János Valery Gyuricza

Psychosocial consequences of labelling in healthy people with mild hypertension: development of a patient-reported outcome measure

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Tese apresentada à Faculdade de Medicina da Universidade de São Paulo para obtenção do título de Doutor em Ciências.

Programa de Saúde Coletiva
Orientadora: Profa. Dra. Ana Flávia Pires Lucas D’Oliveira
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To my grandfathers.

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‘Doctors have different attitudes to treatment. Some few treat their patients as individuals; some treat the labels which they have fixed to their patients; some treat the general public; some treat the patient's relatives and some few treat the doctor himself.’

(Sir George Pickering, Journal of the Royal Society of Medicine
Volume 71 December 1978)

'Tis but thy name that is my enemy;
Thou art thyself, though not a Montague.
What's Montague? It is nor hand, nor foot,
Nor arm, nor face, nor any other part
Belonging to a man. O, be some other name!
What's in a name? That which we call a rose
By any other name would smell as sweet;
So Romeo would, were he not Romeo call'd,
Retain that dear perfection which he owes
Without that title. Romeo, doff thy name,
And for that name which is no part of thee
Take all myself.’

(Juliet, in Romeo and Juliet)

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LIST OF ABBREVIATIONS

CVD	Cardiovascular Disease
EM	Explanatory Models
CAPES	Coordenação de Aperfeiçoamento de Pessoal de Nível Superior
CLH	Consequences of Labelling Hypertension Questionnaire
COS	Consequences of Screening Questionnaire
PROM	Patient Reported Outcome Measure
IRT	Item Response Theory
CFA	Confirmatory Factor Analysis
CTT	Classical Test Theory
LD	Local Dependence
DIF	Differential Item Functioning
CHW	Community Healthcare Workers
UBS	Unidade Básica de Saúde (primary healthcare clinic)

RESUMO

Gyuricza JV. *Consequências psicossociais do rótulo de hipertensão em pessoas saudáveis com hipertensão leve*: desenvolvendo uma medida de resultados relatados pelo paciente [tese]. São Paulo: Faculdade de Medicina, Universidade de São Paulo; 2020.

A hipertensão é uma condição assintomática comum presente em pessoas com baixo risco de eventos cardiovasculares futuros, que representam aproximadamente dois-terços das diagnosticadas com hipertensão. As evidências científicas mais recentes não recomendam o tratamento farmacológico para hipertensão leve como medida de redução de mortalidade cardiovascular. Ademais, a “sobreidentificação” de pessoas com hipertensão ocorre como resultado de campanhas de conscientização, rastreamento, acesso facilitado a medida de pressão arterial e prática clínica inapropriada, acentuando o potencial de sobrediagnóstico. São rarefeitas as evidências sobre as consequências negativas não intencionais do diagnóstico de hipertensão sob o ponto de vista do paciente sem doença cardiovascular, assintomático e de baixo risco cardiovascular. O objetivo geral desta tese foi o de desenvolver e validar um questionário com validade de conteúdo e propriedades psicométricas adequadas, capaz de medir as consequências psicossociais do diagnóstico de hipertensão leve. As pessoas que participaram deste estudo foram selecionadas entre pessoas com diagnostico de hipertensão sem outras comorbidades em São Paulo, Brasil. Foram selecionadas da lista de pacientes de unidade básicas de saúde ou por meio de mídias sociais e contatos pessoais. Três etapas principais permitirem alcançar o objetivo geral: 1) O método de tradução *dual-panel* foi utilizado para itens que oriundos de quatro versões de questionários da família *Consequences of Screening* (COS), originalmente em dinamarquês. Estes itens tiverem suas validades de conteúdo e face confirmados em entrevistas individuais e grupos focais; 2) Uma análise de conteúdo qualitativa foi independentemente realizada por três pesquisadores em onze entrevistas individuais semiestruturadas e quatro grupos focais, o que permitiu a obtenção de insights sobre os modelos explicativos de hipertensão e sobre as consequências psicossociais do diagnóstico. Estas entrevistas e grupos também subsidiaram a geração de novos itens, resultando numa lista de itens; 3) Uma versão preliminar do questionário foi construída, composta por toda a lista de itens, e em seguida usamos análise Rasch para filtrar a lista de itens, descartando aqueles que não se adequavam à suas dimensões e estabelecendo as propriedades psicométricas (unidimensionalidade, dependência local e funcionamento diferencial do item) do questionário. Análise fatorial confirmatória foi usada para confirmar os modelos derivados, e confiabilidade foi medida usando-se o coeficiente alfa de Cronbach. O estudo qualitativo permitiu a observação de consequências psicossociais do diagnóstico em uma ampla variedade de dimensões psicossociais, como por exemplo medo da morte, invalidez, envelhecimento, pressão e controle de pessoas próximas, vergonha, culpa e ansiedade. Para obter alta validade de conteúdo, foram criados 52 novos itens que foram acrescidos aos itens traduzidos, resultando numa lista de 133 itens divididos em 22 domínios e 2 partes. A análise psicométrica da lista de itens permitiu a seleção dos melhores itens, produzindo um questionário específico com alta validade de conteúdo para as consequências psicossociais do diagnóstico de hipertensão. Este questionário se chama Consequências do rótulo de hipertensão e é composto por 71 itens em 15 subescalas além de 12 itens solitários. Foi possível demonstrar que as subescalas apresentam unidimensionalidade, medidas invariantes e confiabilidade adequadas.

Descritores: Impacto psicossocial; Hipertensão; Sobremedicalização; Pesquisa qualitativa; Medidas de resultados relatados pelo paciente; Psicometria; Inquéritos e questionários.

ABSTRACT

Gyuricza JV. *Psychosocial consequences of labelling in healthy people with mild hypertension*: development of a patient-reported outcome measure [thesis]. São Paulo: “Faculdade de Medicina, Universidade de São Paulo”; 2020.

Hypertension is a common asymptomatic condition present in people at low risk of future cardiovascular events. These people represent approximately two-thirds of people diagnosed with hypertension. The best available evidence does not support pharmacologic treatment for mild hypertension to reduce cardiovascular mortality. Additionally, overdetection of hypertension also occurs, and this practice is supported by public awareness campaigns, screening, easy access to testing and poor clinical practice, enhancing the overdiagnosis potential. Moreover, sparse patient-oriented evidence is observed on harmful consequences of diagnosing hypertension in people without previous cardiovascular disease, asymptomatic and with low cardiovascular risk. Therefore, qualitative and quantitative evidence regarding the potential for unintended psychosocial consequences of diagnosing hypertension are required. The overall aim of this thesis was to develop and validate a patient reported outcome measure with high content validity and adequate measurement properties that would be capable of measuring the psychosocial consequences of labelling mild hypertension. My study population was selected among people diagnosed with hypertension without comorbidities in São Paulo, Brazil. Informants were selected among the general population from lists of patients of primary healthcare clinics, or from a social media and social network. Three main steps occurred to achieve the overall aim: 1) We used the dual-panel method to translate selected items from four different versions of the Consequences of Screening (COS) family of questionnaires that were originally in Danish into Brazilian Portuguese. These items were tested for face and content validity in single interviews and focus groups; 2) A qualitative thematic content analysis was performed by three researchers on eleven semistructured single interviews and four focus groups to obtain insights on the explanatory models of hypertension and on the psychosocial consequences of labelling hypertension. These groups also allowed the generation of new items for our questionnaire, resulting in a pool of items; 3) After surveying a draft questionnaire composed of the item pool, we used Rasch analysis to screen the item pool, discarding those that did not fit their dimensions and to establishing the psychometric properties (unidimensionality, local dependence, and differential item functioning) of the questionnaire. We used confirmatory factor analysis to confirm the derived measurement models, and assessed reliability using Cronbach's coefficient alpha. During the qualitative study we observed unintended consequences of the diagnosis in a broad range of psychosocial dimensions, for example fear of death, disabilities, or ageing, pressure and control from significant others and guilt, shame and anxiety. To achieve high content validity, we generated 52 new items that we added to the translated in the item pool. The result was a set of 133 items divided into 22 domains in 2 parts. The psychometric analysis of the item pool allowed to select items and validate a condition-specific questionnaire with high content validity for people diagnosed with mild hypertension. This measure is called Consequences of Labelling Hypertension (CLH) and encompasses in total 71-items in 15 subscales and 12 single items. Adequate unidimensionality, invariant measurement and reliability of the scales were demonstrated.

Descriptors: Psychosocial impact; Hypertension; Medical overuse; Qualitative research; Patient reported outcome measures; Psychometrics; Surveys and questionnaires.

1. PERSONAL BACKGROUND

I am a general practitioner. Since my first consultations in the clinic, I started wondering what was going on. Frequently, adults of all ages came for follow up of hypertension. Most often, they came mentioning uncontrolled blood pressure and carried a list of antihypertensives.

I used to ask them if they liked taking those pills, how they used them, and why they needed them for, and the answer was always:

- Hypertension!

And what came after that was what started to amuse me the most:

- "I have high blood pressure, and I feel my blood pressure when it is high! I was diagnosed when I had a 'crisis of pressure': in the hospital, they measured my blood pressure and told me I had high blood pressure and should take those pills. Now, whenever I feel the blood pressure is high, I take the pills."

I always asked complementarily, when, and why the person had such a crisis, and what they meant with "I feel when the blood pressure is high". Frequently, the crisis was related to life events and their social environment, and a colourful palette of symptoms was described. The blood pressure was measured after the perception of such symptoms and then took the place of the life events as a trigger of these symptoms. Many of those labelled with hypertension presented similar stories of hypertension being diagnosed in critical situations. Their life stories told me a lot more about their symptoms than their blood pressure.

After experiencing again and again this brief dialogue, I gradually noticed that my idealized hypertension was very far from the every-day life hypertension of my patients. Those people were possibly not suffering from the hypertension I knew about (a symptomless risk factor), nevertheless they really believed that they had hypertension. There was a conflict of explanatory models between the patients' and my own. They might have been incorrectly diagnosed, but for sure they were labelled as "hypertensives".

This perception directed me to investing the time of the consultation on telling my labelled patients what hypertension was, what was the meaning and physiology of blood pressure and all about the biases and the possible relationships between their symptoms, their blood pressure and their everyday life experiences. My personal background (supposing I was correct, and the others were wrong), strongly influenced me to think that the consequences of labelling could be relevant. What to say about an incorrectly labelled person?

I am not sure that my good intentioned explanations were what the patients needed at the time, if they were beneficial, or even if they were understood. My impression (my desire?) was that some patients decreased the number of antihypertensives in the prescription and a few of them were ‘cured’. I remember that I have not made any new diagnosis of hypertension in the last 3 years working in the clinic. There were many more labels awaiting to be removed, which everyday proved to be a never-ending task.

2. BACKGROUND

2.1. HYPERTENSION: RISK FACTOR OR DISEASE?

Accurately measured persistent blood pressure elevation – hypertension – is a risk factor for cardiovascular disease (CVD), and most of the times it is not a cause of symptoms[1]. The blood pressure is a physiologic variable easily affected by everyday activities and emotions[2]. In fact, the correct diagnosis requires that the blood pressure is measured more than once in controlled conditions, including being asymptomatic during the measurement[3].

When blood pressure elevation can be related to acute signs and symptoms such as chest pain, dyspnoea, oedema and neurological signs, then we are facing the cases in which the blood pressure elevation is an emergency since those are signs and symptoms related to acute CVD. In these cases, the blood pressure elevation is part of a syndrome: one of the possible signs of acute CVD. Moreover, in chronic cases of cardiovascular disease (for example congestive heart failure or angina pectoris) the monitoring and control of the blood pressure is mandatory to lower the chance of acute decompensation and hypertension is avoided with medication[1].

However, most frequently hypertension is a finding from preventive strategies supported by health policies, in which asymptomatic people have their blood pressure assessed in the physical examination. In these cases, hypertension is not a cause of CVD: it is a marker of population risk association with CVD, accompanied by physiopathologic plausibility[1,4]. In this case, the term “hypertension” is supposed to be used in the absence of clinically relevant CVD.

What defines the existence of hypertension in medical practice are not clinical signs and symptoms, but the numeric average value of the blood pressure, obtained by several indirect measurements and categorized by a threshold. The following chart (chart 1) describes the classification and current thresholds for hypertension in Brazil[5].

Chart 1 - Hypertension classification according to Brazilian Guidelines of Hypertension.

Classification	Systolic (mmHg)	Diastolic (mmHg)
Normal	<120	<80
Pre-hypertension	121-139	81-89
Stage 1 hypertension (mild)	140-159	90-99
Stage 2 hypertension (moderate)	160-179	100-109
Stage 3 hypertension (severe)	>179	>109

Two characteristics challenge the decision of where to set a threshold for the diagnosis of hypertension: blood pressure averages are normally distributed among the general population[6] whereas the relative risk of CVD increases with higher blood pressures in a quasi-linear relationship without a clear inflection in the curve that could identify a threshold between “yes-hypertension” and “no-hypertension”[7]. Additionally, if we define the threshold using standard deviations in a normal curve, then for each population a different threshold will be defined. Consequently, there is no certain blood pressure value where the threshold can be set[8].

Moreover, any blood pressure value is related to the incidence of cardiovascular diseases and a threshold might be unnecessary. One might argue that a threshold is relevant for research and clinical guidelines, since in both cases it is necessary to clearly identify and separate groups. In fact, the threshold is a useful mechanism of dichotomizing a continuous parameter in clinical practice and in populations to standardize the clinical assessment and interventions. However, the research on the epidemiologic basis of hypertension as a risk factor has been conducted with the blood pressure averages as a continuous variable and not with the dichotomized labels of hypertension[9]. Furthermore, cardiovascular risk calculators used today in clinical practice also do not dichotomize hypertension[10].

Risk calculators are much more tools to define the probabilities which might support the treatments directed to the relevant components of that single calculated risk than tools to decide for standardized treatment based on pre-defined thresholds[11,12]. Hence, a smoker with high blood pressure levels will benefit more from quitting the smoking habit, than from taking anti-hypertensive medication. In fact, according to the Framingham cardiovascular risk calculator: in a 55-year-old male with 160 mmHg average systolic blood pressure, the number needed to treat for smoking cessation is 13, whereas it is 20 for anti-hypertensive medication. Other calculators also point to smoking cessations as a better intervention than anti-hypertensives in both men and women above 40 years old, while physical activity and 'healthy' diet have similar impacts as anti-hypertensives (http://chd.bestsciencemedicine.com/calc2.html). Hence, hypertension should not be regarded as the preferable target for the prevention of cardiovascular disease[13]. It might be more effective to define targets and goals with the patient, in a patient-centred health care setting. Additionally, the more interventions proposed for the patient, the less the patient is likely to adhere[14,15].

When hypertension is kept as part of the components of the cardiovascular risk and not overestimated as a self-defined disease, there might be no need for dichotomization. Besides, population preventive strategies do not require any threshold since they target and address the whole of a population and intend to 'shift the curve to the left'. Furthermore, RCTs use *ad hoc* or guidelines' thresholds to define the selection of relevant subjects for intervention. *Ad hoc* thresholds are not thresholds for the clinical practice, since they were defined for the RCT, and might be far away from the threshold that better weighs benefits and harms in clinical practice[16]. Similarly, guidelines thresholds in clinical practice should be the starting point for informed choice, and not starting point for pharmacologic treatment[17,18]. Furthermore, the lower the threshold, the bigger the lower risk group of people diagnosed with hypertension and exposed to the harms of the diagnosis leading to less net benefit of the intervention[19].

The concept of disease is subject to social, cultural and economic influences that have varied over time[20]. During the last 50 years, we witnessed a growing tendency to classify variations of the normality, personal characteristics and everyday life experiences as medical diagnosis. Hypertension is one showpiece of this trend.

In the last two decades, a few authors have stripped evident these influences, describing how hypertension became a case of overdiagnosis, medicalization and disease mongering[21,22], three related concepts.

Soon after blood pressure averages were identified as a risk factor in the natural history of cardiovascular disease, blood pressure elevations were considered suitable for preventive treatment. This is one of the milestones of current medicine paradigm, in which people became target of preventive treatment before a disease is established[23].

In some way, the setting of a blood pressure threshold for hypertension defined the limits between sick and healthy and blurred the boundaries between disease and risk factor. In the following decades, the threshold gradually decreased and expanded over the group of healthy individuals, turning them into sick, leading to medicalization[24,25]. This process of widening the definition of hypertension dramatically increased the cases suitable for diagnosis[26]. In most cases these newly diagnosed could be regarded as overdiagnosed.

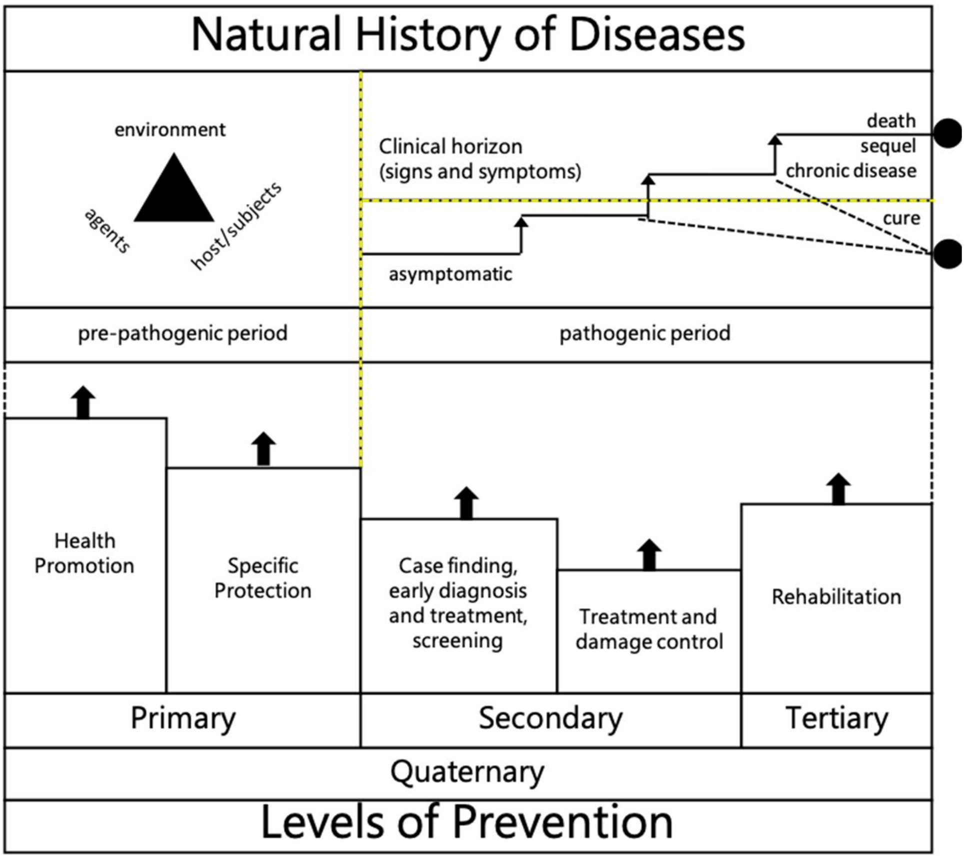
The blood pressure threshold appoints the label. The threshold creates an artificial clear-cut boundary that dichotomizes a continuous variable. In clinical practice, dichotomizing hypertension might be inadequate because of two possible reasons:

- It gives the wrong message. Dichotomizing suggests that if you are below the threshold, you are safe. On the opposite, those above the threshold are doomed, certain death is lurking behind the corner, and everything must be done to keep the blood pressure under control[27,28].
- It overmedicalizes. The label can be the alternative (and maybe more comfortable) explanation for other concurrent life processes that trigger unpleasant bodily responses via neuroendocrine perturbations.

Hypertension was consistently established as a risk factor in epidemiological studies but was translated as a peculiar “disease” among doctors and patients. Hypertension “disease awareness” campaigns made sure that everyone got worried about it, influencing doctors and patients alike in the pursue of a mythical health and in the crusade against aging and death[22]. Additionally, the private sector explores the easy access to blood pressure measurement and sponsor the outdoor disease awareness campaigns frequently seen in Brazilian public places, during which healthcare professionals offer free blood pressure measurement and hypertension advices. Disease mongering made mild elevations of the blood pressure become a silent killer disease.

To better understand hypertension in our current paradigm, I will briefly present three public health concepts public health: the natural history of disease[29], prevention[23,30] and risk factors[31].

Among others, Leavell and Clark[29] described the concept of ‘natural history of disease’, consolidating the fields of health promotion and prevention of diseases before they show symptoms. This was made in a context of progressive specialization and costs of curative medicine. They described it as a process from a pre-pathogenic period, to a pathogenic period. The pre-pathogenic period is a broad homeostatic relationship of people with the inner and outer environments. In this period, it is impossible to identify among the population, those that will continue to the pathogenic period. The pathogenic period starts with the onset of a disease, defining the subgroup of the population that might develop into cure, sequel, chronic disease, or death.



Source: Adapted from Leavell and Clarck[29].

Figure 1 - Natural history of diseases and levels of prevention: the original three levels described by Leavell and Clark and the fourth proposed by Jamoulle.

These two periods are divided by an undefined line, where risk factors and causes populate the scenario on the pre-pathogenic side, and early asymptomatic disease develops on the pathogenic side. In many cases, the onset of disease is silent until the clinical horizon is crossed.

Looking back at figure 1, another concept is exposed: the idea that all natural history of disease can be described from a preventive viewpoint[23]. Prevention are planned actions designed to avoid undesirable outcomes. Depending on the period of the natural history of a disease, four prevention categories can be described.

The goal of primary prevention is to reduce the incidence of a disease by reducing population drivers of disease. The goal of secondary prevention is to lower the disease's burden by early diagnosis, thereby facilitating cure or preventing it spreading or its long-term effects. Tertiary prevention focuses on rehabilitation with the goal of reducing the severity of impairment associated with an established disease. Later, a fourth level of prevention was added by other authors[32,33].

Quaternary prevention is a category underlying all other three, much more recently proposed in 1986 and reflects the “action taken to protect individuals (persons/patients) from medical interventions that are likely to cause more harm than good”[34].

Regarding hypertension, blood pressure lowering interventions based on the cardiovascular risk (or on the mere presence of hypertension) is defined as primary prevention, whereas the same interventions in patients with cardiovascular disease is defined as secondary prevention.

As a risk factor, hypertension is part of the natural history of cardiovascular disease at the pre-pathogenic period. Hypertension alone is a poor predictor of cardiovascular outcomes[12] being one risk factor among others identified in the cardiovascular risk assessment: diabetes, smoking, cholesterol and socioeconomic conditions[1].

Hypertension is present in roughly 30% of the adult population worldwide, it is the leading global risk factor related to preventable death and it is considered to account for 7% of global DALYs[35,36]. Albeit the relationship between the blood pressure and cardiovascular disease has strong and consolidated evidence, hypertension is not a cause of cardiovascular disease.

Nevertheless, epidemiology can only identify certain groups of people with similar characteristics as being more susceptible to cardiovascular disease in a defined population. The incidence of CVD is higher in populations with higher blood pressure averages. However, it is not possible to further identify the exact person, namely the cases that will develop cardiovascular disease, based on the blood pressure level, since a risk factor is a population probability.

Risk factors are population relationships determined by long-lasting cohort studies, such as the Framingham heart study[37]. The strength of association between a risk factor and an outcome is not sufficiently strong to define it as a cause of disease. Risk factors might be regarded as population determinants of incidence for a disease in the pre-pathogenic period[38]. Hypertension is neither necessary nor sufficient to explain the cases of cardiovascular disease.

2.2. POPULATION AND HIGH-RISK STRATEGIES FOR PREVENTION

Rose has described two different preventive strategies that can be adopted, defined in relation to the target population and to the objectives of the strategy: the high-risk strategy and the population strategy[30,38]. High-risk strategies are primary or secondary prevention strategies targeted to people that will most likely develop the disease, to avoid it (primary) or to make early diagnosis and early treatment (secondary). On the other hand, population strategies are the ones directed to the whole population.

Rose also divided preventive strategies in additive and reductive[39]. Reductive measures are actions aimed at reducing artificial exposures in the way of living, known to be pathogenic, of higher risk or detrimental to health, especially in industrialized societies[40]. Additive preventive measures are generally interventions professionally delivered in the body or in the environment, alien to the ecology-economy-physiology of the daily life of humans. Most often, high-risk strategies are also additive, whereas population strategies are reductive[40].

A successful generic high-risk strategy would diagnose correctly all the risk factors, treat accordingly and lead to lower cases of disease and mortality rates with high quality of life within the high-risk group in a population[30]. From the patient's perspective, the high-risk strategy might seem alluring, since it is an action directed against hypertension in the individual level. From the population perspective, it is targeted to a smaller part of the population that potentially has more benefits than harms: the high-risk group[19]. This strategy is additive and is highly dependent on the healthcare system, frequently diverting resources from the ill to the healthy (or potentially ill), reaffirming Tudor Hart's inverse care law[41].

In Brazil, the HiperDia program is an example of a national health policy focusing hypertension (and diabetes) adopting a risk strategy to prevent cardiovascular disease in public primary healthcare services[42,43]. According to the guidelines, all adults over 18 should have their blood pressure measured whenever assessing a primary health care clinic (opportunistic strategy) and repeat the measure at least every 2 years if the blood pressure is below the threshold[5,44-46].

In the high-risk strategy, it is necessary to define, search, identify and intervene with those people at high-risk. One type of high-risk strategy is a screening program[47]. A screening program is most often a laborious, expensive intervention, and a few conditions need to occur to achieve this strategy's goals:

- the prevalence of the outcome is high: true for cardiovascular disease; true for hypertension.
- the outcome is strongly related to the target of screening: true to cardiovascular disease; true for hypertension.
- the screening test is accurate: true for cardiovascular disease; not true for hypertension[48,49];
- the screening test threshold is set at the very best level: almost true for cardiovascular disease; not true for hypertension.
- the diagnostic test is accurate: true for cardiovascular disease; not true for hypertension.
- early diagnosis of the disease is possible: true for cardiovascular disease; not applicable for hypertension.
- treatment is available: true for cardiovascular disease; true for hypertension.

One might argue that hypertension is more frequent than other cardiovascular risk factors and it is easier to measure the blood pressure than the other risk factors, thus being a good candidate as first line input in the process of assessing the global cardiovascular risk[9]. However, the result of this strategy has been that the global risk approach frequently stops at the blood pressure assessment and is frequently not completed, potentially leading to the overtreatment of hypertension[13].

Furthermore, the screening test and the diagnostic test for hypertension are two different stages of the diagnostic process. Both are based on the same thresholds for blood pressure levels, frequently confusing patients and physicians. In the case of the screening test, either opportunistically or in universal coverage, a single measure (or the average of more than one measurements in the same encounter) is made, which is used to identify the person who needs further investigation in search for the average of a series of blood pressure measurements (diagnostic test) to make the diagnosis of hypertension[50]. It would be expected in this scenario that at all times, all measurements carefully respected standardized steps for an accurate measurement of the blood pressure in order to correctly diagnose all screened individuals. Since this diagnostic process is not at all perfect, it is always expected some amount of error. These expected errors are called false positives and false negatives results and are also expressed as sensitivity and specificity of the tests.

Added to the expected errors, there are the unexpected errors of clinical practice and the diagnostic process. Poor clinical practice is the main driver of this kind of error. Finally, there are the planned errors: the interferences of third parties aiming goals not related to better healthcare outcomes. Disease mongering and market-oriented disease definitions are examples of planned errors[51-53]. One example of disease mongering dressed as a preventive strategy are the popular health campaigns that occur in public places (subways, parks, shopping centres) offering poor quality non-standard blood pressure measurement for those passing by.

On the other hand, population strategies tend to be reductive[39,40]. Population predictors of incidence depend on biomarkers but also on lifestyle, culture and socioeconomic conditions, and can be observed during the pre-pathogenic period of disease[31,38]. This strategy needs to reach everyone and is frequently considered a matter for health policies that depend on multiple stakeholders and depend less on healthcare services. A successful population strategy would improve life conditions to everyone and move the distribution of blood pressure averages in a population to lower mean values, leading to lower morbidity, mortality and higher quality of life within the whole population.

Examples of successful population strategies for cardiovascular disease prevention are the higher taxation on tobacco and alcohol products, restriction of salt use in the food industry and the support for bicycle pathways. From the patient's perspective, the population strategy is inconspicuous since it does not act directly against hypertension in the individual level.

Finally, based on all previous arguments, it seems to be more rational to develop population rather than high-risk strategies for hypertension[54]. Additive strategies have greater potential for harm and medicalization, thus requiring the support of solid evidence[39].

Although there is strong evidence for the benefits of treatment for moderate and severe hypertension (blood pressure averages above 160/100), studies have failed to prove that pharmacologic treatment is beneficial for the group of people labelled with mild hypertension[55]. Mild hypertension is defined as blood pressure averages between 140/90 and 160/100. This is the biggest group of people with hypertension, and potentially the most harmed by the labelling effects of the diagnosis. This hypothesis is supported by the balance between benefits and harms of interventions as suggested by Glasziou and Irwig[19]: patients at greatest risk of disease will have the greatest net benefit as benefits to patients usually increase with risk while harms remain comparatively fixed.

In the literature, the potential benefits of diagnosing hypertension have been far more investigated and reported compared with the potential harms. Nevertheless, the benefits of the population preventive pharmacologic interventions in mild hypertension were not yet established, and there might be harms instead[19,56]. Harms are not restricted to side effects or biomedical harms. One of these harms might be the psychosocial consequences of the diagnosis.

2.3. BUILDING AND INSTRUMENT FOR THE MEASUREMENT OF THE PSYCHOSOCIAL CONSEQUENCES OF LABELLING HYPERTENSION

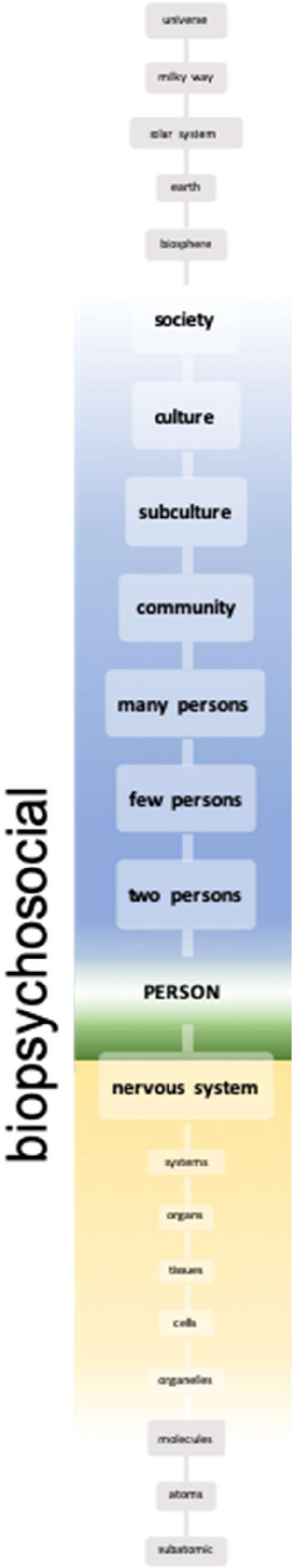
Psychosocial is more than the sum of psychological and social dimensions. It is a broad term and has been widely used in the literature with different meanings[57]. In Brazilian health literature (specially in mental health) and in international medical literature, psychosocial has been used as an adjective to indicate comprehensiveness of care and patient-centeredness, going beyond biomedical aspects.

The psychosocial dimensions of health are frequently associated with the importance of being mentally, emotionally, socially and spiritually sound, in other words, a part of ‘good health’. Psychosocial factors such as stress, hostility, depression, hopelessness, and job control have been associated with physical health-particularly heart disease[58].

The use of ‘psychosocial’ as a noun leads to the definition of a psychosocial construct. ‘Psychosocial’ is a way of stressing that psychological and social dimensions are inseparable.

In this thesis, I will not try to make the term less broad. Instead, I will try to give it meaning and make it possible to be measured in the case of mild HAS. I borrowed Engel’s biopsychosocial model and hierarchy of natural systems[59,60] to help me define what psychosocial might be: something that goes beyond the biological condition of human existence.

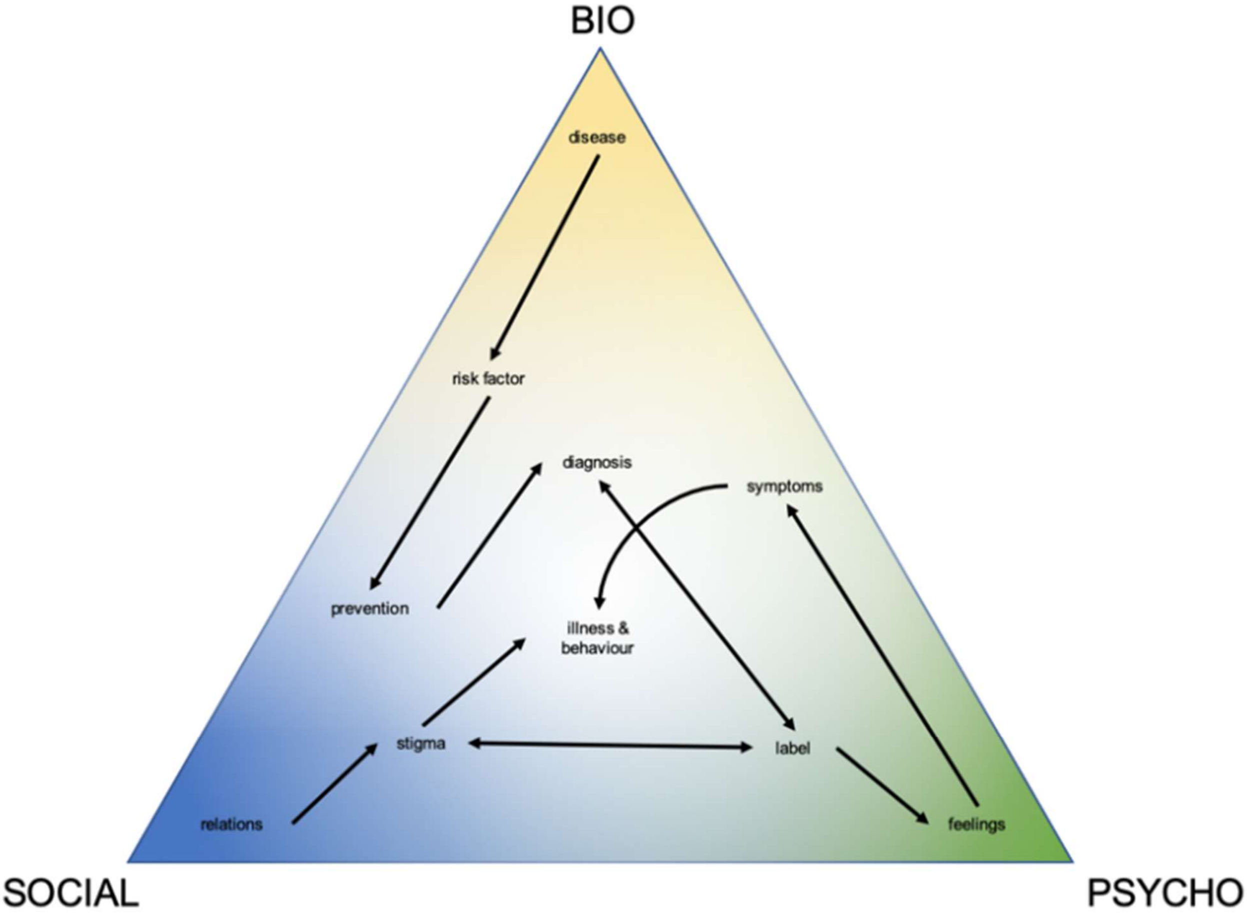
The psychosocial dimensions can be understood as part of the illness experience (the individual experience of being sick), whereas the biological (biomedical) dimension can be understood as disease, the set of signs and symptoms that can be labelled with a diagnosis[61]. Biological meaning all the common processes that take place in living creatures and are not exclusive to human nature. Of course, the boundaries between biological and psychosocial dimensions are not well defined, and it is probably impossible to define at which point the psychosocial emerges from the biological, as well as how much the psychosocial influences the biological. However, the distinction made in this thesis is a necessary analytical feature.



Source: Adapted from Engel's systems hierarchy.

Figure 2 - Engel’s biopsychosocial model and hierarchy of natural systems.

The higher we move in Engel's systems hierarchy (figure 2), gradually less biological and more psychosocial the levels become, until we reach the person, a 'biopsychosocial being'. If we than consider the psychological dimension as an emergence of the nervous systems, which is in its turn, immediately below the person level, we can define psychosocial on Engel's natural systems as everything that includes psychological and higher levels until the social level.



Source: Author's elaboration.

Figure 3 - The biopsychosocial model in the context of this thesis.

Figure 3 helps define 'psychosocial' in the context of this thesis. The biological (BIO), psychological (PSYCHO) and social (SOCIAL) are respectively represented in the yellow, green and blue vertices of an equilateral triangle, while illness and behaviour are in the centre. The biologic dimension contains the hypothetical cases of high blood pressure leading to cardiovascular disease. The psychological dimension contains the feelings related to the experience of being labelled as hypertensive and living with the diagnosis of hypertension. Finally, the social dimension contains the influences of hypertension in all levels in Engel's systems hierarchy situated above the person. The colours in the picture merge, suggesting the gradual relative predominance of each dimension while illness and behaviour are in the white biopsychosocial centre, where everything is merged.

People present to physicians with complains, most frequently with symptoms and signs. Diagnosis is the way physicians categorize people. It is a process of determining which disease explains the set of symptoms and signs presented by a person. Diagnoses rely on labels to designate the diseases' names: labels are tools for communication. In clinical practice, diagnosis also has the meaning of label: to diagnose is to label. However, according to Link and Phelan, the label is something that is affixed regardless of the validity of the designation and may lead to stigmatization[62]. Labelling may result in discrimination and status loss, influencing the person's behaviour[2,56,63].

Hypertension might be a "diseaseless" diagnosis that leads to labelling related illness: a label that names feelings as illness, giving meaning to psychosomatic symptoms related to life experiences; a label that triggers feelings and symptoms giving substance and name to the illness experiences. Sir George Pickering suggested that hypertension labelling may evoke a feeling of fear of the affliction of a serious disease in a patient[4]. My personal background suggested that the diagnosis of hypertension objectified the subjective individual experiences and medicalized the feelings and symptoms related to everyday life experiences, labelling them as hypertension.

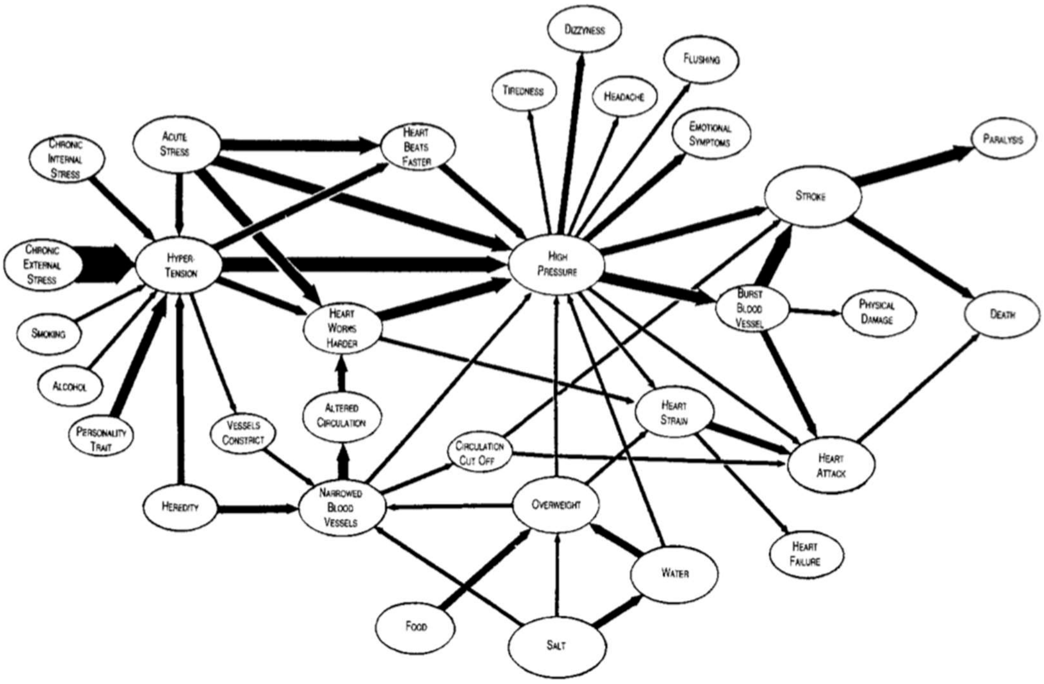
None of the previous studies about labelling effects in hypertension discussed the idea of hypertension as a label in the socio-anthropological sense, according to the literature review performed for this thesis. The expression 'labelling hypertension' is freely used in the literature without a common definition[2,63]. But is the diagnosis of hypertension a label that leads to stigmatization? How do people react to this label? How was the label affixed? Is there any effect of being labelled? What do people think when they are labelled? What are the psychosocial consequences of being labelled with hypertension?

In this thesis, I assume that people labelled with hypertension do not need to be correctly diagnosed with mild hypertension to experience the psychosocial consequences of labelling. The psychosocial consequences of labelling are the range of effects expected to occur in people’s life because of the label of hypertension affixed.

To better understand the illness experience of hypertension labelling, explanatory models of illness and disease can be used[64,65]. Explanatory models are the notions individuals and groups have of a certain topic. Each person has their own explanatory model, but it is expected that within a certain cultural group, people will share explanatory models[64,65]. Studies have addressed belief systems and explanatory models in health and described sickness as the union of illness and disease. This distinction between illness and disease has been widely described by anthropologic and sociologic studies[61,65].

Illness is the explanatory model for a person who is ill, whereas disease is the medical explanatory model; nevertheless, both models interact and are culturally determined[64,65]. Kleinman’s explanatory models were used to describe a patient’s understanding of the causes, symptoms, treatments and prognosis of hypertension[66,67], but appear to not yet have been used to understand the psychosocial consequences of the diagnosis and labelling. Kleinman[64,65] suggests that patient’s explanatory models usually are not fully articulated, tend to be less abstract, may be inconsistent and even self-contradictory, and may be based on erroneous evaluation of information.

Blumhagen[68] has described lay and professional explanatory models of hypertension among male American veterans in Seattle using Kleinman’s explanatory models. His findings among lay explanatory models were nicely structured in the following figure (figure 4). In this figure, the width of the arrows and the size of each node are proportional to the number of people who gave that item in their individual models.



Source: Blumhagen et al(68).

Figure 4 - Cognitive domain of hypertension.

More recently, explanatory models were used to address the link between them and adherence to treatment in older adults[67]. In Brazil, Fleischer[43, 69, 70] has contributed describing cultural aspects of hypertension and blood pressure from an anthropological perspective. Her findings suggest that Brazilian explanatory models share similar characteristics with other cultures which is in line with qualitative studies using explanatory models that described similar explanatory models of hypertension across different cultures[71,72]. A few examples of similar characteristics are: symptoms are often related to blood pressure; hypertension is a disease; erratic adherence related to the use of medication based on symptoms.

Fleischer[43,69,70] and Blumhagen[68] supported the hypothesis that the meaning ascribed to illness terms in popular health belief systems are drawn from the definitions of everyday language rather than from professional jargon. This finding is relevant because it makes possible for communication breakdowns between healthcare providers and patients. It raises the question: are the doctor and the person treating the same hypertension?

Furthermore, none of the previous studies directly addressed the question of the psychosocial consequences of labelling hypertension from the patient's perspectives. All literature I found during this research project was based on the ideas and explanatory models of the research groups. To grab the patient's perspective, it is necessary to conduct a study in a primary health care setting with people diagnosed with mild hypertension and without other comorbidities: it is necessary to exclude comorbidities, because they might also influence how people perceive themselves and reflect on how they feel in general and in particular to hypertension. Since hypertension is regarded as asymptomatic, the illness experience of having hypertension can be related to the experience of being labelled.

Additionally, since this is a group for which the benefits of treatment have not been established it is of great relevance to know the psychosocial consequences on them.

Nevertheless, there are examples of previous qualitative studies in hypertension addressing causes and symptoms of hypertension and attitudes to treatment reported in a systematic review[14]. On the other hand, I found only three qualitative studies on the effects of labelling hypertension published in English, Spanish or Portuguese. They have indicated that people experience subjective changes regarding their self-conception and experience multiple psychosocial consequences[73-75]. However, the Brazilian and the Iranian studies were conducted among hospitalised patients (not the low risk primary healthcare patients), whereas the study conducted in Denmark explored how primary healthcare patients experience and adapt to hypertension. Further qualitative work is needed in the medical field to observe if the diagnosis of hypertension is in fact a relevant event in different contexts and how it impacts people's lives from a patient-centred perspective.

Such is the effect of the diagnosis of hypertension, that in the past, studies have been conducted to address these effects and documented negative psychosocial consequences of labelling[2,63]. The bulk of evidence points to poorer interpersonal relationships, greater absenteeism and increased healthcare service use, among others, as consequences of being labelled as hypertensive[76-82].

Later, a few studies have used SF-36[83] (short-form health survey) and suggest that hypertension has impact in quality of life[84]. More recently, psychological distress was measured with the GHQ-12[85] (12-item General Health Questionnaire) and was found as a consequence of hypertension labelling[86].

These studies are the basis for what we know about the effects of labelling hypertension. However, they were conducted with methods that are not considered the gold standard and do not fit the purpose of this thesis.

Both SF-36 and GHQ-12 are generic measures designed to cover broad aspects of health and are widely used in different settings. The psychometric properties of any questionnaire cannot be assumed to be the same in any population, before evidence in this direction are described[87]. Additionally, there are a few limitations in the use of generic measures:

- may not be relevant in any target population and setting.
- will most likely be insufficient to cover the whole area of a specific research question.
- will probably address irrelevant questions for a specific research question.

In other words, generic measures might lack content coverage and content relevance for specific conditions: they may address topics that are irrelevant to individuals with hypertension and might not comprehensively address all relevant topics[88-90]. On the other hand, specific instruments are more responsive than generic tools, as they address more relevant topics to the person responding the questionnaire[90].

Specific measures of psychosocial well-being have been developed in the past, from the depression scales in the 1960s[91,92] to the development of unmet needs scales for cancer patients in recent decades[93]. However, these questionnaires do not address the psychosocial consequences of labelling hypertension. They most likely do not have content validity for this construct and are not suitable to address the research questions of this thesis.

Nonetheless, to achieve high content validity (content coverage and relevance), in addition to assessing previous studies on the subject, it is necessary to reassess the knowledge and experiences from the target population's viewpoint. Psychosocial aspects of life are typically assessed via patient-oriented perspectives. The most appropriate way to do this is by conducting qualitative studies that can identify patient's perspectives and relevant outcomes, namely 'patient-reported outcomes'[88]. Patient-reported outcomes are "evidences on patients' perspectives" that can be measured via questionnaires called patient-reported outcome measures (PROM)[94-96]. These perspectives can be assessed qualitatively to generate items, which are later tested for content validity to create a draft questionnaire that can then be investigated for its psychometric properties[97].

Specific questionnaires have been developed and used to assess quality of life in people with hypertension (e.g. CHAL and MINICHAL). However, these questionnaires were not developed from the patients' perspective; thus, they potentially also lack content coverage and relevance (content validity)[98-101].

To accurately and comprehensively measure the outcomes related to hypertension labelling in the context defined in this thesis, I intend to develop an instrument that captures the nature and extent of the psychosocial consequences of being labelled with hypertension and how these change over time. I aim for high content validity and for a questionnaire capable of providing a score.

Methods have been developed that allow accurate measurement of a construct such as the psychosocial consequences of labelling hypertension[102]. One of them is the combination of the development of PROMs and validation using item response theory (IRT)[96,103-105]. In this recipe, IRT can provide evidence of unidimensionality of a set of items hypothesized to measure different nuances of the same construct. Such evidence is necessary, to be able to postulate that the scores of each item can be added in a sum-score of all the items in the unidimensional scale[106].

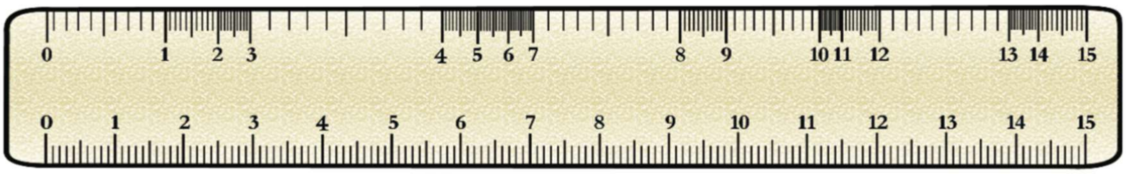
Brazilian Portuguese version of MINICHAL has been analysed with IRT and concluded to be suitable for the identification of the worsening of quality of life in hypertension[107]. However, the questionnaires were not self-applied and the inclusion criteria did not exclude people with hypertension and comorbidities.

An example of this type of questionnaire is the Consequences of Screening (COS) questionnaire[108-111]. COS is a family of questionnaires addressing various screening scenarios for life-threatening diseases, which is not the case of hypertension. However, it has been shown in qualitative studies that in spite of these differences in severity, living with hypertension is sometimes compared to living with life-threatening diseases[112]. The first questionnaire of this series was developed to capture the psychosocial consequences of abnormal and false-positive screening mammography for breast cancer and was named the COS-BC[108]. Later, additional versions were developed to address other screening scenarios for life-threatening, non-communicable diseases, including lung cancer, abdominal aortic aneurism and cervical cancer[109-111]. The COS questionnaires were developed in Danish and have a two-part common core questionnaire, in which the first part measures the negative psychosocial consequences at any time during the screening process, while the second part assesses changes in the long-term psychosocial consequences of screening after a final diagnosis.

When summing raw scores of items in a scale, an assumption of unidimensionality is made. In other words, in unidimensional scales, the items describe different aspects of the same construct and can be added. There are two complementary approaches when analysing data from questionnaires' responses: the classical test theory (CTT) and item response theory (IRT).

It is increasingly recognized that scores generated from questionnaire scales are more valid if analyses based on item response theory (IRT) have been conducted(113-115). Traditionally, questionnaires were validated using analyses based on classical test theory (CTT), such as Cronbach's alpha and correlation analysis. However, these methods are insufficient to establish unidimensionality[116].

Both CTT and IRT can be used to assess the dimensionality of a scale. When CTT methods are used, items correlations and Cronbach's alpha are employed to address internal consistency. However, the total score in CTT does not take into consideration which items are more or less difficult but only which person have more or less ‘ability’ to answer the tests questions, in other words, CTT assumes that systematic effects in the responses of a questionnaire are due only to the variation in the latent trait. In CTT it is assumed a normal distribution of data, that the items are distributed in an interval scale and that the raw scores are linearly correlated[88].



Source: courtesy of Prof. John Brodersen.

Figure 5 - Ruler with ordinal scale on top, interval scale at the bottom

Opposed to CTT, IRT models make no assumption of normal distribution of data and can include data distributed in an ordinal scale (figure 5). Ordinal scales are more accurate in describing polythomic items scores, since it can be assumed that the distances between thresholds of the polythomic items scores are most likely unequal. IRT models consider both the ‘ability’ of the respondent and the difficulties of each question[115].

Additionally, IRT Rasch models provide a formal representation of perfect measurement assuring the following characteristics of measurement: criterion-related construct validity, unidimensionality, additivity, specific objectivity, sufficiency and reliability[117-120]. Therefore, Rasch models are regarded as the strictest IRT models and the only IRT models that ensure invariant measurement (included in the concept of specific objectivity) and the only IRT models in which the sum-score represents all the information needed (included in the concept of sufficiency). In this thesis, criterion-related construct validity will not be tested, since no other measure has been previously developed for the psychosocial consequences of labelling hypertension.

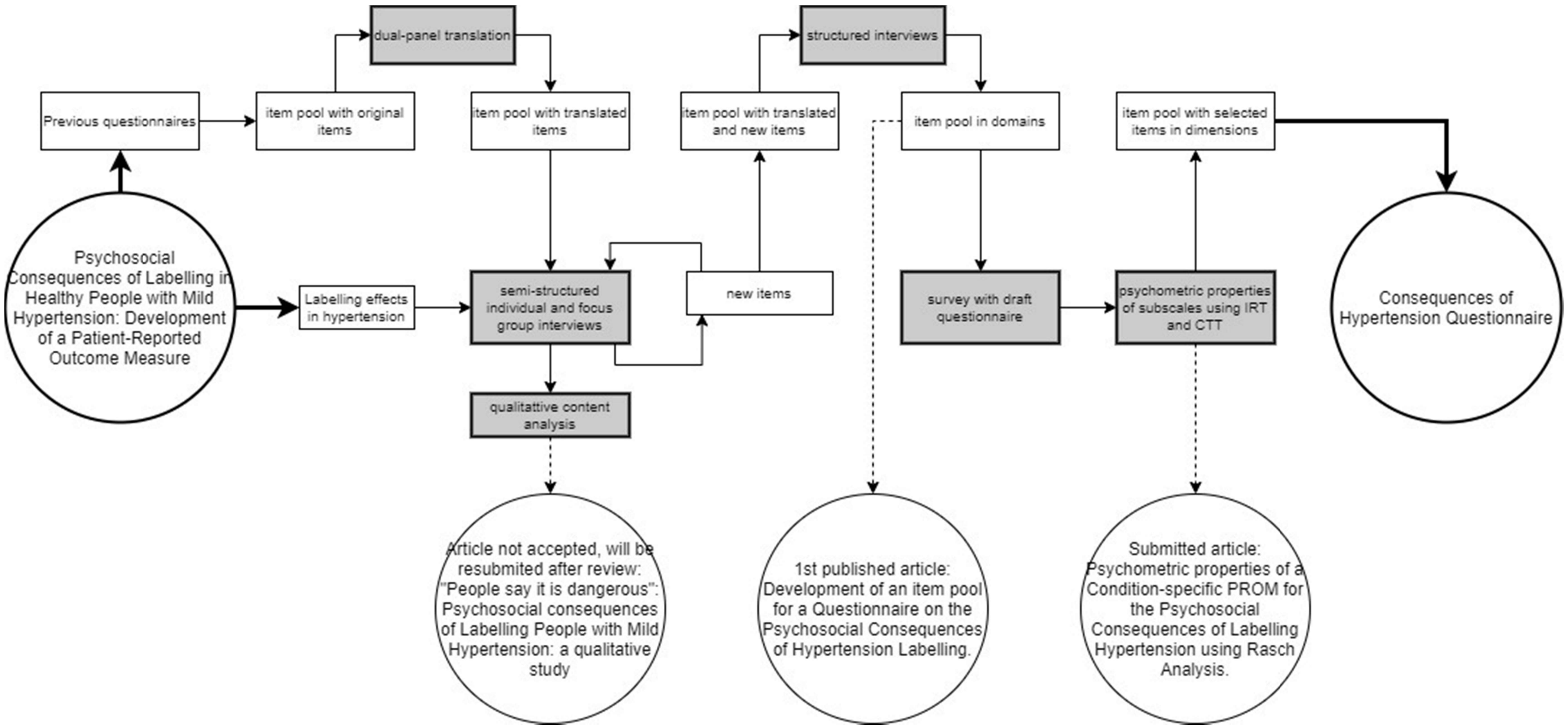
3. AIMS OF THIS THESIS

The overall purpose of this thesis was to develop and validate a questionnaire with high content validity and adequate measurement properties that would be capable of measuring the psychosocial consequences of labelling mild hypertension. The overall purpose is threefold.

- To investigate the explanatory models of hypertension and the unintended psychosocial consequences of diagnosing mild hypertension in people without comorbidities in a Brazilian context.
- To develop and categorize a pool of items for a condition-specific multidimensional questionnaire composed of multiple subdimensions with high face and content validity to measure the psychosocial consequences of being diagnosed with mild hypertension.
- To test in each of the subdimensions in this pool of items for unidimensionality and invariant measurement using Item Response Theory Rasch models.

4. METHODS

I have used mixed methods during this thesis to achieve the aims. Figure 6 describes the steps of this thesis, the grey boxes stress the methodological steps. Each of these steps are described below in the methods section.



Source: Author’ s elaboration.

Figure 6 - Steps of the thesis

To assess face validity, a systematic literature search was conducted in Medline and PsycINFO for articles in English and Portuguese to identify questionnaires used to assess the psychosocial consequences of being diagnosed or labelled with hypertension. We used a broad set of search terms related to hypertension (high blood pressure, blood pressure, arterial pressure, hypertension and risk factor); labelling (diagnosis, stereotyping, stigma and awareness) and PROMs (quality of life, patient outcomes, surveys, questionnaires and patient-reported outcome measures). We selected the questionnaires that suited our needs and then cherry-picked all items that seemed relevant.

4.1. DUAL-PANEL TRANSLATION

We translated all cherry-picked items from COS questionnaires into Brazilian Portuguese using the dual-panel method[121]. The dual-panel method consists of the two following panels: bilingual panel and lay panel.

4.1.1. Bilingual panel

First, in São Paulo, I conducted a bilingual panel including John Brodersen and four people who were bilingual (fluent in Danish and with mother tongue in Brazilian Portuguese). The panel members were asked to translate all instructions and items from Danish into Brazilian Portuguese. If there were divergences in the translations, they were asked to discuss and find a consensual translation. If the panel members could not reach consensus, they could generate two or more versions and leave it up to the next panel to decide which translation was most close to lay Brazilian Portuguese language.

4.1.2. Lay panel

Second, the lay panel included people living in São Paulo and who had no knowledge of the Danish language. The members of the lay panel were five community healthcare workers (CHW). In addition, one of the bilingual experts helped during the lay panel. He translated discussions and questions from Portuguese into Danish and vice-versa, allowing the participation of John Brodersen, my co-supervisor and developer of the COS family of items. The translated items were read together with the group, and I asked if the versions produced by the bilingual panel were expressed in easily understandable lay language. After this session, a draft questionnaire in Brazilian Portuguese was designed and qualitative methods were used to improve it.

4.2. FACE AND CONTENT VALIDATION OF THE ITEM POOL

The construct of the psychosocial consequences of labelling hypertension in people without comorbidities needed to be qualitatively explored. I explored it with semi-structured individual and focus groups interviews. We expected the individual interviews to allow deeper insights, whereas the focus groups were expected to promote debate around topics, allowing a broader exploration.

We planned two parts for these interviews: during the first part people were encouraged to talk about the circumstances and experience of being diagnosed with hypertension, and what changed in life after that; during the second part the item pool was explored with the person or the group.

4.2.1. Semi-structured individual interviews and focus groups

We recruited the informants *ad hoc* from the public primary healthcare services in São Paulo (Unidade Básica de Saúde - UBS), social media and a social network for single interviews and focus groups. The informants were selected purposefully to obtain a wide range of experiences and variety regarding age, time from diagnosis, education level, gender and ethnic origins. Informants selected from the UBS were identified in the list of people diagnosed with hypertension. Informants selected from social media responded to an invitation posted on Facebook. In addition, the researchers' social network suggested a few of the informants. A telephone contact identified the inclusion and exclusion criteria among eligible informants and invited them for the face-to-face single interviews and focus groups. The inclusion criteria were: Informants raised in

Brazil aged 18 years or older who self-referred the diagnosis of hypertension, were prescribed antihypertensive treatment, and presented with no other chronic or disabling conditions. Whenever available, we assessed the person's files to confirm blood pressure levels: we did not measure the blood pressure of our volunteers.

The psychosocial dimensions focused on included bodily perceptions; ageing; death; psychological aspects; interpersonal relations (family, friends and colleagues) and broader social relations such as work and employment, leisure, citizenship, political engagement and economics. All these relevant psychosocial aspects of everyday life are in accordance with patient-centred clinical methods, Engel's biopsychosocial model and explanatory models of hypertension[60,64,122,123] which formed the theoretical background of this research.

A semi-structured interview guide was developed to assess each informant's EM of hypertension and the psychosocial experiences related to the diagnosis of hypertension. This guide could evolve from one interview to the next, depending on the information we obtained from the interviews. A similar guide was used during the focus groups interviews. The guide included the following categories and subcategories:

1. Explanatory Models of hypertension: what, why, when, where and how?
2. Psychological effects: body perception and feelings about ageing, death and disease.
3. Social effect: ethics, relations with others (family, friends and others), public spaces, employment, citizenship and economy.

During up to ninety minutes, the informants were encouraged to openly discuss their knowledge and experiences of being diagnosed with hypertension, and I asked them to elaborate when necessary. The informants were not directly asked about symptoms or side effects; however, they were requested to elaborate whenever these topics spontaneously emerged. I allowed issues to emerge that were relevant for the informants, and during focus groups, we had an active role by asking other informants to state their opinions on that specific issue. The field notes regarding the interview situation, the body language, the role of each informant, the process and other impressions were written during and immediately following the interviews and used to contextualise the interview accounts.

All interviews were conducted face to face by me. During the focus groups Lucas Bastos was also present. We decided data saturation had been achieved when we agreed that no new relevant information was being revealed in additional interviews, and we had obtained a sufficient amount of material to achieve our objective[124]. We conducted the focus groups interviews after the single interviews. We invited five people per focus group. Digital technology was used to record the audio of all interviews and focus groups, and then the audios were transcribed verbatim.

The focus-group interviews consisted of two parts: first, we led an open-ended discussion for 30 to 45 minutes focusing on hypertension, and for the next 90 minutes, we discussed the items in the item pool. In these groups, all the items were tested, but we first focused on the newly generated items. We asked the group if the items were understandable, represented experiences that they might have had (content relevance) and if there were any domains or items missing or irrelevant (content coverage).

The informants in the individual interviews completed a draft questionnaire containing the item pool during a think-aloud session[125]. All were asked to formulate opinions on the instructions, on the items and on the layout of the questionnaire.

4.2.2. Content analysis

Ana Flávia, Lucas Bastos and I listened to the audio files and read each transcript from single interview and focus groups many times to explore the results. From our phenomenological perspective, we analysed the data by using thematic content analysis[126]: We used the event of diagnosis as a milestone for changes in psychosocial dimensions and searched for comprehension of the patient’s EM of hypertension and how the EM affects psychosocial aspects of the informants lives.

We analysed all the interviews and agreed regarding the coding structure and coding each transcript separately. When our interpretations differed, quotes representing units of meaning (codes) were compared and discussed repeatedly. Codes were grouped to generate categories. We compared the codes with the original text to ensure the codes were rooted in the material. Those categories were discussed and related to the theoretical framework, until we agreed on a set of themes and subthemes. Some themes emerged from the empirical material, and other themes were derived from the theoretical background that supported the creation of the interview guide described in the methods section. The software Nvivo® was used to manage data.

Later, we read and discussed the content of the interviews; if lack of content coverage was identified, we formulated new items that reflected informants’ verbatim expressions (whenever possible), categorised the items into previous domains and suggested new domains when new items did not fit into the previous domains. These new domains and items were then added to the item pool for the next steps.

4.2.3. Structured Interviews

Finally, I conducted four 60-minute structured individual interviews. The informants were given a list of all items and asked to elaborate on all the new condition-specific items and to categorise them into pre-determined domains.

Given that recently elaborated items were tested, the informants were told they could be categorised into one of the existing domains, or if necessary, a new domain could be suggested. Similar suggestions on an item were considered evidence to categorize that item or to lead to the creation of a new domain, while items without similar suggestions were left for later discussion with my supervisors.

4.3. PSYCHOMETRIC ANALYSIS

To run the psychometric analysis of the item pool, a survey had to be conducted to obtain real responses.

4.3.1. Survey with draft questionnaire

In this survey, our target was a sample of the Brazilian population and the inclusion criteria to apply the new questionnaire were: to be older than 18 years old, to be healthy (no self-reported health condition) and to have only hypertension (self-reported hypertension and no other self-reported comorbidity). We collected information about age, gender, ethnic origin, self-reported presence of hypertension, comorbidities, time from diagnosis of hypertension and level of education.

In this study, our target was a sample of the Brazilian population, and the inclusion criteria were: to be older than 18 years old, to be healthy (no self-reported health condition) and to have only hypertension (self-reported hypertension and no other self-reported comorbidity). We collected information about age, gender, ethnic origin, self-reported presence of hypertension, comorbidities, time from diagnosis of hypertension and level of education. A draft questionnaire composed of all the items in the item pool was sent to a target population by using the following strategies. We first used the Survey Monkey® Internet-based questionnaire manager to format digital and printed versions of the questionnaire and then distributed it in different media platforms, such as e-mails, WhatsApp® messages and Facebook® invitations. All invitations included a link to the digital questionnaire and could be forwarded to other people. We targeted healthy people and people living with hypertension, but we accepted responses from everyone and used the collected information to separate our target population from the rest afterwards. We also distributed printed versions of the questionnaire among the community healthcare workers around four different primary healthcare clinics. All questionnaires were self-applied. Data were collected in 2017. The responses in the printed versions were transcribed to the data bank by the first author. The draft questionnaire included an informed consent form and sociodemographic items. All items that were tested are described in appendix A.

4.3.2. Psychometric properties

We selected Rasch model analysis(127) to screen the items and to establish the psychometric properties of this questionnaire because given that it assumes unidimensionality (Rasch models assume that all items reflect an underlying construct), it allows to investigate the fit of the items to a hypothesised dimension and how these items are interrelated and ordered on a latent continuum; thus, it supports the addition of the raw scores of items into a single score[115].

We referred to the qualitative material whenever an item did not fit the model and tried to understand why they did not fit. We aimed at two features of the Rasch models during the psychometric analysis: local response dependence (LD)[128] and differential item functioning (DIF)[129]. LD occurs when two items capture unique common information independently from what is supposed to be measured by the item set. That is, the answer of an item should not influence the answer of another item. Meanwhile, DIF occurs when the expected responses of individuals with the same level (but belong to different groups defined by an external factor) for a measured construct differ. That is, an external factor should not influence the answer of an item[130]. We included age (defined as age above or below 40), gender (male or female), ethnicity and the presence or absence of hypertension in our analysis.

To provide the measurement of psychosocial consequences consistent with Rasch measurement theory, the scales calculated from the data collected for psychometric analysis should fit a graphical Rasch model (GRM)[131-133]. The overall model fit was assessed using the Andersen conditional likelihood ratio test[134] and the individual item fit was evaluated by comparing observed and expected item-rest score associations[96].

We also evaluated item fit graphically by dividing the sample into five score groups. For each item, we plotted the item mean score in each interval and compared all the scores to 95% confidence regions of the model expectations.

For each item, the observed mean score in each class interval was plotted as a line together with a shaded area that indicates the 95% confidence region of the model expectations. Thus, when curves are contained in the shaded area, the observed data match the model expectations and thus indicate item fit.

The following was the modelling strategy:

(i) evaluating the fit of the COS core items in their previously identified domains to the Rasch models;

(ii) evaluating the fit of the COS core items to a GRM derived using item screening procedure, assessing the issues of COS core problematic items and removing them from the scale;

(iii) adding COS disease-specific items to the scale;

(iv) evaluating the fit of the COS disease-specific (+ COS core) items to the GRM, assessing the issues of COS disease-specific problematic items and removing them from the scale;

(v) adding new items to the scale;

(vi) evaluating the fit of the new items (new + COS items) to GRM, assessing the issues of problematic items and removing them from the scale;

(vii) if possible, confirming the dimensionality of the derived scales by using confirmatory factor analysis (CFA);

(viii) evaluating reliability using Cronbach's coefficient alpha.

After the Rasch model analysis, we used CFA and Cronbach's alpha to confirm our findings. In CFA and Cronbach's alpha, missing data were excluded, and only complete responses were assessed. We used the evidence of local dependence found in the Rasch model analysis to indicate the correlated error terms in the CFA model. CFA was used only for scales with four or more items after the Rasch model analysis. Rasch model analysis was conducted using the computer programme DIGRAM[135]. CFA and Cronbach's alpha were conducted in STATA.

The null hypothesis of the statistical tests in the Rasch model analysis was that the model fits. We adjusted p-values by using the Benjamini-Hochberg(136) procedure to control the false discovery rate at 5% and thus took values above 0.05 as cut-off values for model fit. In CFA, the cut-off values were 0.06 for RMSEA and 0.95 for CFI. Values above 0.70 for Cronbach's coefficient alpha were considered adequate.

4.4. ETHICS

All informants provided their informed consent, and the study was approved by the Faculdade de Medicina da Universidade de São Paulo ethical committee, CAAE 54699716.0.0000.0065.

5. RESULTS

5.1. CONTENT ANALYSIS

I conducted 11 in-depth single semi-structured interviews (table 1) in the last 3 months of 2016 and in the first 3 months of 2017 in a location the informants found least inconvenient: mostly at their private homes. After the single interviews, I conducted four focus group interviews (table 1) in an easily accessible location: either the UBS or one of the informant's home that lived nearby the clinic. Focus groups comprised informants with similar characteristics regarding sex. There was no other person during the interviews besides the informants, Lucas Bastos and me. The single interviews lasted from 30 to 90 minutes, whereas the open-ended discussion in the focus groups lasted 30 to 45 minutes .

The study population had a broad range of sociodemographic characteristics. We interviewed people regardless of sex with a broad age-range of 21 to 74 years and who had been diagnosed with hypertension from 1 month to 30 years before. Our informants included illiterate, low, medium or high level of education and different sorts of work, including two health professionals. We also included Informants of different ethnic group (the informants' characteristics are listed in table 1. Although we aimed at five participants for each focus group, many did not show up, and focus groups had to be conducted with three participants. Group 3 was composed of men, which proved to be more difficult to recruit. We included only those that either had records of blood pressure levels below 160/100 or who self-referred blood pressure levels below 160/100 at the time of the diagnosis and during follow-up.

Table 1 - Subjects characteristics and participation

Order	Qualitative phase	Name	Sex	Age	Ethnic	Education (years completed)	Time since diagnosis (years)	Local
1	semi-structured individual	Iago	male	30	white	18	4	public place
2	semi-structured individual	Julieta	female	21	black	9	4 months	home
3	semi-structured individual	Othello	male	36	white	19	3	work
4	semi-structured individual	Jessica	female	35	mixed	8	1 month	UBS
5	semi-structured individual	Desdemona	female	36	white	16	4	home
6	semi-structured individual	Horacio	male	46	white	11	1.5	UBS
7	semi-structured individual	Cordelia	female	44	white	20	9	work
8	semi-structured individual	Ophelia	female	64	white	11	7	home
9	semi-structured individual	Viola	female	65	white	11	22	home
10	semi-structured individual	Gertrudes	female	64	mixed	11	15	home
11	semi-structured individual	Romeu	male	44	mixed	18	8	work
1	focus group	Livia	female	42	mixed	11	12	UBS
1	focus group	Cecilia	female	43	white	15	2	UBS
1	focus group	Placida	female	50	black	15	15	UBS
2	focus group	Angela	female	57	mixed	8	17	UBS
2	focus group	Helena	female	65	mixed	11	30	UBS
2	focus group	Eugenia	female	74	white	5	20	UBS
3	focus group	Bras	male	43	black	11	3	UBS
3	focus group	Quincas	male	65	mixed	8	8	UBS
3	focus group	Camilo	male	65	white	illiterate	15	UBS
4	focus group	Rita	female	51	mixed	16	13	Home
4	focus group	Sofia	female	55	white	11	3	Home
4	focus group	Virgilia	female	56	white	16	1	Home
1	structured	Bento	male	45	white	19	10	work
2	structured	Capitolina	female	40	white	20	4	work
3	structured	Glória	female	44	white	26	9	work
4	structured	Pedro	male	40	white	20	3	public place

The single interviews and the focus groups data were combined for the analysis. In the first content analysis, we identified 42 categories. After discussions between Ana Flavia, Lucas Bastos and I, these categories were merged into two main themes, seven subthemes and 14 subsubthemes. The two main themes were patient's EM of hypertension and psychosocial consequences. For details regarding the subthemes and subsubthemes, see chart 2. Patients describe a wide range of patient's EM and psychosocial consequences. We first treat patient's EM and psychosocial consequences separately and provide quotes demonstrating their content. Next, we demonstrate how patient's EM and psychosocial consequences may be related and describe the resulting conceptual model.

Chart 2 - Patient's EM of hypertension and psychosocial consequences of the diagnosis and their subthemes and sub-subthemes.

Theme	Subtheme	Sub-subtheme
Patient's explanatory models of hypertension (patient's EM)	What is hypertension?	
	Intertwined relationship with symptoms	A cause of symptoms
		A consequence of symptoms
	Causes of hypertension	Habits and lifestyle
		Bad genes
	Prognosis of hypertension	Course and severity
		Treatment
Psychosocial consequences of the diagnosis	Emotional consequences	Fear
		Shame and guilt
	Behaviour consequences	Lifestyle changes
		Adherence to treatment
	Relational and social consequences	Family
		Friends
		Work

5.1.1. Patient's explanatory models of hypertension

In the interviews, hypertension was reported as a chronic disease/condition and an intermittent increase in blood pressure associated with everyday life experiences. For some of the informants, their contexts could be the cause of symptoms and blood pressure elevation; but frequently, this relation was not clear because the cause of symptoms could also be attributed to the blood pressure elevation. Despite the differing opinions regarding hypertension being or not-being a disease, almost all the informants considered hypertension a chronic condition with potentially long term and short-term severe consequences (i.e. death or disability), which can be caused by insufficient compliance with the medical recommendations.

5.1.1.1. What is hypertension?

The typical answer to 'What is hypertension?' was 'I don't know', followed by models describing values of blood pressure levels and its relationship with some norm. When describing hypertension, the informants frequently used the word 'disease' or its negation, 'not a disease'. Most of the informants said hypertension is a chronic disease, and symptoms, pharmacological treatment and potential severe outcomes were reported as justifications. Few informants said hypertension was 'only a condition', and one informant said hypertension was 'nothing'; these comments were usually from informants that regarded hypertension as asymptomatic. Overall, many informants expressed the thoughts like Jessica, who described hypertension as 'harmful to her health'.

Othello stated:

> *"What the fuck! Now, I am a chronic patient."* (Othello)

None of the informants had received a hypertension diagnosis during a preventive asymptomatic casual measure. In all cases, there was a relevant stressful context during which their blood pressure was measured, and hypertension diagnosed. Iago described the life events around the diagnosis:

> *"I used to work as a lawyer, and I was under a lot of pressure to approve one specific project. One day I felt really ill with a strong headache, my whole body was aching. I had a crisis at work and ended up at the hospital. At the hospital, I was told that my pressure was as high as 18 over 12, something like that. I have never had this past history of pressure."* (Iago)

5.1.1.2. Intertwined relationship with symptoms

Patients provided two descriptions for symptoms: no symptoms related to blood pressure and symptoms when their blood pressure was high. In this case, patients identified several symptoms and emotional factors that helped them monitor and feel the presence of an elevated blood pressure and prevent cardiovascular outcomes, merging them as causes and consequences of hypertension. Informants justified blood pressure elevation symptoms as related to stressful events. On the other hand, they could recognise that stressful events per se could trigger symptoms followed by blood pressure elevations. Viola describes one of these stressful events:

> *"After my daughter was diagnosed with a disease, my BP is always high. I have been very worried about her. Sometimes, I feel my BP elevate when she is feeling ill. When she is stable, I am ok. I can feel when my blood pressure is high, you know, I can feel it, and I get worried. Then, I stay at home, and I know that what I am feeling is because of the pressure."* (Viola)

The same symptom could be recognised as a cause and consequence of hypertension, and thus was observed as intertwined. Ophelia provided a clear perspective of this intertwinement:

> *"I noticed that there was something wrong with my pressure because I had problems to sleep. I also noticed this in my heart: some shocks during the night. When my pressure rises, I know that it has risen, I get my blood pressure device and rush to measure. It has been a while since this is not happening, but I assure you that I will not die from a stroke!"* (Ophelia)

5.1.1.2.1. A cause of symptoms

On one hand, hypertension explained the bodily and emotional discomforts. For Juliet, her blood pressure was the cause of her headaches.

> *"Every time I am in pain or feeling I might faint, I say: 'it is my pressure!' Before I discovered it, I could not feel it [the blood pressure], I just felt headache."* (Juliet)

5.1.1.2.2. A consequence of symptoms

On the other hand, hypertension was explained by bodily and emotional discomforts. For Cordelia, her anxiety was the cause of her blood pressure elevation. However, an opposite message was provided by the doctors when their aim was to control the blood pressure.

> *"My anxiety often triggered my blood pressure, and I was taken to the hospital because it was elevated. The doctors used to ask if I was anxious, (…) and kept the blood pressure under control."* (Cordelia)

5.1.1.3. Causes of hypertension

Patients reported modifiable and nonmodifiable causes of hypertension. The modifiable causes of hypertension included, for example, diet, alcohol consumption, perceived stress and physical activities, and were categorised under the sub subtheme 'habits and lifestyle'; by contrast, the idea of a genetically inherited trend described the nonmodifiable cause under the sub subtheme 'bad genes'.

5.1.1.3.1. Habits and lifestyle

These modifiable causes were considered personal choices, and when medical orders were not followed, these modifiable causes were considered failures. Most subjects considered hypertension a consequence of how they took care of their bodies and health, that is, a consequence of their individual behaviour.

Gertrudes stated:

> *"It is up to me to control my high blood pressure: less salt, no smoking and no drinking. Everyone knows that."* (Gertrudes)

5.1.1.3.2. Bad genes

Additionally, the nonmodifiable causes were impersonal, not controllable, and could balance their individual responsibility. As a counterweight to what the informants mentioned as a consequence of their own actions, they frequently mentioned hypertension as genetic, described their family history, and regarded their diagnosis a result of 'bad genes'. This type of inheritance served as an explanation for the diagnosis: The problem was with the 'body machinery'; thus, the hypertension diagnosis was a foregone conclusion, a biological fate. Desdemona merges both sub subthemes in her interview:

> *"Overweight, sedentary lifestyle and bad genes. I think this is all. I used to live at the countryside and was very active, with 15 kg less. Here I am inactive. I cook at home, so my food is good. I don't like living alone here, far from my family. Putting all together, bad genes, since my father and mother are both hypertensive."* (Desdemona)

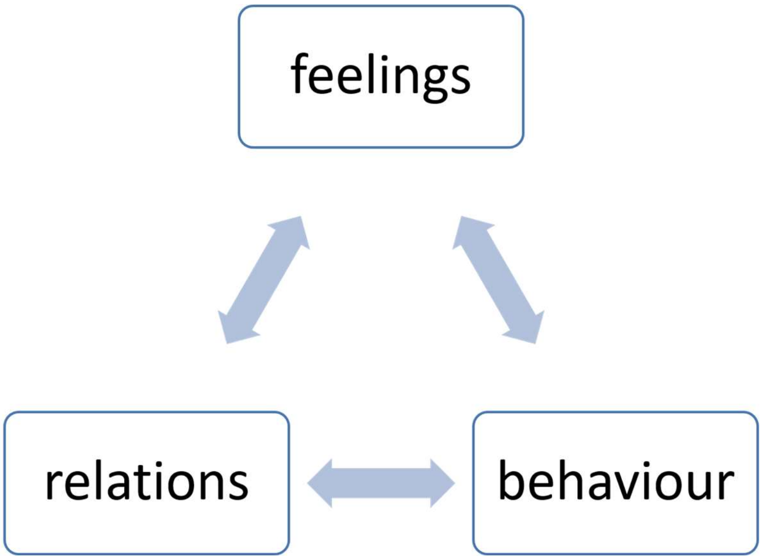
5.1.1.4. Prognosis of hypertension

Informants described hypertension as a condition that leads to serious health consequences, including strokes, heart attacks, disability and death. This description was more of an inexorable condition than a probability of adherence to pharmacologic and non-pharmacologic measures and reflected what the informants saw and heard from doctors and the media. The informants indicated that they had considered the possibility of severe consequences, and these consequences could occur in the distant future or at any moment. We observed that pharmacologic treatment made the illness more concrete and was considered the most critical and effective intervention to avoid negative outcomes, although nonpharmacologic measures, for example, stress control and change in lifestyle and habits, were also recognised.

> *“I have seen a lot of people with blood pressure problems, some even died.”* (Juliet)
>
> *“High blood pressure leads to, as I heard a doctor say on TV a few days ago, leads to a stroke. If I can eat with less salt, be physically active (…) if I can take these precautions, I will live happily for the rest of my life, if God wills. I am not afraid. Frankly, the only thing that I am afraid of is a stroke – God, do not give me that!”* (Ophelia)

5.1.2. Psychosocial consequences of the diagnosis of hypertension

We divided the psychosocial consequences into three, interconnected analytical dimensions: feelings (intrasubjective and intersubjective), behaviours (understood by the informant as individual choice but also result of relations) and social relationships: a trialogue (figure 7).



Source: Author’s elaboration.

Figure 7 - The trialogue between feelings, relations and behaviour

The diagnosis was perceived as a threat and triggered psychologic reactions. These feelings had a direct effect on personal relations with family, friends and at work and motivated irregular changes in behaviour (adherence to pharmacologic treatment and lifestyle changes). Adherence to medical orders was frequently difficult and resulted in additional fear and worries. The need for behavioural change affected personal relations that sometimes resulted in unwanted controls on their life and habits, and was reflected as more elaborate psychological reactions, such as guilt and shame. One informant, Horacio, related he observed no impact on his social relations, suggesting that some people experience no consequences in social relations as an effect of the diagnosis of hypertension.

Furthermore, the impact on personal relations was reflected as changes in behaviour and triggered further psychological reactions, such as envy and rage.

5.1.2.1. Emotional consequences

Feelings were triggered by the patient's EM. The event of the diagnosis was a relevant milestone for all subjects, and the memory of experience persisted and elicited feelings.

5.1.2.1.1. Fear: risk of dying or becoming ill

The major psychologic reaction elicited by the diagnosis was fear: fear of stroke or heart attack, disease, ageing, sequelae, or death. Because most of the informants considered hypertension dangerous in the short and long term and a **cause** of stroke or heart attack, the shade of death or disability was always present for almost all the informants, especially if they did not adhere to treatment or were unable to control the stress. Ophelia explained that she was afraid of having a stroke and the impact this fear had on her behaviour.

> *"Of course, I am afraid of a stroke and stay forever in a bed. Doctors say that high BP can cause a stroke. I am afraid of it myself. I do everything with caution, because I am afraid of a stroke."* (Ophelia)

5.1.2.1.2. Shame and guilt: what others might think?

Other feelings elicited by the diagnosis were shame and guilt: shame of using medication in front of others, and shame of appearing to be older or ageing. Othello, a highly educated man, tells us about that phenomenon:

> *"It is not a good idea to leave my medication on my desk. I don't like when people ask me about this subject. I am not 50 or 60 years old to be asked about my health. Nobody asks me about it! At the most, my mother tells me to lose weight. I would get really pissed off if someone asks me about this subject. I don't like when people approach me about it."* (Othello)

The impact of diagnosis and illness fades over time. But even many years after diagnosis, failure to comply with the new expected behaviours may trigger guilt, as described by Iago:

> *"I feel guilty, because I do not feel sick anymore, and I forget my pills. Sometimes, I measure the BP again, and then I think that it is too high. I lost some weight during the last 12 months, and my BP decreased as well. At the time of the diagnosis, it was almost 140! I also feel afraid of a stroke because of an abrupt elevation of the BP. I forget to take my pills, and when I remember it, I realise I should not forget anymore."* (Iago)

5.1.2.2. Behavioural consequences

The diagnosis cast a shadow on the informants' future health. The fear was linked to the diagnosis of disease or premature death that they must control through compliance with lifestyle changes and prescribed pharmacologic treatment. In this manner, fear was a motivation for change; however, frustration was also present when the informants encountered frequent difficulties in adherence.

Beyond the recommendations of the medical system, for many of the informants, psychological stress management was also a critical factor to control blood pressure elevation and avoid the risk of a sudden event. Jessica was recently diagnosed and described the impact of the diagnosis regarding how she started managing stress:

> *"What changed the most was my way of life. I was more hectic, nervous and now I control myself. I used to be very nervous, and ain't anymore. A try to control myself because I know it can affect me. Also, my food and my behaviour with my kids changed."* (Jessica)

Fear was also an impetus for changes in lifestyle and habits and frequently followed by the idea of 'now I have to take care of myself'. The diagnosis influenced behavioural changes demonstrated to reduce blood pressure, but the duration of these changes was short. Othello described his initial motivation gradually decreasing.

> *"It has this immediate effect of motivating to avoid it. I went to the cardiologist, took my medication, changed my lifestyle. But little by little, this effect vanished. Nowadays, it is just a discomfort, worst when I think about it, but nothing that bothers me. Doesn't keep me awake at night."* (Othello)

Cordelia exercised with caution whenever she forgot her medication. She described how she accepted the diagnosis as an imminent risk in the absence of medication, which interfered with some of her daily activities:

> *"When I forget the medication, I get worried because I like to go to the gym in the morning. Once I forgot and went to the gym. I did not run or train with strength that day, I took it easy. I was apprehensive. But usually I do not forget, I wake up and take it. In this way, medication becomes an obligation and forgetting is not a problem anymore."* (Cordelia)

Some informants took treatment for granted, other informants doubted if 'the need' for medication was genuine, and others used medication successfully according to their patient's EM, that is, they had symptoms that were relieved after taking the medication, and the medication helped them feel as if their blood pressure was under control without the need for lifestyle changes.

5.1.2.3. Relational and social consequences

The severe outcomes attributed to hypertension affected personal relations because they were afraid of becoming ill and not being able to perform their roles in their families. Additionally, some informants mentioned that their relatives were also concerned about them, which increased their compliance.

Subjects reported that they felt controlled by their families and friends. This control reminded them of the diagnosis. Family and friends were reported to be attempting to fit the informants into how a patient diagnosed with hypertension should behave according to their patient's EM. Changes in lifestyle were necessary, difficult, and sometimes annoying because of the pressure of significant others.

Genetic inheritance also promoted attrition between family members that did not inherit the same 'bad genes'. A few of the subjects resisted and attempted to go on with their lives after making minor changes. Compliance also decreased fear and increased feelings of relief. Two young informants—Iago and Othello—described the how their social relations control their behaviour in similar terms.

> *"People remember it all the time. For example, when I go to some friend's barbecue, they say: You can't eat this because you have high blood pressure. I will eat it, stop paining my ass, I react. I will eat it because I like it."* (Iago)
>
> *"My mother checked the (BP) device. She started gossiping to my wife: look, he measured it, and it was elevated. You have to talk to him. He has to take care of himself. He has been too stressed."* (Othello)

Other relations were also affected by the diagnosis. Cecilia, in a focus group, reported fear of losing her job because of hypertension and not finding a new job; and Othello was embarrassed regarding having to take pills at work in front of colleagues. Others mourned over not being able to go to parties, drink alcohol, or eat *feijoada* and *churrasco*, and how those sacrifices impacted leisure and social activities.

> *"At first, I did not take my medication, because I wanted to be able to drink beer. (...) My friends liked to drink on weekends. If I stop (the medication) on Friday, like a lot of people does to be able to drink on weekends, then what is the use of the medication? The blood pressure will rise. I was afraid of drinking alcohol and taking my medication at the same time."* (Othello)

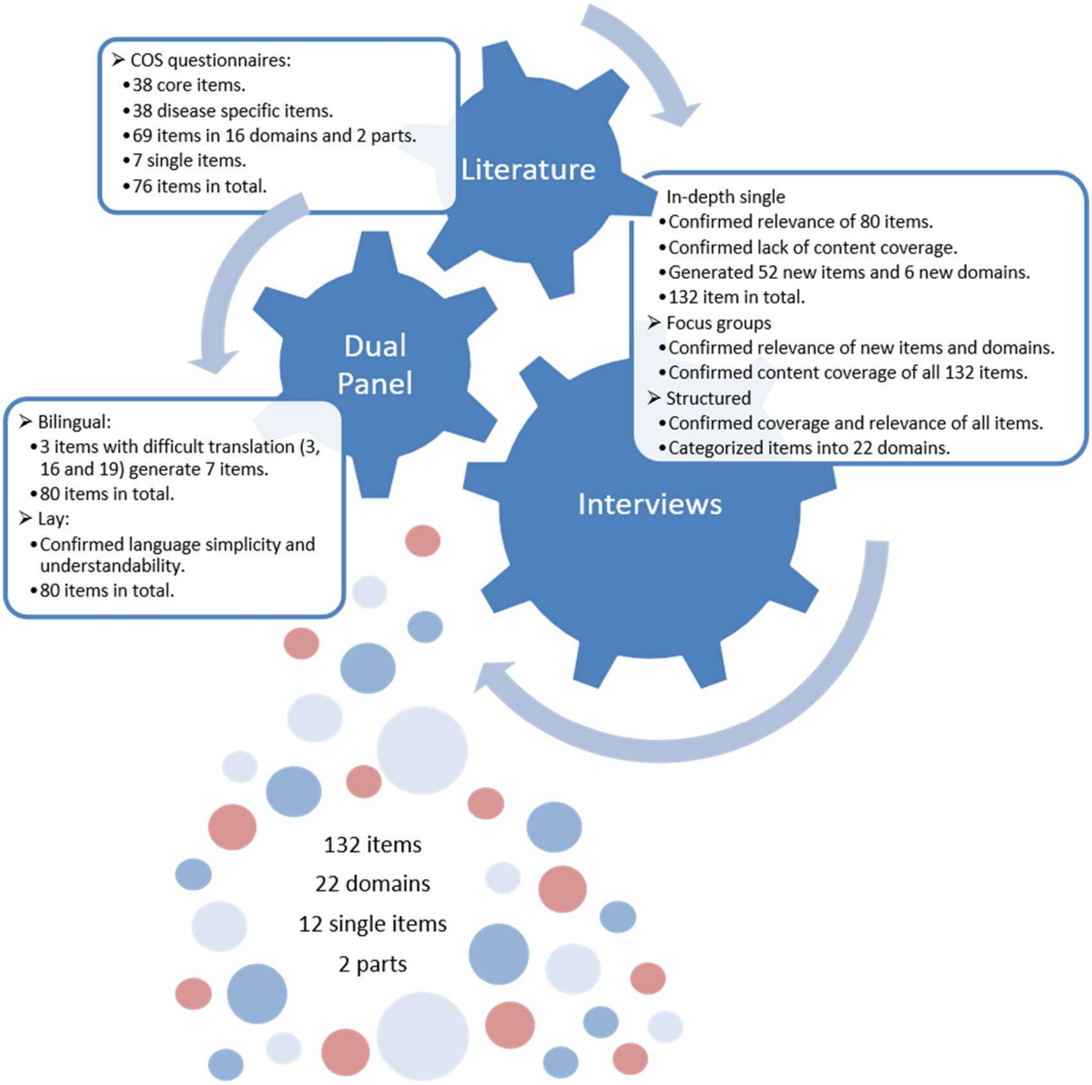
There were very few reports regarding the cost of treatment related to transport, medicine, exams or cost of professionals, as Brazilian health system provides it for free.

5.2. ITEM POOL

Looking back at figure 6 describing the steps of this thesis, the development of the item pool required the selection and translation of original items followed by content validation of these items in qualitative interviews. News items were created and added along this process. Figure 8 describes the methodological steps and results of this part of the study.

No condition-specific PROM on the consequences of labelling people with hypertension was identified. Therefore, the COS questionnaires were chosen as the only relevant source of items. We selected 76 items (55 items from part I and 21 from part II) from the 4 COS questionnaires; Half of which (26 from part I and 12 from part II) are present in all COS questionnaires and compose the core items. The other half (29 from part I and 9 from part II) is present in COS as disease specific items.

The domains were firstly developed in the original versions of COS, where items were grouped according to their meanings, based on the content validation. The simplified name of each domain does not fully describe the domain's content. The table in the appendix A lists all items (item pool) with their respective Brazilian Portuguese wordings, domains, parts, positions, origins, meaning in English or Danish and response categories. A total of 69 items out of these 76 items were representative of 17 different domains: 12 in part I and 5 in part II, while 7 items were regarded as single items: 2 in part I and 5 in part II.



Reference: Author’s elaboration.

Figure 8 - Methods overview

5.2.1. Dual panel

Three 76 core items generated more than 1 version in Brazilian Portuguese, resulting in a total of 80 items.

5.2.1.1. Bilingual panel

All original Danish items, except three from part I, did reach consensual Brazilian translation. These three items were given more than one Brazilian version: Items 16, 93 and 94 were three Brazilian items representing different translated and adapted versions of the original Danish item 16 (‘I felt bothered’); items 19 and 20 are two versions of original Danish item 19 (‘I felt paralyzed’); and items 3 and 4 are also two Brazilian versions of the original Danish item 3 (‘I felt scared’). Therefore, after conducting this panel, the 76 original Danish items became 80 Brazilian items.

5.2.1.2. Lay panel

The group confirmed the instructions’ and items’ translations as lay language and understandable. They were unable to select one item out of the versions for items 3, 16 and 19, and therefore all were kept, confirming all 80 items. One sensitive suggestion was confirmed during this part, which was related to the inversion of the pronominal preposition in Brazilian Portuguese. Although this represents a grammatically incorrect form of the sentences, it is directly related to the way Brazilian people speak. All the sentences were then rewritten from ‘Senti-*me…’* to ‘*Me senti…’*.

5.2.2. Interviews

We used the second part of the same individual semi-structured interviews, focus groups and individual structured interviews with 27 informants of both sexes, aged 21-74 years, being diagnosed with hypertension 1 month to 30 years ago, education level low to high, including illiteracy, and various ethnic groups (table 1).

5.2.2.1. Think aloud session

Our informants’ content-validated the 80 translated items. In total, we generated 52 new items (35 for part I and 17 for part II) for 12 domains. Twentyfive of these new were encompassed in 6 new domains. In part I, 3 new domains were generated: the ‘blood pressure-related’ domain encompassing 3 items, the ‘social relations’ domain encompassing 7 items and the ‘results of diagnosis’ domain encompassing 2 items. In part II 3 new domains were also generated: the ‘hypertension-related’ domain encompassing 2 items, the ‘patient role’ domain encompassing 8 items and the ‘preoccupation with health’ domain encompassing 3 items.

5.2.2.1.1. Instructions

Three options of instructions for part I were designed based on our previous experiences with questionnaires. We offered our informants these three options and asked them to elaborate on them:

- How have you been feeling the last month? (*Como você se sentiu no último mês?*) (Or)
- How have you been feeling the last week? (*Como você se sentiu no ultimo semana?*) (Or)
- How do you feel nowadays regarding blood pressure? (*Como você se sente hoje em dia com relação à pressão?)*

The informants suggested that the best way to frame the instruction of part I was the first option: ‘how have you been feeling the last month?’, and we chose this one for the questionnaire. They suggested that the second option included a too short of a period, while the third was rejected because it was too broad.

Complementary part II was opened with the question: Taking everything into account: the diagnosis, the follow-up, the exams, the pills… (*Levando tudo em consideração: o diagnostico, o seguimento, os exames, os remédios …*); and part II has items introduced by the sentence: … after I knew I had high blood pressure … (… *depois de saber que tenho pressão alta* …). No changes were suggested in this part.

5.2.2.1.2. Response categories

The original COS was developed with polytomous items. Part I had the following possible answers:

- No, not at all/no, not even once (*não, nem um pouco/não, nem uma vez*)
- Yes, a little/yes, a few times (*sim, um pouco/sim, poucas vezes*)
- Yes, some/yes, sometimes (*sim, não muito/sim, às vezes*)
- Yes, a lot/yes, many times (*sim, muito/sim, muitas vezes*)

A few items had a fifth option: I don't know (*não sei*), and one item was relevant to counting the number of missing days at work and had the option: 0, 1–2, 3–4 or 5 or more; I don't work. These response categories were confirmed to be relevant, comprehensive, understandable and easy to complete.

The same was found for the translation of the original response categories in part 2. All items were polytomous, with the following possible answers:

- A lot less… *(muito menos)*
- Some less… *(um pouco menos)*
- The same as before…*(o mesmo que antes)*
- Some more… *(um pouco mais)*
- A lot more…*(muito mais)*

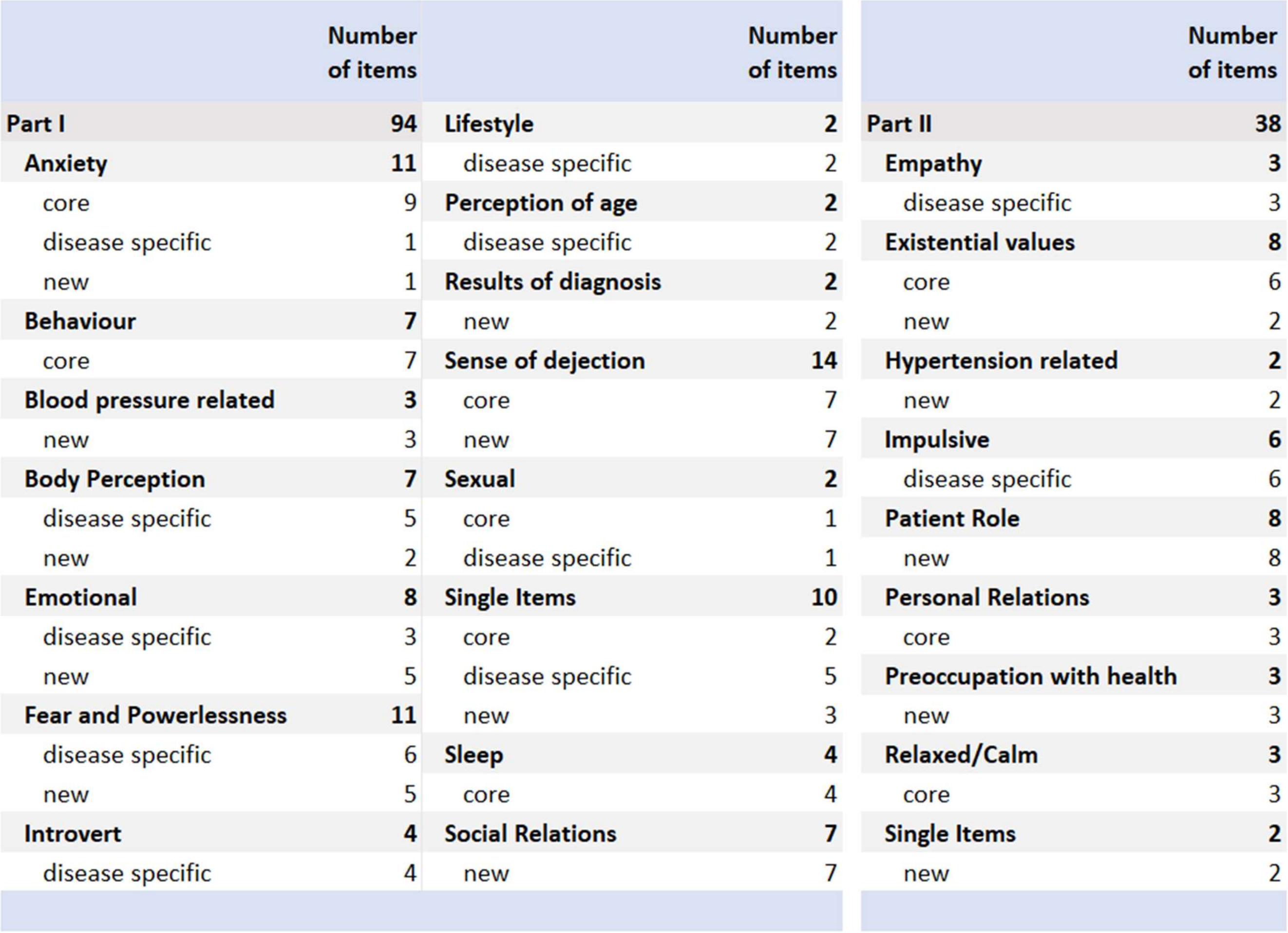
5.2.2.2. Focus groups

No new items were developed. The groups confirmed high content validity of the 133 items.

5.2.2.3. Structured interviews

Five new items (3 from part I and 2 from part II) could not be categorised by the informants into any of the existing domains and were therefore regarded as single items (chart 3).

Chart 3 - Number of items in each domains, and their origins.



	Number of items
Part I	**94**
Anxiety	**11**
core	9
disease specific	1
new	1
Behaviour	**7**
core	7
Blood pressure related	**3**
new	3
Body Perception	**7**
disease specific	5
new	2
Emotional	**8**
disease specific	3
new	5
Fear and Powerlessness	**11**
disease specific	6
new	5
Introvert	**4**
disease specific	4
Lifestyle	**2**
disease specific	2
Perception of age	**2**
disease specific	2
Results of diagnosis	**2**
new	2
Sense of dejection	**14**
core	7
new	7
Sexual	**2**
core	1
disease specific	1
Single Items	**10**
core	2
disease specific	5
new	3
Sleep	**4**
core	4
Social Relations	**7**
new	7
Part II	**38**
Empathy	**3**
disease specific	3
Existential values	**8**
core	6
new	2
Hypertension related	**2**
new	2
Impulsive	**6**
disease specific	6
Patient Role	**8**
new	8
Personal Relations	**3**
core	3
Preoccupation with health	**3**
new	3
Relaxed/Calm	**3**
core	3
Single Items	**2**
new	2

We also asked the informants to allocate the versions of the two original items without a consensual translation to a domain: items 16, 93 and 94 (originally item 16) and items 19 and 20 (originally item 19). Items 16 and 93 were categorised in a different domain (‘anxiety’) compared to item 94 that stayed in the original domain (‘sense of dejection’). Items 19 and 20 were both categorised as belonging to the domain of ‘sense of dejection’.

5.3. SELECTION OF ITEMS AND UNIDIMENSIONALITY OF THE SCALES

5.3.1. Data collection for the statistical psychometric analysis - sample

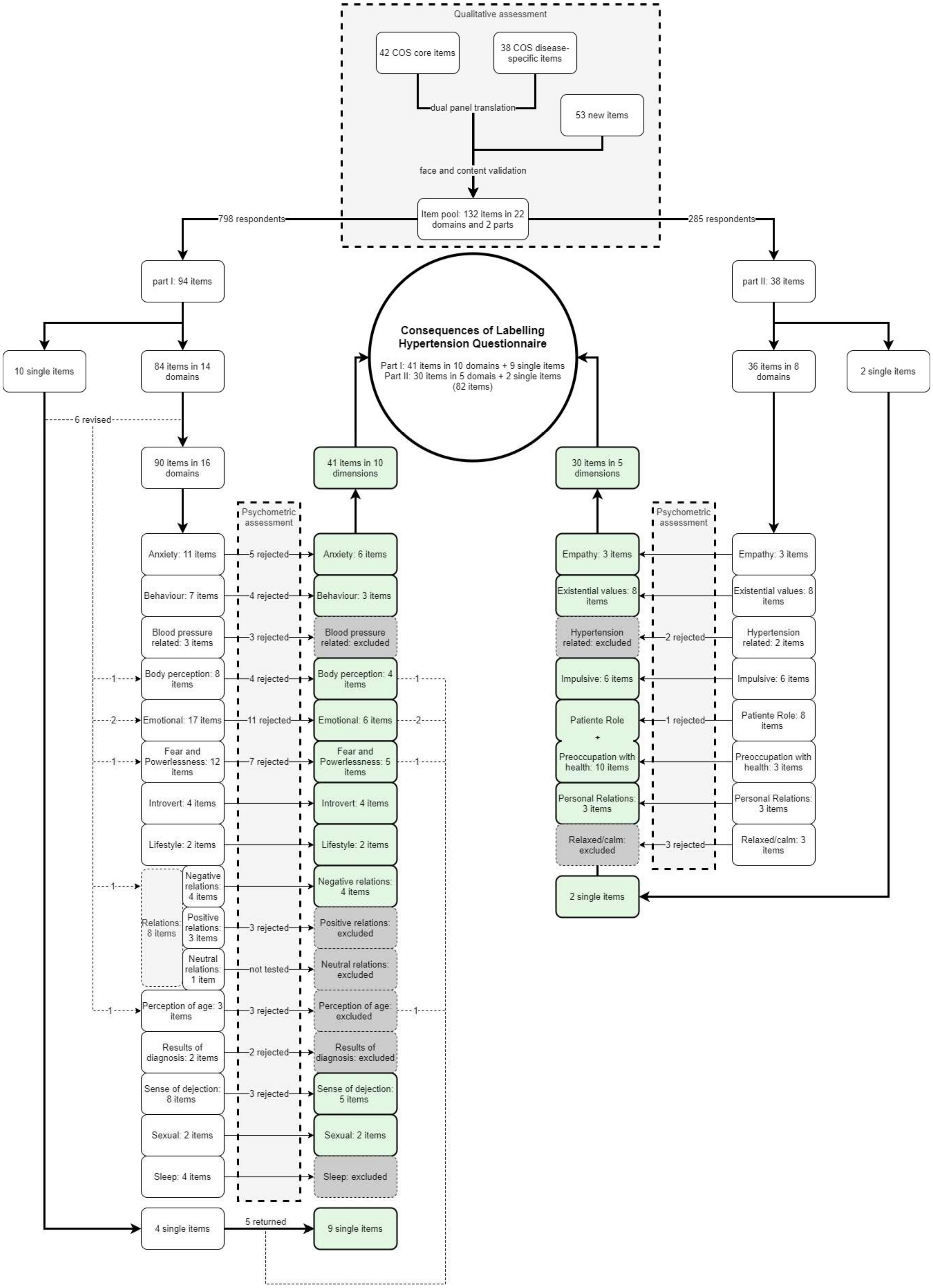
I collected 1,118 responses in this survey. After the exclusion of 319 informants with self-referred comorbidities, the validation sample consisted of 798 respondents living in all five Brazilian regions and 26 states that were recruited via different media platforms in the following proportion: 47.1% responded via the WhatsApp® link, 36.7% responded via the Facebook® link, 9,7% responded the email invitation and 6,4% responded the paper version.

Table 2 - Population characteristics

Characteristics	**no hypertension *n* = 513**		**hypertension *n* = 285**	
mean age, years	39.4 (18 - 73)		53.0 (20 - 85)	
mean education, years	17.6 (0 - 32)		11.7 (0 - 30)	
mean time from diagnosis, years	-		10.1 (0.1 - 40)	
Gender				
male	138	27%	63	22%
female	375	73%	222	78%
Ethnic origin				
afro + multi	124	24%	104	36%
caucaso + asian	386	75%	180	63%
Response media				
e-mail	67	13%	11	4%
Facebook	140	27%	153	54%
printed	3	1%	48	17%
WhatsApp	303	59%	73	26%

Out of the 798 respondents, 285 (35.7%) were diagnosed with hypertension, 597 (74.8%) were female, 460 (57.6%) were over 40 years old, 566 (70.9%) were Caucasian, and 204 (25.5%) had less than 11 years of education. All 798 respondents completed part I, whereas 285 respondents with hypertension completed part II (table 2).

Forty-four (46.8%) of the 94 items in part I were rejected, thus 41 items in 10 dimensions (figure 9): ‘anxiety’, ‘behaviour’, ‘body perception’, ‘emotional’, ‘fear and powerlessness’, ‘introvert’, ‘lifestyle’, ‘negative relations’, ‘sense of dejection’ and ‘sexual’ and 9 single items remained.



Source: Author’s elaboration.

Figure 9 - Process of selection of items for the final questionnaire.

Six (15.7%) of the 38 items in part II were rejected, remaining 2 single items and 30 items in 5 dimensions: ‘empathy’, ‘existential values’, ‘impulsive’, ‘patient role + preoccupation with health’ and ‘personal relations’. This yielded a 71-item questionnaire with 2 parts, 15 dimensions and 11 single items. The main reason for the exclusion of items was 65% of the cases failed to fit, followed by 30% of DIF cases. All DIF cases were found in the items of Part I. The main variable responsible for DIF was the presence of hypertension found in seven of the 17 items that were excluded for this reason. Age was responsible for DIF in five items, gender in three and ethnicity in two items (table 3).

Table 3 - Excluded items

Part	Domain	Q of origin	item number	comment
I	Anxiety	core	2	no fit
		core	3	no fit
		core	4	no fit
		core	93	too many missing responses
		new	61	no fit
	Behaviour	core	6	DIF
		core	9	DIF
		core	11	DIF
		core	18	DIF
	Blood pressure related	new	30	DIF
		new	57	DIF
		new	90	DIF
	Body Perception	disease specific	42	DIF
		new	64	DIF
		new	69	no fit
	Emotional	disease specific	43	no fit
		disease specific	44	no fit
		disease specific	49	DIF
		new	63	no fit
		new	74	no fit
		new	76	no fit
		new	83	DIF
		new	70	no fit

(cont.)

Table 3 - Excluded items

Part	Domain	Q of origin	item number	comment
I	Fear and Powerlessness	disease specific	50	DIF
		disease specific	58	DIF
		new	66	DIF
		new	73	DIF
		new	77	DIF
		new	79	DIF
	Perception of age	disease specific	41	no fit
		disease specific	47	no fit
	Positive relations	new	85	no fit
		new	87	no fit
		new	89	no fit
	Results of diagnosis	new	65	no fit
		new	80	no fit
	Sense of dejection	core	20	19 fits better than 20
		core	21	DIF
		new	91	DIF
	Sleep	core	7	no fit
		core	17	no fit
		core	23	no fit
		core	26	no fit
	Social Relations	new	88	neutral
II	Hypertension related	new	132	no fit
		new	133	no fit
	Patient Role	new	119	no fit
	Relaxed/Calm	core	98	no fit
		core	102	no fit
		core	110	no fit

The GRM check showed that as the domain score increased, items' mean scores also increased, indicating that all items within a domain measure the same construct. All plots are presented in the appendix B (Selected items graphical model check).

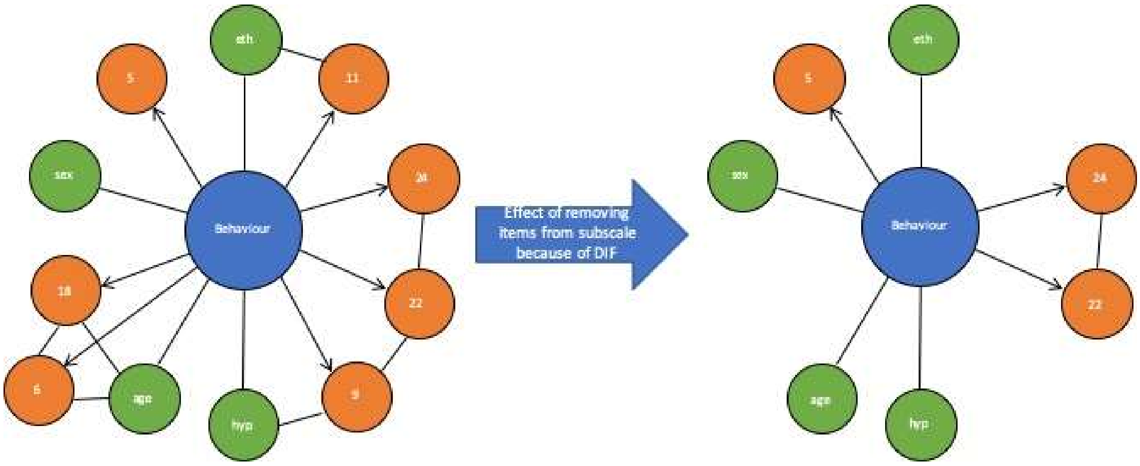
5.3.2. Measures of dimensionality of the items

5.3.2.1. PART I

We had 10 single items for Part I that were derived from the content validation study. Based on the qualitative assessment of the item pool, we hypothesised that six of them (35, 36, 45, 52, 75 and 81) could be tested in the following domains—35 in ‘body perception’, 36 in ‘emotional’ and in ‘introvert’, 81 in ‘emotional’, 52 in ‘emotional’ and in ‘fear and powerlessness’, 45 in ‘perception of age’ and 75 in ‘negative relations.’ Item 75 found fit in the domain, whereas the five other items were rejected in the tested domains. The nine items that failed to find a place in a subscale were kept as single items.

A few examples of the effects of removing items will be presented in figures below (figures 10 to 13). The blue circle in the centre represent the latent trait: the item’s dimension; the green circles are the variables in the population (sex: male or female; age: over 40 or other; ethnicity: Caucasian or other; hypertension: present or absent). The orange circles represent the items tested. The lines between a green and an orange circle identify differential item functioning; the lines between two orange circles are local dependencies. The arrows point at the items.

Twenty-eight items derived from COS-core were tested in five different dimensions: ‘anxiety’, ‘behaviour’ (figure 10), ‘sense of dejection’, ‘sexual’ and ‘sleep’. The ‘sleep’ (figure 11) dimension which was composed only by core items, did not fit the Rasch model analysis no matter the combination of the four sleep items. Fourteen of the remaining 24 items fitted the four other respective dimensions.



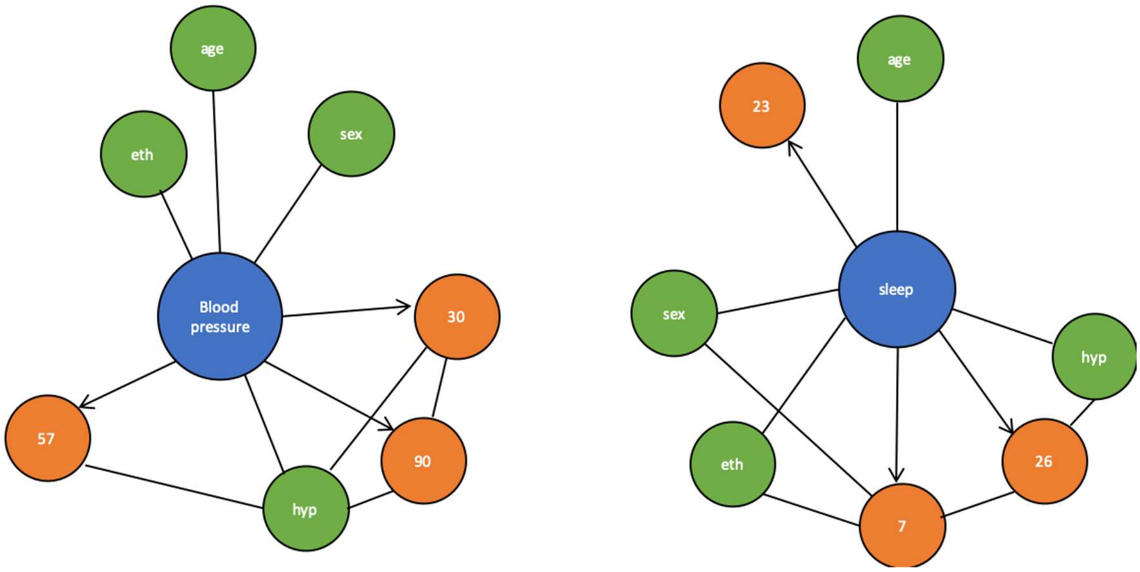
Source: Author’s elaboration.

Figure 10 - Effect of removing items from Behaviour subscale.

Twenty-eight items derived from other COS disease-specific questionnaires were tested in eight different dimensions: ‘anxiety’, ‘body perception’, ‘emotional’, ‘fear and powerlessness’, ‘introvert’, ‘lifestyle’, ‘perception of age’ and ‘sexual.’ Four of these dimensions had altogether 12 items rejected: ‘body perception’, ‘emotional’, ‘fear and powerlessness’ and ‘perception of age’, whereas 16 items fitted the respective domains.

Thirty-four new items were tested in nine different dimensions. Four of these were newly created dimensions: ‘blood pressure related’ (figure 11), ‘relations negative’, ‘relations positive’ and ‘results of the diagnosis’. The five other dimensions that had new items tested were ‘anxiety’, ‘body perception’, ‘emotional’ (figure 12), ‘fear and powerlessness’ and ‘sense of dejection’. Twenty-three new items were rejected and 11 were accepted in the tested dimensions.

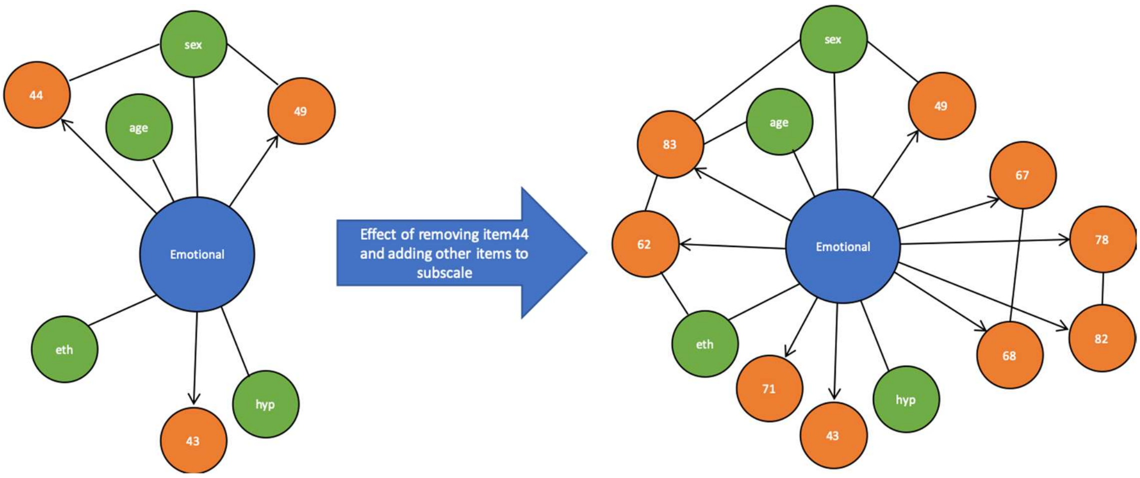
Six items (62, 67, 68, 70, 71 and 82) did not fit ‘sense of dejection’. We hypothesized that these items could be tested in ‘emotional’ and were then tested together with all 8 previous ‘emotional’ items (43, 44, 49, 63, 74, 76, 78 and 83) and 2 of the single items (36 and 81). The result was an ‘emotional’ dimension with 6 new items (62, 67, 68, 71, 78 and 82).



Source: Author’s elaboration.

Figure 11 - Two examples of poor item fit in the GRM: ‘blood pressure related’ and ‘sleep’ subscales.

Eight items comprised the ‘social relations’ dimension (72, 75, 84, 85, 86, 87, 88 and 89). The first analysis that included all items suggested two subscales with opposite relational effects and one neutral item. We then excluded the neutral item (88) and split the items in two dimensions: ‘positive relations’ with Items 85, 87 and 89 and ‘negative relations’ with the remaining Items 72, 75, 84 and 86. The ‘positive relations’ dimension failed to find fit, but the ‘negative relations’ found fit with DIF with age for Item 72 (being judged): those over 40 years old consistently scored lower than those under 40 who have the same total score.



Source: Author’s elaboration.

Figure 12 - Effect of removing item 44 and adding other items to Emotional subscale.

Items 27 and 59 in the ‘sexual’ dimension showed DIF with gender. Women consistently scored higher on item 27 and lower on item 59 compared with men.

In the ‘emotional’ dimension, item pairs 67/68 and 78/82 had LD. In the ‘anxiety’ dimension, item pairs 25/29 also had LD. The same was revealed for item pair 22/24 in ‘behaviour’, item pairs 37/38 and 46/53 in 'body perception', item pair 75/84 in 'negative relations' and finally item pairs 10/19 and 12/19 in 'sense of dejection'. In all these cases, these pairs fitted the scales.

Items 3 and 4 were different versions of the same item, and we included only one of them at a time in the ‘anxiety’ dimension. We began with two versions of the scale, each with either Item 3 or 4 and then tried to add new items. However, in both versions, these items misfit and were excluded from the final version of the scale. Items 19 and 20 were also two different versions of the original item. The ‘sense of dejection’ dimension showed good fit with Item 19.

The following domains had no items selected and were excluded from the final questionnaire: ‘blood pressure related’ with three items, ’perception of age’ with two items, ‘positive relations’ with three items, ‘results of the diagnosis’ with two items, ‘sleep’ with four items and ‘neutral relations’ with one item. The results of the Rasch model analysis are shown in Table 4 with the selected set of items for each subscale.

Table 4 presents the CFA parameters for scales with four or more items in Part I. Two scales had an RMSEA above 0.06 (‘anxiety’ and ‘fear and powerlessness’), whereas none had CFI below 0.95. All 10 accepted scales were tested for internal consistency with Cronbach’s alpha coefficients. Two scales, ‘lifestyle’ and ‘sense of dejection’, had alpha values below 0.7.

Table 4 - Part I psychometric analysis results

	Rasch model analysis results									Confirmatory Factor Analysis results							Internal consistency
Scale	number of items tested	number of items selected	selected item's number	Obs Gamma	Exp Gamma	p Gamma	CML	df	p	Chi-square	df	p	rmsea	(90% CI)	CFI	TLI	Cronbach's-alfa
Anxiety	11	6	13	0.68	0.66	0.4238	32.2	17	0.046	32.74	8	0.0001	0.062	(0.041 to 0.085)	0.986	0.974	0.839
			14	0.66	0.67	0.7108											
			15	0.70	0.68	0.2933											
			16	0.70	0.69	0.6270											
			25	0.72	0.73	0.9487											
			29	0.74	0.79	0.0961											
Behaviour	7	3	5	0.47	0.47	0.9782	18.9	17	0.332								0.708
			22	0.67	0.65	0.4518											
			24	0.53	0.65	0.4588											
Body perception	8	4	37	0.67	0.69	0.4448	14.7	29	0.987	0.57	0	0.000	0.000	(0.000 to 0.000)	1.000	1.000	0.806
			38	0.71	0.69	0.4994											
			46	0.78	0.71	0.0122											
			53	0.61	0.65	0.087											
Emotional	17	6	62	0.54	0.55	0.7250	54.2	34	0.015	20.35	7	0.005	0.049	(0.025 to 0.074)	0.987	0.987	0.851
			67	0.80	0.79	0.5293											
			68	0.77	0.78	0.8697											
			71	0.58	0.54	0.2895											
			78	0.64	0.64	0.8008											
			82	0.67	0.67	0.9595											
Fear and Powerlessness	12	5	39	0.74	0.68	0.0276	34.2	23	0.063	37.27	5	0.000	0.090	(0.064 to 0.118)	0.978	0.955	0.837
			40	0.70	0.72	0.3932											
			48	0.74	0.72	0.2410											
			51	0.66	0.67	0.6991											
			92	0.63	0.66	0.1502											

(cont.)

Table 4 - Part I psychometric analysis results

Scale	Rasch model analysis results									Confirmatory Factor Analysis results							Internal consistency
	number of items tested	number of items selected	selected item's number	Obs Gamma	Exp Gamma	p Gamma	CML	df	p	Chi-square	df	p	rmsea	(90% CI)	CFI	TLI	Cronbach's-alfa
Introvert	5	4	31	0.66	0.67	0.6729	17.1	11	0.106	5.47	2	0.065	0.047	(0.000 to 0.095)	0.997	0.990	0.804
			32	0.69	0.67	0.3415											
			33	0.75	0.68	0.0186											
			34	0.62	0.67	0.0248											
Lifestyle	2	2	54	0.55	0.55	0.9049	5	5	0.418								0.599
			56	0.55	0.55	0.9049											
Negative relations	4	4	72	0.66	0.67	0.8606	10	11	0.513	0.01	1	0.921	0.000	(0.000 to 0.034)	1.000	1.007	0.777
			75	0.64	0.66	0.5218											
			84	0.69	0.66	0.1838											
			86	0.65	0.65	0.9637											
Sense of dejection	8	5	1	0.43	0.47	0.2385	39.4	32	0.172	9.98	3	0.019	0.054	(0.019 to 0.093)	0.988	0.960	0.682
			10	0.45	0.51	0.1050											
			12	0.60	0.57	0.3060											
			19	0.63	0.59	0.2673											
			94	0.51	0.46	0.1434											
Sexual	2	2	27	0.66	0.66	0.9170	11.3	5	0.045								0.722
			59	0.66	0.66	0.9170											

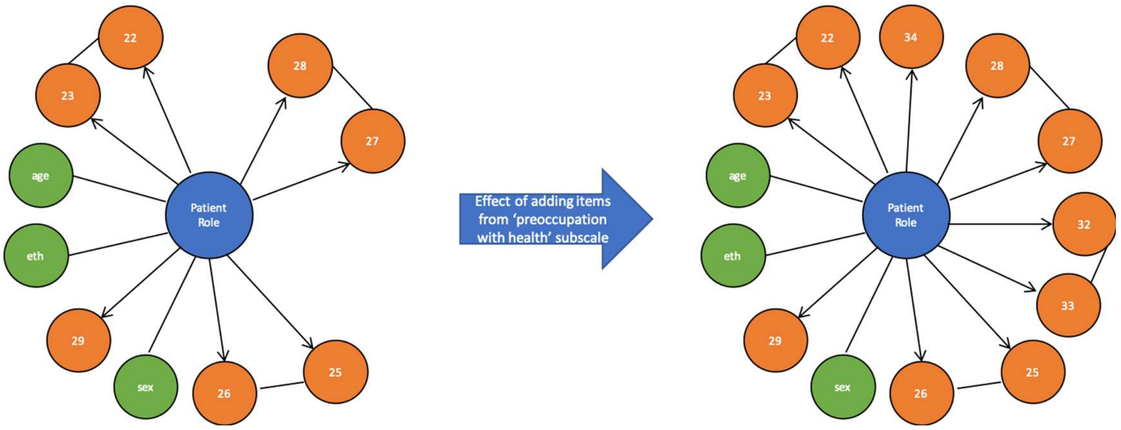
5.3.2.2. PART II

Twelve items derived from COS core were tested in three different dimensions: ‘existential values’, ‘personal relations’ and ‘relaxed/calm.’ The ‘relaxed/calm’ items neither fitted the Rasch model analysis nor formed a scale. All other core items found fit. Local dependence was observed between Items 103 and 104.

Nine items derived from COS disease-specific items were tested in two different dimensions: ‘empathy’ and ‘impulsive’. All items were accepted. Local dependence was found between items 111 and 113.

Fifteen new items were tested in four different dimensions: ‘existential values’, ‘hypertension related’, ‘patient role’ and ‘preoccupation with health’. The ‘existential values’ dimension was the only one that had items from more than one origin tested (core and new). Three of the items were rejected: one in the ‘patient role’ dimension (item 119) and two in the ‘hypertension related’ dimension (items 132 and 133). We had two single items for part II, both new items.

The qualitative assessment of the items of ‘patient role’ and ‘preoccupation with health’ suggested that they could be all part of a combined scale, called the ‘patient role + preoccupation with health’ subscale (figure 13). The Rasch model analysis with both scales combined had a nice fit with no DIF, resulting in a new 10-item scale: items 117, 118, 120, 121, 122, 123, 124, 127, 128 and 129.



Source: Author’s elaboration.

Figure 13 - Effect of merging 2 subscales ‘patient role’ and ‘preoccupation with health’.

Table 5 presents the CFA parameters for scales with four or more items in Part II. Two scales had RMSEA above 0.06 (‘impulsive’ and ‘patient role + preoccupation with health’), whereas none had CFI below 0.95. All five accepted scales were tested for internal consistency with Cronbach’s alpha coefficients described in Table 5. None had an alpha below 0.7. The following domains had no items selected and were excluded from the final questionnaire: ‘hypertension related’ with two items and ‘relaxed/calm’ with three items.

Table 5 - Part II psychometric analysis results

	Rasch model analysis results									Confirmatory Factor Analysis results							Internal consistency
Scale	number of items in the pool	number of items selected	selected item's number	Obs Gamma	Exp Gamma	p Gamma	CML	df	p	Chi-square	df	p	rmsea	(90% CI)	CFI	TLI	Cronbach-alfa
Empathy	3	3	108	0.63	0.63	0.9952	6.6	9	0.712								0.733
			111	0.8	0.77	0.5605											
			113	0.74	0.76	0.7248											
Existential values	8	8	96	0.68	0.65	0.4768	31.0	23	0.124	31.48	18	0.025	0.054	(0.019 to 0.085)	0.982	0.972	0.860
			97	0.81	0.66	0.0107											
			103	0.77	0.72	0.3584											
			104	0.65	0.71	0.2318											
			105	0.71	0.64	0.1639											
			106	0.61	0.65	0.3898											
			125	0.69	0.76	0.0622											
			126	0.71	0.76	0.2814											
Impulsive	6	6	107	0.58	0.68	0.0558	19.7	11	0.494	23.18	9	0.006	0.079	(0.040 to 0.119)	0.971	0.952	0.834
			109	0.68	0.68	0.8914											
			112	0.68	0.68	0.9438											
			114	0.78	0.69	0.0684											
			115	0.72	0.68	0.4113											
			116	0.69	0.69	0.9400											

(cont.)

Table 5 - Part II psychometric analysis results

	Rasch model analysis results									Confirmatory Factor Analysis results							Internal consistency
Scale	number of items in the pool	number of items selected	selected item's number	Obs Gamma	Exp Gamma	p Gamma	CML	df	p	Chi-square	df	p	rmsea	(90% CI)	CFI	TLI	Cronbach-alfa
Empathy	3	3	108	0.63	0.63	0.9952	6.6	9	0.712								0.733
			111	0.8	0.77	0.5605											
			113	0.74	0.76	0.7248											
Existential values	8	8	96	0.68	0.65	0.4768	31.0	23	0.124	31.48	18	0.025	0.054	(0.019 to 0.085)	0.982	0.972	0.860
			97	0.81	0.66	0.0107											
			103	0.77	0.72	0.3584											
			104	0.65	0.71	0.2318											
			105	0.71	0.64	0.1639											
			106	0.61	0.65	0.3898											
			125	0.69	0.76	0.0622											
			126	0.71	0.76	0.2814											
Impulsive	6	6	107	0.58	0.68	0.0558	19.7	11	0.494	23.18	9	0.006	0.079	(0.040 to 0.119)	0.971	0.952	0.834
			109	0.68	0.68	0.8914											
			112	0.68	0.68	0.9438											
			114	0.78	0.69	0.0684											
			115	0.72	0.68	0.4113											
			116	0.69	0.69	0.9400											

6. DISCUSSION

One main aspect of this thesis is the confirmation during the interviews of both the relevance of the theme of study for each affected person and the connection between my results and previous results aiming other psychosocial consequences of medical interventions. We were able to identify these similarities and build up on previous research. Our qualitative content analysis produced insights on the consequences of labelling hypertension and reflected the domains that matched our subjects' experiences that had been developed for the COS questionnaires, thus validating them.

6.1. EXPLANATORY MODELS AND EFFECTS OF LABELLING HYPERTENSION

For our informants, hypertension was a chronic, deadly disease/condition related to individual habits, lifestyle and genes. It could be silent or symptomatic. Hypertension could trigger acute symptomatic exacerbations related to stress. Additionally, the informants missed the biomedical conceptualisation and diagnostic criteria for hypertension, transforming a risk factor in a disease which will cause disability and death if left untreated. The diagnosis set a biographical milestone, after which informants were constantly reminded of their risk of death or disability. Life was not the same anymore: from the moment of diagnosis hypertension became a fearful attribute.

Moreover, our results showed that the EM are fundamental to understanding the psychosocial consequences of the diagnosis of hypertension. The psychosocial consequences were rooted in the patient's EM, became a patient's illness experience and were described by fear of ageing, disabilities and death; control, pressure, guilt and shame related to interpersonal relationships; anxiety regarding work and leisure. Fear was the main impetus for behavioural and relational changes. Although informants had a broad range of characteristics, they shared similar stories, understandings and effects of the diagnosis, possibly related to the elements they've got from doctors and health awareness campaigns on hypertension[66,71,72,137].

Similarly to the systematic review of Marshal and colleagues, which confirmed that among different cultures, the diagnosis is frequently established during major life events[14], our informants measured their blood pressure during stressful situations. The 'normal' acute symptomatic events related to the stressful situations (emotional and somatic reactions) were attributed to the blood pressure elevation. Consequently, healthy adults were experiencing symptomatic events related to stress and were diagnosed with hypertension. In this manner, the diagnosis made previously healthy people ill: transformed a risk factor simultaneously in the cause and the consequence of stress-related symptoms, named and explained the illness experience becoming a 'diseaseless' illness and a self-fulfilling prophecy. The diagnosis was something that provoked illness without subjacent disease.

In the web of events around the diagnosis of hypertension, the medical encounter might be only one anchor point. For our informants, the illness process began with the personal awareness of a change in body feelings (symptoms) and continued with the labelling of the sufferer (diagnosis). The diagnosis of hypertension named the psychosomatic reactions to stress and medicalised the informants' illness experiences. Hypertension was a label that explained extreme discomfort or suffering and promised a treatment for these symptoms while the events that triggered the emotional reactions were left in the background[64,65]. The diagnosis was an explanation and acted as a blinker that forced the person to have one focus and lose peripheral vision. After the diagnosis, people's perspectives narrowed and the diagnosis was permanently in sight: the informants had terrible jobs, ill relatives, stressful relationships and sometimes hypertension. In this manner, the diagnosis could also act as a relief, counterbalancing the pressure of social conditions and giving a "magic pill" to treat it.

In many cases, the medical diagnosis can be beneficial when the illness experience is named and classified as a disease: symptoms are explained, and effective treatment may now be possible[47]. Unfortunately, this might not be the case of hypertension without comorbidities. In our cases of hypertension, the diagnosis induced the adoption of standard therapies, whereas the aim was for a population effect on the prevalence of cardiovascular disease. It seems that if this diagnosis is potentially a harmful event that might change people's lives for the worse, many otherwise healthy people will experience illness related to being labelled without a clear benefit of the diagnosis: at the individual level, the risk factor becomes a disease; at the population level, no benefit of pharmacologic interventions has been observed in patients at low CVD risk to reduce CVD events[48].

The diagnosis is a crucial moment which triggers reactions that might be beneficial or harmful[138]. Our results confirmed qualitative results in the literature demonstrating similarities in the EM of hypertension in different settings[74]: described the psychosocial consequences of the diagnosis of hypertension as mostly negative effects and demonstrated that being diagnosed with hypertension constitutes a biographical disruption with subsequent adaptation, characterised by reinterpreting and giving new meanings to experiences and sensations. Many of the accounts from the Brazilian informants shared similar interpretations compared with Danish informants. This relevant finding suggests external validity because both cultures are geographically opposite in the Western world. Notably, qualitative studies on people's perspectives on hypertension have suggested that beliefs are remarkably similar across ethnic and geographical groups[66,137,139-142].

Some of the patients might have had a false-positive diagnosis or the misdiagnosis might have been a result of poor clinical practice[143], since they self-referred blood pressure below 140/100. We considered that having an antihypertensive prescribed and a self-report of hypertension was more relevant for the labelling effects of the diagnosis than blood pressure levels. Additionally, many people – lay and healthcare providers – use the word hypertension (and its correlates) with different meanings at different times[70]. In the Brazilian-Portuguese language, words related to high blood pressure (i.e. pressure and tension) have many meanings and uses that overlap. This is also supported by anthropological research among Brazilians with hypertension that has described how people (patients and healthcare providers) used different meanings for the same words and produced at least two different diagnoses, which are neither always identified nor acknowledged by the healthcare system[43,69,70]. Moreover, blood pressure and psychological tension are physiologically connected and are not easily untangled: acute symptomatic events and the medical diagnosis of hypertension are experiences that overlap because both have a relationship with the blood pressure elevation: the blood pressure elevation is part of the acute stress 'syndrome' and it is 'captured' during the clinical assessment. This might explain the phenomenon of the intertwined 'cause and consequence' relationship between the blood pressure elevation and symptoms.

In our results, people changed their habits (or thought it was necessary to change their habits) and sometimes felt guilty when they could not achieve medical standards. An utilitarian argument for diagnosing mild hypertension in clinical practice might be that the diagnosis (and consequently fear) can act as motivation to adopt a healthy lifestyle[144], helping people make 'better choices'. This phenomenon sometimes occurred, but the duration was not long. Over time, fear faded away and the early motivation weakened. Moreover, these 'better choices' to avoid risk are defined by medical standards and disregard personal preferences, values and contexts. People make choices, but the choices made are determined by the presentation of the social, cultural and economic aspects of life. 'Healthy lifestyle' depends on income, abundance, price, access and many other attributes beyond individual choices as the informants conceived, but the risk-avoiding behaviour becomes a moral duty related to self-control, self-knowledge and self-enhancement[145] blaming and placing in the person the problems rooted in broader contexts and social conditions that cannot be efficiently changed individually.

We have conducted single interviews and focus groups with similar themes. This is one of the strengths of this study, since this allowed us to explore in depth each interview and cover a broader area in the focus groups and allowed us to explore commonalities and disagreements, resulting in the focus groups mostly reinforcing the accounts of the single interviews. However, our focus groups were composed of few participants, which might have produced poorer focus groups' contents. We interviewed only a few residents of São Paulo, and this factor could limit the experiences to this population. Nevertheless, because of the demographic history of Brazil, we believe that this number does not limit the broadness of cultural viewpoints. We recommend this hypothesis to be tested by similar studies in different settings.

6.2. ITEM POOL

To achieve high content validity of a measure about psychosocial consequences of being diagnosed with mild hypertension we included a total of 132 items divided into 22 domains in 2 questionnaire parts: Part I encompassed 94 items in 14 domains, part II 38 items in 8 domains.

Ten items remained as single items in part I and two remained in part II. Although a single item does not necessarily have a high measurement precision like a scale, it could be wise to keep these items for content coverage because if a single item has high relevance informants might interpret a questionnaire without such single items as having lack of content coverage: they think important questions are missing.

We did not find any previously published PROMs addressing the psychosocial consequences of labelling people with mild hypertension in our literature search. Qualitative studies describe similar experiences in people living with cancer and people living with cardiovascular disease[111]. Moreover, John Brodersen has previously developed the COS questionnaires. The use of previously developed items could be a fast way to the development of new scales, saves time and money and is a common practice: the COS itself was based on previously developed items[108]. We selected the COS questionnaires for the following reasons: accessibility to the content, plausible similar psychosocial consequences between false positives and overdiagnosed in a screening context, the diagnosis of a chronic condition and already established psychometric properties of COS (in Danish and Swedish).

My choice of translation method was based on its prior use in the development of many other disease-specific measures in up to 30 languages[146]. Recruiting CHWs as informants for the lay panel was found to be a strength since they have a broad social network and a wide range of cultural experiences and are similar to the target of this questionnaire.

We have generated a very large item pool. This seems like a weakness of this study, since a very long questionnaire might have limited use. However, this is one of the strengths of this study, because it provides a broad range of items for every domain. This broad range of items describes different nuances and will provide enough elements for the psychometric analysis of each domain. As expected, after the psychometric analysis, the item pool was significantly reduced. This will be described in the next session.

Face validity was confirmed in the interviews. The qualitative supported the domains and items inherited from COS. However, numerous new items had to be added to achieve high content validity of the item pool. Another strength of our study is the population for the interviews, which included informants with a broad range of sociodemographic characteristics including health professionals. All of them were residents of São Paulo, which might be a limitation. However, many were migrants from other Brazilian regions. Moreover, we conducted a qualitative study on the psychosocial consequences of being labelled with mild hypertension, and achieved data saturation before conducting any of the group interviews, which might indicate that we had achieved high content coverage for most of the psychosocial consequences of being labelled with mild hypertension.

We asked our informants in single interviews to evaluate 80 translated items from the COS. All the items were found to be relevant and were included in the final draft of the questionnaire. This result might indicate that patients living with the diagnosis of mild hypertension share similarities with those experiencing abnormal results in screening for cancer and abdominal aortic aneurism – diseases that are regarded by most lay people as deadly life-threatening diseases with poor prognoses.

The fact that 52 new items and 6 new domains emerged from our qualitative study indicates that the COS were not comprehensive in a context of mild hypertension. Most of the items were derived directly from transcriptions of words or sentences from the information’s verbatim expressions. However, a few were generated based on our analyses of the meaning condensation of the interviews.

One example is the item on pride. No informant used the word pride to refer to their experiences, but we noted a sense of pride in their statements referring to efforts and achievements in controlling hypertension and complying with medical prescriptions. The wording of this pride item and other items were confirmed in the following focus-group interviews.

The methods described in this thesis represent a consistent way to achieve high content validity for PROMs. We used three different qualitative methods because each of them had a different focus and complemented each other, which we see as a strength. Furthermore, if we attempted to address all our needs with every informant, the result would be a very tiresome interview. The purpose of the in-depth semi-structured individual interviews was to gain insight into the consequences of labelling mild hypertension, to describe the consequences of this diagnosis, and to test the COS for content validity in this setting. These interviews were also part of our qualitative study on the psychosocial consequences of labelling hypertension. After that, the informants were exposed to a draft version of the questionnaire, allowing them to reflect and evaluate the instructions and the items' content validity. A similar method was used with the focus-group interviews, where we only showed the items after the group had the opportunity for open-ended reflection to discuss and debate the psychosocial consequences of being labelled with mild hypertension.

6.3. THE FINAL VERSION OF THE QUESTIONNAIRE

A measurement tool, which covers psychosocial experiences after the diagnosis of hypertension, was developed and validated, encompassing a total of 82 items divided into two parts and 15 scales (10 in Part 1 and five in Part 2). We established known-group validity for the total score and proved that the instrument discriminates well between cases and controls.

The final scale is a multidimensional group of subscales, which, in turn, are unidimensional. By dividing the multidimensional scale in unidimensional subscales, we identified the key elements of the psychosocial consequences (a multidimensional construct by definition) to provide content coverage and relevance. We also measured each element within their own unidimensional subscale.

This study revealed that being labelled with hypertension has common psychosocial consequences with having abnormal screening results for breast cancer, lung cancer, cervical cancer and aortic aneurism, all of which were previous targets of the four different COS versions[108-111]. This finding is supported by the inclusion of COS 'disease-specific' items, which were accepted in the final version of the questionnaire. These results may also provide a comparison between the psychosocial consequences of labelling hypertension and the psychosocial consequences related to false positive results of screening related to such four conditions.

However, we do not expect that the new questionnaire, which is composed of new and inherited items from the COS family, is the same metric as the COS questionnaires. New items were generated, and they expanded the final version of the questionnaire, altering the composition of the item sets inherited from COS and thus measuring a different (but with similarities) construct from the COS versions. Hence, the psychosocial effects of labelling hypertension share similarities with the effects of being screened but are, to an extent, different from the other psychosocial effects measured by the COS questionnaires.

New subscales specifically relevant for people labelled with hypertension were developed. The scale 'relations negative' strengthens the social aspects of the psychosocial consequences of labelling, whereas the scale 'patient role' strengthens the labelling effects, suggesting that the labelled people develop actions and attitudes expected from the labelled condition. These relevant aspects are found in the qualitative content analysis in this thesis.

The scores generated from questionnaire scales are further valid if analyses based on item response theory (IRT) are conducted[113-115]. We used Rasch model analysis, one subgroup of IRT models. The selection of Rasch model analysis allowed us to start from our qualitatively developed domains, submit them in a survey and test if the response data fit the Rasch model[115].

All items were excluded using a data driven method. However, we found a strength, that is, our statistical psychometric analyses were not purely exploratory, but mostly confirmatory. We used Rasch model analysis to confirm our hypotheses: items were relevant, covered different aspects of the target outcome and worked well together. We referred to the qualitative material to analyse the impact of the exclusion on the subscales' content coverage and to explore possibilities to fix the excluded items' issues. Given that the developed subscales had adequate psychometric properties and enough items to allow for adequate content coverage, the excluded items may have their revised versions retested in the future.

The exclusion of items based on LD and DIF aim at including only items that are correlated through the latent trait, in this case, the psychosocial consequences of labelling hypertension composed of its identified sub-dimensions.

Traditionally, questionnaires are validated using analyses that are based on classical test theories, such as Cronbach's alpha and CFA. These methods are insufficient to establish unidimensionality[116], but can be used complementarily to support the Rasch model analysis results. In this study, the derived subscales were confirmed using CFA but should ideally be confirmed in a new dataset.

The overall result is that the CFA models confirmed the measurement models derived using Rasch model analysis. Internal consistency reliability was also confirmed for most of the subscales. However, two of them, 'lifestyle' and 'sense of dejection', had values of Cronbach's coefficient alpha below 0.7, suggesting that they lack reliability. These subscales should be reviewed in the future. We also tested reliability with the sum of the scores of each sub-dimension for each of the questionnaire's part with Cronbach's alpha above 0.85, indicating that the subscales work well together.

The final set of items was composed of a long questionnaire, which might not be of practical use. If it proves to be a problem for future use, the 11 single items can be excluded because they also make the results difficult to interpret. Moreover, subscales that are composed of more than five items can be easily shortened to produce an easy-to-apply questionnaire. Long questionnaires may provide improved content validity and identify nuance in the psychosocial consequences of labelling hypertension. Future studies can aim to disclose floor/ceiling effects, supporting the qualitative evaluation of content coverage.

This study has certain limitations. Considering that the questionnaire was distributed online (mobile and personal computer), making clarifications whilst completing the items was difficult (although available) for the participants. In a scenario with a wide range of reading abilities, a self-applied questionnaire can be less accessible. Certain items also showed DIF with gender and age, indicating that when using this scale, we must be careful when comparing the effects between male and female and people with different ages. Item 5 was found to be wrongly translated during the analysis. Therefore, further tests are recommended for this item in the 'emotional' dimension. Another recommendation is to retest the 'behaviour' dimension without this item. Note that Item 14 in Part 2 was never tested.

Another limitation of this study is that the sampling was based on an open design because no control existed on whether the subjects had really undergone a diagnosis of hypertension; specifically, a diagnosis of mild hypertension. We intended to measure the impact of labelling and assumed that such an effect requires the subject to recognise himself or herself as hypertensive, and not that the correct diagnosis is clinically identified. This assumption is justifiable because previous literature and our own qualitative findings in previous steps of the development of this questionnaire suggested that the effect of hypertension labelling is unrelated to the correct diagnosis of hypertension[63]. Furthermore, the prevalence of mild hypertension among people without comorbidities is far greater than that of moderate and severe hypertension[147]. When we included only those without comorbidities, we expected to remove most people with moderate and severe hypertension.

7. CONCLUSIONS

7.1. THE LABELLING EFFECTS OF HYPERTENSION CAN BE MEASURED

This study asked people about their life after the diagnosis of hypertension. The objective was to gain insights on the labelling effects of hypertension using qualitative methods. It shows that the diagnosis of hypertension is a label because it was affixed by an external agent, accepted (sometimes with resistance) by the person and had psychosocial consequences for the person. Content analysis looked for reports on labelling effects attributable to the diagnosis of hypertension and helped develop the items described in the second part.

The results suggested that the diagnosis interfered in people's lives, identifying psychosocial harms in a context in which 'epidemiologic benefit' has not yet been proven, especially in the group of people labelled with mild hypertension.

Brazilian's patient's explanatory models share similarities with other populations. Diagnosing mild hypertension in the Brazilian context clearly has negative psychosocial consequences, related to the patient's EM. These consequences are mostly regarded as harms to well-being. Moreover, the diagnosis names illness experiences in people that do not benefit from medical treatment, exposing them to fear, blame, guilt, control and a higher risk of collateral effects and medicalisation.

In fact, hypertension was a 'diseaseless' diagnosis that lead to labelling related illness. For the person, it was a label that named illness experiences and gave meaning to symptoms and feelings and it was a label that triggered feelings and symptoms giving substance to the illness experiences. The diagnosis objectified the subjective individual experiences.

Translation of items from other sources and qualitative assessment of the interviews with people with mild hypertension supported the generation of a great number of items, categories, and domains.

This set of items is a strong argument for content coverage and relevance. All items from previous questionnaires were considered relevant, suggesting similarities between the effects of labelling and the effects of false positive results of screening.

Item response theory was used to confirm unidimensionality of the scales, resulting in dimensions with valid measurement capability.

A new condition-specific questionnaire with a total of 82 items in 15 scales was developed for people labelled with hypertension; the questionnaire had high content validity and adequate psychometric properties. This measure is called ‘Consequences of Labelling Hypertension Questionnaire’ (CLH), which covers two parts of the psychosocial experiences after the diagnosis of hypertension. The adequate reliability, unidimensionality and invariant measurement of the subscales were demonstrated using Rasch model analysis. However, further examinations are required for the final subscales in a new dataset to confirm the results presented here and promote improvements to this questionnaire.

7.2. IMPLICATIONS FOR RESEARCH

Little is known about illness experiences related to labelling mild hypertension. This topic is relevant because approximately one third of the world’s population is considered hypertensive and may be affected by the diagnosis. Does the diagnosis and the label affect different people in different manners? What aspects are important in these differences? Can these differences be measured? What are the EMs of the doctors and nurses? How do the psychosocial consequences develop along in time for the subjects? These are a few questions that the evidence from this study does not answer.

Because patient’s EM are related to the model healthcare providers explained the problem during the episode of care of the diagnosis, considering how doctors, communities and societies in general understand and give meaning to the diagnosis of hypertension is worthwhile.

The results of this study support the development of further research to address the effects of labelling in a quantitative manner, since it is relevant to measure how much the diagnosis of hypertension can lead to unintended psychosocial harm and be able to compare it in different research settings, and weight more comprehensively the benefits and harms of population approaches of diagnosis and treatment.

The CLH is not designed to be used in clinical practice. However, research on the psychosocial consequences of labelling is relevant for clinical practice and for population studies. It is a tool that can be used in future research with hypertension, especially in scenarios of screening, preventive population strategies and in intervention studies willing to access all possible results of the interventions.

7.3. IMPLICATIONS FOR PRACTICE

These results are relevant for the clinical practice because they support the idea that labelling with a diagnosis is potentially harmful. Doctors must develop skills to address patient's EM. This development is part of a patient-centred encounter and helps refine the chances of establishing a clinically relevant diagnosis, especially in this particular group of people, who might not benefit from the available treatment of the labelled condition. Furthermore, medical doctors must be more aware of the effects of context on blood pressure and the potential of labelling and psychosocial consequences of the diagnosis of hypertension.

Doctors must use caution when diagnosing and communicating diagnoses to patients, because doctors' and patients' EMs are diverse and differ from the public health explanatory model of hypertension as a risk factor. Public health campaigns should use clear messages about risk factors to avoid medicalisation and labels should be carefully and consciously used. The risk strategy applied to mild hypertension is based on labelling people using an arbitrary threshold with high costs for the healthcare system.

I think that hypertension alone shouldn´t be the target of high-risk strategies, as it is not a good predictor of cardiovascular disease in the individual level on its own. In my opinion hypertension shouldn´t be the target of screening either since it does not satisfy all the above conditions.

8. REFERENCES

1. Kaplan NM, Victor RG, Flynn JT. Kaplan's clinical hypertension. 11th ed. Philadelphia: Wolters Kluwer; 2015.

2. Pickering TG. Now we are sick: labeling and hypertension. J Clin Hypertens (Greenwich) [internet]. 2006 [cited 2020 nov 23];8(1):57-60. Available from: https://doi.org/10.1111/j.1524-6175.2005.05121.x

3. Symptoms in hypertension. Br Med J [internet]. 1973 [cited 2020 nov 23];1(5851):433-4. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1588484/?page=1

4. Pickering G. Hypertension in general practice. J R Soc Med [internet]. 1978 [cited 2020 nov 23];71(12):885-9. Available from: https://journals.sagepub.com/doi/abs/10.1177/014107687807101207

5. Malachias MVB, Gomes MAM, Nobre F, Alessi A, Feitosa AD, Coelho EB. 7th Brazilian Guideline of Arterial Hypertension: Chapter 2 - Diagnosis and Classification. Arq Bras Cardiol [internet]. 2016 [cited 2020 nov 23];107(3 Suppl 3):7-13. Available from: https://doi.org/10.5935/abc.20160152

6. Wolf-Maier K, Cooper RS, Banegas JR, Giampaoli S, Hense HW, Joffres M, et al. Hypertension prevalence and blood pressure levels in 6 European countries, Canada, and the United States. JAMA [internet]. 2003 [cited 2020 nov 23];289(18):2363-9. Available from: https://jamanetwork.com/journals/jama/fullarticle/196535

7. Kannel WB. Fifty years of Framingham Study contributions to understanding hypertension. J Hum Hypertens [internet]. 2000 [cited 2020 nov 23];14(2):83-90. Available from: https://www.nature.com/articles/1000949

8. Pater C. The Blood Pressure "Uncertainty Range" - a pragmatic approach to overcome current diagnostic uncertainties (II). Curr Control Trials Cardiovasc Med [internet]. 2005 [cited 2020 nov 23];6(1):5. Available from: https://trialsjournal.biomedcentral.com/articles/10.1186/1468-6708-6-5

9. Kannel WB. Elevated systolic blood pressure as a cardiovascular risk factor. Am J Cardiol [internet]. 2000 [cited 2020 nov 23];85(2):251-5. Available from: https://www.ajconline.org/article/S0002-9149(99)00635-9/fulltext

10. Allan GM, Garrison S, McCormack J. Comparison of cardiovascular disease risk calculators. Curr Opin Lipidol [internet]. 2014 [cited 2020 nov 23];25(4):254-65. Available from: https://doi.org/10.1097/MOL.0000000000000095

11. Allan GM, Nouri F, Korownyk C, Kolber MR, Vandermeer B, McCormack J. Agreement among cardiovascular disease risk calculators. Circulation [internet]. 2013 [cited 2020 nov 23];127(19):1948-56. Available from: https://www.ahajournals.org/doi/full/10.1161/circulationaha.112.000412

12. Wallis EJ, Ramsay LE, Jackson PR. Cardiovascular and coronary risk estimation in hypertension management. Heart [internet]. 2002 [cited 2020 nov 23];88(3):306-12. Available from: https://heart.bmj.com/content/88/3/306.full

13. Marchant I, Nony P, Cucherat M, Boissel JP, Thomas SR, Bejan-Angoulvant T, et al. The global risk approach should be better applied in French hypertensive patients: a comparison between simulation and observation studies. PLoS One [internet]. 2011 [cited 2020 nov 23];6(3):e17508. Available from: https://doi.org/10.1371/journal.pone.0017508

14. Marshall IJ, Wolfe CD, McKevitt C. Lay perspectives on hypertension and drug adherence: systematic review of qualitative research. BMJ [internet]. 2012 [cited 2020 nov 23];345:e3953. Available from: https://www.bmj.com/content/345/bmj.e3953

15. Kronish IM, Ye S. Adherence to cardiovascular medications: lessons learned and future directions. Prog Cardiovasc Dis [internet]. 2013 [cited 2020 nov 23];55(6):590-600. Available from: https://doi.org/10.1016/j.pcad.2013.02.001

16. Tsioufis C, Thomopoulos C, Kreutz R. Treatment Thresholds and Targets in Hypertension: Different Readings of the Same Evidence? Hypertension [internet]. 2018 [cited 2020 nov 23];71(6):966-8. Available from: https://www.ahajournals.org/doi/10.1161/HYPERTENSIONAHA.118.10815

17. Haase CB, Gyuricza JV, Brodersen J. New hypertension guidance risks overdiagnosis and overtreatment. BMJ [internet]. 2019 [cited 2020 nov 23];365:l1657. Available from: https://www.bmj.com/content/365/bmj.l1657.full

18. Krumholz HM. Blood pressure guidelines as starting point in clinical decisions. BMJ [internet]. 2018 [cited 2020 nov 23];360:j5862. Available from: https://www.bmj.com/content/360/bmj.j5862.full

19. Glasziou PP, Irwig LM. An evidence based approach to individualising treatment. BMJ [internet]. 1995 [cited 2020 nov 23];311(7016):1356-9. Available from: https://www.bmj.com/content/311/7016/1356.full

20. Canguilhem G. The normal and the pathological. New York: Zone Books; 1989.

21. Welch HG, Schwartz L, Woloshin S. Overdiagnosed : making people sick in the pursuit of health. Boston, Mass.: Beacon Press; 2011.

22. Moynihan R, Cassels A. Selling sickness : how the world's biggest pharmaceutical companies are turning us all into patients. New York, NY: Nation Books; 2005.

23. Arouca S. O dilema preventivista : contribuição para a compreensão e crítica da medicina preventiva. São Paulo/SP; Rio de Janeiro/RJ: Editora UNESP; Editora FIOCRUZ; 2003.

24. Illich I. The medicalization of life. J Med Ethics [internet]. 1975 [cited 2020 nov 23];1(2):73-7. Available from: https://jme.bmj.com/content/1/2/73

25. Illich I. Medical nemesis : the expropriation of health. New York: Pantheon Books; 1982.

26. Pickering TG. Do we really need a new definition of hypertension? J Clin Hypertens (Greenwich) [internet]. 2005 [cited 2020 nov 23];7(12):702-4. Available from: https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1524-6175.2005.04149.x

27. Pickering GW. Hypertension : causes, consequences and management. 2nd ed. Edinburgh Scot.: Churchill Livingstone; 1974.

28. Kloetzel K. O rastreamento das doenças: da teoria à prática (com especial atençäo à hipertensäo arterial). Diagn tratamento. 2002;7(3):6-.

29. Leavell HR, Clark EG. Preventive medicine for the doctor in his community : an epidemiologic approach. 3rd ed. Huntington, N.Y.: R. E. Krieger; 1979.

30. Rose G. Strategy of prevention: lessons from cardiovascular disease. Br Med J (Clin Res Ed) [internet]. 1981 [cited 2020 nov 23];282(6279):1847-51. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1506445/

31. Ayres JRCM. The historical and epistemological development of epidemiology and the concept of risk. Cad Saude Publica [internet]. 2011 [cited 2020 nov 23];27(7):1301-11. Available from: https://doi.org/10.1590/S0102-311X2011000700006

32. Jamoulle M. First do not harm. J Midlife Health [internet]. 2015 [cited 2020 nov 23];6(2):51-2. Available from: https://www.jmidlifehealth.org/text.asp?2015/6/2/51/158940

33. Jamoulle M. Quaternary prevention, an answer of family doctors to overmedicalization. Int J Health Policy Manag [internet]. 2015 [cited 2020 nov 23];4(2):61-4. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4322627/

34. Martins C, Godycki-Cwirko M, Heleno B, Brodersen J. Quaternary prevention: reviewing the concept. Eur J Gen Pract [internet]. 2018 [cited 2020 nov 23];24(1):106-11. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5795741/

35. DALYs GBD, Collaborators H, Murray CJ, Barber RM, Foreman KJ, Abbasoglu Ozgoren A, et al. Global, regional, and national disability-adjusted life years (DALYs) for 306 diseases and injuries and healthy life expectancy (HALE) for 188 countries, 1990-2013: quantifying the epidemiological transition. Lancet [internet]. 2015 [cited 2020 nov 23];386(10009):2145-91. Available from: https://doi.org/10.1016/S0140-6736(15)61340-X

36. Forouzanfar MH, Liu P, Roth GA, Ng M, Biryukov S, Marczak L, et al. Global Burden of Hypertension and Systolic Blood Pressure of at Least 110 to 115 mm Hg, 1990-2015. JAMA [internet]. 2017 [cited 2020 nov 23];317(2):165-82. Available from: https://jamanetwork.com/journals/jama/fullarticle/10.1001/jama.2016.19043

37. Mahmood SS, Levy D, Vasan RS, Wang TJ. The Framingham Heart Study and the epidemiology of cardiovascular disease: a historical perspective. Lancet [internet]. 2014 [cited 2020 nov 23];383(9921):999-1008. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4159698/

38. Rose G. Sick individuals and sick populations. Int J Epidemiol [internet]. 1985 [cited 2020 nov 23];14(1):32-8. Available from: https://doi.org/10.1093/ije/30.3.427

39. Tesser CD, Norman AH. Geoffrey Rose e o princípio da precaução: para construir a prevenção quaternária na prevenção. Interface (Botucatu) [internet]. 2019 [cited 2020 nov 23];23: e180435. Available from: https://doi.org/10.1590/interface.180435

40. Rose G. The strategy of preventive medicine. Oxford: Oxford University Press; 1992.

41. Hart JT. The inverse care law. Lancet [internet]. 1971 [cited 2020 nov 23];1(7696):405-12. Available from: https://doi.org/10.1016/S0140-6736(71)92410-X

42. Souza CS, Stein AT, Bastos GA, Pellanda LC. Blood pressure control in hypertensive patients in the "Hiperdia Program": a territory-based study. Arq Bras Cardiol [internet]. 2014 [cited 2020 nov 23];102(6):571-8. Available from: https://doi.org/10.5935/abc.20140081

43. Fleischer S. Ilusões Oferecidas às Pessoas com ‘Problemas de Pressão’ na Ceilândia,DF. Revista AntHropológicas [internet]. 2016 [cited 2020 nov 23];27(2):97-119. Available from: https://periodicos.ufpe.br/revistas/revistaanthropologicas/article/view/24024

44. Malachias M, Plavnik FL, Machado CA, Malta D, Scala LCN, Fuchs S. 7th Brazilian Guideline of Arterial Hypertension: Chapter 1 - Concept, Epidemiology and Primary Prevention. Arq Bras Cardiol [internet]. 2016 [cited 2020 nov 23];107(3 Suppl 3):1-6. Available from: https://doi.org/10.5935/abc.20160151

45. Brasil. Ministério da Saúde. Caderno de Atenção Primária: Rastreamento. Saúde [internet]. Brasília (DF): Ministério da Saúde; 2010 [cited 2020 nov 23]. Available from: http://bvsms.saude.gov.br/bvs/publicacoes/caderno_atencao_primaria_29_rastreamento.pdf

46. Brasil. Ministério da Saúde. Estratégias para o cuidado da pessoa com doença crônica: hipertensão arterial sistêmica [internet]. Brasília (DF): Ministério da Saúde; 2013 [cited 2020 nov 23]. Available from:

http://bvsms.saude.gov.br/bvs/publicacoes/estrategias_cuidado_pessoa_doenca_cronica.pdf

47. Raffle AE, Gray JAM. Screening : evidence and practice. Oxford ; New York: Oxford University Press; 2007.

48. Mitka M. Many physician practices fall short on accurate blood pressure measurement. JAMA [internet]. 2008 [cited 2020 nov 23];299(24):2842-4. Available from: https://jamanetwork.com/journals/jama/article-abstract/182134

49. Abbasi J. Medical Students Fall Short on Blood Pressure Check Challenge. JAMA [internet]. 2017 [cited 2020 nov 23];318(11):991-2. Available from: https://jamanetwork.com/journals/jama/article-abstract/2653029

50. Garrison GM, Oberhelman S. Screening for hypertension annually compared with current practice. Ann Fam Med [internet]. 2013 [cited 2020 nov 23];11(2):116-21. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3601388/

51. Moynihan R, Heath I, Henry D. Selling sickness: the pharmaceutical industry and disease mongering. BMJ (Clinical research ed) [internet]. 2002 [cited 2020 nov 23];324(7342):886-91. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1122833/

52. Shankar PR, Subish P. Disease mongering. Singapore Med J [internet]. 2007 [cited 2020 nov 23];48(4):275-80. Available from: http://smj.sma.org.sg/4804/4804ra1.pdf

53. Blasco-Fontecilla H. Medicalization, wish-fulfilling medicine, and disease mongering: toward a brave new world? Rev Clin Esp (Barc) [internet]. 2014 [cited 2020 nov 23];214(2):104-7. Available from: https://doi.org/10.1016/j.rce.2013.08.012

54. Blackburn H. Population strategies of cardiovascular disease prevention: scientific base, rationale and public health implications. Ann Med [internet]. 1989 [cited 2020 nov 23];21(3):157-62. Available from: https://doi.org/10.3109/07853898909149926

55. Diao D, Wright JM, Cundiff DK, Gueyffier F. Pharmacotherapy for mild hypertension. Cochrane Database Syst Rev [internet]. 2012 [cited 2020 nov 23];8:CD006742. Available from: https://doi.org/10.1002/14651858.CD006742.pub2

56. Heath I. Waste and harm in the treatment of mild hypertension. JAMA Intern Med [internet]. 2013 [cited 2020 nov 23];173(11):956-7. Available from: https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/1687525

57. Paiva VSF. Psicologia na saúde: sociopsicológica ou psicossocial? Inovações do campo no contexto da resposta brasileira à AIDS. Temas em Psicologia [internet]. 2013 [cited 2020 nov 23];21:531-49. Available from: http://pepsic.bvsalud.org/pdf/tp/v21n3/v21n3a02.pdf

58. Macleod J, Davey Smith G. Psychosocial factors and public health: a suitable case for treatment? J Epidemiol Community Health [internet]. 2003 [cited 2020 nov 23];57(8):565. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1732553/

59. Engel GL. The need for a new medical model: a challenge for biomedicine. Science [internet]. 1977 [cited 2020 nov 23];196(4286):129-36. Available from: https://science.sciencemag.org/content/196/4286/129.long

60. Engel GL. The clinical application of the biopsychosocial model. Am J Psychiatry [internet]. 1980 [cited 2020 nov 23];137(5):535-44. Available from: https://doi.org/10.1176/ajp.137.5.535

61. Hofmann B. On the triad disease, illness and sickness. J Med Philos [internet]. 2002 [cited 2020 nov 23];27(6):651-73. Available from: https://doi.org/10.1076/jmep.27.6.651.13793

62. Link BG, Phelan JC. Conceptualizing stigma. Annu Rev Sociol [internet]. 2001 [cited 2020 nov 23];27:363-85. Available from: https://www.annualreviews.org/doi/abs/10.1146/annurev.soc.27.1.363

63. Ogedegbe G. Labeling and hypertension: it is time to intervene on its negative consequences. Hypertension [internet]. 2010 [cited 2020 nov 23];56(3):344-5. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2924446/

64. Kleinman A. Concepts and a model for the comparison of medical systems as cultural systems. Soc Sci Med [internet]. 1978 [cited 2020 nov 23];12(2B):85-95. Available from: https://doi.org/10.1016/0160-7987(78)90014-5

65. Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. Ann Intern Med

[internet]. 1978 [cited 2020 nov 23];88(2):251-8. Available from: https://doi.org/10.7326/0003-4819-88-2-251

66. Bokhour BG, Cohn ES, Cortes DE, Solomon JL, Fix GM, Elwy AR, et al. The role of patients' explanatory models and daily-lived experience in hypertension self-management. J Gen Intern Med [internet]. 2012 [cited 2020 nov 23];27(12):1626-34. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3509311/

67. Hurwicz M-L, Rose M. Older Adults Explanatory Models of High Blood Pressure. Health [internet]. 2016 [cited 2020 nov 23];8(7):680-93. Available from: http://dx.doi.org/10.4236/health.2016.87072

68. Blumhagen D. Hyper-tension: a folk illness with a medical name. Cult Med Psychiatry [internet]. 1980 [cited 2020 nov 23];4(3):197-224. Available from: https://link.springer.com/article/10.1007/BF00048414

69. Fleischer S. O "Grupo da Pressão": notas sobre as lógicas do "controle" de doenças crônicas na Guariroba, Ceilância/DF. Amazônica - Revista de antropologia [internet]. 2014 [cited 2020 nov 23]. 2014;5(2):454-77. Available from: http://dx.doi.org/10.18542/amazonica.v5i2.1502

70. Fleischer S. Os problemas de pressão: entre os problemas da vida e os problemas do mundo. In: _____ (ed.). Descontrolada: Uma etnografia dos problemas de pressão. São Carlos: EdUFSCar, 2018.

71. Heurtin-Roberts S. ‘High-pertension’ - The uses of a chronic folk illness for personal adaptation. Soc Sci Med [internet]. 1993 [cited 2020 nov 23];37(3):285-94. Available from: https://doi.org/10.1016/0277-9536(93)90260-B

72. Garro LC. Culture and high blood pressure: understandings of a chronic illness in an Ojibwa community. Arctic Med Res. 1988;47 Suppl 1:70-3.

73. de Castro VD, Car MR. Daily living with hypertension: changes, restrictions and reactions. Rev Esc Enferm USP [internet]. 2000 [cited 2020 nov 23];34(2):145-53. Available from: https://doi.org/10.1590/S0080-62342000000200004

74. Sångren H, Reventlow S, Hetlevik I. Role of biographical experience and bodily sensations in patients' adaptation to hypertension. Patient Educ Couns [internet]. 2009 [cited 2020 nov 23];74(2):236-43. Available from: https://doi.org/10.1016/j.pec.2008.08.007

75. Shamsi AP, Dehghan Nayeri NP, Esmaeili MP. Living with Hypertension: A Qualitative Research. Int J Community Based Nurs Midwifery [internet]. 2017 [cited 2020 nov 23];5(3):219-30. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5478742/

76. Alderman MH, Lamport B. Labelling of hypertensives: a review of the data. J Clin Epidemiol [internet]. 1990 [cited 2020 nov 23];43(2):195-200. Available from: https://doi.org/10.1016/0895-4356(90)90185-R

77. Haynes RB, Sackett DL, Taylor DW, Gibson ES, Johnson AL. Increased absenteeism from work after detection and labeling of hypertensive patients. N Engl J Med [internet]. 1978 [cited 2020 nov 23];299(14):741-4. Available from: https://www.nejm.org/doi/full/10.1056/NEJM197810052991403

78. Alderman MH, Charlson ME, Melcher LA. Labelling and absenteeism: the Massachusetts Mutual experience. Clin Invest Med. 1981;4(3-4):165-71.

79. Mossey JM. Psychosocial consequences of labelling in hypertension. Clin Invest Med. 1981;4(3-4):201-7.

80. Bloom JR, Monterossa S. Hypertension labeling and sense of well-being. Am J Public Health [internet]. 1981 [cited 2020 nov 23];71(11):1228-32. Available from: https://ajph.aphapublications.org/doi/10.2105/ajph.71.11.1228

81. Charlson ME, Alderman M, Melcher L. Absenteeism and labelling in hypertensive subjects. Prevention of an adverse impact in those at high risk. Am J Med [internet]. 1982 [cited 2020 nov 23];73(2):165-70. Available from: https://doi.org/10.1016/0002-9343(82)90173-5

82. Soghikian K, Fallick-Hunkeler EM, Ury HK, Fisher AA. The effect of high blood pressure awareness and treatment on emotional well-being. Clin Invest Med. 1981;4(3-4):191-6.

83. McHorney CA, Ware JE, Jr., Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Med Care. 1993;31(3):247-63.

84. Trevisol DJ, Moreira LB, Kerkhoff A, Fuchs SC, Fuchs FD. Health-related quality of life and hypertension: a systematic review and meta-analysis of observational studies. J Hypertens [internet]. 2011 [cited 2020 nov 23];29(2):179-88. Available from: https://doi.org/10.1097/hjh.0b013e328340d76f

85. Goldberg DP, Hillier VF. A scaled version of the General Health Questionnaire. Psychol Med. 1979;9(1):139-45.

86. Hamer M, Batty GD, Stamatakis E, Kivimaki M. Hypertension awareness and psychological distress. Hypertension [internet]. 2010 [cited 2020 nov 23];56(3):547-50. Available from: https://doi.org/10.1161/HYPERTENSIONAHA.110.153775

87. Hobart JC, Williams LS, Moran K, Thompson AJ. Quality of life measurement after stroke: uses and abuses of the SF-36. Stroke [internet]. 2002 [cited 2020 nov 23];33(5):1348-56. Available from: https://www.ahajournals.org/doi/10.1161/01.STR.0000015030.59594.B3

88. Streiner DL, Norman GR, Cairney J. Health measurement scales: a practical guide to their development and use. Fifth edition. ed. Oxford: Oxford University Press; 2015.

89. McKenna SP, Doward LC. Integrating patient-reported outcomes. Value Health [internet]. 2004 [cited 2020 nov 23];7 Suppl 1:S9-12. Available from: https://doi.org/10.1111/j.1524-4733.2004.7s103.x

90. Wiebe S, Guyatt G, Weaver B, Matijevic S, Sidwell C. Comparative responsiveness of generic and specific quality-of-life instruments. J Clin Epidemiol [internet]. 2003 [cited 2020 nov 23];56(1):52-60. Available from: https://doi.org/10.1016/s0895-4356(02)00537-1

91. Zung WW. A Self-Rating Depression Scale. Arch Gen Psychiatry [internet]. 1965 [cited 2020 nov 23];12:63-70. Available from: https://doi.org/10.1001/archpsyc.1965.01720310065008

92. Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. Arch Gen Psychiatry [internet]. 1961 [cited 2020 nov 23];4:561-71. Available from: https://doi.org/10.1001/archpsyc.1961.01710120031004

93. Pearce NJ, Sanson-Fisher R, Campbell HS. Measuring quality of life in cancer survivors: a methodological review of existing scales. Psychooncology [internet]. 2008 [cited 2020 nov 23];17(7):629-40. Available from: https://doi.org/10.1002/pon.1281

94. Doward LC, McKenna SP. Defining patient-reported outcomes. Value Health [internet]. 2004 [cited 2020 nov 23];7 Suppl 1:S4-8. Available from: https://doi.org/10.1111/j.1524-4733.2004.7s102.x

95. Baldwin M, Spong A, Doward L, Gnanasakthy A. Patient-reported outcomes, patient-reported information: from randomized controlled trials to the social web and beyond. Patient [internet]. 2011 [cited 2020 nov 23];4(1):11-7. Available from: https://doi.org/10.2165/11585530-000000000-00000

96. Brodersen J, Doward LC, Thorsen H, McKenna SP. Writing Health-Related Items for Rasch Models - Patient-Reported Outcome Scales for Health Sciences: From Medical Paternalism to Patient Autonomy. In: Christensen KB, Kreiner S, Mesbah M. (ed.). Rasch Models in Health. Applied Mathematics Series. London, UK: ISTE Ltd.; 2013. p. 281-98.

97. Soutello AL, Rodrigues RC, Jannuzzi FF, Sao-Joao TM, Martinix GG, Nadruz W, Jr., et al. Quality of Life on Arterial Hypertension: Validity of Known Groups of MINICHAL. Arq Bras Cardiol [internet]. 2015 [cited 2020 nov 23];104(4):299-307. Available from: http://dx.doi.org/10.5935/abc.20150009

98. Wan C, Jiang R, Tu XM, Tang W, Pan J, Yang R, et al. The hypertension scale of the system of Quality of Life Instruments for Chronic Diseases, QLICD-HY: a development and validation study. Int J Nurs Stud [internet]. 2012 [cited 2020 nov 23];49(4):465-80. Available from: https://doi.org/10.1016/j.ijnurstu.2011.10.010

99. Roca-Cusachs A, Ametlla J, Calero S, Comas O, Fernandez M, Lospaus R, et al. Quality of life in arterial hypertension. Med Clin (Barc). 1992;98(13):486-90.

100. Dalfó i Baqué A, Badia i Llach X, Roca-Cusachs A. Cuestionario de calidad de vida en hipertensión arterial (CHAL). Atención Primaria [internet]. 2002 [cited 2020 nov 23];29(2):116-21. Available from: https://doi.org/10.1016/S0212-6567(02)70516-7

101. Badia X, Roca-Cusachs A, Dalfo A, Gascon G, Abellan J, Lahoz R, et al. Validation of the short form of the Spanish Hypertension Quality of Life Questionnaire (MINICHAL). Clin Ther [internet]. 2002 [cited 2020 nov 23];24(12):2137-54. Available from: https://doi.org/10.1016/S0149-2918(02)80103-5

102. Tennant A, McKenna SP. Conceptualizing and defining outcome. Br J Rheumatol [internet]. 1995 [cited 2020 nov 23];34(10):899-900. Available from: https://doi.org/10.1093/rheumatology/34.10.899

103. Brodersen J, McKenna SP, Doward LC, Thorsen H. Measuring the psychosocial consequences of screening. Health Qual Life Outcomes [internet]. 2007 [cited 2020 nov 23];5:3. Available from: https://hqlo.biomedcentral.com/articles/10.1186/1477-7525-5-3

104. Nguyen TH, Han HR, Kim MT, Chan KS. An introduction to item response theory for patient-reported outcome measurement. Patient [internet]. 2014 [cited 2020 nov 23];7(1):23-35. Available from: https://doi.org/10.1007/s40271-013-0041-0

105. Brodersen J, Thorsen H, Cockburn J. The adequacy of measurement of short and long-term consequences of false-positive screening mammography. J Med Screen [internet]. 2004 [cited 2020 nov 23];11(1):39-44. Available from: https://doi.org/10.1177%2F096914130301100109

106. Andrich D. Controversy and the Rasch model: a characteristic of incompatible paradigms? Med Care [internet]. 2004 [cited 2020 nov 23];42(1 Suppl):I7-16. Available from: https://www.jstor.org/stable/4640697

107. Borges JWP, Moreira TMM, Schmitt J, de Andrade DF, Barbetta PA, de Souza ACC, et al. Measuring the quality of life in hypertension according to Item Response Theory. Rev Saude Publica [internet]. 2017 [cited 2020 nov 23];51. Available from: https://doi.org/10.1590/s1518-8787.2017051006845

108. Brodersen J, Thorsen H. Consequences of Screening in Breast Cancer (COS-BC): development of a questionnaire. Scand J Prim Health Care [internet]. 2008 [cited 2020 nov 23];26(4):251-6. Available from: https://doi.org/10.1080/02813430802542508

109. Brodersen J, Thorsen H, Kreiner S. Consequences of Screening in Lung Cancer: Development and Dimensionality of a Questionnaire. Value Health [internet]. 2010 [cited 2020 nov 23];13(5):601-12. Available from: https://doi.org/10.1111/j.1524-4733.2010.00697.x

110. Brodersen J, Siersma V, Thorsen H. Consequences of screening in cervical cancer: development and dimensionality of a questionnaire. BMC

Psychol [internet]. 2018 [cited 2020 nov 23];6(1):39. Available from: https://doi.org/10.1186/s40359-018-0251-2

111. Brodersen J, Hansson A, Johansson M, Siersma V, Langenskiöld M, Pettersson M. Consequences of screening in abdominal aortic aneurysm: development and dimensionality of a questionnaire. J Patient Rep Outcomes [internet]. 2018 [cited 2020 nov 23];2(1):37. Available from: https://jpro.springeropen.com/articles/10.1186/s41687-018-0066-1

112. Bolejko A, Wann-Hansson C, Zackrisson S, Brodersen J, Hagell P. Adaptation to Swedish and further development of the 'Consequences of Screening - Breast Cancer' questionnaire: a multimethod study. Scand J Caring Sci [internet]. 2013 [cited 2020 nov 23];27(2):475-86. Available from: https://doi.org/10.1111/j.1471-6712.2012.01035.x

113. Tennant A, McKenna SP, Hagell P. Application of Rasch analysis in the development and application of quality of life instruments. Value Health [internet]. 2004 [cited 2020 nov 23];7 Suppl 1:S22-6. Available from: https://doi.org/10.1111/j.1524-4733.2004.7s106.x

114. Linden WJvd, Hambleton RK. Handbook of modern item response theory. New York: Springer; 1997.

115. Christensen KB, Kreiner S, Mesbah M. Rasch models in health. London: John Wiley & Sons; 2013.

116. Wright BD, Mok M. Rasch models overview. J Appl Meas. 2000;1(1):83-106.

117. Rasch G. An Informal Report on a Theory of Objectivity in Comparisons. In: Van der Kamp L, Vlek C, editors. Psychological Measurement Theory. Leyden: University of Leyden; 1967. p. 1-19.

118. Andersen EB. Sufficient statistics and latent trait models. Psychometrika. 1977;42(1):69-81.

119. Rosenbaum PR. Criterion-related construct validity. Psychometrika. 1989;54(4):625-33.

120. Bartholomew DJ. The statistical approach to social measurement. San Diego, Calif.: Academic Press; 1996.

121. Swaine-Verdier A, Doward LC, Hagell P, Thorsen H, McKenna SP. Adapting quality of life instruments. Value Health [internet]. 2004 [cited 2020 nov

23];7 Suppl 1:S27-30. Available from: https://doi.org/10.1111/j.1524-4733.2004.7s107.x

122. Levenstein JH, McCracken EC, McWhinney IR, Stewart MA, Brown JB. The patient-centred clinical method. 1. A model for the doctor-patient interaction in family medicine. Fam Pract [internet]. 1986 [cited 2020 nov 23];3(1):24-30. Available from: https://doi.org/10.1093/fampra/3.1.24

123. Brown J, Stewart M, McCracken E, McWhinney IR, Levenstein J. The patient-centred clinical method. 2. Definition and application. Fam Pract [internet]. 1986 [cited 2020 nov 23];3(2):75-9. Available from: https://doi.org/10.1093/fampra/3.2.75

124. Fontanella BJ, Ricas J, Turato ER. Saturation sampling in qualitative health research: theoretical contributions. Cad Saude Publica [internet]. 2008 [cited 2020 nov 23];24(1):17-27. Available from: http://dx.doi.org/10.1590/S0102-311X2008000100003

125. Someren M, Barnard Y, Sandberg J. The Think Aloud Method - A Practical Guide to Modelling Cognitive Processes. London: Academic Press; 1994.

126. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nurs Health Sci [internet]. 2013 [cited 2020 nov 23];15(3):398-405. Available from: https://doi.org/10.1111/nhs.12048

127. Rasch G. Probabilistic models for some intelligence and attainment tests. Copenhagen: 1960.

128. Christensen KB, Makransky G, Horton M. Critical Values for Yen's Q3: Identification of Local Dependence in the Rasch Model Using Residual Correlations. Appl Psychol Meas [internet]. 2017 [cited 2020 nov 23];41(3):178-94. Available from: https://doi.org/10.1177%2F0146621616677520

129. Holland PW, Wainer H, Educational Testing Service. Differential item functioning. Hillsdale: Lawrence Erlbaum Associates; 1993.

130. Brodersen J, Meads D, Kreiner S, Thorsen H, Doward L, McKenna S. Methodological aspects of differential item functioning in the Rasch model. J Med Econ [internet]. 2007 [cited 2020 nov 23];10(3):309-24. Available from: https://doi.org/10.3111/13696990701557048

131. Kreiner S, Christensen KB. Graphical Rasch Models. In: Mesbah M, Cole BF, Lee M-LT, editors. Statistical Methods for Quality of Life Studies: Design, Measurements and Analysis. Boston, MA: Springer US; 2002. p. 187-203.

132. Kreiner S. Validity and objectivity: Reflections on the role and nature of Rasch models. Nord Psychol [internet]. 2007 [cited 2020 nov 23];59(3):268-98. Available from: https://doi.org/10.1027/1901-2276.59.3.268

133. Kreiner S, Christensen KB. Validity and Objectivity in Health-Related Scales: Analysis by Graphical Loglinear Rasch Models. Multivariate and Mixture Distribution Rasch Models: Extensions and Applications. New York, NY: Springer New York; 2007. p. 329-46.

134. Andersen EB. Conditional inference for multiple-choice questionnaires. Brit J Math Stat Psychol [internet]. 1973 [cited 2020 nov 23];26(1):31-44. Available from: https://doi.org/10.1111/j.2044-8317.1973.tb00504.x

135. Kreiner S, Nielsen T. Item analysis in DIGRAM: guided tours. Research Report 13/06. Copenhangen: Department of Biostatistics, University of Copenhagen; 2013.

136. Benjamini Y, Hochberg Y. Controlling the False Discovery Rate: A Practical and Powerful Approach to Multiple Testing. J Roy Stat Soc B [internet]. 1995 [cited 2020 nov 23];57(1):289-300. Available from: https://www.jstor.org/stable/2346101

137. Hurwicz M-L, Rose M. Older Adults' Explanatory Models of High Blood Pressure. Health [internet]. 2016 [cited 2020 nov 23];8(7):680-93. Available from: http://dx.doi.org/10.4236/health.2016.87072

138. Bedson J, McCarney R, Croft P. Labelling chronic illness in primary care: a good or a bad thing? Br J Gen Pract [internet]. 2004 [cited 2020 nov 23];54(509):932-8. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1326113/

139. Kolb SE, Zarate-Abbott PR, Gillespie M, Deliganis J, Norgan GH. Perceptions About High Blood Pressure Among Mexican American Adults Diagnosed With Hypertension. Fam Community Health [internet]. 2011 [cited 2020 nov 23];34(1):17-27. Available from: https://doi.org/10.1097/fch.0b013e3181fdec84

140. Dela Cruz FA, Galang CB. The illness beliefs, perceptions, and practices of Filipino Americans with hypertension. J Am Acad Nurse Pract [internet]. 2008 [cited 2020 nov 23];20(3):118-27. Available from: https://doi.org/10.1111/j.1745-7599.2007.00301.x

141. Taylor KD, Adedokun A, Awobusuyi O, Adeniran P, Onyia E, Ogedegbe G. Explanatory models of hypertension among Nigerian patients at a University Teaching Hospital. Eth Health [internet]. 2012 [cited 2020 nov 23];17(6):615-29. Available from: https://dx.doi.org/10.1080%2F13557858.2013.771151

142. Beune EJAJ, Haafkens JA, Schuster JS, Bindels PJE. ‘Under pressure’: how Ghanaian, African-Surinamese and Dutch patients explain hypertension. J Hum Hypertens [internet]. 2006 [cited 2020 nov 23];20(12):946-55. Available from: https://doi.org/10.1038/sj.jhh.1002094

143. Brodersen J, Schwartz LM, Heneghan C, O’Sullivan JW, Aronson JK, Woloshin S. Overdiagnosis: what it is and what it isn’t. BMJ Evid Based Med [internet]. 2018 [cited 2020 nov 23];23(1):1-3. Available from: https://doi.org/10.1136/ebmed-2017-110886

144. Bedson J, McCarney R, Croft P. Labelling chronic illness in primary care: a good or a bad thing? Br J Gen Pract [internet]. 2004 [cited 2020 nov 23];54(509):932-8. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1326113/

145. Dean M. Risk, calculable and incalculable. In: Lupton D (ed.). Risk and Sociocultural Theory: New Directions and Perspectives. Cambridge: Cambridge University Press; 1999. p. 131-59.

146. McKenna SP, Doward LC. The translation and cultural adaptation of patient-reported outcome measures. Value Health [internet]. 2005 [cited 2020 nov 23];8(2):89-91. Available from: https://doi.org/10.1111/j.1524-4733.2005.08203.x

147. Kaplan RM, Ong M. Rationale and public health implications of changing CHD risk factor definitions. Annu Rev Public Health [internet]. 2007 [cited 2020 nov 23];28:321-44. Available from: https://doi.org/10.1146/annurev.publhealth.28.021406.144141

APPENDIX A - All items in Brazilian Portuguese and the ad hoc translation

Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation				
I	1	YES	core	Sense of dejection	Me senti preocupado	I felt worried	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	2	NO	core	Anxiety	Me senti preocupado com meu futuro	I felt worried about my future	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	3	NO	core	Anxiety	Me senti amedrontado	I felt frightened	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	4	NO	core	Anxiety	Me senti com medo	I felt scared	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	5	YES	core	Behaviour	Me senti irritado	I felt annoyed	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	6	NO	core	Behaviour	Me senti mais quieto do que o normal	I felt more quiet than usual	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	7	NO	core	Sleep	Dormi mal à noite	I slept badly at night	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	8	YES	core	Single Items	Fuji dos meus pensamentos me ocupando com tarefas práticas do dia-a-dia	I ran away from my thoughts, busy with day-to-day practical tasks	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	9	NO	core	Behaviour	Me senti com dificuldade de me concentrar	I felt hard to concentrate	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	10	YES	core	Sense of dejection	Me senti com a sensação de que o tempo não passava	I felt that time was not passing	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	11	NO	core	Behaviour	Tive mudanças em meu apetite	I had changes in my appetite	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	12	YES	core	Sense of dejection	Me senti triste	I felt sad	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	13	YES	core	Anxiety	Me senti emotionalmente fora do meu normal	I felt emotionally out of my normal	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.

Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation				
I	14	YES	core	Anxiety	Me senti inquieto	I felt restless	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	15	YES	core	Anxiety	Me senti nervoso	I felt nervous	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	16	YES	core	Anxiety	Me senti ansioso	I felt anxious	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	17	NO	core	Sleep	Tive dificuldade de pegar no sono	I had difficulty falling asleep	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	18	NO	core	Behaviour	Me senti mais fechado	I felt introverted	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	19	YES	core	Sense of dejection	Me senti sem iniciativa	I felt without initiative	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	20	NO	core	Sense of dejection	Me senti sem vontade	I felt unwilling	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	21	NO	core	Sense of dejection	Me senti deprimido	I felt depressed	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	22	YES	core	Behaviour	Tive dificuldades em realizar meu trabalho e outras tarefas semelhantes	I had difficulties doing my job and other similar tasks	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	23	NO	core	Sleep	Acordei cedo demais	I woke up too early	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	24	YES	core	Behaviour	Tive dificuldades em realizar tarefas de casa	I had difficulties doing domestic work	no, never	yes, few times	yes, sometimes	yes, most of the time
I	25	YES	core	Anxiety	Me senti a ponto de entrar em pânico	I felt about to panic	no, never	yes, few times	yes, sometimes	yes, most of the time
I	26	NO	core	Sleep	Passei a maior parte do tempo acordado	I spent most of the time awake	no, never	yes, few times	yes, sometimes	yes, most of the time

Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation				
I	27	YES	core	Sexual	Tive menos desejo sexual	I had less sexual desire	no, never	yes, few times	yes, sometimes	yes, most of the time
I	28	YES	core	Single Items	Dias faltados no trabalho	Days missed at work	0	1 or 2	3 or 4	5 or more
I	29	YES	disease specific	Anxiety	Me senti em estado de choque	I felt in shock	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	30	NO	new	Blood pressure related	Fiquei com medo da pressão alta o tempo todo na cabeça	I had the fear of high blood pressure all of the time in the head	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	31	YES	disease specific	Introvert	Me senti inseguro	I felt insecure	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	32	YES	disease specific	Introvert	Me senti com pena de mim mesmo	I felt sorry for myself	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	33	YES	disease specific	Introvert	Me senti em uma situação desesperadora	I felt in a desperate situation	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	34	YES	disease specific	Introvert	Fiquei com humor muito variável	I was in a very variable mood	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	35	YES	disease specific	Single Items	Me senti mais cansado do que de costume	I felt more tired than usual	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	36	YES	disease specific	Single Items	Guardei meus pensamentos só pra mim	I kept my thoughts just for myself	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	37	YES	disease specific	Body Perception	Me senti doente	I felt sick	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	38	YES	disease specific	Body Perception	Tive a sensação de que havia algo errado com meu corpo	I had a feeling something was wrong with my body	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	39	YES	disease specific	Fear and Powerlessness	Me senti fora de controle	I felt out of control	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.

Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation				
I	40	YES	disease specific	Fear and Powerlessness	Me senti com o corpo frágil	I felt my body fragile	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	41	NO	disease specific	Perception of age	Senti que a idade chegou	I felt that old age has come	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	42	NO	disease specific	Body Perception	Me senti como se meu corpo fosse uma máquina que não funciona	I felt like my body was a non-working machine	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	43	NO	disease specific	Emotional	Me senti azedo	I felt sour	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	44	NO	disease specific	Emotional	Me senti zangado	I felt angry	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	45	YES	disease specific	Single Items	Me senti como se estivesse no vazio	I felt like I was in the void	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	46	YES	disease specific	Body Perception	Me senti como um estranho em meu próprio corpo	I felt like a stranger in my own body	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	47	NO	disease specific	Perception of age	Me senti mais velho do que sou	I felt older than I am	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	48	YES	disease specific	Fear and Powerlessness	Me senti sem forças	I felt strengthless	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	49	NO	disease specific	Emotional	Chorei mais do que de costume	I cried more than usual	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	50	NO	disease specific	Fear and Powerlessness	Me senti sem sorte	I felt unlucky	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	51	YES	disease specific	Fear and Powerlessness	Me senti vulnerável	I felt vulnerable	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	52	YES	disease specific	Single Items	Me senti fragilizado	I felt weak	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.

Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation				
I	53	YES	disease specific	Body Perception	Me senti como se qualquer coisa pudesse me afetar	I felt like anything could affect me	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	54	YES	disease specific	Lifestyle	Mudei meus hábitos de atividade física	I changed my exercising habits	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	55	YES	disease specific	Single Items	Pensei na morte	I thought about death	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	56	YES	disease specific	Lifestyle	Mudei meus hábitos alimentares	I changed my eating habits	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	57	NO	new	Blood pressure related	Pensei que seria melhor se não soubesse que tenho pressão alta	I thought it would be better if I didn't know I have high blood pressure	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	58	NO	disease specific	Fear and Powerlessness	Tive medo de fazer esforço físico	I was afraid of doing exercises	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	59	YES	disease specific	Sexual	Me senti insatisfeito com minha vida sexual	I felt dissatisfied with my sex life	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	60	YES	new	Single Items	Pensei na minha fé	I thought of my faith	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	61	NO	new	Anxiety	Me senti impaciente	I felt impatient	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	62	YES	new	Sense of dejection	Me senti culpado	I felt guilty	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	63	NO	new	Emotional	Me senti desequilibrado	I felt unbalanced	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	64	NO	new	Body Perception	Senti que não tenho saúde	I felt that I am not healthy	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	65	NO	new	Results of diagnosis	Me senti em dúvida	I felt in doubt	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.

Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation				
I	66	NO	new	Fear and Powerlessness	Me senti sem saber o que esperar	I didn't know what to expect	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	67	YES	new	Sense of dejection	Me senti desmotivado	I felt unmotivated	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	68	YES	new	Sense of dejection	Me senti desestimulado	I felt discouraged	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	69	NO	new	Body Perception	Me senti fraco	I felt weak	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	70	NO	new	Sense of dejection	Me senti frustrado	I felt frustrated	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	71	YES	new	Sense of dejection	Me senti indiferente	I felt indifferent	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	72	YES	new	Negative impact on relations	Me senti sendo julgado	I felt that I was being judged	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	73	NO	new	Fear and Powerlessness	Me senti com pavor	I felt terrified	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	74	NO	new	Emotional	Me senti preso	I felt trapped	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	75	YES	new	Negative impact on relations	Me senti sendo forçado a fazer coisas que não quero	I felt being forced to do things I don't want to do	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	76	NO	new	Emotional	Me senti orgulhoso	I felt proud	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	77	NO	new	Fear and Powerlessness	Me senti apreensivo	I felt apprehensive	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	78	YES	new	Emotional	Me senti com raiva	I felt angry	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.

Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation				
I	79	NO	new	Fear and Powerlessness	Me senti impotente	I felt helpless	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	80	NO	new	Results of diagnosis	Me senti surpreso	I felt surprised	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	81	YES	new	Single Items	Me senti tranquilo	I felt calm	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	82	YES	new	Sense of dejection	Me senti chateado	I felt upset	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	83	NO	new	Emotional	Me senti envergonhado	I felt ashamed	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	84	YES	new	Negative impact on relations	Me senti controlado pelos outros	I felt that I was controlled by others	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	85	NO	new	Postitive impact on relations	Me senti apoiado	I felt supported	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	86	YES	new	Negative impact on relations	Me senti excluído	I felt excluded	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	87	NO	new	Postitive impact on relations	Me senti cuidado	I felt being cared for	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	88	NO	new	Neutral impact on relations	Me senti diferente	I felt different	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	89	NO	new	Postitive impact on relations	Me senti importante	I felt important	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	90	NO	new	Blood pressure related	Tive sintomas de pressão alta	I had symptoms of high blood pressure	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	91	NO	new	Sense of dejection	Me senti culpado por não cuidar de mim mesmo como deveria	I felt guilty for not taking care of myself as I should	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.

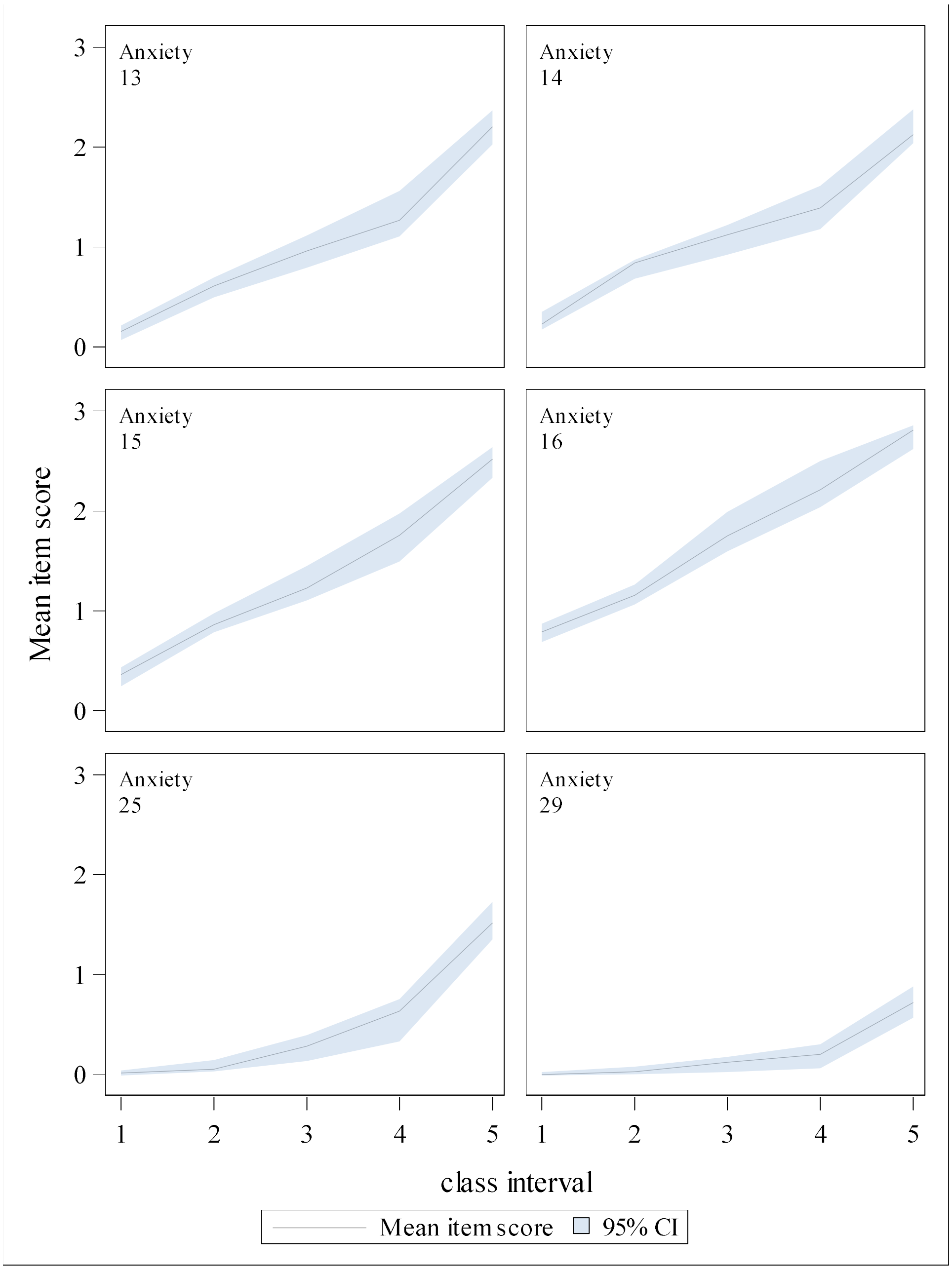
Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation				
I	92	YES	new	Fear and Powerlessness	Me senti assustado	I felt scared	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	93	NO	core	Anxiety	Me senti agitado	I felt agitated	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	94	YES	core	Sense of dejection	Me senti incomodado	I felt bothered	no, not at all.	yes, a little bit	yes, some bit.	yes, a lot.
I	95	YES	new	Single Items	Você tem pressão alta?	Do you have a high blood pressure?	yes	no		

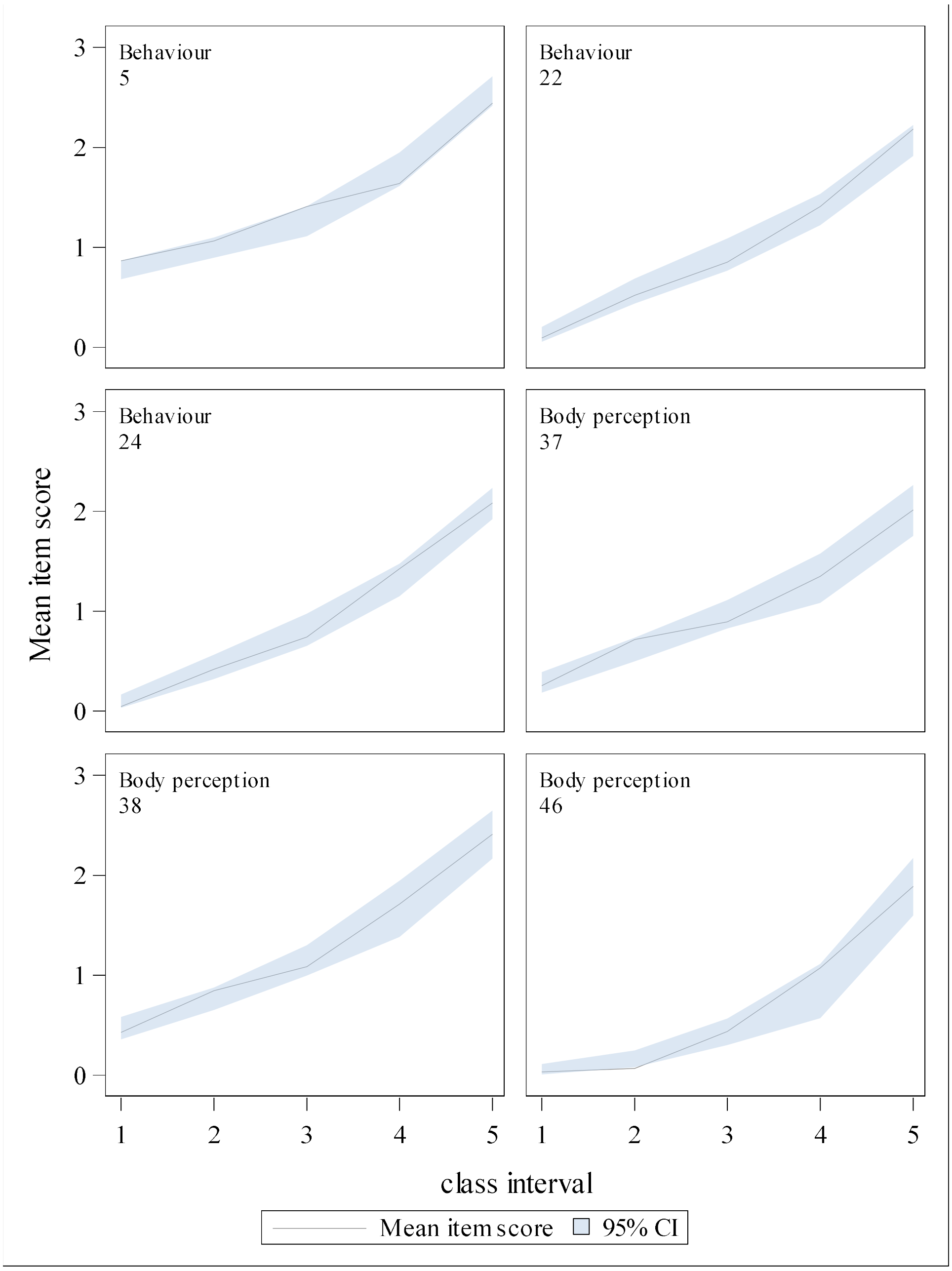
Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation					
II	96	YES	core	Existential values	eu fiquei pensando na vida	I kept thinking about life…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	97	YES	core	Existential values	minha alegria de viver ficou	my joy of living became…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	98	NO	core	Relaxed/Calm	me senti tranquilo	I felt tranquil…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	99	YES	core	Personal Relations	a minha relação com a minha família ficou	my relationship with my family became…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	100	YES	core	Personal Relations	a minha relação com meus amigos ficou	my relationship with my friends became…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	101	YES	core	Personal Relations	a minha relação com outras pessoas ficou	my relationship with other people became…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	102	NO	core	Relaxed/Calm	me senti calmo	I felt calm…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	103	YES	core	Existential values	a minha visão do futuro ficou	my vision of the future became…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	104	YES	core	Existential values	a minha sensação de bem-estar ficou	my sense of well-being became…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	105	YES	core	Existential values	a minha percepção sobre a vida ficou	my perception of life became…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	106	YES	core	Existential values	o valor que dou a vida ficou	the value I give in life became…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	107	YES	disease specific	Impulsive	a minha energia ficou	my energy became…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	108	YES	disease specific	Empathy	meu sentimento de responsabilidade pela minha família ficou	my sense of responsibility for my family became…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	109	YES	disease specific	Impulsive	tenho aproveitado a vida	I have enjoyed life…	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before

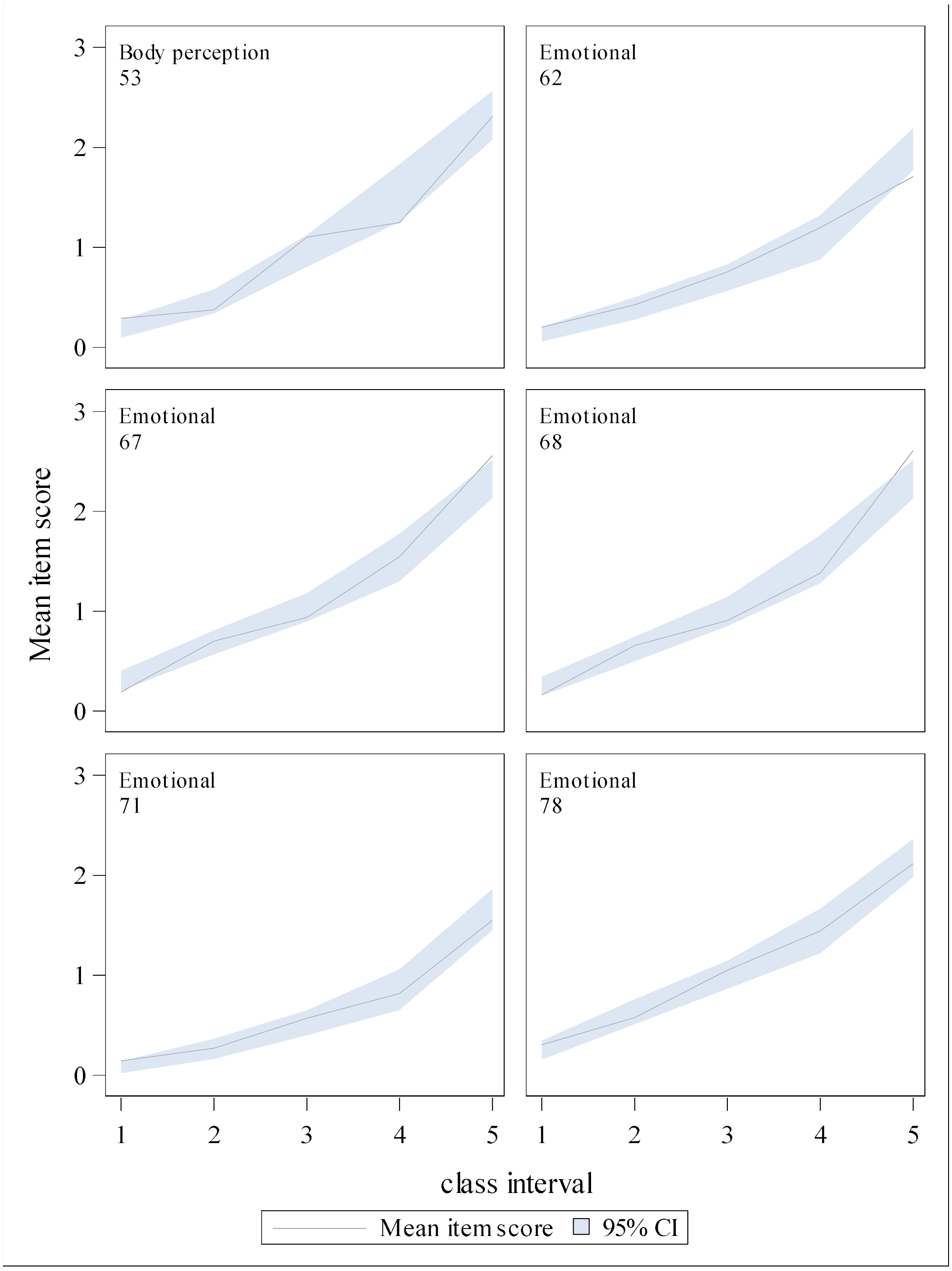
Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation					
II	110	NO	core	Relaxed/Calm	me sinto aliviado	I feel relieved...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	111	YES	disease specific	Empathy	minha compreensão dos problemas alheios ficou	my understanding of other people's problems became...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	112	YES	disease specific	Impulsive	me sinto impulsivo	I feel impulsive...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	113	YES	disease specific	Empathy	a minha capacidade de ouvir problemas alheios ficou	my ability to hear other people's problems became...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	114	YES	disease specific	Impulsive	a minha vontade de me envolver com algo novo ficou	my desire to get involved with something new became...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	115	YES	disease specific	Impulsive	a minha vontade de me envolver com algo arriscado ficou	my desire to get involved with something risky got...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	116	YES	disease specific	Impulsive	tenho feito coisas que utrapassam meus limites	I've been doing things that push my limits...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	117	YES	new	Patient Role	frequento consultas médicas	I go to doctor's appointments...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	118	YES	new	Patient Role	faço exames	I do laboratory tests...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	119	NO	new	Patient Role	me sinto fazendo mal para mim mesmo	I feel bad for myself...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	120	YES	new	Patient Role	me sinto com dificuldades em seguir orientações médicas	I have difficulty following medical advices...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	121	YES	new	Patient Role	me sinto cuidando de mim mesmo	I feel taking care of myself...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	122	YES	new	Patient Role	tomo medicamentos	I take medicines...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	123	YES	new	Patient Role	me sinto dependente de remédios	I feel dependent on medicines...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before

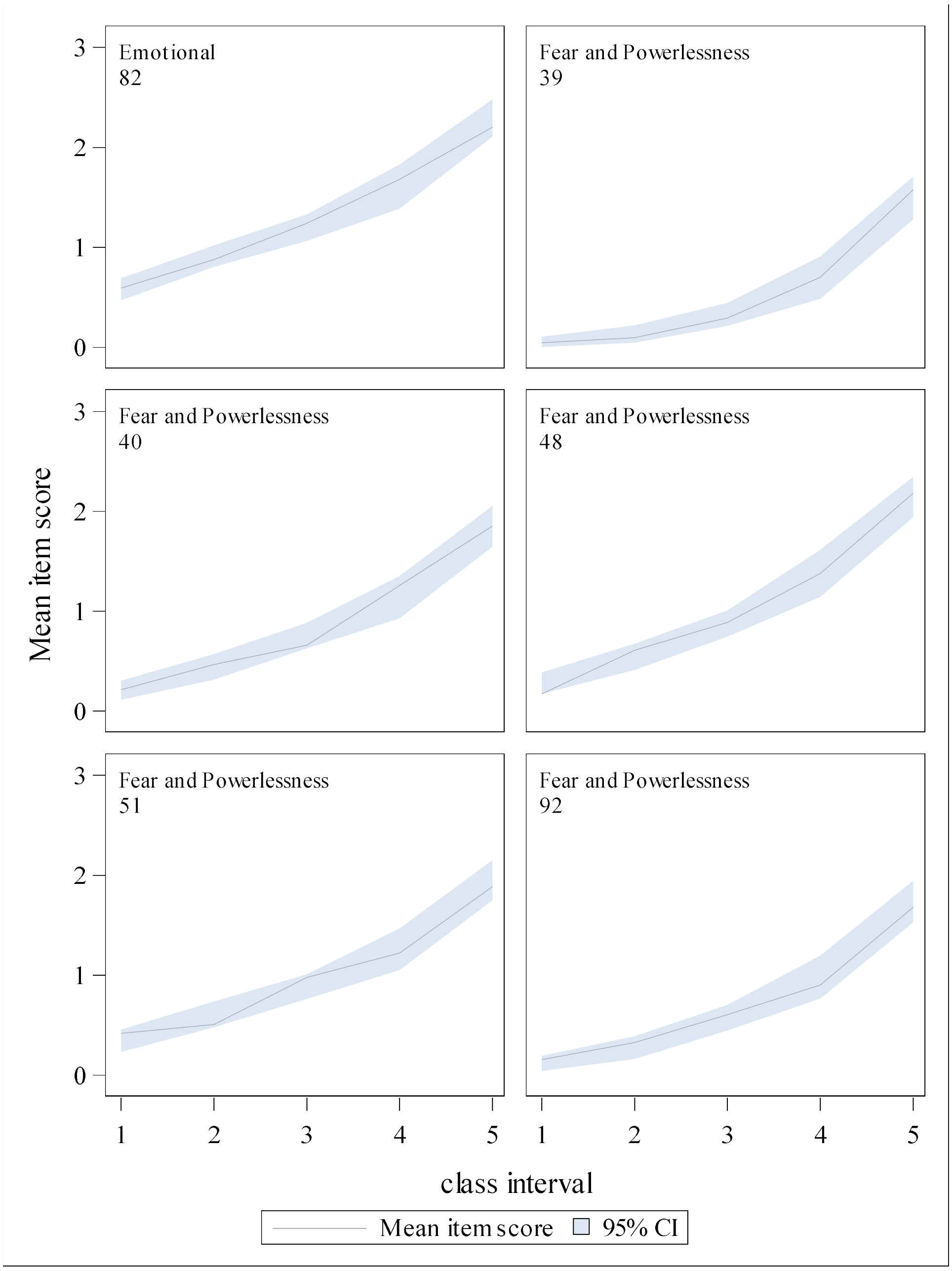
Part	Item number	Included in final version	Questionnaire of origin	Domain	Brazilian Portuguese version	ad hoc English translation					
II	124	YES	new	Patient Role	me sinto confiante em orientações médicas	I feel confident in medical advice...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	125	YES	new	Existential values	me sinto como se não fosse mais normal	I feel like I'm not normal anymore...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	126	YES	new	Existential values	me sinto como se não fosse mais o mesmo	I feel like I'm not the same anymore...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	127	YES	new	Preoccupation with health	me sinto preocupado com sintomas de pressão alta	I feel worried about symptoms of high blood pressure...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	128	YES	new	Preoccupation with health	me sinto preocupado com meus hábitos e estilo de vida	I feel worried about my habits and lifestyle...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	129	YES	new	Preoccupation with health	me sinto preocupado com os tratamentos	I feel worried about the treatments...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	130	YES	new	Single Items	meu desempenho no trabalho ficou	my work performance became...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	131	YES	new	Single Items	minha prática sexual ficou	my sexual practice became...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	132	NO	new	Hypertension related	minha ansiedade com relação a pressão alta ficou	my anxiety about high blood pressure got...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before
II	133	NO	new	Hypertension related	penso que eu não tenho pressão alta	I think I don't have high blood pressure...	a lot less than before	little bit less than before	the same as before	little bit more than before	a lot more than before

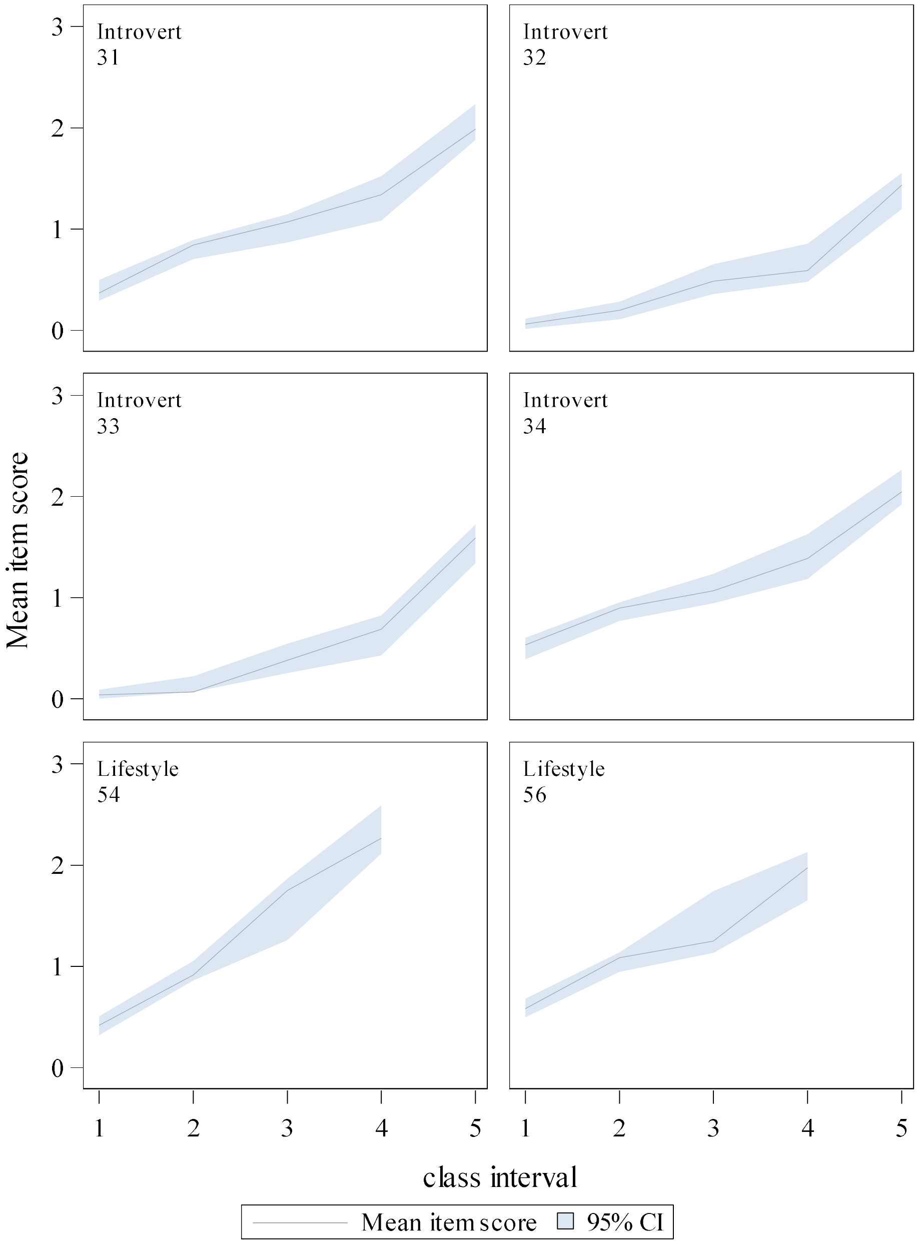
APPENDIX B - Selected items graphical model check

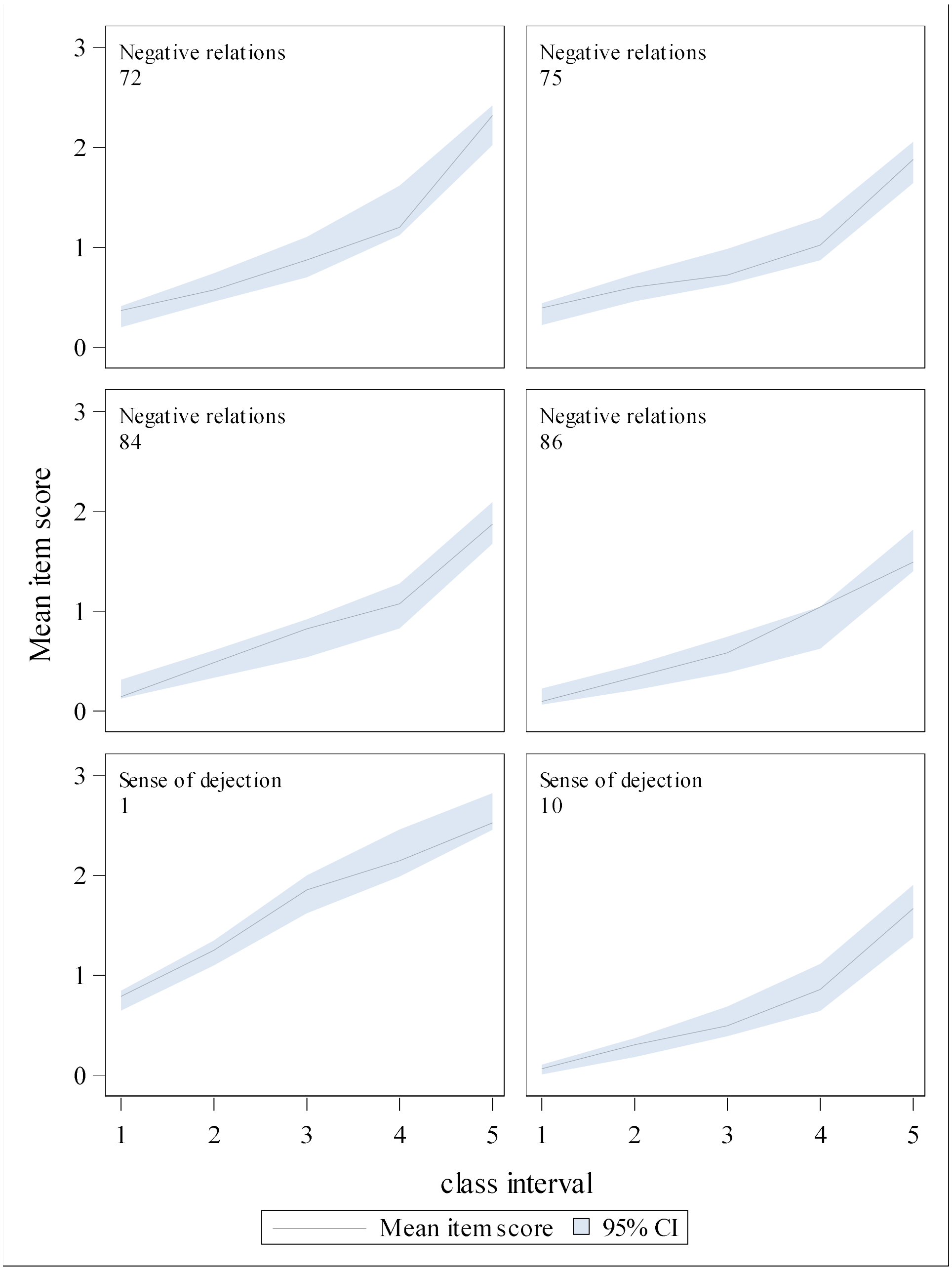


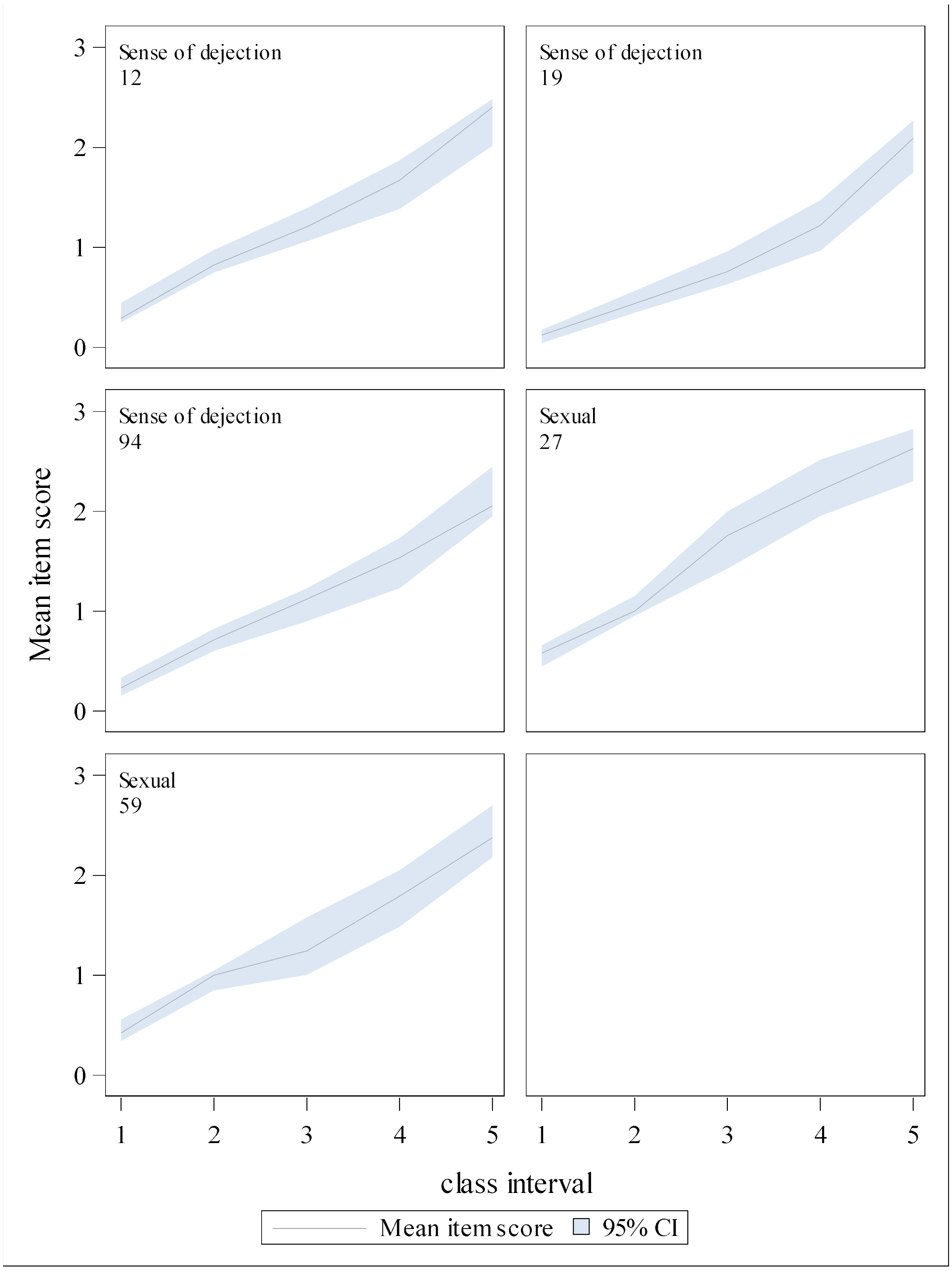

Behaviour
5
Behaviour
22
Behaviour
24
Body perception
37
Body perception
38
Body perception
46
Mean item score
0
1
2
3
1
2
3
4
5
class interval
Mean item score
95% CI

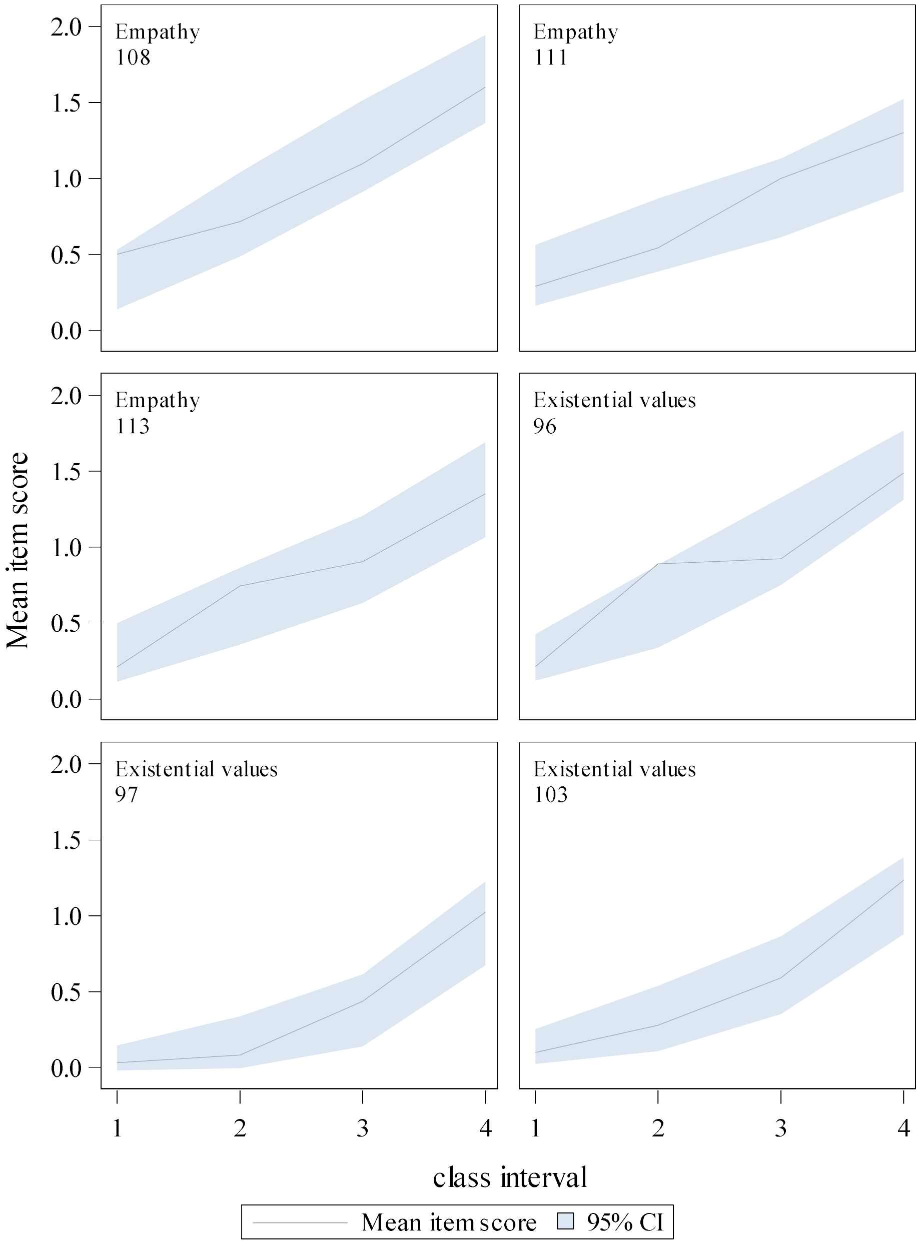

Body perception
53
Emotional
62
Emotional
67
Emotional
68
Emotional
71
Emotional
78
Mean item score
0
1
2
3
class interval
1
2
3
4
5
Mean item score
95% CI


Emotional
82
Fear and Powerlessness
39
Fear and Powerlessness
40
Fear and Powerlessness
48
Fear and Powerlessness
51
Fear and Powerlessness
92
Mean item score
0
1
2
3
class interval
1
2
3
4
5
Mean item score
95% CI


Introvert
31
Introvert
32
Introvert
33
Introvert
34
Lifestyle
54
Lifestyle
56
Mean item score
0
1
2
3
class interval
1
2
3
4
5
Mean item score
95% CI


Negative relations
72
Negative relations
75
Negative relations
84
Negative relations
86
Sense of dejection
1
Sense of dejection
10
Mean item score
0
1
2
3
1
2
3
4
5
class interval
Mean item score
95% CI


Sense of dejection
12
Sense of dejection
19
Sense of dejection
94
Sexual
27
Sexual
59
Mean item score
0
1
2
3
class interval
1
2
3
4
5
Mean item score
95% CI


Empathy
108
Empathy
111
Empathy
113
Existential values
96
Existential values
97
Existential values
103
Mean item score
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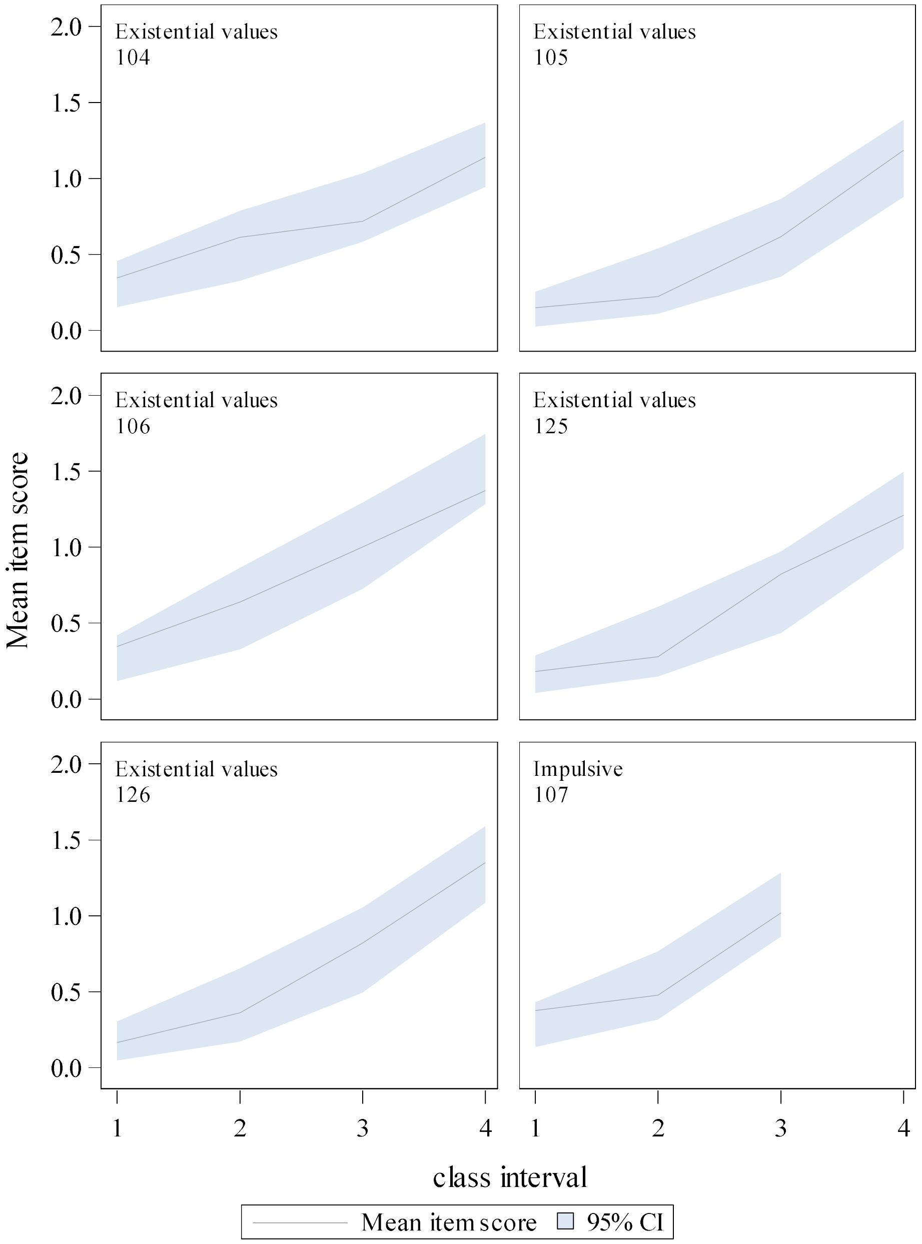
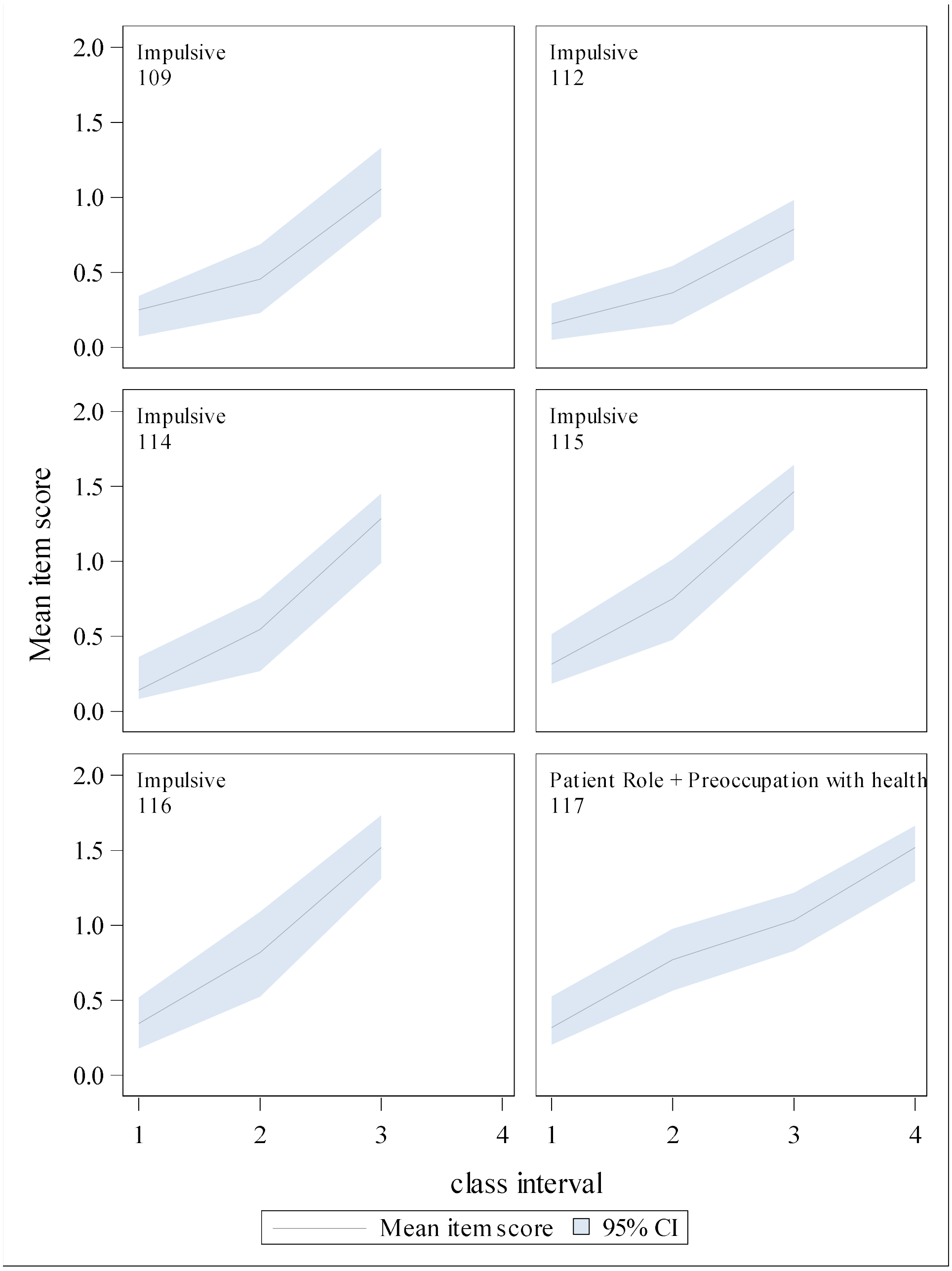
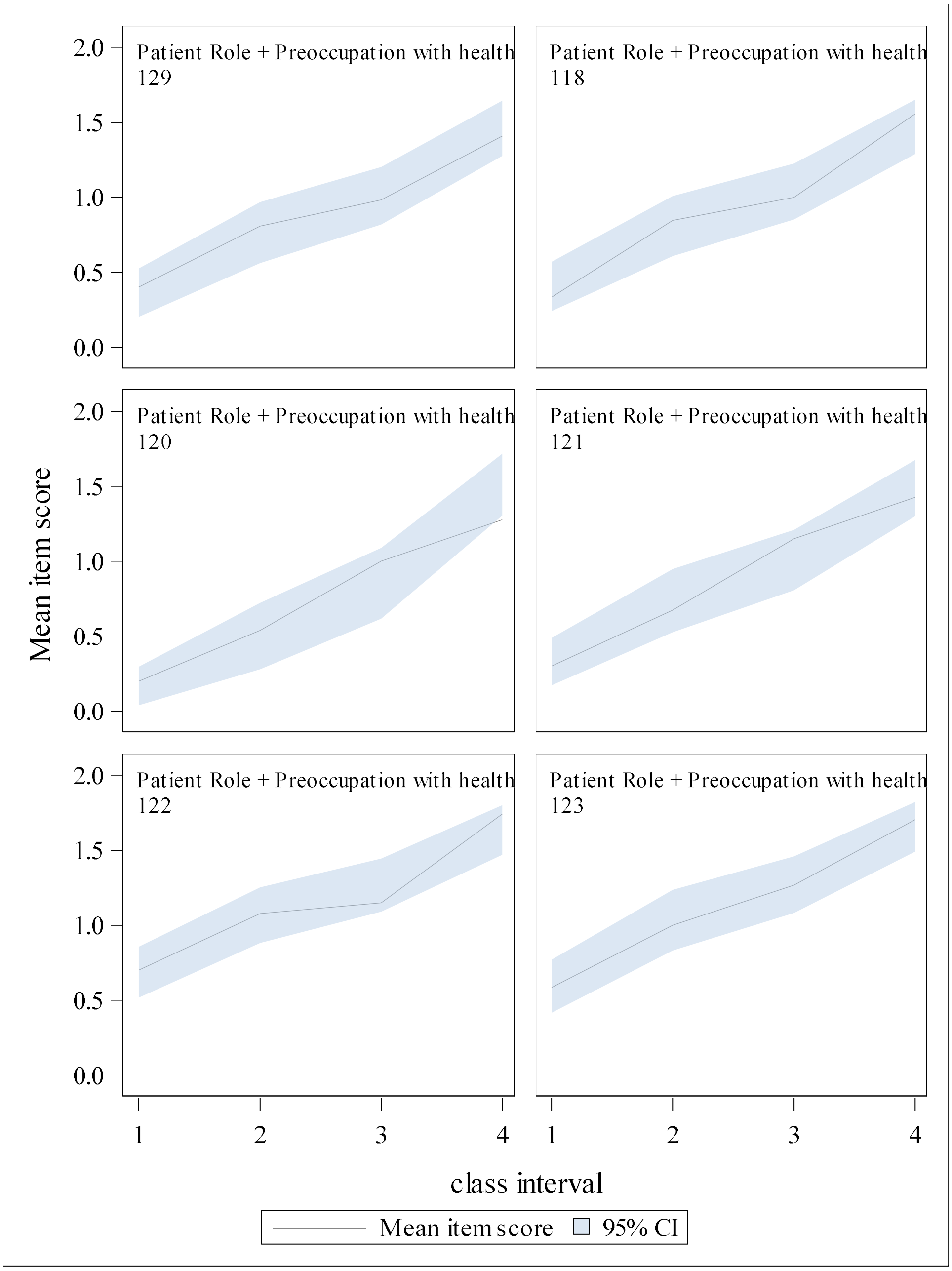
0.5
1.0
1.5
2.0
1
2
3
4
class interval
Mean item score
95% CI


Existential values 104
Existential values 105
Existential values 106
Existential values 125
Existential values 126
Impulsive 107
Mean item score
0.0
0.5
1.0
1.5
2.0
1
2
3
4
class interval
Mean item score
95% CI



Mean item score
2.0
1.5
1.0
0.5
0.0
Impulsive
109
Impulsive
112
Impulsive
114
Impulsive
115
Impulsive
116
Patient Role + Preoccupation with health
117
1
2
3
4
class interval
Mean item score
95% CI


Patient Role + Preoccupation with health
129
Patient Role + Preoccupation with health
118
Patient Role + Preoccupation with health
120
Patient Role + Preoccupation with health
121
Patient Role + Preoccupation with health
122
Patient Role + Preoccupation with health
123
Mean item score
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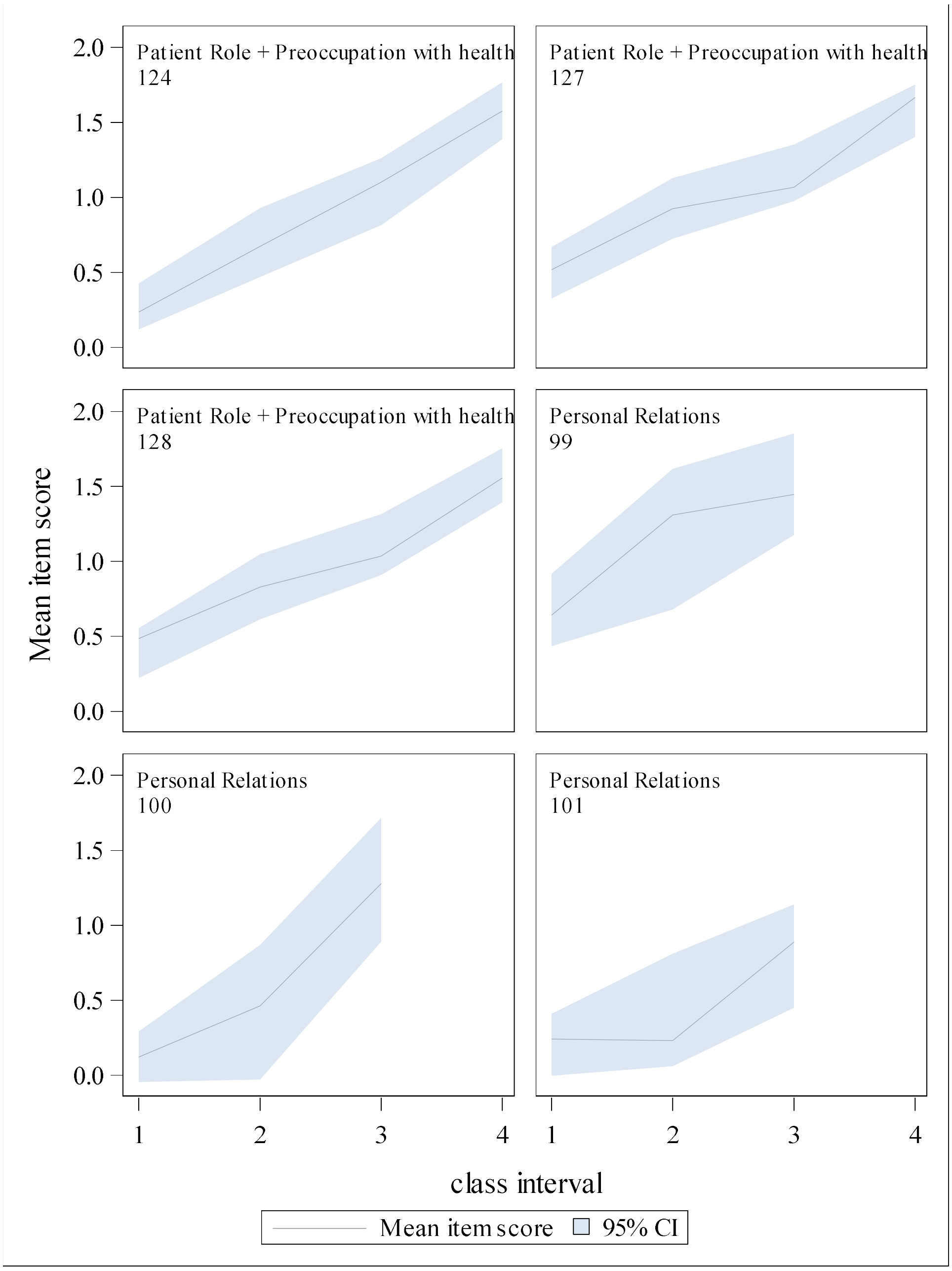
1.5
1.0
0.5
0.0
1
2
3
4
class interval
Mean item score
95% CI


Patient Role + Preoccupation with health
124
Patient Role + Preoccupation with health
127
Patient Role + Preoccupation with health
128
Personal Relations
99
Personal Relations
100
Personal Relations
101
Mean item score
2.0
1.5
1.0
0.5
0.0
1
2
3
4
class interval
Mean item score
95% CI

APPENDIX C - Final version of the questionnaire

Questionário

para pessoas
com diagnóstico de Pressão Alta

Através da aplicação deste questionário esperamos compreender como se sentem as pessoas diagnosticadas com Pressão Alta.

É importante que você responda a todas as questões.

Parte 1: Como você se sentiu no último mês?

1. Me senti preocupado.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

2. Me senti irritado.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

3. Fugi dos meus pensamentos me ocupando com tarefas práticas do dia-a-dia.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

4. Me senti com a sensação de que o tempo não passava.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

5. Me senti triste.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

6. Me senti emocionalmente fora do meu normal.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

7. Me senti inquieto.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

8. Me senti nervoso.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

9. Me senti ansioso.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

10. Me senti sem iniciativa.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

11. Tive dificuldades em realizar meu trabalho e outras tarefas semelhantes.

○ não, nem uma vez ○ sim, poucas vezes ○ sim, às vezes ○ sim, muitas vezes

12. Tive dificuldades em realizar tarefas de casa.

○ não, nem uma vez ○ sim, poucas vezes ○ sim, às vezes ○ sim, muitas vezes

13. Me senti a ponto de entrar em pânico.

○ não, nem uma vez ○ sim, poucas vezes ○ sim, às vezes ○ sim, muitas vezes

14. Tive menos desejo sexual.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito ○ não sei.

15. Quantos dias faltados ao trabalho no último mês?

0	1 ou 2	3 ou 4	5 ou mais	não trabalho.
○	○	○	○	○

16. Me senti em estado de choque.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

17. Me senti inseguro.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

18. Me senti com pena de mim mesmo.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

19. Me senti em uma situação desesperadora.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

20. Fiquei com humor muito variável.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

21. Me senti mais cansado do que de costume.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

22. Guardei meus pensamentos só pra mim.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

23. Me senti doente.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

24. Tive a sensação de que havia algo errado com meu corpo.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

25. Me senti fora de controle.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

26. Me senti com o corpo frágil.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

27. Me senti como se estivesse no vazio.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

28. Me senti como um estranho em meu próprio corpo.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

29. Me senti sem forças.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

30. Me senti vulnerável.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

31. Me senti fragilizado.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

32. Me senti como se qualquer coisa pudesse me afetar.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

33. Mudei meus hábitos de atividade física.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

34. Pensei na morte.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

35. Mudei meus hábitos alimentares.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

36. Me senti insatisfeito com minha vida sexual.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito ○ não sei

37. Pensei na minha fé.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

38. Me senti culpado.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

39. Me senti desmotivado.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

40. Me senti desestimulado.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

41. Me senti indiferente.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

42. Me senti sendo julgado.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

43. Me senti sendo forçado a fazer coisas que não quero.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

44. Me senti com raiva.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

45. Me senti tranquilo.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

46. Me senti chateado.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

47. Me senti controlado pelos outros.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

48. Me senti excluído.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

49. Me senti assustado.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

50. Me senti incomodado.

○ não, nem um pouco ○ sim, um pouco ○ sim, não muito ○ sim, muito

Parte 2: Levando tudo em consideração: o diagnóstico, o seguimento, os exames, os remédios...

...depois de saber que tenho pressão alta...

1. depois de saber que tenho pressão alta eu fiquei pensando na vida...

muito menos pensamentos sobre a vida	um pouco menos pensamentos sobre a vida	o mesmo que antes	um pouco mais pensamentos sobre a vida	muito mais pensamentos sobre a vida
○	○	○	○	○

2. depois de saber que tenho pressão alta minha alegria de viver ficou...

muito menos alegria de viver	um pouco menos alegria de viver	a mesma que antes	um pouco mais alegria de viver	muito mais alegria de viver
○	○	○	○	○

3. depois de saber que tenho pressão alta a minha relação com a minha família ficou...

muito menos próxima	um pouco menos próxima	a mesma que antes	um pouco mais próxima	muito mais próxima
○	○	○	○	○

4. depois de saber que tenho pressão alta a minha relação com meus amigos ficou...

muito menos próxima	um pouco menos próxima	a mesma que antes	um pouco mais próxima	muito mais próxima
○	○	○	○	○

5. depois de saber que tenho pressão alta a minha relação com outras pessoas ficou...

muito pior	um pouco pior	a mesma que antes	um pouco melhor	muito melhor
○	○	○	○	○

6. depois de saber que tenho pressão alta a minha visão do futuro ficou...

muito menos otimista	um pouco menos otimista	a mesma que antes	um pouco mais otimista	muito mais otimista
○	○	○	○	○

7. depois de saber que tenho pressão alta a minha sensação de bem-estar ficou...

muito menos bem-estar	um pouco menos bem-estar	o mesmo que antes	um pouco mais bem-estar	muito mais bem estar
○	○	○	○	○

8. depois de saber que tenho pressão alta a minha percepção sobre a vida ficou...

muito pior percepção sobre a vida	um pouco pior percepção sobre a vida	a mesma que antes	um pouco melhor percepção sobre a vida	muito melhor percepção sobre a vida
○	○	○	○	○

9. depois de saber que tenho pressão alta o valor que dou a vida ficou...

muito menor valor	um pouco menor valor	o mesmo que antes	um pouco maior valor	muito maior valor
○	○	○	○	○

10. depois de saber que tenho pressão alta a minha energia ficou...

muito menos energia	um pouco menos energia	a mesma que antes	um pouco mais energia	muito mais energia
○	○	○	○	○

11. depois de saber que tenho pressão alta meu sentimento de responsabilidade pela minha família ficou...

muito menos responsabilidade	um pouco menos responsabilidade	a mesmo que antes	um pouco mais responsabilidade	muito mais responsabilidade
○	○	○	○	○

12. depois de saber que tenho pressão alta tenho aproveitado a vida...

muito menos	um pouco menos	o mesmo que antes	um pouco mais	muito mais
○	○	○	○	○

13. depois de saber que tenho pressão alta minha compreensão dos problemas alheios ficou...

muito menor	um pouco menor	a mesma que antes	um pouco maior	muito maior
○	○	○	○	○

14. depois de saber que tenho pressão alta me sinto impulsivo...

muito menos impulsivo	um pouco menos impulsivo	o mesmo que antes	um pouco mais impulsivo	muito mais impulsivo
○	○	○	○	○

15. depois de saber que tenho pressão alta a minha capacidade de ouvir problemas alheios ficou...

muito menor capacidade	um pouco menor capacidade	a mesma que antes	um pouco maior capacidade	muito maior capacidade
○	○	○	○	○

16. depois de saber que tenho pressão alta a minha vontade de me envolver com algo novo ficou...

muito menor vontade	um pouco menor vontade	a mesma que antes	um pouco maior vontade	muito maior vontade
○	○	○	○	○

17. depois de saber que tenho pressão alta a minha vontade de me envolver com algo arriscado ficou...

muito menos corajoso	um pouco menos corajoso	o mesmo que antes	um pouco mais corajoso	muito mais corajoso
○	○	○	○	○

18. depois de saber que tenho pressão alta tenho feito coisas que utrapassam meus limites...

muito menos vezes	um pouco menos vezes	a mesma que antes	um pouco mais vezes	muito mais vezes
○	○	○	○	○

19. depois de saber que tenho pressão alta frequento consultas médicas...

muito menos vezes	um pouco menos vezes	a mesma que antes	um pouco mais vezes	muito mais vezes
○	○	○	○	○

20. depois de saber que tenho pressão alta faço exames...

muito menos vezes	um pouco menos vezes	a mesma que antes	um pouco mais vezes	muito mais vezes
○	○	○	○	○

21. depois de saber que tenho pressão alta me sinto com dificuldades em seguir orientações médicas...

muito menos dificuldades	um pouco menos dificuldades	a mesma que antes	um pouco mais dificuldades	muito mais dificuldades
○	○	○	○	○

22. depois de saber que tenho pressão alta me sinto cuidando de mim mesmo...

muito menor auto-cuidado	um pouco menor auto-cuidado	o mesmo que antes	um pouco maior auto-cuidado	muito maior auto-cuidado
○	○	○	○	○

23. depois de saber que tenho pressão alta tomo medicamentos...

muito menos medicamentos	um pouco menos medicamentos	o mesmo que antes	um pouco mais medicamentos	muito mais medicamentos
○	○	○	○	○

24. depois de saber que tenho pressão alta me sinto dependente de remédios...

muito menos dependente	um pouco menos dependente	o mesmo que antes	um pouco mais dependente	muito mais dependente
○	○	○	○	○

25. depois de saber que tenho pressão alta me sinto confiante em orientações médicas...

muito menos confiante	um pouco menos confiante	o mesmo que antes	um pouco mais confiante	muito mais confiante
○	○	○	○	○

26. depois de saber que tenho pressão alta me sinto como se não fosse mais normal...

muito menos estranho	um pouco menos estranho	o mesmo que antes	um pouco mais estranho	muito mais estranho
○	○	○	○	○

27. depois de saber que tenho pressão alta me sinto como se não fosse mais o mesmo...

muito menos vezes	um pouco menos vezes	o mesmo que antes	um pouco mais vezes	muito mais vezes
○	○	○	○	○

28. depois de saber que tenho pressão alta me sinto preocupado com sintomas de pressão alta...

muito menor preocupação	um pouco menor preocupação	a mesma que antes	um pouco maior preocupação	muito maior preocupação
○	○	○	○	○

29. depois de saber que tenho pressão alta me sinto preocupado com meus hábitos e estilo de vida...

muito menor preocupação	um pouco menor preocupação	a mesma que antes	um pouco maior preocupação	muito maior preocupação
○	○	○	○	○

30. depois de saber que tenho pressão alta me sinto preocupado com os tratamentos...

muito menor preocupação	um pouco menor preocupação	a mesma que antes	um pouco maior preocupação	muito maior preocupação
○	○	○	○	○

31. depois de saber que tenho pressão alta meu desempenho no trabalho ficou...

muito pior desempenho	um pouco pior desempenho	o mesmo que antes	um pouco melhor desempenho	muito melhor desempenho
○	○	○	○	○

32. depois de saber que tenho pressão alta minha prática sexual ficou...

muito pior	um pouco pior	a mesma que antes	um pouco melhor	muito melhor	não sei
○	○	○	○	○	○