	arms	0.225
Invisibilization	Item 38 (Invisibilization)	3	age	0.107
		2	population	0.372
		2	percentage	0.304
		9	in the eyes of	0.262
	Item 39 (Without any sign capable of operating as negative symbolic capital)	6	number of patients	0.071
		2	sign	0.495
	Item 40 (Absence of biological markers)	11	person	0.077
		5	pain	0.377
Isolation	Item 41 (Isolation as a product of disintegration)	6	medical test	0.331
		1	anyone	0.116
		1	house	0.084
	Item 42 (Isolation as a protective mechanism)	3	[patients] association	0.589
		1	home	0.485
		4	end	0.227
Self-blaming	Item 44 (Self-blaming)	7	body	0.213
		1	world	0.154
		9	mind	0.103
		4	action	0.932
	Item 45 (Psychologization of symbolic violence with the effect of self-blaming)	7	emotion	0.421
		8	important thing	0.148
		6	cause	0.07
		6	attitude	0.058

These keywords are the keywords with significant differences. That is, the keywords in which the p-value of the Fisher distance (the Mahalanobis distance was also considered; the Fisher and Mahalanobis distances were the two measures of local association considered together with the Wilks' lambda statistic as a measure of global association) of the average or medium vectors of their relevance scores for the relevant item with respect to all other items or some of them was <0.0001 . This meant that each of the keywords indicated was associated in a statistically significant way with the item indicated because the medium scores of this keyword for the given item systematically differed from the medium scores of relevance that the same keyword presented for all or some of the other items; in short, there was an item for which the keyword acquired a special relevance that it did not have for other items. This coincides with what intuition tells us should happen: there are certain words that are associated with certain semantic fields, and this result is precisely what was pursued with the test carried out and explains its logic. In most cases the Wilks lambda test of global differences (an equivalent of the Chi-square χ^2 test for continuous variables) prevented the alternative hypothesis H_A from being discarded (at least one of the mean or average or medium vectors is different from the other), but in in other cases there were minimal local differences, notable but not detectable with the Wilks lambda global differences test which indicated that it was necessary to accept the null hypothesis H_0 (the medium vectors of the 41 classes are equal). In these cases, these keywords have also been included. On the other hand, as can be seen, only 41 items have been considered instead of the initial 46, because this test can only be applied in the case of groups with more than one observation, so that the 4 items that only contained a fragment of text could not be included in this test. These groups are as follows: Item 12, Item 16, Item 34, and Item 46. Item 37 does not appear either because this item refers to a mechanism of symbolic violence that does not have an explicit textual translation, but an implicit behavioral translation of some of the authors of the letters, who send them without identifying themselves, anonymously, silencing their identity so that it is not publicly known that they suffer from CFS/ME. Obviously, since this Item 37 does not include text, it could not form part of this analysis. In total, 319 different Mahalanobis-Fisher-Wilks analyses have been performed, that is, one for each keyword. Analyses that, due to their length, have been impossible to reproduce in their original format, and which are summarized in the attached table.

The analysis developed also shows that the criterion used to determine the number of keywords to retain (N) has nothing to do with one of the most widespread based on Donohue's formula (cited by Guo et al., 2017:7): $N = \frac{1}{2}(-1 \pm \sqrt{1 + 8I_1})$, where I_1 represents the number of keywords that appear only once. In the case of this analysis, the total number of keywords that form part of the co-occurrence matrix is 1,243, of which 924 appear only once. So, according to this formula, the total number of keywords to retain would be 42. But there are at least two reasons to reject this formula for the purposes of this particular research. First, having 46 groupings of items (41 operational), this number is neither relevant nor does it seem that it can have any kind of relevance because it would mean opting for less than one keyword per item, which makes no sense since, when constructing each of the scale's items, the information provided by a single keyword for this purpose is manifestly insufficient. In addition, in the second place, Donohue's criterion is not valid if what is intended is to stratify keywords according to classes with which they would be associated in a statistically significant way, as is the case: indeed, it seems that Donohue's formula does not takes into account a fundamental contextual aspect in order to select the keywords, such as their organization in semantic fields, something that the analysis developed, based on the thematic organization of the terms according to themes and subthemes (or their "social structure"), has taken into account. Donohue's formula is an artifact or a mathematical abstraction that pretends to be a kind of absolute and that operates within a social void that is completely inadmissible in this research. Therefore, the Mahalanobis-Fisher-Wilks strategy has been chosen to decide which are the most decisive keywords associated with each of the 41 items.

Annex 3.2: Measures of association (global, Chi-square [χ^2] from Monte Carlo simulations; and local, significances per cell with Fisher's exact test —marked in red if significant for $\alpha=0.05$) between the grouping of keywords based on co-occurrence analysis and the grouping of keywords based on the previous qualitative thematic content analysis – validation of the previous qualitative thematic content analysis

It might be thought that the analysis just carried out, with which a classification of the keywords according to qualitative items and mechanisms of symbolic violence has been obtained, and the analysis of co-occurrences of keywords that has produced another grouping of keywords (Annex 2), should present certain coincidences. That is, whether with one method (quantitative analysis of co-occurrences and clusters) or the other (qualitative thematic content analysis), the same keywords should be part of the same groups. Verifying this would also serve not only to validate the previous qualitative thematic content analysis, but also the analysis strategy deployed in the previous Annex 3.1; that is, they would validate each other.

This is exactly what will be done next. Given that what we have are two variables, namely, on the one hand the grouping of keywords based first on the qualitative thematic content analysis and then on the multidimensional Mahalanobis-Fisher and Wilks' lambda tests, and on the other the clustering of keywords from co-occurrence analysis, the analysis strategy is quite simple. It is only necessary to carry out a bivariate contingency table analysis to see, first, if these two variables are dependent or independent (the hypothesis is that they are highly dependent), and then, if their degree of association is high or low (the hypothesis is that they will be very intense associations).

Due to the relatively small number of keywords with statistically significant associations obtained (215, in reality there are 176 keywords, but some are part of more than one group) and the relatively high number of groups (13 for one variable and 11 for the other), it is expected that many of the cells of the contingency table will contain less than 5 cases, which will exceed the traditional 20% of cells with less than 5 cases that is conventionally considered the threshold for administering the Chi-square test (Agresti, 2007:40, 156; Howell, 2011). So, to overcome the non-compliance with the assumptions of the asymptotic method (fundamentally, that the data set is large), it will be necessary to base the test carried out on 5,000 Monte Carlo simulations to adapt the sample size to the stipulated requirements of the Chi square test (Hope, 1968; Howell, 2011). Because of this same requirement of 5 or more cases per cell in the contingency table, it will be necessary to use Fisher's exact test instead of statistics such as adjusted residuals, which are also based on Chi-square, to measure local associations between variables in the cells.

Mechanism		G1	G2	G3	G4	G5	G6	G7	G8	G9	G10	G11	G12	G13	TOTALS
SELFBLAM	F	1	0	0	1	0	2	2	1	1	0	0	0	0	8
	%	2.38%	0.00%	0.00%	6.25%	0.00%	10.53%	11.11%	8.33%	6.25%	0.00%	0.00%	0.00%	0.00%	3.72%
	Signific. (Fisher)	1.000	1.000	1.000	0.467	1.000	0.150	0.137	0.373	0.467	1.000	1.000	1.000	1.000	
ISOLATIO	F	3	0	1	1	0	0	0	0	0	0	0	0	0	5
	%	7.14%	0.00%	5.26%	6.25%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	2.33%
	Signific. (Fisher)	0.052 (c)	1.000	0.373	0.323	1.000	1.000	1.000	1.000	1.000	1.000	1.000	1.000	1.000	
INSUNCAR	F	0	8	5	1	4	3	2	1	2	1	0	0	0	27
	%	0.00%	34.78%	26.32%	6.25%	18.18%	15.79%	11.11%	8.33%	12.50%	6.67%	0.00%	0.00%	0.00%	12.56%
	Signific. (Fisher)	0.003 (a)	0.003	0.071 (c)	0.700	0.492	0.714	1.000	1.000	1.000	0.700	0.600	1.000	1.000	
DISINTEG	F	14	3	3	2	2	3	3	0	0	1	1	0	0	32
	%	33.33%	13.04%	15.79%	12.50%	9.09%	15.79%	16.67%	0.00%	0.00%	6.67%	14.29%	0.00%	0.00%	14.88%
	Signific. (Fisher)	0.001	1.000	1.000	1.000	0.542	1.000	0.736	0.221	0.138	0.705	1.000	1.000	1.000	
DELEGIT	F	0	0	0	1	5	0	0	0	5	0	1	0	0	12
	%	0.00%	0.00%	0.00%	6.25%	22.73%	0.00%	0.00%	0.00%	31.25%	0.00%	14.29%	0.00%	0.00%	5.58%
	Signific. (Fisher)	0.129	0.371	0.606	1.000	0.003	0.606	0.606	1.000	0.001	1.000	0.333	1.000	1.000	
EUPHEMIZ	F	6	0	0	0	1	0	0	0	0	0	0	0	0	7
	%	14.29%	0.00%	0.00%	0.00%	4.55%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	3.26%
	Signific. (Fisher)	0.000	1.000	1.000	1.000	0.536	1.000	1.000	1.000	1.000	1.000	1.000	1.000	1.000	
AHV	F	4	1	3	6	2	6	6	0	1	3	0	1	1	34
	%	9.52%	4.35%	15.79%	37.50%	9.09%	31.58%	33.33%	0.00%	6.25%	20.00%	0.00%	33.33%	33.33%	15.81%
	Signific. (Fisher)	0.248	0.138	1.000	0.025	0.540	0.090 (c)	0.045	0.221	0.477	0.712	0.600	0.405	0.405	
IMPDIS	F	6	1	0	0	0	0	1	0	1	0	1	0	0	10
	%	14.29%	4.35%	0.00%	0.00%	0.00%	0.00%	5.56%	0.00%	6.25%	0.00%	14.29%	0.00%	0.00%	4.65%
	Signific. (Fisher)	0.005	1.000	0.606	1.000	0.604	0.606	0.591	1.000	0.546	1.000	0.287	1.000	1.000	
INVISI	F	0	3	0	0	1	2	0	0	1	0	1	0	0	8
	%	0.00%	13.04%	0.00%	0.00%	4.55%	10.53%	0.00%	0.00%	6.25%	0.00%	14.29%	0.00%	0.00%	3.72%
	Signific. (Fisher)	0.360	0.042	1.000	1.000	0.585	0.150	1.000	1.000	0.467	1.000	0.236	1.000	1.000	
NONRECOG	F	8	7	6	4	7	2	4	10	5	10	3	2	2	70
	%	19.05%	30.43%	31.58%	25.00%	31.82%	10.53%	22.22%	83.33%	31.25%	66.67%	42.86%	66.67%	66.67%	32.56%
	Signific. (Fisher)	0.043 (b)	1.000	1.000	0.590	1.000	0.039 (b)	0.435	0.000	1.000	0.007	0.685	0.248	0.248	
SILEN	F	1	0	0	0	0	0	0	0	0	0	0	0	0	2
	%	0.00%	0.00%	5.26%	0.00%	0.00%	5.26%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.93%
	Signific. (Fisher)	1.000	1.000	0.169	1.000	1.000	0.169	1.000	1.000	1.000	1.000	1.000	1.000	1.000	
TOTALS		42	23	19	16	22	19	18	12	16	15	7	3	3	215 (100%)

(a) However significant the association established in this cell is, it cannot be highlighted because there are 0 cases in this cell.

(b) It does not seem very advisable to highlight this association as significant because the proportion corresponding to the number of cases is lower than the average proportion. Apparently, this statistic is rather reflecting an under-representation.

(c) The association for this cell is bordering the significance threshold for $\alpha=0.05$.

As can be seen, the forecast regarding the need to resort to Monte Carlo simulations has been fulfilled, because of the 143 cells in the table, 126 (88%) contained less than 5 cases. This magnitude far exceeds the traditional 20% of cells with less than 5 cases that is conventionally considered permissible to safely administer the Chi-square test.

The value of the Chi square test from Monte Carlo simulations has been 199.095, very far from the critical value of 152.127 that would mark the independence between variables, which for $GL=10$ is associated with a probability that both variables are independent <0.0001 . This implies that, for $\alpha=0.05$, the hypothesis of association between the two variables must be accepted and the null hypothesis rejected, so that there is a clear relationship between the classification of keywords based on the quantitative analysis of co-occurrences and clusters and the one based first on qualitative thematic content analysis and then on multidimensional Mahalanobis-Fisher and Wilks' lambda tests. That is, from two different methods, very similar results have been reached. It should also be said that the intensity of the association between the classification of keywords based on both methods is very high, and very surprising given the usual conservative tendency of the statistics used, such as the contingency coefficient, which here takes a value of 0.693, or Cramer's V, with a value of 0.304. These statistics usually underestimate the intensity or strength of the real association (López Roldán & Lozares Colina, 1999:18). But beyond these statistical indicators, in the table these strong associations have been represented visually based on the coincidence between the cells with associations marked as significant (with their values in red font) and the majority concentration of observations in the yellow cells (from 5 cases) to red (14 cases) —the cells with different shades of green range from 0 to 4 cases and precisely this, the relative lack of observations, is what we wanted to highlight with the green tones. These 17 cells (12% of the total) that contain 5 or more cases (keywords) concentrate 56% (120) of the observations. This means that there is not a dispersion of the cases in many cells but in a few: those in which certain mechanisms of symbolic violence and certain groups of co-occurrences of keywords coincide. In summary, there is a clear similarity between the two keyword classification methods, which proves the complementarity between qualitative approaches based on thematic analysis of texts and quantitative approaches based on the analysis of keyword co-occurrences.

Annex 4: Version 0 or preliminary of the symbolic violence scale in Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME)

1. Research presentation letter for participants

[Version for individual participants]

The survey in which you are about to participate is part of the research project “The circuit of symbolic violence in Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME): Development of a symbolic violence scale.” This research is the PhD dissertation of Xavier Gimeno Torrent that he has been carrying out since 2020 in the format of a compendium of articles. This researcher does his work within the framework of the PhD program of the Department of Sociology of the Autonomous University of Barcelona. So far, two articles have been published out of a total of 6 planned. This is a completely original project, which has no known precedents within the international panorama of CFS/ME social studies, and that is why it is having quite an impact around the world. It is a research which has not received or is receiving any public or private funding or crowdfunding in any of its stages for any purpose. The author also does not receive any type of funding or remuneration, but devotes all his time in a completely selflessly way, approximately 1,460 hours a year, to this research since 2018.

The first article of this research was published in 2022: Gimeno Torrent, X. (2022). The circuit of symbolic violence in Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME) (I): A preliminary study. *Health Care for Women International*, 43(1-3), 5-41. <https://doi.org/10.1080/07399332.2021.1925900>. The accepted version of the manuscript can be consulted free of charge, without any kind of paywalls, at: <https://bit.ly/3TDasPV>. This article has obtained very high social impact scores (<https://tandf.altmetric.com/details/107619422>), and the analytical model that is developed is being used in the research of the research group that, among others, includes Anne Kielland of the Fafo Institute of Norway, founded by the Norwegian Confederation of Trade Unions in 1982 (https://en.wikipedia.org/wiki/Fafo_Foundation). Xavier Gimeno Torrent’s collaboration with these researchers is being very close and several joint articles are planned between him and some researchers from this group.

The second article was published in January 2024: Gimeno Torrent, X. (2024). Los héroes de la ELA: la estructura social de los discursos triunfalistas de superación y celebración de un enfermo y legitimación de una enfermedad. *Papers: Revista de Sociologia*, 109(1), e3225. <https://doi.org/10.5565/rev/papers.3225>.

Two more articles are scheduled to be published soon. One on the social structure of symbolic violence towards the patient in which the visibility of a list of 230 diseases is analysed, and the other that constitutes the version 0 or preliminary or pretest of the symbolic violence scale in CFS/ME. This article has been published as gray literature (<https://bit.ly/48VQCEc>). This is precisely the article in the field work in which you are about to participate.

That is why I would like to sincerely thank you for your invaluable collaboration in this task, without which my work would not be possible. **You should know that all the information you provide me will be completely confidential and anonymous. Furthermore, it will be treated in an aggregated manner, making it completely impossible for anyone, not even myself, to identify you.** If you have any difficulty during the survey or identify any aspect that you think could be improved and you consider it necessary, I would appreciate it if you could contact me at the following email address xavier.gimeno@xaviergimeno.net.

Sincerely,
Xavier Gimeno Torrent.

[Version for collective participants]

Dear Sirs/Madams,

I am addressing you as a researcher and promoter of the research project “The circuit of symbolic violence in Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME): Development of a symbolic violence scale.” My name is Xavier Gimeno Torrent, and this research is my PhD dissertation, which I have been carrying out since 2020 in the format of a compendium of articles. I do my work within the framework of the PhD program of the Department of Sociology of the Autonomous University of Barcelona. So far I have published two articles out of a total of 6 planned. This is a completely original project, which has no known precedents within the international panorama of CFS/ME social studies, and that is why it is having quite an impact around the world. It is a research which has not received or is receiving any public or private funding or crowdfunding in any of its stages for any purpose. I do not receive any type of funding or remuneration either, but I devote all my time in a completely selflessly way, about 1,460 hours a year, to this research since 2018.

The first article of this research was published in 2022: Gimeno Torrent, X. (2022). The circuit of symbolic violence in Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME) (I): A preliminary study. *Health Care for Women International*, 43(1-3), 5-41. <https://doi.org/10.1080/07399332.2021.1925900>. The accepted version of the manuscript can be consulted free of charge, without any kind of paywalls, at: <https://bit.ly/3TDasPV>. This article has obtained very high social impact scores (<https://tandf.altmetric.com/details/107619422>), and the analytical model that is developed is being used in the research of the research group that, among others, includes Anne Kielland of the Fafo Institute of Norway, founded by the Norwegian Confederation of Trade Unions in 1982 (https://en.wikipedia.org/wiki/Fafo_Foundation). My collaboration with these researchers is very close and it is planned to carry out various joint articles with some researchers from this group.

The second article was published in January 2024: Gimeno Torrent, X. (2024). Los héroes de la ELA: la estructura social de los discursos triunfalistas de superación y celebración de un enfermo y legitimación de una enfermedad. *Papers: Revista de Sociologia*, 109(1), e3225. <https://doi.org/10.5565/rev/papers.3225>.

Two more articles are scheduled to be published soon. One on the social structure of symbolic violence towards the patient in which the visibility of a list of 230 diseases is analysed, and the other that constitutes the version 0 or preliminary or pretest of the symbolic violence scale in CFS/ME. This article has been published as gray literature (<https://bit.ly/48VQCEc>). This is precisely the article for the field work on which I would like to ask for your collaboration.

At this stage of the research it is planned to begin conducting interviews with people who suffer from CFS/ME. One of the ways to contact sick people is through patient associations. That is why I am writing this letter to you. There are other possible alternatives, but the diversity of situations of the people who are part of institutions like yours favors the study of a much wider range of circumstances surrounding the disease. This is my main object of study, all the social aspects that affect CFS/ME, producing the invisibility of the disease and the relegation and social disintegration of the sick.

To achieve this objective, your collaboration, if you finally wish to participate in this research, would consist of the following. In the first stage, it is necessary to administer a set of questionnaires, in total there are 4 different questionnaires, to the members of the Association who want to participate. Of course, participation is voluntary, but the more members who participate, the better for the next phase of the research. It would be necessary to ensure that people who want to participate in the research have as much time as possible to answer the questionnaires, so that they answer the greatest number of members.

As I have always done in this project (see section 3 “Data and methodology,” p. 7, of the first article published in 2022), one of my highest priorities would be to always guarantee the anonymity of the people who answer the questionnaires. For this reason, each set of questionnaires will ask the respondent for an anonymous identifier that only the person surveyed and the Association will know. This identifier may be, for example, a member number, or any other number or code previously assigned by the Association that is known to both. This identifier

will be associated with the real identity of each member. But only the Association will have access to the list where the equivalence between anonymous identifiers and real identities will appear. In turn, the Association will not have access to the results of the completed surveys. In this way, the anonymity of the results and identities is guaranteed, since no one has access to both things at the same time, making it impossible to know who answered what.

The goal of this first phase is to lay the foundations for the second, which consists of conducting group and individual interviews —depending on the case, it is possible that the most seriously ill people will not be able to participate in the group interviews, so in these cases the most advisable thing will be to do individual interviews. Given that the people who participate in the discussion groups and interviews will have to be selected, the administration of the set of 4 questionnaires, which is fundamentally a 0 or preliminary version of the symbolic violence scale, will be the way to select, from the analysis of their responses, the people who will participate in the group and individual interviews. Thus, the selection will be based on a stratified random sampling based on the results of the multivariate analysis of the survey.

But, of course, when asking each selected person if they wish to participate in individual interviews or focus groups, it will be necessary to contact them. And it will be the Association who will have to do it, because I will have no way of doing it, nor will I know their identities. I reiterate that my top priority is to ensure the anonymity of people participating in the research, and I have no intention of violating this requirement. I have no interest in it, nor does my research perspective privilege the individual as a unit of analysis or as an object of study. I dedicate myself to studying social facts. I also want to emphasize that I understand that very often anonymity is essential to confidently answer certain questions that, to be answered honestly, require the identity of the person answering to be preserved. Also from this perspective, anonymity is essential, both for me and for this research. With these explanations I want to make it very clear that I understand the value that preserving the anonymity of your members has for you, since anonymity is also essential for the quality of my work. And that is precisely why I have insisted so much on this topic and wanted to give you so many details about the procedure to guarantee the anonymity of its members. Both you and I need this issue to be respected and the maximum guarantees to be offered in this regard.

Later, in the second phase, when the group and individual interviews have already been held, I will analyse these qualitative materials, always preserving the identity of the participants, of course. The objective of this analysis will be to obtain the definitive scale of symbolic violence in CFS/ME. It may not differ much from the current version 0 or preliminary, but obtaining qualitative materials from interviews and focus groups is essential for the quality of the scale.

Finally, I would like to say that there are already several research groups around the world (Colombia, Norway, USA) interested in the circuit of symbolic violence in CFS/ME model, and the scale will be the main product of research from which to apply it in the field. I have no doubt that, with its generalization, much more will be known about everything that CFS/ME patients must suffer and that they could perfectly avoid themselves because it is a social addition that is not inherent to the disease. And all this will be possible thanks to Associations like yours. That is why I would like to thank you very sincerely for your invaluable collaboration in this task, without which my work would not be possible. If you have any doubts or questions, or need more details about my proposal, I would appreciate it if you could contact me at the following email address xavier.gimeno@xaviergimeno.net. In any case, I take this opportunity to greet you and I remain at your disposal, waiting for your response.

Sincerely,
Xavier Gimeno Torrent.

2. *Tips and instructions for answering the survey*

Next, I will explain some things that you should keep in mind when answering this survey. These are important questions that you should know before doing so, thus I would appreciate it if you read this section carefully, or if someone could help you read it if you need help.

- **This survey is expressly aimed at people who suffer from chronic fatigue syndrome (also called myalgic encephalomyelitis) (CFS/ME) as a primary illness and its questions always refer to this illness.** So only people who suffer from at least this disease can answer it. If you have other illnesses apart from this one, you can also answer it, but CFS/ME must be the illness that affects you the most.
- It is possible that some of the people who answer or want to answer this survey are affected very severely by CFS/ME and have a hard time answering it. If this is the case, and they have someone to help them, it would be preferable for this person to help them do it. But if you do not have anyone to help you, it is worth answering the survey in stages, on successive days or when you feel stronger to do so. **It is not at all necessary that you answer all the questions or sections at once. You can organize the survey response however you can or consider appropriate. In all cases, it can be answered with the help of other people and it is not a requirement to answer it individually without anyone's help.** The last thing I would want is for answering a survey to harm the health of people who suffer from CFS/ME.
- **IF YOU NEED IT, YOU CAN ACTIVATE THE “READ ALOUD” FUNCTION, AVAILABLE IN SOME BROWSERS SUCH AS GOOGLE CHROME OR MICROSOFT EDGE, AND THE BROWSER WILL READ THE ENTIRE SURVEY ALOUD TO YOU.**
- In most surveys of this type, it is common to tell respondents to keep the last week or the last month in mind when answering. In this survey, the time horizons go much further than the usual ones, simply because, for many of the people who are going to answer, these horizons do not exist, since their social rhythms and the time schemes based on these shared rhythms have long been lost. They disappeared from their lives. So, **it is possible that for some patients, those who can lead a more normal life, it makes sense to think about the last week or the last month when answering the questions, but for those whose illness affects them more severely, time has stopped, it is frozen, and for them it will not make any sense to adopt these time frames of reference.**
- **It is important to keep in mind that some questions ask for information that must be provided by a person other than the respondent. In these cases, it is explicitly necessary for the person surveyed to ask these other people if they give their consent to provide this information for the scientific research purposes of this study.**
- **THIS IS NOT A SURVEY FOR ADMINISTRATIVE OR CONTROL PURPOSES OF ANY KIND, NOR ECONOMIC-SIDE, NOR SOCIAL-SERVICE-SIDE, NOR MEDICAL-HEALTHCARE-SIDE SYSTEM, ETC., ITS SOLE PURPOSE IS SCIENTIFIC RESEARCH.**
- **Finally, the person surveyed must also give their consent to provide all the information provided for the scientific research purposes of this study. You just have to check the box below, you should not give any kind of personal information or similar.**

☐ **Yes, I agree to provide all the information that I will provide for the scientific research purposes of this study.**

3. Demographic and health data

Leave this line blank, do not write or mark anything. SOURCE: ☐ Association ☐ Internet IDENTIFIER: _____

1. Age: _____ years old.
2. Sex: ☐ 1. Woman ☐ 2. Man
3. What is your country of origin?

<input type="checkbox"/> 1. Morocco	<input type="checkbox"/> 10. India
<input type="checkbox"/> 2. Romania	<input type="checkbox"/> 11. Argentina
<input type="checkbox"/> 3. Italy	<input type="checkbox"/> 12. Russia
<input type="checkbox"/> 4. Pakistan	<input type="checkbox"/> 13. Senegal
<input type="checkbox"/> 5. Colombia	<input type="checkbox"/> 14. United Kingdom
<input type="checkbox"/> 6. Honduras	<input type="checkbox"/> 15. Bolivia
<input type="checkbox"/> 7. France	<input type="checkbox"/> 16. Ukraine
<input type="checkbox"/> 8. Venezuela	<input type="checkbox"/> 17. Spain/Catalonia
<input type="checkbox"/> 9. Peru	<input type="checkbox"/> 18. Other countries _____
4. In which municipality do you live? _____
5. Level of FINISHED studies (answer with the highest qualification you have, tick only one box):

<input type="checkbox"/> 1. Elementary school not completed (I have not finished Spanish EGB/ESO or equivalent)
<input type="checkbox"/> 2. Social guarantee programs (for those people who have not finished elementary school)
<input type="checkbox"/> 3. Elementary school (Spanish EGB, ESO or equivalent, incl. obligatory secondary school)
<input type="checkbox"/> 4. Secondary school (Spanish BUP, COU, “bachiller,” “bachillerato” or equivalent)
<input type="checkbox"/> 5. Intermediate level vocational training (F.P. I or “módulo profesional de grado medio”)
<input type="checkbox"/> 6. Advanced specific vocational training (F.P. II or “módulo profesional de grado superior”)
<input type="checkbox"/> 7. University diploma (Spanish “Diplomatura,” former 3-year degree, currently expired)
<input type="checkbox"/> 8. University degree (Spanish “Licenciatura,” former 4-5-year degree, currently “grado”)
<input type="checkbox"/> 9. PhD, master’s degree or studies that are accessed with a university degree
6. Regardless of when you were diagnosed, how long have you been sick? _____ years.
7. What year were you diagnosed with CFS/ME? Year _____.

8. Who took the lead in suggesting the diagnosis of CFS/ME?

- ☐ 1. It had to be me, I had prior information about CFS/ME.
- ☐ 2. It had to be me, I had family, friends, or acquaintances who suffered from CFS/ME.
- ☐ 3. It was my doctor, who had the necessary knowledge about CFS/ME.
- ☐ 4. Other _____

9. Where were you diagnosed with CFS/ME?

- ☐ 1. In the public healthcare CAP/dispensary, my GP.
- ☐ 2. In a public healthcare hospital unit specializing in CFS/ME, a medical specialist.
- ☐ 3. In the emergency unit of a public healthcare hospital.
- ☐ 4. In a private consultation with a private family doctor.
- ☐ 5. In a private hospital unit specializing in CFS/ME, a medical specialist.
- ☐ 6. In the emergency unit of a private hospital.

10. What were you diagnosed with that year? PLEASE write down the exact name of what you were diagnosed with as it appears in your health documentation or medical history. If you have the disease code, write it down as well; if not, do not write anything in the "Code" box. If there are comorbidities (other diseases), list the diseases, up to 4, that you consider to affect you the most; if there are none, do not write anything in "Comorbidities 1-4."

Exact name _____

Code _____

Comorbidity 1 _____

Comorbidity 2 _____

Comorbidity 3 _____

Comorbidity 4 _____

11. Profession (current or last) _____

12. Do you work?

- ☐ 1. I do not work nor can I do it and I can afford not to work.
- ☐ 2. I do not work nor can I do it but I need to work.
- ☐ 3. I work and fortunately I do it without great difficulties.
- ☐ 4. It costs me a lot to work but I cannot afford not to work.
- ☐ 5. I work because I have to support myself but for my health I should not do it at all.

13. Do you have a couple?

- ☐ 1. No, I am single.
- ☐ 2. Yes, but we are separating/divorcing.
- ☐ 3. I am separated/divorced.
- ☐ 4. Yes, and we live together.

14. Approximately, what is your and your couple's income level? (If you have and he/she agrees to give this information, check the corresponding box for your couple; if you do not have or your couple does not agree to give this information, do not check anything.)

YOURS

YOUR COUPLE

- | | |
|--|--------------------------|
| <input type="checkbox"/> 1. No income | <input type="checkbox"/> |
| <input type="checkbox"/> 2. 300 euros or less | <input type="checkbox"/> |
| <input type="checkbox"/> 3. Between 301 and 450 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 4. Between 451 and 600 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 5. Between 601 and 750 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 6. Between 751 and 900 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 7. Between 901 and 1,200 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 8. Between 1,201 and 1,500 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 9. Between 1,501 and 1,800 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 10. Between 1,801 and 2,100 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 11. Between 2,101 and 2,400 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 12. Between 2,401 and 2,700 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 13. Between 2,701 and 3,000 euros | <input type="checkbox"/> |
| <input type="checkbox"/> 14. More than 3,000 euros | <input type="checkbox"/> |

15. Are you treated by a unit specialized in CFS/ME?

- ☐ 1. No, only my GP in the public healthcare system, I do not have a specialized doctor.
- ☐ 2. No, only a family doctor from private healthcare.
- ☐ 3. Yes, a specialized public healthcare unit.
- ☐ 4. Yes, a specialized private healthcare unit.

16.Are you affiliated with any organization for patients?

☐ 1. Yes

☐ 2. No

17.Do you have a family?

☐ 1. Yes, but I live alone.

☐ 2. Yes, and I live with my family.

☐ 3. No, I do not have a family.

☐ 4. Other _____

18.Do you have a caregiver?

☐ 1. No, I do not need it.

☐ 2. Yes, and is one of my relatives.

☐ 3. Yes, and is a person very close to me (friends, etc.).

☐ 4. Yes, and is a person who takes care of me on a paid basis.

☐ 5. Other _____

19.Does your health condition allow you to leave the house, do some type of physical activity, however minimal?

☐ 1. No, I cannot leave the house at all. I have _____ without leaving home.

☐ 2. Yes, I go out _____ times a week.

20.Do you think about suicide due to CFS/ME?

4. Always	3. Often	2. Sometimes	1. Rarely	0. Never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21.What do you find hardest about suffering from this disease?

☐ 1. The disease itself.

☐ 2. What it means socially to have it, its high social cost in many areas of my life.

☐ 3. Both the one and the other.

☐ 4. Other _____

4. Symbolic violence scale in CFS/ME (original version non-shortened)

	4. Strongly agree	3. Agree	2. Neither agree or disagree, not sure, indecisive, or indifferent	1. Disagree	0. Strongly disagree
1. The State/Public Administration (the public healthcare system and doctors, Social Security and medical assessment tribunals, disability impact assessment centers and scales, and courts of law and judges) does not recognize my CFS/ME and I do not enjoy the same rights that other sick people have (sick leave, benefits, disability pensions, and other aid).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. For the State/Public Administration (the public healthcare system and doctors, Social Security and medical assessment tribunals, disability impact assessment centers and scales, and courts of law and judges) I am just a number, I am invisible, and they treat me with absolute indifference and coldly, as if I counted for nothing, not very humanely, cruelly, in a totally unworthy way and they do not respect me, they do not treat me as a person deserves to be treated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. The lack of recognition of CFS/ME by the State/Public Administration (the public healthcare system and doctors, Social Security and medical assessment tribunals, disability impact assessment centers and scales, and courts of law and judges) also makes my family (husband, wife, children, brothers or sisters, etc.) suffer a lot and affects them daily.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. The State/Public Administration (Ministry of Social Action and Citizenship) makes you wait inordinately to summon you for the disability impact assessment, it resolves possible claims very late (years) if they do not grant it, if you claim judicially the same thing happens, and I suspect that they do this expressly to discourage sufferers from requesting assessment and recognition of their disabilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I had to go to court to have my disability caused by CFS/ME recognized since the INSS did not grant it to me in any way, but all this was useless, because finally the judge also denied it to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. The Ministry of Social Action and Citizenship violates my rights when it does not recognize the disability caused by CFS/ME and does not provide me with the relevant pensions, the judicial system when it allows these injustices, and the Department of Health when it does not face the consequences when I ask them for explanations about my diagnoses or lack thereof and it does not tell me anything.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I do not know how to explain nor do those around me understand that doctors, after going through many specialists, doing a lot of tests, and writing countless reports, say that I am sick and that I cannot carry out any common or work activity, but the ICAM and its doctors ignore all the diagnoses and discharge me medically.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. The medical assessment tribunals and ICAM doctors have mistreated, humiliated, and despised me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. It is very difficult for me to accept the limitations that CFS/ME causes me and I do not accept it, I feel very helpless and I think that others cannot accept me like that either.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I believe that the State/Public Administration (the public healthcare system and doctors, Social Security and medical assessment tribunals, disability impact assessment centers and scales, and courts of law and judges) should apologize to me for all the abuse, mistreatment, insults, and humiliation that I have had to suffer from them since I have been sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. As a CFS/ME patient I am completely helpless and abandoned by public healthcare system, I do not have adequate medical care, nor specialists who know my illness, I do not have doctors to treat me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. The severity of the CFS/ME that I suffer from means that my family members have to permanently take care of me on a daily basis, and this has had a negative impact on their work, their leisure, and their well-being, but the institutions do not help us at all.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. CFS/ME has wiped out all my income, but the State/Public Administration does not give me any help to support myself even though I am having a hard time financially. I have no money.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	4. Strongly agree	3. Agree	2. Neither agree or disagree, not sure, indecisive, or indifferent	1. Disagree	0. Strongly disagree
14. As a CFS/ME patient, I consider myself discriminated against, because I live in a territorial area where there are no diagnosis and treatment units for my illness or those that exist are terrible, while patients who live preferably in Barcelona and their area of influence have healthcare and socio-sanitary care that, without being what it should be, is better than what I can have, which I have requested in these better prepared units but they have denied me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I believe that the State/Public Administration of our country does practically nothing to promote public funding of CFS/ME research.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Very often, when some members of the Public Administration (relevant authorities, doctors, medical experts, social workers, judges, etc.) address me, they do so from a position of superiority that places me as below them and that makes me feel bad but I am not in a position to reply them for fear that if I do they will not grant me what I ask for and that I need so much to live. They treat me like I was a little kid or a fool, but I have to shut up and suck it up.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. The ICAM does not respect doctors' diagnoses: when I went to have my degree of disability assessed, I presented a lot of reports and medical tests, but the ICAM, after 5 or 10 minutes asking me useless questions and asking me to do tests on the style, standing on tiptoe and moving my arms up and down, they discharged me, casually ignoring all the reports, evidence, diagnoses, and my medical history, compiled over the years. They consider that I have a psychosomatic illness and that nothing is wrong with me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. It has taken me many years to obtain the diagnosis of CFS/ME: during this time I have been to countless doctors' offices, many specialists have visited me, and they have told me that I had many things that did not correspond to what was happening to me, most of the time chronic fatigue was a secondary symptom of diseases that had nothing to do with CFS/ME.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. The ICAM forces medical discharges based on economic criteria, they forced me to return to work without respecting the medical criteria and scales, only because if they gave me another sick leave it would be permanent, because it was over and they did not want to continue paying what I was entitled to perceive as a seriously ill person that I am with no possibility of improvement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I am a regular user of alternative therapy offices such as acupuncture, shiatsu, homeopathy, Bach flowers, Zen, and yoga, etc. I believe that these remedies and a careful diet can cure me and I follow the advice and recommendations of these doctors as much as I can to alleviate my suffering.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I constantly feel that people in my work environment, acquaintances, doctors, the ICAM, etc., do not believe my illness, they think that I pretend and invent it, that I am a fibber or a hysteric "and that I do it only to draw a pension." "Since you look so nice....," if I laugh it is that I am not sick, and if I cry I make a lot of fuss about nothing. This, for example, has had employment consequences when it comes to being able to request sick leave from my company, among others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I very often feel misunderstood by doctors, Public Administrations, society in general and my family and friends in particular because of CFS/ME. This disease generates a lot of incomprehension and misunderstanding.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Very often I have to endure being told, from someone talking to my face or behind my back, that what I really am is crazy, neurasthenic, hysterical, exaggerated, or lazy and to go home and rest, that what I have is laziness, that I am fine to work and that if I had cancer it would be something else. Sometimes I have been afraid to take sick leave for fear that they will think I am lazy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I feel constantly questioned by my environment: work, friends and acquaintances, doctors, ICAM, family, etc., who do not take my illness seriously and say that "it is a nonsense," I always have to give explanations to everyone to justify myself, I am tired of listening to people's advice on how to improve my health and my situation, tired of anyone passing by feeling entitled to tell me that "I look so nice and I cannot be so bad in health..." or that "they are tired too," without having the slightest idea of my illness or how I am. I feel like everyone is judging me and I am on a trial with no defense.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	4. Strongly agree	3. Agree	2. Neither agree or disagree, not sure, indecisive, or indifferent	1. Disagree	0. Strongly disagree
25. Because of CFS/ME I have had to abandon many things that I liked and that defined me as the person I was before I became ill: my profession and my job, I cannot take care of my family as before, I cannot carry out leisure activities that I used to do because I get tired, I have had to stop seeing the people I usually had contact with because I never know how I will feel the day I make an appointment with them, etc., in short, I have had to abandon what my previous life was.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. CFS/ME has disrupted my life, both I and my family members or my closest circle have had to learn to live with the limitations of all kinds and the rhythms of life that this disease imposes to have a minimum quality of life, and they have had to adapt to it at all costs. This disease changes the daily lives of everyone who comes into contact with it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. For me, trying to follow the normal rhythms of life is a cause of permanent conflict because I often find that I meet someone but the next day I have to cancel the date because I am exhausted, and some people get angry with me; many friends get angry with me because they can almost never see me; they criticize me because I cannot follow an activity; they disapprove me because I cannot eat the same as everyone else; I spend many personal days at work because there are days when it is impossible for me to go and that is not seen favorably in my work; I cannot follow the normal work day, they have had to adapt my schedule, and yet I suffer a lot, I force myself to work beyond my capabilities. I make a lot of effort to try to be a normal person living with health problems that prevent me from leading a normal life and that make it difficult to have a good relationship and good understanding with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. My life now has nothing to do with the one I led before the illness, for example: I have been fired or I have had to leave my job because I cannot work at all; I cannot run the house and even going shopping or cooking is a sacrifice for me; I have left school, university or secondary school; I cannot read, go to concerts, play sports, or even watch TV or go to the movies; I barely interact with anyone, and if I do it is exceptionally and the effort takes its toll on me in the following days or weeks; I cannot leave home; I spend a lot of time in bed or on the sofa; nobody wants to have any contact with me, many have distanced themselves from me since they have gotten fed up with me and my illness because I am always sick. I cannot lead a normal social life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I feel like I am death in life, I have no hopes or expectations for life or the future. This disease is hell, very hard, it leaves you immersed in a well of uncertainty and the most absolute despair and discouragement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. My couple gets fed up with me because of CFS/ME. He/She has divorced or separated from me, has thought about it, or is about to do so.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. It is very difficult for me to internalize that I have an illness that is incompatible with the pace of life I led before: I resist recognizing that I must change my life, abandon my profession, my job, run a house, meet my friends, etc., and it is hard for me to stop. This is still being very hard for me, it is like stopping feeling useful. I lie to myself telling me that all this will change one day and I am putting off as long as I can the moment to stop my pace of life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. CFS/ME is a very aggressive disease that harms me greatly both physically, morally, and emotionally, but it will not be able to defeat me, it will not break my will, I am stronger than it, it will not defeat me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I spend the week pretending that I am fine, putting on a good face with a smile on my face, and crying secretly so as not to make the lives of those around me uncomfortable or bitter so that they do not distance themselves from me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I make an effort not to cause pity or compassion in anyone, the last thing I would want is for them to pity me or see me as a victim of this damned disease, and that is why I also flee from self-pity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. With this illness I have learned to value small things that I did not appreciate before and that have now become great for me: the value of everyday life, slowness, patience, and serenity; of a sunset; of the leaves of a tree as they fall; of the passing of the seasons; to go slower without any rush; to eat with my family and be with them; of looking at the flowers in the garden, for example. This illness has made me realize that you should be happy with the little things that life puts in front of you.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. I try to be discreet with everything that has to do with CFS/ME. I do not want to make public what I think is too personal and that no one needs to know. I do not want people to know that I suffer from CFS/ME.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	4. Strongly agree	3. Agree	2. Neither agree or disagree, not sure, indecisive, or indifferent	1. Disagree	0. Strongly disagree
37. On more than one occasion I have hidden my identity as a CFS/ME patient even though the situation required that I identify myself as such. I do not want to be identified as having CFS/ME because of the possible repercussions this may have on different aspects of my life (for example, at work). I am afraid of the consequences this may have for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I feel that I suffer from an invisible illness, imperceptible in the eyes of society. This invisibility makes me feel as if my case does not exist for anyone.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Since I do not wear crutches, I am looking good, I can walk, and I do not have any or many of the signs that usually socially define a disabled person, most people believe that I am fine, that I do not have any illness and that nothing happens to me. This makes me feel like what happens to me does not matter to anyone.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I believe that if there were some biological marker for CFS/ME or some objective medical proof of the degree of suffering or pain it causes, this disease would no longer be invisible. Surely this way, cases like mine would begin to be taken into account and CFS/ME sufferers would stop being transparent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. I hardly leave the house, nor do I have contact or talk to anyone. I am very alone.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. I barely leave the house because I feel protected there. I feel very uncomfortable talking to most people, and when I go out and talk to someone, I end up talking to other people who are in the same situation as me: other CFS/ME sufferers, older people who often live alone, people who suffer from other diseases misunderstood by society, etc. I would really like to be able to go out and talk to people who could make me feel welcomed and understood, but I feel that there is an insurmountable barrier between people who cannot understand my suffering and me, so the best thing is to stay at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. I would really like to have someone with whom I could talk and communicate, a person who would be willing to listen to me sincerely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. For many years, and still often now, I have come to think that I was lazy and did not know how to organize myself, that I was incapable of combining my work and taking care of the house and my family, that I was sick because of me since I did not know how to change aspects of my life and my attitude towards life that I had to change, that you put up the barriers yourself by believing that you are chronically ill, that the illness was in my body and in my mind because my illness was I.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Many people around me, including doctors who treat me or have treated me, think and say that I have inadequate life attitudes, that I must change my way of thinking and facing life because these attitudes are harmful to me and contribute to CFS/ME because the body somatizes certain vital conflicts, complains, and CFS/ME appears. I have been recommended to see a psychologist/psychiatrist more than once to cure CFS/ME, and I have gone, or am going to treat CFS/ME because I have been told that it can be cured with psychological therapy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Doctors have recommended me to take medication and prescribed pills for anxiety and depression, I am taking drugs or have taken it in the past because I have been told that these medications can help relieve CFS/ME.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Acronyms and explanation

- CFS/ME: Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.
- ICAM: Institut Català d'Avaluacions Mèdiques (Catalan Institute of Medical Assessments), currently called Sub-directorate General of Medical Assessments-ICAM. In Catalonia, it is responsible for carrying out the medical assessment, inspection, management, and control of medical and health processes related to the benefits of the Social Security system for work disabilities, and depends on the Department of Health of the Generalitat of Catalonia, the government of the autonomy of Catalonia ([https://canalsalut.gencat.cat/ca/salut-a-z/a/avaluacions-mediques/qui-hi-participa/icam/index.html#googtrans\(ca|en\)](https://canalsalut.gencat.cat/ca/salut-a-z/a/avaluacions-mediques/qui-hi-participa/icam/index.html#googtrans(ca|en)))).
- INSS: Instituto Nacional de la Seguridad Social (Spanish Social Security Administration). In Spain, it is the agency that manages the contributory economic benefits of the Social Security System, depending on the Ministry of Employment and Social Security of the government of Spain (https://es.wikipedia.org/wiki/Instituto_Nacional_de_la_Seguridad_Social).

5. Black and white lists

Now I would like you to give me 5 or fewer names: of people (for example: doctors, civil servants, lawyers, ministers, presidents, judges, etc.), institutions of all kinds (for example: governments or States, ministries, companies, health insurance companies, disability impact assessment' agencies, patient organizations, etc.), or roles ("my family," "my husband/wife," "my friends," "my boss at work," "my doctor," "my lawyer," "the judge who handled my claim against Social Security System," etc.); in this case it is not required to say names, but rather these or other specific roles), any person, public or private organization, or role that 1) you consider has contributed negatively to your personal situation with regard to the disease, 2) you consider that has contributed positively to your personal situation regarding the disease; **that is, 5 or less negative contributions and 5 or less positive contributions.** The designated people, organizations, or roles must have had some **direct relationship with you**, even if you have not had any direct face-to-face contact, but some of their actions must have affected you negatively or positively in some way. All contributions are worth the same, there is no order or hierarchy of importance, neither negative nor positive. It is not a negative or positive score in order of contribution.

Negative contributions

Positive contributions

6. Survey quality assessment

Now I would like to ask you 4 questions to know how I did it, if I did it well or not and I need to improve the survey. Answer from 0 to 10 with whole numbers without decimals. Note that, many times, the best score is not 10, but 0, this is indicated in each question. If someone have helped you answer the survey and you consider it necessary, the person who helped you can also answer the questions with you.

1. Did you find it difficult to understand the questions? Here you are rating the difficulty of the questions from 0 to 10. (0 Very easy, I have read them only once – 10 Very difficult, I have had to read them several times.)

Rating:_____

2. Has the duration of the survey been an effort for you? Here you are rating your degree of tiredness from 0 to 10. (0 I have not gotten tired at all – 10 I have gotten very tired, it has been a detrimental effort for me.)

Rating:_____

3. Has the 5-point response scale always in the same direction from 4 to 0 made it easier for you to answer? Here you are rating from 0 to 10 the ease of remembering the 5 categories of the scale. (0 I did not remember the categories and I looked at them every time – 10 It was very easy, I remembered the categories without difficulty.)

Rating:_____

4. Do you think this survey has served to capture what happens to CFS/ME sufferers from a social point of view? Here you are rating your degree of identification with the questions from 0 to 10. (0 I have not felt identified at all, I have not seen my situation reflected at all

in the questions – 10 I have felt very identified, I have seen my situation very reflected in the questions.)

Rating:_____

7. *Duration of individual and group interviews of the second phase*

1. In the second phase of this research, individual and group interviews will be carried out with those who wish to do so. I am well aware that simply participating in an activity like this often takes a heavy toll on your health in the days that follow. But what do you think the optimal duration of these interviews should be to minimize this cost? (Please express the duration in minutes, taking into account that the maximum duration of these interviews cannot exceed 2 hours [120 minutes].)

Optimal duration:_____ minutes.

Some explanatory notes about the survey

In this section it is worth making some notes on the foundations on which some of the survey questions are based. Nothing will be commented on chapters 5 and 6 of the questionnaire for obvious reasons, and only the following will be said about chapter 4. Generally, surveys in the form of a scale in social or medical sciences, very common in psychology and medicine, often have very short statements. However, those on the scale in chapter 4 are very long. This is because they want to capture phenomena that have a very complex conceptualization, that if they were asked with statements such as “you suffer doxical imposition,” or “you are disintegrated,” for example, they would have few possibilities of response, when not directly null.³ The best way to

3 This is an obvious example, applied to the formulation of survey questions, of what Pierre Bourdieu called scholastic fallacy (2000:49-92). However it is answered, it is obvious that no one will understand a question like this. But there are other cases of questions that are much more dangerous because they incur what Bourdieu and Passeron (1966a) also called the ‘illusion of transparency’ since they seem immediately accessible to understanding, as Kant said, but they transmit to the respondents some poorly controlled meanings that lead to erroneous responses. This is the case of a question like “In the last year, have you experienced any type of discrimination because of...? You have felt upset, you have been denied something, you have been harassed or you have felt inferior...” This is a real example taken from the 2021 Barcelona health survey (Bartoll-Roca et al., 2021:166). The question is not specific at all, it does not specify anything, it does not give any illustrative example of what it asks, we do not know what “discrimination” is, however we think we know it; it is a paradigmatic example of the type of direct questions that should never under any circumstances be asked in a survey (Bourdieu & Passeron, 1966b) and that transmit a false sense of clarity. Here in reality the same scholastic fallacy as before is committed, but in this case fostered by the action of a social context favorable to the answer and the question on issues of ‘discrimination,’ which, due to an effect of symbolic violence very common in the relationship between respondent and interviewer, leads the people surveyed to automatically respond to the questions that the interviewer imposes on them, even if they do not understand a single bit of what is really being asked, normally due to the sheer theoretical, epistemological and methodological incompetence of the person who has designed the survey, which also does not have the slightest idea of what it is looking for because it has not done a good construction of the object of study (Bourdieu et al., 1991:33-56), if he/she has done any construction at all. In the 2021 Barcelona health survey, the results of this specific question showed a clear gradient by age, for both men and women, *when it came to stating* that they had suffered discrimination, so that the younger the age, the more discriminations. In turn, according to social classes, “the highest percentage of people *who stated* [my italics] that they had suffered some discrimination were women from more affluent classes, around 21%” (Bartoll-Roca et al., 2022: 47). These two results are clearly counterintuitive and contrary to what good sociological common sense, intuition, or good judgment would dictate, and anyone with a little insight would realize this. What these results are revealing to us is that the younger the age (for men and women) and the higher the social class (only for women from affluent classes), the greater the degree of awareness of discrimination, which is not at all comparable to greater discriminations. In a question like this, lacking the most basic epistemological vigilance in its formulation, respondents express their degree of adherence to the values conveyed by the question, in this case, the fight against discrimination and inequalities. Explained in this way, these results make all the sense in the world and are totally coherent, especially in a historical and social context like the current one that is especially sensitive to these issues.

proceed, therefore, is from indirect but very detailed questions, focused on specific cases of the designated phenomena. The result of this is quite extensive narrative explanations that appeal to the daily life of the person surveyed and that are full of examples so that he/she can feel identified with some of the aspects that appear in the statement. It is precisely this requirement of ensuring that respondents feel identified with the question statements that explains why keyword co-occurrence analysis and multidimensional Mahalanobis-Fisher-Wilks tests were used to isolate keywords and associate them with each one of the items that should be part of the scale: precisely to generate this identification by using in these statements some keywords that other patients had previously used in the materials analysed. In turn, the writing of the statements is closely based on the review of the qualitative analyses, and when it has been considered pertinent, more or less literal examples extracted from these researches have been incorporated. And given these explanations, all that remains is to focus on chapter 3 of demographic and health data, which is the main reason for this section.

Questions 1, 2, and 3 about age, sex, and country of origin respectively are three of the basic axes of stratification in social sciences, so they are unavoidable. We know, on the other hand, that the age and duration of the disease (questions 6 and 7) play a fundamental role in the health status of the patients (Kidd et al., 2016), and it is expected that this will affect the level of symbolic violence suffered. The other basic stratification axis is social class. It is not within the scope of this research to proceed from a very complex conceptualization of social class, but I believe that the approach considered is the most appropriate. In this sense, an attempt will be made to differentiate individuals according to their social class based on a combined approach of more purely contextual characteristics with social properties ascribed to the individual and their family context. Regarding the first aspects, according to some authors, the type of healthcare received functions as an axis of social class stratification, differentiating according to levels of primary and tertiary care (Wearden & Chew-Graham, 2006; Euba et al., 1996), and I add that in a context like ours, the level of healthcare will have to be disaggregated according to whether it is public or private (questions 9 and 15). From this point of view, question 4, about the municipality in which the respondent lives, together with question 14 of the symbolic violence scale (chapter 4 of the survey), should help to further outline the possibilities of obtaining healthcare of the person surveyed, since with them we know if they are located within a territorial health area that discriminates against CFS/ME patients or not, without needing to ask anything about the specific unit that treats them (if the case), a question that seems very risky to me and not advisable to ask, because it could arouse misgivings that would not help at all to gain the trust of the respondent. Regarding the second aspects, during the analysis of the 77 letters to the editor of the first article I already had the opportunity to identify that the levels of symbolic violence experienced by the patients seemed to be clearly stratified based on two closely interrelated dimensions such as the profession and the level of education. It seemed to be seen that “the ill people accustomed to receiving greater professional recognition, who are usually those who carry out trades that place them in a higher social position (orchestra directors, professors, architects, mayors, senior managers of leading musical institutions, etc.)” (Gimeno Torrent, 2022:10), were those who experienced a greater degree of symbolic suffering. To verify this hypothesis with a larger population sample, questions 5 (level of education) and 11 (current or past profession) are essential. But these analyses raised the question of knowing whether this greater degree of symbolic suffering was because the patients of these professions were more sensitive than others to the lack of a recognition that they had always had and had never lacked, or because they were exposed to higher levels of symbolic violence. Perhaps it will be difficult to answer this question,

The latter is a key element to interpret the age gradient and very probably also the social class gradient, particularly in the case of affluent classes that are always willing to make a profit, social benefit from *noble causes*, and much more when it comes to the cause of feminism, which is usually the heritage of women. On the other hand, the mania with gradients among medical epidemiologists is well known, and will probably lead many of them to believe that the question is exemplarily well formulated and, thus, they will also take their results as good, when it is very clear that ‘gradients’ are no guarantee of anything. If this question had asked about specific cases and examples of discrimination extracted from an in-depth, statistically representative research, such absurdities would not have been obtained and the percentages of discrimination would have decreased drastically.

but I think that the most promising way to do so is the whole battery of questions about material conditions of life, which, as cannot be otherwise in the case of sick people, on this occasion are also closely linked to those referring to the material support provided by the family. Thus we have questions 13 (has a couple), 17 (has a family), 14 (income level of the respondent and the possible couple), and 12 (does he or she work or not). We know that this last aspect discriminates between sicker and less sick people (Castro-Marrero et al., 2019).

Then there are questions about the health of the person surveyed. The hypothesis is that these questions are inevitable because there will be a clear association between the degree of severity of the disease and the symbolic violence suffered. Thus, it is known that one of the essential stratification axes of the health status of CFS/ME patients is whether they can leave the house or not (Pendergrast et al., 2016) (question 19). Question 10, about diagnosis and comorbidities, has a double objective. Firstly, by knowing the exact name of the diagnosed disease (it is requested that the name be noted as accurately as it appears in the patient's medical documentation), it is hoped that it will be possible to know the degree of severity of the disease, because in principle the diagnosis is based on standardized medical scales that allow us to distinguish between greater and lesser severity; although if this is not feasible, there are alternative ways to find out (question 12 about whether the respondent works can also be used in this sense). The same applies to comorbidities, it is likely that the more there are, the worse the patient's health will be, and they will suffer higher levels of symbolic violence. Probably the most extreme degrees occur among people who need a caregiver (question 18). Question 8, on the other hand, attempts to establish whether the patient himself had to suggest his diagnosis due to the medical staff's lack of knowledge about CFS/ME, a very common phenomenon of which we do not know the magnitude in our country and that this question try to determine.

Finally, with question 16, people affiliated with patient organizations are distinguished from those who are not. The hypothesis is that these are people who might have nothing in common, being in very different positions in the social space. Although this question is unnecessary for those surveyed recruited from patient organizations, it is essential for those recruited from the Internet (social networks). And it is expected that some of the members of the patient organizations will send their personal link to the survey to other sick people who are not part of their organization, so in the end it will be essential to ask this question to all the people who answer the survey. The question 20 is an indicator of suicidal ideation among CFS/ME patients, who often do not meet the criteria for depression (Devendorf et al., 2020), to establish the association with the symbolic violence scale, which in these cases could explain this phenomenon. What the last question 21 attempts to validate is the hypothesis of the preeminence of the social effects of CFS/ME over those purely due to the illness, as the patients repeatedly stated in the letters, and which I already had the opportunity to preliminarily explore in the first publication of this research project (Gimeno Torrent, 2022): on that occasion, 60% of the content of the letters corresponded to the "testimony that the patients gave of the enormous suffering of social origin that implies suffering from the disease" (Gimeno Torrent, 2022).

References

- Agresti, A. (2007). *An Introduction to Categorical Data Analysis* (2nd ed.). Wiley.
- Bartoll-Roca, X., Pérez, C., & Artazcoz, L. (2021). *Manual metodològic de l'Enquesta de Salut de Barcelona 2021*. Agència de Salut Pública de Barcelona. <https://www.aspb.cat/wp-content/uploads/2022/11/ASPB-Manual-Enquesta-Salut-2021.pdf>.
- Bartoll-Roca, X., Pérez, C., & Artazcoz, L. (2022). *Informe de resultats de l'Enquesta de Salut de Barcelona del 2021*. Agència de Salut Pública de Barcelona. https://www.aspb.cat/wp-content/uploads/2022/11/ASPB_Enquesta-Salut-Barcelona-2021.pdf.
- Bourdieu, P. (2000). *Pascalian Meditations*. Stanford University Press.
- Bourdieu, P., & Passeron, J.-C. (1966a). *Introduction à la sociologie I: Sociologie et Sociologie spontanée* (Film). IPN. <https://www.xaviergimeno.net/sociology-tv/bourdieu-passeron-i>.
- Bourdieu, P., & Passeron, J.-C. (1966b). *Introduction à la sociologie II: Vigilance épistémologique et pratique sociologique* (Film). IPN. <https://www.xaviergimeno.net/sociology-tv/bourdieu-passeron-ii>.

- Bourdieu, P., Chamboredon, J.-C., & Passeron, J.-C. (1991). *The Craft of Sociology: Epistemological Preliminaries*. Walter de Gruyter.
- Castro-Marrero, J., Faro, M., Zaragoza, M. C., Aliste, L., Fernández de Sevilla, T., & Alegre, J. (2019). Unemployment and work disability in individuals with chronic fatigue syndrome/myalgic encephalomyelitis: A community-based cross-sectional study from Spain. *BioMed Central Public Health*, 19, 840. <https://doi.org/10.1186/s12889-019-7225-z>.
- Devendorf, A. R., McManimen, S. L., & Jason, L. A. (2020). Suicidal ideation in non-depressed individuals: The effects of a chronic, misunderstood illness. *Journal of health psychology*, 25(13-14), 2106-2117. <https://doi.org/10.1177/1359105318785450>.
- Euba, R., Chalder, T., Deale, A., & Wessely, S. (1996). A Comparison of the Characteristics of Chronic Fatigue Syndrome in Primary and Tertiary Care. *British Journal of Psychiatry*, 168(1), 121-126. <https://doi.org/10.1192/bjp.168.1.121>.
- Gimeno Torrent, X. (2022). The circuit of symbolic violence in Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME) (I): A preliminary study. *Health Care for Women International*, 43(1-3), 5-41. <https://doi.org/10.1080/07399332.2021.1925900>.
- Guo, D., Chen, H., Long, R., Lu, H., & Long, Q. (2017). A Co-Word Analysis of Organizational Constraints for Maintaining Sustainability. *Sustainability*, 9(10), 1928. <https://doi.org/10.3390/su9101928>.
- Hope, A. C. A. (1968). A Simplified Monte Carlo Significance Test Procedure. *Journal of the Royal Statistical Society. Series B (Methodological)*, 30(3), 582-598. <https://doi.org/10.1111/j.2517-6161.1968.tb00759.x>.
- Howell, D. C. (2011). Chi-Square Test: Analysis of Contingency Tables. In M. Lovric (Ed.), *International Encyclopedia of Statistical Science* (pp. 250-252). Springer. https://doi.org/10.1007/978-3-642-04898-2_174.
- Kidd, E., Brown, A., McManimen, S., Jason, L. A., Newton, J. L., & Strand, E. B. (2016). The Relationship between Age and Illness Duration in Chronic Fatigue Syndrome. *Diagnostics*, 6(2), 16. <https://doi.org/10.3390/diagnostics6020016>.
- López Roldán, P., & Lozares Colina, C. (1999). *Anàlisi bivariàble de dades estadístiques*. Universitat Autònoma de Barcelona.
- Pendergrast, T., Brown, A., Sunnquist, M., Jantke, R., Newton, J. L., Strand, E. B., & Jason, L. A. (2016). Housebound versus nonhousebound patients with myalgic encephalomyelitis and chronic fatigue syndrome. *Chronic illness*, 12(4), 292-307. <https://doi.org/10.1177/1742395316644770>.
- Perianes-Rodríguez, A., Waltman, L., & Van Eck, N. J. (2016). Constructing bibliometric networks: A comparison between full and fractional counting. *Journal of Informetrics*, 10(4), 1178-1195. <https://dx.doi.org/10.1016/j.joi.2016.10.006>.
- Van Eck, N. J., & Waltman, L. (2023). *VOSviewer Manual: Manual for VOSviewer version 1.6.19*. Universiteit Leiden, Centre for Science and Technology Studies. https://www.vosviewer.com/documentation/Manual_VOSviewer_1.6.19.pdf.
- Wearden, A. J., & Chew-Graham, C. (2006). Managing chronic fatigue syndrome in UK primary care: Challenges and opportunities. *Chronic Illness*, 2(2), 143-153. <https://doi.org/10.1177/17423953060020020901>.